

A Saga of  
**INDIAN EPILEPSY ASSOCIATION**  
40 Years of Journey

Editor

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**INDIAN EPILEPSY ASSOCIATION**

A Saga of  
INDIAN EPILEPSY ASSOCIATION  
40 Years of Journey

A book of historical interest published on completion of 40 years of Indian Epilepsy Association and released during ECON 2013 at Hyderabad in February 2013

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## *Preface*

- Dr HV Srinivas

The Indian Epilepsy Association (IEA) was registered in 1970 and the first meeting was held in January 1971. IEA celebrated 40 years of completion with a satellite meeting of International Bureau for Epilepsy in Kochi in 2011. It was proposed to bring out a book featuring the origin and growth of the movement of epilepsy through Indian Epilepsy Association.

The book is a compilation of biographies of Presidents from the time of inception and gives an insight into the then prevailing situations for creating awareness in the society. Some of them had already written their biographies for the book “A Saga of Indian Neurology – Reflections of Former Presidents”. A few of them have taken pains to rewrite their biography with an emphasis on epilepsy movement.

It was an arduous task to collect information from member chapters. A few were very prompt in responding to the request while others required repeated reminders. In the end it was quite satisfactory to note the good response from all of them. One can see the various innovative methods taken up for public education and awareness programmes by several chapters.

It requires persistence, pursuance and zeal to carry on social education to create awareness which can be achieved by the active participation of the non-medical fraternity of the chapters. Some chapters have maintained a log book of the activities and were

able to give extensive write-ups, while others had to write the activities of their chapters in a general format. Some chapters have expressed the difficulties they faced in implementing the activities while others have suggested ways and means to improve the activities further.

I had requested for 3-4 photographs from each chapter depicting the various activities. Subsequently I wrote to all the chapters to send more photographs which can be collaged. Those who had maintained photo album were able to do so. The outcome of all this exercise is the updating of list of present office bearers and the current membership.

As I was associated with Indian Epilepsy Association for a number of years as an Office Bearer I managed to trace the History of IEA from various sources and pieced it together.

The book also includes a great deal of important information spanning over 40 long years; a list of office bearers over the years, venue of the conferences and recipients of orations and awards. The IEA is proud to have members who received international recognition which is also listed.

I thank Dr Arjundas for readily accepting to write a foreword to this book. My sincere thanks to all the Presidents who were willing to share their experiences and write about themselves. I thank all contributors for having spared the time and interest to write about the activities of the chapters. This book misses the biography of Dr VS Saxena, who for reasons best known to him could not contribute his write up, which would have given a ring-side view of the developments of IEA.

I thank IAN for having permitted us to reproduce some of the articles from the book.

In the GC Meeting at Hyderabad in August 2012 it was decided to request financial grant for publication of this book from IEA - 18th IEC Trust. The request was turned down by the Trust. With persistence and help funds were raised from various sources in particular the pharmaceutical companies, Sanofi, Torrent Pharma and well wishers. Our sincere thanks to all the contributors.

I thank Ms Deepa and Mr Dinesh Kumar for the cover design of the book.

I thank Mrs Meena Chandramohan for copy editing the book, Mrs. Theresa Pinto for secretarial assistance and Mr Mohan Kumar of Aditi Enterprises for bringing out this book in an excellent format.



## *Foreword*

- Dr Arjun Das

Epilepsy, in earlier days, was treated by family physicians with available medicines. There were families with history of epilepsy in several generations and were not cluttered by the modern semiologies, changing classification and modern drugs, nor were they confounded with modern technology of imaging.

The treatment was bromide mixture and later phenobarbitone and phenytoin. Valproates were the first broadspectrum antiepileptic drugs. By this time zarontin had disappeared. The first great advance in 1950s was the EEG and some changes in thinking and classifications. Then came preferential treatments. Today we have almost tailor-made treatments for various classified types of epilepsies. The saga is of geometric progression in knowledge, imaging, nuclear medicine, etc.

From L P needle-threaded-enamelled wire temp to spike recording to modern multimodal studies; from stereiotaxic amygdalotomies for temporal lobe epilepsy to tailored surgery of complex partial and focal seizures is a great leap forward.

The emphasis also was on education of patients, carers and more important the lay persons. While it was realized that with modern advances epilepsy can be well controlled in large majority, the myths, misconceptions and stigma attached to epilepsy required attention. Awareness about epilepsy in employers and educational authorities

improved the chance of employment and admission to educational institutions. The education and awareness has shifted from adults to school going children – the future citizens of our country.

The Indian Epilepsy Association through its several chapters has been doing yeoman service to the community to create awareness about epilepsy.

Dr Srinivas has the patience and capacity to record, the nostalgic events, for us and for the newer generations who missed the pioneering period and the growth of IEA.

I am sure all of us will keep this copy as a reference volume chronicling the Saga of IEA.

(Dr Arjundas is Consultant Neurologist, Vijaya Health Centre and Mercury Hospital, Emeritus Professor at Dr MGR Medical University and Visiting Professor to Institute of Neurology)

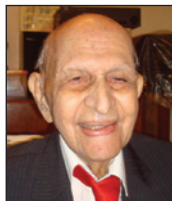
## FOUNDER OFFICE BEARERS

President



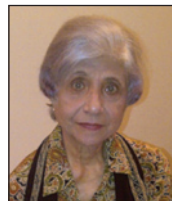
Dr Baldev Singh

Secretary



Dr EP Bharucha

Treasurer



Dr Roshan H Dastur

Members



Dr AD Desai



Dr TK Ghosh



Dr KS Mani



Dr KV Mathai



Dr B Ramamurthi



Dr NH Wadia

## GOVERNING COUNCIL (2011-2013)

President



Dr HV Srinivas

Past President



Dr Pravina Shah

President Elect



Dr VV Nadkarni

Secretary General



Dr MM Mehndiratta

Treasurer



Dr CM Sharma

Editor



Dr VS Saxena



## Members



Dr Bindu Menon



Dr Ashok Kumar



Dr Sudhir Shah



Mr KV Muralidharan



Dr B Rajendran



Ms Carol D'Souza



Dr Gagandeep Singh



Dr Pratap Sanchetee



Dr Ganguly



Dr V Natarajan



Dr Atul Agarwal

## PRESIDENTS

Dr Baldev Singh	1971-1983
Dr TK Ghosh	1983-1986
Dr KS Mani	1986-1989
Dr TK Ghosh	1989-1991
Dr B Ramamurthi	1991-1994
Dr Anupam Dasgupta	1994-1996
Dr KS Mani	1996-1998
Dr Devika Nag	1998-2000
Dr BS Singhal	2000-2002
Dr KK Sinha	2002-2005
Dr PK Sethi	2005-2007
Dr VS Saxena	2007-2009
Dr Pravina U Shah	2009-2011
Dr HV Srinivas	2011-2013

# History of Indian Epilepsy Association

**Dr HV Srinivas**

*President*

Epilepsy is a common neurological disorder affecting people across the globe irrespective of caste or creed. The disease is known to mankind since several centuries and unfortunately the stigma and myths attached to epilepsy continue to hold in the society even today in spite of scientific advances. This has resulted in untold sufferings for persons with epilepsy (PWE) who are discriminated in all walks of life – admission to educational institutions, sports, employment, marriage, driving, etc. Today epilepsy is treatable in 80–85% of patients. However almost 100% of PWE and their families suffer from deep social stigma which is also responsible for the large treatment gap particularly in developing countries. In other conditions like hypertension and diabetes it is enough if one educates the patient and may be the immediate relative, however when it comes to epilepsy the entire society needs to be educated to prevent discrimination of PWE. Incidentally, the word “epileptic” is no more in use; instead the current terminology is “person with epilepsy” (PWE).

## **International Scenario**

International League Against Epilepsy (ILAE), was founded by physicians in 1909, but its original intent was clearly inclusive, as Article IV of its first constitution which clearly stipulates: “Any

person, who is interested, either scientifically or practically in the work of the League can become a member of the League". Thus non-medical members could also become members of the International League through membership of the national organisations. The creation of a sister international association to represent PWE and their families and carers had been suggested by leading members of the ILAE over the years. Perhaps, the most prominent of these was by the great American epileptologist, William G Lennox, in 1939. However, it was only in 1961 that International Bureau for Epilepsy (IBE) finally came into existence in Rome and the emblem — a candle — was also established at that time. Dr George Burden from the British Epilepsy Association became the first Secretary General of IBE. In 1974, a Declaration of Intent was adopted to merge IBE and ILAE. Epilepsy International was thus established. However, as both lay members and professional chapters were reluctant to merge, Epilepsy International was dissolved in 1985 and IBE resumed its separate identity. The IBE is an organisation of lay persons and professionals interested in the medical and non-medical aspects of epilepsy. The IBE addresses such social problems as education, employment, insurance, driving licence restrictions and public awareness. IBE currently has 126 members from 93 countries. IBE & ILAE work in close liaison and the international conferences are held as a joint conferences.

### **Birth of Indian Epilepsy Association**

Even in the early years stalwarts Dr Baldev Singh and Dr EP Bharucha realised that non-medical members would contribute a great deal in propagating the social aspects of epilepsy to dispel the myths and stigma attached to it. In the late 1960's some members of Neurological Society of India (NSI) thought about forming a separate body to address various issues related to epilepsy, both medical and social.

Dr Anil D Desai was designated Secretary of Epilepsy section within NSI and during 1968–1969, he along with Dr Eddie P Bharucha and Dr Noshir H Wadia went about in a missionary zeal to form a new society, without disturbing the constitution of NSI. The new Society would have members independent of NSI and include lay members interested in the specialty in any capacity. The new society was named Indian Epilepsy Association (IEA). A new constitution for IEA was formulated incorporating the essential objectives, and rules under the Societies Registration Act XXI of 1860. Dr Baldev Singh, Dr BRamamurthi, Dr TK Ghosh, Dr EP Bharucha, Dr AD Desai, Dr NHWadia, Dr KV Mathai, Dr KS Mani and Mrs Roshan H Dastur were the members of the first Governing Council (GC) who registered IEA on 21 March 1970 in Bombay and started having regular meetings. In the first meeting held on 27 January 1971, Dr Baldev Singh was appointed as Chairman, Dr Eddie P Bharucha as Secretary General and Dr (Miss) FN Kohiyar as Treasurer. This meeting, to ensure effective work in all important cities, took the decision to form local branches/chapters with at least 15 members in each. The movement spread with enthusiasm and by 1972 the Central Office in Bombay had 35 members (including 9 founder members), Bombay branch had 8, Madras 25, Delhi 31 and Bangalore 24 members. The annual membership fee at that time was Rs 10. IEA received a major contribution of Rs 10,000 from the PC Bharucha Trust which was much appreciated.

The GC on 18 December 1973 authorised Dr Bharucha to work towards the affiliation of IEA to the International Body, IBE and in the GC meeting at Vellore on 19 December 1974 it was informed that IBE had accorded affiliation to IEA. The affiliation provided us with an opportunity to host the 18th International Congress, in New Delhi, much before our own first annual conference which was held in December 1993 at Chennai. The conference was attended

by over 1200 delegates which not only gave immense opportunity for IEA to interact with several foreign delegates but also provided us with surplus funds, which was pooled into forming a Trust—"IEA – 18th IEC Trust" which was registered in April 1992.

In the beginning IEA was affiliated to both IBE and ILAE . However this could not continue as the International bodies, IBE and ILAE did not agree for one association to be affiliated to two bodies. Hence an independent body, Indian Epilepsy Society (IES) was formed in 1997 consisting of medical doctors and professionals which was affiliated to ILAE. IEA continued its affiliation to IBE. It is heartening to note that IEA and IES are working together in the field of epilepsy and have organized joint annual conferences since 1999.

The IEA was initially managed by stalwarts like Dr KS Mani and Dr Bharucha as Secretaries and subsequently by Dr VS Saxena and Dr HV Srinivas.

### **Activities of IEA**

The activities of the central office were mainly to guide and coordinate various programmes of the several chapters in the country, including national and international conferences and symposia. The Governing Council has representation from a large number of states (12–16) and meets twice a year; once during the midterm meeting in the city where the annual conference is to be held and again along with the annual conference. Until recently the travel expense for the midterm meeting was borne by the members themselves, subsequently the managing committee members were being reimbursed. Since the last two years travel expenses of all the GC members are also reimbursed. The GC discusses various issues and formulates guidelines for various activities in the country in a cohesive manner.

## **Annual Conferences**

Until 1993 only annual general body meetings were held on the side lines of the Annual Conferences of NSI. The first scientific meeting was held on 23 December 1993 in Chennai along with the annual conference of NSI, which continued till 2001. From 2002 onwards it was clubbed with the IAN and the conference was held for one and half days – the second day mainly consisting of programmes for non-medical people. This was overlapping with the CME programme of IAN. The conference was in the same venue or in a different venue but in the same city. Once the IES was formed it was a joint annual conference from 1999 onwards. Gradually the number of delegates, both medical and non- medical, increased and it was decided to hold stand alone conferences from 2009 onwards. The first one was held at Tirupati in 2009. The activities within the conference steadily increased with the introduction of BM Sharma oration in 1997 at Jaipur where Dr B Ramamurthi delivered the first oration. To honor persons who have done good service in social aspects, HC Bajoria award was started in Lucknow conference in 2002 and Dr HV Srinivas was the first recipient. IES introduced the Dr BC Bansal – Uma Bansal Oration, Mrs Shobha Arjundas Oration and Dr AD Sehgal Oration. Subsequently awards for the best paper, both medical and non- medical, and also prizes for best poster presentation were introduced. Foreign speakers were invited with introduction of guest lectures and breakfast seminars; pre-conference workshops were added with a galaxy of foreign speakers participating. In the forthcoming ECON 2013 the academic activities have been further strengthened with the introduction of late evening and post dinner academic sessions in addition to pre conference and post conference workshops. The participation of non-medical persons – persons with epilepsy, carers and other organizations – steadily increased so much so that a parallel session “Epilepsy & Society” of two hours on the second day of the conference is being organized. The highlight

of the conference is “KS Mani patients’ session” with participation of persons with epilepsy. This session is in the memory of late Dr K S Mani who is popularly referred to as “father of epileptology”. IEA Bangalore chapter donated a sum of Rs 50,000 as a corpus towards conducting the session during the annual conference of IEA and the prize money is distributed to the participants.



Inauguration of ECON 2012, Kochi

The annual conferences have been attracting more and more delegates both medical and non-medical. Starting from 60 medical and 4 non-medical delegates in the first annual conference of 1993 at Madras the number has now increased to 400 medical and 100 non-medical delegates in the recent conference.

### **Activities of Chapters**

Several chapters continue their activities, round the year, consisting of monthly camps for diagnosis and management of epilepsy with distribution of antiepileptic drugs (free or subsidised), awareness lectures to students in schools, colleges, NGOs, social organizations, articles in newspapers, magazines, interactive discussions on radio, TV and street plays. Some chapters conduct seminars and CME programmes for professionals, in particular primary care physicians emphasizing on the current diagnosis and management of epilepsy besides the social aspects of epilepsy. Others conduct regular counseling services, epilepsy clinics, self help groups and



support groups and yoga classes. Public education on prevention of epilepsy, in particular head injuries due to road traffic accidents and infections like neurocysticercosis due to poor hygiene were also conducted. In 2006 Sanvedana Foundation, along with IEA Pune chapter started a unique activity – the “Marriage Bureau” for people with epilepsy to help persons with well controlled epilepsy find a life partner, and in 2008, a matrimonial meet for people with epilepsy was organised. Many of these activities have been elaborated by the respective chapters in this book. However a few chapters which started off enthusiastically could not continue and so have become defunct. They are Mysore, Hubli, Baroda, Surat, Calicut, Amritsar, Kolhapur, Rohtak, Varanasi and Vellore.

There are also neurologists who are not associated with IEA, but doing service to the community to dispel the myths and stigma associated with epilepsy.

### **Activities with Governmental Organizations**

A few chapters have actively involved governmental organizations to make the programme effective while many others have channelised it through voluntary organizations and NGOs. Some of those who coordinated with governmental agencies include Bangalore chapter which participated in the monthly district level mental health programme, by staging a play on epilepsy followed by interactive discussion. Several departments including health and family welfare, district administration, lawyers association and medical association took part in this programme — a gathering of over 2000 people. IEA Bangalore chapter is also running a counselling centre very successfully at Neurology outpatient of Victoria Hospital, a government hospital, for the last several years and recently added two more such centers at Central Government Health Scheme (CGHS) dispensaries at Koramangala and at Vijayanagar.

The Tirupati chapter conducts special monthly camps for persons with epilepsy, uninterruptedly, coordinating with various agencies. Requirements of medicines for one month are distributed free to all patients. One hundred and sixty-seven camps have been organized till the end of 2012 (with an average attendance of 500). Indore chapter collaborated with the social justice department of MP Government for developmental and learning disabilities and conducted workshops on epilepsy awareness. Teachers from different schools from rural areas around Indore and other cities in MP participated in this workshop. Three training sessions were conducted in addition to didactic lectures, educational slides and a film on epilepsy.

### **Newsletter**

The Central Office Newsletter initially started as a hand typed and cyclostyled copy distributed to about 100 members. The newsletter appeared in print in 1992 and was well managed by successive editors - Dr Pravina Shah (1992 to 1996 and 2002 to 2005) and Dr Atul Agarwal (1996 to 2002) and from 2005 ably managed by the current editor Dr VS Saxena. The newsletter is now a 24 page multi-colored feature covering both international and national activities and activities from the chapters. The newsletter has colorful photographs and on sidelines general information and quotations too.

In addition to the quarterly newsletter “Epilepsy India”, of central office, several chapters viz., Bombay, Bangalore, Lucknow, Indore, Kolkata and Thiruvananthapuram have their own newsletters in English and regional languages.

### **Website**

The website of IEA was launched in 2001 and was inaugurated by Dr BS Singhal the then President of IEA. The website has several

features including a brief history, executive committee members, office bearers of various chapters and FAQs on medical and social aspects. The website is frequently updated detailing the activities of chapters in addition to announcements of forthcoming events. Epilepsy India newsletter and newsletters of other chapters are uploaded onto the website for wider dissemination. The IEA memorandum is also on the website for ready reference.

### **Short Films on Epilepsy**

A few chapters viz., Bombay, Kolkata, Jodhpur, Pune and Bangalore have brought out interesting and educative films on epilepsy.

IEA-18th IEC Trust, sponsored a film “The story of Priya” or “Mirgi Sahi Gyan Sahi Samadhan” in Hindi and eight regional languages all with subtitles in English. The film was distributed to all the chapters and a pharmaceutical company was able to screen this in more than 120 centers for public education. An animated documentary film on epilepsy was produced by West Bengal chapter initially in Bengali and subsequently in Hindi and English which was screened in schools, colleges and during national epilepsy day celebrations.

### **National Epilepsy Day**

In the General Body Meeting of IEA held at Indore on 16 December 1990, Dr Eddie Bharucha and Dr Pilo Bharucha proposed a coordinated nation wide programme on a particular day to create awareness which was supported by other members and the decision to celebrate 17 November of every year as National Epilepsy Day (NED) was taken. Many chapters continue the activities for a week as the National Epilepsy Week. The activities are varied consisting of public forum, skit, road shows, seminars, drawing competitions, essay competitions, panel discussions, audio visual screening and media coverage – newspapers, radio and TV. The focus of the national epilepsy day is always public education to create awareness about

epilepsy. In the recent years a theme is identified for NED to have a coordinated effort to bring out the issue. The themes were Prevention of Epilepsy (2009), Women and Epilepsy (2010), Epilepsy in Teens (2011) and Employment and Epilepsy (2012). All these activities are well covered in the newsletter.

### **Diploma in Epilepsy Care**

The Diploma was started by Bangalore University in collaboration with IEA, CBR network in June 2006. The duration of the course is one academic year and the study material consists of five modules, each module having 4 CDs, in addition to printed material for all modules. The study centers recognized are all chapters of IEA, teaching hospitals and epilepsy clinics. Diploma in epilepsy care is conceptualized with an intention to impart education on social aspects of epilepsy to paramedical personnel, in addition to anyone who is working in the field of epilepsy. The course will benefit families with a PWE, teachers, nurses, community health care workers, CBR workers, teachers in special schools and primary health care professionals including medical doctors, EEG technicians and those working in voluntary services like IEA and Spastic, etc.

### **IEA-18th IEC Trust**

IEA-18th IEC Trust was formed with an initial corpus of Rs. 35 lakhs in 1992 – the excess of income over expenditure from 18th International conference held in New Delhi in 1999. Subsequently excess of income over expenditure from 3rd Asian and Oceanian Epilepsy Congress held in 2000 in New Delhi was added to the corpus. IEA-18th IEA Trust provides financial grants towards activities related to epilepsy in research projects both medical and social, public awareness campaigns, conferences, seminars, workshops, travel grants for national and international meetings for both medical and non-medical persons.

Besides medical doctors from IEA, persons with epilepsy have also participated in international conferences since 1998, some of them with financial assistance from IEA-18th IEC Trust.

## **LEGAL ISSUES**

### **Epilepsy and Marriage**

The Hindu Marriage Act 1955 and Special Marriage Act 1954 specifically state that a marriage under these acts can be solemnized, if at the time of marriage neither party suffers from recurrent attacks of insanity or epilepsy. IEA petitioned the concerned authority to delete epilepsy from the draconian law. Repeated letters and petitions to successive Prime Ministers, their cabinet colleagues and members of parliament from 1987 to 1996 brought forth nothing except vague assurances and empty promises. Dr Bharucha collected more than 1500 signatures as part of the petition to the speaker of the Lok Sabha. He also helped in a public interest litigation in the 1990's before Kerala high court. Dr Ramamurthi too in his own inimitable style kept up the pressure on the politicians, ministers, MPs.

IEA Bangalore chapter represented by Dr KS Mani along with Dr B Ramamurthi from Madras and Dr EP Bharucha from Bombay petitioned before supreme court on 9 September 1996 and this was admitted as a public interest litigation. The cost of litigation, Rs. 50,000, was met by IEA Bangalore chapter from donations. Subsequently the Government of India took note of this and the Rajya Sabha passed the bill on 30 November 1999 and the Lok Sabha followed suit on 20 December 1999. The President gave his assent to the bill on 30 December 1999. It took nearly twelve years of struggle to get the desired result.

### **Epilepsy and Driving**

World wide (USA, UK, Australia, Singapore, etc) a person with epilepsy is issued a driving license to drive a personal vehicle if he or

she is seizure free for more than one to two years, even if the person is taking antiepileptic drugs. It is well established that motor vehicle accidents are much more common due to reckless driving, drunken driving and cell phone distraction. The chances for a person to have a seizure while driving and meet with an accident is infinitesimally small. IEA approached the Minister of Surface Transport in 2002 and again in 2005 with an appeal to introduce amendments in regulations concerning driving and epilepsy in the Indian law. The Ministry of Surface Transport recently forwarded the application to the Ministry of Health. The latter in turn, seeing the scientific merit in the case, worked out recommendations in consultation with IEA. However, these recommendations have a long way to go before they are notified as amendments in the law.

### **Epilepsy and Disability**

Though epilepsy is well controlled in 75–80% of patients there still is a group of 20-25% who have difficulty to control epilepsy. “Post-traumatic seizures and epilepsy” have found a place in Indian disability legislation, but there are no clear guidelines with regard to their measurement and/or certification. It is now proposed that “Disabling epilepsy” should be included in the group with disabilities, to derive appropriate benefits under the Persons with Disability Act. Recently, a draft bill prepared by the Ministry of Social Justice and Empowerment has widened its definition of disability to include chronic neurological conditions such as epilepsy, learning disability and speech and language disability. In a move to focus on the problems of the disabled, the Social Justice Ministry has carved out a separate department.

### **Epilepsy and Discrimination**

It is a well-known fact that persons with epilepsy are discriminated in every walk of life, from admission to educational institutions to employment, largely because of ignorance on the part of the

employers/administrators. In western countries there are anti discriminatory laws to address such situations. IEA needs to look into these aspects also. However the legal experts say that even now the discrimination can be challenged under the Fundamental Rights Act.

### **IEA and IBE**

IBE earlier had regional representation and the Asian-Oceanian was one such region. This was later split into two regions – South East Asia Region and Western Pacific Region in 2005. The IBE South East Asian Region consist of members from India, Indonesia, Srilanka, Thailand, Hongkong and later Nepal and Bangladesh. Each region has a Vice-President, Chair, Vice-Chair and Secretary.

On the occasion of the Golden Jubilee of IBE and completion of 40 years of IEA, a Satellite meeting of IBE was organized at Kochi in August 2011. Members from Bangladesh, Indonesia, India, Nepal and Srilanka attended the meeting. Mr Mike Glynn, President of IBE was the chief guest.

IBE has been making efforts to have “World Epilepsy Day”, to coordinate the activities internationally. However so far it has not been approved by WHO.



Inauguration of Satellite Meeting of IBE at Kochi, August 2011

The Association has grown to the present strength of 28 chapters across the country with a total strength of over 2000 members. However considering the magnitude of the problem and the large population of our country there is still a need for more chapters to be formed and more active participation of both professionals and lay persons to achieve the goals of IEA.

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Presidents of  
INDIAN EPILEPSY ASSOCIATION





## DR BALDEV SINGH (1904–1998)

President—Indian Epilepsy Association

1971 – 1983

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by Dr M Gourie-Devi

Prof. Baldev Singh, father of Neurology in India, fondly known as PAPA NEURON, an eminent neurologist and neuroscientist, a humanist, was born on 6 April 1904 and after an illustrious career spanning six decades passed away on 2 February 1998 leaving behind his students, neuroscientists, research scholars and patients grieving the loss. I had the good fortune of being trained under his tutelage for DM Neurology and deem it an honour to pay my humble tribute through this biography.

He belonged to an aristocratic family, born at Zaffarwal Dutta (now in Pakistan) and brought up at a village near Amritsar. Under the influence of his brother he pursued education in science subjects and later completed MBBS from King Edward Medical College at Lahore in 1927 with many gold medals and awards. Dr Singh then moved to UK where he trained at the London Hospital. He used to tell us many interesting anecdotes of the interaction with Drs Collier, Kinnear Wilson, Russell Brain and Critchley. He was fascinated by neurosurgery but could not pursue it as he had to return to India because of his wife's illness. After completing MRCP he returned to India and established a lucrative practice in Amritsar and led a luxurious life. Passion to teach students and do research led

him to accept an honorary position at Amritsar Medical College. Development of a model for anemia, attempt to differentiate tuberculosis from Hodgkin's lymphoma by injecting filtrate from emulsified lymph node into rabbit cerebellum were some of his interesting contributions.

Dr Baldev Singh had a deep interest in structure and function of the brain from his graduate days when he used to dissect the brain. Recording of activity of brain was gaining importance at that time and he tried to construct an equipment but unfortunately was not successful. EEG recording was a novelty and Dr Singh came to know about the efforts of Dr Narasimhan at Madras and spent some time learning the technique. In 1950 he contacted Prof. Gibbs at Chicago and spent a year working on EEG and experimental studies on cats, examining the role of thalamus on spike and slow wave.

On his return to India he moved to Christian Medical College, Vellore where Dr Jacob Chandy had established a comprehensive neurosciences department with neurosurgery, neurology and basic neurosciences. Dr Singh was asked to set up an EEG laboratory and an experimental laboratory. It was a period of great excitement when surgery for epilepsy was initiated at CMC. In later years he used to mention (when I was training in neurology for DM degree at AIIMS in 1960s) that the years spent at Vellore were memorable for the close interaction with Dr Chandy and facing challenges in establishing neurology and EEG services. The years in CMC also had a great influence on his lifestyle which went through a major transformation from luxurious to simple living.

The formation of the Neurological Society of India in 1951 was a major initiative of four stalwarts, Dr Jacob Chandy, Dr Baldev Singh, Dr B Ramamurthy and Dr ST Narasimhan with all specialties of

neurosciences involved in the activities and growth of the Society. Dr Baldev Singh had the rare distinction of having been the President of Neurological Society of India in 1962 and again in 1971.

The next journey was to Tirath Ram Hospital in New Delhi in 1955 where he was asked to establish neurology services by Col Amir Chand. Dr Baldev Singh was a very popular neurologist and patients used to throng to the hospital to consult him and it used to be said that “there was no patient with neurological disorder in North India who would not have consulted him”. Not satisfied with clinical work alone he collaborated with Prof. BK Anand, Professor of Physiology at Lady Harding Medical College which continued even after Dr Anand moved to All India Institute of Medical Sciences and they made seminal contributions in the field of consciousness, the effects of yoga and meditation, feeding behavior and sleep.

Dr Sushila Nayyar, Union Health Minister invited Dr Baldev Singh to take up the responsibility of establishing neurosciences at AIIMS and consequently he joined as Professor of Neurology in 1965 and with the appointment of Dr PN Tandon as Professor of Neurosurgery, the next 3 years saw rapid development, of international standard, of the departments of Neurology and Neurosurgery and other allied sciences. I was lucky to have been enrolled for DM Neurology in the first batch of students and there were excellent clinical and basic neurosciences teaching sessions not just during seminars but also at bedside clinics. After the clinical case presentation and discussion of diagnosis and differential diagnosis, Dr Baldev Singh always had an interesting question about the underlying pathophysiology which we would find difficult to answer. In his inimitable gentle style he would explain the physiological basis of the disorder. I recall that after very busy neurology clinics which used to extend up to 7 pm or beyond, both Prof. Baldev Singh and Prof. Tandon would accompany

my colleague Dr BB Sawhney and me to our respective hostels and then only would they go to their homes.

Dr Singh led a spartan life eating food, unpalatable to the resident doctors, with relish at the Men's hostel. After retirement in 1968 he was appointed as 'Emeritus Professor of Neurophysiology for life' and he continued to guide PhD candidates and do research in collaboration with Prof. GS Chinna in areas of consciousness, sleep and high altitude physiology till 1991 when he moved to his home in Amritsar. In February 1996, I went to Amritsar from Bangalore to meet him and although he had visual problem and difficulty in walking, he was energetic and eager to know the latest developments in neurology, particularly about the prospects of stem cell therapy in degenerative neurological disorders. I was fascinated to know his insights and views.

He was conferred numerous awards, some of the prestigious ones are Basanti Devi Amir Chand Award by Indian Council of Medical Research, Air Marshal Subroto Mukherjee Award and Hon. Brigadier of Indian Army. The highest award of Padma Bhushan was conferred on him by the President of India in 1971. It was with great humility that he accepted these numerous accolades.

On the scene of Indian Neurology the foot prints of Dr Baldev Singh will be long lasting for generations of neurologists to emulate his ideas, ideals and dreams.

### **Acknowledgements**

I have included considerable information from biography of Dr Baldev Singh by Dr S Pandya, Dr S Kalyanaraman and Dr PN Tandon published in 'Evolution of Neurosciences in India' edited by Dr K Rajasekharan Nair. I express my grateful thanks to the editor for the permission.

(Dr M Gourie-Devi is Emeritus Professor at IHBAS, New Delhi and Senior Consultant in Neurology, Sir Ganga Ram Hospital, New Delhi).

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DR TK GHOSH (1912–1996)

President—Indian Epilepsy Association

1983 – 1986; 1989 – 1991

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by Dr Kalyan B Bhattacharyya

If one has to choose the founder of neurosciences in West Bengal and the Eastern part of India, the palm goes unhesitatingly to Dr Tarit Kumar Ghosh. Everything said, he is the first pure neurologist in this part of the country and in every analysis, he initiated the scientific practice of neurology in Calcutta.

Dr Tarit Kumar Ghosh was born on 23 January 1912, the day Netaji Subhas Chandra Bose, the valiant freedom fighter from Bengal, was born in 1897. He was groomed in a middle-class family in Howrah, and he had his moorings quite early in life in the freedom movement, organised and propagated by Mahatma Gandhi, that gripped the entire intelligentsia throughout the length and breadth of India. He passed SSLC in 1929 with distinction and the intermediate examination, two years later. While he appeared for the interview for admission at the Carmichael Medical College, now named RG Kar Medical College, Sir Kedar Nath Das, known universally for devising the Das obstetric forceps, and a formidable personality, was the Principal. Dr Ghosh performed admirably and was interviewed later by luminaries like, Dr Bidhan Chandra Roy, the peerless clinician and later, the Chief Minister of West Bengal who passed both the MRCP and FRCS examinations in London, Sir Nilratan Sircar, a physician of great repute and the chief physician to Rabindranath



Tagore in his terminal days, and Sir UN Brahmachari, the discoverer of urea stibamine for the treatment of Kala-azar. He stood first in the interview and at the end of the first year, was chosen as the Class Assistant in physiology. Those were the days just following the Civil Disobedience Movement, initiated by Mahatma Gandhi in 1930. One day when all the students left the college in order to participate in a protest against the British excesses, SC Mohalanabis, his Professor of physiology, detained him for about ten minutes in the classroom and when nobody turned up, he said, *'You have done your duty as a Class Assistant and now you may leave to do your duty for the country!'*

Neurology was a fledgling discipline and there was no provision for specialized training in the subject those days. Dr Ghosh observed that the only teacher who knew something about neurology was Dr Bidhan Chandra Roy and he found his lectures arresting and compelling. He had the good fortune of serving as his House Physician and was soon admitted into his affections. Initially, he chose to specialize in internal medicine and cardiology and Dr Roy appointed him as a Research Scholar in 1940 and paid him a sum of forty rupees a month from his own fund. Four years later, he funded a project on epidemic dropsy, where he inducted Dr Ghosh and granted him one thousand rupees for the project. Meanwhile, he got admission for MD (Medicine) at University of Calcutta in 1944.

Dame Providence smiled on him when in 1947, Dr BC Roy visited the USA and met Dr IS Wechsler, Chief of neurology and neurosurgery at Mount Sinai Hospital, where he discussed at great length the possibility of training an Indian incumbent in neurology. The meeting turned fruitful and after returning to Kolkata, he asked Dr Ghosh to proceed to New York. In 1948, soon after the independence of India, Dr Ghosh, a committed young man with a vision and a challenge ahead, combined with a queer feeling of uncertainty and trepidations, sailed in a cargo ship, since nothing more cozy, caring

and comfortable was at hand. His sojourn to the port of Boston took him thirty-one days and then, with sea sickness and other attendant problems notwithstanding, he travelled to New York by train. He was received by Dr Wechsler who arranged for his training in neuropathology with Dr Joseph Globus, EEG with Dr Hans Strauss, neurophysiology with Dr Brickner, psychology with Drs Weinstein and Khan, neuroradiology with Dr Schlesinger, neurosurgery with Dr Ira Cohen and experimental neurology with Dr Morris Bender. Dr Wechsler, himself, taught clinical neurology and supervised the total programme. Additionally, he introduced him to the librarian so that this young man from a developing country could have easy access to the books, journals and the reprints. He also started visiting other notable centres like, Johns Hopkins Hospital, Massachusetts General Hospital and the Philadelphia Medical College Hospital. In 1948, he had the good fortune of listening to Wilder Penfield, the outstanding neurosurgeon from Canada, and he vividly remembered one of his sayings, *'I believe that a new day will dawn tomorrow and that in its light will be found an understanding of the nervous system. Mental as well as physical activity will then be recognised as a function of the brain and neurosurgery and psychiatry will lose the separate authority conferred upon them by ignorance until there remains only neurology. Neurology will then stand forth as a single discipline to which internists, psychologists, surgeons, chemists and physiologists will contribute.'* When his tenure in the USA was coming to an end, Dr Wechsler, along with John Fulton, the outstanding neurophysiologist, and Joseph Globus, the neuropathologist, called him and promised him a bright future in New York. However, Dr Ghosh declined the offer and expressed his desire to return to India at the earliest.

Dr Ghosh was always in communication with his mentor, Dr BC Roy, during his period of stay at Mount Sinai and would apprise him about the need of an EEG machine for the diagnosis of epilepsy and some other neurological conditions. This was further buttressed by

a letter from Dr Wechsler, who certified his progress. He joined the Carmichael Medical College, his alma mater, and incidentally, from where Dr BC Roy too, finished his undergraduate medical career, after being rusticated from Medical College, Bengal for his upright stance and righteous anger against the high-handed British administrators. Dr Ghosh, however, had the uncanny feeling of not being much welcome and found the authorities reluctant towards the growth of neurosciences as a separate discipline and they even refused to purchase an EEG machine, and that too, after Dr BC Roy, possibly, the most notable personality from Bengal had recommended.

Troubled by the horrors and harshness, trials and tensions in order to create a department in his alma mater, Dr Ghosh realized that his life would soon be docketed into an insignificant hole and therefore, he chose to move to the Presidency General Hospital in order to initiate a new Department of Neurology, in spite of the fact that it was a teaching centre. Again, he was not treated favourably and was asked to set up his department in a derelict and decrepit corner of one of the dilapidated buildings and he soon refurbished it into a workable laboratory. He once wrote, *'At Dr Roy's suggestion, in 1949, I went to Col. NC Chatterjee, Surgeon Superintendent...., with a scheme for the EEG department, a sketch plan and Dr Frederick Gibbs' book on electroencephalography— my personal copy. These languished in the Writers' Buildings till 1951...'* His efforts in the new place were successful to a large extent and a new Postgraduate Medical Institute was created by the combined effort of some other luminaries of that time, which still exists as the forerunner for training postgraduate and post-doctoral students in the city. After the EEG department was opened on the 2nd of May 1951 and inaugurated by Dr BC Roy, he submitted a scheme for the creation of a combined department of neurology and neurosurgery and in 1954, the posts for one senior neurosurgeon, two junior neurosurgeons, one neurologist and one psychiatrist were sanctioned by the Government of West Bengal.

True to his vision and foresight, Dr BC Ray during one of his visits to Vienna, invited Dr Herbert Kraus, the noted neurosurgeon, to come to Calcutta and train the aspiring neurosurgeons. Dr Kraus came in 1955 and trained a number of them, most notably, Dr Ashok Kumar Bagchi, the former President of the Neurological Society of India, who spent some time in Vienna with him as well.

A curious association took place between Dr TK Ghosh and a noted industrialist, hailing from the Bangur family in Calcutta, who had been suffering from a tumour in the brain and Dr Kraus operated on him. The surgery was successful and the patient's family happily donated a sum of rupees three lakhs which helped Dr Ghosh establish the Bangur Institute of Neurology inside the premises of the Institute of Post-graduate Medical Education and Research. The Institute came into existence on the 10th of June 1962, when Dr BC Roy inaugurated it. This was his last public meeting, twenty-one days before his sudden death when the city was actually celebrating his eightieth birthday. Things took a turn for the worse for Dr Ghosh after the demise of Dr BC Roy and he was soon transferred to a different college. He summarily resigned from service though at a later date was appointed as Honorary Professor and Director in his old place of work, where he continued till 1971, the year of his retirement. Thereafter, he served as a Consultant in various hospitals and was inducted into the Board of a number of pharmaceutical companies, in various capacities, in Kolkata.

If Dr Ghosh deserves the appellation of the founding father of neurosciences in Kolkata, it bears recall that another eminent neuroscientist from Kolkata, Prof. RN Roy, considered to be one of the founders of neurosurgery in the city and the first ever Resident of Professor Jacob Chandy at the hallowed Christian Medical College, Vellore, continued from where Dr Ghosh left, and his tireless effort, ably assisted by his contemporaries and students, helped the Bangur

Institute of Neurology to achieve a place of eminence. However, by every analysis, Dr Ghosh's greatest contribution to the growth of neurosciences in India was in the creation of the Bangur Institute of Neurology.

Dr Ghosh had abiding and lasting connections with the Neurological Society of India and he was instrumental, among others, to disseminate the spirit of such an academic society throughout the country. When it was initially founded in Patna in 1951, it consisted of only four members, namely Jacob Chandy, B Ramamurthy, Baldev Singh and ST Narasimhan. Dr Ghosh joined the next year at the insistence of Prof. Ramamurthi and became its second President in 1953, succeeding Prof. Jacob Chandy, while Prof. Ramamurthi continued as the Secretary.

Dr Ghosh's primary interest lay in the study of epilepsies and he conducted a number of studies on this subject, particularly based on the grants from the Indian Council of Medical Research. He was one of the earliest examiners for DM in neurology and incidentally Prof. Gourie-Devi, the eminent neuroscientist, who was trained at the All India Institute of Medical Sciences with Prof. Baldev Singh, was his first examinee in 1968. She once told me that Dr Ghosh could recall the cases and her answers in the examination whenever he met her anywhere. He received the '*Most Prominent Teacher in Medicine Award*' from Calcutta University and the prestigious Barclay Medical Award of the Medical Society. He was the President of the Science Club of Calcutta, Director of the Rotary Club, Calcutta and was also in the field of art and music in various societies of the city.

My personal association with Prof. Ghosh was limited; I fastened onto neurology when he retired from active practice of neurology, both in terms of academic inputs and actual management of patients and he was then basking in the glory of the past and not even able to

communicate properly. Though his failing health was not permitting him to function with the same vibrancy and ebullience, he did not lose much of his old vivacity and alacrity and was always ready to join an occasional meeting in the city. Whenever, I met him, I found him talking to the senior professors and I kept lurking behind somewhere, and yet I could feel his penchant for literary allusions, which again, was virtually the trademark of his generation. With all humility, I submit that he struck a responsive chord with me somewhere and somehow, though it is not yet clear to me how it all happened. Later in his life, he was particularly distressed at the quality of teaching in neurosciences, was particularly vocal about the system of recruiting teachers in the institute he built with his sweat and blood. Once he lamented, *'I had to fight and suffer in my persistent effort at creating facilities and providing a 70-bedded neuroscience institute. The progress, however, has been slow. Things have worsened since my retirement and will continue to do so unless the present incumbents are energetic and devoted. The separation of the departments of neurology and neurosurgery is a retrograde step. It is not pleasant to witness one's life's work being dismantled... but such is the world... The current status of neurology, neurosurgery and the neurosciences in general remains undefined, exposed to continuous onslaught from various quarters. Lure of financial gain and higher administrative positions induce some promising neuroscientists into joining the stream for power. Attempts are also noted to submerge the neurosciences into a secondary position. We need institutes of neurology in different regions of India and the performances of our neuroscientists must be re-evaluated... Neurologists are facing competition not only from specialists in general medicine but also from neurosurgeons who are usurping patients who do not have surgical problems. The cooperation between neurologist and neurosurgeon that we dreamt of has disappeared, There is senseless competition between them.'* Once in a meeting at his residence, way back in 1987, when I was virtually a toddler in neurology, he asked me to join in order to

listen to a few words about his disappointments and tribulations. He exclaimed in utter exasperation that his dreams had fallen apart and he had little in his life to look forward to. He died an unhappy man on the 9th of April 1996. Prof. RN Ray from Calcutta, Prof. Sunil Pandya from Mumbai and Prof. S Kalyanaraman from Chennai have written exhaustively on his life and works. These are contained in a wonderful volume, entitled, *'Evolution of Neurosciences in India'*, edited by Prof. Rajasekharan Nair from Thiruvananthapuram, Kerala. The legendary Prof. B Ramamurthi too, alluded to his association with Prof. Ghosh in his magnificent autobiography, *'Uphill All the Way'*.

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Photo courtesy—Dr VS Saxena

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## My reminiscences of Dr TK Ghosh

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by Dr RN Roy

Dr Tarit Kumar Ghosh was born in Howrah, West Bengal on 23 January 1912. He received his medical education at the then Carmichael Medical College (presently RG Kar Medical College) from 1931-37 and MD (Medicine) from Calcutta University in 1944.

My association with Dr Ghosh dates back to February 1957 when I first met him at the Neurological Society of India annual meeting held in Agra which was attended amongst others by Prof. Wilder Penfield of Canada. Dr Ghosh invited Prof. Penfield to visit his centre at Calcutta, the first Department of Neurology established by the Govt of West Bengal at the SSKM Hospital campus, Calcutta in May 1955. Prof. Penfield visited the Department in 1957. Dr Ghosh later told me that the idea of setting up an Institution of Neurology in Calcutta had taken roots in his mind after his meeting with Prof. Penfield.

The idea, however took time to take a concrete shape. Dr Ghosh motivated a beneficiary, a patient belonging to an established commercial house in Calcutta, who was operated at the SSKM Hospital, to donate a handsome amount of money towards the establishment of an Institute of Neurology. Accordingly the money was donated to Govt of West Bengal and with the active support



of the then Chief Minister Dr BC Roy, the foundation stone of the proposed Bangur Institute of Neurology was laid on 10 June 1962. This event was perhaps the most significant contribution by Dr Ghosh to the cause of neurosciences in the eastern part of the country.

Bangur Institute of Neurosciences (BIN) (as it is now called) has grown and become the foremost centre of training, teaching and research in neurology, neurosurgery and allied sciences. Dr Ghosh trained a number of postgraduate students during his stint of 30 years as a teacher of neurology at the Institute of Postgraduate Medical Education & Research (IPGME&R), Calcutta and BIN, Calcutta. Epilepsy was Dr Ghosh's lifetime passion. He was a National Investigator on Epilepsy under the ICMR, a member of the Expert Committees of various Universities and similar Institutes in the country.

Among the various awards and honors he received were: the "Most prominent teacher in Medicine Award" of Calcutta University and the prestigious Barclay Medal Award of the Asiatic Society, Calcutta. He delivered the Ronald Ross Memorial Oration of IPGME&R, Calcutta. Prof. Ghosh was elected the President of the Neurological Society of India in 1953.

He had many other interests as well. He was President, Science Club, Calcutta, President, West Bengal United Nations Association of Calcutta (1963), Director, Rotary Club, Calcutta and President, Presidency College Alumni Association, Calcutta (1985–86). Prof. Ghosh was an active member of various musical societies of the city.

His wife, Mrs. Kalyani Ghosh is a distinguished singer of Rabindra Sangeet and has a number of albums to her credit. They are blessed with two daughters.

A father figure of neurology in the country, Dr Ghosh passed away on 9 April 1996 after a brief illness.

(Dr RN Roy is Senior Consultant Neurosurgeon, Park Clinic, Kolkata)

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Dr K S Mani (1928 – 2001)

President—Indian Epilepsy Association  
(1986 – 1989) and (1996 – 1998)

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by Dr HV Srinivas

Kalayanasundaram Subramaniam Mani, (KS Mani) was born on 18 October 1928 in Madurai, Tamil Nadu. His father was Prof. of Therapeutics at Madras Medical College. He received his BSc degree in 1947, MBBS in 1952 and Postgraduate degree in Medicine (MD) in 1956 from Madras Medical College, Madras. Subsequently in June 1957 he joined All India Institute of Mental Health, Bangalore, then a Mental Hospital. He learnt clinical neurology and EEG from Dr Leiberman of UK who was a neuro-psychiatrist appointed by WHO. In 1960 he went to UK and took advanced training in neurology and neuropathology at the famous National Hospital for nervous Diseases at Queen Square London, and Maida Vale Hospital, London. After his return to India he continued to work in Bangalore, climbing the ladder from the post of research assistant to that of Prof. and Head, Dept of Neurology and for a brief period as Director of NIMHANS. All India Institute of Mental Health was under the Central Government and the Mental Hospital under the Government of Karnataka. Dr Mani along with Dr RM Varma and Dr GN Narayan Reddy popularly called as “Trios” worked relentlessly to amalgamate the two into one autonomous unit and thus the National Institute of Mental Health and Neuro Sciences (NIMHANS) was formed in 1994. It was my good fortune that Dr Mani persuaded me to leave Gulbarga and join NIMHANS.

He was a very strict disciplinarian and at times short-tempered but very affectionate and had a strong personality belying his diminutive stature and frail physical frame! He instilled discipline and regularity of maintaining the teaching session at NIMHANS which is continued even to this day.

At the time of my joining NIMHANS, I still remember that he ended his brief introduction saying that he did not like “calendar gazing“. On seeing my puzzled look, he explained that he did not like the trend of government employees looking at the holiday list and applying for leave so that they can have a long weekend or an extended holiday. Of course for him there was no holiday at all! He was well known for eliciting and documenting history and meticulous neurological examination. He built up the department of neurology and worked on several projects with scientific contributions.

When he was In-charge Director of NIMHANS, in addition to being the Head of Neurology Department, he would strongly recommend, as Head of the Department, for purchase of some equipment but once he sat in the Director’s chair he would reject his own application giving priority to other Departments!

His seminal contributions include clinical description of hot water epilepsy, South Indian paraplegia which later was termed as tropical spastic paraplegia, a study of epidemiology of epilepsy in India under PL 480 scheme, ICMR along with other neurologists in different centers. He took voluntary retirement in 1978 and started private practice.

As a practicing neurologist he was meticulous in record keeping and would write down the case sheets himself. He restricted his practice to patients with epilepsy and spent considerable time in history taking, clinical examination and writing the case record. Patients

used to feel that too much time was being spent for history taking and examination; while the trend was that doctors did not have time to listen to the patient's complaints. He not only spoke about medical aspects but used to spend considerable time emphasizing on the various social aspects of epilepsy. That was his passion. If the patients were irregular for follow-up he used to feign anger and shout at them only to pacify and talk to them in a very friendly manner, before they left the room. He was ably assisted by his wife Dr Geeta Rangan a neurologist who had a knack of playing with the EEG machine, so much so that she could knock it down and reassemble it!. She was indeed very good at attending to the finer details of the machine and EEG records.

Dr Mani's special interest was social aspects of epilepsy, patient and public education. He was a master in demonstrating various types of seizures on stage so much so that we used to tell him that, if at all he had a genuine seizure, it may be difficult for us to diagnose it !

My association with him strengthened further when we jointly undertook the Yelandur Epilepsy Project in 1990 which went on for over five years. The trips to Yelandur was initially once a month, at our own cost. He did not believe in asking for funds. A population of 65 thousand spread over forty villages and eleven tribal villages were covered for epidemiological study. Persons with epilepsy were identified and given free antiepileptic drugs delivered to the door of the patients and followed-up. The important outcome of this is the study of natural history of untreated epilepsy in the community published in international journals and widely quoted. The antiepileptic drugs phenobarbitone and phenytoin were obtained gratis from pharma companies and distributed free, every month, practically at the doorsteps of the patients through the primary health care workers who were also distributing anti-tubercular and anti-malarial drugs. He was meticulous to the point of obsession,

with regards to punctuality, record maintenance and analysis of data.

His penchant for micro management is exemplified by the fact that he used to affix postal stamp on all the Newsletters of the IEA-Bangalore Chapter, and then take it personally to the postoffice for bulk posting! When he used to pull me up saying that I should spend more time in the field of epilepsy, I argued that I am a general neurologist with special interest in epilepsy and not an epileptologist like him, who breaths epilepsy, eats epilepsy and lives epilepsy!

He has over 100 publications in national and international journals and in popular textbooks of epilepsy. He is known as the father of epilepsy in India for his contributions to the epilepsy movement in India.

He was the founder member of Indian Epilepsy Association, Central Office and also IEA Bangalore chapter both of which he nurtured for nearly three decades till his death. He was elected as the President of Neurological Society of India in 1972, Secretary General of IEA (1991–1996) and President of IEA for two terms (1986–1989) and (1996–1998). He was instrumental in relentlessly pursuing, for over twelve years, to get the amendment of Indian Marriage Act to delink epilepsy from divorce.

He held many honorary positions, including Honorary Consultant in Neurology to the Armed Forces Medical Services. He was Member of the Indian Council of Medical Research Expert Committee in Neurology, Fellow of the Academy of Sciences, Fellow of the Academy of Medical Sciences, Vice-President of the International Bureau for Epilepsy (1989–1993), and, from 1989 to 1993, Chairman of the joint ILAE/IBE Commission on Developing Countries. He was the president of the 18th International Epilepsy Congress held in New

Delhi and along with Dr Maheshwari, Secretary-General made the congress a great success and memorable event. He was the President of IEA, 18th IEC Trust from 1992–1998.

He received the Lifetime Achievement Award from the TS Srinivasan Department of Clinical Neurology and Research, Public Health Center in Madras. He is the only Indian bestowed with all the three prestigious awards by International Bureau for Epilepsy and International League Against Epilepsy (IBE–ILAE), the Ambassador for Epilepsy award(1975), Social Accomplishment award (1997) and Lifetime Achievement award (2000). Unfortunately he did not live to receive the last award.

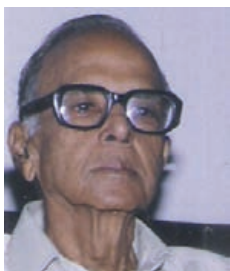
He donated all his prize money from local societies and IBE /ILAE to IEA. IEA did not fail him as Bangalore Chapter started KS Mani Memorial Patient Session in all its annual conferences , the most apt way to perpetuate his memory. He was a singer and had training in music, and also a dramatist, which he used freely to demonstrate various types of epilepsy.

His sudden demise after a brief illness has left a void in the field of epilepsy.

His wife Dr Geeta Rangan a neurologist died prematurely in March 2010.

(Dr HV Srinivas is a Consultant Neurologist at Sagar Hospital and Agadi Hospital, Bangalore)

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**DR B RAMAMURTHI (1922 – 2003)**

President—Indian Epilepsy Association

(1991 – 1994)

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by Dr AV Srinivasan & Dr MB Pranesh

### **Early life and education**

Dr Ramamurthi Balasubramaniam was a globally renowned neurosurgeon, author, editor, a pioneer in neurosurgery in India and often recognized as the Father of Neurosurgery of India.

Dr Ramamurthi was born on 30 January 1922 in Sirkazhi, South India. His father Captain TS Balasubramaniam was an Assistant Surgeon in the Government Hospital. His grandfather's brother Shri G Subramania Iyer, was one of the founders of the English daily 'The Hindu'. He studied at the ER High School in Trichy. He completed his MBBS at Madras Medical College, Madras in 1943 and was awarded the Best Outgoing Student and the "Johnstone Gold Medal". He completed MS in General Surgery from the Madras Medical College and went on to complete FRCS at Edinburgh in 1947.

The young Dr Ramamurthi was selected by the Madras Government for training in neurosurgery and left for Newcastle in January 1949. He received training under Prof. GF Rowbotham at Newcastle, and then spent time with Prof. Geoffrey Jefferson at Manchester. He visited various centers in Europe. In 1950, Dr Ramamurthi proceeded to the Montreal Neurological Institute and spent four months with Prof. Wilder Penfield. On completing his training he



returned to Madras, bringing back with him the traditions of the British, American, Canadian and European schools of neurosurgery. In his words “one must be precise to be a neurosurgeon” and for that precision he considered mental and physical discipline a must. He would never miss coming to the hospital or seeing patients. Even when he was unwell and unable to walk, he made ward rounds in a wheelchair! He was keenly interested in music and its effect on the brain, as he was in “Consciousness”.

### **Career**

He started the Neurosurgical Department, in 1950, at Government General Hospital, Madras and the First Head Injury Unit in India. He started the Dr A Lakshmipathi Neurosurgical Centre at the Voluntary Health Services (VHS) Hospital at Adyar in 1977-1978, named after his father-in-law, Dr A Lakshmipathi.

His interest in epilepsy began when he was getting trained in 1948 by Dr Penfield at Montreal Institute of Neurology (MIN), which was the first institute in the world to have all branches of neurosciences under one roof. The six months stay there stimulated him in various aspects of neurosciences. In his studies on epilepsy, Dr Penfield was helped by Dr Jasper, who took EEG to great heights.

Dr Ramamurthi felt that there should be an institute on the lines of MIN in Madras. Thus, the Institute of Neurology, Madras came into existence in the early 1970s after tremendous struggles with politicians and bureaucrats. Stereotaxy was becoming a tool for research and also for therapy. He also started the first epilepsy clinic in India in a govt hospital where free drugs were given for a week at a time which was a great boon to the patients. The first EEG machine in India was installed by Dr S T Narasimhan, in his Neuro Hospital at Kilpauk, Chennai.

Dr Ramamurthi, an accomplished clinical neurosurgeon, brought to the bedside all his skills as a superb clinical neuroscientist. His diligence and orderliness was remarkable. His perception of clinical sense was a creation and the memories of classes a recreation. His teaching was uncomplicated, memorable and practical. He advocated clinical neurology as the pillar of neurosurgery and integrated the science of neurosurgery with the basic sciences. For three decades, he was responsible for recruitment, selection and training of neurosurgeons, leaving his imprints on the lives of generations of young neurosurgeons in the country.

Stereotaxy was introduced by him with the help of Dr Col Sangamlal, – Surgeon General of Madras Presidency and later with the help of Dr RG Krishnan, Dean of MMC. He was joined by Dr V Bala Subramaniam, Dr TS Kanaka and Dr S Kalyana Raman – the former two were trained by Dr Narabayashi in Japan and the latter by Prof Gillingham in Edinburg.

Dr Ramamurthi was one of the pioneers to establish and promote stereotactic surgery in India. Along with his colleagues he succeeded in making the Madras Institute of Neurology an international leader in the field. Besides using it for patients with movement disorders, its scope was extended for use in the management of epilepsy, pain relief, cerebral palsy, drug addiction and some psychiatric disorders.

Dr G Arjundas and Dr K Jagannathan added to the medical neurology care of epilepsy patients. Funds were wanting for the Epilepsy program; luckily the US Govt chipped in with the PL 480 fund — which gave a big boost for epilepsy care and research. A new Swedish EEG machine was acquired. EEG papers were scarce those days as they were imported. Dr Arjundas started recording on of the back side of old EEG paper. The epilepsy proforma was brought

out which took six months of hard work with repeated discussions. This document is valid even today. As the need for a Biochemist was felt for better treatment of patients, Dr K Valmikinathan was sent to Queen Square, London for one year training with Dr Cummins, the father of Neurochemistry. He returned with a Gas Chromatography machine – a gift from Dr Cummins – which helped in testing anti epileptic blood levels and in conducting many other tests.

With training and experience gained at the Montreal Neurological Institute, surgery for epilepsy was started. Several procedures like cortical ablation, hippocampectomy, amygdalotomy, temporal lobectomy were done by the team headed by Dr Ramamurthi. Dr Zaheer Ahmed Sayeed joined after training in Montreal. He introduced cortical electrography after craniotomy in the surgical treatment of localisation related epilepsy. Dr Arjundas introduced sphenoidal recording for all TLE patients. These were the first in the country. Only three drugs were available those days to treat epilepsy — diphenyl hydantoin, gardenal and mysoline. In 1979 there were roughly 14,000 recorded patients of Epilepsy ! The follow-up was inadequate , as it is even today, but that does not take away the merit of the work done. Dr S T Narasimhan, who was in charge of the EEG, requires a special mention here. He was trained in New York Institute of Neurology and was an Honorary but a fulltime worker. He had profound clinical knowledge and skills but unfortunately never got the teaching post as he was an LMP. His appointment as Hon Prof of Electroencephalography came a few days after his death. By the early sixties, referrals increased, mortality reduced and neurosurgery was accepted by his colleagues and the public. Temporal lobectomies were started only in the mid-sixties.

Dr Ramamurthi served as the Dean of the Hospital and Principal of the Madras Medical College and Honorary Vice-Chancellor of the Madras University during his long and extensive years as a teacher,

mentor and guide. He was appointed as the President of the World Federation of Neurosurgeons in 1987 and also served as the former President of the National Board of Medical Examinations in India. Amongst the many units of neurosurgery he helped set up, the National Brain Research Centre (Manesar), as an apex body for the coordination of brain research in the country, was his dream come true.

He was a Fellow of the (i) National Academy of Medical Sciences, (ii) Academy of Sciences, (iii) Indian National Science Academy and (iv) Royal Society of Medicine of London. He was the Founder Secretary of the Neurological Society of India and Founder Editor of Neurology India. He was the Founder President of the Accident Victims Association, amongst many other things.

He has over a hundred publications in peer reviewed journals. This included various facets of diagnosis and treatment of a variety of tumors — especially pituitary adenomas and acoustic neurinoma, slow-growing gliomas or craniopharyngiomas. New clinical signs were described. Aphasia and bilingualism were studied, as was use of biofeedback technique and yoga for disorders of the higher nervous system. His scientific publications dealt with the prevention of head injury, strategies to reduce mortality, management of intracranial hematomas, growing skull fractures and post-traumatic psychological effects. He was invited to write a chapter for the Handbook of Clinical Neurology edited by PJ Vinken and GM Bruyn. He took part in the Hans Berger symposium in Edinburgh in 1970 and presented his work on epilepsy, including the psychological aspects. He was the Editor of the I and II editions of Textbook of Neurosurgery; Consulting Editor of Textbook of Operative Neurosurgery (in press); has served on the Editorial Advisory Board of many national and international journals including the Journal of Neurosurgery, Indian Journal of Surgery and Surgical Neurology.

His involvement in social activities started from his college days when he joined the 'Quit India' movement in 1942 and was imprisoned. His heroes were Gandhiji and Churchill. He was vocal and actively involved in movements against unjust laws affecting female epilepsy patients, and worked incessantly for the introduction of a law favoring the use of crash helmets.

He addressed the IMAs emphasizing various aspects of epilepsy and head injury. He had a missionary zeal to do good for the common man, deeply influenced by Gandhiji's ideals. He was a patriot to the core and wanted India to be a leader in the fields of neurology and neurosurgery. While on the one hand he went to address the smallest branches of the Indian Medical Association in remote areas, he was an eagerly sought after person to advise the highest policy-making bodies like the ICMR, DST, DBT, Health Ministry, etc.

### **Honors & Awards**

He was (i) Honorary Surgeon to the President of India (ii) Honorary Brigadier, Indian Army. He was awarded the Padmashri, Padma Bhushan and the Dhanwanthri Award. He was recipient of Sir John Bruce Gold Medal from the Royal College, Edinburgh.

The Dr Ramamurthi Neurosciences Museum was established at the VHS Hospital on his 80th birthday, in 2002. He was hopeful that the museum would one day become the national museum of neurosciences, thus placing on record the efforts of those who strived to develop the specialty in the country.

He wrote his autobiography titled "Uphill all the way" which was released by the Chief Minister of Tamil Nadu, Sri Karunanidhi in January 2000.

He was married to Dr Indira Ramamurthi, an obstetrician and gynaecologist and is survived by two sons, Vijayaraghavan Ramamurthi, a journalist, and Ravi Ramamurthi, a neurosurgeon.

(Dr AV Srinivasan is Emeritus Professor, Dr MGR Medical University and former HOD & Professor of Neurology, Institute of Neurology, Madras Medical College)

(Dr MB Pranesh is Emeritus Professor of Neurology and former HOD, PSG Institute of Medical Sciences and Research, Coimbatore)

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## DR ANUPAM DASGUPTA

President—Indian Epilepsy Association  
(1994 – 1996)

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I was born in Kolkata on 1 October 1934. I completed my premedical education at Presidency College, Kolkata and joined Calcutta Medical College in 1951. Throughout my education I received scholarships and also won several gold medals. In the final MBBS examination I stood first in the University. Subsequently I did PhD under Dr JA Simpson in Northern General Hospital under the Edinburgh University. I was the only person from Asia to receive the Edinburgh University Fellowship to do PhD in EMG and Neurophysiology. In 1959, I passed MRCP from Edinburgh with neurology as a special subject in my first attempt. In 1970, at the age of 36, I was the youngest Fellow from Asia to be awarded FRCP (Edinburgh). In 1972, I was awarded FRCP (USA), and in 2004, FRCP (London).

### **Training**

My main training in neurology was under Dr JA Simpson in Northern General Hospital, a wing of Edinburgh University, for over 3 years; and in Mount Sinai Hospital, Chicago (a wing of Chicago Medical School) for two years.

After 20 years of service, in 1990, I took voluntary retirement as Professor and Head of Neurology Department of NRS Hospital,

Kolkata. I have trained several MBBS, MD (Medicine) and DM (Neurology) students and was examiner for MBBS, MD and DM, DNB and PhD courses of many Indian Universities.

### **Contribution to neurosciences**

I still take active part in developing neurology in eastern India. I have about 100 publications in national and international journals to my credit and have contributed chapters on neurology in textbooks and other books (about fifteen in number) and was the Associate Editor, Journal of Neurology (an NSI publication). Besides being the President of Indian Academy of Neurology, I was also the President of Indian Epilepsy Association (Central Office) and WB chapter and ex. President of Rotary Club of Calcutta (South Central).

I am a recipient of the lifetime award for services in neurology from: Indian Academy of Neurology along with Asian-Oceanian Neurology Society; Indo-Canadian Neurology Society along with Calcutta Neurological Society and Madras Neuro Trust. For academic upliftment, I have contributed to scholarships to merit students of 10 schools in 24 parganas in West Bengal for the last 10 years. I have also contributed money to poor students and helped to lay water supply lines, latrines, hostels in 10 schools in West Bengal and one in Bangladesh. I have been conducting medical camps in West Bengal 3–4 times a year for the last 10 years, and the money earned is given away to poor patients to buy medicines and to poor students to buy books and pay examination fees.

I am married to Chitra Dasgupta, a homemaker and am having two sons. The elder son has done his MBA from Rochester University, USA and is now working in Buffalo, USA as Senior Vice-President in a bank. The second son has passed MD, MRCP and is now working in UK as CCST.



I am presently working as Head & Director of Neuroscience (Medicine), AMRI Hospital, Dhakuria, Kolkata.

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## DR DEVIKA NAG

President—Indian Epilepsy Association  
(1998 – 2000)

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I was born on 28 December 1938 at London Hammersmith hospital, UK. My father was Col. Sukumar Nag, who opted to become a doctor and joined the Indian Medical Service (IMS) in London. My mother was the grand daughter of Rai Bahadur Jagdish Chandra Guha of Mymensingh of East Bengal. I lost my father when I was 3 years old and my younger sister was a few months old.

My mother was devastated at the young age of 22 years. She was determined to educate both of us and I was sent to the Calcutta La Martiniere Girls School. I was precocious for my age and did not find studies too hard. I got two double promotions from standard 1 to 3 and again from standard 6 to 8. After a couple of years at Christ Church, Lucknow, I went to Loreto Convent. I was very studious and hard-working and stood first in all exams in school. In 1954, I stood 1st in Senior Cambridge from Loreto Convent in UP and was awarded a two years merit scholarship. I was and still am passionately fond of reading literature, biography, philosophy, fiction, non-fiction, poetry and detective stories. I did not at that time ever want to be a doctor. My dream was to become a writer of best sellers. My mother thought this was impractical and suggested that several famous writers like AJ Cronin, WS Maugham and Chekov were doctors initially. Reluctantly I joined the famous Isabella Thoburn College in 1955 and passed intermediate science in 1957. I obtained 1st position

among the women candidates in the premedical test in UP and got a one year merit scholarship. I joined the prestigious King George Medical College, Lucknow in 1957 and passed MBBS in 1962 with eight gold and two silver medals, followed by MD (medicine) with three gold medals including the Vice-Chancellor's gold medal for the best postgraduate women student in Lucknow University. Needless to say that residency those days in medicine was male dominated and some of my male colleagues made attempts to make me leave medicine in disgust and opt for gynecology or pathology which were considered ideal for women. The faculty too was reluctant to take me in. I remember my most senior teacher telling me "what is the use of your doing medicine, you will get married; you should learn to cook well; you will be depriving a male candidate of this seat." The challenge to prove otherwise was profound and I grimly held on until exams were over. Once the faculty found I was willing to work long hours and harder than the others they encouraged me.

When I was doing my MD residency, Prof. PN Tandon, who had just arrived from Montreal was working in the Department of Surgery as a neurosurgeon. I was always sent to him for referrals as he invariably started seeing cases late in the afternoons only, after his operations were over. I was impressed by his meticulous history taking and detailed neurological examination. Prof. NN Gupta under whom I wrote my thesis was especially interested in neurology and this made me want to become a neurologist. In the 1960's the war in Vietnam with involvement of USA led to many young doctors being drafted as a result of which several vacancies were available for residency in USA. I was thrilled to have finally made it to Harvard and I felt lucky to have been chosen. The teaching and the research there showed me how little I knew of neurochemistry, neuropharmacology, neuropathology and electron microscopy. In 1972 I undertook a postgraduate course at the National Hospital, Queen Square, London. On returning to India I was at a loss as to what to do. There was no Department of Neurology

in Uttar Pradesh. Neurology cases were always a part of Department of Medicine. I worked with the newly built Vivekananda Polyclinic from 1971 to 1973 where I did clinical medicine and neurology with minor surgery without any recourse to EEG, EMG or radiology. On joining I found that there were no other facilities that were taken for granted in Boston. I had six beds in the verandah of Medicine ward and took classes, rounds and OPD for students in medical neurology. Luckily by the herculean efforts of Prof. NN Gupta in 1975, a full fledged Department of Neurology was created in KGMC with 32 beds. I was appointed head with two lecturers and residents rotating from medicine, psychiatry and neurosurgery. I was appointed as Professor and Head of the first independent department of Neurology in the state in 1977. It was an uphill task all the way. I was intrigued to see seizures and other neurological syndromes in certain villages of UP. In 1976 the government of UP advised the Industrial Toxicology Research Institute (ITRC), Lucknow to investigate an outbreak of paralysis at Unnao district. Dr Zaidi the then Director needed a clinician and I went along with their team. After examining and analysing the cases it proved to be lathyrism due to high levels of manganese in the drinking water. Fluorosis was another problem in selected pockets of UP. These problems whetted my interest in neurotoxicology. Several papers were presented at NSI and IAN meetings and data published. We studied the effects of chronic exposure to organochlorine, organophosphates, pyrethrins and aluminum phosphide in humans. This could be replicated in the laboratory at ITRC.

In 1978 the first Clinical Toxicology unit (CSIR) was established in the Department of Neurology at KGMC—both ITRC and CDRI collaborated with us. From 1984–1988 we studied the effects of the Bhopal gas tragedy at Madhya Pradesh.

In 1981 the first DM neurology course was started in UP. I had two supportive colleagues Dr AM Kar (a wonderful organiser) and Dr

Rakesh Shukla (a meticulous academician). Later Dr Atul Agarwal another old student joined from Meerut Medical College and did yeomen work in epilepsy. I retired from KGMC on 30 June 1999 and was conferred Professor Emeritus in Neurology by Lucknow University. My experience of neurological cases in UP were quite different to what I saw abroad. I am glad I returned to India although I did go back a couple of times to USA when I was discouraged in Lucknow.

### **Awards & Honors**

I received the best teacher award from KGMC in 1991, 12 national orations (API, NSI, IEA, IAN, and IANSc.), UP Ratna Award 2007 and Bachawat Lifetime Achievement Award 2011 by Indian Academy of Neurosciences. Dr MS Sanjeevi Rao Oration 1977 Nizam's Institute of Medical Sciences (Hyderabad), Kamla BK Anand Oration, All India Institute of Medical Sciences (New Delhi). Dr BC Bansal Oration, IEA (Mumbai). IEA Presidential Oration on Gender and epilepsy: A clinician's experience 1999, Hyderabad.

### **Some of the positions held by me are:**

MCI inspector for DM and DNB (neurology) 1993–1995. Dean, Indian Academy of Neurosciences, 1994–96, Founder Fellow of Indian Academy Neurology, President of UP Neuroscience Society 1995–96, Fellow of American Academy of Neurology, Member of IBRO, Fellow of National Academy of Sciences, 1994. President of Indian Academy Neurosciences, 2000–2001, President of Indian Epilepsy Association 1998–2000. Vice-President of Indian Epilepsy Society, 1999–2000. President of Alzheimer's Disease and Related Disorders (ARDSI), Lucknow branch, 2000–2001. Honorary Consultant in Neurology, Armed Medical Forces India, 2001–2005. Vice-President II WFN Neurotoxicology division, 2001. I have been DM examiner at various postgraduate institutes.

I have 182 scientific papers, 8 chapters in national and 3 in international books, a monograph on 'A status report on neurotoxins', a book on 'Biological neurotoxins in India' (supported by Department of Environment and Forest, Govt. of India) to my credit. Conducted 1st and 2nd Epilepsy Workshops in KGMC, Lucknow, 1993 and 1994. President of UP Chapter of IEA, 1993. Initiated IE Newsletter UP Chapter, Lucknow, 1993 onwards Co-Editor Dr Atul Agrawal.

### **Public Education**

Regular public awareness programs on epilepsy especially in schools, rotary club, women's associations, NBRI, IMA are conducted. Epilepsy Day is celebrated every year with painting competitions for children with epilepsy. Also question-answer sessions for patients and family forum are held. Counselling of special groups children, adolescent girls and women with epilepsy are conducted.

I continue to be President of Indian Academy of Neurosciences, Lucknow branch, and am member of ICMR Task Force for research in Neurosciences under Chairperson Professor Gourie-Devi. I am a member of the Executive Council of the CSM Medical University (former KGMC) and am the Chairperson of the Ethics Committee at Dr RM Lohia Institute of Medical Sciences. I am grateful for the faith, wisdom and encouragement of my mother who by God's grace is still with me. My days are busy in neurological work and research; I still have time to read. I shall end with a quote by Robert Browning: "What I aspired to be, and was not, comforts me".

I am currently senior Consultant Neurologist at Mayo Medical Centre (a private hospital) in Lucknow.

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## DR BS SINGHAL

President—Indian Epilepsy Association  
(2000 – 2002)

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I was born on 23 January 1933 at Mount Abu, which is now in the state of Rajasthan. Before independence in 1947, Mount Abu was a centrally administered region. The Governor General of India had Mount Abu as his residence during the summer months. Nearly all the princely states of Rajasthan had their palaces in Mount Abu. The rulers used to bring their entourage to Mount Abu along with their personal doctors. The British used to send their soldiers for vacation and rest to Mount Abu. In school, every class had only 11-15 students. Several eminent persons visited this hill station, which had only 4500 inhabitants when I was born. Exposure to these persons and interaction with dedicated teachers of my school made a great impression on me in my early life.

We had a hospital called ‘Adams Memorial Hospital’ for the benefit of local residents. The cleanliness and hygiene were of very high standard. The attending doctor was an ‘LMP’ (Licentiate Medical Practitioner). The Medical Officer of the British troops used to make a weekly visit for general supervision. As a student and member of my school’s Red Cross Society, I used to give elementary help to the medical staff of the hospital along with my colleagues. This was my first exposure to the medical world.

My older brother used to get seizures. Regrettably, neither the local doctor nor the various visiting doctors of the Maharajas could diagnose his condition. Such was the state of ignorance prevailing at that time. Sadly, this did affect my brother's career. It was an Austrian physician Dr Robert Heilig (who was at the SMS Medical College, Jaipur, in 1949) who instantly made the right diagnosis from the history alone. I was at that time a premedical student in Maharaja's College, Jaipur. He prescribed 'Rutonal', a phenobarbitone derivative which was hard to obtain except from the representative of May & Baker (pharma company) in Mumbai. It controlled the seizures effectively for a long time. This was my first experience of how ignorant society and even the medical fraternity was with regard to epilepsy and how misdiagnosis ruined careers.

After completing my schooling in Mumbai in 1948, I did two years of premedical (inter science) at Maharaja's college in Jaipur. The attraction was that I received a scholarship of rupees 16 per month from Rajasthan University for standing in the merit list provided I studied in a college affiliated to Rajasthan University. After partition, Mount Abu was merged with Greater Bombay. When I finished premedical and sought medical admission, I faced a problem. I had the domicile of Bombay, so Rajasthan would not grant me admission, and Bombay University admitted only students who passed premedical from colleges attached to Bombay University. Fortunately Grant Medical College had four seats reserved for merit students from other universities. I got admission in this category having stood first in the Intermediate Science examination of Rajasthan University. Thus, Grant Medical College became my alma mater and I enjoyed my long association with this world-renowned college. These were probably the best years of my life with wonderful colleagues and excellent training.



After medical graduation I was fortunate to work under great teachers like Dr RV Sathe (physician), Dr JS Moos (cardiologist) and Dr NH Wadia (neurologist). After passing my MD in medicine I was encouraged to go abroad by my brother, and received guidance and help from Dr Moos and Dr Wadia. Dr Wadia was kind enough to give me letters of introduction to his colleagues and seniors in the UK. His recommendation helped me get a residency job at Maida Vale Hospital, affiliated to the Institute of Neurology at Queen Square, London. Dr Wadia's encouragement, guidance and support inspired me to take up Neurology as my career. During one of his visits to London, I accompanied him to the 'Chalfont Epilepsy Centre.' This visit and my brother's illness encouraged me to take keen interest in the care of patients with epilepsy. I learnt about EEG interpretation during this period. Thus I became a neurologist with special interest in the care of patients with epilepsy.

Dr Wadia was very keen that I join him as his junior colleague at the Grant Medical College and Sir JJ Group of Hospitals. Regrettably he was imprisoned in Lisbon (Portugal) when India invaded Goa. Despite being in such a stressful predicament, Dr Wadia had me in his thoughts and wrote to his colleagues to look after me and help in getting me appointed to his department at JJ Hospital. It was also his guidance which helped me get an attachment to a private trust hospital – Bombay Hospital (now a postgraduate Institute).

Dr Eddie P Bharucha and Dr Anil Desai (KEM hospital), Dr PM Dalal (Nair hospital) and Dr NH Wadia (JJ Hospital) trained several neurologists at these three great medical institutions. Dr Wadia initiated several activities which continue even today. At the JJ Hospital we had clinical sessions every Tuesday (akin to grand rounds in American universities and Wednesday teaching sessions at Queen Square) where interesting cases were presented and discussed. These continue even today. With the help of his colleagues

in other institutions, he set the precedent of monthly meetings on every second Saturday of the month. Such monthly meetings are now conducted by the Bombay Neurological Association. He was keen to start support societies for patients affected by neurological disorders; he helped create societies like the 'Spastics Society' and he was the founding member of Indian Epilepsy Association (IEA). His interests enabled me to involve myself in the activities of the IEA. In March 1972, with the start of the Bombay Chapter of IEA, Dr Chicot Vaz and I were made the joint secretaries. This was the beginning of my long association with the Bombay chapter of IEA. I worked hard to achieve the goals of IEA. I had guidance and encouragement from Dr EP Bharucha, Dr Anil Desai, Dr NH Wadia, and other seniors. We tried to educate the senior students and teachers in various schools through lectures. These were largely coordinated by our social worker Mrs Sarla Mody. This endeavour to educate and involve the young students continued for several years. We also attempted to increase awareness through the media especially radio and television. Lectures were also arranged through organizations like Rotary Club of India and Lions International.

I should acknowledge that, all along, I received great help from Dr Eddie Bharucha and his wife Mrs Piloo Bharucha. Eddie and Piloo took interest in several ventures. Greeting cards were printed and sold in aid of the Bombay branch of IEA. Lapel buttons with the IEA emblem for all IEA members and an epilepsy folder titled 'The Truth About Epilepsy' were also made. Other activities included painting competitions for school children, invited lectures by celebrities like Mr Sunil Dutt of Bollywood and academic sessions for medical students and family physicians. We enlisted eminent persons like the legendary cricketer Mr Vijay Merchant on the Advisory Board of our chapter. This helped in arranging press conferences and disseminating information about epilepsy in the newspapers.

There were several other notable events during my tenure as the secretary of the Bombay branch of IEA. In November 1974, IBE (International Bureau for Epilepsy) delegates Mr. George Burden, Dr Harry Meinardi, Dr Peter Jeavons and Dr Morris Parsonage visited Mumbai. We took this opportunity to organize educational programs in medical schools, lectures in corporate lecture halls and meeting of Lions club for the lay persons. We also arranged a television interview and a press conference. Their visit enabled us to establish important links with international organizations.

In the same year Dr SN Bhagwati (my neurosurgical colleague) got us a sponsorship from his cousin Mr Atul Bhagwati of Bhagwati Charity Trust for the making of a film on Epilepsy. Eminent film director Mr Shyam Benegal agreed to make the film without taking any charges for himself. A total of Rs. 45, 000/- went into making the film. A preview of the film, titled 'Epilepsy', was held at Liberty Mini Theatre in April 1976. Clearance was also obtained from the Film Censor Board for unrestricted public screening. The film was also shown at a Press Conference held at the Tea Centre in Mumbai in November 1976. It was then donated to the Films Division of India for dubbing in 14 languages and broadcast all over India.

All organizations need funds for their charitable activities. Keeping this in mind, I ventured to organize charity film shows with the help of my colleagues. Arranging such events requires a huge effort. I should acknowledge the help I received from Dr Ram Vatwani (a senior resident in Neurology at Grant Medical College at that time and now a consultant neurologist in Bahrain). The first such fund raising event was a charity film premiere 'The Return of the Pink Panther' organized at the Regal Theatre in December 1976. Dr Eddie Bharucha got us the theatre free of charge from his friend Mr Sidhva (who owned the theatre). In February 1981, the second fundraising Charity Film premier of Alistair Maclean's 'Bear Island' was shown

to a full house. Dr Ram Vatwani again helped to make this a huge success. On both these occasions we got a chance to screen Mr Shyam Benegal's film on Epilepsy.

Those were the days when we had no powerpoint presentations. We needed posters and banners to project what can be done for persons with epilepsy and what are the do's and don'ts. Fortunately for me Dr Pravina Shah (doing neurology at KEM hospital, Mumbai) knew Mr Arundekar, an artist, who made fabulous posters and banners for us. This also brought Pravina into playing an active role in promoting the cause of epilepsy (a big gain for the chapter). Pravina has been playing a big role since for the cause for epilepsy.

February 1981 was an important month for some useful and important happenings. With the help of my colleagues I organized the 'Epilepsy Week' from 15–21 of February 1981. Banners were put up at prominent petrol pumps; announcements were made in the newspapers and a press conference was organized.

During this week the film "Epilepsy" was screened and a panel discussion for the lay public on "Epilepsy & Society" was organized. The beautifully designed and informative posters on epilepsy were exhibited at the Birla Kreed Kendra at Chowpatty. Some of the other activities during the epilepsy week included radio talks, telecast shows, exhibition of documentary film in all theatres, a medical seminar with the help of Indian Medical Association for family physicians, talks for the lay public through Rotary club chapters, and lectures in schools and colleges. Posters were exhibited at railway stations and other public places. The poster exhibits became very popular and were frequently requested for exhibition by institutions and charitable organizations. Finally they were housed near the Neurology ward No 23 of JJ Hospital. Needless to say, all this would

not have been possible without the full cooperation I received from my colleagues and seniors.

Epilepsy awareness programs and lectures at various schools continued with the help of Mrs Sarla Mody through the following years. In 1983, I was happy that Dr Pravina Shah took over from me as the secretary of the Bombay chapter. From 1995 till date, the Bombay branch has wanted me to continue as the President of the Bombay chapter. It has been a matter of great joy and happiness to see the significant progress made by the Bombay chapter over the years. The new initiatives undertaken by Pravina and her colleagues have had a powerful impact on society at large. As secretary, she first organized business meetings at her residence at Dar-ul-mulk where she served delicious snacks. Now the meetings are held at their new office in a Municipal School Building, at Nana Chowk, near Grant Road Station in Mumbai which was very kindly given to them by the Mumbai Municipal Corporation. In 1992 it was decided that 17 November would be designated as National Epilepsy Day each year. Cultural activities and educational seminars are organized regularly by the Bombay chapter.

At the new office premises Pravina and her colleagues started the 'E-cell' with several activities. Yoga classes, Art and Craft teaching sessions, counseling and support group meetings are regularly held at this centre. A helpline is also run from this office. Pravina was also instrumental in creating the 'Samman group' – their members meet regularly at this centre and have excelled in many spheres. Pravina is a source of inspiration to people like Carol D'Souza, Kavita Shanbag and others who have become totally involved with her E-cell and Samman group activities. A member of the Samman group, Kavita Shanbag, wrote and sang a theme song on epilepsy which has received great praise and appreciation both in India and abroad. Urvashi Shah, well known clinical psychologist, has

given a great hand to support these activities and deserves due acknowledgment.

At the national level it has been a pleasure for me to attend the annual meetings of the Indian Epilepsy Association (IEA) designated as ECON. I participated in the 20th International Epilepsy meeting in Oslo, Norway in 1993 and presented data on epilepsy and neurocysticercosis in the congress workshop on 'Epilepsy in the tropics' at the same meeting. I was elected as President of IEA in 2000 and Indian Epilepsy Society (IES) in 2003. The community has given me much more than what I deserved for whatever I did as my duty. It honored me with several orations and awards. I was invited to give the Prof. BM Sharma Oration, at the ECON of Indian Epilepsy Association at Jaipur in 2005.

Besides my involvement with care of persons with epilepsy, I took keen interest in other societies caring for patients with neurological disorders. I have been involved with the activities of Multiple Sclerosis Society of India (founded by late Mr Tobaccowala) from its very inception. I founded the Parkinson's Disease and Movement Disorder Society in 2001. As a secretary of this Society and with the help of my colleagues like Dr Jimmy Lalkaka and Dr Urvashi Shah, I organized the '7th World Parkinson's Day International Symposium' in Mumbai in 2003. The Society now has 10 support groups in Mumbai and has recently started a new chapter each in Nasik and Goa. I am grateful to the coordinator Dr Maria Barretto for the great work she has done to promote the cause of Parkinson's disease and its care givers. As a practicing consultant neurologist I continue to care for patients with neurological disorders including epilepsy. Together with my colleagues I have been organizing well attended educational programs (titled Neurology Update, Mumbai) every alternate year since 1996. Internationally renowned Epileptologists like Profs Jerome Engel, Tim Pedley, Olivier Dulac, Sohel Noactor,

Hans Luder and Simon Shorvon have been invited to talk on various aspects of epilepsy. I am very pleased at the significant advances that have taken place in recent years in the medical and surgical management of epilepsy with newer diagnostic tools, newer drugs, and surgical techniques. It gives me great satisfaction to refer difficult and refractory cases to my colleagues who are specializing in epilepsy in the tertiary centers in India.

For all that one does and achieves one has to thank all who have contributed. I am grateful to my teachers, my colleagues and patients. I would like to thank my secretary, Ms Katie Vania, who has been of great help in all that I did for IEA. My wife Asha Singhal (a gynecologist) has lent me support and stood by my side through all these years. My son Aneesh (Associate Professor of Neurology, Harvard Medical School, Mass. General Hospital, Boston) and daughter Seema (Prof. of Hematology and Oncology at North Western University, Chicago) never complained when I spent hours away from home in pursuit of clinical responsibilities and involvement with Medical Associations like IEA. Witnessing the birth of the IEA and IES and seeing them grow and blossom over the years to what they are today fills me with great pride and joy. I am confident that these organizations will significantly decrease the “treatment gap” in our country and will ultimately succeed in bringing epilepsy ‘out of the shadows’.

### **Editorial Comment**

Besides epilepsy, Dr Singhal took interest in the varied activities as a neurologist. He attended national and international conferences on neurology. He was President of the Neurological Society of India in 1986. He is a member of several international associations including American Academy of Neurology, American Neurological Association, Association of British Neurologists and French Neurological Society. He was the Vice-President of the Asian Oceanian Association of

Neurology(2004–2008), and Regional Director for the World Federation of Neurology (WFN) for 2005–2009. He was the President of the Movement Disorder Society - Asian and Oceanian section for 2009–2011. He has been a member of several research groups of the WFN. As a representative from India and adjoining Asian regions, he was invited to serve on the Working Group of World Health Organization (WHO) for multiple sclerosis and Parkinson's disease.

For his contributions as a neurologist, he received several awards and gave several orations. Some of these include : Netaji Memorial Oration, Association of Physicians of India (1984), Dr Ramamurthi Oration, Neurological Society of India, Madras (1993), Prof. RN Chatterjee Oration (13th Annual Conference of the Association of Neuroscientists of Eastern India) (1999), Dr BC Roy National Award 1999, Priyadarshni National Academy Award, Mumbai, for outstanding contribution to the field of medicine (2004), Wockhardt Award for Medical Excellence in Neurology (2005), Prof. BM Sharma Oration, Indian Epilepsy Association, Jaipur (2005), Lifetime Achievement Award and Gold Medal (2010) and Dhanvantri award (2010). Also in loving recognition of his work, late Dr Sorab Bhabha, a brilliant young neurologist of Mumbai (we miss him) had proposed the Singhal oration in his honor at the World Federation of Neurology meetings. The first such oration was given at the International Congress at Bangkok.

He has done clinical research and has over 200 publications in national and international journals and book chapters. The major contributions have been in the field of non-compressive myelopathies and demyelinating diseases. He was able to recognize and describe a form of leukodystrophy unique to the Indian subcontinent in Agarwal community (megalencephalic leukoencephalopathy with subcortical cysts). Through international collaboration he subsequently identified the genetic defect in this condition.



With Dr Devika Nag of Lucknow, he edited the book on “Epilepsy in India” with contributions by Indian authors which was published by the Indian Epilepsy Association in 2000.

Dr Singhal continues to serve the community as a neurologist with special interests in epilepsy, multiple sclerosis and Parkinson’s disease.

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## DR KK SINHA

President—Indian Epilepsy Association  
(2002 – 2005)

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by Dr DK Jha

Dr Krishna Kant Sinha, was born on 11 January 1931, in ‘Maner’, in Patna district of Bihar. His father was a teacher. His formal education began at Maner Lower Primary School in 1935 when he was only 4 years old. Two years later, he was shifted from Std. II of Maner Lower Primary School to Std.V of Maner English High School.

In 1946 at the age of 15 years, he passed his matriculation with first division. He passed his intermediate from BHU with first division in 1948 and in the same year took admission to the MBBS course at Dharbhanga Medical College. He passed MBBS in 1953 with highest marks in Medicine and Surgery and received the gold medal for the highest aggregate. He was also awarded Honours in Medicine, a rare distinction even today. He passed his MD (Medicine) from Dharbhanga Medical College in 1956 and for the next two years served in the department of Medicine at Dharbhanga Medical College as Resident Medical Officer.

In 1958, he went to England for his MRCP and advanced training. The preparatory training program for MRCP at Edinburgh was highly educative and stimulating. Theory classes were conducted

from 8-12 in the mornings and the afternoon sessions were marked for intensive clinical training in the wards of Edinburgh General Hospital and Royal Infirmary. For the next three months he had an exposure of more than 30000 slides in these lecture classes which were delivered by distinguished teachers of Edinburgh Medical University including the famous Stanley Davidson of “Davidson’s Principle & Practice of Medicine” fame and Donald Hunter who was the Editor of Robert Hutchison’s book ‘Clinical Methods’. He was awarded MRCP in 1959 from Royal College of Physicians, Edinburgh. For next three years he worked as resident and registrar in neurology and neurosurgery in various hospitals of United Kingdom.

He came back to India in 1961 and was posted as medical officer at Patna Medical College for one and half years. Meanwhile, in 1960, a new medical college — Rajendra Medical College and Hospital (RMCH) had been started at Ranchi. On 22 July 1962 he joined as Tutor in the department of Medicine, RMCH. He was the first teacher to join the newly formed department of Medicine of this new Medical College. Three years later in 1965 he was promoted as Lecturer in the same department and designated as Neurologist. In the same year he decided to hone his clinical skills further and left, for a year, to the USA where he joined as senior resident, neurology, at VA Hospital, Hynes, Chicago, affiliated to North Western University Medical School. This was a 2800 bedded hospital of which 275 beds were marked for neurology.

By now he had started his full-fledged private practice which picked up very fast and his popularity as a good physician and neurologist increased tremendously in the undivided state of Bihar and subsequently to the whole of the eastern India. In 1976 on 29 February, the Govt of Bihar banned private practice in three medical colleges namely Patna, Ranchi and Dharbhanga. He could not afford to lose

the huge base of private patients which had been created over the years and hence six days later on 6 of March 1976 he resigned from the service without any hesitation. Even after leaving the medical college he did not allow his interest in academics to get subdued. He started an organization called “Academic Medical Forum”, the only one of its kind in Ranchi whose main purpose was to update the private practitioners of the city with latest developments of medical science by holding weekly and fortnightly clinical meetings, a practice still being continued by this forum.

In 1984, he started a journal ‘Physician India’ which continued for two years. This journal was noticed by the executive committee members of Neurological Society of India (NSI) and during the national conference of NSI at Varanasi in 1984 he was given the charge of publishing the CME book of “Progress in Clinical Neurosciences” and convening the CME programs. In 1985 during the Annual Conference of NSI at Patna, the two-volume hard bound CME book of NSI “Progress in Clinical Neurosciences” was released containing state-of-the-art articles mostly contributed by authors from abroad who were masters in their fields. This endeavour was highly appreciated and he was entrusted to continue the publication for the next six years i.e. 1985 to 1990. In 1990 when the Association of Neuroscientists of Eastern India (ANEI) was formed he became the founder secretary and continued till 1997. He was asked to organize its CME programs which he continued to do uninterruptedly till 2004. During the 1st CME program of ANEI held at Ranchi in 1991 he brought out the CME book on “Advances in Clinical Neurosciences” as founder chief editor which continued uninterruptedly for 14 editions till 2004. From 2000 to 2004 this was supplemented by an additional book “Some Aspects of History of Neurosciences” of which 4 editions were published and he was again the founder chief editor.

In 2000, the Jharkhand state was created and he was unanimously elected the founder chairman of the Association of Physicians of India, Jharkhand chapter. In 2001 when a local Hindi Newspaper 'Hindustan' conducted an extensive state level survey to find out the most popular person in Jharkhand, he was ranked number one. The then, Chief Minister of Jharkhand, Mr. Babu Lal Marandi and Union Minister of Finance, Mr. Yashwant Sinha were ranked next only to him. This reflects the immense popularity gained by him over the years which was mainly because of the wide spread belief among people about his charismatic touch of healing. He was awarded the Fellowship of Royal College of Physician of Edinburgh (FRCP), Indian Academy of Neurology (FIAN) and Indian College of Physicians (FICP). In 2009 he was awarded the gifted teacher award by API. He became president of ANEI for 1999–2000. He was elected president of IEA and IES in 2003 and 2004 respectively. He is a life member of NSI, IAN, API, IES, IEA, Indian Red Cross Society (IRCS), Academic Medical Forum (AMF), (ANEI) and Associate Life Member of American Academy of Neurology (AAN). He has regularly organised many state level, zonal and national conferences of API and ANEI including the historic first annual conference of IAN held in 1993 at Ranchi.

He has published the following 27 books as chief editor: Progress in Clinical Neurosciences (1985 to 1990 – 6 volumes), Advances in Clinical Neurosciences (1991 to 2004 – 14 volumes), Some Aspects of History of Neurosciences (2001 to 2004 – 4 volumes), New Trends in Medicine (1999 and 2003 – 2 volumes) and Movement Disorders (2012 – a monograph published by API). He has more than 225 publications in national and international journals. His main areas of interest in research are hereditary ataxia in eastern India, Japanese encephalitis in eastern India, movement disorders, Parkinson's disease, Wilson's disease and hereditary and genetic disorders of the nervous system. His extracurricular areas of interest are: history of

India, history of medicine and medical events, gardening and social service.

Presently he a consultant neurologist at Ranchi and serving mankind, his first and foremost passion.

(Dr DK Jha is Assistant Professor, Dept of Medicine, RIMS, Ranchi)

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## DR PK SETHI

President – Indian Epilepsy Association  
(2005 – 2007)

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Dr PK Sethi had an outstanding undergraduate career at All India Institute of Medical Sciences, New Delhi. Due to the exigency of emergency in the country as a result of conflict with China, he volunteered for service in the Army Medical Corps (AMC). He saw active service in the Indo-Pak war and showed highest order of valor and thus was awarded Vishist Seva Medal. In 1966 he was assigned to work with Dr Baldev Singh, Professor of Neurology AIIMS as a medical research pool officer. He worked very diligently, under tiring circumstances at high altitude and produced an excellent thesis on “The effect of high altitude on nerve conduction velocity, H-reflex and simple reaction times in human beings”. This is the first study of its kind in literature. His interest in high altitude led him to study the pulmonary diffusion capacity, myocardial blood flow and metabolism at high altitudes.

Dr Bernard H Smith, Professor of Neurology at State University of New York at Buffalo was very impressed with his work as a neurologist and research worker. While in States he helped in delineating a new familial syndrome — “Alstroms syndrome”. His paper on *facial myokymia* was important because it localized, for the first time, the site of the lesion responsible for facial myokymia. He was again first in describing the pathophysiology of crying

epilepsy and coining the word “*Quiritarian- Epilepsy*” to describe it which is now internationally accepted. Both these papers were subsequently reviewed in editorials of the British Medical Journal. His work on the neuromuscular problem in snake bites was very fascinating and he was awarded Gen Amir Chand award for the same. He has been the first to draw attention to the entity of seizures with disappearing CT scan lesions, which later drew the attention of several other neurologists. He has over 130 national and international publications to his credit. He helped in establishing good Neurology Centers at Lucknow, Calcutta and Delhi while in army. He took premature retirement from the army in 1986. Since then he is with Sir Ganga Ram Hospital, a 500 bedded multi-specialty hospital. There he established the Department of Neurology from its infancy to its present state. He helped to develop one of the finest clinico-electrophysiology laboratory in this country. He also helped to get the Neurology Department recognized at the national level and got its training program approved for postgraduate training in neurology. The department is running one of the largest successful Carotid Endarterectomy Programmes in the country.

During his tenure in army, and later in civil, he has contributed in major ways in teaching his students. Several doctors have passed through his hands, learning neurology and have become specialists and head of the departments in their own rights. He has been writing on various aspects that fascinated him.

He has been President of Indian Epilepsy Association and is President of IEA-18th IEC Trust since the last nine years. As chair of IBE of south-east region he has contributed both at the international and national levels in organizing various conferences and helping the cause of epilepsy with special emphasis on social aspects and stigma regarding this disease. He has been taking very active lead



in organizing various free epilepsy camps to make the community aware of epilepsy. His other interest is in strokes and he gives regular lectures, holds various free camps and runs a free clinic to emphasize the preventive aspect of stroke. With his colleague Dr Sujeela Maini, he runs a very active anti-tobacco program. He also runs camps educating people about dementia.

He launched the “Brain Care Foundation of India” — a non-profitable organization with the sole aim of helping patients with various neurological problems. As a founder president of this organization he runs various camps on educating the community in various parts of India about brain care and also care of the patients with neurological problems and their care givers.

He has launched a website [www.braincarefoundation.com](http://www.braincarefoundation.com) which aims to spread knowledge about the brain, both in health and diseases. The site also provides information, to a lay person, about various neurological diseases like epilepsy, stroke, demyelinating disease, CNS infections, brain tumor, etc. in a very simplified way and also has various articles emphasizing on how to keep the brain healthy. Linked with the foundation is a blog [www.braindiseases.wordpress.com](http://www.braindiseases.wordpress.com) which is a very active blog dealing with various aspects of brain and brain diseases. Already 15,000 people have visited the site in a short span of a few months. Individual queries are regularly answered. In this electronic age, this seems to be the best way to reach people and to spread knowledge about the brain.

### **Contribution to cause of epilepsy**

Dr Sethi is one of the earliest members of Indian Epilepsy Association who joined it in its infancy. In 1987, he was requested by Dr Mani, Professor of Neurology at NIMHANS and by Dr Bharucha to take up the job of treasurer for the upcoming 18th international epilepsy

conference to be held in Delhi. This was a major challenge as it was for the first time that an international conference was being held in India. It was a challenge to arrange funds and coordinate with the president, Dr Mani and secretary, Dr Maheshwari to arrange meetings with the office bearers of international epilepsy congress, both international league against epilepsy and international bureau for epilepsy. The conference was one of the major events in the history of epilepsy in India and a major game changer. The conference went off very well and was appreciated by all the delegates. The IEA was permitted to keep the left over amount of rupees 50 lakhs to be used for the growth of epilepsy movement in India. In order to utilize this fund appropriately, the IEA-18th International Epilepsy Conference Trust was formed. Dr Mani was the first president of this trust, Dr Vinod Saxena was the secretary and Dr Sethi was the treasurer. Dr Bharucha was the spirit behind this trust who helped to formulate rules and regulations and duties of the trust.

Dr Sethi as the treasurer participated in all the activities of the Trust and coordinated with different members from time-to-time to formulate various plans not only to utilize the money but also to increase the money in the fund. The trust funded several activities of Indian Epilepsy Society, various conferences, research projects related to epilepsy and also sponsored individuals to attend conferences both in India and abroad. Dr Sethi was very particular that epilepsy awareness programmes, specially in small towns and villages, should get preference and a newsletter was started. He was elected as president of (i) the trust twice between 1998-2007 and (ii) Indian Epilepsy Association from 2005-2007. For his contributions in the field of Neurology he was awarded Padma Shri by the President of India in 2002.

Currently he is an emeritus consultant and advisor at Gangaram Hospital. He also runs a private OPD and teaches neurology DNB

students. His wife Dr Shashi K Sethi is the pediatrician who retired as a chief from Majeedia hospital. His daughter, Dr Nitika works as an internist at Maryland, USA and his son, Dr Nitin is a neurologist and epileptogist in New York Presbyterian Hospital.

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**DR PRAVINA U Shah**

President – Indian Epilepsy Association  
(2009 – 2011)

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My life has had many ups and downs but as I look back I feel I was blessed with the right kind of support at the right time from wonderful friends and family.

### **My Childhood**

I grew up in Pydhonie, a crowded area of Mumbai, where giving, taking, sharing and caring was the norm amongst the people who lived in our chawl. Born on 6 April 1944, I was the eldest of 4 sisters and a brother. One incident made a deep impact on me. Once my father was very sick, bedridden and had no money to call a doctor. The doctor who was called by my neighbor came and treated him without charging a fee. This made me realize the importance of timely medical help and started my admiration for the noble medical profession. Right from 4th standard I was constantly inspired to become a doctor. I was educated at the Shri Shakuntala Kantilal Jain Girls' School at Marine Lines in Gujarati medium and started learning English alphabets only in the 8th standard. My teacher Ms Perinben Antia gave me special coaching in English and made me read the life history of Nobel Laureate Dr Albert Schweitzer saying that in future I should be like him.

### **Joining the medical profession**

After my inter science at Jaihind college, I joined Seth GS Medical

College and KEM Hospital in June 1963. My mother had chronic bronchitis and cor pulmonale for 6-7 years and was bedridden from 1964 onwards. As I was the eldest, it was my responsibility to look after my sick mother and home. My second sister was handicapped due to TB meningitis and right hemiparesis and that worried the family. During the last term of my final MBBS my mother expired. However my siblings and father took over all the household duties to enable me to carry on with my studies. I did reasonably well due to my regular coordinated study and cannot forget the guidance from my Pharmacology teacher Dr Ashok Vaidya. He taught us what Sir William Osler had quoted “The good physician treats the disease; the great physician treats the patient who has the disease” and made me study books and patients in coordination. This is really the foundation of my clinical acumen.

I then did my MD in General Medicine. My first 6 months was under Dr FM Narielwala who taught basic patient care and learning discipline. Those 6 months with him gave me a strong foundation in clinical medicine. His concern for patient care and comfort was exemplary. I chose Psychiatry for my 2nd posting and retrospectively I think it has helped me in management of epilepsy and other neurology patients and their family members. I then became a Neurology Registrar with Dr EP Bharucha and Dr VP Mondkar. After passing MD Medicine I was lost regarding future decisions. During this period I started liking Neurology but always thought it a nihilistic branch: that most patients have diagnosis but hardly any treatment. Dr Bharucha and Dr Mondkar inspired me to do MD in Neurology and then I found a ray of hope in Epilepsy. I slowly realized that here was one condition where one needs time, concern and commitment and without many gadgets one could do a lot. I also realized that epilepsy was a multifaceted problem and though the medical part was taken care of, the psychosocial facet was neglected. That gave me direction and a goal to achieve. What motivated me to work for the psychosocial

benefit of patients and raise epilepsy awareness was the agony and depression on the faces of parents whose daughters were sent back after marriage simply because of epilepsy.

Neurology was an Honorary unit but the teachers were dedicated and taught very well. Dr EP Bharucha was the seniormost and hosted many international neuroscience experts who I had the good fortune to meet. Neurology was a happening department and I enjoyed my tenure of 7 years from Registrar to Associate Professor. There were daily ward rounds, out patient clinics, diagnostic procedures like angiography, myelogram and pneumoencephalography. Brain cutting sessions in Neuropathology Department every Wednesday were the best learning modality. What interested me most were the busy Epilepsy Clinics on Wednesdays and Saturdays. During this period (1972-73) we were lucky to have Dr SS Seshia as a consultant, apart from Dr Bharucha and Dr Mondkar. He really impressed us as an excellent clinician, teacher and human being. After he immigrated to Canada, I had my junior colleague and friend Dr Shaila Kulkarni (Dr Vaishali Nadkarni) with me for almost 5 years and we had a great time together (this friendship continues to date). I was also very close to her parents who were my neighbours at Gamdevi. My initial neurology career of 7 years at KEM Hospital was shaped by Dr VP Mondkar and Dr EP Bharucha. Apart from rich clinical material what gave depth and understanding were the brain cutting sessions conducted by neuropathologists Dr DH Deshpande and Dr AP Desai. Dr Mondkar was a strict and astute clinician and his pursuation for accurate documentation and discipline taught me basic neurology and sincere patient care.

These 7 years coincided with personal, family and financial stress. Both my bosses were supportive as well as my husband and our families. Though our Gujarati families were conservative and traditional they have always encouraged and supported my professional career. My

father and my mother-in-law are my role-models and their blessings and good wishes have worked for me.

After my MD in Neurology I took up an Asst. Hon. position to Dr PM Dalal at Nair Hospital. Strict but forthright Dr Dalal gave me training in administration. He gave me the freedom and confidence to conduct independent departmental work. During my early phase of practice Dr BS Singhal once kept me as his locum at Bombay Hospital and that gave me tremendous confidence. In 1979, I went to the Institute of Neurology at Queen Square London for 3 months as an observer. This helped me greatly in my professional growth.

### **Back to KEM Hospital as HOD Neurology**

In 1983 I was appointed as Head of Neurology Department at KEM Hospital. This was a great challenge. To start with I was nervous and shy but I slowly picked up administrative skills.

When I started in 1983, I had the ambition of developing three new facilities: comprehensive epilepsy care, neurophysiology and neuro intensive care unit. Slowly and steadily with outside donations, administrative support and having an expert like Dr Dilip Karnad, neuro intensive care for neurology and neurosurgery started. Dr Shubha Pandya and Dr Khushnuma Mansukhani developed neurophysiology. Dr Nilima Kshirsagar helped with the therapeutic drug monitoring and newer AEDs drug trials and in later years Dr Sangeeta Ravat, Dr Mohinish Bhatjivale and Dr Urvashi Shah helped to develop epilepsy surgery program. Gradually therapeutic drug monitoring and epilepsy surgery programme was added. Epilepsy support group and E-cell activities were efficiently managed by Carol and Manisha. Thus we have medical, surgical and psychosocial wings of this comprehensive care. Dr Sangeeta and Dr Urvashi in the last 10 years have done commendable work on the surgical front.

I am grateful to Dr EP Bharucha for introducing me to Epilepsy and the Indian Epilepsy Association and to Dr Richard Masland (former President, World Federation of Neurology) for his guidance and excellent vision. I met Dr Masland in 1983 when he visited Mumbai and Delhi and was fortunate to arrange an academic program and spend time with him for 3 days. By then I was clear about my interest in Epilepsy and he recognised that. He called me to USA for 4 weeks in 1988 to spend one week with him, one week at Montreal Neurology Institute (MNI), a week at Cleveland Clinic and one week as a minifellow at Winston-Salem with Dr Kiffin Penry. This gave my future work a strong foundation. I went with an idea to know the basics of Epilepsy surgery at MNI but Dr Masland convinced me to first spend time, energy and resources raising epilepsy awareness among patients and the community at large and then perhaps a decade later launch an epilepsy surgery program. He was a visionary and his suggestion guided me to start a psychosocial movement. This has been a great boon as I see it now after almost 25 years. There is a definite shift in the thinking process of people and the treatment gap has reduced.

Nineteen years as Head of the department of a prestigious institute was challenging and enjoyable. Students of DM neurology and residents were a constant source of inspiration which motivated me to grow the patient services. So many experiences and so many events of this period are imprinted in my mind, the important ones being EEG workshop by Collin Binnie, neuroradiology sessions with Dr Ravi Ramakantan, ECON 2001, exhaustive ward rounds, OPDs of almost 150-200 patients, parties, dinners, Sahyadri hotel tea sessions and ultimately the most touching farewell arranged by my follower Dr Sangeeta.

A lifetime memory is my illness with Malaria in 1993. I was serious with hemodynamic instability due to Malaria falciparum and the



Dean Dr Pragna Pai along with Dr Dilip Karnad and my residents shifted me in an ambulance to KEM ICU from Jain Hospital. I survived only because of the KEM team of doctors and the blessings of all patients. It was really a second chance at life. It was the same Medical Neuro ICU which my team and I created and inaugurated just 6 weeks prior to my illness which I was the first to use!

### **Other Interests**

My interest in handicapped children led to a long association with Spastics Society (now ADAPT) i.e. Founder Mithu Alur and her team and Jai Vakeel Institute for mental retardation i.e. Mrs Shroff. Almost 25-30 % of these children have epilepsy. I have sweet memories of Pam Stretch while she was in India with Spastics Society. This has also been the stimulus for my niece (more like my daughter) Saranga to become a Special Educator and passionately work for these children.

### **Conwest Jain Clinic Hospital**

From 1977 onwards I have been an Honorary Neurologist at Conwest Jain Clinic Hospital which has been very fruitful and rewarding. This institute is very dear to me and it gave me an opportunity to develop contacts to raise donations for KEM Hospital to develop the Neuro ICU, Neurophysiology and Epilepsy Support Group. The Research Society has partially supported our Rural Epilepsy work.

### **Fortis Hospital**

Due to unavoidable family circumstances we shifted our residence from Gamdevi to Vikhroli in 2005. It was a stressful patch but colleagues, family members and especially my students really helped me to come out of this crisis. In a way relocation has been a blessing in disguise. I joined Fortis Hospital (formerly Wockhardt) at Mulund. Being a University teacher I was able to start DNB Neurology. The first student, Dr Dhanashree Chonkar has passed out and is now

a consultant with us and the second student Dr Dhara is in her second year. This attachment fulfills my academic and financial requirement.

### **Indian Epilepsy Association**

My contact with the Indian Epilepsy Association began in 1974 and I became more active after 1981. I remember various Bombay chapter meetings and AGMs of the Central Body. I used to appreciate Dr Mani's passion and Dr EP Bharucha's soft but useful suggestions. They both have encouraged and supported me. Dr Singhal as President of Bombay chapter has been constantly supporting and guiding us. Over the years, interactions with Dr Saxena and Dr HV Srinivas have been extremely useful especially concerning administrative nitty-gritties. Our long telephonic conversations often involve a difference of opinions but we always keep the interest of the cause uppermost. Whatever my portfolio, I have always participated in all IEA activities with great interest and passion.

All the activities of our Bombay Chapter focus on:

1. Increasing the confidence of patients and family members and keeping them at ease and comfort through education and counseling.
2. Giving a boost to the hidden talents of patients.
3. Personality development of patients.
4. Raising epilepsy awareness especially amongst school children through presentations and competitions.
5. Subsidizing anti epileptic medications.
6. Lectures to improve understanding of themselves and their disorder.
7. Rural epilepsy clinics.

Our support group Samman has also encouraged building of support groups in other cities.

All this has been possible due to teamwork, guidance by our seniors, support of all neurology colleagues, involvement of residents of KEM hospital, patients and family members being partners of all programs and financial support from well wishers. I have been President of IEA and have tried my best to have an overall improvement particularly in National Epilepsy Day activities across the country.

We still have to tackle important issues like epilepsy and driving, people with disabling epilepsy to have the same rights as those given to other disabilities, availability of medical expertise and antiepileptic drugs in rural India and an overall decrease in both primary and secondary treatment gap.

I will work till the end of my life for epilepsy so that every patient lives happily and with dignity.

I am currently a consultant neurologist at Fortis Hospital, Mulund, Mumbai.

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## DR HV SRINIVAS

President—Indian Epilepsy Association  
(2011 – 2013)

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While the country was staging “Quit India Movement”, I staged a “Quit Uterus Movement” and was born on 9 August 1942 in Kurnool, Andhra Pradesh. I was born into a middle class family, the eldest of six children. My father was a press reporter of “The Hindu”. My initial schooling was at Kurnool in Telugu medium, although my mother-tongue was Kannada. I joined intermediate course at Kurnool taking mathematics as a main subject which would have led me to an engineering course and not a medical degree. During the state reorganization, my father was transferred to Gulbarga, which was amalgamated into Karnataka from the Nizam’s State (as our mother-tongue was Kannada). As he was transferred to Gulbarga in the middle of the academic year I had to quit the intermediate course and lost one academic year in the process. At Gulbarga I joined PUC course which had both mathematics and biology, keeping myself open for engineering and medical courses.

After completing PUC my father wanted me to do BSc and MSc and join as a teaching staff in a science college, for two reasons. Firstly, economically he could not afford to send me away to a medical college (there was no medical college in Gulbarga then) and secondly he felt, as I was thin framed and under-weight, being at home would help me look after my health! It was by sheer chance, that a visit

from a well-wisher, who emphasised that if I became a doctor I would be able to financially support my siblings, changed my father's mind and I made my entry into Karnataka Medical College, Hubli. I was interested in physiology (I stood first in the university) and this led me to medicine and subsequently to neurology. After finishing MBBS in 1963, I was keen to do MD Medicine. However due to economic reasons, I had to do a stint as a railway medical officer at Hyderabad for a year. At the end of one year I utilized the railway pass to scout around for a postgraduate seat in medicine.

I was offered a seat for MS (General Surgery) at Pune, which I refused and got admission for MD (General Medicine) at KM School of Postgraduate Medicine and Research, Ahmedabad, which I completed in 1967. My interest in neurology enabled me to take classes in physiology of nervous system for first year MBBS students while doing my MD. I recollect, now with horror, how for differentiating the type of stroke an LP used to be done, and if it was blood stained then it was diagnosed as haemorrhagic stroke and if it was clear then it was an ischemic stroke! While many of my friends had anxiety and stress on the eve of examination I used to relax by going to a movie, to the consternation of my friends! I passed my MD with merit.

I joined as a faculty in Department of Medicine at MR Medical College, Gulbarga and continued there for the next five years, during which time I developed a keen interest in neurology and was on the look out for admission for DM Neurology. When I went to Bombay I had an opportunity to join DM (Cardiology) which I refused and was fortunate to join the 1st batch of DM Neurology at Grant Medical College and JJ Group of Hospitals under the guidance of Dr NH Wadia and Dr BS Singhal. The hostel stay in Bombay was indeed very difficult, that too after having experienced five years of comfortable life with family, having nice homemade food. It

was tough to start off as a student once again after having been an Associate Professor in Medicine. However due to my passion for neurology all these were secondary. It was a pleasure to be guided by teachers like Dr Wadia and Dr Singhal and associated with batch mates Dr Katrak and Dr Bhat. I also got the best paper award during the NSI meet at Vellore. Dr Sarosh Katrak, Dr MS Bhat and myself were the successful students of the first batch of MD (Neurology) from Bombay University in 1975. For a brief time I toyed with the idea of settling in Bombay and applied for an Honorary teaching job in one of the teaching hospitals. But I was denied the job because I did not belong to Maharashtra. (May be this was a blessing in disguise, as I subsequently joined NIMHANS, Bangalore).

I returned to the Department of Medicine at Gulbarga Medical College and my wife, Obstetrician and Gynecologist, started her Nursing Home and we settled in Gulbarga. Dr KS Mani, Prof. and Head of Neurology, at the just formed NIMHANS, Bangalore was on the look out for fresh faces to join his Department. He came to know about me through Dr Wadia and when he visited Gulbarga to give a guest lecture, he spoke to me and my wife persuading us to move to Bangalore. We did not entertain this idea, and forgot all about it until I received an application from NIMHANS to apply for the post of lecturer. After a lot of persuasion by Dr KS Mani we wound up our establishment at Gulbarga and moved to Bangalore in 1976.

The first thing Dr Mani told me was that I should be prepared to accept the post of Lecturer in Neurology at NIMHANS from being an “Associate Professor in Medicine” at Gulbarga Medical College, for which I readily agreed, as I was keen to pursue an academic career in neurology. I cherished the memories of my six years stay in NIMHANS. A structured teaching programme was in place, the camaraderie between various departments was enjoyable, as was the clinical teaching and interaction with students. At that time

only two students were taken per year for DM; we were more like a family and my wife used to host small parties for all the residents particularly during Diwali, which we all still cherish.

My interest was drawn towards the subject of epilepsy as I was in Dr KS Mani's unit. The Saturday mortality meetings and Tuesday brain cutting sessions were very informative and interesting. The Department was like a family, we did not have to sign the attendance register and everyone knew what the others were working on. Due to financial constraints, I had to take a painful decision of resigning from NIMHANS, in 1982. Some of my friends like Drs Deshpande, Vidyasagar and Kalyanasundaram also left NIMHANS for the same reason (if I had the present day pay scale and the perks and benefits I am sure I would not have left the coveted post at NIMHANS!).

My mentor Dr KS Mani had already left NIMHANS and started practice and I remember him telling me that I was the first full time practicing neurologist with DM (Neurology) in Bangalore, while he himself was a “pseudo neurologist”! My association with him continued and in fact strengthened further. He initiated me into the field of epilepsy, in particular the social aspects. After his retirement from NIMHANS, Dr Mani started the Yelandur rural epilepsy study for epidemiological study as well as treatment and follow-up of patients with epilepsy. I was his co-worker in the well known and often quoted “Yelandur study - a rural epilepsy project”. There were two teams Drs Mani, Geetha Rangan and Shamantakamani in the first team and Drs. Krishna Reddy, Kalyanasundaram and myself in the second team. Every fortnight one team used to visit on a weekend and over a period of a year the two teams surveyed a population of sixty five thousand — the entire expenditure was borne by the individuals themselves. The antiepileptic drugs supplied free by pharmaceutical companies were distributed to the patients. The project was for five years.

My basic interest is teaching clinical neurology, which I have been doing for the last 25 years, so much so that I am popularly known among postgraduates who say "if it is Wednesday it is HVS's class". I have actively participated in the teaching programmes, symposia and seminars, with a focused vision of teaching clinical neurology to postgraduates in medicine. I was trained in the pre CT Scan era where neurological investigations included direct puncture carotid angiography, pneumoencephalography and burrhole ventriculography – from today's standards these investigations seem barbaric. I learnt imaging interpretations like CT and MRI along with my students. The flipside of the advances in neuroimaging and other investigations is that the present generation of medical doctors, especially the primary care physicians, feel that history taking and neurological examination can be bypassed and investigations ordered right away. Unfortunately this is not so and may in fact mislead the clinician to a wrong diagnosis. I emphasise that clinical diagnosis is far more important today—not only to order appropriate investigations but also to interpret the investigative results.

After starting practice, I felt there was a need to have a forum wherein the neurologists and neurosurgeons from NIMHANS and those practicing/working in other hospitals and medical colleges can interact and get to know each other. Thus an informal "Neuro Club" was formed in 1983 of which I was the founder member and secretary. It was an arduous task to start off but it was well worth it in the long run. As membership to the Neuro Club grew, Bangalore Neurological Society was formed and registered in 1993 for which once again I was the founder secretary. The Society is in full flow today with monthly clinical meetings held with absolute regularity, orations and its own website.

Dr Mani was very keen on the social aspects of epilepsy and public awareness campaign. He inducted me into the Indian Epilepsy



Association and along with him I actively pursued the goal of public education to create awareness about epilepsy.

Dr Mani who started not only the IEA Central Office but also the IEA Bangalore chapter, inducted me into the Bangalore chapter initially and subsequently the Central Office. At different times I was an office bearer in the Bangalore chapter donning all caps – Executive Committee Member, Secretary, Vice-President, President and Editor of the Newsletter of Bangalore chapter. Subsequently I was the governing council member of Central Office, IEA, Treasurer and in the later years Secretary and currently the President. The long awaited Karnataka State Neurosciences Academy was formed in 2010 of which I was the Founder President.

I was the organising secretary for the very first Annual Conference of Indian Epilepsy Association held at Madras in December 1993 and also for the Conference held at Bangalore in December 1994. In 2001 when I was the Secretary General, a website was created for IEA. The Annual conferences of IEA used to be held with IAN and NSI conferences. The first stand-alone conference of IEA was held in February 2009 at Tirupati when I was the Secretary. The IEA Central Office members used to meet only during the annual conference, subsequently a midterm meeting was held in the place where the next annual conference was to be held. However all the members had to pay for their travel and the local organizers used to arrange for accommodation if required. Gradually as the strength of membership of IEA increased it was decided to have stand-alone epilepsy congress and the first such independent conference was held at Tirupati with the blessings of Lord Venkateswara and hosted by Dr Vengamma of IEA Tirupati chapter. The travel expenses for midterm meeting was initially reimbursed only for managing committee members but now it is being reimbursed for all the governing council members also.

I was the driving force behind starting the Distance Education Programme leading to Diploma in Epilepsy Care (DEC), a course for non-medical persons, in collaboration with CBR and Bangalore University, the first of its kind in South East Asia. Six batches of students have already completed the course. On behalf of IEA the ground work has been done to liberalize the driving license regulation in keeping with the advances in the west.

During my tenure as President of IAN, I embarked on a project to create “IAN guidelines for management of common neurological disorders” i.e. headache, stroke, Parkinson’s disease, neuro infection, etc with the support of neurologists working in the respective fields. I have edited the book “A Saga of Indian Neurology – Reflections of Former Presidents” published by Indian Academy of Neurology.

I am currently Chairman, South East Asia Regional Executive Committee, International Bureau for Epilepsy (IBE) (2009–2013); President, Indian Epilepsy Association, Central Office (2011–2013). Some of the orations I have delivered include: HC Bajoria Oration at Joint IEA-IES Conference, 2002; Dr B Muralidhar Oration, Tirupati, 2003; YP Vittal Endowment Lecture at Bellary, 2006; KS Mani Memorial Orations at (i) IEA, Cochin, 2008 (ii) Sahyadri Neurocon 2009, Shimoga (iii) Bangalore Neurological Society, 2009; IMA Dharwad Diamond Jubilee Oration, Dharwad, 2010; Tirupati Oration in Epileptology, Tirupati, December 2010.

My wife Dr Pushpa Srinivas is a long time friend and classmate right from undergraduate days. She recently retired as Professor of OBG from Bangalore Medical College. We have two children a son, HS Sachin who is a Strategy Management Consultant in Sandeigo, USA married to Aparna a Biotechnologist; a daughter Minoti married to Mukund, both architects, staying in Sydney. We have 3 lovely grand daughters, who are aged between 3 and 6 years and whose

company we always look forward to. It is often asked “why is it that grandparents and grandchildren are so close to each other?” the answer is “because they have a common enemy (parents)” and we too are no exception to this.....

I am currently Visiting Consultant and Postgraduate Teacher for DNB Neurology, Narayana Institute of Neurosciences, Narayana Hrudayalaya; Consultant Neurologist at Agadi Hospital and Sagar Hospital, Bangalore.

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Chapters of  
INDIAN EPILEPSY ASSOCIATION

## CHAPTERS

<b>Andhra Pradesh</b>	Hyderabad
	Kakinada
	Nellore
	Tirupati
	Visakhapatnam
<b>Assam</b>	Guwahati
<b>Bihar</b>	Patna
<b>Delhi</b>	Delhi
<b>Gujarat</b>	Ahmedabad
	Anand
<b>Jharkhand</b>	Ranchi
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	Shimoga
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## Hyderabad Chapter - Andhra Pradesh

*Dr J M K Murthy – Founder Secretary*

The Hyderabad Chapter of Indian Epilepsy Association was formed on 16 June 2005 with 24 members and was affiliated to the central body.

The Founder Office Bearers were:

President - Dr M V R Reddy  
Secretary - Dr J M K Murthy  
Treasurer - Mr Johnsy Thomas

The Chapter celebrated National Epilepsy day the following two years. Subsequently the Chapter was virtually in hibernation till 2009 when it was rejuvenated.

From the time of its inception the Chapter has been engaged in monthly epilepsy camps in the villages (initially 22 villages and now 65 villages) adopted by Byrraju Foundation (now it is Care-Byrraju Foundation) around Bhimavaram, west Godavari district in Andhra Pradesh. The team includes a neurologist (Dr J M K Murthy) and a psychiatrist (Dr Vijay Seshadri). They visit the villages every month for two days and identify the people with epilepsy and follow-up those who have been identified earlier. People with epilepsy are given free antiepileptic drugs once a month. This service is being provided uninterruptedly since 2005. The program on Comprehensive Rural Epilepsy Study South India (CRESSI) has brought about good awareness as well as a positive attitude towards epilepsy in the community reducing the treatment gap. More than 2500 people with epilepsy have benefited by the programme and at present about 680 people with epilepsy are on free drugs supplied by the Foundation. Apart from this the other patient-related programs include lectures to lay people about epilepsy and write-ups about epilepsy in the local newspapers and radio talks.



Dr J M K Murthy examining and prescribing a patient with epilepsy during one of the camps in Eduru village



Dr Vijay Seshadri, psychiatrist, counseling a patient with epilepsy during one of the camps in Unikili village



Patients with epilepsy waiting in the out-patient clinic of a medical center in one of the villages

## Activities

2007: Dr Sita Jayalakshmi and Dr P Vijaya conducted a free Epilepsy camp at Guntur on national epilepsy day. All the patients with epilepsy (PWE) who attended were examined in detail and were given free medicines and counseled. This was followed by an awareness lecture by Dr Sita about epilepsy. Later an interactive question and answer session was conducted.

2008: An awareness program was conducted on All India Radio by Dr Sita Jayalakshmi about various aspects of epilepsy. On the occasion of national epilepsy day a write-up on epilepsy was published in local newspapers. An awareness program on epilepsy, epilepsy in children and epilepsy in pregnancy was conducted on Eenadu TV.



2009: The chapter organized an awareness program for patients' relatives at Nizam's Institute of Medical Sciences which was attended by patients with epilepsy and their care givers. The meeting was inaugurated by releasing balloons into the air. Later Dr Sita Jayalakshmi gave a lecture on epilepsy, causes, management and dos and don'ts in the management of epilepsy. Dr Shanmukhi, clinical psychologist discussed about the early identification of psychiatric and behavioral problems in epilepsy and the role of evaluation and counseling. Later an interactive question and answer session was conducted.

2010: A series of awareness lectures were conducted by IEA Hyderabad exclusively for the teachers in various schools. The teachers were informed about what is epilepsy, its causes, the stigma which the children might face and how to take care of a child during an attack of epilepsy. Interactive question and answer sessions were conducted.

2011: An awareness talk was delivered on epilepsy in children and in adolescents on Eenadu TV to improve the understanding of the public. On the national epilepsy day all the patients with epilepsy were given free booklets with information on epilepsy in the local language and in English.



An interactive question and answer session on epilepsy conducted by Dr Sita Jayalakshmi on behalf of IEA



An awareness lecture by Dr Sita Jayalakshmi, on behalf of IEA, at DAV Public School

Dr T Suryaprabha and her team including Dr Naresh Rathod, Mr. Kranthi Reddy, Mr Praneeth Reddy and Ms Hemalatha conducted an awareness program on epilepsy for school children in Government Urdu Medium School located in Khairatabad, Hyderabad. The school is located in slum area. Awareness program was first planned for teachers. After an introduction about details of the program, teachers were given a questionnaire on the basic understanding and attitudes towards epilepsy and also the stigma scale to know the prejudices about epilepsy. After knowing their views, the team gave an interactive presentation and cleared the doubts. The presentation was mainly on causes of epilepsy, myths and facts and first-aid during seizures. Two videos were shown, one on different types of seizures and the other on do's and don'ts during a tonic-clonic seizure. The session was then open for questions from teachers. The teachers were very impressed with the video on the different types of seizures as they were unaware of the types of seizures other than generalized tonic-clonic seizure. At the end of the session the teachers were given a set of questionnaires. By this re-testing we could educate the teachers about the myths, facts, and basic concepts of epilepsy.

After educating teachers, the team initially administered a questionnaire to know the attitude towards epilepsy and stigma about epilepsy to 100 students of classes VIII - X of the same school. A detailed presentation was given on the causes of epilepsy, myths and facts, and first-aid during seizures. Students were also shown videos on the various types of seizures and do's and don'ts during a tonic-clonic seizure. After the video session, the team asked the students whether they had encountered any of these situations in their daily routine. The observations were a lot of stigma, not aware of cause of epilepsy, and no knowledge about do's and don'ts during an epileptic attack. The practice of holding hands, legs, and head tightly is still followed during seizure along with placing keys in the

hands, rubbing the body with Zandubalm (a herbal medicine), and making the patient smell sandal.

The Chapter has conducted two Clinical EEG workshops in 2006 and 2007. The members are actively associated with the tri-monthly clinical meetings of the Pediatric Epilepsy Society of Hyderabad.

The Chapter was renamed as Epilepsy Association of Hyderabad on 8 May 2012 and registration applied for under the Indian Societies Registration Act as it is now a mandatory requirement. The Epilepsy Association of Hyderabad will be organizing the 14th Joint Annual Conference of Indian Epilepsy Association and Indian Epilepsy Society from 8-10 February 2013 in Hyderabad. The Association will also conduct a “Course in Clinical Epileptology” for residents in internal medicine and pediatrics on 10 February 2013. We sincerely wish to diversify patient-related activity in future.

The Chapter has 36 Life Members

The present Office Bearers are:

President - Dr M V R Reddy  
Secretary - Dr J M K Murthy  
Treasurer - Mr E S S Kiran

## Kakinada Chapter - Andhra Pradesh

*Dr D Seshagiri Rao – Founder Secretary*

The Kakinada Chapter was started in 2003 with 27 founder members.

The Founder Office Bearers were:

President	: Dr P Durga Raju
Vice President	: Dr N Narasimha Rao
Secretary and Treasurer	: Dr D Seshagiri Rao

### **Activities**

#### Lectures and Symposia

A number of lectures and symposia by eminent speakers were organized for under-graduate and post-graduate students, faculty of medicine and paediatrics, family physicians and paramedical personnel. Topics covered were: 1. Overview of epilepsy 2. Management of first seizure, 3. Status epilepticus, 4. Newer anti epileptic drugs, 5. Electroencephalography, 6. Paediatric epilepsy, 7. Epilepsy and psychosis, 8. Epilepsy surgery

Dr D.Seshagiri Rao, Secretary addressed many branches of IMA in east and west Godavari districts of Andhra Pradesh on various aspects of epilepsy. Awareness programmes were conducted for medical officers of primary health centres of east Godavari district who treat people with epilepsy (PWE) in semi-urban and rural areas. They were mainly updated on the basic principles of epilepsy management. Paramedical personnel were also educated about first aid and need for compliance of treatment.

#### Community activities

Epilepsy camps were organised in various towns of east Godavari district, (Tuni, Mandapeta, Rampachodavaram) and west Godavari



Dr D Seshagiri Rao (a) examining a person with epilepsy (b) with local staff of Byrraju Foundation (c) at an epilepsy camp

district (Palakollu), in collaboration with voluntary organizations. Antiepileptic drugs (AED) were distributed free of cost and PWE and their care takers were appraised of first aid measures during a seizure and precautions during antiepileptic drug treatment.

Between 2005 and 2010, Dr D Seshagiri Rao participated in epilepsy camps in 70 villages of east Godavari district, in association with Byrraju Foundation — a voluntary organization. In each village PWE were identified and AEDs were given free of cost. In 2010, repeat visits were made in 20 of the villages.

Dr D Seshagiri Rao submitted a project entitled “Integrated Rural Epilepsy Care at District Level”, integrating district administration, teaching institute and District Medical & Health Services, to the District Collector, east Godavari District for perusal and approval.

The Chapter has 20 Life Members.

The Founder Office Bearers continue in office.

## Nellore Chapter - Andhra Pradesh

*Dr Bindu Menon – Founder President*

The Nellore chapter was formed on 3 January 2008 and has been registered under the Society Registration Act xxxv of 2001. The founder president of the chapter Dr Bindu Menon started the chapter with 28 members, which include medical and non-medical persons.

### The Founder Office Bearers were:

President	- Dr Bindu Menon
Vice President	- Dr Guntur Vidya Sagar
Secretary	- Dr Marigar Rajesh Kumar
Treasurer	- Dr Sree Ram Sateesh

The inauguration of the chapter was held in Narayana medical college auditorium. Dr Gourie-Devi and Dr VS Saxena were the chief guests. Inaugural programme was attended by 250 people from all walks of life. Dr V S Saxena spoke on missions and goals of IEA. He presented the GEMIND book and also left few copies of the book for the Association. Prof. Gourie-Devi gave a talk on the 'Controversies in the management of the first seizure'. Dr Bindu showed few videos of epilepsy patients. There was excellent interaction between the audience and the speakers. Both the dignitaries emphasized that Epilepsy continues to have lots of myths with treatment gap and there was an urgent need for education in this area. After the



Dr Gourie-Devi inaugurating the Nellore branch of IEA

inaugural function, there were more people interested in joining as members. We felt we had made a good start indeed.

The chapter's initial footstep was dispelling the myths about epilepsy. It was observed that the patients and their family members were not well informed. Their fund of information will go a long way in making them confident as well raising their self esteem. Keeping this in mind an eight page patient educational booklet in Telugu was released. The booklet covered information on what is epilepsy, whether it is hereditary, causes, employment, education, use of vehicles, types of epilepsy and instruction on compliance. A pictorial representation of positioning of patient after seizure with do's and don'ts was also given. This booklet is being distributed to all patients and has definitely improved the understanding of epilepsy among the family members too.

The chapter has been continuously striving for educating the public by organizing various medical camps with free treatment. The chapter organized camps in the hospital campus and in several places around Nellore, so that a wider population could be covered. All camps had prior media and road coverage in the mandal where the camp was to be conducted. Each camp used to register around 60-70 patients. The camps found that few patients had chronic epilepsy; however they were not on medication. Few patients had monetary constraints while others expressed ignorance of the disease. These patients were duly counseled and asked to regularly follow-up.

Nellore has rural mandals (45) and urban wards (50). With a population of over 6 lakhs, medical care is predominantly taken care of by registered and private medical practitioners. Regular continuing medical educational programmes are conducted for registered and private medical practitioners and general physicians. Medical officers of Nellore district and the surrounding area attend the teaching programmes which emphasizes the importance of lay persons correct diagnosis, appropriate treatment and prevention



Few activities of the chapter

of epilepsy. Educational pamphlets for general public have been prepared and handed to them during the meetings which they in turn distribute in their regions. This ensured wider coverage of dissipation of knowledge. The Association has been appreciated for organizing such educational programmes for primary health care doctors who attend the programme in large numbers. Videos of epilepsy patients are also shown and there is good interaction among the audience.

The chapter has taken active interest in educating school and college teachers and students. The school educational programme first focuses on knowing their fund of information. This is done by distributing closed ended questionnaires. We found that the first aid knowledge was very poor, with people still resorting to placing iron rods in hand, etc. Subsequently lectures with pictures, videos and interactions are carried out. Teachers are educated about absence seizures with video demonstration. In the same way, the programmes are carried out in nursing colleges and other allied

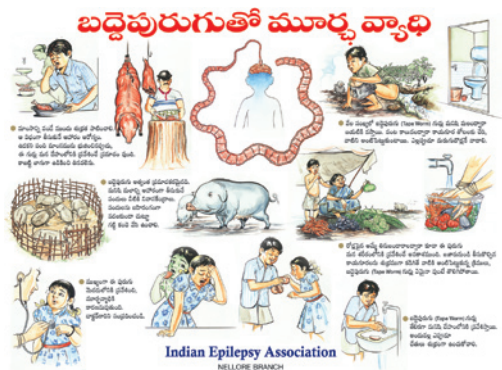


medical specialties. The chapter also continues its awareness programmes in other charitable organizations like rotary club, walkers association, among various others. Articles about epilepsy are frequently published in newspapers.

National epilepsy day is celebrated every year spanning over weeks to a month. During that period all educational activities are intensified and all activities are given wide press and media coverage. There was a theme based awareness approach for National Epilepsy Day. In 2009, the chapter focused on the prevention of Epilepsy and Epilepsy prevention awareness week was held from 9-16 November. On these days the booklets sent by the central office was distributed to the public who were also counseled about the ways of preventing epilepsy. The booklet was also translated to the local language. The information, both in English as well as Telugu, was put up in flexi board and poster forms and displayed in strategic locations.



Epilepsy comic



Neurocysticercosis prevention poster

The chapter also organizes painting competition for children. Children with epilepsy are invited from the epilepsy registry telephonically. Painting/drawing, essay competitions are held in various schools and colleges. The topic chosen is in close relation to the social cause of epilepsy. One of the essay topics was 'My friend has epilepsy' for

which there was a very good participation from college students. A road rally was also conducted, in the main junction of Nellore town, with the help of nursing students and members of the chapter. The road rallies witnessed lot of curiosity from the general public. Pamphlets were distributed to all pedestrians and vehicle owners. These rallies have helped in bringing about greater awareness about epilepsy and to send the message that epilepsy is nothing to be ashamed of.

In the hospital premises short plays and dramas are held along with distribution of pamphlets. The students play and enact about persons with epilepsy. These shows are viewed with great enthusiasm and we feel that they give a lot of carry-home messages.

The print media regularly covers the functions/activities. Articles on frequently asked questions and other facts about epilepsy are frequently published in newspapers. Interviews are regularly given in the local channels. Few of the interviews are direct telecasts with questions from the public. The media coverage has definitely made a mark to reduce the stigma of epilepsy in the public.

A 24 page colored comic book for school children has been published. The comic depicts the myths of people towards epilepsy and guides the reader about precautions, treatment and approach. The comic is in a school setting with a child shown to be having his first seizure in the class room. The response of the fellow students is depicted. It also shows pictures of great people with epilepsy. The comic has been appreciated by the students and teachers alike. Three thousand copies have been distributed so far.

Neurocysticercosis is a preventable form of epilepsy. It is also a common cause of epilepsy in India. As part of epilepsy prevention programme, a poster and a sticker have been designed with pictorial representation about the mode of spread of neurocysticercosis and how it leads to epilepsy. Also, how one could prevent epilepsy is

pictorially represented. About 1500 comics, posters and stickers have been distributed in schools in and around Nellore. The poster and sticker have also been displayed in bus stops, railway stations and hostels. These pictures were drawn by Mr S Pani, an artist. The awareness programmes were discussed at the Collector's office who applauded the idea and joined hands to officially help display the posters and stickers. With the help of DMHO during the deworming programme, these comics and posters were distributed which helped in creating awareness among the school teachers and children.

The Association is also striving hard to uplift the life of people with epilepsy. In this aspect the chapter has been granted funding under the Promising Strategy Programme by the International Bureau for Epilepsy. Under this project, the Association will help 5 persons with epilepsy from the neighboring villages of Nellore who come for regular follow-up. Initially they will be trained, for 6 months, in cell phone repair techniques by qualified personnel. After finishing their training, they will be given the infrastructure for establishing an outlet in their villages which will help the villagers, who otherwise have to go to the neighboring city to repair their cell phones. This training will make them independent and also build their confidence. The project will help in the social upliftment of persons with epilepsy by empowering them with jobs.

The Chapter is constantly growing and presently has 50 Life Members.

The Founder Office Bearers continue in office.

## Tirupati Chapter - Andhra Pradesh

*Dr B Vengamma – Founder President*

The Tirupati chapter was inaugurated on 22 November 1997 by late Dr KS Mani, father of Epilepsy Movement in India.

The Founder Office Bearers were:

President	-	Dr B Vengamma
Vice President	-	Dr Y Raghava Reddy
Secretary	-	Dr A Sudhakar Reddy
Treasurer	-	Dr P Subramaniam

At the inaugural meeting a 4 page pamphlet in Telugu on “Epilepsy - Primary Principles” and a 14 page booklet in Telugu on “Epilepsy - Precautions and Prevention” which were prepared by the branch, were released for free distribution to persons with epilepsy and general public.

Members of the Bangalore Chapter of Indian Epilepsy Association enacted a skit entitled “Epilepsy – down the ages” during the inaugural function at Thyagaraja Mandapam, Tirupati

The main objectives of the branch are:

- To educate the public about the causes, treatment and management of epilepsy
- To dispel myths
- To help, rehabilitate and integrate people with epilepsy in the society
- To create self help groups
- To fight unjust laws affecting the patients.

This is being done by organizing public awareness programmes and bringing out pamphlets and booklets in Telugu regarding medical and

social aspects of epilepsy. Preparing audio visual aids demonstrating different types of epilepsy and enacting skits regarding social aspects of persons with epilepsy are some of the other methodologies that are adopted in this regard.

National Epilepsy Days and cultural and awareness programmes are being conducted regularly over the years.

Identity cards designed by our branch are being given to persons with Epilepsy, free of cost, with an advice to keep the cards with them at all times.

### **Activities**

#### 1997

To educate the school children we organized a guest lecture by Dr KS Mani, Consultant Neurologist of Bangalore on “Epilepsy” in the SVU campus school for 9th and 10th class students on 22 November 1997. He also delivered a guest lecture on “Epilepsy – Practical aspects” to primary care physicians, interns and final year MBBS students in SV Medical College Campus on the same day.



Inauguration of IEA Tirupati chapter, November 1997



National Epilepsy Day celebrations – Awareness programme and drawing competition

A “Panel discussion on Epilepsy “ was held for doctors of the Indian Medical Association, Tirupati Branch on 23 November 1997.

### 1999

In February, special monthly camps for persons with epilepsy were inaugurated. One month’s requirements of medicines were given free to all patients attending the camps.

### 2000

On 18 March an “Epilepsy Awareness Programme” (poster and video presentations) was inaugurated by Dr S Aruna, Minister for Health and Child Welfare, A.P. The Honorable Minister also inaugurated a “Sports Meet” for persons with epilepsy organized on that occasion. About 50 patients participated in various sports events. A drawing competition was also conducted for the young patients.

A lecture-cum-video programme on epilepsy was organized at Kiran English Medium High School, Tirupati on 17 November as part of National Epilepsy Day programme. Dr B Vengamma was the principal speaker. An essay competition for school children was also organized on that occasion.

Dr B Vengamma, President of the branch gave a guest lecture on “Recent Advances in Epilepsy Management” at the State Indian Medical Association conference at Nellore on 2 December.

### 2001

A website was launched on 14 January, highlighting the activities of the Branch. The website can be accessed at [http:// www. Balajiepilepsy.homestead.com](http://www.Balajiepilepsy.homestead.com).

On 17 February, a lecture on “Epilepsy Management” by Dr HV Srinivas, Neurologist from Bangalore was arranged for doctors and PG students of SV Medical College in connection with the Silver Jubilee celebrations of our monthly special camps for persons with epilepsy.

On 18 February the following events were arranged:

- Epilepsy awareness programme through posters
- Sports competitions for patients
- Community lunch for patients and their attendants.

On the occasion of the National Epilepsy Day on 17 November a painting competition was arranged for persons with epilepsy at SVIMS.

### 2002

On 19 May, Dr P Satish Chandra, Professor of Neurology, NIMHANS, Bangalore gave a guest lecture on “Past, Present and Future of Anti-epileptic Drugs” for the benefit of medical practitioners at Tirupati, under auspices of the branch.

As part of the National Epilepsy Day on 17 November the following programmes were arranged in association with the Department of Neurology, SVIMS and the Regional Science Centre, Tirupati.

#### Topic

- Painting contest : Epilepsy - Out of shadows
- Essay writing contest : Epilepsy and your awareness

- Elocution contest : Epilepsy is not an impediment for achieving excellence
- Open house quiz

### 2003

Indian Epilepsy Association, Tirupati Branch in association with Department of Neurology, SVIMS, Tirupati organized a “Symposium on Epilepsy” on 15 March.

On 16 March the Golden Jubilee Function of special monthly camps for persons with epilepsy was organized.

A street play on epilepsy was enacted by the members of the Bangalore chapter of the Indian Epilepsy Association. A community lunch was organized for the patients and their attendants which was sponsored by M/s. Bhimas Paradise Hotel, Tirupati.

A Counseling Centre at SVIMS for persons with epilepsy was inaugurated on 29 August by Prof. P Satish Chandra, Professor of Neurology, NIMHANS, Bangalore. The main objectives of the centre are:

- To enhance the awareness about epilepsy.
- To provide social, psychological and moral support to people with epilepsy.

### 2004

A function was arranged on the occasion of 70th special camp for persons with Epilepsy and National Epilepsy Day on 21 November. An information pamphlet on epilepsy was released. Epilepsy awareness programme through street plays in rural areas was inaugurated in addition to painting competitions and essay writing contests.

### 2005

On 20 November drawing and painting competitions were held for children with Epilepsy in the age group of 5-15 years at SVIMS, Tirupati. Essay competitions were also conducted for the final year





(a) 100th Special monthly camp for persons with epilepsy and donation of EEG Machine, May 2007 (b) ECON-2009 (c) IEA Tirupati Oration in Epileptology, 2010 (d) IEA Tirupati Oration in Epileptology, 2011

MBBS students and postgraduate students (General Medicine) of S.V. Medical College, Tirupati on the following topics:

- Epilepsy classification, diagnosis and principles of management.
- History of epilepsy and genetics of epilepsy.

Nearly 125 students took part in the competitions. Prizes and certificates of merit were given to the winners.

## 2007

The Tirupati Branch of the Indian Epilepsy Association in collaboration with Department of Neurology, Sri Venkateswara Institute of Medical Science (SVIMS), Tirupati organized a Colloquium on Epilepsy in memory of late Dr KS Mani on 19 May at SVIMS, Tirupati. The

theme of the colloquium was: “Living with Epilepsy, We can ! We will ! ”

Drs VS Saxena, HV Srinivas, P Satish Chandra, Anuranjan Anand and Praveena U Shah were the distinguished faculty for the colloquium.

As part of epilepsy awareness programmes of our branch, Dr Bindu Menon, Secretary IEA, Tirupati, undertook school/college based health-education programmes during 2007 - 2008.

The awareness programme consisted of alerting the teachers recognize seizures in the school-going age children, fight myth and stigma, about the do's and don'ts and general information of epilepsy. The programme was very interactive and both the teachers and students came forward and asked queries.

#### 2008

On 16 November the students of the College of Nursing, SVIMS, enacted two epilepsy awareness programmes. The first one was in the folklore style of story telling called *Burra Katha* in Telugu. The second one was a skit emphasizing importance of medical treatment, precautions, life style modifications, education, empathy and empowerment and also to dispel the myths and superstitions that are prevalent in our country.

On 17 November essay and elocution competitions were held for nursing and physiotherapy students of SVIMS on the topic “Epilepsy – My Perspective”.

#### 2009

The awareness programme for the National Epilepsy Day 2009 was based on the theme “Prevention of Epilepsy – Neurocysticercosis, Head Injuries & Birth Injuries”. A painting competition was organized for persons with epilepsy in the age group of 5 to 14 years on this occasion. Nearly 25 boys and girls took part. Prizes were awarded to the winners and the others were given certificates for

participation. The faculty and students of the College of Nursing organized awareness programmes in ten high schools. Lecture-cum-demonstration methods with the help of Posters were utilized for conveying the message regarding various aspects of epilepsy.

### 2010

In November, twelve high schools located in and around Chandragiri area of Chittoor District were covered for conveying the message regarding various aspects of epilepsy. The programmes were interactive in nature and the young students, parents and teachers greatly benefited from it.

On 21 November, the students of the College of Nursing, SVIMS, enacted a skit on the theme “Women with Epilepsy – Their Quality of Life” bringing out various phases in the life of affected women, which was well appreciated.

### 2011

From 2–11 November the faculty and students of the SVIMS College of Nursing organized awareness programmes on epilepsy in sixteen high schools located in and around Renigunta area of Chittoor District as part of National Epilepsy Day celebrations.

Also, the students of the College of Nursing, SVIMS, enacted a skit bringing out certain normal problems faced by persons with epilepsy and the needed remedial measures. It had four parts entitled (i) Story of Mayuri (ii) Marriage of Priya (iii) Golden advice of the grandmother (iv) Sports and Games. The audience greatly appreciated the sincere efforts of the students.

### Continuing Medical Education Programs for Medical Professionals

These are being arranged regularly with guest lectures from invited faculty and symposia on Epilepsy.

### EEG Workshop at Tirupati

The Department of Neurology, SVIMS, Tirupati, in association with

the Indian Epilepsy Association, Tirupati Branch organized an EEG Workshop on 1 and 2 November 2008 at SVIMS, Tirupati,

The aim of the workshop was to create better awareness and understanding among the medical and para-medical professionals about the time tested diagnostic tool EEG in the light of latest developments in medical imaging techniques.

### Special Free Monthly Camps For Persons With Epilepsy

These are being organised by the Indian Epilepsy Association, Tirupati Branch since February, 1999. These camps are co-sponsored by Department of Neurology, SVIMS and Friends of SVIMS Society.

At present an average of about 550 patients are attending these camps every month. Each patient's case history is recorded, evaluated and the patient is given free medication for one month. Tests prescribed at these camps are performed at concessional rates at SVIMS.

Overwhelming majority of the patients (95%) are from the lower strata of the society and rural areas. They cannot afford the prolonged treatment required for epilepsy. Expenditure incurred towards medicines is about Rs. 1,00,000 for each monthly camp.

These camps, while alleviating the suffering of poor persons with epilepsy, are making lot of difference in the lives of majority of the patients.

So far one hundred and sixty-two camps have been conducted and the total cost of medicines distributed free is about Rs. 1.08 crores.

This is made possible with generous contributions from SVIMS and TTD authorities and the donations from philanthropic public, some pharmaceutical companies and from M/s Ameri Cares of USA.

Our chapter has been registered with Ministry of Social Justice and Empowerment, New Delhi under Indo US bilateral agreement for receiving donations free of customs duty. We are also registered

with Ministry of Home Affairs for receiving donations under Foreign Contribution Regulation Act.

Functions to commemorate the 25th, 40th, 70th and 100th special camps for persons with epilepsy were organized in befitting styles with distinguished invitees, educational and cultural programmes.

#### Honour to Dr B Vengamma

Dr B Vengamma, President, was honoured with *Harish Chandra Bajoria Award* at the 12th Annual Joint meeting of Indian Epilepsy Association and Indian Epilepsy Society held at Nagpur in October 2004 in recognition of her services to the cause of epilepsy and persons with Epilepsy.

#### Donation of Digital EEG Machine

On the auspicious occasion of the 100th special camp day, the Tirupati Branch of the Indian Epilepsy Association donated a Digital EEG Machine costing about Rs. 6 lakhs to the Department of Neurology, SVIMS with a request to the authorities to extend concessions to the poor persons with epilepsy who need these tests.

#### Free Medicine Distribution Center

Whenever available, the anti-epileptic medicines donated by M/S Ameri Cares is being distributed free to regular out-patients also.

#### 10th Joint Annual Conference of IEA and IES – ECON 2009

ECON 2009 was held on 7 and 8 February 2009 at Tirupati. It was of historic importance because, for the first time it has been dissociated from the Annual Conferences of the Indian Academy of Neurology / Neurology Society of India and was conducted as a “stand alone” conference. The Tirupati Branch was honoured to organize this conference successfully.

#### Epilepsy Teaching Programs

The Department of Neurology, SVIMS in association with the Indian Epilepsy Association, Tirupati Branch organized a Epilepsy Teaching

Program on 4 December 2010 at Tirupati. The second Epilepsy Teaching Program was held on 10 December 2011 at Tirupati

IES,IEA-18th IEC Trust with financial assistance from Abbott India Ltd has prepared a teaching module with the assistance of leading neurologists of our country on management of epilepsy.

The program was conducted keeping in view the pressing need for educating, equipping and inspiring primary care physicians to be involved actively in delivering better epilepsy care services especially in the rural areas of our country.

The primary aim of this program is to convey that close interaction among physicians, general practitioners, neurologists and epileptologists could make a great difference in spreading the message that epilepsy could be easily treated at primary and secondary levels and thus building confidence among persons with epilepsy.

#### IEA, Tirupati Oration in Epileptology

The Tirupati Branch of the Indian Epilepsy Association donated Rs. three lakhs to SVIMS, Tirupati, with a request to institute in the Department of Neurology, an annual oration entitled “IEA, Tirupati Oration in Epileptology” commencing from 2010.

Dr HV Srinivas, Consultant Neurologist, Bangalore and President Elect of IEA delivered the first oration on the topic” Epilepsy & Society”. Dr Srinivas delivered an erudite and thought provoking lecture bringing out the myths, superstitions and discriminations that existed and exist, about epilepsy, from the medieval to the present times. He called for concerted efforts on the part of individuals, voluntary organizations and the Governments to empathize with the plight of persons with epilepsy and strive for improving their quality of life. He paid glowing tributes to Late Dr KS Mani, an eminent Epileptologist, for his untiring efforts to assist the PWE, especially with regard to marriage laws and drug compliance.

The second Oration was organized on 10 December 2011. Dr P Satish Chandra, Director, NIMHANS, Bangalore delivered the Oration on the topic “Challenges in the Diagnosis & Management of Epilepsy”. Dr Satish Chandra delivered an erudite lecture bringing out the intricacies involved in the present day diagnosis of epilepsy and the problems that have to be overcome in the process. He also enumerated the chronological development of remedies for the disorder. He presented the details of efficacies of various medicines available at present for different types of epilepsy. He also touched upon the surgical treatment of epilepsy being practiced at NIMHANS as a collaborative effort between various departments of NIMHANS.

The Chapter has 120 members – 51 Life Members and 69 Annual Members.

The present Office Bearers are:

President	- Dr B Vengamma
Vice-President	- Dr Y Raghava Reddy
Secretary	- Mrs M Nagarathna
Treasurer	- Prof. P Subramaniam

## Visakhapatnam Chapter - Andhra Pradesh

*Dr Venkateswarlu – Founder Secretary*

It all started with the unanimous decision of neurologists of the Visakhapatnam to start a local chapter of Indian Epilepsy Association after they were enthused by one of the performances of a team at national conference of the Indian Epilepsy Association. National Epilepsy Day, 17 November 1996, which happened to be a Sunday was marked for the event. DrKrishnamoorthy Srinivas, a senior neurologist from Chennai was the chief guest and delivered the inaugural address. As public participation is very important for the success of such an event, all efforts were made to reach the public. The Medical Officers of all the public sector undertakings were addressed well ahead of time to communicate to all the patients on their rolls. Coverage was given in all newspapers about the date and venue of the meet. A popular auditorium, Visakha Urban Development Authority (VUDA) Children's Theatre was identified as the venue. Usually this venue is not allotted to others during second half of November as VUDA plans a series of events to mark children's day which falls on November 14th. But the authorities could be convinced about the nature of the event and that children were the important beneficiaries of this programme.

### The Founder Office Bearers were:

Secretary - Dr K Venkateswarlu

Treasurer - Dr K Satya Rao

Members - Dr B Subba Rao, Dr G Butchi Raju,  
Dr Y Prabhakara Rao, Sri M Satyanarayana,  
Sri S Venkata Rao

On the eventful day, a large gathering collected at the venue. Arrangements were made to register the names of the patients





Dr Krishnamoorthy Srinivas speaking at the inauguration of the Visakhapatnam chapter of IEA on 17 November 1996

who were willing to become members. The meeting was chaired by Dr Sriram, Superintendent, King George Hospital, Dr R Venkataramana, Principal, Andhra Medical College along with Drs K Venkateswarlu, K Satya Rao, B Subba Rao, and Y Prabhakara Rao.

The chief guest, Dr Krishnamoorthy Srinivas delivered an inspiring lecture about medical and social aspects of epilepsy which was well received by the audience. This was followed by interaction with audience who posed a variety of questions and which were answered by Drs K Venkateswarlu, K Satya Rao, B Subba Rao, and Y Prabhakara Rao. The entire programme was video recorded by local TV media and relayed the same evening. The event was widely covered in all the national and local newspapers next day.

Thus the stage was set for a new awakening. Another proposal mooted by the members of the local IEA was that service should include improvising access to antiepileptic drugs which were expensive. Mr. Muralidharan of Novartis who was local area manager at that time took the initiative to come forward to supply carbamazepine (Tegritol) at Re 1. The proposal was that a patient would pay 50 paise for the tablet and find a charitable organization to fund the rest. Soon Sanofi Aventis pharma also joined hands to supply sodium valproate on similar terms. The Sankar Foundation which runs a popular eye hospital now was, at that time, also funding a successful programme of distributing antituberculous drugs for sputum positive pulmonary tuberculosis patients free of cost. Late Sri Sankara Rao was generous enough to accept the request of IEA and came forward to contribute to the just cause. The members

including representatives of Novartis and Sanofi Aventis used to run a clinic every Saturday between 12 and 2pm to attend to the requirements of the patients. The Association thankfully remembers the services of late Sri Satyanarayana of erstwhile Parke Davis who helped organise this Epilepsy Service Centre, for a very long time, which is active even today.

It was Mr KV Muralidharn of Novartis who took the initiative to invite late Dr KS Mani from Bangalore to inaugurate the Epilepsy Service Centre. Dr Mani lost no time and drove straight from the airport to Hotel Dasapalla where he addressed a packed gathering about the social aspects of epilepsy. A favorite target of Dr Mani was school children who he believed are a very receptive audience. The Principal of a popular school was approached to permit Dr Mani to address their children. The Principal reacted strongly and was not willing to expose her children to such a horrendous disease like epilepsy! She also expressed her concern that the parents of the children may object to their wards being introduced to such a stigmatised illness. In spite of persuasive efforts, she did not yield. Then the Principle of another school, Sri Satya Sai Vidya Vihar, was approached, who was more receptive and conceded to the request to accommodate Dr Mani. The audience was 9th and 10th class students. An expert in captivating audience, Dr Mani in his inimitable style spell bound the students with his mimicry of various seizures while trying to dispel



Dr KS Mani (seated 2<sup>nd</sup> from left) at the inaugural function of the epilepsy service centre

the myths. The effect of his lecture was obvious by the fact that the interaction lasted longer than the lecture and much to the disappointment of the children the session had to be cut short as Dr Mani had to rush to

catch his flight. The inaugural function of Epilepsy Service Centre was chaired by the then District Collector, Sri MV Gopal, IAS, Sri Parvathi Kumar, President, World Teacher's Trust, Sri. Sankara Rao, Chairman, Sankar Foundation and Dr K Venkateswarlu, founder Secretary, Indian Epilepsy Association. The meeting was attended by luminaries of Visakhapatnam apart from public.

In 2002, late Sri Sankara Rao expressed his inability to continue the contribution for personal reasons. Then came the savior in the form of Sri Virchand Bothra, Managing Director of Bothra Charitable Trust who continued to support the good cause. He is the worthy son of a noble father, late Sri RC Bothra whose philanthropy touched every aspect of human life in Visakhapatnam.

Following the example of Dr KS Mani, the local chapter continued the good work of addressing the children of various schools. In spite of good local standing of the doctor members, it was not easy to convince the school administration unless one of the members or their wards is the victim of this malady.

Considering the fact that most of the people will be comfortable if they have educational material in local language, IEA brought out a booklet containing information in both Telugu and English on various aspects of epilepsy including do's and don'ts. Sanofi Aventis was kind enough to fund the cost of the publication. Dr C Dharma Rao, a popular orthopedic surgeon and Superintendent of



Addressing school children



Epilepsy camp

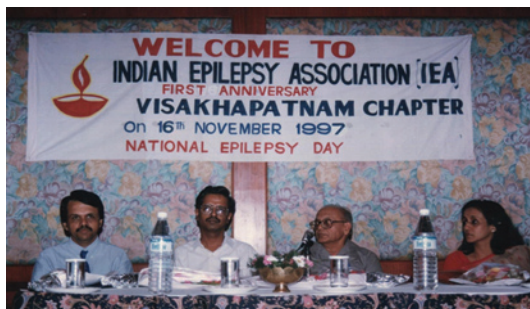
King George Hospital, at that time, released the booklet at a public function.

Epilepsy pregnancy registry was inaugurated in December 2000. With the help of Dr Sanjeev Thomas from SCTIMST, Trivandrum, a CME was organized which was attended by 200 OBG specialists, physicians, neurologists and neurosurgeons. Various topics related to management of epilepsy in pregnancy were discussed. In the next 10 years about 300 completed pregnancies were analysed and data presented. The study had a low rate of teratogenic malformations in the offspring of women with epilepsy (3.6%). The reason for this low rate was attributed to predominant practice of monotherapy, limited use of sodium valproate and prescribing minimal effective dose of antiepileptic drugs.

On every National epilepsy day, IEA contributes articles to popular newspapers on various aspects of epilepsy like divorce, law, driving, neurocysticercosis, etc.

National Epilepsy Day celebrations are conducted with fervor. An epilepsy camp is organized in one of the public sector undertakings and members of the families of employees suffering from epilepsy are treated and counseled. This is followed by a meeting wherein one of the members of IEA, Visakhapatnam chapter would address the gathering about various aspects of epilepsy. Painting competition for children is conducted and prizes distributed to winners (courtesy Abbot Pharma). A film on epilepsy is also screened.

One of the important facets of epilepsy programme is educating primary care doctors about



National Epilepsy Day, 1997

the principles of epilepsy management. If the fruits of advances in epilepsy management were to reach the needy, the knowledge has to percolate downstream. Often the epilepsy camps conducted locally and outstation are followed by a CME for doctors.

The members of the local chapter seize every opportunity to approach the organizers of any public gathering to give them 5 minutes to explain about epilepsy .

IEA analysed the data of 1000 epilepsy patients, who had undergone neuroimaging, with the help of Department of Neurology, Andhra Medical College, Visakhapatnam, and concluded that 40% of epilepsy in north coastal districts of Andhra Pradesh is due to neurocysticercosis.

In 2007, Andhra Medical College, Visakhapatnam organized a medical exhibition for 10 days. This event is done once every 5-10 years and public participation is usually very encouraging. People turn up in large numbers and it is a very popular medium of reaching the masses effectively. IEA setup a stall with posters, computer graphics and models to disseminate knowledge about epilepsy. On an average about 2,000 people visited the stall and gained useful information.

The IEA obliges requests from various NGOs for conducting camps for epilepsy patients in their areas. The local chapter utilises every such opportunity to educate the patients and public about this much-tainted illness.

It has been a long journey and the walk has been relatively smooth thanks to the support of colleagues, members of IEA, media and district officials. Any such effort to improve the quality of life of an underprivileged segment is a continuous effort with improvisations as and when the situation demands. Though an arduous task, the

satisfaction one derives at the end of the day makes the experience memorable and worthwhile.

The Chapter has 42 members – 22 Life Members and 20 Annual Members

The present Office Bearers are:

President	-	Dr VC Bothra
Vice-President	-	Dr K Venkateswarlu
Secretary	-	Dr RV Narayana
Treasurer	-	Dr K Satya Rao

## Guwahati Chapter (North East Region) - Assam

*Dr Monalisa Goswami Sarma – Secretary*

The North East (NE) Chapter was formed on 30 June 2006 at Guwahati, Assam. The meeting was attended by neuroscientists of North Eastern states namely Assam, Meghalaya, Tripura and Manipur. Later, it was approved at the General Body meeting of IEA held at Bangalore on 5 October 2006.

### The Founder Office Bearers were:

President	- Dr BC Kakati
Vice-President	- Dr N Upadhyay
Honorary Secretary	- Dr Pratap Sanchetee
Honorary Treasurer	- Dr Nabajyoti Barkataky
Hony Joint Secretary	- Dr Judy Laldinpuii

There are 30 members in this chapter including neurologists, neurosurgeons, neuroradiologists, neurophysiologists, neuropathologists and neuroanaesthetists. The Chapter meets at regular intervals to discuss various issues on epilepsy and host awareness programmes within Guwahati. The first outdoor activity of the chapter was



Towards seizure free India

launched on 17 November 2006 on the occasion of National Epilepsy Day, at Morigaon, about 60 km east of Guwahati. The programme was started with an epilepsy awareness lecture by Dr P Sanchetee the chapter's Secretary, followed by free epilepsy

treatment camp where about 200 epilepsy patients were evaluated and treated and free samples of anti-epileptic drugs distributed.

Dr Nabajyoti Barkataky took over as Secretary of the chapter from Dr P Sanchette and continued the activities with vigour. The first CME programme of IEA – NE Chapter was held on 26 May 2007 at Guwahati Medical College. Dr VS Saxena, the then President of IEA presided over the function and spoke on biochemistry of AEDs. Dr Arijit Chattopadhyay (Kolkata) and Dr SK Sinha (Patna) were the other two dignitaries who spoke on paediatric and geriatric epilepsy issues respectively. The second CME was held on 7 June 2008 at Guwahati. Dr Joy Desai (Mumbai) discussed about refractory seizures, Dr Mihir K Roy (Kolkata) about status epilepticus and Dr Chandan Roy (Agartala) about paediatric pseudoseizures. The meeting concluded with an in-depth talk by Dr KM Bopanna, an eminent epilepsy surgeon from Bangalore.



Interactive sessions





Painting competition

In the last couple of years, the meetings of the chapter have been held together with the meetings of the Neuro Club of Guwahati. At regular intervals, members of the chapter have taken up the issue of raising awareness amongst the people of Assam regarding epilepsy by organizing awareness meets and other activities in their respective places of work. They have regularly organized painting competitions for children with epilepsy on National Epilepsy Day along with awareness meetings for the caregivers. Several members have participated in radio and television shows on several occasions to raise awareness among people which is woefully poor.

In the last meeting held on 10 November 2012, it was resolved to increase the number of members and to actively involve all members in awareness activities.

The Chapter has 29 Life Members.

The present Office Bearers are:

President	: Dr (Mrs) Ajaya Mahanta
Vice-President(s)	: Dr Ashok Kayal, Dr Navanil Baruah
Honorary Secretary	: Dr Monalisa Goswami Sarma
Honorary Treasurer	: Dr Munindra Goswami
Hony Joint Secretaries	: Dr RR Das, Dr Marami Das

## Patna Chapter - Bihar

*Dr Ashok Kumar – Founder President*

In 2008 when Dr Ashok Kumar went to attend a Joint Annual Conference of IEA & IES at New Delhi he realized the need for creating awareness about epilepsy in his state in the manner it was being done in other parts of India and abroad. He discussed this with noted neurologist Dr KK Sinha, who appreciated it very much and took him to Dr HV Srinivas. It is with their support and guidance that the Patna chapter conceptualized.

The chapter was formed in November 2008, when enthusiastic doctors, neurotechnicians, neurophysiotherapists, nurses of IGIMS, Patna and some like minded people and social workers in and around Patna sat together in a meeting to become members and elect their office bearers.

### The Founder Office Bearers were:

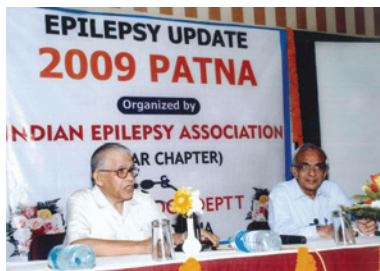
President	- Dr Ashok Kumar
Vice-President	- Dr Udayan Narayan
Secretary	- Dr Arshad Yahya
Treasurer	- Mr Binay Pandey

### **Activities**

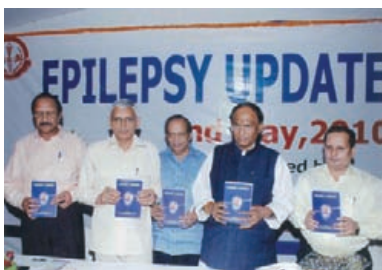
The chapter organized various awareness programmes with interactions between patients and doctors. Epilepsy Updates 2009 and 2010 and Neurology Updates 2011 and 2012 were also organised. These conferences were a great success as was evident from the increasing number of participants in successive conferences to share and gain knowledge from the eminent speakers.



Dr Ashok Kumar delivering vote of thanks at Epilepsy Update 2009. Honble Governor of Bihar (chief guest) extreme left.



Padmashree Dr SN Arya and Dr HV Srinivas at Epilepsy Update 2009



Padmashree Dr CP Thakur (ex Union Health Minister, India, 2nd from left) releasing book on “Epilepsy—A Review” edited by Dr Ashok Kumar, at Epilepsy Update 2010.



Dr JMK Murthy delivering a talk at Epilepsy Update 2010.



Dr Ashok Kumar giving a bouquet to Sri Shatrughan Sinha at Neurology Update 2011.



Dr Ashok Kumar lighting the lamp at the inaugural function of the Neurology Update 2012. Sri Uday Narayan Chaudhary (Honble Speaker Bihar Vidhan Sabha) looks on.

Two of our founder members (Secretary and EC member) who were inspired with their interaction with noted neurologists during conferences are now pursuing DM in Neurology.

The Chapter has 76 Life Members.

The present Office Bearers are:

President	- Dr Ashok Kumar
Vice-President	- Dr Udayan Narayan
Secretary	- Dr Rakesh Kumar
Treasurer	- Dr Binay Pandey

## Delhi Chapter - Delhi

*Dr MM Mehndiratta – Secretary*

The Delhi Chapter was formed in December 1974

The Founder Members were:

Dr AD Sehgal

Dr Vimla Virmani

Dr MC Maheshwari

Dr Meena Gupta

National Epilepsy Day is celebrated on November 17 every year by spreading awareness regarding epilepsy to the general public. On this



A young girl with epilepsy being awarded



Drawing and painting competition



A running race for children with epilepsy

occasion painting, running race and creative writing competitions are organized for children with epilepsy. Also, occupational therapy students of the Department of Neurology, GB Pant Hospital, New Delhi perform plays to clear the myths about epilepsy. A question-answer forum is organized where queries related to epilepsy are answered by neurologists.

The Chapter has 100 Life Members.

The present Office Bearers are:

President	-	Dr Meena Gupta
Secretary	-	Dr MM Mehndiratta
Treasurer	-	Dr LK Malhotra

## Ahmedabad Chapter - Gujarat

*Mr Upendra Divyeshvar – Founder Secretary*

Ahmedabad chapter was formed in March 2008.

The Founder Office Bearers were:

President	-	Dr Sudhir V Shah
Vice President	-	Dr Parimal Tripathi
Hon. Secretary	-	Mr Upendra Divyeshvar
Hon. Treasurer	-	Mr Hitesh Sanghvi

### Activities

A notable feature is the periodic meeting of self help group of parents of children with epilepsy, who share their experiences and anxieties about their children. During these meetings eminent neurologists explained about the various aspects of epilepsy, its treatment and the various types of brain surgeries. They also explained how episodes of hysteria are different from epilepsy. The parents are also informed



Doctors addressing the audience



Lighting of the lamp



Team of expert doctors replying to the questions



Gathering at Ahmedabad to celebrate National Epilepsy Day



Gathering at Parimal Garden to celebrate National Epilepsy Day



Warm welcome to Dr Sudhir Shah



Audience listening to the lectures about Epilepsy at Thakorebhi Desai Hall, Ahmedabad

about various aspects of epilepsy in children, the new medications, their availability and side-effects and about the insurance for challenged children.

National epilepsy day is celebrated on 17 November every year when drawing/painting competitions are held for children in schools and colleges.

The Chapter has 26 members – 25 Life Members and 1 Annual Member.

The Founder Office Bearers continue in office.



## Anand Chapter - Gujarat

*Dr Anil Patel – Founder Secretary*

Anand, the milk city of India, is a small town in central Gujarat and is known world over for its co-operative dairy movement which heralded the white revolution in India with operation flood of National Dairy Development Board. Amul Dairy was started around the time of independence of India by Mr Tribhovandas Patel with inspiration from the Iron man of India, Sardar Vallabhbhai Patel who belongs to a nearby village, Karamsad. Soon afterwards Dr Verghese Kurien joined and since then various institutions like National Dairy Development Board, Gujarat Milk Marketing Federation, Institute of Rural Management, Veterinary College, Agriculture University, Vidya Dairy for Dairy students, IDMC, etc, have come up to give Anand its present identity.

The idea of Anand Branch of IEA germinated during the Indo-German Epilepsy Symposium organized by Dr KS Mani, from 4-6 December 1992. Dr Anil Patel had attended the symposium and met the luminaries of IEA. Soon correspondence was initiated with the then Secretary General Dr KS Mani, who was very encouraging, prompt,

enthusiastic and supportive. The doctors from and around Anand under the leadership of Dr Anil Patel and senior physician Dr DC Patel decided to organize an epilepsy symposium inviting physicians, pediatricians and psychiatrists from all over Gujarat and faculty from Ahmeda-



Inauguration of the Chapter by Dr (Mrs) P Kaul in the presence of Dr Pravina Shah

bad, Vadodara and Mumbai. The Anand Branch of Indian Epilepsy Association was also founded at the same time in 1993 with the formal permission and blessings from Dr KS Mani, by a letter dated 15 February 1993.

The Founder Office Bearers were:

President	-	Dr DC Patel
Vice-President	-	Dr JD Lakhani
Secretary	-	Dr Anil Patel
Treasurer	-	Dr Ashok Johri

There were twenty-one founder members who were medical professionals from Anand and nearby places.

The inauguration of the branch was organized on 28 March 1993 in the presence of Dr Pravina U Shah, the then editor and member Governing Council, IEA. To coincide with the inauguration a symposium on epilepsy was organized on the same day. Different aspects of epilepsy were discussed during the symposium by renowned speakers. Dr Ajit Sowani, a neurophysician from Ahmedabad spoke on Classification and Diagnosis of Epilepsy, Dr Keyur Buch, neurophysician from Vadodara spoke on EEG in epilepsy, Dr Vrajesh Majumdar, radiologist from Vadodara spoke on Brain Imaging in Epilepsy, Dr Ranjit Acharya, neurophysician from Ahmedabad spoke on Medical Management of Epilepsy and



Dr Pravina Shah delivering the keynote address at the inauguration of the chapter



Dr DC Patel, Founder President, IEA Anand felicitating Dr (Mrs) P Kaul at the inaugural function



Dr Ajit Sowni giving a lecture in Epilepsy Symposium 1993



Dr Keyur Buch speaking to relatives of patients with epilepsy



Dr Sudhir Shah giving a lecture on Epilepsy

Dr Sudhir Shah neurophysician from Ahmedabad spoke on Recent Advances in Epilepsy. The keynote address 'Holistic Approach to Epilepsy' was delivered by Dr Pravina U Shah. The symposium was moderated by Mrs P Kaul, a retired professor of neuromedicine of Baroda Medical College. The symposium was attended by doctors from all over Gujarat and was a great success.

### Activities

The following activities were carried out since its inception, though the chapter is not very active of late.

Dr Mayank Patel, neurophysician from Ahmedabad spoke on myoclonic epilepsy along with a video show of different types of epilepsies during the 1st AGBM on 12 June 1993.

Dr DC Patel moderated the Panel Discussion on epilepsy during the 2nd AGBM on 29 May 1994. The panelists were Dr (Mrs) Jyoti Mannari, Dr Keyur Buch, Dr Satish Pandya and Dr Santosh Agnani.

Two articles on the aims and objectives of Indian Epilepsy Association and the various aspects of epilepsy were published in Gujarati language in the local Gujarati daily 'Naya Padkar'.

A lecture-cum-question-answer session for general public was organized on 16 March 1997. Dr Keyur Buch spoke on epilepsy in

the local language and answered questions from patients and their relatives.

The Anand Branch is not able to sustain its earlier enthusiasm because of several factors, chief being general lack of interest among its members. We have not been able to induct non- medical members who can energize or guide the medical members. Here we expect to be guided by more active chapters like Bangalore and Mumbai.

The Chapter has 35 Life Members.

The present Office Bearers are:

President	-	Dr NS Panchal
Vice President	-	Dr Depak Karia
Secretary	-	Dr Anil Patel
Treasurer	-	Dr Himanshu Patel

## Ranchi Chapter - Jharkhand

*Dr S Haque Nizamie – Founder Secretary and current President*

I happened to meet Dr KS Mani and joined Indian Epilepsy Association, Bangalore Chapter in 1983 as a life member. Subsequently, I came in touch with Dr EP Bharucha who was Secretary General of IEA and both he and Dr Mani encouraged me to start a chapter of IEA in the then undivided Bihar. This is how the Ranchi Chapter of IEA came into existence on 12 May 1992 with 25 founding members out of which 4 were patients or their relatives.

### The Founder Office Bearers were:

President	-	Dr HP Narayan
Vice President	-	Dr LN Sharma
Hony. Secretary	-	Dr S Haque Nizamie
Treasurer	-	Dr D Ram

### **Down Memory Lane**

It may be interesting to note the genesis of IEA Ranchi Chapter. In the Central Institute of Psychiatry I was seeing many cases of epilepsy. In the wards there were cases of epilepsy with psychiatric complications and OPD had some patients of epilepsy. I realized the relevance of a facility for these cases and a weekly, special clinic for epilepsy was started in 1988, perhaps, one of the earliest of its kind in the eastern part of the country. From the beginning, the approach was not only



(a) Founder President Dr HP Narayan addressing the gathering (b) Epilepsy Camp at CIP in 1992 (c) Awareness Programme 1992

to control the seizure with medicines but also to pay attention to the psychosocial issues related to epilepsy. The epilepsy clinic starts with a group meeting of patients and their relatives conducted by a clinical psychologist to highlight emotional and social problems and also to learn from experiences of each other. Patients and their relatives are actively involved in the management of the problem and they are encouraged to share their experiences with their family and community members. This activity evolved into a self-help group which met once a month in the homes of one of the patients. Over this background when Dr EP Bharucha asked me whether a chapter of IEA for Bihar could be started in Ranchi we were ready for it. In the latter half of 1991 we submitted a proposal to start a chapter of IEA at Ranchi which was endorsed by the Governing Council of IEA on 15 March 1992. Thus the saga started on 12 May 1992 and by June 1992 the membership increased to 44, by October 1992 it was 47 with two life members and 14 of them were patients or their relations. In 1992 the chapter started a variety of activities e.g, panel discussion on psychosocial aspects of epilepsy for relatives of persons with epilepsy and lay persons, talks on management of epilepsy for medical doctors, training of anganwadi workers to identify children with epilepsy, talk on epilepsy to members of a ladies club, refresher course in epilepsy for nurses, public awareness programme on epilepsy for school teachers, etc.

The National Epilepsy Day on 17 November 1992 had an update on epilepsy in which many experts spoke on various aspects of epilepsy



(a) Dr KS Mani Centre for Cognitive Neurosciences (b) Dr KS Mani and Dr Nizamie at CIP, Ranchi, 1994 (c) Epilepsy CME at CIP in 1992

and Dr TK Ghosh, a senior neurologist from Calcutta was the chief guest. It was attended by 350 doctors and medical students from Rajendra Medical College and Hospital, Ranchi. In subsequent years many neurologists of repute delivered lectures. Dr KS Mani, who was Secretary General of IEA, came for two National Epilepsy Day celebrations. Incidentally, the Centre for Cognitive Neurosciences in CIP, Ranchi is named after Dr KS Mani.

The programmes conducted in 1992 became a kind of template for future activities. Year after year these activities are conducted with the addition of some new activity. Every year camps are held for identifying and managing cases of epilepsy in rural areas, hand bills and pamphlets are brought out on various aspects of epilepsy for lay persons and medical doctors, articles on epilepsy are published in local newspapers, awareness programmes are conducted in schools and colleges, surveys regarding knowledge, attitude and practices about epilepsy are conducted in various sections of the community, antiepileptic drugs are provided at concessional rates to the patient members of the chapter and partnering with local NGOs in conducting various programmes, etc. Central Institute of Psychiatry provided its resources liberally to conduct various activities.

### **Development of Activities**

Various booklets and handouts were developed over the years which included patient information on do's and don'ts of epilepsy, childhood epilepsy, psychosocial issues on Epilepsy, non-convulsive variants of epilepsy, diagnosis and management of epilepsy for medical doctors which have been distributed among patients, caregivers and people attending outpatient department of CIP. The initial work done by the Ranchi Chapter resulted in an exhaustive case record that is being used in the Epilepsy Clinic of CIP, Ranchi to gather clinical details of the patients. The Chapter is active in spreading awareness regarding epilepsy and related issues in the community by organizing regular awareness programmes, medical camps and workshops working



(a) Speakers from Kolkata at CME, 2008 (b) Awareness Meet at CIP, 2009 (c) Freedom from Epilepsy, 2010 (d) Epilepsy Day, 2012 (e) Epilepsy CME at CIP, 2012 (f) Fight against Epilepsy, 2012

closely with CIP which remains the official secretariat of the chapter since its inception. With regular inputs from eminent professionals in the field of epilepsy, an annual CME is organized for postgraduate students and general practitioners which is held in the first week of December at CIP. Every year more than 250 delegates attend the CME and noted speakers in the field of epileptology grace the occasion with their informative lectures. An Annual General Body meeting of the Chapter is held after the CME every year.

Ranchi Chapter of IEA has remained a vigorous platform for activities, non-medical aspects of epilepsy have been a prominent area of concern and patients and their relatives have remained significant partners.

The Chapter has 83 Life Members.

The present Office Bearers are:

President	-	Dr S Haque Nizamie
Hony. Secretary	-	Dr Sayeed Akhtar
Hony. Treasurer	-	Dr Masroor Jahan



## Bangalore Chapter - Karnataka

*Mr KV Muralidharan -Secretary*

Dr KS Mani not only started IEA Central Office but also the Bangalore Chapter which was formed in 1971.

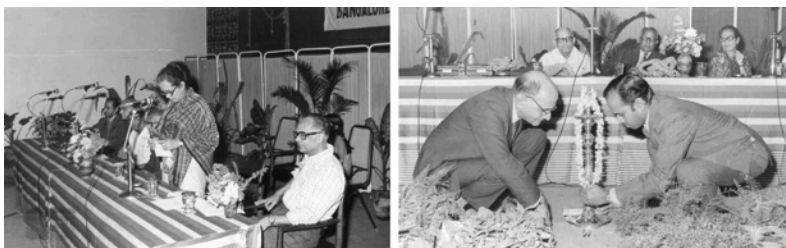
The Chapter was run almost exclusively by non-medical people and has been most active. The Bangalore chapter was shaped during the formative years by non-medical members from various fields like RA Nayak, CM Reddy, Vijayam Krishnamurthy, BV Rathnaiah Shetty along with Dr Kalyanasundaram under the leadership of Dr KS Mani. The Bangalore Chapter as part of its objectives has organised annual holiday camps for children with epilepsy from different strata of society without any of their relatives accompanying them. The Chapter carried out public awareness programmes on epilepsy through lectures, information booklets available in English and other local languages, stickers, greeting cards and cinema slides.

My earliest memory of the chapter's activity was the film on epilepsy acted by all of us with Dr Mani in the lead role. It was an amateurish affair done on a shoe string budget but the film turned out to be very good and became a corner-stone for our entire future awareness programmes.

Another activity very religiously undertaken was the day long outing for children with epilepsy (without their parents); the children always looked forward for that day. Later the activity turned out to be an overnight stay at a hill station where all the member patients and their caretakers too were taken. Most of the activities were patient centric and I would like to chronologically record activities of the past decade and a half.

### **1980**

A National Seminar on the Social Aspects of Epilepsy was held in



Stalwarts of yesteryear which include Dr EP Bharucha, Dr Anil Desai, Dr Baldev Singh at National Seminar on Social Aspects of Epilepsy, Bangalore, 1980



Dr KS Mani lighting the lamp of 4th NSE, 1999

the premises of Canara Bank Auditorium, Bangalore on the 12th and the 13th of July 1980 under the auspices of the Bangalore Chapter of Indian Epilepsy Association. About 250 delegates attended the seminar, consisting mainly of patients and their relatives, representatives from industries and some postgraduate trainees, particularly in neurology, neurosurgery, psychiatry and allied sciences. This seminar was primarily meant to exchange information with the general public about epilepsy in its varied social aspects. A highlight of the seminar was the Patients' Forum on the second day which went on for nearly two hours in which patients and their relatives were the prime speakers. Another highlight of that day was the Panel Discussion in which various aspects not covered earlier were emphasized and certain others re-emphasised.

## **1986**

In October 1986 an International Seminar on Epilepsy was held by the Bangalore chapter. Prof Harry Meinardi, Ms Corry Gerrits from Netherlands and Mr Robert Gourley from Australia were the foreign participants. Several issues pertaining to epilepsy and law with reference to marriage, health, insurance and driving were discussed.

## **1988**

One of the earliest activities undertaken was the supply of carbamazepine and sodium valproate at cost price which meant a substantial saving to the patients.

## **1989-95**

In 1989 support groups for the patients was formed and in 1990 the Yelandur rural epilepsy programme was initiated, which later became a landmark study of epilepsy in a rural area.

An international seminar on epilepsy was held in August 1995 at Bangalore in the children's Hospital at Rajarajeswari Nagar where besides leading neurologists of our country, Dr.Harry Meinardi and Dr. Sylvfenius also participated.

In 1996 Bangalore chapter filed a public interest litigation in the supreme court on the then existing law of epilepsy and divorce, for which the entire funding was met by contributions from the chapter members.

In 1997 Dr Mani was honored with "Social Accomplishment Award" by IBE / ILAE. That year Dr Jerome Engel Jr, the president of ILAE, visited the chapter and spent a few hours with our members.

The national epilepsy day was held at Tirupati when the Tirupati chapter was inaugurated by Dr Mani. Dr Vengamma extended the invitation to our chapter and Bangalore chapter staged a play "Epilepsy Down the Ages", which received stunning applause.

In 1998 the national epilepsy day was celebrated with a painting

competition for the PWE and a seminar which was inaugurated by Mr Srinath a famous Kannada cine actor. That year the Bangalore chapter also hosted a two day 4th National epilepsy conference. Dr Harry Meinardi was one of the speakers and Dr Devika Nag the then president of IEA inaugurated the conference.

In 1999, 4th National seminar on epilepsy was conducted in March. A seminar was held on national epilepsy day at Mysore and a walkathon staged at Bangalore. For the first time a street march was staged with a band and announcements, much to the amusement of Dr Mani but later, he too was happy as this activity brought in a lot of crowd to the function. The march past was flagged off by Dr H Narasimhaiah, former Vice-Chancellor of Bangalore University and a renowned educationist. Sadly this was the last Epilepsy day that Dr Mani took part in. The year also saw Bangalore chapter being registered as a society under the instructions of the central chapter. Another very important event that took place in the history of IEA was that on 30 December 1999 the President gave his assent for the amendment of the Hindu Marriage Act.



National Epilepsy Day celebrations

The year 2000 started with a bang as Mr Tony Greig visited our chapter. An accomplished speaker that he is, he narrated his life as a person with epilepsy, his trials and tribulations in dealing with it and coming to terms with his condition. This was truly inspirational.

Another very distinguished visitor was Prof. John S Duncan Medical Director, Institute of Neurology, Queen Square London, who spoke on “Fits, Faints and Funny Sounds”. The chapter extended awareness campaign to rural areas and staged a drama at Gandhipura village about 40 km away. The year also saw the chapter taking hitherto unheralded step of staging street plays in busy corners of the city as an awareness campaign. This was organized under the leadership of Dr Rajaram a well known name in the theater circles. This was an instant success. People would stand rooted to the spot to watch the dramas and carry home the messages. Since 2000 it has become a hallmark of the chapter’s awareness activity. National epilepsy day was presided over by a sitting High Court judge, Justice R Gururajan and had some very famous theater personalities like Ms Arundathi Nag and Mukhya Manthri Chandru lending their support to the cause.

The year 2001 saw the sad demise of Dr KS Mani. It is unfortunate that he could not receive in person the Lifetime Achievement Award conferred on him by IBE-ILAE. He got the intimation but he passed away before he could receive it.

The street play in rural settings got a fillip with financial assistance from IEA-18th IEC trust. We were able to cover more than 50 places in and around Bangalore.

The national epilepsy day was a grand affair with a seminar on various aspects of epilepsy in relation to insurance, driving, employment law and education, with eminent specialists in the respective fields participating in the sessions.

In 2002 besides going to various towns and villages for the awareness campaigns added activity of counseling for persons with epilepsy

was started. This had a very positive response and is one of the major activities of the chapter even today. National epilepsy day was held at a very popular school in Rajajinagar and again it was packed with entertainment, information and awareness and for the first time included school children. This was inaugurated by Ms Umasri a famous cine and theater personality.

In 2003 the chapter members were specially invited for the golden jubilee celebrations of epilepsy camp at Tirupati and distinguished themselves with an eminently impressive Telugu play on epilepsy. Another unique programme for persons with epilepsy (PWE) was meeting the top Indian cricketers which was arranged courtesy Dr Satishchandra. The PWEs were thrilled to meet their heroes like Sachin, Dravid, Ganguly, Kumble in flesh and blood. Mr John Wright the coach of the Indian team released the FAQ English booklet while Mr Kumble released the Kannada version. Mr Dravid spoke and appreciated the work that was being done by the chapter. The theme of the epilepsy day was “Child and Epilepsy”. and the chief guest was Bikku Anand, Secretary, Mahabodhi Society.

The year 2004 saw a value added activity of addressing school children on the myths and misconceptions and awareness programme about epilepsy and essay competition for the children. The street plays and counseling clinics continued as major activities.

National Epilepsy day had a very distinguished Guest of Honour — Dr Sudarshan — a Magsaysay award winner and also Right to Livelihood (alternate to Nobel Prize) awardee. He was closely associated with Dr Mani and Dr Srinivas in the Yelandur rural epilepsy project. Dr VS Saxena the then Vice-President elect, IEA Central office graced the occasion. The theme was “women and epilepsy” and all the lectures and the skit was centered around this theme.

The year 2005 was a landmark year as under the initiative of Dr HV Srinivas and untiring efforts of Dr Srinivas, Dr P Satishchandra Dr



Street plays and epilepsy awareness campaign

Sanjib Sinha, Dr Praveena Shah, Dr Urvashi Shah and Dr Indumathi Rao the “Diploma in Epilepsy care” course was introduced, in collaboration with CBR Network under Bangalore University’s Distance Education Programme. This was the first of its kind in Asia and only the second university to offer the course in the world.

A host of lectures were delivered in rural areas like Haveri and Shimoga. There were lectures at NMKRV college a leading institution in the state exclusively for Women. The National epilepsy day had Dr RM Varma, Prof. Emeritus Neurosurgery as the chief guest and Prof. Indumathi Rao Director, CBR network (South Asia) and Prof Umadevi Principal, NMKRV college as Guests of Honour. Another innovation was the deployment of a “display van” with the Ten Commandments of Epilepsy displayed on either side of the van. The van went around the city for two days prior to the National Epilepsy day distributing hand bills, thus eliciting a very good response from the general public.



In 2006 also the chapter had the privilege of hosting the 7th Joint Annual Conference of Indian Epilepsy Association and Indian Epilepsy Society under the Chairmanship of Dr HV Srinivas and Dr GT Subhas as its Organizing Secretary. It recorded the best attendance at that time and won accolades from many quarters for the good arrangements and for its scientific contents. The National epilepsy day was conducted at Kanakpura, a Taluk headquarters, 60 km away from Bangalore. An enthusiastic crowd actively participated.

The year 2007 started with an innovative motor cycle rally to bring awareness about the importance of wearing proper standard helmets. Over 250 motor cyclists participated in the 10 km long procession. A display van lead the procession with a display of benefits of wearing and adverse effects of not wearing a helmet which was appreciated by the law enforcers and was widely covered by the press. The entire programme was conceived by Mr Janardhan, IEA Bangalore Chapter EC Member who went about the task with a missionary zeal.

The Tirupati branch of IEA, again invited us to attend the 100th uninterrupted special monthly camp aptly titled “Dr KS Mani Memorial Colloquium on Epilepsy.” A free weekly epilepsy clinic was started.

On National Epilepsy Day quiz programme for college students was conducted and the first three students were awarded prizes by Prof. BK Chandrasekhar, Chairman, Karnataka Legislative Council and chief guest for the function.

In 2008 many awareness programmes were conducted at various venues - schools, womens’ organizations, science forum, religious places, CGHS dispensaries, Accountant General’s office, nursing colleges, etc. On the National Epilepsy day, the Assistant Commissioner of Police lead the walkathon and Dr Parameswara, former IMA and API president delivered the keynote address. An inter medical college quiz programme on epilepsy was conducted in





National epilepsy day celebrations, walkathon and stalls at the exhibition

which over 12 medical colleges participated. Dr Sanjib Sinha who conceived and executed the programme was highly appreciated.

In 2009 the new president Dr GT Subhas took over and with him came a few revolutionary ideas. His first thoughts were why not make the National Epilepsy day “A week long affair” and concentrate on the future generation of the country, the school children. He coordinated with the neuropathology department of NIMHANS headed by ever obliging and willing Dr SK Shankar for teaching programmes. The department of neuroepidemiology, NIMHANS, headed by Dr Gururaj and departments of anatomy, physiology and neurology of Bangalore Medical College were also roped in to arrange a grand exhibition

for three days. Stalls were arranged at Bangalore Medical College and Research Institute. There were exhibits of human brain, with the physiology department beautifully and electronically displaying the functions of the brain. The cynosure of the exhibition was the the neuropathology stall which displayed various specimens of the brain with cysticercosis, stroke, head injury, birth defects, etc. The neuroepidemiology stall put up various posters on the consequences of not being properly protected on a two wheeler which was very apt for the adolescent school children who formed the bulk of the visitors. The exhibition attracted over three thousand school children from more than fifty schools over a three day period. Now for the past three years this exhibition has become a regular feature during our National Epilepsy Day celebrations.

In 2010 the chapter continued its activities on counseling at various venues like CGHS, Bangalore Medical College and Mallige Nursing home, school programmes at rural places involving overnight stay and awareness programmes at various levels. The theme of the year was “Women and Epilepsy” and all the activities were geared towards that.

In 2011 all the earlier activities continued with vigor and enthusiasm. As the theme for year was “Epilepsy in teens,” the exhibition theme was “Epilepsy Anatomy to Treatment” with a special focus on Teens. The venue for the exhibition and the National Epilepsy day was, very appropriately, Indira Gandhi Institute of Child Health. The exhibition and awareness campaign drew record crowds from near and far schools.

In 2012 the highlight of the activity was launching of the rural epilepsy awareness programme including visits to schools in rural areas. This was made possible by the generous donation of a well equipped publicity van carrying a logo “Hope on wheels” by UCB India Pvt Ltd.

Dr KS Mani being a perfectionist and a stickler for rules had laid a solid foundation as to how the Association should function (for example EC Meet every month, AGB in the 3rd or 4th week of May, complete transparency in accounts). The onus of carrying out the activities without deviating from the basic tenets in the “post Mani period” fell on Dr HV Srinivas, who has very admirably guided the chapter for over a decade. His wise counsel, gentle persuasion and the respect that he commands for his fair but no-nonsense approach has made the Bangalore chapter one of the most active chapters of the country.

The Chapter was instrumental in instituting Dr.K.S.Mani memorial session for the patients and care givers during the Joint Annual Conference of IEA and IES. The chapter also instituted the KS Mani oration under the Bangalore Neurological Society every alternate year.

The Chapter has 278 Members – 271 Life Members and 7 annual Members.

The present Office Bearers are:

President	-	Dr GT Subhas
Vice-President	-	Dr GN Manjunath
Hon-Secretary	-	Mr KV Muralidharan
Treasurer	-	Dr Sanjib Sinha

## Belgaum Chapter - Karnataka

*Dr G M Wali – Founder President*

*Dr AO Saroja – President*

The Belgaum Chapter of the Indian Epilepsy Association has been existing for the last 12 years and is actively involved in educating and caring for patients with epilepsy in and around Belgaum. It was founded by Dr GM Wali, Professor and Head of the department of Neurology at the KLE Society's Jawaharlal Nehru Medical College.

The Founder Office Bearers were:

President - Dr GM Wali  
Secretary - Dr Kavita Mogale  
Treasurer - Dr VD Patil

The branch was inaugurated on 13 May 2000 at the KLES Hospital and Medical Research Centre in the presence of late Dr KS Mani as the chief guest and Dr HV Srinivas as the guest of honour. The inauguration was marked by a workshop on epilepsy by Dr KS Mani. This was attended by general practitioners, rural doctors, nurses and anganwadi workers. At the same time Dr HV Srinivas conducted a CME on epilepsy for the postgraduate students of the Jawaharlal Nehru Medical College, Belgaum. Social luminaries of Belgaum



Dr (late) KS Mani lighting the lamp at the inaugural function of the Chapter



Dr HV Srinivas speaking at the inaugural function of the Chapter

including Dr Prabhakar Kore, Chairman of the KLE Society, the then Divisional Commissioner Mr Coutinho, Dr HB Rajashekar and Dr Col AK Singh took part in the inauguration. The initial membership was 133 including 6 life members. The branch was approved by the central committee of the IEA through its letter dated 29 June 2000.

During the inaugural year the branch conducted workshops for rural health workers and anganwadi workers on the eve of National Epilepsy Day. Epilepsy related articles were published in the lay press and prerecorded skits on epilepsy obtained from the Bangalore chapter were shown on the local TV channels.

Thereafter the last decade has seen the branch making continuous efforts to create awareness about epilepsy in Belgaum and surrounding districts. These events have become a regular affair and have included the following activities:

1. Monthly epilepsy camps

Since 2002, free epilepsy camp is conducted regularly on the first Saturday of each month in the premises of the Neurology dept. of the KLE Hospital, Belgaum. During each camp, about 100 patients with epilepsy were examined by adult and paediatric neurologists of the branch. Parents and the other caregivers of these patients were counselled regarding education, driving, marriage and pregnancy. These camps were possible due to the immense support from the local paediatricians and practitioners. Pharmaceutical companies rendered their support by providing free antiepileptic medications to the needy patients, financial support for the prize money and also by providing educational materials on epilepsy.

2. Painting competitions for children with epilepsy were conducted on the eve of National Epilepsy Day. About one hundred children participated actively in the competition and prizes were awarded to the best paintings and consolation prizes were given to all

the participants to promote awareness and to create self-confidence in them. These children were also evaluated and necessary advice regarding epilepsy was given. A separate interactive session for the patients and their caregivers



A view of the painting competition

to address the problems faced and myths regarding epilepsy were conducted. These sessions were conducted by the branch with neurologists and psychiatrists addressing in detail the psychosocial aspects related to epilepsy. Video presentations for caregivers of people with epilepsy were also conducted.

3. Publication of interactive articles on epilepsy in local dailies with an intention of imparting scientific and humane approach towards this disease.
4. Community outreach programmes were conducted in places outside Belgaum. Such camps have been conducted in Nesargi village, Mudhol, Ramdurg and Jamakhandi. The village housewives were the main targets for training regarding the social aspects of epilepsy. The response has been gratifying. This has been possible with active support from the administration of KLES Dr Prabhkar Kore hospital which provided the logistic support of manpower and the dissemination of information. Awareness sessions were held for nursing staff at the nursing college during one of the National Epilepsy Day celebrations.
5. A booklet entitled 'A small book of epilepsy' was published in 2001. This booklet has been translated into Kannada and Marathi and distributed free to the patients, their relatives as well as general public.

## 6. Continuing Medical Education

A CME program was conducted for physicians and general practitioners in September 2003 in which 75 delegates participated. Practical issues in the management of epilepsy like clinical and laboratory evaluation of suspected epilepsy, initiation and optimisation of treatment, special problems of women with epilepsy were covered.

In addition, issues regarding the duration of therapy in epilepsy was also covered. The members of the branch delivered lectures on these aspects followed by interaction with the attendees.



Awareness lectures

The success of the branch is attributed not only to the office bearers of the branch who are elected regularly as per the rules of the IEA but also to all the medical and paramedical staff of the department of Neurology of the KLE Hospital. The Director of the KLE Hospital and principal of the JN Medical College have always helped the branch with the necessary infrastructure for conducting various activities. Throughout the years the branch has been actively supported by members of various pharmaceutical companies, social workers and philanthropists of Belgaum.

### **Hurdles / difficulties faced**

As the Association includes members working in teaching institutes, private practitioners, medical professionals from other departments, technical and support staff, service oriented events from the Association face hurdles. As these services are non-profitable, the

involvement of technical and supporting staff is a challenge. While counselling and epilepsy care is possible on an individual basis by the doctors and is provided on fairly regular basis, the same services to the community at large with outreach programs have been difficult.

### **Future Plans**

- The branch plans to conduct regular epilepsy camps and awareness programs at nearby Primary Health Centres.
- It is also planned to conduct awareness programs at the local schools and colleges in addition to continuation of the earlier activities like the regular monthly free epilepsy clinics at the KLES Dr Prabhakar Kore Hospital and MRC, Belgaum and the painting competitions.

The Chapter has 27 Life Members.

The present Office Bearers are:

President	-	Dr AO Saroja
Secretary	-	Mrs Meenaxi
Treasurer	-	Dr Kutub Mukandar



## Mangalore Chapter - Karnataka

*Dr Lekha Pandit – Founder Secretary*

The Mangalore chapter was formally inaugurated in March 2001. The secretariat was at KS Hegde Hospital, Deralakatte, Mangalore.

The Founder Office Bearers were:

President	-	Mr Vinay Hegde
Vice-President	-	Dr IG Bhat
Secretary	-	Dr Lekha Pandit
Treasurer	-	Dr Rajesh Shetty

The primary aim of the Chapter was to improve awareness of epilepsy among the lay public and patients and make medications affordable to patients.

### Activities

A corpus fund was raised through contributions from philanthropists, doctors and corporate sponsorer. Through the kind sponsorship of Sun Pharmaceuticals, a subsidized program for sale of carbamazepine and sodium valproate was initiated which is continuing successfully even today. More than 250 patients with epilepsy in

and around Mangalore avail of this patient friendly initiative. Free medicines like gardenal and phenytoin sodium are distributed to poor patients. Awareness programs are held every year for patients. In addi-



A view of the lamp lighting ceremony at the inaugural function of the chapter

tion nursing students and physiotherapy trainees are taught first aid and management of patients with epilepsy. Through the benevolence of sponsors, the high school education of several students with epilepsy was facilitated. Two students have completed ITI (diploma) training in refrigeration technology and are employed by KS Hegde hospital. One student was sponsored for OT technician training at Mangala Nursing home, Mangalore.

The Chapter has 45 Members – 30 Life Members and 15 Annual Members.

The Founder Office Bearers continue in office.

## Shimoga Chapter - Karnataka

*Dr A Shivaramakrishna – Founder President*

The Shimoga branch was formed in 2003 under the auspices of Sahyadri Neuropsychiatric Association involving neurologists, neurosurgeons and psychiatrists of Malnad region. The branch was inaugurated by Dr D Nagaraja, former Director of NIMHANS who stressed the need for IEA branches at peripheries to educate the public about epilepsy. He also requested all members to be committed and continue the branch actively.

The Founder Office Bearers were:

President	-	Dr A Shivaramakrishna
Vice-President	-	Dr KR Sridhara
Secretary	-	Dr AV Nagaraja
Treasurer	-	Dr Narayan Panji

### **Activities**

The chapter has been organizing programmes for the last 9 years to help and educate people with epilepsy. The activities of the branch are as follows :

#### Monthly camp

On the first Sunday of every month a free camp is organized at Rotary Blood Bank. Patients are examined, treatment advised and drugs issued at concessional rates. About 60-100 patients, from Shimoga and surrounding districts attend the camp every month. We provide information on epilepsy to the patients and their relatives during the camp.



Medical camp at Thirthahalli

The drugs required are met by samples provided by pharmaceutical companies. One third of the monthly requirement of the drugs for every patient is provided free and the rest is supplied at a concessional rate.

### National Epilepsy Day

The national epilepsy day (NED) is observed each year on 17 November. Games and drawing competitions are conducted for patients and their relatives. The drawing competition is conducted in two categories based on the age (below 10yrs and above 10yrs). The winners are given attractive prizes. Essay competitions for public and patients on various aspects of epilepsy mainly centering



Drawing competition for patients



Games for patients

on the theme provided by national body is also held. In addition we organize a quiz program on epilepsy for patients and public to educate them about the illness. Articles on various aspects of epilepsy are published and discussions and talks are held on Radio Bhadravathy. The chapter has organized several skits on epilepsy enacted by students mainly to educate the public on epilepsy. The NED activity concludes with a public program in which an invited guest would address the gathering on social aspects of epilepsy. There are lectures or group discussions/panel discussions to highlight the theme of the year on epilepsy. We plan to expand the activities of NED by having programs like lectures, group discussions and debates for teachers, anganvadi workers and nurses on identifying

epilepsy, first-aid treatment and motivating the public for early and proper treatment spread out during the month of November.

### Purple Day programme

This programme was held in April 2012 for the first time when various activities were taken up to educate the public. Articles were published in local papers and weekly magazine 'Sudha' narrating facts on Epilepsy. Various activities were taken up at the clinics of neurologists and psychiatrists of this region to mark the Purple day. We plan to continue with this activity adding newer programs.

The chapter has been organizing programmes outside the town for the last 9 years. This is with an intention to spread facts about the disease in semi-urban areas and villages where there is still a lot of stigma attached to epilepsy. Motivation of these people to start treatment and continue with it is very essential. We have arranged programmes at Thirthahalli, Bhadravathy, Sagar and Sringeri which includes free checkup, issue of drugs, educative lectures and interactive sessions with patients and public. The local service organizations and doctors help us in executing these activities.



Educative program on epilepsy for the public



View of gathering in the public programme

The chapter has been arranging CMEs for IMA doctors to update their knowledge on diagnosis and treatment of epilepsy. Doctors play a very important role in educating patients regarding compliance of treatment. Practitioners of alternative medicines are involved to

ensure proper awareness and treatment of the patients. Educating our colleagues on the need for continuing medication even during concurrent illnesses and pregnancy needs to be emphasized.

#### Dr KS Mani Memorial Oration

This oration is being organized since the last two years in the memory of Dr KS Mani's contribution in the field of epilepsy, his dedication and his commitment towards patients with epilepsy. Dr HV Srinivas and Dr R Sreenivasa delivered the orations.

These are some of the activities taken up by our chapter. The road is still long. People do not start treatment for several years, drug-default is very common and resistant seizures pose real problem. Social stigma attached to the disease and marriage problems need to be addressed. The following observations were made by us :

- People come forward to attend camps and for drugs but the turn-out for the educative programs has not been very encouraging. People do not want to be identified as having epilepsy in view of the stigma in the society. Hence most of our activities reach patients and their relatives but not the public in the larger perspective.
- If those who have been treated and are in the main stream of life come forward and motivate others it would be a great help, but again we find it difficult to motivate them to come forward and participate in such an activity.
- Patients with poor response to drugs mostly look towards organizations like IEA for drugs. Thanks to Govt. policies , most of the first line drugs are now supplied free in govt hospitals. The problem is for those who are on second line drugs. Providing free drugs to them is becoming a big financial burden for the branch. But it is a fact that free camps and providing drugs certainly support our activity. Involving pharmaceutical companies to

help the poor patients will go a long way in helping to serve them better.

- Paramedical personnel, anganvadi workers, teachers and other health care personnel at the peripheries should be educated on identifying Epilepsy, be trained to motivate patients with epilepsy to start treatment early and stay with the treatment.
- Doctors also need to be motivated to carry on the message to the public.
- IMA branches and voluntary organizations should be involved more to organize activities in different places.

The members of the association have been actively participating in these activities. The pharmaceutical companies and philanthropists of the town have also been helping us both financially and physically. We hope to do more in the coming years to remove misconceptions about epilepsy and help patients with epilepsy to come to the mainstream of life.

The chapter has 74 Members – 14 Life Members and 60 Annual Members.

The Founder Office Bearers continue in office.

## Kochi Chapter - Kerala

*Dr B V Rajendran – Founder Secretary*

It was in 1993 that late Prof KS Mani and Prof KV Mathai decided to energize the IEA activities. Kerala being a small state, Prof Mathai suggested that it should be treated as a Chapter and have branches under the Kerala Chapter. Initially, three branches i.e. at Thiruvananthapuram, Kochi and Calicut were formed. Later these branches too were renamed as Chapters. Thiruvananthapuram and Kochi are active, though Calicut is in slumber. It is hoped that Calicut too will become active under energetic youngsters like Dr Pradeep Kumar.

The Founder Office Bearers were:

President	-	Dr P Sreekumar
Secretary	-	Dr BV Rajendran
Treasurer	-	Mr Parameswaran

The inauguration of the branch was an event to cherish Dr HV Srinivas, the then President of IEA Bangalore Chapter, inaugurated IEA Cochin on 23 April 1993 in a colourful ceremony at the IMA Hall, Cochin. On 26 September 1993, a seminar on various aspects of epilepsy was organized as the first Scientific programme of the nascent branch. Prof KS Mani, Prof Kalyanaraman, Prof KV Mathai, Prof Rajashekharan Nair and Advocate Sri Govind Bharathan delivered lectures on various aspects of epilepsy. The symposium was formally inaugurated by late Sri Rajan, IAS, Managing Director TELK and former District Collector, Ernakulam.

Since its inception IEA Kochi has undertaken a host of programmes in social and medical aspects of epilepsy.



### School Awareness Programme

Since 1994, IEA Kochi started an awareness programme for teachers and high School students in and around Kochi.

Two to three schools were targeted each year and members of the chapter made presentations on medical and social aspects of epilepsy. Interactive as they are, the students are usually more involved than the teachers. We have covered over twenty-five schools over the years.

### Outreach programme - Cochin Rural Epilepsy Services (CORES)

Started at first at Malippuram in Elamkunnappuzha Panchayath on the island of Vypeen in 1994, free consultation and antiepileptic drugs (AEDs) were offered to the poor patients with epilepsy in that area.

This was subsequently shifted in 2004 to another Panchayath - Chellanam, a fishing village, where we visit on the first Thursday of every other month and give free AEDs to patients. This has been going on for the last eight years without a break. In this context, IEA Kochi wishes to thank Sun Pharma, Abott Health Care and Abbott India, who not only provide the AEDs but also their personnel, who help in the conduct of the free clinic and distribution of the prescribed AEDs. Fifty patients attend the free clinic and one patient has undergone epilepsy surgery successfully.

### The KS Mani Workshop and KS Mani Oration

The first KS Mani workshop was organized in 2005 and then subsequently in 2007 and 2009. These were very well attended and the faculty were drawn from all over India.

The KS Mani Oration was held in 2006, 2008, 2010 and 2011. Dr Satish Chandra, Dr HV Srinivas, Dr Solomon Moshe and Dr K Radhakrishnan were the orators respectively.

Public Contact Programmes

In addition to school contact programs, IEA Kochi observes National Epilepsy Day by conducting painting competition for school children



Car rally organised by Round Table India 131



Dr Beena and Dr Rajendran lighting the lamp at the inauguration of NED in November 2009



Eminent speakers at various functions

with epilepsy and talks on TV and FM radio. We organized a motor vehicle rally at Cochin, with pamphlets and mike announcements to create awareness on preventable epilepsies. This was jointly organized by the Round Table India 131.

### Publications

The leading English weekly, The Week, brought out a supplement on epilepsy in 1993 due to the efforts of IEA Cochin.

Prof Meinardi, the then President, ILAE released a ready reckoner on epilepsy for practicing physicians and pediatricians, authored by me in 1994.

### IBE Satellite Symposium

To commemorate the Golden Jubilee of IBE and forty years of IEA a Satellite Symposium was held in Cochin on 7 August 2011. This coincided with the midterm meeting of IEA and IES

Mike Glynn, the President of IBE inaugurated the Symposium and delivered the Inaugural Address. Executive Committee members of South East Asian Region ie. from Bangladesh, India, Indonesia, Nepal and Sri Lanka participated and spoke on the various activities of their respective countries. There was wide media coverage for the event and Mike Glynn was interviewed by The Hindu correspondent Mrs. Shyama Rajagopal, in which he highlighted the roles of IBE and the activities of the member countries.

### The 13th Joint Annual Conference of Indian Epilepsy Association and Indian Epilepsy Society (ECON 2012)

Cochin was privileged to host this mega event. With Dr KP Vinayan as the Organizing Secretary and myself as the Chairman we could conduct the programme with the support of members of Kerala Association of Neurologists (KAN) and Cochin Neurological Society. According to the delegates, numbering 330, the Faculty members and the Central Office Bearers of IEA and IES ECON 2012 was a

roaring success. The highlights were many, but the pre-conference EEG workshop held on 23rd and 24th February was unique with international and Indian faculty drawn from the who is who of epileptology. The idea was mooted by Prof K Radhakrishnan, Professor of Neurology and Director, Sree Chitra Thirunal Institute, Thiruvananthapuram.

This workshop was modeled on the Australian programme, with multiple work stations and the faculty interacting with groups of 10 delegates each. One hundred and thirty delegates registered for the workshop. Dr KP Vinayan worked tirelessly for coordinating the programme. We acknowledge the partnering support of M/s UCB Pharma who made it possible to conduct the workshop outside Australia for the first time.

ECON 2012 was inaugurated by Hon. Minister for Social Welfare, Sri MK Muneer (a medical doctor himself). There was a cultural programme, again unique in the sense, that Sri Raman Bharadwaj, Veena Maestro, gave a wonderful veena recital. He is a person with epilepsy who has successfully undergone epilepsy surgery. He was accompanied on the Violin by Sri Shankara Narayanan, also a person with epilepsy and on the Mridangam by Dr Murali Krishna Menon, a leading neurologist of Cochin.

#### Honouring a Colossus

Prof KV Mathai, former Professor of Neurosurgery, CMC Vellore is one of the founding members of I.E.A. who is amidst us even now. Though he was the Chief Patron of ECON 2012, he was unable to attend the meeting due to indifferent health. Hence Dr KP Vinayan, Dr Mahesh Sambasivan and myself drove to his house at Thadiyoor, about 120 km from Cochin, on 15 July and presented a *Ponnada* and memento to him .

#### Have we done enough?

Honestly, I cannot answer this. Posterity will judge the past. But

we have strived to create awareness about epilepsy in our area of operation. So there is some sense of satisfaction.

The present President Mrs Suchitra Narayan and Secretary Dr KP Vinayan (now an IES Ex Com member) are two high voltage persons who can take IEA Kochi to greater heights.

The strength of any organization depends on the support of the members. IEA Kochi is lucky to have members like Mr Ramesh Kini, Dr Mathew Abraham, Dr Gigy Kuruttukulkam, Dr Reji Paul, Dr Parameswaran, Mr VR Parameswaran, Dr KP Vinayan, Dr Ajai Perti, Dr Mahesh Sambasivan, Dr Anand Kumar, Dr Suresh Kumar, Mr Chandrakanth Sanghani, Mrs Suchitra Narayan and Dr Murali Krishna Menon to name a few.

We have received tremendous support from IEA and IES Central Offices from the likes of Dr HV Srinivas, Dr Satish Chandra, Dr Mehindratta, Dr VS Saxena, Dr CM Sharma and Dr Satish Jain. Prof KV Mathai, Prof K Radhakrishnan and Dr P Sreekumar have always guided and helped us. Dr Pradeep and Dr Salaam from Calicut and Dr Gilvaz from Thrissur have responded to our SOS innumerable times.

It will be inappropriate not to mention my wife Saraswathi who has always worked in tandem with me for all IEA Kochi activities

I take this opportunity to wish the next generation of IEA, Office Bearers all the very best and hope that they take IEA Kochi to greater glory.

The Chapter has 72 Life Members.

The present Office Bearers are:

- President - Mrs Suchitra Narayan
- Secretary - Dr KP Vinayan
- Treasurer - Mr VR Parameswaran

## Thiruvananthapuram Chapter - Kerala

*Dr Jayachandran D – Founder Secretary*

The Trivandrum Chapter was formed on 28 January 1993.

The Founder Office Bearers were:

President	- Prof M Sambasivan
Vice-President	- Prof K Rajasekharan Nair
Secretary	- Dr D Jayachandran
Treasurer	- Dr Anandam

### **Activities**

Indian Epilepsy Association Thiruvananthapuram is actively involved and collaborating with the R Madhavan Nayar Centre for Comprehensive Epilepsy care (RMNC) in several programmes. RMNC was established in Sree Chitra Tirunal Institute Medical Sciences and Technology (SCTIMST), Thiruvananthapuram with the following objectives:

- 1) Medical, surgical, psychosocial and occupational management of individual patients with epilepsy
- 2) Educate the primary and secondary care physicians about current trends in the management of epilepsy
- 3) Enhancement of public awareness about epilepsy in order to dispel the prevailing misconceptions

Prof K Radhakrishnan, Senior Professor of Neurology and Director, SCTIMST, a renowned neurologist and epileptologist and a very active member of the Indian Epilepsy Association of the Thiruvananthapuram Chapter is heading the RMNC. Dr K Radhakrishnan and his team carefully designed and executed an epidemiological study of epilepsy in Kerala. A door-to-door survey was conducted covering the entire population of 2,38,102 persons residing in 43,681 households in 10 Panchayaths in a semi-urban area of Central Kerala through a three-

phased survey and ascertained an age adjusted epilepsy prevalence of 4.7 per 1000 population in Kerala.

#### Rural Epilepsy Care

Dr K Radhakrishnan and his team established epilepsy clinics in two relatively backward area of Central Kerala which are running successfully for the past 16 years at Primary Health Centre Changaramkulam, Malappuram (first sunday of every month), and Ansar Hospital, Perumpilavu, Thrissur (third sunday of every month). Nearly 50-60 patients are examined by a team consisting of a neurologist and a medical social worker (members of Indian Epilepsy Association) from RMNC, SCTIMST. In addition epilepsy education program for general medical practitioners and lay public are being undertaken regularly in or near the clinic area.

#### Epilepsy and Pregnancy

A Registry for epilepsy and pregnancy was formed under the leadership of Prof. Sanjeev V Thomas, Department of Neurology, SCTIMST in 1998. This is the first of its kind in India. At present 14 centers are functioning effectively in different parts of the country. More than 2000 patients are registered in this registry. A unique feature of this registry is follow-up of children for an extended period of 12 years. Epilepsy Association sponsored National Registry of Epilepsy and Pregnancy is currently ascertaining the data from multiple centers in the country and comparing with those from the European Registry. The registry has extended the service outside the institute to distant areas through a out-patient clinic in Government Women and Children's hospital, Thycaud, Thiruvananthapuram

#### Epilepsy Self Help Group

The Epilepsy Self Help Group was registered under Literary and Scientific Charitable Society Registration act 1955 on 30 December 1998 with the following objectives :

- 1) Providing an opportunity for individuals with epilepsy and their

families to meet, share experience, exchange information and offer emotional support to each other.

- 2) Increasing knowledge about epilepsy for its members and public.
- 3) Organizing clinics and conducting studies in various aspects of epilepsy and related fields.
- 4) Conducting community education campaigns/workshops/conferences to make the public more knowledgeable about epilepsy and reduce the stigma attached to this disorder.
- 5) Advocating for non-discriminatory practices regarding persons with epilepsy and promote rights of people with epilepsy.
- 6) Fund raising to support activities of the group and assist deserving epilepsy patients.
- 7) Sponsoring training activities for members and arranging recreational/leisure activities for epilepsy patients.
- 8) Publishing leaflets/pamphlets/newsletters for furthering knowledge about epilepsy among members and public.
- 9) Collaborating with any professional Epilepsy Association at State/National or International level or any Voluntary/Governmental organization for achieving the said goals.
- 10) To do any act, service, research work, necessary for the social benefit of the epilepsy patients and to control/eradicate epilepsy ailments.

It publishes a quarterly epilepsy newsletter 'Pratheeksha'. About 500 copies of this are distributed among the patients and relatives. Articles written by experts and patients provide good education material. We are making pratheeksha available through the local libraries at the village panchayath level to ensure a wider distribution of the educational material to the lay public. The Epilepsy Self Help Group conducts medical camps once in three months. Over 100 patients register for the camp.



### Group Counseling

For the past 23 years group meetings for persons with epilepsy and their caregivers are being conducted at the SCTIMST. These sessions are arranged for one hour prior to the epilepsy clinics on Wednesdays and Fridays and are attended by 30 persons with epilepsy and their families. In these group counseling sessions, the participants share their experiences and a professional team comprising a psychologist and a medico-social worker reinforce positive approaches, attitudes and achievements of the participants.

### Epilepsy Educational through the State Resources Centre

The State Resource Centre of Kerala conducts monthly training programs for the *preraks* (adult education volunteers) in different districts of Kerala. Nearly 100 *preraks* and beneficiaries take part in this continuing educational program. Two hours of this program are being allotted for epilepsy education per month. RMNC provides resource persons and necessary reading material for this purpose.

### School Educational Program

A program to educate teachers and school children is being undertaken through lectures and question-answer and quiz sessions. These sessions are rotated through different governmental and aided schools of Kerala, covering the urban and rural areas of the state. Similar programs are conducted in schools under the leadership of Dr PA Muhammed Kunju, Prof. and Head, Paediatric Neurology, Sree Avittom Thirunal Hospital, Thiruvananthapuram in collaboration with Child Health Centre, Thiruvananthapuram, as part of their School Health Programs.

### Epilepsy Camp in North Paravur in 2011

Epilepsy Camp and Awareness program was conducted in North Paravur, Ernakulam District on 13 March 2011. Dr Ram Sekhar Menon, Dr Panduranga Ramesh Wattamvar, Dr Davis Manuel, Dr Anis Jukkarwala, Dr Jeevan S Nair and Dr Jayachandran D (Secretary IEA, Thiruvananthapuram) of RMNC participated

The program was organized by Junior Chamber of Commerce, North Paravur. Ninety patients with epilepsy were examined and counseled by the team members. A public awareness and question-answer session was conducted by Dr Ramsekhar N Menon and Dr Jayachandran D. A film on epilepsy “The Untold Story” and Mirgi (Malayalam) developed by IEA/18th IEC Trust were shown during the program.

### National Epilepsy Day Program

RMNC, SCTIMST conducts regular programs every year on November 17 to observe the National Epilepsy Day (NED). A regular feature of the NED program is painting competition for children with epilepsy, a seminar on epilepsy, and a patient session.

National Epilepsy Day – 2011 was observed on 17 November in AMC auditorium with talks on medical and social aspects of epilepsy, panel discussion with good interaction between patient carers and neurologists.



Prof K Radhakrishnan, Director SCTIMST inaugurating the NED 2011



Patient session and painting competition during NED 2011 at SCTIMST, Thiruvananthapuram



National Epilepsy Day Program 2012 (a) Sri TK Rajiv Kumar, Film Director, addressing the gathering, (b) Panel Discussion, (c) Interactive Session

There was a painting competition for children with epilepsy in which 18 children participated. The students were divided into two groups and prizes were distributed to winners and participants.

#### Epilepsy Camp and Awareness Program in District Hospital, Idukki

An Epilepsy Camp and awareness Program was conducted on 20 November 2011 in District Hospital, Idukki. The program was organized and sponsored by Health Oriented Project Establishment (HOPE), a Charitable Organization at Pilathara, Kannur. One hundred and eight patients with epilepsy were examined and counseled by a team consisting of Dr Ashalatha R, Dr Gopal Krishna Dash, Dr Pournami Sarathchandran, Dr Prasanth Varghese, Dr Himanshu and Dr Jayachandran D, Secretary, IEA, Trivandrum.

An awareness Program and question answer session was conducted for the patients/relatives and general public. A film on epilepsy “Sahi Gyan Sahi Samadhan”(Malayalam) was also shown to participants

and public. The participants and organizers conveyed their satisfaction for providing the service.

The Chapter has 80 Life Members.

The present Office Bearers are:

President	- Dr M Sambasivan
Vice-President	- Dr K Rajasekharan Nair
Secretary	- Dr D Jayachandran
Treasurer	- Mrs Aley Alexander

## Indore Chapter - Madhya Pradesh

*Dr VV Nadkarni – Founder Secretary*

The Indore Branch was inaugurated on 15 September 1981. Dr EP Bharucha the then Secretary General of IEA was the chief guest. There were 7 life members and 6 annual members.

### The Founder Office Bearers were:

President	- Dr BC Chhaparwal
Vice-President	- Mr Neminathji
Secretary	- Dr VV Nadkarni
Treasurer	- Mr LB Hariani

The MP Chapter started functioning with regular meetings with patients. In those days epilepsy movement was in its infancy and a lot of patients came from villages with lack of information on epilepsy. Hence our core group members started epilepsy awareness lectures. In 1990, Indore Neurological Association had the honor of hosting the 39th Annual National Conference of Neurological Society of India and also the Annual General Body Meeting of IEA at Indore. From 1991 onwards National Epilepsy Day celebrations were held every year which was widely covered by news and media for creating public awareness on epilepsy.

### **Activities**

An E-cell at Gita Bhavan Hospital is functioning since 2000 on all Saturdays. The main objectives of this Cell is to enhance awareness about epilepsy, provide psychosocial support to patients and impart training in yoga to improve their quality of living. So far 7500 patients have been counseled at the E-cell. In addition the E-cell is helping to resolve marriage issues, education and employment and psychological problems.



Cultural activities

In 1995, we started a unique programme on yoga and epilepsy at Indore where patients with refractory epilepsy were trained in yoga by Dr BK Bandre (Yog Guru). A booklet on benefits of Yoga for Epilepsy was published and distributed in the IBE session during the International Epilepsy Conference held at Dublin, Ireland in 1997. Subsequently in 2000 a scientific paper on yoga and epilepsy was presented at the 3rd AOEC Conference held at Delhi. We have now enrolled many members of IEA who are persons with epilepsy (PWE) for yoga training and 95% have reported reduction of stress and seizures. Dr Jaymala Shah, Life Member and yoga specialist conducts special classes for the patients at Gita Bhawan Hospital, Indore.

In 2001, we started to focus on community based activities in epilepsy to improve the Quality of Life (QoL) of PWE. A group of twenty members from the NGO, Queens Welfare Society, joined hands with IEA to support the noble cause and decided to hold

monthly workshops and camps on the first saturday of every month at Gita Bhawan Hospital. President of the Queens Welfare Society Ms Urvashi Wagle and Mrs Vidhya Kibe helped us in our social endeavour by building self help groups and camps where education for epilepsy and, yoga training by experts was provided. A 16 page booklet on “Yoga for Epilepsy” and a 4 page pamphlet in Hindi on “Epilepsy–Precautions and Prevention” prepared by the branch are distributed free of cost to all persons with epilepsy. To help persons with epilepsy keep track of their ailment, “Epilepsy follow-up Record” was printed and distributed free of cost.

At present, an average of about 100-130 patients are attending these camps every month. Each patient’s case history is recorded, evaluated and the patient is given free medication for one month. EEG, CT MRI scans and biochemical investigations are performed at concessional rates. Women with epilepsy are given antenatal advice for safe pregnancy. Job opportunities are provided after vocational training.

Mr Sagar Kulkarni, IEA Member and PWE, who had to face several problems in life has now got a permanent job as a software engineer in Infosys despite revealing that he has epilepsy. He has also found an amicable life partner and is leading a happy married life. This was possible only due the continued support from the chapter, which provided him with free medicines and counseling services.

#### Special Monthly Camps for Persons with Epilepsy

- a) Dental hygiene camps were regularly conducted at Gita Bhawan Hospital in 2004 to detect side effects of anti-epileptic drug (AED) eg. gum hypertrophy.
- b) A bone mineral density test camp was organized in March 2007 where 80 patients were enrolled. Osteoporosis was seen in 12.8 % of patients on AED and osteopenia in 57.14 % . Patients were





Interactive sessions

given free calcium and vitamin D supplements, and were advised to do weight bearing exercise and prevent falls.

- c) Epilepsy camp for free biochemical tests like hemogram, calcium, phosphorus, alkaline phosphatase and serum creatine was organized on 4 June 2011. Anemia was seen in 73% of patients.

One hundred and one monthly epilepsy camps were organized between 2001–2009 and free medicines worth Rs 38.67 lakhs distributed. This was possible with the help of several donors and the free samples provided by pharma companies. Recently the 125th camp was organized on 4th August 2012 where an epilepsy team from Kokilaben Dhirubhai Ambani Hospital addressed the members. The main focus was on epilepsy surgery for refractory epilepsy with interviews of patients who had undergone epilepsy surgery. The take home message was that early surgery in refractory epilepsy should be considered.





Awareness programmes

An annual newsletter is being published since 2004 onwards reporting the activities of the Chapter. Booklets on epilepsy eg. “Mirgi ke sath jiwan”, in Hindi and “Yoga for Epilepsy” have also been published.

### National Epilepsy Day Celebrations

NED is being celebrated since 1991 onwards and the programmes include:

1. CME program for doctors on epilepsy in other cities around Indore.
2. Special guest lectures.
3. Poster, exhibitions, video and lecture presentations for the public and school and college students.
4. Sports and drawing competitions for persons with epilepsy.
5. Several celebrities have graced the occasion and created awareness about epilepsy among the patients.

Public awareness programs through skit shows, videos films and dramas on themes on epilepsy were other prominent activities. A walkathon was held in November 2006 and motorbike rally in November 2009 to create awareness among the public.

We have a long way to go on the road un-travelled and look forward to the help and participation from philanthropists in India and abroad to achieve our goals.

In November 2009 the MP Chapter promoted the Theme for prevention of epilepsy from 1) Birth Injury and Epilepsy 2) Head Injury and Epilepsy 3) Neurocysticercosis and Epilepsy. For public awareness posters were put up in hospitals, railway station, bus stand and schools and colleges.

The chapter organized an awareness education programme in association with the Social Justice Department of MP on epilepsy for school teachers from rural areas around Indore. Three workshops were organized from 10 February to 19 March 2012. The teachers (about 100) attended these workshops in 3 batches. The teachers were trained to identify children with epilepsy and help in education of such children. It was seen that 30% of teachers were ignorant about epilepsy.

ECON 2010 was hosted by the IEA – Indore Chapter. Two hundred and fifty delegates registered for the pre-conference workshop and 350 delegates and 115 patients registered for the conference.

Travel fellowships were given to patients to attend the ECON National Conferences held at Mumbai (2001), Nagpur (2004) and Ludhiana (2011)

Three candidates (Mr Vibhav Nadkarni, Mrs Neelam Ranade and Mrs Anita Motwani) successfully completed Diploma in Epilepsy Course (DEC) from Bangalore University. They received training at

Mangesh Neuro Centre, Indore and Gita Bhawan Hospital, Indore under the guidance of Dr VV Nadkarni.

An additional activity of IEA MP Chapter was started at Bhopal by Dr TN Dubey, Prof. of Medicine, Hamidia Hospital, Bhopal. This was inaugurated by Mrs Aruna Shukla, Director of Medical Education and Health Services in 2003. This chapter has been organizing activities on National Epilepsy Day (NED) since 2003.

The Chapter has 180 members – 73 Life Members and 107 Annual Members.

The present Office Bearers are:

President	- Dr VG Dakwale
Vice-President	- Dr Deepak Mansharamani
Secretary	- Dr VV Nadkarni
Joint Secretaries	- Mr Hariani and Ms Madhvi Tiwari

## Bombay Chapter - Maharashtra

*Ms Carol D'Souza – Vice-President*

Over the last 40 years various individuals have contributed towards the progress and growth of the Bombay Chapter. Though it is not possible to thank everyone and detail the hard work put in by them, a few people such as Dr Eddie Bharucha, Dr Bhimsen Singhal, Dr Freny Kohiyar, Dr Pravina Shah and Ms Carol D'Souza deserve special mention and gratitude. To limit 40 years of work to these pages was indeed a difficult task.

The Bombay chapter was formed on 11 March 1972.

The Founder Office Bearers were:

President	- Dr Noshir Wadia
Vice-Presidents	- Dr Anil Desai and Dr SM Merchant
Jt. Hon. Secretaries	- Dr Bhimsen Singhal and Dr Chico Vas
Hon Treasurers	- Dr Freny Kohiyar and Dr AC Mehta

### **Activities**

#### 1973-80

By the end of 1973 various sub-committees had been formed and various proposals looked into. A medical camp was organized at Marve Beach from 20-30 May 1973 for children with epilepsy and an epilepsy education program for 60 teachers of Colaba Municipal Schools was held on 5 October 1974.

One of the big events in 1974 was the visit of IBE delegates Mr George Burden, Dr Harry Meinardi, Dr Peter Jeavons and Dr Morris Parsonage on 11 and 12 November. During their visit they participated in a seminar on (i) Epilepsy in Children and Adults and (ii) epilepsy education, in addition to a press conference and a televised interview.

An educational film 'Epilepsy' was released on 30 April 1976 which was donated to the Film Division of India for dubbing into 14 languages for all-India broadcast. The rights of the film rested with the Films Division. The film was sponsored by M/s Bhagwati Charity Trust and eminent Film Director Mr. Shyam Benegal directed the film. On 2 December 1976 the Chapter held its first fundraising event – a charity film premier of 'The Return of the Pink Panther'.

In 1979-80, to successfully educate children, leaflets on the do's & don'ts of epilepsy were printed and used for school awareness programs. Lapel buttons with the IEA emblem and an epilepsy folder titled 'The Truth About Epilepsy' were made. In 1980 the legendary cricketer and tireless social worker Mr Vijay Merchant became a member of the Advisory Board of the Bombay Chapter.

#### 1981

The Epilepsy Week was held on a grand scale from 15-21 February. The following activities took place during the week:

The documentary film on 'Epilepsy' was shown and there was a panel discussion for the lay public on 'Epilepsy and Society'. Epilepsy posters were exhibited at the Birla Kreed Kendra at Chowpatty, at main railway stations and at premises of social welfare organizations. 'Doctors Talk It Over' was aired over radio. Through the courtesy of the Films Divisions of India, the documentary film 'Epilepsy' was shown throughout the week at various cinema houses. A fundraising charity film premier of Alistair Maclean's 'Bear Island' was shown and a symposium for medical practitioners was held at IMA Hall.

During the year, 19 lectures were arranged at various schools where the film on epilepsy was shown. One thousand greeting cards were also printed and sold.

#### 1982-87

Epilepsy awareness lectures continued in various communities and social organizations as well as in a few schools. The epilepsy posters

were exhibited at the medical expo held in Pune from 1-10 May 1984. An Epilepsy workshop was organized in March 1985 by Dr EP Bharucha and Mrs Sarla Mody.

On 21 December 1986 a painting competition was organized for children with epilepsy. There were 75 participants. Noted actor and MP, Mr Sunil Dutt who was the Chief Guest gave away the prizes. In early 1987 greeting cards were made from the paintings that won prizes.

#### 1988-90

1988 again was not a very active year but a lot of effort went into getting funds for the 1989 International Congress. In 1989, Ignatius Misquitta, a person with epilepsy, wrote a letter to the editor of the Times of India suggesting that a National Organization, to look after the needs of people with epilepsy, should be formed. Dr Eddie Barucha and Dr Pravina Shah asked Mr Ignatius to join the IEA. This was the beginning of active patient involvement in the Association. Ignatius was Vice-President of the Chapter from 1997 to 2003. He has been and will always be a role model for other people with epilepsy.

#### 1991-93

Dr Pravina Shah presented a son-et-lumiere on the “Story of Epilepsy” and also launched her book ‘Epilepsy Facts’ in Hindi and English. Another important event that took place was the formation of the epilepsy self help/support group. The support group’s first meeting was held on psychologist Neeta Sodhi’s terrace and subsequent meetings were held in Dr Pravina Shah’s residence on Saturdays. The meetings were later shifted to Conwest Jain Hospital and Research Center.

#### 1994-96

On 17 November 1994 the chapter organized a cultural event performed by patients and medical students. There was also a panel

discussion on post-traumatic epilepsy. Support group meetings were held every Saturday at KEM Hospital from 1994-98. The Chapter set up an Epilepsy Information Center at KEM Hospital. In 1996 Samman members had the opportunity to interact with Ms. Hanneke de Boer, IBE President, and Mr Richard Holmes, Secretary General, 22nd International Epilepsy Congress. On 17 November 1996, 56 children with epilepsy took part in a painting competition. Neurologists and people with epilepsy were felicitated on the occasion.

### 1997

The Bombay Chapter brought out the first issue of its newsletter 'Epilepsy News', edited by Ms Carol D'Souza and Dr Pravina Shah, in January. On 23 February a lecture on 'Epilepsy, its symptoms, causes, diagnosis and treatment' was organized for lay persons at KEM Hospital.

Samman had grown in size and it was felt that a closer bond would be forged among members if an outstation camp was held. A camp was organized from 16-20 April. There were 18 participants and 10 faculty members. Each day began with a yoga session and remaining sessions focused on epilepsy education and empowerment. The camp generated a lot of enthusiasm which led to a spurt of activities. On 25 May the chapter organized an interactive workshop on 'Your emotions and epilepsy'.

In the 50th year of our independence, NED was celebrated with a program titled "Freedom" on 16 November with a dance performance and panel discussion which focused on the rights and responsibilities of people with epilepsy.

During the year a 20 minute film titled 'One in every hundred' was made which formed part of the audio visual festival in Dublin.

### 1998

The Epilepsy Educator's Workshop was held from 17-19 April. This training-the-trainer workshop had 108 participants comprising

para-medicals, volunteers, caregivers and people with epilepsy. The medical and psychological aspects of epilepsy and epilepsy education through the performing arts and through the internet were covered by eminent neurologists and professionals from various fields. School awareness program continued through 1998. A corporate awareness program was also initiated by Ignatius Misquitta. The 'E-remedial' program was organized by the chapter from 3-4 October to get to know the problems faced by parents and family members of children with epilepsy. NED was celebrated on 15 November with the inauguration of E-cell and a song and dance program titled 'Ankur'. The Center was so named as we felt that 'E' stood not only for Epilepsy but also a lot of our goals such as Education, Empowerment, Encouragement, Employment, etc. Venue for Samman meetings shifted to the centrally located E-cell at JSS Municipal School Building.



Stalwarts Dr EP Bharucha, Dr BS Singhal and Dr NH Wadia at E-Cell



The group with Baba Amte at Nagpur

## 1999

Support group meetings continued every 2nd and 4th Saturday of the month with birthdays being celebrated on the 4th Saturday. Counselling and psychotherapy was conducted on Wednesday afternoons and yoga sessions were held every Sunday morning. Samman members put up an epilepsy awareness skit for children of JSS Municipal School, Nana Chowk in February. Brain Awareness Week was held from 14-21 March. Dr BS Singhal and Dr Pravina



Shah gave public lectures and Samman members participated in a 'Brain March' on the 19th. 'Umang' a drama workshop for children with epilepsy was organized at 'E-cell' from 20-25 May by Shivdas Ghodke Director 'Natyashala' and Bipin Vartak. Simultaneously there were informative lectures for the parents. An essay competition on the topic 'My friend has epilepsy' was arranged in November. There were 255 entries which gave an insight into the students' perceptions of epilepsy.

### 2000

Counselling sessions by psychologists continued every Tuesday and Wednesday. Support group meetings were held every 2nd and 4th Saturday. Yoga classes were conducted every Sunday. Carbamazepine was supplied to members at a reduced rate. Epilepsy Day was celebrated on 19 November with a program called 'Anand Jyot'. Sixty-two students of 8-10 standards from 21 schools enthusiastically participated in a poster competition titled 'Helping the underprivileged'. Prior to the poster competition, the Chapter organized epilepsy awareness programs at few of the schools that were participating in the poster competition.

### 2001

E-cell activities, Samman meetings, counseling and psychotherapy sessions continued. Carol D'Souza was invited by Hanneke de Boer to deliver a talk on "Living with epilepsy in the world today" at the 2nd phase launch of the Global Campaign Against Epilepsy held in Geneva from 12-13 February. She was also part of a select group that participated in the global press conference after the launch in Geneva. On 21 August the chapter mourned the passing away of Dr Piloo E Bharucha. ECON 2001 – was hosted by Bangalore Chapter. The book 'Conquering epilepsy' which contained stories of people living with epilepsy edited by Carol D'Souza was launched by actress Waheeda Rehman during the Patient Forum.

## 2002

Support group meetings, craft classes, field visits, yoga and confidence building sessions continued with greater enthusiasm and participation. Carol D'Souza participated at the Global Campaign Against Epilepsy (GCAE) anniversary press conference held at the Van Gogh museum in Amsterdam and Leadership workshop on International Capacity Building at New Orleans organized by the Epilepsy Foundation of America (EFA) and thereafter she attended the EFA Annual Conference. Information and awareness campaign at churchgate railway station, comprehensive epilepsy course, epilepsy phone-in program were other activities. Twelve Samman members attended E-CON 2002 held at Lucknow and put up a skit at the patient's session. NED was celebrated on 17 November with 'Indradanush'-- a fun fair cum exhibition and sale of handicrafts and food items prepared by Samman members. Our website: [ieasamman.org](http://ieasamman.org) was also launched on the occasion.

## 2003

A research on 'Living with Epilepsy' was conducted with the main objective to assess whether epilepsy was a disability or not and if so who was most affected.

A questionnaire was prepared and circulated to neurology departments all over India. Approximately 1000 forms were filled and returned. In March we sent a proposal to the Dorabji Tata Trust for sponsorship of a school awareness research project to be conducted over a period of 2 years. This was granted and Sheetal Agarwal was the main researcher. Two touching and inspiring short films titled 'E Family Care Services' and 'Caring for the Caregivers' were produced.

On 16 November, Epilepsy day was celebrated with a program titled 'Out of the Shadows', a cultural program and a panel discussion. The focus not only during the program but also during the year was on epilepsy and ability/disability.

## 2004

Samman meetings, excursion trips and yoga classes continued. Anti-epileptic drugs were given to members at a subsidized rate.

An early Intervention Program was held on 25 April. Phase I consisted of getting to know the individual needs and expectation of participants. Twenty-five families registered for this program. The needs of participants largely revolved around educational and behavioural assessment. Phase II involved medical, psychological and educational assessment. This was conducted in June. Phase III began in July and continued for the rest of the year. It comprised of functional literacy, value education and pre-vocational activities. Non-school going children attended sessions on weekdays whilst school going children were taken on the weekends.

The program on Epilepsy Beyond Seizures held in September focused not just on epilepsy but also on educational and behavioural management with both national and international faculty.

On 17 November an awareness program was conducted at CST Railway Station where 10000 pocket cards with epilepsy information as well as the 2005 calendar were distributed to lay persons.

## 2005

Support Group Meetings and counseling continued. Forty-four children were holistically assessed and guided during the Early Intervention and Remedial programme.

A fundraiser 'Everygreen Melodies' by the group 'Keep Alive' was held on 8 January. Beginning Oct-Dec the Chapter started its own newsletter 'Epilepsy Care' with Dr Pravina Shah as editor and Carol D'Souza as co-editor. This newsletter was distributed to GPs, neurologists, IEA members in Maharashtra and to principals of 275 schools.

During the Epilepsy Week Celebrations from 15-25 November, creative talent competition for people having epilepsy, epilepsy quiz competition and awareness program were conducted.

### 2006

During the year counseling, special education, yoga and support group meetings continued.

Life Skill Training Program which started on the 18 of September involved sessions on yoga, counseling, general education, english and computer education, craft, personality development, cooking and outdoor learning trips. Four issues of Epilepsy Care was brought out. In addition to tegrital, tegrital CR, valparin CR, frisium and topamac was given at discounted rates to members.

### 2007

Counselling, special education, yoga, support group meetings and medicine subsidy continued. As a fundraiser the film 'Kal, Aaj Aur Kal' was screened on 14 April. ECon 2007 was held in Mumbai. Excess money raised from this event went towards sponsoring poor



A few activities of the chapter – Epilepsy camp, poster exhibition and gift from Santa

patients' epilepsy surgeries and medicine subsidy for our members. On 17 November, the chapter participated in the event organized by Dr Nirmal Surya who launched his film 'Asha – The Hope' and raised awareness about epilepsy. Thirty-one patients, out of whom 26 had epilepsy, attended the first Rural Epilepsy Camp on 18 November. The second camp was conducted on 16 December which was attended by 21 new patients and 17 follow-up patients. Fifty-one people were diagnosed with epilepsy and medicines distributed to them.

Life stories of people with epilepsy written by Carol D'Souza were printed in a series of 3 booklets each having 2 life stories in english and Hindi. This was printed by MacMillan India Limited and sponsored by USV Limited.

### 2008

Counseling, special education, yoga and support group meetings were conducted throughout the year. Rural Epilepsy Clinics at Pen continued. A musical fundraiser 'Ek Shaam...Amar Saaz Aur Awaaz Ki' was held on 19 April.



Cultural programmes – skit and yoga

A blog [ecellin.wordpress.com](http://ecellin.wordpress.com) created and managed by Carol D'Souza has up-to-date information on forthcoming programs of the Chapter and details of events and support group meetings. It also gives information on epilepsy OPDs, guides parents and is interactive, informative and helpful.

### 2009

Support group meetings, counseling and special education continued.

### 2010

In addition to support group meetings, counseling, special education and yoga we started computer classes once a week on Thursdays. and the E-STAR (Epilepsy Student and Teacher Awareness Reach-out) Program in association with UCB Pharma.

From April-December we had art, craft and general knowledge classes twice a week. and counseling sessions with the participants and their families. Additionally Kavita Shanbhag who was in the process of doing an Art Based Therapy course started conducting sessions at E-Cell.

### 2011

Support group meetings, counselling, yoga and art based therapy continued at E-Cell throughout the year. Using art forms such as music, drama and visual arts Kavita Shanbhag conducted 30 therapeutic sessions. Epilepsy training and awareness programs for health workers from different regions of India was organized by the National Association for the Blind. On 13 June, 11 July and 7 November we were invited to educate the health workers about epilepsy management and treatment. Epilepsy month consisted of epilepsy awareness drive at Parel, a press conference, interviews on FM news channel and exhibition-cum-sale at the Indus festival of charities held at YMCA, Colaba.

## 2012

Support group meetings, counseling and yoga are regular activities. The Chapter was invited to raise epilepsy awareness amongst employees of the Essar Group. Ecellin.wordpress.com set up and managed by Carol D'Souza is regularly updated and continues to receive good feedback. Rural medical clinics are conducted at Pen once every 12 weeks: so far three camps on 4 March, 27 May and 5 August have been held. Around 95 patients attended each clinic. The chapter decided to support some of the members who have active seizures through the E-empowerment program. They make paper bags and crochet items at E-Cell and also help in any routine work they are capable of doing. The products made by them are bought by the Chapter and given as gifts or sold at sales organized for NGOs. This program started in April and continues to date.

### Honours / Awards received by Members of the Chapter

- Dr Noshir H Wadia - Padma Bhushan - April 2012
- Dr Pravina Shah - Social Accomplishment Award and  
Ambassador for Epilepsy Award, June 2011
- Kavita Shanbhag - Outstanding Person with Epilepsy Award,  
October 2010
- Carol D'Souza - Outstanding Person with Epilepsy Award,  
May 2008  
Ambassador for Epilepsy Award, June 2009
- Ignatius Misquitta - Outstanding Person with Epilepsy Award,  
August 2004
- Dr Eddie Bharucha - Ambassador for Epilepsy Award, 1975
- The chapter has 270 Members, 266 Life Members and 4 Annual Members.

The present Office Bearers are:

President	-	Dr BS Singhal
Vice-Presidents	-	Dr SH Ravat
		Ms Carol D'Souza
		Ms Kavita Shanbhag
Secretary	-	Dr PU Shah
Joint Secretary	-	Dr UR Shah
Treasurer	-	Mr Ashok Parekh



## Nagpur Chapter - Maharashtra

*Mrs Nandini Deshmukh Bal – Founder Secretary*

*‘I firmly believe that with exceptions no one can achieve what he or she has done without God’s grace and the help and support of others’* (Padma Bhushan Dr NH Wadia; Epilepsy India, April – June 2012).

With God’s grace and inspiration from Dr GM Taori, an eminent neurologist, the Nagpur Chapter (previously: Vidarbha Chapter) came into existence in 1990. As a social worker and a research project worker at Central India Institute of Medical Sciences, (CIIMS), Nagpur, I accompanied Dr GM Taori to various national and international epilepsy congresses at Bangalore, Delhi, etc., where I had the opportunity to meet great personalities like Dr NH Wadia and late Dr KS Mani. The experience of attending these conferences was extremely motivating. The confidence of dashing, talented persons with epilepsy (PWE) sharing their success stories in the patient’s forum was unbelievable. It changed my attitude and perspective towards persons with epilepsy.

### The need and the foundation

In our region, deep rooted problems were related to ignorance, myths, superstitions and misconceptions about epilepsy. This was very common especially in the rural population. Taking a person with epilepsy to a neurologist was the last option. It was seen that people from the metro cities were free of shame and fear about epilepsy and were living in a more open social system. Hence we thought that we must bring about the same change in the attitude of people from the Vidarbha region. This resulted in starting a chapter in this region, to include people from Nagpur, Amravati, Chandrapur, Akola, Yavatmal and other nearby towns and cities which was named as ‘Vidarbha

Chapter’ However the name was later changed to ‘Nagpur Chapter’. The first meeting was held at CIIMS, Nagpur.

The Founder Office Bearers were:

- |           |   |                           |
|-----------|---|---------------------------|
| President | - | Late Dr M. K. Khandelwal, |
| Secretary | - | Ms. Nandini Deshmukh,     |
| Treasurer | - | Mr. B. N. Sathaye.        |

Difficulties faced in the initial period

Twenty-two years ago it was difficult to get members to start a regional chapter on epilepsy as there was very little knowledge and awareness about this subject even amongst doctors and other professionals. There was a lot of uncertainty and risk involved in the initiation of such a unique project and a looming fear of failure of the project. To start with, it took a lot of effort and persuasion to convince people on a one-to-one basis to become members of such an activity. In fact this is where the actual awareness creation started.

Patients and their relatives had many doubts and wrong notions about epilepsy. Preparing them for routine medical evaluation for epilepsy was itself a difficult task. In such a scenario, giving them the idea of the brighter side of Indian Epilepsy Association (IEA) was a continuously uphill journey. They would constantly ask us defiant questions as to what they would benefit by attending programs of IEA or by becoming its members and demanded instant solutions for unemployment and marriage problems. Many people used to attend the programs and never turn up again. This was very disheartening and disappointing. But since we had decided to make a success out of this venture, we kept on relentlessly.

**Activities**

In the initial stage our activities began with simple techniques like personal counseling, arranging parents’ meetings, conducting awareness programs and camps in rural areas. Slowly but steadily

it progressed as people from social, medical, paramedical and educational fields joined us.

Dr CM Meshram and Dr Sudhir Bhawe were some of the other early members who were very dynamic and instrumental in taking the chapter to a higher level. They had prepared a very interesting format of people-education, where Dr Meshram would describe the different types of seizures and Dr Bhawe would literally 'act' them out for clear demonstration. This was a program with qualities of 'edutainment' as it is now called. It was performed many times and repeated again 2 years ago during the installation of Dr Chandak as President for 2009-11.

For the first time the following activities were conducted:

In 1989 Ms Nandini interviewed Dr Mukund Baheti, a neurologist, about epilepsy. The interview was in Marathi and was telecast by Mumbai Doordarshan in their health program: 'Arogya Sampada'.

A picnic was was organized at Ramtek and Mansar in 1999.



The first picnic: seen in the photo along with the patients are Dr Nitin Chandak, Dr Mukund Baheti and Dr Shekhar Lamdadhe



Adventure camp for adolescents with epilepsy

A cultural evening, organized jointly by IEA, Nagpur Chapter and Rotary Club of Nagpur, by People with Epilepsy was held at IMA hall during 1999-2000. The programme included dances, songs, tabla

recital and poem recital. Members of ‘Sweekar’ (self-help group of mentally challenged people and their parents) also participated in this program which was well attended.

A play ‘Bholu ka kyaa hogaa?’ was staged during the installation program of 1999. All the participants were members of IEA. This was restaged during the national conference of ECON 2004 held in Nagpur where it won a prize. Since then, this play has been staged several times to raise the social awareness.



(a) A PWE performing at the cultural event (b) The first staging of ‘Bholu ka Kyaa Hogaa?’ (c) Mrs Vishakha Morone performing the single actor skit.

Diagnostic and screening camps for epilepsy were organized at ‘Anandvan’, Warora which is a nationally known organization for the

rehabilitation and treatment of leprosy, founded by late Shri Baba Amte.

School and college based awareness programs were held as a unique awareness-drive during the tenure of Dr Ravindra Jharia (2002). We still continue this tradition in collaboration with Dr TR Bandre who conducts 'Science and Environment Fair' in government aided high schools.

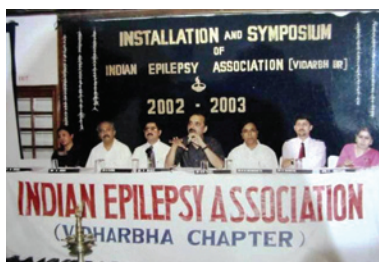
The year 2004 was a milestone in the 22 year history of the chapter. The 5th Joint Annual Conference of Indian Epilepsy Association and Indian Epilepsy Society ECON-2004 was organized from 28-29 October 2004 at Nagpur.



Inauguration of ECON-2004 at Nagpur



Symposium on Epilepsy held in November 2008 in collaboration with Silver Jubilee celebrations of CIIMS, Nagpur



Panel discussion

An Epilepsy Update for general practitioners was held in 2008 in collaboration with the Silver Jubilee functions of CIIMS, Nagpur.

The purpose was to orient and update the general practitioners regarding the approach and recent advances for management of epilepsy at the basic level.

The first meeting of the self-help / support group, ‘*Samvaad*, (a dialogue)’ was held on 16 January 2009 when Mrs Yashoda Wakankar from Sanvedana, Pune visited us. Since then the support group has been working with the people with epilepsy at a more direct level. The members of *Samvaad* are encouraged to participate in all the activities of the chapter which are directed towards solving the day-to-day problems related to psychosocial problems of PWE. Regular monthly meetings and counseling sessions are also conducted.

The first workshop on occupational guidance for scholastically challenged people with epilepsy was held in March 2010. A booklet on occupational guidance for low scholastic performers amongst the PWE ‘*Vyavasaay Maargadarshika*’ was brought out on the occasion.

The single-actor Marathi play ‘Saarthak’ (written by Ms Nandini) was staged in March 2011 during a program held for occupational rehabilitation of people with epilepsy. As the act is performed by a single artist, the ease of performance was the novel idea behind this skit which portrays the various problems faced by a female PWE at various stages of life.

We arrange for stalls to be put up for sale of artifacts made by PWE, on various occasions such as Ganesh Festival, Diwali, etc. The first ‘stall’ for the sale of objects made by PWE was kept in the mainstream markets during ‘Diwali Mela’ at Kasturchand Park, Nagpur in October 2011. Very recently, in September 2012, a similar stall was put up in the regular ‘Pretty Home exhibition/sale’ in Nagpur. This stall was part of around hundred other stalls selling a variety of goods from regular commercial vendors. Considering it was our first such attempt, we made a reasonable profit.

Adventure camping was introduced for adolescents with epilepsy. They were taken along with other adolescents for a structured adventure camp under controlled circumstances where the PWE participated shoulder to shoulder with others. The physical expression of this equality spoke much more than any of the awareness programs.

Personality development programs were held in 2011 for PWE who were encouraged to take active part in skits and express themselves. Such innovative activities have been planned on a regular basis.

A walkathon with school children from Saraswati Vidyalay in collaboration with regional engineering institutes (VNIT) was held in November 2011. The enthusiasm of the school children in making the banners and slogans and during the rally was contagious.

An innovative outreach program was held on 26 March 2012 — the purple day. Under this programme people coming for a routine evening walk in public places like ‘Traffic Park’ were tied a ribbon and told about epilepsy on a one-to-one basis.

Members of *Samvaad*, represented the chapter at ECON-2012 at Kochi. Mr Pramod Waratkar (IEA member and PWE) spoke in the patient forum and gave the perspective of a rural PWE who is working for awareness in his village which was much appreciated.

We had started the chapter with just a handful of people. Since last 22 years we have been working in many directions to help PWE become self-sufficient and independent. They face a number of hurdles in the spheres of social interaction, marriage, getting jobs and retaining them, etc. An open public forum and a panel discussion is held every year at each and every installation ceremony. The panel includes a neurophysician, a neurosurgeon, a pediatrician, a psychiatrist, a social worker and a lawyer. Vocational guidance, marriage counseling, encouragement to take part in recreational activities by taking talent competitions, quiz contests, arranging

family picnics are some of the regular activities of our chapter. Focus is being given to financial/ occupational rehabilitation of PWE and their families. In collaboration with *Sanvedana* from Pune, we have also started a branch of the marriage bureau.

The Chapter has 162 Life Members.

The present Office Bearers are:

President	- Dr Poornima Karandikar
Vice-President	- Mrs Sandhya Durge
Secretary	- Dr Pawan Adatia
Joint secretary	- Mrs Shobha Sarode
Treasurer	- Dr Sachin Joshi



## Pune Chapter - Maharashtra

*Dr Nandan Yardi – President*

The Pune chapter was started in 1991 during an epilepsy CME meeting with Dr KS Mani as chief guest. The chapter conducted several activities including patient forum for the general public. There was a lull in between for several years during which the group was not meeting and activities appeared suspended. There were 22 members at this time. In the interim period Dr Nandan Yardi made efforts, through Mr Godbole, of Bank of Maharashtra, Pune Lokmangal branch, which resulted in epilepsy being included as a reimbursable disorder in the Bipartite agreement for all bank employees and their dependents across India, by which medical care and medication became reimbursable.

### **New Beginnings.....**

Having been given the baton by Dr Rajendra Kale and support from the IEA hierarchy, epileptologist Dr Nandan Yardi, took up the task of rejuvenating the Pune chapter on 1 June 2007, as President of IEA Pune chapter. At this time a CME and public forum chaired by Dr Mohan Agashe, senior psychiatrist and ex-director, Film and TV Institute of India, was held when a movie on epilepsy made by Dr Nandan Yardi and Dr Mohan Agashe, for WHO SEARO region was screened for public. The IEA Pune chapter is being helped by secretary Yashoda Wakankar, Dr Hemant Sant, Dr Satish Nirhale, Dr Rahul Kulkarni, Dr Sudhir Kothari, Dr Anil Awachat and Mrs Radhika Deshpande from the executive committee.

Since this event there is no looking back and programmes were conducted in coordination with *Sanvedna Foundation*, an active epilepsy support group started by a person with epilepsy (PWE) Ms Yashoda Wakankar whose epilepsy was well controlled after under-

going epilepsy surgery. She had active support from her father who is her inspiration, Dr Anil Awchat a versatile author and literary figure and Radhika Deshpande, and her daughter Sanika, a PWE whose epilepsy was also well controlled with surgery.

Sanvedana Foundation epilepsy support group was started in 2004 and was already conducting various activities viz, epilepsy counseling center on every Wednesday evening, PWE and their parent's meetings on every third Sunday, awareness program, etc. After the re-birth of Pune Chapter, Sanvedana Foundation and IEA Pune Chapter started working together.

### **Epilepsy Marriage Bureau activity**

In 2006 Sanvedana Foundation started a unique activity — the “Marriage Bureau for people with epilepsy.” This activity was started because the core members of Sanvedana in the epilepsy counseling center realized that youngsters with well controlled epilepsy had problems getting married. Many marriages broke up because their epileptic condition was not disclosed before marriage. Hence Sanvedana Foundation core committee started the marriage bureau for people with epilepsy.

Many articles on this topic were published in the newspapers all over India and we got tremendous response! (more than 50 phone calls every day!) It was then that we realized how marriage is a very serious issue for people with epilepsy. More than 150 people with epilepsy registered in the epilepsy marriage bureau. We also realized that not only a marriage bureau but also a matrimonial meet for people with epilepsy was needed.

On 11 May 2008, Sanvedana arranged a matrimonial meet for people with epilepsy. (It was probably the first epilepsy matrimonial meet in India.) [www.aarogya.com](http://www.aarogya.com) helped Sanvedana for the publicity. The program went on very well with tremendous response. More than



Matrimonial meet for PWE

250 people were present including 21 brides and 28 grooms. The families were not only from Maharashtra, but also from Karnataka. Dr Pradeep Diwate, senior neurologist was the chief guest and author and famous writer in Marathi, Dr Anil Awchat was invited as a speaker. Sanvedana is proud to announce that six marriages were fixed after the first matrimonial meet! Carol D'souza, Kavita Shanbhag, Vice-Presidents of IEA Mumbai Chapter were also present for this event with several other members of the Mumbai Chapter. After this successful matrimonial meet, one of the members, Mr Phatak has taken the lead of running this epilepsy matrimonial service and has succeeded in arranging several successful marriages where both parties understand the need for support of persons with controlled epilepsy.

On 21 November 2010, Sanvedana Foundation arranged the second Matrimonial Meet to which an overwhelming response was witnessed with 30 brides and 25 grooms from all over India participating in the event. Members from Indian Epilepsy Association, Pune, Mumbai and Nagpur Chapters were present for this event. Dr Rahul Kulkarni, neurologist was the chief speaker, Mrs Vandana Kulkarni, the marriage counselor, was the co-speaker and Dr Anil Awchat - famous writer and trustee of Sanvedana was the chief guest. We are very happy to note that till date sixteen marriages have been solemnized and all of them are leading a happy life.

## Other Activities

National Epilepsy Day of 2007 was celebrated in Bharati Hospital. Radhika and Yashoda were invited to speak about epilepsy along with Dr Surekha Rajadhyaksha.

A “Yoga for Epilepsy” session was arranged for IEA and Sanvedana members by Mr Uday Pendse, yoga teacher and researcher. Dr Nandan Yardi described the usefulness and virtues of yoga for epilepsy and showed the various asanas and kriyas that have been researched and published by him in the medical journals “Seizure” and “Epilepsy.”

Sanvedana Foundation got a chance to participate in the well-known social NGO’s exhibition: *Dene Samajache*, which was held in the first week of October 2008. ‘Artistry’ institute arranges this exhibition every year. Sanvedana members provided information about epilepsy to all the visitors.

NED of 2008 was celebrated in Patrakar Nagar’s hall, Dr Hemant Sant and Dr Nandan Yardi discussed psychosocial aspects and treatment



(a) Volunteers at work (b) Audience participation (c,d) Interactive sessions

trends in epilepsy with the support group and other attendees.

National Epilepsy Day in mental hospital was celebrated on 18 November 2009. Sanvedana Foundation was invited for this event. More than 50 parents of the epilepsy patients were present. Radhika spoke on “parenting”, and Yashoda on “Importance of SHG for the parents”. Psychiatrists, nurses and neuro-psychologists also spoke in this event.

The Pune chapter celebrated National Epilepsy Day on 29 November 2009 in collaboration with Sanvedana. Dr Nandan Yardi and Dr Satish Nirale were present . Dr Anil Awchat was the chief speaker.

Interviews of all the self-help groups were arranged by Akashwani, Pune. Ms Yashoda, Mr Phatak and Dr Sant of Sanvedana were also interviewed.

Dr Ravindra Somani, a physician and neurocare specialist from Ahmednagar was interested in starting a self help group, for which he contacted Sanvedana. After two meetings it was decided that Dr Somani would start Sanvedana’s Ahmednagar Chapter. Dr Somani and his wife arranged a big event for the inauguration.

The Institute for Psychological Health in Thane invited Sanvedana to start a new epilepsy self help group. Uttejan epilepsy support group’s activity started in November 2009 under Ms Yashoda’s guidance.

The National Epilepsy Conference ECON 2010 held at Indore in February 2010, was attended by 10 members of the Chapter. Ms Yashoda spoke about marriage and epilepsy and about the activity of the epilepsy marriage bureau in Pune.

Fifteen members from the Pune chapter attended ECON 2011. Ms Sanika Deshpande – a Sanvedana member – showed a film about epilepsy at the conference. The film was made by Sanika and her team of animation artists under the guidance of Dr Nandan Yardi.



Awareness programmes

The film was appreciated by Reliance communications and Sanika got a job in the company for her animation skills.

The neurologists and the psychiatrists of Aurangabad arranged the first ever epilepsy support group meeting in Aurangabad in March 2011. Core group members from Sanvedana went there to encourage and inaugurate the new epilepsy support group.

Twelve members from the chapter attended the National Epilepsy Conference ECON 2012 held in Cochin. Sanvedana members took part in patients forum and discussions on marriage and epilepsy, parenting, childhood, education and epilepsy, social problems, epilepsy awareness, etc.

Ms Yashoda Wakankar received the “Outstanding person with Epilepsy Award” during the Asian and Oceanian Epilepsy Congress held in Philippines on 22 March 2012. It was a great achievement for Ms Yashoda who also attended the Symposium for people with epilepsy held during the same conference.

“Purple Day” was celebrated by Sanvedana Foundation and Indian Epilepsy Association on 25 March 2012. Dr Nandan Yardi, Dr Rahul Kulkarni and Dr Sudhir Kothari spoke on “Epilepsy in Childhood”, “Marriage and Epilepsy” and “Old-age and epilepsy”. Dr Nandan Yardi is the regional ambassador of Purple Day.

However we have miles to go before we sleep and miles to go before we sleep.....

The Chapter has 53 Life Members.

The present Office Bearers are:

President	- Dr Nandan Yardi
Vice-President	- Dr Hemant Sant
Secretary	- Mrs Yashoda Wakankar
Treasurer	- Dr Satish Nirale

## Ludhiana Chapter - Punjab

*Dr Gagandeep Singh – Founder President*

The Ludhiana Chapter was formed in June 2008 with 22 members.

The Founder Office Bearers were:

President	-	Dr Gagandeep Singh
Honorary Secretary	-	Dr Parampreet Singh
Treasurer	-	Dr Sandeep Kaushal

The chapter has members not only from Ludhiana but also from Chandigarh, Amritsar and Jalandhar. The chapter holds regular events during the epilepsy week in November and on the Purple Day in spring every year.

The Chapter organised ECON 2010, the 18th Joint Annual Conference of the Indian Epilepsy Association and Indian Epilepsy Society from 25-27 February 2010. The Conference was attended by 274 delegates. The Conference was preceded by a workshop entitled, “Seizures, semiology and syndromes” and featured three orations. There were guest lectures on law and epilepsy by distinguished speakers from the judiciary and media, a debate on provision of epilepsy-related treatments to the community and a clinico-pathological conference.



ECON-2011. Dr Gagandeep Singh, Organising Secretary addressing the conference delegates



Dr Samuel F Barkovic, Melbourne, Australia being felicitated for the Prof BM Sharma Oration





Play on epilepsy by Bangalore Chapter



Street play at Conference Centre



Epilepsy monthly camp

The chapter has been holding monthly camps in an urban slum of Ludhiana for the last 2 years. Antiepileptic drugs are provided free of cost during these camps to about 115 patients. In this context, the Chapter is grateful to many pharmaceutical companies for providing the medicines.

The Chapter has 22 Life Members.

The Founder Office Bearers continue in office.

## Jaipur Chapter - Rajasthan

*Dr Chandra Mohan Sharma – Treasurer*

The Jaipur Branch of Indian Epilepsy Association was started in 1978. Initially, there were only 5 members including Dr Brij Mohan Sharma, founder member and the membership fee was Rs. 30/- per year. Total membership amount was Rs. 150/- from five full members. We were all physicians working in the Dept. of Medicine and we started this branch. In 1991 our membership rose to 50, with 20 ordinary members, all practicing doctors and 30 Associate Members, all relatives of patients with epilepsy.

In 1978-79 free consultations were given and free investigations done for epilepsy patients once a week in our medical outpatient department. Every week we saw 20-30 patients and gave them free medicines for one month. The medicines were arranged by our member colleagues from physician samples and donations. By April 1981, the number of epilepsy patients increased to 50 every week, 15-20 new patients being added every week. With increasing number of patients the problem of distribution of free medicines in our weekly Epilepsy Clinic arose. I approached the Medical Superintendent of SMS Hospital, who was kind enough to sanction 100 tablets of phenobarbitone per month for free distribution to the epilepsy patients. Even this meagre amount could not serve our purpose as the number of patients was increasing steadily.

A close friend (late) Sh. Harish Chandra Golecha, the eminent philanthropist and owner of the prestigious Prem Prakash Cinema agreed to give the proceeds of one premier film show to the Epilepsy Association. Then, I approached the finance minister and finance secretary to the government of Rajasthan for making this charity film show tax free. A new feature film “Ek duje ke liye” was given

free of charge for one show at Prem Prakash Cinema by the film distributor Sh. HC Heerawat. Another good friend Sh. SN Goenka, owner of Friends Printers, Jaipur provided free printing of the tickets of the premier cinema show, epilepsy association donor cards and publicity. Thus, on 7 July 1981 we collected a sum of Rs. 19,470/- from this charity film show which was deposited in a fixed deposit account and interest generated from this was used for purchasing medicines. One month's supply of these medicines were distributed to the poor epilepsy patients. In March, 1991 when I retired as Prof. and Head of Neurology Dept., there was a fixed deposit amount of Rs. 30,000/-.

After the retirement of DrBrij Mohan Sharma the founder member of IEA Jaipur Chapter, the activities continued. On National Epilepsy Day we have been organizing public education and awareness program with different themes suggested by the IEA central office. This program is being attended by a large number of patients and their family members and is well covered by local TV Channels and the print media. On this day for the last few years, programs are also organized in various schools to educate students regarding epilepsy, as children are the best to spread this knowledge to their family members. The public education program covering various aspects



Awareness programme

of epilepsy including its cause, types of seizures, prevention of seizures, treatment and rehabilitation of patients are provided. This is followed by an interactive discussion. A drawing competition for children with epilepsy is organized and the winners are given prizes. A cultural program is also organized in which patients present events like dance, songs and poetry and the participants are given prizes. The Jaipur Branch has also organized the Annual Conference of IEA twice successfully. The first one was held on 17 December 1997 where we felicitated stalwarts of neurosciences Dr Eddie Bharucha, Dr KS Mani, Dr KV Mathai, Dr GM Taori and Dr Arjun Das for their immense contribution in the field of neurology. We also started the Prof. BM Sharma oration which was delivered by neurosurgeon Dr Ramamurthi. The conference was very well attended. There were free



Inaugural function of EPICON-97

papers, posters, guest lectures and the presidential oration by Dr KS Mani. Dr Mani's oration was so interesting that even the health minister of Govt. of Rajasthan sat through the full presentation. There was a banquet following the academic session at Sisodia Rani ka Bagh where all the delegates enjoyed the Rajasthani hospitality and folk dance by famous Rajasthani folk dancer Gulabo. The second



Colorful evening at Sisodia Rani Bagh during ECON-2005



Inaugural function of ECON-2005



Educational posters



Painting competition

conference was held on 22 and 23 September 2005, jointly by the IEA and IES. This was also well attended by delegates from all over India. Around 30 patients and caregivers of Samman group from Mumbai participated in the event. There were free papers, award papers and guest lectures. Prof. BM Sharma oration was given by Dr BS Singhal. The second day of social aspects on epilepsy was also well attended despite the fact that Indian Academy of Neurology conference was also being held at the same place.

We have been distributing free drugs, to all the poor and needy patients once a month. In future, the Jaipur chapter plans to help more number of poor patients by distributing free drugs, counseling sessions for the patients and their relatives, education programs on Doordarshan and Akashwani TV channels. Every year in March there will be CME Program which will include lectures by experts on the subjects. On the last Sunday of every month a free camp will be organized for poor patients of epilepsy in Jaipur. Along with the camp, epidemiological studies will also be conducted in various parts of Jaipur. Depending upon the response, later on, bigger camps will be organized in other districts of Rajasthan.

The Chapter has 97 Life Members

The present Office Bearers are:

- President - Dr Brij Mohan Sharma
- Secretary - Mr Deen Dayal Sharma
- Treasurer - Dr Chandra Mohan Sharma

## Jodhpur Chapter - Rajasthan

*Dr Pratap Sanchetee – Founder President*

Western Rajasthan has a large number of people with epilepsy. However, ignorance about the disease, practice of being treated by quacks, a lot of stigma and large treatment gaps are characteristics of the area. Though, the state branch of IEA was active, its penetration into this part of the state is inadequate. Thus a need to form a chapter of IEA at Jodhpur was felt and it started functioning in 2004 after approval from IEA central office.

### The Founder Office Bearers were:

President - Dr Pratap Sanchetee  
Vice-President- Dr RS Jain  
Secretary - Dr Rajeev Mathur  
Treasurer - Dr Balwant Mardia

### **Activities**

Meetings are held at regular intervals to discuss issues relating to epilepsy. National Epilepsy Day is held on 17 November every year with good response from the public. Public awareness programs are conducted by members in Jodhpur and adjoining areas.

Epilepsy camps and awareness drives are being organised by all members of IEA Jodhpur chapter at intervals.



Epilepsy camp organised by Dr Nagendra Sharma





Epilepsy camp organised by Dr Sanchetee

A project on “Survey of public knowledge, attitude and practices about epilepsy in western Rajasthan” has been undertaken by Dr Pratap Sanchetee in July 2010. This has been funded by IEA-18th IEC Trust. More than 800 subjects have been interviewed at different places in western Rajasthan. Presently analysis of data is underway and soon a final report will be submitted.

Dr Nagendra Sharma, neurosurgeon is organising free epilepsy camp on the 30th of every month since February 1999. More than 36,000 patients have been benefited by it. He has produced two books on epilepsy in Hindi. A documentary on epilepsy has been produced in collaboration with EMRC, Jodhpur and it was released on 17 November 2012

The Chapter has 25 Life Members

The present Office Bearers are:

- |                 |   |
|-----------------|---|
| President       | - Dr Pratap Sanchetee                   |
| Vice-Presidents | - Dr Nagendra Sharma, Dr Amita Bhargava |
| Secretary       | - Dr Rajeev Mathur                      |
| Treasurer       | - Dr Balwant Mardia                     |

## Chennai Chapter - Tamil Nadu

*Dr V Natarajan - Secretary*

IEA Chapter Madras (now Chennai) was formed in 1971.

The Founder Office Bearers were:

President & Secretary - Dr B Ramamurthi,  
Treasurer - Dr G Arjundas

Subsequently Dr G. Arjundas, Dr CU Velmurugendran and Dr Prithika Chari were successive secretaries. Dr CU Velmurugendran and Dr Zaheer Ahmed Sayeed were the past treasures.

Dr Ramamurthi made it a point to address as many IMA meetings in Tamil Nadu on epilepsy to dispel myths, superstitions and stigma attached to epilepsy. The Epilepsy clinic started at the Institute of Neurology which was held every Friday morning became very popular.

The Chapter used to periodically organize lectures for the public and professionals and conduct camps.

At present, during the National Epilepsy Day fortnight, in November every year, the following programs are conducted:



Public forum - A section of the audience on NED



CME on Epilepsy at Madras Medical College





At Marina beach with celebrities



Public Forum Interactions

1. Drawing and slogan coining competitions for children and adults attending the Epilepsy Clinics at Government General Hospital and Government Stanley Hospital.
2. Faculty interaction with patients and their carers in public forums at the three Government Hospitals attached to teaching institutions viz., Madras Medical College, Stanley Medical College and Kilpauk Medical College. The programme is also being conducted at Government Rajaji Hospital, Madurai and PSG Medical College Hospital, Coimbatore.
3. CME programs for postgraduates in Medicine, Pediatrics and Neurology at Madras Medical College, Institute of Child Health, Chennai, Madurai Medical College, Madurai and Tirunelveli Medical College, Tirunelveli. CME programs and public education programs were also organized individually by Dr Prithika Chari, Dr ES Krishnamurthy in Chennai and Dr J Ramachandran in Kanchipuram.
4. Educative talks on epilepsy in schools by IEA members.
5. Radio talks, TV shows, write-ups in newspapers and snippets on the TVs in railway stations are also done.
6. Public awareness programs on epilepsy by a gathering of neurologists at Marina Beach on the National Epilepsy Day with a celebrity and launching of balloons to mark the occasion.

Other notable features achieved by the efforts of the members were:

1. All the standard anti-epileptic drugs like sodium valproate, carbamazepine, phenytoin, phenobarbital and clonazepam/clobazam were made available in all government district and taluk hospitals free of cost to the patients with epilepsy (PWE).
2. Ensuring one month's supply of the above medicines at a time, thus reducing the number of visits to the hospital.
3. Obtaining free bus passes for the PWE and one attender within the city to attend the hospital for review and collection of medicines.
4. Running sheltered workshops for PWE to get vocational training in the manufacture of chalk, candles, and get trained in book binding and tailoring.

A bakery unit is planned at the Government General Hospital, to help patients with epilepsy to become self sufficient.

The Chapter has 101 Life Members.

The present Office Bearers are:

President	-	Dr CU Velmurugendran
Secretary	-	Dr V Natarajan
Treasurer	-	Dr K Bhanu



Institute of Obstetrics & Gynecology-  
Theme Women & Epilepsy

## Trichy Chapter - Tamil Nadu

*Dr R Sundararajan – Founder Secretary*

The Trichy Chapter was established on 1 August 1997 at the behest of Dr KS Mani who visited Trichy to deliver the Trichy API endowment lecture.

### The Founder Office Bearers were:

President	-	Ms Tara Sundararajan
Vice-President	-	Mr TV Srinivasan
Secretary	-	Dr R Sundararajan
Treasurer	-	Mr RN Gupta
Joint Secretary	-	Mr S Umamaheswaran

The Branch started functioning with the aim of increasing awareness about epilepsy among the public and doctors and extending medical help to rural epilepsy population. The Society adopted the slogan “*Valippu Noi Vazhkaikku Thadaiyalla*” which means epilepsy is not an obstacle to life.

### **Activities**

#### ***Public awareness programme:***

##### *Pamphlets and Posters*

Educative handouts on epilepsy are printed in local language and distributed mainly in villages. Pamphlets in English are circulated among the urban population. T-shirts, notebooks, computer CDs, etc, carrying our slogan and spreading the message that epilepsy is not an obstacle to life, continue to be distributed among the public .

Public interaction program with 175–200 participants lasting for 3 hours, starting with a lecture by a leading personality, including, at times, a skit on epilepsy and ending with dinner has been an annual event. Myths and facts on epilepsy are explained in detail for



Awareness programme for school children

over two hours. The entire program is videotaped and its subsequent coverage by media adds to the public awareness.

The Association has prepared a multimedia presentation on medical and social aspects of epilepsy, with liberal use of audio and video clips. Separate presentations are there in Tamil and English and for different population like persons with epilepsy and their family members, students, nurses and paramedics and physicians.

Quiz programs on epilepsy, in the local language, are conducted for the public and medical students. Coloring, painting and essay competitions are held for school and college students. Cash and kind rewards have added to the excitement; right answers provided after the program add to educating the participants.

A multimedia presentation is displayed everyday in the clinic of Dr R Sundararajan and doubts on epilepsy clarified. Computer disks are given free as and when requested. A self learning interactive program in Tamil (the local language) and English, on a touch screen computer is available 24/7 at the centre.

National Epilepsy Day provides a good opportunity to conduct awareness programs and the branch has never failed to capitalize.

### ***Medical and Paramedical Awareness Programme***

Lectures on medical and social aspects of epilepsy are delivered by medical and non-medical members of the branch to varying types

of audience: persons with epilepsy and their family members, medical sales representatives, physicians, medical college students, nursing students, patients, villagers, school and college students and finally public on the streets! Continuing Medical Education lectures by eminent speakers form part of awareness among the medical fraternity.

### **Project CORE (Control of Rural Epilepsy)**

The Branch started a worthy project, Control of Rural Epilepsy (CORE), in 1997. About 60 villages, under the Annavasal Union of Pudukottai District were identified for the project. This district has been declared “backward” by the Government of Tamil Nadu. There are poor medical and transport facilities in and around the Union.

Twenty social workers were trained to screen the population for epilepsy. A questionnaire was prepared in Tamil for the purpose of door to door survey. Suspected people with epilepsy were examined in detail by professionals every week. The false positive



Rural epilepsy project

cases were advised suitably and dropped from the project. Detailed medical records are maintained for the patients registered under the project and patients are treated free of cost, including medicines and followed-up regularly. Wherever indicated, investigations and in-patient treatment are done free with the help of sister organizations in Trichy. Drug compliance and regularity of follow-up are ensured wherever possible with the help of 12 “village contact persons”.

Women from remote villages were taught first aid and when and how to give intrarectal diazepam for febrile convulsions. It was

surprising to many that seizures, though had not stopped completely, were no longer a major hindrance to studying, playing, working and in general, living !

The project offered excellent opportunity to spread awareness on epilepsy



Public awareness campaign

among the rural population. Many villagers came forward to narrate how their myths on epilepsy were dispelled and how persons with epilepsy can lead normal lives, even within a year of participating in the program. Videos of their stories created stunning impact on both the urban and rural public. Some of these were used in the computer CD that were distributed free of cost as an awareness medium.

Registration was stopped when clinically confirmed epilepsy patients reached 1000, at the end of March 2003. New walk-in patients were seen once, advised suitably and directed to the local PHC. After 10 years of free service at the villages, for the last 5 years the project is continuing at the care centre in Trichy with around 60 resistant seizure patients availing free medical advice and medicines.

Spreading awareness amongst the public and the medical fraternity continues to be our motto.

The Chapter has 20 Life Members.

The Founder Office Bearers continue in office.

## Lucknow Chapter - Uttar Pradesh

*Dr Atul Agarwal –Secretary*

IEA UP chapter was started by Dr Devika Nag, Prof & Head of Department of Neurology, KG Medical College, Lucknow in 1986 by enrolling her departmental colleagues and few other members from the city. The number gradually grew to 50 by 1991, 100 by 1993, and 200 by 2003.

The Founder Office bearers were:

President	-	Dr N N Gupta
Secretary	-	Dr Devika Nag
Treasurer	-	Dr AM Kar

From the very beginning the chapter has been actively involved in social issues related with epilepsy. The painting competitions for children with epilepsy are being organized every year on National epilepsy day (in the middle of November as per convenience and school holiday) along with awareness lectures for general public; for the last 24 years. Initially this competition was organized inside KGMU campus. Later it was held once in IMA building and now since the last 5 years it is being held in the seminar hall of Vivekanand Hospital with the help of members of department of Paediatrics, headed by Dr Kiran Zutshi and prizes are distributed to the winners.

Various experts and members of IEA UP chapter have spoken about the disease on All India Radio, FM channels and television trying to educate the public and helping to remove misconceptions from their minds. Faculty members of department of Neurology, KG Medical University, Lucknow visit various schools and colleges of Lucknow for interactive sessions with students and teachers.



Educational programme

Dr Rakesh Shukla, who also works for IMA Lucknow as President organized 2 CME's/Debate at IMA Bhawan. The first in October 2002 was on 'First seizure – to treat or not' and the second one in November 2012. Nukkad nataks (street plays) on epilepsy written by famous satirist Padmashri Mr KP Saxena have been enacted in different parts of the city by artists of Kadambari group under the able direction of Mr Vinod Misra for many years spreading the message to the masses.

With the help of the local NGO at Shahjahanpur, 'Helpline', the chapter had a Mega Epilepsy Camp for 2 days in November 2005 at Baba Vishwanath Dharamshala. Preparations took more than 3 months with involvement of more than 100 PHC's and doctors. More than 1100 pre registered epilepsy patients were seen by 6 senior neurologists for 2 days. Drs Atul Agarwal, Sanjeev Jha and R K Garg from Lucknow; Drs Anil Gupta, Vinay Agarwal and Dr Tarun Agarwal travelled from Moradabad to Shahjahanpur for seeing patients. All EEGs of attending patients as and when advised by



doctors were done immediately at the venue itself free of cost, and report delivered within 2 hours. More than 100 CT scans of head, as advised by specialists were also done free of cost at 2 CT scan centers in the city immediately. Drugs for one month as prescribed by doctors were given to patients free of cost. Good arrangements for food, lodging and transportation were made by active members and volunteers of NGOs. A huge exhibition on epilepsy consisting of 30 poster boards carrying details of disease, do's and don'ts and management was inaugurated by DM of Shahjahanpur and was open for general public. Awareness material on Epilepsy printed in Hindi was also distributed. An interactive program with general public and specialist doctors was held at Town Hall in the evening which continued for 3 hours. It was chaired by Commissioner of Bareilly and smoothly conducted by Dr Alok Agarwal who was also an active planner of the camp. Follow up drug distribution camps were done every month for 2 years.

Dr Tarun Agarwal at Moradabad has been active in organizing epilepsy camps at his clinic on 17th November every year for the last 15 years. The registered patients are seen free of cost and even EEGs are done without any charge. Printed epilepsy related material is distributed to these patients and general public.

To educate primary physicians in proper management of epilepsy, three CMEs were organized by department of Neurology, KG Medical



Skit and painting competition



Interactive session

University, Lucknow in 1993, 1995 and 1997. These were attended by a large number of practicing physicians, pediatricians, and residents. The lectures were also published in form of books, which were distributed to delegates for future reading and reference.

Epilepsy meets were frequently organized in Department of Neurology to discuss various important medical topics. Members of department of Neurology, KG Medical University, Lucknow have been involved in delivering lectures outside Lucknow also — at forums of physicians, pediatricians and IMA. These activities have been held at Sitapur, Sultanpur, Barabanki, Shahjahanpur, Rai Bareilly, Faizabad, Meerut, Varanasi, Allahabad, Kanpur, Saharanpur, Dehradun, Bareilly, Moradabad and other districts all over UP and Uttarakhand.

Two international seminars on epilepsy were successfully organized by Prof. Devika Nag at KGMU. Invited international speakers in the first seminar in 1987 were Dr Peter Fenwick, Dr Jerome Engel and Dr Elves. Drs Peter Wolf, P Bittencourt, Oliver Dulac and Onkar Markand delivered lectures in the second seminar in November

2000. This seminar was held immediately after the AOA conference successfully organized at Delhi. A large number of doctors from Neurology, Medicine, Pediatrics and other departments benefitted by the deliberations.

The 3rd Joint annual conference of IEA/IES was successfully organized by Prof U K Misra at SGPGIMS, Lucknow from 30 – 31 October 2002. It followed the annual conference of Indian Academy of Neurology. There was an interesting debate on epilepsy caused by neurocysticercosis. Controversies in use of albendazole, steroids, and duration of AED treatment were presented by Dr Sunil Pradhan and Dr Satish Jain. There was a useful EEG workshop in this conference.

The chapter started its 16 page quarterly newsletter “Epilepsy Bulletin” in 1994 which continued till 2002. Dr Atul Agarwal was its Editor. It contained report of activities of the chapter, intimation of forthcoming events and other useful information for patients and relatives and general public in Hindi as well. Efforts are being made to restart its publication. The chapter plans to enroll more patients and persons from society to reach the 500 mark figure in the next few years and plans more awareness and counseling activities.

The chapter has 213 members – 211 Life Members and 2 Annual Members.

The present Office Bearers are:

- |                |                   |
|----------------|-------------------|
| President      | - Dr Devika Nag   |
| Vice-President | - Dr R K Garg     |
| Secretary      | - Dr Atul Agarwal |

## Kolkata Chapter - West Bengal

*Dr Goutam Ganguly, GC member of IEA*

Indian Epilepsy Association in West Bengal has a long history. Even before the West Bengal chapter was formed in 1987 the epilepsy programme was being conducted under the leadership of late Prof. TK Ghosh.

In a meeting held under the chairmanship of late Prof. Shyamal Kumar Sen in 1987 the West Bengal chapter of the Association was formed.

The Founder Office Bearers were:

President	-	Dr. Shyamal Kumar Sen
Secretary	-	Dr. Anupam Dasgupta
Treasurer	-	Dr VS Saxena

The office of the chapter was at the Bangur Institute of Neurology. In its early days the Association used to function with very few members. The main focus was to spread awareness about the disease in the community. There used to be camps in the city and suburbs to educate people about the scientific knowledge about epilepsy. The camps were organized with the help of NGOs like Lions club, Rotary club or local clubs. In one of the first meetings held in a mofussil town, more than hundred people attended. In the camps, patients with epilepsy were examined by experts and free antiepileptic drugs were distributed. Camps were also organized in schools for screening and providing free consultations to children with epilepsy. Over time, many new members were inducted from doctors and also from different sections of the society. Besides neurologists, doctors from other branches of medicine and also family members of persons with epilepsy were encouraged to become members of the Association with an idea to strengthen the campaign against prejudices prevalent in the society.



Awareness programmes

Since its formation many renowned neurologists of the state became its office bearers (president and secretary) — Dr AmbarChakraborty, Dr NN Sarangi, Dr Trishit Roy, Dr AbhijitChatterjee, Dr Arabinda Mukherjee, Dr Prasanta Kumar Gangopadhyay, Dr Bibhukalyani Das, Dr Salil Bhattacharya, Dr Asit Senapati, Dr Anjan Bhattacharya, to name a few.

The first newsletter of the West Bengal chapter of IEA was published in 1990. Since then it has become an instrument of communication to its members.

The Association has also organized many academic programmes as part of its activities like EEG workshop and symposium, formulating guidelines about management of epilepsy, etc. In one of its first



Public education

CME programmes held in 1988, dignitaries like Dr BS Singhal, Dr P Satishchandra and Dr Nimal Senanyeke from Sri Lanka delivered guest lectures. The first EEG workshop was organized in 1993 at the Nightingale Hospital. In 2007 another EEG workshop was organized by the state chapter at Bangur Institute of Neurosciences. Both these were very successful and helped doctors of the state to learn and refresh their knowledge.

Every year seminars, symposiums, CME programme, etc., are organized by the Association involving physicians, pediatricians, gynaecologists, and general practitioners as well as paramedical staff to update and refresh their knowledge about the subject.

As majority of persons with epilepsy are children, schools are targeted for creating awareness. Students Health Home in West Bengal has been providing free medical treatment to poor students. Members of the Association have been imparting their services through this organization.





Patient care and education

Every year many camps are being organized at various parts of the state by the chapter. Many of these camps are organized in remote places where modern medical facilities are unavailable. These camps are meant to provide scientific information and counseling to persons with epilepsy and their family members. Various issues related to epilepsy e. g. treatment, marriage, employment, rights of persons with epilepsy, etc. are discussed in these camps. Many national and international experts graced these camps. Persons with epilepsy, their family members, and care-givers were involved in open discussion with the experts in these camps.

The National Epilepsy Day is celebrated every year with various activities, like organizing rallies, drawing competitions, publishing articles in newspaper, talk show in TV, radio, etc. Sometimes celebrities are involved in these activities.

In 2005, the West Bengal chapter after numerous meetings of the expert committee formulated a guideline for management of epilepsy.

The idea of publishing the consensus guideline was to propagate the current scientific knowledge about the disease management among physicians, pediatricians, and general practitioners who usually treat persons with epilepsy. This was published and circulated free of cost among the members and also among physician and pediatricians of the state.

The Chapter has 122 Life Members.

The Present Office Bearers are:

President	-	Dr Tapan Goswami
Vice-President	-	Dr Sagar Basu
Secretary	-	Dr Alak Pandit
Treasurer	-	Dr Arindam Das



## OTHER INFORMATION

## MILESTONES

1. 21 March 1970 – Indian Epilepsy Association (IEA) officially registered at Bombay.
2. 27 January 1971 – First meeting of the Governing Council in Bombay.
3. 19 December 1974 – Affiliation of IEA to IBE (International Bureau of Epilepsy).
4. October 1989 – 18th International Epilepsy Congress hosted by IEA in New Delhi.
5. November 1991 – First National Epilepsy Day organised.
6. April 1992 – Formation of IEA-18th IEC Trust.
7. 1992 – First printed Newsletter of IEA circulated.
8. December 1993 – First Annual Conference of IEA held along with NSI (Neurological Society of India) at Chennai, continued till 2001
9. 1997 – Formation of Indian Epilepsy Society (IES) with medical professionals affiliated to International League Against Epilepsy (ILAE).
10. December 1999 – First Joint Annual Conference of IEA - IES at Hyderabad.
11. December 1999 – Amendment of Hindu Marriage Act.
12. 2001 – Launching of IEA website.
13. December 2001 –“K S Mani patients session” was started during the annual conference at Mumbai.
14. October 2002 – Annual conference of IEA held along with IAN (Indian Academy of Neurology) continued till 2008
15. June 2006 – Launching of Distance Education Programme - Diploma in Epilepsy Care (DEC).
16. February 2009 – First stand alone conferences of IEA and IES.

## OFFICE BEARERS of IEA – CENTRAL OFFICE

<b>Year</b>	<b>President</b>	<b>Secretary</b>	<b>Treasurer</b>
1971-1983	Dr Baldev Singh	Dr EP Bharucha	Dr(Ms) F Kohiyar
1983-1986	Dr TK Ghosh	Dr EP Bharucha	Dr(Ms) F Kohiyar
1986-1989	Dr KS Mani	Dr EP Bharucha	Dr(Ms) F Kohiyar
1989-1991	Dr TK Ghosh	Dr EP Bharucha	Dr(Ms) F Kohiyar
1991-1994	Dr B Ramamurthi	Dr KS Mani	Dr VS Saxena
1994-1996	Dr A Dasgupta	Dr KS Mani	Dr VS Saxena
1996-1998	Dr KS Mani	Dr VS Saxena	Dr HV Srinivas
1998-2000	Dr Devika Nag	Dr VS Saxena	Dr HV Srinivas
2000-2002	Dr BS Singhal	Dr VS Saxena	Dr HV Srinivas
2002-2005	Dr KK Sinha	Dr VS Saxena	Dr HV Srinivas
2005-2007	Dr PK Sethi	Dr HV Srinivas	Dr CM Sharma
2007-2009	Dr VS Saxena	Dr HV Srinivas	Dr CM Sharma
2009-2011	Dr Pravina U Shah	Dr MM Mehindiratta	Dr CM Sharma
2011-2013	Dr HV Srinivas	Dr MM Mehindiratta	Dr CM Sharma

## OFFICE BEARERS OF THE CHAPTERS FOR 2012

	PRESIDENT	SECRETARY
<b>Andhra Pradesh</b>		
<b>Hyderabad</b>	Dr MVR Reddy	Dr JMK Murthy
<b>Kakinada</b>	Dr P Durga Raju	Dr D Seshagiri Rao
<b>Nellore</b>	Dr Bindu Menon	Dr Marigar Rajesh Kumar
<b>Tirupati</b>	Dr B Vengamma	Mrs M Nagarathna
<b>Visakhapatnam</b>	Dr VC Bothra	Dr RV Narayana
<b>Assam</b>		
<b>Guwahati</b>	Dr (Mrs) Ajaya Mahanta	Dr Monalisa Goswami Sarma
<b>Bihar</b>		
<b>Patna</b>	Dr Ashok Kumar	Dr Rakesh Kumar
<b>Delhi</b>		
<b>Delhi</b>	Dr Meena Gupta	Dr MM Mehndiratta
<b>Gujarat</b>		
<b>Ahmedabad</b>	Dr Sudhir V Shah	Mr Upendra Divyeshvar
<b>Anand</b>	Dr NS Panchal	Dr Anil Patel
<b>Jharkhand</b>		
<b>Ranchi</b>	Dr S Haque Nizamie	Dr Sayeed Akhtar
<b>Karnataka</b>		
<b>Bangalore</b>	Dr GT Subhas	Mr KV Muralidharan
<b>Belgaum</b>	Dr AO Saroja	Mrs Meenaxi
<b>Mangalore</b>	Mr Vinay Hegde	Dr Lekha Pandit
<b>Shimoga</b>	Dr A Shivaramakrishna	Dr AV Nagaraja
<b>Kerala</b>		
<b>Kochi</b>	Mrs Suchitra Narayan	Dr KP Vinayan
<b>Thiruvananthapuram</b>	Dr M Sambasivan	Dr D Jayachandran
<b>Madhya Pradesh</b>		
<b>Indore</b>	Dr VG Dakwale	Dr VV Nadkarni

<b>Maharashtra</b>		
<b>Bombay</b>	Dr BS Singhal	Dr PU Shah
<b>Nagpur</b>	Dr Poornima Karandikar	Dr Pawan Adatia
<b>Pune</b>	Dr Nandan Yardi	Mrs Yashoda Wakankar
<b>Punjab</b>		
<b>Ludhiana</b>	Dr Gagandeep Singh	Dr Parampreet Singh
<b>Rajasthan</b>		
<b>Jaipur</b>	Dr Brij Mohan Sharma	Mr Deen Dayal Sharma
<b>Jodhpur</b>	Dr Pratap Sanchetee	Dr Rajeev Mathur
<b>Tamil Nadu</b>		
<b>Chennai</b>	Dr CU Velmurugendran	Dr V Natarajan
<b>Trichy</b>	Ms Tara Sundararajan	Dr R Sundararajan
<b>Uttar Pradesh</b>		
<b>Lucknow</b>	Dr Devika Nag	Dr Atul Agarwal
<b>West Bengal</b>		
<b>Kolkata</b>	Dr Tapan Goswami	Dr Alak Pandit

## FORMATION OF CHAPTERS

Bangalore	1971
Madras	1971
Bombay	1972
Delhi	1974
Jaipur	1978
Indore	1981
Lucknow	1986
Calcutta	1987
Nagpur	1990
Pune	1991
Ranchi	1992
Trivandrum	1993
Anand	1993
Cochin	1993
Visakhapatnam	1996
Trichy	1997
Tirupati	1997
Belgaum	2000
Mangalore	2001
Kakinada	2003
Shimoga	2003
Jodhpur	2004
Hyderabad	2005
Guwahati	2006
Nellore	2008
Ahmedabad	2008
Ludhiana	2008
Patna	2008

# INDIAN EPILEPSY ASSOCIATION

## 28 CHAPTERS



## MEMBERSHIP OF CHAPTERS

Chapters	Life	Annual	Total
<b>Andhra Pradesh</b>			
Hyderabad	36		36
Kakinada	20		20
Nellore	50		50
Tirupati	51	69	120
Visakhapatnam	22	20	42
<b>Assam</b>			
Guwahati	29		29
<b>Bihar</b>			
Patna	76		76
<b>Delhi</b>			
Delhi	100		100
<b>Gujarat</b>			
Ahmedabad	25	1	26
Anand	35		35
<b>Jharkhand</b>			
Ranchi	83		83
<b>Karnataka</b>			
Bangalore	271	7	278
Belgaum	27		27
Mangalore	30	15	45
Shimoga	14	60	74
<b>Kerala</b>			
Kochi	72		72
Thiruvananthapuram	80		80
<b>Madhya Pradesh</b>			
Indore	73	107	180



Maharashtra			
Bombay	266	4	270
Nagpur	162		162
Pune	53		53
Punjab			
Ludhiana	22		22
Rajasthan			
Jaipur	97		97
Jodhpur	25		25
Tamil Nadu			
Chennai	101		101
Trichy	20		20
Uttar Pradesh			
Lucknow	211	2	213
West Bengal			
Kolkata	122		122
Total			2458

## Annual Conferences

Conference	Date	Venue
<b>Nineteenth</b>	25 – 26 February 2012	Kochi
<b>Eighteenth</b>	25 – 27 February 2011	Ludhiana
<b>Seventeenth</b>	06 – 07 February 2010	Indore
<b>Sixteenth</b>	07 – 08 February 2009	Tirupati
<b>Fifteenth</b>	21 – 22 October 2008	New Delhi
<b>Fourteenth</b>	03 – 04 October 2007	Mumbai
<b>Thirteenth</b>	5 – 6 October 2006	Bangalore
<b>Twelfth</b>	22 – 23 September 2005	Jaipur
<b>Eleventh</b>	28 – 29 October 2004	Nagpur
<b>Tenth</b>	27 – 28 September 2003	Visakhapatnam
<b>Ninth</b>	30 – 31 October 2002	Lucknow
<b>Eighth</b>	14 – 15 December 2001	Mumbai
<b>Seventh</b>	15 –16 December 1999	Hyderabad
<b>Sixth</b>	16 –17 December 1998	Thiruvananthapuram
<b>Fifth</b>	10 December 1997	Jaipur
<b>Fourth</b>	10 December 1996	Calcutta (Kolkata)
<b>Third</b>	15 December 1995	New Delhi
<b>Second</b>	17 December 1994	Bangalore
<b>First</b>	20 December 1993	Madras (Chennai)

- From 1999 onwards, IEA & IES held joint conferences
- In 2000 Annual Conference was not held, as 3rd Asian & Oceanian Epilepsy Congress was held in New Delhi
- From 2009 onwards The Annual Conference is held in February as stand alone conference (earlier it was held along with NSI/IAN conferences).

## Recipients of Prof. BM Sharma (BMS) Oration and HC Bajoria (HCB) Award

Date	Venue	BMS Oration*	HCB Award
10 December 1997	Jaipur	Dr B Ramamurthi	---
16 – 17 December 1998	Thiruvananthapuram	Dr KV Mathai	---
15 – 16 December 1999	Hyderabad	Dr N Senanayake	---
14 – 15 December 2001	Mumbai	Dr R Sachdeo	---
30 – 31 October 2002	Lucknow	Dr ON Markand	Dr HV Srinivas
27 – 28 September 2003	Visakhapatnam	Dr G Arjundas	Dr VV Nadkarni
28 – 29 October 2004	Nagpur	Not scheduled	Dr B Vengamma
22 – 23 September 2005	Jaipur	Dr BS Singhal	Dr PU Shah
5 – 6 October 2006	Bangalore	Not scheduled	Dr GM Taori
3 – 4 October 2007	Mumbai	Dr Nilima A Kshirsagar	Dr Atul Agarwal
21 – 22 October 2008	New Delhi	Not scheduled	Dr ES Krishnamoorthy
7 – 8 February 2009	Tirupati	Dr Ambar Chakravarty	Dr Meena Gupta
6 – 7 February 2010	Indore	Not scheduled	Dr Shobini Rao
26 – 27 February 2011	Ludhiana	Dr Sam Berkovic	Dr Urvashi Shah
25 – 26 February 2012	Kochi	Not scheduled	Dr Pritika Chary

\*BMS Oration is given every alternate year from 2003 onwards

## IBE / ILAE Awards

The following received the awards under various categories:

### **Life Time Achievement Award**

Dr KS Mani	2001
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### **Social Accomplishment Award**

Dr KS Mani	1997
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Dr Pravina U Shah	2011
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### **Ambassador for Epilepsy Award**

Dr KS Mani	1975
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Dr MC Maheshwari	1989
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Dr VS Saxena	1991
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Dr EP Bharucha	1995
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Dr Satish Jain	2001
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Dr MM Mehndiratta	2007
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Ms Carol D'Souza	2009
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Dr Pravina U Shah	2011
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### **Asian & Oceanian Outstanding Achievement Epilepsy Award**

Dr P Satishchandra	2010
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Dr K Radhakrishnan	2012
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### **Outstanding Person with Epilepsy Award**

Mr Ignatius Misquitta	2004
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Mr K C Janardhan	2006
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Ms Carol D'Souza	2008
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Ms Kavitha Shanbhag	2010
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Ms Yashoda Wakankar	2012
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## Diploma in Epilepsy Care (DEC) - List of Candidates

### 2006- 2007

No	Name	Place	Profession
1	Ms Ragasree	Bangalore	Medical student
2	Ms Dipti Kashyap	Bangalore	Psychology student
3	Ms Neelam Ranade	Indore	Works with a neurologist
4	Mr Vibhav Nadkarni	Indore	Engineer
5	Mr Muralidharan KV	Bangalore	Counsellor

### 2008-2009

No	Name	Place	Profession
1	Mr HK Damodar Rao	Bangalore	Pharma representative
2	Ms Sucheta Kulur	Bangalore	Counsellor
3	Dr Poornima	Tirupati	Medical doctor
4	Ms Yashodha Wakankar	Pune	Counsellor
5	Mr Dharma Raman	Chennai	Lawyer

### 2009-2010

No	Name	Place	Profession
1	Dr Lopa Dalal	Anand	Medical doctor
2	Mr M Pradeep	Mysore	Engineer
3	Mr Upendrakumar Diyeshvar	Ahmedabad	Bank employee
4	Ms Manjula Sharma Mahesh	Ramanagaram	Housewife
5	Dr Surendra Kumar Pal	Chandigarh	Medical doctor
6	Mr Vijay Kumar Dogra	Una	Teacher
7	Ms Kamala Hegde	Bangalore	EEG technician

No	Name	Place	Profession
8	Ms Sharadamma	Bangalore	EEG technician
9	Ms Sneha Shetty	Bangalore	Nursing student
10	Ms Amritha	Bangalore	Nursing student
11	Mr Mohamed Kashif	Bangalore	Nursing student
12	Mr Nagaraju BC	Bangalore	EEG technician
13	Dr Ravindra Babu	Bangalore	Medical doctor
14	Mr Shyam Kumar	Bangalore	Pharma representative
15	Ms Vidyavathi K	Bangalore	Housewife
16	Ms Mahajabeen	Bangalore	Pharmacist-CGHS
17	Mr Sathya Prakash TN	Bangalore	HRD/Counsellor

### 2010-2011

No	Name	Place	Profession
1	Ms T Pankajakshi	Bangalore	Nurse CGHS
2	Mr Manjunath Upase	Bangalore	Pharmacist
3	Mr Mohan Kumar R	Bangalore	Psychologist
4	Mr Umesh R	Bangalore	Pharmacist
5	Ms Uma SL	Bangalore	Psychologist
6	Ms Pallavi H Karvi	Bangalore	Psychologist
7	Mr Jayakumar R	Bangalore	Pharmacist
8	Mr Keshav G	Bangalore	Pharmacist
9	Mr Theju Kumar S	Bangalore	Physiotherapist

### 2011-2012

No	Name	Place	Profession
1	Dr Jamuna Sunil Kumar	Bangalore	Medical Doctor
2	Dr Kiran S Murthy	Bangalore	Medical doctor
3	Dr Niyas	Bangalore	Medical doctor
4	Mr Ramesha S	Bangalore	Physiotherapist
5	Mr Sai Vishal P	Bangalore	Physiotherapist
6	Mr Gowthama G	Bangalore	Pharmacist

No	Name	Place	Profession
7	Mr Parameswaran R	Bangalore	Pharma representative
8	Ms Anitha Motwani	Indore	EEG techincian
9	Mr Jayabharath Reddy	Bangalore	Physiotherapist
10	Mr Ranjit Kuar	Ludhiana	Nurse
11	Mr Harendra Kumar Tyagi	Bhagalpur	Physiotherapist
12	Mr Sukhaveer Singh	Delhi	Physiotherapist

### 2012-2013

No	Name	Place	Profession
1	Ms P Sipi	Kochi	Clinical neuro-physiologist
2	Ms Rathna Anand	Bangalore	Nurse
3	Ms Aboli A Bhatwadekar	Nagpur	Volunteer IEA
4	Ms Sobha Yuvaraj Sarode	Nagpur	Chemist
5	Ms S Ranjana	Bangalore	PhD in pharmacology
6	Ms S Dwajani	Bangalore	PhD in pharmacology

## ANNOUNCEMENT

ADMISSIONS OPEN FOR 2013  
BANGALORE UNIVERSITY OFFERS  
**DIPLOMA IN EPILEPSY CARE**

On Distance Mode

(in collaboration with CBR Network, South Asia and  
Indian Epilepsy Association)

Duration of the Course - One Year  
Medium - English, Kannada, Hindi.  
Eligibility - A pass in 10 + 2 or  
equivalent examination.

### WHO WILL BENEFIT

Families with a person with epilepsy (PWE), teachers, nurses, community health care workers, CBR workers, teachers in special schools and primary health care professionals including medical doctors, EEG technicians and those working in voluntary services like IEA and Spastic Society and anyone interested in the field of epilepsy.

Eligibility, application forms and other details can be obtained at CBR Network (South Asia), 134, 1st Block, 6th Main, 3rd Phase, Banashankari 3rd Stage, Bangalore 560 0085.

Ph: 080 26724273 / 267242221 or by sending an e-mail to [cbrnet@airtelmail.in](mailto:cbrnet@airtelmail.in); [ieablr@vsnl.net](mailto:ieablr@vsnl.net); [muralidharankv@gmail.com](mailto:muralidharankv@gmail.com)



MEMORANDUM OF ASSOCIATION  
of  
INDIAN EPILEPSY ASSOCIATION

Society Registration No. 47 / 70 GBBSD

Public Trust Act Reg. No. F-2055 BOM

November 2000

1. **Memo:** The name of the Society shall be the “Indian Epilepsy Association”.
2. **Office:** The Registered Office of the Society shall be situated in Bombay.
3. The aims and objectives of the Society shall be as under:
  - (a) To promote the better treatment and care, welfare and rehabilitation of persons suffering from Epilepsies.
  - (b) The collection, compilation, advertisement and dissemination of knowledge concerning Epilepsies in every field.
  - (c) To disseminate knowledge and understanding of the disease amongst the lay public and the patients and their relations and to make known to the public the various difficulties facing the disabled and handicapped, so as to facilitate their adjustment into Society.
  - (d) To promote, guide, co-ordinate, organize, finance and conduct research and experimental work in all aspects of Epilepsy calculated to be of benefit to the disabled and the handicapped.
  - (e) To provide training facilities to medical, scientific and other technical staff working in the Society.
  - (f) To publish books, monographs, periodicals and papers

concerning the Epilepsies in every field and regarding the Society's work.

- (g) To maintain close association and co-operation among individuals and institutions devoted to alleviation of those suffering from Epilepsy.
- (h) For more effectively carrying out the above objects, to seek affiliation with international institutions or societies formed for promoting the above objects.
- (i) In accordance with law, to buy, purchase, take on lease or in exchange, hire or otherwise acquire any movable or immovable property of any tenure or description and any estate or interest therein and any rights or privileges which the Society may think necessary or convenient for the promotion of its objects, and to construct, maintain and alter any building or erections necessary or convenient for the work of the Society.
- (j) In accordance with law, to sell, let, lease, mortgage, gift, dispose or, manage, develop, build or alter or improve or turn to account all or any of the property or assets of the Society as may be thought expedient with a view to the promotion of its objects.
- (k) To receive and accept donations, gifts, grants or contributions in cash or kind from any person or persons, association, society, company, authority or Government for the furtherance of the aims and objects of the Society and upon such terms and conditions as the Society in its absolute discretion may think fit.
- (l) To engage, employ and remunerate persons for carrying on the work of the Society on such terms and conditions as may be determined from time to time.
- (m) To receive, undertake and execute any trusts and to take over

institutions which may lawfully be undertaken and taken over by the Society and may be conducive to its objects.

- (n) To borrow or raise money for the purpose of carrying out the aims and objects of the Society on such terms and by giving such security as may be determined from time to time.
- (o) To invest money of the Society which cannot be applied immediately or at an early date for carrying out its aims and objects in Public Securities that is to say:
  - (i) In the first mortgage of an immovable properly situated in any part of India if the property is not leasehold for a term of years and the value of the property exceeds by one-half the mortgage money.
  - (ii) In securities of the Central Government or any State Government .
  - (iii) In stocks, debenture or shares in companies, the interest or dividend on which has been guaranteed by the Central or any State Government.
  - (iv) In debentures or other securities for moneys issues by or on behalf of any local authority in exercise of the powers conferred by an Act of the Central or State Legislature.
  - (v) In securities expressly authorized by an order which the State Government may make in this behalf.
  - (vi) In debentures or other as the Charity Commissioner may be a general or special order permit the money of the Society to be so invested.
  - (vii) In such other securities as may be authorized under the provisions of the Bombay Public Trusts Act, 1950, from time to time.
  - (viii) In such other securities as may be authorized by law from time to time.

- (p) To draw, make, accept, discount, endorse, negotiate, buy, sell, execute and issue bills of exchange, Government of India and other Promissory Notes, Cheques, Warrants, Debentures and other negotiable or transferable instrument or securities.
- (q) To establish and support or aid in the establishment and support of any charitable associations or institutions and to subscribe or guarantee money for charitable purposes in any way connected with the purposes of the Society or calculated to further its objects.
- (r) To do all acts, matters and things as are incidental or conducive to the attainment of the above aims or objects or any one or more of them.

4. The first members of the Governing Council shall be as under –

	<b>Name</b>	<b>Address</b>	<b>Occupation</b>
1.	Dr Baldev Singh	Dept of Neurology All India Institute of Medical Sciences Ansari Nagar, New Delhi 16	Neurologist
2.	Dr B. Ramamurthi	2nd Main Road, CIT Colony Madras – 4	Neurosurgeon
3.	Dr T.K.Ghosh	Govt Housing Estate Flat No 5, Block No 1, 28/1 Gariahat Road, Calcutta	Neurologist
4.	Dr E.P. Bharucha	251 Dadabhai Naoroji Road Bombay 1	Neurologist
5.	Dr A.D. Desai	534, Sandhurst Bridge Bombay 7	Neurologist
6.	Dr N.H. Wadia	Ben Nevis, Bhulabhai Desai Road Bombay 26	Neurologist
7.	Dr K.V. Mathai	Christian Medical College & Hospital Vellore 4	Neurosurgeon
8.	Dr K.S. Mani	All India Institute of Mental Health Post Bag No 15, Bangalore 27	Neurologist
9.	Mrs. Roshan H Dastur	Asst. Dean's Bungalow KEM Hospital Compound, Parel Bombay 12	Social worker

6. We, the several persons whose names and addresses are subscribed, are desirous of forming a Society in pursuance of this Memorandum of Association.

	<b>Name</b>	<b>Address</b>	<b>Occupation</b>
1.	Dr Baldev Singh	Dept of Neurology All India Institute of Medical Sciences Ansari Nagar, New Delhi 16	Neurologist
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7.	Dr K.V. Mathai	Christian Medical College & Hospital Vellore 4	Neurosurgeon
8.	Dr K.S. Mani	All India Institute of Mental Health Post Bag No 15, Bangalore 560 027	Neurologist
9.	Mrs. Roshan H Dastur	Asst. Dean's Bungalow KEM Hospital Compound, Parel Bombay 12	Social worker

## **RULES AND REGULATIONS**

### **1. INTERPPRETATION**

1. Interpretation : The marginal notes hereto shall not affect the construction hereof and in these presents unless there is something in the subject or context inconsistent therein:

“The Society” means Indian Epilepsy Association or IEA.

“ The Act” means the Societies Registration Act XXI of 1860.

“The Governing Council” means the Governing Council for the time being.

“The Chairman” means the Chairman or President for the time being.

“The Secretary” means the Secretary General or Chapter / Branch Secretary as relevant and

“Treasurer” means the Treasurer of IEA or Chapter . Branch Treasurer as relevant.

“Office” means the registered office of Society.

“Central Office” means the office of the Secretary General.

Words importing the singular number also include the plural number and vice versa.

Words importing the masculine gender also include the feminine gender and vice versa.

## **II. MEMBERSHIP**

@@\*\*2. The Society shall consist of not less than seven members.

(a) Membership of the Society is open to:

(i) any person aged 18 years and above

(ii) he must be willing to work for the aims and objectives of the society.

@@(iii) There are two types of members viz. Ordinary Members and Life Members. These include patients, relatives, professionals dealing with epilepsy and any other person interested in epilepsy.

@@(v) The local chapter / branch shall have the power to admit or reject the applications for membership. However, the Governing Council retains the ultimate right to accept or reject any membership. The decision of the Governing Council shall be final.

He must be proposed by a valid member and seconded by another valid member. There shall be no entrance fee. Annual subscription will be Rs. 100/- for Ordinary Members and a one time payment of Rs. 1,000/- for the Life Members.

Membership of the Association shall commence from the date of the approval of his candidature and shall cease on his death, resignation or on his failure to pay the dues towards the Association or indulges in misconduct or does anything contrary to the rules or objectives of the Association.

Misconduct means transgression of any definite rule of action, any act forbidden by the Rules of the Association, dereliction from duty, unlawful or improper behaviour, misdemeanor, impropriety, offence involving moral turpitude which would undermine the objectives of the Association.

A member in arrears of subscription for 3 months is not a valid member (or a member of good standing) and ceases to be a member of the Indian Epilepsy Association without any intimation. This shall be decided at the chapter / branch level. If he wishes to rejoin he must clear all arrears of subscription. The Governing Council of the central office, however, retain the ultimate right to terminate any membership.

Notice for the annual general body meeting addressed to a member shall be considered as proof of membership.

Honorary Members: These shall be limited to those over 70 who have been Ordinary Members of the Association and who have worked actively in the field of Epilepsy for 10 or more

years, upon acceptance of their applications by a three-fourths majority of the Governing Council present at the time of voting. No voting rights.

Honorary Corresponding Members shall be those who have done distinguished work in the field of Epilepsy from countries other than India. No voting rights.

## **IIA. PATRONS**

- @@3. The Association shall also have as Patron any person who shall pay to the Association a donation of Rs.15,000/- or more. They shall receive one copy of all communications, Newsletters, etc. They shall have no voting rights. Power to make by-laws relating to members: The Governing Council shall have power to make, rescind or vary bye-laws relating to the patronage of the Association.

## **III. MEETINGS**

4. When Ordinary Meetings to be convened: An Annual General Meeting of the Society shall be convened and held at least once in each year at such place and on such date and at such time as shall be determined by the Governing Council.
5. Business of Ordinary Meeting: The purpose of an Annual General Meeting shall be:
  - (a) To receive, consider and pass the Accounts of the Society and the Report of the Governing Council which shall be submitted to the meeting.
  - (b) To review the work and to discuss the policy of the Society.
  - (c) To transact any other business or matter which any member of the Society may wish to place before the



meeting. No member of the Society shall however be entitled to move any resolution in respect of such business or matter unless a copy of the proposed resolution signed by him shall have been sent to the Central office of the Society, seven days before the date of the meeting.

6. Extraordinary Meetings: Extraordinary General Meetings of the Society may be convened at any time by the Governing Council for the transaction of any business.
7. Notice of Meetings: At least twenty-one days' notice, specifying the place and day and hour of meeting, and in the case of an Extraordinary General Meeting the nature of the business to be transacted shall be sent by post to each member who has registered with the Society an address in India, provided that the inadvertent omission to send a notice or the non-receipt of the receipt of such notice by any member shall not invalidate any resolution passed or proceedings taken at such meeting. Any meeting may be held on shorter notice than above specified if more than one-half of the members of the Society agree in writing.
8. 'Service of Notice: Service of the notice shall be deemed to have been effected on the day following that on which it is posted.

#### **IV. PROCEEDINGS AT MEETINGS**

9. Chairman of General Meeting: The Chairman shall preside at every meeting of the Society or if the Chairman shall not be present, a Chairman of the Meeting shall be elected at the Meeting.
10. Power to adjourn general meeting: The Chairman of the Meeting may, with the consent of a majority in number of

members present, adjourn any meeting from time to time and from place to place, but no business shall be transacted at any adjourned meeting, other than the business left unfinished at the meeting from which the adjournment took place.

@@ 11. Quorum: At any meeting a quorum shall be five persons present.

@@ 12. When a Quorum not present meeting to be adjourned: If within half an hour from the time appointed for the holding of any meeting, a quorum is not present, the meeting shall stand adjourned to the same day of the following week at the same time and place and if at such adjourned meeting a quorum is not present within half an hour from the time appointed for holding the meeting, the members present shall constitute a quorum.

@@13. Casting Vote: Every question submitted to a meeting shall be decided in the first instance by a show of hands and in the case of equality of votes, the Chairman of the Meeting shall have a casting vote in addition to the vote to which he may be entitled as a member.

@@ 14. How a question to be decided at Meeting: At any Meeting every question shall be decided by a show of hands and a declaration by the Chairman of the Meeting that a resolution has on a show of hands been carried or carried unanimously or by a particular majority or lost and an entry made to that effect in the Minute Book shall be sufficient evidence of the fact, without proof of the number of proportion of the votes recorded in favour of or against such resolution.

## V. VOTES OF MEMBERS

### @@ 15. Voting rights

At every meeting of the Association in the event of voting on any topic / subject / issue etc, each chapter / branch shall authorize one person to vote on its behalf. In the event a valid chapter / branch is not represented in the General body Meeting it can authorize any other person, who is a valid member of the Indian Epilepsy Association to vote on its behalf

### @@\*\*16. Minimum membership for voting purposes for each chapter/branch shall be twenty.

There shall be one vote for every fifty members or part thereof as follows:

20 – 50 members	1 vote
51 – 100 members	2 votes
101 – 150 members	3 votes
151 & above members	4 votes

## VI. MANAGEMENT

17. Governing Council: The supervision of the work of the Society and management of its affairs shall be entrusted to the Governing Council.

18. Governing Council to be Governing Body: The Governing Council shall be the Governing Body of the Society within the meaning of the Societies Registration Act 1860, and save as herein provided shall have in addition to the powers hereby conferred all the power conferred by the said Act.

### @@19. Application of Income and Property: The income and property of the Society whence so ever derived, shall be

applied solely towards the promotion of the aims and objects of the Society as set forth in its Memorandum of Association, and no portion thereof shall be paid or transferred directly or indirectly, by way of dividend, bonus or otherwise howsoever by way of profit to the members of the Society provided however that nothing herein shall prevent the payment of reasonable and proper remuneration and expenses to any officer or servant of the Society or to any member of the Society or Governing Council in return for or incurred in connection with any services actually rendered to the Society, nor prevent the payment of interest at a rate not exceeding 6 per cent annum on money lent or reasonable and proper rent for premises demised or let by any member of the Society or Governing Council.

## **VII. GOVERNING COUNCIL**

20. The Governing Council shall consist of not less than five and not more than thirty one members.
- @@\*\*21. All valid members of the Society- medical or lay – shall be eligible to be elected as office bearers of the Society. Every member satisfying the eligibility clause can stand for an election as an office bearer or Governing Council Member and shall be proposed by any valid member (of at least 3 years standing) and seconded by another valid member (of at least 3 years standing) of the Indian Epilepsy Association. The electorate of the office bearers shall be on an all India basis while that of other Governing Council members shall be the respective chapters.

The Governing Council shall consist of : -

	Term Years	Electorate	Eligibility –continuous valid Mem- bership for not less than ..... years
President	2	All India	10
Vice President	2	All India	8
Secretary General	4	All India	5
Treasurer	4	All India	5
Editor	4	Appointed	5
Members	2	State/UT	3
Immediate			
Past President	2		
Ex-officio – President, Indian Epilepsy Society			
Ex-officio – Sec. General, Indian Epilepsy Society			

@@\*\*22. The office bearers shall be President, Vice President, Secretary General and Treasurer.

Local chapter / branch whose representative has been elected to the Governing Council shall make every effort to sponsor him to attend the bi-annual Governing Council meeting. If a Governing Council member does not attend two consecutive meetings without any valid reason he shall cease to be a member of the Governing Council.

@@\*\*23. Elections shall be by postal ballot. Canvassing in any form for any election shall disqualify the candidate.

@@ 24. Power to co-opt : Additional persons may be co-opted as the Governing Council shall from time to time decide, provided that there shall never be more than thirty-one members of the Governing Council. Co-opted members shall be no more than five.

25. Casual vacancies: Any casual vacancies which may occur by reason of resignation or otherwise may be filled by the Governing Council and the person so appointed shall continue to be the member of the Governing Council until the next election of the Society.

26. Continuation in office in certain events: if for any reason an Annual General Meeting is not held on the date due for the holding thereof the Society and the persons elected at the previous meeting shall continue to serve until the next meeting is held.

#### **VIII. CHAIRMAN & VICE – CHAIRMAN**

- @@27. The Governing Council, at its meetings every year, shall, in the absence of the elected President, appoint the elected Vice President/Secretary General/Treasurer to be the Chairman of the meeting. But such Chairman shall not have the right to nominate any member to act as a Chairman in his absence or otherwise at subsequent meetings.

#### **IX. PROCEEDINGS OF GOVERNING COUNCIL**

- @@ 28. Meeting of Governing Council and Quorum: The Governing Council may meet together for the dispatch of business, adjourn and otherwise regulate their meetings and proceedings as they think fit and may determine the quorum necessary for the transactions of their business. Until otherwise determined, three members shall be a quorum. No meeting shall become incompetent to transact business from want of a quorum after the Chair has been taken. The Governing Council shall meet at least twice every year. Most business will be carried out by correspondence only.
- \*\*29. Who may summon meeting: The Secretary General shall summon a meeting of the Governing Council at least twice an year.

30. Chairman of the Meeting: The Chairman shall preside at all meetings of the Governing Council. If the Chairman shall not be present at any meeting the Vice-Chairman shall preside and if neither is present the members shall elect a Chairman of the meeting.
31. How questions to be decided: Questions arising at any meeting shall be decided by a majority of votes and in case of an equality of vote the Chairman of the meeting shall have a second or casting vote.
32. Powers of Quorum: A meeting of the Governing Council for the time being at which a quorum be present shall be competent to exercise all or any of the authorities, powers and discretions for the time being vested in or exercisable by the Governing Council generally.
33. Resolution: The Governing Council may also transact its business by circular resolution.
34. When resolution without meeting valid: A resolution in writing which has been circulated to all the members of the Governing Council for the time being in India and assented to by a majority of such members shall be as valid and effectual as if it had been passed at a meeting of the Governing Council duly called and constituted.
35. Minutes to be made: The proceedings of all meetings shall be recorded in a Minute Book and the minutes signed by the Chairman of the next meeting shall be accepted as a true record of the business transacted at the meeting.
36. The Chairman may invite any person to attend any meeting of the Governing Council but the invitee shall not have the right to participate in the proceedings of the meeting or to vote thereat.

## X. OFFICERS

### 37. Officers and office of the Society:

- (1) The Governing Council may from time to time appoint stipendiary secretary, stenographer and servants of the Society and shall have the power to determine the duties and authorities and fix their remuneration with full power to terminate their services as and when necessary or required.
- (2) The Governing Council may delegate to the Secretary General, Treasurer and other office bearers such powers as may be necessary or required to enable each official to carry out his duties respectively.
- (3) The Central office of the Society shall be situated where the Secretary General is located.

@@\* All legal disputes / matters shall be decided by the Courts within the jurisdiction where the Secretary General is located.

@@\*\*(4) **Managing Committee:** This will consist of the President, Vice President, Secretary General and the Treasurer to take decisions in the name of the Governing Council between meetings of the latter. It may make changes in the budget of the Indian Epilepsy Association not exceeding the total amount of the budget.

@@\*\*(5) **Powers / Responsibilities of office bearers:** The office bearers shall be President, Vice President, Secretary General and Treasurer.

- (i) **President:** He shall preside over the meeting of the Managing Committee, Governing Council and of the general



body. He shall have a general control of all matters connected with the management of the Association.

**@@(ii) Vice President:** In the absence of the President, he shall act as President to conduct the meetings of the Managing Committee, Governing Council and the General Body.

**(iii) Secretary General:** He shall be the Chief Executive Officer of the Association. He shall carry out the day-to-day administration and also carry out the decisions of the Managing Committee, Governing Council and general body. He shall prepare the agenda for all the meetings of the Committees in consultation with the President. He shall also be responsible for maintenance of the minutes book. He shall have the custody of all registers and papers related to the Association except accounts books. In an emergency matter, the Secretary General shall take suitable action in consultation with the President and shall report the same at the next meeting of the Managing Committee and also the Governing Council. He may keep with him a sum as decided by the Governing Council from time to time as imprest amount to meet any contingent expenditure.

**(iv) Treasurer:** He shall maintain an account

of money received and spent. He shall also deal with all financial matters with members of central office, chapters / branches in the country and also IBE and other similar organizations to which Indian Epilepsy Association is affiliated. All accounts books of the Association shall be in the custody of the Treasurer who shall provide the same to the auditors as and when required. He shall present a statement of income and expenditure at every meeting of the Governing Council and shall also be responsible for presenting the audited statement of accounts at every annual general body meeting. He may keep with him a sum as decided by the Governing Council from time to time as imprest amount to meet any contingent expenditure. The Treasurer shall prepare the budget for the next financial year and present it to the Governing Council.

## **XI. COMMITTEES**

38. The Governing Council may appoint a committee or committees (under the name of special committees or sub-committees or under such other name or names as may be determined at the time of appointment) for special purposes, consisting of such one or more persons (whether members of the Society or not) as they may think fit and may delegate to such committees, such powers and authorities as may be thought fit. Any committee so

appointed shall, in exercise of the powers so delegated, conform to any regulations that may from time to time be imposed upon such committee shall be governed by the provisions herein contained for regulating the meetings and proceedings of the Governing Council so far as the same are applicable thereto, and are not superseded by any regulations made by the Governing Council. Each committee shall fix its own quorum. Additional members may be co-opted as the sub-committee may from time to time decide.

## **XII. CONSTITUTED ATTORNEY**

39. Power to appoint attorney: The Governing Council may appoint any person or Corporation to be the constituted attorney of the Society for any purposes or purpose.

## **XIII. SUITS AND PROCEEDINGS**

40. Power to sue: The Society shall sue and be sued and all applications or legal proceedings on behalf of or against the Society shall be brought, made and taken in the name of such persons as shall be appointed by the Governing Council for the purpose.

## **XIV. SEAL**

41. The seal of the Society shall not be used except in pursuance of a resolution of the Governing Council.  
A document to which the seal of the Society is affixed shall be signed on behalf of the Society by at least two

members of the Governing Council and countersigned by the Secretary General.

## **XV. PROPERTY OF THE SOCIETY**

### **42. Vesting of Moveable Property:**

- (i) All property of the Society shall vest in the Governing Council, who shall have the power to sell, mortgage, exchange, gift or otherwise deal with the same in accordance with law and also to purchase, take on lease, accept gift, grants and donations and otherwise acquire any moveable or immovable property, according to law.
- (ii) The Governing Council shall have the power to accept gift, grants, donations, provided in the opinion of the Governing Council the conditions attached are not onerous and not inconsistent with the aims and objects of the Society or otherwise objectionable.

## **XVI. FUNDS**

- 43. Funds of the Society: All Bank accounts and deposits shall be opened, kept and made in the name of the Society.
- 44. Management of Funds: The Governing Council shall have the management of the funds of the Society and shall have power to invest in the name of the Society or in the name of its nominees, lend or otherwise deal with the same and to investments from time to time according to law, and to incur such expenditure as it may think necessary and proper.
- 45. Power to borrow: The Governing Council shall have the power to borrow money for the Society upon such terms

as to security and rate of interest or otherwise as the Governing Council shall decide, but in accordance with the law applicable to the Society.

46. All cheques, bills of exchange, promissory notes (expressly including promissory notes of the Government of India) and other similar documents shall be drawn accepted or made on behalf of the Society and all cheques be endorsed by the Treasurer and such other person as shall be nominated from time to time by resolution of the Governing Council.
47. Accounts: The Governing Council shall cause true and proper accounts to be kept of all sums of money received and expended and all matters in respect of which such receipts and expenditures take place and of the assets, credits and liabilities of the Society. The financial year of the Society shall be from 1 April to 31 March of every year. The Governing Council shall cause the Treasurer to present reports of the finance of the Society at each regular meeting of the Governing Council.
48. Audit: The accounts of the Society shall be audited once in each year by an Auditor or firm of auditors who shall be Chartered Accounts within the meaning of the Chartered Accountants Act XXXVIII of 1949 appointed by the Governing Council every year with power and authority to fix and pay remuneration if required.

## **XVII. ANNUAL LIST**

49. List of Governing Council to be filled yearly: The Governing Council shall cause to be filled once in every year on or before the 14th day succeeding the day on which the Annual General Meeting of the Society is held a list with

the registrar appointed under the Societies Registration Act, 1860, of the names / addresses and occupations of the members of the Governing Council.

#### **XVIII. BYE-LAWS**

50. Power to make bye-laws: The Governing Council shall have power to make bye-laws for the conduct and government of all committees, and for the conduct and government of the Society, officers and agents of the Society or for any other purposes whatsoever provided that such bye-laws shall not conflict with these rules and regulations. The Governing Council may delegate to such committee or committees appointed by it the power to make, rescind and vary the bye-laws relating to and for the purpose of the work carried out by such committee or committees. The Governing Council will however be entitled to revoke the said power.

#### **XIX. AMENDMENTS**

51. Amendments: These Rules and Regulations may be amended by any meeting of the Society convened in the behalf by an ordinary resolution provided that notice of the proposed amendment shall have been given in writing by a member and circulated to all members of the Society, 21 days in advance of the meeting to be convened for such purpose. Such amendments may be accepted by the Meeting with or without modification.

#### **XX. PUBLICATIONS**

- @@52. The publications shall be the official organ of the Society and shall be published 2-4 times a year. The Editorial

Board shall consist of Editor (appointed by Governing Council) and an Advisory Board, all from amongst the members of the Society and selected by the Governing Council.

## **XXI. CHAPTERS**

@@\*\*53.(i) Each State shall have one chapter and branches as required. The chapter shall be in the State/Union Territory capital. The branches can be in other places in the State/Union Territory. The minimum number required to form a chapter / branch shall be twenty.

\*\* (ii) Each chapter/branch shall follow the rules of the Indian Epilepsy Association. The chapters/branches are, however, permitted to register under the respective state laws but this shall not have the effect to alter, delete, repeal or modify the rules and regulations of the Indian Epilepsy Association. This is only to enable the chapters/branches to obtain financial and other assistance from the State Government and or its agencies and also to facilitate in filling their Income Tax returns in their respective State. This shall not create any independent right to separate from the Indian Epilepsy Association and use its name. They shall elect their own office bearers. The chapter/branch shall formulate its own electoral process for the sake of practical convenience. All valid members of the chapter/branch shall be eligible to be elected as office bearers in a chapter/branch. Rule 21 of the Rules and Regulations of the Association however, shall apply *mutatis mutandis* (with respective differences having been considered). Subscription renewals for the next

financial year shall be collected in advance by March 31 of each year, with 3 months (June 30) as grace period.

(iii) The Chapter / Branch Secretary shall send to the Central Office by 30 June –

- 50 per cent of all subscriptions as capitation fee
- Audited statement of accounts
- Report of annual activities
- List of names and address of all members who belong to the Chapter/Branch
- Indicating those who are office bearers.

\*\* (iv) All communications from the central office to the members of the chapters/branches shall be sent to the respective chapter/branch Secretary, who in turn shall arrange to send them to their individual members. However, notices for general body meeting and voting papers shall be sent direct by the central office.

\*\* (v) Defaulting chapters / branches: Any chapter / branch which has not observed any one of the obligations, duties and responsibilities as enshrined in Rule 53 shall lose its affiliation to the Indian Epilepsy Association. The Secretary General shall send them two reminders. If obligations are not met by the time of the next Governing Council meeting, the letter shall exercise the powers to disqualify the defaulting chapters/ branches. In such an event the central office shall notify all valid members. Ordinary and Life – of the defaulting chapter/ branch through the next central office newsletter or if possible individually. The Life members of that chapter / chapter shall be transferred to the central office who shall communicate with them directly. The voting in the general body by the members of the central office



shall be in accordance with the clause applicable to all valid chapter/branch (as specified in Sec VII, Rule 21).

## **XXII. DISPUTES**

- \*\*54.** Any dispute between the members(s) /chapter(s) / branch(es) on the one hand and the central office on the other is to be settled amicably. If such is not possible, the Governing council shall have the right to appoint a Commission (under Rule 38) with its own terms and references who will go into any act(s) of omission or commission of member(s) / chapter(s) /branch(es) which are against the rules and objectives of the Indian Epilepsy Association and submit his report to the Governing Council within 3 months. After notice to the party for its comments, if any, on the report within four weeks of receipt, the Governing Council has the right to accept or reject the report. The decision of the Governing Council shall be final and binding on the parties.

## **XXIII. DISSOLUTION OR AMALGAMATION**

- 55.** In the event of the dissolution of the Association the funds of IEA shall not be divided between the members of the Association. The same shall be transferred to a Trust / Association having similar objectives and recognized under the provisions of Section 80-G of the Income Tax Act of 1961.

We, the undersigned being members of the Governing Council of the Society do hereby certify that this Memorandum of Association and the amended Rules and Regulations are a correct copy of the Memorandum

of Association and the amended Rules and Regulations of the Society, which were passed at the Extraordinary General Body Meeting at Lucknow on March 1, 1997 (marked with\*) and the Extraordinary General Body Meeting at Trivandrum on December 16, 1998 (marked with \*\*)

	Name	Address	Occupation
1	Dr K S Mani President	No. 1, Old Veterinary Hospital Basavangudi, Bangalore 560 004	Neurologist
2	Dr(Ms) Devika Nag Vice President	'Srinivas' 24, Newberry Road, Lucknow 226001	Neurologist
3	Dr V S Saxena Sec.General	"Sannidhi", K -10/10, DLF Qutub Enclave II Gurgaon 122 002	Pharmacologist
4	Dr H V Srinivas Treasurer	613, 15th Cross, 1st Phase J.P.Nagar Bangalore 560 076	Neurologist
5	Dr A. Das Gupta	30-A Aswini Dutta Road Calcutta 700 029	Neurologist
6	Dr H P Naryan	"Narayaneeyam" Bariatu Road, Ranchi 834008	Neurosurgeon
7	Dr Meena Gupta	23/143 Lodi Colony New Delhi 110 003	Neurologist
8	Mr. R Mahadev	1302 'Gurukrupa' 7th Main II stage, West of Chord Rod Bangalore 560 086	Engineer
9	Dr B S Singhal	Bombay Hospital 12 New Marine Lines Bombay 400 020	Neurologist
10	Dr B Rajendran	Westside Hospital Pvt Ltd Moulana Azad Road, Kappalandimukku, Kochi 682 002	Neurologist
11	Dr V V Nadkarni	Mangesh Neuro Centre 1 Kanchan Baug, Opp Jal Auditorium , Indore 452 001	Neurologist
12	Dr C M Sharma	150 Hari Marg , Civil Lines Jaipur 302006	Neurologist
13	Dr C U Velmurugendran	61 OVM Street, Chepauk Chennai 600005	Neurologist

	Name	Address	Occupation
14	Dr Atul Agarwal	55-A Ravindra Pall, Fauzabad Road, Lucknow 226016	Neurologist
15	Dr Trishitanand Roy	Bangur Insitute of Neurology 52/1 A Sambhu Nath Pandit Street, Calcutta 700 025	Neurologist

Dated this Sixteenth day of December 1998.

The Memorandum of Association & Rules and Regulations of Indian Epilepsy Association have been printed after duly incorporating amendments passed by the General Body of the Association and approved by the Dy. Charity Commissioner, Bombay Region on 18th April 2000.

/\*/ - Passed at Extraordinary General Body Meeting of the Society held in Lucknow on March 1, 1997.

/\*\*/- Passed at Extraordinary General Body Meeting of the Society held in Trivandrum on December 16, 1998.

@@ - For amendments in the EGB Meeting at Hyderabad on 9th February 2013.

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