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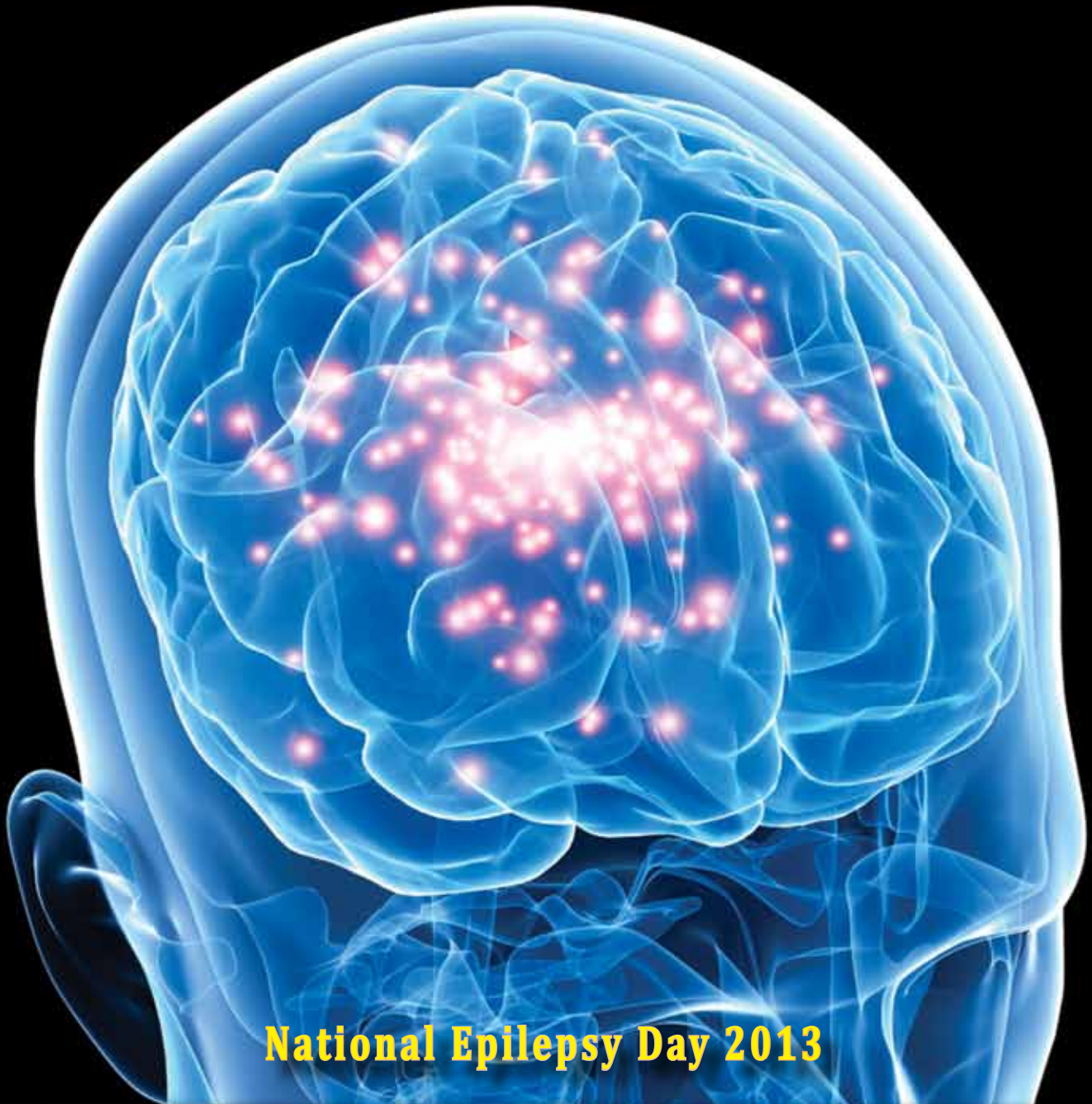
Issue 2, 2014



# Epilepsy India



Newsletter of the Indian Epilepsy Association & Indian Epilepsy Society



## National Epilepsy Day 2013



# Contents

Editorial.....	3
Message.....	4
Ketogenic Diet - the Indian scenario .....	5
From the heart .....	8
Letter to the Editor.....	8
National Epilepsy Day 2013 .....	9
Obituary .....	20
Announcement for availability of Financial Grants.....	20
Nomination Form for the post of President Elect-IES.....	22



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The most important event of the year, Econ 2014, got over at Kolkata in February.

Looking back, the conference met all criteria in exacting detail. The content, the orations and the hospitality were excellent, not to forget the quality of Pre conference workshop.

The next issue of EI will be dedicated to ECON 2014.

A most heartening feature of 2013 were the National Epilepsy Day (NED) activities of various Chapters. All in all, 13 Chapters have sent their reports, which are included in the current issue of EI. To observe a particular day means not only to create awareness, but also be a binding force for the Association. In the case of NED, this assumes greater significance, as epilepsy diagnosis carries a lot of unwanted and unwarranted baggage. Let us remember the medical and social issues faced by a PWE. If we keep at creating awareness about epilepsy, the PWE can get rid of this excess baggage and be integrated in the society. After all, everyone wants to be an integral part of the Society.

While National Epilepsy Day is being observed in India on 17th November from 1991 onwards, there has been a long mooted move by ILAE to have a World Epilepsy Day on the lines of World Diabetes Day and World Heart Day. This dream is now closer to reality. Dr. Satish Jain, President Elect IEA, writes about the need for a World Epilepsy Day and how we can continue the work we are doing to shed light on Epilepsy in his message in this issue.



The previous issue carried an article on understanding Ketogenic Diet. In this issue we carry the topic forward with the Indianising of Ketogenic Diet contributed by Dr. J. Nathan from Bombay, who is a pioneer in this field in India and whose work has been recognised by ILAE. The work behind making an unpalatable and difficult diet into one savoury for Indian palates must have been a Herculean task indeed. My dear friends, please give Dr. Nathan a big hand.

Before we sign off, a most heartening incident was a letter of appreciation for EI, from the respected Academician Prof. M. Gourie Devi. Thank you, Madam, for the encouraging words. ■

## THE MICHAEL PRIZE 2015

For the best contribution to scientific and clinical research which promote further development in epileptology

### Announcement for the 2015 Michael Prize

Awarded for the first time in 1963 to encourage epilepsy research in Germany, to date the MICHAEL PRIZE is one of the most highly regarded international awards for the best contribution to scientific and clinical research which promote further developments in epileptology. The MICHAEL PRIZE is awarded biennially and is specially designed to attract younger scientists not older than 45 years of age.

### The prize fund is 20,000 Euros

For the MICHAEL PRIZE 2015 may be considered : up to a maximum of three papers in English language - at least one of them, published or not yet published, must be from the period 2013/2014.

Papers, publications or manuscripts, together with a curriculum vitae, should be submitted to STIFTUNG MICHAEL before December 31, 2014.

**References are not required. Entry form and upload: [www.michaelpreis.de](http://www.michaelpreis.de)**

Since 2006 the MICHAEL PRIZE is sponsored by UCB International.

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Epilepsy is the name for a group of disorders of the brain characterized by a tendency to recurrent 'seizures' or 'fits'. The fits can lead to loss of awareness or consciousness, disturbances of movement, sensation (including vision, hearing and taste), autonomic function, mood and mental function. Anyone can be affected by seizures. Going by an approximate prevalence figure of 1% among the general population, the number of epilepsy patients in the whole of India is estimated to be about 12 million (in the current population of about 1.2 billion).

Epilepsy is a unique disorder that can profoundly influence people's ability to participate fully in society. Birth injuries, infections including worm infestations, vascular disease, tumors and subtle developmental abnormalities of the brain are the important causes of epilepsy. Many patients have epilepsy without any such detectable brain disease and in most such cases epilepsy is thought to be due to hereditary factors.

Epilepsy is almost always treated by using anti-epileptic drugs (AEDs). Various studies have shown that up to 70% of newly diagnosed cases of children and adults with epilepsy can be successfully treated with AEDs. For some patients with poorly controlled epilepsy, surgical treatment is helpful. As per WHO, 3 out of 4 people in the world with epilepsy do not receive treatment at all, mainly due to misconceptions, lack of awareness, economic and social reasons.

A national or international awareness day is usually set by major organizations or governments to commemorate a cause, medical research or a public health issue or condition of national or international importance. According to World Health Organization (WHO), global public health campaigns offer great potential to raise awareness and understanding about health issues and mobilize support for action, from the local community to the international stage (<http://www.who.int/campaigns/en/>).

For e.g., World Diabetes Day was created in 1991 by the International Diabetes Federation and the World Health Organization in response to growing concerns about the escalating health threat that diabetes now poses. The World Diabetes Day campaign engages millions of people worldwide in diabetes advocacy and awareness. The campaign draws attention to

issues of paramount importance to the diabetes world and keeps diabetes firmly in the public spotlight (<http://www.who.int/pmnch/media/events/2013/diabetesday/en/>).

Similarly, a World Epilepsy Day would help in focusing attention on epilepsy and various social and clinical aspects surrounding its management. Besides national and international campaigns on epilepsy, awareness-creation efforts in developing countries, particularly in rural areas, could focus on the causes of epilepsy and the treatment that should enable dispelling the myths, stigmas and common superstitions and unscientific associations around epilepsy (possession by demons, evil spirits etc.). These are examples of areas which could do with much greater sensitization and public awareness.

Additionally, a new theme for the campaign could be chosen for World Epilepsy Day every year. These themes could address issues facing the global epilepsy community around which it is important to have continued public debate and discussion, for instance, Epilepsy and disability, employment, marriage, education, leisure activities, treatment, prevention etc. Also, while the day itself would be celebrated on a particular day, the themed campaigns could last the whole year.

Commemoration of a day in this form would also provide an opportunity to bring the latest facts and figures, research and policies of national and international agencies, scientific institutions and public authorities into the public domain thereby focusing global attention on a major public health challenge.

Whether in the form of a street play competition among college students, a rural health mela focusing on dispelling common myths around epilepsy, door to door visits and counselling by trained health-care workers, or creating online platforms for conversation on epilepsy related issues through social media – a day commemorated to epilepsy would contribute significantly to creating a space for dialogue and debate on this important public health concern, thereby supplementing the efforts of governmental, non-governmental and international organizations towards creating a healthier world.

# Ketogenic Diet - the Indian scenario

Dr. J. Nathan



The use of the ketogenic diet (KD) was started in India in 1996 by Dr. J. Nathan after training at the Johns Hopkins Hospital, USA with the late Dr. John Freeman and Ms. Millicent Kelly.

The first problem was the difficulty in using American recipes in India. So, to Indianize the recipes a team of dietitians led by the author actually prepared Indian recipes. A bank of 100 recipes was fashioned and a book prepared with basic instructions included. However, as India is multilingual we had to translate these into at least three Indian languages. A few of our patients were so illiterate that they could not read numerals in Roman figures and therefore had to be taught how to use the weighing scale.

There was also a lot of resistance to the use of fasting in the initial phase of introduction of the KD especially from the parents. Also, hospitalisation entailed a fair expense to the parents, especially as most Indians do not have medical insurance. So, in late 1997 a short carbohydrate washout period was introduced during which very low carbohydrates were given. As there was no fasting phase we stopped hospitalization. Patients reached urine ketone level of 4+ in 2-4 days and the calculated ketogenic diet was started after this. Since 1998 we have been using a total out-patient approach. Most centres in the world now follow this.

## Use of lower ratios

Our centre is the first to have begun using lower ratios (Ratio is the fat in gms to the protein + carbohydrate in gms) and which are as effective as long as good urine ketone level of 4 plus is maintained. In the west 3:1 to 4:1 ratio is universally used while we routinely use ratios of 2:1 to 3:1 (Average-2.5:1)

## Tailor-made diets

India has a large number of vegetarians and even some who will not eat anything that grows below the ground, like onions, potatoes, garlic etc. Therefore recipes have to be tailor-made depending on the region of origin. Along with our special recipe book we provide patients with a demonstration recipe CD. For illiterate patients we give calculated recipes in

the form of measuring cups and spoon.

## Use of Soy

As compared to Western KD where protein is mainly of animal source in the Indian KD, as protein content of vegetarian food is low, it is largely from soybean products. Soy is associated with a decrease in the risk of coronary heart disease. Soya bean is a rich source of lecithin. Soy also contains soluble fibre which interferes with the absorption and metabolism of cholesterol and thereby decreases serum cholesterol. It is also a good source of minerals like iron and calcium, which are deficient in the KD.

## Use of Spices

We encouraged the use of spices from the very onset and recent evidence points to several advantages of this.

**Turmeric :** This bright yellow coloured powder is derived from the ground root of turmeric (a relative of ginger) and its main active constituent is curcumin. Curcumin has the ability prevent seizures as well as to protect seizure induced memory impairment. It also ameliorates oxidative stress.

**Cumin seeds :** The water extract of *Nigella Sativa* L. (black cumin seed) has antiepileptic effects in children with refractory seizures. Javad et al 2007, reported on administering an aqueous extract of black seed (40mg/kg/8h) to 20 children for 4 weeks, the mean frequency of seizures decreased significantly ( $p < 0.05$ ) as compared to with those who were on placebo.

**Saffron :** In traditional medicine, saffron has been used as an anticonvulsant remedy. Hosseinzadeh reported that the aqueous and ethanolic extracts of stigmas of *C. sativus* have anticonvulsant activity in PTZ and MES-induced petit mal and grand mal seizures. The extracts showed activity against maximal electroshock seizures implying that the extracts can improve tonic clonic seizures and the ethanolic extract possesses a sedative effect, and an anticonvulsant effect.



## Comparison of different studies : Seizure control with duration for adults and adolescents

Study Name	Duration	<50%		50-90%		>90%		100%	
		Adult	Adol	Adult	Adol	Adult	Adol	Adult	Adol
Barborka	1-46			32%	12%			9%	3%
Mady	12				16%		13%		
Mosek	3			22%					
Neal	3				50%				
Klein	4--26			42%				8%	
Nathan	6	54%(14)	24%(4)	15%(4)	18%(3)	15%(4)	41%(7)	15%(4)	18%(3)
Nathan	12	46%(12)	12%(2)	27%(7)	18%(3)	12%(3)	35%(6)	15%(4)	35%(6)

### Use of KD in children and infants

In our centre we have treated 328 adults, adolescents, children and infants the youngest being 4 months and the oldest 52 years. Responder rate (more than 50% control) has been 75.8% for infants, 66% for children, 100% for adolescents and 42.9% for adults. Over 90% reduction in seizures was seen in 51.6% infants, 36% children, 33.3% adolescents and 28.6% adults.

### Use of KD in adults too

We have the largest and longest series of the use of KD in adults and adolescents in modern time (see Table).

### Importance of daily checking of urine ketones

We insist that patient check their urine 3-4 times a day, throughout the duration of the ketogenic diet.



**1. Khakra** - 2 Portions  
Calories - 690 Kcal; KD Ratio- 2.5:1



**2. Sev** - 2 Portions  
Calories - 690 Kcal; KD Ratio- 2.5:1



**3. Pedas** - 2 Portions  
Calories - 690Kcal; KD Ratio - 2.5:1



**4. Dudhi Halwa** - 2 Portions  
Calories - 690 Kcal; KD Ratio- 2.5:1



**5. Pizza** - 1 Portion  
Calories - 370 Kcal, KD Ratio- 2:1

We believe this helps in improving the outcome of many patients.

### Normalisation of lipids

High lipid levels are a frequent side-effect in Western KD. In India our traditional diet pattern contains different types of fat namely SFA(Ghee/Butter), MUFA (Groundnut oil/Mustard/Olive oil) and PUFA. Using this analogy our patients were put on mixed oil KD (MOKD), with SFA: MUFA: PUFA (Sunflower / safflower / soyabean / corn) of approximately 1:1.2:1.17 to normalize the lipid levels. Besides, other sources of saturated fats like cream, egg yolk etc. were restricted in their diet till the lipid levels came down to normal. This study showed that MOKD maintains normal lipid levels which is independent of calories, ratio used and age of patient and also restriction of SFA normalises blood lipids.

### Use of high PUFA to improve efficacy

In spite of above good blood ketone levels, a subset of patients on KD still did not have adequate seizure control so we looked at whether changing the type of ingested fat would improve the outcome. MOKD used by us comprises of 32.15% PUFA. We switched to the use of only safflower oil which has a higher PUFA content consisting of 78.2% PUFA. Later, patients were shifted to safflower oil and flaxseed oil with cod liver oil in a ratio of 2.8:1 (N6:N3).

A total of 10 (out of 27) patients had more than 90% reduction (of these 3 had 100% reduction) with a responder rate of 66% (> 50% reduction). No

serious side-effects were seen.

One of the many proposed mechanisms of KD is the elevation of polyunsaturated fats (PUFA) which could be responsible for the increased resistance to seizures in ketotic brain tissue.

### Socio-Economic Problems

- Cost of food items – some find ghee expensive - we subsidize or give it free
- Cost of investigation – we get concessions.
- Cost of keto- diastix – we often provide this.
- Cost of medications – will go down in the majority.
- Problems in family – is solved by good pre-counseling and regular follow-up.

### Spreading the use of KD in India and Asia

It is imperative in a large country like India that there should be several centres offering KD. However, due to physician indifference and often incredulity towards KD there was initially a poor response. After ten years that is from 2006 following several presentations at national level conferences around 30 teams (doctor and dietician) have been trained. At present several centres are actively offering KD. Two centres use mAD almost exclusively while the others use mainly KD. We have also trained over 30 teams from Malaysia, Indonesia, Sri Lanka and Singapore.

*Dr. J Nathan has been recently appointed for 5 years to a 12-member international task force to spread the use of KD.*

## Nominations invited for Asian Oceanian Outstanding Achievement Epilepsy Award (AOOAEA)

- AOOAEA awards will be conferred during 10th AOEC to be held at Singapore from Aug-10-12, 2014 during the opening ceremony.
- The members of IEA & IES are invited to submit their nominations for outstanding person in field of epilepsy.

For further details, please contact secretariat of IEA/IES

**Dr. Man Mohan Mehndiratta**

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My name is Chakradhar and I am 23 years old. I am from Nellore district. I am second child to my parents. My father is working in an electricity department. My mother is working as a teacher in a private school. My elder brother is also working in a private hospital.

When I was born, my weight was 4kg. I was healthy till my 7th month. At the age of 8th month I suffered with brain fever. Because of this I got fits it seems. At that time they joined me in hospital at Chennai. I was in coma by that time. I was there in I.C.U for one month. That was my second life. At that time I was unable to drink milk from my mother. They used to feed milk through syringe in to my nose. I was unable to hold my neck too; my hands and feet were also not working properly. My neighbors and relatives used to say having a life for this child is waste. But Doctors gave hope and advised my parents to do exercises daily. My parents did exercises to me. I returned to normal life after this gradually. My parents took complete care of my health. They used to take me to the doctor every 15 days and they have given me Gardenal Tablet.

After that, my aunt was working as a staff nurse in a Hospital. I stayed there in the same hospital for 15 days. They told my parents to undergo surgery for my brain but my parents were afraid of surgery. Even my aunt also took care of me. They took me to another private hospital. I was prescribed other fits tablets also because of frequent seizures even being on Gardenal. After changing my medicines, I used to get fits for 4 to 5 times per year.

Throughout my school life, I used to go with my mother for studies. As she is a teacher, I studied my LKG to 10th class in English medium. Doctors asked me to laugh, cry and lead a normal life, but my parents were so afraid to leave me alone at any time. During my 8th standard, one of my teachers told my mother not to let me study and to have me at home instead of coming to school. But my mother was stubborn with her decision to make me study.

During my 10th standard (2008), I was sick again with fever and jaundice because of that. I was in coma again. I was there in ICU for 7 days. That was like my third life. I again recovered from this illness. Now, it's almost 3 years since I got fits.

I feel doctors gave me and my family lot of moral support. They told me that I can continue my studies; I am doing with my works regularly. Now I am pursuing my polytechnic civil engineering, Not only that, I laugh, I watch TV, sometimes I also cry. I also help my mom in house works, outside works also. I would like to continue my further studies and dream about my job.

I would like to tell my friends with epilepsy; to believe in doctors and to have confidence on them. To have self confidence and to be bold. Having these feelings in mind, even though the disease is like a mountains, he feels it like nails, when there is no self confidence and boldness in mind, even though the disease is so small like a nail, it swells in their mind and makes them unhealthy. So, patients with epilepsy please don't waste your valuable 100 years life. You be happy and make others happy too.

I thank the association for giving me the opportunity to write my life story.

## *Letter to the Editor*

Dear Dr. Rajendran,

Congratulations to you and Dr.Vinayan for the excellent publication of Epilepsy India, Issue 1, 2014. The information on ketogenic diet would be very useful not only to the professionals but also to the care givers of people with epilepsy.

I was delighted to see the photo of Prof. Satish Chandra receiving the prestigious Basanti Devi Amir Chand Prize. (I have seen this photo earlier). It is satisfying that he is maintaining the lineage as I received the same award in the year 1997.

Look forward to the next issue of Epilepsy India.

Warm regards,

**Prof. M. Gourie Devi**



# National Epilepsy Day 2013

## Bangalore Chapter

Reported by  
**Damodar Rao**

■ IEA Bangalore Chapter observed National Epilepsy Day 2013 on 16th, 17th Nov. 2013. The programme was held at the auditorium of the College of Nursing, NIMHANS, Bangalore focusing on the theme “Epilepsy and caregiver” and general education information epilepsy awareness. This was well attended by the students of various schools, nursing students, Persons with Epilepsy, caregivers and general public.

■ On 16th Nov. 2013, a medical exhibition was inaugurated by Dr. R.H. Sharada Prasad, Principal and Secretary, Sri Vani Education Institution and Dr. Indumathi Rao, Regional Advisor, CBR network South Asia by releasing the theme balloons. A unique brain bank of NIMHANS displayed brain specimens in various Neurological disorders. The nursing students of NIMHANS had prepared colourful and informative posters and charts along with models of brain. The neuroepidemiology department exhibited posters and models depicting the importance of helmet and other statistical aspects. The Pharma industry also actively participated and distributed informative booklets / handouts.

■ Dr Sharada Prasad, Dr. Indumathi Rao & Dr H V Srinivas addressed the gathering consisting of the students of various schools, nursing students, PWEs, caregivers, doctors and general public stressing on the importance of scientific and social aspects of epilepsy. Dr. R.P. Joshi and Dr. G.N. Manjunath of IEA Bangalore Chapter, gave useful information about



epilepsy utilizing the additional media. More than 950 students & teachers from ten schools attended the exhibition .

■ On Sunday, the 17th Nov. 2013, National Epilepsy Day 2013 was observed. Sri V.B. Patil, IAS, Commisioner, Department of Health and Family Welfare, Govt. of Karnataka graced the occasion as the Chief Guest. Sri P. Venkateswar, IIS, Additional Director General of Press Information Bureau, Govt. of India was the Guest of Honour. The highlight of the programme was the talks by the caregivers sharing their first hand experience. They beautifully brought out the positive effects of support by the caregivers to the PWE.

■ A scientific talk by the eminent neurologist Dr. H.V. Srinivas on the theme of NED 2013 was well appreciated by the audience. Dr. P. Satishchandra, Director and Vice-Chancellor of NIMHANS elaborated the various social aspects of epilepsy. The Chief Guest Sri V.B. Patil, emphasized the need for reaching out to the rural areas

and involving the primary care setup of the state government to further the aim and objectives of IEA. Sri P Venkateswar, promised to use his good offices to spread the awareness about epilepsy to one and all by involving IEA in various camps etc. being conducted by their department throughout Karnataka.

■ Two skits, one highlighting the theme of Caregivers in Epilepsy by Sri Venkatesh and his troupe, was followed by a skit by the students of the Nursing college, NIMHANS on social aspects of epilepsy.

# National Epilepsy Day 2013

## Kochi Chapter

Reported by  
**Dr. Rajendran**

■ IEA Kochi along with Kerala Association of Neurologists held an awareness camp for public at Alleppy. This programme was in connection with the Mid-Term meet of Kerala Association of Neurologists. Hon. Minister of State for Civil Aviation, Sri. K.C. Venogopal, inaugurated the event. About 200 patients attended.

■ On 10th November an awareness class, essay competition and a quiz programme for high school students was conducted at MIMS Hospital, Kottakkal. This was jointly organised by IEA Cochin, MIMS Hospital and the leading Malayalam daily Malayala Manorma. The winners were presented with cash prizes, mementos and certificates.

■ MIMS Hospital and IEA Cochin jointly conducted a CME Programme on epilepsy at Kottakkal on 17th November. Dr Mohammed Musthafa of ALMAS Hospital Kottakkal, Dr. Mohammed Asahraf of



MIMS Calicut, Dr. B. Rajendran of MIMS Kottakkal and Dr. Lukeman Mullah of MIMS Calicut, spoke on various aspects of epilepsy. 45 Doctors attended the session which was very interactive. The same day Ms. Remitha, Medical Counsellor, MIMS Hospital gave an awareness talk on various Psychosocial aspects of epilepsy. The topic was introduced by the CEO of MIMS Hospital Dr. Mohanakrishnan, an eminent ENT Surgeon. The programme was conducted at the Malayala Manorama office, Malappuram and 35 High School students participated.

■ At Kozhikode, as part of the NED awareness programme, brightly coloured balloons with NED messages were flown at the Mananchira square in the city, followed by a CME on Epilepsy. The events were well covered by the media. The programme was conducted by the Kerala Association of Neurologists (KAN).

## Chennai Chapter

Reported by  
**Dr. V. Natarajan**

■ Programmes were held in different parts of Chennai related to the National Epilepsy Day. On 17th November the IEA Chennai Chapter organised a CME programme wherein interesting epileptic cases were presented from different teaching institutions of Chennai. As there was not sufficient time to discuss the large number of cases brought for discussion, another session had to be arranged to accommodate them. A large number of Postgraduates and Neurologists of the city took part in the discussion.

■ The National Epilepsy Day programme was held on 18th Nov.



2013 at Government General Hospital, Chennai to improve the public awareness on Epilepsy. Important issues like first aid, marriage, child bearing etc. were discussed and the doubts of the patients and carers were clarified. The Dean of the Madras Medical College and the faculty of the Institute of Neurology, participated in this programme.

■ Apart from the above programmes a competition on painting was conducted for children with Epilepsy at the Government Royapettah Hospital by the Neurology Department.



# National Epilepsy Day 2013

## Mumbai Chapter

Reported by  
**Carol D souza**

Epilepsy CME thru Webinars for Doctors during National Epilepsy Week (11-20 Nov. 2013)

■ The Indian Epilepsy Association, Mumbai Chapter, under the stewardship of Dr. Jayanti Mani undertook an online initiative to mass educate practicing doctors (General Practitioners, Family Physicians and Postgraduate doctors) across India on Epilepsy. Twelve Neurologists across the country who are Key Opinion Leaders in Epilepsy conducted live webinars on contemporary and vital topics that provide information to diagnose and manage epilepsy patients.

Talks were given by Dr. Roop Gursahani, Dr. Sangeeta Ravat, Dr. Joy Desai, Dr. Jayanti Mani, Dr. Arabinda Mukherjee, Dr. Manjari Tripathi, Dr. S. Sitajayalakshmi and Dr. Ashalata Radhakrishnan.

The webinars were conducted from major cities including Mumbai, New Delhi, Kolkata, Hyderabad, Trivandrum.

Over 1300 viewers from more than 100 cities and towns across India participated in the webinars, with an average of 170 viewers per webinar.

■ Awareness program for patients at Kokilaben Dhirubhai Ambani Hospital (KDAH) in association with IEA BC (17.11.2013) under the stewardship of Dr. Jayanti Mani.

The epilepsy team at KDAH organized a patient awareness program in association with Indian Epilepsy Association. Almost 200 patients attended this highly interactive program. It started off with a brief introduction of the services provided for management of complex epilepsy in the hospital by the CEO Dr. Ram Narain. This was followed by short talks by Dr. Jayanti Mani, adult Neurologist

and Epileptologist, Dr. Pradnya Gadgil, Paediatric Neurologist and Epileptologist and Neurosurgeon Dr. B. Anandh. They spoke about the common doubts about adapting patient's lifestyle in epilepsy, precautions for special circumstances like epilepsy in pregnancy, myths surrounding epilepsy, comorbidities such as developmental delays, learning disorders, schooling problems etc. associated with childhood epilepsy. Thereafter a film on epilepsy was shown which addressed similar issues.

Three patient families shared their experiences with epilepsy and the challenges involved. It was very impressive and touching at the same time to hear first-hand how families deal with epilepsy.

This was followed by an insightful talk by Carol D'Souza about the common problems faced by patients with epilepsy and the beneficial activities of the IEA BC.

■ Awareness program for general physicians at Fortis Hospital, Mulund (17.11.2013) under the stewardship of Dr. Pravina Shah. There was a half day 'Update on Epilepsy' seminar. Speakers were Dr. Sangeeta Ravat, Dr. Yogesh Godge, Dr. Rakesh Singh, Dr. Shekhar Patil and Dr. Pravina Shah. 80 General Practitioners participated.

■ 'Conquering Epilepsy' Book launch on 21.11.2013 at Hotel Krishna Palace, Mumbai and press conference on 22.11.2013 at the Press Club of Mumbai.

The book Conquering Epilepsy edited by Psychologist Carol D'Souza was launched on 21.11.2013 at Hotel Krishna Palace by eminent Neurologist Dr. Noshir Wadia. Dr. Wadia congratulated Carol for putting together a book which would be helpful to all neurologists, their patients and anyone going through a difficult time and lauded the efforts of neurologist





# National Epilepsy Day 2013

Dr. Pravina Shah, President of the Indian Epilepsy Association (IEA) as well as Dr. B.S. Singhal, Patron of the IEA BC for the growth of the Indian Epilepsy Association.

'Epilepsy is a hidden disorder' said Dr. Pravina Shah 'in that people with epilepsy look just like any other'. She also said that people do not reveal they have the disorder due to the stigma associated with it. At the press conference held on 22nd Nov., Carol D'Souza stated that reasons for stigma have come from past beliefs that people with epilepsy were possessed when a seizure occurred. And though we are better informed now that it is a brain disorder, negative attitudes towards people with epilepsy still remain. In view of this it's all the more courageous for 27 people with epilepsy to talk about their lives and have it published. 6 caregivers who have lost family members who had epilepsy have also given their accounts. The book has been published through donations made in their memory.

At the launch people with epilepsy whose lives have been narrated in the book spoke of how they have overcome difficulties relating to education, employment and marriage. Caregivers spoke of the family support they had and the determination of their own children which helped them cope and helped their children become achievers.

It is hoped that this book would help dispel the stigma surrounding epilepsy, help others having epilepsy become more confident and independent and enable all people with epilepsy to say "I have

epilepsy, so what, epilepsy does not have me".

Though a few press people attended the launch on the 21st, many more (21) attended the Press conference at the Press Club. This resulted in a TV news clip and a few press articles.

■ 'We Got Talent', a competition under the stewardship Dr. Nirmal Surya founder Chairman and Trustee of Epilepsy Foundation on 17.11.2013.

17th November has typically become the day of the year where we celebrate those having epilepsy and their carers. This year Epilepsy Foundation made its best and largest ever effort into making this day special. "We Got Talent" a competition for patients which garnered entries from all over India at Y. B. Chavan Hall. An exhibition was also arranged in the form of stalls providing another showcase for those talented individuals with epilepsy. Shri. Milind Deora, Shri. Chhagan Bhujbal, Shri. Sachin Ahir, Shri. Anil Sharna, Anu Malik and many other glitterati from the Political and Bollywood worlds were present to show their support to the cause. Cash prizes were awarded to the most deserving.

The participating patients and the audience alike in the end hoped that this was the first of many more such celebrations. All in all, what mattered most were the genuine smiles and happiness on the faces of those lives darkened by epilepsy. In that we achieved what we set out to do and clearly sent out the message that people with epilepsy were able and capable.

## Indore Chapter

Reported by

**Dr. V. Nadkarni**

Epilepsy foundation of India organized 'We Got Talent' on 17th Nov. 2013 in Mumbai. There was several participants from all over India, where two members of Indore Epilepsy Visheshagya Association Samiti, M.P. Chapter, Indore participated.

Priti Borasi received the first prize for her 'Lavni dance' & Pankaj Parmar received 3rd prize.



# National Epilepsy Day 2013

## Kolkata Chapter

Reported by

**Dr. Prashanta Kumar Ganguly**

Epilepsy Day Celebration, jointly organized by Neuro Update Kolkata and AFX Animation, was held on 15th Dec. 2013 at 98 Regent Place, Kolkata, due to school and college examination schedule, so that most of the Epilepsy patients and their guardians could participate.

■ In the awareness programme, many General Physician along with Prof. (Dr.) P. K. Ganguly MD, DM Ex HOD Neurology, Calcutta National Medical College, Prof. (Dr.) S.N. Ghosh MS, Mch, HOD Neuro-Surgery B.I.N, Dr. Atanu Biswas, MD DM, Neuro-Medicine BIN and Dr. A. Das MD exchanged their views and

experiences and cleared the doubts of many PWEs and their caregivers. An Animation movie was shown on Epilepsy, Migraine and Alzheimer's to the patients. Children were specially involved for this awareness programme so that they have the right information from their childhood.

■ The second part of the programme was the 'Sit and Draw contest', Health checkup, animation show and prize distribution for the Epilepsy patients and the other children.



## Ranchi Chapter

Reported by

**Dr. S. Akhtar**

The Indian Epilepsy Association, Jharkhand State Branch, Ranchi Chapter observed National Epilepsy Day on 18th Nov. 2013 and an awareness program was held on 18th and 21st Nov. 2013 at the general OPD and epilepsy clinic held weekly at Central Institute of Psychiatry, Ranchi respectively which was attended by 400 participants including patients and their caregivers.

The occasion was graced by the Director of Central Institute of Psychiatry, Dr. D. Ram and Professor of Excellence, Dr. S. Haque Nizamie by flagging off balloons symbolizing freedom from epilepsy. After

this a documentary show and pamphlet distribution was arranged for patients at the epilepsy clinic and the Erna Hoch Center for Child and Adolescent Psychiatry, Central Institute of Psychiatry, Ranchi.

This event marked a weeklong celebration during which various awareness programs were conducted in collaboration with Central Institute of Psychiatry. A special painting competition was also held for children admitted at the Erna Hoch Center for Child and Adolescent Psychiatry, Central Institute of Psychiatry, Ranchi.





# National Epilepsy Day 2013

## Nellore Chapter

Reported by  
**Dr. Bindu Menon**

■ National Epilepsy Day was observed by Nellore Chapter keeping the theme - Care givers and Epilepsy – in mind. Several functions were organized over 2 months to spread awareness. Main function was organized in the local town. Patients along with their care givers were invited. General public, school and college students and teachers were given invitation cards. District Collector Shree N. Sreekant inaugurated the function. President Dr. Bindu Menon gave the inaugural address briefing the audience about the development in epilepsy treatment and stressed that epilepsy was no longer an illness with stigma. Shree Sreekant, District Collector, applauded the Association for the regular activities being held and informed the public that seeing the posters displayed in town by the association he was amazed to know that many great men suffered from epilepsy. He spoke to the patients and care givers that the disease has seen a new light and is as common as any other ailment. Prize distribution was conducted for all the competitions held. 1st, 2nd, 3rd and consolation prizes were distributed for the drawing and essay competition held in various schools and colleges.

■ A Poster 'Prevent cerebral palsy, Prevent epilepsy' was released by the District Collector. 1000 posters were made and with the help of District Medical Health officer it was distributed to 75 primary health

centers, 15 community health centers, 10 urban health centers, and 3 area hospitals. Apart from that, the same was distributed in various clinics and private hospitals. Posters were given to the child and welfare section.

The program began with the association members performing a skit about a person with epilepsy and his journey through life. The members had practised for the skit for about a month. The skit was highly appreciated and a huge appreciation for the members is in order.

■ A cultural program for the public was also organized which included mimicry and magic show. They were a few differently abled and epilepsy patients who performed during the function.

Pamphlets regarding epilepsy and its information were distributed to all during the function. The function was a huge success with over 500 attendees. Refreshments were served during the function.

■ A free epilepsy camp was held and over 80 patients were given free medication.

■ Painting competition was held for children with epilepsy. 35 children attended the competition. All were given gifts and prize winners were given prizes during the function.





# National Epilepsy Day 2013

■ Painting and essay competition were held in several schools and colleges. The topic for essay was 'My friend has epilepsy'. This year we received requests from other schools also expressing their desire to participate in such activities next year. The Association has noted this and will make it in a larger scale next time.

■ Awareness programs were held in 3 schools where they were briefed about epilepsy and an interaction was done later. Regular school programmes are held.

This month awareness programmes were held in 4 schools. A medical camp was also held in the Govt. girl's high school. Few students who had neurological ailments were examined along with their guardians and were given advice. The school programs have been a great success. With the questionnaire to students we have an idea of the awareness level and it also helps us to focus on the areas of awareness. Students are very enthusiastic and expressed lots of doubts.

## Jaipur Chapter

On National Epilepsy Day 17th Nov. 2013, the Jaipur Branch of Indian Epilepsy Association organized a public education program. The program held at Jaipur Medical Association Hall in the SMS Medical College Campus.

Approximately 100-150 patients, their relatives, doctors and journalists, attended the program. The Principal and controller of SMS Medical College, Dr. Subhash Nepalia inaugurated the program. Dr. Chandra Mohan Sharma, while addressing the gathering informed that the slogan for the year was importance of caregivers in the management of patients with epilepsy. Press and public can play important role in spreading this message to every one in our country.

Dr. B.L. Kumawat, Associate Professor of Neurology SMS Hospital, explained about the myths in epilepsy, its causes in various age groups, precautions during pregnancy and "Do's and Don'ts" in epilepsy. Dr. Trilochan Shrivastava, Associate Professor explained to the audience the importance of

Reported by  
**Dr. C.M. Sharma**

preventive aspects of the disease. Dr. Dinesh Khandelwal, Neurophysician, addressed the gathering and discussed about general guidelines regarding treatment and side effects of the drugs. The resident doctors of the department also participated in the program.

Dr. Chandra Mohan Sharma stated that epilepsy is treatable with drugs and surgery and stressed that people should consult qualified doctors and avoid quacks.

Many of the patients also shared their experiences with the other patients and their relatives.

On the occasion, exhibition of posters in Hindi were displayed to explain the details of epilepsy, its treatment and remedies. A drawing competition was held among the children with epilepsy and the best five of them were awarded prizes. School bags, color pencils and drawing boxes were distributed by various pharmaceutical companies to all the children who attended the program. Free anti-epileptic drugs were distributed to patients.





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## Group companies



# National Epilepsy Day 2013

## Pune Chapter

■ The members of Indian Epilepsy Association, Pune Chapter, organized a huge public awareness programme in Pune city on the occasion of National Epilepsy Week from 16th November to 24th November in affiliation with Sanvedana Foundation epilepsy support group, and with the help and initiative of the MBA students of Symbiosis College.

■ The agenda of the program was to create awareness about epilepsy using various methods such as articles about epilepsy in the newspapers, both in local and English language, online branding and promotion of the epilepsy awareness program on the social websites such as Face Book, Twitter etc., through creating the pages and teaser page posting.

■ Advertisements on auto rickshaws and Buses in Pune for the promotion of epilepsy awareness to inform as many people as possible about the awareness walks on 16th and 17th November, with the details about the time and location. This promotion was done on 75 auto rickshaws in all over Pune city!! We immediately started getting phone calls from families with epilepsy! And the rush in our epilepsy counselling centre also increased!

■ T-shirts and caps were designed for the awareness campaign which were distributed at the awareness walk to those who showed genuine interest. Our volunteers also wore them on all campaign days. Many banners and placards for epilepsy awareness were displayed.

■ On 16th November, First 'Purple Walk' on Mahatma Gandhi Road. The team carried banners, placards

and posters, and tried to create awareness with the announcements.

■ Our second "Purple Walk" on Fergusson College Road, which was inaugurated by famous singer Dr. Salil Kulkarni. More than 100 members of Pune Chapter and Sanvedana Foundation attended. Dr. Nandan Yardi, the President of Pune Chapter also participated in the walk.

■ Street plays at many places for epilepsy awareness had a huge impact. The drama team of Roopkala from Mumbai performed the plays in 6-7 places in Pune city. They covered various topics like misunderstandings and misconceptions about epilepsy, treatment for epilepsy, marriage problems and marriage bureau for people with epilepsy etc. For every street play there were more than 50 viewers from the street.

■ Sanvedana Foundation's Initiative : Way For Purple - Epilepsy Awareness Walk Campaign was covered by IBN Lokmat and the message reached out to a lot more people. Interviews of Dr. Nandan Yardi (President of IEA Pune Chapter) and Mrs Yashoda Wakankar (Secretary, IEA Pune Chapter) were arranged on the TV Channels.

■ Seminar about epilepsy on 24th November, to sum up the epilepsy awareness week. Dr. Nandan Yardi (epileptologist) and Dr. Rahul Kulkarni (Neurologist) had a very good interaction with the people with epilepsy and their families. Dr. Anil Awachat, a famous thinker and author from Pune was invited as a chief speaker. Mr. Deepak Shikarpur, famous IT industrialist and the District Governor of Rotary Club was invited as a chief guest.



Reported by  
**Yashoda Wakankar**



# National Epilepsy Day 2013

## U.P. Chapter

Reported by  
**Dr. Atul Agarwal**

■ 14.11.2013 - A free Epilepsy camp was organized at Takshila Public School, Beta Gokul, Shahjahanpur Road, Hardoi by Abbott India Ltd in collaboration with e chaupal of ITC. A total of 70 patients were evaluated. Dr. Agarwal told the gathering about all aspects of disease and answered the questions of audience. Free drugs for 3 weeks were distributed to each patient.

■ 16.11.2013 - Painting competition for children with epilepsy was organized at Vivekanand Hospital, Lucknow by Dr. Kiran Zutshi, Consultant Paediatrician; in which 36 children participated. The prizes were distributed by the Chief Guest Swami Shri Para Roopanandji Maharaj of Ram Krishna Mission, Lucknow (provided by Abbott Pharma). After the competition Public awareness lectures were given by various specialists.

■ 17.11.2013 - Dr. Atul Agarwal spoke on Epilepsy on All India Radio Lucknow in 'Aapka swasthya' discussing all aspects of Epilepsy, First Aid, management and various myths associated with the illness.

A public awareness and patient education programme was organised by Dr. Rakesh Shukla (Professor in Neurology, KGMU) at IMA Bhawan, Lucknow. About 50 patients and their family members and 50 nursing students of the K.K. Institute of Nursing, participated. Dr. Atul Agarwal (Secretary, IEA UP Chapter), Dr. Vimal Kumar Paliwal (Assoc. Prof. in Neurology, SGPGIMS, Lucknow), Dr. Ajai Kumar Singh (Assoc. Prof. in Neurology, RMLIMS, Lucknow), Dr. Shameem Ahmed Ansari (Consultant Paediatrician), Dr. Siddhartha Koonwar (Asst. Prof. in Paediatrics, KGMU) and Dr. Rakesh Shukla spoke on various aspects of epilepsy. Dr. Rukhsana Khan (President) and Dr. Vijay Kumar (Secretary) IMA Lucknow Branch were also present

on the occasion. Two short films on epilepsy "Mirgi: Sahi Gyan Sahi Samadhan", and "Wings of Freedom" were screened on this occasion. This was followed by an interactive question-answer session. Educational material related to epilepsy was distributed to the patients. The programme was supported by M/s. Sanofi Aventis Ltd. and received wide coverage in the print media.

■ 20.11.2013 - Prof. A.K. Thakkar Head, Department of Neurology at Dr. Ram Manohar Lohia Institute of Medical Sciences, Lucknow started a Refractory Epilepsy Clinic from 20th Nov. 2013. On the occasion of clinic inauguration, Dr. Sangeeta Rawat, Head of the Neurology Department at KEM Hospital and Seth GS Medical College, Mumbai was the Chief Guest and she delivered a guest lecture on 'Epilepsy – Yesterday and today'.

Dr. Atul Agarwal discussed about Epilepsy, its types, investigations and management with students and teachers of Adarsh Higher Secondary School, Ahimamau, Lucknow.

■ 24.11.2013 - An Epilepsy Quiz was held for undergraduate and postgraduate students of Era Lucknow Medical College, by Prof. Ajay Kohli. Dr Atul Agarwal presented 100 interesting questions related to Epilepsy to audience in KBC style. The first and second prizes were given to Vishal Singh and Dr Sunit Maini respectively. Many consolation prizes and books were given for good interaction and participation certificates were given to all (supported by Novartis Pharma).

■ 1.12.2014 - Dr. Atul Agarwal gave a lecture on "Epilepsy Management: From guidelines to practice" to a gathering of 90 physicians in API-DIAS programme organized by Abbott Pharma.



# National Epilepsy Day 2013

## Shivamogga Chapter

IEA, Shivamogga Branch conducted many activities this year as part of its NED activity.

■ Competitions were organised for the patients including races like spoon and lemon race, ball in the bucket, put the sticker to face blindfolded etc, drawing competition and quiz competitions.

■ The winners were given prizes. Dr. Girish Kulkarni, Asst. Professor of Neurology, NIMHANS, Bangalore was the Chief Guest for the NED program on 17th Nov.



Reported by

**Dr. A. Shivaramakrishnan**

He delivered a talk on Epilepsy and it was followed by interaction with patients.

■ A live program on Epilepsy was arranged on Spandana TV channel. Dr. K.R. Sridhara and Dr. A. Shivaramakrishna participated in the discussion and questions posed by viewers was answered.

■ A CME program was arranged for the IMA Doctors - Dr. Girish Kulkarni spoke on 'Management of Epilepsy' and Dr. Madhusudhan spoke on 'Management of spontaneous intracerebral hemorrhage'.

## Tirupati Chapter

■ As part of the National Epilepsy Day 2013 this year we have arranged for a Neuroepidemiological Survey in Kotala Village of Chandragiri Mandal, Chittoor District, A.P. The survey was conducted during the period 7th to 14th November, 2013. The details collected will be studied by the faculty of the Department of Neurology, SVIMS in course of time, for further follow-up.

■ On 12th Nov. 2013 the students of College of Nursing, SVIMS enacted a skit at Kotala Village bringing out problems faced by persons with Epilepsy and the needed remedial measures. The villagers greatly appreciated the messages conveyed through the skit and the sincere efforts of the students.

■ The 178th monthly camp for persons with Epilepsy was held on 17th November, 2013. About 350 patients

and about 150 patients attendants were present. An awareness programme with the help of posters was organized for the benefit of Persons with Epilepsy and their attendants.

■ Competitions like singing competitions, drawing competitions and indoor games were conducted and prizes and participation certificates were distributed to the winners and participants by Dr. B. Vengamma, President, Tirupati Branch. She also outlined the significance of the National Epilepsy Day and reported about the camps being held for the past 178 months where one month's requirements of Medicines are distributed FREE to all persons with Epilepsy who attend the Camp.

■ The local media covered these events in detail.



Reported by

**Dr. B. Vengamma**

# Obituary

## Prof. Sanat N. Bhagwati (17.12.1928-14.12.2013)

Born in an illustrious family, his father was the chief Justice of Gujarat. He completed his MBBS and Masters in Surgery from Seth G.S. Medical College and KEM Hospital and was immensely influenced by the works of Dr. Ginde at KEMH which motivated him to take up neurosurgery.



He went for his training in Neurosurgery as advised by Prof. H.M. Dastur to United Kingdom at the Atkinson Morley Hospital under the guidance of Dr. Wiley McKissock where he learnt the nuances of neurosurgery.

He understood the philosophy of paediatric neurosurgery when he trained with Dr. Anthony Riamondi at Chicago Children's Hospital. After returning to India, he became a full time consultant neurosurgeon in Bombay Hospital and continued his active association till he fell ill in 2012. He also became Associate Professor of Neurosurgery at JJ Hospital and Grant Medical College with Prof. Ginde where he also taught and cultivated the concepts of neurosurgery in many young neurosurgeons.

Later on he became Professor Emeritus at both these hospitals and continued his associations. He held many positions at various societies and contributed immensely in the growth of these societies and furthering their role in medical field.

1) He was the President of Neurological Society of India (1988-89); 2) President International Society for Paediatric Neurosurgery (ISPN) in 1995; 3) Hon. President of Asian Australasian Association of Neurosurgical Society in 2007; 4) He was the founder of Indian Society for Paediatric Neurosurgery and also founded the Skull base Society India.

His work in the field of academics was unsurpassed. His passion for neurosurgery was evident in his numerous publications and textbooks. His academic areas were several, special mention must be made of: 1) TB meningitis; 2) Paediatric Meningiomas; 3) Pituitary tumors; 4) Medulloblastomas; 5) Craniopharyngioma.

He had the vision to institute "Dr. Ginde Oration" at the Bombay Hospital in 1991 wherein masters and experts in various fields of neurosurgery from all over the world were invited to give a scientific talk and also conduct a live surgery workshop. This provided an opportunity to local neurosurgeons to rub shoulders with the doyens of this field and learn from them. His legacy continues and will forever live with us and guide us.

## Dr. Gajendra Sinh (18.8.1921-14.12.2013)

Dr. Gajendra Sinh was born to the princely family ruling Kathiawara, 32 km from Alirajpur. He did his schooling at Charterhouse, England returning to India when World War II broke out.



He did his premedical at St. Xavier's College, Bombay where he met the lady who was the national table tennis champion and married her!

He graduated from the Grant Medical College and Sir J. J. Group of Hospitals in 1947 and did his FRCS from England and Edinburgh. Trained in neurosurgery under Dr. Jacob Chandy, Christian Medical College and Hospital, Vellore, he started the Department of Neurosurgery at Grant Medical College and Sir J. J. Group of Hospitals in 1959.

He retired from his alma mater on superannuation and worked at Bombay Hospital, Sir Hurkissondas Narottamdas Hospital, Breach Candy Hospital and Parsee General Hospital. He founded the Department of Neurosurgery at Jaslok Hospital and Research Centre and continued to work in it till his death.

He was elected Secretary and later President of the Neurological Society of India.



### IEA-18th IEC Trust Announcement for availability of Financial Grants

This is to bring to notice of the members of IEA and IES that the above Trust has been involved in various aims and objectives to help amelioration of human distress in those afflicted with epilepsy.

With such an objectives in mind, the Trust promotes studies in epilepsy to disseminate knowledge, promote research, social services by providing financial grants.

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Sannidhi, K10/10 DLF City-II, Gurgaon 122002  
Email: drvssaxena@gmail.com  
Phone 0124-4363035/36/37



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\*Indian Pediatrics. 2009 Aug; 46(8): 669-73

**ELECTIONS 2014-2016**  
**INDIAN EPILEPSY SOCIETY**  
**NOMINATION FORM for the post of President Elect-IES**

Name of the Post : .....

Name and Address of Nominee : .....

.....

.....

Proposed by

Seconded by

Signature .....

Signature .....

Name and Address .....

Name and Address .....

.....

.....

IES No. LM .....

IES No. LM .....

I, Dr. .... hereby give my consent for my nomination  
for the post of PRESIDENT ELECT of INDIAN EPILEPSY SOCIETY, the election for which is to be held in 2014.

Signature:

Name and Address:

IES No. LM .....

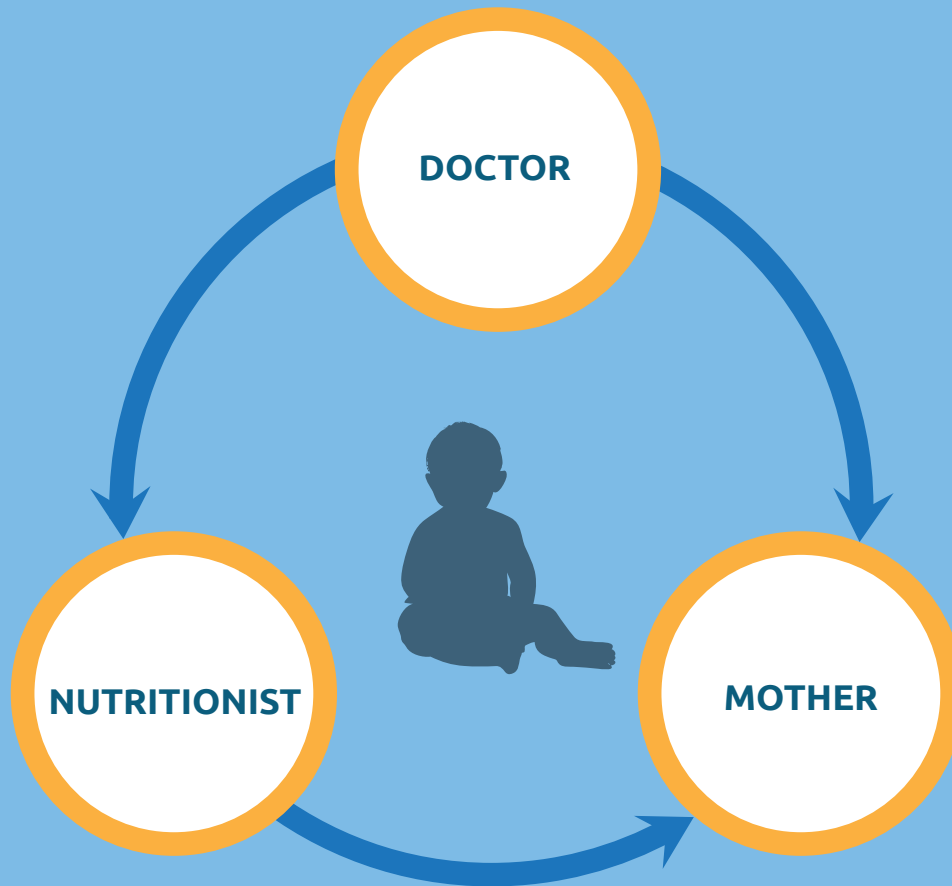
Last date & Time for Receipt of Nomination : April 30, 2014, 05:00 PM

Last Date & Time of Withdrawal : May 15, 2014, 05:00 PM

Last date & Time of Receipt of Ballot Paper : June 25, 2014 05:00 PM

- P.S. Only LM can file in nominations, propose and second.
- Please enclose a brief bio-data of the nominee in not more than 200 words.
- Completed form should be sent to: Dr. Pravina U. Shah, Godrej Towers 4/191,  
Opp. Godrej Memorial Hospital, Vikhroli East Mumbai 400079. Res Tel No. 25742121

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# A MILLION PATIENTS WITH INTRACTABLE EPILEPSY IN A COUNTRY WITH A POPULATION OVER A BILLION

Source: Neurology Asia 2007

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