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# Epilepsy India



Newsletter of the Indian Epilepsy Association & Indian Epilepsy Society



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Hello All,  
Greetings from the office bearers of Epilepsy India!

At the very outset, we would like to thank all of you who have unanimously elected us as Editors – Epilepsy India.

The April issue of *Epilepsy India* could not be brought out for reasons beyond the control of the present team. It was understood that both the April and the July issue would be brought out by the former team led by Dr. V.S. Saxena. We are very happy to say that from this issue onwards, the new team will strive to bring *Epilepsy India* to your door step on time.

The team led by Dr. V.S. Saxena has done a tremendous job during their tenure. The format, the content, the editorials and the punctuality were outstanding. Take a bow, Dr. Saxena.

ECON 2013 was a resounding success. The noteworthy feature was the dinner sessions of case presentations which were very well attended and were extremely interactive. The three orations stood out for their content, and the quality of the orators. Dr. J.M.K. Murthy and Dr. Sita Lakshmi along with their co-organizers did a superb job in hosting the conference. The famed Hyderabad hospitality was very much in evidence at every juncture. The short inaugural function was something that every one appreciated. The cultural programme was really excellent. Kudos to Dr. J.M.K. Murthy, Dr. Sita Jayalakshmi and their team.

We are now living in exciting times. Thanks to the progress in molecular genetics we are able to understand the fundamentals of epileptogenesis. The increasingly sophisticated imaging techniques offer effective surgical options to persons with difficult-to-treat epilepsies. It is also heartening to note that some centers in India are now offering Indianised and palatable ketogenic diet to children with refractory epilepsy. In spite of all these developments, we are

still in the dark at the first level of anti epileptic drug prescription. To quote Prof. E.H. Reynolds, former President of ILAE “we still do not understand the actions of anti epileptic drugs, with the possible exception of Vigabatrin.”

In India more emphasis has to be laid on preventable epilepsies. Good antenatal and perinatal care is the mantra for preventing devastating effects of cerebral palsy and consequent seizures. Similarly, better enforcement of use of helmets for two wheeler users, including pillion riders, can go a long way in preventing post traumatic epilepsy. Another scourge in our country is the problem of neuro infections- viral, tuberculous, cysticercosis and of late HIV related infections.

A look at the figures will tell us the magnitude of the problem. Road traffic accidents (RTA) rank ninth in the order of disease burden and it may reach third position by 2020. In India there are six lac RTA per year, the mortality arising from these is one lac a year. This is  $2\frac{1}{2}$  times the US figures. Seventy percent deaths in RTA are due to head injury. The tragedy is that the age group of the victims - 20-40 years - is the most productive years of their lives. Post traumatic seizures occur in 4-30 percent of survivors (Dr. Major Natasha Singh, 20th CME Genpact Medical Team). Seizures occur in two third cases of Neurocysticercosis (Sunil Pradhan, Ramakant Yadav Neurology Asia 2004;9 supplement 1). One third of cerebral palsy victims have seizures (Singh P. et al J Child Neurology, March 18(3):174-9).

Neuro Scientists must be proactive in getting this message to the officials (Governmental and NGOs in related fields) so as to impart sufficient training in areas of safe motherhood, environmental sanitation and implementing and enforcing strict road safety rules.

Let us together make a beginning in this endeavour and hope that by the end of this decade we can reduce the burden of preventable epilepsies. ■





*During* the past 4 years the League has taken significant steps and worked relentlessly to accomplish its mission “A world in which no person’s life is limited by epilepsy.”

Based on our strategic plan developed in 2009, many activities took place. To promote the advancement of knowledge and education in all areas of epilepsy, we work closely with regional and task oriented commissions to create effective and highly educational congresses as well as internet education via VIREPA. Various task forces were created to deal with specific topics such as the definition of epilepsy, preclinical evaluation of novel treatments, stigma and guidelines, among many others. We are pleased with the growth of EPILEPSIA under the masterful guidance of the current editors, Drs. Simon Shorvon and Phil Schwartzkroin, and are looking forward to the transition to the new editorial team led by Drs. Gary Mathern and Astrid Nehlig. In fact, we went further and created a new educational arm in EPILEPTIC DISORDERS under the expert guidance of Dr. Alexis Arzimanoglou who will work very closely with Drs. Nehlig and Mathern to promote our publishing agenda.

More importantly, we are looking forward to the continuous efforts of our chapters to work with us productively and augment the delivery of epilepsy care in their country. Nobody knows better the local needs and realities than the members of our chapters. Together we can bridge the gaps and also take advantage of our very active collaboration with WHO, to involve governments in the delivery of care in all countries whether resources rich or poor. Many of these efforts are taking place in India where there is a rapid growth of the delivery of epilepsy care for this country’s huge population, and we are very proud that we have been able to collaborate with the leadership of Indian epileptology to further improve the lives of people with epilepsy.

We firmly believe that by working together we can make significant changes in the world, and there will be a day that we will identify not only better treatments for the majority of people with epilepsy, without side effects but also cures on certain occasions. Through the expanding growth of research that takes place world-wide, and with the collaborations across several regions we hope to reach our goals. The League is here to assist in organizing these efforts through the democratic elections of our representatives who are willing to work together for a world in which no person’s life is limited by epilepsy.

I would like to thank all the people who dedicated their precious time to the functions of the League. I am looking forward to the next 4 years for continuing advancements under the expert guidance of our President-Elect, Dr. Emilio Perucca. We have worked together for the last 4 years and we are ready to ensure a very smooth transition.

Thank you for your help and support.



# ECON 2013 REPORT

**Dr. S. Sita Jayalakshmi**  
Organising Secretary



*The* 14th Joint Annual Conference of Indian Epilepsy Association and Indian Epilepsy Society was held on February 8-10, 2013 at Hotel AVASA, Hi-Tec City, Madhapur, Hyderabad.

ECON2013 offered three days of rich scientific programme which included one day Pre-conference Workshop on 'Difficult to Treat Epilepsy & Epilepsy Syndromes' and 'Seizure Emergencies'. This was followed by a post dinner session of Interactive case discussions during which the delegates' active participation made the discussions more interesting and informative.

On the other two days, the scientific programme included two breakfast sessions and four orations. The IES presidential oration was delivered by Dr. Pravina U. Shah on 'Treatment Gap in India - Let's meet the challenge'. The Prof. B.M. Sharma Oration was delivered by Dr. Samuel Weibe on the topic 'Living with Epilepsy: Perils & Progress'. Dr. V. Ramesh delivered the guest lecture 'Approach to epilepsies and epilepsy syndromes associated with metabolic disorders'. Dr. S. Katrak delivered the Dr. B.C. Bansal and Uma Bansal Oration on 'Common issues in the management of Epilepsy - My experiences'. This was followed by another guest lecture 'Antiepileptic drugs when to add and when to substitute' by

Dr. Deiter Schmidt. There were two parallel platform sessions in which 12 papers were discussed. This was followed by the walking poster session. The post dinner session on seizure semiology discussed various interesting and complex seizure semiologies and its relation to pre surgical evaluation.

On day two of the main conference, the breakfast session was followed by a symposium on 'Advances in imaging in epilepsy'. This was followed by the symposium on Epilepsy & Psychosocial Aspects. The parallel IEA session was on Epilepsy and society. In this, students of psychology performed a play on Epilepsy and Stigma. This was followed by a session on Epilepsy and disability and all aspects including neurologic, pediatric, psychiatric and psychosocial issues and epilepsy were discussed. A play was performed on 'Overcoming Barriers - Conquering Epilepsy' by the members of IEA Chapters, Indore, Bengaluru and Mumbai. These sessions made patients who attended the conference not only realize the facts about epilepsy but also helped them in knowing dos & donts in their day to day activities of life.

The Sri H.C. Bajoria Oration was delivered by Ms. Carol D'Souza on 'Beyond medicine - What people





# ECON 2013 REPORT



with epilepsy need'. The K.S. Mani Memorial Patient Forum discussed the issues related to Epilepsy & Employment. It discussed the Patient, Legal and Employer's perspectives.

There was a half day session (Post conference workshop) 'Clinical Epileptology' for Residents in Internal Medicine and Pediatrics, hosted by Epilepsy Association of Hyderabad.

For those who attended the ECON 2013, the AP Medical Council allocated 15 credit hours and for the post-conference workshop three credit hours.

We received 59 abstracts online. Out of these, six were selected for the award paper session, 12 for the platform session and rest of the 41 for the poster session. The best presented papers which were more informative, were awarded accordingly. The best platform paper was awarded to Dr. Vikas Dhiman for his presentation 'Semiological characteristics of adults with psychogenic non-epileptic seizures (PNES): An attempt towards a new classification.'

Total 452 delegates and 40 patients participated in the ECON 2013. About 180 Residents from Internal Medicine and Pediatrics were registered for Post-conference workshop.



## ECON 2014 – KOLKATA

Jan 31-Feb 2, 2014 @ The Taj Bengal



The 15th joint Annual conference of the IEA and IES is going east. ECON 2014 is being held in Kolkata on **February 1st and 2nd, 2014**, with the preconference on **January 31st, 2014**.

The venue is the famous Taj Bengal.

The organizers assure us that Kolkata in Jan – Feb has lovely weather and is beautiful to visit. Apart from the academic feast being organized, there are many cultural and historical sites to visit in Kolkata and nearby. So do come with your family and colleagues.

Avail of the early bird offer till **October 31, 2013**.

Details are available on the site [econ2014.org](http://econ2014.org) or else you can contact the organizers at

**Conference Secretariat, ECON 2014**

**Room No. 29, Calcutta Medical Research Institute – CMRI,**

**7/2 Diamond Harbor Road, Kolkata 700 027**

**Ph: 033- 3090 3090 Fax 033-24567880**

**Email: [info@cmrihospitals.co.in](mailto:info@cmrihospitals.co.in)**

# Treatment Gap (TG) - Let's face the challenge



Dr. Pravina U. Shah

Presidential Oration - ECON 2013



*Epilepsy* is a common and potentially serious neurological disorder, that can be diagnosed and treated inexpensively. Historically, epilepsy has received little public health attention despite poor health outcomes and potentially devastating social consequences from untreated disease. There are 50 million persons with Epilepsy(PWE) worldwide and 80% of them are in developing world.

Our ultimate goal is to improve quality of life (QOL) of persons with Epilepsy. QOL, to a great extent depends on seizure control and seizure control depends on Early diagnosis, Early initiation of proper therapy and Social acceptance. Early Diagnosis has enormous relationship with TG.

It is estimated either by Direct Prevalence Studies or indirectly from Calculation through Consumption of Anti Epileptic Drugs (AEDs).

TG is defined in terms of those people with epilepsy who are not treated at all (Primary TG ) or not appropriately treated (Secondary TG ), and is the result of an array of medical, political (Govt.), social, economic, and cultural factors. It is expressed as a percentage.

ILAE, IBE, and WHO have launched Global Campaign Against Epilepsy (GCAE ) in 1997 - **Out of the Shadows** and its mission is to improve acceptability, treatment, services and prevention of epilepsy worldwide. GCAE has Demonstration Projects in Latin America, China and S.E. Asia. The message from these large community based trials is that " Epilepsy can be treated with inexpensive and effective drugs at the community level by primary health professionals with basic training."

Primary TG in developed countries is <10% while in developing countries is 60 to 90 %. In India it is 38 to 90%, rural more than urban and semi-urban areas.

Kerala state has minimum i.e. 38%. So approximately 3 to 6 millions PWE would not have been treated any time.

The important reasons for Primary TG are:

- \*\* Stigma
- \*\* Non or poor availability of
  - \* Medical expertise
  - \* Diagnostic facilities
  - \* AEDs
- \*\* Non or poor affordability for

- \* Travel cost – Both for patients and caretakers
- \* AEDs
- \*\* Reachability - \*Transport facility - specially in monsoon
- \*\* Lack of Educational Services

Reachability being an important cause for TG, we thought that we need to reachout to provide medical expertise and resources to rural setting so we started a rural camp at Aarav village in Pen District Raigarh, Maharashtra (100 kms from Mumbai) in Nov. 2007. Infrastructure is provided by Ashokbhai at his farm house. Announcements of the camps were posted on trees with the co-operation of the caretaker of Farm House and Sarpanch of Pen. Later free announcements started on local cable. Awareness through word of mouth (chemists also informed patients) also played an important role. The team consists of Neurologist, Gen. Practitioner, Special Educator, Psychologist, Physio-therapist, Samman volunteers & Local volunteers.

On first camp day, 18th Nov. 2007 there were 31 patients. 29 were Epilepsy. Out of these 29, 21 patients were already diagnosed and investigated and they were advised AEDs. However continuity of the prescribed medication and regular follow up was a big issue. So naturally control rate of seizures was very low. This gave us a direction that only diagnostic camp is not the need of the hour but what is most essential is **regular supply of AEDs and follow up** for seizure control for reducing Secondary TG. The first patient Sita amazed us. She has recurrence of seizures due to stress of being driven out by husband because of Epilepsy, in spite of the fact that she having Epilepsy being declared in writing on Rs.100/- stamp paper in presence of Grampanchayat members before marriage. We of course counselled her, started regular treatment, they complied well and she is seizure free. She is officially divorced and now remarried.

We give five basic AEDs i.e. Phenobarbitone, Phenytoin, Carbamazepine, Sodium Valproate, Clobazam and syrup Paracetamol at nominal cost. We have developed liaison with :

- \* Doctors in the area
- \* Pathologist for relevant blood tests
- \* School for special children to refer children with comorbidities like mental retardation and cerebral palsy.



- \* Orphanages and schools around to educate them
- \* Hospitals in Mumbai for difficult cases and Epilepsy surgery.

So far total No. of patients seen (34 clinics: Earlier every 8 weeks and now every 12 weeks) are 400 : Epilepsy 305 and others non Epilepsy. Average attendance during each clinic is 90 patients. Two patients are seizure free after Epilepsy surgery at K.E.M. Hospital. Many ladies had safe deliveries and some young boys are employed as seizures are controlled.

There are other models run by other Neurologists and Pediatricians in other parts of India and each has unique method and usefulness.

**\*\*Tirupati** - Under the leadership of Dr. Vengamma the 166th monthly camp for persons with Epilepsy was held on 18th November, 2012 (Third Sunday of the month). About 150 patients attended.

**\*\*LifeLine Express** is a rural outreach CSR initiative of Abbott India, in partnership with the NGO Impact India which runs India's only hospital on wheels. This specially designed train runs across the length and breadth of India's extensive rail network to reach the hinterland. Dr. Mamta Bhushan of the All India Institute of Medical Sciences (AIIMS) supports the NGO to travel to all places where the train reaches to diagnose, treat and counsel the 200+ patients who come to each camp. In 2012, Abbott India conducted over 15 Lifeline camps.

**\*\*Badhte Kadam** - A pediatric epilepsy campaign aims to bring children with epilepsy 'out of the shadows' through ensuring access to specialists, particularly in non-metro and semi-rural towns. In partnership with Dr. Anaita Hegde of Wadia Children's Hospital, Mumbai, Abbott India plans and executes these camps in select non-metro towns of Maharashtra which enable 'children with epilepsy' to receive free expert diagnosis, counselling and treatment. The care-givers of these children also benefit from counselling and patient education tips given by Dr. A. Hegde and her staff. In 2012, Abbott India conducted over 12 Badhte Kadam camps.

**\*\*Epilepsy Foundation** - Under the leadership of Dr. Nirmal Surya, with the collaboration of National Rural Health Mission Rural Diagnostic Camps in different districts of Maharashtra are being organised for last 2 years with the team of Neurologists, EEG technicians, Physiotherapists, Speech therapists and Counsellors. Thousands of patients are benefited so far.

With all these different reachout programs, awareness programs on National Epilepsy Day i.e. 17th November using different media i.e. TV, Radio, Newspapers, Books, Pamphlets, Posters and Seminars there is shift in thinking among patients and relatives and thus **Primary TG** has reduced to 50%

What worries me is not just **Primary TG** but rising incidence of Secondary TG. All my senior colleagues have the same experience. The study from K.E.M. Hospital Mumbai by Dr. Sangeeta Ravat and her team also showed the same observation. It means that patients have gone for medical help soon after first episode, started the treatment but discontinued it and have come back with recurrence of seizures. Apart from the reasons like non-availability and non-affordability the important fact is that patient has not either understood or realized the value of regularity of AEDs and discontinued the treatment. If he does not get seizure for a while he stops the medication abruptly without consulting any body. Recurrence of the seizure and then he goes to the doctor again. To treat recurrence is more difficult. This can be avoided by making patient understand well at the beginning of the therapy all about duration and system for withdrawal of AEDs.

The reasons responsible for **Secondary TG** are as follows.

- \*\* Patient Related
- \*\* Communication - Patients do not communicate honestly and regularly with their doctors.
- \*\* There is lack of understanding for
  - \* duration of therapy
  - \* compliance for AEDs, medical follow up
  - \* dosage schedule, alternate names of AEDs
  - \* regularity of Life Style
- \*\* Worry about side-effects so they discontinue AEDs or reduce the dosage
- \*\* Poor control, this leads them to alternative systems of medicine.
- \*\* Physician related -
  - \* scarcity of Time, Concern, Commitment
  - \* Competent - Communicative - Compassionate- Often less than required

#### So what should be done?

- \*\* Patient should know that it is tailored individualized therapy and patient should not compare him with other patients.
- \*\* Management should be as per affordability and always patient centered.



- \*\* First few visits – duration of therapy must be explained
- \*\* Prescription should be perfect and detailed
- \*\* Importance of compliance – seizure diary must be known.
- \*\* Alertness for side-effects during followup visits
- \*\* Counselling of whole family
- \*\* If forced to taper off AEDs - Just before marriage - this should not be followed.
- \*\* Forthcoming events of stress - exams, interviews, travel abroad - this is not the time to start tapering of the AEDs.

Apart from these individual level efforts we also need **education programs** for different groups like community at large, local general practitioners and school children and teachers. We need to have attitude of co-operation with faith healers rather than confrontation. They should be able to diagnose genuine epilepsy from pseudoseizures. Refer epilepsy cases to available medical expert and happily treat pseudoseizures. These efforts will certainly reduce Primary TG.

### Secondary TG

#### \*\* Education

\* to **Family members and caretakers of the patients** must be educated and counselled properly about the illness, treatment schedule specially long duration of therapy, side-effects of AEDs and importance of **regular lifestyle** and **regular followup** with the treating doctor.

\* to **Family physicians, General physicians and Pediatricians**. They are often the first point of contact so they must be competent enough to handle emergency situation and guide the patients properly. We are few Neurologists across the country and we cannot treat all patients of epilepsy so let them treat but treat properly.

\*to **Gynecologists and Obstetricians** so that they guide pregnant women with epilepsy properly.

\* to **young neurologists** periodically with CMEs.

\* to **undergraduates and interns** so that they are well sensitized about multifaceted aspects of Epilepsy.

My Message to young colleagues is that :

\* Be competent, compassionate, communicative to patient and family in the same wave length of their capability of understanding and have Time, Concern and Commitment for them.

\* Right at the beginning spend enough time to emphasize importance of COMPLIANCE and long term therapy.

- Plan management as per their affordability to ensure sustainability.
  - Spend at least one Sunday in 2 months for rural OPD on regular basis.
  - Participate actively for educational and awareness activities for doctors, school children and community at large.
  - Encourage E-Support groups of your patients.
- The Government must develop Community/ Rural Health Care Model. It can be as follows.

- Identification camps - Door to door survey and regular follow up by paramedic follow up by expert at least every three months.
- Intensive health education to community and school children.
- Training in practical Epileptology to local doctors
- Institution of inexpensive AEDs at monthly or bimonthly interval at subsidized cost / free.
- Home distribution of AEDs in very distant places where transport is not available by mobile clinic.

We at organisational level ( IEA or IES ) must do advocacy proactively for :

- National epilepsy health care system
- Regular supply of primary AEDs
- Minimum cost of AEDs
- NGOs, medicine adoption projects, distance education program
- More specialized epilepsy centers in country
- Prevention of epilepsy - to work with ongoing programs for perinatal care, driving rules, and infections i.e. personal hygiene.

At the end of the day, we have to be hopeful and positive since my colleagues and I know that we have young, energetic and competent youngsters to carry forward Epilepsy Management even better.

*The Setting Sun said "Who will take up my work?" The world heard this and yet remained responseless. There was an earthen lamp, it said: "Lord! I will exert myself to my utmost" - Rabindranath Tagore*

### References

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- \* Meinardi et al Epilepsia 2001; 42 : 136-149
- \* Gourie-Devi et al Epilepsia 2003; 44(suppl 1 )58-62

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# Indian Epilepsy Association - The Road Ahead

Dr. H.V. Srinivas, Past President IEA



*In the* management of a person with epilepsy (PWE) just seizure control is not enough. To dispel the myths, misconception and stigma attached to epilepsy, and to integrate the PWE into society, patient education, public education is the need.

Indian Epilepsy Association (IEA), which is now 40 years old, with 28 chapters and more than two thousand members, is very much involved in this. However a lot more needs to be done.

The issues to be tackled are :

a) Public education, b) Patient education and counseling, and c) Epilepsy and law.

**Public Education** - A lot of work is being done by IEA through National Epilepsy Day celebrations, lectures, and street play, TV and Radio talks and so on, but it is still far below requirement. The best way to reach a larger audience, particularly in the rural area is through Doordarshan TV channel which has a larger penetration to the rural mass and also utilization of local TV channels in the regional languages through what is called as 'social advertising'. We do see a few advertisements regarding health issues however epilepsy related social issues need to be screened frequently to make an impact. This requires political will from IEA and lobbying with the concerned authorities. In addition, for the urban areas the FM Radio channel should be tapped for spreading the message about various aspects of epilepsy. The other important long term target is educating the high school children. It is always easy to teach or impress a person when they are not yet biased! Some chapters have been doing this at random but the ideal situation is to influence the respective state government (as education is a state subject) as well the central government (for CBSE curriculum) and incorporate one lesson on epilepsy for 9th & 10th std students. This would indeed change the perception about epilepsy as these children are the future of citizens of India. This again requires political will on the part of IEA chapters and lobbying with the concerned educational authorities.

**Patient education and counseling** - The medical fraternity - family physicians and primary health care doctors - can influence and change the wrong notions regarding epilepsy in the community,

provided they emphasize on the social aspects, besides seizure control. Often times the doctor concentrates on the medical management of epilepsy and has no time for educating the patients on social aspects. Hearing lies utilization of non medical persons to meet the objectives of IEA. The primary health care workers who are in contact with community in their area need to be educated regarding the social aspects of epilepsy. The IEA has started a distance education programme of Diploma in Epilepsy care (DEC) in English, Kannada and now in Hindi. The Govt. should be persuaded to make it compulsory or give incentives so that the PHC workers can enroll for this course and spread the message. It is time to have 'Epilepsy counsellors' who can assist the Neurologists, be it in teaching hospital, corporate hospital, and private practice. 'Epilepsy counselors' should have training in counseling course and then do DEC.

Finally, **Epilepsy and Law** - IEA after a prolonged struggle was successful through the efforts of Dr. K.S. Mani, Dr. Bharucha and others to get the constitution of Hindu marriage act amended so that, since 1999, epilepsy is no more a ground for divorce. IEA is pursuing the matter regarding epilepsy and driving, to implement the international standards of allowing a person with epilepsy to drive a personal vehicle when he or she is seizure free for one to two years. In western countries like UK and USA there is specific 'Antidiscrimination law' which comes to the rescue of people with epilepsy, if they are denied education, employment etc. when they are otherwise eligible. We still do not have such a Law but one can certainly use the legal recourses under the 'Fundamental Rights Act' if there is any discrimination. It may be worth considering 'Antidiscrimination Law' in the near future.

A lot more work needs to be done by IEA, but the road to success is through involvement of non-medical persons, who have a passion to work and have time to do so. The best way is to encourage their participation and give them positions in the executive committee and other such responsibilities, while the medical persons can concentrate on lobbying through Government and the media. ■

*Epilepsy* walked into our life on 26th Dec. 1992, the day after Christmas.

**V.R. Parameswaran**

Our son, who was born in 1984, was 8 years old then. We had gone out in the evening and after getting back home, I was about to leave for my office to catch up with some work. As I was getting down the stairs, my wife called out saying that something is wrong with our son. I rushed upstairs to find him looking dazed, going limp and drooling slightly. He definitely looked disoriented. We asked him what he was feeling. He was not responding at all. I remembered that we had given him a soft drink about half an hour back and my first thought was that this was a case of food poisoning!

Looking at him, my first thought was that we were going to lose him! We rushed him to the hospital (which was a 5 min. drive away) where his paediatrician was practising. As I rushed my son inside, the nurses took one look at him and said that none of the doctors were in the hospital at that moment and that I better take him to another hospital. My heart sank.

The hospital that immediately came to my mind was about 3 minutes drive away. The doctor there was an acquaintance of mine. I used to meet in social gatherings. He had also treated me earlier for the ache in my lower back when he was in another hospital. I had considered him a General Physician.

I rushed my son to this hospital. The paediatrician there started asking me questions like, 'what did he eat', 'has it happened before' etc., etc., without really moving into action. I was not getting anywhere. I asked for my acquaintance. I was told that he was not available in the Hospital at that time and that he was at home. I got his residence phone number and called him at his residence. I just told him, 'I am in trouble. Some thing is wrong with my son and your people are asking me questions instead of doing something about it'. He immediately came over. Took one look at my son and said, 'your son is going to get a seizure, there is nothing serious'. It was precisely at that moment that my son started convulsing. He also told me and my wife that it is not a pleasant sight and that we were better off leaving the room and that he

would take care of it. As we were leaving the room, we could see the fits becoming violent. After about 5 minutes the doctor came out and said that the seizures are over and we could see our son now. The A.E.D. was started immediately. Later on I understood that our son had a 'GTCS in status'.

We went home and only later did I know that my acquaintance is a trained Neurologist! When all this was happening, both of our parents reached the Hospital. We not only had medical support but also emotional support.

I do not think that we went through the 'denial phase' at all. We had total faith in the physician. That I think solved most problems for us. But my wife and I did go through a short period of 'soul searching', did we do anything wrong in bringing him up?



We did do a scan and there was no abnormality detected. We came to terms with the fact that our son has epilepsy and that we need to take special care about his sleep and drug compliance.

We let him have a normal childhood without any restrictions in playing and other activities. I distinctly remember that he got the 'balance' in cycling in 5 minutes flat! Just made him sit on the cycle, gave the cycle a push and that was it! We put him through swimming lessons, but never let him swim without supervision.

We saw to it that there was 100% drug compliance and that there was no deprivation of sleep. Whenever we had to go out, we saw to it that we always travelled during day time.

He never had seizures after the first episode in 1992. Around 1996 we did think of withdrawing the 'AED'. Around this time we found that our son was mildly dyslexic. He was approaching his school finals and we decided that we will think of withdrawing the 'AED' after his school final examinations are over.

At some point in time, our son did ask us as to why he was being asked to take the medicine he was taking. We told him that we will tell him at an



appropriate time. We simply told him 'just trust us; That was sufficient for him.

After his school final examinations, in 1999, he went across to Chennai for the holidays. That trip was probably his first over-night travel. After he got back from his holidays, we were planning to explain to him why he was taking the drug all along and that we were going to taper and wean him off the drug.

He got back from Chennai and sometime in the evening of the day he got back, he said that he was feeling funny! We just made him rest that day. An 'EEG' was taken the next day. There were abnormalities and it was decided that he needs to continue the drug till he was 24.

We explained his condition to our son and also impressed upon him the 'dos' & 'dents'.

We never had much trouble bringing up our son, he was by and large very compliant. He had got used to taking the medicine and at times used to ask for it even if we had forgotten!

As he was mildly dyslexic, we did not expect too much out of him academically. We just put him through a degree course in commerce. He completed the course in 2004.

Even when he was in college, we had told him that after his college, he needs to venture out, start to learn living on his own. He moved over to Chennai

after his college to stay with my sister-in-law in Chennai. He got himself a job with an auditor initially as an Assistant. He lived with my sister-in-law for a year or so. Then he moved on to a manufacturing company in the Stores Dept. He also moved out of my sister-in-law's place to live on his own.

He is now 28 and works for a major construction company. As he has to attend night shift at times, he is still taking the 'AED'. Recently we discussed the possibility of tapering and stopping the 'AED' but the doctor felt that it would be done best under supervision! As our son does not mind taking the drug we have left it that for the time being.

He is at a critical juncture in his life, where he needs to get married and raise a family of his own. As I said earlier, we consider ourselves very lucky that we got immediate medical aid. So when the Dr. Rajendran and Dr. Sreekumar initiated the formation of a Branch of the Association in Cochin, I immediately agreed. I have been holding some office or other all these years. I consider it as something I need to do by way of 'giving back'.

My only regret at this point in time is that not very many parents have come out so far to take an active part in the activities of the Association. We do not have a single patient who is active. I am plugging on under the fond hope that before long some one will come forward to take things along. ■

**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, Learning Difficulty Specialists, EEG Technicians and those working in Voluntary Services like IEA & 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 at [cbrnet@airtelmail.in](mailto:cbrnet@airtelmail.in); [ieabl@vsnl.net](mailto:ieabl@vsnl.net) [muralidharankv@gmail.com](mailto:muralidharankv@gmail.com)



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- Greater response in refractory childhood epilepsies and febrile seizure prophylaxis

**Designed to treat epilepsy differently & conveniently**





## Brain implant 'predicts' Epilepsy seizures

*A brain* implant may be able to predict epilepsy seizures by picking up the early warning signs, a small study suggests.

The device uses the brain's electrical activity to tell patients if their risk of a seizure is high, moderate or low.

The study on 15 people, published in the *Lancet Neurology*, showed the device worked in some patients.

The Charity Epilepsy Action cautioned that it was still early days, but said it could be an 'exciting development'.

Epilepsy is thought to affect 50 million people worldwide. Abnormal activity in part of the brain causes seizures signals were collected from the surface of the brain and sent down wires to another implant in the chest. This beamed the data to a hand-held device which worked out the odds of a seizure.

The trial was run at three hospitals in Australia and was funded by the manufacturers NeuroVista.

The results were mixed. For the first four months the brain was monitored so the system could learn a patient's brain waves before a seizure.

Only eight patients then progressed to the stage where the device was fully activated and they were constantly informed of their chance of a seizure. It was

between 56% and 100% effective in those patients.

Prof. Mark Cook, from the University of Melbourne, said if the technology could be proven it could help remove the unpredictable nature of epilepsy.

"Being able to predict the events with many minutes or hours lead time could have significant impact on independence."

This could change the way the illness is treated. For instance, our current strategy of giving medications continuously because of the unpredictable occurrence of events could alter the types of medications being developed.

"Short-acting therapies may prove to be effective without subjecting patients to the long-term problems that currently available therapies may cause."

Commenting on the findings, Christian Elger and Florian Mormann, from the University of Bonn Medical Centre, described the results as "a major milestone... showing for the first time, to our knowledge that prospective seizure prediction is possible".

They added: "Whether this performance is also sufficient for clinical applications is unclear, this will depend on how well patients tolerate false alarms or missed seizures."

Simon Wigglesworth, deputy chief executive of Epilepsy Action, said more research was needed, particularly given the "small sample size and the inconsistencies in the data collected".

"If a person is able to be alerted when they are about to have a seizure, this could help them to take steps to make sure they are safe during the seizure. The device could also be a useful tool for carers of people with epilepsy," he said.

"Predicting seizures may help us to understand more about the ways seizures can be managed and ultimately prevented."

Courtesy : <http://www.bbc.co.uk/news/health-22342448>





## Marijuana and its receptor protein in brain control Epilepsy

*Ingredients* in marijuana and the cannabinoid receptor protein produced naturally in the body to regulate the central nervous system and other bodily functions play a critical role in controlling spontaneous seizures in epilepsy, according to a new study by researchers at Virginia Commonwealth University.

The study, the first to look at marijuana and the brain's cannabinoid system in live animals with spontaneous, recurrent seizures, suggests new avenues that researchers can explore in their search for more-effective drugs to treat epileptic patients who don't respond to today's anticonvulsant medications or surgery.

The results appear in the Oct. 1 issue of the *Journal of Pharmacology and Experimental Therapeutics*.

"Although marijuana is illegal in the United States, individuals both here and abroad report that marijuana has been therapeutic for them in the treatment of a variety of ailments, including epilepsy," says Dr. Robert J. DeLorenzo, Prof. of Neurology in the VCU School of Medicine.

"But the psychoactive side-effects of marijuana make its use impractical in the treatment of epilepsy," said DeLorenzo, who was the lead author on the article. "If we can understand how marijuana works to end seizures, we may be able to develop novel drugs that might do a better job of treating epileptic seizures."

Epilepsy is one of the most common neurological conditions, characterized by spontaneously recurrent seizures. Approximately 1 percent of Americans have epilepsy, and 30 percent of those patients are

resistant to conventional anticonvulsant drug treatments. Cannabinoids have been used as a natural remedy for seizures for thousands of years, and studies since at least 1974 have found that the primary psychoactive compound in marijuana displays anticonvulsant properties.

DeLorenzo and his colleagues in the VCU Department of Neurology and the Dept. of Pharmacology and Toxicology have been studying

the therapeutic effects of marijuana on epilepsy and other illnesses for more than a decade. They were the first three years ago to show that cannabinoids work at controlling seizures by activating a protein known as the CB1 receptor that is found in the memory-related area of the brain, the nervous system and other tissues and organs in the body. Research has shown that the CB1 receptor is responsible for the psychoactive effects of marijuana. It also is responsible for controlling excitability and regulating relaxation.

The current study was designed to evaluate the role of the CB1 receptor and function of the body's cannabinoid system in regulating seizures.

The team injected chronically epileptic rats with different combinations of six drugs: 1) an extract of marijuana, 2) two synthetic drugs that include the key psychoactive ingredients in marijuana, 3) the common anticonvulsant drugs Phenobarbital and phenytoin and 4) a drug to block the activation of the CB1 receptor by cannabinoids in the brain. The marijuana extract and synthetic marijuana drugs completely eliminated the rats' seizures, which averaged three over a 10-hour period. The Phenobarbital and phenytoin failed to completely eliminate the seizures. Injection of the CB1 antagonist significantly increased the both the duration and frequency of seizures, in some cases to a level consistent with a severe, prolonged form of epilepsy known as status epilepticus.

"This study indicates that cannabinoids may offer unique advantages in treating seizures compared with currently prescribed anticonvulsants," DeLorenzo said. "It shows not only the anticonvulsant activity of exogenously applied cannabinoids but also suggests that the brain's cannabinoid system works to limit seizure duration by activating the CB1 receptor. Understanding the factors that contribute to seizure initiation and termination has important implications for our ability to treat epilepsy and for the potential development of novel anticonvulsant agents."

DeLorenzo's team is now assessing the dosage requirements and evaluating the long-term effects of using cannabinoids for epilepsy in animals.

Courtesy [http://www.news.vcu.edu/news/Marijuana\\_and\\_its\\_receptor\\_protein\\_in\\_brain\\_control\\_epilepsy#.UZRabbxPnyI.email](http://www.news.vcu.edu/news/Marijuana_and_its_receptor_protein_in_brain_control_epilepsy#.UZRabbxPnyI.email)





## Steven Gerrard pens doodle to raise funds for epilepsy charity

*Steven Gerrard*, captain of the famed football team Liverpool and a member of the England football team joined a team of sports stars who have each donated a doodle auctioned on eBay to raise money for an epilepsy charity, Epilepsy Action.

February 8th, 2013 was 10th anniversary of National Doodle Day in England and sketches from famous faces across sport went up for sale on the auction website.

Here's Steven Gerrard's effort.

Steven Gerrard provided this sketch of him wearing the Liverpool shirt alongside his wife and children. Gerrard has played every single minute of every Liverpool match this season – all 2,250 of them – but managed to find time to sketch himself arm-in-arm with his wife Alex and three children, Lilly, Lexie and Lourdes.

They are standing in a goalmouth each wearing a shirt reading 'You'll Never Walk Alone' with 'reach for your goals forever' across the top.



Bidding was open for 10 days and all money raised went to Epilepsy Action, which supports 600,000 people across the UK with epilepsy.

Other sportsmen and women who have donated their works of art include Sir Bobby Charlton, retired jockey Lester Piggott, former cricketer David Gower, ex-Formula One driver Mark Blundell, former Liverpool striker John Aldridge, ex-England manager Graham Taylor, Olympic silver medal winning gymnast Louis Smith, former Manchester United manager Ron Atkinson, ex-England striker Brian Deane, gold medal winning swimmer Katy Sexton and England and Arsenal footballer Stephanie Houghton.

Read more: <http://www.dailymail.co.uk/sport/football/article-2275541/Steven-Gerrard-pens-doodle-raise-funds-epilepsy-charity.html#ixzz2U12G4DmF>



## Congratulations !

**Dr. Bindu Menon** received the **UGADI VAIDYA RATNA AWARD** on 3rd May, 2013 at Ravindra Bharti, Hyderabad from Dr. K. Masilamani, District Medical Health Officer, Nellore. The award was given by the Sir C.V. Raman Foundation for her selfless and outstanding contribution in Social Welfare Activities in Epilepsy.





# Branch Activities

## Epilepsy Day celebration at Jaipur

*On* National Epilepsy Day, 17th November 2012, Indian Epilepsy Association, Jaipur Branch organized a public education program. The program held at Jaipur Medical Association Hall in the SMS Medical College Campus. All the local newspapers covered the news on 16th November for maximum awareness amongst the public regarding the program.

Around 200-250 people including patients, their relatives, doctors, pharma representatives and journalists attended and actively participated in the program. The program was inaugurated by Dr. Subhash Nepalia, Principal & Controller of SMS Medical College. In his speech he exhorted the patients and their relatives to take anti-epileptic

drugs regularly as in the case of patients with Hypertension and Diabetes Mellitus. Dr. Chandra Mohan Sharma addressed the gathering and stated that this

year on National Epilepsy Day the Indian Epilepsy Association had decided to focus on epilepsy and employment. Many of the patients facing problems at the work place discussed their problems with other patients and experts. Dr. Sharma stressed especially to press and media to spread the message to all patients with epilepsy and their relatives to fight for their rights if employers harass any patient due to epilepsy. This message should reach to everyone in our country. Press and public can play important role in removing stigma about epilepsy and employment.

Dr. Anjani K Sharma, Prof. of Neurology spoke on the various types of epilepsy. Dr. Arvind Vyas, Prof. of Neurology insisted that patients should not miss a single dose of drug as this can precipitate the seizures. Dr. B.L. Kumawat, Associate Prof. of Neurology, SMS Hospital, explained about the myths in epilepsy and its causes in various age groups, precautions during pregnancy and "Do's and Don'ts" in epilepsy. Dr. Trilochan Shrivastava, Associate Professor explained the

importance of preventive aspects of the disease. Dr. Dinesh Khandelwal, Assistant Professor, addressed the gathering and discussed about general guidelines regarding treatment and side-effects of the drugs. Dr. Deepak Jain, Dr. Ravindra Singh and Dr. Shailesh Dixit also discussed the various aspects of epilepsy.

All the Neurologists of SMS Hospital Jaipur had an interactive session with patients and their relatives, answered their queries and explained to the patients regarding importance of the role of detailed history narrated by the eyewitness for the correct diagnosis of epilepsy. They emphasized that the video recording by mobile camera phone is a very convenient tool for this purpose. They also explained the role of surgery in patients with intractable epilepsy.

At the end of the function Dr. Chandra Mohan Sharma stated that epilepsy is treatable with drugs and surgery and gave emphasis on getting treatment from qualified doctors not from the quacks.

On this occasion an exhibition of posters in Hindi was put up 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 cash prizes courtesy Len Brook Pharma. School bags, color pencils and drawing boxes were distributed to all the children who attended the program. Free anti-epileptic drugs were distributed to patients.





# Branch Activities

## Tirupati Branch

At the outset, the Association would like to place on record the help and co-operation extended by the authorities and staff of Sri Venkateswara Institute of Medical Sciences (SVIMS), Tirupati in all the activities undertaken by the Association.

The Association is indeed very grateful to the Director, faculty members of the Dept. of Neurology, Nursing staff and students and all others for all the assistance extended. But for these kind hearted people, the Association would not have been able to serve the poor persons with Epilepsy of this area.

As on March 31, 2013 our Branch had 51 Life members and 69 Annual members. Counseling of persons with Epilepsy attending SVIMS is being done regularly. Identification cards designed by us and booklets in Telugu on Epilepsy are being given to all persons with Epilepsy free of cost.

The special monthly camps for persons with Epilepsy were continued without any interruption. The average attendance in these camps is now around 600. One month's requirement of medicines is being distributed FREE to all patients. 170 camps have been organized till the end of March, 2013. At present, the monthly camps are being organized every 3rd Sunday for logistical reasons. M/s. Americares, a charitable organization based in USA is continuing the donation of anti-epileptic drugs for free distribution to those attending the monthly camps and regular O.P. Dept. at SVIMS.

Tirumala Tirupati Devasthanams (TTD) have kindly agreed to donate medicines worth Rs.1,00,000/- (Rupees One lakh) per month since July, 2011 under S.V. Pranadana Trust Scheme. The Association is very grateful to the authorities of T.T.D. for their kind gesture. This is in addition to Rs. 10,000/- worth of medicines per month being donated by SVIMS.

Tests prescribed by doctors for the patients attending the camps are being performed at concessional rates at SVIMS. EEG tests for



poor patients are being performed at a nominal cost of Rs. 130 for poor patients using the portable Digital EEG machine donated by the Association in 2007 to the Dept. of Neurology, SVIMS, Tirupati.

### National Epilepsy Day 2012 Celebrations at Tirupati, A.P.

On 17th Nov., 2012 an awareness programme for the benefit of school teachers of Chittoor District of A.P. was arranged. 87 teachers sponsored by the

Government attended the programme.

Sri G.V. Srinadh Reddy, member, T.T.D. Board of Trustees was the Chief Guest for the Inaugural function. Faculty and D.M. students of the Dept. of Neurology, SVIMS were the resource persons. Various aspects of epilepsy such as superstitions, diagnosis and management, education and rehabilitation were discussed with charts and audio-visual aids.

The 166th monthly camp for persons with epilepsy was held on 18th Nov. 2012 (3rd Sunday of the month). About 615 persons with epilepsy and 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.

Dr. B. Vengamma, President of the Tirupati Branch of Indian Epilepsy Association, outlined the significance of the National Epilepsy Day. She also reported about the camps being held for the past 166 months.

Guruji Dr. K. Venkatesan, a spiritual leader of Chennai and Sri Prasanth Narayan, an industrialist of Bangalore, who were the guests of honor, were greatly impressed by the service activities of the Tirupati

Branch and assured of all help to sustain and improve the activities of the Branch.

A skit enacted by the students of the College of Nursing, SVIMS, bringing out certain problems faced by persons with Epilepsy and the needed remedial measures, was greatly appreciated. The local media covered these





# Branch Activities



events .

IEA Tirupati is grateful to the IEA - 18th IEC Trust for their partial financial assistance to organize this year programmes.

## IEA Tirupati Oration in Epileptology

The Tirupati Branch of the Indian Epilepsy Association donated Rs. 3 Lakhs to Sri Venkateswara Institute of Medical Sciences (SVIMS), Tirupati, with a request to institute in the Dept. of Neurology, SVIMS an Annual Oration entitled “**IEA TIRUPATI ORATION IN EPILEPTOLOGY**” commencing from the year 2010.

Dr. S. Kalyanaraman, Former Professor of Neuro Surgery, Madras Medical College and a Senior Consultant at Chennai delivered the THIRD ORATION on the topic “**Frequently asked questions by Patients and Caregivers about Epilepsy**” on 8th December, 2012. Sri L.V. Subramanyam IAS, Executive Officer, Tirumala Tirupati Devasthanams was the Chief Guest.

Dr. Kalyanaraman delivered an erudite lecture bringing out the various myths and superstitions that exist even today in our country. Then he presented in detail, in his inimitable style, information required for patients with seizures, their parents, teachers, friends, employees, caregivers and neighbors. He also dealt with the medication, precautions, side effects of drugs and various other social aspects related to Epilepsy. There was a lively discussion following the lecture of the senior-most Neuro-Surgeon of our country.

The Association is registered with the authorities under Section 12(A) of the Income Tax Act and donations to the Association will qualify for exemption under Section 80(G) of the Income Tax Act.

The Association would like to thank very sincerely

all the donors for their generous contributions and AmeriCares for their donations. The Association is equally grateful to T.T.D. and SVIMS authorities for their continued financial assistance.

Some important highlights of the 170 special camps conducted till end of March, 2013 are given below :

Average attendance per camp About 600

Total cost of medicines distributed

free till March, 2013

Rs. 1,17,50,763

SVIMS & S.V.Prandana

Trust contribution

Rs. 54,28,660

Donation from AMERICARES and from Pharmaceutical Companies and

benevolent donors

Rs. 63,22,103

Finally the Association would like to place on record its sincere appreciation and gratitude to the following who made this “Sacred Service” a reality against all odds :

- (i) Dr. B. Vengamma, Director and Prof. of Neurology, SVIMS.
- (ii) The Executive Officer, T.T.D. and S.V. Pranadana Trust.
- (iii) Medical Superintendent, Principal, School of Nursing, Asst. Director of Nursing, Nursing Superintendents and other officials of SVIMS.
- (iv) Mr. K. Vivekanand, Medical Records Officer, his colleagues and students, Nursing staff & Nursing students.
- (v) Faculty and Staff of Dept. of Neurology.
- (vi) Members of the Friends of SVIMS Society and the Indian Epilepsy Association.

**Dr. B. Vengamma** (President)

**Dr M. Nagarathna** (Secretary)





# Branch Activities

## Mumbai Branch

### SYNOPSIS

- Given information over the phone and to visitors
- Conducted individual, family & group counselling
- Given special / remedial education
- Conducted yoga classes
- Given medicines at a reduced rate
- Had Support Group Meetings on the 2nd and 4th Saturdays of each month.
- Conducted Awareness Programs
- Conducted rural epilepsy camps

### DETAILS OF OUR MAIN PROGRAMS

#### Rural Epilepsy Camps, Pen

Four rural epilepsy camps were held at Pen, Raigad district on 1) 27th May 2012, 2) 5th August 2012, 3) 28th October 2012, 4) 27th January 2013.

An average of 90 patients attended each camp where medicines are given free or at a very nominal rate.

We are thankful to Mr. Ashokbhai Parekh who continues to provide us infrastructure to conduct this camp which started on 18th November 2007, and thankful to General Physician Dr. Wagle of Conwest Jain Medical Research Society who attends to patients at each camp along with Dr. Pravina Shah and Samman volunteers.

#### Epilepsy Training & Awareness Programs

- A training program for health workers from different regions of India was organized by the National Association for the Blind. On 4th October we were invited to educate these workers about epilepsy management and treatment. Dr. Pravina Shah and Carol D'Souza participated in this program.
- Kavita Shanbhag arranged a radio interview in Hindi wherein Dr. Urvashi Shah was interviewed on Trinayani FM Radio during their program Mud Mud Ke Na Dekh on 7th November, 2012.
- Kavita Shanbhag also arranged a radio interview in Marathi wherein Dr. Sushil Tandel was interviewed on Asmita Vahini FM Rainbow channel on 16th November, 2012.
- On 21st November 2012 we had an epilepsy education program at the corporate office of Axis Bank at Worli. It was initiated by Meera Rajendran of Axis Bank. Dr. Urvashi Shah, Ignatius Misquitta, Kavita Shanbhag and Carol D'Souza participated in this program.

### Support Group Meetings - 2nd & 4th Saturdays

At each support group meeting a topic is discussed and members are encouraged to give their views on the same. Details of support group meetings are given on my blog **ecellin.com**. As decided at the last AGM we started giving members an opportunity to conduct support group meetings. Every 4th Saturday a member was made responsible for the arrangement / making of snacks. Salil, Christopher and Ashish, had a few meetings on – prayer and anger management, Nola conducted one on EEGs, I had done a few Saturdays on '8 ways to Beat the Blues' (a program detailed by renowned Psychiatrist Robert Mittan especially for people with epilepsy) and a couple of Saturdays on **Changing Habits that Don't Work for Us**, I also did a presentation on **'Beyond Medicine – What People With Epilepsy Need'**. Kavita Shanbhag conducted a meeting with ABT games. Dr. Urvashi Shah and Dr. Sujata Kanhere and Mr. Prakash Kadam took care of the Diwali celebration whilst our Catholic members took care of Christmas Celebrations. Members celebrated important events in their individual lives with the support group by bringing special treats. All our regular members have contributed in this way and we thank them all.

### EMPOWERMENT PROGRAM

The Empowerment program started in February 2012 continued through the year. In this program members who have uncontrolled epilepsy come to ECell and make handicrafts like paper bags and crochet items. Our Association buys their products and sells it for them or uses the items as gifts. 80 crochet bags made by Tanvi Marathe were purchased by ECON 2013 (Indian Epilepsy Association National Conference).

#### Samman Association

At last Samman has a separate identity of its own. After working for two years we were finally able to register Samman as a separate Association on 22nd August 2012.

#### Epilepsy Day Celebrations

We celebrated Epilepsy Appreciation Day on 24th November 2012 at Ravindra Natya Mandir. Prior to the event we had asked members and caregivers to send in their entries for the **'Living Courageously With Epilepsy Award'** and **'Caregiver of the Year Award'**. The former was awarded to Shenaz and the latter to all the five caregivers who entered the competition. Members who were trained by Medha Deolalkar did a welcome dance. We also had a Fancy Dress Competition and took this opportunity to

# Branch Activities

celebrate Late Alpana Palan's life with us with a very touching presentation about the time she spent with us.

After a snack and tea break we had a music program performed by Ashokbhai and his Guru Gagan Singh and teenage vocalist Priyanka along with backup musicians. We thank Ashokbhai and his team for this enjoyable performance.

## **Exhibition cum Sale**

This year we participated in two exhibitions cum sale: the first at the Child Raise Diwali Mela held in Matunga and the second at the Indus Festival of Charities which was held at the YMCA Colaba on 8th December. As usual we enjoyed interacting with the other participating NGOs and selling our products.

## **ECON 2013 - Hyderabad 9th & 10th of February**

12 Samman members/caregivers attended this conference. They performed a skit at the patients' session. Dr. Pravina Shah gave the Presidential Oration and Carol D'Souza gave the Bajoria Oration. Three days prior to the conference, we organized sight seeing tours which covered Salarjung Museum, Nizam Museum, Birla Temple, Chowmohalla Palace, Golconda Fort, Zoo Park, Lumbini Park and Ramojee Film City.

**BLOG:** [Ecellin.wordpress.com](http://Ecellin.wordpress.com) set up and managed by Carol D'Souza has received good feedback. ■



# **Indian Epilepsy School 2013**

Jointly organized by

**Indian Epilepsy Society (IES) ■ Indian Academy of Neurology (IAN)**

Under the aegis of

**Asian Epilepsy Academy (ASEPA) ■ Commission on Asian & Oceanian Affairs (CAOA)**  
**International League Against Epilepsy**



Date : November 13-16, 2013 (Wednesday to Saturday)  
Venue : Hotel Claridges Surajkund, National Capital Region, Delhi



**Pre-conference EEG Workshop**  
**Organized by Indian Epilepsy Society**  
**Nov. 12th-13th, 2013 (Tuesday-Wednesday)**  
**Venue : Janakpuri Super Speciality Hospital**  
**Govt. of NCT of Delhi, C-2/B, Janakpuri, New Delhi**  
**Course Organizer : Dr. Man Mohan Mehndiratta**  
**Course Director : Dr. Manjari Tripathi**

## **Venue - The Claridges**

Nestled in a forested neighborhood, making it the perfect place for repose, The Claridges, Surajkund, Delhi, NCR, is set amid sylvan surroundings overlooking the 10th century heritage Surajkund Lake Complex. The luxury business resort's tranquil ambience belies its proximity to the busy South Delhi residential and commercial centers. Stylish elegance reflected in its minimalistic décor and state-of-the-art facilities combine with advanced environment friendly features to create a soothing and refined ambience.



### **COST DETAILS**

Accommodation

Room Type	INR	Inclusions
Single	10500	Room with all meals & taxes
Double	11500	

**Distances :** International Airport 25 Kms - 45 min;  
Domestic Airport 22 Kms- 45 min.; City Centre 20 Kms-35 min.

**Indian Epilepsy School 2013**  
**From Nov. 13th-16th, 2013 (Wednesday thru Sat.)**  
**Organized by Indian Epilepsy Society**  
**& Indian Academy of Neurology**  
**Course Organizers:**  
**Dr. Man Mohan Mehndiratta & Dr. Manjari Tripathi**

**The registration will be limited to 50 delegates and we are happy to inform you that we have already started receiving the registrations.**

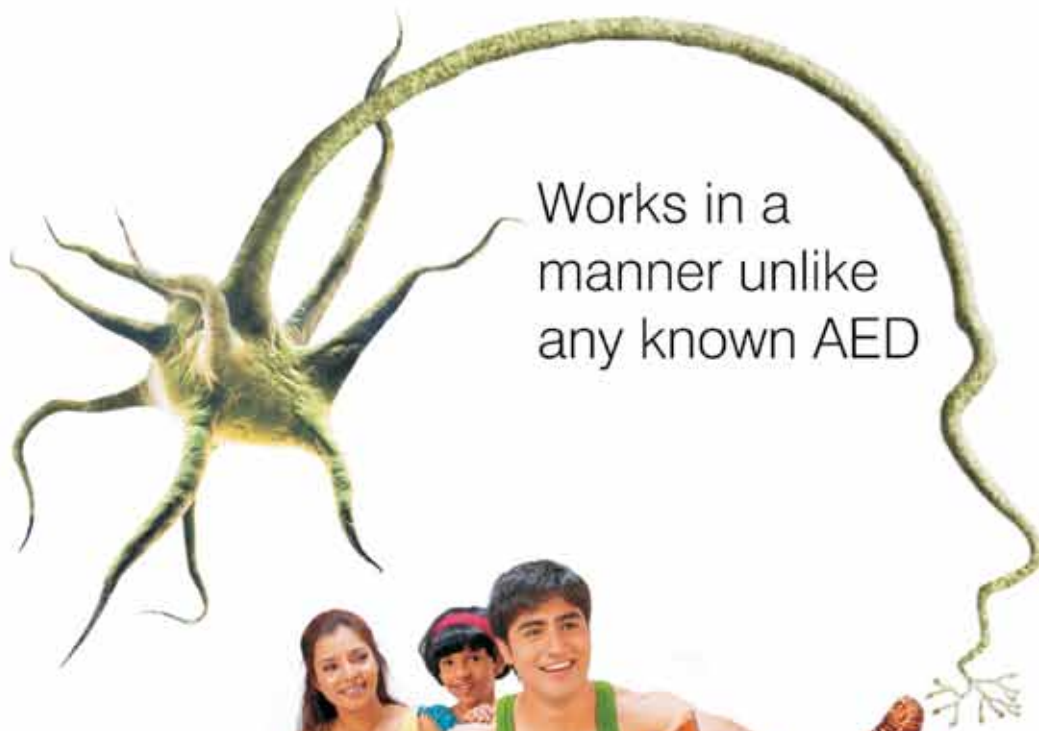
**For Registration Forms : <http://www.ilae.org/Visitors/Congress/congressinfo/IndianEpilepsySchool-2013.pdf>**



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