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# Epilepsy India



Newsletter of the Indian Epilepsy Association & Indian Epilepsy Society



**30th International Epilepsy Congress, Montreal**

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Dear All,

The 30th International Epilepsy Congress, the biennial meeting of International League against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE), was held between June 23- 27, 2013, in Montreal, Canada.

The Montreal conference brought a lot of cheer for us Indians. Seventy delegates, invited Lectures by Dr.K.Radhakrishnan, Dr Gagandeep Singh and EI Co-Editor Dr.Vinayan, platform presentations by Dr Sangeeta Ravat and Dr Manjari Tripathi, and forty posters presentations is a great achievement for Indian Epileptology. In addition Dr.K.Radhakrishnan and Dr K.P.Vinayan were in the review committee for the abstracts.

Another matter of pride for us is the elevation of Dr. Mehndiratta as Vice President – South east Asia region of the International Bureau of Epilepsy and also as member of the Commission on Asian and Oceanian Affairs.

EI team salutes all of you.

The Midterm meeting of IEA and IES at Kolkata was very fruitful. Held at the Taj Bengal, which is the conference venue for ECON2014, the meeting also saw the launch of Epilepsy India under a new team.

The vexing problem for any physician treating epilepsy is the breakthrough seizure, caused by non compliance (NC). This may be in the form of drug NC

or life style NC. In my own practice drug NC was the cause of break through seizures in a vast majority. The perception of compliance from the patient's point of view depends on a number of factors. Epilepsy being a paroxysmal disorder produces a sense of complacency after a seizure free interval of weeks or months, which is a major reason for poor compliance. In a developing nation like India, financial consideration is also a major concern for the patient, especially those on poly therapy using newer anti epilepsy drugs (AEDs). The compliance decreases with multiple dosing. Of course, this can to a large extent, be overcome by using sustained release or chrono preparations. The compliance can be made better if the physician spends more time with the patient not only at entry, but also during every follow up visit.

In this issue, Dr Rathore and Dr Radhakrishnan from Sri Chitra Institute Trivandrum, examine the problem of compliance and they offer certain practical solutions which we can incorporate in our practice. Carol D'Souza, brought out this very beautifully in her Bajoria Oration at Econ 2013, Hyderabad entitled "Beyond Medicine - What people with Epilepsy need". Her oration is published in this issue and the points she raises need to be remembered by all of us who are treating people with epilepsy.

The story of Amrita Bashyam from Bangalore will be an inspiration to persons with epilepsy. How she overcame the medical and social issues connected with epilepsy is a lesson which no text book can provide. Let us salute Amrita. ■

# 30th International Epilepsy Congress, Montreal

The 30th International Epilepsy Congress, the biennial meeting of International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE), took place between June 23- 27, 2013 at Palais des congrès de Montreal, Place Jean – Paul Riopelle, Montreal, Canada .

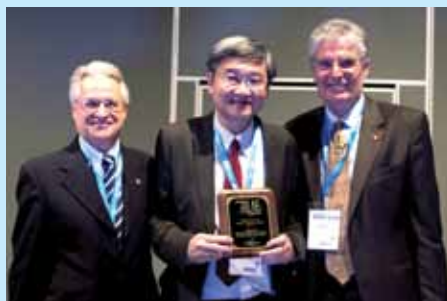
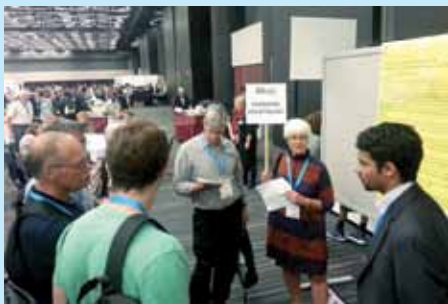
The congress opened with a welcome ceremony on 23rd June with addresses from Dr. Solomon Moshe, and Mr. Mike Glynn, outgoing presidents of ILAE and IBE respectively. This was followed by the award ceremony which consisted of the presentations of the Ambassador of Epilepsy award, the Social Accomplishment award and the Life time achievement award. Dr. Juhn A Wada (of Wada test) received the life time achievement award for his pioneering work in Epilepsy. Ms. Jane Hanna (UK) was the recipient of the social accomplishment award for her work related to SUDEP. Michael Prize for the best contribution to scientific and clinical research in epileptology was awarded to Dr. Ding Ding (China). This was followed by a welcome reception at the congress venue.

In the ensuing days, the congress showcased the current understanding of the neurobiology of epilepsy along with newer trends in the diagnosis

and management. There were special sessions dedicated to the proposed modifications in the definition and organization of epilepsies, which if adopted, will have a major impact on the clinical practice of epileptology. Another highlight of the congress was the combined sessions with sister organizations like World Federation of Neurology (WFN) and American Epilepsy Society (AES). The morning case oriented teaching and video sessions were very well appreciated. Dedicated sessions on the controversies pertaining to diagnosis and management of epilepsy and the role of therapeutic guidelines were other unique features of the congress.

“Mission Impossible “- the EPI- QUIZ was the star attraction of the Montreal Congress. It was really entertaining to watch the teams consisting of several stalwarts in epileptology fighting against each other. Dr. Manjari Tripathi represented India in this event. In view of its popularity, it is hoped that EPI- QUIZ will become a regular feature in the future congresses.

The congress received more than 1250 scientific abstracts for presentation, which in itself was a record. The abstract review committee selected



## Dr. Vinayan K.P.



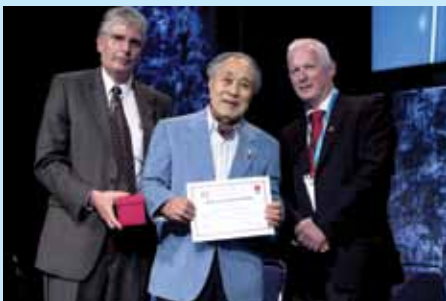
72 abstracts for platform sessions. Prof. K. Radhakrishnan and Dr. KP Vinayan were part of the abstract review committee. There were dedicated guided tours during the poster viewing sessions.

Considering the distance, India was well represented in the event. There were around 70 delegates from India. Travel bursaries were awarded to Dr. Sarat Chandra, Dr. Siby Gopinath, Dr. Lakshminarayanan, Dr. Praveen Raju and Dr. Shaily Shukla for their scientific work. From India, around 40 abstracts were presented during the poster session. In the platform session, Dr. Sangeeta Rawat presented her work on the surgical outcome of bilateral hippocampal sclerosis by noninvasive evaluation and Dr. Manjari Tripathi presented her work on the degree of concordance in seizure phenomenology between the clinical descriptors of caregivers and video and video- EEG recordings. Both the scientific papers were very well appreciated.

Prof. K Radhakrishnan gave two illuminative lectures in the congress. He spoke on the role of Antiepileptic drugs (AED) in patients with epilepsy associated with brain tumors in the Asian Epilepsy

Academy (ASEPA) course on the 26th morning. He was also a faculty in the main session on withdrawing AED. He emphasized the need for increased physician awareness about the expectations of families and patients and the need for proper patient education at the time of drug withdrawal. Dr. K P Vinayan discussed the issues in the diagnosis and management of status epilepticus in the neonates, as a part of the symposium on pediatric status epilepticus. In the session on controversies in epilepsy due to Neurocysticercosis, Prof. Gagandeep Singh dealt with the complex relationship between mesial temporal sclerosis and neurocysticercosis.

And finally it was the time for transition. New organizational teams lead by Dr. Emilio Perruca (ILAE) and Dr. Athanasios Covanis (IBE) formally took over office during the congress. Prof. Mehndiratta is representing India in the IBE board as the Vice president, South East Asia. Hope the new leadership will be able to take the international epilepsy movement to greater heights!





# Treatment Compliance in Epilepsy

**Dr. Chaturbhuj Rathore**  
**Dr. Kurupath Radhakrishnan**



As in any other chronic disease, compliance to the prescribed treatment is extremely important for ensuring the optimal outcome in patients with epilepsy. Though quite widespread and well reported in literature, treatment noncompliance is not well recognized by the clinicians in routine practice. This can lead to poor seizure control with associated physical injuries and psychological problems, thus adversely affecting the patient's overall quality of life. At the same time, failure of a physician to recognize the extent of noncompliance may result in unnecessary investigations and treatment changes leading to increased health care costs. Treatment compliance in epilepsy is not restricted to the medical treatment alone but also encompasses compliance to various life style and behavioral modifications regarding daily activities such as sleep, avoiding alcohol, driving and swimming.

Recently, there is a growing debate about the use of the term "compliance" which has connotations of subservience and which puts the entire onus of the compliant behavior on the patient. In other words, it means that the problem of noncompliance lies with the patient without realizing that it can result from a variety of clinical, social, psychological and other factors. Some authors have suggested "adherence" as an alternative term which roughly means what is expected of the patient as opposed to compliance. Though this term implies a more mutual arrangement of co-operation and agreement between the patient and physician, this is not universally accepted and the term "noncompliance" is still widely used.

## **PREVALENCE AND CAUSES OF NON COMPLIANCE**

Noncompliance is a multifactorial and complex attribute. Compliance to epilepsy treatment is influenced not only by the medical condition but also by the various psychological, social, occupational, demographic and cultural factors. The type and

the extent of the noncompliance also varies from missing occasional doses to completely stopping the treatment or being compliant to AED regimen while being noncompliant to life style modifications.

Various studies have reported that approximately 30–50% of persons with epilepsy are noncompliant to the extent of interfering with their optimal treatment. A longitudinal follow-up study from epilepsy clinic at Medical College and Hospital, Burdwan, West Bengal, in which 1450 new patients with epilepsy were followed up over one year, reported that 620 (43%) patients discontinued the treatment.<sup>1</sup> Among them 88.7% patient had breakthrough seizures for more than two occasions. In this study, one-third of the patients were illiterate, the majority was from lower socio-economic class and almost all had visited epilepsy clinic for the first time. On the contrary, in a study of 200 patients attending the epilepsy clinics at Sree Chitra Tirunal Institute for Medical Sciences and Technology (SCTIMST), 96% patients reported a compliant behavior regarding medicine intake while one-third felt that there is no harm in occasionally missing an AED dose.<sup>2</sup> Majority of these patients were literate and had attended the epilepsy clinic multiple times. These two studies suggest the effect of psychosocial factors on the extent of noncompliance. Studies from western countries have also reported variable noncompliance rates of 30-50% depending upon the definition of noncompliance used and how the noncompliance was measured.

Various factors found to be associated with noncompliant behavior also vary as per the study setting (Table 1). In the above mentioned study from Burdwan, patients who discontinued treatment reported that cost of medicines consumed 40% of their total income.<sup>1</sup> The important factors which led to discontinuation of treatment were financial

**Table 1**  
**Factors associated with noncompliance and strategies to improve compliance**

Factors associated with Noncompliance	Strategies to improve compliance
Medical Factors Complex AED regimens Frequent dosing Polytherapy AED related side-effects Difficult to control seizures Ineffective doctor patient communication Memory problems	Simplify AED regimens Once or twice daily dosing Avoid polytherapy and overtreatment Consider presurgical evaluation in suitable patients Establish effective doctor patient communication Explain the nature of disease and need for the regular treatment Setting alarms and messaging services Use of pill organizers and multi-compartment pill containers
Psychosocial factors Younger age Financial constrains Inaccessible health systems Non-availability of medicines locally Cultural beliefs and superstitions Stigma associated with epilepsy Fear of AED side-effects Illiteracy	Choosing cost-effective and locally available drugs Establish effective doctor patient communication Patient education and public awareness programs

overburden (90%), unemployment (29%), frustration and despair (21%), non-availability of medicines locally (20%), superstitions about epilepsy (17%), and marital disharmony (10%).<sup>1</sup> In the study from SCTIMST, we found that effective doctor-patient communication, internal locus of control and more number of clinic visits were positively correlated with improved compliance.<sup>2</sup> Other factors found to be strongly associated with noncompliance are younger age including adolescents, complicated AED regimens and the use of polytherapy, feeling of stigma associated with epilepsy and AED use, presence of AED related side-effects, and not realizing the importance of continued AED use. Complicated AED regimens including frequent daily dosing have been found to be associated with increased rates of noncompliance. Majority of patients prefer once daily dosing which is easier to incorporate in their daily routine. Some studies have shown that patients with generalized tonic-clonic seizures (GTCS) and those with a higher seizure frequency are more likely to be noncompliant. However, it is possible that patients with GTCS are more likely to consult a physician

immediately than those with partial seizures. In India, patients with difficult to control epilepsy often lose faith in the drugs and try other medical systems and alternative forms of therapy. Parental attitude also affects the compliance in children. Parents with a good knowledge of epilepsy had a positive impact on their children's compliance. On the other hand, parents who had higher expectations about their children's academic achievements showed less compliance probably because of the fear of cognitive side-effects of AEDs. Few studies have also shown that patients belonging to families in higher socio-economic class are less likely to be compliant, suggesting that compliant behavior is not dependent on the economic factors alone.

### MEASURING COMPLIANCE

The measures of compliance, though not perfect, can be largely divided into two groups: direct and indirect. Direct methods of measuring compliance include estimations of drug levels in blood, saliva or hair. Indirect methods include patient self-report through interview or questionnaire, pill counts,

electronic monitoring systems, and medication refills. Estimation of drug levels in blood can provide a direct objective measure of compliance, but has certain limitations. Single AED level estimation provides the measure of compliance at a given time point and cannot give an idea about the long-term compliance. This is further affected by the phenomenon of “white coat compliance” where a patient may be compliant only for few days before the appointment. Serial random estimation of blood levels has been suggested to overcome this limitation, but is not a practical method especially in developing regions. Similarly, the estimation of blood levels to measure compliance is not applicable to many of the newer AEDs.. Estimation of drug levels in hair and saliva appears to be less reliable.

The most common and easiest method to measure the compliance is through patient self report using interviews or questionnaires. However, there is no validated self reporting tool to measure compliance and the results vary as per the method used. Patients have tendency to give socially desirable responses leading to over-reporting of compliance. The method of counting the remaining pills in the patient’s container as a measure of compliance is more suitable for a research setting within a controlled atmosphere rather than in routine daily practice as patients can alter the number of pills in many ways. In the Medication Event Monitor System, or event recorder, standard pill bottles with inbuilt micro sensors that record bottle openings, each of which is considered a dose are used. This can give an idea not only about the dosing but also about the timing of dosing. However, it has the same limitations as pill counting. In a country like India, patient self report through a clinic interview appears to be the most suitable method for measuring the compliance.

### STRATEGIES TO IMPROVE COMPLIANCE

Identifying the cause for the noncompliance and the directed corrective measures is the most important strategy to improve compliance (Table 1). In India, the major factors associated with noncompliance are financial constraints, inaccessible health care system,

social stigma, illiteracy, wrong cultural beliefs and superstitions. This is further compounded by the inadequate doctor-patient communication due to the large number of patients attending the epilepsy clinics. Although many of these factors requires large scale changes in the health care system in India, a few small measures at clinic level can help in improving the compliance. This includes prescribing cost-effective and easily available AEDs according to the financial status of the patient, keeping the drug regimens as simple as possible, and improving the doctor-patient communication. An effective doctor-patient communication should focus on explaining the nature of disease and the need for the long-term regular treatment, providing adequate information about medication regimen, removing anxiety and fear of AED side-effects, and involving patients in their decision making. At the community level, it can be achieved by conducting large scale public awareness programs which can also help in removing the stigma associated with epilepsy. For patients with complicated AED regimens, strategies like pill organizers and multi-compartment pill containers may be beneficial. In patients with memory problems, innovative strategies including setting up alarms and reminders through mobile message services (SMS) can help in improving compliance.

Noncompliance to the AED treatment and towards life style modifications is a widespread problem in epilepsy which results in inadequate seizure control and increased health care costs. Recognizing the extent of the noncompliance and identifying the correct cause can help in minimizing it by employing directed measures. An effective doctor-patient communication and educating patients about the epilepsy treatment is the most important strategy at clinical level in our country.

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# Beyond Medicine – What People with Epilepsy Need

Carol D'Souza



At Econ 2013 I was given the honour of speaking at the Bajoria oration and I chose to speak on 'Beyond Medicine – What People with Epilepsy Need'. I researched this topic with our Support Group members and on different epilepsy sites and discussion groups. Caregivers / People with epilepsy not only reported their needs but also detailed how these could be satisfied. These I have given below in italics.

## Beyond Medicine What Caregivers and People with Epilepsy Need from their Doctors

### 1. Attention

*"We are each unique when it comes to epilepsy – we may have the same symptoms but we have very different experiences, before during and after"; the doctor could "Look at me as a person who understands his illness and is relaying what he feels."*

Often after a patient begins reporting, the doctor feels s/he has heard this story many times before, and s/he begins writing the prescription. The appeal from patients and caregivers is: Each of us is different! Give us appropriate attention. It is very important to our comfort level and consequently our ability to report all that we want.

### 2. Proper Investigation

*"The doctor kept increasing medicines each time I had a seizure and it was not helping. I learnt the hard way that I had to tell him about the other stressors in my life". "I am in awe of my doctor and sometimes forget to report even what I want to. Please ask the doctors to simply ask us at the end of the consultation if there is anything more we need to tell them."*

Many times patients have a 'Not asked won't tell' policy. Doctors would do well to probe for triggers other than did you sleep well, eat well and take medicines on time.

### 3. Information on Side Effects of Medication

*"I suffered hair loss for many months and ascribed different reasons for it." The doctor could "Tell me about*

*the side effects of medicines. Reassure me that side effects are what I should watch for and not what will be. Also inform me of the supplements I need to take to counter side effects."* How much should the doctor tell a patient is often the doctor's dilemma. Doctor's should inform which side effects would stabilize with time and which side effects need to be reported immediately in case experienced.

### 4. Advice on when to take medication

*"No one ever told me when to take pills, just to take them twice a day".* Doctors need to Prescribe simple regimens and inform that doses twice a day need to be taken 12 hours apart (e.g. 8 am, 8 pm), thrice a day would mean approximately 8 hours apart (e.g. 6 am, 2 pm, 10 pm). Doctors also need to inform whether it is to be taken before, after or during meals. Further, doctors need to consider all the medications used by the patient and not just the anti-epileptic drugs, as well as consider the daily routine of the patient and if possible coincide the dose with a daily ritual. Research shows that patients inform they are regular with their medication even though they may often be taking medicines later than the scheduled time or forgetting to take a dose now and then. Doctors need to probe whether patients are really being compliant.

### 5. Information on Seizures & What to do in an emergency

*"I want information on exactly what a seizure is and the different types; information on first aid and what can be done in special situations etc" "I want simple explanations".* The doctor could keep such information in the waiting room area, on posters and/or leaflets especially if he does not have the time to impart the same.



There are times when doctors may keep a stock of information. However this fails to get replenished. Though there is abundant information available on the internet, it is in the waiting rooms that people have the most time. Information is needed not only on what to do in case of a tonic clonic seizure but other seizures as well, and what to do in crisis situations e.g. having a seizure when eating; or what to do in case of a missed dose.

## 6. Advice on The Importance of Keeping A Daily Journal

*"I am taking my medicines daily and writing down whenever I get a major or minor seizure. What else can I do to control my uncontrollable seizures?"* The doctor could ask me not only to write if I had a major or minor seizure but emphasize that a daily journal on other aspects can help identify triggers, seizure types and medicine reactions. That it is very important to keep a fully detailed daily journal to identify seizure triggers.

One third of patients continue to seize, and two third are not happy with their seizure control and side effects of medication. Soon after onset parents or people with epilepsy are most

conscientious about keeping records. If right in the beginning it could be emphasized that a daily journal is necessary which entails a proper record of events preceding the seizure it could identify triggers. People with android based mobile phones could download the Seizure Tracker Ap which is extremely useful or log onto the seizuretracker.com website where these details can be entered and stored in given formats. Both are easy to use.

## 7. Referrals to Epilepsy Associations, Para-medicals, Support Groups

"Tell your patients from the word 'go' that they have more options than just medicines. The doctor could inform patients of Associations / support groups that help people with epilepsy. And that if needed they could go seek help from a psychotherapist / special

educator/yoga therapist etc. Doctors also need to advise about the lifestyle changes needed to enable better control of seizures.

## 8. A Second Opinion

*"I am often in a quandary, if I go for a second opinion and the second doctor changes my medication, should I go back to my 1st doctor and report it to him?"* It would be nice if my own doctor could refer me to another for a second opinion – so at least I know I am going to another doc who is respected and whose prescription I can report back.

Patients who are not getting their seizures under control definitely want a second opinion. So even if their primary neurologist feels the case will remain intractable no matter who they go to, even in that case, discuss with your patients if they would be more comfortable taking a second opinion.

## 9. Sensitivity

*"I have been to five neurologists so far for my child. Each one takes the history in front of my child whose uncle died from epilepsy.... What the doctor says can make or break caregivers. The doctor needs to be sensitive to the feelings of the people in front of him."*

A mother poured out her heart on how insensitive the doctors were in front of her child and often just disregarded his feelings or that he was even there, when she spoke about his epilepsy and how this affected her child. She said she will always remember the fifth neurologist who looked her son in the eye, hugged him and said that he would be fine. In the medical profession it can be easy to become immune or insensitive to people's suffering. Doctors must guard against that; they need to be compassionate.

## Other Needs of People with Epilepsy

### 1. Independence

*"For some years my only trouble with epilepsy was my overprotective parents. So I rebelled in all possible forms. I had to fight like crazy for every small piece of freedom. My neurologist stood by me." "Can I live instead of just waiting for the next seizure?" "I would even prefer a shorter life in exchange for its fullness". "I will not keep a pet dog. No way, I know what it is like to walk from one end of the room to another". "I think when a person's independence is taken away, not*

*having the freedom to go places, having the feeling of being treated like a little kid, ... all these things make it hard for a person with seizures to feel normal. I mean, I know they mean well.... But, I don't want to feel special, I want to feel normal...."* Report adults with epilepsy.

It would help if parents/caregivers put themselves in the shoes of the person with epilepsy and likewise the child could put himself in place of his parent. It would lead to a better understanding. Parents, generally, are far more overprotective than they need to be. Seizures are chance events and one cannot take care of chance events all the time.

## 2. Interaction & Socialization

*"There is a fine line between healthy caution and overprotectiveness and I have to restrain myself from being overprotective"* reported a caregiver. To bring up a confident, independent child, the child needs to go to school, play, be given appropriate responsibilities, make his own decisions, and needs to learn from his own mistakes. Take precautions, inform significant others and promote independence. Parents must move beyond the fears of possible problems and let their children know more about what they can do and not what they cannot.

## 3. Exercise

Research has shown exercising provides enormous benefits to the body and mind but is it good for people with epilepsy. Here's what they say *"My son used to get 15-20 drop attacks per day (Lennox Gastaut), but I noticed that when I walked him in the mall (for about 20 minutes) he did not have any drop attacks, so I knew then exercise is helping to reduce his seizures."* *"I get the damn things everywhere even when exercising."* *"All my seizures except one have been due to exertion. I know high intensity workouts are not for me."* *"I have ridden my bike to work for about 10 years, so I get plenty of exercise. I have had 3 seizures while exercising - 2 while on my bike, and 1 while in an exercise class. I don't feel like the exercise was the cause of these. I just try to stay off busy streets, and ride on the sidewalk when there is one."*

Certified Personal Trainer with active epilepsy says *"I can offer a lot of insight on this topic. Stress and oxygen levels in the brain can be two seizure triggers."*

**a) Stress :** Although exercise can be a stress reliever it is also a stress on your body to perform that exercise. We all know that excessive stress can either indirectly or directly lead to more seizures. The key word is excessive. If you are doing weight training you are not usually exerting too much effort and getting rest in between sets but when you doing cardiovascular activity you are typically working at a constant rate and the stress you put on your heart becomes higher and this one ties into point number two.

**b) Oxygen :** Not getting enough oxygen to the brain. Low intensity cardiovascular exercise that puts little stress the heart and body like walking or leisure biking should not be enough intensity to really stress your heart and body out unless you are very obese or have a known heart condition. What can affect your oxygen levels is over over-exertion. While for some a jog might feel comfortable for others a jog might make them sweat profusely and they may have trouble talking while doing the jog.

There are so many benefits of exercise that no one should be afraid of it, there just has to be some caution. Don't over exert and Do what's comfortable.

If you are having a bad day don't push yourself. Every body is different, know your body and know your epilepsy. After all there have been people with epilepsy who have been professional sports persons: Marion Clignet, Chanda Gunn, Jonty Rhodes and late Tony Greig to name a few.

## 4. Good Nutrition

Meals should not only be regular but balanced. There should be a good liquid balance as well. Sugar levels should be steady and moderate. Foods to be avoided as they cause blood sugar levels to fluctuate are: sweets, caffeine & alcohol.

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Epilepsy as a condition requiring intervention / treatment has been recognized since 2000 BC (Labat 1951). However, very little has been done to understand the multiple difficulties many people suffering from Epilepsy undergo.

The WHO and ILEA European Report (2011) describes Epilepsy as a 'hidden disability'. Epilepsy, in many cases, is also associated with a host of co-morbid disorders (apart from the effect of medication) like depression, anxiety, specific learning disabilities, ASD, ADHD, cerebral palsy, mental retardation, mental illness, memory problems, executive function, difficulties with co-ordination etc and psycho-social issues of – attention, anxiety, affect & mood, social & interpersonal interaction, conduct & behavior and self esteem which are very often overlooked. This can lead to disabling conditions and low quality of life for persons with Epilepsy.

Disability is defined as an evolving concept, resulting from the interaction between persons with impairments and ....attitudinal and environmental barriers that ...hinders full and effective participation in society on an equal basis with others (United Nations Convention on the Rights of Persons with Disability (UNCRPD).

To enable persons with Epilepsy to have a better quality of life, it is important that we recognize the possibilities of co-morbid conditions, identify them early on, and provide rehabilitation or strategies as individually required.

Persons with Epilepsy have rights, and the new Draft Bill on Disability in India has also included Epilepsy as a disabling condition. Persons with

Epilepsy need opportunities to express the difficulties they face in doing everyday things, not just about medicines. First and foremost, professionals need more awareness and training to recognize the co-morbidities. Families and the persons with Epilepsy can then become partners in the rehabilitation process as required. Society also needs to be made aware of the special needs and rights of the persons with Epilepsy.

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<http://www.who.int/topics/disabilities/en/>

<http://www.un.org/disabilities/default.asp?id=259>



The first issue of Epilepsy India under the new editorial team was released jointly by Dr. Praveena Shah, President, Indian Epilepsy Society and Dr. V.V. Nadkarni, President, Indian Epilepsy Association during the midterm executive committee meeting at Hotel Taj Bengal, Kolkatta.



I was a school going kid when I was told I had Epilepsy. The very sight of the tablets made me feel sick and I made up excuses to not have them and was forced to swallow the things down.

One year down and I was still making trips to the doctor and was still swallowing tablets. This led to me to feeling sorry for myself and I was scared. I refused to take part in any competition in school as I felt I would have a convulsion anytime. This behavior was encouraged by the people around me as they were extremely protective.

Little did I realize that I was missing out on some wonderful opportunities that life was offering me, just because I had made Epilepsy reign supreme in my mind.

Society was not very helpful in making me feel normal - friends in college who saw me get an attack ran away from me. It was tough to befriend people who lacked awareness and were afraid to approach you and treat you like a normal girl.

As people were passing out of college and leaving the country to study further-- all I thought of was Epilepsy and how unfair things were. "Why me?? " was all that went through my head! I wasted time locking myself up in a room and blaming Epilepsy for the situation I was in. It was as if I had dug a deep hole and had fallen into it.

One year later.. It was time to crawl out. Through family support, will power and a determination to not end up dead, I got back on my feet. Picked up the little confidence that I had, and worked at getting my self confidence back.

I stopped the "why me? " nonsense and learned to live with what I had. I accepted reality and worked with it. Instantly with confidence and acceptance the "why me?" changed to a "so what?"

I had to take control of my life and decide what to do with it. I had to also realize that Epilepsy was no big deal. It was not going to kill me and was very common. People just did not talk about it due to society.

I have overcome the negativity that Epilepsy can bring along with it-- namely depression, fear, self doubt, no ambition, low self worth. It was not an easy process and took time but was worth it.

Twenty years on, do I get my attacks? Oh yes.. but that has not stopped me from realizing my dreams and moving ahead in life. I have learnt that you have to take control and not give a small problem like Epilepsy too much importance.

You do give it respect by taking your medication on time and visiting the doctor, but nothing more.

Life is beautiful and worth living. Do not lock yourself, your ideas and dreams up due to a simple problem like Epilepsy.

We are all normal and have to be treated so.

Cheers,

**Amrita Bhashyam**

*(Amrita works as a soft skills trainer at CMC, Bangalore.)*

## Children with epilepsy advised to take vitamin D



A recent review article highlights possible problems with bone health in children and young people with epilepsy.

They may be at a higher risk of broken bones than youngsters without epilepsy – and may benefit from extra vitamin D.

The review was done by doctors at Leicester Royal Infirmary's Department of Paediatric Neurology. Their work shows that bone health in young people with epilepsy may be a bigger problem than was previously thought. These young people may be two or three times more likely to break bones than others their age.

Previous research has shown that epilepsy can affect bone health in some groups. Some anti-epileptic medicines can affect bone metabolism. This is a process that gradually replaces old bone tissue with new tissue – important in healing fractures, for instance. The medicines can prevent the body doing this as effectively as it should.

These medicines can also negatively affect bone density – so that a person's bones contain less minerals than they should. This makes them easier to break. Previous research has shown increased risks of poor bone-health in older people or menopausal women, for example. However, literature has suggested that young people with epilepsy are not at increased risk of broken bones.

The review from Leicester Royal Infirmary disagrees. While the previous research says that young people are not at a higher risk, the review points out that these older studies only looked at very small numbers of people. They also failed to take into account other factors that could affect bone health in youngsters with epilepsy. These include things like other conditions, how mobile the young person is, what their diet is like and whether they are obese.

The Leicester team say that further research in this area is urgently needed. Still, they say that in the absence of reliable scientific evidence, young people with epilepsy should be prescribed a low-dose vitamin D supplement. This should lower the possible risk of fractures.

In the article published in *The Journal of Paediatric Neurosciences*, authors state: "Low-dose vitamin D supplementation... is now recommended for healthy children and it is biologically feasible that children with epilepsy may be at higher risk of clinically significant deficiency. It is important that neurologists ensure that low-dose vitamin D supplementation should be prescribed... in children with epilepsy."





## Accidental science : New protein treatment

A recent study into how synapses – the junctions that connect brain cells – are built has had an unexpected result. Scientists have accidentally developed a new epilepsy treatment

Suzanne Paradis and her research colleagues at Brandeis University (Massachusetts, US) were conducting an experiment into synapses. Synapses are the links between brain cells that carry signals from one brain cell to another. In a person with epilepsy, the electrical activity spreads across brain cells through these synapses.

There are three different types of synapse. Specifically, Suzanne's team were looking at GABAergic synapses. GABAergic synapses are named after gamma-Aminobutyric acid – a chemical called a neurotransmitter that carries signals in the nervous system. GABAergic synapses naturally limit the spread of signals (including epileptic activity).

Suzanne's team figured out that a protein called Sema4D was an essential building block for this type of synapse. They found that when the protein was removed, brain cells could no longer build GABAergic synapses – the kind that limits epileptic activity. Then one member of the team – Marissa Kuzirian – suggested that they try adding Sema4D to brain cells to see what happened.

The team did not expect the results. Within 30 minutes,

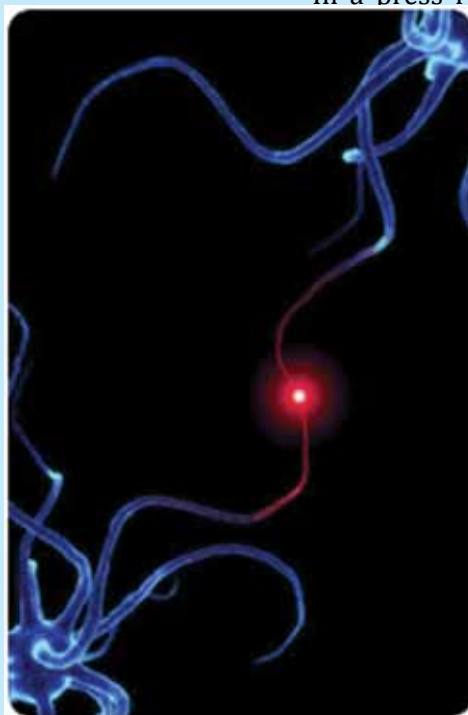


dozens of new GABAergic synapses had been created – much, much more quickly than the team could have guessed. They immediately realised how important this might be in treating a condition like epilepsy. Adding the protein to the brain cells of a person with epilepsy may lead to new GABAergic synapses – stopping the spread of seizure activity.

To test their idea, Suzanne's team used a slice of mammal brain that was treated to create seizure-like conditions in the laboratory. Sema4D was then added to the brain tissue. Within half an hour, the electrical activity in the tissue had reduced significantly – falling from the levels of a seizure and back almost to normal.

In a press release, Suzanne said "We were not intending to study epilepsy, yet we discovered something we didn't know before. That's why funding basic research is so important. You never know where the next big, groundbreaking discovery is going to come from."

Suzanne is careful to point out that this research is in its early stages. Much more must be done to turn their discovery into a treatment for epilepsy in living humans. Their initial findings were published in an online edition of The Journal of Neuroscience on 22 May.



# Forthcoming Events



## 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)



## 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
Double	11500	meals & taxes

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

**Official Event Manager**

**Ice Travels**

Contact us for any query & Reservation

Email : [ies2013@icetravelsco.in](mailto:ies2013@icetravelsco.in)



#### 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>

# Branch Activities

## Nellore Chapter, Andhra Pradesh

The Epilepsy Association Nellore chapter holds regular epilepsy camps with free distribution of medicines at outreach areas. Free epilepsy camp was held on May 5th at Pragati Charities at Nellore. The charity has around 250 mentally challenged children. In the last camp 22 children had epilepsy (Dec 2012), now there are 28 children. It was noted that most children had hypoxic brain damage with congenital hemiplegia. It was felt that more awareness among pregnant women is required and the association plans to do the same. Nellore chapter also conducted another camp in the old age home on 22nd May 2013.

The home has 38 members. Epilepsy screening was done and two people were identified as having epilepsy, which were post stroke seizures. The Second Video EEG workshop was held on 25th May 2013 at Narayana hospital. Guest Speakers Dr Sitajayalakshmi and Dr Lokesh Lingappa were the course directors; Dr Bindu Meno was the course convenor. Around 75 delegates attended the workshop. Neurologists, psychiatrists, Paediatricians and neurosurgeons from Tirupati and Nellore attended the programme. There was a good response and excellent interaction.



## Second Video EEG Workshop, Nellore



The second Video EEG Workshop was held on 25th May 2013 at Narayana Hospital, Nellore by the Indian Epilepsy Association, Nellore Branch. Dr. Sita Jayalakshmi and Dr. Lokesh Lingappa were the Course Directors. Dr. Bindu Menon was the Course Convenor. Around 75 delegates attended the workshop. Neurologists, Psychiatrists, Paediatricians and Neurosurgeons from Tirupati and Nellore attended the programme. There was a good response and excellent interaction.





# Branch Activities

## Madhya Pradesh Chapter

Indian Epilepsy Association, Madhya Pradesh Chapter conducts regular epilepsy camps on the first Saturday of every month.

An Epilepsy workshop was held in Gita Bhawan Hospital on 3rd August 2013. Public awareness on epilepsy was organized at this camp. The focus was on Women with epilepsy. Information on epilepsy and its effects in adolescence, marriage & pregnancy were discussed. Psychologist Madhvi Tiwari gave counseling services for these patients. Information was screened through an LCD projector by Mrs. Neelam Ranade EEG Technician, and who also has a Diploma In Epilepsy Care. There was a screening of an educational film on epilepsy "Mirgi Sahi Gyan Sahi Samadhan" for patients. Dr.V.V.Nadkarni & Dr.Kurechiya examined 85 patients. Free EEGs were done for 20 patients. The tests were sponsored by Alkem Pentacare division Division. Painting materials were distributed to children with epilepsy by Intas Pharma.

Refreshments were provided for patients by donors Mr.Notandas Lalwani, Mr.Narayansingh,& Mr.Bhatiya. Free Medicines distributed through the Gita Bhawan staff & philanthropist Mrs. Anita Motwani, Dr. Pradeep Meheshwari, Dr. Jaymala Shah, Mrs. Neelam Ranade helped in drug distribution.



## Congratulations !



**Prof. Man Mohan Mehndiratta**, has been elected as the Vice President - South East Asia of the International Bureau of Epilepsy (IBE) and also as the member of the Commission on Asian and Oceanian Affairs (CAOA) of the International League Against Epilepsy (ILAE). He will be co-coordinating the activities of the ILAE and IBE in the Asia-Oceania region.



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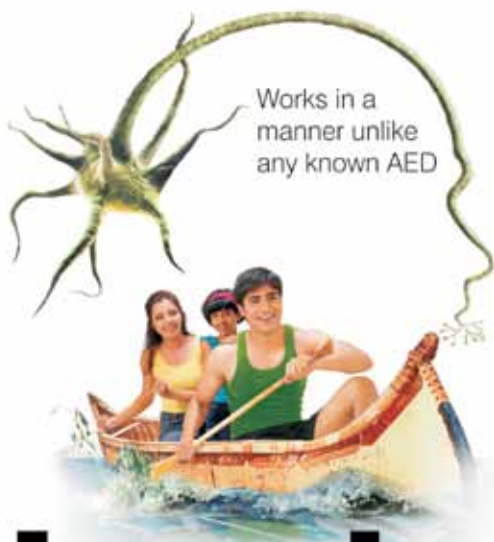
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