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# Epilepsy India



Newsletter of the Indian Epilepsy Association & Indian Epilepsy Society

## 9th Asian Epilepsy Surgery Congress Is epilepsy preventable ?



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## Should Indian Epilepsy Association and Indian Epilepsy Society take the lead?



In India road traffic accidents, Neuro infections and life style diseases like stroke, are the major contributors to preventable epilepsies. Two wheeler drivers and pillion riders are the main victims. With fifty three percent head injury victims developing seizures, implementation of existing Motor Vehicle Act rules comes under scrutiny. The direct and indirect economic burden is huge.

About 1500-4000 cases of Japanese Encephalitis are reported every year from various parts of India. The death rate is about 30 percent. The survivors are usually left with severe neurological handicaps in which seizures are often refractory. Transmitted through culex mosquito bites, the Japanese encephalitis virus gets amplified in pigs and wading birds like ducks. The animals and birds do not exhibit the illness. Vaccine costs about Rupees 160/ per dose. Two doses are recommended 4 weeks apart. Even administering the low cost anti-epileptic agents like phenobarbitone and phenytoin (to be given virtually lifelong in these cases) will be a huge amount compared with vaccinating the children in endemic areas.

Neurocystercosis has to be tackled with health education and perhaps segregating pigs in pig pens away from human habitation.

Health education is again important in stroke prevention and there by post stroke seizures.

The Role of IEA and IES is to form a task force to liaise with traffic authorities, public health officials, epidemiologists and importantly sister organizations like Indian Academy of Paediatrics and Indian Medical

Association towards achieving the aims of preventing epilepsy.

The 10th Epilepsy School and the 9th Asian Epilepsy surgery Congress was conducted in October 2015 at Udaipur. This was inaugurated by the President of IBE Athanasios Covanis. As reported by the organisers Prof Manjari Tripathi and Prof Sarat Chandra, about 250 delegates from not only India but also from many other parts of Asia attended and was a resounding success. Kudos to the organisers.

The IEA Kochi Chapter initiated an awareness ride by motor cycle enthusiasts who rode from Kochi to Ooty distributing leaflets at every pit stop, on the importance of helmets for drivers and riders. The hand-outs were in Malayalam, Tamil and English. The response was enormous. This issue carries the ride experience narrated by the team captain Mr. Suresh Balaraman.

The agony of a mother is brought out by Ms. Shilpa Pillai who shares her experience of coping with her child's difficult to treat epilepsy.

Kerala be not proud! The most literate State in India should bow her head in shame, as an article by Ms. Jane von Gaudecker R.N., PhD, University of Virginia, narrates the sorry state of women with epilepsy in a Northern District in Kerala.

The ECON 2016 at Vizag organised by Dr Venkateshwaralu and Dr Narayana promises to be very exciting fare. Please attend in large numbers.

Wishing all our readers a Merry Christmas and Happy New Year.



# Is epilepsy preventable?

**Dr. Rajendran B.**

**Dr. Vinayan K.P.**

Yes! Certain epilepsies are preventable. Seizures occurring after head injuries, after brain infections like meningitis and encephalitis, cerebral palsy (birth injury related) and after stroke fall into this group.

## HEAD INJURY AND EPILEPSY

53% cases after head injury develop epilepsy. Here the role of helmets for two wheeler drivers and riders assumes great importance. The Union Government of India in Section 129 of the Motor Vehicles Act 1988, made it clear that, a person driving or riding a motorcycle of any class or description has to wear a helmet. Exemptions were for riders in side car and persons of Sikh religion wearing traditional turban. Funnily enough, the Government of Kerala (of the most literate State in India), issued a notification in 2003 (Rule 347 A) exempting pillion riders from wearing helmets. Thankfully, Justice Chidambaresh, of the Honourable High Court of Kerala, stayed the Government notification in 2015, stating that this was in contravention to Section 129 of the Motor Vehicle Act of 1988.

A look at the autopsy data will reveal the magnitude of the head injury related deaths and epilepsy. Autopsy studies in road traffic accidents (RTA) conducted between April 2009 and September 2010, from Government Victoria Hospital, Bangalore, revealed that 23.69 percent of deaths in 249 autopsied cases were pillion riders and none of them were wearing helmets. Shockingly only 35 percent victims were wearing helmets!

Another autopsy series from Government Medical Colleges, Calicut and Trichur in Kerala, showed that only 38 percent of the victims were wearing helmets.

Consider the following facts:

- 53 percent of head injury victims develop epilepsy.

- Properly worn good quality helmets reduce the severity of head injuries by 70%.
- Properly worn good quality helmets reduces the likely hood of deaths in RTA by 39%.

This is an area in which IEA and the concerned authorities should work together to create awareness and also ruthlessly implement the existing laws.

## NEUROCYSTICERCOSIS AND EPILEPSY

This is a condition caused by the infestation of the brain by the eggs of pork tapeworm, scientifically termed *Taenia Solium*. Pigs shed the eggs in their faecal matter and humans accidentally consume them in contaminated foods. Also these eggs reside in the muscles of pigs and improperly cooked pork meat will transmit the eggs to human beings.

The eggs develop into adult worms in the human intestines and the segments of the worm carrying thousands of eggs are discharged in the feces of infected persons. Open defecation, which is a practice in India, leaves the eggs in the soil and contaminates vegetables, which if taken infects people. This is the reason why vegetarians also develop Neurocystercosis. Seventy percent of Neurocystercosis cases present as epilepsy!

- Pork eaters make sure to eat PROPERLY COOKED PORK.
- Vegetarians taking uncooked vegetables in the form of salads etc. MAKE SURE TO SOAK THE VEGETABLES IN SALT WATER FOR A FEW MINUTES before washing and making salads. Salt water kills the eggs.

## OTHER BRAIN INFECTIONS AND EPILEPSY

Encephalitis or brain fever, caused by viral infections can cause deaths and also leave the surviving victims with severe handicaps of which

epilepsy is of major concern. The Japanese B Virus has been causing several epidemics (large breakouts) since 1955. Tamil Nadu, Uttar Pradesh, Assam, Bihar, Karnataka, Manipur, Goa, Pondicherry, Andhra Pradesh and recently Kerala and Maharashtra had epidemics of Japanese Encephalitis.

The virus is injected to humans by certain species of Culex mosquitoes which in turn gets the virus from pigs and wading birds (prevalent in paddy fields and mangroves).

The need of the hour is for the Public Health Authorities to act with trained Epidemiologists and other Medical personnel.

In 2013, a vaccine was launched through Public-Private initiative, by the Indian Council of Medical Research and Bharat Biotech. Called the JENVAC, this should be made available through appropriate agencies to be delivered in endemic areas by the Government. IEA should take the lead in this regard too.

### **STROKE AND EPILEPSY**

Lifestyle diseases like stroke can cause seizures in about 11-12 percent of patients in five years post stroke. Importance of reducing obesity, tight control of diabetes, hypertension, stopping smoking and alcohol abuse etc. should be highlighted by Health care providers at every opportunity while interacting with public.

### **PREVENTABLE EPILEPSIES IN CHILDREN**

The developing brain is highly prone to many types of injuries. Insults to the brain may occur before birth, during delivery or after birth. Many of these insults are preventable. Affected children survive with neurodevelopmental disabilities and epilepsy. Epilepsy in most of these children is very severe and significantly affects the rehabilitation process and the final developmental outcome.

Birth injuries are common causes of epilepsy in later life. Epilepsy is seen in up to 60% of children with cerebral palsy. Proper medical and nutritional support to the pregnant mothers has consistently

shown to reduce the incidence of brain injuries and in turn, subsequent development of epilepsy. Maternal malnutrition along with early childhood marriage and pregnancies contribute to the prevalence of developmental disabilities like cerebral palsy and epilepsy. Appropriate medical care during delivery will help reduce the occurrence of brain injury related to cardio respiratory compromise in the new born. Prompt feeding of the baby in the immediate new born period will reduce the chance of occurrence of hypoglycemia (low glucose in blood). Neonatal hypoglycemia has shown to be clearly associated with later development of resistant childhood epilepsies. Most of these children have a peculiar pattern of brain injury predominantly affecting the occipital lobes.

Infections in new born period, infancy and early childhood significantly affect the development of the brain. Neonatal sepsis and meningitis are very prevalent in rural India, resulting in significant brain damage and later development of epilepsy. It can be prevented to a greater extent by ensuring proper aseptic practice during the delivery of the baby. As described above, many of the brain fevers may be prevented by good public health practice and appropriate vaccinations. H. Influenza, a common cause for meningitis in infancy can be completely prevented by vaccination. Another vaccine preventable disease is Rubella. This virus, if it infects the mother during the pregnancy period, produces significant brain damage in the unborn child, resulting in major neurodevelopmental disabilities and epilepsy. There is good evidence that we will be able to completely eradicate this congenital rubella syndrome by mass immunization.

It is time that IEA and IES actively interact with the concerned Governmental Authorities and other arms of Medical Profession like IMA (the National President being Dr. Marthandan Pillai, a Neurosurgeon himself) to spread the awareness about these preventable epilepsies and develop appropriate strategies to reduce the prevalence of these disorders in the community.



# The 10th Indian epilepsy school and the 9th Asian Epilepsy Surgery Congress - Udaipur October 23rd - 25, 2015



**Dr. Manjari Tripathi**  
**Dr. Sarat Chandra**



The 10th Indian epilepsy school and the 9th Asian Epilepsy Surgery Congress was held at the historic city of Udaipur in India on October 23rd - 25th, 2015.

This school and congress had a unique CME for the Neurology and Neurosurgery students and young practitioners who had an interest in Epilepsy and Epilepsy surgery. 250 participants actively contributed to the program and its success. The President of International Bureau for Epilepsy, Athanasios Covanis inaugurated the program. Participants were from all over India and Asia.

The school had experienced teachers who have been teaching in the epilepsy schools of the past. There was a rich mixture of talks and small group EEG discussions. There was an extensive cover of the

most important topics and current practices in EEG and epilepsy.

The Asian Epilepsy Surgery Congress had some of the best scientific advances not only from the Asian sub-continent but also from the rest of the world. The topics included some of the basics of epilepsy surgery to the more recent advances in the field. In addition, there were "How I do it, video sessions" which demonstrated the surgical techniques from some of the masters in this field.

ASEPA part II exam was held at the venue on 25/10/15. Eleven participants appeared for the exam.

We trust that each of the participants took back rich memories and learning.







# Marriage and Epilepsy : Struggles of Women living with Epilepsy in Kerala, South India

**Jane von Gaudecker, RN, PhD**  
Clinical Assistant Professor, School of Nursing  
University of Virginia, Charlottesville, Virginia USA



The psychosocial burden associated with the stigma of living with epilepsy can be a bigger hurdle than the disease itself. Many studies from developing countries that have looked at the burden of stigma have shown the struggles that people living with epilepsy face, particularly women living with epilepsy.

I recently conducted an ethnographic study on epilepsy, its psychosocial consequences and its treatment gap among women in the outskirts of Kozhikode district of Kerala, South India. These are women who were identified as receiving treatment from traditional healers and who were either not on any AEDs or receiving AEDs intermittently. The study describes their daily lives; their thoughts and perceptions about epilepsy; and their customs, traditions and beliefs regarding the disease. Spending a maximum of two weeks' time with each participant, data were collected through in-depth interviews, participant observation and field notes.

Potential participants were identified from local traditional healers' consultation areas, and through word of mouth. One of the problems encountered in the conduct of this study was that I came to be recognized as the "epilepsy lady" by the women I contacted, even though I dressed traditionally while conducting the study and spoke Malayalam with native fluency.

For this reason, of the 21 potential participants identified, in spite of assured confidentiality, 8 women of marriage age or their families refused to allow the women to be part of an "epilepsy" study for fear of being recognized by the community as someone with epilepsy and for fear of disadvantages in marriage negotiation. Comments from these potential participants

included: "Can't we talk over the phone? If you come here, neighbors will enquire ... they will come to know [about her epilepsy]..." "There is nothing I want to talk [to anyone] regarding this disease..." In a mother's words regarding her daughter who has epilepsy: "After waiting long, people have started approaching us with marriage proposals for her. If she is participating [in the study], she may stay at home forever [without getting married]."

Six women eventually enrolled and completed the study. The general belief in the community about epilepsy was that it was caused by certain supernatural forces, including possession by evil spirits, casting of spells by someone else or curse of God. Although the initial treatment sought was allopathic medications (AEDs), eventually the women transitioned to traditional medicines. All participants, irrespective of their religious beliefs and faith, had conducted rituals, prayers, and offerings as suggested by the faith healers as well as those that were in accordance with their convictions.

The story of two of those women and their struggles with marriage and marriage negotiations are illustrative of the many issues associated with marriage in women with epilepsy.

Ms. Sudha was a 45 year old unemployed woman with elementary school education. Her first seizure was in a bus when she was 13 years old.

Along with many changes these seizures brought to her life, the biggest was the termination of all her education options. When she was 15, her parents, who were illiterate, started worrying about finding an appropriate bridegroom for her. They concealed the history of her epilepsy and married her to



Traditional firewood stove in rural Kerala. A common source of burn injuries for women with epilepsy.



an already married man much older than she. She continued living with her parents because they considered her to be their responsibility and her husband visited her a few days every week.

Nine years later, upon witnessing a seizure, her husband felt cheated and blamed the participant and her family. He took his wife to a neurologist in the city for treatment but later divorced her. She brought up her two daughters while depending on the rest of her family for financial support and the charity from well-wishers in her community. Her lamentations of living with the disease continued when she found that her disease was also affecting marriage negotiations for her daughters. She has tried different types of treatments for her epilepsy and is currently on AEDs, though not on prescribed dosage due to financial constraints and side-effects of the medications. Obtaining AEDs requires that she travel approximately 2 hours each way with the further cost of doctor's fees and transportation. She also has to plan to purchase the medications during this visit because the pharmacy in the neighborhood village does not sell the medicines she needs.

MsGirija is a 29 year old woman with graduate education holding a clerical job in a local shoe company. She is the mother of a two year old child. She has nocturnal seizures and describes them as catamenial in pattern. Like other participants, she has undergone many types of treatments for her seizures. Her family took her to a hospital when she had her first seizure and she was started on AEDs. Immediately after this, her grandfather, who did black magic, conducted rituals and gave her an amulet to wear around her waist. At the time of the interview, she was on treatment from the traditional healer who was slowly weaning her off the AEDs and increasing the dose of traditional medicine.

Concealing her history of epilepsy, her parents got her married three



Working in Kerala kitchen grinding coconut on a stone.

years ago. She had seizure reduction around the time of her marriage and thought it appropriate to conceal her epilepsy from her fiancé then. However, her husband came to know about her disease when he enquired in the pharmacy about the purpose of the medication she was taking and later witnessed one of her seizures. He felt cheated and blamed

her family for concealing her epilepsy from him. He started behaving differently, consuming alcohol and emotionally abusing her. His words to her were: "You have this disease, your family cheated me, and so now, whatever I do, you have to adjust accordingly and live." They also stopped social interactions, especially visiting her husband's family for fear of disclosure of her seizures.

Her family feels guilty and feels responsible for her care, supports her in child care, and provides financial support for epilepsy treatment. She quietly tolerates the emotional struggles and says: "If I have to tell anyone about his behavior, I will also have to explain my disease and I don't want that." She regretted being married, wished her husband realized that her disease was not her mistake, and was emotional throughout the conversation on life after marriage.

All four participants in the study who started experiencing seizures prior to marriage had stories about struggles of living with epilepsy after marriage and during marriage negotiation. Their stories reflect the need for culturally appropriate intervention to create awareness and to educate the public regarding epilepsy and thereby reduce stigma. Further research is deemed important to better understand the attitude of community stakeholders regarding epilepsy and in providing acceptance of and access to more effective treatments.

*Reproduced with the kind permission of Jane Von Gaudecker*

*Source : Epigraph*



Making Ayurvedic medicinal oil.



Preparing herbals at a local medicinal company

Epilepsy, spasms, Valparin, EEG, urine ketones, Carnisure – I had never paid attention to these words before. A couple of them I had never even heard about. But today, I use most, if not all, these words on a regular basis.

Since my son was diagnosed with Infantile Spasms when he was seven months old, my life has changed forever. The first few weeks since his diagnosis, we were in a state of chaos not knowing what to do. We were like a cage of lab mice that ran hither thither. We rushed to meet every specialist we were recommended, not once slowing down to think through the cloud of confusion.

Initially he was diagnosed with West's Syndrome. We got the myoclonic seizures controlled with ACTH, in just five days of administering the hormone. A different kind of spasm broke out in January this year. Since then we have been trying to bring his spasms under complete control. He is on anti-epileptic drugs and very recently we got him started on the ketogenic regime. He is one year and eight months old now.

We have no known cause on the outbreak of these spasms, neither a reason as to why they still occur. His EEG shows spikes and abnormality, again with no clear inference on why. His metabolic blood test (TMS) came back normal. His MRI was normal the first time. A repeat test was done a few weeks ago, of which the results are being studied by a team of experts. We have given blood samples for genetic testing, also under study.

The diet seems to have reduced visible spasms considerably. He gets vacant spells where he goes silent and stares at us, or blankly at a random object. Sometimes on a photo frame, hooked high up on the wall.

Ever since Shiva's diagnosis, we have had to navigate several challenges. From accepting that our son had a serious health condition, to hunting for answers, to providing him with the best medical

support we could find to braving closed doors on our faces. Our biggest challenge has been trying to build a bridge of communication with medical professionals. We have been told several times to let people 'do their jobs' instead of showering them with questions and cross-questioning them on their choice of treatment. Things would be so much easier if they understood that we are doing our job. As parents we have a million questions about everything related to our son, and his treatment.

We are in constant conflict of mind. While providing the anti-epileptic drugs, we fear of the implications it may have on his other functions, like his liver for instance, or regression in development or loss of vision or hearing. While reading up can be a boon, it is as much a curse. This is where literacy comes as a hindrance – too many questions, leading to too many conflicts, leading to hasty decisions and actions. It is a matter of choosing the lesser evil – the deep blue sea or the devil.

We have joined virtual support groups, through Facebook mostly. Most of the members are based in the US or UK, with a handful of Indian parents who remain dormant. In India, such support groups are sparse, especially in Kerala. There are active groups in Bangalore, and families like us who have the means to travel up and down are blessed with the opportunity to mingle with other parents and meet therapists and experts. During most of our interactions with hospitals we have observed that there area depressing number of children who seem to be affected with neurological conditions. In the run to attend to every patient, hospitals seem to side line one very important matter – database. If there was a system to collate information from families on their child's condition and history, it could be a very useful resource. Not only will it help other families in the future, but also be extremely vital for research work which could perhaps yield life-saving treatment options.



We have also been maintaining a record of his spasms, tests, results, medication and diet. It has evolved from noting down just one field to a more comprehensive one. There are gaps of lost data or approximation, but we have recorded much of it and continue to do so. It has been of immense help and we would advise any parent with a similar story to maintain such records of their child – from the very beginning. Medical practitioners could also urge parents to begin a medical diary on their children, right from the day they are diagnosed.

His motor development is at par with his peer group. His cognitive skills are delayed. Again, with no knowledge of how delayed. One Developmental Consultant said – six or seven months, while a neurologist said nine months. Another consultant said he seems to be ‘getting there’. That was six months ago. He does not imitate us or look towards where we point but he gives us beaming smiles every time we smile at him or try to cuddle him. He bites anything that he can hold, including our shoulder, neck and jaw and still cannot hold a glass to drink or sip through the straw, but he can pick up and eat bites of food we keep on his food tray. He doesn’t stack blocks or rings and neither does he play with shapes. But he is attracted to bright colours (loves red) and he likes to explore textures. Especially when they have rough or pointed edges. He cannot climb down a step as he doesn’t look down to see where he walks, but he can climb chairs, beds and even stairs with support. He doesn’t ask for anything but food. When he is hungry he will come to me, nudge me, growl, frown in exasperation and reach out to plates/anything else on the dining table or his high chair that indicates he wants to be fed. He doesn’t call me Amma, or anything else but he has started mimicking us when we call him chakkara (a Malayalam word of endearment). He also says the word cheerfully. He seems to understand when I am sad, and has surprised me with hugs and



a kiss-like bite when I yearn for one from him. He communicates with me in a manner that defies many, if not all, rules of science and medicine and has often tried to convey to me that he is going to be fine soon and will grow into a smart, fine young lad.

We are now at a state of limbo. Shiva is our first and only child. We don’t know if we will be able to give him a sibling. Results of the genetic testing will decide that. Until now we had never known the real depth of epilepsy. We knew that it was something to do with fits, but nothing more. We didn’t have to. We have been reading up on the condition on the internet and have observed that there isn’t much done on this field, and whatever has been done was repetitive and slightly inconsistent. It gives us hope that this is a field with plenty of research possibilities. It could perhaps mean that with the fast-paced progress in science and technology, we could have ground-breaking discoveries on treatment and cure to eradicate such illnesses, such monsters. This possibility, alongside the many success stories and miracles we see online, is what we rely on and what keeps us going.

We do not know what is happening to him. He has become a case study, a file number. We do not know what the future holds. We do not know if we are eligible to bring back our dreams and hopes, or not yet at least. All we can do is wait and watch as drug and luck decide what to do with his fate. We have been blessed with family and close friends who understand and undertake any difficulties to offer a helping hand. This has been our core strength.

I am a writer. Yet, I cannot find the words to explain the emotion of a parent whose only child has ‘the worst thing to happen to someone at this tender age’. I have a lot of hope and a constant prayer that we, and every parent who are sailing on the same boat, find relief and cure for our babies.

## Walk organised to create awareness on epilepsy

An epilepsy awareness programme was organised on Sunday November 15th 2015 to mark National Epilepsy Day.

An Epilepsy Awareness walk organised by the Indian Epilepsy Association, Visakhapatnam Branch, along with the Department of Neuro Sciences of Seven Hills Hospital, was flagged off by Joint Collector J. Nivas at old Central Jail Road. "Epilepsy is not a social stigma. It is like any other neurological disorder. People having epilepsy are to be treated equally like

any other citizen and should not be isolated. They can perform all the duties like any other individual," the Joint Collector said on the occasion. President of Indian Epilepsy Association K.V. Lu and Director of Seven Hills Stroke Center and secretary of Indian Epilepsy Association, Visakhapatnam Branch, R.V. Narayana, spoke.

Source: <http://www.thehindu.com/news/cities/Visakhapatnam/walk-organised-to-createawareness-on-epilepsy/article7883002.ece>

## Brave Heart : Ayesha Noor, who fought epilepsy to become a black belt in Karate

New Delhi: Ayesha Noor, 19 year old girl from Kolkata has been in the news for all the good reasons. She is a gold medallist in karate at both national and international level.



Ayesha who was brought up in the slum area of Kolkata has fought dangerous disease like epilepsy and took it as a challenge to become one of the renowned Black Belt in Karate.

Recently an NGO The Independent Television Service (ITVS) has made a documentary on this wonder girl

Ayesha's father is an auto driver and they spend their life in a single room house at Mofidul Islam Lane in central Kolkata's Beniapukur.

Ayesha starts her day with a rigorous training at the Ramleela ground in Entally.

During her leisure time on Sunday evenings she also trains the girls in self-defence at a park opposite Rajabazar Science College in Kolkata.

"It has been a struggle. My father died, my mother sews for a living. Food at home is short. But my parents always told me to work hard and I did. Thanks to my coach, MA Ali. Without him nothing would have been possible," said Ayesha to a news channel.

Her coach, Ali won gold medal at a major tournament in 1988 and also trained Ayesha's brother who brought her to Karate class one day.

She also mentioned her secret of hard work that she idolises Olympian boxing medallist Mary Kom of Manipur.

Ayesha has become a campaigner for the gender rights in the whole world with her achievements in boxing and the challenges that she faced in her life.

Source : <http://www.indiatvnews.com/sports/other/ayesha-noor-who-fought-epilepsy-to-became-a-black-belt-in-karate-4014.html>





## Research reveals anti-seizure mechanism of ketogenic diet therapy

Exciting new research has revealed for the first time a mechanism behind one of the ketogenic dietary therapies often used in treating people with poorly controlled epilepsy. And scientists are hopeful the groundbreaking discovery could lead to potential new dietary therapies.

Ketogenic dietary therapies have been used since the 1920s as an alternative treatment for epilepsy, particularly in children who seizures do not respond to medication.

The dietary therapies are high in fat and low in carbohydrate with a moderate use of protein. This alters the way that energy is burned in the body, using fat rather than carbohydrates as the main fuel.

Changes in the body's fuel source means the body produces ketones - water-soluble molecules generated by the liver - and until now it was thought that the anti-seizure mechanism of the diet was the generation of these ketones.

However the new research by scientists at Royal Holloway University of London and University College London, has identified a specific fatty acid - decanoic acid - that shows potent anti-seizure mechanisms. The research is published in the scientific journal Brain.

### Decanoic acid and the MCT diet

Decanoic acid is a main component of one of the ketogenic dietary therapies - the medium chain triglyceride (MCT) diet - which was developed in the 1970s as an alternative to the classic ketogenic diet. The MCT diet is based around fats derived from coconut oil. It is increasingly used for treating children but is often poorly tolerated by adults.

Decanoic acid is one of the three fatty acids in the MCT diet and it has been found to directly affect receptors in the brain and decrease seizure activity.

Professor Matthew Walker, right, from UCL and co-author of the study, told Epilepsy Society: 'This is likely to have a large impact on the dietary treatment of epilepsy as it may be possible to use diets enriched in decanoic acid and avoid many of the unwanted side-effects of the present MCT ketogenic diet.'



'Not only that but this research has started to reveal a host of potential therapies based around fats that are much more powerful than decanoic acid, opening up the possibility of using a pill rather than a diet.'

### Diet and brain function

Katrin Augustin, one of the researchers from Royal Holloway said that the research changes the way we think about nutrition.

'We are showing for the first time that dietary fats can alter brain function,' she said. 'What we eat may not only affect our physical health but also our mental function, which means we may be able to regulate brain function by changes in our diet.'

'Finding a direct action for fatty acids explains why ketosis often does not correspond to seizure control, and that could be very reassuring for both patients and clinicians. It means that low ketone levels may not at all be a reason to discontinue the diet.'

### Ketogenic diet research at Epilepsy Society

At Epilepsy Society a key area of research is trying to understand why some people respond to the ketogenic diet while others don't. Director of clinical genetics Professor Sanjay Sisodiya said the latest research was an important and interesting study which leads to new understanding of the way the ketogenic diet might work to help control seizure.

'Alongside this important study we hope that our genetic research will lead to a better understanding of why ketogenic diets work for some people but not for others,' he said. 'This will hopefully take the trial and error element out of prescribing the diet, which has to be carefully monitored. In time, we hope that we will know which treatment will work best for each individual from the point of diagnosis.'

**Related articles :** Ketogenic diet could reduce seizures in adults with epilepsy.

Source: <http://www.epilepsysociety.org.uk/news/research-reveals-anti-seizure-mechanism-ketogenic-diet-27-11-2015#.Vnvi0PI97IU>



Indian Epilepsy  
Association



Indian Epilepsy  
Society



Epilepsy Association  
of Vizag

# **ECON 2016**

## **17<sup>th</sup> Joint Annual Conference**

**of Indian Epilepsy Association & Indian Epilepsy Society**

**(February 12<sup>th</sup> - 14<sup>th</sup>, 2016)**



**APMC has awarded 5 cme Credit Hours  
(APMC / EME / 572 / 2015)**

Hosted by

**Indian Epilepsy Association  
Visakhapatnam Chapter**



## Branch Activities

### Indore

Report by  
**Dr. V.V. Nadkarni**

Indore Epilepsy Visheshagya Association Samiti (IEVAS) conducted National Epilepsy Day program at Pritamlal Dua Sabhagrham on 15th November 2015 from 10 AM to 3 pm. The function was inaugurated by Shri Ramvilas Rathi Trustee of Gita Bhawan Trust.



President Dr. V.G. Dakwale addressed the gathering with special focus on epilepsy surgery. Dr. V.V. Nadkarni secretary IEVAS presented the annual report for the year 2014-15. Dr. A.M. Gandhe, Medical Director, Gita Bhawan Hospital presided over the function and reiterated the continuous support for our chapter. Annual Newsletter of IEVAS Indore Chapter for 2015 was released by the Chief Guest. This was followed by a scientific session on epilepsy with the participation of Dr. O.P. Lekhra, Neuro Physician, Medanta Hospital, who spoke on "Approach to Epilepsy Management".

Dr. Jaymala Shah, Yoga Guru, gave a demonstration on Yoga. This session was to create awareness on stress reduction through yoga. A person with epilepsy demonstrated the yogasanas.

To encourage people with epilepsy, a cultural program including dance performances by Miss Kajal Sharma and Mr. Pankaj Parmar was organized. A poster exhibition on epilepsy was organized at the venue to create awareness on different aspects of epilepsy. A film on epilepsy by the 18th IEC Trust "Mirgi Sahi Gyan Sahi Samadhan" was screened in Hall 2. Creativity in children suffering from epilepsy is best appreciated through drawing & painting for which a painting competition was organized for children at the venue & 20 children participated. Talented children were rewarded with certificates of participation & prizes.

A quiz competition on knowledge & facts about epilepsy was organized for caregivers of patients was organized in which 65 adults participated.

All the members & caregivers of patients received handouts on epilepsy. A free epilepsy camp was conducted in which 65 patients were examined & treated. Antiepileptic drugs were distributed to all the patients.

## Branch Activities

### Nashik

Report by  
**Dr. Mahesh L. Karandikar**

'Karandikar Medical & Educational trust' has been conducting several activities to spread awareness amongst the society regarding Epilepsy.

For the epilepsy awareness month November 2015, an exhibition prepared by the dedicated staff members and by members of the 'SHWAS', a self-help group for persons with epilepsy was organized. Various social issues like education, marriage, works and driving in relation to people with epilepsy were highlighted. Posters depicted the causes and types of epilepsy and first aid measures in simple form. This exhibition was open to the public and was attended

by people of different age groups and social strata. All those who visited the exhibition were given purple ribbons to propagate the message of 'living safe with epilepsy' and making lives of people with epilepsy socially amenable.

Under the dedicated efforts and guidance from Dr. Mahesh Karandikar, 'Karandikar Trust' has been conducting similar activities in the form of exhibitions, competitions, talks to improve the awareness and creating a positive outlook towards epilepsy since last several years through their self-help group, SHWAS.

# Branch Activities

## Kochi : No Helmet? No Ride!! - Riding for a cause – Against Helmetless Riding

Report by  
**Suresh Balram**

My friends and I were in the habit of setting out on 2 wheeler rides to different destinations in Kerala. And, on the last occasion, on a ride to Valparai, we witnessed a 2 wheeler accident involving helmetless rider and pillion. A little after Chalakudy, a stray dog darted across, the bike hit the dog and they came crashing. The locals there rushed them to a nearby hospital, and we moved on. On our return, we got to know that the pillion died due to head injury.



Planning our next trip, in consultation with my brother Dr. Rajendran, we decided to ride for a cause - Helmet Awareness. A trip to Ooty was planned thru Kottakkal, Manjeri, Nilambur and Gudalur, and return thru Coimbatore, Palakkad and Trichur, so that we could cover two vastly different routes. Indian Epilepsy Association, Kochi responded instantly to sponsor our ride, to which we are ever grateful.

On the 12th of November, we were flagged off by Dr. P. Sreekumar, Founder President of IEA, Kochi at 2 pm, attended by a cross section of the society, families and friends of the riders, and media persons. We had printed leaflets in Malayalam and Tamil explaining the seriousness of head injuries and how helmets could prevent serious head injuries and thereby epilepsy. Destination for the evening was Kottakkal, and at our brief pit stops on the way, we distributed leaflets in Malayalam, which attracted a lot of curious passersby.

The next morning, a group of Doctors attached to Malabar Institute of Medical Sciences, Kottakkal, led by Neuro Surgeon Dr. Shaji had organized a flag off at the busy Changuvetti Junction. The first five two wheeler riders seen riding at that junction with helmets on, were stopped and given vouchers for free medical checkup at MIMS. We are lost for words to thank them for such a kind gesture in support of our ride. The event was so well received, that the traffic cops had to come into action to clear the traffic block that followed.

We were flagged off to our final destination by Dr. Shaji and his team. Malayalam leaflets were distributed at Manjeri and Nilambur and the Tamil leaflets came in handy from Gudalur onwards. After a day's rest, we rode back via Kotagiri, Mettupalayam, Coimbatore, Palakkad and Trissur. We distributed leaflets and orally urged 2 wheeler riders to start wearing helmets even for the shortest of rides. We even had strangers requesting us to pose for selfies with them!! There were instances when motorists requested us to stop for photographs. The kind of curiosity we could kick up all along, gives us a feeling that the message must have reached quite a good number. But the conversion rate, is a serious grey area. Repeated forays may be the answer.

My team members @ Team Helmet look forward eagerly to ride again for epilepsy awareness to other areas.





## Sixth IEA - Tirupati Oration in Epileptology

Report by  
**Dr. B. Vengamma**

The Tirupati Branch of the Indian Epilepsy Association donated Rs. THREE Lakhs to Sri Venkateswara Institute of Medical Sciences (SVIMS), Tirupati, with a request to institute in the Department of Neurology, SVIMS an annual ORATION entitled "IEA Tirupati Oration In Epileptology" commencing from the year 2010.

The SIXTH Oration was organized on 5th September, 2015 at Sri Padmavathi Auditorium, SVIMS at 3.00 pm. Dr M. Gourie - Devi, Emeritus Professor of Neurology, Institute of Human Behaviour and Allied Sciences, New Delhi and Former Director/Vice Chancellor, NIMHANS, Bangalore delivered the Sixth Oration on the Topic "Impact of Pharmacogenomics on the treatment of epilepsy."

The highlights of her Oration are as indicated below:

Epilepsy is a chronic neurological condition manifesting as recurrent, unprovoked epileptic seizures. It represents the most common chronic neurological disorder after headache, with an estimated 50 million people affected worldwide and 8 million in India. It is an extremely heterogeneous disorder, comprising a large spectrum of different seizure and syndrome types with multiple underlying etiologies.

Conventional treatment consists mainly of drug treatment, with brain surgery and vagal nerve stimulation reserved for selected refractory cases.

More than 15 antiepileptic drugs (AEDs), with several different mechanisms of action, are available and several more are being developed. Nevertheless, up to one in three patients with Epilepsy continue to have seizures despite optimal medical treatment. The average annual cost of refractory Epilepsy is enormous.

Additional indirect costs are related to the high prevalence of unemployment and comorbidity (e.g., depression) in patients with refractory epilepsy. Even in patients with controlled Epilepsy, medical therapy is fraught with problems. These are mainly related to the unpredictability of efficacy, adverse drug reactions (ADRs) and optimal dosing in individual patients. At present, clinicians base their choice of drug and initial dosing in individual patients mainly on factors such as Epilepsy type, age, gender, co medication, concomitant disease and regulatory issues. Further dose adjustments are based on seizure frequency and occurrence of ADRs. In practice, it often takes several years of trial and error before an acceptable balance is found between efficacy and toxicity.

Pharmacogenomics refers broadly to the study of the entire spectrum of genes that determine drug behavior and sensitivity, establish a relationship between genotype and patients response to drug treatment and comprehensively identify genes, functional polymorphisms associated with the observed variability in drug response.



AED efficacy, resistance, toxicity and dosing are all influenced by multiple factors. These comprise environmental factors, patient-related factors, factors related to the Epilepsy and genetic factors. Pharmacogenomic studies the influence of genetic variants on individual drug responses. Identification of genetic factors influencing AED response could enable prediction of response in individual patients. This could lead to more rapid seizure control with fewer ADRs and thus to an improved quality of life for patients with Epilepsy. Establishing the genetic determinants of AED response could also uncover potential novel drug targets and mechanisms of action. This could then lead to the development of new, more efficacious AED.

The main conclusions are:

1. For patients treated with AEDs, Pharmacogenomics holds the potential for a significant reduction (40-50%) in

I) Adverse drug reactions

ii) Inadequate seizure control

2. Drug response can be modulated by a number of

non-genetic factors such as co-medication and concurrent diseases.

3. Pharmacogenomics has the potential to improve public health by avoiding delay in instituting the most appropriate drug and cutting the cost of "trial and error" treatment.

It is now time for Epilepsy research groups, geneticists to join efforts and set up large-scale, rigorously designed Pharmacogenomic association studies in large, well-phenotyped cohorts of patients. Although several challenges remain, it is likely that firm and potentially clinically relevant results will ultimately emerge, offering hope for a more efficacious treatment for patients with epilepsy.

The erudite lecture was followed by a lively and interesting discussions. Dr. M. Gourie Devi was felicitated by, Dr. B. Vengamma, Senior Professor of Neurology, SVIMS and President, IEA, Tirupati Branch and other Senior Members of Medical fraternity. She was also presented with a Silver Memento, on behalf of the Department of Neurology, SVIMS, Tirupati Indian Epilepsy Association, Tirupati Branch.

## Branch Activities

### U.P. : Free Medical Consultancy & Diagnosis camp

Report by  
Dr. Tarun Agarwal

In our mission "Aik Abhiyan Andhere se Ujaley Ki Ore", this year on the occasion of Epilepsy day, we organized a Free Medical Consultancy & Diagnosis camp at Neuro Care Clinic, Gandhi Nagar, Moradabad in association with AASHO Charitable Trust on 15th November 2015, Sunday, This was the 22nd consecutive clinic. We tried to reach out to patients with help of flex banners, electronic media & local and national newspapers. The camp was highly successful with the attendance of 247 patients.

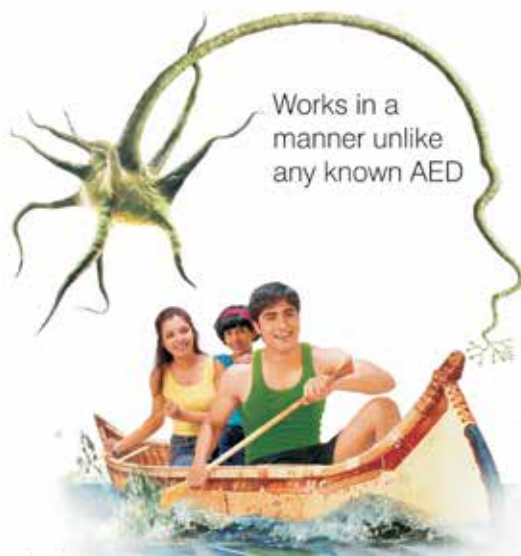
Patients were given free consultation, required diagnosis and medicines free of cost which will continue for a year. In this camp the patients came from all around the U.P and Uttrakhand.

74 EEG, 24 CT - Scan and 7 MRI were done free of cost. Free drugs were distributed to promote drug compliance. Tea and snacks were also distributed to the patients and their attendants throughout the day.

We also showed how to live with epilepsy & various safety issues and common tips at various places- at work, while travelling etc. through posters and videos. Epilepsy related literatures were also distributed.

We acknowledge the co-operation of Mohan CT & MRI Centre, Amit MRI Centre and the team from AASHO charitable Trust.





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