

July-September 2016

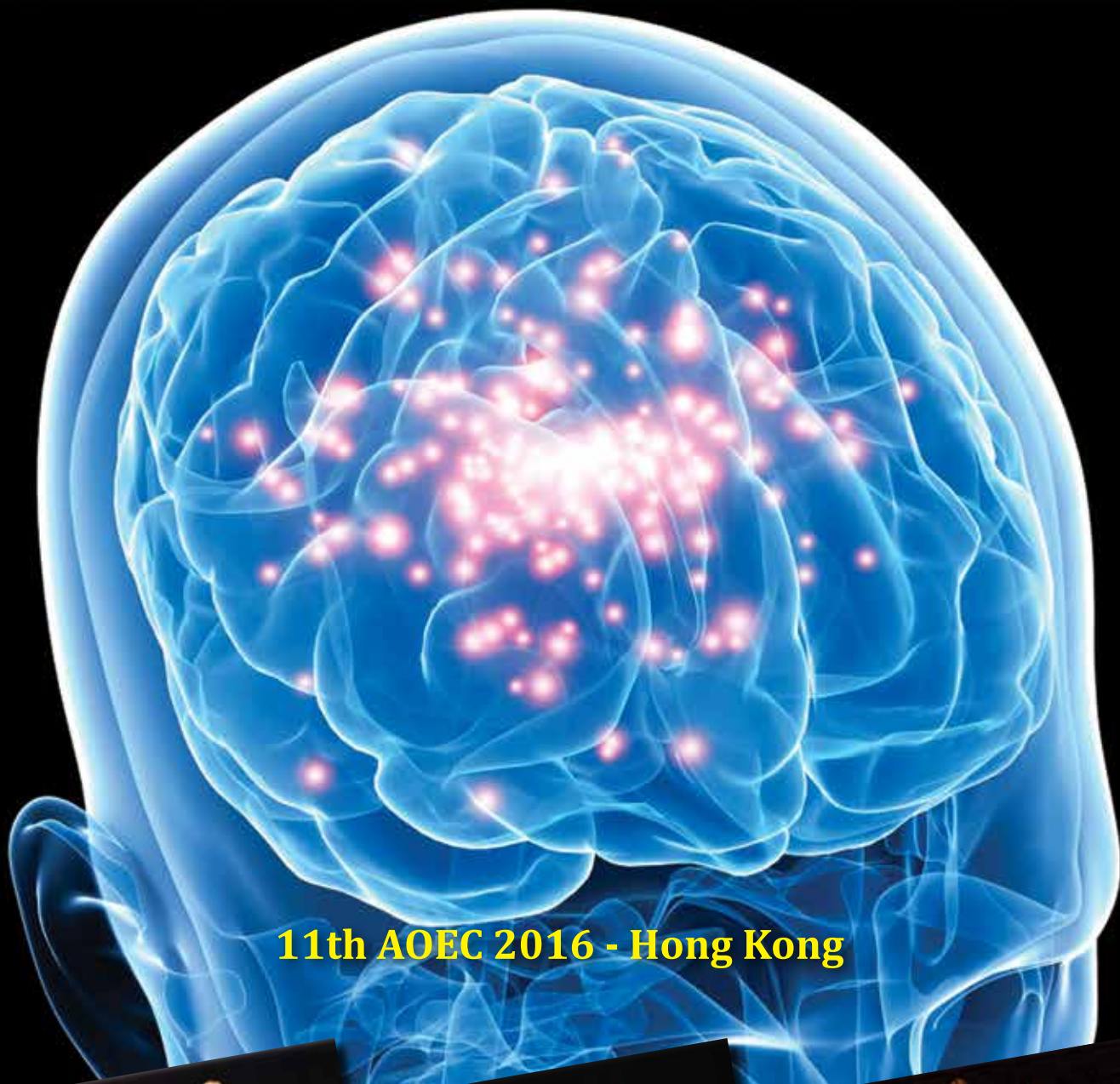
Issue 3, 2016



# Epilepsy India



Newsletter of the Indian Epilepsy Association & Indian Epilepsy Society



**11th AOEC 2016 - Hong Kong**



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The Asia Oceania Epilepsy Congress 2016, held at Hong Kong, recognized the potential of Indian epileptologists and epilepsy support groups. Six speakers and chairpersons were from India. Drs. Satishchandra, Saratchandra, Manjri Tripathi, Man-

Mohan Mehindratta, and Sheffali Gulatti were the worthy candidates. To cap this, two of the four Asia Oceana Epilepsy Achievement awards were given to Mr. K.V. Muralidharan from Bangalore and Dr. Manjari Tripathi from Delhi. From the IBE section Ms. Amrita Bashyam, a person with epilepsy, received the award. We salute you.

There has been an explosion in the number of anti-epileptic medications produced in the last two decades. Have they caused a paradigm shift in epilepsy management? Dr. H.V. Srinivas, Senior Neurologist and Epileptologist from Bangalore, gives his views in this edition. He contends that the older drugs are as good as the newer ones and only in higher doses (eg: sodium valproate more than 800 mgs / day) will be a cause of concern. The newer drugs come with higher treatment costs and this in turn may cause compliance issues too. Please read on and give your views.

Pharmacogenomics is a fast developing field in medicine. What it brings out is the way the genes affect the behaviour of a drug in an individual. This has implications in efficacy as well as tolerability of a drug in a given population. The best example is the association of a certain HLA type in Han Chinese and development of serious side effects to the drug Carbamazepine, in the form of the dreaded Steven Johnson Syndrome. Prof M. Gourie Devi, in her Tirupati Oration held in September 2015, has highlighted the importance of Pharmacogenomics in Medicine. Dr. Vegamma Naidu has been kind enough to send an abstract of the oration for our readers.

The Neurosciences community lost a giant in April this year. Prof. Noshir H. Wadia breathed his last in April. Dr. Mathew Abraham remembers his erstwhile teacher and mentor in this issue.

This issue also carries a first person account of how ketogenic diet helped fight epilepsy as told by Ms. Naomi Schacter from USA. She is now a sophomore in Goucher College in States. This should influence more centres in India for using ketogenic diet in refractory epilepsies that are not amenable for surgery.



This issue carries the story of Ms. Paulomi Mondal - her battle with epilepsy. The narration is straight from her heart, and shows her fortitude and positive approach to her epilepsy. She exhorts to take every day as a challenge, not to listen to unsolicited advice, and importantly on drug compliance and career ambition. This spirit is what we would like from all patients with epilepsy.

We are glad to inform that Prof. P. Satishchandra from NIMHANS has been nominated as co-chair for the 12th AEOC at Bali in 2018. He has appealed to all of us working in the field of epilepsy to send suggestions for the scientific content of the conference. We should take this as an opportunity to give our inputs for framing the scientific programme. Details are carried in this issue.

We have received Chapter activities from Tirupati, Shivamogga and from the Jodhpur chapter of the Indian Epilepsy Association and from the Epilepsy Foundation Mumbai. The Jodhpur Chapter under Drs. Sanchetee and R.K. Surekha are actively involved with a hospital in Gulbpara of Bhilwara dist in Rajasthan, which deals with persons with epilepsy (PWE). Initiated in 1978 with four patients under the aegis of a trust, it now caters to over 7,000 patients. Most of the patients are from a very low socio- economic status and it was found that a large majority initially sought the help of quacks and faith healers for their malady. The latter observation should propel IEA to be more proactive in epilepsy awareness campaigns. Kudos to Drs. Sanchetee and Surekha for their dedication.

We urge all chapters to send us their activity reports so that we may publish them in the Newsletter and motivate slumbering chapters.

Id Mubarak to all our readers.

# Newer Antiepileptic Drugs : Have they made paradigm shift in Epilepsy Management ?

**Dr. H.V. Srinivas, Bangalore**



Epilepsy is an eminently treatable condition, in 75% to 80%, largely by primary or first line drugs Phenobarbitone (PB), Phenytoin (PTH), Carbamazepine (CBZ) and Valproic Acid (VPA). However a small but significant group of 20% to 25% do not respond to the primary or first line drugs.

To address the latter group a number of newer antiepileptic drugs were added to the therapeutic armamentarium. Even though the newer drugs came into market with fond hope of controlling seizures which not who responded to primary drugs, it has been a disappointing experience, both for the Pharma companies and for the Neurologists and patients, as newer drugs are able to achieve further control of seizures in only 3%-5%. The search is still on and quite a few drugs are expected to hit the market soon. In the mean time advances in surgical management of epilepsy have given a new hope for are drug resistant patients with excellent results, provided the selection of patients are meticulous.

Even today VPA is the drug of choice in IGE, absences, JME and also used beneficially for partial seizures. It is indeed a good broad spectrum antiepileptic drug, time tested, cost effective. Similarly CBZ even today is the best AED for Complex Partial Seizures (CPS).

When the newer drugs did not make any impact in terms of seizure control, the attention was shifted to the side effects of the primary drugs and banking on lesser side effects, newer AEDs are promoted. If the indication for newer AED is on the basis of lesser side effects, the question is how many develop side effects and at what dose. Everything in life has side

effects including marriage! The word 'side effects' is on the side, the main effects being good. When the side effects are more than the main effects, obviously you divorce! Similarly if the side effects are unacceptable in a given patient then change the drug.

One should keep in mind the cost of the drug and the duration of treatment. Today VPA 200mg by a good Pharma Company costs Rs.34 for 10 tablets and on an average a patient requires three tablets per day and so per month the expenses would be Rs.340. As against this Levetiracetam (LEV) 500 mg costs Rs.115 for 10 tablets and on an average of two tablets per day, Rs.690. Most important the duration of treatment is 2 to 3 years of seizure free period and in JME, it is perhaps life long in almost 80 percent of patients. Large number of our patients cannot afford sustained expensive treatment.

No doubt there are several publications extolling the virtues of newer antiepileptic drugs particularly in women, but this data are collected by the institutions and neurologists where a good number of the patients are on higher dose of AED. To get a correct picture of the economic condition, affordability to sustain, and impact of side effects on day-to-day living one has to do extensive community studies. Remember there was a time when epilepsy was considered to be 'incurable' or at best requires 'life long treatment'. This concept was changed with several community studies collecting data from door to door and the statement was modified accordingly that "epilepsy is eminently treatable", 'the duration of treatment is not lifelong but two to five years of seizure free period'

and what is more important, “spontaneous remission of 20–25%” was observed in several studies.

VPA and CBZ are known to increase congenital malformations marginally, VPA in particular neural tube defects. Often times we used to see women on valproate consulting a Physician / Neurologist after they become pregnant, usually after three months of pregnancy, by which time whatever effects on the fetus were to happen, would have happened, so we were asking the patients just to continue VPA and advised a high resolution abdominal Ultrasound by 16th week of pregnancy, to detect major malformations which may require termination. Decision in life was easy !. Those who were on VPA were advised to have Folic acid from the date of marriage to reduce the incidence of neural tube effects. Recently VPA is put under microscope to look for more and more side effects to discredit. Now we have several reports mentioning that VPA continues to affect the fetus throughout pregnancy, which is recognised after birth in the form of lower IQ, cognitive developmental delay autism – all recognised at the age of 3 to 6 yrs. This in effect bans the prescription of VPA throughout pregnancy. VPA is in the market for more than 40 years and now we are recognising the delayed effects in children. It is wise to remember that LEV is presently in the

‘honeymoon phase’ everything looking Ga ga and good and when another batch of newer AED enter the market they will fish out the late side effects of LEV. I am not saying there are no side effects to primary AEDs but use your judgement, when it happens (like weight gain, tremors) then only switch over to other drug. VPA upto 800mgs per day does not cause significant side effects, and is still recommended during pregnancy too. The primary prescription should be for cost effective first line AED.

To conclude the aim with which the newer AED was introduced (to control seizures) is unfortunately not realised. This has shifted the focus to promote the newer AED by looking at side effects of primary drugs with more and more concentration. We have already driven away PB and to some extent PTH. Now the target is VPA & CBZ. What really worries me is that the present generation of Neurologists have abandoned VPA in all women, fearing the risk and not only that they spread the message to Primary Care Physicians that VPA should be kept at a distance.

Newer antiepileptic drugs have not made paradigm shift in epilepsy management, but they are trying to carve a niche /share a small piece, quoting side effects of primary drugs.



**The next ECON will be held on 18th and 19th of February at Patna.**

**The pre-conference workshop is on 17 th February.**

**Dr. Ashok Kumar, Prof. of Neurology, IGIMS, Patna, is the Organizing Secretary.**

**Knowing his skills and dedication this conference is bound to be exciting.**

**Please attend in large numbers.**

## Dr. Noshir H Wadia (1925 - 2016)



It is with great sadness we write the obituary of **Prof. Noshir H. Wadia**, who passed away on Sunday, the 10th of April 2016, at the age of 91. Prof. Wadia was universally regarded as the founder of contemporary Indian Neurology.

Prof. Wadia was born in Surat, and did his pre-medical education at St. Xaviers College, and then his MBBS & MD from Grant Medical College Bombay. He then went on to clear his MRCP (London) in 1952. He did his initial training in Neurology with Mr. G.F. Rowbotham, at Newcastle, and later was the first Asian Registrar to the legendary Sir Russel Brain, at the Maide Vale and London Hospital.

He returned to Bombay, to set up the Department of Neurology at his alma-mater. He developed this into a Centre of excellence. He was also the Director of the Department of Neurology at the Jaslok Hospital, Bombay, which became another great centre for training in the subject. He was a very astute clinician, and a passionate teacher. This is what he will be remembered for, having influenced the lives of hundreds of students, many of whom have had distinguished careers in Neurology in India and abroad.

Prof. Wadia was a very dedicated researcher, making original contributions in the field of C.V. anomalies, and the neurological effects of Manganese exposure. His seminal work was in the identification of an autosomal dominant variety of Cerebellar ataxia, later designated as SCA-2. He also was the one to identify a new adult Polio-like illness following Acute Haemorrhagic Conjunctivitis in 1971.

Prof. Wadia served in many capacities in the Indian and International neurology community. He became the first recipient of the WFN Gold Medal for services to neurology at the World Congress of Neurology at Bangkok in 2009. The Government of India conferred the Padma Bhushan on him in 2012.

For his students, he was a revered teacher, guide, mentor and guru. He touched their lives in many ways - by the depth of his knowledge, kindness of heart, broadness of mind and generosity of spirit. He was a very compassionate physician, and above all, a great and much-loved human being.

May his soul rest in peace.

# Report on 11th AOEC 2016

**Dr. (Prof) Man Mohan Mehndiratta**  
Secretary General  
Indian Epilepsy Society



11th AOEC (Asia Oceania Epilepsy Congress 2016) was held from May 13-16, 2016 at Hong Kong Convention and Exhibition Center.

This is the regional congress of ILAE and IBE. More than 1300 delegates from across the country attended the meeting. There were a total 48 sessions. The important sessions were ASEPA Education symposium, Chairman Symposium on auto immune encephalitis, genetic and epilepsy, epilepsy and behavior, new paradigm of AED therapy. Six speakers and chairperson were invited from India namely Drs. Satish Chandra, Sarat Chandra, Manjari Tripathi, V.S. Saxena, Sheffali Gulati and Man Mohan Mehndiratta.

A total of 25 bursaries were awarded and we are happy to inform you that eight Indian participants received travel bursaries.

A total of 324 posters were presented. The highlight of the congress was Asia Oceania Epilepsy Achievement Award, out of four recipients, two were from India namely Dr. Manjari Tripathi and Mr. K.V. Muralidharan. From the IBE section the name of Amrita Bhasyam was recommended by Indian Epilepsy Association. Amrita is a Person With Epilepsy (PWE) and she has not only managed to overcome difficulties with Epilepsy but also is independent and employed on a good position. Congratulations to all the three award winners.



Dr. Manjari Tripathi, Mr. K.V. Muralidharan and Ms. Amrita Bhasyam receiving award during Asia Oceania Epilepsy Congress 2016

12th AOEC will be held in Bali in 2018.

## Call for Session Proposals at the 12th AOEC at Bali, Indonesia, June 2018

Dear All,

Greetings from 12th AOEC organizing committee.

You may be aware that 12th AOEC conference is being proposed to be held in Bali, Indonesia in June 2018. Scientific Organizing Committee has requested opinion leaders and experts like you all to send your proposal for any of the scientific sessions. Website gives all the details regarding the format of the previous scientific programmes - 11th AOEC recently concluded at Hong Kong.

I am very happy to inform you that I am the Co- Chair for 12th AOEC, if you want any specific subject to be included, you could either send it to me or you can submit directly as per the announcement made by 12th AOEC, which I have forwarded below.

I will certainly try to include as much as possible so that we will have good representation from our country

**Dr.P. Satishchandra**, MBBS, DM(Neurology), FAMS, FIAN, FRCP (London)

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### The 12th Asian &Oceania Epilepsy Congress Jointly organised by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE)

Dear friends,

The 12th Asian &Oceania Epilepsy Congress will take place in Bali, Indonesia, June 21-24, 2018

#### Call for Session Proposals

#### Announcing an open call for proposals for sessions at the 12th AOEC

Deadline for submission: **August 17, 2016**

The Scientific and Organising Committee (SOC) would like to provide you with the opportunity to submit a proposal for sessions to form part of the scientific programme.

The aim of the SOC is to create a comprehensive programme which will encompass topical and varied themes. Please note that the SOC will be responsible for the final selection of sessions and that presentations and/or speakers may be changed or amended whenever it is deemed appropriate.

Please refer to the recommendations before submitting a proposal, and submit your proposal using the official form. Click the links below for further details on how to submit your session proposal or to make suggestions for session topics: <http://cts.vresp.com/c/?ILAEIBECongressSecre/65c4552c81/24d41f0f9e/31b5ab9e1>

#### Scientific and Organising Committee

**Congress Co-chairs :** Buyng-In LEE, P. SATISCHANDRA, Kurnia KUSUMASTUTI

**Members:** Denise CHAPMAN, Ding DING, John DUNNE,  
KhengSeang LIM, Tatsuya TANAKA, Ada YUNG

Please direct any enquiries to **Philippa** in the Congress Secretariat  
email : [bali@epilepsycongress.org](mailto:bali@epilepsycongress.org)



## Ways to stay happy and positive with epilepsy

**Paulomi Mondal**

Epilepsy in common man's term is suffering from periodical fits or seizures. This particular disease can occur at any age. Even a new born can suffer from epilepsy. Are you thinking whether it is curable? Well, it totally depends on you. So you must be thinking that can we leave this just on fate? No, you can't. You have to be more positive. Routine check-ups and a fixed timing for your medicines should be followed. You should never make the mistake to skip your medicines. This will affect your health.

### **How to live life in a better way with this disease?**

I, being a victim of this neurological disorder since the age of thirteen, do understand the consequences very well.

### **Live your life**

Take it as a part of life. Enjoy and live every minute of your life to the fullest. Do not forget that life is precious.

### **Stop listening to unsolicited advice**

Do not pay heed to what others say. There is a misconception about this disease among many residents in our country. You might get to hear many gossips about yourself wherever you visit. Just make sure that whatever happens you are not going to be negative. You are a normal human being like any of your other friends or colleagues.



Let me relate a story over here. Few days back one of my colleagues got to know that I am a person with epilepsy. So he asked me what it was. I explained it to him in plain terms. Well, he made a fun of this disease. I tolerated it many times. This kind of a reaction was completely new to me. I felt like I wasn't speaking to an educated man but someone who hasn't even seen the face of a school building. After it became intolerable, I spoke with him and made it clear that I wasn't liking it at all. You have to be tough enough to make a person say sorry if he has made fun of your illness.

### **Make your career and fulfil your dreams**

Emphasize more on your career and make your life successful. Due to epilepsy you might forget to pen down some known answers in your exam paper. This happens with almost everyone who suffers from this disease. You shouldn't give up. I would suggest you should fight against all odds. Be optimistic and everything will fall in place.

I would like to conclude by saying that epilepsy isn't a curse. Why don't you take it otherwise? You are suffering from this disease because you can face it. Everyday of your life is a new challenge. Take it as a golden opportunity and gain success in all the challenges of your life. When you take it in this way then only you can evolve as a fighter.

## Ray of Hope for PWE at a Remote Town in Rajasthan

Shri Pragma Mirgi Rog (Epilepsy) Hospital was established as a charitable institution at Gulabpura town of Bhilwara district of Rajasthan. The population of this small town is around 30,000. This hospital is working with full dedication in the services of PWE (People with Epilepsy) since 1978 and has made a mark in epilepsy care in the region. Our mission is "better life for these patients with good control of seizures and free from myths and stigmas to all section of the society with a focus on economic weaker segment". Our values are services with Empathy, Respect and Trust.

This hospital is run by Jain Society namely Shri Pragma Mirgi Rog Niwarak Samiti in memory of Late Guru Pujya Pravartak Shri Panna Lal Ji Maharaj (Swetamber Jain Saint). The journey started with just four patients which have now swelled to 7200 patients per month now. These patients are coming from nearly 71 district of India, covering more than 12 states i.e. Rajasthan, Gujarat, M.P., Chattisgarh, Punjab, Delhi, Maharastra, U.P., Bihar, Haryana, Tamilnadu and Assam. Every month 150-170 new patients are added. Complete information of each patient has been computerized at the centre. We have also prepared a Patient Diary of 32 pages which contains all the information about epilepsy to educate patient, family members and caregivers. This diary has record of patient's illness, treatment and progress which is updated at every visit. A positive impact in awareness, treatment and prognosis has been observed after institution of this diary.

Every month camp is being organized at the hospital premises. Initially few camps were also organized under the leadership of Dr. Pratap Sanchetee, Neurophysician, Jodhpur. Dr. Sanchetee is President of Jodhpur Chapter of Indian Epilepsy Association of India and also adviser to this hospital. Presently it is successfully run by a team of doctors under the leadership of Dr. R.K. Surekha, Neurophysician from Mahatma Gandhi Hospital,

Jaipur.

This hospital has its own building with well equipped three consultation chambers, air-cooled large waiting cum demonstration area, document room and medicine dispensing room. This centre has a computerized EEG machine and a technician for it. A LED TV has been installed in waiting area where films on Epilepsy are being screened to educate the patients or family members. All patients are supplied with free generic medicines. All activities of this centre are financed through charity and our future projects are construction of a night shelter for outstation patients, holding awareness camps at centre and at other cities, frequent medical camps, installation of a CT scanner and rehabilitation services.

Some of the important lessons learnt by us while serving these patients are as below:

1. There is tremendous lack of awareness about efficacy of treatment, marriage, education, social life, employment, intelligence and role of faith healers etc. They often feel that treatment is incomplete and life-long and have lost all hopes of cure or control.
2. Approximately 98% are poor and cannot afford treatment outside. It gives us a great satisfaction in serving them.
3. A significant number of patients have spent thousands of rupees with quacks or at other places looking for a cure and better future.
4. There is an immense need of educational and public awareness program for patient, caregivers and public. These patients require good rehabilitation plan.
5. Patients and caregivers visiting this centre are satisfied, have faith in treatment and come for regular visits. Credit perhaps goes to group approach.
6. We invite you all to visit this unique centre at a remote city of Rajasthan.



# Branch Activities

## 26 March 2016 – Purple Day Report by Epilepsy Foundation

Purple Day is an event designed to raise awareness of EPILEPSY – MIRGI.

26th March has been observed as Purple Day across the world and for past few years, Epilepsy Foundation also have been actively involved to create awareness about epilepsy in Mumbai and Maharashtra.

Nearly 50 patients and their caregivers were present at Shri Siddhivinayak Temple from 10



am to 4 pm and they distributed Epilepsy related materials to all the devotees to create awareness about epilepsy after taking blessing from Lord Ganesha.

Around 200 patients of epilepsy and their caregivers were present at 20-25 spots across the city, those include (National Park, Mahim Church, Mahim Darga, Jain Mandir at Borivali, Mahalaxmi Temple as well as various suburban railway stations – (Dadar, Borivali, Bhaiyandar, Virar, Byculla, Thane etc.). Activist of Epilepsy Foundation besides giving the awareness material and Purple balloon they also put purple ribbon to public.

Many of them carried placard in the hand to raise awareness on Epilepsy.

The Special attraction this year was Lighting of Bandra-Worli Sea Link to purple on 26th March with the help of MSRDC.

## NED & World Epilepsy Day activities - Shivamogga Branch

The following activities were organised by IEA, Shivamogga Branch in November 2015 as part of NED activity.

- 1) Drawing competition for patients and their relatives.
- 2) Games for patients.
- 3) Speech by Dr. Shivayogi, President, IMA, Shivamogga on Myths and Misconcepts about Epilepsy. Prizes were distributed to winners of the activities conducted.
- 4) Free medical check-up of patients with Epilepsy and free drug were distributed. About 60 patients attended the camp.

### Activities organised as part of World Epilepsy Day on Feb 8th 2016

- 1) Quiz program was conducted for the patients and their relatives by Dr. Ramaprasad and Dr. Shivaramakrishna. Winnere were awarded prizes.
- 2) Dr. K.R. Sridhar, Dr. A. Shivaramakrishna and Dr. Karthik spoke on various aspects of Epilepsy. About 75 patients and relatives participated in the Quiz and educational program.

- 3) Free medical check-up camp and free distribution of drugs was conducted and about 60 patients participated in that.
- 4) A CME was organized in association with IMA, Shivamogga. Speakers : Dr. A.H. Harish on '**Approach to Management of Epilepsy**'; Dr. S.T. Aravind on '**Psychological co-morbidity in Epilepsy**'; Dr. Prasanna on '**Epilepsy Surgery**'.
- 5) An educational and interactive program on Epilepsy was organized at Sahyadri Science College. 150 students participated. Dr. K.R. Sridhar & Dr. A. Shivaramakrishna conducted the program.



## IEA, Tirupati Oration in Epileptology

Reported by  
Dr. B. Vengamma

The 6th Oration was organized on 5th Sept., 2015 at Sri Padmavathi Auditorium, SVIMS. Dr. M. Gourie Devi, Emeritus Professor of Neurology, Institute of Human Behaviour and Allied Sciences, New Delhi and Former Director/Vice Chancellor, NIMHANS, Bangalore spoke on “**Impact of Pharmacogenomics on the treatment of Epilepsy**”.

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 co morbidity (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. 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 Dept. of Neurology, SVIMS, Tirupati.



## How I Controlled My Seizures by Switching to a Ketogenic Diet

In a way, my story is simple: I changed what I ate and stopped having debilitating seizures.

But it wasn't so simple getting to that point.

When I was just 12 years old and in eighth grade, I began having terrible migraines. They were so bad that I'd have to leave school and sleep for several days before I felt like myself again, and the only thing that made me feel better was vomiting.

I went to a neurologist, who ordered an electroencephalogram (EEG). The results were very abnormal, and from that EEG, she figured out I was having absence seizures, which, according to the Epilepsy Foundation, cause a short period of "blinking out" or staring into space. I'd have hundreds of absence seizures each day, causing one side of my face to twitch and my mouth to droop.

### Side Effects : Gaining weight and losing my hair

Now I had an answer: Epilepsy.

But I had a hard time accepting my diagnosis. Though the seizures lasted no more than 15 seconds, they completely interrupted my life. In school, I'd miss parts of what my teachers said in class, as well as parts of conversations with other people. I had seizures during gymnastics (fortunately, I was never injured), and I even had them while I slept.

My seizures dominated my life. I saw multiple neurologists and constantly tried different medications. I had many EEGs, both at home and in the hospital, and each time a neurologist ordered one I had to wear electrodes in my hair, making me look and feel weird.

By the time I reached my junior year of high school, the seizures and medications I took to control them were so incapacitating that I could barely think. The side effects from the medications were terrible: I

gained weight, my hair fell out, I could barely wake up each morning, and my cognitive abilities decreased with each passing day.

### The Diet that Changed my Life

Finally, I made a decision that changed everything for me.

On November 1, 2014, when I was a senior in high school, I started the modified Atkins diet (MAD) to try to control my seizures.

This highly restrictive, high-fat, low-carb diet puts the body into ketosis, meaning it raises your ketone levels — basically mimicking the effects of fasting.

On MAD, instead of using mainly carbohydrates for energy, my body began using fat. I ate only 15 grams of carbohydrates per day, high amounts of fats, and no more than 4 ounces of protein per meal. My doctor and my mom both thought it would be the best thing for me to do to help control my seizures, since medication alone had not yet done the job.

Eating according to MAD was so much harder than you can imagine. When I competed in gymnastics, I practically lived on carbs. I loved to eat pasta, pizza, bread, fruit, and chocolate. On MAD, I could only eat low-carb breads, and there was only one type my mom and I found that didn't interfere with my seizure control. The only fruits I could eat in a quantity that was actually satisfying were raspberries and blackberries, which are both pretty low-carb.

### Inspired to change the Way I thought about food

At first, I was really embarrassed by this diet because it made me feel even more strange than I already felt. I didn't want to eat in front of other people, and for a while, I stopped eating out at restaurants. I had a hard time committing to the diet because I didn't fully understand and accept the impact that the seizures had on my life.



My perspective changed during my first visit to the NYU Langone Comprehensive Epilepsy Center in New York City, near where I live in New Jersey. The dietitian I saw there told me about a woman around my age who became seizure-free within one week of starting MAD. Not only this, but she was off all of her medications and was driving, which really inspired me.

I realized that although I was nowhere near seizure control after two months of being on MAD, I had never felt so clearheaded and cognitively able until that point. I knew then that, despite my ongoing seizures, I wanted to continue this diet.

### **Simplifying my diet even more**

My mom took me to the Johns Hopkins Epilepsy Center in Baltimore. Together with her, my doctor, and my dietitian, I changed my approach: Instead of trying to replace familiar, processed foods with low-carb versions, I found it more effective to eat a simpler diet. With the exception of dinner, I began eating nearly the same foods every day, and surprisingly, I wasn't bothered by the lack of variety.

I adopted a new mindset: Even though food is one of the most important things in my life, I have to treat eating as one of the least important parts of my day.

### **In the closet about my mad diet**

I'd told very few people that I had epilepsy or that I was eating according to MAD until the summer of 2015, when I began working for the first time at the sleepaway camp I'd attended for nine years. The camp kept kosher and barely had any of the meat meals I'd relied on. I wondered if I should continue keeping all this to myself, or if I even could.

Finally, I "came out." I began telling my fellow staff members and friends that I had epilepsy and was on MAD. That decision became a major milestone in my life, and I felt like a weight had been lifted off my shoulders.



Several months later, when I started at Goucher College in Baltimore, I decided there was no reason to be embarrassed about having epilepsy or being on MAD, and that I wanted to be open about it. I told my roommate about my seizures before I even met her, and she was totally accepting.

Being on the diet only added to my busy college workload, but while at Goucher, I became seizure-free for the first time. And I came out to everyone

about my epilepsy diet. This past March, I posted a link on Facebook to a podcast about the ketogenic diet produced by WNYC Studios, where my dad works. It felt so liberating, and I was very proud of myself.

### **Finally Seizure-Free**

Now, I enjoy sharing my story to inspire others and to clear up people's misconceptions about epilepsy — and because I'm really proud of what I've accomplished. On May 2, I posted on Facebook that I had been seizure-free for 100 days! The support I received even from people I hadn't talked to in a long time was amazing.

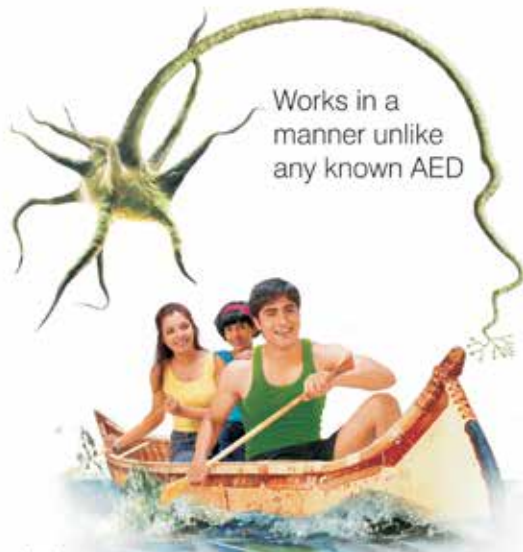
It was then that I realized I had taken control by staying on this diet. I had a lot of help, especially from my mom, but I was the one putting the right foods in my mouth to make my seizures stop.

This past school year was the best I've ever had — academically, socially, medically, and mental-health-wise. I have never felt so happy or self-confident, and I attribute that completely to the ketogenic diet.

And the person I thank most of all is myself.

**Naomi Schachter is a sophomore at Goucher College. This is her first article for a national publication.**

Source :<http://www.everydayhealth.com/columns/my-health-story/how-i-controlled-my-seizures-by-changing-my-diet/>



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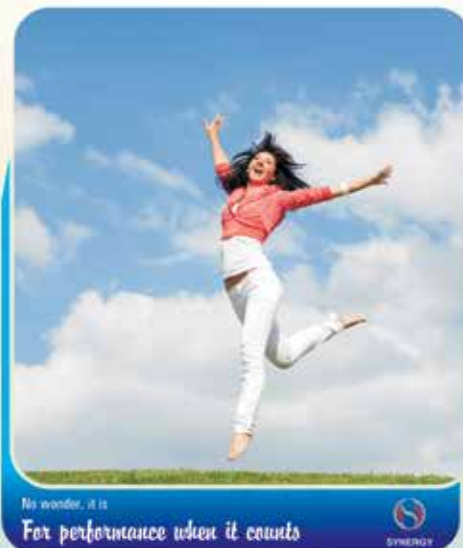
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