

# EPILEPSYINDIA



INDIAN EPILEPSY ASSOCIATION & INDIAN EPILEPSY SOCIETY

## $\mathcal{N}$ e w s t e t t e r

July - September 2009 Issue 3, 2009

### Editorial



#### Dear Friends.

A newly launched website is devoted to works of art created by persons with epilepsy. The artists have got a platform to talk about their art and their medical condition and the visitor an insight to how the artists developed their fine sense.

Common human sufferings pain, illness and disability have been

interpreted in various cultural-historical epochs. One of the best known paintings of Pablo Picasso *Guernica* (detail shown alongside) seems to correlate pain with an obvious element of suffering. It is interesting that in art and literature, there are very different ways of depiction or incorporation within a structure of the plot or the frame. Psychoanalyst Victor Emil Frankl explains: "Suffering makes humans clear-sighted and the world transparent."

Historically, epilepsy features in the Old Testament. Cassandra's prophetic sayings are accompanied by the phenomena of frothing at the mouth, convulsion and spitting blood. The relationship with prophecy is remarkable .Divination - soothsaying - was a synonym for epilepsy in ancient Rome in a French term for epilepsy: *mal des prophètes*. In Dante's *Divine Comedy* (1307), there is comparison between the condition of the sinner with an atonic seizure caused by the devil and the subsequent disorientation.

Shakespeare used the theme of epilepsy in describing an epileptic fit in the protagonist in *Julius Caesar* (1599). In *Othello* (1604), the Venetian general falls to the ground while listening to a distressing report and the witness standing close by (lago) terms this an epileptic event.

This connection continues in modern literature; Thomas Mann's *Joseph and His Brothers* (1933); Christa Wolfs *Cassandra* (1983) and M. Dostoevsky several characters who suffered from seizures.

Art is a creative expression and interpretation of thoughts, feelings and aspirations both bright and desolate. The conspicuously frequent use of epilepsy as the subject matter for art may be due to the ubiquitous nature of epilepsy through the ages. Also equally due to the dramatic and extremely demonstrative manifestations

which confront an onlooker. Its mystical ideas, religious views, superstitions and abstruse theories have deeply moved but confused lay public and such ideas have indeed persisted till today.

Against this backdrop, it is therefore hardly surprising that epilepsy as a depressing, frightening and in many stigmatising affliction, is repeatedly a subject of the artistic divestment of the human being in the visual arts, literature or even music.

A unique representation of neuro-anatomical features with an artistic flourish comes from an American academic and artist Janet Yagoda Shagam. She combines the seemingly unrelated motifs of sea horses and the almond tree

The 'hippocampus' one each in the two temporal lobes is reminiscent in its form to a sea horse. ('Hippocampus guttulatus' from the Greek: 'hippos' = horse, "kampulos" = curved). It may be the originator of adult-onset focal epileptic fits and hippocampectomy could help.

Amygdala or the 'almond kernel' (from the Greek 'amygdala' or the almond tree) lies close to the hippocampus and may even be the starting point for focal epileptic fits and amygdalo -hippocampectomy may help in some case.

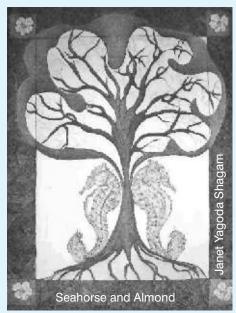
The engraving "Seahorse and Almond© 2006 (Desitin)" combines the two such apparently contrasting motifs, sea horses and the almond tree in an artistically impressive and

appealing way, and in doing so closely connects the two themes visual arts and epilepsy in a contemporary manner.

Hope the readers of EI will contemplate and enjoy this creative aspect in dealing with epilepsy.

Best wishes

**Dr VS Saxena** *Editor* 



### **EPILEPSY INDIA**

# NEWSLETTER OF INDIAN EPILEPSY ASSOCIATION & INDIAN EPILEPSY SOCIETY

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IES-Executive Committee 2008-201023

### **NOTICES**

#### AMBASSADOR FOR EPILEPSY



Carol D'Souza, Mumbai

El congratulates Ms Carol D'Souza for being awarded Ambassador for Epilepsy. Her citation reads:

- Invited speaker to several international congresses.
- · Manages IEA Bombay Chapter.
- Member British Medical Journal patients advisory committee.
- Spoke on behalf of presons with epilepsy at the WHO.

Pl. also see page 4 for other Ambassadors for Epilepsy Award for the Year 2009

### **IEA-18<sup>th</sup> IEC Trust**

## Information for members of IEA and IES Availability of Financial Grants



This is for the information of all members of IEA and IES that financial grants are provided by the IEA-18<sup>th</sup> IEC Trust towards funding of the following related to epilepsy:

- Research projects, both medical and social
- Conferences, seminars, workshops
- Training and education of personnel
- Travel grants for national and international meetings
- Public awareness campaigns

For further queries and application forms, please correspond at

Indian Epilepsy Association -18th International Epilepsy

Congress Trust

Sannibli, K-10/10 DLF City-II, Gurgaon-122002

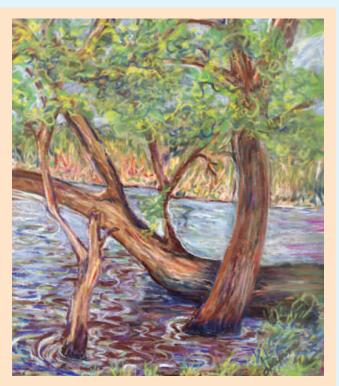
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# ART CONTEST FOR PEOPLE WITH EPILEPSY



Expressions of Courage® is a national art contest for people with epilepsy. The contest showcases the talent and inspiration of people across the country living with the condition.

Ortho-McNeil Neurologics®, Division of Ortho-McNeil-Janssen Pharmaceuticals, Inc, in partnership with the Epilepsy Foundation, invites people diagnosed with epilepsy of all ages to share their artwork in this year's contest. The contest will be open for entries from May 11, 2009 through August 28, 2009. A panel of epilepsy advocates, art industry representatives and healthcare experts will serve as contest judges.

Artwork may be created in ink, pencil, crayon, paint or a combination of these materials and must be on paper or board no larger than 8 ½ by 11 inches. Contest entries will be categorized into three age groups: children ages 12 years old and younger; teens age 13 to 17; and adults 18 years of age and older. Multiple submissions will be accepted.

Please send original artwork and a completed entry form to:

Expressions of Courage® c/o Ortho-McNeil Neurologics® 389 Pittstown Road Pittstown, NJ 08867

### **INTERNATIONAL HONOURS**

### **LIFE TIME ACHIEVEMENT AWARDS 2009**

The Lifetime Achievement Award in Epilepsy is given jointly by the International Bureau for Epilepsy (IBE) and the International League against Epilepsy (ILAE). The Award is given to an individual to recognise and honour his or her exceptional and outstanding personal contribution over a long period of time to activities that advance the cause of epilepsy.

The Award consists of two commemorative and inscribed silver candlesticks, a financial prize of US\$ 5,000, a scroll, and the name of each recipient is added to the Lifetime Achievement Award winners' Hall of Fame maintained by IBE and ILAE.



### MAIN HONOURS AND DISTINCTIONS

Peadiatric Neurologist, Scientist & Research Director

Prof. Jean Aicardi, France

- Ambassador for Epilepsy.
- Ramon y Cajal Award.
- Peter Emil Becker Award, Germany.
- Aicardi's syndrome was described in 1969 and Aicardi-Goutieres syndrome in 1984.
- Author of 259 articles in international peer journals, 111

- President, IBE 1997-2001.
- Member of chair of a number of IBE Commissions.
- Co-chair 2001- 2005 LAE/IBE/WHO Global Campaign Against Epilepsy.



Ambassador for Epilepsy.

Society for the care of PWE.

- The Spike & Wave Award of the Dutch Branch of ILAE.
- The IBE/ILAE Award for Social Accomplishment.
- Dutch Royal Decoration: Officer in the Order of Oranje Nassau.

### SOCIAL ACCOMPLISHMENT AWARD



Dr Michael Hills, New Zealand

The Social Accomplishment Award in Epilepsy is given to an individual to recognise his or her outstanding personal contribution to activities that have resulted in a significant advance in the social well being and or quality of life of people with epilepsy.

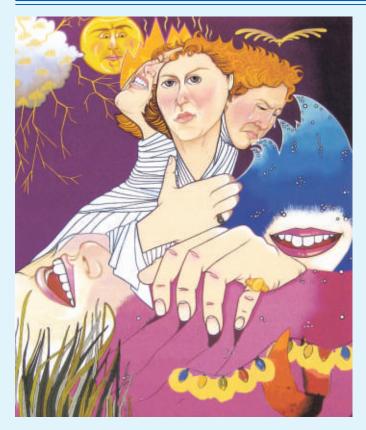
It consists of an engraved glass trophy, a financial prize of US\$ 5,000, a certificate and the name of each recipient is added to the Award winner's Hall of Fame maintained by IBE and ILAE.

Dr Michael Hills has interest in the disability field originated in his own experience of epilepsy throughout adulthood. He has been an IBE Vice President, Past President of Epilepsy New Zealand, and on the Council of the New Zealand Neurological Foundation. He received an Ambassador for Epilepsy award in 1999.

#### OTHER AWARDEES OF AMBASSADOR FOR EPILEPSY AWARD FOR THE YEAR 2009

SI. No.	Name	Country	SI. No.	Name	Country
1.	Ettore Beghi	Italy	7.	Shichuo Li	China
2.	Anne Berg	USA	8.	Lilia Nunez Orozco	Mexico
3.	Warren Blume	Canada	9	Cidgem Ozkara	Turkey
4.	Normal Delanty	Ireland	10.	Ernest Somerville	Australia
5.	Jacqueline French	USA	11.	William Theodore	USA
6.	Shunglon Lai	Taiwan			

### **CREATIVE SPARKS**



#### Source: International Epilepsy News, Issue 1, 2009

For centuries there has been an important connection between art and epilepsy, both in the representation of the condition through art and literature, and as depicted in the artistic endeavours of persons with epilepsy.

On the 7th May Jim Chambliss saw a dream come through when a new website devoted to works created by persons with epilepsy globally was launched.

Artists whose work will be displayed on the website are also invited to write about the most significant influences in their art.

Although Jim Chambliss began his professional career as an attorney, his epilepsy drove him in an entirely different direction –to art. Now his goal is to give voice to a global community of artists with epilepsy, many of whom use their artistic talents as a way of describing their epilepsy, the sensation of having a seizure, or how their lives are affected by epilepsy. Chambliss explains:

One of the things that describes what I am doing as a goal is to show how a picture is worth a thousand words. And we are going to find over a thousand pictures as we begin to help people understand the individual with epilepsy rather than just the condition.

Again Chambliss explains: "We are interested in artistic influences of people with chronic medical condition such as epilepsy and migraines. What is it that sparks creativity?"

He adds, "Almost all artists want to have their artwork seen and interpreted. However, what we want to convey in an exhibit is not cause and effect; that is you are not a good artist because you have epilepsy, but rather epilepsy is simply one of the many factors that make a person uniquely human."

Chambliss's piece "Blindsided" is one example of this: "This is a representation of when I had a seizure in December 1998.I stiffened and fell flat on my face on a hardwood floor, but I have no memory of the event. Later my face and persona were not recognizable to me. I had a broken nose, chipped teeth, and one eye swollen closed."

Chambliss says, "I am often reluctant to speak of the cognitive damage from my brain injury and the altered behaviors from epilepsy, because of the stigma that can stem from brain impairment. It is so easy for even the best intentioned of people to proliferate the stigma of epilepsy through focusing only on the negative impact

that confronts a person with partial brain impairment without balancing the positive attributes of the individual as a whole."

"I have fortunately been able to recover, adjust, and move on to a point where the brain injury in 1998 and epilepsy do not hold me back in 2009. My personal

experiences have made me m o r e empathetic and understanding of the plight and frustrations of people with epilepsy, while m o r e impassioned to help."

You can also contact Jim at

Jimchambliss@msn.com



### **CREATIVE SPARKS Contd...**

### **Up Against the Glass**

Phil Thomson, Australia



I want to make reference in my art to the fact that I have epilepsy because it has such a profound effect on my imagination, visual senses, emotions, and on my perception and observation of every thing around me. What I would most like people to know about epilepsy is that it is a condition that effects and alters every aspect of human consciousness. It exposes someone who has epilepsy to states of perception that are experienced by relatively few of the overall population surrounding them.

### **Spring**

Emma Brockett, Australia



Our personalities are governed by our brains. Obviously those with epilepsy, in theory, will perceive art and make art in a different way from those who don't have epilepsy. Also artists with epilepsy may display similarities only found in people with epilepsy, or.

I would like to encourage people with epilepsy, including myself, to feel that they can be upfront about their epilepsy and not fear the consequences of such a disclosure. I have been told many times, living in fear, is not a productive way of living at all.

#### The Guardian

Myron Dyan, USA



I have been showing my work for a few years now, and my main theme is that all people regardless what their condition or circumstance can contribute not only to themselves, but to others as well. I have attempted to show in all my work all the inner pain and beauty that can be manifested with a condition as severe as epilepsy, but also a way out of that pain!

Life is not always kind but we must be strong and fight for our dreams and never, never give them up for any one, any condition, or circumstance. Once we have found our way down the pathway to our dreams then giving to other became part of that healing process. So I hope that in some small way my art will help others find their own way to wholeness so that we can all see all the way home!!

### **CREATIVE SPARKS Contd...**

#### Portrait of the Artist as a Blind Man

John Bramblitt has epilepsy and is blind; he is also a talented artist

John Bramblitt's sight began to deteriorate when he was 11 years old, but no one realized what was happening. He started having seizures when he was two years old and his doctors think his loss of vision is due to nerve damage, possibly caused by his seizures

A student at North Texas University, he was majoring in English and creative writing when he lost his eyesight completely. Suddenly, all of his main artistic diversions were derailed. He could no longer draw, read or write passions he believed would carry him through the worst of times.

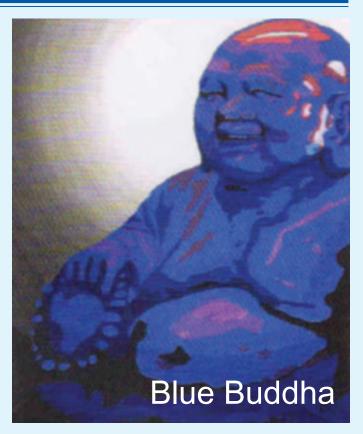
"For about a year I couldn't do any thing,"he says. He became deeply depressed and worried about being a burden on his parents, even though he had been living independently since he was 18 years old.

"I wanted to tell people that even thought I have a disability, I'm still me," he explains.

As a budding writer and artist who suddenly had to



contend with blindness and intensifying seizures, John seemed to have every reason- every excuse-to descend info self pity and artistic paralysis. But, instead, he found a way to overcome the obstacles in his life. His first objective was to find a means of marking the outlines of his drawings with raised lines-something similar to the



way Braille is written as raised dots. This is what he calls the "bones" of the painting. Eventually he came across a fast drying substance called Puffy Paint, that served his purpose. John draws mainly in loops and circles and, he says, each circle represents in his mind some colour or shadow or place of light.

Then he searched for the best type of paint. Living in Denton, Texas, a college town, because artists' supply shop was nonplussed when he asked to look at all the paints, touch them and determine which one was going to work best. it seems that different colour oil paints feel unlike one an other because they are made of different substances.

When he first started painting, he was angry. He signed his paintings with two circle that are X'd out to signify his lost sight. He painted almost constantly for six months and, before he knew it, his anger had subsided and he felt calmer than he ever had.

In the midst of his collection, a laughing blue Buddha takes centre stage. He says he was drawn to the figure of Buddha because of his seizures. The statue of Buddha looked so calm and happy –like "a calm little centre of the universe that everything can rotate around."

With thanks to Lisa Boylan, Epilepsy Foundation, who sent us this story.

### 2009 EPILEPSY PIPELINE UPDATE

### By Joyce Cramer, President, Epilepsy Therapy Project

The biennial conference devoted to clinical trials on antiepileptic drugs: "Antiepileptic Drugs-10," was held in Coral Gables, FL, on April 15-17, 2009. The conference gathered physicians, researchers, industry representatives, venture funders and FDA personnel with interests in epilepsy. The goal was to review the



current state of affairs of epilepsy drugs and devices and to see what is coming down the pipeline.

Epilepsy experts discussed everything from animal models to how to predict whether drugs would stop seizures, to patient recruitment for clinical trials. The conference was a lively review of review of mechanisms of action, types of preclinical and proof-of-principle drug testing, and of thorny issues related to later stage clinical trials for regulatory approval.

#### **Preclinical Development**

The increasing number of animal models with good resemblance to human epilepsy is bringing us to models that apply to human disease. Longstanding evidence that head injury creates a high risk for development of epilepsy has led to a recent surge of interest in preventive treatment for post-traumatic seizures. Approaches to protecting the brain and preventing epilepsy after head injury are high priorities for epilepsy researchers.

#### **Clinical Trial Endpoints**

The conference discussed the best endpoint for documenting that a new seizure drug is working. Currently, most trials either count numbers of seizures and look at the mean (average), median (the point for which numbers of seizures are half are above and half below) or number of patients whose seizures are cut in half or better (responder rate). A new method was discussed as being better in some circumstances, namely measuring the time to the 1st, 2nd, 3rd, etc. seizure. Among other advantages, it allows quick discovery of ineffectiveness for trial participants, so they can exit the trial and try something else.

#### **Device Trials**

Many of the estimated one million people in the USA with treatment-resistant epilepsy may benefit from devices that stimulate the brain to prevent or abort seizures. The only currently approved device to reduce seizure frequency is the vagus nerve stimulator (Cyberonics), which stimulates a nerve in the neck. Several experimental brain

stimulation devices, some in advanced stages of testing, were discussed. The FDA device reviewer provided the FDA perspective on devices. She noted that future devices that combine drugs or biologics with devices will require thoughtful evaluation to determine the efficacy and safety of all components.

#### **Special populations**

What pediatric syndromes should be studied? The child neurologists' view of epilepsy often is based on age of onset. Historically, pediatric studies have focused on infantile spasms, Lennox-Gastaut syndrome and childhood absence epilepsy. Recent evidence that vigabatrin is useful for infantile spasms as a new treatment to ACTH for this disorder. Several drugs have been tested for efficacy in Lennox-Gastaut Syndrome, the most recent being rufinamide (Banzel). An NIH study comparing valproate (Depakote), lamotrigine (Lamictal) and ethosuximide (Zarontin) surprised many clinicians by showing superiority of ethosuximide. Unfortunately, the mixture of many different types of seizures in pediatric syndromes such as Lennox-Gastaut makes trials for specific seizure types harder to interpret.

#### Formulations and delivery systems

Although neurologists and professional organizations have spoken out against mandatory substitution of generic for branded epilepsy treatments, the laws in many states allow pharmacists to make these changes without physician approval. The problem is that generic drug suppliers change, and one generic may not be as well absorbed into the bloodstream as another. Frequent changing from one to another generic drug can lead to inadequate blood levels, resulting in breakthrough seizures.

### 2009 EPILEPSY PIPELINE UPDATE

Acute repetitive seizures (ARS) are clusters of seizures experienced by some patients. These events are less urgent than is status epilepticus, but ARS still require quick therapy.

The benzodiazepines (lorazepam=Ativan, diazepam=Valium, midazolam=Versed) are classic treatments for rapid seizure control but usually are delivered by injection into a vein or muscle. A new concept is the use of nasal sprays to deliver a benzodiazepine. It is assumed that this approach would be more acceptable to patients than is the currently available rectal diazepam administration (Diastat, Valeant). Studies of ARS are complicated by the need to find the uncommon patients who experience sufficient clusters.

#### Patient recruitment in clinical trials

The number of patients appropriate for a typical clinical trial (having a minimum of four seizures per month) is decreasing for a variety of reasons. More patients may be controlled by the current medications or fewer patients are willing to enroll in trials. Altered inclusion criteria might increase the number of people eligible for a trial. Another approach is to perform studies globally, although this requires extensive assessment and training all investigators and coordinators all over the world.

#### **Epilepsy pipeline review**

The pipeline review was divided into sections based on stage of assessments, starting with the most advanced treatments (phase 3) and concluding with those in preclinical testing. Extensive information is available elsewhere about the efficacy and adverse effect profiles for the following antiepileptic drugs now in phase 3 testing (preparation for submission to FDA):

- Brivaracetam is similar in structure and mechanism to levetiracetam (Keppra). It may have fewer adverse effects than does Keppra.
- Carisbamate probably has multiple mechanisms of action. Its tolerability and adverse effect profile are good. Clinical trials are continuing to define efficacy against partial-onset seizures at the optimal dose.

Eslicarbazepine is similar in structure to carbamazepine (Tegretol) and oxcarbazepine (Trileptal). Efficacy against partial-onset seizures and tolerability is good, likely without the safety concern of low blood sodium (hyponatremia) seen with related drugs. The drug has been approved for use in Europe. The epilepsy field is entering an exciting time, when multiple new medications and probably several new devices, will become available. None is the "magic bullet" that we all want, but each will be something new to try, for people not experiencing satisfactory results with current therapy. The Epilepsy Therapy Project continues to strive to develop new treatments for epilepsy and to communicate the current state of knowledge to people who care about epilepsy.

Compound/Device	Trade Name	Company
Brivaracetam	Rikelta	UCB Pharma
Carisbamate	Comfyde	OrthoMcNeil
Eslicarbazepine	Stadesa (US), Zebinix (EU)	Sepracor (US), Eisai (EU)
Retigabine		Valeant/GSK
Vigabatrin	Sabril	Lundbeck
Clobazam	Frisium	Lundbeck
Intranasal Midazolam	Versed	Ikano Therapeutics
Modified-release oxcarbazepine		Supernus Pharmaceuticals
Responsive Neurostimulation System		Neuropace

(Edited by Robert Fisher for epilepsy.com)

### **NEWS ABOUT CHAPTERS**

#### WEST BENGAL CHAPTER

#### Reported by: Dr Goutam Ganguly

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5. Dr S.K Somani

6. Dr S Mukherjee

7. Dr A Pandit

8. Dr B.K Roy

9. Dr K.C Ghosh

Like other years we had planned to organize our activities

- a) Holding periodical camps especially into the rural areas.
- b) Arranging Scientific meetings on Epilepsy.
- c) Increasing the strength of members of the association and
- d) To consolidate the financial positions.

#### **Our Activities**

We organized three (3) rural and two (2) urban camps during this period.

1. On 5th April 2008, a camp was organized at "Bikash" Bankura, 265Kms away from Kolkata. The programme continued for whole day and this programme was divided into two parts i) in the morning and ii) in the afternoon. In the morning session, we have examined 45 children of mentally retired with seizure and advised them for proper treatment. Free medicines were distributed amongst the ailing children. In the afternoon session, discussions and question-answering session was held amongst the parents and guardians. Professor T. Roy and Dr S. Basu delivered their views on the different aspects of epilepsy, especially mentally retardation and its preventive measures with the

importance of proper antenatal, perinatal and neonatal care interlining present health care system. Other members which include Prof. A Sennapati, President, Dr G. Ganguly, Dr T. Goswami, Dr K.C. Ghosh and Dr Ashis Dutta were also shared their views.

- 2. One urban camp was held at Chinsurah, Hooghly on 5th October 2008 wherein 32 persons with epilepsy were examined and advised them properly. Dr G. Ganguly took part in interactive session with guardians and parents and that was found to be very interesting and attractive.
- 3. National Epilepsy Day programme in 2008 has already been reported in El, Issue, 2009.
- 4. On 8<sup>th</sup> January 2009, we again reassembled in "Bikash" Bankura and 51 mentally retarded children having seizure were thoroughly screened and arrangements were also made for free distribution of medicines to them. In the afternoon an open discussion with parents and guardians was held in which Prof. T. Roy, Dr G. Ganguly, Dr K.C.Ghose, DrManas Sinha and Dr Amit Vyas took part in this programme.
- 5. We have conducted another camp on 22, Feb, 2009 at Sheoraphuli, District Hooghly which was organized by Sheoraphuli Sebanicketan, in which Dr G. Ganguly, Dr T. Goswami and Dr B. Bose attended the camp. We have examined 32 patients and advised them for proper treatment.
- 7. The last camp was held at Sreekhanda, Katwa, Burdwan in collaboration with Lion's club of Greater Kolkata within the premises of BISWA BANDHU MISSION. Total 190 patients were screened of which 20% had seizure. Prof. Trishit Roy and Dr G. Ganguly interacted with the patients and parents and guardians, Other members mainly Dr K.C.Ghosh, Dr Anish Ghosh and Doctors of Lion's Club of Greater Kolkata had also participated in the session.

In spite of our efforts being put, there is a scope for organizing more camps, seminars, interaction with the patients, especially in the rural areas and also interactive session against the social myth and prejudice with the active help of press and media. There should be rational use of AEDS and we should not swayed away by the propaganda of pharmaceutical companies.

Our sincere thanks to the editor of our News Letter Dr Sagor Bose who single handedly brings out the News Letter periodically highlighting the various issues and programme in the News Letters. I request our members to contribute regularly to our News Letters. My special gratitude to our outgoing beloved President Prof. A.K. Senapati who had always given his prudent advice and pleasant company throughout his tenure .Lastly I welcome the new governing body with their active participation, sincere coordination and sharing the views for the betterment of our chapter.

### **NEWS ABOUT CHAPTERS**

### MADHYA PRADESH CHAPTER

# Activities of Indian Epilepsy Association M.P. Chapter.

#### Reported by: Dr V V Nadkarni

Newly elected Executive Committee of Indian Epilepsy Association (MP Chapter)

Dr V G Dakwale President
Dr Deepak Mansharamani Vice-president
Dr V V Nadkarni Secretary
Dr O P Lekhra Jt.secretary
Mr L B Hariani Treasurer

We conducted epilepsy following camps and first Saturday workshop on every month.

Ist camp on 6th December 2008 I: 65 patients with epilepsy attended the workshop. Dr V V Nadkarni presided over the function. Patients were given counseling by our Psychologist Madhavi Tiwari.for positive thinking in depression She explained about home based activities for women. She demonstrated



Distribution of Seizure Diary

envelope & box making for disabled persons, so that they can acquire minor jobs .Queen's Welfare Society Epilepsy support group distributed free medicines .Refreshment were provided for patients by donors Mr.Lalwani & Mr.Bajaj.. One patient had convulsion during the camp .The other patient in self help group helped him during the attack and assisted the nursing staff. Caregiver was not afraid of the episode of convulsion which was very frightening attack for new patient .Awareness in epilepsy has helped the patients to understand the epilepsy. (Photo enclosed)

2nd camp on 3rd January 2009: There was a educational training for information on epilepsy through LCD presentation by Mrs. Neelam Ranade (who has graduated in Diploma Epilepsy Care) on problems related to pregnancy, sports, & drug compliance. Dr V V Nadkarni and Dr Garima Airen examined the patients during the camp. 70 patients were examined and given free medicine by Mrs. Vidya Kibe, Mrs. Sunita Jain.(Members Queen's Welfare Society) for one month. The free medicines were supported by 1) Sitaram Hospital Charitable Trust 2) Tolabai Memorial Charitable Trust, 3) Jajoo Trust.



Actual convulsion in a person who is being given first aid by a PWE

**3rd camp on 7th February 2009:** During a workshop identifying patients who can participate in performance during the ECON 2010, either as a drama or music recital by the patient's. Yoga Demonstration was given by Dr Jaymala Shah (Yoga therapist). Medical Director of Gita Bhawan Hospital Dr Gandhe presided the function. Mrs. Sunita Jain and Mrs Subhada Joshi members of Queen's welfare society distributed free medicines for needy patients.80 Patients attended the camp.

**4TH camp on 7th March 2009:** There was workshop held in Gita Bhawan Hospital .Chairman of Gita bhawan Trust Mr. Babulal Baheti presided the function .75 patients and queen's Welfare society members and the team from Gita Bhawan Hospital attended the camp. In which UCB Pharma distributed seizures diaries and small booklets for epilepsy information Do's & Don't.

**5th camp on 6th April 2009 :** IST Saturday workshop was conducted and 80 patients attended the camp. Dr V.V. Nadkarni and Dr Garima Airen examined and provided medicines. Distribution of free medicines done by Mrs. Urwashi Wagle and Mrs. Sunita Jain Queen's Welfare Society epilepsy support group. Free investigation provided for needy patients.



### **IEA BIHAR CHAPTER-EPILEPSY UPDATE PATNA-2009**

### GOVERNOR ASKS FOR AWARENESS ABOUT EPILEPSY

The Governor of Bihar R L Bhatia asked the medical fraternity to create awareness about epilepsy among the people so that the people suffering from the disease could take advantage of latest methods of treatment.

Inaugurating a Epilepsy Update, Patna, 2009' organized jointly by the state chapter of Indian Epilepsy Association (IEA) and neurology department of Indira Gandhi Institute of Medical Sciences (IGIMS), he said that the lack of awareness among the people, particularly those in rural areas, about this disease deprived a large number of epilepsy patients of treatment. The medical science has made rapid strides in this field and people should take advantage of it, the governor said.

He described epilepsy as neurological condition in which there are brief disturbances in the functioning of brain. He said that this disease can be treated with specialised care.

The governor lauded the IEA for organizing such a function and also released a book on epilepsy edited by Dr Ashok Kumar of IGIMS, Patna.

Earlier, speaking on the occasion, former Union minister Dr C P Thakur recalled that when he was studying in PMCH he thought that the incidence of epilepsy was rare in India. "But, when I went to UK for higher studies, I found many people suffering from this disease," he said.

"In fact, this disease is much common in developing countries and people get their relatives suffering from epilepsy treated at private clinics," Dr Thakur said. He said there are many questions related to the disease which require solution.

Later in the day, several prominent doctors from different states delivered their lectures. Dr Ashok Kumar threw light on different diseases with epilepsy like symptoms, but added that they were actually not epilepsy. He said that many such patients are often prescribed anti-epileptic medications for years and sometimes even referred for epilepsy surgery.

Source :Alok Mishra, Times News Network, 11 May 2009

### TRENDS IN EPILEPSY RESEARCH

'Neonatal Hypoglycemic Brain Injury (NHBI)' - A Common Cause of Infantile-onset Remote Symptomatic Epilepsy'

The study links infantile onset of epilepsy to neonatal hypoglycemia

Indian Paediatrics, suggests that the major cause of infantile onset epilepsy in India is hypoglycaemia in the newborn period. Low Birth Weight (LBW), poor neonatal feeding and chesarean delivery were found to be significant risk factors for neonatal hypoglycaemia.

According Dr Vrajesh Udani, lead researcher of the study, "The aim of this paper was to study the causes of remote symptomatic epilepsy with onset in the first three years of life. Patients with NHBI were also studied for risk factors and clinical features." The study, which covered 100 patients (63 males 37 females) over a period of four months, found that the mean age of seizure onset was 13.9 months (1-36 months). In 88 out of 100 patients, the diagnoses of the radiologists completely concurred.

Epilepsy has its highest incidence in infancy. At this time, a unique interface exists between normal brain maturation and the epilepsy, which may have profound effects on the infant's cognitive development.

The cause of infantile remote symptomatic epilepsy is different from those at other ages. "In developed countries these appear to be mainly developmental disturbances of cortical architecture. In developing countries implicate perinatal encephaloclastic (braindamaging) conditions as major contributors for remote symptomatic epilepsy, especially for West syndrome," the study states.

"What became clear from parent interviews was that a common scenario leading to neonatal hypoglycaemia was a delay in establishment of feeding in a low birth weight newborn delivered by caesarean section. The baby unfortunately gets underfed/starved in the first one-two days leading to neonatal hypoglycaemia and consequent acute brain injury.

Thus, it was concluded, perinatal brain-damaging etiologies, especially neonatal hypoglycaemia, are responsible for half the symptomatic epilepsies starting in the first three years of life. The best way to avoid neonatal hypoglycaemia is to feed the newborn (preferably breast feed) within two hours of birth."

Source: Indian Paediatrics, Feb. 2009

### **EPILEPSY AROUND THE WORLD**

# PAKISTAN: VICTIMIZED FOR HAVING EPILEPTIC SEIZURES



LAHORE, 28 May 2009 (IRIN) - For many years, Nuzhat Bibi, 19, had no idea what was wrong with her. "I would have periodic fits, sometimes three times a month, sometimes more

often, when I would first see bright lights and then fall to the ground as a strange smell of burning spread around me. I can never remember what happened. When I woke up I felt totally exhausted. My mother said I had lost control of my limbs and that my eyes rolled up,".

Nuzhat Bibi had her first seizure when she was 15, following a head injury. The local 'hakim' (traditional healer) at the village, suggested to "cure" her. The young woman has been fortunate. Her husband, an educated office assistant in Lahore, took her to a doctor. She was diagnosed with epilepsy, and is currently on medication and has not had a seizure for nearly two years.

#### "Poorly understood"

Nadir Ali Syed, consultant neurologist at the Aga Khan University Hospital in Karachi said that epilepsy is poorly understood and even educated people sometimes act with extreme insensitivity and even cruelty towards those suffering from it.

According to Muhammad Abdullah, secretary of the Karachi-based Epilepsy Association of Pakistan, "attitudes regarding the disease are a big problem especially in rural areas."

Part of the social problem arises as epilepsy is often confused with mental illness. Faisal Sadiq, a psychiatrist in Lahore said that in many cases the "stigma attached in our society to mental illness means treatment has not been sought for years and families had sometimes gone to extraordinary lengths to cover up the condition."

#### Epilepsy more common in rural areas?

This is despite the findings, from the 2007 study, which showed epilepsy was more common in rural areas. The reasons are unclear but may be linked to socioeconomic deprivation. According to the World Health Organization, close to 90 percent of epilepsy cases worldwide are found in developing regions.

As far as knowledge about the disease goes, Abdullah said in urban areas the situation had improved, and the Epilepsy Association regularly "sets up camps and so on to create awareness".

Source: IRIN, Health & Nutrition.

### USA NATIONAL WALK FOR EPILEPSY



THOUSANDS of WALKERS UNITE with CELEBRITIES IN WASHINGTON DC TO RAISE AWARENESS about SEIZURES and EPILEPSY

Participants Hope a United, Activist Voice Will One Day Lead to a Cure

Based on the numbers of people gathered on the National Mall March 28, 2009, it's clear the epilepsy community is comprised of more than fair-weather friends. Much more. Undaunted by spring showers, muddy walk conditions and cool temperatures, walkers gathered from all over the country to help people with epilepsy, their loved ones, caregivers and health care professionals. They joined television stars and sports celebrities on the Mall to show unmitigated support for the third annual National Walk for Epilepsy. Over the past two years, the event has raised more than \$2 million dollars and engaged more than 13,000 walkers. Today's event is expected to increase those numbers significantly. Money raised from the Walk helps create essential programs for people with epilepsy and aid in the search for a cure. The National Walk for Epilepsy was hosted by the Epilepsy Foundation, with financial support from Ortho-McNeil Neurologics®, Division of Ortho-McNeil-Janssen Pharmaceuticals, Inc.

By Lisa Boylan, Epilepsy USA Senior Editor.

### EPILEPSY AROUND THE WORLD Contd...

#### **BRAINWAVE**



#### Epilepsy-prevalence research to be launched

New research pinpointing for the first time the prevalence of epilepsy in Ireland has been launched in Dublin.

The Prevalence of Epilepsy in Ireland Study was commissioned by Brainwave — the Irish Epilepsy Association — and conducted by the UCD Centre for Disability Studies. Data from the study was presented for the first time on May 19. This will help to identify current and future service needs for those living with the condition.

Not only is this the first time that Irish data will be available, it is also the first fully nationwide prevalence study to have been carried out on epilepsy anywhere in Europe. The event is part of National Epilepsy Week, which took place from May 18 to 24.

Source: Public Health13 May 2009

### SRI LANKA VALUES CLOSE TIES WITH SAUDI ARABIA

Foreign Minister Rohitha Bogollagama said that Sri Lanka values the friendship with Saudi Arabia and other Arab countries since the island nation has deep rooted relations with the Middle East region from time immemorial.

The Saudi Fund For Development (SFD), has given a grant of SR 40 million for the construction of the National Neuro -Trauma Center in Colombo and SR 75 million to build an Epilepsy Hospital in Colombo .

### USE OF DIFFERENT AED FORMULATIONS IN DEVELOPING COUNTRIES



The knowledge of different formulations was less among the interviewed PWE is Brazil, especially those with less schooling level and of lower socioeconomic classes. There was frequent AED formulations switching. Break through seizures (14.5%) and increased adverse effects (12.2%) were referred when the AED formulation change was done, mainly by those PWE with less education, and probably the individuals more compromised by the epilepsy burden. This fact should alert health experts and regulatory authorities, especially in developing countries with limited health expenditures, in which generics promote a great impact in the treatment of several medical conditions, that AEDs should be considered a special group regarding generics and similar drugs public policies.

Guilhoto LMFF, Alexandre V, Martins HH, Santos CM, Lin K, Silva ARCO, Mesquita S, Castro A, Masuko A, Yacubian EMT.

Source: International Ep News Issue1, 2009

Avoid having your ego so close to your position that when the position falls, your ego goes with it.

— Colin Powell

### EPILEPSY AROUND THE WORLD Contd...

### COPING WITH EPILEPSY: WELWYN GARDEN CITY WOMAN TELLS HER STORY



To raise awareness, one woman with epilepsy has spoken to the WHT of her experiences of the neurological condition. Chrys Barton 36, had her first seizure in February 2008.

Just out of the blue and for no apparent reason. It took more than a year to be diagnosed temporal lobe epilepsy. In between there was also thought of being "drinker" or a "psychiatric patient".

After developing the condition Chrys had to surrender her driving licence and has not been able to work since May 2008.

She has also taught her seven-year-old daughter what to do if she has a seizure.

She had a call alarm fitted since so it has taken some of the responsibility from her. "The condition has rid us of our independence; I have had to learn to rely on my friends and family.

"I cannot go anywhere unattended, I have very poor memory or can wander off unknowingly and my speech can become garbled.

"I am lucky I have good friends that are there for both myself and my daughter and help us with all of our needs.

"Hopefully my condition will eventually be managed by medication, but I know it's not going to happen overnight."

Chrys added: "It is frustrating to suddenly be struck by a condition that turns your life upside down especially when there is no known cause.

"This is the reason I felt compelled to turn a bad situation into something good and to try to stay positive instead of being in denial which is why I started the local fundraising campaign in support of Epilepsy Action."

Source: Epilepsy Action

# PRINCE REVEALS HE HAD EPILEPSY AS A CHILD



Prince (Musician)

Legendary and often reclusive rock star, Prince, revealed he had epilepsy on PBS's Tavis Smiley show last night. The Grammy and Oscar award-winning musician said, "I used to have seizures when I was young and my mother and father didn't know what to do and how to handle it, but they did the best they could with what little they had."

Prince said he had to deal with a lot of things in life and attributed his past extravagant behavior to being teased as a kid. "Early in my career I tried to compensate for that by being as flashy as I could and as noisy as I could." He said he had never spoken publicly about his epilepsy before, but he is enjoying this time in his life when he can reflect on his experiences and talk about them openly.

To get past the teasing from his peers, Prince said, "I went into self and taught myself music." He stayed with it, practicing constantly, and soon the neighborhood kids were talking about him—this time with admiration instead of derision. He said, "Once I got that support from people, then I believed I could do anything."

Prince Rogers Nelson born June 7, 1958 in USA, performs under the mononym of Prince. He is a prolific songwriter and composer, having released several hundred songs both under his own name and with other artists. He has won seven Grammy Awards, a Golden Globe, and an Academy Award. He was inducted into the Rock and Roll Hall of Fame the first year he was eligible in 2004. Rolling Stone ranked Prince #28 on its list of the 100 Greatest Artists of All Time.

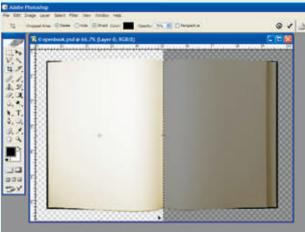
### **EPILEPSY: INSIGHTS & STRATEGIES; INNOVATIVE ONLINE JOURNAL**

Unique Peer-Reviewed Resource Honours the Expertise of Those Touched by Epilepsy.

An innovative new type of medical journal has been launched by www.epilepsy.com, the world's most visited website about epilepsy. This quarterly journal is written and reviewed by people who live with epilepsy, not by medical professionals. The goal of the new publication is to provide information and advice from those who have

not by medical professionals. The goal of the new publication is to provide information and advice from those who have years of experience living with epilepsy, people who have found a way to face the everyday challenges. Unlike most online community resources, the journal articles are edited for clarity and reviewed for medical accuracy. As with professional medical journals, the journal content is reviewed for relevance by an editorial board of peers, in this case, people who have perspective on living with epilepsy. Supplementary

medical comments are provided by the medical staff of



The publication fills the information gap between the nuggets of useful information that can be mined on the internet and a true medical journal.

#### About epilepsy.com

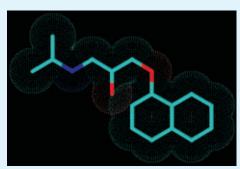
Epilepsy.com is an online resource that was developed by the Epilepsy Therapy Development Project to provide in-depth information and community for people living with epilepsy.

About the Epilepsy Therapy Project

The Epilepsy Therapy Project is a non-profit organization whose mission is to advance new therapies for people living with epilepsy. Founded in 2002 by a group of parents, distinguished physicians and researchers, the Epilepsy Therapy Project supports the commercialization of new therapies through direct grants and investments in promising academic and commercial projects. The organization has raised over six million dollars towards its mission. Learn more at.

Source: Epilepsy Therapy Project

### **OFFICE-OFFICE**



A new research has discovered the heaviest element yet known to science.

The new element, Governmentium (Gv), has one neutron, 25 assistant neutrons, 88 deputy neutrons, and 198 assistant deputy neutrons, giving it an atomic mass of 312. These 312 particles are held together by forces called morons, which are surrounded by vast quantities of lepton-like particles called peons.

Since Governmentium has no electrons, it is inert; however, it can be detected, because it impedes every reaction with which it comes into contact. A tiny amount of Governmentium can cause a reaction that would normally take less than a second, to take from 4 days to 4 years to complete.

Governmentium has a normal half-life of 2-6 years. It does not decay, but instead

undergoes a reorganization in which a portion of the assistant neutrons and deputy neutrons exchange places. In fact, Governmentium's mass will actually increase over time, since each reorganization will cause more morons to become neutrons, forming isodopes.

This characteristic of morons promotion leads some scientists to believe that Governmentium is formed whenever morons reach a critical concentration. This hypothetical quantity is referred to as critical morass.

When catalyzed with money, Governmentium becomes Administratium, an element that radiates just as much energy as Governmentium since it has half as many peons but twice as many morons.

Contributed by : Dr A. Banerjee, New Delhi

#### Editor's note:-

www.epilepsy.com.

Indian babus worst in Asia was a headline on p 1 of TOI 04 June 2009. The "country's suffocating bureaucracy" has been ranked the least efficient in a business survey by Political and Economic Risk Consultancy. "They are power centres in their own right at both national and state levels and extremely reluctant to reform". The survey said that working with India's civil servants was a "slow and painful process". (Singapore was ranked the most efficient for the 3rd successive year.)

**VSS** 

### WHY DO WE SHOUT?

'Why do we shout in anger?' A saint asked his disciples, 'Why do we shout in anger? Why do people shout at each other when they are upset?'

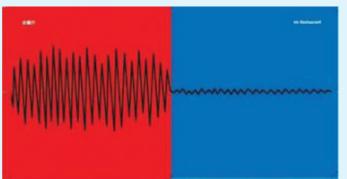
His disciples thought for a while, one of them said, 'Because we lose our calm, we shout.'

'But, why do you shout when the other person is just next to

you?' asked the saint. 'Isn't it possible to speak to him or her with a soft voice? Why do you shout at a person when you're angry?'

Disciples gave some other answers but none satisfied the saint.

Finally he explained, 'When two people are angry at each other, their hearts distance a lot. To cover that distance they must shout to be able to hear each other. The angrier they are, the stronger they will have to shout



to hear each other through that great distance.'

Then the saint asked, 'What happens when two people fall in love? They don't shout at each other but talk softly, why? Because their hearts are very close. The distance between them is very small...'

The saint continued, 'When they love each other even

more, what happens? They do not speak, only whisper and they get even closer to each other in their love. Finally they even need not whisper, they only look at each other and that's all. That is how close two people are when they love each other.

'MORAL' said the saint: 'When you argue do not let your hearts get distant, do not say words that distance each other more, else there will come a day when the distance is so great that you will not find the path to return!'

#### PEOPLE URGED TO "WATCH YOUR LANGUAGE" PERSON-FIRST

ESSEX, USA— Members of the Essex County Accessibility Advisory Committee are urging people to "watch their language" as they note that certain ways of describing those with a disability can be harmful.

Some definitions of "disabled" include such language as "decrepit" No one wanted to be described using such language.

"Words are powerful and the language we use is of utmost importance in our society today. The word disabled means broken down, not working, decrepit, helpless, incapable, incapacitated, injured and powerless. Nobody living with a disability wants to be identified by it. It's a matter of dignity and respect. Inaccurate descriptors perpetuate negative stereotypes and reinforces an already incredibly powerful attitudinal barrier.

The committee notes that "a disability is what a person has, not what a person is".

The committee states the proper term is "people with disabilities." Instead of mentally retarded, the terminology should be "person who has a cognitive disability." Instead of using language stating the someone is epileptic, quadriplegic or autistic, the committee urges phrasing like "person who has epilepsy", "person who has quadriplegia" or "person

who has autism." Instead of "is brain damaged", the committee said "person who has a brain injury" is preferred. "Person who uses a wheelchair" is proper language rather than "confined to a wheelchair or wheelchair bound" while "person who has a learning disability" is preferable than "is learning disabled." The committee asks that instead of stating "is developmentally delayed", it is better to say "person who

has a developmental disability" and instead of using phrasing like "is a Down's person" it is better to say "person who has Down's syndrome."

Other examples include saying "person who has a psychiatric disability" rather than saying "mentally ill". Stating "person who is deaf/blind" rather than "deaf/blind person" is more appropriate and instead of "birth defect", using "congenital disability" is preferred.

"Disability touches everyone. It is the largest minority group – the minority of everybody. It can take a long time to acquire one and it can also take a fraction of a second. "Part of quelling the fear is modifying your perception and modifying your perception changes your. Using Person First language is a great place to start. So, please think before you speak. Watch your language!"



## NEWS & VIEWS ON DRUGS

# LAMICTAL ODT ORALLY DISINTEGRATING TABLETS

The FDA has approved Lamictal ODT (lamotrigine, from GlaxoSmithKline) orally disintegrating tablets. This approval was based on the demonstrated bioequivalence of Lamictal ODT to Lamictal tablets. Lamictal ODT offers an option to patients with bipolar disorder or epilepsy who have difficulty swallowing tablets.

Lamictal ODT is indicated for the long-term treatment of bipolar disorder to lengthen the time between mood episodes in patients ≥ 18 years of age who have been treated for mood episodes with other medication. Lamictal ODT is also indicated in combination with other drugs to treat certain types of seizures (partial seizures, primary generalized tonic-clonic seizures, generalized

seizures of Lennox-Gastaut syndrome) in patients  $\geq 2$  years of age, or as monotherapy when changing from other drugs used to treat partial seizures in patients  $\geq 16$  years of age.

Lamictal ODT is expected to be available in 25mg, 50mg, 100mg, and 200mg dosage strengths.

# FDA APPROVES NEW WARNING LABEL FOR ANTIEPILEPTIC DRUGS

The Food and Drug Administration (FDA) on May 9th, 2009 approved new labeling for 11 antiepileptic drugs that will warn patients that using these medications carries an increased risk for suicidal thoughts and behavior. In addition to putting the warning on the label, manufacturers of these drugs will be required to develop a patient medication guide to provide information on this risk. The agency's decision is based on an analysis of 199 placebo-controlled clinical studies of these therapies.

While the FDA has been considering this move, it has met with resistance from the medical community. At the 62nd Annual Meeting of the American Epilepsy Society (AES), a panel of epilepsy experts disputed the FDA findings based on what they considered to be questionable methodology used to arrive at the conclusions. The panel also commented on the possible negative effect this warning label would have on managing epilepsy because many parents would be reluctant to have their children take these medications.

Source: Food and Drug Administration, USA

# NEW GUIDELINES ON PREGNANCY WITH EPILEPSY

New guidelines developed by the American Academy of Neurology and the American Epilepsy Society show it's relatively safe for women with epilepsy to become pregnant, but caution must be taken, including avoiding valproate that can cause birth defects.

The guidelines were published in the EarlyView section online of Epilepsia and presented April 27, 2009, at the American Academy of Neurology's Annual Meeting in Seattle.

The guidelines also suggest, if possible, women with epilepsy should not take more than one epilepsy drug at a time during pregnancy since taking more than one seizure drug has also been found to increase the risk of birth defects compared to taking only one medication.

Overall, data is reassuring to women with epilepsy planning to become pregnant.

Also women with epilepsy are not at a substantially increased risk of having a Cesarean section, late pregnancy bleeding, or premature contractions or premature labor and delivery (advised against smoking). Also, if a woman is seizure free nine months before she becomes pregnant,

it's likely that she will not have any seizures during the pregnancy.

Levels of seizure medications in the blood tend to drop during pregnancy, so checking these levels and adjusting the medication doses should help to keep the levels in the effective range and the pregnant woman seizure free.

The guidelines state that phenytoin and phenobarbital should be avoided in order to prevent the possibility of decreased thinking skills in children.

Source: American Academy of Neurology, Annual Meeting, April 27, 2009, Seattle.

#### Editor's note:-

The above observations seem to be derived from usage of valproate in rather high doses with which we are not familiar. Both British and Indian Registries of Pregnancy and Epilepsy do not yet warrant such a caution. May be we should wait until European or ILAE guidelines emerge. Till Then consider jury to be out on the subject.

**VSS** 

## NEWS & VIEWS ON DRUGS

# EPILEPSY COULD BE HALTED WITH NOVEL ANTICONVULSANT COMPOUND

Epilepsy is a neurological disorder, marked by the brain's abnormal electrical activity, which leads to recurring seizures. However, scientists hope that they have identified a new anticonvulsant compound, 'paxilline', which may cease the progression of epilepsy.

The study by Carnegie Mellon University researchers is based on a previous work in which scientists identified a specific molecular target whose increased activity is linked with seizure disorders- a potassium channel known as the BK channel.

"We have found a new anticonvulsant compound that eliminates seizures in a model of epilepsy," said Alison Barth, associate professor of biological sciences at Carnegie Mellon's Mellon College of Science.

She added: "The drug works by inhibiting ion channels whose role in epilepsy was only recently discovered. Understanding how these channels work in seizure

disorders, and being able to target them with a simple treatment, represents a significant advance in our ability to understand and treat epilepsy." and the researchers found that after a first seizure, BK channel function was markedly enhanced.

Thus, the neurons became overly excitable

and were firing with more speed, intensity and spontaneity, which led the researchers to believe that the abnormal increase in the activity of the channels might play a role in causing subsequent seizures and the emergence of epilepsy. In the current study, the researchers tested this theory by blocking the ion channels using a BK-channel antagonist called paxilline.

Using an experimental model for epilepsy, Barth tested whether paxilline could reduce or prevent experimentally induced seizures, as it could normalize aberrant brain activity induced by previous seizures.

And to their surprise, the researchers discovered that the compound was effective at completely blocking subsequent seizures. The drug is orally available, and works in the low nanomolar range," said Barth.

As the drug is effective in low concentrations and can be taken as a tablet, it could turn out to be an especially promising compound for treatment in epilepsy patients.

The researchers believe that targeting the BK channels and the abnormal brain activity that they induce might one day be used as a way to prevent the progression of seizure disorders over time, thus attacking the root cause of epilepsy.

Source-ANI

### PROBLEMS WITH SWITCHING EPILEPSY DRUGS

Dr Brien J. Smith and Eric Hargis, president and CEO of the Epilepsy Foundation, talked about the causes of the common neurological condition and how many people it affects.

Members of the epilepsy community have reported

experiencing seizures and other harmful side effects after switching from one version of an antiepileptic drug (AED) to another, whether the switch was brand-to-generic, generic-to-brand, or generic-to-generic.

These variations, however slight, can mean the difference between controlled epilepsy and breakthrough seizures, or, in some

cases death.



Mr. Eric Hargis and Dr Brien J. Smith

Source: Epilepsy Foundation, USA

# NEWS & VIEWS ON DRUCKS

# SEPRACOR'S STEDESA (ESLICARBAZEPINE ACETATE)

Sepracor's STEDESA™ (Eslicarbazepine Acetate) New Drug Application has been formally accepted for review by the FDA.

The drug is now under formal review for adjunctive therapy in the treatment of partial-onset seizures in adults with epilepsy. The acceptance of the filing means that the FDA has made a threshold determination that the NDA is sufficiently complete to permit a substantive review.

Sepracor claims "STEDESA represents a significant and near-term opportunity for Sepracor, and the FDA acceptance of the NDA is yet another step forward in one of our near- and mid-term corporate objectives of expanding and advancing our pharmaceutical product pipeline."

STEDESA, a new chemical entity, is a novel voltage-gated sodium channel blocker. STEDESA has been studied in three Phase III, multi-center, randomized, placebo-controlled trials, which involved more than 1,000 patients from 23 countries. Patients involved in the trials had a history of at least four partial-onset seizures per month despite treatment with one to three concomitant antiepileptic drugs. During the trials, patients were randomized to eslicarbazepine acetate or placebo, and after a 2-week titration period, were assessed over a 12-week maintenance period with continued follow-up over a one-year, open-label period.

BIAL-Portela & Ca, S.A. (BIAL), Portugul pharmaceutical company, was responsible for the research and development of eslicarbazepine acetate which Sepracor will commercialize in the U.S. and Canada.

Sepracor is seeking approval of STEDESA for adjunctive therapy with once-daily doses of 800 mg and 1200 mg in the treatment of partial-onset seizures in adults with epilepsy.

### EPILEPSY DRUG MAY WORK AGAINST THE DISEASE IN MANY WAYS

A drug that can potentially prevent epilepsy caused by a genetic condition may also help halt epilepsy caused by brain injury, according to a new study.

Scientists at the Washington University School of Medicine (WUSM) in St Louis found that the FDA-approved drug Rapamycin blocks brain changes believed to cause seizures in rats.

Last year, the same group showed that Rapamycin prevents brain changes in mice triggered by one of the most common genetic causes of epilepsy, tuberous sclerosis (TS).

"We hope to shift the focus from stopping seizures to preventing the brain abnormalities that cause seizures in the first place, and our results in the animal models so far have been encouraging," said senior study author Michael Wong.

One percent of the population has epilepsy, which can result from genetic mutations, brain injuries and environmental insults. According to Wong, one-third of that group does not respond well to current anti-seizure medications.

"Researchers have traditionally tested potential epilepsy drugs on animals that were already having seizures," Wong said. "We may be able to improve our success rate by stepping back a little and trying to find a treatment that can halt the disease process prior to the start of seizures."

Rapamycin is currently being evaluated in clinical trials as a treatment for the brain tumours caused by TS, said a WUSM release.

Source: The Journal of Neuroscience, June 2009

### **FORTHCOMING EVENTS**

### 12 - 17 July 2009 Kiel, Germany

3rd Baltic Sea Summer School on



#### **Epilepsy**

Information: www.epilepsy-academy.org



31st July, 2009

**VIREPA Distance Education Courses** 



Location: Online

Information: http://www.epilepsyacademy.org/ homepage/de/ eurepa activities/9.html



6-13 September 2009

3rd Eilat International Educational Course : PHARMACOLOGICAL TREATMENT OF EPILEPSY



email:eilatedu@targetconf.com Visit our website:www.eilat-aeds.com



### 28 & 29th November 2009

#### **IX NEUROPEDICON - 2009**

(The National Conference of the Neurology Chapter of Indian Academy of Pediatrics)



Venue: Karnataka Institute of Medical Sciences (KIMS), Hubli Day 1 – 28 Nov. 2009: Various Aspects of Childhood Epilepsies

Day 2 – 29 Nov. 2009: Mixed Bag Symposium on Childhood Neurological Problems.

For further Conference Details:

**Conference Secretariat:** 

Organizing Chairman - Dr KMP Suresh

Consultant in Epilepsy – Child Neurology & Clinical Neurophysiology Advanced Neurodiagnostics – Child Neurology Hospital & Regional Epilepsy Referral Centre.

No. 1 & 2, 2nd Floor, Mallikarjun Avenue, Koppikar Road,

HUBLI - 580 020 - Karnataka - INDIA

Contact No.: 0836 - 4250428 -268596 - 2282428

Mobile: 09448272428, e-mail: drkmpsuresh@hotmail.com

For further Details of Conference - Visit Website : www.iapneurologyindia.com

### October 15 – 18, 2009

3rd Beijing International Epilepsy Forum

Beijing, People's Republic of China



Abstracts submission deadline: May 31, 2009

please e-mail your abstract to: caae2008@sina.com; or: caae@caae.org.cn

To register for The Second Beijing International Epilepsy Forum, please register online or download the registration form and return it to the Forum Secretariat by fax to +8610-65250423 or by email to: caae@caae.org.cn

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#### 22 - 23 October, 2009

43rd Congress of the Japan Epilepsy Society

**AND** 

24 October 2009

International Symposium on Pharmacogenomics in Epilepsy



Hotel New Castle (Hirosaki City)/Hirosaki Chamber of Commerce and Industry

Theme: The Way to New Avenue in the Treatment of Epilepsy - From Standardization to Individualization Information: www.c-linkage.co.jp/jes43



### 7th - 8th November, 2009

### Epilepsy Surgery Evaluation, Surgical Procedures And Rehabilitation

Venue: JLN Auditorium, AllMS, New Delhi, INDIA
Organizing Secretary Dr P Sarat Chandra
e mail: asepaworkindia@gmail.com
website: www.aiims.edu/asepa.htm

A Workshop on Epilepsy Surgery by ASIAN EPILEPSY ACADEMY AND (ASEPA), Commission on Asian and Oceanian Affairs, International League Against Epilepsy.

### **FORTHCOMING EVENTS**

### OINT MEETING OF IEA & IES 6,7 FEBRUARY 2010, INDORE





IEA-18th IEC Trust



Dr V G Dakwale, Chairperson



Dr V V Nadkarni, Organizing Secretary



Dr O P Lekhra, Jt. Secretary



Dr A M Gandhe, Medical Director Gita Bhawan Hospital

#### **Conference Highlights**

Pre conference workshop -Pediatric Epilepsy update 5th February, Friday, 2010 This workshop will include wide ranging topics of interest to both pediatricans and neurologist, with lectures and interactive case presentations.

Conference: 6<sup>th</sup>-7<sup>th</sup> Saturday/Sunday 2010

Symposia/Lectures, Interactive sessions, Panel Discussion Patient & Public Awareness program Award & Fee Paper sessions

**Banquet & Cultural Program** 

#### **Important Dates**

31th August 2009 Last Date of early Registration 30th October 2009 Last Date of Abstract Submission 30<sup>th</sup> November 2009 Last Date of Mid Registration 5<sup>th</sup> February 2010 Pre-Conference Workshop 6th, 7th February 2010 Conference

Others

### Registration Fee

#### Conference 6th & 7th February 2010

Category	Before 31st Aug. 09	Before 30th Nov.	Spot 09
IEA/IES Member	Rs. 1500/-	Rs. 2000/-	Rs. 2500/-
Non-Members PG students	Rs. 1700/-	Rs. 1800/-	Rs. 2500/-
+ Paramedicals	Rs. 1000/-	Rs. 1200/-	Rs. 1500/-
Foreign Delegates Accompanying	USD 200/-	USD 250/-	USD 300/-
Persons	Rs. 1000/-	Rs. 1200/-	Rs. 1500/-

\*PG Students must submit bonafied certificate from Head of the Department.

Pre Conference Workshop 5th Feb. 2010 (Limited Registration apply at the earliest)

Category	Before 31st Aug. 09	Before 30th Nov. 09	Spot
Consultants		Rs. 1000/-	Rs. 1200/-
PG students		Rs. 600/-	Rs. 800/-

\*PG Students must submit bonafied certificate from Head of the Department.

Category Before **Before** Spot 31st Aug. 09 30th Nov. 09 Patients & Relatives Rs 100/-Rs 100/-Rs 100/-

Rs. 550/-

Rs. 600/-

Rs. 500/-

Only 7th Feb. 2010

Conference Secretariat: Dr VV Nadkarni, Organizing Secretary Gita Bhawan Hospital & Research Centre Manoramagani Indore 452001

Phone: 0731-2491863,(ext206),0731-4095470(Direct)

TeleFax: 0731-4095470, Mob 98260-20232

### 19th - 21st February, 2010 **International Workshop on Epilepsy** G.B. Pant Hospital, New Delhi

Department of Neurology is organizing an International Workshop on Epilepsy at G.B. Pant Hospital, New Delhi.

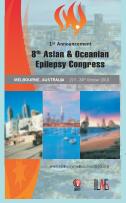
For further details contact Prof. Vinod Puri Room # 504, Academic Block Department of Neurology G.B. Pant Hospital, New Delhi- 110002. Ph: 91-11-23231298, 23233001 Extn. 5504

M: +919811105060, 9718599302 Fax: 91-11-23238695

E-mail:

internationalworkshop2010@gmail.com, vpuri01@gmail.com

### 21st - 24th October, 2010



8th Asian & Oceanian **Epilepsy** Congress -Melbourne, Australia

Melbourne was recently announced as the venue for the 8th Asian Oceanian Epilepsy

Congress, which will take place next year. This will be the first IBE/ILAE

congress to been held in Australia since Sydney hosted the 21st International Epilepsy Congress in 1995.

The first announcement is now in circulation and the congress website will soon be live. In the coming months we will also be bringing news of the special programme for people with epilepsy and their carers to be held during the congress.

> For further information or to creceive a copy of th first announcement

contact melbourne@epilepsycongress.org

### INDIAN EPILEPSY ASSOCIATION



### **GOVERNING COUNCIL 2009- 2011**

Dr Pravina U Shah	President	(2009-11)
Dr V S Saxena	Imm. Past President	(2009-11)
Dr H V Srinivas	President Elect	(2009-11)
Dr MM Mehndiratta	Secretary General	(2009-13)
Dr C M Sharma	Treasurer	(2009-13)
Dr V S Saxena	Editor	(2009-13)

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Ms Carol D'Souza	Maharashtra	Secretary General-IES	Ex-Officio Member

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