



# EPILEPSY INDIA



INDIAN EPILEPSY ASSOCIATION & INDIAN EPILEPSY SOCIETY

## Newsletter

July - September 2011

Issue 3, 2011

### Editorial

#### Dear Friends

#### **Once you choose hope, anything is possible: Christopher Reeve**

Christopher Reeve (1952 – 2004) star of Superman had everything going for him. He was hand picked for the role out of over 200 aspirants including Arnold Schwarzenegger. His selectors felt that no one had the combination of the body, mind and spirit. The film proved to be the technically slickest with, humanness and wit wrapped around. No wonder even the hard-boiled film reviewers praised his role to the extent that some mentioned that his enaction had Jesus-like quality!

Prophetic words later to be proved more than true. He refused many roles saying that the genre or script needed just 'some one with a strong body'. In his filmic travelogue, he distinguished himself as a director, producer, screenwriter and lastly as a best-selling author.

Reeve took up horse riding in 1985 though initially allergic to horses, so he took antihistamines. By 1989 he was taking part in competitive events. As with every other sport in which he participated sailing, scuba diving, skiing, aviation, wind surfing, cycling, gliding, parasailing, mountain climbing, baseball and tennis. He took horse riding seriously and even his allergies soon disappeared.

In 1995, Reeve became a quadriplegic after being thrown from a horse in an equestrian competition. For the rest of his life he would need a wheelchair and assisted respiration.

He had fractured his cervical spine and had stopped breathing for three minutes before paramedics arrived. He had a tumultuous clinical course. With constant ventilators and inability to have any motor movements Reeve could only stare at life of permanent disability and dependance. He contemplated suicide and asked his wife Dana, who said:



*"I am only going to say this once: I will support whatever you want to do, because this is your life, and your decision. But I want you to know that I'll be with you for the long haul, no matter what. You're still you. And I love you."*

Her fortitude gave him fresh hope and reinforced his resolve to face the dark and painful time. Till a fatal drug allergic reaction claimed him in 2004.

He went through the bitter and harrowing medical treatments and rehabilitative care hoping that medical research will rescue his condition. Dana explored all avenues for his treatment and felt that the Americans should try a more holistic approach combining the individual and the scientific modes of treatment available. A trained actress and a singer, she also loved horse-riding but she abandoned it for the sake of her husband.

He appeared frustrated with the pace of stem cell research in the U.S. which led him to Israel where this debate was decided on "... secular law must prevail over religious teachings...", On CNN's *Larry King Live* Reeve said, "Israel has a very progressive atmosphere. They have socialized medicine so that doctors and patients do not have the problem of profit or trying to get insurance companies to pay for treatment. They work very well together and share their knowledge"

Reeve (and Dana) became an activist and won several high awards and accolades. He used to speak feelingly and impromptu and always got thunderous standing ovations. He headed the American Paralysis Association and the

National Organization on Disability. He co-founded the Reeve-Irvine Research Center, now a leading spinal cord research center. His Foundation gave away \$65 million for research and \$8.5 million in quality-of-life grants. He did more to promote research on spinal cord injury and other neurological disorders than any other person before or since. ►►



# EPILEPSY INDIA

## NEWSLETTER OF INDIAN EPILEPSY ASSOCIATION & INDIAN EPILEPSY SOCIETY



*Superman's famous aerial survey over New York skyline.*

*"I don't drink before I fly"*

*was his memorable quip turning down an offer for one.*

His autobiography, *Still Me*, has been best seller all for the positive stream of messages which come through.

***The man who could not move, did not stop moving.***

"After the movie *Superman* came out I was frequently asked 'What is a hero?' I remember the glib response I repeated so many times. My answer was that a hero is someone who commits a courageous action without considering the consequences—a soldier who crawls out of a foxhole to drag an injured buddy to safety. And I also meant individuals who are slightly larger than life: Houdini and Lindbergh, John Wayne, JFK, and Joe DiMaggio.

"Now my definition is completely different. I think a hero is an ordinary individual who finds strength to persevere and endure in spite of overwhelming obstacles; these are real heroes, and so are the families and friends who have stood by them."

With dignity and sensitivity, he described the journey he made—physically, emotionally, spiritually - heroic battle to rebuild a life all but given up.

A great story of courage which amply shows that hope remains one of the most powerful expectation for a positive outcome which all humans rely on at different times.

Best Wishes

**Dr VS Saxena**

**Editor**

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## HONOURS LIST

### SOCIAL ACCOMPLISHMENT AWARD-2011



Dr Pravina Shah

IBE & ILAE have conferred the Social Accomplishment Award for 2011 on Dr Pravina Shah, Mumbai.

Every two years one individual who has carried out outstanding activities

aimed at the social benefit of

people with epilepsy, is recognized by the International Bureau for Epilepsy and the International League against Epilepsy. This Award consists of a scroll and \$ 1,000.

This award will be presented to her during the 29th IEC in Rome on 20th August 2011.

Dr Pravina Shah was the Professor and Head of Neurology at the King Edward Memorial Hospital in Mumbai India for 19 years. She is the immediate past President of the IEA and currently a private consultant.

She pioneered the support group movement in Mumbai with a missionary zeal and enthusiasm. She started E-Cell a dedicated center to care for people with epilepsy.

Dr Shah organized numerous national workshops creating awareness about the psychosocial impact of epilepsy. She has worked tirelessly to dispel myths and taboos about epilepsy engaging the media and reaching out to opinion makers in the government. She initiated a unique program to educate thousands of school children in Mumbai. She conducts regular epilepsy camps for the impoverished, marginalized rural populations.

As a visionary she helped sensitize the country to psychosocial issues of epilepsy; Dr Shah says that in her journey with epilepsy she is a 'taker' rather than a 'giver' having been enriched by the learning from the lives of people with epilepsy.

### Michael Prize for 2011



ILAE announced Michael Prize 2011 for Dr Eleonora Aronica, neuropathologist at the University of Amsterdam's Academic Medical Center. Her award is based on a career that has centered on examining the molecular changes that occur in human epilepsy and in animal models.

Every two years, the Stiftung Michael from Germany awards the Michael Prize for outstanding epilepsy research performed by young investigators (under the age of 45). The awardees receive 20,000 euros.

Dr Aronica will speak about her research at the International Epilepsy Congress in Rome on August 29 with a talk entitled "Focal Lesions in Human Epilepsy: A Molecular and Neuropathological Perspective."

Edward Bertram, MD

Information Officer

### Morris Coole Prize-2011



ILAE announced the Morris-Coole Prize for Laura Jansen, MD, PhD.

Dr Jansen is a pediatric neurologist and assistant professor of Neurology at the University of Washington and Seattle Children's Hospital. Her study described how the maturation of GABA receptors

was impaired in the cortex of children with epilepsy.

The Morris-Coole Prize is given annually in recognition of an outstanding research paper published in *Epilepsia* the previous year on any field of epilepsy research, either clinical or basic.

Dr Jansen will receive \$ 5,000 and present a lecture, 'Impaired maturation of cortical GABAergic inhibition in pediatric epilepsy' at the International Epilepsy Congress in Rome.

Edward Bertram, MD

Information Officer



# GOLDEN JUBILEE OF INTERNATIONAL BUREAU FOR EPILEPSY 1961-2011



## Harry Meinardi Looks back with Pride



Harry Meinardi

Although the IBE was conceived in 1961 in Rome it was delivered at its first formal meeting on Thursday, September 4<sup>th</sup> 1965 in Vienna.

The next important step took place during the 10<sup>th</sup> World Congress of

the International Society for Rehabilitation of the Disabled in Wiesbaden Germany.

There the first Constitution of IBE was agreed upon during a meeting on September 15<sup>th</sup> 1966 in Grunerwald. The following officers were elected:

### WHAT IS IBE

*The International Bureau for Epilepsy (IBE) was established in 1961 as an organisation of laypersons and professionals interested in the medical and non-medical aspects of epilepsy. The IBE addresses such social problems as education, employment, insurance, driving licence restrictions and public awareness.*

*The Bureau also works in close liaison with the International League against Epilepsy (ILAE), an organisation of medical professionals involved in the medical and scientific issues of epilepsy. IBE is funded mainly by membership dues from its chapters and by financial support from other contributors.*



- Mrs Ellen Grass, USA
- Dr Amparo Areaya, Chile
- Dr Mogens Lund, Denmark
- Dr Karl-Axel Melin, Sweden
- Miss Irene Gairdner, England
- Mr George Burden, England

In the Constitution, provision was made for each corporate member (a national state organization or institution) to nominate a representative to the Council. The newly elected President gave the following message:

One of the special meetings at the congress in Wiesbaden was organized by IBE and its topic, appropriately, was Epilepsy and Insurance.

Reports of the peripatetic Secretary General George Burden. The most authoritative summary of activities is obviously his quadrennial report to the General Assembly.

The office of the IBE in its early days thrived because of the generous assistance of the British Epilepsy Association, ►►



# GOLDEN JUBILEE OF INTERNATIONAL BUREAU FOR EPILEPSY

## 1961-2011

which allowed their employee George Burden and his personal secretary Isabel Little to spend half of their time on IBE business. But now that IBE had been established it was time that it should also “hold up its own trousers”

A grant from the International Society for Rehabilitation of the Disabled (ISRDI), made possible because of an anonymous donor in USA, created the financial situation in which this became feasible.

Not only did IBE organize meetings as part of establishing IBE as the international umbrella organization of national organizations or individuals caring for the social aspects of epilepsy the George Burden Secretary General travelled widely. At the end of 1965 he visited Canada, the USA, New Zealand, Australia, Thailand, India, Greece and Italy.

In 1996 he took part in the launch of an Irish Epilepsy Association. In 1967 the Secretary General took part in meetings of the German League and of the joint Austrian and Swiss sections of the ILAE. Furthermore he visited the Belgian social organisation.

### WHAT IBE DOES

*The International Bureau for Epilepsy provides assistance by offering international support, by creating means for worldwide exchange of information and, where possible, by setting standards which provide an international policy focus and identity for all persons with epilepsy. Much of this work is accomplished through the IBE working commissions, composed of volunteers who are experts in their subjects.*

*To improve international understanding of epilepsy, IBE publishes a quarterly magazine, the International Epilepsy News, which keeps readers informed on international developments. In addition, IBE publishes a comprehensive range of reports and information booklets covering a wide range of subjects, including education, employment, insurance, driving regulations and self-help groups.*



The 29<sup>th</sup> International Epilepsy Congress is now on the horizon and I hope that IBE will be able to welcome at least one representative from each member association to Rome, which will be the highlight

of our jubilee celebrations. One of the most interesting events will be a special gala dinner to celebrate those exceptional people who have been awarded with Ambassador for Epilepsy Awards since they were first introduced soon after IBE was founded.

And have you seen the new changes to the IBE website to highlight IBE's Golden Jubilee?

All the best,

*Mike Glynn*

*President*

In 1968, assisted by a grant from the British Commonwealth Foundation, he visited Nigeria and Ghana and some other commonwealth countries.

IBE membership at the time of the 1969 General assembly was”

- 22 National and State Associations.
  - 21 Institutions
  - 54 Individual Members
  - 18 ILAE members (chapters) by virtue of the inclusive subscription agreed at the onset.
1. While usage of the term 'epileptic' as a pronoun to describe a person with epilepsy was common parlance in the 1960's, such usage is no longer acceptable. The acceptable terms is a person with epilepsy'.
  2. Likewise, the word 'handicapped' is now also frowned upon. It is preferable to say that the person 'has a disability'.

**Source Intl Ep News Issue 4,2010**

# 40TH ANNIVERSARY OF INDIAN EPILEPSY ASSOCIATION 1971-2011



## IEA FOUNDER MEMBERS



Dr Baldev Singh



Dr B Ramamurthi



Dr TK Ghosh



Dr EP Bharucha



Dr AD Desai



Dr NH Wadia



Dr KV Mathai



Dr KS Mani



Mrs Roshan H Dastur

### INDIAN EPILEPSY ASSOCIATION - Then & Now

**Dr VS Saxena**

In the late 1960's some members of Neurological Society of India felt that the cause of the patients of epilepsy will be better served if there was a separate body devoted exclusively to their needs which were not just medical but as importantly social.

Due to his abiding interest in the issue, Dr Anil D Desai, Bombay was chosen to form such a body. He was designated Secretary of the Epilepsy Section within NSI. In the years between 1967 and 1970, he along with Dr Eddie P Bharucha and Dr Noshir H Wadia worked energetically to lay down its Constitution. The Indian Epilepsy Association was thus formed on 21 March 1970 in Bombay.

There were nine founder members, Dr Baldev Singh, Dr B Ramamurthi, Dr TK Ghosh, Dr EP Bharucha, Dr AD Desai, Dr NH Wadia, Dr KV Mathai, Dr KS Mani & Mrs Roshan H Dastur.

The aims and objectives of IEA were put out in details in the Constitution. These are, however, being paraphrased as the **Mission Statement** opposite.

IEA members started having regular meetings of its Governing Council and in the first meeting held **forty years ago** on 27th Jan 1971. Dr Baldev Singh was appointed Chairman, Dr Eddie P Bharucha Secretary and Dr (Miss) FN Kohiyar Treasurer.

The membership drive was taken up with lot of interest across the country. Chapters were soon opened in Bombay, followed by Bangalore, Delhi, UP, Indore etc. Between 1967 and 1970 important developments took place as we had some influential international visitors. George Burden the then Secretary General of IBE with his activist wife Sylvia and epileptologists like Harry Meinardi and Maurice Parsonage visited India in fact more than once. They were able to see activities of our ►►

### *Mission Statement.*

**Indian Epilepsy Association earnestly devotes itself to promoting better treatment and care of persons with epilepsy, advancing welfare for such persons and helping to rehabilitate them in society. In pursuance for this commitment, IEA will endeavour to create wider awareness in public and assist towards improvement of scientific knowledge for medical and technical people by encouraging active participation in conferences, workshops and seminars and maintaining links with relevant institutions nationally and internationally.**



# 40TH ANNIVERSARY OF INDIAN EPILEPSY ASSOCIATION 1971-2011



*Dr KS Mani leading Dr Baldev Singh Chairman and Dr EP Bharucha S-G for the GC meeting on 19 Dec 1974 in Vellore*

Chapters in Bombay, Bangalore and Delhi. They suggested that IEA should affiliate with IBE which will help it to be in the international mainstream of developments in the field of epilepsy. Those were not the days rapid communications and internet. All depended on snail mail with little or few chances of such collaborations.

The Governing Council of IEA then took a decision on 18 December 1973 to go ahead and authorised Dr EP Bharucha to finalise affiliation. After much correspondence and his personal visit to the UK, the GC which met on 19 December 1974 in Christian Medical College, Vellore was informed that the affiliation was duly accorded by IBE. (the photo above was taken just before the meeting). There were many issues which needed resolution main being of externising capitation money as the extant laws on foreign exchange were very stringent and daunting.

We can only look back with pride and satisfaction of the decisions taken then with considerable foresight. IEA has been a net gainer since that decision was taken. The foremost achievement was to get an international congress to India in 1989.

The enthusiasm with which the new body was growing had to be tampered with the initial organizational issues and financial realities. The members listed slowly and the opportunities for interactions were less as till 1993 we had only annual business meetings on the sidelines of NSI meetings. Only local activities remained the focus. The annual membership fees was a meager ten rupees and but for a timely donation of Rs 10,000 from Dr PC Bharucha Trust could not have kept going. Our first scientific meeting took place on 23 December 1993 in Chennai. We never looked back since then.

A small seed into an acorn grew.

These and associated determined efforts of a band of committed workers have been rewarded by the current over-2000 membership from 29 Chapters spread through out the country.

The activities of IEA and its Chapters were so devised as to dovetail into the aims and objectives of the Association.

The Central office provides leadership, monitors and fine tunes activities across the country. Increasing awareness, ensuring welfare of PWEs and seeking betterment of treatment modes remain the basic themes.

IEA-18th IEC Trust registered in April, 1992 has ever since been the lifeline of financial activities for promotion of all causes related to epilepsy.

The 18th International Epilepsy Congress-1989 was the high point of achievement of IEA as it opened up opportunities which were not even contemplated as we tried to ensure financial viability. When flush with surplus funds, we did not even know how to deal with it. Here again wisdom prevailed and we took a far reaching decision. We formed a registered Trust in April 1992 and by judicious management of the proceeds we support a great number of epilepsy related activities till this day.

IEA has influenced legislation in two important areas, divorce and epilepsy link in 1999 and driving license requirements in 2007.

Not all problems of epilepsy have gone away. A great diversity of population, superstition and stigma still prevent a majority to ask for medical help. Rational treatment still eludes most patients. A holistic approach is needed to rehabilitate or improve their quality of life.

We have a serious impediment that awareness campaigns could not find Government subsidy for a health cause which is seemingly a lower priority with them and even public, unlike some more fashionable health causes.

It needs to be mentioned that an active Indian Epilepsy Society as the medical/scientific body formed in 1997 with similar basic objectives immensely helps the cause of epilepsy. There is true synergy in the two organisations now.

IEA continues to strive as it can make a difference to the cause and spread of the message through higher and selfless commitment to IEA.



## IEA Celebrates 40th Anniversary

### Satellite Meeting in Cochin on 06 & 07 August 2011

To celebrate the 40th Anniversary of IEA & to the Golden Jubilee of IBE, IEA is holding a special meeting in Cochin. The Chief Guest will be Mr Mike Glynn President of IBE and the members of the South East Asia Region of IBE have also been invited.



# THE DISASTER OF TSUNAMI IN JAPAN

## IN SOLIDARITY WITH JAPAN EPILEPSY SOCIETY

Message from Japan  
Epilepsy Society(JES)

Dear Colleagues

On behalf of the  
Japan Epilepsy  
Society(JES),  
I am writing to express  
my sincere gratitude to  
you and your Epilepsy Society.

Since the disaster was devastating and immense, it is anticipated that the support will be long term for JES. In order to consolidate information and facilitate effective and expeditious support, JES Disaster Response Headquarter was established with me as Chief.

To construct an epilepsy medical care network by requesting related societies to cooperate with epilepsy medical care during disasters and registering members of related societies who consent to cooperation as "doctors cooperating with epilepsy medical care during disaster". This network will facilitate smooth provision of epilepsy care not only during the Great East Japan Earthquake Disaster but also any other disaster. Before the network is completed, a list of institutions with epileptologists is distributed to relevant organizations.

Thank you again for your support.

Yours sincerely,

Sunao Kaneko

President, Japan Epilepsy Society(JES)

Masako Watanabe, Secretary General, JES

National Center of Neurology and Psychiatry, Tokyo, Japan

During 29th IEC, Rome, there will be a  
SPECIAL PLATFORM SESSION  
on 29 August between 14:30-16:00  
"Epilepsy care after a major  
natural disaster" which will be Chaired  
by Prof Sunao Kaneko, Japan



Dear Prof Kaneko & Prof Watanabe,

Thank you for the major humanitarian effort. Prof Tatsuya Tanaka in Brussels in early April gave us all the news first hand.

We are all certain that your effective leadership will indeed be the light which will hold hope for so many.

We are all so highly impressed with all the needed actions taken by your Society and the great spirit and discipline of the Japanese population. We pay homage and bow our heads to the great will shown by all of you.

Best wishes for always

Vinod Saxena

## IEA ELECTIONS FOR THE PRESIDENT-ELECT (2011-13)



This is for the information of all members of IEA that DR VV NADKARNI, Indore has been declared elected as President-Elect IEA 2011-13

Dr VS Saxena

Returning Officer IEA

## EPILEPSY INDIA

### NON-DELIVERY DUE TO INCORRECT/INCOMPLETE ADDRESS

This is for the attention of all members of IEA & IES and Chapters/Branches that due to incorrect/incomplete addresses, the newsletter fails to reach members. There have been large number of returns of EI of which due intimation has been sent to the Chapters concerned. Since these returns have caused financial loss which we can ill afford, we may not be able to continue posting at the same address if the mail is returned more than once.

All, including Chapters/Branches are requested to provide complete addresses along with PIN Code and landmark if any. If the phone number is included, it will help the courier to track the address better.

All members having email account must also provide that also so that communications can be kept up with the members.

Dr VS Saxena, Editor

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

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



This is for the information off all members of IEA and IES that financial grants are provided by the IEA-18th IEC Trust towards founding 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  
please write to:-

e-mails : [drvssaxena@gmail.com](mailto:drvssaxena@gmail.com) or  
[sannidhivss@gmail.com](mailto:sannidhivss@gmail.com)

## EUROPEAN DECLARATION ON EPILEPSY



Members European Parliament had the opportunity to sign the Written Declaration during the first EU Plenary Session in Strasbourg, on 9<sup>th</sup> to 12<sup>th</sup> May 2011.

### First results

The good news is that we are off to a good start: a total of 242 Members European Parliament have now signed the declaration! However we still need a further 124 (as of 10th June, 2011) MEPs to sign up in order for the declaration to be carried. This will not be an easy task!

Epilepsy Advocacy Europe, the joint task force of IBE and ILAE in Europe, has sent a short Thank You message to each MEP who signed the declaration and would also encourage a short message from your association(in Europe) to those MEPs who signed and to encourage their colleagues to sign the declaration next month.

### Please support our efforts

**Ms Ann Little, Executive Director IBE, Dublin**

## JOURNALISTS RECOGNISED FOR EXCELLENCE IN REPORTING ON EPILEPSY

Mike Glynn, award judge and President of IBE, commented, "This year's Excellence in Epilepsy Journalism Award saw a increased number of entries, with the overall standard being particularly high. A total of 43 entries from 17 countries were submitted, ranging from messages of hope to moving personal accounts, which reflects that the consistency of message on epilepsy is united across the globe. We congratulate and thank all journalists who submitted entries for their dedication to responsible and educational reporting on epilepsy."

### Winners

#### Print category

Makiko Tatebayashi for her article Let's Know Epilepsy, which featured as a seven-part series in the Japanese newspaper Yomiuri Shimbun.

"Let's Know Epilepsy". "The quality of writing and investigative reporting were befitting for an article with an estimated audience reach of 10 million people. Its focus on people living with epilepsy as well as the disease itself has helped to demystify epilepsy and bring it to the forefront of the public consciousness."

### Online Category

Jessica Solodar " Seizures triggered by video games: Underestimated and undiagnosed" posted on the web-site [epilepsy.com](http://epilepsy.com).



"This article is a persuasive call to action for a greater awareness and understanding of photosensitive epilepsy,"

### Broadcast category

Niamh Maher, series producer for "This Is Me", for her documentary "Not Out", which was broadcast on Raidió Teilifís Éireann 1.



"Niamh Maher's observational documentary is a personal, insightful and inspiring piece of journalism,"

**The award, a joint initiative of the IBE and UCB announced winners of award to improve understanding of epilepsy around the world.**

# UNDERSTANDING EPILEPSY:

## A Special Article from Brainwave, Issue, 2011

### Are we now better informed about epilepsy?

According to a recent study undertaken by the Department of Neurology at St James's Hospital and the School of Medicine, Trinity College, Dublin many people with epilepsy are not well informed about their disorder.

There are widespread misconceptions about epilepsy, its origin, diagnosis, treatment and prognosis. Patients scored slightly better on questions related to the particulars of their own condition rather than general epilepsy-related facts. The researchers suggest that this is due to "a deficit in information transfer from health professionals rather than general lack of interest of engagement".

Another key finding is that patients tended to get more questions relating to legal issues and safety wrong compared to questions on medication and social issues.

On the positive side, the vast majority of people were able to describe their treatment regimen, which may imply good general compliance.

The results of this Irish study show both similarities and notable differences when compared to the US and UK studies mentioned above. Compared to the American study, Irish patients scored better on legal issues regarding employment, but worse on legal requirements for driving. In the UK study, patients scored lower on questions related to their personal condition rather than general knowledge of epilepsy, the opposite of what was found in Ireland.

Clearly, this study highlights the fact that there is a need for better education on specific epilepsy-related matters particularly in relation to personal safety, legal and employment issues.

Question	Correct Answer	% of correct replies
People with epilepsy should avoid strenuous work because this can provoke seizures	False	48%
An EEG can always prove the diagnosis of epilepsy	False	58%
People with epilepsy are as capable as other people	True	94%
All people with seizures should avoid working with open machinery	False	19%
Every seizure destroys a number of nerve cells in the brain	False	38%
People with seizures should not swim without an accompanying person	True	75%
All people with epilepsy should avoid flashing or strobing lights (eg. disco lights, TV or computer screens)	False	48%
In most cases, doctors can control epileptic seizures with medication	True	86%
If your seizures are controlled for some months, you can reduce the dose of anti-epileptic medication	False	42%
All people with epilepsy have similar symptoms	False	71%

Question	Correct Answer	% of correct replies
If a patient expects a seizure, he/she should take an additional dose of anti-epileptic medication	False	75%
On job applications, a patient should always disclose his/her epilepsy condition	False	31%
People with epilepsy can take an active part in sports	True	90%
An epileptic seizure always results in loss of consciousness	False	60%
People who seize only during sleep may hold a driver's license	True	25%
Everyone can have a seizure, given the appropriate circumstances	True	69%
Blood samples can be used to measure the concentration of anti-epileptic medication in the body	True	77%
Epilepsy is a symptom of mental illness	False	81%
If persons with epilepsy drive, they must inform the driving authorities about their condition	False	10%



## IEA-ANDHRA PRADESH-TIRUPATI CHAPTER-ACTIVITIES

*Reported by: Dr B Vengamma*

1. The special monthly camps for persons with Epilepsy were continued without any interruption. The average attendance in these camps is now around 500. One month's requirement of medicines are being distributed free to all patients. Hundred and Forty Six camps have been organized till the end of March, 2011.

2. M/s Americares, a charitable organization based in USA is continuing the donation of antiepileptic drugs for free distribution to those attending the monthly camps and regular OP Department at SVIMS.

3. Tirumala Tirupati Devasthanams have kindly agreed to donate medicines worth Rs 50,000 per month since January, 2009 under SV Pranadana Trust scheme. The association is very grateful to authorities of TTD for their kind gesture.

This is in addition to Rs 10,000 worth of medicines per month being donated by SVIMS.



4. Test prescribed by doctors for the patients attending the camps are being performed at concessional rates at SVIMS.

The students of the College on Nursing, SVIMS, enacted a SKIT on the



theme "Women with Epilepsy -Their Quality of Life" bringing out various phases in the life of affected women, which was very well appreciated.

An awareness programme with the help of posters was

also organized by the students of the College of Nursing, SVIMS for the benefit of Persons with Epilepsy and their attendants.

IEA, Tirupati Oration in Epileptology

The Tirupati Branch of the Indian Epilepsy Association donated Rs Three Lakhs to Sri Venkateswara Institute of Medical Science (SVIMS), Tirupati with a request to institute in the Department of Neurology, SVIMS an annual Oration entitled " IEA, Tirupati Oration in Epileptology" commencing from the year 2010. Dr HV Srinivas, Bangalore, delivered the oration "Epilepsy & Society".

## IEA-WEST BENGAL CHAPTER-ACTIVITIES

**Reported by: Dr Gautam Ganguly, Kolkata**

1. An interactive seminar on epilepsy management was held by Dr (Prof) PK Ganguly, President, IEA, WB Chapter alongwith Dr Debal Laha and Dr Debasish Das on the last week of September-2010 with general physicians at Swabhumi, Kolkata

2. A workshop was arranged on EEG at the Park Hotel, Kolkata, on 4<sup>th</sup> and 5<sup>th</sup> of December, 2010. The workshop was attended by more than 60 neurologists and more than 20 EEG technicians from West Bengal. Eminent neurologists like Drs Anupam Dasgupta, NN Sarangi, Trishit Ray, Ambar Chakroborty, AK Senapati, S Basu, PK Ganguly and others were present to make the programme very informative.

The DM Residents of BIN also took active part by presenting some interesting cases in this workshop.

3. A full day epilepsy camp was held on 6<sup>th</sup> June 2010 at Yuba Sangha in Chandannagar, Hooghly. A detailed discussion was held on preventable Epilepsy, social misconception and prejudice regarding Epilepsy.

4. On 22<sup>nd</sup> August 2010 an IEA awareness camp was held to convey the measures that should be taken to prevent Epilepsy. This program was highlighted by the local news channels.

5. On September and October-2010 awareness camps were held at Chandannagar coupled with interactive discussions among Epilepsy patients. A sit and draw competition was held for patients below 15 years of age. Snacks and consolation prizes were given to all the contestants along with special prizes for the winners.

6. On the occasion of National Epilepsy Day on 17<sup>th</sup> November the following programme were organized:

A sit and draw competition was held among children below 15 years of age, where 48 patients participated and

the best paintings were selected for the Novartis Calender 2011. Snacks and consolation prizes were given to all the contestants.

A poster presentation in Bengali was held to educate Epilepsy patients and care-givers.

A slide show presentation was conducted in Bengali by Dr (Prof) Gautam Ganguly, Secretary, IEA, WB chapter, where social aspects of epilepsy were highlighted. A CD on epilepsy (MIRGI-in Bengali) sent by the central committee was also shown. It was appreciated immensely by all the viewers.



**Camp held at BUDGE BUDGE**

An interactive session was held by the members of the IEA with the patients and their care givers. The programme was broadcast on local cable on 24<sup>th</sup> November.

An awareness program was held for students at Bethun College, Kolkata & Milanghat School. School bags were distributed among the students by Dr (Prof) PK Ganguly, Dr Debal Laha, Dr Debasish Das along with a CD on Epilepsy Awareness.

7. A public awareness camp was held on 20<sup>th</sup> February at Budge Budge in association with Rotary Club, where Prof Trishit Roy, Dr Gautam Ganguly, Dr Sumita Mukherjee, Dr Biman Ray, Dr Alope Pandit, Dr Asit Senapati took active part. A slide presentation was also given to the patients participating in the camp.



## NEWER ANTIEPILEPTIC DRUGS AND PREGNANCY: TERATOGENICITY

A recent study on teratogenicity of newer AEDs is that of Molgaard-Nielsen and Hviid (2011).

These authors described a population-based cohort study of 837,795 live births in Denmark between 1996 and 2008. They examined the occurrence of major birth defects (identified within a year of birth) after first-trimester fetal exposure to the newer-generation antiepileptic drugs lamotrigine, oxcarbazepine, topiramate, gabapentin, and levetiracetam.

The data were obtained from the Medical Birth Registry and from other, linked registries. Infants with birth defects related to identified chromosomal aberrations, genetic disorders, and other known causes were excluded. Odds ratios were calculated after adjusting for confounding variables such as maternal epilepsy and the use of older antiepileptic drugs.

### Important findings were:

1. There were 49 infants with a major birth defect among 1532 infants with a history of first-trimester exposure to newer antiepileptic drugs; these figures were 19,911 among 836,263 infants without a history of such exposure. The absolute risk was 3.2% vs 2.4%, respectively. After adjustment for confounders, the difference in risk was not significant (OR, 0.99; 95% CI, 0.72-1.36).

2. The risks were likewise not significant when individual drugs were examined. Birth defects with lamotrigine were identified in 38 of 1019 exposed infants (3.7%; OR, 1.18; 95% CI, 0.83-1.68). These figures were 11 of 393 with oxcarbazepine (2.8%; OR, 0.86; 95% CI, 0.46-1.59) and 5 of 108 with topiramate (4.6%; OR, 1.44; 95% CI, 0.58-3.58). Only 59 and 58 infant had first-trimester exposure to gabapentin and levetiracetam, respectively, and birth defects with these drugs were 1 and 0, respectively.

3. The risks with lamotrigine remained nonsignificant when higher and lower dosing (using 250 mg/day as the separator) were separately examined.

4. The findings remained nonsignificant in various subgroup analyses, such as in women with differing parity, in women who had drug exposure during a specific period of gestation, and in women with different diagnoses.

5. The findings remained nonsignificant when teratogenicity in individual organ systems was separately

examined. The only exception was a small increase in eye defects (4 cases) associated with lamotrigine therapy.

### Conclusions

First-trimester exposure to lamotrigine, oxcarbazepine, topiramate, gabapentin, and levetiracetam does not appear to be associated with an increased risk of major birth defects.

### Comments

1. Too few infants had been exposed to oxcarbazepine, topiramate, gabapentin, and levetiracetam for the analysis to have been adequately powered to detect a significant risk. Topiramate, in particular, stands out because the crude risk was high (4.6%). A previous study identified significant teratogenic risks with topiramate (Hunt et al, 2008).

2. Antiepileptic drugs are prescribed for indications such as epilepsy, mood disorders, migraine, and neuropathic pain. Some of these indications are associated with behaviors or treatments that independently increase the risk of major birth defects. Such confounds cannot easily be controlled for. Despite this, the risks with antiepileptic medications were not significantly elevated in the different analyses.

3. The authors did not present data on the risks associated with antiepileptic medication combinations.

4. The increased risk of eye defects with lamotrigine could be a chance finding given the small number of identified cases (n=4), the absence of a consistent eye defect, and the large number of subgroup analyses conducted.

5. The validity of the findings of this study may be compromised if the women prescribed antiepileptic medications did not actually take the medicines because they knew that they were pregnant and were afraid of teratogenicity.

6. The study did not examine abortions, whether spontaneous or induced, and this could also compromise the validity of the findings because major malformations could increase spontaneous abortions; and malformations detected through screening could increase induced abortions.

### References

Hunt S, Russell A, Smithson WH, Parsons L, Robertson I, Waddell R et al. Topiramate in pregnancy: preliminary experience from the UK Epilepsy and Pregnancy Register. *Neurology* 2008; 71: 272-276.

Molgaard-Nielsen D, Hviid A. Newer-generation antiepileptic drugs and the risk of major birth defects.

**Source: JAMA, USA 2011; 305: 1996-2002.**





# NEWS & VIEWS ON DRUGS

## ANTIEPILEPTIC DRUGS TIED TO FOLATE AND VITAMIN B<sub>12</sub> LEVELS



Oral substitution of folates and vitamin B<sub>12</sub> normalizes levels in 95 percent of patients

**Treatment with many commonly used antiepileptic drugs is associated with reduced serum folate or vitamin B<sub>12</sub> levels.**

Treatment with many commonly used antiepileptic drugs (AEDs) is associated with reduced serum folate or vitamin B<sub>12</sub> levels.

Michael Linnebank, MD, from the University Hospital Zurich in Switzerland, and colleagues evaluated the association between AED treatment and serum folate and vitamin B<sub>12</sub> levels. A total of 2,730 AED-treated and 170 untreated epilepsy patients, and 200 healthy individuals were enrolled, and their serum folate and vitamin B<sub>12</sub> levels were measured. Three months of oral vitamin supplementation was given to 141 patients with folate or vitamin B<sub>12</sub> levels below the reference range.

The treatment with carbamazepine, gabapentin, oxcarbazepine, phenytoin, primidone, or valproate was linked to reduced average serum folate levels, and increased frequency of folate levels below the reference range compared to all patients, untreated patients, and healthy controls. Vitamin B<sub>12</sub> serum levels were higher in patients treated with valproate, compared to all patients, untreated patients, and healthy controls; whereas, B<sub>12</sub> levels were lower in patients treated with phenobarbital, pregabalin, primidone, or topiramate, compared to all patients. Higher mean corpuscular volume (MCV) and homocysteine plasma levels were found in patients with folate or vitamin B<sub>12</sub> levels below the reference range; vitamin substitution reduced MCV and homocysteine levels and restored vitamin levels to normal in 95 percent of patients.

"Treatment with most of the commonly used AEDs is associated with reduced folate or vitamin B<sub>12</sub> serum levels and is a risk factor for hyperhomocysteinemia. Oral substitution is effective to restore vitamin, MCV, and homocysteine levels," the authors write.

**Source: *Annals of Neurology* February 2011**



## GENETIC SCREENING CAN HELP LOWER THE RISK OF ADRS

Genetic screening can help lower the risk of adverse drug reactions among epilepsy patients, a finding that represents a step forward in the application of pharmacogenomics in the clinical field, a research team from the nation's leading research institute said yesterday.

Their study showed that through genetic screening, drug-induced syndromes such as -Stevens-Johnson Syndrome (SJS) and Toxic Epidermal Necrolysis (TEN) can be prevented among users of carbamazepine, a drug used to treat an intense facial pain condition called trigeminal neuralgia, said Shen Chen-yang (沈志陽), leader of the Academia Sinica research team.

There are about 20,000 to 30,000 users of carbamazepine in Taiwan.

In the study, 4,877 patients at 23 hospitals who were taking carbamazepine were screened for a specific genotype (HLA-B8\*1502).

The 372 patients who tested positive for the genotype were given an alternative medication, while those who tested negative continued with carbamazepine, he said.

### MONITORING

After two months' of monitoring, it was found that there were no incidents of SJS or TEN among the people who had been taken off carbamazepine. 218 of the patients who remained on carbamazepine developed minor to widespread rashes, which were, however, unrelated to SJS or TEN.

The study illustrated that HLA-B8\*1502 screening is effective in preventing adverse drug reactions, but also hinted at its usefulness in developing personalized medicine.

**"Scientifically speaking, the results of gene testing should be more precise than a record of family medical history," Shen said, adding, however, that at the moment, genetic screening is quite expensive and is not widely used in clinical practice.**

**Source: *New England Journal of Medicine* 24 March 2011**

# NEWS & VIEWS ON DRUGS

## EISAI EXTENDS NEUROSCIENCE PARTNERSHIP WITH UCL

Eisai Neuroscience PCU and University College London (UCL) are to launch joint research projects in the neurodegenerative disease arena including biomarker research in three areas: neuroinflammation, neurovascular/mitochondria, and proteostasis related research.

UCL campus has long been home to an Eisai research facility, and joint research activities have included the exchange of personnel.

Eisai is to integrate its UCL research functions into its Eisai European Knowledge Centre, located in Hatfield, Hertfordshire. The partners say these changes will facilitate knowledge creation through an even deeper level of open innovation.

Eisai discovered and developed Aricept, the world's biggest selling Alzheimer's disease.

Perampanel was developed through the partnership is now nearing the market.

The drug is a highly selective, non-competitive AMPA-type glutamate receptor antagonist.



## PERAMPANEL

Perampanel is showing early promises of significantly reducing seizures in drug resistant epilepsy. The results were seen in a clinical trial using a 12 mg dose of the drug being higher than previously tested.

The results of the research which involved 387 United States Latin America indigenes, were presented in American Academy of Neurology 63rd Annual Meeting held in Honolulu.

To arrive at the results, participants received (in addition to their regular medications) 12 milligrams of perampanel for 19 weeks and the effects were compared with those who received a placebo pill once daily. There was a 14-percent reduction in the frequency of seizures in those who took 12 milligrams of perampanel compared to the placebo group—findings that have increased confidence in seeking FDA approval.

## RETIGABINE FOR DIFFICULT TO CONTROL EPILEPSY

GlaxoSmithKline (GSK) recently launched Trobalt® (retigabine) in the U.K., the first in a new class of antiepileptic drugs (AED), for the adjunct treatment of adults with partial-onset seizures, and demonstrated significant effects in a treatment-resistant patient population.

Retigabine is the first and currently only AED to target neuronal potassium channels, which are involved in inhibitory mechanisms in the brain, and are thought to have a role in seizure control.

In the UK, retigabine has been tested in 1,365 patients across all phase I, II and III studies. Phase III studies for

retigabine demonstrated significantly improved seizure control, with a greater number of patients achieving a reduction in the number of seizures by 50 percent or more, compared with placebo.

Retigabine, jointly developed by GSK and Valeant, is also known as ezogabine and is currently not approved for use in the United States.

## QUOTES

*"God grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference."*

*"God, give us grace to accept with serenity the things that cannot be changed, courage to change the things which should be changed and the wisdom to distinguish the one from the other."*

*Reinhold Niebuhr*



## NEWS & VIEWS ON DRUGS

### NEW ANALYSIS SHOWS POTENTIAL COST SAVINGS OF ADDING LACOSAMIDE (VIMPAT)

**Lacosamide was used as add-on therapy for adults with uncontrolled partial-onset seizures. The clinical trial simulated pharmaco-economic model to analyze standard anti-epileptic drug therapy with and without lacosamide as add-on therapy in adults with uncontrolled partial onset seizures over a time horizon of two years in the USA.**

The treatment with lacosamide was associated with:

- an incremental gain of 6,730 avoided seizures and 38 quality adjusted life years (QALY) for a cohort of 1,000 patients, compared to the standard therapy arm of the analysis
- an estimated dollar value ranging from \$223 to \$733 per seizure avoided and an estimated dollar value of \$39,574 per QALY gained, compared to the standard therapy arm of the analysis
- 77% of patient simulations after 2 years of treatment fell within the acceptable thresholds of cost-effectiveness in the US, known as the willingness-to-pay threshold, which is \$50,000 per QALY

QALY is a standard calculation used by health economists to compute a dollar amount for each additional year of life added by a therapy and a value for the quality of that life. In standard practice, if the QALY resulting from a therapy is less than \$50,000 per year (the estimated value of a year of life in perfect health) then that therapy is seen as meeting the standard of willingness-to-pay.

Cost- and utility-effectiveness analyses help to quantify the economic rationale for a treatment, which is an important factor in evaluating the use of a potential therap. These findings provide additional support for lacosamide's utility as an antiepileptic drug in the reimbursement community, and among healthcare professionals and patients."

"This analysis shows the potential for cost savings when adding lacosamide to a treatment plan and, when

combined with more than five years of efficacy and safety data and more than 100,000 patient exposures worldwide, further underscores lacosamide's role in the treatment of epilepsy," added Kathleen Bos, MD, Vice President, US Medical Affairs, UCB, Inc.

#### Study Details

This analysis was based on published data from two pivotal, multi-national, clinical trials that have yielded more than five years of safety and efficacy data supporting long-term use of lacosamide. The model simulated the treatment pathway of a hypothetical cohort of 1,000 patients over two years from the third party payer perspective in the United States in 2010. Standard cost- and utility-effectiveness ratios were calculated based on two years of therapy compared with five other standard therapies: carbamazepine, lamotrigine, levetiracetam, topiramate, and valproate. Separate arms of the cohort compared lacosamide used as an add-on therapy with standard therapies versus those therapies used without lacosamide.

#### About Cost-Effectiveness Analysis

Cost-effectiveness analyses calculate the dollar value of changes in health status based on the use of a particular therapy versus standard cost of care. They are increasingly used to determine the relative value of therapies by public and private insurers for reimbursement decisions and in the development of clinical practice guidelines. Additionally, the more subjective health benefits resulting from a therapy, known as utility-value, are commonly determined through QALY calculations. QALY calculations calculate a dollar amount for each additional year of life added by a therapy and a value for the quality of that life. Quality is defined according to a variety of measures including physical mobility, ability to carry out activities of daily living, absence of pain and discomfort, and absence of anxiety and depression. In standard practice, if a therapy has shown a QALY under \$50,000 per year, it is considered to have met the standard of willingness-to-pay.

**Source: Paper presented at the 16th International Society for Pharmacoeconomics and Outcomes Research Meeting, USA, May 31, 2011 PRNewswire**



## RESEARCH IN EPILEPSY

### FOLLOWING THE TRAIL OF CELL DEATH IN PATIENTS WITH EPILEPSY



Wilma Friedman

Seizures in patients with epilepsy cause progressive cell death in the brain, but the cause was not well known. Professor Wilma Friedman of the Department of Biological Sciences at Rutgers University, Newark.

Identified a likely cause in post-seizure damage is P75, a receptor for growth factor.

"When a growth factor called ProNGF binds to the P75 receptor on damaged nerve cells following a seizure, it causes them to die," Friedman says. "Understanding this process can help determine how to prevent cell death."

This research has the potential not only to benefit people with epilepsy, but also those who suffer seizures as a consequence of traumatic brain injuries and strokes. In addition, it may shed some light on how to prevent cell death in degenerative conditions such as Alzheimer's disease.

A key to learning how the ProNGF growth factor works with the P75 receptor is following it through the brain after a seizure. Scientists will biologically tag the proNGF growth factor in mice, follow where the growth factor goes in to the brain. Once the process is better understood, researchers will test various molecules, already approved by the Federal Drug Administration, in hopes of finding one that blocks the P75 receptors and thereby prevents cell death.

**Source:**

<http://newarkbioweb.rutgers.edu/department/FacultyProfiles/friedman.html>. May 05, 2011

### ADVANCED TECHNOLOGY REVEALS ACTIVITY OF SINGLE NEURONS DURING SEIZURES

***Findings conflict with traditional view of how seizures begin***

The first study to examine the activity of hundreds of individual human brain cells during seizures has found that seizures begin with extremely diverse neuronal activity, contrary to the classic view that they are characterized by massively synchronized activity. The investigation by Massachusetts General Hospital (MGH) and Brown University researchers also observed pre-seizure changes in neuronal activity both in the cells where seizures originate and in nearby cells.

Findings suggest that different groups of neurons play distinct roles at different stages of seizures.

It may be possible to predict impending seizures, and that clinical interventions to prevent or stop them probably should target those specific groups of neurons.

Current knowledge in the brain during seizures largely comes from EEG, which reflect the average activity of millions of neurons at a time. This study used a neurotechnology that records the activity of individual brain cells via an implanted sensor.

The participants had the sensors implanted in the outer layer of brain tissue to localize the abnormal areas prior to surgical removal. The sensors recorded the activity of from dozens to more than a hundred individual neurons over periods of from five to ten days, during which each patient experienced multiple seizures. In some participants, the recordings detected changes in neuronal activity as much as three minutes before a seizure begins and revealed highly diverse neuronal activity as a seizure starts and spreads. The activity becomes more synchronized toward the end of the seizure and almost completely stops when a seizure ends.

**Source:** *Nature Neuroscience*, May 25, 2011



## EPILEPSY AROUND THE WORLD

### AUSTRALIA



#### Wally Lewis laces up for political protest

If Wally Lewis former Brisbane Broncos captain hadn't undergone delicate brain surgery for epilepsy in 2007, at Melbourne's Austin Hospital the rugby league legend is not

sure what his quality of life would be.

It was surgery that delayed for years, wouldn't have possible years of research that ally lowered of brain that Lewis had

Lewis addressed rally to protest sparked by reports up to \$400 million may be cut to the

Lewis had surgery that been without medical dramatic the risks damage feared.

a Brisbane potential cuts to

*Another brave initiative taken by Wally Lewis whose story has featured twice in Epilepsy (India Issue 2, 2010 & Issue 1, 2011) -VSS*



National Health and Medical Research Council budget. In 2006, he suffered a seizure on-air while reading the sports segment for Channel Nine's 6pm news in Brisbane. However Lewis had another personal experience His daughter Jamie-Lee was born profoundly deaf with 99% chances of going to a deaf school, doing sign language and continuing to struggle for the course of her life. Thankfully the massive intervention of the cochlear implant allowed her to go to a regular school. She's also been involved in sport throughout her life [Jamie has represented Australia playing water polo]. "Neither my wife Jacqueline or I believe she would have been gifted with these opportunities had it not been for the cochlear implant and medical research.

**Source: Brisbane News 19 April 2011**

### BANGLADESH



#### Superstition hampers epilepsy prevention

Around 40 percent epilepsy-affected children of the country are deprived of medical services every year due to superstition, neurologists say.

"The [epilepsy] affected children are equally meritorious to other children," said Professor Dr Kazi Deen Mohammad of Bangabandhu Sheikh Mujibur Rahman Medical University (BSMMU) at an international workshop in Dhaka.

The two-day workshop on 'Symptom and Detection of Children Epilepsy' was organised by Society of Neurologists of Bangladesh (SNB), Centre for Neuro-development and Autism in Bangladesh, Neurology Foundation, Dhaka and BSMMU.

Neurologists from Australia, Singapore, Thailand and India also attended the workshop.

Kazi, SNB president, said: "Proper treatment can cure the disease completely. But, most of the affected children in rural areas are taken to quacks rather than to the qualified physicians only because of superstition."

He lamented 90 percent of the patients go to other physicians sidetracking neurologists. "As a result, it has been impossible to prevent the disease in our country," he observed.

Dr MA Mannan, president of Bangladesh Epilepsy Foundation, said medical services for the disease needs to be modernised.

"It's the number-one disease of the world and we all have to work together to prevent it," he stressed.

**Source: [bdnews24.com/aha/rm/rdd/pks/ssr/1800h](http://bdnews24.com/aha/rm/rdd/pks/ssr/1800h)**

## EPILEPSY AROUND THE WORLD

### MALTA



#### European Epilepsy Day- Malta

*Reported by: Dr Janet Mifsud,  
IBE Vice President Europe*

The launching of the European Epilepsy Day in Malta was welcomed heartily. Making the Epilepsy issue an agenda of the day contributed a great



deal to the World Campaign "Epilepsy Out of the Shadows"

The Caritas Malta Epilepsy Association (CMEA) issued press releases and relevant articles in various newspapers to mark the day. The President of the Association Mario Dimech gave an interview on one of Malta's leading TV stations during the prime time news bulletin. This interview got great reviews from several people who contacted the association.

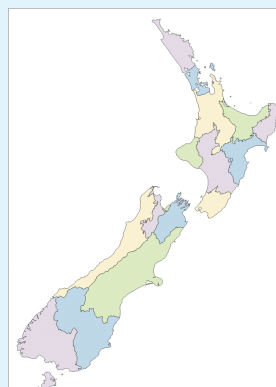
One of the main activities held for this occasion was an "Epilepsy Day On Campus" organised by the medical pharmacy and dental students in conjunction with CMEA. The Parliamentary Assistant to the Minister of Health attended this initiative and was very interested to know more about the work being done both locally and internationally regarding epilepsy. Besides boosting the profile of this activity, the presence of distinct personalities help enormously to improve the services given to people with epilepsy and their families and obviously also increase awareness.

Needless to say we look forward to celebrating next year's Epilepsy Day with equal earnest.



New Zealand's  
**INDEPENDENT NEWS MEDIA**  
[www.scoop.co.nz](http://www.scoop.co.nz)

### NEW ZEALAND



#### Waikato Epilepsy Awareness Programme Proves a Hit

The Epilepsy New Zealand Waikato Branch has experienced a significant increase in demand for their services, and is now higher than the national average of the 16 branches nationwide.

The 2010 results just in, show that the Waikato branch has seen a record number of people with epilepsy using their services in the area of support, an increase of 38%. Plus there was an overall increase of 14% on all people in the area, with or without epilepsy, seeking information on the condition. This included schools, rest homes and employers.

Epilepsy New Zealand National Field Manager, Verity Colgrave, said that she is "extremely proud of the huge efforts of the two permanent support and information staff here in the Waikato. We put it down to their hard work that we have now seen the Waikato come out on top."

The success of the branch has come from the public displays in high pedestrian areas including shopping malls, libraries and events that our staff attended. Most importantly the free public seminars held twice monthly at the Waikato Branch office.

"Along with seminars presented in house and throughout the community, Epilepsy New Zealand services include working with people who have epilepsy to provide information and support. Personal appointments can be made with our Field Officers, but people are welcome to attend our seminars first, as many questions will be answered. We also provide representation for people with epilepsy to other agencies, health professionals and employers."



# EPILEPSY AROUND THE WORLD

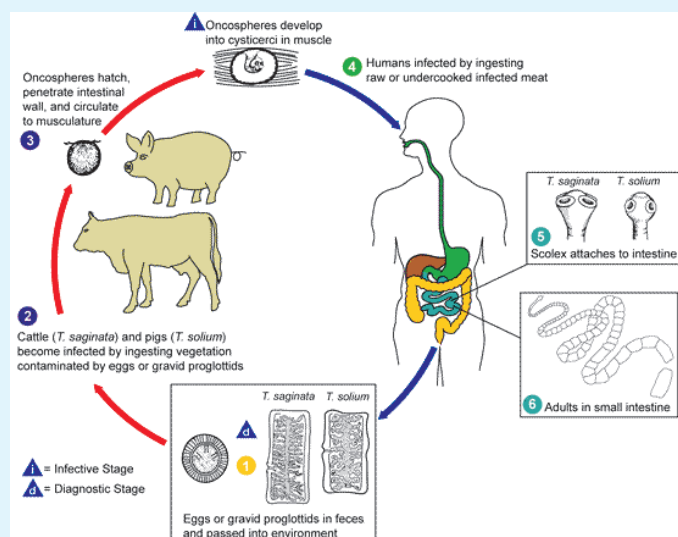
## UGANDA



### Ugandan Patients to be Tested for Epilepsy and Neurocysticercosis

Five neurologists from Germany & Austria examined nearly 1000 epilepsy patients in the Gulu and others districts in northern Uganda.

Neurocysticercosis is the number one cause of seizures and epilepsy in the developing world.



*Taenia solium* is a tapeworm that people get from eating raw or undercooked “measly pork”. The pork meat has cysticerci (the larval stage) which in the human intestine mature to an adult tapeworm. Here the tapeworm attaches to the intestine and produces thousands of eggs.

Most people are asymptomatic and only become aware of the tapeworm by noticing segments of the worm in their feces.

Human cysticercosis occurs either by the direct transfer of *Taenia solium* eggs from the feces of people harboring an adult worm to their own mouth (autoinfection) or to the mouth of another individual, or indirectly by ingestion of food or water contaminated with the eggs. When the person ingests the eggs, the embryo escape from the shell and penetrates the intestinal wall, gets into the blood vessels, where they spread to muscle, or more seriously, the eyes, heart or brain where it is the major cause for epilepsy.

## UK



### Former mayor looks back on epilepsy battle

FORMER Highworth mayor Steve Weisinger has spoken of his battle with epilepsy, having been diagnosed with the condition as a baby.

Father of two Steve, 48, had his first epileptic seizure at the age of 10 months old and said the diagnosis came as a huge shock to his parents at the time.



Steve Weisinger

Throughout his childhood, Steve suffered a number of seizures up until the age of six, when they appeared to stop. However, when he was 11 and in his final year at primary school, he was struck down by a major fit.

When he reached the age of 17, he had been seizure-free for more than three years and passed his driving test at the

age of 18. But 20 years after his last seizure, he said the condition “came back to haunt me”.

No medication could control his epilepsy due to where the scar was on his brain, and in 2006, at the age of 43, Steve underwent an operation at the Neurology and Neurosurgery Hospital in London to remove the left temporal lobe of his brain.

“I had been told there was a 70 per cent chance of it being a success, a one per cent chance that something could go drastically wrong, and a 29 per cent chance of things being slightly worse.

“But I have completely recovered, I haven't had a fit since, I've got my driving licence back and my life has completely changed – I no longer have to depend on public transport, my children feel far more relaxed with me and it shouldn't ever come back.”

“It's nice to be able to go and help others who have been through or are going through what I have been through,” he said.

**Source: Swindon Epilepsy Support Group**

# EPILEPSY AROUND THE WORLD

## USA



### David Axelrod: Epilepsy “Terrorism of Brain”

David and Susan

Axelrod launched **CURE Epilepsy 1st Annual West Coast Benefit** in San Francisco, Ca.



John Vogelstein and David Axelrod

In his keynote address at the Four Seasons David Axelrod, former Senior Adviser to President Obama called epilepsy, “terrorism of the brain.”

Despite the introduction of many new drugs over the last 50 years, the percentage of people with epilepsy who cannot control their seizures has not changed. It's over 30 percent.

Fred Vogelstein said “The way we treat and think about epilepsy is in the dark ages. It still scares people so much that those with seizures lose jobs and relationships because of it.”

**CURE**  
Citizens United for Research in  
**EPILEPSY**



It's time we  
found a cure.



Chair Person

URE, Citizens United for Research in Epilepsy, is a volunteer-based nonprofit organization founded by parents of children with epilepsy who were frustrated with their inability to protect their children from the devastation of seizures and the side effects of medications. Unwilling to sit back and accept the debilitating effects of epilepsy, these parents joined forces to spearhead the search for a cure. Administrative costs

are kept to a minimum so that money raised can go directly toward epilepsy research aimed at finding a cure. It is a nonprofit organization dedicated to finding a cure for epilepsy by raising funds for research and by increasing awareness of the prevalence and devastation of this disease.

### CURE Research Grants

Since its inception in 1998, **CURE** has raised \$15 million to fund epilepsy research and other initiatives that will lead the way to a cure to seed grants to young and established investigators to explore new areas and collect the data necessary to apply for further funding by the National Institutes of Health (NIH). To date, **CURE** has awarded over 107 cutting-edge projects.

### CURE-Sponsored Conferences

**CURE** co-sponsored the National Institutes of Health Conference, *Curing Epilepsy: Focus on the Future* in March of 2000. This White House-initiated conference was the first of its kind to focus on epilepsy. Since then, **CURE** has also lent support to other relevant workshops and conferences, including the March 2007 NIH Conference.

### CURE Advocacy

has helped raise federal expenditures by the NIH on epilepsy research.

### Increasing Public Awareness

**CURE** is dedicated to increasing public awareness about epilepsy.

## Let Non-Medical Personnel Administer Epilepsy Drug

A Sacramento Bee editorial states that "California Senate leaders ... need to permit a vote" on legislation (SB 161) that "would authorize school administrators, teachers and other volunteer staff members to administer a prescription drug in suppository form that can stop seizures." Some of the state's top experts on epilepsy testified in legislative hearings that people who aren't nurses are perfectly capable of administering [the drug], and that the consequences of doing nothing are severe. The Bee concludes that "hard-working and dedicated school employees ought [to] be able to choose to volunteer to help a child in distress."

"Senate Leaders Should OK Vote on Epilepsy Bill" (Sacramento Bee, 5/23/2011)



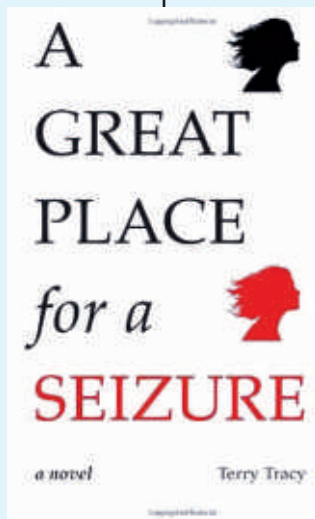
## BOOK REVIEW

### New novel gives insight into world of epilepsy

"A Great Place For A Seizure" (ISBN: 1453834702) by Terry Tracy tells the story of one of the 50 million people in the world who live with epilepsy

A debut novel by Terry Tracy, gives readers a glimpse of life with epilepsy. Mischa Dunn's family leaves Chile in the wake of the 1973 coup d'etat that installs a military dictatorship. She settles comfortably in her newly adopted country, the United States, until one day an unexplained seizure in a library transforms her forever. The novel follows Mischa from adolescence to adulthood as she struggles to deny, defy and accept her epilepsy.

Through humor and insight, Tracy draws the reader into Mischa's tale that travels across three continents over thirty years. Mischa's family and friends accompany her on this journey with hopes for the better and painful confusion over how to help. An unusual heroine, Mischa is not a glorified survivor, but an individual with obvious flaws and some virtue. "A Great Place for a Seizure" is not the story of a disability, but of a life led with a disability.



Tracy notes, "Epilepsy is still a mystery for many. From movies and television, people know what a seizure looks like from the outside, but what is it like from the inside? What does a person with epilepsy feel and think? How does epilepsy affect a person's life? How does a person with epilepsy view the world and how does the world view a person with epilepsy?"

Biographical research has shown that Vincent Van Gogh, Socrates, Harriet Tubman, Isaac Newton, Fyodor Dostoyevsky, Emily Dickinson, Napoleon Bonaparte, Agatha Christie and Vladimir Lenin all had epilepsy. American singers and songwriters Prince and Neil Young, actor Danny Glover and British theologian Karen Armstrong are among them.

A blog post says 'totally blown away'!! What an amazing novel. The first thing I loved about it was the table of contents. The library, the coffee shop, the office, etc. These are the answers to the jeopardy question 'Where is a great place to have a seizure?' Now, I have to admit that sarcasm and irony are without a doubt my favorite forms of humour so this book appealed to me from page one".

### QUOTABLE QUOTES

**Dr Abdul Kalaam.....**

"It Is Very Easy To Defeat Someone,  
But It Is Very Hard To Win Some

**Shakespeare.....**

"Never Play With The Feelings Of Others  
Because You May Win The Game  
But The Risk Is That You Will Surely Lose  
The Person For A Life Time".

**Napoleon.....**

"The world suffers a lot.  
Not because of the violence of bad people,  
But because of the silence of good people!"

**Einstein.....**

"I am thankful to all those who said NO to me  
Its because of them I did it myself.."

**Abraham Lincoln.....**

"If friendship is your weakest point then  
you are the strongest person in the world"

**Shakespeare.....**

"Laughing Faces Do Not Mean That There Is  
Absence Of Sorrow!  
But It Means That They Have The Ability To  
Deal With It".

**William Arthur.....**

"Opportunities Are Like Sunrises, If You  
Wait Too Long You Can Miss Them".

**Hitler.....**

"When You Are In The Light, Everything  
Follows You,  
But When You Enter Into The Dark, Even  
Your Own Shadow Doesn't Follow You."

**Shakespeare.....**

"Coin Always Makes Sound  
But The Currency Notes Are Always Silent.  
So When Your Value Increases  
Keep Yourself Calm and Silent"

## LAUGH!!!!!!!!!!!!!!!!!!!!!! IT IS GOOD FOR YOUR HEALTH

😊 *Ad In Hospital Waiting Room:*

*Smoking Helps You Lose Weight ... One Lung At A Time!*

😊 *On a bulletin board:*

*Success Is Relative. The more The Success,  
The more The Relatives.*

😊 *When I Read About The Evils Of  
Drinking...*

*I Gave Up Reading*

😊 *My Grandfather Is Eighty And Still  
Doesn't Need Glasses....*

*He Drinks Straight Out Of The Bottle.*

😊 *You Know Your kids Have Grown Up  
When:*

*Your Daughter Begins To Put On Lipstick..  
Or when your Son starts To wipe It Off*

😊 *Sign in a Bar :*

*Those Of You Who Are Drinking To Forget,  
Please do Pay In Advance.'*

😊 *Sign In Driving School:*

*If Your Wife Wants To Learn To Drive, Don't  
Stand In Her Way....*

😊 *Behind Every Great Man,*

*There Is A Surprised Woman.*

😊 *The Reason Men Lie*

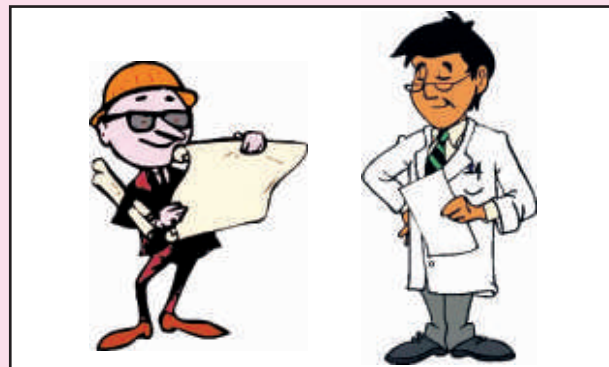
*Because Women Ask too Many Questions..*

😊 *Advertisement In Shop:*

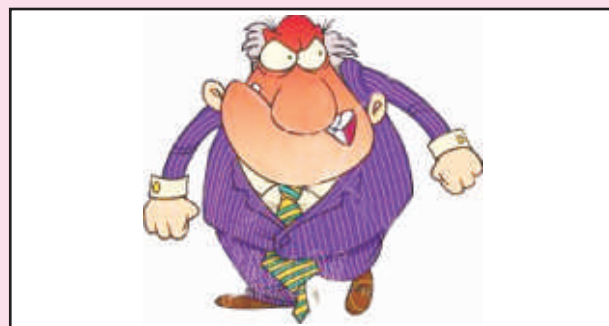
*Guitar, for sale..... Cheap..... . .....no  
strings attached.*

## REALITY

Most 'First Class' students get technical seats, some become Doctors and some Engineers.



\* The 'Second Class' pass, and then pass MBA, become Administrators and control the 'First Class'.



\* The 'Third Class' pass, enter politics and become Ministers and control both.



\* Last, but not the least, The 'Failures' join the underworld and control all the above.



## FORTHCOMING EVENTS

☞ **17th - 29th July, 2011**

**VENICE, ITALY**



### **Advanced International Course: Bridging Basic with Clinical Epileptology-4**

Sponsored by ILAE and by the Fondazione Istituto Neurologico C. Besta

Course Directors: Marco de Curtis (Italy), Astrid Nehlig (France) and Jeff Noebels (USA)

ISNV President: Giuliano Avanzini (Italy)-INSV Director: Francesco Paladin (Italy)

Registration Form are available on web sites: [www.ilae.org](http://www.ilae.org); [www.epilearn.eu](http://www.epilearn.eu) Applications should be sent to the Course Secretary, Metella Paterlini, at [epilepsysummercourse@univiu.org](mailto:epilepsysummercourse@univiu.org) (fax+39-02-700445211) before March 1st 2011.

Full and partial financial support is available for a limited number of applicants.

Registration fee (2300 € and 2000€) includes 12 night accommodation in single or double rooms, full board and coffee breaks for the entire duration of the course, access to the course and to the Venice International University course syllabus.



☞ **18th - 25th September, 2011**

**Eilat, Israel**



### **4th Eilat International Educational Course: Pharmacological Treatment of Epilepsy**

Princess Hotel, Eilat, Israel  
Sponsored by the ILAE Commission on European Affairs and the Hebrew University of Jerusalem

<http://www.eilat-aeds.com> under Forthcoming Conferences

For more information contact the Secretariat at

[eilatedu@targetconf.com](mailto:eilatedu@targetconf.com)



☞ **21st - 24th September, 2011**

**China**



### **4th CAAE International Epilepsy Forum (CIEF)**

Formerly the Beijing International Epilepsy Forum  
Nanjing City, Jiangsu Province, People's Republic of China  
Sponsored by the China Association of Epilepsy

Call for abstracts - submit to

[caae2008@sina.com](mailto:caae2008@sina.com)

<http://www.caae.org.cn>



☞ **18th - 19th February, 2012**

**Tokyo, Japan**

### **15th Annual Meeting of the International Symposium on Surgery for Catastrophic Epilepsy in Infants**

Tetusmon Memorial Hall, The University of Tokyo, Tokyo, Japan  
Abstract Submission Deadline: 31 October 2011

<http://www.iss-jpn.info>



☞ **17th - 19th February, 2012**

**Mumbai, India**



*Inauguration of Neurology Update on February 2010 in Mumbai*

Neurology Update 2012 will be held on Friday 17, Saturday 18, and Sunday 19<sup>th</sup>, February 2012 at the Taj Mahal Palace, Mumbai.

This update will focus on Stroke, Epilepsy, Movement disorders, Autonomic Neuropathies, Immune mediated demyelinating disorders and Myasthenia gravis with participation of invited 11 international faculty members.

Organizing Chairman - Dr. B. S. Singhal.

Conference Secretariat

**Niloofer Patel, FTC Events**, M-33, Cusrow Baug, S. B. Road, Colaba, Mumbai - 400 039.

Tel.: +91 22 2282 5108,

Fax: 91 22 2282 2134

Email: [numum2012@ftcevents.com](mailto:numum2012@ftcevents.com)

Website:

[www.neurologyupdatemumbai.com](http://www.neurologyupdatemumbai.com)



☞ **6th - 10th May, 2012**

**Eilat, Israel**

### **Eleventh Eilat Conference on New Antiepileptic Drugs (Eilat XI)**

Eilat, Israel

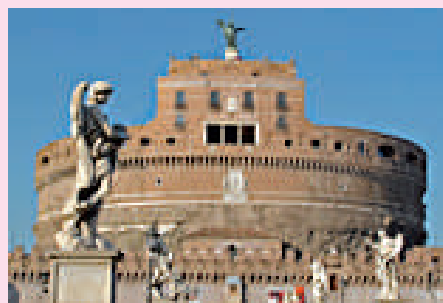
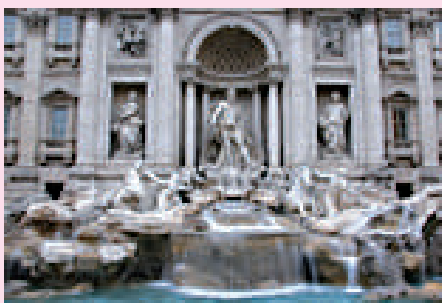
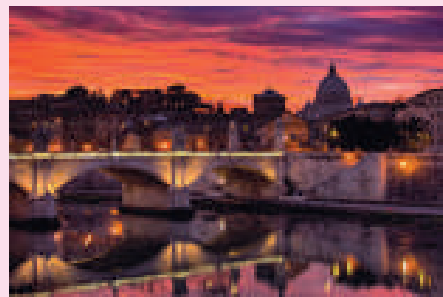
<http://www.eilat-aeds.com>





## FORTHCOMING EVENTS

### ☞ 28th August - 1st September, 2011 29th International Epilepsy Congress, ROME 2011



#### 29<sup>th</sup> IEC SAOC



Mike Glynn (Ireland), Co-chair  
Emilio Perucca (Italy), Congress Director  
Janet Mifsud (Malta)

Solomon Moshe (USA), Co-chair  
Federico Vigevano (Italy),  
Scientific Programme Director  
Giovanni Battista Pesce (Italy)

#### Registration Fees

	Early Registrations upto 13th May 2011	Mid Registrations 14th May- 15th July 2011	Late Registrations 16th May- 12th August 2011	On-Site Registrations 28th August- 1st September 2011
Regular	€ 655	€ 755	€ 820	€ 865
Junior ( <i>under 40 years old-copy of passport required</i> )*	€ 500	€ 570	€ 605	€ 630
One Day Only	€ 250	€ 275	€ 300	€ 325
Accompanying Person	€ 190	€ 190	€ 190	€ 190

#### VENUE

**Marriott Rome Park Hotel,**  
**Via Colonnello Tommaso Masala, 54**  
**Rome, 00148 Italy**

Phone: 39 06 658821

Fax: 39 06 65882750

#### SECRETARIAT CONTACT DETAILS

29<sup>th</sup> INTERNATIONAL EPILEPSY CONGRESS

ILAE / IBE Congress Secretariat

7 Priory Hall, Stillorgan, Dublin, Ireland

Tel.: +35312056720 Fax.: +35312056156

E-mail.: [+rome@epilepsycongress.org](mailto:+rome@epilepsycongress.org).

Website.: [www.epilepsyrome2011.org](http://www.epilepsyrome2011.org).

## FORTHCOMING EVENTS

✉ **22nd -25th - March, 2012**

### 9TH ASIAN & OCEANIAN EPILEPSY CONGRESS, MANILA 2012



The 9<sup>th</sup> Asian & Oceanian Epilepsy Congress will be held in Manila, Philippines from the 22<sup>nd</sup> to the 25<sup>th</sup> of March 2012, organised jointly by

the regional associations of the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE).

The Scientific Organising Committee and the Scientific Consultative Committee have put together a scientific programme which includes the following topics:

Main Sessions	Epileptic Networks and Seizure Propagation Epilepsy Genes and Beyond The Impact of Epilepsy Epilepsy and the Developing Brain
Post Main Sessions	The Genetics of Epilepsy Anxiety and Depression Epilepsy and Autism
Parallel Sessions	Psychosis and Epilepsy: A Multi-disciplinary Approach Neuroimaging of Epilepsy: Therapeutic Implications Epilepsy and Sleep Pharmacogenomics and Antiepileptic Therapy Epilepsy and Pregnancy Novel Surgical Approaches Challenges in the Diagnosis and Treatment of Status Epilepticus Sex and Epilepsy
Practical Sessions	Workshop: Global Campaign Against Epilepsy Workshop: Epilepsy in Adolescence

An exciting **epilepsy and society programme** for people with epilepsy and their carers will run in conjunction with the congress. More details on the

epilepsy and society programme will be announced shortly on the congress website: [www.epilepsymanila2012.org](http://www.epilepsymanila2012.org)

Competitive hotel rates are available via the accommodation managers, Intas for the 9<sup>th</sup> AOEC. Abstracts must be submitted in English through the official website [www.epilepsymanila2012.org](http://www.epilepsymanila2012.org). The abstract system will open in June and be available until November.

A number of travel bursaries will be available for the 9<sup>th</sup> AOEC; further details on this will shortly be announced on the congress website [www.epilepsymanila2012.org](http://www.epilepsymanila2012.org)

June 2011	Registration opens
June 2011	Abstract submissions system opens
November 2011	Abstract submission deadline
December 2011	Early registration deadline
22nd - 25th March 2012	Congress dates

#### SCIENTIFIC ORGANISING COMMITTEE (SOC)

##### Co-chairs:



Josephine CASANOVAGUTIERREZ  
(Philippines)



Robert COLE  
(Australia)



Byung-In LEE  
(Korea)

##### Members:



Ding DING  
(China)



Simon HARVEY  
(Australia)



Patrick KWAN  
(Hong Kong)



Andrew PAN  
(Singapore)



Vinod SAXENA  
(India)



Tatsuya TANAKA  
(Japan)

## INDIAN EPILEPSY ASSOCIATION



### GOVERNING COUNCIL 2011- 2013

Dr H V Srinivas	President	(2011-13)
Dr Pravina U Shah	Imm. Past President	(2011-13)
Dr V V Nadkarni	President - Elect	(2011-13)
Dr M M Mehndiratta	Secretary - General	(2009-13)
Dr C M Sharma	Treasurer	(2009-13)
Dr V S Saxena	Editor- Epilepsy India	(2009-13)

### MEMBERS - (2011 - 13)

Dr Bindu Menon	AP	Dr Pratap Sanchetee	Rajasthan
Dr Ashok Kumar	Bihar	Dr V Natarajan	Tamil Nadu
Dr Sudhir Shah	Gujarat	Dr Atul Agarwal	UP
Mr KV Murlidharan	Karnataka	Dr Gautam Ganguly	West Bengal
Dr B Rajendran	Kerala	President - IES	Ex-Officio Member
Ms Carol D'Souza	Maharashtra	Secretary General-IES	Ex-Officio Member
Dr Gagandeep Singh	Punjab		

### Request for Membership of IEA & IES

Readers are requested to seek membership of IEA and IES for their Colleagues & Friends. Please go to the website [www.epilepsyindia.org](http://www.epilepsyindia.org) for details & membership forms..

## INDIAN EPILEPSY SOCIETY



### EXECUTIVE COMMITTEE 2010-2012

Dr Satish Jain	President	2010 - 2012
Dr Rakesh Shukla	Imm. Past President	2010 - 2012
Dr P Satishchandra	Vice President	2010 - 2012
Dr MM Mehndiratta	Secretary - General	2010 - 2012
Dr Manjari Tripathi	Treasurer	2010 - 2012
Dr V S Saxena	Editor-Epilepsy India	2009 - 2013
Dr P Sarat Chandra	Member	2010 - 2012
Dr Satish K Gulati	Member	2010 - 2012
Dr RV Narayana	Member	2010 - 2012
Dr VV Nadkarni	Member	2010 - 2012
Dr Parampreet S Kharbanda	Member	2010 - 2012
President-IEA	Ex-officio Member	2010 - 2012
Secretary General-IEA	Ex-officio Member	2010 - 2012





A way of life™

- Impressive seizure control<sup>1-5</sup>
- Effective for most people with epilepsy<sup>2,3,6-9</sup>
- More than just seizure control<sup>3,9-21</sup>



**References:** 1. Gambardella A et al. Neuropsychiatry Dis Treat. 2008; 4(1):33-8. 2. Brodie MJ, Perucca E, Ryvlin P et al. Neurology 2007; 68:402-408. 3. Noachtar S, Andermann E, Meyvisch P, et al and the N166 Levetiracetam Study Group, Neurology 2008; 70:607-616. 4. Sills GJ, Leach JP, Wilson EA et al. Poster presented at 61st AES, Philadelphia USA Dec 2007. 5. French J and Arrigo C. Epilepsia 2005; 46(2): 324-326. 6. Glauser TA, Ayala R, Elterman RD, et al. Neurology 2006; 66:1654-60. 7. Morrell MJ, Leppik I, French J et al. Epilepsy Res 2003; 54: 153-161. 8. Ferrendelli JA, French J, Leppik I et al. Epilepsy Behav 2003; 4: 702-709. 9. Keppra\* (levetiracetam) prescribing information, UCB India, Aug 2009. 10. Otoul C, Arrigo C et al, Clin Neuropharmacol 2005; 28: 72-78. 11. Cereghino JJ, Biton V and Abou-Khalil, et al. Neurology 2000; 55: 236-242. 12. Perucca E, Gidal BE, Baltes E. Epilepsy Res, 2003; 53: 47-56. 13. Panayiotopoulos CP, Principles of therapies in epilepsies. Epileptic syndromes and their treatment, 2007:161-163. 14. Ragueneau-Majlessi I, Levy RH, Meyerhoff C, Epilepsy Res. 2001; 47:55-63. 15. Levy RH, Ragueneau-Majlessi I, Baltes E, Epilepsy Res, 2001; 46:93-99. 16. Panayiotopoulos CP, Principles of therapies in epilepsies. Epileptic syndromes and their treatment. 2007:156. 17. Ragueneau-Majlessi I, Levy RH, Janik F. Epilepsia. 2002; 43:697-702. 18. Szagor M, Bourgeois BFD. Pediatr Neurol. 2005; 33:227-234. 19. Mullin P, Stern JM, Delgado-Escueta AV, et al. Epilepsia. 2001; 42(suppl 7):184. 20. Diaz R A et al. Neurologist. 2008 Nov; 14(6 Suppl 1):S55-65. 21. Gomer B., Wagner K., Frings L, et al. Epilepsy & Behavior 2007 (10):486-494.

Please refer to the full Prescribing Information before prescribing Keppra®. Available on request from UCB India Pvt. Ltd. 504, Peninsula Towers, G.K. Marg, Lower Parel, Mumbai-400 013.

