



EPILEPSY INDIA



INDIAN EPILEPSY ASSOCIATION & INDIAN EPILEPSY SOCIETY

Newsletter

July - September 2010

Issue 3, 2010

Editorial

Dear Friends

In the recent months most of us have been or know of some one who has been victim to the Icelandic volcanic ash. Seventeen thousand flights a day had been grounded and hundreds of thousand passengers in at least 25 countries have been thrown out of gear resulting in great loss and inconvenience to individuals, airlines and economy.

Eyjafjallajökull volcano in Iceland started it all but scientists warn that such activity could last for many years. In the past eleven centuries, 205 eruptions have come in cycles in this land of fire and ice. The quiet of past 5 decades has been replaced by a period of activity.

There are at least two more volcanoes apart from Eyja...well it is easier to call it E15. A volcanologist Thor Thordarson from Edinburgh University predicts more build up to cause traffic disruption over many months or possibly years.

How does one face these dark portends? Well Icelandics led the way by wry humour. Just before the volcanic ashes, Iceland had a testing time in form of a severe economic down turn but they bore the calamity with *sangfroid*. Some say by laughing their way to bankruptcy. Now they say, "When our economy died, its final wish was to have its ashes scattered across Europe".

Darker the cloud or grimmer the situation, the survivors will find a different approach to go around the obstacle. Humour may well serve but it will carry the label of being 'black' or 'sick'. Still humour has helped people and societies to laugh their way out of miseries.

During World War II, Field Marshal Montgomery could hardly suppress his laugh and pride when a badly injured soldier on enquiry on his health state remarked, "It only hurts when I laugh". The constant bombings of most living areas in Britain had many brave reactions. A sign out side what was once a shop and now with its roof blown out said "More open than before".

Humour in these situations helped keep the morale high which eventually brought glory to the nation.

In our ancient culture *Natyashastra* defined humour as, *atmasha* or on self and *parasha* based on others. We all laughed with (and at) Charlie Chaplin for the extreme situations he created for himself. We called him a great comedian. Of course, we would not like to be in those predicaments and our laughter became a nervous escape from reality.

Even out of grave situations, people have laughed at things less obvious. I serve "Famous Grouse Whisky" only to friends who do not know this story. In 2001 the Prince of Nepal sorted out his family grouses by first getting drunk on this brand and then shooting the family down. British had their own take by inventing a story. Prince Charles seems to have told his mother, the Queen "So you won't let me marry Camilla, why don't you and the family come over to my place for dinner on Friday night".

It could hardly be considered humour when a reporter asked Mrs Abraham Lincoln coming out of the theatre minutes after her husband was fatally wounded "Apart from that, how was the play" (you may already see a parallel in today's TV coverage).

The FIFA craze may have its own stories. A man sitting in the stadium with one vacant seat next to him was asked if the seat belonged to any one "Yes, it was for my dear departed wife" Deeply touched, the enquirer next

sympathized, "Surely, some relative could have accompanied you to share your sorrow" "No, they are all at her funeral".

Life may also be taken less seriously—as no one has got out of it alive. Chesterton said that angels could fly as they take them selves lightly. Only their freedom seriously. GB Shaw says on his epitaph "I knew if I stay around long enough something like this would happen" We are here only for a fixed period, clocking in reverse our passage

through time. Even with 50 years of active working life, we may get no more than 2500 Sundays to relax.

Even those few days of relaxation may be interrupted by E15 or similar event.

During the period of ashen clouds, I saw a person with epilepsy being interviewed on BBC. The grounding had led to running out of his prescribed medication and he feared getting a fit. Not to be so caught, carry enough stock (in original pack) and adhere to the dosing intervals despite different time zones. Take along doctors' prescription so that it could be filled in another country. (Some thing should surely be better than nothing). Enjoy both, the plans you made and which got unmade despite yourself. Check on sleep, meals and recreation and be forewarned that trip interruptions could take place.

There is enough of seriousness around, now be sincere in enjoying life at the same time.

Best wishes

Dr VS Saxena
Editor



EPILEPSY INDIA

NEWSLETTER OF INDIAN EPILEPSY ASSOCIATION & INDIAN EPILEPSY SOCIETY

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OBITUARY

DR GEETA RANGAN, BANGLORE 03 FEBRUARY 1948-16 MARCH 2010

Dr Geeta Rangan a distinguished neurologist and epileptologist from Bangalore died on 16 March 2010 after a short illness.

She had her early education in Allahabad before joining Calcutta Medical College. She finished her medical degree with distinction. She left her mark on not just fellow students but also many teachers who appreciated her for her zeal, earnestness and above all real involvement with patient welfare. These traits were ever to remain with her through out her life. She was frank and outspoken with courage of conviction. She later moved to Delhi for her MD in General Medicine at AIIMS. She was one of the brightest postgraduates who once again made her mark with her research on tuberculous meningitis and passed out in 1973 with flying colors. Her next academic move was to NIMHANS, Bangalore to pursue DM in Neurology. Working under Prof KS Mani during this time she developed keen interest in epilepsy.

Subsequently she married Prof KS Mani and together they established Neurology Clinic in private practice in Bangalore. She took leading role in carrying out the much acclaimed 'Yelandur Epidemiological Research Study'. Her meticulous record keeping and attention to smallest detail helped the study to be model for epidemiological work under elementary conditions.

She worked as a faculty and developed departments of neurology in St. John's Medical College, Manipal Hospital and Sathya Sai Medical Institution at Bangalore. Again at

the end of her career she developed another neurology department at Vydehi Medical College. She had a number of publications in the field of epilepsy.

She was closely associated with Indian Epilepsy Association through its Bangalore chapter for nearly two decades. She was the editor of the "News letter of the Bangalore Chapter" for nearly a decade. She was on the Editorial Board of Epilepsy India for 5 years during which she contributed articles, reviews and general commentary on the events. She played very keen role in creating awareness of epilepsy in the community through stage plays, children picnics, camps, lectures etc.

After the demise of Prof Mani, she spent her free time in professional activities and leisure time in gardening and playing with her pet dog Gabby. She had great love for animals. Prof Shymal Sen her teacher and her class mates Dr Ambar Chakrabarty and Dr Abhijit Chatterjee remember her carrying stray kittens in her apron pocket while in the medical college.

EI and the members send their condolence to the bereaved family now just her mother and her elder brother and his family.

IEA and EI will remember her for her immense concern for the suffering with her own care-free and yet committed life.

Dr P Satishchandra, Bangalore and Dr VS Saxena, Gurgaon



Dr Geeta Rangan

'Be kinder than necessary because everyone you meet is fighting some kind of battle.'



Of all the things you wear, your expression is the most important.



The heaviest thing you can carry is a grudge.



One thing you can give and still keep....is your word.



Your mind is like a parachute...it functions only when open.

ANNOUNCEMENT FOR IEA ELECTIONS FOR GC 2011-2013

INDIAN EPILEPSY ASSOCIATION ELECTIONS-NOMINATION FORM For President Elect and GC Members 2011-13

Name of the Post : President Elect / GC Member

Name of the Nominee_____

Address:_____

Proposed by : _____ Seconded by : _____

Address _____ Address _____

IEA No. _____ IEA No. _____

Proposer's Signature _____ Seconder's Signature _____

I, _____ hereby give my cosent for my nomination for the post of the _____
_____ Indian Epilepsy Association, for the GC 2011-2013.

Telephone No. _____ Signature _____

e-mail Id. _____ Membership Number _____

Last Date of Receipt of Nomination : 5th November, 2010 5.00 PM

Last Date for Withdrawal : 26th November, 2010 5.00 PM

Last Date for Receipt of Ballot Papers: 31ST December 2010 5.00 PM

(In case of election)

Only valid members can file nominations or propose

A bio-data of the nominee (in upto 200 words) may be enclosed

Eligibilty Criteria: Continued valid membership for President Elect-8 years, GC Members- 3 years

Completed nomination form should be sent to:

Dr VS Saxena

Returning Officer-IEA

SANNIDHI, K 10/10, DLF Outab Enclave II, Gurgaon – 122002.

Ph.: 0-124-4363035/36/37, 2350035

email. drvssaxena@gmail.com

ANNOUNCEMENTS

NATIONAL EPILEPSY DAY 2010



Dear Friends,

Dr Pravina U Shah, President IEA was recently in Delhi in connection with the meeting of IEA-18th IEC Trust. National Epilepsy Day (NED) featured

as an agenda item and some preliminary discussion was held to make this event more impactful so that maximum good could result from the efforts of the Chapters. This discussion continued outside the meeting as well.

We would really appreciate helpful suggestions towards NED 2010. We propose

→ We hold programs for school children-They being the future citizens, any effort on them will go a long way.

We request all members, secretaries of chapters and GC members to give ideas to make it effective, economical and practical.

→ Women and Epilepsy-This should be focused for gynecologists and obstetricians by different chapters, cities and towns so that they are managed positively during pregnancy specially with respect to AEDs.

→ We should also keep in mind that IBE celebrates its Golden Jubilee in 2011 when the meeting will be held in Rome in late Aug 2011. As one of the most active members of IBE, we should wholeheartedly participate in the Rome event. More over, 2011 is the 40th year landmark for IEA so a special meeting in form of a satellite meeting before Rome meeting could get participation of IBE personalities.

→ We could propose essay & quiz competition for different age groups.

Hoping to hear from you

Dr Pravina U Shah, President, IEA

Dr VS Saxena, President, IEA-18th IEC Trust & Vice President -SEAR, IBE

THE MICHAEL PRIZE-2011

For the best contribution to scientific and clinical research which promote further development in epileptology

Announcement for the 2011 Michael Prize

The MICHAEL PRIZE was awarded for the first time in 1963 to stimulate epilepsy research in Germany; it is now one of the most highly regarded international awards for the best contribution to scientific and to clinical research which promote further development in epileptology.

The MICHAEL PRIZE is awarded biennially and specially designed to attract younger scientists (normally not older than 45 years of age).

The prize fund is EUROS 20,000

Up to a maximum of three papers in English language may be considered, at least one of which – published or not yet published – must be from the period. The papers, together with a curriculum vitae, should be submitted by electronic mail to STIFTUNG MICHAEL before December 31st, 2010.

e-mail: StiftungMichael@t-online.de

Since 2006 the MICHAEL PRIZE is sponsored by UCB International.

IEA CONSTITUTIONAL AMENDMENT PROPOSAL

Dear Friends,



While the Constitution as laid down must be held sacrosanct, there come times when we need to change to help propel the Association forward.

Such a requirement was discussed in Secretary-general's report in the GC which met on 05 Feb 2010 in Indore.

The Committee so appointed wishes to consult the general membership of IEA so that the members may contribute their thoughts and suggestions in areas related to the Constitution (can be seen on the website, epilepsyindia.org).

Please send your suggestions by 30 July 2010 to:

Dr VS Saxena

Chairman, IEA Constitutional Revision Committee

K10/10, DLF City-II, Gurgaon 122002

email: drvssaxena@gmail.com

INVITATION PHOTO COMPETITION

EPILEPSY WITHOUT WORDS



US\$7,000 in Prizes!

The International Bureau for Epilepsy launches a special photography competition as part of its Golden Jubilee celebrations.

The competition, open to all, is the first of many initiatives being planned to celebrate IBE's Golden Jubilee in 2011. Titled Epilepsy Without Words, the competition is open for entries from 15th May 2010 until the closing date on 1st March 2011.

A special photo gallery, displaying all entries received, will be open on the IBE website www.ibeepilepsy.org

from 1st June 2011 and the competition winners will be announced during the 29th

International Epilepsy Congress in Rome in late August 2011.

The competition is open to everyone – professional and amateur photographers alike.

Prizes

Digital Camera Category:

- 1st Prize: US\$3,000 ● 2nd Prize: US\$2,000
- 3rd Prize: US\$1,000

Mobile/Cell Phone Category:

- 1st Prize: US\$500 ● 2nd Prize: US\$300
- 3rd Prize: US\$200

For further information contact Mrs Ann Little, IBE Executive Director at ibedublin@eircom.net or visit our website www.ibe-epilepsy.org.

Source: Brainwave, Ireland

PUBLICATION FOR PRACTISING CLINICIANS AVAILABLE

Dear Colleagues,

With the kind permission of the World Federation of Neurology, we are pleased to make available to you a publication from the WFN's Seminars in Clinical Neurology series "Epilepsy: Global Issues for the Practising Neurologist."

This publication was chaired by Jerome Engel of the University of California at Los Angeles with a panel of international experts. The focus is on issues that are more commonly faced in the developing world, but this book also has broader application. You can find this publication on the League's web site (<http://www.ilae-epilepsy.org/visitors/initiatives/>)



as well as on the web site of the WFN (www.wfneurology.org).

The WFN site also has other publications in the Clinical Neurology series that you may find of interest.

Another publication that you may find of interest is the guidelines for epilepsy management published by Indian Epilepsy Society, also available on the Leagues web site (<http://www.ilae-epilepsy.org/visitors/initiatives/>) or the IES (www.epilepsyindia.org).

This announcement is provided as a service to the international epilepsy community to make our members aware of materials that may be of interest to them.

Edward H. Bertram, III, M.D.

Information Officer, ILAE

EUROPEAN EPILEPSY DAY TO TAKE PLACE FROM 2011



Epilepsy is to get its own awareness day across Europe from next year. European Epilepsy Day will take place annually on the second Monday of February. It will be launched on 14th February 2011, the Feast Day of St Valentine, who is reputed to have had epilepsy.

This important event is being created with the support of the International League Against Epilepsy (ILAE) and will be organised through EUCARE (a joint initiative of IBE and ILAE) and the International Bureau For Epilepsy (IBE) European Regional Committee.

The aim of European Epilepsy Day will be to promote epilepsy awareness at regional level through educational and promotional activities. It will send out the right signals to the European Union, where more and more emphasis is being placed on the need for medical and lay associations to work together on initiatives requesting the support of the European Parliament.

A survey of lay and scientific European epilepsy organisations found huge support for the move and planning is now underway to make a large impact politically and in the media across the continent.

"Life in USA"

*"When we were young kids growing
up in America, we were
Told to eat our vegetables at dinner
and not leave them.
Mothers said, think of the starving
children in India
And finish the dinner.'
And now I tell my children:
Finish your homework. Think
of the children in India
Who would make you starve, if you don't. "*

.....Thomas L. Friedman

REPORT ON EDUCATION IN EPILEPSY TO PARAMEDICAL AND NURSING STUDENTS AND STAFF

Reported by: Dr Manjari Tripathi & Staff Sister Nirmal Thakur



Epilepsy is often hidden and because it is so persons having it or caregivers do not seek therapy or support. Often the caregiver does not know how to handle epilepsy or a seizure when it occurs. Surprisingly so this happens even in trained medical and paramedical staff. As a part of this endeavour basic dos and

don ts of epilepsy were included in the CBSE health manual as reported before and now are to be available with the ASHA trainer manual in the National rural health mission booklets. This has been made possible by understanding and cooperation from the health ministry so much so that training of trainers will be imparted by Dr Manjari Tripathi in the NRHM meets held periodically.

The dos and donts of epilepsy and facts and myths are listed and demonstrated specially the safety and recovery position . This is also now to be included in the Life support

manual being bought out by the Trauma centre AIIMS as seizure is a common manifestation in acute trauma. Persons undergoing Life support course will be imparted by demonstration and well as videos on the recovery position, dos and donts and preventive aspects of epilepsy.

This will go a long way in probably reducing the incidence of this disease.

Scope of the training: For all paramedical staff learning the course on Life support offered by AIIMS Trauma centre and the ASHAs training staff.

Participants: Nurses, ASHAs, paramedical staff, caregivers of persons with epilepsy.

Leadership: Dr Manjari Tripathi Asso Prof Neurology, Sister Nirmal Thakur, Dr Tarun Seem Director , NRHM, Shri Amarjeet Sinha NRHM.

Expected result: Training of persons who may witness a person with epilepsy for better first aid and care during a seizure, educating persons about the myths and facts of epilepsy.

Focus of the activity: To bring epilepsy care and education to the forefront.

DISABILITY AND EPILEPSY- BENEFITING THOSE WHO ARE LEFT BEHIND

There are these persons who have epilepsy and are left behind by the society.

Some people with epilepsy do not consider themselves to be persons with a disability. It can apply when a person has frequent seizures which affect mobility, co-ordination, or ability to perceive risk of physical danger, but it is difficult to apply to those in whom seizures are well controlled and no treatment-related side effects occur.

Literature describes epilepsy predisposing to an invisible disability. It is difficult to detect a person living with a seizure disorder without having been told first or having witnessed a seizure. However, regardless of how well their seizures are controlled, many people with epilepsy or a seizure disorder encounter the same attitudinal, environmental and social barriers felt by people with other disabilities.

Epilepsy can be considered a disability because people with epilepsy face barriers similar to those faced by people with other disabilities :

- in getting an education,
- in finding employment,
- in finding housing, and
- in gaining respect from others
- in there ability to find a spouse due to stigma and prevailing myths about this condition.

As with other disabilities, efforts are being made today to increase public knowledge and awareness of the abilities and needs of persons with epilepsy, in order to break down barriers which exist due to lack of understanding and unacceptable mindset and attitudes.

In this direction we at AIIMS when have seen a person with epilepsy for a minimum followup of two years are calculating the extent of disability by seeing the IQ, physical disability and using IDEAS and the seizure burden. The resulting percentage is being used for helping these persons out hopefully reducing the burden and discrimination they face due to this disease.

A National Level Quiz by some one like Siddharth Basu to anchor it.was present at one of the National Epilepsy Day at AIIMs a few years back.

In collaboration with : Dr Ashima Nehra (Asso Prof, Neuropsychology), Dr Manjari Tripathi (Asso Prof, Neurology), Prof Dr Vasantha Padma, (Prof, Neurology), Neuro Disability clinic, AIIMS.

Dr Manjari Tripathi

Associate Professor

NIH Fellow (UCLA)

Department of Neurology, AIIMS

New Delhi

TEACHING PROGRAM FOR EPILEPSY MANAGEMENT IN INDIA

Reported by: Dr S Jain, New Delhi

An Expert Group Meeting to finalize the contents of the teaching program for Epilepsy Management in India was held at Goa from April 2-3, 2010. The Meeting was attended by Drs Gagandeep Singh, Parampreet Singh, Manjari Tripathi, P Sarat Chandra, UK Misra, A Pauranik, Sangeeta Ravat, Jayanti Mani, JMK Murthy, Sita Jayalakshami, R Sridharan, VS Saxena (President IEA-18th IEC Trust & Course Coordinator) and Satish Jain (President IES & Course Director).

Dr VS Saxena Chaired the meeting. He welcomed all the

m e m b e r s a n d apprised the Experts about the role and mandate of the IEA-18th IEC Trust and emphasized that educational activities in regards to epilepsy was an area in which the IEA-18th IEC Trust had always played an important role since its inception in 1992.

The GEMIND was a major achievement of the IEA-18th IEC Trust

in collaboration with the Indian Epilepsy Society (IES) and the present educational program was an extension of the GEMIND. He thanked Abbott for providing an unrestricted educational grant to the IEA-18th IEA Trust for this program. He also thanked the IES for providing the professional help of its members for this important educational activity.

Dr Jain introduced the basic concept of the Teaching Program for Epilepsy Management in India. He discussed the methodology to be followed and requested all the members to give their inputs on the contents of teaching program. The Experts then discussed various aspects one by one in great detail with everyone giving their inputs. It was the consensus that the Teaching Program will essentially be based on the GEMIND and will be of 3 hrs (180 minutes) duration. The teaching module will consist of

4 sessions of 25 minutes each (20 minutes of teaching material with 5 minutes of interaction) and 1 session dedicated to Case studies (50 minutes). There will be a MCQ quiz before and after the teaching sessions (30 minutes) to assess the impact of the teaching program.

The experts felt that in order to maintain uniformity in the teaching, the same slides/videos should be used by all. The 'Course material' will be provided to the participants by the IEA-18th IES Trust at a nominal and subsidized cost. A certificate of attendance will be given to all participants who complete the course. The MCQs can be subjected to

'Error Analysis' for improvement in the course content. There was also a proposal to award suitable prizes and incentives for the trainees who perform particularly well in the MCQs. A core group o f ' T r a i n e d Physicians' could be formed. This could be used for imparting training in future programs. The members felt that we



First row Drs Parampreet Singh, Jayanti Mani, P Sarat Chandra
Manjari Tripathi, Gagandeep Singh, R Sridharan
Sitting A Pauranik, Sita Jayalakshami, Sangeeta Ravat
Vinod Saxena, Satish Jain, UK Misra & JMK Murthi

could also use telemedicine and teleconferencing to enhance the delivery of the teaching material to a larger audience.

Effort will be made to get necessary permissions for credits for the teaching program that could also be used as a teaching module for MBBS, MD students. The teaching programs will be organized by the IEA-18th IEC Trust primarily in cities where there are no medical colleges. A meeting of a sub-group to finalize the course contents was held in New Delhi on 5/6 June 2010. This sub-group consisted of Drs VS Saxena, M Tripathi, P Sarat Chandra, Gagandeep, Parampreet and S Jain.

The meeting came to an end with a vote of thanks to the Chair.

EPILEPSY COUNSELLING CENTRE IN BANGALORE

Reported by: Dr NR Suresh, Bangalore

The Central Government Health Scheme (CGHS) provides comprehensive health care facilities for Central Govt. employees and pensioners and also their dependents residing in CGHS covered cities all over India. Medical facilities are provided through Wellness Centers (previously known as CGHS dispensaries) These Wellness centers form the back bone of the scheme throughout India. In Bangalore, there are 10 such centers located in different parts of city.

Each centre has at least 35 to 40 Persons with epilepsy (PWE) under their care and receiving treatment with uninterrupted supply of anti epileptic drugs; However these wellness centers work from 7.30 am to 1, 30 pm only and most of the time there is heavy rush of other patients, because of which doctors are not able to devote much time for PWE ,who actually need counseling on various issues related to epilepsy.

Keeping this in mind, in order to give value added service to PWE and devote exclusive time for them , we started Epilepsy Counseling Services at our wellness centre ,which works from 7.30am to 7.30pm and the same was inaugurated on 7TH April 2010 on World Health Day ,which received wide coverage through print and visual media. These services are provided once a month on every first Wednesday between 3pm to 7pm to begin with and will be made more frequent in a few months.

Counseling services are offered in following areas:

- Epilepsy & education / school / college
- Epilepsy & sports and leisure activities
- Epilepsy & employment
- Epilepsy & sex / marriage /pregnancy / childbirth / breast feeding
- Any other issues raised by PWE.

These services are not restricted to CGHS beneficiaries only, even outsiders can also avail this service.

counselling



I gratefully acknowledge the encouragement, support & guidance given by Dr HV Srinivas, Dr P Satish Chandra and Dr GT Subhas through Indian Epilepsy

Association, Bangalore chapter which is also giving logistic support in all our activities . I am thankful to Shri Damodar Rao and Ms Deepthi who counsel with great passion and dedication & which has received wide appreciation from our beneficiaries. The lively



interactive sessions arranged by our CGHS Centres with active participation by the neurologists were a huge success.

If other CGHS wellness centers located all over India, start such Epilepsy Counseling Centers with active participation by local branches of Indian Epilepsy Association, it will be tremendous morale booster for PWE under their care and there by contributing to the cause of Global Campaign Against Epilepsy.

EPILEPSY PIPELINE UPDATE 2010



Joyce Cramer, President,
Epilepsy Therapy Project

Reported by: Joyce Cramer

President, Epilepsy Therapy
Project

The Epilepsy Pipeline Update –
2010.

- 11 companies working on devices and hybrids to detect or prevent seizures, some by brain stimulation and others by direct drug delivery into the brain.
- 4 groups described new animal models or genetic approaches to understanding epilepsy treatment period.
- 11 companies described drugs (new molecular entities) or biologics (gene-based treatments)
- 4 companies described early clinical studies with drugs already evaluated for basic safety in humans.
- 7 companies described late stage clinical studies of drugs ready to be submitted to the FDA for regulatory review.
- 6 companies provide updates all of already marketed drugs, including new information about mechanisms of action and potential new indications.

This conference was particularly important in the 2010 environment because most major pharmaceutical companies have greatly reduced or eliminated their basic research programs. Instead, they are relying on venture funds to support start-ups with new ideas. This risk is shifted to investors who win on less than 1 in 10 of their investments. Large companies then pick the winners for something already de-risked.

BIOMARKERS

With the expanding number of available therapies, the next question is how can we predict which treatment (particularly drug) will be appropriate for an individual

patient? Although the electroencephalogram is a physiological biomarker, its use has been limited to differentiating between primary and partial onset epilepsies. The new era of genomics should be leading us toward a match between drugs that work on specific ion channels and patients who have genetic abnormalities for that channel. This new technology allows sophisticated research comparing large numbers of genes, proteins and protein fragments to learn what differentiates affected and non-affected people, as well as responders and nonresponders to treatments. An example of a poorly understood problem is sudden unexplained death in epilepsy (SUDEP) for which neither is a predictor known nor is the mechanism for death understood. Ongoing research in animal studies suggest that potassium and sodium channels occurring in both heart and brain tissue might be at fault. Defects in these channels may be the link between cardiac arrhythmia and SUDEP. Studies in humans are needed to confirm this hypothesis for a rationale for preventing the tragedy of SUDEP. Variance in other ion channels may alter cellular excitability that leads to seizures and epilepsy. Avenues for prediction all seizure susceptibility may come from better understanding of genetic mutations in individuals predispose them to seizures. These markers may be the “path to the pot of gold” that improves epilepsy treatment for millions around the world.

The good news is that although we already have more than 15 approved therapies for epilepsy, so many scientists are continuing to search for new approaches. Today we must ask whether the start-up companies will be able to bring their ideas to fruition, and deliver new therapies to people with epilepsy. Venture capital funds have reduced their investments in early-stage ideas that traditionally move ideas forward. More and more entrepreneurs come to Epilepsy Therapy Project for a grant or seed investment so they can continue developing their idea.

TOPAMAX SETTLEMENT RESULTS IN \$81 MILLION PAYMENT OVER OFF-LABEL PROMOTION

Following whistleblower lawsuits filed against Johnson & Johnson subsidiaries over illegal marketing and promotion for the epilepsy drug Topamax, the Justice Department has reached a settlement of \$81 million with the drug makers.



Ortho-McNeil Pharmaceutical LLC and Ortho-McNeil-Janssen Pharmaceuticals have admitted that they promoted Topamax between 2001 and 2003 for uses that were not approved by the FDA. Under the terms of the Topamax settlement, Ortho-McNeil Pharmaceutical will plead guilty to a criminal misdemeanor violation and pay a \$6.1 million fine. Ortho-McNeil-Janssen Pharmaceuticals has agreed to pay more than \$75 million.

Although Topamax was only approved for treatment of epilepsy and preventing headaches, the medication was promoted for unapproved psychiatric uses. The drug makers had outside physicians join sales representatives when they visited health care providers and spoke at meetings and dinners about prescribing Topamax for psychiatric uses that were not approved by the FDA as safe and effective.

The allegations were brought to the federal government's attention after two individuals filed whistleblower lawsuits under the False Claims Act. As a result of the settlement, whistleblower compensation of more than \$9 million will be paid to the individuals who brought the suits.

Topamax (topiramate) generated more than \$2 billion in annual sales for Johnson & Johnson before a generic version became available last year. Side effects of Topamax have been linked to an increased risk of suicide and suicidal thoughts, which has been added to a black box warning for the medication and other epilepsy drugs. Research has also linked the use of the drug during pregnancy to a risk of Topamax birth defects, such as cleft lips, cleft palates, genital defects and other birth malformations.



MY EPILEPSY DIARY IPHONE APP HELPS PEOPLE WITH EPILEPSY MANAGE SEIZURES, SYMPTOMS AND TREATMENT



The Epilepsy Therapy Project (ETP), an NGO dedicated to accelerating new therapies for people living with epilepsy and seizures and the parent organization of epilepsy.com, released a novel iPhone application called My Epilepsy Diary. It's touted as a "state-of-the-art, comprehensive data-gathering and reporting tool designed to improve epilepsy care," and released as part

of an integrated suite of consumer health tools and information – the Epilepsy Therapy Project Clinical Organizer.

According to the official press release, My Epilepsy Diary goes beyond conventional medication diaries, capturing "comprehensive and multi-dimensional information" which not only helps people with epilepsy, but also their families and physicians. Users can track events and manage epilepsy and treatments together with their healthcare team. Moreover, the app also helps track medications and dosages, and users can even setup email or text reminders to take medications.

Then there's a Personal History module that allows for building of much more detailed profiles, which include non-epilepsy-specific details of the patient's life and health, including familial patterns.

It's great to have a tool like My Epilepsy Diary available. Unfortunately, it's an iPhone thing only at the moment, and I hope ETP will also bring its app to other platforms at some point in the future.

By Dusan Belic

[My Epilepsy Diary \(FREE\) \[iTunes link\]](#)

MORE SEIZURE DRUGS DO NOT EQUAL MORE SIDE EFFECTS



Reviewed by Zalman S Agus, MD; and Dorothy Caputo,

Increasing the number of antiepileptic drugs needed to control seizures does not appear to heighten the risk of adverse events among patients, a cross-sectional survey showed.

Overall, 36.5% of epileptic patients reported having an adverse event, and the rate did not differ significantly according to the number of drugs in the treatment regimen, Emilio Perucca, MD, PhD, of the University of Pavia in Italy, and colleagues reported online in *Epilepsia*.

Nor was there a significant association between the number of adverse events and the antiepileptic drug load ($P=0.16$).

Action Points

According to Perucca and his colleagues, about one-third of people with epilepsy do not have their seizures controlled with medications. Surgery helps in some of these cases, but for the rest, the goal of treatment becomes a reduction in the frequency of seizures with antiepileptics without intolerable side effects.

The researchers questioned 809 patients with refractory epilepsy who were consecutively enrolled at 11 tertiary referral centers in Italy. All were 16 and older (mean age 40.7).



The mean duration of epilepsy was 23.9 years and the median seizure frequency was 2.5 per month.

More than three-quarters (77.7%) had failed to respond to at least three drugs. Less than one-quarter (22.5%) were currently receiving monotherapy, most commonly with carbamazepine, oxcarbazepine, or lamotrigine.

The most common antiepileptics used for polytherapy were levetiracetam, carbamazepine, lamotrigine, oxcarbazepine, topiramate, valproic acid, phenobarbital, and clobazam.

More than one-third of patients reported adverse effects from antiepileptic treatment during an unstructured interview, most commonly somnolence, tremor, memory problems, and visual disturbances. There were similar rates among those on monotherapy and those on polytherapy.

The score on the questionnaire -- which could range from 21 to 84 -- was similar in patients on monotherapy (42.8) and those on polytherapy (42.6).

The antiepileptic drug load was calculated as the ratio of the prescribed daily dose to the average therapeutic dose for all of the drugs taken. The load increased from 1.2 for patients on monotherapy to 2.5, 3.7, and 4.7 for those taking two, three, and four or more drugs, respectively.

There was no correlation between the number of adverse events reported and the antiepileptic drug load.

The study was conducted under the auspices of the Italian League Against Epilepsy (LICE) and the Italian Pharmacological Society (SIF) and was supported by the Italian Medicines Agency (AIFA) within the independent drug research program. One of the study authors was supported by a grant from the CAPES Foundation, Brazil.

Source reference:

Canevini M, et al "Relationship between adverse effects of antiepileptic drugs, number of coprescribed drugs, and drug load in a large cohort of consecutive patients with drug-refractory epilepsy" Epilepsia 2010;

GINKGO MAY INCREASE SEIZURE RISK IN EPILEPTICS

Researchers in Germany suggest the popular herbal remedy Ginkgo biloba be restricted because patients with epilepsy may face an increased risk of seizures.

Eckhard Leistner and Christel Drewke of the Institut für Pharmazeutische Biologie in Bonn, Germany, said that many people use Ginkgo biloba to treat Alzheimer's disease, memory loss, depression, headache, irritable bladder, alcohol abuse, blood vessel blockages, lack of focus and dizziness.

The researchers reviewed Ginkgo studies and found 10 reports that indicated Ginkgo may increase the risk of seizures in those who have epilepsy or that the effectiveness of anti-seizure medications may be reduced. In addition, the researchers suggested Ginkgo may have harmful effects in those who don't have epilepsy, who took raw or roasted Ginkgo seed or drinking Ginkgo tea.

Source : Journal of Natural Products.

MEDTRONIC EPILEPSY DEVICE DOES NOT MEET GOALS - FDA

The Food and Drug Administration said that an experimental implantable device for epilepsy developed by Medtronic (MDT: 44.63, 0, 0%) failed to meet its primary goal of statistically reducing the number of seizures in patients.

Medtronic's device, which is already used in patients with Parkinson's and patients with severe obsessive-compulsive disorder.

The FDA said that the device provided "no statistically significant differences" in seizure-free days during the 90-day blinded phase of the study. Patients, both using an active device and a placebo, both recorded an average of 3.3 seizures a month.

However, there was some reduction in the number of seizures for patients during a longer-term un-blinded study, which is the benchmark that Medtronic wishes the panel to use when determining its effectiveness.

WHEN CLINICAL TRIALS MAKE HISTORY: DEMONSTRATING EFFICACY OF NEW ANTIEPILEPTIC DRUGS AS MONOTHERAPY

Emilio Perucca, Pavia, Italy

Regulatory requirements to demonstrate the efficacy of novel antiepileptic drugs (AEDs) as monotherapy differ between Europe and the United States. European regulators require a comparison with an established, optimally dosed AED, typically using a noninferiority design, whereas the U.S. Food and Drug Administration (FDA) demands demonstration of superiority versus a comparator. Because placebo cannot be used as sole therapy and it is unrealistic to expect that a new AED will



be more efficacious than established agents at full dosages, superiority monotherapy trials in epilepsy have traditionally relied on inclusion of controls treated with a suboptimal (low-dose) comparator. In the most common design, refractory patients are randomized to conversion to monotherapy with a full dose of the investigational agent or

a low-dose active control, and are required to exit the trial if seizures deteriorate. Efficacy is demonstrated when exit rates are lower in the full-dose group than in controls. Although this design is efficient in demonstrating superiority, the use of suboptimal treatments has been increasingly criticized on ethical grounds. A meta-analysis has now demonstrated that patients randomized to suboptimal treatments in all previous trials had similar outcomes, thereby allowing the build up of a dataset of historical controls against which response to investigational AEDs can be compared in future trials. Use of historical controls has been accepted by the FDA, subject to compliance with rigorous methodologic requirements. Although the avoidance of suboptimal treatments in future trials is a welcome development, the conversion-to-monotherapy design is still far from being fully satisfactory and is not exempt from methodologic concerns.

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LACOSAMIDE

UCB announced that the antiepileptic drug (AED) Vimpat[R] (lacosamide) (C-V) demonstrated significantly fewer partial-onset seizures versus placebo in adults living with epilepsy, according to a Phase III clinical study.

This study was one of three that supported the approval of Vimpat by the U.S. Food and Drug Administration (FDA) in 2008 for use as an add-on therapy for the treatment of partial-onset seizures in people with epilepsy who are 17 years and older. Previous studies have demonstrated that Vimpat has a novel mechanism of action. It is available as oral tablets and as an intravenous (IV) infusion to allow for consistent treatment in a hospital setting. Although Vimpat demonstrated clinical benefits at both doses in this study (400 and 600 mg/day), as measured by several efficacy endpoints, the maximum FDA-approved dose is 400 mg/day.

"This and other studies demonstrate Vimpat's established efficacy and tolerability, with almost 3,000 patient years of exposure. In addition, no clinically significant pharmacokinetic drug interactions were observed in clinical trials when Vimpat was used in combination with seven different AEDs as well as several commonly used medications," said James Zackheim, PhD, CNS Medical Director at UCB.

Uncontrolled seizures and medication side effects pose challenges to independent living, learning and employment, and the goal of epilepsy therapy is seizure freedom with minimal side effects. While treatment with one drug is ideal, fewer than half (47%) of newly-diagnosed patients become seizure-free with their first AED.

Source: Epilepsia March 2010.



MORE PROTECTION URGED FOR OFF-LABEL DRUG USERS

Despite research showing that adverse reactions to the epilepsy drug Carbamazepine are very frequent, patients who have such reactions will not qualify for the Department of Health's (DOH) drug relief program because the drug is mainly prescribed by doctors for "off-label" use said, Democratic Progressive Party (DPP) Legislator Huang Sue-ying in Taiwan.

Doctors may legally prescribe drugs off-label if the drug is safe to use and found to be effective in treating a certain condition that it has not yet been approved for. For example, Carbamazepine, which has been officially approved for use in treating epilepsy, is also often prescribed by doctors as a mood stabilizer or pain reliever.

Huang cited statistics from the Drug Relief Foundation, which showed that from 2005 until last year, there were 299 cases of patients who had adverse reactions to drugs but could not receive compensation. Of the 299 cases, 101 (34 percent) were patients who used off-label drugs.

As many as 5 percent of people in Taiwan carry a gene that has shown to increase the risk of developing Stevens Johnson syndrome as a reaction to taking Carbamazepine. As a result, compared with the relatively low rate of white Caucasians who carry this gene, Taiwanese are 30 times more at risk of developing the syndrome in reaction to the drug.

Source: Shelley Huang, Taiwan

NEWS & VIEWS ON DRUGS

AED'S AND BONE DAMAGE

Those on anti-epileptic drugs should include milk in their diet to prevent bone damage as they face a two to six times increased risk of fracture.

A team of researchers from the Sri Venkateswara Institute of Medical Sciences (SVIMS), Tirupati, has found that people on anti-epilepsy drugs show low calcium and vitamin D content in their body and are thus exposed to the risk of fracture. They should have a calcium and vitamin D-rich diet to reduce the risk.

"There is a two to six times increased risk of fracture among people with epilepsy. There is mounting evidence



of anti-epilepsy drug-induced bone changes, particularly with medicines like carbamazepine, phenytoin, phenobarbitone and valproate. Low dietary

calcium accelerates the parathyroid response to vitamin D insufficiency," the researchers pointed out in the study.

The SVIMS team comprising Dr B Mohan, Dr CV Harinarayan, Dr MN Raj, Dr TK Afsana, Dr Vemuri Swapna and Dr G Hima Bindu studied about 350 people with epilepsy and found that low dietary calcium could affect patients in all age groups.

"Our study showed that the diet of all patients with epilepsy was deficient in total calories and calcium. The Indian Council of Medical Research recommends daily dietary allowance of calcium of 400 mg in adults, 1,000 mg in pregnant and lactating women," the researchers pointed out.

Low dietary calcium leads to decreased plasma calcium which triggers secondary hyperparathyroidism (overactivity of parathyroid glands) leading to osteoclast (bone cells) activity and calcium release from bones. With ageing, there is reduced intestinal calcium absorption and increased bone resorption than formation.

Source: Deccan Chronicle, Hyderabad, May 28, 2010

MEMORABLE LEAVE APPLICATIONS !!! In Hinglish

"Since I have to go to my village to sell my land along with my wife , please sanction me one-week leave."

"as I want to shave my son's head ("mundan" ceremony) , please leave me for two days.."

"as I am marrying my daughter , please grant a week's leave.."

"As my mother-in-law has expired and I am only one responsible for it , please grant me 10 days leave."

"Since I've to go to the cremation ground at 10 o'clock and I may not return , please grant me half day casual leave"

"I am suffering from fever , please declare one-day holiday."

"As I am studying in this school I am suffering from headache. I request you to leave me today"

"I am enclosed herewith..."

"Dear Sir: with reference to the above , please refer to my below..."

"My wife is suffering from sickness and as I am her only husband at home I may be granted leave".



IMPROVED MANAGEMENT OF SEVERE EPILEPSY MAY REDUCE TREATMENT COSTS

"Health Care Costs Stratified By Epilepsy Severity In A US Commercially Insured Setting."

Improved treatment of severe epilepsy could reduce the overall cost of the condition, according to research presented at the annual meeting of the International Society of Pharmacoeconomic Outcomes Research (ISPOR) in Atlanta, Georgia.

According to the authors, the annual cost of non-drug treatment of epilepsy increases disproportionately with the severity of the disease, while antiepileptic drug (AED)-related costs remain stable regardless of disease severity.

This analysis indicates that the high cost of treating severe epilepsy is due mainly to the expense of emergency room visits, hospitalizations, and other non-AED related costs.

It follows, therefore, that providing patients with better treatment strategies to reduce the occurrence of seizures - which could translate to fewer emergencies and hospitalizations -- could help keep the overall cost of treatment in check and reduce the financial impact to the healthcare system.

Study details the two-year observational study looked at the U.S. insurance records of 9,163 epilepsy patients who filed at least two claims for AEDs. Total costs of treatment ranged from \$6,000 to \$33,000 USD per year over a two-year period, depending on disease severity, which was rated based on the number of epilepsy-related emergency room visits, with greater than or equal to three visits considered "most severe." Annual costs were categorized as either "AED" or "non-AED" costs. "Non-AED" costs included concomitant medications and "other" costs, such as emergency room visits, hospitalizations, lab and radiology tests, and physician visits.

The study was sponsored by UCB Inc., maker Vimpat(R) (lacosamide) C-V and Keppra XR(R) (levetiracetam) extended-release tablets.

<http://www.prnewswire.com/mnr/vimpat/34012/>

NOCTURNAL SEIZURES



Nocturnal seizures occur in a person while he is in a state of drowsiness or is sleeping during night or day. People may be unaware that a seizure has occurred during their sleep. The occurrence can however be identified by the headache during the day. Nocturnal seizures affect both children as well as

adults.

Nocturnal Seizures Causes

- Head injury or trauma, may even start years after the head injury.
- Intake of alcohol in excess or other toxic substances or drugs.
- An infection of the brain. of [brain tumors](#).
- Brain development defect before birth and hereditary conditions.
- Lead poisoning, meningitis and encephalitis, are some other causes behind such epileptic seizures.
- Due to fever in children are known as febrile seizures.
- Although it is not confirmed, diphtheria-tetanus-pertussis (DTP) vaccine could also be a possible cause.

Nocturnal Seizures Treatment

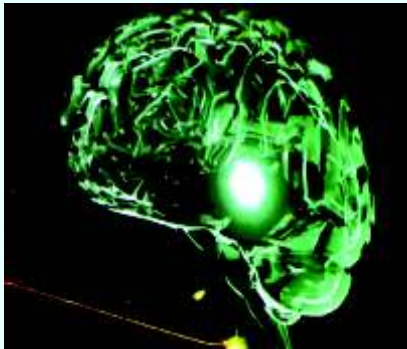
The physicians recommend a sleep study which lasts for a night, in which complete video monitoring of a person's sleep is done. This helps in identifying the type of seizure that has occurred. Afterwards, appropriate medication is recommended. The Anti-epileptic drugs (AEDs), have been successful in preventing nocturnal seizures in patients to a great extent.

Besides epilepsy medication, sleep on a low bed with padded headboards, without pillows, should keep furniture away and keep safety mats next to the bed, should avoid smoking in bed. Also, having a comfortable and stress free sleep is very important. For that, eliminating caffeine from the diet, following certain relaxation techniques and forming a fixed sleeping routine and pattern is very essential.

*Published: Reported by: Aastha Dogra BUZZLE.COM
April 27, 2010*

RESEARCH ON EPILEPSY

UNCONTROLLED BRAIN ACTIVITY LINKED TO EPILEPSY



An American study has shed new light on the mechanism behind epilepsy attacks in the brain.

Neuroscientist Douglas A. Coulter, the co-author of the research study, from The Children's

Hospital of Philadelphia, said: "By better understanding the detailed events that occur in epilepsy, we are gaining knowledge that could ultimately lead to better treatments for epilepsy, and possibly for other neurological diseases.

"Temporal lobe epilepsy, in particular, often resists current treatments." For the research, Coulter and colleagues, collaborated with a team led by co-senior author Philip G. Haydon, of Tufts University School of Medicine.

In epilepsy, excessive signalling between neurons can lead to epileptic seizures. However, glia can regulate those signals. Among the glia astrocytes-the particular focus of this research.

This study shows that changes in astrocytes are key to brain dysfunction and opens the potential for novel therapeutic strategies in epilepsy. The researchers focused on an abnormal condition called reactive astrocytosis, known to occur in many neurological diseases. The astrocytes swell to a large size and change expression levels of a number of proteins. The impact of reactive astrocytosis on brain function is difficult to investigate because it usually occurs in the context of brain inflammation and abnormal changes in surrounding cells.

The researchers solved this problem by using a virus to selectively cause reactive astrocytosis without triggering broader inflammation and brain injury, in a mouse model. They were able to focus on how the altered astrocytes affected specific synapses in neurons in the brain's hippocampus.

Studying the neuronal circuitry in brain slices from the mice, the study team found that changes in reactive astrocytes profoundly reduced the inhibitory control over brain signals. Healthy brain function requires a delicate balance between excitation -- the firing of brain signals -- and inhibition, which limits those signals. Enzyme glutamine synthetase is a key actor in a biological cycle that regulates the balance. The current study found that

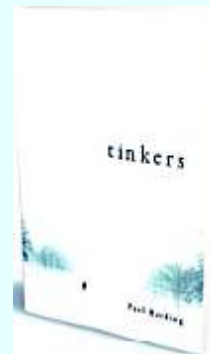
reactive astrocytosis reduces the supply of that enzyme, which in turn decreases inhibition and allows neurons to fire out of control.

In epilepsy, inhibition is not working properly, and uncontrolled signalling leads to epileptic seizures.

Because both disrupted inhibition and reactive astrocytosis are known to occur in other neurologic conditions, including many psychiatric disorders, traumatic brain injury, and neurodegenerative disorders such as Parkinson's disease, our findings may have wide implications." Significantly, the researchers were able to dampen neuronal excitability in the animals' brain slices by adding glutamine, an amino acid that is depleted as a result of reduced glutamine synthetase activity.

Source: Nature Neuroscience.

PULITZER PRIZE FOR EPILEPSY-THEMED NOVEL



Paul Harding has won the 2010 Pulitzer Prize for fiction for his debut novel *Tinkers*. The book has been described as "a powerful celebration of life in which a New England father and son, through suffering and joy, transcend their imprisoning lives and offer new ways of perceiving the world and mortality".

The novel has received a starred review in *Publishers Weekly* and they commented: "Harding's outstanding debut unfurls the history and final thoughts of a dying grandfather surrounded by his family in his New England home. George Washington Crosby repairs clocks for a living and on his deathbed revisits his turbulent childhood as the oldest son of a smalltime traveling salesman [with epilepsy]. The descriptions of the father's epilepsy and the cold halo of chemical electricity that encircled him immediately before he was struck by a full seizure are stunning, and the household's sadness permeates the narrative as George returns to more melancholy scenes".

In a recent interview, the author revealed the background to the story. "My great-grandfather did have epilepsy and left the family when he found out that my great-grandmother intended to have him committed to an asylum. But that is all my grandfather ever told me about it... I tried to keep the epilepsy pretty clinical and the character himself a mystic".

Source: Brainwave, Ireland

SAMSUNG ISSUES HEALTH WARNINGS OVER 3D TVS



By Sonya Bryskine

As the hi-tech frenzy continues over the 3D home theatre TVs, Samsung has released health warnings that may be associated with the new technology.

"If you or any of your family has a history of epilepsy or stroke, please consult with a medical specialist before using the 3D function," said the website warning.

Samsung advises that medical help must be sought if the viewer experiences altered vision, dizziness, muscle twitching, confusion, nausea or convulsions.

"Parents should monitor and ask their children about the above symptoms as children and teenagers may be more likely to experience these symptoms than adults."

Viewing in 3D mode may also cause motion sickness, perceptual after effects, disorientation, eye strain, and decreased postural stability. It is recommended that users take frequent breaks to lessen the likelihood of these effects.

Samsung also does not recommend watching 3D if the viewer is in poor physical condition, need sleep or have been drinking alcohol.

Watching TV while sitting too close to the screen for an extended period of time may damage eyesight. The ideal viewing distance should be at least three times the height of the TV screen.

It is recommended that the viewer's eyes are level with the screen.

REAL-TIME BRAIN MAPPING TECHNOLOGY SHOWS POTENTIAL FOR IMPROVING EPILEPSY AND BRAIN TUMOR PATIENT OUTCOME

Epilepsy surgery may be performed in patients who have seizures associated with structural brain abnormalities, benign brain tumors and cortical dysplasia, malformations of blood vessels, the genetic disorder tuberous sclerosis, and strokes. The goal of epilepsy surgery is to identify an abnormal area of brain cortex from which the seizures originate and remove it without causing any major functional impairment.

In brain tumor surgery, the aim is always to maximize the resection while minimizing the loss of neurological function. Malignant gliomas usually occupy, or are continuous with functional brain tissue, making them difficult to completely resect. The need to preserve functions like language and movement must be balanced with the necessity for maximal tumor resection.

The gold-standard method of determining cortical functional in brain surgery has been electrocortical stimulation (ECS). ECS works by disrupting the normal cortical function to evoke movement or create transient functional disruption.

Researchers at the University of Washington, Seattle, explored the role of broadband electrocorticographic measurement, with the goal of improving the efficacy of brain mapping technology. The results of this study, Real-Time Electrocorticographic Mapping of Eloquent Cortex.

For the motor movements testing, each patient performed repeated opening and closing of the hand for 3-second periods.

Patients were asked to state verbs in response to nouns that were presented. While performing verb generation, primary mouth motor areas were consistently identified, as were areas consistent with Broca's and auditory speech.

The findings were substantiated by ECS in the same patients. Broadband ECoG changes can be captured in real time to identify eloquent cortex. This study demonstrates the existence of a powerful new tool for functional brain mapping in the operative and chronic implant setting and warrants further testing.

Source: (78th Annual Meeting of the American Association of Neurological Surgeons, Philadelphia).

RESEARCH ON EPILEPSY

CHILDREN WITH EPILEPSY FEEL ON PAR WITH HEALTHY SIBLINGS

Parents disagree, may underestimate their quality of life, researchers say



Children with epilepsy view their quality of life as being as good as that of their healthy

siblings, a new study reveals.

The finding suggests that despite the numerous challenges they face in the form of seizures, cognitive and learning disadvantages, social stigma and the effects of medication, children with epilepsy have a far more positive take on their well-being than their parents have.

The study is the result of research conducted by scientists at the University of California, Los Angeles, and led by Dr Christine Bower Baca, a clinical instructor in UCLA's department of neurology.

The research team interviewed 143 children with epilepsy (matching each one to a sibling without epilepsy) and their parents. Interviews were conducted eight to nine years following a diagnosis of epilepsy. Among the children with the condition who were assessed, the average age was 12.

In terms of ranking such quality of life variables as behavior, general health, self-esteem and physical function, Baca and her colleagues found that parents rated their child with epilepsy much lower than their healthy child.

Children with epilepsy, in contrast, felt they were on par with their healthy siblings.

In this regard, parental perception of their epileptic child may be distorted because of their perception that they have a child that is 'sick. Such a distortion could lead to an underestimate of the child's quality of life.

Noting that children and parents may not always share the same concerns, Baca added that children and parents "may draw on different values and perspectives to evaluate quality of life" without realizing it. Getting a handle on these critical differences in perspectives, she said, could be helpful down the road when designing support services for children as they enter adulthood.

Baca and her team reported the findings online in *Value in Health*.

Source: Health day News May 24, 2010 and Epilepsy Foundation, USA

WHAT WILL HAPPEN WHEN THE IPL IS NATIONALISED



1. The new Commissioner of the IPL, replacing Lalit Modi, will be an IAS officer, transferred from the Warehousing Corporation of India
2. Mayawati will however, demand that the new Chairman should be her own candidate, Mr Dalit Modi.
3. The name of Mumbai Indians will immediately be changed to Mumbai Manooos. It will, naturally, field only Maharashtrians (preferably Maharashtrian Brahmins). All other players will have their legs broken. Zaheer Khan will have his house burned down.
4. The Chennai Super Kings team will be renamed Dravida Cricket Kazhagam. Subsequently one faction will break away and the team will split into DCK (DMK) and AIADCK, owing allegiance to Karunanidhi and Jayalalitha respectively
5. Each political party will have its own team: BJP Bantams, Congress Cobras, CPI Cadres, Samajwadi Strikers, CPM Challengers, Trinamul Tigers etc
6. Auction of players will be replaced by teams calling for tenders for players. The lowest priced players will be picked.
7. Cheerleading will be done by speeches by ministers during breaks in the match. Cheerleaders will be replaced by retired Air-India flight attendants who will perform folk dances of the states.
8. Sonia Gandhi will insist that 30% of each team should be reserved for be women
9. Mayawati will demand that SC/ST players will need to run for only 11 yards instead of 22 yards between the wickets
10. Third Umpire requests will have to be filled in triplicate and duly notarized
11. All Third Umpire decisions will be referred to a Joint Parliamentary Commission.
12. IPL matches will be shown only on Doordarshan. on the day following the match, from 4 a.m. to 7.30 a.m. or from 3.30 a.m. to 7p.m, subject to satellite link-up availability
13. Between each innings break Doordarshan will telecast the news in Hindi, followed by news for the hearing impaired.
14. Pakistan will immediately announce its intention to start its own version of the tournament called PPL and Mr Zardari will make a visit to Washington to meet President Obama and seek an additional grant of \$1 billion to fund it

EPILEPSY AROUND THE WORLD

AUSTRALIA



'Boo hoo' says booted backbencher

A Queensland politician has been booted out of parliament and banned for a week after repeatedly

interrupting a speech promoting awareness about epilepsy.

Outspoken opposition MP Rob Messenger was kicked out of the chamber after interjecting during a speech by state health minister Paul Lucas, who [recently revealed he suffered from the disorder](#).

Speaker John Mickel warned Mr Messenger to stop interrupting several times, before deciding to kick him out until the beginning of parliamentary question time.

MPs then voted along party lines to remove the vocal backbencher for a full week.

The incident comes two months after Mr Lucas revealed an [epileptic seizure](#) had been behind his admission to a hospital.

"I have sympathy for Mr Lucas's epilepsy and others who have epilepsy; however I have more sympathy for the parents who have obviously through no fault of their own been put through a horrific set of circumstances," he said.

Mr Lucas said he was "extremely disappointed" with Mr Messenger's interjections - not because he personally had epilepsy but because the MP was overshadowing efforts to raise general awareness of the condition.

DANIEL HURST, brisbanetimes.com.au

GHANA



A conference on Community Mental Health opened in Accra to empower people with mental illness and epilepsy and their primary care givers.

The conference focuses on increasing the role of users in

Community Mental Health. Mental users are people who have experienced mental illness or epilepsy. It will strengthen existing partnerships and new ones will be established to achieve a greater impact on sustainable development.

It is expected that decisions reached from the conference will benefit people with mental illness and epilepsy in Ghana and Nigeria.

The Minister of Employment and Social Welfare, Enoch Tei Mensah noted that, stigmatization is one of the major challenges facing people with mental problems, adding that, there is the need to discuss mental health issues on various social platforms to educate people on mental health and its associated problems.

The out-going Chairman of the Parliamentary Select Committee on Health and the Deputy Minister of Water Resources, Works and Housing, Dr Mustapha Ahmed called for the review of the mental health law. He noted that since the law is outmoded, it is unable to capture the needs of mental health users.

He stated that the Parliamentary Select Committee has discussed the draft bill with the Minister of Health which will soon be sent to cabinet.

The Chief Psychiatrist at the Psychiatric hospital, Dr Akwasi

Osei said the absence of mental users in the formulation of government policies concerning mental health is wrong since they should have a say in determining their needs.

He attributed the delay in the passage of the Mental Health Bill into law to the lack of a strong user group to advocate and push the bill to parliament.



EPILEPSY AROUND THE WORLD

HONG KONG

Out of court settlement for British journalist



A Hong Kong hospital has reached an out of court settlement with a British journalist whose Malaysian-born wife died suddenly

after suffering an epileptic fit at the hospital 10 years ago.

The final settlement approved by the High Court of Hong Kong on March 31, was expected to be "substantial", said Martin Jacques who is the author of the international bestseller *When China rules the World*.

"After 10 years of refusing to admit that anything went wrong, the hospital caved in and as desperate to settle just a fortnight before the trial was to begin," Jacques said in an interview. His wife Harinder Veriah, who was admitted at Rutthonjee Hospital after suffering an epileptic fit on Jan 1, 2000, died the next day.

Jacques insisted that clinical negligence was responsible

for her death as she had complained to him about being at the "bottom of the pile" in the hospital.

He added that he did not feel jubilant about the settlement but it was some semblance of justice for his wife's death. "Money is money. It is not Hari's life. It can't bring her back," said Jacques. It does not go away but I have learnt to live with it."

He added that their now 11-year-old son, Ravi, was doing well and adjusting well despite his mother's absence while growing up.

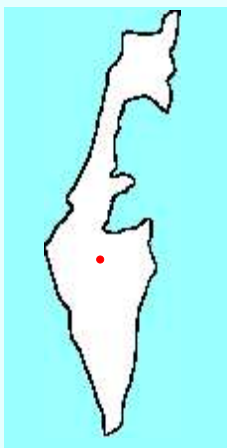
"He is aware of his loss although his mother died when he was only 16-months-old."

The boy placed a plaque at a tree that the father planted at Veriah's grave three ears ago that said 'I have cried many times in the night for you. I miss you.

The coroner, Dr Stephen Chan, overturned the natural causes verdict, saying that serious questions had to be raised about the quality of care she received at the hospital.

ISRAEL

Witches do not cause epilepsy



By JUDY SIEGEL-ITZKOVICH

National epilepsy center in Beersheba seeks to change the stigma around epilepsy.

Alexander the Great, Julius Caesar, Napoleon Bonaparte, Leonardo da Vinci, Charles Dickens, Vincent van Gogh, Thomas Edison and Agatha Christie were known for their talents and accomplishments – not for the fact that they suffered from epilepsy.

And people today also prefer that they get credit for their achievements and not for their having this neurological condition which affects one in 100 children and 100 to 150 adults.

That is probably the main reason why – out of the 60,000 patients here – only a small fraction are members of EYAL, the Jerusalem-based Israel Epilepsy Association (www.epilepsy.org.il). They don't want to suffer from the

millennia-old stigma attached to its neurological attacks that may be accompanied by frothing at the mouth and used to be regarded as a sign of mental illness or being "bewitched."

Because of this stigma, Soroka University Medical Center



opened the Anita Kaufmann Epilepsy Education Center in 2004. Funded with money left by Kaufmann, a US lawyer who developed epilepsy after suffering a severe fall at 14 and died in 2003, the Beersheba center serves the whole country. It was set up by social worker and physiotherapist Galit Greenberg and continues to function with support from Kaufmann's parents, who live in New Jersey .

EPILEPSY AROUND THE WORLD

KENYA



By ALEX NDIRANGU

Epilepsy: Beyond the stigma, fear and social myths

Paul Kioi, chairman of the Kenya Society for Epilepsy and a neurologist, says great care should be taken at birth to ensure the child does not develop debilitating conditions later in life.

"Epilepsy is one of the conditions that many people pick at birth, yet it is preventable," he says.

"The younger the brain, the more likely it is to develop epilepsy since the cells are still developing."

Child bearing and certain physical activities and sports that you involve your children in could predispose them to epilepsy.

Birth, in particular, can lead to oxygen inhibition in the child's brain, which could lead to epilepsy later on.

Injuries to the head, especially through falls and accidents, are other causes of epilepsy.

Prof Kioi says 75 per cent of all epilepsy occurs to children and people below 20 years.

"The younger the brain, the more likely it is to develop epilepsy since the cells are still developing," he says.

The disorder, in the majority of patients, goes into remission before adulthood.



Karyn Aussems, the executive director of Youth on the Move — an epilepsy awareness group — says the public should broaden its understanding of the condition and thereby reduce the stigma faced by sufferers.

Kennedy Ochieng, who lives with epilepsy, says: "My parents recall a serious head injury when I fell from a tree in our compound. I was three years old."

NEPAL



Khagisara comes from a poor village in Nepal's Surkhet District and

suffers from epilepsy. In the past her family have taken her to a witch doctor for treatment. She recently had an epileptic fit while she was alone preparing food and fell into the kitchen fire, burning both her legs severely. Some

time later her mother-in-law found her and pulled her from the fire, saving her life.

Treatment was not possible in the village. It took her family three days to raise a loan equivalent to US\$275, enabling them to transport her to Bheri Zonal Hospital in Nepalgunj and buy medicines. The money was used up within a week. However, Bishnu Bhattarai, the INF patient advocate at the hospital, was able to help Khagisara and a carer with money from an INF 'poor fund', enabling them to have the food and medicines needed for recovery.

EPILEPSY AROUND THE WORLD

UK



Cameron 'almost gave up politics when son Ivan died'

David Cameron on the death of his son Ivan - Clip courtesy ITV

Conservative Prime Minister David Cameron has admitted he almost gave up politics after his son Ivan died last year.

Mr Cameron thought "to hell with everything" after the death of the six-year-old, who suffered with epilepsy and cerebral palsy.

But he realised that, "bit-by-bit, you've got to get on with your life", he added.

His son's illness had given him an "enormous spiritual connection."

'Great gift'

Asked if he felt like "packing it all in" after Ivan's death, Mr Cameron, whose wife Samantha is pregnant with the couple's fourth child, said: "Yeah, to start with I thought.

"You do, it's just such a shock you can't really come to terms with it to start with.



David Cameron

But, bit by bit, you start to think, 'Well, I need to get on with my life'. And to me my life is politics, it's public service, it's what I do, it's being a Member of Parliament, it's wanting to make a difference. That's what I want to do.

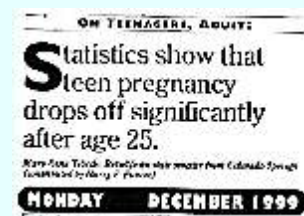
"And the first person who says this to you, you actually want to thump them because you think, 'You have no idea how tough this is, looking after a child who can't walk or talk and has to have 24-hour care and is on huge amounts of medicines and has unbelievable, painful epileptic fits'.

"But after a while you do realise that it is a great gift and that this person is bringing great joy and happiness to your family."

SOME HEADLINES AROUND THE WORLD



What goes around comes around!



I would have guessed 20.

Utah Poison Control Center reminds everyone not to take poison

*Children Act Fast, So Do Poisons is the theme for National Poison Prevention Week, arch 26 - 26. The Utah Poison Control Center (UPCC) would like to take the opportunity to remind everyone giving or taking medicine. Check the dosage each use. * Avoid taking medicine in front of children. * Never refer to medicine as candy.

This one says it all.

County to pay \$250,000 to advertise lack of funds

Lane County will spend up to \$250,000 this year publicizing its tight financial picture, in hopes that voters in November will approve higher taxes for public safety services. It's an amount for county spending on publicity that has been unparalleled in at least the past 10 years. And it's

Did we elect these people?

Federal Agents Raid Gun Shop, Find Weapons

State Observer Arrested Previously

What are the odds?

Ten Commandments Supreme Court says some OK, some not

The Supreme Court has ruled that some of the Ten Commandments are constitutional, while others are not. The court's decision is a landmark ruling in the ongoing debate over the role of religion in public life.

I didn't know we could choose.



Please, anyone, if you've seen this man . . .



I'm saying GREAT paint job.

FORTHCOMING EVENTS

☞ 10th & 11th July 2010

WORKSHOPS ON EPILEPSY AND EEG



Department of
Neurology,
Neurosciences
Centre



All India Institute
of Medical Sciences

Ansari Nagar, New Delhi - 110029,
INDIA

Dear Friends,

It gives us great pleasure in announcing the forth coming "WORKSHOPS ON EPILEPSY AND EEG" to be held by the IES, BIANNUALLY at AIIMS, CMET department AIIMS- for EEG and Epilepsy, **after the success of the fourth such in January 2010, the fifth one is slated on 10th and 11th July 2010.** The workshops aim at a hands on training on EEG and epilepsy and are planned to be highly interactive and an excellent learning experience for students/ residents/ technicians dealing in EEG and epilepsy. The workshops will be certified on EEG training by the IES and will provide an excellent platform to learn basic and advanced EEG. The registration is limited to 30 participants to enhance one to one interaction. It is free and early come early served. Outstation participants will have to arrange their own accommodation.

Dr. Manjari Tripathi

Workshop Director , Associate Professor
Department of Neurology, Room No 705,
Neurosciences Centre
All India Institute of Medical Sciences
New Delhi, India, 110029.
Tel: 26594494 (O), 26123446 (R),
9868398269/ 9868225507 (M)
Email: eegepilepsyaiims@gmail.com



☞ 1st -4th August, 2010



CATAGENA
1-4 August 2010

6^o Congreso Latinoamericano de EPILEPSIA

6th Latin American Congress on Epilepsy
(6th Congreso Latinoamericano de

Epilepsia), Cartagena. The congress is held under the auspices of the International League Against Epilepsy and the International Bureau for Epilepsy.

There will be interaction between colleagues and the presentation of recent research. The ALADE (Academia Latinoamericana de Epilepsia de la ILAE) didactic courses and the discussion groups will have a more practical focus.

Cartagena de Indias is a UNESCO World Heritage Site and marvel at its splendid colonial architecture, its colourful streets and the welcoming character of its people.

Drs Carlos Acevedo, Manuel Campo, Daniel Nariño



☞ 3rd - 5th September, 2010

Welcome to AESC 2010 Taipei

Dear friends,

Asian Epilepsy Surgery Society and



the Organizing Committee of the 4th Asian Epilepsy Surgery Congress would like to extend warm welcome for the upcoming meeting.

In the past three years, we had successful meetings of the Asian Epilepsy Surgery Society held in Korea, China and Japan. In the 4th AESC, our scientific program will reflect the conceptual revolution in epilepsy surgery and will cover a whole spectrum of epileptology issues, including presurgical evaluation, microsurgical surgical technique and outcome assessment.

Yang-Hsin Shih, M.D.

Professor and Director, Neurological
Institute
Taipei Veterans General Hospital, Taiwan
President, 4th Asian Epilepsy Surgery
Congress



☞ 3rd - 7th December, 2010

The American Epilepsy Society Annual Meeting is the premiere meeting for epilepsy and other seizure disorders. The



Annual Meeting is an international forum for the exchange of current findings in epilepsy research. Information is communicated and disseminated through symposia, lectures, scientific exhibitions, poster and platform presentations.

The Annual Meeting attracts attendees from all over the world and provides educational and networking opportunities for the academic and practicing neurologist, epileptologist, neurophysiologist, neuroscientist, neurosurgeon, internist, pediatrician, pharmacist, nurse, social worker and other professionals.

Annual Meeting: December 3-7, 2010
Location: San Antonio, TX



☞ 25th - 27th February, 2011

ECON 2011

Pre Conference Workshop and 12th Joint Annual Conference of Indian Epilepsy Association and Indian Epilepsy Society at Hotel Life,



Ludhiana. Organising Secretary:
Gagandeep Singh, Department of
Neurology, Dayanand Medical
College, Ludhiana, 141001, Punjab,
India; Tel: +919915554561
Fax: 0161-2308383; e-mail:

econ2011@econ2011.in ; Website:
www.econ2011.in



FORTHCOMING EVENTS

📅 **25th - 27th August, 2010**

12th European Conference on Epilepsy and Society
Porto, Portugal

On behalf of the Organizing Committee, we are pleased to invite



you to Porto to attend the 12th European Conference on Epilepsy & Society taking place from 25th to the 27th of August 2010. The conference aims to inform people with epilepsy and their families, as well as those working in the field of epilepsy about new developments in epilepsy treatment, associated cognitive dysfunction related to epilepsies and the psychosocial implications that derive from this common brain disorder and, of course, to provide solutions. The theme of the conference is "Epilepsy... so what?". Above all, this meeting will facilitate

communication and exchange of ideas among people with epilepsy and professionals in the field right across Europe. The programme includes morning plenary sessions and afternoon discussion groups with as large as possible participation by delegates. Special emphasis is being placed on Posters, so we would encourage you to prepare your latest work for submission. We are also planning a special Youth Session and a musical Karaoke event.

We look forward to welcoming you to the attractive city of Porto for what is going to be an excellent gathering of wonderful people. In this way we believe we will not only increase our knowledge and understanding of epilepsy but we will also fulfill the goals of the International Bureau for Epilepsy.

For more information, please log on to www.epilepsyandsociety.org

📅 **21st - 24th October, 2010**

8th Asian & Oceanian Epilepsy Congress - Melbourne, Australia

Melbourne has been selected as the venue for the 8th Asian and Oceanian Epilepsy Congress. This will be the first IBE/ILAE congress to be held in Australia after the 21st International Epilepsy Congress held in Sydney in 1995.

The second announcement is already available on website. There will be a special programme for people with epilepsy and their carers during the congress.

Send Abstract before 4th July 2010

For further information or to receive a copy of the programme.

Contact: melbourne@epilepsycongress.org



Registration Fees

	Early Registration (On/Before 9th July 2010)	Late Registration (10th July to 8th October 2010)	On-site (From 21st October 2010)
Senior	US\$ 300	US\$ 350	US\$ 400
Trainee / Non Physician*	US\$ 150	US\$ 175	US\$ 200
Subsidised Registration**	US\$ 150	US\$ 150	US\$ 150
Accompanying person	US\$ 100	US\$ 100	US\$ 100

INDIAN EPILEPSY ASSOCIATION



GOVERNING COUNCIL 2009- 2011

Dr Pravina U Shah	President	(2009-11)
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Dr V S Saxena	Editor	(2009-13)

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INDIAN EPILEPSY SOCIETY



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Secretary General-IEA	Ex-officio Member	2010 - 2012

In partial seizures

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Vinlep™

Oxcarbazepine 150, 300 & 600 mg tablets

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A winning start in newly diagnosed patients



High seizure free rate¹

- At 1 year, 72.2% patients achieved complete seizure freedom¹



1. G. Pauletto, Seizure 2006; 15, 150-155.

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Oxcarbazepine Tablets VINLEP™

COMPOSITION: Vinlep 150, 300, 600: Each film coated tablet contains Oxcarbazepine IP 150mg, 300mg, 600mg respectively. **INDICATIONS:** Monotherapy and adjunctive therapy in the treatment of partial seizures (which include seizure subtypes of simple, complex and partial seizures evolving to secondarily generalized seizures) in adult patients. Adjunctive therapy in the treatment of partial seizures in children aged 4-16 years. **POSOLGY AND METHOD OF ADMINISTRATION: Adults and elderly patients:** Monotherapy and adjunctive therapy - Treatment should be initiated with a dose of 600 mg/day (8-10 mg/kg/day) given in 2 divided doses. Good therapeutic effects are seen at doses between 600 mg/day and 2400 mg/day. Dose may be increased by a maximum of 600 mg/day increments at weekly intervals. **Children:** In adjunctive therapy, Vinlep should be initiated with a dose of 8-10 mg/kg/day given in 2 divided doses. Dose may be increased by a maximum of 10 mg/kg/day increments to a maximum daily dose of 60 mg/kg/day. **Hepatic impairment:** No dosage adjustment in mild to moderate hepatic impairment. Caution when dosing in severely impaired patients. **Renal impairment:** Vinlep therapy should be initiated at half the usual starting dose (300 mg/day) and increased slowly. **CONTRAINDICATIONS:** Hypersensitivity to the active substance or to any of the excipients. **SPECIAL WARNINGS & PRECAUTIONS FOR USE:** *Hypersensitivity* - Drug should be discontinued and alternative treatment started. *Dermatological effects* - includes Stevens-Johnson syndrome, toxic epidermal necrolysis and erythema multiforme. Median time to onset was 19 days. Discontinue Vinlep and prescribe another anti-epileptic drug. *Hyponatraemia* - In patients with pre-existing renal conditions associated with low sodium or in patients treated concomitantly with sodium-lowering medicinal products, serum sodium levels should be measured prior to therapy, thereafter two weeks and monthly intervals for first three months. Patients with cardiac insufficiency and secondary heart failure should have regular weight measurements to determine occurrence of fluid retention. In case of fluid retention or worsening of the cardiac condition, serum sodium should be checked. Patients with pre-existing conduction disturbances should be followed carefully. *Hepatic function* - Discontinue Vinlep in case of suspected hepatitis. *Hematological effect* - Discontinue drug if significant bone marrow depression develops. *Hormonal contraceptives* - Treatment with Vinlep may render the contraceptive ineffective, non-hormonal forms of contraception are recommended. *Alcohol* - Possible sedative effect, exercise caution. *Withdrawal* - Withdraw gradually to minimize potential of increased seizure frequency. **PREGNANCY & LACTATION:** Potential benefits must be carefully weighed against the potential risk of foetal malformations. Minimum effective dose should be given. Monotherapy should be administered. Folic acid supplementation recommended during pregnancy. Vitamin K1 should be administered as a preventive measure in the last few weeks of pregnancy and to the newborn. Vinlep should not be used during lactation. **UNDESIRABLE EFFECTS:** The most commonly reported adverse reactions are somnolence, headache, dizziness, diplopia, nausea, vomiting and fatigue occurring in more than 10% of patients. **For full prescribing information, please write to:** Sanofi-Synthelabo (India) Ltd., 54/A, Sir Mathuradas VasANJI Road, Andheri (East), Mumbai - 400 093, India. Source: Vinlep PI dated March 2009. Date: March 2009.

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