



EPILEPSY INDIA



INDIAN EPILEPSY ASSOCIATION & INDIAN EPILEPSY SOCIETY

N e w s l e t t e r

October - December 2011

Issue 4, 2011

50 Years

The Spark that Lit the Flame



Dear Friends,

Golden Jubilee of IBE at Rome 2011

IBE chose to go back to Rome for its Golden Jubilee celebration as it was founded in this City in 1961. Rome The Eternal City is one of the most popular tourist destinations for its historical sites and architectural marvels. The city is also internationally recognized as a prime art and cultural centre unique and typical characteristics and architecture.

It was not surprising that our Congress also attracted more than 4000 delegates from over 50 countries. Just as Rome was not built in a day, seeing and experiencing all its enticements and offerings is no minor feat.

The Mayor of Rome alluded to a painting *Transfiguration* by Raffaello which showed enlightened Christ over the darker lot of a person possessed of demon. The painting depicts that after the unsuccessful attempts of the Apostles, Transfigured Christ frees the boy of his plight possibly epilepsy.

The Congress commenced with a slick and smooth inaugural function highlighted by a short film on Rome done by the noted film director Franco Zeffirelli - remember his lyrical *Romeo and Juliet* but more on it later.

The delegates had a great musical evening organised in Auditorium Conciliazione, the location of the 1961 inaugural meeting of IBE. The military band La Banda dei Carabinieri plumed in the most attractive attire were conducted scintillatingly by Ten Col Massimo Martinelli. The musical tradition ranged from George Bizet's *Carmen* to Giuseppe Verdi's *Aida*, Italian classics such as *O sole mio*, *Mattinata*, *Volare*, and even modern American classics like *New York New York*. (I would have loved to listen to *Al Di La* or *An evening in Roma* as well).

There was a special dinner for all the Ambassador award winners since inception who could be present in Rome. Nearly ninety attended this dinner and were given a special commemorative pin. This function and some more celebratory events were organised by the Immediate Past President Ms Susanne Lund, Sweden.

The fifty-year history was complied in a volume by Ms Hanekke de Boer. Important landmarks were converted into a Milestones exhibition.

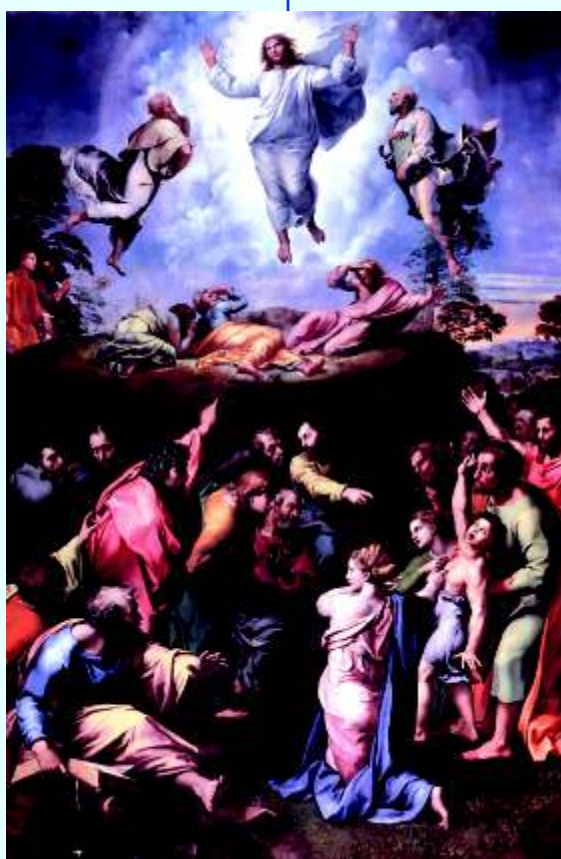
Many were not been able to get over the short film made as a travelogue for Rome by Franco Zeffirelli. The film

beautifully brought out the city's old heritage and historicity through ages and monuments.

St Peter's Basilica, Fountain of Trevi, Barberini's city sculptures and fountains in Piazza Navona and above all examples of Michelangelo's all round genius whether it was the construction of St Peter's, its staircase or immortal masterpiece sculptures like *Moses* or *Pieta*, the latter according to cognoscenti may be considered the most evocative statue in the world. No wonder the film highlighted *Pieta*. There was the resounding finale of Andrea Bocelli's operasinging.

The short film combined the artistic wonders of yore with

lyrical addition of modern films like *La Dolce Vita* (Frederico Fellini); the famous scene in Trevi Fountain where a statuesque Anita Ekberg goes into a trance with Marcello Mastroianni following like a zombie. Zeffirelli felt and we all agree that, Rome can be enjoyed no better than by watching the film *Roman Holiday*, *Cinderella* in reverse story directed by William Wyler. This is an all time classic with Audrey Hepburn as the European princess and Gregory Peck as the American press reporter. Some of the mood evoking scenes were beautifully reprised.





The incognito princess taking off on a Vespa scooter down Corso Vittorio Emanuele, Audrey was at her innocent best.

The other famous scene was at *Bocca della Verita*, the Mouth of Truth where the legend is that if you're given to lying, you put your hand in there, it'll be bitten off.

The reporter seems to feign his hand has been bitten off (given as he was to "gold-plated, triple-decked, star-spangled lies").

The resulting shriek from the Princess is said to have been completely natural and unrehearsed as she was never informed about the scene.



The ending of the film in front of the assembled press has never been equalled for its ultimate bitter-sweet quality. When asked to compare various capitals she visited, she exclaims at first with diplomatese "Each in its own way was unforgettable. It would be difficult to..." but later with the slightest hint of a quiver on her face "...Rome, by all means, Rome. I will cherish my visit here in memory as long as I live."

Her wonderful acting won her all the awards Oscar, Golden Globe, New York Film Critics and BAFTA, perhaps the only time one actress won all these awards in the same year. She, her director and her film rate in the top 10 in each of the respective categories of all time world's great movies. The film has been widely copied (*Chori Chori* 1955, memorable for its music and little else), but originals remain originals.

And at the end of your trip, when you're asked about your favourite part of your Italian visit, you may also echo the words "Rome. By all means Rome."

I wish all readers happy celebrations during the coming festivities.

Dr VS Saxena

Editor

NEWSLETTER OF INDIAN EPILEPSY ASSOCIATION & INDIAN EPILEPSY SOCIETY

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29th INTERNATIONAL EPILEPSY CONGRESS, ROME, 28 AUGUST-01 SEPTEMBER 2011

Report by Dr VS Saxena while at Rome

29th International Epilepsy Congress took place from 28th August to 01 Sept 2011 in Rome. It attracted more than 4000 delegates the highest number since the last two congresses. Marriott Rome Park Hotel the largest venue available for such meetings in Rome appeared invaded with not a spare nook available in lobbies, exhibition hall, lecture rooms. Its location far from the city indirectly helped holding delegates to the site. But you really couldn't hold back the determined from exploring all the history, art and culture of this arguably the most visited tourist city in the world.

For all of us in IBE, it was a landmark event as we assembled to celebrate the Golden Jubilee of the Bureau founded as it was in Rome in 1961. This meeting is recorded to have taken place in Auditorium Conciliazione just across St Peter's Basilica. This auditorium was used for a delightful military band performance on 30 August. (see Edit). The grand finale of the jubilee function was when Mike Glynn President IBE cut a ceremonial cake during the General Assembly on 31 August.

Welcome message from the Mayor of Rome

The Mayor of Rome welcomed the delegates with a message that alluded to Raffaello's work in Vatican City titled 'the Transfiguration' which probably described the plight of the then patients with epilepsy, shown in darker hue with the transfigured Christ in the lit part of the painting.

The Opening Ceremony was to the point and with short and crisp speeches by the Presidents of IBE, ILAE, Organising Committee and the Congress Director Prof Emilio Perruca who let the emotion get the better of him on successful culmination of a task so well delivered. The much awaited Awards presentations came towards the end. Of course, with the absolutely delightful short film on Rome by Zeffirelli.



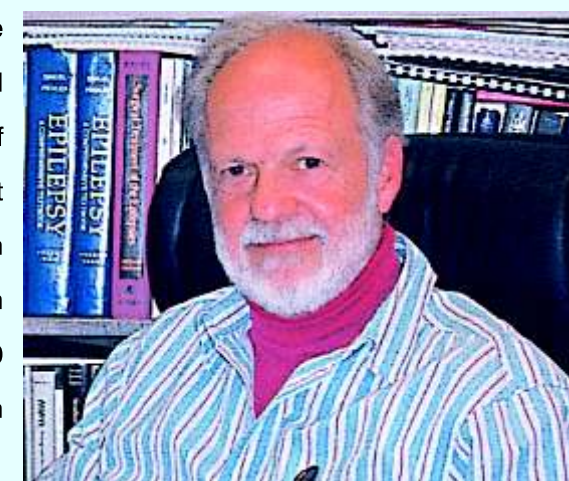
Mike Glynn cutting ceremonial cake with IBE Executive



Carabinieri Band with their Conductor

Lifetime Achievement Award

Lifetime Achievement Award is the highest award given jointly by IBE and ILAE. This year it was awarded to Prof Jerome Engel Jr of USA. A great recognition of his signal contributions in the field appreciated far and wide through the world and as he said by over 500 others who either worked or trained with him and spread through the world.



Social Accomplishment Award

Social Accomplishment Award had special significance for us in India as Dr Pravina U Shah, Mumbai was chosen for this honour (please see Issue 3, 2011). She was recognised for her past contributions as also her constant involvement with social activities in her Chapter and for being an inspiration to her Chapter as well as others to follow her selfless service to the PWEs.



Apart from these two very popular choices, there were 12 Ambassador Awards given this year.

29th INTERNATIONAL EPILEPSY CONGRESS, ROME, 28 AUGUST-01 SEPTEMBER 2011

Honouring Ambassadors for Epilepsy -Celebrating 50 years of IBE.

Though without any monetary value the awards given jointly by IBE and ILAE are highly treasured by those who receive it and those who aspire to get one!



The awards were first proposed by Mrs Ellen Grass the then IBE President in 1968 to honour exceptional contributions to international epilepsy movement. The list of recipients is a virtual Who's is Who of epileptology with names such as Burden, Dreifuss, Gastaut, Mani, Bharucha, Loeber, eBoer, Meinardi, Engle roll out of the 296 so honoured from 46 countries in the past 43 years. India has contributed 7 namely Drs Eddie Bharucha, KS Mani, VS Saxena, MC Maheshwari, S Jain, MM Mehndiratta and Ms CD'Souza.

During the Rome meeting there was special dinner for the Ambassadors wherein two from India attended. It was a delightfully relaxed convivial occasion as nearly ninety Ambassadors from two dozen countries had themselves photographed separately from different periods and then in one whole group of

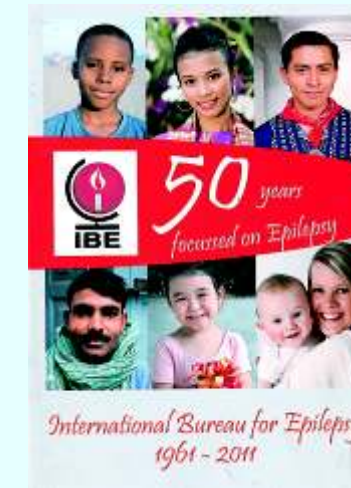
those who could be present in Rome.

There were 12 new Ambassadors this year :

Ms Susan Axelrod, (USA), Dr Hasan Aziz (Pakistan), Dr Lionel Garmant, (Canada), Dr Jaime Fandino (Colombia), Dr Andres Kanner (USA), Dr Weiping Liao (China), Dr Wolfgang Loscher (Germany), Dr Eli Mizrahi (USA), Dr Rosey, Panelli (Australia), Dr Asla Pitkanen (Finland), Dr Steve Schachter (USA) & Dr Walter Van Emde Boas (Netherlands)



50 Years focussed on Epilepsy IBE 1961-2011



Looking Back and Gazing Forward-A condensed history of IBE's first 50 years-compiled by Hanneke M deBoer

The history of IBE was brought in with the problem of epilepsy as faced by over 50 million people around the world.

Epilepsy is responsible for high level of suffering and despite effective treatment being available there is still a wide treatment gap and deep social stigma. Much may have changed in the past 50 years since IBE was formed but at the same time much more needs to be done to address fresh issues.

The first secretary general of IBE, George Burden was elected to this post in 1961 in Rome. Older members of IEA would recall that he visited India more than once during late

60's. The first time he came perhaps coincided with the formation of an Epilepsy Section under the umbrella of Neurology Society of India. He may have even influenced the formation of IEA in 1971 and then later helped IEA to be affiliated with IBE in 1974.

The book records that ever since 1961, there was a general consensus with which IBE and ILAE both worked together. By 1973 it was decided to revise their respective Constitutions so as to accommodate their Presidents and Secretary-generals on each others' boards. This practice continues in a constructive and a harmonious manner. Till date both organisations have at least one annual joint meeting to keep abreast of each other's decisions which impact epilepsy movement. I bear personal testimony to this extremely coordinated relationship in the past few years.

In July 2007 was given the status of an NGO with Special Consultative Status on Economic and Social Council (ECOSOC) of the United Nations affording it a place in council meetings, present reports and be in a position to influence issues related to epilepsy.

IBE runs a special membership drive and has currently 126 members from 93 countries in the WHO designated 7 regions.



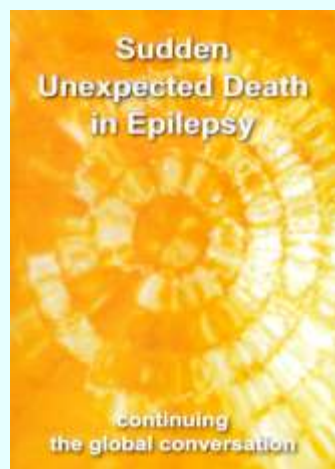
29th INTERNATIONAL EPILEPSY CONGRESS, ROME, 28 AUGUST-01 SEPTEMBER 2011

Scientific programme

There were nearly 900 Abstracts in 14 categories received from the delegates. These Abstracts are available on the Congress website. Fifty-five of these abstracts were selected for platform presentations and the rest were put up as Posters. The poster section was very popular as the content was scientifically first rate and the display area very good and spacious. The other popular sections were Teaching Programmes, Workshops, How to Series and Case-Oriented Learning Series and Video Sessions.

The unique feature was **close integration of scientific and social issues** often faced by the professions and PWE or their carers. Interesting topics were “**When do you consider epilepsy cured?**”, “**Impaired consciousness in epilepsy**”, “**Epilepsy during puberty, the wonder years**”, “**Older slowing down and seizing up-epilepsy strikes again**”, “**Challenges in developing new approach in classification of epilepsy**.”

“Avoiding epilepsy deaths”



Over the years studies have shown that PWE have shorter life span with 2-3 fold increase in mortality and 24 fold increase in SUDEP. It has been reported that at least 1 in 100 PWE per year may get SUDEP. This symposium aimed to establish ways prevent unnecessary deaths and suing research to find cause and cure for SUDEP.

JP Leach (UK) called these as 'deaths in the shadows'. The known economic cost was US\$69,000 due to unnecessary seizures and US\$ 74,000 in cost of drugs the person did not require in the first place. **J Noebels, USA** brought scientific facts that SUDEP was rare, unpredictable, irreproducible by experiments, without relation with number or severity of seizures, anonymous and impossible to stratify risk. He brought out the connection between SUDEP and Sudden

Arrhythmia Death, more common and more identifiable as Na channelopathy and genetic features are behind this.

Expanding on the topic was the Post-Presidential Symposium “**Epilepsy Destroys Lives**” where both medical and social aspects were discussed.

A special publication titled “Sudden Unexpected Death in Epilepsy, Continuing the Global Conversation” was published by IBE with the help of Epilepsy Australia, Epilepsy Bereaved SUDEP Aware was distributed to delegates through their stall. In the Forewords Mike Glynn and Nico Moshe emphasised how SUDEP has been ignored as a real problem and what should be done to address the issue so that lives are not lost unnecessarily.



“Epilepsy and the visual arts and in literature ”



Peter Wolf, Jim Chambliss and Steven Schachter

This was an interesting session where Steven Schachter spoke about how art helps PWE in coping better. The persons artistic expression could offer a window to his brain by his choice of colours and expressions used.

Jim Chambliss has devoted great deal of time to this seemingly abstract area but he

enjoys unique position being trained as a barrister, a head injury landing him as a PWE and then his turning full attention to art and study of other artists including a very well mounted and unique research the results of which he presented. Accomplished and engaging artist and conversationalist with genuine wide interests and talents, he could enlighten any one even remotely interested. A great personality by all counts. Those interested to know more about him may contact him at jimchambliss@msn.com

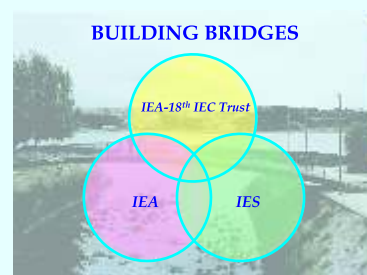
“Epilepsy: alternative, spiritual and traditional therapies”

The session had Pete Engel holding forth on areas such as *Budhist Shamatha* to focus attention and *Vipassana* for insight. Meditators were shown to have increased fibre connectivity and volume increases in hippocampal, amygdala and insular regions demonstrated by fMRIs and EEG.

29th INTERNATIONAL EPILEPSY CONGRESS, ROME, 28 AUGUST-01 SEPTEMBER 2011

"Synergising and advocacy: bringing IBE and ILAE together at national and regional levels"

Janet Mifsud, Malta spoke on the need to synergise and advocate. **Mary Secco**, Canada spoke on her experience with a local organisation.



Vinod Saxena, Janet Mifsud and Mary Secco

I spoke in the session to bring out the excellent and fulfilling outcome of this collaboration of the experience having worked with both IEA and IES. The pioneering and committed social work since 1971; the hosting of 18th IEC, the first in a developing country and naturally with wide sceptism and hurdles; culminating in formation of a charitable trust were all examples of this hard work. Since formation of IES in 1997 we have worked in close and cohesive collaboration. This is how the basic ideologies of IBE and ILAE have been implemented.

IBE General Assembly



There was an extensive agenda all completed with unusual efficiency and to the satisfaction of all. The high point was cutting the celebratory cake on the 50th anniversary.



Hand Over Hand



Ms Denise Chapman and Ms Vania Power at IBE Stand

The public image of epilepsy mistakenly emphasises its rarity, disability, its social, educational and employment exclusion and sporting non-exclusion. London Olympics 2012 followed by 10th European Congress on Epileptology gives an opportunity to break barriers of prejudice, ignorance and superstition.

Morris Family (of Morris Coole Epilepsia Prize) have sponsored this project which will assemble photographs of young children with epilepsy in a sporting context with world athletes. Anyone who knows an Olympian athlete is encouraged to contribute to this cause. The General Assemblies of IEA and ILAE were given a very persuasive address by Mr Morris. His enthusiastic and well delivered appeal was commendable but indeed more laudable was his commitment to our cause.

Travel grants from IEA-18th IEC Trust, India

Drs MM Mehndiratta, Meena Gupta, Kiran Bala, Manjari Tripathi, P. Saratchandra, UK Misra, J. Kalita, Bhaskar Malla Rao, Ashalatha and Ms Aley Alexander were offered travel grants to cover their registration and 50% of airfare if they fulfilled the general conditions of having a paper accepted and not having utilised any such grant from the Trust in the past 3 years.

29th IEC Travel Bursary awardees from India

There were three, Dr KM Jeyraj, Dr Sita Jaylakshmi and Mr VR Parameswaran.

29th IEC was great event marked by joyous IBE celebration and great scientific and social fare for all the delegates. **The 30th IEC will be held in Montreal, Canada from 23 to 27 June 2013** and we can look forward to more exciting news on this in the coming months.



Dr Ding Ding, China & Mr Micheal Alexa, Austria



EDITORS NETWORK MEETING INTERNATIONAL BUREAU FOR EPILEPSY



Reported by Chair: Robert Cole, Australia



Presentations were made by Robert Cole and Ann Little and editors/ *representatives from* Japan, India, Austria, China, Taiwan, Ireland, Finland, Denmark, Sweden, Morocco, Norway, Malta and Belgium (details available on internet).

India

- Dr Vinod Saxena represents the two bodies in India (Indian Epilepsy Association and Indian Epilepsy Society) and produces a joint newsletter quarterly with 3,000 copies which is sponsored by UCB and is free to members. They produce hard copies and provide their newsletter electronically on their website. It contains both ILAE and IBE news, frequently answered questions (on their website), new drug information, new research articles and international. They have a section on drugs for healthcare professionals and doctors. They also feature research and patient stories. A special feature is their "Epilepsy Around the World" section. They also publish information from their 28 chapters who hold independent activities in both cities and rural areas. This Rome congress was also published and the 9th AOEC in Manila will also be promoted.

Outstanding Persons Awards 9th AOEC, Manila

- The Outstanding Persons Awards were established in Japan at the 4th AOEC and are unique to the Western Pacific and South East Asian regions
- The idea of the 'Outstanding Persons with Epilepsy Awards' is to encourage people with epilepsy to not be ashamed of their condition and to overcome the heavy culturally defined stigma and discrimination that exists in the region. These awards are unique to the Western Pacific and South East Asian regions

- To continue the tradition, this Award will again be presented at the 9th Asian & Oceanian Epilepsy Congress, Manila, Philippines, 22–25 March 2012

<http://www.epilepsymanila2012.org>

- Members are particularly encouraged to feature the "Epilepsy & Society Symposium" and the "Outstanding Persons with Epilepsy Awards" in your newsletters and magazines because the potential 17 individual awardees from the 17 IBE full member countries deserve the recognition

Promoting and reporting 9th AOEC, Manila

This congress is a joint initiative between the Western Pacific Regional Executive Committee and the South East Asian Regional Executive Committee & should be heavily promoted.



IBE/UCB 2011 Journalism Award

Excellence in Epilepsy

Journalism Award 2011

Sponsored by UCB

- The 2011 Excellence in Epilepsy Journalism Award is now open
- It recognises outstanding reporting on epilepsy
- The Excellence in Epilepsy Journalism Award is a joint initiative between the International Bureau for Epilepsy (IBE) and UCB, which recognises journalists who have excelled in reporting on epilepsy

journislmawards@excellenceinepilepsy.com

NEXT MEETING (face to face)

- The next face to face meeting will be held at the 9th Asian & Oceanian Epilepsy Congress, Manila, PHILIPPINES, 22–25 March 2012

<http://www.epilepsymanila2012.org>

Colombian Law Provides Protection for Individuals Suffering from Epilepsy

The law for protecting the rights of people with epilepsy came into force in Colombia November 11, 2010. The Colombian League Against Epilepsy was working for 40 years and now found a champion in Senator Manuel Virgüez who assisted in the writing of the law and led it through the complex legislative process.

PAHO to Consider Action Plan on Epilepsy

The Pan American Health Organization (PAHO) which includes representatives from countries of North and South America considered report and strategic plan prepared by Dr Jorge Rodriguez from PAHO and Drs. Carlos Acevedo and Marco Medina as part of the Global Taskforce of the International League Against Epilepsy (ILAE).

Institute of Medicine undertakes study of epilepsy in the US

“The IOM is undertaking a new study that will consider the public health dimensions of the epilepsies in the United States—including health care and human services, health literacy, and education. The IOM will recommend priorities in these areas in order to better understand the public health impact of the epilepsies and to meet the needs of people with epilepsy and their care givers.

EU Clinical Trials Registry

The online register gives for the first time public access to information on interventional clinical trials for medicines authorised in the 27 EU Member States and Iceland, Liechtenstein and Norway. The database also allows the public to search for information on clinical trials authorised to be carried out outside the EU if these trials are part of a paediatric investigation plan.

Gary W Mathern, MD.

Chair Strategic Taskforce of the ILAE

EUROPEAN DECLARATION ON EPILEPSY PASSED IN EUROPEAN PARLIAMENT



The efforts of the epilepsy community to ensure the rights of people with epilepsy and to improve treatment opportunities and increase support for epilepsy research was rewarded when the European Parliament approved the Written Declaration on Epilepsy. On the final signing session on September 15, 2011, the Declaration was signed by 459 of the 736 Members of the European Parliament (MEPs).

The Declaration outlines the enormity of the problem of epilepsy in Europe, the costs associated with this disease, the lack of adequate treatment faced by many Europeans with epilepsy, the discrimination they face and the underfunding of epilepsy research. The Declaration in turn calls on the European Commission and Council to prioritize epilepsy as a major disease, encourage expanded epilepsy research, ensure equal rights and protections for people with epilepsy and perform health impact assessments in all member states and across the European Union.

This groundbreaking Declaration was the result of exceptional effort of the European Advocates for Epilepsy Working Group of MEPs, the Joint Task Force from the International Bureau for Epilepsy and the Commission on European Affairs of the ILAE, ILAE and IBE European chapters and associations*, many individuals committed to epilepsy. This group spent countless hours working with MEPs of the member states to educate them about the issues faced by people with epilepsy and the effects that epilepsy has on society at large.

Special thanks go to the five MEPs who introduced the Declaration: Gay Mitchell (Ireland), Nirj Deva (England), Marian Harkin (Ireland), Peter Skinner (England) and Angelika Werthmann (Austria).

For further details about the issues of epilepsy in Europe and the benefits of the Declaration, please see the video message from Emilio Perucca, Co-chair of the Joint Task Force <http://www.ilae>

[epilepsy.org/visitors/initiatives/EuropeanDeclaration2011.cfm](http://www.epilepsy.org/visitors/initiatives/EuropeanDeclaration2011.cfm)

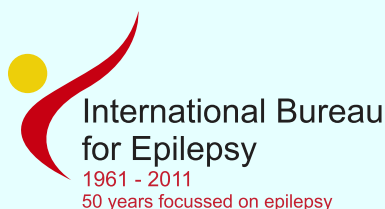
Edward Bertram, MD

University of Virginia

Information Officer, ILAE

*namely Co-chairs Emilio Perucca, Mike Glynn, Asla Pitkanen, Hanneke de Boer, Retta Kalviainen, Janet Mifsud, Michel Baulac and Christian Elgerand

IE NEWS JUBILEE AWARD



The IE News Jubilee Award is an initiative of the International Bureau for Epilepsy (IBE) to reward the best contribution submitted to International Epilepsy

News (IE News). The award has been introduced as part of IBE's Golden Jubilee celebrations and to mark 48 years of IE News, the quarterly magazine of IBE.

Whether you report on epilepsy at international or local level, on medical or social aspects of the condition, you could win this great award!

Award Rules

- Reports and articles, to be considered for the award,

must be submitted by email to ibedublin@eircom.net before the closing date of 31st December 2011.

- Articles must be written in English and be the original work of the applicant.
- The article must be between 750 and 2000 words in length.
- Photographs may accompany the submission but it is not compulsory to do so.
- IBE reserves the right to publish any article submitted.

Prize

There will be one prize winner, who will receive financial support to attend an IBE or IBE/ILAE congress of the winner's choice, up to a maximum of US\$2,000. The prize funds may not be used for any other purpose and must be used before the end of 2013.

Award Criteria

An independent judging panel will judge entries, looking for responsible, informed and original stories. Entries will also be assessed on the following specific criteria. The work:

- Helps increase awareness and understanding of epilepsy
- Gives a voice to people with epilepsy
- Is well researched, compelling, uses language responsibly when writing about epilepsy.

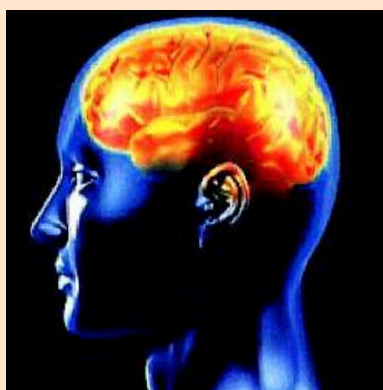
Remember!

Closing Date: 31st December 2011

Entries to: ibedublin@eircom.net

Good Luck!

EpiNet



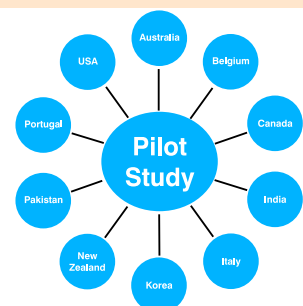
www.epinet.co.nz
Why YOU should join

A multinational project to:

- establish registries to follow patients with particular types of epilepsy
- ask questions that pharmaceutical companies are not asking
- run investigator-led trials on a very low budget.

EpiNet

Epileptologists from 10 countries are entering patient details into the EpiNet Database:



A multinational project to encourage clinical research in epilepsy

Why you should join

- You will participate in very worthwhile, investigator-led clinical research.
 - You will get an on-line database of your epilepsy patients.
- You will get a clinically useful summary that contains your patient's full drug history and results of investigations.

The **EpiNet** project is open to epileptologists anywhere in the world who:

I have access to the Internet, and
I am interested in clinical research

We want you to join us!

More Information and a demonstration can be seen at:

www.epinet.co.nz

or contact: pbergin@adhb.govt.nz



SEAREC South East Asian Regional Executive Committee

Report from Dr HV Srinivas and Regional Committee



On the occasion of Golden Jubilee celebration of IBE and completion of 40 years of IEA, a Satellite meeting of IBE was organized inviting South East Asians Regional Executive Committees. Those who attended were from Bangladesh, Indonesia, India, Nepal and Sri Lanka.

The chief guest Mr Mike Glynn President IBE inaugurated by the traditional "Lighting of the Lamp" which symbolized dispelling the darkness and ignorance related to epilepsy and bringing in the light and knowledge.

He elaborated on the formation of IBE and its progress over the last five decades. He emphasized the role of lay people in the organization which is of key importance. The IBE has 126 members in 93 countries world wide, with seven regional committees . There is a proposal from China for International Epilepsy



Day on 28th June. Very recently the European Epilepsy day was launched on 14th of February 2011 and there are different epilepsy awareness days in many countries.

He highlighted several programmes the IBE has been undertaking which includes Global Campaign Against Epilepsy (GCAE) in collaboration with ILAE & WHO ; A d v o c a c y regarding health, employment, education, driving, legislation and social activities for person with epilepsy, intervention for epilepsy through WHO Gap action programme and promising strategies programme which include current projects in India, Nepal and Bangladesh.

Epilepsy Assn Meet Held

Express News Service

Kochi: The International Bureau of Epilepsy (IBE), a non-governmental organisation working for the welfare of epilepsy patients, held a satellite meeting at IMA house here on Sunday in connection with its 40th anniversary.

IBE president Mike Glynn was the chief guest. Epileptologists from India, Sri Lanka, Indonesia, Bangladesh and Nepal participated in the meeting.

The focus of the meeting was on the status of epilepsy care in South East Asia and strategies for improving the care in the region.

Patients and public also participated in the meeting and interacted with the luminaries seeking advice for their individual problems.

International Bureau of Epilepsy is a non-governmental organisation that works in collaboration with World Health Organization (WHO) to improve the medical care of such patients.

The next national conference of the Indian Epilepsy Association and Indian Epilepsy Society will also be held at Cochin in February 2012.



*Mr Kabindra Man Pradhan,
Nepal*

**Mr Kabindra Man Pradhan
(Secretary General - Nepal
Epilepsy Association)** A Civil
engineer by profession has taken
intense interest in the
Association. Epilepsy is a
common neurological diseases

but the communicable diseases is still highly prevalent in
this land locked country. As is common else where, social
stigma, treatment with witch doctor, smelling of the old
shoes and socks to abort
an attack are still
prevalent.

N e p a l E p i l e p s y
Association is a Non
G o v e r n m e n t a l
Organisation founded in
1986, which provides
holistic care to persons
with epilepsy and also public education to increase
awareness in the society through booklets articles, health
education and awareness programmes.

The Association runs weekly epilepsy clinics providing
subsidized / free medicines, counselling in epilepsy
centers and camps, provides health education to villagers
and illiterate people about prevention and management of
epilepsy.

The Nepal Epilepsy Association has several partner
internationally. Plans include establishment of two more
epilepsy centers, free epilepsy camps, plans to have
international standard epilepsy center in Kathmandu and
a tele documentary film on epilepsy with the financial
assistance from IBE Promising Strategies Programme.



*Dr Hemav Rajbhandari,
Vice President, NEA
while attending 29th IEC in Rome*

**Dr HT Wickramasinghe -
(President - Epilepsy
Association of Srilanka-EASL)**



*Dr HT Wickramasinghe,
Srilanka*

The basic health care for persons
with epilepsy in Sri Lanka is quite
adequate, with free investigations
and treatment. EASL was founded in 1989 and Prof Nimal
Senanayake and Mr Hemal Pereis were the founding
members who worked with great enthusiasm. The
association had a news letter and a good number of
members who were actively participating. Unfortunately,
for various reasons the Association is not functioning for
over a decade now.

This year we have decided to revive the its old glory.



*Dr Muzharul Mannan
Bangladesh*

**Dr Muzharul Mannan, (Secretary
General - Bangladesh Epilepsy
Association) -** Bangladesh has
about 125 million population with less
than 150 neurologists. In his
epidemiological study he observed

that epilepsy is a common health problem with
superstition stigma still prevalent. 30 -40percent are
treated by traditional healer and 50-60 percent remains
seizure free with four primary antiepileptic drugs. However
the most common cause for non compliance is cost of
drugs. The Association was started in 1992 and got
affiliated to IBE in 2005. The goals of the Association
include increased social acceptability . The Association
runs weekly free medical clinics, quarterly awareness
programmes and half yearly training programmes for care
givers and health professionals. With the help of IBE a
documentary film is being produced for public education.

SATELLITE MEETING OF IBE AT COCHIN - 7 AUGUST 2011



*Dr Archdiat Agoes
Djamil, Indonesia*

Dr Achdiat Agoes Indonesia (Board of Advisors & Past President Indonesian Epilepsy Association)–

Indonesia is a conglomerate of 13 thousand islands with a population of 227 millions and established 2 million people with epilepsy. Stigma attached to epilepsy is prevalent as in other neighbouring countries. The organization has 17 chapters spread all over the country. The Association aims to improve awareness and provide public education to dispel the myths and fears about epilepsy. This is done through seminars and outbound activities. The Indonesian Epilepsy Association is concentrating on four aspects- promotion, prevention, treatment & rehabilitation for persons with epilepsy. The management is primarily at the level of Primary Health Care Centers .

Dr MM Mehndiratta(Secretary General - Indian Epilepsy Association) – IEA was established in 1971, and presently has 28 chapters with more than 2000 members (Medical, Non- Medical and people with epilepsy). Activities for Persons with Epilepsy (PWE) are carried out by various chapters of IEA, which include Counseling, monthly camps, diagnosis & free drug distribution, subsidized medicines, essay, painting & quiz competitions, special education & support groups, sports, Rural epilepsy programme etc.

National Epilepsy Day is celebrated on 17th November every year by most of the chapters by holding public awareness programmes, sports, scientific exhibition, painting and essay writing competition etc for children with epilepsy.

Joint annual conference of Indian Epilepsy Association and Indian Epilepsy Society is organized every year, where in medical and social aspects are covered.

Support Groups: Mumbai, Pune, Bangalore, Indore, Trivandrum chapters run very active programs to counsel PWE and their caregivers; "Sanvedana", in Pune has a unique distinction of setting up a marriage bureau for

people with epilepsy under the leader ship of Ms. Yashoda Wakankar..

Epilepsy India News Letter is published quarterly and circulated to all members.

Website of IEA. www.epilepsyindia.org is a very informative site detailing IEA activities.

Diploma in Epilepsy Care (Open to National & International students) a value added course for teachers, nurses, persons with epilepsy and carers, primary health care worker etc is conducted in association with CBR Network and Bangalore University.



*Mr Kabindra Man Pradhan, Nepal, Dr HT Wikhramasinghe, Sri Lanka
Dr Achdiat Agoes Djamil, Indonesia, Dr M Mannan, Bangla Desh
Dr HV Srinivas, India, Mr Mike Glynn, Ireland
Dr Vinod Saxena, India, Dr MM Mehndiratta, India*

IEA has taken initiative in defining disability in PWE whose seizures are uncontrolled.

Awards

- This year (2011) IEA is proud to note that Dr Pravina Shah has been honored with Social Accomplishment award by IBE & ILAE.

- In 2010, at Melbourne Conference -Mrs Kavita Shanbagh has received Outstanding Person with Epilepsy Award and Prof P Satishchandra received Asian & Oceanian outstanding Achievement Epilepsy Award.

- IEA already has seven members who have received Ambassador for Epilepsy Award - Drs EP Bharucha, KS Mani, MC Maheswari, VS Saxena, Satish Jain, MM Mehndiratta, Carol D'Souza and Dr KS Mani was earlier bestowed with Social Accomplishment Award.

REPORT OF ACTIVITIES 2010-11

UTTAR PRADESH-LUCKNOW

Reported by: Dr Atul Agarwal, Lucknow



1. **Painting competition for children with epilepsy** was organized at Vivekanand Hospital, Lucknow in which 43 children participated. The first two prizes were given to Mohit Sharma & Sonal Sehgal.
2. **Public awareness lectures** were given by various specialists. Dr Atul Agarwal and Dr Niranjan K Singh.
3. Dr Atul Agarwal spoke on epilepsy on FM radio channel Lucknow.
4. Dr Atul Agarwal spoke to students and teachers of "St Columbus Inter College, Gomti Nagar and HAL School, Faizabad Road, Lucknow" about epilepsy, its causes, first aid, various myths associated with illness.
5. An **Epilepsy Quiz** was held for undergraduate students of Era Medical College, Lucknow by Prof. Ajay Kohli.
6. Dr Atul Agarwal spoke on about Epilepsy, IMA Sultanpur.



PEDNEURO WORKSHOP - 2011

"Hands on Workshop Cum Symposium on Neurodiagnostics"

EEG - EMG - NCV - EP (BAER & VEP)

27th May to 29th May 2011, Hubli - Karnataka

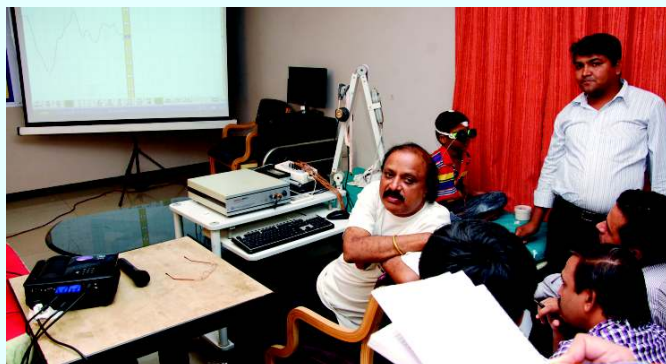


Dr KMP Suresh gave a brief introduction to EMG and NCV.

Dr Suresh Rao Aroor - senior pediatric neurologist gave an extensive hands on training on procedures of EMG and NCV (MNC - SNC- RNS- H-reflex) and its use and limitations in pediatric neurology practice.

The 3 days extensive workshop concluded with Valedictory Function with presentation of Certificate of attendance to all the participants and a brief expectations and remarks of the workshop.

The participants were highly impressed on the proceedings of the workshop and were very thankful to the organizers for arranging such extensive hands on training cum workshop - symposium on pediatric neurodiagnostics and various aspects of management of childhood epilepsies. They were of the opinion that such workshop should be held quarterly or at least by annually.



NEWS & VIEWS ON DRUGS

DOSAGE FACTORS AND SAFER ALTERNATIVES TO ANTIEPILEPTIC DRUGS DURING PREGNANCY

A new study published by The Lancet Neurology (June 6, 2011) (thelancet.com) this month indicates that four of the most commonly prescribed antiepileptic drugs may increase the risk of major birth defects among infants when taken during early pregnancy, a risk that is even further increased with higher doses of the medications. Researchers involved in the study report that the rate of birth defects was higher with increased doses for all the antiepileptic drugs. Furthermore, the greatest risk to the fetus was seen with the highest doses of valproic acid.

Determining the appropriate dosage for an epilepsy patient is equally as important as choosing the type of drug itself, a concept which has been largely unexplored in the past. While previous studies have indicated that valproic acid, in particular, may increase the risk of birth defects among exposed infants, few studies have taken into account the impact of individual doses on the risk of birth defects. This new study compares the top four antiepileptics: valproic acid (Depakote), carbamazepine (Tegretol), lamotrigine (Lamictal), and phenobarbital.

These findings are significant because they provide specific information about the dose, but it is difficult to avoid prescribing these drugs if seizure control is not possible with alternative medications. As Dr Torbjorn Tomson, of the Karolinska Institute in Stockholm, Sweden has stated, "Present guidelines caution on the use of valproic acid in pregnancy, but offer little guidance on alternative options and how to manage women whose seizures cannot be controlled by other drugs."

Instead, doctors are, more or less, choosing to prescribe a low dose of a higher-risk drug rather than a high dose of a lower-risk drug because the incidence of major birth defects associated with the former may be lower.



NEURONTIN RESEARCH WAS SO FLAWED IT DESERVED TO BE CALLED MARKETING, NOT SCIENCE



The road from conception to useful application for a new drug therapy, when properly navigated, is fully

mapped, carefully followed, scientifically rigorous and honestly appraised.

In the case of Neurontin, critical parts of that journey took a few unauthorized detours, according to a report in the Archives of Internal Medicine.

Researchers at the Yale School of Medicine documents these were misrepresented as a clinical trial.

Instead, they said, it was a "seeding trial," which they described as "An important form of marketing."

Joseph Ross, MD, said that Study of Neurotonin: Tritrato to Effect, Profile of Safety (STEPS) "was a seeding trial posing as a legitimate scientific study."

The breach wasn't against the law, but it wasn't ethical because the purpose was primarily to promote.

The Yale team said, "Data quality during the study was often compromised," and some documents appeared to suggest that marketing personnel helped to collect data and witnessed the trial, not just the results.

Source: Archives of Internal Medicine, 27 June 2011.

NEWS & VIEWS ON DRUGS

FDA ENCOURAGES PREGNANT TOPIRAMATE USERS TO HELP TRACK BIRTH DEFECTS BY ENROLLING IN ANTIEPILEPTIC PREGNANCY REGISTRY

Topiramate causes a number of birth defects in women, eg. craniofacial defects, cleft lip and palate. These defects form before most women know they are pregnant, US Food and Drug Administration (FDA) recommends doctors advise their patients to enroll in the North American Antiepileptic Drug (NAAED) Pregnancy Registry.

What does the NAAED Pregnancy Registry Do?

Operating out of the Massachusetts General Hospital, the NAAED Pregnancy Registry tracks women who become pregnant while taking an antiepileptic drug. In 1997, six drug manufacturers decided to help fund the registry to collect data on the frequency of major birth defects caused by antiepileptics.

Normal pregnancies produce children with cleft lip and palate 0.17% of the time, though most antiepileptics increase the likelihood to 0.38-0.55%. Topiramate increases the likelihood to 1.4%, a substantially larger amount.



*I Chose The Road
Less Travelled, Now, Where
The Hell Am I?*



DRUG IMPROVES BRAIN FUNCTION IN CONDITION THAT LEADS TO ALZHEIMER'S

Levetiracetam improves memory and brain function in adults with a form of cognitive impairment, a Johns Hopkins University study has found.

The findings raise the possibility to slow the abnormal loss of brain function in some aging patients before their condition becomes Alzheimer's. The researchers emphasize, however, that more studies are necessary before any such recommendation can be made.

The new study, also shows that excess brain activity in patients amnesic mild cognitive impairment, (MCI), contributes to brain dysfunction that underlies memory loss. Previously, it had been thought that this hyperactivity was the brain's attempt to "make up" for weakness in its ability to form new memories.

The clinical study, funded by the National Institutes of Health, tested 34 participants, some of whom were healthy older adults and others who had aMCI. Each person participated in a sequence of two treatment phases lasting two weeks each. Patients received a low dose of levetiracetam during one phase and a placebo during the other.

After each treatment phase, the researchers evaluated subjects' memory and conducted functional magnetic resonance imaging of their brains. Compared to the normal participants, subjects with amnesic MCI who took the placebo had excess activity in the hippocampus, a part essential for memory. But when they had been taking levetiracetam for two weeks, the excess activity was reduced to the same level as that of the control subjects; memory performance in the task they performed also was improved to the level of the controls'.

Source: *The International Congress on Alzheimer's Disease Paris, July 20, 2011*

AGE OF EPILEPSY ONSET LINKED TO COGNITIVE IMPAIRMENT

Age of seizure onset may be a significant predictor of cognitive impairment in preschool children with epilepsy.

Age of seizure onset may be a significant predictor of cognitive impairment in preschool children with epilepsy.



Half of preschool children with epilepsy have some degree of cognitive function retardation

Kati Rantanen, from the University of Tampere in Finland, and colleagues assessed the frequency of cognitive impairment, level of cognitive functions, and epilepsy-related factors correlating with cognitive impairment in preschool children with active epilepsy. The medical records of 64 children, aged 3 years to 6 years 11 months, were used to extract

medical data and results from prior psychological evaluations.

The investigators found that epilepsy prevalence was 3.2 per 1,000 children. Fifty percent of children with epilepsy had cognitive function within normal or borderline range, 22 percent had mildly retarded cognitive function, and 28 percent had moderately to severely retarded cognitive function. Complicated epilepsy, age at onset of epilepsy, abnormal magnetic resonance imaging, and additional neurologic problems were correlated with cognitive impairment. The only significant predictor of cognitive impairment was age at the onset of seizures.

"Early-onset epilepsy is a risk factor for cognitive impairment. Furthermore, the cognitive impairment can already be demonstrated during preschool years in children with relatively short duration of epilepsy," the authors write. "In clinical practice, we should pay more attention to early intervention to improve the subsequent cognitive and psychological outcomes of these children."

Source: *Epilepsia*, May 13, 2011

SEIZURE ACTIVITY LINKED TO OVULATION CYCLES

Secondary generalized tonic clonic seizures (GTCSs) occur with almost a 30% greater frequency during anovulatory than during ovulatory phases of menstrual cycles, and women with these seizures have significantly higher estrogen-to-progesterone ratios, lending more weight to the theory that female hormones play a role in seizure activity, according to new research.

The frequency of complex partial seizures (CPSs) and simple partial seizures (SPSs) did not differ according to ovulation status, the study shows.

About a third of menstrual cycles in women with epilepsy are anovulatory, which is 3 times greater than women in the general population. Having more such cycles may be linked to the tendency to have more generalized convulsive seizures.

The new results support earlier evidence that estradiol may promote seizures, whereas progesterone may inhibit them.

"The findings from this study suggest that the ratio of estrogen to progesterone may be an important factor," said lead study author Andrew G Herzog, director, Harvard Neuroendocrine Unit, Beth Israel Deaconess Medical Center, Wellesley, Massachusetts. "This is something that one can alter by adding progesterone or lessening estrogen."

"If you don't ovulate, you don't make progesterone, hence the importance of estrogen-to-progesterone ratio," explained Dr Herzog. "Estrogen tends to promote seizure occurrence and progesterone has a metabolite that has powerful antiseizure properties comparable to barbiturates and benzodiazepines."

Source: *Epilepsia*, July 20, 2011

WHO IS READING YOUR EEG? SHOULD YOU CARE?

Real life cases: a typical month at an epilepsy center ...

- BC, 66 year had a single episode of passing out upon standing after a thyroid biopsy. She first felt dizzy and sweating, and then slumped to the ground. There was no convulsion. Her EEG was read as showing spikes and she was put on a seizure medication.
- AH 70 year presented with several weeks of dizziness, headaches and falls. After her EEG showed “ongoing temporal lobe seizures”, she was treated with several seizure medications. Symptoms worsened.
- LM 58 year had episodes of left eye throbbing pain and numbness, nausea, poor balance, and feeling hot and sweaty. Her EEG reportedly showed “epileptiform abnormalities”, but her symptoms did not improve with seizure medications.
- AA 22 year had episodes of blurry vision when working on her computer. Her EEG reportedly showed spikes she was put on a seizure medication. Her symptoms did not improve.
- None of these patients had seizures. (*The EEG in were all above 4 cases reviewed and were normal.*)

The misdiagnosis of epilepsy is common. About 30% of patients seen at referral epilepsy centers for difficult seizures do not have seizures and have been misdiagnosed. Such a wrong diagnosis of seizures has serious consequences and can in fact be life-changing.

The diagnosis of seizures and epilepsy should be based primarily on a good history, not EEG. not MRI.

Nothing replaces the history. In fact most people with epilepsy have normal MRIs and normal EEGs!

A major contributor to the misdiagnosis of seizures is the tendency to over-read normal tracings as abnormal.

How big is this problem?

It is difficult to quantify the problem, as taught at every

medical school and during neurology training (“we do not treat the EEG”). It is also why most epilepsy specialists agree that “routine interictal EEG recording is one of the most abused investigations in clinical medicine and is unquestionably responsible for great human suffering”

Why are EEGs so commonly over-read?

The main reason is the lack of training and standard in EEG, and the wrong assumption that all neurologists are trained to read EEGs.

Possible solutions & recommendations

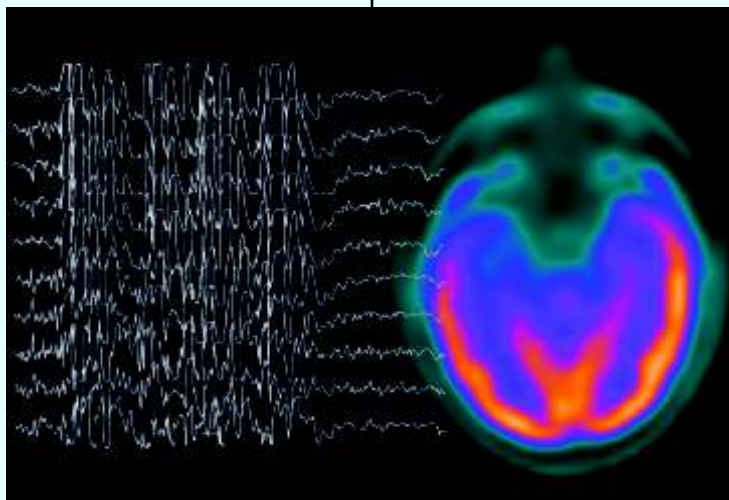
1. Use a backup or confirmatory interpretation.

This is nearly universal for electrocardiograms (ECGs). ECGs are routinely read by non-cardiologists in managing patients. However, as a safeguard against serious errors,

a confirmatory and “official” reading by a cardiologist almost always follows.

2. Define competencies in EEG

Clearly, many neurologists who read EEGs are not adequately trained to do so. So, how do we ensure that neurologists who interpret EEGs are qualified to do so? There should be better, more and mandatory EEG training during neurology residency.



Key Points

- The combination of vague, nonspecific symptoms plus a mis-read EEG is a common cause of wrong diagnosis of seizures.
- There is no mandatory EEG exposure during Neurology training.
- EEGs are frequently over-read, i.e. read as “abnormal” when they are really normal
- If the diagnosis sounds wrong and is based largely or only on the EEG, get another opinion.

Source: Benbadis Sr: The Tragedy of Over-Red EEG's and Round Diagnosis of Epilepsy: Expert Rev Neurother 2011: 10,343

RESEARCH IN EPILEPSY

SELECTION OF SEIZURE DRUG FOR BRAIN TUMOR PATIENTS MAY AFFECT SURVIVAL

Brain tumor patients who take valproic acid along with standard treatment may live longer.

Despite some limitations, the choice of seizure medications in brain tumor patients should be carefully considered as it may give people a few more months.

Researchers from the European Organization for Research and Treatment of Cancer (EORTC) and the National Cancer Institute of Canada (NCIC) Clinical Trials Group analyzed the use of epilepsy drugs by 573 brain tumor patients enrolled in a clinical trial evaluating radiation therapy with and without temozolomide. When treatment started, 175 patients were not taking a seizure drug, while 398 patients were receiving anti-seizure medicine. Of these, 97 were taking valproic acid as their only anti-seizure medication.

Results showed that patients treated with both chemotherapy and radiation fared better. However, those patients who also received valproic acid as medication for seizure prevention had an even more improved outcome. Those 97 patients lived an average of 3 months longer compared to the patients not receiving valproic acid.

Unfortunately, patients receiving valproic acid in addition to temozolomide and radiation therapy were more likely to suffer a decrease in blood platelets and white blood cells. Furthermore, taking valproic acid did not increase survival in the group of patients that received radiation therapy without temozolomide.

Source: American Academy of Neurology
31 August 2011

PLURALS IN ENGLISH LANGUAGE

The English language has some wonderfully anthropomorphic (the attribution of a human form, human characteristics, or human behavior to nonhuman things, e.g. deities in mythology and animals in children's stories) collective nouns for the various groups of animals.

We are all familiar with:

- a **Herd** of cows
- a **Flock** of chickens
- a **School** of fish
- a **Gaggle** of geese.

However, less widely known:

- **Pride** of lions
- a **Murder** of crows (as well as their cousins the rooks and ravens)
- an **Exaltation** of doves and, presumably, because they look so wise
- a **Parliament** of owls 🦉

Now consider a gathering of Baboons. They are the loudest, most dangerous, most obnoxious, most viciously aggressive and least intelligent of all primates.

And what is the proper collective noun for a group of baboons?

Believe it or not a **Congress**

Anon.

STOP SAYING "EPILEPTIC"

The purpose of this study was to evaluate the impact upon attitude and perceived stigma of using different terms for referring to persons with epilepsy among teenagers. High school students received one of two versions of a brief questionnaire and of the Stigma Scale of Epilepsy (SSE).

The versions differed only in the term used: "people with epilepsy" (PWE) in the group-1 (N = 109) and "epileptics" in group-2 (N = 105). Group-1 responded that 62% of PWE and group-2, that 93% of epileptics have more difficulty finding employment. Group-1 responded that 37% of PWE and group-2, that 70% of epileptics have more difficulties at school. Group-1 responded that 41% of PWE and group-2, that 87% of epileptics are rejected by the society. None of individuals in group-1 indicated that they were prejudiced toward PWE, whereas 3% of group-2 indicated that they were prejudiced toward epileptics.

The SSE score (range from 0 to 100, higher the score, higher the degree of perceived stigma) was 49 [confidence interval (CI) = 46.9–52.0] for group-2 and 45 (CI = 42.4–48.2) for group-1 ($p = 0.03$). In conclusion, the words we use can influence our perceptions and have consequences in terms of social stigma associated with epilepsy.

We should refrain from using the term "epileptic" to refer to a person with epilepsy, and consider the importance of our choice of words as part of the effort to bring epilepsy out of the shadows.

P. T. Fernandes et al.

Epilepsia, 50(5):1280–1283, 2009

NEW SURVEY BY INTERNATIONAL BUREAU FOR EPILEPSY HIGHLIGHTS 'WHAT REALLY MATTERS' TO PEOPLE WITH EPILEPSY TODAY

A new, on-going European survey to assess what really matters to people living with epilepsy today has been commissioned by the IBE,

Presented at the 29th IEC ROME, the preliminary results of the survey, drawn from over 120 patients in 17 countries, show that weight gain is considered to be the most bothersome unwanted effect associated with epilepsy medication. Dizziness and slowing of mental agility were listed as being the next most disturbing unwanted effects. In general, survey respondents acknowledged that they experienced side effects with their current epilepsy treatment, although stated that they were not unduly bothered by this, and many stated that they simply forget to raise the issue of unwanted effects.

"We believe this type of people with epilepsy-centric insight is vital in helping us to improve epilepsy care in the future", points out IBE President Mike Glynn. "Enormous progress has been made over the past five decades in epilepsy care and treatment, but there is still a long way to go. Sadly, epilepsy still continues to take its toll, impairing the physical, psychological and social functioning of those affected and their families. We must listen to people with epilepsy and acknowledge what they really feel about their epilepsy and associated treatment approaches in order to improve their daily lives."

The survey was funded through an unrestricted educational grant provided by Eisai. The field work commenced in July 2011 and will end mid-September this year. Full survey results will be available before the end of 2011.

EPILEPSY AROUND THE WORLD

CANADA



Street performers busking for epilepsy at 12th Toronto BuskerFest

The annual event that was held in support of epilepsy in late August and run until Aug. 28. BuskerFest is a pay-



what-you-can event and all proceeds will go to Epilepsy Toronto.

History of Busking

Busking, or street performing, dates back to antiquity and is used as a form of income for those who entertain anyone doing anything, like fire breathing, card tricks, street theatre, clowning, magic, juggling and the list goes on.

The 1952 Charlie Chaplin talking motion picture "Limelight" and the classic 1954 Italian Federico Fellini film "La Strada" portray both famous acts.

A lot of modern day celebrities have been known buskers, such as Bruce Springsteen, Paul McCartney, Bon Jovi, Sting and Cirque du Soleil's Guy Laliberte.

Toronto's BuskerFest

This year's BuskerFest featured elite acrobat performers, aerial artists, contortionists, fire jugglers, magicians and musicians from all over the world,

The epilepsy event is recognized as one of the globe's premiere events.



DUBAI



Watch out for signs of epilepsy

Fits are common in children and constitute one of the main reasons for visiting a hospital or clinic.

In the West, most children with epilepsy are evaluated at least once in a Neurology center. This trend is fast catching up in the Gulf States as well, according to Dr Rajshekher Garikapati, Specialist Neurologist, Zulekha Hospital, Dubai.

Occasionally, the problem lies in identifying some behaviour change in the child as an epileptic fit.

The only fool-proof way to finally label a fit as non-epileptic is to visualise the activity of the child during the event.

Control of fits can be achieved with a single drug.

Fits come with a cost to the child. Apart from the immediate risk of falling down and hurting themselves, these children also suffer other subtle problems such as decline in performance at school due to lack of attention and poor memory, make them shy and inhibited at school, avoiding social contact.

"It is vital that such a child be given the best of care. Ensure that your child with epilepsy is seen by a neurologist and given the standard of care as dictated by the International League Against Epilepsy (ILAE)," said Dr Garikapati.

news@khaleejtimes.com

FINLAND



TRUFFLE DOGS REVEAL CLUES ABOUT CHILDHOOD EPILEPSY

A new epilepsy gene has been found in the Lagotto Romagnolo

dogs, known for their gift for truffle hunting. The gene discovery made by Professor Hannes Lohi and his research group at the University of Helsinki and the Folkhälsan Research Center offers a new candidate gene for human benign childhood epilepsies.

Crucial insights

Professor Lohi and his research group say that the new gene discovery in the Lagotto Romagnolo dog breed provides new perspectives into the development of a child's brain and the remission mechanisms in childhood epilepsies. In addition, the identified gene has enabled the development of a DNA test for the Lagotto Romagnolo breed.

"This gene discovery is significant for both dogs and humans. Every third Lagotto Romagnolo carries the gene mutation in its genome and we have now developed a gene test to be used by breeders to eliminate the disease from the breed. Furthermore, the gene has not previously been linked to human epilepsies, which makes it a new candidate gene for especially childhood epilepsies," explains Hannes Lohi.

Canine DNA bank

Together with his research group Lohi has built a large canine DNA bank in Finland with over 35,000 samples from 250 breeds. The DNA bank has played an important role in the present and ongoing studies.

Source: YLE, University of Helsinki, PlosGenetics 28 July 2011

SIERRA LEONE



Stigma Is Toughest Foe in an Epilepsy Fight

Freetown, Sierra Leone — On a sweltering morning on a red-earth lane a few blocks from the largest mosque in this West African capital, Jeneba Kabba stands up.

A tall, striking woman with a serious manner, Mrs Kabba has been sitting under an awning in the outdoor



VIGIL At an epilepsy clinic, a mother attends her son, who has had a severe seizure.

classroom of a vocational training program for people with epilepsy, to learn skills like tailoring, weaving, tie-dyeing and soap-making, as well as reading.

Her composure belies what she has survived traditional healers to drive out the demons thought to cause epilepsy; even forced to drink a two-liter bottle of kerosene. Mrs Kabba not only survived but is happily married and has a child. She has been seizure-free for 10 years with the help of phenobarbitals of two tiny groups of advocates.

The Epilepsy Association of Sierra Leone opened this vocational training program 11 years ago, Dr Radcliffe Durodami Lisk, the only neurologist in this nation of six million people. In one of Africa's poorest countries, where scarce health care resources and the stigma surrounding epilepsy add up to a "treatment gap" of more than 90 percent

"There is growing appreciation for the importance of noncommunicable chronic diseases in these regions," said Dr Gretchen Birbeck, a global epilepsy expert who directs a clinic outside Lusaka, the capital of Zambia.

They say their most intractable problem is still the intense stigma surrounding epilepsy, which often acts as a bar to treatment.

EPILEPSY AROUND THE WORLD

UK



Driver with epilepsy jailed for highway death

An Essex man with epilepsy has been jailed for three-and-a-half years for causing the death of a young woman by dangerous driving.



Laura Williams was a front seat passenger in the Mini involved in the crash

Laura Williams, 23, died after the car Giles Furnival, 33, of Winfields, Basildon was driving struck the car she was travelling in on the M25.

Furnival, who had pleaded guilty, was sentenced at Chelmsford Crown Court.

He was also disqualified from driving for five years and ordered to take an extended driving test.

Essex Police said Furnival had failed to tell the authorities about his epileptic condition.

His car hit Ms Williams' boyfriend's car at speed on the motorway at Thurrock on 29 September last year.

'Innocent victim'

Insp Keith Whiting said: "Our investigation showed that Mr Furnival had suffered from epilepsy since he was a teenager but had never informed the DVLA.

"He suffered several epileptic episodes every month and it appears it was only a matter of time before he suffered an episode at the wheel.

"Unfortunately Laura Williams was the innocent victim in this incident.

ZIMBABWE



Stigma complicates epilepsy treatment

Stigmatisation remains a major challenge in dealing

with epilepsy in Zimbabwe as some people wrongly associate it with witchcraft.

Zvanaka Gomo, a campaigner at the Epilepsy Support Foundation (ESF) told Standard-Health&Fitness that the lives of people living with the condition were endangered by "seizures and the stigma attached to the disease".

Gomo was commenting on the introduction of electroencephalography (EEG) services by the foundation for the first time in Zimbabwe.

The acquisition of the EEG system was supported by the British Embassy for the Epilepsy Clinic to increase its support to disadvantaged people with epilepsy.

The effective use of EEG will help doctors treat seizure disorders more effectively.

According to the commission on the developing world of the International League Against Epilepsy (ILAE), a combination of traditional beliefs, poverty, lack of medical care and inability to fulfill social roles has a negative impact on the lives of people living with epilepsy.

One aspect influencing stigma is that many people believe epilepsy is contagious and can be spread by urine or saliva excreted at all times during a convulsion.

By Perpetua Chikololere

ANSWERS GIVEN BY STUDENTS

- ★ A vibration is a motion that cannot make up its mind which way it wants to go.
- ★ The tides are a fight between the Earth and Moon. All water tends towards the moon, because there is no water in the moon, and nature abhors a vacuum. I forget where the sun joins in this fight.
- ★ When you breathe, you inspire. When you do not breathe, you expire.
- ★ Many dead animals in the past changed to fossils while others preferred to be oil.
- ★ I am not sure how clouds get formed. But the clouds know how to do it, and that is the important thing.
- ★ Cyanide is so poisonous that one drop of it on a dogs tongue will kill the strongest man.
- ★ Thunder is a rich source of loudness.
- ★ "Water is composed of two gins, Oxygin and Hydrogin. Oxygin is pure gin. Hydrogin is gin and water."
- ★ "H2O is hot water, and CO2 is cold water."
- ★ "Dew is formed on leaves when the sun shines down on them and makes them perspire."
- ★ "To keep milk from turning sour: keep it in the cow."

PASSING DRIVING TEST....

A teenage boy had just passed his driving test and asked his father for the use of the car.

His father said 'You bring your grades up from a C to a B, study your Bible a little, and get your hair cut. Then we'll talk about the car.'

The boy settled for the offer.

After about six weeks his father said, 'Son, you've brought your grades up and I've observed that you have been studying your Bible, but I'm disappointed you haven't had your hair cut.

The boy said, 'I've read the Bible that Samson had long hair, John the Baptist had long hair, Moses had long hair...and there's even strong evidence that Jesus had long hair.'

This Dad was certainly smart as his reply:

'Did you also notice they all walked everywhere they went?'

THE WORLD'S MOST FAMOUS STATUE

Michelangelo's David Is To Be Returned To Italy



After a two year loan to the United States , Michelangelo's David is being returned to Italy



His Proud Sponsors were:



Tha's what he gets for living in America
!!!!!!!

Now he is too heavy to stand for long. They need to build a bench for him.

FORTHCOMING EVENTS

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 19th, 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 BS Singhal.
Conference Secretariat

Niloofer Patel, FTC Events, M-33, Cusrow Baug, SB Road, Colaba, Mumbai – 400 039.

Tel.: +91 22 2282 5108,

Fax: 91 22 2282 2134

Email: numum2012@ftcevents.com

Website:

www.neurologyupdatemumbai.com



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>



25th -26th - March, 2012 Hotel Bolgatty Palace, Cochin



Cochin



Release of logo by Mike Glynn



Bolgatty-Palace

Dear Friend,

Welcome to Cochin. It is a great privilege to host the 13th National Conference of the Indian Epilepsy Association and Indian Epilepsy Society, E-CON 2012. The team of Indian Epilepsy Association, Cochin, Kerala Association of Neurologists (KAN) and the Cochin Neurological Society (CNS) will jointly shoulder this onerous responsibility.

An academic feast awaits you. A chance to unwind with old friends and colleagues, in the relaxing ambience of God's Own Country - these are things you can look forward and cherish at E-CON 2012. Kerala is a must-see destination according to the National Geographic – what with its languorous backwaters, sandy beaches, misty hills and rejuvenating Ayurvedic massages

The Scientific committee is busy working on a great academic feast. For the first time, we plan to hold a two day Epilepsy Workshop of international standards, with an eminent foreign and Indian faculty.

Cochin is the Queen of the Arabian Sea, a happening city with a glorious past, robust present and every prospect of becoming the Gate way to South India in the very near future. Come then, with your family, and enjoy the warm hospitality of gracious hosts. You will surely carry back with you fond memories of a great experience.

Regards,

The organizing committee, E-CON 2012

Registration fees:



Dr B Rajendran
Chairman

Category	Before October 31,2012	Before December31,2012	Spot
IEA/IES members	Rs 1750	Rs 2500	Rs 3000
Non members	Rs 2000	Rs 3000	Rs 3500
Residents/ PG students	Rs 1200	Rs 1500	Rs 2000
Non doctor IEA members	Rs 1000	Rs 1200	Rs 1500
Accompanying person	Rs 1000	Rs 1200	Rs 1500
Foreign delegates	USD 200	USD 250	USD 300



Dr Vinayan KP
Organizing
Secretary

Online registration open !
Abstract submission is now open !
Deadline for submission of abstracts –
November 30, 2011
Visit www.econ2012.in for more details

Conference Secretariat
Dr KP Vinayan, Organizing Secretary,
Mr Parameswaran, Treasurer
E-CON 2012, KAN Office, IMA House,
Cochin, Jawaharlal Nehru Stadium Road,
Palarivattom Post, Cochin 682 025



6th - 10th May, 2012 Eilat, Israel

Eleventh Eilat Conference on New Antiepileptic Drugs (Eilat XI) at Royal Beach Hotel, Eilat, Israel

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



FORTHCOMING EVENTS

✍ **22nd -25th - March, 2012**

9TH ASIAN & OCEANIAN EPILEPSY CONGRESS, MANILA 2012



The 9th Asian & Oceanian Epilepsy Congress will be held in Manila, Philippines from the 22nd to the 25th 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

Competitive hotel rates are available via the accommodation managers, Intas for the 9th AOEC. Abstracts must be submitted in English through the official website 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 9th AOEC; further details on this will shortly be announced on the congress website www.epilepsymanila2012.org

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

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