



EPILEPSY INDIA



INDIAN EPILEPSY ASSOCIATION & INDIAN EPILEPSY SOCIETY

Newsletter

April - June 2011

Issue 2, 2011

Editorial

Dear Friends

If the Spring is in the air and there is a spring in your step, it is all par for the course. The gloom of colder clime is being uplifted. The First date of the Month however has some interesting connotations and traditions and we may all have our favourites to recount. Sample these:

🍷 A New Republic; *The Guardian* published a supplement detailing about San Serriffe a small republic of 7 semicolon shaped islands in Indian Ocean. A series of articles described its two main islands Upper Caisse and Lower Caisse, its capital Tahoma and its ruler General MT Bodoni. There were numerous enquiries on how to get to this newly discovered holiday destination. Very few checked the date of publication First April and that the names pertained to printers terminology!

🍷 New carrots: Tesco announced successful development of genetically modified 'whistling' carrots with holes at their end. Once fully cooked, the holes will emit a whistle.

🍷 Metric clock: An Australian paper announced introduction of metric time: 100 seconds to a minute, 100 minutes to an hour, 20 hours to a day and called these millidays/ centidays /decidays. The introduction was shown to be welcomed by the Deputy PM and by display of a 'metric clock' at Adelaide. There were enough number of people who wanted to know if it was possible to convert their analogue clocks.

🍷 Planetary Alignment, effects of: BBC2 announced once in a life time astronomical event at exactly 09.47 am when Pluto will pass behind Jupiter, temporarily causing gravitational alignment. If someone jumped in the air at exactly that moment, they will experience strange floating feeling. Soon after that moment passed, BBC received numerous calls from listeners having experienced the sensation. One lady reported that she and her eleven friends had risen from their chairs and floated around the room!

Apart from the tom-foolery of First April, this may be autosuggestion or as medical science explains placebo effect on which they are so heavily reliant in comparative studies. And the scientists are not joking but dead serious. Would you believe that? More on it later.

William Lipscomb a Nobel Laureate wrote serious scientific papers ending in "We wish to thank the computer for several laudable suggestions during the course of the study". He is also claimed to have used the science or sense of retroscopy (hindsight in simpler words).

Often studies are published with impressive titles e.g. "Whether beer froth obeys the Exponential Decay Law". I have myself studied this law very closely as it applies to the rising bubbles in a glass of champagne, their size, their number and the velocity of upward movement of the bubbles. I could publish no meaningful results as the bubbles reached the targets in CNS faster.

There has been more astounding research too. Cows that have names give more milk than those who don't have names. Sing to the flower buds and they bloom earlier and better. Fake medicines are more effective if they are more costly.



"Prickly?" "No keeping cool till science figures me out!"

When I was trying to seriously study clinical pharmacology in the UK, Sam Shuster in New Castle a dermatologist came out with a witty take "Placebo Pharmacology". Now I could offer "Placebo Pharmaceuticals" as an answer to the industry plagued by expensively researched but toxic drugs which regulators-enforced early exit from the market.

Years back, I read Norman Cousins (*Anatomy of an Illness*) who used humour and laughter as

therapeutic tools to get out of his crippling ankylosing spondylitis. His doctors had given him only 1 in 500 chance of recovery but he successfully beat the odds by checking out of the hospital, into a hotel with loads of Marx Bros comedies. The resulting laughter sessions gave him hours of painless sleep.

So could Cousin's recovery be considered a mechanism of the placebo effect? His physicians believed so but he also attributed much to the close relationship he had with his medical team. This interaction is now nearly universally accepted and statistically verified as the single most important predictor of positive outcome.

Hoping that some of the health issues which afflict us will respond to the laugh therapy.

Best Wishes

Dr VS Saxena
Editor

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NEWSLETTER OF INDIAN EPILEPSY ASSOCIATION & INDIAN EPILEPSY SOCIETY

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IEA -Election for G C 2011-2013



The ballot papers were posted to all members on 16 Feb 2011. The members should post these back so as to reach me latest by **28 April 2011**.

Dr VS Saxena, Returning Officer IEA
K10/10 DLF City-II, Gurgaon 122002

IEA-18th IEC Trust

Information for members of IEA and IES Availability of Financial Grants



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

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

For further queries and application forms, please correspond at

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HONOURS FOR OUR MEMBERS

ECON 2011 LUDHIANA

Award Paper/Poster

BEST PAPER - MEDICAL

Dash G K, Radhakrishnan A, Kesavadas C, Abraham M, Radhakrishnan K. Effect of lesion status on surgical management of extra temporal parietal epilepsy.

BEST POSTER - MEDICAL

Zanmera P, Shukla G, Singh H, Gupta A, Goyal V, Srivastava A, Behari M Markedly disturbed sleep in medically refractory compared to controlled epilepsy- a clinical and polysomnographic study.

BEST POSTER – Non-MEDICAL

Muralidharan KV, Members of IEA Bangalore Chapter, Innovative method of public education street play/ road show.

2ND BEST POSTER-Medical

Kaushal D, Paul B S, Singla M, Singh G Ictal brain spect: an effective localisation tool for patient with epilepsy.

2ND BEST POSTER-NON MEDICAL

Talakad S, Satishchandra P, Netravati, Bhat K, SinhaS, Udupa K, Raju T R Modulation of Heart rate variability with adjuvant yoga therapy in Patients with refractory epilepsy.

PADMA BHUSHAN DR SK MUKHERJEE AWARD

Dr VV Nadkarni, Indore receives
the prestigious award



Dr VV Nadkarni has been awarded the prestigious Padma Bhushan Dr S K Mukherjee Memorial Rashtriya Chikitsa Award for the services in the field of epilepsy and social achievement.

Chief Minister of Madhya Pradesh Honourable Shivraj Singh Chauhan presented this award to Dr V V Nadkarni on 19th February 2011 in MGM Medical College Indore .The award ceremony took place in the presence of the Ministers of Health & Industries and the Mayor of Indore.



IBE NEWS - EUROPEAN EPILEPSY DAY, 14TH FEBRUARY 2011

• **European Epilepsy Day**, an initiative of the **International Bureau for Epilepsy (IBE)** supported by the **International League Against Epilepsy (ILAE)**, to which EU President **Jerzy Buzek** has sent his message of support, was officially launched on 14 February, to coincide with Valentine's Day; Valentine being the patron of epilepsy.

Representatives from **26 patient epilepsy association in 20 European countries** attended a number of events in the EU Parliament in Strasbourg.

The events are hosted by **Gay Mitchell MEP** and supported by the **EPP Group**. IBE President **Mike Glynn** and ILAE President **Nico Moshé** also attended, together with a representative from the World Health Organization (WHO), which partners IBE and ILAE in the Global Campaign Against Epilepsy.

IBE President Mike Glynn said:

"Epilepsy is more than a medical diagnosis. It is a condition that brings with it serious social, economical, physical and psychological consequences for the person receiving the diagnosis and for family members and carers. In launching **European Epilepsy Day**, IBE, supported

by ILAE plans to bring about real change for the 6 million people with epilepsy living in Europe."



ILAE President Nico Moshé stated:

"It is very important to highlight the fact that epilepsy can be a potentially devastating disorder that can kill. We must bring the attention of the general public, governments and funding agencies to the plight of people with epilepsy, many of whom suffer from ongoing

seizures and associated comorbidities including SUDEP (Sudden Unexpected Death in Epilepsy)."

Facts about Epilepsy

- Epilepsy is a collective term for a large group of disorders of the brain that are characterized by seizures.
- A seizure is like an internal electrical storm. It is the consequence of abnormal, excessive discharges of nerve cells.
- Seizures are symptoms of the disorder, they are not the disorder itself, yet it is the seizures and associated stigma, rather than the condition itself, which ruin the lives of people with epilepsy.
- Epilepsy is the most common serious brain disorder and a global problem that recognizes no class distinction or global boundary, affecting all ages, races, social classes, and countries.
- Forty per cent (40%) of children with epilepsy have difficulty at school; PWE in Europe experience high levels of unemployment; and people with epilepsy are exposed to stigma and prejudice.
- **Based on a UK government report, it has been shown that SUDEP (Sudden Unexpected Death in Epilepsy) is responsible for 33,000 deaths in Europe each year, of which 40% are preventable.**
- **With appropriate treatment, up to 70% of people with epilepsy become seizure-free. Yet only 40% of people with epilepsy in Europe receive appropriate treatment.**

ILAE NEWS- PRESIDENT'S MESSAGE



Dr Nico L Moshe, President ILAE has send the following message:-

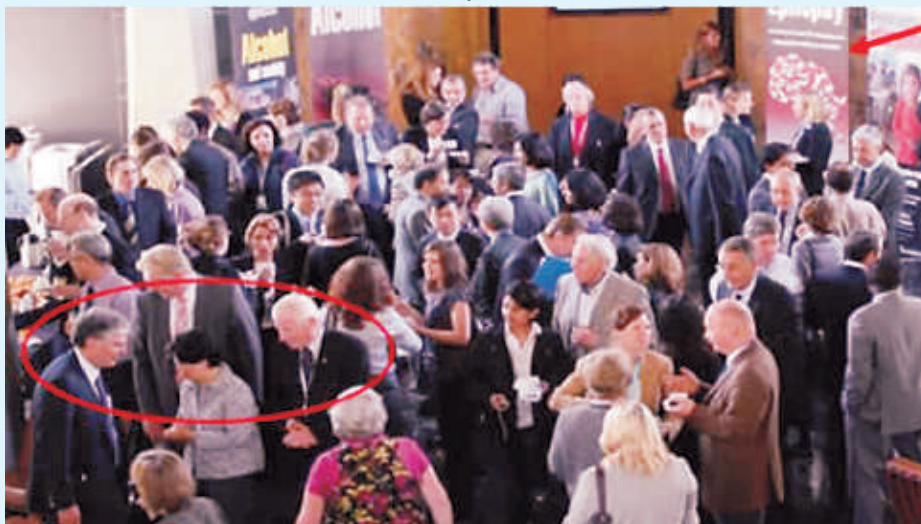
During the past year the League has continued its worldwide campaign aimed at improving epilepsy care by emphasizing education and research. At our

Solomon (Nico) L Moshé Centenary Celebration in Budapest, we set an aggressive agenda as outlined in the article "The ILAE at the Threshold of Its Second Century: Year 1" (*Epilepsia* 52:185-87; <http://www.epilepsia.com>).

In November 2010 the League met with representatives of the African Chapters in Senegal, and the meeting resulted in the much anticipated formation of the Commission on African Affairs (CAA) which is now chaired by Dr Gallo Diop.

The League was invited to participate at the WHO-organized meeting entitled "Mental Health GAP Forum" held in Geneva on 7 October 2010. We wish to express our deepest appreciation to Dr Shekhar Saxena, Director of the Mental Health and Substance Abuse Department, for all his efforts in support of epileptology worldwide.

The photo (in center) was taken at the launch of the "Intervention Guide" at the World Health Organization "MHGAP Forum" in Geneva, Switzerland on 7 October



Dr Margaret Chan, Director General of WHO, discussing with Dr Mike Glynn and Dr Solomon Moshé, issues related to epilepsy (circle). The arrow points to the Epilepsy Poster, describing the WHO-related activities.

2010. Attendance included 22 member states, 11 ambassadors, WHO Collaborating Centers and other international organizations, including ILAE and IBE, which contributed their strategic guidance to the WHO on raising the priority given to mental health.

A landmark publication was the launch of the **EURO GCAE Report** in Porto in August 2010. This report outlines the status of epilepsy care within the European region and provides a common basis for working toward broad solutions to the many problems that vex our patients.

Together with the IBE we have formed a joint Task Force to address issues relating the support of epilepsy

care and research within the European community. Our goal is to enlighten health officials and ministers of countries comprising the European Union, as to how we can augment epilepsy research and provide improved care.

In the year 2011 we will celebrate the 50th Anniversary of the IBE and the 75th Anniversary of the American Epilepsy Society. We congratulate both organizations for reaching these milestones, and look forward to a brighter future for people with epilepsy.

A report from our Latin American colleagues is in preparation, and will address issues affecting the Americas in collaboration with the Pan American Health Organization (PAHO).

For full message see website:- ilae-epilepsy.org

ECON-2011-LUDHIANA - 12TH JOINT ANNUAL CONFERENCE OF IEA & IES, 25-27TH FEBRUARY 2011

Reported by Dr Gagandeep Singh, Ludhiana



Dr PU Shah, President IEA addressing the Audience

The 12th Joint Annual Conference of Indian Epilepsy association and Indian Epilepsy Society and Pre-Conference Workshop was held at Ludhiana on February



Section of the Audience

25-27, 2011 at Hotel Majestic Park Plaza, Ludhiana.

The theme of the one-day Pre-Conference Workshop held on February 25th was "Seizures, Semiology and Syndromes". The workshop faculty comprised of Dr Samuel F Berkovic (Melbourne, Australia), Dr Matthew Walker, London, UK), Dr Kurupath Radhakrishnan (Thiruvananthapuram), Dr Jayanti Mani (Mumbai), Dr Sangeeta Ravat (Mumbai), Dr Ashalata Radhakrishnan (Thiruvananthapuram), Dr Parampreet Kharbanda (Chandigarh) and Dr Gagandeep Singh

(Ludhiana). The workshop program was carefully designed and conceived by Dr Parampreet Kharbanda. It comprised of didactic lectures as well as interesting and interactive case discussion by Dr Nandan Yardi, Dr Manjari Tripathi and Dr JMK Murthy.

The main conference commenced on the morning of February 26th. Six papers were presented for the award paper session. The competitors for the award paper session included Dr Monika Singla (Ludhiana), Dr H Hassan (Thiruvananthapuram), Dr G Dash (Thiruvananthapuram), Dr G Gupta (Kanpur), Dr M Jain (Ludhiana) and Dr Dhananjay Duberkar (Ludhiana).

The IES Presidential Oration was delivered by Dr Satish Jain, who spoke on "Indian Epilepsy Society – making virtue of a necessity". This was followed by the B C Bansal and Uma Bansal Oration and the B M Sharma Oration. Both Dr B.C Bansal and Dr B M Sharma were present during the orations.



Dr Satish Jain receiving the Presidential Oration Award from Dr Prabhakar and Dr Mehndiratta

The B C Bansal and Uma Bansal Oration was delivered by Prof M M Mehndiratta (Juvenile myoclonic epilepsy – is it really benign?), while the B M Sharma oration was delivered by Dr Sam Berkovic (Sodium channels and

ECON-2011-LUDHIANA - 12TH JOINT ANNUAL CONFERENCE OF IEA & IES, 25-27TH FEBRUARY 2011



Prof BM Sharma Oration Award for Dr Sam Berkovic

epilepsy: from clinic to basic mechanisms). Guest lectures were also delivered during the meeting by Dr IMS Sawhney (Swansea, Wales; "Epilepsy in the



Dr Mehndiratta receiving the B C Bansal and Uma Bansal Oration Award from Dr B C Bansal

teens"), Honourable Justice Ravindra Bhat (New Delhi; "The law and epilepsy") and Ms Merry Barua (New Delhi; "People with epilepsy, the CPRD and the new law"). Two topical symposia were organized; the topics and speakers included: Cortical dysplasias: (Dr Vrajesh Udani, Mumbai, Dr Kesav Das Chandrashekar, Thiruvananthapuram and Dr Matthew Abraham, Thiruvananthapuram) and Seizure Emergencies (Dr Joy Desai, Mumbai, Dr Matthew Walker, London, UK and Dr JMK Murthy, Hyderabad).

The Conference also featured a clinico-pathological conference, for which the clinical discussant was Dr Malla Bhaskara Rao (Mumbai) and the pathological discussant was Dr M C Sharma (New Delhi); and a debate on the steps to reduce treatment gap in epilepsy. The debate revolved around community measures to improve access to simple antiepileptic drugs (supported by Dr S Haque Nizamie (Ranchi) and measures to provide more advanced treatments including epilepsy surgery to more and more people (Dr Manjari Tripathi, New Delhi). Six platform presentations in addition to the award papers and 27 posters were presented during the Conference. Awards were given for the best paper and posters.

On February 27, a special session was organized for people with epilepsy and their carers. During this session, Dr Apoorva Pauranik (Indore) spoke on "The portrayal of epilepsy in films and media in India" and



Dr Urvashi Shah receiving the H C Bajoria Award from Dr Pravina Shah and Dr Sangeeta Ravat

Dr Debashish Chowdhury spoke on "The making of a film on epilepsy". Two short films were screened: "Mirgi sahi gyan, sahi samadhan: the story of Priya" and "Asha – the hope". The former was developed under the aegis of

ECON-2011-LUDHIANA - 12TH JOINT ANNUAL CONFERENCE OF IEA & IES, 25-27TH FEBRUARY 2011



Poster Session

Indian Epilepsy Society and the latter was conceived and developed by Dr Nirmal Surya (Mumbai). A street play on epilepsy was also shown. This was developed by Mr. Ashok Lal with inputs from Ms Priyanka Malhotra (both from New Delhi).

The H C Bajoria Award was presented to Dr Urvashi Shah (Mumbai). She spoke on "Beyond seizures: optimizing epilepsy management". In the K S Mani Patient Forum a lively public debate was conducted. The topic of the debate was "To reveal or not to reveal (the diagnosis of epilepsy)". Mr K V Murlidharan (Bengaluru) spoke for the motion and Mr Rizwan Mirja (Indore) spoke against the motion. The Conference concluded with the Valedictory Function. Awards to the participants in the Patient Forum the awards for the best and second-best posters in both medical and non-medical categories and the Best ward Paper (medical category) were presented during the Valedictory Session.

In all, the Conference was attended by 274 delegates. The Conference was inaugurated by Sh Sunil Kant Munjal, Managing Director, HeroCorps Ltd.,

and President, Managing Society, Dayanand Medical College, Ludhiana. Ms Merry Barua, Chairperson of Action For Autism was the Guest of Honour. The Chief Guest spoke at length on the social scene involving epilepsy in the country. The delegates were addressed during the inaugural ceremony by Dr Pravina Shah, President, Indian Epilepsy Association, Dr Satish Jain, president, Indian Epilepsy Society and



Street Play on Epilepsy

Dr Man Mohan Mehndiratta, Secretary to both Indian Epilepsy Association and Indian Epilepsy Society. The Inaugural Function was followed by an entertaining magic show given by Samrat Shankar.



Entertaining Magic Show

NATIONAL EPILEPSY DAY

ANDHRA PRADESH - TIRUPATI

Reported by: Prof B Vengamma, Tirupati

From 9th November, 2010 to 12th November, 2010 the faculty and students of the SVIMS College of Nursing organized Awareness Programmes on Epilepsy in Twelve High Schools located in and around Chandragiri area of



Chittoor District for the benefit of students of higher classes, parents and the Teachers.

The Programmes were inaugurated on 9th November, 2010 at the Government Boys High School by Dr B Vengamma, Director, Professor of Neurology & President, Indian Epilepsy Association, Tirupati Branch.

Lecture cum Demonstration methods with the help of Audio Visual aids, were utilized for conveying the message regarding various aspects of Epilepsy. The topics covered are:

1. Causes and Risks
2. Clinical aspects
3. Superstitions and Facts
4. Management
5. Education & Employment



6. Women with Epilepsy

7. Do's and Don'ts

8. Rehabilitation & Responsibility of the Society

The programmes were interactive in nature and the young students, parents and teachers were greatly benefited by the programmes.

The 142nd monthly camp for persons with Epilepsy was held on 21st November, 2010 (Third Sunday of the month). About 650 persons with Epilepsy and about 150 patients' attendants were present.

The students of the College of Nursing, SVIMS, enacted a Skit on the theme "Women with Epilepsy – Their Quality of Life" bringing out various phases in the life of affected women, which was very well appreciated.

An awareness programme with the help of Posters was also organized by the students of the College of Nursing, SVIMS for the benefit of Persons with Epilepsy and their attendants.



Sri J Sathyanarayana IAS, Chairman, Specified Authority, Tirumala Tirupati Devasthanams, Tirupati was the Chief Guest. Dr B Vengamma, Vice Chancellor and Director of Sri Venkateswara Institute of Medical Sciences, Tirupati, was the Guest of Honour. Dr B Vengamma, Professor of Neurology, SVIMS, Tirupati, and President of the Tirupati Branch of Indian Epilepsy Association, outlined the significance of the National Epilepsy Day.

She also reported about the camps being held for the past 142 months where in One Month's requirement of Medicines are distributed FREE to all the persons with Epilepsy who attend the camp.

The Chief Guest was greatly impressed by the service activities of the Tirupati Branch and assured of all help to sustain and improve the activities of the Branch.

NATIONAL EPILEPSY DAY

DELHI-GTB HOSPITAL

Reported by: Dr LC Thakur, Delhi



We celebrated National Epilepsy Day on 18th November 2010 by a public lecture which was delivered by Dr LC Thakur Director Professor and Head of Department of Neurology, GTB Hospital & University College of Medical Sciences, Dilshad Garden Delhi. On Public awareness and participation in dealing with children with Epilepsy. Main stress was on their Education and discrimination they face at School and in the society at large. Social aspects were also taken for discussion.



There was also a question and answer session direct with public. They very much appreciated the session and demanded more of such discussions in future as well. A drawing competition was also held for Epileptic Children who attended Neurology Clinic. Prizes were also



distributed to encourage them to continue with their creativity and should not be inhibited because of their disease. Children took it very sportingly and were very happy and cheerful in this activity.



NATIONAL EPILEPSY DAY

MAHARASHTRA-KDA HOSPITAL, MUMBAI

Reported by: Dr Jayanti Mani, Mumbai



Lto R: Dr Shekhar Patil, Dr Jayanti Mani
Dr Pravina Shah, Ms Archana
Ms Priyanka and Dr Malla Bhaskara Rao

Five million people with epilepsy are living in India. A number of governmental and non-governmental organizations work for the betterment of these people. In India, the National Epilepsy Day is celebrated on November 17, every year with various educational and



Dr Pravina Shah giving a prize to the winner of the Epilepsy Quiz awareness programmes for doctors as well as people with epilepsy.

Kokilaben Dhirubhai Ambani Hospital & Medical Research Institute celebrated the national epilepsy day by conducting a day long event on the Sunday, 21 November 2010.

The morning session was a **scientific programme** for doctors, including general practitioners, physicians and pediatricians. Dr Jayanti Mani, Neurologist, Dr Shekhar Patil, Pediatric Neurologist and Dr Malla Bhaskara Rao, Neurosurgeon presented scientific data highlighting the recent advances in the diagnosis and management of epilepsy, including surgery for drug resistant epilepsy. During the interactive session with a number of doctors, illustrative cases have been presented and questions were answered.



A rapt audience at the patient education session

The afternoon session was an epilepsy **awareness programme for people with epilepsy** and their families. Short informative talks discussed the myths and facts about epilepsy followed by the screening of a film on epilepsy. People with epilepsy shared their personal experiences about living and coping with epilepsy.

They also actively participated in the quiz on epilepsy, as well as during the question and answer session.

The highlight of the meeting is launching of satellite activity center of the self-help group for people with epilepsy by Dr Praveena Shah, eminent neurologist of Mumbai.

NATIONAL EPILEPSY DAY

EPILEPSY WEEK-MAHARASHTRA - NAGPUR

Reported by: Dr Sachin Joshi, Nagpur

We conducted a free diagnostic camp at Chindhwarra on 14/11/2010. The camp was held in association with Lions



Club. We tried to reach to patients with help of flex banners, handouts and local GP's help. The camp was highly successful with attendance of 154 patients attending the camp. First we played the CD on epilepsy education for the people attending the camp. The people appreciated the CD. All patients were evaluated and free distribution of the medicines was done. Approx. 60% of the total patients were having general tonic clonic seizures, 20% were complex partial and 20% were focal epilepsy. Nearly 20% patients were consulting a neurologist for the first time.

Dr Nitin Chandak, Dr Mukund Baheti, Dr Nilesh Agrawal, Dr Pawan Adatiya, Dr B D Deshmukh and Dr Ankur Jain treated the patients and also answered many queries from the patients. Mrs Nandini Baldeshmukh noted social worker of our branch counselled all the patients and emphasised importance of regular treatment. All the patient were given the handouts and leaflets. Mr Dinesh Potdar and Adv. V N Patil worked hard to make the camp successful.

We celebrated epilepsy day by conducting various awareness programmes at high schools as per your instruction to reach out high school students.

On 19th of November, we conducted a programme at Tandapeth High School. Dr Pawan Adatiya, Psychiatrist conducted the programme. Students from 5th standard to 10th Std attended the programme.

On 24th November we conducted programme at the Dyanvikas School. Dr Ankur Jain Neurologist delivered a lecture for nearly 250 students. He tried to dispel myths about epilepsy by giving scientific information to the students.

On 26th November we conducted a programme at Nagpur High School. Dr BD Deshmukh, ex-President IEA



(Nagpur Chapter) delivered a lecture for nearly 200 high school students.

At every school, we started the programme by showing CD on the epilepsy which made our speakers task of teaching about epilepsy a lot easier. At every lecture, every speaker tried to emphasis on good, clean hand wash to prevent neurocysticercosis. Every speaker patiently answered enthusiastic queries from the students.



UTTAR PRADESH-LUCKNOW

Reported by: Dr Atul Agarwal, Lucknow



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 by the Chief Guest.

Swami Shri Para Roopanand ji Maharaj of Ram Krishna Mission, Lucknow (provided by Abbott pharma). All the participants were also given coloring books, tiffin boxes and participation certificates. After the competition Public awareness lectures were given by various specialist. Dr. Atul agarwal discussed about various types of epileptic fits and importance to recognize them by details of history to be obtained from patient, family members & other eye witness. Dr Niranjan K singh elaborated on management issues, first aid, do's & don't and other precautions to be observed by patients. The audience consisted of children and their parents and questions were answered by experts.

Dr Atul Agarwal spoke on Epilepsy on FM channel Lucknow discussing myths associated with the illness.

18 Nov2010, 8am. Dr Atul Agarwal told students and teachers of “St Columbus Inter College, Gomti Nagar, Lucknow” about Epilepsy, its causes, first aid, various myths associated with illness.

24 Nov. An Epilepsy Quiz was held for undergraduate students of Era Medical College, Lucknow by Prof. Ajay Kohli. Dr Atul Agarwal presented 75 interesting questions. First prize was given to rashi jha. Participation certificates were given to all. (Supported by Novartis Pharma).

24 Nov. Posters competition on Epilepsy was held for students of Era Medical College, Lucknow First prize was won by team of Rashmi Jha.

Dr Atul Agarwal told students and teachers of Hal School, Faizabad Road, Lucknow on 20th Nov about epilepsy, its



causes, first aid, various myths associated with illness. Bookmarks provided by central office of Indian Epilepsy Associated were distributed to students during these interactive sessions at schools.



मिर्गी : इलाज करायें, झाड़-फूंक नहीं

मिर्ची दिवस आज लखमऊ (एरुदुमली)। मिर्ची कोई बेशकी की है, यह केवल दिमाग में घुंघुने वाले विद्वान लोगों में हीने वाले मनुष्य ही है। अर्थात् न्यूट्रिशनियस्ट प्रोफेसर अजुन आम्बाल के अनुसार यहिल के

भिर्गी के कारण

- ▶ व्यवसाय में लम्बे समय तक सुखद आना
- ▶ सुपोर्टिव में गिर में चौड़ा सपोर्ट लाना
- ▶ रक्त में होने वाला संक्रमण
- ▶ डीन लाम्प
- ▶ रीनिगवर्स्टिस व अन्य यौनरोग संक्रमण
- ▶ परिवार में किसी को होने में खतरा

इलाज के लिए सलाह

१. चित्त में धीमे रहना
 २. विभिन्न देश जेतने
 रहना।
 ३. एक वक्र में
 धीरे धीरे घुमने पर जल्द
 ही चित्त भ्रम हो।
 ४. चित्त को उपवास
 में रहने दुर्लभ रहना।
 ५. आश्चर्य को स्मरण में
 होना।
 ६. चित्त में उपवास
 में रहने धीरे धीरे को कहते
 हैं।
 ७. चित्त को जितने जितने

[illegible]

तत्काल चिकित्सक से संपर्क करें यदि

- ▶ झटका पेश निम्न से ज्यादा समय तक रहे
- ▶ एक सप्ताह में दो बार झटके आना
- ▶ गर्भाशय में झटके आना
- ▶ गर्भि के दौरान मरीज की स्थिति संभर होना
- ▶ झटके के बाद स्थानांतर होने में ज्यादा समय लगना
- ▶ लंबे समय पर होना, भयानक या ख़तरा में लगना

आज

संज्ञासूचक २९ अक्षरानां २-०-१० मी. ३ मी. ३

जुता संधाना कर सकता

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है नुकसान

[illegible]

Unsafe delivery of child may result in epilepsy

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NATIONAL EPILEPSY DAY

FREE MEDICAL CONSULTANCY & DIAGNOSIS CAMP, MORADABAD-UP

Reported by: Dr Tarun Agarwal, Moradabad

In our mission “एक अभियान... अन्धेरे से... उजाले की ओर”, this year



on the occasion of Epilepsy day, we organized a Free Medical Consultancy, Diagnosis & treatment camp at Neuro Care Clinic, Gandhi Nagar Moradabad on dated 21st November Sunday, which was Seventeenth in the row.

In this Camp around 268 patients were given free consultation. This free consultation will valid for round the



year. In this camp the patients came from all around the UP, Uttarakhand and even Delhi also.

This day was specially marked to spread the awareness regarding Epilepsy to the general public and especially for Women, which was the theme of the year 2010 by IEA i.e. “women & Epilepsy”.

In this camp 79 EEG, 28 CT-Scan, 10 MRI were done free of cost. Free Drugs distributed to promote drug compliance. Tea and snacks were also distributed to the patients and their attendants throughout the day.

We also showed how to live with epilepsy & various safety issues and common tips at various places- at work, while travelling etc through posters and videos. Epilepsy related literatures were also distributed.



A lot of coverage has done by local news channel before and after the camp. We have also given the advertisement in various leading newspapers like Hindustan Times, Amar Ujala, Dainik Jagran, Dainik Aaj, Yug Bandhu who covered the surrounding areas.

We also received kind Co-operation by Diagnostic Centers- Mohan CT & MRI centre & Amit MRI centre.



IES - EPILEPSY TEACHING PROGRAMME

Reported by: Dr P Sarat Chandra, New Delhi



The epilepsy teaching programme was held in Orissa for the first time, this was in keeping with the goals of the ETP to bring epilepsy teaching to the physicians and pediatricians.

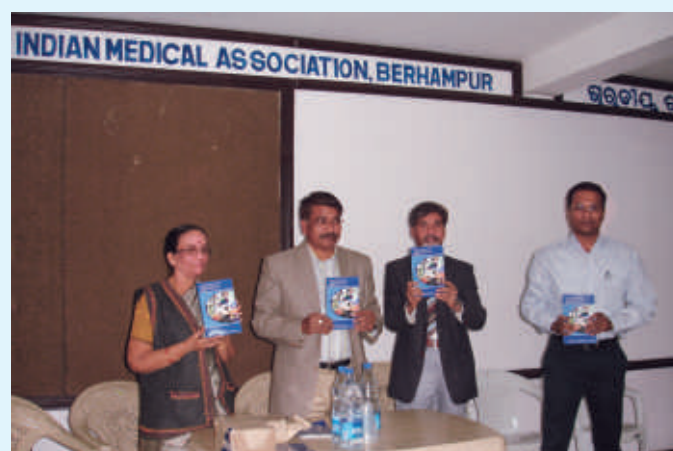
This was received enthusiastically by about 175 physicians and pediatricians in and around the town of Berhampur. The venue was the Indian Medical Association Hall on the 20th December 2010. The program was conducted by Dr Manjari Tripathi, Dr P Sarat Chandra, Dr Sunil Aggarwal, Dr Uma Padhy and Dr P Suvarna Devi.



The standard set of teaching material was that of the ETP it was for the first time that such an event was organized in this part of the country. Classification, videos of seizures, when to treat a first seizure, anti epileptic agents, refractory epilepsy were also covered.

The GEMIND was released for the first time in Orissa and 200 copies were distributed.

This was followed by viewing of the movie on epilepsy and its awareness by villagers from nearby villages and volunteers from the 19 teaching program saw persons and children with epilepsy from remote areas of the state. The persons and children with epilepsy had been sounded about the camp and collected by an ever enthusiastic team of PHC and CHC doctors who had participated in the program.



The entire 2 day event was very fruitful and a promise and request for such further interactions was an indication of its success.

The camps were conducted under the aegis of iREAP Indian rural epilepsy education and prevention.



AMERICAN EPILEPSY SOCIETY MEETING IN SAN ANTONIO USA-03-06 DEC 2010 - HIGHLIGHTS

The meeting had over 1200 presentations and 4500 attendees.

The co-existence of epilepsy in people with psychogenic non-epileptic seizures indicates a prevalence of 30-60% of epilepsy in PNES. More recent studies have demonstrated an incidence of 9-13% suggesting that discontinuation of AEDs in a patient with no significant risk factors for epilepsy might be a reasonable course of action. About 98% of patients with PNES have an affective disorder during their lifetime.

- To identify a conductor in the neuronal orchestra, just find where the GABA cells are.

The music analogy is fairly powerful as inhibitory cells are responsible for the tempo in the circuitry. I also finally understood why benzodiazepines which work great for status epilepticus early, lose their efficacy late in SE. The explanation has to do with the turnover of GABA-A receptors, the internalization of receptors with selective subunit composition, leading to a progressive use-dependant reduction of GABA-A mediated inhibition (Goodkin et al., 2008, Goodkin & Kapur, 2009).

- At the Antiepileptic Therapy symposium, the emphasis was on the KCNQ1 channel that is expressed in heart and CNS, and a loss of function mutation of KCNQ1 results in prolonged QT syndrome and seizures in mice (Goldman et al., 2009; Glasscock et al., 2010).
- The pro-convulsant functional interaction between Interleukin 1-beta and NMDA receptors (Balosso et al., 2008), might explain in part, why our epilepsy patients often have exacerbations of seizures during minor systemic illnesses. The role of Interleukin 1-beta, interaction with NMDA receptors, and the Toll-like receptors are also upregulated in human epileptic brain and their activation by HMGB1 appears also pro-convulsant (Maroso et al., 2010). Experiments demonstrating Interleukin 1-beta levels after a febrile seizure were predictive of developing subsequent epilepsy in experimental model (Dube et al., 2010).

- Camfield and colleagues examined whether children with intractable focal epilepsy experienced a substantial period of remission at 10-30 years of follow-up.

- Hesdorffer and colleagues discussed a meta-analysis of pooled data from several epidemiological studies on SUDEP extracting the most powerful risk factors.

- Christensen and colleagues presented mortality data in a large Danish cohort of people with epilepsy, and Meador and colleagues revealed the age 4.5 year results of the NIH study on cognitive functions of children exposed in utero to antiepileptic drugs.

- ILAE symposium addressed differences in clinical trials for seizure drugs across the world for randomized control trials for regulatory approval of antiepileptic drugs in Europe (pragmatic comparative trials) as compared to the United States (placebo controlled trials), and doing epilepsy surgery with fewer diagnostic tests as compared to multiple tests which gives great hope for many patients with intractable epilepsy in the countries with few resources. A pilot study in Uganda (Boling et al., 2009), a country with a GDP of \$1,200 per capita perform standard anterior temporal lobectomy at a cost of \$100 dollars. The consortium placed one video EEG bed in a pediatric hospital and trained nurses. Out of 10 cases operated, 60% were seizure-free and 20% had >90% improvement in seizure frequency. These results appear comparable to the full-dress approach that might cost several thousands of dollars.



Dr Manjari Tripathi (Treasurer IES) carried forth a message inviting AES members to participate in ECON held in February every year.

In the past notable AES members have been invited as Orators and Guest Speakers. Membership opportunities, workshops and teaching program could also work for delivering this program.

We will like to continue with this good practice.

NEWS & VIEWS ON DRUGS

LONG-TERM USE OF LACOSAMIDE ON PARTIAL-ONSET SEIZURE FREQUENCY

Lacosamide reduced seizure frequency and improves patient-reported quality of life measures on a long-term basis.

An open-label extension study analyzed patient-reported outcomes and found that, after a year of treatment patients reported significant improvements in all aspects of seizure severity and across almost all health-related quality of life (HRQoL) assessments, including social functioning and emotional well-being.

Source: AES Meeting, San Antonio, USA

Dec 3-6, 2010.

OPEN-LABEL EXTENSION STUDY OF USL255 (EXTENDED-RELEASE TOPIRAMATE) FOR PARTIAL ONSET EPILEPSY

PREVAIL, the Phase III study, is being conducted under a Special Protocol Assessment (SPA) agreements with the U.S. Food and Drug Administration (FDA). The PREVAIL study is entitled "Randomized, Multicenter, Double-Blind, Placebo-Controlled, Parallel-Group, Phase III Study to EVALuate the Efficacy and Safety of USL255 as Adjunctive Therapy In Patients with Refractory Partial-Onset Seizures."



CLOBAZAM EFFECTIVE IN LGS

The frequency of drop seizures declined significantly for patients with Lennox-Gastaut Syndrome (LGS) who received the highest doses of clobazam in a double-blind, placebo-controlled trial.

Patients in the 0.5-mg dose group experienced an average decrease of 47.8% and those in the 1.5-mg group had an average decrease of 69.5%.

In the trial, 238 patients aged 2-60 years with clinical and EEG-confirmed LGS who experienced drop seizures during a 4-week baseline phase were randomized to placebo or 0.25 mg, 0.5 mg, or 1.5 mg of clobazam up to a maximum daily dose of 40 mg. Following the treatment period (a 3-week titration phase and a 12-week maintenance phase), the investigators compared the percentage decrease in mean weekly drop seizures during the maintenance phase against the baseline rate for the modified intention-to-treat population of 217 patients.

Source: AES Meeting, San Antonio, USA

Dec 3-6, 2010.

FDA ADDS LEVETIRACETAM TO WATCH LIST

The US Food and Drug Administration (FDA) has released its latest list of drugs to monitor based on potential signs of serious risks or new safety information identified in the agency's Adverse Event Reporting System (AERS).

Levetiracetam Stevens-Johnson's syndrome,
(Keppra, UCB Inc) toxic epidermal necrolysis

The agency is also studying the 12 other drugs to determine whether they are causally linked to the possible risks reported through AERS from July 1, 2010, through September 30, 2010. In the meantime, the FDA considers them pharmacologically innocent until proven guilty. Physicians should not stop prescribing these drugs, therefore, nor should patients stop taking them, according to the agency.

NEWS & VIEWS ON DRUGS

SUDEP LINKAGE WITH LAMOTRIGINE

Two new studies have found an association between lamotrigine and increased risk for sudden unexplained death in epilepsy (SUDEP).

One study, a pooled analysis of previous case-control studies, showed lamotrigine therapy was associated with SUDEP. This analysis also uncovered additional risk factors that have not been previously reported, including female sex and learning disability.

The second analysis, a retrospective, population-based study, suggested that women in particular taking lamotrigine may be at higher risk for SUDEP.

Combined Analysis

The first study, a combined analysis of 4 previously published case-control studies from the United States, Sweden, Scotland, and England, was performed by the Epidemiology Task Force of the International League Against Epilepsy (ILAE) and funded by the ILAE.

The 4 studies each included between 20 and 149 cases and between 80 and 602 controls. The combined analysis consisted of 289 cases and 958 controls.

For the study, SUDEP was defined as (1) having a history of epilepsy, defined as one or more seizures during a 5-year period; (2) death occurring suddenly; (3) death unexpected with no life-threatening illness; and (4) death remaining unexplained after all investigative efforts, including autopsy. Definite SUDEP included criteria 1 through 4 and probable SUDEP included criteria 1 through 3. SUDEP is the most common condition-related cause of death in chronic epilepsy.

Previous case-control studies had found that increased frequency of generalized tonic-clonic seizures, polytherapy, increased duration of epilepsy, and younger age at onset carry an increased risk for SUDEP.

The new pooled analysis confirmed these associations and identified other factors that appear to increase the risk for SUDEP.

Lamotrigine therapy was associated with a significantly increased risk, with an adjusted risk ratio of 1.88 (95% confidence interval, 1.23 – 2.87). Female sex was also a

risk factor, and, in subgroup analysis, learning disability and alcohol abuse were also associated with SUDEP risk.

The association between lamotrigine therapy and SUDEP was first observed in 2007 in a case series — but the association still needs further study.

Possible mechanisms could be lamotrigine is less effective in idiopathic epilepsy syndromes, or its cardiac effects.

Retrospective Review

The second study investigated the potential relationship between SUDEP and anticonvulsants through a review of hospital records and post mortem reports of deceased people with a diagnosis of epilepsy, along with data from the national Causes of Death Registry in Norway. Dag Aurlien, Stavanger University Hospital in Norway.

During a 10-year period in the Norwegian county of Rogaland, which has a population of 375,000, the researchers identified 26 patients with SUDEP, including

15 females and 11 males. All but one were taking AED medication, either as monotherapy or as polytherapy. Ten of the 26 were taking lamotrigine, 7 were treated with carbamazepine, 8 with valproate, 3 with vigabatrin, 3 with oxcarbazepine, 3 with phenytoin, 2 with topiramate, and 1 with phenobarbital. Of the 10 patients taking

lamotrigine, 9 were female and 1 was male.

This study found a statistically significant higher incidence of SUDEP in patients treated with lamotrigine also a higher incidence of SUDEP among women treated with this LTG.

Interpret With Caution

Asked to comment on these 2 studies, Donna C. Bergen, MD, professor of neurological sciences at Rush University Medical Center, Chicago, said Well-controlled, prospective monotherapy studies of SUDEP would be the ideal way to study.

SUDEP is estimated to account for between 8% and 17% of deaths in people with the disorder, with an overall higher incidence of SUDEP in males. The mortality rate is higher among people with epilepsy than in the general population.

Source: AES Meeting, San Antonio, USA Dec 3-6, 2010.



NEWS & VIEWS ON DRUGS

ELAN PHARMA SENTENCED FOR OFF-LABEL MARKETING OF

Elan Pharmaceuticals, Inc. (EPI) pleaded guilty today to a misdemeanor violation of the Food Drug and Cosmetic Act for the illegal promotion of the epilepsy drug Zonegran. Elan was also sentenced to pay a criminal fine of \$97 million and forfeit \$3.6 million in substituted assets.

In addition to the criminal plea.

Elan promoted the sale of Zonegran for a wide variety of improper off-label uses including mood stabilization for mania and bipolar disorder; migraine headaches; chronic daily headaches; eating disorders; obesity/weight loss; Parkinson's Disease; monotherapy and for a variety of seizures in children under the age of 16.

When companies and their employees are identified, they will be held accountable for their illegal activity.



"The inherent vice of capitalism is the unequal sharing of the blessings. The inherent blessing of socialism is the equal sharing of misery"

W. Churchill

NEW EPILEPSY TREATMENTS ON THE HORIZON

Perampanel

Perampanel, a selective, noncompetitive alpha-amino-3-hydroxy-5-methyl-4-isoxazolepropionic acid (AMPA) receptor antagonist was tested as an add-on therapy for partial onset seizures in the first of three multinational, placebo-controlled trials.

In the Eisai-sponsored study of perampanel, 712 patients aged between 12 and 72 years with refractory partial seizures were randomized to treatment with 2, 4, or 8 mg/day of perampanel or placebo following a 6-week

baseline phase. The patients were being treated with 1-3 concomitant antiepileptic drugs.

At the end of the 19-week treatment phase, the median change in seizure frequency from baseline for the intention-to-treat

population was significant in the 4-mg and 8-mg groups, with reductions of 28.6% and 33.5%, respectively, compared with nonsignificant reductions of 16.3% and 13.8% in the 2-mg and placebo groups, respectively. The treatment phase included 6-week titration and 13-week maintenance periods.

Treatment-related adverse events – most often dizziness, somnolence, and headache – caused a low number of patients in each group to withdraw from the trial.

G.L. Krauss, professor of neurology at Johns Hopkins University in Baltimore.

Source: AES Meeting, San Antonio, USA Dec 3-6, 2010.

RESEARCH IN EPILEPSY

MORE UNCONTROLLED SEIZURES AND DRUG-RELATED SIDE EFFECTS IN EPILEPSY PATIENTS WITH LOW SOCIOECONOMIC STATUS.

Patients with epilepsy and low socioeconomic status (SES) are more likely to have uncontrolled seizures, drug-related side effects, and a lower overall quality of life. The study also indicates that low SES patients used the hospital emergency room more often and had more visits to a general practitioner than epileptic patients at higher socioeconomic levels.

The Centers for Disease Control and Prevention (CDC) estimates that two million Americans have epilepsy and roughly 140,000 new cases are diagnosed each year. Epileptic patients with incomes below the poverty level in California were 50% less likely than those with higher income (not in poverty) to report taking epilepsy medication.

Disparities in healthcare may be due to access difficulties, 566 adult patients with epilepsy from three clinics in Houston and New York City serving a low-SES population, and one in Houston serving high-SES patients were interviewed at baseline regarding healthcare use, seizure frequency and type, anti-epileptic drug (AED) side effects, and outcomes during the prior three-month and one-year periods. The survey was repeated several times during the year-long study period.

Indicators of SES—income, education, employment, and insurance coverage—were significantly lower for patients at low-SES sites compared to the higher-SES site.

Low-SES patients had significantly higher likelihoods of poor outcomes—2.2 to 3.9 times more likely to have uncontrolled seizures and 4.9 to 16.3 times more likely to have AED side effects—compared with higher-SES patients.

Source: *Epilepsy and Behaviour*, Nov 2010, Begley CE

Epilepsy Therapy Project and Epilepsy.com Launch "My Epilepsy Diary" as New Android Mobile App to Improve Epilepsy Care

The Epilepsy Therapy Project (ETP), a non-profit organization dedicated to accelerating new therapies for people living with epilepsy and seizures and the parent



organization of epilepsy.com, today announced that it has expanded the use of its online epilepsy diary management tool with the launch of a new app developed to run on the Android mobile operating system.

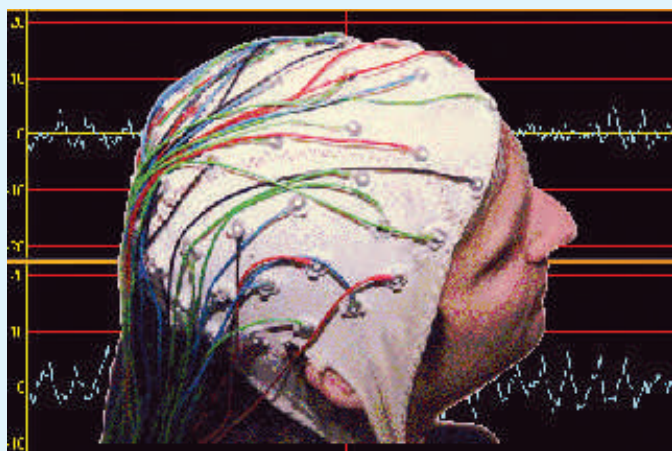
"My Epilepsy Diary" is a comprehensive data-gathering and reporting tool designed to advance epilepsy care by improving the quality, accuracy and speed in which information can be recorded and shared between patients with epilepsy and their physician.

Now available at no charge through the Android Market and on www.epilepsy.com, the My Epilepsy Diary app is yet another critical step forward by the Epilepsy Therapy Project to provide people with epilepsy with state-of-the-art tools to better manage their epilepsy.

RESEARCH IN EPILEPSY

RISK OF EPILEPSY MEASURED, MAY BE STILL HIGHER

One in 26 Americans will develop epilepsy at some point in their lifetime, according to a population-based study. Lifetime risk up to age 50 was 1.6% and rose to 3.0% at age 80.



Given the current U.S. population, nearly 12 million individuals (3.9%) can be expected to develop epilepsy in their remaining lifetime, the researchers forecast based on their findings from the population of Rochester, Minn. However the data come from individuals diagnosed 31 to 50 years ago.

The study may underestimate lifetime risk of epilepsy -- particularly for males -- since life expectancy has risen in the U.S., the researchers noted.

The lack of surveillance data gives epilepsy a disadvantage in research funding compared with other chronic conditions of similar public health impact, and hampers the public health response to it.

Hesdorffer's study marks the first to measure lifetime risk (current age through remaining lifetime, adjusted for competing risk of dying) for epilepsy, which the group called useful both for physicians and public health planning as a forecast of the burden in the community.

The impact of this calculation is greatest in the elderly who have the highest incidence, an important concern given the aging population.

The group used linked medical records from all facilities in Southeastern Minnesota to identify the 412 Rochester residents with epilepsy onset (two or more unprovoked seizures) from 1960 through 1979.

More cases were diagnosed toward the later portion of the study period, representing a trajectory of growth and aging of the population. Lifetime risk -- defined as risk through age 87 -- also increased over time, from 3.5% in 1960–1969 to 4.2% in 1970–1979.

The median age at epilepsy incidence was 25.9 years, but 26.9% were 60 or older at diagnosis.

Cumulative incidence was 0.9% to age 20, 1.7% to age 50, and 3.4% to age 80. This measure diverged from lifetime risk noticeably after age 70 as competing risk of mortality grew.

Men were more likely to develop epilepsy than women (1 of 21 versus 1 of 28).

The researchers noted that these data could be used for individual risk prediction with the usual caveats that lifetime risk was based on population estimates without taking into account individual risk factors and family history.

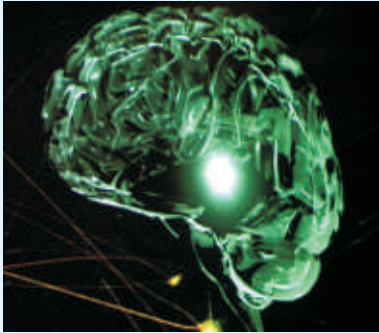
The projections would likely generalize to other developed countries with comparable sociodemographics but not those with substantially lower life expectancy.

Source:

Hesdorffer DC, et al "Estimating risk for developing epilepsy: A population-based study in Rochester, Minnesota" *Neurology* 2011; 76: 23–27.

RESEARCH IN EPILEPSY

UNCONTROLLED BRAIN ACTIVITY LINKED TO EPILEPSY



An American study has shed new light on the mechanism behind epilepsy attacks in the brain that could ultimately lead to better treatments for epilepsy.

Excessive signaling between neurons leads to epileptic seizures, astrocytes, glia can regulate those signals.

This study shows that changes in astrocytes are key to brain dysfunction and opens the potential for novel therapeutic strategies in epilepsy. Reactive astrocytosis occurs in many neurological conditions. 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 used a virus to selectively cause reactive astrocytosis without triggering broader inflammation and brain injury, in a mouse model to focus on the altered astrocytes in the hippocampus.

The study found that changes in reactive astrocytes profoundly reduced the inhibitory control over brain signals.

Reactive astrocytosis reduces the supply of glutamine synthetase which in turn decreases inhibition and allows neurons to fire out of control.

Reactive astrocytosis are known to occur in many psychiatric disorders finding may have wider implications. The researchers were able to dampen neuronal excitability in the animals' brain slices by adding glutamine.

Source: *Nature Neuroscience*, May 2010, Douglas A. Coulter, *The Children's Hospital of Philadelphia*.

MORTALITY, MORBIDITY LOW AFTER SURGERY FOR INTRACTABLE EPILEPSY

Anterior temporal lobectomy (ATL) for intractable temporal lobe epilepsy (TLE) is associated with a low morbidity rate and no mortality during a 16-year period, a new study has found.

The retrospective study found an 8% incidence of morbidity after the surgery and includes transient complications. The risk for postoperative morbidity increased with more medical comorbidities and also with increasing patient age and lack of private insurance.

The results should alleviate concerns of some neurologists that this surgery may be too risky.

Postoperative Complications

Previous research has shown surgery eliminates seizures in 60% to 80% of TLE patients compared with only 10% of patients who receive additional medications instead of surgery. Neurologic complications included (2.7%), transfusion of packed red blood cells (2.3%), and hematoma (1.2%). There was no mortality, and no patients had a deep vein thrombosis or pulmonary embolism.

The incidence of postoperative morbidity directly correlated with increasing patient comorbidity, the study authors report. The complication rate was 7.8% among those with no comorbidities compared with 25.0% in those with 3 comorbidities. Most patients were relatively healthy: 82.3% had no comorbidities, only 0.5% had 3 comorbidities, and no patient had more than 3 comorbidities.

Source: *Arch Neurol*. February 14, 2011

THE HISTORY OF THE CHILEAN LEAGUE AGAINST EPILEPSY AND THE DRUG BANKS



From a report by Dr. Carlos Acevedo Sch., President of LICHE.

The Chilean League against Epilepsy (LICHE) was founded in May 6th, 1953 by Dr. Alfonso Asenjo, with its volunteer work mainly of the delivery of the AEDs carried out by the physicians' wives of the hospital.

LICHE's work continued like this for 30 years until a fortuitous event changed the history. The wife of a famous TV show host, raised a donation US\$ 1.000 to buy AEDs. As an NGO, it was not required to pay income tax payment by selling AEDs through a Drug Bank.

Several procedures were needed to make Drug Banks work and to sell AEDs. The prices were kept 20% lower than pharmacies. The first clients were patients of physicians' members of LICHE, later extended to other Neurologists. Also, a gratuity rule was established in variable percentage that was applied according to a table that was made by a social worker and the volunteers. This way Drug Banks began to work, growing slowly but surely. This way, a kind of circuit was designed where in the first place, patients that have economic resources buy their drugs at the Drug Banks and in the second place, people with epilepsy who ask for help at the social service department, get gratuity thanks to the surplus obtained by the drugs sales.

The physicians of the Board of Directors created a list of drugs which included all available AEDs in the country and other drugs with comorbidities. The Ministry of Health requires an application each time that a new drug is added to the Drug Bank's list.

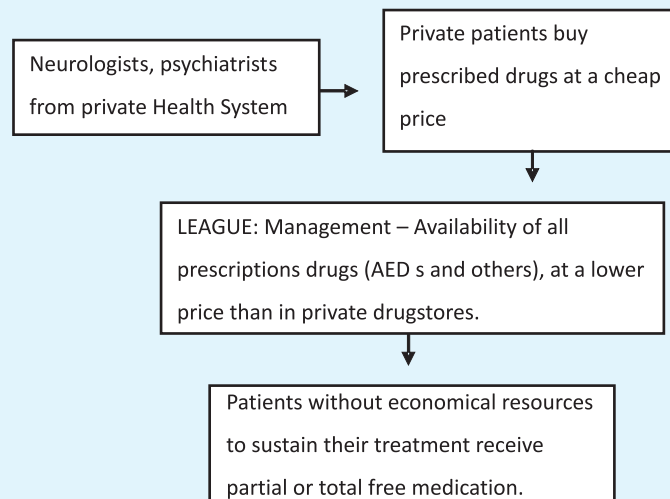
LICHE's growth has been explosive: from one headquarter downtown of Santiago, it increased to 7 Drug Banks located in different areas of the city according to social needs and market studies. Drug Banks were established in the most important cities of Chile, covering 90% of the country's population.

The economic stability and the volunteers' commitment allowed establishing, first, a social work development that helps people with epilepsy in issues such as family, education and work. Second, it allowed establishing two

educational centers, one for children with epilepsy and learning difficulties and another as a labor workshop for youngsters and people with epilepsy and mental disability. Both centers are free of charge for people with epilepsy. Third, there is a complete medical service which treats more than 3500 patients with epilepsy, many of them of high complexity. There is also a clinical laboratory to measure plasmatic levels of AEDs and an EEG laboratory.

Another important decision in LICHE's history was to create a National Association of Chilean League against Epilepsy (ANLICHE) a Full Member of IBE since 1999.

The money surplus from sale of drugs allows unaffording people with epilepsy, to receive free AEDs and other medical and laboratory services. This surplus also



finances other operations of LICHE, including 158 employees who work for the Institution and to finance social and education activities of LICHE. The volunteering and the Board of Directors work for free.

SOLIDARITY

Those who have economic resources help those that do not, to get the same AEDs and treatment.

"We are not just a cheaper drugstore".

CONCLUSION

The medications Banks constitute an original way to self-finance for institutions such as Leagues against Epilepsy and they can become an important source to help for epileptic people.

EPILEPSY AROUND THE WORLD

DUBAI



2nd East Mediterranean Epilepsy Congress in Dubai

PRINCE Bandzile patron of the Swaziland Epilepsy Organisation was invited to

attend the 2nd East Mediterranean Epilepsy Congress in Dubai.

This is in recognition of having put the Swaziland Epilepsy Organisation on the map of the Global Campaign against Epilepsy.

All the East Mediterranean countries participated.

Renowned experts in the field of epilepsy took part in the congress to share their knowledge on the educational aims of the meeting.



PRINCE BANDZILE'S ADDRESS

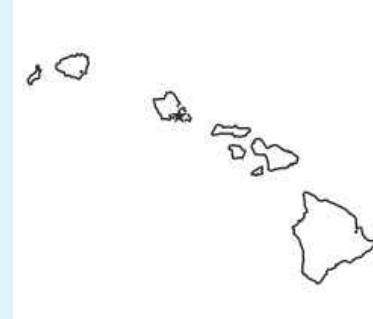
He highlighted the Swaziland Epilepsy Organisation which has established partnership with the Ministry of Health, the Deputy Prime Minister's office, such as UNICEF and others.

These benefits include;

- i) Information gathering in raising awareness and campaigns to help those affected by epilepsy.
- ii) Networking
- iii) Driving regulations for patients with epilepsy and mental health patients
- iv) Safety and monitoring of AEDs
- v) Practical approach to genetic testing and clinical presentation to the testing decision.
- vi) The Prince also highlighted the shortages of human resources for health in Swaziland and specific facilities that deal with epileptic patients in Swaziland.

Finally Prince Bandzile networked with the executive leadership of the International League against Epilepsy which comprised of: Dr Solomon L Moshe, Dr Sam Wiebe, Dr Emilio Peruca.

HAWAII



Health and Pest

Advice

Seizure inducing aspartame added to anti-seizure drugs

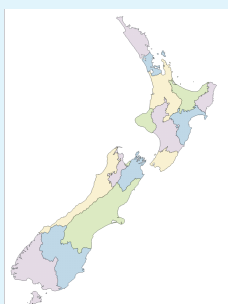
The Pacific Epilepsy Society in affiliation with the Epileptic Foundation of Maui has completed a seven year study on Epilepsy and Seizures, finding that epilepsy is at an all time high in Hawaii and the western states and Pacific Ocean Territories. There has been a 100% increase over the two previous years.

Dr Glenn Mabson of the Epileptic Foundation of Maui believes the reason for the increase is a change in formulation of several of the major anti-seizure drugs:

The most profound reason for the spectacular increase in seizures is the inclusion of aspartame in Dilantin, Depacote, Tegratol and several others produced since 150 people who took the new Dilantin capsule found the seizure rate increased in every case. An employee, in fear of his job would not reveal his name, but said they were adding aspartame.

Dr Allen Stein, Neurosurgeon, President of the Epilepsy Foundation of Hawaii (a separate organization from the above) is sympathetic to the makers of ASPARTAME and routinely prescribes these drugs. I believe this contributes to the increase of epilepsy in these areas.

EPILEPSY AROUND THE WORLD



NEW ZEALAND scientists lead quest to treat brain diseases

NZ scientists are leading a new quest to find treatments for brain



diseases like Alzheimers and epilepsy.

Neuroscientists have tested drugs on the brains of animals but the drugs have not been effective on humans.

Now scientists working with brains donated by people who have suffered from brain disease have developed a way to grow test-ready cells from brains.

The University of Auckland is leading the way and Professor Mike Dragunow said is important to advancement in technology.

They must study the human brain tissue itself.

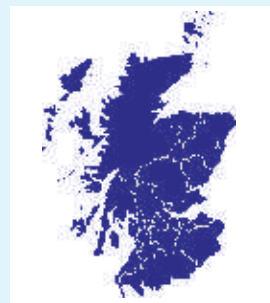
It's not an easy process, to keep the cells alive, to maintain and then to study them.

The development is set to be shared with neuroscientists from all over the world at a convention in Auckland.

Scientists now hope that they can develop a drug that treats the cause of brain disease, stopping its progression.

Source: ONE News , 31 January, 2011

SCOTLAND



Unique Workplace Guide to Epilepsy Scotland

Employers can now use a free occupational health guide to help existing staff members or new recruits with epilepsy. This

handy new resource covers legal responsibilities and how to handle the most common workplace issues.

Epilepsy Scotland Chief Executive Lesslie Young commented: "We devised this unique guide to make life easier both for those in HR/Personnel and employees who develop seizures. Our helpline callers repeatedly told us of organisations where working practices fell short of providing the best support possible. This prompted us to partner with occupational health experts in the public, private and voluntary sector and produce this practical tool for employers.

"This is the UK's first occupational health guide to epilepsy. It showcases examples of good practice. The specific condition guide explains how a prompt and appropriate occupational health assessment, clear communications with an employee, and a customised risk assessment for their duties also benefits the organisation.

"Sixty years ago it was often difficult to find or keep a job if you had epilepsy or it was not well controlled. Epilepsy is no longer a reason to be excluded from the job market. We are delighted that the Society of Occupational Medicine sees this innovative guide as an enhancement to good practice. It is an honour to have the Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon as our guest speaker at tonight's Scottish Parliament reception to highlight this guide."

Health and Medicine All Scotland February 22, 2011

EPILEPSY AROUND THE WORLD

UK



Teesside epilepsy trust fund reaches £60,000 milestone

A trust fund set up in the memory of 10-year-old Teesside girl has raised £60,000 to help epilepsy sufferers.

Abbie Clarke, from Coulby Newham, near



Abbie Clarke was diagnosed with epilepsy at the age of five. Middlesbrough, died in her sleep from sudden unexpected death in epilepsy (Sudep) in December 2006. Her parents Tracey and Richard set up a trust fund to help develop a children's epilepsy database.

Cash from the fund has also been used to set up a support group for families run by specialist epilepsy nurses.

The family have worked closely with staff at Middlesbrough's James Cook University Hospital, where Annie was treated.

Mr Clarke said: "The money has come from all sorts of fundraisers, including our annual walk which raised £5,000.

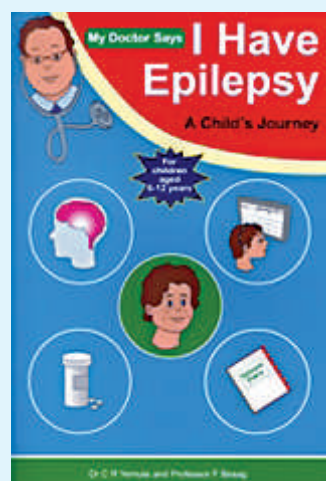
"We will continue to work closely with James Cook to help young people with epilepsy and ensure Abbie's legacy lives on."

New book helps children understand epilepsy

An innovative new book to help children come to terms with epilepsy has been launched in Bedford.

"My Doctor Says I have Epilepsy - A Child's Journey" has been written by Bedfordshire Community Health Services paediatricians Professor Frank Besag and Dr Chinia Yemula, with a foreword by Epilepsy Action.

It is aimed at children as young as six, to help them understand the condition which affects over 400,000 people in the UK.



The book tells the story of "Jack", a nine-year-old boy who has epilepsy and takes readers on his journey. It explains what causes the condition, and the medicines that he takes to help control it.

It uses an illustrated story format, with fun and humour, and contains activities including puzzles and a word search to engage the interest of the young readers.

Co-author Dr Yemula explained the idea behind the publication.

He said: "Children love reading books. They learn about so many things in life from books and we felt it was a good medium to explain about such a complex condition as epilepsy.

"I took it to children at Newnham Middle School and they loved reading the book. They enjoyed it so much and one of the comments from a child was that they liked the fact that it didn't use complicated scientific words, it just used basic words they could understand."

Nine-year-old Anastasia, who has epilepsy, also gave her approval.

"It was easy to read and I liked the pictures," she said. "My friends will see it is not such a scary thing."

LIFETIME ACHIEVEMENT AWARD FOR RENE LEVY

Professor and Chair Emeritus of Pharmaceutics
Rene Levy has received the 2011 **Arthur A Ward,
Jr Achievement in Epilepsy Award** from the



Epilepsy
Foundation
Northwest.

Throughout his
career, Levy has
established
himself as a
world-renowned
expert in
epilepsy

Rene Levy is being honored for his work on antiepileptic drugs. medications. Levy's research focuses on how to optimize the use of antiepileptic drugs and minimize drug interactions.

He has published hundreds of articles and co-edited several books, including *Metabolic Drug Interactions and Antiepileptic Drugs*, which released as a fifth edition in 2001.

"Receiving the Arthur A Ward, Jr Award is especially meaningful in view of the unique impact that Dr Ward had at the onset of my career," said Levy. "While he was a world leader in the surgical treatment of epilepsy, he also had a deep appreciation for the importance of the pharmacological treatment of epilepsy. He attracted several scientists like myself who became full participants in his department."

In 1989, Levy was named an Ambassador for Epilepsy by the International Bureau of Epilepsy.

MISCELLANEA

OFFICIALESE

*Or Ever Wondered What is Really
Behind Involving You In Correspondence?*



1. **For your information, please. (FYI)**
Meaning: I don't know what to do with this, so please keep it.
2. **Noted and returned.**
Meaning: I don't know what to do with this, so please keep it little while.
3. **Review and comment.**
Meaning: Do the dirty work so that I can forward it.
4. **Action please.**
Meaning: Get yourself involved for me. Don't worry, I'll claim the credit.
5. **For your necessary action.**
Meaning: It's your headache now.
6. **Copy to.**
Meaning: Here's a share of my headache.
7. **For your approval, please.**
Meaning: Put your neck on the chopping board for me please.
8. **Action is being taken.**
Meaning: Your correspondence is lost and I am trying to locate it.
9. **Your letter is receiving our attention.**
Meaning: I am trying to figure out what you want.
10. **Please discuss.**
Meaning: I don't know what the hell this is, so please brief me.
11. **For your immediate action.**
Meaning: Do it NOW! Or I will get into serious trouble.
12. **Please reply soon.**
Meaning: Please be efficient. It makes me look inefficient.
13. **We are investigating/ processing your request with the relevant authorities.**
Meaning: They are causing the delay, not us.
14. **Regards.**
Meaning: Thanks and bless you for reading all the crap.

MISCELLANEA

WHAT AN ATTITUDE

1. Lost his job
2. Applied for post of land officer and didn't get it
3. Started business and failed
4. Wife died of a fatal disease
5. Experienced nervous breakdown
6. Got defeated for legislature
7. Tried for nomination in a political party and lost
8. Contested for senate and lost
9. Contested in election for speaker in legislature and lost
10. Contested for vice president and lost
11. Again contested for senate and lost

**AND TWO YEARS LATER.....
GOT ELECTED AS PRESIDENT
OF AMERICA**



ABRAHAM LINCOLN

BRILLIANT ADVICE



Lessons learnt Early in Life

Bill Gates while addressing some High School children mentioned at least 10 things they will not learn in school.

Rule 1: Life is not fair - get used to it!

Rule 2: The world won't care about your self-esteem. The world will expect you to accomplish something BEFORE you feel good about yourself.

Rule 3: You will NOT make \$60,000 a year right out of high school. You won't be a vice-president with a car phone until you earn both.

Rule 4: If you think your teacher is tough, wait till you get a boss.

Rule 5: If you mess up, it's not your parents' fault, so don't whine about your mistakes, learn from them.

Rule 6: Before you were born, your parents weren't as boring as they are now. They got that way from paying your bills, cleaning your clothes and listening to you talk about how cool you thought you were. So before you save the rain forest from the parasites of your parent's generation, try delousing the closet in your own room.

Rule 7: Your school may have done away with winners and losers, but life HAS NOT. In some schools, they have abolished failing grades and they'll give you as MANY TIMES as you want to get the right answer.

This doesn't bear the slightest resemblance to ANYTHING in real life.

Rule 8: Life is not divided into semesters. You don't get summers off and very few employers are interested in helping you FIND YOURSELF. Do that on your own time.

Rule 9: Television is NOT real life. In real life people actually have to leave the coffee shop and go to jobs.

Rule 10: Be nice to nerds. Chances are you'll end up working for one.

FORTHCOMING EVENTS

☞ **8th - 10th April, 2011**

TOKYO, JAPAN

International Symposium on Neonatal Seizures and Related Disorders (ISNS)



8-10th April, 2011

**Under the Endorsement of ILAE,
Pediatrics Commission**

**[The 14th Annual Meeting of
Infantile Seizure Society (ISS)]**

Juntendo University Campus, Tokyo,
Japan, April 8-10, 2011

website: www.iss-jpn.info

President : Professor Shinichi
NIIJIMA, Department of Pediatrics,
Juntendo University Nerima Hospital,
Tokyo Japan

Only electronic application on line
will be accepted. Instructions on
website

**Fellowships for younger attendees
and others are available.**

ISS Secretariat :

<iss-contact@iss-jpn.info>

Yukio FUKUYAMA, MD

Child Neurology Institute

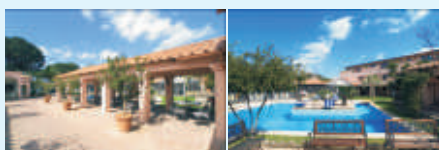
6-12-17-201 Minami-
Shinagawa, Shingawa-ku, Tokyo,
140-0004, Japan



☞ **29th May - 4th June, 2011**

ROMA, ITALY

International League against Epilepsy
Commission on European Affairs/



European Advisory Council

Lega Italiana Contro l'Epilessia

5th Migrating Course on Epilepsy

**A limited number of bursaries has
been approved.**

**Successful applicants, with priority for
age up to 45 years, will
be duly advised.**

Registration fee: 1000 Euro.

It includes accommodation
(sharing twin room), full board and
access to all the educational activities
(lectures, tutorials, case discussions,
video-sessions). Fee

does not include any travel expense
and/or local transfers to reach
the course venue.

The payment of the registration fee will
be required at a later stage to all
admitted participants.

For further information and updates,
please visit the ILAE web site
(section: "Upcoming
congresses and meetings") :

www.ilae-epilepsy.org;

Contact

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Federico Vigevano:

federico.vigevano@opbg.net

The Organizing Committee:

Peter Wolf, Alla Guekht, Milda
Endziniene, Nebojsa Jovic, Joanna
Jedrzejczak, Federico
Vigevano, Jana Zarubova.



☞ **17th - 29th July, 2011**

VENICE, ITALY



Advanced International Course: Bridging Basic with Clinical Epileptology-4

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

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

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

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

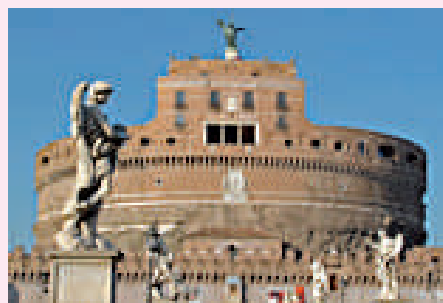
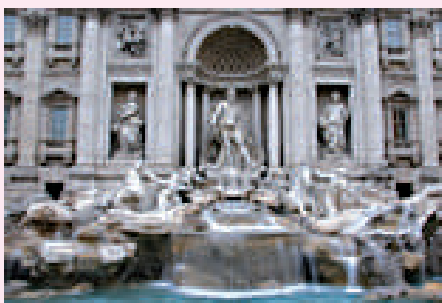
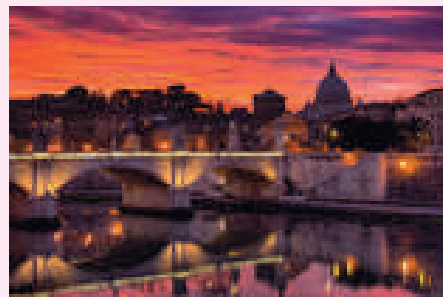
Full and partial financial support is
available for a limited number of
applicants.

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



FORTHCOMING EVENTS

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



29th IEC SAOC



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

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

Registration Fees

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

Abstract Submission Deadlines 31st March 2011

VENUE

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

Phone: 39 06 658821

Fax: 39 06 65882750

SECRETARIAT CONTACT DETAILS

29th INTERNATIONAL EPILEPSY CONGRESS

ILAE / IBE Congress Secretariat

7 Priory Hall, Stillorgan, Dublin, Ireland

Tel.: +35312056720 Fax.: +35312056156

E-mail.: rome@epilepsycongress.org.

Website.: www.epilepsyrome2011.org.

FORTHCOMING EVENTS

☞ **22nd -25th - March, 2012**

9TH ASIAN & OCEANIAN EPILEPSY CONGRESS, MANILA 2012



Some members of the SOC in a local event

Dear Friends and Colleagues,

It is with great pleasure that we announce that the 9th Asian & Oceanian Epilepsy Congress (AOEC) will be held in Manila, Philippines from the 22nd to the 25th March 2012, organised jointly by the regional associations of the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE).

We, along with our Scientific Organising Committee (SOC) and Scientific Consultative Committee (SCC) colleagues, are currently putting together a scientific programme which should be of great interest to all, encompassing recent scientific, clinical and social developments in the field of epilepsy. "Epilepsy and the Developing Brain", "Epilepsy Genes and Beyond", "The

Impact of Epilepsy and its Treatment", "Advances in AEDs Therapy" and "Epileptic Networks and Seizure Propagation" are among the main topics being discussed. There will be a Chairman's Symposium, the Masakazu Seino Memorial Lecture, a comprehensive range of main, post main and parallel sessions as well as practical video sessions, lively debates and 'How To' sessions. The Asian Epilepsy Academy (ASEPA) will once again organize a series of didactic lectures pertaining to crucial aspects of contemporary epileptology given by world-renowned experts in their respective fields. Furthermore, an exciting epilepsy and society programme for people with epilepsy and their carers will run in conjunction with the Congress.

SCIENTIFIC ORGANISING COMMITTEE (SOC)

Co-chairs:



Josephine
CASANOVAGUTIERREZ
(Philippines)



Robert COLE
(Australia)



Byung-In LEE
(Korea)



Ding DING
(China)



Simon HARVEY
(Australia)



Patrick KWAN
(Hong Kong)



Andrew PAN
(Singapore)



Vinod SAXENA
(India)



Tatsuya TANAKA
(Japan)

Members:

Important Dates for your Diary

Registration begins June 2011

Abstract Submission begins June 2011

Abstract Submission deadline November 2011

ILAE / IBE Congress Secretariat, 7 Priory Hall,
Stillorgan, Dublin 18, Ireland

Tel: +353-1-2056720 | Fax: +353-1-2056156

Email : rome@epilepsycongress.org

In partial seizures

Start

Vinlep™

Oxcarbazepine 150, 300 & 600 mg tablets

The *Winning advantage* of efficacy and tolerability

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.

For the use only of a registered Medical Practitioner, Hospital, Laboratories

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. **POSODOLOGY 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 Vasani Road, Andheri (East), Mumbai - 400 093, India. Source: Vinlep PI dated March 2009. Date: March 2009.

Group
sanofi aventis
Because health matters

Sanofi-Synthelabo (India) Limited, 54/A, Sir Mathuradas Vasani Road, Andheri (E), Mumbai 400 093. Tel: (91-22) 2827 8000. Fax: (91-22) 2837 0939

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