

October-December 2014

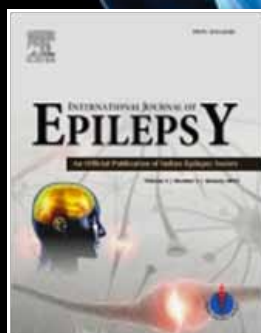
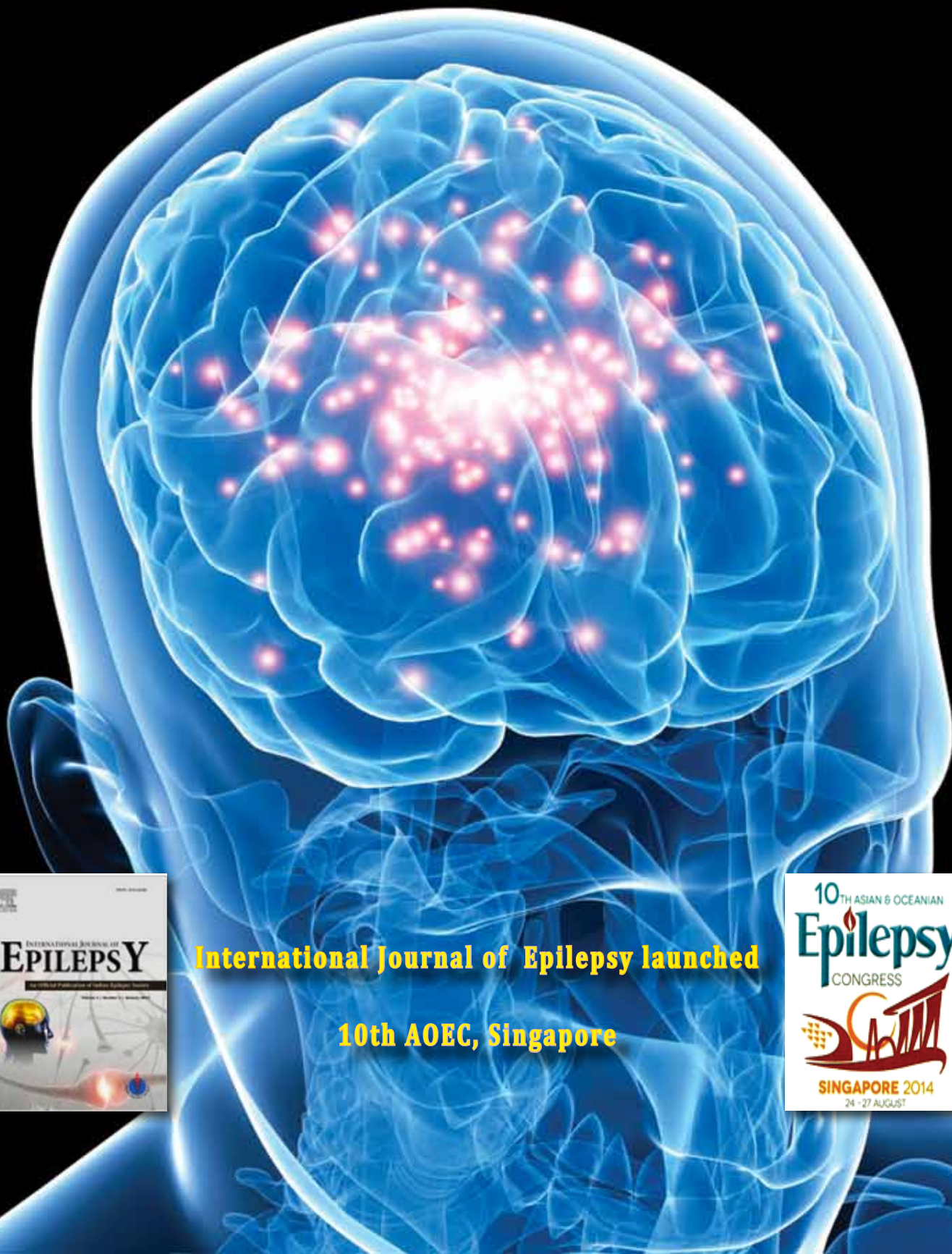
Issue 4, 2014



Epilepsy India

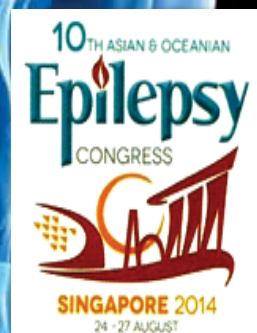


Newsletter of the Indian Epilepsy Association & Indian Epilepsy Society



International Journal of Epilepsy launched

10th AOEC, Singapore



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CHAK DE INDIA

Navrathri, Bakrid and Diwali Greetings!

EI team feels proud of the performance of the Indian contingent at the 10th Asian Oceanian Epilepsy Congress held at Singapore. Dr Saxena was Co Chairperson, Dr Mehindratta and Dr Manjri Tripathi were in the Scientific Panel. This is indeed proof that Indians working in the field of epilepsy are getting their due recognition. The ASEPA exams had 14 candidates of whom three were Indians, and two of them passed the exams.

The story of Ms. Shenaz Haveliwala is an inspiration to all persons with epilepsy. The award of Outstanding Persons with Epilepsy was rightly presented to this "Lion Heart". Her courage and never say die attitude, is brought out in this issue in her own words.

The IBE Newsletter acknowledged the contribution of Dr Bindu Menon of Nellore and Dr Natrajan of Chennai in their efforts of setting up cell phone repairs facility and bakery unit respectively, for persons with epilepsy.

The EI team had requested some of our members to air their views on the new operational definition of epilepsy. Dr H.V. Srinivas has sent his views which is carried in this issue. The major concerns which he

raised were:

- To label a person after a first seizure as PWE if there is a risk of sixty percent chance of recurrence is purely speculative.
- Persons having myoclonic jerks only without a single GTCS being labelled as a PWE.
- Epilepsy is considered resolved only after a PWE has had a ten year remission with five years off AED.

All the three contentious issues carry a lot of psycho social burden. We invite further discussion on this topic.

Ms. Suchitra Narayan, President, IEA Kochi, was the Bajoria Orator at Econ 2014, Kolkatta. Her Oration is included in this issue. She has given a road map on a holistic approach to the management of epilepsy.

Another moment to cherish was the release of the first issue of International Journal of Epilepsy, the child of Indian Epilepsy Society with Dr. Mehindratta as the Chief Editor. The editorial team had been ceaselessly working for months on this. Congrats to the Captain and the team.

And last but not the least, is the EI cover page featured in the ILAE website home page with the link to the last issue carrying the discussion on the new operational definition of epilepsy.

CHAK DE INDIA



IEA-IES Joint Meeting at Chennai on 30-31 August 2014

International Journal of Epilepsy (IJEP) – release of the inaugural issue

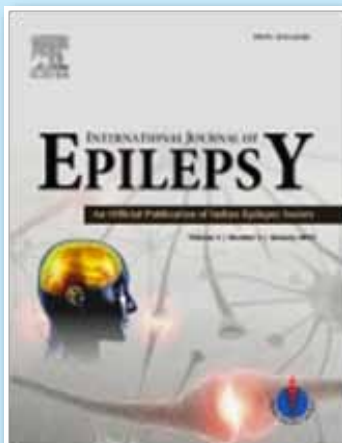
Reported by
Dr. Vinayan K.P.



It is a proud moment for the Indian Epilepsy Society (IES). The inaugural issue of International Journal of Epilepsy (IJEP), the official scientific journal of IES has been formally released in August 2014. With the launch of IJEP, IES enters the league of select national epilepsy societies who have their own in-house scientific journal.

“This journal symbolizes the long held dream of all the members of the society”, said Prof. Man Mohan Mehndiratta, Editor – in- Chief of IJEP and the Secretary General of IES. “It was years of hard work and perseverance. We were fortunate that we could get associated with Elsevier, a major international publishing house of repute for our journal. A lot has to be learnt from their professionalism and commitment for excellence” he added.

The inaugural issue was very well received. The front cover and the layout are really impressive. In the foreword, Prof. Byung in Lee, Chair, Commission of Asia-Oceania Affairs (CAOA), International League Against Epilepsy (ILAE) has congratulated the visionary leadership of the IES in bringing out an international epilepsy journal, which will be a boon for epilepsy research and practice not only in India, but for the whole Asia- Oceania region.



True to its name, the inaugural issue features original research articles from around the world, including the group of Prof. Jerome Engel from UCLA. In addition to the review articles and case reports, the journal also has a clinical quiz section on epilepsy, which is a novel feature.

“I would like to thank my young and dynamic editorial team for the success of this issue. All of them are really enthusiastic and eager to contribute” said Prof. Mehndiratta. “The real challenge will be to keep up the momentum and to elevate our journal to the status of other well reputed journals from ILAE, Epilepsia and Epileptic Disorders. I am sure we have the potential to achieve that goal” he concluded.



by **Ms. Swathi Nair**

Report on 10th Asian Oceanian Epilepsy Congress (AOEC), Singapore, 7th -10th Aug. 2014

Dr. Man Mohan Mehndiratta
Vice President South East Asia IBE &
Secretary General-Indian Epilepsy Society



This biennial congress was jointly organized by International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE) and CAOIA IN Grand Copthorne Waterfront Hotel, Havelock Road Singapore from 7th August -10th August, 2014 under the able leadership of co-chairs: Byung-In Lee, Vinod Saxena and Shih Hui Lim. Dr Lim is a veteran organizer. More than 1, 300 members from Asian Oceanian Region participated in the Congress.

ASEPA part II examination was also held on 6th August, 2014 from 1030 Hrs-1630 Hrs. The examiners were as follows: Andrew Bleasel, Derrick Chan, Man Mohan Mehndiratta, Byung-In Lee Kheng Seang Lim, Akio Ikeda, Shih-Hui Lim, Josephine Casanova-Gutierrez, John Dunne, Nigel Tan, Ernest Somerville, Dan Yang Fang, John Dunne, Chong-Tin Tan and Andrew Pan.

A total of 14 candidates appeared and 12 passed. From India three candidates appeared in the examination and 2 out of 3 passed the examination. ASEPA Part 1 (written) EEG Certification Examination was conducted on Friday, 8th August 2014

India stood out prominently and played very significant role in the success of the congress. The tables



and graphs shown below are self explanatory:

International Bureau for Epilepsy related activities:

One of the highpoint for IBE is the Epilepsy & Society Symposium on Saturday 9th August of interest to both individuals living with epilepsy, their care givers and Non-Governmental Organizations engaged in the well-being of people with epilepsy. Some of the highlights of this symposium include the welcome address by IBE President Athanasios Covanis. This was followed by interaction on topics of interest to PWE such as AED Compliance and considerations, Non-compliance and epilepsy-related injury, Death and SUDEP, AEDs and

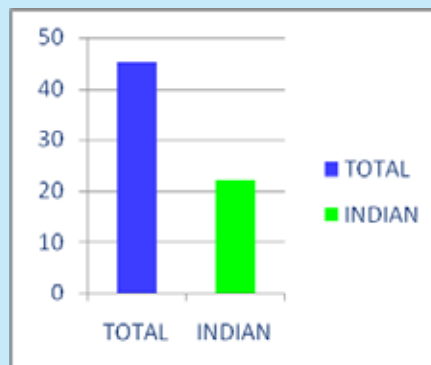


bone health/pregnancy, Epilepsy and employment, Stigma and epilepsy, Sports and epilepsy, School and epilepsy, Non medication therapies and solutions in epilepsy etc.

IBE honors the Outstanding Persons with Epilepsy, who received their awards during the 10th AOEC Opening Ceremony from South East Asia Region. Ms. Shenaz Haveliwala an IEA-Mumbai Chapter member received this prestigious award.



Jubilant Ms. Shenaz Haveliwala with Dr. Man Mohan Mehndiratta and Dr. Pravina U. Shah



PROMISING STRATEGIES 2007-2014

The IBE Promising Strategies Program has been running for 7 years and is one of the most successful of all IBE's initiatives. The aim of the program is to assist Members - particularly those in developing nations - through the provision of financial support for projects whose objective is to improve the quality of life of people with epilepsy. To date, 81 projects in 38 countries have received a total of US\$330,000 in funding. Showcased here are the projects supported to date in the IBE South East Asia and Western Pacific Regions.

INDIA

Cell phone repair

In the cell phone repair project, the association helped 3 people with epilepsy to be trained in telephone repair techniques by qualified engineers for a period of 6 months. After training they were given materials to establish an outlet in their village where they can continue with the work, thereby making them independent and self-sufficient.

CHINA

Web based messaging

China Association Against Epilepsy created a web based system to share resources, provide links to professionals and build up a patient/doctor instant messaging scheme, as well as special interest groups for patients and professionals, such as the Lennox-Gastaut syndrome group.

NEPAL

Video and Poster Production

To raise awareness about epilepsy and its treatment, the Nepal Epilepsy Association received funding to produce and distribute simple and illustrative posters in the Nepali language. A second project funded by PSP helped develop a documentary film 'A new life for Juna' which will be shown in Singapore.

MONGOLIA

Demystifying Epilepsy

In the last few years Mongolia Epilepsy Association has been working with IBE and has organized a series of 'Quality of life' programs, thanks to Promising Strategies Program support, in seven rural areas and cities. The association is now ready and eager to go to the remaining 14 provinces to achieve its objective.

TIBET

Epilepsy Patient Centre

Set up in the Department of Neurology of the First People's Hospital in Tibet, patients were invited to visit the centre for monthly information talks for people with epilepsy and parents. Using QQ, the popular instant messaging program, an online Tibet Epilepsy Patients Group was set up.

INDIA

BAKERY SKILLS

In India, it is difficult for people with epilepsy to find jobs due to discrimination. Through this project, the Indian Epilepsy Association trained a group of people with epilepsy in the craft of baking and bakery management. Training was provided by qualified bakers who are already running successful units. The students were supported in purchasing new materials and were also trained in management skills.

INDONESIA

Information and Support

Many people with epilepsy are kept at home. Children don't have a proper education and adults become dependent on other people, and no job. PERSPE created a program of education and support with information leaflets and the provision of low cost AEDs.

LAO PDR

Tackling a 90% treatment gap

Laos PDR is a low income, multiethnic, landlocked country of 6 million inhabitants. Approximately 52,000 people have epilepsy, with a treatment gap of over 90%. Epilepsy awareness is being raised in teachers and pupils in schools in 4 provinces, taking advantage of the training of doctors in the same cities. In this way it is hoped to train more people with epilepsy and to help them contact their local trained doctor. Radio spots are translated into three ethnic group languages and sent to all local stations.

MALAYSIA

TRAINING CENTRE FOR STUDENTS IN ASD SPECTRUM

Research shows that at least 20% to 40% in the ASD spectrum will develop epilepsy when they reach adolescence. Due to their learning disability and health conditions, teaching students with autism is challenging, requiring highly structured facilities and expertise. The Special Needs Learning Centre (SNLC) was set up in 2001 to meet the educational and training needs of the increasing number of children diagnosed in the Autism Spectrum Disorder (ASD).

TIBET China

Epilepsy Awareness

In Tibet, due to its special geographical location, there is little public awareness about epilepsy. Unique religious beliefs have increased negative attitudes towards people with epilepsy. Many Tibetans believe demons are caused by demons and seek out cures through religious rituals. The objective of the project was to promote epilepsy prevention and increase knowledge.

The IBE Newsletter highlighting two Promising Strategies CELL PHONE REPAIR AND BAKERY PROJECT Program from India



07.08.2014 ILAE Convention Chapter: From India Satish Chandra, Man Mohan Mehndiratta and Manjari Tripathi participated

INDIA

Indian Epilepsy Society (IES)

History and Goals:

- The Indian Epilepsy Society (IES) was constituted and registered with the Registrar of Societies, Govt. of India, Delhi on May 13, 1997. The main objectives of the IES are to:
 - Maintain the highest standard in the ethics and practice for the promoting of prevention, diagnosis, treatment and care of all persons with epilepsy.
 - Promote and encourage research concerning the epilepsies.
 - Improve education, and dissemination of knowledge concerning epilepsy.
 - Maintain a good liaison with the organization of lay people - Indian Epilepsy Association (IEA).
- Details of a contact person for international liaison and a website address:
 - President: Dr. P. Dattaschandra, Director / Vice Chancellor & Senior Professor of Neurology, National Institute of Mental Health & Neuro Sciences, (NIMHANS), Bangalore - 560 029. Email: drsatishchandra@yahoo.com
 - Secretary-General: Dr. Man Mohan Mehndiratta, Director, Professor of Neurology & Head of Department of Neurology, Jawahar Puram Superspeciality Hospital (an autonomous teaching institution National Capital Territory Delhi) New Delhi- 110058. Email: indianepilepsysociety@gmail.com / Website: www.epilepsyindia.org
 - Treasurer: Dr. Manjari Tripathi Professor Neurology Department of Neurology Room No 305, Neuroscience Center, AIIMS, New Delhi, India, 110029. Email: manjari2tripathi@gmail.com
- Membership Medical Professionals, There are more than 430 life members. The IES is affiliated to ILAE.
- IMPORTANT ACTIVITIES OF INDIAN EPILEPSY SOCIETY
 - Annual Conference of Epilepsy 2014 was held at Kolkata, January 31-February 2, 2014. More than 430 delegates attended the event. 2015 conference will be held in Chennai February 8-9, 2015.
 - International Journal of Epilepsy (IJE) has been launched by the society. There will be four issues per year. The journal contents will comprise of original research articles, review articles, Case reports, journal club, case reports, image of the month, Drug corner, historical aspects etc. The editorial board will comprise of experts from different regions of the world. Dr. (Prof) Man Mohan Mehndiratta will be the Editor-in-Chief.
 - Indian Epilepsy School was organized in November 13-16, 2013 in Delhi. The residential Indian Epilepsy School was organized under the aegis of CAOR, ASEPA and ILAE in a peaceful location from 13-16 November, 2013. The theme of the school was "Enhancing Clinical acumen in Epilepsy Management". Five foreign faculty i.e. Professor Lin Shih-Hui (Singapore), Derrick Chan (Singapore), M. S. Gopinath (Australia), John Stern (USA) and S.B. Hong (South Korea) and 14 national as well as local faculty during Epilepsy School. Total 116 delegates from different parts of the world, participated in Epilepsy School. The faculty from USA and Asia Pacific region has been invited. ASEPA, CAOR-ILAE has endorsed the school.
 - 8th Annual EEG Workshop Was organized at Jawahar Superspeciality Hospital from November 12-15, 2013. A total of 120 delegates and 40 faculty members attended the workshop. ASEPA I & II examination was also conducted during the workshop.
 - The 'Guidelines for Epilepsy Management in India' (GEMIND) were released in October 2008. The GEMIND are a milestone in the true sense and perhaps the first example of a national professional body formulating guidelines for a common disorder in India.
 - The Epilepsy Teaching Programme (ETP) developed by the IES is an extension of the GEMIND and aimed to train over 1500 doctors spread all over the country during the first year itself. The electronic version of the GEMIND is available on: www.epilepsyindia.org and the ILAE website: http://www.ilae-epilepsy.org. Epilepsy Conference was held on July 12-15, 2014 in Goa. IEA-RAI Master classes will start soon.
 - Recognizing the importance of the issue of "Epilepsy & Disability" to millions of people with epilepsy in India, the IES strongly felt the need to take this important aspect of epilepsy as early as possible. A meeting of ILAE-ETP was organized at New Delhi. The consensus arrived at the Expert Group Meeting of the IES has been forwarded to the concerned officials of the Ministry of Health and Family Welfare and Ministry of Social Justice & Empowerment, Govt. of India for their kind consideration and appropriate action.

To sum up IES membership has grown up very well and it is actively engaged in teaching the family and general physicians for adequate management of epilepsy.

Man Mohan Mehndiratta
Secretary-General Indian Epilepsy Society

INTERNATIONAL LEAGUE AGAINST EPILEPSY

ILAE

Established 1909

www.ilae.org

Indian Epilepsy Society poster highlighting its various activities was displayed during the congress

Ensuring Quality of Life for Persons with Epilepsy

Suchitra Narayan

Consultant Special Educator & Founder
Sanskriti Resource Centre for Inclusion, Kochi
President-IEA – Kochi



What is Quality of Life (QoL) for a Person with Epilepsy (PwE)? Is it only about ensuring that the person is seizure free or are there other aspects that we need to consider as well? How often do we think about this? These have been the questions that have bothered me in my 30 years of practice as a Special Educator working with persons with various disabilities, many of whom have epilepsy. I have often observed that many of them had issues that were beyond the purview of “being treated by medicines or surgeries and beyond driving licenses and marriage” (those are needs after 18!!) as we are prone to discuss at various forums!! What about their life earlier, and what about all the other needs?

Quality of Life for any person is when the person is included in society, and can function effectively at various stages of their life, in his or her own way to the best possible extent. For this, changes have to be made to the environment and the person may also need additional support in terms of learning, handling emotions, building self esteem etc. What one requires at 3 is not what one needs at 8 or 12 or 16 or 40. A child whose developmental needs are not met cannot grow up to be a confident adult.

To understand what those “needs” are, we need to refer to the wealth of research on **co-morbidities** that are known to exist with Epilepsy beyond the control of seizures.

Acknowledging co-morbidities

Unless we try to understand the range of co-morbidities that go beyond Psychosocial into the Cognitive, Physical, Neurological, Linguistic / Communication, Mathematical, Mental Health, Self-Help, Life Skill needs (Dunn WD et al, 2003;

Krishnamoorthy et al, 2007; Lodhi & Agarwal, 2012; Aldenkamp, 2006; Vinayan KP et al, 2005; and many others like them from across the world) - how do we hope to provide any kind of QoL?

How can we address or even try to understand the diverse needs of the PwE if we do not **take the time to listen** to their difficulties / needs at least during conferences? Imagine if there were no PwE!! Actually, we as professionals would face a huge vacuum if there were no PwE. Conferences exist because there are PwE and pharmaceutical companies would have less business - just as the “business” of schools cannot exist without children!! In management terms, the PwE is the client or customer In Gandhiji’s words ([GFTI] 1970).

“A customer is the most important visitor on our premises. He is not dependent on us. We are dependent on him. He is not an interruption on our work. He is the purpose of it. He is not an outsider on our business. He is a part of it. We are not doing him a favour by serving him. He is doing us a favour by giving us an opportunity to do so.

Therefore **unless we can meet the ‘real needs’** of the customer i.e. the PwE, we will never be able to provide the QoL that they are entitled to. Below is reproduced a fairly comprehensively drawn out diagram (Austin JK, Caplan R. 2007) showing “the web of Needs” that could impact QoL of any PwE.

The co-morbidities featured in this table are Cognitive and Linguistic. However from various researches mentioned earlier we do know that the list is much longer.

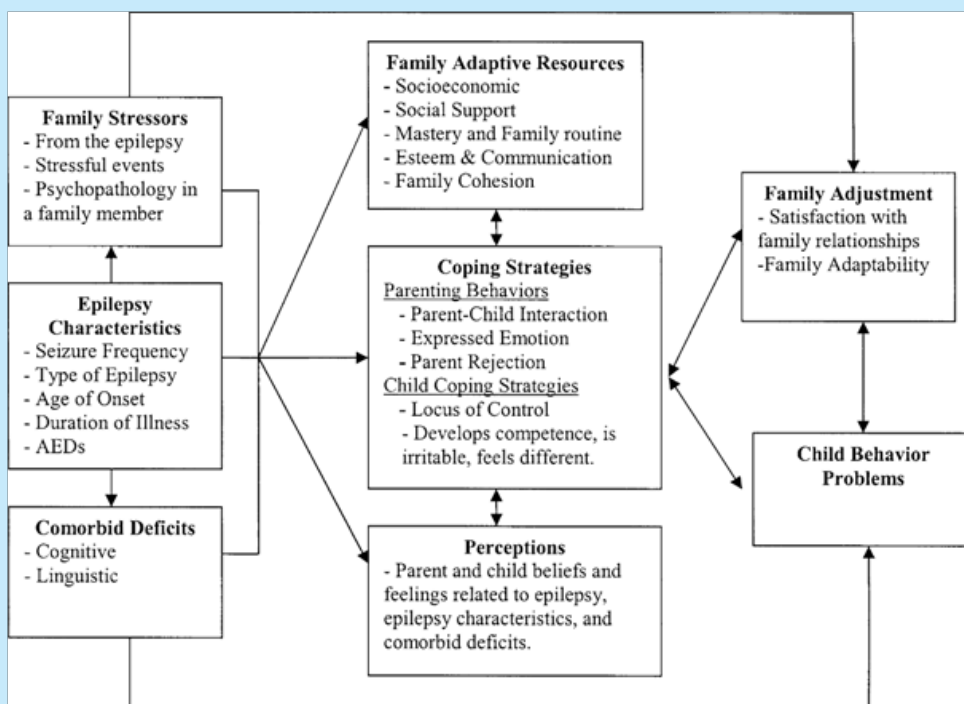


FIG. 1. Proposed integrated theory on epilepsy and behavior in children and adolescents.

Recognizing Neuro-cognitive, Neuro-psychiatric, Neuro-muscular needs etc. as well

The problems faced by persons with epilepsy apart from the psychosocial (Dodrill, 1984) also very often include various co-morbid disorders (ILAE Comorbidity Task Force, 2009) like - Motor skill disorders, Mood disorders, Learning disorders, Mental retardation, Communication disorders, Pervasive Developmental Disorders, Attention Deficit and Disruptive Behaviour Disorders, Sleep disorders, Impulse control disorders, Personality disorders (DSM - IV - TR classification) etc; all of which do not come under psychosocial or environmental factors. (Guidebook-UCLA and DSM - IV-TR)

Aldenkamp (2006) has emphasized that “Memory impairment, mental slowing, and attention deficits are the most frequent cognitive disorders associated with epilepsy. Sometimes, individual patients find these cognitive consequences more debilitating than the actual seizures”.

Addressing gaps to ensure QoL for PwE

In India, over the years, apart from various studies to understand the deeper implications of the treatment of epilepsy, the different kinds of medications and its efficacy, alternate therapies, and perhaps more lately about surgeries too; **very little research seems to be done about the co-morbid conditions even though it is a major goal of the ILEA Hence there is a huge gap in the understanding of the condition indeed!!**

Cross (2011) in ‘EPILEPSY IN THE WHO EUROPEAN REGION: Fostering Epilepsy Care in Europe’ states that the major problem identified across the European area was “insufficient professional education and knowledge about Epilepsy, and lack of epidemiological data, violation of patients’ rights and employment problems.” In the same article, under the heading “Legislation”; Cross goes on to say that – “People with hidden disabilities, such as epilepsy, are among the most vulnerable in any society. Jacoby in the United Kingdom (142) stated that all chronic diseases affect quality of life but epilepsy has a greater impact.”...

Unless a person / child with epilepsy gets a **good education**, and / or is provided **rehabilitation** (Ponds & Hendricks, 2006) or **strategies** (Baxendale, 2008); **to cope with the co-morbid issues** (Krishnmoorthy et al, 2007); they will never be able to enjoy a good QoL. Lodhi and Agarwal (2011) record Cognitive dysfunction to be “one of the major contributors to the burden of epilepsy”. They go on to state that “It can significantly disrupt intellectual development in children and functional status and quality of life in adults”.

Awareness and disclosure

Could some of the problems associated with non-disclosure of these facts be because the patient

– doctor time is limited during each visit? Is there disclosure to the patient about the possible totality of the implications of seizures and medications? Ponds and Hendricks (2006) state otherwise – *“Patients often are not informed about the implications of their memory problems in everyday life,”* - Could it be that family and / or the patient think that they should only share medicine related issues with the doctors? Could it be that patients and families think that nothing can be done about these issues – reconciling to a condition where the PwE gets a lot of pity / sympathy as a “sick person” and no / limited expectations are placed on the person?

Acknowledging that **co-morbidities exist with Epilepsy in many cases, and that they can cause disabling conditions for the PwE** (WHO fact sheet 168) would be the first step in take a holistic perspective of the condition.

“Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,” United Nations Convention on the Rights of Persons with Disability (UNCRPD) - of which India is a signatory since 1st October 2007.

Another landmark event that has taken place in recent times is the Draft Bill on Disability in India wherein an addition was made in September 2012 to include Epilepsy as a disability. (This Bill has been drafted in India 22 years after the inclusion of epilepsy as a disability in the Americans with Disability Act 1990!) The Draft Bill has been accepted by the Cabinet on December 12th 2013 and so now PwE have **legal rights to access appropriate diagnosis and rehabilitation** – a point that we need to remember while we interact with the PwE in our professional capacity. Not doing right by the PwE would be a Human Rights violation.

Is society really aware of the implications of both these documents? Without “real awareness” what kind of perceptions do we have as a society about epilepsy - the co-morbidities, and its’ implications?

The way forward

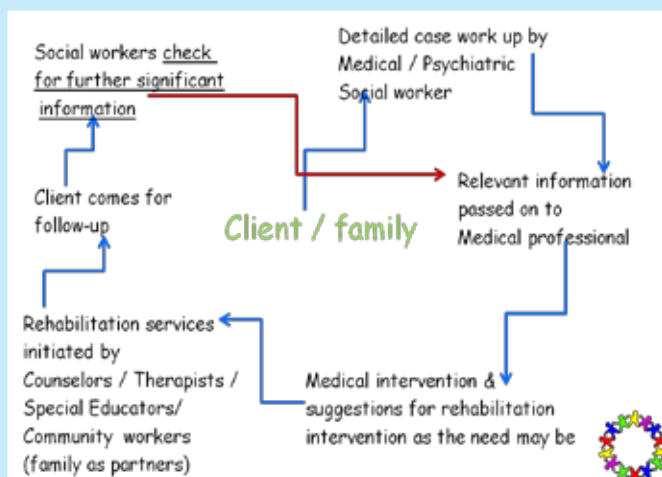
So what is true QoL for a PwE in India? Being seizure free? Perhaps we need to ask the PwE and **take the time to listen to them** as clearly articulated by **Carol D’Souza** in her **Bajoria Oration at ECON 2013**. These were very similar to what researchers across the world had to say as well - a) *the need for professionals to pay attention to what the PwE has to say; as each person’s experience is unique;* b) *help PwE and their carers feel comfortable and encourage them to articulate their specific concerns;* c) *ensure that the PwE and the family understand the implications/side effects of the medicines;* d) *check with PwE / family if they are really compliant with their medication and if there are any specific difficulties they are facing while taking the medications;* e) *need for professionals to be sensitive to the feelings of the PwE and the care givers* f) *encourage the PwE and their family who feel the need, to take a second opinion etc.*

All this definitely means taking time. So who do we need to **spend time** with?? The PwE for sure, as Carol mentioned; and their family members, and perhaps even gather information from peers, teachers, colleagues etc.

Granted that, with the large population of India and consequently the large number of patients who seek medical help daily, it would be difficult for Medical professionals to spend adequate time to gather enough data about co-morbidities and other concerns from the PwE or their families to get a truly comprehensive picture of the needs of the PwE. However this could be easily addressed by following a **multi-disciplinary team approach**. Below are two diagrammatic representations of how this could be achieved.

The process would be carried out like illustrated below.





The Social Workers will definitely need specific / guided training for about a year perhaps, just like medical students do a year of internship before they actually get their degree. The Medical professional who is supported by the Social Worker would then have a better understanding of the needs, and recommend rehabilitation where Therapists (Occupational, Physio, Speech), Special Educators and / Counselors will need to be involved to provide the necessary rehabilitation techniques (Ponds & Hendricks, 2006) and strategies (Baxendale, 2008) that will help the PwE manage his / her life better. This is time consuming and cannot be done in the short time the PwE usually gets with the medical professional.

The issues related to time, lack of resources / professionals etc can easily be dealt with using the family members / grass-root level workers as valuable resource – our vast population! When family members are empowered, they have a vested interest and would do their best to serve the needs of the PwE - so there will be no loss of quality. Second, the information that is imparted to the family member is specific to their needs and as each individual's needs are different there is no way that the professional will become redundant, as it still requires the professional to diagnose and plan the programme. It's only carrying out the plan that is executed by the family member or grass-root level worker. In rural areas, where access to better services is limited, training grass root level workers in primary rehabilitation techniques has

reduced the need for senior professionals.

This is a tried and tested method in India in many of the premier institutions serving the needs of Persons with Disability (PwD) within the country - even in rural areas.

Conclusion

We in India need to acknowledge and recognize co-morbid issues related to Epilepsy, create awareness in the larger society, talk about it openly and work on providing support beyond medicines and surgeries to the PwE. Recognizing the disabling effects will go a long way in being able to remove the various barriers and **help the PwE access appropriate support as a legal right under the constitution of India.** We **need research** to feed into culturally specific rehabilitation for the PwE. We **need to use the media** – visual, audio and print; as well as **seek the help of social organizations** like the Rotary, Lions etc just like we have done for Polio eradication **to create better societal awareness.** We need to have **more training programmes for professionals** to update their knowledge on co-morbidities and its impact on QoL for the PwE, **develop a multi-disciplinary team approach for the rehabilitation of the PwE,** as well as **have scientific programmes for early intervention and cognitive training of the PwE,** and provide them with **strategies to cope** with their difficulties.

Michael Prize:

Applications due by 31 Dec. 2014

Applications are now being accepted for the 2015 Michael Prize. This prize, presented biannually, is an international award for the best scientific and clinical research promoting the further development in epileptology by scientists under 45 years of age. The prize is awarded biannually and consists of €20,000 and will be presented during the International Epilepsy Congress in Istanbul.

Read more about the prize and previous winners. Apply at Stiftung Michael.

The practical clinical definition of Epilepsy – Current definition 2014 (Epilepsia, 55(4):475-482, 2014)

How does it affects my clinical practice ?

Dr H V Srinivas
Consultant Neurologist, Bangalore



According to the current definition :

1. At least two unprovoked (or Reflex) seizures occurring greater than 24 hours apart.
2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
3. Diagnosis of an epilepsy syndrome

Item No 1. This is what is being considered in clinical practice now. This seems to be very practical definition as the first unprovoked seizure does not necessarily lead to a second seizure in a great majority. It is better to wait for the second seizure to happen, if at all, before a diagnosis of “epilepsy” is made with all its medical and social implications. Once an epilepsy diagnosis is made, the medical treatment extends to a minimum of two to five year seizure free period, depending on the type of epilepsy. More important and devastating to the patient and the family is the societal attitude, the stigma, lowering of the self esteem - all related to the diagnosis of epilepsy .

Item No 2. Envisages the diagnosis of “epilepsy” even with one unprovoked seizure, if there is a “high risk of recurrence”. Now this is purely speculative, depending on the statistical data which again differs widely. I would rather wait for a second seizure to occur rather than suggesting a diagnosis of epilepsy at this stage with all its medical and social consequences described above. Of course as mentioned in the article, the diagnosis does not necessarily mean starting of treatment, but for me, even to make a diagnosis is creating uncertainty and unhappiness in the patient and family

Item No 3. Consider a patient having an occasional myoclonic jerk suggestive of JME but no GTCS any time. I would not like to tell the patient

that he has epilepsy (epilepsy syndrome) nor would I start on antiepileptic drugs. I only suggest to keep a diary of jerks and see me if they become more frequent or if there is a generalised seizure. According to the present definition this situation has to be labelled as “epilepsy”.

“Epilepsy is considered to be resolved “ when seizure free for ten years with no antiepileptic drugs for the last five years. It implies that the person no longer has epilepsy although it does not guarantee that it will not return. This again means that the person will carry the label of “epilepsy” for atleast ten years with all the social implications mentioned above. The life of the patient and the care givers will become more difficult, because of the extended period of label of epilepsy. Currently once a person is seizure free for two to five years, the drug is withdrawn depending on the type of epilepsy and the patient is informed of the possibility of recurrence, again depending upon the type of epilepsy. Generally, if there is no recurrence within a year of stopping of antiepileptic drugs, the patient and the doctor are happy, as the risk of recurrence tapers off considerably.

Epilepsy is considered as a “disorder” which according to the new definition is being considered as a “disease”. This change in the nomenclature does not really matter to the patient, as it is too fine a differentiation between “disorder” and “disease” to be appreciated by medical doctors, let alone patients.

I am aware that the new definition of epilepsy has been arrived at by ILAE task force spending a lot of time and putting in great efforts and discussions. However I feel that the new definition has added to the confusion and has increased the “diagnosis” of epilepsy and continues the label of “epilepsy” for a longer period than necessary.



**Life is so beautiful,
Just don't lose hope, overcome fear!**

With brilliant mark sheets and a seat in a prestigious engineering university, my family was sure about my future success. I had a very lively and easy childhood.

In 2005, at the age of 19, one week before my examinations, I lay down on my mother's lap complaining of a headache. The next thing I remember was waking up in the hospital ICU. And, that was the first time I heard the word 'viral encephalitis'.

After mechanical engineering, I had decided to major in laser technology, a reality I had built in my head. I couldn't go back to university since I used to get seizures every day. Side effects of drugs were terrifying. My social life was hampered.

Mom and dad left no stone unturned. Everything they could do, was done. It was during this one year that I became part of the 'college editorial board' in the Times of India. I was still getting seizures almost every day. A miracle was my only hope.

Eventually I had to undergo a surgery at Sree Chitra Institute in Trivandrum. It was then that I came across patients from all walks of life; people from different cultures, age groups, cities, financial backgrounds. All of them bound by one common thread-epilepsy. It felt so relieving to know that I was not alone. There were millions battling with me.

Unfortunately, for me, surgery was not a complete success. I have been on several AED's since the past nine years. I was desperate to support my medical expenses, at the same time, was fully aware that it will be difficult for me to find a job in another company. That is when, I decided to start a business of my own. I renovated my father's old warehouse in Fort to a conference hall. Since it is a commercial area, close to high court, there is a need for out of court settlements, arbitration matters etc. Giving it out on rent, I now support the finance of my own medicines. The hall is called SoboConnect and is now used for professional and other general meetings as well. It has made me feature in India's national business magazine 'Entrepreneur India'. Epilepsy could never stop me.

Promoting Sobo Connect I learned the art of website designing. At the same time I did not give up on my academics. Studying through correspondence, I graduated in the stream of commerce last year.

Currently, I'm working at the Indian Epilepsy Association (Mumbai Chapter) as a special educator for young adults with epilepsy. Along with regular studies, I strive to teach my students the importance of courage and persistence. In life, it does not matter how slowly you go, as long as you don't stop.

Just after I let happiness rule my life, in 2011, Dr. B.S. Singhal honored me with the 'Most Courageously Living with Epilepsy' award.

The same year, my story was featured in a book 'Conquering Epilepsy' edited by Carol D'souza.

I continue to get seizures and struggle to overcome the side effects of my current medication but I'm happy I've learned to visualize the world my way. If you walk with hope in your heart, you never walk alone.

Few weeks ago, I received an award by the International Bureau of Epilepsy. I was invited to Singapore to receive a prestigious award at the Asian and Oceanic Epilepsy Conference as the 'Outstanding Person with Epilepsy'-2014. I encountered patients, delegates, doctors from various nations, cultures. It was overwhelming to see my work getting a global recognition.

My profession makes me so happy. It's now that I have become so much more grateful to Allah and can see the beauty in all his plans. Life will move forward, just keep in mind that there is light at the end of every tunnel.

For Epilepsy day this year, I will be in Trivandrum, to the same epilepsy ward I was admitted in for my surgery in 2007. Only difference is that this time, instead of being a patient I'll be going as the guest of honor. Life is bringing me back to where I started from. It is such a proud feeling. Where there is a will, there is a way!

ECON 2015

16th JOINT ANNUAL CONFERENCE OF INDIAN EPILEPSY ASSOCIATION & INDIAN EPILEPSY SOCIETY

VENUE : TAJ COROMANDEL, CHENNAI

DATE : 6,7&8 February 2015

Dear Colleagues

Greetings from Chennai!!!

The members of the IEA, Chennai, feel honoured to have been given the privilege of hosting ECON 2015 at Chennai. The venue will be TAJ COROMANDEL HOTEL in CHENNAI and the dates are 6th to 8th February 2015.

The theme of the Pre Conference Education Programme on the 6th of February will be "Epilepsy Update for the Practicing Neurologist", tailored to the needs as required, for managing persons with Epilepsy

The two day conference on 7th and 8th February is designed to enhance further our knowledge on Epilepsy through a series of lectures, orations and case discussion forums, by eminent Epileptologists from within and outside the country.

We are privileged to have with us, Dr. Emilio Perucca, Dr. Raman Sankar, and Dr. Soheyl Noachtar as our International Faculty, to share their wisdom.

We extend a very cordial invitation to each one of you to come and share the rich academic fare and experience the traditions and culture of CHENNAI, TAMILNADU.



We look forward to meeting you at CHENNAI to revive old ties and make new ones.

Welcome to Chennai for Econ 2015.



Dr. V Natarajan

Organising Chairman

Dr. U. Meenakshi Sundaram

Organising Secretary

ECON 2015 - Organising Committee

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Dr. K Srinivas, Dr. K Srinivasan, Dr. M Veeraraghava Reddy

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INTERNATIONAL FACULTY



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Professor of Neurology,
University of Munich
Germany.



Prof. Emilio Perucca, MD, PhD
Professor at the University of
Pavia and Director of the Clinical
Trial Centre at the C. Mondino
National Neurological
Institute in Pavia



Prof. Raman Sankar, MD, PhD
Professor of Neurology and
Pediatrics & Chief of Ped.
Neurology at the David Geffen
School of Medicine at the Uni-
versity of California, Los Angeles

REGISTRATION

Pre Conference Workshop Registration: Details for the Pre Conference Registration

Categories	Upto 31 Oct. 2014	Upto 31 Dec 2014	Spot
IEA/IES Members	Rs:1,500.00	Rs:2,000.00	Rs:3,000.00
Resident/PG students	Rs:1,000.00	Rs:1,500.00	Rs:2,000.00
Conference Registration:			
Details about Conference Registrations			
Categories	31 Oct. 2014	Upto 31 Dec 2014	Spot
IEA/IES Members	Rs:2,500.00	Rs:3,000.00	Rs:6,000.00
Non Members	Rs:3,000.00	Rs:3,500.00	Rs:6,500.00
Resident/PG Students	Rs:1,500.00	Rs:2,000.00	Rs:3,000.00
Non Doctors IEA Members	Rs:2,000.00	Rs:2,500.00	Rs:3,000.00
Accompanying Person	Rs:1,500.00	Rs:2,000.00	Rs:4,000.00
Foreign Delegates	USD250	USD300	Rs:USD500

Website : www.econ2015.com

Conference Secretariat:

Marundeshwara Enterprises
A2, Shanthi apartments
18, TTK 1st Cross Street
Alwarpet
Chennai- 600 018
Ph: 91 44 24353079,
24328152, 24357194
Telefax: 91 44 24320605

9th IES EEG Workshop

Case Based Basics to Advanced EEG Workshop

Date : 29th & 30th November (Saturday & Sunday), 2014

Venue : Novotel & HICC Complex, (Near Hitec City), Cyberabad Post Office, Hyderabad

The Faculty includes : Afshan Jabeen, Hyderabad; Ashalatha Radhakrishnan, Trivandrum; Atma Ram Bansal, Delhi; Bindu Menon, Nellore; Gagandeep Singh, Ludhiana; Jayanti Mani, Mumbai; Lokesh Lingappa, Hyderabad; Man Mohan Mehndiratta, Delhi; Manjari Tripathi, Delhi; JMK Murthy, Hyderabad; Nandan Yardi, Pune; Parampreet Kharbanda, Chandigarh; S. Raghavendra, Bengaluru; Rajesh Iyer, Bengaluru; C. Rathore, Vadodara; Ramesh konanki, Hyderabad; Sanjb Sinha, Bengaluru; P. Satish Chandra, Bengaluru; Sita Jayalakshmi, Hyderabad; T. Surya Prabha, Hyderabad; KP Vinayan, Cochin; K. Venkateswarlu, Visakhapatnam

Organized by :
Indian Epilepsy Society
in association with
Krishna Institute of Medical Sciences
&
Pediatric Epilepsy Society Hyderabad

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Forthcoming Events

WORKSHOP ON ADVANCED TECHNIQUES IN EPILEPSY SURGERY

21-22 November, 2014

Amrita Institute of Medical Sciences
Kochi, Kerala

Contact Person : **Dr. Ashok Pillai**
Phone: 0484-4001303, 1309, 1316. 9400998070
brashok@aims.amrita.edu,
dr.ashok.pillai@gmail.com

ELECTROENCEPHALOGRAPHY & VIDEO EEG WORKSHOP

Date : 27-28 December 2014

**Sree Chitra Tirunal Institute for Medical
Sciences & Technology**
Thiruvananthapuram, Kerala

Organising Chairman : **Dr. Sanjeev V. Thomas**
Organising Secretary : **Dr. Ashalatha Radhakrishnan**
Mobile: 98474 16321 (7-8 pm)
E-mail: drashalatha@sctimst.ac.in



Bakery Unit of IEA Chennai

Reported by
Dr. V. Natarajan



After several trials and tribulations, finally the bakery unit of the IEA was started on July 4th 2014, at the Institute of Neurology, Government General Hospital, Chennai. This was possible largely due to the untiring efforts and persistence of our Chennai IEA treasurer and Head of the Department, Institute of Neurology, Professor K. Bhanu who despite several odds managed to secure a place to house the unit in the Institute of Neurology itself and also procured an instructor.

Four persons with Epilepsy, whose seizures are reasonably controlled and who expressed a desire to undergo this vocational training were chosen as the first batch of trainees. 24 training sessions

spread over 2 months are held with a qualified instructor to train them in making cakes, cookies and buns. The proceeds of the sale of these products produced at a low volume at present are being used to sustain the training course with the assistance of the local IEA chapter.

It is proposed to retain one of the well trained trainees as an instructor on payment to train further batches.

We thank the parent body of the IEA for standing by us and goading us to persist with the efforts throughout this inordinate period of delay.





Omega-3 fish oil 'could reduce seizure frequency for epilepsy patients'

Approximately 2.3 million adults and around 470,000 children in the US have epilepsy, a lifelong neurological condition characterized by recurrent seizures. Now, a new study claims epilepsy patients could reduce seizure frequency by consuming low doses of omega-3 fish oil every day.

Consuming low doses of omega-3 fish oil every day for 10 weeks appeared to reduce seizure frequency by a third among patients with epilepsy, according to researchers.

The research team, led by Prof. Christopher DeGiorgio of the Department of Neurology at the University of California-Los Angeles (UCLA) School of Medicine, says their findings may be particularly useful to epilepsypatients who no longer respond to medication.

They publish their findings in the *Journal of Neurology, Neurosurgery & Psychiatry*.

Omega-3 fatty acids can be obtained through consumption of oily fish - such as a trout, mackerel, tuna, herring, sardines and salmon - and fish oil supplements.

Past studies have indicated omega-3 can stabilize heart rhythm and prevent heart attacks. Prof. DeGiorgio says this is important for individuals with epilepsy, since they are at higher risk of heart attack than those who do not have the condition. Furthermore, the team notes that omega-3 has been linked to reduced brain cell excitability among epileptics, which may curb seizures.

However, they point out that previous studies looking at such associations using high-dose fish oil have been inconclusive.

As such, the team set out to determine the effects

of high-dose and low-dose fish oil on the cardiovascular health and seizure frequency of epileptic patients.

Low-dose fish oil supplementation 'reduced seizures by more than 30%'

For their study, the researchers enrolled 24 participants with epilepsy who had stopped responding to antiepileptic medication.

Fast facts about epilepsy in the US

- Around 150,000 new cases of epilepsy are diagnosed in the US every year
- Approximately 1 in 26 people will be diagnosed with epilepsy at some point in their lives
- Epilepsy can be caused by numerous conditions that affect the brain, such as stroke, braintumor and head injury.

Each patient was subject to three different supplementation regimes, each of which lasted for 10 weeks and were divided by a 6-week period. These were:

☐ Low-dose fish oil supplementation: three fish oil supplements daily - the equivalent of 1,080 mg of omega-3 - plus three placebo supplements (corn oil)

☐ High-dose fish oil supplementation: six fish oil supplements daily - the equivalent of 2,160 mg of omega-3

☐ Three placebo supplements twice a day.

The researchers found that the fewest number of seizures occurred - 12 a month - when participants were following the low-dose fish oil regime, compared with 17 a month on the high-dose regime and around 18 a month for the placebo regime. This means the low-dose regime represented a 33.6% reduction in seizures.

The team also found that two of the patients following the low-dose fish oil regime had no seizures at all during the 10-week trial, while none of the patients taking high-dose fish oil or placebos were seizure-free.

Furthermore, blood pressure fell by 1.95 mm/Hg among patients following the low-dose fish oil





regime, while high-dose fish oil was linked to an increase of 1.84 mm/Hg in blood pressure.

The team notes, however, that they found no link between fish oil and severity of seizures, changes in heart rate or blood lipid levels.

Commenting on their findings, the researchers say:

“The primary finding is that low-dose fish oil was associated with a reduction in seizure frequency of 33.6% compared with placebo. Though the size of the trial will require confirmation, the magnitude of the effect on seizure frequency is similar to many randomized trials of antiepileptic drugs.

The reduction in blood pressure indicates that low-dose fish oil may exert a positive cardiovascular benefit in this cohort with drug-resistant epilepsy, a finding of some importance, given the recent data that the risk of death due to myocardial infarction is significantly higher in people with epilepsy.”

Prof. DeGiorgio and his team admit, however, that their study is subject to some limitations. For example, they note that exposure to each of the supplementation regimes was relatively short, therefore it is unknown as to whether low-dose fish oil sustained reduced seizure frequency.

They conclude that a large, randomized controlled trial of the effects of fish oil on epilepsy is warranted in order to confirm their findings.

Medical News Today recently reported on a study claiming omega-3 fish oil may protect against brain damage caused by alcohol abuse.

Source: [http:// www.healthcanal.com / brain-nerves/54946-low-doses-of-fish-oil-may-reduce-seizures-in-patients-with-drug-resistant-epilepsy.html](http://www.healthcanal.com/brain-nerves/54946-low-doses-of-fish-oil-may-reduce-seizures-in-patients-with-drug-resistant-epilepsy.html)

WEMU Epilepsy Detector Could save Lives



Those who go through fits of epilepsy do know how uncomfortable the feeling can be, not to mention the more serious cases being potentially life threatening, too. Well,

a concerted effort by Bioserenity, a French medical device company, alongside a British epilepsy organization known as Epilepsy Action, as well as a French epilepsy organization, Efappe, has resulted in the WEMU – a smart clothing system and companion app that is capable of monitoring as well as diagnose epilepsy.

All this while, standard epilepsy diagnosis and treatment would have to fall back upon seizure recordings via fixed monitoring systems that are

only available within the confines of a hospital. This severely impacts the accessibility of such fixed systems, and not only that, majority of the patients' seizures will go unrecorded. This indirectly leads to suboptimal diagnosis and lack of proper treatment. Not so with WEMU, as this smartwear hopes to improve the accuracy of diagnosis, as well as lower diagnostic time while letting medical caregivers offer a more accurate drug regimen.

The WEMU will comprise of a smart shirt and a smart hat that sports a slew of dry-sensors. These sensors will be able to monitor the patient's cardiac, muscle and brain activities constantly, and these sensors are powered by a rechargeable battery pack via embedded electronic circuitry. All physiological data picked up will be sent to a smartphone app through the Bluetooth route. Hopefully it will be able to enter mass production soon.

Read more about science and Wearable Tech.
Source: Medgadget.

An entirely new experience in treating epilepsy

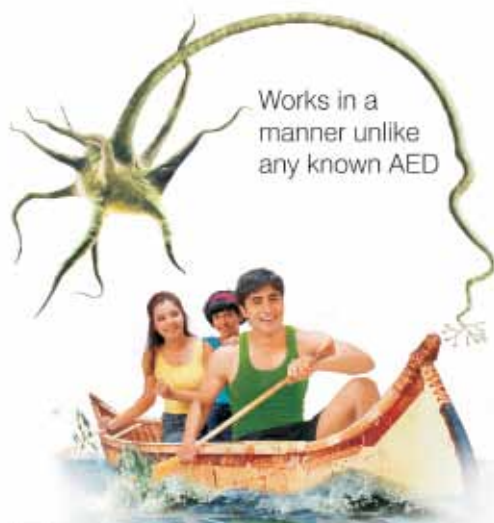
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