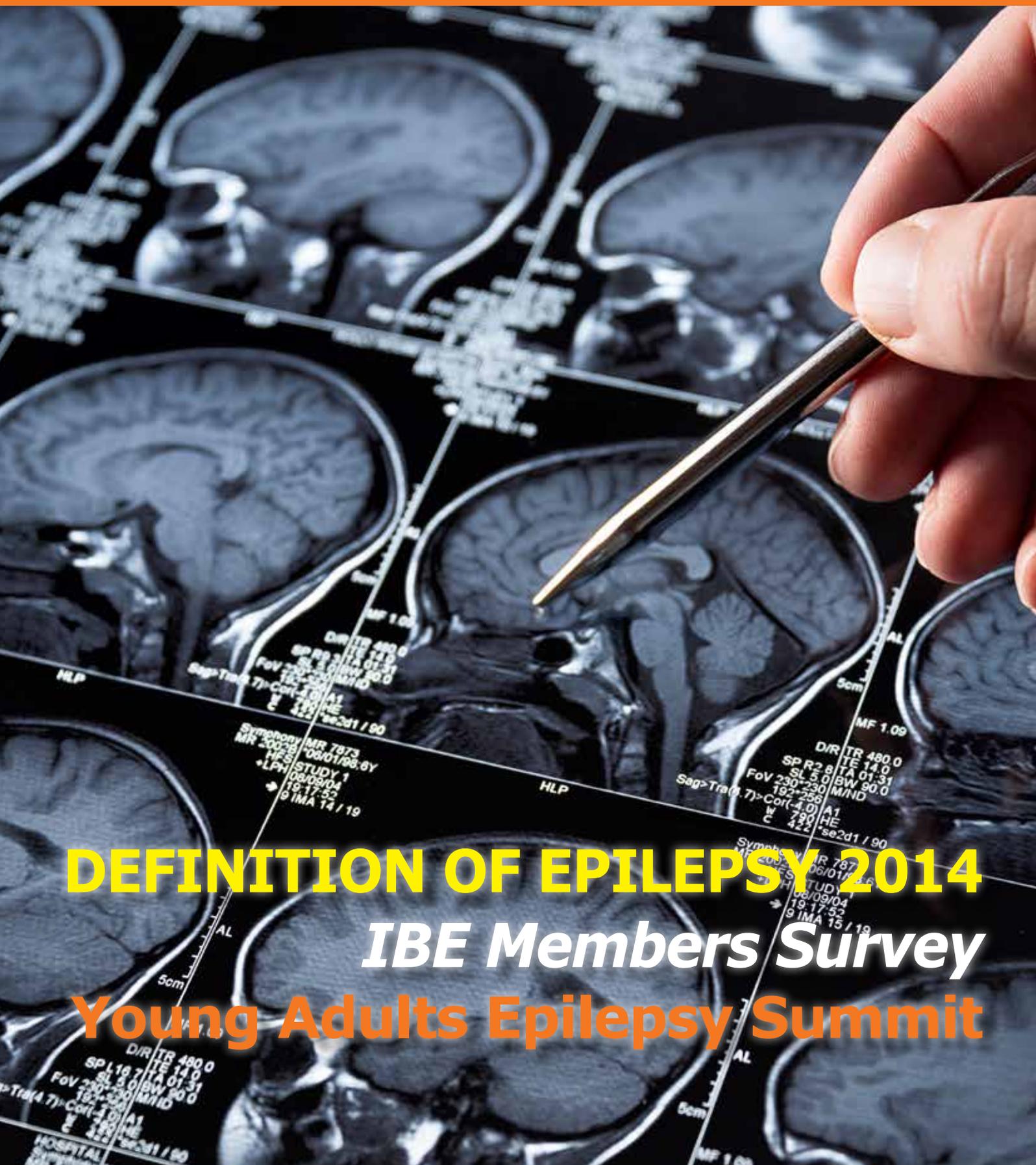


INTERNATIONAL

Epilepsy News

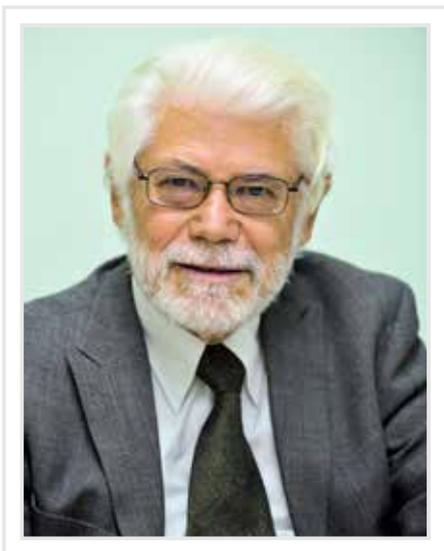
Reporting epilepsy news for 51 years

1963-2014



DEFINITION OF EPILEPSY 2014
IBE Members Survey
Young Adults Epilepsy Summit

PRESIDENT'S LETTER



Epilepsy newly defined

Other denominations from the same period were: 'sacred disease', 'black disease' and 'Heracles' disease' as epileptic seizures resemble the insanity that captured Hercules before he killed his wife and children (Foesius 1588). It has taken therefore the international scientific community so many years to agree with Hippocrates that epilepsy is a disease but fortunately not a "sacred" or "black". Hippocrates is considered to have described epilepsy as a clinical entity for the first time.....

Dear friends, you will also read in this issue the results of the Members Survey and learn that we have formed an Strategic Plan Task Force to draft a plan of action for IBE for the next five years.

The IBE Executive Committee met in Athens in September over two days of intense discussion and the Management Committee continues regular communication using conference calls and, more recently, Skype video. The committee will meet again in Dublin in March 2015.

By the time you read this I will have attended a meeting in Bulgaria and also spoken at the EpiCon 2014 International Conference on Epilepsy in New Delhi. These meetings present opportunities to raise the profile of IBE among undergraduate students, special educators and school and college counselors, research scholars and others.

With best wishes to all,

Athanasios Covanis
President

Dear Friends

After many years of discussion, you will read in this issue that the ILAE Definitions Task Force developed a practical (operational) definition of epilepsy, designed for use by doctors and patients.

The results have now been published (Fisher RS et al. A practical clinical definition of epilepsy, *Epilepsia* 2014; 55:475-482) and adopted as a position of the ILAE. Therefore, we have a new definition on what is epilepsy and specifically that epilepsy is a disease.

This means that the following groups:

1. Newborn infants with devastating epileptic encephalopathies with high mortality rate and severe cognitive dysfunction in all those who survive to two years of age.
2. People with epilepsy who are well controlled with one or two AEDs, live normal lives and hold a high position in the society e.g., teachers, university professors, politicians etc. and
3. Those who have drug resistant epilepsy

all have a disease, epilepsy?

A brief anamnestic history: The word epilepsy is derived from the Greek 'epilepsia' which means 'to take hold of' or 'something falls upon a man' or even 'to seize or catch him'. However the term 'epilepsy' from the ancient Greek word 'epilamvanin' was used for the first time by Hippocrates (460-357 B.C) and Aristotle (384-322).



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INTERNATIONAL RELATIONS AND PARTNERSHIPS

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IBE is in official relations with the World Health Organisation (WHO).

ECOSOC

IBE enjoys Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC).

CoNGO

IBE is a member of The Conference of NGOs in Consultative Relationship with the United Nations CoNGO.

EFNA

IBE is a member of the European Federation of Neurological Associations (EFNA).

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In this issue



Dear Readers



In this issue of the magazine we have some very important issues to report. Many of you will already be aware that a new Definition of Epilepsy has been produced. This comes after two years of intense concentration by the ILAE Definitions Task Force, of which there were two IBE members - Carlos Acevedo (former Secretary General

and former IE News Editor) and Mike Glynn (Immediate Past President). We are devoting several pages of the magazine to this important issue.

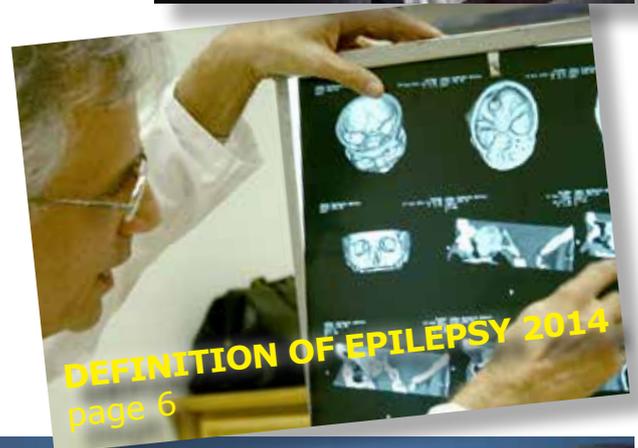
We also have an extensive report on the Members Survey that was carried out earlier in the year in the capable hands of Sari Tervonen, the current Secretary General. The information provided by the members will play an important role in the review of IBE's Strategic Plan, which is currently underway.

A very successful first Young Adult Epilepsy Summit took place in Washington DC in July, organised by the IBE North American Regional Committee and supported by the Epilepsy Foundation of America. You can read about this and meet one of the participants. And we will introduce you to more of the participants in future issues.

We have news from Mauritius, from Buenos Aires and from the WHO Regional Committee meeting in Manila. And much more besides.

Until next time - happy reading.

Ann Little
Editor



Coming in the next issue



STRATEGIC PLAN UPDATE



International Epilepsy Day 2014 Special Issue

66th Regional Committee of the WHO WPR

The World Health Organization Regional Committee for the Western Pacific took place in Manila in October to review WHO's work of the previous year and to discuss major health issues. IBE was represented at the meeting by Dr Shichuo Li (China), from the China Association Against Epilepsy. Dr Shichuo had the distinguished opportunity to present an oral statement at the meeting.

Call for a WHO Western Pacific Strategic Action for Epilepsy

1. About 65,000,000 people have suffer epilepsy worldwide, a quarter (16,250,000) of whom live in Western Pacific Region. Epilepsy imposes enormous physical, psychological, social and economic burdens on individuals, families and countries, especially due to misunderstanding, fear and stigma.
2. Up to 90% of people with epilepsy are not properly diagnosed, nor do they receive appropriate treatment (“treatment gap”), especially in resource-poor countries.
3. However as shown in China, epilepsy care can be provided for less than \$25 per person with epilepsy per year, so that, if proper policies and action were taken by governments, epilepsy control would not be a large financial burden to member states.
4. The 66th World Health Assembly adopted the WHO's Comprehensive Mental Health Action Plan 2013-2020 in May 2013, which included actions for epilepsy control. In November 2012, the Pan American Health Organization (PAHO/WHO) approved a Strategic Plan on Epilepsy for the American continent, which gave an example of WHO regional action on epilepsy control.
5. Dr Shin Young-soo, Regional Director of WHO/WPRO said in the Third SIDS meeting: “Fighting NCDs requires a whole-of-government and whole-of-society approach”. This may apply in setting up strategic actions for epilepsy control.
6. The time to act is now in the WHO Western Pacific Region, in order to set up a Strategic Action Plan for epilepsy control through coordinated efforts at country level designed to introduce and implement national epilepsy programs and services; to minimize the treatment gap by facilitating access to affordable medicines; and to establish awareness initiatives to educate the public about the nature of the disease and thereby remove stigmatization.



The items to be discussed at the 3-day meeting included:

- The importance of mental health and the heavy burden of mental disorders;
- Antimicrobial resistance and the need for a strong action plan to combat this emerging threat in the Region;
- Strengthening immunization programmes to build on achievements and improve access to vaccinations;
- Preventing and mitigating risks associated with disasters through the prevention, preparedness, response and recovery.

In his opening address to the Regional Committee, WHO Regional Director for the Western Pacific, Dr Shin Young-soo reminded Member States that the Western Pacific Region has long been a hotspot for many emerging diseases, and how managing SARS, the first major disease outbreak of the 21st century, has made them stronger so that they are better prepared than ever for Ebola virus disease. Results from a recent survey of the Region's members showed good preparedness to detect and respond to Ebola, and a regional emergency operations centre is on high alert.

“The risk for transmission here is low,



but the consequences are high so we must be prepared,” he concluded. “The Ebola crisis drives home a simple truth - investing in health security during so-called normal times is absolutely vital!”

Dr Ian Smith, Executive Director of WHO's Office of the Director-General, spoke on behalf of Director-General Dr Margaret Chan. His remarks also focused on the growing Ebola crisis, raising the following points:

- The outbreak shows the world's growing social and economic inequalities.

- Rumours and panic spread faster than the virus.
- The world is put at risk when a deadly virus hits the destitute.
- Decades of neglected basic health systems and services can bring a fragile country to its knees. .
- There is a lack of research and development incentive as evidenced by the absence of an Ebola vaccine.
- The world is ill-prepared to respond to a severe, sustained and threatening public health emergency.

Photos:

- Previous page: main photo: delegates at session. Inset photo: Dr LI Shichuo presents his statement
- Above Dr LI Shichuo and Dr Shin Young-soo, Regional Director of WHO/WPRO.
- Left: Dr LI Shichuo and Dr Shekhar Saxena, Director of the Department of Mental Health & Substance Abuse, WHO Headquarters, Geneva.



DEFINITION OF EPILEPSY 2014

A Task Force of 19 members, 2 years of dedicated work, 100's of emails, 22 draft manuscripts and 313 comments public comments were involved in finalising the new operational definition of epilepsy

When the Definition of Epilepsy 2014 was published recently it was not done lightly and followed two years of intense work. Prof Bob Fisher, Chair of the ILAE Definitions Task Force explains:

"Few manuscripts in the epilepsy literature have undergone such an extensive review and revision process. Obtaining consensus from 19 strongly opinionated authors was itself a challenge, and then four additional layers of commentary and revision ensued:

1. from the public;
2. from the comment review Task Force;
3. from *Epilepsia*;
4. by the ILAE Executive Committee.

The resulting definition and publication were much strengthened by this process and better aligned with the way clinicians think about epilepsy."

What was the reason for this mammoth task? Prof Fisher explains:

"In 2012, Solomon Moshe, and the incoming ILAE president, Emilio Perucca, reconstituted a Definitions Task Force with 19 members, including three current or past ILAE presidents, a current and prior editor of *Epilepsia*, several current and past presidents of national societies, members with clinical and epidemiologic expertise, representatives of the

resource-poor world, and representatives of the International Bureau for Epilepsy.

The Task Force included individuals with epilepsy.

The immediate charge was to clarify and make operational, that is, practical and usable, the definition conceptualized in 2005."

Prof Emilio Perucca, ILAE President sees this paper as a major achievement and a new milestone in epilepsy:

"The publication of an operational definition of epilepsy is a milestone for the epilepsy community as it represents a new direction in the creation of such a consensus document.

"This document in fact will carry the designation of "League position" using a new process. This means that the definition is endorsed by our organization, its membership, and the international epilepsy community."

How did task force go about drafting the new definition of epilepsy

Operational (Clinical) Definition of Epilepsy 2014

A person is considered to have epilepsy if they meet any of the following conditions:

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.

Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years.

and what procedures were taken to ensure that the entire epilepsy community was involved?

In his commentary, which you can read in full at <http://www.ilae.org/Visitors/Centre/documents/Definition2014-commentFisher.pdf>, Bob Fisher explains the background to the process, which dates back more than a decade and then tells how the Definitions Task Force, reconstituted in 2012, undertook its task:

"The definitions process began more than 10 years ago when the ILAE Executive Committee, under the leadership of Jerome Engel, Jr., formed the Definitions of Epilepsy committee", Fisher says. He continues:

"After multiple meetings and a dozen drafts of a manuscript, the committee published in 2005 a conceptual definition of epilepsy with two points at variance with the traditional "two unprovoked seizures" definition. The first was that epilepsy could be considered to exist after one unprovoked seizure, provided there was an enduring predisposition for another.

The second concept was to incorporate psychobiologic and social consequences of epilepsy into the definition. The committee did not provide specific meaning of the phrase "enduring predisposition," and so it remained a concept. Nevertheless, the conceptual definition generated controversy."

Jump ahead to 2012 and the start of work by the new group. Again, Prof Fisher, as Chair of the Definitions Task Force, is best placed to describe how the work was done:

"The Task Force met in person and communicated by way of hundreds of emails. Points were debated, and ultimately 22 drafts of a manuscript were reviewed by the coauthors. The presubmission draft of the manuscript was posted on the ILAE website with an invitation for the epilepsy public to provide comments. A total of 313 individuals did so, many with great thoughtfulness and detailed suggestions and criticisms. The signed comments can be found at <http://www.ilae.org/Visitors/Centre/Definition.cfm>.

"Overall, there were 174 positive comments (56%), 64 negative comments (20%), and 75 neutral comments (24%). Comments with at least two criticisms were counted as being negative, even when accompanied by effusive praise. The authors categorized the public comments and substantially altered the manuscript and definition based on prevailing themes.

"After the manuscript was revised based on the public comments, a new task force was empaneled to evaluate whether the revision adequately reflected the public view. The new task force agreed, with a few provisos, that the comments had been addressed. The manuscript was submitted to *Epilepsia*. Thirty-three anonymous comments were received from five reviewers, and the article was

again revised in accord with those suggestions. After acceptance of the manuscript by *Epilepsia*, the ILAE Executive Committee voted to make the definition a position of the ILAE."

Epilepsy a Disease

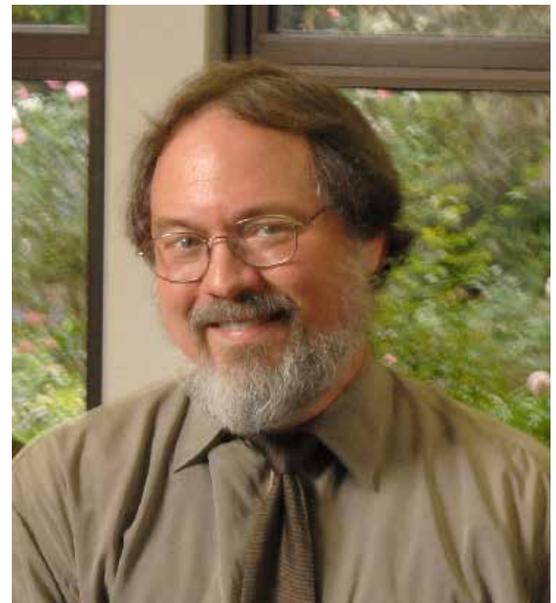
For lay people, one of the issues that raised most debate was the decision to call epilepsy a disease. Epilepsy has traditionally been referred to as a disorder or a family of disorders, rather than a disease, to emphasize that it is comprised of many different diseases and conditions.

The term disorder implies a functional disturbance, not necessarily lasting; whereas, the term disease may (but not always) convey a more lasting derangement of normal function. Many heterogeneous health problems, for example, cancer or diabetes, comprise numerous subdisorders and are still considered to be diseases. The term "disorder" is poorly understood by the public and minimizes the serious nature of epilepsy. The ILAE and the International Bureau for Epilepsy (IBE) have recently agreed that epilepsy is best considered to be a disease.

On page 10 of this issue, Mike Glynn, who is a member of the Definitions Task Force writes convincingly of the reasons he believes it is correct to describe epilepsy as a disease.

Epilepsy should be called a disorder according to the 23% who spontaneously so commented when the manuscript was uploaded to the ILAE website inviting comment. The ILAE Executive Committee decided in favor of calling epilepsy a disease, and the Task Force did not further debate the issue. The ILAE Executive Committee decided in favor of calling epilepsy a disease, and the Task Force did not further debate the issue.

The biggest concern was that the use of the word 'disease' to describe epilepsy could further increase the stigma that people with epilepsy face with 'disease' often being mistakenly connected to contagion. This is a particular worry for people with epilepsy living in developing nations where stigma is particularly problematic. On page 9 you can read some of the comments (both positive and negative) that were posted by com-



DEFINITIONS TASK FORCE

- Robert S Fisher, USA
- Carlos Acevedo, Chile
- Alexis Arzimanoglou, France
- Alicia Bogacz, Uruguay
- J Helen Cross, UK
- Christian E Elger, Germany
- Jerome Engel Jr, USA
- Lars Forsgren, Sweden
- Jacqueline A French, USA
- Mike Glynn, Ireland
- Dale C Hesdorffer, USA
- Byung-In Lee, Korea
- Gary W Mathern, USA
- Solomon L Moshe, USA
- Emilio Perucca, Italy
- Ingrid E Scheffer, Australia
- Torbjörn Tomson, Sweden
- Masako Watanabe, Japan
- Samuel Wiebe, Canada

mentators, not only on the subject of whether or not epilepsy should be called a disease, but on other aspects of the documents also.

But for now, we will leave the last words to Prof Fisher:

"Few manuscripts in the epilepsy literature have undergone such an extensive review and revision process.

The resulting definition and publication were much strengthened by this process and better aligned with the way clinicians think about epilepsy.

Codifying that thinking is the purpose of a definition. As new information and experience accumulate, the way clinicians and researchers view the term "epilepsy" will evolve, and another revision of the definition may be required— it is hoped not any time soon."

Definition of Epilepsy 2014:

A perspective for patients and caregivers, prepared by ILAE

Seizures and epilepsy are not the same. An epileptic seizure is a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain. Epilepsy is a disease characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition. Translation: a seizure is an event and epilepsy is the disease involving recurrent unprovoked seizures.

The above definitions were created in a document generated by a task force of the International League Against Epilepsy (ILAE) in 2005. The definitions were conceptual, (theoretical) and not sufficiently detailed to indicate in individual cases whether a person did or did not have epilepsy.

Therefore, the ILAE commissioned a second task force to develop a practical (operational) definition of epilepsy, designed for use by doctors and patients.

The results of several years of deliberations on this issue have now been published (Fisher RS et al. A practical clinical definition of epilepsy, *Epilepsia* 2014; 55:475-482) and adopted as a position of the ILAE.

A commonly used definition of epilepsy heretofore has been two unprovoked seizures more than 24 hours apart. This definition has many positive features, but also a few limitations. This definition does not allow the possibility of "outgrowing" epilepsy. Inclusion of the word "provoked" seems to imply that people who have photosensitive seizures provoked by flashing lights or patterns do not have epilepsy; whereas, most people think that they do.

Some individuals, who have had only one unprovoked seizure, have other risk factors that make it very likely that they will have another seizure. Many clinicians consider and treat such individuals as though they have epilepsy after one seizure.

Finally, some people can have what is called an epilepsy syndrome and these individuals should meet the definition for having epilepsy even after just one seizure. You cannot have an epilepsy syndrome but not have epilepsy. The new definition of epilepsy addresses each of these points. A person is considered to have epilepsy if they meet any of the following conditions:

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

Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years.

In the definition, epilepsy is now called a disease, rather than a disorder. This was a decision of the Executive Committees of the ILAE and the International Bureau for Epilepsy. Even though epilepsy is a heterogeneous condition, so is cancer or heart disease, and those are called diseases. The word "disease" better connotes the seriousness of epilepsy to the public.

Item 1 of the revised definition is the same as the old definition of epilepsy. **Item 2** allows a condition to be considered epilepsy after one seizure if there is a high risk of having another seizure. Often, the risk will not precisely be known and so the old definition will be employed, i.e., waiting for a second seizure before diagnosing epilepsy. **Item 3** refers to epilepsy syndromes such as benign epilepsy with central-temporal spikes, previously known as benign rolandic epilepsy, which is usually outgrown by age 16 and always by age 21. If a person is past the age of the syndrome, then epilepsy is resolved. If a person has been seizure-free for at least 10 years with the most recent 5 years off all anti-seizure medications, then their epilepsy also may be considered resolved. Being resolved does not guarantee that epilepsy will not return, but it means the chances are small and the person has a right to consider that she or he is free from epilepsy. This is a big potential benefit of the new definition.

What will change as the result of this new definition? Although revision of the definition has generated some controversy, it is likely that real-world changes will be fairly minor. Some people will be able to

say their epilepsy is resolved. Others may encounter the problems and stigma of being told that they have epilepsy after one seizure in some circumstances, rather than after two seizures.

The definition might stimulate research on how likely another seizure is after a first seizure in various clinical circumstances.

Governments and regulatory agencies, people who do therapeutic trials for epilepsy, insurance companies and other third-party payers might have to adjust some of their definitions.

One reason changes will be small is that individuals with one seizure and a high risk for another are currently practically thought of as having epilepsy by many treating physicians. This process simply formalizes that thinking.

Making a diagnosis of epilepsy is not the same as deciding to treat. Some seizures are minor; some patients choose to avoid the side effects of medications. Treatment decisions will be individualized between a person with epilepsy and a physician. Sometimes, information is incomplete; for example, a possible seizure may not have been observed. In these conditions it can be impossible to confidently diagnose epilepsy using any definition. Clinicians will apply best judgment when faced with such incomplete information and often will wait for future developments.

This practical definition is designed for clinical use. Researchers, statistically-minded epidemiologists and other specialized groups may choose to use the older definition or a definition of their own devising. Doing so is perfectly allowable, so long as it is clear what definition is being used.

In the process of developing the revised definition of epilepsy, consensus was reached by forging opinions of 19 co-authors of the publication, while accounting for criticisms by five anonymous journal reviewers and over 300 public commenters on the ILAE website. The revised definition is not perfect. It will become more useful over time as we gain better information on seizure recurrence risks. But for now, the new definition better reflects the way clinicians think about epilepsy.

COMMENTS: Definition of Epilepsy 2014

A total of 313 comments were submitted when the draft Definition of Epilepsy document was posted on the ILAE website. Of these 174 were positive, 67 were negative and 75 were neutral. Most of the comments featured here are responses to the decision to refer to epilepsy as a disease. They are not representative of all comments received, which cover a range of issues.

Why does the new definition call epilepsy a "disease" instead of another term like neurologic disorder or condition of the brain? So many medical documents claim that epilepsy is not a disease. It sounds like it is contagious and could cause further stigma to people with epilepsy. Some syndromes and circumstances could warrant the word "disease" but this isn't necessarily true for the majority of people who have epilepsy.

We would also like to feedback comments we have received from our epilepsy community on the new definition of epilepsy. We had an overwhelming response on social media to the news that epilepsy will now be defined as a disease.

As long as research continues, things can change everyday, (hopefully for the better). People are afraid to even say they have Epilepsy because others back off when they hear the word. Everyone assumes that all of us with this have drop to the floor convulsive seizures and have no idea that I can have a seizure while in a conversation with you and you just assume I'm not paying attention. Education is very important to get out to the public, just like the cancer society has done.

Epilepsy is NOT a DISEASE! It is a Neurological condition affecting part of the brain or the brain in general! I have had epilepsy for 40 years now and am well controlled. I re-iterate, it should not be called a DISEASE!

"Strongly agree that epilepsy is a disease and not a disorder"

In the United States, this definition could cause serious repercussions for the acquisition and qualification of social services. The description of what constitutes epilepsy should be broadened not politicized by hair splitting. This recommended definition does not help the population at large. The poll is an excellent way to gauge the public opinion.

The authors are to be commended for this piece of work, and for the way they have engaged the epilepsy community in formulating their proposal, including this poll. One definition for resolved I would have like to have seen would be "seizure free for 5 years off AEDs", without a need to achieve 10 years seizure freedom.

I disagree with the concept of epilepsy as a disease. Disease suggests a single pathogenesis, a progressive nature. Disease is stigmatising it sounds like epilepsy can be caught - there are disease epidemics. Disorder is a better term.

I disagree with the concept of epilepsy as a disease. Disease suggests a single pathogenesis, a progressive nature. Disease is stigmatising it sounds like epilepsy can be caught - there are disease epidemics. Disorder is a better term.

Many of the recommendations seem impractical for people with seizures. The 10 years with 5 years off medications definition does not account for the fact that many adults who are seizure-free do not want to come off medications even if they have been seizure-free for years. Likewise the 1 seizure plus high-risk group makes it easier to justify diagnostic tests but it is hard to expose a young child to medication for several years on the basis of 1 seizure.

EPILEPSY: A chronic, life-long, non-communicable Disease

Report by Mike Glynn,
IBE Immediate Past President,
CEO of Epilepsy Ireland and a
member of the ILAE Definitions
Task Force

All over the world, at least 30% of people with epilepsy continue to have seizures on an ongoing basis. This figure can rise to as high as 90% in some developing countries. For these people there can be no question that epilepsy represents an acute, chronic and life-threatening disease. Some of the people fortunate enough to have gained control of their seizures give back a huge amount as volunteers and staff members to help those whose epilepsy remains drug-resistant and not controlled. These people form the very backbone of IBE member associations around the world.

However, many of the up to 70% people with epilepsy, whose epilepsy is controlled, are very happy to move on with their lives, forget about their epilepsy and refer to it as just a small "disorder" which upset their lives for a while. In fact, Wikipedia currently suggests that "disorder" may refer to randomness, civil disorder or disease.

The "mistaken belief that epilepsy is a benign condition" (Hanna et al 2002) is almost certainly what led to SUDEP being hidden for 80 years, even though it is now recognised as a leading cause of deaths in people with epilepsy.

Using mild terms, such as "disorder", to describe epilepsy undoubtedly contributes to this notion that it is benign. The renowned American public relations practitioner Lynda Resnick said that "when people affected by epilepsy are reluctant to expose their condition, the public remains in the dark about it –the tragic irony that has made patient care and raising funds for research more than challenging" (Resnick, 2009). Resnick also made the point that "epilepsy is a disease in the shadows" and this is why it has not gained the same prominence as other diseases (Resnick, 2009). Would prostate and breast cancer and heart traumas

receive the same attention if those who suffered from them refused to allow them to be called diseases but insisted they were just "disorders"? Definitely not.

The general public does not recognise epilepsy as a serious problem (Engel, 2010). As long as this situation continues, the search for cures for epilepsy to ensure that nobody has to live a life curtailed by seizures, will be stymied through lack of proper funding for research and care, and through a lack of support from the public. According to Reynolds and Rodin (2009) there is a great unresolved debate about whether epilepsy should be viewed as a separate symptom of underlying brain disease or as one or more idiopathic diseases or syndromes. However there is no debate amongst epileptologists about whether or not epilepsy is a disease: only what type of disease or diseases it is. This debate has continued in some form from the time when the ancient Greeks called epilepsy the sacred disease even while Hippocrates held the view that it was a brain disease. As early as the 3rd century Galen classified epilepsy into three categories of disease (Reynolds & Rodin, 2009). These attempts to achieve a better form of classification of epilepsy as a disease continue to this day.

The new ILAE Definition of Epilepsy states that "Epilepsy is a disease of the brain" (Fisher et al 2014). This is a very important step forward in ensuring that legislators, public health officials, media

people and funders see epilepsy for what it is: a major serious health issue which can destroy lives.

The epilepsy community should now begin to build on this new start to create a future where no person's life is blighted by this chronic disease.

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THE ICE BUCKET CHALLENGE



The Presidents of IBE and ILAE - Thanos Covanis and Emilio Perucca - showed themselves to be good sports recently, when they agreed to accept the Ice Bucket challenge in the name of epilepsy.

The three minute video, which is on YouTube, features an Ice Bucket challenge of a slightly different kind.

Unlike the original version of the challenge, where the person about to be doused with the dreaded bucket of freezing water, nominates the three victims he or she would like next to take the challenge, the Presidents took the opportunity instead to talk about epilepsy - what it is, statistics on prevalence

rates, issues of prejudice and discrimination, and the need for further research to improve services and reduce the treatment gap.

They then challenged anyone watching the video to take the following four actions:

- to learn more about epilepsy;
- to fight discrimination and help in advocating for better epilepsy care;
- to help support epilepsy research;
- and to join IBE and ILAE in celebrating the first International Epilepsy Day on 9th February 2015.

Then Lynne Covanis had the chance to do what many wives would love the opportunity to do. With a smile on her face she lifted the green bucket filled with cold water and ice cubes and poured it over their heads!

Video link: <http://bit.ly/1sWW7tG>.

CARRYING THE BATON FOR EPILEPSY

At the end of July, all eyes were on Glasgow as it played host to the 20th Commonwealth Games, welcoming over 5,000 athletes and nearly a million visitors to the city. IBE Members in Commonwealth and many former Commonwealth countries will probably have spent hours watching the event on their TVs to see how their local heroes were performing.

For Epilepsy Connections, an IBE Associate Member based in Glasgow, there was a hero of a different sort. In October 2013, the Queen of England wrote a message to Commonwealth citizens to be read out at the Opening Ceremony of the Games. Her message was placed inside a special Baton, which was passed from hand to hand by thousands of Queen's Baton Bearers in 70 Commonwealth nations and territories. After an epic 288-day journey and having travelled 190,000km, the Baton finally arrived in

Glasgow's Celtic Stadium on 23rd July and the Queen declared the Games open.

On the final stages of its journey, the Baton reached Scotland on 14th June, where 4,000 Baton Bearers joined the country's biggest ever relay in more than 400 communities, visiting all 32 of Scotland's Local Authorities.

Shirley Maxwell, Executive Director of Epilepsy Connections, nominated Brian Rocks, one of the organisation's long-standing supporters, to be a Baton Bearer. On 18th July and cheered on by his family and dozens of well-wishers despite the 7am start, Brian proudly took his place in the Relay as the Baton travelled through his local community in Clydebank.

Brian said, "It was a great day and an honour to represent people with epilepsy as well as the people of Clydebank".



YOUNG ADULT EPILEPSY SUMMIT

By: Michael Kennedy, Canadian Epilepsy Alliance

When Eduardo Garcia Landrau was 13 years old he had his first tonic clonic seizure. In the proceeding years, Landrau would try and fail nearly a dozen anticonvulsant medications, undergo major surgery to treat his seizures and ultimately, learn to live with intractable epilepsy.

Landrau is not alone in his struggle with epilepsy. The debilitating disease affects 50 million people around the world – 80 per cent of whom live in developing countries and 90 per cent live their lives without access to antiepileptic drugs.

For three days in July, 20 young adults ranging in age from 21 to 29 came together in Washington, DC to identify a project the group could spearhead that would improve the lives of other young adults living with epilepsy.

The invitational Summit was supported by the Epilepsy Foundation and the North American Region Committee of IBE.

Participants from across the region: United States, Canada, Jamaica and Puerto Rico competed for the right to attend this inaugural summit. Each participant was asked to submit a one page personal statement with details of how epilepsy had impacted their life. They gathered to share inspirational stories of struggle, resolve and perseverance. The group brought a wide and important range of personal and lived experience to the first-of-its-kind conference.

“This particular cohort of young adults is an especially important group because of the diversity that they bring to the

table – geographic, cultural and personal,” says Philip Gattone, President and CEO of the Epilepsy Foundation in the United States. “It’s important to get this diverse perspective in order to really understand how you can build an initiative, or a series of initiatives, that can really have a meaningful impact.”

The weekend schedule was packed with discussions, workshops and valuable insight from an often-untapped resource: people living with epilepsy everyday of their lives.

Participants discussed the shame and oppressive fear that often accompanies stigma. Myths and misconceptions about epilepsy were also discussed with participants agreeing they just want to be considered normal and to be given the same chance any of their peers would receive.

In a heartwarming exercise, each participant was asked to share something they wished people knew about them and their life with epilepsy. Stories of untold courage and perseverance resonated throughout the room as young adults discussed tales of woe and turning hardships into blessings.

“Every time I reach a new step in my life I encounter an obstacle that challenges my progress and, sometimes, that obstacle is insurmountable,” said Eduardo Garcia Landrau.

“I wonder if my brother’s death could have been prevented by a detection device,” said Julia Buldo-Licciardi, 25, of her late brother who died in his sleep during

a seizure. “I just wish my brother could be alive and in that room instead of me.”

“It has been a relief being here and hearing that I’m not the only one who went through my formative years living with epilepsy and suffering from depression and anxiety,” said Gail Valentine, who travelled to the conference from Jamaica.

“I have had uncontrolled seizures that have caused me to be hospitalized several times in the last year, but I am still on track to finish a PhD,” said Canadian Kathleen Gaudet.

“The greatest impact for me was the emotional discussion on the challenges of telling others that you have epilepsy. The young adults shared both positive and negative experiences of disclosing their condition to relatives, classmates, teachers and employers. Subsequently, when the group chose to champion a project that aims to educate through sharing of their personal stories we knew that we had succeeded in inspiring these young adults” says Mary Secco, Chair of IBE North America Region and Summit Co-Facilitator.

The goal of the weekend was to identify a project that this remarkable group of twenty-something’s could take on to affect change. Epilepsy education was a consistent theme among many of the projects discussed. Ultimately, the group chose a project that aims to educate and inspire through personal stories using social media channels to distribute their messages.



Perseverance of the Heart

By: Eduardo García Landrau



The year was 1998, I was thirteen and had many dreams. I finished elementary school with excellent grades and had been accepted into a very competitive high school. My free time was spent practicing tennis and playing in official tournaments, where I was considered among the best in the category to which I belonged. My success led me to dream of making further progress in the sport so I could become a champion, and get a scholarship to study veterinary medicine in college. At age 13 life is full of possibilities, and I sought them all, but I was about to learn that sometimes we are faced with the task of maneuvering circumstances that challenge those possibilities, and in their process test our ability to persevere.

With my whole future ahead of me I entered into teenage-hood, ready to discover who I was as a person in the process. Then one day, as I prepared to go to school, I unexpectedly experienced my first seizure. It was a tonic-clonic and complex partial seizure. I was confused and disoriented. My parents did not know what was happening, and took me to a hospital very scared. The doctors told us that I had a seizure, and that simple statement ushered the beginning of many changes in my life for myself and for my whole family.

I stopped being a student of outstanding grades and became a student with learning difficulties. It was disappointing to no longer be defined by the same academic excellence which had been a part of who I was until that point. I could not continue playing tennis or compete at

tournament level because playing required a great deal of concentration that became a burden; it was an effort that I could not tolerate. The side effects of the medication made me gain many pounds, affecting my athleticism. My identity as I knew it was being challenged from all fronts and as a result I started to become depressed. It was too much to handle for a thirteen-year-old boy.

My dream of becoming a professional tennis player slowly vanished, and with it the possibility of a scholarship for the higher education I aspired to. Despite this, I refused to be defined by my circumstances - my heart was stronger than that - and after three years of psychiatric help, changing schools and the unfailing support of my family I was able to finish high school. My dreams began reforming as I got back on track, and for the first time in a long time I began to see the light of hope at the end of the tunnel.

I was ready to try to achieve my other dream of becoming a veterinarian and was accepted to the University of Puerto Rico, Mayaguez Campus program in Animal Science. I moved away from home, without the direct support of my parents who bravely let me go. Completing my undergraduate studies came with its own deal of difficulty, but perseverance continued to be present as a character trait of mine, and after seven years and much effort I earned my bachelor's degree. Throughout this time my partial seizures continued almost every day, and tonic-

clonic seizures once a month. The reality of studying veterinary medicine while also struggling with epilepsy made me realize this dream may not be reached as I originally hoped, but perspective allowed me to look forward for new opportunities to come.

Today I am 29 years old and I have found the balance of making difficult choices for the wellbeing of my health and the fulfillment of my dreams. I feel I have found my way in life. Recognizing my limitations, I have reshaped my goal of becoming a professional tennis player through discovering and developing my abilities as an instructor of the sport. Whenever I have the opportunity I share my experiences with other people who also have epilepsy about how to feel more integrated in society. I also seek to educate others on this condition so it could be better understood and de-stigmatized in the process. Epilepsy does not have to be the end of dreams. The future for the 21st century and global communication should be for human beings with epilepsy to learn how to recognize and manage the condition, and not be ashamed or embarrassed of it. Strength of heart can conquer all, for it is in the heart that perseverance lives and thrives, and allows us to achieve our dreams.

WORLD MENTAL HEALTH DAY IN MAURITIUS

Empowering women with epilepsy to become self-sufficient

Pictured from left: Mr Youssouf Noormamode; Mr Kadress Pillay, Chairman, National Empowerment Foundation; Ms Nina Gopaul, Assistant Vice President CSR, Partners in Progress Foundation Ltd. At the podium: Mrs Valerie Rawat, CEO Apollo BRAMWELL Hospital/ Honorary President Edyecs.



To celebrate World Mental Health Day, Edyecs Epilepsy Group Mauritius organized an awards ceremony at its Epilepsy Health Service Center on 9th October 2014, with the presentation of certificates and sewing machines to fourteen women with epilepsy who have been trained in a sewing and embroidery program, with the aim of assisting them to create small home businesses.

The ceremony was attended by Chief Guest, Mr Kadress Pillay, Chairman of the National Empowerment Foundation, Apollo Bramwell Hospital CEO, Mrs Valerie Rawat and the Vice President

Corporate Social Responsibility of the Partners in Progress Foundation, Ms Nina Gopaul. Other guests present were Mr Ajay Sowdaguar and Mr Guiness from the Ngo Trust Fund, representatives of the European Union Decentralised Cooperation Programme and Maroof Ahmed, Second Secretary, Embassy of the United States of America.

Youssouf Noormamode, President of Edyecs Mauritius spoke on the need to empower women with epilepsy by helping them achieve economic social integration by becoming productive citizens in the community.

The ceremony was widely broadcast on MBC TV Channel News and Radio.

Intensive training lasted for six months and was conducted by a Mauritius Qualifications Authority trained specialist in sewing and embroidery. The participants received training in a number of areas, including how to set up and run a small home business to generate income.

The training project was funded by the Partners in Progress Foundation, under its Corporate Social Responsibilities programme.



INTERNATIONAL EPILEPSY DAY

LOGO COMPETITION



Are you an art student, a graphic designer or are you an amateur artist? Would you like to create a logo to celebrate International Epilepsy Day and at the same time win yourself a prize of US\$250?



Introduction

On 9 February 2015, the 1st International Epilepsy Day will be launched. An initiative of the International Bureau for Epilepsy and the International League Against Epilepsy, this is set to become an annual world day to raise awareness about epilepsy across the globe both in the general public and at government levels. Every campaign needs a logo and we invite you to help us find the perfect logo for this event. By doing so, not only will you have your work used by epilepsy associations around the world, you also have the chance to win a prize for your efforts.

You can also find full information, including the Entry Form on our website www.ibe-epilepsy.org.

How should it look?

- Modern, clean and uncluttered.
- Dynamic.
- Bright and colourful not Black/White.
- The message should be positive.
- No colour preference.
- It must relate to both IBE and ILAE – this could involve use of the two logos in a novel or discreet way.

Specifications

- Suitable for website, Social Media and printed materials
- File type should be EPS.
- Photoshop PSD files are not acceptable.
- Image size of the file must not exceed 1280 x 1024 pixels.
- The file size must not exceed 5MB.
- Clipart may not be used.
- The acronym IED must not be used.
- The text International Epilepsy Day must be used in such a way as to leave it easy for translation to other languages.

How to enter

- Entries should be sent to ibedublin@eircom.net, accompanied by the completed entry form.
- There is no limit on the number of entries allowed, but each entry must be submitted separately and accompanied by separate completed entry forms.
- All work must be original.
- If the design is the work of more than one person, all persons involved in its creation must be named on the entry form.
- Entries are submitted on the understanding that copyright of the winning design will pass to IBE and ILAE. Logos that are not chosen as the winner remain the copyright of the designer.
- The closing date for all entries is 31 October 2014. No entries received after this date will be considered.
- The winner will be announced on 7 November 2014 and will receive US\$250 as the winner's prize.
- The judges reserve the right not to announce a winner if no entry is deemed suitable for use.



Earlier this year, Sari Tervonen, IBE Secretary General carried out a survey of IBE members, which was kindly facilitated by the Finnish Epilepsy Association, of which Sari is CEO. The survey was conducted online and the responses collated automatically. A total of 45 Member associations (out of a total of 132) completed the survey paper and, to each of these associations, IBE sends it thanks. The opinions of the Members are vital in identifying IBE's future direction.

Responses by IBE Region

The first figure indicates percentage of total responses from the region. The figure in brackets indicates the percentage of IBE's total membership located in that region)

AFRICA:

24% (14% of membership)

EASTERN MEDITERRANEAN:

0% (5% of membership)

EUROPE:

40% (45% of membership)

LATIN AMERICA:

11% (12% of membership)

NORTH AMERICA:

7% (4% of membership)

SOUTH EAST ASIA:

9% (7% of membership)

WESTERN PACIFIC:

9% (13% of membership)

The survey was divided into 4 sections:

1. Information on the responding association
2. Views on IBE's communications strategy and how it can be improved
3. Views on IBE's involvement in congresses and how this could be improved for Members
4. Views on IBE's current strategy and suggestions for IBE's future strategy.

At the request of the IBE European Regional Executive Committee, an extra set of questions was included in the survey sent to Members in Europe. A report on this part of the survey will be included in the next issue of EPIfocus, the magazine of the European committee.

Of responses: 76% came from Full Members and 24% from Associate Members. This rate is in close ratio to IBE's total number of Full and Associate Members.

To get an idea of the size and geographical spread of the responding association, we asked how many branches/offices/affiliates each had.

The number of branches, offices or affiliates

- 23%: None
- 57%: Between 1 and 10
- 14%: Between 11 and 50
- 7%: More than 50

We also asked about staffing levels, i.e. the numbers of paid full-time, paid part-time staff and volunteer numbers. As expected, there was a wide divergence in responses to these questions.

Staffing Levels

Paid full time staff:

- 32% have no paid staff
- 27% have between 1 and 3
- 25% have between 4 and 20
- 16% have more than 20

Paid part time staff:

- 39% have none
- 18% have between 1 and 3
- 30% have between 4 and 20
- 14% have more than 20

On the question of volunteer numbers, figure ranged from none right up to 100,000+. While, naturally, the bigger the organisation the greater the number of volunteers it was likely to have, there were also differences across the board in how organisations defined what it considered a volunteer to be.

Of even more interest is the type of activities in which these volunteers were participating. Some of these may give food for thought to other associations,



MEMBERS SURVEY

What you told us!

so here are some quoted examples:

■ Our organisation has 50 to 100 volunteers. They are the basis of the organisation and also have a formal role in deciding how this organisation spends the money it generates. The volunteers' primary role is to plan and implement different social activities such as camps, network groups and info-meetings.

■ We have 4 and 20 volunteers who are given an honorarium when the association receives any project grants from project proposals. Their responsibilities are to raise awareness about epilepsy countrywide and support persons with epilepsy and their parents; to provide access to medication and encourage youths with epilepsy to engage in livelihood support programmes.

■ We have more than 40 volunteers who follow up on support groups in villages; to pay home visits; they run errands for those unable to move; and provide reports on observed seizure patterns of those fortunate to have drugs. They also establish other support groups in new villages and work with persons with epilepsy to initiate beneficial projects for individuals or groups.

■ We have 30 volunteers and their role is to mobilize persons with epilepsy to attend health centers; to assist with

medication collection; to assist with training for persons attending epilepsy clinics, and to provide peer counseling.

■ We have 10,000+ volunteers whose activities include awareness raising activities; support in bringing services to local communities (camps and support groups); advancing the mission of the association through volunteering at fundraising activities; and building participation in advocacy. Administrative activities are also included in our volunteer program (such as answering phones, filing, compiling information packs, etc).

■ We have about 220 volunteers who support people with epilepsy who reside at our institute in long-stay residential care. They go out for walks with them, go shopping together, or visit clients and chat with them. They can also provide support by accompanying clients during swimming lessons or helping out with recreational activities, such as sports activities or days out.

Collaboration with other groups:

Now, more than ever before, there is emphasis on the importance of collaboration with other organisations involved in similar work, with stakeholders, government departments and other NGOs.

The survey included questions on the type and spread of collaboration in which the responding association was involved.

Do you collaborate with other organisations?

70% collaborated with **government departments**

54% collaborated with the **national ILAE chapter**

51% collaborated with **IBE members** in other countries

73% collaborated with **other NGOs**

Other collaborations included: WHO, PAHO, CDC (centers for disease control), the pharmaceutical industry, clinics and hospitals.

Funding sources

Without funding, no organisation could survive. The survey responders were provided with a list of possible sources of funding and were asked to tick as few or as many as applied:

63% indicated that they received funding from donations.

58% received part of their funding from membership fees

56% received funding from fundraising

47% were supported by the pharma industry

33% received project funding

30% had support from government funds

16% received bequests

33% also indicated support from other sources.

Activities of IBE

When asked to comment on how well IBE communicated on its activities, including Promising Strategies, European Epilepsy Day, Global Campaign Against Epilepsy, lobbying with global organisations such as WHO and the UN, IBE came out moderately well, scoring an average of 3.71 out of a possible 5.0. Promising Strategies came out on top with a score of 4.05. However, more interesting to IBE (and I am sure to you, the reader) is how our Members thought we could improve. Here are some comments:

■ I think that - in many ways - the IBE has the exact same challenges that we do; we have to communicate about a very difficult disease - that has an incredible amount of different angles. But in general I think it may be wise to follow the "Keep it simple" strategy; however difficult that may be.

■ All members should send a report of activities done every year to their regional office with recommendations of activities to be carried out the next season.

■ IBE should support education in national languages, cooperation with national IBE members and support webinars or other easy available communication methods for people with epilepsy and the public for sharing of good practice, especially in social issues.

■ We would suggest that more on the Global Campaign Against Epilepsy, WHO and UN be known to members with details on progress. And to possibly link or connect national IBE member associations with each country representative of WHO and UN, so that by the time each association meets or contacts them it may facilitate discussions/contacts. This can only be done by informing them about the existence of IBE members in each country with an official letter and with a copy to members.

■ In an age when most of us are suffering from information overload the challenge is to manage competing demands for our attention. I suspect my scores above reflect my level of interest in each of the topic areas listed i.e. I'm more interested in European matters and Promising Strategies than the Global Campaign, which somehow seems remote and nebulous. However, the Global

Campaign web pages on the WHO site do not compare well with web pages on EED and Promising Strategies. The Global Campaign information is admirably comprehensive but it's just too much; overwhelming, in fact.

I have to say that as a "mere" Associate Member, with limited capacity to contribute to activities, I've found the IBE office staff accessible, approachable and responsive, and I feel that sufficient information is provided about IBE's work to ensure that stakeholders have an understanding of what IBE does and of their successes. Whether this means the communication strategy is effective is impossible to say without sight of the strategy document.

I suspect there are issues about stakeholder engagement and it may be that opportunities for face-to-face communication could be better exploited. It is probably also appropriate for IBE to further develop its digital communications at this time, but this won't in itself secure member buy-in, not least due to language barriers. I wonder what interest /results Facebook and Twitter are generating for IBE at present?

■ Involve members at an earlier stage to help increase active participation and motivation. Does IBE has a vision/strategy for the coming few years? Perhaps something worth considering?

Information Strategy

Some very interesting comments were received on improving IBE's information strategy including:

■ I would suggest that IBE make an extra effort to use simple English in its communications, to help those who are not English speaking associations, and volunteers or others involved in epilepsy work who are interested in IBE activities.

■ This information has to reach non professional people. In this way introducing other languages than English could be useful.

■ I am a bit at a loss at who the audience is that the IBE is aiming to attract. Is it Members or is it the public and until that is clarified it is difficult to pass an opinion.

■ It is not always clear what IBE is currently 'up to' (this includes updated reports from the various Commissions/

Task Forces). The IE News seems to appear too sporadically.

■ The new electronic version of the IE News and other communications will improve information since they we can link these to our websites.

IBE's Future Strategy

We also asked for your comments and suggestions on IBE's future strategy and these comments are of particular interest to us with a task force currently undertaking this work. You said:

■ IBE needs to have 3-4 main goals that should be written clearly. The theme "Epilepsy is more than seizures" is a good starting point for clarifying a goal.

■ Aim to strengthen national policy and legislative frameworks, which will create a conducive environment for epilepsy organizations to achieve their visions and objectives.

■ What is needed is to create some kind of funding for countries with very little resources to attend and participate in all IBE programs. There is the need to strengthen the partnership of IBE and WHO, and consolidate in our respective countries.

■ We must continue to make a deliberate effort to involve leaders-- advocates, marketers, fundraising professionals and innovators from communities around the world who are not scientists or clinical specialists in epilepsy. Laypersons should be leading IBE. Our amazing scientists, researchers, clinicians and other medical professionals are highly valued and should share in our mission with their role in ILAE.

■ Involve Members as much as possible in the strategy definition process (I suppose this survey is one way of achieving this) - a bottom-up approach to make members feel they are being heard.

Concluding comment

All of the comments and suggestions will be carefully reviewed by the Strategic Plan Task Force by the end of November 2014. Thanks are extended, once again, to all those Members who, not only took the time to tick the boxes, but also made great efforts to provide honest constructive criticism, which gives us vital insights to assist in planning the way forward.

Initiatives and Strategic Plan for Epilepsy in the Americas



Dr Devora Kestel

A meeting to discuss the Strategic Plan for Epilepsy in the Americas met during the congress in Buenos Aires in September. Among the participants were Dr Devora Kestel, PAHO Department of Mental Health, Washington DC and Dr Viviana Venegas, Ministry of Health, Chile. Dr Kestel presented an update on the Epilepsy Report for the Latin America and the Caribbean (2013), explaining the importance of the publication. She emphasized that the information in the report that comes from ministries of health is considered official, whereas information from other sources cannot be considered as valid.

Dr Kestel explained that the information is updated at least once a year as new data are collected. PAHO is always interested in receiving information requests and educational material support and in general topics related to the Strategic Plan.

Dr Marco Medina and Dr Carlos Acevedo, co-chairs of the Strategic Plan Task Force, gave an update on activities for the last 12 months:

1. Training courses, including ALADE and LASSE, epidemiology initiatives, pharmacotherapy and primary health care.
2. A pilot plan to develop primary care services in Santa Cruz in Bolivia.
3. Reinforcement of educational campaigns related to Latin American Epilepsy Day, celebrated annually on 9th September.
4. Application by the Chilean League against Epilepsy for approval as a WHO/PAHO Collaborating Centre in Latin America. This is now in the process of approval in Geneva. An application by Honduras, which was

initially started by Dr Jorge Rodríguez, is now in place.

5. Reinforcement of the ILAE North American Commission and start-up of specific initiatives. The first will be a distance-training course for epilepsy specialist nurses in Latin America, with Vicente Iragui as the Latin American representative and José Cavazos collaborating
6. Completed listing of essential antiepileptic drugs by PAHO to incorporate Valproic acid as liquid formula and tablets of 125-200-500 mgrs.
7. Workshop in Santiago (2013) with presentations by Argentina, Colombia, Chile, Honduras, Mexico and Uruguay. Ministries of Health of five countries in the region attended. Dr Jorge del Aguila PAHO representative of Chile; Dr. Hugo Cohen, sub-regional advisor; Dr. Jorge Rodríguez PAHO Mental Health Chief; and Dr Alfredo Pemjeam, Mental Health Chief of Chile, also attended.

Dr Tomas Mesa and Dr Patricia Braga, ILAE Educational Commission, reported on the Strategic Plan, Area 3: Education and Awareness in the Public and presented key elements:

1. Public Educational programs:
 - Educational materials (*Mr Mauricio Olave*)
 - Communication strategies (*Dr Li Li Min, Ms Catalina Durán*)
2. Working models for education in specific subpopulations. Initial model: education to teachers (*Dr Patricia Braga*)
3. Psycho-educational groups (*Dr Tomás Mesa, Ms Delfina Fuentes*)

Dr

Viviana Venegas, representing the Ministry of Health of Chile gave an account of the main activities in which the ministry has been engaged in relation to the management of epilepsy in the past year. This includes the addition of Lamotrigine and Levetiracetam to the therapeutic group of AEDs for the national plan of epilepsy in Chile. Dr Venegas also reported the beginning of an education plan for primary health team-care through a video course (e-learning) throughout the country, which is being done jointly with the Chilean League against Epilepsy and the Catholic University of Chile.

It also reports the start of activities for the development of self-help groups in patients who are being treated at the local health services throughout Chile.

Dr Carlos Guerrero, representing the AED commission, reported on a meeting of the group in Buenos Aires and the development of a work plan. The commission also drafted a list of required AEDs on four levels that increase in complexity. The next step will be to present this information to countries in the region and to monitor changes that may.

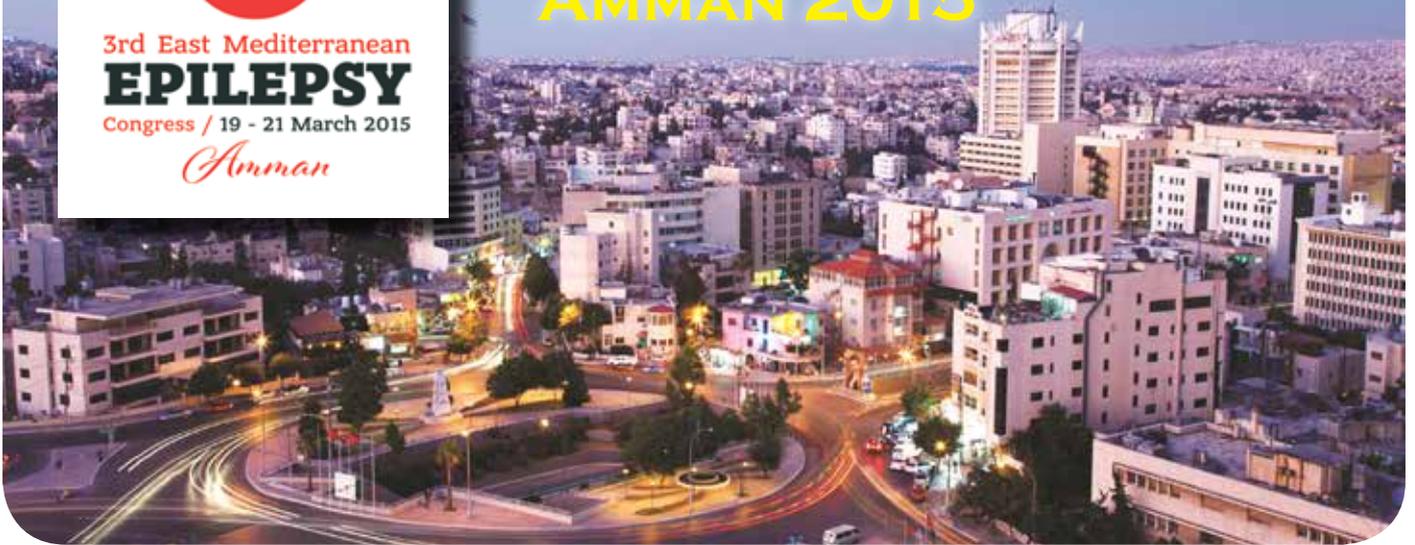
A helpful exchange of views followed, with the conclusion that three-way relationship between ILAE, IBE and PAHO continues to be strong. There was also consensus that an improvement in communication channels is to be addressed. PAHO has educational materials and work plans that are tested and validated and are available on request. It was agreed that there is a need for interventions, including quantitative indexes, to measure the impact of ongoing actions.

FUTURE CONGRESSES



3rd East Mediterranean
EPILEPSY
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**3RD EAST MEDITERRANEAN
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