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From The Information Officer



The ILAE has a bad case of attention deficit disorder with regard to epilepsy, which is partly encouraged by the many issues to address as we forge ahead on our mission to assure that no one's life is limited by epilepsy. These diverse issues have been highlighted by the Institute of Medicine report released earlier this year. The report emphasizes the need for improved epidemiology, education, access to care and qualifications of the healthcare providers. The Pan American agreement and the European Written Declaration on Epilepsy, make epilepsy a healthcare priority, but the path to that goal is not well defined. There is a push to increase funding for clinical and basic research to improve treatment and potentially to find cures. With so many demands and potential directions there is a great danger of paralysis as the epilepsy community tries to respond to so many different needs for action. Although there is great enthusiasm and energy in response to these historic documents, it is possible that by pursuing all of the goals at one time, we will lose the focus that is needed to educate health and science authorities on how to move forward. Clear, well considered and, most importantly, workable plans are needed. As Nico Moshé and Emilio Perucca emphasize in this edition, it is critical that we speak with one voice as we work toward our goal. And the first steps in implementation have started. Gary Mathern reports on the initial steps

in response to the Institute of Medicine report, and Carlos Acevedo and Marco Tulio Medina share how the Pan American Plan and Strategy for Epilepsy has energized many of the countries in Latin America.

Key to the effort of moving the cause of epilepsy forward is communication within the community to share ideas and bring new ideas home. As Sam Wiebe writes, the Regional Congresses are a significant component in that effort as they are the venue where we all come together and talk with each other. And these meetings bear fruit. Peter Bergin outlines the evolution of EpiNet, an international database that is intended to facilitate cross-border research and clinical collaboration. Karijn Aussems describes how patient attitudes about epilepsy can affect access to treatment and how important it is to create an atmosphere of possibility as a component of a successful national plan. As we report, the League has also been busy bringing clinical and laboratory researchers together with government, industry and patients at a recent workshop at the London meeting, to plot a course for finding the next generation of better treatments. All of these efforts gained momentum or were brought to light at a Regional Congress. The message to keep this momentum in the new year is get involved, keep focused and work together so that our community speaks with one voice. We will then be heard.

Edward H Bertram
Information Officer

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Receive news from ILAE, highlights of articles, The Congress updates and more.

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<https://www.facebook.com/ILAE.Epilepsy>

Message From The President & President-Elect



**SPEAKING WITH ONE VOICE
AS WE STAND UP FOR EPILEPSY**

Solomon L Moshé
President

Emilio Perucca
Treasurer &
President-Elect

The ILAE has a vision: A world in which no person's life is limited by epilepsy. It also has a mission: To educate health professionals, patients, care providers, governments and the public worldwide about the resources that are essential to understanding, diagnosing and treating epilepsy. Yet, despite the fact that epilepsy is an ancient disease, described for at least 4,500 years, there is still difficulty in accepting that it is a disease that needs and can be treated with the hope of a cure one day.

To accomplish our mission we are working with our sister organization, the **International Bureau for Epilepsy (IBE)** as well as the **World Health Organization (WHO)**, to develop strong relationships with governments, consumer-based organizations, foundations, individual philanthropies and industries so that people with epilepsy can obtain the care they deserve. Our special relationship with WHO led to the development of the **Global Campaign Against Epilepsy**. More recently we have developed a similar relationship with the **Pan American Health Organization (PAHO)**, the WHO's division in the Americas), and this relationship is laying the groundwork for increasing the awareness of the public to the plight of people with epilepsy. As these joint programs evolve, we hope to coordinate services and treatments so that they reach everyone in need. Ultimately, our goal is to prevent epilepsy and to decrease its burden around the world.

The Global Campaign Against Epilepsy, with the initial slogan "Out of the Shadows," provided a forum to increase the general awareness of the scope of the burden of epilepsy and the great treatment gap that exists. This information was used to assist national health agencies in the development of national epilepsy programs. Fifteen years after the start of this program much has been accomplished, but it is time to move forward, time to stand up for epilepsy and speak with one voice to address not only the treatment gap but also gaps in access to care, knowledge, education, research, advocacy and legislation. We are all working together for a common cause, as we develop the platform for international and national plans so that people with epilepsy will no longer suffer from this disease and its consequences. We must organize our efforts towards clear goals that do not distract from our ultimate success in assuring that no one's life is limited by epilepsy.

In this fight to change perceptions and to assure support for people with epilepsy we need to make sure that we present the facts as they are. We should also be aware of the need to change the public's perception of epilepsy. Just recently in South Korea, a major breakthrough was made with the change in its name to avoid using an ideograph that implied that a person with epilepsy is 'crazy' or 'has received a divine punishment'.

The recent report from the United States Institute of Medicine (IOM) has given us many tools and facts to use in our fight to make epilepsy visible and a healthcare priority, and we should not be afraid to cite them. In 2010, Ms. Linda Resnick published a piece in the **Huffington Post** about the problems of epilepsy and the need to change public perceptions after she met with a group of consumers and epilepsy leaders.

This document powerfully reflects the issues we are facing. I am taking the liberty to reproduce an edited version of Ms. Resnick's document (below) by adding a few of my thoughts as well as data from the IOM report in italics: Here it is: Epilepsy hijacks *the lives of one out of 27 children in the classroom. Epilepsy is an indiscriminate and unpredictable group of ever changing diseases that can affect any age group and manifest itself in seizures, sometimes brain damage as well as cognitive and psychiatric disabilities. Even if significant comorbidities are not present, the constant fear that the person may suffer a seizure, lose control resulting in the loss of a job or a close personal relationship, is enough to make people with epilepsy hide their disease and even withdraw from daily activities.* Because epilepsy is a little understood and often stigmatized disease, many patients and families are reluctant to acknowledge the condition publicly. This *in turn* affects patient care, early diagnosis, medical research, advocacy and their lives. With the *many* recent advances in brain research, the time is now. *What stands between us and a cure for epilepsy is awareness of the needs and increased funding opportunities to address the plight of people with epilepsy. It is time to STAND UP FOR EPILEPSY: WITH ONE VOICE.*

Our collaboration with the WHO and PAHO ensures that epilepsy will be at the forefront of the diseases that WHO designates as critically important, especially since over two-thirds of people with epilepsy can be treated with current medications (although such medications may cause side effects). As we are working towards the development of better drugs and other treatment modalities (surgery, diets, etc.) and possibly cures, we need to emphasize to governmental agencies that it is essential current available drugs are readily available and are of high quality; that surgery is a front line treatment when drugs fail; and that services are available to ensure people with epilepsy have a productive life. Together with WHO and PAHO we will enhance access to interventions and establish clear therapeutic and research priorities. We are developing effective training courses for non-epileptologists and other primary care providers; through our long-distance education arm (VIREPA), we will improve distance education in many languages so that primary care providers have a better understanding of how to diagnose and treat epilepsy. We need to modify local care paradigms that ignore the real needs of people with epilepsy and develop country-specific standards for the care of people with epilepsy. We also have to approach epilepsy as a chronic disease that requires different interventions according to the age of the person. To be successful, we need everyone involved and committed to our mission. Please join in. To accomplish this, we need to STAND UP FOR EPILEPSY AND SPEAK WITH ONE VOICE. If we do, we will win.

View from The Secretary General



Samuel Wiebe
Secretary General

Because the ILAE is an organization of National Chapters, one of the most gratifying developments in the organization is the birth of new Chapters and their successful incorporation into the ILAE family. At last count, 109 National Chapters are members of the ILAE, and we have had the pleasure of welcoming seven new Chapters: Bolivia Cameroon, El Salvador, Kosovo, Kuwait, Nigeria and Sri Lanka. Applications from 23 additional countries are at various stages of maturity. This includes a new Caribbean Chapter composed of several countries, a development which was made possible by the most recent amendment to the ILAE Constitution. This allows the consolidation of several countries from one geographic area or territory into a single Chapter.

What does the ILAE provide to its Member Chapters? These are some of the benefits:

At the most basic level, the largest benefit is obtaining from the ILAE official status as the national professional epilepsy organization. There can be only one ILAE Chapter in each country (or group of countries in a territory); therefore, being officially designated as the ILAE Chapter provides the national organization with the formal jurisdiction to approach governments, organizations and individuals in such an important capacity.

Chapters in good standing have the right to vote in the election of the ILAE leadership, as well as in important decisions brought to vote during the general assembly of Chapters. Being an ILAE Chapter means having a voice in the International Epilepsy Community.

Chapters from resource poor countries have access to discounted or no-cost access to *Epilepsia*, the official journal of the ILAE. For more information on eligibility and no-cost, contact gus@epilepsycongress.org, or visit **HINARI**.

The ILAE provides the Chapter members bursaries for Congresses, workshops, fellowships and other educational activities.

By being active participants within their Regional Commissions, individual Chapters can benefit from the educational, legislative and healthcare resources that are developed within the ILAE Regional Commissions.

One of the most important mandates of the ILAE is education of professionals providing care to people with epilepsy around the world. Increasingly, support from the ILAE for educational activities at all levels (eg. primary healthcare, secondary and tertiary care) is being coordinated through ILAE specific Commissions, and in many cases through its six Regional Commissions (ie., Africa, Asia & Oceania, Eastern Mediterranean, Europe, North America, Latin America).

The ILAE Commissions receive funds from the ILAE through a standardized budget review process every year, to help organize and implement such educational activities, many of which are specific to the countries and Chapters within that Region. It cannot be overemphasized how important it is for individual Chapters to participate actively in their regional activities, not only to gain access to the existing educational resources, but also to determine where resources should be allocated to be most effective. We need everyone's input to achieve our goals.

Examples of Educational activities available to Chapter members can be found here on the [ILAE official website](#), and under the microsite for each of the world Regions (for example, [Latin America](#)).

An important development of regional activities from which individual Chapters can benefit is the Regional Epilepsy Congresses, held every two years in each Region. These Congresses afford Chapter members the opportunity of educational and academic enrichment that is not only very high quality, but also highly relevant to their geographic and cultural context. The Regional Congresses have gained increasing success and popularity, as attested by the most Regional Congresses held in 2012: November 2012 in Quito, Ecuador (7th Latin American Congress on Epilepsy), September 2012 in London, England (10th European Congress on Epileptology), March 2012 in Manila, Philippines (9th Asia and Oceania Epilepsy Congress), June 2012 in Nairobi, Kenya (1st African Epilepsy Congress), and December 2012, San Diego, USA (4th North American Regional Epilepsy Congress during the American Epilepsy Society Annual Meeting).

Commission on European Affairs Awards at the London European Congress



Meir Bialer
School of Pharmacy Institute for Drug
Research, Faculty of Medicine, The Hebrew
University of Jerusalem, Jerusalem, Israel



Simon D. Shorvon
Institute for Neurology,
University College London,
London, UK

The Tenth European Congress on Epileptology (ECE) took place in London from September 30th to October 4th, 2012. Since the first ECE in 1994 the ECE has grown to become one of the major international Congresses in epileptology. This year nearly 4,000 people actively participated in the various sessions of the Congress including several new initiatives of Epilepsy Olympiad, ECE-Forums, Nobel/Field Medal lectures, interface lectures and a "How to do" course.

The following European awards were given during the opening ceremony of the London-ECE:



The first award was the European Epileptology Award, initiated by the CEA in 2002. This award is for a lifetime contribution to epilepsy clinical and research work, and is awarded every two years at the ECE. The recipient of the 2012 CEA European Epileptology Award was Christian Elger, Professor of Epileptology at the University of Bonn in Germany. Prof Elger has carried out definitive work in basic and clinical fields in epilepsy and has set up a large clinical service, including a leading world surgical program for epilepsy. Previous recipients of this award were: Peter Wolf (2002), Charlotte Dravet (2004), Giuliano Avanzini (2006), Simon Shorvon and Uwe Hieneman (2008), Martin Brodie and Yehezkel Ben-Ari (2010). The European Epileptology Award includes a prize of €10,000.

In the last few years, the ILAE, under President Nico Moshé, has encouraged increased recognition of contributions to epilepsy at the regional level. The CEA has followed that lead, and, starting at the London-ECE three new non-monetary awards were given.



The first award was the CEA European Education Award and the first recipient of this award was Prof Alla Guekht from the University of Moscow in Russia. Prof Guekht was recognized for her achievement in organizing and running many outstanding educational courses that were oriented to the newer countries of the CEA where there is not always a well established epilepsy community for professionals. Her commitment to education is renowned.



The second award was the CEA Young Investigator Award and the first receipt of this award was Dr Pasquale Striano from the G. Gaslini Institute of the University of Genova in Italy. Dr Striano was recognized for his numerous publications in clinical epilepsy as well as on epilepsy genetics. The award is given in recognition of outstanding contributions to epilepsy research at an early stage of a career in order to stimulate a promising research in epileptology.



The third award was the CEA European Service Award, and the first recipient of this award was Ms Ann Little from Dublin, Ireland who is the Executive Director of the International Bureau of Epilepsy (IBE). She has supported the CEA over many years and was instrumental in the recent success of the CEA in achieving recognition of epilepsy in the European Parliament's Written Declaration on Epilepsy, an accomplishment that is opening new possibilities for improved epilepsy care and research within the European Union.



In addition to the above CEA awards, the ILAE-British Branch gave the Excellence in Epileptology Award to Tomis Panyiotopoulos, for his outstanding work in epilepsy semiology, classification and electrophysiology.



Finally, the 2011 Morris-Cooles Epilepsia Prize was awarded to Sebastian Schuchmann for the article "Respiratory alkalosis in children with febrile seizures" (*Epilepsia* 52: 1949-1955, 2011). In the prize-winning article, Schuchmann, from the Department of Experimental Neurology of the CharitU in Berlin, and coworkers showed that blood pH is abnormally alkaline in children admitted to hospital because of febrile seizures, while age- and fever-matched children admitted without seizures had systemic acidosis. In agreement with the hypothesis that alkalosis triggers febrile seizures, the affected children had a respiratory infection whereas the control fever group had gastroenteritis. This is an annual award running since 2007 and previous recipients have been Dr Zita Gajda, Dr Nicola Marchi, Dr Julie Jacobs, Dr Yao-Chung Chuang, and Dr Laura Jansen. The winner receives a monetary prize of \$5,000 and a gold Morris-Cooles pin.

Four of the award winners were speakers at the Symposium of Excellence in Epileptology, and they gave the following lectures:

- *Pharmacoresistance in epilepsy: A clinical view* C. Elger
- *From Hippocrates to the "next generation sequencing era": A clinical perspective on epilepsy genetics* P. Striano
- *The significance of defining type of epilepsy* T. Panayiotopoulos
- *Respiratory alkalosis in children with febrile seizures* S. Schuchmann

The next CEA awards will be given at the 11th ECE in Stockholm, Sweden (June 29th - July 3rd, 2014) and the call to suggest candidates will be issued at the end of 2013.

2012 Chapter Recognition Awards

The International League Against Epilepsy paid tribute to six Chapters with a total of 375 years of service to people with epilepsy.

**100 years of service:
ILAE Chapter of Great Britain**



Simon Shorvon accepted award

**75 years of service:
Dutch League**



Gerrit-Jan de Haan, President, accepted award

**50 years of service:
Israeli Chapter**



Ilan Blatt, President, accepted award

**50 years of service:
Italian League**



Roberto Michelucci, President, accepted award

**50 years of service:
Swiss League**

**50 years of service:
French League**



Günter Krämer, President, accepted award



Alexis Arzimanoglou accepted award

Joint AES / ILAE Translational Workshop to Optimize Preclinical Epilepsy Research

London, UK, September 28 - 29, 2012

A joint International League Against Epilepsy (ILAE) and American Epilepsy Society (AES) translational workshop to optimize and accelerate preclinical epilepsy therapy discovery was held in Customs House Hotel, London UK, on September 28 - 29, 2012. The workshop was organized by Drs French, Galanopoulou, O'Brien, and Simonato was attended by 49 international investigators.



Jacqueline French



Terence O'Brien



Aristeia Galanopoulou



Michele Simonato

The incentive behind this initiative was the realization that, despite the significant advances and introduction of many antiseizure drugs into clinical practice, there are still unmet urgent needs to find treatments for drug-resistant seizures. There are additional needs and desires for antiepileptogenic and disease-modifying therapies for the epilepsies and their comorbidities. The high cost associated with the discovery and validation of new therapies and the growing concern that a large number of preclinical discoveries fail to pass clinical testing have generated the concern that new strategies and methods are needed to optimize and de-risk the process of anti epilepsy therapy discovery. These issues were highlighted in a recently published Joint AES / ILAE report [Galanopoulou et al. *Identification of new epilepsy treatments: issues in preclinical methodology*. *Epilepsia* (2012): vol 53(3):571-82]. The joint ILAE / AES effort to address these issues continued through the ongoing collaboration of two Task Forces: the Preclinical Epilepsy Drug Discovery Task Force of the ILAE Commission on Neurobiology (chaired by Terence O'Brien and Michele Simonato) and the AES Translational Task Force (chaired by Helen Scharfman and Steven Roper). Seven working subgroups were created to address specific topics and had multiple discussions and teleconferences, in preparation of the London workshop. The purpose of the workshop was to identify and recommend optimal methodologies, strategies and infrastructure developments to accelerate and de-risk the discovery, validation, and translation of preclinical discoveries into clinically successful therapies for seizures, epilepsies and their comorbidities.

The workshop opened with welcome comments by the current presidents of the ILAE, Solomon (Nico) L Moshé, and the AES, Frances E Jensen, who emphasized the commitment of their organizations to support the goals of the workshop and the initiatives that would enhance and accelerate the discovery of new therapies for epilepsies and comorbidities.

Each working subgroup then presented its summary presentation and proposal followed by group discussions. Working Group 1, chaired by Jacqueline French, outlined the common epilepsy syndromes that present clinical "gaps to care" or provide opportunities to test new antiepileptogenic therapies. This group discussed whether the existing animal models and preclinical behavioral tests might predict a drug's efficacy and tolerability in human patients. Working Group 2, chaired by Aristeia Galanopoulou, presented the issues surrounding the optimization of technical and methodological aspects in the conduct and reporting of preclinical studies that assess pharmacological and nonpharmacological treatments. This group also reviewed the regulatory requirements that need to be met, and the infrastructure developments needed to realize these goals. Working Group 3, chaired by Karen Wilcox, addressed the specific challenges in developing, validating and meeting regulatory expectations for treatments targeting drug-resistant seizures. Working Group 4, chaired by Asla Pitkanen, presented a description of an optimal preclinical design for antiepileptogenesis studies, and discussed the challenges and possible next steps to facilitate the process. Working Group 5, chaired by Amy Brooks-Kayal, highlighted the complex interactions between epilepsies and comorbidities and presented a critical overview of the current state of preclinical testing for anti-comorbidity treatments. A proposal for improving the existing infrastructure and resources was also included. Working Group 6, chaired by Jerome (Pete) Engel Jr, identified the needs and strategies for the discovery and validation of biomarkers for epileptogenicity, epileptogenesis, and pharmacoresistance. Working Group 7, chaired by Michele Simonato and Terence O'Brien, presented a proposal for multicenter preclinical trials and criteria to select candidate therapies for transition to clinical testing.

Invited speakers from pharmaceutical industry and funding agencies were also incorporated in the program. Henrik Klitgaard (UCB SA) discussed the increasing difficulties in bringing better treatments to the clinic and the expectations of the pharmaceutical industry. He also presented possible strategies to de-risk drug discovery for seizures and epilepsy syndromes in need of better therapies. Elisabetta Vaudano (Innovative Medicine Initiative (IMI)) presented an overview of the IMI model of public-private partnerships to support drug development. Rajesh Ranganathan (**National Institute of Neurological Disorders and Stroke** (NINDS)) gave an overview of the current state of funding of translational studies in epilepsy, as well as the history and future goals for the Anticonvulsant Screening Program of the NINDS.

To create a roadmap to achieve the goals of new and better treatments for epilepsy, a panel discussion helped to set priorities, goals and next steps. Panelists included representatives of the sponsors of the London workshop, Nico Moshé (ILAE), Frances Jensen (AES), Steve White (CURE), Roger Porter (Epilepsy Therapy Project), and Daniel Smith (Autism Speaks), Vicky Whittemore as a representative of the NINDS, as well as two international investigators involved in anti-epilepsy therapy discovery, Emilio Perucca and Terence O'Brien.

The workshop was made possible through the generous co-sponsorship by the ILAE, AES, CURE, Epilepsy Therapy Project, and Autism Speaks. The active participation of Drs. Whittemore, Fureman, and Ranganathan was also valuable in interfacing with the parallel initiatives from NINDS. Other contributors to the working groups included: Alexis Arzimanoglou, Kevin Bath, Elinor Ben-Menachem, Ann Berg, Edward Bertram, Amy Brooks-Kayal, Jim Cloyd, Andrew Cole, Stephen Collins, Mark Dichter, Tracy Dixon-Salazar, Ed Dudek, Pete Engel, Dan Friedman, Greg Holmes, John Huguenard, Frances Jensen, Rafal Kaminski, Andres Kanner,

Jaideep Kapur, Henrik Klitgaard, Merab Kokaia, Holger Lerche, Jeffrey Loeb, Wolfgang Loescher, John Messenheimer, Istvan Mody, Solomon L Moshé, Astrid Nehlig, Jeffrey L Noebels, Manisha Patel, Emilio Perucca, Asia Pitkanen, Roger Porter, Michael Privitera, Jong Rho, Robert Ring, Michael Rogawski, Dieter Schmidt, Graeme Sills, Daniel Smith, Helen Scharfman, Kevin Staley, Eugene Trinka, Elisabetta Vaudano, Annamaria Vezzani, Matthew Walker, Steve H White, Samuel Wiebe, and Karen S Wilcox. The summaries and recommendations of the proceedings of the London workshop will be published in a special supplement in *Epilepsia*.

PAHO One Year Later



Carlos Acevedo
IBE Coordinator



Marco Tulio Medina
ILAE Coordinator

The Pan American Strategic Plan on Epilepsy is a reality. In the year since the Plan was started on January 2012, there have been a number of important advances. First of all, a survey was elaborated about human and technical resources for epilepsy. The survey was validated by WHO and it updated the information in the atlas of international epilepsy resources that was published by WHO in 2005. To date there have been responses from 24 countries. Unlike the 2005 survey, which was completed by neurologists in each country of the Region, this time the responses came from the Ministries of Health. This information is essential for determining needs and developing plans for moving the Strategic Plan forward in the coming year. The survey results will be made available in the very near future.

An important step in taking the Plan forward was made at the VIIIth Latin American Epilepsy Congress in Quito this past November, when a Memorandum of Understanding was signed by the leaders of PAHO, ILAE and IBE. This Memorandum gives an official stamp to the Strategic Plan. During the opening ceremony of the Congress, Dr Marco Tulio Medina (ILAE), Dr Carlos Acevedo (IBE) and Mr Jorge Rodríguez (PAHO) clearly outlined the importance of the agreement for epilepsy in the Region, and a Regional Workshop focused on the steps that the countries in the Latin American Region have made in the first year. The results have been tabulated by Dr Eduardo Barragán, Secretary of ILAE Latin American Commission and are [available here](#) and on the ILAE and Latin American Commission websites.

Everyone has agreed that the success of the Plan will depend on steady and continuous work by each of the countries governed by the agreement. To encourage continued efforts the regional members agreed to hold another Regional Workshop in the second week of August in Chile. The workshop will focus on countries in which innovative, successful and low cost initiatives are in place or under development with the objective to highlight the efforts in the poorest countries which have the greatest needs of improved epilepsy care to close the treatment gap. In addition, contacts with the national Ministries of Health will be encouraged to develop better contact between the Ministries and IBE and ILAE representatives. It is essential to have the health authorities actively involved in the development of new initiatives for people with epilepsy.

We should not forget that the agreement creating the Strategic Plan is valid for 10 years and there is always inertia around initiatives like this. However, the visible enthusiasm and commitment of the participants foretell the start of significant changes during 2013. We also have to mention the strong bonds that the Strategic Plan has brought between the ILAE North American Commission and the initial contacts of Epilepsy Foundation of America, which will allow looking for common roads. We have also realized that public outreach to make people outside the epilepsy community aware of the plight of people with epilepsy is essential. These efforts have started to take form with the efforts of Dr Li Li Min and Patricia Tambourgi, a Brazilian journalist, as they have started to create a series of video reports about the importance of the Plan to help improve the suffering of people with epilepsy. We look forward to the progress that we will make in the next several years.

The EpiNet Project



Peter Bergin
Founder of EpiNet and
President of the New
Zealand Chapter

One of the great difficulties in performing clinical research in epilepsy, especially for syndromes that are not common, is the inability to identify sufficient candidates at a single or the typical small number of epilepsy centres that constitute study consortia. The EpiNet Project was commenced in 2007 when a group of neurologists from New Zealand decided to set up an internet-based platform that could be used to undertake clinical research in epilepsy. The ILAE had published a report in 2006, which emphasised the lack of high quality evidence regarding the management of people with epilepsy. In large part, this problem exists because epilepsy does not have a single cause and seizures can take many forms, and can be caused by an enormous range of different pathological processes. Members of the New Zealand Chapter of the ILAE realized that better information would be obtained if studies focused on more specific patient groups. They concluded that the best way to approach this problem would be for large numbers of investigators to contribute patients to studies. However, New Zealand has a population of only 4 million people, and it was never going to be practical to run highly focused studies in such a small country. An international patient database was needed, so EpiNet was developed so that the data could be accessed via the Internet by multiple investigators.

The EpiNet database has been designed to achieve several goals simultaneously:

- It provides each user (and centre) with a clinically useful database for their own use
- It provides an epilepsy record that can be shared between and updated by clinicians who may be based in different centres
- It provides a summary of important information (e.g seizure history, results of investigations and drug history) in a single place; this can be printed out and given to the patient if so desired
- De-identified data is entered into the international research database; within this database, registries for specific patient groups or clinical scenarios can be easily established
- The platform has been created specifically to run large, simple, pragmatic randomised controlled trials

The database has been repeatedly tested and refined, first with a New Zealand-wide study and then with an international pilot study. In the latter study, 80 investigators or research assistants from 25 centres in 13 countries registered 1,050 patients into the database. Following feedback from participants, substantial changes were made to the database, and a new version was released in September of this year. The EpiNet Project is now being overseen by a steering group of seven epileptologists from five countries. A

memorandum of understanding has been produced in which several important principles underpinning the collaboration are outlined. One of these is that individual investigators remain in control of their datasets at all times.

Registries of first seizure patients and of patients commencing their first AED were established after the release of the latest version of the software. Patients in these registries will be followed indefinitely. We are interested to see what AEDs are used by neurologists in different clinical circumstances, and what decisions are made when the first AED fails. Soon, we intend to set up a registry for patients who are discontinuing their AEDs because they are seizure free. Can we determine if the rate of AED withdrawal influences the risk of recurrence? What is the predictive value of an EEG in these circumstances?

In 2013, we intend to commence our first randomised controlled trial in patients with new onset epilepsy. Depending on the seizure type, patients will be randomised to receive levetiracetam, sodium valproate or lamotrigine.

The EpiNet Steering Committee is keen to expand the collaboration. We would like as many epileptologists and neurologists as possible to join this research project. We want this project to be a true cooperative venture, with all participants having a real sense of ownership. Any investigator is therefore welcome to propose a registry or clinical trial. In particular, we invite epileptologists who have an interest in an uncommon condition to use the EpiNet platform to set up a registry, since this type of multinational collaborative approach may be the only way that information on large numbers of patients with rare syndromes can be collected. We hope that EpiNet will not only facilitate better understanding and treatment for the epilepsies but also create more transnational interaction.

A more detailed overview of the project is available at [EpiNet study group](#).

A demonstration of the database and the memorandum of understanding are also available at this site.

Please contact **Dr. Peter Bergin**

A Program of Youth on the Move in Kenya



Karijn Aussems
Director
Youth on the Move

One of the great difficulties in treating epilepsy in many societies without a strong culture of science-based medicine is getting people to accept the diagnosis and to take standard medications as prescribed. In many countries, including Kenya, there is a common belief that it is essential to provide free drugs to reduce the treatment gap, with the assumption that poverty and the lack of financial resources is the primary reason for a failure to take appropriate medications. Although this lack of money certainly contributes to not taking medications, there is also another reason. Many times poor people in Kenya tell us that they gave a goat to the traditional healer who promised a cure from epilepsy. Only later did they find out that the promised cure wasn't as effective as promised. In Kenya at least, if the family had sold the goat instead, they could have paid for phenobarbital for three years. Although limited resources clearly play a role in not receiving effective treatment, knowledge of the treatment options and the attitude that treatment can make a difference also are very influential factors in the health status of people with epilepsy.

Although awareness of options, affordability and access have a major influence on AED intake, attitude of the patient and family also has a major impact. As a child with epilepsy, I was very well aware of my epilepsy, and the AEDs were accessible and affordable. However, I regularly left the drugs untouched, sometimes to avoid the side-effects, sometimes because I forgot, but also as an act of rebellion. I am not sure that my neurologist ever took my rebellious spirit into consideration when he increased the AED doses to treat my continued seizures.

One of the keys to ensuring that people with epilepsy take care of themselves is to encourage the right attitude. It starts with the provision of knowledge. Part of the problem is that people with epilepsy in many countries won't acknowledge that they have the condition. Often people state that they faint or have leprosy, not knowing it is epilepsy. In Kenya, the Ministry of Health blames the health sector for the lack of understanding about epilepsy on the part of their patients: "service providers never really get to know what their clients understand. Thus they often assume that what they have said, advised or given has been accepted and will be done, only to be surprised later that no change has taken place in terms of behavior or practice and therefore health outcomes."

To improve the control of epilepsy, we firstly need to assess the understanding of the person with epilepsy, and then offer knowledge in their (street) language. Knowledge is the key to acknowledgment, but not yet acceptance. Therefore, the next step to achieve a healthy and productive life with epilepsy is coaching. In coaching, we use Acceptance and Commitment Therapy (ACT). A person with epilepsy can be stressed by fearing a seizure to come. Acknowledgment, acceptance and commitment to take the treatment can therefore reduce two major barriers to success: stress and non-adherence. According to ACT, accepting the condition and making the commitment to focus on opportunities rather than hindrances could indirectly lead to symptom reduction.

Since 2008, Youth on the Move in Kenya has offered epilepsy training and coaching in layman's language, with the goal of achieving acceptance and commitment among Kenyan youth with epilepsy. We see that this significantly boosts their self-esteem, health and hope for a future in which they can rely on themselves. Every year youth coordinators receive formal training in the many social and medical aspects of epilepsy as well as on counseling and developing youth participation. The involvement of these coordinators is essential because they can reach their contemporaries far better than adults, and they can share common experiences.

Youth on the Move empowers youth with epilepsy through intense personal guidance to help build their skills, to stand up for themselves and to transform their desires into realistic plans and actions. As they learn life skills on how to live beyond epilepsy, we also teach them professional skills about how to pass this information on to their community members. Youth on the Move participants go to schools, churches and other social institutions to create awareness about the condition in layman's language. During these sessions, they share their personal experiences, which encourages their audience to be more free in sharing about their challenges regarding epilepsy.

In 2012, the youth with epilepsy have achieved a record of educating 23,330 people on the disease. See more about the program at <http://www.youth-on-the-move.com/eng/home.html>.



Follow-up on the Institute of Medicine 2012 Report: Epilepsy Across the Spectrum



Gary W Mathern
Chair Strategic Task Force

On March 30, 2012, the Institute of Medicine (IOM) released its much anticipated report on the epilepsies titled "Epilepsy Across the Spectrum: Promoting Health and Understanding." During the two years the IOM Committee worked on this project, more than 80 people provided presentations and personal stories about their experience with epilepsy and the frustrations of finding effective care. The report highlights gaps in the knowledge and management of epilepsy, and suggests actions to promote better understanding and care. The report is nearly 540 pages in length (available as a PDF at www.iom.edu/epilepsy), and it emphasizes that epilepsy should be thought of as a spectrum of diseases (the epilepsies).

The report has five key messages:

- Epilepsies are common and complex neurological diseases that affect health and quality of life, and the focus of treatment must go beyond control of seizures
- Effective treatments are available, but timely referral and access to quality treatments fall short everywhere. Better data are needed to improve epilepsy identification and quality of care
- Health professionals must be better educated about epilepsy and proper treatments
- Education efforts need to be sensitive to health literacy and cultural considerations
- The stigmas associated with epilepsy have to be eliminated

Based on the testimony and findings the IOM Committee developed 13 recommendations involving improved surveillance and prevention, education for patients and families, accreditation of healthcare providers, and improved collaboration between patient advocacy and professional organizations to take "ownership" of these diseases.

Since the release of the report, has anything important happened? The simple answer is yes. To promote communication a synopsis of the report has been published in *Epilepsy & Behavior* and will be available as a free PDF download for 12 months (<http://www.sciencedirect.com/science/article/pii/S1525505012004465>). A shorter summary along with an introduction is available in the December issue of *Epilepsy Currents* from the American Epilepsy Society (<http://www.epilepsycurrents.org/doi/pdf/10.5698/1535-7511-12.6.243>) (<http://www.epilepsycurrents.org/doi/pdf/10.5698/1535-7511-12.6.245>). As the Committee noted, one of the most compelling aspects of their study was the testimony provided by patients and families, only a small portion of which could be included in the final report. The full testimony has been gathered, edited and is now available online and is highly recommended reading (<http://dx.doi.org/10.1016/j.yebeh.2012.10.003>). In addition, in part due to the IOM report, the U.S. Centers for Disease Control (CDC) published findings in the November 15th issue of its Morbidity and Mortality Weekly Report (MMWR) featuring their estimates of epilepsy prevalence and discussion of treatment gaps and access to specialty care for the first time in 20 years (http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6145a2.htm?s_cid=mm6145a2_w). Furthermore, several sub-committees have been formed as part of the original Vision 20/20 group, one of which is creating a simple screening tool that can be used by patients and caregivers to define when it is time to seek another opinion about epilepsy care. That tool is expected by the end of 2013.

While all these activities are exciting and show the immediate impact of the report on the epilepsies, it is important that we consider how to use the report internationally, especially in light of the European Written Declaration on Epilepsy and the Pan American Health Organization (PAHO) Strategy and Plan for Action. The IOM recommendations should be integrated into the PAHO initiative to improve care for people with epilepsies throughout the Americas, and the European initiative. The report documents the many problems of the epilepsies and provides objective evidence on how we must move forward. The report is an essential tool in our discussions with health agencies. There are many needs, and it will be critical for ILAE along with our sister organizations, including IBE and WHO, to identify which recommendations to initiate and implement first to have the greatest impact world-wide on taking care of patients with epilepsy. This will be a complex task with many voices involved, but with only so many resources to go around we will need to identify and focus on those strategies with the greatest and most immediate impact. It is essential that we work together with common goals and that we speak with one voice to deliver our message clearly and accurately to those allocating healthcare resources. This effort is just beginning. As our mission moves forward, we encourage the international epilepsy community to get involved locally or through the international organizations to achieve the League's mission that no one's life is limited by epilepsy.

Purple Day



Purple Day, which emphasizes epilepsy awareness, is March 26th. It started with a presentation on epilepsy to a third grade class in Nova Scotia and has grown to a global campaign drawing awareness for epilepsy. Purple Day founder Cassidy Megan will color the world with purple in March, without using a single crayon in her box. It started with the then nine-year-old disclosing the details of her life with epilepsy to her classmates. The young girl asked her school principal if everyone in the Halifax school could wear purple to show support for people with epilepsy. The support shown that day in 2008 has spread.



Cassidy Megan

Cassidy is now 13 years old and was recently awarded the Queen Elizabeth II Diamond Jubilee Medal in recognition of founding Purple Day. The Canadian Parliament passed a law in June making every March 26th Purple Day in Canada.

Now efforts to take the campaign global have spread to more than 60 countries around the world thanks to the partnership of the **Anita Kaufmann Foundation** and the Epilepsy Association of Nova Scotia. To learn more about Cassidy and Purple Day go to www.purpleday.org.

Bookstore on the ILAE Website

There has been a steady increase in the number of books published that are relevant to epilepsy that members of the League will likely find useful for their practice or research. However, keeping up with the books that are available is no easy task. To help make the job easier we have created this Bookstore as a service to our membership. In it publishers can provide information on their epilepsy-related books. They may also provide information on where and how to purchase the books. The League does not sell the books. [View Bookstore](#).

The Bookstore is in the early stages of evolution, and we expect to add new titles and publishers on a regular basis, so please check back frequently for new additions.

There are currently seven books listed. If you have authored a book, please encourage your publisher to list their book on this website. The cost is minimal.

Farewells Listing on Website

ILAE hosts a [Farewells](#) web page where we commemorate our departed colleagues in epilepsy and the contributions that they have made to the field. It is our intention that this section for memorials be open to obituaries for anyone who has been active in the field of epilepsy in any capacity: clinical, social, scientific, psychological, to name but a few. There are no academic, professional or geographical requirements to be considered for inclusion in this section. There are many great things that are done locally to improve the lives of people with epilepsy, efforts that are critical in the battle against this condition. Unfortunately some of the most important contributions are done away from the limelight and may not catch the attention of the larger international community. It is the intention of this section that anyone who has been active in the field be included and have their efforts and successes more widely known. The only real criterion is that the individual worked to help relieve the burden of epilepsy somewhere in the world.

The memorial articles are written by those who knew the person. The goal is to tell your colleagues in epilepsy who this individual was and what the contributions were. Photographs are welcome.

There are two parts to this section: recent deaths and archives. The latter allows League members to learn about those who have gone before and the contributions they made as well as acts as a resource for those who wish to look into the history of epilepsy and those who contributed to it. We look forward to your remembrances of our valued departed colleagues. Please send them or any comments or suggestions that you may have to farewells@ilae.org. We will also welcome multiple remembrances from our members. The success of this project will depend entirely on your efforts to help preserve the memories and the accomplishments of our friends and colleagues.

Upcoming Congresses and Educational Events



30th International Epilepsy Congress
23-27 June, 2013
Montreal, Quebec, Canada
<http://www.epilepsycongress.org>

7th Educational Epilepsy Symposium and Multiple Sclerosis, Parkinson's Disease Update

Egyptian Epilepsy Association in collaboration with the ILAE and CEMA
17-20 January, 2013
Beirut, Lebanon

Contact: nihal.maharem@icomgroup.org
Outside Egypt contact: shaimaa.elkhatibe@icomgroup.org

3rd Course on Epilepsy Surgery Advanced Course

22-26 January, 2013
Brno, Czech Republic

An advanced interactive course on surgically remediable epilepsies, presurgical evaluation, scalp and intracranial EEG, neuropsychology, imaging and psychiatric issues of surgical patients before and after surgery.
Application Deadline: 1 November, 2012

[Course programme and details](#)

Training in Neurotherapeutics Discovery and Development for Academic Scientists

27 February - March 2, 2013
Bethesda, MD, USA

www.neurotherapeuticscourse.org

AAN Annual Meeting

13-16 March, 2013
San Diego, CA, USA

[Information, Registration and Program](#)

4th London-Innsbruck Colloquium on Status Epilepticus and Acute Seizures

4-6 April, 2013
Salzburg, Austria

[Information, Registration and Program](#)

15th International Neuroscience Winter Conference

9-13 April, 2013
Sölden, Austria

[Conference information](#)

The 7th World Congress on Controversies in Neurology (CONy)

11-14 April, 2013
Istanbul, Turkey

<http://www.comtecmed.com/cony/2013/>
cony@comtecmed.com

6th International Epilepsy Colloquium: Tumoral Epilepsy and Epilepsy Surgery
20-24 May 2013

- Epileptology Course - May 20-21
- 3D Stereotactic EEG in Epilepsy Surgery - Hands-on workshop - May 22
- 6th International Epilepsy Colloquium - May 22-24
- Source Imaging in Epilepsy - May 24

Information and Registration**European Forum on Epilepsy Research**

25-27 May, 2013
Sponsored by IBE and ILAE
Dublin, Ireland

Congress Website**XII Workshop on Neurobiology of Epilepsy (WONOE 2013)**

New technologies to study the epileptic brain
A satellite event of the 30th IBE/ILAE International Epilepsy Congress
19-22 June, 2013
Lake Dupuis, Laurentian Mountains, Quebec, Canada

Information**XXIst World Congress of Neurology**

21-26 September, 2013
Vienna, Austria, focusing on Neurology in the age of globalization.
http://www2.kenes.com/wcn/congress/Pages/Welcome_Message.aspx

11th European Congress on Epileptology

29 June - 3 July, 2014
Stockholm, Sweden

Congress website**10th Asian & Oceanian Epilepsy Congress**

24-27 August, 2014
Suntec International Convention & Exhibition Centre, Singapore

Complete Congress listing**EPIGRAPH****Share with your colleagues**

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