The International League Against Epilepsy at the Threshold of its Second Century: Challenges and Opportunities*

In July 2009, during the 28th International Epilepsy Congress in Budapest, Hungary, the International League Against Epilepsy officially entered its second century. The League was inaugurated at a side meeting held during the XVIth International Medical Congress, on August 30th, 1909, in the Salle Donau of the Hotel Bristol, in the same city, Budapest. Forty-six people, mainly neurologists and psychiatrists, were present. The 3500 people from 100 countries who attended the 28th International Epilepsy Congress had the opportunity to walk through an exhibit featuring the Hotel Bristol and the ILAE Centenary Exhibition. The exhibit is now posted in the League’s website (www.ilae.org).

**Key Words:** Strategic plan, constitution, education, global campaign, research, infrastructure, information dissemination

Reflecting on that founding event 100 years ago, ILAE members should be very proud of our accomplishments. With chapters in over 100 countries, the ILAE has become the recognized international society of medical and allied health professionals who share the goal of improving the lives of persons with epilepsy throughout the world. For the League to reach this point required the personal effort and commitment of numerous individuals who volunteered their time in many capacities over the years. This accomplishment is the result of international teamwork to promote education, training and research; of communication of new research findings and guidelines through our congresses and our world-recognized journal Epilepsia; and of novel joint ventures with the World Health Organization (WHO) and other international bodies related to epilepsy. The ILAE has also helped to bring epilepsy “out of the shadows” through the Global Campaign Against Epilepsy. This important partnership between the ILAE, WHO and the International Bureau for Epilepsy (IBE) has helped to identify medical and financial resources available for epilepsy care by geographic region, determine areas of treatment gaps, and raise awareness and reduce social barriers for individuals with epilepsy. The League members and partners all share a common vision: to create a world in which no person’s life is limited by epilepsy.

This impressive record of accomplishment is the result of the enlightened leadership by our past Presidents and their respective Executive Committees, as well as the devotion and hard work of hundreds of professionals who donated their time to carry out the League’s goals.

Celebrations of historical achievements provide important opportunities to review the past and look toward the future and its challenges. The beginning of the League’s second century offers us unprecedented opportunities to improve epilepsy care worldwide through a coordinated program of education, research, and the development of centers of excellence in countries worldwide.

Epilepsy is a disorder affecting humans for many millennia. There are detailed writings about its symptoms, causes, consequences and treatments even in ancient cultures. Some of the causes we now know are genetic in origin; some have remained unknown. Often epilepsy is related to structural/metabolic disorders. It is frequently associated with many of those conditions – infections (including HIV and parasitic infections), malnutrition, intoxications, neoplasms, stroke, and traumatic brain injury – that afflict people all over our planet. Developing preventative strategies, as well as safe and effective treatments, are of paramount importance. Unfortunately, there are still many gaps not only in knowledge but also in the availability of resources to deliver effective health care in many regions of the world.

During the next four years (2009-2013), and, hopefully beyond, we will need to work together to:

- Enhance collaborative international education, training, and research to improve the quality of life for all persons with epilepsy, regardless of gender, age, or geographical location;
- Foster initiatives to improve the medical care of people with epilepsy, by reducing the treatment gap which is highly prevalent in many countries of the world; and

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- Identify, mentor and develop the next generation of the League leaders.

The keyword for all these initiatives is we: the members of our Society. Our League needs all of you in order to achieve its goals. Indeed, to paraphrase one of my boyhood heroes, former U.S. President John F. Kennedy, it is not what the League can do for you, but what you can do for the League. The League, in turn, is developing mechanisms to recognize your selfless contributions.

Careful preparation is the key to success. Here is what the new Executive Committee has achieved so far:

**Establish a strategic plan:** The previous ILAE Strategic Plan was created a number of years ago. As such a plan is pertinent for any volunteer professional organization, the ILAE must revisit its Strategic Plan periodically, to make changes that reflect areas where goals have been met as well as to better meet the current international climate of professional education and training, and to take optimum advantage of available resources. To develop this Plan, the League’s secretariat asked all our chapters and commissions for their input in identifying the League’s needs and challenges. The list of identified needs was then used by a Strategic Planning Task Force, chaired by Gary Mathern, to develop specific recommendations. The Task Force started its work in December, 2008, and it is fitting that we recognize the considerable time and effort that the members of this Task Force (www.ilae.org) devoted to the formulation of this Plan. Their advance document was fine-tuned during a two-day meeting in Budapest (July 3-4, 2009) and ratified by the Executive Committee on July 26th. This Strategic Plan (www.ilae.org) now constitutes the template for ILAE activities over the next four or more years. Gary Mathern will continue to chair the newly-constituted Strategic Plan Task Force, to develop measurable outcomes, facilitate interactions among regional and topic-oriented commissions, and advise the Executive Committee on action items relating to the Plan.

**Disseminate the League’s message and augment the delivery of information:** When compared to other disorders, epilepsy is often not recognized as an important medical and scientific condition. This neglect may be due in part to the demographics: Epilepsy affects mostly the young and the underprivileged, and when, a potentially influential person suffers from epilepsy, the person or the press may hide the condition. Also epilepsy is a common feature of many other diseases with higher profiles: e.g., infections, malnutrition, stroke, cancer, diabetes, and dementia, where recurrent and unpredictable seizures may aggravate the underlying condition – burdening patients, care takers and society (education/family/employment) without their recognition of the critical importance of the seizure contribution.

Our goal, addressed in partnerships with WHO, IBE and other influential organizations, will be to acutely raise the awareness and importance of epilepsy and epilepsy research. One example of such a step was our collaboration with the European Football Association (UEFA) during the recent European football championship held in Sweden, for players under 21 years of age. This event, co-organized with the Commission of European Affairs, consisted of two short football matches played by athletes with epilepsy from all over Europe, just before the European Championship semi-finals kick-off on 26 June 2009. The teams also included several top-level former professional footballers, who generously agreed to come to Gothenburg and Helsingborg to support our cause. The League has sent letters to the UEFA leadership expressing our heartfelt gratitude and deepest appreciation for organizing this memorable football event that raised public awareness on the plight of all those individuals afflicted with epilepsy.

Similar initiatives will contribute to improving knowledge about epilepsy and, most importantly, emphasize that people with epilepsy are entitled – and able – to live a life that meets their expectations, and to engage fully in social and professional activities. We are currently working with Mr. Christopher Morris-Coole to develop a project to raise public awareness of epilepsy during the 2012 London Olympics. The goal will be to “recruit” Olympic athletes who will be presented as supportive role models for children and adults with epilepsy throughout the world, and will encourage and enable their participation in sport.

Almost 30% of all people with epilepsy continue to have seizures despite our best medical efforts and our increasing insight into relevant brain mechanisms. Thus, it is important that we emphasize to governmental organizations and other agencies the importance of innovative research to prevent and cure epilepsy. The insights gained by these research efforts will not only lead to better care but also to wider understanding of normal brain functions. Of all brain disorders, epilepsy is the one that offers a unique opportunity to understand normal brain functions; seizures are born from excessive dysfunction of existing neuronal circuits, and are often not the result of loss of function that accompanies many neurological diseases. Ed Bertram, our Information Officer is spearheading an effort to promote the epilepsy-related research agenda. To this end, each Commission and Task-Force has a designated information officer who will work with Ed to coordinate efforts to encourage epilepsy research.

**Amend the ILAE constitution to ensure wide regional representation:** Because the needs in each country are different, we must develop a method for evaluating each regional situation and for developing a country-appropriate plan. To identify the varying regional conditions and needs, it is essential that each region have a voice and strong representation at the level of the League’s Executive Committee. For this reason it is important to look at our constitution to ensure that each region is well represented. This step is necessary not on-
ly to provide a true global perspective on the problem of epilepsy, but also to allow us to develop plans for epilepsy care tailored for each region. ILAE members and chapters throughout the world should provide the League with an understanding of what is needed locally, to create the relevant expertise and to deliver the care. Toward this end, it is important to encourage all channels of interaction, including face to face meetings as well as web-based communication. Our three Vice-Presidents, Tatsuya Tanaka, Michel Baulac and Marco Medina, together with Simon Shorvon, will review and update the constitutional proposals that Emilio Perucca and I drafted during the past four years and submit a comprehensive proposal to the Assembly held in 2011 in Rome. If approved, this updated constitution will also serve as the blue print for the constitutions of our Regional Commissions, so that we all work together under the same guides and conditions.

Develop a cohesive program for the Global Campaign: The goals of the Global Campaign include dissemination of information on the magnitude, burden, diagnosis and treatment of epilepsy (and available resources for delivering treatment); support to governments and health care providers in formulating and implementing comprehensive services by offering successful models of epilepsy care; support to countries in fighting stigma and discrimination; and support for research capacity in developing countries. Access to expert care itself requires a series of steps. Even in countries with established expertise, many patients do not make use of these opportunities because they do not know the resources exist. In other countries, the expertise is overburdened or does not exist at all. We plan focused efforts to identify areas that will benefit from the development of local care providers who understand the unique issues faced by the local population and can work effectively in that environment. Such individuals must be identified, and we must mentor them and provide the long term support that will allow them to grow professionally. We must also support the development of local health care infrastructure that can reach and help all who are in need.

The mission statement of the Global Campaign is: “To improve the acceptability, treatment, services and prevention of epilepsy worldwide.” Its strategy includes two parallel and simultaneous tracks:

- To raise general awareness and understanding of epilepsy, for instance by organizing Regional Conferences on Public Health
- To support Departments of Health in identifying national needs and promoting education, training, treatment, services, research and prevention.

The current Global Campaign efforts are led by a Secretariat consisting of a member of the ILAE, a member from IBE, and a member from WHO. Because the success of the Global Campaign is of paramount importance to both the Bureau and the League, the two respective Presidents, Mike Glynn and Nico Moshe, will lead the effort together with Dr Tarun Dua (representing the WHO). Ms Hanneke DeBoer will serve as the Coordinator for the Secretariat of the Global Campaign Against Epilepsy and will report directly to the respective Executives. Current activities include:

Demonstration projects: These projects are aimed at reducing the treatment gap and morbidity of people with epilepsy, using community-level interventions, training and educating health professionals, dispelling myths underlying stigma, identifying the potential for prevention, and developing models that integrate epilepsy control into the health systems of the participating countries. According to the Global Campaign action plan, two countries with different cultural and economic backgrounds will be selected in each WHO Region. If a country is not selected for a demonstration project, a national project can be developed.

Community Based Projects: These are initiatives generated by persons or organizations working in resource-poor countries. These projects are concerned with prevention or improvement of care and services, or with quality of life issues of people with epilepsy. The initiatives derive from knowledge of local needs obtained through direct exposure. These community-based projects are smaller and more limited in scope and duration than Demonstration Projects.

Projects on Legislation: People with epilepsy experience violations and restrictions of both their civil and human rights. Well-crafted legislation, based on internationally-accepted human rights standards, can prevent violations and discrimination; promote and protect human rights; enhance the autonomy and liberty of people with epilepsy; and improve equity in access to health care services and community integration. Additional projects may include the creation (in collaboration with WHO, governmental agents, and with ample support from our Commissions) of a diagnostic manual that can be used worldwide; the development of guidelines with global impact that can be used by all our constituents; and collaborations within regions for the delivery of specialized services to persons with epilepsy.

Reorganization of the League’s infrastructure: A key step in achieving our goal of global epilepsy care is the creation of a League infrastructure that will support our global efforts. The League has grown rapidly in size, diversity and complexity, but our operational side has not kept up with this growth. We need to develop electronic and administrative support systems designed to meet our goals. Sam Wiebe, our Secretary-General, has already begun to catalogue our activities and consolidate the various offices that handle League affairs. In this task he is working closely with Peter Berry, our Chief Staff Officer and Richard Holmes the Director, our International Director of Meetings. The changes in infrastructure will

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undoubtedly require additional financial and human resources, strategic fund-raising, and a call for our members to volunteer their time to support our programs. Our Treasurer, Emilio Perucca, is working to create and then dispense the necessary resources so that the entire international epilepsy community benefits with greater financial effectiveness and productivity. Indeed, the third goal of the Strategic Plan is to develop mechanisms whereby the ILAE shall ensure its ongoing organizational and financial viability. Several action points have been implemented, including the creation of a Finance Committee headed by Emilio.

Restructure the League’s Educational agenda: During the past four years, the League, under Peter Wolf, developed an ambitious agenda to promote educational activities in all our regions. Learning from our past experiences, we plan to create effective educational programs geared at region-specific needs and, when possible, in various languages. Under the leadership of CT Tan, the Education Commission will coordinate our educational efforts as dictated by the Strategic Plan, and according to the needs of regional commissions and academies in conjunction with the topic-oriented commissions. Each commission will have a designated Education Officer who will work with the Education Commission to deliver our services in a cost-efficient fashion. There is a pressing need to develop an African Epilepsy Academy. This Academy will oversee all the educational initiatives in Africa, including Francophone, Lusophone and Anglophone projects.

We plan to develop a virtual repository of our educational materials accessible to all. Sharing of information will be enhanced by the delivery of programs through electronic means, or via more conventional methods such as summer schools or migratory courses. The Education Commission will develop specific curricula based on a ‘needs assessment’ campaign, geared at the educational level of the trainees, that will provide consistent messages for the delivery of care in regions with similar needs. Courses for professionals with limited knowledge of epilepsy (including non-neurologists and other health care providers) will be aimed at an appropriate entry level. Other courses will provide incremental knowledge as required, and some may offer opportunities for advanced training locally or abroad.

In conjunction with the Global Campaign, the Education Commission will play a key role in reducing the burden of epilepsy and facilitating the rehabilitation of people with epilepsy. Specialist training is needed on multiple levels to reach all those concerned with epilepsy management. Regarding medical practitioners, there is a need for the development of eligibility criteria for entry to training programs and accreditation of training centers, based on local needs. Since nurses and social workers can be important providers of primary care and liaison services at the community level, they too require specialized training. The League will develop a plan for training and support that will create the essential infrastructure and health care networks for people with epilepsy. Current technology provides virtually immediate access to information and to consultation anywhere in the world; we must invest in these technologies that will help us support colleagues around the world.

Finally, the Commission will coordinate the efforts to identify, mentor, and develop the next generation of the League leaders.

Translational Research: Translational research is the process involved in moving discoveries in the laboratory to the clinical level, to develop new treatments for patients. Successful translational research involves researchers who recognize the potential clinical/treatment value of a new laboratory finding. Thus, to enhance translational research, we need to recruit researchers who are trained in the clinical sciences but who also have a strong background in basic science research. It is this group that will close the very real gap that now exists between the clinic and the laboratory. As we move forward, we must be sure that we have trained enough translational researchers to perform this important work.

One very important development that has helped epilepsy research move ahead so quickly in recent years has been the introduction of a number of animal models that have features in common with human epilepsies. Using such models, we can (for example) now study the effect of seizures on the brain, as well as examine how seizures and their consequences can be influenced by age and gender. The availability of these models will allow us to develop new epilepsy treatments. The epilepsy field is fortunate in the availability of such realistic animal models, which are helpful in predicting how a seizure—or a treatment—is likely to affect the human patient.

Translational research is a major focus of the ILAE’s Neurobiology Commission, which has been charged to raise the visibility and demonstrate the importance of epilepsy research to the clinical community (as well as to basic scientists). The Neurobiology Commission of the ILAE is actively involved in developing plans to strengthen translational epilepsy research. Key to moving new epilepsy treatments forward is the education of clinicians in basic science and the basic scientists in clinical epilepsy. Both groups must actively interact. The ILAE will foster this interaction by designing symposia that include a focused and relevant basic science component in predominantly clinical programs, or a clinical component in a basic science program. One current program to bring these groups together is the Workshop on the Neurobiology of Epilepsy (WONOEP), which is held every two years in conjunction with the International ILAE Congress.

Translational research in developing countries will require an effective infrastructure that includes improved education as well as an augmentation of local resources. In this setting, it is important to emphasize research aiming at solving the problems of specific cau-
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The International League Against Epilepsy (ILAE) was established in 1953, when 46 physicians from different countries and territories joined together to advance the understanding and treatment of epilepsy. The organization has since grown to include thousands of members, representing a multitude of disciplines and countries worldwide. The ILAE has played a pivotal role in the development of epilepsy science and care, especially in areas of infection, perinatal injuries, and head trauma. The organization is dedicated to advancing the understanding and treatment of epilepsy, promoting the development of local support structures, and fostering educational programs in epilepsy care.

The ILAE has established collaborative efforts with various organizations, including the International Brain Research Organization (IBRO), the Academy of Sciences for the Developing World (TWAS), the Federation of European Neurosciences, the American Epilepsy Society, as well as state ministries to promote research and training in many resource poor countries.

Promotion of Epilepsia, the League’s journal: Epilepsia is a world-recognized journal that helps disseminate our research advances. The Executive Committee is happy to announce that the two current editors, Phil Schwartzkroin and Simon Shorvon, have agreed to stay on as editors for the next four years. Together we are working to further enhance the journal, with on-line enhancements that will ensure the widest visibility, ample access to our members and corporate sponsors, the creation of country and region-specific ‘digest’ issues, and the development of volumes dedicated to specialized aspects of epileptology as ‘daughter’ journals under the banner of Epilepsia, our brand name.

New commissions: The engine that runs our League consists of our Commissions and Task Forces. To date, all regional commissions have been formed (www.ilae.org) and already working to develop their agendas for the next four years according to the Strategic Plan. We will soon develop a regional commission on African affairs. This is a region in which we must begin to address the myriad of local problems and needs. The positive experiences of the League through successes of the Commission of Asian and Oceanian Affairs and the Commission on Latin American Affairs will undoubtedly speed up this process of developing a Commission on African Affairs. In addition, we have begun to form plans to form additional chapters from all countries and territories worldwide.

The chairs and members of the topic-oriented commissions are also in place. Each commission will include members responsible for specific tasks that are identified in the Strategic Plan. In addition to including the past-chairs to provide continuity, each commission will have a chair(s), a secretary, a treasurer, an education officer, an information officer, and a member/officer overseeing translational efforts. These officers will liaise with each other, and with the League’s officers, on projects of common interest.

As part of our mission to enhance the delivery of care to our constituents, the Pediatric Commission has formed a partnership with Autism Speaks to establish a bridge of communication between Autism Speaks and the League in order to foster educational programs on autism spectrum disorders (ASD) and epilepsy, and to encourage studies on issues common to (and of importance to) both ASD and epilepsy, such as classification/diagnosis, epidemiology, genetics, neurobiology/neuropathology, and new effective treatments. We anticipate that all our commission will develop similar intra- and inter-League projects.

A very special commission is the newly formed Past Presidents Commission. Chaired by Giuliano Avanzini, it is composed by our past Presidents. Their task is to assess the successes and the failures of their respective Presidencies, and to provide guidance to our Executive. By gaining access to the collective experience and memory of our past leaders, we hope to avoid the common trap of ‘history repeating itself’ so that we move efficiently forward towards our goals.

Another extremely important Task Force is the one commissioned to develop a Conflict of Interest Policy for our leaders in the Executive and on the Commissions and Task-Forces. It is chaired by our Past-President, Peter Wolf. The development of a clear and transparent policy is a priority for all of us as we may represent many interests in our professional lives.

Summary

Today’s clinical and scientific achievements, combined with the possibility of rapid dissemination of information world-wide, offer the ILAE dazzling possibilities to advance the care of people with epilepsy. While we continue celebrating our Centennial (and the Bureau’s Golden Jubilee in 2011), we will also modernize our global professional society. We will identify and attract the talented women and men from all parts of the globe who are willing to devote their clinical and research careers to help people with epilepsy. We also must reach out to other groups of health care personnel, including neuropsychiatrists, as we begin to study the various co-morbid conditions associated with the epilepsies. Indeed, it is interesting that many of the original 46 founding members of our League were psychiatrists.

It will take several years of dedicated effort on the part of our chapters and members, and the development of the necessary support structures, to create a world in which epilepsy is no longer a burden on anyone. Even in countries with established expertise, many patients do not make use of these resources because they do not know that they exist. In other countries, the expertise is overburdened or does not exist at all. This problem can be solved by focused efforts to identify areas that will benefit from the development of local care providers who understand the unique issues faced by the local population and can work effectively in that environment. We must support the development of local health care infrastructure that can reach, and help, all who are in need. And we must invest in mentoring our young generation of epilepsy care providers, and of-
fer them the long-term support that will allow them to grow professionally. As an international organization, ILAE strives to provide the necessary educational and mentoring opportunities, as well as the administrative infrastructure, that will allow gifted professionals to thrive. With our Strategic Plan, the ILAE is in the process of creating educational, clinical and research agendas, with benchmarks to measure progress and success. To achieve our goals, it is important that we work together ‘from the bottom up,’ taking into account the experiences from all geographic regions to create a world where epilepsy no longer limits anyone.

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