Published in final edited form as:

Epilepsia. 2012 January ; 53(1): 215–219. doi:10.1111/j.1528-1167.2011.03330.x.

THE INTERNATIONAL LEAGUE AGAINST EPILEPSY AT THE THRESHOLD OF ITS SECOND CENTURY: YEAR 2

SOLOMON. L. MOSHÉ, MD¹, EMILIO PERUCCA, MD², SAMUEL WIEBE, MD³, and GARY W. MATHERN, MD⁴

¹Saul R. Korey Department of Neurology, Dominick P. Purpura Department of Neuroscience and Department of Pediatrics, Laboratory of Developmental Epilepsy, Montefiore/Einstein Epilepsy Management Center, Albert Einstein College of Medicine and Montefiore Medical Center, Bronx, New York, USA

²Clinical Pharmacology Unit, Department of Internal Medicine and Therapeutics, University of Pavia, and National Neurological Institute IRCCS C. Mondino Foundation, Pavia Italy

³Departments of Clinical Neurosciences and Community Health Sciences and Hotchkiss Brain Institute, University of Calgary, Alberta, Canada

⁴Departments of Neurosurgery and Psychiatry & Biobehavioral Sciences, The Intellectual and Developmental Disabilities Research Center, and The Brain Research Institute; David Geffen School of Medicine, University of California, Los Angeles, USA

Keywords

Strategic plan; constitution; education; global campaign; research; infrastructure; information dissemination

In July 2009, the International League against Epilepsy (ILAE) developed its four-year strategic plan. This is the second year progress report, prepared by the management committee and the chair of the Strategic Task Force, with input from several key leaders, to highlight progress toward achieving the plan's goals. Additional information regarding our activities can be found at our renovated website (www.ilae-epilepsy.org).

Correspondence to: Solomon L. Moshé, Albert Einstein College of Medicine, Kennedy 316, 1410 Pelham Parkway South, Bronx, NY 10461, USA, Ph: 718-430-2447, Fax: 718 430-8899, solomon.moshe@einstein.yu.edu.

Disclosures

SLM has received research support from NIH: R01 NS20253 (PI), R01-NS43209 (Investigator), 2U01-NS45911 (Investigator), and the Heffer Family Foundation. He is serving on the Editorial Board of Neurobiology of Disease, Epileptic Disorders, Brain and Development and Physiological Research. He has received a consultancy fee from Eisai a speaker's fee from GSK. EP received speaker's or consultancy fees and/or research grants from Bial, Eisai, GSK, Johnson and Johnson, Novartis, Pfizer, UCB Pharma, Upsher-Smith and Vertex. He receives research support from the Italian Ministry of Health, the Italian Ministry for University and Research, the Italian Medicines Agency and the European Commission of the EU. He also serves in the editorial boards of Acta Neurologica Scandinavica, CNS Drugs, Epileptic Disorders, Epilepsy Research, Seizure, Lancet Neurology, Expert Reviews in Neurotherapeutics, Clinical Pharmacokinetics, Therapeutic Advances in Drug Safety, Frontiers in Clinical Trials and Pharmacotherapy and Clinical Drug Investigation.

SW serves on editorial boards for Neurology, Epilepsy & Behavior, Epileptic Disorders, and the Canadian Journal of Neurological Sciences, and receives research support from the Alberta Heritage Foundation for Medical Research (grant 20050756) and the Hotchkiss Brain Institute.

GM serves on the editorial boards of Neurology®, Epileptic Disorders, Journal of Neuropathology & Experimental Neurology, Epilepsy & Seizures, Surgical Neurology International, and Epilepsy Research and on the Data Management Committee of Neuropace, Inc.; and received research support from NIH (R01 NS38992 [PI] and R21 NS606075 [PI]).

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Goal 1: ILAE shall serve all health professions as the premier international resource for current and emerging knowledge on epilepsy prevention, diagnosis, treatment, and research

As the major international epilepsy organization, ILAE is taking the lead in developing practice guidelines for clinical questions faced by clinicians managing people with epilepsy. A new Task Force on Guidelines, chaired by Tim Pedley, has been appointed. The aims are: to compile and review existing epilepsy guidelines; identify those that can be adopted world-wide or in specific parts of the world; assess the needs of the League's chapters around the world; identify the most important areas for new guideline development; determine whether a topic or question is best served by a formal clinical practice guideline (which may be hindered by the paucity of methodologically rigorous evidence) or by a position paper representing the consensus of experts supported by the available evidence. Because the development of guidelines is time-consuming and expensive, the League may partner with organizations such as the World Federation of Neurology (WFN), the American Academy of Neurology (AAN) and the European Federation of Neurological Societies (EFNS) in this project. To succeed, the League will seek the help of many volunteers and provide necessary staff support.

The Epidemiology Commission and Marco Medina continue their work with the World Health Organization (WHO) to develop the epilepsy-related codes for the ICD-11.

The League's website has been redesigned. Jean Gotman, our Web and Media Director, and Ed Bertram, our Information Officer, are hiring a Web manager. Each Commission has the responsibility to oversee the content of its section and to create links to ILAE activities, including Long Distance Education and Global Outreach. A Web Editorial Board tasked to provide advice on development and use of the web site has been appointed. The new web-based social networking Community Suite (Higher Logic) for ILAE groups is now fully operational. Plans are progressing to provide our Chapters access to ILAE Social Media.

The League has made arrangements with Wiley-Blackwell to make *Epilepsia* available on line at no charge to our constituencies in resource-poor countries belonging to the Hinari program. In addition, the League is discussing with Wiley-Blackwell the creation of a sister on-line journal to accommodate the needs of our constituents, while maintaining a high impact factor for *Epilepsia*. Plans are underway for appointment of the next Editors-in-Chief. By 2013, Phil Schwartzkroin and Simon Shorvon will have completed 8 years of service in this capacity, which is the maximum allowed by the constitution. We anticipate that the new Editor(s) will be appointed by January 2013 and will begin their tenure with the new Executive in 2013.

The 29th International Epilepsy Congress was held in Rome Aug 28th – Sept 1, 2011. Nearly 4,000 delegates attended this highly successful Congress. Its program aimed at integrating all aspects of epilepsy (including medical, research, social and novel therapeutic approaches) in each session. A prime example was the Presidential symposium entitled 'Avoiding Deaths in Epilepsy'. During the 29th Congress the IBE celebrated its 50th anniversary with two exceptional events: A get together of the Ambassadors of Epilepsy, a highly prestigious honor initially conceived by IBE and now conferred by joint deliberations of the IBE and ILAE Executive Committee every two years; and a magnificent concert. Work is ongoing for the preparation of four Regional Congresses scheduled for 2012, including the 9th Asian-Oceanian Epilepsy Congress in Manila (21–25 March 2012), the 10th European Congress of Epileptology in London (30 September–4 October 2012), the Latin American Epilepsy Congress in Quito (14–17 November 2012) and the African Epilepsy Congress in Nairobi

(21–23 June 2012). The latter will be the first African Congress organized jointly by the ILAE and the International Epilepsy Bureau (IBE) and represents a major component of the educational activities targeted to the African continent by our newly formed Commission on African Affairs. The 30th International Epilepsy Congress will be held in Montreal, Canada on June 23–27, 2013.

During the 29th International Congress held in Rome, Dr. Jerome Engel Jr received the Life Achievement Award and Dr. Pravina Shah the Social Accomplishment Award. Dr. Eleonora Aronica was the Michael Prize winner and Dr. Laura Jansen was the recipient of the Morris-Coole Epilepsia Award. Twelve new Ambassadors for Epilepsy were elected (Table 1).

The regional commissions are establishing bi-annual awards that recognize regional accomplishments. The Commission on European Affairs (CEA) established the European Epileptology Award in 2002. The latest awards were bestowed on Drs Yehezkiel Ben-Ari and Martin Brodie during the 9th European Congress in Rhodes in 2010. The CEA plans to expand the number of awards starting in 2012. During the 2012 London Congress there will be up to two European Research (clinical and basic) Awards for Young investigators, one for Education and one for Service to Europe. The Asian-Oceanian Commission granted their first awards during the 8th AOEC in 2010. The recipients of the Asian and Oceanian Outstanding Achievement Epilepsy Awards included Drs Hasan Aziz, Tatsuya Tanaka, Kazuichi Yagi, P. Satish Chandra and Xun Wu.

The League solidified the organizational and financial stability of the long distance education program by acquiring direct supervision of this initiative, and by investing in the expansion of the Virtual Epilepsy Academy (VIREPA) to promote teaching courses under the coordination of regional academies. To this end, the Education Commission through its Task Force on Distance Education, led by Walter van Emde Boas, has instituted approaches to increase the attractiveness and accessibility of ongoing courses, and has added new courses on pediatric epilepsies and EEG, psychiatric aspects, and sleep and epilepsy. Moreover, plans are underway to organize a course for primary caregivers in Sub-Saharan Africa in collaboration with the Task Force on Seizures and Epilepsy in the Tropics, the African Commission and the WHO.

The Education Commission led by CT Tan is developing ways to make educational material generated during our congresses freely available through the League's website. This was started with a trial run of voice/power point slides captured during the Melbourne AOEC, and the "How to" education session during Rome IEC. In Rome, through an effort coordinated by our Information Officer, many presenters addressing timely topics were also interviewed to produce videos which are currently posted on the League's website. This will be a regular feature of future congresses. The Education Commission is creating an open access, online Textbook of Epilepsy (Shi Hui Lim, Editor), housed in the ILAE website. We expect the first edition to be available in the first quarter of 2012. We plan translations of the textbook into Spanish, and Chinese.

Congresses are being reorganized to promote translational research venues that allow for better communication between basic scientists and clinicians.

The Neurobiology and the Education Commissions are developing proposals for further training of professionals, including a combination of residential courses with hands-on tutoring of research proposals that are likely to impact resource-poor regions favorably. This initiative may include guidance in preparing grant applications, provision of seed grants, and monitoring research progress. The Academies of the Regional Commissions have developed year-round, 1–2 day teaching courses in various parts of the regions. For example, the Asian Academy (ASEPA) organizes about 10 such courses yearly. These reach out to diverse

populations, address different needs, and are generally more cost effective than traditional large congresses. The longer and more in depth “summer schools” continue to be organized in Europe and Latin America, and have also been launched in Asia. Other projects by the regional commissions/academies include visiting professorships between the North America and the Caribbean/Latin America; fellowships by the Asian and Latin American Commissions, EEG certification examination and publication of congress proceedings by ASEPA.

Vital partners in basic research collaborations are the International Brain Research Organization (IBRO) and the Society for Neuroscience. An important aim is to identify and publicize possible funding sources for such programs, and increase public and government awareness of the needs of people with epilepsy.

Discussion is underway with the WFN and the International Child Neurology Association (ICNA) to develop collaborative visiting professorships for Africa. The key aim is to create a long term relationship between institutions. This initiative will involve the Education, North American and African Commissions.

Finally, three commission-related reports were published: Blumcke et al 2011; Gaillard et al 2011; Thurman et al 2011

Goal 2: ILAE shall serve as an international information resource and leader for optimal, comprehensive epilepsy care

We continue our Global Campaign efforts together with IBE and WHO. Because several additional initiatives do not fall under the collaborative efforts of the Global Campaign, together with IBE we created the Global Outreach Task Force, chaired by Helen Cross and Shichuo Li with expert assistance from Hanneke De Boer. Its primary aim is raising awareness of global educational and service initiatives in epilepsy throughout the world. The Task Force has identified a new slogan, initially proposed by Mike Glynn, President of IBE: **Stand up for epilepsy**. The slogan is in the process of being registered.

The second *SUDEP, A Global Conversation* book was launched in Rome six years after the first edition with forewords by the ILAE and IBE Presidents. Much has changed since the earlier edition was launched at the Paris IEC and almost all of it for the better in relation to epilepsy deaths. However, much remains to be done especially in the area of prevention and in regard to people at risk of SUDEP being warned of it together with their loved ones. This book brings together contributions on the subject of SUDEP from all around the world including pieces from many developing countries.

ILAE and IBE are engaged in several regional activities to highlight the public health dimensions of the epilepsies, and to prioritize allocation of resources to epilepsy health care and research. These initiatives include the production of an epilepsy report by the U.S. Institute of Medicine (IOM) (<http://www.iom.edu/Activities/Disease/Epilepsy.aspx>), the finalization of the Pan American Health Organization (PAHO) Strategy for the Americas, (http://new.paho.org/hq/index.php?option=com_content&task=view&id=5272&Itemid=3841&lang=en), and the support for the European Written Declaration on Epilepsy endorsed by the European Parliament (<http://www.ilae-epilepsy.org/visitors/initiatives/EuropeanDeclaration.cfm>).

The IOM report will specifically address the following questions: How can the public health burden of epilepsy for patients and families be more accurately assessed? What priorities for future population health studies could inform treatment and prevention? How can the access

to health and human services and the quality of care for people with epilepsy be improved? How can the education and training of professionals who work with people with epilepsy be improved? How can the understanding of epilepsy in patients and the general public be improved to create supportive communities? The report will be released in 2012.

The 51st Directing Counseling of the Pan American Health Organization (PAHO; which includes representatives from countries of North, Central and South America), approved and endorsed the Action Plan on Epilepsy for the Americas on September 29, 2011. The Action Plan was prepared by Dr. Jorge Rodriguez from PAHO and Drs. Carlos Acevedo and Marco Medina as part of the Global Taskforce of the ILAE and IBE. The Action Plan highlights the problems associated with epilepsy care throughout the developed and developing countries of the Americas and lists specific goals and anticipated deliverables that would positively impact epilepsy care in the region, with a 10 year focus on epilepsy.

In Europe, efforts are ongoing to advocate for political actions in the fight against epilepsy. The executive body of the European Union (EU) is its Commission. The two key Commissioners who can influence healthcare and research in epilepsy are European Commissioner John Dalli, Commissioner for Health and Consumer Policy and European Commissioner Máire Geoghegan-Quinn, Commissioner for Research, Innovation and Science. During European Epilepsy Day, both Commissioners held meetings with delegations from IBE and ILAE led by the two Presidents at the European Parliament in Strasbourg. A Joint Task Force of ILAE and IBE, co-chaired by Emilio Perucca and Mike Glynn and including members of the ILAE and IBE regional governing bodies (CAE and EREC respectively), has also been established under the name Epilepsy Advocacy Europe (EAE). EAE aims at making epilepsy care and research a priority in the agenda of the European Union (EU) and national governments in the European region. Its first action was to obtain the endorsement of the Written Declaration of Epilepsy by the European Parliament. This was achieved with a majority vote of the European Parliament on September 15, 2011. The Declaration calls for the EU to support research and innovation in the prevention and early diagnosis and treatment of epilepsy; to prioritize epilepsy as a major disease that imposes a significant burden of illness across Europe; to encourage Member States to ensure equal quality of life, including education, employment, transport and public healthcare, for people with epilepsy; to encourage effective epilepsy health impact assessments on all major EU and national policies; and to introduce appropriate legislation to protect the rights of all people with epilepsy. The next steps will be to capitalize on the Declaration by ensuring that its recommendations are adopted by the European Commission and by national governments. A European Conference on Epilepsy is being planned with participation of all major stakeholders from the European Commission, the European Council, national governments, funding organizations, lay organizations and the medical and research community.

Our collaborative efforts are beginning to bear fruit. In November, 2010, the Colombian Congress passed a law establishing special measures of protection for people with epilepsy with principles and guidelines that call for comprehensive care of people with epilepsy.

Five additional Task Forces have been established: The *Seizures and Epilepsy in the Tropics Task Force* (chair P. M. Preux), working in close collaboration with the Global Outreach Task Force, aims at addressing issues pertaining to seizures and epilepsy in the tropics, in particular as they relate to etiology, socio-cultural aspects and management. The *Stigma Task Force* (N. Jetté, chair) with support from the North American Commission, aims at determining ways to combat epilepsy-related stigma and its consequences worldwide. The *Task Force on Sports and Epilepsy* (G. Capovilla, chair), has two main aims: 1) to seek out and foster opportunities for interactions with major sports authorities and organizations to

increase awareness about epilepsy worldwide; 2) to increase participation of people with epilepsy in sports activities according to their capabilities. The *Task Force on Pre-clinical Drug Discovery* (M. Simonato and T. O'Brien, chairs) intends to develop standardized definitions, pathways, techniques and endpoints for the discovery and pre-clinical development of new epilepsy treatments, and to enable a stronger evidence base to identify optimal candidates to take forward to clinical development. The *Task Force on ILAE Reports* (E. Bertram, chair), will develop guiding principles for writing reports generated by the ILAE, standardize processes for their internal and external review, and develop criteria for their designation as official position statements of the League.

The Taskforce on Sports and Epilepsy is launching an exciting project to create a collection of photographs of famous sports persons meeting people with epilepsy. The photographs will convey the message that people with epilepsy, like athletes themselves, can be inspired to achieve their goals and lead full and active lives. The collection is intended for publication as a book of photographs, and the images will be made available to National Chapters for advocacy initiatives in their own countries.

The ILAE's strategic plan includes a role as the global leader in epilepsy education. To this end, under the leadership of Ed Bertram, the League developed a series of short, patient-oriented videos dealing with common issues faced by patients (what is epilepsy?, symptoms, diagnosis, treatment, surgery, pregnancy, stigma, where to find treatment, causes and prevention). Although most of the 3-minute videos were designed for web use, two shorter videos with a clear concise message will be used for public news broadcasts (pregnancy and living with epilepsy).

The League has undertaken a campaign to draw attention to the successes of members of our constituency and the importance of epilepsy. Letters have been written to appropriate authorities (deans, regional and national health ministers) about important contributions made by our colleagues (awards, organization of successful events, publication of important documents, elections to leadership positions, celebrations). Authorities will receive the message that epilepsy-related work provides much positive publicity for their institution or country and that epilepsy is an important health problem. We encourage further interaction with the national chapters in these initiatives. As with any such effort, the results can be slow in appearing and require regular reinforcement, but feedback from some members have suggested that these efforts have resulted in first contacts with health ministers as well as positive responses from deans.

During the 29th International Epilepsy Congress in Rome, the General Assembly ratified seven new National Chapters (Bolivia, Cameroon, El Salvador, Kosovo, Kuwait, Nigeria, and Sri Lanka), for a total of 108 active chapters. In addition, applications from 14 countries are being processed. The League's secretariat is revising the rules for chapter incorporation to increase participation. Regional commissions are exploring ways in which isolated clinicians can easily interact with the League in countries and territories where formation of an ILAE Chapter is unfeasible.

Goal 3: ILAE shall work to ensure its ongoing organizational and financial viability

The new Constitution was ratified by the General Assembly at the 29th International Epilepsy Congress held in Rome on August 31, 2011 and is available on the website (www.ilae-epilepsy.org). It ensures that all regions have a voice and a seat in the Executive Committee. In 2013, the League will be electing its new officers. The dates for each step

will be communicated to all chapters by the Chair of the elections committee, Past President Peter Wolf.

The new Conflict of Interest policy is also available on the website.

To enhance communication among commissions and with the leadership, a Commission Chair meeting is held annually. Here, Regional and Task Oriented Commissions present their work and identify synergies for collaboration. The Commission Chairs will meet again in December 2011 to identify projects congruent with the 2009 ILAE Strategic Plan that can be completed in 2012 and 2013. In addition, the League's leadership has asked Commissions to include plans to disseminate reports and activities to stakeholders and to implement action items.

As discussed in the Year 1 report, steps have been taken to enhance the management of our financial resources and improve transparency in reporting and disclosing financial data. Our Finance Committee and Financial Advisory Subcommittee, which include members of the financial and corporate world, have worked effectively to this end. The most important product of these activities has been the finalization of a new Investment Policy intended to improve returns on the League's investments while maintaining a conservative approach consistent with the organization non-profit status and goals. One of the goals will be for the League to be able within the next 10 years to derive a sufficient return from investments to support activities at the current level, thereby compensating for a projected loss in revenue from congresses and other sources. The new Investment Policy also recognizes the international scope of our activities by making provisions for diversification in currency and world markets. To this end, the Executive Committee endorsed the recommendation of Finance Committee and Financial Advisory Subcommittee to switch the management of the League's investment to a new Financial Manager with expertise in operating at the international level. The performance of the latter will be monitored closely according to predefined benchmarks. Finally, the new Investment Policy recognizes potential conflict of interest issues by forbidding direct investments into industries which develop/market pharmaceutical products and medical devices.

Acknowledgments

We again thank the many volunteers who contribute their time and energy toward accomplishing the League's strategic aims and overall mission to improve the lives of people with epilepsy throughout the world. We also thank our administrative staff, in Hartford: Peter Berry (Chief Staff Officer), Donna Cunard (Financial Manager), Priscilla Shisler (Leadership Liaison) and in Dublin (in close collaboration with the IBE) Gus Egan and Carla Glynn (Chapter Services Coordinators) under the direction of Richard Holmes, International Director of Meetings.

We gratefully acknowledge the advice and input we received from Ed Bertram, CT Tan, Walter De Boas, Jean Gotman, Mike Glynn, Phil Schwarztrkroin, Simon Shorvon and Tim Pedley in the preparation of this manuscript. We also thank Phil Schwarztrkroin and Simon Shorvon for editorial assistance.

References

- Blümcke I, Thom M, Aronica E, Armstrong DD, Vinters HV, Palmini A, Jacques TS, Avanzini G, Barkovich AJ, Battaglia G, Becker A, Cepeda C, Cendes F, Colombo N, Crino P, Cross H, Delalande O, Dubeau F, Duncan J, Guerrini R, Kahane P, Mathern G, Najm I, Özkara C, Raybaud C, Represa A, Roper SN, Salamon N, Schulze-Bonhage A, Tassi L, Vezzani A, Spreafico R. The clinicopathologic spectrum of focal cortical dysplasias: A consensus classification proposed by an ad hoc Task Force of the ILAE Diagnostic Methods Commission. *Epilepsia*. 2011; 52:158–174. [PubMed: 21219302]
- Gaillard WD, Cross H, Duncan JS, Stefan H, Theodore WH. Task Force on Practice Parameter Imaging Guidelines for the International League Against Epilepsy, Commission for Diagnostics.

Epilepsy imaging study Guideline criteria: Commentary on diagnostic testing study guidelines and practice parameters. *Epilepsia*. 2011; 52:1750–1756. [PubMed: 21740417]

Thurman DJ, Beghi E, Begley CE, Berg AT, Buchhalter JR, Ding D, Hesdorffer DC, Hauser WA, Kazis L, Kobau R, Kroner B, Labiner D, Kiow K, Logroscino G, Medina MT, Newton CR, Parko K, Paschal A, Preux P-M, Sander JW, Selassie A, Theodore W, Tomson T, Wiebe S. Standards for epidemiologic studies and surveillance of epilepsy. *Epilepsia*. 2011; 52:2–26. [PubMed: 21899536]

Table 1

Ambassador Award Recipients

Axelrod, Susan (USA)	Loescher, Wolfgang (Germany)
Aziz, Hasan (Pakistan)	Mizrahi, Eli M. (USA)
Carmant, Lionel (Canada)	Panelli, Rosemary (Australia)
Fandino, Jaime (Colombia)	Pitkanen, Asla (Finland)
Kanner, Andres (USA)	Schachter, Steven (USA)
Liao, Wei-Ping (China)	Van Emde Boas, Walter (The Netherlands)