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THE INTERNATIONAL LEAGUE AGAINST EPILEPSY AT THE THRESHOLD OF ITS SECOND CENTURY: YEAR 1

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Abstract

In July 2009, the International League against Epilepsy (ILAE) developed its four-year strategic plan in collaboration with past, current, and future leaders (www.ilae-epilepsy.org). This is the first yearly progress report, prepared by the management committee and the chair of the Strategic Task Force, to highlight progress toward achieving the plan's goals.

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

Our Commissions have been charged with fulfilling the Strategic Plan through their activities. Reports published or accepted for publication in *Epilepsia* in the past 12 months

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EP received speaker's or consultancy fees and/or research grants from Bial, Eisai, GSK, Johnson and Johnson, Novartis, Pfizer, Sanofi-Aventis, Pfizer, Sepracor, UCB Pharma and Valeant. 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.

S W 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 (20050756)

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]).

are shown in Table 1. These relate largely to activities initiated during the previous term under Peter Wolf and reflect the continuity of the work of our organization. ILAE also is developing guidelines with other organizations such as the World Health Organization (WHO), the World Federation of Neurology, and the American Academy of Neurology. The Epidemiology Commission and Marco Medina are working with WHO to develop the epilepsy-related codes for the ICD-11.

Jean Gotman has been appointed Media Director and will work with Ed Bertram to improve communication within the League. He is redesigning the website, ensuring that each Commission controls the look and content of its section and creating portals to our activities including long distance education and global outreach. A new web-based program (Higher Logic) is in place to facilitate communication and interaction for ILAE projects. The League is working with Wiley-Blackwell to make *Epilepsia* available on line to our constituencies in resource-poor countries belonging to the Hinari program.

The League solidified the organizational and financial stability of the long distance education program by acquiring direct control and investing in the expansion of the Virtual Epilepsy Academy (VIREPA) and is promoting teaching courses under the coordination of regional academies. The Education Commission led by CT Tan is developing ways to make educational material generated from our congresses freely available through the League's website, working on publishing an online Textbook of Epilepsy and on the delivery of tele-education. 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 experience and opportunities. The Regional Commissions and their respective academies have developed year-round courses. Vital partners in basic research collaborations are the International Brain Research Organization and the Society for Neuroscience. An important aim is to identify and disseminate knowledge of possible funding sources for such programs, and increase public and government awareness to the needs of people with epilepsy.

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

Together with the International Epilepsy Bureau (IBE), we have expanded the mission of the Global Campaign into the Global Outreach Task Force, chaired by Helen Cross and Shichuo Li with the expert assistance of Hanneke Do Boer and the WHO. Work on a new vision statement is underway. Members of the epilepsy community in the US, Vision 2020 group (organized by the American Epilepsy Society) and the League proposed a vision statement that can be used by our constituents. The next step will be to test key phrases expressing the global message of our cause to see how they resonate with the public and with the people with epilepsy.

To better understand public health dimensions of the epilepsies, the League has joined the vision 2020 group to work with the US Institute of Medicine to prepare a report on the challenges faced by people with epilepsy and the opportunities to improve care and research. Concurrently, a group was formed in Europe comprised of representatives of the ILAE Commission for European Affairs and the IBE European Regional Executive Committee with the aim of sensitizing policymakers to the need to improve epilepsy care across the European region.

The League is holding an organizational meeting in November 2010 to create the African Regional Commission. This Commission will reach out to countries where an ILAE chapter has not yet been formed to stimulate the development of local constituencies.

Models of cost effective interventions have been developed from projects in China and Brazil, and additional information is coming from Georgia and Bolivia. New projects have been approved for Ghana and Karnataka State in India, and we are considering a project in a developed country to investigate discrepancies in access to epilepsy care. There is a concerted effort to enlist public figures or prominent organizations with a wide audience to disseminate information and appeal to the public and philanthropists. In 2009, the League developed a collaborative effort with the Union of European Football Associations (UEFA) with young athletes with epilepsy and former football stars playing together before the semifinals of the Under 21 European Championships in Sweden.

As epilepsy can be a manifestation of many diseases and epilepsy in turn can aggravate underlying disorders, we have formed alliances with key organizations such as Autism Speaks. We plan to assess the effects of comorbid conditions on outcomes as well as 'holistic' treatments for the full gamut of symptoms linked with epilepsy. In these endeavors, it is important to have 'local champions' that will move the project forward in terms of execution and financial support. In addition, we have begun discussing potential collaborations with global philanthropic organizations such as Project Hope, aiming at helping individual countries build a sustainable local infrastructure.

We have received applications from 22 countries and have provisionally accepted five chapters for a total of 108 active chapters. The League's secretariat is reviewing and modifying the rules regarding chapter incorporation. Regional commissions have been asked to facilitate ways in which isolated clinicians can easily interact with the League in countries and territories where formation of an ILAE Chapter is currently unfeasible.

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

The ILAE is an organization of Chapters. The local Chapter is the key actor in finalizing most initiatives. Several of the Regional Commissions have already developed strategic plans to interact more effectively with individual Chapters.

Because regionalization is important in the governance of the ILAE, a task force led by Tatsuya Tanaka is proposing a Constitutional amendment developed with feedback from Regional Commissions. It will ensure that every region participates in the decision making process and in the management of the League's affairs. The document will be submitted for ratification to the General Assembly at the 29th International Epilepsy Congress in 2011 In Rome.

The Task Force on Conflict of Interest, led by Michel Baulac, has proposed a new policy currently under consideration by the League's Commissions.

To enhance the management of our financial resources and improve transparency in reporting and disclosing financial data, a Finance Committee has been instituted, together with a Financial Advisory Subcommittee in charge of monitoring the performance of the ILAE's investment portfolio and advising on investments. Both include volunteer members who are senior professionals in the corporate environment and have agreed to advise us on a regular basis. A new system for budgetary applications from the ILAE Commissions has been initiated so that projects can be assessed for their impact and cost effectiveness.

A new contract was signed with Wiley-Blackwell, who will continue to publish *Epilepsia* for at least the next 5 years. Together, the League and the publisher are seeking short- and medium-term strategies to improve the financial success of our journal. The editors are working with Wiley Blackwell to determine if there is an unmet, fundable, need in the market for educational products directed to non-epilepsy specialists and thus impact care globally.

The League and IBE have signed a new contract with Chancel, the company that organizes our international and regional congresses. A new contract is being negotiated with Association Resources, the firm that provides our administrative services..

Goal 4. The ILAE will address and implement thought-provoking and innovative concepts that advance the League's vision and mission long term

The Executive Committee is exploring ways to augment our interactions with all our partners including corporations. The aim is to take on a significant major initiative that would impact epilepsy research, education, and patient care for years to come. This 'Big Idea' will be developed in tandem with the external message we will identify and deliver to all concerned: people with epilepsy, caretakers, caregivers, governments, non-government organizations and the general public.

We again thank the many volunteers who contribute their time and energy toward accomplishing our strategic aims in our overall mission to improve the lives of people with epilepsy throughout the world.

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.

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Table 1

Commission Reports 2009–2010

Guidelines for imaging infants & children with recent onset epilepsy	Commission for Neuroimaging, Subcommittee for Pediatric Neuroimaging	Gaillard et al., 2009
Disparities in epilepsy: Report of a systematic Review by the NA Commission of ILAE	North American Commission Task Force on Disparities in Epilepsy Care	Burneo et al. 2009
Genetic testing in the epilepsies	ILAE Genetics Commission	Ottman et al, 2010
Revised terminology & concepts for organization of seizures & epilepsies	ILAE Commission on Classification & Terminology 2005–09	Berg et al, 2010
Pregnancy registries: Differences, similarities & possible harmonization	Commission on Therapeutic Strategies of ILAE	Tomson et al, 2010
Definition of drug resistant epilepsy	Task Force ILAE Commission on Therapeutic Strategies	Kwan et al, 2010
The clinico-pathological spectrum of focal cortical dysplasias: a consensus classification	Ad hoc Task Force of ILAE Diagnostic Methods Commission	Blumcke et al, 2010 In Press