

## INTERNATIONAL LEAGUE AGAINST EPILEPSY

### STRATEGIC PLAN – JULY 2009

**ILAE's vision is a world in which no person's life is limited by epilepsy.**

**ILAE's mission is to ensure that health professionals, patients and their care providers, governments, and the public world-wide have the educational and research resources that are essential in understanding, diagnosing and treating persons with epilepsy.**

#### 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.**

**Aim 1 -- Articulate internationally applicable guidelines for the diagnosis and treatment of persons with epilepsy.**

#### *Recommendations:*

1.1.1 Establish systematic reviews for the manner in which medical and other health professionals diagnose and treat persons with epilepsy. This would include but is not limited to:

- ✓ Identifying gaps in the body of knowledge and/or standards
- ✓ Developing guidelines, where appropriate
- ✓ Seeking partnerships with other relevant organizations.

1.1.2 Reach out to health professionals in all regions of the world who are taking care of persons with epilepsy by making it easier for them to access practice guidelines, classification schemes, consensus agreements, and learning opportunities. This would include but is not limited to:

- ✓ Web resources
- ✓ Epilepsia
- ✓ Epigraph
- ✓ Capturing and using educational material generated from the International and Regional meetings (in different languages)

- ✓ Capturing, reviewing, and adapting educational information gathered from other organizations involved with epilepsy care
- ✓ Making the educational content of meetings available in real time and on the web for professionals who cannot attend meetings
- ✓ Ensuring that the web content is available for underserved areas in the format most consistent with each region's needs and in the appropriate language, as resources allow.

1.1.3 Serve as an informational resource to national and regional groups as they develop statements regarding prevention, diagnosis, and treatment of epilepsy that are based on best medical evidence, while providing for regional variability and cultural needs.

**Aim 2 -- Stimulate and enhance international education and training that concentrates on the prevention, diagnosis, and treatment of epilepsy.**

*Recommendations:*

1.2.1 Create a coordinated business plan for all ILAE educational activities. Base future educational programs on a careful cost-benefit analysis of previous programs, taking into consideration regional and local needs. The analysis should include:

- ✓ Evaluation of current and previous programs
- ✓ Prospective post-program analysis
- ✓ Inter-regional collaboration.

1.2.2 When planning educational programming, utilize available resources and base the content for both meetings and courses on the specific needs of the target audience.

1.2.3 Encourage local and regional ILAE groups as well as other health care professionals both inside and outside ILAE to capitalize upon ILAE assistance and resources as they plan and conduct needs assessments within their constituency.

1.2.4 Ensure that educational outreach intended for underserved areas is delivered in a format most consistent with each region's needs and in the appropriate language.

**Aim 3 -- Stimulate and enhance basic and clinical research in epilepsy.**

*Recommendations:*

1.3.1 Facilitate the development of best methodologies for basic and clinical research in epilepsy.

1.3.2 Identify and catalog research centers and teams world-wide whose work is devoted to epilepsy research, both clinical and basic science.

1.3.3 Encourage and facilitate the development of multi-national collaborative research.

1.3.4 Serve as a resource to link prospective clinicians and researchers in epilepsy care with mentors and locations for their training.

1.3.5 Encourage efforts that translate basic research into clinical care, while taking into consideration an international perspective.

1.3.6 Identify and disseminate knowledge of possible funding sources to accomplish each of the aims and recommendations listed above.

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## Goal 2

**ILAE shall serve as an international information resource and leader for optimal, comprehensive epilepsy care.**

**Aim 1 -- Work with local organizations, ILAE Chapters and Regional Commissions, the International Bureau for Epilepsy (IBE), and the World Health Organization (WHO) through the Global Campaign Against Epilepsy to catalog current practices of epilepsy care in specific regions and then to determine needs.**

*Recommendations:*

2.1.1 Update the Epilepsy Atlas Project\* as needed to analyze the availability of adequately trained professionals, access to diagnostic tools, access and use of medications, access and use of comprehensive evaluations and treatments (e.g. telemetry and surgery).

\* The report, entitled *Atlas: Epilepsy Care in the World 2005*, was developed within the framework of the ILAE/IBE/WHO Global Campaign Against Epilepsy.

2.1.2 Catalog the geographic areas and types of gaps that exist in the care and treatment of persons with epilepsy. Identify the priorities for which ILAE might facilitate professional development, recognizing that local needs will vary.

**Aim 2 -- Promote and facilitate initiatives that improve standards of comprehensive epilepsy care to include diagnosis, treatment, and social care. Reduce, in sustainable ways, the treatment gap throughout the world.**

*Recommendations:*

2.2.1 Develop models for cost-effective interventions, including methods of prevention, specifically suited to address deficiencies identified in Goal 2, Aim 1. Take into account local specificities in resources and social conditions. Identify tools for measuring outcomes.

2.2.2 Promote and facilitate the implementation of appropriate interventions.

2.2.3 Identify public and private financial resources to apply such interventions, including the establishment of partnerships with other organizations and local health authorities.

2.2.4 Disseminate information about successful regional programs that have improved care. (For example, increase the availability of antiepileptic drugs by establishing drug banks).

2.2.5 Where invited, provide guidance for standards of self-assessment of care in local and regional areas.

**Aim 3 -- Interact with governmental groups in establishing resources for comprehensive epilepsy care.**

*Recommendations:*

2.3.1 Further promote mechanisms within the ILAE for expanding partnerships with IBE and WHO (through the Global Campaign Against Epilepsy) to focus interaction and coordination with governmental agencies to develop models for care delivery.

2.3.2. With the guidance of regional structures, identify and mentor emerging ILAE leaders in specific countries and regions of the world so that they can assist ILAE with its interactions with NGO and government resources.

2.3.3. Identify the variety of successful models of epilepsy care as they are developed through demonstration projects, evaluate which model(s) will be most appropriate for specific countries, and facilitate transitioning models of epilepsy care to those countries for implementation.

**Aim 4 -- Enable health care professionals in all countries to have an active relationship with ILAE.**

*Recommendations:*

2.4.1 Whenever possible, establish an operating ILAE chapter in every country or UN/WHO recognized area of the world where professionals practice epilepsy care.

2.4.2 In countries and UN/WHO recognized areas of the world where formation of an ILAE chapter is currently impractical, facilitate ways in which isolated clinicians can easily interact with the League.

2.4.3 Review and modify, as necessary, the ILAE rules regarding chapter incorporation in order to remove impediments to chapter formation in countries and UN/WHO recognized areas of the world.

2.4.4 Encourage Regional Commissions to coordinate chapter activities so that local and regional initiatives complement and contribute to the successful implementation of ILAE's strategic plan.

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**Goal 3**

**ILAE shall work to ensure its ongoing organizational and financial viability.**

**Aim 1 -- Examine ILAE's organizational structure to ensure that it is efficiently and effectively dedicated to fulfilling ILAE mission.**

*Recommendations:*

3.1.1 Reconfirm that ILAE is an organization of chapters, not of individuals. Empower chapters to become fully developed in order to fulfill ILAE's mission. Establish a dedicated task force to explore chapter development strategies that will work in different parts of the world.

3.1.2 Enlist ILAE Regional Chairs to address the issue of how best to deal with dysfunctional chapters.

3.1.3 Accept that regionalization is important in the development of ILAE. Ensure adequate and equitable regional representation on the ILAE Executive Committee.

3.1.4 Establish *Standards of Procedures* for all ILAE operations, taking into account the level at which each step or task needs to be accomplished. Articulate the Standards using straightforward, simple language. Make the Standards widely available, possibly translating the text into several additional languages.

## **Aim 2 -- Enhance communications and volunteer participation within ILAE**

### *Recommendations:*

3.2.1 Charge the Executive Committee (EC) with developing ways to enhance communication with key participants including commission and task force members, chapter leaders, and other individual volunteers.

3.2.2 Explore ways of improving inter-chapter and chapter-EC communications. Evaluate the possibility of conducting virtual chapter conventions by telephone and/or webinar.

3.2.3 For the purpose of enhancing communication, consider providing financial support for representatives from chapters with limited resources so they might attend chapter convention of the international and regional congresses.

3.2.4 Improve the transparency in reporting and disclosing financial data to ILAE members. Provide opportunities for interactive discussion of these data where possible.

3.2.5 Review the ILAE website structure, format, content, and languages to address how best to use the site to meet the communication, education, and promotion needs of ILAE. This would include exploring:

- ✓ ways to improve how the ILAE website relates to numerous related websites.
- ✓ consideration of different providers to construct and manage the website.
- ✓ the value of conducting a workshop to examine the issues of the ILAE website.
- ✓ the potential to establish a fee-for-content section within the ILAE website.

3.2.6 Design ways for ILAE to improve its exposure to and communication with the medical community and public at large.

3.2.7 Establish a system of awards that recognize regional accomplishments as ILAE grows and its efforts multiply globally.

**Aim 3 -- Streamline ILAE's administrative structure and review its financial operational practice to ensure an efficient and effective management.**

*Recommendations:*

3.3.1 Establish an ILAE Finance Committee, chaired by the ILAE Treasurer. Enlist Committee members from finance / business-related professions. The Committee will be responsible for:

- ✓ monitoring all ILAE financial matters and make timely recommendations to the Executive Committee
- ✓ recommending ways to secure and diversify ILAE's main income sources
- ✓ ensuring that income and expenses are in line with the ILAE's goals and aims
- ✓ developing an internal control system
- ✓ reducing ILAE's fixed costs, including streamlining its various administrative offices
- ✓ monitoring ILAE's financial business plan, reserves policy, and investment portfolio.

3.3.2 Through the Finance Committee, establish an external finance advisory council whose members include senior professionals from the corporate environment. The council's task would be to offer periodic advice on ILAE investment options and its reserves policy.

3.3.3 Identify ways to make ILAE educational activities more cost effective.

3.3.4 Examine registration fees for congresses conducted by ILAE to determine if the fees can be kept sufficiently low to encourage more participants to attend.

**Aim 4 -- Diversify and enhance the financial resources of ILAE**

*Recommendations:*

3.4.1 Establish a resource development task force, working through the Finance Committee or Executive Committee. The task force will be given responsibility to:

Organize a series of facilitated workshops so that ILAE leaders at the global, regional, and local level better understand how to plan and implement a variety of fund-raising initiatives.

Create strategies to harmonize efforts for central fund raising with those fund-raising initiatives accomplished regionally.

Draw from the Strategic Plan those ILAE global or regional projects that are suitable for fund-raising efforts.

Explore the potential for a multi-year fund-raising campaign that will capitalize on ILAE's Centenary milestone and other accomplishments.

Establish a mechanism and articulate a rationale to encourage personal financial contributions from individuals dedicated to ILAE.

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#### **Goal 4**

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

- Explore ways to utilize electronic media, including social media portals such as Facebook, Plaxo, Linked In and others, to deliver information, education, and networking opportunities to the widest possible audience within ILAE's Chapters and Regions and to other health professionals and consumers whose work relates to epilepsy and epileptology.
  - Optimize revenue opportunities available to ILAE with the goal of reducing the League's dependence upon any one source of funding by diversifying ILAE's income base.
  - Maintain an awareness of and sensitivity to the demographics, cultures, and geographic distribution of members of the profession. Incorporate that awareness into specific efforts that encourage all members of the profession to become active in the implementation of ILAE's strategic program portfolio.
  - Take every opportunity to promote the scientific issues that pertain to epilepsy and epileptology, especially within the basic science community and for translational research.
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