

Global Outreach

In 1997 the WHO, ILAE, and IBE decided to join forces in order to raise epilepsy awareness to a level that had never before been achieved. This partnership is the ILAE / IBE / WHO Global Campaign Against Epilepsy (GCAE) – “Out of the Shadows.” Its mission statement is “To improve the acceptability, treatment, services and prevention of epilepsy worldwide.”

In 2009, a Task Force was established with an aim to establish a Strategic Plan with action points to forward wider development of activities within the GCAE and raise awareness of achievements. A Strategic Plan was finalized, with four main goals:

- To improve the visibility of epilepsy and the activities of the Global Campaign in all countries
- To promote activities of all epilepsy projects on a country and regional level
- To assess and strengthen healthcare systems for epilepsy
- To increase partnerships and collaboration with other organizations.

It has become clear, however, that throughout the world, there are many initiatives that could be interpreted as global outreach that are in need of raised awareness. However, such activities are not necessarily directed through the collaborative efforts of the GCAE. The Task Force was therefore renamed for ‘Global Outreach’ with a primary aim of raising awareness of global educational and service initiatives in epilepsy throughout the world.

Examples of activities that have been undertaken within the remit of the Task Force for Global Outreach over the last four years have included:

1. Launching of the Global Campaign website in June 2010 at the European Congress in Rhodes, www.globalcampaignagainstepilepsy.org, with information about current activities, regional reports, and up-dated information about demonstration projects.
2. Development of a new slogan for use worldwide ‘Stand up for Epilepsy.’
3. Completion of a Demonstration Project in Georgia in 2011. Demonstration projects remain a key activity of the Global Campaign Against Epilepsy. The general objectives are to reduce the treatment gap and social and physical burden, educate health personnel, dispel stigma with an ultimate goal of developing a variety of successful models of epilepsy control that can be integrated into the healthcare systems of the participating countries and Regions and, finally, applied on a global level. In China, where the Demonstration Project completed in 2004, the “Global Campaign” activities have, under the support of the Chinese government, extended continuously into rural area, and are now implemented in 135 counties of eighteen provinces, covering a total population of 75 million.



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Visiting Clinics during the Demonstration Project in China



In these Regions, 83,518 people with convulsive epilepsy are now on medication of phenobarbital and / or valproic acid, free of charge. The possibility of further projects is being explored in Ghana, Vietnam, Cameroon, and India, and a project is currently underway in Honduras.

4. Completion of a model for assessment of epilepsy services and resources, piloted in Tajikistan, with plans for replication in two additional European countries.
5. Regional reports on Epilepsy were published in EMRO and EURO and launched at stakeholder meetings in the respective regions. Such reports have now been published in all Regions of the world, and stakeholder meetings held. In particular, specific initiatives have been undertaken:

- a. Within the Pan American Health Organization, a Strategic Plan for epilepsy from the program for Mental Health and Neurological Disorders has been developed for implementation in Latin America
- b. All Health Ministers in the Americas have signed this plan. On 14 November 2012, the Pan American Health Organization (PAHO / WHO), the International League Against Epilepsy (ILAE) and the Interna-

tional Bureau for Epilepsy (IBE) signed a Memorandum of Understanding that bonds them in a 10-year-long partnership to deploy the Strategy and Plan of Action on Epilepsy for the American continent

- c. The Institute of Medicine Report on Epilepsy has implications for the USA. It is unclear whether it has wider implications for other countries at present
 - d. Within Europe, the European Task Force on Epilepsy has been active and a written declaration on epilepsy was passed through European Parliament in 2012. A European Research Forum was held in May 2013
6. Completion of the documents that had been developed within the project on Epilepsy and Legislation “Basic Principles for epilepsy legislation” (setting out basic principles and rights that should be considered when drafting legislation related to epilepsy) and the “Guidance Instrument for Developing, Adopting and Implementing Epilepsy Legislation” produced on CD. This CD will be disseminated during the International Epilepsy Congress in Montreal, Canada.
 7. The Task Force jointly published WHO guidelines on management of neonatal seizures. Within the WHO mental health Gap Action Program (mhGAP), the Task Force contributed to the development of the Chapter on epilepsy in the evidence-based intervention guide for the management of mental, neurological, and substance use disorders in non-specialized health settings.
 8. The Task Force contributed to the new WHO Global Burden of Disease project, which will result in comprehensive estimates of the burden of epilepsy, its disabling sequelae and its role as a risk factor for other diseases and injuries.

Activities continue on a global scale, and it remains within the remit of the Task Force to raise awareness of such initiatives, encouraging dissemination of information on activity.



Training the Trainers in Brazil



Raising Awareness in Senegal