

## Strategic Plan: Epilepsy in America 2012 (PAHO)

### History

During the 51 PAHO meeting in Washington, on September 29 2012 at 11:57am, the strategy and action plan for Epilepsy in America was approved and written in English, Spanish and Portuguese. While discussing the project, ministries of health and their representatives were very optimistic and supported the initiative, especially USA, Canada, Mexico, Cuba, Chile, Honduras and Guatemala. Even more, Dr Carlos Acevedo and el Dr. Marco Tulio Medina, (IBE and ILAE representatives) gave a message supporting this action. It is important to highlight that Dr. Jorge Rodríguez, Dra. Mirta Roses Periago (PAHO Director), Dr. S Gross (PAHO director's assistant) and PAHO team efforts were essential to get this accomplishment. This is the first time in more than 100 years that epilepsy becomes a priority among healthy issues in America.



The launching of this Project took place in a workshop in October 19 to 21 2011, in a session where an alliance was established among Ministry of Health, (Vice-president), OPS/OMS, IBE, ILAE, National University (Vice Chancellor) and the global campaign. During this workshop a group was founded and following steps agreed for future meetings.

PAHO web page has 4 different versions in English, Spanish, French and Portuguese. If you want to download the document you can do it freely at:

[http://new.paho.org/hq/index.php?option=com\\_content&task=view&id=5723&Itemid=4139&lang=pt](http://new.paho.org/hq/index.php?option=com_content&task=view&id=5723&Itemid=4139&lang=pt)



At the 7th Epilepsy Congress in Quito, another meeting took place with an active participation of important authorities from PAHO, ILAE, IBE, latinamerican Comision and Chapter presidents from latin american countries.

Information and new strategies were updated and a document was signed by dr. Jorge Rodríguez, Myke Glynn and Nico Moshé and handed over on november 14<sup>th</sup>, 2012 at 7:15 pm.

On november 16<sup>th</sup> a taskforce meeting was held to establish a specific date in august 2013 in Chile to track these actions and follow up plans from all countries involved.

**Actions and follow up plans from countries involved:**

**Last update November 2012**

| Country          | ILAE   | IBE   | ACTIONS AND PROGRESS  |
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| <b>Argentina</b> | Dr. Roberto Caraballo<br><a href="mailto:rhcaraballo@arnet.com.ar">rhcaraballo@arnet.com.ar</a>  |   | <ul style="list-style-type: none"> <li>• Ministry of Health already contacted in August 2012.</li> <li>• Sebastián Laspuir, held a meeting with local OPS and Dr. Hugo Cohen.</li> <li>• September 2012 the tool for epilepsy resources evaluation was completed.</li> <li>• October 2012 Ministry of Health designates Dra. Analia Peña and Olga Charreau, responsible for the development of the program.</li> <li>• November 2012 ALAE, a group from the bureau, is incorporated to the program. They will have a meeting at the end of the month with local OPS and ministry of health.</li> <li>• Ministry has actively participated; actually they are trying to include the Project within others about chronic diseases, with some difficulties to get it done.</li> <li>• They have a specific law for this program; the idea is to develop a national plan with a responsible for each province to provide primary care physicians with appropriate training on the disease.</li> </ul> |
| <b>Bolivia</b>   | Dr. Mario Camargo<br><a href="mailto:drmariocamargo@hotmail.com">drmariocamargo@hotmail.com</a>  | Dr. Federico Fortun<br><a href="mailto:federicofortun@gmail.com">federicofortun@gmail.com</a>     | <ul style="list-style-type: none"> <li>• IBE is now official and ILAE/IBE meeting already took place.</li> <li>• Ministry of health reunion is expected but still not scheduled.</li> </ul>   |
| <b>Brazil</b>    | Dr. Luciano de Paola<br><a href="mailto:luciano.depaola@gmail.com">luciano.depaola@gmail.com</a> | Brasil: Dr. Luis Octavio Caboclo.<br><a href="mailto:locaboclo@ig.com.br">locaboclo@ig.com.br</a> | <ul style="list-style-type: none"> <li>• They have had meetings between ILAE/IBE and the ministry since June 2012, have already started material development and some actions.</li> <li>• An alliance has been created between the Academy of</li> </ul>  |

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|                   |   |  | Neurology and the Brazilian Society of Pediatric Neurologists to get more impact, still with some difficulties to contact the ministry.   |
| <b>Chile</b>      | Dra. Perla David<br><a href="mailto:socepchi@tie.cl">socepchi@tie.cl</a>                              | Dr. Carlos Acevedo<br><a href="mailto:carloredoacevedo@yahoo.com">carloredoacevedo@yahoo.com</a> | <ul style="list-style-type: none"> <li>• Chilean Society has proposed working to favor pharmacologic treatment and the implementation of the national program non-refractory epilepsy</li> <li>• 2011 OPS: Strategic plan for epilepsy<br/>"Diagnosis can be done in unskilled contexts"</li> <li>• 2000 Chile: Epileptology Society of Chile and Ministry of health: policy and plan for epilepsy.</li> <li>• 2008 Chile: Clinic Guide for epilepsy in children: GES plan &lt; 15 years old.</li> <li>• 2009 Chile: Clinic Guide for epilepsy in Adults: GES plan<br/>"diagnosis and treatment must be decided by a neurologist and follow up can be mixed primary and secondary care. The purpose of treatment in secondary level.</li> <li>• Information and education in Chile:<br/><a href="http://www.ligaepilepsia.cl">www.ligaepilepsia.cl</a> (Bureau)<br/><a href="http://www.minsal.cl">www.minsal.cl</a> (Ministry of health Chile).</li> </ul> |
| <b>Colombia</b>   | Dr. Orlando Carreño<br><a href="mailto:carrenoepilepsia@hotmail.com">carrenoepilepsia@hotmail.com</a> | Dr. Jaime Fandiño<br><a href="mailto:fandinojaime@gmail.com">fandinojaime@gmail.com</a>          | <ul style="list-style-type: none"> <li>• Frequent meetings have been held with Ministry of health and OMS/OPS representatives.</li> <li>• OPS will sponsor the epilepsy guides that the league is developing as a first step to implementing the 1414 epilepsy law.</li> <li>• After this, an agenda will be elaborated in conjunction with other themes that belong to the plan, such as information campaigns, etc.</li> <li>• We expect these guides for next year and also, the first national congress to diffuse epilepsy with 250 participants.</li> </ul>   |
| <b>Costa Rica</b> | Dr. Franz Chaves<br><a href="mailto:casa.aguamiel@gmail.com">casa.aguamiel@gmail.com</a>              | Dra. Rocio Quesada<br><a href="mailto:roques@racsa.co.cr">roques@racsa.co.cr</a>                 | <ul style="list-style-type: none"> <li>• In Costa Rica social security covers the 100% of population, so medication is available for all.</li> </ul>  |

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|                     |   |  | <ul style="list-style-type: none"> <li>No communication has been established with the ministry of health yet.</li> </ul>  |
| <b>Cuba</b>         | Dra. Lilia Chacon Morales<br><a href="mailto:lilia.morales@infomed.sld.cu">lilia.morales@infomed.sld.cu</a>                 | Dr. Fabelo<br><a href="mailto:fabelo@infomed.sld.cu">fabelo@infomed.sld.cu</a>                                 | <ul style="list-style-type: none"> <li>A meeting with ILAE/IBE already took place, generating a formal proposal with a strategic plan that is still waiting for approval from OPS y MINSAP.</li> </ul>  |
| <b>R.Dominicana</b> | Dr. Diogenes Santosvilloria<br><a href="mailto:Diogenes_santosvilloria@hotmail.com">Diogenes_santosvilloria@hotmail.com</a> | Dr. Franklin Montero<br><a href="mailto:frmontero@yahoo.com">frmontero@yahoo.com</a>                           | <ul style="list-style-type: none"> <li>No communication has been established neither with the ministry of health nor OPS representatives.</li> </ul>  |
| <b>Ecuador</b>      | Dr. Patricio Abad<br><a href="mailto:pabad@hmetro.med.ec">pabad@hmetro.med.ec</a>   | Dr. Galo Pesantez<br><a href="mailto:gpesantez@vio.telconet.net">gpesantez@vio.telconet.net</a>                | <ul style="list-style-type: none"> <li>LECE presented to the MSP the National plan for Epilepsy and the IBE with Dr. Galo Pesantez presented the law project to protect epileptic patient in the National Assembly.</li> <li>We hope to get favorable results in these two themes for the OPS/OMS meeting in November 2012.</li> <li>Lectures for physicians at schools have been implemented due to the diffusion of epilepsy education.</li> <li>Web page in process with quality information for patients.</li> </ul>  |
| <b>Guatemala</b>    | Dr. Henry B. Stokes<br><a href="mailto:henrystokes@neurologiaparatos.com">henrystokes@neurologiaparatos.com</a>             | Dr. Henry B Stokes<br><a href="mailto:henrystokes@neurologiaparatos.com">henrystokes@neurologiaparatos.com</a> | <ul style="list-style-type: none"> <li>The first ALADE course was executed in Guatemala with the Support physicians Guilca Contreras and Loreto Ríos and around 100 participants from all over the country.</li> </ul> <p>On March 23rd, the law initiative “integral law for epilepsy” was presented, with the invaluable help from deputy Luis Fernando Pérez, Now President of the human Rights commission, and Deputy Roberto Kestler, President of health commission and his team. Their advice included technical, legal and political aspects to create a legal framework that will impact our patients and families by:</p> <ol style="list-style-type: none"> <li>1- Guarantee full Human rights, complying with the established in the Carta Magna, encouraging tolerance and cutting off discrimination. Which sometimes impacts negatively in patients more than the disease itself.</li> </ol> |

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|                 |   |   | <p>2- Promote an awareness campaign for general population to increase knowledge and comprehension towards our patients “let epilepsy out of the shadows”. Based on the worldwide campaign from ILAE, INTERNATIONAL BUREAU FOR EPILEPSY (IBE) and OMS. Transform our patients from ghosts to heroes.</p> <p>3- Promote free access to new medication in the national health formulary. So far they have been denied to low income population increasing death risk among epileptic patients.</p> <p>4- Create a specific budget for the development of the <b>UNIDAD NACIONAL DE EPILEPSIA Y NEUROCIRUGIA FUNCIONAL</b> that will provide multidisciplinary attention with high quality modern technology in Neurology and will be the national reference of epilepsy and neurologic diseases. One of the main functions of the center will be the realization of clinical population studies for statistic registration. In order to support public laws to more effectively control this illness.</p> |
| <b>Honduras</b> | Dr. Lázaro Molina<br><a href="mailto:jlazarohn@yahoo.com">jlazarohn@yahoo.com</a> | Dr. Eduardo Rodas<br><a href="mailto:fundehep@yahoo.com">fundehep@yahoo.com</a>         | <ul style="list-style-type: none"> <li>• IBE Chapter was founded (by President Eduardo Rodas), it has legal recognition.</li> <li>• Since October 2011, an alliance was established with Secretary of Health OPS/OMS, IBE, ILAE, National University (Vice chancellor) and global campaign.</li> <li>• Also a project started to demonstrate global campaign in Juticalpa (Treatment gap) and finally the local strategic plan was defined.</li> <li>• Neurologists’ training has gone forward to reduce treatment gap, working hard in the program for the prevention of neurocysticercosis..</li> </ul>   |
| <b>México</b>   | Dr. Horacio Senties<br><a href="mailto:sentiesh@yahoo.com">sentiesh@yahoo.com</a> | Dra. Lilia Nuñez Orozco<br><a href="mailto:lilianuor@yahoo.com">lilianuor@yahoo.com</a> | <ul style="list-style-type: none"> <li>• A meeting with Ministry of Health is on hold.</li> <li>• A reunion took place in June 2012 with Dr. Horacio Senties</li> </ul>   |

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|                  |   |  | <p>(CAMELICE), Dr. Rubio Donnadiue (Epilepsy Priority Program), Dra. Lilia Nuñez (IBE), Dr. Juan Carlos Resendiz, Dr. Eduardo Barragán and Dr. Mario Alonso Venegas, to establish a situational diagnosis of epilepsy in Mexico and to develop a follow up plan for SSA and PAHO.</p> <ul style="list-style-type: none"> <li>In Mexico there is a national priority program that has 63 centers focused on primary care education. Printed material is available for PCPs such as clinical guides, and brochures. Lectures for family members are also available and an annual congress is organized for Specialists, PCPs and patients.</li> </ul>   |
| <b>Nicaragua</b> | Dr. Foad Hassan<br><a href="mailto:fhassan@cablenet.com.ni">fhassan@cablenet.com.ni</a>         | Dr. Foad Fassan:<br><a href="mailto:fhassan@cablenet.com.ni">fhassan@cablenet.com.ni</a> | <ul style="list-style-type: none"> <li>Contact with OPS and Dr. José Gómez Started. No contact with Ministry of health so far.</li> </ul>   |
| <b>Panama</b>    | Dr. Fernando Gracia<br><a href="mailto:fegra@medicospaitilla.com">fegra@medicospaitilla.com</a> | Dr. Ernesto Triana<br><a href="mailto:erentri15@hotmail.com">erentri15@hotmail.com</a>   | <ul style="list-style-type: none"> <li>Lectures have already started.</li> <li>A meeting with the Ministry of Health is planned.</li> </ul>   |
| <b>Paraguay</b>  | Dra. Marta Cabrera<br><a href="mailto:mafrec@yaho.com.ar">mafrec@yaho.com.ar</a>                | Dr. Oliveira   | <ul style="list-style-type: none"> <li>First two meetings with ministry of health to discuss the strategic plan and the work planed for primary care and general practitioners.</li> <li>In the 3rd meeting with minister of health Dra Esperanza Martinez, the team was conformed and in the next month the first five hospitals will be chosen along with the physicians that will be trained.</li> <li>These hospitals will be the first reference for primary care physicians. 5 more EEGs were solicited with internet connection to Cenadine, the idea is that all of this is coordinated by them in agreement with the Medical Science Faculty of the National University of Asuncion, the ministry of Health and Lipalep (Paraguayan league against Epilepsy) and Paraguayan Chapter ILAE).</li> <li>We have had reunions with some members of the Health commission of the chamber of deputies with very good outcomes.</li> </ul> |

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|                    |  |   | <ul style="list-style-type: none"> <li>• Legal advice has been offered to work on the subject and fight for the cause.</li> </ul>  |
| <b>Perú</b>        | Dr. Alberto Díaz Vazquéz<br><a href="mailto:a.diazvasquez@hotmail.com">a.diazvasquez@hotmail.com</a> | Dr. Julio Espinoza<br><a href="mailto:jijperu@hotmail.com">jijperu@hotmail.com</a>                | <ul style="list-style-type: none"> <li>• No meeting has been held neither with the ministry of health nor with PAHO representative.</li> <li>• Have already established medical education for PCPs but not for Neurologists.</li> </ul>  |
| <b>Uruguay</b>     | Dra. Patricia Braga<br><a href="mailto:patbraga@adinet.com.uy">patbraga@adinet.com.uy</a>            | Dra. Alicia Bogacz<br><a href="mailto:alicia.bogacz@gmail.com">alicia.bogacz@gmail.com</a>        | <p>A National Program for Epilepsy treatment is in process:</p> <ul style="list-style-type: none"> <li>• Including different levels of attention and correlation ensuring the access for free chronic medication (actually it only excludes levetiracetam, from the existing DAE in the market) to more users.</li> <li>• Enable the access for the epilepsy surgery program to public users that requires it.</li> <li>• Conversations with M.S.P., Sub secretary, Dr. Leonel Briozzo and Director of Chronic prevalent diseases program Dra. Clara Niz.</li> </ul>   |
| <b>Venezuela</b>   | Dr. Luis Linares<br><a href="mailto:luis.e.linares@hotmail.com">luis.e.linares@hotmail.com</a>       | Lic. René Scull.<br><a href="mailto:rscull@yahoo.com">rscull@yahoo.com</a>                        | <ul style="list-style-type: none"> <li>• We have prepared information about the scholarships for the Venezuelan society of Neurology with the authorities.</li> <li>• Delivery of the congress material held in Ecuador was approved to each SVN member.</li> <li>• We are waiting for the audience with the national assembly to get the approval of the protection for the epileptic law.</li> <li>• We will have a symposium about quality of life in May 26<sup>th</sup> in UCV auditorium, where OPS/OMS representatives will be incorporated to encourage participation in favor of epileptic people in this country.</li> </ul> |
| <b>El Salvador</b> | Dra. Claudia Valencia<br><a href="mailto:claudvz@yahoo.com">claudvz@yahoo.com</a>                    | Dr. Francisco Posadas<br><a href="mailto:chicoposadero@hotmail.com">chicoposadero@hotmail.com</a> | <ul style="list-style-type: none"> <li>• Unsuccessful approach to the Ministry of health. No contacts have been established to start this work.</li> <li>• Recopilation of information about neurology societies is in process to get support for the campaign.</li> </ul>   |



### **Latin American Committee ILAE**

President: Dr. Manuel Campos: (Chile): [biomedica@entelchile.net](mailto:biomedica@entelchile.net)  
General Secretary: Dr. Eduardo Barragán (México). [neurodoc@prodigy.net.mx](mailto:neurodoc@prodigy.net.mx)  
Treasurer: Dra. Patricia Braga (Uruguay): [patbraga@adinet.com.uy](mailto:patbraga@adinet.com.uy)  
Legal Aspects: Dra. Silvia Kochen (Argentina): [skochen@gmail.com](mailto:skochen@gmail.com)  
Global Campaign: Dr. Alejandro Scaramelli (Uruguay): [scaram@adinet.com.uy](mailto:scaram@adinet.com.uy)  
Investigation: Dra. Beatriz González (Venezuela): [becastle@gmail.com](mailto:becastle@gmail.com)  
Dra. Magnda Nunes (Brazil)

### **Latin American Committee IBE**

President: Dra Lilia Núñez Orozco: (México): [lilianuor@yahoo.com](mailto:lilianuor@yahoo.com)  
Vice-president: Dra Elza Marcia Yacubían (Brazil): [yacubian@terra.com.br](mailto:yacubian@terra.com.br)  
General Secretary: Dr. Tomás Mesa (Chile). [tmesa@med.puc.cl](mailto:tmesa@med.puc.cl)  
Past President: Dr. Carlos Acevedo (Chile). [carlosoacevedo@yahoo.com](mailto:carlosoacevedo@yahoo.com)  
Director: Sr. Fonoaudiólogo Mauricio Olave (Colombia): [mauchi118@yahoo.com](mailto:mauchi118@yahoo.com)

### **Executive Committee PAHO**

**Dr. Marco Tulio Medina (Honduras):** [marcotmedina@yahoo.com](mailto:marcotmedina@yahoo.com)  
**Dr. Carlos Acevedo (Chile):** [carlosoacevedo@yahoo.com](mailto:carlosoacevedo@yahoo.com)  
**Dr. Li Li Min (Brazil):** [limin@fcm.unicamp.br](mailto:limin@fcm.unicamp.br)