

International Bureau for Epilepsy

Promoting and supporting the work of 122 member associations in 92 countries around the world

BURO VENEZOLANO CONTRA LA EPILEPSIA VENEZUELAN BUREAU AGAINST EPILEPSY



COUNTRY OF OPERATION

Venezuela

TYPE OF IBE MEMBER

Full member

DATE ORGANISATION WAS CREATED

Creada el 20 de Octubre de 2001 en el Marco del "I Simposio Científico Saliendo de las Sombras", en Caracas.

DATE ORGANISATION FIRST AFFILIATED TO IBE

Afiliada al Buró Internacional en el año 2003, en el marco del 25º Congreso Internacional de Epilepsia en Lisboa, Portugal.

TYPE OF ORGANISATION

Formada como Membresía Organizada.

RANGE OF OPERATION

Rango de operación a escala Nacional.

OBJETIVOS

1. Promover la difusión de la información sobre EPILEPSIA, a través de campañas educativas a nivel nacional, en escuelas de primaria, secundarias y Universitaria.
2. Mantener talleres educativos programados de manera continua, para los docentes en los diferentes estados del país así como a todas las Sociedades de Padres y Representantes.
3. Promover la aprobación de la Ley de Protección a la Persona con Epilepsia, ante la Asamblea Nacional venezolana; creada y presentada en conjunto con LIVECE y el Buró Nacional en el año 2009.
4. Favorecer la formación de organizaciones de personas con Epilepsia, sus familiares y amigos, definidos como Grupos de Autoayuda.
5. Participar en los eventos científicos de LIVECE, incorporando temas que se relacionen con la calidad de vida de dichas personas.
6. Participar con LIVECE en la programación y ejecución de Trabajos de Investigación así como en Jornadas para medir incidencia y prevalencia de Epilepsia en el País.

LOGROS:

- Creación de la Unidad de Psicología, Terapia de Lenguaje, Terapia Ocupacional y Recuperación Escolar, en la sede de LIVECE.
- Se han abierto seis capítulos del Buro en diferentes regiones del País.
- Existen 267 personas que se han registrado en internet y se integran en diferentes actividades en la región capital.
- Son miembros todos los que manifiestan su deseo de participar, por lo tanto hay profesionales de diferentes áreas, personas con epilepsia, etc.
- El 15 de mayo 2010 se realizó una Jornada de Despiñaje de Epilepsia, a escala nacional, donde participaron 55 profesionales médicos neurólogos de adultos y de niños, con la aplicación de un protocolo de preguntas diseñado para tal fin.
- Se logran acuerdos en asamblea de miembros para la promulgación de la Ley de Protección al Epileptico y su final aprobación gubernamental.
- La organización trabaja de una manera conjunta con LIVECE (Liga Venezolana Contra la Epilepsia) y GAPE (Grupo de Amigos y familiares de Personas con Epilepsia).
- Se logra apoyo para la creación de la unidad de monitoreo prolongado en epilepsia, a través de donativo por parte de la Asociación de Diplomáticos.
- Se logran apoyos para el curso de Ampliación en Epilepsia diseñado por LIVECE, el cual será dictado en la Universidad Central de Venezuela.
- Esta en restauración la página Web de LIVECE que da acceso al Buro.

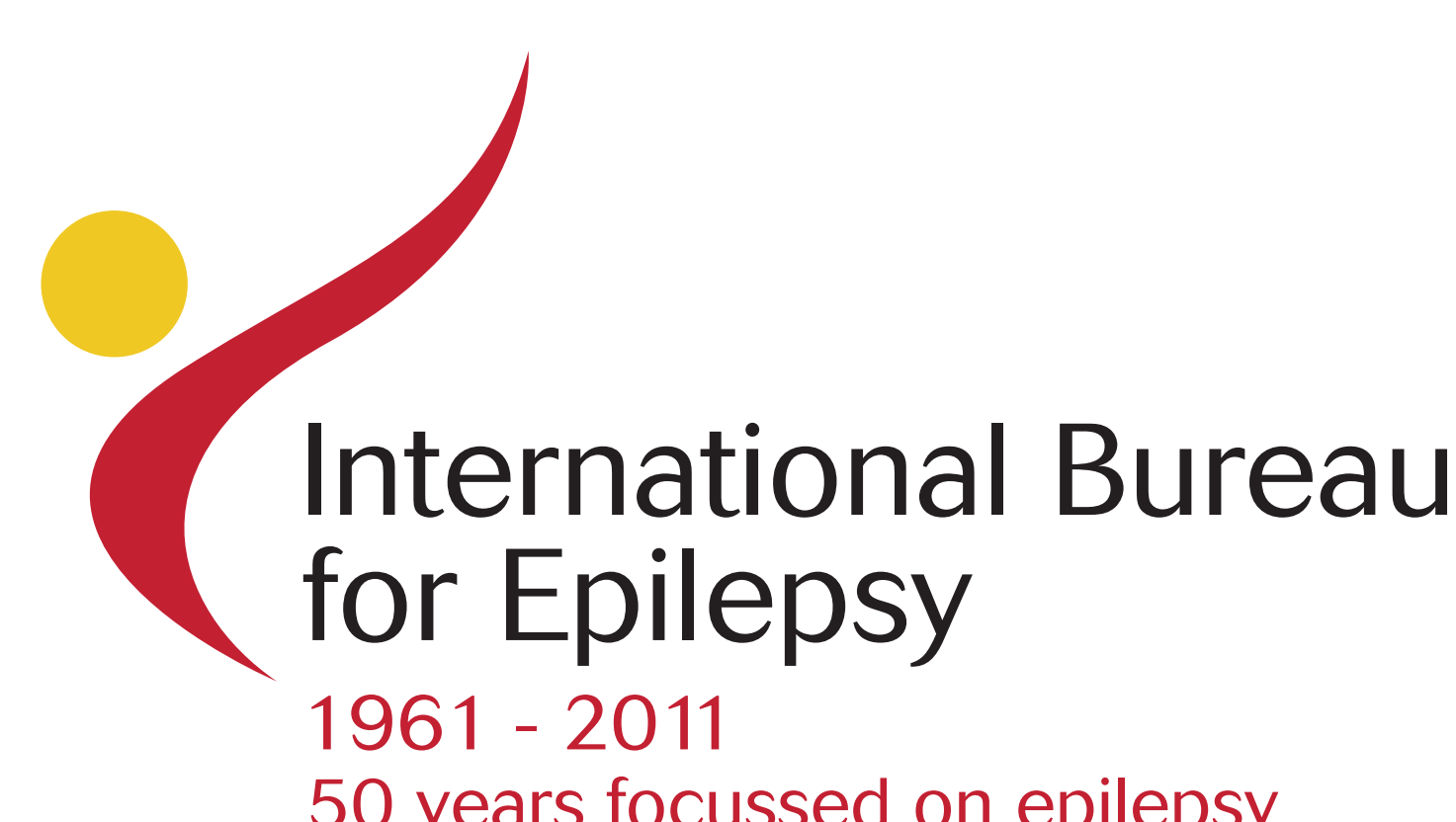


SEDE PRINCIPAL:

Qda Honda a Sta. Rosa, Edf. Táchira, PB, Local 3. Caracas 1050, Venezuela. Telf. +58 (212) 578.2737

PERSONA CONTACTO:

Lic. Rene Scull (Presidente), Caracas Telf. +58 (414) 274.8008. Email: rscull@yahoo.com



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

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GROUP "ACCEPTATION" OF PERSONS WITH EPILEPSY (GADEP), MEXICO



COUNTRY OF OPERATION

Mexico

TYPE OF IBE MEMBER

Full member

GROUPS AFFILIATED TO THE MEXICAN FULL MEMBER OF IBE

Founded 19 years ago, the Mexican Chapter has grown up through the foundation of new affiliated groups in different cities.

Guadalajara has a group named **GAPE**, directed by Dr Leonardo Llamas, which organises regular sessions to inform people of the different aspects of epilepsy. Another group, called Epilepsia en tus Manos (Epilepsy in your Hands) was developed in Monterrey, and is looked after by a woman with epilepsy together with several well organized collaborators. The youngest group was created this year in Morelos, a state south of Mexico City. This group is run by a person with epilepsy and has attracted the support of public authorities for resources to help with issues such as employment and the provision of medication, amongst others. The group is looking for a medical advisor for their city, Cuernavaca, which is located south of Mexico City.

INFORMATION SESSIONS IN GADEP

Every year there is an information programme on the first Saturday of each month, advertised in Metro stations, hospitals, churches, schools, etc., with a special advertising poster.

www.epilepsiahoy.com

Our website remains very active in promoting our activities, answering questions about epilepsy, showing lectures or videos about epilepsy presented in congresses and providing links with other associations in Latin America and other regions.

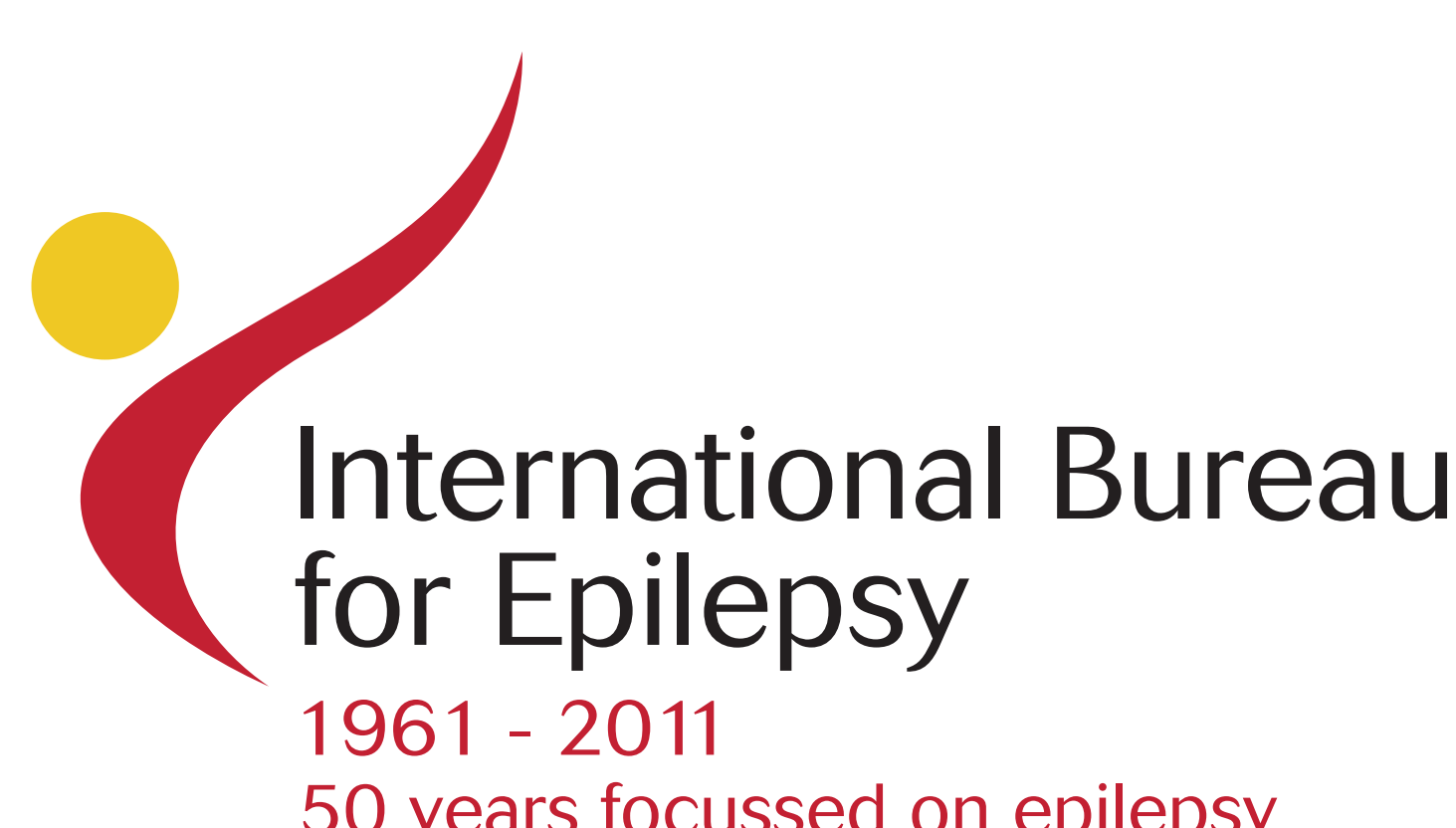
CONGRESSES IN MEXICO

The Mexican Chapter has organized three biennial congresses for people with epilepsy along with the Mexican Chapter of ILAE. This year, the Mexican Chapter will organize another congress in Queretaro, a city located northwest of Mexico City, on August 27-29, 2010.



CONTACT

Dr Lilia Nuñez Orozco, GADEP, San Francisco 1384, 7o Piso B, Col. Del Valle, Mexico DF 03100, Mexico



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SOCIEDAD DOMINICANA UNIDOS POR LA EPILEPSIA, "SODOUE, Inc."



PAIS

Republica Dominicana.

TIPO DE MIEMBRO IBE:

Full member.

FECHA DE CREACION:

Julio 2005.

FECHA DE AFILICACION AL IBE:

Junio 2009.

TIPO DE ORGANISACION:

Individual.

ALCANCE OPERACIONAL:

Nacional.

MISION:

Servicios de orientación a pacientes, familias, instituciones, profesionales y al público en general sobre las epilepsias y su repercusión en el entorno socio-familiar, escolar y laborar de estos pacientes.

OBJETIVOS:

Objetivos Fundamentales:

- Crear una organización sin fines de lucro integrada por pacientes, médicos, terapeutas, miembros y colaboradores, que surjan como respuesta a la necesidad de contribuir al desarrollo integral de los niños, niñas, adolescentes y adultos con epilepsia en la Republica Dominicana, tendente a mejorar la calidad de cuidados ofrecidos, a través del diagnostico, seguimiento terapéutico y apoyo individual, familiar y social.
- Aumentar el nivel de conocimiento en la población a fin de mejorar la calidad de vida de los pacientes y las familias de los pacientes con epilepsia.

Objetivo Específicos:

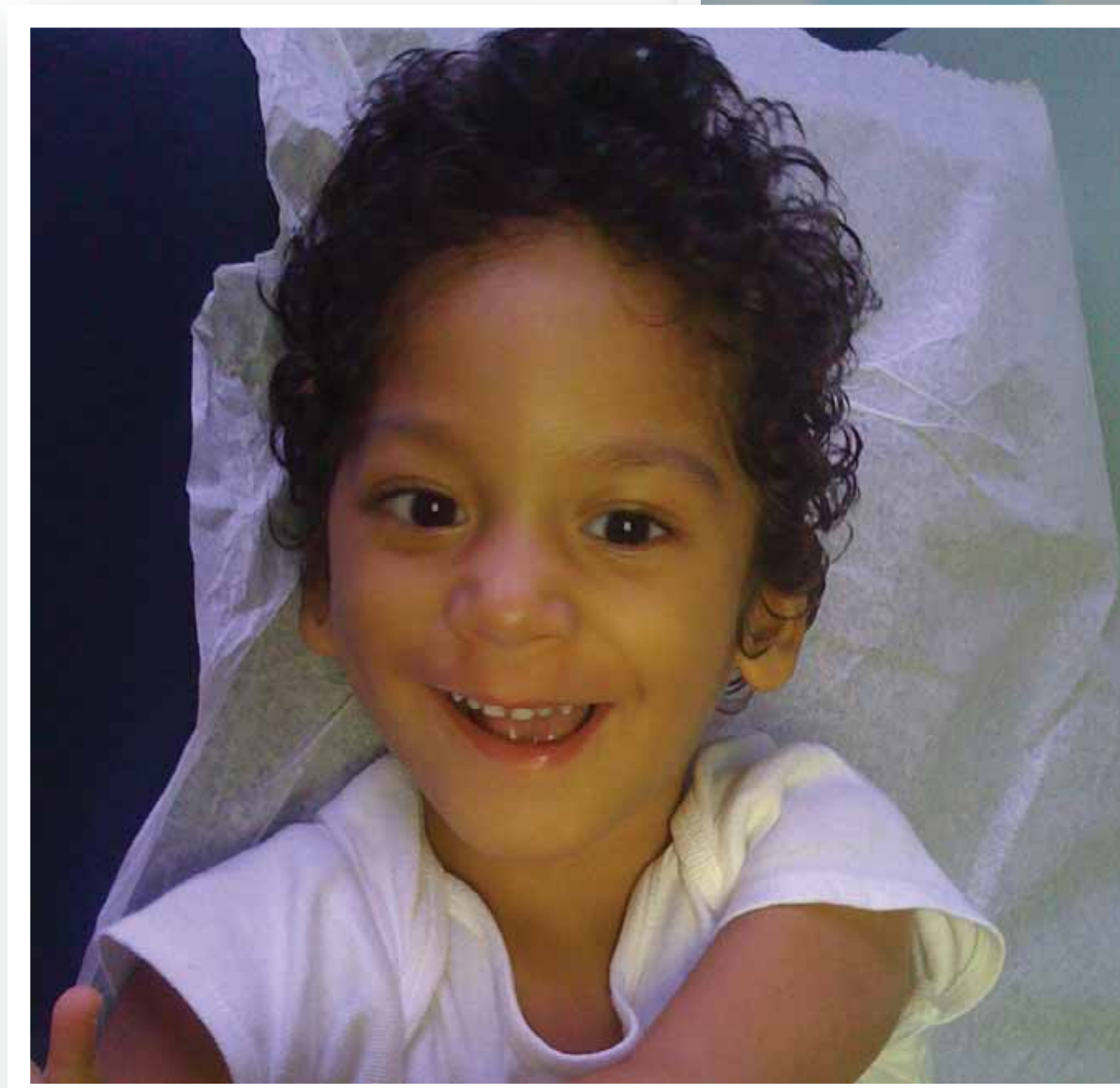
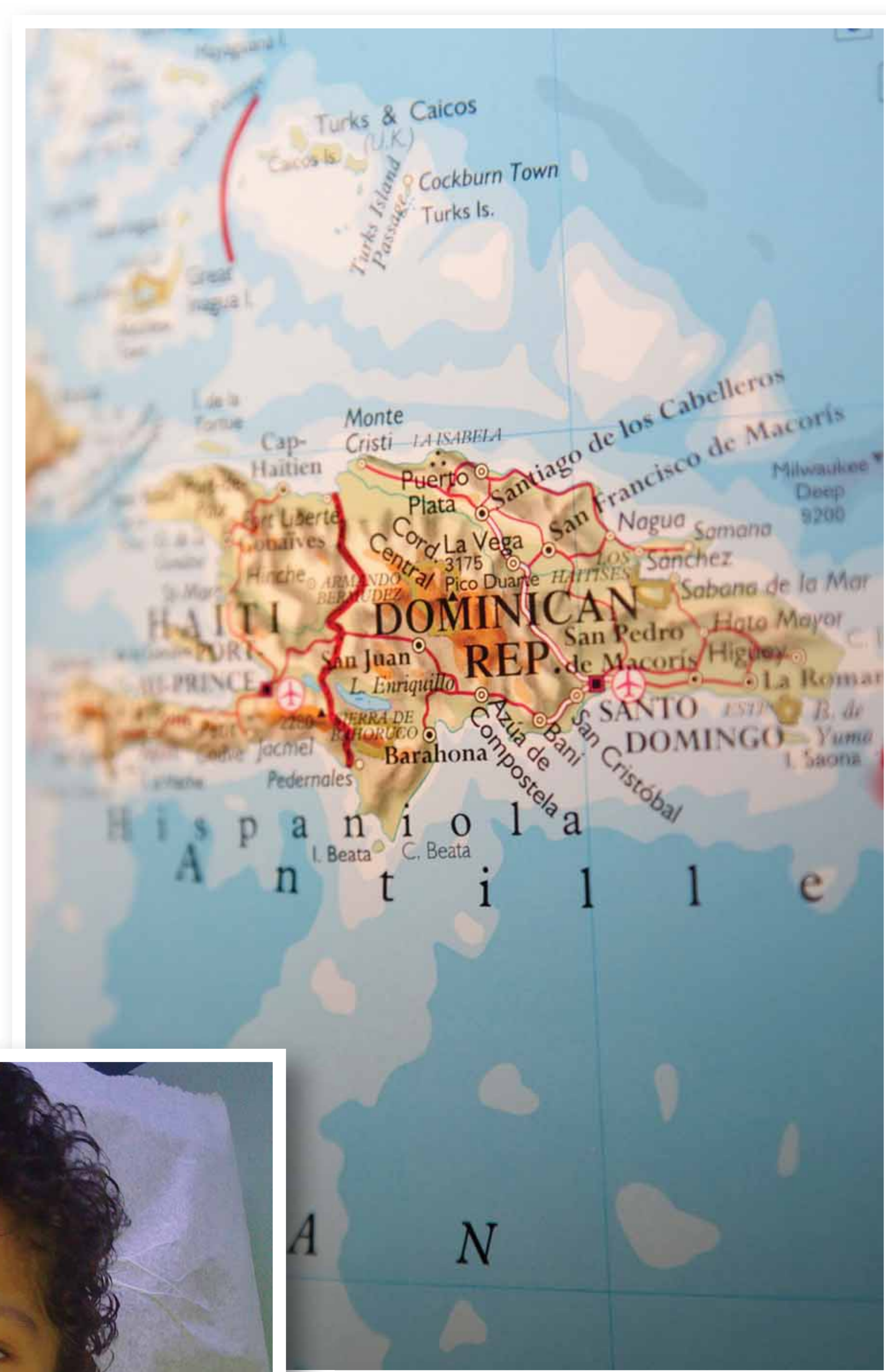
- Crear conciencia sobre la importancia de la detección temprana de las epilepsias.
- Contribuir al apoyo y educación individual y familiar de los pacientes con epilepsia.
- Desarrollar programas de seguimiento terapéutico interdisciplinario.
- Impulsar programas para la capacitación de profesionales del área.
- Organizar y desarrollar eventos, seminarios, charlas para el desarrollo de la educación en torno a los pacientes con epilepsia.

ESTADISTICAS:

Grupo individual, 435 miembros, difusión de contenido de "charlas-taller" a través de diferentes medios de comunicación nacional (radial, escrita y televisiva).

ACTIVIDADES ANUALES REGULARES 2009-2010:

reuniones tipo "charla-taller" dirigidas a pacientes y familiares de pacientes con epilepsia, ofrecidas gratuitamente por diversos profesionales de diferentes instituciones. Discusiones abiertas. Grupos de autoayuda. temas tratados: "Epilepsia, Discapacidad y Aceptación", "Epilepsia y Depresión", "Epilepsia y Dinámica familiar", "Epilepsia y Sueño", "Epilepsia y Escuela", "Epilepsia y Neurodesarrollo", "Epilepsia y Sexualidad", y "Epilepsia y Sociedad".



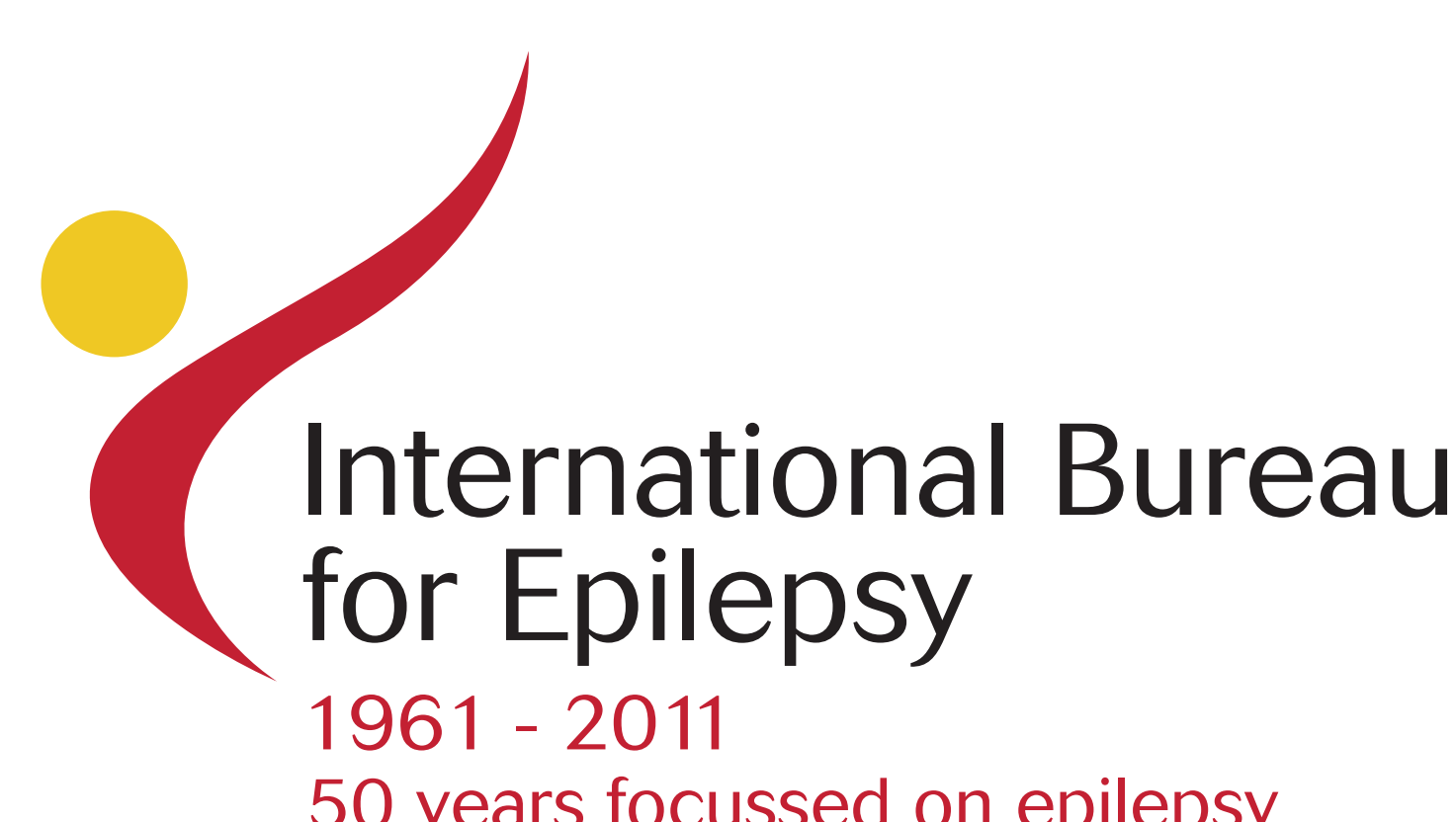
CONTACTO:

"SODOUE, Inc."

Nombre: Franklin Montero

Dirección: Cesar Dargam, 10, Edificio Torre azul, Suite 504. La esperilla. Santo Domingo, D.N., Republica Dominicana.

Email: frmontero@yahoo.com.



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CENTRO NACIONAL DE EPILEPSIA Y ASOCIACIÓN DE PADRES DE NIÑOS CON EPILEPSIA - ECUADOR



COUNTRY OF OPERATION

Ecuador

TYPE OF IBE MEMBER

Full member

La Asociación de Padres de Niños con Epilepsia (APNE) y el Centro Nacional de Epilepsia CNE), conjuntamente constituyen el Capítulo Ecuador del International Bureau for Epilepsy (IBE) desde el año 1991.

Son **entidades de beneficencia** que han logrado con creces sus objetivos al constituirse en la casa de quienes más necesitan, en el refugio cálido y fraterno del paciente con epilepsia y de sus familiares.

Sus logros han calado en el corazón del pueblo y así hemos avanzado parejos en armonioso compás de anhelos y satisfacciones.

Conocemos que la cumbre esta a la vista, mas no podemos perdernos en el espejismo de lo logrado y seguimos empeñadamente fieles al principio original de llegar y comenzar de nuevo, pues el camino no se detiene con nuestro caminar, sino que avanza presuroso mientras se renueva la vida y la esperanza.

Son muchas las exigencias y nuevos retos, más la fe y el propósito van parejos y en el sendero aparecen nuevos horizontes que llenan de brisa fresca e inspiración al alma.

ALCANCE DE ACCIÓN:

Nacional

OBJETIVO DE LA ORGANIZACIÓN:

Atención holística al paciente con epilepsia y a su familia.

Número estimado de personas con epilepsia en Ecuador: 200.000

Miembros de nuestra organización:

- Personas atendidas: 10.000
- Profesionales médicos: 8
- Otros: Psicólogos, educadores, tecnólogos: 18
- Otros colaboradores: voluntarios 30

El **Centro Nacional de Epilepsia**, fue creado en el año 1989, y constituye el vínculo de referencia nacional e internacional tanto para el cuidado de sus pacientes como para el establecimiento de proyectos de investigación, prevención y difusión de conocimientos.

Para el diagnóstico y tratamiento del paciente con epilepsia contamos con los equipos más avanzados de investigación ya sea, a través de sus propias instalaciones o en cooperación con entidades asociadas nacionales o internacionales.

Son constantes las investigaciones a la par que las publicaciones de revistas, artículos y libros editados por el Centro Nacional de Epilepsia, en los que participan profesionales de universidades e instituciones nacionales e internacionales; esto nos permite, mantenernos al día de los avances científicos.

CONTACTO:

Dr. Galo Pesántez Cuesta

Dirección: Berrutieta Oe – 180 y Pasaje Acevedo, Quito - Ecuador

Correo electrónico: cnepilepsia@andinanet.net

www.centronacionaldeepilepsia.com

ASOCIACIÓN DE PADRES DE NIÑOS CON EPILEPSIA

Se conformo en el año 1987 y sorteando toda suerte de vicisitudes continua siendo la madre tierna que acoge a todos quienes afligidos llegan a su seno. Sus logros se han multiplicado con creces y su influencia ha sido replicada a nivel de todo el territorio patrio y en otras naciones.

Sus objetivos se plasman en dos palabras: **esperanza y solidaridad.**

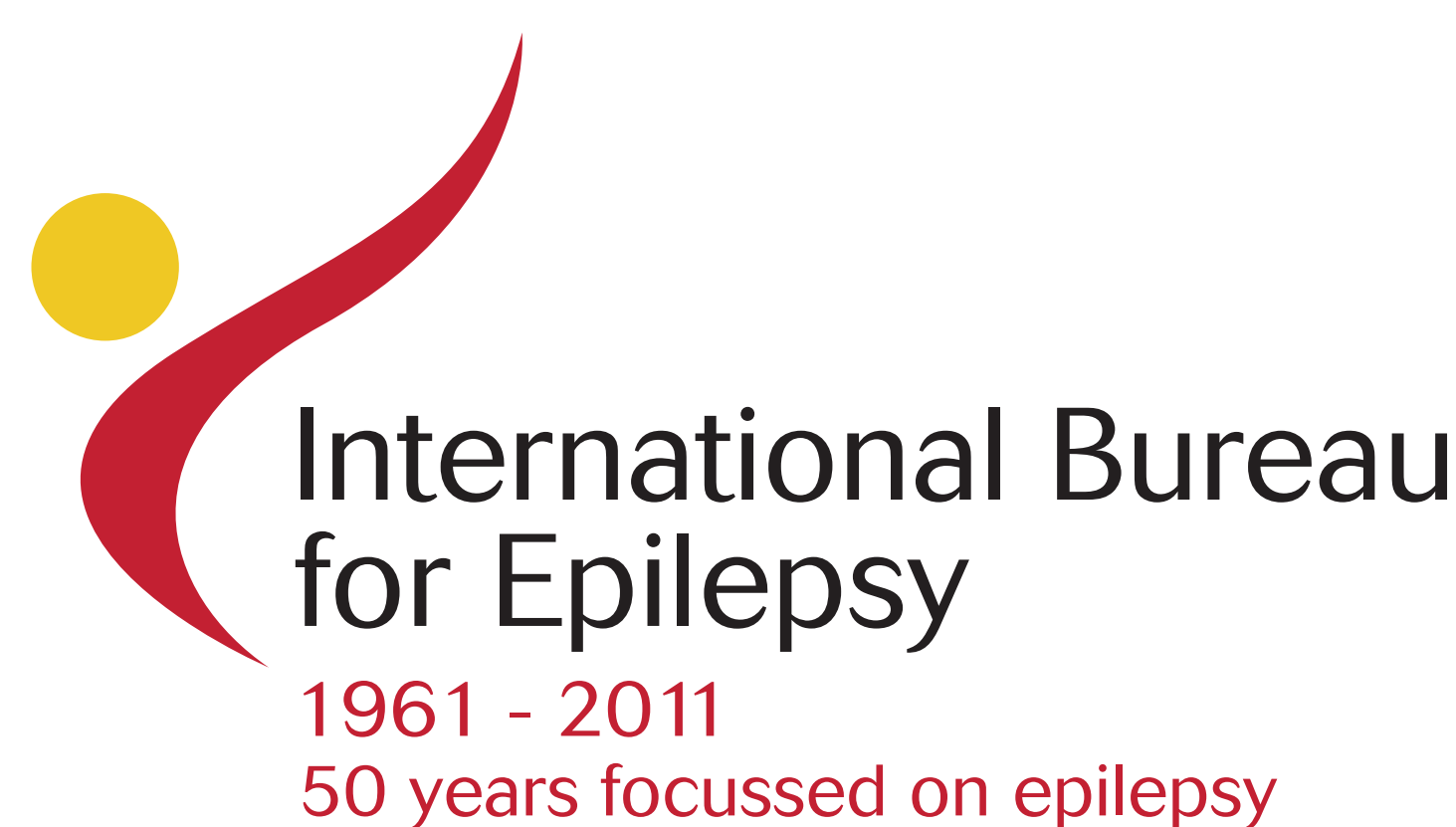
DIA NACIONAL DE CONCIENTIZACIÓN Y LUCHA CONTRA LA EPILEPSIA

El cuarto sábado mayo de cada año se realizan conferencias y marchas en las diversas ciudades del país para apoyar esta iniciativa de tipo social

PSICOMOTRICIDAD: UNA ALTERNATIVA PARA EL TRATAMIENTO DEL PACIENTE CON EPILEPSIA

En el año 2005 se conformo la Escuela de Neurología del Desarrollo y Psicomotricidad (Neuropsicomotricidad), con el auspicio de la Organización Internacional de Psicomotricidad y el Centro Nacional de Epilepsia.

La neuropsicomotricidad es considerada como la ciencia del futuro y plantea alternativas preventivas y terapéuticas que permitan lograr la armonía psicofísica del individuo.



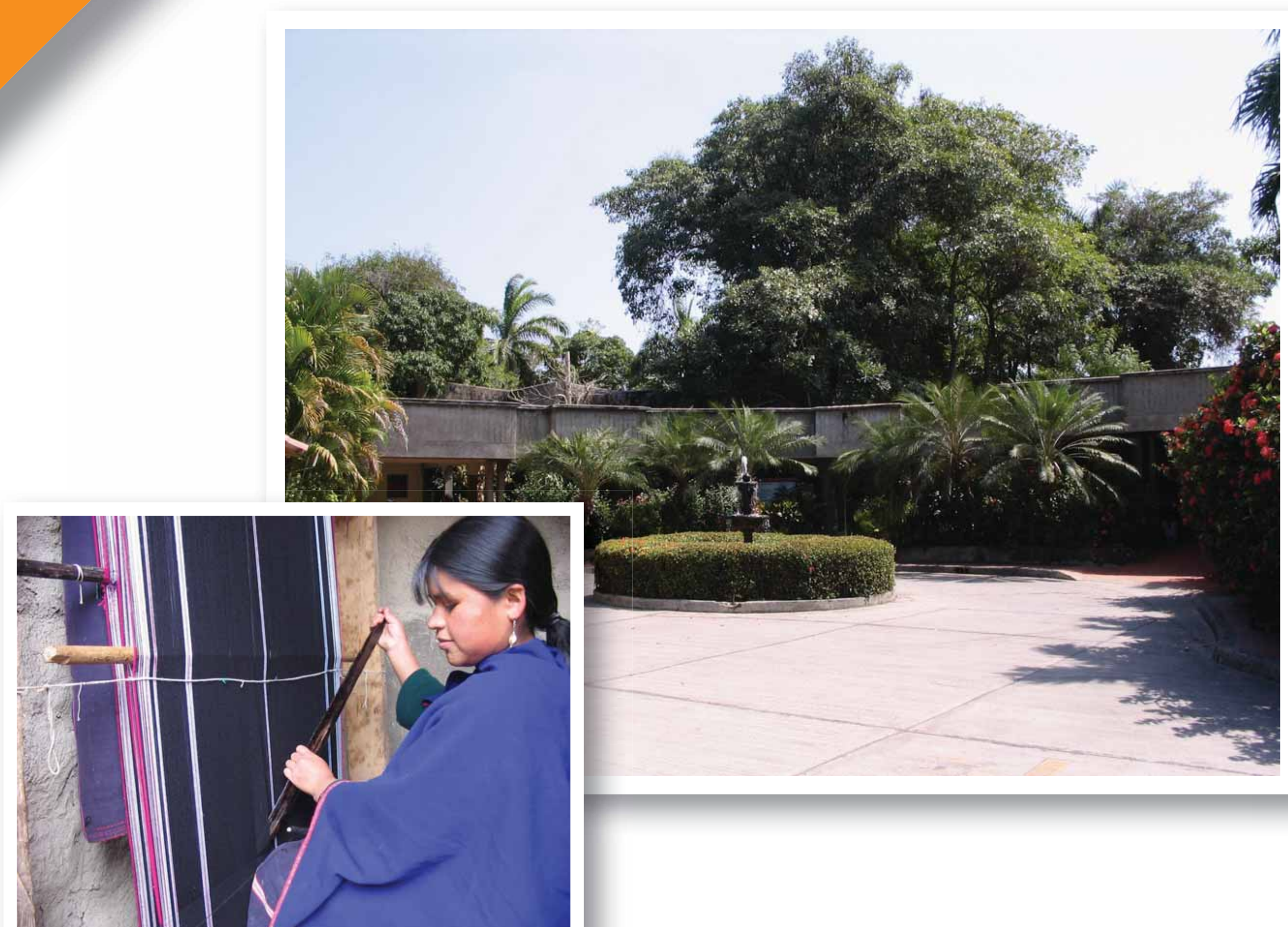
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FUNDACIÓN INSTITUTO DE REHABILITACIÓN PARA PERSONAS CON EPILEPSIA – FIRE, COLOMBIA



COUNTRY OF OPERATION

Colombia

TYPE OF IBE MEMBER

Full member

DATE ORGANISATION WAS CREATED

Fundada en 1970.

DATE ORGANISATION FIRST AFFILIATED TO IBE

1975.

TYPE OF ORGANISATION

5 Organización regional

MISIÓN ESTATUTARIA

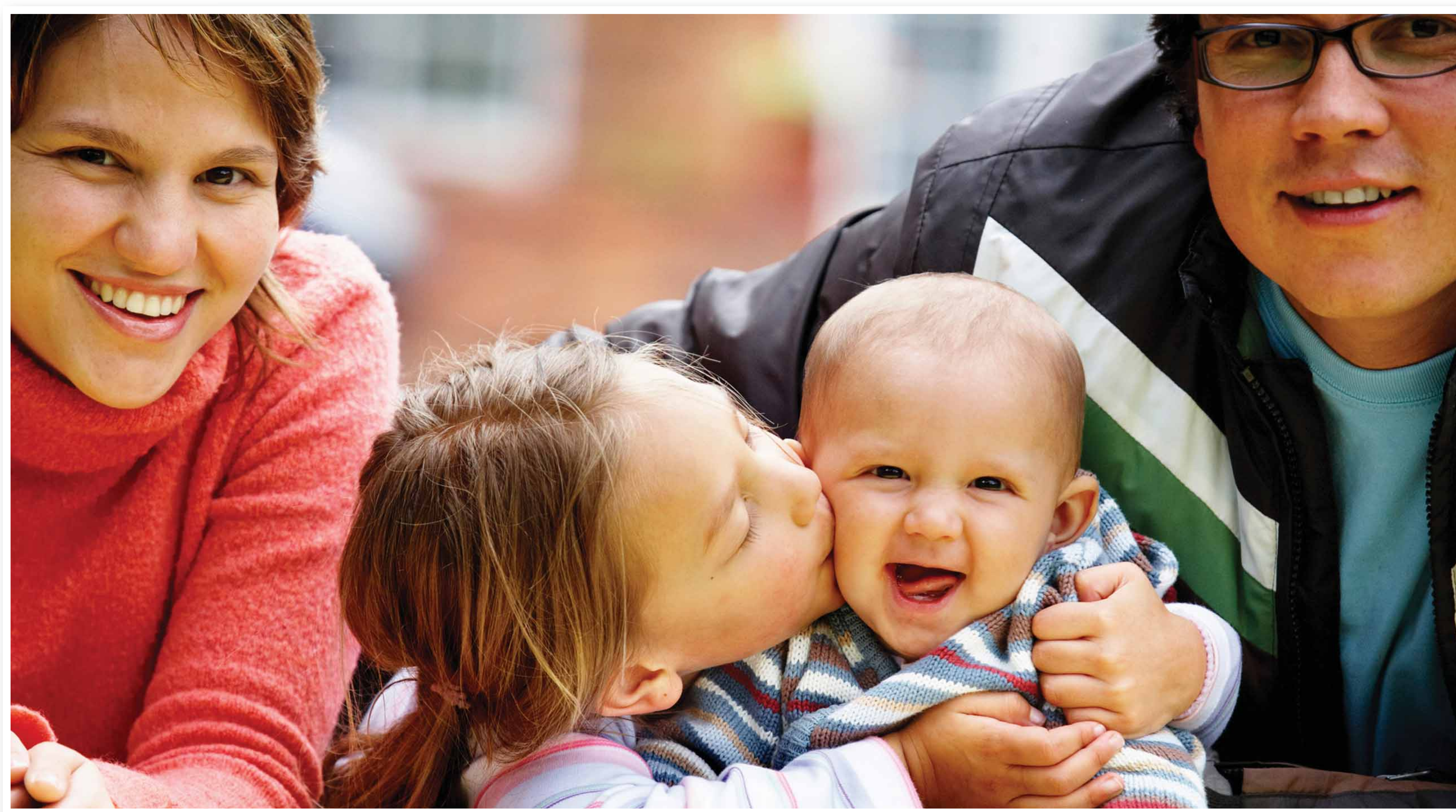
Rehabilitación y habilitación de personas con epilepsia.

- La protección, aún con métodos de protección permanente, el Hogar Clínica, cuando no haya posibilidad de los padres para sostenerlos.
- La colocación en la comunidad en forma competitiva.
- La rehabilitación neuropsicológica para los pacientes operados de epilepsia.
- La educación a distancia para los habitantes de regiones apartadas.
- La investigación de programas como: CCR (Cita Conjunta de Rehabilitación), GR (grupo de Rehabilitación Neuropsicológica) FAMIEMPRESAS (programa en familia para educación laboral).

Colombia tiene un 20 por mil de prevalencia en epilepsia. Hay aproximadamente 800.000 personas con epilepsia.

El logro principal es haber conseguido que la Corte Constitucional de Colombia haya aprobado el proyecto de ley antidiscriminatorio para las personas con epilepsia y la educación masiva al pueblo colombiano en epilepsia, como la dotación de centros de salud y hospitales para la atención y diagnóstico de la epilepsia.

Otro logro es el 740 pacientes rehabilitados y operados de cirugía de las epilepsias y haber ganado el Award Internacional en Voluntariado del IBE.

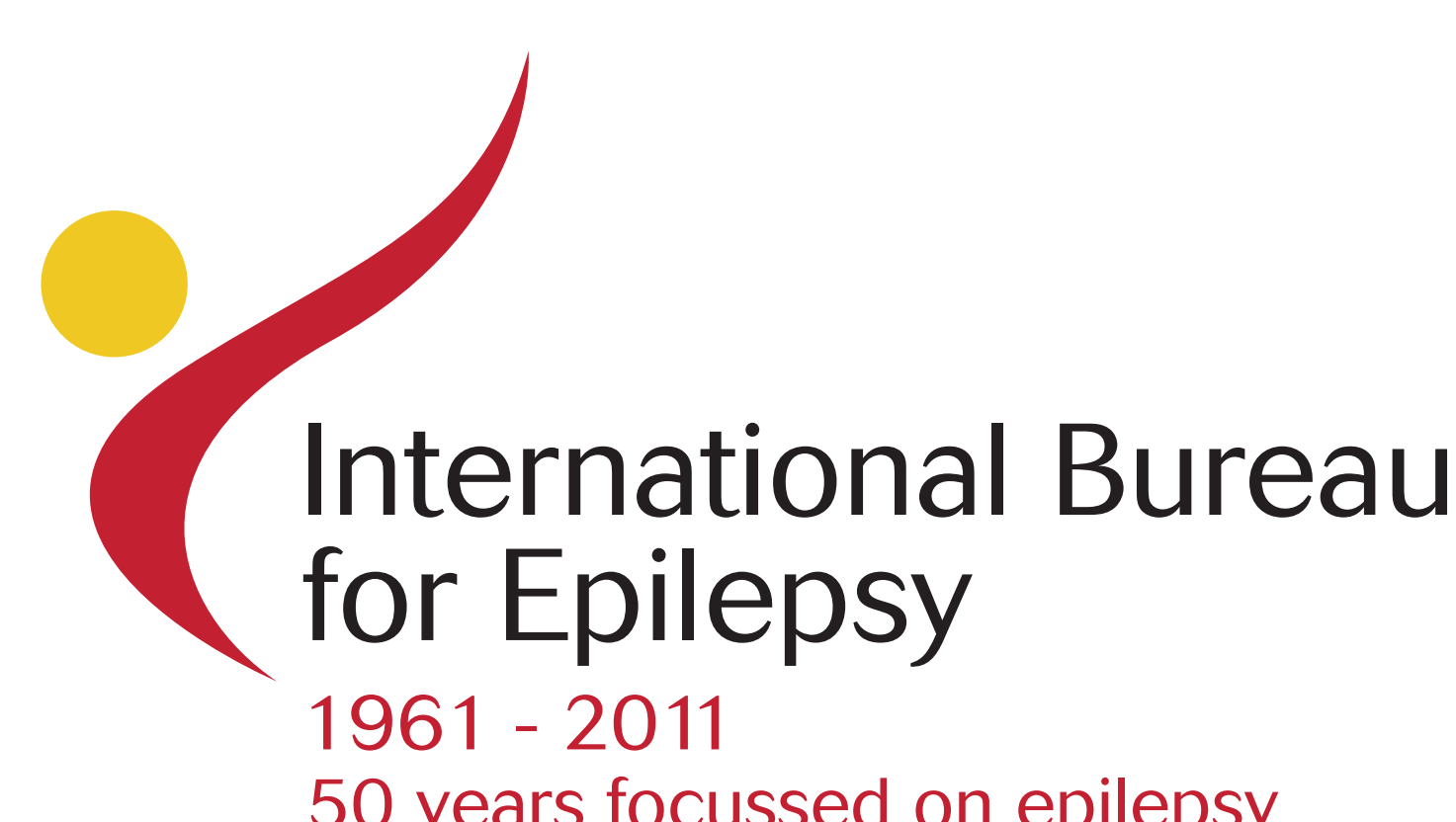


SEDE PRINCIPAL

Fundación Instituto de Rehabilitación para Personas con Epilepsia – FIRE, Barrio Ternera, Calle 1ª., Calle del Eden, Cartagena, Colombia.

Director Ejecutivo: Jaime Fandiño-Franky MD
T: +57 56618 127 Email: ligayfire@gmail.com

www.epilepsiacolombia.org



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

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ASOCIACIÓN NACIONAL DE LIGAS CHILENAS CONTRA LA EPILEPSIA, CHILE



COUNTRY OF OPERATION

Chile

TYPE OF IBE MEMBER

Miembro de pleno derecho

DATE ORGANISATION WAS CREATED

La Asociación Nacional de Ligas Chilena contra la Epilepsia fue fundada en 1997.

DATE ORGANISATION FIRST AFFILIATED TO IBE

En septiembre de 1999 la Asociación se afilió al IBE.

TYPE OF MEMBERSHIP

Membrecía organizacional

RANGE OF OPERATION

Nacional.

TYPE OF ORGANISATION

Los miembros de la Asociación Nacional de Ligas Chilenas contra la Epilepsia se encuentran a lo largo de nuestro país y son:

- Liga Chilena contra la Epilepsia de Santiago, fundado en 1953
- Liga contra la Epilepsia de Valparaíso, Viña del Mar, fundado en 1957
- Club Epilépticos de Arica
- Liga contra la Epilepsia de Iquique
- Liga Chilena contra la Epilepsia de Antofagasta
- Liga Chilena contra la Epilepsia de Copiapó
- Liga Chilena contra la Epilepsia de La Serena
- Liga contra la Epilepsia Valparaíso, Filial Quintero
- Liga contra la Epilepsia de Valparaíso, Filial La Calera - Quillota
- Liga Chilena contra la Epilepsia, Curicó
- Liga Chilena contra la Epilepsia, Talca
- Liga Chilena contra la Epilepsia, Concepción
- Liga contra la Epilepsia de Los Ángeles
- Liga Chilena contra la Epilepsia, Temuco
- Corporación contra la Epilepsia Valdivia
- Corporación contra La Epilepsia Osorno
- Agrupación Liga contra la Epilepsia de Puerto Varas
- Liga contra la Epilepsia Puerto Montt

GOAL

El objetivo es ofrecer ayuda médica, social a personas con epilepsia, así como educar a las personas en general sobre este síndrome.

HISTORIA DE ANLICHE

En 1997 se creó la Asociación Nacional de Ligas Chilenas contra la Epilepsia (ANLICHE), miembro del Bureau Internacional de la Epilepsia (IBE).

El objetivo de formar tal organización fue difundir en todo Chile el conocimiento integral de la epilepsia; intercambiar información con instituciones públicas y privadas; apoyar el estudio e investigación de sus causas y tratamientos; promover la creación de centros especializados y la atención integral de la persona con epilepsia; y promover la educación y capacitación a los voluntariados de todo el país sobre Epilepsia.

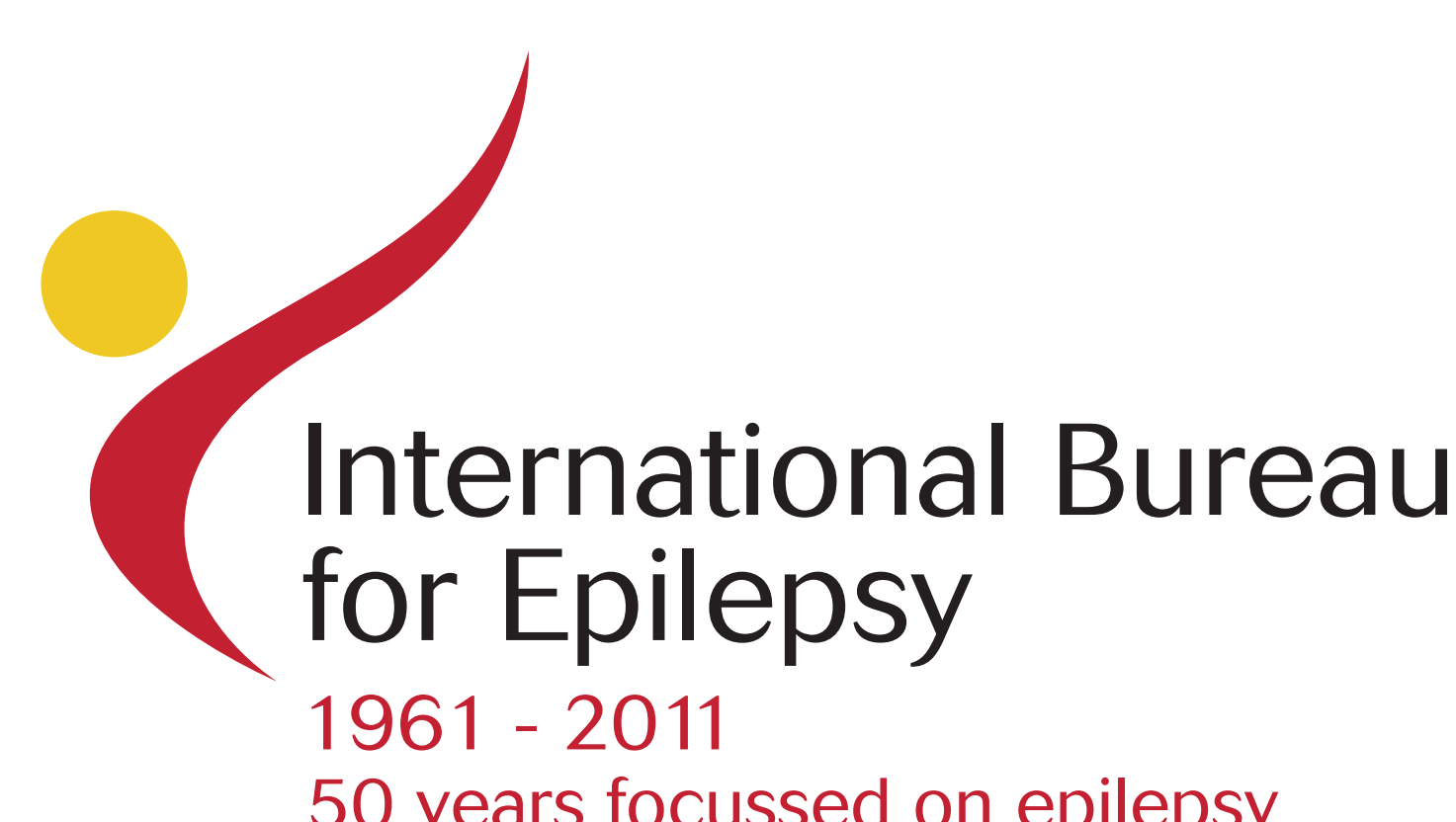
ANLICHE está formado por agrupaciones, clubes, organizaciones, e instituciones de todo Chile desde Arica a Punta Arenas. El directorio está constituido por doce miembros: seis por derecho propio (presidente, vicepresidente y presidenta del voluntariado de la Liga Chilena contra la Epilepsia; presidente y secretario general de la Sociedad de Epileptología de Chile; y el past president de ANLICHE) y seis elegidos por la Asamblea General Ordinaria anual (director por la Zona de Valparaíso, Zona Norte, Zona Central, Zona Sur y dos elegidos entre los miembros del voluntariado de la Liga Chilena contra la Epilepsia), los que se desempeñan en forma totalmente gratuita.

Anualmente los miembros de ANLICHE se reúnen para intercambiar experiencias; ideas; darse apoyo y motivación; además de recibir capacitación y educación en epilepsia, con charlas dictadas por connotados profesionales chilenos y extranjeros. Los encuentros se han realizado en: Santiago, Antofagasta, Temuco, Valparaíso, Puerto Montt, Los Angeles, Talca, Concepción, Curicó y La Serena.



CONTACT

Dr. Carlos Acevedo Schwartzmann, Presidente
Dirección: Patriotras Uruguayos 2236 - Santiago
email: anliche@ligaepilepsia.cl
www.ligaepilepsia.cl



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ASSOCIAÇÃO BRASILEIRA DE EPILEPSIA (ABE) BRAZILIAN EPILEPSY ASSOCIATION



COUNTRY OF OPERATION

Brazil

TYPE OF IBE MEMBER

Full member

DATE ORGANISATION WAS CREATED

1987.

DATE ORGANISATION FIRST

AFFILIATED TO IBE

1999.

TYPE OF ORGANISATION

Individual and organisational membership.

RANGE OF OPERATION

National.

MISSION

To improve the conditions of treatment of people with epilepsy, offering support and orientation to them and their families.

GOALS

- To promote general understanding of epilepsies
- To disseminate knowledge and provide subsidies for better medical and social understanding of epilepsies
- To provide information on epilepsy to the population in general, in order to reduce stigma and prejudice
- To form self-help groups and to enable professional rehabilitation
- To militate for appropriate provision of antiepileptic drugs in public medical facilities

STATISTICS

Brazil is a country of continental dimensions, with approximately 190 million people and many regional differences.

A recent cross-sectional epidemiological survey disclosed a prevalence of epilepsy of 18.6/1000. There are an estimated three million people living with epilepsy in Brazil.

People with epilepsy in Brazil face marked contrasts in the quality of medical assistance: on the one hand, a very well established public-funded program of epilepsy surgery; on the other hand, the continuous need to struggle for appropriate basic treatment and adequate provision of medications.

REGULAR ACTIVITIES

ABE holds a monthly meeting, where people with epilepsy and their families are invited to discuss various topics and to share their experiences with other people.

Every year a special meeting is organized during the celebrations of the Latin America Epilepsy Day, in September.

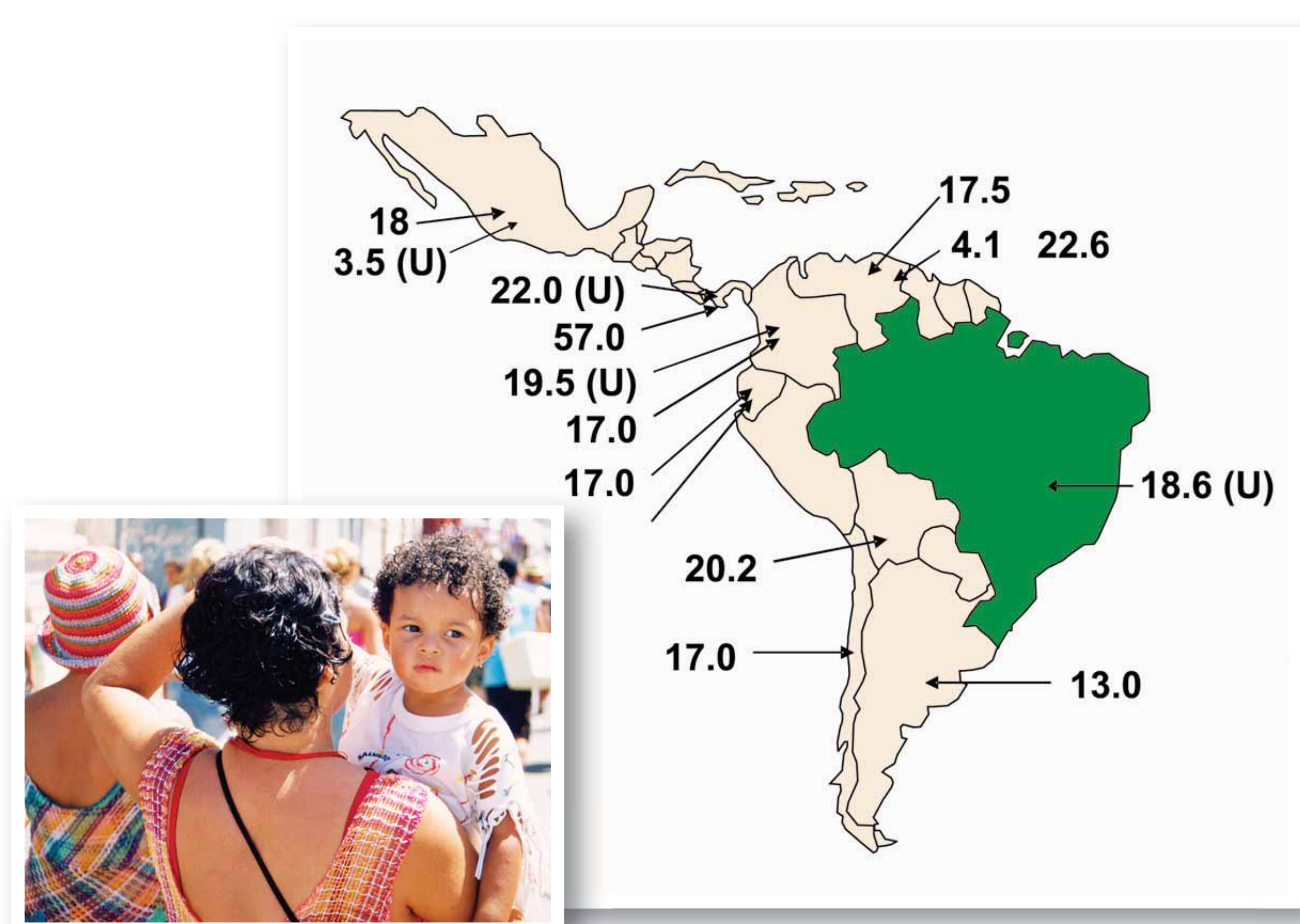
EDUCATION

ABE has organized an educational program aimed at teachers in public schools in São Paulo, Brazil's most populated state. Over a thousand teachers attended the program, which included topics regarding identification of epilepsy in children, basic care of people with epilepsy and initiatives directed to the reduction of the stigma associated with this condition.

A symposium was organized to discuss the matter of generic antiepileptic drugs and their impact on the treatment of people with epilepsy.

RESEARCH

ABE members translated to Portuguese and validated three international instruments for measurement of Quality of Life in epilepsy: ES-55, QOLIE-31 and QOLIE-89.



CONTACT DETAILS

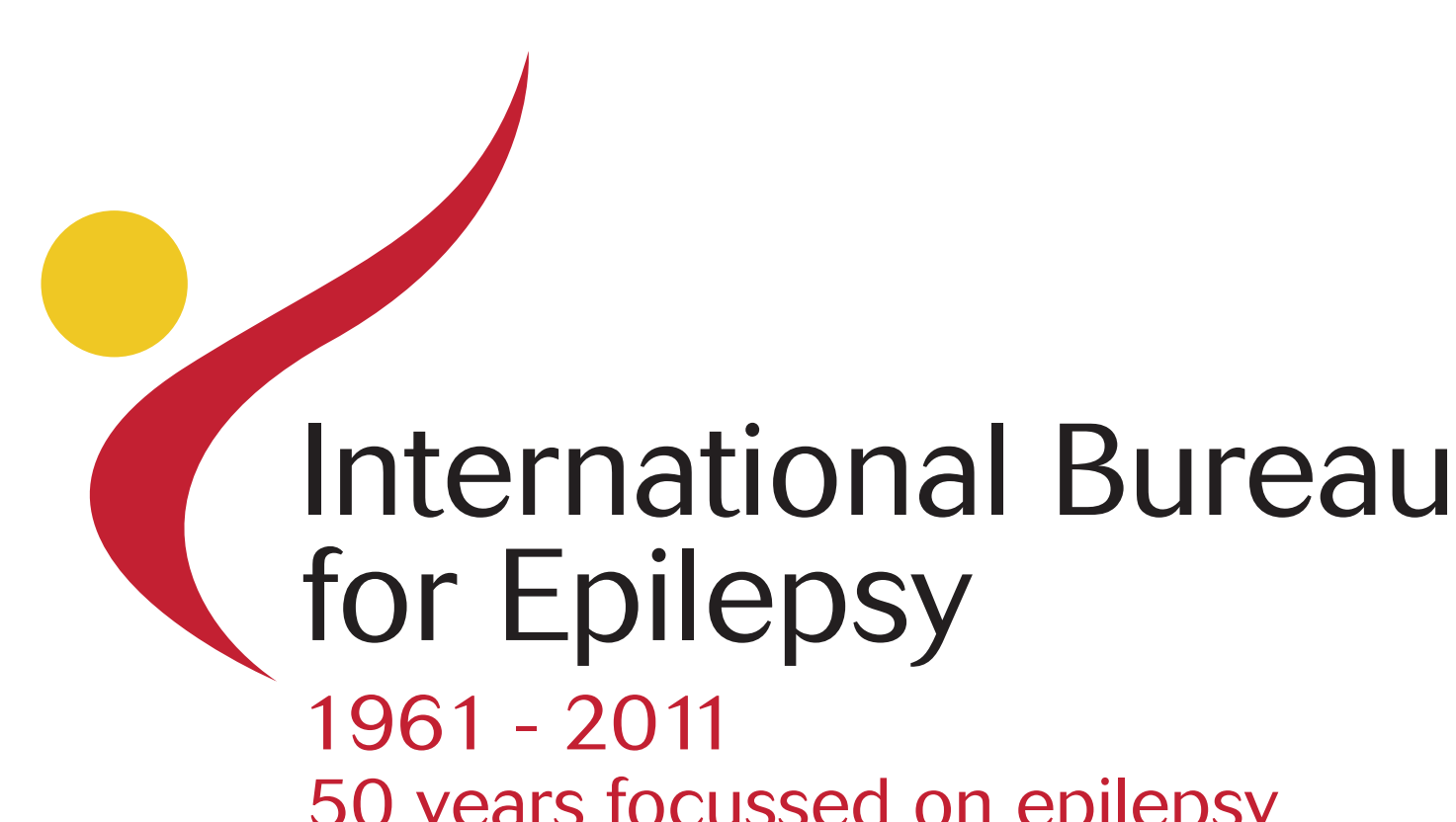
Name: Luís Otávio Caboclo (President)

Address: R. Botucatu, 862, Vila Clementino - São Paulo, SP, Brasil, CEP: 04023-062

Telephone: 55.11.5549-3819

E-mail: locaboclo@ig.com.br

Website: <http://www.epilepsiabrasil.org.br>



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GUATEMALA CHAPTER OF ILAE AND IBE



COUNTRY OF OPERATION

Guatemala

TYPE OF IBE MEMBER

Full member

Our association was created in the early 1980s, very close to the International Epilepsy Congress of Kyoto Japan in 1981 that became an important landmark in epileptology because of the adoption of the internationally accepted classification of epilepsy seizures that provided the basis for the classification of epilepsy syndromes in 1989. We are proud to say that the Guatemala Chapter of ILAE and IBE was present at those events.

At the present time the Guatemala Chapter of IBE has 21 sub-chapters in the main centres of the country and has made strategic alliances with other institutions such as the Guatemala Red Cross, the Guatemala Ministry of Health.

At the present we are in a new phase of trying to develop the Drugs Bank for AEDs in order to make medication more accessible for underprivileged people with epilepsy who represented more than 85% of people with epilepsy in our country.

Each of the 21 sub-chapters was formed by people in the community with a special interest in serving families, people with epilepsy, physicians, neurologists, and other professionals with a common goal: helping those that are in need of better services.

By way of continued education for physicians, lay people, and other groups, we have produced educational material and have also participated in radio broadcasts, TV programs and have produced written material that is circulated by both in hardcopy and electronically.

In the different regions where the association has subchapters, in addition to people in the community interested in helping people with epilepsy and their families, we have incorporated a neurology medical resident in adult neurology, paediatric neurology or clinical neurophysiology who plays an important role in diagnosis, treatment and follow up, and also works on the social aspects of epilepsy.

As part of the accomplishments of our IBE and ILAE chapters, Dr Henry Stokes was awarded the highest award Guatemala can give through its National Congress or General Assembly – the knight or caballero del Honorable Congreso de Guatemala. Dr Henry Stokes was also presented, by the President of the Republic of Guatemala, with an Ambassador of Peace for Guatemala and the World award.

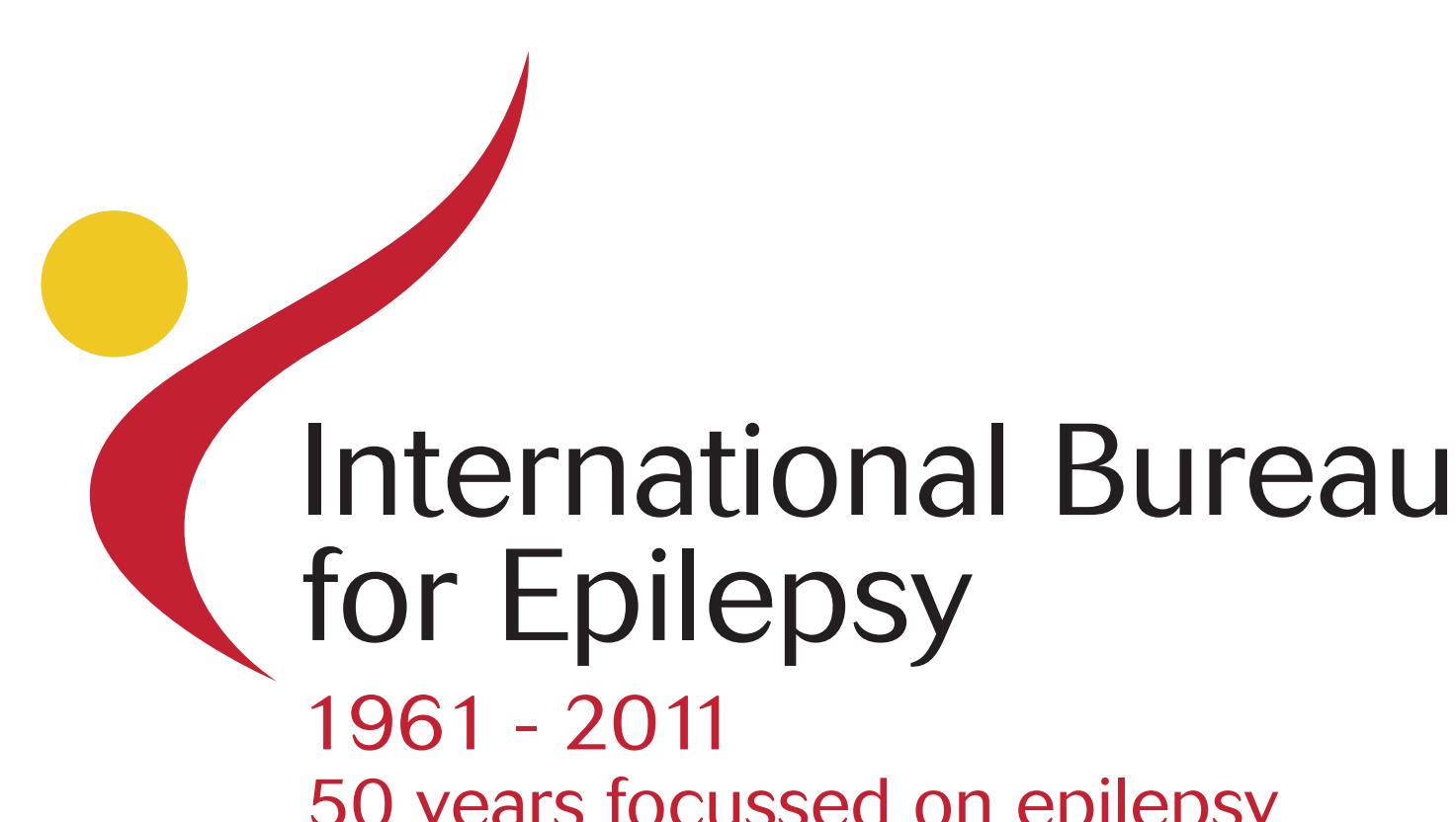
Guatemala is a country with a diversity of ethnic groups, each one with its own language, and this creates difficulties in communication. The official language is Spanish but less than 50% of the population reads and speaks Spanish. So in order to reach most of the population of Guatemala Dr Henry B Stokes, President of Guatemala IBE, created audio information in CD format translated them into most of the regional languages. The project was provided with funding under the IBE 'Promising Strategies Program'.

As part of the new accomplishments of our IBE Chapter we are planning a special strategic alliance with the Guatemala Red Cross and in remote areas of the republic both entities are working together for the benefit of people living in remote areas of Guatemala.



CONTACT DETAILS

Dr Henry Stokes, IBE Guatemala Chapter, 6a Calle 2-48, Zona 1, Guatemala City, Guatemala.
T: +50 222 382 107
Email henry-stokes@neurologiaparatodos.com



International Bureau for Epilepsy

Promoting and supporting the work of 122 member associations in 92 countries around the world

ASOCIACIÓN DE LUCHA CONTRA LA EPILEPSIA, ARGENTINA



This Association works tirelessly since 1961 to bring epilepsy out of the shadows and light the way for those suffering from this disease, informing the community and offering medical and psychological treatment, to improve their quality of life.

MISSION

To protect the person with epilepsy and their families and end the myth that epilepsy is a shameful disease.

Patients and families receive care and education necessary to accept and understand this condition. To this end, we have also organized since early 1986, self-help groups consisting of patients with epilepsy and / or relative. These groups are run by medical professionals and psychologists of this field.

Gradually we have incorporated service and attention.

We carry out our work with recognized integrity and it is difficult to translate into so few words, the vocation and the love that makes this work.

HISTORY

ALCE stands for ASOCIACIÓN DE LUCHA CONTRA LA EPILEPSIA and was founded on October 10th 1961.

We added gradually the necessary services and expanded dissemination (in schools in the Capital and the Interior).

- Courses were organized for teachers and the general public
- We tried to approach patients and relatives, who found no remedy for the condition or the desperation derived from it
- Gained experience through more than 3,500 cases, many of them used the services of our Bank of Medicinal Products
- Finally, on August 3rd, 1973 the Institute of Epilepsy Tucumán was inaugurated and began care in a house donated by the Municipality.

Since then we have seen more than 6,000 cases, with 90% improvement, which includes patients discharged for overall improvement.

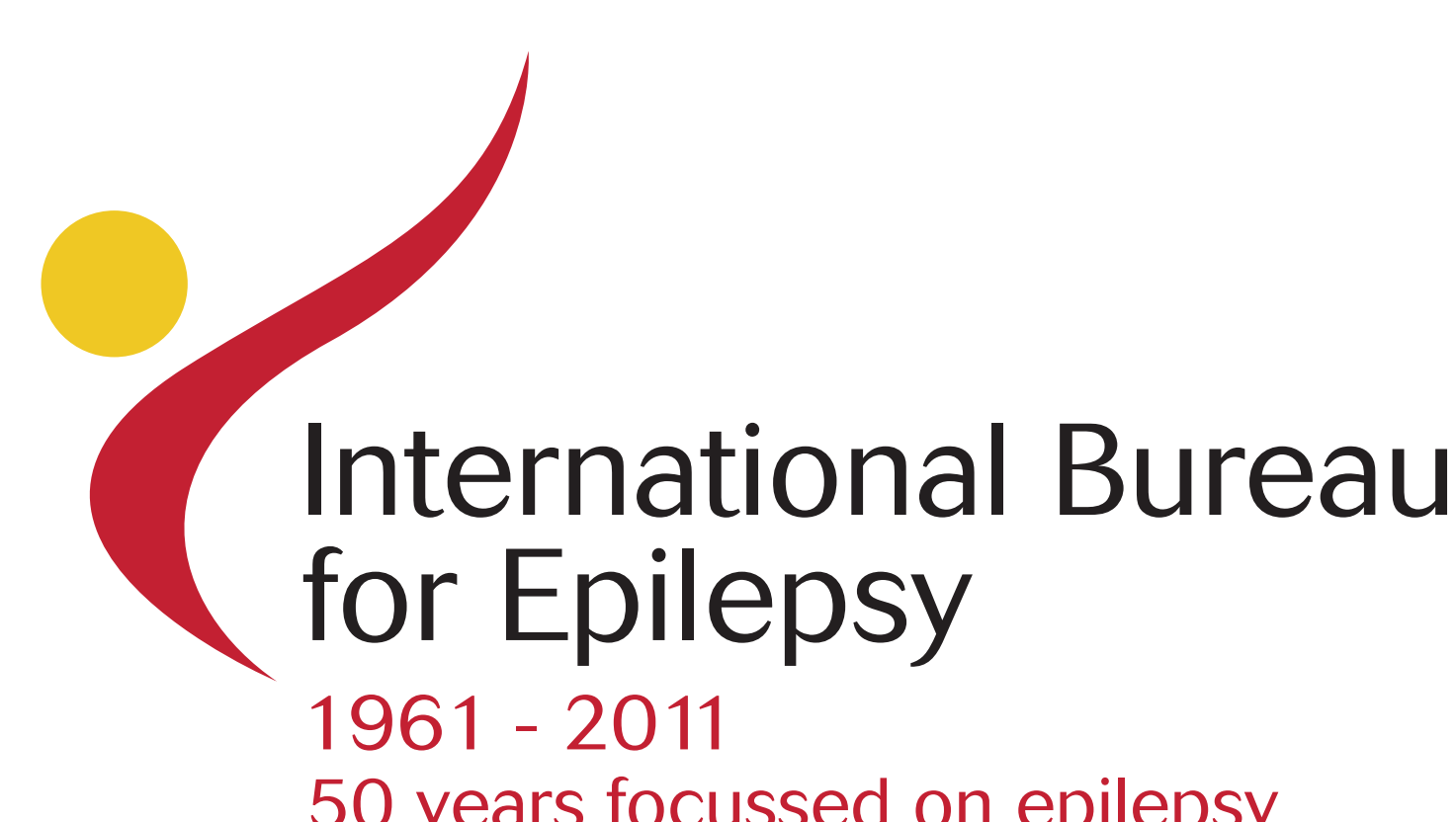
ALCE carried out 5 International Conferences and 1 Symposium to provide all professionals in the country with information on technical advances and treatment implemented in the world. The last Congress was held in the month of May 2001, obtaining positive results.

After the Congress in May 2001, there were intensive courses for physicians. It should be noted that the institution suffered all the vicissitudes that happened in Argentina which affected the association economically and therefore reduced the expansion of the activities.

In 2006 to mark the 45th anniversary, ALCE decided to "relaunch" in order to progress with the activities that had been carried out throughout its history, repeating the broadcast by various media.

CONTACTO:

Asociación de Lucha contra la Epilepsia,
Tucumán 3261,
1189, Buenos Aires, Argentina.
T/F: +54 114 862 0440
asoalce@aol.com



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

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FUNDEPI – ARGENTINA



TYPE OF IBE MEMBER:

Associate Member

DATE THE ORGANIZATION WAS CREATED:

1993

TYPE OF ORGANIZATION:

Individual & organizational membership

RANGE OF OPERATION:

National

THEIR MEMBERS ARE:

people with epilepsy, families of people with epilepsy and medical professionals.

GOALS

- The better access to antiepileptic drugs for people with epilepsy
- The better access to surgery for people with epilepsy
- Enhance the quality of life for people affected by epilepsy
- The needs of people with epilepsy, including awareness about epilepsy education, diagnosis, treatment, care, service and prevention.
- Campaign for more specialist doctors in epilepsy.
- Campaign for more medical research into epilepsy.
- Campaign for the need of specialist medical centres for epilepsy in our country.

MISSION

We worked very hard to create a programme for a special epilepsy week every year, during which we promote awareness of epilepsy and the improvement of the quality of life for people with epilepsy, taking into account the psychological & social impact of epilepsy.

We advocate for medical professionals who generally have a better knowledge of treating people with epilepsy.

We encourage governments of health to address the needs of people with epilepsy, including awareness, education, diagnosis, treatment, care, service and prevention.

We support government laws of epilepsy regarding drugs for the patients and discrimination for people with epilepsy.

EPIDEMIOLOGY

The prevalence lifetime of Epilepsy in Argentina was 6,2/1000 ; and active epilepsy was 3,8/1000 , (4.0 for female and 3.5 for males)

(Neuro epidemiology 2007;28:8-15; Prevalence and clinical features of Epilepsy in argentine.)

In our center data epidemiology about syndromes are: partial syndromes: 56%, generalised syndromes: 31%, partial or generalised syndrome: 7.4% and special syndromes: 5.2%.

We analyze the social and economical aspects in 3217 epileptic patients followed in our Epilepsy Center. We have collected data about various aspects of working activities, especially with regard to gender and educational level.

The ability to hold down a suitable job is a pivotal step in the rehabilitation of the persons with epilepsy. The rate of unemployment in persons with epilepsy is however around three times higher than in the general population. With regard to Education, we couldn't find significant differences in the rate comparatively to other people.

However, impressive as the scientific and therapeutic progress may be, its fullest effect cannot be achieved without tackling the complex problems of the social and economical aspects of epilepsy, which are far from being solved.

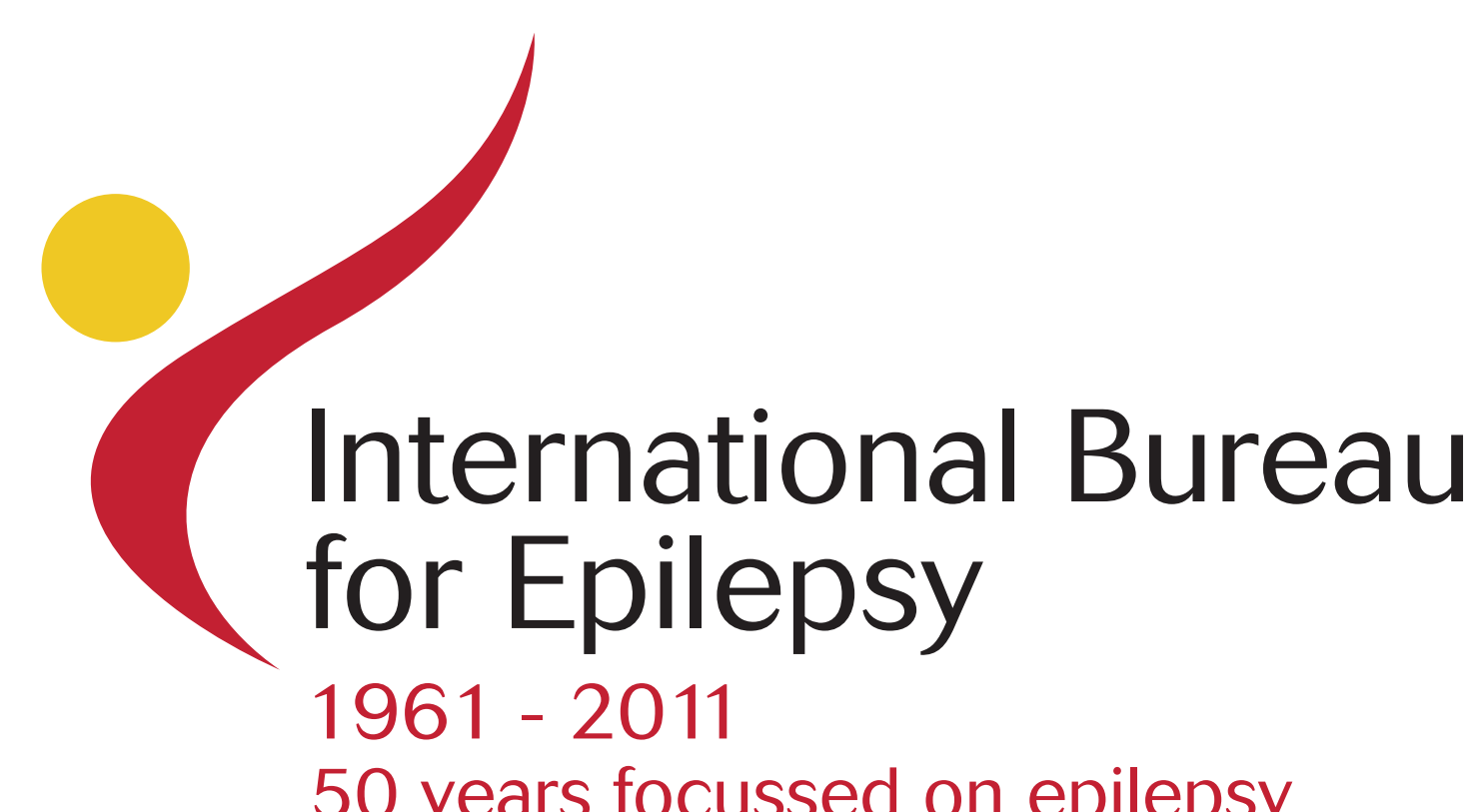
Agreement between FUNDEPI and INADI (National Institute discrimination against xenophobia and racism)

Recommendations Driving Laws to National Authorities



CONTACTO:

FUNDEPI,
Rocamora 4122,
Ciudad de Buenos Aires (148),
Argentina.
T: +54 114 127 0233
skochen@mail.retina.ar
Contact: Dr Silvia Kochen



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

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BURÓ DE EPILEPSIA DE CUBA



The Epilepsy Bureau of Cuba was founded in 1987 and immediately affiliated to IBE. Since then it has maintained Full Membership status. The organisation has nationwide presence which gathers together people with epilepsy their families and health professionals interest in the condition. The Epilepsy Bureau of Cuba organises educational activities, promotional campaigns, information events and special publications. Jointly with the Cuban League Against Epilepsy we form the epilepsy section of the Neurosciences Society of Cuba.

Among the activities which have taken place in recent year, especially significant place in participation in the promotion in Cuba of the Global Campaign Against Epilepsy 'Out of the Shadow'.

Monthly meetings are organised by the Epilepsy Bureau of Cuba in which people with epilepsy, their families, professionals and other interested parties participate and discuss issues of interest and social issues that affect people with epilepsy.

A final word about the book the Psychology of Epilepsy. The contents of the book are used to promote participation and debate. Epilepsy is beginning to emerge from the shadows and, by just reading this text, you have contributed to this. It is clear, now you must help to multiply this information in your community.

What we all must know is that to suffer from this condition alone is different to having other chronic non-transmittable illnesses, because in general the prognosis is more favourable. There is nothing enigmatic in being deeply affected.

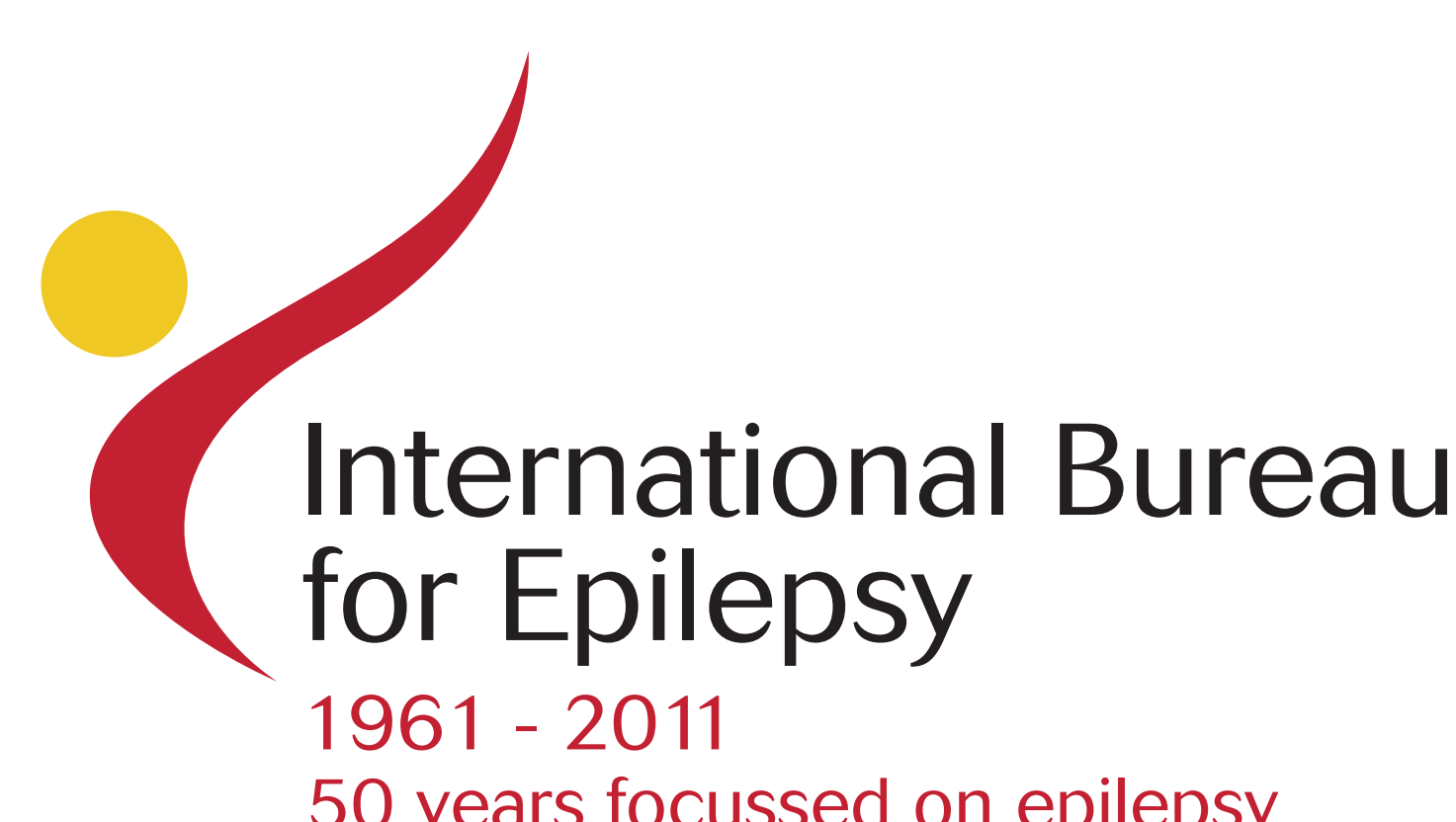
Ensure that every child can play freely with only the necessary precautions that his or her condition demands, so that every schoolchild can discover his intellect without artificial limitations and that every adolescent can construct his or her future and discover love without fear or feelings of groundless inferiority. Defend also the right of every adult to realise his professional dream and to enjoy parenthood without absurd questioning, of every older person to enjoy the satisfaction of his family which will shape and inform the next generations.

Finally, defend life because it is only by doing so that epilepsy will escape to the light.



CONTACTO:

Justo Reinaldo Fabelo Roche, PhD
Coordinador
Capitulo Cubano de la IBE,
Hospital Psiquiatrico de la Habana,
Ave Independencia
No 26520, Reparto Mazorra
Boyeras, Ciudad Habana,
CP 19220, Cuba.
fabelo@infomed.sld.cu



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

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PERUVIAN ASSOCIATION OF EPILEPSY



PERU

Population estimate: 29.11 million. Approximately 30% of the population lives in the Lima/Callao urban area.

Ethnic groups: Indigenous (45%); mixed background ("mestizo") (37%); European (15%); African, Japanese, Chinese, and other (3%).

Languages: Spanish is the principal language. Quechua, Aymara and other indigenous languages also have official status.

Education: Literacy--96% in urban areas, 80% in rural areas.

Health: Infant mortality rate (2006)--29.96 per 1,000.

Life expectancy: (2007)--68.33 years male; 72.04 years female.

Unemployment in Lima (2009): 8.4%; underemployment (2009): 44.66%.

Peru is the fifth most populous country in Latin America (after Brazil, Mexico, Colombia, and Argentina). Twenty-one cities have a population of 100,000 or more. Rural migration increased the urban population from 35.4% of the total population in 1940 to an estimated 74.6% as of 2005.

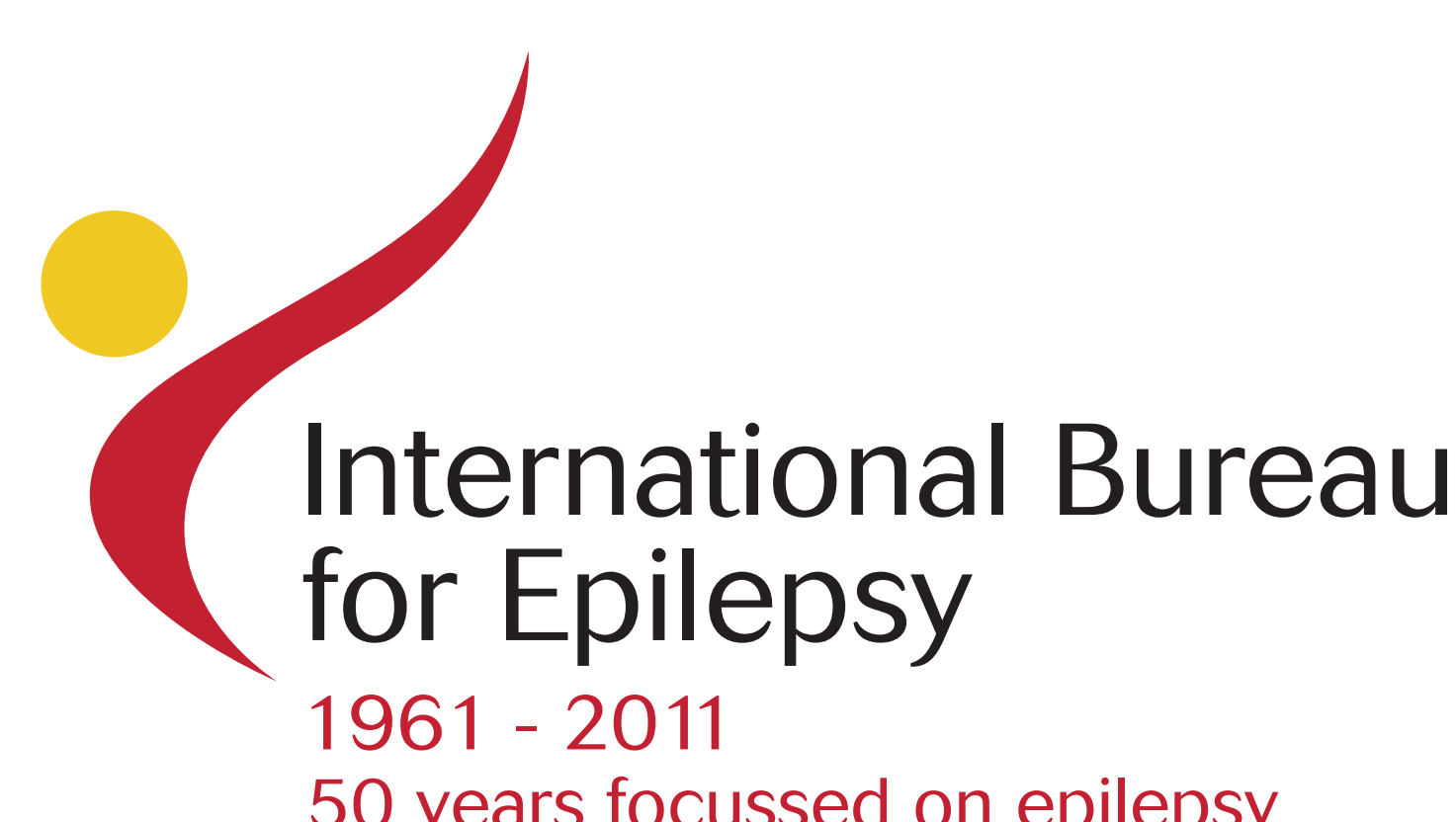
Most Peruvians are either Spanish-speaking mestizos - a term that usually refers to a mixture of indigenous and European/Caucasian - or Amerindians, largely Quechua-speaking indigenous people. Peruvians of European descent make up about 15% of the population. There also are small numbers of persons of African, Japanese, and Chinese ancestry.

Peruvians of Amerindian descent who have adopted aspects of Hispanic culture also are considered mestizo. With economic development, access to education, intermarriage, and large-scale migration from rural to urban areas, a more homogeneous national culture is developing, mainly along the relatively more prosperous coast. Peru's distinct geographical regions are mirrored in a socioeconomic divide between the coast's mestizo-Hispanic culture and the more diverse, traditional Andean cultures of the mountains and highlands and Amazon indigenous communities east of the Andes.



CONTACTO:

Peruvian Association of Epilepsy,
Los Nandues 160 401,
Surquilo, Lima, Peru.
T: +51 144 20961
E: jjjperu@hotmail.com
Contact: Dr Julio Espinoza.



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

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AUCLE

"Asociación Uruguaya Contra la Epilepsia"



Uruguay has a population of 3.300.000 inhabitants and the incidence of epilepsy is 1%, which is approximately 30.000 people with epilepsy.

AUCLE "Asociación Uruguaya Contra la Epilepsia", is a national organization that resides mainly in Montevideo, the capital of the country.

It was founded in 2005 in Montevideo and in August of the same year in Paris, it was accepted by the General Assembly as a Full IBE Member.

The principal aims of AUCLE are to improve the quality of life of all the people with epilepsy in personal, family, work and social aspects, reducing the stigma and increasing the knowledge about the illness.

Actually AUCLE has 34 active members, who are people with epilepsy, their relatives or friends, teachers, social workers, psychologists and medical doctors.

It works closely with the ILAE Uruguayan chapter, LUCE, to develop self-help groups for people with epilepsy and their families.

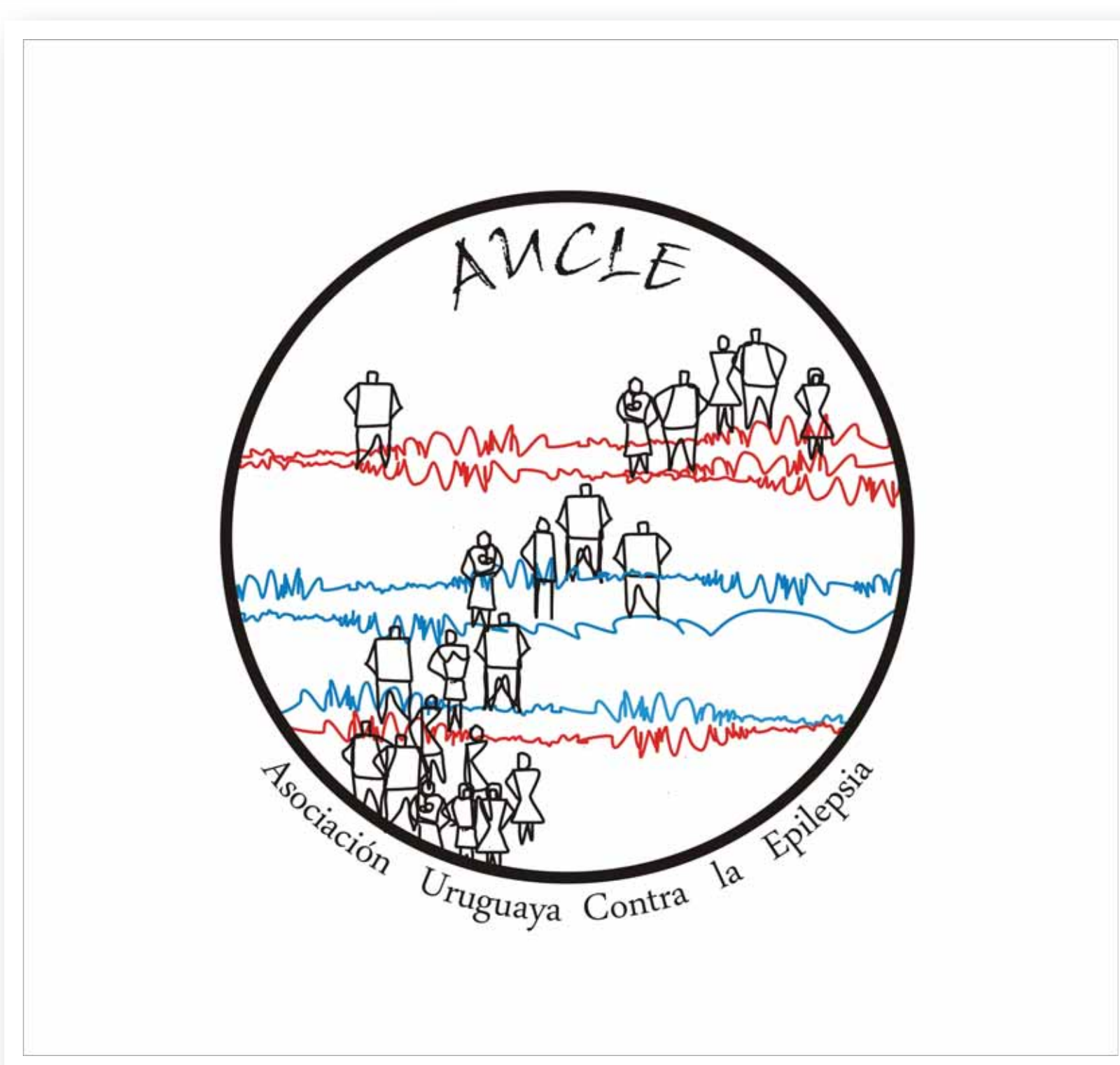
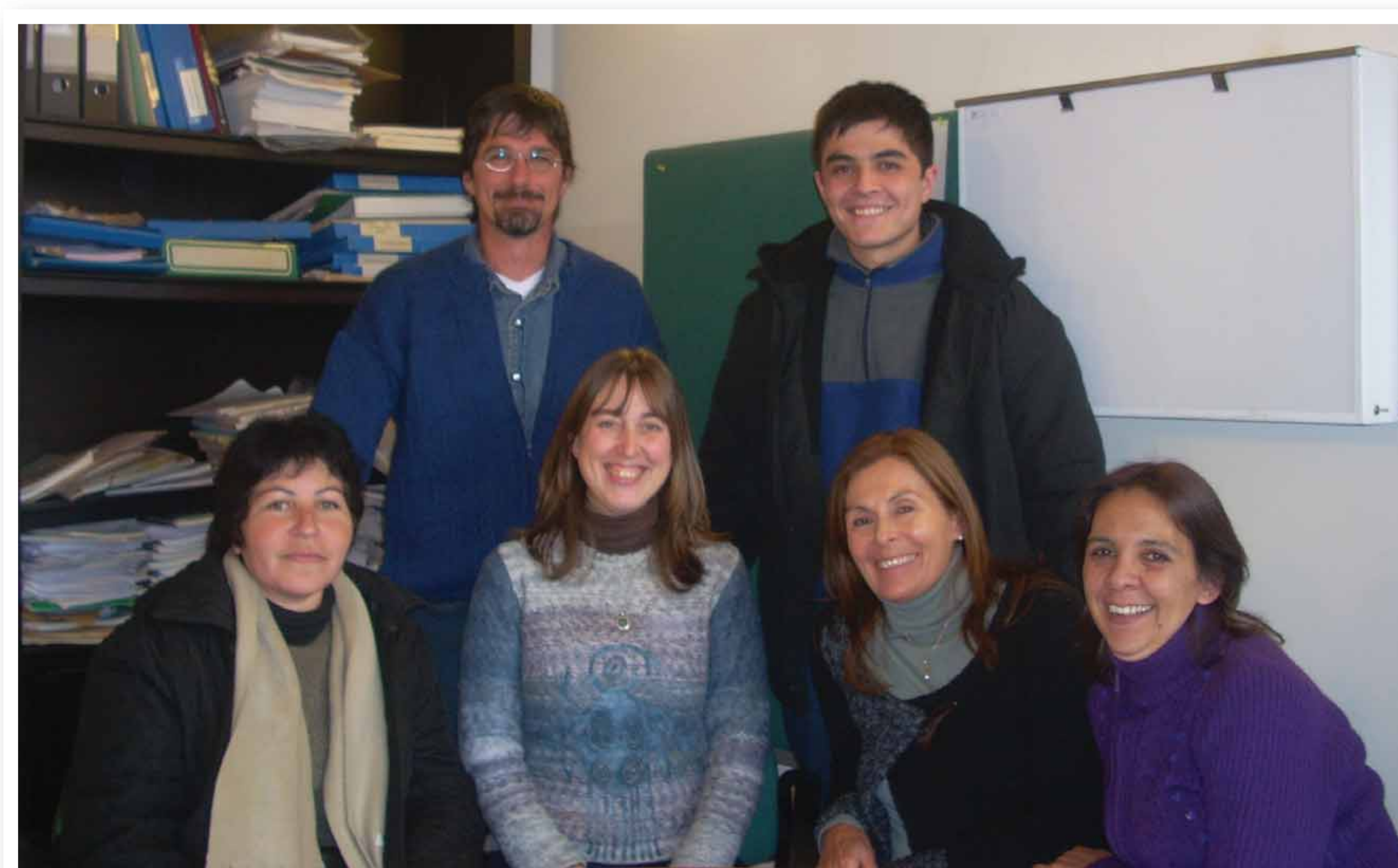
AUCLE is planning to have a regular course with basic information about epilepsy for teachers of primary and secondary level and the School of Policies officers, who are important providers of information in our society

A campaign called "The house of people with epilepsy" is on course in order to obtain funding to have a place with better conditions than the place we actually have. It will allow us to bring training courses in differences areas that increase educational and labour opportunities for people with epilepsy.

A group of postsurgical patients are working with a team chair by Dr. Patricia Braga to improve and adapt to our culture the questionnaires of quality of life. They are building their own Facebook to exchange experience.

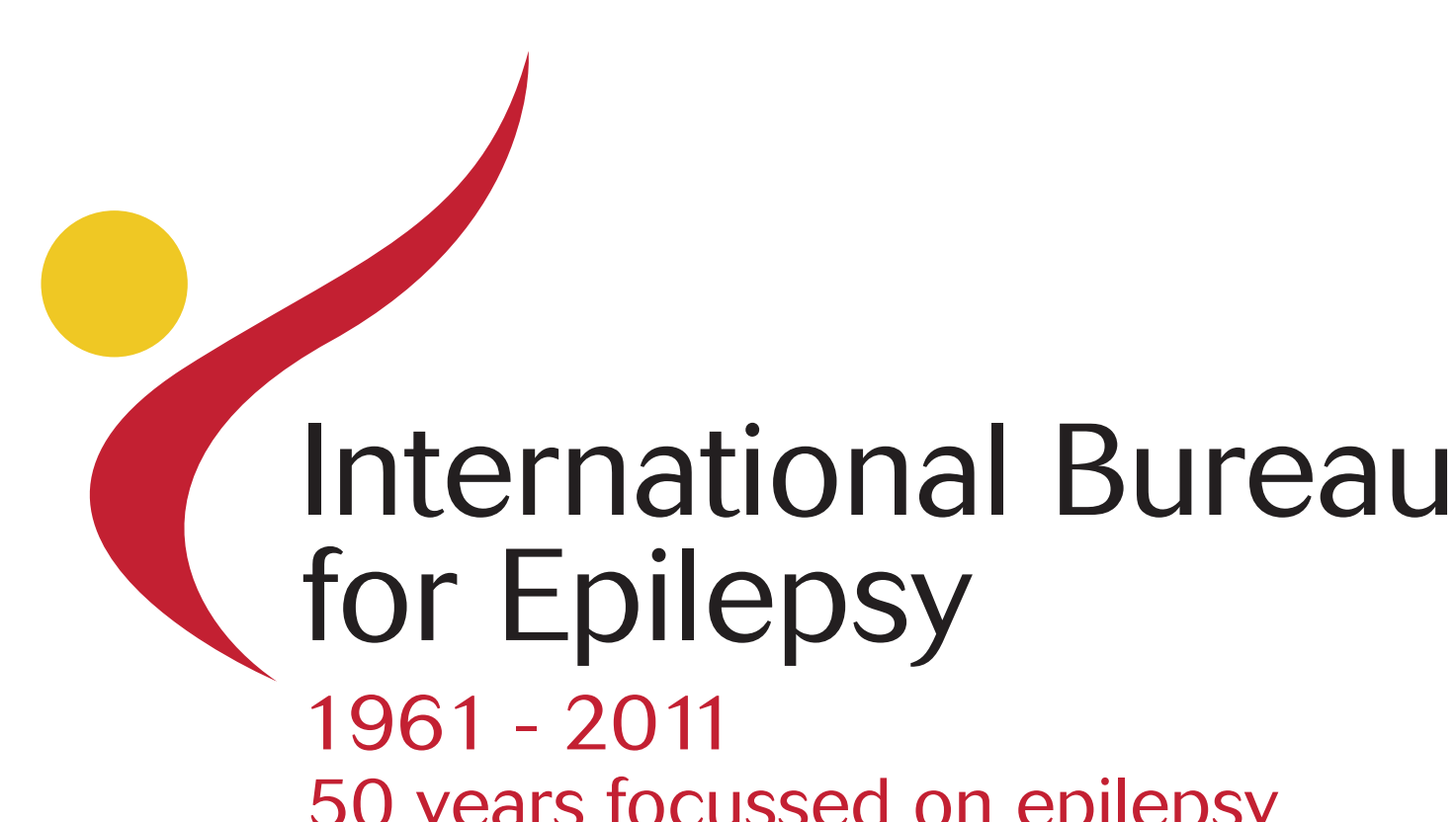
The challenges for the short term future are:

- Increase the number of active members
- Provide greater support and more benefits to the people with epilepsy
- Expand the vision of the society in general about our organization.



CONTACTO:

Dr. Alicia Bogacz
Address: 8 de Octubre 2610
11600 Montevideo Uruguay
E-mail: abogacz@hotmail.com / Aucleuuguay@gmail.com



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

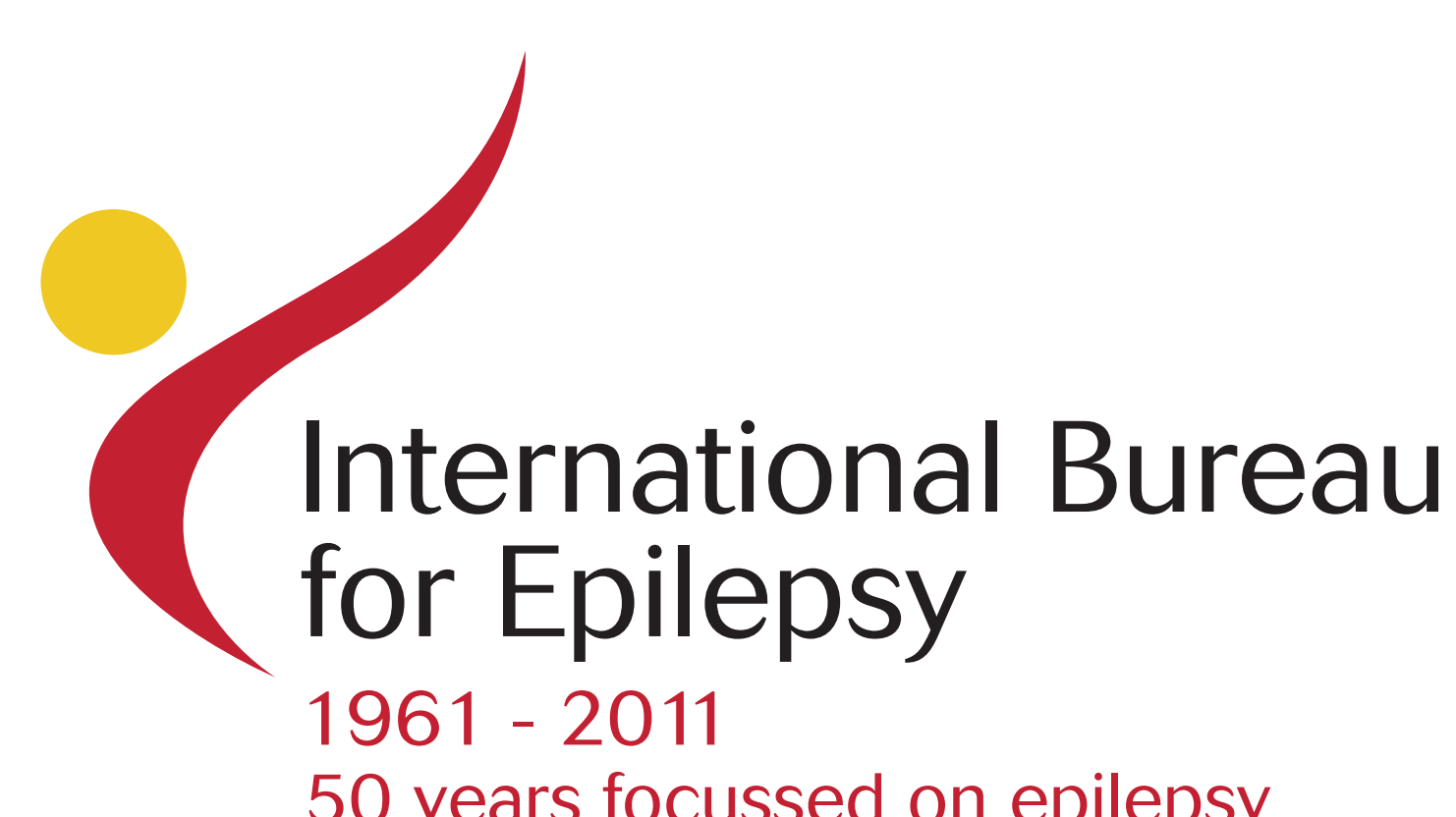
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MEMBERS IN THE LATIN AMERICA REGION

Argentina:	Asociación de Lucha Contra la Epilepsia FUNDEPI (Associate Member)
Brazil:	Associação Brasileira de Epilepsia (ABE)
Chile:	ANLICHE
Colombia:	FIRE
Cuba:	Capitulo Cubano de la IBE
Dominican:	Republic SODOUE
Ecuador:	Centro Nacional de Epilepsia
Guatemala:	IBE Guatemalan Chapter
Mexico:	Group "Acceptation" of Epileptics
Peru:	Peruvian Association of Epilepsy
Uruguay:	Asociación Uruguay Contra la Epilepsia (AUCLE)
Venezuela:	Venezuelan National Bureau



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