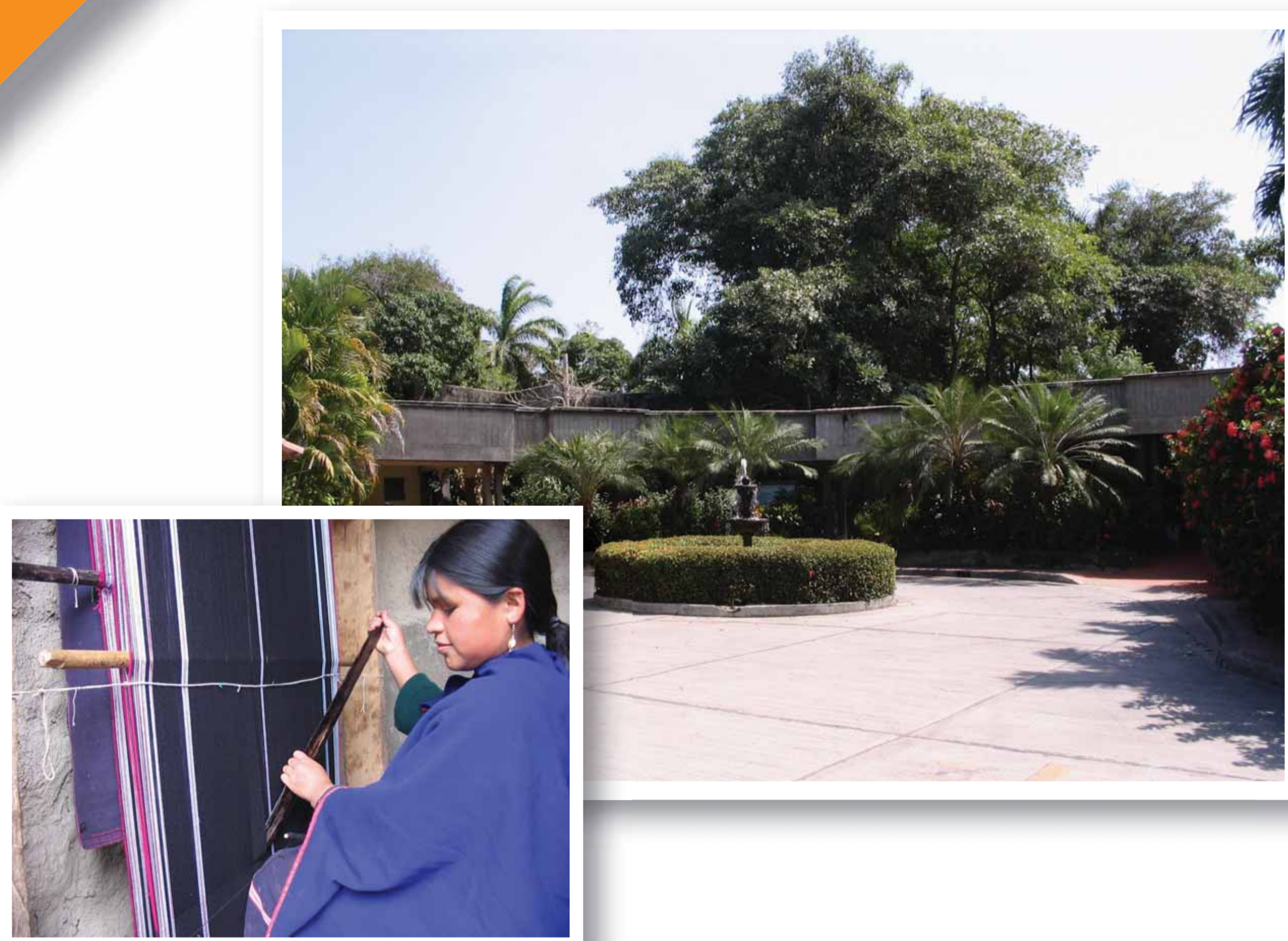


International Bureau for Epilepsy

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

FUNDACIÓN INSTITUTO DE REHABILITACIÓN PARA PERSONAS CON EPILEPSIA – FIRE



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

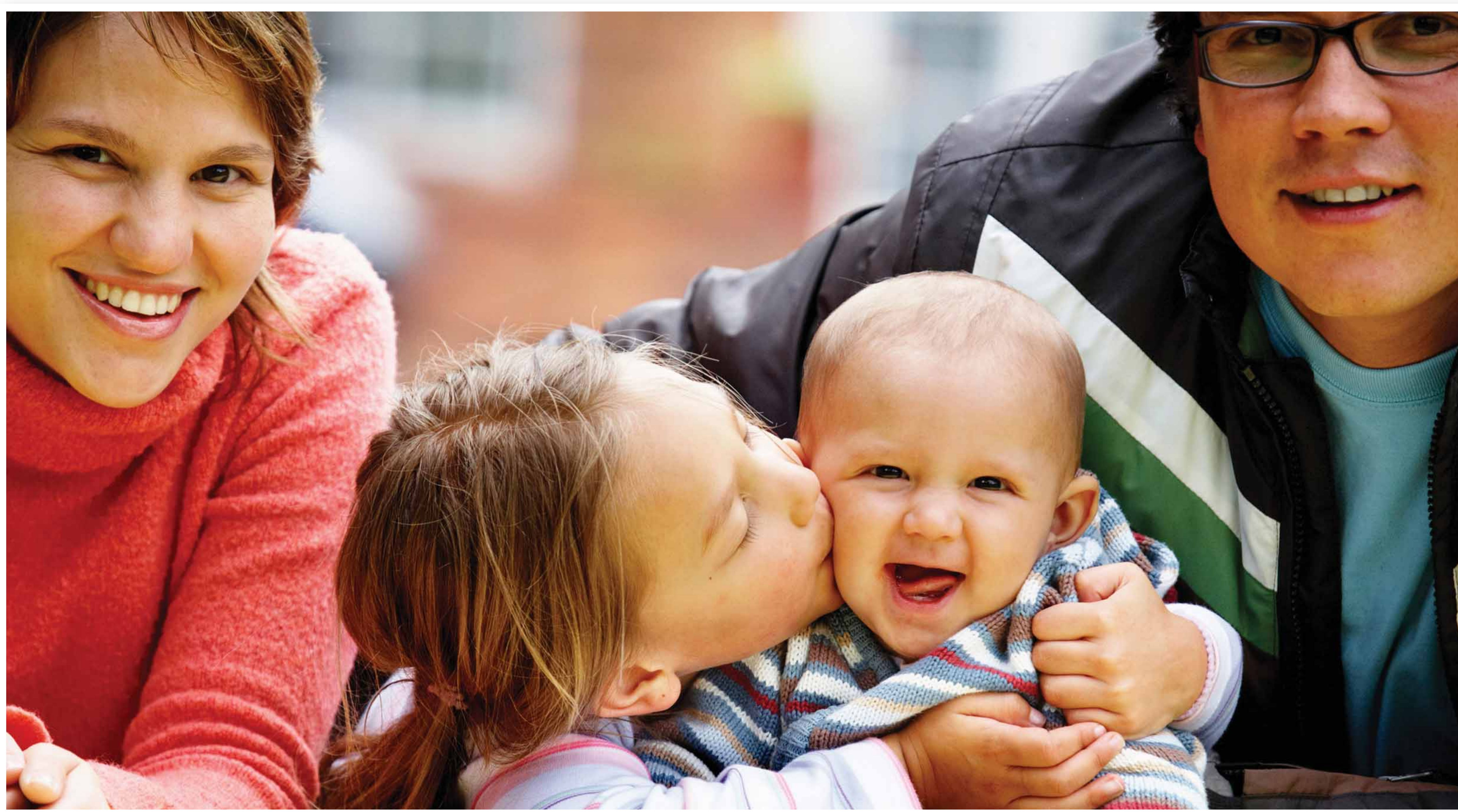
Rehabilitación y habilitación de personas con epilepsia.

- 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

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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.

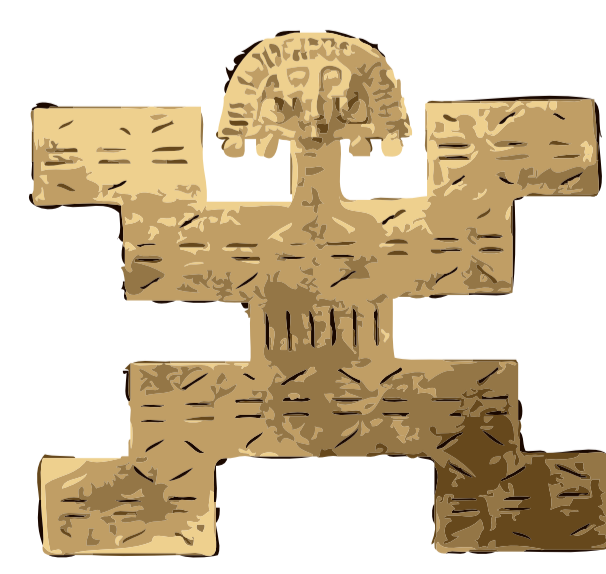
ANLICHE está formado por agrupaciones, clubes, organizaciones, e instituciones de todo Chile desde Arica a Punta Arenas. El directorio está constituido por doce miembros: seis por derecho propio (presidente, vicepresidente y presidenta del voluntariado de la Liga Chilena contra la Epilepsia; presidente 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

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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

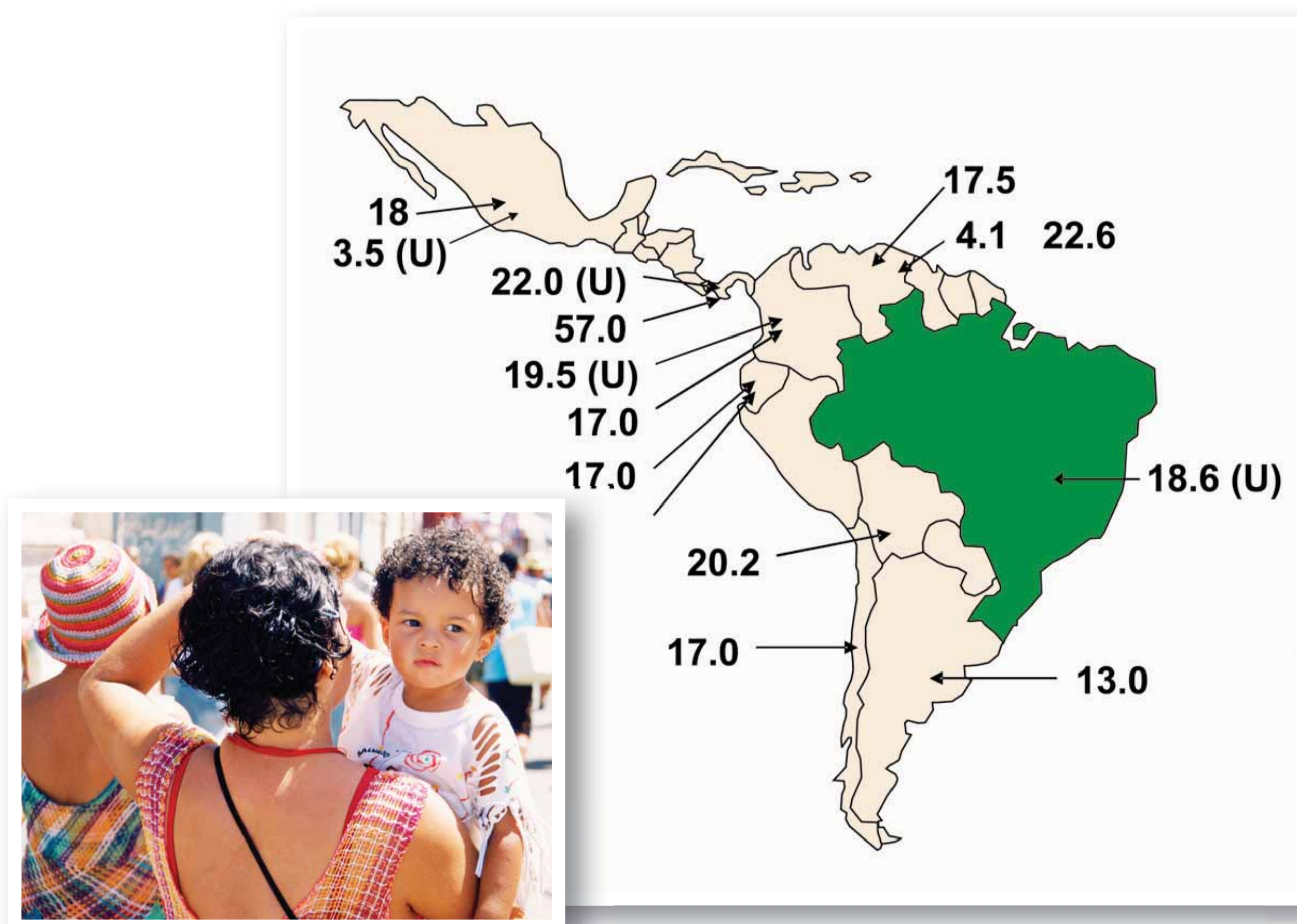
To improve the conditions of treatment of people with epilepsy, offering support and orientation to them and their families.

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 (Fig 1: Map). 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

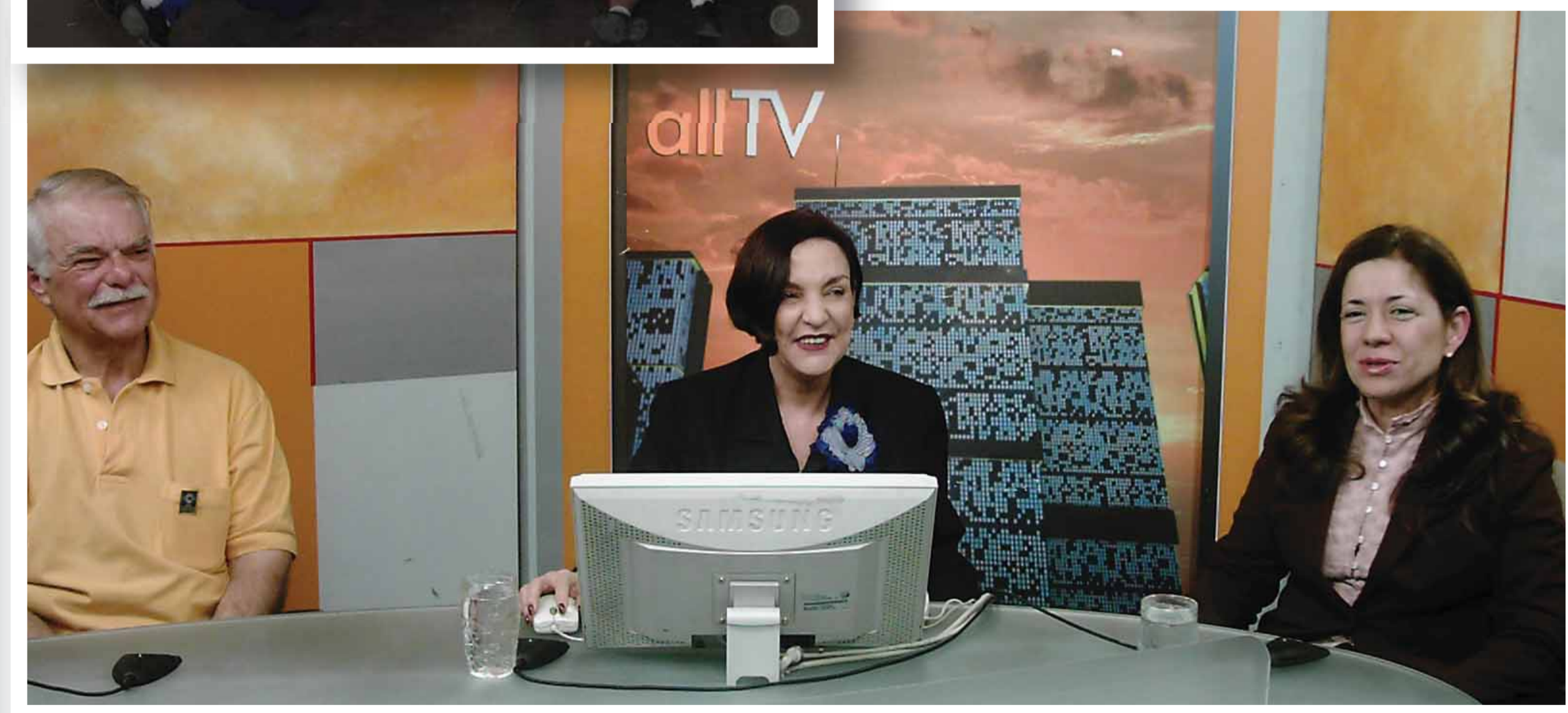
ABE holds a monthly meeting, where people with epilepsy and their families are invited to discuss various topics and to share their experiences with other people. Every year a special meeting is organized during the celebrations of the Latin America Epilepsy Day, in September (Fig 2).

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: ESI-55, QOLIE-31 and QOLIE-89.



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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, and the Guatemala Chapter of ILAE, as well as with the University of San Carlos de Guatemala based program of residency training in adult clinical neurology, paediatric clinical neurology and clinical neurophysiology.

Each of the 21 sub-chapters of the Guatemala Chapter of IBE 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.

From the beginning we have always worked closely with ILAE Guatemala Chapter.

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 and he plays an important role in diagnosis, treatment and follow up, and also works on the social aspects of epilepsy.

This physician travels to the communities he serves once every 10 days, and we wish to inform you that he is supported by the University of San Carlos, the main State University of Guatemala, the 3rd university established in America in colonial days.

Each sub-chapter of IBE and ILAE has a board of directors with an executive committee; the president is elected and most of the time this is a lay member.

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'.

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.

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.

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.

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.

At the present time we have advanced in the Guatemala Society working the World known campaign of bridging the Epilepsy out of the Shadows. This team work has produced great achievements in the social aspects of Epilepsy.

In the last two years we have developed a joint initiative between the IBE and ILAE Guatemala Chapters and the San Carlos University, represented by the Neurology Residency training program of the Hospital General Guatemala and the Epilepsy Surgery program has been developed and we are happy about the results and general outcome.

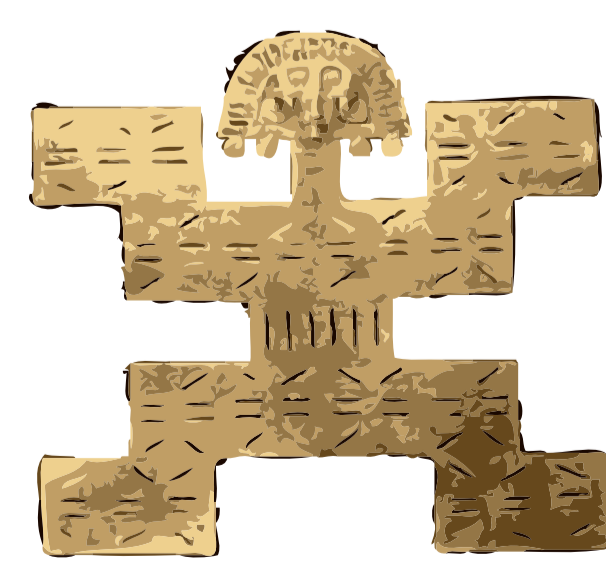


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