

PROMISING STRATEGIES 2012

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- Establishes a strategy that makes a difference in improving accessibility to accurate, timely, necessary and culturally appropriate information or services
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- Is a strategy that can be used to generate policies and initiatives to address systems issues and common problems impacting people with epilepsy and their families
- Is likely to be implemented in collaboration with other strategic partners and has a mechanism to evaluate results and get feedback to continue to improve the program.

More than fifty applications were received following the latest call for letters of intent. The applications were reviewed by the relevant Regional Executive Committee, with their recommendations presented to the International Executive Committee. A total of 20 new projects, in 19 countries, were then selected by the International Executive Committee for funding this year.

In this issue you can read about 11 of the latest projects. The next issue will include information on the remaining nine projects.

Information on all 70 projects, funded to date, can be found on the IBE website, where you can also find further information on funding criteria. The next call, for projects to be considered for funding in 2013, will be circulated to IBE member association in September 2012.

The Other Side of Epilepsy

BULGARIA



THE OTHER SIDE OF EPILEPSY campaign of APDE will introduce an innovative way to focus on target groups in order to break stereotypes and epilepsy stigma. Lavender (the plant and its colour) are symbols of the campaign. The initiative will involve representatives from various community groups who are affected by epilepsy:

TARGET GROUPS:

- ↻ Parents of children with epilepsy and parents of healthy children;
- ↻ Teachers and students;
- ↻ Journalists from national and regional media.

The objectives of the campaign are: **i)** to raise awareness about epilepsy by generating positive media reports - provided in an interesting and engaging way; **ii)** to inform the various target groups on how to recognize and how to cope with epilepsy - providing information about treatment, symptoms and control of epilepsy; **iii)** to train health journalists from national media; **iv)** to stimulate dialogue with state institutions, in order to encourage an active state policy for epilepsy; **v)** to maintain constant media interest in the campaign; and **vi)** to improve public awareness of epilepsy, eliminate stigma and generate positive attitudes in society towards those suffering from epilepsy.

CAMPAIGN ACTIVITIES:

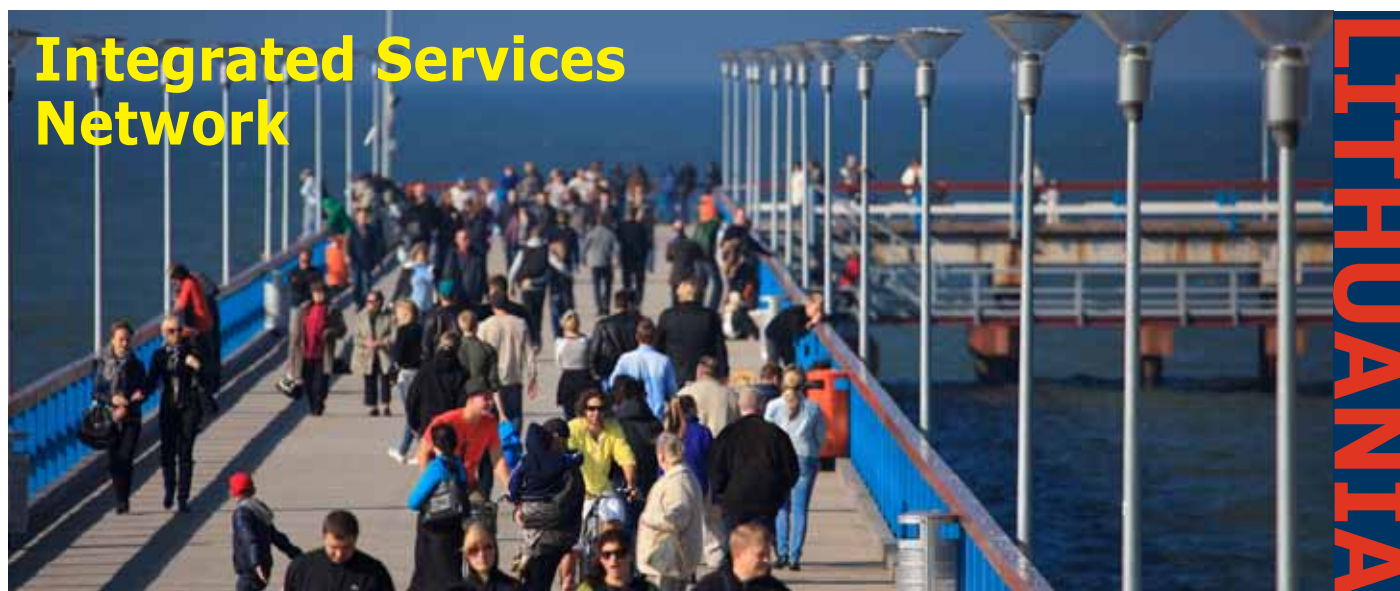
Among the planned activities are distribution of printed information on epilepsy to target groups; creation of a filmed ad campaign; organisation of an art exhibition, press conferences; and the symbolic planting of lavender shrubs.

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The Georgian Society of Young Epileptologists (GSYE) is in permanent search of more efficient ways to improve public understanding of epilepsy and tolerance. The present idea is three-fold:

1. To organise a full-day event at the city's largest shopping mall, preferably on a public holiday weekend to attract as much attention as possible. The event will include distribution of epilepsy-related information booklets and souvenirs. Snacks will also be served and a puppet-show staged for children. A large monitor will show a short documentary on social stigma of epilepsy. Journalists from national television and radio broadcasters will be invited to report on the event.
2. To make use of a top-rated talk show on the popular television channel, which will focus on epilepsy-related problems, as well as on our past and future projects. The programme will feature, among others, experts invited to the studio, who will take live phone calls from viewers and conduct a live opinion survey - the first ever live epilepsy-related opinion survey on Georgian television.
3. To keep the public constantly informed and interested in epilepsy-related issues and to organize opinion polls through the Internet, especially via social networks.



The aim of this project of LESIA is to develop a network structure of integrated services, aimed at the provision of decentralized services, increased access to service provision, engagement of non-governmental organizations as well as provision of integrated services tailored to the individual needs of people with epilepsy.

The expected outcome is a sustainable provision of services on a regional level and maximum on-site provision of services for people with epilepsy. As Lithuania does not have the financial capability to establish a National Centre for Epilepsy, this would

be an economical model, not only for the target group of people with epilepsy, but also, for the state. The network would facilitate access of the target group to comprehensive service provision such as treatment, counselling on various epilepsy related issues, social rehabilitation and professional rehabilitation. The model of integrated services network would cover all levels of treatment and health care.

The project outcomes would serve as the basis for the development of a National Epilepsy Programme.

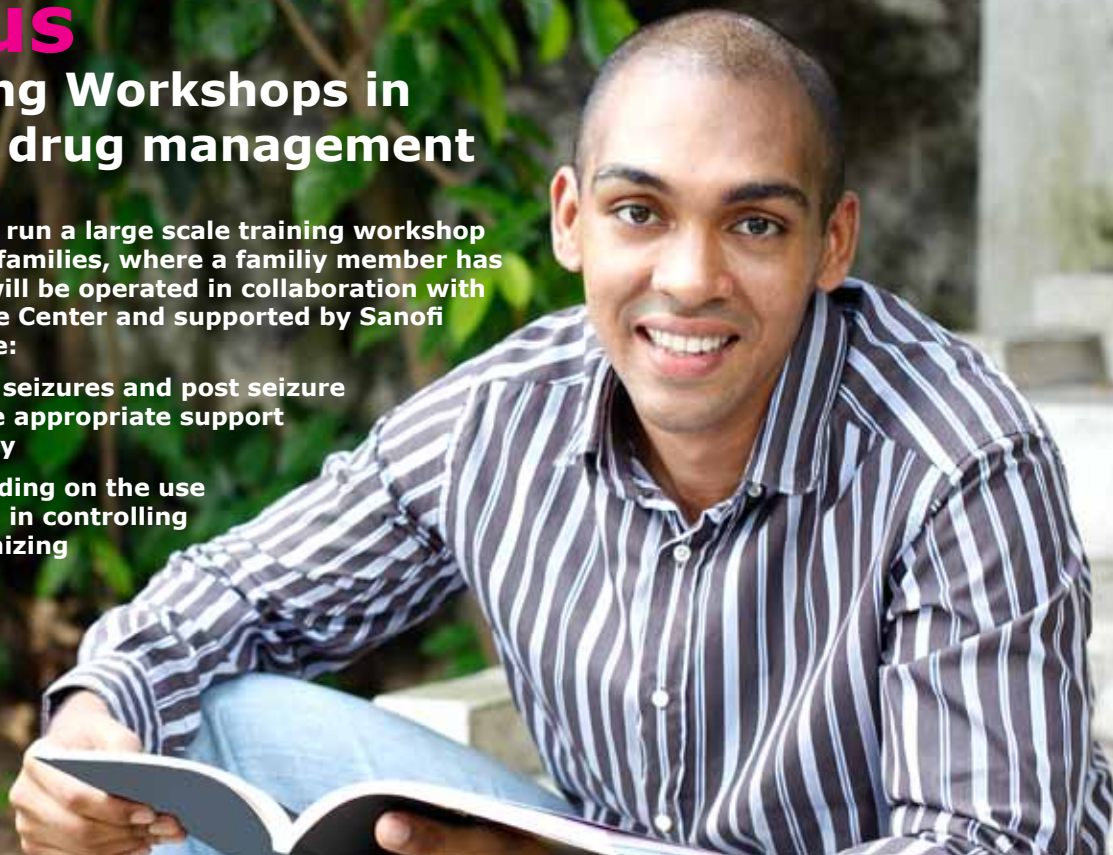
Argentina Bangladesh Brazil Bulgaria Cameroon Chile China
Colombia Czech Republic Ecuador The Gambia Georgia
Guatemala Haiti India Indonesia Kenya Laos Lebanon

Mauritius

Family Training Workshops in anti-epileptic drug management

Edycs Epilepsy Group will run a large scale training workshop for 100 newly registered families, where a family member has epilepsy. The workshop will be operated in collaboration with the Epilepsy Health Service Center and supported by Sanofi Aventis. Its objectives are:

- to help in recognizing seizures and post seizure activity and to provide appropriate support to people with epilepsy
- to promote understanding on the use of anti-epileptic drugs in controlling seizures, while recognizing potential side effects
- to build confidence in parents responsible for administering emergency epilepsy medication.



Kick Start

Career Development Training for People with Epilepsy

Suitable employment is a very important step towards the independence of people with epilepsy and is also one of their biggest challenges. Given Namibia's unemployment figure of 51%, and the current difficult worldwide economic situation, finding employment has become even more difficult.

After conducting an Epilepsy Schools Awareness program during 2011, it has become clear that the average school leaving student is not fully able to make a career choice; does not have a sufficient grasp of the career possibilities available; lacks basic skills required; and does not know how to present themselves to potential employers.

Epilepsy Namibia has, therefore, developed a supportive program for school leavers and the unemployed with epilepsy. This program consists of Career Development Seminars, and Small Business and Information Technology Training.

We believe that people with epilepsy stand a better chance to find suitable jobs if they can make informed decisions, present themselves properly and have the skills required.



NAMIBIA

Lithuania Mauritius Mongolia Namibia Nepal The Philippines
Romania Sierra Leone South Africa Swaziland Tanzania Tibet
Togo Uganda Western Pacific Islands Zambia Zimbabwe

ZAMBIA

GOING BANANAS!

As an income generating project, the Epilepsy Association of Zambia plans to develop a banana plantation. One thousand banana trees will be planted and are expected to start producing fruit within six months of planting.

The association expects that the plantation will produce sufficient quantities of fruit to meet local supply needs. The funds raised, through the sale of the banana crop to the local public, will be used to support members of the association.

The trees will be grown at the Promising Strategy site where other activities, supported by previous rounds of Promising Strategies funding, such as vegetable growing, jam making and poultry rearing, are already taking place.



School Epilepsy Clubs - *informing Uganda's young people*

The Epilepsy Support Association of Uganda (USAU) is setting up School Epilepsy Clubs in 20 secondary schools around Kampala. It is estimated that a target group of 10,000 young people will be reached. The aim is to sensitize teachers and school managers on the needs of students who have epilepsy and to create a conducive and favourable environment for students with epilepsy, so as to encourage them to perform better in their studies.

The clubs will teach students about epilepsy, using a range of materials and ESAU will follow the HIV/AIDS model and structure

already being used in the schools, so that teachers managing the HIV/AIDS clubs in the schools will already be used to mobilizing students.

The young students with epilepsy, or their siblings, will be brought together for an annual day of special activities. The holiday camp activities will include counselling, information on epilepsy and reproductive health, relationships and sexuality, and careers. Young professionals with epilepsy will be invited to deliver motivational talks to the students at the camp.



UGANDA

Crafting new career opportunities



CODEF is introducing income generating activities - including pig rearing, hairdressing, and tailoring - to support 45 people with epilepsy who live in the north west of Cameroon.

Living on less than a dollar a day, 20 of those to be trained reported being subject to discrimination and

25 also said that they had not attained any level of primary education.

CODEF believes that every person living with epilepsy has the right to be an active citizen in their community and to achieve both social and economic sufficiency. Developing a trade will help them to achieve this goal.



ZIMBABWE - Training in Best Practice

The prevalence of uncontrolled epilepsy is very high in rural areas of Zimbabwe, where 80% of native Zimbabweans reside. This is underpinned by cultural beliefs that reinforce resistance to the medical control of epilepsy. It prevails in backgrounds where knowledge about the management of epilepsy remains scant among health professionals. Unregistered clinicians continue to earn a living from unsuspecting individuals, families and communities that care for persons with epilepsy. The majority of the practitioners is unlicensed and lacks the requisite technical expertise to reduce the strain caused by epilepsy. The health gap presents extra tragedies to the already depressed conditions of people with epilepsy, reducing their self-images, self-esteems and self-opinion.

Against this backdrop, the Epilepsy Support Foundation of Zimbabwe intends to facilitate in regulating and strengthening community-based rehabilitation by providing training in best practices in the management of epilepsy to health professionals and community-based psycho-social practitioners.

This will result in improved access to health care to the affected individuals, families and care givers. Advertently, this will enhance the overall well-being in society of people with epilepsy, facilitating the significant advances required in integrating their quest for belonging and beneficial participation in national development on equal basis with others.

National Learner Awareness Programme for Primary Schools

The National Learner Awareness Programme of Epilepsy South Africa will be piloted by its National Office during 2012. This preliminary countrywide initiative aims to:

- Derive its purpose directly from the UN Convention on the Rights of Persons with Disabilities;
- Link to the Life-Skills programme of the South African curriculum and therefore be endorsed by the South African Department of Education;
- Be adaptive to the needs and capacities of different age groups;
- Take on the form of an inter-active awareness kit that involves the class in simulative activities while learning about epilepsy and inclusive education.

The vision of the organisation is to develop a culture of inclusion of persons with epilepsy at the psycho-social life stage model: age six to eleven, in South Africa, Africa and globally. We believe this intervention will help to develop a generation of epilepsy- and disability-sensitive people who will be able to convey this culture to future generations.



LEBANON: Sweet Success Training in Chocolate Sales and Marketing

In 2010, the Association for the Care of People with Epilepsy in the Lebanon received support from the Promising Strategies Programme to develop a Chocolate Making initiative for young people with epilepsy, called the ECAL project. Now that it is running successfully, the association believes it is time to encourage the people with epilepsy working in the project to become more involved in all aspects of the endeavour from manufacture, through marketing, to the point of sale.

To achieve this, the association is planning to offer an ESP course (Arabic and English for Specific Purposes) to teach those involved all about the work they do, from the terminology that relates to their work, to all the procedures that pertain to production, and the social skills they need in order to sell the produce. Included in the training will be a simulation of face-to-face communication situations with customers.

In the absence of schools for Special Education Needs and the Ministry's support, due to the current economic crisis in Lebanon, and as long as people with epilepsy are forced to leave school once they have seizures, the support of the Promising Strategies Program plays an important role in helping people with epilepsy become more communicative and independent social citizens.



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In the last issue we introduced the projects funded in the African, Eastern Mediterranean and European regions. In this issue we feature the projects in the Latin American, South East Asian and Western Pacific regions. Information on all 70 projects, funded to date, can be found on the IBE website. The next call, for projects to be considered for funding in 2013, will be circulated to IBE member associations later this year.

ALCE Club - ARGENTINA

Young people with epilepsy in Argentina experience significant stigma, which can significantly reduce their self-confidence and, as a result, their quality of life.

The Asociación de Lucha Contra la Epilepsia (ALCE) is developing a social club for young people with epilepsy - the ALCE Club. The aim of the club is to improve the quality of life of persons with epilepsy by providing a range of leisure and learning activities in a social context. Activities will include:

- Film screenings, with follow up discussions;
- DVD and a book libraries, which the young people will help to create themselves;
- Artistic workshops to encourage an interest in music and art;
- A toy library for the younger members of the club to enjoy.

The objectives of the ALCE Club, which will take place twice weekly, are:

- To encourage interaction among people with epilepsy attending the Club and to provide a link for their peers and families
- To increase the young people's confidence so that they can discuss the problems they face because of their epilepsy, both with other people with epilepsy and with the public in general.



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Fruit and Vegetable Dehydration Project

People with epilepsy unable to find work, due to poor qualifications or discrimination, will have the chance to undertake training on this project in Curicó City, which will provide them with the skills to work independently, raising family income and, at the same time, improving self-esteem and quality of life. The project will consist of one year's training in dehydration techniques for 10 people with epilepsy. Specific objectives are:

- To develop a fruit and vegetable dehydration workshop with commercial potential to enable the participants to achieve financial independence and to strengthen their personal autonomy.

- To provide the opportunity for the workshop participants to exchange their experience on living with epilepsy. The products sold will, in turn, provide the necessary funds to support further development of the project so that more people can be trained in the future. The students will have training during 3-hour lessons once a week, where a farming technician will teach them the correct techniques in dehydration. Other professionals will also help to complement the training process, including a food-handling technician and a business administrator to assist in marketing plans.



REMOTE REHABILITATION PROGRAM

In Colombia it is common for children with epilepsy and learning difficulties not to attend school. They live in remote rural areas and parents often cannot afford transport to school. As a result, the children grow up without rehabilitation care and become a severe burden on the family and society. The FIRE 5-step education program is trying to improve things for these children.

1. Using Latin American Rehabilitation guidelines (GLARE), FIRE meets with the child's parents. The group consists of a psychologist, a special educator, a speech therapist, a physiotherapist and a social worker.
2. The child is evaluated and an agreed diagnosis is made, evaluating the stage of knowledge at which the child currently is (for example 30%).
3. The group then estimates the percentage of knowledge to be reached in 30 months and this is explained to the parents.
4. The program, which is simple but with a defined progress and in which the parents are trained, runs for the 30 months, with check-ups every three months.
5. At the 3 months' evaluation, if the child has passed the exam, he or she will progress to Level 2 and so on for 10 periods, after which the goal will have been reached.

The program has been running for 10 years, and

approximately 150 children have enrolled. 70% have completed the course and 30% have dropped out for many reasons, the prominent reason being lack of money for the trip to FIRE every three months.

The Promising Strategy support will be used to cover the cost of stationery and financial aid to parents for transportation to FIRE. With this support, FIRE expects to have 100% success.

COLOMBIA



Information Program - on the move!

Arica is a fishing port located in the north of Chile. The Arica chapter of ANLICHE is organising a novel way, through a range of initiatives, to raise epilepsy awareness. Using mobile information exhibitions, the association is going out into the community to encourage discussion about epilepsy. The association will visit 10 public services, 33 schools, 14 centres for people with a disability as well as the community at large. The program will be promoted on TV and on radio, as well as in the printed press.

Materials will include posters, CDs and information brochures as well as the use of audiovisual materials. The information will be provided by a social worker, a neurologist, and a social technician. People with epilepsy will also talk about what life is like when you are living with the disease.

Support from the Promising Strategies Program will enable the association to purchase the necessary equipment for the project.



Arica City CHILE

Cell phone repairs



INDIA Nellore Calling

Epilepsy is engulfed by social stigma and misunderstanding in India. With a view to dispelling misconceptions about the disease, the Indian Epilepsy Association was established in 1970 and has been actively involved in educational activities and awareness raising since then.

Nellore is a city, with several connecting neighbouring villages, from which people with epilepsy come for regular follow up care. Cell (mobile) phones are a very useful commodity used by almost everyone, even in the villages. However for any minor or major repairs one needs to visit the neighbouring city.

Persons with epilepsy face problems that affect their higher education. This further creates problems in finding employment. With the help of the mobile phone repair project, the association will be able to help 5 selected persons with epilepsy. Initially they will be trained in cell phone repair techniques by qualified persons with training continuing for a period of 6 months. Subsequently, since they have finished their training, they will be given the infrastructure to establish an outlet in their villages where they can continue with this work.

This training will make them independent, self-sufficient and will build self confidence through the provision of a trade and employment.

Information & Support

The population of Indonesia is around 240 million, who live in 30 provinces on 13,000 islands, with the majority on low economic, social and education levels. While there are no data on prevalence of epilepsy in Indonesia, based on worldwide figures, it is estimated that 2.4 million people in Indonesia will have epilepsy. Not all of them have the opportunity to have good medical services because there are a lot of problems that come from one source, i.e. stigma in the community. Many people with epilepsy are being kept at home. Children don't have a proper education and adults become dependent on other people, and jobless.

The project, proposed by PERPEI (Indonesian Society against Epilepsy), will last 5 years, with the following activities:

- Preparation of posters, booklets, leaflets and magazines telling the true facts about epilepsy
- Training healthcare providers through seminars in 16 provinces
- Providing low cost anti epileptic drugs to those on low income
- Helping families of people with epilepsy to have good economic income through skills training
- Supporting and encouraging people with epilepsy to create a self help group and to have meetings once a month to share their experiences so they can support each other.



Indonesia

Tackling a 90% treatment gap in LAO PDR

Lao PDR is a low income, multi-ethnic, landlocked country of 6 million inhabitants. Approximately 52,000 people have epilepsy, with a treatment gap of over 90%. Misconceptions, false beliefs, fear and stigmatization are common. Since 2008 the ICTE program has been working to improve healthcare and living conditions for people with epilepsy. A major objective is to increase awareness in the general public, including health authorities, so that a national policy for epilepsy care can be set up. Three radio programs on epilepsy have been broadcast daily in the capital over a two year period and 12 to 15 doctors have been trained on a 3-day basis every two months in the province.

As a first step, the radio spot and leaflets on epilepsy will be

distributed in all 38 schools in the capital, Vientiane. Pupils and teachers will hear about the new outpatients' clinic in Sethathirat hospital with possible treatment for epilepsy available. As a second step, epilepsy awareness will be raised in teachers and pupils in 24 schools in 6 provinces, once every two months, over a 3-day period, taking advantage of the training of doctors in the same cities. In this way, it is hoped to trace more people with epilepsy and to help them contact their local trained doctor. Radio spots will be translated into three of the major ethnic group languages and sent to all local stations.

Those involved in the project say that health education must play a prominent role in the consultation process for people with epilepsy.



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MONGOLIA



Mongolia is the 17th largest country in the world with a population of just 2.7 million, divided into 22 major administrative units - 21 provinces and the capital city of Ulaanbaatar.

Population density is very low and many herdsmen still follow a nomadic style of life making them even more scattered and difficult to reach. Because of their way of life, riding horses as a principal means of transport, there is the probability that trauma-based epilepsy is higher than in other countries and this makes the occurrence of partial epilepsy in Mongolia particularly high.

Mongolia has huge territories of desert, steppes and mountains but with a very low level of infrastructural development, making it very difficult to deliver epilepsy care. As a result, very few people with epilepsy will receive regular care from doctors. Due to their nomadic lifestyle, it is economically difficult to deliver adequate medical services. People with epilepsy have to travel to

the capital Ulaanbaatar for diagnosis and treatment and those from remote areas will spend between US\$500 and US\$800 for transportation, accommodation and meals for themselves and a caregiver who will accompany them to the city.

In 2006, Mongolia Epilepsy Association started a “Quality of life” program to improve health education on epilepsy among the population, including people with epilepsy, their family members, family doctors and young neurologists. This program has been very successful and the hope is to roll the program out to cover all 21 rural provinces of Mongolia.

In the last few years the association has been working with IBE and has organized a series of “Quality of life” programs, thanks to Promising Strategies Program support, in seven rural areas and cities. Mongolia Epilepsy Association is now ready and eager to go to the remaining 14 provinces to achieve its objective.



Tibet Epilepsy Patient Center

Project Objectives:

- Raise awareness about epilepsy among people with epilepsy and their families;
- Offer an alternative means to access medical advisers for people living in rural areas;
- Offer a platform for building self-help networks.

Methods:

- Set up the Tibet Epilepsy Patient Center in the Department of Neurology of the First People's Hospital in Tibet;
- Invite epilepsy patients in the department to join the center;
- Conduct a monthly lecture for patients and their families;
- Using QQ, the popular instant online messaging program, to set up an online Tibet Epilepsy Patients Group;
- Invite people with epilepsy and their family members to talk about their lives in schools and communities.

Perspective results:

- An increased awareness about epilepsy among people with epilepsy, their family members and medical workers;
- Successful online access to medical carers through QQ group;
- Increased knowledge in the general public on living with epilepsy;
- Improved self-confidence in people with epilepsy through the peer support of the self-help networks.