

Promising Strategies Program

The Work Begins!

IBE is providing financial support for new and innovative initiatives aimed at improving the quality of life for people with epilepsy in developing countries. Meet the first 13 IBE member organisations selected to receive Promising Strategy funding and learn about the projects planned.



ARGENTINA

National Guidelines for Driving for People with Epilepsy

At the present time Argentina imposes a carpet ban on driving for people with epilepsy. As a result it is reported that few people with epilepsy declare their condition and many continue to drive. In a country where traffic accidents are the first cause of death for people under the age of 35 and where the risk for (non-medical related) accident is 16 per 10,000 cars compared with 2.1 in the UK, there is an urgent need to address the crisis.

FUNDEPI, the Argentinean Associate Member will undertake research to profile drivers and risk factors to determine optimal seizure-free interval for driving licence provision and to support measures to improve driving laws. Working with people with epilepsy the association will produce a consensus proposal for driving for people with epilepsy and work with the regulatory government department to encourage its adoption into law.

Producing epilepsy information CDs

Guatemala is a large nation with great diversity of ethnic groups and languages. Although Spanish is the official language of the country, less than half the population speak it. In addition, in particular in rural and isolated areas, the incidence of illiteracy is very high. Because of this printed information on epilepsy is not practical—either because it cannot be understood or because it cannot be read.

To overcome this difficulty, Dr Henry Stokes proposes to produce low-cost audio cassettes and CDs, in a range of languages spoken in Guatemala, explaining epilepsy. The CDs can be played on mass transmission radios, on personal CD players or could be used by community groups to educate both people with epilepsy and members of the community at large on the true facts about epilepsy.

GUATEMALA



Tomato Farming - attaining self-sufficiency

Cameroon has a high prevalence of epilepsy, with 5.8% of the population affected, often due to cysticercus. Add to that the terror and fear epilepsy generates, because of its association with witchcraft and mysticism and it is easy to understand why life for people with epilepsy is very difficult in Cameroon.

In 1980, Sister Franca de Simone, an Italian missionary nun, began working to improve the medical services available to people in Cameroon and since 1997 the emphasis has been on epilepsy.

Apart from the provision of epilepsy care, supported by Professor Raffaele Canger and the Italian Episcopal Conference, Sister Franca has begun projects to help people with epilepsy become self-sufficient through revenue generated from the cultivation of community plots and the production of commercial crops.

The support provided by the Promising Strategies Program will fund Sister Franca and people with epilepsy in Nyamanga and Mbangassina regions with their tomato-growing project.



CAMEROON



ZAMBIA

Poultry Rearing Project

The Epilepsy Association of Zambia has plans to train people with epilepsy in poultry husbandry so that they can learn a skill that will help them become self-sufficient and, at the same time, help the association to raise funds to run further epilepsy information and training programmes.

The association, in collaboration with the Cheshire Home Community Programme, currently dispenses AEDs to almost 200 people with epilepsy each month. Many of these people have no gainful employment.

Through the poultry rearing project, it is hoped that some of these people will attain a skill to help them win gainful employment. Revenue from sales of the chickens reared will assist the association with its future work.



ECUADOR

Providing epilepsy medication to people of scarce economic resources

In Ecuador it is estimated that only 15 to 20% of people with epilepsy receive treatment, due mostly to poverty. For the past 5 years, the Centro Nacional de Epilepsia APNE, supported by the National Council for Disabilities, has been providing free medication for up to 500 people with epilepsy of low economic means. Unfortunately this year the National Council for Disabilities was unable to support the project. Through the provision of free medication, APNE believes that people with epilepsy receive not only economic support but also moral support, for them and for their families, through the realisation that they are not abandoned.

In addition, the delivery of the medication happens during support meetings, so that people with epilepsy are encouraged to become involved in finding out more about their condition and there is also the opportunity to talk about problems and difficulties encountered.

Benefits that have been witnessed since the project began include increase in compliance, reduction in the number of seizures, improved self esteem, better employment opportunities which, in some cases, have allowed people to begin buying their own medication.

UGANDA

Community Drugs Bank Project: to bring epilepsy 'out of the shadows'

The idea of a Drug Banks originated in Chile and the success of the initiative has encouraged other IBE member associations to emulate the concept. The purpose of the Ugandan Community Drugs Bank is to supply cheap and accessible drugs to people with epilepsy in their communities on a non-profit basis. This concept differs to the Ecuador project in that those receiving medication will pay for it, but at a rate that is affordable, based on ongoing stringent means-testing.

About 90% of Uganda's population lives in rural areas. For people with epilepsy, this has meant long difficult journeys to access medication. With the Community Drugs Bank in operation, in the future AEDs will be brought to the people who need them by nurses and healthcare workers travelling to remote villages within Uganda.

Regular provision of medication will provide stability and stamina to people with epilepsy, helping them to participate in community initiatives and thus reducing stigma. It will also increase the number of people with epilepsy attending clinics and help to capture data and statistics to help plan for future service delivery.

SIERRA LEONE Textile Training

The Epilepsy Association of Sierra Leone will provide textile training to 50 people with epilepsy. The students will first learn the basics of machine sewing and will go on to produce saleable goods such as bed sheets and pillowcases as well as more intricate pieces including children clothes and ladies frocks.

On graduation from the 2-year course, each newly trained person will be provided with a follow-up kit to help them establish their own tailoring workshops and to pass their training on to others.

The objective of the project is to improve the socio-economic status of the trainee, by empowering them to be gainfully employed.



GAMBIA

The project of the Gambia Epilepsy Association involves training in tailoring, food and nutrition and vegetable-growing for 30 people with epilepsy. At the end of the programme, which will involve student placements in various vocational institutions, the participants are expected to have the necessary skills to attain a meaningful living. The objectives of the programme include advocacy for employment, education and civil rights of persons with epilepsy. To achieve this, the association will liaise with the Ombudsman's office and will host an awareness seminar for employers. The anticipated challenges include irregularity in attendance due of seizures caused by non-compliance. However it is hoped that the team of experienced personnel monitoring the programme, will help in preventing undue levels of absence.

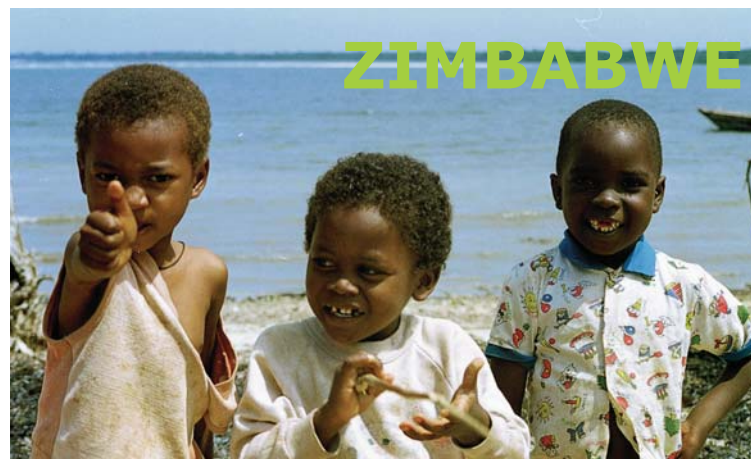


ROMANIA

EPI-Caravan: bringing education & medical services to rural areas

Official data in Romania shows the just 55% of people with epilepsy receive treatment. In addition, it has been found that the prevalence of epilepsy in rural areas is well below average. ANBER has initiated campaigns to raise awareness in rural areas and to find the 'missing' people with epilepsy. The association has found that people living in isolated areas have great difficulty in reaching medical services and is beginning a new project, called EPI-Caravan, to bring epilepsy services to these people.

The project will screen for new cases, review older cases, and educate the community to reduce stigma and facilitate social integration of people with epilepsy.



ZIMBABWE

Demystifying Epilepsy

Epilepsy Support Foundation, Zimbabwe is initiating a special programme targeting rural districts within the country in order to destroy the myths surrounding epilepsy that discourage people from seeking diagnosis and treatment. The project seeks to put reliable educational measures in place to make people aware that epilepsy is treatable and to make epilepsy services accessible. Once the project is in place, it will be used as a model for replication in 59 more districts.

The activities of the project will include a survey of current attitudes, knowledge, beliefs and practices. An important element will be workshops for traditional healers and herbalists.



MAURITIUS

'Massage Therapy' Training

To improve the quality of life of people with refractory epilepsy, Edcys Epilepsy Group Mauritius has created a Massage Therapy training program for people with epilepsy, in collaboration with the Massage Therapy Clinic, Port Louis.

The objectives of the program are to promote Massage Therapy as an alternative treatment for people with uncontrolled seizures with stress, depression and fatigue, and to empower the families of people with refractory epilepsy, through training, in understanding massage therapy and its benefits, mastering massage techniques and their application.

The program will include collaboration of a multidisciplinary team involving medical professionals, massage therapy specialists and trained epilepsy specialists in the planning and implementation of the project.

The expected results include a lowering in the frequency of seizures and reduced levels of stress and depression.



SOUTH AFRICA

Entrepreneurship Development Program

Currently in South Africa most people with epilepsy are financially dependant on their families and a small government disability grant (\$100 per month). Together with the discrimination and stigmatisation experienced on a daily basis, this situation is degrading and prevents integration into society.

An integral part of Epilepsy South Africa's National Economic Development Programme entails capacity building of identified personnel within its branch network to enable them to assist potential entrepreneurs with epilepsy and related disabilities with the establishment of sustainable self-owned micro and small business enterprises. The process is facilitated by the organisation's National Economic Development Manager who is a qualified and experienced Master Trainer in the International Labor Organisation's Start and Improve Your Business (SIYB) Programme. The SIYB Programme was developed by the International Labor Organisation and is used in over 90 countries.

Quality of Life Program - improving public knowledge of epilepsy in Mongolia

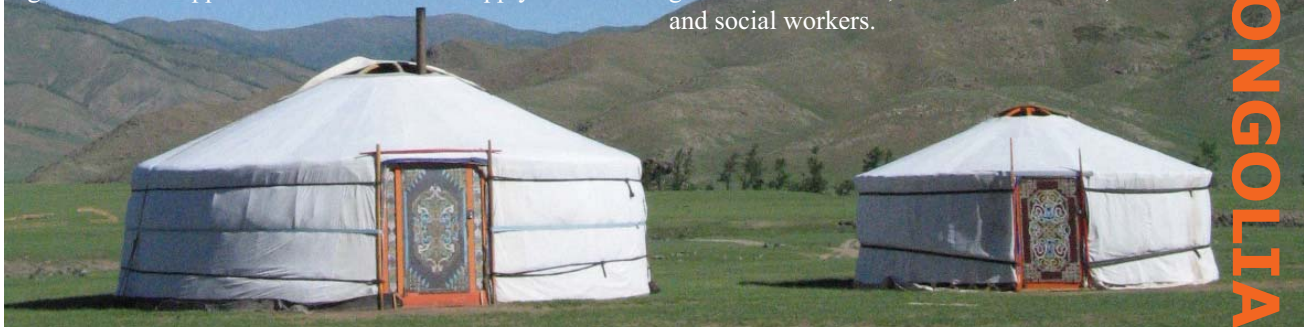
According to national health data for 2003 and 2004, the number of people with epilepsy increased by over 10% within this time period. The major cause of epilepsy in Mongolia is trauma - a preventable cause. This is an important point to convey to the general public.

The stigma associated with epilepsy in Mongolia denies most people adequate education and employment and makes it difficult to socialise in public. There is no government support and an insufficient supply of

AEDs. The nomadic lifestyle in rural Mongolia makes it difficult for regular medical monitoring and points up an urgent need for mobile EEG machines.

As a first step in improving conditions, the Mongolian Epilepsy Association will work to improve public knowledge in order to reduce stigma and improve the quality of life of those with epilepsy.

Target groups include the general public, government offices, the media, doctors, nurses and social workers.



MONGOLIA