

Promising Strategies Program 2011



SWAZILAND Poultry Rearing

With 69% of Swazis living below the poverty line, the situation for people with epilepsy is even more difficult. The Swaziland Epilepsy Association is launching a poultry rearing project to improve the socio-economic status of people living with epilepsy and other disabilities, by providing them with a job.

The project will also help to promote independent living and better self-esteem amongst members of the association's support group.

Day-old chicks will be raised to maturity and then sold to generate profits. Ten per cent of the mature chickens will be retained to replenish stock and to ensure sustainability of the project.

The China Association Against Epilepsy (CAAE), a nationwide professional social organization, was officially inaugurated with the approval of the Ministry of Civil Affairs of China in June 2005. There are around 9 million people with epilepsy in China, including 6 million people with active epilepsy. Moreover, there are an additional 0.4 million new cases diagnosed each year.

Based on these figures, it is estimated that there are approximately 30 million epilepsy carers (including parents and relatives) in China. Caring for a person with epilepsy is often a difficult task; taking its toll physically, mentally and emotionally. The economic burden of each family is huge, especially for people living in rural areas.

The aim of this project is to promote public awareness for carers of people with epilepsy and to improve their quality of life. The project will investigate the mental health, quality of life and economic status of carers; and will also encourage carers to communicate and exchange their experiences.

CHINA Caring for the Carers



NEPAL Documentary Film



Although Nepal boasts grandeur in its cultural and natural diversity, more than 75% of the population is still dependent on agriculture and more than 70% of the population lives below the poverty line. About 1% of the population is living with epilepsy and many unrecorded deaths could be due to epilepsy and related diseases.

Nepal Epilepsy Association (NEA) is producing a documentary as a means of increasing awareness about epilepsy. The short documentary will focus on the social stigma of epilepsy, its impact on society, and on the possible ways of prevention and treatment of the disease.

Post production, it will be broadcast on various national television channels, including the government-owned TV channel. The film will also be shown to local people who come for their treatment to various camps, as well as in NEA's epilepsy clinics at Lazimpat, Kathmandu and Dolakha.



The Foundation for the Rehabilitation of people with Epilepsy (FIRE) is a nonprofit institution created in 1975 by the Colombian League against Epilepsy and the Cartagenian community, to offer integral support to people with epilepsy and other associated disorders and disabilities.

The aim of the HomeClinic project is to help people with epilepsy and their families through the creation of a welcoming space, where pupils can develop basic life skills such as independence in dressing, feeding, bathing and other everyday activities. The general purpose is to educate with dignity, regardless of the physical or mental health of the person, using individual and group activities, involving the family and the community. HomeClinic hopes to improve the quality of life of those attending the course, and their families.

The program is for young children with epilepsy and associated syndromes in the age group of 4 to 10 years of age.

ECUADOR Neuropsychomotricity

Neuropsychomotricity is a modern, interdisciplinary science, framed in the context of neuroscience, which provides guidelines for the harmonic development of the individual. It bases its principles on a combination of neurology and psychomotricity, taking as basic the concept of the mental-physical structure unit.

The National Center for Epilepsy is a charitable institution mainly focused on the low income sectors of Ecuador. It was founded in 1989 and has a multidisciplinary team to treat people with epilepsy and their families. The centre is also developing strategies for dissemination of information in the community about the reality of this disorder.

Through a recent partnership agreement signed between the National Centre for Epilepsy and the Ministry of Education of Ecuador, there is an intention to spread neuropsychomotricity to professionals working in the field of psychology and health in schools, so they can apply this support directly to children with psychomotor difficulties and epilepsy.



The population of the Islands in the Western Pacific region is over 2 million, with an estimated 40,000 people with epilepsy. It is unclear what epilepsy and neurological services are available in the islands. Neither are there data regarding the treatment gap or the cost of epilepsy medication.

To establish information on the situation for people with epilepsy in the Pacific Islands, Epilepsy New Zealand has proposed a project with the following objectives:

- Conduct research into the epilepsy services available to the Pacific Islands in the IBE Western Pacific Region, with a view to introducing and/or improving services.
- Quantifying the treatment gap and implementing measures and services to reduce it.
- Establish longterm self-sufficient service organisations, connected to the IBE, in each island nation.

The **IBE Promising Strategies Program** is now 5 years old and is one of the most successful of all IBE's initiatives. Set up in 2006, as a means of supporting members through the provision of financial support for projects aimed at improving the quality of life of people with epilepsy, to date **50 projects in 33 countries** have received a total of **US\$250,000** in support.



The Indian Epilepsy Association provides services to support educational activities such as continuing medical education programmes, training programmes in epilepsy for general practitioners and occasional education forums in epilepsy for people with epilepsy.

In India, it is difficult for people with epilepsy to find employment due to the discrimination that surrounds epilepsy. Through this project, the association will train a group of people with epilepsy in the craft of baking and bakery management. Training will be provided by qualified bakers who are already running successful units. The students will be given support to purchase raw materials and will also be trained in management skills. This training will give them confidence to establish their own business, which will in turn improve their morale and quality of life.

Epilepsy Awareness

Epilepsy is one of the most common neurologic disorders in the world. However, in Tibet, due to its special geographical location, there is very little awareness about epilepsy amongst the public. The unique religious beliefs have increased negative attitudes towards patients with epilepsy and their treatment. Many Tibetans believe seizures are caused by demons and seek out cures through religious rituals.

The objectives of this project are:

- To promote epilepsy prevention and knowledge in local medical workers, to empower them to provide guidance and treatment to patients.
- To promote understanding of epilepsy in people with epilepsy and their family members, and to motivate them to seek medical treatment.
- To promote epilepsy prevention and increase public awareness.



In Zimbabwe, as in most parts of Africa, epilepsy is misunderstood and, as a result, people with the disease suffer stigma, exclusion and discrimination. This is a major reason why people with epilepsy are not receiving treatment.

The Epilepsy Support Foundation (ESF) is a registered voluntary organization, established in 1990, to support the welfare of people living with epilepsy through treatment, education, awareness, advocacy, networking, medication, diagnosis, counseling and social support services.

This project consists in initiating an innovative lobbying and advocacy programme whereby people with epilepsy speak and write about their condition, successes and challenges. These testimonies will be available in books, DVDs and as adverts in the print and electronic media. The testimonies will be produced in different dialect languages.

Next Call: Information on all of the **50** projects that have been funded to date can be found on the IBE website, where you can also find information on funding criteria. www.ibe-epilepsy.org/promising-strategy. The next call for **Letters of Intent**, for projects to be considered for funding in 2012, will be circulated to all IBE member associations in late September 2011.



LITHUANIA Legislation Survey

Lithuania has registered 24,000 people with epilepsy, of whom 20% are employed, 30% have special training and 37% have only their disability pensions as a source of income. Research undertaken by LESIA (Lithuanian Association for the Integration of People with Epilepsy) has shown that people with epilepsy are discriminated against in the areas of education, vocational training and employment.

With this project, LESIA will conduct an analysis of the laws in the social sphere in the light of the UN Convention of the Disabled. Surveys will be carried out amongst people with epilepsy regarding treatment quality; quality of life; and the impact of legislation for people with epilepsy in finding employment in the free labour market. The results of the project will be an evaluation of existing laws and drafting of amendments for consideration and adoption by the Parliament of Lithuania.



Soccer Camp

HAITI

33 Project covering all seven IBE regions, have received support from the Promising Strategies Program Fund.

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| 1. Argentina | 19. Mongolia |
| 2. Bangladesh | 20. Namibia |
| 3. Brazil | 21. Nepal |
| 4. Cameroon | 22. Philippines |
| 5. Chile | 23. Romania |
| 6. China | 24. Sierra Leone |
| 7. Colombia | 25. South Africa |
| 8. Czech Republic | 26. Swaziland |
| 9. Ecuador | 27. Tanzania |
| 10. Ethiopia | 28. Tibet |
| 11. The Gambia | 29. Togo |
| 12. Guatemala | 30. Uganda |
| 13. Haiti | 31. Western Pacific Islands |
| 14. India | 32. Zambia |
| 15. Kenya | 33. Zimbabwe |
| 16. Lebanon | |
| 17. Lithuania | |
| 18. Mauritius | |

Children with epilepsy in Haiti are excluded from all activities including, sometimes, schooling. With this project the Canadian Epilepsy Alliance will organise a 2-week soccer camp during the summer for children aged between 7 and 16, girls and boys with epilepsy, regardless of their levels. During this time, the children will be involved in play-and-learn activities cared for by well trained soccer teachers, volunteers and medical professionals

Trainings will focus on technical-tactical coordination and will be provided in a fun way. The physical portion of the camp aims to educate young people about physical activity. It will also convey the values of mutual respect and openness to others, values that accompany the conduct of all activities.

During the educational part of the camp, physician and nurses will teach children about basic hygiene, good eating and sleeping habits as well as answer questions about epilepsy. Volunteers will also participate in cultural activities with the children, including reading, singing and dancing sessions.