



International Bureau for Epilepsy

PROMISING STRATEGIES 2005 - 2018

HELPING TO MAKE A DIFFERENCE

US\$350,000+ provided to 83 PROJECTS in 37 COUNTRIES



SOME PROJECTS FUNDED TO DATE

HEALTH ISSUES

- ECUADOR: Provision of AEDs to meet government deficiency
- UGANDA: Development of a Drugs Bank
- ROMANIA: EPI-Caravan: bringing education & medical services to rural areas
- MAURITIUS: Massage Therapy
- KENYA: Training in Epilepsy Management
- NAMIBIA: Onyose Project (Epilepsy Management)
- TOGO: Bridging the gender gap
- CHINA: Supporting carers
- ECUADOR: Neuropsychomotricity course

HUMAN RIGHTS AND LEGISLATION

- ARGENTINA: National Guidelines for Driving
- ARGENTINA: Review of legislation protecting people with epilepsy
- CZECH REPUBLIC: Children's survey
- FIJI: Research on epilepsy services on Pacific Islands
- LITHUANIA: Research project on legislation protecting people with epilepsy

TRAINING AND EMPLOYMENT

- CAMEROON: Tomato Farming
- ZAMBIA: Poultry Rearing
- SIERRA LEONE: Textile Training
- GAMBIA: Tailoring and Vegetable Growing
- SOUTH AFRICA: Entrepreneurship Development Program,
- GAMBIA: Tailoring classes
- TANZANIA: Training young people in vegetable growing
- LEBANON: Training in chocolate making
- SWAZILAND: Poultry rearing
- COLOMBIA: Home Clinic project
- INDIA: Bakery skills training
- HAITI: Children's soccer camp

PUBLIC EDUCATION

- GUATEMALA: Epilepsy Education CDs
- ZIMBABWE: Demystifying Epilepsy
- MONGOLIA: Quality of Life Program
- BRAZIL: Epilepsy at School: Teaching the Teachers
- ETHIOPIA: Awareness raising program
- CHILE: Juanito Animated Videos
- MAURITIUS: Teacher Training
- PHILIPPINES: Multimedia Education Pack
- SOUTH AFRICA: Self-advocacy training workshops
- CHINA: Seahorse craft club
- BANGLADESH: Educational video
- NEPAL: Documentary film – New Life for Juneli
- TIBET: Epilepsy awareness campaign

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PROMISES KEPT

FEEDBACK FROM ASSOCIATIONS SUPPORTED BY PROMISING STRATEGIES OVER THE LAST THIRTEEN YEARS IS TESTAMENT TO THE SUCCESS OF THE PROGRAM

MALAYSIA

VOCATIONAL TRAINING

We organised a visit to a vocational training centre for students with Autistic Spectrum Disorders, of which some have epilepsy, in 2013. Promising Strategy Program funded a carpentry and woodworking program, which allowed the students to learn the process of assembling and improve their fine motor skills.

Kheng-Seang Lim, Malaysia Society of Epilepsy



CHINA



“In developed areas in China, Promising Strategy Programs brought people with epilepsy and their families online education and advice, as well as face-to-face psychological support. In resource-poor areas, efforts were made, not only to extend epilepsy education to rural areas, but also to make epilepsy care go deeper to provide more precise comprehensive care to meet the different requirements of people with epilepsy.”

Ding Ding, China Association Against Epilepsy

Understanding, knowledge and attitudes towards epilepsy

“Promising Strategies allowed our program team conduct a survey, among patients, their family members and general public, which serves as an essential basis for improving the training programs and elaborating the national program on epilepsy in Mongolia.”

*A. Tovvudorj,
President, Mongolia Epilepsy Association*

MONGOLIA



SOUTH AFRICA

“The support of the Promising Strategies Program enabled Epilepsy South Africa to establish an education and awareness programme for young children. This initiative has now grown into an element of our new youth initiative, “The Nicholas Project.”

Marina Clarke, CEO Epilepsy South Africa



ABOUT THE PROGRAM

It is estimated that, globally, there are more than 50 million people living with epilepsy. The true figure is unknown because epilepsy is still a hidden disease as a consequence of the stigma to which people with epilepsy are subjected. Epilepsy is a treatable disease and, with correct medication, more than 60% of people with epilepsy could have their seizures controlled. Yet, even in wealthier countries, a significant percentage do not receive appropriate treatment. The figure rises substantially for those living in low income countries, who struggle to access epilepsy medication.

Lack of treatment imposes a huge financial burden on national health systems; and research and legislation remain key issues in improving the quality of life of persons affected by epilepsy.

While early diagnosis and intervention, coupled with appropriate treatment and care, are the best tools for optimising treatment, for many people with epilepsy, the social problems connected to a diagnosis of epilepsy are more difficult to deal with than the seizures themselves. Stigma and discrimination impact on every aspect of the life of a person with epilepsy from schooling to employment and from social and personal relationships to family life and parenthood.

Days lost to seizures and cognitive impairment, in some cases due to medication side effects, can detrimentally

affect the education of a young person with epilepsy. It is also well known that a person with epilepsy may find themselves excluded from their school of choice, simply because of their epilepsy. Lower graduation grades will then reduce options to access higher education and to find suitable employment. Add the issues of stigma and discrimination and the situation further deteriorates.

Supporting people with epilepsy in self-empowerment, through capacity-building, education and peer support, is central to what the International Bureau for Epilepsy does. We also work to promote health literacy to help people with epilepsy make sound health-care decisions for themselves, and we undertake educational initiatives to disseminate information from end-users to policy-makers and authorities and vice versa.

BACKGROUND

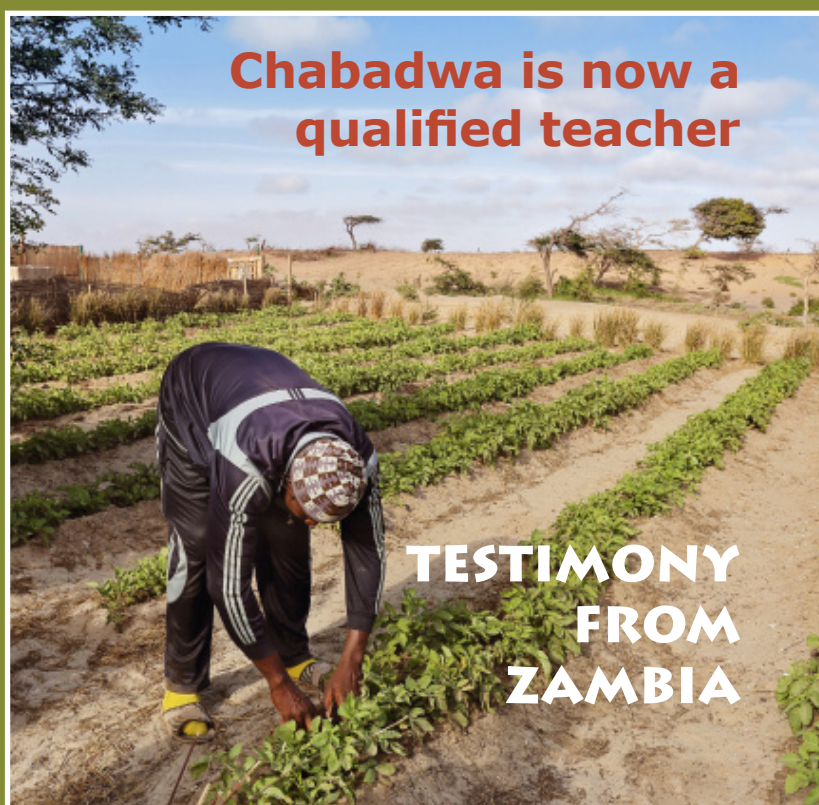
The International Bureau for Epilepsy (IBE) is committed to finding new and innovative solutions to the problems impacting people with epilepsy and their families world-wide. As part of this commitment, since 2005, IBE's Promising Strategies Program has been providing financial support to IBE chapters for small enterprises and initiatives that address the problems faced by people with epilepsy, particularly in developing nations. To date, almost US\$350,000 has been provided in support of 83 projects in 37 countries.

Our members have been able to learn skills in gardening, chicken rearing, jam making and leadership. The gardening project is the most outstanding of all and has provided funds for school going members and operational activities for the Association. Testifying to this achievement Chabadwa Successor Phiri has commented:

“I wish to thank you greatly for the support from IBE through the Promising Strategy Project. Through this program, I learnt how to make jam of various flavours and sell for support towards my education. I am at college and the Association also bought a blender to improve the quality of my jam. Thank you greatly.”

Chabadwa is now a qualified teacher and waiting to be deployed by the Government, through the Ministry of Education.

Epilepsy Association of Zambia





MIRIAM'S STORY

My name is Miriam Gallardo Oliveros. I live in Chile and I have had epilepsy since I was 10 years old. In the Promising Strategy Program hairdressing workshop that ANLICHE Chile teaches, I learned this beautiful job. With my effort and dedication, I opened a hairdressing salon in my house, where I have my own clientele. This allows me to obtain my own income, buy my own medications and help with the sustenance of my house. However, the most rewarding thing for me was to become a Hairdressing Instructor in the workshop. I like to teach and, through teaching, I can encourage other women like me or caregivers of patients with epilepsy, to go ahead and convey that everything is possible if one proposes it. I am happy for that and grateful to have had this opportunity in the Chilean League against Epilepsy.

HOW A PROMISING STRATEGY LOOKS

Ideally, a Promising Strategy contains many of the following:

- is based on measurable, realistic, and time specific objectives
- is innovative and represents the development of new solutions to common problems impacting people with epilepsy and their families
- establishes a strategy that makes a difference in improving accessibility to accurate, timely, necessary and culturally appropriate information and/or services
- has the potential for replication of positive results if the program is implemented in a similar environment with a similar target population as its original pilot demonstration
- is likely to be implemented in collaboration with other strategic partners
- has a mechanism to measure results and get feedback to continue to improve the program

SELECTION OF PROJECTS

Each round of funding opens with a call for Letters of Intent, requesting a short outline of the proposed project. From the Letters of Intent, a shortlist is created and

successful candidates are asked to submit a full proposal that must include a required list of details, including:

- description of how the organisation has the capacity to conduct the proposed project;
- details of the problem to be addressed by the project and anticipated impact;
- details of the objectives of the program, which should be realistic and measurable;
- activities planned to achieve the objectives of the program;
- an overall budget.

The application is also required to explain how the project outcomes will be measured, and how the program will continue beyond funding from the IBE.

THE FUTURE

Thirteen years on, it is now time to pause and reflect on the many successful outcomes, those projects that have continued to run successfully when funding support ended, or which have grown and adapted into other initiatives. We also need to consider those projects that disappointed, by failing to deliver or by falling short of expectations, and to study why things did not go to plan.

Capturing feedback and reviewing the stage reports submitted from all 83 projects that have been supported by

Promising Strategies, will give us a very clear picture of the program to date. In this way, we can consider improvements for the future.

We also need to take on board new technologies that have revolutionised communications. Equally important is the change in role of the patient in decisions made on their care and treatment. The revolution in communications, technology and innovation, opens new and exciting options to advance connectivity, engagement and resilience, in a fast-changing world. These technologies provide a cost-effective means of equipping both young and old with the training, information and self-confidence to play active roles in their society. Seeing how these new technologies can positively impact on projects will be an exciting element of our review.

The call of the World Health Organization, the European Union, and social and political scientists for a redistribution of power between patients, experts and specialists in policy and decision-making that concerns them, is also a huge step in the right direction.

The previous tokenistic involvement of patient groups in the development of health policies and the design of health services is becoming a thing of the past. The added value of patient input, throughout the patient pathway, is being recognised.

Through Promising Strategies funded programs, IBE can play an important role in supporting people with epilepsy with the knowledge, understanding and confidence to be equal partners in the decision-taking that will affect their healthcare, education, employment opportunities and legal rights.

With knowledge comes power, and one of the core ele-

ments to the next round of Promising Strategy Projects will focus on electronic or mobile technology projects aimed at equipping people affected by epilepsy with the expertise needed to be an equal partner in all aspects of their healthcare.

This recognises the key aims and objectives of a Promising Strategy - to foster effective and innovative public health practice with regards to epilepsy.

HOW CAN YOU HELP?

The growth and development of Promising Strategies is limited only by our capacity to fund new projects.

Since the program began in 2005, each call for Letters of Intent has been heavily oversubscribed.

With increased funding we can do two things:

1. we can provide a small level of funding to a number of new microprojects that will help support people with epilepsy and those who care for them through training workshops, awareness raising, lobbying and advocacy campaigns, or other activities to improve the lives of those affected by epilepsy;
2. we can study some of the successful projects funded previously, where there was a commonality of purpose or design, and use the knowledge gained from these projects to build program templates that can be easily adapted by IBE chapters around the world for use at local level.

To progress Promising Strategies, we need your help and support. Even a small amount of funding can help us positively impact on the lives of people living with epilepsy in resource poor regions of the world.

Together we can make a real difference.

EPILEPSY ON THE MOVE

Bringing epilepsy services to remote areas of Namibia

The Promising Strategies Program (PSP) funding for "Epilepsy-on-the-move" has enabled Epilepsy Namibia to identify the most efficient way to deliver services in Namibia. We have used the experience from "on-the-move" to develop a national mobile service, that hopefully will be fully funded soon.

The program for training at care institutions done with PSP funding also forms part of the National service. PSP funding helps us to present, develop and test programs and projects for future expansion.

HARMIENA RIPHAGEN, EPILEPSY NAMIBIA



MAJOR SUCCESS IN TACKLING NEUROCYSTICERCOSIS IN COLOMBIA

**Ministry of Health
considering
expansion
across the region**

One year on and already the project of FIRE, IBE's chapter in Colombia, is making an impact in the eradication of neurocysticercosis in a rural town supported by Promising Strategies.

Neurocysticercosis is the first cause of epilepsy in the Caribbean region. A common problem in poor towns is lack of running water, no sewage systems and appalling garbage collectors. Pigs roam the streets, eating faeces and rubbish that can contain copious amounts of fertile eggs of *taenia solium* (tapeworm). In the pigs' intestine, the eggs develop into moveable larvae that can reach the blood stream. Soon, these larvae reach the muscles and can stay there for a long time.

Humans can then eat this contaminated meat, and once consumed, the parasite follows the same cycle as in the pig. However, in this case, the larvae go directly through the blood stream to the brain, where they remain as cysts until they are destroyed by the body's defenses.

When this happens, strange substances are emitted from the cysts that irritate the brain. A focal seizure occurs which can generalize to tonic clonic. But it can also lead to a cognitive deficit. About 40% of patients with neurocysticercosis will develop epilepsy.

When a child or an adolescent is attacked by the parasite, there is the potential for mental retardation and

permanent epilepsy. These patients consult FIRE, the IBE chapter in Colombia, looking for special education because they are refused admission to normal schools. These terrible problems could be avoided by fighting the cause i.e. lack of sanitation and contaminated pork.

The Colombian Government alone is incapable of solving the sanitation problem; the inhabitants are almost totally defenseless in organizing it themselves; so, it's

necessary that entities such as FIRE, supported by Promising Strategies funding provide assistance.

Progress to date:

1. introduction of the project by FIRE personnel to local volunteers.
2. house to house survey in the small town of Mahates, which has 7,000 dwellings and a population of approximately 23,000.
3. meetings with community leaders and school managers.
4. provision of 250 mgs. of Albendazole to each inhabitant every six months in collaboration with local health authorities to ensure the population becomes free of *Taenia Solium*.

5. creation of a communal herd of 150 purebred piglets in substitution for the vagrant pigs.

The Ministry of Health, recognising the promise of this project is now considering supporting its expansion across the entire Caribbean region of Colombia.

The life cost and catastrophic sequels are an enormous burden for the government, families and society in general.

Rehabilitation for cognitive sequelae of neurocysticercosis is also a hard task for a developing country.

Our Project is feasible and necessary.

*Jaime Fandiño Franky
FIRE, Cartagena, Colombia*