

GLOBAL CAMPAIGN AGAINST EPILEPSY

The Global Campaign: Past, present and future

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INTRODUCTION

The ILAE/IBE/WHO Global Campaign against Epilepsy “Out of the Shadows” is a partnership between the World Health Organisation, the International League Against Epilepsy and the International Bureau for Epilepsy. This Campaign is much needed for the following reasons: (1) Epilepsy is the most common serious brain disorder; (2) Epilepsy is a global problem affecting all ages, races, social classes and countries; and (3) Epilepsy imposes enormous physical, psychological, social and economic burdens on individuals, families and countries, especially due to misunderstanding, fear and stigma. The above mentioned problems are universal but are greatest in the developing world where 80% of the 50.000.000 people with epilepsy live and as many as 80-90% receive no diagnosis or treatment. These problems are too complex to be solved by individual organisations. Therefore the three leading organisation in the field of epilepsy decided to join forces, form a partnership, in the ILAE/IBE/WHO Global Campaign Against Epilepsy, with the aim to reduce the treatment gap and bring epilepsy “out of the shadows”.

The mission statement of the Campaign is: to improve the acceptability, diagnosis and treatment, services and prevention of epilepsy world-wide. The strategy of the Campaign includes two parallel and simultaneous tracks: (1) Raising general awareness and understanding of epilepsy, for instance by organising Regional Conferences on Public Health; (2) Supporting Departments of Health in identifying the needs and promoting education, training, treatment, services, research and prevention nationally, by initiating demonstration projects.

CAMPAIGN ACTIVITIES GLOBALLY AND IN THE REGION

Assistance with regional conferences

The Campaign was launched in the South-East

Asian Region (SEARO/WPRO) on 10 November 2000, with the development, formal announcement and unanimous agreement of the Asian and Oceanian Declaration on Epilepsy. Technical Consultative meetings on epilepsy and the implementation of the Campaign took place in Manila, Philippines (WPRO) and Bangkok, Thailand (SEARO) both in 2001 and Yangon, Myanmar (SEARO) in 2002. A Regional Conference will take place in Beijing, P.R. China in 2004.

Assessment of country resources on epilepsy

WHO is producing an Atlas on country resources for epilepsy and a survey questionnaire was developed by epilepsy experts, covering the profile of epilepsy resources available on a country level. The work started in 2001 and data is now available from over 130 countries (Table 1). This data will also be used for the WHO Regional Reports on Epilepsy.

Assistance with regional reports

Status reports on the implementation of the GCAE are being prepared in all six WHO Regions, which will include the data collected through the questionnaires. These documents are intended to be tools for advocacy and instruments for dialogue with governments, health care providers, donors and other partners. To date the reports for SEARO and WPRO are both ready for printing.

Sessions during international congresses

Sessions and presentations on the progress of the Campaign are held during many regional and international conferences, including during the 5th AOEO Conference, Bangkok, Thailand and the International Beijing Epilepsy Conference to be held in Beijing, P.R. China, in October 2004.

Publications, including newsletters

Campaign articles have been published in, or

Table 1: Assessment of country resources for epilepsy (up to August 2004)

| Region | WHO Member States | No. Respondents | Population |
|--------------|-------------------|----------------------|------------|
| AFRO | 46 | 27 (59%) | 78% |
| AMRO | 35 | 20 (57%) | 97% |
| EMRO | 21 | 11 (52%) | 75% |
| EURO | 52 | 40 (77%) | 88% |
| SEARO | 11 | 8 (73%) | 99% |
| WPRO | 27 | 23 (85%) | 99% |
| Others | 12 | 5 (42%) | |
| Total | 192 + 12 | 129 + 5 (67%) | 93% |

AFRO: WHO Regional Office for Africa

AMRO: WHO Regional Office for the Americas

EMRO: WHO Regional Office for the Eastern Mediterranean

EURO: WHO Regional Office for Europe

SEARO: WHO Regional Office for South-East Asia

WPRO: WHO Regional Office for the Western Pacific

submitted to peer reviewed journals, such as: *Epilepsia*, *Neurology* and the *WHO Bulletin*. Both *Epigraph* and *IE News* as well as national newsletters of ILAE/IBE chapters published a number of articles on Campaign activities. Annual and quarterly reports are produced in order to continue raising awareness and interest for the Campaign and its activities. Campaign newsletters are published 3 - 4 times per year and sent to over 600 addresses on each occasion. A Campaign brochure has been updated and reprinted and over 1,000 copies have been distributed world wide. Brochures and leaflets have been developed in many countries.

Assistance with the development of guidelines

Consensus guidelines are being developed on the treatment of epilepsy in childhood adolescence. These Guidelines are the first set of WHO Guidelines on Epilepsy which will be developed. The Guidelines will serve as a prototype, a template for future guidelines within the framework of the Global Campaign.

Assistance with fundraising

It is not easy to obtain the funds necessary for the growing number of activities within the framework of the Campaign. The Campaign Secretariat has been involved in or has stimulated grant applications and approached possible donors.

Stigma project

Under the Campaign a grant application for a pilot project on stigma in epilepsy was submitted to the Fogarty Foundation, which was subsequently awarded. This project will involve ethnographic studies to explore prevailing beliefs and attitudes to epilepsy in two developing countries, P.R. China and Vietnam (WPRO). It will define theoretical models of stigma and its link to disease burden and it will develop validated and culturally specific measures of outcome for use in future intervention studies. Through its implementation, the project will enhance social science capacity in these two countries and facilitate development of strong collaborations for future related research activities.

Coordination of Demonstration Projects

Under the Campaign Demonstration Projects have been developed and initiated. Demonstration Projects illustrate good practice in providing services to people with epilepsy and will be used as models of what can be achieved. Demonstration Projects have been established or are being initiated in many countries. This number has risen during the last 4 years from 4 to 18 countries. In SEARO: Projects being planned in India, Indonesia, Myanmar, D.P. Korea, whilst the Project in WPRO, P.R. China, will be finalised by the end 2004. In the review of the work of WHO during 2003, WHO Director General, Dr.

Lee Jong-Wook, mentions the Project in China as one of the “key events and landmarks that highlight the range of issues in which WHO has been involved in 2003”.

PLANS FOR THE FUTURE

Many of the ongoing activities of the Campaign are expanding, both in size and in numbers, for instance the Demonstration Projects. Furthermore, the focus of the Campaign has extended to the most vulnerable population groups in the developed world.

The foundation EPilepsy CAre in DEveloping Countries (EPICADEC) decided to wind up its activities. Its assets have been transferred to the joint ownership of ILAE and IBE. These funds will be used for a project supporting local initiatives in developing countries in agreement with the objectives of the ILAE/IBE/WHO Global Campaign Against Epilepsy.