



PAPER TO CABINET

To: Cabinet
From: Executive Director, Social Change and Mental Health
Date: 03 December 1999
Topic: GLOBAL CAMPAIGN: BRINGING EPILEPSY OUT OF THE SHADOWS

Background

a) Impact on health

- Epilepsy is one of the most common serious brain disorders worldwide and it imposes a large economic burden on health care systems. Epilepsy is universal with no age, racial, social class, national, nor geographic boundaries.
- There are 40-50 million sufferers in the world today, 85% of whom live in developing countries (Fig. 1, Annex 1). An estimated two million new cases occur each year globally. At least 50% of cases begin at childhood or adolescence (Fig. 2, Annex 1).
- Epilepsy has serious physical, psychological and social consequences. Epilepsy has a significant mortality (four times the expected rate in young adults). There is a hidden burden associated with stigma and discrimination in the community, work place, school and home.
- 70 to 80% of people with epilepsy could lead normal lives if properly treated. However, in developing countries 60 to 90% of people with epilepsy receive no treatment due to inadequacies in health care resources and delivery, and due to social stigma.

b) Existing activities

In 1997 three international organizations, the World Health Organization (WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) joined forces to initiate a Global Campaign Against Epilepsy (GCAE).

On initial stage the strategy of the campaign was essentially focused on advocacy and awareness activities:

- In 1998 at a meeting in Heidelberg sponsored by the German Government, the European Declaration on Epilepsy was unanimously adopted (Annex 2);
- In 1998 and the first half of 1999, twenty-seven countries have joined or are planning to join the Global Campaign Against Epilepsy.

Experience of initial stage of the campaign created rationale for suggestion of a second stage of the GCAE with a new and more ambitious goal: to improve health care services, treatment, prevention, and social acceptance of epilepsy worldwide. A Consultative Meeting on Epilepsy held in WHO/HQ in April 1999 with participation of representatives from IBE, ILAE, WHO Regional Advisers and experts recommended to boost the Campaign and to proceed with demonstration project on epilepsy within the GCAE frame (Meeting Report: MNH/NND/99.3). This project would have to work as part of a country's current health system in order to ensure that epilepsy interventions would be sustainable and able to provide appropriate care over long term including availability of essential antiepileptic drugs.

Strategy and Proposal

The strategy of the GCAE includes two parallel and simultaneous tracks: 1) raising of general awareness and understanding of epilepsy, and 2) supporting Departments of Health in identifying needs and promoting education, training, treatment, services, research and prevention nationally.

1. To provide a platform for general awareness on epilepsy, the following is proposed:
 - to intensify and boost the Campaign in the year 2000 with the participation of the Director-General of WHO, WHO Regional Directors and Presidents of relevant NGOs;
 - to announce a Global Awareness Day for Epilepsy; and
 - to organize regional conferences on public health aspects of epilepsy in the six WHO Regions, including a Declaration on Epilepsy, based on the European model.
2. To assist Departments of Health in the development of national programmes on epilepsy, the following was proposed:
 - to provide information and support for national initiatives under the GCAE; and
 - to initiate demonstration project in China (WPRO), Honduras (AMRO), Jamaica (AMRO), Panama (AMRO), Senegal (AFRO), and Zimbabwe (AFRO)¹.

The objectives of the demonstration projects are:

- to reduce the treatment gap and the physical and social morbidity of people suffering from epilepsy by intervention at a community level;
- to train and educate health professionals;
- to dispel stigma and promote a positive attitude to people with epilepsy in the community;
- to identify and assess the potential for prevention of epilepsy;
- to develop a model for promotion of epilepsy control worldwide and for its integration in the health systems of participating countries.

Evaluation criteria: Reduction in treatment gap, change in public attitudes, potential for prevention.

Duration: 4 to 5 years.

Partners

Within the framework of the GCAE, WHO has already established a good working relationship with the professional (ILAE) and lay (IBE) NGOs for epilepsy. The Regional Offices of AFRO, EURO and AMRO are actively involved.

Partnerships are being developed among organizations of the United Nations system, nongovernmental organizations, WHO collaborating centres, the private sector, academic and research groups, Foundations and donors.

The following WHO departments have already expressed support: Department of Child and Adolescent Health Development, Department of Resource Mobilization and Office of Press and Public Relations. Contacts are being established with the clusters of Communicable Diseases, Non-Communicable Diseases and Department of Essential Drugs and Other Medicines in the cluster of

¹ **Criteria for country selection in project** are: willingness to participate, political contacts, availability of key WHO Collaborating Centre or country representative, IBE/ILAE /other epilepsy organizations, existence of basic primary health care infrastructure, regular and basic AED supply, facility of communication.

Health Technology and Pharmaceuticals. A proposal to approach the pharmaceutical industry for financial support was considered by the Committee on Private Sector Collaboration (CPSC). A copy of this decision is attached as Annex 3.

All the neuroscience NGOs including the World Federation of Neurology and the International Child Neurology Association support the Global Campaign Against Epilepsy.

Recommendations

1. In the year 2000 to intensify and boost the GCAE and announce a Global Awareness Day for epilepsy in the presence of the Director-General, Executive Director as well as the Presidents of the participating NGOs. Regional offices will replicate similar high visibility events in all Regions, in the presence of Regional Directors, NGOs and media-attracting personalities.
2. In 2000 initiate the development of demonstration project as model for the reduction of treatment gap and stigma, improvement in education, training and health care delivery, and promotion of prevention.
3. During the period 2000-2004 hold regional conferences on public health aspects of epilepsy, including a Declaration on Epilepsy as a basis for regional political action.
4. Within the next six months organize a meeting with appropriate United Nations agencies and representatives of the pharmaceutical industry to explore the possibility of furthering collaboration and mobilizing resources for the campaign in accordance with the WHO Guidelines on Interaction with Commercial Enterprises and the aforesaid decision of the CPSC.