



"Out of the Shadows"

Newsletter of the ILAE/IBE/WHO Global Campaign against Epilepsy

June 2001

"Out of the Shadows"

an introduction

Caroline Morton, Co-ordinator GCAE Newsletter
ILAE/IBE/WHO Global Campaign against Epilepsy

Dear Readers,

This is the first newsletter of the Global Campaign against Epilepsy!

Many of you will already be aware of the *International Epilepsy News* and *Epigraph*, the newsletters of the International Bureau for Epilepsy and the International League against Epilepsy respectively.

The GCAE newsletter will focus specifically on activities related to the Global Campaign. We will keep you regularly informed about the global, regional and national activities of the Campaign, as well as updating you on new initiatives and developments within the Campaign.

We will also start a 'future congress' column where congresses which are being organised under the auspices of, or including sessions on, the Global Campaign against Epilepsy, will be highlighted.

Furthermore, we encourage the readers to submit articles on national activities under the Campaign.

If you have any suggestions concerning this newsletter then please do not hesitate to contact us at the Editorial Correspondence address (see page 3).

Progress Report

January-June 2001

H.M. de Boer, J. Engel jr., L.L. Prilipko
The Campaign Secretariat

In February there was the highlight of the Campaign so far, the Launch of the 2nd Phase in Geneva. Representatives from:

- * 13 missions of WHO country members
- * 24 national member organisations IBE/ILAE
- * 4 NGO's in neuroscience/neurology and
- * 17 Private Sector

attended this event, which was a huge success, both according to IBE and ILAE, and according to WHO, standards.

Dr. Gro Harlem Brundtland, the Director General of WHO, spoke at the Launch and amongst others she said:

.....So we are facing the two challenges of reducing stigma and of building up capacity to correctly diagnose and treat epilepsy patients world-wide.

It can be done.....

As you know, the secret for the success of the Campaign lies in the partnership, the partnership between ILAE and IBE and with WHO. Dr. Brundtland also remarked on this partnership by saying:

.....The collaboration between the International Bureau for Epilepsy, the International League against Epilepsy and the WHO has shown that when people with different backgrounds and roles come together with a shared purpose, creativity is released and expertise is used in innovative and constructive ways.....

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Since the Launch, the Secretariat of the Campaign met on a number of occasions to discuss ongoing activities and plan new ones. The following will give you an idea, on what is going on in the world concerning the Global Campaign:

Argentina:

Preparations are being made and a meeting planned to initiate the first Demonstration Project in Latin America.

China:

The first phase of the Demonstration Project has now been completed and the findings of the epidemiological study will be published soon.

Congress sessions:

A session was organised on the Campaign in Buenos Aires during the 24th International Epilepsy Congress.

Conferences:

Regional Conferences on Public Health are being planned for later on this year or at the beginning of next year in the Western Pacific and the Eastern Mediterranean Regions of WHO. Furthermore, regional symposia are being planned, for instance, in Azerbaijan.

Regional Declarations:

Preparations are being made to launch the North American Declaration on Epilepsy in Washington in September.

Senegal/Zimbabwe:

A Consultative Meeting on the Implementation of the Global Campaign against Epilepsy took place in Harare, Zimbabwe on June 4-5 of this year. A report on the activities in Africa will be included in a future newsletter.

White Paper on Epilepsy:

In March, the European White Paper was launched at the European Parliament in Brussels, Belgium. The development and publication of similar white papers in the other WHO regions is being discussed.



P. Lee (President IBE), L.L. Prilipko (WHO - Campaign Secretariat), J. Engel jr (ILAE - Campaign Secretariat), B. Saraceno (Director, Dept. Of Mental Health and Substance Dependence, WHO), H.M. de Boer (IBE - Campaign Secretariat), J. Bowis (Member European Parliament), G. Avanzini (President ILAE)

Other issues under discussion:

- the twinning/collaboration of chapters, where one well-developed chapter assists a less developed chapter, or one IBE Friend helping another
- the development of educational materials for the illiterate
- the development of medication banks following the Chilean model
- the regular publication of articles on epilepsy and on the Campaign in peer-reviewed journals
- the development and expansion of the Campaign website:

http://www.who.int/mental_health/Topic_Epilepsy/Epilepsy_1.htm

- the development of a (electronic) newsletter on the Campaign (of which this is the first issue)

The Secretariat of the Campaign underwent a change, as Prof. E.H. Reynolds retired from most of his international epilepsy work. He was succeeded by Prof. J. Engel jr, the past-president of ILAE. Prof. Reynolds will be missed, as we owe him our gratitude for all he contributed to the Campaign, after all the Campaign was his brainchild. However, he promised to continue to support the Campaign, an offer the present Secretariat will certainly take him up on.



E.H. Reynolds, H.M. de Boer, L.L. Prilipko

Finally, the global activities of the Campaign obviously involve large sums of money, which none of the three organisations have themselves. Therefore, fundraising activities are also an important part of the work of the Secretariat. A first meeting with possible "donors" is scheduled for September in New York. Discussions with separate donors are ongoing. Another meeting will be organised in Geneva, Switzerland, either later this year or early next year.

So much is being accomplished, and this is only what the Secretariat is aware of. Some of the chapters inform the Secretariat on a regular basis concerning the Campaign activities in their countries and we will try and include those reports, not only in our annual report, but also on the website. Information and photographs are therefore very welcome. It cannot be repeated enough, this is a joint effort: a partnership, between WHO, ILAE and IBE but also between these organisations, their national chapters, the regional and local WHO offices!

Global Campaign Session

At the 24th International Epilepsy Congress, Buenos Aires, Argentina, 18 May 2001

The session was chaired by H.M. de Boer and E.H. Reynolds and contained a wide variety of speakers from the different regions. The programme covered the following topics:

The Demonstration Projects
(*Prof. A.G. Diop, Senegal*)

Regional Conferences and Declarations
(*Prof. P. Wolf, Germany*)

Activities in the Latin-American Region
(*Dr. C. Acevedo Schwarzman, Chile*)

Transnational Initiatives: a British and South African Collaboration
(*Ms. J. Liddle, U.K. and Ms. K. Pahl, South Africa*)

Living with Epilepsy in a Developing Country
(*Mrs. C. D'Souza, India*)

Despite the session being held on the very last day of the congress (and following the gala dinner of the previous evening!) the session was well attended. The general discussion, which followed the presentations, was lively and we would like to thank those who contributed to the discussion.



C. Acevedo Schwarzman (Chile), C. Miranda (Regional Advisor WHO for the America's), J. Liddle (UK), K. Pahl (South Africa), P. Wolf (Germany), H.M. de Boer (IBE - Campaign Secretariat), A.G. Diop (Senegal), C. D'Souza (India)

Future Congresses

7th Mediterranean Epilepsy Conference

22-25 November 2001
Athens, Greece

8th Epilepsy & Society Conference

3-6 May 2002
Seville, Spain

2nd Latin American Congress on Epilepsy

29 May-1 June 2002
Foz do Iguassu, Brazil

4th Asian Oceanian Epilepsy Congress

12-14 September 2002
Nagano, Japan

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