



“Out of the Shadows”

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

June 2002

Global Activities

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

Dear Readers,

This first issue of 2002 includes a summary of activities carried out in the first quarter of this year. We hope that reading about these actions will inspire those countries, who have not yet organised launched the Global Campaign against Epilepsy in their countries, to be thus motivated to do so. Likewise, countries that have already been extremely active will hopefully be encouraged to continue their hard work.

We also invite you to submit your articles on GCAE activities taking place in your area. Please continue to keep us informed. Thank you.



Annual Report 2001 now available

The annual report of the activities which have taken place under the banner of the ILAE/IBE/WHO Global Campaign against Epilepsy in 2001 has been printed and already distributed to over 500 addresses world-wide.

The annual report includes details on the history and the background of the Campaign, plus information on activities carried out globally, regionally and nationally and the action plans for the coming years. Special attention is also given to the Launch of the 2nd Phase of the Campaign, which took place in February last year.

If you have not yet received a copy of the annual report, or indeed if you would like to receive more copies, then please contact us and we shall send you these free-of-charge.

Furthermore, we would also like to share two special WHO messages that were sent after receipt of the annual report:



Quote from Dr. Gro Harlem Brundtland, Director-General of WHO:

...I am very pleased to note the success of the Campaign and look forward to seeing even more progress in next year's report. You and your colleagues in IBE, ILAE and, not forgetting WHO, are to be congratulated on your efforts.



Quote from Dr. M. Belhocine, Director, Prevention & Control of Non-Communicable Diseases WHO/AFRO:

...Glancing through the chapter headings reveals well thought-out features that are truly inspiring to the reader. The report is easy to read and we intend to use it both as a tool and a motivation for scaling up our interventions.

-
- 1 **Annual Report 2001**
 - 2 **Quarterly Report on the activities of the ILAE/IBE/WHO Global Campaign against Epilepsy: January-March 2002**
 - 3 **Progress of the Demonstration Project in Senegal**
 - 4 **Report on Control of Neurocysticercosis**
 - 5 **Future Congresses**

Quarterly Report on activities of the ILAE/IBE/WHO Global Campaign against Epilepsy

January-March 2001

Hanneke M. de Boer
Co-Chair ILAE/IBE/WHO Global Campaign against Epilepsy

The first three months of this year proved to be a very busy period, with many ongoing activities in various parts of the world, whilst new activities were initiated according to the existing Plan of Action:

1. The development and dissemination of the Annual Report
2. Meeting of the Campaign Secretariat with the Regional Advisors on Mental Health and representatives of the Dept. of Mental Health
3. The questionnaire on country needs and resources
4. Demonstration Projects
5. Press Conference
6. Fundraising

The development and dissemination of the Annual Report

The report over 2001 was prepared in time for IBE and ILAE Executive Committee meetings in March and sent to a growing mailing list of ca. 500 addresses world-wide.

Meeting of the Campaign Secretariat with the Regional Advisors on Mental Health and representatives of the Dept. of Mental Health

The Regional Advisors for Mental Health meet once a year for a three-day period at WHO headquarters in Geneva. This year the meeting took place on 10-13 March and for the first time epilepsy was placed on the agenda.

Dr. B. Saraceno, Director, Department of Mental Health & Substance Dependence, reported on the activities of the Campaign in 2001 and the Plan of Action for 2002-2003. The Regional Advisors then reported on the activities concerning epilepsy in their regions:

AFRO:

Dr. C. Mandlhate, WHO Regional Adviser on Mental Health, considers the Campaign a perfect example of partnership. Two technical consultative meetings for the implementation of the Campaign activities in the African Region have been held - in Zimbabwe (June 2001) for the Anglophone countries and in Togo (March 2002) for the Francophone countries.

Following the first meeting it was recommended to expand the Campaign activities in Africa and 6 more countries developed activities during the last 6 months of 2001. Epilepsy is now a priority in the African Region. The questionnaire on country resources has been translated into French. A Regional Report on Epilepsy will be developed this year.

EMRO:

Dr. A. Mohit, WHO Regional Adviser on Mental Health, proposes to organise a Regional Conference on Epilepsy to take place in Cairo towards the end of this year.

SEARO:

Dr. V. Chandra, WHO Regional Adviser on Mental Health explained that epilepsy is one of the highest priorities in the region and epilepsy projects in the region aim at identification and treatment of people with epilepsy, focussing on tonic clonic seizures. An inter-country meeting will be held and videos will be produced on identification and treatment and on stigma.

PAHO/AMRO:

Dr. C. Miranda, WHO Regional Adviser on Mental Health, reported that the protocol for the demonstration project in Argentina has been approved and the pilot project will soon be finalised. El Salvador is developing a national plan for health care, which will include epilepsy and contacts will also be made with Chile concerning similar activities that are being developed.

EURO:

Dr. W. Rutz, WHO Regional Adviser on Mental Health, reported that epilepsy is not a big priority in Europe although it is in the forefront of people's minds. However, he did report on some ongoing activities:

- integration of policies on epilepsy
- anti-stigma activities
- endorsement of the European White Paper on Epilepsy and the European Declaration
- will provide support to epilepsy activities/congresses where possible
- will collaborate with the Campaign Secretariat concerning the assessment of country needs using the questionnaires on country resources and the collected data will be used for the development of a regional report on epilepsy.

WPRO:

Dr. H. Hermann, WHO Regional Adviser on Mental Health had left her position and no replacement has yet been found, therefore no report was made. However, a technical consultative meeting on the implementation of Campaign activities in the Western Pacific Region was held in the Philippines last year and recently three processes have been initiated that present an unprecedented opportunity to this Region:

- the adoption of epilepsy as a priority in the Regional Strategy for Mental Health endorsed by the 52nd Regional Committee of WPRO in September 2001
- the launch of the Global Campaign against Epilepsy
- the inclusion of epilepsy as a priority condition in the World Health Report 2001

The questionnaires on country needs and resources

Questionnaires were first sent to countries where the IBE and ILAE have member organisations and are now being sent by the WHO Regional Offices to countries where IBE and ILAE have no members. In the meantime, the questionnaire has been translated into French and Spanish. The data will be collected on a global and regional level.

Demonstration Projects

China: the project is still going strong. A meeting took place in Geneva in May to audit the outcomes thus far.

Zimbabwe: the implementation of the project has been delayed due to the political situation, travelling was not safe and the epidemiological data has not yet been collected.
Senegal: in the epidemiological phase of the project, five surveys have been held any other activities have taken place. More details can be read in the report further on in this newsletter.

Press Conference

On 13 February a press conference took place in the Van Gogh Museum in Amsterdam, the Netherlands. This conference was made possible through an unrestricted grant from Sanofi-Synthelabo. The occasion of this media event was the anniversary of the Launch of the 2nd Phase of the Campaign and its purpose was to highlight the major concern of the Campaign: the reduction of the treatment gap. The programme not only included presentations from the professionals but also, more importantly, by people with epilepsy who spoke about what it is like to live with epilepsy, the associated stigma and how they have come 'out of the shadows'. The press conference was attended by, amongst others, 48 journalists from 15 European countries. The President of IBE, Philip Lee wrote:

Congratulations and thanks for the excellent press conference...I have never seen so many journalists at an epilepsy press conference before... I'm sure the Campaign will be well reported as a result of this...

It also seems appropriate to share a quote from - Carol D'Souza (India):

I was only able to come out of the shadows after interacting with others like myself. I joined the group thinking that with my experience I would be able to help others, but looking back, I find I have been helped the most. What I have experienced within this group goes beyond anything money can buy...I stand before you here today only as proof that persons with epilepsy can achieve, get married and live normal lives, in spite of epilepsy

Filicity September (South Africa):

...it is of utmost importance that people with epilepsy become empowered and practice their rights. We must make a stand and take up our rightful place in life. I would like to conclude by encouraging everyone to leave the silence to the lambs and to make a joyful noise in preaching the gospel of epilepsy. I have learned that responsibility brings about independence

Carina Mühl (Netherlands):

...I would like to finish my presentation by showing you a Van Gogh picture, named "Woman planting vegetables". She is doing this on her own, but she knows she will harvest. Just like your own positive attitude towards a high quality of life whilst having epilepsy... even though it may be difficult at times

Progress of the Demonstration Project in Senegal



Amadou Gallo Diop, MD, PhD

The first phase of the project in Senegal has been achieved. From August 2001 preparations have been made concerning the protocol, with an important meeting held in Harare, Zimbabwe convened by the WHO Afro Mental Health Dept. and the Secretariat of the GCAE. Following this, the material for the surveys was elaborated and designed. The management office has also been organised and equipped. Enquirers have been trained on the site hosting the demonstration project in Senegal: Pikine, a suburb area of Dakar, which is characterised by promiscuity, poverty and a heavy health burden. Five surveys have been planned:

- Prevalence and Treatment Gap
- Knowledge, Attitude and Practice among Health Workers
- Knowledge, Attitude and Practice among general population
- Quality of Life of People with Epilepsy
- Service Delivery for People with Epilepsy

These surveys required the participation of enthusiastic students and enquirers, the population and the Senegalese League against Epilepsy. The results have been collected after groundwork during September and October 2001. The statistical analysis benefits from the expertise of the 'Institut Santé et Développement' of the University of Dakar. The results are soon to be published. In summary, an important prevalence rate of 17 per 1000 people has been detected (versus 12 per 1000 in 1989 on the same site and 8 per 1000 as the mean national rate). Also, a huge lack of knowledge and poverty of quality of life and service delivery for people with epilepsy has been detected.

A documentary on epilepsy is being realised and will benefit from the participation of the First Lady and the Ministry of Health, plus a famous singer and wrestler, who will all deliver messages for the awareness of epilepsy. Materials for training and education are under preparation. The next steps will be the organisation of training for health professionals, a communication programme for the general population, consultation for patients and the setting up of a drug bank, following the Chilean model.

Report on control of Neurocysticercosis

Cysticercosis of the central nervous system (neurocysticercosis) is the most important neurological disease of parasitic origin in humans. It causes morbidity and in areas where *Taenia solium* is endemic, is known to be a leading cause of epilepsy, which has profound social, physical and psychological consequences. meat product. Animal vaccines are under development.

Responses and WHO activities

In 1993, the International Task Force for Disease Eradication declared *T. solium* a potentially eradicable parasite, for the following reasons: (i) the life cycle requires humans as definitive hosts; (ii) tapeworm infections in humans are the only source of infection for pigs, the natural intermediate host; (iii) the transmission of infection from pigs to human beings can be controlled; (iv) no reservoir for infection exists in wildlife. It is therefore expected that the strategic use of anthelmintics against the adult parasite in people and the larval parasite in swine, combined with health education and regulation of pig slaughter, is sufficient to interrupt transmission, but this approach has yet to be proven in practice.

Taeniasis and cysticercosis do not lead to sudden large-scale international outbreaks of disease and therefore would not seem to constitute an appropriate subject for international notification. Nevertheless, health ministries should be strongly encouraged to set up national surveillance and reporting systems, and adopt a more active approach towards prevention and control of these diseases.

As a step towards promoting the control of human cysticercosis, particularly as a preventable cause of epilepsy, WHO will invite experts to an informal consultation with the aim of reaching consensus on crucial elements such as clinical diagnosis in resource-poor settings, surveillance and reporting methods, and cost-effective and sustainable intervention strategies. The successful outcome of the application of these elements should vindicate the control approach and lead to the elimination of the disease. Enhanced control of human cysticercosis and cysticercosis of the central nervous system will contribute to several international initiatives such as the ILAE/IBE/WHO Global Campaign against Epilepsy.



Future Congresses

Where Global Campaign sessions are planned:

2nd Latin American Congress on Epilepsy

29 May-1 June 2002, Foz do Iguassu, Brazil

www.epilepsia.org.br/latino2002

4th Asian Oceanian Epilepsy Congress

12-14 September 2002, Nagano, Japan

www.saitama-med.ac.jp/aoec4

EDITORS

Hanneke M. de Boer, the Netherlands

Jerome Engel jr., U.S.A.

Leonid L. Prilpko, Switzerland

CO-ORDINATOR GCAE NEWSLETTER

Caroline Morton, the Netherlands

ASSISTANT

Kathy Fontanilla, Switzerland

ADVISORS

Giuliano Avanzini, Italy

Philip Lee, U.K.

COPYRIGHT

ILAE/IBE/WHO Global Campaign against Epilepsy, or as otherwise stated.

EDITORIAL CORRESPONDENCE

Caroline Morton, International Bureau for Epilepsy, P.O. Box 21, 2100 AA

Heemstede, the Netherlands

Tel: + 31 23 5291019/Fax: + 31 23 5470119

Email: ibe@xs4all.nl