

“Out of the Shadows”

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

April 2003

Regional Special

Hanneke M. de Boer, Jerome Engel jr., Leonid L. Prilipko

Secretariat ILAE/IBE/WHO Global Campaign against Epilepsy

Dear Friends,

On the occasion of the annual meeting of the WHO Regional Advisors on Mental Health organised by the Director of the Department of Mental Health and Substance Dependence, Dr. B. Saraceno, it seemed a good idea to produce a special issue of the Campaign Newsletter, focussing on Campaign related activities in the Regions.

Last year, for the first time, a session related to the Global Campaign against Epilepsy was included in the programme of this meeting. Also for the first time representatives of IBE/ILAE and the Global Campaign were invited to participate.

During this session the Campaign Secretariat reported on the prospects and progress of the Campaign activities and a plan of action for the coming years was discussed.

Furthermore the Regional Advisors reported on the activities under the umbrella of the Campaign which had taken place in their respective regions, whilst they also presented their plans of action for the coming biennium.

All emphasised that they considered the Campaign a perfect example of a partnership.

This year, in April, a similar meeting will take place, again with the participation of representatives of the Global Campaign.

We wish to welcome you to this special edition of our Newsletter, that highlights the Regional activities that are currently taking place under the umbrella of the ILAE/IBE/WHO Global Campaign against Epilepsy.

NB: *This Newsletter has been produced in close collaboration with the WHO Regional Advisors for Mental Health.*

REGIONAL ACTIVITIES SPECIAL

- 1 AFRO
- 2 AMRO/PAHO
- 3 EMRO
- 4 EURO
- 5 SEARO
- 6 WPRO

Implementation of the Global Campaign Against Epilepsy in the African Region

Information from Dr. Custódia Mandlhate

Regional Advisor for Mental Health for the WHO AFRO Region

Following the adoption of the African Declaration on Epilepsy in May 2000 in Dakar, Senegal, and the Launch of the Second Phase of the Campaign in February 2001 in Geneva, Switzerland, many activities have taken place in the African Region. These activities include:

Two consultative meetings on the implementation of the Global Campaign Against Epilepsy in the African Region in Harare, Zimbabwe (June 2001/March 2002) with the participation of representatives from Cameroon, Ethiopia, Kenya, Lesotho, Mozambique, Senegal, South Africa, Swaziland, Tanzania, Togo, Uganda and Zimbabwe and in Lomé, Togo in March 2002 with the participation of Algeria, Benin, Burundi, Burkina Faso, Cape Verde, Chad, Congo, Democratic Republic of Congo, Côte d'Ivoire, Gabon, Guinea/Conakry, Mali, Mauritania, Niger, Rwanda, Senegal and Togo.

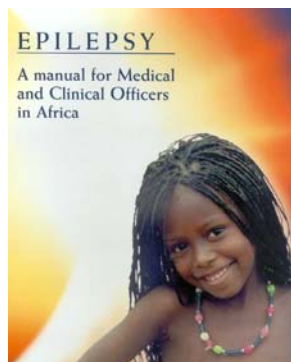


Participants at Consultative Meeting on Epilepsy in Africa in Harare, October 2002

The inclusion of epilepsy as part of the "African Exhibition on: Poverty and Health, Challenges for Development". This exhibition was launched in New York in 2002 and displayed during the last session of the Regional Committee in Harare (Zimbabwe) in 2002.

The national launch of the Campaign in selected countries: Kenya, Lesotho, Mozambique, Swaziland, Tanzania and Uganda in 2001 and Burkina Faso, Chad, Congo and Mauritania for 2002-2003.

The Manual: "Epilepsy: a Manual for Medical and Clinical Officers in Africa" (English version) has been completed. It has been disseminated to the countries in the Region through the WHO country Offices. A follow up of its utilisation is required.



The Manual: "Epilepsy for Medical and Clinical Officers in Africa".

The questionnaire on country needs and resources to control epilepsy has been translated into French and 70% of the countries in the Region have returned the data completed questionnaire.

A draft document entitled: "Epilepsy in the African Region: Bridging the Gap", has been prepared. This document when ready, will be an advocacy tool and an instrument for dialogue with governments, other partners and donors. A meeting, jointly organised by WHO, IBE and ILAE brought together selected experts from Ethiopia, Senegal, South Africa, Tanzania, Togo and Zimbabwe. The aim of this meeting was to review the draft of this document for its improvement, to review the status of the implementation of the Demonstration Projects in Senegal and Zimbabwe and to agree on a joint (WHO/IBE/ILAE) biennial plan of activities to intensify the GCAE in the African Region.

The development and publication of this document has been supported by an unrestricted educational grant from Sanofi-Synthelabo.

Good interaction with Headquarters and the WHO Country Representatives Offices as well as improved collaboration with the various partners, (the International League against Epilepsy, the International Bureau for Epilepsy and various partners at country level) contributed greatly to the effective implementation of the activities planned in the Region. However, delays of the submission of good quality project proposals is one of the major constraining factors, calling for action to improve the capacity and managers at country level.

National Activities

National activities took place in around 20 countries in the Region. Some examples of such activities are given below:

Launch 2nd Phase GCAE, Rodrigues Island, Mauritius

On 14 April, the EDYCS Epilepsy Group (IBE Friend) of Mauritius, in collaboration with ABRO (Association pour le bien-être des Rodriguais) will launch its 2nd Phase "Out of the Shadows" Campaign in Rodrigues Island.

Two officials from EDYCS will travel to the island with a view to:

- Meeting parliamentarians to highlight epilepsy

- Sensitise the community on epilepsy
- Set up branches of EDYCS for people with epilepsy
- Establish an epilepsy information unit at ABRO
- Collect statistics on epilepsy cases
- Train community leaders and volunteers in epilepsy
- Visit the Queen Elizabeth Hospital and meet stakeholders

"Out of the Shadows" in Uganda

(Reproduced with kind permission from the International Epilepsy News, nr. 4, 2002).

An effort was made to highlight epilepsy during the celebrations for World Mental Health Day. The Ministry of Health was very supportive and, with the support of WHO, several posters and brochures were printed and distributed. Due to the increased awareness about epilepsy, the Ministry of Health invited the Epilepsy Support Association of Uganda (IBE member) to participate in a review of the national mental health act.

The implementation of the Global Campaign against Epilepsy in the AMRO/PAHO Region

By Dr. Claudio Miranda

Regional Advisor for Mental Health for WHO

After the inauguration of the Latin American Epilepsy Day - September 9, 2000 as a part of the GCAE, by the PAHO/WHO representative, and the Minister of Health from Chile, the Declaration for epilepsy in Santiago, Latin America was launched.

The following outcomes can be listed:

1. Training modules developed and evaluated in the Pilot Study in Epilepsy in Argentina
The protocol for the Demonstration Project has been developed and approved. Due to the difficult situation in the country the start of the Project needed to be postponed, but activities have now been initiated to commence with the Project, including undertaking fundraising activities.
2. In Chile, within the scope of the Campaign, a national plan for epilepsy care has been developed and similar activities are taking place in El Salvador.
3. A Demonstration Project in Epilepsy has also been initiated in Brazil, under the coordination of Dr. Li Li Min, from State University of Campinas (UNICAMP). A meeting took place in August last year with representation of AMRO/PAHO, the IBE and ILAE chapter and with the participation of Prof. Ley Sander, the Campaign's scientific project leader in order to finalise the protocol for the project. This Project is a pragmatic research programme, focussing on the evaluation of quality and outcome of the delivery of integrated epilepsy management in primary care settings. The methodology has three main components:
 - a. Epidemiological estimation
 - b. Medical interventions

c. Training, education and social intervention. As a part of the latter component, the Brazilian Ministry of Health will send a letter to WHO Headquarters, requesting the training of Family Health teams (there are 17.000 teams in the country) in epilepsy management to be considered as a part of the GCAE.

4. Within the framework of the GCAE a grant proposal for a Demonstration Project in Epilepsy in Guatemala has been submitted to the US National Institute of Health, which hopefully will lead to a third Demonstration Project in the Region.
5. The questionnaire on country needs and resources have been translated into Spanish, has been disseminated and is presently being collected



Dr. Claudio Miranda and Prof. Ley Sander (scientific project leader of the Demonstration Projects in Latin America)

National activities

National activities took place in more than 15 countries in the Region. Some examples of such activities are given below

Canada

Epilepsy Canada's *Out of the Shadows* awareness campaigns aim at increasing the public's awareness and sensitivity towards epilepsy.

Last year a survey on epilepsy issues was disseminated to gather information, thoughts and opinions, which will help to focus the efforts on the issues that are most important to people with epilepsy in Canada. Brochures incorporating the Campaign logo were developed.

This year's campaign will launch the video *Just Like You* featuring musician Paul Shaffer, Epilepsy Canada's National Spokesperson.

USA

The Global Campaign was launched in Washington DC with a gala. The "Out of the Shadows" theme will be utilised for nation wide fundraising and awareness campaign.

Activities in the EMRO Region

Intercountry Meeting on Epilepsy as a Public Health Concern in the Eastern Mediterranean Region

Under the aegis of the Global Campaign Against Epilepsy of the World Health Organization (WHO), International League against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE), a meeting "Epilepsy as A Public Health Concern in the Eastern Mediterranean Region" was held in Cairo, Egypt, on 3 and 4 March 2003. This meeting was supported by an unrestricted educational grant from Sanofi-Synthelabo.

Over 40 representatives from 25 countries in the region participated in this important event.

The meeting was a great success, as can be seen from the following letter from Philip Lee, IBE President:

"...I thought it was a tremendous success for the Global Campaign and for WHO, IBE and ILAE. We managed to establish many new and worthwhile contacts with important people in the region and I am sure this will help the Campaign and the cause of epilepsy to develop and prosper in the future. The agreement of a Regional Declaration on Epilepsy for the Eastern Mediterranean region now means that all parts of the world are covered by such documents"

Professionals from health and social sciences sectors and representatives from universities coming from the member states of the Eastern Mediterranean Region unanimously agreed to the following Declaration:

CONSIDERING THAT:

- epilepsy is the most common serious chronic brain disorder, estimated to affect at least 50 million people in the world of which at least 4 million live in the Eastern Mediterranean Region,
- contrary to many misconceptions, epilepsy is a brain disorder with natural causes and requiring medical treatment,
- it is often not realised that epilepsy is treatable, and that most people with epilepsy can lead productive lives as a result of relatively inexpensive, cost-effective treatment,
- in parts of the Eastern Mediterranean Region many people, especially in rural areas, have no access to appropriate healthcare provisions and treatment,
- general information about epilepsy, trained expertise, diagnostic facilities, antiepileptic drugs and surgery are not available for or affordable by many people with epilepsy, for geographic,

financial, cultural or communication reasons,

- epilepsy has serious physical, psychological and social consequences for the afflicted and their families,
- the impact of epilepsy is most severe in children and adolescents,
- epilepsy does not receive adequate attention in existing national health plans in many countries.



Participants in the Intercountry Meeting in Cairo

We call on the governments of the member states of the Eastern Mediterranean Region, national and regional, public and private organisations, all health care providers, and the general public to join us in taking strong and decisive action to meet the objectives of the Global Campaign Against Epilepsy of the WHO/ILAE/IBE “Epilepsy: Out of the Shadows”.

Specifically we urge action to:

- address the needs with respect to epilepsy in terms of prevention, access to trained personnel, modern diagnostic equipment, antiepileptic medication, surgical treatment where necessary, and social integration,
- include antiepileptic drugs in the list of essential drugs in all countries, and make them constantly available to avoid the serious consequences of treatment interruptions,
- educate and train health care and other relevant professionals and volunteers on all levels of health care about epilepsy,
- educate those affected by epilepsy, their families and the general public about epilepsy as a universal neurological condition, to eradicate misconceptions, and empower the affected to seek appropriate treatment and improve their quality of life,
- eliminate discrimination in all spheres of life, particularly concerning school and employment,
- encourage the public and private sectors and NGO's to get involved in the local activities of the Global Campaign against Epilepsy,

- encourage basic and applied research on epilepsy as an integral part of epilepsy services on all levels,
- proclaim a National Epilepsy Day,
- encourage regional and international co-operation

Cairo, 4 March 2003.

Questionnaires on country needs and resources

The questionnaires were sent out to the participants of the above meeting and so far 50% have been completed and returned.

National activities

National activities took place in around 5 countries in the Region. Some examples of such activities are given below.

Tunisia

A training programme for doctors was organised throughout the country. A brochure in Arabic was published aiming at the general public and people with epilepsy.

Contacts have been established with the authorities.

Activities towards a national epilepsy day are taking place.

Saudi Arabia

A session on the Global Campaign was organised during the national conference in this country. A liaison officer for the Campaign was appointed

Campaign activities in the EURO region

A Demonstration Project in Europe

Demonstration Projects have been implemented in different developing countries during the second phase of the GCAE. It must be born in mind, however, that the concept of developing versus developed countries is not as sharp as it is currently perceived and that underdeveloped areas (either geographically or culturally defined), can be identified even in economically very advanced countries.

Typical examples are the Native American enclaves in USA and Canada, and some communities of immigrants in industrialised countries, such as Italy, France, Spain, Germany and other European countries, where an increasing number of jobless people migrate from Africa and Middle East.

These considerations occurred to Prof. Giuliano Avanzini, president of ILAE, whilst talking with the governor of an Italian Rotary section. It was proposed to create a reference point for immigrants with epilepsy in Milano, Italy, where they can find any medical and social support they may need.

The local Rotary section will carry out the initial fundraising to create the basic facilities whereas the medical and social work will be provided on a voluntary basis by people of the

Italian League Against Epilepsy (the ILAE chapter) and the Associazione Italiana Contro l'Epilessia (the IBE chapter).

The implementation of the European White Paper on Epilepsy

Parliamentary Advocates for Epilepsy

Following the Launch of the White Paper in the European Parliament (EP) in Brussels in March 2001, several members of the European Parliament agreed to back the Campaign by forming a political lobby group at the EP entitled "Parliamentary Advocates for Epilepsy".

More than 40 Members of the European Parliament from all parties have pledged their willingness to be associated with this initiative. The group brings together individual members of the European Parliament who represent their member states from a range of political parties.

The role of the group will be to place epilepsy on the European health agenda. It is also hoped that the group will help establish national political support groups.

(Reproduced with kind permission from the Epilepsy News, Brainwave - the Irish Epilepsy Association; issue 17 - winter 2001/2002)

Development of an action pack

An action pack has been devised by a group of experts in epilepsy:

- To provide local epilepsy organisations (IBE and ILAE chapters) with the support, guidance, tools and motivation to enable them to locally implement a political campaign.
- To provide a programme of possible activities for consideration with examples of best practice and action plan templates.
- To motivate and unite epilepsy groups to collectively leverage change across governmental and public affairs audiences across Europe.

The action pack covers the following issues:

1. Introduction
2. How to use the European White Paper on Epilepsy
3. Effective communication and communication tools
4. Developing alliances
5. Examples of best practice
6. Model campaign and templates

The production of this action pack has been supported by an unrestricted educational grant from UCB Pharma.

Conference in Moscow

A conference "Epilepsy as a Public Health Concern" is being organised in Moscow, Russian Federation on 13/14 May 2003.

The desired outcomes of this conference will be:

1. to involve the Minister of Health
2. the development of a national plan for epilepsy
3. to assist in setting up a post-academic epilepsy training programme



Red Square, Moscow

Participants will include government officials, epilepsy experts from Russia and from the international epilepsy world as well as representatives of WHO Headquarters and of the Regional WHO Office.

The development of evidence based guidelines

According to the Global Campaign Against Epilepsy (GCAE) action plan, evidence based guidelines on the treatment of epilepsy in childhood and adolescence are to be developed.

These guidelines will be developed in close collaboration with the WHO Department on Child and Adolescent Health and Development IBE and ILAE experts and with the WHO collaborative Centre, Oasi, Sicily, Italy.

A first preparatory meeting has already taken place in Geneva and a work plan was developed.

A further meeting is planned to take place in Sicily in June of this year.

Fogarty grant

An application was submitted for a Fogarty International Centre Planning and Development Grant to develop an international research initiative responsive to the call for research into brain disorders in the developing world.

The proposed initiative would involve: primary and secondary research to inform development of approaches to reduce stigma in epilepsy and the disease burden associated with it; and the development of research capacity in the social sciences in the developing countries where the project will take place.

Questionnaires on country needs and resources

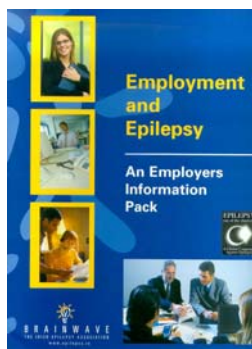
A total of 20 countries out of the 52 this Region counts, completed and returned the questionnaire.

National activities

National activities took place in 35 countries in the Region. Some examples of such activities are given below.

Ireland

An Employers Information Pack has been produced as part of the Global Campaign activities in the country. A national launch of the pack is being prepared.



Employers Information Pack

The pack contains leaflets about:

1. questions employers frequently ask about epilepsy and employment
2. support that can be offered to employers by the national IBE chapter (Brainwave, the Irish Epilepsy Association)
3. general information about epilepsy and employment for employers
4. information about epilepsy
5. information about employer's rights and obligations

Sweden

The annual conference of the IBE chapter "Conference Epilepsiforum" was organised as part of the Global Campaign "Out of the Shadows".

"...I am happy to see that the Campaign has reached the national level in Sweden and that this conference is a joint initiative of the Swedish Chapters of IBE and ILAE..."

stated Dr. Gro Harlem Brundtland in her special greetings to the members of this conference. The audience of which consisted of people with epilepsy and parents, nurses, social workers, politicians, therapists and teachers.

The main purpose of the conference was education and to focus on the special needs for people with epilepsy, the health care situation in Sweden and the empowerment of people with epilepsy.

The Netherlands:

A press conference was organised in the van Gogh Museum in Amsterdam, The Netherlands. The occasion for this media event was the anniversary of the Launch of the second phase of the Global Campaign. The purpose was to highlight the major concern of the Campaign, the reduction of the treatment gap. The agenda for the event included presentations by professionals and by people with epilepsy themselves, who spoke about their lives with the disorder. 48 journalists attended the conference from 15 countries, as well as by the presidents of both IBE and ILAE.

This event was supported by an unrestricted educational grant from Sanofi-Synthelabo.



Speakers and members of the panel at the press conference (from left to right) Filicity September (South Africa), Gary McDermott (Ireland), Ria Bremer, facilitator (The Netherlands), Carina Mühl (The Netherlands), Carol D'Souza (India), Andreas Habberstad (Norway). All panel members have epilepsy themselves

Activities in SEARO

Intercountry meeting in Myanmar

After the very successful intercountry meeting in Bangkok, Thailand in November 2001, which was organised by the WHO Regional Advisor for Mental Health in the SEA Region, a further meeting was convened in Yangon, Myanmar last September.

The overall objective of this meeting was to finalise a community based approach for the identification and management of generalised tonic-clonic seizures (major fits) in the community.

Some specific objectives were:

1. to discuss the country experiences in the implementation of the draft questionnaire to identify
2. generalised tonic-clonic seizures (major fits) in the community
3. To finalise the questionnaire to identify generalised tonic-clonic seizures in the community
4. To finalise the "best practice guidelines" for the management of generalised tonic-clonic seizures in the community



Participants in the intercountry meeting in Yangon, Myanmar

The anticipated outcome of the workshop was the finalisation of the protocol for the identification and management of generalised tonic-clonic seizures in the community.

Extensive work had been done, prior to the meeting, on the development of a simple questionnaire to identify tonic-clonic seizures.

A draft questionnaire to identify tonic clonic seizures in the community had been tested in India, Sri Lanka, and in a number of other countries. The data of these tests were discussed at the meeting.

A training module for community based health care providers on the identification and management of major fits has been developed. The objective of this manual is:

To train community-based health care providers (including general physicians, paramedical health workers, Registered Medical Practitioners and others who provide health care to the community in the identification, management, follow-up and care of persons with major fits.

Projects will be set up in a number of member countries in the Region in order to diminish the treatment gap. The treatment gap in the member countries of the SEA Region varies from 50 - 80%. In India alone 20% of people with epilepsy are treated appropriately. The objective of the projects is to provide appropriate treatment to at least 60% of those people who need treatment.

Questionnaires on country needs and resources

A total of 90% of the questionnaires have been completed and returned and analysis of the data can now be initiated.

National activities

National activities took place in around 5 countries in the Region. Some examples of such activities are given below.

India

A Regional Conference took place in November 2000, under the auspices of the Global Campaign. A "Declaration" was adopted.. A booklet was prepared by a panel of experts from the region, providing valuable information to lay people and policy makers

Sri Lanka

A contact person was appointed for the Campaign

N.B.: Validation projects took place both in India and Sri Lanka (hospital based), as well as in a number of other countries.

Campaign activities in the Western Pacific Region



From left to right: Dr. Li Shi Chuo (Wf Fiji), Hanneke M. de Boer (Campaign Secretariat), Dr. Leonid L. Prilipko (WHO Headquarters)

Regional Report on Epilepsy

Much preliminary work for the development of a Regional Report entitled: "A call to attention and action" has already been done and the report and it is expected to publish the report by the end of this year.

Demonstration Project in China

The second phase of the Project is now in full swing and both the training and interventions have started.

Already 2,228 patients have been screened and are being treated. Furthermore, 3 more provinces now want to joint the project. In Shanghai, the first urban area in the Project, the epidemiological study will also be included. The epidemiological results in the provinces are expected to be similar to the results obtained thus far, therefore no epidemiology will be performed. These new projects will be called: national projects.

The Demonstration Project in China is now the biggest intervention project organised by WHO ever.

It is highly likely that the Project will lead to a national programme, as in fact the project is already spreading.

In results of the first phase of the Project will be published in the May issue of the journal Neurology along with an editorial on the Campaign.

Questionnaires on country needs and resources

As one of the activities of the GCAE in the Western Pacific Region (WPR) of WHO, the questionnaire was distributed to selected informants in each of the 37 member states in the Region, typically prominent epilepsy clinicians or public health officials with responsibility for epilepsy treatment policy or programmes. To date 25 countries have returned the completed questionnaire, representing 99.5% of the total population of the Region.

An excellent report on this survey has been produced by Dr. Shi Chuo Li, WHO Representative in the South Pacific.

National activities

National activities took place in around 5 countries in the Region. Some examples of such activities are given below

Dragon boat racing in Australia

In March of this year the Melbourne International Dragon Boat Festival, an annual event, took place and a team of people with epilepsy, nurses and doctors participated in the race as an 'Out of the Shadows' exercise in order to raise awareness for epilepsy.

The event was covered by the local press, with more to come in a number of hospital magazines, the Department of Human Services etc.



The participants in the Dragon Boat Race wearing Campaign t-shirts

Epilepsy awareness week in the Philippines

As a part of the Global Campaign against Epilepsy "Out of the Shadows" an epilepsy awareness week was organised. During this week seminars were organised for non-medical audiences as well as for various medical schools and neurology training courses.

The weeklong celebration culminated in a series of "walkathons", with the participation of people with epilepsy and their carers, medical students and representatives of the pharmaceutical industry.



A poster produced by the Philippine League against Epilepsy to advertise the "Walking Out of the Shadow of Epilepsy" Walkathon

EDITORS

Hanneke M. de Boer, the Netherlands
Jerome Engel jr., U.S.A.
Leonid L. Prilipko, Switzerland

CO-ORDINATOR GCAE NEWSLETTER

Caroline Morton, the Netherlands

EDITORIAL 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