Dear Readers,

Welcome to the 2nd issue of our newsletter, a special edition that highlights a few of the Global Campaign activities that are currently taking place on the African continent. The consultative meeting, which was held in Zimbabwe, was a major step towards promoting the Campaign in Africa. As a result of this meeting, many African countries that had not yet been actively promoting the care of people with epilepsy have now been stimulated to do so. The ball has started rolling, and we hope that it will continue its momentum.

We would also like to thank those persons who have already indicated that they will be submitting articles for future issues of the Global Campaign newsletter, we very much look forward to receiving your stories.

Happy reading!

The countries in red have organised activities under the Global Campaign.

**Epilepsy: A Healthcare Priority in Africa**

**Consultative Meeting on the Implementation of the Global Campaign against Epilepsy in the African Region**

H.M. de Boer (the Netherlands), C. Mandlhate (Zimbabwe), Kathryn Pahl (South Africa) and L.L. Prilipko (Switzerland)

**Introduction**

The meeting “Epilepsy: a Healthcare Priority in Africa” held in Dakar, Senegal on the 5 and 6 May 2000 adopted the African Declaration on Epilepsy.

In December 1999 the WHO Cabinet and Dr. Brundtland, the Director-General of WHO, had already decided that epilepsy would be a priority in the area of neurology and a number of recommendations were made in the Cabinet Paper. It was particularly recommended that the GCAE should be implemented in all 6 regions of WHO.

Following this recommendation, Dr. C. Mandlhate, WHO Regional Advisor for Mental Health for Africa, decided to organise a “Consultative meeting on the implementation of the Global Campaign against Epilepsy in the African Region”.

Furthermore, she realised that to date in the WHO African Region a number of countries are not engaged in activities under the GCAE. Therefore, Dr. Mandlhate felt it to be a challenge to assist the WHO Member States in the development of national programmes by providing appropriate information to be used to initiate activities to support people with epilepsy and their families. Some countries in the different Regions of WHO have already been selected to initiate Demonstration Projects (Senegal and Zimbabwe) and more countries will progressively benefit from the lessons learnt here.
This meeting brought together different professionals from twelve selected countries; members of the International League against Epilepsy and the International Bureau for Epilepsy and individuals from some academic institutions.

The Meeting
The meeting took place in Harare, Zimbabwe from the 4th to the 5th of June 2001. Two participants came from each of the twelve selected countries: Cameroon, Ethiopia, Lesotho, Kenya, Mozambique, Senegal, South Africa, Swaziland, Tanzania, Togo, Uganda and Zimbabwe.

Criterion for selection was: one participant from the Public Sector (Government, Health or Social Service, Training or Research Institutions) and the other one from an Association or NGO active in the field of epilepsy. Both participants having had experience in the field and a leadership role in order to ensure the follow up of the meeting.

The main objective of the meeting was to facilitate the implementation of the WHO/ILAE/IBE Global Campaign against Epilepsy (GCAE) in the countries of the African Region

The good news is, that since this meeting two countries already (Uganda and Mozambique) are planning Global Campaign projects, such as a launch event, the production of leaflets and the education of special target groups on epilepsy.

The programme
Following the opening ceremony, the appointment of the chair, vice-chair and the agenda and the programme of work were adopted.

A historical background on the Global Campaign against Epilepsy (GCAE) was given by L.L. Prilipko (WHO) and H.M. de Boer (IBE), both members of the Campaign Secretariat.

After this the floor was given to Dr. Mohammed Belhocine, Director of the Division of Non-Communicable Diseases who spoke on behalf of the Regional Director of WHO/AFRO.

He finished by saying:

“I can assure you that AFRO is highly committed to translate your recommendations into concrete actions and to build up strong and sustainable partnerships towards more and more successes in the prevention and management of epilepsy”.

Following this, Prof. A.G. Diop presented the African Declaration on Epilepsy, which was adopted in May 2000 in Dakar.

After these presentations, country representatives were given the floor to present their reports, followed by plenary discussions.

From the discussions it became very clear that the participants appreciated the opportunity of sharing experiences and that the represented countries were at different levels concerning the development of epilepsy related activities. The achievements and the challenges were discussed at length.

The following day started with a plenary feedback of the previous day, followed by some comments. The role of the main Partners of the GCAE (IBE, ILAE and WHO) was then discussed. The importance of partnerships was emphasised over and over again (information, experience and expertise sharing) as a basis for the success of the interventions to support people living with epilepsy and their families.

Encouragement for the designation of focal persons or the creation of chapters of the IBE and ILAE at country level was expressed.

Senegal and Zimbabwe are the two countries, which have been selected for the Demonstration Projects of the Global Campaign against Epilepsy in the African Region. Prof. A.G. Diop and Dr. J. Mielke, principal investigators, presented in plenary the summary of the draft protocols and general comments for their improvement were provided. Improved protocols will now be available very soon and the first phase of the projects should start at the latest by the beginning of October 2001.

Furthermore, participants were divided into three working groups to discuss priority interventions, recommendations and actions to be taken as a follow up of the meeting. The main findings and recommendations were presented by the rapporteurs and adopted by the participants. The participants expressed concern on a number of issues and each country was encouraged to consider these as activities, to be selected for the development of action plans to support people living with epilepsy and their families.
In spite of each country’s uniqueness a broad base of commonality was identified in dealing with the issues facing people with epilepsy, including:

- social and cultural beliefs contributing to poor “help-seeking behaviours”;
- stigma, existing even among health workers;
- the non-availability and inaccessibility of antiepileptic drugs;
- the need to strengthen partnerships by improving communication among the different players at country level and the creation of IBE and ILAE chapters where none exist;
- the need to encourage income generating activities for people with epilepsy and their families.

The main findings and recommendations were presented by the rapporteurs and adopted by the participants. Concern was expressed on a number of issues and each country was encouraged to consider these as activities to be selected for the development of action plans to support people living with epilepsy and their families.

- Development of strategic partnerships: This was regarded as the key element for success
- Epilepsy education for various target groups: Accurate and accessible information will reduce the stigma of epilepsy.
- Research and training: Africa-specific research needs to be encouraged and the results to be co-ordinated and disseminated.
- Prevention, both of causes and consequences of epilepsy: most of the causes of epilepsy in Africa are preventable.
- Development of guidelines for epilepsy management: some countries have already produced national guidelines for the management of epilepsy, specially at primary health care level.
- Collaboration with the traditional healers: through information sharing, research and training collaboration should be encouraged. Information and education of the public in general is also important, to enable people to make informed choices.
- Setting up of Drug Banks following the Chilean Model
- Under the GCAE umbrella, to investigate possibilities to acquire affordable AEDs: most of the countries have reported to have in their Essential Drug List one or two antiepileptic drugs.
- Empowerment of people living with epilepsy and their families through the encouragement of income generating projects
- Increase participation of African delegates at international conferences on epilepsy - the “Star for Africa” initiative

Finally a list of action points for WHO headquarters, WHO-AFRO, IBE and ILAE, WHO country offices and IBE and ILAE chapters, National Mental Health Coordinators and National Focal Persons for Epilepsy was drawn up to ensure a follow up of the meeting. The meeting proved to be a great opportunity for experience sharing and an example of an excellent partnership.

A follow up of the recommendations is crucial for the sustainability of these initiatives. Communication among the different partners will have to be strengthened and the description of good practices encouraged.

**First National Campaign against Epilepsy in Ethiopia**

**Zenebe Gedlie Damtie**
Chief Executive Officer, Epilepsy Support Association of Ethiopia

From 17-22 March 2001, the first national Campaign against Epilepsy under the aegis of the ILAE/IBE/WHO Global Campaign was organised in Ethiopia by the Epilepsy Support Association of Ethiopia and Future International Consulting.

The event was a great success. A panel discussion was held which four ministers attended: the Minister of Labour and Social Affairs, the Minister of Education, the Minister of Health and the Minister of Information and Culture. All four of them, as well as the Executive Director and a representative of WHO, delivered keynote speeches.

They all expressed their commitment towards people with epilepsy in Ethiopia.

A workshop was also held under the title: Trends of Epilepsy Management at the Primary Health Care Level. Enthusiastic discussions took place by all participants and an Ethiopian Declaration against Epilepsy was adopted unanimously.

A mass rally guided by a police music band attracted the attention of many people in the streets of the capital while participants urged the public to change their attitudes towards people with epilepsy.

They also asked the government to provide them with the necessary care (antiepileptic drugs) and support.

The media coverage of the event was terrific: many photographs, which appeared in the local newspapers.

The most important issue is, however, that this Campaign is not an end in itself, it is the beginning of future collaboration and partnership between the governmental and non-governmental organisations working in the field of epilepsy.

The Secretariat of the ILAE/IBE/WHO Global Campaign against Epilepsy was most impressed by this event and at the request of the organisers sent letters of appreciation to the sponsors and collaborators of this first national event in Ethiopia.
Participants at the mass rally in Ethiopia, the slogans translate as:
“Epilepsy is not contagious”;
“Let us break the silence around epilepsy
“Stop discrimination at the workplace/school for people with epilepsy”;
“The government should provide aed’s and support to people with epilepsy”.

Epilepsy “Out of the Shadows” in Mauritius

Youssoof Noormamode
President EDYCS Epilepsy Group

The Epilepsy Group of Mauritius celebrated its Epilepsy Day in July 2001, an activity under the ILAE/IBE/WHO Global Campaign against Epilepsy. The day started with a meeting with the Minister of Women and Child Protection and a presentation on the European White Paper on Epilepsy.

People with epilepsy were part of the official delegation and shared their view and concerns with the Ministers as well as with other stakeholders. Following this there was a press conference involving the EDYCS Epilepsy Group, the new IBE member in the country.

Furthermore the Lord Mayor of Port Louis attended and the day ended with an epilepsy public forum under the aegis of the Municipal Council of Port Louis.

Earlier this year, EDYCS was also actively involved in the celebrations concerning World Health Day. The Lord Mayor of St. Louis, the Deputy Prime Minister, the Minister of Justice, the Minister of Social Affairs and a representative of the Ministry of Education were among the guests of that day.

There was a posters/painting exhibition, epilepsy information leaflets were distributed, funds collected, there was an epilepsy information desk, a public survey and much, much more.

The following day a Public Fair was organised which attracted some 6,000 people. An information epilepsy desk was set up and over 1,000 people were sensitised to epilepsy.

In the mean time, contact has been established with the local WHO office and indeed WHO offered to provide EDYCS with technical assistance and guidance.

As a result of all these activities, numerous donor organisations in the country now show a strong commitment to join EDYCS in its endeavour to bring epilepsy out of the shadows!

Public fair in Port Louis, Mauritius

Future Congresses

Where Global Campaign sessions are planned:

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