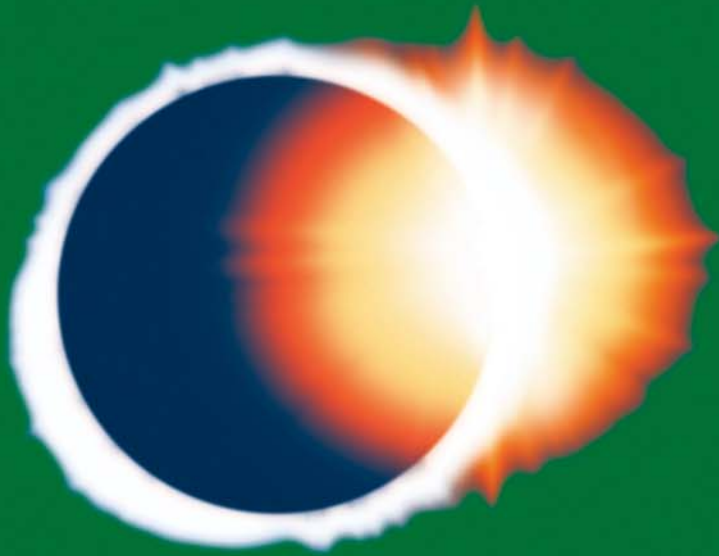


A N N U A L R E P O R T 2 0 0 3



Global Campaign Against Epilepsy

Out of the Shadows



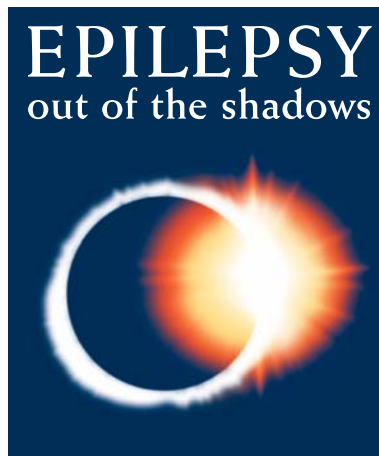
World Health
Organization



International
Bureau for Epilepsy



International League
Against Epilepsy



Bringing Epilepsy "Out of the Shadows"

The ILAE/IBE/WHO Global Campaign against Epilepsy is a joint initiative of the World Health Organization (WHO), the International League against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) to bring epilepsy "Out of the Shadows" by improving the diagnosis, treatment, prevention and social acceptability of the disorder world-wide.

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ILAE/IBE/WHO Global Campaign against Epilepsy

June 2004

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1. Issues and challenges

Recent WHO data suggest that psychiatric and neurological disorders, including epilepsy, are among the most important contributors to the global burden of human suffering. Moreover, there is strong evidence that these conditions impose a range of deleterious consequences on the course and outcome of comorbid chronic diseases. The burden of neurological disorders is particularly difficult in people living in developing countries in absolute and relative poverty. In addition, the Native American enclaves in USA and Canada and some jobless immigrant communities in the industrialised world are also ill-equipped to deal with these problems.

WHO regards epilepsy as a priority. The WHO Mental Health Global Action Programme (mhGAP) follows from the events of 2001 to provide a clear and coherent strategy for closing the gap between what is urgently needed, and what is currently available. The Programme, which will last for 5 years (2002-2007), has adopted the slogan: "Close the Gap, Dare to Care" and epilepsy is specifically mentioned in this Programme.

Of an estimated 450 million people who are affected with mental and neurological disorders worldwide, around 50 million will have epilepsy.

Since 1997, ILAE, IBE and WHO are trying together, in partnership, to raise epilepsy to a level of awareness that could not be achieved ever before, despite all efforts by each of the separate organisations and their affiliates. This report illuminates the results of this partnership, which, after all, aims at bringing epilepsy "Out of the Shadows".

In response to these challenges, the three leading international organisations working in epilepsy have joined forces to bring epilepsy "Out of the Shadows" in the ILAE/IBE/WHO Global Campaign Against Epilepsy, whose mission statement is "To improve the acceptability, treatment, services and prevention of epilepsy world-wide". Its goals, objectives and strategies are as follows:

Goals:

- To reduce the burden of epilepsy by decreasing the treatment gap and promoting the inclusion of epilepsy care in national health care plans.
- To improve the understanding of epilepsy.
- To promote primary and secondary prevention of epilepsy
- To improve epilepsy care – medical, social and psychological
- To reduce the limitations encountered by people with epilepsy and their families

Objectives:

To assure that governments and health care providers place epilepsy on the health and development agenda in order to formulate and implement cost-effective responses to epilepsy

Indicators:

- Proportion of targeted countries that have implemented reforms in the area of epilepsy care
- Number of countries that have increased their budget for epilepsy care
- Number of countries participating in the Campaign

Strategic approaches:

Dissemination of information on the magnitude, burden, diagnosis and treatment of epilepsy as well as information on available resources; provision of support to governments and health care providers for formulating and implementing comprehensive services by offering successful models of epilepsy care, provision of support to countries for fighting stigma and discrimination, support research capacity in developing countries.

2. Ongoing activities and current achievements

2.1 Demonstration Projects

Demonstration Projects have been established or are being initiated in many countries. This number has risen during the last 4 years from 4 to 16 countries. The initial countries being: Argentina, China, Senegal and Zimbabwe. Projects have been developed and implemented in Brazil and Pakistan, whilst projects are in various stages of planning in: AFRO: Kenya, EMRO: Afghanistan, Djibouti, Sudan, Somalia, Yemen, EURO: Georgia, SEARO: India, D.P. Korea, Myanmar and Indonesia.

Zimbabwe, AFRO

The Project aims to improve the quality of life of people with epilepsy in rural areas and is in the second phase of its development. Much has been achieved but progress has been hindered by financial and human resource problems, which are expected to be solved during this biennium.

Senegal, AFRO

The Senegalese Project has been completed. A survey has been conducted among a population of 4,500 people. A prevalence rate of 14.2% was found and the treatment gap amounted to 52%. This data will be submitted soon to peer-reviewed journals. Educational activities within the Project encompassed a.o.:

- Development and dissemination of awareness raising materials
- Organisation of focus groups with youth and women's associations on issues related to epilepsy
- Organisation of training seminars for teachers, the general public and private enterprises
- Public education for the entire country through local radio stations and national television

Argentina, AMRO/PAHO

A pilot Project has been completed. Work is being done on the statistical analysis of the studies performed on the general public, clergy and teachers. The study will be

published in Spanish and in English. The protocol for the Demonstration Project has been finalised. An updated budget and a plan for fundraising are being developed.

Brazil, AMRO/PAHO

A two-day workshop has been held in Brazil with the participation of representatives of the Brazilian League and Bureau and of the Campaign Secretariat. This national Project officially started on the 27th of September 2002. The first two phases, namely the epidemiological survey and the capacitation of health care providers, has been accomplished within a nine months period. As a part of the education component, the Brazilian Ministry of Health sent 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 part of the Global Campaign.

Pakistan, EMRO

Through a local initiative a Comprehensive Epilepsy Control Programme (CECP) was launched in Karachi in March 2001 and is now extending services all over Pakistan. A paper on the Project has been submitted to the WHO Bulletin.

China, WPRO

In China, 55,616 people were screened in 5 provinces. A paper based on the outcomes of the first phase of the Demonstration Project was published in "Neurology" in May 2003 and in a number of Chinese journals. A total of almost 2,000 new patients were treated. The lifetime prevalence of epilepsy was previously thought to be approximately 4/1,000. Thus it was estimated that there would be around 5 million people with epilepsy in China. Now, the prevalence is known to be nearer 7/1,000. Therefore, the number of people with epilepsy is more likely to be around 9 million. These preliminary results have already had an important political impact in China and it has been suggested that the Project should be expanded to the rural areas of the entire country.

2.2 Conferences and meetings with participation of the Campaign Secretariat

January	Teleconference re: Fogarty Grant Meeting members Secretariat, Heemstede, The Netherlands
February	Teleconferences re: Fogarty Grant
March	Joint ILAE/IBE Executive Committee and Preparatory Strategic Planning Meetings, Basel, Switzerland Regional Conference in Cairo, Egypt Meetings on EPICADEC (Epilepsy Care in Developing Countries), Heemstede, The Netherlands
April	EPICADEC Symposium, Breda, the Netherlands on the occasion of its dissolution and the transfer of EPICADEC assets to IBE/ILAE Meeting Regional Advisors, Geneva, Switzerland Meetings on EPICADEC, Heemstede, The Netherlands
May	Conference on Epilepsy as a Public Health Concern, Moscow, Russia Meetings on EPICADEC, Heemstede, The Netherlands
June	Technical Consultative Meeting, Campinas, Brazil Meeting on Guidelines, Troina, Sicily. Meetings on EPICADEC, Heemstede, The Netherlands
September	Meeting on Fogarty Grant, Heemstede,

October	The Netherlands International Epilepsy Congress Lisbon, Portugal: a session on the Campaign was organised Meeting members Secretariat, Lisbon, Portugal Consumer meeting organised by WHO, Geneva, Switzerland Meeting on EPICADEC, Amsterdam, The Netherlands
November	Meeting members Secretariat, Heemstede, The Netherlands
December	International Congress Global Forum for Health Research, Geneva, Switzerland: a presentation on paper on the Campaign was presented Meeting members Secretariat, Geneva, Switzerland

Details of the most important activities described above are given below:

Conferences Cairo, Egypt.

As part of general awareness-raising, a regional conference on public health aspects of epilepsy has been organised. The goals of the conference were to review the present situation of epilepsy care in the region, to identify the country's needs and resources, to control epilepsy at a community level, and to discuss the involvement of countries in the Global Campaign. One of the outcomes was the adoption of the Eastern Mediterranean Declaration on Epilepsy, followed by its wide distribution via mass media channels. The Declaration can be found at the end of this Report (Annex I and II).

The meeting was attended by 50 participants from 25 countries, including local experts and government representatives.



From left to right: Prof. G. Avanzini, President ILAE; Prof. F. Vartanian, Chair Organising Committee; Dr. L.L. Prilipko, Programme Leader Neurology and Neuroscience, WHO Headquarters; Dr. W. Rutz, WHO Regional Advisor for Mental Health in Europe at the conference in Moscow.

Moscow, Russia

A conference on Epilepsy as a Public Health Concern in the Russian Federation was convened in Moscow, Russia on 13-14 May 2003. The goals of the meeting were to:

- 1) introduce and promote the ILAE/IBE/WHO Global Campaign Against Epilepsy "Out of the Shadows" in the Russian Federation
- 2) raise awareness of epilepsy
- 3) discuss the state of epilepsy care nationally and globally
- 4) develop recommendations and a specific plan of action for 2004-2005 at country level.

The participants of the conference agreed that it is important for Russia to join the ILAE/IBE/WHO Global Campaign Against Epilepsy because in Russia, like in any country in the world, there are severe problems related to the delivery of treatment of this worldwide serious brain disorder.

Data presented at this conference has shown the need for a more detailed assessment of the current situation regarding epilepsy care in the Russian Federation. The data also demonstrated that there is a need to elaborate the recommendations on primary and secondary prevention of epilepsy as well as to define relevant standards of treatment and legislation based on the international experience and achievements in this area.

There were approximately 60 participants representing most of the regions of the Russian Federation, including representatives from the Ministry of Health.

On this occasion the European Declaration on Epilepsy was translated into Russian (Annex III).

Meetings

Technical Consultative Meetings

Through the years technical consultative meetings have been organised by the WHO Regional Advisors for Mental Health in collaboration with the Campaign Secretariat with the following aims:

- 1) to review the present state of epilepsy in the regions
 - 2) to discuss regional reports on epilepsy
 - 3) to review the implementation of the Global Campaign, including the progress of demonstration projects
 - 4) to develop a framework of action for countries
- This year such a meeting took place in Campinas, Brazil (AMRO/PAHO) on 13-14 June.

Secretariat Meetings

The Campaign Secretariat met in full only twice this year due to time and financial constraints. However, members met at conferences and meetings of Secretariat members were held in Geneva, Switzerland. Furthermore, monthly teleconferences have ensured good communication and enhanced the progress of the Campaign.

In 2003 two meetings were held in Geneva, involving the Presidents of ILAE and IBE.

Meeting with Regional Advisors

The annual meeting of the Regional Advisers for Mental Health was held in WHO Headquarters in Geneva in March 2003. For the second year, "epilepsy" appeared on the agenda and representatives of the Campaign Secretariat were invited to participate in the discussions on this topic.

Meetings on the development of Guidelines for the Treatment of Epilepsy in Childhood and Adolescence

The Secretariat participated in the meetings of the working group in Sicily, Italy in June 2003 and in Lisbon, Portugal October 2003. The OASI centre



Working group on Guidelines: from left to right: L.L. Prilipko, H.M. de Boer, R. Guerrini, J. Engel jr., H.F.A. Hartmann, G. Avanzini, O. Dulac, M. Elia, F. Vigevano, L. Bolis, M. Weber, C. Acevedo, A. Covanis. Not included in the picture are: E. Beghi and W.A. Hauser

(WHO collaborating centre) in Sicily, Italy, will assist in the production of the Guidelines and act as a focal point for the collection and dissemination of all working materials; once finalised the GCAE will implement the Guidelines through its network.

Members of the Working Group include:

Carlos Acevedo	IBE Latin American Commission, paediatric neurologist - Chile
Giuliano Avanzini	President ILAE - Italy
L. Bolis	Oasi Centre - Italy
Ettore Beghi	ILAE Healthcare Policy Commission - Italy
Hanneke M. de Boer	IBE - the Netherlands, (Campaign Secretariat)
Thanos Covanis	Member IBE Executive Committee, paediatric neurologist - Greece
Maurizio Elia	Oasi Centre - Italy
Jerome Engel Jr.	ILAE Taskforce on Classification - USA (Campaign Secretariat)
Renzo Guerrini	ILAE Commission on Paediatrics - Italy (working in the UK)
Hans Hartmann	Department of Paediatrics, Hannover Medical School - Germany
Allen Hauser	ILAE Commission on Epidemiology - USA

Philip Lee	President IBE - UK
Leonid Prilipko	WHO - Dept. Mental Health and Substance Abuse - Switzerland (Campaign Secretariat)
Federico Vigevano	Past President Italian League Against Epilepsy - Italy
M. Weber	MW, WHO Dept. - Switzerland

These Guidelines are the first set of WHO Guidelines on epilepsy which will be developed. The Guidelines will serve as a prototype, a template for future guidelines within the framework of the Global Campaign. An extensive discussion took place on whether the Guidelines should be evidence-based and the following was agreed:

- the Guidelines will be consensus Guidelines rather than evidence-based and recommendations will be made to develop evidence-based Guidelines for certain topics whenever appropriate;
- the Guidelines will be targeted at developing countries, with the algorithm giving optimal solutions and ways of dealing with less if facilities are not available;
- the Guidelines will aim at primary health care workers with a rudimentary medical background;
- the final product should consist of a simple and clearly written algorithm for seizures and epilepsy, (not a detailed differential diagnosis) and for treatment;

- each box in the algorithm will be accompanied by a written document;
- the language used in the Guidelines will be ordinary jargon, which will need to be field-tested prior to publication thereof.

Preparatory Strategic Planning Meeting

A Preparatory Strategic Planning Meeting was organised in Basle, Switzerland in February 2003 following the meetings of the Joint Executive Committees with the following aims:

- to discuss the progress and the prospects of ongoing activities
- to start the thinking process for the next phase of the Campaign
- to initiate the organisation of a strategic planning meeting to be held in 2004/5
- to discuss fundraising activities



Discussions at the Preparatory Strategic Planning Meeting

After lively discussions the following was recommended:

- To create an internationally understood and accepted knowledge base of epilepsy, founded on an understanding of fundamental mechanisms
- To achieve access to appropriate medical care (accurate diagnosis and effective treatment)
- To achieve universal primary and secondary prevention of epilepsy within acceptable ethical guidelines
- To reduce the limitations encountered by people with epilepsy and their families

Teleconferences

Teleconferences form an important method of communication for the Campaign Secretariat. The following conferences were held:

- Monthly conferences involving all members of the Secretariat, to discuss ongoing activities and stimulate new initiatives
- Daily phone calls involving some members of the Secretariat concerning the day-to-day running of the Campaign
- Monthly teleconferences with Regional Advisors: to discuss activities in the Regions
- Teleconferences with various Principal Investigators: in order to discuss the progress of the Demonstration Projects
- Teleconferences with the Scientific Project Leader and Regional Facilitator, concerning the co-ordination of the Demonstration Projects
- Teleconferences with organisers of meetings and conferences, in order to assist in the organisation of various activities

All meetings and conferences have been carefully minuted.

2.3 Other activities

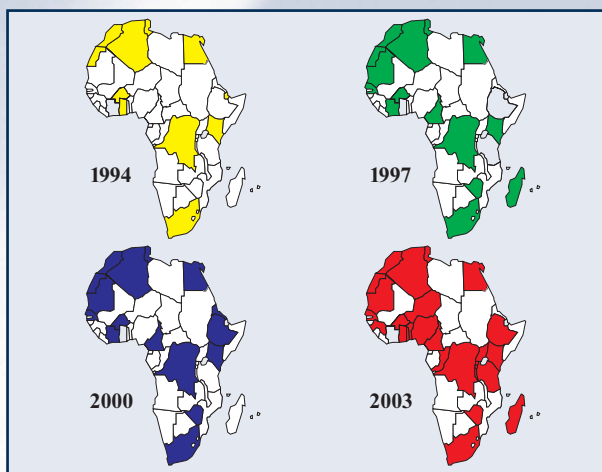
Other activities include:

Questionnaires on Country Resources: more than 120 had been completed and were entered in the database by the end of 2003. Data collection is ongoing.

Regional Reports are being developed in all six WHO Regions. These reports are meant to be political tools, describing the present situation concerning epilepsy and epilepsy care in each region. Included in the reports will be country data collected through the Questionnaires on Country Resources for Epilepsy.

Chapter development through Campaign activities is also pursued in order to support existing initiatives and to facilitate skills transfer.

Through Campaign activities many new contacts have been made and old ones renewed and the number of IBE/ILAE members (Chapters) has grown significantly as can be seen in the picture below.



Increasing number of contacts in Africa

2.4 Publications

Campaign articles have been published in, or submitted to peer reviewed journals, such as: *Epilepsia*, *Neurology* and the *WHO Bulletin*.

Both *Epigraph* and *IE News* as well as national newsletters of IBE/ILAE Chapters published a number of articles on Campaign activities.

Annual and quarterly reports were produced in order to continue raising awareness and interest for the Campaign and its activities.

Campaign newsletters were published 3 times and sent to over 600 addresses each time.

The Campaign brochure was expanded, updated and reprinted. Over 1,000 copies have been distributed world wide. Brochures and leaflets have been developed in many countries.

Inserts were included in congress bags of the 2,000 participants in the International Epilepsy Congress in Lisbon, Portugal (October 2003) providing information on the Campaign plus advertising the Campaign session.

Publications in peer-reviewed journals:

- Aziz H. Country Example within the Framework of the Campaign. *Epilepsia* 2003; 44, (Suppl 8): 25
- Boer H.M. de. The African Commission and its links with the ILAE/IBE/WHO Global Campaign Against Epilepsy. *Epilepsia* 2003, 44, (Suppl 8): 33
- Boer H.M. de. The Global Campaign Against Epilepsy as a Model for Raising Awareness. *Epilepsia* 2003, 44, (Suppl 8): 24
- Boer H.M. de, Engel J. Jr., Prilipko L.L. The Global Campaign at a glance: A Progress Report. *Epilepsia* 2003; 44, (Suppl 8): 24
- Diop A.G., Boer H.M. de, Mandlhate C., Prilipko L.L. The Global Campaign against Epilepsy in Africa. *Acta Tropica* 2003; 87:149-59
- Engel, J. Jr. Bringing epilepsy out of the shadows. *Neurology* 2003; 60:1412
- Meinardi H. Demonstration Projects in Africa. *Epilepsia* 2003, Vol 44, (Suppl 8): 25
- Ndoye N.F. Prevalence Rate and Treatment Gap in the Pikine (Senegal) Demonstration Project Site of the Global Campaign Against Epilepsy. *Epilepsia* 2003; 44, (Suppl 8): 125,
- Pachlatko C. Twinning Partnership: Visible Benefits within the Framework of the Global Campaign. *Epilepsia* 2003; 44, (Suppl 8): 25
- Pahl K. Regional Report on Epilepsy in Africa: An awareness-raising tool. *Epilepsia* 2003; 44, (Suppl 8): 25
- Sander J.W. Progress Report on the Demonstration Projects. *Epilepsia* 2003, 44, (Suppl 8): 25
- Sow A.D., Gueye C.S.K. Use of Various Methods to Increase Awareness of Epilepsy at Pikine (Senegal) in the Context of the Demonstration Project of the Global Campaign Against Epilepsy. *Epilepsia* 2003; 44, (Suppl 8): 195
- Wang W.Z., Wu J.Z., Wang D.S., Dai X.Y., Yang B., Wang T.P., Yuan C.L., Scott R.A., Prilipko L.L., Boer H.M. de, Sander J.W. The prevalence and treatment gap in epilepsy in China: an ILAE/IBE/WHO study, *Neurology* 2003; 60: 1544-545

Other publications

- Boer H.M. de. Epilepsie in andere landen, is er een verschil? *NeuroNieuws*, jaargang 18, nummer 4: 14, 2003
- Boer H.M. de, Engel J. Jr., Prilipko L.L. Activities of the ILAE/IBE/WHO Global Campaign. *Epigraph*, 2003
- Boer H.M. de. Sixth Regional Declaration on Epilepsy Completed. *International Epilepsy News* 1: 3, 2003
- Sander J.W. Epilepsy in Developing countries often left untreated. *International Epilepsy News* 2: 16-17, 2003
- Uranek K. Bringing epilepsy out of the shadows. *Pathways* (Novartis), Volume 4, number 1, 2003

3. Preparations for future activities

For WHO a plan of activities was prepared within the framework of the Campaign for the years 2006/7

Expected results	Indicators	Target	Baseline
To improve the acceptability, treatment, services and prevention of epilepsy world-wide	Decrease the treatment gap in epilepsy by improving the diagnosis and treatment.	20% decrease in the treatment gap in epilepsy by initiating and developing demonstration projects in seven more selected countries, thus covering all six WHO Regions.	At present, the treatment gap in epilepsy is estimated at 80% globally. Demonstration projects have been initiated and developed in six countries in three WHO Regions.
	Number of countries incorporating epilepsy care in national health care plans.	3-5 countries	Low priority is given to epilepsy care world-wide.
	Number of countries involved in the development of tools to reduce stigma in epilepsy and the disease burden associated with it.	At least 5 countries.	At present there are no validated tools to fight stigma in epilepsy, and the burden of this disease is very high.

Already the following activities are being developed and funds being secured by, or in collaboration with, the Campaign Secretariat.

Atlas on Epilepsy: In 2000, WHO launched the project Atlas to provide information about health resources in different countries. The first in this series was published in October 2001 as "Atlas: Mental Health Resources in the World". WHO now plans to produce an "Atlas on Country Resources for Epilepsy" and a survey questionnaire was developed covering the profile of epilepsy resources available in the country. The work started in 2001. We now have data available from over 120 countries.

The objectives of this report include collection, compilation and dissemination of relevant information on epilepsy resources in the majority of countries in the world. It will provide global and regional analyses on epilepsy resources data, collected from over 120 countries to date, although it is believed that even more countries will be included.

Countries who have submitted completed surveys by the end of 2003		
Region	N countries replied	% total for region
AFRO	33	72%
AMRO/PAHO	19	53%
EMRO	10	46%
EURO	38	73%
SEARO	8	73%
WPRO	23	82%
Global total	131 completed surveys = 67%	

Atlas data not only provide a clear picture of the existing resources and crucial needs in countries around the world, but also provides a baseline for monitoring changes over time. The Atlas should drive global and regional epilepsy programmes. On a global level the data will help to make the world more aware of exactly how deficient epilepsy resources are and provide an

impetus to international efforts to enhance these resources. This data will be used for the WHO Regional Reports on Epilepsy. On a national level, the analysis identifies areas that need urgent attention by health planners and policymakers within countries. The Atlas will be included both on the WHO and on the Campaign website and the data will be updated on a regular basis.

Georgia, EURO: The possibility of raising funds for the initiation of a Demonstration Project in Georgia has been explored by the Campaign Secretariat. Georgia had been selected at the recommendation of Prof. Peter Wolf, as well as the WHO Regional Advisor for Mental Health in Europe and other experts. Georgia had been selected as it is a small country with active IBE and ILAE chapters and a WHO country representative who is also very motivated to initiate a Project within the framework of the Campaign. Contact has been established with the national WHO representative and with the IBE/ILAE Chapters.

New developments:

During the past year the focus of the Campaign has extended to the most vulnerable population groups in the developed world.

USA, AMRO/PAHO: A new project amongst Navajo Indians is being planned. The idea for this project is a response to a request for proposals on health disparities from the US National Institutes of Health which may fund the study if it is accepted.

Italy, EURO: A project has been proposed to create a reference resource for immigrants with epilepsy in Milan, Italy, where they can find the medical and social support they may need. Funds have been raised to initiate a pilot project.

EPICADEC, Netherlands, EURO: Background: The foundation EPilepsy CAre in DEveloping Countries

decided to wind up its activities. Under its Constitution, its assets would have to be transferred to an organisation(s) with goals similar to those of EPICADEC.

The Executive Board of EPICADEC then proposed to transfer the assets of EPICADEC to the joint ownership of the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). The following agreement determines the conditions thereof: The funds are held in a named, dedicated fund. IBE and ILAE, acting together, will utilise the money subject to the following:

- A project supporting local initiatives in developing countries in agreement with the objectives of the ILAE/IBE/WHO Global Campaign Against Epilepsy
- Providing workers in developing countries with means to obtain and exchange information about ways to reduce the burden of epilepsy

The Local Initiatives Project aims to develop and implement procedures that guarantee efficient and fair financial support of local initiatives (bottom up) in the field of epilepsy.

In order to guarantee that the initiatives are prioritised according to contents rather than project formulation and presentation, the Local Initiatives Project will assist the applicants with the formulation of promising projects, thus allowing support for grass root level needs. A member of the former executive board of EPICADEC has been charged with the development of the Local Initiatives Project within the framework of the Global Campaign Against Epilepsy. This person is designated Local Initiatives Project Leader. The restricted fund is managed by the Secretariat of the Global Campaign Against Epilepsy and the Local Initiatives Project Leader together, according to procedures set by ILAE and IBE.

India, Indonesia, Myanmar, Nepal, D.P. Korea, SEARO: WHO SEARO has launched an initiative with the objective to enhance the capacity of the existing health care delivery system to identify and manage epilepsy in the community.

Funds permitting, projects will be set up in the above mentioned countries to diminish the treatment gap. The objective is to provide appropriate medication for at least 60% of untreated people with epilepsy.

Vietnam and China, WPRO: Under the Campaign a grant application for a pilot project on stigma in epilepsy was submitted to the Fogarty Foundation, which was subsequently awarded. There is a general agreement that stigma and exclusion are common features of epilepsy in both the developed and developing countries and a major contributor to the burden associated with the condition. Reducing the stigma of

epilepsy is therefore key to reducing its impact and so improving the quality of life.

This project will involve ethnographic studies to explore prevailing beliefs and attitudes to epilepsy in two developing countries, China and Vietnam. It will define theoretical models of stigma and its link to disease burden. It will develop validated and culturally specific measures of outcome for use in future intervention studies. Through its implementation, the project will enhance social science capacity in these two countries and facilitate development of strong collaborations for future related research activities.

4 Administration and Finance

Through WHO Headquarters and through the WHO Regional Offices, funds are provided for: Demonstration Projects, regional conferences, technical consultative meetings, etc.

Through IBE/ILAE, funds are provided for the administrative running of the Campaign

Fundraising

As in previous years it has not been easy to obtain the funds necessary for the growing number of activities. This year, for the first time, the Campaign Secretariat has been involved in or has stimulated grant applications. During 2003, 2 grants have been applied for, one of which was awarded by the Fogarty Foundation.

The Campaign Secretariat would like to thank the following organisations, institutions and private donors for their support to the Global Campaign against Epilepsy: "Out of the Shadows", a joint project of the International League Against Epilepsy, the International Bureau for Epilepsy and the World Health Organization:

Dutch National Epilepsy Fund, Houten, the Netherlands

IBE/ILAE Chapters, Friends and Commissions

Fogarty Foundation, National Institute of Health, USA

Oasi Centre, Sicily, Italy

Rotary, Milano, Italy

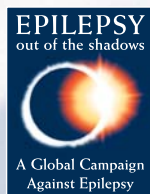
Sanofi-Synthélabo, Paris, France

Stichting Epilepsie Instellingen Nederland, Heemstede, the Netherlands

UCB Pharma, Brussels, Belgium

and all others who have contributed to its success.

5. Annex I



EASTERN MEDITERRANEAN DECLARATION ON EPILEPSY

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. 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,

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, March 04, 2003



Annex II



إعلان مجموعة شرق المتوسط حول الصرع

في إطار الحملة العالمية ضد الصرع، التي ترعاها منظمة الصحة العالمية، والتحالف الدولي ضد الصرع، والمكتب الدولي المعني بالصرع، عُقد اجتماع، في القاهرة، يومي 3 و4/3/2003، بعنوان «الصرع باعتباره مشكلة من مشكلات الصحة العمومية التي تسبب القلق في إقليم شرق المتوسط». وقد شارك في هذا الاجتماع مهنيون من قطاعي الصحة والعلوم الاجتماعية وممثلون لمختلف الجامعات من الدول الأعضاء في الإقليم. وقد وافق المشاركون بالإجماع، على إصدار الإعلان التالي:

بالنظر إلى ما يلي:

- أن الصرع هو أكثر الاضطرابات الدماغية المزمنة والوخيمة، شيوعاً، إذ يقدر أنه يصيب ما لا يقل عن 50 مليون شخص في العالم، يعيش ما يناهز 4 ملايين منهم في إقليم شرق المتوسط؛
- أنه خلافاً للكثير من الأفكار الخاطئة السائدة، فإن الصرع يُعدُّ اضطراباً دماغياً، له أسباب طبيعية، ويتطلب علاجاً طبياً؛
- أن كثيراً من الناس يجهلون أن الصرع مرض قابل للعلاج، وأن كثيراً من المصابين به يمكنه أن يعيشوا حياة مثمرة ومنتجة، إذا ما تلقوا العلاج اللازم، وهو علاج رخيص الثمن نسبياً، وفعال؛
- أنه في بعض أنحاء إقليم شرق المتوسط، ولاسيما المناطق الريفية، لا يحصل الكثير من المواطنين على التوريدات الصحية الملائمة أو العلاجات المناسبة؛
- أن المعلومات العامة حول الصرع، وحول الخبرات المدربة، وحول المرافق التشخيصية، وحول الأدوية والجراحات المتاحة لمعالجة الصرع، لا تتوافر للكثيرين من مرضى الصرع، أو أنهم لا يستطيعون دفع تكاليفها، وذلك لأسباب جغرافية، أو مالية، أو ثقافية، أو لقصور في الاتصال؛
- أن للصرع عواقب جسدية ونفسية واجتماعية وخيمة على المصابين به وعلى عائلاتهم؛
- آثار الصرع تكون أكثر شدة في الأطفال والمراهقين؛
- أن الصرع لا يحظى بالاهتمام الكافي في الخطط الصحية الوطنية الراهنة، في كثير من البلدان.

فإننا نناشد حكومات الدول الأعضاء بإقليم شرق المتوسط، والمنظمات الوطنية والإقليمية، في القطاعين الخاص والعام، وجميع مقدّمي الرعاية الصحية، وعموم الجمهور، أن ينضموا إلينا في اتخاذ إجراءات قوية وحاسمة لتحقيق أغراض الحملة العالمية ضد الصرع، التي ترعاها منظمة الصحة العالمية، والتحالف الدولي ضد الصرع، والمكتب الدولي المعني بالصرع، تحت شعار: «الصرع: خارج الظل». ونحث، بشكل خاص، على العمل على تنفيذ الأمور التالية:

- تلبية جميع الاحتياجات من حيث الوقاية من الصرع، وتوفير العاملين المدربين، ومعدّات التشخيص الحديثة، والأدوية المضادة للصرع، والعلاج الجراحي عند اللزوم، إضافة إلى إعادة تأهيل المرضى وإدماجهم في المجتمع؛
- إدراج الأدوية المضادة للصرع في قائمة الأدوية الأساسية في جميع البلدان، والعمل على توفيرها بشكل مستمر، تجنّباً للأثار الوخيمة المترتبة على توقّف العلاج؛
- تثقيف المهنيين الصحيين والمتطوعين المعنيين، في جميع مستويات الرعاية الصحية، على التعامل مع الصرع، وتدريبهم على تقديم الرعاية الصحية اللازمة؛
- تثقيف مرضى الصرع، وعائلاتهم، والجمهور عموماً، بشأن الصرع باعتباره مرضاً عصبياً شائعاً، وذلك من أجل استئصال الأفكار الخاطئة، وتمكين المرضى من البحث عن المعالجة المناسبة، ومن ثمّ تحسين جودة حياتهم؛
- التخلّص من جميع أشكال التمييز في كل مناحي الحياة، ولاسيّما في ما يتعلق بالالتحاق بالمدارس، والتوظيف؛
- تشجيع القطاعين العام والخاص، والمنظمات اللاحكومية، على المشاركة في الأنشطة المحلية التي تنقذ في إطار الحملة العالمية ضد الصرع؛
- تعزيز وتشجيع البحوث الأساسية والتطبيقية في مجال الصرع، باعتبارها جزءاً لا يتجزأ من الخدمات الصحية المتعلقة بالصرع، على جميع المستويات؛
- إعلان يوم وطني للصرع؛
- تشجيع التعاون الإقليمي والدولي في هذا المجال.

القاهرة، في 2003/3/4



World Health
Organization

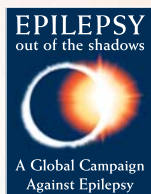


International
Bureau for Epilepsy



International League
Against Epilepsy

Annex III



Европейская декларация по эпилепсии 25 октября 1998 г.

На совещании в Гейдельберге, Германия, 25 октября 1998 г. более 100 руководителей европейских профессиональных и общественных организаций, представителей ВОЗ и медицинских экспертов из правительственных и университетских кругов единодушно приняли следующую декларацию:

- В Европе в настоящее время эпилепсией страдают шесть миллионов человек; в тот или иной период жизни эпилепсией болеют 15 миллионов человек.
- Эпилепсия влечет за собой глубокие физические, психологические и социальные последствия.
- Более всего от невыявления и недостаточного лечения страдают дети, подростки и пожилые.
- При надлежащем лечении более трех четвертей больных эпилепсией могут вести нормальную жизнь без припадков.
- Эпилепсия обходится странам Европы более чем в 20 миллиардов европейских валютных единиц в год, и эту сумму можно было бы значительно сократить за счет эффективных действий.

Мы призываем правительства стран Европы, Европейский союз и всех организаторов и практических работников здравоохранения вместе с нами включиться в активные и решающие действия для достижения задач Глобальной кампании против эпилепсии, инициированной ВОЗ, Международной противозепилептической лигой (МПЭЛ) и Международным бюро по эпилепсии (МБЭ).

В частности, мы настоятельно призываем предпринимать действия в целях:

- улучшения понимания эпилепсии среди населения и, таким образом, снижения стигматизации
- устранения дискриминации по отношению к лицам, страдающим эпилепсией, на рабочих местах
- оказания помощи людям, страдающим эпилепсией, в понимании своего состояния и обеспечения им практической возможности обращаться за соответствующим лечением и вести полноценную жизнь
- улучшения знаний работников медико-санитарной помощи и других специалистов в отношении эпилепсии в ходе их базовой и последующей профессиональной подготовки
- обеспечения наличия современной материальной базы, оборудования, квалифицированных специалистов и полного комплекта антиэпилептических лекарственных средств, с тем чтобы обеспечить точную диагностику и последующее наиболее эффективное лечение
- содействия научным исследованиям по эпилепсии и ее лечению
- поощрения тесных связей между правительствами, органами и учреждениями здравоохранения и социального обеспечения, а также национальными отделениями МПЭЛ и МБЭ
- оказания поддержки публикации специального документа в качестве подробного изложения позиции общественного здравоохранения в отношении эпилепсии в Европе
- обеспечения практической помощи странам с недостаточно развитыми службами борьбы против эпилепсии как в Европе, так и за ее пределами.

Общие данные

Эпилепсия является одним из наиболее распространенных серьезных заболеваний головного мозга человека. Она поражает людей всех рас и социальных классов во всех возрастах, но более всего в детстве и пожилом возрасте. В мире эпилепсией страдают по меньшей мере 40 миллионов человек. В тот или иной период жизни эпилепсия поражает 100 миллионов человек.

Большинство людей неправильно понимают, что такое эпилепсия и это приводит к страху, скрытности, стигматизации и повышению риска социальных и юридических последствий. В некоторых европейских странах эпилепсия все еще не признается как расстройство головного мозга, и до 40% страдающих ею, возможно, не получают лечения. Продолжительность жизни больных эпилепсией сокращается. Фактически, в конкретных группах больных эпилепсией риск смертности может быть в два раза выше, чем у остальной части населения.

МПЭЛ опубликовала документ "Надлежащие стандарты ведения эпилепсии в Европе". Однако специалисты, занимающиеся лечением эпилепсии, зачастую не имеют достаточного объема специализированных знаний в отношении этого заболевания. В некоторых странах не всегда имеются противоэпилептические лекарственные средства, либо они недоступны по цене. В ряде европейских стран материальная база диагностики не соответствует имеющимся потребностям.

Хотя исследования ВОЗ и Всемирного банка показали, что эпилепсия представляет собой серьезное экономическое бремя, очень немногие европейские страны имеют национальные планы борьбы против эпилепсии.

Эпилепсия влечет за собой глубокие физические, психологические и социальные последствия:

- Многие дети с эпилепсией не получают достаточного школьного образования.
- Доля безработных непропорционально высока среди лиц с эпилепсией, в основном из-за невежества работодателей. Эта доля в два–три раза превышает общий показатель, а также показатель для лиц с другими инвалидностями.
- Многие люди страдающие эпилепсией скрывают свое состояние. Это способствует социальной изоляции, низкой самооценке и может привести к потере веры в будущее и депрессии.
- Многие люди с эпилепсией не располагают достаточными знаниями о своем состоянии. Женщинам с эпилепсией зачастую не хватает информации в отношении правильного поведения во время беременности и деторождения.
- Качество жизни пожилых зачастую понижается в связи с заболеванием эпилепсией.
- Многие лица с эпилепсией сталкиваются с серьезной проблемой в связи с ограничением независимости передвижения.

Задачи Глобальной кампании против эпилепсии, проводимой совместно Всемирной организацией здравоохранения, Международной противоэпилептической лигой и Международным бюро по эпилепсии, таковы:

- повысить осознание общественностью и специалистами того, что эпилепсия является широко распространенным, поддающимся лечению расстройством головного мозга
- повысить уровень понимания обществом причин этого заболевания и способов борьбы с ним
- содействовать просвещению общественности и подготовке специалистов по вопросам эпилепсии
- выявлять потребности лиц с эпилепсией на национальной и региональной основе
- поощрять правительства и медико-санитарные органы принимать меры для удовлетворения потребностей лиц с эпилепсией, включая повышение осведомленности о проблеме, просвещение, диагностику, лечение, уход, службы и профилактику.

Information

Further information on the Global Campaign against Epilepsy can be obtained from:

The International Bureau for Epilepsy

Key Contact: Hanneke M. de Boer
Stichting Epilepsie Instellingen
Nederland
Achterweg 5
2103 SW Heemstede
The Netherlands
Tel: + 31 23 55 88 412
Fax: + 31 23 55 88 419
E-mail: hdboer@sein.nl

The International League against Epilepsy

Key contact: Jerome Engel jr.
Reed Neurological Research Center
UCLA School of Medicine,
710 Westwood Plaza
Los Angeles, CA90095-1769 USA
Tel: + 1 310 825 5745
Fax: + 1 310 206 8461
E-mail: engel@ucla.edu

The World Health Organisation

Key Contact: Dr. Leonid L. Prilipko
Department of Mental Health and
Substance Abuse
20 Avenue Appia
1211 Geneva 27 - Switzerland
Tel: + 41 22 791 3621
Fax: +41 22 791 4160
E-mail: prilipkol@who.int

Regional Offices of WHO:

WHO Regional Office for Africa (AFRO)

Cité du Djoué, P.O. Box 6
Brazzaville, CONGO
Cel Phone: 00242 22 56 18
Direct Phone: 0047 241 39385
Operator: 00 47 241 39498 Ext/39385
DNC Fax: 0047 241 39514
E-mail: agossout@afro.who.int

WHO Regional Office for the Americas (AMRO)

525, 23rd Street,
NW Washington, DC 20037, USA
Tel: + 1 202 974 3000
Fax: + 1 202 974 3663
E-mail: mirandac@paho.org

WHO Regional Office for the Eastern Mediterranean Region (EMRO)

W.H.O. Post Box 7608,
Abdul Razak Al-Sanhouri Street,
Naser City, Cairo-11371. EGYPT.
Tel: + 20 2 276 5391
Fax: + 20 2 276 5415
Residence: + 20 2 272 2364
Mobile: + 20 12 792 3052.
E-mail: murthys@emro.who.int

WHO Regional Office for Europe (EURO)

8, Scherfigsvej
DK-2100 Copenhagen Ø,
Denmark
Tel: + 45 39 17 1572
Fax: + 45 39 17 1865
E-mail: MFM@who.dk

WHO Regional Office for South-East Asia (SEARO)

World Health House,
Indraprastha Estate
Mahatma Gandhi Road
New Delhi 110002, India
Tel: + 91 11 331 7804/7823
Fax: + 91 11 332 7972
E-mail: chandrav@whosea.org

WHO Regional Office for the Western Pacific Region (WPRO)

P.O. Box 2932
1099 Manila, Philippines
Tel: + 632 52 88 001
Fax: + 632 52 11 036
E-mail: wangx@wpro.who.int

Anyone interested in following the progress of the Campaign will be able to do so from the regular updates on the relevant web sites:

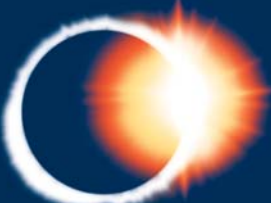
www.who.int/mental_health/management/

www.globalcampaign-epilepsy.org (joint IBE/ILAE Campaign site)

www.ibe-epilepsy.org

www.ilae-epilepsy.org

EPILEPSY
out of the shadows



A Global Campaign
Against Epilepsy