



# 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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A sheltered workshop employing people with epilepsy

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# Background

## The history

It seems appropriate to commence this annual report as in previous years<sup>1</sup> with a brief description of the background and the history of the Global Campaign Against Epilepsy (GCAE).

The following is a calendar of the main events that took place since the beginning of the GCAE:

- 1997** Launch of the 1st Phase of the Campaign in Geneva <sup>2/3</sup>, Switzerland (WHO Headquarters) and in Dublin (22nd International Epilepsy Congress)
- 1998** First Regional Conference on Public Health took place in Heidelberg, Germany and the first Regional Declaration on Epilepsy<sup>2</sup> was unanimously adopted.
- 1999** Approval of Cabinet Paper on the Campaign by the Director-General and the Cabinet of WHO (Attachment I)
- 2000** Four more Regional Conferences took place: in Senegal, Africa; in Chile, Latin America; in India, South East Asia and in the USA, North America.
- More than 1,200 representatives from WHO, ILAE and IBE, other nongovernmental organisations and UN agencies, governments, universities and health care providers from well over 100 countries, representing millions of people with epilepsy, were involved in the development and adoption of all Regional Declarations
- 2001** Launch of the 2nd Phase of the ILAE/IBE/WHO Global Campaign against Epilepsy in Geneva<sup>4/5</sup>

The more recent history may be found in the references above and elsewhere in this report.

<sup>1</sup> Annual Report ILAE/IBE/WHO Global Campaign against Epilepsy 2000

<sup>2</sup> WHO Press Release 1997

<sup>3</sup> WHO Fact Sheets 165-168, 1997

<sup>4</sup> Press Release WHO/7, 12 February 2001

<sup>5</sup> WHO Fact Sheets 165-168 Revised February 2001

## The rationale

Epilepsy is the most common serious brain disorder and a global problem affecting all ages, races, social classes and countries. It imposes enormous physical, psychological, social and economic burdens on individuals, families and countries, especially due to misunderstanding, fear and stigma. These problems are universal but are greatest in the developing world where 85 % of the fifty million people with epilepsy live and up to 90% or more receive no diagnosis or treatment.

The Global Campaign against Epilepsy "Out of the Shadows", is a joint initiative of the International League against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE) and the World Health Organization (WHO). Each of the organisations had tried to make a difference, but none really succeeded. It seemed therefore a rather logical step to try and join forces, form a partnership, which is exactly what the Campaign is, a partnership!

The mission statement of the Campaign is:

To improve the acceptability, diagnosis, treatment, services and prevention of epilepsy world-wide".

After all 70-80% of people with epilepsy could live normal lives if appropriately treated.

## The strategy

The objectives of the Campaign are:

- to increase the public and professional awareness of epilepsy as a universal treatable brain disorder
- to raise epilepsy on to a new plane of acceptability in the public domain
- to promote public and professional education about epilepsy
- to identify the needs of people with epilepsy on a national and regional basis
- to encourage governments and departments of health
- to address the needs of people with epilepsy, including awareness, education, diagnosis, treatment, care, services and prevention

The Campaign includes international, regional and national components, which are interrelated.

The strategy of the Campaign includes two parallel and simultaneous tracks; it provides a platform for general awareness and understanding of epilepsy by organising:

- the Launch of the 2nd phase of the Campaign in the year 2001; and
- the Regional Conferences on Public Health Aspects

And within the second track the Campaign will assist Departments of Health in identifying the needs and promoting education, training, treatment, services, research and prevention by:

- providing information and support for national initiatives and
- initiating Demonstration Projects

During the initial stage the strategy of the Campaign was essentially focussed on advocacy and awareness activities, which is clear from the activities that took place during this phase.

Experience of the initial stage of the Campaign, however, created the rationale for the suggestion of the Launch of a 2nd Phase of the Campaign with new and even more ambitious goals: to improve the health care services, treatment, prevention and social acceptance of epilepsy world-wide.

The main activities to achieve these goals are the initiation and implementation of Demonstration Projects in a number of selected countries.



## Annotation

The achievements of the Campaign during this calendar year will be described further down, but in short they are summarised below:

**January** Publication of the annual report for 2000.

**February** Launch of the 2nd phase of the Campaign (Geneva, Switzerland), amongst others in the presence of the Director-General of WHO. Various P.R. (public relations) materials, folders, posters and fact sheets were produced for the occasion.

**March** Launch of the European White Paper on Epilepsy in the European Parliament, (Brussels, Belgium).

**June** Technical consultative meeting on the implementation of Campaign activities in Africa, organised by the WHO Regional Office in Africa jointly with GCAE Secretariat and WHO headquarters (Harare, Zimbabwe).

**July** Publication of the first GCAE Newsletter.

**July** Technical consultative meeting with the principal investigators for the Demonstration Project in Argentina, in the presence of the WHO Regional Adviser on Mental Health, AMRO, representatives of the Ministry of Health, GCAE Secretariat, etc. (Buenos Aires, Argentina).

**August** Development and mailing to 196 countries of a Questionnaire on Country Resources in Epilepsy.

**November** Technical Consultative Meeting on the implementation of Campaign activities in the Western Pacific Region, organised by the WHO Regional Office for the Western Pacific, jointly with the GCAE Secretariat and WHO headquarters (Manila, Philippines).

Workshop on the future activities under the umbrella of the Campaign in the South-East Asian Region, organised by the WHO Regional Office for South-East Asia, jointly with the Campaign Secretariat (Bangkok, Thailand).

**December** WHO/NGO (non-governmental organisation) meeting and working meeting of the GCAE Secretariat.

# Global activities

## The Launch

The year 2001 has seen a major event in the GCAE. On 12 February the Launch of the 2nd Phase of the GCAE took place at WHO headquarters, Geneva, with the active participation of the Director-General of WHO, Dr. Gro Harlem Brundtland, Executive Director of the WHO cluster of Noncommunicable Diseases and Mental Health, Dr Derek Yach, and Director of the Department of Mental Health and Substance Dependence, Dr Benedetto Saraceno. Furthermore, senior WHO staff from a number of clusters and departments responsible for or related to the GCAE, were participating as well as the Regional Advisers on Mental Health from all six WHO Regional Offices, John Bowis, MEP (Member of the European Parliament), representing national governments and the European Parliament and both Executive Committees of IBE and ILAE.

Finally represented were:

- 13 missions of WHO country members
- 24 national member organisations IBE/ILAE
- 4 NGO's in neuroscience/neurology
- 17 private sector

The programme of the Launch as well as the speech presented by Dr. Gro Harlem Brundtland, Director-General of WHO are attached (Attachment 3)

A press conference followed and provided the Campaign with time on radio and TV across the world, as well as space in the print media.



From left to right (front) Prof. J. Engel Jr., Hanneke M. de Boer, Dr. Derek Yach, Dr. Gro Harlem Brundtland, Dr. Benedetto Saraceno, Dr. Leonid Prilipko, Dr. Edward H. Reynolds, Philip Lee.

In order not to lose the momentum of the day, the official Launch event was followed by a symposium on public health aspects of epilepsy and the role of the GCAE, where the main problems related to epilepsy were discussed and the main directions of the Campaign were clarified.

The next day, a technical consultative meeting was convened by the Secretariat, which was attended by all WHO Regional Advisers on Mental Health, the members of the

IBE/ILAE Executive Committees and the principal investigators of the various Demonstration Projects. The meeting was held at WHO headquarters. The main objectives of the meeting were to discuss:

- the present state of affairs in the regions (concerning epilepsy related activities)

- the needs in the regions
- the way forward in the regions

It was unanimously decided to increase activities on epilepsy in all regions including:

- the initiation of anti-discriminatory legislation
- approaching governments
- the organisation of Technical Consultative Meetings in order to implement the Campaign in the various regions.

In the afternoon of the same day, the principal investigators from Argentina, China, Senegal and Zimbabwe met with the project co-ordinators with the objective:

- to clarify and agree on plans of action related to the development of the Demonstration Projects on epilepsy in those countries.

From the outcomes of those two days it may be concluded that the Global Campaign is now gaining such participation and commitment that it can be seen as a truly effective vehicle for improving the situation of people with epilepsy world-wide. This then will lead to concerted action from all those involved and will cause the shadows of epilepsy, which were dispelled in Geneva, to also recede across the rest of the world.

#### Country resources for epilepsy

A questionnaire on country resources for epilepsy was developed by a group of experts with the aim to map the resources for epilepsy world-wide. The questionnaire was sent to IBE and/or ILAE members and to all WHO country members. All were invited to complete this questionnaire. At present the data is being collected at the IBE office in Heemstede.

#### Sessions and lectures at international conferences

The Campaign's Secretariat follows an active policy as far as participation in international conferences/congresses is concerned. It is felt that creating and enhancing awareness never ceases and indeed that it is essential for the Campaign to be known by as many people, who are involved in epilepsy care, as is possible, as well as make as many people as possible aware of the problems surrounding this disorder and of the existing treatment gap.

Since the initiation of the Campaign a number of sessions on the Campaign were organised at regional, national and international congresses. The following sessions took place in 2001:

- Buenos Aires, Argentina: 24th International Epilepsy Congress
- Athens, Greece: 7th Mediterranean Conference
- London, U.K.: World Congress WFN (session on European White Paper)

A number of presentations on the Campaign, involving the GCAE Secretariat were given, at a variety of national, regional and international epilepsy or other neurology-related congresses:

- Flemish League Day, Gent, Belgium
- The Launch of the 2nd Phase of the Campaign, Geneva, Switzerland

- The Launch of the European White Paper, Brussels, Belgium
- European Sanofi-Synthelabo Symposium, Lisbon, Portugal
- 24th International Epilepsy Congress, Buenos Aires, Argentina
- Technical Consultative Meeting, Harare, Zimbabwe
- World Congress World Federation of Neurology, London, England
- World Congress of World Headache Alliance, New York, USA
- Congress organised by Global Forum for Health Research, Geneva, Switzerland
- Annual Epilepsy Congress, Caracas, Venezuela
- Technical Consultative Meeting, Manila, Philippines
- Technical Consultative Meeting, Bangkok, Thailand
- NGO Meeting, Geneva, Switzerland



Speakers in session on Campaign in Buenos Aires: from left to right: Carlos Acevedo (Chile), Claudio Miranda (WHO Regional Advisor for Mental Health in the American Region), Janet Liddle (UK), Kathy Pahl (South Africa), Peter Wolf (Germany), Hanneke M. de Boer (Secretariat Campaign, The Netherlands), A. Gallo Diop (Senegal), Carol D'Souza (India).

## Information on the Campaign

Information on the Campaign may be obtained from various sources.

- Almost every WHO Mental Health Bulletin had information on the Campaign (see <http://www.whomsa.org/it/text2/neuroscience.html>)

The articles attracted considerable interest. The following figures show for each article:

- a. the number of PDF printouts of complete issues of the Bulletin containing the article
- b. the number of separate HTML downloads/printouts of the article
- c. the total number of times the article has been downloaded and/or printed out (a+b), as recorded until the end of 2001.

Issue	Article	PDF printouts (a)	HTML downloads (b)	Total (c)
2	New PAHO/WHO initiative	469	393	862
4	The IBE/ILAE/WHO Global Campaign: consultation	843	348	1.191
6	The Global Campaign	1.528	3.765	5.293
7	Dakar conference	1.644	172	1.816
9	Launch Phase II	664	86	740
9	Managing epilepsy care	664	33	697

- Both web sites of ILAE ([www.ilae-epilepsy.org](http://www.ilae-epilepsy.org)) and of IBE ([www.ibe-epilepsy.org](http://www.ibe-epilepsy.org)) give information on the Campaign as well as the WHO site ([http://www.who.int/mental\\_health/Topic\\_Epilepsy/Epilepsy1.htm](http://www.who.int/mental_health/Topic_Epilepsy/Epilepsy1.htm))

## Publications

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To date the following articles were published on the Campaign itself or concerning the Campaign. As these have never been listed before, on this occasion, all publications we know of since the beginning of the Campaign, will be included:

### 1997

1. Bringing epilepsy out of the shadows: R. Kale:  
British Medical Journal: 315: 2-3, 1997
2. WHO Fact Sheets 165-168: 1997

### 1998

3. World Health Forum, 1998;19(1):107-8
4. Global Campaign against Epilepsy, agenda for IEA/EAS: K.S. Mani:  
Neurology India, 46, 1-4, 1998

### 1999

5. New PAHO/WHO Initiative: WHO Mental Health Bulletin, no. 2,  
March 1999
6. The IBE/ILAE/WHO Global Campaign against Epilepsy: consultation  
on progress and project strategies: WHO Mental Health Bulletin, no. 4,  
September 1999
7. Consultative Meeting on Epilepsy Project: MNH/NND/99.3, 1999
8. Towards a coherent public-health analysis for epilepsy: D.K. Pal, S. Nandy,  
J.W.A.S. Sander: The Lancet 353(9): 1-3, 1999
9. International Epilepsy News issue: 134, p. 8, 1999

### 2000

10. The Global Campaign against Epilepsy: bringing epilepsy out of the shadows:  
WHO Mental Health Bulletin, no. 6, March 2000
11. Dakar conference adopts the African Declaration on Epilepsy as Global  
Campaign against Epilepsy is launched in Africa: WHO Mental Health  
Bulletin, no. 7, September 2000
12. Epilepsy Management at Primary Health Level: Protocol for a demonstration  
project in the people's Republic of China: WHO/MSD/MBD/00.11, 2000
13. The ILAE/IBE/WHO Global Campaign against Epilepsy: Bringing  
Epilepsy "Out of the Shadows": Epilepsy and Behaviour 1, S3-S5 (2000)

14. International Epilepsy News: 138, p. 4-5, 2000
15. International Epilepsy News: 139, p. 16-17, 2000
16. International Epilepsy News: 140, p. 15, 2000
17. International Epilepsy News: 141, p. 4-7, p. 10-12, 2000
18. Annual Report ILAE/IBE/WHO Global Campaign against Epilepsy 1999

## 2001

19. Launch of Phase II of the WHO/ILAE/IBE Global Campaign against Epilepsy: Out of the Shadows: WHO Mental Health Bulletin, no. 9, March 2001
20. Managing epilepsy at primary care level: a demonstration project in China: WHO Mental Health Bulletin, no. 9, March 2001
21. Progress in the epilepsy demonstration project in China: WHO Mental Health Bulletin, no. 10, June 2001
22. Epilepsy: From prejudice to hope in WHO's South-East Asian Region: WHO Mental Health Bulletin, no. 10, June 2001
23. European White Paper on Epilepsy and Call to Action: WHO Mental Health Bulletin, no 10, June 2001
24. "Out of the Shadows": the newsletter of the ILAE/IBE/WHO Global Campaign against Epilepsy: WHO Mental Health Bulletin, no. 11, September 2001
25. Implementing the Global Campaign against Epilepsy in the African Region: WHO Mental Health Bulletin, no. 11, September 2001
26. The World Health Report 2001. Mental Health: New Understanding, New Hope
27. Consultation on Priority Setting in the field of Epilepsy Research: MSD/MBD/01.1, 2001
28. Changes in Public Attitudes toward Epilepsy in Hungary: Results of Surveys conducted in 1994 and 2000: Zsuzsanna Mirnics, Gyoörgyi Czíkora, Tibor Závecz and Peter Halász: *Epilepsia* 42(1):86-93, 2001
29. The treatment gap in epilepsy: the current situation and ways forward: H. Meinardi, R.A. Scott, R. Reis, J.W.A.S. Sander: *Epilepsia* 42(1):136-49, 2001
30. ILAE/IBE/WHO Global Campaign "Out of the Shadows": Global and Regional Developments: E.H. Reynolds: *Epilepsia* 42(8):1094-1100, 2001
31. The treatment of epilepsy in developing countries: where do we go from here? R.A. Scott, S.D Lathoo, J.W.A.S. Sander: *Bulletin of the World Health Organisation*, 2001, 79(4)

32. Epilepsy: Out of the Shadows: From Prejudice to hope: P. Satishchandra, G. Gururaj, Q.D. Mohammed, N. Senanayake, O. Silpakit: World Health Organisation, Regional Office for South East Asia, 2001
33. Annual Report ILAE/IBE/WHO Global Campaign against Epilepsy 2000
34. "Out of the Shadows: ILAE/IBE/WHO Global Campaign against Epilepsy: 2001
35. An Introduction to the Global Campaign and its Demonstration Projects: 2001
36. Global Campaign Newsletter no.'s 1 – 3: 2001
37. International Epilepsy News: 142, p.23, 2001
38. International Epilepsy News: 143, p. 15, 2001
39. International Epilepsy News: 144, p. 4-5, 2001
40. WHO Fact Sheets 165 -168: Revised February 2001
41. Press Release WHO/7: 12 February 2001
42. A European White Paper on Epilepsy – Call to Action: EUCARE, 2001
43. Epilepsy – death in the shadows:, Sir Liam Donaldson, Chief Medical Officer UK and Wales: Annual Report 2001

Of course, this list is far from complete. It would be much appreciated if readers who are aware of other articles relating to the Campaign forward hard copies of these articles (or references) to the office of the Secretariat in the Netherlands.

Numerous articles on the Campaign appeared in the newsletters of the national members of IBE/ILAE and various articles on the Campaign are still under preparation.

# National and regional activities

## Introduction

The Global Campaign provides a framework for concerted action at a global, regional and national level to bring "epilepsy out of the shadows". These activities themselves prove over and over again the importance of the partnerships. The partnership between the International League against Epilepsy and the International Bureau for Epilepsy with the World Health Organization. The partnership with the Regional Offices of WHO and with the Regional Commissions of IBE/ILAE and the partnership with the national IBE/ILAE chapters and local WHO offices; but also the partnership with the other NGOs in neurology and neurosciences and finally the partnership with governments, health care providers and with the private sector.

## National activities

The main players in the Global Campaign are the national chapter of IBE and ILAE, and the WHO Regional Offices, who know best the local problems, needs and solutions for people with epilepsy in their own countries.

Activities in the many countries that are participating in the Campaign vary from the translation of Campaign materials, to organising poster campaigns, to having discussions with health ministers, who, in a number of occasions, themselves got involved and launched activities within their respective countries.

There were media campaigns, articles were published and there was press, radio and television coverage.

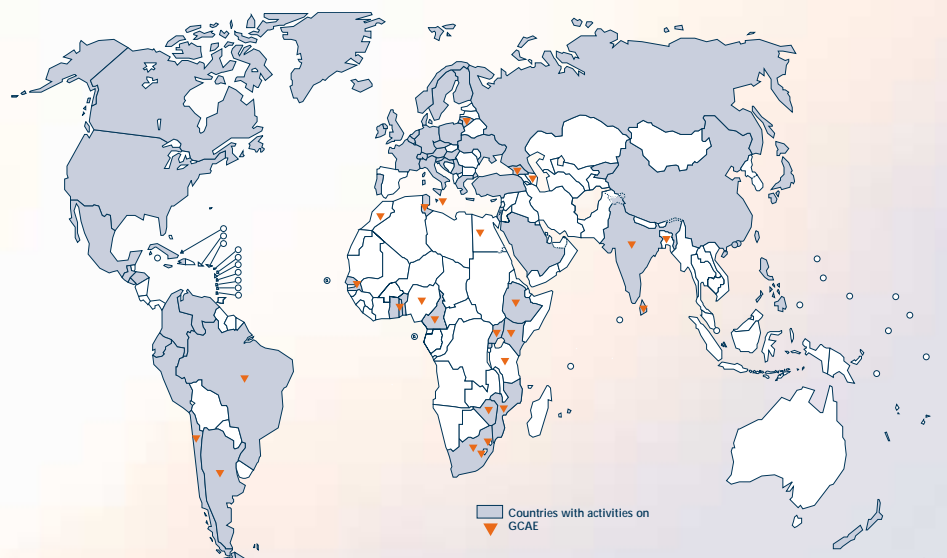
The map shows how many countries are already involved in the Campaign.

## Regional activities (EURO, AFRO, AMRO, WPRO, SEARO)

In 5 of the 6 WHO Regions regional activities were organised concerning epilepsy and the Campaign. Activities in the 6th Region (Eastern Mediterranean Regional Office) are planned to commence in 2002.

## Global Campaign against Epilepsy

The designations employed and the presentation of material on this map do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dashed lines represent approximate border lines for which there may not yet be full agreement.



## Europe

### Launch of the European White Paper on Epilepsy

Following the recommendation in the European Declaration on Epilepsy, the European White Paper on Epilepsy has now been developed by EUCARE<sup>6</sup> in partnership with both IBE and ILAE, in support of the Global Campaign. It was launched in the European Parliament in Brussels, Belgium on 22 March, 2001. The White Paper was the culmination of several years' work by many people working in the field of epilepsy.

A White Paper can be defined as a statement on a particular topic, together with recommendations for political action; it is a tool that may be used to approach governments, health professionals and health care providers.

It identifies the most pressing problems for people who have the condition and outlines the way in which governments can best allocate resources in order to reduce the burden of epilepsy on society.

The overall aim of the White Paper is to improve awareness, to educate, inform, influence and shape opinions about epilepsy within the heart of European political institutions.

Dr Benedetto Saraceno and Dr Leonid Prilipko from WHO headquarters and Dr Wilfried Kreisel, Executive Director, WHO Office at the



Drs. Prilipko and Saraceno represented WHO at the Launch of the European White Paper in the European Parliament.

European Union, also participated in the Launch. In his presentation Dr. Saraceno emphasised that:

*...the burden of disease concerning epilepsy is vast and much greater than it should be, as epilepsy is a treatable disorder and the treatment is relatively cheap. The ILAE/IBE/WHO Global Campaign against Epilepsy also has an important role to play in the reduction of the treatment gap in Europe. Initiatives such as the development and the Launch of this White Paper provide important tools to reach this goal...*

The White Paper was endorsed by Dr. W. Rutz, the WHO Regional Adviser for Mental Health in Europe. He wrote:

*...The Launch of the European White Paper on Epilepsy is the culmination of much hard work on the part of dedicated organisations and professionals in the field of epilepsy. Its preparation strongly reflects the policies of the European section of the WHO – multidisciplinary team work,*

*co-operation between different sectors of society, and a holistic approach to meet the needs of those suffering from neurological and brain disorders...*

The Launch was furthermore attended by people involved in epilepsy from all over Europe, including members of IBE and ILAE, members of the European Parliament, the European Public Health Alliance and the European Commission, journalists and public relations agencies from many different European countries.

With the launch of the European White Paper, experts in epilepsy called upon members of the European Parliament, the public and the medical community to share their knowledge and unite in action to improve the lives of the six million people with active epilepsy in Europe.

<sup>6</sup> European Concerted Action and Research in Epilepsy

## Africa

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

The meeting was convened by the WHO Regional Office for Africa (AFRO) in collaboration with the Campaign Secretariat, in Harare, Zimbabwe on 4-5 June 2001.

The meeting brought together different professionals from 12 selected countries<sup>7</sup>. Two participants came from each of the countries, one local WHO representative and one representative of IBE/ILAE.

The main objective was:

To facilitate the implementation of the WHO/ILAE/IBE Global Campaign Against Epilepsy (GCAE) in the countries of the African Region

Furthermore specific objectives were:

- To create a consensus on the need to consider Epilepsy as one of the priorities of the Mental Health area of work in the participating countries
- To identify priority interventions for the development of country action plans in line with the African Declaration on Epilepsy.
- To provide appropriate comments for the improvement of the Draft Protocols of the Demonstration projects of the GCAE in selected countries of the African Region.



From left to right L.L. Prilipko (WHO Headquarters), F. N'tone (Cameroon), C. Mandlhate (Regional Adviser WHO), H. Meinardi (ILAE), M. Belhocine (Director Division of Non Communicable Diseases WHO/AFRO) relaxing after a full day of discussions.

- To define and strengthen partnership among the key players of the GCAE, namely World Health Organization, International League Against Epilepsy, International Bureau for Epilepsy and other relevant organisations or individuals.

The participants discussed priority interventions, recommendations and actions to be taken as a follow up of the meeting.

The following findings and recommendations were adopted by all participants:

- Development of strategic partnerships
- Epilepsy education for various target groups
- Research and training
- Prevention, both of causes and consequences of epilepsy
- Development of guidelines for epilepsy management

- Collaboration with the traditional healers
- Setting up of Drug Banks following the Chilean Model, the Uganda experience and to explore linkages with the Bamako Initiative
- Under the GCAE umbrella, to investigate possibilities to acquire affordable antiepileptic drugs (AEDs)
- 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

A follow-up of the recommendations is crucial for the sustainability of these initiatives, therefore an action plan was developed. Communication among the different partners will be strengthened and the description of good practices encouraged.

<sup>7</sup> Cameroon, Ethiopia, Lesotho, Kenya, Mozambique, Senegal, South Africa, Swaziland, Tanzania, Togo, Uganda and Zimbabwe

## Americas

### **Meeting of Principal Investigators concerning the initiation and implementation of a Demonstration Project in Argentina.**

The meeting was convened by the WHO Regional Office for the Americas (AMRO/PAHO) in collaboration with the Campaign Secretariat, in Buenos Aires, Argentina on 6-7 July, 2001.

The aim of the meeting was:

- to discuss the prospect and progress of a Demonstration Project in Argentina

A pilot study is being performed in the region, impelled by AMRO, using training modules initiated previously in Washington. All documents being used during the project may also be used in the Demonstration Project that is being initiated under the auspices of the Global Campaign.

It was decided that the aforementioned study must be completed before a Demonstration Project can start.

Following this discussion, the draft protocol for the Project in Argentina was explained and potential problems were discussed.

Finally, a plan of action for the initiation and implementation of the Project was made, together with a timetable.

## Western Pacific Region

### **Consultation on Epilepsy**

This meeting was convened by the WHO Regional Office for the Western Pacific (WPRO) in collaboration with the Campaign Secretariat, in Manila, Philippines on 14-15 November 2001

The main objectives were:

- to review the present state of epilepsy in the Region
- to discuss a draft Regional Report on Epilepsy
- to review the implementation of the GCAE in the Region, including the progress of the Demonstration Project in China
- to develop a framework of action for countries in the Region

The meeting brought together clinicians with expertise in the field of epilepsy, leaders of the Global Campaign Against Epilepsy, and senior staff from WHO. Representatives from 11 countries attended the meeting<sup>8</sup>. In addition, representatives from China attended in order to present a report on the Demonstration Project in that country.

The meeting ended with an extensive discussion on potential actions in 7 areas:

1. Setting up (or further development) of lay and professional epilepsy organisations.
2. The design and implementation of community based treatment and prevention service.
3. Public education regarding epilepsy using a wide range of methods
4. The design and implementation of relevant epidemiological research on prevalence, the treatment gap and on lay epilepsy knowledge, attitudes and practices.
5. Potential areas of inter-country co-operation and information exchange
6. The need for legislative reform regarding discrimination against people with epilepsy
7. Methods and avenues for fundraising (resource mobilisation)



Dr. Helen Herrman (WHO Regional Adviser Western Pacific Region), Dr. Richard Nesbit (Director of Programme Management, WHO Western Pacific Region), and Dr/ Li Shi Chuo.

<sup>8</sup> Australia, Cambodia, China, Fiji, Japan, Korea, Laos, Malaysia, Papua New Guinea, Philippines, and Singapore

At the end of the meeting the following interim actions and resolutions were agreed upon by the participants:

- to support the ILAE/IBE/WHO Global Campaign against Epilepsy
- to support the continuation and further development of the Demonstration Project in the People's Republic of China
- to endorse the plan to produce a Regional Report on epilepsy. It was agreed that this Report should take into account the results of the survey on country needs and resources and the discussions that occurred during the meeting. Furthermore the concept of a regional "epilepsy map" was endorsed
- to inform the Regional Adviser on Mental Health about epilepsy related activities linked to the GCAE in their respective countries
- to endorse the concept of inter-country exchange and support within the Region



Participants of the Intercountry Consultation

### South East Asian Region

#### **Intercountry Consultation on the Development of a Strategy for Community-based Neuro-psychiatric Services.**

This meeting was organised by the WHO Regional Office for South-East Asia (SEARO) in Bangkok, Thailand on 19-21 November 2001.

The objectives of this meeting were:

- to review the experiences of member countries in community-based neurological and psychiatric services for priority conditions
- to develop a broad strategy for implementation of community-based neurological and psychiatric services
- to develop guidelines for pilot testing of the strategies in selected countries

Representatives from 9 out of the 10 SEARO countries<sup>9</sup> met in Bangkok, Thailand. Furthermore, some experts from Europe and the USA participated, as well as representatives from the Campaign Secretariat.

The following recommendations were made and unanimously agreed upon by all participants.

- a series of pilot Demonstration Projects on epilepsy are to be developed in the SEARO within the broad framework of the Global Campaign against Epilepsy (Indonesia – Bali, Myanmar and India)
- a project to validate diagnostic criteria to be initiated in December 2001
- validation to be done at a clinical and at the community level
- validation will aim at the provision of a questionnaire to be used by identifiers and care providers
- validation will be performed in 100 confirmed cases of epilepsy, 50 cases with non-epileptic seizures and 50 cases of other neurological disorders
- validation will be performed in a population of 5 to 10 thousand involving health care workers and specialists
- validation of the projects in India and Sri Lanka (hospital-based) and all member countries (community-based)

<sup>9</sup> Bangladesh, Bhutan, DPR Korea, India, Indonesia, Myanmar, Nepal, Sri Lanka, Thailand

- validation of the projects to start on 15 December 2001 and to be completed within 3 months
- ethical clearances etc. to be co-ordinated by WHO/SEARO (Dr. Vijay Chandra)
- to have the projects co-ordinated by: Dr. Vijay Chandra (SEARO), Dr. Satish Jain, Dr. S. Kapoor and Dr. K. Anand.

Concerning the development of a Regional Report on Epilepsy, the following was recommended and again unanimously agreed:

- there is a need to develop a SEARO report on country needs and resources for epilepsy control in collaboration with the Global Campaign against Epilepsy – an editorial board should be formed to co-ordinate this. The Board will consist of: Dr. Vijay Chandra (SEARO), Dr. Satish Jain (India), Dr. Nyan Tun (Myanmar) and Dr. Ranjani Gamage (Sri Lanka)

In addition it was recommended and agreed to:

- generate video's on epilepsy and other educational materials using materials which are available through IBE and the ILAE/IBE Resource Centre

## Demonstration projects

### Background

The main activities to achieve the Campaign's goals are the initiation and implementation of Demonstration Projects in a number of selected countries, which are: Argentina, China, Senegal and Zimbabwe.

According to the plans of action for the Campaign, and following the recommendations of the WHO Cabinet, these demonstration projects serve as models for the reduction of the treatment gap and stigma, the improvement in education, training and health care delivery and the promotion of prevention. They provide assistance to Departments of Health in the development of national programmes on epilepsy.

The objectives of the Demonstration Projects are:

- to reduce the treatment gap and the physical and social morbidity of people suffering from epilepsy by intervention at a community level
- to train and educate health professionals
- to dispel stigma and to promote positive attitudes towards people with epilepsy in the community
- to identify and assess the potential for prevention
- to develop a model for promotion of epilepsy control world-wide and for its integration in the health systems of participating countries

Criteria for country selection are:

- the willingness to participate
- the availability of political contacts
- the availability of WHO collaborative centres or country representative
- the availability of IBE/ILAE members
- the existence of basic primary health care infra-structure
- a regular and basic AED supply
- the facility of communication

Assessment Indicators will be:

- the reduction of the treatment gap
- the training and education of health professionals
- the dispelling of stigma
- the identification and assessment of the potential for prevention
- the development of models for promotion of epilepsy control world-wide
- the reduction of the economic burden
- the reduction of the individual burden

## Progress report

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- Argentina** – the first meeting of investigators took place in Buenos Aires, July 2001  
– protocol being finalised
- China** – protocol completed and published  
– first phase completed (epidemiological study)  
– second phase launched in 2001 and being carried out (training professionals about epilepsy)  
– report on the first phase will be published in a peer-reviewed journal shortly
- Senegal** – first meeting of investigators took place in Harare, Zimbabwe, June 2001  
– protocol completed  
– first phase initiated.
- Zimbabwe** – first meeting of investigators took place in Harare, Zimbabwe in June 2001  
– protocol completed  
– first phase initiated

During the 1st phase of these Projects, amongst others, the prevalence of epilepsy and the size of the treatment gap are being measured.

The first results of the assessments are now coming in from the People's Republic of China (PRC) and show the true figures instead of earlier assumptions. In the past the prevalence of epilepsy had been estimated to be approximately 4.4/1,000 and it was from such figures that it was also estimated that there would be around 5 million people with epilepsy in the country.

However, the estimates about the total number of people with epilepsy in PRC rise to nearly 9.000.000 as the life-time prevalence was found to be 7/1,000.

Of great concern are the figures for the treatment gap. It was previously estimated that in the PRC 50% of people with active epilepsy would not be receiving treatment. The project's survey has found, however, that the treatment gap for active epilepsy stands at 62.6%.

In view of this study's experience, the world-wide prevalence of epilepsy and its treatment gap may also be massive underestimates.

# Activities of the Campaign Secretariat and of the Executive Board

## Secretariat and Executive Board

The Secretariat of the Campaign underwent a change this year, as Dr. E.H. Reynolds retired from most of his international epilepsy work. He was succeeded by Prof. J. Engel Jr., the past-president of ILAE.

The Secretariat of the Campaign met on a number of occasions, mostly in Geneva at WHO headquarters, but from time to time in other parts of the world in connection with various other meetings/congresses that were taking place.

The Executive Board only met in full on the occasion of the annual meeting of the Executive Committees of IBE and ILAE in Basle, Switzerland, in March. However, meetings with individual members of this Board took place whenever appropriate, whilst communications by phone and e-mail were ample.

Again this year finances were extremely tight but the targets set for this year could be reached.

A considerable number of IBE and ILAE chapters informed the Secretariat on a regular basis concerning the Campaign activities in their countries, which then, through the Newsletter can be shared with others all over the world, after all the Campaign is a joint effort, a partnership, between WHO, ILAE and IBE but also between these organisations, their national chapters, the regional and local WHO offices.

## Activities of the Secretariat

Below follows a brief summary of the activities of the Secretariat during 2001:

- January** Geneva, Switzerland: Preparations for the Launch of the 2nd Phase of the Campaign
- February** Geneva: Launch 2nd Phase ILAE/IBE/WHO Global Campaign
- March** Geneva: Working meeting  
Brussels, Belgium: Launch of the European White Paper
- April** Geneva: Working meeting and a meeting with Dr. D. Yach, Executive Director, Noncommunicable Diseases and Mental Health cluster
- May** Paris, France: meeting with potential donor
- June** Harare, Zimbabwe: Technical Consultative Meeting on the implementation of the Campaign in Africa  
London: meeting with NGOs and working meeting
- July** Buenos Aires, Argentina: Technical consultative meeting on the prospects and progress of a Demonstration Project in Argentina
- October** Paris, France: Meeting with potential donor  
Geneva: Working meeting
- November** Beijing, China: Meeting at Ministry of Health on Progress of Demonstration Project  
Manila, Philippines: Technical Consultative Meeting  
Bangkok, Thailand: Inter-country consultation
- December** Geneva: WHO meeting with NGOs and working meeting of the Secretariat.

## Information and public relations

### P.R. (public relations) materials

The mailing list of the Campaign is growing rapidly and all new Campaign materials were sent to everyone showing an interest, including a large mailing following the International Epilepsy Congress in Buenos Aires, Argentina, where many participants visited the Campaign booth and requested Campaign materials.

The Campaign brochure and the previous annual report are almost out of stock and according to the action plan for the coming period, the existing Campaign materials will be reviewed, updated and upgraded. In view of the Launch of the 2nd

Phase of the Campaign a meeting folder and a poster were designed. The existing WHO fact sheets were updated.

With all activities progressing and expanding the workload of the Secretariat also grows.

The success of the Campaign has become very visible and its model is being copied by many, within WHO but also by other non-governmental organisations. Still much needs to be done to bring epilepsy out of the shadows!

### Campaign newsletter

During the course of 2001, the need was expressed for a regular stream of information update to those working with the Global Campaign against Epilepsy, and other interested parties. This culminated in the production of the GCAE Newsletter "Out of the Shadows", of which 3 issues were circulated in 2001.

The very first newsletter was tentatively "launched" in June 2001 with a distribution list of more than 400 addresses world-wide. The format chosen was a contemporary, full-colour, 4-page newsletter, A4 size, and where possible with photos to accompany the articles. The newsletter is produced in-house at the office of the Secretariat in the Netherlands.

The response received has been tremendously enthusiastic and encouraging, on both format and content.

The newsletter aims to focus specifically on activities related to the Global Campaign and keeps readers regularly informed about its global, regional and national activities, as well as by providing updates on new initiatives and developments.

A special section on "future congresses", which is a recurring feature in every issue of the newsletter, highlights those epilepsy congresses that will have a programme session dedicated to the Global Campaign against Epilepsy.



Campaign stand at the 24th International Epilepsy Congress, Buenos Aires, Argentina.

# Action plan for 2001

## Launch 2nd phase Campaign

- Organise Launch event: 12 February 2001                      done

## Fundraising

- Finalise fundraising document                                      done
- Organise meetings with potential donors                      in progress
- Make contact with World Bank, UNICEF  
and other interested agencies                                      in progress

## Regional conferences

- Development of regional reports
  - Europe    done
  - Africa    in progress
  - Latin America    to be done
  - USA    to be done
  - South East Asia    in progress
  - Western Pacific    in progress
- Organisation of regional conferences
  - Eastern Mediterranean Region                                      in progress

## Campaign sessions/presentations

- International Epilepsy Congress                                      done
- World Congress of World Headache Alliance                      done
  - New York, USA
  - Presentation    done
- World Congress WFN, London, England
  - Session on European White Paper                                      done
  - Presentation on Campaign    done
  - Congress organised by Global Forum
  - for Health Research    done
  - Presentation    done
- Annual Epilepsy Congress Venezuela
  - Presentation    done
- ILAE Mediterranean Epilepsy Congress,  
Athens, Greece
  - Campaign session    done





## Action plan for 2002-2003

### Fundraising

- Update fundraising document in progress  
Meetings with donors
- Contacts with World Bank

### Regional conferences

- Preparations for Regional Conferences and Declarations
  - EMRO — conference to be held April/May 2002
  - EURO/Azerbaijan — conference to be held 2002

### Regional reports/White Papers

- AFRO December 2002
- WPRO March 2002
- SEARO 2002
- EMRO 2003

### Campaign sessions

- Japan: AOEO September 2002
- China: ICNA September 2001
- Brazil: Latin American Conference May/June 2002
- South Africa September 2002
- Tunisia October 2003

### Demonstration projects

- The development and implementation of demonstration projects in all regions: In Senegal and Zimbabwe (AFRO) projects will be commencing shortly. In Argentina (PAHO) the protocol is near completion, pilot projects being planned to be set up in Myanmar, India and Indonesia (SEARO)

### Development of evidence-based materials (in collaboration with Evidence and Information Policy Cluster)

- Organise technical consultation meetings of experts in order to collect epidemiological data on country and regional levels including the economic burden of DALY's 2003

Develop Guidelines on the treatment of epilepsy with essential drugs in collaboration with the Department on Health Technology and Pharmaceuticals Cluster

- Organise a number of technical Consultative Meetings to develop guidelines on the treatment of epilepsy with essential drugs 2002

Develop Normative documents in Collaboration with CAH and the Health Technology and Pharmaceutical Cluster and UNICEF, NGO's and others

- Guidelines on the treatment of epilepsy in childhood and adolescence, organise technical consultative meetings 2002

Development of Global Report on Country resources for epilepsy

- Surveys to be sent out globally 2001/2002
- Outcomes to be entered in data base 2002
- Report to be prepared, printed and distributed 2003

Organisation of Regional Consultative meetings for the implementation of activities in epilepsy care

- Meetings to initiate exchange of ideas to enhance national and transnational collaboration between NGO's and WHO regional and national offices AFRO March/April 2002

Education and training

- Prepare and produce video's 2002/2003
- Prepare and produce written materials on epilepsy, treatment, quality of life, etc., for professionals, people with epilepsy, the general public and special target groups

Public relations

- PR materials to be reviewed, upgraded, printed and disseminated

## Photos from the Launch



From left to right: Hanneke M. de Boer, Dr Derek Yach, Dr Gro Harlem Brundtland, Dr Benedetto Saraceno, Dr Leonid Prilipko, Dr Edward H. Reynolds, Philip Lee.



Participants of the Launch continue discussions during the coffee break.



From left to right: Dr A. Gallo Diop (Senegal) and Dr Custodia Mandlhate (Zimbabwe – AFRO).



From left to right: Dr Edward H. Reynolds (UK), Dr Gro Harlem Brundtland, Hanneke M. de Boer (The Netherlands) and Dr Jerome Engel Jr (USA).



From left to right: Dr Helen Herrman (Regional Advisor for Mental Health – WPRO), Dr Claudio Miranda (Regional Advisor for Mental Health – AMRO/PAHO), Dr Natalio Fejerman (Argentina).



From left to right: Dr Harry Meinardi (The Netherlands), Dr Vijay Chandra (Regional Advisor for Mental Health – SEARO).



From left to right: Dr Wolfgang Rutz (Regional Advisor for Mental Health – EURO), Dr Peter Wolf (Germany).



From left to right: Dr Custodia Mandlhate (Regional Advisor for Mental Health – AFRO), Prof. Josemir W.A.S. Sander (UK), Dr Ahmed Mohit (Regional Advisor for Mental Health – EMRO), Sir John Bowis MEP (UK), Dr Jerome Engel Jr (USA).

# Attachment I

## Paper to cabinet

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To: Cabinet  
From: Executive Director, Social Change and Mental Health  
Date: 03 December 1999  
Topic: GLOBAL CAMPAIGN: BRINGING EPILEPSY OUT OF THE SHADOWS

### Background

#### **a) Impact on health**

- Epilepsy is one of the most common serious brain disorders worldwide and it imposes a large economic burden on health care systems. Epilepsy is universal, with no age, racial, social class, national nor geographic boundaries.
- There are 40-50 million sufferers in the world today, 85% of whom live in developing countries. An estimated two million new cases occur each year globally. At least 50% of cases begin at childhood or adolescence.
- Epilepsy has serious physical, psychological and social consequences. Epilepsy has a significant mortality (four times the expected rate in young adults). There is a hidden burden associated with stigma and discrimination in the community, work place, school and home.
- 70 to 80% of people with epilepsy could lead normal lives if properly treated. However, in developing countries 60 to 90% of people with epilepsy receive no treatment due to inadequacies in health care resources and delivery, and due to social stigma.

#### **b) Existing activities**

In 1997 three international organisations, the World Health Organization (WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) joined forces to initiate a Global Campaign Against Epilepsy (GCAE).

On initial stage the strategy of the campaign was essentially focused on advocacy and awareness activities:

- In 1998 at a meeting in Heidelberg sponsored by the German Government, the European Declaration on Epilepsy was unanimously adopted;
- In 1998 and the first half of 1999, twenty-seven countries have joined or are planning to join the Global Campaign Against Epilepsy.

Experience of initial stage of the campaign created rationale for suggestion of a second stage of the GCAE with a *new and more ambitious goal: to improve health care services, treatment, prevention, and social acceptance of epilepsy worldwide*. A Consultative Meeting on Epilepsy held in WHO/HQ in April 1999 with participation of representatives from IBE, ILAE, WHO Regional Advisers and experts recommended to boost the Campaign and to proceed with demonstration project on epilepsy within the GCAE frame. This project would have to work as part of a country's current health system in order to ensure that epilepsy interventions would be sustainable and able to provide appropriate care over long term including availability of essential antiepileptic drugs.

### Strategy and Proposal

The strategy of the GCAE includes two parallel and simultaneous tracks: 1) raising of general awareness and understanding of epilepsy, and 2) supporting Departments of Health in identifying needs and promoting education, training, treatment, services, research and prevention nationally.

1. To provide a platform for general awareness on epilepsy, the following is proposed:
  - to intensify and boost the Campaign in the year 2000 with the participation of the Director-General of WHO, WHO Regional Directors and Presidents of relevant NGOs;
  - to announce a Global Awareness Day for Epilepsy; and
  - to organise regional conferences on public health aspects of epilepsy in the six WHO Regions, including a Declaration on Epilepsy, based on the European model.
2. To assist Departments of Health in the development of national programmes on epilepsy, the following was proposed:
  - to provide information and support for national initiatives under the GCAE; and
  - to initiate demonstration project in China (WPRO), Honduras (AMRO), Jamaica (AMRO), Panama (AMRO), Senegal (AFRO), and Zimbabwe (AFRO)<sup>2</sup>.

<sup>2</sup> Criteria for country selection in project are: willingness to participate, political contacts, availability of key WHO Collaborating Centre or country representative, IBE/ILAE /other epilepsy organisations, existence of basic primary health care infrastructure, regular and basic AED supply, facility of communication.

The objectives of the demonstration projects are:

- to reduce the treatment gap and the physical and social morbidity of people suffering from epilepsy by intervention at a community level;
- to train and educate health professionals;
- to dispel stigma and promote a positive attitude to people with epilepsy in the community;
- to identify and assess the potential for prevention of epilepsy;
- to develop a model for promotion of epilepsy control worldwide and for its integration in the health systems of participating countries.

Evaluation criteria: Reduction in treatment gap, change in public attitudes, potential for prevention.

Duration: 4 to 5 years.

#### Partners

Within the framework of the GCAE, WHO has already established a good working relationship with the professional (ILAE) and lay (IBE) NGO's for epilepsy. The Regional Offices of AFRO, EURO and AMRO are actively involved.

Partnerships are being developed among organisations of the United Nations system, non-governmental organisations, WHO collaborating centres, the private sector, academic and research groups, Foundations and donors.

The following WHO departments have already expressed support: Department of Child and Adolescent Health Development, Department of Resource Mobilization and Office of Press and Public Relations. Contacts are being established with the clusters of Communicable Diseases,

Non-Communicable Diseases and Department of Essential Drugs and Other Medicines in the cluster of Health Technology and Pharmaceuticals. A proposal to approach the pharmaceutical industry for financial support was considered by the Committee on Private Sector Collaboration (CPSC).

All the neuroscience NGO's including the World Federation of Neurology and the International Child Neurology Association support the Global Campaign Against Epilepsy.

#### Recommendations

1. In the year 2000 to intensify and boost the GCAE and announce a Global Awareness Day for epilepsy in the presence of the Director-General, Executive Director as well as the Presidents of the participating NGO's. Regional offices will replicate similar high visibility events in all Regions, in the presence of Regional Directors, NGO's and media-attracting personalities.
2. In 2000 initiate the development of demonstration project as model for the reduction of treatment gap and stigma, improvement in education, training and health care delivery, and promotion of prevention.
3. During the period 2000-2004 hold regional conferences on public health aspects of epilepsy, including a Declaration on Epilepsy as a basis for regional political action.
4. Within the next six months organise a meeting with appropriate United Nations agencies and representatives of the pharmaceutical industry to explore the possibility of furthering collaboration and mobilizing resources for the campaign in accordance with the WHO Guidelines on Interaction with Commercial Enterprises and the aforesaid decision of the CPSC.

## Attachment II

### Programme of the Launch of the 2nd Phase of the ILAE/IBE Global Campaign against Epilepsy "Out of the Shadows"

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Chairperson: Dr. B. Saraceno, Director Department of Mental Health and Substance Dependence

09.00-09.15

- Introduction
  - Dr. D. Yach, Executive Director
  - Noncommunicable Diseases and
  - Mental Health

09.15-09.30

- Opening remarks
  - Dr. Gro Harlem Brundtland
  - Director-General
  - World Health Organization

09.30-09.45

- The Global Campaign against Epilepsy
  - Mrs. H.M. de Boer
  - Past-President
  - International Bureau for Epilepsy

09.45-09.55

- The Global Campaign against Epilepsy Plans and actions
  - Dr. E.H. Reynolds
  - Past-President
  - International League against Epilepsy

09.55-10.05

- Epilepsy in the world today: A medical point of view
  - Dr. J. Engel Jr.
  - President
  - International League against Epilepsy

10.05-10.15

- Epilepsy in the world today: A social point of view
  - Mr. Ph. Lee
  - President
  - International Bureau for Epilepsy

10.15-10.25

- The role of Governments
  - Mr. J. Bowis, OBE, MEP
  - Representative of the European Parliament

10.25-10.35

- Living with epilepsy in the world today
  - Mrs. C. D'Souza

10.35-10.40

- Closing remarks
  - Br. B. Saraceno, Director
  - Dept. Mental Health and Substance Dependence

11.00-12.00

- Press Conference

## Attachment III

Presentations during the Launch of the 2nd Phase of the ILAE/IBE/WHO Global Campaign against Epilepsy "Out of the Shadows" Geneva, 12 February 2001

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Dr Gro Harlem Brundtland, Director-General

World Health Organization

I would like to welcome you all to this launch of the second phase of the Global Campaign against Epilepsy. I am especially pleased that this event today marks the beginning of a year where mental health and brain disorders will be the global focus of attention.

As you all know, the theme for this year's World Health Day is mental health and brain disorders, and so is the subject of this year's World Health Report.

Our advocacy effort will concentrate on reducing stigma associated with mental ill health and neurological disorders on raising awareness about the many effective, affordable treatments that are available but underused, both in developing and industrialised countries.

I will mark the World Health Day twice this year; first in Nairobi on the fourth of April where the Kenyan health authorities for the first time will arrange an "Open Day" at the country's main mental hospital. Then, we will celebrate again here in this room on 6 April in what we hope will be a warm and forceful celebration of the benefits of inclusion and care.

The World Health Report will give a comprehensive review of what we know: about the current and future global burden of mental ill health and neurological disorders; about the effectiveness of prevention and the availability and restraints to treatment; and about the policies needed to ensure that stigma and discrimination is broken down and effective prevention and treatment are put in place and funded.

I am confident that our efforts this year will take mental health a large step forward towards equal priority and respect with physical aspects of health.

*This past century has seen spectacular changes in the way we live and think. Human brilliance and technology have come together to propose solutions we dared not imagine forty years ago. We have conquered diseases that once seemed insurmountable. We have saved millions of people from premature death and disability. And our search for better solutions to health is, as it should be, ceaseless.*

Mental health is a central part of overall health. When I took office, two-and-a-half years ago, I was convinced that WHO should devote considerable energies to addressing the challenges posed by mental disorders. Since then, my resolve has only been strengthened.

There is also an increasingly strong evidence confirming the close relationship between health and development. Ill health taxes the economy of whole nations as well as bringing terrible burdens on families. By reducing the burden of disease, we also improve the conditions for reducing poverty.

When we talk about reducing the toll from the diseases that cause and perpetuate poverty, we often focus on malaria, HIV/AIDS, tuberculosis, early childhood diseases and problems linked to pregnancy and birth. But we could also include mental and neurological disorders.

An estimated 400 million people alive today suffer from mental or neurological disorders or from psychosocial problems such as those related to alcohol and drug abuse. Around fifty million of them suffer from epilepsy. Many of them suffer silently. Many of them suffer alone. Beyond the suffering and beyond the absence of care lie the frontiers of stigma, shame, exclusion and, more often than we care to know, death.

Of those who suffer from epilepsy, around 85% live in developing countries. There are two million new cases occurring in the world every year.

What neurological disorders have in common with mental ill health is that these conditions are victims of stigma, ignorance and fear. As a result, these diseases receive low priority by authorities and health personnel in many countries.

Stigma and discrimination have several consequences: they limit the degree to which patients attend treatment; they limit the degree to which health workers are being trained adequately to identify, assess and treat disorders; they may even limit the willingness of mental health care providers to intervene. They also reduce the abilities of the patients to live normal lives in their communities and workplaces and in some circumstances prevent them from earning a living altogether.

Up to 80% of persons with epilepsy could lead normal lives if properly treated, but the overwhelming majority of patients does not get any treatment at all. The WHO Regional Office for the Americas estimates that out of five million people with epilepsy in the Region, 3.5 million are believed to be untreated.

A recent survey of 30 Latin American countries revealed that none of them had national policies for epilepsy. In sub-Saharan Africa, there is one neurologist for four million people.

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

It can be done. Epilepsy is not difficult to diagnose if health personnel have received minimum level of training. And it can be effectively treated with safe and inexpensive medication. The main anti-epileptic drug, phenobarbitone, can be produced and sold for as little as \$5 per person per year.

The difference can be between total disability and a fully normal life. Research from the United Kingdom shows that around 70% of the estimated cost of epilepsy are caused by premature mortality and disability, leading to need for care and lost productivity.

As health workers, we know that few opportunities are as gratifying as that of being able to restore someone back from despair to a normal life. The Global Campaign Against Epilepsy, which was so aptly named "Out of the Shadows" is based on that inspiration.

The collaboration between the International Bureau for Epilepsy, the International League Against

Epilepsy and WHO has shown that when people with different backgrounds and roles come together with a shared purpose, creativity is released and expertise is used in innovative and constructive ways.

The original objectives of this campaign were:

- to increase awareness, both among health professionals and the general public, of epilepsy as a universal and treatable disorder;
- to raise epilepsy to a new plane of acceptability in the public domain;
- to improve education about epilepsy;
- to identify the needs of people with epilepsy; and
- to encourage governments to address the needs of people with epilepsy.

The first three years have focused on the first three objectives: increasing awareness, creating acceptance and improving education. Much work has gone into the campaign and special care has been taken to involve a broad spectrum of experts and professionals.

Activities to improve awareness have been held in over 50 countries world-wide. More than 1200 health professionals from more than 100 countries have participated in consultations to shape the work in countries and to formulate regional declarations against epilepsy.

In doing so, the campaign has built the foundations for achieving the last two objectives. How well we have succeeded in creating awareness and reducing stigma – at least among decision makers in countries around the world, will determine to what extent we will succeed in convincing governments to address the needs of those living with epilepsy.

We are here to launch the second phase of the global campaign. And I am pleased to say that judging from the momentum the campaign has created, the considerable efforts from all who are involved have been a success.

*We can today announce four demonstration projects against epilepsy in four countries: Argentina, China, Senegal and Zimbabwe.*

These four demonstration projects will assess the number of people suffering from epilepsy in the project area and train primary health care workers within the existing primary health service how best to diagnose and treat epilepsy patients. In China, the project will cover a population of nearly three million people.

The projects will run for four to five years. The experiences they will yield will form the basis for developing national programmes in the four countries and to assist other countries in designing their own programmes.

We have come a long way since the campaign started three years ago. We can now enter the second stage reassured that we are making real improvements to the lives of hundreds of thousands of people, and we are laying the foundations for lasting improvements for millions more.

With that inspiration in mind, let us all to do our best to make this second phase of the global campaign a success, and that we can bring epilepsy out of the shadows.

## Contact addresses

### Information

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

The International Bureau for Epilepsy  
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**EPILEPSY**

out of the shadows



A Global Campaign  
Against Epilepsy