

INVITED COMMENTARY

The origins and early development of the ILAE/IBE/WHO global campaign against epilepsy: Out of the shadows

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Abstract

The International League Against Epilepsy (ILAE)/International Bureau for Epilepsy (IBE)/World Health Organization (WHO) Global Campaign Against Epilepsy was launched in Geneva and Dublin in the summer of 1997. The second phase of the Campaign was launched by a major event in Geneva, led by WHO Director General Dr. Gro Harlem Brundtland in February 2001. Since then, the Campaign has been gathering momentum around the world culminating in the WHO General Assembly Resolution (WHA 68.20) on Epilepsy in May 2015 supported by 194 countries. Recently, the World Federation of Neurology and other neurological non-governmental organizations (NGOs) have joined forces with the Epilepsy Campaign, leading to the WHO General Assembly Resolution (WHA 73.10) in May 2022 promoting a 10-year Intersectoral Global Action Plan (IGAP) for Epilepsy and Other Neurological Disorders. I was privileged to serve as the first Chairperson of the Global Campaign Against Epilepsy and this year all my documents and correspondence relating to the Campaign have been delivered to the Wellcome Collection in London. These are the basis for this detailed account of the origins and early development of the Campaign. I describe the events leading to the birth of the concept, planning for the Campaign, the launch, development, and the achievements of phase one. This first phase focused on awareness raising, education, and involvement, especially within WHO, ILAE, and IBE, including a series of five Regional Public Health meetings and Declarations on Epilepsy. In 1999, the WHO raised the status of the Campaign to the highest level, the first ever for a Non-Communicable Disease, resulting in the high profile launch of phase two in 2001, paving the way to the continuing global momentum and achievements, including the 2015 and 2022 WHO Resolutions.

KEYWORDS

campaign, epilepsy, global, IBE, ILAE, WHO

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1 | INTRODUCTION

The International League Against Epilepsy (ILAE)/International Bureau for Epilepsy (IBE)/World Health Organization (WHO) Global Campaign Against Epilepsy was launched in Geneva and Dublin in the summer of 1997. The strategic aims of the Campaign included:

1. To raise public, political, and professional awareness and understanding of epilepsy as a universal treatable brain disorder.
2. To identify the needs of people with epilepsy on a global, regional, and national basis and to encourage Departments of Health to develop their own national Campaigns to promote the prevention, diagnosis, treatment, services, and care of people with epilepsy.¹

In February 2001, the new Director General of WHO, Dr. Gro Harlem Brundtland, led the launch of the second phase in Geneva, having raised the status of the Campaign to the highest WHO level, the first ever for a Non-Communicable Disease.² Since then the Campaign has been gathering momentum around the world, including Demonstration Projects in developing countries, notably China. In May 2015, the General Assembly of WHO unanimously approved Resolution WHA.68.20 which urges all member states to develop national health care plans for epilepsy management, particularly in low- and middle-income countries.^{3,4} More recently, the World Federation of Neurology (WFN) and other neurological non-governmental organizations (NGOs) have joined forces with the Epilepsy Campaign and in May 2022 the General Assembly of WHO unanimously approved Resolution WHA.73.10 promoting a 10-year Intersectoral Global Action Plan (IGAP) for Epilepsy and Other Neurological Disorders.^{5,6}

What began 25 years ago as a global initiative for people with epilepsy has now evolved into a global action plan to include people with other neurological disorders. I was privileged to serve as President of ILAE from 1993 to 1997 and the first Chairperson of the ILAE/IBE/WHO Global Campaign Against Epilepsy from 1997 to 2001. Recently, all documents relating to my Presidency and Chairmanship have been gathered up for storage and future access at the Wellcome Collection in the United Kingdom (SA/ILE/Acc2676.Jan 2023). This has given me the opportunity to review the origins and early development of the Global Campaign based on these documents covering the period 1993–2001.

2 | THE BIRTH OF THE CONCEPT

The ILAE and IBE are two among several neurological/neuroscience NGOs affiliated to WHO. As President of

ILAE I attended my first two annual meetings of these NGOs with WHO in Geneva in December 1993 and 1994. It seemed to me that these were merely forums for the exchange of information and for WHO to ask for some help and advice. No-one asked the WHO for help or advice. It occurred to me that the potential existed for a much more active and productive relationship with WHO and that a partnership between the professional (ILAE), the public/patients (IBE) and the political (WHO) could be a powerful one for addressing the needs of people with the common, universal, hidden, neglected, and stigmatized brain disorder of epilepsy.

Therefore, on May 27, 1994, I wrote to the new Director of the Division of Mental Health at WHO, Jorge Alberto Costa e Silva, asking if I could meet with him in Geneva to discuss ILAE/WHO relationships in more detail? Jorge Alberto Costa e Silva readily agreed but the meeting was postponed three times in 1994/1995. I eventually went to Geneva to meet him on January 16, 1996. I brought with me Pierre Jallon, who we had appointed Chairperson of the ILAE/IBE Commission on Developing Countries, not only because of his commitment to developing countries but also because he was based at the University of Geneva in close proximity to WHO. Jorge Alberto Costa e Silva brought with him, as expected, Leonid Prilipko, Head of the Section of Neuroscience within his Department, and also unexpectedly Shichuo Li, who I did not know. I was delighted to learn not only that Shichuo Li had a personal interest and commitment to people with epilepsy in China but also he was the current Chairman of the Executive Board of WHO. There was a considerable meeting of minds that day on which the concept of the ILAE/IBE/WHO Global Campaign Against Epilepsy was born. I flew home, much encouraged, to sell the idea to the League and the Bureau, while Jorge Alberto Costa e Silva and Shichuo Li set about seeking WHO support.

3 | PLANNING THE CAMPAIGN

The need for a Global Campaign for the huge, hidden, and neglected global problem of epilepsy was readily understood by the Executives of ILAE and IBE, especially as recent studies had confirmed the treatment gap in developing countries varied between 60% and 98%, especially in rural areas, and that a cheap and largely effective medication, that is, phenobarbitone, was theoretically available.⁷ Some in IBE had reservations about a partnership with the unfathomable and bureaucratic WHO, especially if there were any financial demands, the IBE's finances being much less substantial than those of the ILAE. A few in both Executives questioned whether a Division of Mental Health was an appropriate vehicle for a Campaign

TABLE 1 Major platforms for announcing and raising awareness of the ILAE/IBE/WHO global campaign against epilepsy September 1996–July 1997.

September 01–05, 1996	ILAE European regional congress (The Hague)
September 06–07, 1996	ILAE/IBE Asian and Oceanian Regional Congress (Seoul)
December 06–09, 1996	50th anniversary meeting of the American Epilepsy Society in association with the Epilepsy Foundation of America (San Francisco)
New Year 1997	Launch of Epilepsy Centre (Beijing)
March 02–05, 1997	Pan Arab Symposium on Epilepsy (Riyadh)
June 30, 1997–July 05, 1997	Joint ILAE/IBE/WHO Symposium at ILAE/IBE International Epilepsy Congress (Dublin)

for a brain disorder, albeit that many people with epilepsy had additional mental health issues. I pointed out that a joint fundraising campaign would be mounted and that epilepsy is a bridge between neurology and psychiatry, as well as a window on brain and psychological function. Furthermore, the Epilepsy Campaign could be a model for other neurological NGOs.

At a meeting of the Executive and Long Range Planning Committees of the ILAE in London in November 1994 I persuaded the ILAE to invest for the first time in a part-time public relations officer within a joint Public Relations Committee of ILAE and IBE. Don Whiting of Harrison Cowley UK was appointed. This Committee met for the first time in London on April 04, 1996 when ideas for a global awareness raising Campaign, including key messages and promotional events, were first discussed.

On May 24, 1996, Pierre Jallon and I met again in Geneva with Jorge Alberto Costa e Silva, Leonid Prilipko, and Shichuo Li, this time with Don Whiting and Chris Powell from the Public Relations Department of WHO, when further details of a global awareness raising campaign were discussed and developed.

On June 06–07, 1996, an International Workshop on Epilepsy in Developing Countries was organized in Geneva by Pierre Jallon with the financial support of ILAE and WHO. The 40 delegates included representatives from Africa (Ethiopia, Senegal, South Africa, Togo, Tunisia), South America (Brazil, Colombia, Uruguay, Ecuador, Venezuela), Asia (India, Indonesia, Pakistan, Sri Lanka, the Philippines), China, and Eastern Europe (Russia, Slovenia, Turkey). Others participating included the members of the Developing Countries Commission; the Chairpersons of the ILAE Commissions on Antiepileptic Drugs, Epidemiology, Education, Economics, and Tropical Diseases; the President of IBE, Hanneke de Boer, and three representatives of WHO (Leonid Prilipko, Aleksandar Janca, C. Liana Bolis). The Workshop focused on the epidemiology, diagnosis, treatment, care, and needs of people with epilepsy in different countries and regions of the developing world as a basis for global, regional, and national actions within the proposed Global Campaign. The proceedings were published in *Epilepsia*.⁸

Immediately following the Workshop an International Advisory Committee (initially referred to as a “Task Force”) met for the first time on June 10, 1996 in Geneva to begin planning the objectives, policies, messages, and organizational details of the Campaign prior to a formal launch in 1997. The Committee consisted of officers of WHO, ILAE, and IBE, including Leonid Prilipko for WHO, Hanneke de Boer for IBE and myself for ILAE, together with Pierre Jallon, several ILAE/IBE Commission chairpersons, Don Whiting and Igor Rozov, the latter replacing Chris Powell from WHO Public Relations. The Committee identified several events over the forthcoming 12 months which could serve as platforms for promoting and planning the Campaign (Table 1). The Committee met again for the second time on September 01, 1996 at the time of the first announcement, press conference and press release of the Campaign at the ILAE European Congress of Epileptology in The Hague, Netherlands. This was immediately followed by a further announcement and press conference at the first Asian and Oceanian Congress of ILAE/IBE in Seoul, South Korea on September 06, 1996.

At the same time, all ILAE and IBE chapters were informed of the concept and planning for the Campaign and were asked to complete a questionnaire on their interest, experience, and willingness to participate. It was emphasized that the ultimate objective of the Campaign was to stimulate, encourage, and support their own Departments of Health to develop their own national Campaigns involving professionals, public, and politicians, according to local needs and resources.

The Advisory Committee met for the third and final time on December 06, 1996 in San Francisco at the time of the 50th anniversary meeting of the American Epilepsy Society in association with the Epilepsy Foundation of America. At this event, the IBE Executive formally agreed to be a partner in the Campaign, together with ILAE and WHO, and President Hanneke de Boer became a dedicated advocate. Thereafter, Hanneke de Boer, Leonid Prilipko, and I served as a Management Committee/Secretariat answerable to the ILAE and IBE Executives and to the Division of Mental Health at WHO as we finalized the details for an agreed launch and action plan for the

Campaign in Geneva and in Dublin at the time of the 23rd ILAE/IBE International Congress in the summer of 1997. This involved regular day trips by Hanneke and myself to Geneva, both before and after the launch of the Campaign.

In the months prior to the Launch, much time and effort were spent in developing Campaign information, brochures, videos, articles for medical journals,⁹⁻¹¹ a logo and press releases in collaboration with public relations advisors, Igor Rozov (WHO) and Don Whiting (ILAE/IBE), all designed to bring epilepsy “Out of the Shadows.” The Campaign information included a mission statement and objectives (Table 2), as well as summaries of the history, etiology, epidemiology, prognosis, social consequences, economics, scientific, and medical advances of epilepsy (WHO Fact Sheets 165–168).

The WHO alerted all its six Regional Offices, that is, AFRO in Harare, EMRO in Alexandria, EURO in Copenhagen, PAHO in Washington DC, SEARO in New Delhi and WPRO in Manila. The ILAE and IBE planned to develop their Regional structures, which at that time were only fully developed in Europe.

4 | THE LAUNCH OF THE GLOBAL CAMPAIGN

The “Out of the Shadows” Campaign was formally launched in Geneva on June 19, 1997 at a press conference attended by officers of the League, Bureau and the Division of Mental Health of WHO. Interestingly, it was not attended by the then Director-General of WHO, Dr. Hiroshi Nakajima, but it was supported by the Assistant Director-General, Dr. Fernando Antezena. Also supporting were John Bowis MP, OBE, a Minister of Health in the UK Government, and Congressman Tony Coelho, Chairman of the US Presidential Committee on

TABLE 2 Mission and objectives of the ILAE/IBE/WHO global campaign against epilepsy.

MISSION:

To improve acceptability, treatment, services, and prevention of epilepsy worldwide.

OBJECTIVES:

1. To increase public and professional awareness of epilepsy as a universal, treatable brain disorder.
2. To promote public and professional education about epilepsy.
3. To change attitudes, dispel myths, and raise epilepsy on to a new plane of acceptability in the public domain.
4. To identify the needs of people with epilepsy on a national, regional, and global basis.
5. To encourage governments and departments of health to develop their own national campaigns to improve prevention, diagnosis, treatment, care, services, and public attitudes.

the Employment of People with Disabilities, who earlier had initiated the Americans with Disabilities Act. In retrospect, this was a relatively low-key launch of phase 1 of the Campaign, in comparison with the much bigger launch of the second phase of the Campaign with the new Director-General of WHO, Dr. Gro Harlem Brundtland, in Geneva in February 2001.^{1,2}

However, the Campaign was also launched in more style and visibility 3 weeks later, on July 07, 1997, at the 23rd ILAE/IBE International Congress in Dublin, now supported by Irish President, Mary Robinson, all the officers of the League and Bureau, together with Jorge Alberto Costa e Silva and Leonid Prilipko of WHO, and many of the approximately 5000 delegates at the Congress. On this occasion a Symposium was held on “The Politics of Epilepsy” with contributions from John Bowis; US Congressman Tony Coelho; Irish Senator Joe Doyle and Irish MEP Mary Benotti.

5 | EARLY DEVELOPMENT: THE FIRST FOUR YEARS

The achievements of phase 1 are summarized in Table 3, but here I will describe these in more detail and how they came about.

Following the launch of the Campaign in 1997 major changes in the structure and function of WHO were initiated in 1998 by the new Director General Dr. Gro Harlem Brundtland, which considerably facilitated the Epilepsy Campaign. For the first time ever Dr. Brundtland, a Norwegian physician, gave equal priority to Non-Communicable Diseases, including Mental Health, and to Communicable Diseases, hitherto WHO's highest priority. This led to new Sections or “Clusters” within the above two priorities. The Division of Mental Health, which was now headed by Benedetto Saraceno, who replaced Jorge Alberto Costa e Silva, was now a sub-division of a new Section entitled “Social Change and Mental Health,” led by Y. Suzuki of Japan.

On December 07, 1998 Leonid, Hanneke and I had a very encouraging meeting in Geneva with Y. Suzuki and Benedetto Saraceno, encouraged by Shichuo Li who by then was an Assistant Director General. Y. Suzuki suggested that the Epilepsy Campaign could be greatly boosted by developing a “Cabinet Paper” which, if approved by the Cabinet, the new highest decision-making structure of WHO, would raise the status of the Campaign to the highest WHO level with Director-General support.

Throughout 1999, Leonid, Hanneke, and I, with the support of the Division of Mental Health together with input from the Executives of ILAE and IBE and the International Consultative Committee, worked tirelessly

TABLE 3 Achievements of phase 1 of ILAE/IBE/WHO global campaign against epilepsy 1997–2001.

GLOBAL	Awareness raising/education/ involvement WHO Cabinet Paper, December 1999 Planning for second phase launch, February 2001
REGIONAL	Regional Conferences/Declarations Europe, October 1998 Africa, May 2000 Latin America, September 2000 Asia/Oceania, November 2000 North America, December 2000 European Parliament White Paper March 2001
NATIONAL	Awareness raising and or political initiatives in 50 ILAE/IBE Chapters

to develop the Cabinet Paper. With this in mind the Consultative Committee met in Geneva on April 26–27, 1999, together with the Regional Advisors for Mental Health in AFRO (Custodia Mandlhate) and PAHO (Itzhak Levav) to promote sustainable action plans for addressing the treatment gap and the needs of people with epilepsy in developing countries, including the concept and planning of Demonstration Projects in different Regions to guide and encourage local national initiatives in those Regions, including China (WHO/MSD/MBD/00.11). The Proceedings of that meeting were also published by WHO (WHO/MHH/ND/99.3) and fed into the Cabinet Paper.

Earlier in the autumn of 1998, as a result of the initiative of ILAE Secretary General, Peter Wolf, a Conference was held in Heidelberg on October 24–25 with the financial support of the Federal German Ministry of Health on the theme of “Epilepsy as a Public Health Problem in Europe.” Over 100 leading professional and lay delegates from chapters and organizations in almost every country in Europe, including Russia, supported by Wolfgang Rutz, Regional Mental Health Adviser for Europe, and John Bowis MEP, now a leading spokesperson for public health in the European Parliament, highlighted the needs of 6000000 people with epilepsy in Europe. This led to the European Declaration on Epilepsy which called on the Governments of Europe, including the European Parliament and all healthcare providers, to take strong and decisive action to meet the objectives of the Global Campaign Against Epilepsy.¹²

The main thrust of phase one was in raising awareness, acceptance, and involvement, not least in the League, the Bureau and WHO. With this in mind throughout 1998 and 1999, the Management Committee was in regular

contact with the ILAE/IBE Chapters. By November 1999, 50 ILAE/IBE Chapters had informed the Committee that they had begun or were in the process of developing their own awareness-raising or political initiatives, also fed into the Cabinet Paper. At the same time, the League and Bureau Executives were planning Regional structures, beginning with the ILAE Asian and Oceanian Commission. The business case for the Campaign was also being developed with the guidance of Walt Schaw, a US Business Consultant, temporarily employed by the ILAE. In order to ensure maximum support within WHO the Management Committee had several meetings in Geneva in 1999 with the Heads of potentially important related Sections or Clusters, including “Child and Adolescent Health and Development,” “Essential Drugs,” “Resource Mobilization,” “Non-Communicable Diseases,” and “Public Relations.” Earlier in December 1998, the WFN and all neurological/neuroscience NGOs had given their support to the Campaign.

On December 03, 1999 the Cabinet Paper was approved by WHO, giving an enormous boost to the Campaign. This paved the way for a new major launch of the Campaign, led by the Director General, which took place on February 12, 2001 with a new more ambitious goal to improve treatment, care, prevention, and social acceptance of epilepsy worldwide, including a 4-year Action Plan involving Demonstration Projects to promote national initiatives, including China, encouraged by the Regional Offices of WHO. The Cabinet approval also facilitated four further Regional Conferences on Public Health Aspects of Epilepsy, which led to Regional Declarations on Epilepsy in Africa (Senegal) on May 06, 2000, Latin America (Chile) on September 06, 2000, Asia and Oceania (India) on November 13, 2000 and North America (Washington) on December 01, 2000. In all 1200 experts from more than 100 countries participated in these Regional Conferences and Declarations.¹² On March 22, 2001 John Bowis MEP, presented a “White Paper” on Epilepsy to the European Parliament based on the European Declaration.¹³

6 | THE LAUNCH OF PHASE 2 AND THEREAFTER

The launch of the second phase of the Campaign in Geneva on February 12, 2001 has been described in detail in a Supplement of *Epilepsia* and will not be amplified here.¹⁴ In summary, it was a much more high-profile event than the initial launch in 1997, now including speeches by Director-General Dr. Gro Harlem Brundtland; the Head of Non-Communicable Diseases Derek Yach; the Head of Mental Health Benedetto Saraceno; Presidents Jerome Engel Jr of ILAE and Philip Lee of IBE; Hanneke de Boer



FIGURE 1 Launch of the second phase of the ILAE/IBE/WHO Global Campaign Against Epilepsy, Geneva, February 12, 2001. Left to right: Hanneke de Boer (IBE); Derek Yach (Head of Non Communicable Diseases, WHO); WHO Director General Dr. Gro Harlem Brundtland; Benedetto Saraceno (Head of Mental Health, WHO); Leonid Prilipko (Head of Neuroscience, WHO); Ted Reynolds (ILAE).

and myself; and John Bowis MEP² (Figure 1). It was attended by all the WHO Regional Health Advisers; the Officers of the ILAE and IBE, together with representatives of their Regional Commissions and representatives of other neurological NGOs. Following the morning launch and press event a Symposium on “Public Health Aspects of Epilepsy and the Role of the Global Campaign Against Epilepsy” was held in the afternoon.² The launch and especially the speech by the Director-General was a milestone in the social history of Epilepsy.²

I am not qualified to describe in any detail the further developments of the Campaign. I am aware, however, how all successive Executives of the League and the Bureau played their part in expanding the momentum and reach of the Campaign, together with Tarun Dua in WHO, who succeeded Leonid Prilipko, who sadly died in 2007. Sadly in 2015, we also lost Hanneke de Boer who had succeeded me as Chairperson of the Global Campaign and who had contributed so much to the Campaign.¹⁵

I am aware that the 2009–2013 ILAE Executive led by Solomon (Nico) L. Moshé initiated a major boost to the Campaign with the Presidents of ILAE and IBE now chairing.¹⁶ Furthermore, on September 15, 2011, the European Parliament passed the “Written Declaration on Epilepsy,” promoted by Irish MEP Gay Mitchell, which led to a considerable increase in European Union funding for epilepsy research in succeeding years.¹⁷

I also know how the 2013–2017 ILAE and IBE Executives, led by Emilio Perucca and Athanasios Covanis and supported by WFN President Raad Shakir and his Executive, successfully promoted the 2015 WHO General Assembly Resolution (WHA 68.20)^{3,4} and how, with the

initiative of succeeding Executives, this evolved into the current 2022 WHO IGAP Resolution (WHA 73.10).^{5,6} I also know that any WHO General Assembly Resolution requires the unanimous or almost unanimous support of all the 194 member states. The 2015 and 2022 Resolutions therefore reflect the degree to which the Campaign has become truly global. Finally, I am aware of the leading role of China and Russia in promoting both the WHO General Assembly Resolutions, the former through Shichuo Li in both China and WHO, and the latter through Alla Guekht, who has had a significant influence, both as an officer of ILAE and WFN.

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CONFLICT OF INTEREST STATEMENT

I have no conflicts of interest to disclose.

ETHICS STATEMENT

I confirm that I have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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