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From global campaign to global commitment: The World Health Assembly's Resolution on epilepsy

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SUMMARY

Tuesday May 26, 2015, will be remembered as an historic day in the fight against epilepsy. On that date, the World Health Assembly approved unanimously the Resolution on the “Global Burden of Epilepsy and the Need for Coordinated Action at the Country Level to Address its Health, Social and Public Knowledge Implications,”¹ which urges Member States to implement a coordinated action against epilepsy and its consequences. This event, which comes almost 20 years after the establishment of the Global Campaign against Epilepsy, is another landmark in the longstanding collaboration among the World Health Organization (WHO), the International League Against Epilepsy (ILAE), and the International Bureau for Epilepsy (IBE) in addressing the needs of people with epilepsy. It also acted as a catalyst for other professional societies, including the World Federation of Neurology (WFN), to join forces in promoting a common action against epilepsy. The Resolution did not happen by chance, but came at the end of a long journey that involved the hard and tireless work of many dedicated individuals around the globe.

千里之行，始於足下 A journey of a thousand miles
begins with a single step.

Lao Tzu (604–531 BC)

HOW DID IT ALL START?

The Resolution finds its roots in the realization that epilepsy is virtually unique in terms of its magnitude and the

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nature of the many burdens that it brings on individuals and society. Epilepsy affects >50 million people worldwide and is the most common serious chronic neurologic disease.² It affects individuals, irrespective of age, gender, ethnic background, and geographic location. Its incidence is higher in low-income countries, mostly related to differences in the influence of risk factors such as infections and suboptimal antenatal and perinatal care.³ In a recent study, which compared the Global Burden of Disease imposed by 220 conditions affecting all organs and systems, severe epilepsy ranked fourth in terms of disability weight.⁴ The life of people with epilepsy is devastated by many factors, including seizures,⁴ a heavy burden of comorbidities,^{5–8} and the side effects of antiseizure medications.⁹ In addition to the clinical manifestations of the disease, people with epilepsy and their families are faced with the consequences of pervasive stigma. This can lead to prejudice and discrimination in legislation, schooling, employment, marriage, and other aspects of social life.¹⁰ Some forms of epilepsy are also associated with a major increase in mortality risk. In a prospective study of 245 children with epilepsy over a period of 40 years, 33 (55%) of the 60 deaths during follow-up were related to epilepsy.¹¹ Worldwide, the number of cases of sudden unexpected death in epilepsy (SUDEP) can be estimated at about 60,000 per year, or 8 cases per million, with epilepsy ranking second only to stroke among selected neurologic diseases in terms of years of potential life lost.¹² In low- and low middle-income countries, even higher mortality rates can be ascribed to status epilepticus and seizure-related accidents, particularly drowning.¹³ Such a heavy burden of morbidity and mortality translates into huge monetary costs to individuals and to society: In a recent comparison of total direct healthcare costs of neurologic diseases in Canada, the total cost of epilepsy was found to be second only to that of Alzheimer's disease and other dementias.¹⁴ Epilepsy also ranked second (after hospitalized traumatic brain injury) in terms of both indirect economic costs due to premature death and working age disability.

Another important uniqueness of epilepsy compared with many other chronic diseases is that it is easily treatable in the majority of cases with inexpensive medications. For example, the cost of phenobarbital, a drug that is effective in freeing people from most seizure types, can be as low as US \$ 0.008 per one 100 mg tablet, implying that a yearly supply of medication at efficacious doses would cost less than US \$ 3 per person.¹⁵ Yet, the majority of those with epilepsy who live in low- and low middle-income countries do not have access to regular treatment, and are therefore prevented from living normal and productive lives.¹⁶ It is notable that the treatment gap, which is invariably associated with an awareness and knowledge gap, is not limited to severely resource-restricted countries, but it is also present to a lesser extent and in different forms in highly advanced societies.^{16,17} It was the realization of the large public health impact, and the many unmet needs of people with epilepsy,

that brought together ILAE, IBE, and WHO in 1997.¹⁸ Thanks largely to the vision of four individuals, Dr. Edward (Ted) Reynolds, ILAE President, Ms. Hanneke De Boer, IBE President, Dr. Leonid Prilipko, Head of the Section of Neuroscience at WHO, and Dr. Shichuo Li, Chairman of the WHO Executive Board, the Global Campaign against Epilepsy (GCAE) was born (Fig. 1). Eighteen years later, due to a fortunate combination of events, one of those leaders, Dr. Shichuo Li, in a completely different capacity, found himself in a key position to facilitate the process that led to the Resolution.

A LONG JOURNEY

The first few years of the Global Campaign focused on increasing awareness, creating acceptance, and promoting education.¹⁸ Over the subsequent years, the “Out of the Shadows” campaign unfolded, resulting in the finalization of regional conferences and Declarations in all six WHO regions.^{19–24} A seminal publication produced jointly by WHO, ILAE, and IBE in 2005 provided updated comprehensive information on the burden of epilepsy in different regions and emphasized the ubiquitously unsatisfactory quality of epilepsy care and also the large disparities in levels of care between and within regions and countries.²⁵ Under the auspices of the Global Campaign, demonstration projects were undertaken over the years in several countries and provided further valuable information on the burden of epilepsy and its determinants in different contexts, as well as intervention models to address the treatment gap.²⁶ In 2008, WHO launched the WHO Mental Health Gap Action Programme, which includes epilepsy as a priority disease for intervention.²⁷



Figure 1.

The pioneers of the Global Campaign against Epilepsy. From left to right, Edward H. Reynolds (ILAE President, 1993–1997), Shichuo Li (Chairman of the WHO Executive Board, 1996–1997), Hanneke De Boer (IBE President, 1997–2001), and Leonid Prilipko (Director, Section on Neuroscience, Department of Mental Health, WHO 1996–2007). Reproduced from Ref. 18, with permission. *Epilepsia* © ILAE

The last 6 years saw important developments in the approach taken by ILAE and IBE in addressing the unmet needs of people with epilepsy. In particular, it has become clear that all efforts made by the two organizations in promoting epilepsy awareness, care, and research need to be supplemented, and preferably driven, by direct mobilization of all stakeholders, including national societies, associations, and individuals with epilepsy, along with their families and friends. The mobilization, which today can reach unprecedented effectiveness thanks to the use of modern communication media, should be aimed at stimulating concrete actions at local, national, and international levels. The first testing of a broad application of this approach came in 2011 with the joint ILAE-IBE campaign to support the Written Declaration of Epilepsy at the European Parliament, an initiative spurred by Gay Mitchell, a Member of the Parliament (MEP) highly dedicated to our cause.²⁸ Through mobilization of national chapters, associations, and individuals, made largely possible by the tireless work of Ann Little—IBE Executive Director—MEPs were approached individually and provided with material about the nature and needs of epilepsy, and actively encouraged to support the initiative.²⁹ To be approved, the Written Declaration required supportive signatures by at least 369 of a total 738 MEPs, not an easy task when about 95% of declarations submitted to the Parliament fail to achieve the minimum number of signatures. The Written Declaration of Epilepsy was approved with support from 459 MEPs, the highest number of signatures ever achieved for any Written Declaration in the current EU term! Among the first concrete results from the Declaration, in the subsequent year, the European Commission allocated more than EUR 50 million to support epilepsy research.

Successful collaborative advocacy initiatives involving a broad range of stakeholders have not been limited to Europe. An important outcome of such initiatives is the report on epilepsy by the Institute of Medicine,¹⁷ which is very influential in setting healthcare and research priorities in the United States and other countries. Another important milestone was the Pan American Action Plan on Epilepsy developed by the WHO Region of Americas.³⁰ The implementation of the latter saw WHO working in collaboration with ILAE and IBE in promoting epilepsy awareness and healthcare projects in collaboration with governments from many countries of the region.

These initiatives set the scene for a major new development: the approval of an Epilepsy Resolution by the World Health Assembly.

THE INITIAL DRAFT

The mechanism that led to the development of the Resolution was set into motion by the initiative of one country, the People's Republic of China. This did not happen by chance.

First, The People's Republic of China had played a pioneering role in addressing the epilepsy treatment gap by conducting, in conjunction with WHO, ILAE, and IBE, one of the most successful demonstration projects in the history of the GCAE. The project, implemented initially in six provinces between 2000 and 2004, demonstrated the feasibility of diagnosing and treating epilepsy at the primary care level.³¹ Not only was the project successful in reducing the treatment gap and increasing the proportion of seizure free individuals, but it also demonstrated that the care model was cost-effective. For example, the mean total annual healthcare and time costs of managing epilepsy in a sample of individuals from the Ningxia province decreased from 213 yuan per person at baseline to 46 yuan after the intervention.³² In the Shanghai region, the mean cost per patient decreased over the same period from 1,493 to 92 yuan. Based on these results, the Chinese health authorities have now extended the project to 18 provinces covering a population of 75 million people, and the intervention is being up-scaled further.

Secondly, the Resolution was facilitated by collaboration between the Chinese health authorities and the China Association Against Epilepsy (CAAE), which had been established by Dr. Shichuo Li shortly after his return to China in 2003. This communication, and China's successful experience with the GCAE project, led the Chinese authorities to believe that the time was ripe for a call for epilepsy action to be taken to a global level.

In the fall of 2014, The People's Republic of China made a formal request to WHO to have epilepsy included in the agenda of the 136th WHO Executive Board meeting, which took place in Geneva from January 26 to February 3, 2015. At the same time, the Chinese authorities worked on a draft Resolution to be presented for discussion at the Board.

BUILDING UP MOMENTUM

The preparation of the draft Resolution led to overwhelming enthusiasm and intensive mobilization of ILAE and IBE, including their national chapters and associations. The response from our constituencies was enthusiastic and extremely gratifying. In some countries, effective contacts with governments were made mostly by IBE members, in other countries by ILAE members, and in most cases there was remarkable synergism between lay and professional organizations. It soon became apparent that governments of many countries were highly supportive of the initiative and concurred that the magnitude of the medical, social, and economic burden of epilepsy justified a coordinated effort.

As communication with Member States unfolded further, it became clear that the level of support was so strong that some governments were considering co-sponsoring the Resolution. The first country to take an active step in that regard was the Russian Federation, which liaised with the Chinese delegation in advancing the draft of the Resolution. Another co-sponsor that came in at a later stage was the Maldives.

SUCCESS!

The agenda item on epilepsy and the draft Resolution were discussed at the 136th WHO Executive Board meeting on February 2, 2015. The support was overwhelming, with 28 countries, some speaking on behalf of other nations from the same region, standing up and making positive statements about the Resolution. Valuable suggestions to refine the text came from several countries, and eventually the Executive Board voted unanimously to submit the Resolution to the 68th World Health Assembly. In addition to the People's Republic of China, the Russian Federation, and the Maldives, four other countries (Argentina, the Islamic Republic of Iran, Japan, and Panama) requested to co-sponsor the resolution at the Board meeting.

At that point, action shifted to maintaining the momentum and ensuring approval of the Resolution at the 68th World Health Assembly (Fig. 2). Partner societies, including the World Federation of Neurology (WFN) and Health Action International, joined forces with ILAE and IBE in supporting the effort. The decisive moment came on May 26, 2015 when the Resolution was unanimously approved by the Assembly. Again, many countries stood up making strong supportive statements, and many more requested to be listed as co-sponsors. ILAE, IBE, WFN, and Health Action International also made official statements. Between the Executive Board meeting and the World Health Assembly, a total of 42 countries from five continents made official statements (some also on behalf of other nations), and 19 countries were co-sponsors (Table 1). As a signal of the level of representation, the list of countries that made supportive statements included all the five most populous nations of the world, that is, the People's Republic of China, India, the United States of America, Indonesia, and Brazil. Rarely has a Resolution enjoyed such a level of support.

WHAT IS IN THE RESOLUTION AND WHAT DOES IT MEAN?

The Resolution is divided into four sections, which explain the need for a coordinated action against epilepsy at the country level and provide specific details on how that action should be structured.¹

The first section lists key facts about the global burden of epilepsy, summarizes previous initiatives taken by WHO in the area, with explicit acknowledgement of the ILAE and IBE partnership, and explains how a coordinated action against epilepsy at the country level is in line with the policies set by United Nations institutions, including the Millennium Development Goals.

The second section urges Member States to take a set of specific measures targeting the burden of epilepsy, including the promotion of epilepsy awareness and education; the establishment of national healthcare action plans for epilepsy, to overcome inequalities and inequities in health,



Figure 2.

Delegates from WHO, ILAE, and IBE at the 68th World Health Assembly, Geneva, Switzerland, 18–26 May, 2015. From left to right, Athanasios Covanis (IBE President), Shekhar Saxena (Director, Department of Mental Health and Substance Abuse, WHO), Shichuo Li (Chair, ILAE-IBE Joint Task Force on Global Research Advocacy), Tarun Dua (Medical Officer, Department of Mental Health and Substance Abuse, WHO), Emilio Perucca (ILAE President), Brooke Short (Fellow, Epilepsy Program, WHO), Alla Guekht (Co-chair, ILAE-IBE Joint Global Outreach Task Force), Ann Little (IBE Executive Director), and Mary Secco (Co-chair, ILAE-IBE Joint Global Outreach Task Force).

Epilepsia © ILAE

social, and other related services; the integration of epilepsy diagnosis and management into primary healthcare where appropriate; the implementation of strategies for epilepsy prevention and to improve access to medicines; the need to improve investment in epilepsy research; and the engagement of civil society and other partners in these actions (Table 2).

The third section extends a specific invitation to international, regional, national, and local partners from within the health sector and beyond, to engage in, and support, the actions detailed earlier.

The last section requests the WHO Director-General to (1) “review and evaluate actions relevant to epilepsy that WHO has been leading, coordinating, and supporting in order to identify, summarize, and integrate the relevant best practices with a view to making this information widely available, especially in low- and middle-income countries”; (2) “develop, in consultation with relevant stakeholders . . . a set of technical recommendations guiding Member States in the development and implementation of epilepsy programmes and services, and to provide technical support to Member States in actions for epilepsy management, especially in low- and middle-income countries”; and (3) “report back to the Seventy-first World Health Assembly on progress in the implementation of this resolution”.

Table 1. Delegations that made official statements in support of the Resolution on The Global Burden of Epilepsy at the 136th WHO Executive Board meeting and/or at the 68th World Health Assembly

Albania	Lithuania
Argentina	Malaysia
Australia	Maldives
Azerbaijan	Malta
Bahrain	Nepal
Benin ^a	Panama
Brazil ^b	Poland
Canada	People's Republic of China
Chinese Taipei (observer)	Republic of Korea
Czech Republic	Romania
Democratic Republic of Congo ^a	Russian Federation
Egypt ^c	Saudi Arabia
Georgia	Suriname
Ghana	Swaziland
Greece	Tanzania
India	Thailand
Indonesia	Timor-Leste
Iraq ^c	United Kingdom
Islamic Republic of Iran	United States of America
Italy	Uruguay ^d
Japan	Venezuela
Lebanon	

Countries shown in bold requested to co-sponsor the Resolution.

^aAlso speaking on behalf of the 47 Members of the African Region.

^bAlso speaking on behalf of the 35 Member States of the Region of the Americas.

^cAlso speaking on behalf of the 21 Member States of the Eastern Mediterranean Region.

^dAlso speaking on behalf of the 12 Member States of Union of South American Nations.

The Resolution sends a strong message to the governments across the world and to the international community about the need to treat epilepsy as a major health priority and to establish specific actions to address the needs of people with epilepsy. It is notable that the recommendations made to Member States encompass all critical aspects, including prevention, diagnosis, access to medications, medical and social services, removing disparities in epilepsy care, fighting stigma and discrimination, and promoting epilepsy research. In their statements made to the Assembly, many Member States expressed their commitment to step up specific actions, and they often made reference to priorities already identified within their national setting.

An important component of the Resolution relates to the role mandated to WHO to guide Member States in the design and implementation of action plans against epilepsy and to provide support to these actions, particularly in low- and middle-income countries.

WHAT ARE THE NEXT STEPS?

The Resolution already produced some important achievements. It has strengthened the alliance of WHO, ILAE, and IBE, and it has enhanced the sense of belonging within the ILAE and IBE constituencies. Equally important, it has increased the awareness of epilepsy as a global problem within medical and neurological communities. It was gratifying to see WFN and Health Action International to join forces with ILAE and IBE in supporting the Resolution.

Table 2. Recommendations made to Member States by the 68th World Health Assembly Resolution on the Global Burden of Epilepsy¹

- (1) Strengthen effective leadership and governance, for policies on general health, mental health, and noncommunicable diseases that include consideration of the specific needs of people with epilepsy, and make the financial, human, and other resources available that have been identified, as necessary, to implement evidence-based plans and actions;
- (2) Introduce and implement, where necessary and in accordance with international human rights norms and standards, national healthcare plans of action for epilepsy management, aiming to overcome inequalities and inequities in health, social, and other related services, paying special attention to people with epilepsy living in conditions of vulnerability, such as those living in poor and remote areas, including by strengthening public healthcare services, and training local human resources with proper techniques;
- (3) Integrate epilepsy management, including health and social care, particularly community-based services, within the context of universal health coverage, including community-based rehabilitation, into primary health care, where appropriate, in order to help to reduce the epilepsy treatment gap, by training nonspecialist healthcare providers to provide them with basic knowledge for the management of epilepsy so that epilepsy can be diagnosed, treated, and followed up as much as possible in primary healthcare settings, as well as by empowering people with epilepsy and their carers for greater use of specified self and home care programmes, by ensuring a strong and functional referral system and by strengthening health information and surveillance systems to routinely collect, report, analyse, and evaluate trends on epilepsy management
- (4) Support the establishment and implementation of strategies for the management of epilepsy, particularly to improve accessibility to and promote affordability of safe, effective, and quality-assured antiepileptic medicines and include essential antiepileptic medicines into national lists of essential medicines;
- (5) Ensure public awareness of and education about epilepsy, in particular in primary and secondary schools, in order to help to reduce the misconceptions, stigmatization, and discrimination regarding people with epilepsy and their families that are widespread in many countries and regions;
- (6) Promote actions to prevent causes of epilepsy, using evidence-based interventions, within the health sector and in other sectors outside health;
- (7) Improve investment in epilepsy research and increase research capacity; and
- (8) Engage with civil society and other partners in the actions referred to in paragraphs 1–7 above.

As a major gesture of collaboration, WFN decided to dedicate to epilepsy World Brain Day 2015, which was celebrated worldwide on July 22, 2015, and invited WHO, ILAE, and IBE to participate in World Brain Day activities.³³ This led neurologic societies around the globe to work closely with ILAE chapters, IBE associations, and national health authorities in raising awareness about epilepsy and working toward the implementation of the Resolution.

The Resolution provides our members with a powerful tool to engage governments into taking concrete action to improve epilepsy care, promote public awareness, and allocate resources to epilepsy research. ILAE, IBE, and WHO have already started drafting a set of supporting documents aimed at assisting stakeholders in ensuring that the Resolution translates into effective actions.

As mentioned in the Resolution, WHO will complete a review of past epilepsy-related activities to identify the best practices and models to address effectively the burden of epilepsy, and will make such documentation available to its partners and Member States. ILAE, IBE, WFN, and other stakeholders also look forward to working together with WHO in producing technical recommendations to guide Member States in developing and implementing national and regional epilepsy action plans. Special focus will be on low- and middle-income countries, and one of the top priorities will be to remove the many hurdles that prevent universal access to medicines. It is unacceptable that many essential epilepsy medicines are not readily available in several regions, particularly in the public sector, and that the price of these medicines in low-income countries is several-fold higher compared with high-income countries.^{19,34,35} Planned activities include the organization of meetings and workshops to facilitate the involvement of all stakeholders, including policy makers, and the engagement of all relevant national and international institutions.

These are great times for all those who strive for better lives for people with epilepsy. The Resolution is just the beginning—it is our duty to fully exploit this unprecedented opportunity. By working together, there are no limits to what we can achieve.

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