The road to a World Health Organization global action plan on epilepsy and other neurological disorders

Alla Guekht1,2,3 | Martin Brodie4 | Mary Secco5 | Shichuo Li6 | Nancy Volkers3 | Samuel Wiebe3,7

1Moscow Research and Clinical Center for Neuropsychiatry, Moscow, Russia
2Russian National Research Medical University, Moscow, Russia
3International League Against Epilepsy, Flower Mound, Texas, USA
4International Bureau for Epilepsy and Epilepsy Unit, University of Glasgow, Glasgow, UK
5International Bureau for Epilepsy, London, Ontario, Canada
6China Association Against Epilepsy, Beijing, China
7Department of Clinical Neurosciences, University of Calgary, Calgary, Canada

Correspondence
Samuel Wiebe, Foothills Medical Centre, 1403–29 Ave SW, Calgary, Alberta, T2N 2T9, Canada.
Email: swiebe@ucalgary.ca

Abstract
The World Health Organization (WHO) has recognized epilepsy as a public health imperative due to its occurrence at all ages in all regions of the world, its high impact on disability-adjusted life years and psychosocial aspects, and the accompanying stigma. The International League Against Epilepsy and the International Bureau for Epilepsy have established crucial collaborations with regional and global organizations to promote epilepsy as a treatable disease, close the treatment gap in care, education, and research, and eradicate stigma. In November 2020, the efforts of these three organizations—with support from WHO member states, the World Federation of Neurology, and the European Federation of Neurological Associations—culminated in the unanimous approval of a WHO resolution to create and implement an Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders. This unique achievement is built on more than 2 decades of collaboration and effort, and heralds extraordinary opportunities to work toward a world where no person’s life is limited by epilepsy.

KEYWORDS
global action plan on epilepsy, IBE, ILAE, World Health Organization

1 | HISTORIC WORLD HEALTH ORGANIZATION RESOLUTION OF 2020

November 12, 2020 will be remembered as the day of a global milestone victory for people who suffer from epilepsy around the world. On that day, during the 73rd World Health Assembly (WHA), countries from around the world which are members of the World Health Organization (WHO) unanimously approved a resolution to develop a 10-year Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders.1

This historic accomplishment was the culmination of long-standing, effective collaboration of the member states (the Russian Federation, which initiated the resolution, and cosponsors: Australia, Belarus, Bhutan, China, Colombia, Eswatini, the European Union and its member states, Guyana, Iceland, Jamaica, the Philippines, and the United States) and leading professional organizations, with technical support from the WHO secretariat. The International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) played a fundamental role at every stage of development of the resolution, in collaboration with the World Federation of Neurology (WFN) and the European Federation of Neurological Associations (EFNA). We describe major events leading to this momentous resolution, its implications for epilepsy around the world, and the way forward.
2 | INTRODUCTION/BACKGROUND

The importance of epilepsy from a public health and humanitarian perspective cannot be overemphasized. It is the most common serious chronic neurologic disease, affecting more than 50 million people of all ages, genders, ethnic backgrounds, and geographic locations worldwide. About 80% of people with epilepsy live in resource-poor countries, where risk factors such as infections and suboptimal pre- and perinatal care are more prevalent.

The lives of people with epilepsy are disrupted by seizures, comorbidities, and the side effects of antiseizure medications (ASM). They also face discrimination and prejudice as consequences of widespread social stigma. People with epilepsy have been denied employment and education, and they face barriers to marriage, parenthood, and other aspects of social life.

Mortality is nearly threefold higher in people with epilepsy, compared with the general population. Epilepsy ranks third among chronic neurologic diseases in terms of disability-adjusted years of life lost, and sudden unexpected death in epilepsy is second only to stroke in terms of potential years of life lost among chronic neurological conditions.

On the other hand, effective epilepsy treatment saves lives. Epilepsy is ranked in the top five noncommunicable diseases for treatment cost-effectiveness. One year of ASM can cost as little as US$5 in resource-poor settings.

Despite this, about 75% of people with epilepsy in low- and middle-income countries do not receive adequate treatment. This treatment gap is not limited to resource-poor areas; it also occurs in different forms in high-income countries, especially in areas with low levels of health care access, health literacy, and epilepsy awareness.

A primary aim of the ILAE and IBE has been to advocate for people with epilepsy by addressing these issues. Over the years, the ILAE and IBE have established crucial collaborations with regional and global organizations to promote epilepsy as a treatable disease, close the treatment gap in care, education, and research, and eradicate stigma. In addition to country-level support through their local organizations, the ILAE and IBE have strongly supported multilateral advocacy initiatives such as the 2011 European “Written Declaration on Epilepsy,” the 2011 Pan American Health Organization “Strategy and Plan of Action on Epilepsy,” and the US Institute of Medicine report “Epilepsy Across the Spectrum.”

However, the ILAE and IBE also recognize that comprehensive and inclusive advocacy actions require multilateral initiatives involving global partners with the capacity to reach local health service decision-makers and grassroots organizations. For decades, the advocacy endeavors of the ILAE and IBE have engaged the WHO in constructing a growing edifice of global actions, culminating in the recent approval of the resolution for a global action plan for epilepsy. The road to this resolution has been paved by the hard work and dedication of the leaders and volunteers who preceded us, and by important achievements that set the stage for current progress, many of which have been aptly described by Covannis et al. A timeline of some key events follows.

3 | 1997: THE GLOBAL CAMPAIGN

In 1997, the ILAE, IBE, and WHO established the Global Campaign Against Epilepsy, with the tagline “Out of the Shadows.” Up to that time, this was one of the most ambitious global initiatives. Initially, the campaign focused on epilepsy awareness, acceptance, and education. Demonstration projects in several countries provided more information on the burden of epilepsy and potential ways to decrease the treatment gap. A project in China found that about 9 million people had epilepsy in that country, but with a treatment gap of 63%, most were not being treated. In rural areas of six provinces, the demonstration project trained physicians to better diagnose epilepsy and prescribe treatment, reducing the treatment gap to 13%.

Also as a result of the Global Campaign Against Epilepsy, the WHO included epilepsy as a priority condition in its Mental Health Gap Action Program, which includes evidence-based guidelines for nonspecialist health care providers. Covannis et al. provide a history of the Global Campaign Against Epilepsy and progress toward the passage of Resolution WHA 68.20 in 2015.

4 | 2015: RESOLUTION WHA 68.20

May 26, 2015 marks another crucial date for global advocacy in epilepsy. On that day, years of collaborative efforts among the ILAE, IBE, and WHO member states—notably China—culminated in the approval of WHA Resolution 68.20, titled
“Global Burden of Epilepsy and the Need for Coordinated Action at the Country Level to Address Its Health, Social and Public Knowledge Implications.” Endorsed by all 194 WHO member states, this historic resolution consists of four sections: (1) recognition of the global burden of epilepsy; (2) need for country-level actions such as urging member states to take specific actions in the areas of health policy, health care action plans, health care coverage, education and research, and public engagement; (3) an invitation for multilateral engagement; and (4) a call for the WHO secretariat to improve health information and surveillance systems to get a clearer picture of the global burden of epilepsy and its economic impact, as well as to measure progress in improving access to care for people with epilepsy.18

WHA Resolution 68.20 accomplished the important milestones of establishing the diagnosis and treatment of epilepsy as an international health priority and identifying actions at a country level. It also provided a roadmap for engaging key stakeholders, such as WHO member states and WHO departments to bring epilepsy to the forefront in global health initiatives.

5 | 2018–2019: THE GLOBAL REPORT ON EPILEPSY

In 2018, the WHO joined efforts with the ILAE and IBE to create the first WHO global report on epilepsy: "Epilepsy: A Public Health Imperative."2

The report was launched in June 2019, on the 110th anniversary of the ILAE, during the International Epilepsy Congress in Bangkok, with participation of WHO, ILAE, and IBE officials. The 146-page report is a global call for action to combat stigma, change legislation, and address the gaps in epilepsy knowledge, care, and access to safe and affordable antiseizure medicines around the world. The summary of the report (https://www.who.int/mental_health/neurology/epilepsy/report_2019/en/) is available in the six main WHO languages (Arabic, Chinese, English, French, Russian, and Spanish).

The report was created by a large group of international epilepsy experts and includes results from surveys completed by professional and lay organizations from dozens of countries. It comprehensively describes the impact that the condition has on people with epilepsy, their families and communities, and society at large. It provides clear evidence for epilepsy as a public health priority, and strongly encourages investment to reduce its burden. Special attention is paid to the prevention of epilepsy, access to quality services and affordable medicines, and reducing premature deaths.

The report notes preventive interventions as one of several, broader public health responses in maternal and newborn health care, communicable disease control, injury prevention, and cerebrovascular health. It also highlights the pressing need for increased investment in research, as well as integrating epilepsy care into primary health care, ensuring that all people with epilepsy have access to quality and affordable care.

6 | TOWARD AN ACTION PLAN ON EPILEPSY AND OTHER NEUROLOGICAL DISORDERS: THE LONG AND WINDING ROAD

6.1 | January 2019: Positioning Epilepsy on the WHO Agenda

Following Resolution WHA 68.20, described above, it became clear to the ILAE and IBE that further actions would be required to make meaningful inroads in addressing the needs of people with epilepsy globally. The initial step would require including epilepsy as an item in the already-full agenda of the WHO Executive Board. In January 2019, epilepsy was taken up as a priority by the Russian Federation. At the 144th WHO Executive Board meeting, with support from Chile, China, Indonesia, and Jamaica, the proposal by the Russian Federation to include epilepsy in the agenda of the 146th Session of the WHO Executive Board was approved. This created a remarkable opportunity to advance our quest for an action plan on epilepsy.

6.2 | May 2019: Raising Epilepsy Awareness at the WHA

Now that epilepsy was itemized for discussion by the WHO Executive Board, it was crucial to ensure that member states had sufficient awareness of the proposed epilepsy items to be discussed, as well as their global importance. The Russian Federation submitted an application to the WHO Director General for a side event at the 72nd WHA, entitled: “Epilepsy: A Public Health Priority.” The application was cosponsored by China, Colombia, Croatia, Guyana, Honduras, Kazakhstan, Mexico, Slovenia, Tunisia, and Zambia. This side event would bring together policy-makers, nongovernmental organizations, patients, health care leaders, and member states to discuss key directions for an epilepsy action plan. Attendees also had an opportunity to learn about the WHO global epilepsy report “Epilepsy: A Public Health Imperative.”

This epilepsy side event was approved by the WHO Director General and took place at the 72nd meeting of the WHA, with participation by more than 120 delegates from 39 countries.22 Panelists and attendees provided statements about the enormous burden of epilepsy from the viewpoints
of advocates, policy-makers, clinicians, and family members of people with epilepsy. Event participants agreed that health and social needs were top priorities that could be addressed in a global action plan on epilepsy.

6.3  Fall 2019: Preparing to Make Our Case to the WHO Executive Board

The inclusion of the epilepsy item on the agenda of the 146th WHO Executive Board meeting and the success of the WHA side event made it clear that there was an opportunity to pursue the aim of articulating global actions for epilepsy. In preparation for the WHO Executive Board meeting, member chapters and associations of the ILAE and IBE around the world mobilized to garner support from their governments. This led to strong support from member states, including official letters to the WHO from Chile, Georgia, Honduras, Italy, Guyana, Ivory Coast, Kazakhstan, North Macedonia, and Tunisia. The leadership bodies of the American Epilepsy Society, US Epilepsy Foundation, Australian Epilepsy Society, Swiss League Against Epilepsy, Swedish Epilepsy Society, and Oman League Against Epilepsy received positive feedback from their respective governments.

6.4  February 2020: The 146th WHO Executive Board Meeting—A Turning Point

The 146th WHO Executive Board meeting was a turning point on the long road toward an action plan for epilepsy. During this meeting, a draft decision proposing an action plan for epilepsy was presented by the Russian Federation and received strong support from member states. It was cosponsored by 37 member states, including Chile, China, Eswatini, Germany (on behalf of 27 European Union countries), Guyana, Kazakhstan, Honduras, North Macedonia, Russia, Tajikistan, and Zambia. Furthermore, support was expressed by more than 80 countries, including Australia, Finland (speaking on behalf of eight Nordic countries), Gabon (speaking on behalf of 47 African countries), Georgia, India, Indonesia, Italy, Iran, Japan, Sudan, Thailand, Tunisia (speaking on behalf of 21 Member States of the Eastern Mediterranean Region), and Turkey.

Member states from all regions of the globe acknowledged the burden of epilepsy, the need for strengthening leadership and governance in epilepsy, the need to facilitate a comprehensive health care response, the importance of eradicating stigma, and the need to enhance prevention and research in epilepsy. The majority of speakers expressed support for developing a plan of action to address epilepsy as a public health priority. The importance of incorporating epilepsy treatment into primary health care and providing access to ASMs was underlined. Speakers acknowledged that epilepsy and other neurological disorders co-occurred frequently, and there was a unique opportunity to develop synergistic, cost-effective measures to reduce not only the burden of epilepsy but also the burden of other neurological disorders. Important statements in favor of the draft decision were made by the ILAE, IBE, and World Federation of Neurology.

The decision of the 146th WHO Executive Board encouraged member states to discuss a possible draft resolution on further action on epilepsy and other neurological disorders for consideration by the 73rd WHA, and requested the Director General to take two specific actions: (1) expand the scope of the report to be submitted for consideration by the 73rd WHA by adding a new section entitled “Synergies in Addressing the Burden of Epilepsy and Other Neurological Disorders,” and (2) develop technical guidance on strengthening country actions against epilepsy and its comorbidities and make this guidance available on the WHO website.

This decision was unanimously adopted by the WHO Executive Board, with more than 120 countries cosponsoring or supporting these items and clearing the way for a discussion on further action on epilepsy and other neurological disorders to take place at the 73rd WHA.

6.5  November 2020: Decision Time—The WHA

Held annually, the WHA is the decision-making body of the WHO. It includes delegates from all WHO member states who discuss and vote on specific agenda items prepared by the WHO Executive Board (www.who.int/about/governance/world-health-assembly). The 73rd WHA was held in May 2020 and November 2020 in virtual format, due to the COVID-19 pandemic. Before the November meeting, an intense period of activity to create a draft resolution was undertaken by the Russian Federation, cosponsoring member states, WHO secretariat, ILAE, IBE, and other collaborators. The draft resolution recognizes that epilepsy and other neurological disorders are the leading cause of disability-adjusted life years and the second leading cause of death worldwide, and that epilepsy and other neurological disorders disproportionately impact people living in low- and middle-income countries. It notes with concern that the risk of premature death in people with epilepsy is three times higher than in the general population. It highlights that epilepsy is a highly treatable condition and that more than 70% of people with epilepsy could live seizure-free if they had access to appropriate treatment. The resolution also notes that epilepsy and other neurological and mental health disorders often coexist and can be compounded by other health conditions, and that epilepsy can be caused by stroke, traumatic brain injury, and other neurological disorders.
The draft resolution was presented at the 73rd WHA, being cosponsored by the Russian Federation, Belarus, Bhutan, China, Colombia, Eswatini, the European Union and its member states, Guyana, Iceland, Jamaica, the Philippines, and the USA. A number of other countries spoke in favor of the resolution (Box 1). The resolution “Global Actions on Epilepsy and Other Neurological Disorders” was unanimously approved. The key points of the resolution are presented in Box 2.

The approval of the resolution for an action plan would have been impossible without the strong advocacy of the ILAE and IBE country chapters and associations before their own governments. This was key to the success of the proposal. We thank our members for their commitment and their energy, and we take the opportunity to encourage all of us to persevere. The support and leadership of member states listed throughout this report was invaluable. Finally, this remarkable accomplishment is also the result of outstanding collaboration among the WHO, ILAE, IBE, WFN, and EFNA.

6.6 | Finally—The Action Plan

A draft global action plan on epilepsy and other neurological disorders is to be submitted at the 150th WHO Executive Board meeting in early 2022, with an intention to submit the plan to member states for endorsement at the 75th WHA later that year.

The global action plan is a WHO document, which will be developed with support from all relevant stakeholders. The ILAE and IBE have had a key leading role throughout the entire journey, and will continue to be proactive in its development, providing material and expert support to WHO as required and collaborating with stakeholders throughout the process.

Steps for developing the global action plan are well underway. The ILAE and IBE are supporting the WHO-prepared timelines to develop a Technical Brief in Epilepsy,

**BOX 1** Delegations that made official statements in support of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders

- Russian Federation
- Australia
- Bahrain
- Belarus
- Bhutan
- Canada
- China
- Colombia
- Eswatini
- European Union and its member states
- Guyana
- Iceland
- Jamaica
- Mexico
- Philippines
- Sri Lanka
- United States of America
- Uruguay

Note: Countries shown in bold requested to cosponsor the resolution.

**BOX 2** Key elements of the WHO resolution to develop a global action plan on epilepsy and other neurological disorders

The resolution requests the WHO Director General to:

1. Develop, in consultation with member states and in full collaboration with United Nations organizations and relevant nonstate actors, a 10-year Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders, supporting universal health coverage, to address the gaps in promotion of physical and mental health, and prevention, early detection, care, treatment, and rehabilitation, as well as social, economic, educational, and inclusion needs of persons and families living with epilepsy and other neurological disorders, and the ongoing need for research to improve prevention, early detection, treatment, care, and rehabilitation, including treatment options with the potential to cure epilepsy and other neurological disorders.

2. Include in the intersectoral global action plan ambitious, but achievable, global targets on reducing preventable cases of, and avoidable deaths resulting from, epilepsy and other neurological disorders, strengthening service coverage and access to essential medicines, improving surveillance and critical research, and addressing discrimination and stigma.

3. The resolution also urges member states to provide the appropriate support to WHO to develop the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders. Finally, it calls on all relevant stakeholders to provide appropriate support to WHO and partners to develop the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders.


as requested by the WHO Director General, and to contribute to the consultation process for the development of the global action plan with member states, United Nations agencies, and other relevant nonstate actors. We face exciting times of intense activity, and very much look forward to the end product.

6.7 | Calling on Our Constituencies—Again!

What does this global action plan mean for our member chapters and organizations around the world? In short, the adoption of this historic resolution provides three key opportunities:

1. An unprecedented opportunity to ensure that epilepsy is placed high on local governments’ agendas;
2. An opportunity to optimize the synergies in services and care with other neurological comorbidities, and to use epilepsy as an entry point to improve health systems across neurological conditions; and
3. An opportunity to reach out to other sectors to address stigma and exclusion, and to change legislation that is currently discriminatory against people with epilepsy.

This will, therefore, require action from all our members. The global action plan will be developed from now until September 2021. We anticipate that during the second half of 2021, the draft will undergo informal consultations with governments so that it is ready for consideration by the WHO Executive Board in early 2022, and for adoption by all governments when they meet at the WHA in May 2022.

In the months preceding the WHA, many chapters engaged effectively with their governments to generate support for the resolution. This engagement made a huge impact. It resulted in 38 countries cosponsoring the resolution, and many others voicing their public support. We encourage our members to continue delivering the message to their local governments as we enter the final stretch of this journey.

CONFLICT OF INTEREST

A.G., M.S., N.V., and S.L. have nothing to disclose. S.W. has received unrestricted educational grants from UCB Pharma, Sunovion, and Eisai. M.B. has received speaker and consultancy fees from UCB Pharma, Eisai, Xenon, Arvelle Therapeutics, and Sanofi.

ORCID

Martin Brodie © https://orcid.org/0000-0003-1781-2892
Nancy Volkers © https://orcid.org/0000-0002-2768-2318
Samuel Wiebe © https://orcid.org/0000-0002-1061-9099

REFERENCES
