

# Epilepsy: A public health priority

## Event Report

SIDE EVENT AT THE 72<sup>ND</sup> WORLD HEALTH ASSEMBLY

22<sup>ND</sup> MAY 2019

*Prof Alla Guekht, ILAE Vice-President, Mrs Mary Secco, IBE Secretary-General, Prof Shichuo Li, GOTF Co-Chair, Dr Meredith Fendt-Newlin, Consultant*

## Introduction

The annual World Health Assembly (WHA) convenes the leading voices for global public health to engage in strategic discussions about how to tackle the world's most pressing health concerns. A side event at the WHA is a tremendous opportunity to highlight specific health care domains before WHO Leadership and top-level health care authorities from all over the world. The demand for the slots for side events is very high, as there are many applications from the Member States and non-state actors in official relations with WHO. These applications are selected through a competitive process where “the international public health significance and relevance of the topic for a number of WHO regions is considered” according to [WHO website](#).

Epilepsy affects over 50 million people, making it one of the most common neurological diseases worldwide. It carries a high risk of premature mortality and accounts for increased disability. Persons with epilepsy are stigmatized in all societies, with the consequences of prejudice and discrimination adding to the medical burden of the disease. Epilepsy affects people of all ages, sex, race and income levels, but poor populations and those living in vulnerable situations, in particular in low- and middle-income countries, bear a disproportionate burden, posing a threat to public health and economic and social development. Epilepsy is the only severe and disabling neurological disease that is fully treatable in the majority of cases. About two thirds of persons with epilepsy may achieve complete seizure control with inexpensive medications.

Four years after the landmark WHA resolution on the global burden of epilepsy (WHA68.20), unanimously approved in 2015, the side event on 22<sup>nd</sup> May 2019 was a major milestone. The Resolution WHA68.20 urges the WHO Member States to take coordinated action to address the health, social and public knowledge implications of the disease. It also requests that the WHO provide technical support to Member States for epilepsy management, especially in countries with poor access to services and resources, where the burden of epilepsy is great. The WHA side event was an opportunity to continue building momentum following the Resolution WHA68.20 to make epilepsy a public health priority.

The Russian Federation, one of the co-sponsors of the WHA 68.20, submitted an application to host the official side event alongside the 72<sup>nd</sup> WHA. The application was co-sponsored by Croatia, China, Honduras, Kazakhstan and Zambia, and supported by the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE) and the World Federation of Neurology (WFN). The joint application was successful and the slot on May 22<sup>nd</sup> was given. This meeting was the first-ever official side event of epilepsy during the World Health Assembly.

At a later stage, the side event was co-sponsored by Colombia, Guyana, Mexico, Slovenia and Tunisia, so the event was in fact co-hosted by 10 Member States (representing European, Asian, Latin American and African regions). These countries and others in attendance reaffirmed their commitment to taking action to address the needs of people living with epilepsy, promoting epilepsy care and research worldwide, reducing the treatment gap and fighting stigma. The side event flyer can be found in **Figure 1**.



**SAVE THE DATE!**

**Epilepsy: A Public Health Priority**

Side event at the 72<sup>nd</sup> World Health Assembly  
**Date and time:** Wednesday 22 May 2019, 12.30-14.00 **Venue:** Palais des Nations, Room XXIV

**Co-hosted by:**  
the Russian Federation, China, Colombia, Croatia, Kazakhstan, Mexico, Slovenia, Tunisia and Zambia  
with contributions from the ILAE, IBE and the WFN

Epilepsy affects over 50 million people worldwide. Among neurological diseases, it accounts for the highest disability life year rates and carries a high risk of premature mortality. Persons with epilepsy are stigmatized in all societies, with the consequences of prejudice and discrimination adding to the medical burden of the disease. Epilepsy affects people of all ages, genders, race and income levels, but poor populations and those living in vulnerable situations, in particular in low- and middle-income countries, bear a disproportionate burden, posing a threat to public health and economic and social development.

Epilepsy is the only severe and disabling neurological disease that is fully treatable in the majority of cases. About two thirds of persons with epilepsy achieve complete seizure control with inexpensive medications.

This side event will bring together policy makers, NGOs, patients, health care leaders and Member States to develop next steps for the implementation of WHA68.20. The Global Epilepsy Report will be presented and key directions of the Epilepsy Action Plan will be identified.

**Refreshments and a light lunch will be served**  
*Interpretation from/to Russian and English provided*

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**ILAE** International League  
Against Epilepsy

**IBE** International Bureau  
for Epilepsy

**WFN**  
WORLD FEDERATION  
OF NEUROLOGY

**Figure 1: WHA side event flyer**

## Objectives

The event had four main objectives:

1. To review the scope and magnitude of the burden of epilepsy globally and to identify the underlying systemic issues affecting access to UHC and essential medicines.
2. To pre-launch the Global Epilepsy report and to discuss the key strategies for strengthening leadership and governance in epilepsy, facilitating a comprehensive health care response, eradicating stigma, and enhancing prevention and research in epilepsy.
3. To learn from the experiences of Member States who have implemented demonstration projects to improve epilepsy care and access to anti-seizure medicines.
4. To strengthen Member State commitment to develop a plan of action to address epilepsy as a public health priority.

## Event programme

The side event was chaired by Prof Evgeny Kamkin (Deputy Minister of Health, the Russian Federation), Prof Shichuo Li (China), Dr Svetlana Akselrod (UN Inter-Agency Task Force on Noncommunicable Diseases (NCDs) and Global Coordination Mechanism on NCDs, WHO), and Prof Alla Guekht (ILAE). The event began with opening remarks from chairpersons, followed by the statements from China (Prof Shichuo Li), Croatia (Prof Silvio Basic),

Kazakhstan (Dr Leila Dairbaeva), Tunisia, (Prof Chahnez Triki) and Zambia (Sharon Kapambwe). Then Dr Neerja Chowdhary spoke on behalf of the WHO Department of Mental Health and Substance Use, followed by the non-state actors in official relations with WHO representatives: ILAE statement given by Prof Alla Guekht, ILAE Vice President; WFN on behalf of Prof. William Carroll, WFN President (presented by Alla Guekht in her capacity of the WFN Elected Trustee); and IBE by Mrs Mary Secco, IBE Secretary-General. Details of their remarks are below and can be shown in **Figure 2**. Following panelists remarks, the event was opened to statements from attendees, who represented diverse stakeholder views.



**Figure 2: Board of the side event**

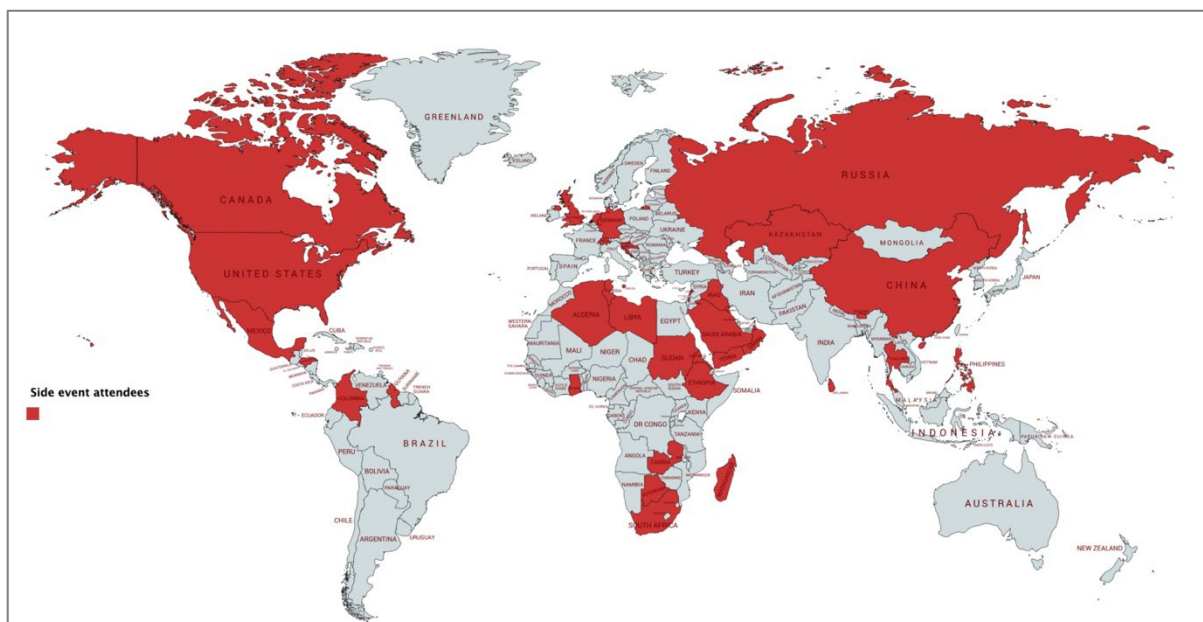
#### Attendees

In total, there were more than 120 attendees at the event, representing 39 different countries across all six WHO regions and income groups (low, middle, and high-income countries) (see **Figures 3 & 4**). There was also diverse attendance from the public sector, UN, non-governmental organizations (NGOs) and academia, including:

- Thirty representatives of the Ministries of Health and Permanent missions, representing 23 countries
- Eleven WHO representatives from Country Offices and others
- Representatives of 15 NGOs and eight public health institutes



**Figure 3: The packed conference hall of the side event**



**Figure 4. Map of countries represented at the event**

#### Summary of presentations

The event was opened by Prof Evgeny Kamkin (Deputy Minister of Health, the Russian Federation) who noted that epilepsy represents a high burden both from economic and social perspectives. Following adoption of the Resolution WHA68.20 in 2015, the Russian

Federation coordinated measures at the country level to reduce the burden of epilepsy. They continue to implement a strategy which includes large scale research on epilepsy—especially the provision of treatment and medication in the Russian Federation—and support global work with more than 40 countries to address the burden of epilepsy. He called on all participants of the WHA side event to undertake their plans of action for epilepsy during the session of the WHA 72.

Dr Svetlana Akselrod (WHO) spoke about *Multi-sectorial action on epilepsy*. She described the high burden of epilepsy within the context of NCDs, for example that it is one of the most common neurological conditions and accounts for a significant proportion of the world's burden of disease. She stated “multisectoral action is needed” to tackle the burden, by delivering better health services, engaging with education and the social sector, and empowering communities to raise awareness of epilepsy and break down stigma. Dr Akselrod described WHO's close collaborations with countries to enhance epilepsy care, demonstrating that there are simple, cost-effective ways to treat epilepsy in primary care even in low-resource settings.

From China, Prof Shichuo Li spoke about *Advances of epilepsy control in China*. He started by stating 9.6 million people currently live with epilepsy and there are approximately five hundred thousand new cases per year. The China Association Against Epilepsy was established in 2005 and now 27 of 31 provinces have epilepsy associations. In the 1990s China conducted The Global Campaign Against Epilepsy Demonstration Project, results of which continue to inform countries around the world of the achievements that can be made from integrating epilepsy in primary care at a low cost. China hopes that countries will continue to implement Resolution WHA68.20 and calls on countries to (i) make epilepsy as public health priority; (ii) strengthen public education; (iii) develop legislation to protect patient rights; and (iv) establish health care policies for epilepsy.

Croatia's Prof Silvio Basic discussed *Epilepsy stigma in the modern society*. He explained that both in developed and developing countries, people with epilepsy face numerous obstacles and disadvantages in everyday life, which restrict them in professional and social endeavors, despite many successful people in history that have thrived with a diagnosis of epilepsy. In Europe, even where the standards of diagnosis and therapy are high, the treatment for epilepsy remains inadequate. In Croatia, epilepsy treatment centres have been opened and care is now provided without additional funds, but with redistribution of funding from health authorities. Dr Basic finished by emphasizing the importance of positive attitudes, education and raising public and professional awareness about epilepsy to overcome this major health problem.

From Kazakhstan, Dr Leila Dairbaeva gave a talk on *Epilepsy and universal health coverage*. As a practicing clinician, she started by sharing personal experiences from people with epilepsy and their families, saying, “they are all waiting for real improvements in their lives.” There is a need for an appropriately trained health care workforce, including both primary care workers and specialists. As part of the National Epilepsy Programme in the Republic of Kazakhstan, a roadmap was developed for improving care for people with epilepsy, with the support of the Minister of Health E.A. Birtanov. Grounded in the Declaration of Alma Ata

1978, and its resurgence in 2018 with the International conference on primary health care hosted in Kazakhstan, Dr Dairbaeva underscored the importance of addressing epilepsy with universal health care. Kazakhstan supports the work of WHO and health systems around the world in order to raise epilepsy as a priority and to improve access to quality care through universal health coverage.

From Tunisia, Prof Chahnez Triki described *Epilepsy in the Eastern Mediterranean region*. She raised the figure that epilepsy is amongst three of the most frequently presented neurological disorders with 4.7 million people suffering from epilepsy in just nine Eastern Mediterranean countries. In 2003 a regional declaration was adopted which called for actions including: a Regional epilepsy congress; celebration of advocacy initiatives like Epilepsy Day; an outreach strategy to increase community awareness across countries; and translation of ILAE materials into Arabic. Prof Triki said there are no systems for collecting data and few epidemiological studies from the region. There is a high treatment gap from 60-98%, with few neurologists and few effective primary care approaches currently being implemented; most people having to pay out of pocket for treatment. There is a need to consider epilepsy as a public health priority, which will enable the development of a global action plan for epilepsy.

The Ministry of Health, Zambia, was represented by Sharon Kapambwe, who spoke about the situation for people living with epilepsy in the country. She explained epilepsy treatment is highly institutionalized and community treatment is still sought from traditional healers. There is a lack of data on current cases and high levels of stigma and discrimination. Zambia is moving toward a primary health care approach to treat epilepsy. Dr Kapambwe finished by saying there is a need to support epilepsy research.

Dr Neerja Chowdhary, WHO Department of Mental Health and Substance Use, described the *WHO Programme on reducing the epilepsy treatment gap* and spoke about the long-standing collaboration between WHO, ILAE and IBE, starting with the launch of the Global Campaign Against Epilepsy to increase epilepsy awareness at global, regional and national levels more than 20 years ago. Dr Chowdhary reiterated the importance of the Resolution WHA68.20, giving strength to defeating epilepsy, and stated that “WHO recognizes epilepsy as a public health priority.” It’s part of WHO’s mental health Gap Action Programme (mhGAP) which has been supporting countries to integrate epilepsy management into primary health care. WHO has also shown that epilepsy care can be cost-effectively integrated into the primary health system in low-resource settings through work in Ghana, Mozambique, Myanmar and Viet Nam.

Statements were made from non-State Actors ILAE, WFN and IBE. Prof Alla Guekht, ILAE Vice-President, gave a presentation on the important role that ILAE has played as the world's preeminent association of health professionals and scientists working toward a world where no person's life is limited by epilepsy. The efforts of ILAE have garnered support from many member states, including 43 that made strong statements in favor of the Resolution WHA68.20 with commitments to step up actions against epilepsy and 19 countries named as co-sponsors. Prof Guekht highlighted the need to strengthen Member State commitment to develop a plan of action to address epilepsy as a public health priority by sharing key data on its global burden and the steps that have been taken so far to date. Further funding and research is also needed to address the burden. She shared information about the launch of

the new Global Epilepsy Report, forthcoming in June 2019, and encouraged Member States to promote the report with their respective health authorities and advocacy groups.

The statement on behalf of Prof William M Carroll, WFN President, commended the inclusion of the epilepsy side event in this year's WHA, its sponsorship by key state actors, and for WFN to be able to participate as a non-state actor with the ILAE and the IBE. The WHO is not alone, as demonstrated by the state and non-state actors engaged in this side event, and they stand ready to support the initiatives required to implement a global action plan.

From IBE, Mrs Mary Secco, Canada, IBE Secretary-General, gave a statement about the burden of epilepsy and the challenges faced by people living with epilepsy and their families. She described the important role of the IBE in improving the social condition and quality of life of people with epilepsy and those who care for them. By funding social programmes and through advocacy efforts, IBE is working with 135 chapters in 104 countries to reduce the burden of epilepsy. Mrs Secco promoted the upcoming launch of the Global Epilepsy Report and shared details from the report about how stigma can be reduced by a variety of stakeholders from public and private sector, policymakers, practitioners, and people with epilepsy and their families.

Prof Evgeny Kamkin from the Russian Federation gave brief closing remarks before opening the floor to statements from the attendees and Member States present. He said epilepsy represents one of the most prominent priorities in brain disease. The Russian Federation is advocating for a global action plan for epilepsy, which will be an agenda item at the next WHO Executive Board meeting in February 2020.

#### [Key discussion points](#)

The side event had excellent attendance and provided a platform for discussing the important challenges faced by countries in prioritizing epilepsy as well as the innovative solutions and lessons from around the world. It served as an opportunity for scaling up of Member States' political commitment towards addressing the gaps in epilepsy care and moving forward with commitment to action from the hosting countries and those in attendance.

**The burden of epilepsy:** Nearly all presenters/panelists as well as statements from the attendees included remarks about the immense burden of epilepsy. These came from the perspectives of policymakers, clinicians, advocates and family members of people with epilepsy, and the statements reflected the critical challenges facing people all around the world in every community. Country level actions from the co-hosts and others (the Russian Federation, China, Colombia, Croatia, Kazakhstan, Mexico, Honduras, Slovenia, Tunisia and Zambia) were shared on how the burden of epilepsy is (and can be) addressed.

**Stigma and discrimination:** Related to the burden of epilepsy, stigma was also a theme pervasive through the discussion at the side event. It was a key topic from statements made by Prof Silvio Basic from Croatia and Mrs Mary Secco of IBE; also, the mother of a person with epilepsy from Lebanon shared a story of the stigma that she and her daughter faced which prevented her from accessing education as a child. Stigma was described for its impact on



help-seeking, particularly for the health sector, and results in people turning to traditional healers in some countries (e.g. mentioned by Zambia).

**Reducing the treatment gap, especially with universal health coverage:** Global, regional and country level figures on the treatment gap were shared during the side event. These data made clear that far more people are living with epilepsy than those who have access to quality and affordable care in their communities. Training of health providers across the system (from primary care through specialists) is a necessary step to reducing the treatment gap. This was linked to achievement of the Sustainable Development Goals through promotion of universal health coverage and access to medicines, which will help to enhance treatment of epilepsy alongside other NCDs and other conditions. Dr Leila Dairbaeva from Kazakhstan reiterated that the Declaration on Primary Health Care in Astana, Kazakhstan in October 2018 is another global commitment to act on universal health coverage for epilepsy.

### Next steps

1. Launch in June 2019 and promoting of the first **global epilepsy report**, *Epilepsy: a public health imperative*. Member States and other attendees were made aware of the launch and upcoming availability of the report; and encouraged to share the report with stakeholders in countries across the world and promote widely on social media. Everyone who attended the event received flyers about the report and details of where to access it once launched **Figure 5**). The report is now available here: [https://www.who.int/mental\\_health/neurology/epilepsy/report\\_2019/en/](https://www.who.int/mental_health/neurology/epilepsy/report_2019/en/)
2. Sharing of information from the event, including **video on WHO social media**: Prof Evgeny Kamkin (Deputy Minister of Health, the Russian Federation) Video in Russian with English subtitles; Alla Guekht, the ILAE Vice-President and Mary Secco, the IBE Secretary-General  
[https://www.who.int/mental\\_health/neurology/epilepsy/report\\_2019\\_videos/en/](https://www.who.int/mental_health/neurology/epilepsy/report_2019_videos/en/)
3. The next major step is advocating for a **Global Action Plan** in the next WHO Executive Board in February 2020. This will support sustained and coordinated action to prioritize epilepsy in public health agendas is required at global, regional and national levels



# EPILEPSY

A public health imperative

This is the first global report on epilepsy and an important milestone in translating the World Health Assembly resolution (WHA68.20) on the global burden of epilepsy into action. It is time to highlight epilepsy as a public health priority to strongly encourage investment in reducing its burden, and to advocate for actions to address gaps in epilepsy knowledge, care and research.

This report is a call for action to ensure that every person with epilepsy has access to the care and treatment they need, and the opportunity to live free from stigma and discrimination in all parts of the world.

COMING SOON..!

## The burden

The burden of epilepsy is high and often neglected on public health agendas. Epilepsy is one of the most common neurological diseases, affecting over 50 million people worldwide of all ages living in countries of all income levels. The risk of premature death in people with epilepsy is up to three times higher than in the general population. Roughly half of adults with epilepsy have at least one other health condition. Psychiatric conditions, such as depression and anxiety, make seizures worse and reduce quality of life. Epilepsy has significant economic implications in terms of health care needs and lost productivity at work.



## Stigma and discrimination

In all parts of the world, people with epilepsy are the target of discrimination and human rights violations. The stigma of epilepsy can discourage people from seeking treatment and has consequences for quality of life and social inclusion. Improving knowledge and raising awareness of epilepsy in schools, work places, and communities is needed to reduce stigma. Legislation based on internationally-accepted human rights standards can prevent discrimination and rights violations, improve access to health care services, and raise the quality of life for people with epilepsy.



## Prevention

An estimated 25% of epilepsy cases are preventable. The major modifiable risk factors for epilepsy are: perinatal insults, central nervous system infections, traumatic brain injury and stroke. Preventing epilepsy is an urgent unmet need. Effective interventions for prevention are available and delivered as part of broader public health responses in maternal and newborn health care, communicable disease control, injury prevention and cardiovascular health.

## Addressing the treatment gap

Nearly 80% of people with epilepsy live in low- and middle-income countries. Furthermore, three-quarters of people living with epilepsy in those countries do not get the treatment they need. Yet, up to 70% of people with epilepsy could become seizure-free with appropriate use of cost-effective antiseizure medicines. A significant proportion of the burden of epilepsy could be avoided by scaling-up routine availability of antiseizure medicines, possible at an annual cost of around US\$ 5 per person. It is feasible to integrate epilepsy treatment into primary health care – training non-specialist providers, investing in continuous supplies of antiseizure medicines and strengthening health systems can substantially reduce the epilepsy treatment gap.



## The time to act is now

Sustained and coordinated action to prioritize epilepsy in public health agendas is required at global, regional and national levels. The World Health Assembly Resolution (WHA68.20) sets the framework for increasing investment in epilepsy. There is a pressing need for increased investment in research and addressing the burden of epilepsy through integration in primary health care, ensuring that all people with epilepsy have access to quality and affordable care.



Figure 5: Announcement of Global Epilepsy Report distributed at the event