## **Vice President**

The key activities in 2020 were promoting **epilepsy** as the **public health priority** at the level of the **World Health Organization** (WHO) and Member States, fostering the collaborative efforts in epilepsy, increasing engagement of the Member States, and collaboration with non-state actors.

2020 began with intensive preparation for the **146th session of the WHO Executive Board** (EB) meeting. In the fall of 2019, the Russian Federation led a request to the WHO for a decision to approve an Action Plan on Epilepsy. This request was supported by the People's Republic of China. In preparation for the 146 WHO EB meeting, International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE) organizations around the world mobilized extensively to garner support from their governments for this decision on epilepsy. As communication with WHO Member States and Missions unfolded, the level of understanding and support for the need to address the burden of epilepsy and development of an Action Plan continued to grow.



Alla Guekht

In January 2020, in preparation to the 146 WHO EB meeting, the Permanent Mission of the Russian Federation in Geneva, with the support of the Permanent Mission of the People's Republic of China and in collaboration with the WHO, initiated a round of consultations with Permanent Missions in Geneva with the proposal to request the Director-General to develop a global action plan on epilepsy, in consultation with Member States and other relevant stakeholders. The consultations were extremely effective, resulting in contributions from representatives of the Missions of Member States from all regions of the globe. At the 146 WHO EB meeting, the Global Report "Epilepsy: a public health imperative" and the messages it conveyed were well noted by all attendees. The imperative to address the many outstanding gaps in the prevention and treatment of the condition was highlighted.

An important development during the 146 WHO EB meeting was the acknowledgement of the frequent co-occurrence of epilepsy and other neurological disorders. This presented a unique opportunity for scaling up implementation of synergistic, cost-effective measures to reduce the burden of epilepsy and other neurological disorders. Accordingly, it was suggested that the Report to be presented at the 73rd session of the World Health Assembly (WHA) be expanded to reflect this. The expansion consists in adding a new section on "Synergies in addressing the burden of epilepsy and other neurological diseases" and a statement encouraging the Member States to contribute to ongoing discussions on the "Draft Resolution on epilepsy and other neurological diseases" to be presented for consideration by the 73rd WHA. There was also a plan for a request to prepare a Technical Policy Brief on Epilepsy by including a set of essential immediate actions to strengthen country actions against epilepsy and its comorbidities. This was submitted as a Draft Decision on epilepsy proposed by the Russian Federation, China, Eswatini, Guyana, North Macedonia, and Zambia.

The agenda item on epilepsy and the Draft Decision were discussed at the 146 WHO EB meeting on 6 February 2020. The support from Member States was overwhelming, with more than 120 countries highlighting the need to address the global burden of epilepsy and co-sponsoring or supporting the Draft Decision described above. Powerful Statements were presented by the ILAE (Samuel Wiebe), IBE (Action Amos), and World Federation of Neurology (WFN) (Bill Carroll).

The Draft Decision was co-sponsored by 37 Member States: Chile, China, Eswatini, Germany (on behalf of 27 EU countries), Guyana, Kazakhstan, Honduras, North Macedonia, Russia, Tajikistan, and Zambia. Furthermore, support was expressed by over 80 countries, including Australia, Finland (speaking on behalf of 8 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, facilitating a comprehensive healthcare response, eradicating stigma, and enhancing 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 in primary healthcare and providing access to antiseizure medication was underlined. The Member States thanked the Russian Federation for the leadership in proposing the Draft Decision and the WHO Secretariat for preparing the documents for the item on epilepsy, including the Report by the Director-General.

The <u>adoption of the Draft Decision</u> at the 146 WHO EB meeting was a landmark event, demonstrating outstanding support by more than 80 Member States and unprecedented co-sponsorship by 37 Countries. This outstanding support at the governmental level became possible owing to the unprecedented mobilization the ILAE and IBE Chapters, and we are sincerely grateful to the leadership and members of the ILAE and IBE local organizations, Executive Committees, the ILAE and IBE Regional Commissions, and to the Joint Global Outreach Task Force. The ILAE greatly appreciates the continuous and fruitful collaboration with the WFN and its long-standing support for epilepsy at the WHO.

The great success at the 146 WHO EB meeting was a tremendously important milestone, building upon the landmark achievements of the ILAE and IBE in collaboration with the WHO, including the Global Campaign, Resolution WHA 68.20, and Global Report on epilepsy.

Read the full report on the meeting – <u>Epilepsy at the 146 Executive Board meeting of the World Health</u> <u>Organization: Overwhelming Support by More than 120 Member States.</u>

As the need and scope of epilepsy advocacy significantly increased, the **Global Advocacy Council** was assembled by ILAE President Sam Wiebe in spring 2020 (first meeting on 9 May); I was appointed the Chair of the Council.

The Council worked very efficiently and productively, having 23 meetings and triggering several important activities in epilepsy advocacy. I would like to thank the Council members for their commitment and excellent work.

## **Global Advocacy Council Members**

Neha Kaul (Australia)

Alla Guekht (Russia), **chair**Martin Brodie (UK)
Roberto Caraballo (Argentina)
Tarun Dua (Switzerland)
Julie Hall (UK)
Akio Ikeda (Japan)
Nathalie Jetté (USA)
Angelina Kakooza (Uganda)

Shichuo Li (China)
Karen Parko (USA)
Emilio Perucca (Italy)
Philippe Ryvlin (France)
Mary Secco (Canada)
Nicola Specchio (Italy)
Chahnez Charfi Triki (Tunisia)
Eugen Trinka (Austria)
Sam Wiebe (Canada)

## The following were the **key achievements of the Council in 2020:**

- Approval of the Resolution WHA73.10 (<u>see below</u>)
- Development of the Regional WHO activities (see below)
- Contribution to the Goal 3 of the ILAE Strategic Plan
- Modification of the Advocacy part of the ILAE Website, initiating social medial activities
- Research advocacy and other initiatives

Adoption of the WHA 73.10 Resolution "Global Action on epilepsy and other Neurological Disorders" on 12 November 2020 was a landmark event. On that day, during the 73rd WHA, countries from around the world which are members of the WHO unanimously approved a resolution to develop a 10-year Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders. This historic accomplishment was the culmination of long-standing, effective collaboration of the Member States (the Russian Federation, which initiated the resolution, and co-sponsors: 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 ILAE and IBE played a fundamental role at every stage of development of the resolution, in collaboration with the WFN and the European Federation of Neurological Associations (EFNA). This paper, published in Epilepsia, describes major events leading to this momentous resolution, its implications for epilepsy around the world, and the way forward.

**Development of the Regional WHO activities** was of strategic importance. For the first time in history, the Regional Chairs and other Council members contributed meaningfully to the official Meetings of the WHO Regional Boards (WHO South-East Asia 73rd Session; WHO Europe 70th Session, PAHO 72nd Session, WHO Western Pacific 71st Session, WHO Eastern Mediterranean 67th Session, and in collaboration with the IBE, 70th Session of WHO Africa). ILAE Representatives made oral/video/written statements. Because of COVID-19 pandemic, only virtual participation was possible.

## Collaboration with the WHO European Office for the Prevention and Control of Non-communicable diseases (NCD Office)

Non-communicable diseases (NCD) are one of the WHO priorities; the significant comorbidity between epilepsy and NCDs is well-known. The synergy in addressing major NCDs and epilepsy is essential for raising national capacity, enhancing leadership, promoting intersectoral action, and enabling countries to adopt best practices and use international material. In light of this synergy and collaboration with the European NCD Office, the virtual conference on Brain Diseases was organized in Moscow on 18 – 29 November 2020, followed by the virtual meeting and discussion on the ongoing collaborating projects on comorbidity of epilepsy and mental disorders, epidemiology of epilepsy, etc. The conference was an important step in raising the profile of epilepsy for the WHO and the Member States and dissemination of the information on Resolution WHA 73.10, as well as for strengthening the collaboration between the ILAE and the World Federation of Neurology. The international faculty of the conference was truly excellent, and the meeting was attended by more than 2000 doctors and healthcare authorities from Russia and more than 10 Eastern European Countries.

Fruitful collaboration with the WFN and International Child Neurology Association, as well as European Academy of Neurology (EAN) and the World Stroke Organization (WSO) continued to expand in 2020. The WFN extensively supported the ILAE at the 146 WHO EB meeting and Resolution WHA 73.10.

I served in several commissions as the Management Committee Liaison, including the board of ILAE-Europe, Commission of Psychiatry, Epilepsy and COVID-19 Commissions, Epilepsy and Driving Task Force. Please see reports of these commissions.

Submitted by Alla Guekht