

International Bureau for Epilepsy (IBE) Launches Toolkit for Making Epilepsy a Priority in the Americas

10 June 2004. The International Bureau for Epilepsy (IBE) is pleased to announce the launch of the *Advocate's Toolkit for Making Epilepsy a Priority in the Americas*. Developed in partnership with the Pan American Health Organization (PAHO), and enriched by insights from persons living with epilepsy and their families, the publication provides a structured approach to prioritize epilepsy as a public health concern, empowering advocates to influence policy and drive impactful change.

The toolkit builds upon recent advancements in global health policy, particularly the World Health Organization's Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP). Unanimously adopted by all 194 WHO Member States in May 2022, IGAP sets a strategic objective to strengthen the public health approach to epilepsy. Policymakers are mandated to enhance epilepsy service coverage and update discriminatory legislation, safeguarding the rights of individuals with epilepsy and other neurological conditions.

"Epilepsy affects five million people in the Americas, transcending geographical boundaries and social strata. Making epilepsy a priority is not just a medical necessity but a moral imperative," said Dr. Jarbas Barbosa, Director of PAHO. "This toolkit empowers civil society organizations, communities, and individuals to unite in prioritizing epilepsy and work towards a future where no one faces the challenges of epilepsy alone."

Valentina Kahn, a pediatric physiotherapist from Chile who lives with epilepsy, authored the foreword for the publication. She expressed her belief that every person with epilepsy deserves the chance to thrive. "This toolkit will empower communities in the Americas to enhance epilepsy awareness and advocacy, ensuring that all individuals with epilepsy can lead fulfilling lives," she emphasized.

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About the Toolkit

The Advocate's Toolkit offers a structured approach to making epilepsy a priority, equipping advocates with the knowledge and tools needed to influence policy and drive change. It emphasizes the engagement of a wide array of stakeholders to create a unified and powerful advocacy front, ensuring that epilepsy is recognized and addressed as a critical public health concern. For additional information about the Advocate's Toolkit and to access the publication, please visit <https://bit.ly/AdvocatesToolkit>.

About The International Bureau for Epilepsy

The International Bureau for Epilepsy (IBE) is a global organization representing the voice of people with epilepsy and their caregivers. With a vision of bringing about transformational social change for people with epilepsy, IBE serves as an umbrella organization for 160 national epilepsy organizations (IBE Chapters) across 110 countries worldwide. Drawing on six decades of experience in epilepsy advocacy, today IBE is focused on policy advocacy, awareness-raising, capacity-building, knowledge creation and exchange, and partnership development. IBE's inclusive structure fosters collaboration, best practice sharing, and peer-to-peer learning across its network of chapters in both high and low and middle-income settings. IBE maintains working relations with the World Health Organization (WHO) and the United Nations General Assembly, alongside a collaborative alliance with the International League Against Epilepsy (ILAE).

About Epilepsy

Epilepsy, one of the most common neurological diseases globally, affects more than fifty million people of all ages¹ While seizures are the most well-known symptom, many people with epilepsy can achieve seizure control or even freedom from seizures,

¹ [Epilepsy \(who.int\)](http://www.who.int)

reducing the impact of the condition. However, others may have drug-resistant, rare, or complex epilepsy with debilitating comorbidities and high levels of associated disability. Despite its prevalence, epilepsy is often neglected in public health agendas. Individuals with epilepsy face a heightened risk of premature death, up to three times that of the general population. Additionally, roughly half of adults with epilepsy contend with at least one other health condition, exacerbating the complexity of their care.