



ILAE-IBE Joint Statement on International Epilepsy Day 2023

Call to: *Step Up Against Stigma* to improve the lives of people with epilepsy worldwide.

February 13th 2023 – Today, on International Epilepsy Day, the International League Against Epilepsy (ILAE), and the International Bureau for Epilepsy (IBE) are calling for greater understanding and intersectoral action to tackle the stigma and discrimination faced by people with epilepsy worldwide.

“More than 50 million people around the world live with epilepsy,” says Dr Francesca Sofia, IBE President. “For many of these people, the stigma attached to epilepsy is often more difficult to deal with than the disease itself.”

“Stigma, fueled by fear and misconceptions, takes many forms and can be present in the family, community, school, clinic, and workplace. As a result, people with epilepsy may not seek the help they need and are at real risk of social exclusion. This can create a major economic burden and have a negative impact on mental wellbeing and overall quality of life,” she concludes.

Addressing stigma and discrimination is a key component of the WHO Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders. The plan was unanimously adopted by the 194 Member States of WHO in May 2022.

“Epilepsy has significant personal, health, economic and social inclusion consequences for people living with the disorder and for their families and communities, the response should not be anything less than integrated, comprehensive and engaging all of society,” stated Dr Dévora Kestel, WHO Director for Mental Health and Substance Use.

The Intersectoral Global Action Plan calls for 80% of countries to have developed or updated their legislation to promote and protect the rights of people with epilepsy by 2031.

Examples of good practice that can support governments, NGOs, and communities in reducing stigma and changing discriminatory legislation can be found in *Improving the Lives of People with Epilepsy: A Technical Brief* launched by WHO in December 2022.

A detailed mapping of discriminatory legislation in the Africa region has been completed by IBE with work now ongoing in other regions. The IBE’s *Advocate’s Toolkit for Reducing Epilepsy Stigma in Africa* provides a useful resource for policy makers and advocates seeking to change legislation and attitudes.

“In virtually every corner of the world, epilepsy is misunderstood. Epilepsy is treatable and people with epilepsy can live full lives” according to Prof. Helen Cross, ILAE President. “International Epilepsy Day allows us to come together, to stand up against stigma and discrimination, and to build a world where no person’s life is limited by epilepsy and the harmful myths that surround it.”

*** ENDS

Resources

1. World Health Organization. [*Draft Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031*](#). Geneva; 2022.
2. World Health Organization. [*Improving the Lives of People with Epilepsy: A Technical Brief*](#). Geneva; 2022
3. International Bureau for Epilepsy. [*Advocate’s Toolkit for Reducing Epilepsy Stigma in Africa*](#); 2022.