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Joint Statement for the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE)

Agenda Item: Address by the WHO Regional Director for Europe: the state of health in the WHO European Region, including lessons learned from the COVID-19 pandemic

The International League Against Epilepsy (ILAE) promotes evidence-based care and treatment for people with epilepsy through more than 26,000 professionals world-wide. The International Bureau for Epilepsy (IBE) improves the social condition and quality of life of people with epilepsy and those who care for them through a network of 140 chapters in 100 countries. The ILAE and the IBE partnered with the WHO to produce the [2019 Global Report on Epilepsy](#) that concluded that epilepsy should be considered a public health imperative.

The ILAE and the IBE appreciate the work of the WHO and Member States to address the unprecedented COVID pandemic. While the acute needs of COVID patients and the urgency to control outbreaks is recognised, the needs of people with epilepsy have, however, often not been well integrated into the response of some Member States.

In response to an ILAE global COVID survey, around a third of patients who were able to access medication prior to the pandemic stated that they have had significant difficulties with regular supply during COVID, around a quarter report an increase in their seizure frequency and over a third of patients were unable to access regular support from healthcare professionals.

In addition, the neurological consequences of COVID infection are increasingly being recognised and, though uncommon, appear to include new onset epilepsy and seizures.

It is estimated that over 6 million people suffer from epilepsy in the European region, of whom 70% could live seizure free with treatment that costs, on average, only USD 5 per year. 15 million people across the region will suffer a seizure at some point in their lives. However, it is estimated that around 40% of people with epilepsy in this region do not have access to appropriate treatment. Premature death in people with epilepsy is three times higher than in the general population. Stigma is common and people with epilepsy face needless discrimination and exclusion.

The health and psychosocial needs of people with epilepsy and the importance of increased research into the potential neurological impact of COVID infection require urgent attention. The ILAE and the IBE would be willing to work closely with the WHO and Member States to ensure that these critical elements can be effectively integrated now into the emergency response as well as form an important element for consideration for pandemic planning in the future.

Prof. Eugen Trinka

Chair, ILAE-Europe Executive Board