



(Via Email)

**22<sup>st</sup> July 2022**

Minister Stephen Donnelly TD,  
Minister for Health,  
Department of Health,  
50 – 58, Block 1,  
Miesian Plaza,  
Baggot Street Lower,  
Dublin 2,  
D02 XW14.

**RE: WHO Intersectoral Global Action Plan on Epilepsy and other Neurological Conditions**

Dear Minister,

I trust this finds you well and we wish you a happy and healthy World Brain Day 2022 (July 22<sup>nd</sup>). I am writing to you regarding the Intersectoral Global Action Plan on Epilepsy and other Neurological Conditions (IGAP) which was unanimously adopted by WHO member states at the recent World Health Assembly meeting in Geneva.

Given that epilepsy affects almost 50 million people worldwide – and over 40,000 people here in Ireland – the IGAP is an acknowledgement of what must be done at national and international levels to improve the lives of people living with epilepsy.

Key priorities of the IGAP include:

- To raise the prioritisation of, and strengthen governance for, epilepsy and other neurological disorders.
- To provide effective, timely and responsive diagnosis, treatment, and care for all patients.
- To implement strategies for promotion and prevention of epilepsy and other neurological disorders.
- To foster research and innovation into, and strengthen information systems, for epilepsy and other neurological disorders.
- To strengthen the public health approach to epilepsy.

Epilepsy Ireland has been in contact with Ireland's WHO delegates in relation to this plan since 2020 and we very much welcome its adoption. We hope that all governments will now take steps to ensure that targets set out in the IGAP are met by 2031. These include:

- All countries will have at least one functioning awareness campaign or advocacy programme for neurological disorders by 2031.
- The output of global research on neurological disorders doubles by 2031.
- By 2031, countries will have increased service coverage for epilepsy by 50% from the current coverage in 2021.
- 80% of countries will have developed or updated their legislation with a view to promoting and protecting the human rights of people with epilepsy by 2031.

Ireland has taken positive steps over the past decade or so in its response to improving epilepsy care. The work of the HSE's Epilepsy Clinical Care Programme, part of the Clinical Strategy and Programmes Division was central to this, for example by increasing the number of epileptologists and Epilepsy Specialist Nurses, publishing the Model of Care and a range of Standard Operating Procedures for epilepsy, expanding epilepsy monitoring services and implementing an Integrated Care Pathway for Acute Seizure Management which has acted to reduce emergency admissions and hospital bed-days.

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*Working to achieve a society where no person's life is limited by epilepsy.*



We are also innovators in e-health through the Epilepsy Electronic Patient Record and more recently the development of the associated patient e-portal, part-funded by EI, which has the potential to significantly improve patient-centred epilepsy care if mainstreamed. We also now have an SFI-backed, world-class epilepsy & neurology research centre at RCSI (FutureNeuro) which is an international leader in the search for novel diagnostics and therapeutics as well as the development of new e-health technologies.

Given the successes that Ireland has achieved by enabling a national focus on epilepsy and by resourcing (in part at least) the implementation of a national programme, the approval of the IGAP now provides us with an opportunity to collaboratively develop and implement the next level of critical transformation that is required here. For example, we still have one of the lowest ratios of consultant neurologists per head of population in Europe; we need to better integrate clinical genetics into epilepsy diagnosis and treatment; expand our epilepsy surgery programme; embed new e-health technologies into clinical practice; and there is an urgent need to tackle preventable epilepsy deaths including those from Sudden Unexpected Death in Epilepsy (SUDEP).

Following the adoption of the IGAP, we believe Ireland can and should be global leaders in its implementation by actively and strategically seeking to improve the lives of people living with epilepsy and their families. Epilepsy Ireland and the entire epilepsy community (people with epilepsy, healthcare professionals, researchers etc.) are ready – and more than willing – to assist and work with the Department of Health and all policy makers in realising the vision of the IGAP here in Ireland.

In September 2023, the International Epilepsy Congress, the world's most important epilepsy scientific conference will be held in Dublin. This provides a great opportunity and a one-year timeframe to collaboratively develop and launch Ireland's IGAP implementation strategy and to demonstrate our commitment to improving the lives of people with epilepsy and other neurological conditions.

We would be very grateful if you can provide an update regarding your Department's plans on implementing the IGAP, and in particular if the Department will commit to establishing a working group involving key partners to develop and implement our national response.

We look forward to hearing from you shortly.

Yours sincerely,

A handwritten signature in black ink that reads "Peter Murphy".

Peter Murphy,  
CEO,  
Epilepsy Ireland.