



Head Office: 249 Crumlin Road, Dublin 12.
Tel: 01 4557500; Email: info@epilepsy.ie; Web: www.epilepsy.ie

2nd August 2023

Deputy Leo Varadkar,
An Taoiseach,
Department of the Taoiseach,
Government Buildings,
Merrion Street Upper,
Dublin 2, D02 R583.

RE: International Epilepsy Congress & The Intersectoral Global Action Plan on Epilepsy and other Neurological Conditions

Dear Taoiseach,

I trust this finds you well. I am writing to you in advance of the 35th International Epilepsy Congress (IEC), which is taking place in the Convention Centre Dublin from September 2nd to 6th.

The IEC is organised every two years by the International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE) and is the biggest international scientific epilepsy meeting. It was last held in Ireland in 1997.

It is expected that over 3,000 professionals in epilepsy care will make their way to the congress this year.

As the local epilepsy patient organisation, Epilepsy Ireland has been working closely with the IBE and the ILAE in planning the Congress, and we are delighted to hear that you will be providing opening remarks to delegates at the welcome ceremony.

With that in mind, we are writing to you as we believe that the Congress represents an incredible opportunity for Ireland to be seen as leaders within the global epilepsy community by taking an initial step to commit to implementing the Intersectoral Global Action Plan on Epilepsy and other Neurological Conditions (IGAP) which was unanimously adopted by WHO member states in June of last year.

Given that epilepsy affects almost 50 million people worldwide – and over 45,000 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.

Epilepsy Ireland is the trading name of Brainwave - The Irish Epilepsy Association.

*Company limited by guarantee. Registered in Dublin 77588. CHY No: 6170. Registered Charity Number: 20010553.
Registered Office: 249 Crumlin Road, Dublin 12.*

Directors: H. Behan, M. Dowdall, P. Fahey, M. Fitzsimons, C. Grieve, D. Gray, A. Kealy, P. Kehoe, A. Kilroy, M. King, S. O'Brien, C. O'Dea.



- 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.

Under the IGAP, national governments are required to take steps to ensure that targets set out in the plan 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 baseline coverage in 2021.
- 80% of countries will have developed or updated their legislation with a view to promoting & 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 a Model of Care for Epilepsy 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.

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 Epilepsy Ireland, 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 has quickly become 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 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).

Epilepsy Ireland is the trading name of Brainwave - The Irish Epilepsy Association.

*Company limited by guarantee. Registered in Dublin 77588. CHY No: 6170. Registered Charity Number: 20010553.
Registered Office: 249 Crumlin Road, Dublin 12.*

Directors: H. Behan, M. Dowdall, P. Fahey, M. Fitzsimons, C. Grieve, D. Gray, A. Kealy, P. Kehoe, A. Kilroy, M. King, S. O'Brien, C. O'Dea.



Head Office: 249 Crumlin Road, Dublin 12.
Tel: 01 4557500; Email: info@epilepsy.ie; Web: www.epilepsy.ie

We are privileged to have the International Epilepsy Congress taking place in Ireland next month and with the eyes of the global epilepsy community on Dublin, an announcement committing to implementing the vision of the IGAP in Ireland will be resoundingly heard across the world, acting both as a stimulus for other governments to do likewise and as a motivation for international delegates to work for better outcomes for people with epilepsy globally.

Ireland has a proud recent history in leading the way on the international stage. For example, we created a global domino effect being the first country to introduce a smoking ban in 2004; and in 2015, we were the first country in the world to legalise same-sex marriage by popular vote.

The Congress, and in particular, your address, offers another opportunity to show the way, by committing to the goals and targets of the IGAP on epilepsy and other neurological disorders.

Epilepsy Ireland, as well as the Irish medical community, stand willing and ready to work with the Department of Health and other stakeholders in realising the vision of the IGAP here in Ireland.

We urge our Government to give the strongest consideration to making an announcement to coincide with the Congress.

If we at Epilepsy Ireland can be of any further assistance, please do not hesitate to get in touch. We look forward to hearing from you.

Yours sincerely,

Peter Murphy
CEO, Epilepsy Ireland

CC:
Tánaiste Micheál Martin
Minister Eamon Ryan
Minister Stephen Donnelly

Epilepsy Ireland is the trading name of Brainwave - The Irish Epilepsy Association.

*Company limited by guarantee. Registered in Dublin 77588. CHY No: 6170. Registered Charity Number: 20010553.
Registered Office: 249 Crumlin Road, Dublin 12.*

Directors: H. Behan, M. Dowdall, P. Fahey, M. Fitzsimons, C. Grieve, D. Gray, A. Kealy, P. Kehoe, A. Kilroy, M. King, S. O'Brien, C. O'Dea.

