



Together we can achieve a society where
no person's life is limited by epilepsy

15th September 2023

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

Dear Taoiseach,

I trust this finds you well. I am writing to you on behalf of Epilepsy Ireland to thank you for your recent contributions to the 35th International Epilepsy Congress in Dublin, and for taking the time to meet representatives of the national and international epilepsy community.

In particular, I would like to once again thank you for your kind words about the impact of Epilepsy Ireland's involvement in the Congress and our history in working alongside the HSE and other state bodies to improve the lives of people with epilepsy in Ireland.

As you know, the Congress was a major international event for the global epilepsy community. To host it in Ireland was a tremendous honour and your input has been instrumental in elevating Ireland's standing and role within this community.

As you referenced in your opening address, we were proud to host the first-ever public sessions within the Congress, widening its scope from the medical and scientific community to include people living with the condition and their families. We hope to have started a new legacy which will forever be linked to Ireland.

Several young people with epilepsy from across Ireland also took part in a global youth summit at the Congress - an inspiring event that sought to address longstanding issues such as the misunderstanding and stigma associated with epilepsy and how we can all work together to make the future brighter for the generations to come.

We were particularly proud that Epilepsy Ireland volunteer, Wayne O'Reilly from Wexford was presented with a Golden Light award at the opening ceremony of the Congress – one of just three global recipients recognised for his impact in raising awareness of the condition.

I would also like to once again thank you for your Government's commitment to progressing a number of key epilepsy-related issues in recent months. These include



Together we can achieve a society where
no person's life is limited by epilepsy

the establishment of an inquiry into the historical licensing and prescribing of Sodium Valproate; and addressing the longstanding issue of deferred sittings of the Leaving Cert exams for students with epilepsy who experience a seizure during their exams.

We are looking forward to an upcoming meeting with your cabinet and party colleague, Minister Heather Humphreys, where we hope to see progress on another longstanding issue facing people with epilepsy - improved access to the Free Travel scheme for those disqualified from driving due to their epilepsy.

As you referenced in your opening address to the Congress, epilepsy can be a stigmatising and challenging condition for those living with it, and we need to continue to work together to continue our journey towards a society where no person's life is limited by epilepsy.

Epilepsy Ireland is a small organisation that makes a big impact. We receive circa 20,000 contacts to our service each year, delivered by our regional Community Resource Officers based across Ireland. We play an active role in the wider community by training up to 3,000 teachers, SNAs and allied healthcare professionals in *Epilepsy Awareness and the Administration of Buccal Midazolam* each year.

We also play a key role in investing in Irish epilepsy research, and this year, we passed the €1.5 million mark in total investment in basic, clinical, e-health and health services research over the past decade.

Despite this impact, there are real and significant challenges, not least of which relates to the funding model for Section 39 organisations like Epilepsy Ireland. Static funding levels for over a decade, in the face of increasing costs, greater demands on our service and a slowly recovering fundraising environment has led to a crisis within the sector, for example in terms of recruiting and retaining key staff and maintaining current levels of services. All this combines to impact on the people we want to help most – people with epilepsy and their families. These issues have been widely documented and I would encourage your government to take steps to address these funding issues before it is too late for community-based organisations like Epilepsy Ireland and many others.

There are of course wider issues facing the epilepsy community that we also must work together to progress.

Prior to the Congress, I wrote to you regarding the WHO's recently adopted *Intersectoral Global Action Plan on Epilepsy & Other Neurological Conditions (IGAP)*. This Plan sets targets for all Member States to achieve over the next decade to improve the lives of people living with epilepsy.

The knowledge, passion and will exists within the epilepsy community (medical professionals, research community, people with epilepsy and patient organisations) to ensure that Ireland not only meets the targets but becomes a shining light for other countries to aspire to. Under the framework of IGAP, several key priorities for the entire epilepsy community can be progressed, including but not limited to:

- **Ensuring all consultant and specialist nursing posts are filled;** working with our colleagues in the Irish Epilepsy League, we know how epilepsy services are under severe pressure and need further capacity to better support adults and children with epilepsy.
- **Expand clinical genetic services;** in your opening address, you referenced the work of researchers at RCSI & FutureNeuro in expanding our knowledge of epilepsy genetics. This world-leading research must be capitalised on to ensure a more accurate and faster genetic diagnosis, to enable precision treatment.
- **Improved and faster access to new treatments;** new medications to reduce the burden of epilepsy, particularly that of rare and complex epilepsies are being developed. Fenfluramine for example is the latest drug to enter the reimbursement process, offering great hope for families impacted by Dravet syndrome and Lennox Gastaut syndrome. Even if successful, access is still at least a year away, time that many children and adults do not have. Access to new, proven treatments must be improved.
- **National Strategy to reduce epilepsy-related deaths & SUDEP;** while Epilepsy Ireland has led the way with several initiatives aimed at improving awareness of SUDEP, promoting risk management and encouraging/funding research on epilepsy deaths in Ireland, a national multi-stakeholder approach must be taken to develop and implement a strategy tackling the incidence of SUDEP and epilepsy-related deaths.
- **Enhancement of e-health initiatives;** a third of all epilepsy patients are currently recorded on the Epilepsy Electronic Patient Record, a resource which has been developed in stages over the past 20 years. With upcoming plans to reform e-health infrastructure, it is vital to protect, secure and develop this vital enabler of epilepsy care.
- **Developing Integrated Care pathways;** in your speech to Congress delegates, you referenced the impact of Epilepsy Ireland's Sláintecare-funded project which provided a joint EI/HSE early intervention self-management and education programme to people with a new diagnosis of epilepsy. Although funding for this project ceased in 2021, it provided us with clear evidence that there is huge potential for developing and supporting a community-based model of care that would support many of the 45,000 people with epilepsy in Ireland, in line with Sláintecare's core principles.



Together we can achieve a society where
no person's life is limited by epilepsy

While much work has been done over the past decade to improve the care and lives of people with epilepsy, progress cannot stop now and the IGAP is a golden opportunity to do this. However, we need the support of Government to progress and address the points above, and the many others which have not been listed.

The will, determination, skills, and knowledge exist on the ground, and with appropriate supports and a co-ordinated approach, much more can be progressed within the framework of the IGAP to deliver a truly excellent service to those living with epilepsy.

Thank you again for your kind words of support for Epilepsy Ireland last week and I hope this will lead to a renewed focus on partnership between Epilepsy Ireland and your Government in meeting the needs of people with epilepsy in Ireland. I would appreciate any response you may have on the points outlined above and should you wish to meet and discuss these points in further detail, we would welcome this opportunity.

Both Epilepsy Ireland and the medical/research community are on hand at all times to discuss these challenges and solutions further with you and your Government, and we would be delighted for the opportunity to do so.

Together, we can achieve a society where no person's life is limited by epilepsy.

Yours sincerely,

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

Peter Murphy
CEO, Epilepsy Ireland