



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

14th October 20224

Mr. Stephen Donnelly TD,
Minister for Health,
50 – 58, Block 1,
Miesian Plaza,
Baggot Street Lower,
Dublin 2,
D02 XW14
(via email)

RE: SUDEP Incidence Study

Dear Minister,

I hope this finds you well. I am writing to you regarding an important recently published study (attached) which is of critical importance to the epilepsy community in Ireland.

This study, by Dr. Yvonne Langan (St James's Hospital & TCD) and Dr. Ena Lynn (Health Research Board) has, for the first time, established the true incidence of Sudden Unexpected Death in Epilepsy (SUDEP) in Ireland.

As the name suggests, SUDEP is the most devastating consequence of epilepsy. SUDEP is defined as "*sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in an individual with epilepsy with or without evidence for a seizure and excluding documented status epilepticus where postmortem examination does not reveal a cause for death*".

The study establishes the incidence as **1:1400** per annum of those living with epilepsy, equating to **33 premature deaths every year**.

Minister – we are writing to you to seek your support in working with us to try and reduce these numbers. For far too long, we have heard from bereaved families who never knew about SUDEP until it was mentioned in the pathology results of their loved ones.

There are many different risk factors for SUDEP, some of which are modifiable and some of which are not (e.g. age, sex). We know that many deaths can be prevented by addressing the modifiable risk factors. In particular, if we can improve early access to specialist care and treatment for people with epilepsy in Ireland, it is more likely that a person will become seizure-free – one of the most critical risk factors.

Unfortunately, just this week, as we prepare for SUDEP Action Day (October 16th), we have been approached by two families who have lost loved ones due to SUDEP. Both families noted how their loved one was not yet officially diagnosed with epilepsy and were awaiting appointments and assessments for several months. These deaths are clear examples of why we need to improve access to specialist care.

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Board of Directors: H. Behan, A. Chalke, M. Curran, P. Fahey, M. Fitzsimons, C. Grieve, A. Kealy, P. Kehoe, A. Kilroy,
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We also believe that we can reduce SUDEP deaths simply by educating patients about it and the steps they can take to address a range of lifestyle risk factors. Unfortunately, surveys undertaken by Epilepsy Ireland have found that 1 in 3 people with epilepsy had no prior knowledge of SUDEP. Of those that were aware, most had discovered it online rather than from a trusted source such as an epilepsy specialist. This needs to change.

These and several other initiatives can and should be implemented as part of a national strategy to reduce epilepsy-related deaths in Ireland, and we are seeking the Government's commitment to develop and implement such a strategy urgently with input from a range of stakeholders including clinicians, patients with epilepsy and bereaved families.

Until now, most of the initiatives to date taken around SUDEP have been led by Epilepsy Ireland, often supported by the fundraising efforts of bereaved families. For example:

- We established the Epilepsy Deaths Register for Ireland to gather vital data to support epilepsy deaths research.
- We have funded several SUDEP research studies including the aforementioned incidence study as well as studies looking at the underlying causes of SUDEP.
- We offer our members breathable pillows at a reduced rate to reduce the risks associated with sleep seizures.
- SUDEP & risk education is a vital part of our education, support and self-management services.
- We have recently established a new service to reimburse patients with the costs of seizure detection devices which may play a role in reducing deaths by alerting caregivers to seizures.
- We train almost 3,000 professionals annually (teachers, SNAs, care professionals) in the acute management of seizures in the community.
- We organise SUDEP Action Day in Ireland annually to highlight SUDEP and promote awareness of risk factors.
- We will shortly be licencing the UK-developed SUDEP and Seizure Safety Checklist for use in Ireland. This is a tool, widely used in the NHS to support patient-clinician communication on SUDEP and risk.

The projects listed above are just a few of many projects which have been supported by bereaved families over many years. In fact, this first of its kind study which we are writing to you about, also would not have been possible without the fundraising efforts of bereaved families and supporters of Epilepsy Ireland.

We cannot continue to work in isolation on this issue, which continues to devastate families across Ireland each year, and the 45,000 people with epilepsy cannot continue to depend on the fundraising efforts of bereaved families to drive action on reducing SUDEP and epilepsy-related deaths.

This is a public health priority, and we must seize the opportunity that the publication of this landmark study has presented to gather all stakeholders together to take co-ordinated action against SUDEP.

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This will take time, investment and continued collaboration, but it will save lives. We have worked together with you on other issues of importance affecting the epilepsy community and hope you will be equally supportive of the need to address epilepsy deaths in Ireland.

There is already a strong rationale for taking this within existing policy. The HSE's National Clinical Programme for Epilepsy, in its 2016 Model of Care states that "*it is an aim of this programme to reduce the number of lives lost to epilepsy primarily through improvements in seizure control and standardized pathways...*". Furthermore, a national SUDEP strategy would significantly advance Ireland's obligations under the World Health Organisation's *Intersectoral Global Action Plan on Epilepsy and Other Neurological Conditions*, which was adopted by all member states in 2022, aiming to improve access to care and quality of life for people with epilepsy and other neurological disorders.

A final point in relation to the new study on SUDEP in Ireland is that this research has not concluded. While the incidence rate of SUDEP has been established at 33 deaths p.a., work is now continuing to establish the incidence of **total** epilepsy-related deaths in Ireland each year. We currently estimate that there are approx. 130 epilepsy-related deaths annually, including those due to seizure-related accidents and injuries, status epilepticus, as well as SUDEP. Further data will be forthcoming.

I enclose a copy of the incidence study for your information, and we would welcome the opportunity to meet with you to discuss these issues further.

I look forward to hearing from you.

Yours sincerely,

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

Peter Murphy,
Chief Executive Officer,
Epilepsy Ireland

CC:

An Taoiseach, Simon Harris TD.

Tánaiste & Minister for Foreign Affairs & Defence, Micheál Martin TD.

Minister for Children, Equality, Disability, Integration and Youth of Ireland, Roderic O'Gorman TD.

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