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Deputy Dara Calleary, TD
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

RE: PQ 16113/22

To ask the Minister for Health the strategy his Department has in place for the management of epilepsy in Ireland; the extra investment he has provided for in epilepsy care since taking office; if there is any research underway into sudden death syndrome as a consequence of epilepsy; and if he will make a statement on the matter.

Dear Deputy Calleary,

The Health Service Executive has been requested to reply directly to you in relation to the above parliamentary question, which you submitted to the Minister for Health for response. I have consulted with the National Clinical Programme for Neurology (NCPN) on your question and have been informed that the following outlines the position.

Epilepsy is a chronic disease characterised by unpredictable, sometimes lifelong, often dangerous seizures resulting in involuntary alterations in behaviour and consciousness. The condition affects about one in every 100 people. In Ireland, it is thought that there are approximately 40,000 sufferers, of which approximately 70% are well controlled on medication, leaving about 12,000-15,000 people who have breakthrough seizures and are in regular contact with secondary and tertiary hospital services.

The vision for the transformation of epilepsy care in Ireland is best described in the HSE Epilepsy Model of Care, launched in 2016 (located at: <https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/epilepsy-model-of-care.pdf>). Some progress has been made towards the realisation of the Model of Care, with the development of the Epilepsy Electronic Patient Record (EPR), which has received additional funding for enhancement in 2022. Standardised clinical documentation, sharing and exchange of patient information between clinicians, as well as performance monitoring and evaluation area is key to the success of the model of epilepsy care. This is facilitated by a secure centrally-hosted web-based electronic patient record (EPR), which is providing authorised clinicians across Ireland with access to complete, timely patient records when and where required.

Through the Sláintecare Integration Fund (SIF), an epilepsy care outreach programme for vulnerable adults received funding (project #366) in 2020 and a pilot project was run in St James Hospital, Dublin. Despite the emergence of the pandemic and episodic re-deployments of staff, unprecedented progress has been made in the development of pathways of care that are integrated, scalable and transferable.

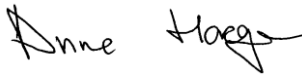
In 2021/2022, NCPN have worked in collaboration with the HSE Scheduled Care Transformation Programme (SCTP) on the development of a national pathway of care for those accessing epilepsy services. It is endeavoured that, over a 5-year period, annual incremental investment will be sought in order to realise the epilepsy pathway of care and enhance the provision of care provided to this population group. This will include investment in diagnostics, enhanced digital health pathways and staffing resources.

Five additional consultant neurology posts and two additional clinical neurophysiology posts have been funded under Winter Plan funding 2021. These additional posts will support the overall neurology service, which would include epilepsy.

Research is ongoing with Sudden Unexpected Death in Epilepsy (SUDEP). Neurophysiology Department in St. James Hospital, in collaboration with Epilepsy Ireland and the Irish Institute of Clinical Neuroscience and the Health Research Board, are researching the incidence of SUDEP in Ireland with research nursing staff employed in this work. Additionally, neurophysiology representatives from Ireland sit on a steering committee of an international multicentre case control study of SUDEP, which is being led by a Lead Investigator based in New Zealand.

I trust this information is of assistance to you, but should you have any further queries please do not hesitate to contact me.

Yours sincerely



Anne Horgan
General Manager