PRESS RELEASE

Wednesday, 15th May 2024

Funding is ineffective without the commitment to follow through with action, warns NAI

The <u>Neurological Alliance of Ireland (NAI)</u> is calling for urgent action from the Government to follow through on investment commitments for neurological services.

Presenting to the Joint Oireachtas Committee on Health today (15.05.24), the NAI, which brings together 30 non-profit organisations advocating for the rights of people in Ireland living with neurological conditions, will outline how the current recruitment ban and delays in appointing key frontline staff are seriously impacting the delivery of services for people with neurological conditions and undermining the track record of Government on neurological care.

Speaking in advance of the presentation, **Magdalen Rogers, NAI Executive Director** said: "We have seen significant investment in neurological care over the last number of years but with limited follow through in implementation. Progress has been undermined due to the ongoing recruitment ban and delays in delivering on commitments that have been made to people living with neurological conditions.

"In October 2022, funding was secured for 21 specialist neurology nursing posts. Unfortunately, the benefits of this significant investment have yet to be fully realised in hospitals across the country – in Waterford, Sligo, Limerick, Galway and Dublin. 13 of these vital nursing posts are held up due to the current recruitment ban.

"In 2022 and 2023 funding was also secured for four of the nine required community neurorehabilitation teams. Promises made to the Health Committee to see community neurorehabilitation teams in HSE CHO areas 2, 4, 6 and 7 fully functional by early 2024 have not yet been realised. A full year on, we still have the same situation we outlined to the Committee this time last year where only two of nine teams are up and running nationwide.

"Community neurorehabilitation teams, the delivery of long-term community neurorehabilitation services and inpatient neurorehabilitation beds are among the key deliverables outlined in the National Neurorehabilitation Strategy. We are currently behind on the delivery across all of these areas, with funds still not being released to enable these vital services to be delivered.

"Today we are calling for a renewed commitment from the Government to deliver on their promises."

Patient Experience

Also speaking at the committee hearing, Richelle Flanagan, a person living with Parkinson's Disease and a registered dietician, said "We have the worst ratio of neurologists to patients in Europe at 1.3 neurologists to 100,000 people in Ireland versus a European average of nine. Whilst we are seeing declines in mortality in cancer, diabetes and heart disease, we are seeing an increasing mortality rate in many neurological conditions. This is due to lack of access to neurologists, specialist nurses and appropriately staffed neurorehabilitation teams to provide care.

"People with neurological conditions, in particular people with Parkinson's, account for the longest length of stay in hospital. These hospital costs could be reduced by neurorehabilitation teams in the community treating preventable issues such as constipation, malnutrition and swallowing issues. A national audit of services for people with Parkinson's identified that 90 per cent do not have access to mental health services, 85 per cent do not have access to a dietitian, 67 per cent do not have access to an occupational therapist and 61 per cent do not have access to a speech and language therapist. The reality is that without multidisciplinary care patients end up declining faster.

"In fact, we know that one third of people with Parkinson's suffer complications while in hospital and 30 per cent have lost mobility following discharge. This ultimately costs the state more in terms of hospital costs, not to mention a loss of quality of life and lived years for those living with the disease. It is sheer neglect of those who don't have a voice to demand more of their health services due to the volume of disability they and their families are facing."

The Neurological Alliance of Ireland will present the current situation to the Joint Oireachtas Committee on Health and have three key asks:

- For Government to enable the funds that have already been committed to specialist neurology nurses and community neurorehabilitation services to be actively translated into actual services on the ground.
- A request for the HSE to deliver an immediate action plan to tackle the shortage of inpatient specialist rehabilitation beds.
- To begin to tackle the regional inequity in access to consultant neurology services by providing funding in this year's Budget to support the development of dedicated outpatient neurology services for Portlaoise, Bantry, Mayo, Letterkenny and Wexford hospitals.

Speaking alongside Magdalen Rogers, Executive Director of the Neurological Alliance of Ireland were:

- Alison Cotter, Advocacy Officer, MS Ireland;
- Richelle Flangan, a person living with Parkinson's Disease;
- Professor Sinead Murphy, National Clinical Lead Neurology.

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Notes to Editors

Spokespersons available for media interviews:

- · Mags Rogers, Executive Director at the NAI; and
- Richelle Flanagan, person with lived experience of early onset Parkinson's disease.

About the Neurological Alliance of Ireland

The Neurological Alliance of Ireland (NAI) brings together over thirty non-profit organisations to advocate for the rights of the over 860,000 people in Ireland living with a neurological condition.

Founded in 2003, the NAI advocates for the development of quality services for people with neurological conditions. Its campaigns are rooted in the experience of its members and the people and families with whom they work. The NAI provides a united and expert voice on neurological care through advocacy, policy development and awareness raising.