

# PRE BUDGET SUBMISSION

2024





# PRE BUDGET SUBMISSION



The Neurological Alliance of Ireland (NAI), the national umbrella for over thirty neurological charities, is calling for the following investment in neurological care services in this year's Budget.

- Funding to fully staff a community neurorehabilitation team in each of the 9 CHOs around the country as outlined in the National Neurorehabilitation Strategy: a key commitment in the current Programme for Government. \*
- Funding to put in place a multidisciplinary team for the only dedicated neurology service for Irish patients with long COVID in St James's Hospital Dublin. \*

(\*Detailed costings are available on request)

Over 800,000 Irish people are living with neurological conditions affecting the brain and spinal cord<sup>1</sup>. A ten-year framework published by the World Health Organisation (WHO) in May 2022 outlines that neurological care must be a priority for WHO countries given the scale of the global health challenge represented by neurological disease<sup>2</sup>. The WHO framework highlights that neurological conditions now represent the leading cause of disability-adjusted life years and second leading cause of death worldwide.

#### Background and Context

Access to neurological care services continues to be critically impacted by COVID19 disruption and decades of underinvestment pre pandemic

> Research on the impact of the COVID19 pandemic on access to neurological care services, carried out by the NAI during 2022, shows that access to vital neurological care services has been seriously impacted by a combination of disruption to services due to the COVID19 pandemic and underinvestment in these services pre pandemic<sup>3</sup>. Neurological care services lacked the capacity to return in the medium term to pre pandemic levels, leading to unacceptable delays and lack of access to supports for individuals with neurological conditions and their families.

A survey of 194 people with neurological conditions and their family members carried out in August 2022 questioned respondents about the extent to which access to services for their neurological condition had returned to pre-pandemic levels. Respondents noted that access had not returned to pre-pandemic levels across a range of services, especially appointments with their neurologist (20%), scans (23%), access to nurse specialists (20%) and neurorehabilitation services (15%).

When asked an additional question about their access to a range of vital services over the twelvemonth period, August 2021 to August 2022, the most difficulty was reported in accessing consultant neurology (20%) and physiotherapy (15%) services. 14% of respondents reported that they had experienced difficulty in accessing all services while 11% had paid privately for healthcare for their neurological condition.

Interviews with a range of service providers across neurological care services highlighted the lack of investment and underdevelopment of neurological care services pre pandemic as a major factor in limiting the capacity of neurological care services to return to pre pandemic levels.

1 Strategic Review of Neurology and Neurophysiology Services in Ireland (2007) Report commissioned by the National Hospitals Office Health Services Executive 3 Examining the consequences of the COVID19 pandemic on access to care for people with neurological conditions in Ireland. Neurological Alliance of Ireland. (Draft Report for Publication September 2023).

2 Intersectoral Global Action Plan on Neurological Disorders and Epilepsy 2022-2031 (2022) World Health Organisation

## Background and Context

#### The Neurological Alliance of Ireland is seeking priority investment in neurological care services in Budget 2024

- To address the impact of the COVID19 pandemic which has had a serious impact on access to neurological care services for existing patients
- To tackle the underinvestment in neurological care pre pandemic, especially in relation to community neurorehabilitation services
- To meet the needs of the emerging cohort of patients experiencing the neurological consequences of the COVID19 pandemic

## Ask 1

Funding to fully staff a community neurorehabilitation team in each of the nine CHOs around the country as outlined in the National Neurorehabilitation Strategy: a key commitment in the current Programme for Government.

"Demand for community neurorehabilitation services, already high pre pandemic, is now critical due to the combined needs of those who needed to be discharged early and missed out on neurorehabilitation, those impacted by the curtailment or closure of services due to lockdown and those requiring rehabilitation after the virus": Opening Statement from the Neurological Alliance of Ireland to Oireachtas Committee on Health May 2023 Community neurorehabilitation teams provide short-term intensive rehabilitation input (up to 12 weeks) with access to multidisciplinary services including physiotherapy, speech and language therapy, occupational therapy, social work and neuropsychology.

The Implementation Framework for the National Neurorehabilitation Strategy 2019-2021 committed to establishing one team in each of the nine HSE CHO areas around the country. However, the promise to fund a team within each of the nine CHO areas, in line with the commitment in the current Programme for Government to implement the National Neurorehabilitation Strategy, has still not been delivered.

The Neurological Alliance of Ireland is calling for funding in this year's Budget to support a fully staffed community neurorehabilitation team in each of the nine CHOs around the country.

Community neurorehabilitation teams are critical to tackling the lack of access to neurorehabilitation in the community. The consequences are a significant, and preventable, level of disability resulting in higher healthcare utilisation and increased costs to the health service through earlier admission to nursing homes, need for home care supports as well as increased likelihood of falls and subsequent hospital readmissions. The lack of neurorehabilitation teams in the community is exacerbating the problem of delayed discharges: further limiting access to inpatient neurorehabilitation in facilities such as the National Rehabilitation Hospital.

The bed day saving from having the national network of community neurorehabilitation teams in place is up to 42,000 bed days annually, based on an average saving of 3 bed days if they can be discharged to a community neurorehabilitation team<sup>4</sup>.

## Ask 2

Funding to put in place a multidisciplinary team for the only dedicated neurology service for Irish patients with long COVID in St James's Hospital Dublin.

> There can be significant neurological consequences both in the medium term and longer term for long covid patients, a survey of over 3,762 patients across 56 countries found 88% reporting cognitive dysfunction or memory problems six months on from contracting the virus<sup>5</sup>. Most of the patients attending Ireland's only neurology clinic for long Covid sufferers have yet to return to work fully, a year and more after they were infected. Of the 40 patients attending the clinic, 80% were working before they contracted Covid19. Just 34% of these have returned to work, while 44% are off work at least a year later and 22% are on reduced hours<sup>6</sup>.

There is currently just one consultant neurologist staffing the only dedicated long COVID neurology service in Ireland, based in St James's Hospital Dublin, but a wider multidisciplinary team with neurology expertise is needed to support the range of complex neurocognitive needs of these patients.

4 National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland: From Theory to Action: Implementation Framework 2019-2021 (February 2019) Health Services Executive

5 Characterising Long COVID in an international cohort: 7 months of symptoms and their

impact. Davis et al (2021) E Clinical Medicine (Part of The Lancet Discovery Science Vol 38 101019 August 2021

6 https://www.irishtimes.com/health/2023/04/20/two-thirds-of-patients-at-long-covidneurology-clinic-yet-to-return-to-work-fully-seminar-told/

### List of NAI Members

Acquired Brain injury Ireland Alzheimer Society of Ireland An Saol Aphasia Ireland Ataxia Foundation Ireland Aware Bloomfield Health Services Cheshire Ireland Chronic Pain Ireland Croí Dystonia Ireland Early Onset Parkinson's Disease Association (EOPD) Epilepsy Ireland Headway Huntington's Disease Association of Ireland Irish Heart Foundation Irish Hospice Foundation Irish Motor Neurone Disease Association Migraine Association of Ireland Move4Parkinsons Multiple Sclerosis Society of Ireland Muscular Dystrophy Ireland National Council for the Blind Neurofibromatosis Association of Ireland Neurology Support Centre North West MS Therapy Centre Parkinson's Association of Ireland Peamount Healthcare Polio Survivors Ireland PSPA Ireland Slanu Stroke Rehab Spinal Injuries Ireland Spina Bifida Hydrocephalus Ireland The Rehab Group

#### **Associate Members**

Brain Tumour Ireland

Syringomyelia Chiara Malformation Support Group



Neurological Alliance of Ireland Coleraine House, Coleraine Street, Dublin 7 CHY 14889 www.nai.ie o1 8724120 Find us on Facebook Follow us on Twitter @naiireland Follow us on Instagram @nai\_ireland