



**Opening Statement to the Joint Oireachtas Committee on Health**

**“Impact of COVID19 on Neurological Services, Care and Capacity”**

**March 30<sup>th</sup> 2022**

On behalf of the Neurological Alliance of Ireland I would like to thank the members of the committee for the opportunity to appear in front of you today. I want to commend the Committee for providing our umbrella organisation, representing over 30 patient organisations, with the opportunity to highlight the impact of COVID19 on access to services for people with neurological conditions and the effects of the pandemic on an already under resourced area within our health services.

I want to begin by paying tribute to all those who provided services and supports to people with neurological conditions and their families throughout the pandemic and continue to work to mitigate the impact on the care and treatment of people with neurological conditions. In particular I want to acknowledge the often taken for granted work of the voluntary sector in its response to the pandemic, as highlighted in the 2021 National Economic & Social Council report from the Dialogue Forum with voluntary organisations and highlighting in the words of HSE CEO Paul Reid "the importance of building a new relationship with Section 38 and Section 39 organisations grounded on mutual trust and respect". It is vital that the sustainability issues that threatened the sector pre-pandemic, and were considerably heightened by the collapse of public fundraising, are addressed to ensure these organisations remain a vibrant and essential part of our healthcare system. There is also a need to have effective mechanisms of funding, administration and governance which properly recognise and integrate the specialism and expertise of voluntary organisations in the management of chronic disease within the health system.

In common with countries throughout the developed world, COVID19 has had a serious impact on access to care and treatment for people with neurological conditions due to the closure and curtailment of services and redeployment of staff. However, in Ireland this impact was exacerbated by the fact that both neurology and neurorehabilitation services were already significantly overstretched and under resourced pre-pandemic. NAI will shortly commence a project to examine in depth the "hidden" impact of COVID19 on people with neurological conditions, including the impact of delayed or curtailed access to treatment and neurorehabilitation services. There is however a clear and immediate indication of the resourcing issues in neurology services evidenced through growing waiting lists and waiting times experienced by patients.

Latest figures available from the NTPF (February 2022) show 23,815 people on waiting lists for a neurology appointment. This compares to 13,218 on the waiting list in 2015. The recently published Waiting List Action Plan commits to a target of ensuring that no one is waiting more than 18 months for an initial OPD appointment. As of January 2022, there are 7,587 patients waiting +18months. This is an increase from the 4,871 waiters in January 2019, pre pandemic. Reducing this number and actively managing the ever-increasing waiting lists for access to Neurology services cannot be achieved without additional investment in resources especially in the context of COVID19 backlogs.

The Neurological Alliance of Ireland carried out a Nationwide Audit of Neurology Resourcing in November 2020. One of the stark findings that emerged from this audit was the critical shortage of nurse specialists across neurology services. According to the Model of Care for Neurology Services in Ireland we have an overall shortfall of one hundred nurse specialists across neurology services. What does this mean in practice for the over 800,000 Irish people living with neurological conditions represented by the member organisations of the Neurological Alliance? It means that four fifths of Irish people living with Parkinson's disease, for example, do not have access to a nurse specialist while there is an absence of nurse specialists in adult neurology services for complex neurological conditions such as muscular dystrophy and Huntington's disease.

This led the Neurological Alliance of Ireland to launch our Patients Deserve Better Campaign to tackle the shortage of 100 nurse specialists within neurology services. I want to pay tribute to the

members of the Committee in recognising their support for this campaign in their local constituencies since the campaign was launched in October last year. Over 90 parliamentary questions have been raised in relation to this campaign and it has been raised on almost twenty occasions under topical issues, commencement matters and other mentions in both the Dail and Seanad.

Investing in nurse specialists in neurology services is critical to reducing waiting lists and improving patient care. We have clear evidence within our own health system of the role of nurse specialists in waiting list reduction and prevention of hospital admission. The Final Evaluation Report on the Benefit of Advanced Nurse Practitioners launched by Minister for Health Stephen Donnelly in May 2021 noted that:

- an average 4.3 patients per ANP are avoiding hospital admission on a weekly basis

- average reduction of 3.9 patients per week from specialist waiting lists

The Neurology Clinical Programme will bring forward proposals for the 2022 Estimates process which will recommend the recruitment of significant additional numbers of nurse specialists in neurology services, as well as other clinical staff, as part of a 5-year plan to implement the Model of Care for Neurology Services. This will require year on year investment in potentially up to twenty specialist nurses each year in order to incrementally tackle the shortage of specialist nurses in neurology.

We are requesting that the Committee make urgent representations to the Minister for Health in support of our key ask to significantly increase staffing numbers within neurology services, particularly in specialist nursing, in line with the Model of Care for Neurology, within the remaining lifetime of this administration.