

## **Opening Statement by Magdalen Rogers, Executive Director, Neurological Alliance of Ireland**

I would like to thank the Chair and members of the committee for including the issue of services for people with neurological conditions in their workplan and for providing the opportunity to speak on this theme this morning.

I would like to introduce Edina O Driscoll, Project Manager for the Neurorehabilitation Demonstrator Project. She is here in a voluntary capacity at our invitation specifically to address any queries in relation to this project which I will mention in the course of my statement.

Over 800,000 Irish people are living with a neurological condition, ranging from common conditions such as migraine, dementia and epilepsy to rare neurological disease with approximately 40,000 additional people diagnosed each year<sup>1</sup>. The Neurological Alliance of Ireland is the national advocacy group for neurological care, representing over thirty patient organisations.

We work closely with the Disability Federation of Ireland in promoting recognition of the need for community supports for people living with neurological conditions and the vital role played by voluntary organisations, including MS Ireland, in providing these services.

I want to briefly highlight an issue that I do not have sufficient time to deal with in detail here, but continues to impact significantly on people with neurological conditions including MS and that is the issue of access to medicines. NAI supports the call by the Medical Research Charities Group and the Irish Platform for Patients Science and Industry<sup>2</sup> for the development and implementation of a national strategy on access to new and innovative medicines in Ireland.

The remainder of my statement will focus on the specific challenges in accessing neurology and neurorehabilitation services and call for investment in a series of specific projects which we in NAI believe could make a significant positive impact.

Neurorehabilitation services are critical to support recovery and prevent disability for people with neurological conditions. The ongoing lack of access to specialist rehabilitation in this country continues to have a devastating impact on individuals and their families resulting in unnecessary disability and impinging on the precious potential for recovery. Ireland has less than half of the specialist inpatient beds needed for a population of its size and community-based services are totally underdeveloped with only three Community Health Organisations having dedicated, but still only partially staffed, neurorehabilitation teams<sup>3</sup>.

A three year implementation framework<sup>4</sup> for the 2011 National Policy and Strategy for Neurorehabilitation Services was finally published by the HSE in February 2019. While implementation of this framework is included as a key action within the Slaintecare Implementation plan, this is impossible without dedicated funding. A critical starting point is the need for investment in the Neurorehabilitation Demonstrator Project.

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<sup>1</sup> Strategic Review of Neurology and Neurophysiology Services (2007) Report Commissioned for the National Hospitals Office, HSE

<sup>2</sup> Steering a course to avoid the Drug Iceberg (Reports November 2017 & February 2018) Medical Research Charities Group (MRCG) and Irish Platform for Patients, Science & Industry (IPPOSI)

<sup>3</sup> "We Need Our Heads Examined" Campaign Leaflet (June 2016) Neurological Alliance of Ireland  
[https://www.nai.ie/assets/66/066FC20D-F533-4231-8B474ADEC2C696F4\\_document/NAI\\_Leaflet\\_Web2.pdf](https://www.nai.ie/assets/66/066FC20D-F533-4231-8B474ADEC2C696F4_document/NAI_Leaflet_Web2.pdf)

<sup>4</sup> National Strategy & Policy for the Provision of Neurorehabilitation Services in Ireland: From Theory to Action. Implementation Framework 2019-2021 (February 2019) Health Services Executive

This project is an innovative collaboration between acute hospitals, the National Rehabilitation Hospital, Royal Hospital Donnybrook, Peamount Healthcare, local voluntary providers and primary care to develop a managed clinical rehabilitation network which will improve access to specialist neuro- rehabilitation for people in CHO areas 6 & 7. This is not just about introducing a new service, this pilot project is fully in line with the aims of Slaintecare to provide an integrated approach to the management of chronic neurological conditions; reducing length of stay in acute hospitals, saving bed days and most importantly making sure that people are receiving the right care, in the right place when they need it.

I now want to move on to a series of proposed projects to address the challenges in neurology services.

The Neurology Clinical Programme recognises that over 20,000 patients are waiting for neurological evaluation at present, of which at least 30% suffer from headache. Headache represents the 2<sup>nd</sup> most frequent condition presenting to AMAU (Acute Medical Assessment Units). In response to this and in collaboration with the Irish Pharmacy Union (IPU) and the Migraine Association of Ireland (MAI), the Neurology programme has developed a new pathway of care that will expedite headache management to a community focused model in an innovative, quality driven and cost-effective way in line with the aims of SláinteCare.

The Programme also recognises that many neurological diseases are rare, requiring national specialist centres of expertise. So, an innovative, agile and sustainable management plan has been developed using Motor Neurone Disease as a model, that integrates care across the hospital community and capitalizes on the expertise of the Voluntary sector to provide high quality evidence based streamlined care for patients from diagnosis, to end of life. Third and finally, the Programme recognises the importance of providing evidence-based disease modifying treatments in a cost-effective manner for neurological disease. The Programme is developing an evidence based treatment pathway for Multiple Sclerosis that can be replicated for other neurological diseases for which new highly effective but costly treatments are anticipated.

In conclusion, the Neurological Alliance are calling for investment in the initiatives outlined this morning as a key opportunity to begin to address the huge challenges faced by Irish people living with neurological conditions. All the proposals are fully costed and ready for implementation and detailed descriptions have already been circulated to the committee or are available on request. Finally, the Neurological Alliance wishes to stress that a commitment to ongoing investment in neurology and neurorehabilitation services needs to be a key part of any Future Programme for Government and we look forward to working with Committee members in shaping future policy.