



NEUROLOGICAL ALLIANCE  
of IRELAND

# **PRE BUDGET SUBMISSION 2022**

**TACKLING THE IMPACT OF  
COVID-19 ON NEUROLOGICAL  
CARE SERVICES**

**COMMITTEE ON FINANCE,  
PUBLIC EXPENDITURE AND  
REFORM**

**JULY 2021**

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## SUMMARY

This submission focuses on the impact of COVID19 on neurological care services already critically under-resourced pre-pandemic and the lack of capacity to meet the backlog of demand post COVID. The COVID19 pandemic has further undermined the provision of services in the community, the majority of which are provided by the not for profit sector, and further exacerbated the problem of long waiting times and lack of access to care for people living with neurological conditions across Ireland.

Action must be taken now to introduce an immediate programme of emergency investment in neurological care services to address a crisis that has been worsened by the impact of COVID19. The Neurological Alliance of Ireland is calling for the following investment in the upcoming Budget:

1. Investment to protect vital neurological care services in the community provided by the not for profit sector.
2. Investment to tackle the highest ever waiting lists in neurology services.
3. Investment in neurorehabilitation services to implement the 2019-2021 framework for the National Neurorehabilitation Strategy in line with the commitment in the current Programme for Government<sup>1</sup>.

## NEUROLOGICAL CARE POST PANDEMIC “THE PERFECT STORM”

Over 800,000 Irish people are living with neurological conditions including dementia, stroke, epilepsy, acquired brain injury, multiple sclerosis and Parkinson’s disease as well as a wide range of rare neurological disorders.

Neurological Care services in Ireland have been historically underfunded and underdeveloped and pre-COVID-19 faced among the longest waiting times within the Irish health system as well as critical gaps at all stages of the pathway from diagnosis to access to treatment and rehabilitation services and long-term care.

The closure/curtailment of services due to COVID-19 had a serious impact on access to treatment and rehabilitation for people with neurological conditions with services in no position to meet pent up demand due to decades of under-resourcing. COVID-19 has placed existing services under impossible pressure, due to the backlog of need: driving up waiting lists, increasing the length of time to access services and exacerbating the dearth of care that existed long before the pandemic. In addition, the future of long-term neurological care in the community is facing its most serious threat to date as a result of the impact of COVID-19 on the not-for-profit sector. Cuts to services or closures within this sector will have a devastating impact on the entire infrastructure of service provision for people with neurological conditions in this country.

As more and more research emerges of the neurological consequences of COVID-19, neurological care services are facing what a recent UK report<sup>2</sup> has termed the “perfect storm” of pent-up demand and long COVID as a new emerging group of neurological patients with complex needs coming on top of services already at breaking point pre-pandemic.

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<sup>1</sup> Our Shared Future: Programme for Government (October 2020) Government Publications (Ireland)

The Neurological Alliance of Ireland, the national umbrella of neurological patient organisations is calling for priority investment in neurological care to address spiralling waiting lists and deteriorating access to care in an area that is key to the long-term recovery from COVID-19.

## EVIDENCE OF THE IMPACT OF COVID-19 ON ACCESS TO SERVICES FOR PEOPLE WITH NEUROLOGICAL CONDITIONS IN IRELAND

The Neurological Alliance of Ireland carried out a nationwide survey of people living with neurological conditions in mid 2021, more than a year on from the onset of the pandemic. Respondents were questioned about their access to a range of essential services over the past six months. The findings indicate the impact of COVID-19 on access to neurological care with access to consultant neurology, physiotherapy, imaging and diagnostic tests and nurse specialists most significantly affected. Of serious concern is the extent to which the survey findings highlight the current (May 2021) continued impact on access to services with over a third of patients still experiencing significant delays in accessing their consultant and over a fifth in accessing physiotherapy/nurse specialists/diagnostic tests and changing or commencing new medications. The June 2020 Consensus Statement<sup>3</sup> issued by the Clinical Advisory Group for Neurology (Ireland) warned that extra resources would be needed for neurology services to cope with the backlog due to COVID-19.

**Table 1: NAI survey: Self report of 170 respondents May 2021**

	Significant Impact of COVID19 on access to this service over the past year	Still currently (May 2021) experiencing very significant delays due to COVID19
Access to Consultant Neurologist	33%	38%
Access to Physiotherapy	18%	18%
Access to Diagnostic tests/ Scans including MRI	21%	27%
Commencing a new medication or changing medication for your neurological condition	9%	21%
Access to a Nurse Specialist	19%	21%

<sup>2</sup> Lessons Learned from the COVID19 Pandemic: Priorities in care for people with neurological conditions after the pandemic (April 2021) National Neurosciences Advisory Group UK

<sup>3</sup> Consensus Statement on Neurological Care Post COVID19 Lockdown (June 2020) Clinical Advisory Group on Neurology, Neurology Clinical Programme HSE/RCPI

## LONG COVID PLACING ADDITIONAL DEMAND ON NEUROLOGICAL CARE SERVICES

*“Evidence strongly suggests that patients surviving COVID-19 are at high risk for the subsequent development of neurological disease”*

(Journal of Alzheimer’s Research & Therapy June 2020)<sup>4</sup>

*“We are facing a secondary pandemic of neurological disease”*

(Robert Stevens, Associate Professor of Anaesthesiology and Critical Care

Johns Hopkins Medicine, Baltimore)<sup>5</sup>

There is increase worrying evidence of the emergence of a significant cohort of patients with neurological needs as a consequence of COVID-19<sup>6</sup>. Evidence is increasingly emerging that COVID-19 is a disease with significant neurological consequences with research suggesting that over a third of patients may suffer neurological sequelae<sup>7,8</sup>. Neurological consequences with a long-term impact include cerebrovascular events (stroke), hypoxia, extreme fatigue and cognitive impairment.

Long-term neurological complications arising from COVID-19 will present to already overstretched neurology services with long waiting lists. These patients will also require access to specialist neurorehabilitation services which were already completely inadequate to meet demand pre COVID and in no position to address additional demand. It is estimated that 5% of COVID-19 patients will need focused, ongoing, intensive specialist rehabilitation<sup>9</sup>. This does not include patients in the community who missed out on rehabilitation due to COVID-19 and those deconditioned due to long periods of cocooning. The Neurological Alliance of Ireland is seriously concerned in relation to the provision being made for recovering COVID-19 patients and the need to ensure that services for people with existing neurological conditions are not placed under additional strain due to the need to cater for this new group.

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<sup>4</sup> Heneka et al (2020) “Individual and long-term consequences of COVID-19 infections for the development of neurological disease. Alzheimer’s Research & Therapy: 12: Article 69 (June 2020)

<sup>5</sup> How COVID-19 can damage the brain <https://www.bbc.com/future/article/20200622-the-long-term-effects-of-covid-19-infection>

<sup>6</sup> Neurological Associations of COVID19 (2020) The Lancet: Sept (1) Volume 19, Issue 9 p.767-783

<sup>7</sup> Henecka et al (2020) Immediate and Long-term consequences of COVID-19 infections for the development of neurological disease. Alzheimer Research & Therapy (12) 69 (April 2020)

<sup>8</sup> Lancet Editorial: The Neurological Implications of COVID-19. June 2020 (19)

<sup>9</sup> Rehabilitation in the Wake of COVID-19: A phoenix from the ashes. British Society of Rehabilitation Medicine (BSRM) April 2020

## **ISSUE 1: VOLUNTARY SECTOR PROVISION OF NEUROLOGICAL CARE: AN UNPRECEDENTED THREAT TO SERVICES**

Provision of neurological care in Ireland is critically dependent on a network of voluntary organisations providing the only long-term and rehabilitative care in the community for people with neurological conditions. These organisations were already struggling preCOVID19 due to successive funding cuts and the increasing cost of providing services. Demand for the services provided by voluntary neurological organisations has grown significantly year on year but the cost of providing these services has increased: including because of increased insurance costs, increased costs involved in complying with regulations/standards etc. In 2020, not for profit organisations faced a further increase in demand for their supports with the onset of COVID-19 and the closure/curtailment of other services.

“The vital importance of not-for-profit organisations in the delivery of everyday care for neurological illness in this country cannot be overstated. They contribute millions each year from fundraised income without which neurological care in this country could not be sustained” Professor Orla Hardiman: National Clinical Lead for Neurology

The threat to the sustainability of not-for-profit neurological patient organisations has serious implications for neurological care in Ireland. Any closure/curtailment of service provision by even a single voluntary organisation in this sector has a devastating subsequent impact on the care and treatment available to patients with that condition.

The sustainability of not-for-profit providers of neurological care has been drastically affected due to the impact of COVID-19 on public fundraising, coming on top of years of underfunding and accumulated deficits. Unless action is taken to protect and resource this sector in the immediate and longer term: neurological care in Ireland, already under resourced and struggling before COVID-19, will be fundamentally undermined at a time of critical need.

### **OUR ASK**

The Neurological Alliance of Ireland is calling for Section 39 organisations to be protected from any cuts in 2022 and that sustainability supports for the community and voluntary sector introduced in the wake of COVID-19 are continued for as long as restrictions continue to impact on public fundraising. The recently published NESC report<sup>10</sup> has highlighted the overwhelming response of voluntary sector health and social care providers to the COVID-19 pandemic. It acknowledges that this response should provide a catalyst for a new relationship with the voluntary sector. For the Neurological Alliance of Ireland, addressing the critical challenge of funding for the true cost of providing services is crucial to protect the sustainability of these organisations in the immediate term<sup>10</sup>.

<sup>10</sup> Building a New Relationship Between Voluntary Organisations and the State in the Health and Social Care Sectors: Paper from the Dialogue Forum with Voluntary Organisations (June 2021) National Economic and Social Forum

*Outpatient Waiting Lists in Neurology Now Stand at 23,252 (May 2021), increasing by over 30% over the past five years. The proportion of patients waiting more than 12 months has dramatically increased: from just 17% in 2016 to 47% in 2021.*

## ISSUE 2: NEUROLOGY SERVICES: SPIRALLING WAITING LISTS AND INCREASING DEMAND

Neurology services, hospital-based services for the diagnosis and treatment of neurological conditions, had one of the highest OPD waiting lists pre-pandemic with waiting times of up to two years to see a neurologist becoming an all too frequent characteristic of the service.

A review of Neurology Resourcing 2015-2020 which was published by the Neurological Alliance of Ireland in March 2021<sup>11</sup> highlighted serious capacity concerns for neurological care services, a situation that has been worsened by the impact of COVID-19 but that was already at breaking point before the pandemic. The findings of an NAI national survey of neurology centres carried out in 2015, and again in 2020 showed that:

- Neurology services remained critically understaffed despite increased demand and activity over the five-year period. Staffing shortages are particularly acute in regional neurology centres such as Limerick, Waterford and Sligo which continue to lack dedicated multidisciplinary teams
- There is a critical shortage of nurse specialists in neurology. Nurse specialists for common conditions such as multiple sclerosis, Parkinson’s disease, epilepsy and migraine fall significantly short of what is required while some conditions such as Huntington’s disease have no access to a nurse specialist.

**Table 2: Current (2021) and recommended CNS Staffing for Parkinson’s Disease and Multiple Sclerosis:** *Source: Resourcing of Neurology Services in Ireland Five Years on 2015-2020 Published by the Neurological Alliance of Ireland March 2021*

	Recommended	Actual
Multiple Sclerosis	30	13.75WTE
Parkinson’s Disease	30	6
Epilepsy	35	22
Migraine	32	4

*Note: This table reflects permanent posts in place. CNS posts in Epilepsy and Migraine funded under the Slaintecare Integration Fund 2020 have not been included*

- The report outlines the serious threat to the sustainability of neurological care in Ireland due to the impact of COVID-19 on an already struggling not for profit sector.

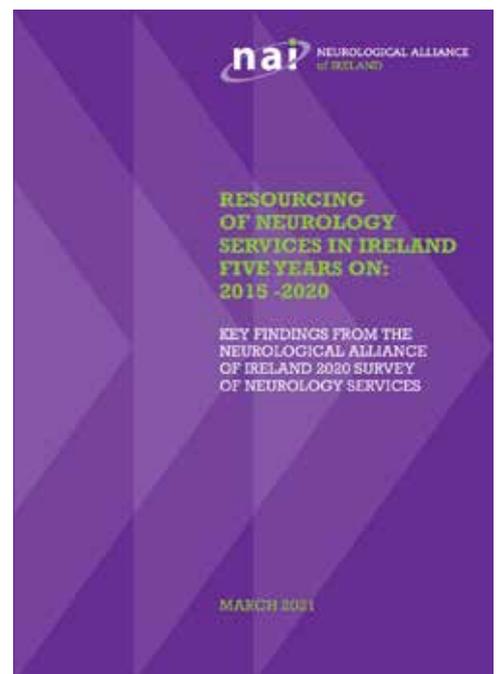
The Neurological Alliance of Ireland, working with the Neurology Clinical Programme, has identified the following priorities for neurology services in 2022

<sup>11</sup> Resourcing of Neurology Services in Ireland Five Years On 2015-2020: Key Findings From the Neurological Alliance of Ireland 2020 Survey of Neurology Services (March 2021) Neurological Alliance of Ireland

## OUR ASK

1. Tackle high outpatient waiting lists in neurology by funding a series of integrated pathways for neurological conditions including migraine, epilepsy and chronic progressive neurological conditions and rare diseases
2. Address the critical shortage of nurse specialists across neurology services
3. Fund the development of a specialist service to respond to emerging need, including the needs of patients presenting with symptoms of long COVID.

Note: Specific costs for investment in neurology services in 2022 will be provided by the National Clinical Programme in Neurology as part of the 2022 Estimates Process



## ISSUE 3: NEUROREHABILITATION IN IRELAND: A CRITICAL DEARTH IN SERVICES EXPOSED BY THE PANDEMIC

Neurorehabilitation services represent a continuum of care from specialist inpatient rehabilitation to long term community supports aimed at preventing further disability and promoting recovery for people with neurological conditions. The COVID-19 pandemic served to expose the serious gaps in neurorehabilitation service provision with the move to discharge patients from acute hospital settings only to find a significant lack of rehabilitation services to support their discharge into the community. The launch of the National Neurorehabilitation Strategy in 2011 and the publication of a three-year Implementation Framework (2019-2021)<sup>12</sup> almost a decade later, has seen little or no investment to deliver on the commitments to put in place a network of hospital and community-based neurorehabilitation services countrywide. Despite the Neurorehabilitation Strategy being a key commitment of the current Programme for Government<sup>13</sup> and the Slaintecare Implementation Plan<sup>14</sup>: the 3 year implementation framework will fail to deliver of any of its commitments when it comes to an end in December this year.



Neurorehabilitation services are faced with exponential demands as a consequence of COVID-19. This is due to a combination of factors (i) patients discharged early from acute hospitals and who didn't get access to post-acute rehabilitation in the acute setting due to the COVID-19 outbreak, (ii) patients who did not get access to rehabilitation because of early discharge home (rehabilitation facilities were only admitting from acute hospitals) and (iii) patients with neurorehabilitation needs who had limited or no services in the community due to the redeployment of health and social care professionals. There is simply no capacity within existing neurorehabilitation services to meet the pent-up demand from COVID-19 and the impact is already being felt in longer waiting times for access to rehabilitation services in the community.

<sup>12</sup> National Policy & Strategy for the Provision of Neurorehabilitation Services in Ireland: From Theory to Action Implementation Framework 2019-2021 (2019) Health Services Executive

<sup>13</sup> Our Shared Future: Programme for Government (October 2020) Government Publications (Ireland)

<sup>14</sup> Slaintecare Implementation Strategy (2018) Government Publications (Ireland)

*“Neurorehabilitation services have been curtailed within both hospital and community settings. The COVID19 epidemic will also place additional pressure on existing services, as those hospitalised will require extensive rehabilitation. Neurological consequences of COVID19 are also anticipated. Additional resourcing of rehabilitation services will be essential to maintain services”*  
(National Clinical Advisory Group in Neurology Consensus Statement)<sup>15</sup>

## OUR ASK

The Neurological Alliance of Ireland are calling for neurorehabilitation teams to be funded in each Community Health Organisation in 2022 in order to address this commitment in the Implementation Framework for the National Neurorehabilitation Strategy implementation of the framework represents a commitment in both the current Programme for Government<sup>16</sup> and the Slaintecare Implementation Plan<sup>17</sup>. Addressing the critical lack of neurorehabilitation services, especially in the community, is also key to the success of the National Trauma Strategy<sup>18</sup>.

This investment would include:

1. Funding the remaining six Community Neurorehabilitation Teams in CHOs 1, 2, 4,5, 8, 9, committed to in the Implementation Framework for the Neurorehabilitation Strategy 2019-2021 and which have not been funded to date. The costing for a Community Neurorehabilitation Team is outlined below

When Pension (4%), Overheads (25%) and equipment costs (approx €80,000) are included, the cost of introducing a 'new' CRT is €3,018,240 per CHO

Profession	WTE	Cost	Salary MM	PRSI	Total	WTE Total
Consultant	2.5		€140,248.00	€13,076.43	€153,324.43	€388,308.11
Medical	2.5		76496	€8,223.32	€84,719.32	€211,798.30
Nursing	45		37137	€3,992.23	€41,129.23	€1,850,833.24
Physiotherapy			43151	€4,643.03	€47,834.03	€0.00
Senior	2		55578	€5,974.64	€61,552.64	€123,105.27
Basic Grade	4.5		43191	€4,643.03	€47,834.03	€115,258.15
Occupational Therapy						
Senior	2		55578	€5,974.64	€61,552.64	€123,105.27
Basic Grade	4.5		43191	€4,643.03	€47,834.03	€115,258.15
Social Work						
Senior	1		81648	€8,627.18	€90,275.18	€88,275.18
MSW	1		48331	€5,197.73	€53,528.73	€31,548.73
Speech and Language						
Senior	1		55577	€5,974.53	€61,551.53	€81,551.53
Basic Grade	2.5	€38,871.00	41,191	€4,643.03	€47,834.03	€119,585.08
Dietetics						
Senior	1		57987	€6,233.40	€64,220.40	€84,220.40
Basic Grade	0	€25,276.00	41,191	€4,643.03	€47,834.03	€0.00
Clinical Psychology						
Senior	1	€145,496.00	81420	€8,732.65	€90,172.65	€90,172.65
Basic Grade	2		84964	€8,972.38	€93,936.38	€143,879.76
<b>Total</b>						<b>€3,728,864.00</b>

BSRM recommended staffing ratios for a 20-bedded Tertiary Rehabilitation Service

2. Addressing the shortfall in funding of CRT teams in 2020 in CHOs 6 and 7 where the funding provided was insufficient to fully staff these teams

<sup>15</sup> Consensus Statement on Neurological Care Post COVID19 Lockdown (June 2020) Clinical Advisory Group on Neurology, Neurology Clinical Programme HSE/RCPI

<sup>16</sup> Our Shared Future: Programme for Government (October 2020) Government Publications (Ireland)

<sup>17</sup> Slaintecare Implementation Strategy and Action Plan 2021-2023 (Page 47) (May 2021) Government Publications (Ireland)

<sup>18</sup> A Trauma System for Ireland: Report of the Trauma Steering Group (2019) Government Publications (Ireland)

## BUDGET 2022 AND OUR MEMBERS

We are supporting the following specific asks on behalf of our member organisations

### Irish Heart Foundation

Budget 2022 should:

- Ensure full funding for the recommendations of the new Stroke Strategy, ensure its publication alongside a comprehensive implementation plan.
- Provide priority funding for research to establish the number of stroke survivors living in Ireland, along with a full assessment of their service and support needs. This should include stroke survivors in nursing homes, who should be fully accommodated in post discharge service provision.
- Ensure that services assisting survivors at all stages of their post-stroke journey are adequately funded.

### Muscular Dystrophy Ireland

#### Long Term Illness Scheme criteria

We view the current list of conditions that make one eligible for the Long Term Illness Scheme as inequitable. Currently, people with all forms of muscular dystrophy and myopathy are eligible for the scheme. However, people with neuropathies such as Charcot Marie Tooth and spinal muscular atrophy (SMA) are not eligible even though they may experience similar levels of physical disability and the need for the support of the Long Term Illness Scheme as people with muscular dystrophy or myopathies.

#### Recommendation:

Review criteria for Long Term Illness Scheme to include neuropathies such as the conditions, Charcot Marie Tooth and spinal muscular atrophy (SMA). We are aware that it is stated that the scheme will be reviewed as part of Sláintecare. However, we would like to see a specific timeline and commitment in place.

#### Medical Card application process

Currently one can only apply for a medical card on the grounds of income or age.

#### Recommendation:

Introduce a separate process for applying for a medical card on the grounds of disability.

## Epilepsy Ireland

As part of Budget 2022 Epilepsy Ireland are calling on the Government to address a longstanding issue impacting on people with epilepsy. If a person with epilepsy holds a driving license and experiences a breakthrough seizure, they will lose that license until they become one year seizure free. In addition to this, due to the nature of their condition, many people with epilepsy will never be able to drive so depend heavily on public transport.

This can place a significant financial burden on people with epilepsy and can create challenges in maintaining employment. Our members Epilepsy Ireland are aware of cases whereby a person has had to give up their employment due to these challenges and in general, have seen how this can lead to a person becoming economically and socially isolated. Therefore, they are calling on the Government to address this issue in Budget 2022 by:

- Granting automatic access to a Free Travel Pass for people with epilepsy who temporarily lose their license due to a breakthrough seizure to ease the burden they face for the period that they are unable to drive.
- Establish the Free Travel scheme as directly applicable benefit to allow people with epilepsy who are unable to drive to apply directly for a Free Travel Pass. Currently, the Free Travel scheme is linked to other payments such as Disability Allowance and Invalidity pension. This makes the benefit inaccessible to those who are in employment and do not meet the strict medical criteria for these schemes.

## PRE BUDGET SUBMISSIONS SUPPORTED BY THE NEUROLOGICAL ALLIANCE OF IRELAND

Neurological conditions now represent the leading cause of disability worldwide according to the World Health Organisation<sup>19</sup>. The Neurological Alliance of Ireland supports the asks in the following submissions: in acknowledgment of the continued economic and wide range of other challenges facing people with disability (including neurodisability) in Ireland.

1. Report on Aligning Disability Funding with the UN Convention on the Rights of People with Disabilities<sup>20</sup>.  
(The Neurological Alliance of Ireland supports the asks outlined in this report to ensure adequate funding is allocated to the national budget for the various sector relevant to the realisation of the rights of people with disabilities in Ireland).
2. Disability Federation of Ireland Pre Budget Submission to the Department of Social Protection (July 2021) calling on the Government to:
  - Increase core social protection rates by €9.80 per year, until 2026, to ensure income adequacy.
  - Publish the Indecon Cost of Disability report and make financial provision in Budget 22 to implement its recommendations.
  - Introduce a €20 per week cost of disability payment for those on Disability Allowance and Blind Pension as an interim measure.

- Address issues of digital poverty which COVID has highlighted by reviewing and updating Household Benefits package and Telephone Support Allowance to include support for internet services, broadband and hardware such as laptops and tablets.
- Raise the €350 threshold on earnings disregard for Disability Allowance by €20.
- Ensure all budget decisions are subject to equality proofing, specifically assessing their impact on disabled people, including taking into account the cost of disability.
- Ensure employment supports for disabled people are not deprioritised, make the Workplace Equipment Adaptation Grant more flexible, consider creating a 'Working from Home' grant, implement recommendations of other disability organisations.
- Work together with other Departments to invest €1.5 million in an Assistive Technology (AT) passport.

## NEUROLOGICAL ALLIANCE OF IRELAND

The Neurological Alliance of Ireland (NAI) brings together over thirty non-profit organisations to advocate for the rights of 800,000 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 and their families. Our campaigns are rooted in the experience of our members and the individuals and families with whom they work. We provide a united and expert voice on neurological care through research, advocacy, policy development and education. Further information is available at [www.nai.ie](http://www.nai.ie) and [www.loveyourbrain.ie](http://www.loveyourbrain.ie)

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<sup>19</sup> Consolidated Report by the Director General (May 2020) World Health Organisation: Pages 8-9

<sup>20</sup> Budget 2022 Pre Budget Submission (July 2021) Oireachtas Committee on Disability Matters

## **LIST OF NAI MEMBER ORGANISATIONS**

*Acquired Brain injury Ireland*

*Alzheimer Society of Ireland*

*An Saol*

*Aphasia Ireland*

*Ataxia Foundation Ireland*

*Aware*

*Bloomfield Health Services*

*Cheshire Ireland*

*Chronic Pain Ireland*

*Dystonia Ireland*

*Enable Ireland*

*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*



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