

STRATEGIC PLAN

2023 – 2027





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OUR 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)

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



FOREWORD



Tom Scott,
Chair Of NAI

We are pleased to bring you the five-year Strategic Plan for the Neurological Alliance of Ireland 2023-2027. 2023 marks the twenty-year anniversary of the formal establishment of the NAI as a national umbrella for voluntary organisations providing services and supports to people with neurological conditions and their families.

Since then, the organisation has succeeded in building an effective coalition of organisations that have worked to together to achieve a significant increase in the recognition and profile of neurological conditions within Ireland.

This year, as we mark twenty years as an Alliance, this strategic framework aims to reflect the contribution the organisation has made and what is required both to sustain its future and to position the umbrella to work with its members and other stakeholders to deliver better care for people with neurological conditions and their families.

Our previous Strategic Plan 2020-2022 committed to an ambitious programme of advocacy, research, and policy development as well as organisational change as the NAI aimed to raise its profile and strengthen its impact.



Mags Rogers,
Executive Director of NAI

The plan was launched three months into the COVID19 pandemic, a time of unprecedented challenge for all of Irish society, but in particular vulnerable groups such as the elderly and those living with chronic illness and disability. Our member organisations within the voluntary sector mobilised an incredible response while facing their own significant challenge with the collapse of public fundraising at a time of spiralling demand for their services.

NAI responded to the pandemic through a comprehensive programme of specialist training and support to its member organisations, as well as research, reporting, and advocacy on the impact of COVID19 on access to care for people with neurological conditions.

By designing and implementing a comprehensive programme of organisational change, the NAI also succeeded in developing an effective online advocacy and communications platform in response to the new opportunities in the digital environment. This has enabled the NAI to significantly increase its profile and impact over the last three years, securing new investment in neurology and neurorehabilitation services, and in attaining recognition

as an expert voice in informing policy development and implementation.

Our new five-year plan 2023-2027 was developed through a comprehensive engagement process involving dialogue with our members, lived experience representatives, and external stakeholders. Our ambitious plan over the next five years is strategic and focussed, with the aim of advancing our shared advocacy, whilst also maintaining strong relationships with our key stakeholders, and always reflecting the voice of those impacted by neurological conditions.

We want to thank everyone who contributed to the development of this plan and we look forward to working in partnership with our membership to ensure its successful implementation.

FOREWORD

Vision

Our vision is an Ireland where people experiencing neurological conditions can achieve their best in life.

Mission

Our mission is to be the alliance that collectively advocates with and for all people experiencing neurological conditions.

Our Values

We are:

- **Inclusive:**

We treat each other with respect, working in partnership, bringing equity, dignity, and collaboration to how we operate, both internally and externally, and to all those we serve.

- **Ambitious:**

We are passionate and ambitious about what can be achieved by our members working together.

- **Empowering:**

Our members are empowered by the collective leadership of our alliance.

- **Trustworthy:**

We operate to the highest standards of governance, underpinned by openness and transparency, bringing excellence to all we do.

About Our Work

The Neurological Alliance of Ireland is the voice of the neurological community in Ireland.

We are a membership organisation, providing a platform for over 30 Irish charities who provide supports and services for the hundreds of thousands of people in Ireland who are experiencing a neurological condition, and their families.

Our purpose is to collectively advocate for the shared and common issues and concerns of our members and, while we do that, to have people experiencing neurological conditions, and their families, achieve their best in life.

Working closely with our members and other stakeholders, NAI acts as a strong platform to drive the development and implementation of policy and best practice to meet the needs of people with neurological conditions and their families throughout Ireland.

We provide an effective network for our members to interface with, and influence key stakeholders including policy makers and public representatives.

We act as a specialist hub to inform and influence health policy as it relates to people with neurological conditions and communicate this to our members.

We maintain a very active and responsive communications platform across our websites and social media platforms, as well as internally through monthly e-updates to our member organisations.

We work through partnership with umbrella organisations, both within Ireland and at European level, to promote greater awareness and support for people living with neurological conditions.

NEUROLOGICAL CARE IN IRELAND: AN OVERVIEW

Neurological conditions are conditions affecting the brain and spinal cord. In May 2022, the World Health Organisation published a ten-year framework for neurological conditions and epilepsy: highlighting that a worldwide response to these conditions is needed, given that they now represent the leading cause of disability adjusted life years, and the second leading cause of death worldwide¹.

Here in Ireland over 800,000 people are living with a neurological condition². The ageing demographic within developed countries like Ireland means that neurological conditions associated with ageing are set to increase significantly over the coming years.

Additionally, due to advances in care and treatment, including improved trauma and perinatal and paediatric care, more people who are born with or who acquire a neurological condition are surviving and require a range of supports in order to live to their full potential.

While there has been significant achievement in some areas, the landscape of neurological care in Ireland is still one of underinvestment and a critical need for development at all stages from diagnosis to long term supports in the community.

The Neurological Alliance of Ireland has been at the forefront of this landscape over the past twenty years, raising the profile of neurological conditions and securing the development of a policy response within the health system. Its challenge remains to ensure that these policies are implemented in full, with appropriate investment in line with the vision of the NAI for an Ireland where people experiencing neurological conditions can achieve their best in life.

¹ *Intersectoral global action plan on epilepsy and other neurological disorders 2022-2031 (May 2022) World Health Organisation*

² *Strategic Review of Neurology and Neurophysiology Services in Ireland (2007) Report Commissioned for the National Hospitals Office, Health Services Executive*

TWENTY YEARS OF THE NEUROLOGICAL ALLIANCE OF IRELAND

2003: NAI formally established as a registered charity

2005: NAI organises its first National Brain Awareness Week to raise the profile of neurological conditions in Ireland

2007: NAI and its members successfully advocate for the establishment of a joint DOH/HSE working group to develop a National Neurorehabilitation Strategy which was finally published in 2011

2010: NAI launches “The Future for Neurological Conditions in Ireland” report with contributions from across the health & disability landscape

2014: NAI successfully campaigns for the restoration of funding to 12 of its member organisations funded under the SSNO scheme

2015: NAI publishes the first national survey of neurology resources in Ireland

2016: NAI launches “We Need Our Heads Examined” campaign for neurorehabilitation services

2018: NAI publishes the first lived experience survey of people with neurological conditions in Ireland

2019: One of the key objectives of the NAI’s “We Need Our Heads Examined” campaign achieved with the publication of a long awaited three year implementation plan for the National Neurorehabilitation Strategy

2021: NAI publishes the findings of a second national audit of neurology resources 2015-2020

2022: NAI secures funding for 23 specialist nurses in neurology through its “Patients Deserve Better” campaign

ACHIEVEMENTS OF THE PREVIOUS STRATEGIC PLAN 2020 - 2022

During the period of our last Strategic Plan the NAI was an effective voice for the shared concerns and issues of our members. By working together, our alliance elevated issues around neurological conditions to the national stage, raised our visibility, and effected significant change for people experiencing a neurological condition in Ireland.

The NAI achieved a number of important results during the period of the previous Strategic Plan:

1. NAI conducted a national audit of neurology resourcing across the eleven neurology centres carried out in partnership with the Neurology Clinical Programme.
2. Development of a national advocacy platform based on the findings of the national audit which enabled NAI members to come together to secure 23 additional specialist neurology nurses in Budget 2022
3. Driving the implementation of the National Neurorehabilitation Strategy, securing two additional community neurorehabilitation teams through the NAI 2022 Pre Budget campaign, ahead of the rollout of national advocacy campaign in 2022/2023 calling for the funding and establishment of community neurorehabilitation teams in each CHO area.
4. Research and reporting on the impact of COVID19 on neurological care services, including a presentation to the Joint Oireachtas Committee on Health and publication of report on online service provision during the pandemic with a foreword by the HSE Lead for Digital Transformation.
5. Rollout of a nationwide project to map community services provided by voluntary neurological organisations in partnership with the Disability Federation of Ireland and the HSE.
6. Continuing to develop and grow National Brain Awareness Week as annual initiative to promote awareness of the brain and brain conditions throughout Ireland.
7. NAI responded to the Covid pandemic in 2020 by taking our work, including our networking events online, while continuing to support our patient groups and advocate for those experiencing neurological conditions.



ACHIEVEMENTS OF THE PREVIOUS STRATEGIC PLAN

Have Your Say
 SURVEY ON THE IMPACT OF COVID-19 ON SERVICES AND SUPPORTS FOR PEOPLE WITH NEUROLOGICAL CONDITIONS

What is This Survey About?
 The purpose of this survey is to understand the impact of COVID-19 on services and supports for people with neurological conditions. We are looking for your views on the impact of COVID-19 on services and supports for people with neurological conditions. We are looking for your views on the impact of COVID-19 on services and supports for people with neurological conditions.

Who Can Complete This Survey?
 You can complete this survey if you are a person with a neurological condition. You can complete this survey if you are a person with a neurological condition.

When Can I Take The Survey?
 The survey is available from 1st July 2022 to 31st July 2022.

Do I Have to Complete The Survey?
 No, it is optional. We would appreciate your feedback, but it is not compulsory.

Joint project to map services provided by voluntary organisations for people living with neurological conditions in the community

What is this project about?
 This project will map services provided in every Community Healthcare Organisation (CHO) region for people living with a neurological condition aged 18 to 65 years.

Why is this project taking place?
 As part of the implementation of the HSE Neurorehabilitation Strategy, local implementation teams will be responsible for a quantitative mapping of service provision in their own CHO. In preparation, this project is required to ensure all the relevant services are captured when the mapping takes place.

What will the result be?
 The result will be a national picture of the services available. The result will be used to support greater understanding and planning of services for people with neurological conditions.

We need your input
 We know that the services that you provide are vital in supporting people living with neurological conditions. It is important that your work is captured and recognised. We are asking all the community and voluntary organisations to participate in a survey in May. Your participation will help us capture the range of community services that are provided to people living with neurological conditions.

How can I find out more?
 For further information contact:
 Magdalen Rogers, NAI neuro@nai.ie
 Maria Lynch, DFI marielynch@disabilityfederation.ie



NAI COVID-19 RESOURCE HUB

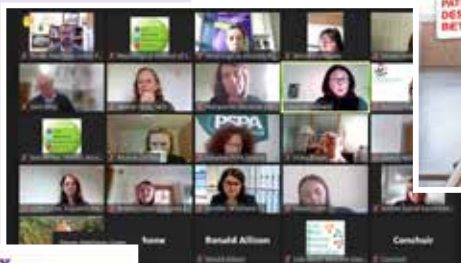
The Resource Hub is a suite of information, resources and advocacy for people with neurological conditions and their families.



LOOKING BEYOND COVID-19: EMBRACING DIGITAL SOLUTIONS FOR NEUROLOGICAL CARE

Love Your Brain
National Brain Awareness Week
 March 14th - 20th 2022

On to www.brainawareness.ie for more details



Only 15% of patients have access to a community neuro-rehabilitation team

Support our campaign: www.patientsdeservebetter.ie

Follow: [#patientsdeservebetter](https://twitter.com/patientsdeservebetter) and join the conversation

WORLD BRAIN DAY
 FRIDAY JULY 22nd 2022

'Brain Health For All'

WORLD BRAIN DAY
 July 22, 2022

#WBD2022 #BRAINHEALTHFORALL

COVID-19 RESOURCE HUB

The NAI Resource Hub is a suite of information, resources and advocacy for people with neurological conditions and their families.

Ireland needs an extra 100 neurology nurses

CONTEXT FOR THIS PLAN. DEVELOPING THIS STRATEGIC PLAN

Context for this Strategic Plan

As we go forward with a new strategic plan, we are cognisant of the landscape we operate within: a General Election is likely during the lifetime of this new Plan, which could lead to a change of government and the possible need to manage a different political dynamic.

Economic uncertainty continues in the aftermath of Covid 19, the onset of the war in Ukraine, ongoing high inflation, and a cost-of-living crisis which can impact patients more than the general population.

The policy environment is a crowded and noisy one in which NAI will have to compete for attention amid the dominance of issues such as housing, the cost of living and the climate crisis.

This will require us to continue to be strategic and focussed in advancing our shared advocacy while maintaining strong relationships with our key stakeholders and always reflecting the voice of patients.

The increased and growing profile of NAI presents both an opportunity for consolidation of the achievements so far, and at the same time creates the challenge of maintaining the pace of progress given the resources available to us as a small organisation.

Developing this Strategic Plan

This plan was developed in late 2022 and early 2023, following the Covid 19 pandemic. All the sessions were conducted successfully using the Zoom online platform.

The Appreciative Inquiry methodology was used in the development of this Plan, allowing members of the Alliance to work together to review the work of the organisation as part of the previous Strategic Plan, and to plan the future. This process was bolstered by the input of three 'critical friends' in a series of workshops at the creation phase.

The perspectives of a range of external stakeholders were gathered and fed into the process, and a Patients Focus Group was facilitated to gather the views and experiences of a range of patients and family members who are experiencing or have experienced neurological conditions.

A review of documents including relevant policies, submissions, and Government was conducted.

Engagement was held with members of the Alliance on the outputs of the process to develop the Strategic Plan.

OUR STRATEGIC GOALS

1. Advocacy & Communications

- Stakeholder engagement to explore a common advocacy platform ahead of the General Election
- Develop a platform and design campaign for General Election
- Have NAI asks included in new Programme for Government.
- Ensure communications activity is strategic and focused on supporting NAI's advocacy asks, including Brain Awareness Week.

2. Members – Engagement & Developing the Network.

- Engage with members around their needs in relation to advocacy and how these get reflected in the work of NAI.
- Organise annual information sharing and structured networking event for NAI members.
- Continue active engagement with members on specific advocacy/campaign initiatives.
- Continue monthly e-zine; ensure all members are signed up to monthly e-zine and conduct a feedback survey.

*The timeframe for the Strategic Plan acknowledges that a review may be required at the point of SSNO funding renewal in 2025.

3. Organisational Development: Governance, Risk & Sustainability

- Devise long term financial sustainability plan.
- Diversify funding, including through partnership models.
- Plan to mitigate top five risks.
- Engage in Board succession planning.
- Engage in Staff succession planning.



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