









# ANNUAL REPORT 2024

































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# FOREWORD

We welcome the opportunity to bring you the 2024 Annual Report for the Neurological Alliance of Ireland. 2024 was marked throughout the world as the "year of elections" and Ireland was no exception with local, EU and general election taking place all in the same year. This created a significant opportunity, as well as a demanding task for advocacy groups but the Neurological Alliance of Ireland was determined to rise to the challenge.

NAI launched its 2024 advocacy campaign during National Brain Awareness Week: focusing on securing neurology services for 5 regional hospitals. NAI mobilised a programme of non-stop advocacy from March to October: including regional events, one to one meetings, Oireachtas Committee hearings and extensive media coverage. Lived experience advocates around the country represented again this year the voice and vision of NAI campaigns.

Working together with our local advocates and member organisations in the regions: the campaign resulted in an unprecedented multi annual investment in neurology services in 2025 and 2026 which was announced by the Minister for Health in October's Budget. Taken together with its successful campaigns in 2022 and 2023, NAI has over the past number of years secured over €4.6m in investment in vital services for people living with a neurological condition throughout Ireland.

No sooner had the NAI concluded its most successful Pre Budget Campaign to date than the organisation embarked on a nationwide campaign to secure the support of candidates ahead of the General Election in November 2024. Nearly one hundred candidates signed the NAI pre-election pledge with many of those candidates successfully elected to take their seats in Dail Eireann. The focus in early 2025 will be on securing a clear commitment to neurological care within the new Progamme for Government.

2024 also saw NAI develop and roll out its most comprehensive national survey of neurological patient experience to date: in collaboration with Neurological Alliances across England, Scotland, Wales and Northern Ireland. The publication of the second Neuro-Mapping Report brought to a conclusion a very successful two-year project with the Health Services Executive and Disability Federation of Ireland to gain critical insights into community neurorehabilitation supports.

Our commitment to ensuring a voice for all members in the work that we do was reflected in our active programme of engagement with our members all throughout this year, providing multiple opportunities for members to be involved in collective advocacy, receive one to one support and information, and engage in

collaborative awareness-raising initiatives such as National Brain Awareness Week and World Brain Day.

We hope that you enjoy this report and look forward to your continued support as we work to build a better future for all those impacted by neurological conditions throughout Ireland.



Pascal Derrien Chair of NAI



Mags Rogers, Chief Executive Officer of NAI

# 2024 IN NUMBERS

€2m

Investment in
Services Secured for 2025,
Rising to €4m in 2026

Regional Campaign Events

861

Responses to 2024 Patient

Experience Survey

110+

Press Coverage Items

1,000+

Views of the NAI 'I Support BAW' Series, during Brain Awareness Week **Bimonthly** 

Members briefing meetings, information webinars & networking opportunities

10

NAI Member E-Newsletters

2

Presentations to Oireachtas
Committees

## NAIVISION

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

#### NAI MISSION

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

#### NAI GOALS

Our organisational goals are outlined in our five year Strategic Plan 2023-2027 launched in August 2023.

#### 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-newsletters. Ensure all members are signed up to monthly e-newsletters and conduct a feedback survey.

# 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.

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

# 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 nearly 40 Irish charities who provide services and supports for the 860,000 people throughout Ireland who are living with 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 applies 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, as well as internally through our monthly e-newsletters.

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



# NAI MEMBER ORGANISATIONS

Irish Hospice Foundation Irish Motor Neurone Disease Association Migraine Association of Ireland Move4Parkinsons Multiple Sclerosis Society of Ireland Muscular Dystrophy Ireland Neurology Support Centre Cheshire Ireland Neurofibromatosis Association Chronic Pain Ireland of Ireland Crann Centre Neurology Support Centre

#### REGIONAL NEUROLOGY CAMPAIGN

NAI launched its 2024 advocacy campaign during National Brain Awareness Week in March 2024, with the aim of securing neurology services across 5 regional hospitals. This followed an extensive consultation with stakeholders in 2023 to agree the target sites for the campaign. NAI worked extensively in partnership with NAI member organisations and with the critical support and engagement of the regional lived experience advocates who represented the voice and vision of the campaign. Together, we engaged in a non-stop journey of regional launch events, briefings, presentations to Oireachtas Committees on Health and Disability Matters and media opportunities, from March right through to Budget Day in October 2024.

We warmly acknowledge everyone who supported the campaign, including our public representatives who did so much to understand and promote the need for access to neurology services on behalf of their constituents.

In Budget 2024, the then Minister for Health Stephen Donnelly announced an unprecedented multi annual funding package of €2m for neurology services, rising to €4m in 2026, in direct response to the NAI campaign.

The allocation provided will fund the recruitment of five additional consultant neurologists and a clinical support member across five regional hospitals: University Hospital Kerry, Midlands Regional Hospital Portlaoise, Wexford General Hospital, Mayo University Hospital and Letterkenny University Hospital.

In total, in direct response to the NAI campaign, thirty posts will be allocated to neurology services in the 2026 HSE service plan.



Outcome of 2024 NAI Advocacy Campaign: Announcement of €2m funding for neurology services in 2025, rising to €4m in 2026.













































#### PRESENTATIONS TO OIREACHTAS COMMITTEES

NAI representatives were invited to present to the Oireachtas Committee on Health in May, and the Committee on Disability Matters in October 2024. Both presentations provided a critical platform to highlight a range of issues including gaps in regional neurology services, the need for investment in neuro-rehabilitation services and provided an important opportunity to showcase the vital work of NAI member

organisations in the implementation of the National Neuro-Rehabilitation Strategy through the long-term neuro-rehabilitation services they provide in communities throughout Ireland. NAI representatives met with HSE CEO Mr Bernard Gloster in September to address issues highlighted by the Health Committee in their meetings in May and July 2024.































#### EU ELECTIONS

NAI launched its manifesto for the EU Elections in May 2024, working together with its partners in the European Federation of Neurological Associations to secure support for neurological issues among election candidates.



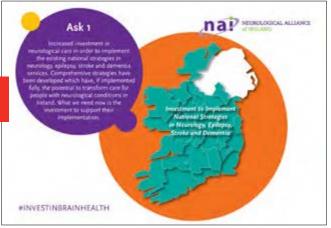


#### GENERAL ELECTION CAMPAIGN

Immediately following on from its successful Pre Budget Campaign, NAI launched its manifesto and campaigned extensively in the lead up to the general election on November 29th.

Nearly one hundred candidates signed the NAI pre election pledge with many of those candidates successfully elected to take their seats in Dail Eireann.

The focus in early 2025 will be on securing a clear commitment to neurological care within the new Progamme for Government.









#### BRAIN AWARENESS WEEK (MARCH 11TH TO 16TH)

National Brain Awareness Week is an annual awareness campaign which is promoted, co-ordinated and led by the Neurological Alliance of Ireland (NAI). It aims to promote greater awareness and understanding of the brain and brain conditions, as well as the need for more investment in services. research and prevention.

It is one of NAI's key campaigns, and preparation and planning start months in advance. In 2024 there were 800,000+ people living in Ireland with a neurological condition, and the NAI is the national umbrella organisation for the 33 + groups that represent them.

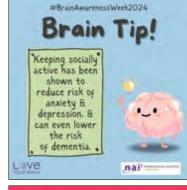
Brain Awareness Week provides NAI, our members, our partners, and the wider network of supporters across hospitals, universities, schools, carers, families and more, with an opportunity to highlight the need for investment in services for people with neurological conditions as well as promoting preventative approaches to neurological diseases. The entire week provides a wealth of opportunities to highlight current advocacy campaigns.

NAI produced a comprehensive information pack and toolkit, which was packed full of promotional materials and information to download and use across social media pages and websites. In the weeks leading up to, and throughout Brain Awareness Week, we rolled out a dedicated social media campaign with a flyer/poster series of Brain Facts, Partner Profiling and Brain Tips, and we launched our I Support BAW video series, which received 1000+ views across our online channels. You can watch our support videos at >> I Support Brain Awareness Week <<

On March 12th, NAI launched our 2024 Patients Deserve Better advocacy campaign, for local neurology services. The campaign called for regional neurology services in 5 hospitals across the country, in Bantry, Wexford, Mayo, Portlaoise and Letterkenny.







nai NEUROLOGICAL ALLIANCE

1 in 3

According to the World Health

Organisation 1 in 3 people

will experience a neurological

condition in their lifetime

**Brain Awareness Week** 

March 11th - 17th

LOPVE #BRAIN AWARENESS WEEK2024

nail NEUROLOGICAL ALLIANCE

800,000

Neurological conditions

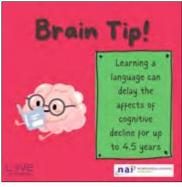
affect the brain and spinal cord

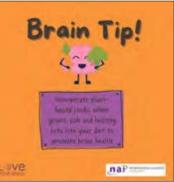
1 in 6

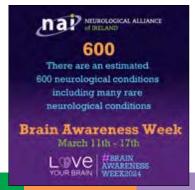
**Brain Awareness Week** 

March 11th - 17th

LOPVE #BRAIN AWARENESS WEEK2024











#### BRAIN AWARENESS WEEK (MARCH 11TH TO 16TH)

PRIL 22 MINE, 2024 - 27/07 MILJOR MARCHAELL, PRINCESSON SEPTEMBER

























#### LAUNCH OF PATIENT EXPERIENCE SURVEY PROJECT: MY NEURO SURVEY

In the early months of 2024, the Neurological Alliance of Ireland partnered up with the Neurological Alliance of England and Alliances in Scotland, Wales and Northern Ireland to join their long-established Patient Experience Survey collaboration. This gave NAI the opportunity to be involved in the largest pan neurological survey project across the UK and Ireland

Three individual surveys were commissioned focusing on the experiences of adults, family carers and children, living with a neurological condition. The work of the NAI lived experience reference group was critical to inform the design of the surveys which were rolled out in the Republic of Ireland.

The patient experience survey collaboration: My Neuro Survey, was launched across the UK and Ireland on July 22nd to coincide with World Brain Day and ran through to November 15th, 2024.

From July 22nd to November 15th NAI promoted and shared the survey across multiple channels and our communication data bases, and we asked our 40 member groups, patient advocates, people with neurological conditions, their family members and carers, to complete the survey and to share their experiences and help improve neurological services for everyone affected by neurological conditions throughout Ireland. The survey was available on the NAI website, www.nai.ie and it was promoted across all our social pages, as well as member websites and social pages.

Findings from across the three surveys - adults, carers and under 18's, will be available through a series of reports and factsheets from mid-year 2025 onwards.







#### NEURO-MAPPING PROJECT

The Phase 2 report of the Joint Neuro-Mapping Project was launched by Minister for Disability Anne Rabbitte in October 2024. The project, a collaboration between the Neurological Alliance of Ireland, the Disability Federation of Ireland and the Health Services Executive, aimed to build on the successful collaboration and strong participation which generated the Phase 1 report in January 2023.

Neuro-Mapping Phase 2 commenced in 2023 and aimed to provide an in-depth focus on community neurorehabilitation services across 3 CHO (community health organisation) areas in the East, Mid-West and West of Ireland.

The report is a testament to the professionalism and expertise of Nicola O Malley, Neuro-Mapping Project Officer with the Neurological Alliance of Ireland together with Marie Lynch Neuro-Mapping Project Manager with the Disability Federation of Ireland and to the strength of the collaboration with our partners in the Disability Federation of Ireland and the Health Services Executive. We continue to work with our partner to successfully integrate the recommendations of the report into the ongoing implementation of the National Neuro-rehabilitation Strategy.



A summary report is available to download at >> Neuro-Mapping Project Phase 2 <<



#### PARTNERSHIPS & COLLABORATIONS

We were delighted to partner with our colleagues at FutureNeuro and many other groups for the **My Moving Brain** project. This is an inclusion project dedicated to ensuring that sport is for everyone, with the first in a series of events taking place on November 16th 2024.

My Moving Brain is a series of community connect events that will open up conversations around brain health and wellness and explore barriers that may prevent people living with brain conditions from participating in sports.

By bringing together individuals, families, caregivers, local sports clubs, coaches, teachers, patient advocacy organisations, clinicians, researchers and the wider public, we hope to identify these barriers and identify ways to increase participation and engagement of people with brain conditions in sport and physical activity. The ultimate goal is to create inclusive sporting opportunities where everyone can experience the enjoyment and benefits that being active can bring. The full details about the My Moving Brain project can be read at >> My Moving Brain – FutureNeuro <<

We were delighted to announce that we became new members and joined the >> European Federation of Neurological Associations (EFNA) <<



The European Federation of Neurological Associations (EFNA) is a non-governmental organisation (NGO) that brings together 21 pan-European neurology patient groups.

Their slogan 'Empowering Patient Neurology Groups' encapsulates their goals as an association. They strive to add capacity to their members , allowing them to be the most effective advocates possible in their own disease-specific areas.

EFNA embraces the concept of Partnership for Progress, working at a high level with relevant stakeholders from the fields of policy, medical, scientific/research, industry, patient partners and other key opinion leaders.

My Moving Brain: M'Inchinn Gluiseachta

Promoting Brain Health & Wellness Through Inclusive Sport



#### MEMBER ENGAGEMENT

In NAI, we are committed to ensuring a voice for all members in all the work we do. This reflected in our active programme of engagement with our members, providing multiple opportunities for members to be involved in collective advocacy and engage in collaborative awareness-raising initiatives

such as National Brain Awareness Week and World Brain Day. We also engage in and support our members' individual awareness days and campaigns, and we promote and champion the work they do across our communications platforms.









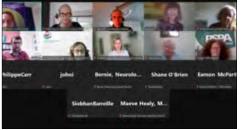










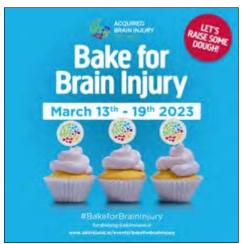








#### MEMBER ENGAGEMENT































We were delighted to welcome two new members in 2024: FND Ireland and Crann Centre.















## OVERVIEW OF NAI GOVERNANCE

- In 2021 our Directors signed off on our compliance with the Governance Code and agreed a mechanism for review on an annual basis.
- Our Board of Directors meets six times a year to oversee all aspects of our activities and finances.
- The Officers of the NAI meet bi-monthly to oversee key aspects of governance including audit, risk management and compliance.
- We undergo an independent financial audit on an annual basis and our financial statements are available on our website.
- In addition to our statutory Directors report we produce an in-depth annual report, reviewing our achievements against our strategic goals.

- Our work is guided by the NAI Strategic Plan 2023-2027; a detailed strategic planning process takes place every three years.
- We are compliant with all relevant legislation including the Charities Act (2009), the Companies Act (2014), Lobbying Act (2015) employment, equality and data protection legislation. We have a range of policies and procedures in place for our day-to-day operations as well as a structure for regular staff training and updates in relation to these policies.
- We provide detailed reports to our funders and work to maintain an organisational culture of transparency and compliance in all areas of our activities.

# NAI FINANCIAL REPORT 2024

#### Statement of Financial Activities for the Year Ended 31st December 2024

#### Income and Expenditure for Year Ended 31st December 2024

	2024	2023
	€	€
Turnover	228,188	213,209
Gross Surplus	228,188	213,209
Expenditure	(233,016)	(184,826)
Operating (deficit) surplus	(4,828)	28,383
(Deficit) surplus before taxation	4,828	28,383
Tax on (deficit)/surplus	-	-
(Deficit) surplus for the financial year	(4,828)	28,283

#### Balance Sheet as at 31st December 2024

		I
	2024	2023
	€	
FIXED ASSETS		
Tangible Assets	505	645
CURRENT ASSETS		
Debtors	1,504	1405
Cash at bank in hand	134,459	160,809
	135,963	162,214
CREDITORS		
(amount falling due within one year)	11,803	( <u>33,366</u> )
NET CURRENT ASSETS	124,160	128,848
TOTAL ASSETS LESS CURRENT LIABILITIES	124,665	129,493
Net assets	124,665	129,493
CAPITAL & RESERVES		
General Funds	124,665	129,493
Members Funds	124,665	129,493
		21.33

NAI is supported by a multi-annual funding programme through the Scheme to Support National Organisations, provided by the Department of Rural and Community Development and administered by Pobal. This scheme covers the period July 2022 to June 2025.

Funding from other sources, including industry sponsorship and membership fees, are clearly outlined in our audited financial statements.

### **OUR PEOPLE**

#### **Board of Directors**

(as at 31st December 2024)

Chair: Pascal Derrien

(Migraine Association of Ireland)

Vice Chair: Alison Cotter

(MS Ireland)

#### **Board Members**

Eamon McPartlin: Lived Experience Representative

Brian O Neill: The Rehab Group

John Inocentes: Dublin Neurological Institute

Sinéad Crawley: Acquired Brain Injury Ireland

Fiona Murphy: Headway

Tara Smith: Epilepsy Ireland

Gillian Murphy: Enable Ireland

Edina O Driscoll: External Board Member

Roisin Molloy: External Board Member

Our warm acknowledgement to Board Members Professor Niall Pender of Headway, Grainne Fogarty of the Rehab Group, Catherine Lacey of Acquired Brain Injury Ireland and Emma Rogan Lived Experience Representative who stepped down in 2024.

We welcomed seven new members to the Board this year, with a clear energy and enthusiasm at their first meeting in December 2024.

#### **NAI Staff**



Magdalen Rogers: Chief Executive Officer of NAI

#### **Sinéad Bradley:**Communications Officer



#### Acknowledgementrs

We would like to thank our partners, whose support enabled us to deliver a wide range of activities and initiatives in 2024









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