





# ANNUAL REPORT









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#### **FOREWORD**



Tom Scott, Chair Of NAI

We welcome the opportunity to bring you the 2021 Annual Report for the Neurological Alliance of Ireland.

2021 was a year when the COVID19 pandemic still impacted significantly on the community and voluntary sector and indeed the country as a whole. In a change from 2020, when there were lengthy periods of lockdown, 2021 became a year of shifting norms when it was difficult to plan ahead in an ever changing environment of rising COVID cases and uncertainty about restrictions.

The not for profit organisations that make up our umbrella faced another year of uncertainty, trying to achieve a balance between reinstating face to face service delivery and protecting the vulnerable people they serve. Once again the sector came under significant financial pressures as traditional face to face fundraising events were once again impacted.

Our focus in NAI in 2021 was about moving forward with the second year of our three year strategic plan and ensuring that our necessary response to COVID19 in 2020 did not significantly derail our existing priorities and commitments

established pre-pandemic. The NAI Strategic Plan 2020-2022 had set ambitious goals around each of the strategic priority areas of Advocacy, Research and Policy Development, Communications, Member Support and Organisational Development and Sustainability.

We were able to secure substantive progress in relation to each of these goals in 2021 due to a strong commitment from the Board, staff team and our members and stakeholders.

We want to acknowledge the support of everyone we worked with throughout 2021. Each and every one of our stakeholders, from our dedicated patient advocates, our member organisations, our clinician partners and our funders reached out to us to support our work as we focused on the three pillars of our strategic approach towards COVID19: response, adaptation and recovery.

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.



Mags Rogers, Executive Director of NAI

# 2021 IN NUMBERS



#### **NAI VISION**

Our vision is an Ireland where people with neurological conditions experience and enjoy full quality of life.

### NAI MISSION

Our mission is to work together to ensure the best services and supports for people living with neurological conditions and their families.

#### **OUR GOALS**

Our organisational goals are outlined in our three-year Strategic Plan 2020-2022, launched in July 2020.

1 ADVOCACY To strengthen its advocacy platform through improved messaging and increased engagement with public representatives and policy makers	4 COMMUNICATIONS  To improve NAI communications in order to raise awareness of the organisation and its messages	
2 RESEARCH & POLICY DEVELOPMENT To utilise research findings and to commission research where required to inform its advocacy and policy work	5 ORGANISATIONAL DEVELOPMENT To secure the future sustainability of the organisation within a framework of best practice in the areas of governance, quality and financial management	
3 MEMBER SUPPORT To improve engagement with members, through providing shared opportunities for advocacy, policy development and awareness	6 SUSTAINABILITY To ensure NAI's impact will extend in the coming years and becomes less reliant on a single source of funding	

raising

# 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. Neurological Conditions affect the brain and spinal cord.

They represent the leading cause of disability throughout the world and include many common conditions such as stroke, migraine, epilepsy and acquired brain injury as rare and genetic conditions.

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.



#### NAI MEMBER ORGANISATIONS

Acquired Brain injury Ireland Parkinson's Association of Ireland Migraine Association Alzheimer Society of Ireland of Ireland Peamount Healthcare Move<sub>4</sub>Parkinsons An Saol Polio Survivors Ireland Multiple Sclerosis Society of Ireland Aphasia Ireland PSPA Ireland Muscular Dystrophy Ireland Ataxia Ireland Slanu Stroke Rehab National Council for the Blind Aware Syringomyelia Support group of Ireland **Neurology Support Centre** Bloomfield Health Services Spinal Injuries Ireland Neurofibromatosis Association of Ireland Cheshire Ireland Spina Bifida Hydrocephalus Ireland North West MS Therapy Centre Chronic Pain Ireland The Rehab Group **Associate Members** Syringomyelia Chiara Malformation Support Group

Brain Tumour Ireland

#### 5 REASONS TO BECOME AN NAI MEMBER



- Become part of Ireland's only dedicated umbrella organisation for charities representing people with neurological conditions
- 2 Stay Informed: Get specific updates on policy issues and developments in the neurological sector
- 3 Make Your Voice Heard: Members of NAI have the opportunity to take part in collective advocacy and awareness raising initiatives

- 4 Collaborate: Have the opportunity to meet and work with other organisations supporting people with neurological conditions
- 5 Have Your Say: Have the opportunity to contribute to joint policy submissions, working groups and other forums as a member of the Neurological Alliance of Ireland

#### COVID19 RESPONSE 2021

From March 2020, NAI, in common with organisations across the community and voluntary sector, initiated an emergency response to COVID19. The main focus of our work in 2020 was on understanding the impact on people with neurological conditions and our own network of organisations. This had to be done rapidly, as the national response to COVID19 evolved in real time with day to day changes in the landscape for both patients and providers.

In 2021 the pandemic was still very much a feature of all our lives. Our COVID19 response in 2021 evolved into a more considered and comprehensive response to addressing the impact of the pandemic, while balancing this with the demands of our ongoing workplan and commitments.

Our most important imperative was to highlight the direct impact of COVID19 on access to neurological care services and ensure this message was heard by public representatives and policy makers. The findings from our Impact Survey in April 2020, right at the beginning of the pandemic, already highlighted the impact of cancelled appointments and tests and delays to treatment changes and access to rehabilitation. The Advocacy section

of this report outlines how the impact of COVID19 on people living with neurological conditions became a central pillar of our advocacy messaging and actions throughout 2021.

Another significant aspect of our COVID19 response in 2021 was the rollout of our Neurological Training Network programme. We recognised that one of the most significant challenges facing our member organisations was the need to adapt and respond to a new way of working, embracing digital technology in order to do everything from delivering services to fundraising, communication and office administration. This had to be done rapidly, in a context where organisations had very limited or no budgets to support training and where even finding the time to attend training was an issue for many organisations.

Our response was a series of online training courses, funded from members contributions and with the support of the Wheel Training Links fund. In total thirteen courses were delivered throughout 2021, reaching over one hundred and fifty staff and volunteers across our member organisations. Our strong relationships with our members meant that we could respond quickly and flexibly to their needs:

offering additional places where they became available and quickly adapting the training programme in response to emerging need. The HSE cyberattack mid year, for example, led us to adapt our training programme to support organisations in relation to cybersecurity.

The third aspect of our COVID19 response in 2021 was to reflect on and learn from the response to COVID19 across neurological care services. We initiated a research project in 2021 to examine the rapid switch to online service delivery during the pandemic and the impact on both providers and patients. Further detail on our publication Embracing Digital Solutions to Neurological Care, is provided later on in this report.

The impact of the COVID19 pandemic will have long term implications for access to neurological care services with a pent up demand on top of already underresourced services. Further work to understand and respond to COVID19 will continue to be a central feature of our work programme into 2022, building on the evidence base and the strong partnerships with stakeholders that we have established over the past two years.

- NAI joins the One Neurology: the Global Advocacy Campaign to Make Neurology a Global Health Priority: March 2021
- Report Launch: Resourcing of Neurology Services in Ireland Five Years On 2015-2020 March 2021
- Submission to the Oireachtas Committee on Health: "The Impact of COVID19 on Access to Services for People with Neurological Conditions" March 2021
- NAI Pre Budget Submission July 2021
- Launch of Patients Deserve Better Campaign October 2021
- Presentation to the Oireachtas Committee on Disability Matters December 2021
- Submission to the Oireachtas Committee on Health: November 2021

#### **Advocacy**

2021 saw the development and launch of our most ambitious and intensive advocacy campaign to date Patients Deserve Better which was launched in October 2021.

The lead in to this campaign began in late 2020 when we launched a second National Survey of Neurology Resourcing across the ten neurology centres nationwide.

Further detail on this project is provided in the next section of this Annual Report Research and Policy Development.

One of the stark findings to emerge from the survey was the critical shortage of clinical nurse specialists across neurology services. The number of specialist nurses for multiple sclerosis, epilepsy, Parkinson's disease and migraine were all significantly below the recommended numbers outlined in the Models of Care for Neurology and Epilepsy, while many neurological conditions including Huntington's disease lacked even a single nurse specialist.

Working closely with our industry partners, and fourteen of our member organisations, NAI designed and developed the Patients Deserve Better campaign to call for action to tackle the nursing shortage. Three campaign launches took place in Limerick, Galway and Cork in 2021 and the campaign will roll out to the other neurology centres in 2022.

The rollout and publication of the National Survey of Neurology Centres, and the design and launch of the Patients Deserve Better campaign, both represent the most significant advocacy projects undertaken to date by the Neurological Alliance. They represent an understanding and recognition by the Board of NAI of the central importance of advocacy to the vision and mission of the organisation and the need to ensure a strong voice on behalf of our member organisations and the people with neurological conditions they represent.

The impact of COVID19 on access to neurological care services was a strong theme and focus for our advocacy work throughout 2021, along with the National Neurorehabilitation Strategy.

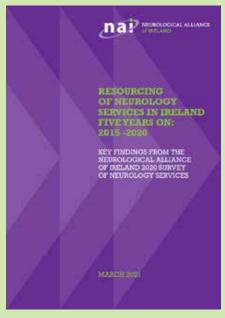
# NAI Advocacy Achievements 2021







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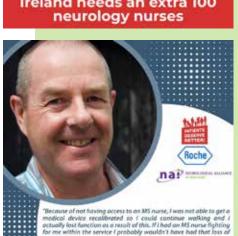




# Patients Deserve Better Campaign

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Robert Jayce, person living with Multiple Scienasis.











# Research and Policy Development

One of the goals of our 2020-2022 Strategic Plan is to utilise research findings and commission research where required in order to inform the advocacy and policy work of the organisation.

In 2021, NAI published the findings of its most significant research project to date, the 2020 national survey of neurology resources in Ireland. First carried out in 2015 to inform the Model Of Care for Neurology Services, the revised and expanded 2020 survey represented a more comprehensive and indepth examination of neurology services, involving over thirty questions and examining service provision and resource needs within each centre.

It is a testament to the commitment from our project partners in the Neurology Clinical Programme, and the support from individual neurologists in each centre, that we had a 100% response rate from each of the ten centres.

The survey findings and subsequent report provide a strong advocacy tool to support the development of Patients Deserve Better and future campaigns as well as those of our member organisations.

NAI also commissioned a research project in 2021 to describe and capture the response to COVID19 across neurological care services. The research, involving interviews, surveys and case examples, examined the rapid switch to online service delivery during the pandemic and the impact on both providers and patients. Embracing Digital Solutions to Neurological Care was launched on World Brain Day July 22nd.

One of the particular strengths that comes across in this document is the extent to which neurological providers have reached out to and listened to service users: pre-empting the two-way conversations that need to take place to involve patients as equal partners in the co-design of all healthcare approaches, including the use of digital technologies. I congratulate the NAI for putting together this very valuable and informative report and look forward to working with them in the future.

Prof Martin Curley: Director of Digital Transformation and Open Innovation: HSE

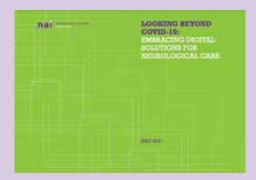


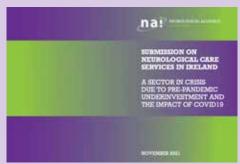
NAI involvement in the mapping of neurorehabilitation services in 2016, highlighted for NAI and its members the lack of a suitable methodology to capture the range of services provided by the voluntary sector to people living with neurological conditions in the community.

In late 2020, NAI partnered with the Disability Federation of Ireland in an application to the Strengthening Disability Services Fund for funding to support a project that would involve describing and mapping these supports nationwide.

Following a successful outcome to the application and release of the funding in late 2021, preliminary work on the project began in advance of a full roll out in 2022.









#### **Member Support**

In addition to providing regular information events and updates, as well as access to a collective advocacy platform, the focus of NAI over the past two years has been around supporting and highlighting the response among our member organisations to the COVID19 pandemic.

We recognised that one of the most significant challenges facing our member organisations was the need to adapt and respond to a new way of working, embracing digital technology in order to do everything from delivering services to fundraising, communication and office administration. This had to be done rapidly, in a context where organisations had very limited or no budgets to support training and where even finding the time to attend training was an issue for many organisations.

Our response was a series of online training courses, funded from members contributions and with the support of the Wheel Training Links fund. In total thirteen courses were delivered throughout 2021, reaching over one hundred and fifty staff and volunteers across our member organisations. Our strong relationships with our members meant that we could respond quickly and flexibly to their needs: offering

additional places where they became available and quickly adapting the training programme in response to emerging need. The cyberattack to HSE systems mid-year, for example, led us to adapt our training programme to offer a course on cybersecurity to our member organisations increasingly concerned to strengthen their response to this threat.

Continued COVID19 restrictions, and the many demands on our members, have led us to maximise the use of online platforms as a way of increasing and extending our ability to stay in touch with our member organisations. However there is no substitute for face to face contact and we will be seeking to explore in-person and hybrid events throughout 2022.









#### **Communications**

In late 2020, NAI commissioned a Communications Strategy, a key deliverable within the current Strategic Plan, which was agreed and adopted by the Board in February 2021. As part of the development of the strategy, NAI engaged with its member organisations, as well external audiences in order to evaluate the effectiveness of existing

communications and how these could be strengthened.

One of the recommendations within the strategy was the opportunity for NAI to build on and expand its social media as a key way for an organisation of its small size to increase its profile and reach to its audiences.

Throughout 2021, we focused on an increased presence on social media, not just around our main awareness initiatives of Brain Awareness Week (March) and World Brain Day (July) but all throughout the year: responding proactively to support the campaigns and activities of our member organisations but also sharing updates and developing and sharing relevant

content for events such as Rare Disease Day and other key awareness dates in the calendar.

The focus throughout 2021, in line with the Communications Strategy, was on targeted communications to support NAI awareness raising and advocacy campaigns, leading to an increase in media coverage and profile for the organisation.

#### Brain Awareness Week





















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DID YOU KNOW

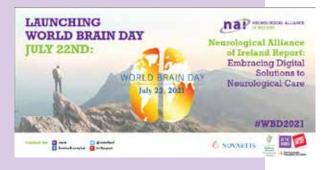
# World Brain Day





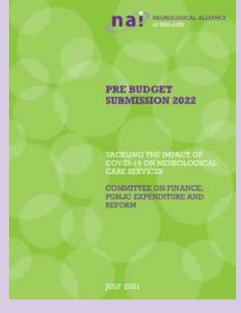
















# Organisational Development and Sustainability

The Board of NAI instituted a comprehensive and ambitious workplan throughout 2020/2021 to review and update all existing policies as part

of its programme of work to achieve compliance with the Governance Code by 2021. Despite the COVID19 pandemic and the additional workload and challenges it represented, the policy review workplan remained on track due in large part to the hard work and

commitment of the Board and staff of the organisation.

The Board of NAI signed off on full compliance with the Governance Code in September 2021.

The Board of NAI take the view that, as an umbrella of other charities, it is particularly important that we act as a positive example in all areas of governance.

### 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 five times a year to oversee all aspects of our activities and finances.

The Officers of the NAI meet bimonthly 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 indepth annual report, reviewing our achievements against our strategic goals.

Our work is guided by the NAI Strategic Plan 2020-2022, 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 2021

#### Income and Expenditure for Year Ended 31st December 2021

2021	2020
152,968	141,375
(151,691)	(141,216
1,277	159
1,277	159
	152,968 (151,691) 1,277

#### Balance Sheet as at 31st December 2021

	2021	2020
	€	€
FIXED ASSETS		
Tangible Assets	325	390
CURRENT ACCETS		
CURRENT ASSETS		
Debtors	365	365
Cash at bank in hand	(124,914)	(124,228)
	125,279	124,593
CREDITORS		
(amount falling due within one year)	(33,323)	(33,979)
NET CURRENT ASSETS	91,956	90,614
TOTAL ASSETS LESS CURRENT LIABILITIES	92,281	91,004
RESERVES		
(Income and Expenditure Account)	92,281	91,004
MEMBERS FUNDS	92,281	91,004

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 June 2019 to June 2022.

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 2021)

Chair: Tom Scott

Vice Chair: Emma Rogan

Treasurer: Barry McGinn

Gillian Murphy: Enable Ireland

Jimmy Smyth: JKS communications

Catherine Lacey: Acquired

Brain Injury Ireland

Niall Pender: Headway Ireland

**Kieran O Driscoll**: Consultant Neuropsychiatrist, Bloomfield

Health Services

Tara Smith: Epilepsy Ireland

Aoife Kirwan: MS Ireland

**NAI Staff** 

Magdalen Rogers: NAI
Executive Director

**Sinead Bradley:** 

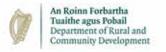
Communications Officer.





#### Acknowledgment of Funders and Collaborative Partners

We would like to thank our funders and collaborative partners, with whose support we were able to deliver a wide range of activities and initiatives in 2021







#### 2021 A BUSY YEAR FOR OUR MEMBERS

















Pacing in the

Workplace

THURSDAY BTH JULY 2021 @18.30PH









































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Follow us on Instagram @nai\_ireland