

ANNUAL  
REPORT

2022



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# FOREWORD

We welcome the opportunity to bring you the 2022 Annual Report for the Neurological Alliance of Ireland.

January 2022 marked the end of COVID restrictions and saw a return to normal activities after an unprecedented two-year period of disruption and change across Irish society due to the pandemic, which presented an overwhelming challenge for our member organisations and the people with neurological conditions and families they work with.

The COVID19 pandemic exposed the serious deficits in resourcing in neurological care services, as services already significantly underdeveloped pre pandemic struggled to cope with the backlog caused by service disruption as well as emerging need.

Our response was to mobilise our largest and most successful advocacy campaign to date, under the Patients Deserve Better platform, which saw an investment of €1.7m investment in neurology nurse specialists announced in Budget 2022: an investment attributed directly to the successful advocacy carried out by the organisations working together under the NAI umbrella.

The second phase of the Patients Deserve Better campaign, launched in November 2022, aims to continue this momentum into the coming year with a specific advocacy focus to tackle the lack of progress in implementing the National Neurorehabilitation Strategy: an issue frequently highlighted by a majority of members when identifying the priorities for NAI.

As the national umbrella body in Ireland representing the over 800,000 people with neurological conditions, we also had to be cognisant of the growing body of international evidence

pointing to the serious impact of the COVID19 pandemic on people with neurological conditions and their families.

Our workplan in 2022 incorporated a dedicated initiative to examine the effects of service disruption, the mental health impact and the consequences of contracting the virus from the perspective of both service users and service providers.

Our achievements in 2022 were only possible through the continued commitment and support of the over thirty voluntary organisations that make up the NAI umbrella. Our collective platform must continue to have as its central focus the vital importance of the voluntary sector in the provision of neurological care services and work to secure a strong base for the integration of this sector into future service frameworks and in much needed investment. Our pioneering Neuromapping collaboration this year with the Health Services Executive and the Disability Federation of Ireland will, for the first time, aim to capture the wide range of essential supports provided by the voluntary sector to people with neurological conditions and their families.

Our focus throughout 2022 was in continuing to realise the goals and targets outlined in our three year Strategic Plan 2020-2022 as well as commencing the development of our next Strategic Plan.

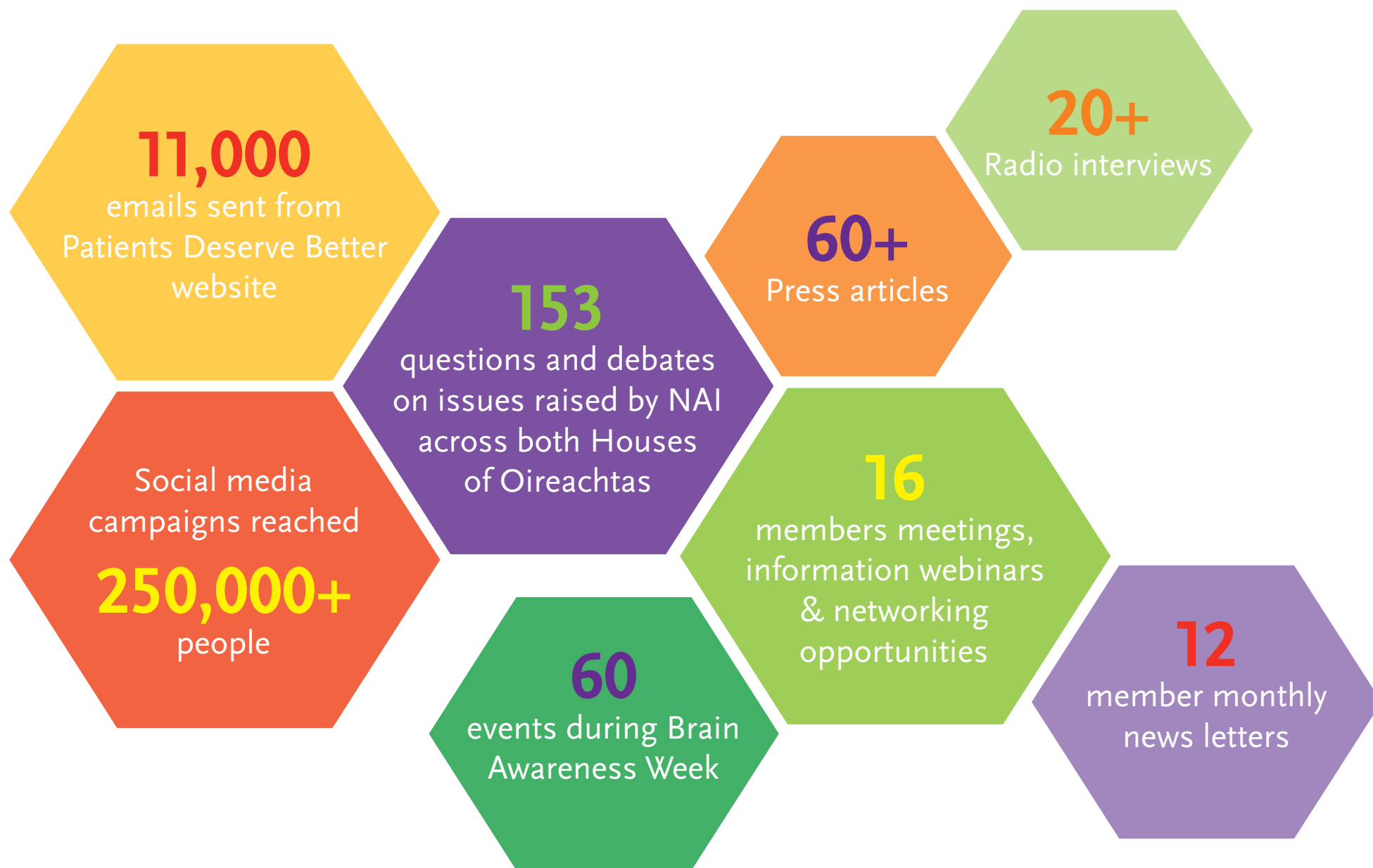
We hope that you enjoy this report and look forward to your continued support as we work to build a better future for all those impacted by neurological conditions throughout Ireland.

**Tom Scott,  
Chair Of NAI**



**Mags Rogers,  
Executive Director of NAI**

# 2022 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.

# NAI GOALS

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



# 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	Dystonia Ireland	Migraine Association of Ireland	Parkinson's Association of Ireland
Alzheimer Society of Ireland	Enable Ireland	Move4Parkinsons	Peamount Healthcare
An Saol	Early Onset Parkinson's Disease Association (EOPD)	Multiple Sclerosis Society of Ireland	Polio Survivors Ireland
Aphasia Ireland	Epilepsy Ireland	Muscular Dystrophy Ireland	PSPA Ireland
Ataxia Ireland	Headway	National Council for the Blind	Slanu Stroke Rehab
Aware	Huntington's Disease Association of Ireland	Neurology Support Centre	Syringomyelia Support group of Ireland
Bloomfield Health Services	Irish Heart Foundation	Neurofibromatosis Association of Ireland	Spinal Injuries Ireland
Cheshire Ireland	Irish Hospice Foundation	North West MS Therapy Centre	Spina Bifida Hydrocephalus Ireland
Chronic Pain Ireland	Irish Motor Neurone Disease Association		The Rehab Group
	<b>Associate Members</b>	Syringomyelia Chiara Malformation Support Group	
	Brain Tumour Ireland		

# PROGRESS ON STRATEGIC OBJECTIVES DURING 2022

## ADVOCACY

2022 saw the culmination of our largest and most successful advocacy campaign to date, securing €1.7m in investment in neurology nurse specialists, an investment attributed directly to the successful advocacy carried out by the organisations working together under the NAI umbrella.

The lead in to the Patients Deserve Better campaign began in March 2021, when we launched the summary findings of our national survey of neurology resourcing across the ten neurology centres nationwide.

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, which launched in October 2021, to call for action to tackle the nursing shortage. Three campaign launches took place in Limerick, Galway and Cork in the final three months of 2021.

In the first six months of 2022, the campaign held further launch events to highlight the shortage of nurse specialists in the remaining neurology centres in Waterford, Sligo and throughout the Dublin hospitals. The campaign was invited to appear in front of the Oireachtas Committee in March, followed by a dedicated Seanad debate that week and a presentation in the AV room in Leinster House in June. Representatives of the NAI met with Minister for Health Stephen Donnelly in July 2022 to coincide with World Brain Day, in order to reiterate the NAI asks ahead of the upcoming Budget.

Testimonies  
in Seanad Eireann  
in relation to the NAI's  
Patients Deserve Better  
campaign 22nd June  
2022

*"I again thank the Minister of State and acknowledge the great work of those involved in Patients Deserve Better. What a campaign they ran. If I were looking for someone to run a campaign for me, I would certainly take advice from them. Their infographics were excellent and their messages were clear. They were really well endorsed. They targeted Deputies and Senators very effectively. It is great that we have that public engagement and close contact with people outside the bubble of Leinster House."*

*"This has been a very effective - I will not call it a lobby group - information campaign which has caught the imagination of Deputies and Senators. It should take a bow. It is a very good way to lobby. It was not confrontational; it was informative. If one wants something done, one should bring people along. That is very effective."*



# PROGRESS ON STRATEGIC OBJECTIVES DURING 2022

## ADVOCACY

The dedicated NAI pre budget campaign culminated in a networking event with Oireachtas members in Buswells hotel Dublin in September. The announcement on Budget Day in October of investment in neurological care services to support the recruitment of 23 additional nurse specialist and two community neurorehabilitation teams was warmly welcomed by the NAI and its campaign partners.

*“The success of the Patients Deserve Better campaign relied on the support of dedicated patient advocates who contributed their own experiences and worked hard at local level to support the campaign nationwide”*

**Mags Rogers NAI  
Executive Director**



# PROGRESS ON STRATEGIC OBJECTIVES DURING 2022

## ADVOCACY

NAI had already begun work in the second quarter of 2022 to design and develop a second phase of the Patients Deserve Better campaign. The impetus for this next campaign was to address an issue consistently at the forefront of advocacy priorities raised by our member organisations: the need to secure investment in community neurorehabilitation services and progress the implementation of the National Neurorehabilitation Strategy.

The campaign was launched in November 2022 and will run until September 2023 with a focus on calling for a dedicated community neurorehabilitation team in each of the nine HSE Community Health Organisation (CHO) areas as outlined in the 2019-2021 Implementation Framework for the National Neurorehabilitation Strategy.



# PROGRESS ON STRATEGIC OBJECTIVES DURING 2022

## ADVOCACY

At European and international level, the NAI continued its membership of the One Neurology initiative, a worldwide partnership of international neurological organisations and regional umbrellas working to make neurology a global public health priority. NAI took part in collective advocacy to promote the adoption of a ten-year framework for neurological conditions and epilepsy (IGAP) by the World Health Organisation which was published in May 2022. NAI organised an information event for World Brain Day July 22nd 2022 which included a presentation from the One Neurology Campaign on the main recommendations of the IGAP.

**WHO Global Action Plan for Brain Health** 

On 27th May 2022 WHO succeeded in prioritising brain health over the next 10 years by adopting the **Intersectoral Global Action Plan (IGAP)** on Epilepsy and other Neurological Disorders 2022-2031. Brain disorders, many of which are preventable and treatable, must now be a priority on the agendas of policy makers. Neurological disorders are the leading cause of disability and the second leading cause of death worldwide. One in three people experience a brain disorder in their life. The IGAP has five strategic objectives with targets.

- 01** **Preventive Neurological Disorders & Strengthen Governance**

Targets

  1. A national strategy to reduce the burden of neurological disorders in 75% of countries by 2031
  2. An awareness campaign to increase understanding of brain disorders and highlight issues such as prevention, discrimination and to reduce stigma in all countries by 2031
- 02** **Effective, Timely & Responsive Treatment, Care & Diagnosis**

Targets

  1. Include brain disorders in a universal health care benefits package in 75% of countries by 2031
  2. Provide essential medicines and basic technologies for management of brain disorders in primary care in 80% of countries by 2031
- 03** **Brain Health Promotion and Brain Disorder Prevention**

Targets

  1. Intersectoral programme for brain health promotion in 80% of countries by 2031
  2. Intersectoral programme for brain disorder prevention in 80% of countries by 2031
- 04** **Research and Innovation**

Targets

  1. Collect data on a core set of indicators for brain disorders
  2. Global research output to double by 2031 from levels in 2022
- 05** **Public Health Approach - Epilepsy as a Model**

Targets

  1. Increase service coverage (e.g. access to inpatient or outpatient facilities) for epilepsy by 80% in 2031 from levels in 2021
  2. Enact legislation to protect people living with epilepsy against discrimination (e.g. in the workplace) in 80% of countries by 2031

**Why is The Intersectoral Global Action Plan Important for Ireland**

The Global Action Plan represents an important opportunity for Ireland to take a lead in the promotion of brain health and the prevention and treatment of brain disorders across the EU, building on the positive initiatives that have taken place in areas such as dementia, epilepsy and stroke care. Ireland has the advantage of experienced clinical leadership and a vibrant world-leading research community in the neurosciences as well as strong existing international collaborations and expertise in the area of brain health. As the national umbrella for over thirty neurological charities, the Neurological Alliance of Ireland has a vital role to play in bringing together stakeholders from across neurology to inform and implement Ireland's response to the Global Action Plan.

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 The neurology patient voice throughout the development of the Global Action Plan and its adoption is key to ensuring its subsequent implementation. EFNA and the community we serve are happy with this progress and are ready for implementation action!

Orla Galvin  
Executive Director,  
European Federation of Neurological Associations

 Adoption of the GAP sends a clear signal to Ireland and other EU governments of the need to develop and implement effective national plans to meet the needs of people with neurological conditions.

Magdalen Rogers  
Executive Director, Neurological Alliance of Ireland  
Epileptology Ambassador





 **OneNeurology Ambassadors meeting**

02 September 2022

Report from the WHO stakeholder meeting on implementation of the IGAP Geneva, 5th August

**10 YEAR GLOBAL ACTION PLAN FOR NEUROLOGICAL DISORDERS & EPILEPSY!**

- The global action plan on epilepsy and other neurological disorders aims to set out clear objectives and actions to improve care, recovery, well-being and participation of people living with neurological disorders across the life-course

# PROGRESS ON STRATEGIC OBJECTIVES DURING 2022

## RESEARCH AND POLICY DEVELOPMENT

Through all its activities, the NAI aims to highlight the vital importance of the voluntary sector in the provision of neurological care services and works to secure a strong base for the integration of this sector into future service frameworks and in much needed investment.

In January 2022, the Neurological Alliance of Ireland commenced a joint project with the Disability Federation of Ireland and Health Services Executive to describe and map geographically the existing community services provided by the voluntary sector to people living with neurological conditions from a national perspective

This important collaboration will, for the first time, aim to capture the wide range of essential supports provided by the voluntary sector to people with neurological conditions and their families.

Work on the project commenced in January 2022 with a comprehensive consultation to agree a detailed service listing to capture the wide range of supports and services provided by the voluntary sector to people with neurological conditions and their families. A nationwide survey of voluntary service provision across all nine CHOs was conducted with over over forty voluntary neurological organisations

taking part. The project also collated and examined a number of examples of joint service initiatives between the HSE and voluntary sector in order to gather information on initiatives that could be successfully replicated in other areas.

A series of stakeholder briefings towards the end of the year provided the opportunity to inform the writeup and final report which will be published early in 2023.

NAI also commenced a project in late 2022 to examine the impact of the COVID19 on access to neurological care services. The impetus for this initiative was the growing body of international evidence pointing to the serious impact of the pandemic on people with neurological conditions and their families in terms of service disruption, neurological and mental health consequences and longer term effects of contracting the virus. The outputs of the project in 2022 included a survey of people with neurological conditions and family carers as well as workshops with both service users and voluntary providers. The project will continue into 2023 with a series of interviews with clinicians and publication of the final report. This project is part of a series of NAI publications and responses to the impact of the COVID19 pandemic

**dfi** **HSE** **nai** **NEUROLOGICAL ALLIANCE of IRELAND**

Disability Federation of Ireland, DFI with the Health Service Executive, HSE, the Neurological Alliance of Ireland, NAI.

### 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 by voluntary organisations to people living with neurological conditions.

**How can I find out more?**  
For further information contact:  
Magdalen Rogers, NAI [mrogers@nai.ie](mailto:mrogers@nai.ie)  
Marie Lynch, DFI [marie Lynch@disability-federation.ie](mailto:marie Lynch@disability-federation.ie)

**CALL FOR  
PRIORITY  
ACTION ON  
NEUROLOGICAL  
CARE IN IRELAND  
IN THE FIGHT  
AGAINST  
COVID-19**



**THE IMPACT OF  
COVID 19 ON ACCESS TO  
SERVICES FOR PEOPLE  
WITH NEUROLOGICAL  
CONDITIONS  
AND  
THE CAPACITY OF THESE  
SERVICES TO RESPOND TO  
DEMAND POST-COVID19**

SUBMISSION TO THE JOINT  
OIREACTHAS COMMITTEE ON HEALTH

MARCH 2021

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

JULY 2021

# PROGRESS ON STRATEGIC OBJECTIVES DURING 2022

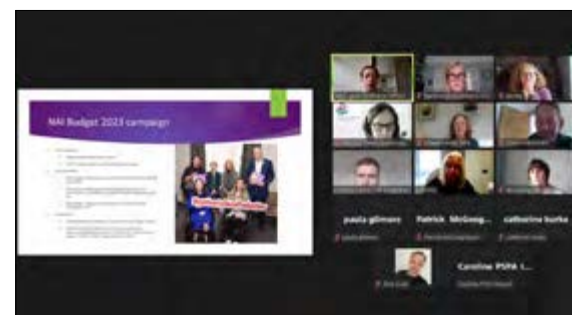
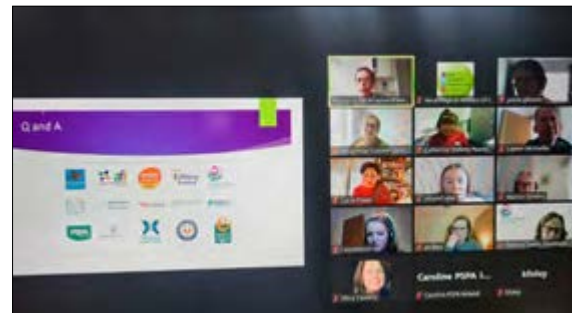
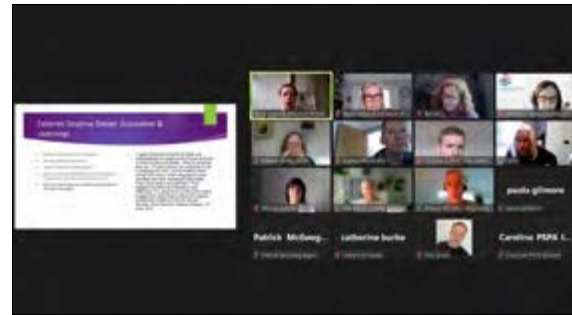
## MEMBER SUPPORT

The NAI Advocacy Campaigns provided an important and effective voice for our member organisations throughout 2022 with over two thirds of our membership signing up as Campaign Partners for the second of our Patients Deserve Better campaigns launched in November 2022.

Throughout the year, we continued to reach out to our members through joint advocacy events, monthly news letters, bi annual network meetings, research workshops and information webinars.

In total, we organised 16 advocacy, information and research and networking events for our member organisations during 2022: that's more than one member's event for every month of the year.

In March 2022 we submitted our final report to the Wheel on our 2021-2022 Training Links initiative where we delivered specialist training courses to 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.



# PROGRESS ON STRATEGIC OBJECTIVES DURING 2022

## MEMBER SUPPORT

While the many demands on members have led us to maximise the use of online communications as a way of increasing and extending our ability to stay in touch with our member organisations, our face to face advocacy and networking events in the AV room Leinster House (June 2022) and Buswells hotel (September) provided a very welcome opportunity for members to come together in person.



# PROGRESS ON STRATEGIC OBJECTIVES DURING 2022

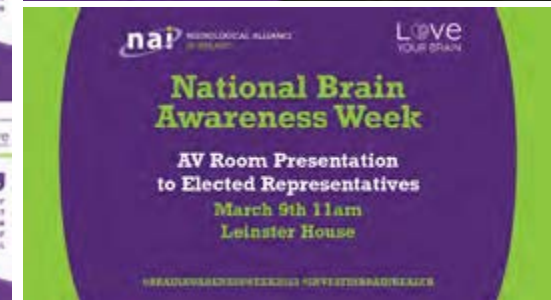
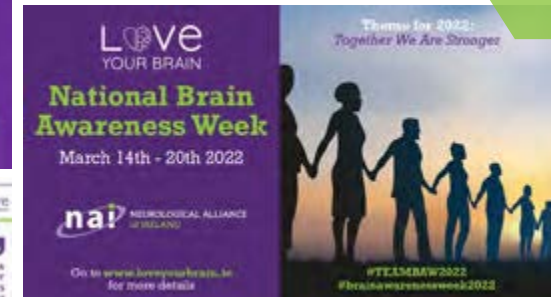
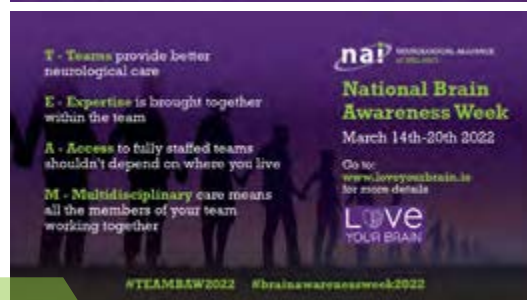
## COMMUNICATIONS

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 2022 we continued to focus on developing and strengthening the profile of NAI on social media. This involved utilising social media as an effective tool to support our advocacy campaigns, as a platform for our own awareness initiatives such as Brain

Awareness Week and World Brain Day and in responding proactively to support the campaigns and activities of our member organisations. Our aim was to ensure a constant online presence throughout the year, sharing relevant content for key awareness dates in the calendar.







# PROGRESS ON STRATEGIC OBJECTIVES DURING 2022

## ORGANISATIONAL DEVELOPMENT AND SUSTAINABILITY

Our focus throughout 2022 was in continuing to realise the goals and targets outlined in our three year Strategic Plan 2020-2022 as well as commencing the development of our next Strategic Plan.

Despite the COVID19 pandemic and significant additional commitments to adapt and respond to its challenges, the commitment of the board, staff and membership ensured that the key strategic goals of the 2020-2022 have been realised. Over the past three years the organisation has considerably enhanced its profile and reputation as an effective advocacy umbrella, strengthened its relationships and engagement with its members and other stakeholders and harnessed social media and online platforms to increase its communications and outreach activities.

Early in the year the Board agreed a workplan to prepare the next Strategic Plan which will see a comprehensive engagement with members and other key stakeholders.

The Board of NAI agree a comprehensive workplan each year to ensure ongoing adherence to the Governance Code, including a comprehensive scheduled review of existing policies and procedures.

In 2022, the NAI successfully applied for three year funding through the Department of Rural and Community Development Scheme to Support National Organisations (SSNO). Competition for funding under the 2022-2025 funding round was high with 230 applicants and only 81 successful organisations. The NAI submitted an ambitious work programme over the next three years: focusing on strengthened community and voluntary sector engagement, research and policy and organisational development and increased representation/advocacy on neurodisability issues.



# 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 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 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 2022

## Income and Expenditure for Year Ended 31st December 2022

	2022	2021
	€	€
Income	163,477	152,968
Expenditure	(154,648)	(151,691)
Surplus for the Financial Year	8,829	<u>1,277</u>
Total Comprehensive Income	8,829	<u>1,277</u>

## Statement of Financial Activities for the Year Ended 31st December 2022 (continued) Balance Sheet as at 31st December 2022

	2022	2021
	€	€
FIXED ASSETS		
Tangible Assets	<u>785</u>	<u>325</u>
CURRENT ASSETS		
Debtors	764	365
Cash at bank in hand	<u>156,816</u>	<u>124,914</u>
	<u>157,580</u>	<u>125,279</u>
CREDITORS (amount falling due within one year)	<u>(57,225)</u>	<u>(33,323)</u>
NET CURRENT ASSETS	100,325	91,956
TOTAL ASSETS LESS CURRENT LIABILITIES	101,110	92,281
RESERVES (Income and Expenditure Account )	<u>101,110</u>	<u>92,281</u>
MEMBERS FUNDS	<u>101,110</u>	<u>92,281</u>

*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 2022)*

Chair: Tom Scott

Vice Chair: Pascal Derrien

Treasurer: Grainne Fogarty

Gillian Murphy: Enable Ireland

Jimmy Smyth: JKS  
communications

Catherine Lacey: Acquired Brain  
Injury Ireland

Professor Niall Pender:  
Headway Ireland

Dr Kevin Foy: Consultant  
Neuropsychiatrist, Bloomfield  
Health Services

Tara Smith: Epilepsy Ireland

Alison Cotter: 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, with whose support we were able to deliver a wide range of activities and initiatives in 2022.



# 2022 A BUSY YEAR FOR OUR MEMBERS



**Chronic Pain Ireland**

**PAIN AWARENESS MONTH**  
01-30th September

2022 Theme  
**Inspiring Pain Freedom**

More Information  
[www.chronicpain.ie](http://www.chronicpain.ie) #PainAwarenessMonth



**Official Launch**  
Friday 22nd July - World Brain Day  
From 5.30pm @ Malloway House

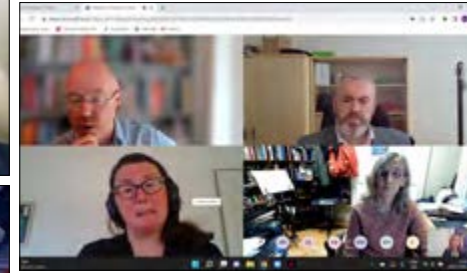


**1 in 5 of us**  
ARE AFFECTED BY A NEUROLOGICAL CONDITION

**Alzheimer's**  
**TEA day** MAY 5th 2022



**Better Together Sessions**  
Medical Supports



**SPINA BIFIDA & HYDROCEPHALUS AWARENESS WEEK 2022**  
#SEEMYABILITY  
[WWW.SBHLIE/AWARENESSWEEK](http://WWW.SBHLIE/AWARENESSWEEK)





NEUROLOGICAL ALLIANCE  
of IRELAND

Neurological Alliance of Ireland  
Coleraine House,  
Coleraine Street,  
Dublin 7  
CHY 14889

[www.nai.ie](http://www.nai.ie)  
01 8724120

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