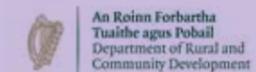




ANNUAL REPORT 2019



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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 Strategic Objectives

Based on the priorities identified by its member organisations, the NAI core objectives for the period of the 2017-2019 Strategic Plan are as follows:

- To advocate for better services and supports for people living with neurological conditions so they may experience and enjoy life
- To expand awareness of the reality of living with neurological conditions
- To strengthen our organisational capacity and sustainability to achieve our purpose as an alliance

Governance

NAI is committed to achieving and maintaining the highest standards of governance in line with the Charities Governance Code published by the Charity Regulator.

Neurological Alliance of Ireland
Coleraine House
Coleraine Street
Dublin 7
Tel: 01 8724120
mrogers@nai.ie
www.nai.ie



Neurological Alliance of Ireland (NAI)



@naiireland

Charity Number: CHY 14889
Neurological Alliance of Ireland is
a Company Limited by Guarantee.
Registered in Dublin, company
registration number 366603

Auditors
Williams Merrigan
22 Clanwilliam Square
Grand Canal Quay
Dublin 2

List of NAI member organisation

Acquired Brain injury Ireland

Alzheimer Society of Ireland

An Saol

Aphasia Ireland

Ataxia Ireland

Aware

Bloomfield Health Services

Cheshire Ireland

Chronic Pain Ireland

Dystonia Ireland

Enable Ireland

Epilepsy Ireland

Headway

Huntington's Disease Association of Ireland

Irish Heart Foundation

Irish Hospice Foundation

Irish Motor Neurone Disease Association

Migraine Association of Ireland

Move4Parkinsons

Multiple Sclerosis Society of Ireland

Muscular Dystrophy Ireland

National Council for the Blind

Neurofibromatosis Association of Ireland

North West MS Therapy Centre

Parkinson's Association of Ireland

Polio Survivors Ireland

PSPA Ireland

Syringomyelia Support group of Ireland

Spinal Injuries Ireland

Spina Bifida Hydrocephalus Ireland

The Rehab Group

Associate Members

Brain Tumour Ireland

Syringomyelia Chiara Malformation Support Group

*Tom Scott,
Chair Of NAI*



Neurological Conditions in Ireland

Neurological conditions are those affecting the brain and spinal cord. They represent the leading cause of disability and the second leading cause of death worldwide. Over 800,000 people in Ireland live with a neurological condition with many experiencing significant and challenging impacts on almost every aspect of their lives as a result of their condition. As populations age across the developed world, more people will develop neurodegenerative conditions and, thanks to advances in surgery and treatment, more people will live with acquired disabling neurological conditions into the future. The World Health Organisation has recognised that neurological conditions represent the greatest challenge to public health systems in developed countries worldwide. Ireland is extremely poorly prepared to meet this challenge, both now and into the future. Underinvestment in the development of services means that most people living with neurological

conditions in this country will struggle to get the level and type of care taken for granted in other developed countries.

The Neurological Alliance of Ireland, as the only umbrella organisation dedicated to representing people with neurological conditions, has a critical responsibility to continue to highlight and address this situation through its ongoing work to promote the development of services and supports for all those affected by neurological conditions.

Neurological Alliance of Ireland

The Neurological Alliance of Ireland is the national umbrella body for over thirty not for profit organisations working with people with neurological conditions and their families. It works to promote the development of services and supports for people with neurological conditions in Ireland through advocacy, policy development, awareness and research.

Foreword

After another extremely busy year for the Neurological Alliance of Ireland, we are delighted to bring you this overview of the organisation's activities in 2019.

While this year saw the umbrella achieve a long-standing goal with the publication of the long awaited implementation plan for the neurorehabilitation strategy, it also challenged us to respond to continued lack of real investment in neurological care, despite years of economic prosperity and recovery. We therefore put significant efforts into developing a support base among political representatives and working together with our members to develop clear messaging in the lead up to a likely general election next year.

We also focused in 2019 on mobilising our community of champions, which includes not just our member groups but increasingly working with dedicated patient advocates, clinicians and researchers to support and promote our messages.

We were delighted with the response to our new revitalised campaign for Brain Awareness Week, for the first time providing all our stakeholders with a common platform to raise awareness and increase the profile of neurological conditions in Ireland.

Our identity, our purpose, and our strength comes from the organisations we represent and who continually trust and support us to be a voice for their issues and concerns. Our primary responsibility must be to continually engage with our membership to inform our priorities and our future direction.

Our new Board worked within a demanding timeframe to develop a comprehensive strategic plan for the next three years which will put forward new ways of working and engaging with our stakeholders to address the challenges we face going forward. We look forward to sharing the plan with all our stakeholders early in the New Year.

We hope that you enjoy this report and look forward to your continued support.

*Mags Rogers,
Executive Director of NAI*



Moving Forward in 2019 Advocacy

One of the core aims of the NAI advocacy campaign for action on neurorehabilitation, “We Need Our Heads Examined” was realised in late 2017 when the HSE agreed to develop an implementation framework for the Neurorehabilitation Strategy and established a national steering group.

Our key advocacy goal in 2019 was ensuring the plan was published, following comprehensive engagement as part of the National Strategy Group throughout 2018. The resulting three-year implementation framework, 2019-2022 provides an important focus for our advocacy efforts as we seek to monitor progress and secure investment to support implementation over the three year timeframe. Another key goal of the 2017-2019

Strategic Plan was securing an opportunity to appear before the Joint Oireachtas Committee on Health in relation to neurology and neurorehabilitation services. This hearing took place in May 2019, with the Neurological Alliance outlining the extent of service gaps and underinvestment and outlining initiatives to begin to address these problems.

NAI developed a Voter Card and contacted all candidates in the lead up to the elections to the European Parliament in May 2019. This provided an important opportunity to work with the European Federation of Neurological Associations around agreed messaging and campaigning, which culminated in a joint event with EFNA for World Brain Day in Dublin on July 22nd 2019.

Love YOUR BRAIN

European Parliament Election Candidates: Show your Support for People with Neurological Conditions

Neurological conditions include stroke, epilepsy, acquired brain injury, multiple sclerosis and Parkinson's disease as well as rare and genetic conditions. Neurological conditions affect 220 million Europeans including 800,000* people in Ireland.

www.nai.ie #loveyourbrain2019

The Neurological Alliance of Ireland are calling on all candidates for the upcoming European parliament elections to agree to the following:

- I will support the aims and objectives of the MEP interest group on Brain, Mind & Pain
- I will work at EU level to increase awareness of neurological conditions as a major public health and social care issue
- I will work at EU level to ensure equitable access to treatment, services and support for people with neurological conditions

* World of Dementia: MEP Interest Group on Brain, Mind & Pain (2018)
* Strategic Review of Neurology and Neurophysiology Services (SRN) Health Services Executive (HSE), report for the National Strategic Office

naⁱ NEUROLOGICAL ALLIANCE OF IRELAND

WORLD BRAIN DAY
July 22, 2019

Take the opportunity to meet with Elected Representatives, Patient Experts and Advocacy Organisations

MONDAY 22 JULY 2019
11am to 12:00pm
Burrells Hotel, Dublin

For full details and to register, go to: <https://na.ie/2019WBDA>

ON WORLD BRAIN DAY HELP US MAKE NEUROLOGICAL CARE A PRIORITY IN IRELAND AND EUROPE

#WorldBrainDay #BrainLifeGoals

Kindly supported by: Biogen, Boston Scientific, IPSEN, MERCK, NOVARTIS

naⁱ NEUROLOGICAL ALLIANCE OF IRELAND

NEUROLOGICAL ALLIANCE OF IRELAND PRE BUDGET SUBMISSION 2020

NAI PRE BUDGET ASKS

- €4.5m investment in neurorehabilitation services
- €2m investment in neurology services
- Protect vital services provided by voluntary organisations

NAI IS SUPPORTING CALLS FOR INVESTMENT IN

- Stroke services €7.7m
- Epilepsy Services €1.13m
- Dementia Services €17.9m
- Home care €110m
- MS Care Centre €600,000

Over 21,000 Irish people are waiting to see a neurologist, waiting times continue to increase

NO new investment in community neurorehabilitation services 8 years on from publication of National Neurorehabilitation Strategy

Successive cuts are threatening vital services provided by voluntary organisations

READ OUR FULL PRE BUDGET SUBMISSION AT NAL.IE

The Neurological Alliance of Ireland is the National Coalition for Neurological Care, representing over 30 voluntary organisations working with people with neurological conditions and their families.

Contact Us:
na.ie | [@naireland](https://twitter.com/naireland) | facebook.com/naireland | 01 8724120

naⁱ is a registered charity under the Charities Act 2009. Registered office: 100, North Circular Road, Dublin 10. Tel: 01 8724120. Email: info@naireland.ie

naⁱ NEUROLOGICAL ALLIANCE OF IRELAND

#BUDGET 2020

800,000 Irish people are living with neurological conditions including stroke, dementia, epilepsy, acquired brain injury, multiple sclerosis as well as rare and genetic conditions

PERFORMANCE REPORT FOR THE CURRENT GOVERNMENT

- ~~Outpatient waiting lists to see a neurologist now stand at over 20,000, the highest ever~~
- ~~No investment in community neurorehabilitation despite publishing an implementation framework for the National Neurorehabilitation Strategy~~
- ~~Unacceptable delays for access to new medications for people with neurological conditions~~
- ~~Continued lack of investment in community supports for people with dementia~~
- ~~Promised National Stroke Strategy not yet delivered~~
- ~~Successive cuts to neurological charities are threatening vital services~~

The Neurological Alliance of Ireland is the national coalition for neurological care, representing over 30 organisations working with people with neurological conditions and their families.

Contact Us:
na.ie | [@naireland](https://twitter.com/naireland) | facebook.com/naireland | 01 8724120



World Brain Day 2019

NAI used the World Brain Day event in Buswells Hotel to launch its Government Report Card on Neurological Care, highlighting the failure to invest in neurology and neurorehabilitation services, as well as delays in implementing policy in relation to dementia and stroke services. The event also saw the launch of our 2020 pre-budget submission. With the increased likelihood of a

general election in 2020, preparations began in 2019 to brief current elected representatives and design materials for a forthcoming pre-election campaign. Individual meetings took place between NAI and the health spokespeople of all the main political opposition parties as well as contacts in the current administration. Meetings also took place with the Clinical Leads of the Rehabilitation Medicine and Neurology Programmes in 2019. Work had begun on the development of an election manifesto in late 2019 in collaboration with the Board and wider membership of the organisation.



Key to achieving NAI objectives is engagement with the clinical and research communities as joint advocates for the needs of people with neurological conditions and their families. In 2019, NAI continued to represent its membership on the Board of Futureneuro, an SFI centre dedicated to neuroscience research and later in the year the umbrella was invited to join the Board of the Dublin Neurological Institute. Both appointments represent important opportunities for NAI to promote the involvement of patient organisations in both research and clinical service provision going forward.

The publication of the Slaintecare plan in 2017 introduced the most ambitious and far reaching proposals for reform of the health system in Ireland in the twenty year history of the Neurological Alliance. The publication of the Action Plan and the establishment of the implementation office in 2019 introduced an urgent need for the NAI to position neurological care within the context of Slaintecare. In 2019, planning commenced for an event and subsequent report in early 2020 which will focus on the implications of Slaintecare for neurological care services.

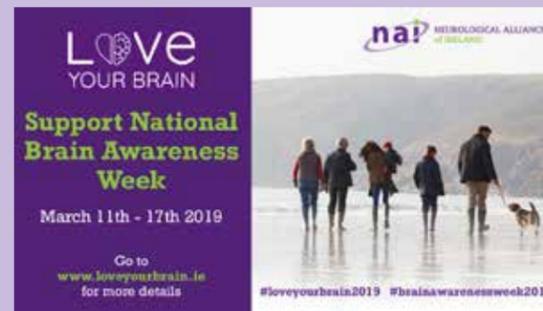


Moving Forward in 2019 Expanding Awareness

National Brain Awareness Week each March represents our key platform for raising awareness of neurological conditions and their impact.

NAI carried out an extensive body of work in 2018 to engage with stakeholders across patient organisations, research institutions and other groups in order to design and deliver a vibrant collaborative campaign around brain awareness. The resulting initiative “Love Your Brain” saw over twenty partner groups coming together to support an awareness campaign around the impact of brain disease, promoting brain health and supporting investment in brain research.

Brain Awareness Week 2019 saw a transformation in the NAI’s annual awareness initiative, with the launch



of a new website and branding, as well as a promotional video by Irish actor Michael Fassbender.

The impact of the week exceeded all expectations and targets as is seen summarised in the image on the right.

Brain Awareness Week 2020 will see new partners coming on Board and a nationwide calendar of events as well as the launch of a series of videos following our successful application to the European Federation of Neurological Associations #BrainLifeGoals project.



Love Your Brain is an awareness campaign developed by the Neurological Alliance of Ireland and its partner organisations to coincide with National Brain Awareness Week

RAISING AWARENESS OF BRAIN CONDITIONS

BRAIN RESEARCH



BRAIN HEALTH



Internationally renowned Irish actor **Michael Fassbender** supports the Love Your Brain campaign and National Brain Awareness Week. Check out his video of support at loveyourbrain.ie

BRAIN AWARENESS WEEK 2019 'THE IMPACT'

- The new dedicated website, loveyourbrain.ie had over **1,500** visitors during Brain Awareness Week
- The Love Your Brain video series, 'In Their Own Word' reached over **11,000** people
- Both #loveyourbrain2019 and #brainawarenessweek2019 **trended during the week**
- Our Facebook posts reached over **30,000** people
- Our Twitter posts were retweeted **650** times and had over **130,000** impressions
- Our partners organised over **60** events nationwide
- We had **coverage** in national and local print and broadcast media throughout Brain Awareness Week

Brain Awareness Week 2019 Launch



Moving Forward in 2019

Strengthening our organisational capacity and sustainability to achieve our purpose as an alliance

Funding and Sustainability

The NAI continues to be reliant on core funding through the Scheme to Support National Organisations delivered by the Department of Rural and Community Affairs and administered by Pobal. NAI successfully reapplied for the scheme in February 2019, securing funding for both staff posts until June 2022.

Unfortunately NAI was not awarded indirect costs in its application, a factor which will require the organisation to curtail some of its activities over the coming two years. Every effort continues to be made by the Board and staff of the organisation to identify and secure alternative sources of funding, including through engagement with existing and new funding partners.

Strategic Planning

The AGM in November 2019 saw the almost complete replacement of the Board at one time with only one long-standing Board member, Patrick Little of the Migraine

Association, remaining in place. We are indebted to Pat for providing important context and experience to facilitate this challenging transition. The existing strategic plan came to an end in 2019 and the new Board commenced a demanding programme of activity in order to develop a new strategic plan for the next three years. An external facilitator was recruited to work with the Board and the wider membership across the second half of 2019.

A comprehensive and challenging review process led us to examine what we have achieved as an organisation, what we need to do in the future and, importantly, how we engage effectively with our members and other stakeholders to deliver on those objectives. We look forward to publishing the plan early in the coming year as well as the launch of a series of videos following our successful application to the European Federation of Neurological Associations #BrainLifeGoals project.



Mags Rogers,
Executive Director of NAI

Our People Board of Directors

(as at 31st December 2019)

Chair: Tom Scott

Acting Vice Chair: Tara Smith

Treasurer: Barry McGinn

Sonya Gallagher: Headway

Patrick Little: Migraine Association

Jimmy Smyth: JKS communications

Catherine Lacey: Acquired Brain Injury Ireland

Niall Pender: Senior Clinical Neuropsychologist Beaumont Hospital

Kieran O Driscoll: Consultant Neuropsychiatrist, Bloomfield Health Services

Emma Rogan: Person with a Neurological Condition

Aoife Kirwan: MS Ireland

Patrick Little Migraine Association of Ireland (resigned 2019)

(Our sincere thanks to Pat, who was a long-serving board member of NAI and guided the NAI through an important transition to a New Board 2018/2019)

NAI Staff

Magdalen Rogers: NAI Executive Director

Sinéad Bradley: Communications Officer.



Sinéad Bradley
Communications Officer

NAI Financial Report 2019

Profit and Loss Account for Year Ended 31 December 2019

	2019	2018
	€	€
Turnover	-	<u>7,700</u>
Gross Profit	-	7,700
Administrative Expenses	(103,973)	(108,745)
Other operating income	104,341	98,120
Operating Profit	<u>368</u>	<u>(2,925)</u>
Profit on ordinary activities before taxation	<u>368</u>	<u>(2,925)</u>
Tax on Profit on ordinary activities	-	-
Profit for Financial Year	<u>368</u>	<u>(2,925)</u>
Retained earnings at start of financial year	<u>90,477</u>	<u>93,402</u>
Retained earnings at end of financial year	<u>90,845</u>	<u>90,477</u>

Statement of Financial Activities for the Year Ended 31st December 2019 (continued) Balance Sheet as at 31st December 2019

	2019	2018
	€	€
FIXED ASSETS		
Tangible Assets	455	455
CURRENT ASSETS		
Debtors	365	365
Cash at bank in hand	<u>110,822</u>	<u>101,369</u>
	111,187	101,734
CREDITORS		
(amount falling due within one year)	(20,797)	(11,257)
NET CURRENT ASSETS	90,390	90,477
TOTAL ASSETS LESS CURRENT LIABILITIES	<u>90,845</u>	<u>90,477</u>
Net Assets	90,845	90,477
Capital Assets and reserves (Profit and Loss Account)	90,845	90,477
MEMBERS FUNDS	<u>90,845</u>	<u>90,477</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 June 2019 to June 2022.

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



2019 A Busy Year for Our Members

As a network of over thirty not for profit organisations, NAI are delighted to support and promote the vital role of not for profit organisations in meeting the needs of people with neurological conditions and their families.

