

ANNUAL
REPORT
2018

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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

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.

Foreword from NAI Chair and Executive Director



*Tom Scott,
NAI Chair*

We are delighted to bring you this overview of the organisation's activities in 2018, another extremely busy year for the organisation.

As an umbrella organisation, our key focus must be on delivering a strong and effective voice for our members. In 2018, we concentrated on improving our outreach to our members to enable them to play an active role in the work of NAI, providing opportunities and platforms for them to work together around advocacy and awareness raising.

The objectives of our campaign for neurorehabilitation services included the development of an implementation framework for the National Neurorehabilitation Strategy, as outlined in the current Programme for Government. Throughout 2018, we focused on co-ordinating the input and engagement of NAI members in this process, developing a model for community neurorehabilitation and ensuring that the plan submitted to the Minister in June of this year included a strong focus on the role of voluntary service providers in the delivery of supports to people with neurological conditions and their families.



*Mags Rogers,
NAI Executive Director*

One of our key commitments for 2018 was to give the same opportunity for members to work together to advocate for neurology services and therefore we launched our Invest in Neurology campaign in March of this year. Communication is key to successful advocacy and in 2018 we concentrated on developing an active presence on social media and providing opportunities for members to share in ongoing engagement with public representatives.

We aimed to provide a strong collective platform for our members for Brain Awareness Week, our main awareness raising initiative. For the first time in 2018, NAI designed and co-ordinated a dedicated awareness campaign, Altered Lives, to provide a common identity and focus for our members around National Awareness Week. NAI also invested considerable time and commitment in the second half of the year to creating an expanded and reenergised awareness initiative for Brain Awareness Week 2019, and we look forward to working with all our partners in a new-look Brain Awareness Week in the year ahead.

The value of effective umbrella organisations lies in their relationships, with their members, their staff and other stakeholders. In 2018, NAI continued to work with other patient organisations, policy makers, clinicians, industry and researchers to increase the profile of neurological conditions across Irish society. The Board of NAI continues to play a vital role in ensuring that the organisation adheres to the highest standards of governance and professionalism as well as providing the direction and expertise to enable the NAI to respond to its challenges.

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

Neurological Conditions in Ireland

Neurological conditions are those affecting the brain and spinal cord. 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. The NAI works to promote the development of services and supports for people with neurological conditions in Ireland through advocacy, policy development, awareness and research.

List of NAI Member Organisations

- | | |
|--|--|
| <i>Acquired Brain injury Ireland</i> | <i>Neurofibromatosis Association of Ireland</i> |
| <i>Alzheimer Society of Ireland</i> | <i>North West MS Therapy Centre</i> |
| <i>An Saol</i> | <i>Parkinson's Association of Ireland</i> |
| <i>Aphasia Ireland</i> | <i>Polio Survivors Ireland</i> |
| <i>Ataxia Ireland</i> | <i>PSPA Ireland</i> |
| <i>Aware</i> | <i>Syringomyelia Support group of Ireland</i> |
| <i>Bloomfield Health Services</i> | <i>Spinal Injuries Ireland</i> |
| <i>Cheshire Ireland</i> | <i>Spina Bifida Hydrocephalus Ireland</i> |
| <i>Chronic Pain Ireland</i> | <i>The Rehab Group</i> |
| <i>Dystonia Ireland</i> | |
| <i>Enable Ireland</i> | |
| <i>Epilepsy Ireland</i> | |
| <i>Headway</i> | |
| <i>Huntington's Disease Association of Ireland</i> | |
| <i>Irish Heart Foundation</i> | <i>Associate Members</i> |
| <i>Irish Hospice Foundation</i> | <i>Irish Association of Speech and Language Therapists</i> |
| <i>Irish Motor Neurone Disease Association</i> | <i>Myaware</i> |
| <i>Migraine Association of Ireland</i> | |
| <i>Move4Parkinsons</i> | |
| <i>Multiple Sclerosis Society of Ireland</i> | |
| <i>Muscular Dystrophy Ireland</i> | |

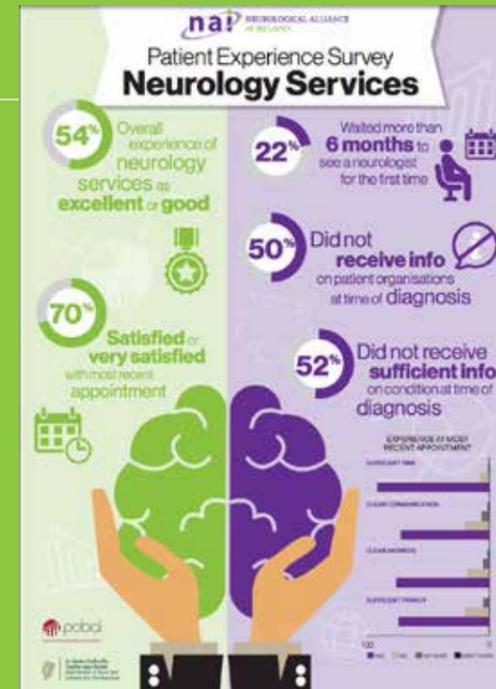
Moving Forward in 2018:

Advocacy

One of the key 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. The focus of NAI for the first half of 2018 was in ensuring a strong role for not for profit organisations in shaping this framework. NAI worked together with Acquired Brain Injury Ireland (representing voluntary service providers) in order to put forward a model of community neurorehabilitation services that involves specialist providers working closely with primary care and other services in the community to ensure an integrated response to individuals with neurorehabilitation needs. NAI organised a consultation event with member organisations in April 2018 and worked closely with the Board subcommittee on neurorehabilitation to provide comprehensive input to all aspects of the implementation framework. The final draft was submitted to the Minister for Health in July 2018.

An important commitment for NAI for 2018 was to bring a similar focus and energy to advocating for investment in neurology services. NAI therefore launched its “Invest In Neurology” campaign in March 2018. NAI organised a series of one to one meetings with elected representatives and held a presentation in the AV Room Leinster House on June 20th. Professor of Neurology Orla Hardiman together with Counsellor Mark Ward spoke to over forty elected representatives, highlighting the impact of long waiting lists and critical understaffing on people living with neurological conditions.

Professor Hardiman was appointed Clinical Lead with the National Neurology Programme in late 2018 and met with NAI member organisations in November to outline her commitment to working closely with the NAI in her new role.



NAI launched the findings of the first Irish patient experience survey of neurology services in December 2018. The research, carried out in collaboration with the Neurology Clinical Programme, highlighted the increasing pressure on neurology services, with patients reporting concern at longer periods between appointments and for diagnostic testing. An important recommendation from the report called for information to patient organisations to be made available in neurology clinics, following the finding that 50% of patients did not receive information on these supports at the time of diagnosis even though they would have welcomed this information at the time.

December 2018 also saw NAI issue a call for responses to its nationwide survey on Living with a Neurological Condition in Ireland. The comprehensive survey, examining a wide range of aspects of living with a neurological condition, was developed through consultation with NAI members and the findings will be launched during Brain Awareness Week 2019.



Throughout the year, NAI continued its work to inform and influence the healthcare agenda in relation to the needs of people with neurological conditions, providing input into policy platforms and initiatives on areas including home care, vocational rehabilitation, mental health needs and awareness of neurodisability.



Moving Forward in 2018:

Expanding Awareness of the Reality of Living with Neurological Conditions

Our national Brain Awareness Week each March represents a key platform for raising awareness of neurological conditions and their impact.

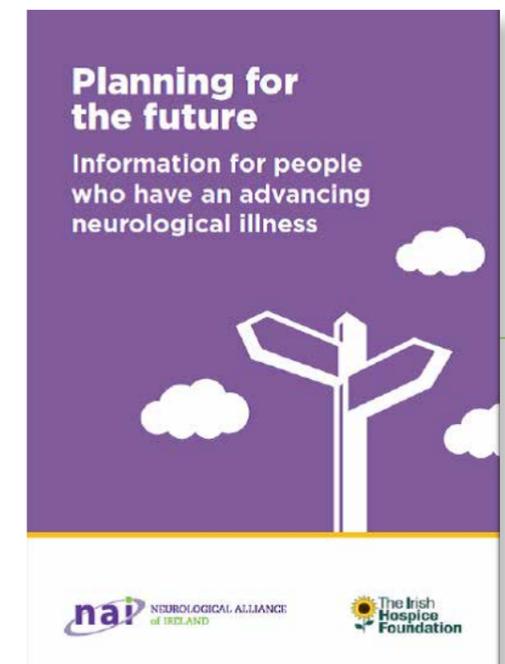
Altered Lives

Brain Awareness Week 2018 was one of the busiest to date for NAI, with the launch of its first dedicated social media campaign to raise awareness of the impact of neurological conditions. Altered Lives provided a platform for people with neurological conditions, patient organisations and other stakeholders in the lead up to and during National Brain Awareness Week March with NAI co-ordinating communications throughout the week through its social media and online calendar of events. NAI developed a fully-equipped partners pack with guidelines and sample communications as well as a comprehensive set of materials including flyers, banners and images for social media.

The NAI keynote conference for Brain Awareness Week in association with the Irish Brain Council saw record attendance necessitating a move to a larger venue in the Royal College of Physicians, Dublin. The event "Research and Healthcare Responses to the Challenge of Brain Conditions in Ireland" was opened by Professor Mark Ferguson, Director of Science Foundation Ireland. The event focused on the increasing collaboration between researchers and patient organisations in Ireland, with many of the poster presentations featuring examples of collaborative research, facilitated and often funded with the support of patient groups.



The week also saw the launch by NAI and the Irish Hospice Foundation of a joint information guide on living with progressive neurological disease. Developed in collaboration with NAI members, the guide provides a vital tool for individuals and their families in coming to terms with the challenge of advancing neurological illness.



Planning for Brain Awareness Week 2019 commenced in June with a series of meetings aiming to increase the number of groups taking part and engage new audiences. By the end of the year, twenty three organisations, including new partners, had come on board and we look forward to a fresh exciting new approach to Brain Awareness Week in the coming year.

Brain Awareness Week 2018:

Events Nationwide

Epilepsy Ireland

Support group in Ballina Family Resource Centre, Mayo

Epilepsy Ireland

Buccal Midazolam Information Session, Donegal

Epilepsy Ireland

Partners & Carers Support Group Gresham Hotel, Dublin

Information and Awareness Event

Tullamore
Speakers Include: Citizens Information Centre – Tom Walsh: Entitlements Dr. Brian McClean – Clinical Psychologist Acquired Brain Injury Ireland Personal Stories from People Living with a Neurological Condition Fiona Colgan – Mental Health Ireland “5 ways to Wellbeing”

Epilepsy Ireland

People with Epilepsy Information & Support Group for Adults Charleville Park Hotel, Cork

Epilepsy Ireland

Awareness & Administration of Buccal Midazolam Information Evening for Parents, Family Members & Carers of Children with Epilepsy Manor West Hotel, Tralee, Co. Kerry

Epilepsy Ireland

Adults STEPS Programme Carmelite Community Centre, Dublin 2

Acquired Brain Injury Ireland

Bake For Brain Injury Nationwide

Headway

Art Exhibition: The Best is Yet to Come Filmbase, Temple Bar, Dublin 2

Parkinson's Association of Ireland @ Dublin Brain Bank

Table Quiz Ruin Bar, Tara Street, Dublin

Epilepsy Ireland

Outreach Sessions Charleville Park Hotel, Ross House, Mallow, Co. Cork

Headway

Information Stand University Hospital Limerick

Headway

Family/Carer Information Evening Headway Limerick Offices

Epilepsy Ireland

Outreach Sessions Roscommon, Cuan Aire, Castlerea

Epilepsy Ireland

Parents Buccal Midazolam Information Session Maritime Hotel, Bantry, Cork

Epilepsy Ireland

Outreach Sessions Bantry, Co. Cork

Epilepsy Ireland

Support Group Imperial Hotel, Eyre Square, Galway

Epilepsy Ireland

Support Group Roscommon, Cuan Aire, Castlerea

Epilepsy Ireland

Support Group for Parents of Children with Epilepsy Mallow, Co. Cork

Epilepsy Ireland

Support Group Nurse Talk with Yvonne Owen Castleblaney, Monaghan

Irish Hospice Foundation @ The NAI

Launch of Joint NAI & Irish Hospice Foundation Guide: Planning for the Future with a Neurological Illness, Dublin

MS Ireland

MABS The Arboretum, Leighlinbridge, Co. Carlow

Irish Heart Foundation

Stroke Support Group Kildare

Irish Heart Foundation

Stroke Support Group Dublin

Irish Heart Foundation

Stroke Support Group Monaghan

Neurological Alliance of Ireland

Research & Healthcare Responses to the Challenge of Brain Conditions Royal College of Physicians, Dublin

PSPA

Dublin Carers Meeting Macro Community Centre

Headway

Presentation on Brain Injury Awareness & Headway Services Limerick Institute of Technology

Epilepsy Ireland

Parents STEPS Programme Carmelite Community Centre, Dublin

Epilepsy Ireland

Parent Buccal Midazolam Information Session Westside Resource Centre, Galway

Migraine Association of Ireland

Information Seminar Royal Hotel, Bray, Co. Wicklow

MS Ireland

Coffee Morning Cranog Centre, Castleblaney

MS Ireland

Newly Diagnosed Meet Up Kingsley Hotel, Cork

Migraine Association of Ireland

Hormonal Migraine In Women Seminar Clayton Hotel, Ballsbridge, Dublin

Speech @ Language Therapy Department

Information Stand & Bake Sale University of Limerick

Irish heart Foundation

Stroke Support Group Dubin

Headway

Day Rehabilitation Centre Coffee Morning, Sandymount, Dublin 4

Irish Heart Foundation

Stroke Support Group Mullingar

Headway

Choir Singing for Brain Injury Awareness Heuston Station, Dublin

Headway

Information Stand Bank of Ireland, Limerick

Brain Tumour Ireland @ Royal College of Surgeons

Information Seminar Mercer Building, Dublin

Chronic Pain Ireland

2 Day Workshop on Self Management Sligo

Dementia @ Neurodegeneration Network Ireland

‘Brain Connections’: Outreach Event Neuroscience Centre, UCC

Headway

Fundraiser Cycle The Hub, Coonagh Cross, Limerick

Epilepsy Ireland

Information Stand Kerry University Hospital

Epilepsy Ireland

Information Seminar Charleville Centre, Tullamore

Epilepsy Ireland

Outreach Sessions Sligo

Epilepsy Ireland

Information Seminar Radisson Hotel, Limerick

Moving Forward in 2018:



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

Board Development

The Board undertook a number of projects in 2018 as part of its ongoing Board Development Programme

GDPR

NAI commissioned an external review of its data protection policies and procedures in advance of the introduction of GDPR legislation across Europe in May 2018 and updated and amended these in accordance with the requirements of the legislation and to promote best practice.

Capacity Review

A subgroup of the Board carried out a review of sustainability and capacity, identifying short and medium term recommendations including the development of an intern programme within NAI to support Brain Awareness Week.

Sustainability

The availability of core funding under the SSNO scheme (to June 2019) continues to be critical to the ongoing sustainability of the organisation. The NAI also acknowledges the support available for particular projects from industry partners in 2018. NAI continues to undertake careful fiscal management, including strict budgeting and diversification of its funding sources. At the end of 2018, the organisation maintained reserves of €90,477.



Our People

Board of Directors

(as at 31st December 2018)

Chair: Tom Scott

Vice Chair: Emma Rogan

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

Patrick Little: Migraine Association of Ireland

Tara Smith: Epilepsy Ireland

NAI Staff

Magdalen Rogers: NAI Executive Director

Sinead Bradley: Administration, Communications
and Events Officer

Mags Rogers



Sinead Bradley

NAI Financial Report 2018

Profit and Loss Account for Year Ended 31 December 2018

	2018	2017
	€	€
Turnover	7,700	8,400
Gross Profit	7,700	8,400
Administrative Expenses	(108,745)	(101,631)
Other operating income	98,120	103,555
Operating (Loss) Profit	(2,925)	10,324
(Loss) Profit on ordinary activities before taxation	(2,925)	10,324
Tax on Profit on ordinary activities	-	-
(Loss) Profit for Financial Year	(2,925)	10,324
Retained earnings at start of financial year	93,402	83,078
Retained earnings at end of financial year	90,477	93,402

Statement of Financial Activities for the Year Ended 31st December 2018

Balance Sheet as at 31st December 2018

	2018	2017
	€	€
FIXED ASSETS		
Tangible Assets	-	-
CURRENT ASSETS		
Debtors	365	365
Cash at bank in hand	101,369	104,632
	101,734	104,997
CREDITORS		
(amount falling due within one year)	(11,257)	(11,595)
NET CURRENT ASSETS	90,477	93,402
TOTAL ASSETS LESS CURRENT LIABILITIES	90,477	93,402
NET ASSETS	90,477	93,402
CAPITAL & RESERVES		
(Profit and Loss Account)	90,477	93,402
MEMBERS FUNDS	90,477	93,402

NAI is supported by a multi-annual funding programme through the Scheme to Support National Organisations, provided by the Department of Housing, Planning Community and Local Government and administered by Pobal. This scheme covers the period July 2016 to June 2019.

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

2018 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.

