

ANNUAL REPORT 2016

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



Neurological Alliance of Ireland (NAI)



@nai_ireland

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 2011 – 2016 Strategic Plan are as follows:

- *To advocate for the full range of high quality supports and services required by people with neurological conditions and their families at both national and local levels.*
- *To build the profile of NAI and support member organisations to raise awareness of neurological conditions and their impact on individuals and families.*
- *To create a network infrastructure for NAI members through which information, support, initiatives and resources might be shared.*
- *To ensure that NAI develops effective partnerships and working relationships with other organisations across the health and disability sector, including the statutory sector, so as to facilitate the achievement of its objectives.*
- *To make the NAI a sustainable organisation through securing ongoing core and project funds.*

Governance

NAI is committed to achieving and maintaining the highest standards of governance. NAI has achieved full compliance with the Code of Practice for Good Governance of Community, Voluntary and Charitable Organisations in Ireland (The Governance Code)

Contents

Foreword	2
Moving forward in 2016: Advocacy	5
Moving forward in 2016: Raising Awareness	7
Moving forward in 2016: Supporting Members	10
Moving forward in 2016: Collaborations	10
Moving forward in 2016: Sustainability	11
Our People	11
Financial Information	12
2016: A Busy Year for NAI Members	14

Foreword from NAI Chair and Executive Director

2016 was certainly one of the busiest years to date for NAI, when we launched a series of campaigns and published our landmark audit of neurology services, in collaboration with the Neurology Clinical Programme. It was a year which saw a reprieve, at least until 2019, in the funding crisis facing the organisation when NAI secured three year funding under the latest round of the SSNO funding scheme (Scheme to Support National Organisations) provided through the Department of Housing, Planning and Local Government and administered by Pobal. The receipt of this funding from June 2016 allowed NAI to concentrate at last on its core business and to put in place a planning process which will see the publication of a three-year Strategic Plan in 2017. Successive campaigns led by NAI in 2014 and 2015 for the restoration of SSNO funding and extension of bridging funding placed a significant demand on the time and resources of our tiny complement of staff but were ultimately successful in highlighting the critical importance of the scheme in sustaining the services and supports provided by our member organisations to people with neurological conditions and their families. We would like extend our deep thanks to all those who supported the NAI campaigns in relation to SSNO funding and we particularly acknowledge the dedication and commitment of our staff who have faced considerable uncertainty about their future over the past number of years.

2016 saw NAI place significant energy and resources into its campaigning and advocacy activities. Feedback from our members points to 2016 as a seminal year in terms of the strength and profile of NAI in its campaigning and advocacy activities.

The NAI campaign in advance of the general election launched in December 2015 following significant planning and preparation in consultation with members. The campaign “800,000 minds matter” included the publication of a manifesto as well as a briefing document on the importance of SSNO funding to neurological organisations. In advance of the launch of the “We Need Our Heads Examined” campaign later in 2016, the campaign leaflet was circulated as part of the NAI pre-election campaign. The launch of this campaign in June 2017 provided a vital platform to call for action on neuro-rehabilitation with the campaign securing significant media coverage and political support through a series of events organised in the second half of the year.

The commitment to increasing awareness of the neurological agenda through the development of policy submissions and reports, continued in 2016 with submissions and publications on neuro-rehabilitation, medical cards, future of healthcare, rare neurological conditions and development of a pre-budget submission.

NAI once again co-ordinated a very successful Brain Awareness Week in March which saw over forty events organised nationwide by our member organisations.

We warmly acknowledge the work of Ava Battles of MS Ireland who stepped down as Chair in October 2016 as required under the terms of our Constitution.

Our work would not be possible without the dedication and commitment of our members, our board and staff and all those who believe in the vision and mission of the NAI.

We hope that you enjoy this report and look forward to your continued support in 2017.



Shona Logan King



Mags Rogers

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

Moving Forward in 2016: Advocacy

Pre-Election Campaign "800,000 minds matter"

The NAI launched its pre-election campaign in December 2015 following significant consultation with members. The campaign included the publication of a manifesto as well as a briefing document on the importance of SSNO funding to neurological organisations. In advance of the launch of the "We Need Our Heads Examined" campaign later in 2016, the campaign leaflet was circulated as part of the NAI pre-election campaign. NAI carried out an extensive programme of contacting election candidates and securing their pledge on neurological issues. Over 60 pledges were secured with NAI following up with successfully elected candidates to remind them of their pledge of support for issues affecting people with neurological conditions over the term of the current Government. In addition, NAI and its members worked together to ensure a commitment to neuro-rehabilitation in the Programme for Government published in May 2016.

Co-ordinated NAI response to Draft Implementation Plan for Neuro-rehabilitation Strategy

NAI organised a series of workshops with member organisations in April 2016 in order to develop a comprehensive response to the publication of a draft implementation plan for the National Neuro-rehabilitation strategy. The workshops and subsequent submission developed by NAI provided an important platform for NAI members to respond to the long-awaited framework. A summary leaflet, reflecting the serious concerns of the umbrella rejecting the plan as unfit for purpose, was developed by the "We Need Our Heads Examined" campaign.

800,000 MINDS MATTER

PLEDGE YOUR SUPPORT FOR IRISH PEOPLE WITH NEUROLOGICAL CONDITIONS

I am asking you to pledge your support as an election candidate in my constituency for the 800,000 Irish people living with neurological conditions such as stroke, acquired brain injury, MS, epilepsy, migraine and dementia.

Ireland's neurological care services are critically underdeveloped which means that thousands of people nationwide face a constant struggle to get the level and type of care they need.

Visit nai.ie/go/campaign_centre to add your name to the list of candidates pledging their support.

Launch of "We Need Our Heads Examined" campaign

A group of NAI members came together in July 2015 to develop a campaign for action on neuro-rehabilitation services. The "We Need Our Heads Examined" campaign, supported by fifteen neurological organisations, was formally launched in the Mansion House Dublin in June 2016.

From June to December 2016 the campaign engaged in a comprehensive programme of activities including individual meetings with elected representatives and a coffee morning in Leinster House in November, attended by over twenty TDs and Senators. The campaign secured significant media attention with coverage in national newspapers and radio throughout the second half of 2016. The campaign met with the Minister for Health Simon Harris in December 2016 and accompanied him on a visit to the National Rehabilitation Hospital later that month. The "We Need Our Heads Examined" campaign will continue into 2017.



Moving Forward in 2016: Raising Awareness

National Brain Awareness Week

Over forty events were organised nationwide by NAI member groups. Headway in Limerick organised a series of events including an awareness walk, art exhibition and launch of a local brain injury co-ordinator hub in the region as well as the launch of the Limerick Run from the Headway office. Move 4 Parkinsons held choir and Irish dancing sessions for people with Parkinsons while the Migraine Association of Ireland organised migraine management seminars. MS Ireland held information seminars as part of its "Living with MS Programme". Epilepsy Ireland organised information stands, parent evenings and support groups for people with epilepsy. ABI Ireland organised local events as part of its annual "Bake for Brain Injury" fundraiser.

We were delighted to welcome new partners, Quest Galway, Trinity Care and an Saol all of whom organised events for Brain Awareness Week 2016.

NAI organised an evening event in Trinity College Dublin "Mind Matters: Understanding and Protecting Your Brain". The speakers were Professor Sabina Brennan, Creator of the "Hello Brain" health promotion campaign, Dr Niall Pender, Senior Clinical Neuropsychologist Beaumont Hospital and Professor Tim Lynch, Consultant Neurologist and Clinical Director of the Dublin Neurological Institute. However, Leona Daly, former Eurostar contestant stole the show with her moving account of undergoing treatment for an extremely rare neurological condition while pregnant.

We wish to extend our warm appreciation to all our members and supporters who continue to ensure the success of National Brain Awareness Week year on year.



Publications and Submissions

The NAI Strategic Plan (2011 to 2016) recognises that NAI policy submissions and publications represent a key mechanism to ensure that policy development across the health and disability sector in Ireland reflects the needs of people with neurological conditions. In addition, NAI submissions provide an important opportunity for member organisations, particularly smaller organisations, to communicate their message. NAI produced a series of publications and policy submissions in 2016, all of which are available on the NAI website [GO](#)

1. NAI pre budget submission for Budget 2016
2. NAI submission to the Oireachtas Committee on the Future of Healthcare
3. NAI response to the call for submissions on the Draft Implementation Plan for the National Neuro-rehabilitation Strategy
4. NAI submission on the Draft Strategic Plan for the Medical Card Unit HSE
5. Report of the NAI conference on Rare Neurological Conditions
6. Summary report on the National Audit of Neurology Services

Conference on Rare Neurological Conditions

In January 2016, NAI organised a conference on rare neurological conditions as part of its ongoing collaborative workplan with the Neurology Clinical Programme. The conference brought together the clinical leads from both the neurology and rare disease programmes together with a patient representative and the rare disease office. The report from the conference is available on the NAI website [GO](#)



Moving Forward in 2016: Supporting Members

NAI Campaigns

NAI campaigns in 2016 provided an important platform for members to advocate as a collective voice on behalf of people with neurological conditions and their families. Feedback from members points to 2016 as a seminal year in terms of the strength and profile of NAI in its campaigning and advocacy activities.

Policy Development

NAI policy submissions represent an important resource for members to contribute to the development of policy, providing a platform to communicate issues on behalf of their own particular client group and as a source of information in the preparation of their own policy responses. NAI provided members with a range of supports in 2016 including organising quarterly meetings of its Policy and Campaign Forum, organising information sessions on the clinical programmes and providing the opportunity to input into NAI policy submissions.

Information Sharing and Networking Opportunities

NAI continued to provide a monthly e-update to its members throughout 2016 with updates on all its activities including upcoming events, policy submissions and campaigns. Feedback from NAI members indicated that briefing sessions organised by NAI on the clinical programmes and the opportunity to comment on the draft implementation plan for the neuro-rehabilitation strategy through structured workshops were particularly useful in 2016.

NAI was delighted to be able to showcase the work of its members Epilepsy Ireland and Move4 Parkinsons on self management at the Future Health Summit in May 2016.

Moving Forward in 2016: Collaborations

As a small organisation, NAI is critically dependent on successful collaboration and effective partnerships to achieve its objectives. NAI continued its strong collaboration with the clinical programmes in 2016, working to secure information and expertise in order to support the launch of the “We Need Our Heads Examined” campaign and publishing finding from the first national audit of neurology services.

NAI also continued to work closely with the Disability Federation of Ireland throughout 2016, sharing policy submissions and updates and working to ensure that the needs of people with neurological conditions are reflected across the work of the DFI. This collaboration was strengthened in 2016 through a revised memorandum of understanding and a submission by the NAI Board to the development of the DFI Strategic Plan in 2016.

NAI worked with the organisers of the Future Health Summit in CityWest Dublin in May 2016 to deliver a workshop on self management of neurological conditions. Following the success of this collaboration, NAI undertook a programme of work in the second half of the year to start planning for a very ambitious one day Neurological Summit in May 2017 in partnership with the organisers of Future Health and the neurology clinical programme.

Moving Forward in 2016: Sustainability

As highlighted in the foreword to this annual report, the success of NAI in securing three year core funding under the SSNO scheme (to June 2019) represents a critical development which will allow the organisation to concentrate on its core business and provide a level of certainty about the organisation as a going concern for the immediate future.

NAI continues to undertake careful fiscal management, including strict budgeting and diversification of its funding sources. At the end of 2016, the organisation maintained reserves of 83,000.

Our People

NAI Board Members

The Board of NAI is made up of members of the umbrella.
Chair: Shona Logan King: The Rehab Group
Vice Chair: Dr Andrea Higgins: Bloomfield Health Services
Treasurer: Mary Fox: Enable Ireland
Sonya Gallagher: Headway
Aisling Farrell: Irish Motor Neurone Disease Association
Grainne McGettrick: Acquired Brain Injury Ireland
Clair Kelly: Muscular Dystrophy Ireland
Wendy Crampton: Epilepsy Ireland (appointed 3.11.2016)
Harriet Doig: MS Ireland (appointed 3.11. 2016)
Patrick Little: Migraine Association of Ireland
Peter Murphy: Epilepsy Ireland (resigned 3.11.2016)
Ava Battles: MS Ireland (resigned 3.11.2016)
Cliona Loughnane: Irish heart Foundation (resigned 7.12.2016)

NAI Staff

Magdalen Rogers: NAI Executive Director
Sinead Bradley: Administration, Communications and Events Officer



Magdalen Rogers



Sinead Bradley

Statement of Financial Activities for the Year Ended 31st December 2016

Profit and Loss Account for Year Ended 31 December 2016

	2016 €	2015 €
<i>Turnover</i>	<u>7842</u>	<u>11,328</u>
<i>Gross Profit</i>	<u>7842</u>	<u>11,328</u>
Administrative Expenses	(96,108)	(86,487)
Other operating income	91,980	80,108
<i>Operating Profit</i>	<u>3714</u>	<u>4949</u>
Profit on ordinary activities before taxation	<u>3714</u>	<u>4949</u>
Tax on Profit on ordinary activities	-	-
<i>Profit for Financial Year</i>	<u>3714</u>	<u>4949</u>
<i>Retained earnings at start of financial year</i>	<u>79,364</u>	<u>74,415</u>
<i>Retained earnings at end of financial year</i>	<u>83,078</u>	<u>79,364</u>

Statement of Financial Activities for the Year Ended 31st December 2016 (continued)

Balance Sheet as at 31st December 2016

	2016 €	2015 €
FIXED ASSETS		
Tangible Assets	-	<u>217</u>
		217
CURRENT ASSETS		
Debtors	520	-
Cash at bank in hand	<u>92,060</u>	<u>89,418</u>
	92,580	89,418
CREDITORS (amount falling due within one year)	<u>(9,502)</u>	<u>(10,271)</u>
NET CURRENT ASSETS	83,078	79,147
TOTAL ASSETS LESS CURRENT LIABILITIES	<u>83,078</u>	<u>79,364</u>
<i>Net Assets</i>	<u>83,078</u>	<u>79,364</u>
RESERVES (Profit and Loss Account)	83,078	79,364
<i>FUNDS</i>	<u>83,078</u>	<u>79,364</u>

2016 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.

