

# 20

## ANNUAL REPORT

# 20

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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.

## 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.

## GUIDING PRINCIPLES

- A commitment to the rights of people with neurological conditions and their families to peer support and specialist services for their own particular condition in accordance with their needs and preferences
- A commitment to the rights of people with neurological conditions and their families to understanding, representation and consideration of their own specific neurological condition and its impact on their everyday lives
- A commitment to the rights of people with neurological conditions to seamless integrated services to meet their needs at all stages of their condition.
- An understanding and appreciation of the autonomy and independence of its own member organisations and their commitment to representing the requirements and preferences of their clients for representation, understanding and specialist support for their specific neurological condition
- A commitment by the NAI to promoting and supporting the development of policy to meet the needs and promote understanding of the experiences of people with neurological conditions in Ireland, including the implementation of existing recommendations and commissioning of further work to explore the significant gaps that remain
- A commitment to working in partnership with its own members and with other organisations to ensure that people with neurological conditions and their families are provided with the full range of supports and services in order to live well with their condition
- A core belief that representation of the needs and experiences of people with specific neurological conditions is strengthened through the collective representation provided by the NAI umbrella.

# GOALS

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

# 7

## STRATEGIC PLAN 2020-2022

### VISION

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

### MISSION

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

### GOALS

NAI has set itself 6 high level ambitious goals, which are summarised below. Further detail on each of the goals are in following pages

GOAL	TARGET BY 2022
<b>1 ADVOCACY</b> To strengthen its advocacy platform through improved messaging and increased engagement with public representatives and policy makers	Development of an Advocacy and Communications Strategy and achievement of NAI Advocacy Programme in terms of investment in neurology and neurorehabilitation services
<b>2 RESEARCH &amp; POLICY DEVELOPMENT</b> To utilise research findings and to commission research where required to inform its advocacy and policy work	Development of a research strategy and research function within NAI
<b>3 MEMBER SUPPORT</b> To improve engagement with members, through providing shared opportunities for advocacy, policy development and awareness raising	Increased member engagement in all areas of NAI activity in particular advocacy campaigns
<b>4 COMMUNICATIONS</b> To improve NAI communications in order to raise awareness of the organisation and its messages	Development of an advocacy and communications strategy in order to improve communication of advocacy messages and two-way communication with key stakeholders, including members
<b>5 ORGANISATIONAL DEVELOPMENT</b> To secure the future sustainability of the organisation within a framework of best practice in the areas of governance, quality and financial management	Ensure Board and Executive adopt and comply with best practice in terms of good governance, financial control and risk management
<b>6 SUSTAINABILITY</b> To ensure NAI's impact will extend in the coming years and becomes less reliant on a single source of funding	Sustainability plan developed by the Board and Executive to secure diversified funding sources in order to continue to deliver an expanded programme of activities

### *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*

*Neurology Support Centre*

*Neurofibromatosis Association of Ireland*

*North West MS Therapy Centre*

*Parkinson's Association of Ireland*

*Peamount Healthcare*

*Polio Survivors Ireland*

*PSPA Ireland*

*Slanu Stroke Rehab*

*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*

## 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.



*Tom Scott,  
Chair Of NAI*

## FOREWORD

2020 will be forever etched in our memories as the year of the global COVID-19 pandemic. The arrival of the disease to Ireland and the announcement of a nationwide lockdown in March of this year radically altered all our lives in a way we had never imagined. Those at most risk within our society, including those with chronic illness, faced months of unprecedented uncertainty, isolation and anxiety as they waited for the development and rollout of a suitable vaccine.

The not-for-profit organisations that make up our umbrella were at the forefront of the response to COVID-19, rapidly moving many of their services online and, vitally, providing condition-specific support and guidance on COVID-19 and later on vaccination to their members. An unprecedented demand for their services came at time when the organisations themselves experienced the collapse of public fundraising and struggled to cope with yet another challenge to their sustainability: coming on top of over a decade of successive cuts in funding to Section 39 organisations.

Our annual report includes a section dedicated to the NAI response to COVID-19. During 2020, we radically adapted our work-plan in order to mobilise a priority response to COVID-19: providing support to our members and promoting awareness of the continuing impact on people with neurological

conditions and their families. While COVID19 was understandably the focus of much of our activity after March 2020, our staff and Board worked incredibly hard to ensure that the other areas of our work-plan for the year were delivered in addition to our COVID-19 response.

At a time of unprecedented change across the health and social care landscape, we launched our three-year Strategic Plan in July 2020, recognising that the challenges facing neurological care in Ireland have not gone away, and in fact risk being exacerbated by the pandemic. It has never been more crucial to provide a strong strategic focus to guide our work as our society and our healthcare system adapt and respond to a new reality for the foreseeable future.

We would like to acknowledge the support and dedication of everyone we worked with throughout 2020. Each and every one of our stakeholders, from our dedicated patient advocates, our member organisations, our clinician partners and our funders reached out to us to support our work during this most challenging of years.

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



*Mags Rogers,  
Executive Director of NAI*

## COVID-19 RESPONSE

NAI mobilised a comprehensive COVID-19 work-plan across all areas of activity from March 2020 onwards: from advocacy, to research and policy development, member support, and communications.

Our initial efforts focused on 'behind the scenes' work to provide a channel of communications with clinicians and ensure that advice and information was rapidly made available to patient organisations.

We were among the first organisations to carry out a comprehensive survey on the impact of COVID-19 in April 2020, capturing the responses of over six hundred people with neurological conditions and their families.

We adapted the theme of World Brain Day 2020 here in Ireland to focus on the impact of COVID-19: designing and delivering a national awareness and advocacy campaign in order to highlight the impact on people with neurological conditions and the patient organisations they rely on for support.

Our submission to the Oireachtas Committee on COVID-19, and our Pre-Budget Submission, highlighted the impact of COVID-19 on an already under resourced neurological care sector and the critical need for investment to address the lack of capacity to cope with additional demand post COVID-19.

Finally, we recognised the huge challenge facing our members in adapting and responding to the challenges of COVID-19, including developing new models of fundraising, service provision and communications. In the Autumn of 2020 we applied for and secured funding to deliver an individualised training programme to our members, tailored to their specific training needs in these areas.

The sections below will provide more detail in relation to each of these initiatives with a commitment to our continued focus on addressing the challenges of COVID-19 going forward into 2021 and beyond.





## ADVOCACY

Our advocacy work in the first quarter of 2020 focused on the upcoming general election and securing commitments to our asks first in party manifestos and finally in the Programme for Government.

The publication of our election manifesto marked the start of a busy period of political engagement both with elected representatives and the staff involved in drafting the manifestos for each of the main political parties. NAI also engaged with representatives during the development of the Programme for Government. Working closely with our member organisations, we successfully secured a commitment to the Implementation of the Neurorehabilitation Strategy within the new Programme for Government.

With the onset of the COVID-19 pandemic, we mobilised a strong advocacy response highlighting the impact on people with neurological conditions and on neurological care services already under resourced pre-pandemic. The impact of COVID-19 also formed the basis for our pre budget

submission later in the year: highlighting the serious threat to neurological care services already struggling pre-COVID. A dedicated advocacy campaign for World Brain Day on July 22nd focused on raising awareness and engaging political support for the challenges facing not for profit neurological providers with almost a third of TDs from the new government supporting this campaign.

Our advocacy work throughout 2020 also included a strong focus on collaboration, working directly with umbrella organisations such as the Wheel and the Disability Federation of Ireland in communicating the distinct issues facing our membership and those they represent. This work included NAI support for the implementation of recommendations for Section 39 organisations providing health and social care services, a key issue impacting on NAI member organisations.

Briefings and representations with elected representatives continued throughout the year, including a meeting with Anne Rabbitte, Minister of State for Disability in November 2020.

## Outcomes from NAI advocacy 2020

- A successful outcome to a dedicated campaign by NAI in 2020 to secure investment in the neurorehabilitation demonstrator project and a commitment to the development of a further implementation framework for the Neurorehabilitation Strategy from 2022 onwards.
- Investment in regional neurology services following a targeted NAI campaign in the lead up to the general election in February 2020 and subsequently: engaging with candidates and elected representatives in Sligo, Limerick and Waterford. Funding for additional neurologists in each of these centres was announced in late 2020.
- A third of TDs supported our #savemycharity online campaign for World Brain Day 22nd July, highlighting the financial impact of COVID-19 on our member organisations.

## RESEARCH AND POLICY DEVELOPMENT

We commenced our 2020 policy focus in January with a seminar aimed at examining neurological care within the context of the Slaintecare vision for the health services. The seminar, and subsequent report, drew attention to the opportunity to support key initiatives within neurological care which can act as vital exemplars but also an important test case for the success of Slaintecare reforms. The presentations and panel discussion included representatives from Slaintecare and Clinical Strategy & Programmes as well as patients, NAI member organisations and clinicians.

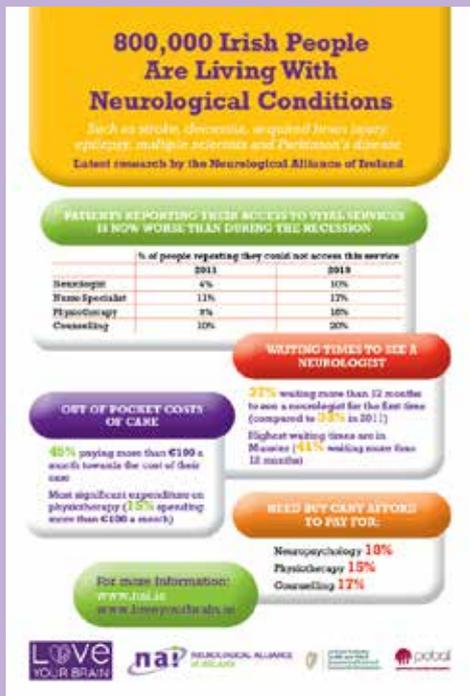
In 2015 NAI carried out the first comprehensive survey of neurology resourcing in Ireland, in collaboration with the National Clinical Programme in Neurology. We revised and broadened the scope of the survey with the aim of rolling out to twelve neurology centres in 2020. The survey examined key resource areas within neurology

services including staffing, access to dedicated beds, waiting times for diagnostic testing and access to neurorehabilitation and other services. The COVID-19 pandemic and the subsequent redeployment of staff led us to delay the rollout until October. All twelve centres completed the survey and we look forward to publishing the findings during Brain Awareness Week 2021.

NAI were among the first umbrella organisations to conduct research on the impact of COVID-19, carrying out a comprehensive survey in April 2020 and obtaining responses from over 600 people with neurological conditions and family members. Our report published in May 2020 indicated the stark challenges faced by this group as well as the vital role played by NAI member organisations in responding to their needs in the face of widespread anxiety and the closure and curtailment of many statutory services.







na<sup>i</sup> NEUROLOGICAL ALLIANCE OF IRELAND | Bloomfield HEALTH SERVICES | AlcoholAction Ireland

Join Our Upcoming Webinar  
**Korsakoff's Syndrome in Ireland: Challenges and Opportunities for a Forgotten Population**  
 Friday 6th November 2020: 11am to 12.30pm

Keynote Speaker: Professor Roy Kesala, Scientific Advisor, Centre of Excellence for Korsakoff and Alcohol-Related Disorders at Vincent Van Gogh Institute of Psychiatry, Netherlands.  
 Chaired by: Prof Cliona Ni Cheallaigh, Clinical Lead, Inclusion Health Service 8H and Assoc Prof, Dept of Clinical Medicine, TCD

Contact [info.ha.essence@gmail.com](mailto:info.ha.essence@icm.com) for more details and to register for the webinar

We also published the findings of our 2019 survey as part of our “Living with a Neurological Condition in Ireland” series. The 2019 survey examined access to a range of neurological supports and services as well as out of pocket expenditure on healthcare reported by people with neurological conditions and family carers. Findings from this survey series have provided important data to inform our ongoing advocacy and contributions to policy development.

Individual projects in 2020 included a series of interviews with key stakeholders

to inform future advocacy around deficits in neuropsychology services as well as organising a webinar on pathways for people with Korsakoffs syndrome in partnership with Bloomfield Health Services and Alcohol Action Ireland.

Through its role as a Board member of the FutureNeuro research institute and the Dublin Neurological Institute the NAI continued throughout 2020 to promote the engagement of people with neurological conditions and patient organisations in both research and service delivery.

## NAI Publications and Submissions 2020

- Living with Lockdown: Report on a Nationwide Survey of the Impact of COVID19 on People with Neurological Conditions
- Submission to Oireachtas Committee on COVID19
- NAI Response to the Call for Submissions on the Lived Experience of People with Disabilities
- Living with a Neurological Condition in Ireland: Full Report of 2019 Survey Findings
- Report “Delivering the Vision of Slaintecare Through Neurological Care”
- NAI Pre Budget Submission 2021
- NAI Annual Report 2019

# COMMUNICATIONS

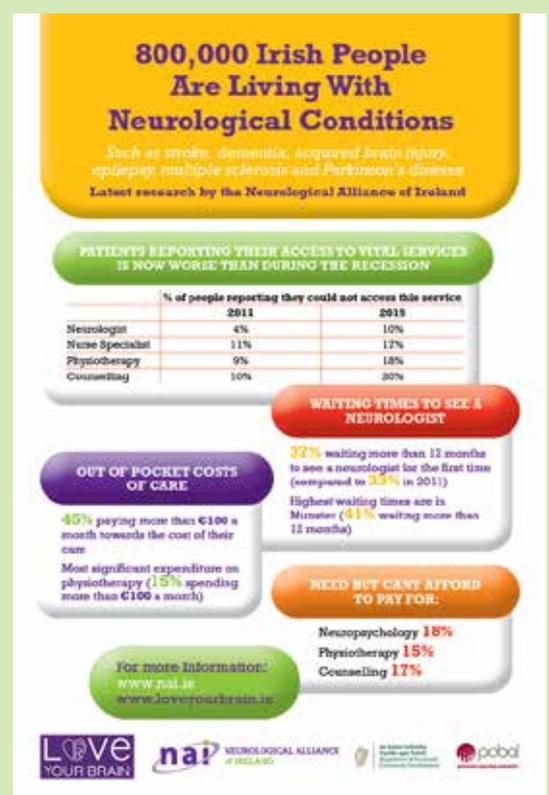
National Brain Awareness Week represents a key focus for our annual work programme for Communications. Plans for Brain Awareness Week 2020 were overwhelmingly impacted by the pandemic and resulting initial lockdown which was announced by the Taoiseach on March 12th, the date of our launch event scheduled to take place in the Mansion House Dublin. Nevertheless we managed to meet our targets for press coverage through working with individual journalists in advance, realising that a major national response to COVID-19 was imminent. Many of the events for our nationwide calendar were adapted to take place online later on during the year.

Two videos in our Brain Life Goals series were launched during Brain Awareness Week. NAI was successful in securing funding for 2020 under this initiative, organised by the European Federation for Neurological Associations (EFNA). The NAI Brain Life Goals project for 2020 aimed to profile a series of initiatives which support people with neurological conditions to realise their personal goals and aspirations. Filming was impacted by COVID-19 restrictions and the final video in the series, along with a new video documentary series based on Brain Life Goals 2021 will be initiated in the New Year when restrictions allow.

Our communications plans after March 2020 quickly turned to World Brain Day July 22nd and making this the principle focus for our communications in 2020. We adapted the theme to COVID-19: The Impact, and introduced a programme of initiatives to understand and highlight the ongoing consequences of the pandemic for people with neurological conditions and our own member organisations.

The second half of 2020 saw the introduction of a dedicated part-time Communications role within NAI which has already led to the redesign and redevelopment of our monthly newsletter, together with a more active social media platform focused on supporting and promoting the work of our member organisations as well as our own messaging and campaigns.

Planning for Brain Awareness Week 2021 commenced immediately after World Brain Day, recognising the significant work needed to adapt the awareness initiative to a completely online format. We look forward to a busy and engaging Brain Awareness Week in March 2021 around our theme of "Access to Services".







## MEMBER SUPPORT

COVID-19 introduced an unprecedented series of challenges for the not for profit organisations that make up our membership. Many of our organisations were already struggling with significant deficits with cumulative funding cuts of up to 20% in the years 2008 to 2014 never restored. Coupled with this were increasing costs in areas such as insurance and the cost of complying with standards/regulations. COVID-19 saw the collapse of public fundraising which our members rely on to try and meet the true cost of providing services and supports. This came at a time when demand on the not for profit organisations increased exponentially as service users were faced with the closure or curtailment of a wide range of statutory supports due to lockdown restrictions and the redeployment of clinical staff.

NAI member organisations mobilised a rapid and extensive response to the needs of their clients, developing online information resources, introducing online services and extending helpline and other outreach supports. The reliance on not for profit organisations was captured in our 2020 survey which showed that 40% of respondents relied primarily on their patient organisation for condition-specific guidance and information in relation to COVID-19.

As the representative umbrella for neurological patient organisations, our focus in NAI was on providing immediate support to our members as well as advocating for action to address the serious impact on their sustainability as a consequence of the pandemic.

## NAI supports to Members During 2020: COVID-19 response

- Carrying out an online advocacy campaign #savemycharity with associated briefings to individual elected representatives and highlighting the issues facing not for profit neurological providers in a submission to the Oireachtas Committee on COVID19.
- Following a needs analysis of our members, NAI developed a programme of specialist training aimed at assisting NAI members to develop new models of fundraising, communication and service provision utilising digital platforms which will be rolled out in 2021
- Ensuring our members had access to up to date access to clinical guidance through facilitating ongoing communication and information sharing with the National Clinical Programme for Neurology.



## ORGANISATIONAL DEVELOPMENT AND SUSTAINABILITY

NAI had an extensive programme of commitments to organisational development in 2020 which were realised despite the challenges and demands of responding to the impact of COVID19.

At a time of unprecedented change across the health and social care landscape, NAI completed work on a three-year strategic plan 2020-2022 and launched it on World Brain Day July 2020. In addition, NAI developed comprehensive individual strategies around advocacy and communications, following an in-depth survey of member organisations and

a workshop with the Board of NAI, in order to provide a strong strategic focus in these areas going forward.

NAI initiated and maintained an active dialogue with funders from the start of the COVID-19 crisis, negotiating timeframes and securing additional sources of funding to support the delivery of COVID-19 specific initiatives including the 2021-2022 Training Links programme. We warmly acknowledge the support and understanding of our funders as we navigated a challenging year in 2020.



Mags Rogers,  
Executive Director of NAI



Sinéad Bradley  
Communications Officer

## OUR PEOPLE

### Board of Directors

(as at 31st December 2020)

Chair: Tom Scott

Vice Chair: Emma Rogan

Treasurer: Barry McGinn

Sonya Gallagher: Headway

Gillian Murphy: (appointed November 2020)

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

## NAI Staff

Magdalen Rogers: NAI Executive Director

Sinead Bradley: Communications Officer.

## NAI FINANCIAL REPORT 2020

### Income and Expenditure for Year Ended 31st December 2020

	2020	2019
	€	€
Income	141,375	104,341
Expenditure	(141,216)	(103,973)
Surplus for the Financial Year	159	368
Total Comprehensive Income	159	368

# Statement of Financial Activities for the Year Ended 31st December 2020 (continued)

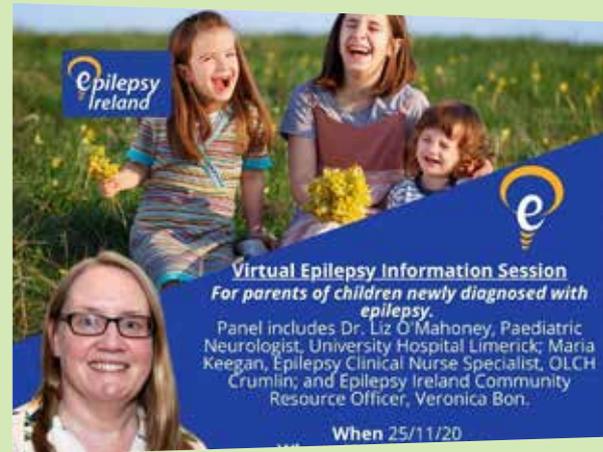
## Balance Sheet as at 31st December 2020

	2020	2019
	€	€
<b>FIXED ASSETS</b>		
Tangible Assets	390	455
<b>CURRENT ASSETS</b>		
Debtors	365	365
Cash at bank in hand	124,228	110,822
	124,593	111,187
<b>CREDITORS</b>		
(amount falling due within one year)	(33,979)	(20,797)
<b>NET CURRENT ASSETS</b>	90,614	90,390
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>	91,004	90,845
<b>RESERVES</b>		
(Income and Expenditure Account )	91,004	90,845
<b>MEMBERS FUNDS</b>	91,004	90,845

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.

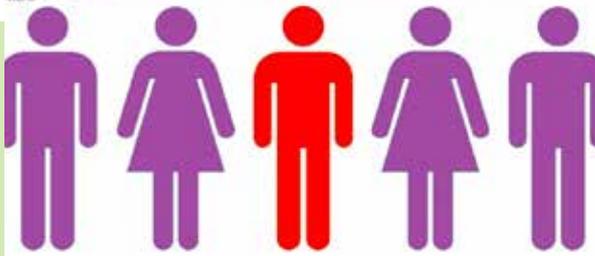
Funding from other sources, including industry sponsorship and membership fees, are clearly outlined in our audited financial statements.

# 2020 FOR OUR MEMBERS





1 in 5 adults live with chronic pain



Support Pain Awareness Month

Visit www.chronicpain.ie



### Parkinson's Research in Ireland

Perspectives from research laboratories, the clinic, industry and those with the condition will be shared over 3 weeks through short, lively talks followed by a Q&A session. **All are welcome!**

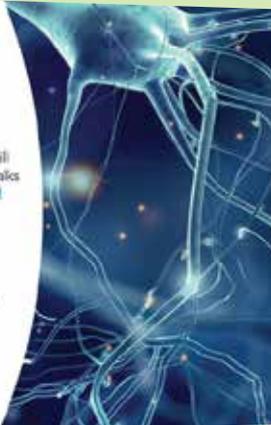
**12 Nov, 6:00 - 7:00 PM**  
 Gary Boyle, Parkinson's Association of Ireland  
 Jochen Pahn, RCSI, PD-MesoQUANT Project Coordinator

**19 Nov, 6:00 - 7:00 PM**  
 Eilis Dowd, NUI Galway Medicine, Parkinson's researcher  
 Catriona McLoughlin, Dublin Neurological Institute

**26 Nov, 6:00 - 7:00 PM**  
 Suzanne Timmons, UCC Centre for Gerontology and Rehabilitation, Parkinson's researcher  
 Jeremy Skillington, Inflexion (Roche)

Register free at Eventbrite: <https://bit.ly/3p8R26d>

Invited Speakers from



# HELP SHINE A LIGHT ON HUNTINGTON'S DISEASE





## MIGRAINE AWARENESS WEEK

#MakeMigraineMatter

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



@nai\_ireland

Registered Charity Number 20049829

NAI is a company limited by  
guarantee. CHY number 366603

Auditors  
Wendy Merrigan & Co  
Chartered Accountants and  
Registered Auditors  
Sandyford, Dublin 18