

**MS IRELAND**  
ANNUAL  
REPORT &  
ACCOUNTS  
**2018**



# MISSION, VISION, AIMS & VALUES

## MISSION

“To enable and empower people affected by Multiple Sclerosis to live the life of their choice to their fullest potential”

## VISION

MS Ireland has a vision of Irish society where all people affected by MS live positive and active lives in the community

## AIMS

**The principal objectives for which MS Ireland exists are:**

- » to facilitate people with MS to control their lives and environment, to live with dignity and participate in the community
- » to provide support for the families and carers of people with MS
- » to co-operate with the medical, scientific, social and caring professions to promote scientific research into the cause of, cure for and management of MS, and the alleviation of medical and social symptoms
- » to exchange and disseminate information relating to MS
- » to provide an identifiable focal point by developing an efficient, effective and caring organisation to serve the needs of people affected by MS

## VALUES

### **Supportive**

“We support individuals whether they are People with Multiple Sclerosis (PwMS), staff or volunteers so that we can work together to fulfil our mission”

### **Transparent**

“Being open and honest in everything that we do”

### **Informative**

“Communicate reliable, accurate and useful information”

### **Empowering**

“Through the provision of information, advocacy and support services we enable people to make informed choices”

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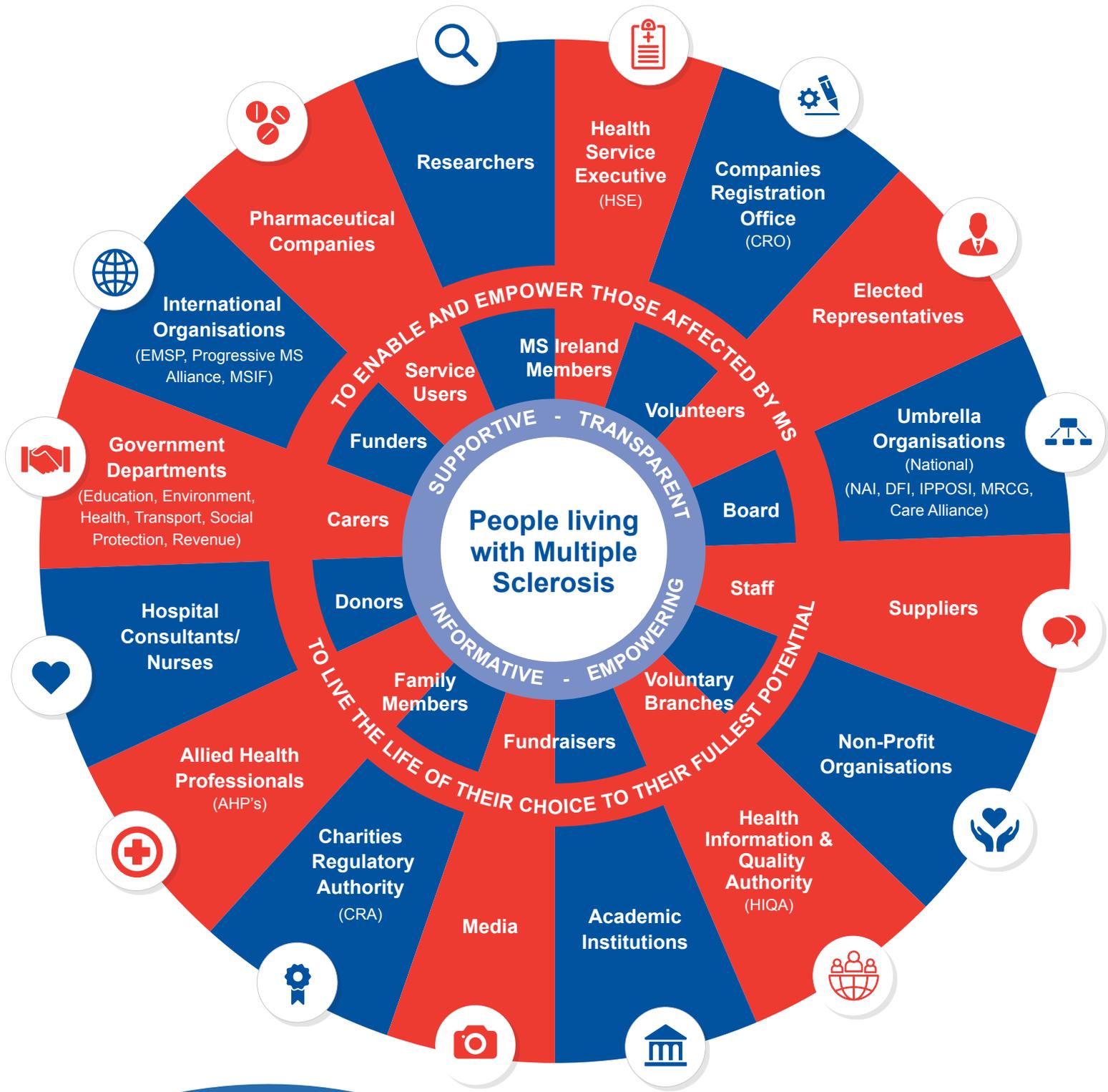
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# STAKEHOLDER MAP





## CHIEF EXECUTIVE & CHAIRPERSON WELCOME

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The Multiple Sclerosis Society of Ireland is the only national organisation providing information, support and advocacy services to the MS community. We work with people with MS, their families and carers and a range of key stakeholders including health professionals, students, and others interested in or concerned about MS to ensure that we meet our goals. We are delighted to welcome you to a review of MS Ireland's activities and services in 2018. In 2018, MS Ireland faced several challenges with continued constraints on our own funding. However, 2018 was an exciting year where MS Ireland's dedicated team of staff and volunteers throughout the country achieved a great deal and continued to work on behalf of people affected by MS in Ireland. This report will highlight and celebrate the successes and achievements and outline the challenges facing the organisation.

In 2018, MS Ireland continued to engage successfully with other organisations on various high profile campaigns across advocacy and research. These included the Neurological Alliance of Ireland's (NAI) 'Invest in Neurology campaign' which calls for greater funding for the provision of adequate neurology services in Ireland. We also worked in partnership with the NAI to campaign for further investment in neurorehabilitation services across the country. As partners of the Irish Platform for Patients Organisations, Science & Industry (IPPOSI) we participated in the development of a charter for greater patient involvement in the medications access and reimbursement system.

MS Ireland contributed to a report published by the Disability Federation of Ireland (DFI) 'The Situation of Younger People with Disabilities Living in Nursing Homes in Ireland' which outlines the inappropriate placement of younger people

with disabilities in nursing homes because of insufficient community supports. MS Ireland was also involved in collective advocacy in relation to home care support as members of the Home Care Coalition and we also participated in the Housing Agency's Community Living Task group.

In Research, last year, MS Ireland published a report 'Disease Modifying Therapies (DMTs) for Multiple Sclerosis: A Review of the Perspectives of Irish People with MS'. The report explores people's experiences of being prescribed DMTs, what information they were given about different DMTs and what additional information and support they would have liked to help them make informed decisions about treatment options.

Arguably the highlight of the year for advocacy and for the organisation as a whole was the MSunderstood Café and bus. In 2018, MS Ireland collaborated with Roche Products (Ireland) to

# CHIEF EXECUTIVE & CHAIRPERSON WELCOME



develop the MS Understood Café, an experiential setting that allowed people to gain an insight into some of the symptoms that people living with MS may deal with on a daily basis. These symptoms were communicated in a number of ways; the floor was uneven, the menu board intermittently blurred, chairs were heavy and difficult to get out of and snacks & sugar packets were tightly wrapped. These modifications made the experience notably different from what someone would expect of a café experience. Following on from the success of the MS Understood Café and the brilliant response we received from those who visited, we decided to bring the MS Understood Café on the road in the form of a bus to various locations around the country. The Café was adapted on a specifically designed bus to provide people with a unique insight into what it is like to live with MS and some of the challenges they may face on a daily basis. Both cafés, sponsored by Roche Products (Ireland), and aimed to highlight the 'Patient's Deserve Better' campaign which advocates for better access to MS medicines. To support this campaign visit [www.patientsdeservebetter.ie](http://www.patientsdeservebetter.ie).

The MS Information Line, MS Care Centre and our regional services continue to be very busy, providing vital support, information and services to the MS community despite very limited resources. World MS Day 2018 was a great success, with

our team using the theme of 'research' and the hashtag #Bringinguscloser with the hope of research, one day, bringing us closer to ending MS. Following on from our very successful inaugural research explored event in 2017, a second event was held in 2018 at Trinity College. This event examined how clinical research is bringing us closer to understanding MS, the importance of patients and researchers working closer together to better inform and support each other and examined the work that is being conducted in Dr Claire McCoy's lab to bring us closer to treatments that may repair some of the damage caused by MS. A new report 'Making Ireland the Best Place to do Multiple Sclerosis Research' was launched at this event.

Our annual conference and Healthcare Professionals Day took place in September in Athlone. We had some brilliant speakers at the conference including the renowned Professor Gavin Giovanoni, who spoke about the quality of life with MS and Dr. Jens Bensi and Dr. Sabina Brennan. Several workshops were held throughout the day on topics related to Multiple Sclerosis and brain health. We have made use of live streaming and recording at all our major conferences and events this year, so as to reach as wide an audience as possible.

# CHIEF EXECUTIVE & CHAIRPERSON WELCOME

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Our Fundraising team celebrated the 31st year of our flagship fundraiser the MS Readathon. In 2018, we were also delighted to announce a new 2 year partnership with the Leinster Rugby team as their charity partner. The players were on hand at the national print museum to launch Readathon 2018 and we look forward to working with them over this period. The Readathon in 2018 had over 8,000 readers and 282 schools took part in raising a grand total of €293,208. Other fundraising activities included skydives, treks, the ever-popular Women's Mini Marathon our abseil and for the first time some brave fundraisers took part in a fire walk.

In 2018, our MS and Me blog remained an ever popular and valuable information source for the MS community. 2018 was the first year our new blog team put pen to paper and shared their inspirational stories with the MS community in Ireland and abroad. Our team of 18 writers from a variety of backgrounds excelled in their blogging throughout the year.

At present, the MS Care Centre is only open for 40 weeks per year as a result of decreases in both Statutory and fundraised income over the last number of years. We want to return to a situation where we are open 50 weeks of the year to meet increased demand. We created a Care Centre business case which the MS community throughout Ireland used to highlight this issue with their local

Politician. In October 2018, MS Ireland presented the MS Care Centre Business Case to TDs and Senators in Leinster House. We were overwhelmed by the support shown by local representatives at the event. A video was released to coincide with the presentation, where Mark Mitchell shared why further investment is important and the services offered at the Care Centre, this is available on our website. We will continue to work on this issue in 2019.

None of our achievements in 2018 would be possible without the dedication of the staff and volunteers who work so hard to make a difference to the lives of people affected by MS in Ireland, including our Board who give their time and expertise for free to support the running of the organisation. We would like to thank everybody who has supported our work in any way, by making donations, engaging in fundraising activities, and raising awareness about who we are and what we do. We anticipate more challenges and uncertainty for the organisation in 2019 but we will never lose sight of our vision, which is of an Irish society where all people affected by MS live positive and active lives in their community of choice. Through our service delivery, information provision, research, advocacy and campaigning, we will continue to strive towards realising this vision in the year ahead. With your support, this is achievable.

**We hope you enjoy reading this report and we look forward to working with you in the coming year.**



*Ava Battles*

**AVA BATTLES**  
**CHIEF EXECUTIVE**



*Marcella Flood*

**MARCELLA FLOOD**  
**CHAIRPERSON**

# STRATEGIC PRIORITIES

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2018 was the fourth year of our five-year Strategic Plan for the period of 2015-2019. This plan builds on the achievements of the previous Strategic Plan (2013-2014), and is based on those guiding principles which are fundamental to the work we do: enabling and empowering people with MS to live the life of their choice to their fullest potential. In preparing the Strategic Plan, we have consulted with our stakeholders.

## The Strategic Priorities in our 2015-2019 Strategic Plan are:



### SERVICES

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To provide quality services nationally to ensure everyone with multiple sclerosis and their families have full access to services and supports when needed.



### ORGANISATIONAL CAPACITY

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Build and strengthen MS Ireland's organisational capacity, to ensure delivery of our Strategic Plan.



### ADVOCACY

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MS Ireland will be the voice for people with MS, driving an advocacy agenda that includes areas of greatest concern to people with MS.



### GOVERNANCE & REGULATION

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Continue to strengthen the governance and regulation of MS Ireland, ensuring compliance with relevant regulatory bodies.



### RESEARCH

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MS Ireland will develop a research strategy that will focus on supporting and participating in research that is in line with member expectations on local, national and international stages.

**Log on to our website to read the full strategic plan:  
[www.ms-society.ie](http://www.ms-society.ie)**



## ACHIEVING IN SERVICES

To provide quality services nationally to ensure everyone with multiple sclerosis and their families have full access to services and supports when needed.

### SPECIFIC OBJECTIVES:

- Enable and empower the MS Care Centre, regions and branches to deliver appropriate supports and services.
- Develop a sustainable and quality community service in tandem with relevant stakeholders.
- Develop a functional structure that supports branches in delivering services to the local community.
- Provision of a quality respite service that is compliant, efficient and sustainable.
- Provision of a confidential information line.
- Quality, up to date, timely, accessible and accurate information will be available to all in a variety of media appropriate to the needs of the various audiences.
- Information will be shared across strategic alliances to ensure most up to date information is available.

**IN 2018, THIS IS WHAT WE  
ACHIEVED IN SERVICES**

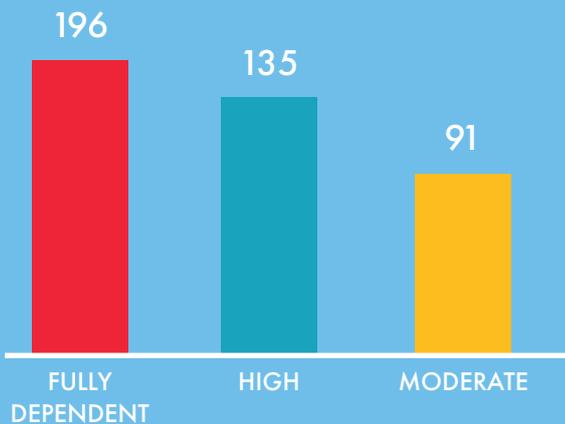
## ACHIEVING IN SERVICES

### THE MS CARE CENTRE

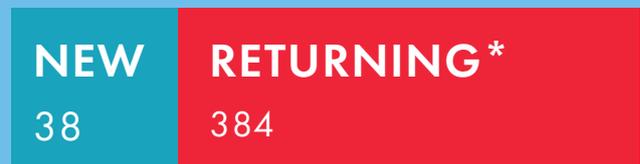
Our MS Care Centre is the only respite and therapy centre for people with MS in Ireland. Providing short-term respite care for people with MS, during a 5, 7 or 12 night stay a resident can avail of therapeutic services, neurological assessments, access to an MS nurse and a range of social activities to allow for complete rest and recuperation. In 2018 the MS Care Centre provided professional, dedicated care for 422 people. Our highly trained staff and specialised equipment ensures a safe and comfortable stay for residents and peace of mind for family members and carers.



### DEPENDENCY



### NEW & RETURNING RESIDENTS



\* SOME RESIDENTS STAYED TWICE OR MORE

### PROFESSIONAL & THERAPEUTIC INTERVENTION



## ACHIEVING IN SERVICES

### IMPROVING THE MS CARE CENTRE



Thanks to ongoing fundraising efforts, donations and volunteers from our generous corporate supporters, we were able to complete a number of improvements to ensure the continued safety, comfort and enjoyment of the Centre.



THREE BATHROOMS FULLY REFURBISHED AND PAINTED



NEW FLOOR COVERING IN THE SUN ROOM



NEW FLOOR COVERING IN THREE BEDROOMS



NEW COFFEE DOCK IN THE KITCHEN

A special **THANK YOU** to the residents and their families who made a donation to the MS Care Centre on foot of their stay. We deeply appreciate their generosity which helps us keep this wonderful and essential service operating.

MS Care Centre staff continue to work very hard to ensure the Centre is fully compliant with HIQA standards, following successful HIQA registration in 2015.

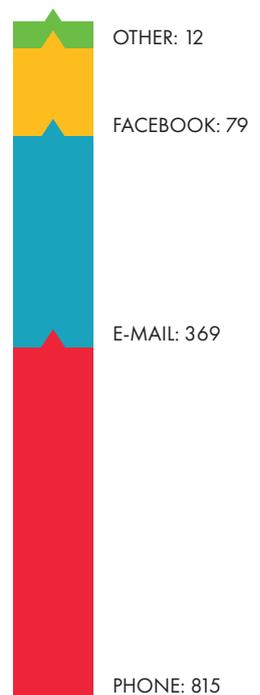


### THE MS INFORMATION LINE

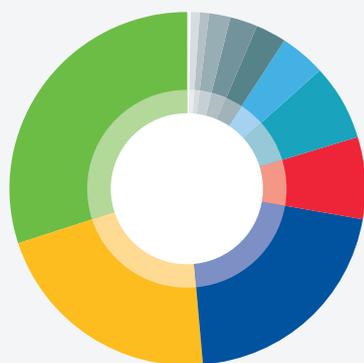
Operating weekdays from 10am-2pm, our dedicated information line provides professional, anonymous and confidential support for people with MS, their families, carers and health professionals.

In 2018, **1,275** people contacted the MS Information Line.

#### HOW PEOPLE MADE CONTACT



#### REASON FOR MAKING CONTACT



## ACHIEVING IN SERVICES

### REGIONAL SERVICES

Our regions provide a range of services to individuals, families and health care professionals in their area. These services are aimed at providing support and information, assisting the person and family to learn about MS and to discover coping mechanisms to improve their quality of life. Casework and living with MS programmes

are two of the main services delivered through our Regional Offices to people and families living with MS. Other services include information to health professionals, service development, public awareness and support to the voluntary Branch structure.

### CASEWORK

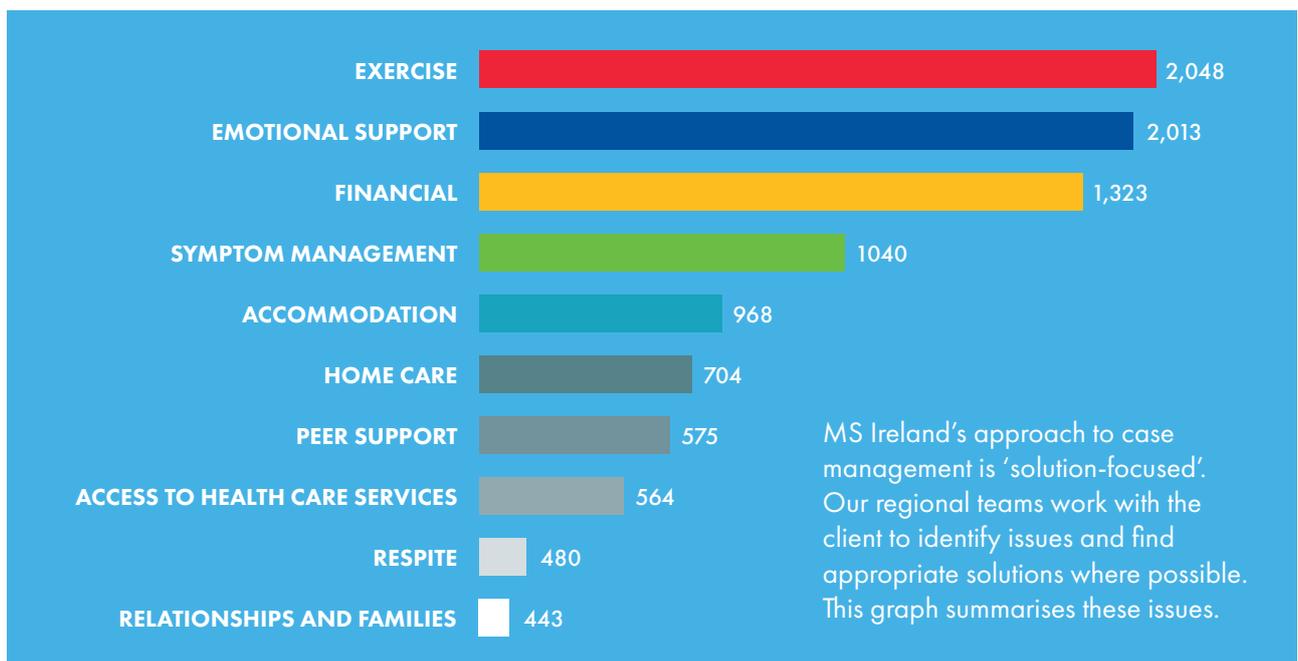
Our casework service revolves around one-to-one meetings, contact with clients, issue exploration/resolution and referrals to other agencies. This is a hugely important service to those newly diagnosed or struggling with the impact their MS is having on a part of their life. Casework allows the person or family to discuss issues and receive information, support and guidance from our trained and professional staff to empower them to make decisions about their life with MS.

**1,953**  
PEOPLE ENGAGED IN  
ONE-TO-ONE SERVICES

**1,049**  
NEWLY DIAGNOSED  
CONTACTS \*

*\* newly diagnosed is defined as having a diagnosis date within the last 5 years.*

### TOP 10 ISSUES PRESENTED BY CLIENTS

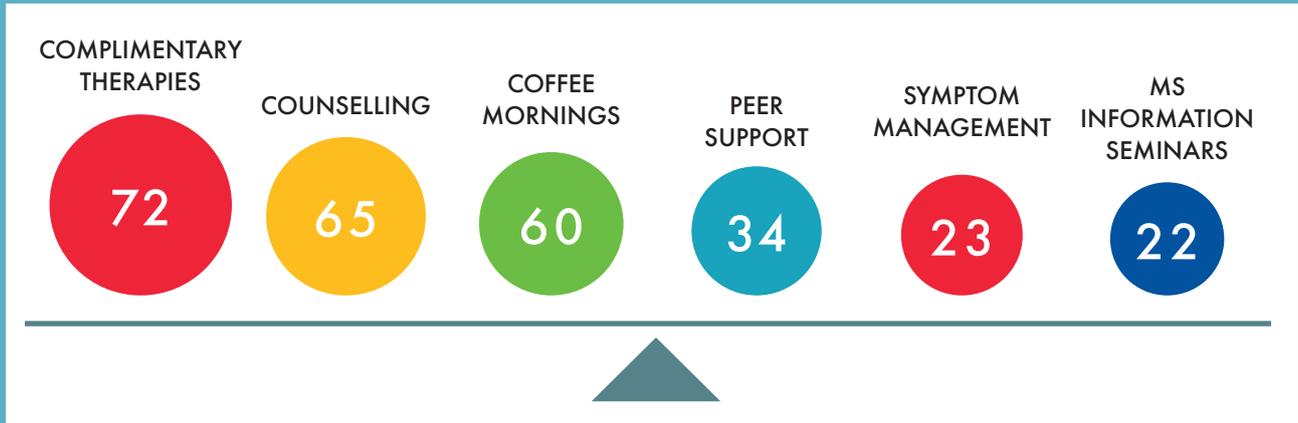


## ACHIEVING IN SERVICES

### LIVING WITH MS PROGRAMMES

Our regional services provide a wide range of group support through programmes, workshops and activities. Types of programmes include newly diagnosed seminars, symptom management; carers support groups, information mornings and yoga sessions.

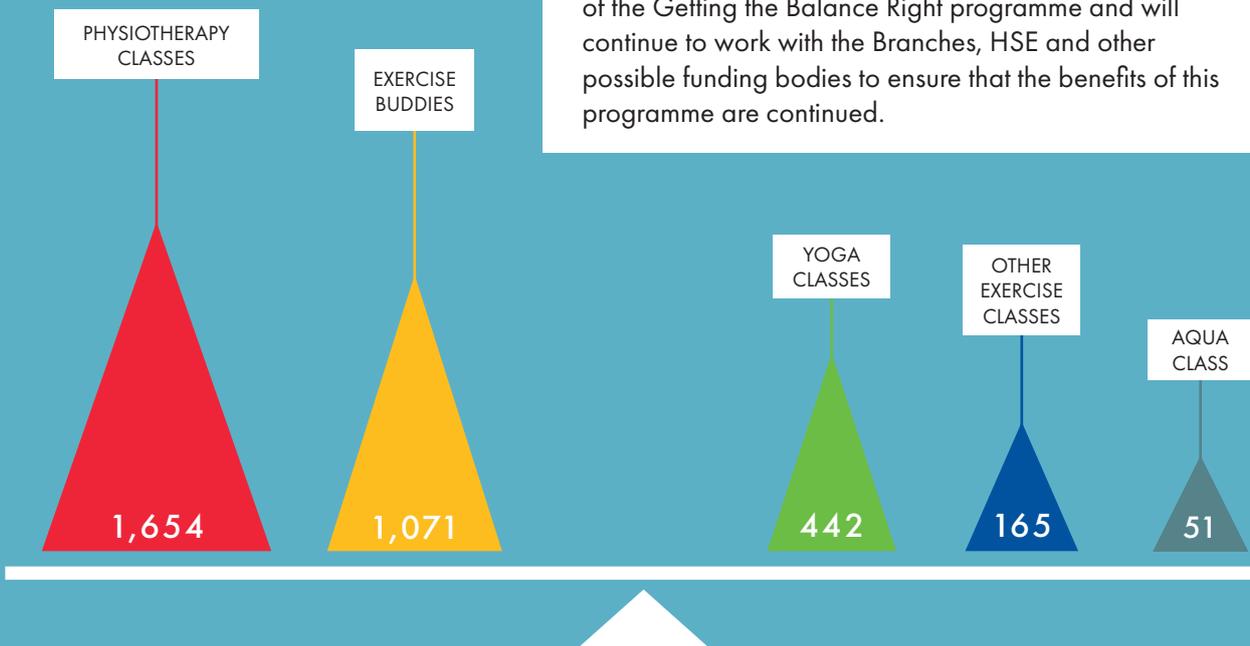
These programmes may be one-off sessions or a ten week course, depending on the nature of the programme. The figures below summarises the types of programmes we ran in 2018:



### GETTING THE BALANCE RIGHT

Getting the Balance Right, our nationwide exercise, health promotion and research programme for people with MS, continues to be an enormous success. The programme offers a range of opportunities for people with MS to maintain and improve a full range of motion, which may have been impacted on as a result of the MS disease process. Interventions range from physiotherapy-led group programmes, physiotherapy 1:1, yoga, gym-based programmes, hydrotherapy and tai chi.

#### IN 2018 WE PROVIDED



MS Ireland continues to be committed to the sustainability of the Getting the Balance Right programme and will continue to work with the Branches, HSE and other possible funding bodies to ensure that the benefits of this programme are continued.

## ACHIEVING IN SERVICES

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### QUOTES FROM THE MS CARE CENTRE

"You connect and communicate with other people with MS, it is the social side really that I love, the people there become your friends .The yoga, the physio and the MS nurse are all fantastic. The nurse is the most important and the support she offers is great, it is the only time I get to see the MS nurse and I can talk to her about anything."

"It is so good to have a rest, secondly its how well you are looked after, the staff there are incredible, they care for all your needs, the nurses, you can chat to them, they are very good listeners, its like a home away from home, you meet people who are in the same boat as you and can share with them what problems you might have"

"It's so important for people with MS to have a respite centre to go to, not just for ourselves, but for the people looking after us , I would be heartbroken without it"

With MS we don't know where to go because accessibility is an issue for us but at the Care Centre all our needs are catered for, you can avail of treatments massages etc., which I cant do locally. We have opportunities there that we wouldn't have otherwise, everything there is accessible to us and is wonderful."

### VOLUNTARY BRANCH SERVICES WORKING TOGETHER



### WORKING TOGETHER: AN INTEGRATED APPROACH

2018 was the seventh year of our integrated model of service delivery. Our professional regional staff worked closely with our dedicated teams of volunteers throughout our branch network to best fund, organise and deliver services

to the local MS community. This team work has meant that we are able to make the best use of all our resources to best address the needs of people with MS and their families. 16 Regional Integrated Meetings took place in 2018.

## ACHIEVING IN SERVICES

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### FIND YOUR LOCAL MS IRELAND

To learn more about services available in your area, contact your local Regional Office. All voluntary Branches can be contacted through their associated regional office.

#### DUBLIN NORTH AND FINGAL REGIONAL OFFICE

Providing services in north county Dublin and city

[na@ms-society.ie](mailto:na@ms-society.ie) | (01) 490 5933

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#### MIDLANDS REGIONAL OFFICE

Providing services in Laois, Offaly, Longford and Westmeath

[midlands@ms-society.ie](mailto:midlands@ms-society.ie) | (090) 647 1137

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#### MIDWEST REGIONAL OFFICE

Providing services in Clare, Limerick and Tipperary North

[midwest@ms-society.ie](mailto:midwest@ms-society.ie) | (061) 303 802

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#### NORTH EAST REGIONAL OFFICE

Providing services in Cavan, Monaghan, Louth, and Meath

[northeast@ms-society.ie](mailto:northeast@ms-society.ie) | (042) 975 4304

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#### NORTH WEST REGIONAL OFFICE

Providing services in Donegal, Sligo and Leitrim

[northwest@ms-society.ie](mailto:northwest@ms-society.ie) | (074) 918 9027

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#### SOUTH EAST DUBLIN AND WICKLOW REGIONAL OFFICE

Providing services in Wicklow and areas of south Dublin

[eca@ms-society.ie](mailto:eca@ms-society.ie) | (01) 678 1600

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#### SOUTHERN REGIONAL OFFICE

Providing services in Cork and Kerry

[southern@ms-society.ie](mailto:southern@ms-society.ie) | (021) 430 0001

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#### SOUTH EAST REGIONAL OFFICE

Providing services in Kilkenny, Wexford, Carlow, Waterford and South Tipperary

[southeast@ms-society.ie](mailto:southeast@ms-society.ie) | (056) 7777 771

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#### SOUTH WEST DUBLIN AND KILDARE REGIONAL OFFICE

Providing services in Kildare and areas of south west Dublin

[swa@ms-society.ie](mailto:swa@ms-society.ie) | (01) 490 5933

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#### WESTERN REGIONAL OFFICE

Providing services in Galway, Mayo and Roscommon

[western@ms-society.ie](mailto:western@ms-society.ie) (091) 768 630

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### VOLUNTARY BRANCHES

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Ballina	Dublin North	Kerry South	Louth	Tipperary
Carlow	Dublin South	Kildare	Longford	Tipperary South
Cavan	Dublin West	Kilkenny	Mayo South	Tralee/West Kerry
Clare	East Wicklow	Laois	Meath	Tuam
Cork City	Fermoy	Leitrim	Monaghan	Waterford
Cork North West	Galway	Limerick	Offaly	Wexford
Donegal	Kerry North	Limerick West	Roscommon	

## ACHIEVING IN SERVICES

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### AGM 2018

MS Ireland's 2018 Annual General Meeting (AGM) was held on 22nd September at the Radisson Blu Hotel Athlone, Co. Westmeath. Dr Edwina Dunne was elected to the Board and Rory Mulcahy and Maurice O'Connor were both re-elected to the Board. Paddy Stronge retired from the Board and the Chairperson thanked Paddy for his 9 years of incredible service on the Board. In his time as Chairperson, she noted he worked almost full time in a voluntary capacity and he will be missed. She said that we look forward to Paddy's continued contribution on the Board's Sub-committees.

### HEALTHCARE PROFESSIONALS INFORMATION DAY

MS Ireland hosted an information day for healthcare professionals on 21st of September at the Radisson Blu Hotel Athlone, Co. Westmeath. The focus of the day was on Promoting Quality of Life, with specific sessions on neurorehabilitation and exercise, gene patterns in the MS population, neurorehabilitation in Ireland the current state of play, physiotherapy research from the University of Limerick, planning for the future with neurological conditions and MS treatments and improving quality of life. Over 80 health care professionals attended.

Afterwards, the videos of the presentations were uploaded to MS Ireland's website.

### LIVING WELL WITH MS CONFERENCE

The Living Well with Multiple Sclerosis conference took place on 22nd of September at the Radisson Blu Hotel Athlone, Co. Westmeath. The theme of the conference was 'Promoting Quality of Life'. Over 170 people were in attendance and over 400 people watched via livestream.



#### LIVING WELL WITH MS CONFERENCE

### PRESENTATIONS ON THE DAY

**Professor Gavin Giovannoni**  
Professor of Neurology Centre, Barts Hospital London

**Dr. Jens Bansi**  
Exercise Scientist, Rehabilitationszentrum, Valens Switzerland

**Angela Edgill**  
Irish Hospice Foundation

**Dr. Kate O'Brien**  
Genomics Medicine Ireland

**Dr. Sabina Brennan**  
Trinity Brain Health and ADAPT, Trinity College Dublin



All presentations are available to view on our website [www.ms-society.ie](http://www.ms-society.ie)

### NETWORKING EVENT FOR RESEARCHERS



World MS day saw two research events held in Dublin which saw speakers from the scientific and medical community joined by people living with MS to speak about ongoing and potential MS research. The first of these events took place in The Royal College of Surgeons Ireland. This MS Research Network Forum saw speakers cover topics including 'Exploring Exercise and Cannabinoids as Therapeutic Targets in MS', 'How Patients Can Help Build MS Research' and 'How to build an MS electronic patient record'.

The second research event was held in Trinity Biomedical Sciences Building. Professor Orla Hardiman discussed 'How Clinical Research is Bringing Us Closer to Understanding MS'. Following Professor Hardiman was Joan Jordan who delivered a presentation titled 'A Patient Voice – Bringing us Closer to Research'. The Final speaker of the evening was Dr Claire McCoy whose presentation focused on 'Bringing Us Closer to Research in Ireland'.

Recordings of the presentations are available in the Research section of our website [www.ms-society.ie](http://www.ms-society.ie)

## ACHIEVING IN SERVICES

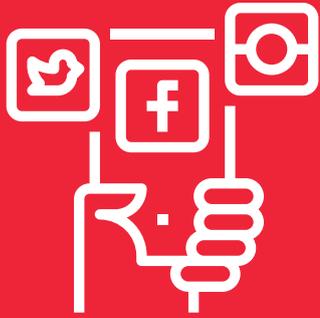
### YOUNG PERSONS EVENT



In November, MS Ireland hosted our first event specifically for young people living with MS, between the ages of 18-35. The event welcomed 68 young people to The Davenport Hotel, to hear three guest speakers discuss; 'Resilience', 'Roadmapping for Success' and 'Relationships & Intimacy'. This event, which was sponsored by Novartis, was also live-streamed to 1,300 viewers

on Facebook and Instagram. Students Unions in third-level universities and colleges across the country organised spaces on campus to host a live stream, allowing young people from all corners of Ireland the chance to come together in remote hubs to view the live stream and engage in discussion.





## SOCIAL MEDIA

Our social media channels continued to grow throughout 2018 and have proven to be an ever popular and important information tool for the organisation. Our 'Tuesday MS Questions' and 'Friday MS Quotes' on Facebook continue to be popular and are great for stimulating discussions. For our young person's event in November, we used Facebook's live stream facility and took questions for the panel via Twitter, Instagram and Facebook.



### Instagram

multiple\_sclerosis\_ireland

2,045 Followers

### Facebook

MultipleSclerosisIreland



16,555 Likes



### YouTube

MSSocietyIRELAND

29,300 Views



### Twitter

@MSIRELAND



8,527 Followers



### E-News

Sign up on our website

2,787 Subscribers

### Website

www.ms-society.ie



155,267 Website Visitors

## EXAMPLES OF A TUESDAY MS QUESTION ON FACEBOOK:

With Thursday being Valentine's Day we want to know your experiences of love and MS. Did MS ever get in the way of your relationship?  
#TuesdayMSQuestion

How do you keep your brain active?  
#TuesdayMSQuestion

## EXAMPLE OF FRIDAY MS QUOTE ON FACEBOOK:

"I have MS. MS does not have me."  
You just do it. You force yourself to get up. You force yourself to put one foot before the other, and God damn it, you refuse to let it get to you. You fight. You cry. You curse. Then you go about the business of living. That's how I've done it. There's no other way

## ACHIEVING IN SERVICES

### MS NEWS MAGAZINE

2018 saw the publication of two editions of MS News. The theme of the spring/summer edition was advocacy. It featured pieces on our advocacy work, medicinal updates, research and personal stories. It also featured a piece on mobility scooters and the latest from our fundraising activities. The second issue for Autumn/Winter focused on MS and self management. This issue explored self management from a practical and personal perspective. In particular, there were feature pieces from health professionals on fatigue management and self managing brain health. Both the spring/summer and autumn/winter editions highlighted regional services and news from the branches as well as updates on advocacy and conference reports.



### MS & ME BLOG

In 2013 MS Ireland launched a community blog as a place for people with MS to share their experiences of life with MS and since then it has been an ever valuable information source for the MS community in Ireland and abroad.

In 2017, we decided to extend and diversify our current blog and recruited some new writers. We put a call out for new bloggers across our social media channels and through internal email looking for potential writers from all different backgrounds. We were delighted with the response and 2018 was the first year of blogging for some of our new bloggers.

In 2018 there were 46 MS & Me blog posts which covered a variety of topics on life with MS. The blog encourages conversation and debate with the aim of supporting and informing people and is shared across all our social media platforms every Thursday.

### eNEWS

Our electronic newsletter eNews was sent every month in 2018 to our subscriber list of 2,787 subscribers. eNews provides monthly updates on various aspects of MS research, services, events and developments. This year, eNews also featured a new monthly series on self-management, covering topics such as fatigue, exercise, stress, personal relationships and goal setting. Our subscriber list was reduced due to GDPR update in May 2018.



## IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Services in 2018:

### ENABLE AND EMPOWER THE CARE CENTRE, REGIONS AND BRANCHES TO DELIVER APPROPRIATE SUPPORTS AND SERVICES

- 422 residents stayed in the MS Care Centre
- 546 individual physiotherapy sessions provided at the MS Care Centre
- 1,953 people engaged in one-to-one casework services

### DEVELOP A SUSTAINABLE AND QUALITY COMMUNITY SERVICE IN TANDEM WITH RELEVANT STAKEHOLDERS

- Numerous group Living With MS programmes run including 34 Peer Support programmes, 23 symptom management sessions, 60 coffee mornings and 23 self-management programmes
- 1,654 Physiotherapy classes, 1,071 Exercise Buddies sessions and 442 Yoga classes provided by community services

### DEVELOP A FUNCTIONAL STRUCTURE THAT SUPPORTS BRANCHES IN DELIVERING SERVICES TO THE LOCAL COMMUNITY

- 16 Regional Integrated Meetings carried out between local MSI staff and voluntary Branches

### PROVISION OF A QUALITY RESPITE SERVICE THAT IS COMPLIANT, EFFICIENT AND SUSTAINABLE

- Maintenance and improvement works carried out by corporate volunteers at the MS Care
- Full compliance with HIQ standards at the MS Care Centre

### PROVISION OF A CONFIDENTIAL INFORMATION LINE

- 1,275 people contacted the MS Information Line, by phone, email and social media

### QUALITY, UP TO DATE, TIMELY, ACCESSIBLE AND ACCURATE INFORMATION WILL BE AVAILABLE TO ALL IN A VARIETY OF MEDIA APPROPRIATE TO THE NEEDS OF THE VARIOUS AUDIENCES

- Two issues of MS News
- eNews every month, including new monthly self-management series
- 46 MS & Me Blog posts
- 759 new followers on Twitter
- 1,629 new Likes on Facebook
- 767 new followers on Instagram

### INFORMATION WILL BE SHARED ACROSS STRATEGIC ALLIANCES TO ENSURE MOST UP TO DATE INFORMATION IS AVAILABLE

- Healthcare professionals event held with over 80 HCPs in attendance
- MS Young Persons Event attended by 67 young people and a further 1,300 live streams of the event.



## ACHIEVING IN ADVOCACY

MS Ireland will be the voice for people with MS, driving an advocacy agenda that included areas of greatest concern to people with MS.

### SPECIFIC OBJECTIVES:

- To liaise and work with umbrella organisations (nationally and internationally) to create a more cohesive and united voice.
- Strengthen current advocacy alliances and develop new links to harness the strength of shared visions.
- Utilise data sets and service delivery experiences available to MS Ireland to inform our advocacy agenda.
- People with MS will have access to effective treatments for their condition, including treatments which can slow, stop or reverse the accumulation of disability.
- To raise MS Ireland's profile as a leading voice and resource for people with MS.

**IN 2018, THIS IS WHAT WE  
ACHIEVED IN ADVOCACY**



## MS CARE CENTRE BUSINESS CASE

We held a briefing on the MS Care Centre Business Case in the AV Room in Leinster House on October 3rd, with the kind support of Senator Victor Boyhan. This briefing was attended by over 50 political representatives and their staff from across the country. Senator Victor Boyhan introduced MS Ireland to the representatives in attendance and provided context for the briefing. Ava Battles, Chief Executive of MS Ireland spoke about the MS Care Centre and the need for an increase in funding. She outlined the benefits of such an investment for both the government

and most importantly, people living with MS. Following Ava was Michael Kilgannon who gave a personal account of his experiences as an MS Care Centre service user and the importance of providing additional funding. Finally, Mark Mitchell, another service user of the MS Care Centre addressed the crowd and gave them an insight into his interactions with the MS Care Centre, complimenting the points made by previous speakers and communicating the importance of further investment.



## ACHIEVING IN ADVOCACY

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### MS EXPLORED

In November 2018, MS Ireland held an event for young people living with MS. This event was supported by Novartis. During this event, three speakers discussed three key-topics. First, Karen Belshaw discussed Mental Resilience and provided the crowd with practical tips on building resilience. Road-mapping for Success was delivered by Michael Kerrigan, former president of the Union of Students in Ireland. This presentation focused on education, training and employment, providing the audience with workable tools and practical information. Sex therapist, Moira Tzitzika presented Relationships & Intimacy which explored some of the difficulties people living with MS can face in relation to intimate relationships. 67 young people living with MS attended the event which was also livestreamed.

MS Ireland encouraged online interaction to reach as many young people as possible and to ensure they had the chance to ask any questions they had for the speakers. As well as developing this

event and live-streaming, MS Ireland worked in partnership with students unions across the country who helped to disseminate information to third-level students about the event. Many opted to set up a live-stream hub on campus which allowed young people living in the area the chance to watch the live stream as part of a community. On the night of the event, there were over 1,500 views of the livestream.



## ACHIEVING IN ADVOCACY

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### SATIVEX

In 2018, MS Ireland put forward a Patient Group Submission for Sativex to the National Centre for Pharmaco-economics (NCPE) for their consideration in the Health Technology Assessment (HTA). We continued to liaise with the pharmaceutical company that markets Sativex.

### OCREVUS (OCRELIZUMAB)

MS Ireland put a Patient Group Submission forward to the NCPE for consideration in during the HTA of Ocrevus. These projects include a website – [www.patientsdeservebetter.ie](http://www.patientsdeservebetter.ie). This website highlighted delayed access people living with MS in Ireland have to new and innovative medicines. The website was a mechanism by which the general public could easily engage in a grassroots campaign. They could select their constituency, input their information, personalise and email and send it to their local representative. This project served to drive an element of our advocacy agenda forward while creating huge public awareness of MS.

### IPPOSI PATIENT CHARTER

As partners of the Irish Platform for Patient Organisations, Science & Industry (IPPOSI) we participated in the development of a charter for greater patient involvement in the medications access and reimbursement system. This charter aims to empower patients by promoting effective partnerships between the patient community and Irish state agencies with responsibility for health technology assessments and reimbursement.





## MS UNDERSTOOD CAFÉ

In addition to the Patients Deserve Better website, MS Ireland collaborated with Roche Products (Ireland) to develop the MS Understood Café. This was an experiential setting that allowed people to gain an insight into some of the symptoms that people living with MS may deal with on a daily basis. These symptoms were communicated in a number of ways; the floor was uneven, the menu board intermittently blurred, chairs were heavy and difficult to get out of and snacks & sugar packets were tightly wrapped. These modifications made the experience notably different to what someone would expect of a café experience. This day long pop-up café experience was recorded and participants' reactions to various difficulties were captured. The video was shared across our other social media platforms. Media coverage and social media sharing drew much attention and praise. This project was nominated for two Irish National Healthcare Awards, 'Public Health Initiative of the Year', which it won and 'Patient

Education Project of the Year – Pharmaceutical' for which it received a commendation. The video that was made also won a Cannes Lions Award at the Cannes Lions Festival of Creativity.

### MS UNDERSTOOD CAFÉ ROADSHOW

Following the success of The MS Understood Café, the MS Understood Café Roadshow was developed. A bus was transformed into a café which was modified to simulate the symptoms of MS. This mobile version of the MS Understood Café toured Ireland over 10 days to help spread awareness. The bus visited locations in Galway, Tipperary, Clare, Wicklow, Limerick, Cork, Wexford and Dublin.

The café and bus acted as awareness and advocacy tools in partnership with the Patients Deserve Better website.



## ACHIEVING IN ADVOCACY

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### NEUROREHABILITATION AND NEUROLOGY SERVICES

MS Ireland worked with the Neurological Alliance of Ireland (NAI) to campaign for further investment in neurorehabilitation services across the country. We encouraged our members to lobby their local TD in relation to Neurorehabilitation and other issues in the Spring/Summer edition of MS

News. MS Ireland also engaged in NAI's 'Invest in Neurology campaign' which calls for greater funding for the provision of adequate neurology services in Ireland. On June 13th, MS Ireland attended an AV Room briefing in Leinster House, organised by NAI. This briefing highlighted the urgent need to invest in neurology services and to increase the number of neurologists and MS nurses.

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### HOME CARE

MS Ireland contributed to a report published by the Disability Federation of Ireland (DFI) 'The Situation of Younger People with Disabilities Living in Nursing Homes in Ireland'. This report outlines the inappropriate placement of younger people with disabilities in nursing homes because of insufficient community supports.

MS Ireland was also active members of the Home Care Coalition which has involved meetings with government officials and media coverage.

### COMMUNITY LIVING TASK GROUP

MS Ireland participated in the Housing Agency's Community Living Task group. This presented an opportunity to feed into disability housing policy. A report from the consultation was published in June and a number of the themes and comments from the submission by MS Ireland in 2017 were reflected or noted. In the final report for greater

standardization and equity of service across the country, the need for greater flexibility in the types of services that can be provided by home care workers, the need for home care workers to receive training in managing particular conditions like MS and improve integration between home care and other services such as hospitals and primary care.

### PRE-BUDGET SUBMISSION

MS Ireland put forward a pre-budget submission asking for increased funding in a number of key areas including; neurology services, neurorehabilitation, community services (including home support) and housing adaptations. We also recommended an increase in the earnings disregard for those in receipt of Disability Allowance or Invalidity Pension when applying for a medical card.

All policy submissions can be viewed on our website [www.ms-society.ie](http://www.ms-society.ie)



## IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Advocacy in 2018:

### TO LIAISE AND WORK WITH UMBRELLA ORGANISATIONS (NATIONALLY AND INTERNATIONALLY) TO CREATE A MORE COHESIVE AND UNITED VOICE

- We participated in the development of a charter for greater patient involvement in the medications access and reimbursement system
- MS Ireland contributed to a report published by the Disability Federation of Ireland (DFI) 'The Situation of Younger People with Disabilities Living in Nursing Homes in Ireland'
- MS Ireland worked with the Neurological Alliance of Ireland (NAI) to campaign for further investment in neurorehabilitation services across the country

### STRENGTHEN OUR CURRENT ADVOCACY ALLIANCES AND DEVELOP NEW LINKS TO HARNESS THE STRENGTH OF SHARED VISIONS

- MS Ireland held an event for young people living with MS. This event was supported by Novartis and attended by 67 people with over 1,500 live streams.
- MS Ireland participated in the Housing Agency's Community Living Task group

### UTILISE DATA SETS AND SERVICE DELIVERY EXPERIENCES AVAILABLE TO MS IRELAND TO INFORM OUR ADVOCACY AGENDA

- Put forward a Patient Group Submission for savitex and ocrevus
- We held a briefing on the MS Care Centre Business Case in the AV Room in Leinster House to keep the care centre open for more days in the year.

### PEOPLE WITH MS HAVE ACCESS TO EFFECTIVE TREATMENTS FOR THEIR CONDITION, INCLUDING TREATMENTS WHICH CAN SLOW, STOP OR REVERSE THE ACCUMULATION OF DISABILITY

- MS Ireland put a Patient Group Submission forward to the NCPE for consideration in during the HTA of Ocrevus
- MS Ireland put forward a pre-budget submission asked for increased funding in a number of key areas including; neurology services, neurorehabilitation, community services (including home support) and housing adaptations

### TO RAISE MSI'S PROFILE AS A LEADING VOICE AND RESOURCE FOR PEOPLE WITH MS

- MS Ireland participated in the Housing Agency's Community Living Task group
- MS Ireland collaborated with Roche Products to develop the MS Understood Café and bus which acted as awareness and advocacy tools in partnership with the Patients Deserve Better website



## ACHIEVING IN RESEARCH

MS Ireland will develop a research strategy that will focus on supporting and participating in research that is in line with member expectations on local, national and international stages.

### SPECIFIC OBJECTIVES:

- By 2019 MS Ireland will have developed and implemented a funding strategy to support research appropriate to the requirements of MS Ireland and its specific members (medical, scientific, and quality of life).
- Collaborate with academic institutions on the delivery of research projects.
- Support and sponsor a number of research projects aimed at improving the quality of life of people with MS and people affected by MS
- A protocol for researchers who engage with MS Ireland (nationally or regionally)

**IN 2018, THIS IS WHAT WE  
ACHIEVED IN RESEARCH**



### WORLD MS DAY

The theme for World MS Day in 2018 was Research. The campaign, which was called #bringinguscloser was about connecting people affected by MS with those involved in MS research, including scientists, students, nurses, fundraisers, volunteers, and more. It was a chance to come together to celebrate what we've achieved in MS research so far, and share our hopes for the future. In keeping with the #bringinguscloser research theme, MS Ireland held two research events on World MS Day. The first, held in The Royal College of Surgeons Ireland (RCSI) saw researchers with an interest in MS come together to discuss their work, from across the island of Ireland. The purpose of this event was for researchers to be able to highlight their areas of current work and discuss opportunities for collaboration and sharing of resources and information.

A second event was opened to the public. This was held in Trinity College. This event examined how clinical research is bringing us closer to understanding MS, the importance of patients and researchers working closer together to better inform and support each other and examined

the work that is being conducted in Dr Claire McCoy's lab to bring us closer to treatments that may repair some of the damage caused by MS. A new report 'Making Ireland the Best Place to do Multiple Sclerosis Research' was launched at this event. The report aims to support researchers and provide people with MS and the public with a better understanding of the research process and ongoing research.



MSIreland

NOVARTIS

### MINDFULNESS RESEARCH - NUI GALWAY

MS Ireland is supporting a research project in NUI Galway €50,000 over two years, 2017-2018. This research project which is being conducted by researchers from the School of Psychology and Centre for Pain Research examines the feasibility of trialling a mindfulness intervention for people living with MS.

### DISEASE MODIFYING THERAPIES FOR MULTIPLE SCLEROSIS: A REVIEW OF THE PERSPECTIVES OF IRISH PEOPLE WITH MS'

In 2018, MS Ireland published a report 'Disease Modifying Therapies for Multiple Sclerosis: A Review of the Perspectives of Irish People with MS'. This report explores people's experiences of being prescribed disease modifying therapies (DMT's), what information they were given about different DMT's and what additional information and support (if any) they would have liked to help them make informed decisions about treatment options. The report also looks at experiences of side effects, reasons why people decided to change DMT's or stop taking them, how people find managing and administering their DMT's and what supports would be useful to make this easier. The survey which provided the information for this report was conducted in late 2017, with 236 people participating in the survey.

### RESEARCH EZINE

MS Ireland published a third issue of our research e-zine, MS Research. This was circulated to approximately 2,787 subscribers.

### INTERNATIONAL PROGRESSIVE MS ALLIANCE

A number of MS Ireland Branches made a donation to the work of the International Progressive MS Alliance during 2018. Their combined contribution amounted to €14,500. These funds will be used to support research into developing treatments for progressive forms of MS.

### MEDICAL RESEARCH CHARITIES GROUP

MS Ireland actively engaged with the Medical Research Charities Group (MRCG) in 2018. This is the national organisation for charities that are active in medical research. During 2018, MS Ireland attended meetings and engaged with the Communications and Advocacy Subgroup as well as their Shared Learning Group on the topic of Public Patient Involvement (PPI) in research.

### PPI IGNITE COLLABORATION

MS Ireland continued our collaboration with the University of Limerick on the PPI Ignite programme during 2018. This scheme is funded by the Health Research Board and encourages universities to involve patients and members of the general public in the design and delivery of research projects.

### DEAN MEDAL

In 2011, to honour the life and work of Dr Geoffrey Dean, a renowned MS scholar, MS Ireland established the Dean Medal. The aim of the award is to enable early career MS researchers to travel to centres of Excellence to enhance their understanding and knowledge of MS. MS Ireland was delighted to award the 2017 Dean Medal to Sravanthi Bandla from NUI Galway. This travel bursary enabled Sravanthi to travel to the University of Glasgow to deepen her knowledge in relation to discovering the therapeutic activity of ER chaperones in the context of Multiple Sclerosis.



## IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Research in 2018:

### BY 2019, MS IRELAND WILL HAVE DEVELOPED AND IMPLEMENTED A FUNDING STRATEGY TO SUPPORT RESEARCH APPROPRIATE TO THE REQUIREMENTS OF MS IRELAND AND ITS MEMBERS

- A research report 'Making Ireland the Best Place to do Multiple Sclerosis Research' was launched on World MS Day 2019. The report aims to support researchers and provide people with MS and the public with a better understanding of the research process and ongoing research.

### COLLABORATE WITH ACADEMIC INSTITUTIONS ON THE DELIVERY OF RESEARCH PROJECTS

- Research networking event held to strengthen relationships between MS Ireland and researchers at Trinity College, Dublin.
- NUI Galway Mindfulness research conducted by researchers from the School of Psychology and Centre for Pain Research examines the feasibility of trialling a mindfulness intervention for people living with MS.
- MS Ireland continued our collaboration with the University of Limerick on the PPI Ignite programme during 2018.

### SUPPORT AND SPONSOR A NUMBER OF RESEARCH PROJECTS AIMED AT IMPROVING THE QUALITY OF LIFE OF PEOPLE WITH MS AND PEOPLE AFFECTED BY MS

- Ongoing funding and practical support provided to researchers investigating mindfulness and MS at NUI Galway.
- Donations made by a number of MS Ireland branches to the International Progressive MS Alliance.
- MS Ireland actively engaged with the Medical Research Charities Group.
- Published a report 'Disease Modifying Therapies for Multiple Sclerosis: A Review of the Perspectives of Irish People with MS'.

### A PROTOCOL FOR RESEARCHERS WHO ENGAGE WITH MS IRELAND (NATIONALLY AND REGIONALLY)

- All researchers who request support in recruiting participants for studies are required to comply with MS Ireland's Protocol for Researchers.



## ACHIEVING IN ORGANISATIONAL CAPACITY

Build and strengthen MS Ireland's organisational capacity to ensure delivery of our strategic plan.

### SPECIFIC OBJECTIVES:

- To enable effective communications to take place at all levels within MSI, internally and externally.
- To ensure that the human resources available to MSI are most effectively deployed in pursuit of our main strategic priorities.
- To ensure MSI remains a viable and sustainable organisation in relation to its funding situation giving specific attention to fundraising.
- To diversify our funding (particularly fundraising) to avoid an overreliance on one channel of fundraising i.e. Readathon.
- To ensure that a functional Branch/Council structure exist.

**IN 2018, THIS IS WHAT WE ACHIEVED  
IN ORGANISATIONAL CAPACITY**

## ACHIEVING IN ORGANISATIONAL CAPACITY

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### RESOURCE ALIGNMENT

The situation in relation to statutory and fundraised income remains challenging.

- » Reduced opening hours at the MS Care Centre remained.
- » Budgets were again reduced and monitored closely.
- » Additional reporting on regional and national level of the costs of service delivery supported efforts.
- » Local Branches were asked to continue their contribution of 15% of their year end net assets to support local services.

### INTEGRATED MODEL OF SERVICE

2018 was the seventh year of the integrated model of working whereby local voluntary Branches and regional staff worked together to plan, organise and fund services for their respective areas. This year more Branches than ever participated in meetings and contributed financially to the provision of Regional services. In each of our 10 regional areas Regional Integrated Meetings took place and often had a senior manager from National Office and a Board member in attendance. These meetings led to a number of outcomes:

- » Better use of monies available as resources are pooled
- » More targeted services as service users are more involved in planning
- » Improved planning as skills, materials and equipment are pooled
- » Improvement in communications

16 Regional Integrated Meetings took place in 2018.

### HUMAN RESOURCES

The following posts were recruited in 2018:

- » Agnes Mujawimana, Financial Assistant
- » Wendy Knott, Admin Resource worker, Southern Region
- » Ann Gill, Nurse in MS Care Centre replacing Rachel Aherne
- » Tríonna Ní Ráinne, Branch Liaison officer,
- » Aoife Lambe, Regional Community worker, North East Region

### INTERNSHIPS AND VOLUNTEERS

MS Ireland continues to utilise a number of interns and volunteers in National Office and the MS Care Centre. Each brings their own skill set to the Society which contributes greatly to our work.

### COMPANY PENSION SCHEME

The trustees of the scheme met in July to review the scheme performance and to review the trustee annual and administration reports. There were no issues arising.

### STAFF TRAINING

In September, service staff attended the information day for healthcare professionals. Ongoing FETAC Level 5 training in Health Skills related areas was carried out in the three Community Employment schemes operated by MS Ireland. Time was also given to staff to complete self-funded training, in line with company policies.

### VOLUNTEERING



MS Ireland would not exist without the invaluable support of volunteers around the country. The majority of our volunteers work within our voluntary Branch Network, directly supporting people affected by MS. Many more volunteers support us at fundraising events, administration work and increasingly through workplace volunteering schemes.

### VOLUNTARY BRANCHES

Our voluntary Branches are a support network for people and families living with MS in local communities. They provide a financial assistance service, access to a number of different therapies and organise various social gatherings.

### CORPORATE VOLUNTEERS



The growth in corporate volunteering has had a wonderful impact as many organisations actively support their employees volunteering work time to MS Ireland and other charities. In 2018, we benefited from the time and talents of many employees from a number of big and small workplaces throughout the country. From administration to gardening to online marketing, we are indebted to the generosity of employers and employees alike.



## PUBLIC RELATIONS

Raising awareness of multiple sclerosis and MS Ireland's services and campaigns amongst the public is an important part of our work to support the MS community in Ireland. Included below are the PR campaign and media highlights from 2018.

### KISS GOODBYE TO MS 2018

Kiss Goodbye to MS 2018, the third year of the campaign in Ireland, brought great support for research and vital services for those living with MS in Ireland. The 2018 campaign was supported by television presenter Lisa Cannon and our brilliant MS ambassadors Sara-Jane Tracy and Rosie McCormack. For the Kiss campaign, Ava Battles and Rosie McCormack appeared on Ireland AM on virgin media where Rosie spoke about the campaign and her life with MS. Susan Carey and Michelle Hanley featured in pieces in the national broadsheets the Independent and the examiner respectively. Regional media relations resulted in strong photo coverage and campaign focused articles. Media relations activity continued from

the launch and throughout the month of May for the campaign. We also had the brilliant Laura Lee, from Cork who also appeared on The Today Show on RTE.



### PUBLIC RELATIONS



#### WORLD MS DAY 2018

World MS Day 2018 took place on Wednesday May 30 with the theme of research and research bringing us closer to ending MS, the hashtag #bringinguscloser was used throughout the campaign. World MS Day raises awareness of Multiple Sclerosis for thousands of people in Ireland and their families and from 2018 onwards it will be held on 30 of May each year. For the campaign in 2018 we had inspirational MS ambassadors who featured prominently on nationally media. Jordan Byrne from Wicklow appeared on the Pat Kenny Show on Newstalk along with Aidan Larkin of MS Ireland. Joran spoke about the theme of the campaign, her life with MS and how she interacts with MS Ireland.

Olivia Kirwan featured in the Irish Daily Star while Katie St Lawrence featured in regional newspapers in Dublin while also appearing on Matt Cooper's show on today FM.



#### MEMBERSHIP

At the end of 2018 our membership stood at **4,574**

## PUBLIC RELATIONS



### MS READATHON 2018

For the MS Readathon in 2018, which was the 31st year of the campaign, we were delighted to welcome our new charity partners, the Leinster Rugby team to the launch of the campaign. The launch took place in the national print museum in Dublin and was attended by a large number of the Leinster squad who were all very enthusiastic to get behind the campaign. On the day we were also joined by 6th class from John Scottus School in Dublin who were all very eager bookworms. Aoife Kirwan, from Kildare, who is living with MS and her young son Adam were there on the day itself to let all the children know what life is like living with MS and why the Readathon is so important in supporting MS Ireland and our services. Debbie Thomas, an Irish author who just released a new book, *My Secret Dragon*, read chapters from the book for all the children in attendance.

We had great media coverage, with articles from MS ambassadors Jenny Mangan and Jordan Byrne appearing in national broadsheets including, *The Irish Examiner*, *The Times Ireland* edition, *The Irish Examiner Feel Good*, *TheJournal.ie*, *Irish Daily Star* and *The Irish Times*.

### IRISH AUTHORS

Ireland's best authors provided enthusiastic quotes about kids reading in support of the readathon. For the past number of years Ireland's authors and illustrators are great supporters of the MS Readathon each year. They include Sarah Webb, Cecelia Ahern, Marita Conlon McKenna, Chris Haughton, Aine Ni Ghlinn, Catherine Doyle, and Clare Hennessy among many others.



### PARTNERSHIPS AND COLLABORATIONS

Working in partnership with those who share a common interest is an essential part of MS Ireland's work. To provide, change and develop services and practices we are proud to collaborate with the following organisations to achieve what we do for people with MS.

#### SIGNIFICANT PARTNERSHIPS IN 2018

- » The HSE and other state bodies such as The Department of Social Protection and Pobal, regarding funding.
- » The University of Limerick (UL), the National University of Ireland, Galway (NUIG), the Medical Research Charities Group (MRCG), Irish Platform for Patients Organisations, Science and Industry (IPPOSI), the Irish Brain Council and Health Research Board (HRB) regarding research and professional information. MS Ireland's CEO Ava Battles is on the Board of IPPOSI and MS Ireland's Information, Advocacy and Research Officer was on the Communications and Advocacy Sub-group of the MRCG and also sat the Board of the MRCG in 2018.
- » The Neurological Alliance of Ireland regarding the campaign for increased investment in neurological services, neurorehabilitation and Brain Awareness Week. MS Ireland's Information, Advocacy and Research Officer was part of NAI's Campaign Working Group for the We Need Our Heads Examined campaign and represented MS Ireland on the Board of NAI.
- » Care Alliance for Carers Week, and participating in the Family Carer Research Group.
- » The Disability Federation of Ireland (DFI) in the areas of health sector cuts, governance, rehabilitation, neurological funding, employment, assistive technology, housing and accommodation, and disability rights. Services Manager Olga Estridge is on the Board of DFI.
- » MS Ireland have also been involved in DFI's Employment Retention Working Group.
- » The European Multiple Sclerosis Platform (EMSP), the Multiple Sclerosis International Federation (MSIF) and the International Progressive MS Alliance in the areas of policy, common goalsetting, research and governance. MS Ireland sits on MSIF's working group for World MS Day.
- » Pharmaceutical companies; in particular Novartis, Roche, Biogen Idec, Genzyme and Merck Serono regarding funding and educational projects and activities. In particular we would like to note the following collaborations in 2018:
  - \* Collaborated with Novartis to support 'MS Explored' an event for young people living with MS.
  - \* Worked in partnership with Roche to develop the MSUnderstood Café, Patients Deserve Better Website and MS Understood Café Roadshow.
  - \* Attending the International Patient Organisation Information Exchange and Global MS Patient Group Summit, organised by Roche.

## ACHIEVING IN ORGANISATIONAL CAPACITY

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### AWARDS

#### PERSON OF THE YEAR AWARD

Mary McKeon and the McKeon/Treacy Family were the recipients of the 'Person of the Year' award. Mary is the Chairperson of the South Dublin Branch. She built up the Branch Committee to become an active and engaged group who foster inclusion and respect for all. It was due to Mary's encouragement that the Branch to date has donated €20,000 towards research. Mary and her family have been huge supporters of MS Ireland, taking part in fundraising activities including marathons, the Camino walk and a skydive. Congratulations to Mary and the McKeon/Treacy Family.



*Person of the Year Award, Mary McKeon*

#### CARER OF THE YEAR AWARD

The 'Carer of the Year' award was presented to Carmel and PJ O'Brien. Carmel and PJ care for their niece, Carol, who was diagnosed with MS when she was 17 years old. This very caring duo also take Carol to MS meetings, coffee mornings and fundraising events which she enjoys. Congratulations to Carol and PJ.



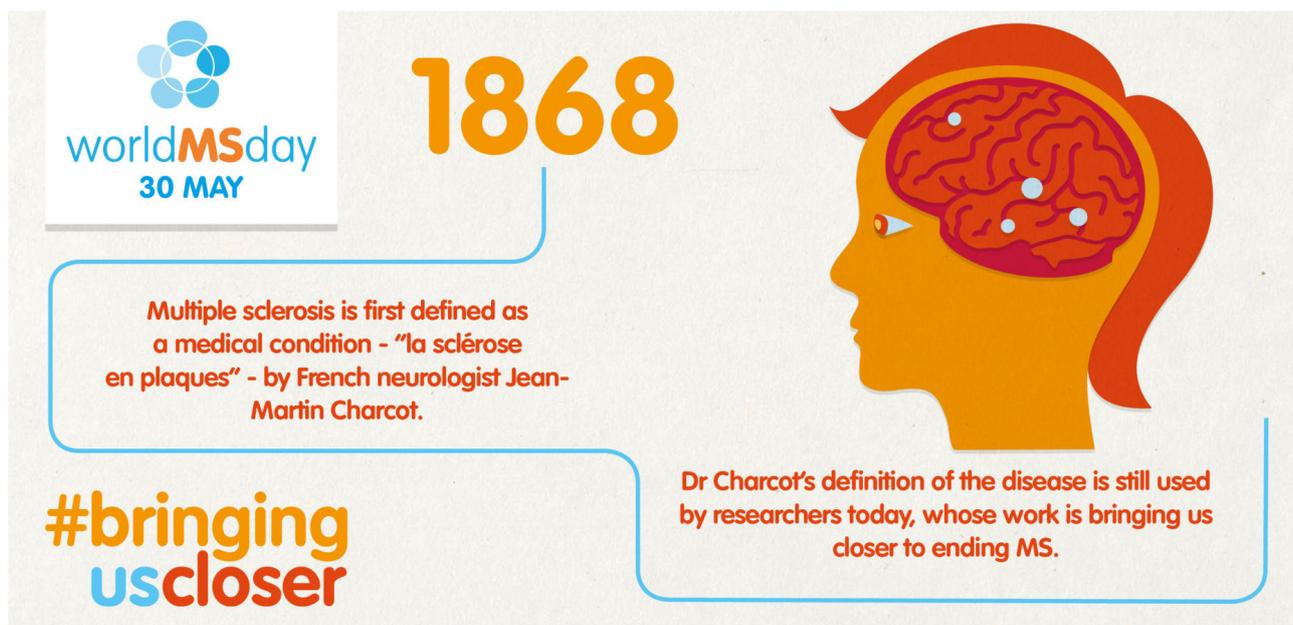
*Carer of the Year Award, Carmel and PJ O'Brien*

#### VOLUNTEERS OF THE YEAR

The 'Volunteers of the Year' award was given to Duncan Pratt and Carol Millington Pratt. Over the years, Duncan and Carol who are described as the 'dynamic duo' have generously given their time and skills to the South Mayo Branch. Carol, the Assistant Secretary of the branch, is efficient and accurate. She has set a very high standard in the roles she has held on the committee. Duncan is the Chairperson of the branch. He is dedicated and witty. Because of their involvement on the Committee, they make participating at meetings and events fun and rewarding. Congratulations to Duncan and Carol.



*Volunteer of the Year Award, Duncan Pratt and Carol Millington Pratt*



### WORLD MS DAY 2018

The theme for World MS Day in 2018 was Research. The campaign, which was called #bringinguscloser was about connecting people affected by MS with those involved in MS research, including scientists, students, nurses, fundraisers, volunteers, and more. It was a chance to come together to celebrate what we've achieved in MS research so far, and share our hopes for the future. Events were organised throughout the country, including coffee mornings and two research events.

On World MS Day we held a research explored event in Trinity College Dublin. This event examined how clinical research is bringing us closer to understanding MS, the importance of patients and researchers working closer together to better inform and support each other and examined the work that is being conducted in Dr Claire McCoy's lab to bring us closer to treatments that may repair some of the damage caused by MS. A new report 'Making Ireland the Best Place to do Multiple Sclerosis Research' was launched at this event. The report aims to support researchers and provide people with MS and the public with a better understanding of the research process and ongoing research.

We held our annual coffee morning in the Care Centre in Bushy Park in Rathgar which was attended by hundreds of friends and family members who use our Care Centre facilities. At the Event there was a tombola raffle, garden plants flower arrangements, a book stall, greeting cards, fiver Friday, old style sweet shop, photography live music and lots more. The event was attended by friends, family and volunteers and was a great success. Regionally there were events held throughout the country to mark the day, in Cork, Donegal, Limerick and Galway to name a few.

# FUNDRAISING 2018

## KISS GOODBYE TO MS BALL

The inaugural Kiss Goodbye to MS Ball was held at The Morrison Hotel Dublin on 26th May 2018. With 140 guests it was a fabulous night raising over €22,500 thousand and putting the Kiss Goodbye to MS campaign firmly on the map in Ireland. The culmination of a month long campaign, the aim of the ball was to raise as much as possible for local and international research projects and services. Speakers on the night included our own Aoife Kirwan, who spoke brilliantly about what MS Research means to her and other young people living with MS and our CE Ava Battles who spoke about her thoughts on the future in relation to MS Research.



Our MC on the night was Diana Bunici who did a fantastic job of running the show and was very encouraging when it came to asking people to dig deep for our raffle. The table raffle and Ring-a-Ruby went down a storm and our silent auction boasted items such as a signed rugby jersey's and a pair of bicycles kindly donated by our corporate partner SAP. All incredible prizes, which helped us raise much needed funds. The item that caused the biggest stir and a ferocious bidding war however, was the walk-on part on Fair City. Keep an eye out for Colm Murphy – next big thing – you heard it here first! The Luna boys provided the entertainment, ensuring everyone was up out of their seats and dancing for the night.

Huge shout out and thanks has to go to the KG TMS Ball committee, specifically Helen Murray and Niamh McCarron, who volunteered their time and were key in getting bums on seats and hunting down raffle prizes. All in all a successful first event.



## MS READATHON 2018

8,829 young readers and almost 283 schools took part in the 2018 Readathon. In doing so they read more than 80,000 books and raised an amazing €293,208 for people living with MS in Ireland. Bobby the Bookworm was the newest addition to the Readathon family and we'll be seeing more of him in 2019. There was great excitement at this year's launch in the print museum with members of the Leinster Rugby squad and students from the John Scottus School helping to get things off the ground. Quite literally!

Two Dublin schools really made the grade this year with St Fintan's in Sutton raising an incredible €7,832.80 and Scoil Bhríde in Ranelagh raising a whopping €8,973.20 including €600 raised by a sixth form cake sale. Shout out and huge THANK YOU to Panasonic Ireland for supporting our MS Readathon campaign and their generous donation of 30 sets of wireless headphones which were won by 30 lucky students

# FUNDRAISING 2018

## CALENDAR & NOVARTIS

Our 2018 calendar photography competition was a great success, with hundreds of amateur photographers submitting entries on the theme 'As Time Goes By'.

A huge thank you to Novartis for kindly funding our calendar campaign again this year.



## TREKS

2018 saw MS Ireland take a group of trekkers to Italy to follow the Via Francigena from Assisi to Rome on the pilgrim route of St Francis of Assisi. This was a really wonderful trek culminating with the final day walking in to St Peter's Square and a visit to the Vatican.

We also took a group to the Hashemite Kingdom of Jordan where we trekked from the Aljoun National Park in the North to Waddi Rum in the South via the Dana nature Reserve and the spectacular pink City of Petra.

## AD HOC SPORTS

We were lucky enough to have many people do a huge variety of sporting events and challenges to raise money and awareness for MS Ireland including: Hugh O'Malley who did the Iron Man Series, Hanna Vickers who did the Great Ireland Run; Rory O'Connell who did the Cork ½ Marathon and Michael Brennan who did the Kilkenny Medieval Marathon.



## DUBLIN CITY MARATHON

We had 25 runners in the 2018 Dublin City Marathon raising over €28k – a huge thank you to all those who ran and particularly those who are running again in 2019!



# FUNDRAISING 2018



## MINI MARATHON

The 2018 mini marathon had over 180 participants who raised over €47,000 for MS Ireland. We had great support from both individuals and groups. We started off with photos at the beginning of the race and ended up with a thank you event which is very much appreciated by the ladies after their run.

## SKYDIVE

MS Ireland has monthly skydives and there are many dare devils out there who want the thrill of jumping out of a plane. This is a tremendous fundraiser and a wonderful experience. Thank you to all those who have skydived for us.



## LEINSTER RUGBY SPONSORSHIP

In 2018, we were delighted to be announced as one of Leinster Rugby's Charity Partners for two seasons, running until May 2020. Leinster Rugby have been very supportive of MS Ireland, offering lots of support in various different ways. Players were able to launch our MS Readathon, as well as making a tailored video for Kiss Goodbye to MS. Our Matchday takeover Day will take place in April v Glasgow Warriors, which promises to be a very successful fundraising outing. Leinster Rugby also support with Match Day tickets for all home games for MS Ireland members, that can be raffled/auctioned off, as well as providing us with "Travel with the Team" away game trip that MS Ireland can use to raise much needed funds. We are looking forward with great excitement as to how this partnership grows over the next two years.

## GOLF

The Slade Valley Golf Club held the Pat Hoey Memorial Golf Day and the Kileen Castle Golf Club held their Charity Day for MS Ireland. We appreciate the support of the golfing community.



# FUNDRAISING 2018

## HARVEY NICHOLS

HARVEY NICHOLS

Recognised as the UK's & Ireland's premier luxury fashion retailer, Harvey Nichols Dundrum announced a two year Charity partnership with Multiple Sclerosis Ireland.

Staff of the internationally renowned retailer nominated MS Ireland as their chosen charity, and already have a lot of events planned throughout the year.



## ABSEIL

In 2018, we have had lots of fundraisers check one off the bucket list by scaling the heights of Croke Park, taking in the beautiful panoramic views of Dublin City, and then abseiling down to the hallowed turf below! Whether they were someone living with MS, taking part for a friend or family member, or simply overcoming their fear of heights, the Abseil has proved to be a very popular event.



## SAP

2018 saw the culmination of our two year Charity Partnership with SAP and what a two years it was! SAP staff engaged with MS Ireland in all manner of ways, everything from climbing the highest mountains in Europe, taking on the Hell and Back Challenge, their interns making bikes to auction off, painting the MS Ireland offices, and many, many, Volunteering days in the MS Care Centre, they really threw everything into the partnership. The fundraising efforts culminated in the "OsKars" event in Citywest, where they raised €25k for MS Ireland. Hats off all round!



## CHRISTMAS JUMPER DAY

So many companies from across Ireland got in the Christmas spirit to help out MS Ireland on our Christmas Jumper Day appeal. Some of the costumes were very 'unique', but everyone had a great time and raised over €20,000 for MS Ireland. A huge thanks to all those who took part – we are already looking forward to the 2019 pictures!

## PERRIGO



Our fantastic supporters Perrigo Company plc donated €40,000 for the refurbishment of our bedrooms in the MS Care Centre in 2017. These works are now complete, and are already having a hugely positive impact for our residents and staff there. Brian O'Broin, Ciara Cassidy & Dr. Grainne Quinn joined Olga Estridge our MS Ireland Services Manager for a cheque presentation last October. We are extremely grateful for the amazing generosity and continued committed support of Perrigo, the lasting impact that they have had on our MS Care Centre residents is second to none.

**AND MANY MORE.....**

**THANK YOU!**

Big **THANKS** to all our fundraisers, donors and supporters for their generosity throughout 2018. We couldn't do it without you!



## IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Organisational Capacity in 2018:

### TO ENABLE EFFECTIVE COMMUNICATIONS TO TAKE PLACE AT ALL LEVELS WITHIN MS IRELAND, INTERNALLY AND EXTERNALLY

- Media coverage secured on a variety of topics including World MS Day, Kiss Goodbye to MS and Irish Independent Neurology Supplement.
- Range of events and activities held up and down the country for World MS Day, 31st May.

### TO ENSURE THAT THE HUMAN RESOURCES AVAILABLE TO MS IRELAND ARE MOST EFFECTIVELY DEPLOYED IN PURSUIT OF OUR MAIN STRATEGIC PRIORITIES

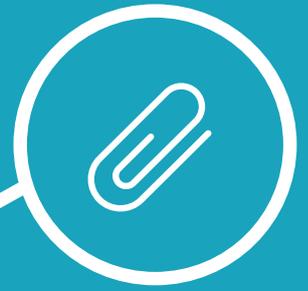
- Use of corporate volunteers in a number of capacities including administration, gardening and online marketing.
- Five new posts were filled throughout the country in the areas of finance, community work and branch liaison.

### TO ENSURE THAT A FUNCTIONAL BRANCH/ COUNCIL STRUCTURE EXISTS

- 16 Regional Integrated Meetings took place.

### TO ENSURE MS IRELAND REMAINS A VIABLE AND SUSTAINABLE ORGANISATION IN RELATION TO ITS FUNDING SITUATION, GIVING SPECIFIC ATTENTION TO FUNDRAISING; TO DIVERSIFY OUR FUNDING (PARTICULARLY FUNDRAISING) TO AVOID AN OVER-RELIANCE ON ONE CHANNEL I.E. READATHON

- World MS Day event held at Trinity College Dublin.
- MS Readathon raised €293,208.
- 2 year partnership with Leinster Rugby announced .
- Perrigo Raised €40,000 which was used to improve the MS Care Centre.
- 2nd annual I MS Ireland Kiss Goodbye To MS ball took place in May
- Continued cost saving measures in place across the organisation, including reduced staff hours and reduced opening hours at MS Care Centre.



## ACHIEVING GOVERNANCE & REGULATION

Continue to strengthen the governance and regulation of MS Ireland, ensuring compliance with relevant regulatory bodies.

### SPECIFIC OBJECTIVES:

- MS Ireland will continually review its own internal rules and regulations.
- Stronger working relationships between National Office/regions/branches to ensure that MS Ireland's governance structure is robust.

**IN 2018, THIS IS WHAT WE ACHIEVED IN  
GOVERNANCE & REGULATION**

## ACHIEVING IN GOVERNANCE & REGULATION

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### WHO WE ARE

MS Ireland is the only national organisation providing information, vital services and support to the MS community. We provide a wide range of specialised services and resources on a national, regional and local level. Services include: Regional Community Worker programmes for one-to-one support; physiotherapy; symptom management courses; newly diagnosed sessions and the MS Information Line, one of the first services used in the time leading up to or following a diagnosis. We also provide the only national respite and therapy centre for people with MS in Ireland. More than two-thirds of the 9,000 people

living with MS in Ireland access these resources. All those affected by the condition rely on MS Ireland to advocate on their behalf on any issues which will impact their quality of life.

### PATRON

MS Ireland is delighted to have Micheal D. Higgins, President of Ireland, as sole patron.

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### ORGANISATION DETAILS

#### AUDITOR

Deloitte  
Chartered Accountants and Statutory Audit Firm  
Deloitte & Touche House  
Earlsfort Terrace  
Dublin 2

#### PRINCIPAL BANKERS

Bank of Ireland  
College Green  
Dublin 2

#### SOLICITORS

Joynt & Crawford  
8 Angelsea Street  
Dublin 2

#### REGISTERED OFFICE

80 Northumberland Road  
Dublin 4

#### CHARITY NUMBER

CHY 5365

#### CHARITY REGULATORY NUMBER

20007867

#### COMPANY NUMBER

296573

#### DATE OF INCORPORATION

19th November 1998

#### YEAR MS IRELAND WAS FOUNDED

1961

# ACHIEVING IN GOVERNANCE & REGULATION

## THE BOARD

MS Ireland is governed by a board of 14 voluntary members. These members have a wide range of experience and skills. Some have MS themselves or have family members with MS. Others have long careers in business, social services and other areas. The Board promotes the

vision, aims and values of the Society and charges the Chief Executive to meet these aims through the various departments, services and resources of the Society. In 2018, the Board met seven times. Significant work was carried out in the areas of finance and funding, governance and strategy.



**BOARD MEMBER 2017/2018**



**BOARD MEMBER 2018/2019**

 CHAIRPERSON	 VICE CHAIRPERSON			
● Marcella ● Flood	● Maurice ● O'Connor	● Robin ● Bradley	● Noelle ● Burke	● Thomas ● Cronin
				
● Edwina Dunne	● Eugene ● Kearney	● Jacinta ● Kelly	● Rory ● Mulcahy	● Ian ● MacDougald
				
● Martin ● Power	● Anne ● Restan	● Mary ● Sheahan Lonergan	● Paddy Stronge	

**RESIGNATIONS/CHANGES**

Paddy Stronge (Resigned 22nd September 2018)

**APPOINTMENTS**

Edwina Dunne (Appointed 22nd September 2018)

## ACHIEVING IN GOVERNANCE & REGULATION

### THE BOARD

#### BOARD COMMITTEES

A number of Board committees inform and complement the work of the Board. Each committee is made up of Board members and others who have

particular interests, experiences and knowledge relevant to the work of the committee.. The Board Committees include the following.

- » Finance, Audit and Risk Committee
- » Governance Committee
- » Nominating Committee
- » Remuneration Committee
- » Research Committee
- » Services Monitoring & Evaluation Committee
- » Strategic Planning and Fundraising Committee

As the need arises, a number of staff and external professionals will be asked to sit on these committees.

#### BOARD ATTENDANCE 2018

	3 FEB	14 APR	26 MAY	30 JUN	22 SEP (i)	22 SEP (ii)	1 DEC	TOTAL
Robin Bradley	x	✓	✓	✓	x	x	✓	4/7
Noelle Burke	✓	x	✓	x	✓	x	✓	4/7
Thomas Cronin	✓	x	✓	✓	✓	✓	✓	6/7
Edwina Dunne	n/a	✓	✓	✓	✓	x	x	4/6
Marcella Flood	✓	✓	✓	✓	✓	✓	✓	7/7
Eugene Kearney	✓	✓	✓	✓	✓	x	✓	6/7
Jacinta Kelly	✓	✓	✓	x	✓	✓	✓	6/7
Ian MacDougald	✓	✓	✓	✓	✓	✓	✓	7/7
Rory Mulcahy	✓	x	x	✓	✓	✓	✓	5/7
Maurice O'Connor	✓	✓	✓	✓	x	x	✓	7/7
Martin Power	✓	✓	✓	✓	✓	✓	✓	7/7
Anne Restan	✓	✓	✓	✓	✓	✓	✓	7/7
Mary Sheahan-Lonergan	✓	x	✓	x	✓	✓	✓	5/7
Paddy Stronge	✓	✓	x	x	✓	n/a	n/a	3/5

Martin Nolan, Chairman of Finance Audit and Risk Committee is a standing invitee of the Board meeting.

Edwina Dunne was co-opted on to the board on February 3rd 2018.

### THE BOARD

#### CONFLICTS OF INTEREST AND LOYALTIES

At every Board meeting, members are asked to state if they have a conflict of interest and/or conflict of loyalty. A register is kept and Board members are asked to complete a form stating their conflict of interest if they have one. MS Ireland also has a Conflict of Interest and Conflict of Loyalty policy.

#### RECRUITMENT AND INDUCTION OF BOARD MEMBERS

Three of our 14 Board Members vacancies are filled on a rotational basis from the council branch representatives. Notification of the remaining vacancies for Board members is advertised in MS News, eNews and on the MS Ireland website. Prospective Board members complete an application form which is considered by the Nominating Committee who then make recommendations to the Board. Once approved by the Board, the chosen candidates stand for election by the members at the AGM. In 2018 one Board member was elected under Article 56 of the Constitution who, with the support of fifteen members, was elected by going directly to the AGM rather than via the Nominating Committee election process.

New Board members are given one afternoon's induction training by the CEO to familiarise them with their duties as Board members, their legal obligations, the governance of the organisation and policies and procedures. Further training can be made available if required.

#### BOARDMATCH IRELAND TRANSPARENCY SCALE

MS Ireland complies with the standards contained in Boardmatch Ireland's Transparency Scale 'A' Standard.

#### SKILLS AND EXPERIENCE

Annually the Nominating Committee with the CEO determine the skills required on the Board. When the Nominating Committee recommend candidates to the Board, they ensure that the skills gap is filled. Candidates are required to be committed to MS Ireland's development, share in its values and be problem solving in their approach as well as having proven professional skills. MS Ireland's Board members have expertise in a wide range of areas including accounting, legal, banking, HR and strategic marketing. For full board profiles log on to our website, [www.mssociety.ie](http://www.mssociety.ie)

#### LENGTH OF TERMS SERVED BY THE BOARD

A Board member is elected on to the Board for a period of three years. The Board member can opt to stand for re-election for a further three years. Each board member can serve no more than three terms of three years on the Board so a maximum of nine years' service as a Board member is permitted.

#### DECISION MAKING PROCESSES

Decisions reserved for the board and those delegate to CEO are listed in the organisations Code of Conduct. Schedule of Matters of the Board are detailed in the Code of Conduct. Log on to our website to read the Code of Conduct: [www.ms-society.ie](http://www.ms-society.ie)

#### RISK MANAGEMENT POLICIES AND PROCESSES

Risks are detailed in a Risk Register which is reviewed by the Board, the Finance, Audit and Risk Committee and the senior management team on a regular basis.

## ACHIEVING IN GOVERNANCE & REGULATION

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### ENGAGEMENT WITH STAKEHOLDERS

MS Ireland communicates with its stakeholders via email, eNews, the website, social media, MS News, council meetings, regional integrated meetings, staff meetings and through correspondence and meetings with third parties.

### GOVERNANCE/ADMINISTRATIVE DETAILS

MS Ireland is the only national organisation working for people and families living with MS. It is a limited company with charitable status. It is governed by a Board of Directors, which is accountable for the financial dealings and overall execution of the Society's vision. MS Ireland's structure enables it to develop as an organisation that continuously meets the needs of the MS community in a professional and accountable manner.

### COMPANY SECRETARY

The CEO Ava Battles is appointed as Company Secretary. Although this is not in line with best practice required by the Governance Code, MS Ireland has a dedicated Governance Committee of the Board which meets regularly and are satisfied that this ensures governance processes and controls are appropriate and the necessary checks and balances are in place.

### THE COUNCIL

MS Ireland's Council is a representative body of the voluntary Branch network. It encourages communication on a range of issues and enhances co-operation between all structures of the Society. In 2018 the Council met three times nationally. All Branches are represented on the Council. Three Council members are elected by Council representatives and sit on the Board of Directors.

### VOLUNTARY BRANCHES

We have 34 voluntary Branches operating across Ireland. See page 14 and 15 for more information on the wonderful work of our Branches.

### MANAGEMENT AND STAFF

The management and staff carry out the day to-day activities of the Society through various services, departments and facilities. These are directed by the Senior Management Team, headed by the Chief Executive. MS Ireland employs 65 people across national and regional offices and 50 Community Employment participants. MS Ireland's work is supported by committed volunteers around the country.

## ACHIEVING IN GOVERNANCE & REGULATION

### MS. AVA BATTLES, CHIEF EXECUTIVE

#### MS. MEMORY CHIPERE

FINANCIAL  
ACCOUNTANT

#### MS. OLGA ESTRIDGE

SERVICES  
MANAGER

#### MR. AIDAN LARKIN

SERVICES DEVELOPMENT  
MANAGER

## REMUNERATION

The number of employees whose emoluments, excluding employer pension contributions, were greater than €70,000 in 2018 is set out below:

1

€70,000 - €80,000

0

€80,000 - €90,000

1

€90,000 - €100,000  
(CEO)

The Remuneration Committee, a sub-committee of the Board, is responsible for making decisions regarding remuneration of the senior management team and those who report directly to the Chief Executive.

## CODES OF PRACTICE

MS Ireland operates in accordance with a number of codes applicable to our work. These codes are a combination of best practice guidelines, policies and procedures that protect the people we work with and ensure that our work is transparent and above reproach.

## THE GOVERNANCE CODE

MS Ireland is fully committed to the standards outlined in the Governance Code. We commit to:

- » Leading our organisation
- » Exercising control over our organisation
- » Being transparent and accountable
- » Working effectively
- » Behaving with integrity

On 13th July 2013 the Board signed up to the principles of Good Governance in the Governance Code.

On 28 Jan 2017 the board certified its compliance with the governance Code with 2 exceptions:

2.1 (b) The CEO is appointed as Company Secretary. MS Ireland has a dedicated Governance Committee of the Board which meets regularly and are satisfied that this ensures governance processes and controls are appropriate and the necessary checks and balances are in place

2.2 (e) MS Ireland does not have an internal audit function. Given the size of the organisation, we have sufficient controls in place and oversight of the controls. All branches are required to have an annual independent audit of their accounts.

In 2017 MS Ireland became a member of the Charities Institute of Ireland Triple Locked Standard – Best Practice in Transparency and Accountability.

## ACHIEVING IN GOVERNANCE & REGULATION

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### GUIDING PRINCIPLES FOR FUNDRAISING

The Statement of Guiding Principles for Fundraising is a guide to best practice developed by a steering group set up in response to the Charities Act 2009. MS Ireland is fully committed to achieving the standards contained within the Statement of Guiding Principles for Fundraising.

#### The Statement exists to:

- » Improve fundraising practice.
- » Promote high levels of accountability and transparency by organisations fundraising from the public.
- » Provide clarity and assurances to donors and prospective donors about the organisations they support.

### NATIONAL FINANCIAL ASSISTANCE REGULATIONS

MS Ireland can offer financial assistance to people with MS to help cover the costs of some expenses associated with the condition. Voluntary Branches raise this money through their fundraising activities.

### CODES OF GOOD PRACTICE TO PROTECT CHILDREN

MS Ireland is fully committed to safeguarding the well-being of all the children and young people with whom we work. Our policy on child protection is in accordance with Children First, the national guidelines for the protection and welfare of children.

### VULNERABLE ADULT PROTECTION POLICY

MS Ireland is dedicated to implementing and promoting measures to protect the right of all service users to be treated with dignity and respect and is committed to ensuring that the organisation provides a safe environment which is free from all forms of abuse, including discrimination, bullying, harassment or sexual harassment, neglect and mistreatment. In achieving this aim, MS Ireland is committed to ensuring that there are policies, procedures, guidance and training for staff and service users that prevent any infringement of this right.

**Log on to our website for further details of all the Codes of Practice MS Ireland subscribes to:**

**[www.ms-society.ie](http://www.ms-society.ie)**

## ACHIEVING IN GOVERNANCE & REGULATION

### FINANCIAL STATEMENTS

The financial statements are prepared under the historical cost convention, in accordance with the Statement of Recommended Practice (SORP) FRS 102 (Revised 2015) "Accounting and Reporting by Charities (SORP 2015)" applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), effective 1 January 2015; and the Companies Act 2014. Financial reporting in line with SORP is considered best practice for charities in Ireland.

### FINANCIAL RESULTS FOR THE YEAR

There was a net incoming resource before exceptional items of €314,853 for the year (2017: €397,448). There was a surplus of €1,759,853 for 2018 after exceptional items. The exceptional items totalled €1,445,000 and are comprised of

investment property of €1,375,000 and property held for resale of €70,000 arising from restricted legacies. Income for the year includes significant Legacies/Donations totalling €178,568 (2017: 175,381). Most of our donors are now restricting funds they give to us and this is putting the organisation under pressure to fund the existing day to day operations.

### FINANCIAL POSITION AT THE END OF THE FINANCIAL YEAR

The fund balances totalled €9,121,312 (2017: €7,361,459) at the end of the financial year. They are comprised of restricted funds of €3,068,374 (2017: €1,575,967) and unrestricted funds of €6,052,938 (2017: €5,785,492)

### THESE FUNDS ARE REPRESENTED BY THE FOLLOWING:

	NATIONAL OFFICE & CEP	BRANCHES	TOTAL
	€	€	€
Tangible Fixed Assets	4,715,838	55,732	4,771,570
Investment properties	1,375,000	-	1,375,000
Net Current Assets (excl. Bank loan)	2,880,393	1,323,232	4,203,625
Bank Term Loan	(1,228,883)	-	(1,228,883)
<b>TOTAL</b>	<b>7,742,348</b>	<b>1,378,964</b>	<b>9,121,312</b>

The tangible fixed assets of the National Office are comprised mainly of the premises at Northumberland Road and Bushy Park Road, Dublin.

### RESERVES POLICY

MS Ireland defines its reserves as its total unrestricted funds. In planning and budgeting for its activities, the company considers the level of unrestricted reserves to maintain a balance between the need to safeguard the continuity

and development of its services and the need for prudent management of its activities as well as providing for contingencies. The Board aims to maintain its total unrestricted reserves level at three months operating costs.

## ACHIEVING IN GOVERNANCE & REGULATION

### EXTRACT FROM AUDITED FINANCIAL STATEMENTS

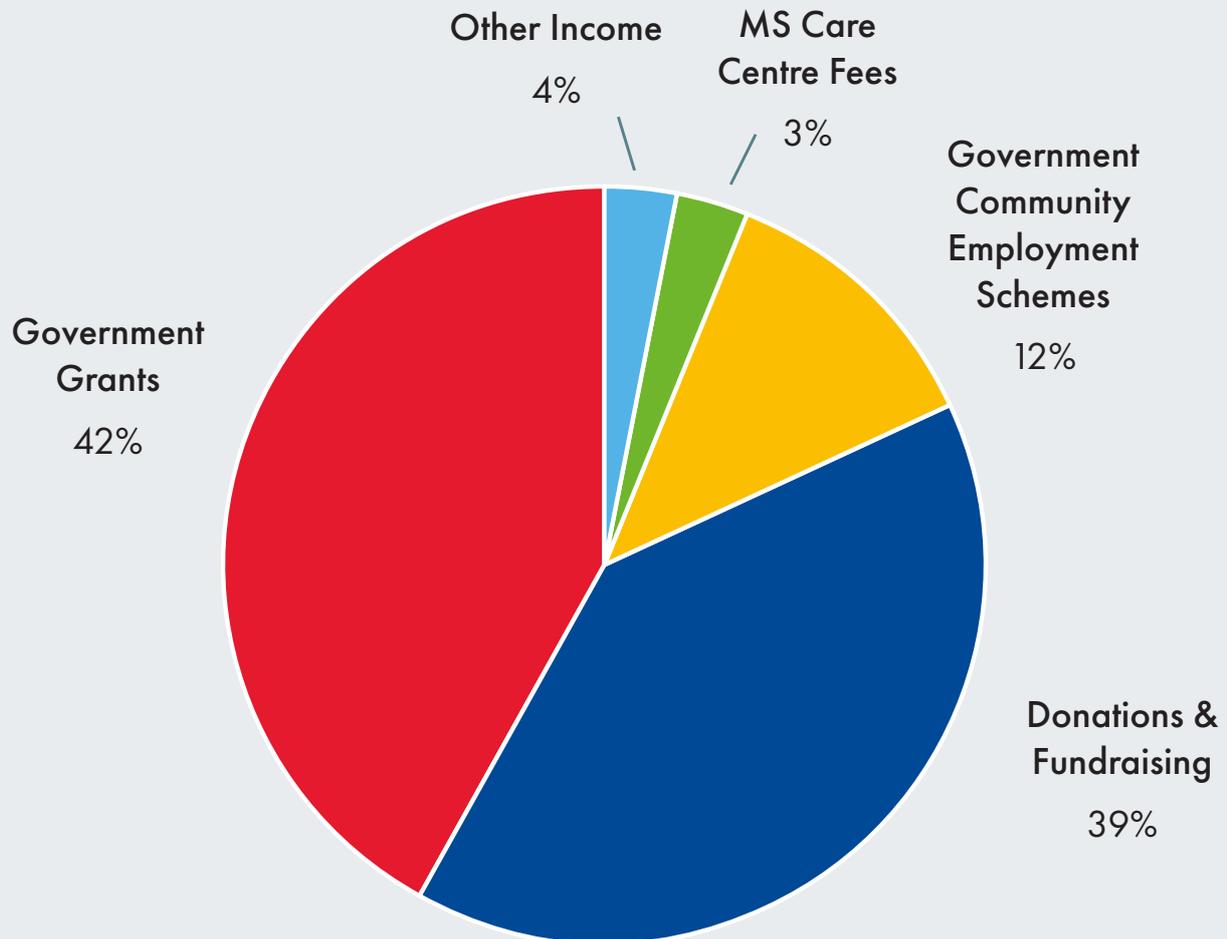
	Unrestricted Funds 2018 €	Restricted Funds 2018 €	Total Funds 2018 €	Total Funds 2017 €
<b>INCOMING RESOURCES</b>				
Income from generated funds				
<b>Voluntary Income</b>				
Donations and fundraising	2,123,457	231,297	2,354,754	2,581,294
Legacies	151,500	27,068	178,569	175,381
Research	-	58,600	58,600	47,930
Subscriptions	1,442	-	1,442	3,280
<b>Income from charitable activities</b>				
Fees received	206,339	-	206,339	213,553
Grants and other service contract income	-	2,784,667	2,784,667	2,695,672
Government schemes	-	784,161	784,161	796,662
Other income	34,962	191,652	226,613	206,692
<b>Total incoming resources</b>	<b>2,517,700</b>	<b>4,077,445</b>	<b>6,595,145</b>	<b>6,720,464</b>
<b>RESOURCES EXPENDED</b>				
<b>Costs of generating voluntary income</b>				
Fundraising	691,422	150,376	841,798	773,632
<b>Charitable activities</b>				
Community services	7,577	2,593,992	2,601,569	2,587,540
Respite care services	13,502	1,920,273	1,933,775	1,976,494
Research	18,394	36,592	54,986	109,693
Local MS services	640,781	207,383	848,164	875,657
<b>Total resources expended</b>	<b>1,371,676</b>	<b>4,908,616</b>	<b>6,280,292</b>	<b>6,323,016</b>
Net income/(expenditure) for the year before exceptional items	1,146,024	(831,171)	314,853	397,448
<b>Exceptional items</b>	<b>-</b>	<b>1,445,000</b>	<b>1,445,000</b>	<b>(1,052,557)</b>
<b>Net income/(expenditure for the year)</b>	<b>1,146,024</b>	<b>613,829</b>	<b>1,759,853</b>	<b>(655,109)</b>
Transfer between funds	(878,578)	878,578	-	-
<b>Net movement in funds</b>	<b>267,446</b>	<b>1,492,407</b>	<b>1,759,853</b>	<b>(655,109)</b>
<b>Reconciliation of Funds:</b>				
<b>Total funds brought forward</b>	<b>5,785,492</b>	<b>1,575,967</b>	<b>7,361,459</b>	<b>8,016,568</b>
<b>Total funds carried forward</b>	<b>6,052,938</b>	<b>3,068,374</b>	<b>9,121,312</b>	<b>7,361,459</b>

INCOME ANALYSIS 2018

€6,595,145

Income of €6,595,145 was received of which 42% was funding from Government Grants mainly HSE, 39% was Donations and Fundraising, 12% was from 3 Department of Social Protection schemes we have in Donegal, Galway and Dublin, 3% was from fees received from Respite Centre residents and 4% from miscellaneous income.

	2018 (€)	2017 (€)
Government Grants	2,784,667	2,695,672
Donations & Fundraising	2,591,923	2,804,605
Government Community Employment Schemes	784,161	796,662
MS Care Centre Fees	206,339	213,553
Other Income	228,055	209,972
<b>TOTAL</b>	<b>6,595,145</b>	<b>6,720,464</b>



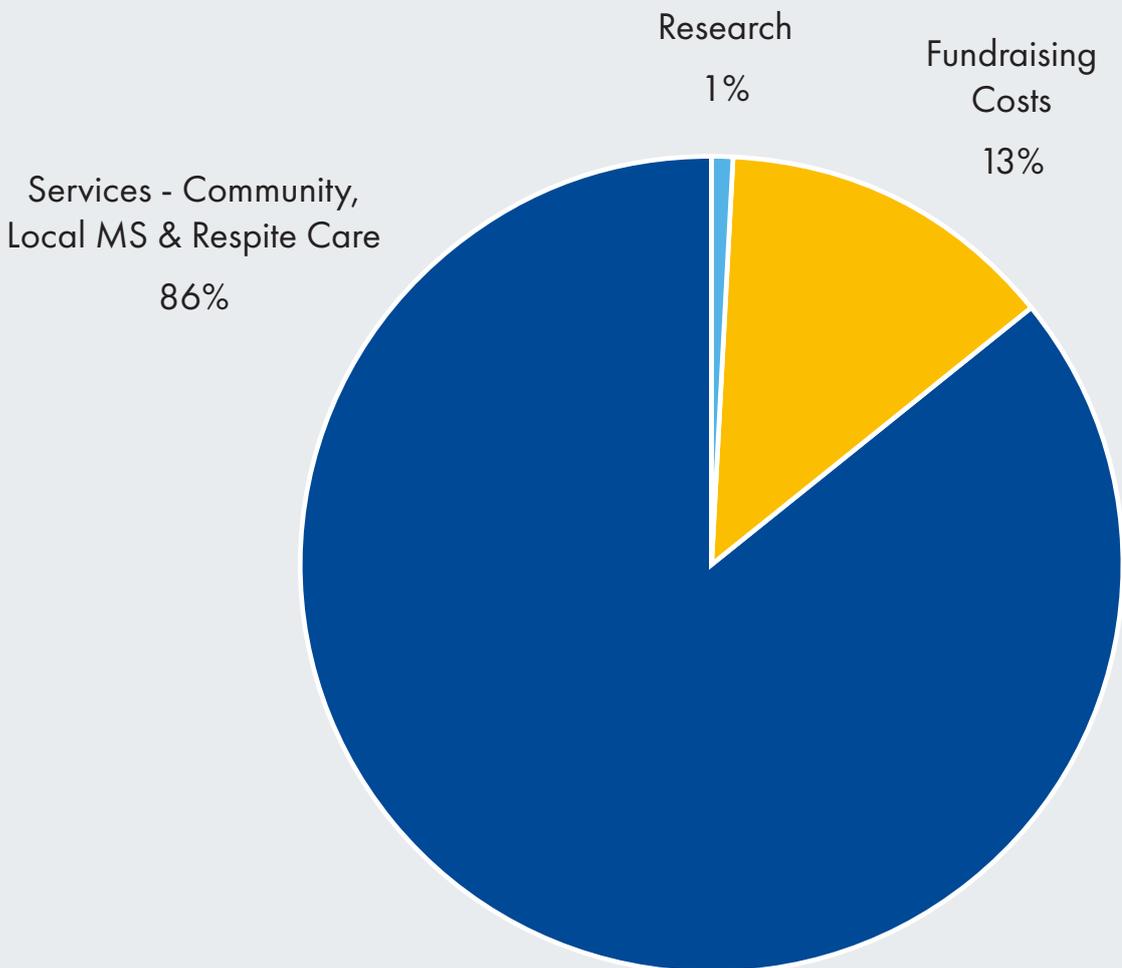
## OPERATIONAL EXPENDITURE ANALYSIS 2018

(excluding exceptional items)

# €6,280,292

€6,280,292 was spent in 2018 of which 86% was spent on Community services and Care Centre respite services, 13% Fundraising and 1% on research.

	2018 (€)	2017 (€)
Services - Community, Local MS & Respite Care	5,383,508	5,439,691
Fundraising Costs	841,798	773,632
Research	54,986	109,693
<b>TOTAL</b>	<b>6,280,292</b>	<b>6,323,016</b>



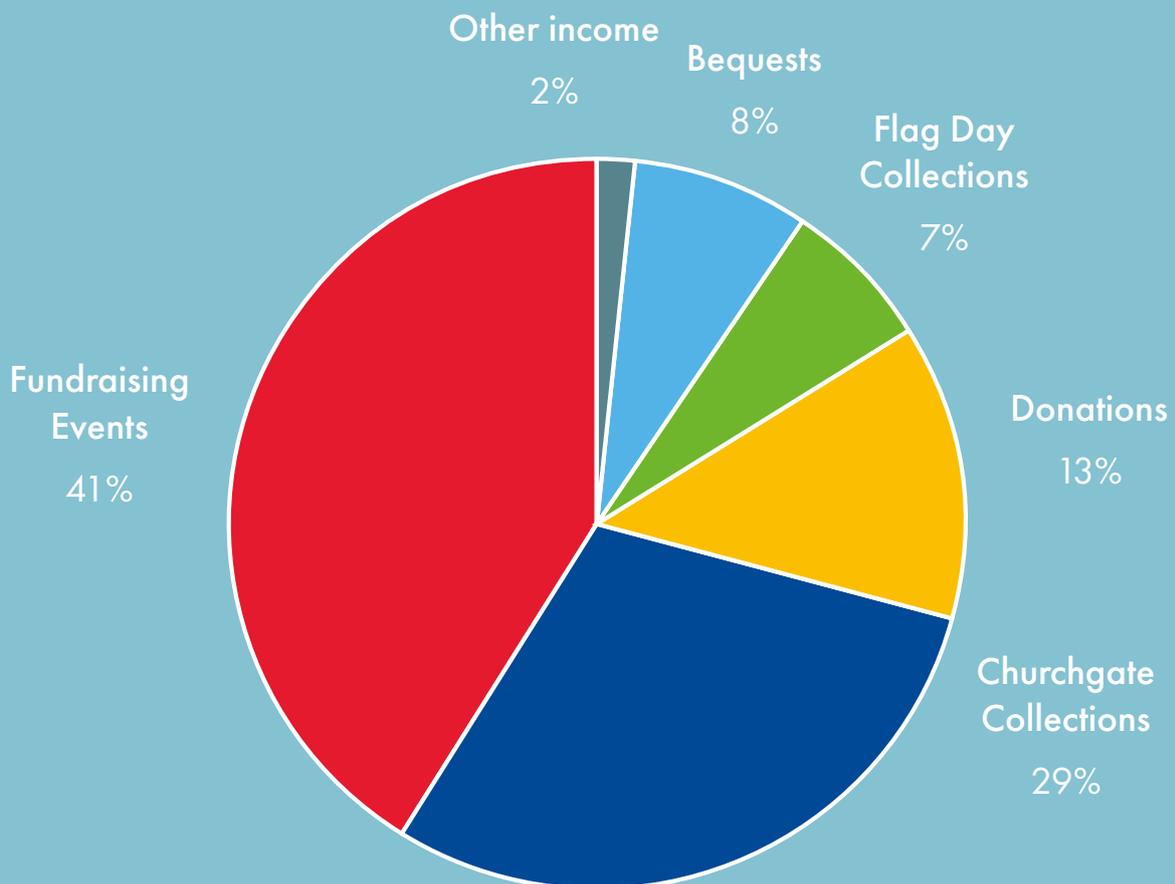
BRANCH INCOME ANALYSIS 2018

€898,524

There were 34 Branches in operation during the year. All the funds raised in the Local Branches is spend locally to provide services for people with MS.

Income of €898,524 was received of which 41% was raised from fundraising events, 29% from churchgate collections,13% from Donations, 7% from Flagdays collection, 8% from Bequests and 2% was from other income such as bank interest, christmas party contributions, etc

	2018 (€)	2017 (€)
<span style="color: red;">■</span> Fundraising Events	369,012	434,291
<span style="color: blue;">■</span> Churchgate Collections	265,151	288,510
<span style="color: yellow;">■</span> Donations	118,159	129,637
<span style="color: green;">■</span> Flag Day Collections	61,125	78,904
<span style="color: lightblue;">■</span> Legacies	70,000	62,013
<span style="color: grey;">■</span> Other income	15,077	12,551
<b>TOTAL</b>	<b>898,524</b>	<b>1,005,906</b>

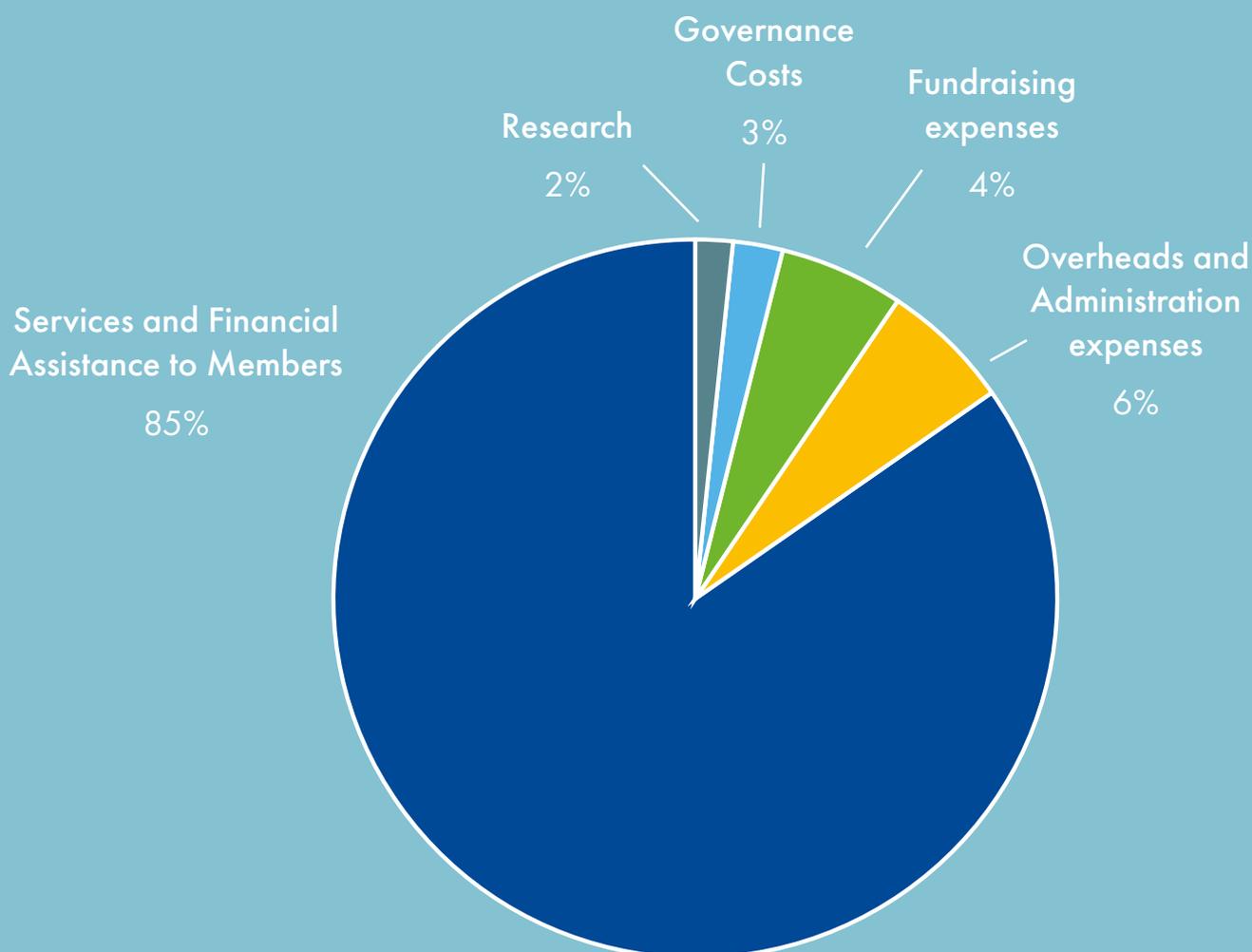


BRANCH EXPENDITURE ANALYSIS 2018

€914,751

€914,751 was spent in 2018 of which 85% was spent on providing services & Financial services to members, 4% on fundraising expenses, 6% Overheads and Administration expenses, 3% Governance and 2% on Research.

	2018 (€)	2017 (€)
Services and Financial Assistance to Members	775,594	783,147
Overheads and Administration expenses	56,536	53,749
Fundraising expenses	39,995	50,351
Governance Costs	25,234	22,748
Research	17,393	15,707
<b>TOTAL</b>	<b>914,751</b>	<b>925,702</b>





## IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Governance & Regulation in 2018:

### MS IRELAND WILL CONTINUE TO REVIEW ITS OWN INTERNAL RULES AND REGULATIONS

- Significant work was carried out by the Board and sub-committees in the areas of:
  - » Finance and funding,
  - » Governance and strategy,
  - » Compliance with Governance Code,
  - » Guiding Principles for Fundraising,
  - » Boardmatch Ireland Transparency Scale,
  - » National Financial Assistance Regulations,
  - » Codes of Good Practice to Protect Children,
  - » Vulnerable Adult Protection Policy.

### STRONGER WORKING RELATIONSHIPS BETWEEN NATIONAL OFFICE/REGIONS/ BRANCHES TO ENSURE THAT MS IRELAND'S GOVERNANCE STRUCTURE IS ROBUST

Three meetings of the Council, the representative body of MS Ireland's Branch network, were held in 2018.



**An Roinn Tithíochta, Pleanála,  
Pobail agus Rialtais Áitiúil**  
Department of Housing, Planning,  
Community and Local Government



**pobal**

government supporting communities

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