

MS IRELAND

ANNUAL REPORT & ACCOUNTS

2019



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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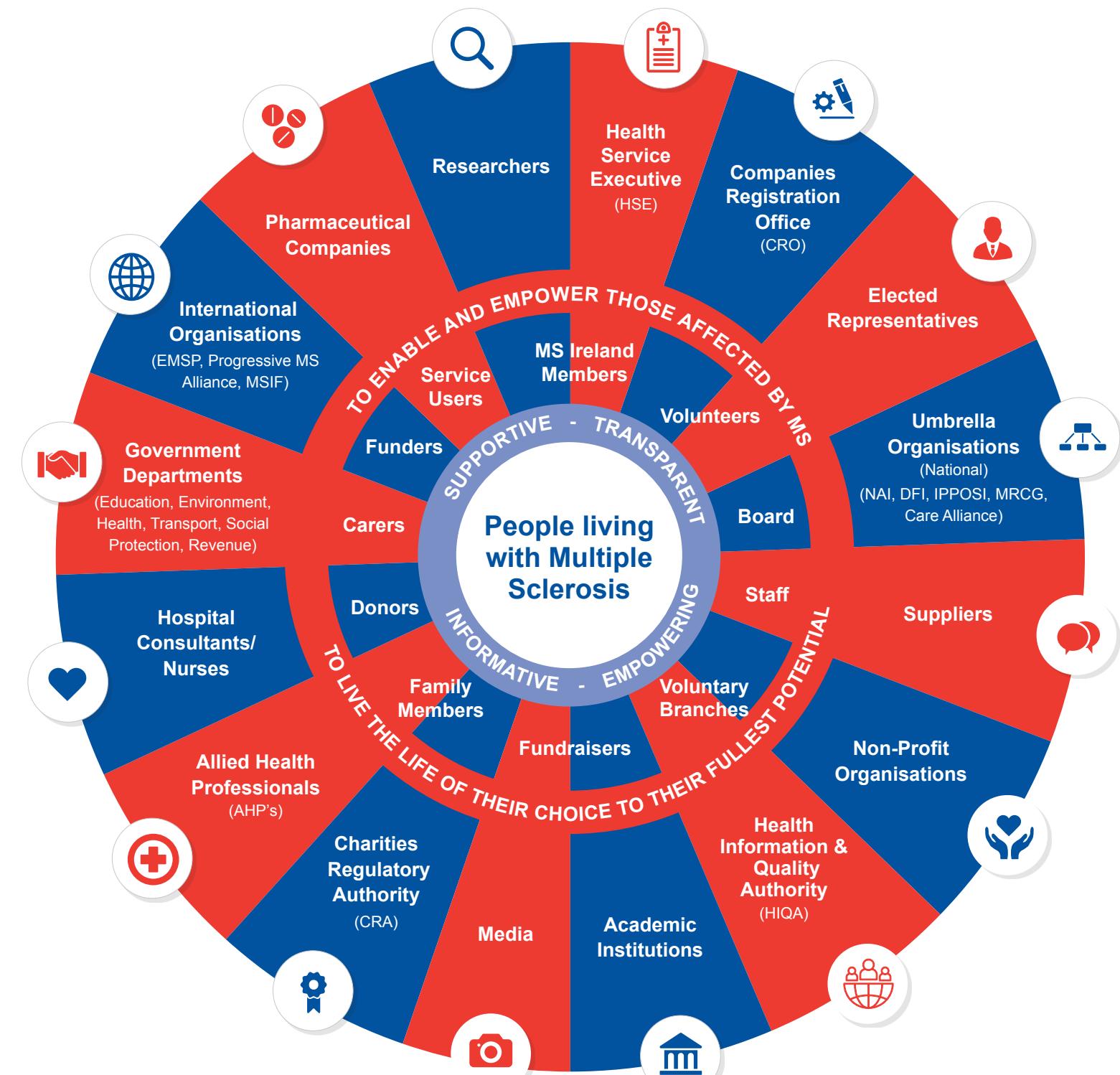
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STAKEHOLDER MAP





CHIEF EXECUTIVE & CHAIRPERSON WELCOME

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 throughout 2019. While we continue to operate in a challenging environment with restrictions on funding, nevertheless, 2019 was an exciting and thoroughly encouraging year. MS Ireland's dedicated team of staff and volunteers throughout the country have remained as steadfast as ever in their determination, have achieved a great deal, and have continued to work on behalf of people affected by MS in Ireland. This report will highlight and celebrate the successes, achievements and challenges that the organisation has faced over the last 12 months.

We continued working with the Neurological Alliance of Ireland (NAI) and its members on neurorehabilitation. In February 2019, the National Neuro-rehabilitation Implementation Strategy was published. This strategy encompassed a ten-step plan to develop neuro-rehabilitation services in Ireland over a three-year period which MS Ireland contributed to.

Throughout the year, we continued our work with the Disability Federation of Ireland (DFI), who advocate on behalf of people living with disabilities. The highlight of 2019 was an event held in DFI offices with Minister for Health Simon Harris and Minister of State for Disability Issues Finian McGrath, in relation to an announcement of an increase in the earnings disregard for people in receipt of disability allowance who are applying

for a medical card. This was a recommendation made in the 'Make Work Pay' report that MS Ireland was involved in.

We were lucky to have been given our very own 'MS House', which was kindly donated to us by Merck pharmaceuticals. The house, which was a portable demonstration unit, allowed people to experience first-hand some of the symptoms and challenges that people living with MS may face, even as they go about their daily tasks in their own homes. The MS house was brought to some of our large events throughout the country, such as our national conference in Limerick and our Care Centre in Dublin on World MS Day, and it received a fantastic response from our community.

CHIEF EXECUTIVE & CHAIRPERSON WELCOME



In 2019, we were also delighted to launch our new website www.ms-society.ie. Our old website felt a bit stale as it had remained relatively unchanged for over 10 years, so, it was long overdue a refresh! The website project took over a year to complete, and involved several months of meticulous research, planning, and content creation involving the whole organisation. Our website is an extremely vital information source for people living with MS, their friends, families and carers, and is also used by our brilliant fundraisers to sign up for our various campaigns. The new website has made fundraising easier with new payment options for our donors and increased functionality while the website is fully optimised for all screens, phones and tablets. We really look forward to seeing how our new site grows and develops in the digital age.

Last year, we also carried out our first national survey of the general public on their awareness and understanding of Multiple Sclerosis. This survey was carried out in partnership with

Novartis and Ipsos MRBI, in which over 1,000 members of the public were asked questions on all things MS-related, testing their knowledge of the condition. The survey brought some interesting results, with 44% of the population having either a poor or a limited understanding of MS, while 1 in 3 people claimed to have a friend or family member living with MS. The results from the survey were used to shape our strategic plan.

In February, we were delighted to learn the news that the famed Irish band Stockton's Wing had reunited and announced both a new tour and single, 'We Had It All'. The band kindly decided to donate all proceeds from the sale of their new single to MS Ireland, and also launched the track at a really special event in our National MS Care Centre. On the day, the staff and residents were treated to some brilliant live performances by the band and special guest Finbarr Furey in what was a truly memorable afternoon. The band toured throughout Ireland in 2019, promoting MS Ireland along the way.

CHIEF EXECUTIVE & CHAIRPERSON WELCOME

The MS Information Line, MS Care Centre and our regional services continued to be very busy, providing vital support, information and services to the MS community despite having very limited resources. World MS Day 2019 was a great success, with our team using the theme of 'visibility' and the hashtag #MyinvisilbeMS. The Invisible MS campaign concentrated on raising awareness of the invisible symptoms of MS and the unseen impact MS can have on a person's quality of life.

After the overwhelming success of last year's inaugural event, we held a second MS Explored event in October, which was created for the interests of younger people living with Multiple Sclerosis. This year's MS Explored topics included Young People and MS, Navigating Work Life, Relationships and Intimacy, and Fitness, which were all led by keynote speakers from various fields including neurology, career psychology, sexuality education, occupational therapy, and neurological rehabilitation. On the day, there was an active fitness workshop which included a movement session, encouraging and empowering those with MS to incorporate a fitness regime into their daily lives.

Our annual conference and Healthcare Professionals Day took place in September in Limerick. The theme was a continuation of the World MS Day theme #myinvisibleMS, highlighting the array of invisible symptoms people with MS can experience. We had some brilliant speakers at the conference including the renowned Professor Alan Thompson, who spoke about the work of the Progressive MS Alliance, and Dr. Jennifer Wilson O'Raghallaigh, who spoke about symptom management. We held several workshops throughout the day on topics related to Multiple Sclerosis, brain health, and invisible symptoms. We decided to take advantage of live streaming in 2019, and we also recorded all our major conferences and events, to allow us to reach as wide an audience as possible.

Our fundraising team celebrated the 32nd year of our flagship fundraiser the MS Readathon, which was launched by Lucy Kennedy and star pupils from John Scottus primary school at the National Museum of Ireland. In 2019, over 349 schools took part in the Readathon, with over 10,400 readers raising a grand total of €350,000. Some other fundraising activities included skydives, treks, the ever-popular Women's Mini Marathon, and our abseil challenge, amongst many other exiting campaigns. In 2019, we were delighted to continue our exciting partnership with the Leinster Rugby team. In both April and December, we had 2 match day takeovers at the RDS. MS Ireland volunteers where on hand around the grounds of the RDS.

In 2019, our MS and Me blog remained an ever-popular and valuable information source for the MS community. 2019 was the second year for our new blogging team as they shared their inspirational stories with our readers in Ireland and all over the world. The team held their annual bloggers meet-up in Limerick after our annual conference, where they had a planning day and a writing workshop. We look forward with great anticipation to see what this talented group will bring in 2020 and beyond.

2019 was the final year of our strategic plan of 2014 to 2019, and while we met most of our strategic aims that were set, we will continue to work on those where we may have come up short. Throughout the course of 2019, work began in establishing our strategic aims for the next 5 years, which include goals that together, as an organisation, we will strive to accomplish. In early January, a strategic planning group was created from all functions of the organisation, our branches, regional community workers, fundraising, information, communication, and from members of the board. During the process, a questionnaire was created and distributed to all our community members in order for the group to gain a real, data driven understanding of the

CHIEF EXECUTIVE & CHAIRPERSON WELCOME

pressing issues facing the MS community as we look ahead to the future. Together this group began the lengthy process of determining the key strategic priorities that we as an organisation should focus on for the next 5 years, all with the aim of enabling and empowering people with MS to live the life of their choice to their fullest potential. We were astounded at how well the group worked, displaying their true dedication to the task at hand, and we very much look forward to announcing our strategic plan in 2020.

None of our achievements in 2019 would have been possible without the dedication and pure devotion 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 voluntarily give their time and expertise 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, what we stand for, and what we do. We anticipate more challenges and uncertainty for the organisation in the future but we will never lose sight of our vision, which is of an Irish society where all people affected by MS can 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 making this vision a reality in the year ahead. With your support, this is entirely achievable.

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

The signature of Ava Battles, written in black ink.

AVA BATTLES
CHIEF EXECUTIVE

The signature of Marcela Flood, written in black ink.

MARCELLA FLOOD
CHAIRPERSON

STRATEGIC PRIORITIES

2019 was the fifth and final 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

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

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



ADVOCACY

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

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



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.

**Log on to our website to read the full strategic plan:
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 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 through a variety of media types, appropriate to the needs of the various audiences.
- Information will be shared across strategic alliances to ensure the most up to date information is available.

IN 2019, THIS IS WHAT WE ACHIEVED IN SERVICES

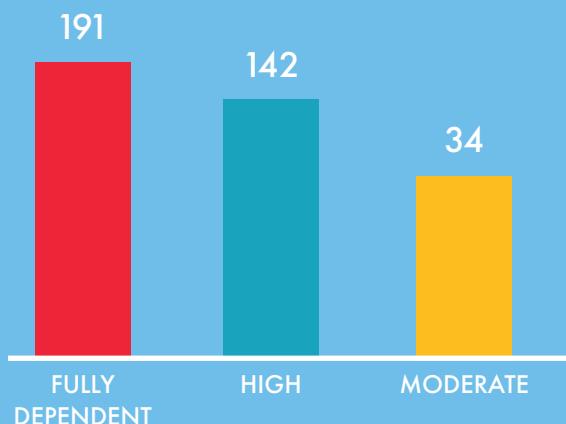
ACHIEVING IN SERVICES

THE MS CARE CENTRE

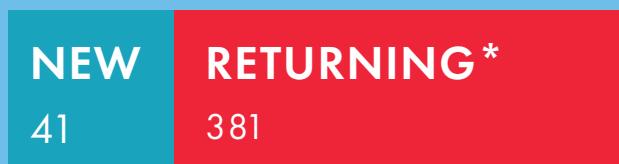
Our MS Care Centre, which provides short-term respite care, is the only respite and therapy centre for people with MS in Ireland. During a 5, 7 or 12 night stay, a resident can avail of therapeutic services, neurological assessments, access to an MS nurse, and a range of social activities to allow for complete rest and recuperation. In 2019 the MS Care Centre provided professional, dedicated care for 422 people. A true 'home away from home' for our residents, our highly trained staff and specialised equipment ensure 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 upgrades and improvements to ensure the continued safety, comfort and enjoyment of the Centre.

In 2019 we replaced the old broken decking outside six bedrooms and the sunroom with new composite decking. We installed an automatic closure on the front door. To comply with fire regulation we installed some new fire doors and automatic closures on all internal doors. We bought 1 new bed and two new hoists and replaced some wardrobes. We updated the sunroom in memory of Margaret Maguire (new blinds, plaque, painted).



We got a new bus (after 20 years!) and we got some roof repairs carried out.

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.

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

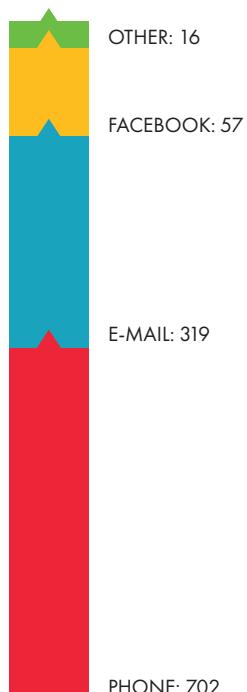


THE MS INFORMATION LINE

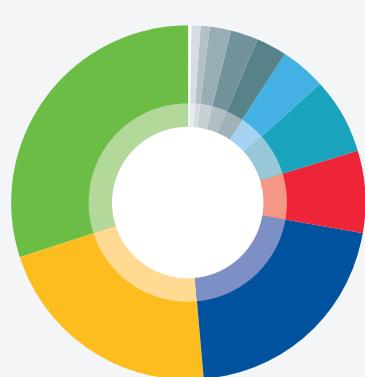
Operating weekdays from 10am-2pm, our dedicated information line provides professional, anonymous and confidential support for people with MS, their families, carers and health professionals.

In 2019, **1,243** people contacted the MS Information Line.

HOW PEOPLE MADE CONTACT



REASON FOR MAKING CONTACT



395	GENERAL INFO
258	HELPLINE SUPPORT
276	TREATMENTS
95	INSURANCE
79	ENTITLEMENTS AND SERVICES
57	ACCESSIBILITY
35	RESEARCH
26	QUERY DIAGNOSIS
9	SHORT-TERM RESPITE
6	COUNSELLING
5	TRANSPORT
2	LONG-TERM CARE

ACHIEVING IN SERVICES

REGIONAL SERVICES

Our Regional Offices 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

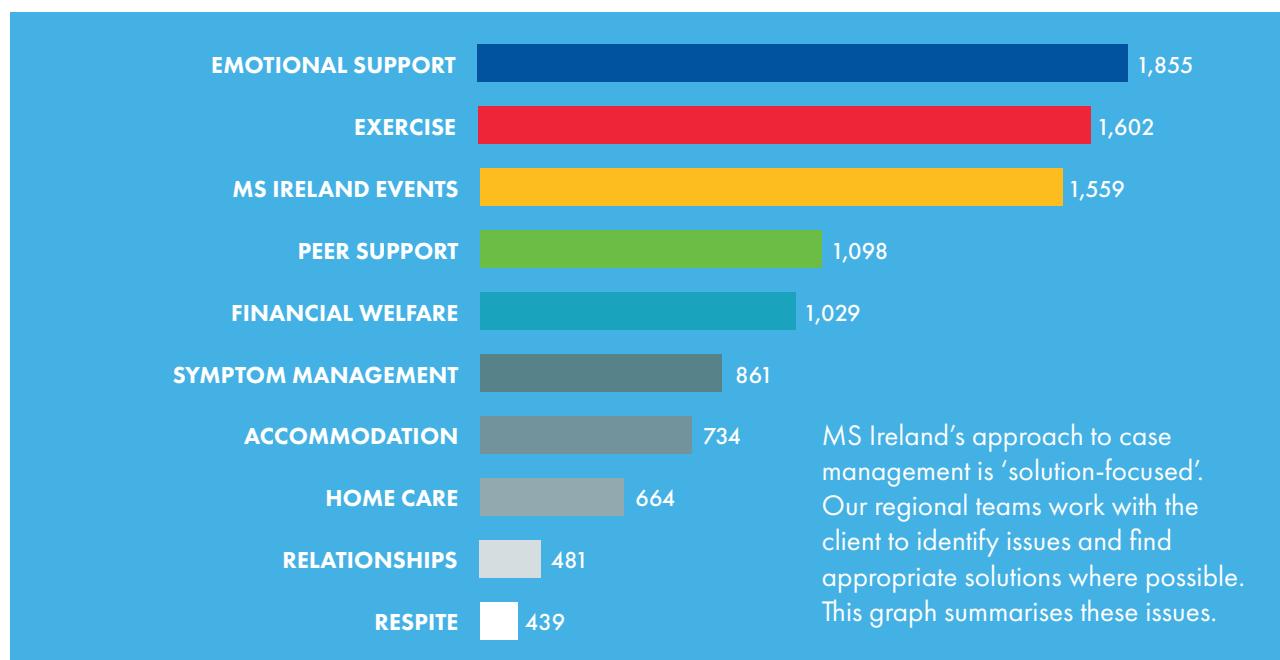
MS programmes are two of the main services delivered through our Regional Offices to people and families living with MS. Other services include providing information to health professionals, service development, public awareness, and support to the voluntary Branch structure.

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 for those struggling with the impact their MS is having on a part of their life. Casework allows the person or family to discuss any issues they may have and receive information, support and guidance from our trained and professional staff to empower them to be informed and make decisions about their life with MS.



TOP 10 ISSUES PRESENTED BY CLIENTS

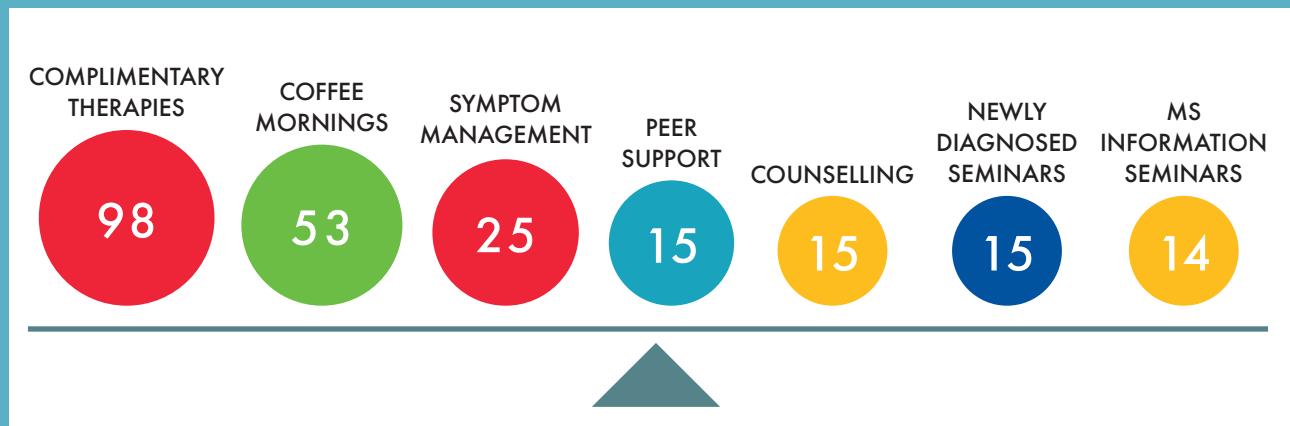


ACHIEVING IN SERVICES

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 and the needs of the individual. The figure below summarises the types of programmes we ran in 2019:

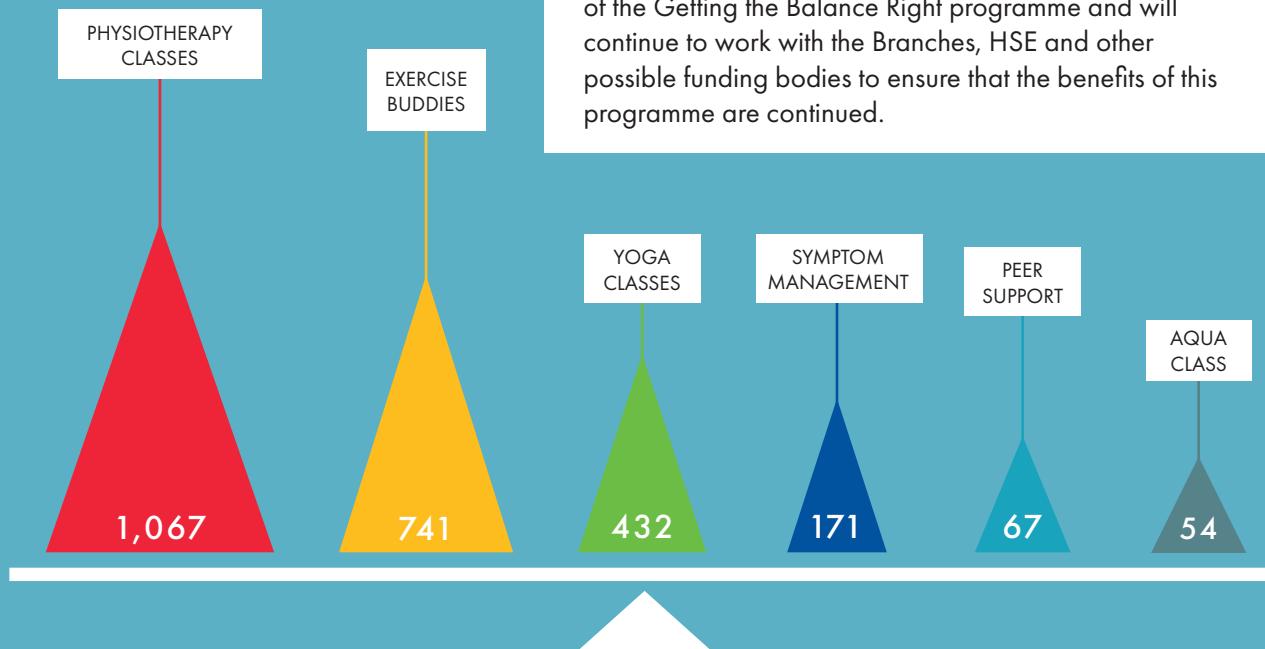


GETTING THE BALANCE RIGHT

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 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 2019 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

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 | (01) 490 5933

MIDLANDS REGIONAL OFFICE

Providing services in Laois, Offaly, Longford and Westmeath

midlands@ms-society.ie | (090) 647 1137

MIDWEST REGIONAL OFFICE

Providing services in Clare, Limerick and Tipperary North

midwest@ms-society.ie | (061) 303 802

NORTH EAST REGIONAL OFFICE

Providing services in Cavan, Monaghan, Louth, and Meath

northeast@ms-society.ie | (042) 975 4304

NORTH WEST REGIONAL OFFICE

Providing services in Donegal, Sligo and Leitrim

northwest@ms-society.ie | (074) 918 9027

SOUTH EAST DUBLIN AND WICKLOW REGIONAL OFFICE

Providing services in Wicklow and areas of south Dublin

eca@ms-society.ie | (01) 678 1600

SOUTHERN REGIONAL OFFICE

Providing services in Cork and Kerry

southern@ms-society.ie | (021) 430 0001

SOUTH EAST REGIONAL OFFICE

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

southeast@ms-society.ie | (056) 7777 771

SOUTH WEST DUBLIN AND KILDARE REGIONAL OFFICE

Providing services in Kildare and areas of south west Dublin

swa@ms-society.ie | (01) 490 5933

WESTERN REGIONAL OFFICE

Providing services in Galway, Mayo and Roscommon

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

VOLUNTARY BRANCHES

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

LIVING WELL WITH MS CONFERENCE



The Living Well with Multiple Sclerosis conference took place on 21st of September at the Radisson Blu Hotel Limerick. The conference theme this year was a continuation of '#myinvisibleMS'. For those living with MS, invisible symptoms can be particularly difficult to deal with, and they can also lead to anger and frustration towards people who don't fully understand how you're feeling inside. It is extremely important to be as open as possible about what you are experiencing with family and friends, to educate them, and to encourage them to educate themselves about MS as much as possible. Over 160 people were in attendance and over 400 people watched via livestream.



PRESENTATIONS ON THE DAY

Professor Alan Thompson

Consultant Neurologist at the National Hospital for Neurology and Neurosurgery at Queen Square

Progressive MS and the work of the Progressive MS Alliance

Professor Roshan das Nair

Professor of Clinical Psychology & Neuropsychology, Nottingham University Hospital

Managing the impact of invisible symptoms

Research Panel including: Dr. Claire McCoy, Edel Murphy & Professor Susan Coote

The importance of the MS voice in research design

Dr. Rebecca Maguire

Psychology Dept., Maynooth University

The importance of psychological wellbeing when living with MS

Dr. Jennifer Wilson O'Raghallaigh

Psychology Department, Beaumont Hospital

The importance of self management in MS

All presentations are available to view on
our website www.ms-society.ie

ACHIEVING IN SERVICES

AGM 2019

MS Ireland's 2019 Annual General Meeting (AGM) was held on 21st September 2020 at the Radisson Blu Hotel Limerick. Dr Rebecca Maguire was elected to the Board and Robin Bradley and Noelle Burke were both re-elected to the Board. Ian MacDougald retired from the Board and the Chairperson thanked Ian for his service.

INFORMATION DAY

MS Ireland hosted an information day for healthcare professionals on Friday the 20th of September 2020 at the Radisson Blu Hotel Limerick. The conference theme this year was '#myinvisibleMS'. One of the many challenges

for people with MS can be the array of invisible symptoms they can experience. With invisible symptoms, you must constantly adjust to the differences between how you look on the "outside" and how you feel "inside", which can be extremely difficult when the world tells you that you "look so good." MS has many faces, and no two people experience the disease in the exact same way. To understand MS, you need to become familiar with the many faces of MS which greet you so you can, together with the person with MS, have the best possible plan. Afterwards, the videos of the presentations were uploaded to MS Ireland's website. Over 95 health care professionals attended the information day.

VOLUNTARY BRANCH SERVICES WORKING TOGETHER: AN INTEGRATED APPROACH



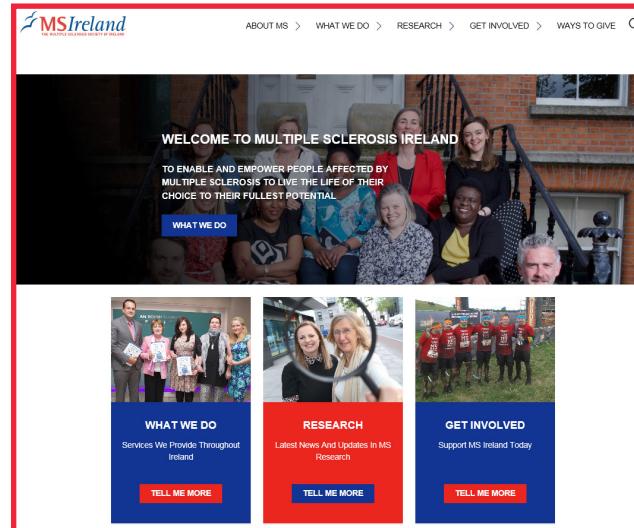
2019 was the eighth year of our integrated model of service delivery. Our professional regional staff worked closely with our dedicated teams of volunteers throughout our branch network to decide how to best fund, organise and deliver services to the local MS community.

This collaborative team work has enabled us to make the best possible use of all our resources to effectively meet the needs of people with MS and their families. 14 Regional Integrated Meetings took place in 2019

ACHIEVING IN SERVICES

MS IRELAND WEBSITE REDEVELOPMENT

In 2019, we were delighted to launch our newly refurbished website www.ms-society.ie. The website redevelopment project was a culmination of over a years' work involving all departments of the organisation. The website is a vital information source for people living with MS in Ireland and caters to those in all steps of their MS journey, from those just diagnosed to people living with the condition for over 40 years. As well as being an extremely valuable information source for people living with MS, the website is also a key communication channel for their friends, carers and families, and also our brilliant fundraisers. The development project required months of detailed planning and research to gain a rich understanding as to what our users wanted and expected from our website. New content was created to meet our users' needs and the website is now presented in an easy-to-use, accessible and inviting format, enabling visitors to easily



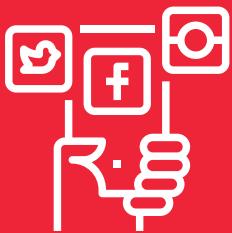
navigate the site to find what they are looking for. The new site allows MS Ireland more in-house control on how we manage and develop the site, and we eagerly look forward to seeing how it will grow over the coming years.

YOUNG PERSONS EVENT



In October, MS Ireland hosted our second 'MS Explored' event, which is specifically designed for young people living with MS, between the ages of 18-35. The event took place in the Gibson Hotel, Dublin and was attended by 48 people, and the event was also live streamed with over 3,000 views on social media. MS Explored topics included Young People and MS, Navigating Work Life, Relationships and Intimacy, and Fitness, which

were all led by keynote speakers from various fields including neurology, career psychology, sexuality education, occupational therapy, and neurological rehabilitation. On the day, there was an active fitness workshop which included a movement session, encouraging and empowering those with MS to incorporate a fitness regime into their daily lives.



SOCIAL MEDIA

Our social media channels continued to grow throughout 2019, and our various profiles have proven to be a go-to place for many, as well as a valued information tool for the organisation. Our 'Friday Quote' and 'Thursday Thank you' on Facebook continue to be favourites with the public, and are great for stimulating discussions and also for thanking those who have supported us throughout the year. Social media has proven to be an exceptional tool for supporting our fundraising events and engaging with our followers online. For our young persons' event in October, we used Facebook's live stream facility and took questions for the panel via Twitter, Instagram and Facebook.



Instagram

multiple_sclerosis_irland

2,765 Followers



Facebook

MultipleSclerosisIreland

17,459 Likes



YouTube

MSSocietyIRELAND

21,255 Views



Twitter

@MSIRELAND

8,796 Followers



E-News

Sign up on our website



2,966 Subscribers



Website

www.ms-society.ie

217,280 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:

"You just do it. You force yourself to get up. You force yourself to put one foot before the other, , you refuse to let it get to you. You fight. You cry. Then you go about the business of living. That's how I've done it. There's no other way."

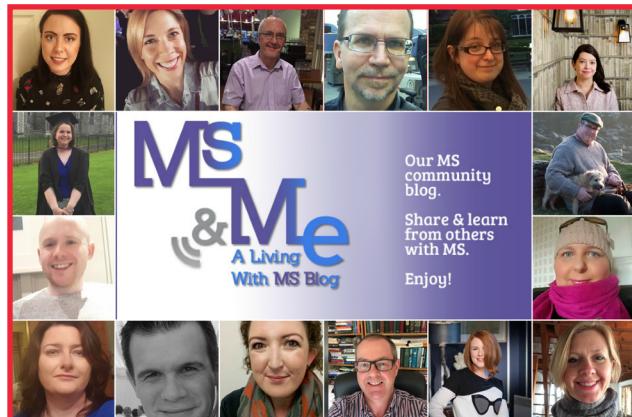
"Dreams may end in ms but MS didn't end my dreams"

"Stay focused on the positive count up the good things one by one you will be amazed at how long your positivity list becomes"

ACHIEVING IN SERVICES

MS NEWS MAGAZINE

2019 saw the publication of two editions of MS News. The theme of the spring/summer edition was Resilience. It featured pieces on our advocacy work, MS and Brexit, managing stress and building resilience as well as research and personal stories. It also featured a piece on mental fitness and the latest from our fundraising activities. The second issue for Autumn/Winter focused on community. We discussed the various roles of individuals in the MS Community in the hope of making our readers aware of the support that exists and some of the opportunities that are available to deepen their engagement with the MS Ireland .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, both in Ireland and abroad. In 2019 there were 44 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. The blog continues to be extremely popular on our social media channels, reaching thousands of people in Ireland and around the world. The bloggers met up for the annual planning day in Limerick in September where they shaped out the blogging calendar for the year ahead.

eNEWS

Our electronic newsletter eNews was sent every month in 2019 to our list of – 2,966 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.



IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Services in 2019:

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

- 422 residents stayed in the MS Care Centre
- 242 individual physiotherapy sessions provided at the MS Care Centre
- 1,991 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 15 Peer Support programmes, 25 symptom management sessions, 53 coffee mornings and 98 complimentary therapy programmes
- 1,067 Physiotherapy classes, 741 Exercise Buddies sessions and 432 Yoga classes provided by community services

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

- 14 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

- 1,243 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 circulated each month to subscribers
- 44 MS & Me Blog posts
- 269 followers on Twitter
- 904 new Likes on Facebook
- 720 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 Research Explored event held, in conjunction with Novartis, attended by 48 young people a further 3,000 streaming.
- New Website created and launched.



ACHIEVING IN ADVOCACY

MS Ireland will be the voice for people living with MS driving an advocacy agenda that includes areas of greatest concern to people living 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.
- Ensure that people with MS will have access to effective treatments for their condition, including treatments which can slow, stop or reverse the accumulation of the disability.
- To raise MS Ireland's profile as a leading voice and resource for people with MS

**IN 2019, THIS IS WHAT WE
ACHIEVED IN ADVOCACY**

ACHIEVING IN ADVOCACY



ENHANCING UNDERSTANDING

MS EXPLORED

On October 12th, MS Ireland in association with Novartis held our second annual 'MS Explored' event for young people living with MS. This event aimed to address some of the topics most relevant to younger people, though it was open to anyone who felt the topics were relevant to them. The talks on the day were led by key speakers from a range of specialties. Neurologist, Dr Maria Gaughan presented 'Young People and MS' – a session which looked at facts and research findings relevant to young people living with MS, in order to arm them with evidence-based information. Career Psychologist, Sinéad Brady, presented 'Navigating Work Life', during which she discussed career tips and advice, and also covered the issue of disclosing your condition in the workplace and during the interview process. Sarah Sproule, Sexuality

Educator and Occupational Therapist presented 'Relationships and Intimacy', a presentation that gave the audience practical information relating to intimacy and relationships, which is a topic that can often be a difficult one to discuss for many people. Professor Susan Coote, Physiotherapist specialising in neurological rehabilitation, gave a presentation on fitness and movement. Fearless Moves, a group that combine HIIT workout sessions with music themes also hosted a movement session after the event. The meeting, which was held in The Gibson Hotel, gave young people living with MS across the country the opportunity to meet, engage, and perhaps learn something new. The event was live-streamed for those who could not attend in person or who preferred to engage remotely. It attracted over 3,000 viewers.



ACHIEVING IN ADVOCACY

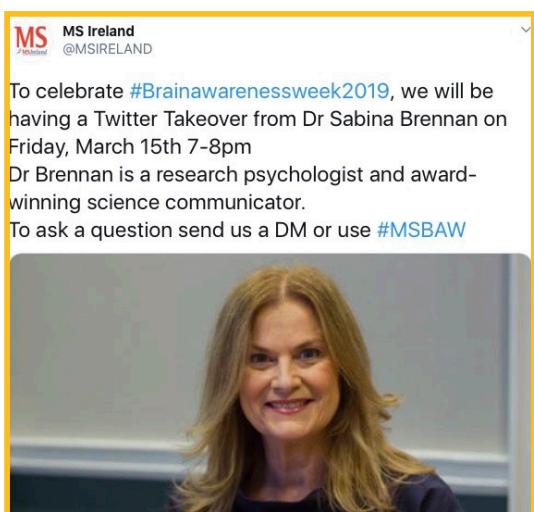
INVISIBLE SYMPTOMS VIDEO



The 2019 theme for World MS Day was 'Invisible Symptoms'. With this theme in mind, MS Ireland produced videos with experts who discussed the issue of invisible conditions and answered questions relating to them. Prof. Orla Hardiman, Consultant Neurologist, answered questions in relation to the invisible symptoms people living with MS can experience and helped to separate fact from fiction by busting some of the common myths about MS.

BRAIN AWARENESS WEEK

As NAI members, MS Ireland took part once again in Brain Awareness Week 2019. This year we invited two experts to do a 'Questions and Answers' session on Twitter – welcoming questions from our community. The first expert to take this on was Dr Claire McCoy, MS Researcher in the Royal College of Surgeons Ireland (RCSI). Dr McCoy answered questions from our community members in relation to MS research. In the second session Dr Sabina Brennan answered questions from our community on the topic of brain health.



POP-UP HOUSE

On World MS Day, MS Ireland opened the MS Care Centre up to those who wished to join us in marking and celebrating the day. In an effort to communicate some of the invisible symptoms some people living with MS face, MS Ireland used a communications tool that was developed by Merck. This communications tool, a pop-up stand with three sides, helped to simulate scenarios for those engaging with it. These sides replicated three common places; the home; public transport, and the work environment. It helped to simulate and communicate the issues people living with MS face, and allowed people to experience first-hand how the invisible symptoms of MS can have an impact in these places. A spongy floor



was a feature, and aimed to communicate gait and mobility issues that some people living with MS experience. Other features included a digital sliding puzzle of a transport map which helped to communicate issues people living with MS may have in processing visual information, and it also highlighted the added layer of difficulty that is involved when performing everyday tasks. The symptoms this pop-up simulated included weakness; mobility issues; visual impairment; cognitive overload and fatigue. The stand was also designed to visually prompt discussion in relation to how misunderstanding MS can impact a person living with the condition and how situations may be more challenging for them.

ACHIEVING IN ADVOCACY

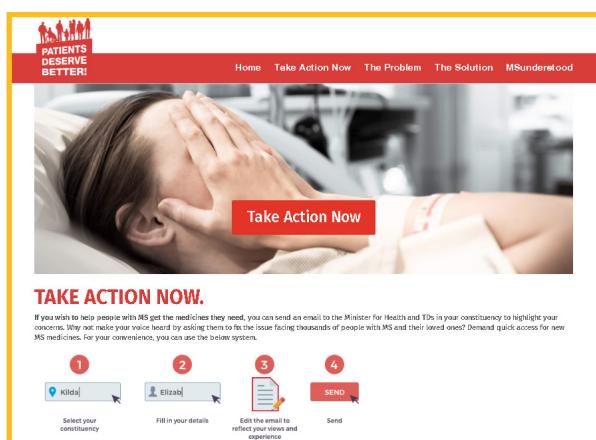
IMPROVING ACCESS

SATIVEX

MS Ireland put forward a Patient Group Submission to the National Centre for Pharmacoeconomics (NCPE) to support Sativex in the Health Technology Assessment process. We continue liaising with the company, marketing Sativex and the NCPE in relation to this medication.

OCREVUS

MS Ireland continued to advocate for Ocrevus to be made available to those who would benefit from it. Throughout 2019, we asked the MS community to actively support our advocacy activities in relation to this medication. We directed our community to the www.patientsdeservebetter.ie website and encouraged them to write to their local representatives requesting they support the community in seeking access to this medication.



The screenshot shows a woman lying in a hospital bed, looking distressed. A red button labeled "Take Action Now" is prominently displayed. Above the button, there's a small icon of a person and the text "PATIENTS DESERVE BETTER". At the top of the page, there's a navigation bar with links: Home, Take Action Now, The Problem, The Solution, and MSunderstood. Below the main image, there's a section titled "TAKE ACTION NOW." with instructions on how to contact your local representative via email. It includes five numbered steps: 1. Select your constituency (dropdown menu), 2. Fill in your details (dropdown menu), 3. Edit the email to reflect your views and experience (text area with a pencil icon), 4. Send (red button). A note at the bottom says: "If you wish to help people with MS get the medication they need, you can send an email to the Minister for Health and TDs in your constituency to highlight your concerns. Why not make your voice heard by asking them to fix the issue facing thousands of people with MS and their loved ones? Demand quick access for new MS medicines. For your convenience, you can use the below system."

Ultimately, negotiations between the HSE and the developer came to a close and Ocrevus was made available to people living with relapsing forms of multiple sclerosis.

USI DISABILITY CONFERENCE



MS Ireland presented at Ability19, a conference for third level students living with disabilities, which was hosted by The Union of Students in Ireland. This conference brought students and student leaders together to discuss disability rights and challenges that exist for students living with disabilities. Topics discussed included issues relating to students living with disabilities in accessing third level education, supports during their studies, and jobs upon completion of their time in third level education..

CHARTER FOR PATIENT INVOLVEMENT IN MEDICINES ASSESSMENT AND REIMBURSEMENT

MS Ireland were delighted to be a signatory of the 'Charter for Patient Involvement in Medicines Assessment and Reimbursement' which was developed by the Irish Platform for Patient Organisations, Science and Industry (IPPOSI). This charter called for changes to the process of assessing and reimbursing medicines in Ireland. The calls for change included a strategic commitment to the advance of patient involvement; education, training and support for patients to facilitate their involvement; access to information and regular communication, and the right to review and appeal decisions.

ACHIEVING IN ADVOCACY



ENHANCING UNDERSTANDING

THE DISABILITY ACTION COALITION

In 2019, MS Ireland joined a new coalition with other organisations providing services to people living with disabilities. MS Ireland is one of nine member organisations that make up The Disability Action Coalition (TDAC). The Disability Action Coalition formed to seek the urgent resolution of issues of underfunding amongst Section 39 disability service providers, in order to secure the future of the organisations and the vital services they provide to thousands of people living with disabilities. TDAC also hoped to resolve serious governance issues for the organisations, and between the organisations and their funder, the HSE. This coalition were incredibly active in 2019

and organised a number of political engagement events. On November 21st, TDAC representatives met with Ministers, TD's and Senators in Leinster House to highlight the significant funding shortfalls threatening Section 39 disability services across the country.

MS Ireland member, Mark Mitchell acted as a spokesperson for this coalition and shared his story in order to highlight the urgent need to recognise this funding crisis, and the real implications it can have on people living with disabilities as funding is eroded.



ACHIEVING IN ADVOCACY



CARERS WEEK

MS Ireland were delighted to be Carers Week partners again in 2019. Events were held across the country to celebrate carers, including physical and online coffee mornings. Ahead of Carers week, a survey was conducted by the Care Alliance and eleven partners, including MS Ireland, which indicated that many family carers are unable to leave their home, and have to rely solely on online supports for information and social connection. Over half (59%) of respondents indicated that they 'often' or 'always' felt lonely or isolated, with only 3% saying they could 'always' make it to social and support events they wished to attend.

NEUROREHABILITATION AND NEUROLOGY SERVICES

As members of the Neurological Alliance of Ireland (NAI), we continued advocating for improved access to neurology services and neurorehabilitation. Throughout the year, we actively took part in meeting with the NAI neurorehabilitation sub-committee – agreeing actions to be taken to further this issue and have it highlighted by key influencers and decision makers. We supported NAI campaigns and activities such as 'Brain Life Goals' for World Brain Day and 'Love Your Brain' for Brain Awareness Week.

LOCAL AND EUROPEAN ELECTIONS

In 2019, Ireland took to the ballot boxes to vote in the Local Authority and European elections. As members of the Disability Federation of Ireland, MS Ireland supported the 'Disability Votes Count' campaign which aimed to make disability a top priority to candidates. We asked our community to highlight accessibility, participation and planning to candidates seeking their support in the Local Authority elections. We asked them to seek a commitment from the candidates to publish the local authority plan for the implementation of the United Nations Convention on the Rights of People with Disabilities (UNCRPD).

At European level, we asked our community to seek commitment from candidates to support the investment of European funds in persons with disabilities. We also asked them to seek commitment on making products, services and infrastructure accessible to people living with disabilities.



IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Advocacy in 2019:

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

- MS Ireland took part in Brain Awareness Week 2019 inviting two experts to do a 'Questions and Answers' session on Twitter – welcoming questions from our community
- MS Ireland is one of nine member organisations that make up The Disability Action Coalition (TDAC). The Disability Action Coalition formed to seek the urgent resolution of issues of underfunding amongst Section 39 disability service providers
- Continued advocating for improved access to neurology services and neurorehabilitation. Throughout the year, actively taking part in meeting with the NAI neurorehabilitation sub-committee
- As members of the Disability Federation of Ireland, MS Ireland supported the 'Disability Votes Count' campaign which aimed to make disability a top priority to candidates

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 40 people with over 3,000 live streams.
- MS Ireland presented at Ability 19, a conference for third level students living with disabilities, which was hosted by The Union of Students in Ireland

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

- MS Ireland were signatories of the 'Charter for Patient Involvement in Medicines Assessment and Reimbursement' which was developed by the Irish Platform for Patient Organisations, Science and Industry (IPPOSI).

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 forward a Patient Group Submission to the National Centre for Pharmacoeconomics (NCPE) to support Sativex in the Health Technology Assessment process.
- MS Ireland continued to advocate for Ocrevus to be made available to those who would benefit from it. Throughout 2019, we asked the MS community to actively support our advocacy activities in relation to this medication.

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

- On World MS Day, MS Ireland opened the MS Care Centre up to those who wished to join us in marking and celebrating the day. Communicated some of the invisible symptoms some people living with MS face, MS Ireland used a communications tool that was developed by Merck, the MS House.
- MS Ireland in association with Novartis held our second annual 'MS Explored' event for young people living with MS. This event aimed to address some of the topics most relevant to younger people



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 those affected by MS.
- A protocol for researchers who engage with MS Ireland (nationally or regionally).

**IN 2019, THIS IS WHAT WE
ACHIEVED IN RESEARCH**

MULTIPLE SCLEROSIS AWARENESS SURVEY



To mark World MS Day 2019, MS Ireland partnered with Novartis to commission a survey to gauge public awareness of the visible and invisible symptoms of multiple sclerosis (MS). A representative sample of 1,000 adults was surveyed. Overall, there was a high awareness of MS amongst the public, but detailed knowledge was lacking.



The research, which was carried out by IPSOS/MRBI, showed that 93% of respondents claim to be aware of MS. 75% of the respondents know someone with MS, and the majority of the respondents believed their knowledge of MS to be either fairly or very good. Although more than one third of the sample claim to have a family member, friend or loved one living with MS and 66% of people believing that they have a good understanding of MS, the findings showed that there are still some key aspects of the condition that remain unclear.

When asked about the symptoms associated with multiple sclerosis, 29% of respondents could not name any. In most cases when prompted, people associated MS with walking difficulties, pain or muscle spasms, fatigue or weakness, balance problems or dizziness, numbness and tingling, and cognitive problems and forgetfulness. When asked if MS was more prevalent amongst men or women, 45% of participants responded that MS affects men and women equally, when research shows us that it actually impacts approximately twice as many women as men.

Levels of awareness in relation to visible symptoms of MS among the general public are relatively high with almost 20% of those surveyed listing muscle degeneration, and 17% mentioning loss of mobility. Only 8% of people identified fatigue as a key symptom, despite almost 90% of people living with MS reporting fatigue as a consequence of their condition.



ACHIEVING IN RESEARCH

STRATEGIC PLANNING SURVEY

2019 brought MS Ireland to the end of a Strategic Plan which helped to plan and guide the work our organisation undertook from 2015-2019. Our strategic planning team felt it was important to engage in consultation activities with our stakeholders in order to create a new strategic plan to take our work forward. MS Ireland undertook a number of activities including focus groups, one-to-one meetings and surveys.

The largest survey we conducted aimed to gather information on the views and experiences of a range of stakeholders. This survey was conducted online using Survey Monkey. It was shared on MS Ireland's website, social media and via an email campaign. Our network of Regional Community Workers and Branches were also provided with a printable PDF version of this survey to facilitate those who may not be able to take the survey online. 1,000 participants took part in the survey including; people living with MS (80.5%), family members of people living with MS (10.2%), MS Ireland staff (2.9%), healthcare professionals (2.4%), volunteers (2.2%), carers (1%) and independent contractors (0.8%). We asked respondents to provide information on topics including the ways in which MS impacts their lives, how they value our current service provision, and what they feel MS Ireland should be aware of as we designed our new Strategic Plan for the period 2020-2024.

The findings of this survey revealed that our network of Regional Community Workers was the service that respondents rated as the most important to them. This was followed by Physiotherapy Assistants/Exercise Buddies as the second most important service. Our most popular communications service was the MS Ireland website, followed by our social media platforms. Email was the most popular way in which respondents wished to be contacted by MS Ireland. Getting the Balance Right, a physiotherapy and exercise based programme

developed for people living with MS, was rated as the most important programme to our respondents. Symptom Management programmes was the second highest rated programme followed by programmes for those newly diagnosed.

TWITTER Q&A WITH DR CLAIRE MC COY

As part of Brain Awareness Week, MS Ireland invited Dr Claire McCoy, Lecturer of Immunology in the Royal College of Surgeons Ireland, to join us on Twitter to answer questions from our community. This event allowed our community members to submit any questions they had in relation to MS research, which Dr Mc Coy answered.



INTERNATIONAL PROGRESSIVE MS ALLIANCE

In 2019, a number of MS Ireland Branches made donations to international MS research through the Multiple Sclerosis International Federation. The combined donations made by these Branches came to a total of €6,000, which went towards research into progressive MS.



ACHIEVING IN RESEARCH

KISS GOODBYE TO MS RESEARCH BALL

2019 saw the second Kiss Goodbye to MS Research Ball hosted by MS Ireland. This event aimed to raise funds to support MS research and to celebrate the fantastic achievements in MS research to date. The ball, which saw 130 guests join us in the Morrison Hotel, Dublin, raised over €20,000 to go towards funding MS research. Kiss Goodbye to MS is an international campaign which raises money which is used to fund vital research into the causes, treatments and possible cures for MS, as well as helping people currently living with the condition.



MEDICAL RESEARCH CHARITIES GROUP

MS Ireland actively engaged with the Medical Research Charities Group (MRCG) in 2019. MS Ireland attended a meeting with the organisation for charities that are active in the medical research space. Our organisation linked in with the MRCG shared learning group for public patient involvement (PPI) in research.

PPI IGNITE COLLABORATION

In 2019, MS Ireland continued our collaboration with the University of Limerick on the PPI Ignite programme. This is a Health Research Board funded scheme which encourages universities to involve patients and members of the general public in the design and delivery of research projects. In May, MS Ireland took part in the University of Limerick PPI Research Fair. This gave us the opportunity to showcase our work and network with researchers. It also gave us the opportunity to see the fantastic work being conducted by other organisations and nurture the culture of shared learning between the groups in order to make PPI a meaningful experience for all involved.

DEAN MEDAL



In 2019, MS Ireland announced that we had opened our applications process for the Dean Medal. The Dean Medal award, established in 2010, is intended to enable new MS researchers to travel to centres of excellence to enhance their understanding and knowledge of MS. Geoffrey Dean was an internationally regarded epidemiologist who in several seminal studies established the importance of environmental influences on the pathogenesis of multiple sclerosis. MS Ireland wishes to encourage the dynamic and innovative work so keenly exemplified by Dr Geoffrey Dean.



IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Research in 2019

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

- To mark World MS Day 2019, MS Ireland partnered with Novartis to commission a survey to gauge public awareness of the visible and invisible symptoms of multiple sclerosis (MS). A representative sample of 1,000 adults was surveyed

COLLABORATE WITH ACADEMIC INSTITUTIONS ON THE DELIVERY OF RESEARCH PROJECTS

- MS Ireland continued our collaboration with the University of Limerick on the PPI Ignite programme during 2019

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.

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

- MS Ireland actively engaged with the Medical Research Charities Group (MRCG) in 2019
- In 2019, a number of MS Ireland Branches made donations to international MS research through the Multiple Sclerosis International Federation.
- As part of Brain Awareness Week, MS Ireland invited Dr Claire McCoy, Lecturer of Immunology in the Royal College of Surgeons Ireland, to join us on Twitter to answer questions from our community.



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 exists

IN 2019, THIS IS WHAT WE ACHIEVED IN ORGANISATIONAL CAPACITY

INTEGRATED MODEL OF SERVICE

2019 was the eighth 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. Our Branches participated in the meetings and contributed financially to the provision of regional services. In each of our 10 regional areas, regional integrated meetings took place at least twice a year and often had a senior manager from National Office and/or 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
- » Local Branches were asked to continue their contribution of 15% of their year-end net assets to support local services.

In total, 14 Regional Integrated Meetings took place in 2019.

RESOURCE ALIGNMENT

The situation in relation to statutory and fundraised income continues to be challenging. Reduced opening hours at the MS Care Centre remained to be an issue, and we continued to push the MS Care Centre Business Case through our membership.

- » 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.

VOLUNTEERING

MS Ireland would not exist without the invaluable support of our fantastic 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, through administration work, and increasingly through workplace volunteering schemes.

VOLUNTARY BRANCHES

Our voluntary Branches are a vital support network for people living with MS and their families in local communities. They raise funds locally for the provision of services in their respective areas, which can include providing a financial assistance service, access to a number of different therapies, and organising various social gatherings.

ACHIEVING IN ORGANISATIONAL CAPACITY

CORPORATE VOLUNTEERS



The growth in corporate volunteering has had a wonderful and very positive impact, as many organisations actively support their employees volunteering work time to MS Ireland and other charities. In 2019 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.

INTERNSHIPS AND VOLUNTEERS

MS Ireland continues to utilise a number of interns and volunteers in our National Office, Care Centre, and throughout the regions. 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 June to review the scheme's 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.

ACHIEVING IN ORGANISATIONAL CAPACITY

HUMAN RESOURCES

Recruitment during 2019 concentrated on replacing necessary leavers or unfilled posts.

Retirees:

- » Mary Blake
- » Tess Kennedy
- » Christine Anne Gill

The following posts were recruited in 2019:

- » Aoife Kirwan Information, Advocacy & Research Officer
- » Pauline McKenna Regional Community Worker
- » Deirdre Gowney Regional Community Worker
- » Janet Lee CNM Care Cent Clinical Nurse Manager 3 (Person in Charge)

- » Derek Hegarty Accounts Assistants
- » Sarah Hourigan Schools Education Executive.
- » Jessica Charters Fundraising Support Administrator
- » Sandra Skalbe Healthcare Assistant.
- » Jackie Baker Financial Controller
- » Alan Montgomery Accounts Assistants
- » Kirstie Kelly Accounts Assistants
- » Maria Alvarez Physiotherapist
- » Karin Brath Senior Corporate Fundraiser
- » Susan Coote Clinical Specialist Physiotherapist

We had staff enter and leave the three CE Schemes and had relief nurses in the MS care Centre.



Our dear colleague, Margaret Maguire sadly passed away on the 12th of June. Margaret was the Clinical Care Manager at the MS Care Centre in Rathgar. She was very passionate about the MS Care Centre and the service it provided. In her role as Clinical Care Manager she had ensured that the MS Care Centre was registered as a provider with the Health Information Quality Authority (HIQA). Margaret achieved a tremendous amount during her career, and she will always be remembered for her kindness, respect and dedication to others.

ACHIEVING IN ORGANISATIONAL CAPACITY

PUBLIC RELATIONS



Raising awareness of multiple sclerosis and MS Ireland's services and campaigns amongst the public is an extremely important part of our work to support the MS community in Ireland. Included below are the PR campaign and media highlights from 2019.

WORLD MS DAY 2019

World MS Day 2019 took place on Wednesday May 30th with the theme of the invisible symptoms of MS, using the hashtag #MyinvisibleMS throughout the campaign. The aim of using this theme was to raise awareness of the invisible symptoms of MS and the unseen impact of MS on quality of life. World MS Day raises awareness of multiple sclerosis for thousands of people and their families in Ireland and around the world, and from 2019 onwards it will be held on 30th of May each year.

For the campaign in 2019 we had inspirational MS ambassadors who featured prominently on national media. Niamh McCarron featured on Virgin Media's Ireland AM along with Ava Battles, discussing her life with MS. Sharon Henvey was on hand at the launch of our World MS Day awareness survey with Orla Hardiman. Sharon also appeared on The Elaine Show on Virgin Media, as well as Jennifer Zamparelli's radio show on RTE's 2FM. There was also a feature piece written on Ciara O'Meara and Jennifer Mangan in The Irish Independent in the lead up to World MS Day.



MEMBERSHIP

At the end of 2019 our membership stood at **4,527**

ACHIEVING IN ORGANISATIONAL CAPACITY

PUBLIC RELATIONS



MS READATHON 2019

For the 2019 MS Readathon, which was the 32nd year of the campaign, we were delighted to welcome the TV presenter and children's author Lucy Kennedy to the launch of the campaign. The launch took place in The National History Museum of Ireland in Dublin. We were also delighted to be joined by our MS Readathon mascot Bobby Bookworm who spoke to some eager fellow bookworms from John Scotus Primary School. At the launch we were also joined by our brilliant MS Readathon Ambassador, Emma Valentine from Cork who, along with her daughter Rowan, celebrated the launch of the 2019 campaign with us.

We had fantastic media coverage, with articles from MS ambassadors, and with Emma Valentine appearing in The Irish Examiner, The Irish Sun, and several other online outlets. Bobby Bookworm also interviewed children from John Scottus primary school about the Readathon and their favourite books in a series of videos used for our social media.

IRISH AUTHORS

Some of 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 have continued to be great supporters of the MS Readathon each year. These include Emma Jane Leeson, Avril O'Reilly, and Lucy Kennedy, amongst many others.



PARTNERSHIPS AND COLLABORATIONS

Working in partnership with those who share a common interest is an essential part of MS Ireland's work. Striving 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 2019

- » 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 the Chairperson of the Board of IPPOSI.
- » 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 Aoife Kirwan is on the Board of NAI and is part of the subcommittee on neurorehabilitation.
- » We worked alongside the Care Alliance for Carers Week.
- » Members of the Home Care Coalition who seek to secure supports that enable people to remain in their own homes.
- » We joined a new coalition, The Disability Action Coalition, which is a group of national disability service providers who receive funding under Section 39 of the Health Act. The coalition came together to campaign for an improved and more secure future for services we provide to people living with disabilities across Ireland.
- » 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. MS Ireland's Services Manager, Olga Estridge, is on the Board of DFI.
- » 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 2019:
 - * Collaborated with Novartis to support 'MS Explored', an event for young people living with MS.
 - * Attending the International Patient Organisation Information Exchange and Global MS Patient Group Summit, organised by Roche.
 - * Merck provided us with the MS Pop-up communications prop.

ACHIEVING IN ORGANISATIONAL CAPACITY

AWARDS

PERSON OF THE YEAR AWARD

We were delighted to award Damien Byrne 'MS Person of the Year.' Damien is a very active member of the East Wicklow Branch. Damien had become aware of significant 'barriers' regarding the geographic region of the East Wicklow Branch; it is a sixty-mile round trip from Arklow to Bray, which makes it impractical for people living in Arklow to attend Bray based coffee mornings. Damien decided to do something about it, and set about putting together a coffee support group in the Arklow Bay Hotel. He started it over 5 years ago, and has run it since then from 11am until 1pm each week. It's a very social event where conversations on numerous topics are discussed. Since the coffee support mornings started, the numbers have swelled to twenty plus on any given morning. This is just one example of the great work Damien has carried out. Congratulations Damien! On the night, the award was presented to Mark Mitchell on Damien's behalf. Limerick Hurlers, Graham Mulcahy, and Richie English were on hand to present the awards.



CARER OF THE YEAR AWARD

The 'Carer of the Year' award was presented to Anne Byrne. Anne is described as "a powerhouse of a woman", who is carer to her daughter Lisa. Anne arrives six out of seven days at Lisa's house,



always with a smile brightening up Lisa's day, and everyone else's as well. Anne supports her local MS Ireland Branch and comes to every bag-packing and bucket collection to raise funds for the Branch. Well done, Anne.

VOLUNTEERS OF THE YEAR

This year we were delighted to present the award to Peter McGuire. Peter was nominated by Sean Murphy on behalf of the Cork City Branch. Peter, his wife Rose and their family have been involved with the Branch for the past 46 years, continuously supporting the annual collections. Their only connection with the Branch was through Peter's friend, Denis Keohane, who was involved with the Branch committee, and he asked Peter if he could help out at the time.. From Sean Murphy's time with the committee in 1979, each year, at the allocation of church gate collections, the Chairman would say "Don't worry about St. Joseph's Church Mayfield, Peter McGuire will cover it." Well done, Peter.





WORLD MS DAY 2019

On May 30th, MS Ireland joined people living with MS and other MS organisations around the world to mark World MS Day. Each year World MS Day focuses on a different theme. This year, the theme was 'My Invisible MS' (#MyInvisibleMS) The aim of using this theme was to raise awareness of the invisible symptoms of MS and the unseen impact of MS on quality of life. Some of the common misconceptions of MS were addressed by a series of 'Myth Buster' images. The campaign invited everyone affected by MS to share their invisible MS symptoms. They were given a voice to express what they wanted others to know and understand about MS, in order to challenge common misconceptions and help people understand how to provide the right support.

Myth

"A person with MS shouldn't exercise."

Truth

Regular, moderate exercise can help with many MS symptoms and benefit overall health and wellbeing.

To mark World MS Day 2019, MS Ireland and Novartis commissioned a piece of research to explore the general public's awareness of MS, including the visible and invisible symptoms of MS. This new research, which was conducted in April 2019 by IPSOS/MRBI, found that 93% of people in Ireland claim to be aware of MS, and more than 44% consider their understanding of the symptoms and details of the condition to be poor. Almost one third of respondents were unable to list any symptoms related to MS.

A range of fantastic events were held throughout Ireland to mark World MS Day including coffee mornings, get-togethers, vintage car shows and information days. The day was also marked in the MS Care Centre where visitors enjoyed refreshments, home-baked goodies and music.



FUNDRAISING 2019

KISS GOODBYE TO MS BALL

Our second Kiss Goodbye to MS Ball was a hoot. Hosted in the Morrison Hotel Dublin for the second year running, 130 guests ate, drank and danced the night away, while raising over €20k towards MS research.

Our MC for the night was Emily Glen, who was exceptionally good at charming our guests into parting with their cash for the table raffle and Dial-a-Day Out. There were of course some other incredible prizes won on the night too.



Ava Battles spoke at the Ball, as did Helen Murray. Helen's speech was incredibly powerful. She spoke about what MS Research means to her, the changes she's seen in her own experience and how she foresees research progressing into the future. Quite rightly, Helen received a standing ovation and a thunderous applause.

We would like to say a massive thanks to all our sponsors and prize donors. A huge shout out and thanks also has to go to the KGTMS Ball committee, specifically Helen Murray and Niamh McCarron, who volunteered so much of their time and were key in getting bums on seats and hunting down raffle prizes.

MS READATHON 2019

2019 was an epic year for the MS Readathon. 10,400 young readers and 349 schools took part across the country, reading over 90,000 books and raising a whopping €350k for people living with MS in Ireland. Bobby the Bookworm was back for a second year and he was getting the low down on all things book-related from the students of John Scottus School. We launched our campaign with our amazing ambassadors Rowan Valentine and her Mum Emma, along with Lucy Kennedy and fourth class from John Scottus.

For the second year in a row, Scoil Bhríde in Ranelagh absolutely outdid themselves, beating their previous colossal record and raising an eye-watering €10,570!

2019 saw us team with Languages Connect, with the aim of getting more students reading in a foreign language. It worked fantastically, as we had participants who read books in Polish, Swedish, Japanese, French, Spanish, Czech, Lithuanian and Portuguese. Languages Connect also very kindly sponsored two extra iPads as prizes for our bookworms.

We were delighted again this year that Panasonic Ireland sponsored 30 wireless headphones. A big thank you also to Gill Publishers who donated a box of beautiful books which we awarded as prizes for the best book reviews and cover art competitions.



FUNDRAISING 2019

STOCKTONS' WING

Stockton's Wing reunited and released a charity single, 'We Had It All', in aid of MS Ireland. We were absolutely thrilled to have been chosen as the beneficiaries of proceeds raised through the sale of the charity single. The band visited the MS Care Centre to launch the single, where the delighted audience were treated to a number of songs. The band have shown huge support to MS Ireland. Our most sincere thanks go to them for helping to raise awareness and vital funds which will go directly towards the provision of services provided by MS Ireland.



TREKS 2019

SLOVENIA

We took 30 people to Slovenia in September 2019 – it is the most spectacular country. From beautiful mountains to picturesque lakes, we were able to experience everything the country has to offer, from the Julian Alps to the Pokljuk Plateau, from Lake Bled to the historic city of Ljubljana. On the last day we were led by our youngest (22 years old) and oldest (81 years old) walkers. Thank you to the 30 walkers who joined MS Ireland on this amazing experience.

CALENDAR & NOVARTIS

Our 2019 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.

Thank you also to our monthly sponsors Tierney's, Cusack Garvey, Merc Partners, The Panel, O'Brien's, Genomics, KBC, Daysha Dev Ops, Logos Publishing, Mallow Credit Union, and Hogan Healthcare.

FUNDRAISING 2019



AD HOC SPORTS 2019

So many exceptional people took on such exceptional challenges for MS Ireland. Amongst them are: Mark Cannon, who by doing Westport Sea2Summit, raised €10k; Barry and Trish Fox raised €15k by cycling Paris2Nice, and Ciaran Slattery who Everested The Conor Pass in Co.Kerry by ascending 9,206 metres, and is now one of the top 25 Irish cyclists to do so.

DUBLIN CITY MARATHON 2019

We had 14 people in Team MS Ireland for the KBC Dublin Marathon, and between them they raised €16k.



MINI MARATHON 2019

With nearly 200 ladies joining Team MS Ireland, the VHI Mini Marathon is still one of the biggest events on the charity calendar. There is such a great spirit of camaraderie and positivity, and it truly makes it a very special day for all concerned. A fantastic €31,000 was raised.



LEINSTER TAKEOVER DAY

We have been charity partners with Leinster Rugby for 2 years, and part of that included 'Takeover' Days. These involved inviting volunteers to come and enjoy a match in return for shaking a bucket for MS Ireland. We are very grateful to our volunteers for their support and their good spirits on such a cold night. We were also very grateful that Leinster Rugby donated the proceeds of the sale of their Book 'Double Delight' to MS Ireland and the Down Syndrome Centre.

FUNDRAISING 2019



SKYDIVES

23 intrepid volunteers decided to jump out of an aeroplane in order to challenge themselves and raise funds for MS Ireland – raising over €20,000 in the process.

ABSEIL

We were lucky enough to host 2 abseils in 2019. We had 70 people between the 2 events, who climbed over the top of Croke Park and abseiled back down, overcoming all sorts of fears. They raised a total of €36,000.



COMMUNITY FUNDRAISING

This is a huge part of our fundraising – and we are so very grateful to so many people who organise a huge variety of different events for us – from bridge nights and head shaves, to Facebook birthday fundraisers and coffee mornings. Some are annual events and others are one- off events, but each makes a massive difference to MS Ireland.

THANK YOU!

Big **THANKS** to all our fundraisers, donors and supporters for their generosity throughout 2019. 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 2019:

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, the MS Readathon and MS Awareness survey
- 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.
- 14 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

- 14 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 our National MS Care Centre.
- Stockton's Wing launched a charity single in Aid of MS Ireland.
- MS Readathon raised over €350,000
- 2nd year partnership with Leinster Rugby.
- 3rd annual 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 2019, THIS IS WHAT WE ACHIEVED IN
GOVERNANCE & REGULATION**

ACHIEVING IN GOVERNANCE & REGULATION

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.

ORGANISATION DETAILS

AUDITOR

Deloitte
Chartered Accountants and Statutory Audit Firm
Deloitte & Touche House
Earlsofrt 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 13 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, law 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 2019, the Board met seven times. Significant work was carried out in the areas of finance, funding, governance and strategy.



BOARD MEMBER 2018/2019



CHAIRPERSON

● Marcella
● Flood



VICE
CHAIRPERSON

● Maurice
● O'Connor



● Robin
● Bradley

BOARD MEMBER 2019/2020



● Noelle
● Burke



● Edwina
● Dunne



● Eugene
● Kearney



● Jacinta
● Kelly



● Rebecca
● Maguire



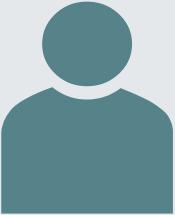
● Ian
MacDougald



● Martin
Power



● Anne
● Restan



● Mary
● Sheahan
Lonergan

RESIGNATIONS/CHANGES

Ian McDougald Retired on 21/9/2019

APPOINTMENTS

Rebecca Maguire appointed on 21/9/2019)

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

- » Branch Development Committee
- » Finance, Audit & Risk Committee
- » Fundraising & Advocacy Committee
- » Nominations & Remuneration Committee
- » People & Organisational Development & Governance Committee

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

- » Research Committee
- » Services Monitoring & Evaluation Committee
- » Strategy Implementation Digital & Innovation Committee

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

BOARD ATTENDANCE 2019

	2 FEB	6 APR	18 MAY	29 JUN	21 SEP (i)	21 SEP (ii)	29 NOV	TOTAL
Robin Bradley	✓	✗	✗	✗	✓	✗	✓	3/6
Noelle Burke	P/L	P/L	P/L	P/L	P/L	P/L	P/L	
Thomas Cronin	✓	✓	✗	✓	✓	✓	✓	6/7
Edwina Dunne	✗	✗	✗	✓	✗	✗	✗	1/7
Marcella Flood	✓	✓	✓	✓	✓	✓	✓	7/7
Eugene Kearney	✓	✓	✓	✓	✓	✓	✓	7/7
Jacinta Kelly	✓	✓	✓	✓	✓	✓	✓	7/7
Ian MacDougald	✓	✗	✓	✓	✗	n/a	n/a	3/5
Rebecca Maguire	n/a	n/a	n/a	n/a	n/a	✓	✓	2/2
Rory Mulcahy	✓	✓	✗	✓	✓	✗	✓	5/7
Maurice O'Connor	✓	✗	✓	✓	✓	✓	✓	6/7
Martin Power	✓	✓	✓	✓	✓	✓	✓	7/7
Anne Restan	✓	✗	✓	✓	✓	✓	✓	6/7
Mary Sheahan-Lonergan	✓	✓	✓	✓	✓	✓	✓	7/7

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

Edwina Dunne resigned from the Board on 26th March 2020

ACHIEVING IN GOVERNANCE & REGULATION

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 13 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.ms-society.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 delegated 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.

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

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

Board member, Rory Mulcahy is appointed as Company Secretary.

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 2019 the Council met two 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 71 people across national and regional offices and 44 Community Employment participants. MS Ireland's work is supported by committed volunteers around the country.

MS. AVA BATTLES, CHIEF EXECUTIVE

MS. JACKIE BAKER

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 2019 is set out below:

1 €70,000 - €80,000

0 €80,000 - €90,000

1 €90,000 - €100,000
(CEO)

The Nominating and 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.

ACHIEVING IN GOVERNANCE & REGULATION

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 transparent and above reproach.

THE GOVERNANCE CODE

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

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

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**

ACHIEVING IN GOVERNANCE & REGULATION

FINANCIAL STATEMENTS

The financial statements are prepared on a going concern basis 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 net incoming resources before exceptional items of €50,931 for the year (2018: €314,853). There was a surplus of €29,029 for

2019 after exceptional items. The exceptional items totalled €21,902 and are in relation to a revaluation of a property held for resale of €70,000 which was revalued to €48,098 giving rise to an impairment charge of €21,902 relating to Branches. Income for the year includes significant Legacies/Donations totalling €97,214 (2018: €178,568). 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 €9,150,341 (2018: €9,121,312) at the end of the financial year. They are comprised of restricted funds of €3,107,939 (2018: €3,038,374) and unrestricted funds of €6,042,402 (2018: €6,052,938).

THESE FUNDS ARE REPRESENTED BY THE FOLLOWING:

	NATIONAL OFFICE & CEP	BRANCHES		TOTAL
		€	€	
Tangible Fixed Assets	4,645,999	58,070		4,704,069
Investment properties	1,375,000	-		1,375,000
Net Current Assets (excl. Bank loan)	2,997,981	1,305,346		4,303,327
Bank Term Loan	(1,232,055)	-		(1,232,055)
TOTAL	7,786,925	1,363,416		9,150,341

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

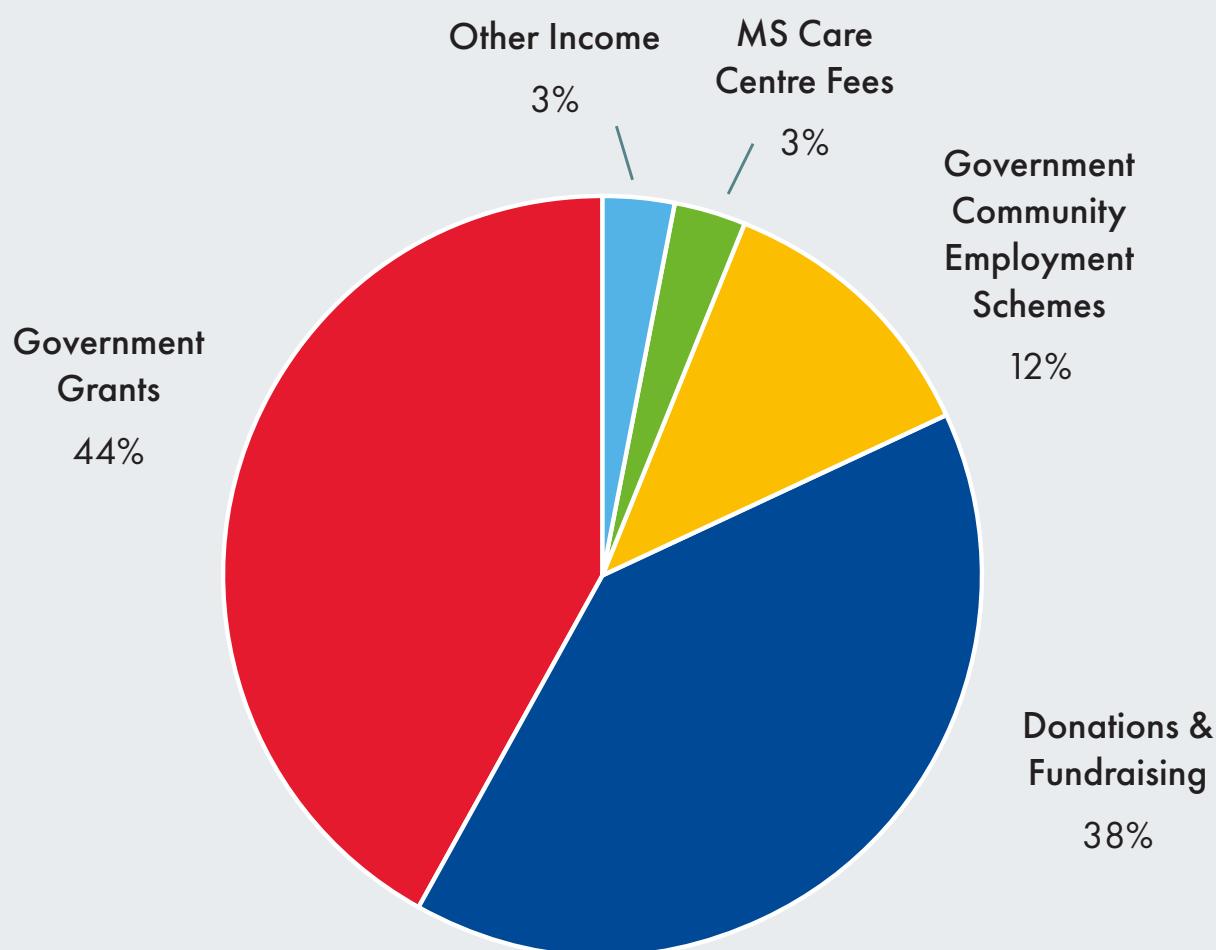
	Unrestricted Funds 2019 €	Restricted Funds 2019 €	Total Funds 2019 €	Total Funds 2018 €
INCOME				
Income from generated funds				
Voluntary Income				
Donations and fundraising	2,090,906	212,030	2,302,936	2,354,754
Legacies	67,214	30,000	97,214	178,568
Research	-	2,884	2,884	58,600
Subscriptions	1,788	-	1,788	1,442
Income from charitable activities				
Fees received	226,106	-	226,106	206,339
Grants and other service contract income	-	2,762,538	2,762,538	2,784,667
Government schemes	-	771,932	771,932	784,161
Other income	28,739	135,617	164,356	226,614
Total income	2,414,753	3,915,001	6,329,754	6,595,145
EXPENDITURE				
Costs of generating voluntary income				
Fundraising	614,088	107,064	721,152	841,798
Charitable activities				
Community services	-	2,658,644	2,658,644	2,601,569
Respite care services	116,895	1,874,285	1,991,180	1,933,775
Research	7,555	10,042	17,597	54,986
Local MS services	724,703	165,547	890,250	848,164
Total expenditure	1,463,241	4,815,582	6,278,823	6,280,292
Net income/(expenditure) for the year before exceptional items	951,512	(900,581)	50,931	314,853
Exceptional items	-	(21,902)	(21,902)	1,445,000
Net income/(expenditure) for the year	951,512	(922,483)	29,029	1,759,853
Transfer between funds	(962,048)	962,048	-	-
Net movement in funds	(10,536)	39,565	29,029	1,759,853
Reconciliation of Funds:				
Total funds brought forward	6,052,938	3,068,374	9,121,312	7,361,459
Total funds carried forward	6,042,402	3,107,939	9,150,341	9,121,312

INCOME ANALYSIS 2019

€6,329,754

Income of €6,329,754 was received of which 44% was funding from Government Grants mainly HSE, 38% was Donations and Fundraising, 12% was from three Department of Social Protection schemes we have in Donegal, Galway and Dublin, 3% was from fees received from Respite Centre residents and 3% from miscellaneous income.

	2019 (€)	2018 (€)
■ Government Grants	2,762,538	2,784,667
■ Donations & Fundraising	2,403,034	2,591,923
■ Government Community Employment Schemes	771,932	784,161
■ MS Care Centre Fees	226,106	206,339
■ Other Income	166,144	228,055
TOTAL	6,329,754	6,595,145



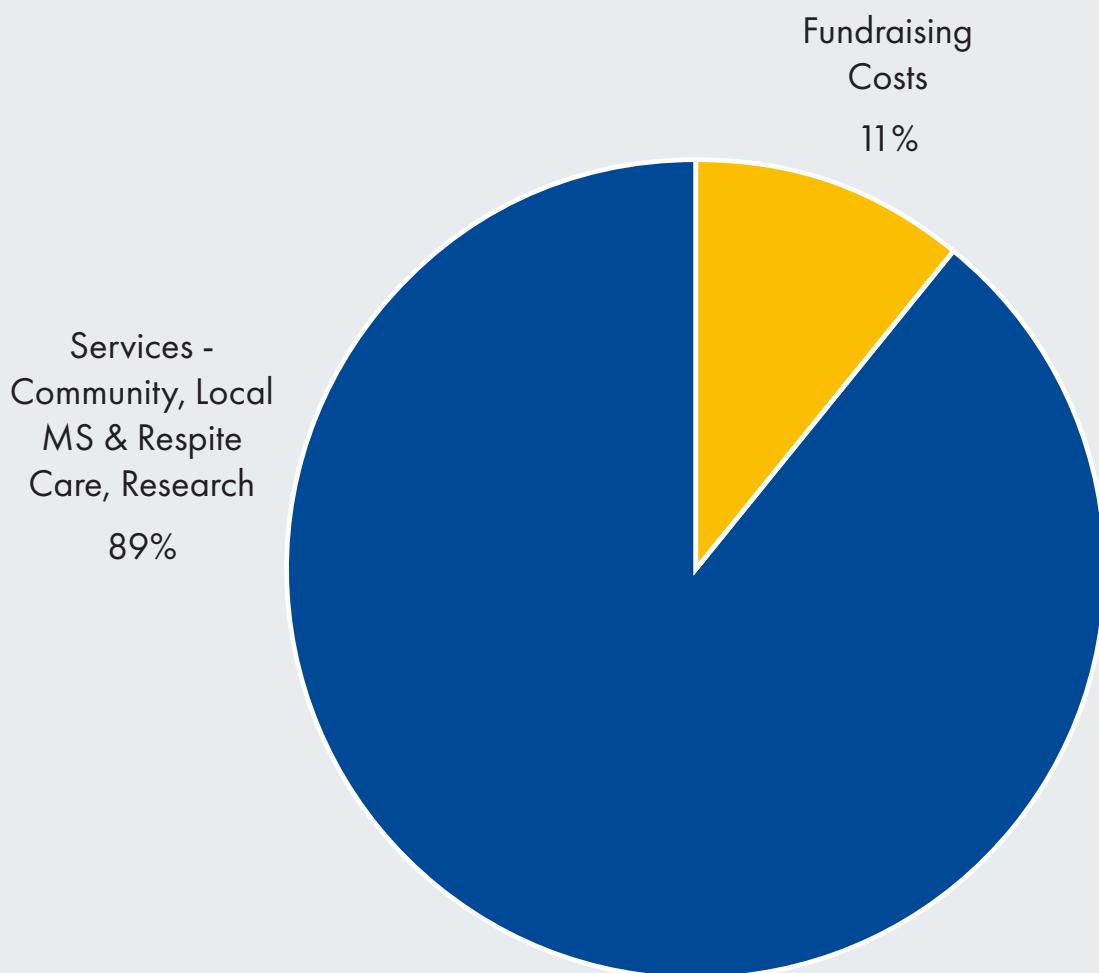
OPERATIONAL EXPENDITURE ANALYSIS 2019

(excluding exceptional items)

€6,278,823

€6,278,823 before exceptional items was spent in 2019 of which 89% was spent on Community services, Care Centre respite services and Research and 11% Fundraising.

	2019 (€)	2018 (€)
Services - Community, Local MS & Respite Care, Research	5,557,671	5,438,494
Fundraising Costs	721,152	841,798
TOTAL	6,278,823	6,280,292



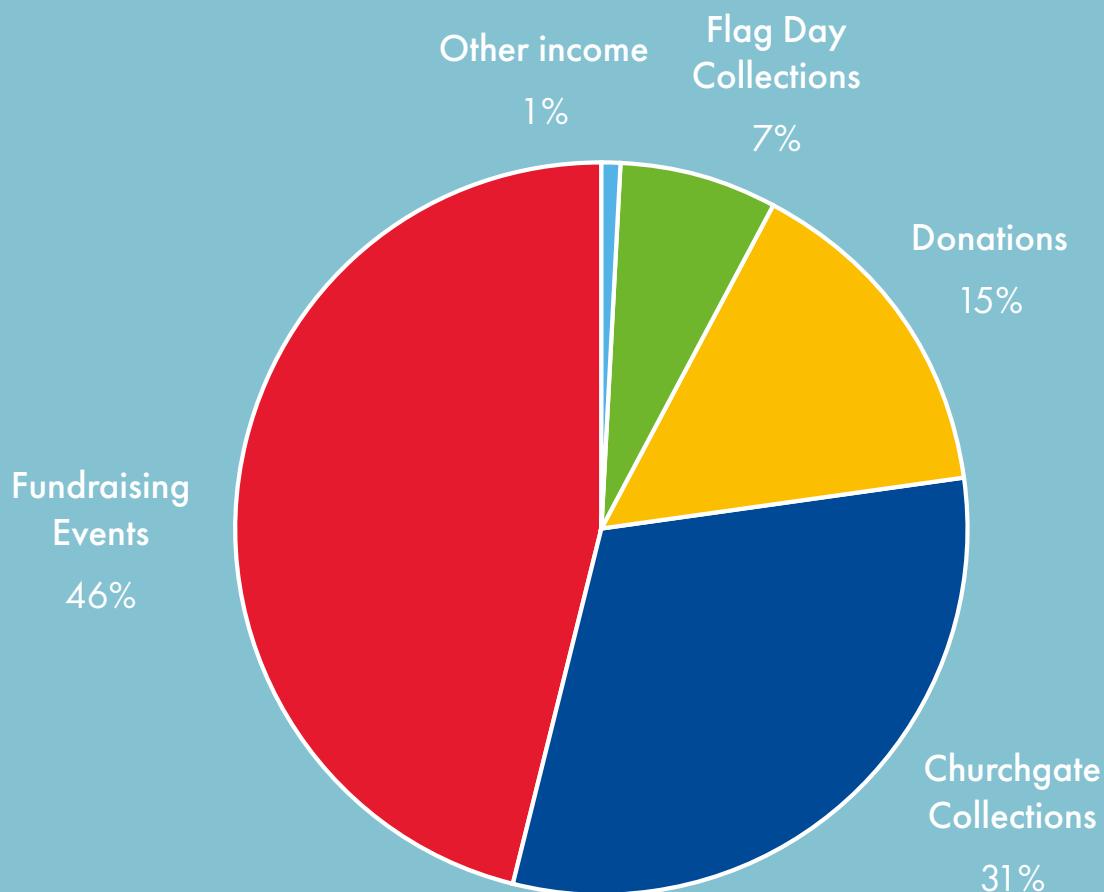
BRANCH INCOME ANALYSIS 2019

€898,510

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

Income of €898,510 was received of which 46% was raised from fundraising events, 31% from churchgate collections, 15% from Donations, 7% from Flagdays collection and 1% was from other income such as bank interest, christmas party contributions etc.

	2019 (€)	2018 (€)
Fundraising Events	411,651	369,012
Churchgate Collections	277,172	265,151
Donations	139,676	118,159
Flag Day Collections	59,254	61,125
Legacies	-	70,000
Other income	10,757	15,077
TOTAL	898,510	898,524

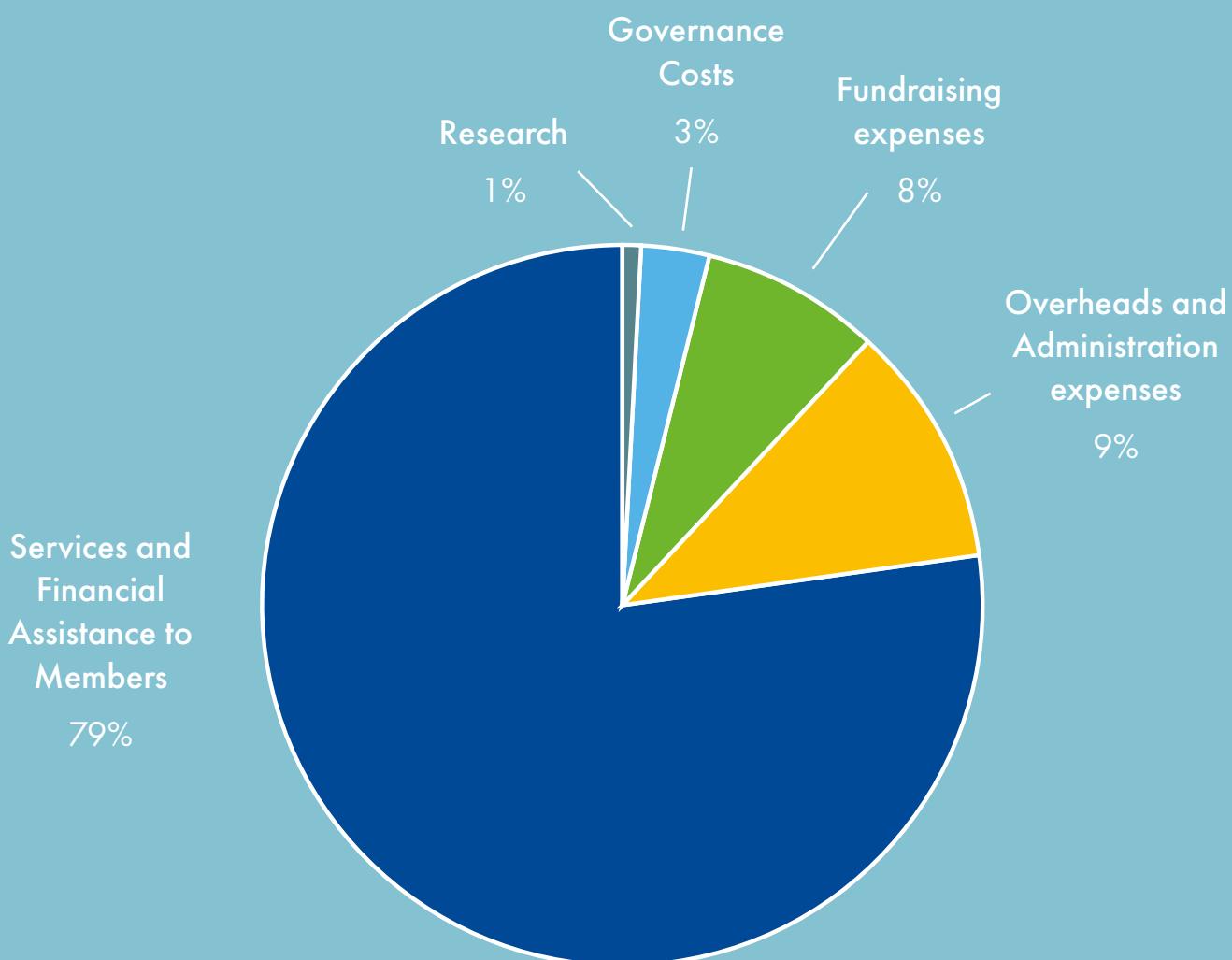


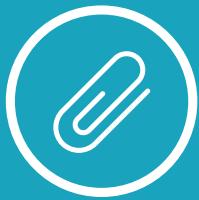
BRANCH EXPENDITURE ANALYSIS 2019

€894,149

€894,149 before exceptional items was spent in 2019 of which 79% was spent on providing services & Financial assistance to members, 9% Overheads and Administration expenses, 8% on fundraising expenses, 3% Governance and 1% on Research.

	2019 (€)	2018 (€)
Services and Financial Assistance to Members	709,602	775,594
Overheads and Administration expenses	83,510	56,535
Fundraising expenses	69,993	39,995
Governance Costs	25,044	25,234
Research	6,000	17,393
TOTAL	894,149	914,751





IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Governance & Regulation in 2019:

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 2019.



An Roinn Tithíochta, Pleanála,
Pobail agus Rialtais Áitiúil
Department of Housing, Planning,
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