MS IRELAND
ANNUAL REPORT & ACCOUNTS
2020

MS Ireland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

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

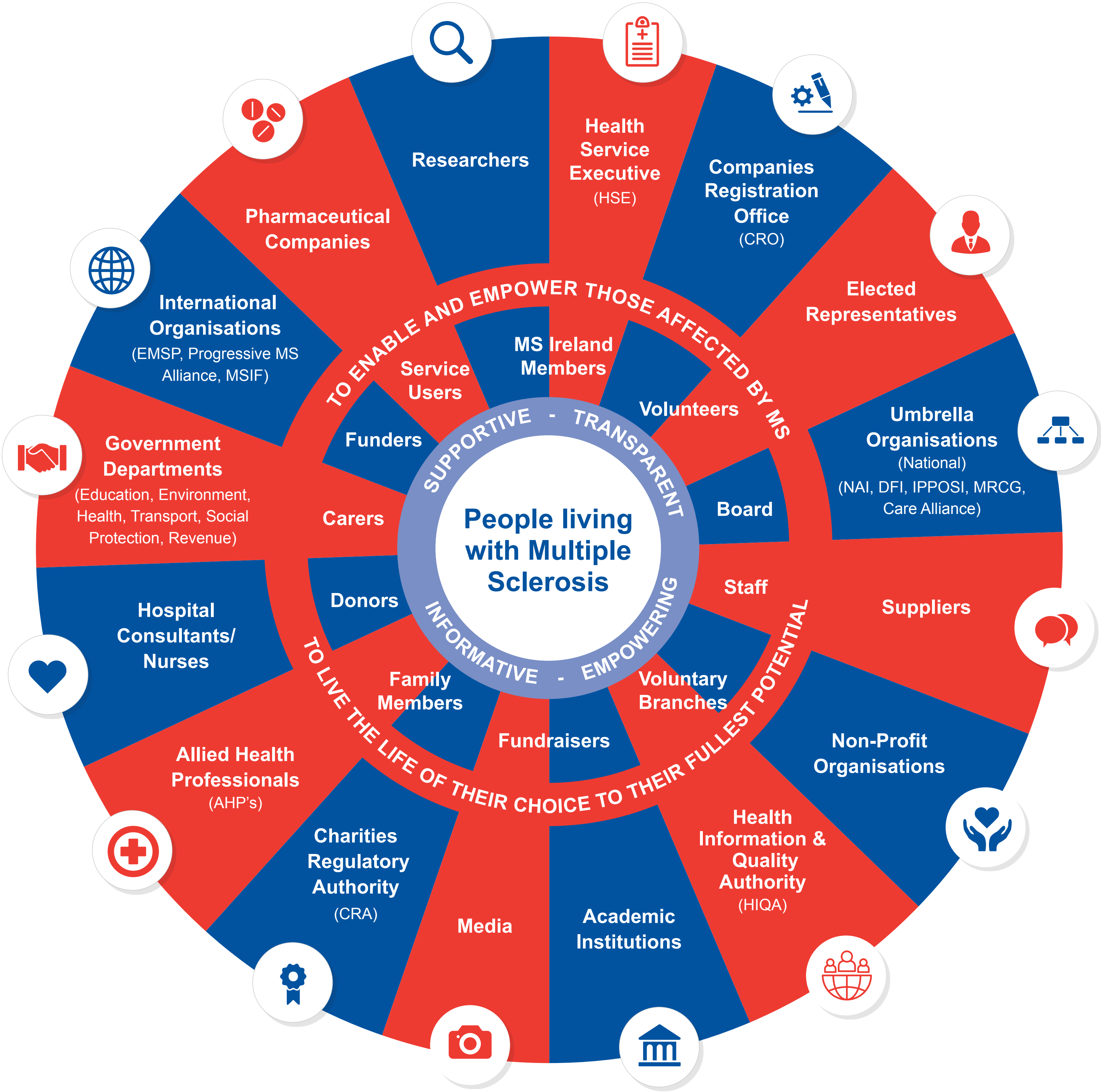
“Communicate reliable, accurate and useful information”

Empowering

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

CONTENTS

STAKEHOLDER MAP



CHIEF EXECUTIVE & CHAIRMAN 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. In March 2020, along with the rest of the world, our lives changed with the onset of the COVID-19 pandemic, something that no one could prepare or plan for. The pandemic brought with it challenges and restraints, not only to us as an organisation but also to those most important to us, the 9,000 people in Ireland living with MS. The past twelve months have been incredibly challenging for our community. Firstly, there was a great sense of uncertainty and worry amongst our community members of what the pandemic might bring for them in terms of their own health and that of their loved ones.

In times of crisis, the most vulnerable in society are most affected. Not only are they more socially isolated, but they are also deprived of some muchneeded services essential to coping with and managing complex conditions like MS. Those living with Multiple Sclerosis often medicate with immunosuppressant drugs to treat the condition. The related side effects put those affected well within the vulnerable section. Add to this the progressive nature of the condition, the weight of all-too-common social isolation, and it makes organisations like ours even more important in these times of great change.

In response to the pandemic, we had to adapt quickly and change our approach while still figuring out how to deliver our much-needed services. Sadly, because of the pandemic for the health and safety of our residents and staff, we had to close our National MS Care Centre temporarily. The suspension of some of our services affected the people with MS we serve greatly. We have been a pillar of support to many people during difficult times, and although we could not attend to many of our clients physically, we still strived to meet their needs throughout an arduous year. Nevertheless, we were not put off course to achieve our mission, to enable and empower people affected by Multiple Sclerosis to live the life of their choice to their fullest potential. While we operated in an unprecedented and challenging environment, we managed to adapt thanks to our dedicated team of staff and volunteers throughout the country who 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.

We are delighted to welcome you to a review of MS Ireland's activities and services throughout 2020. This report will highlight and celebrate the successes, achievements, and challenges that the organisation has faced over the last turbulent 12 months.
In response to COVID-19, MS Ireland established a dedicated COVID-19 Information Centre on

CHIEF EXECUTIVE & CHAIRMAN WELCOME

our website. This housed up-to-date and accurate information on COVID-19 and MS, as well as supports and links to other resources and services that proved to be highly beneficial for our community and beyond. We were in regular contact with healthcare professionals to ensure that the information we provided was relevant, accurate and tailored for our community, while remaining in line with public health advice. We also shared tips from the MS Community on taking care of one's self during COVID-19 pandemic on our information centre. Our website saw an almost 44% percent increase in views compared to the same period last year as people logged on to stay well informed on the latest developments. We were acutely aware that there was specific information people living with MS needed throughout the pandemic and we ensured the website was kept up-to-date with the very latest to meet their information needs.

Furthermore, in response to COVID-19 we also extended the hours of operation of our Information Line, so we were there to help answer our communities' questions and assist them with any concerns they may have with the ongoing situation we were all now confronted with. The Information line is a vital source of support for people living with MS and in 2020 we extended the Information Line opening hours to 10am-5pm Monday to Friday.

MS Ireland had to make some changes to the way we normally work so that we could continue to provide the services and supports that our community needed. In line with guidance from the Government and to ensure the safety of our service users and staff, MS Ireland made several changes in how we work, for example, our network of Regional Community Workers who would often meet our community members in person, now kept in touch over the phone or virtually via Zoom. We have had to ensure that our resources and skills would allow us to work in this new way, so that the service that we provide could continue uninterrupted. In accordance with public health guidelines our staff worked from home and seamlessly managed this transition while remaining ever connected with each other throughout. It is great testament to the staff team that they were able to adapt so quickly and achieve so much in a difficult set of circumstances.

Prior to COVID-19 in early 2020 all our exercise programmers were up and running including our Active Neuro programme in the Mid-West which was just starting its mixed neurological classes in the region. However, with the introduction of restrictions, our in-person classes had to be postponed to prevent putting people with MS at risk.

We were concerned with the impact of people stopping exercising altogether, reduced physical activity leads to decreased strength and balance, worsening walking ability and increasing falls risk, also the social aspect of the classes are so important for people. One of the highlights of 2020 was our transition from offline to online exercise programmes. Largely due to the brilliant work of Professor Susan Coote and her team, we were able to move our exercise programmes online, allowing people to log on, take part and keep active from the comfort of their homes.

In advocacy, MS Ireland continued working with the Neurological Alliance of Ireland (NAI) on several issues including the 'Invest in Neurology' campaign and access to neurorehabilitation. This included a virtual meeting with Minister for State, Anne Rabbitte to discuss the implementation of the Neuro-rehabilitation Strategy. We also engaged with the NAI in relation to our messaging to elected representatives for the Programme for Government. To mark Brain Awareness Week, MS Ireland released a number of videos with neuropsychologist Niall Pender in relation to cognition and MS and top tips for brain health.

In 2020, MS Ireland was delighted to receive the news that a decision had been made to reimburse Ocrevus for people living with early forms of primary progressive MS in addition to those with relapsing forms of MS. Significant work had gone into a collaboration with Roche in 2019 with the MSUnderstood Café and Café Roadshow as well as the Patients Deserve Better website which enabled our members to write to their local representative to highlight the issue of delays in accessing new and innovative medications. This work carried into 2020 and the platform to contact local representatives remained open. We also collaborated with Almirall and conducted a survey to explore resource use in people living with MS who experience spasticity to inform our patient group submission to the National Centre for Pharmacoeconomics to support Sativex in its health technology assessment.

CHIEF EXECUTIVE & CHAIRMAN WELCOME

In ordinary times, MS Ireland would run a number of information events as well as our National Conference. These sessions were not able to go ahead in physical settings due to the restrictions as well as risk to our community. We moved these sessions into a virtual space. In 2020 we hosted a series of information webinars which allowed people in the MS community to access expert information from the comfort of their own homes. We recorded most of these sessions and made them available on our website after the live event. We now have a dedicated section on our website which hosts the various recordings in a catalogue which allows people to access these videos on demand at a time that suits them. The webinars and videos featured leading speakers in the fields of Multiple Sclerosis, Neurology, Physiotherapy, and exercise along with many others.

In research, MS Ireland continued our collaboration with the University of Limerick on the Public and Patient Involvement in Research Ignite programme (PPI). This is a Health Research Board funded scheme which encourages universities to involve patients and members of the public in the design and delivery of research projects. Facilitating PPI is an important element of the research function in MS Ireland. On several occasions, we facilitated PPI workshops with community members and researchers to ensure that people living with MS were active partners in research relating to them. We highlighted the importance of PPI in research in the eZine we circulated in December. This gave a dual perspective on the PPI experience as both a PPI participant and researcher shared their thoughts on the experience. We also developed the 'Researchers profiles' section on our website which aimed to give readers an understanding from our site, of what research is currently being conducted and the key people within the research community in Ireland.

Unfortunately, due to the pandemic our National MS Care Centre had to close in April and remained so until October. The centre is Ireland's only dedicated respite centre for people with MS. It offers short-term respite care to people with MS and other neurological conditions, therapeutic services, neurological assessments, and many social activities in a homely environment considered a 'home away from home' and a place of rest and relaxation for people from all over Ireland. That is why it was a joyful scene to see the centre reopen in October and welcome back residents for some much-needed care, respite, and relaxation. The reopening was only made possible through the dedicated efforts of our Care Centre team.

This year was different for everyone as we all had to adapt to our increasingly online world. But out of adversity is born innovation and in 2020 MS Ireland's fundraising team embraced the challenges that faced them and after 33 years brought our MS Readathon online. The MS Readathon is our biggest fundraising campaign each year and we simply cannot keep our services running without it. We created a website that allowed participants to login and register online while being able to set up groups and keep track of the number of books they read, and amounts raised. The new website also had a 'Big Kids' section as well as a 'Clubs and Groups' section where adults could get in on the Readathon action. We had two inspirational ambassadors, Maggie Green and Olivia Kirwan who shared their stories with the national and regional media encouraging others to take part. In total we had over 3,500 readers take part, over 307 school registrations while raising €425,000. Throughout the year our fundraising team held several other virtual events, including virtual walks, mountain climbs and a host of other physical activity challenges.

World MS Day is the international day to celebrate and shine a spotlight on people living with Multiple Sclerosis throughout the world. Due to COVID-19, our original plans for World MS Day had to change and adapt as we moved our plans online. We had to think a little differently and we decided to mark the day by having an environmentally friendly, 'Virtual Balloon Race'. How the raced worked was once the balloons were virtually launched, they were subject to a simulated set of weather conditions at the virtual launch site, our National MS Care Centre and then raced for seven days, the balloon that travelled the furthest would be the winner. The aim of the campaign was to have 9,000 virtual balloons flying, one for each of the 9,000 people in Ireland living with MS. The theme for World MS Day was #MSConnections and we utilised this theme and message to create awareness for World MS Day and drive sign-ups to our Virtual Balloon Race. A key aim was to engage a wide audience and to make sure we had 9,000 virtual balloons flying high by 9pm on World MS

CHIEF EXECUTIVE & CHAIRMAN WELCOME

Day. Amazingly, we achieved this target with the help of our tremendous supporters with a little over 15 minutes to spare on what was a World MS Day that we will never forget.

In 2020, our MS and Me blog remained one of the most popular and most valuable information source for the MS community. Throughout the year, our team of bloggers wrote each week on how they had been impacted by the pandemic while sharing how they are coping and tips they used to help them get by. This was the current MS and Me blog team's third year together and in 2020 we said goodbye to some of our team members, we thank them whole heartedly for all their efforts over the past three years. We put a call out for new writers and voices at the end of 2020 and look forward with anticipation to what the new team will bring in 2021 and beyond.

2020 brought the first year of our new Strategic Plan 2020-2024. The new Strategic Plan had been a culmination of a full year of effort and input from a planning group from all functions of the organisation. The group facilitated various stakeholder engagement activities so that we could hear a range of thoughts and opinions on what the direction and goals of our organisation should be in the new Strategic Plan. We asked our stakeholders, including people living with MS, their families, MS Ireland staff members, health care professionals and more to take part in focus groups, surveys, and one-to-one conversations. Together, this group determined 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 delighted with the result, and you can read more on page 9 of this report. We were looking forward to officially launching the new Strategic Plan on World MS Day 2020, but unfortunately, these plans had to be put on hold due to the environment we found ourselves in. We did however work strenuously towards achieving our strategic priorities, as set out in our Strategic Plan 2020-2024.

While we were faced with unparalleled challenges and circumstances that none of us could even imagine, MS Ireland still achieved a great deal across the organisation, which we are immensely proud of. None of these achievements in 2020 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 virtual and non-virtual fundraising activities, and raising awareness about who we are, what we stand for, and what we do. Unfortunately, the past year we have lost people living with MS and those close to MS Ireland. We would like to acknowledge and offer our condolences to the friends and families of those who have passed away in 2020. We live with great hope that soon the world as we know it can return to normal or a 'new normal', 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

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

Ava Battles

AVA BATTLES
CHIEF EXECUTIVE

MAURICE O'CONNOR
CHAIRMAN

INTRO TO STRATEGIC PLAN

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 for the group to gain a real, data driven understanding of the 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 in 2020 we were delighted to launch our new strategic plan for the next 5 years.

In 2020, MS Ireland worked towards achieving our strategic priorities, as set out in our Strategic Plan 2020-2024. The Board of MS Ireland is committed to building a Society which is integrated, effective, outcome-driven and accountable.

The key objectives of the Strategic Plan 2020-2024 of MS Ireland are as follows :-

GOAL: SERVICE DELIVERY

Objective 1:
Services Development and New Service Models

Objective 2:
Research

Objective 3:
Advocacy

GOAL: SUSTAINABLE FINANCES

Objective 4:
Grow Sustainable Revenue Base

Objective 5:
Develop Partnerships

GOAL: INNOVATION

Objective 6:
Develop Digital Operations and Governance

GOAL: PEOPLE AND CULTURE

Objective 7:
Develop and Invest in our People

Objective 8:
Grow Branch and Community Volunteer Base

MS IRELAND STRATEGIC PRIORITIES

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

GOAL: SERVICE DELIVERY

OBJECTIVE 1. Services Development & New Service Models

Provide a sustainable service model that delivers quality of life, maximum independence & client satisfaction to our community and stakeholders.

OBJECTIVE 2. Research

Service design and development informed by research, international best practice and outcomes.

OBJECTIVE 3. Advocacy

Improve access to services to ensure PwMS can exercise choice over their lives and careers.

GOAL: SUSTAINABLE FINANCES

OBJECTIVE 4. Grow Sustainable Revenue Base

Increase HSE services and develop regular & recurring giving campaigns to help sustain vital services and new programmes.

OBJECTIVE 5. Develop Partnerships

Leverage and grow our partnered programes to support service development, funding and delivery.

GOAL: INNOVATION

OBJECTIVE 6. Develop Digital Operations & Governance

Develop Digital Operations and Governance structures & strategies to improve operational efficiency and effectiveness.

GOAL: PEOPLE & CULTURE

OBJECTIVE 7. Develop & Invest In Our People

Ensure a fit for purpose organisational design and develop a workforce model for the future, recognising that as the capabilities of our people improve, so does our overall service to clients.

OBJECTIVE 8. Grow Branch & Community Volunteer Base

Grow our volunteer base across our branch network through diverse volunteer opportunities, programmes and ways to get involved.

Goal: Service Delivery

GOAL: SERVICE DELIVERY

OBJECTIVE 1: SERVICES DEVELOPMENT & NEW SERVICE MODELS

Description: Provide a sustainable service model that delivers quality of life, maximum independence & client satisfaction to our community and stakeholders.

During 2020 the Company underwent the first year of its Strategic Plan. It reviewed and developed our suite of services provided by professionals and volunteers. We explored a variety of platforms both online and in person to offer a variety of services. This was an exciting development resulting in many of our programmes being non location specific thus appealing to a potentially wider audience. This offered us an opportunity to capacity build our staff, volunteers and MS community with digital literacy opportunities.

Regional Community Work

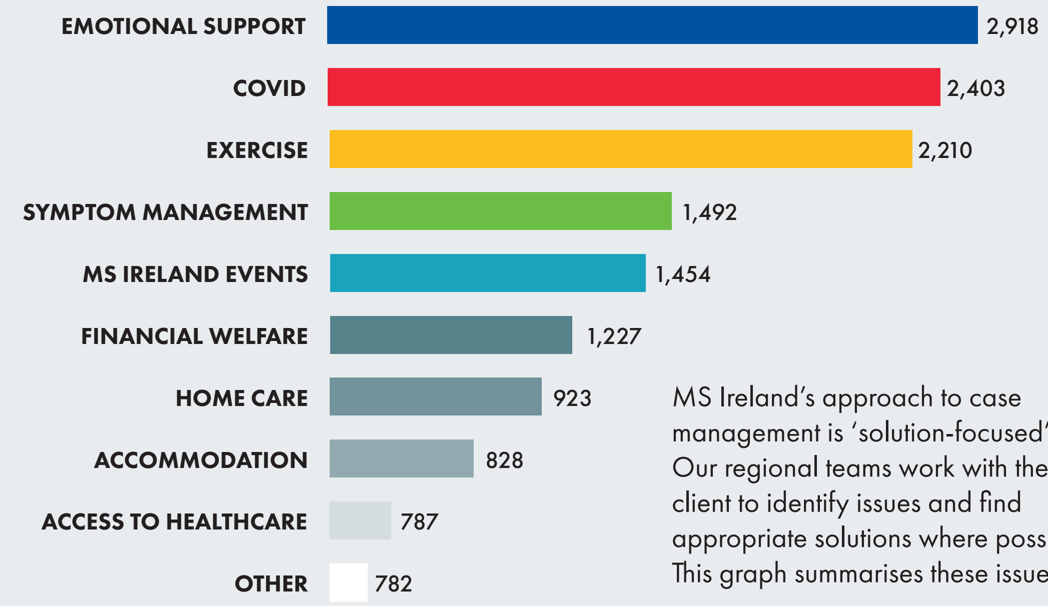
In 2020, MS Ireland ensured the provision of practical and emotional support, community physiotherapy and other physical activity programmes, health promotion, coping strategies and well-being services to PwMS and their families. In March of 2020 as a result of the pandemic (Level 5 restrictions) all services were moved online, policies and procedures were developed to support this response. Programmes that were moved online included 1:1 Case Work, physiotherapy, yoga and peer support groups. In addition to this many information sessions and webinars were developed and made available to the MS community.

3,226
PEOPLE ENGAGED IN ONE-TO-ONE SERVICES

1,031
INDIVIDUALS ATTENDED ONE TO ONE CASE WORK

78
NEWLY DIAGNOSED CONTACTS

TOP 10 ISSUES PRESENTED BY CLIENTS



MS Ireland's approach to case management is 'solution-focused'. Our regional teams work with the client to identify issues and find appropriate solutions where possible. This graph summarises these issues.

GOAL: SERVICE DELIVERY

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. The majority of these services were moved to online platforms in response to the COVID-19 Pandemic.

These programmes may be one-off sessions or a ten-week course, depending on the nature of the programme. The figures below summarise the types of programmes we ran in 2020:

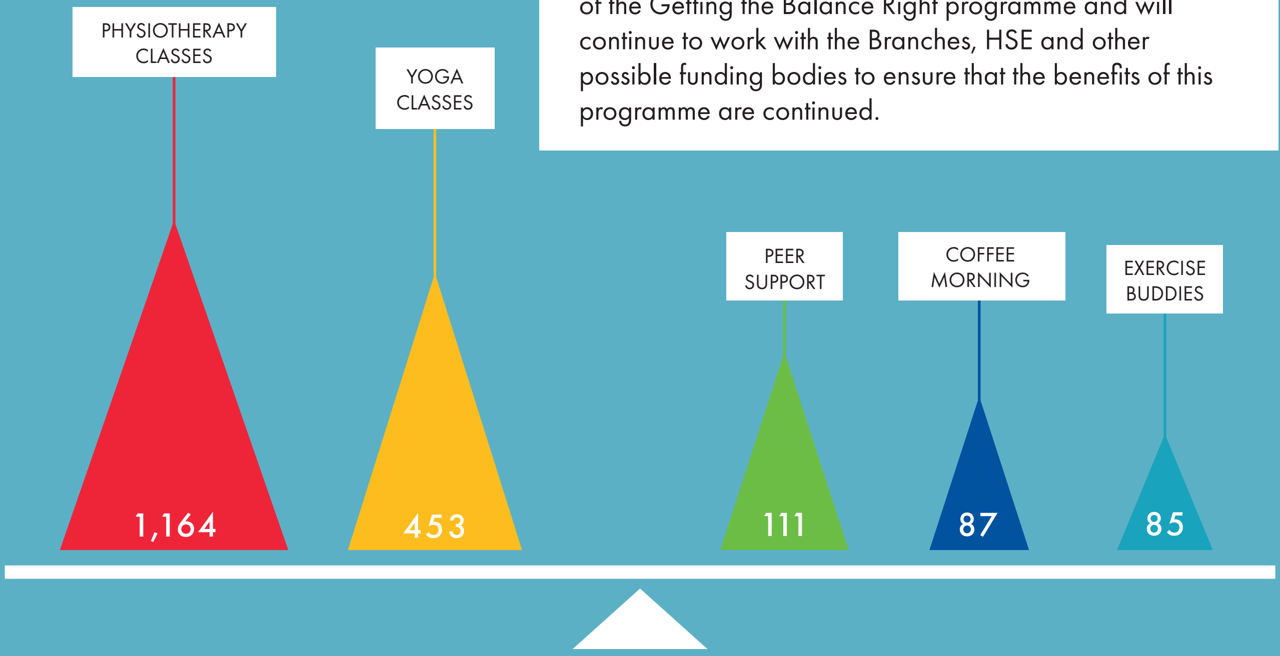
Physiotherapy	Yoga	Coffee	Peer to Peer	MS Information	Symptom Management
101	49	60	26	9	8

GETTING THE BALANCE RIGHT

Getting the Balance Right, our nationwide exercise, health promotion and research programme for people with MS, continues to be an enormous success. The programme offers a range of opportunities for people with MS to maintain and improve a full range of motion, which may have been impacted on as a result of the MS disease process. Interventions range from physiotherapy-led group programmes, physiotherapy 1:1, yoga, gym-based programmes, hydrotherapy and tai chi. Due to Covid-19 we had to move the getting the balance right programme to an online offering.

IN 2020 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.



GOAL: SERVICE DELIVERY

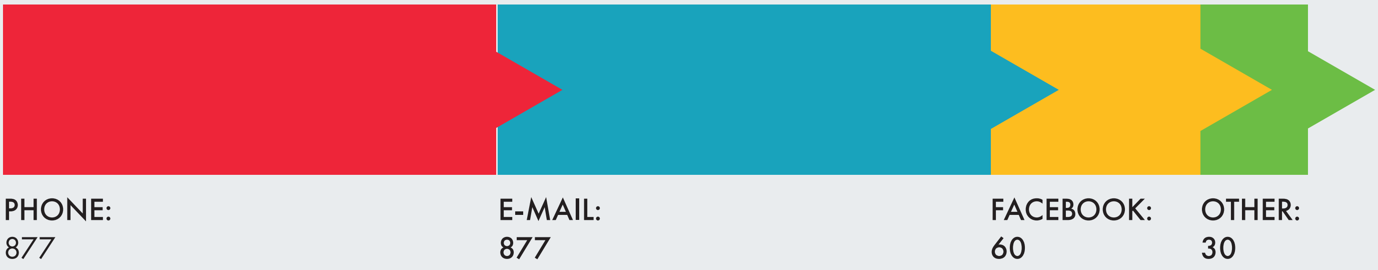
INFORMATION LINE

The Information Line is often the first port of call for a person with MS and/or a family member. This is a confidential service, and the main thrust is the provision of reliable and accurate information and support in a timely fashion. The information is given on an individual basis to people affected by MS ("PaMS") and health professionals through the MS Information Line – Telephone – 1850 233 233. The Information Line hours increased from 9.30 a.m. – 1.30 p.m. to 9.30 a.m. – 5.00 p.m. from April 2020 to January 2021 to respond to the increased need as a result of Covid-19. 1,203 people contacted the Information Line in 2020, 877 of these contacts were by telephone, 236 were by email, 60 via Facebook and the remaining 30 by other means. The information line also signposts to Regional Staff as appropriate and to other appropriate services and/or agencies.

REASON FOR MAKING CONTACT

764	GENERAL INFO
227	TREATMENTS
152	ENTITLEMENTS AND SERVICES
141	HELPLINE SUPPORT
45	SHORT TERM RESPITE
43	COUNSELLING
35	QUERY DIAGNOSIS
25	HEALTHCARE PROFESSIONAL
22	INSURANCE
13	TRANSPORTATION
9	LONG-TERM CARE
3	RESEARCH

HOW PEOPLE MADE CONTACT



In 2020, 1,203 people contacted the MS Information Line.

GOAL: SERVICE DELIVERY

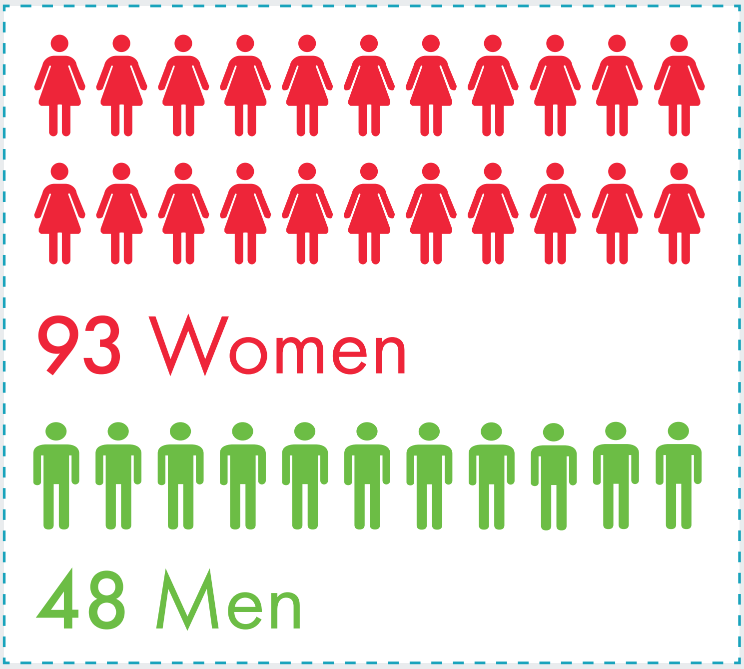
THE MS CARE CENTRE

The MS Care Centre is a 12-bed respite facility. MS Nurse specialist and therapy services are available to our clients. Due to the pandemic the Care Centre was closed from 18th April to 5th October 2020. When it reopened in October, due to infection control and Public Health Guidelines, the capacity was reduced to 6 residents and the length of stay was increased to 12 nights. In 2020 141 people stayed in the Care Centre.

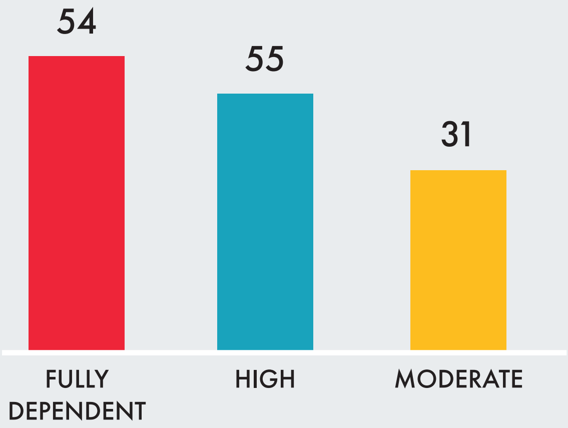
The MS Care Centre is a Designated Centre under the 2007 Health Act; as such it must be registered by the Health Information Quality Authority ("HIQA") in order to operate.

Registration is reviewed on a three-yearly basis by HIQA and was recently approved for registration in October 2020. The work in relation to HIQA is directed and managed by the Clinical Nurse Manager and the Quality Manager at the Care Centre. In November 2020 the Health Information and Quality Authority completed a short notice announced visit to the MS Care Centre.

We had a judgement of compliance on the 12 regulation areas that the inspector covered on the day.



DEPENDENCY



PROFESSIONAL & THERAPEUTIC INTERVENTION

GOAL: SERVICE DELIVERY

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

western@ms-society.ie (091) 768 630

VOLUNTARY BRANCHES

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

GOAL: SERVICE DELIVERY

Pictured Above and below: Some of our branch members taking part in Virtual Events

BRANCHES

In 2020 due to the pandemic Branch activities and fundraising were hugely curtailed resulting in a significant drop in activity levels across a range of activities. MS Ireland staff supported to make the transition from in person to various digital platforms. Branch activities include support groups, social activities, therapies and in some instances, financial assistance. The provision of branch level supports is made possible by voluntary local fundraising.

COMMUNITY EMPLOYMENT SCHEMES

The provision of services and supports throughout the country rely on the quality contribution of our Community Employment Scheme Participants. These individuals come to us through the Department of Social Protection's Community Employment Programme ("CEP"). They hugely contribute to the work of MS Ireland on a day-to-day basis. There are 23 CE participants assisting in the work of the Care Centre, 11 CE participants assisting with the exercise training plans for PwMS in the Western region: 16 visiting PwMS in their homes, carrying out maintenance work for people with MS in the North West region. They provide a tremendously valuable contribution to the work of MS Ireland. As with other services the role of the CE participant was moved to online/telephone support outside of the Care Centre.

SOCIAL MEDIA

Our social media channels continued to grow throughout 2020 and became increasingly important in response to the covid-19 pandemic. Our channels allowed us to distribute the very latest updates in what was a rapidly changing situation keeping our followers and community informed and up-to-date. Our social media channels also offered another avenue for people to engage with us via messages and questions and query on our posts.

We had regular information updates and tips and advice on how to better manage during the pandemic. A highlight of the year was one of our service uses who submitted poetry and artwork that he created inspired by his MS diagnosis. Our '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.

Instagram
multiple_sclerosis_ireland

3,537 Followers

Facebook
MultipleSclerosisIreland

1,826 Likes

YouTube
MSSocietyIRELAND

20,000 Views

Twitter
@MSIRELAND

9,195 Followers

35 Emails sent

E-News
Sign up on our website

5,702 Subscribers
(+2,747, an increase of 93%)

Website
www.ms-society.ie

250,026 Website Visitors

Newly created COVID-19 information centre getting 22,000 unique page views

MS IRELAND WEBSITE

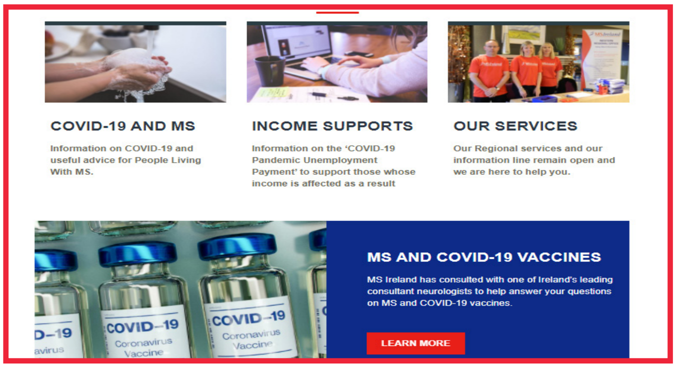
In response to COVID-19, MS Ireland established a dedicated COVID-19 Information Centre on our website which you can access here www.ms-society.ie/coronavirus-covid-19 This houses up-to-date and accurate information on COVID-19 and MS, as well as supports and links to other resources and services that may be useful at this time. We have been in regular contact with healthcare professionals to ensure that the information we are providing is relevant, accurate and tailored for our community, while remaining in line with public health advice.

We have a team of volunteer bloggers who write about their own personal experiences of living with MS. The blogs had 24,936 page views on the MS Ireland Website.

GOAL: SERVICE DELIVERY

WEBINARS

While we have not been able to organise any physical events over the past number of months, we have been keen to ensure we are providing our community with access to medical professionals who can provide up to date, accurate information and answer your questions. By providing information in this format, it can be accessed at a time that suits. Recordings of webinars are added to our website where we have a dedicated an update page on all the latest webinars.



COVID-19 AND MS

Information on COVID-19 and useful advice for People Living With MS.

INCOME SUPPORTS

Information on the 'COVID-19 Pandemic Unemployment Payment' to support those whose income is affected as a result

OUR SERVICES

Our Regional services and our information line remain open and we are here to help you.

MS AND COVID-19 VACCINES

MS Ireland has consulted with one of Ireland's leading consultant neurologists to help answer your questions on MS and COVID-19 vaccines.

MS AND WELLNESS

Taking care of yourself is important and to help with this, MS Ireland introduced a new MS Wellness section on our website. This information on MS and wellness aims to provide people living with multiple sclerosis, their families and carers access to information, tips and tricks to support.

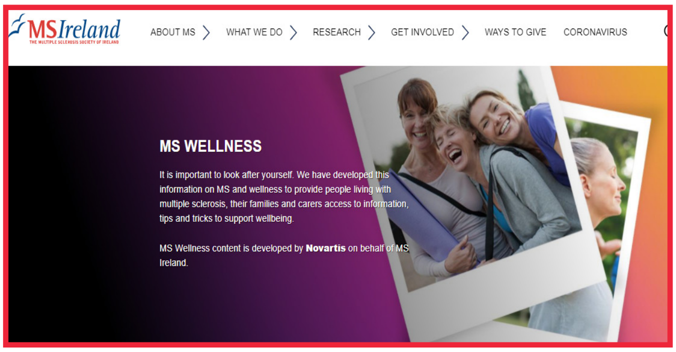
It includes information on relaxation and mental health as well as providing some handy life hacks. The information was developed by Novartis on behalf of MS Ireland. You can check out the MS Wellness section.

MS NURSE VIDEO SERIES

With the support of Roche, MS Ireland produced a series of videos with Clinical Nurse Specialist Maire Hayes which answered questions relating to the COVID-19 pandemic. The questions in these videos were submitted by people within the MS community. It was important to us that people had the opportunity to ask the questions that mattered to them and be given clear answers from a healthcare professional.

SECONDARY PROGRESSIVE MS VIDEOS

MS Ireland in collaboration with Novartis released a video series with information on secondary progressive MS (SPMS). Aimed at supporting those with SPMS, the video series had been developed in close collaboration with leading specialists including Professor Gavin Giovanonni, Professor of Neurology, Blizard Institute, Barts and the London School of Medicine and Dentistry, and Professor Niall Pender, Head of Department of Psychology, Beaumont Hospital and Associate Professor in Neuropsychology, Trinity College Dublin. The series addresses topics including key signs and symptoms, the impact on cognitive ability, bladder and bowel issues and how to access support services.



MS WELLNESS

It is important to look after yourself. We have developed this information on MS and wellness to provide people living with multiple sclerosis, their families and carers access to information, tips and tricks to support wellbeing.

MS Wellness content is developed by **Novartis** on behalf of MS Ireland.

GOAL: SERVICE DELIVERY

OBJECTIVE 2: RESEARCH

Description: Service design and development informed by research, international best practice and outcomes.

Throughout the year, MS Ireland shared numerous opportunities for the MS community to get involved with research. We also circulated research findings. From an international perspective, we collaborated with Multiple Sclerosis International Federation (MSIF) on updates to the Atlas of MS and European Multiple Sclerosis Platform (EMSP) in relation to the MS Barometer.

MS Ireland developed the 'Researchers profiles' (see below) section on our website which aimed to give researchers an understanding from our site, of what research is currently being conducted and the key people within the Research community in Ireland. In December, we held an event for researchers which gave them an opportunity to introduce or update on their research. Researchers from various career stages were in attendance. Prof Orla Hardiman joined this virtual event which was chaired by Professor Susan Coote.

Facilitating Public and Patient Involvements in Research (PPI) is an important element of the research function in MS Ireland. On a number of occasions, we facilitated PPI workshops with community members and researchers to ensure that people living with MS were active partners in research relating to them. We highlighted the importance of PPI in research in the eZine we circulated in December. This gave a dual perspective on the PPI experience as both a PPI participant and researcher shared their thoughts on the experience.

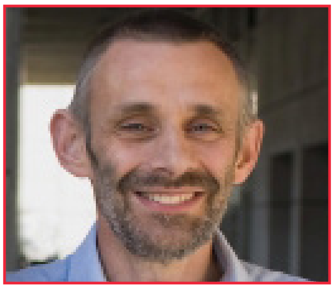
In collaboration with Almirall, MS Ireland conducted research to better understand resource use by people who experience MS related spasticity with the aim of supporting a Health Technology Assessment for spasticity medication. See below for researchers who are on our researchers profile page.

DR. YVONNE DOMBROWSKI
Lecturer, Queen's University Belfast

DR. CLAIRE MCCOY
Lecturer in Immunology, RCSI

PROFESSOR SUSAN COOTE
Chartered Physiotherapist

DR. REBECCA MAGUIRE
Lecturer in Psychology, Maynooth University



PROFESSOR KINGSTON MILLS
Professor Experimental Immunology TCD and Director Trinity Biomedical Science Institute

DR. ERIC DOWNER
Assistant Professor in Human Health & Disease, Trinity College Dublin.

DR. UNA FITZGERALD
Lecturer in Biomedical Engineering Science, NUIG

PROFESSOR TUNDE PETO
Professor of Clinical Ophthalmology at QUB and Consultant Ophthalmologist at the Belfast Health and Social Care Trust, NI, UK

OBJECTIVE 3: ADVOCACY

Description: Improve access to services to ensure PwMS can exercise choice over their lives and careers.

In 2020, MS Ireland continued to advocate for people living with MS, their families and carers on a number of issues and encouraged community members to speak up on the issues impacting them, providing them with the opportunity to be heard by decision makers. We updated position papers and briefing documents, including one on the use of stem cell therapy in MS. We made a number of submissions to political representatives and government including a pre-budget submission and a submission relating to the impact of COVID-19. This submission to the Special Committee on COVID-19 Response outlined some of the issues our community members have faced as a result of the pandemic. MS Ireland co-signed a letter to Minister Donnelly which highlighted that many classed as 'extremely medically vulnerable' were of working age and engaging in working life prior to the pandemic.

We expressed concern that these people may put their health at risk by returning to work too soon in order to avoid severe financial hardship. We asked that the Department take steps to ensure that people were not faced with choosing between protecting their health and paying the bills. We wrote a parliamentary question which was put to Tánaiste Leo Varadkar in relation to the suspension of processing Primary Medical Certificate applications. This question was submitted by Deputy Mark Ward. We advocated for the MS community in relation to medication access. We put forward a patient group submission for Siponimod to the National Centre for Pharmacoeconomics (NCPE) for their consideration in the health technology assessment of this product.

OCREVUS

In October, MS Ireland was delighted to share with our community that access to Ocrevus has been extended to include people living with relapsing remitting MS and early primary progressive MS. This news was very welcome as Ocrevus is currently the only licensed treatment for primary progressive MS. We wish to extend our many thanks to all who engaged with our advocacy activities calling for this medication to be publicly reimbursed for all those it would benefit. This includes supporting the MSunderstood Café and the MSunderstood Cafê Roadshow, both of which aimed to highlight extreme delays in access to new and innovative medications in Ireland. The experiential pop-up Café, supported by Roche, was located on Exchequer Street and opened for one day only – to give unknowing coffee connoisseurs the opportunity to experience some of the symptoms of MS.

GOAL: SERVICE DELIVERY

GENERAL ELECTION

In February, we as a nation took to the polls to elect our new Government. MS Ireland was determined to 'Make MS Matter' to the candidates in General Election 2020. We produced a leaflet to help prompt topics for our members to raise with prospective candidates when they knocked on doors. The leaflet was distributed via email, shared on our social media and through our network of Regional Community Workers across the country. We wait for Government formation.

MEETING WITH ANNE RABBITTE

MS Ireland, as part of the Neurological Alliance of Ireland (NAI) recently took part in a meeting with Minister of State for Disabilities Anne Rabbitte. During this meeting, NAI Executive Director, Mags Rogers, with the support of NAI Board members discussed the issue of access to neurorehabilitation in Ireland. Last year, the Health Service Executive (HSE) published an implementation plan for the National Neurorehabilitation Strategy. This came over 8 years after the launch of the original policy document. The implementation framework is a three-year, ten step plans aiming to develop neurorehabilitation services across the country. Minister Rabbitte committed to supporting this and will further engage with NAI and members, including MS Ireland to progress this issue.

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. In the challenging environment of 2020 this took on new importance as we aimed to capture public attention during an ongoing pandemic. We had two very successfully media runs in 2020 for World MS Day and the MS Readathon where we featured on national television, radio and press as well as having a strong regional showing throughout the country.

RTE BIG LIFE FIX

Rosie Farrell, one of our wonderful MS and Me bloggers, appeared on RTÉ's 'Big Life Fix'. This show sees leading designers, engineers, technology experts and more to find solutions to challenges people face. The solutions help to transform the lives of people who appear on the programme. Rosie, who lives with MS has a love of painting. As a result of the MS symptoms Rosie experiences, she was forced to make some adaptations to her life.

Her love of being active outdoors was curtailed by extreme pain and fatigue. This had a damaging effect on Rosie's wellbeing, but painting helped her to feel like herself again. However, MS continued to intrude on Rosie's life and weakness and fatigue in her arm impacted Rosie's ability to paint. Dr David McKeown, a mechanical engineer and Trevor Vaugh, an innovator and designer, teamed up to create a solution to help. Rosie was delighted with the final result and had this to say, "I have been blown away by what they've done. They've given me back a part of myself I thought was lost and I will never be able to thank them enough.

GOAL: SERVICE DELIVERY

WORLD MS DAY 2020

Our plans for World MS Day 2020 had to be changed due to the uncertainty and restrictions we were living under because of the Covid-19 pandemic. World MS Day 2020 took place on Saturday May 30th with the theme of 'connections' and using the hashtag #MSConnections throughout the campaign.

The MS Connections campaign is all about building community connection, self-connection, and connections to quality care. The theme was a really fitting one in 2020 as our key event for World MS Day was our Virtual Balloon race where, with the help of the wider MS Community we achieved our goal of having 9,000 virtual balloons, 1 for each person in Ireland living with MS.

In the lead up to World MS Day and our virtual balloon race we had several inspirational MS ambassadors feature prominently on national media. Niall McGahon from Co. Galway has been living with MS for the past 5 years and he featured on Newstalk Radio with Mark Cagney and Virgin Media's Elaine show where Niall spoke about his own life living with MS. Ava Battles was also interviewed on Newstalk where she highlighted the importance of World MS Day and our Virtual Balloon race with Ivan Yates.

We had two pieces published by the Journal.ie online featuring Sara-Jayne Tracey and a written piece by Niamh McCarron. Both pieces touched on what life was like living through a pandemic for someone living with a neurological condition.

Having MS in lockdown: 'I was petrified in the beginning, but people are really taking it seriously'

A virtual balloon race is taking place today, Word MS Day, at 6pm to raise money for MS Ireland.

May 30th 2020, 9:30 AM 24,641 Views 7 Comments

SARA-JANE TRACEY WAS a professional showjumper aged in her late 20s when she was diagnosed with Multiple Sclerosis (MS), and told she wouldn't be able to go horse riding again.

After being diagnosed with optic neuritis, and losing power and the sensation in her legs, sometimes experiencing huge amounts of pain, and problems with controlling her bladder, she

I've been living with MS for 10 years now and remote working during Covid-19 is a huge help

Niamh McCarron says people with chronic illnesses and disabilities have been asking for remote working for years, often getting told that it can't be supported, for a whole list of reasons.

May 29th 2020, 12:45 PM 21,532 Views 6 Comments

Niamh McCarron

WHEN I WAS diagnosed with Multiple Sclerosis in 2010 I didn't think I'd find myself sharing tales of how I manage my illness. Actually, at the start, I didn't "think" at all. I was in a fog of taking each day as it came and ignoring it as much as I could.

I was busy, you see. I had a wedding to plan, and I was moving house and I had a busy job. MS was an inconvenience that I just didn't have time for.

Lauren McCauley was featured on RSVP magazine where she outlined how she came to terms with her diagnosis at the age of 18. Grace Kavanagh was profiled on the well-known Facebook page 'Humans of Dublin' where her photo and her story was shared to thousands of the page's followers.

Lauren McCauley

We secured featured pieces on the Irish independent, daily mail, The Star as well as several regional press outlets and radio stations.

GOAL: SERVICE DELIVERY

MS READATHON 2020

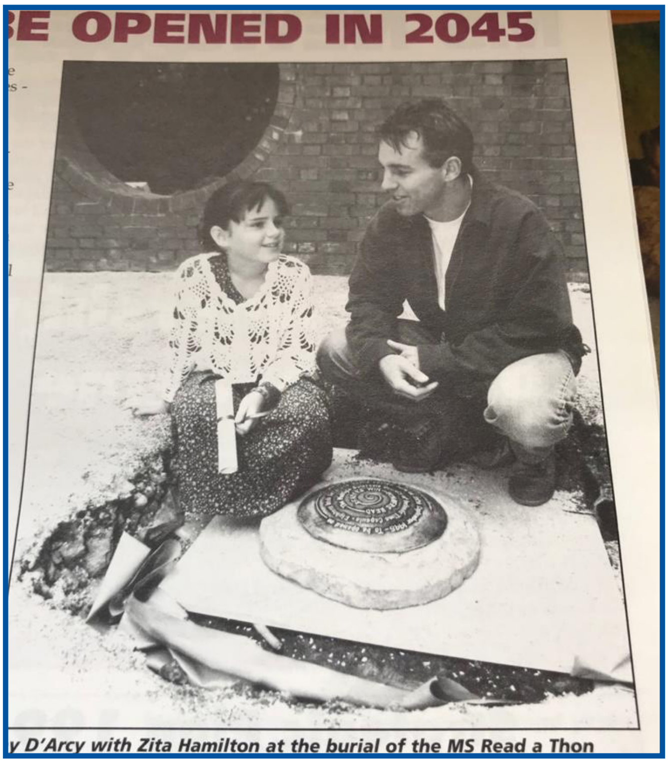
Like everything else, our famous MS Readathon also went virtual in 2020 as thousands of young and adult readers logged on to our new readathon website to sign up and begin our virtual campaign. To celebrate the launch of readathon 2020 we had two brilliant MS Readathon ambassadors who, along with their families spoke to several media outlets telling them why supporting the MS Readathon was so important. Olivia Kirwan from County Dublin was on hand for our photo call in Bremore Castle along with her book loving family. Olivia was featured by national media and appeared on RTE's News2Day where she was interview at her children's school.

Olivia and Katie Kirwan

Maggie Green, a teacher from County Donegal was featured by Eileen Magnier on RTE news and was also covered by the Irish Examiner and the Irish Times. Maggie has been living with MS the past number of years and her whole family took part in the MS Readathon 2020.

We went on a trip down memory lane on Ray Darcy's RTE radio show as Ray spoke to two of our "Guardians of our Time capsule". In 1995, Ray helped us launched the 1995 Readathon by burying a time capsule with a group of schoolchildren and on his show, he spoke to Zita Hamilton and David O'Brien who helped Ray launch the Readathon 25 years ago! Both Zita and David now have their own families and together took part in Readathon 2020. We were also featured on the Journal.ie where Ava Battles spoke about the fundraising challenges for MS Ireland and the MS readathon.

Maggie Green and Family



E OPENED IN 2045

y D'Arcy with Zita Hamilton at the burial of the MS Read a Thon

Goal: Sustainable Finances

GOAL: SUSTAINABLE FINANCES

OBJECTIVE 4: GROW SUSTAINABLE REVENUE BASE

Increase HSE services and develop regular & recurring giving campaigns to help sustain vital services and new programmes.

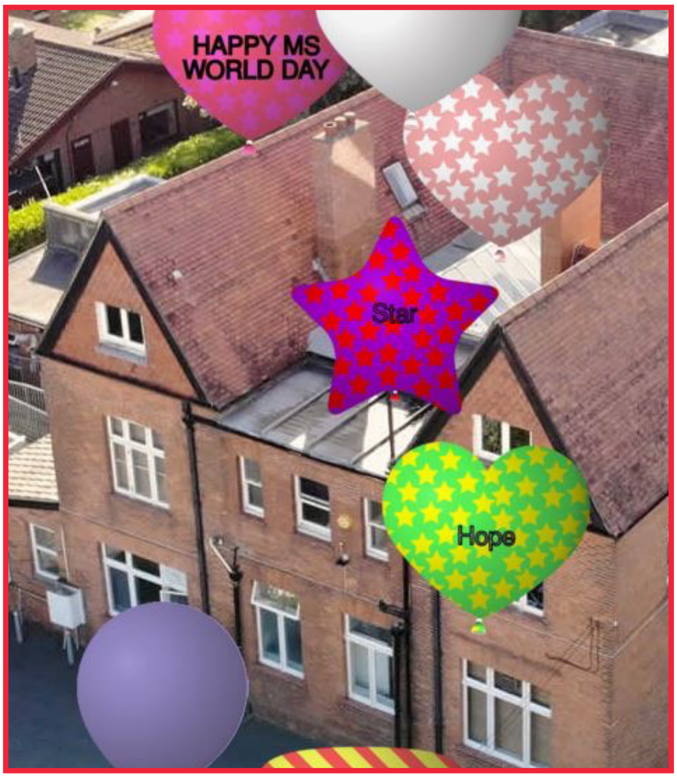
Due to Covid-19 many of our usual large fundraisers had to be first postponed and then cancelled in 2020. But we were delighted that we were able to go ahead with our Flagship event the MS Readathon (virtually) at the end of the year. We also held our first virtual trek and a virtual balloon race for World MS Day. We built on our online giving platforms and increased our donations via Facebook. We were delighted to have the support of our loyal community when we sent out two funding appeals in Spring and at the end of the Summer. MS Ireland was also honoured to continue our corporate partnerships with Perrigo and the Irish Times and we were thrilled to be announced as partners for Maynooth Students Union.

VIRTUAL BALLOON RACE 2020

In April we quickly realised that we were going to have to adapt and innovate if we were to stand any chance of continuing our fundraising efforts for the rest of the year. Our only option was to fully embrace the online/virtual fundraising sphere. And so, the Virtual Balloon Race, the first of its kind in Ireland, came to be. Our aim was to sell 9000 virtual balloons, one to represent each of the individuals currently living with MS in Ireland. Unlike a traditional balloon race – where the balloon can cause harm to wildlife and where helium is used - MS Ireland's Balloon race was 100% environmentally friendly. There were no actual balloons, no strings, no labels, no helium gas. But it was just as unpredictable – like a real race.

Balloons could be decorated and personalised too. Using algorithms, google maps and weather apps, the virtual balloons behaved and flew in the same way as real balloons would. Too much helium and it would burst easier at high altitudes, too little and it might get caught in a tree in Dundrum.
The beauty of the campaign was its inclusivity. Everyone could take part, all ages, and all abilities. We had grandparents buying balloons for their grandchildren who lived outside of their 5km radius and even as far afield as New Zealand. Businesses took part, buying balloons for each of their employees – competition to build and decorate the best balloon was rife.

Virtual launch day was Sat May 30th - World MS Day – from our Care Centre in Bushy Park. As the month went on, we had been watching the number of balloons sold with huge interest. However, things really ramped up 36 hours before the launch, with almost 3000 balloons left to sell to reach our target of 9000. The anticipation was palpable and balloon sales reached fever pitch in the last 8 hours. As the balloons were virtually released and started floating into the air above the care centre at 9.00pm the news started to trickle in that we had sold a whopping 9104 balloons, equating to over €45k. We were blown away with the response, so much so that we have decided to make the Virtual Balloon Race an annual fundraising campaign.



GOAL: SUSTAINABLE FINANCES

MS READATHON 2020

With the uncertainty that surrounded the re-opening of schools in September and the ever-evolving situation of if, when and how students would return, it was obvious that MS Readathon 2020 was going to have to evolve along with the situation. After 33 years we decided to bring our much-loved Readathon online and launch our brand new, interactive website packed full of amazing features. The concept has not changed. Students still read whatever they like, as much as they can for 4 weeks from 1st - 30th Nov in return for sponsorship from family and friends. Students can earn virtual reward badges and stars for the goals they achieve. They can build their avatars, share their campaign on their parents' social media and rate and review the books they read.

There were loads of amazing prizes won during the month of November. We had all sorts of competitions – Reading buddies, book reviews, cover art, county vs county stories, the great work award and even prizes for the teachers. As well as this we had 20 iPad and 60 sets of headphones to give away. We were of course concerned as to how this new format would go down with our regular participants, but we were overwhelmed with how positive teachers and parents were towards the online campaign.

We saw schools such as St. Brigid's Foxrock raise over €24k - the teachers were as stunned as we were, but the students really got into the spirit of it. Other schools of note were:

St Mary's Donnybrook who raised €17k
Our Lady of the Wayside who raised €10k

We were also keenly aware that some parents and schools would prefer their children take part offline and to this end, we still offered the option of taking part in the traditional way – with paper sponsorship cards etc.

Another first this year was letting the grown-ups get involved. Our new website had a Big Kids section as well as a Clubs/Groups section where adults and groups could get in on the READaTHON action. This really took off with Big Kids all over the country taking part. We saw colleagues start weekly book clubs (which are still running), parents whose love of reading was re-ignited and families who sat down together for an hour a night to read instead of aimlessly scrolling a screen.

In total the MS Readathon raised €425,000. Huge thanks must go to Novartis, who very kindly sponsored our fab new Readathon website. Massive thanks also to Gill press who sponsored some book bundles and Tribes press who offered discount codes to all our readers.

GOAL: SUSTAINABLE FINANCES

MICK QUINN

We are so grateful that Mick Quinn stepped in to support MS Ireland at the beginning of the pandemic. Mick decided to walk a Marathon in his back garden to raised funds in memory of his brother Frank. He set a target of €10,000 but that was very quickly exceeded and by the end of the May bank holiday weekend Mick had raised more than €30,000. Mick not only completed his challenge, but he also inspired others to take on different challenges from baking cakes to hitting targets with tennis balls.

MUSIC

The Just Giving platform organised #Challenge32. Mick Donohue decided to do a 32-hour Music Bonanza: This event was very innovative and hugely enjoyed at a social distance by Micks friends, family, and neighbours. Fundraisers have really had to think outside the box, and this is a marvellous example. Clement Clarke (Donegal Branch) was performing concerts in his back garden of a Friday night – someone suggested that he do it via zoom and make some money – this worked out very well with people logging in from all over the world.

Katharine Buckley also organised a zoom gig which was a very successful gig, there were 10 performers from different parts of the world and over 108 different zoom accounts logged in to watch.

VIRTUAL WALK

As you know we would normally have a Trek either in Spring or autumn. In 2020 we made our trek a virtual Camino where we asked people to walk 100kms over 10 days as if they were walking the last stretch of the Camino. We had 36 people join us virtually sending in magnificent pictures of the beautiful countryside where they were walking. Thank you for making our first virtual trek a huge success. We are looking forward to doing this event again this year in a bigger and better way, so we hope you might consider joining us in September.

GOAL: SUSTAINABLE FINANCES

VIRTUAL MINI MARATHON

The 2020 Women's Mini Marathon took place over 10 days at the beginning of October, having been delayed from its normal date of the June Bank Holiday. We are very grateful that 160 ladies from all around the country decided to run, walk, jog 10km virtually with us. This is always a highlight of the fundraising year and we really missed meeting with our runners. Thank you for joining #TeamMSIreland. Again, the mini marathon in 2021 will be a virtual event. We very much hope that we will have participation from all around the country again.

AD HOC SPORTS

Just as 2020 was an extraordinary year, our supporters were extraordinary; they swam, ran, cycled and kicked footballs, to name but a few, whilst socially distanced and raising funds – we could not manage without your support – thank you.

DUBLIN CITY MARATHON

Like so many events the Dublin Marathon 2020 was a virtual event – a huge thank you to all who ran the marathon for #TeamMSIreland

AMBASSADOR PROGRAMME:

As our Readathon moved online in 2020, so too did our Ambassador Programme. From the comfort of their own homes Ambassadors virtually visited schools across the country to engage readers in the Readathon campaign and spread the word about what exactly they are raising money for. This also meant that we could cast the net much wider in recruiting ambassadors for the 2020 programme. Our 19 Ambassadors carried out 70 school visits for a total of 1,086 students. Feedback from the Ambassadors themselves and class teachers was excellent overall with some valuable suggestions for us to implement as we continue to expand the programme in 2021.

GOLF

We were very luck to squeeze in a couple of Charity Golf days thanks to the Lady Captain at Cobh Golf Club and Wednesday Golf Society Members Newlands Golf Club

If you are a member of a Golf Club or society and you would like to nominate MS Ireland for a charity golf day – please contact melaniec@ms-society.ie we would love to get involved.

OBJECTIVE 5: DEVELOP PARTNERSHIPS

Leverage and grow our partnered programmes to support service development, funding, and delivery.

SIGNIFICANT PARTNERSHIPS IN 2020

- 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), Health Research Charities Ireland (HRCI), 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.
- Members of the Home Care Coalition who seek to secure supports that enable people to remain in their own homes.
- We continued our collaboration with The Disability Action Coalition - 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 coalition worked together in the run up to the General Election and once the election was held, we switched focus to ensuring commitment to supporting the Section 39 organisations was made in the Programme for Government.
- 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 goal setting, research and governance. MS Ireland sits on MSIF's working group for World MS Day as well as the working group for the Atlas of MS.
- Pharmaceutical companies; in particular Novartis, Roche, Merck, Alkermes and Almirall partnered with MS Ireland on educational projects and activities, research and supporting information services. In particular, we would like to note the following collaborations in 2020:
    - » MS Ireland collaborated with Novartis to support 'MS Explored', an event for young people living with MS was delivered as a virtual event. Additionally, Novartis supported the development of the SPMS video series as well as the Wellness section on our website.
    - » We collaborated with Roche who provided support for the MS Nurse video series which saw Clinical Nurse Specialist Maire Hayes answer community generated questions on COVID-19. Additionally, Roche supported the Information Line Service, the MS Care Centre and the webinars we created which due to COVID-19 replaced our National Conference.
    - » In response to the needs of our regional staff who, due to the COVID-19 pandemic were unable to physically meet with their clients, Merck supported the purchase of laptops for a number of our Regional Community workers, enabling them to work virtually with their clients
    - » Alkermes supported MS Ireland's Information Line service by providing us with financial commitment to see this service secured for 2020 and 2021.
    - » We collaborated with Almirall on a survey which explored the level of resource used by people living with MS who experience spasticity. The results helped MS Ireland to support Almirall with the health technology assessment of Sativex.

Goal: Innovation

OBJECTIVE 6: DEVELOP DIGITAL PARTNERSHIPS AND GOVERNANCE

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

As the word of the spread of COVID-19 started the week of 9th March many of MS Ireland's group exercise programmes were in full swing and the Active Neuro programme in the Mid-West was just starting its mixed neurological classes in the region. After the Taoiseach's speech on 12th March, it was clear that we would be putting people with MS at risk if we continued the in-person classes and so they were postponed in all regions.

We were concerned if people stopped exercising altogether – reduced physical activity leads to decreased strength and balance, worsening walking ability and increasing falls risk, also the social aspect of the classes are so important for people. We decided to move them online to telehealth. Dr Susan Coote, Clinical specialist Physiotherapist, MS Ireland had previously worked on an MS Project with Novartis and could already see the benefits of physio by video link.

The first thing we did was to set up a "community of practice", for approximately 40 physios around the country who delivered classes, on Microsoft Teams. This meant we could chat about the issues, share information, make suggestions – in essence, we created a space to have a "living document" that evolved as we learned and a place to share information and ideas.

Our main concern was safety – safety for people who had balance problems as they exercised away from the physio or yoga instructor in their own home This led to everyone having an individual call by phone and then Zoom to ensure their safety as they exercised and to tease out any technical issues.

We piloted it in the mid-west getting feedback from class participants about the systems and the online environment and then rolled the system out nationally. 69 classes took place up to Christmas 2020. 95% of those participants agreed or strongly agreed that they would recommend the online programmes to someone else with MS, and 87.5% agreed that they had the help they needed from their regional workers or physios to get set up with Zoom. 92.5% felt physically safe as they exercised at home, and 70% agreed or strongly agreed that they had benefited physically from the programme. In the comments section many people added to that how the classes had helped their mental health during the lockdown.

An unexpected learning was that we were able to offer much more specialised classes by combining people from different counties and regions into groups – for example, a special tailored class for wheelchair users, or a balance class specially for those who don't yet use an aid. Watch this space for our new project in 2021 – Move Smart MS, where we learned from this and offer very tailored, expert physio led programmes.

In the years to come we look to build on our online service offering and develop new innovate digital programmes for our community.

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

PRINCIPAL BANKERS

Bank of Ireland
College Green
Dublin 2

SOLICITORS

Joynt & Crawford
8 Angelsea Street
Dublin 2

REGISTERED OFFICE

80 Northumberland Road
Dublin 4

CHARITY NUMBER

CHY 5365

CHARITY REGULATORY NUMBER

20007867

COMPANY NUMBER

296573

DATE OF INCORPORATION

19th November 1998

YEAR MS IRELAND WAS FOUNDED

1961

GOAL: INNOVATION

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 2020, the Board met seven times. Significant work was carried out in the areas of finance, funding, governance and strategy.

🔵 BOARD MEMBER 2019/2020

🟢 BOARD MEMBER 2020/2021

CHAIRPERSON
🔵 Maurice
🟢 O'Connor

VICE CHAIRPERSON
🔵 Jacinta
🟢 Kelly

🔵 Robin
🟢 Bradley

🔵 Noelle
🟢 Burke

🔵 Thomas
🟢 Cronin

🔵 Edwina
Dunne

🔵 Marcella
🟢 Flood

🔵 Eugene
🟢 Kearney

🔵 Rebecca
🟢 Maguire

🔵 Rory
🟢 Mulcahy

🟢 Aveen
Murray

🔵 Martin
🟢 Power

🔵 Anne
🟢 Restan

🔵 Mary
🟢 Sheahan
Lonergan

RESIGNATIONS/CHANGES

Edwina Dunne Retired on 26/3/2020

APPOINTMENTS

Aveen Murray
Maurice O'Connor Appointed Chairperson
Jacinta Kelly appointed Vice Chair

GOAL: INNOVATION

THE BOARD

BOARD COMMITTEES

The Board is responsible for the strategy, and it creates/appoints committees. The following committees are appointed by the Board to aid in the internal workings of MS Ireland:

1. Digital Innovation and Technology Committee
2. Finance, Audit, Risk and Strategy Committee
3. Services, Advocacy and Research Committee
4. Remuneration and Nomination Committee
5. Governance Committee
6. Organisation and People Committee

BOARD ATTENDANCE 2020

	1 FEB	4 APR	06 JUN	29 JUL	17 SEP (i)	17 SEP (ii)	26 NOV	TOTAL
Robin Bradley	✓	✓	✓	×	×	×	✓	4/7
Noelle Burke	×	✓	✓	✓	×	×	×	3/7
Thomas Cronin	✓	✓	✓	✓	✓	✓	✓	7/7
Marcella Flood	✓	✓	✓	×	✓	✓	✓	6/7
Eugene Kearney	×	×	✓	✓	✓	✓	×	4/7
Jacinta Kelly	✓	✓	✓	✓	✓	✓	✓	7/7
Dr Rebecca Maguire	✓	✓	✓	✓	✓	✓	✓	7/7
Rory Mulcahy	✓	✓	✓	×	✓	×	×	4/7
Aveen Murray	n/a	n/a	n/a	n/a	n/a	×	×	0/2
Maurice O'Connor	✓	✓	✓	✓	✓	✓	✓	7/7
Martin Power	✓	✓	✓	×	✓	✓	✓	6/7
Anne Restan	×	✓	×	✓	✓	✓	✓	5/7
Mary Sheahan-Lonergan	✓	✓	✓	✓	✓	✓	✓	7/7

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.mssociety.ie.

LENGTH OF TERMS SERVED BY THE BOARD

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

DECISION MAKING PROCESSES

Decisions reserved for the board and those 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.

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 2020 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	MS. OLGA ESTRIDGE	MS. CAITRIONA HUGHES	MR. AIDAN LARKIN	MR. MYLES MCPARTLAND
FINANCIAL ACCOUNTANT	SERVICES MANAGER	FUNDRAISING DEVELOPMENT MANAGER	SERVICES DEVELOPMENT MANAGER	HR MANAGER

REMUNERATION

The number of employees whose emoluments, excluding employer pension contributions, were greater than €70,000 in 2020 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.

CODES OF PRACTICE

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

THE GOVERNANCE CODE

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

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

GOAL: INNOVATION

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 €556,648 for the year (2019: €50,391). There was a surplus of €561,648 for 2020 after exceptional items. The exceptional items totalled €5,000 and are in relation to a revaluation of three investment properties with a total value of €1,375,000 which were independently revalued to €1,380,000 in total. Income for the year includes significant Legacies/Donations totalling €111,000 (2019: €97,214). 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 €9,711,989 (2019: €9,150,341) at the end of the financial year. They are comprised of restricted funds of €3,243,779 (2019: €3,107,939) and unrestricted funds of €6,468,210 (2018: €6,042,402).

THESE FUNDS ARE REPRESENTED BY THE FOLLOWING:

	NATIONAL OFFICE & CEP	BRANCHES	TOTAL
	€	€	€
Tangible Fixed Assets	4,504,623	47,542	4,552,165
Investment properties	1,380,000	-	1,380,000
Net Current Assets (excl. Bank loan)	3,525,703	1,261,944	4,787,647
Bank Term Loan	(1,007,823)	-	(1,007,823)
TOTAL	**8,402,503**	**1,309,486**	**9,711,989**

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.

GOAL: INNOVATION

EXTRACT FROM AUDITED FINANCIAL STATEMENTS

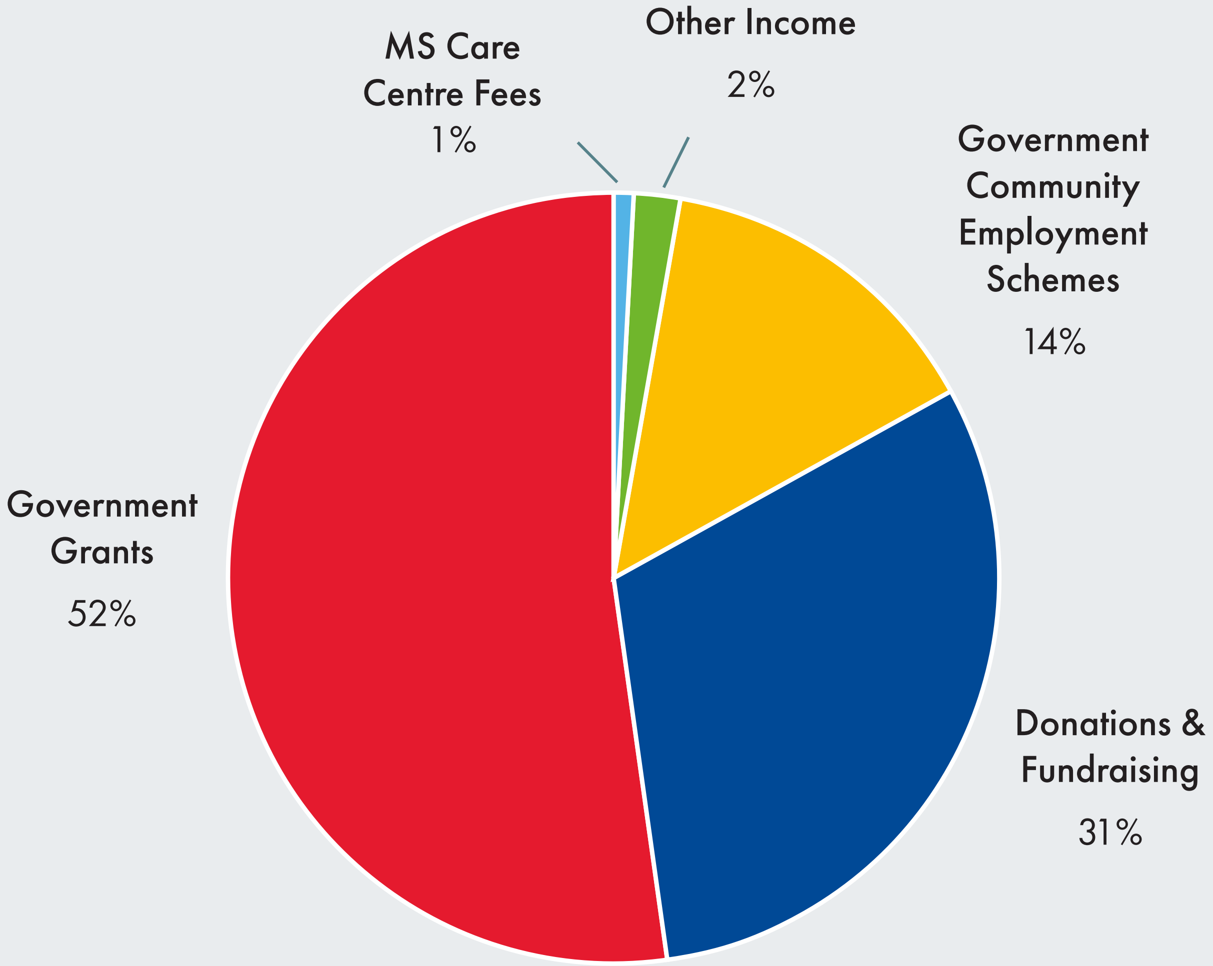
	Unrestricted Funds 2020 €	Restricted Funds 20120 €	Total Funds 2020 €	Total Funds 2019 €
INCOME				
Income from generated funds				
Voluntary Income				
Donations and fundraising	1,436,068	208,149	1,644,217	2,302,936
Legacies	106,000	5,000	111,000	97,214
Research	-	2,234	2,234	2,884
Subscriptions	650	-	650	1,788
Income from charitable activities				
Fees received	82,947	-	82,947	226,106
Grants and other service contract income	-	2,949,315	2,949,315	2,762,538
Government schemes	-	806,639	806,639	771,932
Other income	11,311	115,171	126,482	164,356
Total income	1,636,976	4,086,508	5,723,484	6,329,754
EXPENDITURE				
Costs of generating voluntary income				
Fundraising	431,587	163,242	594,829	721,152
Charitable activities				
Community services	-	2,516,659	2,516,659	2,658,644
Respite care services	104,619	1,534,984	1,639,603	1,991,180
Research	3,000	8,446	11,466	17,597
Local MS services	298,229	106,070	404,299	890,250
Total expenditure	837,435	4,329,401	5,166,836	6,278,823
Net income/(expenditure) for the year before exceptional items	799,541	(242,893)	556,648	50,931
Exceptional items	-	5,000	5,000	(21,902)
Net income/(expenditure) for the year	799,541	(237,893)	561,648	29,029
Transfer between funds	(373,733)	373,733	-	-
Net movement in funds	425,808	135,840	561,648	29,029
Reconciliation of Funds:				
Total funds brought forward	6,042,402	3,107,939	9,150,341	9,121,312
Total funds carried forward	6,468,210	3,243,779	9,711,989	9,150,341

INCOME ANALYSIS 2020

€5,723,484

Income of €5,723,484 was received of which 52% was funding from Government Grants mainly HSE, 31% was Donations and Fundraising, 14% was from three Department of Social Protection schemes we have in Donegal, Galway and Dublin, 1% was from fees received from Respite Centre residents and 2% from miscellaneous income.

		2020 (€)	2019 (€)
🟥	Government Grants	2,949,315	2,762,538
🟦	Donations & Fundraising	1,757,451	2,403,034
🟨	Government Community Employment Schemes	806,639	771,932
🟩	MS Care Centre Fees	82,947	226,106
🟦	Other Income	127,132	166,144
	TOTAL	5,723,484	6,329,754



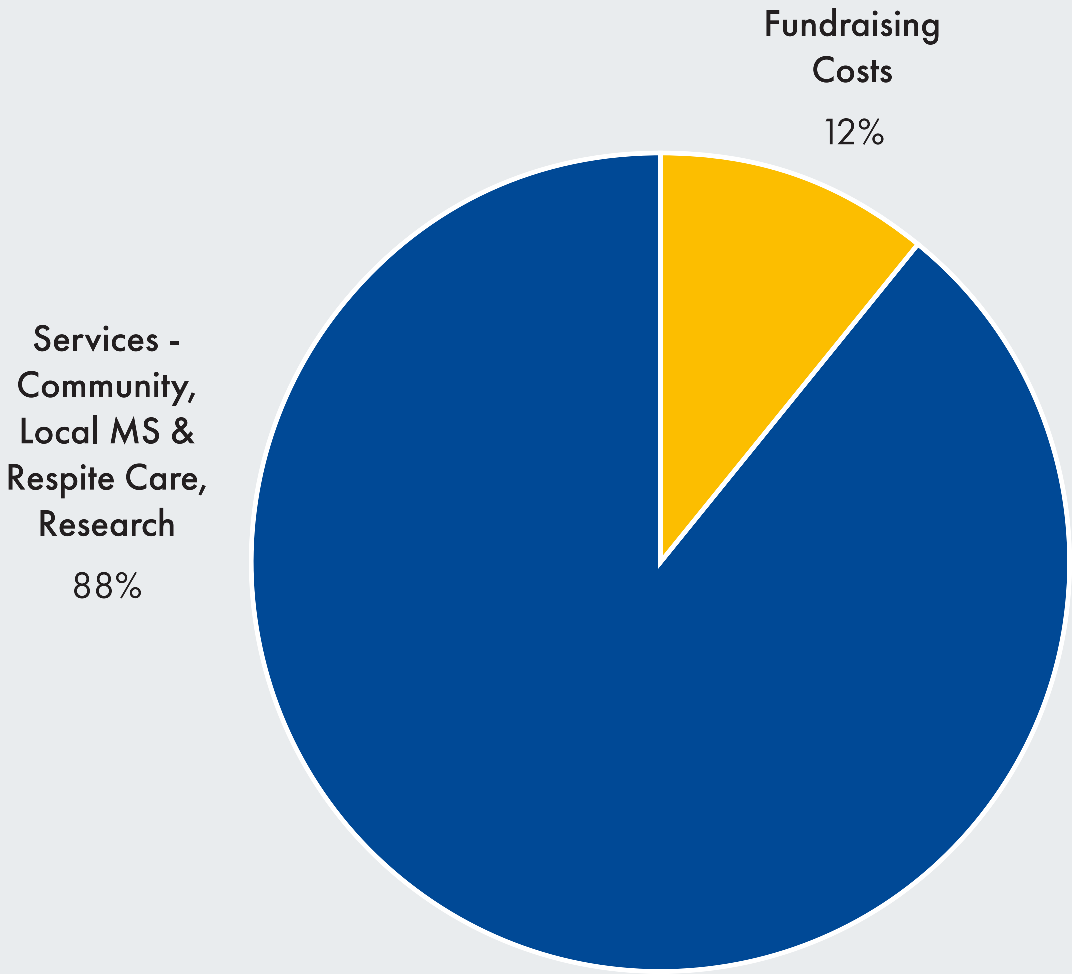
OPERATIONAL EXPENDITURE ANALYSIS 2020

(excluding exceptional items)

€5,166,836

€5,166,836 before exceptional items was spent in 2020 of which: 88% was spent on Community services, Care Centre respite services and Research; and 12% on Fundraising.

		2020 (€)	2019 (€)
🟦	Services - Community, Local MS & Respite Care, Research	4,572,007	5,557,671
🟨	Fundraising Costs	594,829	721,152
	TOTAL	5,166,836	6,278,823



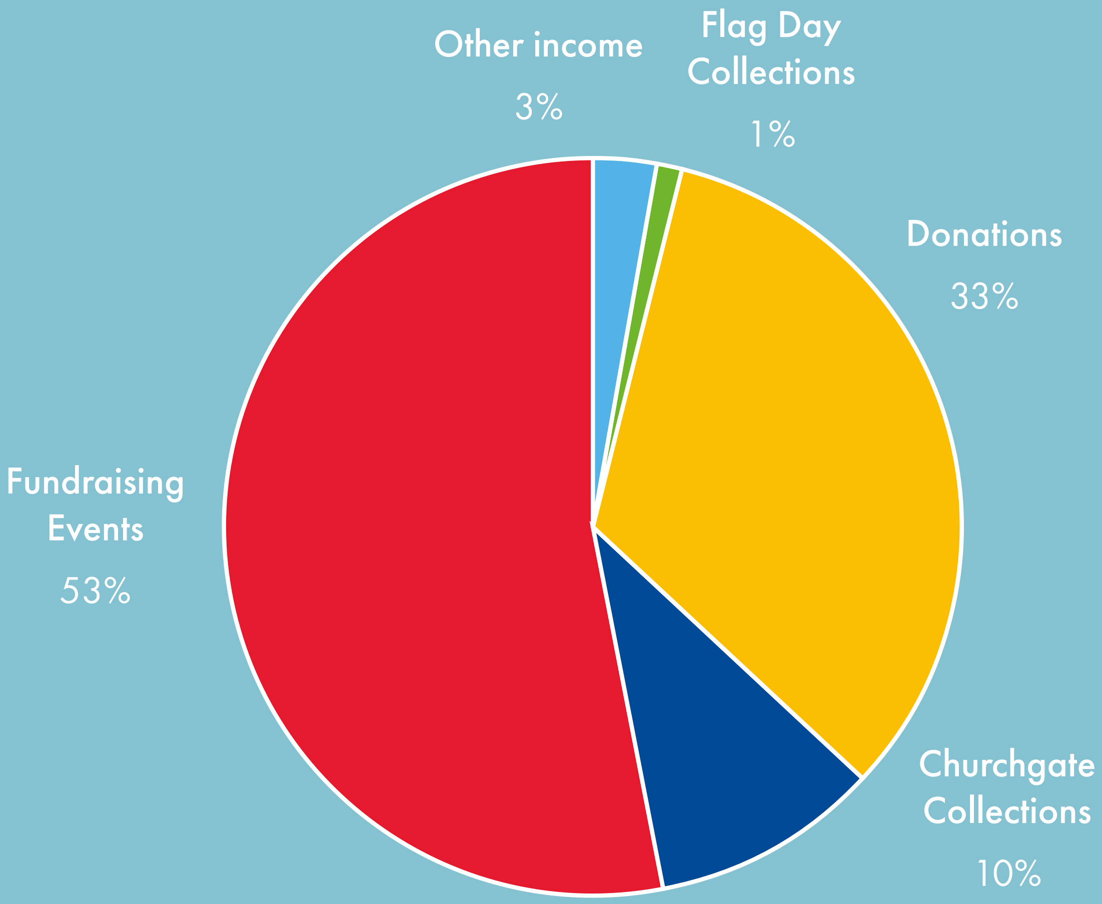
BRANCH INCOME ANALYSIS 2020

€357,696

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

Income of €357,696 was received of which 53% was raised from fundraising events, 10% from churchgate collections,33% from Donations, 1% from Flag days collection and 3% was from other income such as bank interest, Christmas party contributions etc.

		2020 (€)	2019 (€)
🟥	Fundraising Events	188,579	411,651
🟦	Churchgate Collections	34,291	277,172
🟨	Donations	119,729	139,676
🟩	Flag Day Collections	4,647	59,254
🟦	Legacies	-	-
⬛	Other income	10,450	10,757
	TOTAL	**357,696**	**898,510**

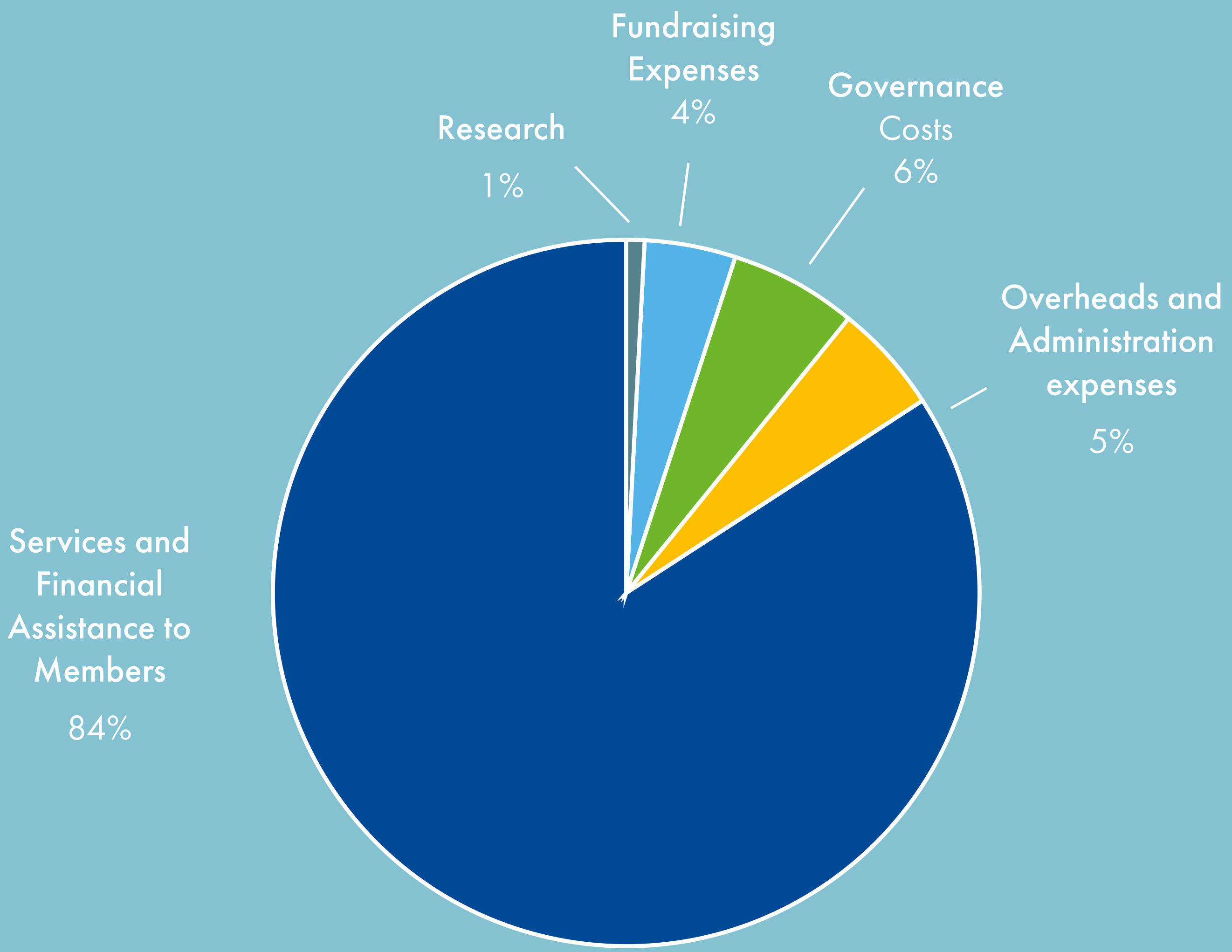


BRANCH EXPENDITURE ANALYSIS 2020

€411,625

€894,149 before exceptional items was spent in 2020 of which 84% was spent on providing services & Financial assistance to members, 5% Overheads and Administration expenses, 4% on fundraising expenses, 6% Governance and 1% on Research.

		2020 (€)	2019 (€)
🟦	Services and Financial Assistance to Members	344,711	709,602
🟨	Overheads and Administration expenses	20,906	105,412
🟦	Fundraising expenses	18,269	69,993
🟩	Governance Costs	24,739	25,044
⬛	Research	3,000	6,000
	TOTAL	**411,625**	**916,051**



Goal: People and Culture

GOAL: PEOPLE AND CULTURE

OBJECTIVE 7: DEVELOP AND INVEST IN OUR PEOPLE

Description: Ensure a fit for purpose organisational design and develop a workforce model for the future, recognising that as the capabilities of our people improve, so does our overall service to clients.

INTEGRATED MODEL OF SERVICE

2020 was the ninth 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.
- Improvement in communications

In total, 14 Regional Integrated Meetings took place in 2020.

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.

HUMAN RESOURCES

Recruitment during 2020 concentrated on replacing necessary leavers or unfilled posts.

NEW HIRES FOR 2020

Dualta Griffin, Physiotherapist
Katie Mc Coll, Accounts Assistant
Triona Cleary, Administrator

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.

GOAL: PEOPLE AND CULTURE

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.

PERSON OF THE YEAR AWARD

STEPHEN CARROLL & FAMILY

We are delighted to award Stephen and his Family 'MS Person of the Year'

Stephen has primary progressive MS, leading to very serious and disabling MS issues. Despite this, Stephen and his family are committed volunteers and Branch members who have supported our Branch and other members and have undertaken significant fundraising for our Branch. Stephen's his young daughters and his wife have stood beside him at all South Dublin events, at bag packing, quizzes and bucket collections, sacrificing their own leisure and sports pursuits. When Stephen has been too unwell to attend, they have still been there, stepping in, often at short notice. Stephen has raised awareness of MS in his own community in Goatstown by organising local quizzes and events and coffee mornings. More widely, as a former Male Voice Member, Stephen has been active in promoting support for MS Ireland at choir events. He is the moving force behind a planned "3 Choirs" fundraising and awareness raising event, involving an international Choir, the Irish Male Celtic Choir and a local Kilmacud/Goatstown Choir which was due to take place at Easter this year – it fell victim to Covid but Stephen is determined it will take place at another time.

Of particular note is Stephen's support for other people with MS. Despite his own illness, disabling fatigue, pain and suffering, Stephen goes out of his way to visit, encourage and support other people with MS

Stephen has visited people with MS in nursing homes, even (or especially) those who can't or don't connect with others. He has travelled when possible to see a member to Kiltipper Woods, which is not at all easy for him. It involves setting aside 2 days of rest (before and after to recover), the actual full day itself in getting ready, planning of transport – 3 days of effort all for a 1 hour visit to cheer up another person with MS. In this year of Covid-19 where everything is so uncertain and unsettling, Stephen has fostered links via WhatsApp with other members of our Branch who are attending the same hospital as him, to share information about what's involved in appointments, what entrances to use, where equipment is , what days infusions are being administered. He has used this to keep people in touch and share experiences.

CARER OF THE YEAR AWARD

KATHLEEN MURPHY ZACCAGNINI

We are delighted to award Kathleen Murphy Zaccagnini Carer of the Year for 2020.

Kathleen's husband Paolo has primary progressive MS, leading to disabling MS issues. Paolo is a wheelchair user and is heavily dependent on his wife for all the essential elements of daily care. Kathleen and Paolo live on their own in a ground floor apartment in Sandymount which has access issues but they are not in a position to move. As Paolo is Italian, they do not have the support of his wider family near at hand. This means that Kathleen has a particularly acute and lonely role as carer. She is an older lady, a grandmother, whose family are abroad and who cannot travel to see them without great difficulty because of her caring role. Despite all of the stress and pressure she bears, Kathleen is a committed volunteer and has supported our Branch and other members and has assisted with our fundraising such as bucket collections and bagpacking. This involves Kathleen getting everything ready to leave Paolo at home and arranging a carer to be there (at her own expense) so that she can come to help with our fundraising. Kathleen does this rather than give a donation in lieu because she understands the need to raise awareness and to support other Branch members by her presence and participation.

Of particular note is Kathleen's support for other carers and people with MS, as noted above, whereby despite her own situation, she goes out of her way to attend events, incurring expenses to do so. Kathleen is extremely self-effacing and modest about all she does.

VOLUNTEER OF THE YEAR

GERRY QUINLAN

This year we are delighted to announce that the winner is Gerry Quinlan

Gerry Quinlan does not have MS, and he does not have family members with MS. What he does have is a big generous heart and an awareness of MS through friends and colleagues. Gerry has fundraised for MS Ireland throughout the years, running the Dublin City marathon and taking part in 5-a-sides and quizzes to raise funds for MS Ireland, as far back at the 1980s. The total amount Gerry has raised over those years is lost in the mists of time, but the unwavering commitment to MS Ireland remains steadfast. In more recent years, Gerry organised and acted as Quizmaster in workplace quizzes which raised over €5,000 for South Dublin Branch and enabled us to start donating to the MSIF. When his own very serious health issues brought about early retirement, Gerry joined the South Dublin Branch of MS Ireland, taking on the role of Treasurer and giving generously of his time and commitment when the transition to new accounts was taking place. Ongoing health concerns meant that Gerry stepped back from the role of Treasurer but he remains on the Committee, participates in events and fundraising (pre-covid) and continues to organise quizzes which have raised a further €3,500 in recent years. In these Covid times, Gerry has set questions and acted as Quizmaster for fun and free zoom quizzes for our Branch which have raised spirits and are extremely popular.

Gerry has had a series of very severe and life-threatening health issues in the past 7 years, and throughout his surgeries Gerry has supported this Branch, achieved the fundraising mentioned above, organised music for our events, run the quizzes. Even now, after the blow of the tragic early loss of his beloved brother to cancer, Gerry is organising our next fun and friendly quiz for 21 August and after that a joint fund raising quiz for the ECA with East Wicklow Branch. Congratulations to Gerry for his support to the South Dublin Branch all these years.

OBJECTIVE 8: GROW BRANCH AND COMMUNITY VOLUNTEER BASE

Description: Grow our volunteer base across our branch network through diverse volunteer opportunities, programmes and ways to get involved.

We worked with our Branches to improve their governance and more Branches signed up to using E-docs (Accounting system for Branches) to record their finances. We also launched a new Branch Handbook which provides a valuable insight into how a Branch should function including its rules and regulations and it also outlines tasks of the Branch Committee members.

MS Ireland is very proud of our staff and volunteers and how quickly they adapted to working in a COVID world and providing services to people virtually.

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

pobal
government supporting communities

Multiple Sclerosis Ireland, 80 Northumberland Road, Dublin 4
T: (01) 678 1600 | F: (01) 678 1601 | MS Info Line: 1850 233 233
E: info@ms-society.ie | W: www.ms-society.ie | Charity Number: 5365 | CRN: 20007867