

MS IRELAND

ANNUAL

REPORT &

ACCOUNTS

2021



MISSION, VISION, AIMS & VALUES

MISSION

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

VISION

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

AIMS

The principal objectives for which MS Ireland exists are:

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

VALUES

Supportive

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

Transparent

“Being open and honest in everything that we do”

Informative

“Communicate reliable, accurate and useful information”

Empowering

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

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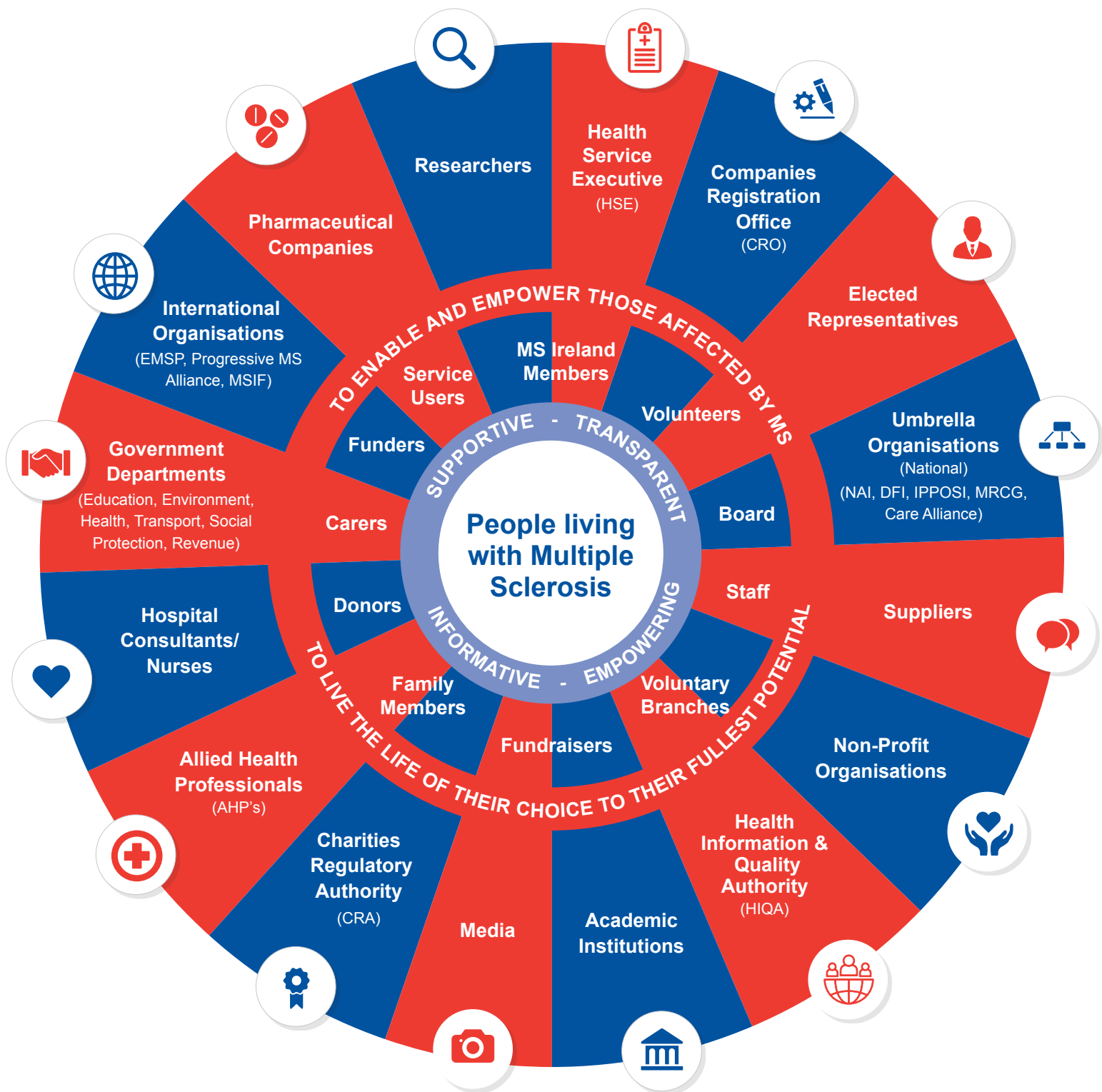
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GOAL: PEOPLE AND CULTURE

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 much-needed 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 race 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.



A handwritten signature in black ink that reads "Ava Battles".

AVA BATTLES
CHIEF EXECUTIVE



A handwritten signature in black ink that reads "Maurice O'Connor".

MAURICE O'CONNOR
CHAIRMAN

INTRO TO STRATEGIC PLAN

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 programmes to support service development, funding and delivery.



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.

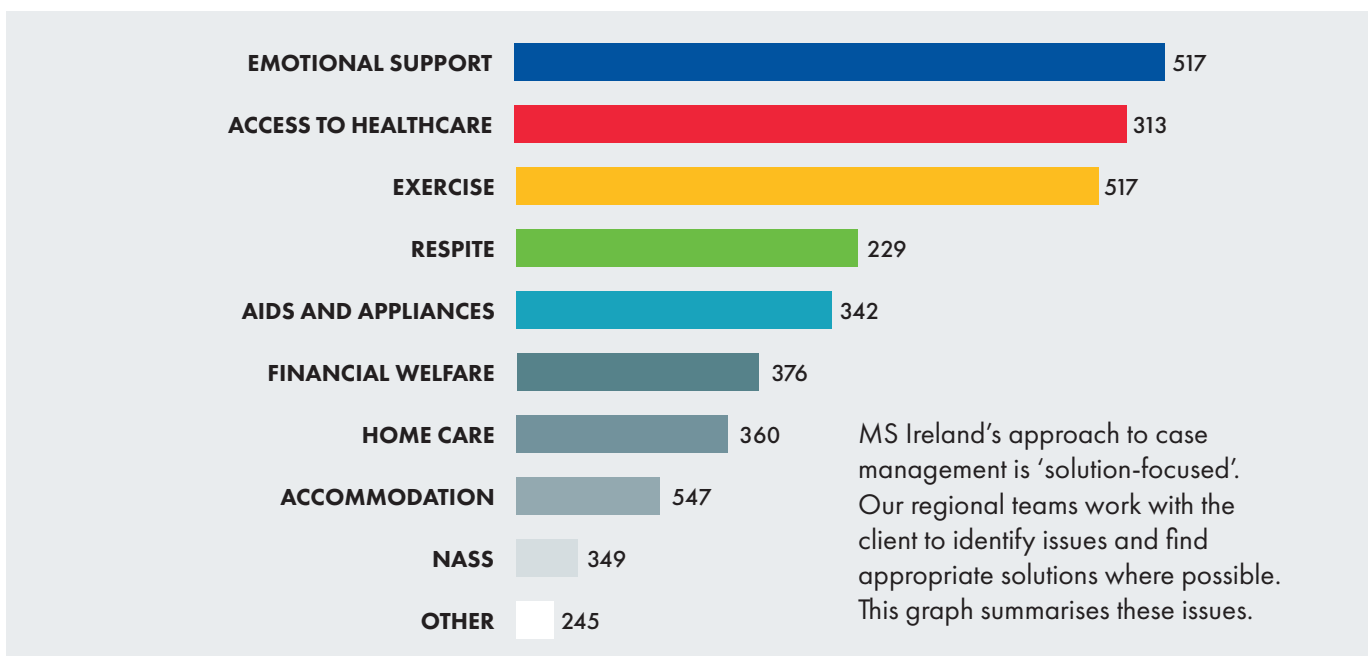
During 2021 the Company underwent the second year of its Strategic Plan. It reviewed and developed our suite of services provided by professionals and volunteers. We explored a variety of platforms both online and in person to offer a variety of services. This was an exciting development resulting in 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 2021, 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. as a result of the pandemic we continued to provide all services 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.



TOP 10 ISSUES PRESENTED BY CLIENTS



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 2021:

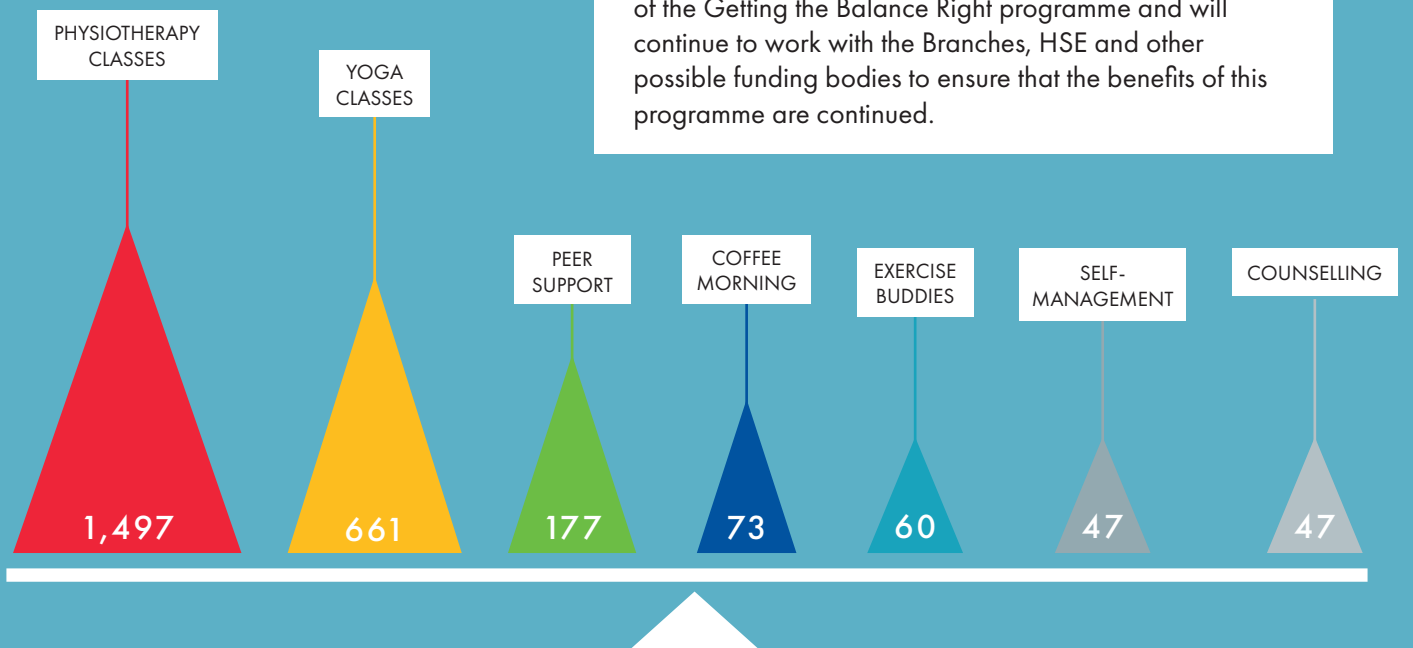


GETTING THE BALANCE RIGHT

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 2021 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.

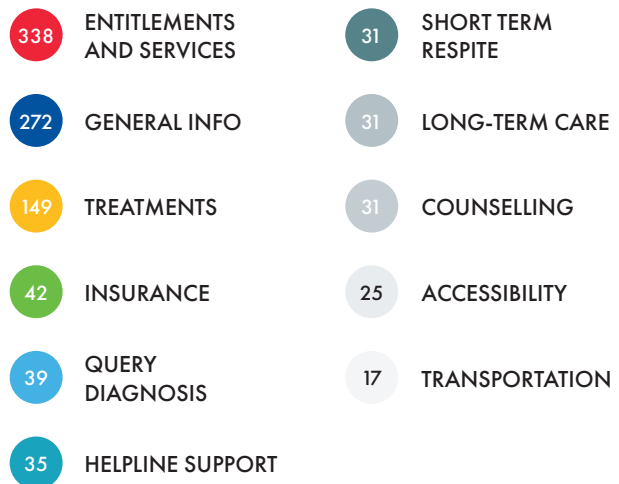


GOAL: SERVICE DELIVERY

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. 1,010 people contacted the Information Line in 2021, 647 of these contacts were by telephone, 240 were by email, 60 via Facebook and the remaining 29 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



HOW PEOPLE MADE CONTACT



PHONE:
647

E-MAIL:
240

FACEBOOK:
60

OTHER:
29



In 2021, **976** people contacted the MS Information Line.

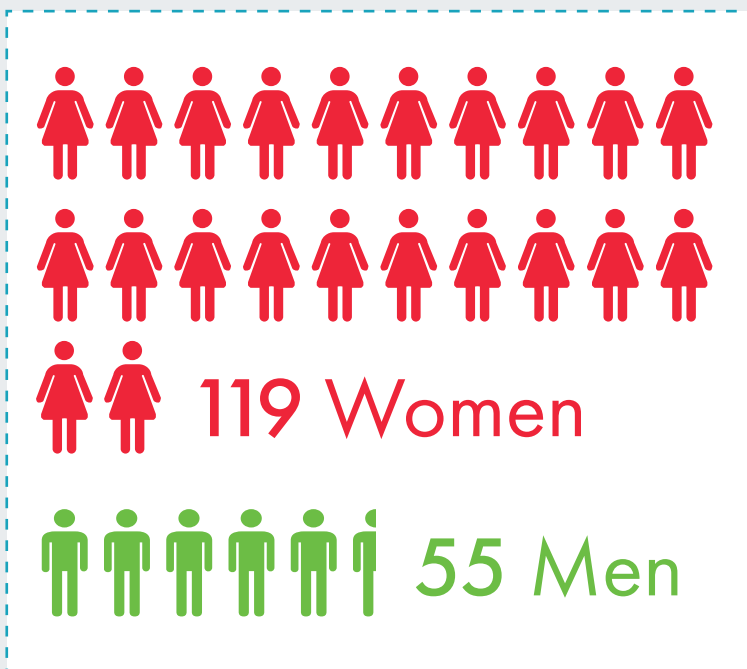
GOAL: SERVICE DELIVERY

THE MS CARE CENTRE

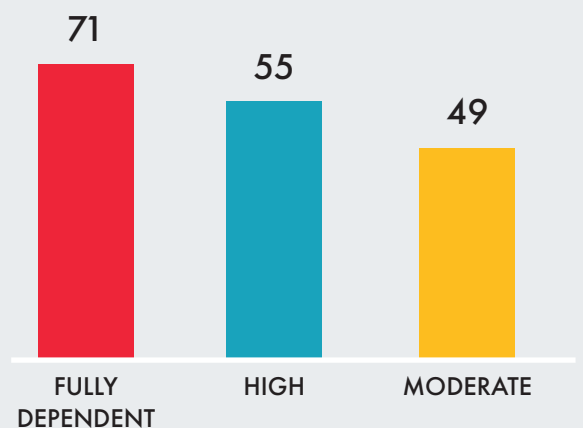
The MS Care Centre is a 12-bed respite facility. MS Nurse specialist and therapy services are available to our clients. In 2021 174 people stayed in the Care Centre.

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. The Care Centre was first registered in 2015. Registration is reviewed on a three-yearly basis by HIQA and was recently approved for reregistered 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 2021 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

updated numbers?



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

GOAL: SERVICE DELIVERY



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

BRANCHES

In 2021 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.

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.



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



SOCIAL MEDIA

Our social media channels continued to grow throughout 2021 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 and we continually shared valuable information updates on general life with MS.



Our 'Thursday Thank you' on Facebook continues to be a favourite 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 promoting our webinars, podcasts advocacy and information events and for supporting our fundraising events and engaging with our followers online.



Instagram

multiple_sclerosis_ireland

3,596 Followers

Facebook

MultipleSclerosisIreland



20,076 Likes



YouTube

MSSocietyIRELAND

186,600 Views



Twitter

@MSIRELAND



9,267 Followers

35 Emails sent



E-News

Sign up on our website

6,552 Subscribers

(+850, an increase of 14%)

Website

www.ms-society.ie



227,434 Website Visitors

(The personal experience blogs had 18,268 page views on the MS Ireland Website).

MS IRELAND WEBSITE

In 2021 the website had a total of 227,434 unique page views with the newly created online services centre having over 3,302 unique page views and our online webinar catalogue 3,428 views. In response to COVID-19, MS Ireland established a series of online webinars featuring some of the leading experts in Multiple Sclerosis research and neurologists from Ireland and abroad, these webinars were added to a new section on our website where visitors can browse and watch the webinars back in their leisure. Due to the impact of COVID-19 we had to change the way we provide some of our services nationally and regionally. While the pandemic has seen the cancellation and postponement of several events, we are still able to provide support by moving our classes online where users can log in from the comfort of their own homes by creating our online services centre. 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.

GOAL: SERVICE DELIVERY

WEBINARS

Throughout 2021, MS Ireland continued to provide our community with access to medical and other professionals who can provide up to date, accurate information and answer questions from the MS community on a wide range of topics through our webinars. In 2021, MS Ireland held 27 webinars on general information such as symptom management to tailored information sessions for groups within our community. Where possible these webinars were recorded and added to our online video catalogue. By providing information in this format, it can be accessed as and when it is required by our community members.



PROGRESSIVE MS WEBINAR SERIES

During 2021, MS Ireland launched a new video series on Progressive MS. The series aimed to help discover new tools and learnings on how those living with progressive MS can be more resilient and provide resources for managing Progressive MS. The series was hosted by MS and Me blogger Robert Joyce, who delved into a variety of topics around progressive MS. Video recordings of this series were made available on MS Ireland's online video catalogue.



UNDERSTANDING MS @ WORK

With the support of Roche Products (Ireland) Ltd. MS Ireland launched Understanding MS at Work which aimed to encourage and enable people living with MS to have beneficial conversations with their employers about their working environment. Videos of people with MS discussing their careers and their conversations with employers were created along with advice on working during the COVID-19 pandemic. A number of short documentaries featuring people living with MS were filmed as part of this project. The videos explored how they approach their daily working lives. A dedicated webpage on the MS Ireland website was created and hosts sections for both employers and employees with information on the entitlements, potential changes faced by people living with MS and emphasises the benefits of providing a flexible work environment for employees living with MS and other chronic conditions.



GOAL: SERVICE DELIVERY



PODCASTS

In collaboration with Novartis, MS Ireland created 'MS Explored – The Podcast'. The aim of this project was to provide valuable information on living with and managing MS. The podcase series was developed in response to a need for additional accessible information resources for the MS community. Topics explored included navigating the patient journey following diagnosis, the impact that living with MS can have on family life, as well as tips and useful advice and sources of support. The podcase explored a range of topics from diagnosis through to managing family life and work pressures. As part of this podcast, top healthcare and other relevant experts as well as people living with MS discussed various topics, providing a mix of expert information as well as first-hand accounts of the lived experience of living with MS.

In addition to the MS Explored podcast, MS Ireland Mid-Western Region shared a three podcast episodes in which three people living with MS reflect on their experiences since being diagnosed with MS. They offered insights into how they have learned to deal with symptoms and they reflect on how their connections within the MS community have helped them.



Societal Cost of Multiple Sclerosis in Ireland 2015



SOCIETAL COST OF MS SURVEY

In 2015, MS Ireland in collaboration with Novartis conducted a survey to quantify the societal cost of MS. As much had changed in recent years, it was decided that the survey would be repeated with the aim of comparing both data sets to understand what had changed from 2015 to 2021 with regard to the cost of MS. Repeating this survey also aimed to provide MS Ireland with data to support our advocacy and other activities.

GOAL: SERVICE DELIVERY

OBJECTIVE 2: RESEARCH

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



together, from the Republic of Ireland and Northern Ireland in order to support collaborative research. The mission of this network is three-fold. First, it supports collaborative research across the island of Ireland that holds the potential to limit the progression of MS. The second is to train future generations of MS researchers and finally, to contribute to global MS research.



An important element of MS Ireland's role in research is facilitating public and patient involvement in research (PPI). MS Ireland facilitated a number of PPI activities with members of the MS community and researchers. The aim of this was to ensure that people living with MS were given the opportunity to be active partners in research which related to them. With the support of Roche Products (Ireland) Ltd, MS Ireland conducted a short survey which explored MS and employment. The aim of this survey was to get a snapshot of employment issues in MS before and during the pandemic. This research helped to inform the information shared as part of the Understanding MS @ Work project.

Throughout the year, MS Ireland shared multiple 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. MS Ireland presented at the MSIF Atlas for Change event, discussing how we had used past Atlas of MS data to inform our advocacy activities. MS Ireland also liaised with the European MS Platform (EMSP) regarding the MS Barometer.

With the support of Almirall, MS Ireland shared a survey to our community which aimed to help to help understand resource use for people who experience MS related spasticity. The data from which was used to inform a submission to the National Centre for Pharmacoeconomics (NCPE) for Sativex – a cannabis-based medication which is used to treat MS related spasticity.

With the support of Roche Products (Ireland) Ltd. we also conducted some research to understand the professional attitudes of healthcare professionals towards MS Ireland. This helped us to better understand their levels of knowledge about MS Ireland and provided us with information which we use to strengthen our relationships with these professions, to ensure that people living with MS are best supported.

In February 2021, the All Ireland Multiple Sclerosis Research Network (AIMS Research Network) was launched. MS Ireland had joined the founding members to be part of the committee. This network brings researchers sharing a common interest in MS

MS Ireland also provided support to healthcare professionals regarding projects they wished to progress which would add immense value to the MS community in Ireland.

GOAL: SERVICE DELIVERY

OBJECTIVE 3: ADVOCACY

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

Advocating for people living with MS, their families and carers continued in 2021. We continued encouraging our community to speak up on issues that impacted them. We updated position papers and made a number of submissions to State bodies including a pre-budget submission and a patient group submission. We liaised with the HSE regarding COVID-19 related impacts on the MS community, ensuring that we kept our community informed on important updates and developments.



MS Ireland joined IPPOSI members in communicating to Government, the importance of prioritising those with chronic or rare conditions for early access to COVID-19 vaccines.

We advocated on regional issues through our network of community workers and the MS community, with the support of National Office.

In December, MS Ireland was delighted to learn that Siponimod had been approved for reimbursement. This news was most welcome as MS Ireland had put forward a patient group submission in support of this product. A product which helped to expand treatment options for those living with progressive MS.



We expressed concern that the guidance in relation to vaccine access was not clear and that the MS community was sub-divided regarding access to vaccine priority based on a number of factors including any disease

modifying therapy they were taking. We expressed that this caused great confusion and concern as there were different approaches taken in different places. We called for greater guidance on this.

MS Ireland joined with the Neurological Alliance of Ireland and fellow members to highlight the lack of neurology nurses in Ireland. The campaign aimed to highlight the need for 100 additional neurology nurses, including MS nurses in order to improve neurology services for people living with neurological conditions including MS. Virtual events were held across the country, with people living with MS speaking at each and having their voices heard by decision makers in their area.



GOAL: SERVICE DELIVERY

PUBLIC RELATIONS



WORLD MS DAY

World MS Day 2021 took place on Sunday May 30th and the theme of this year's campaign was 'Connections'. In the days leading up to World MS Day and on the day itself MS Ireland was featured in national and regional media on television, radio and print.

We had some brilliant ambassadors sharing their stories on what life is like living with Multiple Sclerosis all of which you can now read and watch back below.

NATIONAL TV AND RADIO

MS Ireland was featured on national television and radio for World MS Day. On Radio, Naomi Donaldson and Susan Carey joined Pat Kenny on his breakfast show and Ava Battles was interviewed for their News bulletin.

While on T.V Lauren White Murphy and Sabina Brennan had a segment on Ireland AM and Emma Valentine and regional community worker Patricia Lucey were featured on Virgin Media News For the MS Readathon, Lorna Cahill from county Dublin was our Readathon ambassador. Lorna her daughter Sophia and Author Lorraine Levis were featured on Virgin Media's Ireland AM. Lorna was also featured on RTE News2day alongside her son Harry at his school



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.

As the pandemic continued throughout 2021 many of our usual large fundraisers had to be either moved online or postponed. After last year's overwhelming success with our first ever virtual MS Readathon our Flagship event took place virtually again in 2021 while using traditional direct mail approach as well when schools throughout Ireland returned to the classroom in September. We continued with virtual events like our virtual trek and our virtual balloon race for World MS Day and introduced new virtual campaigns like our very successful 3,000 crunches in march campaign. 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.



VIRTUAL BALLOON RACE 2021

While we may not have hit the dizzying heights of 2020, we still had 3600 balloons in the race this year. Some great PR pieces on TV, Radio, national and regional press added awareness to World MS Day. The winner's balloon ended up near the village of Rasharkin Co. Antrim 13km south of Ballymoney and flew 183.33km

MS READATHON 2021

After the overwhelming success of the 2020 MS Readathon and with the ease with which teachers, parents and children took to the online fundraising, we were delighted to announce that our much-loved Readathon would continue in the virtual realm from now on.

11,000 people signed up (Kids and Big Kids) and between them raised an incredible €340k. Thousands

and thousands of books were read and reviewed on the website.

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 AND a €1000 voucher for CenterParcs Ireland, the lucky winner is holidaying with there with her family this October.

We also ran a "Design an Avatar" competition. We know our Readathon participants are a creative bunch and we asked them to design the newest member of the MS Readathon Avatar family. The new avatar would appear on the site and all our marketing materials for the 2022 campaign.

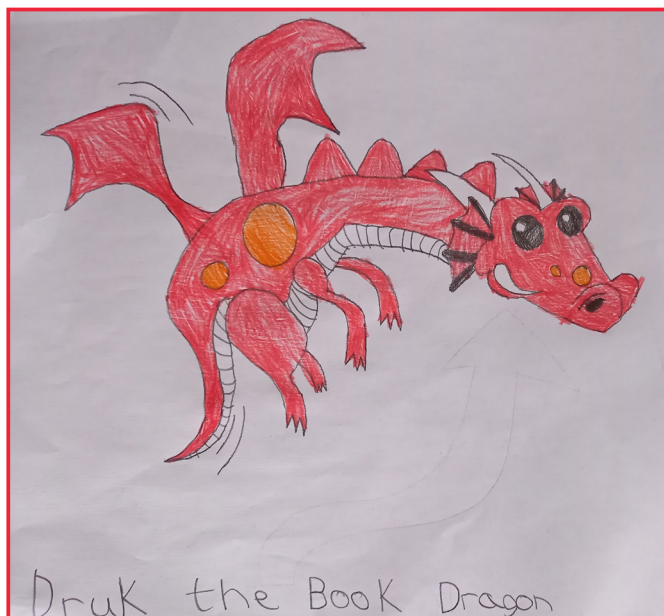
GOAL: SUSTAINABLE FINANCES



We had over 600 entries! It was an incredibly difficult task but we narrowed it down and the winner was 11 year old Adam McAuley from Donegal who created Druk the Dragon. Adam won €1000 worth of books for his school courtesy of our friends at Tribes Press. He also won an amazing mountain bike for himself too. Adam will have a day with the web design team to see his creation come to life.



Our two highest fundraisers were Robert Skelly who raised a whopping €2239.60 and Robbie Kavanagh who raised €1820.88. Amazing work by the lads!!! We were delighted to once again team up with Languages Connect who very kindly sponsored two extra iPads for any children taking part in the MS Readathon reading in a language other than Irish and English.



Languages Connect promotes the many advantages of learning foreign languages –making new friends, connecting with family, learning about other cultures and places, finding interesting careers and lots more. As with the previous year, we were mindful that the online sphere is not for everyone and were more than happy to offer schools and parents the opportunity to take part in the more traditional way with sponsorship cards etc. To this end we had 75 schools take part offline. This is something we will continue to nurture into 2022.

GOAL: SUSTAINABLE FINANCES

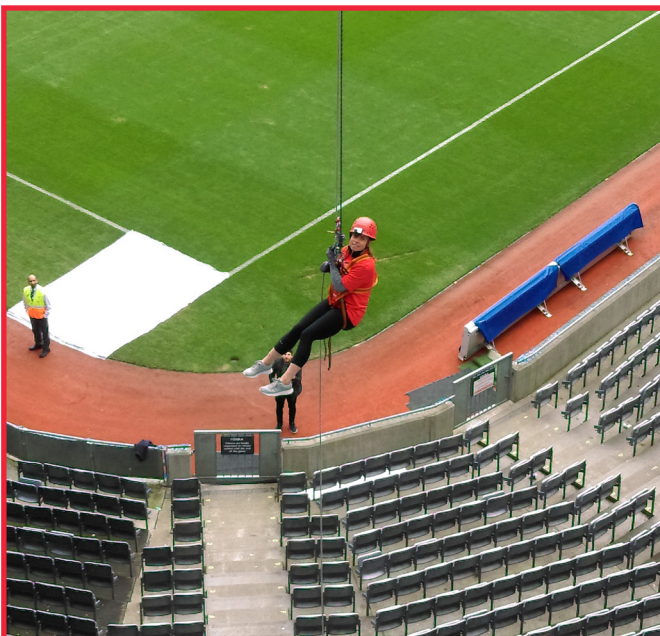
CRUNCH CHALLENGE



We did our first Facebook Challenge in March 2021 – As the country was in lock down and we were in the depths of wintery weather we decided that we should choose an activity that would not require going out or needing equipment. It was also important that we choose an activity that was as inclusive as possible, so with the help of the physios we decided on – 3,000 Crunches in March. We were overwhelmed by the number of people who joined in the challenge: over 1200 people joined our Facebook group and over 750 registered to do the challenge. By the end of March, we had raised over €145,000. A huge thank you to all our participants.

ABSEIL – CROKE PARK

We had our first in person event in the 30th July in Croke Park. It was wonderful to see our 30 intrepid participants getting ready to enjoy the spectacular views of Dublin from the Skywalk before dropping over the big screen to do their abseil.



AD HOC SPORTS

Sunshine for Brain Conditions is a voluntary group who support a variety of charities and in 2021 they chose MS Ireland to be a beneficiary. They held various events during the year including their flagship event – a sunrise walk up Croke Patrick, which was a hybrid event. They also introduced us to the: 1771.45 Henley Mermaids – this intrepid group of ladies planned to swim the Bristol Channel, along with other fundraising events. The swim is 66km and they successfully completed 60km, which is an incredible achievement. Over €4,000



Marathon des Sables – we were approached a long-time supporter Andrew Lynch about his plan to run this Desert Marathon in Morocco – it is 250Km over 7 days in extreme heat! By completing this amazing challenge Andrew raised over €32,000



GOAL: SUSTAINABLE FINANCES

Ad Hoc sports – we are extremely lucky to so many wonderful supporters who have taken on amazing challenges including: Conor Heaphy , Norin Flynn, Kenneth Kavanagh, Michelle Holland and friends, Ben Hunt, Sean O’Shea, Emma Flood, Michael Mooney and team, Julien Jully and Beverly O’Brien to name a few. Thank you



COMMUNITY

2021 was the year for all sorts of events from Bridge tournaments to hot sauce challenges and everything in between! Particular thanks to Ciara Griffin and team, Declan Groeger and team, The Tournafulla and District Vintage Club and many others

>>>>INSERT PIC<<<<<< - which pic?



GOLF

Thank you to the Rathfarnham, Virginia and Milltown Golf Clubs for choosing MS Ireland as the beneficiary of their charity golf days. If you are a member of a golf club would you consider putting MS Ireland forward for These wonderful fundraising events!

WOMEN’S MINI MARATHON

The Mini Marathon was a virtual event in September 2021 - over 170 ladies joined Team MS Ireland to walk, jog or run the annual 10k event. Whilst it was strange to not be together in Dublin running past the Donnybrook fire station, it was still a part of the MS Ireland fundraising calendar! Thank you to all the ladies who joined us on the day.

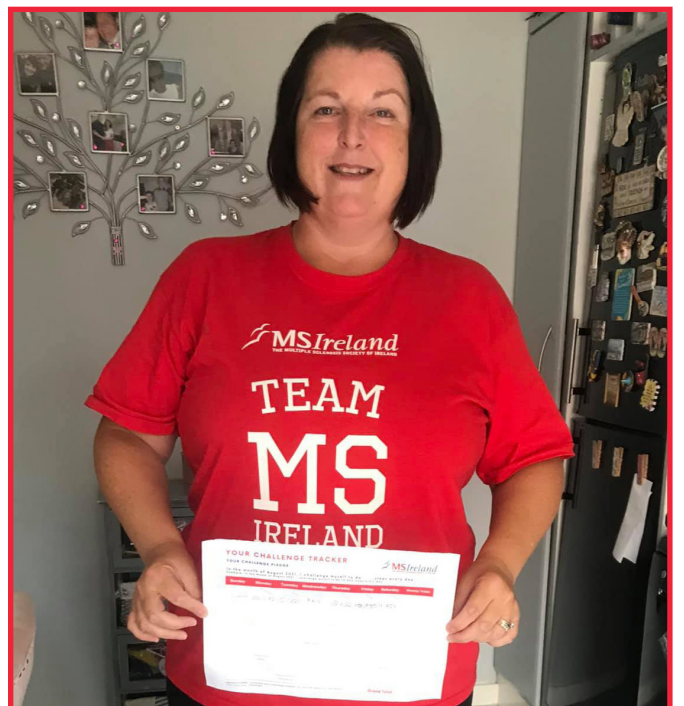


DUBLIN MARATHON

The Dublin marathon 2021 was cancelled for a second year in a row. We look forward to the event in 2022

10,000 STEPS A DAY IN AUGUST

On the back of the success of our Crunch Facebook challenge, and owing to the fact that we were not able to offer a foreign trek – we decided to merge the 2 and do a virtual walking challenge as our second Facebook challenge. We had over 800 in the Facebook group with nearly 500 registering for the challenge. Our participants posted wonderful photos of where they were walking a welcome reminder of what a beautiful country we live in. Thank you to all who participated and helped raise over €40,000



GOAL: SUSTAINABLE FINANCES

OBJECTIVE 5: DEVELOP PARTNERSHIPS

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

SIGNIFICANT PARTNERSHIPS IN 2021

- 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, professional information and in some cases, collaboration.
- The Neurological Alliance of Ireland regarding the Patients Deserve Better campaign which aimed to highlight the severe lack of neurology nurses in Ireland, including MS nurses, as well as 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.
- The AIMS Research Network to connect researchers across the island of Ireland who share a common interest in MS in the hopes of contributing to global MS research, training future researchers and finding potential to limit MS progression.
- HSE COVID-19 Vaccine Community Network which enabled us to obtain and share information directly from the HSE and to have our specific questions regarding the vaccines for people living with MS addressed.
- The Disability Federation of Ireland (DFI) to collaborate on areas such as 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 regarding policy, research, governance and goal setting. 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 Alkermes, Novartis, Roche, Merck, and Almirall partnered with MS Ireland on projects and activities, research and supporting information services. In particular, we would like to note the following collaborations in 2021:
 - » MS Ireland collaborated with Novartis to support 'MS Explored – The Podcast' which aimed to provide people living with MS access to both professional information and the lived experience of others living with the condition. Additionally, MS Ireland with the support of Novartis launched The Societal Cost of MS survey. A survey which would allow a comparative analysis to a previous 2015 survey.
 - » We collaborated with Roche who provided support for Understanding MS at Work as well as research into the professional attitudes of healthcare professionals towards MS Ireland.
 - » Alkermes supported MS Ireland's Information Line service by providing us with financial commitment to see this service secured for 2020 and 2021.



MS Ireland
Jenny
Care Assistant

Goal: Innovation

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.

Service Delivery – Objective 1 – New Models of service delivery and Services Development
Services Development – Getting the Balance Right
In 2021 our Getting the Balance Right programmes continued online delivered by our independent physiotherapy, yoga and fitness instructor contractors. This national programme delivers Health Promoting Physical Activity group programmes for people with MS and in some regions individual sessions are facilitated.

The impact of these programmes is a reduction in the physical and psychological impact of MS and improvements in fatigue, walking and other MS symptoms. Participants benefit not only from the exercise component, but from the peer learning and social support offered by these highly valued programmes.

Programmes are funded largely by our network of branches and also from National Lottery funds. In 2021 eight of our branches were successful in applications to the Bank of Ireland, Begin Together fund.

We provided 101 physiotherapy programmes and 52 yoga programmes with 1,497 Physiotherapy and 661 individual yoga classes.

New Models of service Delivery – Active Neuro

The Active Neuro programme provides physiotherapy led programmes for people with a range of neurological conditions. The programmes used a cross sectoral, integrated care approach working with health, social care and charity sector collaborations to promote health and prevent progression of disability among participants.

Funded by the SlainteCare Integration Fund it was piloted in the mid-west in 2020 and service continued to be delivered in 2021. These online, specialised, symptom specific exercise and education classes, tailored for ability, proved highly effective for people

with neurological conditions.

Active Neuro's evidence-based programs had excellent satisfaction and led to improvements in physical and mental health symptoms. There were significant reductions (44%) in healthcare utilisation, both in terms of primary and tertiary care services following the programme. Active Neuro led to a 30% reduction in the number of falls and a 49% reduction in the number of participants experiencing falls. In 2020 and 2021 Active Neuro delivered 49 programmes for 440 participants with MS (33%), Parkinsons disease (39%) and acquired brain injury (25%).

New Models of service delivery - Move Smart MS

Move Smart MS provides specialist online physiotherapy programmes for people living with MS during the COVID-19 period and beyond, removing the barriers of location, transport and fatigue experienced by our client group. The online environment and national recruitment enable the specialist team to deliver exercise and education to groups of people with MS with a similar symptom focus, age, and ability - not possible in a locally recruited environment thereby enabling a more effective and tailored service to be delivered by the specialist physiotherapy team.

Impact outcomes were initially focused on physical symptoms, however a key impact emerging from the satisfaction survey is that participants gained significant confidence, motivation and developed strategies to continue exercising beyond the end of the programme to self-manage their MS. Additional impact for participants beyond the programme is enhanced through the exercise and education approach of these classes, and through graduation resources for participants, including videos. The impact for the physiotherapy community is sustained through an online community of practise, weekly in-service training, and MS focused CPD opportunities.

GOAL: INNOVATION

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 14 voluntary members. These members have a wide range of experience and skills. Some have MS themselves or have family members with MS. Others have long careers in business, 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 2021, the Board met eight times. Significant work was carried out in the areas of finance, funding, governance and strategy.



BOARD MEMBER 2020/2021



BOARD MEMBER 2021/2022

 CHAIRPERSON	 VICE CHAIRPERSON			
 Maurice  O'Connor	 Jacinta  Kelly	 Carol Barton	 Robin  Bradley	 Noelle  Burke
				
 Thomas  Cronin	 Marcella Flood	 Eugene  Kearney	 Anthony Kelly	 Rebecca  Maguire
				
 Rory  Mulcahy	 Aveen  Murray	 Martin  Power	 Anne  Restan	 Mary  Sheahan Lonergan

RESIGNATIONS/CHANGES

Marcella Flood retired on 17/9/2021

APPOINTMENTS

Carol Barton appointed on 17/9/2021
 Anthony Kelly appointed on 17/9/2021

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, Monitoring and Evaluation Committee
4. Research, Advocacy and Communications Committee
5. Remuneration and Nomination Committee
6. Governance Committee
7. Organisation and People Committee

BOARD ATTENDANCE 2021

	18 FEB	18 MAR	8 APR	27 MAY	1 JUL	16 SEP (i)	17 SEP (ii)	2 DEC	TOTAL
Carol Barton	n/a	n/a	n/a	n/a	n/a	n/a	✓	x	1/2
Robin Bradley	✓	✓	✓	✓	x	x	x	✓	5/8
Noelle Burke	x	✓	✓	✓	x	x	x	x	3/8
Thomas Cronin	✓	x	✓	✓	✓	✓	✓	✓	7/8
Marcella Flood	✓	✓	✓	✓	x	✓	n/a	n/a	5/6
Eugene Kearney	✓	✓	x	✓	✓	✓	✓	✓	7/8
Anthony Kelly	n/a	n/a	n/a	n/a	n/a	n/a	x	✓	1/2
Jacinta Kelly	✓	x	✓	x	✓	✓	✓	✓	6/8
Dr Rebecca Maguire	✓	✓	✓	✓	✓	x	✓	✓	7/8
Rory Mulcahy	✓	x	✓	✓	✓	✓	✓	✓	7/8
Aveen Murray	✓	✓	✓	✓	x	x	✓	x	5/8
Maurice O'Connor	✓	✓	✓	✓	✓	✓	✓	✓	8/8
Martin Power	✓	✓	✓	✓	✓	✓	✓	✓	8/8
Anne Restan	x	✓	✓	x	✓	x	✓	✓	5/7
Mary Sheahan-Lonergan	✓	x	✓	✓	✓	✓	✓	x	6/8

GOAL: INNOVATION

THE BOARD

CONFLICTS OF INTEREST AND LOYALTIES

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

RECRUITMENT AND INDUCTION OF BOARD MEMBERS

Three of our 14 Board Members vacancies are filled on a rotational basis from the council branch representatives. Notification of the remaining vacancies for Board members is advertised in MS News, eNews and on the MS Ireland website. Prospective Board members complete an application form which is considered by the Nominating Committee who then make recommendations to the Board. Once approved by the Board, the chosen candidates stand for election by the members at the AGM. In 2018 one Board member was elected under Article 56 of the Constitution who, with the support of fifteen members, was elected by going directly to the AGM rather than via the Nominating Committee election process. New Board members are given one afternoon's induction training by the CEO to familiarise them with their duties as Board members, their legal obligations, the governance of the organisation and policies and procedures. Further training can be made available if required.

BOARDMATCH IRELAND TRANSPARENCY SCALE

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

SKILLS AND EXPERIENCE

Annually, the Nominating Committee with the CEO determine the skills required on the Board. When

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

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.

GOAL: INNOVATION

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 31 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 73 people across national and regional offices and 46 Community Employment participants. MS Ireland's work is supported by committed volunteers around the country.

MS. AVA BATTLES, CHIEF EXECUTIVE

**MS. JACKIE
BAKER**

FINANCIAL
ACCOUNTANT

**MS. OLGA
ESTRIDGE**

SERVICES
MANAGER

**MS. CAITRIONA
HUGHES**

FUNDRAISING
DEVELOPMENT
MANAGER

**MR. AIDAN
LARKIN**

SERVICES
DEVELOPMENT
MANAGER

**MR. MYLES
MCPARTLAND**

HR
MANAGER

REMUNERATION

The number of employees whose emoluments, excluding employer pension contributions, were greater than €70,000 in 2021 is set out below:

3 €60,000 - €70,000

1 €70,000 - €80,000

1 €100,000 - €110,000
(CEO)

As a result of HSE pay restoration scheme, all salaries were reviewed and restored where applicable in 2021. 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.

GOAL: INNOVATION

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 €450,972 for the year (2020: €556,648). There was a surplus of €450,972 for 2021 after exceptional items (2020: €561,648). Income for the

year includes Legacies/Donations totalling €40,500 (2020: €111,000). 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 €10,162,961 (2020: €9,711,989) at the end of the the financial year. They are comprised of restricted funds of €3,332,469 (2020: €3,243,779) and unrestricted funds of €6,830,492 (2020: €6,468,210).

THESE FUNDS ARE REPRESENTED BY THE FOLLOWING:

	NATIONAL OFFICE & CEP	BRANCHES	TOTAL
	€	€	€
Tangible Fixed Assets	4,382,626	38,450	4,421,076
Investment properties	1,380,000	-	1,380,000
Net Current Assets (excl. Bank loan)	3,850,933	1,280,348	5,131,281
Bank Term Loan	(769,396)	-	(769,396)
TOTAL	8,844,163	1,318,798	10,162,961

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 2021 €	Restricted Funds 2021 €	Total Funds 2021 €	Total Funds 2019 €
INCOME				
Income from generated funds				
Voluntary Income				
Donations and fundraising	1,580,963	212,837	1,793,800	1,644,217
Legacies	10,500	30,000	40,500	111,000
Research	-	2,210	2,210	2,234
Subscriptions	1,220	-	1,220	650
Income from charitable activities				
Fees received	121,687	-	121,687	82,947
Grants and other service contract income	-	3,243,183	3,243,183	2,949,315
Government schemes	-	756,646	756,646	806,639
Other income	19,987	122,264	142,251	126,482
Total income	1,734,357	4,367,140	6,101,497	5,723,484
EXPENDITURE				
Costs of generating voluntary income				
Fundraising	533,677	106,300	639,977	594,829
Charitable activities				
Community services	25,502	2,814,004	2,839,506	2,516,659
Respite care services	119,063	1,727,970	1,847,033	1,639,603
Research	1,973	10,141	12,114	11,466
Local MS services	193,964	117,931	311,895	404,299
Total expenditure	874,179	4,776,346	5,650,525	5,166,836
Net income/(expenditure) for the year before exceptional items	860,178	(409,206)	450,972	556,648
Exceptional items	-	-	-	5,000
Net income/(expenditure) for the year	860,178	(409,206)	450,972	561,648
Transfer between funds	(467,896)	497,896	-	-
Net movement in funds	362,282	88,690	450,972	561,648
Reconciliation of Funds:				
Total funds brought forward	6,468,210	3,243,779	9,711,989	9,150,341
Total funds carried forward	6,830,492	3,332,469	10,162,961	9,711,989

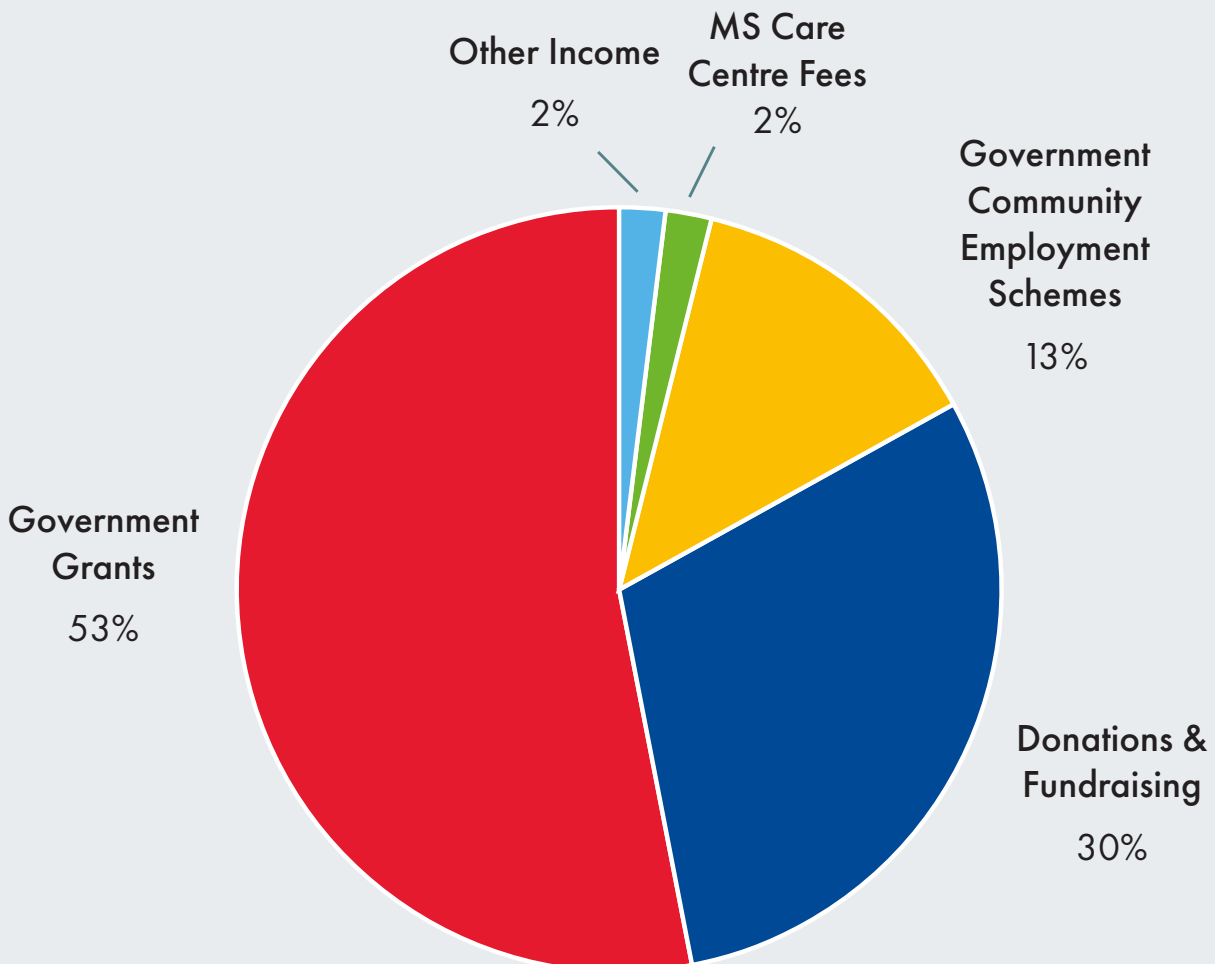
GOAL: INNOVATION

INCOME ANALYSIS 2021

€6,101,497

Income of €6,101,497 was received of which 53% was funding from Government Grants mainly HSE, 30% was Donations and Fundraising, 13% was from three Department of Social Protection schemes we have in Donegal, Galway and Dublin, 2% was from fees received from Respite Centre residents and 2% from miscellaneous income.

	2021 (€)	2020 (€)
Government Grants	3,243,183	2,949,315
Donations & Fundraising	1,836,510	1,757,451
Government Community Employment Schemes	756,646	806,639
MS Care Centre Fees	121,687	82,947
Other Income	143,471	127,132
TOTAL	6,101,497	5,723,484



GOAL: INNOVATION

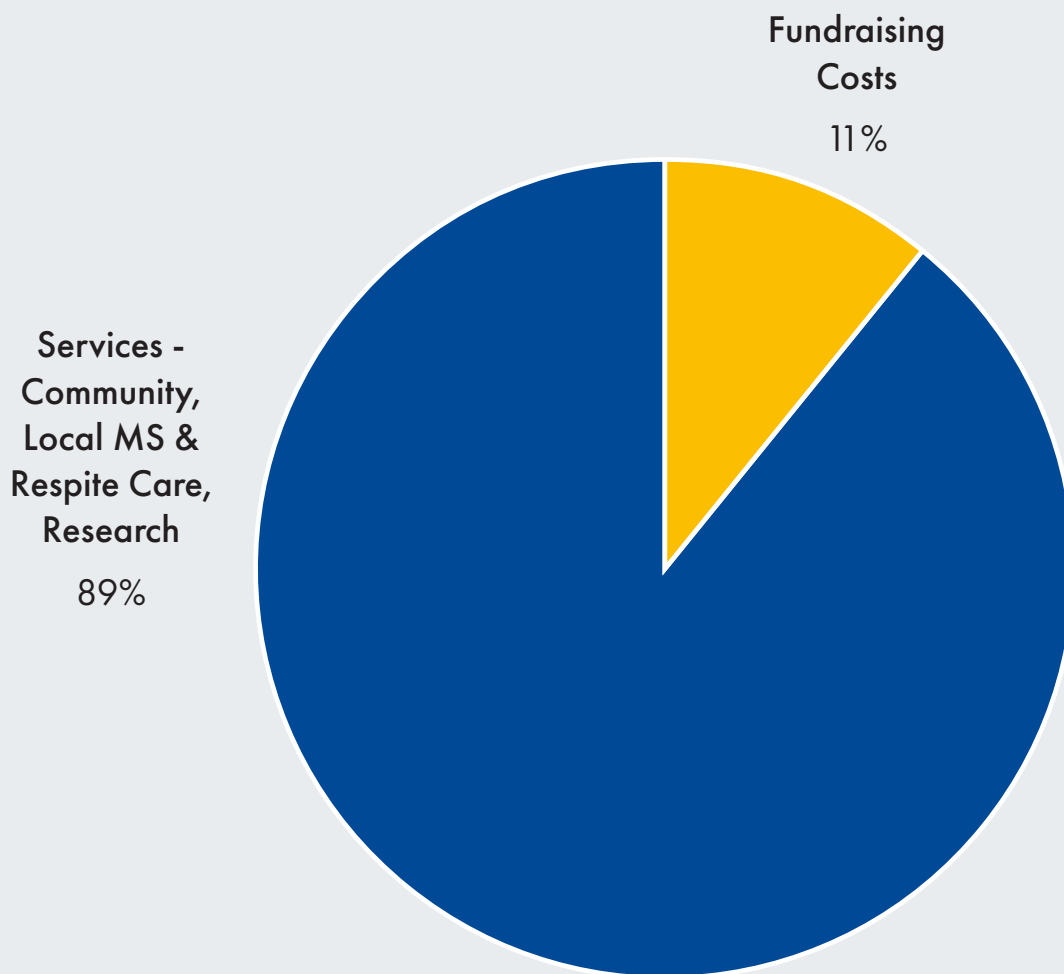
OPERATIONAL EXPENDITURE ANALYSIS 2021

(excluding exceptional items)

€5,650,525

€5,650,525 before exceptional items was spent in 2021 of which: 89% was spent on Community services, Care Centre respite services and Research; and 11% on Fundraising.

	2021 (€)	2020 (€)
■ Services - Community, Local MS & Respite Care, Research	5,010,548	4,572,007
■ Fundraising Costs	639,977	594,829
TOTAL	5,650,525	5,166,836



GOAL: INNOVATION

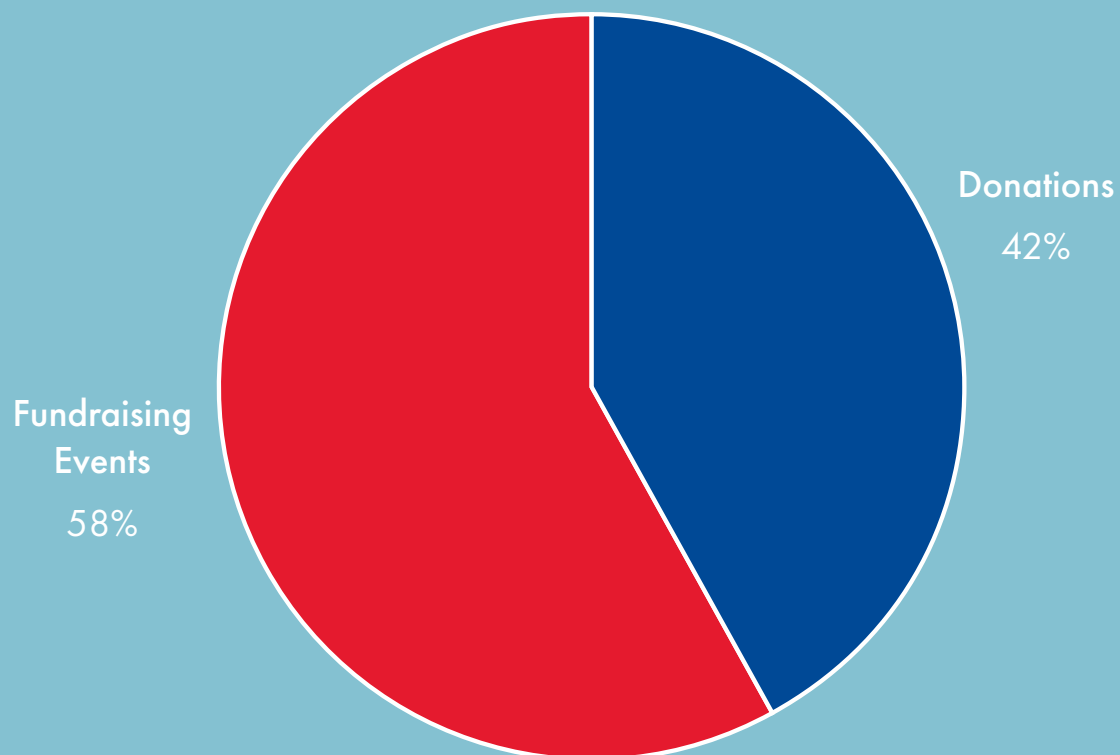
BRANCH INCOME ANALYSIS 2021

€309,709

There were 31 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 €309,709 was received of which 58% was raised from fundraising events and 42% from Donations.

	2021 (€)	2020 (€)
 Fundraising Events	178,184	188,579
 Churchgate Collections	1,340	34,291
 Donations	129,068	119,729
 Flag Day Collections	-	4,647
 Legacies	-	-
 Other income	1,117	10,450
TOTAL	309,709	357,696



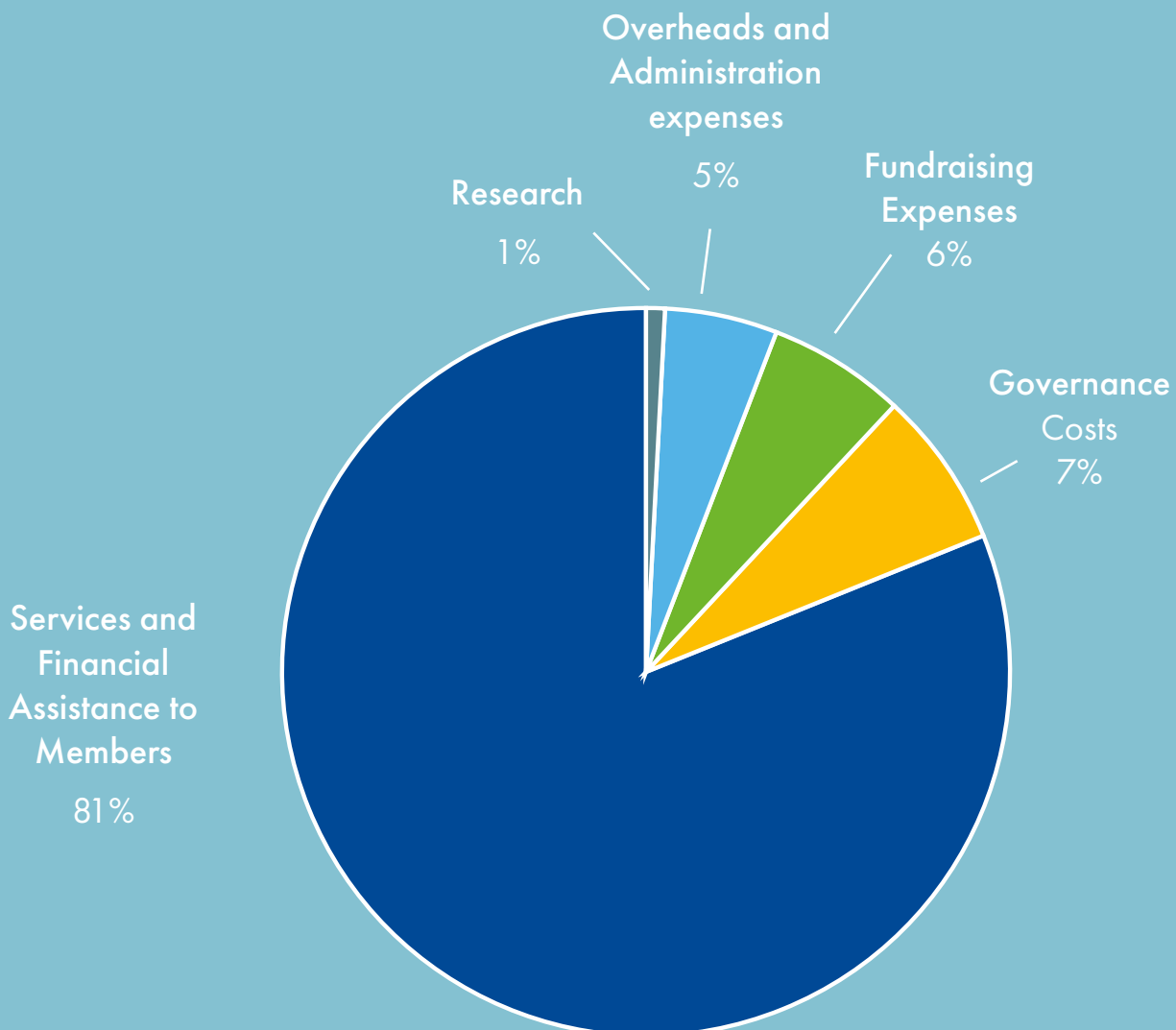
GOAL: INNOVATION

BRANCH EXPENDITURE ANALYSIS 2021

€300,397

€300,397 before exceptional item was spent in 2021 of which 81% was spent on providing services & Financial assistance to members, 7% on Governance, 6% on fundraising expenses, 5% Overheads and Administration expenses and 1% on Research.

	2021 (€)	2020 (€)
Services and Financial Assistance to Members	242,734	344,711
Governance	22,564	24,739
Fundraising expenses	18,113	18,269
Overheads and Administration expenses	14,986	20,906
Research	2,000	3,000
TOTAL	300,397	411,625





Goal: People and Culture

MS Ireland
Manager

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

2021 was the tenth 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, 10 Regional Integrated Meetings took place in 2021 by Zoom or Teams. The main focus of meetings was about continuing to work in a COVID world and how are we as an organisation working and how do Branches fundraise.

RESOURCE ALIGNMENT

We continued to fundraise online and some events started to operate physically. The fundraising space continues to be very challenging both for MS Ireland as a National organisation and our Branches.

- » 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 2021 concentrated on replacing necessary leavers or unfilled posts.

We had 17 starters and 16 leavers.

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.

MS PERSON OF THE YEAR MAIRIN HARRIS

Nominated by Mark Mitchell, MS Ireland's East Wicklow Branch.

Involvement with MS Society: Vice chair of EWB. On the fundraising committee, a former chair of the EWB, among others.

Living in Arklow, Mairin was instrumental in setting up the Friday coffee morning meet ups which has been running very successfully for the past few years and over twenty PwMS in Arklow attend faithfully. Mairin is incredibly supportive to everyone in the community at the coffee mornings and on Zoom due to covid. Mairin likes to get involved and is a great listener offering support by being there and giving people the space to feel comfortable to talk about their MS.

Mairin never misses the support groups and her contribution stands out a long way. Mairin has a positive attitude and has touched the lives of so many people by showing she cares. A very worthy candidate for the MS Person of the Year Award. Any additional information that may be relevant,

From Martina O'Sullivan, EWB Treasurer:

As already mentioned Mairin is a lovely woman always supports coffee mornings, branch meet ups flag days, AGM, lunches, and always with a smile and caring way. Shows great interest to newcomers advising people of different ways to cope with any worries they may have with their ailment her dry sense of humour takes me by surprise all the time she well deserves this honour of MS Person of the Year



Mairin has been the most dedicated branch member of MS Ireland's East Wicklow Branch, and was a member of the original Bray branch. Mairin attends every flag day from Bray to Greystones to Wicklow and Arklow, without fail. She always attends our coffee mornings, AGM's, annual lunch's, Summer BBQ's, and all our branch outings. She even attended the Aras and met Michael D himself. She always supports our MS calendar and Christmas cards faithfully. Mairin tends to hide from the highlights and does not participate in committees. However she makes up for this by her total dedication to the branch.

CARER / HELPER OF THE YEAR HELEN BINIONS

Helen cares for Her husband Clinton Binions. Special elements that make this candidate stand out from all the others. Helen has cared for her husband Clinton since his diagnosis in 2005. Clinton was a dairy farmer in Ballyhad in Co. Wicklow. Two years post diagnosis, Clinton had to use a wheelchair and it was a significant adjustment adapting to life as a wheelchair user.

He introduced me (Mark Mitchell) to the ECDL course by distance learning c/o National Learning Network in Bray. I asked Clinton was it tough going, his reply was, "Well, I was a farmer and I managed, so if I can do it, anyone can."

GOAL: PEOPLE AND CULTURE



Helen oversaw her entire house being adopted for Clinton and drove him to every branch committee meeting, every coffee morning, AGM, annual lunch, all our branch outings and every flag day etc. Helen cared for him single-handedly all of the time though there is wonderful family support. Over the years Clinton has had health issues and Helen always stood by Clinton bring him to all his hospital appointments. Clinton played badminton on winning teams with Helen until his MS.

Helen always a great carer - worked with Riding for the Disabled for over 30yrs. He drove for as long as he could and said giving up driving was one of the hardest things. Then Helen brought him everywhere for his beloved bluegrass/country and gospel bands playing all over Ireland all year round as well as all the Wheel-chair Association and MS meetings and functions. She cared for 5 grandchildren on and off during this time - always cheerful and loving no matter how tough times were. She kept Clinton swimming for as long as possible in Ireland and abroad.

During Covid she has kept him in touch with his family through zoom. Always imaginative and finding new ways of making life more interesting for Clinton. Married 51 years this year

From Martina O’Sullivan, EWB Treasurer:

I met Helen years ago when attending yoga in Shankill she used to bring Clinton to and back from the classes and we go for a cuppa afterwards she was always in good form and she would join in the

conversation, comes up with some good fundraising ideas like wear your wedding dress for MS and even when she had a significant birthday she asked people to give donations to MS society. Helen deserves this award as she is always thinking of others rather than herself, love the way herself and Clinton enjoy. Always doing things together they go on trips away to country music festivals which is brilliant.

VOLUNTEER OF THE YEAR WILLIE DOHERTY

Nominated by Jackie Browne, Chairperson of the Donegal Branch

Involvement with MS Society: Willie has been involved with the Donegal Branch for over 40 years as fundraiser extraordinaire and has served on the Welfare Committee for many years helping those in need with MS.



Willie has dedicated his life to helping those with MS raising tens of thousands of euro to support those with MS. Willie turned 90 years young this year and is as dedicated as ever.

Willie organises church gate collections in 12 parishes, gathers many thousands worth of sponsorship for greens and prizes in the golf classics, sold hundreds of boxes of MS Christmas cards and got prizes sponsored for the MS Christmas dinner. Willie is well known sitting outside Tesco’s selling tickets etc. He went to Lourdes as a carer on 3 occasions. It gives me great pride to nominate Willie to be considered for the volunteer awards – he is one of life’s genuine, caring people and a true champion in helping those with MS all across Donegal and further afield. Willie also won an award from the ME4U Volunteer awards in Donegal.

GOAL: PEOPLE AND CULTURE

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**
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