

The Multiple Sclerosis Society of Ireland Limited Annual General Meeting

Notice and Information Pack

Saturday, 16th September 2023 at 4.00p.m. in the Radisson Hotel, Northgate Street, Athlone & Via Zoom

(Note: The AGM will also be held online via Zoom. The AGM meeting will be recorded). To attend the AGM in person or by Zoom, members need to complete the registration form attached on page 36 and we will send the zoom link to you if you are attending virtually on receipt of your registration form. Otherwise we look forward to welcoming you in Athlone.



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Separate document circulated with the AGM Pack:

Proxy Form



80 Northumberland Road

Dublin 4

Telephone (01) 678 1600 Fax (01) 678 1601

MS Helpline 1850 233 233

website: www.ms-society.ie email: info@ms-society.ie

NOTICE OF THE ANNUAL GENERAL MEETING OF THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND LIMITED

Notice is hereby given that the twenty third National Annual General Meeting of the Multiple Sclerosis Society of Ireland Limited will take place in the Radisson Hotel, Northgate Street, Athlone in person and via Zoom on Saturday, 16th September 2023 at 4.00 p.m.

(Note The AGM will be recorded.) To attend the AGM virtually (via Zoom), members need to complete the registration form on page 36 and we will send the zoom link to you on receipt of your registration form.

The AGM is being held for the following purposes:

The Chairman's Address and Report
The Chief Executive's Address and Report

Ordinary Resolutions

To consider and, if thought fit, to pass the following resolutions which will be proposed as ordinary resolutions:

- To receive and consider the consolidated draft financial statements* for the year ended 31st December 2022 together with the Directors' report thereon
- To re-elect Ms Jacinta Kelly as Director
- 3. To re-elect Ms Aveen Murray as Director
- 4. To re-elect Mr Martin Power as Director
- 5. To elect Mr Sean Martin as Director
- 6. To elect Mr Leslie Warren as Director
- 7. To authorise the Directors to fix the remuneration of the Auditors

*Unfortunately due to staff turnover and sick leave, we are not in a position to have our audited financial statements for the year ended 31st December 2022 ready for the AGM pack. We will present a DRAFT set of financial statements at the AGM on September 16th 2023 and a timetable of when we will reconvene the AGM and present the financial statements to our membership.

By Order of the Board

Rory Mulcahy Company Secretary MS Ireland

11th August 2023

Patron Michael D. Higgins, PRESIDENT OF IRELAND

A list of names and personal details of every Director of the Company is available for inspection to the public at the Company's Registered Office for a nominal fee. Registered Office: 80 Northumberland Road, Dublin 4. Company Registration Number 296573; Registered Charity Number: 20007867; Charity Number: 5365.



80 Northumberland Road

Dublin 4

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website: www.ms-society.ie email: info@ms-society.ie

Re:

24th National Annual General Meeting ("AGM") (since incorporation – the Society was founded in 1961) of the Multiple Sclerosis Society of Ireland Limited on Saturday, 16th September 2023 at 4.00 p.m. in the Radisson Hotel, Northqate Street, Athlone and via Zoom.

Dear Member.

Please find enclosed information regarding the Annual General Meeting ("AGM"). Particular points to note are the following:

1. Flection Information

The Nominating Committee are recommending the appointment of Mr Sean Martin who is listed in your AGM Pack

Mr Leslie Warren is standing for election. Ms Jacinta Kelly, Ms Aveen Murray, Mr Martin Power are standing for reelection.

A candidate must receive in excess of 50% of the votes cast to be elected.

2. Voting at the AGM

Members are entitled to vote on the resolutions being proposed in the enclosed Notice of AGM. Votes for the AGM may be registered in person at the AGM or by proxy, which means that if you are unable to attend or vote at the AGM, you can fill in the attached Proxy Form to appoint the Chairperson, to speak and vote on your behalf at the AGM. A proxy form that is not complete or does not meet the requirements of S.183 and S.184 of the Companies Act will not be counted

To be valid this proxy form (and where applicable, any power of attorney under which it is signed) must reach the Company Secretary by post or by hand to 80 Northumberland Road, Dublin 4, D04 T856 not less than forty-eight hours before the time appointed for the AGM, i.e. by no later than 4.00 p.m. on Thursday, 14th September 2023.

If you have any queries regarding the AGM, please contact Alice in National Office on 01 678 1608.

Yours sincerely

Rory Mulcahy Company Secretary

MS Ireland

Patron Michael D. Higgins, PRESIDENT OF IRELAND

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Annual General Meeting Agenda

Approval of Agenda Approval of the last Minutes Matters arising Chairman's address and report Chief Executive's address and report

Ordinary Resolutions

- 1. Directors' Report* and Financial Statements* 2022
- 2. Re-Election of Ms Jacinta Kelly as Director to the Board
- 3. Re-Election of Ms Aveen Murray as Director to the Board
- 4. Re-Election of Mr Martin Power as Director to the Board
- 5. Election of Mr Sean Martin as Director to the Board
- 6. Election of Mr Leslie Warren as Director to the Board
- 7. Authorise the Directors to fix the remuneration of the Auditors

Please note that the AGM will be recorded

*Unfortunately due to staff turnover and sick leave, we are not in a position to have our audited financial statements for the year ended 31st December 2022 ready for the AGM pack. We will present a DRAFT set of financial statements at the AGM on September 16th 2023 and a timetable of when we will reconvene the AGM and present the financial statements to our membership.



Minutes of the 62nd Annual General Meeting (23rd Annual General Meeting since incorporation) of the Company held in the MS Care Centre, 65 Bushy Park Road, Rathgar, Dublin 6 on Saturday, 17th September 2022 at 4.00 p.m. and by Zoom.

PRESENT: Mr Maurice O'Connor (Chairperson)

Members & Delegates

IN ATTENDANCE: Ms Ava Battles (Chief Executive)

Ms Alice McKeon (Staff - Minutes)

APOLOGIES: As per list available from MS Ireland

The Chairperson, Mr Maurice O'Connor, formally opened the meeting and welcomed all members to the 62nd Annual General Meeting of the Society and 23rd since its incorporation. He said that he hoped this would be the last time that we would be holding the AGM virtually.

The Chairperson took a moments silence to remember our friends who had passed away since our last AGM.

He thanked Jason Power and Triona Ni Rainne for their assistance with the AGM. He thanked Ann McNamara for hosting Martin Nolan, Board members and former Chairpersons to a lunch to commemorate Martin Nolan's 37 years as a volunteer. He said that we owed a huge debt of gratitude to Martin for his service to the Society.

The Chairperson presented the Awards for MS Person of the Year to Seamus Burke, Carer of the Year to Susan Stephens and Volunteer of the Year to Celine O'Rourke. He said it was one of the most difficult things that we have to do to try and distinguish the contributions and amazing citations to select the award winners. He congratulated Seamus Burke, Susan Stephens and Celine O'Rourke.

Approval of the Agenda

The Agenda for the meeting having previously been circulated, was approved by the members present.

Approval of the Previous Minutes

Minutes of the 61st Annual General Meeting of the Society held on Friday, 17th September 2021 having previously been circulated, were taken as read. The Minutes were approved by the Members.

Matters Arising

There were no matters arising.

Chairperson's Address

The Chairperson reflected on the current year which at the beginning of the year the cloud of covid had started to lift and there was a new type of 'normal'. It wasn't long before the invasion of Ukraine happened and the cost of living increased with rising energy costs impacting. Our branches were wondering when they would get back to local fundraising. National Office was dominated by staff turn over and recruitment. Every single aspect of what we do had major staff turnover. There was huge effort to recruit replacements. Resourcing will stabilize now so that staff can focus on their day job of providing services and activities to PwMS. He said in our pre budget submission we were asking for €600K for the Care Centre and €900K to provide physio support nationwide when we are meeting TD's in the Houses of the Oireachtas. The Chairman thanked the members for their continuing support on behalf of the Board. He thanked CE and the Senior Management Team for the support that they have provided to the Board in the last 12 months.



The Chief Executive's Address

The Chairperson called on the Chief Executive, Ava Battles, to give an overview of 2021 and to provide highlights from 2021.

Ms Battles brought the members through some of the work that was achieved in 2021. She said it couldn't have been done without the support of the Board, branch members and PwMS. She said we will look again at the Strategic Plan in 2023 to see where we are at. We had a very busy year delivering services. We provided a lot of our services on line. One to one support we continued to provide through our community work service. We also provided more physio, yoga through our branch network and it was received well by PwMS. We will move to face to face physio in 2022. In relation to the information line, we increased hours because of concerns around covid. It runs now from 9.30 a.m. to 5.00 p.m. The Care Centre was open throughout 2021. We had less number of people because we had reduced the number of bed nights. She thanked the staff in the Care Centre and commended them for the great HIQA reports they have been getting. Branches were heavily impacted upon in 2021 with church gate collections. A lot of branches have started to get out and collect again. We have kept contact with people in the community by telephone and zoom. We have used social media to fundraise and communicate with members via the website. Webinars we held throughout 2021 are available on the website to download. With podcasts we covered lots of different topics, journey of MS diagnosis, interviews with different experts.

We held Readathon, virtual balloon race, and the crunch challenge which was a fantastic initiative in 2020. The abseil wasn't as successful in 2021. Some fundraising projects work, some don't but we have to adapt to the environment that is around us. She thanked the MS community for getting involved in events, she thanked the HSE for our partnership with HSE for community workers. We are trying to deliver our physio programme with the HSE which is so important and it will form part of our pre-budget submission.

The Chairperson called on Mr Martin Power, Chairperson of the Finance, Audit and Risk Committee to give a financial overview of the financial statements for the year ended 31 December 2021.

The Auditor's Report on the Financial Statements of the Company for the year ended 31 December 2021 was taken as read. The Directors' Report for the same year was taken as read.

The Directors' Report and Financial Statements for the year ended 31 December 2021 were submitted to the meeting and considered.

In his presentation to members, Mr Power noted that our Auditors, Deloitte, had issued us with a clean audit report on the financial statements. Profit after expenditure came to €450K. Our income has increased from €5.7M to €6.1M. The increase in income arose due to an increase in government grants and fundraising. Funds carried forward of €10M is in cash and property. Of the €6.1M in income, 53% of it is coming from the Government. We provide substantial services on behalf of the Government. Fundraising is key to supporting the services that we provide and 13% is from the CE scheme. On the expenses side, 89% is spent on community services. There is a fundraising cost and some of the events have costs. All branch income is down substantially from pre-covid times. People don't carry cash and funding has gone on line. Branch expenses spent locally on MS services – 81%.

The Chairperson thanked Mr Power who had taken over from Martin Nolan as Chairperson of the Finance Audit Risk and Strategy Committee. The Chairperson informed the members that Jackie Baker (Financial Controller) had resigned and he welcomed Declan Murphy who had taken over recently from Jackie Baker. The Board will be hearing from Declan Murphy on financial updates. The Chairperson stated that he wanted an improvement next year on getting the audited accounts in early from some branches.

The Chairperson congratulated Anne Restan who had been elected to the Board from Counsel. He thanked the members for sending in their proxy votes.



<u>Ordinary Resolutions</u> – these resolutions required over 50% of the votes cast to be passed After careful consideration the following resolutions were **RESOLVED** by the Members on a poll:

THAT the Directors' Report and Financial Statements for the year ended 31 December 2021, as submitted to this meeting, be and are hereby received and adopted.

THAT Robin Bradley had received a majority of the votes cast and that he was hereby re-elected as a Director to the Board

THAT Noelle Burke had received a majority of the votes cast and that she was hereby re-elected as a Director to the Board

THAT Dr. Rebecca Maguire had received a majority of the votes cast and that she was hereby elected as a Director to the Board.

THAT the Directors are hereby authorised to fix the remuneration of the Auditors.

The Chairperson informed the members that we go out to tender every 5 years for our Auditors. He said we haven't been able to do this because of resource issues. We will retain Deloittes for next year. Before 2023 AGM we will go out to the market for audit services.

CONCLUSION:

The Chairperson congratulated Robin, Noelle and Rebecca on being elected to the Board. He said thanks to Noelle Burke who proposed that we start each meeting with an anonymised case study to see what is going on for PwMS. He noted that Dr Maguire had suggested some research topics for exploring different aspects of living with MS in her first term on the Board.

Mr Sheehy asked in relation to Primary Medical certs, had the panel been reinstituted. CE reported that as far as she knew it had not been reinstituted but that she would refer to Advocacy Officer, Alison Cotter to check what the current position is.

Ms Violet McCann spoke about the great MS physiotherapy programme, MoveSmart. She reported that at the recent Council meeting branches were being asked to contribute €1,000 each to MoveSmart programme. She confirmed that the Meath Branch would like to contribute €1,000 to support the MoveSmart programme.

Mr Clarke reported that his wife, aged 66, no longer gets respite. HSE provide the service up to age 65. She is moved on to the older person services. Mr Clarke was informed that she could continue coming to the Care Centre. He was referred to the regional community workers. CE said that we can certainly take it on as an advocacy issue.

The Chairperson thanked the members for attending. He said we will be reviewing our strategic plan in January 2023 and that we would like to engage with branches around that process and we want to ensure their contribution is listened to and be part of the plan going forward. The Chairperson thanked Alice, the Board members, Jason Power for getting technology going and Ann McNamara and her team for hosting us with a celebratory meal to Martin Nolan.

The business of the meeting was then declared to have been concluded and the meeting terminated at approximately 5.20 p.m.

CHAIRPERSON	COMPANY SECRETARY
DATE	

Financial Statements for the year ended 31st December 2022

Unfortunately due to staff turnover and sick leave, we are not in a position to have our audited financial statements for the year ended 31st December 2022 ready for the AGM pack. We will present a DRAFT set of financial statements at the AGM on September 16th 2023 and a timetable of when we will reconvene the AGM and present the financial statements to our membership.

Directors Report for the financial year ended 31 December 2022

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Directors and Other Information

BOARD OF DIRECTORS	Maurice O'Connor (Chairperson) Jacinta Kelly (Deputy Chairperson) Robin Bradley Noelle Burke Tom Cronin Carol Ellis-Barton Eugene Kearney Dr Rebecca Maguire Rory Mulcahy (Company Secretary) Aveen Murray Martin Power Anne Restan Mary Sheahan Lonergan Leslie Warren
CHIEF EXECUTIVE	Ava Battles
HONORARY LIFE MEMBERS	William Lonergan Allen O'Connor
Finance, audit and risk committee	Martin Power (Chairperson) Robin Bradley Tom Cronin Jacinta Kelly Rory Mulcahy Maurice O'Connor Mr Declan Murphy (In Attendance) (App 15-08-2022) Jackie Baker (In Attendance) (Resig26-08-2022) Ava Battles (In Attendance)

DIRECTORS AND OTHER INFORMATION (CONTINUED)

	REGISTERED OFFICE	80 Northumberland Road Dublin 4, D04 T856
	CHARITY NUMBER	CHY 5365
	CHARITY REGULATORY AUTHORITY NUMBER	20007867
	COMPANY NUMBER	296573
	DATE OF INCORPORATION	19th November 1998
	YEAR MS IRELAND WAS FOUNDED	1961
	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 Anglesea Street Dublin 2

DIRECTORS' REPORT

The Directors present their annual report and the draft consolidated financial statements for the financial year ended 31 December 2022.

In this report the Directors of The Multiple Sclerosis Society of Ireland ("MS Ireland") present its activities, governance, and achievements for the financial year ended 31 December 2022. Draft financial statements will be presented at the AGM with a timetable of when we will reconvene the AGM and present the financial statements to our membership.

THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND MISSION, VISION, OBJECTIVES AND VALUES

MS Ireland's mission is "to enable and empower those affected by MS to live the life of their choice to their fullest potential".

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

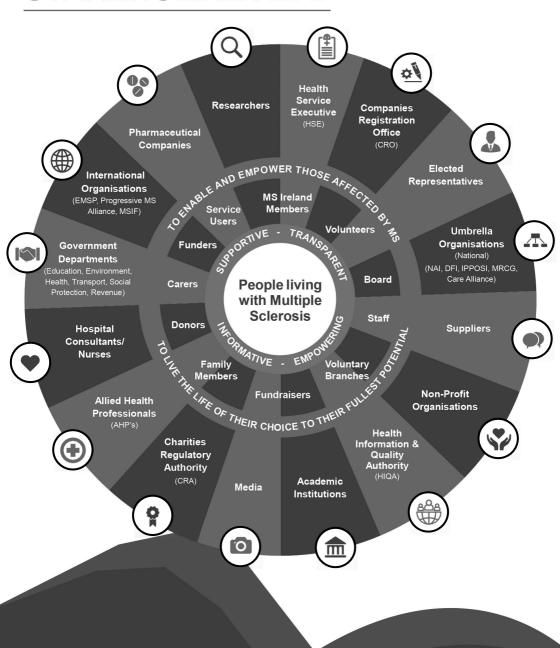
Its principal objectives are:

- To enable and empower people with multiple sclerosis (hereinafter referred to as "PwMS") to live the life of their choice to their fullest potential
- To provide support for the families and carers of PwMS
- To co-operate with the medical, scientific, social and caring professions to promote scientific research into the
 causes of, cure for and management of MS, and the alleviation of medical and social symptoms
- To exchange and disseminate information relating to MS and
- To provide an identifiable focal point by developing an efficient, effective and caring organisation to serve the needs of PwMS.

Values

MS Ireland is committed to being supportive, transparent, informative and empowering. These core values are the fundamental beliefs of our organization.

STAKEHOLDER MAP





DIRECTORS' REPORT (CONTINUED)

STRUCTURE, GOVERNANCE AND MANAGEMENT

The Board

MS Ireland is directed by a voluntary Board which comprises of people with varied backgrounds, some with MS. Its function is to provide leadership, develop strategy, formulate effective policies and oversee their implementation, monitoring the delivery of services, ensure good governance and financial control.

The Board is provided with regular financial and operational information. Detailed budgets are prepared in line with the current Strategic Plan and are reviewed by the Finance, Audit, Risk and Strategy Committee and further reviewed and approved by the Board. Actual results and outcomes are compared against the budget to ensure alignment with the Plan and to maintain tight budgetary control and value for money.

Governance of MS Ireland is conducted in accordance with Charity Regulator Governance Code 2018, its Constitution, and its Bye Laws. These are available on our website www.ms-society.ie

The Board continues to be committed to a high level of transparency and disclosure in relation to staff remuneration. As in previous years, Note 10 to the financial statements provides details on Staff Remuneration in line with the Statement of Recommended Practice (SORP) as developed by the Financial Reporting Council.

The Branches, Council and Committees

MS Ireland's voluntary Branches are primarily run by people with MS and their families. They are governed by an elected committee to organise the activities of the Branch including all the services and fundraising activities. Voluntary Branches work very closely with the regional offices. MS Ireland has a network of 29 voluntary Branches.

The Council is the consultative body that represents the views of the Branches around the country. The Council provides a direct link between members, Branches and the Board. The structure of the Council has changed in parallel with the introduction of the Regional Integrated Meetings (Meetings where regional staff members, a Senior Management team representative and local Branch representatives come together to discuss service delivery in the region and National Office updates).

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

Governance

We want to reassure you that MS Ireland is transparent, ethical and has on-going and effective audit processes in place. We value every donation we receive and are always mindful that it is our duty to use the money to achieve the biggest possible impact for people living with MS.

DIRECTORS' REPORT (CONTINUED)

Here are some facts for you about our governance:

- The Board hold meetings 6 times a year with the Chief Executive in attendance at those meetings. The Chief Executive reports to the Board but is not a member of the Board. MS Ireland's Constitution and Code of Conduct details the process on the selection and rotation of Board members, the roles and duties of the Chairperson and Chief Executive. We require formal disclosure of any potential conflict of interest or loyalty of Directors at meetings. We have a committed and strong Board, currently made up of 62% people living with MS or family members. They give their time for free and receive no payments for their work. However, Board members are entitled to claim for travel and subsistence expenses in attending meetings. In 2022 Board members expenses were €623 (2021: €Nil). No emoluments are paid to Board members. The list of Board members and biographies can be found on our website.
- MS Ireland is a registered charity and is in compliance with the requirements of Charities Governance Code and is listed on the Register of the Charities Regulatory Authority.
- Our annual financial statements are audited by Deloitte Ireland LLP. Accounts for the last number of years can be
 obtained from our website.
- MS Ireland's accounts adhere to the SORP (Statement of Recommended Practice, Accounting and Reporting by Charities) accounting standard. Draft accounts for the year ended December 31st 2022 will be available at the AGM on September 16th, 2023.
- We adhere to the Guiding Principles for Fundraising. The principles set the standard for best practice in fundraising in Ireland.

Management

The Chief Executive, to whom day to day management of the charity is delegated, leads a team of 66 employees working throughout the National Office, the MS Care Centre and 10 regional offices, plus an additional 49 Community Employment workers employed with the support of the Department of Social Protection ("DSP").

The National Office is the base for the overall administrative and support services of MS Ireland, including Information and Advocacy, Finance, Fundraising, IT and Communications. Regional offices provide services to PwMS, people affected by MS ("PaMS") and support to the network of Branches throughout the country. The Care Centre provides respite services. Service development and operations currently sit within the remit of the Chief Executive, the Services Manager and the National Services Development Manager. In 2022 we had a roster system in operation in MS Ireland National Office to ensure a presence in the office daily. The Care Centre was open with ten beds available and our regional offices provided services both virtually and in person.

REVIEW OF ACTIVITIES

Activities for 2022 are reviewed under the headings of MS Ireland's Strategic Plan 2020-2024:

In 2022, 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 goals and 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

DIRECTORS' REPORT (CONTINUED)

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

Goal: Service Delivery

Objective 1: Services Development & New Service Models

During 2022 the Company underwent the third year of its Strategic Plan. It continued to review and develop our suite of services provided by professionals and volunteers. The provision of online services continued. 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 2022, MS Ireland ensured the provision of practical and emotional support through the casework service. Ten Service Level Arrangements (SLA) exist with the HSE in the North West, North East, Dublin (NA, ECA, SWA), South East, Southern, Mid-West, West and Midlands areas. The SLA's state that casework and completion of the NASS database are expected from the Community Worker service. In 2022, 2,316 individuals received a 1:1 casework service nationally. The top presenting issues for PWMS included emotional support, financial welfare, accommodation, aids and appliances, home support, access to healthcare and respite. 198 new referrals were accepted into the casework service in 2022, 48 of those were newly diagnosed in 2022. All reviews were completed on the National Ability Supports System (NASS) database.

The Casework practice group engaged with Quality Matters and completed a significant project regarding casework evaluation and outcomes in December 2022. The completion of this project was required first, to progress Salesforce changes. The Casework Salesforce Project is scheduled for 2023.

Community Workers facilitated the delivery of community physiotherapy and other health promoting physical activity programmes (see below Exercise & Physical Activity), health promotion programmes, coping strategies and well-being services (see Wellness on page 20) to PwMS and their families.

Information Services

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 – 0818 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. to respond to the increased need as a result of COVID 19. 1,655 people contacted the Information Line in 2022, 903 of these contacts were by telephone, 490 were by email, and 262 were made by social media. The information line also provides information to Regional Staff, and to other services and/or agencies as appropriate.

Exercise and Physical Activity Programmes

MS Ireland run several different programmes as part of our exercise and physiotherapy services. Our focus is on health promoting physical activity to enable people to live well at home, reduce disability and symptom severity and improve quality of life. We have a team of directly employed physiotherapists and also engage with independent physio, yoga and fitness contractors around the country to deliver this service.

Evidence gathered in 2022 show that our programmes have a range of benefits including improvements in symptoms and quality of life, reductions in fatigue and mental health issues, reductions in falls and improved confidence to be physically active, and reduced healthcare utilisation.

We had 2,027 participants in 233 programmes and provided 682 individual sessions in our physical activity services in 2022.

DIRECTORS' REPORT (CONTINUED)

Getting the Balance Right (GTBR)

GTBR physio, yoga and fitness instructor-led programmes ran across all 10 of our regions and are reliant on fundraised income and provided by contractors. The service in the West is provided by our directly employed senior physiotherapist and a team of physiotherapy assistants.

There were 69 yoga programmes with 630 participants and 122 physio programmes with 1,078 participants run in 2022. There were 6 fitness programmes with 54 participants attending.

Active Neuro

The Active Neuro programme ran for part of the year (due to challenges with staffing) as a new service in the West, and for 5 weeks in the Midwest on receipt of funding from the HSE in November. In the West we ran two blocks of 3 online Active Neuro classes with a total of 154 sessions.

In the Midwest we ran one short block of programmes for 5 weeks for 2 programmes. Restarting in the Midwest and expanding in the West will be the focus of 2023

Move Smart MS

Twenty-eight Move Smart MS programmes were delivered across three blocks in 2022. 218 participants took part, and the Move Smart MS programme provided 245 1.5 hour long sessions across its programmes. This resulted in 1,808 hours of physiotherapy received.

The unique feature of Move Smart MS is that programmes are tailored to specific symptoms using an exercise and education combination. We ran programmes for High Level Fitness, Dizziness and Balance, Better Balance for Falls prevention, Step it up to the Exercise Guideline, Newly diagnosed, Strength and Balance, Pilates and Seated Fitness.

Physio West

In Galway, Mayo and Roscommon we provided 30 different programmes, to 261 participants taking part in 2,296 sessions. We ran three blocks of 7 online Getting the Balance Right classes with a total of 63 individuals and a total of 1920 sessions. Our directly employed physiotherapist is assisted by physiotherapy assistants optimizing the physios time and the intensity of programmes.

We provided 146 individual sessions to 43 individuals. Sessions were provided at home or at Cheshire House Galway or with an innovative new approach at a local gym to enable the person to integrate into their community resources.

What is the impact of our programmes?

MS Ireland's Health Promoting Physical Activity programmes result in improvements in symptoms such as strength, fitness, balance and walking and a reduction in MS impact, fatigue, depression and anxiety. They also provide a forum for peer learning, social support and a sense of community for those living with neurological conditions. The impacts of our programmes are wide ranging and include:

- Significant reductions (44%) in healthcare utilisation, both in terms of primary and tertiary care services following the programme.
- A 30% reduction in the number of falls and a 49% reduction in the number of participants experiencing falls.
- Clinically and statistically significant improvements in strength (29%), balance (44% right leg, 67.2% left leg) and walking endurance (7.5%) measured objectively.
- Clinically and statistically significant improvements for patient reported questionnaires of MS Impact (32.5%), fatigue (21%), perceived walking ability (26.1%) and mental health (19%).
- 77% of participants reported their confidence in their ability to exercise was significantly or very much better after the programmes

May's story; May had an MS relapse and deterioration in her walking which was managed by her GP with oral steroids, she subsequently had 6 sessions of physiotherapy from Primary Care but was still not steady enough to walk without an aid and return to working as a nurse in an acute hospital. She took part in two blocks of 10 sessions of Active Neuro exercise and education sessions and increased her strength sufficiently for her to return to work, Active Neuro Participant

DIRECTORS' REPORT (CONTINUED)

"Life changing. I'm now able to use a single stick for walking out of the house instead of a rollator. I'm now able to go shopping and walk in the street without getting nauseous and a bad headache. It has given me very positive improvements and definitely provided information, strategies and exercises to continue improving." Move Smart MS Participant

"I find participating in the Getting the Balance right exercise program very beneficial. I can move a lot easier and my transfers are better and more reliable. This helps with the basic tasks like picking things off the floor and transferring to bed and the toilet. I'm less fatigued - exercising gives me energy." Getting the Balance Right Participant

Are people with MS satisfied with their experience?

Participants report excellent experiences and high levels of satisfaction with our programmes.

Participants were asked how satisfied they were with their programmes on a scale of 1-10, the average score was 9.4 for physio and 9.6 for yoga indicating high levels of satisfaction.

"Going to the exercise class means that you are disciplined in doing the exercises and that you are doing them properly. The social part is very important to meet others and to just form a network and to be able to talk with others that understand"

A satisfaction survey was also used for Move Smart MS which uses an Education and Exercise approach – 98% of participants agreed with the statement "The education and chat was helpful for me to manage my MS symptoms better." And 100% of respondents agreed that "The Move Smart MS programme had added benefits to a general exercise class."

The MS Care Centre

The MS Care Centre is a 12 bed respite facility. In 2022, the capacity was increased to 10 residents, with lengths of stay options of 5/7/12 nights. In 2022 228 individuals availed of respite in the Care Centre, with high dependency beds with the greatest demand. The Care Centre continued to operate under HSE advice in line with Covid Management recommendations.

The MS Care Centre is registered by the Health Information Quality Authority ("HIQA"). The Care Centre is monitored every three years by HIQA and was approved for re-registration in October 2020. The Clinical Nurse Manager and the Quality Manager in the Care Centre ensure that the standards and regulations set by HIQA are maintained. The most recent HIQA report has been published and is available https://www.hiqa.ie/areas-we-work/find-a-centre/multiple-sclerosis-society-ireland-ms-care-centre

Wellness Programmes

MS Ireland offers programmes that aim to improve the overall well-being of people with MS. These programmes are facilitated by a combination of MS Ireland staff, external contractors, volunteers and partner organisations (such as the HSE and Education and Training Boards (ETB)). They aim to improve overall well-being by providing up to date information, encouraging peer engagement and support and providing opportunities to improve symptom management.

In 2022, the Community Worker team facilitated FACETS (Fatigue: Applying Cognitive behavioural and Energy effectiveness Techniques to lifestyle). It is a 6 week evidence-based group fatigue management programme run online or in-person specifically for PwMS. The service is offered online nationally 3 times per year and also in regions where staff capacity allows. Each programme is facilitated by 2 MS Ireland Regional Community Workers.

The decision was taken in August 2022 to pause the FACETS salesforce project. This was due to the additional training of staff and a lack of clarity as to whether the upgrades to salesforce would be necessary. The work resumed (and was completed) in February 2023.

Branches

In 2022 MS Ireland staff continue to support Branches to utilise various digital platforms and facilitate hybrid meetings due to the return of in person meetings and activities after the pandemic. Branch activities include support groups, social activities, therapies and in some instances, financial assistance. Capacity building opportunities and training was also facilitated for all Branches. The provision of branch level supports is made possible by voluntary local fundraising.

DIRECTORS' REPORT (CONTINUED)

Community Employment Schemes

The provision of services and supports throughout the country relies on the quality contribution of our Community Employment Scheme Participants. They contribute hugely 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, 12 CE participants assisting with the exercise training plans for PwMS in the Western Region; 16 visiting PwMS in their homes, in the North West Region. Three offices, the North East, the South East and the Mid-West have a number of CE participants that assist with data collection for the Health Research Board, which represents the needs of PwMS.

Social Media

In MS Ireland, we continued to develop our social media throughout 2022. 22,070 people followed our Facebook page, 9,454 people followed Twitter, 5,051 followed us on Instagram and 1,517 on LinkedIn. The Facebook page reach was 1.7m (+22.4% from 2021) and page visits 42,486 (+146%). Instagram reach was 758,283 (+53%) and profile visits were 10,874 (+11%).

We used social media to support our various online fundraisers in 2022. The Facebook/Instagram paid reach was 1.6m (+44%) and paid impressions were 9.6m (+48%).

MS Ireland Website

The MS Ireland website played a crucial role in distributing information and the latest updates during the COVID-19 pandemic with our website seeing an increase in traffic in 2020/2021. In 2022 the website had a total of 231,385 unique page views (-2% 2021). The small drop in total visits is reflected in the Covid pages visits reducing by -88% compared to 2021. The biggest page visit increases were Work with Us +69%, Research +64% and News +46%. There was a 34% increase in downloads from the website. The average page visit duration was 2.12 minutes (-3% from 2021) with average 2.7 interactions (-7%).

The most viewed pages were 1. About MS (34,154 unique page views) 2. Index (30,124) 3. MS and MS Blog (18,634) 4. News (16,672) 5. What we Do (16,617) 7. Research (9,886) 8. Donate (5,656) 9. Checkout (5,380) and 10. Get Involved (5,173) 11. Shop (5,105) 12. Our Services (4,967 13. Events (4,911) 14. Work Us (3,204) and 15. Who Are We (3,043).

The most popular means of accessing our website was from search engines with 54% (52% in 2021) of people accessing our website from this source. Direct entry accounted for 29% (25%) followed by Social Networks at 11% (17%) and finally other websites was 3% (2%) and unknown 3% (4%).

The smartphone is the most popular device used to access our website at 57% (59% 2021), followed by Desktop at 36% (33%) and then Tablets at 3% (4%). Ireland accounted for 77% of our website visitors in 2022.

We have a team of volunteer bloggers who write about their own personal experiences of living with MS. We share these blogs on our website and promote them through social media to signpost our members to this resource. This continues to be a great resource to drive traffic to our website.

Webinars

In continuation of our webinar series, throughout 2022, MS Ireland arranged a number of online information webinars which allowed people in the MS community to access virtually expert led information sessions. We recorded the majority of these sessions and made them available on our website on our dedicated 'Online Video Catalogue section'. Providing the information in this format allows our community to access these videos on demand at a time that suits them.

DIRECTORS' REPORT (CONTINUED)

MS Explored - The Podcast

MS Ireland conducted a survey relating to the MS Explored podcasts identifying relevant topics for future episodes. This data was used to define topics for the next season of this project. We expect the next season of this to begin in 2023.

The MS Circle of Support video series

MS Ireland produced a 5-part videos series which aimed to highlight some of the key roles that exist to support people living with MS. This included a neurologist, nurse, scientist, physiotherapist and an MS Ireland community worker.

Societal Cost of MS Report

MS Ireland in collaboration with Novartis produced an updated publication of The Societal Cost of MS. A cross-sectional, online survey was opened in 2021 which invited people living with MS to take part. This provided us with self-reported data relating to the direct, indirect and intangible costs associated with living with multiple sclerosis in Ireland as well as the cost associated with relapse. The report from this research was published and launched in 2022.

The data from this survey was also compared to data from a previous survey which was conducted in 2015. This helped us to determine what had changed and what had remained the same in the interim.

Young persons' survey

MS Ireland conducted a survey of young people living with MS in Ireland to better understand their experiences with MS Ireland. This was conducted with a view to creating tailored information and supports for young people living with MS so we are best placed to meet the unique needs they may have.

Objective 2: Research

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

Sharing opportunities with our community to engage in and learn more about MS research is an important part of the work that MS Ireland do and throughout 2022, we shared numerous opportunities with our community members. We shared research findings though our eNews, website and social media platforms. MS Ireland collaborated with Multiple Sclerosis International Federation (MSIF) on updates to the Atlas of MS and the European Multiple Sclerosis Platform (EMSP).

MS Ireland have continued to develop the Research section on our website. This involved having up to date Researchers Profiles and call outs on our website and ensuring this section was easy to navigate for people with MS and researchers alike.

MS Ireland has remained active within the research space throughout 2022 through collaboration with the All Ireland MS Research Network (AIMSRN) as well as through Maynooth University and other research organisations. Since late 2022, MS Ireland has been facilitating a collaborative research project between MS Ireland, AIMS RN and Future Neuro which will hopefully result in a catalogue of plain english explanations from researchers which can be accessed by the MS Community. We have also engaged with other research organisations such as the Ulysses Neuroscience through attendance of their Rare Disease Day events.

In collaboration with Maynooth University, MS Ireland is in the process of planning a public lecture around the areas of MS, Neuropsychology, Mental Health and Wellness and have been liaising with various speakers in order to achieve this on the 22nd of May 2023.

We also held an internal research session on the topic of MS and Anxiety attended by our regional teams.

DIRECTORS' REPORT (CONTINUED)

Objective 3: Advocacy

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

Pre-Budget 2023:

During this period, the Advocacy and Research Officer prepared and launched MS Ireland's 2023 Pre-Budget submission and held several meetings with the various party spokespeople on Health including Róisín Shortall TD, Duncan Smith TD and Colm Burke TD. The Fine Gael members of the Health Committee which include Bernard Durkan TD, Senator Sean Kyne and Senator Martin Conway also attended the meeting with Deputy Colm Burke.

At a grassroots level, MS Ireland also invited members of our community to have their voice heard by sending a template letter to their local member, which was included in MS News and also posted online.

Our spokespeople also took part by sending letters to their local member as well as individuals who would have the lived experience of the services we are looking for additional funding for to give the campaign a personal perspective.

MS Ireland also liaised with other organisations particularly with regards to our physiotherapy programme ask for support, which we received from the Irish Heart Foundation, Early Onset Parkinson's Disease Ireland and the Parkinson's Association of Ireland.

MS Ireland also held a Pre-Budget Briefing and Panel Discussion in the AV Room of Leinster House which consisted of a panel discussion with Mags Rogers from the Neurological Alliance of Ireland (NAI) with regards to the MS nurses ask, Dr Susan Coote with regards to the physiotherapy ask and a representative from the Care Centre.

Representatives from Novartis were also in attendance as this acted as a launch for The Societal Cost of MS document outside the gates of Leinster House. This briefing was attended by over 20 Oireachtas members who continually engaged with us regarding our asks after the day. Throughout the Pre-Budget Submission campaign, over 1,000 emails were sent to members of the Oireachtas for their support of our asks.

Dying with Dignity:

As part of the media cycle around Dying with Dignity (DWD), MS Ireland prepared a presentation for our regional teams which clearly stated the law as it stands today as well as analysed the upcoming piece of legislation. We also reassessed and tweaked our statement regarding the topic and are continuing to proactively monitor the topic as it progresses.

Micro-Advocacy:

The Information Advocacy and Research (IAR) working group was also inaugurated during this period as well as engaging in micro-advocacy activities which may be brought to attention by members of our regional team such as escalating a housing issue to Senator Victor Boyhan who gave us a referral to the Director of Housing at Dublin City Council as well as various other small advocacy issues. Issues regarding the Primary Medical Certificate were also escalated to the Department of Finance and issues regarding cessation of services for over 65s which were escalated to the DFI.

National Care Centre Visit:

MS Ireland also welcomed Labour Party Leader, Ivana Bacik to visit the National MS Care Centre. Deputy Bacik was given a tour of the Care Centre by Clinical Nurse Manager, Janet Lee and was given the opportunity to meet a number of our residents. Deputy Bacik also engaged with our 'Pop-Up MS House' set up by Information Officer Aoife Kirwan, which demonstrates the difficulties in everyday life for some people living with MS.

DIRECTORS' REPORT (CONTINUED)

Collaborative Advocacy - Organisations

MS Ireland believe in the power of working in partnership with other organisations. By doing this, we use our collective voice to be heard more clearly. In 2022, MS Ireland continued working with the Neurological Alliance of Ireland (NAI) on a number of issues including a campaign to help highlight the severe shortages of specialist neurology nurses, including MS nurses, across Ireland. This campaign included virtual meetings from various locations, most impacted by these shortages. At each of these events, a person living with MS had the opportunity to speak and share their experience. The Advocacy and Research Officer was also appointed the the Board of the Neurological Alliance of Ireland in December 2022

World MS Day

On May 30th, MS Ireland joined people living with MS and other MS organisations around the world to mark World MS Day. The theme for World MS Day 2020-2022 was 'Connections'. The MS Connections campaign is all about building community connections, self-connection and connections to quality care.

The campaign hashtag was #MSConnections. MS Connections challenges social barriers that leave people affected by MS feeling lonely and socially isolated. It was an opportunity to advocate for better services, celebrate support networks and champion self-care. MS Ireland held an art exhibition in collaboration with Novartis to mark World MS Day 2022. The Art of MS – Symptoms Under the Spotlight' featured 12 original works of art created by people living with MS in Ireland. The aim of the exhibition was to raise awareness of MS and the wide-ranging symptoms associated with the condition. Following a nationwide call for artists living with MS, 12 artworks created by people living with Multiple Sclerosis were selected to be part of this exhibition which was held in Trinity Biomedical Sciences Institute. The exhibition featured paintings, digital illustrations, freestanding sculptures and creative video content all of which aimed to help the viewer better understand what it is like to live with MS day to day.

AGM

The 2022 AGM was held online via zoom on 17th September 2022 at 4.00 p.m. There were 33 members in attendance.

National Conference

In November 2022 MS Ireland hosted a virtual National Conference. This event brought a number of expert speakers together to provide information to the MS community who were able to connect from home. The speakers covered a range of topics including 'Grey and White Matter in MS'; 'Pregnancy and MS', 'MS and Brain Fog' as well as 'Bladder, bowel and sexual dysfunction in MS'. 230 individuals registered for this event. The sessions were recorded and added to our YouTube channel and website.

Goal: Sustainable Finances

Objective 4: Grow Sustainable Revenue Base

After over 25 years, MS Ireland held its final foreign trek to walk the Camino in 2022. While these treks have been an incredible source of income over the years, we recognize that the world has changed since COVID, and we are now looking to invest our time in more sustainable revenue streams, such as one-off Irish challenge events and building on our corporate partnerships.

Online fundraising and challenges continue to grow and be a valuable source of income for the Society. This fundraising space is continually evolving, and we have been proactive in ensuring our staff have up-to-date training. We held three successful Facebook challenges, and hundreds of our community members set up birthday fundraisers on Facebook for us.

DIRECTORS' REPORT (CONTINUED)

Objective 5: Develop partnerships

In order to build capacity around the vast grant and foundation space, we have collaborated with grant specialists 'Yellow Harbour' to build on our successes in this area. We are delighted to have the continued support of Perrigo, the Community Foundation, Bank of Ireland, and the Hospital Saturday Fund, and we were thrilled to be announced as partners of UCS.

At MS Ireland, we have a special community, and we strive to develop strong relationships and partnerships with them. Once again, our community rallied around us, helping to organize some wonderful fundraisers and events, including running marathons, bungee jumps, ladies' lunches, office parties, Cluedo nights, and golf events.

Goal: Innovation

Objective 6: Develop Digital Operations and Governance

Overall Aim: Develop Digital Operations and Governance structures and strategies to improve operational efficiency and effectiveness. Ensure the Organisation has a robust ICT (Information & Communication Technology) strategy roadmap and execution plan, including the financial, tactical and strategic benefits of proposed major ICT initiatives.

- We planned and budgeted the rollout of salesforce across the organization
- The project to develop the system to enable Physio contractors to record attendance and complete the required
 documentation of the treatment episode in Salesforce was completed by the end of 2022. All treatment records
 and attendance statistics are now held in Salesforce optimising clinical governance and reporting.
- Fatigue: Applying Cognitive Behavioural and Energy Effectiveness Techniques to Lifestyle (FACETS)
 The decision was taken in August 2022 to pause the FACETS salesforce project. This was due to the additional training of staff and a lack of clarity as to whether the upgrades to salesforce would be necessary. The work resumed and targeted for completion in February 2023.
- Casework
 - The Casework practice group engaged with Quality Matters and completed a significant project regarding casework evaluation and outcomes in December 2022. The completion of this project was required first, to progress Salesforce changes. The Casework Salesforce implementation project will continue into 2023.
- Recruitment: After several rounds of advertising for a digital specialist we were unable to recruit a suitably qualified person for the role. Recruitment for this role is now on hold.
- Website: Much work to enhance website user experience and navigation of page content was completed and more
 work identified. We continue to make improvements to the site.
- Search Engine Optimisation (SEO) & Google ad words: We engaged a digital agency on retainer to manage our google ad word accounts and a series of campaigns. The first two campaigns launched in early July.

DIRECTORS' REPORT (CONTINUED)

Goal: People & Culture

Objective 7: Develop and Invest in Our People

Recruitment of staff was robust and it presented challenges during 2022. This was a national issue. We acquired Employee Self service module for managing annual leave and absence. Dignity at work training was provided for employees and volunteers. We continued to operate the remote working pattern while waiting on publication of the Remote Working Bill and the Work Life Balance bill. Under the pay restoration for Section 39 organisations, salaries for the majority of MS Ireland employees were increased in 2022.

Objective 8 Grow Branch and Community Volunteer Base

Branches continued to meet through zoom and many held their AGM's on zoom. Some fundraising was done virtually and physically. Compliance training was provided to branches.

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.

DIRECTORS' REPORT (CONTINUED)

RISKS ASSESSMENT AND MANAGEMENT

MS Ireland Principal Risks and Uncertainties

Risk description	Management
Strategy risk MS Ireland's strategic objectives and activities are not properly or sufficiently focused in order for the charity to deliver its mission.	 Our 3-year Strategic Plan outlines the key objectives for the successful delivery of our strategy, with ongoing monitoring and review by the Board and Senior management team. We prepare detailed budgets, operational plans and target outcomes as part of our annual planning cycle. The Board scrutinises and approves any business case and funding requirements for all significant investments. We ensure regular monitoring and reforecasting of financial performance throughout the year.
Funding and fundraising income risk External factors have the potential to significantly reduce income or increase costs, impacting on our ability to deliver services and supports for people with MS.	 MS Ireland provides vital respite, community case work, physio, information symptom management programmes, peer support information and advocacy services to people with MS. We continue to seek further annual investment and section 39 funding to: operate our Care Centre respite centre 52 weeks of the year (currently 40) and allow additional people with MS the chance to avail of a place. provide a sustainable, national physiotherapy service provided by a team of specialist physiotherapists directly employed by MS Ireland, delivered at a regional level using a blend of 'online' and 'in-person' programmes. Our active fundraising team manage a pipeline of fundraising campaigns and events throughout the year and we accelerated development of online platforms to support our fundraising activities. Our senior management team, Finance Audit Risk & Strategy Committee and the Board monitor at regular intervals financial performance throughout the year.
Regulatory environment Changes in government policy, regulatory requirements and/ or charity sector guidance that could negatively impact on MS Ireland's strategy and activities.	 We monitor public policy and the regulatory environment to ensure potential risks can be proactively managed. We work to develop multi-level relationships across government and proactive advocacy campaigns and events to ensure our views are shared. We participate and have representation at key events and forums to help shape the MS services agenda.

DIRECTORS' REPORT (CONTINUED)

Risk description	Management
Technology and cyber risk Operations impacted due to cyber-attack or a breach of MS Irelands' IT infrastructure or services results in loss of data or denial of service.	 We work closely with our IT partners on security, firewall, proxy and antivirus protection measures, with associated vulnerability monitoring and penetration testing. We review & update the IT back-up & recovery plan. We have robust business continuity plans in place and we carry out disaster recovery and penetration testing on a systematic basis.
GDPR risk	We work continuously to ensure full compliance with the General Data Protection Regulations and the Data Protection Act 2014. We have data protection and information security policies in place across the organisation. We work closely with our IT partners to review and continuously improve our data management systems and workforce education and training programmes.
Coronavirus (COVID-19) ongoing risk Ongoing impact of the pandemic on our people and operations.	 We coordinated closely with HSE to ensure our operations and service delivery aligned with government guidance. We ensured regular internal and external communication and supports on Covid-safe measures, hybrid working and wellbeing. Our Health & Safety and business continuity plans were mobilised to ensure we continued to operate safely.
People risk Attracting, developing and retaining talented staff in a competitive employment market. Attracting developing, retaining and training volunteers.	We continuously monitor trends and benchmark compensation and benefits within the charity sector. We continue to strengthen our talent management, development and succession planning programmes. We work to ensure a vibrant and supportive working environment for our staff team.
Reputation risk Failure to appropriately manage our reputation and media attention could impact supporters' and donors' views of the charity and could ultimately result in a reduction in support, donations and income.	 The board ensures the charity meets its legal and regulatory obligations in the course of fulfilling its charitable purpose. The board and senior leadership team regularly review the capabilities required to deliver on the strategy and address issues as they appear. We work to ensure proactive detection, monitoring, reporting and whistleblowing arrangements to enable investigation of potential adverse events and incidents. We carry out digital and traditional media monitoring. The board sets and reviews the charity's strategy. They conduct regular reviews to consider changes in the external environment, social matters and the charity response.

DIRECTORS' REPORT (CONTINUED)

Risk description	Management
Health & Safety risk	 MS Ireland maintains a health and safety policy, with detailed minimum standards, and standard operating procedures which sets out requirements. We work closely with HIQA in completing service audits and inspections and maintaining our quality service record. We keep abreast of H&S education and training programmes to ensure progress in Health and Safety for all our workforce. Risk Registers are reviewed across services to ensure delivery of safe and effective services.
Governance & Leadership risk	 The board ensures a strong governance model including effective committee structures to support board oversight. The board sets risk appetites, taking into account the expectations of stakeholders, and the macroeconomic context. The board meets regularly to discuss strategic, financial, leadership and operational issues and plans throughout the year, with additional meetings convened as required to address emerging issues. We conduct regular board skills audits and agree skills required/skills matrix in line with strategic objectives. Our Nomination and Renumeration Committee review annually board evaluation and succession plan. We provide induction for new board members. We review board training needs and provide relevant training to board. The Senior Management Team (SMT), led by the Chief Executive Officer (CEO), is responsible for executive decision-making. This includes implementing and ensuring compliance with the Society's risk management policy.
Stakeholder Management risk	 We engage with and understand the views of our different stakeholders and taking their views into consideration in strategy and policy development. We review stakeholder communications plans, methods of engagement and distribution channels. We conduct regular service satisfactions surveys.
Service delivery risk	We conduct regular service user satisfaction surveys and monitor service user feedback. Our respite centre completes regular service audits and inspections overseen by HIQA We monitor our systems and controls to promote consistent service delivery and standards.

DIRECTORS' REPORT (CONTINUED)

Service updates

- Regional Coordinators/Regional workers continue to provide a casework as per Government/HSE guidelines
- There are a range of Zoom classes in operation in the regions, these classes range from information sessions, FACETS (Fatique Management), 1:1 physio to group physio classes
- Regular Zoom meetings for all regional staff
- Regional Integrated Meetings returned to in-person and were held on Zoom where preferrable.

Care Centre Update

• The Care Centre continued to operate as per Government/HSE guidelines.

The principal financial impacts of Covid-19

Covid-19 has had a significant impact on Fundraising activities at National Office and throughout the Branch network. Our budget/cash flows for 2022 were updated to take the impact into account.

The Board is satisfied that the operational and financial measures taken by MS Ireland are both appropriate and sufficient in dealing with the on-going impacts and challenges of the Covid-19 Pandemic. The Board continues to regularly monitor developments to ensure the continued stability of the organisation.

FUTURE DEVELOPMENTS

All planned activities will be impacted by the COVID-19 pandemic and are subject to change due to the various response restrictions that may be introduced by Government and on the impact on our revenue generating capacity.

In 2022, MS Ireland launched its Physiotherapy Business Case and Care Centre Business Case.

In addition, to the National Advocacy campaign, in 2022 the Community Worker Service submitted business cases in Sligo/Leitrim, the Midlands and the South East for additional funding to extend Community Worker services having identified the need. A further business case was submitted in Louth/Meath for respite funding for PWMS in the counties due to the large number availing of respite. While there is currently no outcome for these business cases, the teams will continue to advocate locally with the HSE regarding these business cases in 2023.

In 2022, the Community Worker service completed a significant piece of work with Quality Matters regarding measurements and outcomes of casework. This project will progress into the next phase in 2023, requiring a Salesforce review.

Create public awareness of MS and understanding of the needs of people with MS

In 2023, MS Ireland plan to use World MS Day an opportunity to help raise awareness of MS and MS Ireland. We wish to challenge some of the misconceptions about MS with a public awareness campaign that will highlight a range of experiences of living with MS. This will be achieved through a number of key activities which will include a public engagement activity in a central Dublin location, an online campaign inviting people to share their photo, story and connection to MS using a unique and trackable hashtag. We will be hosting a briefing in Leinster House with members of the Oireachtas and hosting a public information event in Trinity College Dublin. In addition to this, buildings from across the country will be illuminated in MS Ireland's iconic red branding in a show of solidarity and celebration of the MS community.

DIRECTORS' REPORT (CONTINUED)

National FACETS programme:

- There were 5 online FACETS programmes provided where Community Workers facilitated in teams of two. 69
 participants have participated in the programmes.
- Training of 6 additional Regional Community Workers took place in December 2022.
- Fatigue Management working group established and the group have agreed to oversee the following deliverables:
 - Development of member facing website page with downloadable resources
 - Redesign of fatigue management booklet
 - · Continue to roll out online and in-person fatigue management programmes
 - · Adapt or develop FACETS so that it is inclusive of non-ambulatory PwMS

Webinars

MS Ireland will continue to work through our calendar of webinars for 2023 to ensure we continue to provide our community with access to expert information and the opportunity to ask the questions that matter to them. National Office will work closely with Regional teams on these webinars. By making online events available nationally, we will ensure the maximum number of people possible are benefiting from our efforts. Recordings will continue to be added to the online catalogue. This will mean that people can access the information after the live event at a time that suits them and from anywhere they wish.

Develop 'Young Persons' services group and online communications platform.

In collaboration with Novartis in 2023, MS Ireland is planning to build on the success of season 1 of the 'MS Explored' podcast and produce a second series of episodes. Our intention is to create another three episodes, inviting both people living with MS and relevant experts on to discuss various topics.

Following on from our survey with young people with MS, MS Ireland is also exploring options in relation to online communications platforms for young people living with MS.

Foster a network of Researchers, PwMS and health care professionals, to enable and participate in MS research and communicate findings.

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 also liaised with the European MS Platform (EMSP) regarding the MS Barometer. MS Ireland continued our work with the All Ireland Multiple Sclerosis Research Network (AIMS Research Network) which brings researchers sharing a common interest in MS 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). As part of this, we attended the AIMS RN Symposium at Queens University Belfast in September.

MS Ireland, with support from Merck Serano Ireland, recently conducted a repeat of a 2016 comprehensive survey of the needs of people with MS. The results of the survey will help us to plan our services and will inform our ongoing advocacy work. It will also help to inform us of where there are gaps currently in service provision and the information gathered will offer us an evidence based platform to campaign on behalf of our community. This provided a vital opportunity for people with MS to have their voices heard and make their needs known.

DIRECTORS' REPORT (CONTINUED)

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.

As part of our World MS Day activities, MS Ireland held a research event which focused on the topic of MS and Cognition, Psychotherapy and Mental Wellbeing. This event received over 100 registrations and received positive feedback on the day.

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.

Fundraising

After several years of no in-person events, we are thrilled to have been able to meet both old and new supporters at various fundraising events throughout the last year, including the Women's Mini Marathon, the Dublin Marathon, skydives, and abseils. We look forward to building on this success in 2023 and meeting even more of our inspiring community in person to thank them for their support.

The introduction of the online MS Readathon was a huge success, and we will continue to offer both online and offline options in the future. Our decision to give book vouchers instead of physical rewards was popular with kids, teachers, and parents in 2022. Our May 50k event while not making the income target, exceeded our expectations when it came to generating awareness of MS in the community for MS Ireland and our event partner, MSIF. We are excited to see even more countries join Ireland in hosting this special fundraising event in 2023 and we are hopeful for a positive fundraising result.

After the successful launch of a new jumper designed by pop artist Lauren Murphy on World MS Day in 2022, we are excited to announce that a newly designed tote bag will be available in the MS Ireland shop in 2023.

Candidates Profiles

Candidates listed in alphabetical order

Ms Jacinta Kelly

Jacinta has more than twenty year's international commercial experience and held senior roles with blue-chip organisations including Ericsson AB, VWR International (Avantor), P&O Group (Maersk) & Exel Logistics (Deutsche Post). Jacinta is currently owner and principal at Firm Thinking, a strategic marketing consultancy that advises clients in Ireland and beyond on strategy, business model innovation and strategic marketing. Jacinta holds an MBA from Kingston Business School London and is a member of the Institute of Directors Ireland.

Jacinta joined the board of MS Ireland in 2017 and served as past Chair of the Strategic Planning Committee with responsibility for development of MS Ireland's five-year strategic plan and development of the digital strategy as current chair of the Digital Innovation Committee. If re-elected to the board, Jacinta will continue to focus on implementing the organisation's strategic and digital initiatives with particular emphasis on Environmental, Sustainable and Governance (ESG) compliance and best practice.



Mr Sean Martin

Sean Martin is a chartered accountant and a partner in PwC. He has over 15 years experience advising companies on acquisitions, disposals and valuations. He has worked with many of Ireland's largest public and private companies.

He lives in Dublin with his wife and two girls. He was diagnosed with MS in 2015.



Ms Aveen Murray

Aveen Murray is an experienced clinician and non-executive director with over 40 years' experience in clinical nursing roles, nursing management and general management both in Ireland and the UK. The majority of her working life was in paediatric hospital care with more recent experience in care of older people, hospice and palliative care provision. Aveen has worked in a national role with the Director of the HSE Clinical Strategy & Programmes Division, supporting the development and delivery of seamless, person centred, quality health and social care services throughout the country, which reflects her commitment to excellence and strong patient advocacy.

Aveen was a non-executive Director on the Board of Temple Street Children's University Hospital. She is currently a member of the Quality & Patient Safety committee of Children's Hospital Ireland. She brings her expertise and experience in leadership, quality improvement, patient safety, advocacy, service development and staff support to her Board roles. Aveen is a nurse and has an MBA. She retired from the public health service in 2015 and since then has worked for the Irish Cancer Society's night nursing service, as a healthcare management consultant and with the national Covid vaccination programme.





Mr Martin Power

Martin is Chief Risk officer in White Horse Insurance. He is an accountant with over 30 years in Financial Services in Investments, Risk and Financial Management. He started his career in Irish Life and was involved in a number of IFSC life companies such as SEB, Handelsbanken and Mediolanum. He is a Certified Accountant (FCCA) 1986, Retirement Planning 2015 with LIA and Operational risk with the Institute of Bankers.

Martin is married with six children, living in Clontarf, Dublin. Martin's brother in law and one of his colleagues in Irish Life have been diagnosed with MS and he would like to use his expertise to substantially improve the lives of those with MS.



Mr Leslie Warren

Leslie has more than twenty year's International Sales & Marketing experience with Masterfoods, and a track record of achieving double digit growth in FMCG in confectionery, petfood & food. For the last 10 years he has managed sales and property management in Waterford and surrounding areas. Experience relevant to board membership include Chairperson Christ Church National School, South East Simon Community Board member, Cork Simon Board Member, Chairperson South East MS Society. Day to day management of not for profit, recruitment, Governance implementation, Fundraising and representation of board at local and national level.



Both professional and personal experiences allow Leslie to offer a positive perspective to the work of the Society and hopefully make a difference to people in Ireland with MS.



REGISTRATION FORM

I will attend the A.G.M. on Saturday, 16th September 2023 at 4.00 p.m. -Please tick one of the boxes YES I will YES I will attend attend not attend virtually e-mail confirmation of your attendance at the AGM to Alice McKeon (E-mail address is: alicem@ms-society.ie) By the 8th September 2023 Name Address Phone/Mobile No. E-mail address (Note: We must have your email address to send you the link to the meeting if you are attending virtually) Branch (if applicable)

Please note that the AGM will be recorded.