MS news
Spring / Summer 2020
Issue
107

MS AND COVID 19

Friends

We know that the last number of months have been incredibly challenging for you. There is uncertainty and worry amongst our community members and we want to reassure you that as the COVID-19 pandemic continues, our priority is you.

Keeping you informed

In response to COVID-19, MS Ireland established a dedicated COVID-19 Information Centre on our website which you can access here **www.ms-society.ie/coronavirus-covid-19** This houses up-to-date and accurate information on COVID-19 and MS, as well as supports and links to other resources and services that may be useful at this time. We have been in regular contact with healthcare professionals to ensure that the information we are providing is relevant, accurate and tailored for our community, while remaining in line with public health advice. You will also find information on COVID-19 on **page 8** of this edition of MS News. We also share tips from the MS Community on taking care of yourself during COVID-19 pandemic on **page 16**.

In response to COVID-19 we have also extended the hours of operation of our Information Line, so we can be there to help answer your questions and provide you with the information you need. The Information Line is now open Monday – Friday from 10am -5pm.

Adapting to meet your needs

MS Ireland have had to make some changes to the way we normally work to ensure we continue to provide the services and supports you need. In line with guidance from the Government and to ensure the safety of our service users and staff, MS Ireland has had to make a number of changes to how we normally work, for example, our network of Regional Community Workers who would often meet our community members in person, are now keeping in touch over the phone. We have had to ensure that our resources and skills would allow us to work in this new way to ensure the service that we provide to you can continue uninterrupted.

We have seen a rise in the number of visitors to our website. In the month of March, our website saw an almost 44% percent increase in views compared to the same period last year. MS Ireland are aware that there is specific information people living with MS need at this time and we are constantly updating our website to ensure we are meeting your needs.

Our annual National Conference which was scheduled to take place in September will no longer be a physical event. Instead we plan to bring the expertise of numerous healthcare professionals to you in your home, through a series of webinars.

Coronavirus and finances

Due to good governance measures in MS Ireland and the prudency of the Board, we are entering this pandemic in a reasonable financial position. We have had to made some changes and alterations to help sustain us during this time. I am sure it will come as no surprise that our finances have taken a hit as a result of COVID-19. Many of the fundraising activities we had planned have been postponed or cancelled and we have had to move some of these activities online, which is a very competitive space with so many organisations having to do the same. The charity sector as a whole, are facing massive difficulties as a result of this pandemic. MS Ireland believe that we could face in the region of 35%-40% of a decrease in funding as a result of the impact of COVID-19. Our fundraising team have been very busy coming up with new ways to encourage support of our organisation, one of which is our Virtual Balloon Race which you will find out about on **page 25**.

Thank you for your support

MS Ireland deeply appreciate the generosity that has been shown by those who have chosen to support us during this time. From donations to organising fundraisers, we greatly appreciate your support! You will find further details of the incredible support we have been receiving in our fundraising section which you will find on **page 24**. If anyone would like to find out more about how to create a fundraiser for MS Ireland, you will find out more here / **www.ms-society.ie/get-involved/fundraise-us/create-your-own-fundraiser**

Planning for our future

Last year, MS Ireland entered the consultation phase of our strategic planning process. We sought input from various stakeholders to help shape and guide our organisation in the coming years. We used this information and data to create a new strategic plan which we plan to launch soon. You will find a summary of our new goals and objectives on **page 11**.

Your voices matter

One of our favourite things, is to hear from you. The voices of people living with MS are so important and in each edition of this publication we provide a platform for people living with MS to share their stories and experiences. On **page 15**, Lauren McCauley tells us about her experiences of receiving a diagnosis of MS at the age of 18. On **page 23** Patrick McCarthy shares his experience living with both MS and epilepsy. Declan Groeger tells us about the Men's Shed for MS on **page 10**. We also feature one of the MS and Me blogs that are published weekly on our website. In this blog, Trevis Gleeson discusses living with MS in a time of COVID-19 cocooning.

We hope you enjoy this edition of MS News. If you have any feedback on MS News or would like to suggest topics for future issues, please contact the editor Aoife Kirwan on 01 6781612 or by email to **aoifek@ms-society.ie**

Ava Battles
Chief Executive

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'MS News' is the magazine of MS Ireland. It exists to foster informed debate and comment about all issues relating to MS. The view of contributors are not necessarily those of the Society. No treatments or therapies should be attempted or products used without qualified medical or professional advice.

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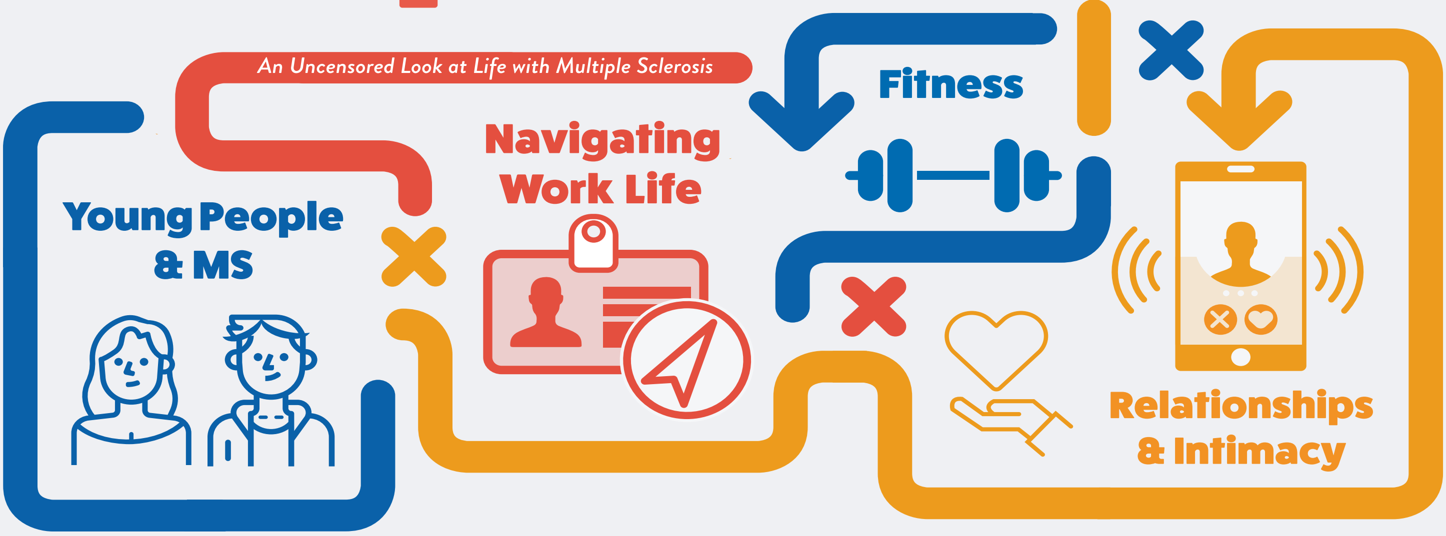
MS Explored



An Uncensored Look at Life with Multiple Sclerosis

Young People & MS

Navigating Work Life

Fitness

Relationships & Intimacy

Save the Date for MS Explored
A meeting for young people living with Multiple Sclerosis

Thursday, 21st May 2020

Watch Online at Multiple Sclerosis Ireland Facebook from 6:30pm

Topics

MS & Cognition | MS & Fertility

For more information see: www.ms-society.ie

This non-promotional meeting is brought to you by Novartis

MSIreland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

NOVARTIS

Date of Preparation: January 2020 | IE02/NEU20-CNF008b(2)

National Conference 2019

MS Ireland's National Conference took place on Saturday, September 21st in Limerick. Our invited speakers included Prof. Alan Thompson who spoke about Progressive MS and the work of the Progressive MS Alliance, Prof. Roshan das Nair discussed Managing the Impact of Invisible Symptoms. The Importance of Self-management in MS was explored by Dr Jennifer Wilson O'Raghallaigh and Dr. Rebecca Maguire spoke on the Importance of Psychological Wellbeing when living with MS. This event was well attended and live streamed for those who wished to listen in remotely. The recordings of this event are still available and can be accessed here: **https://www.youtube.com/user/MSSocietyIRELAND/videos**

MS Ireland's National Conference 2020, was due to take place in September however, as a result of the COVID-19 pandemic this event will no longer take place physically. Instead, we hope to provide access to expert information in a series of webinars over the coming months. Please keep an eye on our social media for more on this.

MS Explored

MS Ireland in Association with Novartis held the second annual 'MS Explored' event for young people living with MS on October 12th. This years topics included Young People and MS, Navigating Work Life, Relationships & Intimacy and Fitness. These talks were lead by key speakers, Dr Maria Gaughan, Neurologist; Sinéad Brady, Career Psychologist; Sarah Sproule, Sexuality Educator and Occupational Therapist; and Professor Susan Coote, Physiotherapist specialising in neurological rehabilitation. Fearless Moves also hosted a movement session. The meeting gave young people living with MS across the country the opportunity to meet, engage and perhaps learn something new. The event was live-streamed for those who could not attend in person or who preferred to engage remotely.

MS Explored Cont.

It attracted over 3,000 viewers. The video of this event is still available and can be accessed here: **https://www.facebook.com/MultipleSclerosisIreland/videos/466391874219152/**

The next MS Explored event is due to take place virtually, on May 21st. Keep an eye on our social media platforms for updates on this.

Ocrelizumab

MS Ireland would like to sincerely thank all those who made contact with their representatives via phone call, email, letter and more in relation to the availability of Ocrelizumab (Ocrevus). Your actions made a difference. MS Ireland welcomed the HSE's decision to reimburse Ocrelizumab for people living with relapsing forms of MS. Our Chief Executive, Ava Battles stated "This is an important milestone for people in Ireland living with relapsing MS. At MS Ireland, we advocate for improved services and access to treatments and the public availability of this drug is a huge step in the right direction. However, access to treatment remains a pivotal issue and we continue to campaign for better treatments for MS, including for those with primary progressive MS who continue to have an unmet treatment need."

MS Ireland will continue to advocate to ensure medication are available to all those who would benefit from them.

The Disability Action Coalition

Mark Mitchell leads the way as the TDAC members approach Leinster House

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

The Disability Action Coalition Cont.

This coalition have been very active in the past number of months and have organsied a number of political engagement events. On November 21st, TDAC represeantatives met with Ministers, TD's and Senators in Leinster House to highlight the significant funding shortfalls threatening Section 39 disability services across the country.

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

Disability Day of Action

On January 31st, MS Ireland as members of The Disability Action Coalition took part in a Disability Day of Action. MS Ireland held a pre-election meeting with general election candidates from the constituencies of Dublin Bay South and Dublin Rathdown.

This gave our service users an opportunity to discuss their experience to illustrate the impact of the erosion of funding of organisations that provide services to people living with disabilities. In this event, and similar events by other member organisations, people living with disabilities from across Ireland had the opportunity to meet with political candidates to highlight the severe €20 million funding deficit needed to provide vital services to people with disabilities across Ireland.

Dr Margaret Kennedy, an MS Ireland service user was one of many who attended our meeting. At that meeting she read a statement to representatives, to give them some insight into what it is like to live with a rare neurological condition within the Irish health system. You can watch Margaret read her statement here: **https://www.youtube.com watch?v=juODlpbpeAM&t=15s**

TDAC and COVID-19

The COVID-19 pandemic has caused significant issues for TDAC member organisations. Vital fundraising can not be conducted as normal and this sudden halt threatens our services. HSE funding cuts have now been implemented causing further difficulty. Our organisations fear

TDAC and COVID-19 Cont.

for the security of our funding in the spending environment after COVID-19. To ensure our Governement were aware of these concerns, TDAC held a virtual briefing, inviting politicians to join us as we outlined our concerns.

For more information on The Disability Action Coalition visit – **www.tdac.ie**

Big Life Fix

MS and Me Blogger, Rosie Farrell with Dr David McKeown and Trevor Vaugh on Big Life Fix

Rosie Farrell, one of our wonderful MS and Me bloggers, recently appeared on RTÉ's 'Big Life Fix'. This show sees leading designers, engineers, technology experts and more to find solutions to challenges people face. The solutions help to transform the lives of people who appear on the programme.

Rosie, who lives with MS has a love of painting. As a result of the MS symptoms Rosie experiences, she was forced to make some adaptations to her life. Her love of being active outdoors was curtailed by extreme pain and fatigue. This had a damaging effect on Rosie's wellbeing but painting helped her to feel like herself again. However, MS continued to intrude on Rosie's life and weakness and fatigue in her arm impacted Rosie's ability to paint. Dr David McKeown, a mechanical engineer and Trevor Vaugh, an innovator and designer, teamed up to create a solution to help.

Rosie was delighted with the final result and had this to say, "I have been blown away by what they've done. They've given me back a part of myself I thought was lost and I will never be able to thank them enough."

You can watch the show here: **https://bit.ly/2R2MWeL**

Brain Awareness Week

To mark Brain Awareness Week, MS Ireland interviewed Dr. Niall Pender, Chief Clinical Neuropsychologist to find out what we need to know about MS and cognition. We asked our community members to submit questions which we could ask Dr. Pender, to ensure that we were giving you the information you want and need on this topic. These questions covered what the most common issues in relation to MS and cognition are, what we currently know about MS and cognition, how medications may impact our cognition and Dr. Pender's top tips for brain health.

Many thanks to Dr. Pender for taking part in the videos which can be accessed here: **https://www.youtube.com/watch?v=sdlsPb4lXYY**

Trinity Discovery

Scientists from Trinity have announced they have made an important discovery that could lead to more effective treatments for people living with MS. Studies have shown that a molecule called 'IL-17', which is secreted from t-cells in the immune system, causes damage to the myelin sheath. The myelin sheath coats the nerves in the central nervous system (CNS). This indicates that IL-17 activates and mobilises disease-causing immune cells in the lymph nodes which then migrate to the central nervous system, leading researchers to believe that IL-17 blocking medications may not need to cross the blood-brain barrier in order to be effective in treating MS.

For further information on this please visit - **https://www.tcd.ie/news_events/articles/new-discovery-provides-hope-for-improved-ms-therapies/**

General Election

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

TradFest

MS Ireland was delighted to be the official charity partners for this year's Temple Bar TradFest. TradFest is an annual music and culture festival organised by the Temple Bar Company which is a not-for-profit organization working on behalf of businesses in the cultural quarter of Temple Bar. The festival which began in 2006, took place this year from the 22nd - 26th of January. As part of our partnership with TradFest, the MSunderstood Café Bus was set up at Dublin Castle on Saturday the 25th of January. This helped us to raise awareness of MS by providing members of the general public the opportunity to experience some of the symptoms of MS for themselves in this bus which was kitted-out with props to help communicate some of the symptoms of MS. These included a blurry menu board to simulate vision issues, tightly wrapped sugar packets to simulate difficulties with dexterity and weakness, uneven flooring and seating which was difficult to rise from. Many thanks to all who supported us.

Strategic Plan

2019 brought MS Ireland to the end of our organisations Strategic Plan 2015-2019. We began our strategic planning process to ensure that we have a plan to best serve people living with MS. A strategic planning team was established and began working on this. We 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. MS Ireland would like to thank everyone who took part in these activities. Details of our new strategic priorities can be found on page 11. At the very time that we were looking to launch the new Strategic Plan, we were confronted with the onset and impact of the Covid-19 pandemic. We planned to share with you our plans for increased service delivery capabilities and greatly improved fundraising income, amongst other things, but we have had to set that aside for the time being. Instead, we are focusing on how MS Ireland can respond to the challenges thrown up by the pandemic.

COVID-19 AND MS

For the past number of weeks, we have been providing information on COVID-19 and circulating updates as we have found out more about this illness. MS Ireland has been in frequent contact with medical professionals to ensure that we are providing quality information, that is tailored for the MS community. Please note that as we learn more about COVID-19 information may change. We recommend that you keep an eye on our website for updates. While we aim to provide the best possible information for our community, the medical advice that you receive from your own healthcare team is the most important as they are aware of the nuances of each individual case. If you have concerns in relation to your own health or that of a loved one, we would advise that you contact a member of your healthcare team who can provide you with more detailed information. COVID-19 information center can be accessed here **www.ms-society.ie/covid-19-and-ms**

About COVID-19

COVID-19 is an illness that can affect your lungs and airways. It is caused by a virus called Coronavirus.

COVID-19 is spread by droplets from coughing or sneezing. This means that it can easily be spread to other people and can survive on surfaces if someone who has COVID-19 coughs or sneezes onto it.

Symptoms of COVID-19

Common symptoms of COVID-19 include;

- **Cough**
- **Fever**
- **Shortness of breath**
- **Breathing difficulties**
- **Chills**

It can take up to 14 days for symptoms to appear and the virus can be spread before symptoms appear.

If you are experiencing symptoms, please contact your GP or call HSELive on **1850 24 1850**.

Protecting yourself and others

The Government have issued guidance to help us to protect ourselves and others from the spread of COVID-19. We have been asked to stay apart in order to protect each other. We all need to practice social distancing, good hand & respiratory hygiene and some people have been advised to cocoon.

This outlines the current guidance from Government and it is subject to change.

Stay home

You should only leave your home to:

- **shop for essential food and household goods**
- **attend medical appointments, collect medicine or other health products**
- **care for children, older people or other vulnerable people excluding social family visits**
- **exercise outdoors - within 5 kilometres of your home and only with people from your household and maintaining a minimum 2-metre distance from other people**
- **travel to work if you provide an essential service. Always maintain a minimum 2-metre distance from other people**

Social distancing

Social distancing is vital to reduce the spread of COVID-19.

You should:

- **Maintain a distance of of 2 metres between you and other people**
- **avoid crowded places**
- **do not make close contact with other people**

Good hygiene and hand washing

Ensuring you practice good hygiene and washing your hands regularly will help to stop the spread of coronavirus as will practice good respiratory hygiene

Cocooning

Some members of the MS community have been advised to cocoon. Cocooning involves remaining at home and away from other people. MS Ireland has a guidance document on who within the MS community needs to cocoon. This information has been guided by a group of neurologists in Ireland and is available on the information center on our website.

MS Medications

It is important not to stop your MS treatment unless you have been advised to do so by a member of your healthcare team. We have guidance on the various MS medications available in the information center on our website.

Most people will remain on their medications as normal but some treatments that are administered in hospitals may be delayed or the frequency of administration may be extended as appropriate. If you have concerns, please contact a member of your healthcare team.

If you have a confirmed case of COVID-19 please contact your neurology team for advice on stopping your medicine.

Monitoring

The decision on monitoring of bloods may vary from one hospital to another. Guidance informed by a group of neurologists in Ireland can be found on our website here **www.ms-society.ie/msmonitoring-bloods-and-covid-19** Please note that this is general information and follow the guidance you are given by your healthcare provider.

MRI’s may be delayed depending on the capacity of the hospitals. Provisions have been made to ensure there will not be any significant delays and those requiring MRI’s for safety surveillance will continue to receive them as normal.

Telemedicine

Clinic appointments may not proceed in their usual way, instead there may be a rise in the use of telemedicine. Some people may already have received a phone call from their team rather than attending a face-to-face clinic appointment. MS Ireland have compiled some advice on preparing for a telemedicine appointment, to ensure that you can make the most of your conversation with your doctor. This can be found here: **www.ms-society.ie/covid-19-ms-and-telemedicine**

MS Ireland during COVID-19

To ensure the safety of the MS community and our staff, we have had to make some changes to the way we work. Our staff are as busy as ever ensuring that we adapt to best meet the needs of our community. Many of our staff have been working remotely, including our network of Community Workers. We will continue to support you through this time and we are available on the phone and via email.

We have extended the hours of our Information Line. It now operates from 10-5, Monday to Friday. We have also created a COVID-19 Information Centre on our website which houses information on MS and COVID-19, community supports, financial supports, mental health resources and more. Check it out here **www.ms-society.ie/coronavirus-covid-19**

Answering your questions

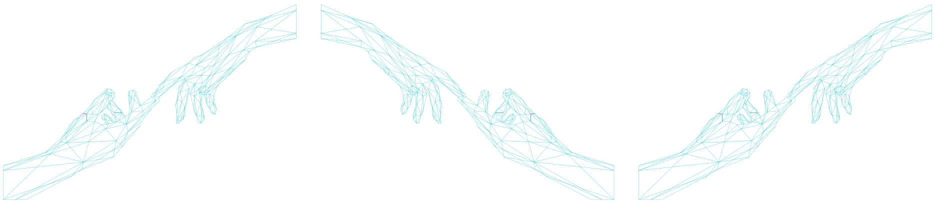
In an effort to have questions on MS and COVID-19 answered, MS Ireland supported by Roche, have enlisted the help of Clinical Nurse Specialist Máire Hayes.

Máire has been answering questions on video which are available to view here **www.ms-society.ie/covid-19-and-ms-clinical-nurse-specialist-maire-hayes**

If you have any questions you would like to submit for future videos, please comment below or email them to **aoifek@ms-society.ie**

MS4MS

Declan Groeger



When I started work on this article it was to be about a group of men living with MS in the Southern Region and our get-togethers. We would normally meet 2 or 3 times a year and over a cuppa and a couple of hours, we would have a chat about all-sorts MS-related. It has been said that ‘men are from Mars and women are from Venus’ largely because of the way we face and address our difficulties. Our coping mechanisms are different; always have been and always will be. Some people never open up about their MS problems and I believe that the ones that do are more comfortable within their own gender group. It makes sense to me because I am one of those Martians who feel more comfortable talking to other Martians; hence the need for, what I lovingly call our Men's Shed for Multiple Sclerosis (MS4MS).

COVID-19 burst into our world early in 2020, unannounced and uninvited, and rocked our social systems to the core. Social-distancing, social-isolation and cocooning were not yet in everyday use. The term lockdown was only used in news bulletins in security-related issues. Up to this point, we could come and go as we pleased and were able. We could hug and shake hands in our everyday greetings and we could sit close together and chat. Oh, how times have changed and not for the better.

We need to be connected now more than ever. We are no longer able to feel the warmth of an embrace or a handshake but we need to stay in touch, we need to communicate, we need to talk. We need to see a human smile, a devilish grin, hear the crack of a joke; modern technology enables us to do just that.

Zoom, House Party, WhatsApp, Messenger and Viber, to name but a few, allow us some sense of human contact with close friends and loved ones without the possibility of getting or giving the infection but they are mere substitutes for human contact. They come with the added bonus of being free to use; the only requirements being a smartphone and the ability to use it.

We can no longer be as selective about the people we talk with; Martians to Martians? I would grab the opportunity to talk to anyone at all but obviously from a safe distance. We need to talk, to communicate with whoever we can. We need genuine conversations.

Nothing will ever replace our MS4MS get-togethers, the camaraderie shared over a cuppa and a cake, our shared experiences and solutions are irreplaceable. We may never get back to where we were but we are adaptable creatures and we will adapt to our new circumstances and limitations.

I hope that by the time of publication COVID-19 will be under control and a vaccine well on the way to being developed but I won’t be holding my breath. We must never forget that we are a band of brothers and we are stronger together.

What have you done or will do to stay in touch?

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 serice model that delivers quality of life, maximum independence & client satisfaction to our community and stakeholders.

OBJECTIVE 2. Research

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

OBJECTIVE 3. Advocacy

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

GOAL: SUSTAINABLE FINANCES

OBJECTIVE 4. Grow Sustainable Revenue Base

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

OBJECTIVE 5. Develop Partnerships

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

GOAL: INNOVATION

OBJECTIVE 6. Develop Digital Operations & Governance

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

GOAL: PEOPLE & CULTURE

OBJECTIVE 7. Develop & Invest In Our People

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

OBJECTIVE 8. Grow Branch & Community Volunteer Base

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

MSIreland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

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Here comes summer

As we come into the Summer months we may welcome the brighter evenings, the milder weather and a rise in temperatures but for some people living with MS may find that the heat can cause their symptoms to temporarily worsen. Even slight changes in body temperature can make it more difficult for the Central Nervous System to conduct messages. During the summer, overheating can be an issue for people living with MS. While symptoms are exacerbated, it is important to remember that this is temporary and heat does not cause more disease activity.

How might heat impact MS?

People might experience extra sensations of pins and needles, tingling, fatigue, cognition problems and issued with their vision. You may experience blurred or doubled vision during or after a workout. This is known as Uhthoff's Phenomenon and is caused by an elevated core body-temperature. Once your body returns to a regular temperature, the effects fade away and you return to your normal vision. It can be disconcerting and even dangerous if you're out running on the roads, so please take care.

Each of us has a comfortable core temperature at which our bodies functions best. Anyone can become overheated, whether it is from being out in the sun too long or in a stuffy room or from not drinking enough water. Here are some tips to maintain a comfortable temperature and deal with the times when you overheat.

Keeping your body cool

- **Hydration is vitally important. Drink plenty of water throughout the day and if you're out in the sun, take regular breaks indoors or in the shade to prevent overheating.**
- **Wear a wide brimmed hat when out in the sun to protect your head, face and neck from burning in the sun. Woven hats allow a breeze to blow through and can help to keep you cooler.**
- **Keep a jug or bottle of cold water in the fridge at home or work. Always make sure the ice tray is filled and ready.**
- **Wear light, loose fitted clothing preferably made of natural fibres such as cotton.**
- **If you get overheated, drink cold fluids and go somewhere cooler. It can be useful to run cold water on your wrists for a few minutes; it aides temperature regulation.**
- **Cold showers and baths are a great way of quickly reducing body temperature. Some people with MS always finish their personal bathing at a colder temperature. If you are taking a cold bath, start off with luke warm water and gradually add cool water.**

Keeping your environment cool

- **Aim to maintain a cool home environment by pulling the blinds or curtains in some rooms to keep out direct sunlight. Open doors and windows to keep air circulating.**
- **Access to an air conditioned room needs to be considered if symptoms are seriously affected by heat.**
- **If you are working indoors sit near an opened window and if possible, have a fan circulating the air in the room.**
- **Keep icepacks available for an emergency.**
- **If you're fatigued, take rest in the shade.**

Being prepared for the heat and taking necessary steps to manage your core temperature and the temperature of your environment, will help you to make the most of any good weather that comes our way.

21st Annual General Meeting (60th AGM since MS Ireland's foundation)

Dear Member,

In this issue of MS News, the call for motions and board nominations are advertised (below). The AGM legal notice will be sent to each member by email (where we have an email address for you) or by post along with the next issue of MS News. Where we do not have a postal or email address for you, service of notice of the AGM on you will be done by posting the notice on the MS Ireland website.

The Annual General Meeting of the Multiple Sclerosis Society of Ireland, at which Board members are elected will take place on Saturday, 19th September in Dublin.

The results of the vote for the board vacancies and motions, if any, plus the council's nomination to the board will be announced at the AGM.

The procedures for motions and board nominations are listed hereunder.

Every registered member is entitled to a vote. For those unable to attend the AGM, proxy papers will be available on our website three weeks prior to the AGM and must be returned to National Office, MS Ireland, 80 Northumberland Rd, Dublin 4 **before 5.00 p.m.** on **Thursday, 17th September 2020**.

Rory Mulcahy
Company Secretary

Motions

Any member or branch may forward a motion to the Governance Committee who will decide on their acceptability for putting before the AGM.

Closing date for receipt of motions is **14th August 2020**.

Call for Board Members

We are currently seeking candidates including candidates with fundraising, sales and marketing and community development experience to go on to our panel of potential Board members. Members, Branches, Council, the Board and staff may propose candidates. All nominations must be proposed and seconded by Members.

Nominations of retiring Board members seeking re-election must be submitted to the Nominations Committee. Other nominations may be submitted either directly to the Nominations Committee, or alternatively, in accordance with the provisions of Article 56 of MS Ireland's Constitution and MS Ireland's Bye-Laws, nominations may also be submitted directly to the Registered Office (MS Ireland's National Office, 80 Northumberland Road, Dublin 4) and marked for the attention of the Company Secretary.

The Nominating Committee will review all nominations, except those submitted to the Company Secretary under Article 56, and will recommend to the Board candidates to go forward for election by the Members at the AGM. Any Member nominated via Article 56 will have their candidacy put before the Members at the AGM.

The Nominating Committee will take into account the range of skills necessary for board membership and where possible, the geographical spread, the gender balance, the experience and the qualifications of the candidates.

All candidates must be in compliance with the requirements for Directors as set out in the Companies Act 2014, the Charities Act 2009 and MS Ireland's Constitution and will be asked to sign a declaration to that effect. The Nominations Committee, on behalf of the Board, needs to be satisfied that no candidate, who legally cannot serve as a Board member, or who has been disqualified or restricted from being a Board member, is put before the Members at the AGM.

Further details and nomination forms are available on the website.

Applicants, wishing to apply for a position on the Board in September 2020, are invited to submit their application form **by 5.00 p.m.** on **Friday, 29th May 2020**. The closing date for Applications under Article 56 of the Constitution is **Monday, 22nd June 2020**.

MS Ireland's 2020 Annual National Awards

It is a great honour to be nominated for the national awards so we would encourage Branches, individual members and staff members to nominate members who they feel deserve recognition. The nominations for this year's Annual Awards are now open. Our Annual Awards are the Society's way of recognising the contribution many of our members make within their families, local communities and MS Ireland.

There are 3 awards and the categories are:

MS Person of the Year

MS Carer/Helper of the Year

MS Volunteer of the Year

Full details and Nomination forms are available on the website or from National Office, tel. **01-6781608**. We would recommend you to return your nomination forms to National Office now. The closing date for receipt of nomination forms is **Friday, 14th August 2020**.

My Story
Lauren McCauley

What do you remember about being eighteen years old? Feeling like a legend, sipping your first legal drink? The buzzing social life you had from the string of 18th birthday parties everyone in your year was having? Maybe, recalling your eighteenth year brings back nightmares of your looming Leaving Cert exams and the anxiety of waiting to get your results. My eighteenth year began with all these standard things and ended with a life-changing MS diagnosis.

My symptoms started around the time of my 18th birthday, and began with a sort of numbness and tingling in all limbs and torso. At the time, my doctors blamed these symptoms on anxiety and stress of my forthcoming Leaving Cert. I continued like this for months, and given how run-down a lot of Leaving Cert students get, I figured my constant exhaustion was normal. I completed my Leaving Cert with numbness in my hands and legs, utterly brainwashed by the hype around the importance of my exams. I remember at times it was like trying to write using a tiny pencil with thick snow gloves on.

Over the summer after my exams, my numbness lessened and I thought no more about it. Instead, I focused on getting dolled up for my Debs and embracing my new student life. However, when it came to starting my Nursing lectures, I was exhausted. Commuting to college and concentrating in lectures became a nightmare and my whole body numbness had returned. While everyone else was busy embracing student nightlife, I was left thinking ‘What is wrong with me?’. I just couldn’t keep up, and left my dream course after one month. I felt like a failure, utterly lost and deflated.

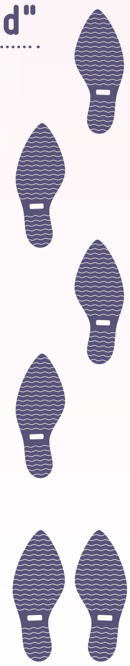
A few weeks later, I completely lost the vision in one of my eyes and was admitted to hospital. After a week in hospital and a plethora of scans and tests, eventually, I received the news ‘You have Relapsing and Remitting MS’. Thinking back to that day, I had no idea what I was in for. Today, nearly five years on, I’m 23 years-old and some of the symptoms I live with day-to-day include chronic nerve pain, numbness, dizziness and fatigue; but there are also many more.

Many people will be diagnosed with MS later in their lives. Perhaps in their late twenties, early thirties or even later. Admittedly, being diagnosed with MS as a teenager, sometimes makes me feel like I’ve been robbed of my twenties. The years of your life where you think you are invincible, while you work hard and play hard.

Being diagnosed with MS in your teens certainly presents its own unique challenges, which are intermingled with the standard problems everyone deals with during the onerous transition from teenager to twenty something. During the first year after my diagnosis, my life was a muddy melting pot of uncertainty, anxiety, low self-esteem and loneliness. Your teens and twenties is a time where everyone is still figuring out who they are, with an MS diagnosis thrown into the mix, my identity was completely shattered, and I had to start again from scratch.

A year after my diagnosis, I started a new course in a new University. The support I received from my family, friends and the staff in DCU was incredible. A few years on, I’ve completed my undergraduate degree, a BSc in Health and Society. I even managed to graduate with first-class honours in November 2019. At present, I’m a PhD candidate in DCU, doing research in the area of missed infection prevention and control in Nursing Care. Who knows what life will throw at me next? But, I will leave you with some lessons MS has thought me so far, and some wise words I’ve picked up along the way. Do your own thing; comparison is the thief of joy. This too shall pass; nothing lasts forever good or bad. You can do anything, but not everything and not all at once. If all you are doing is putting one foot in front of the other, keep moving forward, your speed doesn’t matter, you will get there in the end.

> **"Keep moving forward, your speed doesn’t matter, you will get there in the end"**



Tips from the MS Community

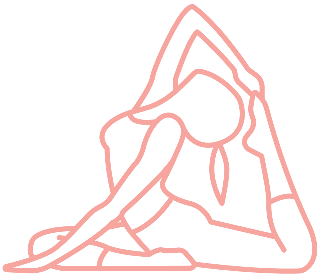
COVID-19 has presented us all with some new challenges. We have been asked to stay apart to protect each other, to adhere to social distancing guidelines at all times and in some situations to cocoon at home. These things may seem simple but they are not always easy. Here people living with MS share what they have been doing and their top tips for managing your physical and mental wellbeing during COVID-19.

Stay informed

- **I try to keep myself informed but not to the point of being overwhelmed.**
- **Limit your exposure to media.**
- **I listen to the news once per day to stay informed. It can be very distressing to constantly read updates and information.**
- **Make sure that the information you are accessing is from a trusted source. There is so much information available at the click of a button and we all need to be mindful that not all information is accurate or helpful.**
- **Online groups are a great way of engaging with other people but be careful as lots of people post opinions as if they are fact. Also, people post information from their country and the guidance can be different here so be sure to check the source.**

Keep active

- **Keeping busy is important, reading, walking, crafting, whatever it is you like to do, do it.**
- **I go for short walks if I have the energy and it isn't raining.**
- **I do yoga, cardio to get my heart pumping and endorphins flowing and a long walk every day with the pooch (within restrictions).**
- **Be careful not to over do it. Keeping up a regular exercise routine that you had pre-COVID-19 is fine but be careful not to take on a new form of exercise which could cause injury.**
- **Exercise by doing what you can, safely.**

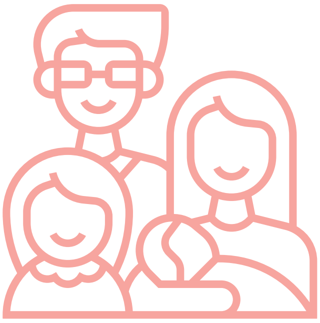


Maintain a routine

- **Routine is important. Wake at a reasonable time and get dressed.**
- **Making my bed is a small accomplishment for the day. It is important to have short, medium and long term goals and then to identify actions or projects that will help t o achieve them.**
- **I try to have some normality to my day by eating at usual times, breakfast at 8am, lunch at 1pm and dinner at 6pm. It helps to keep structure.**
- **I keep different days for different things so there is some order to the week and by body and brain can tell the difference between a weekday and the weekend. I keep all housework for Monday to Friday and only clean as I go on the weekends.**
- **I am working from home and home-schooling. Routine is essential but it's still very tough. I try to have the school work set out in the morning so this can be done while I am working and I look over it later in the day. Sometimes I have to put the schooling to the side and focus on work and other times I am less busy with work and can focus on schoolwork. It's all about finding a new balance.**
- **I make a to-do list of tasks I want to achieve to support me.**

Stay connected with others

- Organising an online group video call with family and friends is amazing.
- Twice a week we have a family games night.
- My mother, sisters and I had a video ‘cookie decorating’ chat. Building an activity into your video chat can make it feel as though you are all working together on something.
- My family have been celebrating birthdays on video chat. We all make sure to have a treat so it feels like a party. We sing happy birthday together, though the timing can be off which is often hilarious.
- I have used the time to reconnect with some people I had lost touch with. It’s a great time to start conversations and check into see how people you may not have spoken to in a while are doing.
- Myself and my friends have a video chat every week where we can have a catch-up.

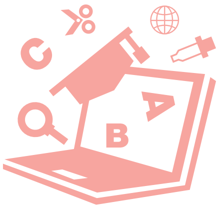


Nutrition and hydration

- Eat nutrient dense foods
- Hydrate.
- Try not to snack on unhealthy foods.
- Keep a fruit bowl close to where you relax in the evening so instead of reaching for unhealthy options you have fruit close to you as a healthy option.

Try something new

- I have found some online classes that I previously would not have been able to attend or engage with.
- I decided to start a fundraiser, it gave me something to work towards and motivate me, while raising money for a good cause.
- I have taken up painting which I have always wanted to do but never felt like I had the time.
- I have started listening to audiobooks while I am doing housework or out on walks.



Don’t be hard on yourself

- Lots of people seem to have mastered how to balance working from home while taking care of their children. What we see on their social media is often not true. Take it easy on yourself, we are all trying to adapt to new ways of working in a very challenging time. Nobody is doing a perfect job and that’s okay.
- It’s great to stick to a routine where possible, but sometimes the day just doesn’t go to plan. When it doesn’t go to plan, there is always tomorrow.

Have some you time

- I give myself one day per week for Netflix.
- Watching a series or a comedy can be a great distraction from all that’s going on in the outside world.
- Every week, I have a bubble bath. I shower the other days in the week but a bubble bath is a little luxury at the end of the work week.
- I cannot go out for a walk but I sit in the garden at least once per day to give myself a little time outdoors.
- I have started journaling at night. I get a great sense of freedom and relaxation when I write about how my day went.

The Little Caterpillar Who Cocoonedn't

Trevis Gleason

COVID-19 has presented many challenges and we as a nation have been asked to remain at home in order to protect each other. People living with MS are no strangers to adapting to changes we did not ask for. Here, Trevis Gleason one of our MS&Me bloggers, explores the impact of COVID-19 restrictions.

These are the strangest of times and not everyone is coping up to social media standard... and that's alright

There has been an absolute overload of social media posts from the newly-minted baking set during our national lockdown. It's not just people digging out Granny's brown bread recipe either. From sourdough novices, to naan Pedars substituting their cast iron skillets for tandoor, American-style cookie mavens, and every kind of pizza the Italians never imagined. And it goes beyond just baking….

It appears to me that every enjoyable, weekend-filling pastime – dancing, singing, crafting, jigsaw puzzling, cooking, gardening, and beyond - has become some sort of contest on the Insta-Snap-Tweet-TikTok-Face machine.

It's as if getting-on, with the noble aim of emerging semi-sane the other side of our sequester, has become a competition. The reality of this 'surreality' now out rates reality TV!

Even an introvert needs a bit of contact

And I suppose that's okay for some. We all fake it until we make it and do what must be done. But that doesn't mean we have to be good at this cocooning thing.

Due to a non-MS related health issue, I've been in something of a self-isolation since December. I tried to get out to the shop on Fridays if I could, just to see a few faces. I'd pick up a few messages and then wait for my wife to collect me on her way home from work.

That I waited for that lift on a tall stool, in a cozy corner of the back room at my local made my Friday afternoons something I looked forward all week. Now, of course, even that is gone. Not only are the pubs shuttered but MS and that other thing have me in the 'cocooning contingent'. I haven't left home in more than a month.

I'm what one might dub an 'extroverted introvert'. The life of a writer can be quite solitary, and I don't mind that too much. I do, however, require a bit of balance to me, along with the sound of my keyboard tapping. I'm sure the postman can tell when I'm having a bit of a sticky point with a sentence or phrase according to the length of the time I keep him chatting at the gate.

We all need a bit (to one extent or the other) of social interaction; time for chin wagging, bantering, or a good-natured bit of slaggin'. For most of us, however, that's just not our hand to play with coronavirus lingering around us.

Home schooling, home working, home moaning

I'm fond of saying that people seldom do "the best they can". What we really mean when we say that is that we're doing "the best we're willing to at the time". But I think this is a case were the vastest majority of us in the MS community, as well as the broader community, are in fact, doing the best we can (with the exception of the odd chancer we read about, driving to some beach outside his 2km zone of acceptability!).

We're getting-on with the business of getting-on by working from home where possible. We're seeing kitchen tables, the odd scrap of plywood, or a stack of books being used as home office furniture. Dining room dressers have been cleaned out as backdrops for video conference calls. Gardening has become a homeschool 'biology' lesson (but no matter how hard Dad tries, the kids aren't buying painting the house as a 6th class 'art project').

And, let's face it, the charity shops are going to be crushed under the very mass of donations we've culled from our collective wardrobes, cupboards, and spare bedrooms once they open the doors.

We don't have to like it or to be good at it… We just have to do it

Those of us with MS know how to get on with things we'd rather not have to.

We learn how to inject ourselves. We figure workarounds to difficulties which we encounter decades before we should have to. We decorate assistive devices as if they were fashion accessories. We leave work too soon and find other ways to keep our lives meaningful.

Like the rest of Ireland, we'll wash our hands, cough or sneeze into a tissue, we'll stay inside our allowable radius. We'll stay home – stay safe, and we will all do our damnedest to flatten the curve so we can get back to whatever normalcy our collective new normal turns out to be.

That doesn't mean we're all going to win a BAFTA for our zoom calls, contend on the bakeoff with our rosemary, olive, and pineapple focaccia, be good at this thing or that we'll even like the situation the littlest bit, at all.

And that's okay. Just like many aspects of living with multiple sclerosis, it's okay not to be okay sometimes. And right now, I suspect I'm not alone in teetering toward the not-okay side.

From my cocoon to yours, I wish you and your family the best of health.

Cheers
Trevis

Trevis' Award-Winning books, Chef Interrupted, Dingle Dinners and Burren Dinners are in the shops now. Follow him via the Life With MS Facebook page and on Twitter.

BLOGGERS WANTED!

As a Society, we are very fortunate to have so many inspiring writers who share their experiences and stories of life with MS to the community. We are putting out a call for new voices to get involved, share your experiences and write for the MS and Me Community Blog.

- **Are you living with MS**
- **A Carer**
- **A Health Professional**
- **A Partner of someone living with MS**

Does this sound like you? Write to us; tell us who you are, what county in Ireland you are from, your age and your connection with the MS Community.

You will also need to send us:

- **One 500 word piece about MS**
- **A letter of motivation telling us why you would like to be part**

GET WRITING AND SEND THEM IN!

Send your work to

communications@ms-society.ie by **Friday, 10th July 2020**. We will contact everyone who submits their 500 word piece and letter of motivation on time.

In the meantime, we invite you to continue to read and enjoy the work of the MS & Me blog team.

Community News

Our network of community Branches have been busy with activities over the past number of months. Unfortunately, as a result of COVID-19 restriction and to ensure the safety of members, many of the events they had planned at this time and in the coming months have had to be postponed or cancelled. Here, we take a look back at some of the highlights that have been submitted.

Fermoy

Staff & management of Sanmina SCI (inc. Fegal O'Dowd, Mary Lenihan, Patrick O'Brien) presenting a cheque for €1,135 to Mary Lonergan, PRO of Fermoy MS Ireland. A sincere 'Thank You' from the MS community for your continued support & participation in the Annual Galtee Walk.

* * *

Branch members attending the Southern Regional Integrated meeting in Macroom which took place in September 2019 and was attended by members from our five branches in the Cork and Kerry region.

Fermoy

Congratulations to Deirdre Casolani, George O Keefe, Una Mason Finn and Basil O'Sullivan.

Fermoy Camera Club & Fermoy Multiple Sclerosis Society in the frame. "A picture paints a thousand words" and that's what four members of the Fermoy Camera Club did recently for the 2020 Multiple Sclerosis Society of Ireland Calendar. Fermoy Branch MSI are delighted so many members of the club participated in the competition & we congratulate everyone & thank you most sincerely for your time and commitment.

* * *

A wonderful afternoon was had by all for the Fermoy Branch Christmas Lunch. Many thanks to all who joined us to celebrate the Christmas Season, good fun & craic. It was lovely to catch-up with everybody. Thanks to all who supplied spot prizes, all the super committee who helped organise the event & a huge thanks to management & staff of Midleton Park Hotel.

* * *

The AGM of the Fermoy Multiple Sclerosis Society took place at Fermoy Education Centre on Sunday 23rd February.

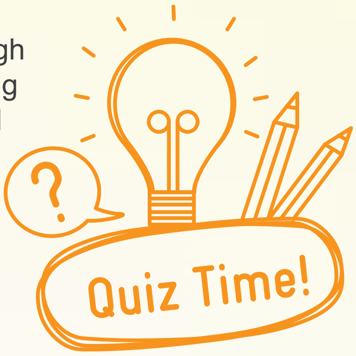
Longford

Presentation of funds from the ‘Christmas Day Run’ to the Longford Branch.

The branch would like to acknowledge with thanks a number of fundraisers over the last few months. The big one being the “Christmas Day Run”. This is an annual event run between Newtowncashel and Lanesboro in Co Longford and is organized by Brigid Mullooly and the greater Flood family with the help of “Peter Hanley Motors”. The branch cannot thank these people enough for the huge sums raised over the last number of years. Next year will be the 30th Anniversary. The latest one raised over €5,200 for the branch.

Presentation of funds of €750 raised from Kearney’s dart league fundraiser.

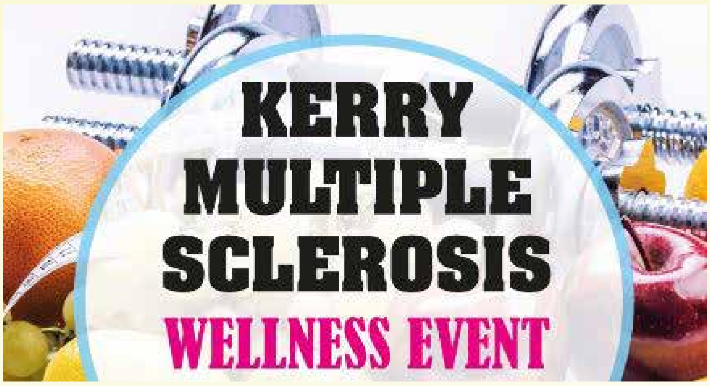
Many thanks to Bronagh Cafferkey for organising a table quiz that raised €2,230!!



South Kerry Branch

Darragh McCarthy from Killarney.

Many thanks to Darragh McCarthy who ran the Dublin City Marathon a second time in 2019 in memory of his late mother. To date he has raised over €10k for MS South Kerry. Thank you, Darragh!



Kerry Held their first ‘Wellness Event’ for the County with some great speakers who all donated their time for this event. This event was well attended and a great day was had all. This event was organised by Susan Carey Fit-Fusion from the Tralee Branch and Jillian O'Sullivan from the South Kerry Branch.

South Dublin Branch

The South Dublin Branch held their AGM on February 29th where following the business of the AGM & election of officers, we presented our ‘Person of the Year’ award to Gerry Quinlan, a former treasurer who has made a huge contribution to the branch.

South Mayo

Pupils from Sancta Maria College, Louisburgh, Co. Mayo, with Ger Butler, who was invited by the School to talk about MS. The pupils raised €1,171 through the MS READaTHON.

Thanks to Tony Candon, South Mayo Branch PRO, who raised €3,591.18 for the Branch through a Sky Dive.

Mary Cribbin, family and friends present Mary's cheque for €841.50 to Duncan Pratt and Liam Cannon of the South Mayo Branch. Mary had a significant birthday recently and asked that she be give money for the local Brach in lieu of birthday presents. Thank you, Mary!

Wexford

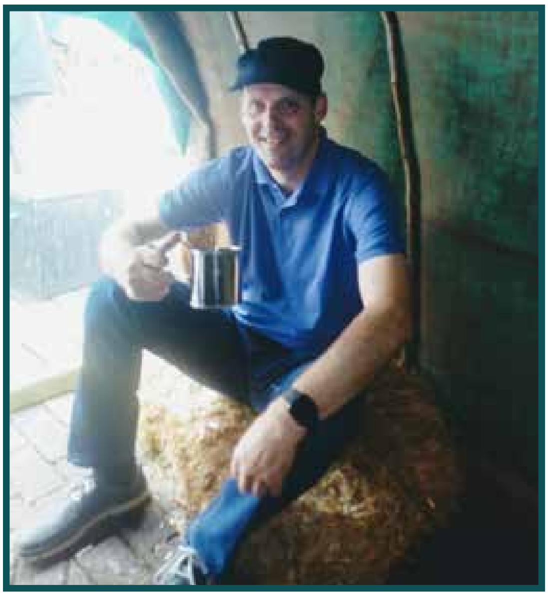
Attendees at the launch of Yoga By MSers.

In October, the Wexford Branch launched a yoga book for people living with MS. The launch was attended by local councillors, politicians, Branch members and supporters. Community Regional worker, Una Gown also attended along with Wexford Branch Chairperson Rubi Murphy and yoga teacher Helen Dunlea. Wexford camogie player, Ciara Storey launched the book titled 'Yoga By MSers'. This can be purchased here **www.ms-society.ie/shop/yoga-msers**

Many thanks to Paddy Donovan for photographing this event.

If your Branch would like to have their activities highlighted in MS News please send details of the activities and high resolution photos to **aoifek@ms-society.ie**

My Story
Patrick Mc Carthy



My final year studying in Coventry University, I went to my doctor due to having constant numbness in my right shoulder. I was referred to a consultant neurologist and I was told that I had Multiple Sclerosis. At the time of my diagnosis, I was familiar with MS as I had worked as a volunteer with my local MS branch. I knew there were different types of MS. From the start, I wanted to live my life as normally as possible in spite of the diagnosis.

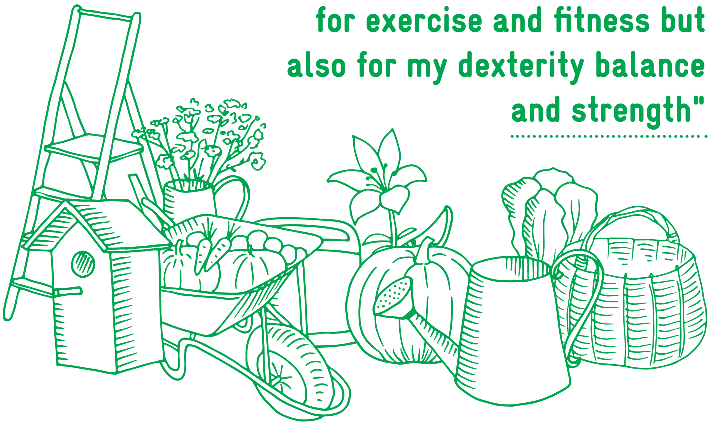
Following my diagnosis, I continued to play Gaelic football without difficulty at senior level for Ballintubber. However, having MS meant that I needed to rest more to regain my daily ability. My work as a social worker took me to Derry. My employers were aware of my diagnosis and were very accommodating. I continued to play Gaelic football and I played with Steelstown, Co. Derry. In 2000 I married Heather and we moved to Letterkenny where I worked initially as a social worker for people with disabilities and then as a social worker in Letterkenny University Hospital.

In March 2006 I had my first epileptic seizure. It was totally out of the blue and occurred in the middle of the night. I ended up in intensive care in Letterkenny University Hospital. I don't remember anything of the event except waking up in hospital with Heather beside me. It was quite a strange feeling. I had been a hospital social worker in the afternoon only to return in the middle of the night as an intensive care patient!

Epilepsy and MS are equally unpredictable and complex. Each has its own specific needs. My wife Heather is great and has the patience of a saint. Even though I like to think I have great organisational skills, Heather keeps an eye on things. Our wonderful children, Katie (17) and Jane (13) have seen my seizures and they have a good appreciation of the situation. They also understand that I may have a little difficulty with my mobility. However, I am grateful that both of the conditions are currently stable.

In 2010, I retired. Retirement has given me the opportunity for alternative pastimes. I like physical exercise so gardening is great. I also do simple manual work mainly for exercise and fitness but also for my dexterity balance and strength. I ensure that I get good quality rest, avoid alcohol and I continue to take my medications. I also enjoy taking part in local activities, such as writing, swimming, walking and participating in GAA activities. I engage in all activities when I feel like it but in moderation.

> "I like physical exercise so gardening is great. I also do simple manual work mainly for exercise and fitness but also for my dexterity balance and strength"

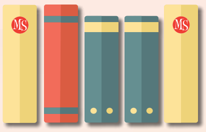


I also volunteer with various organisations locally. I believe that this voluntary work has definitely helped me feel more comfortable around disability issues. In recent times I have started to participate in our Local Park Run on Saturday mornings. This is a great way of meeting people and I can take it at my own pace. We also have our own MS monthly meeting for persons with MS.

As and when MS hits me, it's usually my dexterity and co-ordination that are affected. Epilepsy is also always there in the background and I need to be mindful of triggers that affect me. I have good support from my doctor and pharmacist, as well as from MS Ireland and Epilepsy Ireland. Most importantly, I have support from my family and friends.

MS READaTHON

2020



Lucy Kennedy and students from John Scottus school

10,000 young readers and almost 350 schools took part in the 2019 READaTHON. In doing so they read more than 90,000 books and raised an amazing €350k for people living with MS in Ireland.

Bobby the Bookworm was back and hungrier than ever, interviewing the students at John Scottus School, about all things books.

This years' launch took place at the National Library and our ambassadors Emma & Rowan Valentine and Lucy Kennedy helped get things off to a flying start.

Scoil Bhride in Ranelagh managed to outdo themselves this year raising over €10,000. An incredible amount! We were thrilled when Leinster Rugby player Jenny Murphy said she'd go to the school to accept the cheque on our behalf.

Shout out and huge THANK YOU to Panasonic Ireland for supporting our MS READaTHON campaign again and their generous donation of 30 sets of wireless headphones which were won by 30 lucky students.

Massive thanks also to Languages Connect who sponsored two extra iPads for our bi-lingual bookworms.

MS READaTHON

School Ambassador Programme

This year we are excited to launch our Ambassador Programme nationally which promotes the MS READaTHON by encouraging new schools and libraries to sign up and to maintain relationships with those that have previously taken part.

We hope that this campaign will support the MS READaTHON in raising enough funds so that we can maintain the services we deliver to the MS community.

Contact **Sarah Hourigan** at **sarahh@ms-society.ie** for more information and an application form today.

Back Garden Marathon

Mick Quinn running in memory of his brother, Frank

Over the May Bank Holiday weekend an incredible event took place in the back garden of a house in Dublin. Mick Quinn a long time supporter of MS Ireland walked a marathon over three days in memory of his brother Frank who passed away on April 8th this year. Frank was also a long time supporter of MS Ireland. Mick raised over €30,000 for MS Services to date through his challenge in memory of his brother and you can read more about his story and support this incredible achievement here:

www.justgiving.com/fundraising/mick-quinnwalkforms

NOVARTIS

Calendar & Novartis

Our 2020 calendar photography competition was a great success, with hundreds of amateur photographers submitting entries on the theme Coastal Scenes of Ireland. Huge thanks to Novartis for kindly funding our calendar campaign again this year.

Thank you also to our monthly sponsors Cusack Garvey, Daysha Dev Ops, Genomics Medicines Ireland, Hogan Healthcare, KBC, Leinster Shipping, Logos Publishing, Mallow Credit Union, O'Briens, The Panel & Tierney's.

We would also like to send a big thank you to all our branches who sold calendars. It was a great success all round. This year we are looking to encourage more branches to participate in the calendar campaign as it is an ideal fundraising initiative.

Our calendar competition is back again this year and we will be accepting entries from amateur photographers until the end of June. The theme for our2021 calendar will be **Flora and Fauna of Ireland**. Please send all entries to **jessicac@ms-society.ie**

The Kiss Goodbye to MS

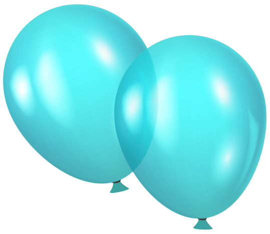
Research Ball 2020

We're back in our adopted home of The Morrison Hotel, Dublin but as a result of the knock-on effects of the COVID-19 pandemic, we are hosting a winter ball instead. The date is now Friday 6th November. For the uninitiated – it's a night of great food, great fun, great prizes and an excuse to get dolled up and strut your funky stuff – all for a great cause.

Tickets are €100 each and can be purchased through our online shop on the MS Ireland website which can be accessed here **www.ms-society.ie** shop or by contacting Sally directly **01 678 1624**.

See you on the dancefloor for some non-socially distanced bopping.

Up, up and away for World MS Day



World MS Day 2020 is set to be a very different affair to previous years. The international day of awareness and fundraising has met a whole new set of challenges this year. Now, more than ever the MS community need support and advice.

In light of this, MS Ireland decided that this year's World MS Day should go off with a BANG! (Virtually)

There are over 9,000 people in Ireland living with MS and so we are launching a Virtual Balloon Race campaign, **#9000balloons**

Using algorithms, live weather systems and Google maps, our virtual balloon racing platform allows balloons to behave, fly and burst just like real balloons.

The premise is simple;

- **Buy a virtual balloon for €5.00 – buy as many as you like!**
- **Customise your balloon, colour, shape, design.**
- **Select the rubber thickness and volume of helium.**
- **All balloons are released on 30th May at 12.00 noon.**
- **The balloon that travels the farthest over 7 days wins the race.**

The beauty is, not only will we raise much needed funds and awareness on World MS Day, but also, unlike traditional balloon races that litter the countryside and endanger wildlife, our virtual balloon race is completely environmentally sound.

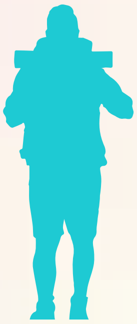
The balloons will be virtually launched for our Care Centre in Bushy Park on **30th May at 12.00 noon**. You can get further details and buy your balloons at **http://rabr.co/msi**

Contact Sally for further details **sallys@ms-society.ie** or call **01 6781624**

#9000balloons

Run With Us

Remember to register for the Women's Mini Marathon. This event has been postponed until September/October but you can still register contact us for a fundraising pack and join Team MS Ireland to raise funds and awareness – please contact **melaniec@ms-society.ie** for more information.



Trek with us

We are planning to do a Celtic Camino from the 18th to the 23rd September. We are planning to do St. Declan's Way from Cashel to Ardmore. We will be walking the Pilgrims walk visiting St Declan's monastery, Holy Well and his grave. Join us for this wonderful trek by contacting **melaniec@ms-society.ie** for further information. Subject to change.

Skydive with us

Are you looking for the ultimate adrenaline buzz? If the answer is yes then sign up for our skydive with The Irish Parachute Club and join our monthly groups or create your own group. Email **melaniec@ms-society.ie** for more information, future dates and register your place.

Golf for us

Are you a member of a golf club? You could ask to have MS Ireland as the beneficiary of your charity golf day, or Captain's day – contact **melaniec@ms-society.ie** for more information.

Thank You

Slovenia Trek - Thank you to all the Trekkers who came with us to Slovenia. This was a truly fantastic trek through the Julian Alps and the beautiful pastures of the Karst, a limestone plateau stretching from the Gulf of Trieste to the Vipava Valley. Then on to the Karawank mountain range, which form part of the border between Slovenia and Austria. Our Trekkers this year ranged in age from 22 years to 81 year! Proving that all ages and abilities are welcome on our annual trek.

Challenges – Thank you to the wonderful people who have taken up many and varied challenges to support Ms Ireland including all the runners who took part in the Dublin City Marathon and raised over 25k; teams who participated in Hell and Back; and groups of ladies who ran in The Women's Mini-Marathon up and down the country and many others who completed wonderful challenges whilst raising funds for MS Ireland.

MS Ireland National Care Centre

The MS Care Centre is the only dedicated respite centre for people with Multiple Sclerosis in Ireland and is a place for residents to learn more about their MS and find ways to self-manage their condition. It's a place where people can come to learn more about their condition, manage their symptoms and feel empowered to live the life of their choosing.

Due to COVID-19, in order to protect our staff and residents our National Care Centre is temporarily closed. All the team at Bushy Park look forward to welcoming our residents back soon and wish everyone health and safety in the coming weeks.

We wish to thank our MS community for their continued support. When we re-open our residents will need our National Care Centre more than ever. If you can support our campaign to ensure we can open as soon as possible, for as long as possible, after this difficult time it would be much appreciated.

Click here **www.ms-society.ie/what-we-do/ms-care-centre** for more information about future reservations or to make a donation to National Care Centre Appeal.

We need you

Do you or a loved one work in an organisation with a charity programme, would you be willing to nominate MS Ireland or put us in contact with your charity team? Whether your organisation is looking for a charity partner, a company-wide challenge or want to get involved in our volunteer programme, our skilled fundraising team are ready to work with your organisation. Our Corporate Fundraiser Karin is waiting to hear from you, email **karinb@ms-society.ie** or call **01 678 1616**.

Support us at

www.ms-society.ie/donate

MS Ireland would like to sincerely thank all who have donated to us through Run 5, Donate 5, Nominate 5.

We love seeing the pictures you tag us in!

MS Ireland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

In the Mid West we are looking at ways that we can provide our one-to-one support and group work either over the phone or online.

Mary
Regional worker, Limerick.

"The most important thing for us at the moment is making sure that people with MS are aware that we are still available by phone to support and help with any issues, whether Coronavirus related or not, as best we can. "

John
Regional Community Worker

"Since the outbreak, these are some of the concerns people with MS have, these are real issues that people with MS need to talk to someone about"

Sean
Regional Community Worker

"It's good to ask our service users the very simple question... how are you?"

Sandra
Regional Worker, Midlands.

We need your support now and in times to come.

Yes! I want to help people with MS.

MS Ireland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

Your details

*If you are completing a monthly donation form, please complete all fields marked with a **

Full Name*:

Address*:

Email Address: ☐ *I am happy to receive emails from MS Ireland*

Phone Number: ☐ *I am happy to receive calls from MS Ireland*

Monthly donation (SEPA Mandate)

**If you are a tax payer, a gift of €21 or more could be worth up to an additional 45% to us at no extra cost to you.*

☐ €10 ☐ €21* ☐ €50 ☐ My own choice of ____________

To be completed by MS Ireland

Unique Mandate Reference

Your Rights: By signing this mandate form, you authorise (A) MS Ireland to send instruction to your bank to debit your account and (B) your bank to debit your account in accordance with the instructions from MS Ireland. As part of your right, you are entitled to a refund from your bank under the terms and conditions of your agreement with your bank. A refund must be claimed witin 8 weeks starting from the date in which your account is debited. Yor rights are explained in a statement you can obtain from your bank.

IBAN*: ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐

**For Direct Debits, your account number and sort code have been replaced by your IBAN & BIC numbers. You can find both of these numbers on your bank statement.*

BIC*: ☐☐☐☐ ☐☐☐☐ ☐☐ **Your BIC number may contain eight or eleven digits.*

Please complete the following:

☐ Can the bank account accept direct debits?

☐ Is there more than one signatory needed to sign on you account?

☐ Is this a Republic of Ireland account?

Creditor:
MS Ireland
Credit Identifier:
IE4ZZZ303335
Creditor Address:
80 Northumberland
Road, Dublin 4

One off donation

☐ €25 ☐ €65 ☐ €250* ☐ My own choice of ____________

**If you are a taxpayer and give €250 or more in a calendar year, we'll send you a form that will allow us to claim up to at least €112 from Revenue, at no extra cost to you!*

☐ I enclose a cheque / bank draft / postal order made payable to MS Ireland

OR

Please debit my: ☐ Visa ☐ Mastercard ☐ Visa Debit

Card Number: ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐

Expiry Date: ☐☐ / ☐☐ Security Code: ☐☐☐

Signature: ______________________ Date: ______________________

Please print and return form to MS Ireland, 80 Northumberland Road, Dublin 4. You can also donate by calling (01) 678 1600 or by going to **www.ms-society.ie/ways-give/regular-giving**

VIRTUAL BALLOON RACE

Race a balloon for €5 & support 9,000 people living with Multiple Sclerosis

RCN: 20007867

MS Ireland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND