



The Art of MS

8



EBV and MS

18



Changing Facility  
In Donegal

20

# MS INFORMATION LINE

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about MS?

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Dear Friends,

We in MS Ireland are lucky to represent a vibrant and strong community. Our mission is to enable and empower people living with MS to live the lives of their choice to their fullest potential. It is important to us that we provide you with opportunities to have your voices heard on the issues that matter to you and to support the wider MS community on issues that impact you collectively. One such issue is the upcoming Budget. MS Ireland have submitted our Pre-Budget Submission for 2023 and your support of this would be greatly appreciated. On **page 15** you will find a summary of our key asks accompanied on **page 14** by a tear-out letter that you can complete and send to your local representative, asking them to support us.



One of our highlights this year was co-ordinating an art exhibition featuring 12 original artworks, created by people living with MS. This opportunity gave these artists the chance to express their thoughts and experiences on symptoms though art... and the results are incredible!! You will find an overview of the exhibition on **page 8**.

Some very exciting news in MS research was reported on earlier this year, when a group of researchers from Harvard University published a paper which found that the risk of developing MS increases 32-fold after infection of the Epstein-Barr virus (EBV). To read more about this, turn to **page 18**.

In keeping with this editions theme of taking action on the issues that impact us, we feature pieces by a number MS community members. In the first, Pat McCarthy discusses crime prevention for people living with MS on **page 7**. On **page 20** Paul Dawson writes about Donegal's first Changing Places step down facility. **Page 19** offers a very special update from Yvonne McGoldrick, a writer who had their letter published in MS News almost 20 years ago!

As in the last edition of MS News, we have used QR codes in this publication. These little black and white squares, similar to a barcode can be scanned on a smartphone, simply by opening the camera and holding it over the code as if you are going to take a photo of it. You must ensure the four corners of the code are visible on your screen. Your phone should then automatically scan the code and provide a link which you can click, taking you directly to the item we provide the code for.

We hope you enjoy this edition of MS News. As always, if you have any comments or would like to contribute, our Editor, Aoife Kirwan would be more than happy to hear from you – **aoifek@ms-society.ie**

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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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## The Art of MS – Symptoms Under the Spotlight

To mark World MS Day 2022, MS Ireland, in partnership with Novartis hosted 'The Art of MS – Symptoms Under the Spotlight', an art exhibition aiming to raise awareness of MS and the wide range of symptoms people living with MS can experience. The exhibition, which opened on Thursday, May 26th featured 12 original artworks created by people living with MS in Ireland.

Following a call for artists living with MS to put forward submissions, a judging panel whittled the incredible entries down to 12 pieces of art which included paintings, sculpture, digital illustrations and video. The art works selected were chosen for their ability to impactfully depict symptoms of MS.

MS Ireland was delighted to have some excellent speakers at the event including Dr Chris McGuigan, Senator Erin McGreehan and Deputy Mark Ward. Our many thanks to all who supported this event.

You can find out more about the exhibition and see the artworks on page 8.



**Dr Chris McGuigan speaking at the opening of the exhibition**



**Deputy Mark Ward addressing the attendees of the exhibition**



**Senator Erin McGreehan sharing her thoughts on the artworks**

## Patients Deserve Better Campaign for 100 additional Neurology Nurses

As part of the Neurological Alliance of Ireland (NAI), MS Ireland have been supporting the Patients Deserve Better campaign which aims to highlight Ireland's lack of neurology nurses.

Based on recommendations, Ireland should have a minimum of 142 neurology nurses in order to improve condition management and increase accessibility of healthcare however, Ireland is 100 nurses short of this standard. Increasing the number of neurology nurses

would assist in resolving issues such as long waiting lists which may help to ensure any deterioration in a persons condition can be mitigated as well as giving them a sense of involvement in their care which can lead to persons living with MS having more confidence to self-manage their condition.

Neurology nurses are a key element of care for people living with MS. Mark Mitchell, who lives with MS, took part in a video for the campaign in which he described his life as being much better now that he has access to his MS nurse and noted that everyone should have access to one as they are 'crucial' for people with neurological conditions.

Since the launch of this campaign in October 2021, MS Ireland has had people living with MS present at each of the launches nationwide and has supported this campaign at both a national and regional level. On the 15th of June, MS Ireland attended the AV room briefing on the campaign for Oireachtas members to call for 20 of these nurses to be included in the upcoming Budget.

The following week we were also in attendance at the Seanad debate around the shortage of neurology nurses at which we were addressed directly by Senator Martin Conway regarding how essential neurology nurses are to people living with MS as well as by Minister of State for the Department of Health Frank Feighan who complimented the success of the Patients Deserve Better campaign and acknowledged MS Ireland's contribution.



**Representatives from Patient organisations including MS Ireland's Research and Advocacy Officer, Alison Cotter outside Leinster House to support the campaign**

## Ukrainian Response

As the devastating events in Ukraine unfolded earlier in the year, MS Ireland took steps to help those living with MS. We knew that some of the people who would be coming to Ireland from Ukraine may have MS and we wanted to be in the best position we could to help support them. We liaised with neurologists and MS nurses to explore steps we could take to help. We also liaised with MS organisations across Europe through our European MS Platform (EMSP) membership and joined the EMSP working group to help where we can. We

produced an information sheet for Ukrainian nationals who come to Ireland and need to access MS services. Through our Information Line, we have responded to information requests from Ukrainian nationals regarding access to MS care and medication in Ireland. Our network of Community Workers have also provided information and support to those who have made contact with us.



## Brain Awareness Week



To mark Brain Awareness Week, 2022, MS Ireland released a series of short videos which aimed to explore the roles of various professionals involved in MS care. The videos were released on a weekly basis starting in January and

finishing on Brain Awareness week. The videos included an MS Ireland Community Worker; a neurologist; a physiotherapist; a researcher and an MS Care Centre staff nurse.

We also held a webinar to mark the occasion. We invited MS Researcher Dr Claire McCoy and Consultant Neurologist Dr Lisa Costelloe to share their thoughts on the findings of the study from researchers in Harvard university which found that the risk of MS increases 32-fold after infection with the Epstein-Barr Virus (EBV). The video can be found here: <https://www.youtube.com/watch?v=j-k8VKHOOMM&t=539s> or scan



## What a Wonderful World MS Day

World MS Day 2022 was buzzing with events and activities. From information stands and coffee mornings to radio segments, the day as well as the lead up to it was filled with information sharing, awareness raising and support.



MS Ireland were lucky enough to have two radio take overs! First up, MS Ireland's Aidan Larkin took over the airwaves of Flirt FM on May 23rd. The session consisted of interviews with: Trevis Gleeson - Chef, MS Blogger, Food Writer and man living with MS; Dr. Jill

McMahon – MS Research Group Biomedical Sciences Dept. at NUIG; Dr. Susan Coote – MS Ireland National Health Promoting Physical Activity Co-Ordinator and Amrit Kaur – Nurse and woman living with MS.

You can listen back here: [https://www.mixcloud.com/FlirtFM\\_Archive/flirt-fm-1800-monday-happy-hour-23-05-22/](https://www.mixcloud.com/FlirtFM_Archive/flirt-fm-1800-monday-happy-hour-23-05-22/) or scan



The second takeover, on Kilkenny City Community Radio took place on May 25th. It was hosted by MS Ireland's Chairperson, Maurice O'Connor. The 2 hour special featured extreme activity fundraiser Andrew Lynch; renowned neurologist Gavin Giovannoni;

MS Ireland's National Health Promoting Physical Activity Coordinator Dr. Susan Coote and South East Regional Community Work Coordinator Katie Hourigan as well as local Kilkenny people either living with MS or caring for a person with MS. Maurice was also be joined by MS Ireland Board member and Associate Professor of Psychology in Maynooth University, Rebecca Maguire as well as chef, food writer, MS Blogger and man living with MS, Trevis Gleason. You can listen back here: [https://soundcloud.com/user-76154967/ms-ireland-takeover?utm\\_source=clipboard&utm\\_medium=text&utm\\_campaign=social\\_sharing](https://soundcloud.com/user-76154967/ms-ireland-takeover?utm_source=clipboard&utm_medium=text&utm_campaign=social_sharing) or scan





### A wonderful coffee morning was held in the MS Care Centre

Our sincere thanks to all who supported World MS Day in whatever fashion you chose to do so. Whether it was listening to one of the radio takeovers, making a donation, engaging with an event that was taking place – your support is very much appreciated.

## Disabled Drivers and Passengers Scheme Appeals Committee

Earlier this year, it came to light that the members of the Disabled Drivers Medical Board of Appeals had resigned. This means that if someone living with applies for a the above scheme and is turned down, there is no mechanism by which they could appeal the decision. MS Ireland raised this issue and Deputy Mark Ward submitted a parliamentary question on the matter to establish when it could be expected that an appeals committee would be in place and the processing of appeals could resume,

A response was provided that indicated that Department of Health and the Public Appointments Service had issued a formal notice inviting expressions of interest from medical practitioners who wished to participate on the Disabled Drivers and Passengers Medical Board of Appeals. We await further information on this matter. Our thanks to Deputy Ward for raising this issue with the Minister.



### Deputy Mark Ward raising the issue of the delay in processing of appeals for the Disabled Drivers and Passengers Scheme

## Understanding Multiple Sclerosis Free Online Course

An upcoming, free 6 week online course is being offered to people living with MS, their families & carers; medical and nursing professionals; allied health professionals; advocates; service delivery staff and support workers. The course titled 'Understanding MS' will begin on September 12th. It requires an approximate 2 hour per week time commitment and aims to improve understanding and awareness of MS. The course

involves modules on;

- Biology and pathology
- Diagnosis and Symptoms
- Demographics and Introduction to Risk
- Risk Factors
- Disease Management and Support Strategies
- Living with MS

Further information on the course and enrolment can be found here: <https://menzies.utas.edu.au/education/free-online-courses> or scan



## SLÁINTECARE INTEGRATION FUND END OF PROGRAMME REPORT



In June, MS Ireland welcomed the publication of the Sláintecare Integration Fund End of Programme Report which set out the achievements of the 123 projects funded through the Sláintecare Integration Fund, including Active Neuro which was delivered by MS Ireland.

Active Neuro employed an integrated care approach to deliver health promoting physical activity programmes for adults with neurological conditions in the community in CHO Area 3. The programme succeeded in having high attendance, excellent satisfaction and led to improvements in physical and mental health symptoms. Specialist physiotherapists were key to Active Neuro's success as outcomes were optimised through a transformative approach to telehealth and exclusive focus on neurological conditions.

The success of Active Neuro has led to MS Ireland's proposal for sustainable funding for a national physiotherapy service, provided by a specialist team of physiotherapists directly employed by MS Ireland and delivered at a regional level using a blend of 'online' and 'in-person' programmes / services.

This service would comprise group health promoting physical activity and symptom management strategies alongside individual treatment to adapt, maintain and prevent as needed by the person living with MS, and other neurological conditions. This is discussed further in our Pre-Budget Submission which you can support by writing to your local Public Representative using our pre-written letter on page 14.



## Education is key to prevention

### By Pat McCarthy

Persons living with multiple sclerosis (like myself) can sometimes be vulnerable. It is important that we recognise our individual ability and circumstances in order to best protect ourselves. Living with a condition like MS can have its challenges. To help protect ourselves, we engage with a healthcare team, often take medications to help prevent or limit damage and often take other measures to maintain good general health.

Just like health awareness, it is important that we are aware of our limitations when it comes to crime prevention. Some people living with MS can experience issues which make security more difficult. When we have information, it empowers us to take preventative measures to help ourselves. So what can we do? The following advice has been informed by information provided on the garda.ie website.



**Knowing your location is important.** Keep your Eircode in a handy location. If you don't know your eircode you can use the Eircode website to input your address and find it. Having this means that you can provide it to the

authorities in the event you require their assistance. This will help them to find you faster. <https://finder.eircode.ie/#/> or scan

**Keep phone numbers to hand** – it can be helpful to have a list of phone numbers for your own support team. This could include a neighbor who you might call upon if there was an issue, a family member, even the local Garda station.

## BEWARE OF BOGUS CALLERS

Some people employ door-to-door traders. It has been known to happen that bogus callers may call to your door claiming to be professional roofers, guttering experts, painters, other trades people or even ticket sellers. They can often 'convince' people that repairs need to be carried out. Sometimes, these individuals carry out very little work and charge excessive fees. Bogus callers can sometimes be deceptive, cause damage to your house or engage in menacing behavior such as demanding money. Some tips to protect yourself from bogus callers are:

- Inform the caller that you never employ people 'cold calling' to your door.
- If you are interested in the services offered, ask for a sales brochure or other documentation that you can subsequently investigate and verify as credible.
- Be particularly careful where sales documentation only displays mobile contact numbers or incomplete addresses.

- If you think their employment is necessary, ask for an itemised written quotation.
- Never engage a person who insists on cash payment for services offered. Always use a method of payment that is traceable.
- Never leave strangers, even bona fide workers, unsupervised in your home.

## SECURE YOUR HOME

- Safely store away items that could assist a break in (ladders, tools etc.)
- Use quality locks on sheds, doors, oil tanks etc.
- Use a chain to secure valuable items such as bikes and tools.
- Don't leave a key outside, even in a hiding spot.
- Turn on lights, use timer switches and sensor lights
- Use your house alarm if you have one.
- Store keys in a secure location that is not easily visible from doors, windows, or letterboxes.
- Record details of and photograph valuables (serial numbers on bikes etc.).
- Do not keep large amounts of cash at home.
- Set reminders to lock your doors, windows, gates at a certain time each day.
- Have your door with a view outside that is adapted to your level.
- If unable to view your property, ask a family member or friend to look around and ensure all is as it should be.
- If you are a farmer, ensure to keep an eye on stock levels.
- Consider a pendant alarm.

Sergeant Paul Wallace, Garda Divisional Crime Prevention Officer advises **"If you have concerns regarding crime prevention, information is available on the garda.ie website or you can speak to your local Gardai for individualised advice and support."**

Remember, dial 999 or 112 in an emergency. 112 will connect you to emergency services on a mobile with no service.

## FOR MORE INFORMATION SEE:

<https://www.garda.ie/en/crime/burglary-theft/what-is-a-bogus-caller-.html>

<https://www.garda.ie/en/crime-prevention/securing-your-home/>



# The Art of MS – Symptoms Under the Spotlight

To mark World MS Day 2022, MS Ireland partnered with Novartis to present a unique collection of original artworks. The painting, digital illustrations, sculptures and video content were all created by people living with MS.

The aim of the exhibition was to explore a wide-range of MS symptoms. The artists produced incredible work with themes exploring bodily integrity, self-image and changing identities. The exhibition was held in Trinity Biomedical Sciences Institute from May 26th to June 1st. Here we explore the various art works.

## Dha Dhomhan By Dearbhla Crosse



**“This painting depicts how those with MS often precariously navigate two worlds. I was drawn to the imagery of water as so much of MS happens beneath the surface. At times, this sense of being overwhelmed is like being submerged, swimming against a tidal wave of symptoms. The ocean represents the turbulence of these emotions. Underwater, images depict my feelings of disconnection and worries that with the passing of time my health will slip away, as sand sifts through an hourglass. Although MS has taken parts of me, it has instilled a renewed sense of purpose and appreciation for my life and the people in it. The butterflies symbolise perseverance, transformation and hope”**

## Untitled By Evelyn O’Keefe



**“My artwork is inspired from the time I rejected an invitation from my medical team to view my MRI scans as I believed they were probably bleak, dark and terrifying. Instead, I wanted the focus of my artwork to depict a different scenario, one filled with optimism, colour and joy.”**

## Secret Central System By Meave Henley



**“My artwork is about the hidden nature of MS for people living with the disease. The sculpture, like me, looks ordinary from the front, nothing unusual. As you walk to the side and back of the sculpture you can see my exposed brain and spine. This is a metaphorical representation of sharing my MS with someone, of opening up that side of myself and letting others into my hidden vulnerability.”**



## Flare Up By Lauren White-Murphy



**“My artwork demonstrates the MS symptoms I experience including pain, weakness, spasms and cognitive issues which often leave me feeling delayed in time. The diamond dust used in the art serves as a reminder of how precious life is despite living with MS.”**

## Strong for You By Marion Mullhern



**“My artwork reflects my feelings and emotions that I experienced after a relapse following the birth of my baby boy. I felt raw, flat, and worried. As a new mother, I recall feeling that my symptoms and medication were pulling me down, I was tired, I saw bright flashes and my feet felt like blocks of ice. I remember stating over and over, ‘my feet are cold’, ‘my feet are cold’, ‘did I say my feet are cold?’ I reminded myself that my baby needed me, so it didn’t matter how I felt anymore which helped to carry me through and the happiness and love I felt for him made me stronger.”**

## Hand of Fate By Rosie Farrell



**“Through metaphorical imagery, my artwork explores my MS symptoms, particularly pain, and how these have forced me to examine my identity. In Irish mythology the raven is misunderstood as representing solely death, but it can just as often signify renewal and a change of fate. Much like the raven, society has a fixed idea of disability as being inherently negative: something to fear and hide from. But for me, MS has just become another facet of my identity however it’s the societal disability I’ve experienced, such as inaccessibility, that has been far more disabling. Hand of Fate looks at how disability marks and shapes us in unexpected ways, how beauty and pain are interconnected, and the positive effects disability can have in moulding our identity.”**

## My Shadow By Ruth Donnelly



**“The inspiration for this piece comes from a poem I wrote describing my feelings about living with MS. The 3 parts represent my life before MS, my experience during my last Relapse and my thoughts concerning my future”.**

### **Part 1**

Self portraits in vivid colour capture a glimpse into my life before MS. They float in bubbles, dreamlike, memories of a past life no longer possible. Disappearing before a dark incoming tide containing hidden depths of uncertainty. It represents the all consuming nature of the approaching illness.

## My Shadow By Ruth Donnelly

### Part 2

The experience of Relapse that caused sight loss. Here the imagery suggests the emotions felt. Empty bubbles replacing the experience of life. Trapped by an attack of MS and isolated by disability the cage also represents pain and spasticity. Suspended from telegraph poles with worn wires, (like lesions on nerve pathways) they symbolise the difficulty in communicating the experience of MS to others. The cage casts the shadow of a wheelchair and the constant threat of further disability.

### Part 3

Soft watercolours capture a calmer acceptance of change. A cracked hourglass represents the temporary nature of human existence. With printed statistics on Relapsing Remitting MS a ticking clock is a reminder of possible limitations ahead. Rolling dice float over footprints in the sand, a chance of maintaining mobility. The dove, a symbol of hope and peace also signifies navigation. To look for balance and remember to live.

## 35 Lesions By Joan Jordan



**“My interactive artwork shows how the brain lesions which cause MS are only visible due to MRI technology, yet I live with the symptoms every day. From fatigue, pain, depression, tingling, spasticity, cognitive fog, incontinence, headache and pins and needles, my symptoms are wide-ranging impacting my body and mind but are invisible to others.”**

## Pouring Out My Troubles By Seamus Burke



**“For centuries, the ritual of sharing a cup of tea has acted as a catalyst for people to discuss and solve problems experienced in life. In this case, the teapot is pouring out some of the symptoms of MS which I experience on a daily basis. I hope that my artwork helps to encourage others to share the symptoms and MS journey they are experiencing every day.”**

### A poem by Seamus Burke

Pouring out my troubles is what I do sometimes, it lightens the load that weighs heavy on my mind. Sometimes it's just the simple things that pull me down, the more complex problems see me constantly wear a frown. It's great to have a listening ear beside you as you speak, someone who understands you in your time of need. A friendly voice on the end of the telephone line can lift you to a higher plane and calm your mind. In this time of lockdown Zoom has played its part, we chat with one and other our problems to impart. Here I am on Facebook, Instagram and Twitter too, now I'm pouring out my troubles to you and you and you. Maybe you are someone just like me when troubles come knocking on your door, the words you could rely on aren't there when you need them most. Find someone who will listen, who will help to share your load and help you on your road.

## Resting in Presence By Sam Gaine



**“I have been a landscape painter most of my working life. Being an artist gives me a great sense of pride, purpose, and meaning in my life. I no longer have the dexterity in my hands to paint but I draw every day. Drawing has almost become a spiritual practice for me. Being creative is my anchor, it has been my light through dark times. I draw in the early hours of the morning after I have rested. Some nights I don’t have the energy to draw, and I just make a line on the page. Showing up is what is most important.”**

## Murmurs By Sarah Hutton



**“My artwork is a self-portrait depicting the changes that I experienced at the time of diagnosis but found so difficult to articulate verbally. My symptoms are mostly hidden from others but are circulating throughout my body and mind daily, including optic neuritis, nerve damage, weakness, fatigue, and pain through to changes in my identity and behaviour. My aim was to illustrate through art the uncertainty and isolation that an MS diagnosis can bring to and ultimately the resilience.”**

## Life with MS – A Visual Narrative Piece By Greystone Scribblers



**“This artwork has been created by four people living with MS and a long-term advocate for people with MS. It is a visual narrative piece which means it has visual and audio elements of the written word. This medium was chosen as one member has lost their sight and the group wanted the piece to be inclusive for all to enjoy. The written word displayed in the piece is reflective of each of their lives navigating MS.”**

To learn more about the artists involved and the exhibition, visit  
<https://www.ms-society.ie/news/art-ms-symptoms-under-spotlight-exhibition>

Or scan





## MS Irelands Physiotherapy and Exercise services

There are many aspects to living well with MS, exercise and physical activity being important components.

Thirty years ago we were telling people with MS to take it easy, whereas now we have evidence that suggests that the rate of relapses is higher in those doing no exercise, also those more physically active (through gardening, housework, moving around the house or the office) have a lower relapse rate. But this is not news to the MS Ireland community and for many years you have been telling us that programmes like physio and yoga are important to you, have important benefits for your symptoms and are not generally available through the HSE; the statutory healthcare provider.

These MS Ireland programmes happen because of the fundraising and grant applications by our regional offices and branches and unfortunately many branches are struggling to sustain the finances needed for these essential programmes. In recognition of the risk the service cannot be sustained, and the extent of the physio, yoga and exercise classes we run, the board created the posts of Physiotherapy/Exercise Coordinator and Administrator on a temporary basis for 2022. One of the first activities was an audit of our services, the key findings of which are reported here.

MS Ireland in 2021 delivered over 120 programmes for over 1000 participants led by physiotherapists, yoga instructors and fitness instructors. The satisfaction data is extremely positive with over 80% agreeing or strongly agreeing with statements about the programmes. The outcomes data is also extremely positive with improvements between 3 and 9.5% in outcomes like the MS Impact and Walking Scales and the Fatigue impact scale. Participants also talk about the social and mental health benefits of logging on each week and chatting to the instructors and other participants, and the motivation

that the classes bring. We engage with over 40 contractors around the country to deliver this service and coordination and standardisation would further enhance the service we deliver. In short, the service is effective and is highly valued by the participants with excellent satisfaction data potentially preventing use of other HSE services and enabling people to live well at home.

These data and the results from our “pandemic physio projects” Active Neuro and Move Smart MS form the basis of a campaign to the HSE for statutory funding of our physiotherapy programmes. We have been meeting with politicians, writing to many more, meeting with HSE personnel in the Disability and Primary Care sectors and will be expanding to other HSE sectors in the future. We are looking for your help with this campaign as part of our pre budget submissions and have enclosed a letter for you to tear out and share with your local politicians. If you can help further by telling your story of how these programmes enable you to live well with MS Susan and Jack would love to hear from you **JackM@ms-society.ie**

**Dr Susan Coote**  
Physiotherapy/Exercise Coordinator





“I found out about the online exercise programme through the MS society and found it suitable to where I was at. Because of Covid it was delivered on line and I found this excellent. I had no travelling and I engaged with others from all around the country. We shared stories, hints and tips and learned from each other experiences and differing journeys. Most importantly for me we had a laugh. Through everyone’s sharing and openness I gained valuable knowledge about falls, risks, and how to minimise them and since I completed the course my walking has improved considerably. My advice to anyone considering the programme would be to give it a try, I think you’ll be surprised at the difference it can make.”

**Paschal**



“I know from the moment I go inside that door, I am cared for instantly, my worries go away from the moment I go in that door, they take my bags, make sure I am ok, provide me with food and tea, it’s a safe place to go, you feel happy knowing that everyone there is looking after you”

**Edel**



“My late wife had MS too. We never got to go on a honeymoon but when we came in here she said to me this was our honeymoon.”

**Martin**



“When I met with the nurse specialist, she goes through all of my medications, my home situation, aids, facilities etc. and may make suggestions and recommendations for me. My life is so much better having access to a nurse specialist and going forward everyone should have access to one. I feel nurse specialists are crucial for people with neurological conditions”

**Mark**

Tear out this letter to send to the Oireachtas members in your constituency and have your voice heard.

If you have any personal details you would like to add in support of our ask, please feel free to write it in.

**An ask for sustainable funding for MS Ireland to deliver a national health promoting physical activity physiotherapy services for people with Multiple Sclerosis, and other neurological conditions total €880,000 per annum**

Currently many people with progressive neurological conditions in Ireland have little or no access to rehabilitation services and are low priority for physiotherapy in primary care. There is a void of post-acute and post-community interventions to promote patients' health through physical activity.

Dear

My name is

I am writing to you to ask you to support the Pre-Budget Submission of The Multiple Sclerosis Society of Ireland.

MS Ireland has three primary asks for Budget 2023 which include:

**An ask to increase annual statutory investment in The National MS Care Centre by €600,000**

The National MS Care Centre is a 12 bedded unit which provides respite care to people living with Multiple Sclerosis and other progressive neurological conditions. MS Ireland are requesting €600,000 additional funding which would see The National MS Care Centre open 350 days per year, providing an additional 1,128 bed nights annually. The National MS Care Centre provides people living neurological conditions, including Multiple Sclerosis, and their caregivers a break and delivers a range of therapeutic services, neurological assessments, and social activities.

Further investment will not only support people living with neurological conditions such as Multiple Sclerosis, but will also support voluntary carers, without whom care in the home would be impossible, relieving further pressure on our health systems and hospital funding.

MS Ireland proposes a sustainable, specialist physiotherapy service to address this need using a blend of 'online' and 'in-person' programmes which provide a pathway of care from rehabilitation to community integration. Using data from a successful SláinteCare/Integration Fund project in the Mid-West, this evidence-based service will provide physiotherapist led, health promoting exercise for people with neurological conditions through a national physiotherapy service across all nine HSE CHOs.

MS Ireland have forecasted that this investment would annually deliver 1,458 participants in group programmes and 3,726 individual appointments and could be rolled out in one national development, or in phased regional stages.

**An ask for the provision of a further 100 neurology nurses in order to address unacceptable waiting periods, delays with diagnosis and treatment, with at least 20 to be provisioned for in Budget 2023**

MS Ireland as members of the Neurological Alliance of Ireland have been supporting the "Patients Deserve Better" Campaign which highlights the lack of neurology nurses across the country. Ireland requires further 100 neurology nurses in order to address unacceptable waiting periods and delays with diagnosis and treatment. Neurology nurses, including MS specialist nurses play a crucial role in the care of people living with neurological conditions. MS Ireland believes that all people living with Multiple Sclerosis should have appropriate access to an MS specialist nursing service.

.....  
Please use this space to add any additional information you may wish to share  
.....



# Pre-Budget 2023 Summary

## National MS Care Centre

An increase of €600,000 in annual investment in the National MS Care Centre to provide an additional 1,128 bed nights per year.

## Physiotherapy

Sustainable funding of €880,000 per annum for national physiotherapy services for people with Multiple Sclerosis and other neurological conditions

## Neurology nurses

Provision of a further 100 neurology nurses in order to address unacceptable waiting periods, delays with diagnosis and treatment

## Cost of disability

Measures to address the cost of disability including an increase in all core social protection rates and the introduction of a cost of disability payment

MS Ireland echo the asks in the pre-budget submissions of Disability Federation of Ireland; Neurological Alliance of Ireland and Family Carers Ireland.

To read our pre-budget submission in full visit [www.ms-society.ie](http://www.ms-society.ie) or scan



# Making your MS Clinic Visit Work for You

MS clinic visits can often be daunting. We can have so many things we want to discuss, questions we want to ask and issues we want to raise. While it is important that the neurologist has the opportunity to ask the questions they need in order to best support you or your loved one, it is also important that you have the opportunity to discuss the issues impacting you and ask the questions that matter to you. In order to strike this balance, it is essential to prepare for the consultation. Here we give you some hints and tips that can help you to prepare so that you can leave the consultation with confidence in your ability to manage or self-manage the condition between consultations.

## At home

- Between clinic visits, keep track of any MS related issues you or your loved one have experienced. This can be done by writing into a notebook, or even into an app on your smartphone.
- When noting any symptoms you experience, it is wise to rate the severity of issue on a scale of 1-5 as well as the duration. This will help you to accurately report the symptoms to the neurologist
- List of all medications that are currently taking - including frequency and dosage.
- Make note of any side-effects of concern.
- In the days leading up to the clinic appointment, make some time to go through your notes to refresh it in your mind.
- Prioritise issues you would like to raise. You can use the accompanying template to help with this.

## During the consultation

- Bring the short notes you have made and use them as a guide to help ensure you get to the issues that matter to you.
- Ask if there is anything you need to do following the consultation. For example, do you need to have bloods taken?
- Ask if your next appointment is being scheduled for you or if you need to book it in.

- Do you need a new prescription?
- If you don't already know, find out how to contact the MS team in the event you experience any symptom – make note of it so you have this information handy if you need it.
- Ask if you need another scan and when might this be expected.
- At the end of your consultation, keep any notes you have made in a safe place so you can easily find them for follow-up.

You don't need to wait until clinic visits to inform your healthcare provider about symptoms you're experiencing. If you have any symptoms should make contact with your MS team.

MS & Me blogger, Willeke Van Eeckhoutte wrote a blog on preparing for your neurology appointment. In it, Willeke discusses her tips on preparing and shares some of her own experience with this. To read Willeke's blog visit <https://www.ms-society.ie/ms-and-me/preparing-your-neurology-appointment> or scan



You can use this template to help you to prompt and prioritise during the consultation.

**Since your last clinic appointment have you experienced any symptoms of MS?**

Don't forget to make note of when it happened, how long this lasted and how severe it was on a scale of 1-10.

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**What medications are you currently taking?**

Include the dosage and frequency.

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**Any side-effects of concern?**

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**What are the top 3 issues you wish to bring up?**

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**Do you know how to make contact with your MS team in the event of experiencing issues of concern or if you have a question?**

If not, ask how you can do this during your next clinic visit and write the information down for future reference.

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**Anything else?**

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**Don't forget to ask for a new prescription if you need one!**



## EBV AND MS

In January, there was great excitement about the findings of a research paper titled 'Longitudinal analysis reveals high prevalence of Epstein-Barr virus associated with multiple sclerosis'. The paper, by researchers in Harvard University, investigated the role of the Epstein-Barr Virus (EBV) in MS. The Epstein Barr virus (EBV) is a herpesvirus which approximately 95% of adults worldwide have been infected with. Symptoms can range from asymptomatic (no symptoms) to infectious mononucleosis (otherwise known as glandular fever). EBV is transmitted through saliva, which can occur in several ways including kissing, sharing food or drinks.



While we have known from previous research on EBV and MS that there was a casual link, this study showed that neurofilaments (a marker of neurodegeneration), were shown to rise in those who would go on to develop MS, only after EBV infection. This tells us that you must be infected with EBV first, prior to developing MS. In fact, it showed that the risk of getting MS is increased 32-fold after infection with EBV.

While further research is needed to understand why only a small proportion of people who have been infected with EBV go on to develop MS, it is now recognised as the strongest infectious risk factor for the development of MS, along with other genetic and environmental factors.

The development of an EBV vaccine (to prevent EBV infection) holds great promise in MS research.

This kind of vaccine would work by educating the immune system to produce antibodies to neutralise EBV and teach immune cells to remove EBV infected cells.

The development of mRNA vaccine technology which was used to address the COVID-19 pandemic, is now being used to develop an mRNA EBV vaccine. In fact, an mRNA EBV vaccine is already in an early clinical trial phase, investigating the safety and tolerability of their EBV vaccine in health adults.

Investigation into whether or not a vaccine can provide long-term immunity against EBV and if boosters would be required to maintain high levels of neutralising antibodies is also ongoing. While this study is at an early stage, the potential outcome is exciting. The successful development of a safe and effective EBV prophylactic vaccine could pave the way for a definitive MS prevention study, where EBV could be removed as a risk factor – preventing MS.



# JUST ASK, DON'T GRAB



## Just Ask, Don't Grab

The outside world can present barriers for people living with disabilities: one such barrier is having help forced upon you from other people.

In recent years, more and more people living with disabilities have reported being dragged across roads into oncoming traffic, had their wheelchairs moved without consent or have experienced being steered around shops.

This misguided help can not only be a dehumanising experience for the person with the disability, but also a safety issue when well-meaning members of the public, sometimes get it wrong.

So, how can I help?

If you want to offer assistance to a person living with a disability, introduce yourself, ask how you can provide any support needed and respect their response.

Disabled people have the right to refuse your help, because they don't always need it! The message is very clear, if you think a person with a disability needs help, just ask, don't grab!



## Letter to the Editor

MS Ireland was delighted to receive an email recently from a past MS News author. Yvonne McGoldrick was kind enough to reach out to us, almost 20 years after her initial letter, to give us a quick update!



People have said "How do you do it?" and I reply "Look at Niamh, she doesn't know I have MS! She is my get up and go." Being a mother of four wonderful children is hectic, busy and fulfilling – a little harder with MS but only if I let it. I would dearly love to be rid of MS but that's not possible, so I make the best of life and live it to the full.

This letter is for all the mums with MS.

### The original letter

On 26 July 2002, my twenty-eight birthday, I gave birth to a beautiful baby girl called Niamh. Less than one month later my great sense of fulfilment and happiness turned to fear, panic and even loneliness.

I was unable to push my new baby's pram very far without dragging my right leg. At the same time, I noticed the same loss of strength in my right arm, some difficulty with speech and an incredible tiredness. I waited almost a year before seeking medical advice. Big mistake. Had I confronted my fears earlier I could have saved myself from one of the loneliest times of my life.

I was diagnosed with MS one year after Niamh was born. Since then, I have been able to rise above my MS. Yes, I have had to make life changes and learned to do things I never thought I could do (self-injecting three times a week, ouch!). I am on a learning curve, a very slow and selective one – I don't like to hear any negative things about MS!

### The update

Hi, I have just come across an article which I wrote for MS News almost 20 years ago. I remember that because the baby I speak of, who shares the same birthday as me, was 20 last week! It is of course, 19 years since I was diagnosed with MS. Well, the great news is, I am very well. I have not had any relapses since then. I am active and independent. I do have some disabilities, but it hasn't stopped me from living a very full and busy life. I wish I knew all those years ago that life could be so good, and MS would not beat me!

### Yvonne McGoldrick



**Niamh McGoldrick with her mum Yvonne on her 20th birthday**



## Game-changing facility in Donegal

*Donegal's first changing places toilet recently opened in the seaside community of Narin/Portnoo. The project involved a massive collaboration between the local community, Donegal County Council patient organisations in the area, local public representatives and local residents. Here, Paul Dawson who was a driving force in seeing this project brought to fruition tells us about the experience.*

My wife and I moved to Portnoo 3 years ago, just before COVID. Being confined to a wheelchair with my MS, it was a great move for me personally and my wife. The beach side property has level access and so it is suitable for my needs. The local community were very keen to show me their new beach wheelchair supplied by Donegal County Council. My first thought on seeing this chair was what a wonderful idea this was, however, it really did not meet the needs of those it was targeted towards (those confined to a wheelchair) as I explained the beach wheelchair was only fulfilling 50% of its potential because there was no available hoist for transfers for wheelchair users. I was approached by community groups regarding the best solution and explained that either a mobile hoist system or a full ceiling track system (as required by CPI) would meet the requirements.

As a former health and safety officer with the Fire Service and obviously due to my own diagnosis, I became very passionate and dedicated to encouraging the installation of the North Wests very first changing places facility. With the support and help of the Dolmon Centre, The Tidy Towns community groups and a huge effort from the community as a whole, we raised the necessary funds to install the toilet. A prominent businessman, Liam McDevit of Narin/Portnoo Golf club purchased the big-ticket item of a ceiling track hoist which was a fantastic gesture. Donegal County Council, through David Friel and Trudy O'Reilly provided invaluable guidance and support. After what felt like several hundred emails back and forth we were all on our way. Besides the fact that we have the first 'Changing Places step down facility' in the North West (or Ireland) is that it was a combined effort by all local politicians past and present who donated on personal grounds, in addition to organised events by the local community such as an open air musical concert featuring the Duck Street Band.

All standards and specifications of a Changing Places step down facility were researched with the assistance of Health Care 21, Catherine Peoples of MS Ireland and Mary McGrenra of Irish Wheelchair Association.

We held an official opening day which was covered by Highland Radio, Donegal Democrat and Changing Places Ireland itself. In attendance at the open day were a combination of members of Donegal County Council and elected members in addition to representatives from MS Ireland, IWA and all other interested parties.

The facility has been running for over a month now and it is great to see it being used by holidaymakers who require its services. It was a fantastic community achievement, and it is fair to say we are quite proud of our position of the very first changing places in County Donegal. I believe it is important to voice our opinions and indeed suggestions to improve the quality of life of anyone in a wheelchair and those alike.

Finally, I also firmly believe it is essential that organisations such as the MS Ireland and IWA should be utilised by all who require their services to support, guide, advise us and most importantly voice our needs.



**Supporters at the opening of the facility**



**The interior of the facility**



## 23rd Annual General Meeting (62nd AGM since MS Ireland's foundation)



Dear Member,

In an effort to reduce costs and with the passing of our Constitution in 2016, we are now able to send AGM notices to you by email. However, we need you to consent to the furnishing of the accompanying AGM financial documentation via our website instead of by post. Please complete the attached slip and return to **Alice McKeon, MS Ireland, National Office, 80 Northumberland Road, Dublin 4.**

We would like to thank those members who have already consented to being provided with the AGM financial documentation via our website.

In this issue of MS News, the call for motions are advertised (below). We have our full complement of Board Members so there will be no call out for Board members this year. 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 this issue of MS News. Where we do not have a postal or email address for you, service of notice of the AGM for 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 re-elected, takes place on Saturday, 17th September 2022 on zoom at 4.00 p.m.

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

The procedures for motions 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 4.00 p.m. on Thursday, 15th September 2022.

**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 was 12th August 2022.

## Annual General Meeting 2022

MS Ireland is holding their 2022 Annual General Meeting (AGM) on 17th September 2022 at 4.00 p.m. The AGM is an important event to inform members about the activities of MS Ireland over the previous year and offers members the opportunity to either put resolutions\* to the Board that might affect change within the organisation or vote on motions already listed. This year's AGM will be held online via the Zoom platform.

MS Ireland is a membership based organisation and the views of the members are highly valued in order to ensure that as an organisation, we remain relevant. Members of MS Ireland are welcome to attend and vote at an AGM – please complete page 60 of the AGM pack. In order to be a registered member of MS Ireland you need to be signed up to lifetime membership.

For those of you who are Lifetime members you will have received AGM documents in this current issue of MS News. If you require any further information on your membership status or how to become a member, please contact Triona Ní Ráinne by email [trionanr@ms-society.ie](mailto:trionanr@ms-society.ie)

Membership forms are available on the MS Ireland website at <https://www.ms-society.ie/sites/default/files/2019-06/MS%20Ireland%20Membership%20Form%2024072018%20%281%29.pdf>



Or scan the QR code.

\*The deadline for resolutions for this year's AGM has now passed.





## FERMOY (Continued)

We are very thankful to Coillte for allowing us to use their wonderful space of: Glansheskin Forest Recreation Area (Kilworth Wood) for this walk.

To the staffs of all the papers and Radio stations who's publications and media cover our branch area of North and East Cork, thank you for accommodating our notes, updates and advertising.



**President Marian Baker presenting cheque to Majella Fitzgerald Hon. Treasurer & Mary Sheahan-Lonergan PRO**

Sincere "Thank You" to Fermoy Bridge Club for hosting a fundraiser recently for the Multiple Sclerosis Society of Ireland, Fermoy Branch.

Carrauntoohil. This wonderful fundraising made it possible for us to continue supporting physio and yoga, and contributing to the MSIF and the Care Centre in 2021, at a time when our usual fundraising sources (backpacking, bucket collections, table quizzes) had dried up. The second presentation was a cheque for €672, raised for us this year by Ann Lynch who held a virtual coffee morning and raffles for our Branch.



**Our many thanks to Ann Lynch**



**Thank you to the 'Energizer Bunnies' for their support**

## South Dublin

Our Branch had a wonderful afternoon in the beautiful grounds of the Care Centre where more than 50 people gathered to enjoy a Hogroast followed by ice cream. It was so good to meet in person and catch up with everyone. We celebrated the birthdays of 2 of our members and supporters - Anne King and Mary Flanagan.

**We took the opportunity to present awards to our 2022 Branch award winners:**

**Person of the Year** - Bronagh Moran

**Volunteer of the Year** - Matty Treacy

**Carer of the Year (in absentia)** - Mary Roche

These award winners will now go on to be nominated for the National Awards.

We wish to thank most sincerely Ann McNamara of the MS Care Centre who made us so welcome on the day, ensuring all was in order. Ann also kindly presented our Chair Gerry Quinlan with his trophy for the 2020 National Volunteer of the Year - due to Covid, the awards were not presented in person that year.

We also had two cheque presentations. The first was on behalf of the "Energizer Bunnies", friends and colleagues of Bronagh Moran, who raised €12,000 for our Branch in 2021, by climbing Croagh Patrick and



**Ann McNamara presenting Gerry Quinlan with his National 'Volunteer of the Year' award for 2020**



**Congratulations to volunteer of the year, Matty Treacy**

A raffle and collection was held to raise funds for the Care Centre. We made up and donated hampers and gifts to raffle and had hairdressing voucher sponsored. The amount raised was €635. The Branch is adding €365 to this so a total of €1,000 will be donated towards the cost of medicine safes for the rooms in the National Care Centre.





Move Smart MS offers free online exercise programmes to anyone living with MS in Ireland. Our programmes differ from standard physio classes for four main reasons.

Move Smart MS is...

- **Online – so accessible from anywhere in the country**
- **Stratified – you’ll participate with others of similar age, stage of MS and ability**
- **Symptom focused – classes are tailored to specific MS issues**
- **Specialist – our physiotherapists specialise in neurological rehabilitation and the challenges presented by MS**

Our next block of classes will take place in September 2022. If you would like to participate, click on the link (<https://www.tfaforms.com/4946681>) or email [movesmart@ms-society.ie](mailto:movesmart@ms-society.ie) Please note that while MoveSmart MS is open to returning participants, repeating the same programme twice is not possible.

## PROGRAMMES

### 1. Newly Diagnosed

This programme is for people with a recent MS diagnosis. You will learn about MS and why physical activity/ exercise is important for living well with MS. Exercises will focus on overall strength, function, and fitness.

### 2. Better Balance

This programme is for people who have had a recent fall or are restricting their activities because they are afraid of falling. This programme will help you identify your personal risk factors and put in place strategies to reduce that risk. Exercises focus on improving strength and balance in standing.

### 3. Strength & Balance

This programme has been designed to help people experiencing muscle weakness, unsteadiness, and walking difficulties. You will learn to identify and use strategies to improve your current ability and classes are tailored for all abilities. Exercises will focus on developing your strength and balance needed for everyday function and walking.

### 4. Pilates

This programme helps you to learn about core stability and the benefits of pilates for people with MS. Guided exercises will focus on developing core strength, leg strength, balance, and flexibility.

### 5. Balance & Dizziness

This programme is designed to help those with symptoms of dizziness/vertigo, unsteadiness, blurry/ jumping vision. You’ll learn more about why these symptoms occur and strategies to help manage dizziness episodes. The class combines balance and vestibular rehabilitation exercises.

### 6. Higher Level Fitness

This programme is for those mildly affected by their MS. This programme aims to teach you how to improve your physical fitness levels through education and guided strength, balance, and aerobic exercise.

### 7. Bladder & Bowel Class

This programme helps those experiencing bladder/ bowel issues. Through open conversations, you will learn more about why you experience these symptoms and strategies to help improve them. Exercise will focus on strengthening the pelvic floor.

### 8. Seated Fitness

This programme is for people who predominantly use a wheelchair to mobilise and will help you to learn the benefits of physical activity for maintaining function. Exercises focus on building upper arm strength, hand coordination and physical fitness in a seated position.

With each evidence-based programme, you will also learn strategies on how to manage other MS symptoms including fatigue. We will then work together to set goals and action plans to help empower, motivate, and support you to put these strategies in place.



## UPCOMING EVENTS

### HELL AND BACK

**Hell and Back** join Team MS Ireland on 1st October and take on one of the toughest courses in Ireland – with thanks to Nine Dots.io (that's not a spelling mistake it is .io) who are sponsors of the event who have chosen MS Ireland as one of their charity partners. Contact **melaniec@ms-society.ie** to get a place.

### ABSEIL

We are back in Croke Park on the 17th October for the adrenalin seekers out there! Contact **melaniec@ms-society.ie** to find out more.



### DUBLIN MARATHON

If you have a roll over place from 2020 and you would like to join Team MS Ireland on October 30th please contact **melaniec@ms-society.ie**



### CHRISTMAS JUMPER DAY

Encourage your workplace and colleagues to wear their most festive jumpers on the 9th December to support MS Ireland. Please contact **melaniec@ms-society.ie**



### CHARITY GOLF DAY

Are you a member of a Golf Club – would you nominate MS Ireland as the charity of the year? These events are fantastic fundraisers, and we can support your event with banners, items for goodie bags etc. Please contact **melaniec@ms-society.ie** Skydive - register via our website **<https://www.ms-society.ie/get-involved/fundraise-us/skydive-ms-ireland>** or contact **melanie@ms-society.ie** for dates that suit you.



### BRIDGE

Do you play bridge? Would you nominate MS Ireland to be a beneficiary of your charity events? Please contact **melaniec@ms-society.ie** for more information.





# FUNDRAISING

## THANK YOU

**Andy Walsh – Barry McGahan & family** – both did the Croke Patrick Walk on the 4th April with Charlie Bird and both raised huge funds and awareness for MS Ireland – thank you so much.

**Andy Walsh**



**Barry McGahan & family**

**Harry McCabe** did an unusual fundraiser – he visited all 40 GAA clubs in County Cavan and scored 3 points in 12 hours! He raised funds for 3 charities including MS Ireland.



Thank you to the staff and students of Donahies Community School who did a walk in April for MS Ireland.

We did our 2nd **3,000 Crunches** in March Facebook Challenge – 350 people joined in and they raised over €35,000.

**Charlie and Megan Campbell** did the Brighton Marathon along with their partners who did the 10k. Between them they raised over €16,000. They have signed up to do the Dublin Marathon 2023!



**Charlie and Megan Campbell who did the Brighton marathon with their respective partners**





# FUNDRAISING

The **Women's Mini Marathon** was finally back in person in June and despite the not so good weather it was a wonderful day. Our 165 ladies did us proud and raised over €19,000.



**Skydive** – we are very thankful to Mags Doyle and her team including Tom and Dave who did a skydive in June and raised over €7,000. Orla Harrison also raised over €3,000 for her skydive.

We had a **Abseil in Croke Park** in June where our intrepid fundraisers got a great view of the city from the skywalk – particular thanks to David & Gina Haughton who raised nearly €5,000.



So many wonderful people take on so many amazing challenges for MS Ireland over a year – to mention a few who went over and above: **Chloe Murphy, Stephen Corridan, Dearbhla Crosse, Niamh Cusack and Sarah Walsh** –

## THANK YOU!

JOIN US IN NOVEMBER FOR  
**A MILLION**  
**EPIC ADVENTURES**  
FOR ONE INCREDIBLE CAUSE



[WWW.MSREADATHON.IE](http://WWW.MSREADATHON.IE)