

Scottish Multiple Sclerosis Register

2020 Report

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A Management Information release for Scotland

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Users should therefore be aware of the aspects of data quality and caveats surrounding these data, all of which are listed in this document.

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Welcome

I am honoured to introduce the tenth annual report of the Scottish Multiple Sclerosis Register. In the past year a lot has changed in the world and we have been through some difficult times.

The register has now been collecting data related to new diagnoses of MS since 2010. Data have now been collected on 4814 people with a verified diagnosis of MS, 535 of whom received a diagnosis in 2019. These people have been adapting



to a new diagnosis of multiple sclerosis during the COVID-19 pandemic and many of the normal support channels offered by the third sector are less available further highlighting the important of NHS MS nurse specialists.

Public Health Scotland have now replaced the Information Services Division (ISD) of National Services Scotland (NSS) and continue to securely store data from the Scottish MS Register. These data are analysed to explore epidemiological trends in MS and also to audit availability and access to MS services throughout Scotland.

In 2020 we have used the Scottish MS Register in conjunction with ECOSS, the Electronic Communication of Surveillance in Scotland System to generate a weekly list of people with MS who have had a positive COVID-19 swab test in Scotland. While only picking up individuals who are on the register this has given us useful information on the incidence of confirmed COVID-19 infections amongst people with MS in Scotland. This work was championed by Professor David Hunt, a neurologist at the Anne Rowling Centre in Edinburgh and will be further explored in the future.

The steering group for the register consists of MS Neurologists, MS specialist nurses, AHPs and patient representatives, along with representatives from the MS Society, Revive MS and the MS Trust. The steering group works with staff from Public Health Scotland who coordinate the register nationally and who collate and validate the results. As always the entire system depends on the hard working MS nurses who enter patient data.

In the past year we have continued to use the Scottish MS register to explore the epidemiology of MS in Scotland resulting in a paper published in the Journal of Neurology. We have also presented data at the European Academy of Neurology Congress.

The register continues to serve as a quality marker for MS clinical services. Information related to prescribing of disease modifying treatments (DMTs) has been collected and will be used to ensure that access to all Scottish Medicines Consortium (SMC) approved treatments is equitable.

Sadly, Dr Belinda Weller, my predecessor as Chair of the Scottish MS Register died in November 2019. She was a warm and sensible neurologist and she is greatly missed.

I would like to thank Chrissie Watters who is our clinical coordinator who continues to strive for improvements in Scottish multiple sclerosis care whilst highlighting the importance of data

submission. Stuart Baird, Martin Paton, Martin O'Neil and our newest analytical team member Sissi Pizzo. The analysts often have to support clinicians who have less understanding of the principles of data management and I am grateful for their regular indulgences. Thanks also to George Mowat-Brown who chairs the patient representative group (PRG) and provides feedback from this group to the steering group.

Again, the most important people to thank are the MS specialist nurses who continue to input data for the register.

The COVID-19 pandemic has highlighted the real time clinical application of SMSR data as we have been able to alert clinicians of infections that they were otherwise unaware of. The effort of the nurse teams in maintaining the register will allow us to develop further 'early warning' or alert systems in the future.

Dr. Niall MacDougall, National Clinical Lead, SMSR Neurology Scottish Multiple Sclerosis Register | National Report 2020

Follow the link below to watch the Welcome video:

https://youtu.be/WZPqUVUgKKs

Foreword

I welcome this year's Scottish Multiple Sclerosis Register report, which sets out the achievements and progress made during 2019. Now in its tenth year, it continues to be a unique database that plays an important role in helping us understand the epidemiology and incidence of MS across Scotland that, with the addition of 535 newly diagnosed people in 2019, brings the total number of people diagnosed over the ten-year period to 4,814. This data is assisting service providers to focus on improving equity of access to services for everyone diagnosed with MS regardless of where they live in Scotland.



I am pleased to say 2019 has continued to see an increase

in the percentage of newly diagnosed people contacted within 10 days of diagnosis from just over 79% to nearly 84% and those contacted by a MS specialist nurse from 98% to 99%.

The utilisation of technologies, digital innovations and adaption of our cultural approaches has proved critical so far in 2020, as we respond to the global public health emergency presented by COVID-19. The Register will continue to be a valuable tool as part of ongoing work to study, understand and make progress in the way care and support is available that meets people's needs and wishes, during this period of uncertainty and change to the delivery of health and social care.

On behalf of the Scottish Government, I would like to offer my thanks and appreciation to everyone involved in sustaining the Register including the analysts and specialist clinical teams across Scotland – whose dedication and commitment make a difference every day to improve the quality of life for people living with MS.

Professor Jason Leitch

Clinical Director, Healthcare Quality and Strategy

Follow the link below to watch the Welcome video:

https://youtu.be/oVqQEJ1SKIE

Results and Commentary

About this release

This release by Public Health Scotland (PHS) provides information from the Scottish Multiple Sclerosis Register (SMSR) on all patients with a confirmed diagnosis with multiple sclerosis (MS) from January 2010 to December 2019

Main Points:

- In 2019, 535 new patients with a confirmed diagnosis of MS were added to the MS Register. This brings the total number of patients newly diagnosed and reported over the nine-year period to 4814.
- The annual incidence in 2019 was approximately twice as high in females than males.
- In line with previous findings, the average annual incidence of MS in the six most northern NHS Boards was greater than the average for the eight southern NHS Boards.
- The proportion of newly diagnosed patients receiving contact with a MS specialist nurse within 10 working days of diagnosis, increased from 79.2% in 2018 to 83.9% in 2019.
- Once a referral was received by the MS specialist nurse, 99.1% of patients were contacted within 10 working days, an improvement from 98.2% last year.

Below you can find statistics per each NHS health board:

Average annual incidence per 100.000 population, 2010 - 1019 data		
NHS Board		
NHS Orkney	17.51	
NHS Tayside	12.28	
NHS Highland	11.80	
NHS Western Isles	11.78	
NHS Ayrshire & Arran	10.49	
NHS Fife	10.44	
NHS Shetland	10.38	
NHS Grampian	9.63	
NHS Dumfries & Galloway	8.86	
NHS Forth Valley	8.84	
NHS Lanarkshire	7.67	
NHS Lothian	7.54	
NHS GG&C	7.48	
NHS Borders	7.08	
Scotland	8.96	

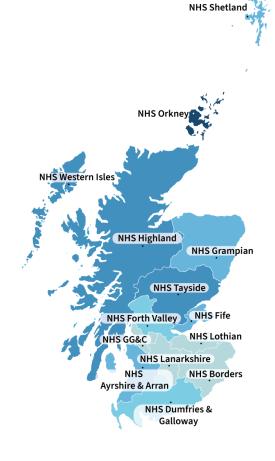
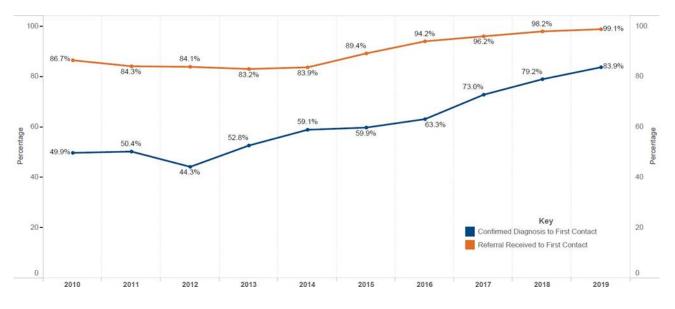


Figure 1: Percentage of patients with a new diagnosis of MS contacted by a MS specialist nurse within 10 working days of confirmed diagnosis and percentage contacted within 10 working days from receipt of referral



Background

The Scottish MS Register is a national register within the Scottish National Audit Programme at Public Health Scotland. The aim of the Register is to improve healthcare for people living with MS in Scotland. Establishing the incidence and interpreting the implications of its demography allows us to facilitate service evaluation and drive health improvement. The data on which this report is produced are provided by neurologists and MS clinical teams via a standard electronic proforma which incorporates the patient journey from referral to diagnosis, including referral to a MS specialist nurse.

Follow the link below to watch the Scottish Multiple Sclerosis Register Report 2020 animation:

https://youtu.be/XJ19-VfFpil

Scottish Multiple Sclerosis Register Data

You can access full SMSR data in the form of an interactive dashboard by following a link below:

https://viz-pre-prod.nhsnss.scot.nhs.uk/#/site/NSS/workbooks/7118/views

Patient

Win the Wilderness: Emily Padfield

When I saw the opportunity to live off-grid in the Alaskan wilderness advertised on a farming forum, it immediately appealed to me. I couldn't wait to get home and tell Mark (my partner of 8 years) all about it.

The advert was quite short, it just asked "would you like to experience living off-grid in the Alaskan wilderness". The short answer to that was yes, and Mark seemed up for it too. Little did we know at that point that there was a house to win at the end of it, that all came later.

During the decision process I can honestly say having MS didn't even come into the reckoning. I am lucky, I know this. My MS flares up from time-to-time in the form of numbness, fatigue, pins and needles and sometimes I do feel I am not perhaps as sharp in the mind as I once was. I do need a nap from time to time (doesn't everybody!) and I now take Gilenya having moved from Copaxone injections about 18 months ago now.

Having been accepted to go on the show (remarkably!) I did worry that my physical fitness and MS might not be up to the challenge. We didn't really know what the whole process would involve and I guess I was thinking more Who Dares Wins (the SAS show) as opposed to how it turned out. I enrolled in a gym (much to Mark's amusement, he put no training in at all!) and tried to get more in shape. I do think I underestimated my fitness levels, working on the farm gives you an inert level of fitness and strength but I am definitely no marathon or even 5k runner!



During the filming, I realised I needn't have worried. Most of the other couples were a good bit younger than me and I didn't feel left behind in the slightest. I guess that's what I struggle with sometimes, judging my activity against others and I have always overcompensated because of MS in everything I do. I guess I feel like I need to prove to myself that I can still do just as much if not more than others to feel like I am topside of it. I know I am lucky when it comes to my disease and I have always felt that. In fact, a month after being diagnosed (at 22) I signed up for a lambing job (12-16 hour days) that pushed me greatly physically before then going on a harvesting gang where we would regularly top 18 hour days. That was my 'running' time as I describe it, when I was running from my diagnosis rather than turning to face it.

There are so many more people worse off than me, with MS or with many other debilitating diseases. I always think that of the things to have, MS is one of the better ones for me currently. I know I am lucky. I don't know how long I will be this lucky so that's why I take on crazy things like Win the Wilderness: Alaska. Right until the end I didn't know if we would win or not. But not once did I think it would be my MS that stopped me.

Mary Wilson

My plan for this year was to enter all Paralympic badminton qualification internationals to give me the chance of gaining as many selection ranking points as possible. The ground work to be able to do this was a Cardiovascular (CV) and Strength/Conditioning gym session 6 out of 7 days plus being coached and playing games with my sparring partner. Late last year I had a severe MS relapse and ended up in hospital, losing the use of my left side. Gradually the strength has come back but it is nowhere like it used to be and I am hoping to be re classified next year into a fairer category for my increased disability.

Unfortunately, the Paralympics have been postponed till 2021. I totally agree with this decision. However, my training regime has been blown apart due to the lack of sports facilities and being unable to associate with other players and my coach. I do believe it was the correct decision for the government to make but that it should have been made much sooner. Keeping self-discipline, a positive attitude and motivation is proving to be an extreme challenge. In the big scheme of things, I need to keep reminding myself that people are dying all over the world and that sport and "my world" must come second to what is going on just now. I have made a weekly calendar and take each day as it comes. One day at a time helps me remain focused and "in the present". This helps me achieve what I have set out to do for that day.



I have put together an indoor gym session which is for strength/conditioning. I was also going out for a brisk walk for a CV hour each day but now have an Achilles injury and cannot walk for exercise which I find very frustrating. As you can imagine this is nowhere near what I need and I am very worried about losing my skills, fitness and court movement. Another year training as best I can and with Secondary Progressive MS is going to be a real challenge. I am already getting more injuries while I train, or don't train the way I used to, and as you know, MS is a strange beast.

I would say try not to be scared. The world is a very difficult place just now for everybody. The thought of just giving up has crossed my mind. But the decision in showing MS that it will not define who I am won through. People would say to me, "you can't do that", or "you will hurt yourself" but that made me even more determined to challenge myself and see just how far in life and sport I could go. Try and get used to having the diagnoses and then ignore it. Make a plan of what you are going to do about it. You can do anything you set your heart on and with your determination and courage, which you may initially believe you do not have, with small steps to begin with have a go at what it is you want to do. There may be many

times you won't manage but each time you will learn from it and one day it will happen. Never say never and don't listen to negative people. You just don't know what you are capable of!

Kirsty Stevens - Charcot

Named after the 'Father of Neurology', Jean-Martin Charcot, who first discovered the neurological condition Multiple Sclerosis (MS) in 1868, Charcot is a surface pattern design label inspired by MS. I was diagnosed with MS, in 2007 and since then I have realised that MS is so unknown, so I use design to raise MS awareness in an innovative way by making this invisible illness, visible. From my own MRI scans I take the lesion shapes, the damage caused by MS and create prints and patterns digitally which are then printed or etched on to various materials, which gives it an impactful permanence much like MS.

Over the past few months my work life and plans for the year have altered dramatically due to the global pandemic, which I am sure it has for us all, but I am finding ways to develop my work in new ways. I was supposed to currently be on research trips in London and Paris for an exciting research and development project taking a retrospective look at the creative workings of 'Father of Neurology' Jean-Martin Charcot.



I am still undertaking this project by researching everything from late 1800s, which I love, reading up on Jean-Martin

Charcot and also drawing from my own MRI scans, which you can see at

<u>www.instagram.com/charcotstudio</u> and <u>www.twitter.com/charcotstudio</u> I am excited to create a new body of work using new techniques and also take these trips when the world opens up again!

I was also recently inspired by this year's World MS Day theme, 'Connections' which made me think about the wonderful MS connections I have made over the past 13 years living with MS and also how I have connected people with MS through my creative practice so I designed this dot to dot to celebrate World MS Day, connect with others and allows them to help make MS visible too by connecting the dots! You can get your own free download online!

www.charcot.co.uk/worldmsday

Let's all stay connected at this difficult time!

Select link below to watch "I Raise Awareness of MS with My Designs" video (you will be taken to BBC Scotland's Facebook page).

https://www.facebook.com/BBCScotland/videos/166979937923094/?v=166979937923094

Patient Information Leaflet

Select link below for Scottish Multiple Sclerosis Register's Patient Information Leaflet (PDF).

https://www.msr.scot.nhs.uk/Documents/SMSR-patient-information-leaflet-200717.pdf

Community Partners

Multiple Sclerosis Centre Mid Argyll

So what have we been up to this year? Wow where do I start, what a year we have had.

Most recent is the fire walk. The photo of the fire walk is Fiona MacInnes who is a local lady who has had MS for over 30 years, this was Fiona's second fire walk for us in the last five years. The fire walk took place on Lochgilphead front green on Friday 23rd of January and we raised an amazing £13,312!



We have purchased our own digesting science kit last year with the help from three private funders to make this happen. The kit arrived late in the year so we are training volunteers at the moment to help us deliver this across Argyll and Bute. We will be working closely with the MS nurse and other local organisations in every area to make these events happen. Our first two are planned for Mid Argyll and Islay with events in Campbeltown and Oban happening soon after.

We are working with professor Lorna Paul of Glasgow Caledonian University to deliver the Giraffe web based physio program. We have physios working with us to assess people and set them up with their very own tailor maid physio exercise program. This allows them to do their physio at home following the program; they log into their own account, keep track of what they do and also feed back to us as to how they are doing. We have over 33 people assessed so far and enjoying being part of the program. We also run a class in the centre for people who can come together to do a basic physio class.

MS Society

- Lanarkshire Project

Launched on 24 October 2019, the Lanarkshire Project provides extensive self-management support, including information events and support sessions, to people affected by MS in Lanarkshire. Working with our local MS Society volunteers and healthcare professionals, the project offers local and online support to people at different stages of their MS journey.

People can access events and services, including newly diagnosed days, themed information events, virtual and face-to- face wellbeing sessions and 'Time to Chat' sessions which focus on different issues identified by attendees affected by the condition.

Activities and events that are part of the project aim to help support people affected by MS at whatever stage they might be in their journey - friends and family, people who are newly diagnosed and those who have been living with the condition for a number of years.

Craig Herbert, 46 from East Kilbride, is a member of the project's steering group and has been co-facilitating sessions as part of the programme. Craig said:

"I've been facilitating self-management sessions with MS Society Scotland for a decade now and I know how much of a difference programmes like this can make."

"I really wanted to give back and, while I believe one day we will have treatments to stop MS, self-management is something that can have a real, tangible effect for people living with the condition today."

"It's really important that people have the opportunity to learn about MS and what they can do to help manage its effects whether they or a loved one have been diagnosed with the condition."

"Having the chance to connect with other and build support networks like this can make a huge difference in the short and long terms."

The Lanarkshire project will expand on these sessions to provide a range of options for anyone affected by the condition in the area.

For more information on MS Society Scotland's Lanarkshire project please visit:

www.mssociety.org.uk/care-and-support/local-support/lanarkshire-project

- My MS, My Way; Tayside

The project, officially launched in June, is a 2-year pilot to support people diagnosed with MS within the last 5 years who live or work in Tayside. An advisory group formed of people living with MS has been set up and meets on a monthly basis and provides steer to the project. The services available under the project include information, free counselling, a Tayside specific helpline and access to wellbeing events. We have already delivered 1 virtual wellbeing event and have scheduled 4 more for the rest of 2020 along with topic specific information webinars.

- Helpline

Our award winning MS Helpline gives emotional support and information to anyone living with MS. We're here Monday to Friday, 9am to 7pm (except bank holidays). It's free to call from landlines and mobiles within the UK. What you tell us is confidential and when you call us, it won't show on your phone bill. Last year we answered 24760 calls UK wide to our helpline. You can send us a direct private message on Facebook messenger between 9am and 5pm Monday to Friday. We also have a confidential email service: <u>helpline@mssociety.org.uk</u>.

MS on your mind? Freephone: 0808 800 80000

- Information webinars

Our information webinars are themed by topic and are co-delivered by a professional with a special interest in a specific area. You'll have the chance to access information you can trust and ask questions about living well with MS.

In 2019 we ran 11 webinars covering a range of topics including cognition and MS, pregnancy and MS, and the science behind MS.

- Time to Chat sessions

For the last 12 months we have also been piloting virtual 'Time to Chat' groups which are an opportunity for people to meet virtually. These sessions have been organised after our information webinars or locally in our Lanarkshire self- management project where the participants discuss a 'topic' of choice.

- Wellbeing sessions

MS Society Scotland's wellbeing sessions have been delivered to hundreds of people across Scotland since 2018, offering support and a chance to connect with others in a similar situation. These have been so successful that they are now being rolled out UK wide.

Designed and produced with people affected by MS, these self-management support sessions aim to increase your knowledge, confidence and skills in managing life with MS. We have a range of sessions that run, for those who are newly diagnosed or who have lived with MS for a while. We have also run sessions for those with Progressive MS and we recently launched sessions especially designed for friends and family.

Find out more at www.mssociety.org.uk/living-well-with-ms-events

Wellbeing Hub

Visit MS Society Wellbeing Hub by following the link below:

https://www.mssociety.org.uk/wellbeing-hub

Stop MS Appeal

Here at the MS Society we are proud to be the UK's leading not-for-profit funder of MS research, investing over £218 million in today's money since we began. Right now we're supporting over 70 active projects worth more than £20 million, including the Edinburgh Centre for MS Research and a further 9 projects across Scotland.



We spend close to $\pounds 5$ million every year on research

and collaboration is key to our culture. We're a founding member of the International Progressive MS Alliance, working to accelerate the development of treatments for progressive MS around the world. We also play a leading global role in generating funding for MS research.

Over the past 20 years MS research has led to major advances in treatment. No other neurological condition has made such great strides and we're now in a position to build on that success and change what it means to live with MS. These efforts - while impressive - are not stopping MS fast enough. That's why in October 2019 we launched our Stop MS Appeal. We plan to raise £100 million to find treatments for everyone with MS. We can see a future where nobody needs to worry about MS getting worse.

To find treatments that slow or stop MS progressing, we're translating knowledge we've gained over the last two decades on how to stop immune attacks, repair myelin, and protect nerves, into potential treatment targets. We're also working with the world's leading experts to identify the most promising options for MS treatment, and create a first-of-its-kind MS clinical trials platform. This will allow us to test and deliver effective treatments for everyone with MS as quickly as possible.

To join #TeamStopMS visit:

https://www.mssociety.org.uk/get-involved/fundraise/stop-ms/team-stop-ms

You can watch Stop MS video by following the link below:

https://youtu.be/Z0RdZo04dJY

MS Trust

Over 100 people are diagnosed with multiple sclerosis every week in the UK. That's one person every two hours.

An MS diagnosis can be devastating, for people with MS and their loved ones. You may feel lost, alone and uncertain of the future. But you don't have to deal with it alone. The MS Trust is here for everyone affected by MS, from the moment of diagnosis and throughout your journey. We're here for you today, tomorrow and every day after, making sure a life with MS isn't a life defined by MS.

We fight to make sure everyone affected by MS can access good quality, specialist care and live the best life they possibly can. We support and train your MS health professionals and fund MS specialist nurses and Advanced MS Champions across the UK. We produce practical, evidence-based information, online and in print, and our dedicated Enquiry Service team are a friendly and knowledgeable voice to speak to for anyone who needs to know more about MS.

- Enquiry Service

Our enquiry service are here to answer your questions on all aspects of MS, whether you have been recently diagnosed, want to know more about a symptom or are trying to decide which medication is best for you. Our service is free to call and confidential. If we can't find the answer, we can direct people to someone who can. You can get in touch with us in whatever way suits you best.

You can call us for free on: 0800 032 3839

Email us on ask@mstrust.org.uk

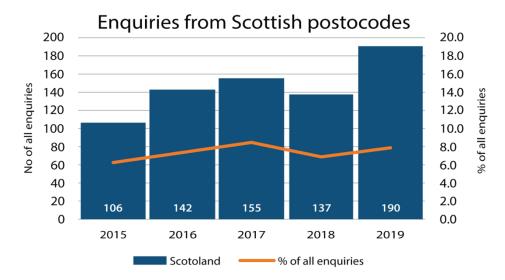


Send us a message to our Facebook page (www.facebook.com/mstrustuk).

"The person I spoke to on the phone was so lovely and so kind. She just listened and directed me to what I could do and steps I could take and I felt so grateful for that. Kindness is such an important thing and it meant a lot to me." – Service user

In 2019 - Service user ealt with nearly 4,000 enquiries, which is their busiest year to date. Of these nearly 8% of them were from people based in Scotland, this number has been growing steadily year after year.

- Trusted information



Wherever you are with MS, our award-winning information service is here for you when you need it. We believe in providing the best help and support so you can take control and live a life with MS, not defined by MS. We produce practical, reliable, evidence-based information, online, in print and in video, covering a whole range of topics, from lifestyle tips to MS symptoms; explaining MS to kids to drugs and treatments. Find our website at https://www.mstrust.org.uk

Despite a drop in the number of publications posted out in 2019 (due primarily to the popularity of our website), over 11% of the publications distributed were requested from people based in Scotland.



The top requested publications for people in Scotland were as follows.

- Top publications in Scotland (number sent):
 - Disease modifying drugs (748)
 - Living with fatigue (588)
 - Making Sense of MS: core pack (398)[#]

- Managing your bladder (390)
- Managing spasticity and spasms (345)*
- Managing your bowels (345)
- Making sense of MS (306)
- Secondary Progressive MS (180)
- Kids' guide to MS (161)
- Primary Progressive MS (124)

Two revised versions of previous publications appeared in October 2019

[#] Combined total for Making Sense Of MS: Core Pack and Making Sense Of MS: Core Book Combined total for

* Spasticity Triggers and Managing Spasticity And Spasms

• Communicating with Scotland

Our flagship publication Open Door, is sent out quarterly to over 18,000 people, of these 1,721 are based in Scotland. The table below shows the breakdown by postcode area.

Post Code	Area	Readers
AB	Aberdeen	173
DD	Dundee	115
DG	Dumfries	62
EH	Edinburgh	285
FK	Falkirk	80
G	Glasgow	282
HS	Outer Hebrides	17
IV	Inverness	104
KA	Kilmarnock	104
KW	Kirkwall	33
KY	Kirkaldy	112
ML	Motherwell	115
PA	Paisley	101
PH	Perth	78
TD	Galashiels	39
ZE	Lerwick	21

Email newsletters are sent out to more than 20,000 people each month, 1,600 of these are distributed in Scotland. Our social media channels have gone from strength to strength in 2019. Facebook closed the year with over 35,000 followers, of these followers over 4,000 people are based in Scotland. Twitter also ended the year on a high, with approximately 45,000 followers, of these 2,700 (6%) are based in Scotland.

- Supporting the MS Community

We're committed to ensuring everyone with MS can access the treatments and services they need and deserve, regardless of their postcode, circumstances or the type of MS they have.

We work collaboratively with MS charities, the NHS, and other decision makers to influence change and ensure the voice of the MS community is always heard loud and clear when it comes to the decisions that are important to them. Our direct services for people with MS, our strong relationships with health professionals, and our evidence-based approach give us the knowledge and expertise to be a trusted and credible voice for change within the MS community.

In 2019 the MS Trust had involvement in the following consultations and appraisals:

- Scottish Health Technologies Group (SHTG)
 Autologous haematopoietic stem cell transplant SHTG has now approved it.
- Scottish Medicines Consortium
 Ocrelizumab for early primary progressive MS SMC has now approved it.
 Fampridine forwalking problems we were invited to participate in November 2019. The final submission due in early Feb 2020.
- Training and funding MS health professionals
 - MS Trust Specialist Nurse Programme

The MS Trust Specialist Nurse Programme provides 80% funding to cover the employment costs of an additional MS nurse post for 15 months in areas of greatest need. In addition to the financial input, the MS Trust also provide a package of mentoring, training and facilitation to support service improvement to the whole MS team.

During 2019 the MS Trust have worked closely with two sites in Scotland through the Specialist Nurse Programme.

We have funded MS nurses in NHS Lanarkshire and at the Anne Rowling Centre in Edinburgh, creating 2 additional, permanent MS nurse roles. MS Trust funding of the MSSN in Lanarkshire finished in March 2019 and for the Anne Rowling Centre in January 2020 – in both instances the new MS nurse posts have continued to be funded by the NHS as permanent posts.

As part of MS Trust funding an evaluation of the added value of the new MSSN role is undertaken and the headlines from the Lanarkshire MSSN team are:

- Increased facility for people with MS taking DMDs to attend clinics just for blood monitoring giving people with MS greater flexibility and enabling the MS nurses to provide longer appointments for all (from 15 to 30 minutes).
- The MS nurses are now able to conduct joint visits with social workers and are providing more home visits to people with MS who are unable to access clinics (63% increase in numbers of home visits).
- They have set up new relapse appointments and a clinic for people newly diagnosed with MS.
- The average number of phone consultations per person with MS per year has increased by nearly 8 times from 2018 to 2019, due to improved provision of phone support.
- Between 2018-2019, 24% more people saw an MS nurse.

You can watch MS Nurse video by following the link below:

https://youtu.be/u6ez7eKcLoA

- MS Trust Annual Conference

The MS Trust Conference runs every year in early November and is open to any health professional working with people with MS; there are usually around 300 health professionals attending. The Conference runs over 2 ½ days with a wide range of eminent plenary speakers and interactive workshops. Health Professionals are able to ensure they keep up to date with developments in the care and treatment of people living with MS and are able to take back practical tips which they can use to improve their practice. The MS Trust provides 80% bursary funding to MS health professionals who attend to cover costs of registration. In November 2019 there were seven health professionals who attended from Scotland.

- Advanced MS Champions Programme

Over the last 18 months the MS Trust have funded six Advanced MS Champions at different sites around the UK. Advanced MS Champions provide clinical care and expertise to people with advanced MS and their families and work with other local health and social care teams to develop and improve patient care and access. Initial findings demonstrate greatly improved outcomes for people with advanced MS and financial savings to the NHS. A report on the outcomes of the programme is expected in summer 2021.

- MS Trust Foundation in MS Care

The MS Trust trains all new MS nurses and Therapists running a week long residential course for all in Stevenage. This provides training and support for this group of Health

Professionals and is accredited by Birmingham City University. The course runs twice a year and 3 health professionals from Scotland attended during 2019; the MS Trust funds the costs of the course for all new MS Specialists attending.

Revive MS

Revive MS Support had a busy year. Following the successful installation of our external, multi-sensory walking area we embarked on some re-modelling of two of our physiotherapy rooms. This required knocking down the adjoining wall and the formation of a doorway that leads directly onto the walking area. However, this was not the only reason for creating a now larger physiotherapy area. Our lead physiotherapist identified a need for an area for those clients who had previously been



active members of larger group exercises, recognising that they have established invaluable group cohesion and support from their fellow members, but due to the deterioration of their condition were struggling to participate in a large group activity.

By the creation of the new treatment area these clients can still attend on the day of their group activity, but receive more support from the physiotherapist whilst still remaining part of their cohesive group. We have a life-long commitment to our clients and continually work in our flexibility to meet their needs at all stages of their path with living with MS, peer support is an immense part. We are indebted to Jordanhill School who helped to raise the funds to make all this possible.

Our group courses are becoming increasingly more available with us now running: a regular four-week Memory Matters Course, a six-week Fatigue Management Course, an eight-week Mindfulness Course and a 6-week Mental Health & Wellbeing Course. We are also running workshops on bowel & bladder problems and sexual dysfunction. Plans are in place to commence with a number of new courses, in particular: Sleep Management; Pain Management and Workplace Management. A number of family orientated sessions using the Digesting Sciences interactive learning activities have been run and have now become a regular feature of our yearly curriculum. We have also continued to embrace the use of the Attend Anywhere platform for the use of our video-link service to those clients who are unable to attend the main centre or our Outreach Clinics.

In our aim to continually develop the range of services we can offer our clients, and in recognition of the challenges that some of our clients face with severe deterioration in their physical health, we have been establishing links with the various hospice providers within Glasgow and further afield.

We have created a network of links that now enable us to directly refer clients for specialist care (with their GP's approval) if their condition deteriorates beyond our capacity to offer services. However, in establishing these links we are aware that hospice care is so much more than end of life care. The hospices that we have made links with are also undergoing radical change in the way they provide services and are now able to offer localised courses, similar to what we offer at Revive (pain management, fatigue management) – this offers us the opportunity of being able to direct clients who live too far from our centre to attend regularly to have access to more localised activities.

Very fortunate for us we also received an exciting new Ambassador for Revive MS Support, Scottish Athlete Laura Muir. She is our first ever sporting Ambassador and is passionate about how physical exercise can make a difference to our clients. We are so much looking forward to working with Laura in the future.

However, the COVID-19 pandemic has had grave consequences for our service, as it has the world over. Despite the challenges it set, a COVID-19 recovery plan is now in place that will see us able to re-establish a live service in line with Government guidelines on the restrictions on movement and social distancing guidance. This will be a slow recovery for our Charity, as COVID-19 has not only hit hard our freedom to provide services for our clients; it has hit us financially also and our ability to fund-raise to support the services we provide will take time.

Challenging times are also the most opportunistic times for change and innovation and Revive MS Support will be taking this particular baton and running hard with it.

• Testimonial - Honor Drysdale

Summary: Diagnosed in 2009 and began attending the Paisley outreach in 2010. She came to Paisley every month, and has been attending Govan since we opened in 2016, benefitting from several therapies and forms of support, physical, emotional and financial. She is a former staff nurse in mental health, working at the RAH in Paisley; she retired through ill health in November 2019.

Honor was given her diagnosis in 2009 aged 38 years. A few months later she read an article in the Paisley Daily Express promoting Revive's new outreach in Paisley where she lives. She telephoned our main centre in Maryhill, was given further information, and arranged to come to the outreach. She attended every month for around 6 years, mainly for complementary therapy, always having the first appointment in the morning as this was negotiated with her manager. She was in full-time employment, working as a mental health nurse in the local hospital.

When Revive opened its new premises in Govan, the Paisley clinic was discontinued as it was so close geographically. Honor has been attending regularly as her disease has progressed. She has accessed support as follows:

• Reflexology: Honor's main issue is nerve pain in her feet. This treatment affords her short term release from pain in both feet. She describes it as "a lifesaver for

neuropathic pain". Therapists have also given her helpful tips about insoles. She has paid for reflexology privately when unable to get an appointment, but says, "it's not the same - the staff here are real experts and you build up a bond. They make you feel so welcome." She described the Complementary Therapy team at Revive as "all excellent, caring, passionate about the role, experts in MS."

- Physiotherapy: Honor has had 2 injuries to her neck and has been attending for blocks of treatment. She was in acute pain before Christmas and our therapist was able to fit her in: "I have never been so relieved." When it's healed she plans to go to the Monday exercise class. She is given exercises to do at home, and once again has been grateful to get special tips about tiger balm and biofreeze to use between treatments.
- Acupuncture: Honor was referred to our acupuncture specialist internally. She attended but didn't feel the full benefit as unfortunately she developed plantar fasciitis.
- Mindfulness: She completed the course and uses it as required. She has found it especially helpful when going for a CT scan at the hospital.
- Welfare & Benefits: Honor states she has had wonderful guidance and support from our Welfare and Benefits Officer. Having reduced her working hours to 4 days and then to 3, she eventually decided to give up work last year. She had never claimed benefits before, didn't know what to do and found the forms overwhelming.

"It's a horrible process but Alan makes it easier. He is so knowledgeable...knows the forms inside out, back to front. He has been brilliant. You can sleep at night knowing he's helping."

Honor feels that the specialist knowledge of MS within the staff team at Revive is absolutely crucial and sets us apart as an organisation.

She says that what is on offer here is "real individualised patient care." She takes every opportunity to praise Revive when engaging with other clinicians in the NHS, such as her consultant.

"From receptionist to all staff, everyone is so helpful. What a team!"

Improvement and Innovation

Multiple Sclerosis Nurse Prescribers

In recent years some of the MS specialist nurses have extended their role by undertaking further qualifications in independent prescribing. This has allowed services to be redesigned to a more flexible and efficient service delivery for patients and released medical resources which has ultimately improved patient care. The map below highlights some of the boards where MS specialist nurses are prescribing.

- 1. NHS Shetland Gowri Saravanan and Dorothy Storey
- 2. NHS Western Isles Rachel Morrison: "Having my prescribing allows me to ensure that patients are assessed and have the medications they need at point of care without the need for them to have to attend their GP. With the ever evolving treatments for MS I have a better understanding of the pharmacokinetics/pharmocodynamics interactions and also using the BNF as nurses we were never shown this in our training is a mine of information.

As I cover 9 Islands it allows me to liaise and suggest treatments to on island GP's who, because they know I am a prescriber, are happy to prescribe for their patients with MS.

It has also increased my confidence in advocating for patient's pharmacology needs and being able to discuss this with colleagues and carers."

- 3. NHS Tayside Suzanne Sinclair
- 4. NHS Forth Valley Yvette Gordon and Madalene Steel: "Yvette and I have both completed our Independent Nurse prescribing course. I completed mine in 2018 and Yvette the following year. This has helped to improve patient care and frees up valuable consultant time. We prescribe all the disease modifying therapies, including biologics, as well as recommending medications for management of multiple sclerosis symptoms and prescribing steroids.

Before patients who were relapsing were either prescribed intravenous steroids at the day medicine unit or we had to contact GPs to prescribe oral steroids, now we are able to assess patients and prescribe oral steroids ourselves, thereby preventing hospital admission and freeing up the GPs time.

The prescribing course has been invaluable for symptom management; we often recommend medication for neuropathic pain and spasticity by using electronic forms which go direct to the GP, we then follow the patient up by telephone to titrate medication.

During the course you are concentrating on medicines within your own area of practice and developing understanding of the mode of action of the medications. The course is hard work but it is definitely worthwhile and has improved the MS Service in Forth Valley".

- 5. NHS Highland Kitty Millar
- 6. NHS Lothian Emily Harrison
- 7. NHS Ayrshire & Arran Lindsay Collins and Mhairi Coutts

Scottish Ballet

The Elevate© Story, So Far...

Elevate[©] is a dance programme for people living with MS.

Development of the programme involved a six-month research and design phase, including a trip to Washington to meet with teams from Georgetown Medstar University Medical Center (Arts and Humanities), and the University of Florida (Center for Arts in Medicine), where health professionals are trialling dance for MS interventions. Scottish Ballet led two Co-Lab sessions in partnership with MS National Therapy Centre (Revive MS Support Glasgow), MS Society Scotland and NHS Scotland. These partners also provided Scottish Ballet with a focus group, observation sessions, taster sessions, training and national contacts.



Since its launch in April 2018, Scottish Ballet has delivered eighty-four Elevate© studio-based classes, with an average of eleven participants in each class. Sessions have been piloted in two base locations; Glasgow and Tayside. We have also established a satellite group in Orkney, where almost 0.5% of the population live with multiple sclerosis. Plans are now underway to deliver focused sessions in Edinburgh.

All of our classes invite participants to be dancers in a non-clinical environment. Equally, the sessions are research, enabling us to feed into a global knowledge base on the benefits of dance. We work closely with local and international partners in academia, health and the arts sectors to undertake research and evaluation of our health programmes, including Royal Conservatoire of Scotland, University of Florida, Georgetown Medstar University Hospital, and Ninewells Hospital and Medical School.

The Class

Each Elevate© one-hour session is delivered by two specialist dance artists and a live musician. Due to fatigue factor, the class is designed with a fluctuating energy flow and draws on mindfulness. The first section of the class includes a mindful settle and gentle mobility to allow people to become centered, reduce anxiety and increase energy. The use of imagery is used throughout the class. This allows people to move freely and to individual capabilities. The class also involves fifteen-twenty minutes of ballet barre. The natural structure of the ballet class targets specific physiological areas that people living with MS require. One of the great focuses of the class is to build confidence in traveling around the space with or without walking aids. As the classes have progressed, the dancers have gained in confidence, with many able to travel without the aid of support.

Feedback

The feedback and demand for the sessions has been positive, and participants have been quick to express their wishes for the classes to continue beyond the funded pilot. Health professionals have also expressed an interest in taking the project forward. Having the time and support to develop and design a programme which implements the best advice available has provided solid foundations for Elevate[©]. A full pilot evaluation report will be available later this year.

"As a total non-dancer, Elevate© has opened my mind and confidence. I feel that my body is responding to the moves, my brain embraces the instructions and wonderful live music. I leave the class with such happiness. I smiled all day." - Elevate[©] participant.

Next Steps

Scottish Ballet Health programmes are currently available digitally, with our Elevate© class reaching over two thousand people per week. Studio sessions will resume when it safe to do so, in line with official public health guidelines. Scottish Ballet is in the process of developing a strategy for SB Health, with the view to it building capacity for health in Scotland.

Scottish Ballet: Elevate© (Dance for Multiple Sclerosis) Below you can find a link to a short film outlining the programme:

https://www.youtube.com/watch?v=jhoKpG6br84&feature=emb_title

For more information please visit Scottish Ballet's website by selecting the link below:

https://www.scottishballet.co.uk/join-in/dance-health-wellbeing/elevate

You can learn more about Scottish Ballet's other health programmes by following the links below:

SB health online community classes

Health At Hand resources for NHS and social care staff

Research

The Anne Rowling Regenerative Neurology Clinic

The Anne Rowling Clinic, is a charitable University of Edinburgh clinical research facility. We deliver research studies and trials for people with neurodegenerative and neuroinflammatory conditions such as MS, MND and the Dementias, as well as hosting NHS Lothian specialist clinics.

Our Scotland-wide research provides people living with these neurological conditions the opportunity to take part in research studies and so be part of innovations and discoveries that will have a positive impact for the future. Alongside the research studies conceived and developed here at the Clinic, we also work on national and international collaborative research projects.

The clinic was founded by author J.K. Rowling in memory of her mother Anne and opened in 2013. In September 2019 Ms Rowling donated a further £15.3m to the Clinic to help improve the lives of people with multiple sclerosis (MS) and similar conditions.

The investment – which is inclusive of Gift Aid – will help create new facilities and support vital research at the Clinic.

"I am delighted to now support the Anne Rowling Regenerative Neurology Clinic into a new phase of discovery and achievement, as it realises its ambition to create a legacy of better outcomes for generations of people with MS and non-MS neurodegenerative diseases.

It's a matter of great pride for me that the Clinic has combined these lofty ambitions with practical, on the ground support and care for people with MS, regardless of stage and type; I've heard at first-hand what a difference this support can make.

I am confident that the combination of clinical research and practical support delivered by Professor Siddharthan Chandran and his exemplary team will create a definitive step-change for people with MS and associated conditions." - J.K.Rowling

You can watch a short video announcing the donation by following this link: <u>https://media.ed.ac.uk/media/1_why6samz</u>

• Current MS Research Studies in the Clinic

More detail on all studies at the Clinic can be found at www.annerowlingclinic.org/research

• Biotin

This study is fully recruited but is still underway. It is looking at whether high doses of Biotin may slow the progression of MS over a period of 28 months in people with progressive MS. Biotin is a vitamin normally present in food and needed for energy production in cells. This trial is being run by MedDay Pharmaceuticals.

• Brain Banking

Some people with MS choose to donate brain and spinal cord tissue for research after they die. The UK Medical Research Council (MRC) Edinburgh Brain and Tissue Bank is the only brain bank in Scotland.

The Bank collects tissue from people with various illnesses and diseases, including multiple sclerosis. Donated tissue is made available to researchers in the UK and around the world who are working towards finding treatments and cures for these diseases. The Bank is extremely grateful for all donations, which make an incredibly valuable contribution to research.

CCMR One

This study is fully recruited and results are being analysed. It is a clinical trial of a drug call bexarotene assessing whether it promotes remyelination in people with relapsing and remitting MS. Bexarotene is already used as an anti-cancer medication. This trial is being run by Cambridge University Hospitals NHS Foundation Trust and the University of Cambridge.

• Exploring Google search and treatment information

Most of us have found ourselves using Google to find more information when we have questions about our health. From researching symptoms to learning more about a newly diagnosed illness or condition, Google is a steady companion in our healthcare decision making. But when people affected by MS Google, do they see the same results and advertisements as their colleagues at work, their family, or their friends? If not, why not?

This study is seeking to measure the quality of results presented within search results and measure the impact of Google's algorithm on the health information presented to Google users who are affected by MS or Parkinson's.

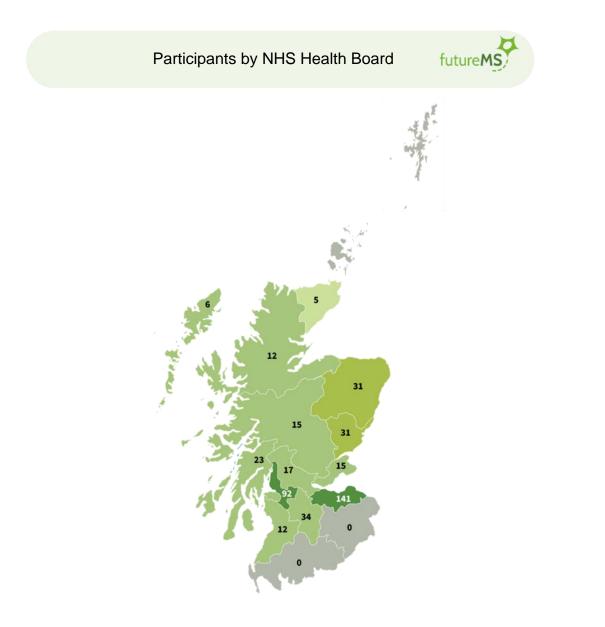
• FutureMS

FutureMS began in May 2016 as a Scotland-wide observational study for people who have recently been diagnosed with relapsing-remitting MS. Led by researchers at the Anne Rowling Clinic, this study is now fully recruited and aims to develop tools that provide an individual MS prognosis to support both personal and clinical decision making and planning.

This project is a national effort with 440 people taking part across 11 health boards and attending sites in Aberdeen, Dundee, Edinburgh, Glasgow and Inverness (see Table 1). Participants have all attended a baseline visit involving an MRI scan, blood tests (for genetic analysis), clinical examinations and health and lifestyle questionnaires. Second visits occur one year later, with most due to have been completed by summer of 2020. This flagship Scottish study will help inform the care and management for those diagnosed with MS, and is the beginning of more individualised healthcare.



FutureMS is funded by Stratified Medicine Scotland Innovation-Centre and Biogen



Quote from FutureMS participant:

"It's just nice to feel like you're helping, almost a comfort thing. It would be great just to have some idea of what I might expect from my MS."

- Information Processing Speed in MS (IPSiMS)

Many people with MS report feeling mentally 'slowed down' and find it difficult to concentrate. This can lead to problems engaging in various activities at home and at work.

The Information Processing Speed Study is fully recruited but ongoing. It aims to use computerised reaction time tests to compare information processing speed differences between people with MS and healthy volunteers. With this study we aim to determine the extent to which information processing speed influences correct decision making. This will help us better understand the mechanisms causing concentration difficulties in MS.

- Microbiome Study

This is an international collaborative study with the University of California, San Francisco looking at comparing the gut microbiome in the gut in people with MS and their partners or carers (http://imsms.org/). We are looking to recruit 500 participants from Scotland and have recently celebrated our 250th participant. A big thank-you to everyone who has taken part. Recruitment remains open for this exciting single visit observational study.

- MS STAT2- Secondary progressive MS simvastatin trial

This UK-wide drug trial looks to investigate the effectiveness of repurposing Simvastatin, commonly used in reducing cholesterol levels, compared to placebo in slowing the progression of disability in people with secondary progressive MS. Participation involves 10 study visits to the Anne Rowling Clinic over the course of approximately 3 years. This study is continuing to recruit beyond target in Edinburgh with efforts continuing elsewhere in the UK.

- MS Theory of Mind Study

Theory of mind refers to an individual's ability to understand that other people have their own thoughts, opinions and beliefs which can differ from our own. Theory of mind is important in social interactions as it allows us to adapt our behaviour and know what information to communicate to others, building on what they already know. This research study is working to find out if, for someone with multiple sclerosis, their theory of mind abilities impact upon their mood, relationship quality and social engagement.

- PHQiMS: measuring depression in MS

This study is testing whether a questionnaire called PHQ-9 can monitor low mood in people with MS. Low mood and depression affects as many as 1 in 2 people with MS at some point in their illness. This is often treatable but can be missed during doctors' appointments.

PHQiMS is a study that tests whether a short questionnaire, PHQ-9, could help to measure and monitor mood in people with MS. This study is fully recruited and the data is being analysed prior to the results being published.

- Regenerative Neurology Tissue Bank

We are building up a comprehensive bank of donated biological samples from people with neurological conditions, including MS, to help our research. People who wish to take part in this study will donate a one-off, anonymous sample of blood, saliva or spinal fluid. The sample is stored and used in future research into the causes and mechanisms of neurological conditions. The samples will be valuable for understanding why these conditions affect certain people and also for the development and evaluation of new diagnostic tests.

- Rowling CARE (Clinical, Audit, Research and Evaluation)

This national research interest registry has been driven by people living in Scotland with neurological conditions, including MS, and those caring for them. The purpose is to increase awareness of current and future research to enable people to participate in appropriate studies or simply to learn about ongoing research activity. Rowling CARE is a valuable resource for identifying potential research participants (www.rowling-care.org.uk).

- SMSR -Diagnostic Interval Study

Emerging evidence suggests that disability prevention in multiple sclerosis is most effectively achieved by people with MS taking disease modifying treatment early after the onset of the disease. Therefore, the argument that time from disease onset to diagnosis and treatment should be minimised has been gaining traction. This study aims to find potentially modifiable factors associated with onset-to-diagnostic interval. By using the records on the Scottish Multiple Sclerosis Register between 2010 and 2017, several factors including sex, age at onset, disease course, family history of MS, socioeconomic status, residence in urban/rural areas and Health Board at diagnosis have been analysed. The results of the study are now being written up and will soon be published in an academic journal and on the Clinic website.

- Vitamin D levels in people with MS

This study aims to improve our understanding of the levels of Vitamin D, and factors affecting this, in people with MS across the UK. This study is now fully recruited and has 500 participants with MS and 500 'matched controls'- people without MS who are the same age and gender and similar ethnic background as the person with MS.

Participants completed a questionnaire containing brief questions about their lifestyle and MS and performed a finger prick blood sample for Vitamin D levels and a cheek swab for genetic testing. This study is led by Wolfson Institute of Preventive Medicine, London and data is currently being analysed prior to results being published.

Events and Awards

We would like to congratulate MS MasterClass graduate Rachel Morrison on Winning the MS7 intermodule project award!

Rachel's project explored the use of an MS Passport in her patient population in the Western Isles, examining the personal, clinical, and cost benefits of a self-monitored, hand-held record of each individual's MS.

The MS MasterClass is a two-module course with an intermodule project carried out locally on an area of interest or need. This MasterClass, a large range of topics were investigated from service audits to digital solutions to disease- modifying treatment (DMT) analysis.

Each delegate produces a poster summarising their project, and after giving succinct presentation on these, the group voted for the top 3 best projects. The three projects chosen were by Rachel Morrison, Natasha Hoyle and the joint work by Neena Singh and Tatiana Christmas, all of whom gave full presentation, with slides, before Rachel was voted winner.

Runner up, Natasha Hoyle examined the variation in length of time from funding approval to treatment commencement of a range of disease-modifying treatments across different geographical areas in her locality in Sheffield.

Other runner up, Neena and Tatiana's joint work carried out at Barts and the London, looked at the prevalence of postprandial somnolence, or 'food coma' in people with MS. Finding that it generally affects people with MS than those without MS, they examined the various self-management strategies that people employ, from altering their portion sizes to dietary choices, to self-managing with caffeine or exercise to combat the effects of this particular form of fatigue.

The Neurology Academy are committed to sharing the evidence they and their peers have gathered to further support the knowledge base of clinicians and quality of care for those living with MS and other neurological conditions. The poster for all of this MasterClass group's research can be found on our website.

Acknowledgements

The Steering Group of the SMSR would like to thank the staff in all of the neurological units in Scotland for their help with data collection and checking. We are extremely grateful for the help and support they have given to help us continually improve the data collected.

This report could not have been written without the help of a great many people. This includes:

- Mary Wilson who was willing to share her experience and inspire many with her achievements.
- Kirsty Stevens who has shared her experience of using MS in a positive way in establishing her business, Charcot. Emily Padfield who demonstrated that MS was not a barrier for her to "Win the Wilderness".
- Clinical, research staff at all hospitals / clinics participating in the register who submitted their local data, provided local reports and commented on drafts of the National Report;
- Health Board colleagues who provided feedback about changes that improved performance in delivery of care for MS patients;
- The Patient Reference Group and those who generously gave their time and welcomed the coordinator to attend their patient groups, who have contributed to this report;
- The SMSR central team and publications team as part of the PHS who coordinate and collate the necessary information to produce the National Report. In particular, thanks to Mike Gurajek for his hard work and guidance to produce a report in more innovative and inclusive platform and improve accessibility of the report.

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