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# INTRODUCTION

## Friends,

Welcome to issue 4 of MS Research.

Over the summer, 415 people from the MS community in Ireland took part in our Research Prioritisation Survey. The purpose of this survey was to establish which areas of research are considered the most important by the MS community in Ireland, to help guide us as to how best to utilise funding for research as and when it is available in the future. The results will also help to inform what information we share in future issues of this eZine. We were delighted to get such a strong response to this survey and you can read a summary of the results on **page 3-4**. A sincere thank-you to everyone that took part!

A summary of the results of the survey were also shared with a group of Irish MS researchers at a networking event on 30 November. This event was very successful and there was a very informative discussion about how the MS research landscape in Ireland can be improved. You can read a report from the event on **page 5-6**.

Also in this issue we have a feature for you on research into possible causes of MS. Understanding possible causes of a disease is crucial not only to preventing future cases but also for helping to improve our overall understanding of the disease and how it works, so potential new treatment avenues can be explored. Go to **page 7** to read this piece.

Aoife Kirwan, Information, Advocacy and Research Assistant with MS Ireland and Shift.MS Reporter, attended ECTRIMS in Paris in October. ECTRIMS is the largest international MS research conference. Go to **page 19** to read Aoife's report.

You'll also find lots of other exciting articles including pieces on potential new treatment for progressive MS Biotin, updates from the physiotherapy team in the University of Limerick, an update from Queen's University Belfast and further news from Irish MS researchers in NUI Galway and NUI Maynooth.

We hope you enjoy the issue. As always, please feel free to make contact with any comments or questions by emailing [harrietd@ms-society.ie](mailto:harrietd@ms-society.ie)



**Harriet Doig**

Information, Advocacy and Research Officer  
Editor of MS Research and MS News



**Professor Susan Coote**

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## Research Prioritisation Survey – Results

By **Harriet Doig** – Information, Advocacy and Research Officer



Between June and October 2017, members of the MS community in Ireland were asked to complete a Research Prioritisation Survey. It is hoped that as and when MS Ireland has funding available for research in the future, the results of this survey will help guide us as to how best to utilise them so that we are funding research that is most in line with the views and needs of the MS community here in Ireland. The survey will also help us to identify and prioritise potential new research partnerships and collaborations, both nationally and internationally, and guide us as to what type of content people would most like to see disseminated in future research eZines.

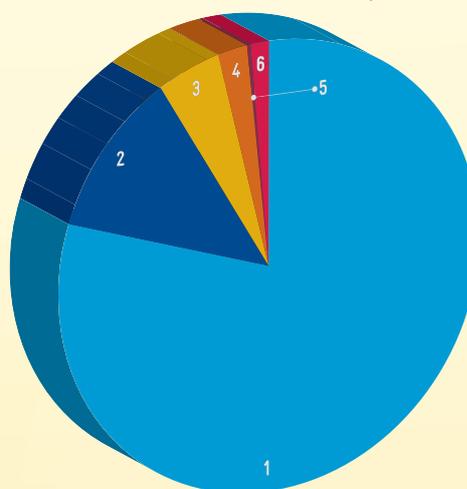
A total of 451 people completed the survey. Below we present a summary of the results. These results were presented to a group of Irish MS researchers at our Research Networking Event on 30 November, and the plan is now to produce a more detailed report which combines the results of the survey with the discussion that took place at the event.

### Volunteers Sought for Genomic Research Study

Irish life sciences company, Genomics Medicine Ireland (GMI) announced an important scientific research study aimed at unlocking the mystery of the genetic and lifestyle factors that contribute to MS. Volunteers with MS currently being treated at St. Vincent's University Hospital, Tallaght Hospital, Cork University Hospital or Altnagelvin Hospital in Derry are invited to participate in the study which aims to identify these factors in order to find better treatments, diagnoses and, ultimately, a cure for MS. GMI also hopes to rollout additional study sites around the country in the future. Interested volunteers should speak with their clinical team at one of the current research sites for more information.

## Sample

**415 people** completed the survey.  
The breakdown of the sample was:



1. People with MS	<b>80.24% (333)</b>
2. Partners/friends/relatives/ carers of people with MS	<b>11.33% (47)</b>
3. Healthcare professionals	<b>4.58% (19)</b>
4. Researchers	<b>2.41% (10)</b>
5. Students	<b>0.24% (1)</b>
6. Other	<b>1.20% (5)</b>

Among the people with MS, 72.81% (241) had relapsing remitting MS, 10.88% (36) had primary progressive MS, 10.27% (34) had secondary progressive MS, 2.72% (9) had clinically isolated syndrome and 3.32% (11) were unsure what type of MS they had.

Of the healthcare professionals, seven respondents were physiotherapists, five were nurses, two were occupational therapists and there was one each of the following: GP, counsellor, community worker, speech and language therapist, care worker.

## Findings

Participants were first given an open-ended question of "What research questions regarding MS would you like to see addressed and why?" Having gone through the results and analysed the responses, the top 10 most common responses were:

- |  |  |
|--|--|
| 1. Treatments/medications/<br>cures    | 6. Stem cells  |
| 2. Causes of MS                        | 7. Fatigue   |
| 3. Mobility/exercise/<br>physiotherapy | 8. Genetics of MS  |
| 4. Progressive MS                      | 9. Cognition   |
| 5. Diet                                | 10. Different types of MS<br>– who gets what type/<br>different symptoms |

# RESEARCH PRIORITISATION SURVEY

Other popular responses included researching why medications cause certain side-effects and how these can be prevented, cannabis and how it can be used to treat MS, the psychological effects of MS, Vitamin D and alternative therapies.

In the next question, respondents were presented with the following list of top 10 research priorities, developed by the MS Society UK and the James Lind Alliance:

1. Which treatments are effective to slow, stop or reverse the accumulation of disability associated with MS?
2. How can MS be prevented?
3. Which treatments are effective for fatigue in people with MS?
4. How can people with MS be best supported to self-manage their condition?
5. Does early treatment with aggressive disease modifying drugs improve the prognosis for people with MS?
6. Is Vitamin D supplementation an effective disease modifying treatment for MS?
7. Which treatments are effective to improve mobility for people with MS?
8. Which treatments are effective to improve cognition in people with MS?
9. Which treatments are effective for pain in people with MS?
10. Is physiotherapy effective in reducing disability in people with MS?

They were then asked "Is there anything that is not on the list above that you think should be included for Irish researchers, and why?"

The majority of respondents said that they agreed with the list and had nothing to add. Of those who stated that they felt there were other topics that should be included in the list, the top three most common responses were:

1. Diet
2. Exercise (besides physiotherapy – several commented that they felt this category should be broadened to include exercises such as yoga, Pilates or swimming)
3. Mental health and psychology

Other popular responses included causes of MS, cannabis, genetics, alternative therapies, safety and effectiveness of different medications (including side effects), stem cells, progressive MS, employment, pregnancy and fertility and the process of neurodegeneration and inflammation. Respondents were then asked "Is there anything on the list above that you do not think should be a priority for Irish researchers, and why?" Again, the majority agreed with the list and did not suggest that anything should be removed. Some respondents commented that prevention shouldn't be a priority as treatment is more important and prevention would be too costly to research. Others stated that they felt some topic areas, such as physiotherapy, were already very

well researched. Others stated that Vitamin D should not be a category on its own as this should come under either prevention or treatments.

Respondents were then asked to select three items from the James Lind Alliance list that they felt were the most important areas for researchers to focus on. Based on this, the top three items were as follows:

1. Which treatments are effective to slow, stop or reverse the accumulation of disability associated with MS? (74.89%)
2. How can MS be prevented? (42.13%)
3. Which treatments are effective for fatigue in people with MS? (31.49%)

Finally, respondents were asked to rank the items on the list on order of importance from one to ten, with one being the most important and ten being the least important. The ranking was as follows:

1. Which treatments are effective to slow, stop or reverse the accumulation of disability associated with MS?
2. How can MS be prevented?
3. Which treatments are effective for fatigue in people with MS?
4. Does early treatment with aggressive disease modifying drugs improve the prognosis for people with MS?
5. How can people with MS be best supported to self-manage their condition?
6. Which treatments are effective to improve mobility for people with MS?
7. Which treatments are effective to improve cognition in people with MS?
8. Which treatments are effective for pain in people with MS?
9. Is Vitamin D supplementation an effective disease modifying treatment for MS?
10. Is physiotherapy effective in reducing disability in people with MS?

Our next task will be to produce a top 10 list for Ireland, based on the responses to all the above questions.

*A sincere thank-you to everyone that took the time to complete the survey! We look forward to working further with the Irish MS research community to try and address the priorities that have been identified.*

If you have any questions or comments about the survey results, please do not hesitate to contact me at [harrieta@ms-society.ie](mailto:harrieta@ms-society.ie)

## Networking Event for MS Researchers

On 30 November, MS Ireland and Novartis hosted a networking event for Irish researchers interested in MS, in Trinity College Dublin.

The purpose of the event was to encourage MS researchers to connect with each other, and to have a discussion on what needs to change to make Ireland a better place to do MS research, and how MS Ireland can support this.

In total, 19 researchers attended from all around Ireland, including Northern Ireland. There was a broad range of research disciplines represented, including bench scientists (lab-based researchers, sometimes also known as 'basic' research), geneticists, physiotherapists and occupational therapists. People with MS were also in attendance, including Joan Jordan, EUPATI graduate, Alexis Donnelly who sits on the Scientific Steering Committee for the International Progressive MS Alliance and Aoife Kirwan, Information, Advocacy and Research Assistant with MS Ireland and Shift.MS reporter.



Harriet Doig, Information, Advocacy and Research Officer with MS Ireland presents the findings of MS Ireland's Research Priorities Survey

The meeting opened with a presentation from Harriet Doig, Information, Advocacy and Research Officer with MS Ireland who presented the preliminary findings of the Research Priorities Survey that MS Ireland conducted in 2017 (see the previous page for a full report on this!). This was followed by Claire McCoy from the Royal College of Surgeons. Claire presented on some of the benefits and challenges of Ireland as a place to do MS research, from the perspective of a scientist working in the area. Claire argued that Ireland should be a lot more prominent as a centre for MS research given our high incidence of MS, our stable population, our strong track record in research generally and our strong and motivated patient groups. At present, however, there is a lack of visibility, no clear leadership and

lack of communication among MS researchers in Republic of Ireland. She described a network for MS researchers in Northern Ireland which comprises of scientists, neurologists and clinical researchers and articulated the need for a similar network in ROI. Infrastructure and resources are also lacking and there is a pressing need to establish an MS registry, Electronic Health Records and a proper system of biobanks. Claire finished on an optimistic note by showing that it is possible to make a difference by working together, using the Epilepsy Lighthouse Project as an example. She also commented that Irish researchers have the advantage of having lots of different funding structures available, including EU funds. This was not the case in Australia, where Claire worked previously.



Claire McCoy, Royal College of Surgeons, presents on the need for a research network in the Republic of Ireland

After Claire, Kate O'Brien, Clinical Operations Officer with Genomics Medicine Ireland presented on 'Discovery opportunities in MS'. Genomics Medicine Ireland are about to commence the first large-scale population-based study of the genomics of MS in Ireland. Kate described why Ireland is a good place to do this type of research – Ireland has a large isolated population with greater genetic heterogeneity than other western European countries, and high numbers of people with MS. Also because Ireland has a relatively small number of neurological centres, communication and collaboration between them should be easier to facilitate. Kate also pointed out other advantages Ireland has – our education system is top 10 in the world rankings and nine of the world's top pharmaceutical companies have a presence here. There are, however, many challenges also that Genomics Medicine have encountered so far including lack of clinician time for research, lack of research infrastructure, lack of a centralised ethics committee making it necessary to get ethical approval from each individual hospital involved in the study, and delays in finalising contracts.



Kate O'Brien from Genomics Medicine Ireland presents on the benefits and challenges of conducting genomics research in MS in Ireland

There was then a facilitated round-table discussion, chaired by Professor Susan Coote, Chairperson of MS Ireland's Research Committee. Lots of great ideas were shared including:

- Facilitation of researchers to contact each other when they need samples, or have samples they are willing/able to share with others
- Creation of an internet platform where researchers can contact each other and share information – Facebook Workplace was suggested as one platform which could be used for this
- Establishment of a Public Patient Involvement (PPI) Network of people with MS, who researchers can contact for assistance with designing studies and grant applications
- Moving towards the standardisation of patient data that is currently recorded at neurology centres, to support the eventual establishment of a registry

A report writer was present at the meeting and a full detailed report of the discussion and recommendations arising from it will follow shortly.

MS Ireland would like to sincerely thank every researcher who took time out of their busy schedules to attend this event. We would also like to thank Claire McCoy and Kate O'Brien for speaking, Professor Susan Coote for chairing and Novartis for their support in organising and running the event.



Professor Susan Coote, Chairperson of MS Ireland's Research Committee, chairs the round table discussion

## MS Research Explored



The networking event was followed directly by the third MS Research Explored event, once again kindly supported by Novartis. As always the event was very well attended, with many more logging on to view the livestream online.

Ava Battles, Chief Executive of MS Ireland, introduced the event and Professor Susan Coote from the University of Limerick then presented on balance and falls in MS, followed by Dr Eric Downer from Trinity College Dublin who presented on his research into exercise and the potential therapeutic benefits of cannabinoids. The final speaker of the evening was Dr Maria Gaughan from St James's Hospital who talked about the importance of the doctor-patient relationship in treatment decision-making. Videos of the presentations are now available on MS Ireland's YouTube Channel – our YouTube handle is MSSocietyIRELAND



**Left to right:** Harriet Doig, Information, Advocacy and Research Officer, MS Ireland; Professor Susan Coote, University of Limerick; Ruth MacIver, MS Brand Lead, Novartis; Dr Eric Downer, Trinity College Dublin; Aoife Kirwan, Information, Advocacy and Research Assistant, MS Ireland; Ava Battles, Chief Executive, MS Ireland; Emma Kinnane, Associate Brand Manager, Novartis; Dr Maria Gaughan, St James's Hospital

## What causes MS?

By **Harriet Doig** – Information, Advocacy and Research Officer

Understanding potential causes of a disease can be crucial in developing treatments and cures. Whilst scientific understanding of what happens in MS has increased greatly over the last few decades, it is still not known exactly what triggers the immune system to start attacking the myelin sheath around the nerves. A number of different theories are the subject of ongoing research. Here we take a look at some of these theories and how scientists are studying them.

### Vitamin D

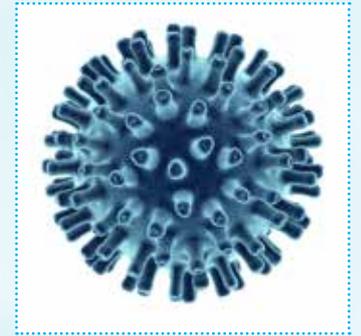


Vitamin D is produced in our bodies when our skin interacts with sunlight, and we also get some from our diet. It has long been theorised that low levels of Vitamin D may play a role in the likelihood of someone developing MS. One reason for this is that MS is known to be more common in countries that are further from the equator and get less sunlight, such as northern Europe, Canada and New Zealand, than it is in hot and sunny countries that are nearer to the equator. It has also been noted that children born with low levels of Vitamin D are more likely to develop MS in later life.

Lots of research has looked at possible links between MS and Vitamin D, and whilst scientists are increasingly convinced that it plays a role, it is still not known exactly how or why low Vitamin D levels may make someone more likely to develop MS. Theories include that Vitamin D plays a role in moderating the movement of immune system cells into the brain and spinal cord, and that Vitamin D may interact with a particular gene that is linked to MS.

### Viruses

It is believed that some viruses may play a role in the development of MS. In particular, the Epstein-Barr virus has been found to be more common in people with MS. A number of studies have investigated a possible link between EBV and MS – for example, one study compared blood samples of 222 U.S. military personnel who developed MS with samples from 444 disease-free but age- and sex-matched controls, and found a striking 36-fold higher risk of MS onset in those with high levels of Epstein-Barr virus antibodies in their blood. Current research is looking at possible mechanisms by which EBV may be linked to MS – whether it is the virus itself that causes the condition, or an immune system response triggered by the virus.



### Genetics



MS is not a directly inherited condition but it is thought that a number of different genes may play a role in someone's risk of developing MS. So far, over 110 different genes have been identified as being possibly linked to MS. Having a relative with the condition is known to increase an individual's risk of developing MS, but only slightly. The good news for parents with MS is that there is only about a 1.5% chance of a child developing MS when their mother or father has it.

There is also some evidence that there may be a link between genetics and Vitamin D in causing MS. Researchers have identified four different genes that appear to cause people to have low Vitamin D levels, and people with these genes are more likely to develop MS.

# CAUSES OF MS

A large-scale research project led by a company called Genomics Medicine Ireland will be commencing shortly. This will be the first ever population-based study of the genetics of MS in Ireland. The research will primarily focus on which gene variants are more frequent in MS patients vs. individuals with no history of MS. They are also hoping to be able to identify DNA variants that may cause differences in an MS patient/participant's disease type, e.g. relapsing remitting MS vs. primary progressive MS. DNA variants may also help predict how a patient will respond to MS medications.

See page 3 for more information on how you can participate in Genomics Medicine Ireland's study.

## Lifestyle factors



Smoking is believed to be a risk factor for developing MS, with the risk of MS approximately 1.5 times higher in smokers than in non-smokers. Again, it is not known exactly why this is the case, but it is possible that the chemicals in cigarette smoke have some effect on the immune system. Smoking is also known to interact with other possible risk factors for MS including the Epstein-Barr virus and the presence of certain genes.

Similarly, some studies have shown that obesity in childhood and young adulthood may make someone more likely to develop MS.

## Disproved theories



Many different theories have been put forward for what causes MS. Some theories that have been proposed but have been found to have little or no evidence to support them include:

- Owning a pet dog
- Having allergies
- Exposure to heavy metals
- Experiencing physical trauma
- The artificial sweetener Aspartame
- Narrowing of the veins from the brain – this theory was behind the controversial CCSVI treatment which several studies have now shown is not effective as an MS therapy

Information for this article has been taken from the following websites:

[www.mssociety.org.uk/causes-ms](http://www.mssociety.org.uk/causes-ms)

[www.multiplesclerosisnewstoday.com/epstein-barr-virus-and-ms/](http://www.multiplesclerosisnewstoday.com/epstein-barr-virus-and-ms/)

[www.nationalmssociety.org/what-is-ms/what-causes-ms/viruses](http://www.nationalmssociety.org/what-is-ms/what-causes-ms/viruses)

[www.multiplesclerosisnewstoday.com/risk-factors-for-multiple-sclerosis/smoking-and-ms/](http://www.multiplesclerosisnewstoday.com/risk-factors-for-multiple-sclerosis/smoking-and-ms/)

[www.nationalmssociety.org/what-is-ms/what-causes-ms/disproved-theories](http://www.nationalmssociety.org/what-is-ms/what-causes-ms/disproved-theories)



A big-thank you to our South Dublin branch who in September donated **€5,000** to the work of the International Progressive MS Alliance! Pictured left to right: Paddy Strong, former Chairperson of MS Ireland; Anne Restan, Board member and South Dublin branch member; Ava Battles, Chief Executive, MS Ireland; Maurice O'Connor, Deputy Chairperson of MS Ireland; Mary McKeon, Chairperson of South Dublin branch.

Thanks also go to the South Mayo branch who recently made a **€500** donation to the International Progressive MS Alliance

## High-dose pharmaceutical-grade Biotin (hdPB) as a potential new treatment for progressive MS

By Harriet Doig – Information, Advocacy and Research Officer



High-dose pharmaceutical-grade Biotin (hdPB), also known as MD1003, is a highly concentrated formula of an essential co-enzyme called Biotin, also known as Vitamin B7 or Vitamin H. High-dose Biotin is currently being investigated as a potential treatment for reversing the effects of progression in MS. Here we look at what Biotin is, how it works and what research is being conducted into its potential usage as an MS therapy.

### How does high-dose Biotin work?

Biotin is involved in various cellular functions including the production of fatty acids and the metabolism of fats and amino acids. There are currently two theories as to how high-dose Biotin might be able to slow disease progression and reverse disability in MS:

- a. Evidence suggest that cellular energy deprivation secondary to demyelination is responsible for the progressive irreversible degeneration of neuronal axons observed in progressive MS. The role of biotin in the tricarboxylic acid (TCA) cycle may lead to increase in production of a chemical called adenosine triphosphate (ATP). This ATP may in turn help restore the axonal energy balance
- b. Biotin may play a role in the synthesis of myelin

### What trials of high-dose Biotin as a potential MS treatment have been conducted so far?

In an early pilot study of 23 patients treated with Biotin for variable lengths of time, over 90% reported some improvements, including in some cases reductions of disability levels as measured by the Expanded Disability Status Scale (EDSS) ratings. In a follow-up study called MS-SPI, researchers conducted a 12-month randomised, double-blind, placebo-controlled trial followed by an open label 12-month extension phase. Patients eligible for this study were people with either primary progressive MS or secondary progressive MS age 18-75 years, who had evidence of disease progression within the last two years. Another study analysed data from an MS database, comparing people with primary and secondary progressive MS who had been treated with Biotin and fampridine (Fampyra), versus those who had been treated only with Biotin. They also looked for severity and frequency of side effects reported from Biotin.

### What did the trials find out?

In the randomised controlled trial, 12.6% of people who took Biotin showed some improvement in their disability levels, compared with none of those who took the placebo. Biotin was also observed to reduce the proportion of patients with confirmed progression. These results suggest that Biotin may be able to both slow or prevent disease progression and also, for some people, reverse the effects of MS-related disability. The other study showed similar results and also indicated that Biotin and fampridine can complement each other in preventing increasing disability levels. Both studies also showed that Biotin is safe and well-tolerated, with low levels of side effects reported.

### How soon is Biotin likely to be available as a treatment option for people with MS?

Further research is needed in order to determine if high-dose pharmaceutical-grade Biotin can be used as a safe and effective treatment for progressive MS. Another large-scale trial, involving 600 patients, is currently recruiting although unfortunately there are no trial sites in Ireland. MS Ireland will keep our members and stakeholders updated when we have any further information.

### Where can I find out more?

Further information about Biotin is available on the following websites:

[www.multiplesclerosisnewstoday.com/md1003-for-multiple-sclerosis/](http://www.multiplesclerosisnewstoday.com/md1003-for-multiple-sclerosis/)

[www.multiplesclerosisnewstoday.com/2017/05/09/medday-new-phase-3-trial-and-belief-in-biotin-potential-to-treat-progressive-ms-interview-with-frederic-sedel/](http://www.multiplesclerosisnewstoday.com/2017/05/09/medday-new-phase-3-trial-and-belief-in-biotin-potential-to-treat-progressive-ms-interview-with-frederic-sedel/)

[www.everydayhealth.com/multiple-sclerosis/treatment/biotin-promising-treatment-progressive-ms/](http://www.everydayhealth.com/multiple-sclerosis/treatment/biotin-promising-treatment-progressive-ms/)

Further information on the process for medications being approved for licensing and reimbursement in Ireland is available in MS Ireland's briefing document and position paper on this issue, which can be downloaded here:

[www.ms-society.ie/pages/living-with-ms/information-centre/ourpublications#Briefing\\_Documents](http://www.ms-society.ie/pages/living-with-ms/information-centre/ourpublications#Briefing_Documents)

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## To investigate the feasibility of an eight week breath-stacking programme in progressive Multiple Sclerosis (MS).

By Elaine Ross – Clinical Specialist  
Physiotherapist, St James's Hospital

### Background

Respiratory problems can occur in MS and may lead to morbidity and mortality (1). Breath-stacking is a suggested low-cost lung volume recruitment technique to address respiratory issues in various neurological populations. Breath-stacking further has been associated with a slower decline in lung function and peak cough flow in MS (2). Limited research has been undertaken investigating breath-stacking in MS.

The primary aim of this study was to investigate the feasibility of an eight week breath-stacking home exercise programme in progressive MS. The secondary aim was to measure its effect on peak cough flow, peak flow measurements, voice, cough, general level of daytime sleepiness, swallowing, fatigue and disease impact.

### Methods

A pre and post observational pilot study design was used. Ethical approval was obtained from St James's Hospital/ Tallaght Hospital ethics committee. Convenience sampling was used to recruit participants from April-May 2016. All participants were referred by their neurologist for routine physiotherapy, had a clinical diagnosis of progressive MS, were cognitively intact, medically stable and without significant respiratory symptoms. Demographic data, including MS and respiratory history was collected by the lead investigator. Baseline peak cough flow and peak flow measurements were recorded by a second investigator, pre breath-stacking and both 15 minutes post and 30 minutes post one cycle of breath-stacking. Participants completed: Leicester Cough Questionnaire (LCI), The Epworth Sleepiness Scale (ESS), SWAL QOL (Clinical rated), SWAL Care (Patient rated), Voice Handicap Index (VHI), MS Swallowing Performance Scale (MSSP), Modified Fatigue Impact Scale (MFIS) and the MS Impact Scale-29 (MSIS-29). All participants and carers were educated in the breath-stacking technique and were instructed to complete 6-8 cycles three times daily of breath-stacking exercises at home for eight weeks and complete a compliance diary. Final testing was then completed eight weeks later, assessing participants' respiratory history, peak cough flow, peak flow measurements, LCI, ESS, SWAL (QOL), SWAL care, VHI, MSSP, MFIS and MSIS-29 respectively. Carer and participant satisfaction questionnaires were also completed.

### Results

Ten people with secondary progressive MS (mean age= 56.7 years) completed the study.

- Mean peak cough flow and peak measures were 276 millimetres (mls) and 268 mls respectively

- No adverse effects were reported. High satisfaction levels with the intervention were reported by all carers and participants
- Reductions in participants' disease impact (16.4 %, 13.5) and fatigue levels scores (26.3%, 10.9) were demonstrated post intervention
- A positive trend in participants' peak flow, MSSP, SWAL (QOL) scores and in subjective cough, phlegm, wheeze, dysphagia, reported number of chest infections and antibiotic use were shown post intervention
- No significant improvements were demonstrated in participants' peak cough flow, peak flow measurements, voice, cough, general level of daytime sleepiness and swallow measurements.

### Discussion

- Respiratory problems can begin early, in mild, moderate and later in progressive forms of MS (1). Low baseline mean peak cough flow and peak flow measures were also demonstrated in this secondary progressive MS population. More research is required to assess the extent, aetiology of this respiratory issue, and its potential impact in all forms of MS
- Breath-stacking was shown in this feasibility study to be an acceptable intervention to use in progressive MS population. Breath-stacking has led to improvements in lung function, respiratory muscle strength, endurance, fatigue and cough augmentation, as well as avoiding hospital admissions and long-term ventilation in other populations such as COPD, asthma, motor neurone disease and muscular dystrophy (3-5). More high quality research investigating techniques such as breath-stacking and also the optimum dose, frequency and intensity is required to address this respiratory issue in progressive MS.

### Conclusion

- This study demonstrated the acceptability and feasibility of a breath-stacking intervention in people with secondary progressive MS. More research is needed into the potential benefits this intervention may have in this population such as reducing fatigue and disease impact levels.

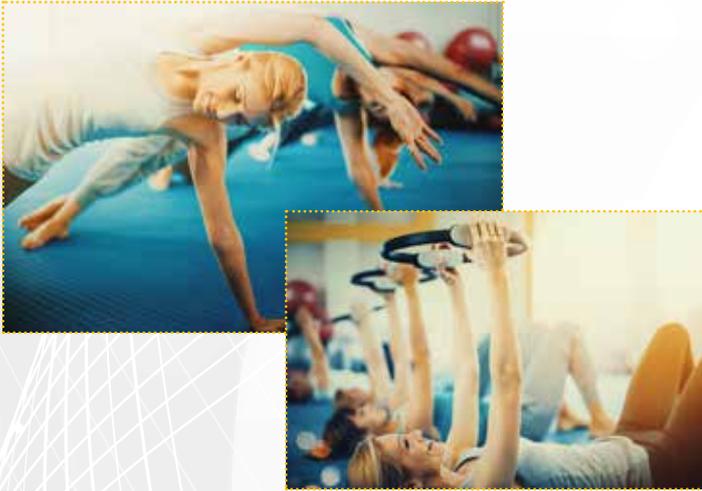
**Limitations:** This feasibility study involved a small sample of convenience. Only participants with progressive MS were used. The order of testing was not randomized.

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## The effects of pilates on mood among people with Multiple Sclerosis – Update

By **Karl Fleming** – University of Limerick



Mood impairments, including symptoms of depression, anxiety and fatigue are highly prevalent among people with MS. Physical activity is a key in symptom management, and there are now many research studies that have shown that exercise has a beneficial effect on mood and mental health outcomes among otherwise healthy adults and adults with diverse chronic illnesses, including MS. Traditional forms of aerobic and muscular strength exercise have positively affected these psychological symptoms, however, non-traditional forms of exercise, including yoga, Tai Chi, and Pilates remain understudied.

In Issue 3 of MS Research, persons with MS were sought to participate in a study to investigate the effects of eight weeks of supervised or home-based Pilates, compared to a wait-list control, on mood among people with MS. An initial group of participants completed the eight-week intervention recently and we would like to sincerely thank all the participants who gave their time to completing this trial. It is proposed to run an eight-week home-based only Pilates trial to further enrich the data set examining the effects of Pilates on symptoms of depression, anxiety and fatigue in persons with MS.

Participants will complete two sessions per week of Pilates, over an eight-week period in the comfort of their own homes. Participants will be randomly allocated to either an immediate-start home-based Pilates group or a delayed-start Pilates group. Throughout the study, participants will complete a series of questionnaires relating to mood symptoms, and level of physical activity. If you are randomly allocated to delayed start, you will complete the questionnaires at the start and then again eight weeks later, and then you will start the Pilates exercise. A new group of participants are scheduled to commence the study mid-November 2017, and recruitment is on-going.

To be eligible to take part in this research, participants must be:

- Adult participants (>18 years), with a confirmed physician diagnosis of MS.
- Have no previous experience in Pilates.
- Free from any other significant health conditions or medical concerns that may prevent safe participation in physical activity.

If you are interested in taking part or have further questions, please contact:

**Karl Fleming** - [karl.fleming@ul.ie](mailto:karl.fleming@ul.ie)  
087 949 9106

**Dr. Matthew Herring** - [Matthew.Herring@ul.ie](mailto:Matthew.Herring@ul.ie)  
061 234 762

**Professor Susan Coote** - [Susan.Coote@ul.ie](mailto:Susan.Coote@ul.ie)  
061 234 278

*This study has been approved by the Faculty of Education and Health Sciences Research Ethics Committee (APPROVAL #2017\_03\_17\_EHS).*



## An exploration of the association between Dual Task Cost and falls in people with MS

By Gillian Quinn - PhD candidate, University of Limerick.

**Supervisors** - Prof Susan Coote, Dr Rose Galvin (UL), Dr Chris McGuigan (St. Vincent's University Hospital)

## Main Findings:

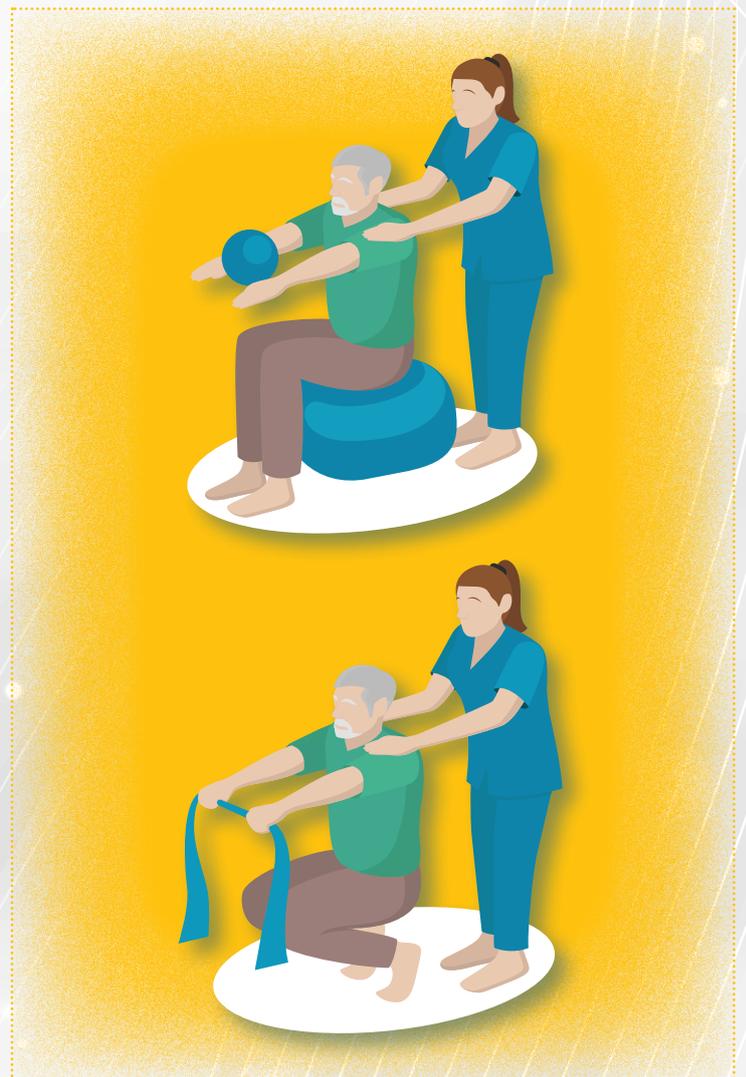
- 56% of the 100 people who took part in the study reported falling over a three-month period; more than half of those had two or more falls
- On average people walked 13% slower when they did the counting task with the walking, in comparison to doing the walking alone. Almost a quarter of the group showed a change in walking pattern and mistakes in counting when doing the two activities simultaneously
- 65% of fallers had reported problems doing two things at once in their initial assessment, and the likelihood of falling was doubled for this sub-group who reported having difficulty doing two things at once

Simply asking if the person has a problem doing two things at once is a quick, easy and cost-free method of establishing dual-tasking ability and may be useful in identifying falls risk. This study adds to the body of evidence examining DTC in people with MS and highlights its potential relevance as a component of falls interventions for people with MS.

This paper is currently under review in the journal, Topics of Geriatric Rehabilitation - special edition focused on balance and mobility issues in MS and Parkinson's Disease.



I work with the MS research team in University of Limerick (UL), led by Professor Susan Coote, and my overall research interest is in the area of falls in MS. We carried out a study last year with the aim of developing a tool to identify who is at risk of falls and needs physiotherapy treatment. During that study we assessed people walking without any distraction and then walking while doing a thinking task at the same time (counting backwards in multiples of three). Being able to do two things at once is essential in everyday life e.g. talking while walking or carrying shopping bags while walking. When a person does a thinking and walking task simultaneously, the performance of one or both tasks can deteriorate, and the measurement of this deterioration is termed dual task cost (DTC). We know from previous studies that people with MS have problems doing two things at once but the possible link with falls in MS is not fully understood. Participants in this study were asked about difficulty doing two things at once as part of a falls screening questionnaire, completed a timed walk under single and dual task conditions and then filled out falls diaries for a three-month period.



## Balance

By **Laura Comber** – PhD candidate, University of Limerick

Symptoms of MS can affect the physical, sensory and thinking processes of the individual. These symptoms can result in people with MS having impaired balance which can result in falls and cause issues for the physical and psychological well-being of the person.

Laura Comber, as part of her PhD with the MS research team in University of Limerick, conducted a systematic review and meta-analysis to quantify balance problems in people with MS in comparison to people without MS to help to inform future falls prevention interventions. If we can understand what aspects of balance are problematic, we can target these in our treatments.

**Data from forty-three research studies was examined to quantify these deficits with some interesting results being found:**

- **People with MS have significant deficits in balance compared to people without MS in a range of tasks including; standing still, standing still with their eyes closed, leaning and reaching, reacting to perturbations such as being pushed or knocked over, and standing on unstable surfaces**
- **These deficits are considerable, despite the relatively low levels of disability of the people with MS included by the studies, the majority of studies were limited to people who used a walking stick at most**
- **The association between these deficits and actual falls has not been well investigated**
- **There is a lack of standardisation about the information these studies provide about balance outcomes which limits the scope of this research**

**This paper is currently under consideration in a journal primarily concerned with walking and posture. By understanding the extent and nature of walking and balance problems we can design more tailored and effective falls prevention treatments for people with MS.**

Do you have Multiple Sclerosis?

Have you had a fall in the last three months?

Don't use a walking aid or use one walking stick or crutch?

### The MS Research Team at UL are looking for people to take part in 12 weeks of falls prevention classes!

Over half of people with MS will experience a fall every three months. The MS research team at UL, led by Professor Susan Coote, have developed a falls prevention intervention for people with MS. In order to assess its suitability and effectiveness for people with MS, we need to run a study.



If you answered 'Yes' to the three questions above, you may be eligible to take part. The study would involve you attending a class delivered by a chartered physiotherapist twice a week for 90 minutes for 12 weeks. The classes will consist of 45 minutes of exercises aimed at improving your strength, balance and walking and 45 minutes of education about preventing falls. Before and after the 12 weeks of classes you will complete three months of daily diaries (these are like a calendar) to record how many falls you have, and attend two assessment days where a chartered physiotherapist will assess your strength, balance, walking and feelings about falls.



The study will be beginning in January 2018. The classes will likely be in the Mid-West and/or West region depending on interest levels. Currently we are looking to make a contact list of people who would be interested in taking part so we can decide the most convenient locations and have people that will be ready to start the study in January 2018.

Should you be interested in taking part or have any questions about the study you can contact **Laura Comber** by email [Laura.Comber@ul.ie](mailto:Laura.Comber@ul.ie) or **Susan Coote** by email [Susan.Coote@ul.ie](mailto:Susan.Coote@ul.ie) or by phone on **061 234 287** and we will send you an information leaflet and answer any questions you have.



## Parents' experiences of a Multiple Sclerosis (MS) diagnosis in their young adult sons/daughters: An interpretive phenomenological study

By **Ciara O'Meara** – M.Ed., M.A.T., BSc., RGN. Nurse Supervisor with Bluebird Care Galway



Multiple sclerosis is the most common neurological disorder in young people in Ireland, specifically across the ages of 20–40 when initial diagnosis occurs (Rejda, Jackson & Giovannoni, 2010; MS Ireland 2017). Given the complexity of the disease and its impact on an individual's quality of life, research is wide ranging with regards to the needs and experiences of individuals with MS (Irish Health 2013; MS Society UK, 2013). However, when one considers the impact such a disease has on the parents of a young adult, research is significantly underdeveloped in this area in Ireland and worldwide. The aim of this study was to explore parents' lived experiences of their young adult sons' or daughters' MS diagnosis. Themes emerging from the exploration of parents' experiences of an MS diagnosis in their young adult son/daughter were: balance, uncertainty, isolation and support.

All parents identified with elements of each of the four themes. Parents acknowledged a personal struggle with balance. They must now balance their biological need to protect their child with the need to respect their position as a young adult with independent reasoning and decision-making abilities. Uncertainty surrounded all parents' experiences of an MS diagnosis, owing to the instability of the disease itself. Uncertainty manifested in terms of unknown disease progression, silent symptoms and the

perceived inability to care effectively. Isolation resulted from a collaboration of other emotions. Fear and guilt experienced by parents often resulted in relationship breakdowns, disruption to family dynamics and contributed to their subsequent inability to ask for help when needed. Experiences of support may have varied among the parents involved but all identified the need for support structures, additional resources and information for those caring for their young adult.

Literature to date has failed to explicitly explore parents' experiences of caring for their young adult son/daughter with MS. MS is a chronic illness considered to be a 'family process' in terms of acceptance and impact. This study has focused on this 'family process' in terms of parents' experiences and in identifying the impact the diagnosis has on their lives. Parents struggle with their new undefined role as a parent for a young adult with a chronic illness. They experience a range of emotions and have questions and concerns, yet they have little to no support in answering those questions and in helping them to accept such a life changing diagnosis. By considering the needs of the parents involved and by adopting a truly holistic approach to MS, only then can parents of young adults be informed and supported and equipped with the appropriate resources in which to effectively care within the context of a chronic illness.

Health care professionals play a vital role in providing support and direction for this particular parent group. This study has identified differences in terms of health care experiences and what the actual support received among parents involved and the impact this subsequently had on the parent. All identified the importance of communication, collaboration and input from health care professionals in providing information and support. Parents look for hope and positivity in dealing with such a diagnosis and health care professionals are in a prime position in which to foster this need.



## Exploring social isolation, loneliness, and social asymmetry as predictors of Complex Post-Traumatic Stress Disorder in Multiple Sclerosis.

By Gary Treacy – PhD candidate, NUI Maynooth



### The researcher and study

My name is Gary Treacy and I am currently undertaking a research PhD program in psychology at Maynooth University. The proposed study is being carried out under the supervision of Professor

Andrew Coogan, Head of the Department of Psychology in Maynooth University; Dr Philip Hyland, Senior Lecturer at the National College of Ireland and Dr Joanna Power, Lecturer at the National College of Ireland.

The title of the current project is **"Exploring Social Isolation, Loneliness, and Social Asymmetry as predictors of Complex Post-Traumatic Stress Disorder in Multiple Sclerosis."** The purpose of this study is to assist with our understanding of how individuals psychologically respond to receiving a diagnosis of MS.

### Background of the study

Being diagnosed with a chronic illness can be a very stressful life event for many people and it is common to see a multitude of different psychological responses among people who experience this kind of traumatic occurrence in their lifetime. Previous studies concerning psychological responses and chronic illness have largely centred on individuals diagnosed with cancer, stroke patients and acute coronary syndrome (ACS) (Ostacoliet et al., 2013). Chronic and life-threatening illnesses have been identified as a significant stressor that may have the potential to trigger psychological reactions like **Post-traumatic Stress Disorder (PTSD)**.

In recent years, some studies have started to focus on the possible association between PTSD and neurological diseases, developing our understanding about the existence and the nature of this association (Qureshi et al., 2010; Yaffe et al, 2010). Irrespective of this awareness, currently only tentative steps are being made to investigate the association between PTSD and the neurodegenerative condition of MS (Ostacoli et al., 2013).

To date, only three studies have investigated the likelihood of an individual meeting the criteria for PTSD subsequent to a diagnosis of MS (Chalfant, Bryant & Fulcher, 2004; Counsell, Hadjistavropoulos, Kehler, & Asmundson, 2013; Ostacoli et al., 2013). To the best of our knowledge, all three studies into PTSD among individuals diagnosed with MS have failed to investigate one of the most significant risk factors highlighted within the trauma and chronic illness literature, that of social isolation and loneliness. It would appear that social support might be important in shaping adjustment to illness among both patients and caregivers (McCabe, McKern, & McDonald, 2004).

### Aims of the study

Despite recent research into the psychological consequences for individuals diagnosed with a chronic illness, it is fair to argue that research into MS is significantly inadequate. The current project wishes to attend to this shortcoming as not only a means of addressing this oversight from a research perspective but to also offer those diagnosed with MS a better understanding of their condition. The current research project will focus on identifying the unique effects that both loneliness and social isolation have in the prediction of developing PTSD and Complex Post Traumatic Stress Disorder (CPTSD) among individuals who have been diagnosed with MS. It is anticipated that highlighting the psychological features of MS will promote greater awareness of the disease and subsequently improve the quality of life of people with MS.

### Participation in the study

As with any research study, the recruitment of participants is central to the execution of a high-quality study. The proposed study wishes to access individuals who have been diagnosed with MS ranging in age from 18 years and above. Participants would be required, on one occasion, to complete an online questionnaire booklet containing numerous psychological measures. The duration of completing the questionnaire booklet is approximately **20 to 30 minutes**.

If you are interested in taking part in this study or would like to know more about it you can contact me at **gartreacy7@yahoo.ie**



## Induced pluripotent stem cells – a window into MS disease?

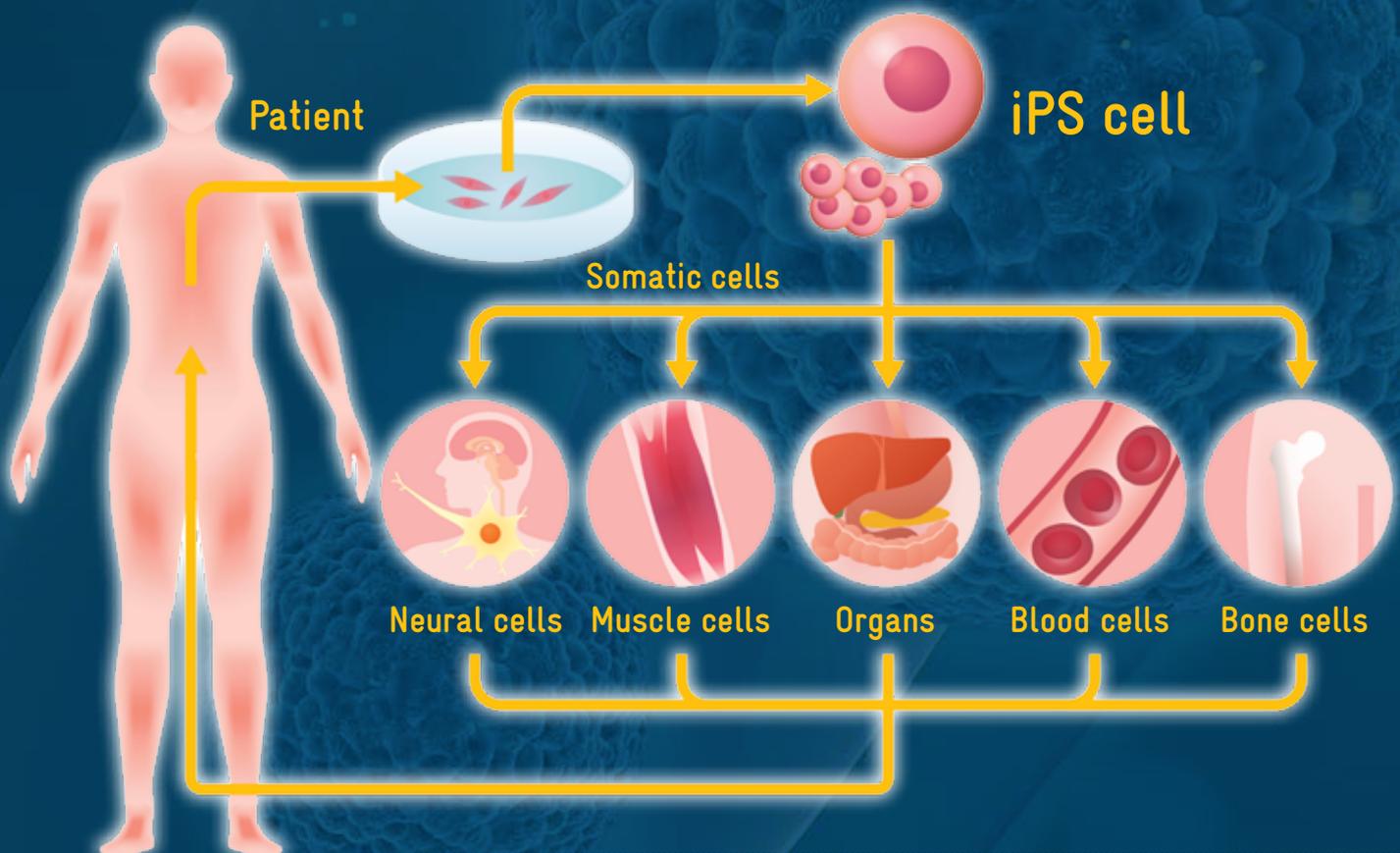
By Dr Una Fitzgerald – NUI Galway, currently on sabbatical at Monash University, Melbourne, Australia



Much of the content of this article is based on that contained in an excellent review paper published in 2016, by Joshua Orack, Jaime Imitola and colleagues, who are based in the U.S.A, Spain and Germany (see detailed information on this article below). This article summarises the various methods that have been developed by scientists, to produce stem cells from adult somatic (non-reproductive) cells. These methods have enabled the production of stem cells using, for example, skin cells, as

a starting point. In a process that can take up to six months, the skin cells are 're-programmed' in the lab, to first become stem cells and therefore are called 'induced pluripotent stem cells' – 'iPSCs' for short. The term 'pluripotent' is used because in theory, these cells, under the right conditions, can become any human cell type in the body. Of interest to those who study brain disorders, is the fact that the iPSCs can, again, under the right conditions, be 'programmed' using molecular factors that are added to cultured cells, to become any brain cell type. Therefore, in theory, we now have the capability to produce unlimited amounts of human brain cells that can be used to investigate a huge number of brain disorders.

So – how does MS fit into this picture? The answer to this question is not straightforward. In contrast, the value of studying iPSC-derived neurons for mono-genic neurological disorders is obvious. For example, an individual has inherited a mutation that causes their neurons to malfunction and this causes their disease. Spinal muscular atrophy is a good example. However, MS is not really like this. It's true that some people may have a genetic 'pre-disposition' towards MS. They may harbour mutations linked to their immune system, which mean that if other environmental conditions such as smoking or low Vitamin D and perhaps a very bad incidence of glandular fever (that puts them in hospital) also occur, that individual may go on to develop MS. However, this doesn't necessarily explain everything about what, in that person, led to their developing MS. How might studying that person's iPSCs shed light on such a complex autoimmune disorder? Scientists now believe that one very important aspect of this kind of research would be the generation of repositories of human MS patient iPSC-derived brain cells. Therefore, many labs and hospitals around the



globe are starting to collect, re-programme and store iPSCs and their progeny, including oligodendrocyte precursor cells.

As most of you know already, the oligodendrocytes are the brain cells that have received most attention when it comes to MS. However, scientists (including me!) now think that there could be defects, as yet undetected, in how neurons, oligodendrocytes and astrocytes function in people with MS. However, before now, we have been unable to study this question, as we have been unable to access large quantities of human brain cells. The 'iPSC revolution' has changed this and has opened the door to more complex analyses of how MS arises in different individuals. These technological advances are what prompted my sabbatical research visit to Monash University in Melbourne, Australia. The goal is to learn how to produce iPSCs and how to re-programme them into first, neural precursor cells, and then, oligodendrocytes and other brain cell types. It is now also possible to produce oligodendrocytes directly from fibroblasts and this is something that will be learned and brought back to Ireland. The process is slow, laborious and expensive.

Between September 2017 and May 2018, the host lab in Melbourne, led by Professor Claude Bernard, (the discoverers of myelin oligodendrocyte protein, a key immunogen in MS), is providing access to iPSCs that are in storage in Melbourne. Professor Bernard's group published seminal work relating to the production of iPSCs and oligodendrocyte precursor cells (OPCs) from individuals with MS (see second reference below and pictures of patient-derived cells shown in Figure 1). Of huge importance, is that some of these cells have been derived from sibling pairs (including twins), where one sibling has MS and the other didn't at the time of sampling.

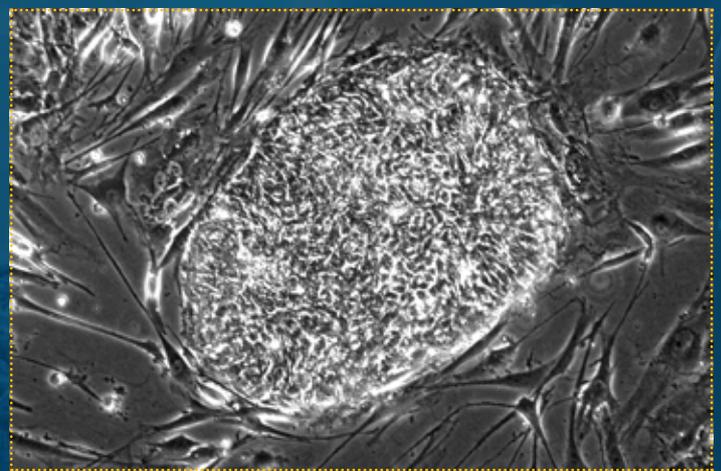


The sabbatical visit is a fantastic opportunity to bring an advanced technology back to Ireland, with the aim of building a repository of cells taken from Irish individuals with MS and their non-affected relatives or other healthy controls. This repository, ideally as part of a new registry for MS, will be invaluable for all MS researchers in Ireland and would be expected to contribute in the longer term to the global effort in dissecting out what could be happening within different individuals who have MS. The cells could help to discover new therapies or they could help to determine whether or not a person is likely to respond to a particular drug. A major challenge in setting up this work in Ireland will be gathering sufficient funds to collect and culture samples and to maintain them in storage so that they can be accessed by researchers and clinicians. The proposed work in setting up the repository will be done in collaboration with consultant neurologist Dr Christopher McGuigan.

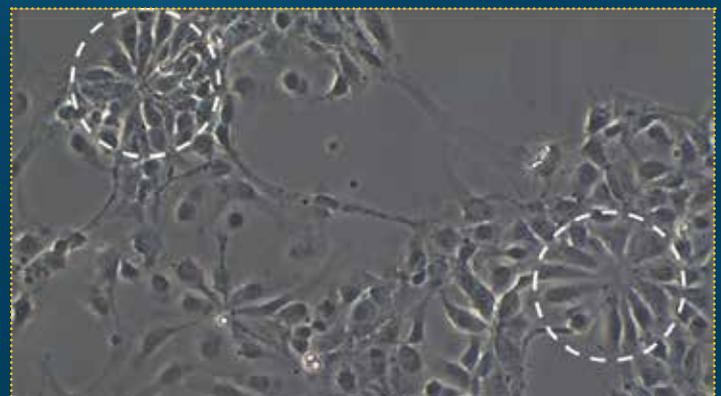
For those who are interested in helping to support this work, please contact Dr. FitzGerald by emailing [una.fitzgerald@nuigalway.ie](mailto:una.fitzgerald@nuigalway.ie) or [una.fitzgerald@monash.edu](mailto:una.fitzgerald@monash.edu)

*Orack JC, Deleidi M, Pitt D, Mahajan K, Nicholas JA, Boster AL, Racke MK, Comabella M, Watanabe F, Imitola J. Concise review: Modeling multiple sclerosis with stem cell biological platforms: toward functional validation of cellular and molecular phenotypes in inflammation-induced neurodegeneration. Stem Cells Transl Med. 2015 Mar;4(3):252-60*

*Payne NL, Aude S, O'Brien C, Herszfeld D, Sun G, and Bernard CC. Application of human induced pluripotent stem cells for modeling and treating neurodegenerative diseases. Nat Biotech 2015 Jan;32(1):212-28.*



A colony of induced pluripotent cells derived from skin sample taken from an individual with relapsing-remitting MS. This island of cells can clearly be seen growing on top of fibroblasts. The fibroblasts, which surround the colony and have long thin processes, are there to support the iPSC colonies, by secreting factors that help the colonies to survive. These cells are ready to be expanded and placed in culture conditions that will turn them into neurons, or astrocytes or oligodendrocytes.



Neural precursor cells generated from iPSCs that were taken from the twin of an individual who has MS. Note the neural 'rosettes' (circled), a self-assembly of cells that occurs in culture and that mimics what happens during the development of the neural tube in the early embryo. The next stage of the project will involve incubating these cells under conditions that will cause them to become oligodendrocytes.

## Identifying molecular targets in the central nervous system for myelin repair in Multiple Sclerosis

By Dr Yvonne Dombrowski – Queen's University Belfast



Queen's University Belfast has a new multiple sclerosis research group. The group around Dr Yvonne Dombrowski is investigating immune mechanisms in the brain and spinal cord that may help repair the damaged myelin in MS. The aim of Dr Dombrowski's research is to identify novel immunological targets to boost remyelination, which will enable the development of novel remyelination therapies for the future.

Dr Dombrowski is a newly appointed lecturer at the Centre for Experimental Medicine at Queen's University. As a trained immunologist and originally from Germany, Dr Dombrowski initially came to Belfast to work with Dr Denise Fitzgerald in her neuroimmunology and MS research team. This work resulted in a recent, well-received publication in *Nature Neuroscience* (1).

Since then Dr Dombrowski started her own independent group and also continues to closely collaborate with Dr Fitzgerald's team. Thus, there are now two research teams in the newly formed MS Research Cluster at Queen's University Belfast - and the cluster keeps growing, with currently 20 researchers and students between the two teams.

Dr Dombrowski's group focuses on the early events after myelin damage, and the events that alert the body of the myelin damage and initiate the repair process. Destroyed myelin is a danger signal for a sensor mechanism termed inflammasome. Inflammasomes are guardians of the body that recognise potential danger situations such as tissue damage (e.g. myelin destruction) or invading micro-organisms during an infection (e.g. bacteria). Inflammasomes then send out alarm signals that alert cells of the immune system to attend to and fight the danger. This is important to clear infections and also to initiate the repair process in the case of damaged tissue. Overall, the initiated immune response will help the body to recover.

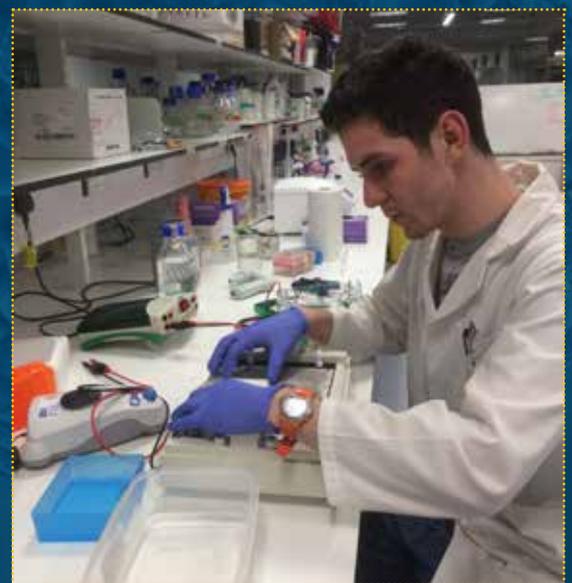
The Dombrowski group has initial results that show that inflammasomes can influence the immune response in a beneficial, myelin regenerating way. The group are now investigating the underlying mechanisms and hope to identify molecular targets that can be used therapeutically to ultimately promote myelin repair; initially in 3D brain slice models and in preclinical models of MS.



**The Dombrowski group**

For this work, Dr Dombrowski recently received a grant from the Freemasons of Ireland Medical Research Fund to support a PhD student in her group. Daniel Crooks (pictured below) will investigate molecular mechanisms in myelin regeneration in MS with a focus on inflammasomes. During his Master's project in Dr Dombrowski's laboratory Daniel discovered that inflammasome signals enhance myelination, the wrapping of myelin around nerve fibres, in a 3D brain slice model. He is now working hard to identify the underlying mechanisms as part of his PhD.

**Daniel Crooks**



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## European Congress of Treatment and Research in Multiple Sclerosis (ECTRIMS) – Paris 2017

**Report by Aoife Kirwan - Information, Advocacy and Research Assistant with MS Ireland and Shift.MS Reporter**

This year, the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) and the American Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) collaborated to give researchers and medical professionals the opportunity to showcase the work they have been conducting to advance the understanding and treatment of multiple sclerosis at MS Paris 2017. 10,157 participants from 99 countries attended. The top five topics covered by submitted abstracts were:

- **Imaging**
- **Immunomodulation/immunosuppression**
- **Long-term treatment monitoring**
- **Risk management for disease modifying treatments**
- **MS symptoms**

One of the main talking points at MS Paris 2017 was the revision of the Mc Donald criteria.

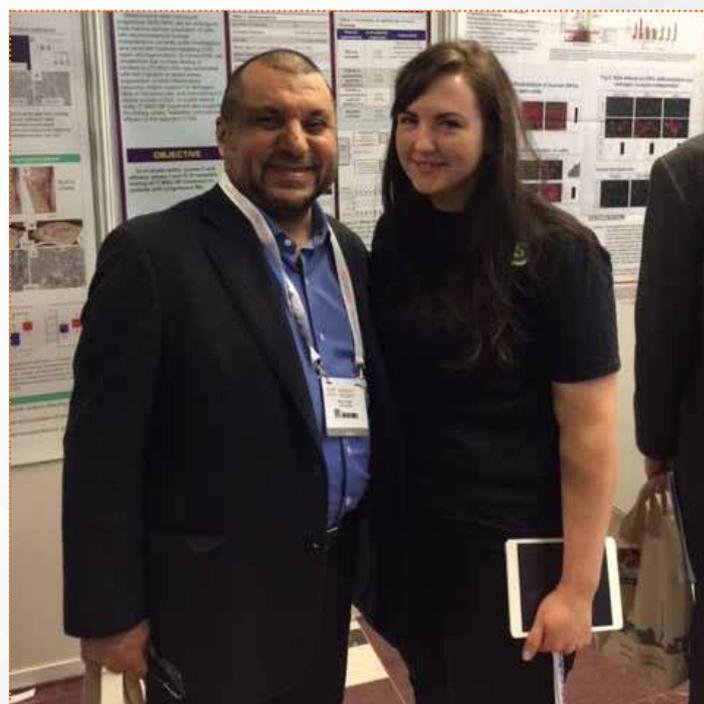
I had the honour of attending as part of the 'MS Reporter' team, with UK based website [www.shift.ms](http://www.shift.ms). Eight people living with MS, as well as three filming buddies, along with the staff from [www.shift.ms](http://www.shift.ms) made up the MS Reporters team. The MS Reporters project is a very unique way of bridging the gap between the medical community and that of people living with MS. Volunteer reporters and filming buddies sign up to take part in this project. They receive online training and are provided with the necessary equipment to use along with their smart phone to record the interviews. The interview is set up between the expert, the reporter and the filming buddy, at a time that suits all. Once the video is recorded it is edited and uploaded for the MS community to engage with. The value of this project was recognised as we were invited to attend and report from MS Paris 2017, by the organisers. We were each given a press pass which granted us entry to all of the presentations at the conference. This gave us the unique opportunity to hear emerging data first hand, and to interview various presenters afterwards. Hearing the thoughts of the professionals on the various emerging data gave us great insight into how this research could translate into positive change and advancement for people living with MS. A range of topics were covered in the videos, from the rise of e-health and the clinical relevance of self-monitoring to the revision and changes to the Mc Donald diagnostic criteria.

There were five changes to the Mc Donald diagnostic criteria. These changes included that the presence of oligoclonal bands in the cerebrospinal fluid may now be used to make a diagnosis in a person with clinically isolated syndrome, once they have further clinical or MRI evidence of dissemination in space. Symptomatic as well as asymptomatic lesions may now be used to determine dissemination in time. Cortical lesions as well as juxtacortical lesions can be used to determine dissemination in space. There has been no change to the diagnostic criteria for secondary progressive MS, other than the fact that the distinction between cortical and juxtacortical lesions has been removed. Finally, a disease course should be determined at the time of diagnosis and reviewed at periodical intervals. In our interviews, it was established that this change to the criteria will allow a faster route to diagnosis and in turn, treatment.

E-health and self-monitoring was discussed as a valid clinical tool. This method of monitoring empowers people living with MS to record their symptoms and report to their clinicians. Inaccurate reporting can be problematic for many, but by embracing self-monitoring apps and keeping track of symptoms and issues, people living with MS can be partners in monitoring their own health. The various professionals interviewed made comments about the validity of these tools in the clinic.

The beauty of the MS Reporters project is that it puts people living with MS in direct contact with experts, so we can ask questions that matter to us. It is a unique and greatly rewarding team to be part of.

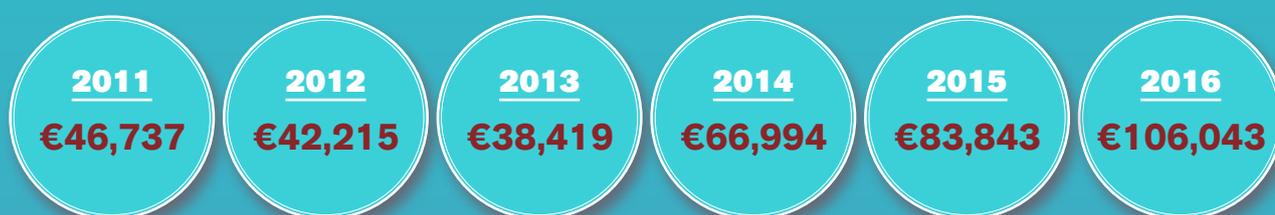
If you are interested in becoming an MS Reporter or filming buddy, visit [www.shift.ms/volunteer](http://www.shift.ms/volunteer) or email [sarah@shift.ms](mailto:sarah@shift.ms)



Dr. Saud A. Sadiq, Director and Chief Research Scientist of the Tisch MS Research Center of New York with Aoife Kirwan

# MS Research Issue 5 will be out in June 2018

## MS Ireland research expenditure 2011-2016



MS Ireland is able to fund research thanks to contributions from the Health Research Board (HRB), the generosity of an individual donor and the hard work of our fundraising team and voluntary branches.



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An Roinn Tithíochta, Pleanála,  
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