

INTRODUCTION

Friends,

Welcome to issue 3 of MS Research. This research eZine is now one year old and we hope you have enjoyed reading our research information updates so far. Please do get in touch if you have any feedback on the eZine or if you want to tell us about any topics you would like to see covered in future issues – you can email harrietd@ms-society.ie

In May, MS Ireland held the very first Irish Red Lab Coat Day. MS researchers around Ireland from a variety of research disciplines donned red lab coats to showcase the vital work they are doing and raise awareness of the importance of MS research. Go to **page 3** to see some of the fantastic photos we received .

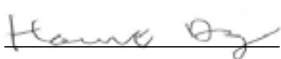
Few issues have captured the public interest so much as medicinal cannabis in recent months. On **pages 4-7** we have an interview with Dr Eric Downer, who is researching cannabinoids and MS at Trinity College, Dublin. Dr Downer explains how and why cannabinoids can be used as MS treatments and also clarifies some of the misunderstandings that commonly arise around this issue when it is reported in the media.

It can be frustrating for people with MS when new discoveries or 'breakthroughs' are reported in MS research which then take many years before they can be applied to treatments and therapies. On **page 21** we have an in-depth piece on the clinical research process, including clinical trials, which explains exactly why the process "from bench to bedside" takes so long.

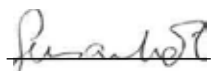
We are also asking for your participation in developing research priorities for MS Ireland – although MS Ireland is not currently in a position to fund much research, we want to find out what is most important to people with MS in Ireland in terms of research topics, so that as and when we have funding available in the future we can best decide how it should be utilised. Turn to **page 19** to read more about our research priorities survey and find out how you can participate.

We also have a range of research updates for you to read about including Pilates studies, genomics medicine and further news from Queen's University Belfast.

Enjoy and we will return in December!



Harriet Doig



Professor Susan Coote



Harriet Doig

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



Professor Susan Coote

Chair of MS Ireland's Research
Committee

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

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EDITOR & EDITORIAL

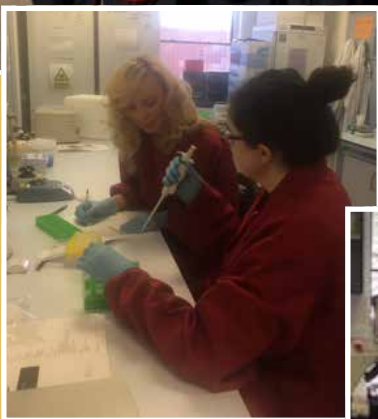
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Red Lab Coat Day held to raise awareness of Irish MS research

On Tuesday 2 May researchers around Ireland donned red lab coats to showcase Irish MS research, inform the public about what is happening around research and thank people who spend their careers looking for better treatments, improved life quality or a cure for MS. This was the first of what will hopefully become an annual event.



Huge thanks to all the researchers that took part in Red Lab Coat Day!



Cannabinoids and MS

Interview with Dr Eric Downer, Trinity College Dublin



Dr Eric Downer is a researcher at Trinity College Dublin who is conducting patient-orientated MS research in a number of areas, including the potential for cannabinoids to be used as treatments in MS. Harriet Doig, Information, Advocacy and Research Officer with MS Ireland, met Dr Downer and interviewed him about his work.



Can you tell us a bit about your background and how you came to be involved in MS research?

I undertook my PhD in neuroscience here in Trinity College and that was my first venture into cannabinoid research. My PhD was based on cannabinoids, specifically tetrahydrocannabinol or THC, the main psychoactive ingredient in cannabis. What we were looking at was the effects of THC on nerve cells, particularly the survival of nerve cells. And what we found was that it was actually quite damaging to these cells. So I suppose the first thing to say is that I have a dual view of cannabinoids, because now I work on therapeutic effects of cannabinoids, but I also understand the detrimental effects of these compounds given my PhD studies.

Following my PhD I undertook post-doctoral research in the field of neuro-inflammation, particularly related to ageing, and I moved away from cannabinoids at that point for some time. During my years as a post-doc I eventually started to venture into MS research. This started when I visited Queen's Medical Centre at the University of Nottingham as part of a post-doc research programme, to specifically study blood cells isolated from MS patients. So that was my first exposure to MS research, and the first time I engaged with MS patients regarding research. At this time we were collecting blood samples from patients and assessing inflammatory changes in the cells. I found that when I was in the clinic I had the opportunity to talk to patients about their condition, their symptoms, and how it has impacted their lives, and I was learning about aspects of the condition that you wouldn't read in a textbook or research paper. I found this inspiring, and it really captured my interest in MS. I think it was at that point I decided that if I ever achieved an academic position during my career, and had the opportunity to start my own research group, I wanted to conduct patient-orientated research in the MS field. My work up to that point had focused on the use of animal models of disease, and I wanted to move away from this and work directly with patients.

I obtained my first academic position at University College Cork in 2013. The first thing I did was set up clinical links with the Mercy University Hospital and Cork University Hospital, and we started recruiting MS patients and assessing blood samples from those individuals. We started to look at inflammatory changes in the blood at a cellular level, and then introducing cannabinoids into the system to determine if cannabinoids could impact the blood cell. I moved to a new academic position in Trinity College two years ago now, and we're setting up clinical links with Beaumont Hospital to recruit MS patients. So I think it was those post-doc years, visiting an MS clinic and talking to MS patients that really excited me about this area of research.

Can you tell us a bit about what we know about cannabis and cannabinoids – what they are and how they interact with the human body?

So everybody has heard of the cannabis plant. A good way to think about cannabis, and the term “cannabinoids”, is that the cannabis plant is a member of the family of cannabinoids. Cannabinoids can be considered as three simple categories. First off, there is cannabis, the plant-derived compounds, and they are discovering new plant-derived cannabinoids all the time – over 100 have been isolated and characterised. THC is the one we know most about, that is the psychoactive component of cannabis. Another plant-derived cannabinoid we know a lot about is cannabidiol or CBD. So that is the first group of cannabinoids, the plant-derived compounds. The second is the group of synthetic cannabinoids, which have been manufactured, often mimicking the structure of the plant-derived cannabinoids. We use synthetics as pharmacological tools in the lab to figure out how cannabinoids act on cells and tissues. The last group are the endogenous cannabinoids. These are cannabinoids that are produced in our bodies. They are a really interesting group. They are “cannabis-like” molecules. We synthesise them throughout our bodies, and they act in the body via a similar mechanism to the components of the cannabis plants. They are actually very abundant in the body as well, for example, we all have high levels of endogenous cannabinoids in our nervous and the immune systems. The two endogenous cannabinoids we know most about from research are anandamide and 2-arachidonoylglycerol, or 2-AG for short. There are some really neat published research studies that have looked at the expression profile of anandamide in 2-AG in MS patients. For example, if you take a blood sample from an MS patient and a healthy individual, you will find that the expression levels of endocannabinoids are often dysregulated in the MS patient blood sample when compared to the healthy control individual. You see this in the blood, you see this in the cerebrospinal fluid, you see this in immune cells. In a nutshell, cannabinoids is an umbrella term to describe the plant, the synthetics and the endogenous groups.

As to how cannabinoids act, there is a huge repertoire of effects they have in the body. They have major effects on the functioning of the nervous and immune systems, which puts them into context in terms of the pathophysiology of MS. For example, cannabinoids modulate several neurotransmitter

systems in the brain, they regulate ion channels in cells, they regulate how cells function and their excitability. Cannabinoids modulate cell signalling events, hence signalling mechanisms within the cell that control how cells and tissues function. Overall, cannabinoids have a multi-targeted effect on the human body, and can regulate many physiological functions in the human body.

There is a huge amount of interest in the area of cannabis and cannabinoids as a potential medicine for a number of conditions, including MS. Can you tell us what the research is currently saying about cannabis as a potential treatment for MS and its symptoms?

In terms of cannabis as a therapy, there are ancient texts that document its use for inflammation, pain, gout and lots of other conditions. So documented therapeutic uses for cannabis are several hundred years old. But how cannabinoids entered the market as prescribed therapies was due to many years of basic lab research across the world, pre-clinical research that was done in cell culture systems and animal models. So in an animal model of MS, the animal develops high levels of spasticity and tremor. What researchers found is that when they administered cannabinoids to these animals, including the synthetic cannabinoids, the plant-derived cannabinoids and also regulated the endogenous cannabinoids system, cannabinoids could be protective in this animal model of MS. Firstly, the animal's symptoms would improve, the spasticity would improve, the tremor would improve. When researchers dissected the brain and spinal cord of these animals that had received the cannabinoids, they found that the cannabinoids could exert neuroprotective and anti-inflammatory effects. Cannabinoids could preserve the blood-brain barrier and cannabinoids could prevent immune cells infiltrating into the brain and spinal cord to promote damage.

This research paved the way for human trials of cannabis-based drugs, such as Sativex. So Sativex, I should mention, is a combination of two plant-derived cannabinoids, THC and CBD, administered as a spray into the mouth. It is very different from individuals taking cannabis, which contains over 100 cannabinoid compounds. What is interesting is that the cannabinoid pharmacological profile in a human is very different too. When an individual smokes

cannabis, the levels of THC in their system will rise very quickly, which will act on the nervous system, which is then associated with psycho-activity in the individual. But Sativex maintains a low blood level of THC in the individual, hence the rapid rise in the blood levels of THC is avoided, and the classic 'high' is bypassed. So Sativex harnesses the beneficial effects that we know cannabinoids possess, but bypasses the psycho-activity. It is a very clever drug pharmacologically.

There are two other cannabinoid-based therapies on the market, Nabilone and Dronabinol, and these have been on the market for quite some time, predominantly in the United States. Nabilone and Dronabinol are prescribed mainly for nausea and vomiting associated with chemotherapy and as appetite stimulants.

Can you tell us about your own research into cannabinoids and MS?

My research is patient-orientated, this is the main driver for me. What we try to do is to recruit healthy individuals and MS patients, obtain a blood sample from the individual, bring the blood sample to the lab, then we isolate the circulating immune cells and place them in a culture dish. We can then expose blood cells from an MS patient and a healthy individual to the cannabinoid drugs and determine if the drug has a therapeutic effect at a cellular level. We have published data that indicates that blood cells from an MS individual display a heightened level of inflammation when compared to blood cells from a healthy individual, which is linked to innate immune activation. The innate immune system is a system that we all have in our bodies that protects us against nasty bugs such as viruses and bacteria. So the innate system appears to be involved in the MS patient at a cellular level. We are introducing cannabinoids into that system in the culture system, to see if and how a cannabinoid can modulate innate immune activation in the cell. In a collaborative project with GW Pharmaceuticals we are investigating the impact of cannabinoids on inflammatory changes in blood cells isolated from MS patients.

What do you think the future holds for cannabis and MS research?

There have been good developments in the last few months here in Ireland. The recent publication of the Health Products Regulatory Authority's (HPRA) report, "Cannabis for Medical Use – A Scientific Review", provides a comprehensive analysis of the provision of medicinal cannabis in an international context, taking scientific advancements in the field into account. This report, which was requested by Minister Harris, recommends that cannabis-based medicines be made available for use in a restricted set of conditions. These include spasticity associated with MS, intractable nausea and vomiting linked to chemotherapy treatment and severe, treatment-resistant epilepsy. This report will be welcome news to patients whose symptoms are refractory to existing medications, and sets Ireland on a path towards providing compassionate access to cannabis-based medicines in a controlled and responsible manner under expert medical supervision.

I think this is a very positive move because it will give hard documentation from the patients' perspective on the beneficial effects, but also on the adverse effects as well. My only hope would be that the media takes a cautionary note when they report on medicinal cannabinoids and make a clear distinction between cannabinoid-based therapies and the raw cannabis plant. I think controlled combinations of cannabinoid compounds, such as Sativex, are really the way forward. This offers a way in which we can harness the beneficial effects of cannabinoids and we can bypass the psycho-activity associated with cannabis abuse.

The media have a responsibility here also, to inform the public about what these drugs are. CBD oil, for example, is a single cannabinoid isolated from the plant that has no psycho-activity, but has beneficial effects in human trials. I think careful reporting of cannabinoids will only help cannabinoid researchers to gain funding to develop research projects to help us understand this more. I think that the common use of the term "cannabis" as an overall umbrella term as an MS treatment doesn't help. It frustrates me that reporting does often not clarify what specific cannabinoid components are being described.

“Cannabis” is often employed as “buzz term” to draw in the reader. This can damage the public view of the cannabinoid system and cannabinoid therapies, and cannabinoid research. With the discovery of new compounds within the cannabis plant, basic research funding is needed to develop research programmes to help us understand how these compounds work and what further therapeutic effects they may have.

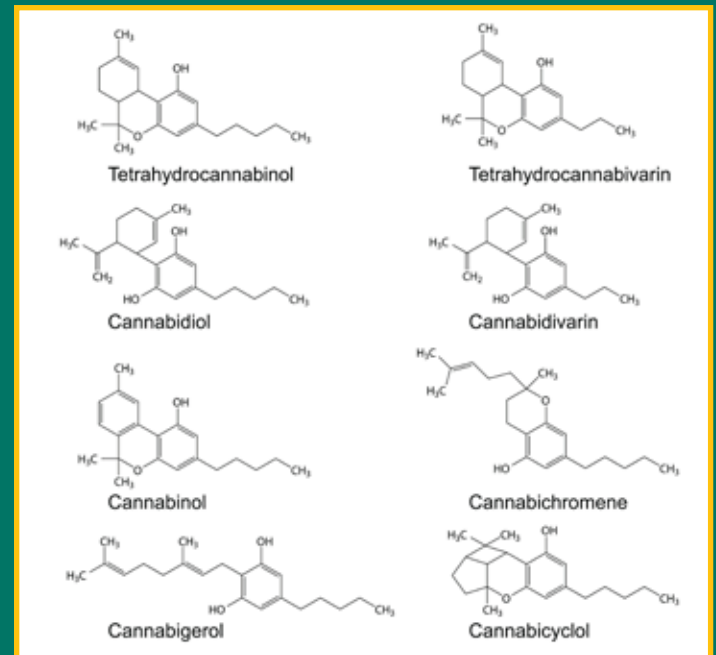
You are involved in a number of other research projects related to MS – can you tell us a bit about those too?

One project we are just finishing, which was actually spurred on by a grant call from MS Ireland two or three years ago, is assessing the therapeutic effects of exercise in a cohort of MS patients. This is a very simple pilot study, in collaboration with colleagues at UCC, Cork University Hospital and the Mercy Unveristy Hospital. In this study individuals with MS come to the exercise lab for several weeks, and they cycle in the lab on a stationary bicycle. It is a quite a minor exercise programme in terms of intensity. We are testing the impact of exercise on disability and inflammation in the blood. We are just submitting that work now for publication and it is quite surprising to see that a minor exercise programme can have multi-targeted beneficial effects in this patient cohort.

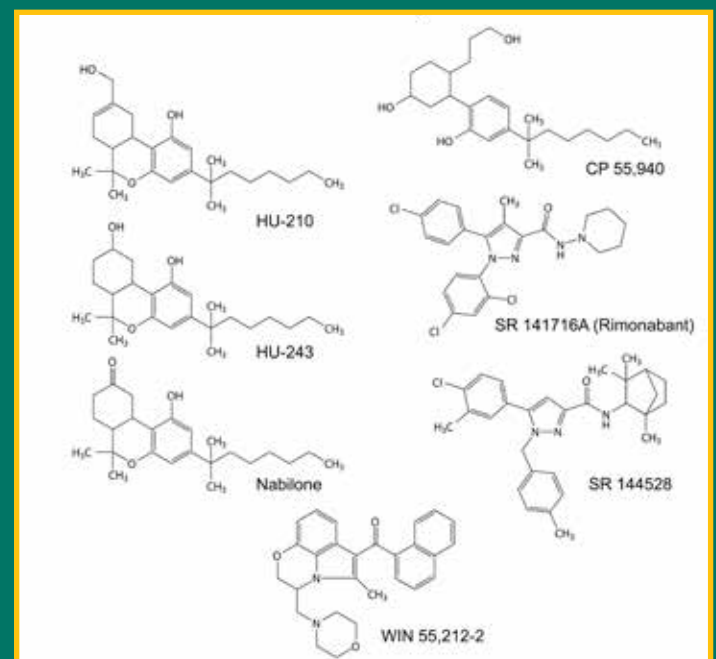
In another study we are looking at post-mortem brain samples. I am very interested in looking at MS from two viewpoints; peripheral effects in the blood and central effects in the brain. We have a collection of brain samples from the UK MS brain bank and we plan to profile novel cell viability markers in the brain. I am really interested in demarcating cellular viability changes in the lesion versus the perilesional area and normal appearing white matter - so healthy tissue towards a damaged site - and try to identify novel viability markers in the area surrounding the lesion. That kind of approach could inform novel therapies, as you could develop a drug that could target cell survival in the MS brain.

So to sum up, the MS research we are doing at the moment is looking at the effect of cannabinoids in blood samples, the impact of exercise in MS patients, and identifying novel viability markers in the MS brain via post-mortem studies.

Structural formulas of main natural cannabinoids



Structural formulas of main synthetic cannabinoids



The Dean Medal Travel Bursary 2017 Applications now open

A travel bursary to encourage the understanding of MS among young researchers, in memory of Geoffrey Dean, MD (1918 – 2009)



Geoffrey Dean was an internationally regarded epidemiologist who in several seminal studies established the importance of environmental influences on the pathogenesis of multiple

sclerosis. His work continues to have relevance to this day. Active in research up to his death, Dr Dean published a total of 120 papers during his illustrious career. His last was published in 2008 at the age of 89.

The Dean Medal award, established in 2010, is intended to enable new MS researchers to travel to centres of excellence to enhance their understanding and knowledge of MS. MS Ireland wishes to encourage the dynamic and innovative work so keenly exemplified by Dr Geoffrey Dean. The third Dean Medal Travel Bursary is now open for applications. Details of the application process are below.

Grant

- MS Ireland offers the Dean Medal to young MS researchers to enable them to undertake short visits to other MS research centres, to learn new techniques or to further joint research projects
- The aim is to encourage cross-fertilisation of skills through collaborative research projects
- One award is made, every two years approximately, to the value of €2,000
- The funds are intended to contribute towards travel and living costs or to top-up an existing grant to extend a visit

Eligibility

- Individuals working in Ireland, preferably young researchers who are directly involved in an MS research project are eligible for nomination
- Before nomination, candidates need to have identified a suitable project and discussed their involvement with the project supervisor of the host institution
- Projects must be related to MS

Nomination of Candidates

Individuals can self-nominate but the nomination should include:

- A letter from the candidate detailing their reasons for nomination
- His or her curriculum vitae
- Testimonies (references) from at least two people with whom the candidate has worked
- A description of the field of research that the candidate wishes to be trained in or the research project that he or she wishes to carry out. This should be written by the applicant and should be a maximum of two A4 pages including the background to the project, aims and methodology to be used. A list of references should be added as an appendix which may also include figures
- A signed letter of support from the project supervisor of the host institution, indicating that appropriate facilities will be made available. The letter should be on institution-headed notepaper
- Candidates are required to submit both electronic and hard copies of all the above documents. Electronic copies are to be emailed to Harriet Doig - harrieted@ms-society.ie. Hard copies should be posted to:

Harriet Doig
Information, Advocacy & Research Officer
MS Ireland
80 Northumberland Road
Dublin 4

Deadline

The deadline for receipt of applications is Friday, 20 October 2017.

Selection

The members of the MS Ireland's Research Committee consider and select successful candidates. Please allow eight weeks.

Evidence of Results

After the Dean Medal has been awarded and the research taken place, a short report will be required for submission to MS Ireland's Research Committee and for publication in MS Ireland's bi-annual research eZine. Electronic copies of reports, papers, abstracts and posters resulting from the visit should also be submitted.

Papers produced as a result of or in connection with Dean Medal funded research should acknowledge MS Ireland's Research Committee. If possible, such acknowledgements should also reference MS Ireland's website www.ms-society.ie

Contact

Queries and nominations for the Dean Medal should be submitted by email to Harriet Doig harrieted@ms-society.ie

Past winners

In 2011 the first award was made to Mary O'Flaherty from NUI Galway. Mary worked in the National Centre for Biomedical Engineering Science and was working on an MS project looking at how molecules associated with a particular kind of cellular stress known as 'endoplasmic reticulum stress' may affect how well brain slices recover from myelin loss. Mary used the bursary to travel to Imperial College London to study with Professor Richard Reynolds regarding a particular procedure used in her studies.

In 2015 a second award was made to Dr Nonnie McNicholas from St Vincent's Hospital who travelled to the Karolinska Institutet in Sweden to further her research into the measurement of cerebrospinal fluid biomarkers indicative of disease progression in people with MS.



Dr Nonnie McNicholas (left) receives the Dean Medal Travel Bursary cheque from Harriet Doig, Information, Advocacy and Research Officer, MS Ireland.



Karolinska Institutet



Registration Now Open

Conference: Family Carer Research in Ireland UCD, Dublin.

Thursday 31 August 2017

Care Alliance Ireland invite you to their 2nd biannual Family Carer Research conference, taking place in collaboration with the UCD School of Nursing, Midwifery and Health Systems on Thursday August 31st 2017.

The conference will take place in The Red Room in the UCD student centre, Belfield, Dublin 4.

Full conference programme will be released closer to the date, and will include oral and poster presentations from a wide range of speakers from across the Not-For-Profit, academic, and statutory sectors. In addition, a number of Family Carers will be speaking and making presentations throughout the day.

Registration for the full day costs €30 per person, which includes lunch and refreshments.

You can find out more details, and register for the conference at <http://bit.ly/2rJNpnl>

A National Biobank for Neurological Disorders?

By Dr Una Fitzgerald and Dr Jill McMahon
NUI Galway



Over the last 12 months, Dr Una FitzGerald, a Principal Investigator based at NUI Galway whose primary research focus is MS, has been surveying clinicians and neuroscientists on their attitudes to translational neuroscience research in Ireland. Views were sought also on the idea of setting up a National Biobank for Neurological Disorders (dubbed the Irish 'Neurobank'). This was prompted by the frustration experienced by Dr FitzGerald and members of her research group at difficulties in collecting clinical samples as part of an MS biomarker research project. While people with MS were very willing to provide samples, it proved difficult to gather clinical details required to make resulting research data publishable. In other countries, it is sometimes possible to contact a Biobank and obtain pre-

consented samples that have ethical approval for use in research and that have a full clinical history.

If an easily accessible, coordinated Neurobank existed in Ireland, it could have a huge impact on translational research, i.e. research that has direct relevance to the clinic and that could impact people with neurological disorders in the shorter rather than the longer-term. Research focusing on biomarkers or induced pluripotent stem cells, or that which makes use of donated brain tissue, are good examples of research that is translational.

Three rounds of surveying were completed, with questionnaires being sent to members of the Irish Institute of Clinical Neuroscience, Neuroscience Ireland and the Neurological Alliance of Ireland. A total of 56 people responded to the survey. Highlights are listed below:

- There is overwhelming support for the idea of setting up an Irish Neurobank
- 30 out of 56 respondents indicated an interest in helping to set up the Neurobank
- 16 clinicians indicated willingness to provide clinical samples/information
- Participants, drawn from hospital consultants, registrars, Senior House Officers, psychologists, academics, Principal Investigators, post-doctoral neuroscience researchers, research fellows and graduates, came from seven institutions and seven different hospitals across Ireland and three outside Ireland
- Participating researchers indicated, overwhelmingly, that the existence of a Neurobank would have a moderate/transformational impact on their research and that it would increase their chances of producing competitive and translatable research

While attending the Irish Neurological Association/Irish Institute of Clinical Neuroscience conference in Dublin in May 2017, (hosted by UCD and led by Dr Janice Redmond), Dr FitzGerald was able to engage with neurologists on the topic of a 'Neurobank'. It became clear that many logistical and financial challenges would have to be overcome in order to set up a Neurobank. Many highlighted the lack of a registry for all neurological disorders. Uncertainty on how to develop a secure funding model into the future was also seen as a barrier. It is hoped that a working group will be convened in the near future to agree a strategy for coordinating effort amongst neuroscientists and clinicians and for approaching possible funders. Sample points for future discussions are as follows:

- Relationship with/impact on pre-existing biobanks, such as the Dublin Brain Bank and biobanks for Motor Neuron Disease, Alzheimer's Disease and Epilepsy, located in different parts of Ireland
- Relationship with existing clinical research networks
- Benchmarking against existing Biobanks in Ireland and abroad
- Feasibility of joining/gaining support from existing European networks
- Feasibility/utility of joining forces with Bioconnect Ireland
- Start-up and running costs
- The possible need for Pharma/other industry to be involved and possible implications
- Possible sources of funding (government/charity/philanthropic)
- Strategy for approaching suitable funding agencies
- A Neurobank for the island of Ireland – implications
- Ethics/privacy/data management and sharing

Dr FitzGerald would be interested in hearing from anyone who would like to get involved in this venture or who has views on any of the above.

To contact Dr FitzGerald, phone **091-494440** or **087-2022013**, or email una.fitzgerald@nuigalway.ie

Also, for further information see <http://www.nuigalway.ie/our-research/people/natural-sciences/unafitzgerald/>

Brain Research in Ireland: Investing in all our Futures – Conference report

By Willeke Van Eeckhoutte
MS & Me Blogger and MS Advocate



On 7 March, the Neurological Alliance of Ireland (NAI) and Irish Brain Council held a joint conference about brain research in Ireland as part of the annual Brain Awareness Week. The event took place in the Science Gallery, Dublin. Featured topics included patient involvement, why brain research needs to be prioritised on the political stage and how the needs of people with brain conditions should be explored to ensure they receive the care they require.

Of the 4.7 million people living in Ireland, a staggering 1.1 million are living with a brain condition. Because research into this field lags behind cancer and cardiovascular research in this country, Mags Rogers, Executive Director of the NAI and Secretary of the Irish Brain Council, rightfully said, “Brain conditions are the greatest medical challenge of our time.”

Ms Rogers’ statement set the stage for engaging talks by, for example, Professor of Neurology Orla Hardiman, who highlighted why Ireland needs a national institute of health research. Sadly, those with neurological illnesses know the reasons all too well: a broken Irish health system, and young doctors leaving Ireland to work in the UK, Canada or Australia. Also, clinical data based on clinical outcomes needs to be used to improve patient care.

MS & Me Blogger and EUPATI fellow Joan Jordan, and Derick Mitchell, CEO of IPPOSI (Irish Platform for Patients’ Organisations, Science and Industry) touched on the subject of patient input and patient-led activities including stimulating research. There is a clear need for partnership between patients, families and academics across different stakeholders to improve research quality.

Kevin Mitchell of the Irish Brain Council described the neuroscience landscape, mentioning that we cannot cure diseases we don’t understand, hence the need for more funding of research of brain-based disorders. Perhaps unsurprisingly, there has been little recent success in the development of new therapies as well as a string of failed clinical trials.

It is not all bad news, however. Mr Mitchell listed some strengths of Irish neuroscience, like having an exceptional international reputation, high patient involvement and Ireland hosting a lot of pharma and ICT companies which make it easier for Irish neuroscience to flourish.

Finishing the conference was Frederic Destrebecq, Executive Director of the European Brain Council. It is sobering to hear that brain disorders are a rising burden to society, especially when there is still no cure for most conditions.

Early intervention, more research and more investment in research is therefore needed on different levels. After all, it starts with the patient, and it should end with the patient.

Irish Brain Council members with the conference programme



The Effects of Pilates on Mood Among People with Multiple Sclerosis

By Karl Fleming, University of Limerick



MS Ireland (2017) indicate that 9,000 people and their families are living with MS in Ireland. Symptoms and severity vary between individuals, affecting the body physically, emotionally and cognitively. Mood impairments, including symptoms of depression, anxiety and fatigue are highly prevalent among people with MS. Physical activity is key in symptom management, and growing evidence supports exercise effects on mood and mental health outcomes among otherwise healthy adults and adults with diverse chronic illness, including MS. Traditional forms of aerobic and resistance exercise have positively affected these psychological symptoms, however, non-traditional forms of exercise, including yoga, tai chi and Pilates remain understudied.

Pilates is easily learned, requires little or no equipment and space, and can provide numerous health related benefits. Pilates research has demonstrated improvements in flexibility, abdominal endurance, balance, posture and blood pressure in healthy populations. A recent systematic review has demonstrated large positive effects of Pilates on depressive and anxiety symptoms and feelings of fatigue, symptoms that are prevalent and poorly treated among people with MS. However, to date no randomised controlled trial has quantified the effects of Pilates on mood outcomes among this population. A research team at the University of Limerick are aiming to examine the effects of Pilates on symptoms of depression, anxiety and fatigue in persons with MS.

The proposed study is a randomised controlled trial that will quantify and compare the effects of eight weeks of supervised or home-based Pilates to a wait-list control, on mood among people with MS. Participants will complete two sessions per week of Pilates, over an eight week period or will have assessments while waiting for a Pilates class. Participants will be allocated to either a group-based Pilates, home-based Pilates or waiting list group. The classes will be provided by a qualified instructor and are free of charge. Throughout the study, participants will complete a series of questionnaires relating to symptoms of depression, anxiety, fatigue, and level of physical activity. Additionally, participants will be provided with a heart rate monitor and Sensewear device to objectively measure intensity and activity during the sessions. An initial cohort is scheduled to commence the study in the last week of May 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**
- **Patient Determined Disease Steps score <3**
- **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)

Dr. Matthew Herring (matthew.herring@ul.ie)

Professor Susan Coote (susan.coote@ul.ie)

Physical Activity Levels Among People with Multiple Sclerosis

By Bláthín Casey, PhD Candidate.

Supervisors: Professor Susan Coote and Professor Molly Byrne

Final year PhD candidate Bláthín Casey, from the University of Limerick, presented a review paper at the recent Rehabilitation in Multiple Sclerosis (RIMS) Conference in Barcelona on 5 May 2017. Her presentation was entitled 'Objective Physical Activity Levels Among People with Multiple Sclerosis'. The presentation was well received. Bláthín's talk was one of five oral presentations presented by the MS Research Team at UL during RIMS. Professor Susan Coote presented twice during the conference while PhD candidates Laura Comber and Gillian Quin also presented on their most recent findings.



The aim of Bláthín's review was to quantify physical activity levels among people with MS and to establish if people with MS are less physically active than an age-matched general population sample. The review included 32 papers that measured physical activity levels among people with MS with mild-moderate disability. These studies largely reported physical activity outputs as steps per day and minutes of moderate-vigorous physical activity (MVPA) per day. MVPA can be thought of as exercising at a rate that you can talk but can't sing. When compared to a large general population sample, people with MS were doing significantly less steps per day and minutes of MVPA per day.

For steps, people with MS were doing on average 5,840 steps per day, whilst the general population sample were doing on average 9,685 steps per day. The same pattern was seen for minutes of MVPA,

people with MS were doing on average 18 minutes of MVPA per day whilst the general population sample were doing 27 minutes. Given that the general population are regarded as physically inactive, these findings suggest that people with MS with mild-moderate disability are less physically active than a general population who themselves are largely inactive.

The focus of Bláthín's PhD is to understand why people with MS do not engage in physical activity behaviours. From there she hopes to develop a theory-based intervention that changes physical activity behaviour among people with MS. She plans to submit her thesis later this year.

Developing falls prevention programmes

By Laura Comber, PhD Candidate.

Supervisors: Professor Susan Coote and Dr Rose Galvin, Department of Clinical Therapies and Health Research Institute, University of Limerick

Psychosocial factors related to falls

Falls are increasingly being recognised as a significant consequence of MS. To date, few studies have been conducted looking at falls prevention interventions for people with MS and at UL we are developing falls prevention programmes. Previous programmes have very much focused on the physical aspects of falls such as balance, strength and walking ability, however few have focused on psychosocial variables

When thinking about falls, the psychosocial variables of interest are fear of falling, restriction of activities due to fear of falling, falls self-efficacy (a person's belief around their ability to prevent falls) and perceived control over falling (for example, 'Falling is something which I can control').

In order to explore the influence of these psychosocial variables on falls we conducted a phone survey with people with MS who had recently experienced a fall. 140 people took part in the survey. We carried out data analysis to identify how these four falls-related psychosocial factors interact with each other and with other MS-related characteristics.

The results of the study showed that 92% of the participants reported a fear about falling and 79% acknowledged that there were things they would like to do but do not do because they are worried about falling. Furthermore, the average falls self-efficacy and perceived control over falling of the group was considerably low. We also took one of the psychosocial factors, the person's belief around their ability to prevent falls (falls self-efficacy) and analysed if the other factors were associated with it. We found that fear of falling, restriction of activities and perceived control were all associated with falls self-efficacy highlighting that these psychosocial factors are important for us to consider individually when we are assessing them in people with MS. Overall the results of the study highlight that fear of falling and restriction of activities are significant problems that contribute to the belief that a person can prevent falls and therefore need to be part of any falls prevention programme.

This study has been submitted for publication in a leading journal. We would like to thank all the participants who gave their time to completing this study and for helping us to publish such interesting results.



Researchers from the University of Limerick presented research on MS and falls prevention at a recent research showcase to mark World MS Day

Can Clinical Balance Measures Predict Risk of Falls in MS?

By Gillian Quinn, PhD candidate.

Supervisors: Professor Susan Coote, Dr Rose Galvin, Dr Chris McGuigan

I work with the MS research team in University of Limerick, led by Professor Susan Coote, and my overall research interest is in the area of falls in MS and particularly looking at how to identify those at risk of falls. In order to develop a reliable falls prediction tool, we first needed to look at the current evidence base and see what has been shown to be sensitive in identifying fallers in MS populations in previous studies. To do this, we carried out a systematic review of relevant studies in this area. The aim of this review was to determine the ability of commonly used clinical measures of balance to distinguish fallers from non-fallers and to determine their usefulness and reliability in identifying those at risk of future falls.

Main Findings:

- 29 studies suitable for inclusion in the review with a total of 3,304 participants
- 49% of those participants were classified as fallers
- Only seven studies used the gold standard of prospective falls monitoring using falls diaries
- The most commonly used measures of balance included the Berg Balance Scale (nine studies), the Timed Up and Go (nine studies), the Falls Efficacy Scale (seven studies) and the Dynamic Gait Index (five studies)
- The measures did show a difference across fallers and non-fallers but had poor ability to predict future fallers

These measures do warrant further investigation but due to low quality study designs and mixed reporting styles it is not possible to recommend one specific clinical balance measure for assessing falls risk in MS.

We investigated the ability of one of the most common measures; the Timed Up and Go test, TUG, to predict falls risk in MS with a study involving data collection from 100 participants attending the neurology service in St Vincent's Hospital, Dublin. We used the gold standard of falls diary reporting and our results showed the TUG does not show a significant difference across fallers and non-fallers and is not reliable for identifying future fallers. We will carry out further analysis to see if adding other factors to the walking test improves its ability to identify those at risk of falls and hence in need of treatment.

This systematic review paper is currently under review in a journal special edition focused on balance and mobility issues in MS. It is only through earlier identification of falls risk in people with MS that we will be able to initiate onwards referral to appropriate falls prevention interventions in a timely fashion.



Save the date!

MS Ireland and Novartis will hold an MS Research Explored event on **Thursday 30 November.**

A networking event for researchers interested in MS will be held on the same day. Timings and venues TBC – stay tuned for further updates!

Research project investigating if an individualised energy conservation program is effective in reducing fatigue in persons with MS.

By Audrey O'Toole
Occupational Therapy student, NUI Galway

Fatigue is experienced by persons with MS 70-90 % of the time and has been frequently described as the most problematic symptom of MS. Fatigue is defined as a subjective lack of physical and/or mental energy which interferes with an individual's usual and desired activities. Within MS there are two types of fatigue: primary fatigue and secondary fatigue. Primary fatigue is related directly to the condition, and is often made worse by heat. Secondary fatigue relates to a range of things including but not limited to side effects of medication, poor sleep and poor nutrition. Secondary fatigue is easier to treat than primary fatigue.



Numerous studies have been completed offering energy conservation programmes to reduce fatigue in a group setting and have been found to be effective. As a part of my fourth year thesis I carried out a study to look at the effectiveness on an energy conservation to reduce fatigue and improve aspects of quality of life for people with MS. This was a small study and included four participants.

This programme was originally developed by Dreiling (2009) and includes several different strategies for participants. The programme was run for one hour a week for four weeks with each person. The first session included education around fatigue and developing an understanding of the individual's own fatigue, while identifying what factors made them especially fatigued. The second half of the session was exploring the use of a journal. This journal helped the individual to keep track of the activities they completed in the week and assisted with planning the following week, ensuring sufficient breaks and prioritising activities.

The second session highlighted the importance of sleep. The second half of this session involved examining the journal and coaching around self-identifying factors that induced fatigue. Working at a slow to moderate pace was highlighted.

The third session comprised of education and demonstration of proper posture and body mechanics. This session included work simplification strategies. Example: sitting instead of standing where possible, avoiding excessive bending, reaching, and delegating tasks to others.

The final session was a summary of sessions to date, as well as the importance of proper breathing and relaxation techniques. The second half of the session was education on equipment or adaptations to the current environment. The equipment that participants reported as being the most useful was a perching stool and a shower chair. The latter was especially useful as the heat from the shower induced fatigue.

Even though this study had a small sample positive results were seen by participants. All participants reported noticeable improvement in their quality of life and all participants reported improvements in some areas of fatigue. Three out of the four participants found the journal very useful as they realised how much they were actually doing in their day. Planning their week and writing down appointments helped with having to remember things. This study would need to be replicated with a larger, more diverse group of people before any conclusions can be drawn but results are promising.

Reference:

Dreiling, D. (2009) 'Energy conservation', Home Health Care Management & Practice, 22 (1), pp. 26-33.

Queen's University researchers make major brain repair discovery



In the last issue of MS Research, we published an interview with Dr Denise Fitzgerald from Queen's University Belfast about her research into reversing the effects of MS. In March, Dr Fitzgerald and her team announced an exciting discovery.

In the study, led by Dr Fitzgerald and Dr Yvonne Dombrowski, it has been discovered that specific cells from the immune system are key players in brain repair – a fundamental breakthrough that could revolutionise the treatment of MS and other debilitating neurological disorders. This is being hailed as a landmark study in unravelling the mysteries of how the brain repairs damage.

Current treatments for MS limit relapses and can slow or prevent progression, but no treatments exist to reverse the damage already done by the condition. The exciting aspect of this new research is that the team have uncovered beneficial effects of immune cells in myelin repair that have potential to reverse myelin damage. The study was an international collaboration including experts in Maynooth here in Ireland, Cambridge, San Francisco, Edinburgh, and Nice.



The research breakthrough, which has been published in Nature Neuroscience, shows that a protein made by certain cells within the immune system triggers the brain's stem cells to mature into oligodendrocytes that repair myelin. The discovery means that researchers can now use this new knowledge to develop medicines which will boost these particular cells and develop an entirely new class of treatments for the future.

Speaking about the importance of the new research, Dr Dombrowski, who is the lead author of the report, explained: "At Queen's we are taking a unique and fresh approach to uncover how the immune system drives brain repair. This knowledge is essential to designing future treatments that tackle neurological diseases, such as MS, in a new way – repairing damage rather than only reducing attacks. In the future, combining these approaches will deliver better outcomes for patients."

Commenting on the findings, Dr Fitzgerald said: "This pioneering research, led by our team at Queen's, is an exciting collaboration of top scientists from different disciplines at Cambridge, San Francisco, Edinburgh and Nice. It is by bringing together these experts from immunology, neuroscience and stem cell biology that we have been able to make this landmark discovery.

"This is an important step forward in understanding how the brain and spinal cord is naturally repaired and opens up new therapeutic potential for myelin regeneration in patients. We continue to work together to advance knowledge and push the boundaries of scientific knowledge for the benefits of patients and society, in a bid to change lives for the better, across the globe."

This work was supported by a number of funders including the BBSRC, Wellcome Trust and Leverhulme Trust.

Media inquiries to Emma Gallagher, Communications Officer at Queen's University on **004428 9097 5384** and emma.gallagher@qub.ac.uk

Further reading

MS Ireland conducted an interview with Dr Denise Fitzgerald about her work, which appeared in issue 2 of MS Research.

You can download the eZine and read the interview here: <http://www.ms-society.ie/pages/research/ms-research-ezine>

Dr Denise Fitzgerald, right, with Harriet Doig, Information, Advocacy and Research Officer with MS Ireland



MicroRNAs

By Claire McCoy

**Principal Investigator in Inflammation,
Biochemistry Lecturer, RCSI**



In August 2016, I was recruited to the Royal College of Surgeons in Ireland (RCSI) to lead a research team that focuses on the role of microRNAs in inflammatory associated-diseases such as MS.

The discovery of microRNAs in the early 2000s has led to a very exciting and rapidly growing area of research. MicroRNAs are extremely small RNA molecules that regulate all aspects of cellular function in the human body. For the past 10 years, I have been working on one particular microRNA called miR-155. miR-155 is an essential microRNA for our immune system. Its role is to mount an appropriate immune response that protects us from everyday infection against bacteria and viruses. However, for reasons that we don't fully understand, miR-155 levels are dysregulated in patients with MS, where it is highly elevated in blood serum, cerebral spinal fluid and in brain lesions. My research has shown that miR-155 is particularly elevated in the immune cells that infiltrate the central nervous system in patients with MS. miR-155 causes immune cells to adopt a pro-inflammatory phenotype, releasing inflammatory and toxic mediators that lead to the neurodegenerative damage associated with MS.

My research aims to investigate the following:

- To understand how miR-155 in immune cells contributes to the damage and pathogenesis of MS
- To elucidate if switching it off can limit MS progression
- To develop novel therapeutics that will target miR-155 specifically in the immune cells of our brain

I am extremely excited to be back in Ireland and undertaking this critical research. I firmly believe that based on the prevalence of MS in Ireland, along with Ireland's strengths in both basic and clinical research in the fields of neurology, neurodegenerative disease and Immunology that Ireland should be at the forefront of MS research, innovation and therapeutics. With the support of MS Ireland, the following research goals and objectives should be considered to improve the current research environment for MS in Ireland.

- To establish a network for all MS researchers in Ireland (both basic and clinically applied) to enhance intercommunication and transfer of knowledge
- To increase patient participation through the dissemination of our research and relaying the critical role they can play in advancing Irish research
- To provide excellence in education and training by utilizing student exchange programs via funding bodies such as Marie Curie and the Irish Research Council
- To enhance Ireland's success in obtaining major funding awards from the Progressive MS Alliance and the National Multiple Sclerosis Society in New York through collaboration and strength in numbers
- To increase Irish-based research studies and publications on epidemiology using Irish-based MS cohorts
- To generate road-maps to commercialization by engaging with select industry partners to support economic revenue in Ireland

Claire has been the recipient of major national and international awards including a Marie Curie Mobility Fellowship and an Australian NHMRC project grant. She has published >21 highly cited and seminal publications in Nature Immunology, Nucleic Acid Research, Journal of Leukocyte Biology and Journal of Biological Chemistry.

To find out more about her research and upcoming job opportunities go to:

<http://pi.rcsi.ie/pi/clairemccoy/index.asp>



Genomics Medicine Ireland to Commence Research in First Ever Population-Based Genomic Research in Multiple Sclerosis



Background:

Irish life-sciences company, Genomics Medicine Ireland Ltd. (GMI) has launched Ireland's first ever population-based study of the genetics of Multiple Sclerosis (MS). The ground-breaking research will employ advanced scientific

technology in genomics, as well as studying key lifestyle and clinical data. This insight will be captured in GMI's scientific platform and analysed to identify risk factors and susceptibility to MS among Irish people.

Genomics is the study of genomes. The word "genome" refers to all the DNA contained in the cells of our body. It's like a very special instruction manual that is unique to you and contains all the information needed to make you, run you and repair you. DNA is a code made up of a four letter alphabet (A,C,G and T) called bases. The order of this code changes slightly from person to person to make you who you are. If you wrote down all the letters of DNA code contained in one cell, it would be 3 billion letters long. So if you put together all the DNA in your entire body, you could reach from earth to the moon nearly 6000 times!

Scientists want to better understand the unique differences in our genomes. These differences are called variants and these variations make us individual - for example, giving us different eye colour or hair colour. Most of these variations have no effect on our health, however, some have been shown to cause or contribute to certain health conditions. Scientists have also discovered that these variations in our genome can influence if we develop a disease, how that disease progresses and how we respond to medications.

Many genetic research projects in the past have looked at very small regions of the genome, e.g. 10,000 to 15,000 base pairs, or looked at a small number of variants scattered across the genome (100,000bp to 1 million bp). Many genetic variants have already been reported which increase a person's risk of developing MS. However, there are many more which are yet to be identified.

This project is different as it aims to identify each of the 3 billion base pairs in a person's genome. Research will primarily focus on which variants are more frequent in MS patients vs. individuals with no history of MS. We will 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. By assessing the control mechanisms that influence the processing of DNA, we also will search for environment and lifestyle factors that influence this process. By integrating all of this information together, we will have a complex set of information which we can interrogate to better understand this complex disease.

"While there is no known cause of MS, it is generally held that it is a combination of factors such as genetics, environment and a person's immune system. MS is not hereditary but the risk factors are increased if a family member has the disease. This study will give us a greater understanding of the role of genetics in MS, helping the development of more targeted therapies for treating and managing the condition. Ultimately, in the longer term, we are looking to gain insights that will lead to the prevention of the disease," said Dr Sean Ennis, Co-Founder, GMI.

Work to date:

GMI is currently establishing research studies at clinical research centres treating MS patients across the country and hopes to rollout sites island-wide in the next 18 months. As individual research sites begin accepting participants, GMI will notify MS Ireland. It will also be launching additional studies in a number of major chronic and incurable conditions where there is a need to better understand the role genetics and lifestyle play in disease and disease progression.

Eligibility:

Eligible adults living with MS will be invited to participate in the study directly by their consultant as each site rolls out.

- **Before volunteering, a member of the research team explains the research study and provides full written detail about the study and what's involved**
- **The patient will have the opportunity to consider this information and to ask the research team member any questions**
- **If the patient decides to enrol, the research team member will take informed consent, ask the patient to provide a blood sample and answer a short lifestyle questionnaire**
- **This will typically take place during the patient's routine hospital appointment**

Future Plans:

The study of genomics has tremendous potential to translate to health improvement for future generations in a number of areas:

- **More accurate and earlier prediction of disease risk**
- **Better understanding of which therapeutics are best suited and at what dosage for each patient (instead of a trial and error approach leading potentially to lack of efficacy or harmful side effects)**
- **Early diagnosis of the disease and identification of the disease subtype**
- **Better understanding of the patient's prognosis and how the disease is likely to progress**



8 STAGES OF RESEARCH



1

PARTICIPANTS ARE INFORMED ABOUT THE STUDY



2

INTERESTED PARTICIPANTS CONSENT TO RESEARCH



3

COLLECT BLOOD SAMPLES AND LIFESTYLE INFORMATION



4

ACGTATGTTAGCGAATCATGC
DNA IS SEQUENCED

5

ACGTACG
AGCTACG
COMPARE DNA SEQUENCE INFORMATION BETWEEN GROUPS

6

PINPOINT GENETIC FACTORS OF DISEASE & PREDICT RISK & PROGRESSION



7

IDENTIFY POSSIBLE NEW DRUG TARGETS & TREATMENTS



8

RESEARCH A CURE FOR MS



Have your say!

What are the most important areas for MS researchers to focus on?



MS Ireland is conducting a survey of the MS community in Ireland, to find out what areas of research are considered the most important by the community.

MS Ireland's funds for research are currently very limited, but it is hoped that as and when funding is available for research in the future, the results of this survey will help guide us as to how best to utilize 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.

Currently, MS Ireland's Research Strategy for 2015-2019 references the top 10 research priorities of the MS Society in the UK, as established through an extensive survey carried out by the MS Society and the James Lind Alliance. MS Ireland wishes to establish if these top 10 priorities are reflective of the priorities of the MS community here in Ireland.

The survey will be made available on MS Ireland's website www.ms-society.ie and via our social media channels shortly. Please keep an eye out for the survey and take 5-10 minutes to complete it so you can have your say in this crucial piece of work. The survey is open to anyone from the MS community, including people with MS, their families and carers, healthcare professionals and researchers.

You can read more about the work of the James Lind Alliance at www.jla.nihr.ac.uk/about-the-james-lind-alliance/

You can read more about the survey carried out by the MS Society UK here: <https://www.mssociety.org.uk/ms-research/how-we-decide-what-we-fund/Setting-MS-research-priorities>

Please contact Harriet Doig, Information, Advocacy & Research Officer, if you have any comments or questions: harrieted@ms-society.ie

Incidence of multiple sclerosis in the Republic of Ireland: A prospective population-based study

By Dr Karen O'Connell, St Vincent's Hospital Dublin

Background to the study:

Multiple sclerosis incidence (number of new cases) and prevalence (total number of cases) is increasing worldwide, with a higher rate seen in women. Traditionally studies have shown that the number of people affected increases as you move north and south of the equator suggesting that something in the environment may be acting as a trigger for the disease. Ireland is a high prevalence country for MS with a previously reported North-South gradient, making it ideal to further explore this concept.

Methods:

This was a national study with the goal of identifying all new cases of confirmed MS (not CIS) diagnosed from 1 March 2014 – 28 February 2015 in the Republic of Ireland. Within the main study there was a smaller group of participants who had a more detailed assessment looking at their clinical details and exploring risk factors associated with MS. Patients were referred by neurologists, MS nurse specialists and MS support services (MS Ireland). The Irish census 2011 was used to obtain population statistics and we calculated the incidence rate – a measure of new cases per year per 100,000 population. We compared the incidence rate in both northern and southern counties to see if Ireland had a North-South gradient, which we had seen in previous studies.

Results:

292 new cases of MS were identified which gave an incidence rate of 6/100,000 population; for women the rate was 8.7/100,000 and for men 3.3/100,000. The female to male sex ratio was 2.7:1, implying for every 27 women who were diagnosed only 10 men were. Mean age at diagnosis amongst the RRMS group was 37 years and 55 years in the PPMS group; there were no gender differences associated with age of diagnosis. Onset was progressive in 10% of cases. A significant difference was seen in incidence rates between the northern region (9.6/100,000) and the southern region (5.1/100,000).

Amongst the smaller study of 113 people the average age at symptom onset in the RRMS group (106 people) was 34 years and 50 in the PPMS group (7 people). 80% had started or were due to start disease modifying therapy at time of review and 77% were taking supplemental vitamin D. Using the hospital depression and anxiety scale mild to severe depressive symptoms were reported in 34% with no prior history of depression. 75% were in full or part-time employment with 8% not working due to disability arising from their MS.

Conclusions:

This is the first study to assess the incidence rate of MS in Ireland and shows that Ireland has a high incidence rate of 6/100,000 population, comparable with the rest of the British Isles, with a persistent North-South gradient. This difference between the northern and southern counties is likely explained by our genetic heritage with the Northwest being more associated with Celtic ancestry and Southeast with Anglo-Norman. This is also supported by previous genetic studies showing differences in distribution of HLA class II associations (specifically the HLA DRB1*1501eDQB1*0602 haplotype) amongst these areas. The age of onset of relapsing remitting multiple sclerosis appears to be increasing over the last 20 years. High rates of depression were again seen early in the disease, highlighting the psychosocial impact of MS on patients. It is important that we as physicians and care workers are aware of this and able to offer our patients support as needed. The prevalence (total number) of people with MS is increasing worldwide and it will be interesting to re-assess our population over time to see if this is due to an increase in incidence (new cases) of MS or due to increased survival, with MS patients now living longer, healthier lives.

Regional Authorities in Ireland

- Border
- Midland
- West
- Dublin
- Mid-East
- Mid-West
- South-East
- South-West



Number of new cases of MS per county, from March 2014-February 2015



From bench to bedside – why does clinical research take so long?

By Aoife Kirwan,
Information, Advocacy and Research Assistant, MS Ireland



Sometimes we see headlines in the media about 'breakthroughs' in MS research. While it is exciting to see these reports, it is important to remember that initial positive results don't automatically translate to a new treatment being made available, and even when they do, it can take anywhere from 10-15 years before the treatments are accessible. Although this wait time can be frustrating, the process that the research is going through is incredibly important. Good quality clinical research is essential for the safety of the people who may benefit from it. Ensuring that the research has adhered to the appropriate protocols and guidelines is imperative. The process involves rigorous testing at various stages.

Clinical research typically begins in the lab. Researchers identify and examine compounds that could potentially treat or manage MS. This early research can be carried out on computer models, human cells or animals. The compound is examined to assess its safety and potential benefit.

The next phase of the research is carried out on healthy humans. This allows researchers to see how the compound acts in the body and how the body reacts to the compound. The side-effect profile of the treatment can also be established at this point. Participants are monitored and side effects or issues are recorded.

The research then moves on to testing in voluntary members of the MS community. Normally this is structured as a double blinded randomised controlled clinical trial. This means that as participants agree to take part in the research, they are randomly assigned to either the control group (who will not receive the experimental treatment) or the experimental group (who will receive the experimental treatment). Neither participant nor researcher will be aware of which group any particular individual is part of. By having both groups, data can be collected from both groups and then compared and analysed to determine the effectiveness and safety of the experimental treatment.

Patient safety is of prime importance when it comes to clinical research. All trials in Ireland have to submit data to the Health Products Regulatory Authority (HPRA) and receive approval from them before the trial can begin.

Clinical research is vital for the development of new treatments for MS. This process cannot happen without participants from the MS community, but participation is entirely voluntary. If you are provided with information on taking part in a trial it is important that you read it. If you are interested in taking part you should be sure that you understand your part in the research and what it means for you. It may be helpful for you to write a list of questions for your healthcare professional, to ensure that you have all the correct information and can make an informed decision.

Some questions you may like to ask:

- What is the purpose of this clinical research?
- How will my safety be monitored throughout this trial?
- How long will the trial last?
- What tests and procedures are involved? How frequently are they carried out?
- Is long-term follow up care provided?
- If I benefit from the experimental treatment, will I be allowed to continue receiving it after the trial ends?
- What are my responsibilities as a research participant?

Information on trials currently taking place in Ireland is available on this website:

<https://www.centerwatch.com/clinical-trials/listings/location/international/Ireland/>

More information on taking part in clinical trials can be found here:

<http://www.clinicaltrials.ie/>



Invitation to participate in workshops to develop a mindfulness programme for people with MS

The Centre for Pain Research in the School of Psychology, NUI Galway is working with MS Ireland to create an on-line mindfulness programme for people living with MS.

Previous research in the UK and elsewhere highlighted that after mindfulness training people living with MS reported improved quality of life and emotional well-being. The programme resulted in less depression and reduced fatigue and these positive effects were still there 6-months after the programme. Standing and dynamic balance was improved while pain was reduced. We want to create programme that will give similar benefits and that people living in Ireland with MS can participate in with ease.

We are in the early stages of development and it is really important that the programme meets the needs of people living with MS. So we would like to invite you to come and share your perspectives with us about what life is like living with MS and what you think should be included as part of a mindfulness programme.

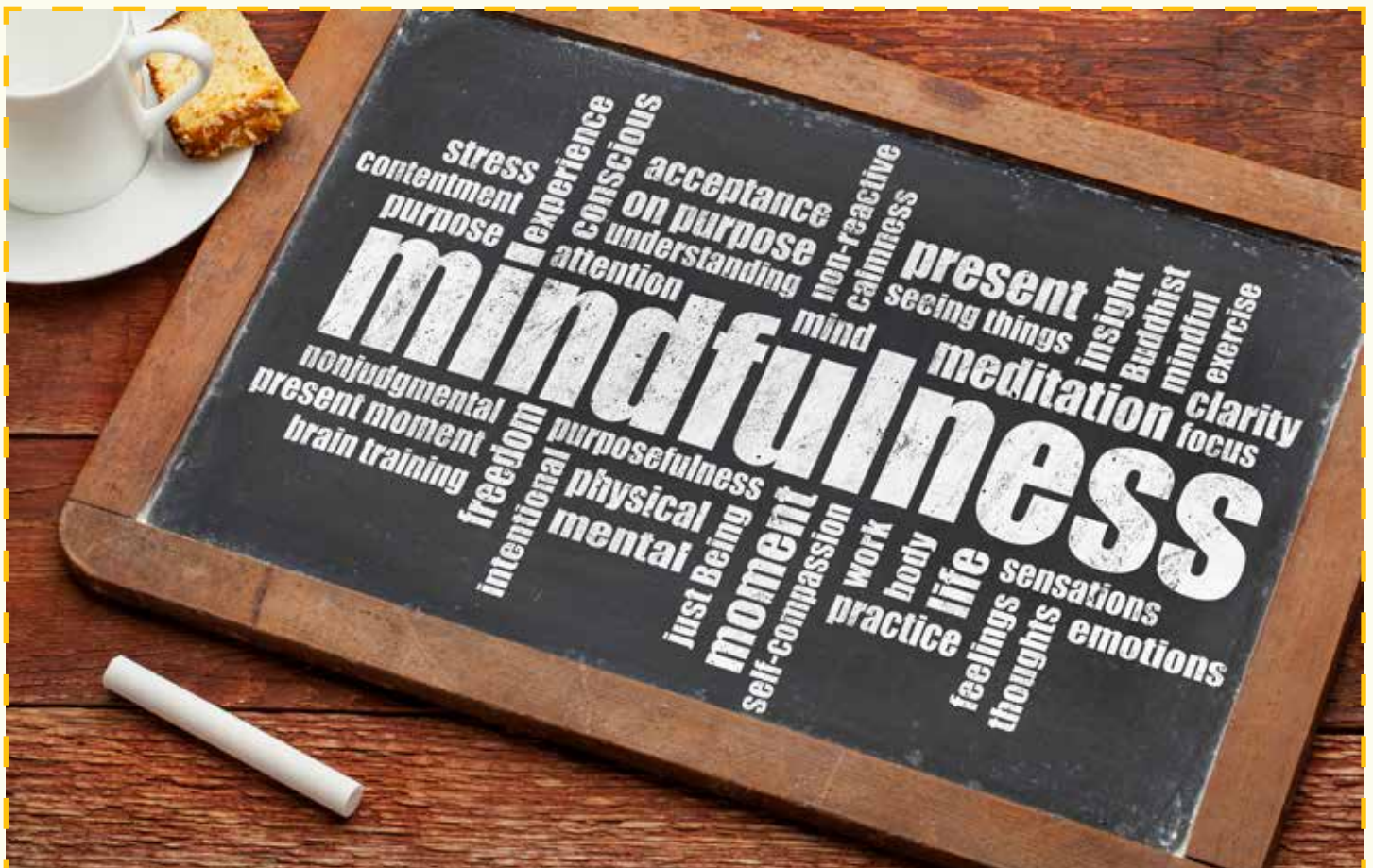
We will be working with a small groups, to explore ideas about some of the challenges and possible solutions. Workshops are planned for:

Dublin on 6th July 6.30pm - 7.30pm MS Care Centre Bushy Park Road, Dublin 6.

Galway on 12th July 6.30pm - 7.30pm MS Ireland Western Regional Office, Cheshire House.

If you would like to take part in this exciting initiative or would like to get more details about what is involved please contact:

Dr. Siobhan O'Higgins on 0862857298 by the 3rd July.



MS Research Issue 4 will be out in December 2017

MS Ireland research expenditure 2011-2016



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