



MS *research*

Issue
01

3



step it up

PHYSIOTHERAPY



16



TREATMENTS

9



COGNITION

INTRODUCTION

Friends,

We are delighted to welcome you to the first issue of MS Research, MS Ireland's new research eZine. This year MS News, our bi-annual information magazine, will be celebrating its 100th issue. It therefore seems fitting to be launching a brand new magazine in the same year.

A lot has changed in the world of MS research since the launch of the first MS News in 1980 – for example, at that time there were no licensed medications available to treat MS and there are now 14. It is very exciting to think about where we may be in another 36 years' time – what will researchers have discovered by then?

Supporting, promoting and funding MS research has always been a core part of what MS Ireland does. Unfortunately, in recent years, the funding the organisation has available for research has been severely reduced due to the ongoing impact of the financial crisis and reductions in both statutory and fundraised income. However, the organisation continues to believe that research is the most beneficial way to improve understanding of the disease, leading to better treatments, interventions, management and ultimately a cure for MS.

MS Ireland continues to support the work of MS researchers in Ireland through our partnerships and collaborations, most notably the ongoing partnership with the University of Limerick which is now entering its 6th year. We also support other researchers by disseminating their findings and helping recruit participants for studies.

With this in mind we are launching the new eZine to keep people affected by MS, healthcare professionals, academics and policy makers informed on the most up to date developments in scientific and social research into MS in Ireland and to support the ongoing work of these dedicated researchers. We will also be using this platform to share the most exciting updates from international MS research.

We hope you enjoy the first issue.



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

CONTENTS

| | |
|--|----|
| Physiotherapy | 3 |
| Dean Medal | 7 |
| Trinity College Dublin | 8 |
| Cognition | 9 |
| Public Patient Involvement | 10 |
| Employment | 12 |
| Bladder | 15 |
| Treatments..... | 16 |
| Myelination Research..... | 17 |
| International Progressive MS Alliance | 19 |

'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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Updates on physiotherapy research from the University of Limerick

The 'Activity Matters' project

By Blathin Casey

Background:

The benefits of physical activity for people with MS are well-known. Despite this people with MS are largely inactive and lead sedentary lives.

The 'Activity Matters' project aims to change physical activity behaviour in this population through the medium of a web and paper based resource. These resources aim to provide a place for people with MS to access information and strategies to enable them to become more physically active.

However, before engaging on the development of a resource to change behaviour we must define the behaviour to be changed. It is understood from health psychology literature that changing behaviour is complex and until a behaviour is truly understood a behaviour cannot be changed. Therefore, one of the first aims of the 'Activity Matters' project will be to understand why people with MS are inactive and what factors might contribute to this. Another primary aim will be to discover what it is that people with MS want from a web based resource that enables them to become more active.

Work to Date:

What do people with MS want from a web based resource - Qualitative interviewing was conducted with a range of people with MS with a range of mobility and activity levels. In summary, participants believed the web resource to be a good idea and suggested that the content of the resource should include a focus on the knowledge of the benefits of being physically active. Illustrating the types of exercise in which PwMS could participate was also discussed. Ensuring information was stratified by mobility level and that the resource was interactive, portraying a 'sense of community' and use of success stories, was also suggested by participants.

The development of a pilot website - Using the information gathered from the qualitative data, the pilot pages of the website were developed. They include; research evidence on the varying types of exercises for people with MS (e.g yoga, swimming, etc.), interactive videos of people with MS and researchers talking about physical activity information among other things.

Assessing the usability and acceptability of the pilot website - The pilot pages of the website have been piloted to a group of people with MS through qualitative methodology. Results suggest that people with MS like the webpages and find them beneficial. However, website functionality like increased font size, better colour and easier navigation around the website are suggested as ways in which the pages can be improved.

International collaboration - An international collaboration with a Canadian university was established after attending a meeting in Boston in adjunct to presenting the 'Activity Matters' research in a conference in Indianapolis in May 2015. This collaboration aims to establish the factors that influence physical activity behaviour in people with MS. A final draft of this paper is underway and suggests self-efficacy, goal-setting and outcome expectancies are important.

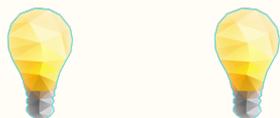
Booklet - Using the content on the webpages, text for the paper resource has been completed. We are awaiting feedback on how best to print this resource.

International Conference Attendance and Dissemination of Work - I will be returning to the Consortium of Multiple Sclerosis Centres (CMSC) Conference in June 2016. I was awarded a scholarship and travel bursary by the CMSC to attend the conference in Washington DC.

Future Plans

- Further development of the website given feedback from pilot of the website.
- Understand the factors that influence physical activity behaviour in people with MS and embed this knowledge into the web resource to ensure effectiveness of the 'Activity Matters' website.

- Test the preliminary effectiveness of the completed Activity Matters website.
- Try and reach healthcare professionals to promote use of the 'Activity Matters' website.
- Print the paper based resource and distribute to people with MS in Ireland.



Falls in MS



**International
MS Falls Prevention
Research Network**

Name - Gillian Quinn, BSc (Physiotherapy), MISCSP, PhD candidate.

Supervisors - Prof. Susan Coote and Dr. Rose Galvin, Clinical Therapies Dept, UL, Dr Chris McGuigan, St. Vincent's University Hospital, Dublin.

Background:

The recent Atlas of MS project found that over 50% of the people with MS in the world live in Europe. In Ireland the incidence of MS is one of the highest in Europe and it is estimated that over 10,000 people live with MS in this country. Falls are a major issue for both the person with MS and the health and social care systems. The falls prevalence in the over 65's is estimated at 30%, however, the falls prevalence of people with MS is greater than 50% (Gunn et al. 2013). Over 50% of people with MS fall in a 3-6 month period, and around 30% to 50% fall multiple times. Coupled with this high prevalence are a greater risk of fracture and a younger age of onset of disease and of falling, all of which place an increased demand on the health and social care services and increase the impact of the disease for the person.

While there has been an increase in our knowledge of the factors associated with falling for people with MS in recent years (e.g. impaired balance, progressive disease state, use of a mobility aid), there is no consensus on the most accurate assessment tool or measure to reliably differentiate between fallers and non-fallers. There is an urgent need to develop a clinical tool that can be easily used in a busy neurology clinic to predict fallers and thus, instigate more timely and appropriate falls prevention interventions. A recent paper (Cameron et al. 2013) suggested that simply asking if the participant had fallen in the past has good sensitivity but only fair specificity in predicting those who will fall. It is hypothesised that asking other questions in addition to whether they had fallen previously would enhance the predictive validity of a questionnaire based assessment. We aim to develop and test the items for a questionnaire to address this issue.

Instrumented gait tests have been used widely in the elderly falls literature, however, as yet there are no studies using instrumented gait tests in the prediction of falls in people with MS. This project aims to collect data on sway, acceleration, and angle of sway using an android phone App during a Timed up and Go (TUG) test which typically takes 6 – 20 seconds to complete. A recent study demonstrated that the TUG correctly classified 68% of fallers when using the total time alone, however adding the instrumented data increased this to 87% (Weiss et al. 2011, Oliver et al. 1997).

Current Research:

The Smartphone study involving a questionnaire and a timed walk assessment and filling out falls diaries for a three month period is now finished recruiting. From November 2014 until March 2016 assessments were carried out on suitable participants and we now have data for 101 participants. The main recruitment process was in the Neurology clinic in St. Vincent's University Hospital, Dublin but we also recruited through MS Ireland in Limerick. The most recent analysis shows that 51% of the group were fallers with over 500 falls recorded from 38 participants over the three month period. The timed gait test (TUG) did show a significant difference between fallers and non-fallers, and further analyses looking at all items on the questionnaire and the instrumented data will be used to develop a fall risk algorithm that can reliably predict those at risk of falling.

A second research study investigating the causes and context of falls in MS involves an interview over the phone or in person and gathers information on where people fall, what they are doing at the time of a fall, their worries and concerns about falling and their opinions on falls prevention interventions. There are currently 89 people with MS recruited for this study, 34 of which have been directly recruited through the MS clinic in St. Vincent's hospital. Initial analysis shows the majority of falls took place inside the home (42%) while doing a mobility activity (48%). The most commonly cited causes for falling are leg weakness, being distracted or not paying attention and poor balance. Only 8% of the group had previously participated in a falls prevention programme, but there is definitely a need and a desire to take part in such interventions as 94% of those surveyed said they would be interested in attending falls prevention programmes.

Future Plans:

Data collection for the Smartphone and timed mobility assessment study is now complete and future work will involve analysing the data and drawing conclusions from it. The phone survey study is ongoing and we hope to finish data collection by the end of June 2016. I plan to disseminate the research findings at a local and international level and have poster abstracts at a neurology conference in Limerick in May and have two posters at an international MS conference in Washington in June. I have also submitted an abstract for the European MS conference in London in September. Study findings and up to date reports will also be communicated through the UL and MS Ireland websites.



Step it Up April 2016



The Step it Up project is funded by the Health Research Board and is a collaboration between the MS team at the University of Limerick and Prof Rob Motl, a well known exercise researcher from the University of Illinois at Urbana Champaign.

Researchers at UL began recruiting people with MS into the Step it Up exercise and education programme in September 2014. The aim of the 10-week programme was to have a positive impact on many MS symptoms such as reduced muscle strength, reduced walking mobility, fatigue and low mood, while also promoting long-term and sustainable management of the condition. Step it Up targeted people with MS who are able to walk independently and who are physically inactive.

Recruitment for inclusion into Step it Up has now finished with over 65 people with MS enrolled in the programme between Galway, Limerick and Cork. All follow-up assessments after the programme have also finished. Currently, the research team at UL are analysing the results in order to test the effectiveness of Step it Up. We hope to have the analysis complete and the findings publicised within the next six months. We will be in touch with participants of Step it Up, MS Ireland members and the wider community of people with MS and their friends and family regarding information evenings where we will present the results of Step it Up in the near future.

Call for participants - Phone Survey

The MS research team at the University of Limerick are recruiting people with MS who have fallen in the past three months to provide information about their falls and what they would like to see included in future falls prevention programs.

Approximately 50% of people with MS will experience a fall in any three month period. Falls can cause significant problems for people with MS. Currently few evidence based falls prevention programs exist. The MS research team aim to develop such a program in the near future. The input of people with MS into the development of this type of program is essential for its success. We have been conducting a study for the past few months in order to gain this insight through a telephone survey conducted by a physiotherapist. 88 people with MS have taken part in the survey so far and we are hoping to increase these numbers this June. The early stages of this study have already provided some interesting results, for example:

- **93% of participants have never taken part in a falls prevention programme.**
- **67% of people with MS who have taken part in the survey are significantly worried about falling and 70% felt their daily lives were restricted by this worry.**
- **Currently participants would like to see exercise, education about falls/hazard risk, education to prevent falls and improving concentration included in the future program.**

To be eligible to take part in this survey participants must:

1. Have a definite diagnosis of MS
2. Be able to walk for 10 metres with or without an aid
3. Have had a fall in the last three months

If you are interested in taking part please contact Laura Comber at 061 234 278 or laura.comber@ul.ie

The phone survey will take approximately 30 minutes at a time that best suits you. For more information you can also visit our webpage at:

www.msresearch.ie/#!context-causes-and-consequences-of-fall/c13z6

Dynamic Mobility

'Dynamic mobility deficits in people with Multiple Sclerosis: A systematic review and meta-analysis'

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

We know that 85% of people with MS have problems with mobility and balance and that these issues have an effect on falls and walking. People with MS highlighted that walking was the most important bodily function in a recent survey of people with MS.

Laura Comber, as part of her PhD with the MS research team and Prof. Susan Coote have conducted a systematic review and meta-analysis to quantify the deficits in walking in people with MS in comparison to healthy controls to help to inform future falls prevention interventions.

Data from 41 research studies was combined to quantify these deficits with some interesting results being found:

- **People with MS had altered a walking pattern compared to healthy controls in the majority of variables investigated**
- **The effect of MS was considerable despite the relatively low levels of disability (EDSS was predominantly below four) included by the studies.**
- **These deficits increased considerably when people with MS were asked to walk at faster speeds**

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



2015 Dean Medal



Dr Geoffrey Dean

MS Ireland established the Dean Medal in 2011 to honour the life and work of Dr Geoffrey Dean, a renowned MS scholar. The aim of the award is to enable new MS researchers to travel to centres of excellence to enhance their understanding and knowledge of MS.

MS Ireland was delighted to award the second Dean Medal Travel Bursary in 2015. The successful applicant was Dr Nonnie McNicholas from St Vincent's Hospital who is planning to travel 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. Below, Dr McNicholas outlines the background of her research and what she is hoping to achieve from her visit to the Karolinska Institutet.

"I am the current UCD Newman multiple sclerosis (MS) research fellow at St. Vincent's University Hospital in Dublin. I am involved in research with the MS group and in the management of people with MS attending the department. The department treats the largest cohort of people with MS in Ireland, and has an established reputation for research in the area.

My fellowship is focused principally on cognitive functioning of newly diagnosed people with MS against a control population; an area which is under-researched in early MS. Cognitive testing will be compared to atrophy measures on annual magnetic resonance imaging (MRI). In addition to this project, the purpose of the fellowship is to further my experience and understanding of new and emerging developments in the management of MS so I can develop an MS service in the future.



Dean Medal winner Nonnie McNicholas (left) with Harriet Doig, Information, Advocacy and Research Officer, MS Ireland

Irreversible disease progression is the major cause of disability in MS for which there are currently extremely limited therapeutic options. There has been a lot of recent interest regarding the measurement of cerebrospinal fluid biomarkers indicative of axonal degeneration and irreversible disease progression in people with MS. This may have a role in guiding treatment decisions, and aid future trials focusing for potential neuroprotective drugs. In Ireland, we do not currently measure cerebrospinal fluid biomarkers in the management of our patients. At the Karolinska Institutet in Stockholm, Sweden, these biomarkers are measured and used to guide treatment decisions in both relapsing-remitting and progressive MS. The department is also involved in research with regard to these biomarkers.

New developments concerning the prevention of disability progression in MS is an exciting and previously neglected area in MS research. I hope to visit the Karolinska Institutet, and learn about their use of neurofilament markers in both a clinical outpatient setting, and in laboratory research. This is an opportunity that I do not have here in Ireland and one that will facilitate future collaborative research between our two departments in the area.

The visit will give me the opportunity to assess the methods used for collection, storage and processing of CSF neurofilament samples. I intend to discuss these methods with the laboratory in St. Vincent's University Hospital on my return, with the intention of developing a similar service in Ireland. I will also have the opportunity to observe clinical consultations, where neurofilament level results are discussed with people with MS; this will allow me to see how results are used to guide treatment decisions, and help develop our own local protocols for the management of progressive MS in Ireland".

Dr. Nonnie McNicholas

Newman Research Fellow in MS,
School of Medicine and Medical Science, University College Dublin,
and St. Vincent's University Hospital, Dublin 4.

From Exercise to Cannabinoids:

Using different strategies to investigate MS via patient-orientated research

Dr. Eric Downer, Assistant Professor in Human Health and Disease at Trinity College Dublin, has a long-standing interest in patient-orientated research, and since obtaining his first academic position in January 2013, he has built his laboratory around patient-orientated research in the field of MS. Dr. Downer's research takes a multi-faceted approach to investigating the underlying mechanisms that drive MS, with a view to developing novel therapeutic interventions in the condition. There are three major research themes ongoing in his laboratory, each tackling a different research question regarding MS.

Firstly, physical activity is proposed to target multiple clinical manifestations in MS, and may improve overall quality of life in MS patients. In this study, Dr. Downer's laboratory investigates whether a cycle ergometry training programme has therapeutic potential in individuals with MS by improving quality of life and depressive symptomatology, while ameliorating cognitive disturbances. This study is conducted in conjunction with a large collaborative team, involving Neurologists at Cork University Hospital, Mercy University Hospital, and Physiologists/Psychologists at UCC. The study is on target for completion by the end of this year, with the data showing promising effects of exercise in a patient cohort.

Dr. Downer's laboratory has recently published evidence [1] that blood cells isolated from patients with MS, when compared directly with blood cells from healthy individuals, behave differently in terms of the inflammatory balance in the cell, which is heightened in MS. In an exciting newly funded project, Dr. Downer's laboratory has formed a collaborative project with GW Pharmaceuticals to investigate the impact of cannabinoids, the ingredients found in the Cannabis Sativa plant, on inflammatory changes in blood cells isolated from MS patients. This is important, in not only improving our understanding of peripheral inflammatory changes that occur in individuals affected by MS, but may expand our knowledge on how cannabinoid-based therapies, such as Sativex®, may act to target the symptoms of the disease.

Dr. Eric Downer



In the final MS study, Dr. Downer's laboratory is looking inside the MS brain. In collaboration with Neuroscientists in UCC, this project is assessing the distribution and cellular expression profile of novel protein markers in human post-mortem brain samples. This study aims to characterize new protein targets that are linked to demyelinating lesions at different stages of MS progression, and hence provide insight into the potential therapeutic role of these new targets in MS.

The MS research avenues currently being undertaken by Dr. Downer's laboratory are varied. His research lab is conducting MS research in blood cells and brain tissue, and in doing so, aims to determine the impact of novel therapies and interventions in MS, in the form of exercise and cannabinoid-based drugs.

Reference:

www.ncbi.nlm.nih.gov/pubmed/26283920



Finally Out Of The MS Closet

Difficulties Experienced by Individuals with Cognitive Problems due to Multiple Sclerosis

According to recent research, cognitive difficulties affect 50–60% of individuals with multiple sclerosis (Amato, Zipoli & Portaccio, 2006). Research has provided information on the severity of the symptoms but there is a paucity in the literature outlining the impact these cognitive difficulties have on occupations. The aim of this study was to examine just that.

Data was collected in Ireland using semi-structured interviews. Seven participants (five female) participated. Participants were mean age of 47 with a range from 23–59 years.

“Cognition and its impact on role maintenance” and **“Participants perception of MS care”** were the two themes that emerged from the interviews following analysis of the data. Participants spoke about how their cognitive difficulties impacted on their daily lives. Specifically, the impact on employment, parenting, education, interests and hobbies were discussed. They spoke about the frustrations both they and their family experience and the impact that their cognition has had on their work, as illustrated by one participant here:

“I have lost the ability to multi-task, losing the details as I move from one thought/task to another. It began to take me much longer to accomplish much less work.”

Participants also detailed their disappointment with research and progress made in this area, and also the lack of recognition, awareness and early intervention of this issue among the healthcare profession, as evidenced below:

“I feel like the medical society don't take this seriously enough at all... I would like the medical profession to look into it more and see if they can help us more with the cognitive difficulties....more recognition and awareness really. It is a big problem”

The findings of this study highlight the impact self-reported cognitive difficulties have on individuals with MS. It also outlines participants' dissatisfaction with MS care and research in this area. The results of this study indicate the need for future research in this area and in the words of one participant:

“It is been long-neglected and is finally out of the MS closet”



Note: Cognition is a term, often used by psychologists, that refers to thoughts and the processes involved in thinking. It includes things like remembering (memory), paying attention, solving problems, planning and using language to name a few! Sometimes in multiple sclerosis some of these areas can function less well than they had previously because of the damage caused to the nerves and brain by MS. Not everyone who has MS has cognitive difficulties and when people do have difficulties there are often a lot of individual differences in how this affects people.

Reference:

Amato, M. P., Zipoli, V., & Portaccio, E. (2006). Multiple sclerosis-related cognitive changes: a review of cross-sectional and longitudinal studies. *Journal of the neurological sciences*, 245(1), 41–46.

Acknowledgements:

We would like to thank all the participants who volunteered their time to take part in this research project and discuss so honestly their challenges with us. We also wish to thank Multiple Sclerosis Ireland for their help in promoting the project.

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Research Supervisor: Dr Sinéad Hynes

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Report from the Drug Information Association EuroMeeting

By Willeke Van Eeckhoutte



But, what is patient centricity? As Guy Yeoman, VP Patient Centricity (PaCe) of AstraZeneca puts it, “Putting patients first is the open and sustained engagement of the patient to respectfully and compassionately achieve the best experience and outcome for that person and their family.” In doing so, the voices of people with chronic illnesses are becoming more important as they are finally given the respect they deserve.

I hope to build on the sessions I attended like ‘Patient-Focused Medicine’; ‘Physician Engagement, Education and Communication’; and ‘Innovative Ways of Patient Engagement in R&D’ as well as presentations and discussions about the availability of medicines in the EU. Listening to engaging and passionate people like Jan Geissler, Director of EUPATI; Alastair Kent OBE, Director of Genetic Alliance UK and Johannes Wimmer, also called the “Online Doctor” to name just a few, was an honour and one I hope to repeat soon.

After four days of being immersed in advocacy and scientific and medical innovation, I foresee a bright future for lasting, meaningful patient partnerships with pharmaceutical R&D as well as new ways of including patient reviews of research in medical journals. Hopefully, next year’s EuroMeeting will see the advocacy fellows discuss patient perspectives in a more direct manner, but Hamburg was an eye-opener as to what is possible. We’re not quite there yet, but we’re on our way.

Last month I won a Patient Advocacy Fellowship to attend the Annual DIA EuroMeeting in Hamburg, Germany. DIA –an independent Drug Information Association– and its patient fellowship is designed to strengthen and support patient collaborations with academia, healthcare, stakeholders, and other patient organisations.

This year the main topic was “INnovation: are you IN or out?” The past two years, patient-centred healthcare is gaining more importance in biomedical research, drug development and policy making to improve patient outcomes. Because the pharmacological research and development field is so vast, patient engagement often seems invisible or non-existent, even when patients are or should be at the starting and end point of medical R&D.

Attending the EuroMeeting and exhibition meant I could attend several conference sessions about the role of the patient in research and development, and represent MS Ireland and its advocacy and policy work at the exhibition. It was an absolute honour doing so, as the society has become a stronghold for many, including myself.



EUPATI (European Patients' Academy on Therapeutic Innovation)

By Joan Jordan



I hadn't previously considered what it's like to be sick or care for someone in a different EU country. I spoke with mothers living in ex-communist countries where wheelchairs are not being made available to their seriously disabled children. I felt very appreciative for the Irish Long Term Illness Scheme and hopeful that we will soon have Individual Health Identifiers- like many of our neighbours. Even though we have umbrella governing agencies like the EMA and the IMI in Europe huge gaps still exist. For example, in the Republic of Moldova: only 35 out of 1,000 MS patients receive reimbursed treatment.

Part of the training involved statistics- which is an area I am very interested in. I never imagined that I would get to apply what I learned during my Leaving Certificate maths classes to a subject so close to my heart. There is another Face to Face training session in September and the rest of the learning is done online. This suits me perfectly as I can proceed at my own pace. I retain knowledge much better in the mornings and do most of my studying then. Following the training, I feel like I am part of something really important- something that can make a difference to the quality of life for patients in Ireland. You can take part too by using the EUPATI toolbox. It's a reliable source of information to give you the A to Z on how medicines are developed. Go online to discover, adapt & share!

www.eupati.eu

Sometimes, it's good to take a step back and look at the big picture. For a person living with a chronic illness like Multiple Sclerosis, it is easy to just focus on your own back yard and not learn from what other patient organisations are achieving and dealing with. We need to find out what is happening in healthcare in Europe and how it affects Irish people with MS.

I got this chance when I attended the EUPATI Face to Face Training in Barcelona in April. There were over 50 patients and patient representatives from 32 countries and 28 disease areas. This included three Irish trainees and four people with MS. Over the course of the week, I got the opportunity to expand my medicines research and design knowledge through small group sessions and interactive lectures. I also networked my socks off and made many valuable contacts!



The EUPATI group at the recent Face to Face training in Barcelona

MSIF Global Employment Survey



A report by the **MS International Federation (MSIF)**, released to coincide with World MS Day, shows that a significant number of people with MS are leaving employment earlier than they need to.

The report, based on data from a global survey of over 12,200 people affected by MS (including 110 from Ireland), shows that 43% of people with MS who weren't working had left employment within three years of diagnosis. This rose to 70% within 10 years of being diagnosed.

The report also reveals that MS symptoms, including fatigue and cognitive impairment, have an impact on people's ability to work.



The good news is that a number of simple changes required to enable people affected by MS to stay in work, such as reasonable adjustments and increased access to treatments, are achievable.

The report includes recommendations for employers, policy makers and researchers. It also encourages people affected by MS to carefully consider telling their employer as soon as possible after diagnosis, so that adjustments can be made in good time.



Eliana, who lives in Lebanon, was working in a paper factory when she started to experience MS symptoms.

After disclosing her diagnosis, she was called to see the HR Officer and felt sure she would be asked to resign. ***"My heart was racing and my joints were trembling on the way to the office. But, instead of asking me to submit my resignation the company decided to help me take care of my health. The HR officer told me that job had been transferred from the manufacturing floor to the factory's office."*** Eliana was moved to an office work station and kept on the same pay level. Her employers also put her in touch with her local MS organisation, the Society of Lebanese Friends of Patients with Multiple Sclerosis (ALSEP).

Ceri Angood Napier, Director of Programmes at MSIF emphasised:

"A diagnosis of MS shouldn't mean someone has to give up working. Some people make a personal choice to leave employment, often due to the severity of their symptoms, or perhaps due to the perspective an MS diagnosis can bring to one's life plans. But the truth is that many people feel they have no choice but to leave a job, even though they are willing and able to stay. We hope that this report will help people affected by MS and MS organisations to raise awareness of employment issues, and to advocate to governments and employers to speed up positive change in workplaces around the world."

Nigel Stribley is the Director of Blue Sky Intermodal (an international marine container leasing company based in the UK). He explained what happened when one of his employees disclosed a diagnosis of MS:

"When one of our employees told us she had MS, we didn't realise what that meant for her and the company. We knew it was our responsibility to research MS in detail and in particular to understand the implications for individuals. The most useful and important thing was talking with our employee to find out what she needed from us. The key issue for her was flexible working to help her manage fatigue so we made changes to accommodate that."

Key Findings From The Report

12,233 people took part in the Global MS Employment survey, an increase of 40% from when the same survey was carried out in 2010. Respondents were based in 93 countries.

- 43% of people with MS who were not in employment had stopped working within three years of diagnosis. This figure rose to 70% after ten years.
- 62% of people with MS who were not in employment said fatigue prevented them from staying in work – far less than the 85% reported in 2010.
- Fewer people had reduced their working hours or taken a short term absence compared to 2010 data.
- More people reported not needing to change their working pattern compared to 2010 data.
- Effective changes and adaptations could keep more people with MS in work.
- Many of the changes required to enable people with MS to stay in employment, such as adaptations in the workplace or access to treatments, are achievable through advocacy.

“Effective changes and adaptations could keep more people with MS in work”

Global MS Employment Report 2016



“More people reported not needing to change their working pattern compared to 2010 data”

Global MS Employment Report 2016



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The full Global MS Employment report is available for download at:

www.msif.org/about-us/advocacy/employment-and-ms/

“62% of people with MS who were not in employment said fatigue prevented them from staying at work - far less than the 85% reported in 2010”

Global MS Employment Report 2016



MS Ireland Report On MS And Employment

On June 2nd, MS Ireland released a set of resources on MS and employment, including a report for policy makers using data from the 'Societal Costs of Multiple Sclerosis in Ireland 2015'.

The report for policy makers highlighted key Irish data on MS and employment, including:

- 9 out of 10 people with MS in Ireland are of working age
- The rate of employment for people with MS in Ireland is 17% lower than the European average (43% compared with an EU average of 60%)
- Over 34% of people with MS have had to permanently withdraw from the workforce as a result of MS
- Total annual productivity losses in Ireland due to MS, amounts to €135.5 million
- Employment decreases significantly with increasing disease severity – 66% of those with severe MS have retired due to their condition, compared to 15.6% with mild MS

The report made a number of detailed policy recommendations:

- Development of specialised early intervention guidelines to support those absent from work to return to work as soon as possible when and where appropriate. These guidelines must specifically account for the needs and experiences of those living with long-term chronic illnesses and how the symptoms of illnesses such as MS impact on work. These guidelines should be developed by the National Disability Authority in consultation with people affected by the conditions and organisations and professionals who support them.
- Access to appropriate and timely workplace assessment services from specialists who have a detailed understanding of particular illnesses and conditions. These specialists may be occupational therapists or organisational psychologists who have received training in particular disability or illness areas, or professionals from relevant

support organisations who have received training in undertaking assessments. Assessments should be conducted in consultation with the multi-disciplinary team of healthcare professionals who are working with the employee. The Employer Disability Information Service should have a role in supporting employers to identify and access specialist assessment services.

- Access to on-going in work supports for both employers and employees. Existing 'job coach' services should be expanded to support job retention for those returning to a position after the diagnosis of a chronic illness or acquisition of a disability. Existing financial supports for employers, such as the Retention Grant and the Workplace Equipment Adaptation Grant, should be expanded in scope so as to cover additional in-work supports such as fares to work if the employee can't use public transport or drive, or employment of a support worker or job coach to provide support in the in workplace, as per the Access to Work model in the UK.
- Appropriate post-employment planning, including access to retraining services and vocational rehabilitation services where necessary. Existing services that provide advice and guidance on employment and education should be expanded and upskilled so as to be able to provide guidance that specifically accounts for the needs and experiences of those living with long-term chronic illnesses such as MS.
- Extension of entitlement to medical cards and other associated benefits on return to work, to avoid the 'welfare trap'.

MS Ireland also continues to stress the importance of people with MS having access to interventions that reduce relapses and disability progression, including early diagnosis and treatment, regular monitoring, and timely access to appropriate medications and therapeutic supports including neurorehabilitation.

You can download 'Multiple Sclerosis and Employment: Facts and Figures' and 'Societal Costs of Multiple Sclerosis in Ireland 2015' from:

www.ms-society.ie/pages/living-with-ms/information-centre/our-publications

Bladder Dysfunction In People With MS

Catherine Browne is a Chartered Physiotherapist and PhD candidate in the University of Limerick, supervised by Dr. Nancy Salmon and Dr. Maria Kehoe.

Catherine is in the final stages of her PhD, exploring bladder dysfunction among people with MS. Bladder dysfunction is one of the most distressing symptoms of MS, however; it has been neglected to date, partly because of the perceived private nature of the problem.

This research project involved 3 strands:

- **The first strand** explored how bladder dysfunction interfered with quality of life for people with MS. Findings demonstrated that bladder dysfunction results in major disruptions to daily activities for people with MS which can create a sense of loss in their lives. People with MS reported learning about their own bodies through experience. Using this knowledge, they attempt to self-manage their bladder symptoms despite current barriers to navigating existing healthcare infrastructure. Barriers include the reluctance to discuss bladder dysfunction and perceptions of current services.
- **The second strand** focused on the perspectives of healthcare professionals concerning bladder dysfunction and current service provision for people with MS in Ireland. Findings demonstrated a “model of clinical practice development” highlighting the interaction between underlying beliefs, practice and experiential knowledge of healthcare professionals. Findings suggest that implementing change within this model may optimise access to services for people with MS.
- **The final strand** involved a large scale online questionnaire examining current management and service provision for people with MS with bladder dysfunction from the perspectives of both healthcare professionals and people with MS. A total of 214 participants completed this questionnaire. Preliminary

analysis suggests that both people with MS and healthcare professionals are interested in more information regarding self-management of bladder dysfunction. Data across all three strands will be synthesised to inform the development of a self-management tool for people with MS with bladder dysfunction.



Call for participants! MS Ireland hosting UCD medical student in summer 2016

MS Ireland is hosting an undergraduate medical student as part of UCD's Student Summer Research Initiative. The student, Matthew McCarthy, will be carrying out a research project on people with MS's experiences of interacting with medical services.

Please go to www.ms-society.ie/pages/research to complete a short anonymous survey. This only takes 5-10 minutes to complete and should help MS Ireland get some valuable insights into how the medical system works for people with MS.

You can contact the researcher Matthew at matthew.mc-carthy@ucdconnect.ie or Harriet Doig at harrieta@ms-society.ie if you have any questions about the survey or the project.

Ocrelizumab

New medication indicated for primary progressive MS.

By Dr Chris McGuigan,
Consultant Neurologist,
St Vincent's Hospital.

Ocrelizumab is a new medication which has recently been shown in three, large phase-three clinical trials to have beneficial effects in both relapsing-remitting and primary progressive MS.

Traditionally MS treatments have targeted 'T' cells in the immune system which we know are involved in the type of inflammation seen in people with MS. Ocrelizumab is a monoclonal antibody which targets 'B' cells, the other main cell line in the immune system which has also been shown to have a role in neuroinflammation.

Two large phase-three studies (Opera I & II) of Ocrelizumab in people with relapsing-remitting MS compared to interferon beta-1a, showed a 46% and 47% respectively, reduction in relapses in the Ocrelizumab treated groups and improvements in disability progression rates and reduction in new MRI lesions. Oratorio was a further phase-three study in 486 people with primary progressive MS who received Ocrelizumab compared to 239 people who received a placebo. The group receiving Ocrelizumab, although still showing some progression in disability, had a 24% reduced rate of disability progression compared to those not getting the active drug. This is the first clinical trial to meet the pre-defined measure of treatment response in primary progressive MS.

Ocrelizumab will be given in hospital by an infusion every six months. From the studies the main side effects encountered were reactions to the infusions such as flushing, headache etc.



The clinical studies lasted for two-years so we do need to see more long-term information to confirm this drugs effectiveness and safety. It is also important to be aware that this drug has not yet received a license in Europe and will then require further approval for reimbursement in Ireland so will not be available from your neurologist until mid- 2017 at the earliest. Until the drug has been given a license (so it can be prescribed) we will not know what groups of people with MS will be approved to receive this medicine.

When available, Ocrelizumab will be a welcome addition to the number of drugs currently licensed for relapsing-remitting MS and may also be beneficial to people with primary progressive MS.



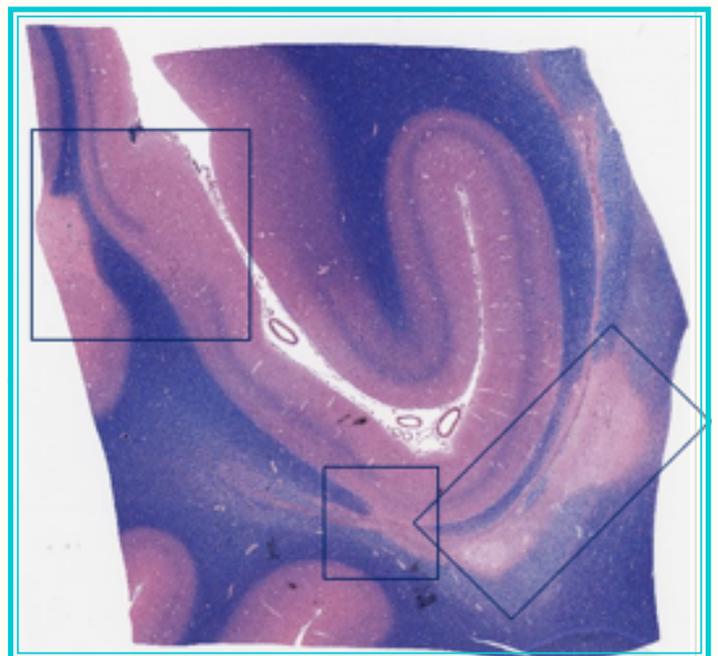
Myelination research – NUI Galway



Dr Una FitzGerald, whose team at the National University of Ireland Galway have been researching MS for over 10 years.

Dr. Una FitzGerald's team at NUI Galway has been doing research into multiple sclerosis for the last ten years. Her approach involves monitoring of the chemicals in our brain cells and how they interact when someone is suffering from the debilitating effects of inflammatory attack, loss of myelin and degeneration of brain cells. The work has focused on examining an in built biochemical stress response, or signalling pathway, that occurs when the protein "factory" of the cell, the endoplasmic reticulum (ER), is overloaded. Called "ER stress", this signalling pathway represents an attempt by the cell to return to a balanced state. If the cell remains in a stressed state for too long, however, and ER stress is chronic, the cell can die.

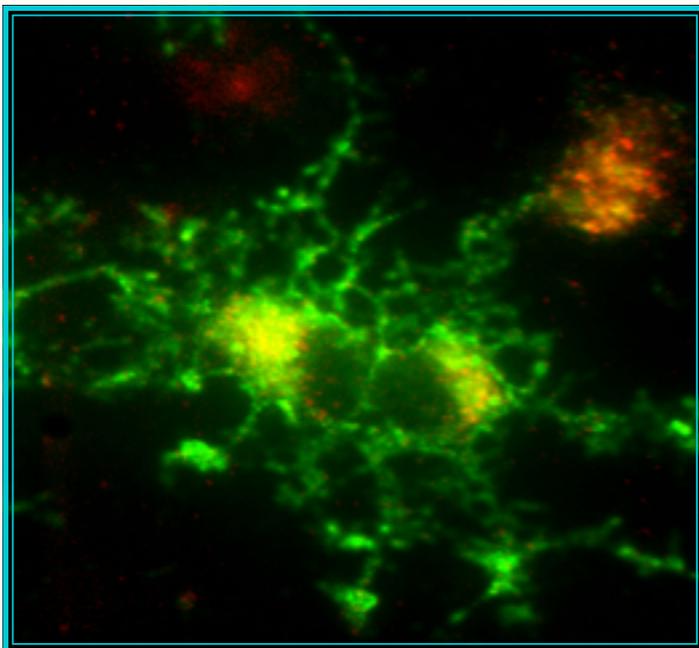
Previously, the FitzGerald group has shown this stress pathway to be initiated in sites of myelin loss in the brains of people with MS and also in an animal model of the condition. As a result, we deduced that higher levels of ER stress-associated chemicals may be present in people with MS, compared to the rest of the population. We have shown that some of these molecules, quaintly named "chaperones" because of how they "take care" of other proteins, are present at higher levels in the blood and saliva of people with MS. At the moment we are examining whether these molecules could act as indicators - or "biomarkers" - of disease progression or reaction to therapies. We feel that development of a useful biomarker in MS could be of great importance as it would be much cheaper and less invasive than the current tests which include MRI scans and lumbar punctures. This project is coordinated by the senior scientist in the group, Dr Jill McMahon, and is ongoing over the period of a few years as we need to collect as many blood and saliva samples as possible. The groups we are testing are: (1) people with MS, (2) people with other neurological conditions besides MS and (3) people with no disease. We are being helped in this by Consultant Neurologists Dr Tim Counihan of Galway University Hospitals and Dr Chris McGuigan of St Vincent's Hospital, Dublin, and hope to expand our sample collection by working with a number of physicians in the Galway area.



Human brain tissue stained for myelin (blue). Boxes indicate where myelin loss has occurred.

MYELINATION RESEARCH

Besides development of potential biomarkers in MS, we are interested in the basic biology of these chaperone molecules and are trying to work out how they might be beneficial to diseased cells. A PhD student in the research group, Sravanthi Bandla, is currently carrying out painstaking analysis of four different chaperones, attempting to see how they behave when added to immune and brain cells, and determining their potential as therapeutic agents in MS. In another PhD project, Michelle Naughton has been looking at what happens when myelin is first laid down in the brain during development, and how ER stress-associated chemicals can affect this process. A clearer understanding of normal myelination, as we grow from embryos to adults, is crucial in understanding what might be going wrong in MS when people fail to make new myelin properly. Michelle has also been examining brain cells called oligodendrocytes. These cells are responsible for making myelin in the brain, and for maintaining its structure, and she is trying to understand the role of the ER stress signalling pathway in these processes. This is done by isolating cells called oligodendrocyte progenitor cells (OPCs) and growing them in a dish until they become adult oligodendrocyte cells, capable of producing myelin. By adding different drugs, that either inhibit or enhance the ER stress signalling pathway, Michelle can work out how important the pathway is for proper myelination.



Oligodendrocytes (stained green), produced in the laboratory from extracted OPCs, starting to produce myelin (orange-red).

In recent years, there has been much media attention given to the idea that iron levels in brain tissue may have an impact on MS. While a direct link has not been proven, it is certainly true that high cellular iron levels can be very damaging to brain cells i.e. neurotoxic. The ER stress signalling pathway is known to impact upon the body's natural systems for controlling the amount of iron in cells and Sinead Healy, a PhD candidate in the FitzGerald group, has been studying the interaction of these two systems. In a project that involves the use of brain slice technology and 3D imaging, Sinead is investigating the effects of iron overload on all the different types of brain cell, and determining what are the downstream effects on ER stress signalling and myelin.

Una FitzGerald's Research Team at NUIG.



Michelle Naughton



Sinead Healy



Sravanthi Bandla



Jill McMahon



Progression

Clues Continue to Emerge -
Report from San Francisco

By Alexis Donnelly

Member of the Scientific Steering Committee of the International Progressive MS Alliance

I recently participated in the Second Scientific Congress of the Progressive MS Alliance (PMSA) in San Francisco (11-13 May 2016). Financed mainly by five large MS societies (USA, UK, Canada, Australia and Italy) it is co-ordinating a global effort to research the mystery of progression in MS and develop therapies to address it. MS Ireland is also contributing with ten further societies (and counting...). The MS International Federation is also assisting.

There are three individuals with MS on the main scientific steering committee of the Alliance - Jonathan Strum (California, USA), Caroline Sincock (Glasgow, UK) and myself - and we all participated enthusiastically at this Congress. It was a thrilling experience but very hard to put into words. There were over 200 delegates - including 140 leading neurologists and laboratory scientists together with staff of various MS societies (including MSIF), people with MS, potential philanthropic donors to the cause and also representatives from the pharmaceutical industry. There were nearly 20 individual presentations in six themed sessions, two panel discussions and a poster presentation session.

For a neuro-nerd like myself, it was all incredibly exciting. There was a tight technical focus on progression in MS. Every presenter and all scientific delegates were leading figures in their fields and most palpably there was an absolute unquestioned commitment to solving this puzzle. There was an obvious sense of collegiality - they were energetically cooperating in a very thoughtful manner - all that mattered was the answer not who found it. I immediately had the sense of looking over the shoulders of giants as they worked on a difficult jigsaw puzzle.

The session themes were chosen along the lines of the Alliance strategy: What is driving progression? What are the biomarkers of progression? (E.g. what blood tests or MRI imaging tests can we use to assess the degree of progression?) How can we use data from old trials, from new genetic tools, from patient databases and

other sources to discover new drug targets, new drugs or re-purpose old drugs? What lessons can we learn from the past to design new and faster clinical trials? What are the latest techniques being used in rehabilitation in order to recover some lost function? How can we harness the knowledge being gathered in the other neurological conditions?

I hope to provide more details on the topics that these questions raised in further articles as there simply isn't enough space here. However, here are some illustrative examples to highlight what was covered. Professor Stephen Hauser (UC San Francisco and a Charcot Medal winner) gave us a demonstration of the Bioscreen - a tablet-based interface to one or more patient databases. It is used during patient appointments to trace the history of each patient and compare it to that of fellow patients in the same situation - how are you doing relative to your peer group? More interestingly it can also be used to forecast how that individual is likely to respond to alternative therapies based on the responses of fellow patients in the same situation - how might you be expected to fare on your current or on alternative therapies?

There was a very interesting session on rehabilitation - techniques to improve memory or using trans-cranial stimulation techniques to improve rehabilitation outcomes. Another presentation focused on the different imaging techniques of which MRI is now capable and may give us clues to what is going on in progression.

The three people with MS on the main scientific steering committee of the Alliance participated in these sessions - as questioners, as panellists and as the people making the opening and closing addresses.

I have lived with primary progressive MS for 25 years and in all that time, the PMSA is far and away the best development I have seen. Uniquely, it has managed to capture the global imagination and generate a momentum and credibility like never before. There is now a world-wide network co-ordinating research and translational effort to ensure maximal effect. To be aware of the existence of this effort is one thing, to participate personally is quite exhilarating. The most important message for people with progressive MS is: progressive MS is on the research agenda - there are now reasonable grounds for hope.

In 2016 to date, two MS Ireland branches have contributed €7,000 between them to the work of the Progressive MS Alliance.

Do you have MS?

Have you had a fall in the last 3 months?

Can you walk for 10 metres?

If you answered yes to these three questions then the MS Research Team at the University of Limerick would like to hear from you!

Why Does this Matter?

We know from a large amount of research that over half of all people with MS will fall every 3 months

Falls prevention for other populations has been very well investigated however in people with MS it has not been given the attention it deserves

The MS Research Team at UL led by Prof. Susan Coote are developing a falls prevention intervention specifically for people with MS

For this to be a successful intervention we need the insight of people with MS who have fallen to help in its design



What Does it Involve?

If you are interested in participating in this study, a researcher will call you and conduct a 30 minute questionnaire with you

The questions will be about your MS, your most recent falls and what you think would be important to feature in the falls prevention intervention we are developing

What Should I do now?

If you are interesting in taking part in this study or would like to know more about it you can contact Prof. Susan Coote by email at

susan.Coote@ul.ie

Postgraduate researcher Laura Comber at

laura.Comber@ul.ie

or call the MS Research Team on

061-234278.

Alternatively you can visit our website at **www.msresearch.ie** for more information.

MS Research
at UL

 **MS Ireland**
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

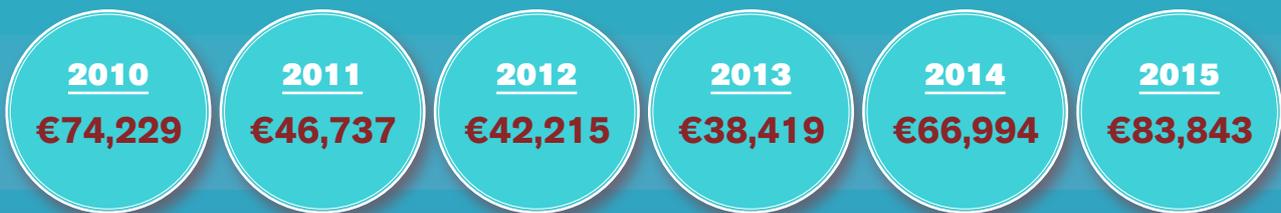
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MS Research Issue 2 – December 2016

- International research – find out about some of the latest key developments in international MS research
- People with MS's experiences of health care services in Ireland
- And many more exciting updates from Irish researchers

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