



## **Research Strategy**

### **2015-2019**

Research is one of five Strategic Priority areas in MS Ireland's Strategic Plan for the period 2015-2019. This document outlines MS Ireland's research priorities for the lifetime of the current Strategic Plan. In addition this document outlines the activities that will be undertaken to achieve these research priorities.

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## **1. Introduction and Background**

Research is a key component in improving the health and quality of life for people with MS.

MS Ireland's research agenda is influenced by a number of issues/topics that include:

- investigations to improve the understanding of the condition's mechanism
- developing disease modifying therapies
- translational research into how this knowledge can be useful and practical
- what interventions can be beneficial
- treatments to improve quality of life
- how service delivery can positively impact

Research is most often stimulated by the scientific and social science community and the desire of people with MS to better understand, manage, prevent or improve their conditions. Aligned to these driving forces is the commercial research agenda driven largely by the pharmaceutical industry. The responsibility of the state to provide more efficacious and appropriate responses to population health also influences MS research. Given these currents in research and policy areas, MS Ireland seeks to identify and articulate their views and priorities of Irish people with MS.

A 2013 study completed by the MS Society in the United Kingdom, in partnership with the James Lind Alliance, identified the top research priority areas for people with MS in that jurisdiction. In Ireland, an internal organisational review carried out by MS Ireland in 2011 identified research as a key priority area, with 83.1% of 930 respondents stating that research is an extremely important function of the organisation.

Since its establishment, MS Ireland has a history of funding and supporting research in many areas of MS. Since the start of the economic downturn in 2008, the funding available to MS Ireland has decreased. Consequently in recent years MS Ireland has not been in a position to fund a substantial amount of research. However, MS Ireland believes that research is the most beneficial way to improve understanding of the disease and continues to support research and researchers in a variety of ways including dissemination of research findings, collaborating with academic institutions and advocating for improvement of the research environment in Ireland.

The aim of this strategy is to provide a plan for how MS Ireland can transform and drive the multiple sclerosis research agenda on a national and international level, making effective use of the limited financial resources available to the organisation.

## **2. Research Priorities**

MS Ireland believes that research is the most beneficial way to improve the understanding of the disease, leading to better treatments, interventions, management and ultimately a cure for MS. MS Ireland supports, promotes and funds scientific and social sciences research. MS Ireland has six main strategic Research Priorities:

1. Funding research when funding is available (Sections 3 and 4)
2. Engaging in partnerships and collaborations with academic institutions and other organisations with an interest in research, so as to develop and progress research projects and facilitate people with MS to take part in research (Sections 5 and 7)
3. Communicate and disseminate key research (funded by MS Ireland and other MS societies, and other research of general interest) to people with MS, researchers, healthcare professionals, policy makers and other stakeholders (Section 6)
4. Creating a forum where researchers from different disciplines can learn about funding opportunities, share information about each other's work, and learn about the needs and interests of people with MS (Sections 5, 6, 7 and 8)
5. To promote Public Patient Involvement (PPI) in research as best practice and develop mechanisms for meaningful PPI (Section 8)
6. To advocate on key issues affecting the research environment in Ireland, and use key research findings to advocate for policy changes and Government investment in services that support people affected by MS (Section 9)

When research funding is available, in deciding how the funding will be utilised, MS Ireland is cognisant of the top 10 MS research priority areas as identified by the MS Society in the UK and the James Lind Alliance<sup>1</sup>, which are<sup>2</sup>:

1. Which treatments are effective to slow, stop or reverse the accumulation of disability associated with MS?
2. How can MS be prevented?
3. Which treatments are effective for fatigue in people with MS?
4. How can people with MS be best supported to self-manage their condition?
5. Does early treatment with aggressive disease modifying drugs improve the prognosis for people with MS?

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<sup>1</sup> <https://www.mssociety.org.uk/ms-research/how-we-decide-what-we-fund/Setting-MS-research-priorities>

<sup>2</sup> <http://www.jla.nihr.ac.uk/priority-setting-partnerships/multiple-sclerosis/top-10-priorities/>

6. Is Vitamin D supplementation an effective disease modifying treatment for MS?
7. Which treatments are effective to improve mobility for people with MS?
8. Which treatments are effective to improve cognition in people with MS?
9. Which treatments are effective for pain in people with MS?
10. Is physiotherapy effective in reducing disability in people with MS?

MS Ireland also recognises the need to conduct research relating to informal caregivers of people with MS and this area will also be considered if funding for research becomes available.

**Key Activities:**

- i. MS Ireland will undertake a research prioritisation exercise, similar in design and approach to that carried out by the MS Society in the UK and the James Lind Alliance, to determine the top 10 research priority areas for people with MS in Ireland.

### **3. Funding**

Due to ongoing budgetary constraints caused by reductions in statutory and fundraised income, MS Ireland is unable to maintain a dedicated fund for research from core funding. For the lifetime of this strategy, MS Ireland will ring-fence funding for research where funds are received from individual or corporate donors that are specified for this purpose, or where funding is obtained from grant-awarding bodies. The exception to this will be the Dean Medal Travel Bursary (see Key Activity iii).

**Key Activities:**

- i. Proactively monitor and pursue potential funding opportunities for research including grant calls from the Irish Research Council, the Health Research Board and the National Disability Authority.
- ii. When ring-fenced funding from donors is available, apply to the Medical Research Charities Group/Health Research Board Joint Funding Scheme. Applications to the Joint Funding Scheme should be in accordance with the top 10 MS research priority areas as outlined above.
- iii. MS Ireland will follow the guidance and process regarding international peer review set out by the MRCG and HRB for the Joint Funding Scheme for all research projects funded by MS Ireland (See Appendix 1).
- iv. Every two years, MS Ireland will award a Dean Medal Travel Bursary of €2,000. In the lifetime of this Strategy, awards will be made in 2015, 2017 and 2019. 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 (see Appendix 2). The successful applicant will be required to submit a report of their activities to MS Ireland, for dissemination via MS Ireland's communication channels (see Section 6).

- v. MS Ireland will provide detailed reports of spending and research activities annually to funders. Summaries will be made available to members, with the detailed reports available on request.
- vi. MS Ireland will actively encourage voluntary Branches to donate a portion of their fundraised income to research.
- vii. MS Ireland will circulate notices about potential funding opportunities from grant-making bodies to our contact list of researchers interested in MS.

#### **4. Research Committee**

MS Ireland's Research Committee is charged with evaluating incoming applications for research funding and monitoring their progress, and directing the overall research strategy of the organisation. The committee shall consist of at least six members, including at least one of the following:

- a) a neurologist
- b) a person with MS
- c) an MS nurse or other healthcare practitioner directly involved with the treatment or carer of a person with MS
- d) a senior professional involved in service delivery or development
- e) a social policy advisor, a health economist or an epidemiologist

#### **Key Activities:**

- i. MS Ireland will maintain a functioning Research Committee, in accordance with the Terms of Reference (see Appendix 3).
- ii. MS Ireland will convene meetings of the Research Committee as and when ring-fenced funding is received for research, to discuss how best to use these funds in accordance with the top 10 MS research priority areas as outlined above (See Section 2).
- iii. The Research Committee will meet at least once per year to review on-going MS Ireland funded research, discuss potential new funding schemes and collaboration opportunities, and review the progress of this Strategy.

## **5. Partnerships and Collaborations**

MS Ireland works in partnership with academic institutions and other organisations with an interest in research. MS Ireland has a Memorandum of Understanding with the University of Limerick in the area of physiotherapy research (see Appendix 4), which is subject to review every three years.

### **Key Activities:**

- i. MS Ireland will maintain the Memorandum of Understanding with the University of Limerick, in accordance with the terms of the Understanding. The Memorandum of Understanding will be reviewed once in the lifetime of this Strategy, in 2017.
- ii. MS Ireland will engage with a student summer research scheme (such as the UCD Patient Advocate Centred Education Research Programme) twice during the lifetime of this Strategy. MS Ireland will identify research projects suitable for undergraduate students that are in accordance with the top 10 MS research priorities (see Section 2).
- iii. MS Ireland will engage with the Irish Research Council's New Foundations scheme to actively seek new potential research collaborations with academic institutions.
- iv. MS Ireland will facilitate and support researchers who have obtained ethical approval from their relevant institutions to seek participants for a broad range of research studies that are in accordance with the top 10 MS research priorities (see section 2), as per MS Ireland's Protocol for Researchers (See Appendix 5) (See Section 7).
- v. MS Ireland will engage with the Neurological Alliance of Ireland (NAI), the Disability Federation of Ireland (DFI), Care Alliance Ireland, the Medical Research Charities Group (MRCG), the Irish Brain Council, the International Progressive MS Alliance and the Irish Platform for Patients Organisations, Science and Industry (IPPOSI) on areas of common interest relating to research. This will include sharing of information and research findings, sharing information about possible funding opportunities, advocacy (see Section 9) and assisting with recruitment of research participants where appropriate.

## **6. Communication and Dissemination**

MS Ireland plays a key role in communicating and disseminating the findings of MS research to people affected by MS, healthcare professionals, policy makers and other stakeholders. MS Ireland maintains a contact list of Irish researchers interested in MS. MS Ireland employs an Information, Advocacy and Research Officer who is tasked with co-ordinating communications between researchers and other relevant stakeholders.

**Key Activities:**

- i. MS Ireland will publish two research eZines per year. The research eZine will contain updates from Irish and international MS research, and will focus on research that is in accordance with MS Ireland's Research Priorities and the 10 priority areas identified by the James Lind Alliance. All researchers on the contact list of Irish researchers interested in MS will be invited to contribute to the eZine. Contributing to the eZine will be a requirement for any researchers that receive funding from MS Ireland. Each edition of the eZine will include as standing features articles relating to Public Patient Involvement (PPI) (see Section 8) and an update on the work of the International Progressive MS Alliance.
- ii. MS Ireland will produce briefing documents and position papers on complex areas of research that attract the interest of the MS community (for example, stem cells research and robotic walking devices). The aim of these papers will be to provide clear and concise information on the topic in question and to establish MS Ireland's organisational position on the topic.
- iii. MS Ireland will hold one 'MS Research Explored' event per year, which will feature talks from Irish and international MS researchers on topics that align with MS Ireland's Research Priorities and the 10 priority areas identified by the James Lind Alliance.
- iv. MS Ireland will facilitate one networking event for Irish researchers interested in MS per year.
- v. MS Ireland will regularly review and update the content in the Research section of the MS Ireland website, with a target of at least two research-related blog posts per month. These would include key developments and findings in MS research, opportunities to get involved in research and research-related events.
- vi. MS Ireland will maintain links on the website to sources of up-to-date research information, including but not limited to MS International Federation (MSIF), the European Multiple Sclerosis Platform (EMSP), Neurology Now, the International Progressive MS Alliance, Multiple Sclerosis News Today and other MS societies.
- vii. Where resources allow, MS Ireland will attend conferences organised by the European Multiple Sclerosis Platform (EMSP), MS International Federation (MSIF), the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) and other relevant events and conferences so as to stay up-to-date with the latest developments in MS research and disseminate them through various channels (eZine, MS News, MS Ireland website, eNews, 'MS Research Explored' events, social media etc). Where resources do not

allow for an MS Ireland staff member to attend such events, reports and summaries from the event will be sought, for dissemination via MS Ireland's communication channels.

- viii. MS Ireland will continue to proactively monitor relevant and reliable sources of news on MS research (including, but not limited to, MS News Today, Neurology Now, the International Journal of MS Care, the MS Trust research eNews, MSIF research eNews) so as to stay up-to-date with the latest developments in MS research and disseminate them through various channels.
- ix. MS Ireland will continue to provide regular updates to our voluntary Branch network on the work of any research organisations and projects that have been supported with donations from the Branches (see Section 3, point v).

## **7. Supporting Researchers**

MS Ireland encourages people with MS to participate in MS research projects. MS Ireland ensures that these projects are ethical, appropriately organised by a recognised institution and sanctioned by that research authority. In accordance with these principles, MS Ireland supports undergraduate and post-graduate researchers in finding participants for studies and disseminating research findings. MS Ireland has developed a protocol for researchers who wish to engage with MS Ireland in this way (see Appendix 5).

### **Key Activities:**

- i. MS Ireland will consider requests from researchers to assist with the recruitment of participants, in accordance with the Protocol. Where the Protocol is satisfied, MS Ireland will use the following channels to share requests for research participants:
  - MS Ireland website
  - Monthly eNews
  - Research eZine
  - Social media
- ii. Researchers on MS Ireland's contact list will be invited to share calls for research participants in the bi-annual research eZine.
- iii. MS Ireland will ask all researchers who use MS Ireland's channels to recruit participants for studies to provide updates on the progress of their research for the research eZine.

- iv. MS Ireland will seek to proactively engage with academic institutions to communicate MS Ireland's research priority areas to researchers considering carrying out MS-related research.

## **8. Public Patient Involvement (PPI)**

According to the Irish Health Research Forum, PPI describes a whole variety of ways that researchers engage with people for whom their research holds relevance. PPI plays an important role in ensuring that patients are informed about research that is relevant to them. This is likely to result in increased patient support for research and the improved likelihood of patient involvement in the case of clinical research<sup>3</sup>.

### **Key Activities:**

- i. MS Ireland will support the work of the European Patients' Academy on Therapeutic Innovation (EUPATI) by encouraging people with MS to get involved in EUPATI projects and to share their experiences via the research eZine and other channels.
- ii. MS Ireland will have at least one person with MS on the Research Committee (see Section 4).
- iii. MS Ireland will include an article on PPI in each issue of the research eZine (see Section 6, point i).
- iv. MS Ireland will support MRCG and IPPOSI on projects that aim to promote PPI in medical research (see Section 5, point iii).

## **9. Advocacy**

MS Ireland advocates on a collective platform for the improvement in services, resources and policies affecting people with MS. This includes advocating for greater Government investment in medical research in Ireland and improvement of the infrastructures that allow such research to take place, such as the development of patient registries. MS Ireland will also use key findings from research to support the organisation's broader advocacy agenda relating to Government policies and services impacting on people with MS.

### **Key Activities:**

- i. MS Ireland will attend board meetings of the MRCG and IPPOSI (see Section 5, point iii) and will maintain a presence on the Communications and Advocacy Sub-Committee of the

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<sup>3</sup> [http://www.mrcg.ie/assets/23/2A2C32C1-AC5A-7DF1-9CEDCA21B1745ED7\\_document/Forum\\_PPI\\_Doc\\_5-15.pdf](http://www.mrcg.ie/assets/23/2A2C32C1-AC5A-7DF1-9CEDCA21B1745ED7_document/Forum_PPI_Doc_5-15.pdf)

MRCG. MS Ireland will use these platforms to bring up issues of concern to the MS community relating to medical research.

- ii. MS Ireland will support the advocacy work of the MRCG, in particular their calls for:
  - Increasing investment for medical research.
  - Appointment of a Director of Research in the Health Service Executive (HSE).
  - Development and maintenance of patient registries<sup>4</sup>.
- iii. MS Ireland will engage with the Irish Brain Council (to the extent that organisational capacity allows), to promote a strong advocacy agenda for investment in and support of the development of brain research in Ireland.
- iv. MS Ireland will develop detailed policy recommendations based on key research findings and will actively seek opportunities to present these recommendations to policy makers.
- v. The Research Committee will review MS Ireland's research advocacy priorities annually.

## **10. Reporting**

- i. Reports on the activities in this Strategy will be provided to the Board of MS Ireland, in advance of every Board meeting.
- ii. Members of MS Ireland will be updated on the progress of the Strategy annually, via the Annual Report.

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<sup>4</sup> [http://www.mrcg.ie/assets/3/EFA033CD-B921-60DE-3372A00EB209D4CB\\_document/MRCG\\_election\\_leaflet.pdf](http://www.mrcg.ie/assets/3/EFA033CD-B921-60DE-3372A00EB209D4CB_document/MRCG_election_leaflet.pdf)

## **11. Contacts**

### **Harriet Doig – Information, Advocacy and Research Officer:**

Tel: 01 678 1600 Email: [harrieta@ms-society.ie](mailto:harrieta@ms-society.ie)

### **Aidan Larkin – National Services Development Manager:**

Tel: 091 768 630 Email: [aidanl@ms-society.ie](mailto:aidanl@ms-society.ie)

### **MS Ireland Research Committee members (as of August 2016):**

- **Chairperson – Professor Susan Coote**
- Dr Patricia Walsh
- Professor Niall Tubridy
- Dr Kilian Smith
- Manfred Hushcka
- Aidan Larkin
- Alexis Donnelly
- Mags Rogers

To make contact with the committee please contact Harriet Doig.

## **Appendix 1**

### **MRCG/HRB Joint Funding Scheme Review Process**

Each charity carries out a peer review of applications.

#### *International peer review:*

At least three international peer reviewers are required for each application. For the purpose of this call an international reviewer is an active researcher (not e.g. a charity administrator) based outside of the Republic of Ireland. Peer reviewer comments must be captured on the standard peer reviewer feedback form provided. The MRCG/HRB policy on confidentiality and conflict of interest must be adopted for the selection of peer reviewers. Peer reviewers should explicitly disclose whether they have a conflict of interest or not on the reviewers form. Those that declare a conflict of interest should not take further part in the review process.

Please refer to Appendix 1 for the MRCG/HRB Confidentiality and Conflict of Interest policy and Appendix 2 for guidance on identifying potential peer reviewers.

#### *Right to respond:*

Once reviews have been received all applicants are afforded the opportunity to respond to anonymised reviewer comments. Please see Appendix 3 for guidance on the Right to Reply process. Responses to peer reviewer comments must be captured on the standard Right to Respond form provided. Applicants must adhere strictly to the guidance provided to ensure a fair competition.

#### *Charity final selection:*

Each charity will have its own final selection step (e.g. internal selection committee) to agree the applications which will be submitted to the MRCG/HRB Joint Selection Committee. Charities will be asked how many applications in total they have received, and how many they have put forward to the MRCG/HRB Joint Selection Committee. Charities must confirm that any person involved in the selection of applications has adhered to the MRCG/HRB confidentiality and conflict of interest policy.

## **Appendix 2**

### **Dean Medal Travel Bursary Information Sheet**

#### **The Dean Medal**

**A travel bursary to encourage the understanding of MS among young researchers**

#### **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.

Geoffrey Dean was born in Wales and spent his early professional life in South Africa studying the variation in prevalence of MS among the different ethnic groups. He expanded these epidemiological studies to include Cyprus, Spain, Malta, Sicily and Ireland. In 1968 he moved to Ireland to become the first director of the newly formed Medico – Social Research Board, the fore-runner of the Health Research Board. Dr Dean established himself and family in Ireland and continued to contribute to the Board after his directorship ceased.

Active in research up to his death Dr Dean pursued other interest areas particularly porphyria variegata. Of the 120 papers produced during his illustrious career, his last was published in 2008 at the age of eighty-nine.

The Dean Medal award 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.

#### **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-fertilization of skills through collaborative research projects.
- One bi-annual award 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 a 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 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 also required to submit electronic copies of all the above documents. Electronic copies are to be emailed to Aidan Larkin [aidanl@ms-society.ie](mailto:aidanl@ms-society.ie)

### Deadline

The deadline for receipt of applications is **Friday, 23<sup>rd</sup> October 2015**

### Selection

The members of the MS Ireland's Research Committee consider and select successful candidates. Please allow 8 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 the MS Ireland's Research Committee. 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 the MS Ireland's Research Committee. If possible, such acknowledgements should also reference MS Ireland's website [www.ms-society.ie](http://www.ms-society.ie)

### Contact

Queries and nominations for the Dean Medal should be submitted by email to Aidan Larkin [aidanl@ms-society.ie](mailto:aidanl@ms-society.ie)

## **Appendix 3**

### **Research Committee Terms of Reference**

#### **MS Ireland**

#### **Terms of Reference**

#### **Research Committee**

##### **1. Establishment**

- 1.1 The Research Committee is established by the Board of MS Ireland for the better governance of the Society in the area of research.
- 1.2 The Board may at any time alter or revoke the composition or terms of reference of the committee.
- 1.3 The Board of MS Ireland may award funding to particular research projects outside the remit of the research committee.
- 1.4 Where MS Ireland receives donations for specific research projects e.g. Quality of Life, Management Strategies etc. MS Ireland will inform the Research Committee.

##### **2. Membership**

- 2.1 The committee shall consist of at least six members, including at least one neurologist, a person with MS, an MS nurse or other healthcare practitioner directly involved with the treatment or carer of a person with MS, a senior professional involved in Service delivery or development, a social policy advisor, a health economist, an epidemiologist.
- 2.2 The term of the committee is three years. Members may be elected for a further term. In general it is expected that on retirement, members would source alternative replacements.
- 2.3 Members who wish to resign can do so through written communication with the Chairman of the committee.
- 2.4 With the consent of the Board, the committee may co-opt members on an annual basis to supplement the skill and knowledge of the committee in line with the nature of applications.

##### **3. Terms of reference**

On behalf of the Board:

- 3.1 The committee will consider, evaluate, monitor and make recommendations to the Board on all matters broadly relating to the Ms Ireland's research agenda..

- 3.2 The role of the committee is solely advisory; the sanction of any expenditure on research is solely the responsibility of the Board.
- 3.3 The committee will follow any and all guidelines from any funding body, e.g. MRCG, HRB etc. thus ensuring compliance with all terms and conditions, particularly relating to applications, reviews, selection and monitoring.
- 3.4 The committee will advertise the Dean Medal bi annually. This will be a travel bursary for a research in the area of MS. This will be an open call and will be awarded by the Research Committee.
- 3.5 The committee will monitor MS Ireland's research agenda and will prioritise potential research projects for consideration.
- 3.6 If MS Ireland receives unrestricted research funds the committee will work from MS Ireland's research agenda in respect of any research call.
- 3.7 Where funding is donated for a specific research area the same guidelines will apply.
- 3.8 Review the Risk Register annually in relation to risks which are relevant to the Services Monitoring and Evaluation Committee and report back to the Finance Audit and Risk Committee on the review and action measures to be taken to reduce the risk.

#### 4. **Proceedings of the committee**

- 4.1 The committee will determine its own procedures and the frequency and locations of meetings.
- 4.2 The minutes of the committee will be made available to the Board to which it will report in whatever manner is deemed most convenient and appropriate.
- 4.3 The proceedings of the committee are confidential and a member shall not, without the consent of the Board, disclose confidential information obtained by that member in the course of their duties.
- 4.4 In the event of an application being submitted for funding by a member of the Research committee or an associate, the member will absent themselves from all discussions and decisions relating to the said application.

**Approved by the Board of MS Ireland**

**Date: November 21<sup>st</sup> 2014**

**Appendix 4**  
**Memorandum of Understanding between MS Ireland and the University of Limerick**



***MEMORANDUM OF UNDERSTANDING***

***between***

**The University of Limerick**

***and***

**The Multiple Sclerosis Society of Ireland**

***for***

**Teaching & Research Collaboration**

## **Memorandum of Understanding**

### **1. Introduction**

- 1.1 The University of Limerick, hereinafter referred to as UL, and the Multiple Sclerosis Society of Ireland, hereinafter referred to as MS Ireland, will enter into collaboration, through teaching and research, to improve understanding of Multiple Sclerosis (MS) and to enhance the quality of life for the person living with MS, their family, community and society in general (subject to and in accordance with this Memorandum of Understanding).

### **2. Retention of Identity**

- 2.1 Notwithstanding the terms and conditions of this Memorandum of Understanding, UL and MS Ireland will retain their respective independent and separate legal identities and nothing in this Memorandum of Understanding will prevent either party undertaking research projects with or on behalf of third parties.

### **3. Teaching & Knowledge Sharing**

- 3.1 UL and MS Ireland shall work collaboratively in such manner and form determined by each of UL and MS Ireland from time to time to increase the knowledge of students and the general community about all areas of MS. Both formal teaching, through new and existing programmes, and informal opportunities, such as public lectures, will be utilised where practicable in the opinion of UL and MS Ireland.

### **4. Research Projects**

- 4.1 UL will develop a range of proposals for research based on the needs of the members of MS Ireland for submission to and consideration by MS Ireland. In turn, MS Ireland will aid UL in its research and in securing funding to undertake mutually agreed MS related research projects.
- 4.2 Each agreed research project will be subject to a separate project specific written agreement that will include details of the project funding, scope, duration, reporting obligations and will set out mutually agreeable intellectual property, confidential information and risk management provisions.
- 4.3 In order to carry out agreed research projects, both parties will engage the services of such staff as each party deems necessary for conducting its work as set out in the project specific agreements.

### **5. Intellectual Property**

- 5.1 Without prejudice to the generality of 4.2 above, both parties will retain ownership of any intellectual property that it developed, owned or licensed prior to the commencement of an agreed research project. Either party may wish to make its intellectual property available royalty free and non-exclusively to the other party for the sole purpose of meeting the requirements of an agreed research project and any such arrangement will be subject to the project specific agreement(s) referred to at 4.2 above.

- 5.2 The ownership and management of any intellectual property, know-how, results, documents and other information produced by either party as a result of undertaking an agreed research project will be set out in a project specific agreement and will be in accordance with the National Code of Practice for Managing Intellectual Property from Publicly Funded Research and the National Code of Practice for Managing and Commercialising Intellectual Property from Public-Private Collaboration Research that prevail from time to time.

## 6. Publication Procedures

- 6.1 Any publications arising from collaborative research projects will be agreed by both parties in advance of their publication. Any additional requirements in relation to publication procedures will be set out in the project specific agreements.

## 7. Termination of Memorandum of Understanding

- 7.1 UL or MS Ireland may terminate this Memorandum of Understanding by giving to the other not less than sixty days notice in writing and subject to any surviving obligations in project specific agreements neither party will be under any further obligation to the other.

## 8. Dispute Resolution

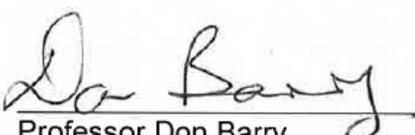
- 8.1 Other than provided for in project specific agreements, UL and MS Ireland agree that in the event of any dispute arising between the parties in relation to this Memorandum of Understanding or any teaching or research collaborative projects, both UL and MS Ireland will make every effort to resolve the dispute themselves within 60 days of the dispute arising.

## 9. Commencement

- 9.1 This Memorandum of Understanding will come into operation on the 23 day of .....*May*..... and may be reviewed by a procedure jointly agreed by UL and MS Ireland every three years thereafter.

  
 Ms Anne Winslow  
 Chief Executive  
 Multiple Sclerosis Society of Ireland

Date: 23/5/11

  
 Professor Don Barry  
 President  
 University of Limerick

Date: 23/5/11



## Appendix 5

### MS Ireland Protocol for Researchers



### Protocol researchers engaging with MS Ireland for support with projects

All requests for assistance with research projects go through a central point nominated by the Senior Management Team; currently this is:

**Harriet Doig - Information, Advocacy and Research Officer**

Email: [harrieta@ms-society.ie](mailto:harrieta@ms-society.ie)

Tel: 01 678 1600

**Undergraduate and post graduate researchers will be required to provide the following:**

- a) A letter from the student's/researcher's supervisor on headed paper regarding the project and/or
- b) Where appropriate we seek evidence that ethics approval has been obtained from the relevant bodies.
- c) A copy of the final questionnaire/study abstract to read prior to putting it up on the website and make observations as necessary.
- d) An information sheet for the potential participant/respondent which explains the project in more depth and makes observations as necessary.
- e) A 200 word (approx.) summary to describe the project.

**Following receipt of the above we will:**

- f) Agree a time frame and reminder alerts.
- g) Put all of this on MS Ireland's website, on this page: <http://www.ms-society.ie/pages/research/get-involved-in-research>. We would then include on email and social media etc.
- h) Ask for feedback when the results are published, these will be archived on the research section of the website <http://www.ms-society.ie/research/blogs/1380>.
- i) Ask the student/researcher to participate in the MS Ireland Blogs and write articles with updates on the research for MS Research, MS Ireland's bi-annual research eZine.