



## Autumn 2011 Progress Report

“The SWIMS Project will do three things. It will enable us to (1) understand what it is like to have MS or CIS, (2) improve the way that changes in MS symptoms and disability are measured—a vital step forward for the testing of new and emerging treatments for MS, and (3) predict what will happen to individuals with MS over time” **Prof John Zajicek, Chief Investigator for SWIMS.**

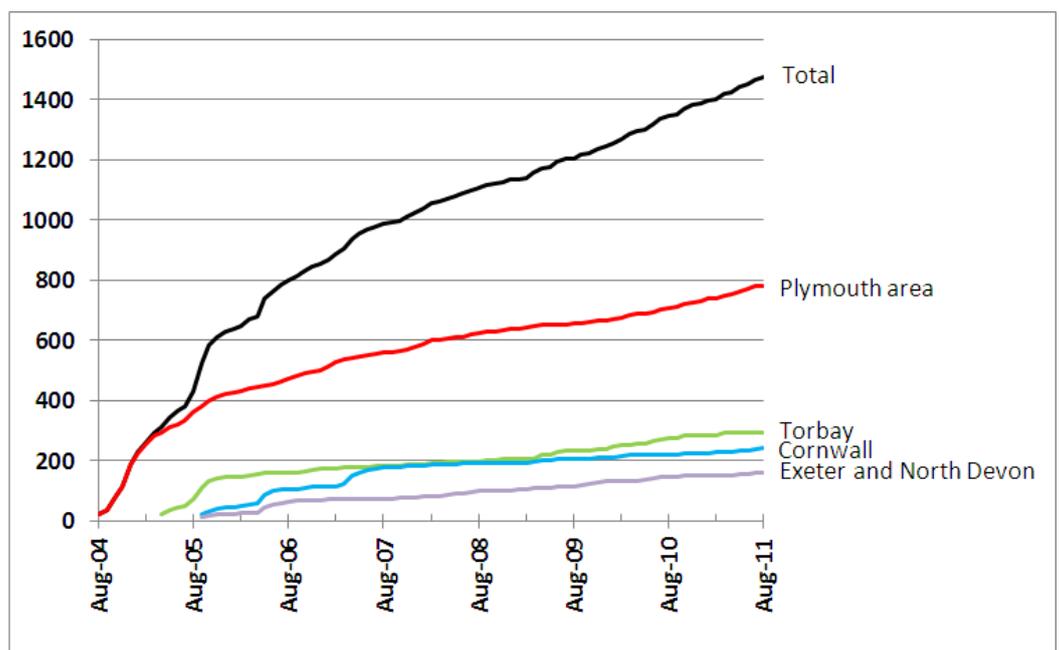
**We would like to welcome those of you who have recently joined the project. We are delighted that you have decided to take part.**

By the end of August 2011 over 1,470 people with MS or CIS had consented to take part (shown below). Some of you have now completed over six years, which is superb and we thank you for your contribution to date.

**MS Frontiers** Five of my colleagues, including representatives from the SWIMS Team, attended the recent MS Frontiers Conference in London. Organised by the MS Society, MS Frontiers is run every two years to bring together experts from across the world to speak on MS research. Researchers,

health professionals, and people with MS attended the event. Researchers presented their latest work on numerous topics, including potential new therapies for MS, advances in the management of symptoms, and the development of a pilot MS register in the UK. A summary of the SWIMS Project was presented and Prof Jeremy Hobart (Consultant Neurologist at Torbay, and SWIMS researcher) presented some work on why it's important to measure MS symptoms and disability from the patient perspective – which is one of the reasons for doing the SWIMS Project.

**Wendy Ingram, SWIMS Project Co-ordinator, Peninsula College of Medicine and Dentistry**



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## Research Opportunities

We know that taking part in SWIMS takes up some of your valuable time and energy; however, we would like to let you know about studies that are taking place in case you are interested in participating in additional research.

*School of Health Professions, University of Plymouth*



### Falls in MS Project

This project is being run by Hilary Gunn (physiotherapist), and aims to identify the risk factors associated with falls in all types of MS. The project has started really well, and has recruited 40 participants so far. There is still plenty of opportunity to get involved as Hilary and her team aim to recruit 150 people in total! Anyone who is **able to walk without assistance from another person** is eligible to participate, **regardless of whether you fall or not**.

Participating in the project involves attending a hospital local to you on a one-off basis for an assessment, followed by recording any falls you may have in a simple diary for 12 weeks. Participants who have already taken part have reported that they have enjoyed the assessment appointment, and that they are diligently filling in their diaries - thank you all for your help!

If you are interested in the Falls in MS Project and would like more information, please do not hesitate to contact Hilary Gunn on **01752 588825**, or email [hilary.gunn100@plymouth.ac.uk](mailto:hilary.gunn100@plymouth.ac.uk).

### MS Core Stability Study

Esther Fox (physiotherapist) is currently running a multi-centre clinical trial investigating different types of physiotherapy exercise for people with mobility and balance difficulties. Esther is looking for people who are experiencing mild to moderate difficulties with balance and mobility, and who are not currently participating in another clinical trial, to take part. It does not matter what type of MS you have. If you are aged **over 18 years**, are **able to walk independently with or without a walking aid** such as a stick, and **have not had a relapse within the past three months** you may be eligible to participate in this study.

The study will require your involvement for 16 weeks in total. You will participate in one-to-one exercise sessions with a physiotherapist over a 12 week period, during which time you will also be asked to undertake a home exercise programme. Over this time you will also be required to undergo three assessment sessions, involving tests of your balance and mobility. Your travel expenses for attending these sessions will be reimbursed.

If you would like further information please feel free to call Esther Fox on **01752 587599** or email [esther.fox@plymouth.ac.uk](mailto:esther.fox@plymouth.ac.uk)

### *Clinical Neurology Research Group, Peninsula College of Medicine and Dentistry*

We are now recruiting to several **clinical trials for people with relapsing-remitting MS**. Each clinical trial has been designed by the pharmaceutical company that has a commercial interest in the drug being studied. Plymouth Hospitals NHS Trust participates in these trials in partnership with the pharmaceutical company, as do many hospitals in the UK and overseas.



We are currently looking for people who fit **all** of the following criteria: have relapsing-remitting MS, one or more relapse(s) in the last 12 months, **either** not currently being treated **or** currently taking a beta-interferon (Avonex or Rebif or Extravia or Betaferon), and normally walk unaided.

There are currently no trials recruiting at our site for people with primary progressive or secondary progressive MS. We are always on the look-out for trials in progressive MS and we will provide an update in future Newsletters.

If you would like to register your interest in taking part in clinical trials for people with MS, please contact one of our research nurses: Nick Pilkington or Marie Roy on **01752 315261**, or by email [nick.pilkington@nhs.net](mailto:nick.pilkington@nhs.net) or [marie.roy@nhs.net](mailto:marie.roy@nhs.net).

## **Muscle Stretch Study: developing clinical guidance for stretching in pwMS**

A team of researchers at the University of Plymouth and the Peninsula College of Medicine and Dentistry have been working to understand more about how stretching can decrease leg stiffness and spasticity, and to provide guidance on the ideal way to do stretching exercises. A number of you have been taking part in this study. Here is an update from the team on the progress of this research.

**Introduction** Symptoms of stiffness and spasticity are reported in up to 80% of people with MS. Management of stiffness and spasticity may include stretching exercises as well as anti-spasticity drugs. Stretches are often self-administered as part of a home programme of exercises prescribed by a physiotherapist. This study was undertaken because it is unclear what the ideal “dose” of stretching is in terms of how much force should be applied, for how long, and how frequently during the day or week.

**The Muscle Stretching Study: Part 1** As a first step we investigated the range of forces that people could apply during commonly prescribed manual stretches for stiffness in the calf muscle at the back of the lower leg. We assessed four stretches for the calf muscles, two of which are shown in the picture opposite.

We measured the forces developed at the ankle during the stretch, the amount of associated muscle activity, and how much muscle lengthening could be achieved. We compared 27 people with MS to a control group of 15 people of the same age, gender and weight who did not have MS. We found that the calf muscle was stiffer and did not lengthen as much in people with MS compared to the control group. Stretches using people’s body weight (such as standing off a step or against a wall, *Figure 1*) produced the most force and greatest lengthening of the muscle. Our findings suggest that, in both groups of people, the stretch was not always performed with the muscle relaxed; this may influence the effectiveness of the stretch.

Stretches in more supported positions (such as in a standing frame, *Figure 2*) could be held for twice as long on average and were associated with less on-

going muscle activity. When the strength of stretch and feelings of safety were taken into account, the supported stretches were preferred by people with more severe symptoms. This preliminary study has allowed us to understand the forces associated with commonly prescribed manual stretches, and how long they can be held for.



Figure 1



Figure 2

**Moving on to Part 2** The next stage of the research involves using a specially commissioned motor, built by engineers in the University of Plymouth, to deliver typical stretches in another group of participants. We use the motor to stretch calf muscles — applying the range of forces that were produced by participants in Part 1 of the study. We are accurately monitoring how muscle stiffness, length and spasticity change after a 30 minute stretch and over a 30 minute period after the stretch. From this we will be able to estimate the impact that commonly prescribed stretches have on muscle stiffness and to determine the short-term impact of stretch force, duration and frequency on stiffness. Recruitment has closed and so we are not looking for new recruits.

**Future plans** In the future we aim to develop a clinical trial of stretching to see whether stretching programs lead to a long term decrease in muscle stiffness and spasticity, and improvement in walking ability.

**Thank you.** We would like to thank all the participants who have given up their time to take part in these studies; without your help and support this research would not be possible.

*Jodielin Ofori, Jenny Freeman, Jon Marsden at the School of Health Professions; John Zajicek and Jeremy Hobart at the Peninsula College of Medicine and Dentistry*

## NICE and Nature News

**NICE update** I write this during August as the England cricket team make a great start to the third test, when the country is being affected by riots in some of our cities, and when the NHS as well as the global economy is under huge pressure. Services are being squeezed everywhere, and it's become incredibly frustrating when trying to obtain new treatments for people.

I've had a moan before about access to cannabis type treatments, whereby I have been stopped from prescribing cannabinoids for any new people who might benefit. In a similar vein, access to 'functional electrical stimulation' is becoming more and more difficult, even though it is recommended by the National Institute for Health and Clinical Excellence (NICE). Functional electrical stimulation can help people's walking ability by the use of an electrical stimulating box. This supplies a pulse of electricity directly to the shin muscle whilst moving, causing the foot to lift. Improvement in walking speed as well as a reduction in falls is possible. It doesn't help everyone, and an assessment by an experienced neuro-physiotherapist is required to test whether someone is likely to find it useful.

This week NICE decided that the first major tablet treatment for people with bad relapses of MS was NOT recommended for use in the NHS because it was too expensive. I do think that the manufacturers have been incredibly greedy in this case, charging around £20,000 per year for this drug (Gilenya, or Fingolimod), and so I have some sympathy for the NICE decision.

On the positive side there are a large number of new treatments for people with relapsing-remitting

MS coming through the system, including several new tablets. I hope that we will be able to use them once they have a licence!

**Genetic Analysis of MS** Another positive development is the publication of an important paper on the genetics of MS in the highly regarded scientific journal *Nature*. This paper concerns a massive international study (known as the 'genetic analysis of MS' study, or GAMS) which involved collecting a blood sample for DNA analysis from over 9,000 people with MS and 17,000 people without the condition as controls. Some people with MS across Devon and Cornwall participated in this study; no doubt some of you kindly donated a blood sample so that your DNA could be analysed. Around 30 new genes linked to MS have been identified as a result of this study. Most of these genes are involved in the immune system, and the results support the theory that MS is due to over-activity of the immune system. Although these results haven't yet led to any new treatments, and they won't help in testing people for MS, they do help immensely in contributing to a greater understanding of MS.

The study is ongoing and if you would like to donate a blood sample please make contact with your local centre:

**Exeter area:** Dr Tim Harrower on **01392 402455**

**Plymouth area:** Angela King on **01752 439841**

**Torbay area:** Andrew Hall on **01803 656612**,  
email [ahall8@nhs.net](mailto:ahall8@nhs.net), or Pauline Mercer on  
**01803 656614**, email [pauline.mercer@nhs.net](mailto:pauline.mercer@nhs.net)

**Best wishes, John Zajicek.**

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**SWIMS Project Coordinating Office, Room N16, ITTC Building, Tamar Science Park, Plymouth, PL6 8BX**

Email: [swimsproject@pms.ac.uk](mailto:swimsproject@pms.ac.uk)

Telephone: 0800 015 3430 (free from most landlines) or 01752 315246

To visit our website go to [www.pcmd.ac.uk/cnrg](http://www.pcmd.ac.uk/cnrg)

