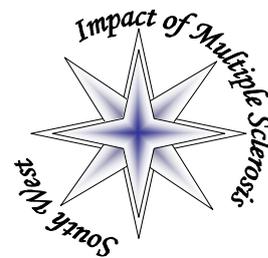


SWIMS News



The South West Impact of MS Project: a long-term study of the impact of MS and CIS on those living with these conditions in Devon and Cornwall

Spring 2012 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. There has been a surge of new recruits from the North Devon area lately and we are delighted that you have decided to take part!

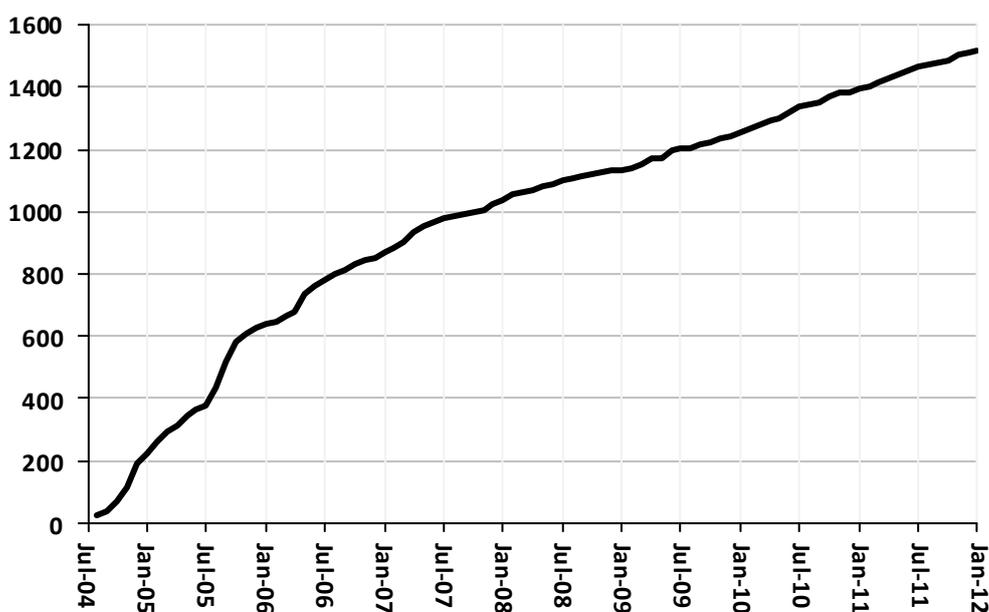
By the end of January 2012 over 1,500 people with MS or CIS had consented to take part (shown below). Some of you have now completed over seven years, which is very much appreciated so we thank you for your contribution to date.

In this issue we include some more of your frequently asked questions. We also provide some information about a new clinical trial in secondary progressive MS that is taking place in our department, and which is currently recruiting volunteers to take part.

In addition there’s a summary of some other research projects taking place in Devon and Cornwall that might be of interest to you.

Lastly, we have a neurologist’s thoughts on some local MS issues.

Recruitment: number of people consenting to take part in SWIMS



Your frequently asked questions

SWIMS is for people who have relapses and I don't, so it's not relevant to me.

The first five pages of the questionnaire booklet are indeed about relapses. If you do not have relapses you can let us know by answering 'no' to the very first question in the booklet — 'Have you had any relapses in the last 6 months?' We would like to stress that this is not just a project for people who are experiencing relapses. **Everyone with a diagnosis of clinically isolated syndrome or MS is very important to this research, regardless of the type of MS.** From page 6 onwards in the questionnaire booklet there are questions that do not focus on relapses.

Why do you ask the same questions each time, in each questionnaire?

One of the aims of SWIMS is to track changes in MS over time (changes due to relapses or due to general progression). This is why we have kept the questions in the booklet the same over the years as this provides the data we need to 'model' changes in MS in a large group of people.

There's no doubt that for some of you the repetitive style of the questions can be frustrating, especially when some of the questions are not relevant to your individual circumstances. We understand that this makes the questionnaire difficult to complete at times. However it is important that the same questions are asked.

In an ideal world the questions would be tailored to individual participants. We would leave out any questions that we are 100% certain do not apply to an individual (based on previous answers) but we are not in a position to offer this format at the moment.

Research Opportunities in Devon and Cornwall

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

Clinical Neurology Research Group, Peninsula College of Medicine and Dentistry

We are now recruiting to a clinical trial for people with **secondary progressive MS**. The trial medication is intravenous, with half the participants receiving a placebo. The treatment will happen at Derriford Hospital, Plymouth, plus clinics at the Tamar Science Park, Plymouth. We can't say whether you will be eligible to take part until we have done various tests and taken blood samples from you. However, to be considered for participation you will:

- be aged 18-58 inclusive
- have had secondary progressive MS for two years or more
- be able to walk (with or without sticks/crutches)
- not have been treated with Tysabri or Campath

If you would like further information about this study, or you would like to register your interest in taking part in clinical trials for people with MS, please contact Marie Roy (research nurse) on **01752 315261** or marie.roy@pcmd.ac.uk.



Research opportunities continued

Balance and Mobility 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. 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. For this research, **it does not matter what type of MS** you have.

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.

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. Hilary's team have had an excellent response to our past requests for participants, and only needs 15 more volunteers to reach the target of 150 people! 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 twelve weeks. Hilary is really keen to recruit the 150 participants she needs for the research, so please do feel free to contact her if you are interested in getting involved.

Hilary can be contacted on **01752 588825**, or email hilary.gunn100@plymouth.ac.uk.

**PHYSIOTHERAPY
WITH
PLYMOUTH
UNIVERSITY**

Understanding mobility problems – your views count!

Charlotte Bolt is a psychologist who has recently begun working with Jeremy Hobart (Neurologist) to improve the measures that are often used in clinical trials to assess MS disease progression. This is important because if disease progression cannot be accurately measured then it will be difficult to prove whether drug treatments (or other interventions) are effective.

People with MS have told us that they often relate worsening of mobility with disease progression, and so it is important to be able to accurately measure changes in mobility. With this in mind Charlotte aims to find out more about which aspects of mobility are affected in MS, and how mobility problems impact on peoples' lives. She is looking for **people with MS of all ages and mobility** to take part in one or more of the following:

One-to-One Interview. Lasts about two hours with a break in-between. Can be arranged anywhere convenient for yourself, or at the Tamar Science Park in Plymouth. Travel expenses to this venue will be paid for.

Focus Groups. Group discussions with four to ten people. There will be four sessions lasting 1hr 30mins spread over a few weeks.

Observation. This will involve being accompanied for a morning, afternoon or whole day by a researcher to examine how MS affects your mobility in your daily life, and what adjustments you have made doing certain tasks.

If this research is of interest to you then please get in touch with Charlotte on **01752 345241** or email charlotte.bolt@pcmd.ac.uk.

News from the Chair

Functional electrical stimulation

Most people will have heard about the Government's difficulties in getting the Health and Social Care Bill through Parliament. Partly, because everyone expected it to get through, the local NHS has been changing in preparation for the brave new world. The result is that many of us working in the NHS don't really know who to contact to get something done. Despite all this, we had some good news from something called the 'Peninsula Commissioning Group', who have decided to make functional electrical stimulation (FES) available on the NHS. This is the first MS treatment we've managed to argue for successfully (unlike other treatments such as Sativex). FES is only suitable for a few people who have difficulty lifting up one of their feet, and consequently may trip over while walking. The next step is to work out who actually pays for it and how we get through the paperwork. Watch this space...

MS treatments on trial

There continues to be considerable excitement around new treatments for early relapsing-remitting MS. We are

taking part in some of these trials and if you are interested in taking part, please contact us. The first trial in secondary progressive disease for a long time is now starting up, and is referred to elsewhere in this newsletter.

Another development is that we are about to start the analysis of the CUPID trial. Many of you took part in this trial, which aimed to assess whether capsules of cannabis might help to slow the progression of MS. We started working on this trial exactly eight years ago, and now hope to have some results by June this year. Trials in progressive disease are rare, and the information from both CUPID and SWIMS will help us to plan for many more trials in the long-term.

The major problem is that clinical trials cost a lot to do, and we were disappointed recently when the MS Society didn't have any money to fund a trial we had designed to test vitamin D in MS. If people want more trials to take place, then spread the word (including to the MS charities). But if there's anyone out there who has some bright ideas about raising £2m (the approximate cost of a single study), then pick up the phone, I'm in my chair!

John Zajicek, Chair of Clinical Neurosciences

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