

# 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



## Thank you to all SWIMS participants

“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” **John Zajicek, Chief Investigator for SWIMS.**

**Welcome to all of the new recruits to the SWIMS Project. We are delighted that you have decided to take part.**

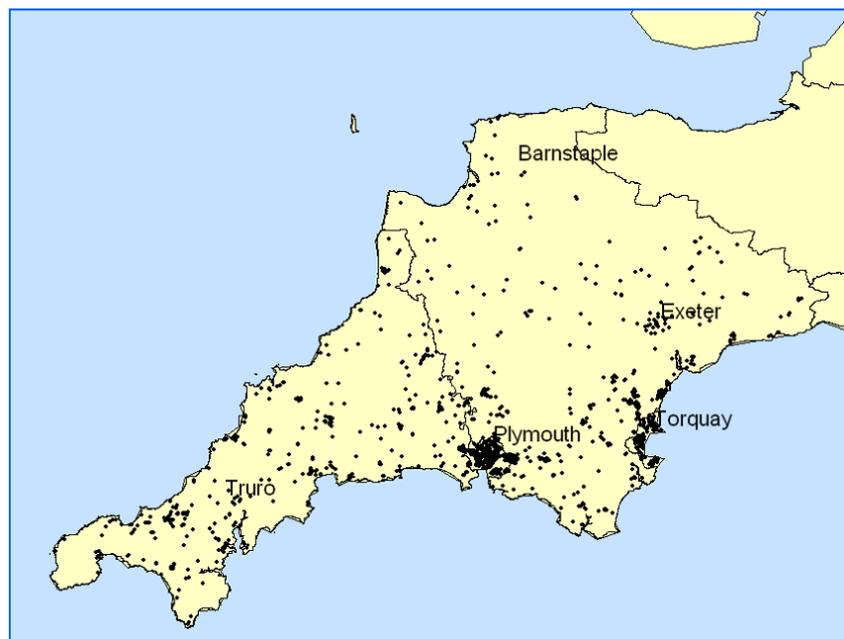
**Also a big thank you to those who have been with us for some time.**

In order for SWIMS to be really successful we need as many people as possible to take part and that’s why we keep a close check on the number of participants. By the end of 2009, 1,243 of the estimated 2,000 people with MS in the region had consented to take part in SWIMS, and that’s really very good. There were 663 participants from the Plymouth region (where recruitment started some months before the other regions), 238

from Torbay, 210 from Cornwall, and 132 from the Exeter and North Devon region.

As you can see from the map below, where each dot represents a participant’s location, most areas in the peninsula are represented. Over 7,500 questionnaire booklets have been returned to us since we began in 2004 and this means that we are well on our way to building a fantastic resource which we will use to meet the objectives of the project (see opposite).

If you do know of anyone who might not have heard about SWIMS then please do spread the word! Jeanette, our Assistant Coordinator, would be delighted to send further information to anyone who is interested.



### In this issue:

- Recruitment update
- MS in the press—“angioplasty breakthrough?”
- New research study on progressive MS
- New clinical trials for relapsing-remitting MS
- Update on on-line SWIMS questionnaires

## ***MS in the press—comment by Professor John Zajicek***

**If you are reading this, then the chances are that you are still taking part in the SWIMS Project – many thanks for this.** We are now starting to gather enough information, on nearly 1300 people with MS and isolated syndromes, to begin analysing all the useful information. We have submitted our first scientific paper, and many more will follow. This first paper introduces the project to the scientific community, and summarises the information that you have provided in your baseline questionnaire. We will of course share our findings with all participants who are interested. Further information about this will be available in future newsletters. I believe that SWIMS will turn into one of the most important research projects for people with MS ever undertaken, so please keep returning those questionnaires.

**One area of interest that has emerged since the last newsletter is a new potential treatment in MS, about which many people have been asking.**

This follows an article on the BBC news recently suggesting that MS may be caused by poor blood flow in the veins coming from the head. Treatment to open the veins (angioplasty and stenting) may therefore improve blood circulation and help to treat MS. The person suggesting this is Dr. Paolo Zamboni, who published results on this treatment in 65 people with MS in December 2009.

I would never want to pour cold water on interesting ideas, but one of the major problems with MS treatments is that “we’ve been here before”. It’s very easy to get carried away with the latest “breakthrough”, but until things have been properly tested, we all have to be very cautious. Many people will remember goat serum, Carrie Loader treatment, magnetic treatment, low-dose naltrexone, etc. Sometimes people make a lot of money from treatments they claim are

breakthroughs, and there are examples of real results from clinical trials actually being suppressed so they can continue to make money!

In order to test treatments for MS, we need well-designed and properly conducted clinical trials, with some people receiving “control” treatment (usually a dummy drug). In one of our previous studies I can remember someone having a fantastic response to capsules, which altered that person’s life for the whole year that she was taking the treatment – and she was actually taking capsules containing vegetable oil (placebo). In Dr. Zamboni’s study there was no control group, and having surgery is a very powerful effect, even if it’s not actually helping the MS. Furthermore, recent use of this treatment outside of clinical trials has led to some serious complications, including a case where the tubes to open the veins moved in to the heart, requiring emergency surgery to save the person’s life. These researchers therefore conclude by saying that much more research is needed – and I completely agree, and wish them well in their endeavours.

**In the meantime, what else are we doing ourselves to help with new treatments?** Well, our large CUPID trial (looking at cannabis-like drugs for people with progressive MS), is coming towards the end, and we should have results in about two years time. People coming off the study seem to be doing well, although neither they nor I know whether they are taking active or placebo capsules. One of the most important outcomes from CUPID is that we will learn an awful lot about how to do trials in progressive MS. We are also about to start some trials of brand new treatments for people in the early stages of MS who are still having relapses (page 3).

***Continued on page 3.***



Prof John Zajicek

***Continued from page 2.***

Finally, if anyone has any questions about MS that they feel would be of interest to everyone else, then let us know, and I will try to deal with some of your questions in future editions of the SWIMS Newsletter – which are already becoming collectors' items (have you got the whole set?!).

Have a good Easter.

## ***MS research at the Clinical Neurology Research Group***

### ***Are you interested in taking part in another research study?***

#### ***Study on progressive MS***

We are looking for volunteers to take part in a new research study which is being led by Dr Jeremy Hobart (Consultant Neurologist at Torbay Hospital). The aim of this study is to investigate how deterioration due to progressive MS should be measured. The purpose of this study is to ensure that clinical trials in MS use the best available rating scales for measuring the effect of treatments.

Taking part involves having a one-to-one interview – at a time and place that suits you - with an experienced researcher, or participating in a group discussion with other people with progressive MS. This research will improve our understanding of how people experience deterioration, and how we can better measure that deterioration. We will then be able to make recommendations for the further development of accurate rating scales for neurological disease such as MS.

The study is being funded by the MS Society. If you are interested in taking part and would like further information please contact Julia Frost (details below). The study is called: "evidence-based rating scale selection for clinical trials of neuro-degeneration in MS".

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#### ***Clinical trials for relapsing-remitting MS***

We are planning to start a number of new clinical trials involving drugs for relapsing-remitting MS in the near future. Each of these clinical trials has been designed by the particular pharmaceutical company that has a commercial interest in the drug being studied. We run the trial on behalf of the pharmaceutical company, in conjunction with many other hospital sites around the UK or sometimes further afield.

Importantly, some of these treatments are in the form of tablets, which should be much more convenient than the currently available injection treatments, such as beta-interferon. If you would like further information please feel free to call our research nurse, Nick Pilkington, after Easter on Freephone **0800 015 3430** or email [cnrg@pms.ac.uk](mailto:cnrg@pms.ac.uk).



CNRG is located at the Tamar Science Park, Plymouth

#### ***Neuropathic pain study***

We have been working for some time to improve upon the scales used to measure neuropathic pain. We now have the funding required to undertake the next step in this research. The consultants involved with this research are planning to contact their patients known to have MS and neuropathic pain, to give further details about what this study involves.

## ***Online SWIMS questionnaires are coming!***

[Submit Questionnaire](#)

**From May 2010 SWIMS questionnaires for people with MS will be available online via the internet.**

The content and timing of the online version is identical to the paper booklet. As with the paper booklets any information you provide is treated as confidential and neither your name, nor any other information which could identify you, appears anywhere with the data you provide. If you have already told us that you would

prefer an online booklet then we will send you a letter the next time your SWIMS questionnaire is due to introduce the process for completing a booklet online. If you have any questions or you would now like to tell us that you'd prefer an online booklet then please contact us on Freephone 0800 015 3430 or email [swimsproject@pms.ac.uk](mailto:swimsproject@pms.ac.uk). The paper booklets will always be available for those who do not wish to complete the questionnaire booklet online.

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

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