

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



Progress Report: up to Summer 2010

“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.

You will see from the graph below that by the end of July 2010 over 1,300 people with MS or CIS had consented to take part. This means that about 70% of the estimated number of people eligible to participate in SWIMS have contributed to the research.

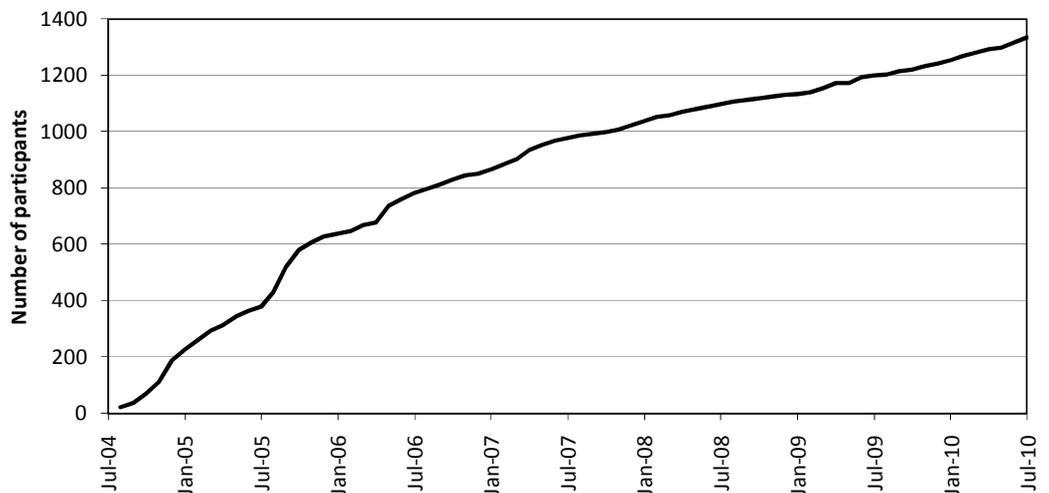
We are still recruiting so if you happen to know of anyone who might not have heard about SWIMS then please do spread the word! Jeanette, our Assistant Coordinator, would be happy to send information to anyone who is interested.

SWIMS is a non-commercial research project, hence we periodically seek funding to run the project from organisations that fund non-profit making research. We are pleased to let you know that the MS Society has granted us funding to cover the next three years.

The SWIMS Project has been designed to trace the experiences of people with MS and CIS over a number of years. The longer the study lasts, the greater the value of the research. So we are particularly grateful to the MS Society for supporting us, and to you for your involvement in this project. Each questionnaire that is returned to us counts towards building a database of information about having MS.

In this issue:

- SWIMS progress report
- Do you want to have your say in local research proposals?
- New clinical trials for relapsing-remitting MS
- Update on new MS drugs
- Forthcoming MS Society Event in Torquay



MS research at the Clinical Neurology Research Group

Are you interested in taking part in another research study?

Lay Persons Research Review Group

Would you like to have your say on new research proposals?

The Clinical Neurology Research Group currently runs a wide variety of clinical trials and research programmes which are aimed at developing new treatments and improving the measurement of neurological disease. This research is funded by Government and non-government bodies. All applications for funding have a lay summary.

We are particularly interested in whether we reflect patient and carer views appropriately. We therefore wish to invite you to join a group of lay reviewers who are affected by neurological disease and can therefore use their expertise to read and comment on each research application.

What will this involve?

We will contact you, by email or letter, with our draft proposals (about five per year) and ask you to read them and make comments on whether, and to what degree, you feel the research proposal has patient and/or carer benefit. We will ask you about ways in which you feel the proposal might be changed to reflect your views.

If you are interested in finding out more information please contact:

Jane Grose

Clinical Neurology Research Group
N13, ITTC Building
Tamar Science Park
Davy Road
Plymouth
PL6 8BX

Tel: **01752 315117**

Email: jane.grose@pms.ac.uk

Clinical trials for relapsing-remitting MS

We are currently running a number of clinical trials involving drugs for relapsing-remitting MS. 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.

At the moment we are looking for people with relapsing-remitting MS, who are not currently taking an interferon or glatiramer acetate (Copaxone), to take part. One study that is open to new volunteers involves taking an oral tablet for relapsing-remitting disease, rather than having an injection. If you would like further information please feel free to call our research nurse, **Nick Pilkington**, on Freephone **0800 015 3430** or email cnrg@pms.ac.uk.

Future clinical trials for MS

There are always new studies coming along, so please feel free to contact us on Freephone **0800 015 3430** if you are interested in clinical trials, whatever type of MS you may have, to see if there's a trial that may be suited to you.



CNRG is located at the Tamar Science Park, Plymouth

Update on MS Research

John Zajicek, Chief Investigator for SWIMS

It seems that virtually every week there are new developments relating to multiple sclerosis that are potentially helpful. This is very encouraging for all concerned, and sometimes it is difficult to keep up! In this issue of the SWIMS newsletter I would like to highlight a few important points:



Licensing of Sativex®: *Sativex®* is a cannabis-based spray given under the tongue which is now licensed (and theoretically prescribable by all doctors in the UK) for treating MS-related spasticity. Spasticity is the increase in stiffness often associated with muscle spasms and discomfort which can be very problematical at different points during the course of MS. Most neurologists will start treating these kinds of symptoms with drugs such as *Baclofen*, *Tizanidine (Zanaflex)*, *Dantrolene* and *Diazepam*.



However, sometimes if people cannot tolerate the side effects of these drugs, or they do not work, then we need to try alternative medications. *Sativex®* is one of these.

The problem arises in the local availability of *Sativex®*. *Sativex®* has not been assessed by the National Institute of Clinical Excellence (NICE) and the scientific work on how effective it is has not yet been published. Locally, it is therefore up to people known as commissioners to make decisions about whether the drug should be made available and who pays for it. There is a move to assess how useful it is by analysing the evidence across Devon and Cornwall, and local neurologists are applying to their relevant committees to be allowed to prescribe it. The recommendation is that this drug is prescribed by hospital doctors so there is understandable reluctance by some GPs to start prescribing *Sativex®*. As a result of all of this there may be delays in getting the drug through to those people who may find it useful, but I must stress that this drug is only suitable for a minority of people who continue to have troublesome symptoms when other drugs have been tried.

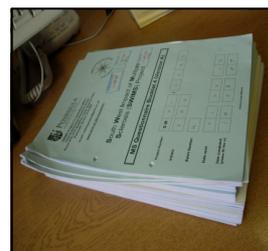


In the meantime, we are continuing with our clinical trial of another cannabis-related compound to see if this particular treatment slows the progression of MS. More information about this trial can be found at www.pms.ac.uk/cnrg/cupid.

Fampridine-SR: *Fampridine* is a drug which blocks potassium channels and, therefore, theoretically improves electrical conduction down the damaged nerve pathways that occur in multiple sclerosis. Studies suggest that this drug may also improve people's symptoms, particularly walking speed. However, although it has a licence in the United States, the European licensing agency has been less convinced by the evidence behind its use and there will be delays in access to this drug in Europe. Nonetheless, this drug may prove useful for a variety of symptoms and we hope to be doing more research on in time.

Disease modifying tablets: For people with relapsing-remitting MS *Beta Interferon* and *Glatiramer Acetate* have been available for some time. More recently, another drug known as *Tysabri* has been licensed and, although this is much more powerful, it has been associated with potential nasty infections, particularly an incurable condition known as PML. We have also been using a lot of *Campath-1H* - a drug which is still in clinical trials. The good news is that there are five new oral treatments for people with relapsing-remitting multiple sclerosis that are approaching licensing. The two most likely to get a licence in the near future are *Fingolimod* and *Cladribine*. Both have been associated with increased risk of infections such as chicken pox and shingles but seem to be at least as effective as the older drugs such as *Beta Interferon*. Obviously, the big advantage is that they come in tablet form rather than injection form. We are taking part in studies of new oral treatments which at this moment are only accessible through clinical trials, but it looks as though they will become increasingly available over the next year or two.

Thank you for continuing to take part in the SWIMS Project and for doing the questionnaires. The more questionnaires you complete the more useful the information will be for everybody with multiple sclerosis throughout the world.



A few of the **8,000** SWIMS questionnaires returned to the coordinating centre to date.

MS Society South West Region - Information Day

**Information day
the way forward
developments
and research**

9 October, 2010 9.30 – 4.30
The Grand Hotel,
Seafront Torquay, Devon.

The South
Devon
Branch and
The South
West Region

Speakers to include Professor John Zajicek, Consultant Neurologist, Derriford Hospital, Dr. Jeremy Hobart, Consultant Neurologist, Derriford Hospital, Dr. Djordje Gveric—MS Tissue Bank, London, Professor Scolding—Stem Cell Research, Bristol University.

Optional Morning Workshops Mr. Cole—Consultant Ophthalmologist Torbay Hospital, Bernadette Porter, Consultant MS Nurse, The National Hospital for Neurology & Neurosurgery, London, Roz Archer—Incontinence Nurse, Torbay Hospital. [workshop places are limited so please state preference at time of booking]

Afternoon question and answer panel
Cost of event - people affected by MS £5, professionals £7.50.
Sandwich, scone, jam & cream plus pastry included.
[Other food available at hotel bar at your own cost]

For further information and to book a place at this event then
please contact Chris Buckingham,
Tel: 01626 332268 or email:
chrisbuckingham195@btinternet.com

Hotel has limited parking, alternative parking available at
Railway Station adjacent to hotel



Multiple Sclerosis Society

MS Helpline: 0808 800 8000 (Freephone)

info@mssociety.org.uk www.mssociety.org.uk

The Multiple Sclerosis Society of Great Britain and Northern Ireland is a
charity registered in England and Wales (207495) and Scotland (SC0 16433)

Your questions...

In the last SWIMS Newsletter we offered to answer any questions you may have about MS that may be of general interest. Some of you emailed questions and comments about **low-dose naltrexone**, **chronic cerebrospinal venous insufficiency** (also known as CCSVI), **stem cell research**, and

the levels of **iron** in the brain. We will dedicate some space in the next Spring newsletter to answer as many of your questions as possible, so if you would like to add another topic to the list then please do get in touch using the contact details given below.

SWIMS Project Coordinating Office, Room N7, ITTC Building, Tamar Science Park, Plymouth, PL6 8BX

Email: swimsproject@pms.ac.uk

Freephone: 0800 015 3430

To visit our website go to **www.pms.ac.uk/cnrg**



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