

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



SWIMS celebrates its fifth birthday!

“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.

It was the 5th anniversary of the SWIMS Project recently, and over 7,000 questionnaire booklets have been received since we commenced the project in 2004. 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). This resource grows ever more useful to us when a large number of people with clinically isolated syndrome or multiple sclerosis continue to take part over many years. We’ve made a great start – thanks to all of you – and we hope that you’ll stick with the project for the long term.

We know that some questions in the

questionnaire booklet may be difficult to answer, or may not be particularly relevant to you. In these situations we suggest that you give the answer that matches most closely to your particular situation wherever possible.

The SWIMS Project Team



New research on stretching programmes What are the effects of stretching on leg stiffness?

Our colleagues at the University of Plymouth are due to start some research which aims to answer this, and related, questions about the stretching programmes used in MS. Stretching is commonly used by physiotherapists to improve muscle stiffness, and home programmes are sometimes undertaken. There is, however, a lack of evidence about how best to implement stretching programmes.

The MS Society have therefore funded Prof Jonathan Marsden’s team at the University of Plymouth to investigate stretching

exercises used by people with MS.

The study will start later this year. People in SWIMS who live in the catchment area for Derriford Hospital, Plymouth, are eligible to take part. Prof Marsden is looking for volunteers with a certain degree of leg stiffness to participate. SWIMS participants who meet the eligibility criteria will receive an invitation to participate directly from the SWIMS Project team in due course. However if you have any questions about this new study please do contact us on 0800 015 3430 or swimsproject@pms.ac.uk.

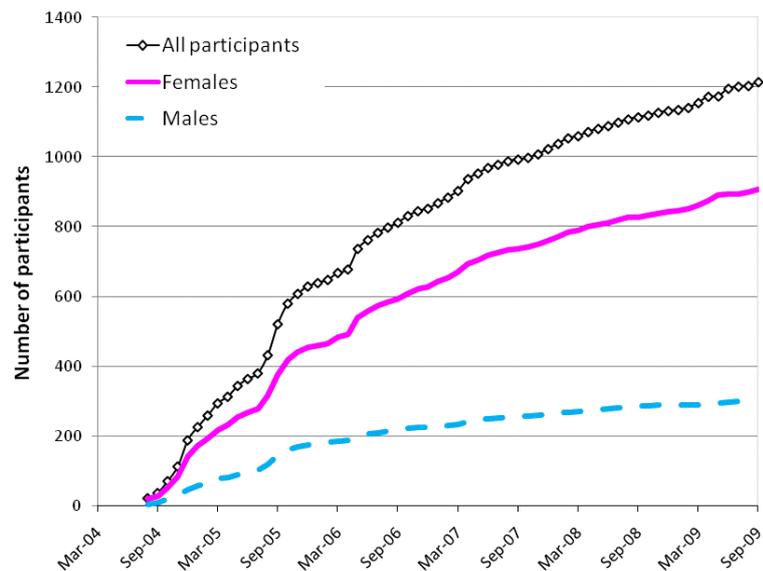


Recruitment update

Penny Garrod, the SWIMS Assistant Coordinator, left the team in April 2009 to start her retirement. Jeanette Sanders has replaced Penny in this role.

By the end of September 2009, 1,219 of the estimated 2,000 people with MS in the region had consented to take part in SWIMS. There were 656 participants from the Plymouth region (which starting recruiting some months before the other regions), 234 from Torbay, 207 from Cornwall, and 122 from the Exeter and North Devon region. MS is more common in women than men, and the proportion of women to men in SWIMS is in keeping with this (see graph below).

We aim to offer as many people as possible the opportunity to take part, so 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.



Online SWIMS questionnaires are coming!

[Submit Questionnaire](#)

Some time ago we announced that it would be possible in the future to complete SWIMS questionnaires online. Arrangements for doing this are nearing completion. We will give further details in due course about how to switch from paper booklets to an online booklet, should you wish to do so. Thanks for bearing with us on this issue.

MS clinical trials at the Clinical Neurology Research Group



Most of the clinical trials currently being run at the Clinical Neurology Research Group (CNRG) are full, and so we are not looking for any further volunteers to take part. There are a number of new clinical trials which we hope to be able to offer in the near future. We will keep you posted about opportunities to take part in a trial, should you wish to. CNRG is located at the Tamar Science Park in Plymouth (opposite).

Genetics of MS Study

“The genetics of complex disease is entering a new and exciting era. The impact of these new discoveries in neuroscience is incalculable at this stage but potentially revolutionary” **Dr Stephen Sawcer, Senior Research Associate, Cambridge MS Genetics Group** (quoted in *Brain journal*, May 2008)



Alison Page,

The Clinical Neurology Research Group (which runs SWIMS) has joined forces with a renowned research group – the **Cambridge MS Genetics Group** — to carry out the Genetic Analysis of MS (GAMS) study.

The aim of GAMS is to identify genes, or genetic factors, that are important in MS. It is thought that genetic factors may influence the likelihood that an individual develops the condition, or the course that MS takes over time, or how an individual responds to treatment. Identifying these genes might result in the development of effective

treatments and preventative measures.

Alison Page is running the study in Cornwall and the Plymouth and Torbay regions, where 790 people with MS have taken part thus far. The study is being run in the Exeter region by Dr Tim Harrower.

What is involved?

A single blood sample is taken from each participant, the genetic material (DNA) is then extracted and sent to the MS Genetics Group in Cambridge for analysis. Each participant also completes a short questionnaire.

Participation requirements:

- Confirmed diagnosis of MS
- Aged 16 years or older

If you are interested in participating, or would like to know more about this study, then please not hesitate to contact Alison Page, the GAMS Research Nurse based at the CNRG, on **01752 315249** or email alison.page@phnt.swest.nhs.uk.

As it's very likely that some SWIMS participants will have participated in GAMS, Alison would like to take this opportunity to thank everyone who has provided a sample for the GAMS study.

A big “thank you” to all SWIMS fundraisers

Sincere thanks are due to a number of people who have recently made kind and generous donations to the SWIMS Project via the Peninsula Medical School Foundation. In addition to monies sent by a number of individuals, £5000 was gratefully received from the Mid Cornwall Branch of the MS Society. Thank you to all those involved in the fundraising. The money donated has been put towards running SWIMS, as intended.

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

The SWIMS Project is currently funded by the Multiple Sclerosis Society of Great Britain, and through the Peninsula Medical School Foundation — a charitable body established in 2002 to support research and education.

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