

SWIMS News



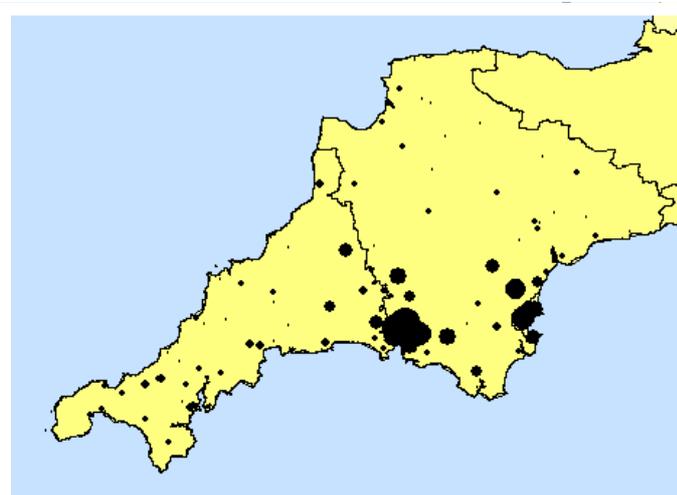
Welcome to the third issue of SWIMS News!

Special points of interest:

- Project progress— SWIMS has been underway for two years.
- We are now recruiting people with MS or with clinically isolated syndrome from the whole of Devon and Cornwall.

The SWIMS Project has now been in progress for two years and the number of people taking part continues to grow. At first we ran the project in the Plymouth area only. Recruitment commenced in the Torbay area in April 2005, and more recently in the rest of Devon and in Cornwall.

We estimate that there are approximately 1800 people with MS living in the combined counties of Devon and Cornwall. So far **800 people** have joined the project.



This map shows the distribution of people taking part (using the first part of each participant's postcode). The concentration of people in the

Plymouth and Torbay regions is due to the fact that the project has been running here for the longest time, and also because of the increased number of people living in the urban areas of the peninsula.

Perhaps you could help us boost numbers by mentioning the SWIMS Project to other people you think might be interested in taking part?

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SWIMS Project progress report

We have now sent out nearly 2000 questionnaire booklets, and we continue to have a great response rate, with 92% being returned. Once again, a **big thank you** for this.

It is very important to the success of the project to have as many questionnaires as possible completed and returned to us. If you change your address we would be grateful if you could let us know so that we can continue to send you your questionnaire booklets.



New SWIMS sub-study for people with MS to commence in Torbay

We are pleased to announce that Dr Jenny Freeman has been awarded a grant from the Torbay Medical Research Fund to look at mobility difficulties over the long-term in people with MS. Few studies to date have looked at how mobility can change over time in people with MS. She hopes to understand better what type of advice and interventions may be most appropriate for people with mobility difficulties. Her study of mobility is a sub-study of the SWIMS Project, and as such it is only open to SWIMS Project participants with MS who live in **Torbay**. Further information will be sent to eligible participants in due course.

Dr Jenny Freeman is Reader in Physiotherapy and Rehabilitation at the University of Plymouth

Clinically Isolated Syndrome

The SWIMS Project is also relevant to people who have been referred at some time to a neurologist because of a single episode of inflammation of the brain or spinal cord, known as Clinically Isolated Syndrome (CIS). This may come to light as:

- temporarily painful vision, double or blurred vision
- a problem with muscle strength, balance or coordination (may affect walking)
- a sensory problem such as pain, numbness or tingling in limbs.

Although CIS is not a diagnosis of MS, we would like to hear from people who have had just one episode of inflammation as well as people who have established MS. Our aim is to identify all people who have had episodes of inflammation, whether a single event or as part of a more progressive course.

Questionnaire booklets are sent to people with CIS once a year only.

MS in the press — comment by Professor John Zajicek

Hughes Syndrome

People may have read some recent articles about this syndrome named after Graham Hughes — a rheumatologist at St Thomas’s Hospital. The other name for the condition is the “antiphospholipid syndrome” and the question most people ask is whether they could have this condition rather than MS. Sometimes it is difficult to be certain about a diagnosis of multiple sclerosis, which is why it is important that people see experts in this condition before a final diagnosis is made. The antiphospholipid syndrome usually presents with recurrent blood clots (often in the veins) and miscarriages. Investigations rely on blood tests looking for something called the anti-cardiolipin antibody and the lupus anticoagulant. These auto-antibody tests are usually part of making the diagnosis in multiple sclerosis. Although Hughes Syndrome can mimic multiple sclerosis, this is very unusual.

Mitoxantrone and Copaxone Combination Drug Therapy

Some people might have seen articles particularly in the Daily Mail about this combination of drugs, which has been heralded as a combination which may “stop MS in its tracks”. Once again, this is an example of poor journalism. These headlines are based on a small number of people who have been treated with this combination in Liverpool. Mitoxantrone has been around for some time and many participants in the SWIMS Project have received it. It is a powerful drug which can cause leukaemia and heart muscle problems. These formidable side effects mean that it can only be given for a relatively short period of time. Copaxone has also been around for a few years and is a mild drug working on the immune system for people with relapsing-remitting disease.

The recent newspaper results were based on very small numbers of patients. There is potential that this combination could be useful for a small proportion of people with aggressive early stage multiple sclerosis. It would not be suitable for people with progressive or more advanced disease. The combination of Mitoxantrone and Copaxone is now going to be tested properly in a large trial in which we are not taking part. However, we are testing other drugs in people with relapsing-remitting disease. The message coming out from all of these studies is that we can achieve strong effects for people with aggressive multiple sclerosis early on in their disease, but there are also major potential side effects, which need to be considered.

What's on for People with MS—an event for Torbay residents

The Forum, Riviera International Centre, Torquay

20th September 2006 10 a.m. - 3.30 p.m.

This is an opportunity for people with MS, carers, and staff to hear about current provision and identify what else needs to be developed.

Sorry, but the event is open to Torbay residents only.

Contact Gill Dunbobbin on 01803 654727 or gillian.dunbobbin@torbay.gov.uk

Sponsored by the Torbay Primary Care Trust

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To find out about research being undertaken by the Clinical Neurology Research Group please visit our website: <http://www.pms.ac.uk/cnrg>