

Issue 2

April 2006

# SWIMS News



## Welcome to the 2<sup>nd</sup> issue of SWIMS News!



Part of the SWIMS Team at the Clinical Neurology Research Group. From left: Penny Garrod (Project Coordinator), Mark Warner & Jeanette Sanders (Data team).

SWIMS has now been in progress for 18 months and continues to go from strength to strength. We published the first SWIMS newsletter in September 2005, and we received some positive feedback from you which was most welcome — many thanks.

### Special points of interest:

- Project progress— SWIMS has been underway for a year and a half.
- Research ethics committees have approved expansion of SWIMS to Cornwall and the rest of Devon.

## Latest News— SWIMS moves into Cornwall, North Devon and Exeter

We are very pleased to report that in September 2005 we received ethical approval to include people from North Devon, Exeter and Cornwall in SWIMS. As a result our number of participants has increased to 670 (figures for April 2006).

We are hoping to let people know about SWIMS through local press releases and the MS Specialist nurses. However, word of mouth has always been important in encouraging people to join, so if you know anyone with MS who may be interested in taking part, please mention us. Thank you.

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## SWIMS website up and running!

Please take a look at our new Clinical Neurology Research Group website which contains updated information about SWIMS and other neurology research. In due course we also hope to introduce an online version of the SWIMS questionnaires. This will enable those of you with Internet access, who wish to do so, to complete the forms online. The address for the SWIMS section of the site can be seen below.

<http://www.pms.ac.uk/cnrg/swims>

## A date for your diaries — Professor John Zajicek is presenting at local branches of the MS Society



Professor of Clinical Neuroscience, at the Peninsula Medical School, John Zajicek will be giving a series of talks about SWIMS, and other ongoing neurology research at the Peninsula Medical School, on the following dates:

- Redruth, Cornwall on Wednesday 26<sup>th</sup> April 2006
- Bath MS Society AGM on Saturday 29<sup>th</sup> April 2006
- Mid Cornwall MS Society AGM, St Austell on Saturday 13<sup>th</sup> May 2006
- Exeter and District MS Society AGM on Saturday 20<sup>th</sup> May 2006



**Please contact your local MS Society branch for further details.**

## Multiple Sclerosis Register

The MS Society has funded some initial research into the concept of a national MS register, and is currently trying to establish what the various stakeholders, including people with MS, might wish to see in this register.

Plymouth will be one of the UK pilot sites for this register, but it is early days, and at the time of writing, we are unable to provide further details.

## 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:

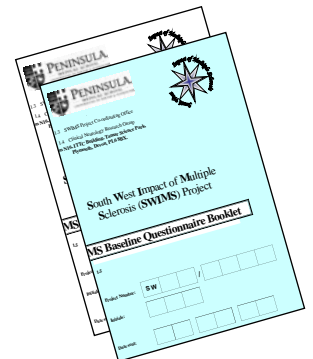
- temporary pain, double or blurred vision
- a problem with muscle strength, balance or coordination (may affect walking)
- a sensory problem such as pain, numbness or tingling in limbs.

**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 Update

We have recently sent out our 10<sup>th</sup> batch of questionnaires and we continue to have an excellent response rate with 92% being returned. Again, a **big thank you** for this.

Although the questionnaires appear repetitive, this is necessary for us to understand how the disease changes and impacts on daily life, in the *long term*. From this we hope to improve methods of measuring the benefit of new treatments, and also assist with more personally relevant prognoses.



## Ideas please! What would you like to see in this newsletter?

If you have any ideas about what should be in this newsletter please feel free to

## Other Neurology Research

If you are interested in research currently being undertaken by the Clinical Neurology Group please see our website: <http://www.pms.ac.uk/cnrg>

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## Staff changes...

- Tracey Jones-Hughes, who took over as SWIMS Project Co-ordinator in September last year, left at the end of February having decided to return to nursing. We all wish her well and good luck for the future! Penny Garrod has now taken over from Tracey.
- We are pleased to report that Wendy Ingram, Tracey's predecessor, who left to have a baby in the summer of last year, plans to return to the Neurology Office soon. Wendy gave birth to a baby girl in October 2005.

