Welcome to our 6th Newsletter

There are now 119 people with MS involved in the SUMS research study!

We would like to say a huge THANK YOU to the therapists & people with MS in each area who have contributed to the study so far.

Our target is 140 – we really need your continued help to recruit the final 21 people

There is lots of information about the SUMS study on the website below which is regularly updated: https://www.plymouth.ac.uk/research/sums

Don’t forget our twitter account!

We tweet updates and photos to raise awareness of the study – follow us to find out more

@SUMSstudy

Study summary

The SUMS study is investigating whether regular use of a standing frame at home is beneficial to people with progressive MS. It is recruiting participants from all of the Healthcare Trusts in Devon, Cornwall, Norfolk and Suffolk. This study provides therapists and people with MS the opportunity to find out how standing frames might impact on a range of issues which are known to be important to people with progressive MS, such as: movement, function, bladder and bowel control, and quality of life.

Understanding this is important so that people with MS can make informed judgements as to whether they wish to participate in a standing programme, and so that therapists, commissioners, and policy makers can understand the benefits that this may bring to patients. In order to take part in the study, a person must fulfil a small range of criteria. We can check the criteria with you over the phone if you are interested in taking part.
New resource

When more help is required to stand in the Oswestry standing frame

Have a look at our website https://www.plymouth.ac.uk/research/sums to see our new video demonstrating how to support someone who finds standing in the frame more difficult.

This new CD will now be sent as part of the resource package for the NHS “treating therapists” to use with those people who it is anticipated will need more help to stand in the frame.

Shaping services by engaging people with MS to share their ideas about future research

January saw 47 people with MS and their family members attending a meeting at the Merlin Centre in Cornwall, organised by researchers and clinical academics from the University of Plymouth. The morning was educational in its focus. Professor Jeremy Hobart discussed the “Brain Health Initiative”, highlighting the importance of keeping the brain as healthy as possible through early diagnosis, early treatments, living a brain healthy lifestyle and effective disease monitoring. Dr Jenny Freeman discussed the importance of keeping physically active and reducing sedentary behaviour, giving some tips as to how this could be achieved, and providing an update of the SUMS study. Dr Hilary Gunn highlighted the challenges many people face in terms of maintaining safe mobility and preventing falls, and drew attention to a new study being undertaken to trial a physiotherapy group based intervention aimed at improving mobility and reducing falls. The afternoon was spent discussing ideas for new research which could help to shape future MS services.
Events/ Dissemination

Therapists attending an MS study day in Canterbury were told about the SUMS study as part of a talk on managing ataxia in people with MS. The study day was held on January 27th at the MS Therapy Centre in Canterbury and was organised by the SELKAM group. The talk was given Dr Wendy Hendrie, Principal Investigator for East Anglia.

Participants were told that people with MS who have ataxia often have reduced mobility. The lack of activity can lead to deconditioning because many people with this disabling symptom are unable to exercise in a standing position because of their fear of falling. Standing frames, used either in an out-patient setting or at home, can provide them with a means of exercising safely in a standing position.

Many therapists in the audience had not used frames for people with MS but were pleased to hear that a study looking into the effectiveness of regular standing was underway.

Events in the pipeline...

Update on local MS research for therapists- St Austell hospital 1st March 2017
Cornwall Partnership NHS Trust Research showcase day at the Eden Project, St Austell 15th March 2017
Abstract accepted for Rehabilitation in MS (RIMS) conference; Barcelona 4-6th May 2017

Update on participants in the South West

We have recruited 61 people
The target is 70 people
Update on participants in Norfolk and Suffolk

We have recruited **58 people**

The target is **70 people**

Meet the Team

If you think you have a patient who may be interested in the study- or are interested in participating yourself, then please get in contact with us. We are very happy to help you decide whether SUMS is right for your patient, or for you.

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Please let us know if you would like any other information in this newsletter, we want it to be interesting and helpful for you.

Thank you for your help and support with MS Research.

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