Welcome to our 2\textsuperscript{nd} Newsletter

The SUMS Study is fully up & running! We are steadily increasing the number of people taking part, and wanted to say a big thank you to the therapists & patients in each area who have contributed to the study so far.

We are now at the stage where participants are undergoing their 20 week assessments so the research process is well underway, and the pool of information being collected is growing.

We have recently had the study approved by the MS Society for circulation and endorsement on their website, which will be another useful source of information for people with MS who may be interested in taking part.

https://www.mssociety.org.uk/ms-resources/standing-ms-sums

Study Summary

The SUMS study is testing 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 and Cornwall and East Anglia. 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.
Hearing more about SUMS

If you would like to hear more about the study, please get in contact with us. We are keen to share information with patients, therapists, and researchers; and can come to your local therapy team or MS group to give a presentation about the study.

Patient Experience of the SUMS Study

We have some participants who are now coming to the end of their involvement in the trial. Below is some feedback we have received from one such person with MS who was allocated to the standing frame group.

“This programme has improved my posture considerably as well as my confidence. It’s been easy to do and is a super piece of kit. My upper body strength has also improved with the exercises I am doing. The best achievement of all though was being able to walk my daughter down the aisle, albeit it with one crutch. This is something I’d definitely like to continue with”

SUMS participant, 22.3.16

Physiotherapist Experience of the SUMS study

We have a group of physiotherapists who are working closely with us to provide input to patients on the trial, below is some recent feedback from a physiotherapist working in Devon:

“As a physiotherapist working in the community I am really pleased to contribute to the SUMS trial. If using the standing frame proves to be beneficial to those with MS, then this is a ‘low tech’ intervention which can be put in place in the home and thus supplement the input which our stretched services provide.”

Kathryn Smith, Senior Physiotherapist, Northern Devon Healthcare Trust.
Neurological Care in the Political Spotlight

A recent article in the BBC news states that a new report by MPs has highlighted the need for better care for people with neurological conditions. It briefly outlines that plans will be made which include better long-term care plans.

http://www.bbc.co.uk/news/health-35660467

Staff changes in the SUMS Team

Our research physiotherapist and study co-ordinator, Emily Rogers, is going on maternity leave in May; and we would like to welcome Danielle Morby who will be covering Emily for 6 months. Danielle will be starting with us soon, and working on the study in the South West until December 2016.

Update on participants in East Anglia

We have recruited **24 people** (from areas highlighted as pink dots on this map)

The target is **70 people**
Update on participants in the South West

We have recruited **25 people** (from areas highlighted as pink dots on this map)

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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Thank you for your help and support with MS Research