



SMA REACH UK and UK SMA Patient Registry linked databases update Summary sheet – Information for families

Background

At present most of the data that is collected on SMA patients in the UK is held within two national databases: the UK SMA Patient Registry and the Smartnet database. The UK SMA Patient Registry is a database of genetic and clinical information about people affected by SMA. It is patient reported and one its main aims is to speed up the process of finding patients eligible for SMA clinical trials. The Smartnet database holds longitudinal data collected by clinicians at routine clinic appointments. SMA REACH UK, an evolution of the Smartnet database, is research project that will continue to collect longitudinal clinical data and will pilot new physiotherapy assessment tools in SMA.

What we are trying to do

The key people involved in these databases have explored an opportunity to collaborate. As a result we are now trying to establish a unique access point (portal) which will allow the data from SMA REACH UK and the UK SMA Patient Registry to be exchanged. Data will continue to remain separate in each database but the portal will allow the exchange of anonymised information about patients including diagnosis, medical assessment and management of SMA. The aim is to enable better preparation for clinical trials and to bring together in one place accurate details about SMA and how the condition changes over time. This will be jointly managed by the Dubowitz Neuromuscular Centre and MRC Neuromuscular Centres in London and Newcastle.

What will this achieve

Integrating information on rare diseases is important as there is only a limited amount of data from patients with these diseases. The exchange of this data will allow doctors and researchers to make the very best use of the information available to them to inform decision making and to prepare for clinical trials in the UK. One of the main aims of the UK SMA Patient Registry is to allow eligible patients to be found more readily for clinical trials. Natural history data from the SMA REACH UK database would be useful to have alongside the registry data as it would give a clearer idea of the clinical picture and prevent as many patients as possible from failing clinical trial screening visits.

Will the data be stored safely

All information will be stored on a secure system and password protected. There are strict regulations controlling who has access to personal information like name, date of birth or NHS number and only anonymised data will be shared via the portal. Only patients who have agreed, by giving their informed consent (as part of either the UK SMA Patient Registry or the SMA REACH UK project) will have their data exchanged via the portal.

About us

This is a collaborative initiative between SMA REACH UK and UK SMA Patient Registry. SMA REACH UK is managed by the Dubowitz Neuromuscular Centre, Great Ormond Street Hospital and the MRC Neuromuscular Centres in London and Newcastle. The UK SMA Patient Registry is coordinated at the Institute of Genetic Medicine at Newcastle University. This enterprise is sponsored by The SMA Trust, the Muscular Dystrophy Campaign and Spinal Muscular Atrophy Support UK (formerly the Jennifer Trust). We are very grateful to these charitable organisations for their continued funding and ongoing support.

For more information about us or the joint initiative please visit our websites

www.smareachuk.com

www.treat-nmd.org.uk/registry