

Who should register?

Adults and children with SMA and a confirmed mutation in the *SMN1* gene who live in the UK or Ireland.

SMA is a rare condition, every single person counts!

How do I register?

You can register online and create an account so that you can view and update your information at any time. If a person is under 16, a parent or guardian must create an account on their behalf.

Register online at:



www.sma-registry.org.uk

If you cannot register online, contact us at the address on the back and we will send you a registration form.

Registration is voluntary and at all times the information remains your property. You have the right to withdraw your consent to participate in the registry at any time.

Contact information:

UK SMA Patient Registry

John Walton Muscular Dystrophy Research Centre
Translational and Clinical Research Institute
Newcastle University
International Centre for Life
Newcastle upon Tyne
NE1 3BZ, United Kingdom
T: 0191 241 8640
E: registries@newcastle.ac.uk
www.sma-registry.org.uk

Registry principal investigator:

Dr Chiara Marini-Bettolo

The TREAT-NMD Network:

www.treat-nmd.org
www.treat-nmd.org/patient-registries/

For further information about spinal muscular atrophy, support and services:

Spinal Muscular Atrophy UK

Unit 9, Shottery Brook Office Park
Timothy's Bridge Road
Stratford-upon-Avon
Warwickshire
CV37 9NR,
T: 01789 267 520
E: office@smauk.org.uk
www.smauk.org.uk

UK SMA
PATIENT REGISTRY



For individuals living with Spinal Muscular Atrophy and resident in the United Kingdom or Ireland



NHS
The Newcastle upon Tyne Hospitals
NHS Foundation Trust



SMAREACH UK
ADULT
SMAREACH

What is a patient registry for SMA?

A database of genetic and clinical information (data) about people affected by SMA.

How is the information used?

Promising new treatments for SMA are becoming available. More treatments are in development and need to be tested in clinical trials. However, SMA is a rare condition and it can therefore sometimes take years to find enough patients for a clinical trial. The Patient Registry can help speed this up.

The Registry also helps specialists gain more knowledge about the condition and the number of people affected by SMA. In addition, it helps capture information from individuals now receiving treatment. This information helps to develop and improve worldwide standards of care for people with SMA.

What information is collected?

- Personal details, such as name, address, date of birth and gender, so that individuals can be identified and contacted.
- Individual's experience of daily life, their activities and quality of life (also known as patient-reported outcome measures or PROMs).
- Clinical and genetic information to inform researchers in their development of treatments, to aid recruitment to clinical trials and to assist access to new treatments.



What other benefits are there?

If you register, you will be told about clinical trials and other studies you may wish to join, but you are not obliged to do so.

You will receive information relevant to SMA about latest research developments and about TREAT-NMD activities.

Collected information will help improve standards of care for people with SMA and will help inform on the impact of new therapies.

Is my data safe?

All the information is stored in a secure server which is protected in a similar way to online bank accounts. Only specially appointed registry staff can look at your information.

Associations:



The UK SMA Patient Registry is a member of the TREAT-NMD SMA Global Registries Network, which collects medical information from national SMA registries worldwide. Only anonymised data is shared with the TREAT-NMD SMA Global Registries Network. You can be sure that your contact details are safe.



The UK SMA Patient Registry also collaborates with SMA REACH UK (children) and Adult SMA REACH, clinical studies that collect doctor-reported data from individuals with SMA. SMA REACH UK is operated by Great Ormond Street Hospital and Adult SMA REACH, by the John Walton Muscular Dystrophy Research Centre, Newcastle. Also participating are the MRC Neuromuscular Centres in London, Newcastle and other neuromuscular centres across the country. SMA REACH studies complement data provided by patients themselves in the UK SMA Patient Registry. Consent for the exchange of limited and specific patient data between the registry and SMA REACH is requested at registration.