

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.treat-nmd.org.uk/registry

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 information at any time.

For further information about Patient Registries and the TREAT-NMD Network:

UK SMA Patient Registry, Institute of Genetic Medicine
Newcastle University, International Centre for Life
Newcastle upon Tyne, NE1 3BZ

+44 (0)191 2418617

registry@treat-nmd.org.uk

www.treat-nmd.org.uk/registry

www.treat-nmd.eu

www.treat-nmd.eu/patientregistries

UK SMA registry curator:

Agata Robertson

Registry principal investigator:

Prof. Hanns Lochmüller



Help for today • Hope for tomorrow
(formerly The Jennifer Trust)

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

Spinal Muscular Atrophy Support UK

40 Cygnet Court, Timothy's Bridge Road
Stratford upon Avon, Warwickshire, CV37 9NW

01789 267520

supportservices@smasupportuk.org.uk

www.smasupportuk.org.uk



UK SMA Patient Registry



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What is a patient registry for SMA?

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

How is the information used?

Promising new treatments for SMA are being developed. These need to be tested in clinical trials but because SMA is a rare condition, it can sometimes take years to find enough patients for a clinical trial. The Patient Registry can speed this up.

The Registry also helps specialists gain more knowledge about the condition and the number of people affected by SMA. This information helps to develop and improve worldwide standards of care for people with SMA.

What information is collected?

- People's personal details; such as name, address, date of birth and gender, so that they can be identified and contacted.
- People's clinical and genetic information, because researchers need this to develop 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 newsletters with information relevant to SMA about latest research developments and about TREAT-NMD activities.

Collected information can help improve standards of care for people with SMA.

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.

The UK SMA Patient Registry is part of the TREAT-NMD Global SMA Registry, which collects medical information from national SMA registries worldwide.

When your data is transferred from the UK SMA Patient Registry to the TREAT-NMD Global SMA Registry, your personal details do not go with it. Your information in the global registry is identified only by a code. You can be sure that your contact details are safe.

How is Spinal Muscular Atrophy Support UK involved with the UK SMA patient registry?

Spinal Muscular Atrophy Support UK funds the UK SMA Patient Registry. By doing this, it is supporting clinical research and ensuring all people with SMA in the UK can be informed about research, clinical trials and best-practice care.

Information you provide to the UK SMA Patient Registry is not shared with Spinal Muscular Atrophy Support UK.