

## Who We Are

We are a charity that has been supporting individuals, families and research for over 30 years. We provide information about the condition, are advocates for better services and access to new treatments, fund research related initiatives and raise awareness.



## How to contact us

**Spinal Muscular Atrophy Support UK**  
40 Cygnet Court  
Timothy's Bridge Road  
Stratford-upon-Avon, CV37 9NW

**Phone:** 01789 267520

Lines open:

- Mon – Thurs (9.00 am – 3.30 pm)
- Friday (9.00am –1.00pm)
- Closed on public holidays.

**Email:** [office@smasupportuk.org.uk](mailto:office@smasupportuk.org.uk)

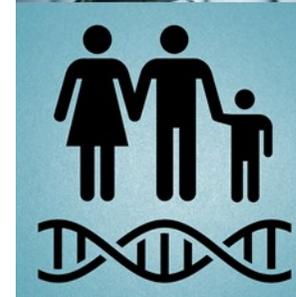
[www.smasupportuk.org.uk](http://www.smasupportuk.org.uk)

Registered Charity No 1106815  
Company Limited by Guarantee No 5137534  
Registered in England and Wales

June 2018

# How We Support Research & Access To New Treatments

## Our Contribution



## How You Can Help Us

We don't receive government funding. Please help us to keep supporting people affected by SMA and researchers addressing the causes, treatment and management of SMA.



[www.smasupportuk.org.uk/donate](http://www.smasupportuk.org.uk/donate)

## Access to New Treatments

We are committed to working with the SMA community to campaign for access to treatments that have proved to be effective in clinical trials. Our current focus is on nusinersen. You can keep up-to-date with what we are doing and get involved by following us on social media and signing up for our monthly E-newsletter:

[www.smasupportuk.org.uk/sign-up-for-mailings](http://www.smasupportuk.org.uk/sign-up-for-mailings)



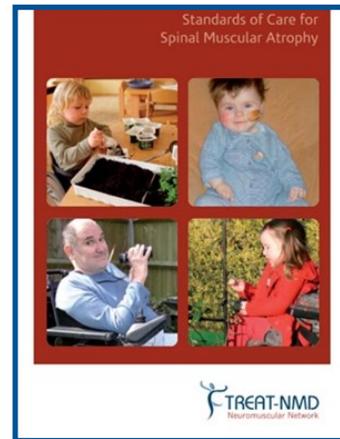
## Input to Research

Researchers who are developing drugs and conducting other studies want to understand the impact of SMA on people's daily lives. Our support services team is often asked to give an overview and, whenever possible, we enable opportunities for people's own voices to be heard directly via surveys and consultations.

## The UK SMA Patient Registry

We help to fund this important database that links adults and children who have SMA with researchers conducting studies, including clinical trials of new drugs or treatments.

## International Standards of Care for SMA



These guide day-to-day care and practice for professionals and families. We helped fund their major review by international experts and patient representative. New standards were published in November 2017. We are involved in producing the updated version for individuals and families due out later in 2018

## International Links

We are active members and funders of SMA Europe, an umbrella organisation of patient and research groups. As well as being a vital information network, it funds and supports scientific and medical research.



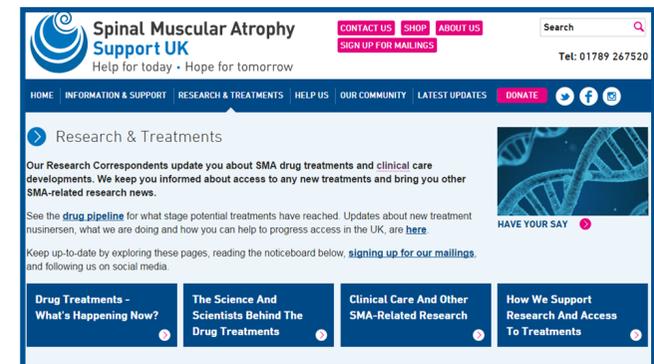
## Research Overview

Our website provides an insight into the work of the research community looking into the causes, treatment and management of SMA.



## Research Updates

Our Scientific and Clinical Care Research Correspondents publish regular updates, for example: the latest results from any clinical trials of drugs being investigated for the treatment of SMA; the latest research into the effects of diet on SMA.



To find out more go to:

[www.smasupportuk.org.uk/research](http://www.smasupportuk.org.uk/research)