

Spinal Muscular Atrophy UK

United Kingdom



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1. About

Supporting, Informing, Advocating.

We're committed to supporting everyone affected by SMA so that they have access to the best care, support and treatment and there will be no barriers preventing full inclusion in society.

2. Your mission

We will work tirelessly to raise awareness of SMA, to be a leading advocate for individuals and families and to ensure timely access to diagnosis, effective treatment, and best management for all affected by SMA.

We will listen to and support our community to make informed choices and will bring together skills, knowledge, and resources in the UK and beyond, in our quest to optimise the future lives of all affected by SMA.

3. Focus

SMA UK produces reliable, timely information on SMA for the SMA Community as well as health care professionals, education providers and the general public.

We provide personalised practical and emotional support services for all those affected by SMA.

We advocate on behalf of the SMA Community to authorities that regulate access to drug treatments, care and services and campaigning on issues that matter to people affected by SMA.

We fund and support research into the clinical development of drug treatments that understand the complexities of SMA and the underlying disease mechanisms and improvements in the clinical care and management of people affected by SMA

4. Coming up

SMA UK are key members of, the UK SMA Newborn Screening Alliance with the aim of achieving the earliest possible introduction of newborn screening for SMA in the UK to deliver the best outcomes from treatment and reduce future healthcare costs.

SMA Clinicians and Patient Groups across the UK want to establish a project (SMA Care UK) to update and implement UK Standards of Care across all ages. The project would address people's evolving care and management needs reflecting developments around treatments, ensuring that those living with SMA are central to this process. Clinicians and patient representatives from across the country would be involved in the establishment of working groups to review each aspect of care.

The SMA UK team

