



# Spinal Muscular Atrophy uk

SUPPORTING • INFORMING • ADVOCATING

## 2025



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# About SMA UK

Spinal Muscular Atrophy (SMA) is a rare, genetic neuromuscular condition causing progressive muscle wasting (atrophy) and weakness leading to loss of movement. This may affect crawling and walking ability, arm, hand, head and neck movement, breathing and swallowing.

There are different forms of SMA and a wide spectrum of how severely children and adults are affected. There is no cure for SMA but since 2016 drug treatments have gradually been introduced worldwide and in the UK, there are now three. For clinical safety reasons, though these are possible for some, they are not available for all who have SMA.

Furthermore, both clinical trial and real-world evidence suggest that if any of these drug treatments are possible, early treatment is necessary to maximise the potential benefits for this progressive condition.

This is why clinicians and patient groups are advocating for the earliest possible introduction of Newborn Screening for SMA in the UK.

Spinal Muscular Atrophy UK (SMA UK) is a national charity, founded in 1985, providing support and information about SMA to all those living with the condition as well as their families. We advocate on improving access treatment and issues surrounding the complexities that living with a rare condition brings.

All our health information is accredited by the Patient Information Forum (PIF) and is available via our website in the form of webinars, podcasts and information sheets. We host virtual and in person events that connect the SMA Community together offering a space to share information and offer peer support.



## Our Vision

Everyone affected by SMA will have access to the best care, support and treatment and there will be no barriers preventing full inclusion in society.



## Our 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.



## Annual Report

Read out latest Annual Report and Financial review [here](#).

# About the Role

Our current chair has been in the position for 6 years and after serving their maximum term, we are seeking a new Chair to lead the charity and help us deliver our four year strategic plan 'Building a future together'.

The chair provides a pivotal role in ensuring the charity has a well governed organisation, strong staff team and board with clearly defined roles and responsibilities, with one shared goal of working towards the organisational mission underpinned by our values and principles.

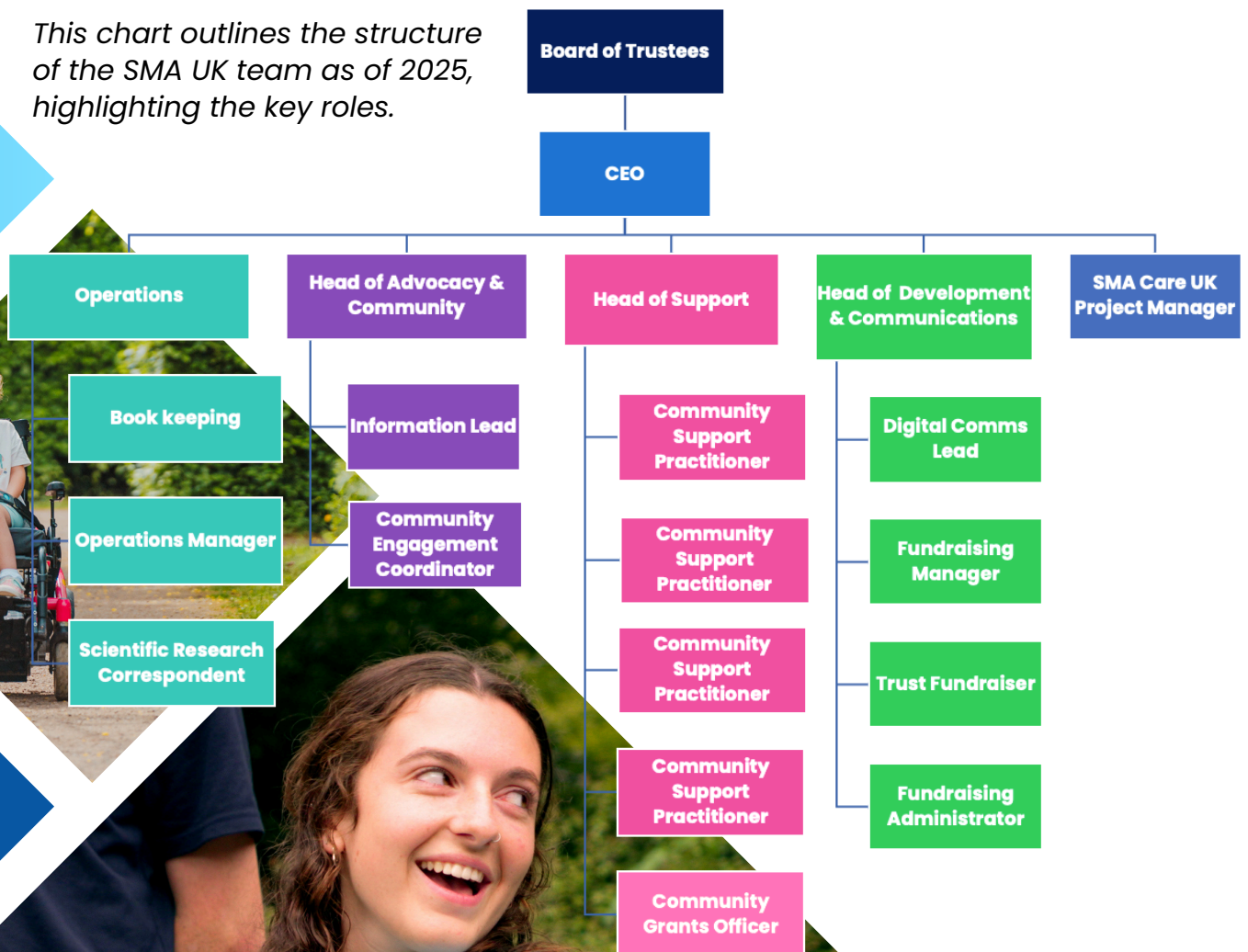
The chair will support the CEO and ensure that the board functions as a unit and works closely with the senior leadership team to achieve agreed objectives.

From time to time the chair will act as an ambassador and the public face of the charity in partnership with the CEO.

An effective chairperson is a key player in ensuring effective governance for the charity.


## Current organisational structure

*This chart outlines the structure of the SMA UK team as of 2025, highlighting the key roles.*





# Role Description



<b>Title</b>	Chair of the Board of Trustees of SMA UK
<b>Reports to</b>	The Board
<b>Term</b>	A maximum of 6 years with reappointment by the Board on an annual basis
<b>Remuneration</b>	The role is voluntary. Travel and other reasonable expenses will be reimbursed
<b>Time and Travel Commitment</b>	Up to 8 hours per month in addition to attendance at board meetings (4 meetings a year, each approx 2.5 hours. Three online, one in person) and to participate in an annual strategy day.

## **Strategic Leadership and governance:**

- Provide leadership to the charity and its Board (12-14 members), ensuring that the Charity has maximum impact for its beneficiaries
- Ensure that the board is able to regularly review major risks and associated opportunities, and satisfy itself that systems are in place to take advantage of opportunities and manage and mitigate the risks
- Ensure that the governance arrangements are working in the most effective way for the Charity
- Develop the knowledge and capability of the Board of Trustees
- Work with the CEO to set appropriate and relevant agendas for Board meetings and the annual strategy day.
- Chair each of those meetings, leading the Board in effective discussion and scrutiny of board papers, and ensuring that decisions taken by the Board are implemented.
- Ensure that the board fulfil their duties and responsibilities for the effective governance of the charity in line with the Charity Commission obligations
- Ensure that Trustees are fully engaged and that decisions are taken in the best, long-term interests of the Charity and that the Board takes collective ownership
- Ensure that the Board of Trustees is regularly refreshed and incorporates the right balance of skills, knowledge and experience needed to govern and lead the charity effectively.
- Monitor that decisions taken at meetings are implemented.
- Ensure the Board of Trustees is diverse, inclusive, and reflective of the community SMA UK serves, with a particular focus on disability representation, inclusion and accessibility.



# Role Description

## **CEO and Executive Oversight:**

- Establish and build a strong, effective and a constructive working relationship with the CEO, ensuring she/he is held to account for achieving agreed strategic objectives
- Support the CEO, whilst respecting the boundaries which exist between the two roles
- Ensure regular contact with the CEO and develop and maintain an open and supportive relationship within which each can speak openly about concerns, worries and challenges
- Liaise with the CEO to maintain an overview of the Charity's affairs, providing support as necessary
- Conduct an annual appraisal for the CEO in consultation with other Trustees
- Ensure that the CEO has the opportunity for professional development and has appropriate external professional support
- Promote effective working relationships between the Board, Senior Leadership Team, and colleagues within SMA UK.
- Comply at all times with the statutory duties of a Trustee under the Charities Act.

## **External relations**

- Act as an ambassador for the cause and the charity
- Act as a spokesperson for the organisation when appropriate
- Represent the charity at external functions, meetings and events

## **Additional information**

- The above list is indicative only and not exhaustive. The Chair will be expected to perform all such additional duties as are reasonably commensurate with the role.

# Trustee Duties

## **Values and Behaviours:**

- Champion the organisation's values – Excellence, Respect, Integrity – and proactively promote inclusion, diversity, equity and accessibility.
- The Chair will play an active role in ensuring the charity operates in a disability-inclusive way especially engaging people living with SMA.

## **Board Delivery**

- Contributing to relevant sub-committees (as appropriate and to be agreed).
- Use own specific skills, knowledge or experience to help the Board reach sound decisions through scrutiny of board papers, Board discussions, and provision of advice and guidance to Board and CEO on new initiatives.

## Financial Oversight

- Ensure that the Board fulfils its duties to ensure sound financial health of the charity, with systems in place to ensure financial accountability.
- Scrutinise reports from the Treasurer and CEO, and be satisfied that the integrity of financial information, financial controls and systems of risk management are robust, fit for purpose and defensible.

# Person Specification

**We are keen to hear from candidates who can demonstrate skills and experience in the following areas:**

## Essential

- An inclusive, inspirational and consultative leader with confidence, authority, and credibility.
- Strong stakeholder management and relationship building skills.
- Excellent communication and presentational skills.
- Commercial and/or fund-raising expertise.
- A commitment to improving the lives of those affected by SMA, as well as promoting inclusion, equity, and diversity more broadly.
- An ability to commit the required time to the role.

## Desirable criteria

- Lived experience of disability
- Demonstrable involvement in governance in the charitable sector
- Charity leadership experience

## Commitment to Inclusion, Diversity, Equity, and Accessibility

SMA UK welcomes applications from everyone. We have a strong commitment to Board diversity including, but not limited to, gender parity, ethnic diversity, and disability. We therefore particularly encourage applications from women, disabled people, and individuals from ethnically diverse communities.

We are happy to discuss any access needs or adjustments during the recruitment process and "We are open to applicants who may be stepping into a Chair role for the first time and will offer induction support.

