Update from Giles Lomax, CEO, January 2024

2023 was another very busy year and, since joining as CEO in May, I have been learning a huge amount about the charity and the incredible work that has been and continues to be done here to support the SMA Community.

Being a father of twins who have SMA Type 2, I have first-hand experience of the challenges the condition brings and understand the power the charity has to support, empower and advocate on the important issues that are faced.

We wouldn't be able to carry out our vital work without our incredible supporters and donors and I would like to take this opportunity to thank you, your family and friends for your continued support through Regular Gift. Here is a brief update on some of the ways in which your donations have made a difference.

Community Connections

Highlights from last year include our Picnic in the Park events which were held over the summer in Essex, Yorkshire and Gloucestershire. Over 150 people attended these and we have exciting plans to increase this even further this year with events across all parts of the UK.

We also hosted an activity weekend at the Calvert Trust for adults living with SMA, which was a huge success and has inspired us to plan similar events in 2024.

Our Living with SMA podcast included lots of new and exciting content from a range of contributors and continues to be popular with the community with over 1,250 downloads last year.

Advocacy & Information

The UK Newborn Screening Committee recommended that plans for a UK-wide pilot of newborn screening for SMA should progress, enabling more information to be collected in the hope of expediting newborn screening for SMA. One of our key priorities for 2024 will be to continue to advocate for Newborn screening and ensure that the SMA Community has continued access to treatment.

In October we were awarded our Patient Information Forum accreditation for our health information, meaning we offer up-to-date and relevant information about SMA to the Community.

Outreach & Support

In 2023 our team were able to support 262 individuals and families with both practical and emotional support seeing an increase of 6% from the previous year.
We have also seen an increase in the number of Healthcare Professionals contacting us seeking advice and support.

In the Autumn, we were delighted to launch our new SMArt Moves grants with thanks to The Motability Foundation. These are designed to help people living with SMA to purchase mobility equipment and wheelchairs and we hope that we will be able to make a huge difference to many people's lives.

Governance

We have recently welcomed some new Trustees, who have a variety of lived experiences with SMA and, over the coming months, we will be working alongside the Board to develop a new strategic plan to ensure the long-term sustainability of the charity that focuses on the SMA community needs.

If you would like to get in touch about any of our plans, we would be very happy to hear from you at 01789 267520 or at fundraising@smauk.org.uk

Best wishes and thank you so much again for your wonderful support.

Giles Lomax
CEO, SMA UK