



EVERY PIECE OF THE PUZZLE: CELEBRATING THE SMA COMMUNITY

WHY WE'RE DOING THIS

Progress in SMA has never been the work of one organisation or one individual.

It has only been possible because thousands of people have each played a part; from families willing to tell their stories, adults living with SMA who have challenged perceptions and advocated for change, clinicians and researchers who have built the evidence, campaigners who refused to give up, and partner organisations working together towards shared goals.

Many people see where we are today, but not the journey that brought us here.

They don't see the years of research that paved the way for treatments, the families who spoke publicly about diagnosis and care, the adults with SMA who continue to campaign for better access and understanding, or the countless conversations, meetings and campaigns that have shaped today's progress.

During SMA Awareness Month, we'd like to shine a light on that journey.

THE IDEA

This year's SMA Awareness Month is an opportunity to celebrate how far we've come as a community and to recognise the many people who have made that progress possible.

Today's SMA landscape looks very different to even ten years ago. We have access to life-changing treatments, newborn screening is set to begin in England from October 2027, research continues to move forward, and more people with SMA are living longer, fuller lives than ever before.

None of this happened by chance. Every breakthrough has been built on years of campaigning, research, clinical expertise, fundraising, policy change and, above all, the voices of people affected by SMA who have shared their experiences to help create change.

This Awareness Month, we want to celebrate every piece of that puzzle.

BY SHARING THESE STORIES, WE HOPE TO:

Celebrate how far the SMA community has come together.

Recognise the many people whose voices, expertise and determination have driven progress.

Highlight the role of families, adults living with SMA, clinicians, researchers, campaigners, supporters and partner organisations.

Reflect on the milestones we've achieved from improving standards of care and access to treatments, to newborn screening and ongoing research.

Inspire hope while recognising there is still more to do to ensure everyone affected by SMA has the support and opportunities they deserve.

HOW IT WILL WORK

Throughout Awareness Month, we'll share a series of stories across our website and social media channels, with each story representing a different piece of the SMA puzzle.

Together, these stories will show that every contribution, big or small, has helped shape where we are today.

Contributors could include:

Adults living with SMA, reflecting on how life has changed over the years.

Families who have shared their experiences to raise awareness and influence change.

Parents whose children have benefited from treatment.

Bereaved families whose voices have helped improve the future for others.

Clinicians who have championed improvements in diagnosis, care and newborn screening.

Researchers who have advanced our understanding of SMA and developed new treatments.

Representatives from partner organisations and charities.

Campaigners, supporters, trustees and volunteers who have driven change over many years.

SMA UK staff and other organisations who have worked alongside the community to advocate for better outcomes.

EACH STORY WILL EXPLORE QUESTIONS SUCH AS:

What has your SMA journey been like?

What changes have you seen over the years?

Why did you choose to use your voice?

What progress are you most proud of?

What does today's SMA landscape mean to you?

What gives you hope for the future?

What would you like people to understand about living with SMA today?

The stories may be shared as written interviews, short videos or a combination of both, depending on what works best for each contributor.

WE'D LOVE YOU TO BE INVOLVED

Every person affected by SMA has helped shape the story we're telling today.

Whether you've shared your family's experiences, taken part in research, campaigned for better services, supported others in the community, or lived with SMA while helping others understand what life is really like, your voice matters.

This campaign is about celebrating every piece of the puzzle and recognising that every contribution has helped create the progress we've seen.

Together, we'll celebrate not only how far we've come, but the community that made it possible and continue to shape what comes next.

Email: portia.thorman@smauk.org.uk