

# ANNUAL REPORT 2023-2024



**Spinal  
Muscular  
Atrophy uk**

SUPPORTING • INFORMING • ADVOCATING

# Chair's Report

I look back over the last 12 months with great pride at the achievements of SMA UK, a year in which amongst other things saw a seamless transition between Angela Smith-Morgan and our new CEO, Giles Lomax. Our Support Team, once again, has delivered an exceptional service to all those affected by SMA and continues to be at the core of everything we do, whether it be providing practical or emotional support to anyone affected by SMA or liaising with neuromuscular advisors and other healthcare professionals to ensure that all those living with SMA receive the best possible care.

The Charity was thrilled to secure a grant from the Motability Foundation which enabled us to launch the SMARt Moves programme supporting the community to access grants for wheelchairs and other pieces of much needed mobility equipment.... A real game changer!

For the 11th year running, we were proud to be awarded our PIF accreditation (Previously the Information Standard) which confirms that our SMA related information has been through a professional and thorough production process and is based on reliable, up-to-date evidence which is communicated clearly.

Newborn screening continues to be a priority for SMA UK and we were delighted that the Newborn Screening committee (NSC) announced in June that an In-Service Evaluation (ISE) would take place. In addition, several SMA UK colleagues were invited to join the SMA in-service evaluation (ISE) partnership board and associated 3 sub-groups to provide expertise and insights into how and when newborn screening for SMA will be delivered in the NHS across the UK. We will continue to do everything in our power to get SMA included on the bloodspot programme.



The team have also advocated on several key topics including ensuring continued access to disease-modifying treatments through the NICE multi technology assessment (MTA) process, an area of work we will keep working on behalf of the community so everyone living with SMA should have access to a treatment if they wish.

Community engagement continues to be a major focus with our Picnics in the Parks, the adults 'Resonate weekend' held in Exmoor in July and our online community networks. In addition, we have launched a new Adult's Advocacy Steering Committee which is a key platform for us to gather insights and key advocacy priorities from the adult SMA community.

SMA UK is here to represent anyone living with and affected by SMA. During the year we launched our new and rebranded website and social media channels, which I hope you agree showcases SMA UK as a modern, forward thinking and agile charity. We have also reviewed our internal data management systems and reviewed our organisational structure which will enable us to serve the community as best as possible.

The success of SMA UK depends on the hard work and dedication of so many people including our volunteer trustees. It was with great sadness that in October we learned of the death of one of our trustees, Clare Gray. Clare was a powerful advocate not only for the SMA community but also for the entire disabled community. She will be greatly missed.



In November, the second terms of four trustees came to an end and following a recruitment process we appointed Maryann Aspinal, Tracey-Jane Bailey-Burnley, Ross Hovey, Jennie Shehan, and Ben Williams as new trustees. I am excited to have them all as part of the board. You can read more about them on our website.

Of course, SMA UK can't operate without you - our generous donors, our wonderful supporters, our incredible volunteers, and of course our amazing team who have all worked so tirelessly to keep on delivering for the SMA community. Thank you!

A handwritten signature in black ink, which appears to read 'Mark Dearlove'.

**Mark Dearlove**  
Chair of the board of Trustees



## CEO Report

As we draw 2023/24 to a close, I can look back on my first year as CEO extremely positively, and our annual report will reflect this with some of the amazing work the team have done on behalf of the SMA community.

Despite the cost-of-living crisis, pressure on the charity sector and impact on securing funds, SMA UK has gone from strength to strength generating income to deliver vital programmes, projects and services that the SMA community really want and need. Over the last 12 months, and moving forward, we will continually review the value in the pound to ensure that funds that are raised directly benefit the SMA community.

I would like to publicly thank all of the staff for their hard work and dedication, we really do have a fantastic team, and I am extremely grateful for our incredible supporters and donors as without your efforts we would not be able to carry out our vital work.

**Giles Lomax**  
Chief Executive Officer

A woman with braided hair and a young girl in a wheelchair are shown in a hallway. The image is overlaid with a blue filter. The woman is smiling and looking towards the camera, while the girl is looking off to the side.

# ADVOCACY UPDATE

**#ScreenTodayForSMA**



## NICE Multi-Technology Appraisal for Risdiplam and Spinraza

### What is it?

The National Institute of Health and Care Excellence (NICE) approved Nusinersen for funding through the NHS in England in July 2019 and Risdiplam in August 2020.

This was on the condition that researchers would collect more information from patients and their clinicians on how well it works, how safe it is and whether or not it is good value for money. This was because, at that time, the NICE committee did not feel there was enough evidence from the clinical trials to answer these questions. SMA, being a rare disease, meant the numbers of participants were not big enough to satisfy a final recommendation.

Both treatments have been funded via time limited Managed Access Agreements (MAA) which come to an end in 2024.

People prescribed either of these drugs, have been completing physio assessments, answering questions and completing patient reported outcomes to create clinical data which will be used as evidence along with data from new clinical trials.

### What is our role as a patient organisation?

From professional discussions with industry and clinicians, it became clear that the clinical evidence was not fully reflecting the real-life experiences of treatment for those living with SMA. Notably, the value of stabilisation for adults and the importance of access for all no matter the severity of the condition.

Working alongside Treat SMA and MDUK, SMA UK led on a response as a unified voice from the SMA community which was submitted to the NICE appraisal committee members.

The work started with an information webinar to inform the community about the appraisal process and how they could contribute their experiences and views of Spinraza and Risdiplam.

A survey was circulated within the SMA community based on the very specific questions the patient organisations were being asked by NICE.

We received 145 responses to the carer survey and 115 responses to the survey for those living with SMA. The data was analysed and summarised and a joint submission will be submitted on the 19th April 2024.

## Newborn Screening

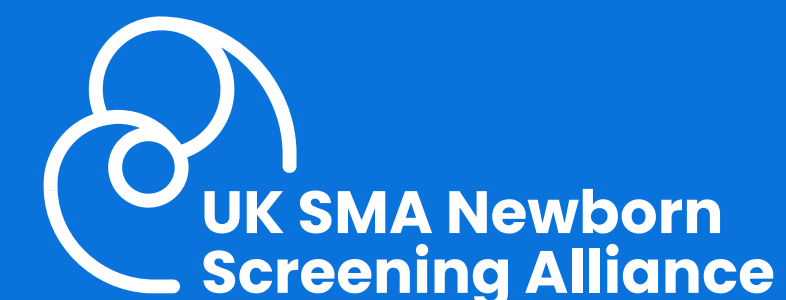
The Newborn Screening Committee recommends that planning starts for an in-service evaluation (ISE) for newborn screening for SMA. The 'pilot' will inform the economic model.

Progress on this work was reported to the June 2023 UK NSC meeting and committee members endorsed a 2-fold recommendation for the project's next steps to simultaneously:

- develop a new comprehensive and flexible cost effectiveness SMA screening modelling study for the UK screening context
- start scoping an in-service evaluation (ISE) of newborn screening for SMA in real world NHS services in the UK

Part of the ISE is to create a number of sub boards including the SMA ISE partnership board. It's role is to oversee the development of the ISE, ensuring it provides robust evidence to support a definitive UK NSC recommendation.

This announcement is progress. It's a decision that shows the impact of the work of the Newborn Screening Alliance (SMA UK & MD UK). But whilst newborns will be screened for SMA during this evaluation, it is not the final decision that we, the SMA community need now, and it does not catch us up with the rest of the world.





## Genomics England's Generation Study

We were delighted to see SMA is on [the list](#) of over 200 treatable conditions for the Generation Study. Genomics England who are running the study describe the project as an "NHS-embedded research study which aims to understand whether sequencing babies' genomes can help to discover rare genetic conditions earlier."

[The Generation Study](#) will sequence the genomes of 100,000 newborns to look for a specific set of rare genetic conditions that affect babies and can be acted on.

The study is not an alternative to newborn screening, its purpose is to evaluate the feasibility of screening newborns for a larger number of childhood-onset rare genetic conditions in the NHS, using whole genome sequencing. It will be exploring the potential risks and benefits of storing an individual's genome over their lifetime. We expect as many as 40 NHS Trusts across England to participate over the course of the study, which runs until March 2025.

## Disability Action Plan 2024

In July 2023, the UK government sought valuable feedback from the disabled community regarding their ambitious goal to transform the UK into 'The most accessible place in the world for disabled people'. SMA UK took proactive steps to gather insights and perspectives from the SMA community, collaborating with numerous other disability-focused organizations to compile a comprehensive response.

Following thorough consideration of all submissions, the government published the action plan on 5th February 2024. This plan outlines strategic initiatives and measures aimed at fostering inclusivity and accessibility across various sectors. For further details on the action plan and its implications, you can find more information [here](#).



## Spinal Bracing

Through SMA UK social networks, it has been made clear that different NHS Trusts across the UK have different paediatric spinal care pathways. Several families are going to the private sector to access braces that they perceive to be more comfortable and more efficacious, often from a recommendation from another family, not a clinician.

To raise awareness of this issue and to lay the foundations for one of the topics proposed for the SMA Care UK Project, SMA UK designed and circulated a survey to the paediatric braced community. Dr Quince, a research fellow from Sheffield Children's Hospital agreed to analyse and summarise the data. The findings highlighted the inequities in provision across the country and have initiated a clinical survey which will go to all specialist sites to establish what their pathways for spinal care look like. The two data sets will be combined into a report which we hope will facilitate trusts across the UK to work towards some alignment in the field.

## Adults Advocacy Steering Committee

To ensure that the priorities of the adult community are heard and that we are representing all members of the SMA community, we launched the Adult Advocacy Steering Committee in August 2023.

Led by our Head of Advocacy and Community, Portia Thorman, and facilitated by social entrepreneur living with SMA, Martyn Sibley, the voices we hear from the working group will shape and form the [SMA Care UK project](#) and furthermore, will inform SMA UK's long and short-term strategic planning.



### How can you help?

Learning from individual experiences is so important when trying to find best practise. If you would like to inform the diagnosis working group of the SMA Care project by sharing your diagnosis story, then our Head of Advocacy and Community would love to hear from you.

**Please email [portia.thorman@smauk.org.uk](mailto:portia.thorman@smauk.org.uk)**

## SMA Care UK

Clinicians and Patient Groups want to establish a project (SMA Care UK) to update and implement UK Standards of Care across all ages. A proposal is due to be finalised in 2023 when SMA UK will endeavour to secure funds to support the first 3 years of the project.

Clinicians and Patient Groups want to establish a project to update and implement UK SMA Standards of Care across all ages and groups. 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.

### The main objectives of the first 3 years of the project would be:

- To review the International Standards of Care (SoC) (2017) with clinicians and patients to identify key aspects of care that require revision / update in light of the changing SMA landscape.
- To establish an UK SMA SoC consensus for each area of care.
- To implement and disseminate a UK minimum recommendation for each aspect of care.
- Address inequalities in care for families and adults between different sites across the UK by campaigning for this UK standard to be accessible to all people who have SMA, no matter where they live.
- Identify areas of care where further work / evidence / research is needed, and work with SMA Europe and other international groups to develop new consensus statements for specific elements of care.
- Link with ongoing international initiatives to update the SoC recommendations based on the evolving therapeutic landscape.

We look forward to updating you as the project develops.

## Childrens Book Project

We were delighted to be awarded a sponsorship from Biogen to produce a new children's book all about SMA. Although SMA UK have previously published books "About SMA and Me" with the introduction of treatment, these are now out of date.

Furthermore, with the possibility of newborn screening for SMA on the horizon it was felt we needed to produce a non-fiction book focusing on:

- The genetics of SMA
- Timeline of scientific progression, how far research has come
- How new treatments work on your body
- Individual differences, why your SMA looks different to someone else's
- SMA health professionals and their role
- Living with SMA and support

The book will be due for publication in December 2024.



## Partner organisations

SMA UK continues to work with partner organisations to bring a united voice on issues which impact those living with physical disabilities. Working with umbrella organisations like Genetic Alliance UK and MDUK we can add the perspectives of those living with SMA to policy campaigns such as improved coordination of care, faster diagnosis and improved care provision.

SMA UK continues to play an active part in the Adults' and Children's REACH networks, bringing the patient perspective to them.

SMA UK continues to work with Industry partners. We supported Roche in a Delphi panel to gain expert consensus on the healthcare resources required by people living with SMA, the outcome of which will inform their economic model for the MTA evidence.

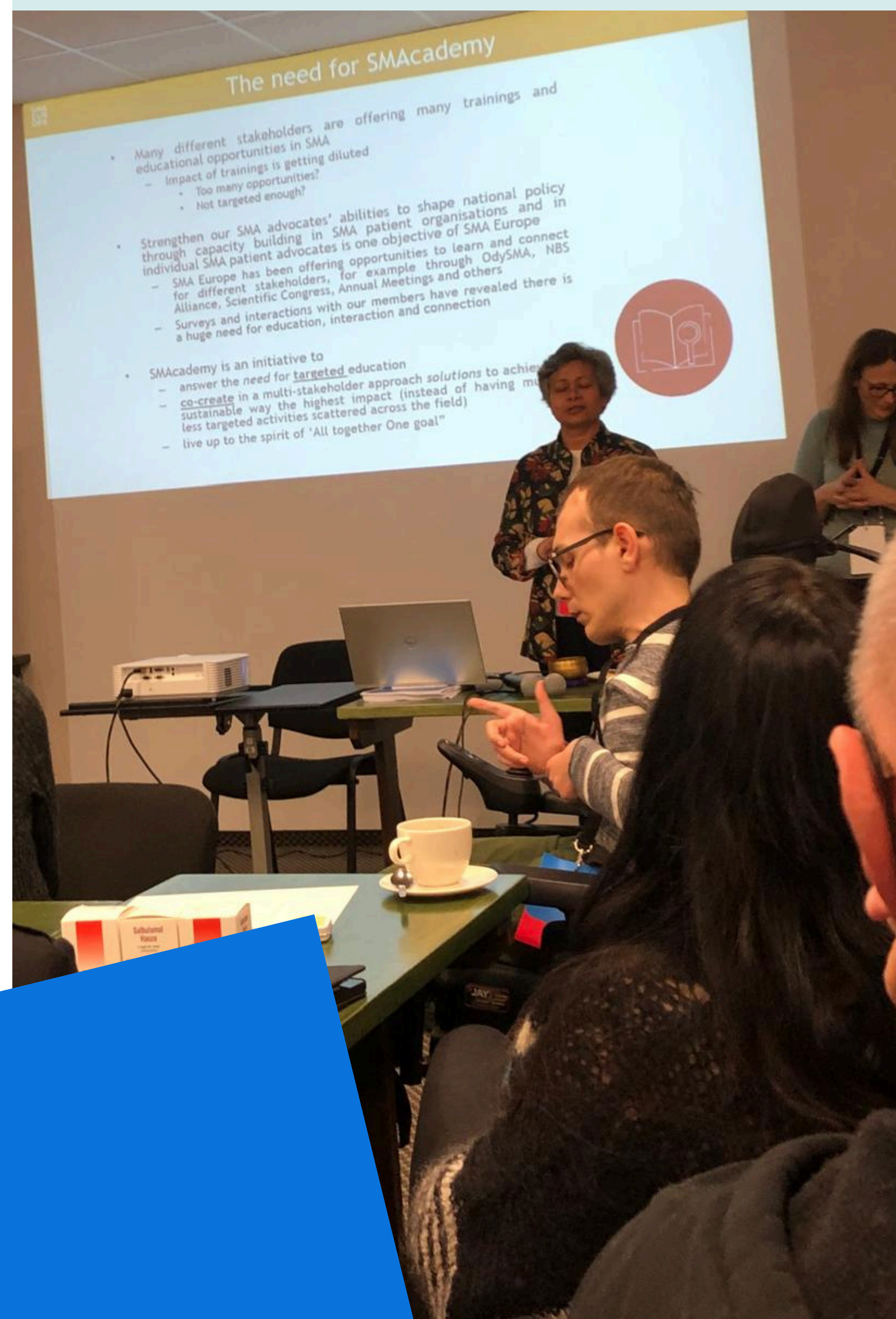
We continue to work with all three leading pharmaceutical companies, ensuring we have regular updates and taking on consultation work if aligned with our strategy.

## SMA Europe

### Annual General Meeting Prague

In April 2023, SMA UK went to Prague to join delegates from around Europe to look at developments made over the last year and discuss the priorities for SMA Europe moving forward.

It was a fantastic opportunity to hear about access to treatment and therapies across Europe and to discuss what gaps still needed to be filled for the SMA community. You can listen to a podcast about the trip [here](#).



### SMA Scientific Congress 2024 Ghent

This was a fantastic conference that brought together specialist clinicians, researchers, and industry and patient advocates working in the field of SMA. Before the event officially started representatives from SMA UK joined a global advocacy event with advocates from over 50 countries around the world, and met early career researchers to explain unmet needs in the SMA field.

UK clinicians and industry experts expressed their gratitude for the work SMA UK are doing and how much they value the working relationships we have formed.

Working with James Sleight, our scientific correspondent who also attended, SMA UK shared a summary of eight research projects from the conference, read it [here](#).



# COMMUNITY ENGAGEMENT

## Picnic in the Parks

Summer 2023 saw the return of SMA UK's Picnic's in the Park events for anyone living with, or affected by, Spinal Muscular Atrophy.

214 people attended three events, hosted in Essex, Yorkshire and Gloucestershire, giving people an opportunity to connect with each other and of course, the SMA UK team.

The positive feedback and sense of community from these gatherings inspired us to plan even more inclusive and engaging events for the future, ensuring that people affected by SMA always have a supportive and welcoming community to turn to.

# picnic in the park



“

**It was lovely to meet up with people from last year and meet new families too. It's so great to build those connections and a support system so you don't feel so alone.**



# RESONATE

## 2023



### Resonate weekend

In July 2023, SMA UK was proud to launch our first Resonate event, an adventure weekend for 21 adults living with SMA at the Calvert Trust, Exmoor.

The weekend featured a full agenda of accessible activities like abseiling, archery, crate stacking, swimming, and zip lining! Each activity was carefully chosen to be both exciting and inclusive, allowing participants to push their limits and try new things.

Resonate 2023 wasn't just about the activities, though. It was also about building new friendships and creating lasting memories.

Check out the highlights and hear from participants about their experiences at Resonate 2023 [here](#).



"I didn't know many other people with SMA before Resonate, and being able to spend time with others experiencing similar things was really valuable.

I was also able to participate in activities I didn't think were possible for me, such as abseiling and zip lining! It was such an amazing couple of days and I've made some brilliant memories – thank you SMA UK!" – Sophie

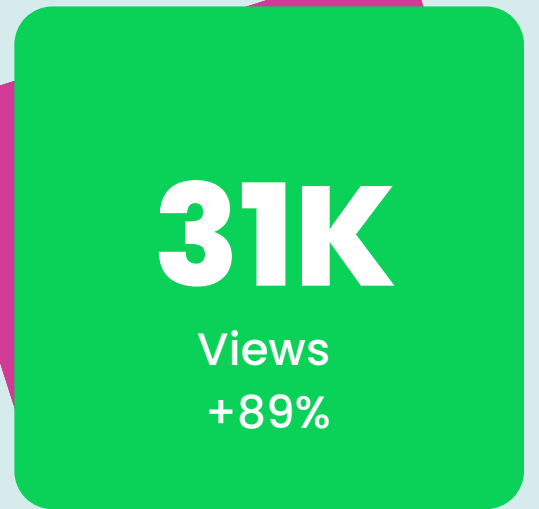
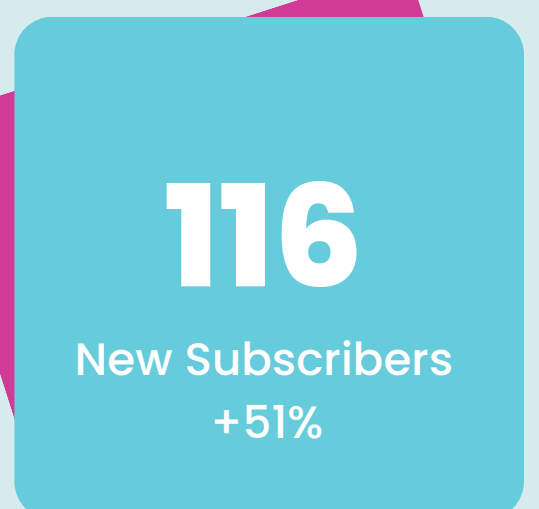



# LIVING WITH SMA PODCAST

## Living with SMA, Podcast and Webinars

SMA UK's advocacy, engagement, support, information and comms teams work closely together to identify the big issues coming from the SMA UK community across the UK.

A topic is agreed and questions are collected from the community via our social channels. Through our close relationships with specialist clinicians and members of the SMA community we are able to create current, informative digital content on YouTube for the SMA community and their support networks, both in the UK and internationally.



## WhatsApp Community Networks

SMA UK's WhatsApp networks connect the SMA community across England, Wales, Scotland and Northern Ireland. They bring a safe, well moderated space for people living with SMA in similar circumstances, who can support each other both emotionally and practically.

The WhatsApp networks have also been a fantastic resource for advocacy purposes, gauging opinion and experience through polls and questionnaires. This has provided insights for all of SMA UK's projects and will continue to do so in the future.



A photograph of two women sitting outdoors on a grassy area, laughing heartily. Both women are wearing white t-shirts with the Spinal Muscular Atrophy UK logo and text. The woman on the left is older with blonde hair tied back, wearing a watch and bracelets. The woman on the right is younger with blonde hair, wearing sunglasses on her head. The background shows a grassy field and trees under a clear sky. The entire image has a semi-transparent purple overlay.

# SUPPORT SERVICES UPDATE



## Support and Outreach Service

Support is at the core of what we do at SMA UK. Over the past year the Support Team has continued to offer high quality practical and emotional advice and support to anyone affected by SMA. We have supported 255 individuals and families across the UK and responded to 76 enquires from education, health and social care professionals.

The team have supported families and individuals with one-off enquires and with more ongoing complex situations, often related to, for example their care and support needs, education, employment, benefits, housing, adaptations, and equipment. We have provided information on treatments and supported people in finding information and further support with their health and wellbeing, signposting to others who may offer help.

The team have written supporting letters that explain the impact of SMA on the individual and have requested that services respond appropriately for that person. Our supporting letters, on many occasions have been successful in securing a positive outcome for the individual - for example maintaining a taxi service to and from school for an 8-year-old boy, and on two separate occasions, ensuring that a family received a full needs assessment for their child. We have attended meetings with adults and families, home visited, and supported emotionally and practically for as long as we have been needed.

Nicola Beer joined the Support Team in August; she comes from a health and social care background and over the last few months has enjoyed getting to know the SMA community.

This map illustrates the spread of location where people are supported.

**255 individuals with SMA and families supported across the UK**





## Flexible Response Grants (FRG's)

SMA UK offers Flexible Response Grants to families and individuals in need. These are managed by the Support Team and are administered via two grant schemes;

### FRG 1

FRG 1, offers financial support to attend hospital for treatment or medical assessments, and this year we gave 47 grants from £20.00 to £656.00.

The largest proportion of these grants have supported children and adults to access disease modifying treatment. There were also grants given in support of acute hospital stays, spinal surgery, sleep studies and other assessments.

### FRG 2

FRG 2, offers financial support with items/services that are not met through other grants/funding sources. This year we gave 31 grants from £74.17 to £1070.00

The largest portion of this grant provided non-NHS equipment, for example car seats with isofix and/or buggy bases, Go-to-Seats, a Squiggles mat, and mobile hoists. There were also smaller grants for urgently needed household items, and support to attend events, for example Resonate.



## Our work with partners

The Support Team continues to link with the Neuromuscular Centres, Neuromuscular Advisors and specialist nurses. We visited Winsford Neuromuscular Centre, seeing what they do and how we can access the support they offer. We continue to link with other charities and organisations to bring the best possible support to the SMA community.



## Toy packs

We have sent out 22 toy packs to newly diagnosed babies, their parents/carers. These packs contain multi-sensory toys specially designed to stimulate young babies and are given to families free of charge.



## Empowering the SMA community through mobility

We are delighted that SMA UK has been awarded a grant from The Motability Foundation, giving us the opportunity to assist people living with SMA in purchasing mobility equipment and wheelchairs through our SMART Moves grant. SMART Moves is split into three grant-giving schemes:



### SMART Moves 1.1

Offering grants to fully fund powered wheelchairs and manual wheelchairs that cost up to a maximum of £5,000.



### SMART Moves 1.2

Offering grants of up to £5,000 towards powered wheelchairs and manual wheelchairs that cost over £5,000.



### SMART Moves 2

Offering grants up to £2,500 for other mobility equipment, including risers, batteries etc.

Ally Allen became part of the team this year, as Community Grants Officer overseeing the administration of our new SMART Moves Grants.

To date, we have had 33 applications for both manual and powered wheelchairs, as well as for repairs, batteries, and tyres.

By working alongside other grant giving charities we have supported several adults to secure funds to purchase new powered wheelchairs. We have also enabled families to access their child's first manual or powered chair.

## Karol's Story

Karol is a lively 2-year-old with SMA Type 1. His mother, Magda, applied to SMART Moves 1.1 for help funding a Panthera Micro wheelchair. Although they had a Wheelchair Services voucher, they still faced an outstanding balance.

SMART Moves stepped in to cover the remaining costs, paying the supplier directly. Thanks to this support, Magda could order Karol's new wheelchair. Here's what Magda had to say:

*"I am absolutely happy and grateful for the incredibly massive help Karol received to get his first wheelchair. A year ago, he was so weak that he couldn't even sit, roll, or touch his toes. Now, he is able to move around in his wheelchair!"*

*Since receiving his new wheelchair, Karol is doing brilliantly. He absolutely loves his wheelchair. His arms and hands are getting stronger, and everyone is so impressed with how easily he navigates narrow spaces and spins, even going backward is lots of fun!*

*We are taking his Panthera to friends' houses so he can move independently and play with friends.*

*Thank you so much for making this possible, and for the huge support from Jo in the Community Support Team when applying."*

# INFORMATION UPDATE



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spinal Muscular Atrophy UK

looking for support?





Trusted  
Information  
Creator



Patient Information Forum

In October we again passed the review that confirmed we remain a Trusted Information Creator, accredited by the Patient Information Forum. The PIF TICK Quality Mark helps people identify trustworthy print and digital health information: [pifonline.org.uk/pif-tick/](https://pifonline.org.uk/pif-tick/)

## Our Website

Our website pages are designed so that anyone can easily find information about the causes, symptoms and effects of SMA alongside information about treatments and care.

To make sure all our information is accurate and up to date, we work with clinical experts and other health professionals, many of whom join us for community webinars which answer questions about health matters.

Our 'Living with SMA' website pages respond to the many questions the SMA community ask us. Topics range from starting school and accessing work, to leisure, travel and adapting your home.

We would like to thank the SMA community for engaging so generously and openly with us to highlight these important topics.

All our information pages were successfully integrated into our new website in time for its launch at the beginning of August 2023. Since then we have had positive feedback from users.

Between then and 31st March 2024, our website top 'hits' were:

Page	Hits
Looking After Your Child	3,590
Treatments & Research	2,645
About SMA	2,622



## New information pages

We published two new information pages for families who have had a recent diagnosis of SMA.

- Hearing your Baby's Diagnosis of SMA
- Hearing your Child's Diagnosis of SMA

As we worked on these, we were very aware that parents could find out that their baby has SMA as a result of the Oxford -Thames Valley and Wessex - based newborn screening for SMA study.

This meant that we had to carefully review many of our information pages to make sure they were sensitive to this possibility.

We will need to update them further when the National Screening Committee's In-Service Evaluation for newborn screening of SMA goes live. We understand this is likely to be sometime in 2025.

You can find these pages [here](#).

## Emergency Care Guide

SMA UK were proud to publish our 'Information Sheet for Emergency Services' in August 2023, the result of months of collaborative work with families living with SMA and specialists clinicians.

Children living with SMA may need extra support to recover from common ailments, requiring emergency care at their local hospital. Frequently, frontline clinical staff will not have come across SMA and we were hearing many distressing stories from families about the difficulties in accessing appropriate care in an emergency.

Our staff teams worked together with clinical experts to produce an information sheet for families to inform paramedics, the A&E team and clinicians working in local children's wards. It provides information that will assist them with their assessment and care pathway development. Carers can download the document from our website [here](#).

You can find all three information sheets in the 'Recently Diagnosed' section of our website [here](#).

# NEW RESOURCES FOR FAMILIES

## Getting your child who has SMA ready for school

Autumn 2016 marked the very beginning of the possibility of disease-modifying treatments for SMA. For children who have SMA Type 1 these have been life-saving, and life-changing for other children who have SMA. Most treated children have gained strength, movement and better health. Though many do have complex care needs, with appropriate support, these children are joining mainstream schools.

As we have heard from families, however, getting a school place, is not always easy. Therefore, we developed a new resource for families, 'Getting your child who has SMA ready for school' to help families as they start to think about primary education options. It was developed with ideas and input from Natalie Smith, Clinical Nurse Specialist at Great Ormond Street Hospital, and families who had experienced this journey already. Thank you to them.

The pack includes:

- A summary for schools about SMA
- Examples of how information about children who have different levels of need could be presented to a school
- Blank templates of these examples that parents can use for their child

Our staff worked with clinical experts and families to create a guide called 'Getting the Right Support and Education' as the education systems are complicated and varies across the UK.



## Community Webinars

We produced five community webinars recorded with health professionals. These have been watched by more than 1,400 people. We would like to thank the volunteers who hosted these and asked the questions posted by the community.

Find them on our YouTube channel:  
[www.youtube.com/@SpinalMuscularAtrophyUK](https://www.youtube.com/@SpinalMuscularAtrophyUK)

### Treatment Updates from Health Professionals

Sept 2023 **Update on Treatments for Adults**

Jan 2024 **Update on Zolgensma in the UK**

### Conversations with Health Professionals

July 2023 **Diet and Nutrition**

Oct 2023 **Exercise and SMA**

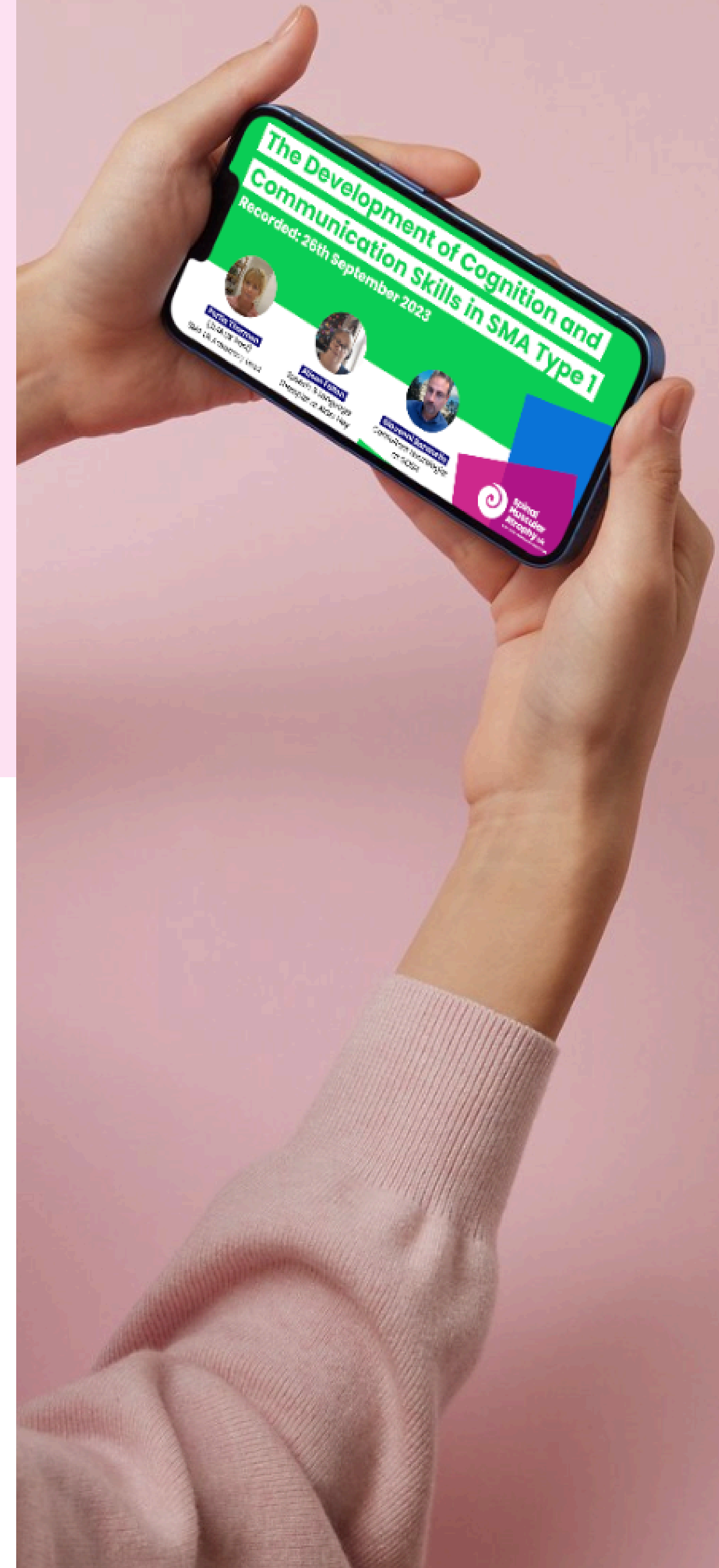
Oct 2023 **The Development of Cognition and Communication Skills in SMA Type 1**

### In 2024/25 we plan to:

Continue to maintain our Patient Information Forum accreditation (PIF) for all our health information.

Continue to develop our Living With SMA section of the website in response to community needs and questions. This will include more information for young people who are beginning to think about leaving school and moving forward into adult years.

We will further update our information sheets so that they are in line with the information published for the National Screening Committee's In-Service Evaluation for newborn screening for SMA (ISE for NBS) when this goes live.



The image shows a person in a wheelchair being hoisted by ropes, likely for a rescue or transport. Another person is assisting from the side. The background is a building with a corrugated metal roof. The entire image is overlaid with a green tint.

# FUNDRAISING UPDATE



## Raising Funds

SMA UK's achievements are only made possible because of our generous donors and supporters. In order for us to continue to meet the needs of all those living with SMA we need to ensure that our fundraising income is sustainable and consistent.

***In 2023/24, through various fundraising activities and donations our raised income was £1,263,853.***

We offered a range of fundraising activities to keep supporters engaged, from challenge events to coffee and cake days, and were successful with a large grant from the Motability Foundation to fund our SMArt Moves programme. We also had a successful year raising income from Trusts and Foundations and through our fundraising campaigns. At the end of January 2024, 155 individuals were supporting us with a regular gift and we gratefully received four legacy gifts.

We continued our digital journey by launching a new website in August 2023, implementing our new branding. This allowed us to offer the SMA community a better user experience when sourcing important information about the condition, as well as a platform to share the community voice and developments within the SMA space.

Thank you to everyone who supported our work in 2023/24. We particularly would like to thank:

- All our wonderful fundraisers and donors
- Our industry partners Novartis, Roche, Biogen & Pfizer
- The charitable trusts and foundations, particularly of note, Provincial Grand Lodge of Warwickshire
- The Motability Foundation for supporting our SMArt Moves grant initiative

## Frazer's Fundraising Story

Frazer Lloyd and 30 of his friends and family, took on the mission of completing the UK Three Peaks Challenge in just 24 hours. The group managed to climb Ben Nevis, Scafell Pike & Snowdon in an incredible 23 hours & 50 minutes and were joined by even more supporters for the final climb.

Not only did they complete this mammoth challenge in an unbelievable time, they also held a fun day – with bouncy castles, face painting and games for the kids, followed by live music from a DJ, a raffle and an auction in the evening!

Their mission was to raise awareness of SMA, inspired by Frazer and Leah's nine-month old son, Frank, who has SMA Type 1. Frank was born in January 2023 and received treatment at Alder Hey Hospital, who continue his care as an Outpatient following a long stay in hospital.

Frank's Grandma, Sharon, says, "He is an absolute inspiration to us all. He defies all the odds that he's up against and powers through. He is an amazing, beautiful, funny, little soul. Our little warrior and adored by our whole group of friends and supportive family."

The family are keen to continue raising awareness of SMA with future events and will be making a donation to SMA UK from the funds they have raised so far. Thank you so much to you all for your amazing support!

## The Big Give Challenge

Thank you to everyone who donated to The Big Give Christmas Challenge; we reached our target of £30,000.



## Ride Scorpion

Participants in the 2023 Ride Scorpion event raised over £26,000. This is a fun cycling event in aid of SMA UK, taking participants through the beautiful Cotswolds countryside covering approximately 65 miles!



## BBC Radio 4 Chirpy Appeal

We were selected to take part in the BBC Radio 4 Appeal Broadcast in August 2023, during SMA Awareness Month. Our appeal first aired on Sunday, 20th August, and was available for worldwide listening. The appeal raised £15,000 while significantly increasing awareness.

Matt Chorley, a Times journalist and broadcaster with two cousins living with SMA and a long-term supporter of SMA UK's work, presented our appeal.



## Trustee Gala Dinner

On 16th May 2023, SMA UK's Trustees hosted "An Evening with Sir Richard Dearlove OBE" at the De Vere Grand Connaught Rooms in London, raising £110,000 for SMA UK.

Over 180 guests listened to Sir Richard Dearlove, former head of MI6, discuss global issues. The event also featured personal stories from SMA advocates, including Portia Thorman and Toby Mildon.

## Plans for 2024/25

With the charity's 40th anniversary approaching we will look at ways of maximising income and engagement with the SMA community and our partners.

We will continue to highlight the importance regular gifts make, as well as offering exciting challenge events and fundraising campaigns to our supporters.



# **DIGITAL COMMUNICATIONS UPDATE**

## SMA UK has a face lift!

The needs of the SMA community are ever changing and we felt that our website, which is our main communication window, needed to deliver information clearly as well as being a platform where the SMA community's voices can be seen and heard, centre stage.

As the decision was made to develop our website, we felt it was also the right time to incorporate a brand refresh in line with the new site.

It was important that we gave the brand a refresh rather than change it completely and wanted a design that represented the charity's mission as a forward thinking, modern and agile one, that can be trusted and recognised as the lead voice for all people living with SMA and their families.

So that we made sure we met the needs of the SMA community within the website and branding, we created a Website Development Committee consisting of a range of people living with SMA, their families, supporters of the charity and staff. The result is a brand and website that has incorporated their valuable feedback and we are very grateful for their input.

In August 2023 we launched the new website along with our new strapline, Supporting, Informing and Advocating which highlights the work we do alongside the SMA community and are areas that we continue to build on as a charity.



### Old Logo



*spinal  
muscular  
atrophy uk*

### New Logo



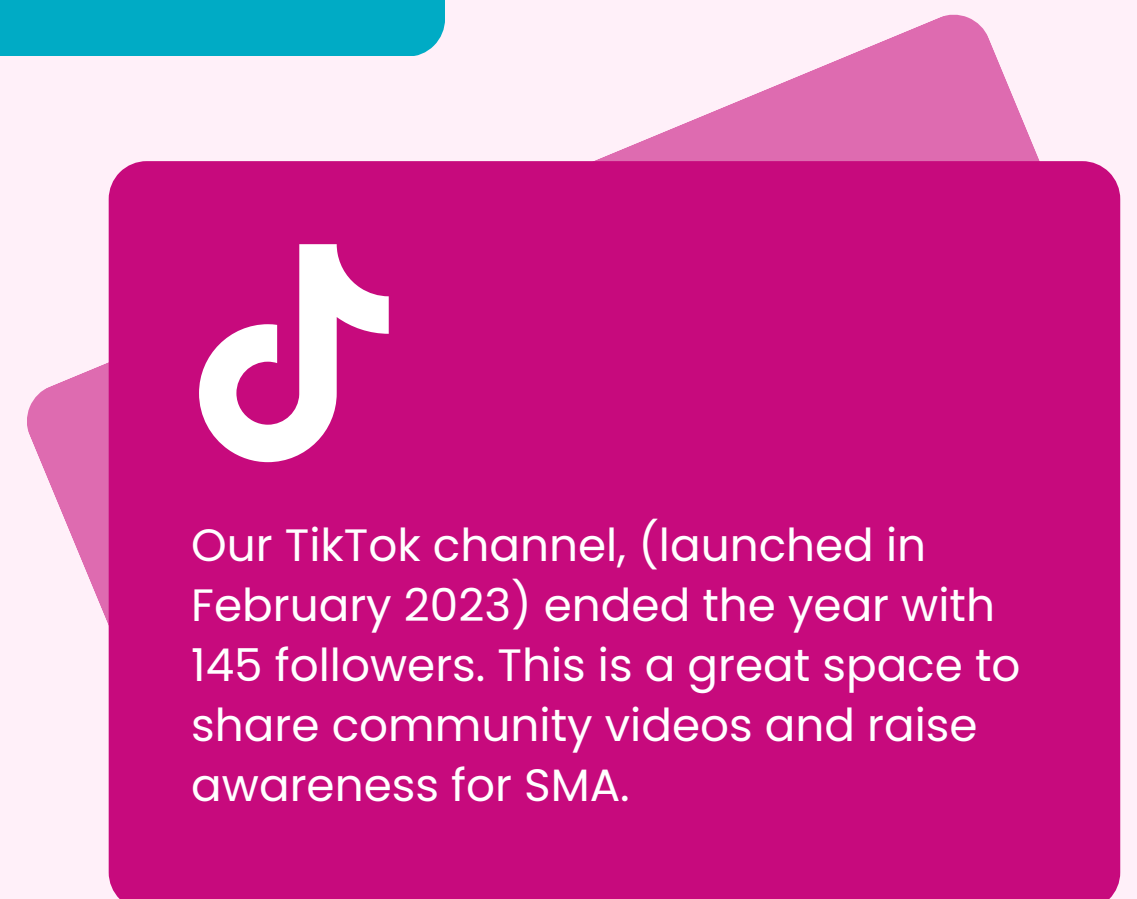
**Spinal  
Muscular  
Atrophy uk**

## Social media update

The implementation of the brand refresh through our social media channels has boosted engagement and reach. In the last year our Facebook, Twitter and Instagram followers increased by 20%.

### In 2024/25 we plan to:

In 2024/25, we will look to increase followers across all social media platforms as a means of engagement and information sharing with the SMA community, leveraging our growing online presence to create meaningful connections and drive collaboration within the community.



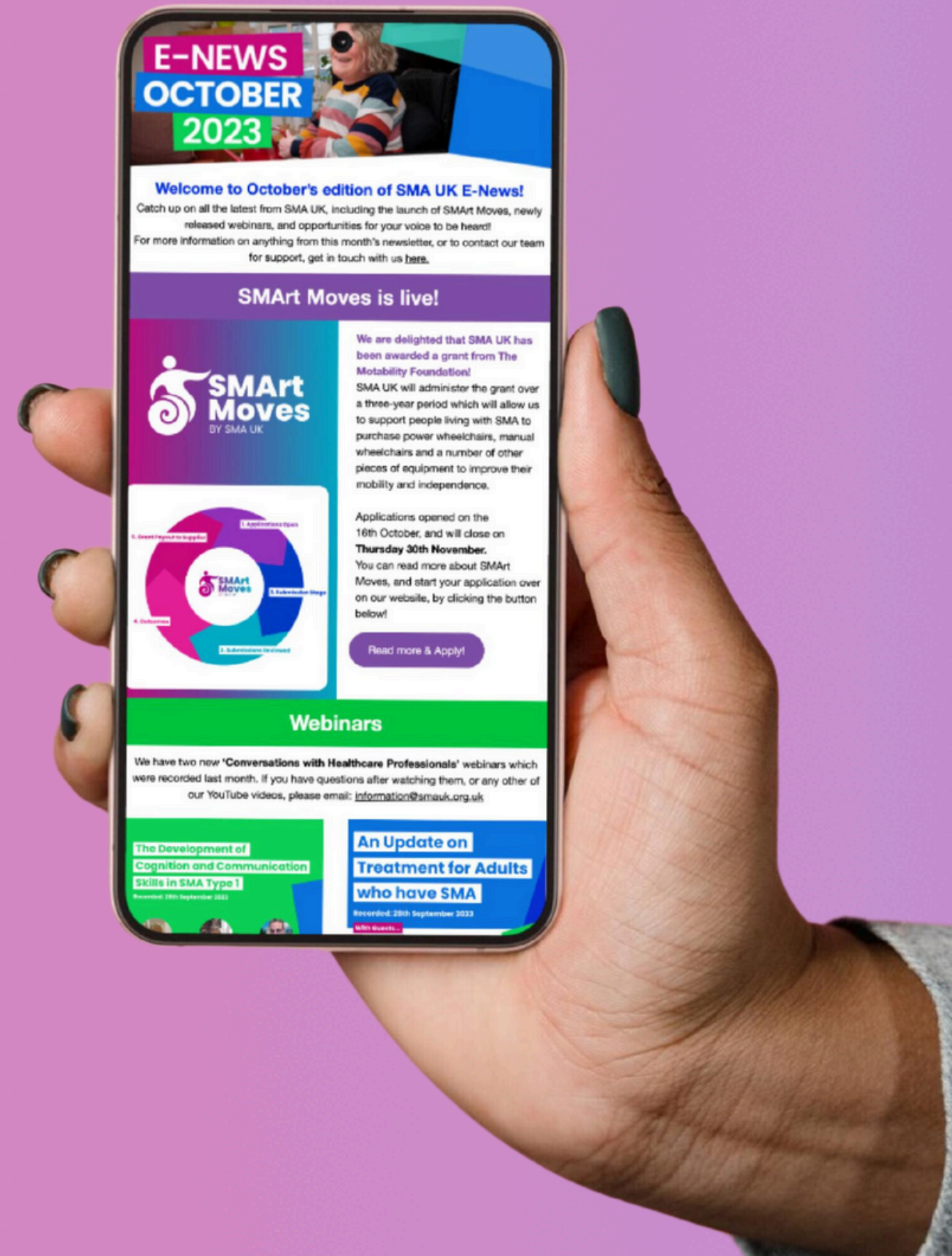




### SMA Matters and e-newsletters

In April and September 2023, we sent out our bi-annual update magazine, SMA Matters. This publication, along with our monthly e-newsletter, serves as a vital platform for us to share the latest and most significant news and information about all things SMA with the community and their networks.

Through these communications, we strive to keep our readers informed about recent developments, research advancements, and upcoming events related to SMA. The magazine features in-depth articles, personal stories, expert opinions, and various resources to support those affected by SMA. Our goal is to ensure that everyone in our community has access to the knowledge and support they need.



**3,889**  
SMA Matters  
Subscribers

**3,736**  
E-News  
Subscribers

## YouTube

### Our YouTube Channel

In the last year, our YouTube channel subscribers grew by 39% to 334. The channel is dedicated to supporting and empowering all those affected by SMA, featuring a range of content aimed at raising awareness about SMA, providing information on the condition, and offering support to those impacted.

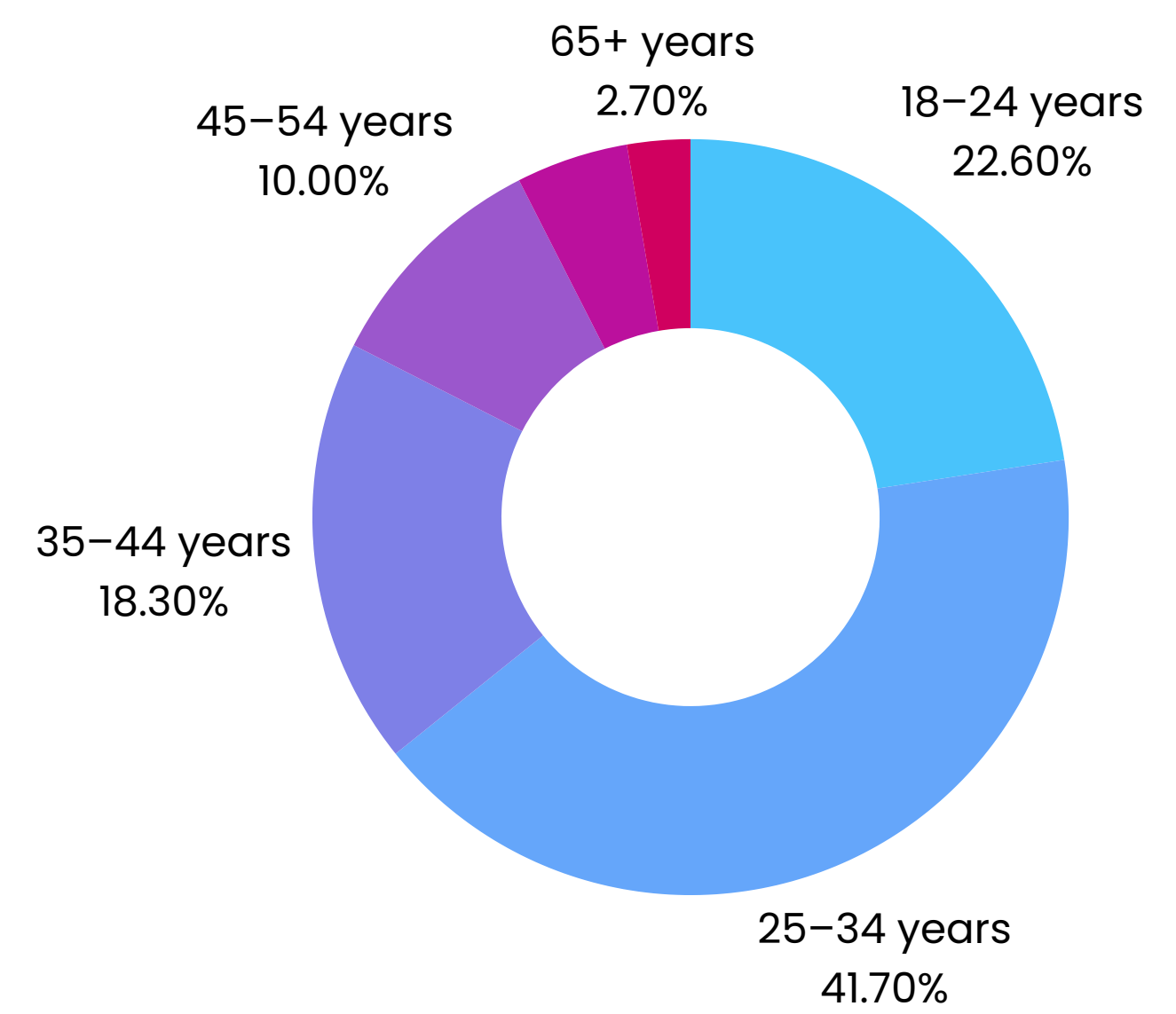
It includes educational videos explaining the causes, symptoms, and treatment options for SMA, as well as personal stories and webinars that discuss living with the condition and advancements in research and care.

### Find us on YouTube @SpinalMuscularAtrophyUK

### Our Audience

As shown in the chart to the right, the majority of our YouTube channel viewers are young adults, with the largest segment being those aged 25-34. This is followed by viewers aged 18-24, and then those in the 35-44 age group. The 45-54 age group also has a notable presence.

Older demographics are less represented, with fewer viewers aged 55-64 and even fewer aged 65 and above. Notably, there are no viewers in the 13-17 age range.





# OPERATIONS UPDATE

[smauk.org.uk](http://smauk.org.uk)

## Our Enhanced Systems

Following on from last year's database upgrade to a customer relationship platform we are now deployed fully and reaping the benefits from the upgrade. We also used the change as an opportunity to increase the number of constituents we can work with on the platform, helping SMA UK with more capacity and retained working historical knowledge of our community.

## Streamlining Operations and Office Strategy

Our IT & Operations department have dived head-long into bringing the automation of some of SMA UK's basic business processes into the 2020s. Our plan is to use the technological automation available to us through Microsoft 365's office tools. This means that new and established staff can all work to common standards of operation across business apps and utilities. We've started with the automation of processes such as expense claiming as well as the charity's financial budgeting processes.

After some due-diligence and cost analysis, the decision was taken to double-down on our existing office space facilities for the foreseeable future. This has given the planning of physical resources a green light to cover the future needs of both office-based and remote home-based staff. It has also allowed for timely renewals of some operational contracts with suppliers affording us good efficiencies over expenditure.

## Long-Term IT Infrastructure Strategy

Our strategy of IT-for-Staff is also ear-marked to begin this year. We plan to embark upon a multi-year strategy to refresh technology used by staff across the board, starting with replacement of our oldest units where needs are justified. The refresh cycle is expected to take up to four years which will mean costs can be kept low each year whilst still delivering on areas of the charity's infrastructure most in need.



### Staff Team

As of April 2023 - March 2024

#### Giles Lomax

C.E.O

#### Portia Thorman

Advocacy Lead

#### Michele Phillips

Outreach and Support Coordinator

#### Claire Holdcroft

Outreach Worker

#### Jo Spicer

Outreach Worker

#### Becci Howell

Outreach Worker

#### Nicola Beer

Outreach Worker

#### Ally Allen

Community Grants Officer

#### Luis Canto E Castro

Community Services Lead

#### Gary Edgecombe

Community Services Assistant

#### Liz Ryburn

Information & Support Coordinator

#### Libby Roper

Communications & Support

#### Lucy De'Lemos

Head of Fundraising & Communications

#### Yvonne Wright

Fundraising Administrator

#### Rebecca Lewis

Fundraising Manager

#### Stacey Shillingford

Trust Fundraiser

#### Bec Noy

Digital Communications Officer

#### Lorna Penning

Finance Officer

#### Martin Penning

Operations, Database, Security

#### Dr James Sleigh

Scientific Research Correspondent

#### Vanessa Christie-Brown

Research Coordinator

# With special thanks to :

**SMA  
EUROPE**

**MUSCULAR  
DYSTROPHY  
UK** | OUR MUSCLES  
MATTER



**SMAREACH UK**

ADULT  
**SMAREACH**



Address: Unit 9, Shottery Brook Office Park, Timothy's Bridge Road,  
Stratford-Upon-Avon, Warwickshire, CV37 9NR  
office@smauk.org.uk | 01789 267520

Registered Charity Number 1106815

## Our Trustees

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Yvette Edwards  
Michael Collins  
Ross Hovey  
Julian Fiorentini  
Ben Morris  
Tim Sheffield

01789 267 520  
office@smauk.org.uk  
smauk.org.uk

