

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 Aspinall, 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, appearing 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 and a young girl are standing in a park. The woman is smiling and looking towards the camera. The girl is looking off to the side. They are both wearing denim jackets. The background is a blue-tinted image of a park with trees and a path.

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."

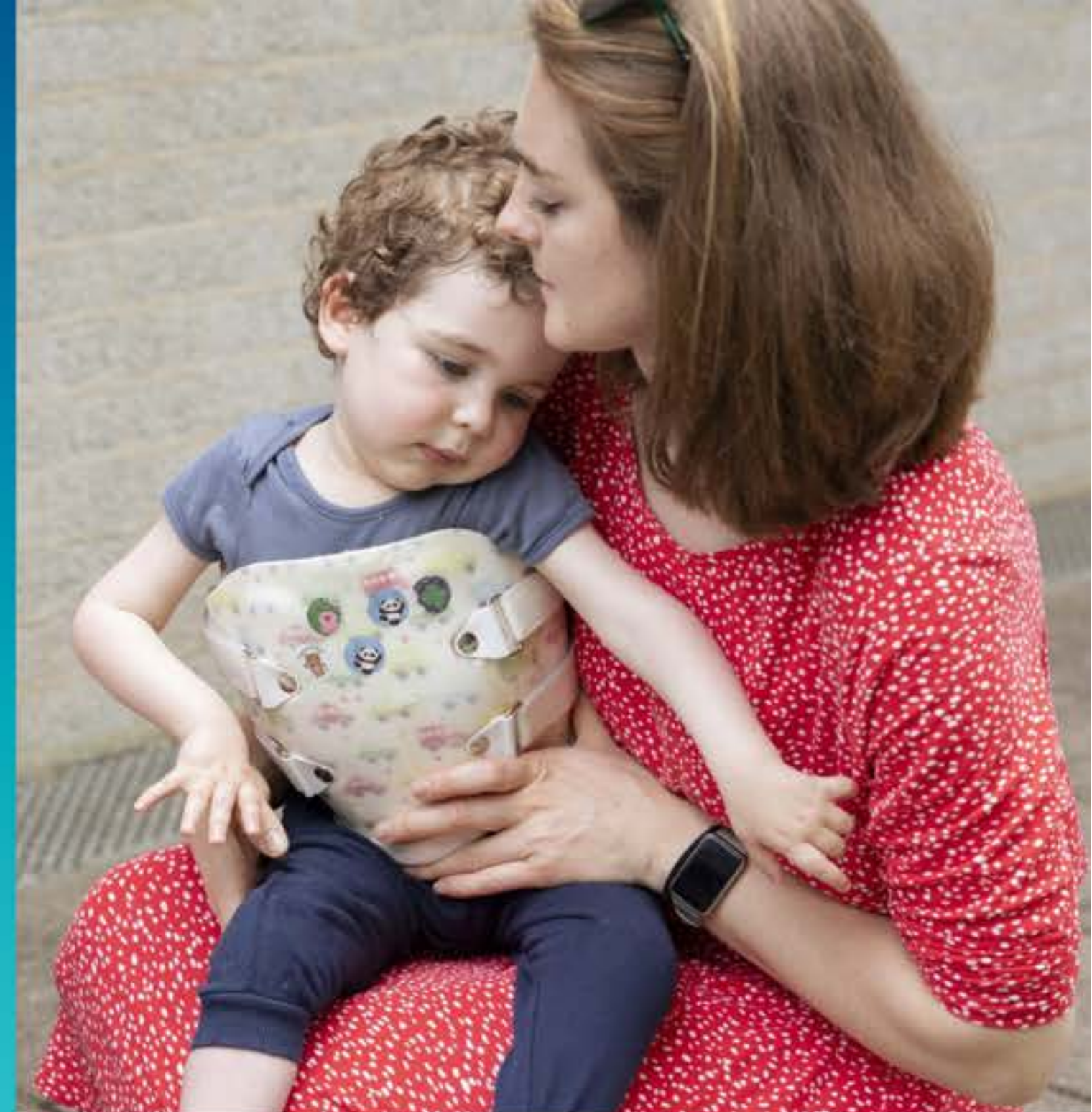
[The Generation Study](#) will sequence the genomes of 100,000 newborns to look for a specific set of rare genetic conditions that affect babies and can be acted on.

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.

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.



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

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.

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 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.

1236

Podcast
Downloads

116

New Subscribers
+51%

1.2K

Watch Time
+124%

31K

Views
+89%



22

Adults

25

Teenagers

86

Families

39

Young Adults



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. They are both wearing white t-shirts with the Spinal Muscular Atrophy UK logo, which features a blue and pink swirl icon and the text 'spinal Muscular Atrophy UK'. The woman on the left is older with blonde hair tied back, wearing a watch and a bracelet. The woman on the right is younger with blonde hair, wearing sunglasses on her head and a red scrunchie. The background shows a grassy field and some 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



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/

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 it's 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



Treatment Updates from Health Professionals

Sept 2023	Update on Treatments for Adults
Jan 2024	Update on Zolgensma in the UK

Conversations with Health Professionals

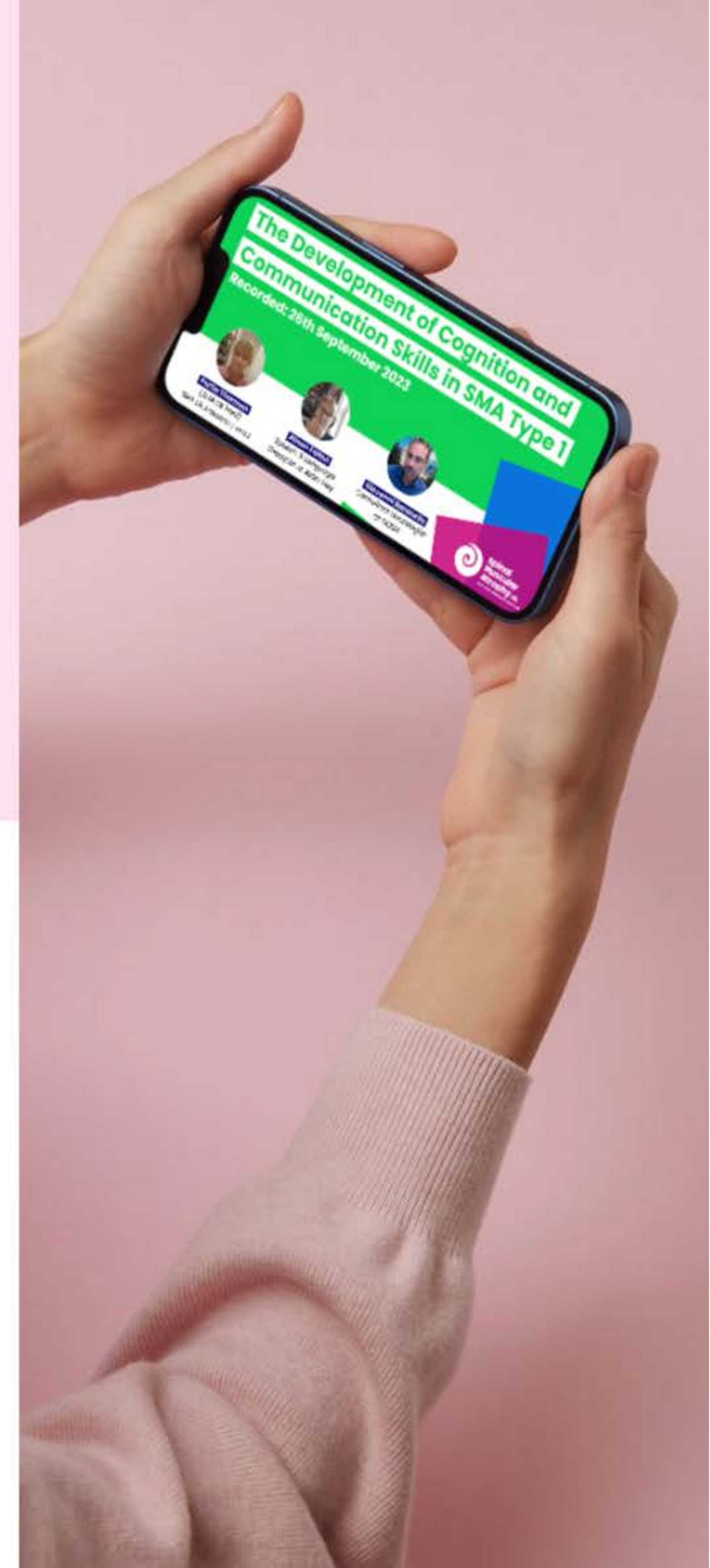
July 2023	Diet and Nutrition
Oct 2023	Exercise and SMA
Oct 2023	The Development of Cognition and Communication Skills in SMA Type 1

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.





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

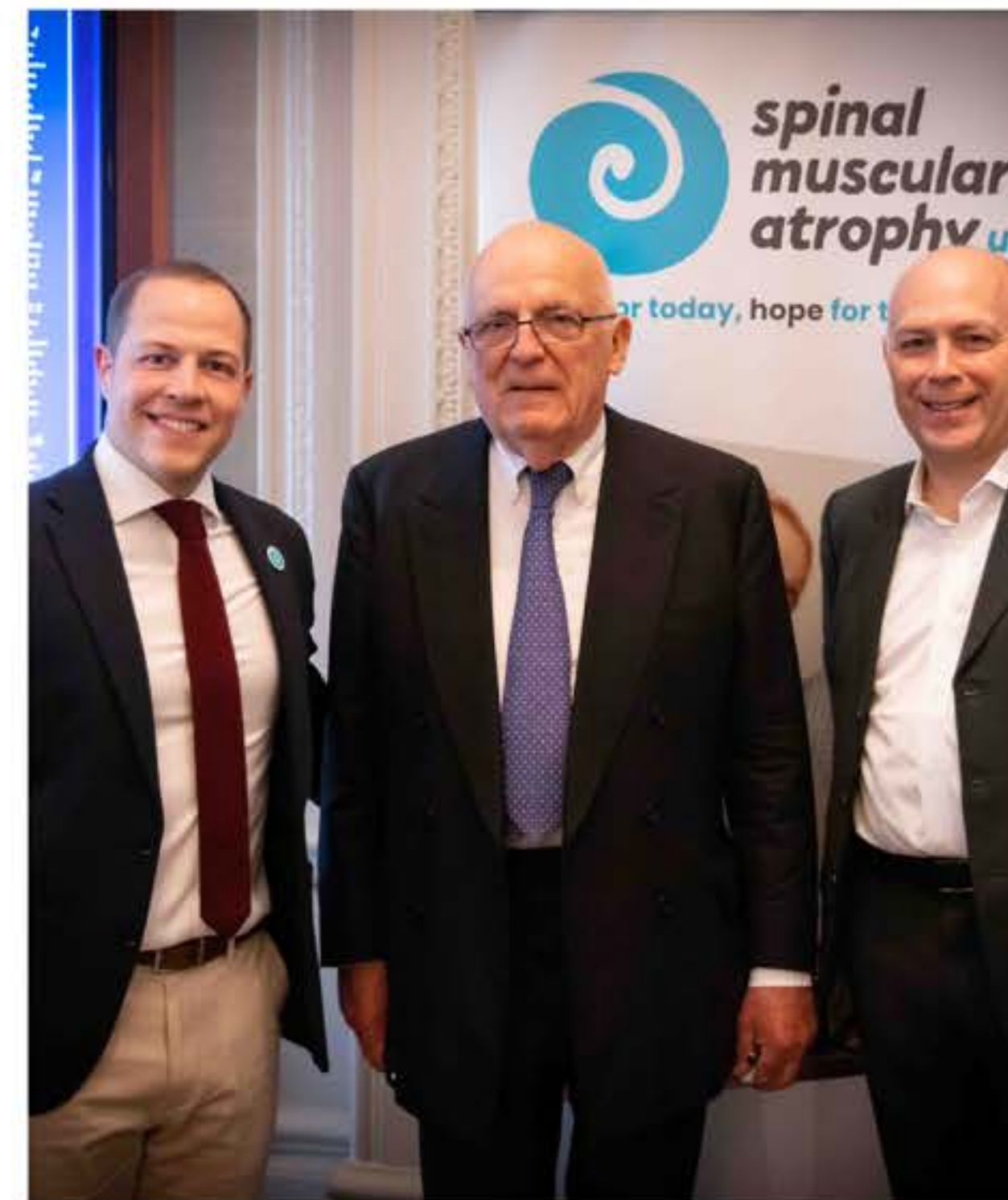
Participants in the 2023 Ride Scorpion event raised over £26,000. This is a fun cycling event in aid of SMA UK, taking participants through the beautiful Cotswolds countryside covering approximately 65 miles!



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.



Our TikTok channel, (launched in February 2023) ended the year with 145 followers. This is a great space to share community videos and raise awareness for SMA.



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



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.

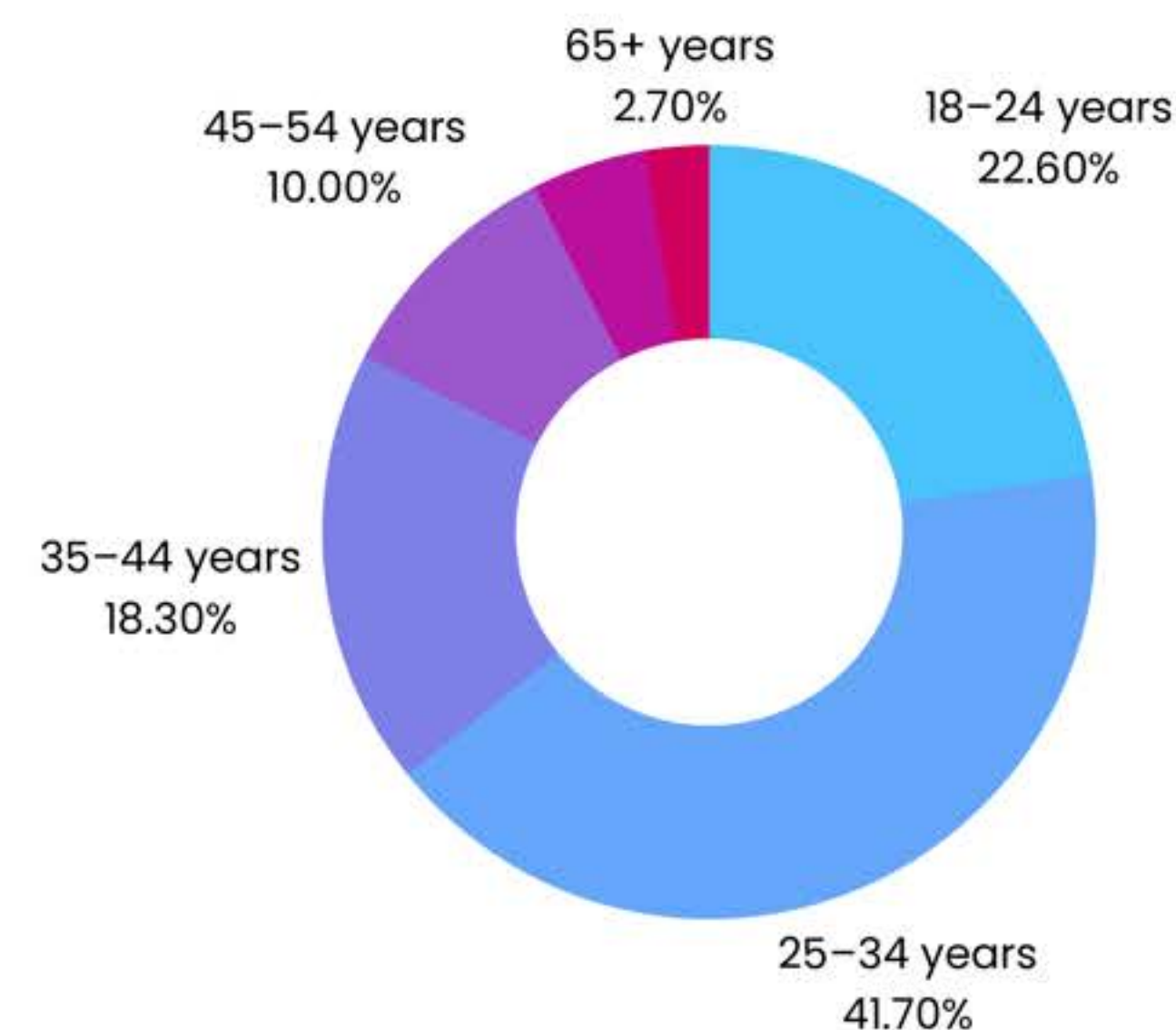
It includes educational videos explaining the causes, symptoms, and treatment options for SMA, as well as personal stories and webinars that discuss living with the condition and advancements in research and care.

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

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

Mark Dearlove, Chair of Trustees
Katharine Jackson, Treasurer
Prof. Kevin Talbot, Senior Advisor to the Board
Casimir Knight
Deborah Waltier
Toby Mildon
Srin Madipalli
Dr. Anne-Marie Childs
Dr Ros Quinlivan
Lauren West
Dr. Alistair Emslie-Smith (MBE)
Yvette Edwards
Michael Collins
Ross Hovey
Julian Fiorentini
Ben Morris
Tim Sheffield

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





FINANCIAL REVIEW

2023– 2024

TREASURERS REPORT

For the Year Ended 31 March 2024

Income for the year was £1,264k an increase of 3.7% on the prior year. This was driven primarily by a £239k grant from the Motability Foundation to provide a 3 year programme of wheelchair and mobility equipment support for people living with SMA. The charity also benefited from a large one off legacy and the National Lotteries Grant of £137k.

The total pharmaceutical funding received during the year was £161k the majority of which is restricted for SMA Care. Pharmaceutical funding was 13% of total income compared to 34% in the prior year.

Specific donation received in 2023/4 were Roche £110k, Novartis £31k, Biogen £15k, Pfizer £5k. We are committed to transparency on pharmaceutical funding and ensure that we do not accept funding from any party if we feel it will place the charity under undue pressure to act in a way that does not support or compromises our charitable objectives or independence.

SMA UK's spending is broadly divided between information provision, support and research – our charitable purpose – and fundraising and administration. We aim to maximise spending on our core purpose and ensure that other costs are carefully monitored. This year, expenditure on fundraising has increased by £34k or 20% due largely to one off expenditure required to run a fundraising event which raised £103k and produced a profit of £81k.

Overall, there has been an increase in expenditure in the year of £80k or 9%. The proportion of SMA UK costs that were spent on its charitable purpose, our value or pence in the pound, was 68p with the majority of resources focused on the provision of support to the SMA community and research.

Our net income for 2023/24 was a surplus of £326k compared to £67k in the prior year. The majority of the 2023/4 surplus relates to restricted funds provided by Motability for the 3 year equipment programme, Pharmaceutical support for SMA Care and various community engagement projects. The surplus is therefore committed to services to be provided in 2024/5 and subsequent years. As a result, SMA UK has finished the year with a strong cash position of £965k, £387k of which is restricted. The charity is operating within its reserves policy and the board will continue to monitor activities and reserves very carefully.



A handwritten signature in black ink, appearing to read 'K Jackson'.

Katharine Jackson
Treasurer

REPORT OF THE TRUSTEES

For the Year Ended 31 March 2024

The trustees present their report with the financial statements of the charity for the year ended 31 March 2024.

The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

As stated in its Memorandum and Articles of Association, Spinal Muscular Atrophy Support UK is established for:

- The relief of people living with Spinal Muscular Atrophy and related medical conditions;
- The relief of persons who are in need after experiencing a bereavement or loss due to Spinal Muscular Atrophy; and
- The promotion of research into the causes and treatment of Spinal Muscular Atrophy.

Public benefit

The Trustees confirm that they have referred to the guidance contained in the Charity Commission's General Guidance on Public Benefit when reviewing the Charity's aims and objectives and in planning future activities.

ACHIEVEMENT AND PERFORMANCE

A detailed overview of the charity achievements and performance can be found in the Annual report 2024

Future plans

We will continue to: advocate for access to the new drug treatments, representing the views of the SMA Community to regulatory authorities and pharmaceutical companies; monitor the roll out of NHS programmes and pharmaceutical initiatives supporting individuals seeking access. We will continue to provide and further develop our information, outreach and support services and opportunities for people in the SMA Community to connect with each other. Our fundraising efforts will need to achieve income levels that will enable us to achieve our goals. We will continue to adapt our working practices to ensure they are safe for both the SMA Community and our staff and trustees.

FINANCIAL REVIEW

Financial position

See Treasurers Report from Katharine Jackson, Treasurer.

Investment policy

No investments are currently held by the Charity.

The investment policy is reviewed annually.

Reserves policy

Restricted reserves will always be applied in accordance with the Trust/donor's award specification. Where there is no specific budget, an element or general (core) overheads will be recovered against those reserves. The percentage recovery date is a matter of judgement; however, costs allocated will be reasonable, proportionate, justifiable and transparent.

Unrestricted cash reserves should be not less than three months of unrestricted expenditure, based on the most recent three-months of unrestricted expenditure.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The Charity is governed by its Memorandum and Articles of Association and constitutes a company limited by guarantee.

Appointment of Trustees

Trustees are recruited as required to fill specific gaps and to complement the management experience of the Board of Trustees. Appointments are made in accordance with the Articles of Association, after the appointment has been approved by the resolution of Trustees.

Organisational structure

All policy, strategy and financial decisions relating to the Charity have to be formally approved by the Board of Directors. The Board meets six times a year on a bi-monthly basis. Three of these meetings are held at the charity's offices in Stratford upon Avon, alternating with meetings held by telephone conferencing.

Risk management

The Trustees have a duty to identify and review the risks to which the Charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

The Trustees carried out regular reviews of the key risks affecting the Charity in the course of the year and took appropriate action.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number

1106815

Principal address

Unit 9 Shottery Brook Office Park
Timothy's Bridge Road
Stratford upon Avon
Warwickshire
CV37 9NR

Trustees

T J D Sheffield (resigned 22.11.23)
C S B Knight (resigned 22.11.23)
Mrs D J Waltier (resigned 22.11.23)
Dr R Quinlivan
T J Mildon
M T Dearlove
Mrs K M Jackson
M P Collins
B M O Morris (resigned 22.11.23)
Ms L E J West
Dr A M E Smith
Dr A M Childs
Mrs K Y Edwards
J M Fiorentini
S Madipalli
Miss C M Gray (resigned 3.10.23)
Mrs T J B Burnley (appointed 22.11.23)
B H Williams (appointed 22.11.23)
Mrs M M Aspinall (appointed 22.11.23)
Mrs J E Sheehan (appointed 22.11.23)
R S Hovey (appointed 22.11.23)

Auditors

Cooper Adams Ltd
Chartered Accountants and Statutory Auditors
12 Payton Street
Stratford upon Avon
Warwickshire
CV37 6UA

Patrons

Professor V Dubowitz

TRUSTEES' RESPONSIBILITY STATEMENT

The trustees are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) including Financial Reporting Standard 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland".

The law applicable to charities in England and Wales, the Charities Act 2011, Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period. In preparing those financial statements, the trustees are required to

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charity SORP;
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the board of trustees on 14 June 2024 and signed on its behalf by:

A handwritten signature in black ink, appearing to read 'M T Dearlove'.

M T Dearlove - Trustee



REPORT OF THE INDEPENDENT AUDITORS TO THE TRUSTEES OF SPINAL MUSCULAR ATROPHY UK

Opinion

We have audited the financial statements of Spinal Muscular Atrophy UK (the 'charity') for the year ended 31 March 2024 which comprise the Statement of Financial Activities, the Statement of Financial Position, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies.

The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

In our opinion the financial statements:

- Give a true and fair view of the state of the charity's affairs as at 31 March 2024 and of its incoming resources and application of resources, for the year then ended;
- Have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'; and
- Have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- The information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- Sufficient accounting records have not been kept; or
- The financial statements are not in agreement with the accounting records and returns; or
- We have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Trustees' Responsibilities Statement, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists.

Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



For and on behalf of Cooper Adams Ltd
Chartered Accountants and Statutory Auditors
12 Payton Street
Stratford upon Avon
Warwickshire
CV37 6UA
14 June 2024

STATEMENT OF FINANCIAL ACTIVITIES

for the Year Ended 31 March 2024

		Unrestricted	Restricted	2024 Total	2023 Total
INCOME AND ENDOWMENTS FROM	Notes	funds £	funds £	funds £	funds £
Donations and legacies	2	624,113	629,526	1,253,639	918,342
Other trading activities	3	3,755	-	3,755	5,743
Investment income	4	6,459	-	6,459	588
Total		634,327	629,526	1,263,853	924,673
EXPENDITURE ON Raising funds	5	203,390	-	203,390	169,411
Charitable activities Provision of support	6	261,941	321,855	583,796	601,569
Governance costs		92,671	-	92,671	64,973
Research related activity		45,745	12,258	58,003	21,570
Total		603,747	334,113	937,860	857,523
NET INCOME		30,580	295,413	325,993	67,150
RECONCILIATION OF FUNDS Total funds brought forward		564,980	91,334	656,314	589,164
TOTAL FUNDS CARRIED FORWARD		595,560	386,747	982,307	656,314

STATEMENT OF FINANCIAL POSITION

31 March 2024

	Notes	Unrestricted Funds £	Restricted Funds £	2024 Total Funds £	2023 Total Funds £
FIXED ASSETS					
Tangible Assets	11	8,762	-	8,762	7,037
CURRENT ASSETS					
Stocks	12	5,628	-	5,628	5,791
Debtors	13	25,598	-	25,598	36,117
Cash at bank and in hand		578,567	386,747	965,314	628,044
Total		609,793	386,747	996,540	669,952
CREDITORS					
Amounts falling due within one year	14	(22,995)	-	(22,995)	(20,675)
NET CURRENT ASSETS		586,798	386,747	973,545	649,277
TOTAL ASSETS LESS CURRENT LIABILITIES		595,560	386,747	982,307	656,314
NET ASSETS		595,560	386,747	982,307	656,314
FUNDS					
Unrestricted funds: General Fund				595,560	564,980
Restricted funds: Various Funds				386,747	91,334
TOTAL FUNDS				982,307	656,314

The financial statements were approved by the Board of Trustees and authorised for issue on 14 June 2024 and were signed on its behalf by:



K M Jackson - Trustee



M T Dearlove - Trustee

STATEMENT OF CASH FLOWS

for the Year Ended 31 March 2024

	Notes	2024 £	2023 £
Cash flows from operating activities			
Cash generated from operations	1	336,003	38,646
Net cash provided by operating activities		336,003	38,646
Cash flows from investing activities			
Purchase of tangible fixed assets		(5,192)	(2,395)
Interest received		6,459	588
Net cash provided by/(used in) investing activities		1,267	(1,807)
Change in cash and cash equivalents in the reporting period		337,270	36,839
Cash and cash equivalents at the beginning of the reporting period		628,044	591,205
Cash and cash equivalents at the end of the reporting period		965,314	628,044

NOTES TO THE STATEMENT OF CASH FLOWS

for the Year Ended 31 March 2024

1. RECONCILIATION OF NET INCOME TO NET CASH FLOW FROM OPERATING ACTIVITIES

	2024 £	2023 £
Net income for the reporting period (as per the Statement of Financial Activities)	325,993	67,150
Adjustments for:		
Depreciation charges	3,467	3,473
Interest received	(6,459)	(588)
Decrease in stocks	163	494
Decrease/(increase) in debtors	10,519	(20,878)
Increase/(decrease) in creditors	2,320	(11,005)
Net cash provided by operations	336,003	38,646

2. ANALYSIS OF CHANGES IN NET FUNDS

Net Cash	At 1.4.23 £	Cash flow £	At 31.3.24 £
Cash at bank and in hand	628,044	337,270	965,314
Total	628,044	337,270	965,314

NOTES TO THE FINANCIAL STATEMENTS

for the Year Ended 31 March 2024

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Office equipment	- 10 - 20% on cost
Computer equipment	- 25% straight line basis

Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular purposes.

2. DONATIONS AND LEGACIES

	2024 £	2023 £
Donations and gifts	717,901	759,199
Legacies	159,944	5,312
Motability	238,500	-
The National Lottery Community Fund	137,294	153,831
	1,253,639	918,342

3. OTHER TRADING ACTIVITIES

	2024 £	2023 £
Merchandise Sales	3,755	5,743

4. INVESTMENT INCOME

	2024 £	2023 £
Bank Interest	6,459	588

5. RAISING FUNDS

Raising Donations and Legacies	2024 £	2023 £
Staff Costs	137,965	133,680
Fundraising and publicity	26,826	21,090
Events and promotions	33,953	12,304
Cost of merchandise sales	4,646	2,337
	203,390	169,411

6. CHARITABLE ACTIVITIES COSTS

Provision of Support	2024 £	2023 £
Staff Costs and other expenses	337,154	373,414
Information and awareness raising	19,722	34,641
Shared experience network	13,783	24,045
Outreach service	77,482	48,285
Welfare and equipment grants	135,655	121,184
	583,796	601,569

Research Related Activity	2024 £	2023 £
Staff costs and other expenses	42,412	18,093
Medical research grants	6,729	-
Other research activities	8,862	3,477
	58,003	21,570

7. SUPPORT COSTS

	Management £
Governance costs	92,671

	2024 £	2023 £
Staff costs and other expenses	75,039	51,285
Professional fees and bank charges	7,311	6,478
Other costs	10,321	7,210
	92,671	64,973

8. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2024 nor for the year ended 31 March 2023.

Trustees' expenses

There were no trustees' expenses reimbursed for the year ended 31 March 2024 (2023: £nil).
Payments in respect of trustee indemnity insurance amounted to £438 (2023: £398).

9. STAFF COSTS

	2024 £	2023 £
Wages and salaries	483,714	461,860
Social Security costs	41,460	43,784
Pension	21,884	20,476
	547,058	526,120

The average monthly number of employees during the year was as follows:

	2024	2023
Management and administration	1	1
Direct charitable expenditure	12	10
Fundraising and publicity	5	5
	18	16

We also engaged contractors in 2024 to assist us with our management and administration 1.2 FTE.

No employees received emoluments in excess of £60,000 (2023: None)

10. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

INCOME AND ENDOWMENTS FROM	UNRESTRICTED FUNDS £	RESTRICTED FUNDS £	TOTAL FUNDS £
Donations and legacies	423,127	495,215	918,342
Other trading activities	5,743	-	5,743
Investment income	588	-	588
Total	429,458	495,215	924,673
EXPENDITURE ON			
Raising funds	169,411	-	169,411
Charitable activities			
Provision of support	157,878	443,691	601,569
Governance costs	64,973	-	64,973
Research related activity	20,686	884	21,570
Total	412,948	444,575	857,523
NET INCOME	16,510	50,640	67,150
Transfers between funds	(367)	367	-
Net movement in funds	16,143	51,007	67,150
RECONCILIATION OF FUNDS			
Total funds brought forward	548,837	40,327	589,164
TOTAL FUNDS CARRIED FORWARD	564,980	91,334	656,314

11. TANGIBLE FIXED ASSETS

COST	Office equipment £	Computer equipment £	Totals £
At 1 April 2023	2,554	20,863	23,417
Additions	-	5,192	5,192
At 31 March 2024	2,554	26,055	28,609
DEPRECIATION			
At 1 April 2023	1,550	14,830	16,380
Charge for year	158	3,309	3,467
At 31 March 2024	1,708	18,139	19,847
NET BOOK VALUE			
At 31 March 2024	846	7,916	8,762
At 31 March 2023	1,004	6,033	7,037

12. STOCKS

	2024 £	2023 £
Stocks held for re-sale	5,628	5,791

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024 £	2023 £
Prepayments and accrued income	25,598	36,117

14. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024 £	2023 £
Taxation and social security	16,273	14,555
Other creditors	6,722	6,120
	22,995	20,675

15. LEASING AGREEMENTS

Minimum lease payments under non-cancellable operating leases fall due as follows:

	2024 £	2023 £
Within one year	15,000	20,094
Between one and five years	7,500	22,500
	22,500	42,594

16. MOVEMENT IN FUNDS

	At 1.4.23 £	Net movement in funds £	At 31.3.24 £
Unrestricted funds			
General fund	564,980	30,580	595,560
Restricted funds			
Various funds	91,334	295,413	386,747
TOTAL FUNDS	656,314	325,993	982,307

16. MOVEMENT IN FUNDS – CONTINUED

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	634,327	(603,747)	30,580
Restricted funds			
Various funds	629,526	(334,113)	295,413
TOTAL FUNDS	1,263,853	(937,860)	325,993

Comparatives for movement in funds

	At 1.4.22 £	Net movement in funds £	Transfers between funds £	At 31.3.23 £
Unrestricted funds				
General fund	548,837	16,510	(367)	564,980
Restricted funds				
Various funds	40,327	50,640	367	91,334
TOTAL FUNDS	589,164	67,150	-	656,314

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	429,458	(412,948)	16,510
Restricted funds			
Various funds	495,215	(444,575)	50,640
TOTAL FUNDS	924,673	(857,523)	67,150

16. MOVEMENT IN FUNDS – CONTINUED

A current year 12 months and prior year 12 months combined position is as follows:

	At 1.4.22 £	Net movement in funds £	Transfers between funds £	At 31.3.23 £
Unrestricted funds				
General fund	548,837	47,090	(367)	595,560
Restricted funds				
Various funds	40,327	346,053	367	386,747
TOTAL FUNDS	589,164	393,143	-	982,307

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	1,063,785	(1,016,695)	47,090
Restricted funds			
Various funds	1,124,741	(778,688)	346,053
TOTAL FUNDS	2,188,526	(1,795,383)	393,143

16. MOVEMENT IN FUNDS – CONTINUED**Statement of funds**

	Balance b/f at 1.4.23 £	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds				
General fund	564,980	634,326	(603,746)	595,560
Restricted funds				
Toy Packs	500	1,675	(2,175)	-
Community Information Webinars	-	5,000	-	5,000
Motability	-	238,500	(110,639)	127,861
SMA Care UK Grant	-	67,354	-	67,354
Community Engagement	-	47,350	-	47,350
UK SMA Newborn Screening Alliance	5,398	15,974	(21,373)	-
SMA Horizons Project	763	(560)	(203)	-
Working with the SMA Community	68,399	137,294	(144,189)	61,504
Website & Digital Comms Development	6,274	-	(6,274)	-
Support Services	-	40,950	(38,930)	2,020
PhD Scholarship Yr2	10,000	-	(6,730)	3,270
SMA and Me Books	-	15,000	(3,600)	11,400
Know No Bounds	-	30,255	-	30,255
Content and Web Development	-	30,733	-	30,733
Total Restricted Funds	91,334	629,526	(334,113)	386,747
TOTAL FUNDS	656,314	1,263,852	(937,859)	982,307

Analysis of net assets between funds

Fund balances at 31 March 2024 are represented by:	UNRESTRICTED FUNDS £	RESTRICTED FUNDS £	TOTAL FUNDS £
Tangible fixed assets	8,762	-	8,762
Stock	5,628	-	5,628
Debtors	25,598	-	25,598
Bank and cash	578,568	386,747	965,315
Current liabilities	(22,996)	-	(22,996)
Total net assets	595,560	386,747	982,307

16. MOVEMENT IN FUNDS – CONTINUED



Toy Packs

Our multi-sensory toy packs are available free of charge to families in the UK for newly diagnosed children. They include items that provide visual, tactile and auditory stimulation. They have been designed to offer entertainment during the day, fun at bath time and comfort at bedtime. They are suitable for infants aged up to 12 months of age.

Community Information Webinars

We ask expert health, education and social care professionals questions on topics of interest and concern to the SMA Community such as on treatments, diet and exercise. These popular webinars hosted by a community member provide easy access to important up-to-date and accurate information.



Motability

SMA UK were awarded a 3 year 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.

SMA Care UK Grant

The SMA Care UK project will bring together members of the SMA community and a range of health care and other professions to update the guidance outlined in Standards of Care (2018) and ensure it is relevant and meaningful to those living with SMA in the UK today. Funding has been received and requested from trusts and industry.

Community Engagement

SMA UK received grants from trusts and pharma to support our community engagement events which included Picnics in the park and our Children's and adults resonate weekends.

UK SMA Newborn Screening Alliance

The Alliance brings together clinicians, patient groups and other stakeholders, determined to achieve the earliest possible introduction of newborn screening for SMA in the UK and in so doing deliver the best outcomes from treatment and reduce future healthcare costs. This fund supports the costs of the Project Manager, the secretariat (SMA UK and MDUK) and communications.

SMA Horizons Project

The SMART Horizon project has the goal to identify new innovation, 'out of the box' therapies for people living with SMA, especially for the chronic population. These therapies may be complementary to the existing ones that target the SMN upregulation.

Working with the SMA Community

This Fund goes towards the costs of our information, outreach and support, community development and advocacy services.



Website & Digital Comms Development

This year this fund was set up to enable the launch of a new website and branding refresh targeted for August 2023. It also increased our Communications staffing capacity, our communications reach and supported the further development of community virtual networks.

Support Services

This fund targeted any Support Services costs that were not covered by any of the other restricted funds that support this work.

16. MOVEMENT IN FUNDS – CONTINUED

PhD Scholarship Yr2

This supports our commitment to fund the 4-year research programme that aims to further understand the motor enlargement process in people who have SMA and how this might be addressed and improve treatment outcomes. It runs from 2022–2025, and is funded jointly with Muscular Dystrophy UK.

SMA and Me Books

The books 'SMA and me' were published in 2016 before disease modifying treatments changed the landscape of SMA. With input from children living with SMA, their families and their clinicians, this new resource sponsored by Biogen, will help children to understand what SMA is, how the treatments work and, importantly, why we now see so many individual differences within the SMA community.

Content and Web Development

As part of our on going website and communications development, we were awarded a grant to strengthen and facilitate Community engagement through our multimedia platforms whilst improving imagery including videos on the SMA UK website.

Know No Bounds

Two members of the SMA Community have set them self a challenge to climb Snowdonia to fundraise for SMA UK to purchase specialise off road wheelchairs therefore aiming to give more opportunities for people living with SMA to explore the great outdoors.



17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2024.

18. CHARITY STRUCTURE

On 4th August 2022 the charity changed from a 'company limited by guarantee' to a 'charitable incorporated organization'.

DETAILED STATEMENT OF FINANCIAL ACTIVITIES

for the Year Ended 31 March 2024

	2024 £	2023 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations and gifts	717,901	759,199
Legacies	159,944	5,312
Motability	238,500	-
The National Lottery Community Fund	137,294	153,831
	1,253,639	918,342
Other trading activities		
Merchandise sales	3,755	5,743
Investment income		
Bank interest	6,459	588
Total incoming resources	1,263,853	924,673
EXPENDITURE		
Raising donations and legacies		
Staff costs and other expenses	137,965	133,680
Fundraising and publicity	26,826	21,090
Events and promotions	33,953	12,304
Cost of merchandise sales	4,646	2,337
	203,390	169,411
Charitable activities		
Staff costs and other expenses	379,565	391,507
Medical research grants	6,730	378
Other research activities	8,862	3,099
Information and awareness raising	19,722	34,641
Shared experiences network	13,783	24,045
Outreach service	77,482	48,285
Welfare, equipment grants and toy packs	135,655	121,184
	641,799	623,139

	2024 £	2023 £
Support costs		
Management		
Staff costs and other expenses	75,039	51,285
Professional fees and bank charges	6,642	6,478
Other costs	10,990	7,210
	92,671	64,973
Total resources expended	937,860	857,523
Net income	325,993	67,150



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



FINANCIAL REVIEW

2023– 2024

TREASURERS REPORT

For the Year Ended 31 March 2024

Income for the year was £1,264k an increase of 3.7% on the prior year. This was driven primarily by a £239k grant from the Motability Foundation to provide a 3 year programme of wheelchair and mobility equipment support for people living with SMA. The charity also benefited from a large one off legacy and the National Lotteries Grant of £137k.

The total pharmaceutical funding received during the year was £161k the majority of which is restricted for SMA Care. Pharmaceutical funding was 13% of total income compared to 34% in the prior year.

Specific donation received in 2023/4 were Roche £110k, Novartis £31k, Biogen £15k, Pfizer £5k. We are committed to transparency on pharmaceutical funding and ensure that we do not accept funding from any party if we feel it will place the charity under undue pressure to act in a way that does not support or compromises our charitable objectives or independence.

SMA UK's spending is broadly divided between information provision, support and research – our charitable purpose – and fundraising and administration. We aim to maximise spending on our core purpose and ensure that other costs are carefully monitored. This year, expenditure on fundraising has increased by £34k or 20% due largely to one off expenditure required to run a fundraising event which raised £103k and produced a profit of £81k.

Overall, there has been an increase in expenditure in the year of £80k or 9%. The proportion of SMA UK costs that were spent on its charitable purpose, our value or pence in the pound, was 68p with the majority of resources focused on the provision of support to the SMA community and research.

Our net income for 2023/24 was a surplus of £326k compared to £67k in the prior year. The majority of the 2023/4 surplus relates to restricted funds provided by Motability for the 3 year equipment programme, Pharmaceutical support for SMA Care and various community engagement projects. The surplus is therefore committed to services to be provided in 2024/5 and subsequent years. As a result, SMA UK has finished the year with a strong cash position of £965k, £387k of which is restricted. The charity is operating within its reserves policy and the board will continue to monitor activities and reserves very carefully.



A stylized handwritten signature in dark ink.

Katharine Jackson
Treasurer

REPORT OF THE TRUSTEES

For the Year Ended 31 March 2024

The trustees present their report with the financial statements of the charity for the year ended 31 March 2024.

The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

As stated in its Memorandum and Articles of Association, Spinal Muscular Atrophy Support UK is established for:

- The relief of people living with Spinal Muscular Atrophy and related medical conditions;
- The relief of persons who are in need after experiencing a bereavement or loss due to Spinal Muscular Atrophy; and
- The promotion of research into the causes and treatment of Spinal Muscular Atrophy.

Public benefit

The Trustees confirm that they have referred to the guidance contained in the Charity Commission's General Guidance on Public Benefit when reviewing the Charity's aims and objectives and in planning future activities.

ACHIEVEMENT AND PERFORMANCE

A detailed overview of the charity achievements and performance can be found in the Annual report 2024

Future plans

We will continue to: advocate for access to the new drug treatments, representing the views of the SMA Community to regulatory authorities and pharmaceutical companies; monitor the roll out of NHS programmes and pharmaceutical initiatives supporting individuals seeking access. We will continue to provide and further develop our information, outreach and support services and opportunities for people in the SMA Community to connect with each other. Our fundraising efforts will need to achieve income levels that will enable us to achieve our goals. We will continue to adapt our working practices to ensure they are safe for both the SMA Community and our staff and trustees.

FINANCIAL REVIEW

Financial position

See Treasurers Report from Katharine Jackson, Treasurer.

Investment policy

No investments are currently held by the Charity.

The investment policy is reviewed annually.

Reserves policy

Restricted reserves will always be applied in accordance with the Trust/donor's award specification. Where there is no specific budget, an element or general (core) overheads will be recovered against those reserves. The percentage recovery date is a matter of judgement; however, costs allocated will be reasonable, proportionate, justifiable and transparent.

Unrestricted cash reserves should be not less than three months of unrestricted expenditure, based on the most recent three-months of unrestricted expenditure.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The Charity is governed by its Memorandum and Articles of Association and constitutes a company limited by guarantee.

Appointment of Trustees

Trustees are recruited as required to fill specific gaps and to complement the management experience of the Board of Trustees. Appointments are made in accordance with the Articles of Association, after the appointment has been approved by the resolution of Trustees.

Organisational structure

All policy, strategy and financial decisions relating to the Charity have to be formally approved by the Board of Directors. The Board meets six times a year on a bi-monthly basis. Three of these meetings are held at the charity's offices in Stratford upon Avon, alternating with meetings held by telephone conferencing.

Risk management

The Trustees have a duty to identify and review the risks to which the Charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

The Trustees carried out regular reviews of the key risks affecting the Charity in the course of the year and took appropriate action.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number

1106815

Principal address

Unit 9 Shottery Brook Office Park
Timothy's Bridge Road
Stratford upon Avon
Warwickshire
CV37 9NR

Trustees

T J D Sheffield (resigned 22.11.23)
C S B Knight (resigned 22.11.23)
Mrs D J Waltier (resigned 22.11.23)
Dr R Quinlivan
T J Mildon
M T Dearlove
Mrs K M Jackson
M P Collins
B M O Morris (resigned 22.11.23)
Ms L E J West
Dr A M E Smith
Dr A M Childs
Mrs K Y Edwards
J M Fiorentini
S Madipalli
Miss C M Gray (resigned 3.10.23)
Mrs T J B Burnley (appointed 22.11.23)
B H Williams (appointed 22.11.23)
Mrs M M Aspinall (appointed 22.11.23)
Mrs J E Sheehan (appointed 22.11.23)
R S Hovey (appointed 22.11.23)

Auditors

Cooper Adams Ltd
Chartered Accountants and Statutory Auditors
12 Payton Street
Stratford upon Avon
Warwickshire
CV37 6UA

Patrons

Professor V Dubowitz

TRUSTEES' RESPONSIBILITY STATEMENT

The trustees are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) including Financial Reporting Standard 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland".

The law applicable to charities in England and Wales, the Charities Act 2011, Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period. In preparing those financial statements, the trustees are required to

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charity SORP;
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the board of trustees on 14 June 2024 and signed on its behalf by:

A handwritten signature in black ink, appearing to read 'M T Dearlove'.

M T Dearlove - Trustee



REPORT OF THE INDEPENDENT AUDITORS TO THE TRUSTEES OF SPINAL MUSCULAR ATROPHY UK

Opinion

We have audited the financial statements of Spinal Muscular Atrophy UK (the 'charity') for the year ended 31 March 2024 which comprise the Statement of Financial Activities, the Statement of Financial Position, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies.

The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

In our opinion the financial statements:

- Give a true and fair view of the state of the charity's affairs as at 31 March 2024 and of its incoming resources and application of resources, for the year then ended;
- Have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'; and
- Have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- The information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- Sufficient accounting records have not been kept; or
- The financial statements are not in agreement with the accounting records and returns; or
- We have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Trustees' Responsibilities Statement, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists.

Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



For and on behalf of Cooper Adams Ltd
Chartered Accountants and Statutory Auditors
12 Payton Street
Stratford upon Avon
Warwickshire
CV37 6UA
14 June 2024

STATEMENT OF FINANCIAL ACTIVITIES

for the Year Ended 31 March 2024

		Unrestricted	Restricted	2024 Total	2023 Total
INCOME AND ENDOWMENTS FROM	Notes	funds £	funds £	funds £	funds £
Donations and legacies	2	624,113	629,526	1,253,639	918,342
Other trading activities	3	3,755	-	3,755	5,743
Investment income	4	6,459	-	6,459	588
Total		634,327	629,526	1,263,853	924,673
EXPENDITURE ON Raising funds	5	203,390	-	203,390	169,411
Charitable activities Provision of support	6	261,941	321,855	583,796	601,569
Governance costs		92,671	-	92,671	64,973
Research related activity		45,745	12,258	58,003	21,570
Total		603,747	334,113	937,860	857,523
NET INCOME		30,580	295,413	325,993	67,150
RECONCILIATION OF FUNDS Total funds brought forward		564,980	91,334	656,314	589,164
TOTAL FUNDS CARRIED FORWARD		595,560	386,747	982,307	656,314

STATEMENT OF FINANCIAL POSITION

31 March 2024

	Notes	Unrestricted Funds £	Restricted Funds £	2024 Total Funds £	2023 Total Funds £
FIXED ASSETS					
Tangible Assets	11	8,762	-	8,762	7,037
CURRENT ASSETS					
Stocks	12	5,628	-	5,628	5,791
Debtors	13	25,598	-	25,598	36,117
Cash at bank and in hand		578,567	386,747	965,314	628,044
Total		609,793	386,747	996,540	669,952
CREDITORS					
Amounts falling due within one year	14	(22,995)	-	(22,995)	(20,675)
NET CURRENT ASSETS		586,798	386,747	973,545	649,277
TOTAL ASSETS LESS CURRENT LIABILITIES		595,560	386,747	982,307	656,314
NET ASSETS		595,560	386,747	982,307	656,314
FUNDS					
Unrestricted funds: General Fund				595,560	564,980
Restricted funds: Various Funds				386,747	91,334
TOTAL FUNDS				982,307	656,314

The financial statements were approved by the Board of Trustees and authorised for issue on 14 June 2024 and were signed on its behalf by:



K M Jackson - Trustee



M T Dearlove - Trustee

STATEMENT OF CASH FLOWS

for the Year Ended 31 March 2024

	Notes	2024 £	2023 £
Cash flows from operating activities			
Cash generated from operations	1	336,003	38,646
Net cash provided by operating activities		336,003	38,646
Cash flows from investing activities			
Purchase of tangible fixed assets		(5,192)	(2,395)
Interest received		6,459	588
Net cash provided by/(used in) investing activities		1,267	(1,807)
Change in cash and cash equivalents in the reporting period		337,270	36,839
Cash and cash equivalents at the beginning of the reporting period		628,044	591,205
Cash and cash equivalents at the end of the reporting period		965,314	628,044

NOTES TO THE STATEMENT OF CASH FLOWS

for the Year Ended 31 March 2024

1. RECONCILIATION OF NET INCOME TO NET CASH FLOW FROM OPERATING ACTIVITIES

	2024 £	2023 £
Net income for the reporting period (as per the Statement of Financial Activities)	325,993	67,150
Adjustments for:		
Depreciation charges	3,467	3,473
Interest received	(6,459)	(588)
Decrease in stocks	163	494
Decrease/(increase) in debtors	10,519	(20,878)
Increase/(decrease) in creditors	2,320	(11,005)
Net cash provided by operations	336,003	38,646

2. ANALYSIS OF CHANGES IN NET FUNDS

Net Cash	At 1.4.23 £	Cash flow £	At 31.3.24 £
Cash at bank and in hand	628,044	337,270	965,314
Total	628,044	337,270	965,314

NOTES TO THE FINANCIAL STATEMENTS

for the Year Ended 31 March 2024

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Office equipment	- 10 - 20% on cost
Computer equipment	- 25% straight line basis

Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular purposes.

2. DONATIONS AND LEGACIES

	2024 £	2023 £
Donations and gifts	717,901	759,199
Legacies	159,944	5,312
Motability	238,500	-
The National Lottery Community Fund	137,294	153,831
	1,253,639	918,342

3. OTHER TRADING ACTIVITIES

	2024 £	2023 £
Merchandise Sales	3,755	5,743

4. INVESTMENT INCOME

	2024 £	2023 £
Bank Interest	6,459	588

5. RAISING FUNDS

Raising Donations and Legacies	2024 £	2023 £
Staff Costs	137,965	133,680
Fundraising and publicity	26,826	21,090
Events and promotions	33,953	12,304
Cost of merchandise sales	4,646	2,337
	203,390	169,411

6. CHARITABLE ACTIVITIES COSTS

Provision of Support	2024 £	2023 £
Staff Costs and other expenses	337,154	373,414
Information and awareness raising	19,722	34,641
Shared experience network	13,783	24,045
Outreach service	77,482	48,285
Welfare and equipment grants	135,655	121,184
	583,796	601,569

Research Related Activity	2024 £	2023 £
Staff costs and other expenses	42,412	18,093
Medical research grants	6,729	-
Other research activities	8,862	3,477
	58,003	21,570

7. SUPPORT COSTS

	Management £
Governance costs	92,671

	2024 £	2023 £
Staff costs and other expenses	75,039	51,285
Professional fees and bank charges	7,311	6,478
Other costs	10,321	7,210
	92,671	64,973

8. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2024 nor for the year ended 31 March 2023.

Trustees' expenses

There were no trustees' expenses reimbursed for the year ended 31 March 2024 (2023: £nil).
Payments in respect of trustee indemnity insurance amounted to £438 (2023: £398).

9. STAFF COSTS

	2024 £	2023 £
Wages and salaries	483,714	461,860
Social Security costs	41,460	43,784
Pension	21,884	20,476
	547,058	526,120

The average monthly number of employees during the year was as follows:

	2024	2023
Management and administration	1	1
Direct charitable expenditure	12	10
Fundraising and publicity	5	5
	18	16

We also engaged contractors in 2024 to assist us with our management and administration 1.2 FTE.

No employees received emoluments in excess of £60,000 (2023: None)

10. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

INCOME AND ENDOWMENTS FROM	UNRESTRICTED FUNDS £	RESTRICTED FUNDS £	TOTAL FUNDS £
Donations and legacies	423,127	495,215	918,342
Other trading activities	5,743	-	5,743
Investment income	588	-	588
Total	429,458	495,215	924,673
EXPENDITURE ON			
Raising funds	169,411	-	169,411
Charitable activities			
Provision of support	157,878	443,691	601,569
Governance costs	64,973	-	64,973
Research related activity	20,686	884	21,570
Total	412,948	444,575	857,523
NET INCOME	16,510	50,640	67,150
Transfers between funds	(367)	367	-
Net movement in funds	16,143	51,007	67,150
RECONCILIATION OF FUNDS			
Total funds brought forward	548,837	40,327	589,164
TOTAL FUNDS CARRIED FORWARD	564,980	91,334	656,314

11. TANGIBLE FIXED ASSETS

COST	Office equipment £	Computer equipment £	Totals £
At 1 April 2023	2,554	20,863	23,417
Additions	-	5,192	5,192
At 31 March 2024	2,554	26,055	28,609
DEPRECIATION			
At 1 April 2023	1,550	14,830	16,380
Charge for year	158	3,309	3,467
At 31 March 2024	1,708	18,139	19,847
NET BOOK VALUE			
At 31 March 2024	846	7,916	8,762
At 31 March 2023	1,004	6,033	7,037

12. STOCKS

	2024 £	2023 £
Stocks held for re-sale	5,628	5,791

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024 £	2023 £
Prepayments and accrued income	25,598	36,117

14. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024 £	2023 £
Taxation and social security	16,273	14,555
Other creditors	6,722	6,120
	22,995	20,675

15. LEASING AGREEMENTS

Minimum lease payments under non-cancellable operating leases fall due as follows:

	2024 £	2023 £
Within one year	15,000	20,094
Between one and five years	7,500	22,500
	22,500	42,594

16. MOVEMENT IN FUNDS

	At 1.4.23 £	Net movement in funds £	At 31.3.24 £
Unrestricted funds			
General fund	564,980	30,580	595,560
Restricted funds			
Various funds	91,334	295,413	386,747
TOTAL FUNDS	656,314	325,993	982,307

16. MOVEMENT IN FUNDS – CONTINUED

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	634,327	(603,747)	30,580
Restricted funds			
Various funds	629,526	(334,113)	295,413
TOTAL FUNDS	1,263,853	(937,860)	325,993

Comparatives for movement in funds

	At 1.4.22 £	Net movement in funds £	Transfers between funds £	At 31.3.23 £
Unrestricted funds				
General fund	548,837	16,510	(367)	564,980
Restricted funds				
Various funds	40,327	50,640	367	91,334
TOTAL FUNDS	589,164	67,150	-	656,314

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	429,458	(412,948)	16,510
Restricted funds			
Various funds	495,215	(444,575)	50,640
TOTAL FUNDS	924,673	(857,523)	67,150

16. MOVEMENT IN FUNDS – CONTINUED

A current year 12 months and prior year 12 months combined position is as follows:

	At 1.4.22 £	Net movement in funds £	Transfers between funds £	At 31.3.23 £
Unrestricted funds				
General fund	548,837	47,090	(367)	595,560
Restricted funds				
Various funds	40,327	346,053	367	386,747
TOTAL FUNDS	589,164	393,143	-	982,307

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	1,063,785	(1,016,695)	47,090
Restricted funds			
Various funds	1,124,741	(778,688)	346,053
TOTAL FUNDS	2,188,526	(1,795,383)	393,143

16. MOVEMENT IN FUNDS – CONTINUED**Statement of funds**

	Balance b/f at 1.4.23 £	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds				
General fund	564,980	634,326	(603,746)	595,560
Restricted funds				
Toy Packs	500	1,675	(2,175)	-
Community Information Webinars	-	5,000	-	5,000
Motability	-	238,500	(110,639)	127,861
SMA Care UK Grant	-	67,354	-	67,354
Community Engagement	-	47,350	-	47,350
UK SMA Newborn Screening Alliance	5,398	15,974	(21,373)	-
SMA Horizons Project	763	(560)	(203)	-
Working with the SMA Community	68,399	137,294	(144,189)	61,504
Website & Digital Comms Development	6,274	-	(6,274)	-
Support Services	-	40,950	(38,930)	2,020
PhD Scholarship Yr2	10,000	-	(6,730)	3,270
SMA and Me Books	-	15,000	(3,600)	11,400
Know No Bounds	-	30,255	-	30,255
Content and Web Development	-	30,733	-	30,733
Total Restricted Funds	91,334	629,526	(334,113)	386,747
TOTAL FUNDS	656,314	1,263,852	(937,859)	982,307

Analysis of net assets between funds

Fund balances at 31 March 2024 are represented by:	UNRESTRICTED FUNDS £	RESTRICTED FUNDS £	TOTAL FUNDS £
Tangible fixed assets	8,762	-	8,762
Stock	5,628	-	5,628
Debtors	25,598	-	25,598
Bank and cash	578,568	386,747	965,315
Current liabilities	(22,996)	-	(22,996)
Total net assets	595,560	386,747	982,307

16. MOVEMENT IN FUNDS – CONTINUED



Toy Packs

Our multi-sensory toy packs are available free of charge to families in the UK for newly diagnosed children. They include items that provide visual, tactile and auditory stimulation. They have been designed to offer entertainment during the day, fun at bath time and comfort at bedtime. They are suitable for infants aged up to 12 months of age.

Community Information Webinars

We ask expert health, education and social care professionals questions on topics of interest and concern to the SMA Community such as on treatments, diet and exercise. These popular webinars hosted by a community member provide easy access to important up-to-date and accurate information.



Motability

SMA UK were awarded a 3 year 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.

SMA Care UK Grant

The SMA Care UK project will bring together members of the SMA community and a range of health care and other professions to update the guidance outlined in Standards of Care (2018) and ensure it is relevant and meaningful to those living with SMA in the UK today. Funding has been received and requested from trusts and industry.

Community Engagement

SMA UK received grants from trusts and pharma to support our community engagement events which included Picnics in the park and our Children's and adults resonate weekends.

UK SMA Newborn Screening Alliance

The Alliance brings together clinicians, patient groups and other stakeholders, determined to achieve the earliest possible introduction of newborn screening for SMA in the UK and in so doing deliver the best outcomes from treatment and reduce future healthcare costs. This fund supports the costs of the Project Manager, the secretariat (SMA UK and MDUK) and communications.

SMA Horizons Project

The SMART Horizon project has the goal to identify new innovation, 'out of the box' therapies for people living with SMA, especially for the chronic population. These therapies may be complementary to the existing ones that target the SMN upregulation.

Working with the SMA Community

This Fund goes towards the costs of our information, outreach and support, community development and advocacy services.



Website & Digital Comms Development

This year this fund was set up to enable the launch of a new website and branding refresh targeted for August 2023. It also increased our Communications staffing capacity, our communications reach and supported the further development of community virtual networks.

Support Services

This fund targeted any Support Services costs that were not covered by any of the other restricted funds that support this work.

16. MOVEMENT IN FUNDS – CONTINUED

PhD Scholarship Yr2

This supports our commitment to fund the 4-year research programme that aims to further understand the motor enlargement process in people who have SMA and how this might be addressed and improve treatment outcomes. It runs from 2022–2025, and is funded jointly with Muscular Dystrophy UK.

SMA and Me Books

The books 'SMA and me' were published in 2016 before disease modifying treatments changed the landscape of SMA. With input from children living with SMA, their families and their clinicians, this new resource sponsored by Biogen, will help children to understand what SMA is, how the treatments work and, importantly, why we now see so many individual differences within the SMA community.

Content and Web Development

As part of our on going website and communications development, we were awarded a grant to strengthen and facilitate Community engagement through our multimedia platforms whilst improving imagery including videos on the SMA UK website.

Know No Bounds

Two members of the SMA Community have set them self a challenge to climb Snowdonia to fundraise for SMA UK to purchase specialise off road wheelchairs therefore aiming to give more opportunities for people living with SMA to explore the great outdoors.



17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2024.

18. CHARITY STRUCTURE

On 4th August 2022 the charity changed from a 'company limited by guarantee' to a 'charitable incorporated organization'.

DETAILED STATEMENT OF FINANCIAL ACTIVITIES

for the Year Ended 31 March 2024

	2024 £	2023 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations and gifts	717,901	759,199
Legacies	159,944	5,312
Motability	238,500	-
The National Lottery Community Fund	137,294	153,831
	1,253,639	918,342
Other trading activities		
Merchandise sales	3,755	5,743
Investment income		
Bank interest	6,459	588
Total incoming resources	1,263,853	924,673
EXPENDITURE		
Raising donations and legacies		
Staff costs and other expenses	137,965	133,680
Fundraising and publicity	26,826	21,090
Events and promotions	33,953	12,304
Cost of merchandise sales	4,646	2,337
	203,390	169,411
Charitable activities		
Staff costs and other expenses	379,565	391,507
Medical research grants	6,730	378
Other research activities	8,862	3,099
Information and awareness raising	19,722	34,641
Shared experiences network	13,783	24,045
Outreach service	77,482	48,285
Welfare, equipment grants and toy packs	135,655	121,184
	641,799	623,139

	2024 £	2023 £
Support costs		
Management		
Staff costs and other expenses	75,039	51,285
Professional fees and bank charges	6,642	6,478
Other costs	10,990	7,210
	92,671	64,973
Total resources expended	937,860	857,523
Net income	325,993	67,150



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Registered Charity Number 1106815