Spinal Muscular Atrophy UK

England & Wales · Charity number 1106815

Details

Other names	SPINAL MUSCULAR ATROPHY SUPPORT UK, THE JENNIFER TRUST FOR SPINAL MUSCULAR ATROPHY, SPINAL MUSCULAR ATROPHY UK THE JENNIFER TRUST
Status	Registered
Legal form	CIO
Registered	2004-11-17
Register	View on the Charity Commission register

Contact

Address	The Mansley Business Centre Stratford Enterprise Park Timothy's Bridge Road Stratford-upon-Avon CV37 9NQ
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Website	www.smauk.org.uk

Activities

Objects: 1. THE RELIEF OF PEOPLE LIVING WITH SPINAL MUSCULAR ATROPHY AND RELATED MEDICAL CONDITIONS AND TO RAISE THE PUBLIC'S AWARENESS OF SUCH CONDITIONS.2. THE RELIEF OF PERSONS WHO ARE IN NEED AFTER EXPERIENCING A BEREAVEMENT OR LOSS DUE TO SPINAL MUSCULAR ATROPHY.3. THE PROMOTION OF RESEARCH INTO THE CAUSES AND TREATMENT OF SPINAL MUSCULAR ATROPHY.

Activities: We provide accurate information and a wide range of support services to anyone who is affected by spinal muscular atrophy, while working to improve access to the best care, services and drug treatments today and funding research projects that can change tomorrow.

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Classification

- **How:** Makes Grants To Individuals, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities, Other Defined Groups

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£1,623,545	£1,359,898	£1,245,954	16
2024-03-31	£1,263,853	£937,860	£982,307	17
2023-03-31	£924,673	£857,523	£656,314	15
2022-03-31	£839,420	£715,466	£589,164	12
2021-03-31	£724,691	£575,342	£465,210	12

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Trustees

Name	Role	Appointed
Dr Gordon Harvey	Chair	2025-11-03
Alistair Mark Emslie Smith		2020-11-26
Ben Hugh Williams		2023-11-22
Daniel Hardy William Worrall		2024-11-21
Dr Anne Marie Childs		2020-11-26
Dr Channa Hewamadduma		2025-10-15
Dr Hassan Sobati		2024-11-21
Jennie Elizabeth Sheehan Sheehan		2023-11-22
Karin Yvette Edwards		2020-11-26
Lauren Elizabeth Jane West		2020-11-26
Maryann Madayag Aspinall		2023-11-22
Robin Jackson		2025-09-01
Srinivas Madipalli		2020-11-26
Tracey Jane Bailey Burnley		2023-11-22

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Spinal Muscular Atrophy UK

England & Wales - Charity number 1106815

Accounts

ANNUAL REPORT

2024-2025



Spinal Muscular Atrophy uk

SUPPORTING • INFORMING • ADVOCATING



Chair's Report

It is amazing to think that this year, 2025, is the 40th anniversary of our charity. Founded in 1985 as the Jennifer Trust and merging with the SMA Trust in 2018, SMA UK is the leading charity in the UK for the SMA community. We have achieved so much during these last 40 years and will continue to be here for all those affected by SMA into the future.

2024/25 was another busy and demanding year for our incredible team and I'm extremely proud to look back at the successes and achievements that we have had over the last 12 months.

In line with our strategy, 'Building a Future Together', supporting anyone living with SMA remains at the core of what we do. Our exceptional Support Team continue to be the backbone of the charity providing information, practical, and emotional support to countless families across the UK. In October, in partnership with Rareminds, SMA UK launched a free confidential counselling service to support anyone affected by SMA.

Turning to advocacy, we continue to campaign for SMA to be added to the Newborn Screening Programme and advocating for NHS funding for both Nusinersen and Risdiplam to continue throuhg consultations leading to their review in being postponed to late 2025. This has allowed the team to gather more information from the community on how positively treatment can affect the outcomes of people living with SMA. Furthermore, after several years of planning, in July 2024, we formally launched the SMA Care UK project working in partnership with John Walton Muscular Dystrophy Research Centre and Newcastle University.

With the website and social media platforms providing regular, up to date and informative PIF accredited information, our community is in the best position to make informed choices and to feel connected with other members of the SMA community.

The finances of the charity remain strong despite the pressures faced by the UK charity sector. This is down to you, our incredible and generous supporters as well as our amazing fundraising team. 2024 was our most successful fund raising year ever with so many fantastic fundraiser events and grants from trusts and foundations.

We received our second year of funding from The Motability Foundation enabling us to deliver the SMArt grants. We also secured a legacy payment from the Edward Gosling Foundation which will help us well into the future.

Four of our trustees ended their terms in office and I would like to say a special thanks to Julian Fiorentini, Michael Collins, Toby Mildon and Ros Quinlivan for their time and expertise whilst serving on the Board. In November we welcomed two new trustees, Hassan Sobati and Dan Worrall and we are excited to have them as part of our Board.

I'd like to thank my fellow trustees for all the time they give as part of the Board and as part of the charity. I would also like to recognise and thank all of my colleagues at the charity who work so tirelessly to ensure that SMA UK delivers for our community.

We are in a strong position but it is important we don't become complacent. There are many headwinds in the world at the moment and we must remain vigilant to the impacts on the economy, society, and our charity.

Mark Dearlove
Chair of the Board of Trustees



CEO’s Report

As we approach SMA UK’s 40th year as a charity, I am so proud to look back on 2024/25, particularly the work the SMA UK team have done on behalf of the SMA community.

In July 2024, after months of consultation, we successfully launched our new 4-year strategy: Building a Future Together (2024- 2028). The strategy aims to build on our strong foundations, experiences and expertise to ensure we deliver the best outcomes for the SMA community and make sure that supporting anyone affected by SMA is at the core of everything we do.

Some of the most recent highlights include the changes we made under our Flexi Grant programme as well as introducing a new free counselling service for those affected by SMA.

I can’t thank our incredible supporters and donors enough for all their endeavors over the last 12 months, from sky dives, marathons and other challenges. Without your willingness to go above and beyond, we wouldn’t be able to carry out our vital work.



Giles Lomax
Chief Executive Officer

SMA UK CEO Giles Lomax with his family. His six year old twins, Zara and Finn are living with SMA, and are the inspiration behind his work with the charity.

ADVOCACY UPDATE



SMA REACH Steering Committee updates

Portia Thorman (Head of Advocacy and Community) continues to represent SMA UK within the REACH (Research and Clinical Hub) UK Steering Committee.

The SMA REACH UK hub is a strong national network of expert clinicians that supports research and clinical care for people with SMA. It helps develop and improve ways to measure how well treatments work - making sure these measures are useful for both patients and clinical trials. As well as discussing current and evolving issues in the SMA field, the steering committee also review applications to access clinical data for research purposes.

Throughout the year, Portia has been sharing the views of the UK SMA community, gathered through collaboration with SMA UK's support team, WhatsApp groups, surveys and in-person community events to help ensure that research focuses on the real needs and priorities of people living with SMA.



Adults' perspective workshops and report

We hosted two insightful workshops in Manchester (17th January 2025) and London (28th February 2025), bringing adults living with SMA and specialist clinicians together to discover adults' perspectives of clinical care across the UK.

The outcome, the "Adults Perspectives Report", focuses on the experiences, priorities, and recommendations for adults living with SMA in the UK. It highlights the challenges faced in transitioning from paediatric to adult care, the gaps in clinical and social care, and the need for improved standards of care (SoC) tailored to adults. It was concluded that a single, comprehensive Standards of Care for adults document is needed to guide best practice, reduce inequities, and support funding for Multidisciplinary Team clinics.

It should reflect the social model of disability, focus on individual needs, and promote collaboration between health and social care teams.

Iryna Bernyk who attended the workshop said:
'As an adult living with SMA, the workshop was truly special for me. It was a fantastic opportunity to not only share my own journey as an adult living with SMA, but, just as importantly, to meet and connect with such an inspiring group of people.

The sense of community, shared determination, and the drive to make a difference were so uplifting. It's moments like these that remind me how powerful it is to be part of this network – not just fighting together, but also learning from each other, supporting one another, and pushing for meaningful change.

I left feeling more connected, more hopeful, and incredibly grateful for being part of such a strong, supportive network."



UK Newborn Screening Commitee (NSC) Progress towards an In-Service Evaluation (ISE)

In February 2025, the UK National Screening Committee (NSC) published an update on the In-Service Evaluation (ISE) for SMA newborn screening. The ISE, similar to a pilot, will screen a percentage of UK newborns over a set period to generate UK-specific evidence. It will inform a final decision on whether SMA should be added to the national newborn screening programme.

To support the ISE delivery, the NSC has established sub-groups focused on laboratories, data and methodology and the clinical pathway. This includes developing parent/professional information. SMA UK is contributing to several of these groups, bringing in vital patient experience.

Delays and Advocacy

Despite planning progress and the commitment of all those involved in the Partnership Board, at the time of writing there was still no confirmed start date for the ISE. We understand the delays have been largely due to the Government's spending review.

SMA UK, alongside Muscular Dystrophy UK, the SMA REACH UK network, and the Newborn Screening Alliance, is actively pushing for progress. We've written to politicians, engaged with the NSC, and raised awareness through meetings, petitions, articles, and public speaking. We're also working with the Scottish government to help prevent inequality in access across the UK.

The Lancet Letter

On 7th February 2025, The Lancet published a powerful letter from leading SMA clinicians, highlighting the stark differences in outcomes between babies born with SMA in the UK and those in countries with newborn screening. The letter shares harrowing statistics, showing that while UK babies treated after symptom onset often face severe disability or death, children in countries like Belgium, treated pre-symptomatically, are thriving.

We urged the SMA community to share this letter and contact their MPs to demand faster action. SMA UK remains committed to securing SMA newborn screening for every baby born in the UK.



ENMC Workshop

The ENMC Workshop SMN-related neurodevelopmental disorder: type 1 Spinal Muscular Atrophy and the brain was held from 31st January – 2nd February 2025.

Portia Thorman, brought the patient perspective to this international expert workshop. It was highlighted that some children with SMA Type 1, who are now living longer thanks to new treatments, may experience developmental challenges such as speech delays, learning difficulties, or behavioral differences.

It was agreed at the workshop that early monitoring, timely therapy (especially speech therapy), and strong family support can make a big difference. Families should be encouraged to share concerns with healthcare providers, who can track development over time and tailor support.

Experts are now working together internationally to:

- Launch a global survey on developmental challenges in SMA
- Develop better care and diagnostic guidelines
- Involve families in shaping future research and support systems

These efforts aim to ensure every child with SMA gets the care and opportunities they deserve.

NICE Multi Technology Assessment (MTA) of Risdiplam and Spinraza

On 19th April 2024, SMA UK, in collaboration with other patient organisations and in consultation with NICE, led a joint response to the External Assessment Group (EAG)'s report evaluating the clinical and economic evidence for Spinraza and Risdiplam.

We submitted our response in September 2024. NICE acknowledged the concerns raised by SMA UK, partner organisations, clinicians, and pharmaceutical companies, including that the EAG report:

- Did not give equal weight to real-world evidence compared to clinical trials.
- Focused narrowly on mobility outcomes, overlooking SMA's broader impact on daily life.
- Did not account for the inherent limitations in trial size and duration in rare diseases like SMA, highlighting the importance of ongoing real-world data collection.
- Overlooked the need for individualised treatment options.
- Failed to value disease stabilisation as a major positive outcome.
- Relied on quality-of-life measures that are too limited to reflect the full benefits of treatment.

In December 2024, NICE postponed its committee meeting on the clinical and cost effectiveness of the drugs and commissioned a new EAG report to build on the original.



Partnerships

SMA UK worked with a number of our partner organisations including Scope, the Disabled Childrens Partnership and Genetic Alliance throughout 2024 on a wide range of campaigns, raising awareness of key issues such as rights on transport, inclusion in education and the need for faster diagnosis.

In December 2024, SMA UK joined the Wheelchair Alliance, an organisation that represents the voices of wheelchair users. We will work with them in calls for a more integrated approach to wheelchair provision and greater prioritisation of wheelchair services in the NHS.

SMA CARE uk

STANDARDS OF CARE FOR SMA



SMA Care UK is a 3-year project established by clinicians and patient groups to update and implement UK Standards of Care for people of all ages living with SMA.

The current Standards of Care for SMA were written before disease-modifying treatments began to emerge and were published in two articles in 2017. A Family Friendly Guide was published in the following year. They covered a wide range of topics such as nutrition and bone health through to respiratory care. The new updated standards (SMA Care UK) will reflect how developments around treatments have changed the care and management needs of people of all ages living with SMA.

Its goal is for this care to be accessible to all who have SMA, wherever they live and whichever hospital they attend. People living with SMA are central to this work. Given the wide-ranging impact of SMA, there are many areas of care to consider. Respiratory, hip, spine, and transition to adult services will be the first topics to be reviewed.

In July 2024, Vanessa Christie-Brown was appointed as the SMA Care UK Project Manager and will be working in partnership with John Walton Muscular Dystrophy Research Centre, Newcastle University. . Vanessa will be working with a team of healthcare professionals and patient representatives to bring the project to fruition.



Partners and funders

We are extremely grateful to our funders who are supporting this project. Biogen, Roche and SMA UK have all committed funding towards SMA Care UK.

Partners: Spinal Muscular Atrophy uk · Biogen · Roche

Funders: SMA REACH UK · ADULT SMA REACH · Spinal Muscular Atrophy uk · MUSCULAR DYSTROPHY UK | OUR MUSCLES MATTER · UK SMA PATIENT REGISTRY · The John Walton Muscular Dystrophy Research Centre · TreatSMA · Newcastle University

INFORMATION UPDATE



PIF Tick Information Guides

Our twenty-seven information guides about SMA and related care, treatment and management topics are all available on our website. We send out printed copies when asked to do so.

Each guide is reviewed by experts and readers interested in the topic. This review is an important part of our information production system which we follow when we produce these guides.

The system supports our aim of producing accurate, evidence-based, up to date and accessible information. It was again accredited by the Patient Information Forum (PIF) this year.

All these guides carry the PIF Tick.
The top four during this report period were:

Looking After Your Child SMA Type 1
Page Views 3,002
Active Users 2,144

Adult Onset SMA Diagnosis and Care
Page Views 1,464
Active Users 1,179

Symptoms and effects of 5q SMA
Page Views 1,463
Active Users 1,041

The Genetics of 5qSMA
Page Views 1,602
Active Users 1,178





We continue to produce many other pages following similar principles. These include information about research and treatments with the top three areas in this section as follows:

Page	Page Views	Active Users
Zolgensma / Onasemnogene Abeparvovec	2,008	1,524
Spinraza/ Nusinersen	1,472	928
Evrysdi / Risdiplam	1,319	1,025

Our website pages about day-to-day living with SMA cover a wide range of topics from nursery and school to travel, sport, equipment and adaptations, financial benefits and many more. Each section focuses on topics of relevance to the age group and were accessed as follows:

Page	Page Views	Active Users
Adults	3,832	1,113
Teenagers	3,152	897
Children	1,840	1,014

‘The support & information section was very helpful when we first received the diagnosis, looking further into that section, the looking after your child with SMA 1 helped to understand the treatment options, how SMA 1 affects the different areas of the body and also the information about the allowances we may be able to receive, I have already ordered a Disabled Living Allowance form.’ – Parent



Webinars

When members of the SMA community raise questions that need expert answers that we don’t have, we do what we can to find them. When possible, this results in a webinar hosted by a community member.

This year we were asked many questions about different types of diet. We were fortunate to find two experts willing to share their knowledge across three webinars that were released in February 2025. At the time of writing, they had been viewed a total of 148 times. There have been other topics where we have not had such success with finding an expert, but we haven’t given up and will keep looking.

We hope the range of information we offer continues to respond to the needs of people new to and living with the condition.

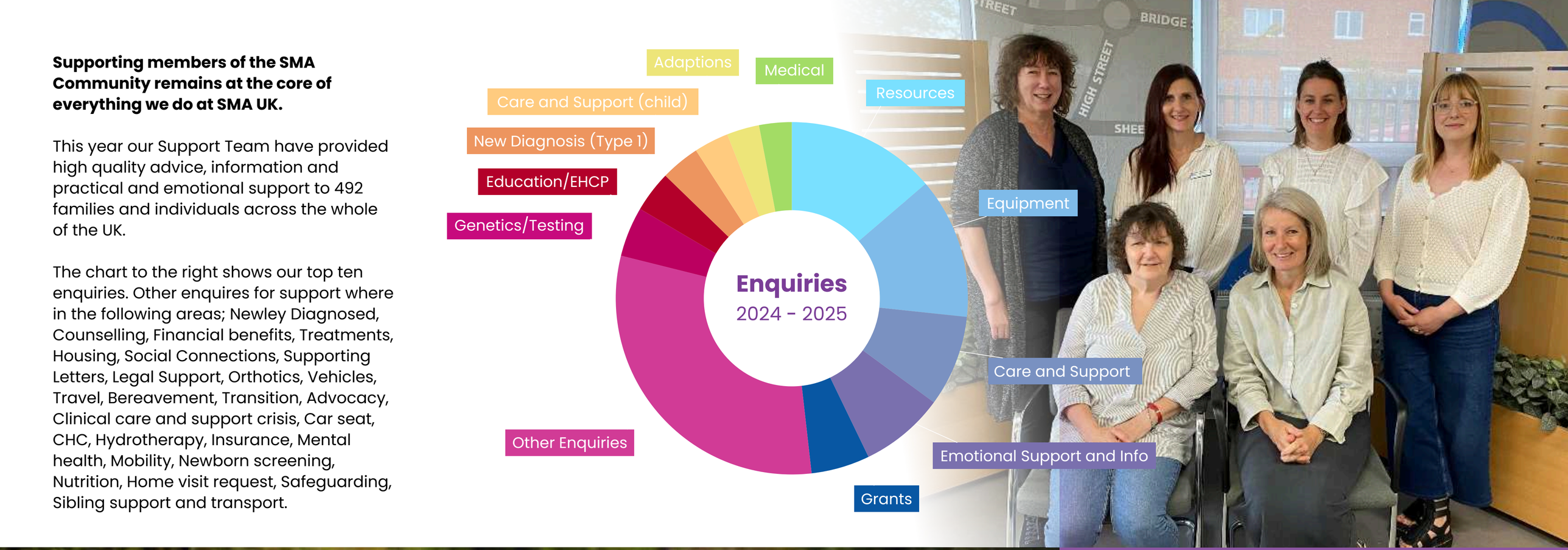
SUPPORT SERVICES UPDATE



Supporting members of the SMA Community remains at the core of everything we do at SMA UK.

This year our Support Team have provided high quality advice, information and practical and emotional support to 492 families and individuals across the whole of the UK.

The chart to the right shows our top ten enquiries. Other enquires for support where in the following areas; Newley Diagnosed, Counselling, Financial benefits, Treatments, Housing, Social Connections, Supporting Letters, Legal Support, Orthotics, Vehicles, Travel, Bereavement, Transition, Advocacy, Clinical care and support crisis, Car seat, CHC, Hydrotherapy, Insurance, Mental health, Mobility, Newborn screening, Nutrition, Home visit request, Safeguarding, Sibling support and transport.





The support provided by the SMA UK Support Team has been incredibly important to me. I received a significant reduction in my care budget which severely impacted my independence and quality of life.

As soon as I reached out to the Team about this, they demonstrated their dedication to providing me with support – meeting with me on numerous occasions, giving me very useful advice, carefully writing supporting letters, guiding me through the process.

This made an enormous difference in helping me through this difficult time and resulted in a re-assessment being performed for my care needs. I am really grateful for their commitment and continued support.

The support team have also responded to 93 enquires from healthcare professionals:

25 enquiries
Resources

12 enquiries
FCG

11 enquiries
Housing

9 enquiries
New Diagnosis (type 1)

8 enquiries
Care and Support (Adult)

5 enquiries
Car Seat

3 enquiries
Education

2 enquiries
Care and Support (Child)
Emotional Support
Legal
Medical
New Diagnosis (type 2)
Supporting letter

1 enquiry
CHC
Equipment
FCG2
Grants
Mailing/first contact
New family/contact with others (LED)
Ongoing support
SMA - SMARD

Transition Workshop

We understand that there are many questions and complexities that arise when a young person is transitioning into adulthood. Therefore, we were delighted to be able to welcome thirteen young people aged 13 – 18 years and their eighteen family members and their carers to this interactive day of free workshops in April 2024.

Hosted by our Support Team and five young adult volunteers at the Midlands Arts Centre, the event was attended by our guest speakers who led sessions that explored a wide range of topics.

Speakers covered key transition topics including the T-KASH framework (Marie McGee), accessing adult health and social care (Jane O'Connor & Lisa Cutsey), housing options (David Abbey), managing PAs at university (Tim & Christopher Pool), university support (Kate Waugh, Birmingham University), driving and transport adaptations (Dominic Hibbin & Becky Brown, RDAC), the Duke of Edinburgh Award (Sarah Lalieu & Matthew Lanham), and accessible travel (Cheryl Everitt).



Attendee feedback:
"Huge thank you to @sma_uk for a great day, and for introducing us to people and opportunities we'd never dream of"



SMArt Moves

Our SMArtMoves grant ran for the second year thanks to The Motability Foundation. This grant has enabled us to support more people living with SMA in purchasing wheelchairs and wheelchair adaptations.

From 1st April 2024 – 31st March 2025 we supported 65 children and adults with new wheelchairs and adaptations.

By working alongside other grant giving charities, we have supported adults to secure funds to purchase new powered wheelchairs.

We have also enabled families to access their child's first manual or powered chair.

The grant scheme is split into three sections:



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 £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.



FlexiGrant programme

In July 2024 we relaunched our FlexiGrant program to the SMA Community. There are two grants:

FlexiGrant 1: A maximum grant of £500 to help with the costs of accessing NHS funded treatment or assessment e.g. travel costs.

FlexiGrant 2: A maximum grant of £600 to assist with buying items that support independence and alleviate hardship.

From the 1st April 2024 – 31st March 2025, we supported 128 people with these grants totalling £40,401.18

Family feedback:
"Thank you so much for the award of this grant. It is greatly appreciated, and we are blown away by the quick turnaround and generosity of SMA UK!"

"Thank you very much to the SMA UK staff for all your help and support, not just with these grants but on the whole. This charity supports the community so well and without the Support Team I'm not sure where my family would be."



Toy Packs

Our multisensory toy packs are sent free of charge to families with babies aged up to 12 months old who have a SMA diagnosis. The items in our packs will entertain during the day, add fun at bath time, and provide comfort at bedtime. They provide visual, tactile and auditory stimulation. 26 toy packs were sent this year and have been well received.

Family feedback:
"I never expected such a lovely toy box- a huge amount of toys and a lovely box it is delivered in and felt I had to call to thank the charity ….you are all AMAZING!!"

"The toys arrived this morning, thanks so much! It's a really lovely box and super generous of the charity to provide all these toys."

Partner Organisations

The Support Team continues to visit and link with Neuromuscular Centres, meeting Neuromuscular advisers and specialist nurses. They work closely with other charities/organisations to provide information, and resources that bring the best possible support to the the SMA Community.

Rareminds Counselling Service

In October 2024, we launched a new pilot counselling service for all those affected by SMA.

Working in partnership with Rareminds, a specialist, nonprofit, rare disease counselling and psychotherapy service, we have been allocated two SMA counsellors offering six to twelve sessions to individuals or couples affected by SMA.

Our dedicated Rareminds counsellors provide a safe, confidential relationship where you can explore difficult thoughts or feelings and consider new ways of working through your difficulties.

During the pilot a total of 14 individuals accessed the service, 10 who have SMA, 3 parents and 1 partner, with 101 counselling sessions provided. Following a full review of the pilot we are continuing to work in partnership with Rareminds to provide this service.



"I found the sessions so helpful. I have had support in the past but never felt they understood / I could talk about my disability and I got exactly what I needed from the sessions. I was supported through ongoing as well as current issues and feel in a much better place now going forward being able to manage challenges. I am very grateful and would highly recommend to others" *- Client*

COMMUNITY ENGAGEMENT UPDATE



SMA UK Ambassadors

In September 2024 we welcomed two volunteer Charity Ambassadors on board! Molly Everitt and Sanah Rauf are working with SMA UK to help spread awareness about SMA and support the important work we do.

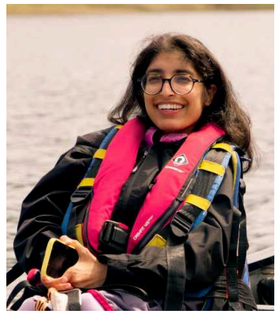


Hi, I'm Molly – one of SMA UK's first Ambassadors! I'm 21 and studying Law with Criminology at the University of Liverpool.

Diagnosed with SMA Type 3 as a toddler, I've been connected with SMA UK ever since, and they've supported me and my family in countless ways.

Thanks to their SMArt Moves grant, I now have a life-changing wheelchair that's boosted my independence.

I'm passionate about raising awareness around accessibility, especially in music venues, and I'm so proud to support a charity that means so much to me. I'm excited to see where this Ambassador role takes me!



Hi, I'm Sanah Rauf – a 27-year-old artist, content creator, and proud SMA UK Ambassador!

I have SMA Type 2 and use my platforms on Instagram and TikTok to share my journey, raise awareness, and inspire others.

With a background in Film and TV, I now run art workshops, speak at events, and create content that promotes self-belief and resilience.

Living with SMA has taught me that mental strength matters most, and I'm passionate about helping others with SMA feel fearless and empowered.



picnic in the park

Thank you to everyone who came and enjoyed our Picnic in the Parks in 2024!

We loved seeing so many old faces as well as welcoming so many new ones to these fantastic afternoons. We hosted six Picnics in the summer at venues in Yorkshire, Cardiff, Edinburgh, Birmingham, Essex and Belfast.

269 people (68 families) attended the events which brought together families and individuals living with SMA for an opportunity to network, share information and have fun!

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

RESONATE 2024





Resonate Adults

Over the weekend of the 26th –29th July 2024, 20 adults living with SMA and their carers attended our third Resonate weekend at the Calvert Trust, Exmoor.

The sun shone and the weekend was packed with fun activities such as kayaking, abseiling, bike riding, and archery! The weekend was an opportunity for attendees to meet new people as well as old friends and have fun in the outdoors!

For twins, Sam and Alex, this was the first holiday they had without family support. They said, “This is one of the first holidays with just PA’s and they have been absolutely amazing it has been a big boost to our independence.”

“All the experiences were amazing. The staff, the activities, the accommodation and the food.”

“Such an amazing weekend and so lovely to catch up with old friends and meet new ones! An absolute highlight of the year! Being able to catch up with some of my closest friends is great as it's hard for us all to meet up as a big group throughout the year and finding somewhere that meets all of our needs.”

“Absolutely amazing time and really enjoyed all the activities and always meets my expectations.”

“It's just been a fantastic opportunity for us as a family. There are very few opportunities that we get to have as a family, but also with other families of children with similar conditions in wheelchairs where we can do activities that everybody else gets to enjoy all the time. Without SMA UK we would probably never have met these other families. It's so nice to see the children just whizzing around together, having fun!” - ***Attendee and parent of child with SMA***





Resonate Kids

During the 3rd–16th September 2024 we hosted our first Resonate for children at the Calvert Trust in the Lake District! 15 young people and children living with SMA attended, along with their parent/carer, enjoying similar experiences and activities to the adult's weekend such as archery, swimming and abseiling.

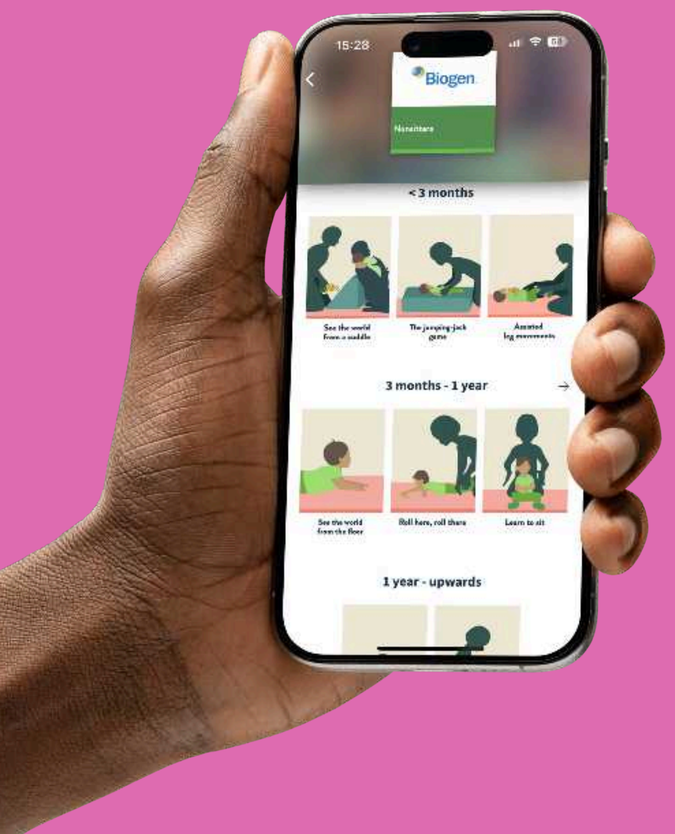


Living with SMA Podcast

Our Living with SMA podcast is an opportunity for the SMA Community to share and discuss relevant topics about living with SMA and disability in general. Working closely with the community and key contributors, we produce regular podcasts that are shared across various digital platforms.

Six new episodes were released this year from “Getting ready for University” to “Motherhood, Parenting with SMA”

During this reporting period we there has been **789** podcast downloads



Biogen’s new exercise app

Working alongside leading specialist physiotherapists we assisted Biogen in creating a new exercise app for people living with SMA.
The app is aimed at both children and adults and consists of exercises that can be done in the home environment. All exercises have been chosen based on level of function and age.

Read more about the app and download it at:
smauk.org.uk/izcz

SMA UK WhatsApp Community Networks

Our Community WhatsApp groups continue to grow in numbers, offering a space to share knowledge and experiences as well as have general conversations with likeminded people.

Our adult groups have become much more active following the adult workshops in January and February 2025, with 10 new members joining the WhatsApp community as a result.

The Families Network has also been especially active, providing invaluable help and support to newly diagnosed members as they join the community.

The Adults WhatsApp group has added 16 new members this year, bringing the total to 40.

The Families WhatsApp group has added 36 new members this year, bringing the total to 110.

The ChariSMA Network (for teenagers) currently has 33 members. Recently, 8 members have transitioned to the Young Adults/Adults Network.

The Young Adults WhatsApp group has added 7 new members this year, bringing the total to 49.

NEW! The Grandparents WhatsApp group has added 26 new members this year, bringing the total to 26.

FUNDRAISING UPDATE



All of SMA UK's achievements, whether it's delivering vital support services, producing accessible information, or advocating for better care are only possible thanks to the incredible generosity of our donors and fundraisers. We are deeply and sincerely grateful for every individual, family, organisation, and foundation who chooses to support our mission. Their dedication enables us to continue our work and make a meaningful difference in the lives of those affected by Spinal Muscular Atrophy.

Looking ahead, it is crucial that we maintain a strong and sustainable foundation of financial support. In order to continue responding effectively to the evolving needs of the SMA Community, and to ensure that individuals and families living with SMA receive the help and resources they deserve, our fundraising income must remain both consistent and resilient. Ongoing support from donors and fundraisers is not just appreciated, it is essential to our ability to grow, adapt, and deliver lasting impact.

In 2024/25, through various fundraising activities, grants and donations our raised income was £1,616,553.

- **Pharma restricted** £264,147.00
- **Trusts unrestricted** £81,808.00
- **Trusts restricted** £311,018.00
- **National Lottery restricted** £120,035.00
- **Trustee event** £133,317.00
- **Motability restricted** £239,000.00
- **Consultancy** £4,087.00
- **Community** £238,577.00
- **Individual Giving** £71,141.00
- **Gift Aid** £38,127.00
- **Legacy** £149,250.00
- **Interest** £5,702.00
- **Merchandise Sales** £3,389.00
- **Corporate unrestricted** £30,235.00









#KnowNoBounds campaign

The KnowNoBounds campaign was founded by Josh Wintersgill to raise awareness about the urgent need for greater accessibility outdoors for disabled people. Driven by a vision of inclusion and empowerment, the campaign also aimed to raise funds to purchase an all-terrain wheelchair that would be available for members of the SMA Community to use.

On 15th June 2024, Josh's campaign partner, Maxwell McKnight, undertook an extraordinary challenge — climbing Mount Snowdon in an X8 off-road wheelchair. Supported by a dedicated and enthusiastic team, Maxwell completed the climb in an impressive 6.5 hours, demonstrating not only the power of determination but also the potential of inclusive technology.





We were thrilled to celebrate this incredible achievement at a launch event hosted in March 2025 at the Stelios Foundation, one of the generous donors to the campaign. During the event, we proudly unveiled the X8 off-road wheelchair, which will be made available for community hire in 2025, giving individuals with SMA the opportunity to explore and enjoy outdoor environments more freely and independently.

Our new X8 wheelchair has been called "Limitless" in honour and loving memory of Clare Gray, a Trustee for SMA UK and advocate for all those living with a disability.



SMA Awareness month 2024

We relaunched our SMA UK Teddy with a competition to name the bear. SMArty the Aware Bear was very popular, and we were delighted to see so many of the community sending in fantastic photos of SMArty being taken on travels across the world!

The Big Give

We were delighted to be selected to take part in the matched funding campaign The Big Give Christmas Challenge once again and we exceeded our fundraising target of £30,000. Our special thanks to those supporters who pledged to make up our ‘matching pot’ for making this possible.



Clay Shoot

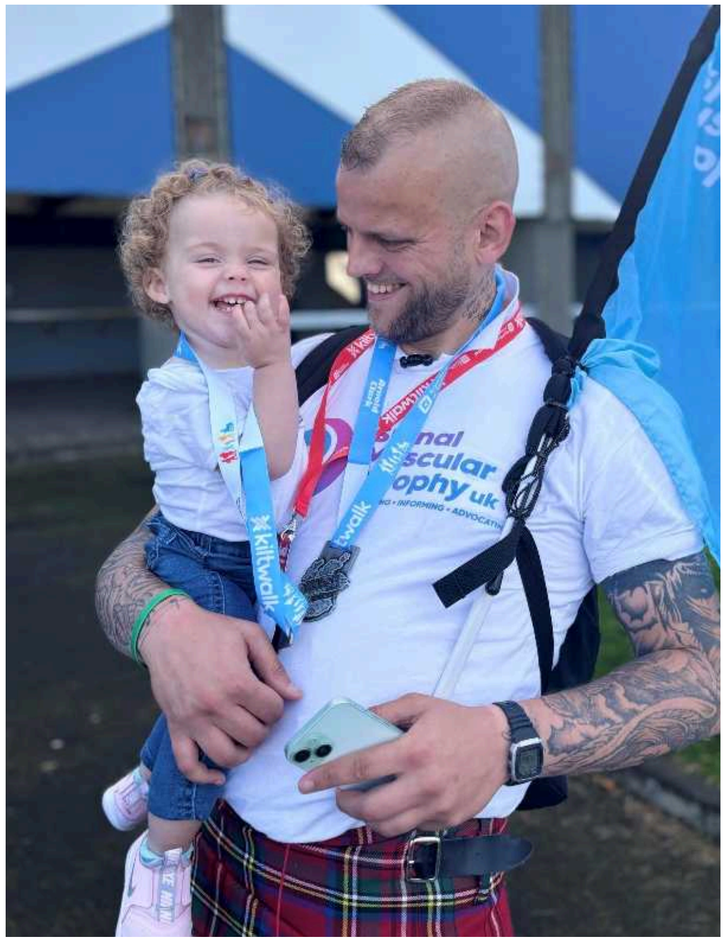
In May 2024 a clay shoot was organised in partnership with the Game and Wildlife Conservation Trust. This was successful in raising £124,868 which was split between both charities, and we are extremely grateful to everyone who joined us for this event and who kindly donated auction prizes.

Individual Giving

We received monthly donations from 158 supporters this year and are grateful for their continuous support. We would also like to extend our heartfelt thanks to everyone who made donations in memory of loved ones over the past year.

These generous and meaningful contributions not only honour those who have passed, but also help us continue our vital work supporting individuals and families affected by SMA.

Furthermore, we are deeply grateful to those who chose to support our work by leaving a gift in their will. These lasting legacies make a profound difference, helping us plan for the future and continue providing vital support and services.



Community Events

We received incredible support from the community, who took part and arranged events all over the country to support SMA UK. The London Marathon and Great North Run continue to be popular events, and we have also seen fundraisers being creative with ideas from family fun days to Himalayan Treks!

Trusts and Foundations

We are forever grateful for the grants we receive from Foundations and Trusts. Both restricted and unrestricted funding ensure that we can continue to offer various workshops, outdoor activities and FlexiGrants to the SMA Community.

Registered with FUNDRAISING REGULATOR

Fundraising Story

Rachel Toth, from Dundee, took SMA UK to new heights by climbing the Himalayan peak Yalung Ri, which rises to an impressive 5,630 metres (18,471 feet).

At the summit, she tied a specially made SMA UK flag alongside Tibetan prayer flags, marking the highest point ever reached by one of our supporters.

Rachel was inspired to take on the challenge by her close friend Alistair, who has SMA Type 3 and is a Trustee of SMA UK.

Her incredible effort raised £3,000 to support the charity's work.

DIGITAL COMMUNICATIONS UPDATE

Social Media Highlights

This year, we continued using our social channels to raise awareness, share real stories, and support the SMA community. Our focus stayed on honest, accessible content, and we saw steady growth across all platforms.

Instagram was our fastest-growing channel with a 12.6% increase in followers, thanks to regular and engaging posts. Facebook remained our biggest community space, growing by 2.4%, while YouTube saw a 15.4% boost in subscribers as more people tuned into episodes of the “Living with SMA” Podcast and informative webinar videos. LinkedIn and X also grew, helping us stay visible in policy, research, and advocacy spaces.

Our most engaging content continued to be personal stories from families and individuals with SMA. Campaigns like SMA Awareness Month in August brought great cross-platform engagement, and we’re seeing the most impact when our community leads the conversation.

Looking ahead, we aim to focus more on short-form video, gathering video content from our upcoming community events. As well as sharing more information about the kind of support our Community Support Team can offer.

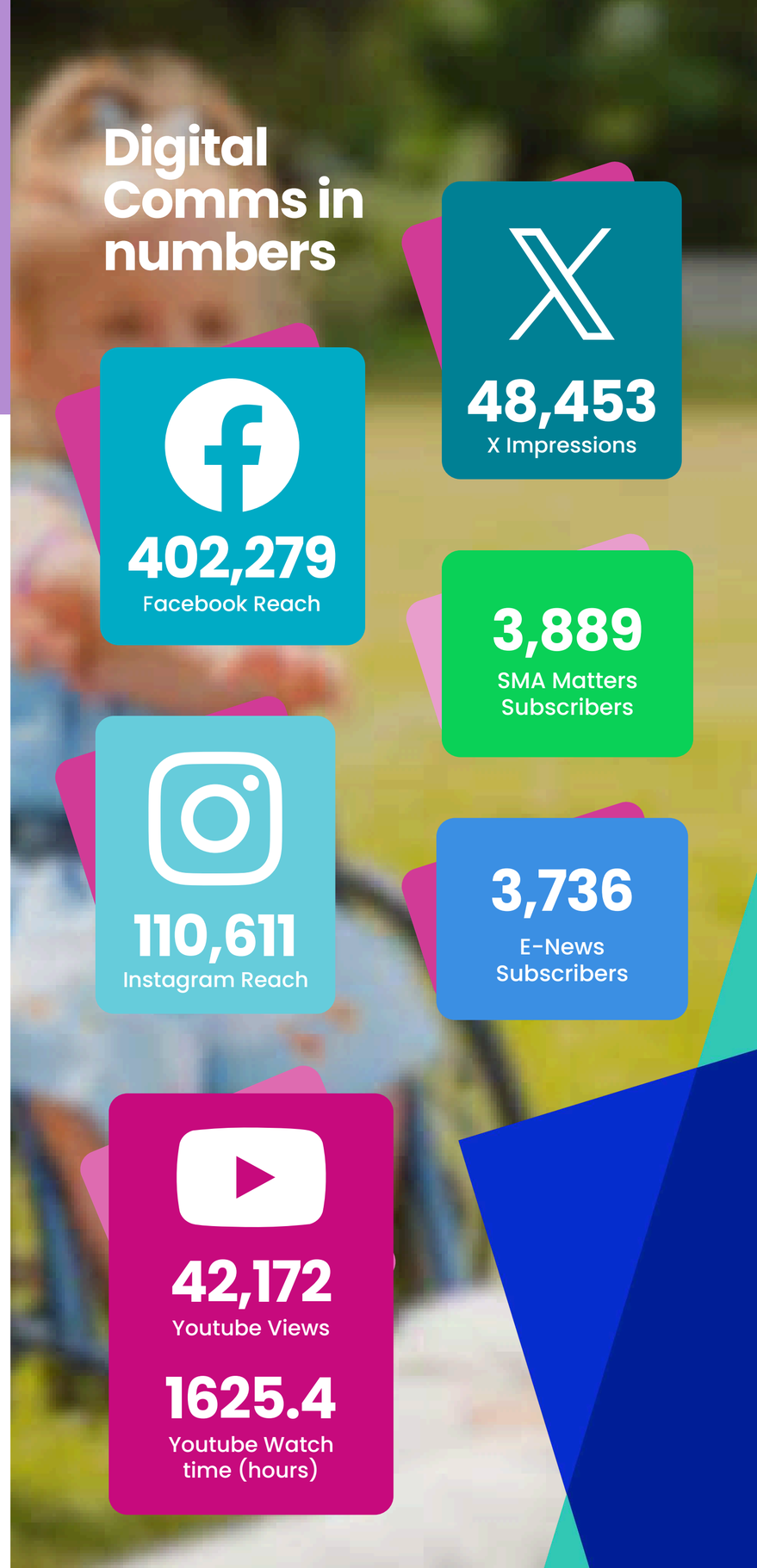
A huge thanks to everyone who shared, liked, and supported us on socials this year, your voices are at the heart of everything we do.



SMA Matters & e-newsletters

In 2024, we continued to keep our community informed and connected through regular updates. We published two editions of SMA Matters, our bi-annual magazine, in April and September. These magazines share a mix of news, community stories, research updates, expert advice, and helpful information to support people living with SMA and those around them.

In addition, we send out monthly e-newsletters. These allow us to stay in touch more often, providing quick updates about what’s happening in the SMA community, and plenty of opportunities for people to get involved with fundraising.



OPERATIONS UPDATE

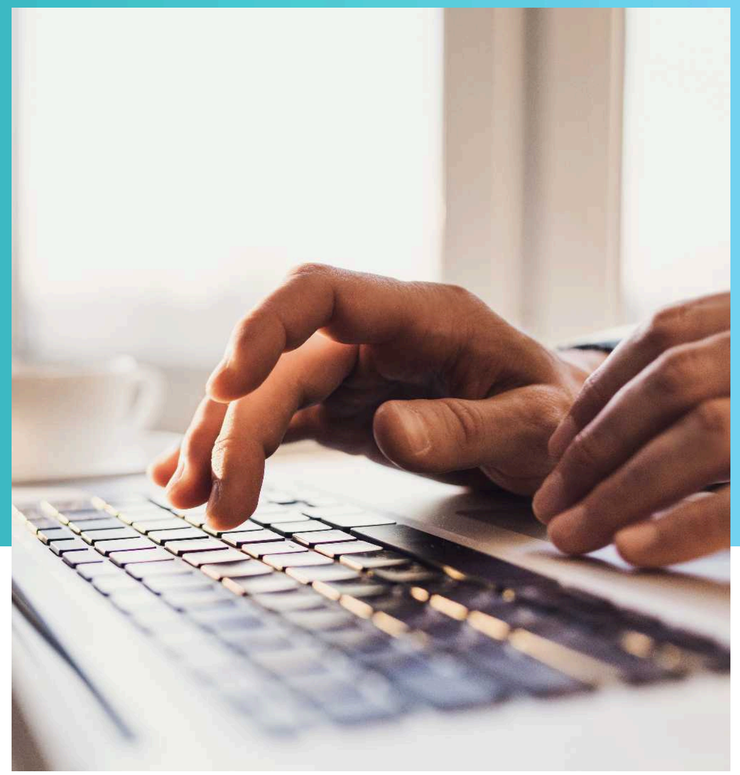


Strengthening Our Digital Infrastructure and Advancing Operational Efficiency
In response to the growing threat of cyber-attacks, we made the strategic decision to review our cybersecurity policies and strengthen our digital defenses. This initiative included a comprehensive upgrade of our firewall systems and antivirus software.

Our efforts culminated on 6 January 2025, when SMA UK achieved Cyber Essentials certification. This UK Government-backed scheme helps organisations protect themselves against the vast majority of common cyber threats. Organisations with Cyber Essentials controls in place make 92% fewer cyber insurance claims, demonstrating the scheme's real-world value.

This certification offers our community the assurance that SMA UK takes cybersecurity seriously and is actively working to keep their data safe. While no system can ever be entirely immune to attack, SMA UK is now better equipped than ever to mitigate cyber risks.

In line with our broader digital strategy, we've also completed a major upgrade of our e-commerce platform. Our shop is now integrated with Shopify, replacing the legacy system previously hosted at smauk.org.uk. Shopify is a global leader in e-commerce solutions for small to mid-sized organisations.



This move delivers both cost savings and enhanced functionality, while also ensuring full compliance with PCI DSS (Payment Card Industry Data Security Standard) offering greater security and peace of mind for those making purchases through our online store.

We have also continued to roll out our IT-for-Staff Strategy, launched last year. This multi-year programme focuses on modernising staff technology across the charity. We began by replacing the oldest laptop computers - some of which were too outdated to run supported versions of Microsoft Windows.

This phased refresh will continue over the next three years, allowing us to manage costs efficiently by spreading investment across multiple financial years.

To round off our progress this year, our IT & Operations team has made significant strides in automating key business processes. This year, we've implemented automation in the approval of Flexible Grants and the way we manage credit card expenditure across the organisation. These enhancements reduce manual effort, increase accuracy, and support our goal of operational excellence.



Staff Team

As of 1st April 2024 – 31st March 2025

Giles Lomax – CEO
Lucy de'Lemos - Head of Development and Comms
Rebecca Lewis – Fundraising Manager
Yvonne Wright – Fundraising Administrator
Stacey Shillingford – Trust Fundraising Officer
Bec Noy – Digital Communications Lead
Michele Phillips – Head of Support
Jo Spicer – Community Support Practitioner
Claire Holdcroft - Community Support Practitioner
Becci Howell - Community Support Practitioner
Nicola Beer - Community Support Practitioner
Ally Allen – Community Support Grants Officer
Portia Thorman – Head of Advocacy and Community
Liz Ryburn – Information Lead
Gary Edgecombe – Community Services Officer
Vanessa Christie-Brown – SMA Care UK Project Manager
Martin Penning - Operations Manager
Lorna Penning – Accounting Administration
Dr James Sleigh – Scientific Research Correspondent
Luis Canto E Castro (last day 31st May 2024)
Libby Roper (last day 29th May 2024)



Our Trustees

Mark Dearlove – Chair of Trustees
Katherine Jackson – Treasurer

Anne Marie Childs
Srinivas Madipalli
Alistair Emslie Smith
Julian Fiorentini
(Resigned 24th June 2024)
Lauren West
Yvette Edwards
Michael Collins
(Resigned 31st December 2024)
Toby Mildon
(Resigned 25th March 2025)
Rosaline Quinlivan
(Resigned 28th Feb 2025)
Tracey Jane Bailey Burnley
Ben Williams
Maryann Aspinall
Jennie Sheehan
Ross Hovey
(Resigned 31st December 2024)
Dr Hassan Sobati
Daniel Worrall

With special thanks to :

SMA EUROPE

MUSCULAR DYSTROPHY UK | OUR MUSCLES MATTER

TreatSMA

GENETIC ALLIANCE UK

Motability Foundation

UK SMA Newborn Screening Alliance

SMAREACH UK

ADULT SMAREACH

UK SMA PATIENT REGISTRY

Spinal Muscular Atrophy uk
SUPPORTING • INFORMING • ADVOCATING

SMA_UK

sma_uk

Spinal Muscular Atrophy UK

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

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



FINANCIAL REVIEW

2024- 2025

TREASURERS REPORT

for the Year Ended 31 March 2025

Income for the year was £1,624k an increase of 28% on the prior year. Revenue was driven primarily by donations from the community of £470k due to tremendous fundraising efforts. The charity also benefited from a large legacy endowment of £200k from the Edward Gosling Foundation and legacy income of £149k.

Significant grant income was received all of which is restricted funding: the second year grant of 239k from the Motability Foundation as part of a programme of wheelchair and mobility equipment support for people living with SMA as well as grants for SMA Care UK of £162k and working with SMA of £120k.

The total pharmaceutical funding received during the year was £264k the majority of which is restricted for SMA Care UK. Pharmaceutical funding was 16% of total income compared to 13% in the prior year. Specific donations received in 2024/5 were Roche £114k, Biogen £90k, Novartis £50k and Scholar Rock £10k. 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 governance. We aim to maximise spending on our core purpose and ensure that other costs are carefully monitored. This year, expenditure on our core purpose charitable activities increased by £335k or 52% due to increased expenditure on the projects Motability, SMA Care, Know no Bounds and community events all of which utilised restricted funding.

Expenditure on fundraising increased by £80k or 39% on prior year due largely to expenditure required to run revenue generating fundraising events.

Overall, there has been an increase in expenditure in the year of £422k or 45% due largely to the grant funded projects which are serving the SMA community. The proportion of SMA UK costs that were spent on its charitable purpose, our value or pence in the pound, was 72p with the majority of resources focused on the provision of support to the SMA community and research.

Our net income for 2024/25 was a surplus of £264k compared to £326k in the prior year. The majority of the 2024/5 surplus relates to restricted funds grants 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 2025/6 and subsequent years. As a result, SMA UK has finished the year with a strong cash position of £1,196k, £660k of which is restricted. The charity is operating within its reserves policy and the board will continue to monitor activities and reserves very carefully.



Katharine Jackson
Treasurer

REPORT OF THE TRUSTEES

For the Year Ended 31 March 2025

The trustees present their report with the financial statements of the charity for the year ended 31 March 2025.

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 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 achievement and performance can be found in the Annual report 2025.

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 enables 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 as a Charitable Incorporated Organisation.

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

Dr H Sobati (appointed 21.11.24)
Dr R Quinlivan (resigned 28.2.25)
T J Mildon (resigned 25.3.25)
M T Dearlove
Mrs K M Jackson
M P Collins (resigned 31.12.24)
Ms L E J West
Dr A M Emslie-Smith
Dr A M Childs
Mrs K Y Edwards
J M Fiorentini (resigned 24.6.24)
S Madipalli
Mrs T J B Burnley
B H Williams
Mrs M M Aspinall
Mrs J E Sheehan
R S Hovey (resigned 31.12.24)
D H W Worrall (appointed 21.11.24)

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 11 July 2025 and signed on its behalf by:



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 2025 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 2025 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

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and 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.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

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.

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

11 July 2025



STATEMENT OF FINANCIAL ACTIVITIES

for the Year Ended 31 March 2025

		Unrestricted	Restricted	2025 Total	2024 Total
INCOME AND ENDOWMENTS FROM	Notes	funds £	funds £	funds £	funds £
Donations and legacies	2	708,423	899,925	1,608,348	1,253,639
Other trading activities	3	3,788	-	3,788	3,755
Investment income	4	11,409	-	11,409	6,459
Total		723,620	899,925	1,623,545	1,263,853
EXPENDITURE ON Raising funds	5	282,699	536	283,235	203,390
Charitable activities Provision of support	6	312,027	620,189	932,216	583,796
Governance costs		100,111	-	100,111	92,671
Research related activity		36,957	7,379	44,336	58,003
Total		731,794	628,104	1,359,898	937,860
NET INCOME/ (Expenditure)		(8,174)	271,821	263,647	325,993
Transfers between funds	16	(1,326)	1,326	-	-
Net movement in funds		(9,500)	273,147	263,647	325,993
RECONCILIATION OF FUNDS Total funds brought forward		595,560	386,747	982,307	656,314
TOTAL FUNDS CARRIED FORWARD		586,060	659,894	1,245,954	982,307

STATEMENT OF FINANCIAL POSITION

31 March 2025

	Notes	Unrestricted Funds £	Restricted Funds £	2025 Total Funds £	2024 Total Funds £
FIXED ASSETS					
Tangible Assets	11	7,914	-	7,914	8,762
CURRENT ASSETS					
Stocks	12	5,672	-	5,672	5,628
Debtors	13	30,364	30,850	61,214	25,598
Cash at bank and in hand		565,889	630,542	1,196,431	965,314
Total		601,925	661,392	1,263,317	996,540
CREDITORS					
Amounts falling due within one year	14	(23,779)	(1,498)	(25,277)	(22,995)
NET CURRENT ASSETS		578,146	659,894	1,238,040	973,545
TOTAL ASSETS LESS CURRENT LIABILITIES		586,060	659,894	1,245,954	982,307
NET ASSETS		586,060	659,894	1,245,954	982,307
FUNDS					
Unrestricted funds: General Fund				586,060	595,560
Restricted funds: Various Funds				659,894	386,747
TOTAL FUNDS				1,245,954	982,307

The financial statements were approved by the Board of Trustees and authorised for issue on 11 July 2025 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 2025

	Notes	2025 £	2024 £
Cash flows from operating activities			
Cash generated from operations	1	223,509	336,003
Net cash provided by operating activities		223,509	336,003
Cash flows from investing activities			
Purchase of tangible fixed assets		(3,801)	(5,192)
Interest received		11,409	6,459
Net cash provided by/(used in) investing activities		7,608	1,267
Change in cash and cash equivalents in the reporting period		231,117	337,270
Cash and cash equivalents at the beginning of the reporting period		965,314	628,044
Cash and cash equivalents at the end of the reporting period		1,196,431	965,314

NOTES TO THE STATEMENT OF CASH FLOWS

for the Year Ended 31 March 2025

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

	2025 £	2024 £
Net income for the reporting period (as per the Statement of Financial Activities)	263,647	325,993
Adjustments for:		
Depreciation charges	4,649	3,467
Interest received	(11,409)	(6,459)
Decrease in stocks	(44)	163
Decrease/(increase) in debtors	(35,616)	10,519
Increase/(decrease) in creditors	2,282	2,320
Net cash provided by operations	223,509	336,003

2. ANALYSIS OF CHANGES IN NET FUNDS

Net Cash	**At 31.3.24 £**	**Cash flow £**	**At 31.3.25 £**
Cash at bank and in hand	965,314	231,117	1,196,431
Total	965,314	231,117	1,196,431

NOTES TO THE FINANCIAL STATEMENTS

for the Year Ended 31 March 2025

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

	2025 £	2024 £
Donations and gifts	1,100,063	717,901
Legacies	149,250	159,944
Motability	239,000	238,500
The National Lottery Community Fund	120,035	137,294
	1,608,348	**1,253,639**

3. OTHER TRADING ACTIVITIES

	2025 £	2024 £
Merchandise Sales	3,788	3,755

4. INVESTMENT INCOME

	2025 £	2024 £
Bank Interest	11,409	6,459

5. RAISING FUNDS

Raising Donations and Legacies	2025 £	2024 £
Staff Costs	164,107	137,965
Fundraising and publicity	24,208	26,826
Events and promotions * * £35,381 (50% of total profit) was paid to the Wildlife Trust because the event was delivered in partnership with the Organisation.	90,820	33,953
Cost of merchandise sales	4,100	4,646
	283,235	203,390

6. CHARITABLE ACTIVITIES COSTS

Provision of Support	2025 £	2024 £
Staff Costs and other expenses	400,816	337,154
Information and awareness raising	30,904	19,722
Shared experience network	12,241	13,783
Outreach service	123,350	77,482
Welfare and equipment grants	364,905	135,655
	932,216	583,796

Research Related Activity	2025 £	2024 £
Staff costs and other expenses	30,277	42,412
Medical research grants	7,105	6,729
Other research activities	6,954	8,862
	44,336	58,003

7. SUPPORT COSTS

	Management £
Governance costs	100,111

	2025 £	2024 £
Staff costs and other expenses	80,303	75,039
Professional fees and bank charges	5,580	7,311
Other costs	14,228	10,321
	100,111	92,671

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 2024.

Trustees' expenses
There were no trustees' expenses reimbursed for the year ended 31 March 2025 (2024: £nil).
Payments in respect of trustee indemnity insurance amounted to £678 (2024: £438).

9. STAFF COSTS

	2025 £	2024 £
Wages and salaries	545,504	483,714
Social Security costs	50,091	41,460
Pension	24,945	21,884
	620,540	547,058

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

	2025	2024
Management and administration	1	1
Direct charitable expenditure	10	12
Fundraising and publicity	5	5
	16	18

We also engaged contractors in 2025 to assist us with our management and administration 1.2 FTE.

No employees received emoluments in excess of £60,000 (2024:None)

10. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

INCOME AND ENDOWMENTS FROM	UNRESTRICTED FUNDS £	RESTRICTED FUNDS £	TOTAL FUNDS £
Donations and legacies	624,113	629,526	1,253,639
Other trading activities	3,755	-	3,755
Investment income	6,459	-	6,459
Total	634,327	629,526	1,263,853
EXPENDITURE ON			
Raising funds	203,390	-	203,390
Charitable activities			
Provision of support	261,941	321,855	583,796
Governance costs	92,671	-	92,671
Research related activity	45,745	12,258	58,003
Total	603,747	334,113	937,860
NET INCOME	30,580	295,413	325,993
RECONCILIATION OF FUNDS			
Total funds brought forward	564,980	91,334	656,314
TOTAL FUNDS CARRIED FORWARD	595,560	386,747	982,307

11. TANGIBLE FIXED ASSETS

COST	Office equipment £	Computer equipment £	Totals £
At 1 April 2024	2,554	26,055	28,609
Additions	864	2,937	3,801
At 31 March 2025	3,418	28,992	32,410
DEPRECIATION			
At 1 April 2024	1,708	18,139	19,847
Charge for year	221	4,428	4,649
At 31 March 2025	1,929	22,567	24,496
NET BOOK VALUE			
At 31 March 2025	1,489	6,425	7,914
At 31 March 2024	846	7,916	8,762

12. STOCKS

	2025 £	2024 £
Stocks held for re-sale	5,672	5,628

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2025 £	2024 £
Prepayments and accrued income	61,214	25,598

14. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2025 £	2024 £
Taxation and social security	17,669	16,273
Other creditors	7,608	6,722
	25,277	22,995

15. LEASING AGREEMENTS

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

	2025 £	2024 £
Within one year	7,500	15,000
Between one and five years	-	7,500
	7,500	22,500

16. MOVEMENT IN FUNDS

	At 31.3.24 £	Net movement in funds £	Transfers between funds £	At 31.3.25 £
Unrestricted funds				
General fund	595,560	(8,174)	(1,326)	586,060
Restricted funds				
Various funds	386,747	271,821	1,326	659,894
TOTAL FUNDS	982,307	263,647	-	1,245,954

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	723,620	(731,794)	(8,174)
Restricted funds			
Various funds	899,925	(628,104)	271,821
TOTAL FUNDS	1,623,545	(1,359,898)	263,647

Comparatives for movement in funds

	At 31.3.23 £	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

Comparative 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

16. MOVEMENT IN FUNDS - CONTINUED

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

	At 31.3.24 £	Net movement in funds £	Transfers between funds £	At 31.3.25 £
Unrestricted funds				
General fund	564,980	22,406	(1,326)	586,060
Restricted funds				
Various funds	91,334	567,234	1,326	659,894
TOTAL FUNDS	656,314	589,640	-	1,245,954

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	1,357,947	(1,335,541)	22,406
Restricted funds			
Various funds	1,529,451	(962,217)	567,234
TOTAL FUNDS	2,887,398	(2,297,758)	589,640

16. MOVEMENT IN FUNDS - CONTINUED Statement of funds	Balance b/f at 1.4.24 £	Incoming resources £	Resources expended £	Fund Transfers £	Balance c/f at 31.3.25 £
Unrestricted funds					
General fund	595,560	723,620	(731,794)	(1,326)	586,060
Restricted funds					
Equipment Grant	-	1,000	(1,000)	-	-
Flexible Response Grants	-	12,000	(12,000)	-	-
Community Information Webinars	5,000	-	-	-	5,000
Motability	127,861	239,000	(299,981)	-	66,880
SMA Care UK Grant	67,354	161,850	(40,653)	-	188,551
Community Engagement	47,350	9,500	(58,176)	1,326	-
Working with the SMA Community	61,504	120,035	(127,231)	-	54,308
Support Services	2,020	18,000	(20,020)	-	-
PhD Scholarship	3,270	10,000	(7,104)	-	6,166
SMA and Me Books	11,400	-	(10,215)	-	1,185
Know No Bounds	30,255	20,535	(29,384)	-	21,406
Content and Web Development	30,733	-	(6,065)	-	24,668
Edward Gostling	-	200,000	-	-	200,000
Adult Advocacy Workshops	-	20,396	(15,101)	-	5,295
The Big Weekend	-	57,707	(1,174)	-	56,533
Short Film NBS	-	29,902	-	-	29,902
Total Restricted Funds	**386,747**	**899,925**	**(628,104)**	**-**	**659,894**
TOTAL FUNDS	**982,307**	**1,623,545**	**(1,359,898)**	**-**	**1,245,954**

Analysis of net assets between funds

Fund balances at 31 March 2025 are represented by:	UNRESTRICTED FUNDS £	RESTRICTED FUNDS £	TOTAL FUNDS £
Tangible fixed assets	7,914	-	7,914
Stock	5,672	-	5,672
Debtors	30,364	30,850	61,214
Bank and cash	565,889	630,542	1,196,431
Current liabilities	(23,779)	(1,498)	(25,277)
Total net assets	586,060	659,894	1,245,954

16. MOVEMENT IN FUNDS - CONTINUED

Flexible Response Grants
Our FlexiGrants support all those living with SMA. We have two grant schemes which are open to all. 1) To help with the costs of accessing NHS-funded treatment or assessment and 2) To assist with buying items that support independence and alleviate hardship

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.

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

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

PhD Scholarship
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.

Know No Bounds
Two members of the SMA Community have set themselves a challenge to climb Snowdonia to fundraise for SMA UK to purchase specialist off road wheelchairs therefore aiming to give more opportunities for people living with SMA to explore the great outdoors.

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

Edward Gosling
SMA UK benefited from a large legacy endowment from the Edward Gosling Foundation of £200k with the ability to draw down £40k per year for charitable activities.

Adult Advocacy Workshops
In January and February 2025, SMA UK held two insightful workshops in Manchester and London, bringing adults living with SMA and specialist clinicians together to discover the adult's perspectives of clinical care across the UK.

The Big Weekend
SMA UK's Big Weekend: Forty and Forward will be held in September 2025 bringing over 400 people from the SMA Community as well as clinicians and organisations with a special interest in SMA and disability.

Short Film NBS
Through an external grant received from Novartis and in partnership with Havas Life London, we have produced a short film highlighting the need for SMA to be added to the Newborn screening programme as fast as possible.

17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2025.

DETAILED STATEMENT OF FINANCIAL ACTIVITIES

for the Year Ended 31 March 2025

	2025 (£)	2024 (£)
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations and gifts	1,100,063	717,901
Legacies	149,250	159,944
Motability	239,000	238,500
The National Lottery Community Fund	120,035	137,294
	1,608,348	**1,253,639**
Other trading activities		
Merchandise sales	3,788	3,755
Investment income		
Bank interest	11,409	6,459
Total incoming resources	**1,623,545**	**1,263,853**
EXPENDITURE		
Raising donations and legacies		
Staff costs and other expenses	164,107	137,965
Fundraising and publicity	24,208	26,826
Events and promotions	90,820	33,953
Cost of merchandise sales	4,100	4,646
	283,235	**203,390**
Charitable activities		
Staff costs and other expenses	431,091	379,565
Medical research grants	7,105	6,730
Other research activities	6,954	8,862
Information and awareness raising	30,905	19,722

Shared experiences network	12,242	13,783
Outreach service	123,349	77,482
Welfare, equipment grants and toy packs	364,906	135,655
	976,552	**641,799**

SUPPORT COSTS		
Management		
Staff costs and other expenses	80,303	75,039
Professional fees and bank charges	7,368	6,642
Other costs	12,440	10,990
	100,111	**92,671**
Total resources expended	1,359,898	937,860
Net income	**263,647**	**325,993**



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Office@smauk.org.uk | 01789 267520

Registered Charity Number 1106815

Spinal Muscular Atrophy UK

England & Wales - Charity number 1106815

Accounts

ANNUAL REPORT 2023–2024



Spinal Muscular Atrophy uk

SUPPORTING • INFORMING • ADVOCATING

Chair's Report



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

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

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

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

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

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

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

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



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

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

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

ADVOCACY UPDATE





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.

UK SMA Newborn Screening Alliance





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.

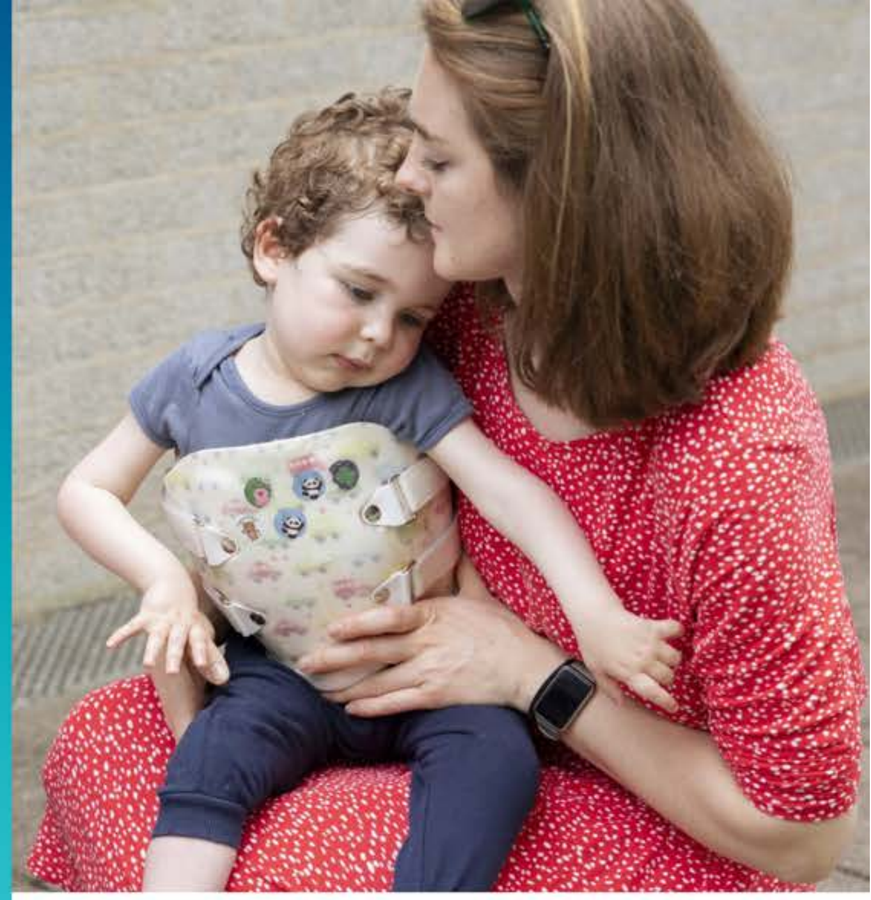
The study is not an alternative to newborn screening, its purpose is to evaluate the feasibility of screening newborns for a larger number of childhood-onset rare genetic conditions in the NHS, using whole genome sequencing. It will be exploring the potential risks and benefits of storing an individual's 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 form 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 developes.

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.

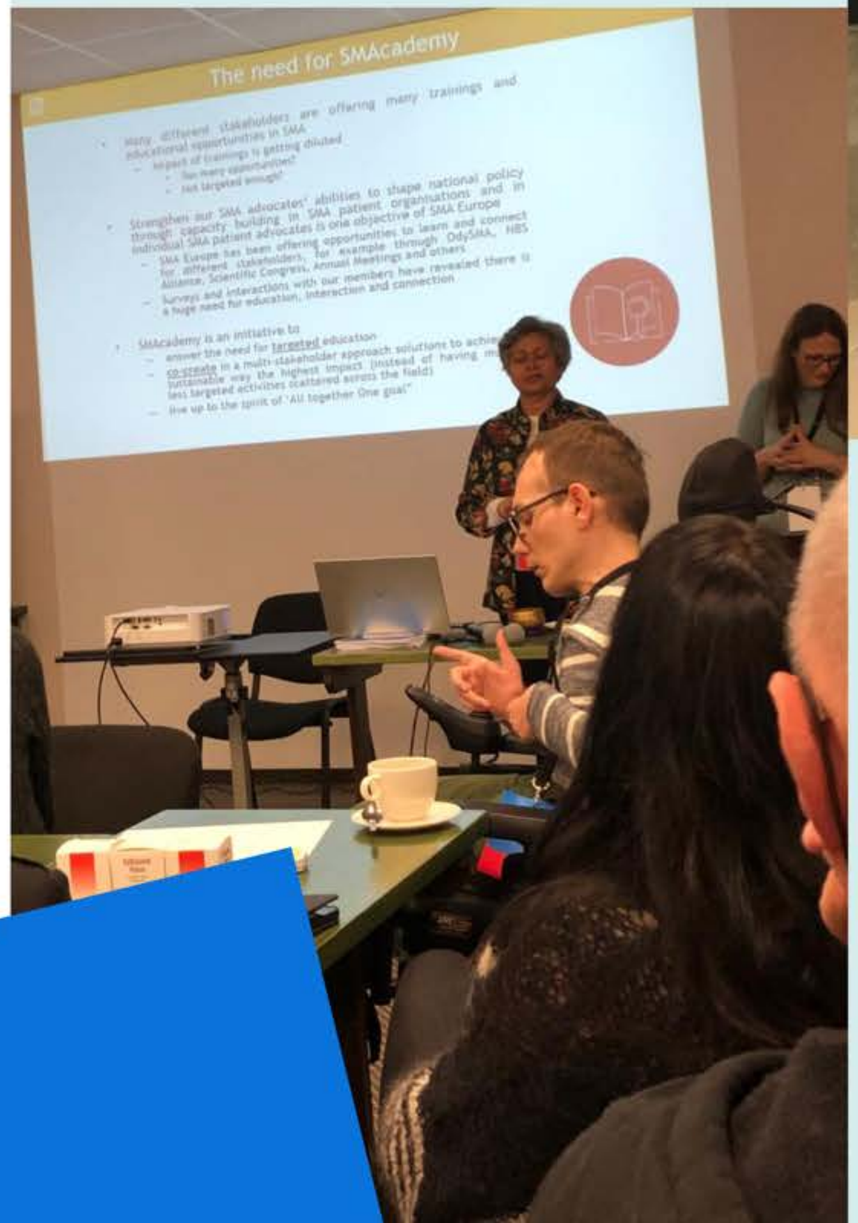
We continue to work with all three leading pharmaceutical companies, ensuring we have regular updates and taking on consultation work if aligned with our strategy.

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 Sleigh, 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.





"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 form 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 Dowloads

116
New Subscribers
+51%

1.2K
Watch Time
+124%

31K
Views
+89%



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.

22 Adults

25 Teenagers

86 Families

39 Young Adults

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 seperate 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.



SMArt Moves
BY SMA UK

Motability Foundation

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



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

Trusted Information Creator

Patient Information Forum

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



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

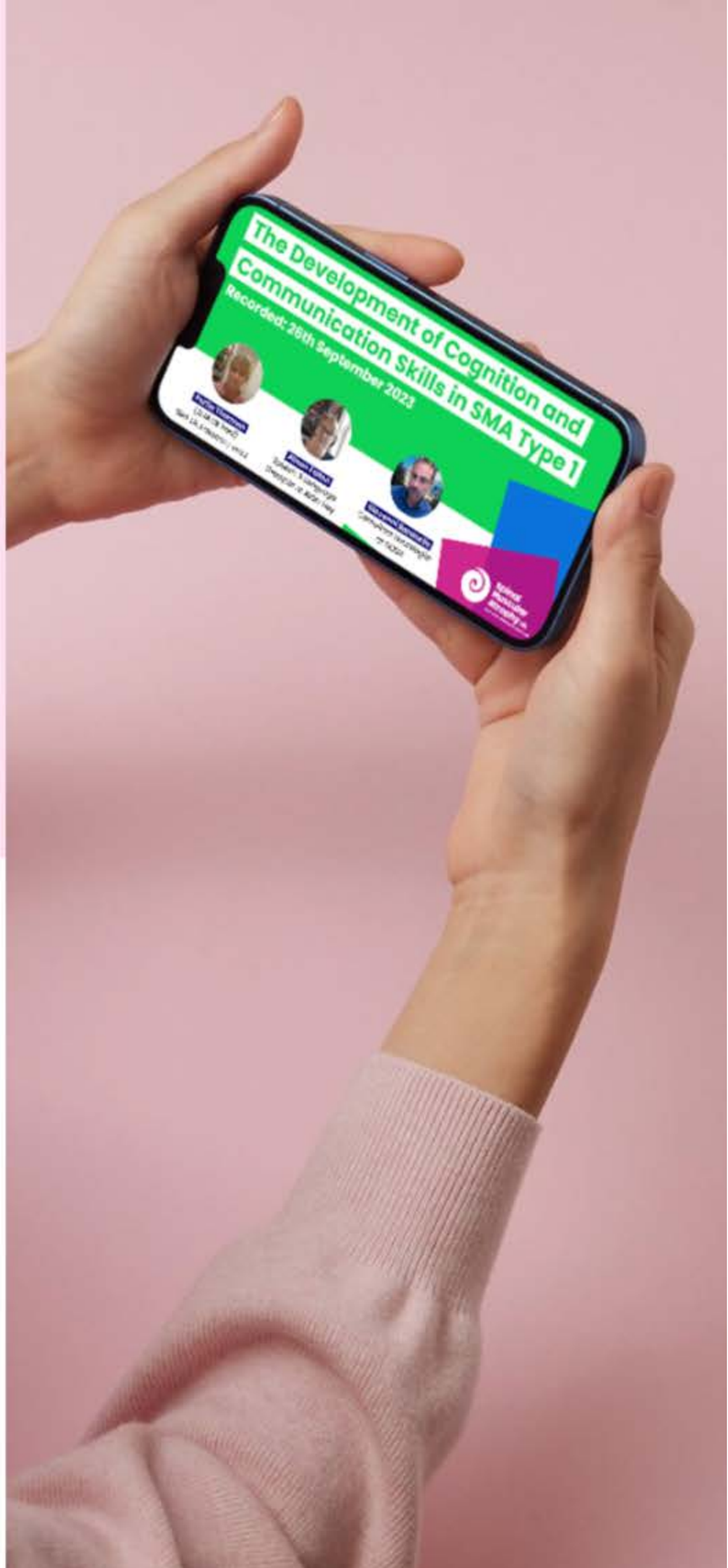


Treatment Updates from Health Professionals

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 actives 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, Scaffell 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 Chairty 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!

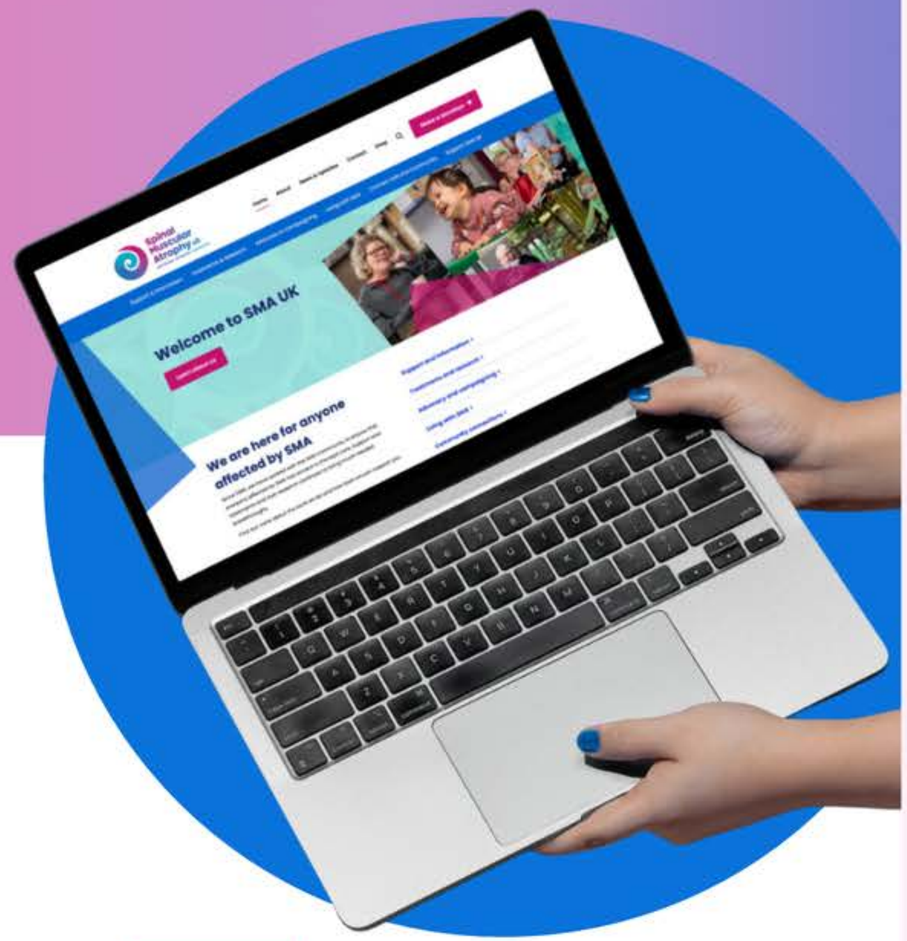
The needs of the SMA community are ever changing and we felt that our website, which is our main communication window, needed to deliver information clearly as well as being a platform where the SMA community's voices can be seen and heard, centre stage.

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.

308K
Facebook Reach

30.3K
Instagram Reach

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.



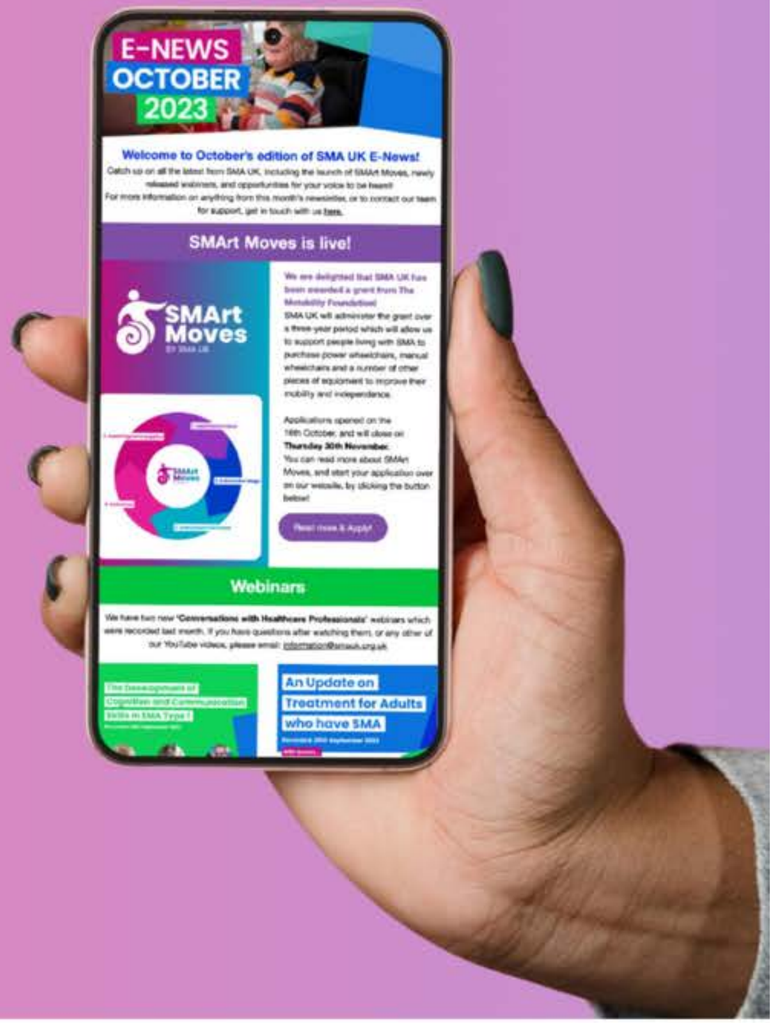
SMA Matters and e-newsletters

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



YouTube

Our YouTube Channel

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

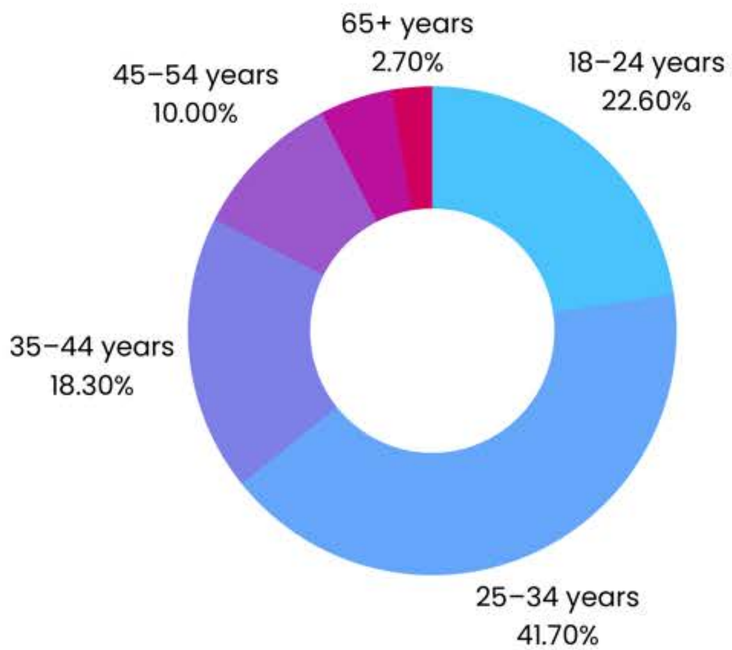
It includes educational videos explaining the causes, symptoms, and treatment options for SMA, as well as personal stories and webinars that discuss living with the condition and advancements in research and care.

Find us on YouTube @SpinalMuscularAtrophyUK

Our Audience

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

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



OPERATIONS UPDATE

smauk.org.uk

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

TreatSMA

GENETIC ALLIANCE UK

Motability Foundation

UK SMA Newborn Screening Alliance

SMAREACH UK

ADULT SMAREACH

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



Spinal Muscular Atrophy uk
SUPPORTING • INFORMING • ADVOCATING

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Registered Charity Number 1106815

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smauk.org.uk

SMA_UK

sma_uk

Spinal Muscular Atrophy 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.



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 enables 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:



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, were we 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.



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 enables 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:



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, were we 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

Spinal Muscular Atrophy UK

England & Wales - Charity number 1106815

Accounts

FINANCIAL REVIEW 2022-23

Spinal Muscular Atrophy uk

SUPPORTING • INFORMING • ADVOCATING



ABOUT SMA UK

Founded in 1985, Spinal Muscular Atrophy UK is the UK's leading charity for Spinal Muscular Atrophy (SMA), a rare, genetic, neuromuscular condition that causes muscle weakness and loss of movement.

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

Our Mission
We work tirelessly to raise awareness of SMA, to be a leading advocate for individuals and families and to ensure timely access to diagnosis, effective treatment and best management for all affected by SMA.

We listen to and support our community to make informed choices and will bring together skills, knowledge and resources in the UK and beyond, in our quest to optimise the future lives of all affected by SMA.

Our Guiding Principles
Spinal Muscular Atrophy (SMA) is a complex and rare neuromuscular condition that affects each individual and their family differently. We will always be respectful of each person's needs and choices. All face the challenge of obtaining the right support, care and opportunities to enable them to live long and fulfilling lives; some face the distress of early bereavement.



TREASURERS REPORT

Income for the year was £924k an increase of nearly 9% on the prior year. The charity benefited from a National Lotteries Grant of £154k and community fundraising has been an important source of income again this year with tremendous efforts from the fundraising team and trustees.

The total pharmaceutical funding received during the year was £314k made up of £208k for support services and £107k for Newborn Screening Alliance together this was 34% of total income as compared to 5% in the prior year. Specific donations received in 2022/23 were £150k from Novartis, £41k from Roche, £9k Abbvie and £8k Scholar Rock. In addition, the following Pharma companies supported the Newborn Screening Alliance: Novartis £67k and Roche £40k. 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, the charity has had to cope with inflationary increases in its staff costs.

The fundraising team is now at full strength led by a Head of Communications and Fundraising to engage in both fundraising and communications work.

Overall there has been an increase in expenditure in the year of £142k or 16.5%. I am pleased to report that the proportion of our costs that was spent on our charitable purpose, our value in the pound, rose from 68p to 69p as resources were focused on provision of support to the SMA community, the Newborn screening Alliance and research.

Our net income for 2022/23 was a surplus of £67k compared to £124k in the prior year. Value for money in our activities and the control of expenditure remains a priority so that the charity is sustainable for the future. As we look to 2023/4 there is continued pressure on fundraising and the need for trust, major donor and pharmaceutical support, especially given the general economic and inflationary environment. We have finished the year with a strong cash position of £628k and the board will continue to monitor activities and reserves very carefully.



Katherine Jackson
Treasurer

*Figures have been taken to the nearest decimal place for the numbers against the pharma income



FINANCIAL REVIEW

REPORT OF THE TRUSTEES

for the Year Ended 31 March 2023

The trustees who, until 4th August 2022, when SMA UK became a Charitable Incorporated Organisation (CIO), were also directors of the organisation for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 March 2023. 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 Constitution, Spinal Muscular Atrophy UK is established for:

- 3.1 The relief of people living with Spinal Muscular Atrophy and related medical conditions and to raise the public's awareness of such conditions.

- 3.2 The relief of persons who are in need after experiencing a bereavement or loss due to Spinal Muscular Atrophy.

- 3.3 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.

STRATEGIC REPORT

Achievement and performance

A detailed overview of the charity achievements and performance can be found in the Annual report 2023.

Future plans

We will continue to listen, advocate and take action on the needs of the SMA community and continue to raise awareness of SMA. The charity will be critical to ensure that we get continued universal access to treatment for every person of all ages and abilities in the SMA community.

We are already strongly advocating through the UK NBS Alliance and parliamentarians to ensure the UK Newborn Screening Committee include SMA into the existing heel pick test. We are acutely aware that further delays can have a devasting impact for families recently diagnosed with the condition and the need for speed is imperative.

The SMAUK team will be working with adults living with SMA to ensure their voices are fundamental in any decision making when shaping the SMA Care UK project.

We know that there are several clinical trials in the pipeline for complementary therapies and our team will make sure the SMA community has up to date, industry recognised information and can make informed decisions to whether they would like to be involved in any trials.

As a charity we would not be able to carry out our vital work were it not for our incredible supporters and donors. We will develop a clear strategic plan to ensure the long-term sustainability of the charity that focuses on the SMA community needs and priorities and drives life enhancing change.

FINANCIAL REVIEW

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, justi fiable 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.

In response to the cost of living crisis and high inflationary environment, Trustees have reduced the reserves policy to two months of predicted future expenditure with an additional buffer of £100,000 to be held in reserve in case of unforeseen funding issues.

STRUCTURE, GOVERNANCE AND MANAGEMENT

GOVERNING DOCUMENT

The Charity is governed by its Constitution .

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 Constitution, 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 Trustees. The Board meets four times a year with an additional meeting for the AGM. Meetings are held virtually or at the charity's offices in Stratford upon Avon or suitable venue.,

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. This is recorded on a Risk register

REFERENCE & ADMINISTRATIVE DETAILS

Registered Company number (until 4th August 2022)
05137534 (England and Wales)

Registered Charity number
1106815

Company Secretary
A Smith-Morgan

Trustees
T J D Sheffield C S B Knight D J Waltier
Dr R Quinlivan T J Mildon
M T Dearlove K M Jackson M P Collins
B M O Morris L E J West Dr A M E Smith
Dr A M Childs
K Y Edwards J M Fiorentini
S Madipalli C M Gray

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

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 (who were, until 4th August 2022, also the directors of Spinal Muscular Atrophy UK for the purposes of company law) 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".

Company law 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 Charitable Incorporated Organisation and of the incoming resources and application of resources, including the income and expenditure, of the charitable company 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 charitable company 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 Charitable Incorporated Organisationand to enable them to ensure that the financial statements, until 4th August 2022, compliedy with the Companies Act 2006. They are also responsible for safeguarding the assets of the Charitable Incorporated Organisationand hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- there is no relevant audit information of which the Charitable Incorporated Organisation auditors are unaware; and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

Report of the trustees, incorporating a strategic report, approved by order of the board of trustees, as the company trustees, on 16/08/2023 and signed on the board's behalf by:



.....

M T Dearlove - Trustee

OPINION

We have audited the financial statements of Spinal Muscular Atrophy UK (Charitable Incorporated Organisation) for the year ended 31 March 2023 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 Charitable Incorporated Organisationaffairs as at 31 March 2023 and of its incoming resources and application of resources, including its income and expenditure, 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';
- Have been prepared in accordance with the requirements of the Charities Act 2011;.

BASIS FOR OPINION

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and 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 Charitable Incorporated Organisationin 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 Charitable Incorporated Organisation 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
- The Charitable Incorporated Organisation has not kept adequate accounting records; 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 (who until 4th August 2022 were also the directors of charitable company (for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they 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 Charitable Incorporated Organisation 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 Charitable Incorporated Organisation 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



David Cooper

STATEMENT OF FINANCIAL ACTIVITIES

for the Year Ended 31 March 2023

	Notes	Unrestircted funds (£)	Restricted funds (£)	2023 Total Funds (£)	2022 Total Funds (£)
INCOME AND ENDOWMENTS FROM					
Donations and Legacies	2	423,127	495,215	918,342	834,596
Other trading activities	3	5,743	-	5,743	5,743
Investment income	4	588	-	588	130
Total		**429,458**	**495,215**	**924,673**	**839,420**
EXPENDITURE ON					
Raising funds	5	169,411	-	169,411	161,871
CHARITABLE ACTIVITIES	6				
Provision of support		157,878	443,691	601,569	379,520
Governance costs		64,973	-	64,973	68,228
Research related activity		20,686	884	21,570	105,847
Total		**412,948**	**444,575**	**857,523**	**715,466**
NET INCOME		16,510	50,640	67,150	123,954
Transfers between funds	17	(367)	367	-	-
Net movement in funds		16,143	51,007	67,150	123,954
RECONCILIATION OF FUNDS					
Total funds brought forward		548,837	40,327	589,164	465,210
TOTAL FUNDS CARRIED FORWARD		**564,980**	**91,334**	**656,314**	**589,164**

STATEMENT OF FINANCIAL POSITION

31 March 2023

	Notes	Unrestircted funds (£)	Restricted funds (£)	2023 Total Funds (£)	2022 Total Funds (£)
FIXED ASSETS					
Tangible assets	12	7,037	-	7,037	8,116
CURRENT ASSETS					
Stocks	13	5,791	-	5,791	6,285
Debtors	14	36,117	-	36,117	15,239
Cash at bank and in hand		536,710	91,334	628,044	591,204
		578,618	91,334	669,952	612,728
CREDITORS					
Amounts falling due within one year	15	(20,675)	-	(20,675)	(31,680)
NET CURRENT ASSETS		557,943	91,334	649,277	581,048
TOTAL ASSETS LESS CURRENT LIABILITIES		564,980	91,334	656,314	589,164
NET ASSETS		564,980	91,334	656,314	589,164
FUNDS	17				
Unrestricted funds:					
General fund				564,980	548,837
Restricted funds:					
General fund				91,334	40,327
TOTAL FUNDS				**656,314**	**589,164**

These financial statements have been audited under the requirements of Section 145 of the Charities Act 2011.

The financial statements were approved by the Board of Trustees and authorised for issue on 16/08/2023 and were signed on its behalf by:



K M Jackson - Trustee

16.08.2023



M T Dearlove - Trustee

16.08.2023

STATEMENT OF CASH FLOWS

for the Year Ended 31 March 2023

	Notes	2023 (£)	2022 (£)
CASH FLOWS FROM OPERATING ACTIVITIES			
Cash generated from operations	1	38,647	130,371
Cash generated from operations		38,647	130,371
CASH FLOWS FROM INVESTING ACTIVITIES			
Purchase of tangible fixed assets		(2,395)	(8,223)
Interest received		588	130
Net cash used in investing activities		(1,807)	(8,093)
CHANGE IN CASH AND CASH EQUIVALENTS IN THE REPORTING PERIOD		36,840	122,278
CASH AND CASH EQUIVALENTS AT THE BEGINNING OF THE REPORTING PERIOD		591,204	468,926
CASH AND CASH EQUIVALENTS AT THE END OF THE REPORTING PERIOD		**628,044**	**591,204**

NOTES TO THE STATEMENT OF CASH FLOWS

for the Year Ended 31 March 2023

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

	2023 (£)	2022 (£)
NET INCOME FOR THE REPORTING PERIOD (AS PER THE STATEMENT OF FINANCIAL ACTIVITIES)	67,150	123,954
ADJUSTMENTS FOR:		
Depreciation charges	3,474	4,253
Interest received	(588)	130
Decrease/(increase) in stocks	494	(29)
Increase in debtors	(20,878)	(6,600)
(Decrease)/increase in creditors	(11,005)	8,923
Net cash provided by operations	**38,647**	**130,371**

2. ANALYSIS OF CHANGES IN NET FUNDS

	At 1.4.22 (£)	2023 (£)	2022 (£)
NET CASH			
(Decrease)/increase in creditors	591,204	36,840	628,044
	591,204	36,840	628,044
TOTAL FUNDS	**591,204**	**36,840**	**628,044**

NOTES TO THE FINANCIAL STATEMENTS

for the Year Ended 31 March 2023

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
Database	- 14.3% on cost
Computer equipment	- 25% on cost

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 corporation 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	2023 (£)	2022 (£)
Donations and gifts	759,199	680,272
Legacies	5,312	25,000
The National Lottery Community Fund	153,831	129,324
	918,342	**834,596**

3. OTHER TRADING ACTIVITIES	2023 (£)	2022 (£)
Merchandise sales	5,743	4,694

4. INVESTMENT INCOME	2023 (£)	2022 (£)
Bank interest	588	130

5. RAISING FUNDS	2023 (£)	2022 (£)
RAISING DONATIONS AND LEGACIES		
Staff costs	133,680	94,642
Fundraising and publicity	21,090	25,817
Events and promotions	12,304	38,702
Cost of merchandise sales	2,337	2,710
	169,411	**161,871**

6. CHARITABLE ACTIVITIES COSTS	2023 (£)	2022 (£)
PROVISION OF SUPPORT		
Staff costs and other expenses	373,414	277,712
Information and awareness raising	34,641	7,465
Shared experiences network	24,045	27,048
Outreach service	48,285	37,923
Welfare and equipment grants	121,184	29,372
	601,569	**379,520**
RESEARCH RELATED ACTIVITY		
Staff costs and other expenses	18,093	64,423
Medical research grants	-	35,072
Other research activities	3,477	6,352
	21,570	**105,847**

7. SUPPORT COSTS	2023 (£)	2022 (£)
Staff costs and other expenses	51,285	48,301
Professional fees and bank charges	6,478	8,939
Other costs	7,210	10,988
	64,973	**68,228**

8. NET INCOME /(EXPENDITURE)	2023 (£)	2022 (£)
Depreciation - owned assets	3,474	4,253
Fees payable to auditor for:		
Audit	1,750	1,500
Other services	3,450	3,265

9. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2023 nor for the year ended 31 March 2022.

Trustees' expenses

There were no trustees' expenses reimbursed for the year ended 31 March 2023 (2022:£nil).

Payments in respect of trustee indemnity insurance amounted to £398 (2022: £398).

10. STAFF COSTS	2023 (£)	2022 (£)
Wages and salaries	461,860	391,466
Social security costs	43,784	34,664
Pension	20,476	17,288
	526,120	**443,418**

THE AVERAGE MONTHLY NUMBER OF EMPLOYEES DURING THE YEAR WAS AS FOLLOWS:	2023	2022
Management and administration	1	1
Direct charitable expenditure	10	10
Fundraising and publicity	5	5
	16	**16**

We also engaged contractors in 2023 to assist us with our management and administration 1.2 FTE.

No employees received emoluments in excess of £60,000 (2022: None)

11. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds (£)	Restricted funds (£)	Total Funds (£)
INCOME AND ENDOWMENTS FROM			
Donations and legacies	579,516	255,080	834,596
Other trading activities	4,694	-	4,694
Investment income	130	-	130
TOTAL	**584,340**	**255,080**	**839,420**
EXPENDITURE ON			
Raising funds	161,871	-	161,871
CHARITABLE ACTIVITIES			
Provision of support	153,498	226,022	379,520
Governance costs	68,228	-	68,228
Research related activity	95,847	10,000	105,847
TOTAL	**479,444**	**236,022**	**715,466**

	Unrestricted funds (£)	Restricted funds (£)	Total Funds (£)
NET INCOME	104,896	19,058	123,954
RECONCILIATION OF FUNDS			
Total funds brought forward	443,941	21,269	465,210
TOTAL FUNDS CARRIED FORWARD	**548,837**	**40,327**	**589,164**

12. TANGIBLE FIXED ASSETS	Office Equipment (£)	Database (£)	Computer Equipment (£)	Totals (£)
COST				
At 1 April 2022	2,554	31,312	18,468	18,468
Additions	-	-	2,395	2,395
At 31 March 2023	2,554	31,312	20,863	54,729
DEPRECIATION	1,391	31,312	11,515	44,218
At 1 April 2022	159	-	3,315	3,474
Charge for year				
At 31 March 2023	1,550	31,312	14,830	47,692
NET BOOK VALUE				
At 1 April 2023	1,004	-	6,033	7,037
At 31 March 2022	1,163	-	6,953	8,116

13. STOCKS	2023 (£)	2022 (£)
Stocks held for re-sale	5,791	6,285

14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR	2023 (£)	2022 (£)
Prepayments and accrued income	36,117	15,239

CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR	2023 (£)	2022 (£)
Social security and other taxes	14,555	14,869
Other creditors	921	3,810
Accrued expenses	5,199	13,001
	20,675	**31,680**

16. LEASING AGREEMENTS	2023 (£)	2022 (£)
Minimum lease payments under non-cancellable operating leases fall due as follows:		
Within one year	20,094	21,150
Between one and five years	22,500	45,146
	42,594	**66,296**

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

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			
General fund	495,215	(444,575)	50,640
TOTAL FUNDS	**924,673**	**(857,523)**	**67,150**

COMPARATIVES FOR MOVEMENT IN FUNDS

	At 1.4.21 (£)	Net Movement in funds (£)	At 31.3.22 (£)
Unrestricted funds			
General fund	443,941	104,896	548,837
Restricted funds			
General fund	21,269	19,058	40,327
TOTAL FUNDS	**465,210**	**123,954**	**589,164**

	Incoming resources (£)	Resources expended (£)	Movement in funds (£)
Unrestricted funds			
General fund	584,340	(479,444)	104,896
Restricted funds			
General fund	255,080	(236,022)	19,058
TOTAL FUNDS	**839,420**	**(715,466)**	**123,954**

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

	At 1.4.21 (£)	Net Movement in funds (£)	Transfer between funds (£)	At 31.3.23 (£)
Unrestricted funds				
General fund	443,941	121,406	(367)	564,980
Restricted funds				
Various	21,269	69,698	367	91,334
TOTAL FUNDS	**465,210**	**191,104**	**-**	**656,314**

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	1,013,798	(892,392)	121,406
Restricted funds			
General fund	750,295	(680,597)	69,698
TOTAL FUNDS	**1,764,093**	**(1,572,989)**	**191,104**

STATEMENT OF FUNDS	Balance b/f at 1.4.22 **£**	Incoming Resources **£**	Resources Expended **£**	Funds Transfer **£**	Balance c/f at 31.3.23 **£**
Unrestricted funds					
General funds	548,837	429,458	(412,948)	(367)	564,980
Restricted funds					
Support into the 2020s:					
- Lotteries Reaching Communities	28,669	-	(28,669)	-	-
- Other Grants	10,000	-	(10,000)	-	-
Toy Packs	350	500	(350)	-	500
Flexible Response Grants	-	-	(200)	200	-
Support Work with Families in Scotland	-	500	(500)	-	-
UK SMA Newborn Screening Alliance	-	106,734	(101,335)	-	5,399
SMA Horizons Project	-	1,080	(317)	-	763
Working with the SMA Community through Covid & Beyond - England	-	153,831	(85,432)	-	68,399
Working with the SMA Community through Covid & Beyond - UK	-	150,000	(150,000)	-	-
Website & Digital Comms Development	-	57,570	(51,297)	-	6,273
Support Services	-	15,000	(15,000)	-	-
PhD Scholarship Yr2	-	10,000	-	-	10,000
Northern Ireland Events	1,308	-	(1,475)	167	-
TOTAL RESTRICTED FUNDS	**40,327**	**495,215**	**(444,575)**	**367**	**91,334**
TOTAL FUNDS	**589,164**	**924,673**	**(857,523)**	**-**	**656,314**

ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted funds (£)	Restricted funds (£)	Total Funds (£)
Fund balances at 31 March 2023 are represented by:			
Tangible fixed assets	7,037	-	7,037
Stock	5,791	-	5,791
Debtors	36,117	-	36,117
Bank and cash	536,710	91,334	628,044
Current liabilities	(20,675)	-	(20,675)
TOTAL NET ASSETS	**564,980**	**91,334**	**656,314**

Support into the 2020s
This includes many of the services and workstreams described in the section, 'Achievements and Performance': information production, outreach, support and advocacy work and the organising of community networks and events and advocacy.

It s funded by :

Lotteries Reaching Communities
This is a 3 year grant (June 2019 - May 2022) to cover 50% of the costs of our 'Support into the 2020s services in England.

Support into the 2020s-Other
Combines donations from Trusts and restricted community donations towards the remaining costs across the UK.

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.

Flexible Response Grants
This fund provides a swift response to an urgent need when no other funding source is available. It may also assist people with travel and subsistence costs when they access treatments. Grants are typically small.

Support with Families in Scotland
A fund that helped to cover the costs of our support work in Scotland.

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. Thesetherapies may be complementary to the existing ones that target the SMN upregulation.

Working with the SMA Community Through Covid & Beyond- England
This Fund, provided by the National Lotteries, supports our information, outreach and support , community development and advocacy services. The 2022/3 grant was the first year of a 4 year grant (September 2022 - August 2026) making a significant contribution to the costs of these services. Contributions from Lotteries will reduce over the 4 year period.

Working with the SMA Community Through Covid & Beyond-UK
This Fund goes towards the costs of our information, outreach and support , community development and advocacy services that are not covered by the National Lotteries grant.

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.

Northern Ireland Events
This fund enables us to offer events in Northern Ireland for adults, children and young people with SMA and their families. These provide opportunities to share experiences and connect up with others in the SMA Community.

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.

18. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2023.

19. 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 2023

	2023 (£)	2022 (£)
INCOME AND ENDOWMENTS		
Donations and gifts		
Donations and gifts	759,199	680,272
Legacies	5,312	25,000
The National Lottery Community Fund	153,831	129,324
Other trading activities		
Merchandise sales	5,743	4,694
Investment income		
Bank interest	588	130
TOTAL INCOMING RESOURCES	**924,673**	**839,420**

	2023 (£)	2022 (£)
EXPENDITURE		
Raising donations and legacies		
Staff costs and other expenses	133,680	94,642
Fundraising and publicity	21,090	25,817
Events and promotions	12,304	38,702
Cost of merchandise sales	2,337	2,710
	169,411	**161,871**

	2023 (£)	2022 (£)
Charitable activities		
Staff costs and other expenses	391,507	342,135
Medical research grants	378	35,072
Other research activities	3,099	6,352
Information and awareness raising	34,641	7,465
Shared experiences network	24,045	27,048
Outreach service	48,285	37,923
Welfare, equipment grants and toy packs	121,184	29,372
	623,139	**485,367**
Support costs		
Management		
Staff costs and other expenses	51,285	48,301
Professional fees and bank charges	6,478	8,939
Other costs	7,210	10,988
	64,973	**68,228**
TOTAL RESOURCES EXPENDED	**857,523**	**715,466**
NET INCOME	**67,150**	**123,954**



Address: Unit 9, Shottery Brook Office Park. Timothy's Bridge Road,
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Office@smauk.org.uk | 01789 267520

Registered Charity Number 1106815

Spinal Muscular Atrophy UK

England & Wales - Charity number 1106815

Accounts

Annual Report & Financial Statements

For the year ending 31st March 2022



spinal muscular atrophy uk

Help for today, hope for tomorrow

Trusted Information Creator

Patient Information Forum

disability confident COMMITTED

Registered with FUNDRAISING REGULATOR

Welcome to our Annual Report and Financial Statements

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Letter from the Chair

2021 was a transformational year for the SMA Community – a year of highs and lows, anxiety and excitement. The impact of Covid and the need for isolation for many was wearing heavy. But, at the same time, there was the very welcome news early in the year that the gene therapy drug Zolgensma™ was approved for NHS use in the UK. Another 'win' was the news later in the year that Evrysdi™ (risdiplam) would also be funded by the NHS. We are delighted as this means there are now three treatments for SMA, with varying eligibility criteria.

We have been providing information and updates about all these developments to assist people so that they can have informed conversations with their clinicians. We have also continued to work closely with our NHS colleagues with the aim of ensuring that treatments reach everyone for whom they are clinically appropriate.

Whilst we are of course excited by the potential of these new treatments, it is widely recognised that all treatments are more effective the earlier they are given. This year, as a key member of the UK SMA Newborn Screening Alliance, we will be working even harder for SMA to be included as part of the routine bloodspot testing of all newborns.

Care, as well as access to treatments, has taken centre-stage for many this year as the NHS and Social Services nationally have struggled to juggle priorities. We have increasingly been able to lend our voice to that of others to advocate on these wider issues. As part of this, we have worked alongside Community members who have shared their experiences of, for example, the shortage of Personal Assistants (PAs), as well as other topics of interest in our growing podcast series.

Our dedicated Outreach & Support Team have worked hard to meet the 30% increase in demand in services in 2021 compared to 2020. At the same time, our income was still impacted significantly by Covid but, thanks to our loyal fundraisers who were again able to take part in, or organise, baking, running, walking, cycling, and more, to support the charity, this gradually picked up over the summer. A special thanks as well to our long-term funding partners such as the National Lottery Community Fund and the pharma sector.

As we look forwards, we know SMA UK has a key part to play in supporting our Community to be more connected, better informed and to build awareness about SMA in the general population. We will share these messages via a range of channels, upgrading our website, and extending our Podcast and Webinar series which shares experiences, stories, life-hacks and challenges, as well as updates from health professionals. At the time of writing, the return to face-to-face events is also happily underway. These are being held regionally throughout the UK in June and July.

Our membership of SMA Europe, which brings together 23 countries who all share the agenda of 'creating a better world for all those with SMA', further extends our reach. In the UK we are also proud to work in partnerships with like-minded organisations such as MDUK and TreatSMA, amongst others.

Internally, our organisation has continued to evolve and develop. Remote working has allowed us to recruit beyond our traditional office base in the Midlands, opening up opportunities to build our team as well as reaching families and adults in ways we had never imagined possible.

Finally, I would like to thank our CEO, Angela Smith-Morgan, her amazing team, and our wonderful volunteers including all the Trustees, who have worked so hard to help SMA UK deliver for our Community.



Mark Dearlove, July 2022

Trustees' Strategic Report

Spinal Muscular Atrophy (SMA) is a rare, genetic, neuromuscular condition causing progressive muscle wasting (atrophy) and weakness leading to loss of movement. This may affect crawling and walking ability, arm, hand, head and neck movement, breathing and swallowing. There are different forms of SMA and a wide spectrum of how severely children and adults are affected.

Based on 2017 global studies of the numbers of people born with and living with SMA, it has been thought that there are between 670 – 1340 children, young people and adults, who have SMA, living in the UK. This was before the new drug treatments and the impact this has had, in particular on the survival of children who have the most severe Type, SMA Type 1. We would therefore expect the population to be slowly increasing as there are now some 65 – 70 babies born each year with some form of SMA. Approximately 60% will be diagnosed with SMA Type 1.



Our Charity

Spinal Muscular Atrophy UK was founded in 1985 as the Jennifer Trust for SMA which merged with the SMA Trust in 2018 to become the charity it is today.

Our Vision

Everyone affected by SMA has access to the best care, support and drug treatments; research continues to bring breakthroughs that improve people's quality of life.

Our Mission

To provide accurate information and a wide range of support services, while working to improve access to the best care, services and drug treatments today and funding research projects that can change tomorrow.



Our Guiding Principles

Spinal Muscular Atrophy (SMA) is a complex and rare neuromuscular condition that affects each individual and their family differently. We will always be respectful of each person's needs and choices. All face the challenge of obtaining the right support, care and opportunities to enable them to live long and fulfilling lives; some face the distress of early bereavement.



Our Strategy

Providing Information and Support Services in the UK for:

- Families and individuals – personalised information about SMA; emotional and practical support; opportunities to have contact with others affected by the condition.
- Wider advocacy for services and access to care and drug treatments.
- Health, education and social care professionals – information about SMA; working with them to support families and individuals.
- The SMA Community - up-to-date information about developments in research, drug treatments, support and disability services, consultations and campaigns.



Working to Improve and Monitor SMA Community Access to:

- Care and support
- New drug treatments and clinical trials
- Equipment and adaptations

We are **advocates** on behalf of the SMA Community to authorities that regulate access to drug treatments, care and services. We **support developments** that improve and monitor access to services and drug treatments.

We work with other charities, with health, education and social care professionals, and with national and international charities and organisations to **campaign** on issues that matter to people affected by SMA.



Funding and Supporting Research:

Pharmaceutical companies are now investing heavily in the clinical development of drug treatments; these are important stepping-stones that we will continue to monitor and support.

Since 1986, we have raised and donated over £5 million in support of research. Our strong connections and collaborations with other UK and international SMA charities and groups, clinicians, researchers and the pharmaceutical industry, ensure best use of any funds we allocate to research-related initiatives.

Where we can make a difference, we will.

Achievements & Performance

Issues faced by the SMA Community

We estimate that there are now as many as 150 children in England who have SMA Type 1 and who have been treated since 2018. They need regular physiotherapy, speech and language therapy, dietary advice and specialist equipment, and family homes need significant adaptations; but these services haven't grown or kept pace with the need. Similarly, many nurseries and schools do not have the experience, and sadly not all show a willingness, to provide the education and facilities needed by these children who are very bright and eager to learn.

Few adults have access to regular physiotherapy despite it being widely agreed that this is vital - as are assessments and advice from other clinical specialists, for example dieticians.

It is well-documented[1] that life costs more for disabled people and their families than for others anyway. On top of this, for many, the combination of Covid, Brexit and insufficient levels of funding for care packages, has presented huge challenges with recruiting and retaining carers / personal assistants. Added to this we now have a potentially huge increase in the cost of living, particularly the cost of energy, which impacts disproportionately on children, young people and adults who need night-time ventilation, a cough assist machine, powered wheelchairs – to name just a few essentials in their lives. Health, education and funding of support, are simply not keeping pace with the growing needs of the current SMA Community, but without these services the full benefits of treatment cannot be realised.

And though this year saw yet another huge breakthrough with the NHS adding funding of risdiplam as a possible treatment, access for many adults has been slow and we are still not home and dry in terms of permanent access for all.

What does the Community want from us?

In September 2021, our survey to the SMA Community asked, 'What do you want from SMA UK?'. We had 145 responses which, given how 'surveyed out' our Community is, was an excellent response rate. Asked what we should provide:

More than 90% said:



Information about SMA, care and services, access to treatments and research and treatment developments.



Outreach and support following diagnosis and at challenging times.

More than 80% said:



Podcasts, videos, people's stories and, when possible, **face-to-face events.**



Advocacy for better, faster access **to treatments** and **newborn screening for SMA**, and access to **better health & social care.**

[1] www.scope.org.uk/campaigns/extra-costs/

What did we do about all this?

Our 2021 Support Services Team (Liz, Jackie, Jo, Maggie, Claire, Libby, Dermot & Michele) worked to respond to all these Community priorities.



Information

We met the Community's request for information by providing relevant, up to date, evidence-based, accurate information relating to SMA – about the condition and its management, clinical trial results and the new drug treatments. These last two topics are covered by our trusty Research Correspondents, James and Vanessa.



We also couldn't do this without the support of the clinical experts who review our information, and without feedback from our target audiences. Our thanks to them all.



"I find your leaflets family-friendly and gentle in the information given, yet clear and concise - they make a huge difference when families are given the diagnosis." **Neuromuscular Care Advisor**

Our website continued to be popular:

Website Visitors

2019	2020	2021
67,795	84,272	101,978

Top Unique Page Views 2021

Page	Unique Views
Information	10,030
Support	7,389
Treatment & Research	7,366
Recent Diagnosis SMA Type 1	6,890
Zolgensma	5,961
Risdiplam	5,736
Nusinersen	5,571

We were audited by, and accredited to, the Patient Information Forum which replaced the Information Standard.

Trusted Information Creator
Patient Information Forum

Living With SMA Website Visitors

2020	2021
2,800	4,600

Divided into three main sections for parents of children, teenagers and adults, this website section builds on knowledge and advice from the SMA Community and SMA UK's Support Team. It covers a whole host of topics including health & wellbeing, equipment, homes, education, work, transport, leisure, and financial, emotional and social support.

We try to extend our reach into the SMA Community by using a number of social media platforms. Our monthly E-news bulletin yet again saw an increase in people on the mailing list to almost 3,300, with an open-rate consistently well above the

sector norm of 21%. These mailings kept the Community informed about access to treatment developments, consultations, surveys, fundraising activities, and other information and news.

We run monthly reports to collect statistics on our social media:

December	2020	2021
Facebook likes	4,865	5,263
Twitter followers	2,110	2,462
Instagram followers	1,537	1,958

We also started putting more content out on LinkedIn and monitoring the stats on this, increasing our followers to 378 by December 2021.

With so many different ways of being in touch, and not always knowing who we're reaching, it's difficult to know exactly how many people we're in touch with have SMA and are in the UK. Our best estimate, based on our mailing list, is that we're in contact with some 780 households where there is a parent of a child / young person who has SMA or an adult who has SMA (2019: 600). Similarly, we're in contact with more than 360 families bereaved by SMA.

Outreach and Support

This service was also high on the Community list as one SMA UK should provide. Though we were again unable to make home visits for most of the year due to Covid, we still provided individual support across the UK by phone, email and Zoom call to parents of children who have SMA and to young people and adults who have SMA, and their families. Everyone's circumstances, requests and needs were different, with more and more people facing the complex and challenging times outlined earlier in this summary.

"We really appreciate all the help and support you give us; without it we wouldn't be at this point we are now. Thank you so much." **Parent**

Affected children, young people or adults	Numbers 2020	Numbers 2021
New to SMA UK	83	113
Returned to SMA UK	124	156
Total	**207**	**269**

As part of this service, we offer families with an infant up to 12 months of age a free multisensory toypack. Though every toy pack we send out means another family is struggling with a devastating diagnosis, we know how much fun and joy they can bring. This year, we sent out 33.



"Thank you so much! The toys are wonderful." **Parent**

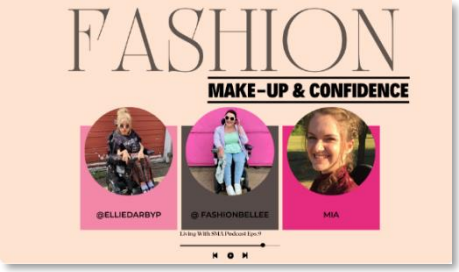
For some queries, we were also able to draw on the tips, ideas and experiences of our generous volunteers who form our Community Questions Network. That's 75 adults who have SMA, parents, grandparents and others.

We wished Maggie, who had been an Outreach Worker with us since 2006, a very happy retirement. We and many in the Community will greatly miss her. Looking forward, though, we are very pleased that Rebecca joins the Outreach Team in July 2022.



Though we continued to focus on the UK, we always replied to overseas enquiries, many from families desperately seeking treatment. We did our best to link people in to support networks and give relevant information.

Podcasts, videos, people's stories and, when possible, face-to-face events



Our response to this priority saw the release of podcasts and videos on an ever-increasing range of topics - made by and with the SMA Community. Recent examples were: PAs Aren't Just For Care; Health Screening; Periods; Employment & Blogging; Hitting Your Forties.

It wasn't possible to plan any face-to-face events given the uncertainty over Covid and that many people were still self-isolating. We did, though, offer a number of virtual events including a 12-week Mindfulness Course. We also continued to offer people the chance to connect up with each other to share experiences, tips and ideas via our community networks.

Network	No. Of members
Adults	89
Young Adults	24

Looking forward to later in 2022, we are venturing into face-to-face events with 6 summer Picnic In The Parks planned in different regions across the UK.



We are also really pleased to have Luis joining the team in May 2022 to help us grow the Living With SMA podcast series.

Advocacy for treatments and access to better health and social care

We responded to this Community priority again when we joined with the other patient groups and clinicians advocating strongly both in England and Scotland. Access to Zolgensma™ for some children who have SMA Type 1 was announced in both countries in March 2022. Positive decisions for access to risdiplam for those who have SMA Type 1, 2 or 3 were announced in December 2021 and February 2022. The other devolved countries also followed these leads.

We continue to be members of the national groups in England that monitor the roll-out of the managed access programmes for Spinraza™ (nusinersen) and Evrysdi™ (risdiplam) and will be involved in the review of these in due course.



Advocacy for treatment has been a huge amount of work and though we have advocated on other issues, when possible, our capacity to do so has been limited. In January 2022, we were therefore delighted to welcome Portia to the team as Advocacy Lead.

We hope our efforts to respond to the Community's priorities have, in some small way, helped to ease the enormous challenges people face today, and that others might echo this parent's reflection:

"What my family most value your service for is as support (being knowledgeable in all things relating to SMA whenever we get in touch to ask about it) and putting us in touch with other families who can offer emotional support, and advocating for access to relevant equipment adaptations etc." **Parent**

Advocacy for Newborn Screening for SMA

The SMA Community has witnessed phenomenal developments over the last few years, with the three ground-breaking treatments that are potentially life-changing for children, young people and adults. Evidence does, though, clearly show that the earlier the treatment, the better the potential outcome, with the best possible outcome if the treatment is given before a baby shows any symptoms. Carried out within a few days of birth, the current NHS newborn blood spot (NBS) screening programme supports the early identification, referral and treatment of babies with nine rare but serious conditions. SMA is not currently one of them so we will be working on the Community's priority to see SMA added to this programme.

To this end, we are members of the UK SMA Newborn Screening Alliance chaired by Professor Laurent Servais, Professor of Paediatric Neuromuscular Diseases at the MDUK Oxford Neuromuscular Centre. The Alliance includes leading SMA experts in the clinical and academic community and patient organisations. SMA UK and Muscular Dystrophy UK form the Secretariat and have worked with Laurent to recruit Project Manager, Alice Fabre. You will be hearing much more from the Alliance in 2022 / 23.

Our advocacy work continued to be enhanced by our membership of many Alliances within the UK and also our membership of SMA Europe. With a mission of "*working to bring effective treatments and optimal care to everyone living with SMA",* it brings together 24 patient organisations from 23 countries. They support each other to advocate and campaign at national level, while also engaging and influencing stakeholders and decisions at European level through SMA Europe itself.

Ukraine Appeal

In March 2022 we joined forces with SMA Europe, TreatSMA and other UK SMA patient groups to provide our SMA Community with a way to help fund and support the Ukrainian SMA families and individuals so terribly affected by the devastating conflict. At the time of writing this report, £3864.66 had been donated and transferred to the SMA Poland charity which is working 24/7 with families in Ukraine to organise emergency transportation and accommodation.

Research Grants

At the end of March, we were delighted to announce with MDUK our joint funding of a four-year PhD studentship in SMA research. This was awarded to Dr Lyndsay Murray of the University of Edinburgh. Dr Murray will be studying an interesting biological mechanism seen in SMA called motor unit enlargement, a process that occurs in the muscles of people with SMA.

We also fulfilled our commitment to contribute funding to SMA Europe's 'call' which will select and fund new research projects.

Fundraising and Our Supporters

We are humbled by the incredible support our donors and fundraisers have given to SMA UK. We could not do what we do without you. Thank you.

Community Fundraising

We were delighted to be able to see a return to some in-person fundraising events during this past year, although we were still feeling the effects of the pandemic with significantly fewer events taking place than in previous years.

Our virtual fundraiser, Marathon in May, was well supported once again, along with our Christmas Jumper Day and annual festive matched funding campaign, The Big Give Christmas Challenge.

We were supported by people taking part in a huge range of events – from Chillswims to Skydives – and were proud to have seven runners in the London Marathon who all did amazingly with their fundraising.

We would like to take this opportunity to thank everyone who made a donation, including our regular givers and those who fundraised in memory of a loved one or left a legacy.



Trust and Corporate Fundraising

We are very grateful to the many Trusts, corporate donors, and pharmaceutical companies, who have generously supported our work again this year. We continued to benefit from the support of the National Lottery Community Fund which also enabled us to attract 'matched funding' from other Trusts and Foundations.

Every donation really does count, and we are so grateful for the continued support of our wonderful Community.

Our Fundraising Team

A thank you also to Caroline who led the Fundraising Team, and Debbie who managed our applications to Trusts. Rebecca and Yvonne have now been joined by Lucy and Stacey. The team looks forward to continuing to work to raise funds so that SMA UK can continue to respond to what the Community wants from the charity.



Report of the Trustees for the year ended 31 March 2022

The Trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 March 2022. 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 Aims

As stated in its Memorandum and Articles of Association, Spinal Muscular Atrophy 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;
- 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.

Strategic Report

Achievements and Performance

See pages 6 - 10.

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 page 15 Treasurer's Report.

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. In response to the changed circumstances of the Covid-19 pandemic, Trustees have temporarily reduced the reserves policy to two months of predicted future expenditure with an additional buffer of £100,000 to be

held in reserve in case of unforeseen funding issues.

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 the 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 four times a year, and the meetings have been held remotely since the COVID pandemic. Going forward the aim is to have a balance of remote and face-to-face meetings**.**

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.

Trustees' Responsibility Statement

The Trustees (who are also the directors of Spinal Muscular Atrophy UK for the purposes of company law) 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".

Company law 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 charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company 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 charitable company 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 charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the Trustees are aware:

- there is no relevant audit information of which the charitable company's auditors are unaware; and

- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number 05137534 (England and Wales)	**Registered Charity number** 1106815
Registered office – Unit 9 Shottery Brook Office Park, Timothy's Bridge Road, Stratford-upon-Avon, CV37 9NR	
Trustees Dr A M Childs, M P Collins, M T Dearlove, K Y Edwards, J M Fiorentini, C M Gray, K M Jackson, C S B Knight, S Madipalli, T J Mildon, B M O Morris, Dr R Quinlivan, T J D Sheffield, Dr A M E Smith, D J Waltier, L E J West.	
Company Secretary A Smith-Morgan	
Auditors Cooper Adams Ltd, Chartered Accountants and Statutory Auditors, 12 Payton Street, Stratford-upon-Avon, Warwickshire CV37 6UA	
Chair M T Dearlove	**Patrons** Professor V Dubowitz

Report of the Trustees, incorporating a strategic report, approved by order of the board of Trustees, as the company directors, on **4th August 2022** ..... and signed on the Board's behalf by:



.....

M T Dearlove - Trustee

Treasurer's Report

This has been a more positive year financially for SMA UK as we have been able to return to a more normal level of activity. Although income is not back to pre-pandemic levels, the charity has benefited from a more stable funding environment enabling the charity to begin to return to previous levels of engagement with the Community.

Income for the year was £839k, an increase of nearly 16% on the prior year. This was driven primarily by an increase in funds from Trustee and Community fundraising events as in-person fundraising has become possible again during the year, with tremendous efforts from the fundraising team and Trustees. The charity has benefited from continued Lottery and Trust funding, but pharma support has decreased on prior year. The ending of the Government furlough and Covid support schemes has resulted in a reduction of £54k in funding which was being utilised to mitigate staff costs.

The total pharmaceutical funding received during the year was £45,250 which was 5% of total income as compared to 15.5% in the prior year. Specific donations received in 2021/22 were £38,725 from Roche and £6,500 from Biogen. The support from pharmaceuticals varies depending on their priorities in any one year and we expect increased support in 2022/3 for the UK SMA Newborn Screening Alliance, of which we are a key member. We are committed to transparency on pharmaceutical funding and ensure that we do not accepting 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-related activities - our charitable purpose - and fundraising and administration. We aim to maximise spending on our core purpose and ensure that other costs are carefully monitored and reduced wherever possible. The charity cut back on expenditure significantly during the height of the pandemic period last year and took a number of steps to reduce costs. This year it has been able to increase its activities in support of the Community and has been pleased to provide research grants (which had been curtailed during the pandemic) via its partnerships with SMA Europe and MDUK. Fundraising expenditure in support of events was increased by £16k with pleasing results in terms of increased fundraising.

The total result of these changes has meant an increase in expenditure in the year of £140k, or 24%. I am pleased to report that the proportion of our costs that was spent on our charitable purpose, our value in the pound, rose from 63p to 68p as resources were focused on provision of support to the SMA Community and research-related initiatives.

Our net income for 2021/22 was a surplus of £124k compared to £149k in the prior year. This result is a strong one given the changes in pharmaceutical and government support and the positive impact that the team have been able to have. Value for money in our activities and the control of expenditure remains a priority so that the charity is sustainable for the future. As we look to 2022/3 there is continued pressure on fundraising and the need for Trust, major donor and pharmaceutical support, especially given the general economic and inflationary environment. We have finished the year with a strong cash position of £591k and the board will continue to monitor activities and reserves very carefully. I would like to thank all the SMA UK team for their hard work, resilience and flexibility during the year.



Katharine Jackson,
July 2022

SMA UK REPORT OF THE INDEPENDENT AUDITORS TO THE MEMBERS OF SPINAL MUSCULAR ATROPHY UK

Opinion

We have audited the financial statements of Spinal Muscular Atrophy UK (the 'charitable company') for the year ended 31 March 2022 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 charitable company's affairs as at 31 March 2022 and of its incoming resources and application of resources, including its income and expenditure, 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 Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and 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 charitable company 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 charitable company'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.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Report of the Trustees has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Trustees.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of Trustees' remuneration specified by law are not made; 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 (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they 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 charitable company'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 charitable company or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

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 charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members 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 charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

David Cooper FCA
(Senior Statutory Auditor)
for and on behalf of Cooper Adams Ltd

Chartered Accountants
and Statutory Auditors
12 Payton Street
Stratford-upon-Avon
Warwickshire
CV37 6UA



……

Date: 4th August 2022

Spinal Muscular Atrophy UK
STATEMENT OF FINANCIAL ACTIVITIES for the Year Ended 31 March 2022

	Notes	Unrestricted Funds £	Restricted Funds £	2022 Total Funds £	2021 Total Funds £
INCOME & ENDOWMENTS FROM					
Donations & legacies	2	579,516	255,080	834,596	720,690
Other trading activities	3	4,694	-	4,694	3,740
Investment income	4	130	-	130	261
Total		584,340	255,080	839,420	724,691
EXPENDITURE ON					
Raising funds	5	161,871	-	161,871	145,613
Charitable activities	6				
Provision of support		153,498	226,022	379,520	308,139
Governance costs		68,228	-	68,228	67,455
Research-related activity*		95,847	10,000	105,847	54,135
Total		479,444	236,022	715,466	575,342
NET INCOME		104,896	19,058	123,954	149,349
RECONCILIATION OF FUNDS					
Total funds brought forward		443,941	21,269	465,210	315,861
TOTAL FUNDS CARRIED FORWARD		**548,837**	**40,327**	**589,164**	**465,210**

*In last year's accounts, this was referred to as ‘Pursuit of Knowledge’.

The notes form part of these financial statements

Spinal Muscular Atrophy UK
Statement of Financial Position at 31 March 2022

	Notes	Unrestricted Funds £	Restricted Funds £	2022 Total Funds £	2021 Total Funds £
FIXED ASSETS					
Tangible assets	11	8,116	-	8,116	4,146
CURRENT ASSETS					
Stocks	12	6,285	-	6,285	6,256
Debtors	13	11,951	3,288	15,239	8,639
Cash at bank and in hand		551,527	39,677	591,204	468,926
		569,763	42,965	612,728	483,821
CREDITORS					
Amounts falling due within one year	14	(29,042)	(2,638)	(31,680)	(22,757)
NET CURRENT ASSETS		540,721	40,327	581,048	461,064
TOTAL ASSETS LESS CURRENT LIABILITIES		548,837	40,327	589,164	465,210
NET ASSETS		**548,837**	**40,327**	**589,164**	**465,210**
FUNDS					
Unrestricted funds: General fund	16			548,837	443,941
Restricted funds: Various – see note 16				40,327	21,269
TOTAL FUNDS				**589,164**	**465,210**

The financial statements were approved by the Board of Trustees and authorised for issue on

4th August 2022 and were signed on its behalf by:

…… ……

K M Jackson – Treasurer **M T Dearlove – Trustee**

The notes form part of these financial statements

Spinal Muscular Atrophy UK
Statement of Cash Flows for the Year Ended 31 March 2022

	Notes	2022 £	2021 £
Cash flows from operating activities:			
Cash generated from operations	1	130,371	172,138
Net cash provided by operating activities		130,371	172,138
Cash flows from investing activities:			
Purchase of tangible fixed assets		(8,223)	(2,574)
Sale of tangible fixed assets		-	1,617
Dividends received		130	261
Net cash used in investing activities		(8,093)	(696)
Change in cash and cash equivalents in the reporting period		122,278	171,442
Cash and cash equivalents at the beginning of the reporting period		468,926	297,484
Cash and cash equivalents at the end of the reporting period		591,204	468,926

Notes to the Statement of Cash Flows
For the Year Ended 31 March 2022

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

	2022 £	2021 £
Net income for the reporting period (as per the Statement of Financial Activities)	123,954	149,349
Adjustments for:		
Depreciation charges	4,253	2,924
Dividends received	(130)	(261)
(Increase)/decrease in stocks	(29)	1,579
(Increase)/decrease in debtors	(6,600)	33,552
Increase/(decrease) in creditors	8,923	(15,005)
Net cash provided by operations	130,371	172,138

2. ANALYSIS OF CHANGES IN NET FUNDS

	At 1.4.21 £	Cash flow £	At 31.3.22 £
Net Cash Cash at bank and in hand	468,926	122,278	591,204
	468,926	122,278	591,204
Total	468,926	122,278	591,204

The notes form part of these financial statements

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, 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 Companies Act 2006. 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
Database	14.3% on cost
Computer equipment	25% on cost

Stocks

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

Taxation

The charity is exempt from corporation 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

	2022 £	2021 £
Donations and gifts	680,272	539,606
Legacies	25,000	-
Government Grants Covid-19	-	54,295
The National Lottery Community Fund	129,324	126,789
	834,596	**720,690**

3. OTHER TRADING ACTIVITIES

	2022 £	2021 £
Merchandise sales	**4,694**	**3,740**

4. INVESTMENT INCOME

	2022 £	2021 £
Bank interest	**130**	**261**

5. RAISING FUNDS

Raising donations and legacies

	2022 £	2021 £
Staff costs and other expenses	94,642	106,829
Fundraising and publicity	25,817	24,891
Events and promotions	38,702	11,939
Cost of merchandise sales	2,710	1,954
	161,871	**145,613**

6. CHARITABLE ACTIVITIES COSTS

Provision of support

	2022 £	2021 £
Staff costs and other expenses	227,712	239,039
Information and awareness raising	7,465	5,941
Shared experiences network	27,048	13,009
Outreach Service	37,923	44,957
Welfare and equipment grants	29,372	5,193
	379,520	**308,139**

Research-Related Activity*

	2022 £	2021 £
Staff costs and other expenses	64,423	32,546
Research-related grants	35,072	16,251
Other research activities	6,352	5,338
	105,847	**54,135**

7. ADMINISTRATION & MANAGEMENT COSTS**

	2022 £	2021 £
Staff costs and other expenses	48,301	42,103
Professional fees and bank charges	8,939	6,407
Other costs	10,988	13,589
Committee expenses	-	5,356
	68,228	**67,455**

8. NET INCOME / (EXPENDITURE)

	2022 £	2021 £
Depreciation – owned assets	4,253	2,924
Fees payable to auditor for:		
- audit	1,500	1,500
- other services	3,265	2,995

*In last year's accounts, this was referred to as ‘Pursuit of Knowledge’.

**In last year’s accounts, these were referred to as Support Costs

9. TRUSTEES' REMUNERATION AND BENEFITS

There were no Trustees' remuneration or other benefits for the year ended 31 March 2022 nor for the year ended 31 March 2021.

Trustees' expenses

Expenses totalling £nil (2021: £nil) were reimbursed to nil (2021: nil) Trustees in respect of travel and subsistence for committee meetings and fundraising activities during the year.

Payment in respect of Trustee indemnity insurance amounted to £398 (2021: £973)

10. ALL STAFF COSTS

	2022 £	2021 £
Wages and salaries	391,466	344,518
Social security costs	34,664	29,811
Pension	17,288	16,108
	443,418	**390,437**

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

	2022	2021
Management and administration	1	1
Direct charitable expenditure	8	8
Fundraising and publicity	3	3
	12	**12**

We also engaged 1.2 FTE contractors in 2021 to assist us with our management and administration.

No employees received emoluments in excess of £60,000 (2021: None)

11. TANGIBLE FIXED ASSETS

	Office equipment £	Database £	Computer equipment £	Totals £
COST				
At 1 April 2021	1,517	31,312	11,282	44,111
Additions	1,037	-	7,186	8,223
At 31 March 2022	2,554	31,312	18,468	52,334
DEPRECIATION				
At 1 April 2021	1,232	31,312	7,421	39,965
Charge for year	159	-	4,094	4,253
At 31 March 2022	1,391	31,312	11,515	44,218
NET BOOK VALUE				
At 31 March 2022	**1,163**	**-**	**6,953**	**8,116**
At 31 March 2021	**285**	**-**	**3,861**	**4,146**

12. STOCKS

	2022 £	2021 £
Stocks held for re-sale	**6,285**	**6,256**

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022 £	2021 £
Prepayments and accrued income	**15,239**	**8,639**

14. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022 £	2021 £
Social security and other taxes	14,869	11,619
Other creditors	3,810	-
Accrued expenses	13,001	11,138
	31,680	**22,757**

15. LEASING AGREEMENTS

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

	2022 £	2021 £
Within one year	21,150	21,550
Between one and five years	45,146	67,296
	66,296	**88,846**

16. MOVEMENT IN FUNDS

Statement of funds

	Balance b/f at 1.4.21 £	Incoming Resources £	Resources Expended £	Balance c/f at 31.3.22 £
Unrestricted funds				
General funds	443,941	584,340	(479,444)	548,837
Restricted funds				
Support into the 2020s – Lotteries Reaching Communities	10,623	129,324	(111,278)	28,669
Support into the 2020s – Other Grants	-	115,056	(105,056)	10,000
Toy Packs	417	700	(767)	350
Toy packs and Flexible Response Grants	8,574	-	(8,574)	-
Northern Ireland Events	1,655	-	(347)	1,308
PhD Scholarship	-	10,000	(10,000)	-
Total Restricted Funds	21,269	255,080	(236,022)	40,327
TOTAL FUNDS	**465,210**	**839,420**	**(715,466)**	**589,164**

Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total
Fund balances at 31 March 2022 are represented by:			
Tangible fixed assets	8,116	-	8,116
Stock	6,285	-	6,285
Debtors	11,951	3,288	15,239
Bank and cash	551,527	39,677	591,204
Current liabilities	(29,042)	(2,638)	(31,680)
Total net assets	**548,837**	**40,327**	**589,164**

Support into the 2020s

This includes the services and workstreams described in the section, 'Achievements and Performance': information production, outreach, sharing experiences (networks and events) and speaking up for SMA (advocacy - in particular for access to drug treatments). It's funded by:

- **Lotteries Reaching Communities**

  This is a 3-year grant (June 2019 - May 2022) to cover 50% of the costs of our 'Support into the 2020s' services in England.

- **Support into the 2020s - other**

  Combines donations from Trusts and restricted community donations towards the remaining costs across the UK.

Toy Packs

Our multisensory 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.

Toy Packs & Flexible Response Grants

This fund covers toy packs as described above and also enables grants to be made to individuals and families affected by SMA. FRGs provide a swift response to an urgent need when no other funding source is available. Grants are typically small. Income in this restricted fund was received as a grant to cover both toy packs and FRGs – to be drawn on flexibly according to need.

Northern Ireland Events

This fund enables us to offer events in Northern Ireland for adults, children and young people with SMA and their families. These provide opportunities to share experiences and connect up with others in the SMA Community.

PhD Scholarship

This supports our commitment to fund a 4-year research programme from 2022-2025, jointly with Muscular Dystrophy UK.

17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2022.

Spinal Muscular Atrophy UK

DETAILED STATEMENT OF FINANCIAL ACTIVITIES for the year ended 31 March 2022

	2022 £	2021 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations and gifts	680,272	539,606
Legacies	25,000	-
Government Grants Covid-19	-	54,295
Community Fund (BLF)	129,342	126,789
	834,596	**720,690**
Other trading activities		
Merchandise sales	4,694	3,740
Investment income		
Bank interest	130	261
Total incoming resources	**839,420**	**724,691**
EXPENDITURE		
Raising donations and legacies		
Staff costs and other expenses	94,642	106,829
Fundraising and publicity	25,817	24,891
Events and promotions	38,702	11,939
Cost of merchandise sales	2,710	1,954
	161,871	**145,613**
Charitable activities		
Staff costs and other expenses	342,135	271,585
Research-related Grants	35,072	16,400
Other research activities	6,352	5,189
Information and awareness raising	7,465	5,941
Shared experiences network	27,048	13,009
Outreach Service	37,923	44,957
Welfare, equipment grants and toy packs	29,372	5,193
	485,367	**362,274**
Support Costs		
Management		
Staff costs and other expenses	48,301	42,103
Professional fees and bank charges	8,939	6,407
Other costs	10,988	13,589
Committee expenses	-	5,356
	68,228	67,455
Total resources expended	**715,466**	**575,342**
Net income	**123,954**	**149,349**

This page does not form part of the statutory financial statements

Partnerships & Affiliations

We are pleased to continue working with many groups, including:



























Notes:



Spinal Muscular Atrophy UK
Unit 9, Shottery Brook Office Park
Timothy's Bridge Road
Stratford-upon-Avon
CV37 9NR

Phone: 01789 267520

Email: office@smauk.org.uk
www.smauk.org.uk

spinal muscular atrophy uk

Help for today, hope for tomorrow

Spinal Muscular Atrophy UK Registered Charity No 1106815
Company Limited by Guarantee No 5137534 Registered in England and Wales

Spinal Muscular Atrophy UK

England & Wales - Charity number 1106815

Accounts

Annual Report & Financial Statements

For the year ending 31st March 2021



spinal muscular atrophy uk

Help for today, hope for tomorrow

Health & care information you can trust

The Information Standard Certified Member

Registered with FUNDRAISING REGULATOR

Welcome to our Annual Report and Financial Statements

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Partnerships & Affiliations

We are pleased to continue working with many groups, including:

Council for disabled children

Disabled Children's Partnership

Genetic Alliance UK
Supporting. Campaigning. Uniting.

Muscular Dystrophy UK
Fighting muscle-wasting conditions

THE NEUROLOGICAL ALLIANCE

SMA Europe

SMA REACH UK

together for short lives

TREAT-NMD
Neuromuscular Network

TreatSMA

Letter from the Chair

For more than a year now, our headlines have been dominated by the global Covid pandemic. The impact on the public has been significant and especially so on the SMA Community. Many of you have faced a year of shielding, stress, and isolation. I hope that during this time, SMA UK has been able to provide support and information that has been of some assistance.

As I write this update, I am heartened by the news that Baby Arthur has become one of the first patients to be treated on the NHS with Zolgensma. This has coincided with the report of zero Covid deaths for the first time since last March. While there may appear to be light at the end of the tunnel, there are still many, many challenges on the horizon. We at SMA UK will continue, amongst other things, to focus our efforts on the campaign for access to the right drugs, support, and care for all those affected by SMA. You can read more about our involvement as well as some of the great outcomes on pages 6 to 10 of this report.

Despite the fact that home visits had to be curtailed, our Outreach & Support service carried on throughout the year, providing individual support in the UK by phone and email to over 200 children, young people and adults who have SMA, and their families. Our website remains an important source of information with more than 84,000 people visiting our site, an increase of almost 20% since 2019. We also added an area dedicated to Covid-related information and responded to your specific questions, working closely with MDUK to channel to leading clinicians. We also started our Community Connections Team, ably led by Martyn Sibley, along with an enthusiastic group of young adults, which provides virtual connections, webinars, videos and now podcasts which further enhances the rich content of information and advice available on our website.

Covid has impacted many aspects of our operation, none more so than fundraising. We were forced to cancel or postpone a number of events and this had the potential to materially impact our finances. However, during the twelve months to 31st March 2021 we benefited from an accelerated payment from the Big Lottery, received support donations from a number of pharmaceutical companies, and made careful use of the government's furlough scheme. Most importantly, we enjoyed tremendous support from the SMA Community. Your overwhelming generosity has meant that our financial position remains sound.

Throughout the year we have been busy improving and strengthening the foundations of SMA UK. I am pleased to report that the Board welcomed 8 new Trustees who bring an exciting range of knowledge and experiences. The work to become a Charitable Incorporated Organisation (CIO) is well underway and in April of this year we lodged our application with the Charities Commission. Finally, I am pleased to introduce you to our new CEO, Angela Morgan-Smith, who started with us in April, too.

I would like to thank all of the retiring Trustees and, especially, my predecessor, Hugo van Vredenburch. His contribution to the charity has been immense. We will miss his thoughtfulness, leadership, wisdom, energy, and, above all, his enthusiasm. In particular, I would like to recognise his extraordinary contribution to our fundraising efforts which included his willingness to get on a bike for a sponsored ride!

Finally, I must thank our extraordinary team at SMA UK, many of whom have worked literally all hours of the day to keep our services going during this very difficult period. I really don't know how you did it! In particular, I want to say a heartfelt thanks to Liz Ryburn, Support Team Manager, and Caroline Dolan, Fundraising Manager for your incredible leadership and unfailing dedication.

Thank you.



Mark Dearlove, 1st June 2021

Trustees' Strategic Report



Spinal Muscular Atrophy (SMA) is a rare, genetically inherited neuromuscular condition affecting children, young people and adults. It causes progressive muscle weakness and loss of movement due to muscle wasting (atrophy). This may affect crawling and walking ability, arm, hand, head and neck movement, breathing and swallowing. The impact and severity of SMA varies greatly. It is thought that there are between 670 – 1340 children, young people and adults, who have SMA, living in the UK and that some 71 babies born each year will have some form of SMA.

Our Charity



The Jennifer Trust for SMA was founded in 1985. In April 2014, it became Spinal Muscular Atrophy Support UK. The SMA Trust was set up in 2003. In 2018, the two merged as Spinal Muscular Atrophy UK.

Our Vision

Everyone affected by SMA has access to the best care, support and drug treatments; research continues to bring breakthroughs that improve people's quality of life, and ultimately aims to find a cure.

Our Mission

To provide accurate information and a wide range of support services, while working to improve access to the best care, services and drug treatments today and funding research projects that can change tomorrow.



Our Guiding Principles

Spinal Muscular Atrophy (SMA) is a complex and rare neuromuscular condition that affects each individual and their family differently. We will always be respectful of each person's needs and choices. All face the challenge of disability and obtaining the right support, care and opportunities to enable them to live long and fulfilling lives; some face the distress of early bereavement.

Our Strategy

Providing Information and Support Services in the UK for:

- families and individuals – personalised information about SMA; emotional and practical support; advocacy for services and access to care and drug treatments; opportunities to have contact with others affected by the condition.

- health, education and social care professionals – information about SMA; working with them to support families and individuals.

- the SMA Community - up-to-date information about developments in research, drug treatments, support and disability services, consultations and campaigns.



Working to Improve and Monitor SMA Community Access to:

- care and support.
- clinical trials and new drug treatments.
- equipment and adaptations.

We are **advocates** on behalf of the SMA Community to authorities that regulate access to drug treatments, care and services. We work with other charities, health, education and social care professionals, and national and international charities and organisations to **campaign** on issues that matter to people affected by SMA. We **support developments** that improve and monitor access to services and drug treatments.



Funding and Supporting Research:

Pharmaceutical companies are now investing heavily in the clinical development of drug treatments; these are important stepping stones that we will continue to monitor and support. Our funding focus will now be on projects that contribute to:

- understanding the complexities of SMA and the underlying disease mechanisms.
- the pre-clinical development of drug treatments.
- improvements in the clinical care and management of people affected by SMA.
- continuing to support, strengthen and develop the capacity of the UK SMA scientific and clinical community.

Our excellent track record of raising and delivering money to the scientific community, along with our strong connections and collaborations with clinicians, researchers, international groups and the pharmaceutical industry, ensure we are not duplicating efforts when we fund and support initiatives that will ease the path to drug treatments and improvements in clinical care.

Where we can make a difference, we will.

Achievements & Performance

Our Team

We have fantastic networks of more than 150 adults, young people and parents in the SMA Community who work with us in various ways and are always willing to review our information, answer questions and offer their experiences, tips and advice.

We have a small Support Services Team of experienced staff (Claire, Maggie, Michele, Jackie, Jo, Dermot, Libby and Liz, with backgrounds in social work, nursing, occupational therapy, mental health, education and disability-related services – 6.3 FTEs). This year, though, saw the team's working hours much reduced at times due to the impact of Covid-19 on the charity's income.

Our Scientific Research Correspondents always make themselves available to us despite their other work and roles: Dr James Sleigh leads his own laboratory research team and Vanessa Christie-Brown is also the SMA Europe Coordinator.

Outreach and Support



"Thank you for checking in on us. It's really nice to know that there's a community out there, even though we haven't physically been out for 3 weeks now, we still feel part of it."
Parent of child, family shielding.

This was a year of shielding, stress and isolation for so many families and adults in the Community.

Children home-schooled, adults working from home, feeling too unsafe to go out, losing jobs and facing financial insecurity, routine healthcare and monitoring impossible for so many, worries about PAs and carers in the home, and who would have priority with the vaccine roll-out. To have your child diagnosed with SMA when you couldn't be with family and friends would have been shattering.

"We hugely appreciate all the support the charity has provided to us; it has been a comfort during these dark days."
Parent of a newly diagnosed baby.

Though we were unable to make home visits for most of the year, we still provided individual support in the UK by phone and email to 207 children, young people and adults who have SMA, and their families. Everyone's circumstances, requests and needs were different with more and more people facing complex and challenging times during the year.

"…we really appreciate all the help, advice and time you gave us through the whole process we know none of this would have been possible without you guys and can't thank you enough - all going well you can come and see the changes for yourself."
Parent negotiating housing adaptations.

"Thank you very much for your support and continued hard work on behalf of us all."
Adult asking advice for a shielding letter.

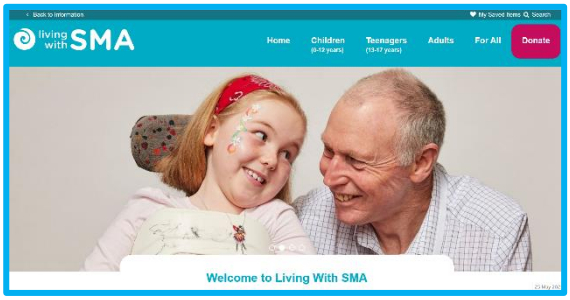
Information

We also did our best to support the Community by developing a whole website area dedicated to Covid-related information that had 2,450 visitors. We were asked many SMA-specific questions that were worrying people and worked with MDUK to channel these to leading clinicians. We were immensely grateful to the clinicians for responding so quickly, on top of their very stressful caring roles, and were able to keep getting answers out to the Community via our website and social media.

During the year, 84,272 people accessed our website (a 19.5% increase on 2020). Information, Support, and Treatment & Research-related pages in the top ten website page views were:

Page name	Total views 2020
SMA Information	6,776
Support	5,512
About SMA	3,368
Nusinersen	4,106
Zolgensma	4,061
Risdiplam	4,074

We remained accredited to The Information Standard, publishing up to date, evidence-based and accurate information relating to SMA – about the condition and its management, clinical trial results and the new drug treatments.



The **'Living With SMA'** website section was visited by 2,800 people during 2020. Divided into three main sections for parents of children, teenagers and adults, it builds on knowledge and advice from the SMA Community and SMA UK's Support Team. It covers a whole host of topics including health & wellbeing, equipment, homes, education, work, transport, leisure, and financial, emotional and social support.

livingwithsma.org.uk

Our monthly E-news bulletin mailing list saw new people sign up. Overall, we saw an increase to just under 3,000 with an opening rate at 28% (2019: 2,900, 26.3% - similar mailings across the sector are 21%). These mailings also kept the Community informed about access to treatment developments, consultations, surveys, fundraising activities, and other information and news. In October, we took a snapshot of our social media reach:

October	2019	2020
Facebook likes	4,458	4,632
Twitter followers	1,694	2,059
Instagram followers	678	1,136

With so many different ways of being in touch, and not always knowing who we're reaching, it's difficult to know exactly how many of them have SMA and are in the UK. Our best estimate, based on our mailing list, is that we're in contact with some 780 households where there is a parent of a child / young person who has SMA or an adult who has SMA (2019: 600). Similarly, we're in contact with more than 360 families bereaved by SMA.

The team also directly supported 67 health, education and social care professionals in their work with people who have SMA.

"Thank you for all the information, it's really helpful and some great resources and contacts for me to link in with to try to resolve the situation I was dealing with."
Neuromuscular Care Advisor – advice on transport / car seats for under 3s.

As members of the UK-wide SMA REACH paediatric and adult clinical networks of professionals from specialist centres, we keep in touch with many more who keep us up to date with developments and the challenges they are facing – which were huge this year. In turn, we keep them informed about issues we are seeing and what we can do to assist.

Though we focus on the UK, we always reply to overseas enquiries, with so many families desperately seeking treatment. We do our best to link people in to support networks and give relevant information.

Multisensory Toy Packs

This year, though we only had 18 requests for these packs for infants aged up to 12 months of age, each one was welcomed by families who were coping not only with the distress of their child's diagnosis but also Covid and their isolation.



"Thank you so much, it is clear a lot of care and consideration has gone into providing toys for throughout the day, playtime, bath time and bedtime. My baby loves the toys and plays with them every day."
Mum of a baby who has SMA Type 1.

Connecting With Others

With the possibility of our long planned face-to-face events out of the question (a family day in London in April 2020, and, in August 2020, the first ever national weekend event for adults to get together and then to be joined by families), we had to think fast to set up new opportunities and do all we could to help reduce the social isolation of the year and the impact of this on people's mental health and wellbeing.



We were delighted to invite Martyn Sibley and an enthusiastic group of young adults to become our 'Community Connections Team' and join us in setting up virtual connections and chats.

Access to treatment, especially how it would be impacted by Covid, was a hot topic, so we started with a health and wellbeing webinar series, with Martyn hosting community webinars with leading UK clinical experts. Other members of the group hosted a wide range of other sessions from: 'Preparing for Uni' to 'Having SMA and becoming a parent', to 'Parents: Ask us anything!'. All were released on social media and have a more permanent home on our Living With SMA pages. There were also several virtual socials - not quite like the real thing, but very much enjoyed by those who did drop in.

Virtual networks also proved to be a lifeline for many - the Adult Facebook Group, Young Adults Network, and one for Community Questions where people aged 18+ affected by SMA share what has worked for them, their tips and ideas.

smauk.org.uk/connect-with-others

Advocacy For SMA

Throughout the year, we worked with many other patient groups, alliances and clinicians on Covid-related issues. This included advocating for people with SMA at risk to be on the extremely vulnerable list and able to access the support they needed to shield. We also advocated for them to be high on the vaccine priorities list, along with their families and carers, and for safe vaccines for children at risk to be made available as quickly as possible. Our support work continues on the many other impacts of the pandemic on family income, mental health, education and access to routine healthcare.

Advocacy for **access to drug treatments** didn't stop. Notably, this year, the National Institute of Health and Care Excellence (NICE) announced that it would conduct an evidence review to see if there should be any change to their recommendation that had limited access to nusinersen for those who have SMA Type 3.

We were grateful to the people who had been affected by this for responding to our surveys about the impact it had had on them. We also heard from people who had had access in other countries about the positive impact treatment had had for them and from families with children in the UK who had access, but treatment would stop if their child didn't gain the ability to walk 5 steps within a year. We were able to submit all this evidence via Biogen to NICE. Clinicians and other groups also gathered and submitted their findings.



The outcome of NICE's decision wasn't known until May 2021, but as this was so momentous for so many, we have to mention here that the recommendation was changed to give access to all who have SMA Type 1, 2 or 3 for whom nusinersen is a clinically safe option.

We continued to work collaboratively with other members of the Managed Access Agreement Oversight Committee, including clinicians and representatives from NICE, NHS England, MDUK and TreatSMA, to monitor the roll-out of nusinersen treatment.

NHS England and Centres that had already started the programme gave it high priority, adjusting monitoring and delivery so that it could continue as safely as possible. Adult delivery, however, faltered badly and though in many areas this was due to the impact of Covid on all hospital services, this was not always the only reason. We therefore worked with others to try to uncover and address what other issues were causing delays.

This year inevitably saw delays in both NICE and the Scottish Medicines Committee (SMC) appraisals of the clinical and cost-effectiveness of all treatments for all conditions. These did, though, start for the gene therapy onasemnogene abeparvovec (Zolgensma™). We gathered community views, wrote joint submissions with MDUK and were patient experts at committee hearings.



Again, it's impossible not to mention here that in April 2021 this one-time gene therapy was given the green light for treating eligible children who have SMA Type 1 for whom it is clinically safe, and also for pre-symptomatic children.

For many who have SMA Type 1 or 2, news of the Compassionate Use Programme (CUP) followed by the UK Early Access to Medicines Scheme (EAMS) for the oral treatment risdiplam was huge. This could be prescribed to those for whom the licensed treatment nusinersen was not clinically suitable.



Yet again, though, this left those diagnosed with SMA Type 3 behind. At this stage, those who had lost walking ability couldn't access nusinersen and no one diagnosed with SMA Type 3 could access risdiplam as these schemes are only provided when a condition isn't life threatening – with SMA Type 3 not considered to be so.

In October, with input from 137 people in the Community who responded to our survey about risdiplam, we again made a joint submission to NICE which had begun its appraisal process.

We argued strongly that the key outcome people are looking for is stabilisation of their condition and that fine motor skills, fatigue levels and impact on breathing are of far more value in the day to day lives of many than the ability to walk. We also argued that the clinical classifications and 'Typing' of SMA was introduced in 1990 by a committee of clinicians and geneticists to promote collaborative studies between different centres and to identify the genes of SMA. It was never designed to be a barrier to access to treatment – and should never be so.

We included in our submission that consideration should be given to the 1% of those diagnosed each year as having SMA Type 4, for whom there is no drug treatment. However, as none of the treatments, thus far, have received licensing authorisation for this group, it has not been possible for the UK regulatory authorities to address this.

With clinical trials and real-world evidence now all showing that early treatment is necessary to maximise the potential benefits of treatment, and pre-symptomatic treatments now available, newborn screening will take centre stage again next year.

In the meantime, clinicians who are part of the UK SMA Newborn Screening Alliance continued their work to prepare pilot studies that will provide the evidence that will be needed. We also worked with SMA Europe and the European Newborn Screening Alliance on their preparations to make this one of their major campaigns.



For more information on all these topics:
smauk.org.uk/treatments-research

Research Grants

Over the last 35 years we have raised and donated £5million in support of research into ground-breaking findings and initiatives that have been key to the development of drug treatments and access to clinical trials.

It was with great regret that, due to the impact of Covid-19 on both MDUK and our funding, we were unable to progress the planned SMA PhD Partnership funding. In March, however, we were able to announce our intention to jointly fund one four-year scholarship to start later in 2021.

In the meantime, we have joined with others to highlight the massive impact Covid-19 is having on all research and clinical trials.

We were able to maintain our commitment to the **UK SMA Patient Registry**. This important database links adults and children who have SMA with researchers conducting studies, including clinical trials of new drug treatments. This is our last year supporting the registry as finally its value has been recognised and funding will now be provided via pharmaceutical grants.

SMA Europe

We remained active members of this umbrella organisation of SMA patient and research groups. With 19 member countries, it is a vital network that is progressing many areas of work seeking to elevate the patient voice by empowering member organisations to advocate and campaign at a national level and by harnessing the network to advance research and influence stakeholders at a European level.

Funding of SMA Europe's research call was also put on hold by all countries this year. We are hoping that by the end of 2021 we will be able to contribute again.

www.sma-europe.eu

Thank you to the Community

Whilst the impact of Covid-19 was felt by everyone this year and income fell, it is only thanks to the kindness and generosity of our supporters that the charity was able to continue to deliver its services in these challenging times.

We are extremely grateful to everyone who kindly made donations of all sizes and came up with ever more inventive ways to raise funds. From those who donate monthly, to marathon runners and schools and businesses who fundraise, every penny counts, and collectively has made a huge impact.

The SMA Community once again showed support through our virtual event, Marathon in May for SMA, and The Big Give Christmas Challenge. This was especially appreciated when so many people were experiencing the impact of Covid-19 on their lives.

With a gap in income left by the cancellation of so many events, we are particularly grateful to organisations that provided support including AveXis (now Novartis Gene Therapies), Biogen and Roche.

Grants from charitable trusts proved once again to be a vital source of income, as was our funding from The National Lottery Community Fund.

We look forward to continuing to work with the SMA Community and all our supporters in the coming year.



Thank you to Trusts and Companies

Thank you to all the charitable trusts and organisations that have continued to support SMA UK, including:

Garfield Weston FOUNDATION

bgc

Roche

NOVARTIS

Biogen

COMMUNITY FUND

HM Government

In partnership with

THE NATIONAL LOTTERY COMMUNITY FUND

Report of the Trustees for the year ended 31 March 2021

The Trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 March 2021. 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 Aims

As stated in its Memorandum and Articles of Association, Spinal Muscular Atrophy 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;
- the promotion of research into the causes and treatment of Spinal Muscular Atrophy.

Structure, Governance & Management

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.

Achievements and Performance

See pages 6 - 10.

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 page 15 Treasurer's Report.

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 of general (core) overheads will be recovered against those reserves. The percentage recovery rate 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. In response to the changed circumstances of the Covid-19 pandemic, Trustees have temporarily reduced the reserves policy to two months of predicted future expenditure with an additional buffer of £100,000 to be

held in reserve in case of unforeseen funding issues.

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 the 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.

Trustees' Responsibility Statement

The Trustees (who are also the directors of Spinal Muscular Atrophy UK for the purposes of company law) 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".

Company law 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 charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company 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 charitable company 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 charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the Trustees are aware:

- there is no relevant audit information of which the charitable company's auditors are unaware; and

- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number	**Registered Charity number**
05137534 (England and Wales)	1106815
Registered office – Unit 9 Shottery Brook Office Park, Timothy's Bridge Road, Stratford-upon-Avon, CV37 9NR	
Trustees M E Fenton (resigned 30.9.20), Dr H Sobati (resigned 30.9.20), Dr D R Hopkins (resigned 9.7.20), H H C Van Vredenburch (resigned 1.2.21), T J D Sheffield, C S B Knight, Mrs D J Waltier, Dr R Quinlivan, T J Mildon, M T Dearlove, Mrs K M Jackson, M P Collins (appointed 26.11.20), B M O Morris (appointed 26.11.20), Ms L E J West (appointed 26.11.20), Dr A M E Smith (appointed 26.11.20), Dr A M Childs (appointed 26.11.20), Mrs K Y Edwards (appointed 26.11.20), J M Fiorentini (appointed 26.11.20), S Madipalli (appointed 26.11.20), Miss C M Gray (appointed 26.11.20)	
Company Secretary Mrs E Ryburn	
Auditors Cooper Adams Ltd, Chartered Accountants and Statutory Auditors, 12 Payton Street, Stratford-upon-Avon, Warwickshire CV37 6UA	
Chair M T Dearlove	**Patrons** Professor V Dubowitz

Report of the Trustees, incorporating a strategic report, approved by order of the board of Trustees, as the company directors, on **8th July 2021** and signed on the Board's behalf by:



.....

M T Dearlove - Trustee

Treasurer's Report

In common with many charities, this has been a difficult year for SMA UK from a financial point of view, as a result of the challenges to fund raising in the environment of the Covid-19 pandemic.

Income for the year was £721k - a decrease of nearly 22% on the prior year. This was driven, primarily, by the reduction in funds from Trustee and community fundraising events which have not been possible due to Covid restrictions. The charity has, however, benefitted from continued Lottery funding as well as pharmaceutical and Trust support and our Fundraising Team have worked tirelessly on virtual events which have mitigated the drop in donation income.

The total pharmaceutical funding received during the year was £112k which was 15.6% of total income as compared to 6% in the prior year. Specific donations received in 2020/21 were £40,000 from AveXis, £39,124 from Biogen and £33,200 from Roche. We are very grateful for the pharmaceutical support of our core services and Community Connections work at a time when fundraising income was severely impacted as a result of Covid-19. We are committed to transparency on pharmaceutical funding and ensure that we do not accepting 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 and reduced wherever possible. The charity took a number of steps to reduce costs in response to the impact of the pandemic. Fundraising expenditure for in-person events was reduced saving £121k. A cautious approach was also taken to research activities, in order to conserve funds during the pandemic, resulting in a year-on-year expenditure reduction of £70k. The charity benefited from Government furlough and Covid support schemes amounting to £54k during the year, in order to mitigate staff costs. In addition, SMA UK has moved to new, more cost-effective premises and renegotiated office infrastructure contracts which put it on an efficient basis going forward.

The total result of these cost control activities was a reduction in expenditure in the year of £272k or 32%. I am also pleased to report that the percentage of our costs that was spent on our charitable purpose, our value in the pound, rose from 56p to 63p as resources were focused on provision of support to the SMA Community.

Our net income for 2020/21 was a surplus of £149k compared to £78k in the prior year. This result has been achieved through the hard work, dedication, and flexibility of all staff under difficult circumstances. The control over activities and conservation of cash mean that the charity is in a good position to resume a more normal level of activity in 2021/22. Even so, the unpredictable impact of the pandemic on the general economy and the pressure on fundraising remains for the coming year. The Board will continue to monitor activities, cash flow projections and reserves very carefully.

I welcome Angela Smith-Morgan as our new CEO and look forward to working with her on the challenges ahead.



Katharine Jackson,
28th June 2021

SMA UK REPORT OF THE INDEPENDENT AUDITORS TO THE MEMBERS OF SPINAL MUSCULAR ATROPHY UK

Opinion

We have audited the financial statements of Spinal Muscular Atrophy UK (the 'charitable company') for the year ended 31 March 2021 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 charitable company's affairs as at 31 March 2020 and of its incoming resources and application of resources, including its income and expenditure, 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 Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and 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 charitable company 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 charitable company'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.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Report of the Trustees has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Trustees.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of Trustees' remuneration specified by law are not made; 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 (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they 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 charitable company'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 charitable company or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

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 charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members 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 charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

David Cooper FCA
(Senior Statutory Auditor)
for and on behalf of Cooper Adams Ltd

Chartered Accountants
and Statutory Auditors
12 Payton Street
Stratford-upon-Avon
Warwickshire
CV37 6UA



……

Date: 8th July 2021

Spinal Muscular Atrophy UK
STATEMENT OF FINANCIAL ACTIVITIES for the Year Ended 31 March 2021

	Notes	Unrestricted Funds £	Restricted Funds £	2021 Total Funds £	2020 Total Funds £
INCOME & ENDOWMENTS FROM					
Donations & Legacies	2	559,142	161,548	720,690	919,833
Other trading activities	3	3,740	-	3,740	5,262
Investment income	4	261	-	261	775
Total		563,143	161,548	724,691	925,870
EXPENDITURE ON					
Raising funds	5	145,613	-	145,613	267,390
Charitable activities	6				
Provision of support		117,464	190,675	308,139	347,386
Governance costs		67,455	-	67,455	109,102
Pursuit of knowledge		52,885	1,250	54,135	123,939
Total		383,417	191,925	575,342	847,817
NET INCOME/(EXPENDITURE)		179,726	(30,377)	149,349	78,053
Transfers between funds	16	(34,484)	34,484	-	-
Net movement in funds		145,242	4,107	149,349	78,053
RECONCILIATION OF FUNDS					
Total funds brought forward		298,699	17,162	315,861	237,808
TOTAL FUNDS CARRIED FORWARD		**443,941**	**21,269**	**465,210**	**315,861**

The notes form part of these financial statements

Spinal Muscular Atrophy UK
Statement of Financial Position at 31 March 2021

	Notes	Unrestricted Funds £	Restricted Funds £	2021 Total Funds £	2020 Total Funds £
FIXED ASSETS					
Tangible assets	11	4,146	-	4,146	6,113
CURRENT ASSETS					
Stocks	12	6,256	-	6,256	7,835
Debtors	13	8,639	-	8,639	42,191
Cash at bank and in hand		447,657	21,269	468,926	297,484
		462,552	21,269	483,821	347,510
CREDITORS					
Amounts falling due within one year	14	(22,757)	-	(22,757)	(37,762)
NET CURRENT ASSETS		439,795	21,269	461,064	309,748
TOTAL ASSETS LESS CURRENT LIABILITIES		443,941	21,269	465,210	315,861
NET ASSETS		**443,941**	**21,269**	**465,210**	**315,861**
FUNDS					
Unrestricted funds: General fund	16			443,941	298,699
Restricted funds: Various – see note 16				21,269	17,162
TOTAL FUNDS				**465,210**	**315,861**

The financial statements were approved by the Board of Trustees and authorised for issue on

8th July 2021 ..... and were signed on its behalf by:





..... **.....**

K M Jackson – Treasurer **M T Dearlove – Trustee**

The notes form part of these financial statements

Spinal Muscular Atrophy UK
Statement of Cash Flows for the Year Ended 31 March 2021

	Notes	2021 £	2020 £
Cash flows from operating activities:			
Cash generated from operations	1	172,138	83,135
Net cash provided by operating activities		172,138	83,135
Cash flows from investing activities:			
Purchase of tangible fixed assets		(2,574)	(1,105)
Sale of tangible fixed assets		1,617	-
Dividends received		261	775
Net cash used in investing activities		(696)	(330)
Change in cash and cash equivalents in the reporting period		171,442	82,805
Cash and cash equivalents at the beginning of the reporting period		297,484	214,679
Cash and cash equivalents at the end of the reporting period		468,926	297,484

Notes to the Statement of Cash Flows
For the Year Ended 31 March 2021

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

	2021 £	2020 £
Net income for the reporting period (as per the Statement of Financial Activities)	149,349	78,053
Adjustments for:		
Depreciation charges	2,924	5,830
Dividends received	(261)	(775)
Decrease/(increase) in stocks	1,579	(5,265)
Decrease in debtors	33,552	6,053
Decrease in creditors	(15,005)	(761)
Net cash provided by operations	172,138	83,135

2. ANALYSIS OF CHANGES IN NET FUNDS

	At 1.4.20 £	Cash flow £	At 31.3.21 £
Net Cash Cash at bank and in hand	297,484	171,442	468,926
	297,484	171,442	468,926
Total	297,484	171,442	468,926

The notes form part of these financial statements

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, 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 Companies Act 2006. 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:

Improvements to property	20% on cost
Office equipment	10 – 20% on cost
Database	14.3% on cost
Computer equipment	25% on cost

Stocks

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

Taxation

The charity is exempt from corporation 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

	2021 £	2020 £
Donations and gifts	539,606	795,531
Government Grants Covid-19	54,295	-
Community Fund (BLF)	126,789	124,302
	720,690	**919,833**

3. OTHER TRADING ACTIVITIES

	2021 £	2020 £
Merchandise sales	**3,740**	**5,262**

4. INVESTMENT INCOME

	2021 £	2020 £
Bank interest	**261**	**775**

5. RAISING FUNDS

	2021 £	2020 £
Staff costs and other expenses	106,829	114,642
Fundraising and publicity	24,891	56,459
Events and promotions	11,939	89,631
Cost of merchandise sales	1,954	6,658
	145,613	**267,390**

6. CHARITABLE ACTIVITIES COSTS

Provision of support

	2021 £	2020 £
Staff costs and other expenses	239,038	242,403
Information and awareness raising	5,941	18,218
Shared experience network	13,009	14,163
Outreach Service	44,957	57,256
Information, support and social events	-	-
Welfare and equipment grants	5,194	15,346
	308,139	**347,386**

Pursuit of knowledge

	2021 £	2020 £
Staff costs and other expenses	59,119	73,345
Medical research grants	16,251	31,084
Other research activities	5,338	19,510
	80,708	**123,939**

7. SUPPORT COSTS

	2021 £	2020 £
Staff costs and other expenses	42,103	72,467
Professional fees and bank charges	6,407	17,107
Other costs	13,589	15,421
Committee expenses	5,356	4,107
	67,455	**109,102**

8. NET INCOME / (EXPENDITURE)

	2021 £	2020 £
Depreciation – owned assets	2,924	5,830
Fees payable to auditor for:		
- audit	1,500	1,500
- other services	2,995	2,950

9. TRUSTEES' REMUNERATION AND BENEFITS

There were no Trustees' remuneration or other benefits for the year ended 31 March 2021 nor for the year ended 31 March 2020.

Trustees' expenses

Expenses totalling £nil (2020: £3,338) were reimbursed to nil (2020: 2) Trustees in respect of travel and subsistence for committee meetings and fundraising activities during the year.

Payment in respect of Trustee indemnity insurance amounted to £973 (2020: £912)

10. STAFF COSTS

	2021 £	2020 £
Wages and salaries	344,518	362,105
Social security costs	29,811	32,485
Pension	16,108	18,345
	390,437	**412,935**

2020 includes SMA Europe staff costs which SMA UK processes for them and are funded by SMA Europe. From 2021 we continue to do this to support SMA Europe but no longer include this income and expense in our accounts.

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

	2021	2020
Management and administration	1	1
Direct charitable expenditure	8	7
Fundraising and publicity	3	3
	12	**11**

We also engaged contractors in 2021 to assist us with our management and administration 1.2 FTE; 0.1 in fundraising and publicity; 0.1 in direct charitable.

No employees received emoluments in excess of £60,000 (2020: None)

11. TANGIBLE FIXED ASSETS

	Improvements to property £	Office equipment £	Database £	Computer equipment £	Totals £
COST					
At 1 April 2020	19,611	4,607	31,312	21,087	76,617
Additions	-	-	-	2,574	2,574
Disposals	(19,611)	(3,090)	-	(12,379)	(35,080)
At 31 March 2021	-	1,517	31,312	11,282	44,111
DEPRECIATION					
At 1 April 2020	19,611	4,217	31,312	15,364	70,504
Charge for year	-	104	-	2,820	2,924
Eliminated on disposal	(19,611)	(3,089)	-	(10,763)	(33,463)
At 31 March 2021	-	1,232	31,312	7,421	39,965
NET BOOK VALUE					
At 31 March 2021	-	**285**	-	**3,861**	**4,146**
At 31 March 2020	-	**390**	-	**5,723**	**6,113**

12. STOCKS

	2021 £	2020 £
Stocks held for re-sale	**6,256**	**7,835**

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021 £	2020 £
Prepayments and accrued income	**8,639**	**42,191**

14. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021 £	2020 £
Social security and other taxes	11,619	10,956
Other creditors	-	13,044
Accrued expenses	11,138	13,762
	22,757	**37,762**

15. LEASING AGREEMENTS

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

	2021 £	2020 £
Within one year	21,550	29,865
Between one and five years	67,296	88,846
	88,846	**118,711**

16. MOVEMENT IN FUNDS

Statement of funds

	Balance b/f at 1.4.20 £	Incoming Resources £	Resources Expended £	Funds Transfer	Balance c/f at 31.3.21 £
Unrestricted funds					
General funds	298,699	563,143	(383,417)	(34,484)	443,941
Restricted funds					
Support into the 2020s – Lotteries Reaching Communities	-	126,789	(153,457)	37,291	10,623
Support into the 2020s – Other Grants	-	-	-	-	-
Toy Packs	1,727	-	(1,310)	-	417
Research - Robert Luff Foundation	1,250	-	(1,250)	-	-
Toy packs and Flexible Response Grants	8,860	-	(286)	-	8,574
Northern Ireland Events	1,655	-	-	-	1,655
Community Connections	-	34,759	(31,952)	(2,807)	-
Total Restricted Funds	17,162	161,548	(191,925)	34,484	21,269
TOTAL FUNDS	**315,861**	**724,691**	**(575,342)**	**-**	**465,210**

Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total
Fund balances at 31 March 2021 are represented by:			
Tangible fixed assets	4,146	-	4,146
Stock	6,256	-	6,256
Debtors	8,639	-	8,639
Bank and cash	447,657	21,269	468,926
Current liabilities	(22,757)	-	(22,757)
Total net assets	**443,941**	**21,269**	**465,210**

Support into the 2020s

This includes the services and workstreams described in the section, 'Achievements and Performance': information production, outreach, sharing experiences (networks and events) and speaking up for SMA (advocacy - in particular for access to drug treatments).

It's funded by:

Lotteries Reaching Communities

This is a 3-year grant (June 2019 - May 2022) to cover 50% of the costs of our 'Support into the 2020s' services in England.

16. MOVEMENT IN FUNDS - continued

Support into the 2020s

Combines donations from Trusts and restricted community donations towards the remaining costs across the UK.

Toy Packs

Our multisensory toy packs are available free of charge to families in the UK for children newly diagnosed with SMA or SMARD. 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.

Research Robert Luff Foundation

This grant contributed to the coordination costs needed to maintain the UK SMA Research Consortium. Since 2016, this has received £1,327,708 from SMA UK**.** It consists of 6 world-class research teams based in Oxford, Edinburgh, Sheffield and London. The teams work collaboratively across 4 main areas:

- Exploring the ways in which SMA affects different organs / systems within the body and which might be targets for treatments.

- Looking at what treatments could be beneficial if used in combination with current SMN-boosting drugs like nusinersen (Spinraza™).
- Developing models to test out potential treatments.
- Looking at new methods of drug delivery including in the womb.

Flexible Response Grants

This fund enables grants to be made to individuals and families affected by SMA. It provides a swift response to an urgent need when no other funding source is available. Grants are typically small.

Toy packs & Flexible Response Grants

This fund covers both purposes as described above. It was received as a grant combining both so was set up separately to allow it to be drawn on flexibility according to need.

Northern Ireland Events

This fund enables us to offer events in Northern Ireland for adults, children and young people with SMA and their families. These provide opportunities to share experiences and have fun.

Community Connections

This project was set up in response to the changes faced by the SMA community and SMA UK due to the impact of Covid 19. In particular it aimed to:

- Help to address the social isolation experienced by people in the SMA community due to Covid-19
- Explore ways to re-set our previous plans to deliver face to face information and support events
- Deliver the virtual events and interactive resources wanted by the community.
- Begin to establish a firm virtual presence so that virtual communication options form part of how SMA UK and the SMA community stay connected

The project was seed funded by Roche and continued through to January 2021 with Lottery Covid 19 funding.

17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2021.

Spinal Muscular Atrophy UK

DETAILED STATEMENT OF FINANCIAL ACTIVITIES for the year ended 31 March 2021

	2021 £	2020 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations and gifts	539,606	795,531
Government Grants Covid-19	54,295	-
Community Fund (BLF)	126,789	124,302
	720,690	**919,833**
Other trading activities		
Merchandise sales	3,740	5,262
Investment income		
Bank interest	261	775
Total incoming resources	**724,691**	**925,870**
EXPENDITURE		
Raising donations and legacies		
Staff costs and other expenses	106,829	114,642
Fundraising and publicity	24,891	56,459
Events and promotions	11,939	89,631
Cost of merchandise sales	1,954	6,658
	145,613	**267,390**
Charitable activities		
Staff costs and other expenses	271,585	315,748
Medical research grants	16,400	31,083
Other research activities	5,189	19,511
Information and awareness raising	5,941	18,217
Shared experiences network	13,009	14,163
Outreach Service	44,957	57,258
Welfare, equipment grants and toy packs	5,193	15,345
	362,274	**471,325**
Support Costs		
Management		
Staff costs and other expenses	42,103	72,467
Professional fees and bank charges	6,407	17,107
Other costs	13,589	15,421
Committee expenses	5,356	4,107
	67,455	109,102
Total resources expended	**575,342**	**847,817**
Net income	**149,349**	**78,053**

This page does not form part of the statutory financial statements



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spinal muscular atrophy uk

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