

ANNUAL REPORT 2022-23



**Spinal
Muscular
Atrophy uk**

SUPPORTING • INFORMING • ADVOCATING

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**I WOULD LIKE
YOUR HELP TO
MEET MORE
PEOPLE WHO
HAVE SMA
LIKE ME!**



WELCOME FROM OUR CHAIR

CHAIR'S MESSAGE

It has been a very busy and exciting year for SMA UK. Highlights include our growing voice and influence through our ongoing advocacy, working in partnership with Duchenne UK to develop a SMART suit, launching the Horizon project with SMA Europe and Cure SMA to develop latest research that can assist those living with SMA, kicking off the SMA Care project plan to update the Standards of Care, and continuing our drive for SMA to be included as part of the routine bloodspot testing of all newborns.

A key pillar of our charity is our dedicated Outreach & Support team who provided support helping over 200 families and adults affected with SMA as well as 50 health, education, and social care professionals through our support line and WhatsApp networks.

At the same time our Information team, working with SMA clinical experts have ensured that the information we share on treatments and care is accurate and up to date, which also resulted in the renewal of our Patient Information Forum (PIF) accreditation.

During the year we approved 65 Flexible Response Grants (FRGs) ranging from £35 to £974. Our FRGs are available in two categories; FRG 1 – Grants to access NHS funded treatment or assessment and FRG 2 – Grants to assist with small equipment, household and support items.

A big thank you to our supporters who continue to give generously as well as raise money through so many different challenges and events including the London Marathon, Ride Scorpion, The Great North Run, Lands' End to John O'Groats and Marathon in May. Your ongoing support and efforts are so crucial in helping us to continue our work. I can't begin to thank you enough.

It is important I take this opportunity to thank Angela Smith-Morgan who as CEO of SMA UK made such an invaluable contribution. I wish her well in her retirement. At the same time I would like to give a very warm welcome to Giles Lomax our new CEO who took up his position in May 2023.

Finally I would like to say a big thank you to our incredible team of colleagues and trustees as well as our partner organisations and committees who make sure SMA UK are here to support everyone living with SMA, day in and day out. Thank you.



A handwritten signature in black ink, appearing to read 'Mark Dearlove', written in a cursive style.

Mark Dearlove
Chair of the board of Trustees
Spinal Muscular Atrophy UK



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.

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

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.

Working to Improve and Monitor SMA Community Access to:

- Care and support
- New drug treatments & 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 work with other charities, health, education and social care professionals, 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.

Our Fundraising

To enable us to fulfil these strategic goals we:

- Value and respect every donor
- Create engaging and innovative fundraising appeals that enable everyone to get involved
- Constantly seek new potential sources of income to help us manage uncertainty in the ever-changing fundraising environment



SIDNEY'S STORY

Sidney's mother knew something was not quite right with her baby, but it was not until Sidney was four months old that the family received his SMA diagnosis.

However, by this time Sidney was already symptomatic and unfortunately damage had been done to his muscles.

He received Zolgensma shortly after diagnosis, and is receiving Spinraza now too which has really helped with his strength and fatigue.

Sidney's mother says, "SMA UK supported us when Sidney was first diagnosed, we reached out to them and they sent us out a pack with information and toys which was really lovely.

The family meet ups that they organise have been a lovely way to meet other people with SMA and their families, and it's been particularly comforting to meet adults living with the condition as well and learning from their experiences.

Sidney is now not only living but he's thriving! With a lot of hard work and determination he is doing very well. He's a cheeky little chap, with a very good sense of humour! He is showing lots of signs of being a very determined little boy. We are beyond proud of how far he has come, we can't thank SMA UK enough for their support throughout."



TRUSTEES AND STAFF LIST



STAFF TEAM

As of April 2022 – March 2023

Employed Staff

Angela Smith-Morgan

C.E.O

Portia Thorman

Advocacy Lead

Dermot Dolan

Resigned 23rd Feb 2023

Community Services Lead

Michele Phillips

Outreach and Support Coordinator

Claire Holdcroft

Outreach Worker

Jo Spicer

Outreach Worker

Becci Howell

Outreach Worker

Jackie Guyler

Retired 31st March 2023

Information & Support

Contracted Staff

Lorna Penning

Finance Officer

Martin Penning

Operations, Database, Security

Luis Canto E Castro

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

David Doubtfire

Retired 31st March 2023

Operations, Database, Security

Dr James Sleigh

Scientific Research Correspondent

Vanessa Christie-Brown

Research Coordinator

OUR TRUSTEES

We currently have a Board of 16 Trustees. They include people living with the condition, relatives and healthcare professionals. Trustees bring a range of skills, knowledge and experience that all help with the smooth and efficient running of the organisation and ensuring that it meets the needs of its diverse membership.



Mark Dearlove
Chair of the board



Katharine Jackson
Treasurer



Professor Kevin Talbot
Senior Adviser to the Board



Michael Collins



Dr. Anne-Marie Childs



Dr. Alistair Emslie-Smith



Yvette Edwards



Clare Gray



Julian Fiorentini



Srin Madipalli



Casimir Knight



Ben Morris



Toby Mildon



Tim Sheffield



Dr Ros Quinlivan



Lauren West



Deborah Waltier

“

My son was diagnosed with SMA-LED, it's a rare condition I didn't know anything about.

Then I was told about SMA-UK and since then, the help and support they have given me, and my son is brilliant.

They helped when my son had his two operations. I would highly recommend the charity for people who have SMA.

*The staff are brilliant and supportive, without the charity **I don't know where I would be today.***

A woman with shoulder-length brown hair, wearing a blue and white striped shirt, is smiling and looking at a comic book. A young boy with glasses, wearing a blue shirt, is also smiling and looking at the comic book. They are both holding the comic book, which features the title 'CAPTAIN AMERICA AND THE FALCON'. The woman is also holding a flyer that says 'MAKE MONEY GET PRIZES with Fast Selling American Seeds'. The background shows a window with patterned curtains and framed pictures on the wall. The entire image has a blue overlay.

INFORMATION UPDATE



Our information service aims to give anyone new to SMA an insight into its causes, symptoms and effects, as well as answering many community questions from those affected by the condition.

SMA UK continues to work with SMA clinical experts so that we are assured that our information about disease-modifying treatments and care given for SMA in our information sheets and webinars is accurate and up to date.

INFORMATION RESOURCES

In October 2022 we received our accreditation from the Patient Information Forum stating that we have met their requirements again and can apply the PIF TICK Quality Mark to our health information. PIF (<https://pifonline.org.uk/pif-tick/>)



Getting ready for School Pack

As more and more children with Type 1 SMA are starting nursery and school, we highlighted a need to make sure that education settings are fully prepared to receive them.

We worked with Natalie Smith, a Clinical Nurse Specialist at GOSH and families who shared their experiences, tips and advice to create a 'Getting Ready for Schools Pack'. The pack includes information about what to ask when visiting potential schools to what additional support your child might need. It also has editable "All About Me" templates that give schools an overview of your child's abilities and needs.

The pack can be requested via our website or our Support & Outreach Team.

Website information

Everything can be found on our website, including the latest clinical trials results for new treatments through to the many aspects of 'living with SMA' – such as emotional and psychological support, accessing equipment, financial support, holidays and transport.

Our website top three 'hits' this financial year were...

Information
landing page

6,052

Recent Diagnosis
of SMA Type 1

5,978

Treatments
& Research
landing page

3,612

WEBINARS 2022/2023

Treatment updates:

Update on drug treatments for children and adults, April 22

Update on Zolgensma in the UK, Nov 22

Conversations with Healthcare Professionals:

New Research Findings: The Amino Acid Diet, Dec 22

Blood Sugar Control During Illness, Feb 23



MAXWELL'S STORY

Maxwell, aged 19, has SMA Type 2 and was diagnosed just before he turned three.

It was quite hard for his parents as there wasn't a lot of information available to them at the time. They were also told that Maxwell wouldn't live past childhood. He has proved them wrong!

When Maxwell was starting school, the Jennifer Trust (now SMA UK), supported the family and they were also able to help get his first wheelchair aged four.

The family attended the Christmas parties that SMA UK previously hosted and Maxwell really enjoyed meeting others at these events.

Maxwell is now a moderator for SMA UK's Young Adults Network Group and appears regularly on the Living With SMA Podcast.

Over the years he has built relationships with others living with SMA through networks and he says this is always really helpful.

Maxwell is studying Business Management and is hoping to be a CEO one day, but he says it been quite hard especially in getting the support he needed throughout his education, but says,

"I believe in the power of community and the importance of sharing valuable information others have learnt. This way, people with SMA, like myself, can overcome challenges together, ultimately thriving."



ADVOCACY

We advocate 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, 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.

For timely and current advocacy activities to take place, it is important we hear and listen to all voices and stories from the SMA Community.

COMMITTEES AND FORUMS

From 1st April 2022 – 31st March 23 SMA UK was represented at the following:

- SMA Europe
- DHSC rare diseases forum
- SMA Reach steering committee.
- Managed Access Oversight Groups (MAOG) for Risdiplam and Nusinersen
- SMA Europe Treatment committee
- Project Hercules working group with Duechenne UK
- UK SMA Newborn Steering Alliance Committee
- UK Newborn Screening collaborative



ACCESS TO TREATMENTS AND TECHNOLOGY

SMA Standards of Care

The International Standards of Care were published in 2017 in the Neuromuscular Disorders Journal. The Family Guide was published in 2018. This was before the SMN2-dependent disease-modifying treatments became widely available. These medications have impacted significantly on the 'natural history' of the condition and changed the way in which the condition progressed over time at different stages and ages.

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. Clinicians and patient representatives from across the country would be involved in the establishment of working groups to review each aspect of care.

In June 2022, work started on the planning phase for this extensive project. The SMA REACH clinical network agreed that the design of the project should be based on the North Star Project which was set up in 2003 to help drive improvements in services and set national standards of care for children living with Duchenne Muscular Dystrophy.

Using the same format, the SMA Care project aims to optimise the care of all those living with SMA by achieving and practising consensus on best clinical management, with agreed protocols irrespective of clinical centre.

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. Clinicians and patient representatives from across the country would be involved in the establishment of working groups to review each aspect of care.

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

- To review the International 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 a 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 are looking forward to updating the SMA Community with progress on this project as we move it forward.

Zolgensma

Working in partnership with Treat SMA and Muscular Dystrophy UK, we submitted detailed evidence on administering Zolgensma to pre-symptomatic patients. On the 9th February 2023, this evidence was presented at the Nice Treatment Committee meeting with positive outcomes.

Zolgensma received approval for pre-symptomatic babies up to 1 year old and with up to 3 copies of SMN2. It was particularly surprising as clinical evidence only went up to 6 weeks of age. SMA UK's representation of the real-world evidence influenced key decision makers.

As you can see from this comment from Karen Facey, Evidence Based Health Policy Consultant & researcher at Edinburgh Uni – specialising in HTA, Patient Involvement and Appraisal of treatments for rare diseases.



Karen Facey

The comment you just made at NICE HST about the actual challenges a family faces in getting a baby who was known to have SMA into treatment was in my opinion a great example of an impactful piece of patient input to decision making. Thank you!

Nusinersen / Spinraza TM and Risdiplam / EvrysdiTM

We continued to be active members of England's Managed Access Oversight Group for Risdiplam / EvrysdiTM and Managed Access Oversight Committee for nusinersen / Spinraza TM . We joined clinical experts and representatives from NICE, the relevant pharmaceutical company and the other two patient groups – Muscular Dystrophy UK and Treat SMA – at meetings.

Each group / committee oversees the operation of the collection of data about clinical and patient reported outcome measures (PROMs) for anyone who is receiving that disease-modifying treatment. This is so that the data will be ready when NICE meets to review all the evidence about that treatment and decide whether to recommend that the NHS continues to fund it when the Managed Access Agreement ends. The group / committee also discuss and address any issues there may be with the roll out of the treatment programme. We have been able to raise any concerns from the community at these meetings and work with the relevant groups to resolve them.

Antimyostatin drugs

We also worked successfully with clinicians to advocate for NHS England to enable access to clinical trials for two of the new antimyostatin drugs. Though the numbers in these trials are very small, it is essential that the UK continues to be a viable centre for future trials.

PROMS

SMA UK, patient groups and clinicians also worked this year with the UK SMA Patient Registry to finalise what PROMs would be collected for consideration by NICE. We worked hard to encourage people to submit their information so that it is included.

SMA Emergency Care Self Advocacy Tool

In March 2023, SMA UK identified the need for the SMA Community to advocate for themselves and their children when in an emergency care setting. Initial meetings have set out its purpose; to alert readers to important information, that may be on an emergency care plan, but making it more accessible for parents, carers, individuals living with SMA, first responders, junior doctors and accident and emergency clinicians.

We are looking forward to working on the resource with plans for it to be published in Summer 2023.

Newborn Screening Alliance 2022–2023

As founded members, we carry out the following activities to ensure that we continue to push for systemic change;

- Ensure positive relationships are carefully formed with the UK Newborn Screening Committee (UKNSC).
- Work with the UKNSC to provide information, case studies and statistics to expedite the evidence collection process.
- Collaborate with Muscular Dystrophy UK in the production of the report 'Newborn Screening for Rare Diseases'
- Participate in a film about the need for newborn screening for SMA, for Genetic Alliance's 'Spotlight on Rare Conditions' series.





PARTNERSHIPS & COLLABORATIONS

SMART Suit

We supported Duchenne UK's application to the Peoples Postcode Lottery in a bid for the £1.25million Dreamfund to develop a SMART Suit and, in May 2022 received the fantastic news that we had been successful! The SMART Suit, will be the first-of-its-kind exoskeleton suit that will help disabled teens and young adults use their arms and upper body. By restoring mobility, the SMART Suit aims to give people living with Duchenne muscular dystrophy (DMD) and other progressive conditions back their strength, independence and dignity. Development work continues.

Angela Smith-Morgan, previous CEO of SMA UK says:

"The prototype of the wearable suit will take three years to develop, and the SMA Community will be a key element in testing designs for suitability for a range of conditions. We are thrilled that the SMA Community will be playing key part in this development which will transform the lives of people living with SMA and other conditions."

Dreamchair

SMA UK partnered with Duchenne UK in another ongoing project, the Dreamchair, helping to develop and test a prototype powered chair which is both affordable, multi-functional, modern and cool for young people living with Neuromuscular conditions.

Horizons Project

In March 2022, SMA Horizons was launched. A project in partnership with SMA UK, SMA Europe and Cure SMA, a researcher has been employed to discover the latest research taking place in the UK that could assist those living with SMA, for example nerve regeneration and robotic assistance technology. Work continues in this area and we are updating the SMA Community accordingly.

SMA Europe

SMA UK is an active member of SMA Europe, with two delegates working closely with colleagues from 24 different European SMA patient groups. We work together to bring effective treatments and optimal care to everyone.

In January 2023, we appointed two new members to SMA Europe to represent the UK. Portia Thorman, Advocacy Lead at SMA UK and Alistair Emslie-Smith a Trustee of SMA UK took over from CEO Angela Smith-Morgan and Casimir Knight, also a SMA UK Trustee.

During 2022, calls for help from SMA Europe saw the creation of the Action for Ukraine fundraising campaign, bringing together SMA UK, MDUK, ACE SMA and Treat SMA to raise funds for those living with SMA in Ukraine

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



AWARENESS RAISING & CAMPAIGNING

Portia Thorman, Advocacy Lead is often asked to represent SMA UK at various conferences and forums. She has spoken at pharmaceutical conferences, clinical meetings, parliamentary round tables and NICE meetings; all with the aim of raising awareness of SMA and the needs of the community.

UK SMA Exchange Forum



In February 2023, We had the opportunity to bring the patient perspective of standards of care in SMA to the top SMA clinicians from across the UK at the UK SMA Exchange Forum. Bringing perspectives from the whole community, collected via our networks at SMA UK we were able to highlight the need for a new standards of care in the UK for SMA.



Rare Disease Day

Hosted by the Genetic Alliance, we attended the parliamentary drop-in at Westminster for **Rare Disease Day** on the 28th February 2023. This gave us an opportunity to raise awareness of the issues facing people living with SMA with MP's and key organisations.

Cost of Living parliamentary drop-Report Launch

On Tuesday 18th October 2022, Muscular Dystrophy UK launched their latest cost of living report setting out key recommendations to improve the support available to ensure alleviate the financial burden people with a muscle-wasting condition are facing. SMA UK's Advocacy Lead, Portia Thorman, joined representatives from MDUK and other advocacy groups to talk to MDUK about the disproportionate impact the cost-of-living rises have had on the disabled community.

SMA Awareness Month 2022

For SMA Awareness Month 2022, we shone a spotlight on SMA, how we work with and support the SMA Community, and how the Community support our activities. sharing infographics with information about SMA; stories and personal experiences from the Community; linked to resources on our website.

We were invited to take part in a Twitter Takeover by the Genetic Alliance and our social media channels showed significant increase in engagement!

Twibbon

We put together a Twibbon, which people could use as their profile picture on their social media profiles to help raise awareness for the month. This was downloaded by 93 people.

Social Media

All our social media channels showed a significant increase in engagement, massively helped by our followers sharing and retweeting content - thank you!

Post reach / Impressions:

Facebook: 66.4K

Instagram: 28.4K

Twitter: 17.4K

Linktree via Instagram: 70% increase on link clicks compared to July



Fundraising

Kelsey Stratford for organising a fabulous fundraising event at The Ivy, Soho and raising over £2,600 for SMA UK! Kelsey has been amazing in raising awareness and supporting us, inspired by her sister, Kennedy, who has SMA Type 1. We were so grateful to everyone who attended and donated their time to make this event such a success!



SUPPORT AND OUTREACH



Our Support and Outreach Team provides personalised practical and emotional support for all those affected by and living with SMA. From access to care and drug treatments to opportunities to have contact with others affected by the condition.

We support families and individuals to access funding for specialist equipment and wheelchairs as well as supporting travel to appointments and overnight stays.

In early March 2022, Maggie McHale a longstanding and valued member of the Support and Outreach Team, who had been working at SMA UK with SMA Community since 2006 retired as did Jackie Guyler, who had been working in the support and information team since 2017.

Michele Phillips moved into the support team and Claire Holdcroft and Jo Spicer continued in their support roles. In July 2022 Rebecca Howell was appointed to the team, a very experienced social care practitioner, who has a family connection to SMA.

This year the team have facilitated and developed links with Neuromuscular nurse specialists and advisors across the country, as well as maintaining connections with the One Gene Nurses from Novartis, sharing our resources and supporting families across the UK.

The Support and Outreach Team have responded to 207 families and adults affected by SMA through our support line and the WhatsApp networks.

Each case is unique and requires hours of time making sure that everyone receives personalised emotional and practical advice and support that is required. Support varies significantly from treatment information and care packages to advice and support obtaining specialist equipment and adaptations. Furthermore, the team have supported and provided information to **50** health, education and social care professionals.

Although received at a devastating time of diagnosis, our free multisensory toy packs were sent to 21 families with babies under the age of twelve months. The packs are colourful and fun, each toy being carefully selected to provide babies with a stimulating experience.

FLEXIBLE RESPONSE GRANTS (FRG'S)

SMA UK uses allocated charitable funds, distributed in the form of grants, to support families with children affected by SMA and adults living with the condition. Grant applications are submitted to the SMA UK Support Team by individuals or health, education, and social care.

There are two FRG schemes in place and applications may be made to one or both by a individual in a financial year.

FRG 1 – Grant to access NHS funded treatment or assessment

In 2022-2023 we provided 43 grants ranging from £35 - £467 (dependent on distance travelled and time spent receiving treatment).

FRG 2 – Grant to assist with small equipment, household and support items

This grant is needs-led and used for urgent items that are not provided through statutory provision.

In 2022-2023 we provided 22 grants ranging from £39 for extra warm bedding for a child to £974 for a travel system which included a lie flat car seat for a newly diagnosed baby.

A photograph of a community engagement event at the Wai Tyler Centre. In the foreground, a woman with long blonde hair, wearing a blue t-shirt with the Spinal Muscular Atrophy logo, stands smiling. To her right, a man in a wheelchair is also smiling. The wheelchair has a red blanket with the word 'STIER' on it. Next to him is a large, colorful mascot character with a rainbow body and a purple top, holding up two thumbs. The background shows the brick building of the Wai Tyler Centre and other people in blue t-shirts. The entire image has a semi-transparent red overlay.

COMMUNITY ENGAGEMENT



We understand how important it is for members of the SMA Community to meet in person but were unable to host face to face events for two years due to Covid restrictions. However, still having to act with some caution in the summer of 2022, we hosted six face to face events for the SMA Community.

Carefully selecting venues that offered lots of outside space we called these new meet ups “Picnic in the Park” giving guests the opportunity to socialise with other members of the SMA Community over a picnic lunch.

Events were hosted in Scotland, Yorkshire, Northern Ireland, West Midlands, Wiltshire and West Sussex with 157 attendees in total. These events enabled people to share experiences and learnings and meet some of the staff from SMA UK.



“Fantastic time at the picnic in the park today. So nice to talk with other families and for our daughter to see other children in wheelchairs like her. We look forward to going to another event!”

“Nice day out at Yorkshire Sculpture Park for a meet up. Nice to meet new people and see how much more support and networking there is now for families affected by Spinal Muscular Atrophy.”



WHATSAPP AND FACEBOOK GROUPS

The introduction of SMA UK’s moderated WhatsApp groups have widened our community engagement even further and have given us a better understanding of the current issues faced by the whole community.

Each group is moderated by two people living with SMA and we have established guidelines and safeguarding procedures in place.



Teenager group (ChariSMA)

Moderated by Jordanne Wozencroft and Maxwell McKnight



Family group

Moderated by Becky Lomax and Amy Williams



Young adults group

Moderated by Luis Canto E Castro and Michele Philips (SMA UK staff)



Adults Facebook group

Moderated by SMA UK Staff

OUR SOCIAL MEDIA REACH :



Facebook Reach : 209,043



Instagram Reach : 27,344



Twitter Impressions : 33,100

LIVING WITH SMA PODCAST

Our Living with SMA Podcast is going from strength to strength with 20 episodes airing and over 8 hours of content. There were 4697 views on YouTube and 1100 downloads from BuzzSprout, our streaming platform. We work with the SMA Community to ensure that all our topics are varied, current and relevant.

Top 5 episodes from YouTube:

Episode 18

Part 1 You've got a friend in me

Episode 20

Part 1 Disability & education

Episode 19

Part 4 SMA life through the ages

Episode 19

Part 2 SMA life through the ages

Episode 22

The Right Mindset

Top 5 episodes downloaded from BuzzSprout:

Episode 19

Part 4 SMA life through the ages

Episode 18

Part 3 You've got a friend in me

Episode 17

Part 3 about toilets

Episode 18

Part 1 You've got a friend in me

Episode 22

The Right Mindset



“

When I was introduced to the Living With SMA podcast, as someone with SMA Type 2, I realised the amazing the potential it had to inform people living with SMA, and that it was a great platform for amplifying the voices of our community.

This has really become a project that is close to my heart because I have seen the impact it has made, not only do I get to meet new faces, but I also get the buzz of seeing the community interact with the episodes, and suggest new episode ideas!

- Louis, SMA UK's Community Services Assistant



RAISING FUNDS



Thank you to everyone who made a donation, organised a fundraising event or took part in a challenge in aid of SMA UK during the 2022/23. We could not carry out our work were it for your support.

The Great North Run in September and the London Marathon in October were well supported and we also had Marathon runners in Dublin, Cardiff, Manchester and Edinburgh throughout the year. The Three Peaks challenge was the event of choice for some of our fundraisers and others even took the plunge with a Skydive.

Our younger supporters got involved in organising bake sales and non-uniform days at their schools and nurseries, which helped to raise awareness and well as funds. A lot of these chose to participate in Christmas Jumper Day in December, which raised a total of around £5,000 and generated lots of festive photos.

A huge thank you, as always, to our regular givers and those who continue to donate and fundraise in memory of a loved one. Your ongoing support is so important in helping us to continue our work.

We will continue to diversify our income streams, not being reliant on a limited number and will engage further with supporters and donors sharing their success stories and the impact their fundraising has on the sustainability of the Charity.

HIGHLIGHTS OF OUR FUNDRAISING ACTIVITIES THIS YEAR

- Our virtual event, Marathon in May supported by the community raised almost £10,000
- After a two year break due to Covid, Ride Scorpion cycle challenge took place in May raising £20,000
- Our Christmas matched funding campaign, The Big Give Christmas Challenge, raised a record breaking £30,000, so a special thanks must go to everyone who donated during campaign week and particularly to our Pledgers for making it possible.
- £191,706 raised by our community fundraisers and corporate partnerships
- £71,699 raised from individual giving and regular donors
- £94,491 received from charitable trusts and foundations
- £30,285 received from Gift Aid



"As soon as we found out my granddaughter had SMA, I wanted to do something positive in the hope we could save another family from going through what we have endured. I decided to sign up for the London to Brighton cycle challenge alongside my son. Of course, the best part was going over the finish line with loud cheers but, at the same time, it was very emotional as my thoughts were about my granddaughter who wasn't well enough to travel, however, throughout the ride we sent her and her Mum regular updates so they could cheer us on from home." - anonymous

"I will be running the London Marathon to raise awareness of SMA and to help SMA UK raise much needed funds, but also, for my niece, her Mum and Dad and big brother. As a family they have faced the worst news, but they never lose hope. And so, I am running for them, and all the families living bravely with SMA." - anonymous



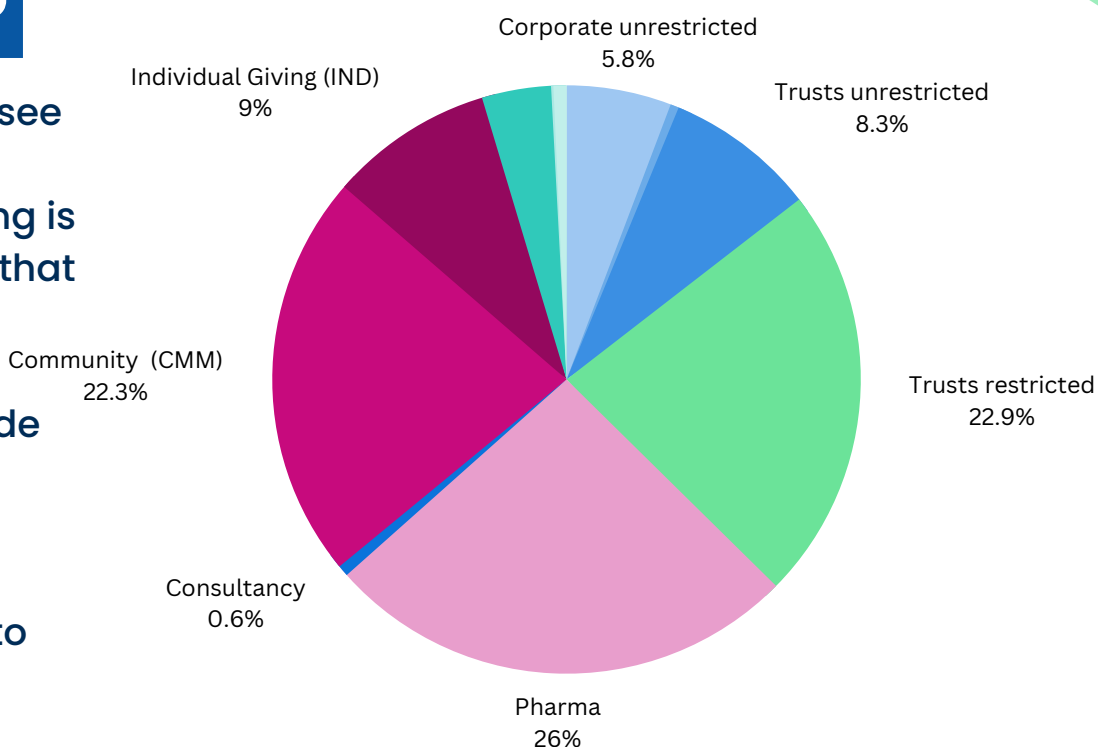
RESPONSIBLE FUNDRAISING

The charity is a member of the Fundraising Regulator scheme and thereby entitled to use the Regulator's logo on its fundraising materials. It operates in accordance with the Code of Fundraising Practice.

As a charity registered with the Fundraising Regulator, we are committed to ensuring our fundraising is legal, open, honest and respectful. Our Fundraising Promise, as set by the Fundraising Regulator, can be found on our website at smauk.org.uk

FUNDRAISED INCOME SOURCES

Whilst it is positive to see that income from community fundraising is strong, we are aware that in this financial year trusts and pharmaceuticals made up half of our overall income. We will be addressing this in 2023/24 with an aim to diversify our income sources and reduce reliability.





OPERATIONS



Evolution of our in-house database information system to provide a service into the next decade. Reliable and with capable functionality, it will deliver greatly improved accessibility to a work-stream centric customer relationship management platform giving improved productivity through advanced web-technology and allow our organisation to give a first-class community service.

Continuation of a comprehensive policy, process and procedures review to ensure the Charity can continue to thrive operationally into the future adhering to the regulations and standards we have done so well following to-date

Our continued monitoring and reviewing of office space in Stratford-upon-Avon and the surrounding areas will help ensure that as a charity we utilise a fit for purpose space to fulfil the needs of the charity going forward. Practical analysis of space requirements such as value per square meter and potential of office sharing will keep us at an optimal cost for office space.

A continuing cycle of infrastructure contracts renewals frequently present SMA UK with the opportunity to reassess and retender incumbent solution providers to optimise value and return on investment. Telecommunications, office equipment and IT provisioning highlight all fall into this category, and this year each of these areas have been through such reevaluating.

FUTURE PLANS FOR SMA UK



In May 2023, Giles Lomax joined the charity as CEO to lead the charity into its next phase.

“It’s evident from the 2022/23 annual report that SMA UK continue to do such vital work on behalf of the SMA community. Being a father of twins who have SMA type 2, I have firsthand experience of the challenges the condition brings to families and individuals and understand the power the charity can have on changing the lives of people living with SMA.

I believe that those personal experiences will add significant value to the organisation as we continue to raise awareness for the condition, strive for change and ensure that anyone affect by SMA can live fulfilled and happy lives.”

Giles Lomax, CEO (as of MAY 2023)

FUTURE PLANS 2023

As the needs of the SMA Community are ever changing we will continue to develop and open our communication channels allowing us to listen, advocate and take action on these needs and issues.

Through raising awareness of SMA the Charity will do everything in our power to ensure that we the SMA Community has continued access to treatment for all.

Newborn screening for SMA is one of our top priorities for 2023/24 and we will continue our advocacy work with the UK Newborn Screening Alliance and parliamentarians so that we do all we can to ensure the UK Newborn Screening Committee include SMA in the heel prick test for newborns across the whole of the UK. We are acutely aware that further delays can have a devastating impact for families recently diagnosed with the condition and the need for speed is imperative.

Representing all people living with and affected by SMA, we are aware that we need to find new ways to listen to, engage with and understand what the key priorities are from the perspectives of both families and adults living with SMA. The SMA UK team will be working with adults and families of children living with SMA to ensure that this happens.

Furthermore, we will endeavour to run Community engagement events across the UK, bringing families and

individuals together to network, share experiences and alleviate some of the impact living with a rare condition can sometimes have.

Clinical trials will still play a big role in the ongoing development for treatments for SMA and with 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.

Our Support and Outreach Team will continue to deliver an exceptional service to all those affected by SMA, over the phone and with face-to-face visits that can start again post Covid. This work is elevated by the Information team who work to produce up to date, accurate health information that is accredited by the Patient Information Forum. We are proud to have held this accreditation since 2012, when it was previously under the Information Standards.

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.



"I am loving my new chair, thank you for all your support"

Amy was in desperate need of a new powered wheelchair which would offer her maximum comfort, support and more freedom. The chair which best suited her needs came at a cost of £25,000.

With support from SMA UK she obtained funding from third party organisations as well as fundraising through friends and family and raised the funds needed – in December 2022 Amy received her new chair!

With this new chair, Amy can start going out more with friends and family where she can drive her chair comfortably for longer periods. With the raisers she can sit at the same height as her peers and her carers can move her with ease now.



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Registered Charity Number 1106815