

SMAatters

SPRING 2024



**Spinal
Muscular
Atrophy uk**

SUPPORTING • INFORMING • ADVOCATING

Welcome from Ben Williams

SMA UK Trustee

Greetings to our incredible supporters and community!

Having joined the Board of Trustees at SMA UK in January 2024, I am pleased to connect with you via our bi-annual newsletter and wanted to take this opportunity to introduce myself.

I have been involved with SMA UK in various capacities ever since my son was diagnosed with SMA Type 1 aged just three months old in February 2021. SMA UK was the first place we turned to after receiving the life-changing news.

Since then, I have tried to support the charity and its aims whenever possible. I have worked alongside SMA UK as an expert in the assessment by NICE of Zolgensma for treating pre-symptomatic babies, in fundraising initiatives, and as part of the 'Every Moment Matters' campaign that featured in the Houses of Parliament in February 2024.

Throughout my involvement, I have been, and continue to be, encouraged by the evolving SMA landscape and by the medical/scientific progress that has been made. Even in the relatively short period since my son's diagnosis, I have witnessed first-hand the approval of new treatments and redefining of the expected outcomes.

Despite the progress, however, challenges persist, and our collective efforts are as crucial as ever.



I will therefore be cycling the entire length of Ireland, 373 miles over three days, in August 2024 along with our CEO Giles Lomax to raise awareness and funds for SMA, in particular the need for newborn screening to come to fruition.

The location and distance have significance: Ireland, unlike the UK, screens for SMA at birth; and the distance represents each of the 308 individuals whose SMA diagnosis has been delayed since the UK last declined to include SMA on the newborn screening programme.

SMA UK is clearly an organisation that matters to me and my family, and joining the Board allows me to play an active role in supporting and shaping its future, helping ensure it maximises its positive impact potential.

Ben Williams

Ben Williams, SMA UK Trustee.

Living with SMA Podcast

Since our last edition of SMA Matters, with support from members of the SMA Community, we have produced seven new Living with SMA Podcast episodes. Topics ranged from taking a summer holiday, to how living with a long-term condition affects your mental health.

Our most popular episode, with 1,400 views to date, was "Keep your goals away from the trolls" - an empowering and emotive episode emphasising the importance of resilience, self-care and building a positive digital community.

This episode features guest Alex Darcy, who has not only confronted online trolls but has turned her experiences into a source of empowerment and advocacy.

Listen to all podcasts here
smauk.org.uk/SMApodcast



Join our Networks!

We are delighted to see the Community networks growing! The networks are a great place to connect with others, share experiences and ask questions. All moderated by members of the SMA Community and select members of SMA UK staff from the Advocacy, Information and Support Teams.



Scan the QR code to find out more on our website and to join any of the groups!

or visit: smauk.org.uk/networks





Asking Questions, Exploring Options

The Support and Information section of our website may be a good starting place to find general information about SMA, including guides for newly diagnosed families. Also, our Living with SMA area offers a wide range of topics for teenagers, adults, and parents of children who have SMA. It is based on knowledge and advice from the Community Support Team.

Q. We're planning to go away this year if we can. We know we'll need holiday insurance but think this might be difficult. Where do we start?

Travel insurance is essential when going abroad and it's wise to have cover.

Many insurance companies issue 'standard' policies that won't cover 'a pre-existing medical condition', so you will need to tell them about you / your child's SMA to make sure you will be covered if you do need medical help.

You might need to let the insurance companies know of any carers or personal assistants going with you.

Make sure to include cancellations and loss or damage of property, including any equipment. Equipment can sometimes be covered through home or equipment insurance. Whatever cover you have, check if equipment insurance would cover the cost of hiring alternative equipment.

If flying, contact the airline in advance and request a 'special declaration of interest' for any equipment insured. This will ensure that no limit can be put on an equipment insurance payout if equipment is damaged by the airline.

There are a number of insurance companies which do offer travel cover for people with pre-existing medical conditions.

Whichever one you contact will ask their own series of questions, which you will need to answer in as much detail as you can. Costs can vary widely so it is worth getting several quotes and comparing them. For the latest suggestions of what travel insurance companies other families have used, please contact our Community Support Team.



Q. We've wondered what type of accessible holiday accommodation might be best, do you have any ideas?

There are many things to consider when thinking about holiday accommodation. This is a big topic that can have many different answers depending on your requirements.

As a general starting point, we would recommend asking about: steps, gradients, width of doorways, sizes of bathrooms, bedrooms, any equipment you may need, and if it is available to use or hire.

We have information, links and "things to think about" when planning a break in the three sections (children, teenagers and adults) in Living with SMA on the website. This also has the shared experiences of others, as well as their suggestions and thoughts - there is much to explore and consider.

If you would find it helpful to talk through your findings, our Support and Outreach Team would be pleased to hear from you.

For more information visit:
www.smauk.org.uk/livingwithsma





In October 2023, we were delighted to open our first round of SMART Moves grants to the SMA Community. Funded by the Motability Foundation, and running for three consecutive years, this grant gives us the opportunity to assist people living with SMA in purchasing mobility equipment and wheelchairs.

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 £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.

Please note:

All grants will be paid directly to the supplier, not the beneficiary. Grants will only be awarded for your chair.



Scan the QR code to find out more about SMART Moves, or visit: smauk.org.uk/smartmoves

Sarah's Story

I'm Sarah and I live in Manchester. I have Type 3 and since around 14, I've been using a wheelchair for long distance walks. Then, more permanently since I was 25 years old.

You won't be surprised to read that it's an extension of me!

I'm Head of Communications and Policy for the brilliant national charity, Activity Alliance. I must travel about, be at high level meetings and deliver workshops among my tasks. The charity is all about disabled people's inclusion in sport and physical activity, so representation matters. And for that, I need a reliable wheelchair to truly show what good inclusion looks like in action.

I have relied on the wheelchair voucher scheme for my last three wheelchairs. This gives you some money towards your chair, but this voucher also needs to cover the maintenance and updates. Every five years, stress levels are high as I need to save and go through the long process of seeing what support I need this time round. It's a £5,000 wheelchair so it's not an easy cost to cover. My chair was seven years old and it was time for a new one.

I'm a proud SMA'er and want more people to know about the condition and have followed SMA UK for a long time. As if by magic, appearing on my Instagram one day in October, I saw the new SMARt Moves grant promotion appear. I couldn't believe my luck and the process seemed easier than most applications I've applied for in my lifetime.

I sent in my application and within weeks, the golden email arrived. I'd been successful. Not only that, but the wonderful Ally also didn't want me to miss the email, so sent me a text too. The personal touch has been the best thing about the whole process. People who just get the stress and needs of someone with SMA.

The SMA team did the rest, sorted the invoice, and communicated with the supplier if needed. The only important task I had was to choose the colour! (Very important!).

I can't tell you how delighted I am with my new chair. As with any custom-made item, I was told to expect it in 14 weeks. Imagine my face when it was ready a month later!

Readers let me present to you my new, silver sparkle chair. It's even more loved as it's come from the people who understand SMA and raise awareness every day.

Thank you SMA UK!



Community Connections

Summer 2024 Events



After a successful summer of in-person meet ups last year, we are excited to bring even more opportunities for the SMA Community to get together, have fun and share experiences in 2024!



Resonate

This accessible activity weekend is open to anyone over the age of 18 with SMA. You will enjoy activities such as abseiling, archery, swimming and zip-lining as well as lots of chances to socialise with friends old and new!

Find out more at smauk.org.uk/resonate

CALVERT TRUST EXMOOR

26TH - 29TH JULY

Resonate Under 18s

Open to teenagers aged 13-17 with SMA and their parent / carer, this new event for 2024 brings all of the fun of Resonate to the younger members of the SMA Community.

Find out more at smauk.org.uk/resonate-under18

CALVERT TRUST LAKES

13TH - 16TH SEPT



Picnic in the park



2024 Picnic in the Park dates

18th May Cardiff

18th May Yorkshire

2nd June Edinburgh

8th June Birmingham

8th June Essex

11th August Belfast

Following feedback from last year, we have added even more Picnic Events to cover the whole of the UK. These meet-ups are free for anyone with SMA and their families to attend and are an opportunity to have fun and meet new people, as well as catch up with old friends and the team from SMA UK.

Booking is essential and you can find out more and book your spaces at smauk.org.uk/picnics2024



Multi Technology Appraisal for Nusinersen and Risdiplam to take place this year.

When the National Institute for Health and Care Excellence (NICE) approved the drugs Nusinersen (in 2019) and Risdiplam (in 2020), it was done so on time limited Managed Access Agreements (MAAs) in England and Wales, which come to an end in 2024.

At the time of approval, the NICE committee felt that there was not enough evidence from the clinical trials to show how well the drugs worked and their cost-effectiveness. Therefore, researchers have been collecting more patient data over this time.

With two treatments being assessed which treat both the paediatric and adult population living with all Types of SMA, sharing all of these perspectives with NICE is a difficult task. As consultees to the appraisal committee, SMA UK, along with TreatSMA and Muscular Dystrophy UK, are acting on behalf of the SMA Community to ensure that the patient voice is heard to give NICE compelling evidence to continue the drugs.



Timeline for MTA

5th January 2024

Invitation to participate sent to all stakeholders.

Forms for completion, appraisal guides and submission templates available.

The final scope, stakeholder list, response to scoping consultation comments and the Equality Impact Assessment available on NICE website.

26th January 2024

Deadline for participation and confidentiality agreements and expert nomination forms.

External Assessment Group (EAG) Protocol sent to stakeholders.

2nd February 2024

Stakeholder Information Meeting (SIM)

15th February – 17th March 2024

NICE MTA Patient and Carer survey by SMA UK, MDUK and TreatSMA.

6th March 2024

Portia Thorman (SMA UK), Andi Thornton (TreatSMA) and Lucy Frost (TreatSMA) have been selected as the patient experts to present at the committee meeting in October.

14th March 2024

2024 virtual information seminar hosted by MDUK on Spinal Muscular Atrophy (SMA) treatment updates.

19th April 2024

Deadline for stakeholder submissions

Early August – Early September 2024

Consultation on EAG report

2nd October 2024

Committee Meeting

Find out more and keep up to date with progress at: smauk.org.uk/mta2024

Newborn screening

In June 2023, the UK National Screening Committee (NSC) requested further evidence to support a recommendation on SMA screening in newborns. To gather this evidence, the UK NSC endorsed a 2-fold request to:

- Develop a new cost effectiveness SMA screening model for the UK context.
- Start planning an in-service evaluation (ISE) of SMA newborn screening in NHS services in the UK.

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

The partnership board will be responsible for the design and delivery of high-quality evidence in respect of the feasibility, acceptability, cost, and clinical-effectiveness of newborn screening for SMA.



Left to Right : Bob Doris MSP, Natalie Frankish (Genetic Alliance UK), Bernadette Phillips, Nathaniel Mitchell, Charlie Mitchell, Sue Webber MSP holding up pledges.)

Every Moment Matters Report

On the 5th February 2024, the Every Moment Matters Report, published by Novartis and supported by SMA UK, was featured in a Houses of Parliament, Westminster Hall Exhibition.

The report highlights the urgent need for newborn screening in the UK and makes some recommendations to support the review and implementation of newborn screening. Portia Thorman, Head of Advocacy and Community, attended the session along with families living with SMA who were featured in the report. This event was a fantastic opportunity to meet with MPs, introducing them to children living with SMA and to raise awareness of the desperate need to speed up newborn screening for SMA.

Newborn Screening: Scotland

On the 5th March, CEO Giles Lomax alongside representatives from Novartis, several clinicians from the Scottish Neuromuscular Network and Genetic Alliance UK, were invited to an expert panel briefing for MSPs to highlight how important it is to introduce newborn screening for SMA in Scotland.

While encouraging commitments have been made by the UK National Screening Committee (UK NSC) to commission a new cost-effectiveness modelling study in tandem with delivering an in-service evaluation (ISE) for SMA newborn screening, there is a need for clarity on Scotland's level of involvement and inclusion within these programmes, and how they align with the ongoing efforts to establish a specific Scottish SMA screening pilot.

SMA Care UK

The new Standards of Care (SoC) will address the evolving care and management needs of all those living with SMA and reflect the impact of disease-modifying drugs on the natural history of the condition. The existing Standards of Care were published in 2017 before we had access to the three-novel disease-modifying drugs - Nusinersen (Spinraza™), Onasemnogene abeparovvec (Zolgensma™) and Risdiplam (Evrydli™).



Consisting of clinicians from the Adult and Child REACH networks and representatives from SMA UK, the Steering Committee met for its first session on the 13th February 2024 to discuss which subject areas will be scoped first.

CEO, Giles Lomax commented: "This is a huge step forward in rewriting the SoC particularly with the ever-evolving care and management of those living with SMA".



Disability Action Plan

At the end of July 2023, the Government published its proposed Disability Action Plan with their ambitious aim to make this country "the most accessible place in the world for disabled people to live, work and thrive". Acting on behalf of people living with SMA in the UK, SMA UK asked you to contribute your views to this important piece of work and responded accordingly.

Some of the initiatives include

- Make playgrounds more accessible
- Help businesses understand the needs of, and deliver improvements for, disabled people
- Make government publications and communications more accessible
- Improve the understanding of the cost of living for disabled people
- Promote better understanding of the UNCRPD (UN Convention of the Right of Persons with Disabilities) across government

On the 5th February 2024, the final Disability Action Plan was published. 32 actions across 14 different areas were set out and the Government has committed to working with disabled people, their organisations and other partners in the coming years.

Read more via the link on our website – www.smauk.org.uk/disabilityactionplan

Latest webinars

Update on Zolgensma in the UK

In this latest episode of 'Treatment Updates from Health Professionals', we are joined by Consultant Paediatric Neurologists Dr Min Ong and Dr Imelda Hughes who give us an update on the Zolgensma programme in the UK and answer many of the questions being asked by the SMA Community.

Watch now on our YouTube channel:
[@SpinalMuscularAtrophyUK](#)

Living with SMA

Our "Living with SMA" section of the website covers a wide range of topics for teenagers, adults, parents of children who have SMA, family and friends and professionals working with the SMA Community.

It is based on knowledge and advice from the SMA Community and SMA UK's Support Team and is a great place to find out more about topics that matter to you.

Visit: www.smauk.org.uk/livingwithsma

Claim your free tickets to Parallel Windsor!



PARALLEL
WINDSOR

Parallel Windsor is a Festival of Inclusivity with Challenge Events for all ages, health conditions and abilities. It is being held in the grounds of the majestic Windsor Great Park on Sunday 7th July.

This fully accessible festival, offers a huge range of activities and entertainment, and all attendees have the opportunity to take part in one of the Challenge Events.

We are delighted to be able to offer ten pairs of tickets free of charge to this event! All that we ask is that you join in with one of the Challenge Events and fundraise as much as you can for SMA UK. Once you are registered, we will provide you with a fundraising pack, T-shirts to wear on the day and support with your fundraising.

Find out more at smauk.org.uk/parallelwindsor

Ride
SCORPION

in aid of SMA UK

Ride Scorpion is a fun cycle event in aid of SMA UK, taking a route through the beautiful Cotswolds countryside.

Last year we were delighted to raise £25,000 and we hope that as many of our supporters as possible will get involved!

The route is approximately 65 miles and riders will enjoy breakfast, a lunch pit stop and a finish line party at the Howard Arms in Ilmington.

Find out more and sign up at smauk.org.uk/ride-scorpion

Scan the QR code for more fundraising opportunities or visit our website at smauk.org.uk/support-us/fundraise-for-us/



Date:

Saturday 11th May 2024

Registration fee:

£50 per person
£150 for team of four



#KnowNoBounds

On 15th June 2024, Josh Wintersgill and Maxwell McKnight will be taking on an epic challenge – to race to the top of Snowdon in all terrain powerchairs! The pair, who both have SMA, are aiming to raise £100,000 for SMA UK as well as raising awareness of the barriers faced by people with disabilities when accessing the outdoors.

It will take between 10-15 people per team to assist Josh and Maxwell to the top of Snowdon; with the teams carrying the necessary kit and equipment such as batteries, portable ramps, food, medical equipment, tyres and more.

At the time of printing they have already raised over £30,000 and the campaign has been featured in the news numerous times. If you would like to help them to reach their target, you can find out more or make a donation at smauk.org.uk/knownobounds/



Christmas Card Design Competition

For the last two years, we have been delighted to offer our supporters the chance to buy Christmas cards exclusively designed for us by Zoe Henderson, who lives with SMA Type 3.

This year, we are running a competition to create a new Christmas card for 2024 and would love to invite children aged 16 or under to submit their designs. The competition is open to children with SMA living in the UK and everyone who enters will receive a small gift as a thank you.



Scan the QR code to find out more and enter, or visit our website at smauk.org.uk/christmas-cards24



Marathon in May is back and anyone can take part! Can you help us to reach our target of £10,000?

We're asking our wonderful supporters to cover the distance of a marathon during the month of May, to raise funds to help us to continue to support those affected by SMA.

You can stroll, roll, run or even hop, skip and jump the distance of 26.2 miles. It doesn't matter how you do it, when you do it or how many days it takes you, as long as you cover the distance of a marathon in May.

The enclosed fundraising pack tells you everything you need to know to take part or you can find out more and sign up at smauk.org.uk/marathon-in-may/

Sign up now!

26.2 MILES



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