

sma matters

Spring 2023

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Welcome

Support has always been at the heart of our charity. The launch of the Outreach Project in 2006 saw the appointment of our first two Outreach Workers - Claire and Maggie - to provide personalised support, information and guidance, including the possibility of visiting families in their own homes.

Since then, so much has changed, not least the understanding of SMA, care and management, and the approval of NHS drug treatments. Our Support and Outreach team has grown and developed in response to these changes but has retained its core purpose of offering individualised support to anyone affected by SMA across the UK, whatever the challenges.

We are now a team of four - and ever expanding, soon to be five. We come from a variety of health and social care

backgrounds covering a wide breadth of knowledge and experience.

We're here to listen in confidence and to offer non-judgemental emotional support, practical advice and guidance, whether you, your child or your family member is newly diagnosed, or at any point 'further down the road'. Connecting in whichever ways suit you best, we can phone, email, Zoom or WhatsApp. When we have capacity, we may be able to home visit.



from left to right, Becci, Michele, Jo and Claire – our Support and Outreach Team

No two people, families, situations or questions are ever the same. Though we may not always know all the answers, we are here to talk through your situation at the pace that's right for you, to offer suggestions and space for you to explore the range of possible ideas and options.

We can't make decisions for you, or give medical advice, which must always come from your / your child's clinical team. But we can, for example, support you with finding relevant information and clarifying the further questions you want to ask your team. We can also guide you through processes and applications for care and support, benefits, Education, Health & Care Plans, and offer supporting letters to highlight the impact SMA has on your / your child's daily life.

If you have a question or would like to talk anything through with us, you're always welcome to get in touch: phone the office on **01789 267520** and / or leave a message, or email us: **office@smauk.org.uk**

Latest videos & Podcasts

Over the past six months we have produced a number of new videos and podcasts. Some of these were aimed at updating our supporters on both the activities of the charity and recent developments in the treatment of SMA, whilst others were focused on sharing experiences with peers.

Just a selection are listed below and you can find all of these and more on our YouTube channel at **[youtube.com/c/spinalmuscularatrophyuk](https://www.youtube.com/c/spinalmuscularatrophyuk)**

Impact: SMA UK

At the end of September we created an in-depth webinar, hosted by Luis Canto E Castro, giving an overview of the achievements of SMA UK since the charity was founded and reflecting on the current situation facing those affected by SMA.

Update on Zolgensma in the UK

In November, SMA UK Trustee Toby Mildon talked to our three expert panelists, Elizabeth Wraige, Jennie Sheehan and Laurent Servais, to share an update on the UK Zolgensma programme and newborn screening for SMA.

Living with SMA – The Right Mindset

Published in December, this podcast featured SMA UK host Ross Lannon chatting to guests Anna Litvinova and Luis Canto E Castro about 'The Right Mindset' with conversations around disability and mental health.

2023 Update: Looking Back, Looking Forward

In January, this short video provided a look back at some of SMA UK's key work and our impact in 2022 as well as an insight into our plans for 2023.

SMA UK Information and Support

Asking Questions, Exploring Options

If you have a question about SMA, the **Information** section of our website may be a good starting point. Here you'll find general information about SMA, including guides for newly diagnosed families. Our **Living With SMA** area also has a wide range of topics for teenagers, adults, parents of children who have SMA and their family and friends, based on knowledge and advice from the SMA Community and SMA UK's Support and Outreach Team.

Q: My child's unwell and I'm worried that they're not eating or drinking enough. Is there any advice?

We always advise that you talk to your child's team for individual medical advice. But after so many questions about this, we also asked Dr Graeme O'Connor, Research Lead for Dietetics at GOSH, if there was any generalised advice he could share. In his webinar, he explains the issues low blood sugar levels can cause for children, the signs to look out for and what to do if you're worried.

Visit this page to watch and listen to this and other conversations with healthcare professionals: smauk.org.uk/health-wellbeing-webinar-recordings

Q: Even as the weather gets warmer, I'm often too cold and I've got my wheelchair, ventilator and hoist to keep charged. I'm worried about my energy bills.

This is a worry for many people. Lots of different websites provide links to organisations and schemes that give detailed information about the support available with energy bills and other cost of living rises. You can check out the Cost of Living sections on livingwithsma.org.uk but it can take time to trawl through and check that you're getting all the support you're entitled to. If you would like to talk your situation through confidentially with one of our team, we can support you to check out all the options.



Q: We're looking for ideas for days out and maybe even a holiday. Any ideas?

This is a huge area and, as always, there's no 'one size fits all' answer! On each area of our Living With SMA website (Children, Teenagers, Adults) we've gathered together ideas, links and 'things to think about' for a whole range of days out and holidays. Based on suggestions and shared experiences, from action-packed adventures to a day at the museum, browsing here may help you explore and narrow down some options. For the latest suggestions of what travel insurance companies other families have used, please contact our Support & Outreach Team.

Take a look at pages 2-3 to find out more about our Team and how to contact them.

smauk.org.uk/information

livingwithsma.org.uk

Social events coming up this Summer..

RESONATE 2023

We are excited to be offering a fantastic opportunity this summer for adults with SMA to come together and enjoy a weekend at the Calvert Trust in Devon.

Taking place from **Friday 21 to Monday 24 July**, this fully-inclusive residential weekend is open to anyone with SMA over the age of 18 and their PA/carer(s) and is fully funded by SMA UK. (A refundable deposit of £25 per person is required to secure a place.)

Each group will have their own accessible room and will be able to enjoy activities such as swimming, abseiling, zip-wire, canoeing and archery! The weekend also includes all meals and evening entertainment.

Spaces are limited and you can find out more at smauk.org.uk/resonate



Following the success of the 2022 Picnic in the Park events, we are delighted to be hosting three more of these in Summer 2023! We have taken on board feedback from last year and have moved the events to a slightly later time to give families more time to travel.

Each event will include a chance to meet the SMA UK team, as well as other individuals and families from the SMA Community.

We have chosen beautiful outdoor spaces, which benefit from being accessible (including Changing Places Toilets) and also have indoor space available in case of rain!

Tea, coffee and cake will be provided, along with a guest speaker, facepainting and children's activities. All you need to bring is your picnic!

picnic in the park

Saturday 13 May

Wat Tyler Country Park, Essex

Saturday 10 June

Yorkshire Sculpture Park

Saturday 8 July

Westonbirt Arboretum

Registration is free for those with SMA and their immediate family / PAs and you can find out more at smauk.org.uk/picnicinthepark



WhatsApp Groups

keeping the
community
connected



SMA UK is excited to have extended our Community Networks to include three new WhatsApp Groups, moderated by volunteers. These include a Teenagers' Network for those ages 13-17, a Young Adults' Network for ages 18-30, and a Families' Network for parents, guardians and primary carers of children and young people with SMA.

The networks aim to offer welcoming spaces for people to meet up and chat, share experiences and ideas and support each other. This is in addition to the individualised and confidential support that is provided by our Support and Outreach Team (pages 2-3).

SMA UK

Why did you decide to volunteer as a moderator?



Amy

I'm passionate about raising awareness for SMA and am keen to connect with and enable families to support each other. Diagnosis was a very lonely time for us, and I feel it is important to be part of something that I know could have helped me had it been around at the time.



SMA UK

What would you say to someone thinking of joining the group?



Amy

Don't overthink it, just join! It can be daunting the thought of joining a group where you don't know anyone and yet you may end up baring your emotions, as facing diagnosis of your child with SMA is tough. We're a supportive network and there will always be someone to share with should you need it.



SMA UK

What type of discussions do you expect to take place?



Becky

The main topics are around a whole range of different challenges with everyday life, as well as good old emotional support and understanding!



Becky

I would say to someone joining the group, enjoy the chats, knowing that you can feel safe talking about your experiences of caring for children with SMA. None of us are experts but we can all relate to each other in some way or another.



Maxwell is 18 years old and has SMA Type 2. He is a new volunteer moderator for the Young Adults' and Teenagers' Networks and is working alongside 25-year-old Jordanne, who also has SMA Type 2.



Amy lives in the South East of England and is Mum to Ollie, aged two, who has SMA Type 1. She is a volunteer moderator in the Families' Network, alongside Becky, who lives in Scotland and has four-year-old twins, Finn & Zara, with SMA Type 2.

SMA UK

Why did you decide to volunteer as a moderator?

Jordanne

I've been involved with SMA UK for a long time and being a moderator gives me a chance to engage more regularly and closely with the community. I had previously been buddied up with some teenagers in the past, so moderating the teenager group in particular is like an extension of that!



SMA UK

What type of discussions take place / do you expect to take place?

Maxwell

We strive to build a sense of community through diverse, meaningful, and, most notably, honest conversations. This includes personal achievements, must-know ways to manage SMA symptoms, or simply a hilarious discussion.



Jordanne

We talk about what's going on in our lives, both disability related and not. We talk about treatment experiences, adaptations and share hints and tips when we find something that may benefit others.



SMA UK

What would you say to someone thinking of joining the group?

Maxwell

You'll find a network of people living with SMA who are open and supportive. In a safe and respectful environment, you can share your experiences and questions with people who understand.



Advocacy Focus:

Newborn Screening

Why is it so important to have Newborn Screening for SMA?

In general, research and real-world evidence suggest that early treatment is necessary to maximise the benefit of the drugs now available to treat SMA. So screening at birth will maximise the benefit of treatments for all.

It follows that newborn screening will also massively reduce the lifetime costs of managing the impact of SMA, including costs for healthcare, equipment and home adaptations, and support at school and work.

What is SMA UK doing to advocate for this?

SMA UK is a founding member of the UK SMA Newborn Screening Alliance – a group of expert clinicians, academics and patient organisations dedicated to securing the earliest possible introduction of newborn screening for SMA in the UK.

Since its creation in April 2022, the Alliance has been working hard to raise awareness of SMA and the importance of treating before symptoms start. The Alliance has represented the SMA Community at Westminster and at both clinical and pharmaceutical conferences, and has

secured rare opportunities to meet with members of the UK Newborn Screening Committee (UK NSC) whose job it is to evaluate the evidence and make the decisions as to which conditions are screened for.

The Alliance has been working closely with the wider rare disease community and have had an active role in MDUK's APPG (All Party Parliamentary Group) research, which will inform a report into how the UK NSC processes need to change for rare conditions.

What is happening now?

The Alliance is delighted that the UK NSC review of whether to include SMA in the UK newborn screening programme has commenced.

When SMA was first assessed for newborn screening in 2018, the UK NSC did not feel that there was sufficient evidence to support a positive recommendation and the decision was made not to screen routinely for SMA.

However, a lot has changed since 2018. The NHS has revolutionised treatments for SMA and a newborn screening pilot is underway in the Thames Valley. There is also greater understanding of what is required operationally to screen for SMA.

We are hopeful that when the new evidence to support newborn screening for SMA is reviewed, the UK NSC will be in a position to recommend that newborns in the UK are screened for SMA via the existing heel prick test.

The Alliance aims to work with the UK NSC to ensure that a positive decision on newborn screening for SMA is made in the fastest possible timeframe.



How can you help?

Now that the review of SMA is underway, we need your support:

For the launch of MDUK's APPG report on newborn screening for rare diseases, we will be holding an **event in parliament on Thursday 11th May 2023** where we hope to raise awareness of SMA and newborn screening with parliamentarians. If you are affected by SMA and are interested in coming to this event at Westminster to lend your support, please contact Alice Fabre, Project Manager for the Alliance: alice.fabre@uksmanewbornscreening.org.uk

In the meantime, please follow our social media channels and share our updates with your networks to help build support. We will also use these channels and the website to keep you up to date with developments and how you can help.



Website: smanewbornscreening.org.uk
Facebook: [@UKSMAnewbornscreeningalliance](https://www.facebook.com/UKSMAnewbornscreeningalliance)
Twitter: [@SMA_NBSalliance](https://twitter.com/SMA_NBSalliance)
Instagram: [@UKSMA_NBSAlliance](https://www.instagram.com/UKSMA_NBSAlliance)

#ScreenTodayForSMA

Thank you!

A huge thank you to all of our fantastic fundraisers and donors for your continued support. We love hearing what you have been doing and receiving your photos! We are here to help with your fundraising, so please do get in touch with us at fundraising@smauk.org.uk or on **01789 267520**.



Rute & Laura were just two of our team of seven incredible London Marathon runners who completed the event in October 2022.



Christmas Jumper Day for SMA took place in December and lots of you joined in to help raise awareness and funds, with almost £5,000 donated in total.



Tegan, Danielle & Denise ran the **Cardiff Half Marathon** and raised an amazing £2,500 for SMA UK, which they were able to double by donating via The Big Give Christmas Challenge!



Giles Lomax cycled from **Land's End to John O'Groats** and his wife Becky organised a Prosecco Night, raising a fantastic total of £5,000.

Farewell to Jackie!

At the end of March, we will be giving a very fond farewell and good luck to 'our Jackie' who is retiring after an amazing almost 20 years working for SMA UK.

Jackie, who currently carries the baton for our longest serving employee, started work at what was The Jennifer Trust, back in September 2003. She first worked within support services responding to enquiries from newly diagnosed families and her fantastic organisational skills soon became apparent as she was involved in the planning of many events over the years!

She was also pivotal in leading what was initially the Peer Support service, training and supporting those volunteer parents, grandparents and adults who gave their time so generously to support the community.

Over more recent times Jackie transitioned into our Information service and has been instrumental in the development of our *Living With SMA* section on our website, working tirelessly to ensure information is accurate and relevant to people living with SMA.

Jackie's calm, compassionate and all-round wonderful personality will be greatly missed by us all, as will her wicked sense of humour. I'm sure that all those who knew her will join us in wishing her a long and happy retirement.



We are here for you

Explore our website at smauk.org.uk to find out more.

Support

From our experienced Outreach and Support Team and the SMA Community.

smauk.org.uk/support

Information

Wide-ranging on many topics including care, tips and ideas for all ages.

smauk.org.uk/information

Community Networks and Voices

Podcasts, videos and personal stories plus webinars with health professionals.

smauk.org.uk/connect-with-others

Treatments & Research

What's available now, advocacy for access and future possibilities

smauk.org.uk/treatments-research

Advocacy & Information: Schools project update



Our 'Getting Ready for Primary School' pack is now ready for families to try out! With so much to navigate at this important time of transition, the pack aims to support families who are thinking about choosing a school for their child who has SMA:

- Ideas and experiences from parents around choices and making decisions.
- Ideas for how to share information about your child and your child's SMA with schools – including blank and example templates.
- Information about the primary school system in England (if you can help us with adapting this for Scotland, Wales or Northern Ireland, please do get in touch!)

Huge thanks to all the parents and education professionals who have contributed to this resource so far, sharing their time, questions, experiences and ideas.

Here's what a couple of our reviewers say:

"It was my pleasure to get involved. Definitely helpful for staff in schools who do not know about SMA and its challenges. I'm sure it will be welcomed by so many families."

–Specialist teacher

"I think it's brilliant and will help a lot of families build confidence selecting the school for their child. A great way to start communication for the school / teachers / local authority"

–Parent of a child already at primary school

To request a copy of the pack, or if you'd like to find out more or get involved by sharing your own questions and / or experiences, call the office or email: information@smauk.org.uk

SMA Care UK

The International Standards of Care for SMA (SoC) were published in 2017. 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 progresses over time at different stages and ages.

Clinicians and Patient Groups want to establish **SMA Care UK** - 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 / updates 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 research is needed and work with SMA Europe and other international groups to develop new consensus statements for specific elements of care.**

The project will draw on any work that has been done to date to address inequity of care and challenges facing the SMA Community and clinicians. SMA UK will continue to gather information from the community about areas of care and services that are concerning families and adults as well as examples of good practice. This information will help prioritise which working groups should be set up first and will provide invaluable material for the working groups. We will also report on progress towards securing this project.

If you think you can help by sharing your experiences then please e-mail portia.thorman@smauk.org.uk



Help us raise £10,000 in May by taking on your own Mighty May challenge!

Over the past five years, you have raised an incredible total of over £70,000 by taking part in our annual virtual Marathon in May. For 2023 we have decided to go Mighty and help our supporters to keep a Mighty Mind and Mighty Body, as well as raising vital funds for SMA UK.

Set yourself a goal of getting active every day in May – this could be by covering a mile a day by walking, running, cycling or using your powerchair. Or by doing exercises such as Yoga and stretching at home or in the garden. Everyone who signs up to take part will also receive a calendar of mindfulness activities to guide them through the month.

Simply get your family and friends to sponsor you and raise £50 or more and you will be sent one of our Mighty May medals as a Thank You!

Visit smauk.org.uk/mightymay to find out more and sign up.



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