

SMA matters

AUTUMN 2023



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**Spinal
Muscular
Atrophy uk**

SUPPORTING • INFORMING • ADVOCATING

Welcome...

to the Autumn 2023 edition of SMA Matters

Since joining SMA UK as CEO in May this year, I have thoroughly enjoyed meeting so many people from the SMA Community at the various social and fundraising events that we have hosted. These interactions are invaluable, giving us the opportunity to listen, advocate and act on your needs, as well as continually raising awareness of SMA; after all that's why we are here.

The SMA UK team is evolving in line with the ever-changing needs of the Community, with two new staff additions over the summer to further support our work to influence and drive permanent and life enhancing change for SMA.

We have also given our branding a refresh and I'm sure you are as delighted as I am with the new look. It represents us as a forward thinking, modern and agile charity that can continue to be trusted and recognised as the lead voice for people affected by SMA.

In this edition, you will see some examples of the work the SMA UK team has been carrying out over recent months. We would not be able to continue our vital work were it not for our incredible fundraisers and donors, so thank you to everyone who has supported us this year.





We are excited to share with you our brand refresh!

As the needs of the SMA Community are ever changing, we felt that our website, which is one of our main communication windows, needed refreshing. It is important to us to be able to deliver information clearly as well as give the Community a space where their voices can be heard and seen, centre stage.

With the decision made to develop the 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 affected by SMA and their families.

To make sure that we met the needs of all of our audiences 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 invaluable feedback and we are very grateful for their input.

Our new strapline – Supporting, Informing and Advocating – highlights the work we do alongside the SMA Community and are areas that we continue to build on as a charity.

Visit our new site at smauk.org.uk





Asking Questions, Exploring Options

The Living with SMA area on our website has a wide range of topics for teenagers, adults, parents of children who have SMA, family and friends, and is based on knowledge and advice from the SMA Community and SMA UK's Support and Outreach Team.

Our Support and Outreach Team is about to answer any questions; they're happy to phone, text message, or email, on a wide range of topics.

Call our office **01789 26750** or email office@smauk.org.uk to reach them.

Q – My child has outgrown their buggy and a replacement is costly – is there support available through SMA UK?

A – We understand equipment can be very expensive and we recognise items need to be replaced as your child grows. We'd always recommend contacting Wheelchair Services in the first instance to talk through your child's needs - you can read more about mobility options and Wheelchair Services on Living with SMA in the 'Powered Mobility' tab: smauk.org.uk/living-with-sma/children-0-12-years/children-0-12-years-equipment

Q – I am an adult living with SMA and sometimes things are overwhelming, and I struggle with my mental well-being – have you any suggestions on how I might manage and cope better when this happens?

A – We recognise that day to day challenges may have a significant impact on mental well-being, and finding ways to build on emotional resilience and support to figure out what works for you is important. It can often help to have support or coping strategies to manage these struggles and challenges, ways that might offer options to stay positive and upbeat, whilst also recognising that life has its ups and downs.

You might like to view the information we have about this on Living with SMA for adults on the 'Emotional and Psychological' tab: smauk.org.uk/living-with-sma/adults-living-with-sma/adults-personal-life or you may find it helpful to listen to our 2-part podcast: Mental Health and Living with a Long-Term Condition: livingwithsma.buzzsprout.com



Community connections: A successful summer!

We were delighted to welcome so many of you to our summer social events, which took place between May and July. Over 200 people of all ages attended three Picnic in the Park events in Essex, Yorkshire and Gloucestershire, and enjoyed meeting new friends and exploring the outdoor spaces.

At the end of July, we also hosted a weekend for adults with SMA at the Calvert Trust in Devon. Everyone had a fantastic time trying the activities on offer at the centre and it was a unique opportunity to spend time as a community. Watch this space for details of our 2024 events coming soon!

We are also looking forward to hosting more Picnic in the Parks in 2024 and hope that many of you will join us!

If you would like to offer feedback or have any questions about our Community Connections events then our Community Services Officer, Gary, would love to hear from you! Get in touch at: connections@smauk.org.uk

picnic
in the
park
2023



RESONATE

2023





SCAN ME

Our Regular Donors are vital in helping us to achieve our objectives for the year and plan for the future

It takes just a few minutes to sign up and you can amend or cancel your donation at any time. Simply visit the link below or scan the QR code to get started. Thank you.

If you're considering making a monthly gift to SMA UK then these are just some of the ways your donation could help:



£5/month

...could help fund a phone call with a member of our Outreach Team for a family who have just received a diagnosis of SMA.

£10/month

...could make a valuable contribution to funding our Research Coordinator who ensures that our information on treatments and clinical trials is up to date.

£15/month

...could help us towards putting on an event where the SMA Community can connect and share experiences.

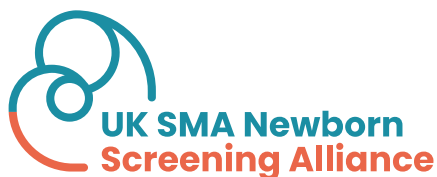
Become an SMA UK Trustee

We are looking for dynamic, inspiring and proactive individuals to join the Trustee Board at SMA UK. We welcome applications from people with a wide range of backgrounds who could utilise their skill set to further enhance the work of the charity, including Human Resources and Legal.

We would be delighted if you would consider becoming part of our small charity in supporting people of all ages affected by SMA. Please email office@smauk.org.uk with your contact details to find out more.

Planning for an SMA Newborn Screening UK-wide pilot to start this year

The UK SMA Newborn Screening Alliance, an initiative established by SMA UK, brings together SMA advocacy groups, leading clinicians and academics as well as representatives from the SMA Community. Together, we have been working closely with the UK Newborn Screening Committee (NSC) to share experiences, statistics and research, not only to speed up the process but also to ensure that the urgency for a UK-wide screening programme, and the real-world impact of late treatment, is fully understood.



Part of the NSC's process is to create an economic model, which will inform the committee about what the predicted costs of screening for SMA in the UK will be versus the benefits. There is already data available on this topic, but the NSC decided that they will use this information to design their own economic model fit for their specific purposes. This decision was a blow to the SMA Community, as the creation of a new economic model could add years to the timeline to getting SMA added to the bloodspot test in the UK.

However, at the recent NSC meeting, held on 6th June, the committee also supported the call to start planning for an in-service evaluation (ISE), which is very similar to a country-wide pilot, at the same time as creating the new economic model.

They emphasised that this was not a recommendation to introduce screening. Rather, it was an innovative way to ensure the economic model being created is as reliable and as accurate as possible. They plan to test out the model with data from the ongoing in-service evaluation. The UK NSC stated that the findings of the ISE would then inform the evidence on which a UK NSC recommendation on newborn screening for SMA will be made.

This announcement is progress, as it is the first time that an economic model has been developed in tandem with an in-service evaluation; it's a decision that shows the impact of the work of the Alliance. However, though newborns will be screened for SMA whilst this evaluation happens, 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.

For more information please visit:
smanewbornscreening.org.uk



Raising awareness of SMA is a key priority for SMA UK

Our Advocacy Lead, Portia Thorman, has had the privilege of speaking within many different forums, including meetings for academics, the pharmaceutical industry, engineers, politicians, the NHS and NICE. She has spoken about many issues, including the importance of coordination of care, the impact of the cost-of-living crisis, and how access to treatment and therapies needs to be equitable for all ages and Types of SMA throughout the UK.

SMA Europe

SMA UK is also part of SMA Europe, an umbrella organisation for SMA patient groups which gives the SMA Community in the UK a place in international research and development.

Together we are the driving force for many research projects focused on bringing the patient perspective to industries who develop drug treatments, therapies, and assistive tools for the SMA Community.

SMA Europe's 4th International Scientific and Clinical Conference, bringing together 842 researchers, healthcare organisations and patient organisations from 66 countries, will happen in March 2024 and SMA UK is very excited to be attending.

If you are interested in finding out more about the work of SMA Europe, we recorded a video after attending SMA Europe's Annual Meeting in Prague on 27-29th April to update you on all their latest research and how you can get involved: www.youtube.com/watch?v=STVpcJSOJA4



Updates on Treatment and Care

Asking the Professionals

During the summer, an expert panel of clinicians - Francesco Muntoni (Consultant Paediatric Neurologist at Great Ormond Street Hospital), Elizabeth Wraige (Consultant Neurologist at the Evelina Hospital), and Anne-Marie Childs (Consultant Paediatric Neurologist at Leeds Children's Hospital) – answered a wide range of questions from the community about NHS-funded treatment for children. Hosted by Amy Williams, one of our Family Network WhatsApp group moderators and mum of Ollie, who has SMA Type 1, you can find this at: smauk.org.uk/treatments-research/uk-access-to-treatment/treatment-updates-health-professionals

Essential Information for Emergency Services

As a result of the many distressing stories about difficulties accessing appropriate care at local hospitals that our Advocacy Lead, Portia, was hearing from families, we have worked with a group of clinical neurology consultants and physiotherapists to produce a new resource for families. Reviewed by parents and clinical staff, and endorsed by the clinical REACH networks, Muscular Dystrophy UK and TreatSMA, "Essential Information for Emergency Services when Assessing and Caring

for a Child who has Spinal Muscular Atrophy" can now be downloaded from the Living with SMA section of our website under the 'Regular and Emergency Care' tab: smauk.org.uk/support-information/recently-diagnosed-with-sma/emergency-care-for-children/

We also regularly release 'Conversations with Health Professionals' on a wide range of topics, including diet and health and wellbeing. These are available to watch on our YouTube channel: Search [@SpinalMuscularAtrophyUK](https://www.youtube.com/channel/UCSpinalMuscularAtrophyUK) on YouTube and we have more in the pipeline so keep an eye out on our social media channels and monthly E-news.



Supporting the SMA Community

Anna's story

Fleeing from Ukraine in 2022, Anna, who has SMA Type 2, came to the UK with her husband. In her haste to leave, she arrived with few belongings and just a manual chair which meant she needed full-time help to mobilise.

The Support and Outreach Team at SMA UK has been supporting Anna with advice and emotional support since she arrived in the UK. She was in desperate need of a powerchair to regain her independence and comfort, however, due to unsettlement in her housing situation and temporary ramping, there was an obstruction with NHS provision.

The Outreach team contacted The Recycle Mobility Centre, who offer refurbished and new mobility equipment.

They were able to offer Anna an ideal second-hand powered wheelchair with the tilt and recline functions that she needs. The chair required some adjustments to suit Anna's needs, but the team at Baldertech were able to adjust the hand control so that Anna can regulate all the functions with just the joystick.

Anna now has her independence back and can move around in comfort for the first time in a year, improving both her physical and emotional wellbeing!

recyclemobilitycentre.com
baldertech.co.uk

Left: Anna with Jason Nicoll from the Baldertech Team who supported Anna by adapting her hand controls.

"Receiving this powered wheelchair has literally changed my life. I have the freedom to move and can finally explore the country. It's fantastic. Thank you so much from all of my family!"



“Receiving this powered wheelchair has literally changed my life. I am loving my new chair, thank you for all your support”

Amy's story

Amy is 36, she has SMA Type 2 and works as a part-time administrator. She got in touch with the Support and Outreach team at SMA UK for help obtaining funding for a new powerchair in 2022.

Wheelchair Services had provided her with a chair four years previously and she was “making do”, but as time went on, she was in more and more pain from sitting long hours in the chair.

Amy's legs and hips were aching, her trunk was not supported, and her hand frequently kept slipping off the controller meaning Amy needed additional carer support too.

She 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.

Fundraising update

SMA Awareness Month

Thank you to everyone who supported SMA Awareness Month in August and especially those who shared their #IAmUnique photos and stories. If you would like to make a donation to support our Awareness Month campaign, then please visit: [justgiving.com/page/sma-uk-awareness-month-2023](https://www.justgiving.com/page/sma-uk-awareness-month-2023)

Supporter Survey

We have set up a new survey for our supporters and fundraisers to help us to ensure that we are organising the best events and opportunities to fundraise that we can! We would love to hear the views of as many of you as possible and the survey will take just five minutes to complete: surveymonkey.co.uk/r/CP5D876



Meet Ugene!

Ugene is the new SMA UK Mascot, who made his first appearance at the London Marathon in April 2023. His aim is to travel the UK raising awareness of SMA and helping our amazing fundraisers to raise even more when they are taking part in events! Ugene has been designed to represent the faulty SMN1 gene, which causes SMA, and his name was chosen after being suggested by one of our supporters on Social Media.



Remembering Nicky

Thank you to Sue and Keith Hornsby, whose daughter-in-law, Nicola Hornsby, passed away in August last year aged just 39. They have recently made a donation to SMA UK in memory of both Nicola and her son Jacob, who was diagnosed with SMA Type 1 and died in 2008.

Forever known as Nicky, she and her husband, Edward, and the rest of their extended family have been great supporters of the charity over the past fifteen years and have fundraised for Jacob's Angel Fund raising over

£28,000, with events ranging from Golf Days, UK and International Bike Rides and Sponsored Walks.

Nicky also gave her time as a volunteer, speaking publicly about her experiences and helping out at events. She will be hugely missed not only by Edward, their son and daughter, Aiden and Evelyn, and the rest of their family but also by the many friends she made within the SMA Community who will remember her generosity and kindness.



Thank you, TJ!

A huge thank you to TJ, whose one-year-old niece Sienna has SMA Type 1, for taking on two epic running challenges for SMA UK this year! He completed the London Marathon in April, raising an amazing total of over £3,000, and is also going to be doing the Great North run in September wearing 'Ugene' the new SMA UK Mascot suit.

He is already planning for 2024, when he is hoping to take part in even more events in support of SMA UK.



Christmas Jumper Day for SMA

Christmas Jumper Day for SMA is taking place on Friday 8th December and we would love you to join us to help raise awareness and funds for SMA UK.

Find out more and order your free fundraising pack at: smauk.org.uk/support-us/fundraise-for-us/organise-your-own-fundraising

The Big Give Christmas Challenge

The Big Give Christmas Challenge is an exciting opportunity for you to DOUBLE YOUR DONATION to SMA UK for one week only! From 28th November to 5th December, we will be aiming to raise £30,000 with our festive matched funding campaign.



Find out more at: smauk.org.uk/support-us/fundraise-for-us/organise-your-own-fundraising



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

