



SMS Together

News, stories and updates from across our SMS community

Hello everyone,

It's been a busy and positive few months. Alongside sharing early insights from the **Springboard Project** and our continued work with **University of Cambridge**, we've also been preparing for our **Family Weekend at Barnstondale**, something we're really looking forward to!

Our community continues to be at the heart of everything we do. We've been incredibly grateful to those who've taken on fundraising challenges, from local events to even securing a place in the iconic London Marathon, your support makes a real difference.

We're also continuing to support and contribute to new research projects, helping ensure that the voices and experiences of our community shape what comes next.

Thank you, as always, for being part of it.



Leeann

Sam Hunt's European Cubing Championship Journey

We're delighted to celebrate an incredible achievement by Sam Hunt, who will be representing himself at the World Cube Association European Championships this July in Arnhem, Netherlands.

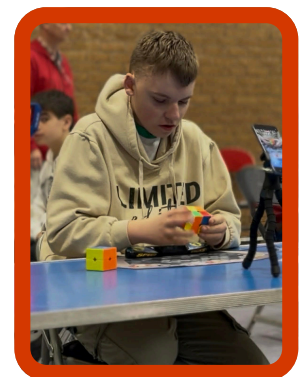
Sam, who is 18, has been cubing for around seven years and competing for the last three. Qualifying for a major international competition is a fantastic achievement and reflects the dedication, skill and determination he has shown over time.

Sam will be travelling with his mum, Salli, to attend the four-day event, where competitors from across Europe will come together to compete.

For Sam and his family, this achievement is about far more than cubing alone. Being able to manage behaviours in a large, busy environment, stay calm when things become frustrating, and navigate such a significant event is wonderful to see, especially when he is motivated by something he loves.

Sam is incredibly excited to attend, compete, and meet some of his cubing heroes along the way. We hear there may be plenty of selfies too.

We wish Sam and Salli the very best for this amazing adventure and will be cheering him on from home.



Fundraising Highlights

We're incredibly proud of our amazing supporters who continue to go above and beyond to raise funds for the SMS Foundation UK. Here's a snapshot of what's been happening recently:

London Landmarks Half Marathon

A fantastic team of 10 runners took part this year including:

Salli Hunt, David Perry, Nick Mortimer, Leeann Stevenson, David McCormick, Christopher Rowe, Tim Dudley, Ben Dudley, Liam Grogan and Kyle Hayes.

Together, they raised an incredible **£5,336** (including **£973** in Gift Aid). An amazing achievement from the whole team!



Manchester Marathon & Shakespeare Half Marathon

Emma Riddell and **Kristina Rauluskeviciute**, alongside the **Babbs Mill runners**, have raised **£915** so far in 2026.

A brilliant effort, and still counting.

London Marathon

Huge congratulations to **Anthony Pitt** and **Adam Mushrow**, who together have raised an incredible **£7,881** (including **£1,231** in Gift Aid).

An outstanding achievement for two incredible runners.

Ibiza Half Marathon

A big thank you to **Matty Bremford**, who has raised an amazing **£2,363** (including **£271** in Gift Aid) from the Ibiza Half Marathon.



Coming Up Fundraising Events

We also have some exciting events just around the corner:

- **Lucy Gabrielsen** taking on both the Copenhagen Marathon and Lillebaelt Marathon (2nd & 10th May)
- **Joe Biddlecombe** running the Edinburgh Marathon (24th May)
- A team of runners at the Great Manchester 10k & Half Marathon (31 May)
- Five runners taking on the Great North Run (13 September)

We are so grateful to every single person who chooses to support the Foundation in this way. Your efforts make a real difference to families living with Smith-Magenis syndrome.

Caught in action...



Kyle Hayes approaches the finish line of the LLHM 2026.



Tim and Ben Dudley running together at the LLHM 2026.



Adam Mushrow after completing the London Marathon.



And finally, a big shout out to superstar Ella who ran the London mini marathon on Saturday for the Foundation. Thank you so much for your support Ella you are amazing!



Barnstondale Family Weekend 2026

We're really looking forward to welcoming families to our 2026 SMS Family Weekend at Barnstondale this June. The weekend is all about bringing our community together in a relaxed, supportive environment, whether that's reconnecting with familiar faces, meeting new families, or simply taking a break from everyday life.

Across the weekend, there will be a mix of outdoor activities, time to unwind, and opportunities to learn and share experiences. Activities include things like zip wire, climbing and archery, all supported by experienced staff, alongside quieter spaces for those who prefer a more relaxed pace.

We'll also be joined by a number of professionals who will be running informal sessions and spending time with families across the weekend, including Dr Gail Reiner, Dr Ashley Liew, Prof Caroline Richards and Dr Kate Baker. They'll be sharing insights and answering questions on topics such as health, sleep, behaviour, education and more.

With a campfire to kick things off on Friday and a disco on Saturday night, it's set to be a brilliant few days. We can't wait to see everyone there.



What are we learning about health and wellbeing in SMS?

Be the first to hear the latest findings from the Springboard Project and our community survey.

We're bringing together the latest research from the Springboard Project with real experiences shared through our 2026 Community Survey.

This session will give you early insight into what's emerging – across health, education, mental wellbeing and more.

Register here:



smith-magenis.org/springboard-webinar/



The BEOND survey is now open!

The survey is open to parents/caregivers of children and adults with Smith-Magenis syndrome. The survey takes about 60 minutes to complete, which can be done online or via post. Every family will receive a personalised feedback report after completing the survey.

This ambitious survey aims to run for 20 years. Our hope is that many families will choose to take part every couple of years so that we can see how responses change over time and get better insights into how individuals develop.

To take part or find more information about BEOND, please visit www.cerebranetwork.com/beond-sms or email **Dr Rory O'Sullivan** at r.osullivan@bham.ac.uk.



The BEOND study is run by the Cerebra Network for Neurodevelopmental Disorders, a collaborative institution including researchers at the University of Birmingham, University of Warwick, University of Surrey, and Aston University.

Join Australia's First Smith-Magenis Syndrome Speech Research Study

Smith-Magenis Syndrome (SMS) Australia is proud to partner with the Translational Centre for Speech Disorders at the Murdoch Children's Research Institute and the University of Melbourne to launch a groundbreaking research program into speech, language and social communication in individuals with SMS. Whether your loved one is a child or an adult, verbal or non-speaking, you can play a vital role in advancing understanding and treatment of SMS.

Individuals of any age with a clinical or genetic diagnosis of Smith-Magenis syndrome, including both verbal and non-speaking participants, can take part.

What's involved?

- All participation is remote and flexible
- Complete online surveys on speech, language, and health
- Upload short recordings of communication
- Join a 1-hour Zoom session with a Speech Pathologist

Register your interest or learn more

Email: ruth.braden@mcri.edu.au | Visit: geneticsofspeech.org.au

Speech, Language and Social Communication in individuals with Smith-Magenis syndrome
An international study

We are running a project looking at speech, language and social communication outcomes in individuals of all ages with Smith-Magenis syndrome.

By improving our understanding of communication in this condition, we hope to improve diagnosis and prognosis, as well as develop more targeted strategies.

We are looking for individuals:

- Of any age
- With a clinical or genetic diagnosis of Smith-Magenis syndrome
- Who are verbal or non-verbal/non-speaking

What is involved?

- Completing online surveys about speech and language skills, and health and medical history
- Completing some online communication recordings
- An online Zoom session with a Speech Pathologist for further assessment (~1 hour)

About us

The Translational Centre of Research Excellence for Speech Disorders examines speech and language in individuals with rare genetic conditions.

We are trying to better understand the strengths and difficulties of communication in children with rare genetic syndromes. Our longer-term aim is to help develop better targeted therapies.

GET IN TOUCH!

If you or someone you know may be interested in helping with this research, we would love to hear from you. You can email us or scan the QR code. ruth.braden@mcri.edu.au

Translational Centre for Speech Disorders
Murdoch Children's Research Institute
50 Flinders Street, Parkville VIC 3052
geneticsofspeech@mcri.edu.au

This project has been approved by the
Royal Children's Hospital Human Research Ethics Committee
(RCH HREC Reference Number 27385)
01.08.2024 v1

CALL FOR PARENTS & CAREGIVERS TO TAKE PART IN A DISCUSSION GROUP

We're inviting parents and caregivers of children with rare genetic syndromes to join a discussion group. This is as part of a PhD project which aims to develop an early anxiety intervention.

You may be eligible to take part in the research if you:

- Are aged 18 or over and live in the UK.
- Are a parent or caregiver of a child under 16 with a moderate to severe intellectual disability related to a rare genetic syndrome.
- Are interested in helping shape the development of effective and accessible anxiety interventions.

If this sounds like you, we'd love for you to take part!

What is involved?

- Completion of a short questionnaire
- Attending a group or interview where you will be asked questions about the acceptability and potential barriers of an anxiety intervention framework we are developing. We will also ask (where applicable) about your previous experience of interventions.

For more information, please scan the above QR code or contact:
Lily Waller (PhD Researcher) Email: lwall21@aston.ac.uk
Dr Jane Waite (Clinical Psychologist) Email: j.waite@aston.ac.uk

Caregivers – we need your voice

A new project from Aston University is exploring anxiety in young people with genetic syndromes, including SMS.

They're looking for parents/carers of under 16s to share their experiences and help design better support.

- Take part in a discussion or 1:1 interview
- Receive a £25 Amazon voucher

Be part of something that could make a real difference.

✉ lwall21@aston.ac.uk

Service Updates...

We've been updating and expanding our website, making it easier to navigate and access key information. Our content continues to be shaped by the experiences of families, helping us build a practical and relevant resource for our community.

A key focus has been education. We've commissioned a series of articles from George Fox on person-centred planning for young people with SMS.

The first two articles – **"The Child Before the Plan"** and **"Understanding the Whole Child"** – are now available on our website.

smith-magenis.org/information.



SMS Training

We offer training to help build a clear, practical understanding of Smith-Magenis syndrome across a range of settings. Sessions can be delivered online or in person (on request), supporting nurseries, schools, colleges, as well as respite, care and supported living services.

"It was extremely helpful and will make a real difference in supporting our team to better meet the needs of the individual."

To find out more or book training, complete our enquiry form on our website, or contact us at support@smith-magenis.co.uk.

smith-magenis.org/training/

Counselling Support

Through our partnership with Rareminds, we offer confidential counselling for parents, carers and family members. Sessions are fully funded and provide a safe space to talk with specialists who understand rare conditions. Referrals are made through the Foundation, with sessions arranged directly. Recent feedback from a parent who accessed our counselling service...

Hi, I just wanted to say a massive thank you to you and the Foundation for putting me forward for the counselling sessions, I just finished them and feel in such a better place than where I was when I started them in November. I dread to think where I would be now if I didn't have that support. Xx

smith-magenis.org/counselling/

SEND Consultancy Service

We offer access to expert SEND advice through our partnership with the SEND Consultancy Service. One-hour consultations for parent carers are fully funded and provide clear, practical guidance – whether you're starting an EHCP, preparing for a review, or challenging decisions. Referrals are made through the Foundation, ensuring priority support for our community.

smith-magenis.org/send-service/

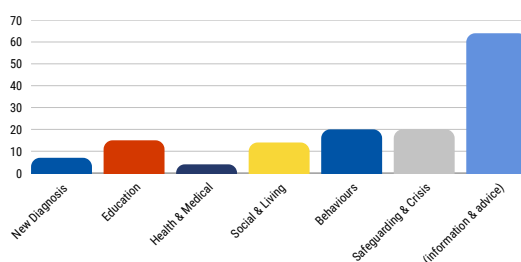
Enquiries & Training: Jan 2026 to Date

43

Professionals trained

144

Enquiries handled



Breakdown of enquiries by theme

If you'd like to support our work and help us continue providing vital services to families, please consider making a donation. smith-magenis.org/donate



Genomics and Mental Health Research Day 2026 at Cambridge University

On 12th June, Leann Stevenson will be speaking at the Genomics and Mental Health Research Day 2026 at University of Cambridge, hosted by the MRC Cognition and Brain Sciences Unit and the NHS Genomics and Mental Health Network of Excellence.

The day focuses on **"Rare Neurodevelopmental Conditions – meeting the post-diagnostic challenges"**, bringing together researchers, clinicians and lived experience voices to share learning and shape future work.

Leann will be speaking as both a parent of a young person with Smith-Magenis syndrome and representing the SMS Foundation UK, and most importantly the SMS community they support, sharing the reality of life beyond diagnosis and what truly makes a difference for families.

It's an important opportunity to ensure lived experience continues to shape research and support, and she is looking forward to being part of the conversation.

A HUGE THANK YOU to our funders for your support

