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SUMMER 2025



THE
CHARLES LEWIS
FOUNDATION

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FOCUS MAGAZINE

Microphthalmia, Anophthalmia & Coloboma Support

Supporting people born without eyes or with underdeveloped eyes



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MACS MAGAZINE | ISSUE 21

Thanks so much to all members
and supporters who've contributed
towards this edition. If you'd like to
feature in the next edition, please
do let us know!

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Update your preferences

We hope you enjoy reading Focus and catching up with MACS' latest news. Remember that the magazine is available to view digitally so if you would prefer not to receive the postal copy, please contact us at **enquiries@macs.org.uk** and we will update your contact preferences.

Chair's Welcome!



HI EVERYONE!

Welcome to the 21st issue of Focus magazine! It's hard to believe how far we've come, and I'm thrilled to be sharing this milestone with such a vibrant and passionate community. As we step into the heart of summer, there's an unmistakable buzz of excitement in the air — and rightly so! This season promises a dynamic calendar filled with meaningful events, inspiring stories, and the perfect opportunity to connect, recharge, and dream boldly.

There's something about summer that invites possibility. Whether it's the longer days or the collective energy of a community gearing up for new adventures, this time of year always sparks fresh ideas and reconnections. We've packed this issue with features and updates to inspire you, inform you, and invite you to be part of everything that's ahead — both over the summer and throughout the rest of the year.

Let's Talk Big: Get Ready for the Big MACS Meet-Up!

One of the most anticipated events on our calendar — and a true highlight of our year — is just around the corner. Yes, we're talking about the Big MACS Meet-Up! For those of you who are new to the community or need a refresher, this isn't just any gathering — it's a celebration of everything MACS stands for: unity, empowerment, creativity, and connection.

This year's Big MACS Meet-Up promises to be the most exciting one yet. Mark your calendars, because this is one event you won't want to miss. Whether you're a long-time MACS veteran or a first-time attendee, you'll find something to ignite your spirit.

This year marks an incredible milestone — the 200th anniversary of Braille! In this issue, we're proud to celebrate two centuries of this revolutionary system that has transformed lives and opened up worlds of possibility for blind and visually impaired people around the globe. Our special feature dives into what braille means to our members.

From personal experiences with learning Braille to reflections on the importance of accessible design in everyday life, this article is both a tribute to the past and a call to action for a more inclusive future. Whether you're new to the world of Braille or deeply connected to it, we think you'll find this piece both inspiring and enlightening.

We also have a truly special article in this issue featuring our very own John. In it, he shares openly and honestly about his life living with a MACS condition, as well as autism and ADHD. It's a beautifully written and powerful piece that sheds light on the challenges, insights, and daily realities of navigating the world with intersecting identities. John's voice is full of honesty, humour, and heart — and his story is one that will stay with you long after you've finished reading.

With warmth and excitement,

Teresa Gordon
Chair of Trustees

If there is any topic or content you would be interested in seeing in the next issue of the Focus Magazine, or perhaps you have something interesting to share with us that we can cover, we'd love to hear from you. Please do get in touch with the fundraising team on the number above or email fundraising@macs.org.uk

Meet the Team

ORGANISATIONAL STRUCTURE

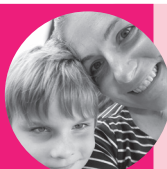
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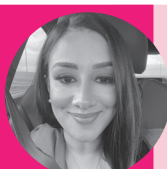
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MACS Team Updates

GREAT NEWS!

We've got some wonderful news from our Member Services Manager, Kim! Just when she thought life was settling down with her 14-year-old daughter, she and her husband Sean — our very own tech volunteer — are thrilled to be expecting a new addition to their family.

This time around, they're preparing to welcome a baby boy, and they can't wait to introduce him to the wider MACS family. Kim is still planning to join us at the Big MACS Meet Up (even if she might be a little wobbly by then!) before heading off on a short maternity leave this autumn. She says the biggest surprise so far has been discovering just how much baby equipment has changed — and how overwhelming the choices can be! Thankfully, big sister Lily has already claimed the role of fashion advisor, so that's one decision sorted.

As many of you know, both Kim and Sean are visually impaired, and they've kindly offered to share parts of their journey with us as they navigate parenthood a second time around. We're so looking forward to hearing their insights and experiences as VI parents once again.



Calendar of Events 2025

Calendar of Events and Activities for the rest of 2025 Plans

- We were thrilled with the fantastic turnout for both our Sailing and Calvert trips — a big thank you to everyone who signed up! We can't wait for these adventures to set sail very soon.
- This month also marks the exciting launch of two brilliant initiatives: our Employability Programme and Jamie's Farm experience. (You may have already seen the buzz in our latest newsletter!) These projects are all about building confidence, skills, and lasting connections — and we're so excited to see them begin.
- Behind the scenes, our counselling project is nearing completion, with final touches being made. We'll be sharing more information on how to access this vital support very soon.
- We're also working on launching a brand-new range of WhatsApp groups — including ones for teens and a dedicated Tech Talk space — to help connect our members across all age ranges and interests. **Stay tuned!**
- A quick heads-up: spaces for our Mersea activity weekend are filling up fast, so if you're thinking about joining us, don't delay!
- All application forms can be found on our website, and if you have any questions at all, the team is always happy to help.



Online Events

July

July: Tech talk and Gaming Zoom - 16th	8pm
July: Online Creative Writing - 22nd	7pm
July: Adults Zoom - 30th	8pm

August

August: MACS Coffee Morning Zoom - 13th	11am
August: Kids Creative Writing zoom - 20th	5pm

September

September: New members Zoom - 11th	8pm
September: Adults Zoom - 24th	8pm
September: Online Creative Writing - 30th	7pm

October

October: MACS Coffee Morning Zoom - 8th	11am
October: Online Creative Writing - 14th	7pm
October: Kids Creative Writing - 22nd	5pm

November

November: New Members Zoom - 12th	8pm
November: Tech Talk And Gaming Zoom - 19th	8pm
November: Online Creative Writing - 25th	7pm
November: Adults Zoom - 26th	8pm

December

December: Quiz - 6th	8pm
December: MACS Coffee Morning Zoom - 10th	11am
December: Kids Creative Writing zoom - 17th	5pm

HELLO

To new members

With new outreach work well underway, we've welcomed lots of new members to the MACS family since the last Focus magazine. Here's a handful of them saying 'hi' and telling you a little about themselves...

ROBBIE



Robbie was born in August 2024, completing our little family. It wasn't until we raised concerns with his eye and took him to our doctor that they referred us on to the hospital at around 8 weeks old and he was diagnosed with a coloboma in his right eye.

Robbie is the happiest, funniest and cheekiest baby going! Although the doctors don't know exactly how the coloboma will affect his vision until he is older, it doesn't seem to hold him back in the slightest - he is so curious and mischievous, he is into everything!

At first, I was very concerned for Robbie's future, the uncertainty of his vision, and how cruel people can be sometimes judging by appearances, but we have embraced his differences that certainly make him unique! Hearing from MACS members has really helped us to understand his condition and strive to find out more information that may be of use to him in the future, so thank you to the people we have met so far and we look forward to meeting more of you soon!

VIOLA



This is Viola, our beautiful bilateral coloboma baby, she will be one in August. She is such a happy, social and kind soul, with a cheeky smile. We noticed there was something different with her eyes at only a few days old, but our concerns were dismissed by the midwife.

Viola was struggling to put on weight and at three months old was admitted to hospital, after lots of tests the conclusion was a suspected milk protein allergy along with many other foods.

We are still in the throes of more tests, but we understand her left eye is a coloboma of the iris and right eye the coloboma goes back to her optic disk. We have been impressed with her Visual Impairment Teacher through the council who has already visited her nursery she will be starting in August.

Viola has an amazing big sister, Mamie who makes her laugh a lot and gives her an abundance of kisses and cuddles! We are mum and dad, Rachel and Gavin and we live together in Royal Leamington Spa.

We are really pleased to have found MACs and are looking forward to meeting more MACs families.

ESME



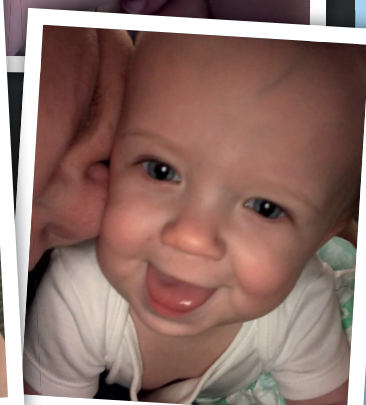
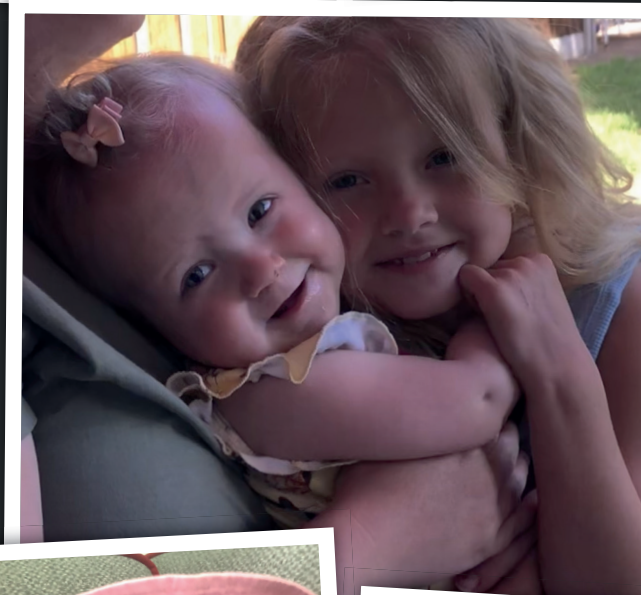
This is Esme on her first birthday 11/04/25. She has iris coloboma and irido-chorioretinal coloboma in both eyes.

LYDIA



Hello, we are Sarah, Phil, Fiona, Esther and Lydia. Lydia was born at the end of 2024, just after Christmas. We first spotted that there was something unusual about her left iris when she was 3 days old. Amazingly we were able to get an appointment with the specialists at Leeds hospitals when she was just five weeks old, and this confirmed that she has an iris and chorioretinal coloboma. We wait to find out how much this will impact her vision, but for now she is a very happy baby and enjoys watching her sisters dancing and pulling silly faces at her."

JEMIMA



Jemima has bilateral coloboma and is very sensitive to light, so she has a range of hats! Jemima's big brother Elliott is excellent at making sure she isn't in the sun; they are the best of friends, and she is very lucky to have a big brother like him. MACS has been such an amazing support system to myself and my family.

Envision Glasses Marla



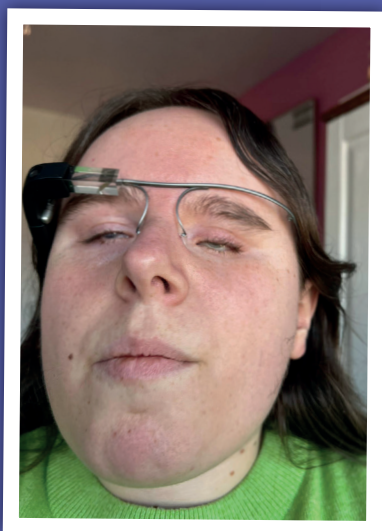
Envisioning and embracing opportunities and enhancing your independent skills with the Envision AI powered smart glasses! How AI and remote human visual assistance can open up the world, allowing blind people to explore and embrace their curiosities hands free with groundbreaking smart glasses!

This is an absolutely intriguing field of AI and robotics called Human Robot interaction or (HRI) which I have had a strong ongoing interest in from a very young age.

Together, we are exploring the benefits of assistive tech gadgets, and how they can assist and give a sense of freedom to blind users like myself.

Here is a selfie photo which I took of myself wearing my Envision glasses. I took the picture independently on my iPhone and I also used Chat GPT to describe the photos and pick out the best ones, as Chat GPT has a feature which can assist completely blind users with photos and help the user to pick out the best ones.

Hopefully they look quite good. I originally took six photos, but I think that these four clearly



show the glasses in the photos. In the photos, I am standing in a room with pink walls by a wooden wardrobe getting ready to go out.

The smart glasses are positioned on my face, the way that you would normally wear your sunglasses, apart from the fact that my glasses have no lenses.

They come with the durable and lightweight titanium frame attached, and you can see where the wide angle camera is protruding out slightly just above my right eye. The thin metal frame goes behind my left ear, and the control panel with the built-in speaker on the glasses goes behind my right ear. The glasses also have a discrete and sleek fashionable design.

They can also be worn on top of regular sunglasses on warmer days, however, in the photos I am wearing just the Envision glasses which is what I usually do. My long, dark naturally curly hair is loose and free and my facial expressions are relaxed, neutral, curious and inquisitive.

In the photos I am also wearing my new lime green jumper, as it was a mild but crisp day, and the lighting is good for a casual selfie.

If you want to find out more about the Envision glasses and what they can do, check out the Envision YouTube channel, or go to the Sight & Sound website and search for Envision glasses.

You can learn more about Envision Glasses at
www.letsenvision.com/glasses/home

Member Milestones



ONE OF MY PROUDEST MOMENTS

I would like to say thank you all for the great support from Adventure Mind especially from the Bendrigg Trust who helped me prepare and support me for this big day.

Speaking at the Adventure Mind conference in front of over 100 people was a great experience. I talked about the things I have done, having a disability in the great outdoors and volunteering with a disability.

It was incredible meeting like-minded people, building bridges with connections and inspiring speakers. Each had an opportunity to talk about their own life experiences and expertise in a range of sectors that support a wide range of people in the great outdoors in an accessible way. It was truly a success in my eyes.



FANTASTIC FELIX

Earlier this year, Felix started preschool. He has taken to it so well and has settled in beautifully. The ladies there adore him, and he's made lots of friends and been invited to many birthday parties! He's won Star of the Week twice in sports—once for tennis and once for cricket.

Felix also started swimming lessons a few months ago. He isn't fond of splashing or getting his hair wet, but he enjoys his lessons each week, and his confidence in the water is growing. He recently received his Duckling 2 badge. We are all so incredibly proud of Felix and everything he achieves. He is so determined and won't let anything stop him!



THERE'S ALWAYS HOPE

23 years ago our daughter was born with one eye undeveloped.

We panicked, we blamed ourselves and we blamed outside influences. The doctor didn't seem to give us any support; Would our gorgeous Eliza have the same opportunities as other children her age, would she lack confidence, would she be bullied?

MACS calmed us down and made us look at the positives. Eliza is now 23, gained a First Class Honours Degree in Fashion Marketing and has a good job and a lovely boyfriend.

And as her dad I say she's gorgeous!!! I think her condition and the help of MACS has been the making of her.

There's always hope. Thank you. **Stuart.**



A BIG MILESTONE FOR EWAN

A big milestone for Ewan as he leaves school and heads to Edinburgh University in September to study Maths and Computer Science. We just found out yesterday that he's been awarded prizes for Advanced Higher Maths, Computer Science, and Physics. And the one that made me cry, he's been made Dux of the school.

This is a massive honour and achievement for the boy who came home in tears every day during the first month of high school, hating it and thinking he'd never fit in or cope with moving to such a huge school (1,500 pupils) after coming from his wee, safe primary school of only 100.

I'm a super proud mum, and Ewan is proof that anything is possible. He hasn't let his eye conditions hold him back.



WELL DONE WILLOW!

Willow (2), who has anophthalmia left eye and microphthalmia right eye and no vision, started nursery in May. She has settled in so well, has made friends and is learning so much, her speech and confidence has bloomed.

THADY IS THRIVING

Thady continues to enjoy nursery, making some lovely friendships and recently spoke at his first assembly in front of a room of about 40 adults. He's preparing for his move up to reception class in September 2025 and very excited.



TRIATHLON SUCCESS

Thea who did her first triathlon last weekend! She really loved it and was helped by her big brother Bradley (11). (Thea Hallas, aged 9, bilateral coloboma)



BEN'S MARATHON CENTURY

A lot of you may know our Ben and how much he enjoys running and walking.

On Easter Monday, he completed his latest challenge: 12 half marathons in 12 days. During this time, he also achieved a huge milestone, his 100th half marathon!

Ben has a small amount of useful vision in his left eye, with slight microphthalmia and other conditions affecting it. He has no vision in his right eye due to severe microphthalmia and wears a prosthetic. He also has a few other diagnoses, but none of this stops him. When he was little, he didn't walk until he was nearly two, often saying his legs felt funny for years. With a high pain threshold, he never called it painful. Then, in 2012, he started running at parkrun.

Back in 2019, he completed his 100th marathon, making him a "Double Agent" in the running community we're part of.

Never let anyone tell you what your child can or can't achieve. They'll create their own incredible achievements, whether it's a smile or a run!

GEORGIA IS COOKING!

Georgia is 10 years old and has recently developed a keen interest in cooking. She now prepares her own healthy snacks after school and even designed and made a three-course meal for her family! Cooking is really boosting Georgia's confidence, and she's getting really good at it.



Georgia was born with Microphthalmia in her right eye. She has worn a prosthetic since she was a baby and now wears a painted shell.



CONGRATULATIONS KIRSTY

I graduated with a PhD in psychology last year. Since then, I have been struggling to find work mainly due to my disability. I am so delighted and incredibly proud that, in May of this year, I started working as a research assistant in the Psychology department at Swansea University.

It is such an amazing opportunity that I hope will open future doors for me as a researcher, and it's even more meaningful that the department saw beyond my disability to the ambitious, confident person I am trying to show the world.

Moreover, I was also given the chance to present my PhD research at a Health Psychology conference at the start of June. My PhD research was focused on the experiences of people living with visual impairment, so I am over the moon to be able to share my findings with other professionals in the field of healthcare, and make sure that the voices of visually impaired people are being heard.

Dr Kirsty Dawn Hill



NEW SCHOOL FOR LOUIS

Louis is currently in his last week in his current school and is about to make a big change to go to a new school starting on Monday. It's a new start for Louis and we are hoping he really enjoys his new school!



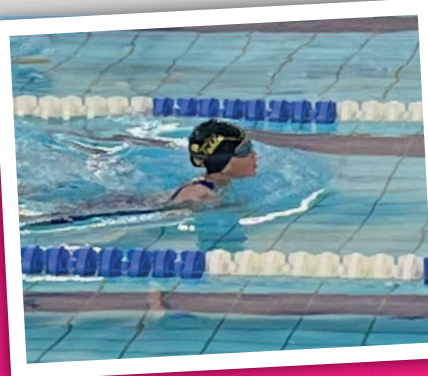
PROUD MUM MOMENT

The last time Bodhi took part in Sports Day was Year 3. He couldn't handle it in the slightest—he can't do competition, busy environments, the pressure of people watching, the cheering. He had the biggest meltdown, hurting himself, ripping out his hair, and using the egg and spoon as projectiles at other parents. I ended up just holding him in the middle of the field, sobbing.

His school told him he was the problem, and that if "he didn't act autistic," nobody would notice... One year. He's been at his new school just one year, not a SEN school, but one that didn't force Bodhi to fit into their box. They let him be Bodhi. And he's thrived.

Today, I watched him at Sports Day, compete in every race and absolutely smash it. I watched him with people and friends who accept him for him, and I watched him shine. His autism and ADHD were never his downfall; they're the beautiful chaos that make him everything his beautiful soul is.

God, I'm so proud to be his mum.



SUPER SWIMMER!

Estoi competed in her first licensed swimming competition last weekend – achieving personal bests in all her races and collected 3 gold and 3 silver medals in her age group category. She absolutely loved the atmosphere and experience!!

Here are some pictures of her from the weekend.

MAKING WAVES

Zara Coote is making waves in the world of para gymnastics. Earlier this year, she was one of four Scottish gymnasts invited to compete at the first-ever international para gymnastics event in Norway—a historic moment as Artistic Gymnastics begins its journey towards inclusion in the Paralympic Games.

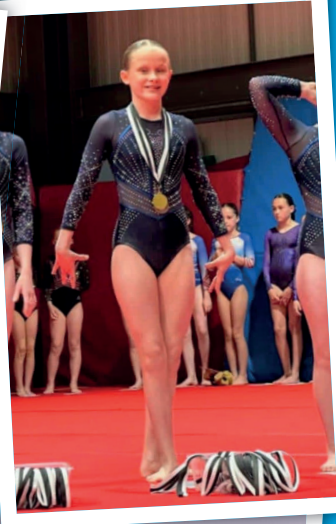
Zara was proudly part of that groundbreaking step, helping to pave the way for future para gymnasts. Following the event, Scottish Gymnastics and British Gymnastics praised the athletes for their incredible performances and highlighted the growing momentum behind para gymnastics in the UK. Zara's involvement places her at the heart of this exciting movement, with hopes of competing at the 2032 Olympic and Paralympic Games in Brisbane.

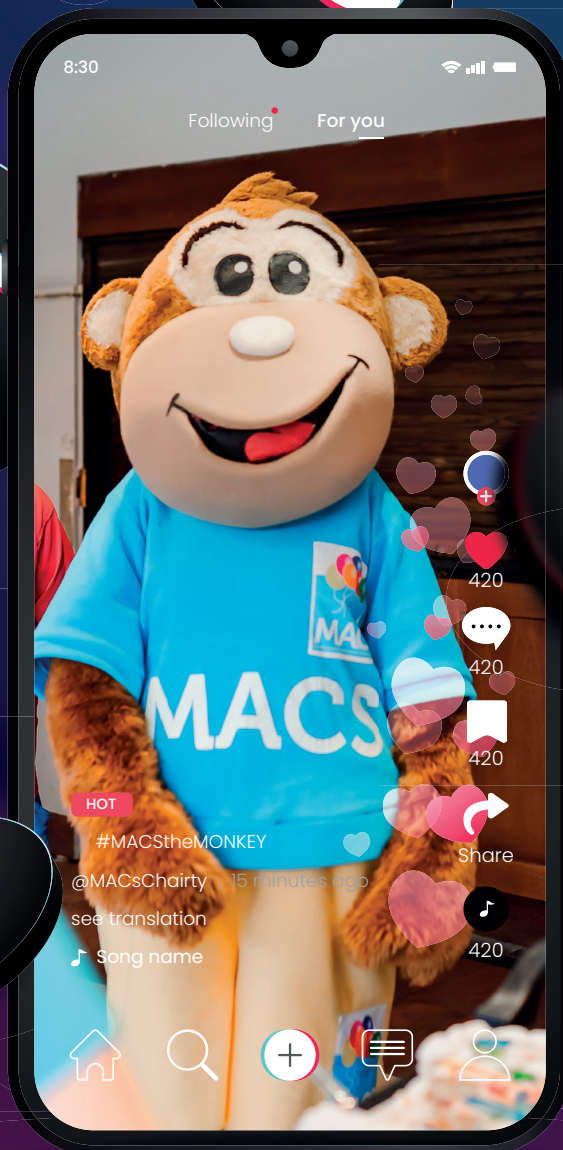
"Nothing is guaranteed, but she's a hard worker and has so much support behind her—including MACS! It's exciting to see her be part of something that could change the future of the sport."

As her dad shared, "Nothing is guaranteed, but she's a hard worker and has so much support behind her—including MACS! It's exciting to see her be part of something that could change the future of the sport."

Since Norway, Zara has continued to shine. At the **Scottish Gymnastics 2025 Championships**, she won **Gold on the uneven bars** in the disability category. She was also recognised at the **South Lanarkshire Disability Sports Awards**, jointly winning the **Female Junior Sportsperson of the Year 2024**.

Most recently, at the **Cumbernauld Classic competition in June 2025**, Zara brought home **Gold on the uneven bars** and **Silver on floor**, further cementing her place as one of Scotland's rising para gymnastics stars. Zara's journey is still unfolding, but it's already clear: she's helping shape the future of para sport, one routine at a time.





We are now on TikTok!

MACS is Now on TikTok: Reaching
More People, in More Ways

At Microphthalmia, Anophthalmia & Coloboma Support (MACS), we've always believed in the power of connection. Whether it's through our Big MACS Meet Up, regular newsletters, online support groups, or one-to-one member check-ins, our mission has always been to support, inform, and unite families and individuals affected by MACS conditions. Now, we're excited to announce a new chapter in our outreach journey: MACS is officially on TikTok!

As social media continues to shape how we communicate, raise awareness, and build communities, we recognise the importance of being present on platforms where people—especially young people—are already spending their time. TikTok, with its short-form video content and creative energy, provides us with an exciting new space to amplify voices, share stories, and celebrate our vibrant MACS community in a fresh and dynamic way.

WHY TIKTOK?

TikTok isn't just for viral dances and lip-syncing trends. It has rapidly become one of the most influential platforms for community engagement, education, and social awareness. With over one billion users worldwide, it offers a huge opportunity to spread our message, connect with younger audiences, and raise awareness of Microphthalmia, Anophthalmia, and Coloboma in an accessible and creative way.

As a charity, we're constantly looking for ways to reach more people and ensure our resources are as inclusive and far-reaching as possible. By joining TikTok, we're adding another string to our bow—another platform where we can:

- **Raise awareness** of MACS conditions through bite-sized, easy-to-understand videos.
- **Showcase the real stories** of our members, celebrating their creativity, achievements, and resilience.
- **Provide educational content** for the wider public to understand what it means to live with a MACS condition.
- **Offer support and encouragement** to individuals and families navigating sight loss, isolation, or the day-to-day challenges of life with a rare condition.
- **Reach young people** on their terms, in a format that speaks their language and embraces their digital world.

CONNECTING WITH MEMBERS IN NEW WAYS

For many of our younger members, TikTok is already a daily part of life. It's where they find inspiration, connect with others, and express themselves. By stepping into that space, we're able to better understand and support their experiences—not just medically or practically, but socially and emotionally too.

Our presence on TikTok gives us the chance to interact directly with members in a more informal, spontaneous way. It allows us to share updates, celebrate successes, promote events, and explore everyday experiences—from mobility tips and assistive tech to MACS-friendly makeup hacks and mental health support—all in a way that's relatable and real.

We're not here to curate a "perfect" feed—we're here to be authentic, compassionate, and representative. By featuring the voices and faces of our community, we hope to empower more people with MACS conditions to feel seen and celebrated.

BREAKING DOWN BARRIERS

Visibility matters. One of the biggest challenges with rare conditions is that they're often misunderstood or overlooked. TikTok gives us the chance to bring MACS conditions into the public eye in an engaging and digestible format.

Through storytelling, humour, creativity, and education, we can challenge stigma, dispel myths, and promote inclusivity. Whether it's a quick explainer on what Microphthalmia is, a "day in the life" video from a MACS member, or behind-the-scenes glimpses into our community events, every post helps to chip away at the barriers of ignorance and isolation. TikTok is also an incredibly accessible platform. With features like auto-captioning and screen-reader compatibility, it helps ensure that content can be enjoyed and interacted with by people with different abilities—something that's very important to us.

WHAT YOU'LL FIND ON OUR TIKTOK

Our content will be a mix of:

- **Educational explainers:** Breaking down medical terms, answering common questions, and busting myths around MACS conditions.
- **Member stories:** From everyday wins to life milestones, we'll be spotlighting the amazing individuals who make up our MACS community.
- **Behind-the-scenes clips:** Giving a peek into the work of the charity, our events, team, and volunteers.
- **Tips & advice:** Including accessible technology, support services, lifestyle hacks, and more.
- **Challenges & trends:** Participating in wider TikTok trends - with a MACS twist!

We also want our channel to grow with our community. That means responding to comments, collaborating with members, and inviting you to share your own ideas, stories, and creativity. If you've got something you'd love to see—or a video you'd like to make with us—we'd love to hear from you!

HELP US SPREAD THE WORD

You can find us on TikTok by searching @macs.the.charity.

Give us a follow, like and share our videos, and help us build a digital space where our community can flourish. Whether you're a MACS member, parent, teacher, friend, or ally—your support makes a difference.

Together, we can make sure that no one with a MACS condition ever feels alone—and that their stories are heard far and wide.

See you on TikTok!

Soap Box Derby



Meet Andy: Racing to Support MACS



Andy is no stranger to challenges, but this year he's taking on an exhilarating adventure to support MACS, inspired by his three-year-old son, Isaac, who was born with a MACS condition.

It all began in 2023 when a family outing sparked an idea that quickly turned into a passion. Andy says:

Fast forward to 2025, and Andy has built his very own soap box (gravity racer) - a sleek, motorless cart designed for speed and powered only by gravity, and is gearing up for a thrilling series of soapbox races to raise awareness and funds for MACS. His racing schedule includes:

"I went with my family to the Humber Bridge Soapbox Derby. I saw what had been built and though it was possible to build a cart myself. I also thought this would be a great activity to do with my son (around 18 months at the time), and as a buildup to a bigger idea of building my own race/track car with him a few years down the line. And on top of that to support a good cause."

- **14th June** Humber Bridge (East Riding of Yorkshire)
- **21st June** Avon Dassett (Warwickshire)
- **29th June** Richard's Castle (Shropshire)
- **26/27th July** Harewood gravity races (West Yorkshire)
- **Date TBC** - Hunstanton (Norfolk)

Soapbox racing, also known as gravity racing, is as exciting as it sounds. It is all about speed, skill, and gravity. Using simple yet creative designs, racers rely on slopes and skill to guide their carts to the finish line, racing against the clock or other competitors.

Traditionally made from wooden crates and roller-skate wheels, modern gravity racers have evolved to use materials like aluminium, fiberglass, and carbon-fibre composites (CFRP). A typical cart features four wheels, a simple steering mechanism and a friction brake. Andy's custom-built cart features a striking livery and promotional design which is supported by CANPACK UK Ltd, ensuring all funds raised go directly to MACS.

Andy has set a fundraising goal of £1,000 and has already secured fantastic support from his employer, CANPACK UK Ltd, who will match his sponsorship up to £2,000. A huge THANK YOU to CANPACK UK Ltd for their generosity! "This fundraiser is about more than the race," Andy shares. "It's about giving children the opportunity to live their fullest lives."

As race day approaches, Andy is rallying support from friends, family, and the community. His JustGiving page is live, and every donation helps MACS continue their vital work. You can join Andy in making a difference by visiting: www.justgiving.com/page/bigwheels.

Let's cheer Andy on as he races for MACS, proving that with passion and purpose, anything is possible!



Regional Volunteers Programme

WE'RE THRILLED TO SHARE THAT OUR FIRST GROUP OF VOLUNTEERS HAS ALREADY SIGNED UP TO OUR TRAINING PLATFORM—AND SOME HAVE EVEN COMPLETED IT!

We've worked hard to make the process as quick and easy as possible, and we're beyond excited that regional meet-ups are just around the corner.

But we're not done yet—we still need more volunteers! Whether you're in a busy region that needs extra hands, or an area where we're still building a team, there's a place for you. If you have just a few hours a month and a passion to get involved, we'll give you all the support and guidance you need.

OUR GOAL IS TO TRULY REFLECT THE WHOLE MACS COMMUNITY.

That means we'd especially love to hear from parents of older children and MACS adults—though everyone is welcome. Please don't underestimate what you can offer. Whatever your background, your contribution matters.

So far, we have volunteers from all walks of life—from experienced teachers and event planners to people whose biggest event was a family BBQ. Every single one is welcome, and every effort is valued equally.

WE'LL PROVIDE THE FUNDING AND TRAINING. YOU BRING YOUR IDEAS. TOGETHER, WE'LL MAKE IT HAPPEN.

If you've been meaning to get involved—or are just on the fence—now is the perfect time to jump in. Email us at: enquiries@macs.org.uk

Let's fill the next issue of *Focus* with amazing regional photos, showcasing the power of our community alongside our national events. Let's come together—and make something incredible.

Panto Reports



We had three pantos last December. Beauty and the Beast in Dunstable with Mel, Cinderella in Chesterfield with Vikki and Beauty and the Beast in Canterbury with Hayley, all organised and attended by our wonderful volunteers, with some help and support behind the scenes, from us. We thank you for all the time and dedication given to putting these events on.

To help fund the costs of the Pantos we received £3,966.07 from the Co-Op Community Partnership scheme. This time we had lots of changes and last-minute bookings, but we got there in the end. The pictures show the huge range of ages that attended, and we have some quotes from attendees here:

"It's a great annual event that we all enjoy and it's lovely to see the other families there."

"We, the whole family, thoroughly enjoyed the show. Age range from 3 to 73!"

"We loved the panto. The touch tour was amazing for our six-year-old blind daughter. Very good experience!"

"It was great all-rounder and so many members came."

"Excellent family event with fun for all."

"Great fun everyone was really friendly."

This is what our Regional Volunteers had to say:

Vikki who organised the Chesterfield panto said: "It was

Canterbury Panto



such a wonderful opportunity to bring families of all ages to laugh and sing during the festive period. The "Touch Tour" is like a behind the scenes tour and an insight to what goes on and is incredibly valuable to the visually impaired community. We are so lucky to get the opportunity to do this as a family and alongside other local families."

Hayley who organised the Canterbury panto said: "A group of parents, children and young people from across Kent and further afield came together to watch Beauty and the Beast at The Marlow Theatre Canterbury. As always the panto did not disappoint with lots of silliness

Chesterfield Panto Touch Tour



Dunstable Panto



and giggles. After the panto some families were able to get together and have a catch up. It always great to see how MACS brings families together to support one and other. Thank you MACS for another great event which is much appreciated by the families and especially the children."

Mel who organised the Dunstable panto said: "Just wanted to say thank you to MACS for funding our panto at The Grove Theatre. Touch Tour and fabulously funny panto. Nice to see so many families again from Bedfordshire, Hertfordshire, Buckinghamshire and beyond. Thanks again Mel x"

If you are interested in becoming a MACS Regional Volunteer and organising events for all members in your in your area, please contact kim@macs.org.uk for further details.

Let's get excited for the Big MACS Meet up



After a fantastic response to our first round of applications, we were thrilled to be able to extend the number of spaces available.

Last year, 130 people joined us for a weekend of socialising—the largest MACS gathering since before Covid. It may have looked a little different from the traditional Family Weekend, but it delivered exactly what we hoped: support, friendship, laughter, and lasting memories.

This year, we set ourselves the goal of growing attendance by 10%. At the time of publishing this magazine, we're delighted to say we've already surpassed 200 attendees—and we're seeing if we can squeeze in a few more!

While we're still finalising the full schedule, here's a sneak peek at what's in store:

- **Circus skills with Rob** – Back by popular demand, Rob creates a welcoming space where everyone—regardless of age, vision level, or additional needs—can give it a go.
- **Music workshops** – A firm favourite, and we're excited to bring the rhythm and joy of music back to Drayton.
- **Let's get moving** – Warm up for the evening disco with some afternoon dancing and fun movement activities.

Between sessions, enjoy a **delicious barbecue** in our own private outdoor space. And that's just the beginning—around the main workshops we'll also have **face painting, inflatables** and a few surprise activities to keep everyone smiling.

And of course, after a lively day of activities, you'll sit down to a **three-course meal** packed with conversation and connection. Then it's on to the **disco**—or if that's not your scene, we'll have a quiet games and chill-out space to unwind.

Finally, if you've still got energy left on Sunday, it's time for **Park Day!** Collect your tickets, say goodbye to the MACS team, and enjoy all that Drayton has to offer with new friends by your side.





MACS Website Resources

Discover the New MACS Website Resources

AT MACS, we believe that support, understanding, and empowerment should be available at every stage of life for individuals affected by Microphthalmia, Anophthalmia, and Coloboma. That's why we're proud to announce a wide range of **new, thoughtfully developed resources now available on our website**—designed to inform, support, and uplift our community from the moment of diagnosis through every life milestone.

Whether you're a new parent, a young person navigating school or employment, or an adult living with a MACS condition, we want you to know: you're not alone. Here's an in-depth look at the new content you'll find, and how it can support you and your family on your MACS journey.

NEWLY DIAGNOSED:

Hearing the words Microphthalmia, Anophthalmia, or Coloboma for the first time can be overwhelming. That's why our new **Newly Diagnosed** section is a crucial starting point for many families. This resource offers clear, compassionate explanations of each condition. It includes:

- What to expect after diagnosis
- Practical guidance and emotional support
- Insights from families with lived experience
- Information on next steps like medical assessments and genetic testing
- Ways to connect with others through MACS events and online communities

INFORMATION ON PROSTHETIC EYES

Many children and adults with MACS conditions wear prosthetic eyes for cosmetic reasons or to support socket growth. Our newly added **Information**

on Prosthetic Eyes section covers everything from fitting and care to understanding the role of an ocularist.

We've collaborated with MACS members who wear prostheses, to provide tips on cleaning, managing discomfort, and how to talk to children about their prosthetic eyes in an age-appropriate way. It covers:

- Why and when prosthetics are recommended
- What to expect during the fitting process (including NAES steps)
- Care tips for cleaning, handling, and maintenance
- How to access specialist services and exercise your choices
- Real stories from MACS families who've chosen — or opted against — prosthetics

BECOMING A PARENT WITH A MACS CONDITION

This heartfelt new section is one we're especially proud of. For MACS adults planning to start a family or who are already parents, **Becoming a Parent with a MACS** Condition offers personal insights and practical advice. Inside this resource, you'll find:

- Key information on genetic testing and inheritance
- Questions to consider before and during the testing process
- What to expect at a genetics appointment
- Emotional support tips for navigating complex feelings
- A personal story from a MACS parent who shares their journey and advice

This guide offers thoughtful insight and reassurance for making informed, empowered choices.

STARTING SCHOOL: WHAT TO EXPECT

Our Starting School resource helps parents prepare for this important milestone with practical advice and lived experience from the MACS community. Inside, you'll find:

- Tips on choosing the right school — mainstream, specialist, or with VI support
- Guidance on applying for an EHCP (Education, Health, and Care Plan)
- Advice from parents and QTVIs on supporting independence and inclusion
- Links to helpful EHCP tools and resources

INFORMATION FOR TEACHERS: CREATING AN INCLUSIVE CLASSROOM

To complement the school preparation section, our **Information for Teachers** resource is a practical guide for educators who may be supporting a MACS child for the first time. This section includes:

- A general overview of MACS conditions
- Tips for supporting social and emotional well-being
- Common myths and how to confidently address them

We encourage parents to share this page with their child's school staff to help foster understanding, reduce anxiety, and promote inclusive learning environments.

MACS TEENS: NAVIGATING INDEPENDENCE

The teenage years are full of self-discovery, change, and growing independence. For MACS teens, these changes often come with additional considerations—around mobility, self-image, and social dynamics. Our MACS Teens resource is designed to help young people with Microphthalmia,

Anophthalmia, or Coloboma feel confident, connected, and empowered. It includes:

- Teen chat groups for peer connection
- Exciting trips and activities like sailing, Jamie's Farm, and more
- Mental health support through podcasts, online sessions, and residentials
- Resources for CVs, employment, and building independence

MACS ADULTS: ENTERING THE WORKFORCE

For many young adults, leaving school or university and entering the world of work is both exciting and daunting. Our Working with a MACS Condition resource offers practical advice and inspiration for navigating careers with Microphthalmia, Anophthalmia, or Coloboma. Inside, you'll find:

- Workplace adjustments and assistive technology
- Career stories from MACS adults across a wide range of professions
- Job-hunting tips and advice on building essential IT skills

This section is designed to empower MACS adults to pursue careers with confidence, whether you're seeking your first job or changing careers later in life.

WHY THESE RESOURCES MATTER

These new resources are more than just webpages and leaflets—they're a reflection of the lived experience of our MACS community. They've been shaped by real questions, challenges, and triumphs shared by members like you.

At MACS, we know that no two journeys are the same. That's why our resources are designed to offer both practical tools and emotional reassurance at every stage of life. Whether you're reading up on prosthetics for the first time or preparing to meet with your child's new teacher, we hope you find clarity, confidence, and community in these pages.

GET INVOLVED: YOUR VOICE MATTERS

We'd love to hear from you. Have an idea for a topic we should cover? Want to share your story to inspire others? Email us at enquiries@macs.org.uk—we're always listening.



Technology Update



family and school staff, it was the answer they had been hoping for—and a special opportunity to meet a visually impaired adult confidently pursuing his passion.

Sean explained how combining Braille with technology offers Elijah an effective solution not only for now but for the future. He's excited to return soon to help set up the equipment.

Sean was thrilled to take on his first formal assignment for MACS, visiting Elijah at his school near Liverpool.

We feel incredibly fortunate to have Sean as part of our team. With over ten years of experience teaching visually impaired young people, he brings a wealth of knowledge—and he's always willing to give his time and travel wherever needed.

Sean was thrilled to take on his first formal assignment for MACS, visiting Elijah at his school near Liverpool.

Elijah's mum, Zoe, had applied through our Helping Hand scheme some time ago for equipment that would enable Elijah to Braille while allowing his sighted teachers and family to read and respond. Unfortunately, the specific equipment they needed was out of stock for the long term, so Sean offered an alternative solution and arranged a visit.

For Sean, it was a nostalgic return to a classroom role he loved. For Elijah's

We'd love for more of our members to tap into Sean's expertise—and keep him from getting bored with his day job! No question is too big or too small. Whether it's writing guides, creating audio demos, visits, Zoom calls, chats, or emails, Sean is here to help. And if he can't, he'll likely know someone who can. You can reach him at sean@macs.org.uk.

We're also happy to share a photo of Sean with Elijah—many thanks to Elijah's family for allowing us to do so.

Sean now works as a programmer and digital accessibility specialist and would like to extend his thanks to MACS for giving him the chance to continue doing what he truly loves: combining technology and education.



Celebrating 200 Years of Braille

This year marks the 200th anniversary of Braille: the tactile writing system that has empowered generations of blind and visually impaired people to read, learn, and thrive. To celebrate this historic milestone, we've gathered reflections from several of our members on what Braille means to them.

First up is Megan Hastings—an author and Secretary of The Brailleists Foundation—who shares her personal connection to this life-changing system.



KARRIE AND LEWIS

This is Lewis who MACS so kindly supported with a new HumanWare Brailenote that he uses every day. Braille has been a saviour for Lewis who along with complete blindness in one eye due to Microphthalmia, has severe fluctuating vision and cerebral visual impairments in his working eye. Meaning accessing regular media is near impossible. At his request, Lewis started learning braille after success with touch typing and is absolutely flying with it. His understanding and knowledge

have seen him fly through levels 1 and 2 and he shall look forward to working on achieving formal qualifications in braille including with maths braille when he starts his placement at The Royal National College for the Blind in September.

Thank you MACS for supporting Lewis in his learning and development with braille. We are forever grateful that he now has daily access to this crucial learning aid.

Kind regards,
Kerrie Tandy
(mum, carer and appointee for Lewis)

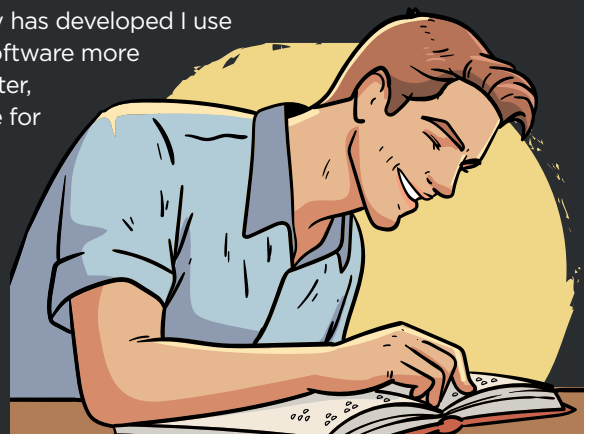
KAREN

I think with braille it is the little things that count a lot. Keziah gets so excited when we are in a chemist, and she is feeling things on the shelf and finds something in braille. It would be so good if there were braille menus in restaurants - especially such as McDonalds and KFC which must have a lot of blind customers and little change to their menu - you'd think that would be quite easy. Keziah would love to find braille on cans and packets in the supermarkets too. You'd think just the name of the contents would be possible. We went to a theatre production once that had the cast and intro to the show in braille available - it made such a strong impression on her. Made her feel seen and catered for.

MATTHEW

I have used braille ever since I was young, initially at school for a lot of my schoolwork, and also I have read several braille books over time. I have found it to be useful and helpful for me to access a wide range of activities.

Over time as technology has developed I use JAWS screen-reading software more and thus use my computer, however, I still use braille for several things today, for example when writing greetings cards, and even things as simple as when I am using the lift in the building where I work to make sure I am going to the right floor!



MEGAN HASTINGS

My love affair with braille began when I was four. I learnt to read and write alongside my classmates. When they were practicing joined up writing, my braille teacher would show me the difference between the 'ch' and 'st' signs and help me distinguish 'ing' from the letter u. I remember reading my first book. It was about a rocket and I loved the story although I got the ms and shs mixed up. It wasn't long after this that I sat in front of the brailier, rolled in a sheet of paper, and started to write. This page of simple sentences and rubbings out was the first of many pieces of writing I would produce over the years.

Braille continued to enrich my life as I grew up. I had mixed emotions when the fourth Harry Potter book came out. I was frustrated that I couldn't read it at the same time as everyone else. My teacher compromised by brailleing a few pages of the book at a time which meant that I read the book far more slowly than I would have liked, constantly pestering my teacher for my next ration of Hogwarts. Feeling the opening chapter unfold under my fingers was magical.

Family holidays saw me travelling along bumpy roads to North Wales with a large volume of The Famous Five stretched across my sister's lap as well as mine. The car would be full of our squabbling (she insisted it wasn't a comfortable way to travel), as well as a boot packed with luggage and all my braille books. My holiday entertainment took up a lot of space, but my parents had learned long ago that there was no question of taking me anywhere without books. Two years later, they

would breathe a sigh of relief when I was given my first electronic braille note-taker. From then on, all my books would be stored on this computer and the car would seem a lot bigger.

To secondary school, where I was expected to study French and German. This brought with it 2 new braille codes. I was forever getting the signs muddled up, so dropping French was a blessing. German braille would become important seven years later, when I would spend a year in Germany. My teaching of English as a foreign language wouldn't have been possible without being able to read or write.

With secondary school came other braille-related challenges. My textbooks were brailled in prisons which could take some time. We studied Macbeth in my third year, and I was surprised to find that my copy was in five volumes. Macbeth isn't a long play, so this seemed excessive even for a braille book! When we came to read the play in class, I discovered that the prisoners had written notes to each other in the text. I tried to smother my laughter as I read: *'Is this a dagger which I see before me, (Black coffee with sugar mate?)'*

Being a brailist at exam time was no laughing matter. Few of my papers had been brailled correctly so that the questions were different from those in the print paper. Without the help of my teacher, I would have lost unnecessary marks.

Special occasions are a big part of growing up and my friends and family pulled out all the stops. They found a commercial card shop which sold braille

greetings cards at a high price, and I would be presented with at least one brailled card every year. I didn't have the heart to tell them that the birthday range wished me a 'nappy hirthday', whilst their Christmas cards read: 'With festive fishes for the season.'

As you can see, being a braille reader gives me a different outlook on life. Who else reads all the boxes in the pharmacy just because they can? I will never get tired of asking for a braille menu in restaurants, even though the answer is usually 'no.' The pleasure I feel when I'm given a menu in a format I can read makes it all worthwhile.

Times have changed since I travelled along that bumpy road to Wales. These days, holidays involve much discussion at the airport as I try to convince security staff that my beloved braille computer is harmless and that, yes, it must be allowed in the hand luggage. They check to make sure the electronic braille display isn't dangerous. Then, they give way to curiosity.

"How does it work?" they ask. I briefly explain how each braille letter is made up of six dots. They want to know more, so I inform them that I have thousands of books stored on this device in addition to all my writing. They make a comment to the effect that braille must take a long time to write. The contractions that constitute grade two braille actually mean that I write as fast as the average person. I seem to have answered all their questions and they let me go. Soon I'll be on the plane, settling back in my seat. My sister flicks the pages of a magazine. As the plane glides along the runway and leaps into the air, I take out my computer and start to write.

ANNA - THE JOY OF BRAILLE

For as long as I can remember, Braille has been a vital part of my everyday life. I first encountered it when I was four years old and recall being captivated by the ultra-tactile experience as I ran my fingers across the page. There has always been a sense of wonder for me in just how much can be communicated through the six precious dots that make up the system, as well as by how the brains of those of us who read it can somehow unravel the

code quickly enough to unscramble its messages - messages that are hidden to most. I love the mystery of it: the fact that I can read in the dark and, even if I'm reading in public during daylight hours, most people wouldn't have a clue as to what my fingers are communicating to my brain. On a practical level, it gives me independence: the freedom to read scripture to myself each day from my Braille Bible, the ability to take down notes and read them back, the opportunity to study and

learn, and so much more. There is a move to reduce the teaching of Braille to young VI children, the thought being that technology can replace all of these things, but this is a concept that I would strongly refute. Technology absolutely has its place, but there is no substitute for the physical ability to read - for its unique ability to equalise us with our peers, both in our ability to spell and communicate and in the additional independence that it gives. May the joy of Braille continue forever!



OLIVER

I love braille. I've been learning braille since January 2024 with my Visual Impairment teacher Caroline.

In my first year I learned uncontracted braille (Grade1) which means every letter has a braille sign. I am now learning contracted braille (Grade 2) which is a way of making words shorter so that books don't become too big and heavy.

I use braille to read, write shopping lists, make birthday and thank you cards and for labelling things. Braille helps people who can't see to read and write. You can find braille in lifts, on medicine packets, on signs and you can get braille books and games too.

STEPHANIE SERGEANT – THE BRILLIANCE OF BRAILLE

I was born with bilateral Microphthalmia and went to boarding school at 4 years old. My Parents were both fully sighted, and Dad learned Braille so that he could send me Braille letters. Our budgie used to peck the edge of the paper to send his love.

By the time I was 6 or 7 I was reading full length books like Treasures of the Snow and Swallows and Amazons. I loved to bury my head in a book and enjoy the freedom of it all. I could read under the covers at night without a torch which was a distinct advantage.

Our secondary school, Chorleywood College, had an extensive library, with big Braille books stored in the cellar as well as the library. I discovered a pamphlet which was a book from the new testament, in an easy to understand translation, and "devoured" that, and Jesus became so real to me through reading it. It is so special to be able to discover knew things for yourself, direct from the embossed page, rather than hearing them, or waiting to be read too. Our exam papers were all transcribed into Braille, and the teachers transcribed our answers into print.

Children attending mainstream schools now need advocates to fight for them to have the right to learn to read and write in Braille. Otherwise they will grow up illiterate.

I went to university to study Psychology, and my Braille notes from lectures were 5 feet high. Recording lectures would have been incredibly time consuming

having to transcribe them afterwards. These days Braille note takers make it far quicker and easier.

I then worked as a computer programmer using an 80 cell one line Braille display to establish all the different column positions in the programming code. I would have found this impossible with speech only. The Print room devised a method of printing my code in Braille so that I could correct it and resubmit the coding. I worked for various companies for 20 years, and when I was off sick with repetitive strain injury 2 sighted employees covered the work I had been doing, which they finished a month later than the deadline I had been given.

Meanwhile at home I discovered the joy of the Clear Vision Library, which takes print picture books for young kids, and interleaves the pages with Braille writing and tactile pictures. I was then able to entertain young children for hours, and they describe the pictures to me. I have now been using these books for 2 years to hear the slower readers in our local school. I had the joy the other week, of hearing one of my slowest readers, reading quite fluently.

I trained as a rehab worker for newly blinded adults and found Braille invaluable for making notes when interviewing clients. Using speech even through earphones is much more intrusive, as listening is so vital when discovering what people really need. I have travelled to Zambia to work with a school for the blind in Ndola and discovered that they need Braille writing frames, and now every pupil

at the school for 150 has their own writing frame.

I work with Bristol Braille technology to develop the Canute Console see their website www.bristolbraille.org. The Canute is 9 lines by 40 cells and was the first multi-line Braille display in the world. It is still the most affordable. Computer programming would be far easier with a 9 line display, and now we are developing Computer-aided design, Maths for an open University course, and mapping the constellations. I have also explored a city map of Bristol and Dublin and played Snake with the Canute Console. The RNIB have produced an SD card of around 6000 Braille books and these can all be read pleasurably on the Canute.

This all shows how many more job opportunities are open to blind people with the use of Braille. Braille allows me to keep track of my finances: I use it to read bank statements and other income mail and receive braille utility bills.

I use it to identify things around my home such as cans of peas or pineapple, shampoo and washing up liquid; Pharmaceutical companies put braille on drug packets, helping me to keep safe;

Braille helps me have an active social life including hymns for church, songs for our singing group, birthday and greetings cards, quiz questions, labelling plants in the garden, and vitally, a braille diary and address book at my fingertips keep me on top of my busy schedule and contacts quickly, discreetly and independently.

DAWN

Why are we teaching braille to a child with some sight? Good question. The simple answer lies somewhere in the answer to, why is the world still reading text? Why are we bothering to teach print reading skills to any child?

Curling up with a good book is a pleasure. Doing nothing but reading is a luxury. It doesn't feel the same to curl up with audible and just listen, there's something in holding the book and turning the pages. A brailist may need to sit at the table and use both hands or to sit cross legged with their book on a tray but the feeling of the page, the action of reading should be the same.

It's about freedom, independence and choice. The freedom to hear your own voice reading aloud or in your head. To rename characters with names you don't like, to give them accents of your own choosing, to determine

their attitude and style of delivery. To be independent of another person reading to you, making you feel small again, making you feel incapable, making you feel less than, making you feel disabled. The choice to use technology as a sighted person does or to read for ourselves. Why do I as a sighted person never have my laptop read a document to me? Why do I never give dictation? Why did I type this and not talk it? Why am I reading it back and not letting the tech read it to me? The answer to all these questions is the reason we teach braille. It's to give people with a visual impairment the same choice as sighted people have.

It is easier to learn the braille code as a sighted person. It is easier to learn anything when we are young and relatively free of responsibilities. So teaching braille to children with a degenerative condition is about future

proofing. It's also about time. It takes years to learn to be a proficient braille reader. The sooner we get started the more likely a child is to be proficient by the time they are an adult or by the time their sight finally and sadly goes completely.

Seeing with a visual impairment is exhausting, can cause pain around the eyes and can give you headaches. Learning braille gives you the choice to rest your eyes and still read. Few people choose to read braille but that is possibly because few children are encouraged to learn it. Things are different in the USA where braille is really encouraged.

The best solution for visually impaired people is the same solution that sighted people choose automatically without thought- a mixture of tech and books. For the visually impaired that means braille.

KIM AND SEAN

Our Member Services Manager Kim and tech volunteer Sean are both Braille users.

Kim says "For me Braille was the voices in my books, the words leaping off the page and my brain giving them sound. I always found it funny when I'd listen to something in audio and it wasn't how I'd imagined it myself at all! Late nights of reading - my parents having no idea because I didn't need the light. Being accused of cheating because my family believe I can read Braille through the back of a playing card (I can neither confirm nor deny this).

Braille was the name on my peg at primary, lunchtimes at secondary feeling included because my sighted friends wanted to learn how to write their names. Braille was being laughed at because I held my choir words upside-down against my stomach because it was easier to read and no one understood how! Braille gave me penpals, labels and many happy shared hours of reading with my daughter. While I'm more of a computer user these days, Braille screen input on my phone

means I can type messages as fast as anyone. Labels on pots avoid a rerun of accidentally trying to feed my family birdseed risotto once. It's games with the family, Christmas cards and happy memories. Braille is my language and I'm so grateful I have it."

Sean adds: "For me, Braille is privacy when using my phone. A way of typing accurately and fast on a glass screen, playing cards or games, and the language in which I think."

A heartfelt thank you to everyone who shared their stories and reflections. Your

experiences highlight the lasting impact of Braille and remind us why it continues to be such a vital tool for independence, learning, and connection. We're grateful for your voices and proud to celebrate this milestone together.



John's Story: MACS condition with autism and ADHD

"Seeing the World Differently: John's Story of Living with MACS, Autism and ADHD"



WHEN you first meet John, his warm smile and quick wit immediately put you at ease. He's got a cheeky sense of humour, a deep passion for the things he loves, and an extraordinary way of seeing the world. John is one of those people who radiates authenticity—he's unapologetically himself, and proud of it. But behind that easy-going exterior is a journey shaped by a rare eye condition and the complexities of being neurodivergent in a world that often expects people to fit inside neat boxes.

John was born with a MACS condition - Microphthalmia, which affects the development of the eyes. In his case, this means that one eye is smaller and has reduced vision. It's something he's lived with his entire life.

"I've always been partially sighted, so I don't know any different"

"I've always been partially sighted, so I don't know any different," he explains. "But it adds another layer to things—especially when combined with autism and ADHD."

While many people are understanding once they're aware, John explains that he's faced a lot of misconceptions—especially in school and healthcare settings. "People often treat each condition separately. They don't always think about how they interact." For instance, navigating a new environment can be doubly difficult when sensory overload from autism is paired with limited vision. "It's not just about being able to see—it's about processing the whole

environment. Bright lights, loud sounds, confusing signage—all of that can be too much.”

Growing up, John recalls that his differences weren’t always immediately visible to others. “It’s strange,” he says. “People often assume you’re fine because they don’t see the disability right away. But the truth is, living with visual impairment and being neurodivergent affects every part of my day, from how I move through the world to how I interact with people.” One of the biggest challenges for John was school. “Mainstream education just wasn’t built for someone like me,” he says frankly. “The noise, the lights, the rigid structure—it was overwhelming. And because I didn’t always understand what was being asked of me, or I’d miss visual cues, I was often labelled as difficult or disruptive.” When John reflects on his time in school, it’s with mixed feelings. “There were good bits and bad bits,” he says. “But mostly, I didn’t feel understood.”

He recalls struggling with focus in class, being told he wasn’t trying hard enough, or was being disruptive when in fact he was overwhelmed or struggling to keep up. “I wanted to do well. I was interested in things. But the way school worked just didn’t fit the way I think and learn.” One major barrier was communication. “I find it really hard to ask for help. Even now, I’ll sit there struggling before I say anything. In school, that meant teachers didn’t realise I was having a hard time.”

John’s ADHD added another layer to his experience. “It’s like having too many tabs open in my brain at once—each one trying to load something different. I’ll be thinking about five different things at the same time, and it’s not that my brain works fast, exactly—it’s more like it’s overwhelmed by trying to do too much at once. That can be a gift when I’m focused on something I love, but it also means I struggle with things like memory, attention, and organisation.”

As an autistic person, John also finds social interaction to be a bit of a minefield. “I like people, but social stuff doesn’t come naturally

to me. I find eye contact hard, and sometimes I say things that others think are blunt or random—but to me, they make perfect sense.” Despite these challenges, John is incredibly self-aware and has developed strategies to cope in a world that isn’t always accommodating. He values routine, clear communication, and environments that are quiet and low-pressure. But he’s also learned the importance of humour and creativity in navigating life.

One of John’s biggest passions is gaming. “Games help me relax and focus,” he explains. “I especially love games where there’s a clear goal or story. It’s immersive but also comforting—like stepping into a world where the rules make sense.” Being part of the MACS community has been transformative for John. “It’s the first time I felt like I belonged,” he says. “There’s something powerful about being with people who just get it—who understand what it’s like to navigate life differently. You don’t have to explain yourself all the time.”

“Speak up for what you need. It might be scary at first, but your voice matters. You know yourself best”

The MACS community doesn’t just offer social connection—it also offers practical support, shared experiences, and a safe space to be vulnerable. “It’s more than just a charity,” John says. “It’s a family.”

John is passionate about raising awareness of what it’s really like to live with MACS and to be neurodivergent. “People often have these stereotypes—like, if you’re blind, you must be totally in the dark. Or if you’re autistic, you must not feel empathy. That’s just not true. Everyone’s experience is different.”

He also wants people to understand that support isn’t about fixing people like him—it’s about meeting them where they are. “Give me the tools,



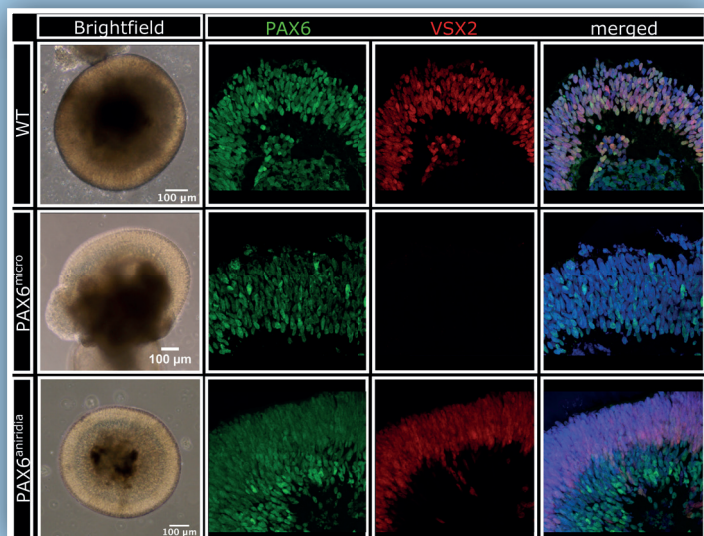
the space, and the understanding, and I’ll thrive. But if you judge me or try to force me to be someone I’m not, it’s not going to work.” One of the areas where John hopes for change is in the world of work. “It’s hard to get a job when employers don’t understand neurodiversity or disability,” he says. “They might think I’m not capable or that I’ll be too much work. But I have so much to offer—loyalty, creativity, attention to detail. I just need a bit of flexibility.”

When asked what advice he’d give to someone who’s just been diagnosed with a MACS condition, autism, or ADHD, John pauses thoughtfully. “Don’t be ashamed of who you are. It’s okay to be different. Find your people, do what makes you happy, and remember—you don’t have to do things the ‘normal’ way to be amazing.” He also stresses the importance of self-advocacy. “Speak up for what you need. It might be scary at first, but your voice matters. You know yourself best.” As our conversation wraps up, John reflects on how far he’s come. “There were times when I felt really lost,” he says. “Like I didn’t fit in anywhere. But now I know that it’s not about fitting in—it’s about finding places where you can be *you*.”

John’s story is one of resilience, humour, and radical self-acceptance. He reminds us that diversity isn’t something to be ‘accommodated’—it’s something to be celebrated. And while the world still has a long way to go when it comes to inclusion, people like John are paving the way for a future where everyone is free to be themselves.



Research Update



Here's an update from Pippa, who completed her PhD research on MAC (Microphthalmia, Anophthalmia, and Coloboma). She's recently had a paper accepted that explores the mechanisms contributing to microphthalmia, and she's kindly provided a summary of the findings in lay terms for this issue of Focus.

PAX6 is a crucial gene for early eye development. It acts as a genetic switch to turn on other genes which are needed to form the cells in the eye during pregnancy. Changes in the gene PAX6 can disrupt the formation of the eye,

leading to a range of different eye conditions, including aniridia, coloboma and microphthalmia. Interestingly, not all changes in PAX6 cause the same eye problems. Depending on where the change occurs in the gene, people can have very different symptoms. To better understand why this happens, we used stem cells derived from the skin of patients to grow 3D “mini-eyes” in the lab (called organoids). These mini-eyes mimic early eye development and help scientists study how different genetic changes affect the eye. We compared mini-eyes from patients with different PAX6 variants and eye conditions: one with a milder PAX6 variant (PAX6aniridia) and typical aniridia, and one with a more severe PAX6 variant (PAX6micro) who had microphthalmia, aniridia and optic nerve coloboma.

We found that the severe variant caused lower levels of key genes, including SOX2 (another gene vital for eye development associated with microphthalmia), as well as disrupted a pathway called Notch signalling, which helps control how cells grow and specialize. These disruptions were not seen in the milder case. This research shows us that not all changes in PAX6 act the same way, explaining why patients with different PAX6 changes can have very different symptoms. This is important for bringing research closer to developing more personalised therapies, based on the specific genetic cause of a patient's condition. It also helps us guide families on the prognosis so we can get the correct specialists in place to help maximise vision and prevent further sight loss.



COULD YOU SHARE YOUR STORY?

Help us improve support for MACS families through research

Hello! My name is Dr Jessica Gates and I'm a health services researcher at Northumbria University. I'm also a MACS parent—my young son was born with Microphthalmia in one eye. Like many of you, I've experienced first-hand the ups and downs of navigating the healthcare system and supporting a child with a MACS condition.

While there is important clinical and genetic research about MACS conditions, there is far less that focuses on the real-life experiences of families. I want to help change that.

I'm starting a small research project that will explore the experiences of parents and caregivers of children with MACS conditions. I'm looking to speak with MACS parents and caregivers (aged 18+) about:

- Navigating healthcare for your child
- The psychological and social impact of your caregiving role
- Your views on how healthcare could be improved for families like ours

Interviews will take place online or by phone and will be informal, friendly conversations. Your experiences could help inform future services, support, and research, and contribute to the existing academic literature on MACS conditions.

If you're interested in taking part, please feel free to contact me for more information:

jessica.gates@northumbria.ac.uk

Please note: Although I am also a MACS Trustee, this research is independent of the MACS Charity and is being conducted as part of my professional work at Northumbria University.

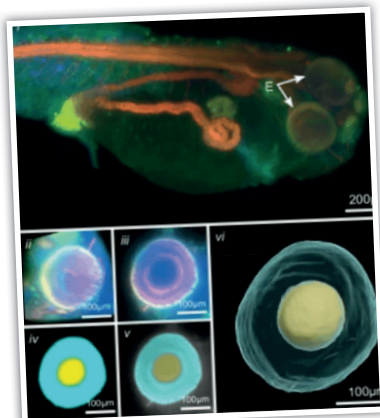
Any questions or comments should be directed to me directly, not to MACS staff. I'm very grateful to MACS for supporting this work and helping to share this invitation with the community.

Thank you for considering taking part—your story matters.



Professor Nicky Ragge – research update for Focus Magazine May 2025.

In this update on Professor Ragge's research in Oxford we'd like to tell you all about two newly published research papers from our team. We will also highlight our latest Vision for GoOD fundraising campaign, and give you a behind-the-scenes look at a recent conference we organised in Oxford to advance the understanding of genetic eye conditions.



Ragge team publishes breakthrough research on 'molecular switches'

The very high-profile journal, Nature Communications recently published our research describing new "gene switches" that control an important eye gene, MAB21L2. This paves the way to identify other important switches that may play a role in the development of

our eyes. In this paper, we describe our research where we identified "on-off switches" ahead of a gene called MAB21L2, which is already known to play an important role in how eyes develop. Here we studied the genetic code of a child born with microphthalmia. We identified a small piece of DNA missing - not from the gene itself, but from the area just before it. By studying this region in depth, we found that it contains regions of DNA that remain almost unchanged across different animal species and appear to act as molecular on-off switches.

Using zebrafish and frogs as model systems, we were able to show that taking away the equivalent piece of DNA caused similar eye problems, such as coloboma. We identified that specific sequences of the missing DNA were acting like switches, helping to control the activity of MAB21L2. We also found that one of these switches interacts with Otx2, also crucial for eye development. We showed that when we disrupt this tiny switch in frogs, the frogs also developed coloboma.

This research clearly showed that changes in the DNA around a gene - not just in the gene itself - can play a huge role in eye development. Our researchers have now started to look closely for more control switches for other eye development genes. We hope this will lead to more diagnoses for affected individuals and a better understanding of the complex pathways for human eye development.

The paper was written with our collaborators in Ghent, Toulouse, Wisconsin, Oxford and more and you can read it online.

Latest publication: GJA8 gene linked to eye disorders - International collaboration finds gene to help improve diagnosis.

In April 2025 the research team, together with international collaborators, published a study describing genetic variants in the GJA8 gene, which makes a protein crucial for eye development. We found 14 variants linked to eye disorders like cataracts, small or missing eyes, and corneal issues. The findings highlight important mutation hotspots and help improve diagnosis, treatment, and genetic counselling for affected families.

Vision for GoOD

Our Vision for GoOD campaign is to raise vital funds for research to understand the genetic basis of congenital eye conditions. Thanks to the existing support, Professor Nicola Ragge's team has already identified new genes and mechanisms involved in eye development —all important breakthroughs that make a difference to patients and families. Not only do we want to increase the research, but we'd also like to raise funds towards a dedicated centre.

By fundraising or spreading the word, you, too can play a key role in advancing this life-changing research. If you'd like to know more, or become involved in the Vision for GoOD campaign, please do drop us a line at:

admin@visionforgood.org

Sir Christopher Ball, 90, longstanding supporter for Vision for GoOD has finished a 10k run/walk on 17 May. One of the supported charities is Vision for GoOD research fund. Our goal, where we'd love your help, is to raise £1 for every metre he runs, £10K in total, you can still donate to this campaign.

5th GoOD Meeting, Oxford

We welcomed scientists and clinicians from around the world to our 5th Genetic of Ocular Development (GoOD) Meeting, in Oxford, England. This international conference brings together clinicians looking after people with MAC conditions and basic scientist working on eye development. As always the meeting was a great opportunity to start new collaborations for the Ragge team.

OUR RESEARCH CONTINUES

In 2025, Nicky's team will continue their work on new 'eye' genes linked to MAC conditions. We'd really love to hear from anyone interested in our study, and especially those with MAC conditions in both eyes, who haven't had a genetic diagnosis through the NHS. Your help could move our research forward and support your family and others in finding a genetic diagnosis. If you are interested, feel free to reach out to eye.genetics.study@brookes.ac.uk or call research coordinator Dorine Bax (01865 534923)

If you would like to request any of the papers mentioned in this article, please contact p0077867@brookes.ac.uk on behalf of the Genetics of Eye Anomalies Study.

Over £315,000.00 raised from London Marathon

2025 London Marathon Highlights!

2025



THE DAY kicked off at Greenwich Park where MACS staff and volunteers gathered to take photos and to wish our runners good luck before they went off to their start zones.

It was a hot day, which made this tough challenge, just that bit tougher, as many of our runners hadn't trained in such warm conditions. This resulted in many runners being unable to complete the race, including one of our

runners who made it to the 40Km mark (24.8miles) before succumbing to the intense heat.

MACS, staff and volunteers then split up with some going to the cheering point at 17mile and others to Horse Guards Parade, after the finish line. We also had a very special photo opportunity thanks to one of our runners, Tirath Chand, who arranged for us to have photos at Number 10 Downing Street.

Tirath Chand



I chose to run for MACS because their charity stood out to me. I wanted to run for a charity that the money I raised would make a huge difference and for MACS I done just that. I work with children in my day job and I just love to make a difference in children's lives especially those who have additional needs whatever that may be.

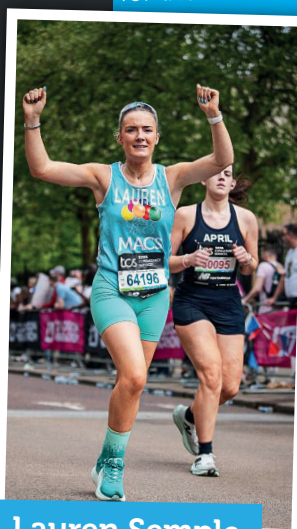
Running the London marathon was an incredible experience for me, never in my life have I experienced an atmosphere like it and it truly left me on a runners high. My favourite part was everyone shouting my name for the whole 26.2 miles as I had my

name on my vest. I felt so encouraged and motivated from the support of the spectators and I was so lucky to be a part of team MACS. The team from MACS were exceptional, their communication throughout was top notch and their support was unmatched! A massive thank you to team MACS!



Sarah Howard

Sarah Howard braved the heat as MACS the Monkey and did an amazing job, in spite of having to go off on a side quest to Halfords for a battery when the fan in the mascot's head had stopped working.



Lauren Semple

Here's what a few of our runners had to say about the event!

Taking part in the 2025 London Marathon was an incredible sporting experience and a true celebration of running. I chose to support MACS because I believe it's important to help those facing vision challenges - eyes are a symbol of freedom and discovering the world, and supporting this cause is especially meaningful to me.

As someone who runs the social media profile "World Marathoner," I love sharing my passion for marathons and connecting with the global running community. Being able to document my journey and inspire others is an important part of my running adventure.

This year's marathon took place on April 27th and brought together a record number of participants. The course led us through the most iconic parts of London-from Greenwich, across Tower Bridge, all the way to the finish line at The Mall near Buckingham Palace. The weather was particularly demanding; from early morning, the heat was intense and the temperature kept rising. Organisers issued warnings about the heat, and there were plenty of mist showers along the route to help runners cool down.

Because of the heat, I wasn't able to achieve my target time, but I still finished in 3:05:21-a result that gave me real satisfaction, especially knowing I was running for MACS and supporting such an important cause.

Despite the challenging conditions, the atmosphere on the course was fantastic-the cheers from the crowds, the energy from fellow runners, and the views of London's landmarks made every kilometre satisfying. It was a day full of positive emotions, the pure joy of running, and a real sense of community.

Before and after the marathon, whenever I wore my MACS singlet around the city, I truly felt like part of a special community. Meeting other runners and volunteers, exchanging smiles and congratulations, created an amazing sense of unity and support that stayed with me long after the race.



Bartosz

"...the atmosphere on the course was fantastic-the cheers from the crowds, the energy from fellow runners, and the views of London's landmarks made every kilometre satisfying."

The 2025 London Marathon was, above all, a great sporting adventure, a chance to meet people from all over the world, and an opportunity to support an important cause. Thank you to everyone who cheered me on and supported my fundraising for MACS-you made this day truly unforgettable.

I would love to come back to London and run this amazing marathon again.

Debbie McLoughlin



On Sunday 27th of April, while 152 MACS runners descended on London, there was a MACS supporter North of the border proudly wearing a MACS t-shirt as she embarked on a challenge of her own.

Debbie McLaughlin, took part in the Glasgow Kiltwalk in aid of MACS and raised a fantastic £300. Great job Debbie! **Well done!**

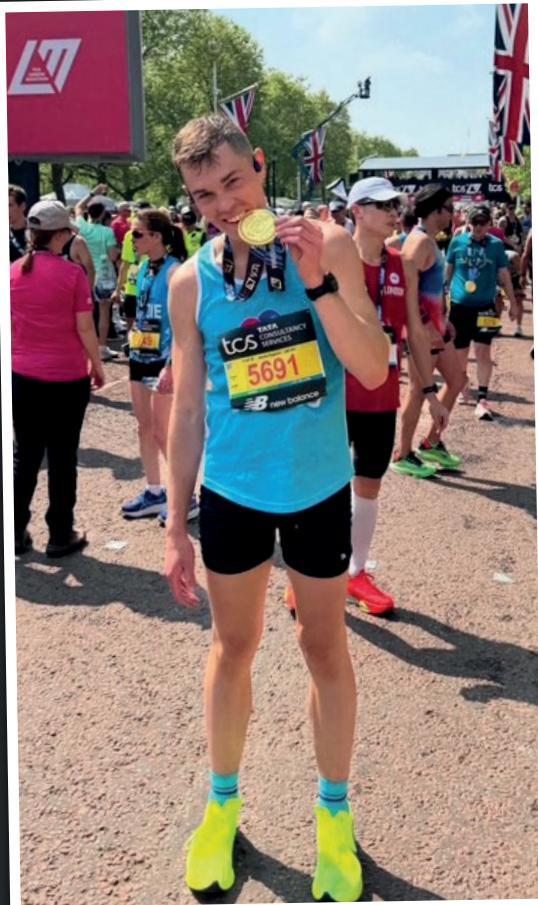
Lindsey Henry



Running the London Marathon had been a dream of mine for quite a few years and every year when the lottery would come, I wouldn't get selected. I was okay with this because I knew fate, timing and life were always at play and so with patience I knew one day I'd hopefully get the opportunity. After not getting it for the 2025 race I scheduled a much needed surgery for my chronic illness Endometriosis and it happened to fall on the week before the race. Time went on and I trained and did all of my RunDisney races throughout the running season. Then in early March I got a call that my surgery needed to be pushed back and then again pushed back a second time. Opportunity opened a door for me and so I went on the marathons website to learn about all the charities involved in the race. What initially drew me to MACS was the logo. The Disney movie Up resonates a lot with me and so then I clicked and learned more about MACS and eye health is also something super important and dear to my heart, so when John at MACS reached back out and said it was not too late for me to start fundraising and running for this incredible charity I got so excited! From the beginning of March to race day I was able to raise £2080 with the help of my friends and family and for that I'm so grateful.

Race day was what I had always dreamed of and more. The entire course was filled with onlookers cheering for you, your charity and wanting you to finish. Multiple times I teared up and just thought, wow, I can believe I am lucky enough to get to be here in this moment and do this. Happy tears again came as I crossed the finish line at Mall.

I still can't believe I got to experience this incredible race and to do it for such a great cause just meant everything to me. Thank you to John and the entire MACS team! I hope to be able to do it again one day!



Connor Scott

Having been based in the Windy City of Chicago, Illinois, it was truly an honor and a privilege to make the trip across the pond to run the 2025 TCS London Marathon in support of MACS. MACS's mission to provide emotional, practical, and community support resonates deeply with my commitment to uplifting those facing unique challenges. As a runner who had completed two world major marathons before London, I know the marathon's power to amplify meaningful causes, and running for MACS allowed me to raise awareness and funds for their vital work. Crossing the finish line on The Mall in London for my third world major was an incredible moment, and one that I will never forget. A big thank you to the entire MACS team for the opportunity and all of your support!



Lisette Wilkinson

THE QUEST

152 MACS runners strong,
We set off on Sunday, where we belong,
With hearts so true and spirits bright,
Together, we faced the sun's fierce light.

Sarah ran as the MACS monkey, a delightful sight,
With playful charm and cheeky grace,
She braved the heat, in that special place.

Sean ran with a wheelbarrow, quite a feat,
Pushing through the crowd, in the blistering heat.

In Mel's Place, I took my stand,
Honoring a legacy, so grand,
For Mel Gordon, whose spirit's bright,
I ran with love, I ran with pride.

For my son Parker, whose vision's dimmed,
I ran with love, my spirit brimmed,
Through miles and miles, I found my pace,
And crossed the finish with a smile on my face.

Despite a fall, I rose again,
With grit and strength, I felt the pain,
Injured and hurting, I pushed through,
Determined to finish, my spirit grew.

My watch and glasses, both did break,
Yet I pressed on, for Parker's sake,
With every step, I felt the strain,
But in my heart, I knew the gain.

With volunteers, a team so grand,
Together, we made a mighty stand,
And under John's watchful eye,
I stayed on course, reaching high.

For the first time, we met those,
With a condition like Parker's woes,
A community, a bond so strong,
In their presence, we felt we finally belong.

To Brent, Ashton, and Parker dear,
I say thank you, loud and clear,
For your support, your love, your cheer,
You made this journey, oh so near.

On the sidelines, you cheered me on,
With whistles blowing, my strength drawn,
With every shout, and every cheer,
You made the finish line so clear.

With tears of joy, I crossed the line,
A moment precious, so divine,
So here's to us, and our noble quest,
For Parker, I ran, and I gave it my best.

Regular Giving

We're so proud of the incredible community we've built together over the years – and your support makes it all possible. By becoming a regular giver, you can help MACS continue to be there for people born without eyes or with underdeveloped eyes, and the families who love and care for them.

Your monthly donation helps provide emotional support, practical advice, specialist equipment, and unforgettable experiences that bring our community closer and reduce feelings of isolation.

- ♥ £5 a month could help fund vital resources for families
- ♥ £10 a month could support local meet-ups and events
- ♥ £20 a month could go towards life-enhancing equipment

No matter the amount, your regular support makes a real and lasting difference. If MACS has been there for your family, or if you want to give back to others on a similar journey, becoming a regular giver is a wonderful way to do just that.

A MASSIVE THANK YOU!

A special thank you to The Charles Lewis Foundation

Did you spot the lovely addition on the front cover that this edition has been supported by The (amazing) Charles Lewis Foundation?

We love sharing with our funders just how much their generosity means, and how it has helped, and there's no better way to show the impact than hearing directly from the people they are hoping to reach – our wonderful members.

If Focus magazine has made a difference to you, we'd love to hear about it and share it with the Foundation. Whether it's a favourite article, a piece of advice that helped, or simply the joy of feeling connected to the MACS community, your words can help us show how much we appreciate their support.



It only takes a few lines - no need for War and Peace! Just drop us an email at enquiries@macs.org.uk and let us (and The Charles Lewis Foundation) know what Focus means to you.

Microphthalmia, Anophthalmia & Coloboma Support

Supporting People born without eyes or with underdeveloped eyes

To find out more about how MACS protect your data, and why we process your personal information, please visit www.macs.org.uk/our-policies.

Registered Postal Address: Microphthalmia, Anophthalmia and Coloboma Support, 71-76 Shelton Street, London, WC2H 9JQ
Registered charity number: 1161897 | Scottish charity number: SC052711





Microphthalmia, Anophthalmia & Coloboma Support

Supporting people born without eyes and with
underdeveloped eyes

Tel: 0800 644 6017 (Enquiries)

Tel: 0800 169 8088 (Members Support)

Web: www.macs.org.uk

Address: MACS (Microphthalmia, Anophthalmia
& Coloboma Support),
71-75 Shelton Street, London, WC2H 9JQ



Microphthalmia, Anophthalmia & Coloboma Support



The conditions



Introduction to MAC conditions

What are they?

Microphthalmia:

Microphthalmia, meaning "small eye," is a condition where a child may be born with one (unilateral) or both (bilateral) eyes that are smaller than usual and have anatomic malformations. While some children with this condition may be blind, others may have some residual sight or light perception.



Anophthalmia:

Anophthalmia means the absence of the eye. A child with anophthalmia may be born without one eye (unilateral) or both eyes (bilateral). In this condition, the eye socket develops differently, which can lead to features like smaller eyelids or changes in the shape of the surrounding area.



Coloboma:

Coloboma is a condition where there's a gap or cleft in one or more parts of the eye, like the iris, retina, or optic disc. It happens when a small gap in the eye, present during early development, doesn't fully close before birth. The effect on vision varies depending on the size and location of the gap - sometimes vision is unaffected, while in other cases, it may cause challenges. In very young children, it can be tricky to determine how coloboma impacts their vision, but doctors gain more insight as the child grows and more precise tests can be done.



How They Occur

The exact causes of **Microphthalmia** and **Anophthalmia** are not yet fully understood, but they are believed to result from disruptions in the developmental process as the eyes form during pregnancy. These disruptions may stem from changes in specific genes linked to eye development, with researchers continually identifying more genes involved in these conditions.

External factors can also influence how these genes work. For example, illnesses during pregnancy, such as chickenpox or rubella, or certain medications like thalidomide, have been associated with these conditions. Environmental factors, such as exposure to insecticides or fungicides, have also been linked.

Coloboma, on the other hand, occurs when part of the eye doesn't fully form during early pregnancy, leaving a gap or cleft in one or more of its structures.

Statistics

- Approximately **114 children** are born with MACS conditions each year in the UK.
- These conditions can involve **vision loss, developmental** challenges, or other congenital differences.
- To date, over **90 different genes** have been linked to various forms of MAC, highlighting the complexity of human eye development during pregnancy. Researchers are still uncovering the roles of many genes involved in this intricate process.