ISSUE 23 SUMMER 2026

FOCUS MAGAZINE

MACS
Microphthalmia, Anophthalmia & Coloboma Support

Microphthalmia, Anophthalmia & Coloboma Support

Supporting people born without eyes or with underdeveloped eyes

@macs.the.charity @macscharity @macsCharity linkedin.com/company/macscharity

Microphthalmia, Anophthalmia & Coloboma Support
Supporting people born without eyes or with underdeveloped eyes is a charity registered in England & Wales (1161897) Scotland (SC052711)

Contacts

Freepost address:
Freepost Plus RTYR–ZUUZ–AULL,
Partridges ATTN: MACS,
3 Eagle Avenue, Magnetic Park,
Desborough NN14 2WD

Family support & new member enquiries:
0800 169 8088

Information, fundraising support & media enquiries:
0800 644 6017

General enquiries:
enquiries@macs.org.uk

Fundraising support:
fundraising@macs.org.uk

Running events:
marathon@macs.org.uk

Registered Postal Address:
Microphthalmia, Anophthalmia and Coloboma Support, 71-75 Shelton Street, London WC2H 9JQ

TikTok: **@MACS.the.charity**
Facebook: **@MACSCharity**
Instagram: **@Macscharity**
LinkedIn: **linkedin.com/company/macscharity**

MACS MAGAZINE | ISSUE 23
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!

Art Editor: **Paul West**
Design: **Southeastwest Design**
www.southeastwest.co.uk

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 **enquiries@macs.org.uk**

Contents

Welcome from the Chair

WELCOME TO THE SUMMER 2026 EDITION OF FOCUS, OUR 23RD ISSUE!

As always, it is a pleasure to introduce another edition of our magazine and to reflect on some of the exciting developments taking place across MACS. This edition is packed with inspiring stories, achievements and updates from our members, volunteers, supporters and staff, all of which highlight the strength of our community.

It is also an exciting time for MACS as we continue to grow and expand the support, opportunities and events we can offer. As part of this growth, I am delighted to welcome two new members of staff to the team: Vikki Pritchard, our Regional Volunteers and Events Coordinator, and Jon Lyons, our new Fundraising Manager.

Both Vikki and Jon bring a wealth of experience, enthusiasm and fresh ideas to their roles, and we are thrilled to have them on board. As we continue to develop our events programme, strengthen our volunteer network and explore new fundraising opportunities, their contributions will help us reach and support even more families across the UK. Together, we are building a stronger and more connected MACS community, and I am excited to see what the future holds.

As you will see throughout this issue, there has been plenty to celebrate across the MACS community over the past few months. From the incredible efforts of our London Marathon runners and fundraisers, to the growing range of events bringing members together, the impact of our community continues to inspire me.

One of the things I value most about MACS is the way we support one another. Through initiatives such as Helping Hands, we are able to help members access opportunities, equipment and experiences that can make a real difference. In this issue, you will read about Zara Coote's remarkable journey in para-gymnastics, including her participation in national and international events. Stories like Zara's demonstrate the importance of ensuring that our members have the support they need to pursue their ambitions and achieve their goals.

Our events programme also continues to go from strength to strength. Whether through family days, coffee mornings, festive pantomime trips or larger events such as the Zog theatre trip, these opportunities provide a chance for members and families to connect, share experiences and build lasting friendships. Seeing so many members come together and support one another is always a reminder of what makes MACS such a special community.

As always, none of this would be possible without the continued generosity, energy and kindness of our members, volunteers, fundraisers and supporters. Your involvement is at the heart of everything we do, and it is what allows MACS to continue providing support, connection and opportunity across our community.

Thank you for being part of MACS. I hope you enjoy reading this Summer 2026 edition of Focus and all the inspiring stories within it.

Warmest wishes,

TERESA GORDON
Chair of Trustees

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.

Who's Who at MACS

We think it's really important that you get to know the people behind MACS. Our team works hard behind the scenes every day to support our members, and this section is a little chance to put faces to names and share a bit more about the people you might speak to, meet, or hear from across MACS.

Board of Trustees

Teresa Gordon
Interim Chair and Acting CEO
Contact: teresa@macs.org.uk

Sarah Hiley
Trustee and Treasurer
Contact: sarah@macs.org.uk

Gary Murphy
Trustee
Contact: gary@macs.org.uk

Rory Hallas
Trustee
Contact: rory@macs.org.uk

Dr Jessica Gates
Trustee
Contact: JessicaGates@macs.org.uk

Harvir Padda
Trustee
Contact: harvir@macs.org.uk

Ross Allen
Trustee
Contact: ross@macs.org.uk

Macs the Monkey
mascot
Contact: enquries@macs.org.uk

Staffing Team

Amy Francombe
Director of Charity Development
Contact: amy@macs.org.uk
07593021655

Member Services Team

Kim Randall
Member Services Development Manager
Contact: kim@macs.org.uk
07517861107

Clare Jones
Member Services Coordinator
Contact: clare@macs.org.uk
07921259635

Sharon Williams
Member Engagement Officer
Contact: sharon@macs.org.uk
07395280764

Vikki Pritchard
Regional Volunteers and Events Coordinator
Contact: vikki@macs.org.uk
07533944790

Fundraising Team

Jon Lyons
Fundraising Manager
Contact: jonlyons@macs.org.uk
07533944794

John Leadbeater
Supporter Relations Officer
Contact: john@macs.org.uk
07921259549

Emily Murphy
Trusts and Foundations Fundraiser
Contact: emily@macs.org.uk
07860778160

Communications & Outreach

Becky Bell
Communications and Outreach Officer
Contact: becky@macs.org.uk
07734954977

From Member to MACS Team Member!

Meet Vikki

Vikki joined MACS in January as our Regional Volunteer and Events Coordinator and has enjoyed getting to know the team and volunteers so far. Vikki first heard about MACS when her daughter Willow was born in 2023 with left-eye Anophthalmia and right-eye Microphthalmia.

"Through the first few months of the unknown and multiple hospital appointments, MACS became my safety and calm zone. Facebook groups meant we could ask questions, share our journey, rant if we needed to and we soon felt like a family and felt less alone. As things settled down, we started to look at the events on offer and attended our first Panto at Canterbury. It was so nice to be around others that knew what we were going through and what we were about. We then went bigger and attended Big MACS Meet up 2025 at Drayton Manor. What a special weekend we had, meeting other families and realising our future didn't look so daunting.

After this weekend I saw an advert for volunteers to host events in local regions, I really wanted to get involved and bring more members together. I hosted my first event in December at the local Panto.

It felt like a full circle moment, being able to attend and then Host so these events go ahead.
And then came another advertisement to join the Team at MACS and it was time for me to push myself further. The first few months have been amazing, getting to know more about the work MACS does for our members, working alongside an amazing team who are always there to support you. I am excited to be adding more Pantos this year across our regions and do look out for bigger events coming soon."

Away from MACS, Vikki is mum to Willow and her two older siblings. Home life is busy and full of adventure along the southeast coast in Deal, where they live with their two cocker spaniels and enjoy being out and about.

"When we're at home, I love being in the garden. We're hoping to get a greenhouse once the garden is complete so we can grow our own vegetables. I also enjoy reading, and we have our own family book club where we meet at each other's houses, discuss our latest reads, and share dinner together. I also love camping holidays and enjoy the slower pace of life they bring."

A warm welcome to Vikki from everyone at MACS. Thank you for all the enthusiasm, care, and hard work you have already brought to the role. We are delighted to have you on the team and look forward to shaping the future of MACS together.

Regional Volunteer Spotlight

We're really excited to shine a light on some of the amazing work happening across our regional volunteer network. Our volunteers play such an important role in bringing members together locally, helping to create opportunities to connect, share experiences, and have fun in their communities.

In this edition, we're hearing from **Sarah**, who has been helping to coordinate local meet-ups and support activities in her area and has already been making a brilliant impact.

Hi, I'm Sarah. I've recently volunteered with MACS to help coordinate local meet ups (I live in Warwickshire, but very close to Leicestershire too). I'm a MACS member as my daughter Freya, now 3, was born with Microphthalmia and Colobomas. It's really important to us that Freya meets children and adults with the same MAC conditions she has, and this is why I volunteered with MACS. I've also just run the 2026 London Marathon for MACS, which I'm incredibly grateful I got to do. Here's a picture of myself, my husband Chris, our eldest Charlie, and Freya after the marathon.

Children at the Zog Threatre Trip

We were involved in the casting of Baby Jimmy in Eastenders

MACS members at the Northern Ireland event/meet-up

The Services Spotlight, what have we been up to?

At MACS we thrive on being busy, but also on collaborating with other organisations, sharing opportunities, and providing information that benefits our community.

Alongside our Northern Ireland meet-up and Zog theatre trip, we've been working hard to reach as many members as possible.

In February, we were delighted to be invited by the RNIB to present to their Northern Ireland members. We approached this with a mix of MACS professionalism and the direct lived experience of our members. The evening was thoroughly enjoyed by all, and we're pleased to welcome new families to MACS as a direct result.

Following this, we were invited by the RNIB to present to a group of professionals, reaching over 200 people who work directly with our members and equipping them with information and insight to support families and signpost to MACS.

We've provided parent/carer talks so far on "stepping back" letting your child lead the way, accessible story time and a fantastic update from Mariya Moosajee and her team. Looking ahead, we have further talks planned on EHCPs, autism and visual impairment, encouraging independent living skills in teenagers, and much more.

We've been involved in a direct call-out to cast the latest Eastenders actor to play baby Jimmy; shared opportunities from VICTA and Seable, which resulted in one of our members being accepted for a fantastic opportunity to travel, and complete a course in furthering independence skills. Now we find ourselves heading into the busiest half of the year.

> '...we were delighted to be invited by the RNIB to present to their Northern Ireland members.'

Behind the scenes we're always looking at ways to improve and streamline services, as you'll see from our "membership update" in this issue.

Membership Update: Important Changes Ahead

We're excited to be launching an important membership update at MACS. While this may cause a little inconvenience for some of our current members, we believe this is a vital step in helping us support and reach as many people living with MACS conditions and parents of children with these conditions as possible.

In February, we were delighted to be invited by the RNIBMACS has grown and evolved hugely over the years, and with that growth our membership records have naturally become varied. Alongside changes to GDPR regulations, we recognised the need to review and refresh our records to ensure they are accurate, up to date, and working effectively for both our members and our charity.

To help us do this, we will be asking all members to complete a new membership form. This update will help us strengthen our records, improve communication, and ensure we can continue providing the best possible support to our community.

What this means for you.

If you have not received an email with a link to the new membership form by the end of August and believe you should have, please contact **enquiries@macs.org.uk** as soon as possible. Please note, this update does not affect professional memberships or Friends of MACS.

In order to remain a MACS member, you will need to register again as a new member. While we understand this may feel frustrating for some, our current records are limited in places, which can make it difficult when organising events and ensuring we have up-to-date information for attendees. In some cases, we only hold an address or an old telephone number, meaning we have no reliable way to get in touch.

Under our previous system, only one person per household would receive newsletters or updates. We have received feedback that many members would like the option for multiple over-18s within a household to subscribe. This is now possible under the new system.

At present, some over 18's have become a little lost in the system, still linked to a parent or carer's account. As we expand our offerings for adults, it is important that we are able to reach you directly and share relevant opportunities, all with the correct permissions in place.

We really appreciate everyone's patience and support with this process and would like to reassure you that once complete, this will create a much clearer and easier system for us all.

If you have previously noted preferences regarding magazines or email updates, please include these again on the new form so your records can be updated with minimal disruption.

If you have any questions, please do get in touch via our enquiries email. We are grateful for your support as we complete this important project and move into the next phase of MACS.

Calendar of Events

There's lots to look forward to over the coming months! From family events and meet-ups to awareness days, online sessions, and festive celebrations, we're excited to share our upcoming calendar of events from July through to January 2027. We hope to see as many of you as possible throughout the rest of the year!

July 27th – 31st
Calvert!
An adventurous outdoor activity break designed to build confidence, independence, and friendships. For those aged 10-18 including siblings. We are able to support those with complex care requirements and have a full care team in attendance.

August 6th – 11th
Sailing
Our MACS sailing voyages help young people build independence, confidence, and friendships while learning new skills and, most importantly, having fun! Delivered in partnership with Ocean Youth Trust South, the voyage supports teamwork, communication, responsibility, and perseverance, while helping young people grow in confidence through new and unfamiliar experiences. For those aged 16-25 including siblings.

August 10th – 14th
Jamie's Farm
A residential experience at a working farm, where young people take part in a structured programme of farming, animal care, cooking, and outdoor activities. The week is designed to support confidence, wellbeing, connection, and a sense of belonging in a safe and supportive environment. For those aged approximately 13-16 with some flexibility around this.

August 14th – 15th
Mersea
A short residential break packed with fun outdoor activities such as archery, climbing, and obstacle courses. A chance to enjoy group sessions, shared meals, and time to connect with other members. For anyone aged 8 and over, adults included. Wheelchair accessible activities available.

August 21st – 23rd
Big MACS Meet-Up
One of our biggest community weekends of the year, bringing families and members together from across the UK. A chance to connect, take part in activities, and share time together. Not to be missed!

September 5th
Quiz!
A fun online community quiz open to all members and families.

September 9th
New Members Zoom
A friendly online session for new members and families to meet the team and connect with others in the community.

September 21st – 27th
MACS Awareness Week
MACS Awareness Week is our annual opportunity to raise awareness, share stories, and celebrate the amazing MACS community. This year we'll be 'Monkeying Around' as we come together to spread awareness, make sure to get involved!

October 7th
MACS Morning Coffee
An informal online catch-up over a cuppa with fellow members and families.

November 11th
New Members Zoom
A welcoming online session for new members and families to connect, share experiences, and learn more about the MACS community.

November 28th
Quiz!
A fun online community quiz open to all members and families, including MACS has talent online show.

We are thrilled to bring you a line-up of festive favourites Pantomimes this year, with Audio Described performances and Touch Tours where possible so that everyone can join in the magic, laughter and fun.

December 5th – 6th
MACS Scotland
Meet-Up & Panto, Aladdin
A festive Scotland meet-up including Saturday activities, evening meal, overnight accommodation, breakfast on Sunday, and a trip to the pantomime to round off the weekend.

December 5th – 6th
MACS Wales Meet-Up & Panto
Beauty and the Beast
Get ready for a fun-filled weekend with the MACS community in Wales! We're bringing families together for a weekend packed with activities, great food, laughter, and a magical theatre trip to see Beauty and the Beast at Cardiff New Theatre.

Both of these events have flexible attendance. If you would prefer to attend only part of the weekend such as the pantomime only, or the activities and overnight stay, please let us know when completing the booking form.

December 6th
Manchester Panto,Dick Whittington
Manchester Opera House
An action-packed production starring comedy sensation Jason Manford and panto favourite Ben Nickless.

December 9th
MACS Coffee Morning
A relaxed online festive coffee morning for members and families to come together and chat.

December 13th
Bristol Panto, Sleeping Beauty,
Bristol Hippodrome
The Pantomime of Dreams starring Strictly come Dancing judge Craig Revel Horwood and Bristol's panto favourite Andy Ford

December 21st
Chesterfield Panto, Beauty and the Beast
Awarding winning little wolf entertainment brings this absolute beast of a furry-tail adventure to Chesterfield, staring local Matthew Siveter as Dame Betty Bon Bon.

December 29th
Southampton Panto, Robin Hood,
Mayflower Theatre
Join Ashley Banjo, Diversity and Max Fulham as they return to Southampton for the most heroic panto of them all, Robin Hood!

Saturday 3rd January 2027 13:00pm
Dunstable Panto, Snow White And The Seven Dwarves
Grove Theatre
for an Audio Described performance of Snow White and the Seven Dwarfs starting Eastenders legend Natalie Cassidy and Viper from BBCs Gladiators

January 3rd 2027
Canterbury Panto, Peter Pan
Marlowe Theatre
Flying to the Marlowe Theatre for 2026, Peter Pan. Starring local legend Ben Roddy, more cast to be announced...

January 16th 2027
Birmingham Panto, Sleeping Beauty,
Birmingham Hippodrome
Dreams will come true at the UKs biggest regional Pantomime starring presenter, radio DJ and podcaster Rylan, local legend Matt Slack, West end star Zoe Birkett and Birmingham's favourite Dame Andrew Ryan.

MACS

Microphthalmia, Anophthalmia & Coloboma Support

Introducing Our New MACS Logo

At MACS, we are always growing. As our community continues to evolve, so too does the way we present ourselves to the world. This year, we are pleased to share something that reflects that journey, our updated MACS logo.

This change is not about moving away from who we are. Instead, it is about making sure our identity truly reflects the MACS of today, while still honouring the history and meaning that has brought us here.

'The previous MACS logo has been a much-loved part of our organisation for many years.'

The previous MACS logo has been a much-loved part of our organisation for many years. For many members and families, it holds memories, familiarity, and a strong sense of connection. We recognise and value that deeply. It has represented MACS through years of growth, community building, and shared experiences, and it will always remain an important part of our story.

However, as MACS has grown, so too has our understanding of how we best represent our community. Over time, it became clear that our previous logo no longer fully reflected the breadth of who we are today, or the range of conditions we support. As awareness has grown and our community has expanded, we wanted our visual identity to better represent that diversity and ensure MACS is clearly and confidently recognised.

The updated logo has been developed with this in mind. Designed by Paul at Southeastwest Design and guided by our Trustees, it is part of a gradual and thoughtful evolution of the MACS brand, rather than a sudden change. MACS has been slowly developing its visual identity over time, and this new logo brings that journey together in a more unified and intentional way.One of the key aims of the new design was representation. MACS supports people of all ages as well as their families living with Microphthalmia,Anophthalmia, and Coloboma, and it was important to us that this is better reflected visually.The updated design has been created to feel more inclusive, clearer, and more representative of the community we support every day.

Alongside this, accessibility and clarity were also important considerations. As MACS continues to grow its digital presence, events, and printed materials, it is essential that our logo is clear, adaptable, and easy to recognise across all platforms. The new design helps support this, ensuring MACS remains visible and consistent wherever people engage with us.

As one member of the team reflected:

"This logo reflects not only who we are today, but where we hope to go together."

This sense of shared direction is central to everything we do. MACS is, and always will be, a community-led organisation. Every step forward we take is shaped by the people within it, members, families, volunteers, and professionals working together to create something meaningful and lasting.

We hope that over time, the new logo will feel familiar, and that it will come to represent the same warmth, support, and connection that MACS has always stood for. While it may look different, its purpose is the same, to bring people together, raise awareness, and support everyone affected by MACS conditions.

Change is never just about what something looks like. It is about what it represents.

A Warm MACS Welcome

Here we are delighted to introduce some of our newest MACS members. These short introductions have been written by parents and carers and offer a personal insight into their experiences as they begin their journey with MACS. Welcome!

LILY

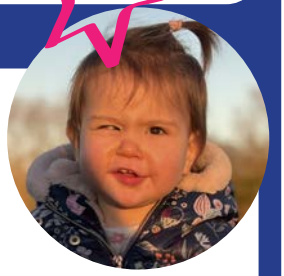
This is my little Lily who was sent as a little miracle from heaven by her nanna, she was born at 38 weeks weighing 6lbs4oz.

We noticed at birth Lily's eye was much smaller and mentioned it a lot to the midwife, We finally were referred to Great Ormand Street and had Lily's results last Friday, she is now 7 months.

It was confirmed Lily has very little vision in her left eye and can probably not see much in this eye due to Coloboma and Micro, she has good vision in her right eye but still has Coloboma but not as severe in her right eye.

She still amazes me everyday and although it's a lot to take on board, joining MACS on Facebook and speaking with a lot of people has really helped me understand, we are still learning everyday as are her big brother and sister as this is all new to us to.

But to us she is perfect.



INDIANA

This is Indiana.

We are new members to MACS after she was diagnosed with microphthalmia in her left eye recently, along with other eye conditions.

MAGGIE

Our daughter, Maggie, joined our family in November and was diagnosed with unilateral anophthalmia at 6 days old.

We quickly found MACS after some frantic googling, joined immediately, and were so warmly welcomed into the fold.

We found the members Facebook group really useful and thank everyone who has shared their stories, advice and photos as it has provided a lot of clarity and hope for the future.

We look forward to meeting others at the Big MACS meetup in August! Much love from Kathryn, Sam, Joey, and Maggie.

ADA

Ada is our beautiful nine-month-old daughter. She was diagnosed with bilateral chorioretinal colobomas affecting her macula and optic nerve and also has a degree of hearing loss.

Ada continues to thrive each day and is such a happy little girl who loves exploring the world around her. She enjoys swimming, is sitting up, feeding herself, and has recently started saying "mama".

She adores her big sister Evie, who is two, and her big brother Jacob, who is four. Although we haven't attended a MACS meet-up yet, the Facebook and WhatsApp communities have been such a wonderful source of support for our family, and we are so grateful to be part of the MACS community.

Zara Coote: Shaping the Future of Para-Gymnastics

With support from MACS Helping Hands, Zara is competing on the international stage and helping shape the future of her sport

MACS Member Zara Coote is a visually impaired para-gymnast who has recently competed on the international stage in Leipzig, Germany, as part of a para-gymnastics showcase and inclusion competition.

Supported by MACS Helping Hands, Zara travelled as part of a UK team alongside gymnasts from City of Glasgow Gymnastics Club and other international athletes from countries including Germany, Estonia and the USA. The event brought together para-gymnasts as part of wider work to develop and test new ideas for the sport.

As part of her journey, Zara shared her thoughts on competing internationally, her experiences in para-gymnastics, and what the sport means to her.

WHAT DOES IT MEAN TO YOU TO COMPETE IN SPACES WHERE PARA-GYMNASTICS IS VISIBLE ALONGSIDE OTHER GYMNASTICS DISCIPLINES?

"I don't feel as though I'm different to everyone else. We all train in the same way and it's the same process for everyone, and it's motivating seeing the level of skill from the mainstream gymnasts."

Q&A WITH ZARA COOTE

HOW DID THE HELSINKI SHOWCASE SHAPE HOW YOU SEE YOURSELF AS A GYMNAST?

"I felt pressure, but in a good way. There were more people and it was a different country, but I felt like I had achieved something quite big."

HOW HAS BEING A PARA-GYMNAST INFLUENCED YOUR SENSE OF IDENTITY, BOTH IN SPORT AND EVERYDAY LIFE?

"I can't ever see myself doing another sport or not having gymnastics. I look forward to training every week and every spare moment I find myself doing gymnastics — even if that's doing cartwheels down the aisle of a supermarket."

"MACS is such a special charity to our family and has been close to our hearts since Zara was little."

DO YOU FEEL YOUR PRESENCE IN THE SPORT HELPS CHALLENGE PERCEPTIONS OF DISABILITY?

"Yes, I feel like it does. A lot of people assume I'm incapable of doing everyday things, so it feels good to show people what I'm capable of and to prove people's expectations wrong."

WHAT IMPACT WOULD YOU LIKE YOUR JOURNEY TO HAVE ON OTHERS?

"To show that you should always give things a try as you don't know where it can take you. I didn't think I would have gotten to this point when I started gymnastics, so I'd love to show people that even if you have a disability, it doesn't hold you back."

Zara's recent experiences in para-gymnastics have taken her from local training halls to national and international trial events that are helping to shape the future of the sport.

The first of these came in Liverpool at the British Gymnastics Championships, where British Gymnastics delivered a trial para-gymnastics event as part of its work to test proposed competition rules in a real-world setting. The aim of the trial was to better understand how scoring systems and classification structures could work in practice as the sport continues to develop.

Zara later travelled to Leipzig, Germany, to take part in a Para Gymnastics showcase and inclusion competition held on 1 May. The event brought together para gymnasts from across the UK, Germany, Estonia and the United States, with athletes performing routines as part of ongoing work to develop a draft Code of Points for the sport.

Zara was one of only a small number of gymnasts with a visual impairment trialling routines at different levels, contributing to the testing of emerging competition rules. She performed strongly across the competition, earning two gold medals and one bronze, as well as achieving top-five placings across all apparatus.

Alongside these competitive milestones, Zara's family have highlighted the wider impact of these opportunities and the role MACS has played in making them possible.

In a message shared with MACS, Zara's family expressed their gratitude for the support that helped her travel to Leipzig:

"We wanted to get in touch to say a heartfelt thank you for the support MACS gave to help Zara travel to Leipzig, Germany, for the Para Gymnastics showcase and inclusion competition on May 1st."

They added that MACS has been part of Zara's journey since childhood, describing the charity as a source of confidence, community and belonging:

"MACS is such a special charity to our family and has been close to our hearts since Zara was little. From those early family weekends and meeting other families who truly understood our journey, to the wider support and encouragement over the years, MACS helped give Zara confidence, community, and an extra sense of belonging at such an important stage in her life."

Reflecting on the experience, they shared how significant the opportunity was for Zara's development both as an athlete and as a young person:

"Beyond the achievements themselves, what means the most is seeing Zara flourish - building confidence, independence, friendships, and believing in what she can achieve. The support of organisations like MACS has played such an important part in helping make that possible."

Zara also shared her own message of thanks:

"Thank you for providing me with this money and support — it means a lot — because if we didn't have it we would struggle to go. Taking part in events like this is helping inspire other young people taking part in disability sport."

As para-gymnastics continues to develop, trial events like those in Liverpool are helping to test and refine how the sport may work in the future, alongside international opportunities such as the Leipzig showcase. Together, these experiences are shaping both the competitive and developmental side of para-gymnastics, while giving athletes like Zara Coote the chance to be part of that journey.

For Zara, these moments reflect a sport she is deeply committed to, one built on enjoyment, progression and opportunity. With support from MACS Helping Hands, she has been able to take part in both national trials and international competitions, continuing to develop her gymnastics while showing what can be achieved when opportunities are made accessible.

Zara's journey is a brilliant example of what can happen when talent, determination and opportunity come together. Everyone at MACS is incredibly proud to have supported her along the way and can't wait to see what she does next.

Member Milestones!
Highlights from our community

Welcome to our Member Highlights! We absolutely love celebrating the amazing achievements, milestones, and memorable moments!

Many of these updates have been lovingly sent in by very proud parents, carers, family members, and friends, making them even more special to share. Every story, no matter how big or small, deserves to be celebrated and we are so proud to share these special updates with you all.

Thank you to everyone who contributed to this issue of Focus. We'd love to include even more member stories and photos in future editions, so please keep sending them in!

LEWIS

Lewis is making amazing progress at his new residential placement at The Royal National College for the Blind in Hereford. It's been a rollercoaster for sure, such a huge transition for him, but Lewis is doing so well and is settling in.

Academically Lewis is flying, as well as learning new independent living skills, passing mobility sessions and trying lots of new activities including finishing as league champions in the college Goalball team. So proud of you Lewis, a role model to all younger MACS children, you can do it all.

CHARLIE

After a difficult start to secondary school, Charlie has gone from strength to strength in his first year. He has embraced every challenge thrown at him and has worked incredibly hard throughout the year.

We are so proud that he was awarded a sports scholarship, which is a real testament to his dedication and commitment. Charlie trains for football five times a week and is developing into a talented footballer. His determination to keep improving and pushing himself shines through in everything he does.

RONNIE

Ronnie turned one in May!

He's roaming furniture, walking while supported and all his other milestones he's got when he's supposed to! waving bye, clapping, first proper word "ball" as well as mum and dad. Enjoyed the two sunny days we got in Scotland.

A DREAM COME TRUE

Hi I'm Christina. Age 24. For the last five years my dream was to buy my own house.

I wasn't sure if I could make that dream come true. Two weeks ago that dream finally came true and I'm happy to say I'm a home owner. Thank you for the support and confidence I have had from the community around me (MACS, family and friends)

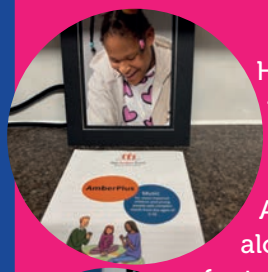
MAEVE

Maeve is up and walking and has received her first cane, there's no stopping her now! She's also transitioning into the big room at nursery and is taking it in her stride! We are so proud of you Maeve.

AVIYAH'S A STAR!

Aviyah is now a teenager, aged 15!
At just 8 weeks old, Aviyah featured in Love It magazine, helping to raise awareness and promote MACS

More recently, Aviyah signed up to the **AMBER Plus Programme** and has already had a special spotlight moment with Derek Paravicini, the extraordinary pianist and musician who is totally blind, has a learning disability, and is on the autism spectrum.



Here are some of Aviyah's milestones:

1. Against all odds, Aviyah can now stand up alone and no longer wears foot splints. She has worked incredibly hard through many hospital visits and fittings to reach this milestone.

2. Aviyah has been canoeing.

3. Aviyah has been rock climbing.

4. Aviyah now uses only her wheelchair 60% of the time at school.

Well done Aviyah!!!

FLO

Flo's milestone is learning to slalom ski, and she's really flying!

Look at her go!

HARLEY

This is Harley trying his very first balance bike, it was such a proud moment for us. Harley has coloboma affecting his iris, retina, and optic discs, so things that might seem small to others can be huge achievements in our world. Seeing his confidence grow, his smile, and his determination reminds us that children really can achieve amazing things when given the chance, support, and encouragement to try.

LUKE

Luke re-submitted his RSL Level 2 Extended certificate in the creative music industry - production and gained a merit with Sound Communities an independent provider in Torbay. He was also featured in their Positive Impact Report.

The iPad he received from MACS through the Helping Hands grant scheme helped him practice and research from home while working towards this achievement. Thank you.

This QR Code links to Lukes Youtube channel where he uploads his created music:

DYLAN

Dylan all dressed up and ready to attend his year 11 prom. So grown up!

KEIRA

Keira has been learning violin for a year now and she just had her first small recital at Ulster College of Music.

BEN

My name is Ben and I have severe microphthalmia in my right eye. I wear a prosthetic as I have no vision in this eye. My left eye has some useful pinhole vision due to Peters Anomaly.

I wanted to say I am very proud of myself and so are my parents and family as I have not long ago completed 12 Marathons in 12 Days from the 26th March until the 6th of April.

It was very hard on some of the days, but there were lots of others taking part and doing different distances, so we all kept each other going. I had lots of fun, we did some days as dressing up, Tutu Tuesday was my favourite.

I really enjoy running as it helps me meet other people and shows that I don't let my vision, or anything else, stop me. On some courses I have a guide, but on short out-and-back routes I can run independently.

I am still continuing with my running, so far I have completed 116 half marathons, 181 marathons, and 15 ultras. Let's see what the rest of the year brings.

LAURA'S MILESTONES

1 Laura's dream came true! She went to Disneyland and met Mickey and Minnie in person. It was truly one of the happiest moments of her life and a dream come true for her.

2 Laura is absolutely thriving in climbing activities. Her dad is a climber, and she has impressively overcome her fear of heights. Through climbing, she has been developing confidence, resilience, safety awareness and trust in herself, while continuously improving her technique. Most importantly, she is having so much fun and discovering just how capable she is.

3 Laura achieved Stage 2 in swimming. Swimming is one of her favourite activities, and she absolutely loves being in the water.

4 Laura achieved a Braille certificate, which has been a very special and meaningful milestone in her journey.

5 Laura performed at a music festival through Bexley Music Academy as part of the choir. She loves singing and music brings her so much joy and confidence.

6 Laura joined the Pony Club and has now completed another wonderful year of dedication to horse riding, something she truly enjoys and looks forward to every week. prom. So grown up!

RUDY

Rudy has recently had to have an NG tube passed due to us finding out his swallow reflex doesn't work correctly and it's taken him some getting used to but he's doing really well with it, he's been doing really good sitting up again which he'd only just started to master before getting his tube and stopped to do for a bit, he's enjoying exploring new things like his first time in a little tikes car, he's responding really well to be ming told instructions like hold on or no (if he's trying to pull his tube or hearing aids) and even his name, he's also started blowing raspberries now, along with clapping it's one of his favourite things to do at the moment

OLIVER

Oliver has completed learning both uncontracted and contracted braille. Just in time for high school which he starts in August. Oliver says he is very proud of himself.

AIDEN

Aiden was nominated for an award at the Active Dundee sports award 25-26. Having being successfully shortlisted from many applicants for the Jenny Wood Allen Memorial trophy for his outstanding achievement in swimming at both local and national levels. He was invited to attend the awards evening yesterday at the Apex Hotel along with 3 others successfully shortlisted nominees in his category.

Aiden was then selected as this year's winner.

The Jenny Wood Allen memorial trophy is an award that celebrates the hard work and dedication in sport from athletes with visual, hearing, physical or learning disabilities.

This is such an achievement for Aiden as shows that even with his diagnosis of bilateral Microphthalmia and coloboma and being registered as having a severe sight impairment that anything is possible with hard work and commitment.

AMAZING LILY!

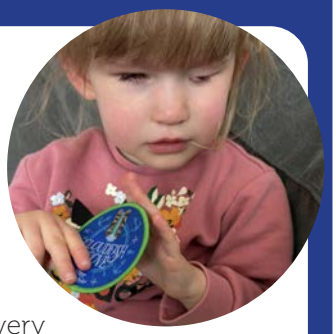
My Lily is the most amazing, brave girl and I am so proud of her. She really is a ray of sunshine and brings such joy to everyone she meets.

Lily is at the age where children are starting to notice her Coloboma and are commenting. I wanted to continue to show her how special her unique beautiful eye is and that there are other children with the same special eye she has.

By taking on the challenge of London I was able to raise awareness of colobomas and the other conditions MACS supports.

Thanks to MACS for letting me be part of team MACS and for all your support.

WILLOW



Willow has been swimming since she was 6 months, with waterbabies and this week she added to her badge collection. She has always been very shy at swimming, but all of a sudden her confidence has grown and she jumps of the side no fear, she is pulling herself along the wall holding on by herself. It's been so great to see her joining in with her peers to the same level.

BODHI

Bodhi has graduated from Year 7 and will officially start Year 8 in two weeks. He has tackled Year 7 head-on with strength and resilience that has amazed us. In spite of his visual impairment, autism and ADHD, he has learnt new routines, met new people, and faced environments he finds challenging.

He has approached this past year with resilience and grace, and has also received recognition from his teachers for the support and encouragement he has shown to his friends.

He is the most amazing boy and we can't wait to see what Year 8 brings.

His very, very proud mum and dad.

Congratulations! To all of our Stars.

Helping Hands

At MACS, we are proud to support members by helping fund equipment, resources and opportunities that can make a real difference to everyday life, independence and personal development.

So far this year, we've been delighted to help fund a range of items and opportunities, including:

- **A tandem bike**
- **Music lessons**
- **iPads**
- **A computer**

Many of these grants are made possible through dedicated funding pots provided by our generous funders, alongside money raised through MACS fundraising activities and the incredible support of our community.

We know that the right equipment or opportunity can open doors and help members build confidence, develop new skills and enjoy greater independence.

At the moment, we also have an exciting opportunity to provide a copy of JAWS to one of our members. If you would like to apply for this, or find out more about the support and funding available, please visit our website or contact the enquiries team.

ZOG at Warwick Arts Centre

A Magical Day Out

Our recent regional event, hosted by volunteer Sarah Wainwright, brought a real burst of magic to the weekend with a trip to see Zog, the much-loved stage adaptation of Julia Donaldson's classic story.

On Saturday 23rd May, members gathered at Warwick Arts Centre to enjoy the feel-good tale of the keenest dragon in Madam Dragon's school. Full of humour, heart and adventure, the production brought the story to life beautifully through creative puppetry and joyful songs, capturing the imagination of both children and adults alike.

It was a lovely opportunity for members to come together, share a special outing, and enjoy a relaxed social day out as part of the MACS community. Members shared how much they enjoyed the experience, with one commenting, "The show was great and it was lovely to see so many members."

A big thank you goes to Sarah Wainwright for hosting the event and making the day possible for everyone who attended.

If you have an idea for an event, or would like to host something yourself, we'd love to hear from you.

> **"The show was great and it was lovely to see so many members."**

Please get in touch with us at enquiries@macs.org.uk and we can explore it together.

COMMUNITY FUND

This event was made possible thanks to players of National Lottery.

Panto Reports: Festive Fun for 140 MACS Members!

In December 2025 and January 2026, over 140 MACS members enjoyed a series of festive pantomime trips filled with laughter, excitement and plenty of Christmas magic.

We always love hearing your feedback, and it's wonderful to see the memories and connections made through these special events.

At the Chesterfield *Jack and the Beanstalk* pantomime, families came together for a fantastic touch tour ahead of the performance. Members had the chance to explore props and costumes, meet members of the production team, and experience the magic of the show in a hands-on way. The audio description helped make the performance even more accessible, creating a memorable evening for everyone involved.

Comments from members included:

"We've all had such a good time. Before we came, it was hard to get the boys to come with them being teenagers. My son said, 'Don't expect me to come next year!' We sat next to a family with a boy about six, and he was so excited. My boys thought it was wonderful. Afterwards, my son said, 'I'd still like to come next year.'"

"Thank you for a lovely evening spent at the pantomime. It was wonderful to see our daughter engage in the performance after attending the touch tour beforehand. The journey to and from the theatre, exploring props and costumes first-hand, and the spontaneity of it all created such a fun atmosphere and made lots of special memories. During the touch tour, we also connected with another family with a similar diagnosis, without these meet-ups, this wouldn't have been possible."

Families from across Kent and beyond also came together to enjoy Canterbury's *Snow White and the*

Seven Dwarfs. With plenty of laughter, silly jokes and festive fun, it was another brilliant opportunity for the MACS community to connect and celebrate together.

At Dunstable's Grove Theatre, families enjoyed a touch tour followed by a brilliantly funny pantomime, bringing together members from Bedfordshire, Hertfordshire, Buckinghamshire and beyond.

We'd also like to say a huge thank you to Mel for hosting the Dunstable panto for the past 15 years. Her dedication has helped create so many wonderful memories for MACS families over the years, and while she has now passed the baton on, we hope to still see her at future MACS events.

Southampton also hosted its very first MACS pantomime, which proved to be a fantastic success. Families enjoyed a brilliant evening together, and plans are already underway for this year's event featuring Diversity in *Robin Hood*.

We always love hearing your feedback from our events and reading about your experiences. It really helps us shape what we do next. As you may have seen in our calendar of events, we have lots more pantomimes lined up towards the end of the year, and we are really looking forward to seeing many members there.

St Andrews Lodge 803 Raises Over £3,000 for MACS

On Saturday 11 October 2025, members and guests of St Andrews Lodge 803, Biggleswade came together at the Tewinbury Farm Hotel in Welwyn Garden City for their annual Ladies Festival, an evening of celebration, generosity and community spirit.

The event proved to be a huge success, raising an incredible £2,100 for MACS. Combined with other fundraising throughout the year, the Lodge has now raised a total of £3,260 in support of the charity.

For Dan, Jen and their daughter Isabelle, the cause they were supporting is deeply personal. Isabelle was born with Microphthalmia, blindness in one eye and Nystagmus, and the family first came into contact with MACS in the early stages of her journey. Since then, the charity has remained a valued source of support, connection and community.

"We've been to a few MACS activity weeks and family days out," said Jen. "They've given us community, confidence, and so much support. We're now privileged to be in a position to give something back." The evening was not only a celebration, but also a reflection of the impact that continued support can have on families living with Microphthalmia, Anophthalmia and Coloboma. Fundraising like this helps MACS continue to provide opportunities, advice and connection for children and families across the UK.

We would like to extend a huge thank you to everyone at St Andrews Lodge 803, and to all those who attended the Ladies Festival, for their kindness and generosity.

Support like this makes a real difference to the work we do, helping ensure that families like Isabelle's continue to feel supported, included and part of a wider community.

Northern Island Meet -Up!
Making Memories at Roe Valley

We had a magical time back in February at Roe Valley Resort, where 48 members came together for a weekend of fun, friendship, and memories that will last a lifetime.

The venue was fantastic, with plenty for both children and adults to enjoy, including a special visit from Macs the Monkey.

On Saturday, members took part in slime-making and Build-a-Bear workshops, alongside plenty of fun, chats, and games throughout the day. The food and company were brilliant, making for a really special atmosphere.

On Sunday, the fun continued with a helter-skelter, golf, a balance trampoline, mini 4x4s, swimming, saunas, and time to explore the beautiful country park. The weather was perfect, making the whole weekend even more memorable.

"Great to meet other folk with wee people at all different ages."

"Thank you so much for organising this weekends event. Great to meet other folk with wee people at all different ages for chats and sharing of experiences..... hopefully we all get to hook up again more often to build all the relationships for adults and kids alike! "

We are already looking ahead to our next event, which will be a day trip or outing. We have some ideas in the pipeline, but we would love to hear from you too. If there is somewhere in Northern Ireland you would like us to visit, please get in touch at **enquiries@macs.org.uk.**

My MACS Weekend By Elodie

Alongside planning future events, we also love hearing directly from our members about their experiences. Here is a lovely reflection from Elodie, who attended our Roe Valley weekend.

In February this year I went to a special family weekend with MACS. It was so fun to meet other kids who understand how I feel. When I arrived, I felt a little nervous, but everyone was so friendly. I met lots of kids my age, some with the same eye condition as me, and others with different things. We talked about how it can be hard losing things like sports or activities at school and we were able to share ways we manage and have fun and do cool stuff.

The activities at the hotel were incredible, there was a pool and outdoor helter-skelter, and pretty fast mini jeeps. We made build a bear, which was very cute. We also made slime, which was sticky but so much fun. One of my favourite parts was playing the piano for some special guests, Stitch and Ariel.

This event was important for me and my family. It helped us feel less alone and showed us we're not the only ones with eye differences. I can't wait to meet my new friends again. Thank you MACS for making this weekend so special. I loved every minute and can't wait for next time.

Love Elodie

Big MACS Meet-Up returns to Drayton Manor

We are really excited to be returning to Drayton Manor for this year's Big MACS Meet-Up. At the time of writing, over 200 MACS members are due to attend, and while spaces and room types are now limited, we still welcome enquiries and last-minute sign-ups.

This year, we've taken everything that worked so well last year and built on it, creating an even bigger and more inclusive weekend for our community.

Thanks to generous funding, we are also pleased to be able to offer Friday night accommodation for those travelling long distances. There are no organised activities on Friday, so anyone arriving for Saturday only will not miss out.

Saturday activities

Saturday will be packed with activities for all ages, including:

- Climbing wall
- Inflatable obstacle course
- Outdoor games
- Accessible storytelling and puppet show
- Penalty shoot-out challenge
- Activity area including planting, build-a-bear and messy play
- Under 5s play area
- Face painting
- Arts and crafts, including the chance to design the next MACS birthday card
- Accessible circus skills, returning as a firm favourite

In the evening, we will come together for a BBQ-style meal, followed by a talent show and disco to round off the day. There will also be a few surprises along the way, and we are confident it will be a fantastic weekend with something for everyone. We are just hoping the sun will make an appearance too!

Sunday

Sunday gives families the chance to explore Drayton Manor Theme Park at their own pace and enjoy the attractions at leisure. Cant wait to see you there!

Meet Sally: Counselling Support at MACS

We are pleased to be launching the next stage of our mental wellbeing support at MACS. We understand that asking for help is not always easy, and that the word *counselling* can mean different things to different people.

MEET OUR COUNSELLOR, SALLY

Hi, I'm Sally and I'm really pleased to be working with MACS.

Mental health and wellbeing is my passion, and I truly believe that putting the person at the centre of all the support I offer is really important. I have lived experience, being blind myself, and I am also a busy, musical mum of two.

I have been a counsellor for almost four years and thrive on helping people build confidence, reduce anxiety, and improve their overall mental wellbeing.

People often have a clear picture of what counselling is, but it can be whatever you need it to be. I am really excited that MACS is able to fund one-to-one counselling sessions for anyone aged 16+ living with a MACS condition, and my whole approach is about finding the pathway that suits you best.

Everything discussed within our sessions is kept confidential. MACS only knows who is accessing support, not what is being talked about. Confidentiality and client safety sit at the heart of everything I do, and if I feel my style of counselling is not the right fit, I am happy to help signpost or refer you to someone better placed to support your needs.

If you are curious about counselling or unsure whether it is right for you, Sally is happy to have an informal conversation beforehand to help you decide if this support feels like a good fit.

If you would like to discuss counselling sessions or find out more, please contact kim@macs.org.uk and your details will be passed on.

I look forward to working with you.

Sally

A recording is available if you'd like to hear more about what Sally can offer before deciding whether to get in touch. Please contact enquiries to request access.

Where in the World is Mini Macs the monkey?

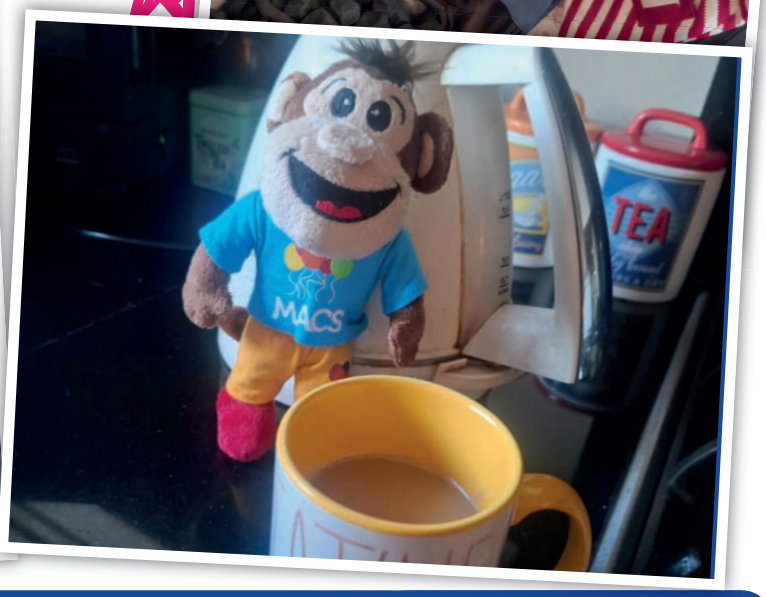
Mini Macs the Monkey has been travelling far and wide, joining members on some truly unforgettable adventures! From snowy Lapland to birthday celebrations and theatre trips, Mini Macs loves being part of the fun and making memories along the way. **Here are some of his latest adventures...**

Lapland Adventure with Jack and Joshua
December 2025 – Lapland

Mini Macs had a magical Christmas adventure in Lapland with Jack and Joshua! During his snowy trip he met Santa, went sledging, got up close with a reindeer, and even enjoyed a fairy-tale horse trek. What a festive adventure!

A Christmas Visit with Georgia
December 2025

Georgia and Mini Macs enjoyed lots of festive fun together. They baked gingerbread cookies, watched *Elf*, and even spent time with some mischievous Christmas elves who had come to visit over the holiday season!



Christmas in Wales
December 2025

Mini Macs enjoyed a wonderful Christmas in Wales with Viola and Mamie. He attended Elf School and successfully graduated, watched a pantomime, met a dancing gingerbread man, and enjoyed a magical light show all about Santa's reindeer, Comet.

CBeebies Land and Birthday Fun with Felix and Phoebe

Mini Macs had a busy and exciting visit with Felix and Phoebe as they celebrated Felix turning four!

The adventure began with a stay at the CBeebies Land Hotel in a Bluey room, along with a visit to the Alton Towers waterpark. Mini Macs joined in the fun and met Little Monster from Justin's House, Bing and Flop, Postman Pat, and even Ubercorn at the disco before settling down for a sleepover in the Bluey bunk beds.

Later in the week, Mini Macs helped Felix celebrate his birthday by opening cards and presents and joining in with birthday cake and candles. The celebrations continued at Felix's soft play party, where Phoebe made sure Mini Macs was included in all the fun, from the ball pit and slides to party food and dinosaur cake.

Felix and Phoebe loved having Mini Macs stay and join their birthday celebrations, and hope he might visit again for another adventure someday.

Bluey's Big Play with Willow!

Mini Macs joined Willow for a trip to the theatre to watch Bluey's Big Play. It looks like he had a brilliant time enjoying the show and meeting some favourite characters along the way!

Mini Macs the Monkey cannot sit still for long! His bag is packed, his passport is ready, and he is waiting for his next big adventure. Would you like to take Mini Macs along on your next trip or special day out? We would love to hear from you!

Please email enquiries@macs.org.uk to invite Mini Macs on his next adventure.

Research Spotlight:
Social Media & Visible Differences

Social media can be a brilliant way to connect, share experiences and find community, but we know it is not always straightforward. Last year, MACS was pleased to support recruitment for a research project exploring the social media experiences of young people with visible differences.

The study has now been completed, and the researchers have kindly shared a summary of their findings with us. We are pleased to share this with our members and hope it offers some interesting insight into how young people with visible differences experience the online world.

A huge thank you goes to the young people who took part and shared their experiences so openly. Their voices are helping to build greater understanding and shape future conversations around social media, identity and inclusion. You can read the summary of the research findings below.

The social media experiences of young people with visible differences

At the Centre for Appearance Research, we spoke to 12 young people aged 13-17 years (9 girls, 3 boys) with a range of visible differences about their social media experiences. This is a summary of the results.

Young people talked about how spending time on social media can be harmful to their mental health. They felt that beauty standards and social comparisons could negatively impact their self esteem and daily life. They felt that online interactions could be harsher due to anonymity, leading to unwelcome comments and questions about their visible differences.

They said:

"I was constantly comparing myself to other people's lives, which made me quite unhappy"

"You've got people commenting horrifying things to people just because there's that screen and there's the anonymity"

"Everyone with clear skin, which may not even be true because of filters, actually affects you because you're like 'why do I not look like these people?'"

Young people talked about ways they protected themselves online, such as being mindful of their audience when sharing content, and using strategies to cope with negative reactions. They said:

"If people are negative, you can just block them"

"I've got a private account that I just let a few people follow and that's where I usually put my day-to-day stuff"

Young people found social media valuable for connecting with others who have visible differences, sharing their experiences, and forming supportive relationships. They felt that increased representation on social media could help reduce stigma and positively impact their self-esteem and how they felt about their appearance. Supportive reactions to posts about visible difference boosted their confidence and sense of belonging. They said:

"I think it just feels good that people are supporting me and what I go through"

"A lot of people I've found similar to me that I probably wouldn't have found if I didn't use social media"
"I feel like this [an image of a midsize model with vitiligo] shows I don't have to be perfect. I don't have to be perfectly slim. I don't have to be ashamed of my birthmark"

Many young people wanted to use social media to support and uplift others. They believed that increasing representation of people with visible differences doing everyday tasks could challenge narrow beauty ideals, prompting people to question their own beliefs and ultimately encouraging societal change. They said:

"If they [people who react negatively to visible differences] see more stuff on social media with visible differences, and they get more used to it, they'll stop commenting on it so much and they'll stop commenting badly on visible differences"

"[My goal is] to help other people that are also going through alopecia to know that they're beautiful and then just to make a stand as well"

Young people used social media intentionally, choosing content and setting limits to maintain a healthy balance. They found it helped them remember happy memories, express emotions, and show gratitude. They felt the impact of social media depended on how people chose to use it, including who they follow and how much time they spend online. They said:

"I try and limit it because it can get a bit out of hand. So an hour or so on each app per day"

"I think if you use it carefully then it can be a good thing, but you just have to be careful not to go down a bad route"

Next steps
This study provided valuable information about what it is like to use social media for young people with visible differences.

We will be combining these results with results from two other studies - one with adults with visible differences, and one with influencers with visible differences. This will give us a better understanding of what it's like to use social media for people of different ages and roles who have visible differences.

Our findings will be used to create resources to help increase awareness of the risks of social media and tips to use it in a positive way. These resources will emphasise the importance of peer support and involving young people with visible differences in decision making, helping their voices be heard.

Thank you so much to everyone who contributed to this important work!
If you have any questions or would like to discuss the research further, please contact **Emma.Waite@uwe.ac.uk**

Professor Nicky Ragge
Research Update for Focus

We're excited to share the latest updates from Professor Ragge's research team in Oxford. Our research continues to focus on the genetics of MACS conditions, anophthalmia, microphthalmia, coloboma and related conditions. In this article, we'll tell you about one of our newly published research papers, our new research clinics, our Vision for GoOD fundraising campaign, and the latest international conference we recently hosted in Ghent, Belgium—bringing experts together to deepen our understanding of genetic eye development conditions.

Our recent research paper that links the KDM2B gene to MACS conditions

Nicky Ragge and her team identified changes in a gene called KDM2B, which plays an important role in early development, in two families with Anophthalmia, Microphthalmia and Coloboma. We found that variants affecting a specific part of the gene can disrupt normal eye formation before birth, sometimes alongside differences in other organs such as the brain, heart or kidneys. This work strengthens evidence that KDM2B is linked to a broader, multi-system condition and highlights how symptoms can vary between individuals. This publication will pave the way for including KDM2B in the NHS diagnostic test panel for AMC conditions, so that other families can be diagnosed.

You can read the paper online:
www.nature.com/articles/s41431-026-02090-1

Welcoming new study participants!
We'd love to hear from any family not yet involved in our research.

We employ the latest genetic testing methods (Whole Genome Sequencing is our gold-standard) and analyse data beyond the standard NHS gene panel. We use advanced techniques that look at RNA, which gives additional information over and above DNA testing, and use other methods not routinely used by the NHS genetics services. We're open to all families, whether you have had NHS testing or not, and our testing can sometimes reach an answer ahead of the NHS diagnostic testing.

We also recruit families who already have a genetic diagnosis, for example when we're studying a specific gene. We're particularly looking for families with genetic variants in the genes STAG2, WLS and ZFHX4. We're planning a publication revisiting SOX2 in the coming years, 2028 will mark 25 years since Nicky and colleagues identified this gene! We'd love to hear from families with a diagnosis involving one of these genes, or any other gene!

If you would like to learn more about taking part in the study, feel free to call Dorine, Nicky's research coordinator on **01865 534923** or **07484 543575** for a friendly chat. You can also drop her an email on eye.**genetics.study@brookes.ac.uk**

Looking after families already taking part
As well as finding new families to join our study we'd like to look after the families that are already taking part, some of which have been involved for nearly 25 years! We will continue to revisit the testing if there is not yet a genetic diagnosis and are aiming to test as many families as possible by Whole Genome Sequencing. Dorine has reached out to many of you in the last few years to explore if you'd like more advanced testing. If you haven't heard from her yet, it would be great if you could get in touch **(01865 534923 /07484 543575** or **eye.genetics.study@brookes.ac.uk**)– she might not have your most recent mobile number or email. Sometimes we need a new sample to do further testing; however, we know that not everyone likes blood tests, so we can use a saliva sample for standard Whole Genome Sequencing.

New research clinics
We have recently set up new paediatric research clinics in Oxford. These will be held in dedicated facilities at the Children's Hospital at the John Radcliffe Hospital and are for families with children aged sixteen and under. The good news is that we still have some dates available for this summer. For older teenagers and adults, we'll continue to host research clinics at Oxford Brookes University. In these clinics, Nicky sees new families and feeds back research findings to families that are already taking part.

Vision for GoOD
Our Vision for GoOD campaign continues to raise vital funds to advance our research into the genetic causes of congenital eye conditions. Thanks to the incredible support so far, Professor Nicola Ragge's team has already uncovered many new genes and biological mechanisms involved in eye development — important breakthroughs that are making a real difference for patients and their families, not just in our cohort, but worldwide.

GOOD
Genetics of Ocular Development

We're now raising funds for a PhD programme. This will allow a clinical ophthalmology registrar to join our research team, helping to drive the identification of the next generation of genes and genetic variants involved in MACS conditions.

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 at whatever level, please do drop us a line at **admin@visionforgood.org**

'By fundraising or spreading the word, you too can play a key role in advancing this life-changing research.'

Podcasts

With the help of GoogleAI we have created podcasts recounting some of our recent publications for a non-scientific audience. So far we have papers and podcasts on the genes: MAB21L2, FBXW11, GJA8, ALDH1A3, and FZD5 (frizzled5); SOX2 and OTX2 are coming soon. Please have a listen! We'd love to hear what you think about these podcasts, and what genes you would like us to include in the next episodes. You can find the podcasts on the Vision for GoOD Website: **https://visionforgood.org/research-papers** .

6th GoOD Meeting, Ghent, Belgium

We were delighted to welcome scientists and clinicians from around the world to our 6th Genetics of Ocular Development (GoOD) Meeting in Ghent, Belgium. This international conference brings together clinicians caring for people with MAC conditions and researchers studying how the eye develops, creating a space where ideas and expertise can be shared. As always, the meeting provided a valuable opportunity for the Ragge team to build new collaborations and strengthen existing partnerships.

For exciting news on anophthalmia, microphthalmia and coloboma research you can follow the GoOD Meeting on Bluesky (**@EyeGenes**).

Our research continues

In 2026, Nicky's team will continue exploring new genes involved in eye development that may be linked to MAC conditions. We'd love to hear from anyone interested in taking part in our study — especially individuals with MAC conditions affecting both eyes, or one eye plus other features affecting the rest of the body, who have not yet received a genetic diagnosis through the NHS. Taking part could help move research forward while also supporting your family and others in finding answers.

If you're interested, please get in touch at **eye.genetics.study@brookes.ac.uk** or contact our research coordinator, Dorine Bax, on **01865 534923.**

The Ragge team in Ghent from left to right: Karthi Jeganathan, Dorine Bax, Solomon Merepa, NickyRagge, Fabiola Ceroni & Richard Holt

The Rainger Group Research Update Spring 2026

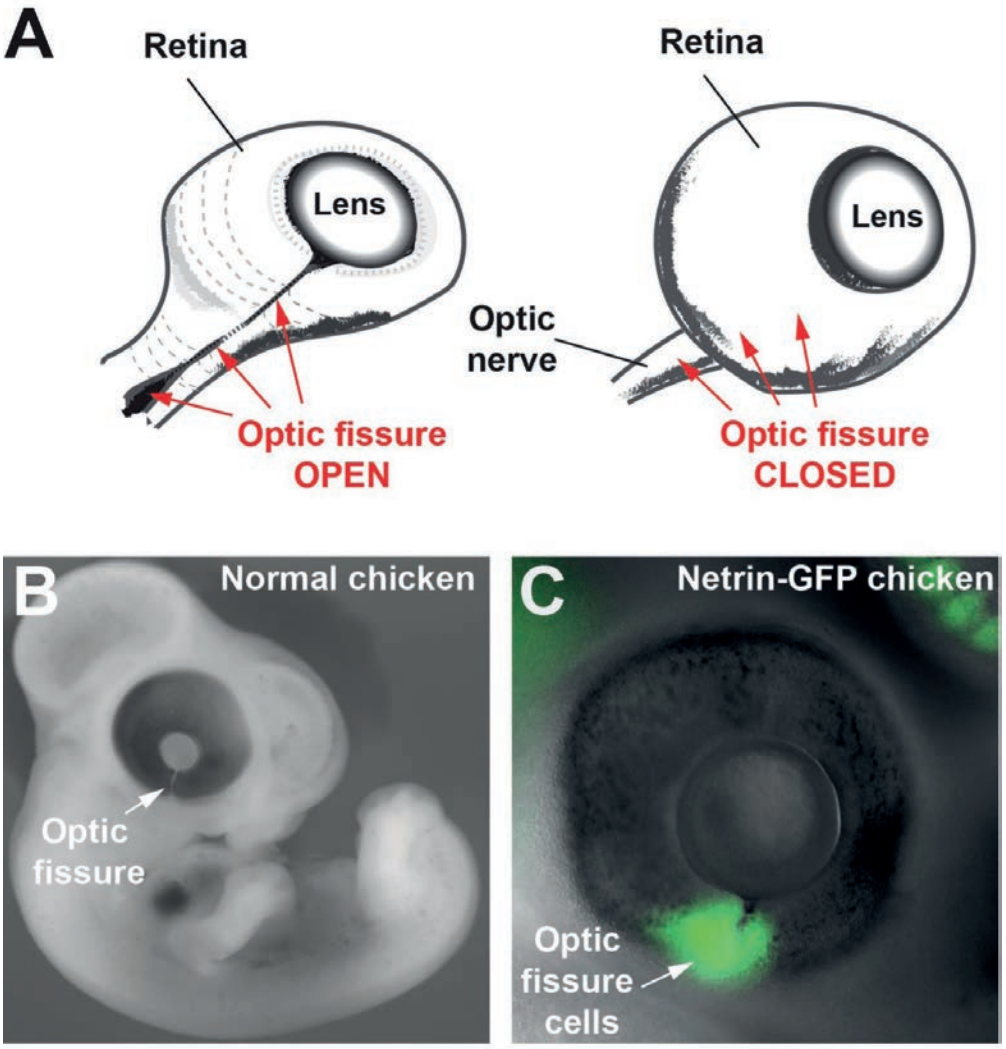
The Roslin Institute, University of Edinburgh

Research has been sent to us by The Rainger Group Research – Update Spring 2026, The Roslin Institute, University of Edinburgh. Here is their full report.

Our lab aims to identify genes that are important for closing gaps during embryonic development and then try and work out how they do this. We call this process "tissue fusion" and a good example of this is the gap present at the bottom of the retina in the early developing eye that must close to complete its 3D spherical structure - a process we call "optic fissure closure". There are also lots of other areas of the developing body where gaps must close, such as the palate and neural tube. Sometimes this tissue fusion process goes wrong and can cause a range of developmental problems such as coloboma in the eye, cleft lip or palate, and spina bifida.

We know that faulty genes are the main causes of tissue fusion defects like coloboma, but in lots of families we can't identify which gene is faulty. So, the starting point for our lab has been to find those genes that are precisely switched on during optic fissure closure and then communicate these back to clinicians so they can check for any faults in these genes in their patients with colobomas. We also then perform broader research to understand what these genes are doing in the developing embryo. We have done this using chicken embryos, as their eyes are remarkably similar to humans in terms of their development, anatomy, and function, and so are the genes they used to regulate eye development. Due to recent technological breakthroughs by scientists at Roslin Institute, chicken embryos are also very good for adding, removing and changing genes using "gene editing". In one recent example, we were able to use gene editing to make the cells in the optic fissure glow fluorescently green during fusion. This allowed us to then specifically separate these cells from the non-green retinal cells and apply a technique called "transcriptomics" to identify all the genes that were only switched on in the green cells. Using this approach, we identified over 400 genes that were associated with optic fissure closure. We are very excited about this experimental tool as the data we have generated can tell us what is unique about these cells and how they might be helping to close the gap. We have also passed the list of optic fissure genes to our clinical collaborators so they can look for any faulty DNA changes in their coloboma patients. Watch this space for future developments! The green cells have a gene called Netrin-1 switched on during tissue fusion, and we previously found that Netrin-1 is important for optic fissure closure in the eyes of embryonic chickens, fish, and mice, and very recently our collaborators in Professor Mariya Moosajee's research group at Moorfields Eye Hospital found a mutation in this gene in a family with coloboma. This nicely illustrates why we do this research. We don't yet know exactly what Netrin-1 does to help the optic fissure to fuse, but we know that it also is switched on in other parts of the embryo to close gaps, and we should be able to share some exciting new developments about Netrin-1 in coloboma and tissue fusion very soon.

'the starting point for our lab has been to find those genes that are precisely switched on during optic fissure closure and then communicate these back to clinicians.'



(A) A cartoon of optic fissure closure in the developing eye. On the left is an eye with a gap at the bottom of the retina – the optic fissure - and on the right this is the same eye at a slightly later stage of development, when the optic fissure has closed. This usually happens during 6-7 weeks of pregnancy in humans, and around 7 days of incubation in a chicken embryo. (B) A chicken embryo at 7 days of incubation with the optic fissure shown. (C) One of our Netrin-1 GFP chicken embryos showing the green fluorescent cells in the optic fissure.

Other recent work in our group has also shown that in chicken embryos, parts of the genome where there are no genes are important for eye development by controlling whether nearby genes are "on" or "off", like a switch. We have shown in the developing chicken eye that there are 100s of these gene switches and we have also found some of the same switches exist in the human genome. We think that any changes to the DNA sequence of these switches could affect the "on-off" control of nearby genes that might be important for optic fissure closure and coloboma. This is a small but important development for MACS research and follows a recent study where the Ragge research group showed that the eye gene MAB21L2 had a disruption in its switch associated with MAC (Focus Magazine Issue 21). Together these are important developments for helping to find new damaged regions in DNA that may cause coloboma and is a very active area of current research for us and other MACS researchers. Work in the Rainger lab has been funded by core funding from the BBSRC and Dr Rainger's UKRI Future Leaders Fellowship, as well as grants from The Roslin Foundation, and several eye charities including Fight for Sight and the Medical Research Foundation with Moorfields Eye Charity. Joe also coordinates an optic fissure closure network that brings together world leading researchers in this field several times a year to discuss and share their research to collaboratively accelerate impactful findings for the MACS community.

Further links:

Scan for further information about the Rainger group's research.

To read about our Netrin-1 GFP chickens Scan.

To read about Mariya Moosajee's work on Netrin-1 in a family with coloboma Scan.

For more info about the gene switches work from the Rainger lab scan.

TCS London Marathon 2026, another Incredible year for Team MACS!

Another year, another unforgettable London Marathon for Team MACS!

This year, our incredible runners have so far raised almost £290,000, with more to come in! We are beyond grateful for every runner, supporter, volunteer and donor who helped make this possible.

The day began bright and sunny at **Greenwich Park**, where MACS staff and volunteers gathered to take photos, calm nerves, and wish our runners the very best of luck before they headed off to their start zones.

Once the race was underway, the MACS team split up across London, with staff and volunteers taking up positions at our cheering point at mile 17 and at Horse Guards Parade after the finish line. From handmade signs and loud cheers to emotional reunions and well-earned medals, the day was filled with determination, celebration and an incredible sense of community.

But don't just take our word for it, here's what some of our Team MACS runners had to say about the day.

Natasha Flunder

The day for me was full of nervous excitement, the unknown as it was my first experience of any marathon. The energy and the experience was something I had never felt before.

From start to finish, the camaraderie, the friendships, the shared experience by so many and so intensely was incredibly warming and emotional. I was fortunate to see my husband Luke and friends at 36km's, my brother in law James at 38km's (volunteering at the Lucozade stand) and my parents, parent in laws and especially our two children Hazel and Joshua in the grandstand at the finish line. An absolute special moment right at the finish.

For me it wasn't about finishing time, it was about the experience and the ability to say I have run and completed in the London Marathon. Final finish time was 5hrs 13mins.

Brian Oliphant

What a privilege it was to run for MACS and help raise funds for A charity that is very close to our hearts.

Our Granddaughter is blind in one eye and the charity has helped our daughter with advice when needed and support.

The experience on the day what can I say it was amazing something we will never forget like wise my wife , Daughter and steven who ran with me.

once again thanks for the opportunity.

Isabelle Tombs

Running for MACS felt so special to me - I was so hopeful to one day support a smaller charity that focused on families, so being able to run the marathon and raise money for MACS crucial work felt so vital.

In a world full of flashy, loud charities, we must remember the ones supporting more niche causes, that change the lives of so many.

Thank you gorgeous MACS, long may you thrive!

Sarah Wainwright

When our daughter Freya was first diagnosed with Micropthalmia and Colobomas, MACS provided support and a community that was there to give us reassurance and guidance. That support hasn't stopped, and has grown through being able to meet other people with MACS conditions and their families at MACS events.

This to me is a small way of giving back to MACS, for recognition of all the amazing work it does that we have witnessed first hand, and in the hope that the charity will continue to grow and thrive so that it will support Freya and those like her when they need it.

To all the members of MACS and everyone who is connected and helps the charity to do what it does, thank you for the support. These 26.2 miles are for you!

Eiméar McDermott-Goulding

I didn't grow up with a charity behind me in Ireland —I had something just as powerful: my mum. She built me up, reminded me of my strength, and never let me believe I was limited by my condition.

It wasn't until later in life that I discovered there was a charity supporting people with my condition, Microphthalmia. I found it randomly one day—and something just clicked.

For the first time, I realised there were children out there walking a path similar to mine.

That's when I made a decision.

I signed up for the London Marathon—not just as a personal challenge, but as a mission. A mission to give back, to raise funds, and to support children who may need that extra encouragement, that extra belief.

Because I know how powerful that belief is.

This isn't just about running 26.2 miles.
It's about breaking barriers.
It's about showing that we are more than what we're told. And it's about being the person I might have needed growing up—for someone else.

David Humpage

It's been a honour of a lifetime to represent MACS in the London marathon this year. The main reason is to get people talking about the charity and understanding what we can do to help yourselves. I'm also at my target now as well and it looks very much like I'll surpass it. I hope you enjoy my story and how you made my dream come true .

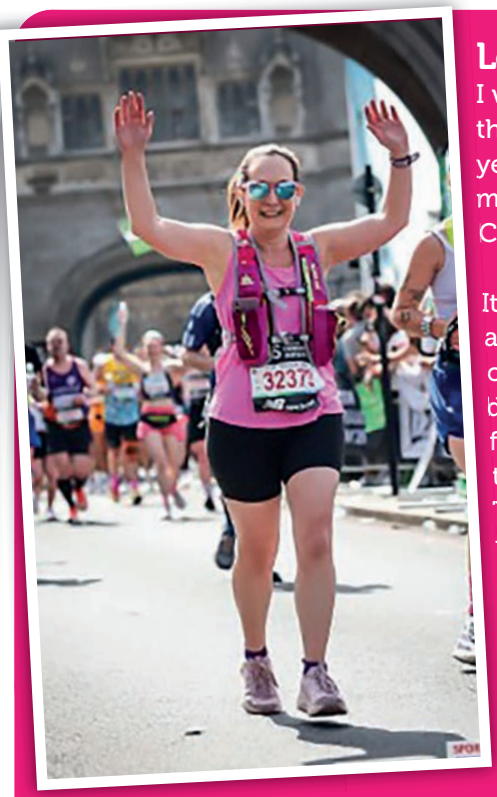
The experience of just walking up to Greenwich yesterday took my breath away. Seeing the lovely folk from @macscharity before I got to the Red wave was beautiful. The walk up through the gates in blackheath to the start line was incredible. The race itself was going well up till 9 mile (I even met the legend that is @shortfatguy_ runsthemajors .. what a guy!!) when I needed a loo break. Started running again, and my hamstring pulled straight away, and it got worse as the day went on. Cutty sark was mental, and my word tower bridge blew my mind. Narrow Street was rammed and then up to mudschute, where I met the @macscharity for a lot of high fives. Canary Wharf was a dark place for me where the pain was getting worse, but I was never going to let anyone down. The Pride section at mile 21 was ultra colourful, and the crowds were fantastic. At mile 22, I had one lady hold a sign up and say I looked fit. I offered her my glasses cos I thought she needed it . Embankment and up to big Ben were incredible. The number of people shouting 'David you've got this' was so beautiful. Turning onto birdcage walk was heaving with supporters.. just the best and then onto the mall where I called my wife in astonishment that I was about to finish the greatest marathon on earth. I jeffed nearly 17 miles, but I didn't care a bit. To the brilliant volunteers, thank you so much for all your hard work. It didn't go unnoticed. Saw Yimmy again briefly and then over to horseguards to meet John and the @ macscharity team. They've made my dream come true, and they told me a third of their income comes from the marathon. It's truly game-changing. I hope in a small way that I've helped to make lives better. The medal is the icing on the cake, but the main reason is to raise those pounds to change lives. We did that in spades.

One more thing... thankyou London, I love you.

Richard Yeo and James

Our whole experience of the marathon was fantastic! The excitement at the start line was great and the support from the crowds for all 26.2 miles was unbelievable.

To have been part of it was awesome. It was great, too, to have a chat and encourage fellow MACS runners on the route and looking out for MACS supporters in the crowd! Around 20 of our family and friends all wore matching tee shirts advertising MACS on the day so it was cool to look out for them! They managed to get to two points at mile 12 and mile 20, it was a needed boost to get us to the end unscathed! We'd definitely do it again! We managed to catch Amy and John once we'd finished so it was nice to put a face to the names on the emails! We have raised over £9,000 and would like to thank our wives, family and friends that helped us with our fundraising events, some effort was put in to making them successful. And also thank everyone that has sponsored, donated and sent us good luck messages too!



Louisa Kent

I was so honoured to run the London Marathon this year in support of MACS and my daughter Lily who has a Coloboma.

It truly was the most magical and emotional day. It is one of the best things I have ever done and I will remember forever how being a part of the MACS team made me feel. There really are no words to explain the atmosphere of running the London Marathon. Everybody was there running for their own reasons but also everyone was in it together. The crowds and entertainment going around was out of this world.

Hope Haynes-Coote

'I loved running the London Marathon for MACS. It was an incredible experience full of support, love and enthusiasm all round, the noise of the crowd, the hard emotional miles and hearing stories of why everyone was taking on such a huge challenge. As someone with a MACS condition myself I feel honoured to have ran for a charity that continue to support me, as an adult member, and raise over £2000 to help in a small way the continued inspirational work of the charity.'

Aran's London 2026

Running the London Marathon for MACS this year was an incredibly rewarding experience.

Having run the marathon previously, my goal for 2026 was to see the results of a more disciplined approach; the difference from last year was night and day! Crossing that finish line was the proudest moment of my journey, as I saw all the hard work and preparation culminate in a significant Personal Best.

A huge part of that success came down to the support from MACS. While I quietly focused on my own training rhythm, the weekly updates became a vital part of my routine. The training plans and tips were instrumental to my progress, and seeing the "Runner of the Week" features provided a powerful sense of community and inspiration.

Beyond the newsletters, the Focus Magazine served as a meaningful reminder of the vital cause I was supporting. The "Member Milestones" section in particular cemented how a little support can vastly change a person's life. Knowing the impact of the funds raised kept my motivation high through every (long!) training mile. I am so proud to have represented MACS and hope the funds I raised can support current and future MACS members achieve something that they will look back at as fondly as I do London 2026!

Francesco Esposito

Running for MACS meant a lot to me because it gave every mile a deeper purpose. Knowing I was running to support such an incredible charity, helping families and raising awareness, made the whole journey far more meaningful than just completing a marathon. It reminded me that the day wasn't only about personal achievement, but about giving back and representing something bigger than myself.

The London Marathon itself was one of the hardest but most rewarding experiences of my life. I was carrying a few injuries going into race day, and honestly, I wouldn't recommend that to anyone, but deferring my place was not an option for me. It made every mile tougher, and there were moments where I really had to dig deep physically and mentally, but the atmosphere in London was unbelievable. Hearing the crowds cheer, strangers shouting your name, and seeing friends and colleagues along the route gave me energy when I needed it most.

Crossing the finish line was emotional because it represented months of hard work, setbacks, pain, and determination.

Fundraising is very challenging, but the support has been incredible. I wish I could have done more, but I'm very happy to have reached 112% of my fundraising target.

Running for MACS made this experience even more special, because I knew every step had been for a cause that truly matters.

John Lee

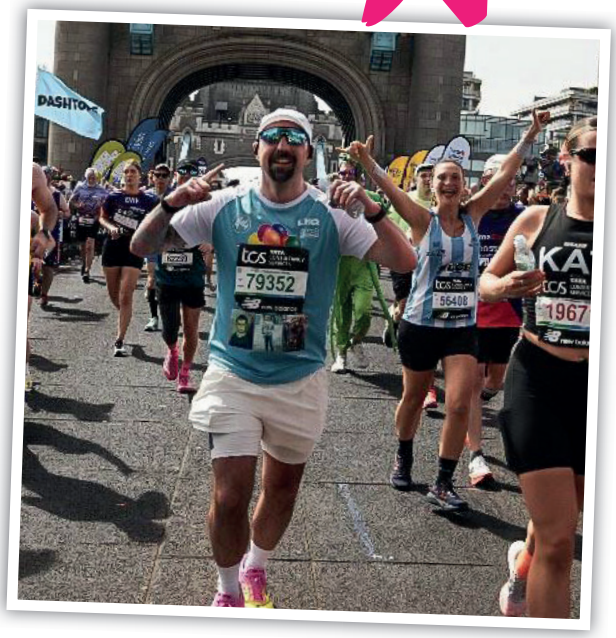
The London Marathon has always been a dream, having spent a good amount of years here. I wanted to encapsulate all I loved about London in one event - the incessant energy of Londoners, the non-stop cheering, the skillful performers, great music and all of that coming together as one London Marathon.

For me, it wasn't just about running but about why I wanted to challenge myself. I did it because I know the human spirit is stronger than any self doubt, the human spirit centres on purpose and the human spirit builds on others.

My purpose was for all the less fortunate out there - including my dad who is severely disabled. He showed me his human spirit through fighting death multiple times and I know deep down he is still with us. This gives me the extra push I needed to cross the finish line in a personal best.

Olivia Nobbs

"Running the London Marathon for MACS was the best thing I've ever done. From only starting running last year, to running a full marathon and smashing my time goal, is something I'm so proud of! It really has proven to me that I can do amazing things and given me so much belief in myself. The atmosphere and support in London was so inspiring and motivating the whole way. I'm so grateful for this opportunity and so proud to have raised so much money and awareness for MACS, knowing it will make such a difference. Thank you to MACS for giving me this opportunity and for all the support during my first ever marathon! I certainly don't think it will be my last!"



Daniel Massey

A marathoner - yes sir
LDN26 completed!
London you were a blast

Months of training led to this victory lap!

I had heard the saying "The person who starts the marathon is not the same person who finishes"

It takes so much of YOU, equally YOU take so much away!!

18-week training block had its ups and downs but couldn't be healthier, happier, and ready to start as I was in that start pen.

Cool, calm, and ready to go somewhere, I've never been before!

Feeling great past the half marathon mark, the vibes through London boroughs were loud, happy and all-round amazing.

Passing through Tower Bridge was special, so special. Went past fridge man and Manny who walked from wolves to London before running, 24,25,28k passed, head down and trying to keep pace that had shifted slightly down.

Honestly, that last 9-10k was horrendous- legs, arms, sides - literally everything hurt and it was stop/start all the way to the finish! I finished it though and that was my goal.

Heading down with Big Ben in the background, through bird walk cage and across to Buckingham palace and seeing the mall finish line ahead a sense of euphoria rose over me and I powered through over the finish line!

London you were amazing.

I was asked by one or two to describe how I felt following the marathon. My reply was "It was one of the best feelings of my life and equally one of the worst" I was humbled and felt superhuman at the same time.

I played my part for the history books. Guinness world record holder now Largest ever marathon participants. 2 elite athletes running sub-2-hour race. (I feel this is impossible and those guys made it possible).

I did a video at the end and said one and done ☑
For now, I'm retired from full marathons, but like Tyson Fury, I may in the future come out of retirement for the right reason/s.

Amazing support to have raised nearly 3k!!! so grateful to have helped MACS raise much needed funding as well as raising there profile within our business via the comms and

Lindsey Henry

"Very grateful to say this was my second year in a row running for Team MACS and it was such an honor! The race itself was just as great as I remembered it the year before, full of people cheering, handing out candy, fun monuments to run by like the Cutty Sark and when you go under the Tower Bridge! Then towards the end when you finally see the London Eye and Big Ben, you know you've almost made it and the tears start forming and you fill with this sense of pride in yourself, like you've done it! Although the race was a challenge for myself as I injured my IT Band, I finished and I'm proud of that and I'm proud to raise awareness for such an important cause! Hope to run for Team MACS again! - Lindsey Henry"

Thanks again John, Becky and the team for all yall do! I truly am so grateful and honored to run for Team MACS! You all are so much fun, so communicative and I love how you all cheer us on, via WhatsApp or in person!!!!!

Running for Jack: Becci Takes on the Manchester Marathon

On Sunday 19th April, MACS mum Becci Hemmerman laced up her trainers and took on the incredible challenge of the Manchester Marathon in support of MACS.

Fundraising challenges are never easy, and training for a marathon takes real determination, dedication and heart. For Becci, this challenge was deeply personal, inspired by her son Jack and the journey their family has been on together.

Becci kindly shared a few words about why she chose to run for MACS, the support her family has received along the way, and the amazing little boy who inspired every mile.

The reason I decided to run for MACS is because of our son Jack. He was born with bilateral coloboma to optic nerve, left eye micro and nystagmus. He's registered severely sight impaired and at age 5 he is just an inspiration. He is currently learning Braille and cane training and he just gets on with it like it's nothing.

When Jack was first born we were devastated to be told his diagnosis at a few months of age. I remember thinking if he's blind he won't be able to see my face to smile, but Jack being Jack, he smiled at 2 weeks old which is crazy early for a new born. From then on he has just smashed everything and proved our worries wrong.

I used to look at him all the time and worry, then one day a parent from the MACS group told me to look beyond his disability and enjoy him as a baby. This made something click inside and that's exactly what I did. I'm so grateful for that person as I would have had some massive regrets now. MACS really helped me in those early days and still continues to be a huge support when ever we have any questions. We loved the big MACS meet up last year and hope to get to one this year where Jack can meet other children with the same Conditions and not feel different.

So far Becci has raised an amazing £433 in aid of MACS. What a brilliant achievement!
Well done Becci!

A Season of School Fundraising for MACS

Throughout the festive season, schools across the region have shown their support for MACS through a range of Christmas fundraising events. From school fairs to student-led activities, these efforts highlight the creativity, generosity and community spirit of pupils, staff and families, all helping to raise funds for MACS!

Rudy with his mini Macs The Monkey

This year, Mill School Bury chose to support us here at MACS with funds raised at their Christmas fair and the reason is very close to home. One of their team, Mrs Fair-Lawton, welcomed her youngest grandson, Rudy, on 2 January 2025. Rudy was born with Bilateral Anophthalmia, meaning he was born without eyes. He also wears hearing aids to manage moderate deafness.

Staff, students, and families at Mill School have been inspired by Rudy's journey throughout the year. His condition, while challenging, has enriched the lives of everyone connected to the school, offering new perspectives and a deeper understanding of the experiences of children with additional needs.

The Christmas fair was a huge success, raising over **£350**, with more funds still coming in through raffles, including a Father Christmas prize and the chance to 'Guess the Name' of **Mini Macs the Monkey**. Activities on the day delighted attendees of all ages, featuring the popular tombola, glitter tattoos, "catch the falling brick," "throw a snowball at the snowman," "guess what's in Santa's sack," and a selection of homemade treats and hot chocolate.

Rudy even had his own Mini Macs the monkey (named **Monkman** by his older brother) and shared his huge smile on his first birthday on 2 January 2026. His journey so far continues to touch and inspire everyone around him.

Mill School's support is a wonderful example how communities can come together to make a difference.

Thank you to everyone who contributed to the fair and helped support MACS!

On **16 December 2025**, Lyng Hall School in Coventry held a fantastic **Christmas Fayre** in support of MACS, raising an amazing **£360!**

The Year 9 foundation students worked incredibly hard to organise the event, running a bake sale, festive craft stall, luxury hot chocolate stand, raffle, and a range of fun activities. They also designed and created decorations and signage, which were sold during the fayre. Their effort, creativity, and dedication truly paid off, and the generous donations from the school community made the event a huge success.

We couldn't be prouder of the students, and a huge thank you goes to everyone at Lyng Hall School for supporting MACS. We're thrilled that Lyng Hall has chosen MACS as their Charity of the Year and look forward to more exciting fundraising events in the year ahead!

Jeans for Genes: Backs MACS with £5,000 Grant

We're thrilled to share that MACS has been awarded £5,000 in unrestricted funding through the Jeans for Genes Grant Programme 2026 – a fantastic boost for our community.

This funding will help us continue supporting our network of over 3,600 members, including more than 1,200 children, young people and adults with a MACS condition, as well as their families. With an estimated 9,300+ people across the UK affected, we know how important it is to keep reaching and supporting more families.

What makes this grant so valuable is its flexibility. It allows us to respond quickly to what you need most – whether that's emotional support, events, information, or simply helping people feel less alone. Just as importantly, it helps us keep MACS free and accessible, so anyone facing a MACS diagnosis can turn to us without barriers.

Jeans for Genes shared their support, saying: "Jeans for Genes is proud to have provided MACS Charity with an unrestricted grant to support their vital work. We are delighted to help strengthen their efforts in improving the lives of children and families affected by genetic conditions."

Unrestricted funding like this is incredibly powerful. It allows us to adapt, innovate and keep building a more connected, confident and supported MACS community – together.

We're hugely grateful to Jeans for Genes for believing in our work and in all of you.

Going for Gold (& Silver)

Founded in 1623, the Worshipful Company of Gold and Silver Wyre Drawers is one of the City of London's historic livery companies, with a proud heritage and longstanding tradition of charitable giving.

THE WORSHIPFUL COMPANY OF GOLD AND SILVER WYRE DRAWERS

We were delighted to connect with a former Master of the Company, who first discovered MACS while sponsoring a family member taking on the London Marathon. That initial connection grew into a conversation - and soon an exciting funding opportunity.

With the Company's strong ties to London, we focused our application on supporting families in the capital. We're thrilled to share that we were successful in securing £1,500, which will enable three London-based families to attend our Big MACS Meet Up at Drayton Manor later this year.

Leslie Hutchinson, Chair, Charity, Fundraising and Events Committee says: "As one of the City Livery Companies the Gold and Silver Wyre Drawers are proud of the contribution they make in supporting local communities and those facing adversity and challenge. We were very impressed with the work carried out by MACS and the considerable impact they have on London based families. We wish them continued success with their ground-breaking work."

This support will help make sure more families can come together, connect, and be part of the wider MACS community - creating memories and friendships that last long after the event.

THE CHARLES LEWIS FOUNDATION

Powered by Partnership: The Charles Lewis Foundation

We're incredibly grateful to The Charles Lewis Foundation for their continued support of MACS – and delighted to share that this year they have awarded us double their usual grant amount in recognition of the strength of our partnership over the past three years.

Many of you may remember that The Charles Lewis Foundation supported the production of FOCUS last year. This ongoing relationship has grown from strength to strength, and this latest award is a real endorsement of the impact of our work and the difference your community makes every day.

Their funding has helped us invest in new, reliable laptops for our team and volunteers – something that might sound simple, but is absolutely vital to how we support you. As a charity working remotely across the UK, technology underpins everything we do: from delivering online events and peer support, to producing newsletters, coordinating activities, and staying connected as a community.

Upgrading our equipment means a smoother, more secure and more consistent experience for both staff and members. It also strengthens our ability to protect sensitive information, improve day-to-day efficiency, and ensure we can continue to grow and develop our services in the years ahead.

We're hugely thankful to The Charles Lewis Foundation for their continued belief in MACS and for investing in the foundations that keep our community connected and supported.

We're hugely grateful to Jeans for Genes for believing in our work and in all of you.

'The Charles Lewis Foundation is proud to support MACS and the meaningful work they do to connect and empower their members. By helping to fund vital but often 'harder to fund' essentials - from communications and equipment to enriching travel opportunities - we are delighted to play a part in strengthening their community and widening opportunities for everyone involved.'

MACS

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

@MACScharity

@MACScharity

MACS Charity

@macs.the.charity

Registered charity no UK: 1161897 Registered charity no Scotland: SC052711

Microphthalmia, Anophthalmia & Coloboma Support

MACS
Microphthalmia, Anophthalmia & Coloboma Support

All about MACS

All about MACS and conditions

MACS started life in 1993 as a small support group run by, and for, parents of children who were born with Microphthalmia (small eye/s), Anophthalmia (no eye/s) or Coloboma (a cleft in the eye/s) or a combination of these conditions.

Every year in the UK, an estimated 114 babies will be born with MACS conditions. Many children will have additional needs or other health challenges. Receiving the diagnosis may be an isolating experience for parents; they may feel hopeless and alone.

MACS now helps over 3,500 people from more than 1,200 families across the UK, supporting them at every stage of their journey by providing peer support, practical help and opportunities to take part in life-changing activity trips.

“Finding MACS when our daughter was born was an absolute ray of light moment, to know that other parents were out there sharing their experiences and that we weren't alone which we absolutely felt at that time was completely up-lifting.”

How does MACS help?

MACS welcomes all UK-based children and adults, parents and carers as members to our warm and supportive community. Our services provide a lifeline to those who experience the impact of MACS conditions and we exist to help the whole family.

“My parents were told that I was blind. They wondered if I’d ever make friends or live independently. Through meeting other families, MACS told them the answer could be ‘yes’.”

Emotional support

We have a helpline, which is manned by MACS volunteers ready to offer a listening ear to anyone who may feel overwhelmed or isolated, particularly during the early stages of their journey.

We also have online community groups, facilitating a safe space for parents, carers and MACS adults to share experiences and answer each other’s questions, with inclusivity and support at the heart of all interactions.

Information and advice

We provide resources and signposting to our MACS community on a variety of topics; from preparing for the first day of school to taking the first step on the career ladder, we work closely with members and professionals to provide support at all stages of the MACS journey.

Adventure and activity

We help to increase the confidence and self-esteem of our young MACS members through residential adventure activities.

Our annual activity trip brings together children aged between 10 to 18 years old for 5 days of adventure, challenges and no parents. We also arrange a sailing voyage each year, where crewmates aged 16-25 learn teamwork, independence, communication, maths and nautical terms.

Regional and national events

We provide opportunities for members of all ages to connect with the wider MACS community, through volunteer-led regional events and our larger annual national overnighter event.

“The MACS annual get-together is the only place we are confident to allow our son to run around with the other children and feel he is safe and understood.”

Helping Hand grants

Making life easier for a visually impaired person can be costly. Our Helping Hand grants can assist members with these costs and make a positive difference to the lives of the adults and children we support.