ISSUE 20
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FOCUS MAGAZINE

Microphthalmia, Anophthalmia & Coloboma Support

Supporting people born without eyes or with underdeveloped eyes

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

Contents

BRAND NEW SERVICES TO 2025

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.

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

MACS

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MACS MAGAZINE | VOLUME 20
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

Chair's Welcome!

HI EVERYONE!

When I spoke to our membership back in October through the monthly newsletter, I referred to the fall of the autumn leaves and how the transition from one season to the next had me reflecting on the direction we're moving in as a charity. Now, as I write this article, snow is falling and Christmas decorations are beginning to be displayed – how time flies!

I talked about how autumn beautifully symbolises our journey as we near the end of the first year of our Plan to Thrive strategy: just as leaves may fall (or old ways are left behind), our roots remain firmly grounded, nurturing our continued growth and resilience. The snowfall makes for just as poignant a metaphor, as it will nurture the ground beneath it and melt away to uncover replenished roots and shoots, ready to grow and thrive...just like MACS!

As we move into the second year of our Plan to Thrive strategy, I wanted to share with you all again what our focusses are, which sit across four key areas:

Our community

1. We aim to build a positive and supportive community, increasing our membership by 10% each year. We know that there are thousands of people living in the UK with a MACS condition that are not members but may not have heard of MACS. We're upping our efforts to reach everyone who needs us.

2. We're working hard to develop and refresh the MACS brand. As our membership evolves and we support and represent more and more teens and adults, the look and feel of our brand needs to reflect this evolution.

3. We've developed a 'Thriving at Thirty' campaign to build awareness and showcase what is possible with a MACS condition. We launched this campaign in summer, with members' milestones being shared at every opportunity and a Thriving at Thirty party to celebrate back in September.

Our support

4. We're strengthening our advice and information so that the MACS community can access age-appropriate information and the latest research. A 'Content Creative Collective' project has taken place with input from members, and new resources are now being developed so the relevant information is at the fingertips of members at every step of their MACS journey.

5. We've developed an engaging events programme, including adventure activity trips, and mass member events that enable members to build connections and access support. We've got some amazing new services planned for 2025 – you can read more about these later in the magazine!

6. We're extending our network of regional volunteers and events nationwide so people can access support and build connections closer to home. We've already got lots of willing volunteers ready for onboarding and training in the New Year, but we still have regions that need covering. There's an article on this further on in the magazine so please do give it a read to find out more.

7. We're developing and extending our range of peer support activities to help increase resilience and wellbeing. The team is currently exploring the best ways to facilitate peer connections outside of the current services and support groups, and particularly on a 1-to-1 basis. We've had some great feedback from people we've 'buddied up' so it's something we want to do lots more of!

8. We're introducing new services to support people with MACS conditions to access their rights & entitlements and employment to foster equitable access to society. Again, you'll read more about this in the 'New Services for 2025!' section.

9. We will continue to provide 'Helping Hand' grants so that people have access to the funds needed to participate in society. With the Cost of Living and general financial pressures that many of our members experience, our Helping Hand grants are as crucial as ever. We've reviewed the application process and have now opened this up on a rolling basis, removing the stricter application window.

Our income

10. We continue to build relationships with supporters and funders, and diversify income streams to fund 100% of charitable costs.

We've seen amazing success in diversifying and growing our income streams, ending 2024 double where we were two years ago! The annual report and accounts for 2024 won't be available until later in 2025, but 2023's info is publicly available on the website and gives a great overview of the direction in which we're heading! Just visit: **www.macs.org.uk/our-impact**

Lastly, being a small remotely based team, with no specific IT or HR department, we need to make sure our infrastructure and internal processes are up to scratch. That's where our last area of work comes in...

Our people and systems

11. Review and improve our current IT & internal controls so that we are equipped to deliver our strategy.

12. Effectively capture and communicate our impact to members and other stakeholders and learn from the insights this brings.

There you have it! We've made some remarkable progress, with massive reassurance from November's annual survey results that we are heading in the right direction!

While these are our key objectives, we continue to live our 'aspirational' value and will respond to needs that arise outside of our strategic focusses. For example, many of the members at our Thriving at Thirty event shared concerns and apprehensions around the use of Accessible Technology... You spoke, we listened! Sean, our new Access Tech Support Volunteer will be joining us in 2025 to help you with all your technology worries. You can read all about him and the support he'll provide in his article later on in the magazine.

I am thrilled with the progress we have made so far and am so excited to see the introduction of new services in 2025. I want to take this opportunity to say a massive THANK YOU to our members for their fantastic input our supporters for their commitment, and the staffing team for the hard work they all put in to bring it all to life.

What a family, what a community.
Yours proudly,

Teresa Gordon
Chair of Trustees

Meet the Team

ORGANISATIONAL STRUCTURE

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MACS Team Updates

and learn about the new roles in the team...

MEET BECKY

Becky has been a MACS member since the charity's inception, having been born with Microphthalmia—giving it a special place in her heart. With a deep passion for art and creativity, and as a recent MA Visual Communication graduate, she is eager to use her skills in communications to raise awareness of MACS, reach new members, and galvanise support.

MEET ROSS

Ross has been a part of the MACS community since 1998, growing up as a MACS child and experiencing firsthand the invaluable support the charity provides. This deep connection has fuelled a lifelong commitment to the organisation, culminating in Ross's role as a Trustee. Ross is currently living in Exeter, enjoying the South West coastline, while working for an AI technology start-up. In his spare time, Ross enjoys exploring the outdoors through cycling, hiking, climbing, and sailing.

WELCOME BACK CLARE!

We're very pleased to welcome back Member Services Co-ordinator, Clare Jones. Clare has been off since April on maternity leave, but is excited to be joining the team again from January, when she'll be helping to get all of the planning and preparations done for our calendar of services and events.

JOIN US!

MACS is looking for new Trustees with the enthusiasm, creativity and commitment to join our board of Trustees. Would you like to join the MACS Board and help direct the future of our fantastic charity? If so, we'd love to hear from anyone who shares our core values and has the passion and commitment to help us improve. MACS is committed to improving the diversity of our Board and so we would particularly welcome applications from under represented communities as well as from Northern Ireland, Wales and Scotland.

We are specifically looking for people who can demonstrate:

- Commitment to and willingness to work in accordance with MACS' principles and values
- Willingness to devote the necessary time and effort
- Strategic vision
- Ability to work effectively as a member of a team
- Good, independent judgement
- Willingness to speak their mind
- Ability to think creatively
- Willingness to participate in fundraising activities when required
- Understanding and acceptance of the legal duties, responsibilities and liabilities of trusteeship
- These are unpaid roles but reasonable expenses can be claimed.

For an information chat with our Interim Chair, Teresa Gordon please email **teresa@macs.org.uk** and we will arrange a call.

To apply please submit your CV and a covering letter to teresa@macs.org.uk. Please make sure your covering letter, which should be no more than 2 pages long, clearly demonstrates your suitability for the role and why you would like to be a MACS trustee.

Can you be a Trustee?

Calendar of Events 2025

7 - 8 September: Mersea Island

Summer TBC: Jamie's Farm Teen Trip

28 July-1 August: Calvert Adventure Trip

5-10 August: Annual Sailing Voyage

First weekend in September TBC: MACS Annual Get-together

November TBC: Employability Day

Online Events

January

January: Quiz – 4th	**8pm**
New members Zoom - 8th	**8pm**
Online creative writing – 28th	**7pm**
January: Adults Zoom – 29th	**8pm**

February

February: MACS coffee morning Zoom – 12th	**11am**
February: online creative writing - 25th	**7pm**

March

March: New members Zoom – 12th	**8pm**
March: Tech talk and gaming Zoom – 19th	**8pm**
March: online creative writing – 25th	**7pm**
March: Adults Zoom – 26th	**8pm**

April

April: Quiz – 5th	**8pm**
April: MACS coffee morning Zoom – 9th	**11am**
April: Kids creative writing zoom – 16th	**5pm**
April: online creative writing - 29th	**7pm**

May

May: New members Zoom – 14th	**8pm**
May: Online creative writing – 27th	**7pm**
May: Adults Zoom – 28th	**8pm**

June

June: MACS coffee morning Zoom – 11th	**11am**
June: Online creative writing – 24th	**7pm**
June: New members zoom – 25th	**8pm**

July

July: Tech talk and gaming Zoom – 16th	**8pm**
July: Online creative writing – 22nd	**7pm**
July: Adults Zoom – 30th	**8pm**

August

August: MACS coffee morning Zoom - 13th	**11am**
August: Kids creative writing zoom – 20th	**5pm**

September

September: New members Zoom – 11th	**8pm**
September: Adults Zoom – 24th	**8pm**
September: Online creative writing – 30th	**7pm**

October

October: MACS coffee morning Zoom – 8th	**11am**
October: online creative writing – 14th	**7pm**
October: Kids creative writing – 22nd	**5pm**

November

November: New members Zoom – 12th	**8pm**
November: Tech talk and gaming Zoom -19th	**8pm**
November: Online creative writing – 25th	**7pm**
November: Adults Zoom – 26th	**8pm**

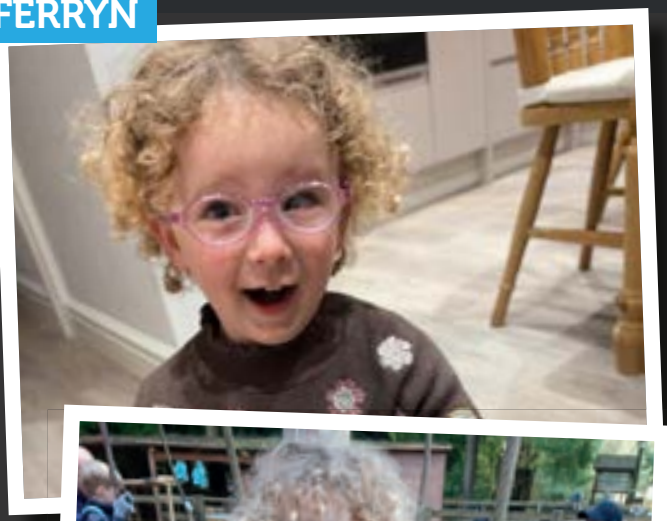
December

December: Quiz – 6th	**8pm**
December: MACS coffee morning Zoom – 10th	**11am**
December: Kids creative writing zoom – 17th	**5pm**

HELLO To new members

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

FERRYN



Ferryn has an optic nerve coloboma (morning glory) in her left eye with cataract and nystagmus. She's recently been given glasses to improve the vision in her right eye.

She's a very funny and happy person and we are grateful to MACs in supporting us to understand her diagnosis which doesn't seem to be holding her back in any way.

Thank you to the parent we met at Moorfields for introducing us to MACs (sorry we never got your name)! We hope your daughter's operation went well.

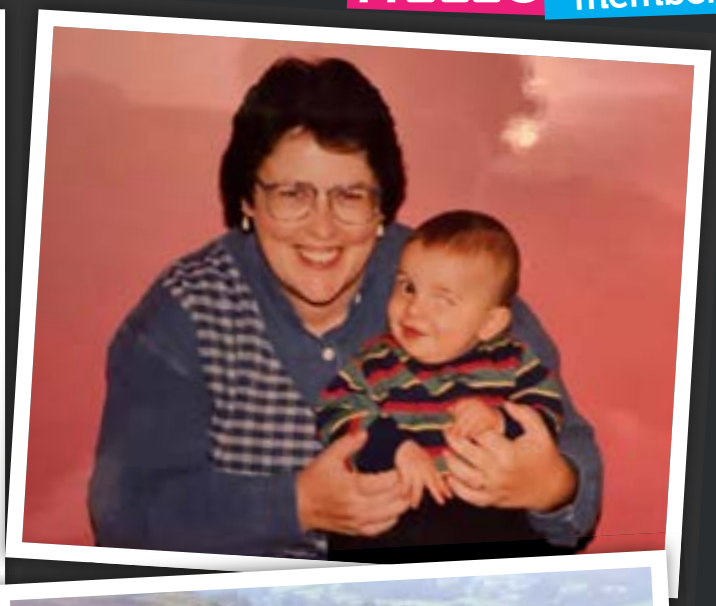
MARINA

Marina was born on a snowy January day in 2024. Shortly after, she was diagnosed with microphthalmia, a cataract, and a detached retina in her left eye. The diagnosis came just weeks after her birth, when we noticed that she wasn't opening her left eye. In those early days, we didn't know what to expect, especially since we hadn't met anyone with a similar condition.

Fortunately, we found excellent paediatric ophthalmologists who were familiar with Marina's diagnosis. They guided us through her treatment options and helped us set realistic expectations for the future.

It was Marina's aunt who discovered MACS online and suggested we reach out. Through MACS, we've connected with a community of families and individuals who have travelled similar journeys. They've generously shared their stories and offered invaluable support. For the first time, we no longer feel alone in this journey, and for that, we are forever grateful. We look forward to meeting more members of the MACS community—hopefully in person very soon!

ADAM



Hi,

I'm Adam, I'm 27 and I have microphthalmia in my left eye. My parents found MACS shortly after I was born and we found invaluable support all the way up to my mid teens when life started to get busy and we lost touch with MACS.

Now over ten years later I've re-joined MACS as an adult and already I've received super helpful advice and a friendly welcome back into the community.

I hope I can find ways to contribute back to MACS as a small repayment for all of the kindness and help I've been lucky enough to receive throughout my life from the charity.

As I was quite young for most of my time with MACS, I asked my mum, Helen, for her thoughts on the impact that the support from MACS had:

"MACS offered invaluable support through their regular newsletter, which contained uplifting articles from similarly affected families as well as supportive professionals. MACS helped Adam understand he was not alone, and meeting other MACS children had a positive influence on Adam's outlook on life when he was growing up."

My mum gave me a message to pass on too...

We were introduced to MACS by our health visitor not long after Adam was born, and they offered invaluable support through their regular newsletter, which contained uplifting articles from similarly affected families as well as supportive professionals. MACS introduced us to Sonia and her microanophthalmic son Tyrone based in Devon who were an inspiration and we met up several times. In 1998 we went to our first MACS AGM at Butlins in Wales and met lots of MACS families, we went on to attend many more AGMs based in Preston. The support from MACS was invaluable as it helped Adam understand he was not alone, and meeting other MACS children had a positive influence on Adam's outlook on life when he was growing up.

Thriving at 30 event

On Saturday 7th September 2024, the MACS family came together to celebrate a monumental milestone: the 30th anniversary of our beloved community. What a weekend it was! From heartfelt gatherings to lively activities, the celebration was a testament to the strength, resilience, and unity that have defined MACS over the past three decades.

A WARM WELCOME AND A JOYFUL START

As guests arrived on Saturday morning, the Wisteria Room buzzed with excitement. The MACS team greeted everyone with goody bags, and the air was filled with laughter from the face painting, balloon modelling, and story time designed especially for the little ones, with teens and adults retreating to the common areas for catch ups with old friends and introductions to new ones. The highlight of the morning was undoubtedly the family photos with MACS the Monkey, a beloved mascot who has been a symbol of our community's fun and spirit.

A SLICE OF HISTORY AND CAKE

Teresa, our dedicated Chair and Acting CEO, welcomed everyone with a heartfelt speech, setting the tone for the day's celebrations. Her words were a reminder of the journey MACS has undertaken—from its humble beginnings to becoming a nationwide network of support. The birthday cake that followed was more than just a sweet treat; it symbolised three decades of shared experiences, achievements, and the many friendships forged along the way.

A FEAST FOR ALL

The Garden Restaurant buzzed with conversation as families enjoyed a delicious buffet lunch. The meal was a perfect opportunity to reconnect with old friends and make new ones, all while savoring a variety of dishes that catered to every taste.

AFTERNOON ACTIVITIES: FUN FOR ALL AGES

Post-lunch, attendees had the chance to dive into a diverse range of activities and workshops. The Circus Skills session was particularly popular, with participants of all ages trying their hand at juggling, acrobatics, and clowning. It was a joyful reminder of the playful spirit that has always been a part of MACS.

AN EVENING TO REMEMBER

As the day transitioned to evening, the Garden Bar was the place to be for pre-dinner drinks. The atmosphere was vibrant, with guests mingling and reflecting on the day's events. Dinner followed, accompanied by the sounds of Swipe Right, a live band that had everyone dancing and singing along - fronted by our very own Director of Charity Development, Amy, the band are naturally big supporters of MACS and donated their time for free! The energy was infectious, and the celebration continued well into the night, creating memories that will surely last a lifetime.


MACS


ADVENTURES WITH
MACS
2023


MACS
Arriving at 30!

A HEARTFELT FAREWELL

Sunday morning offered a chance for a relaxed start with a hearty breakfast and MACS members' exclusive swimming session, before the weekend came to a close. The energy from the previous day lingered as families enjoyed the last few hours together and prepared for check-out. The weekend's events were a perfect blend of nostalgia, celebration, and togetherness.

As we look back on this special weekend, it's clear that the 30th anniversary of MACS was more than just a milestone—it was a celebration of the incredible journey we've all shared. The friendships, the laughter, and the collective spirit of the MACS community were at the heart of every moment. Thank you to everyone who joined us and made this celebration so memorable. Here's to many more years of support, growth, and joy within the MACS family!

Thriving at 30 event

As part of our Thriving at Thirty! Campaign, we asked members to share their experiences of MACS. Here are a few quotes and photos that have kindly been sent in...

Here's Amy!

Here is a photo of Amy who is now 32 years old. We were one of the early member of MACS and greatly benefitted from the support and friendship of Macs, especially in those early days.

Closer together

MACS helps bring us closer as a family, as this would never have happened anywhere else. Aiden struggles with relationships with anyone except his mum and this in itself presents challenges, but with the support from MACS miracles do happen. Aiden struggles to fit in, apart from when he's with his MACS friends enjoying life and being accepted.

Ramblin' Ronin

This is Ronin he's a bubbly, happy toddler, when he was 12 weeks old we found out that he had a unilateral Optic Nerve Coloboma and microphthalmia. We had no idea how this would affect his life. We have recently found MACS, and It has been so wonderful to meet people who are currently on the same journey as us and it's gives us hope for his future. We still don't know how limited his vision is but with MACS by our sides, it will make everything easier. **#teammacs**

MACS First Ever Seable Trip for Adults

In early October six of our MACS adults were lucky enough to be selected to attend a trip to Sicily – funded by MACS, provided by Seable.

SEABLE were fantastic to work with and early reports suggest the group – who were a complete range of ages and sight levels – had a fantastic time. The days were packed with activities and for most of the group it was the first time they'd travelled completely independently.

Often, trips like these are taken for granted – but when you have any form of sight impairment a holiday can be so much more complicated, from finding your way around, translating menus and finding activities to do. Not to mention figuring out local transport. But Seable solve all of that and enable anyone with a visual impairment to enjoy a holiday just as a fully sighted peer might.

This utterly ties in with our aim of providing opportunities to foster independence in our MACS members and we were thrilled it all came together so well.

Our very own Sharon met the members flying from Manchester and was able to safely see them to security. Thank you Sharon for going above and beyond so early on a Sunday morning.

Once in Sicily Seable provide enough guides for the group and also the possibility of doing a different activity if you don't want to do the scheduled one – making it as independent as possible.

Sicily is full of history and there was great excitement before the trip about visiting Mount Etna. It didn't disappoint and was a highlight even if walking on ash did take a bit of getting used to!

Swimming in the sea, visiting a local donkey farm and taking in plenty of history made it an action packed week in the sun – many were thankful for the hotels aircon!

Another highlight was the food with one of the group commenting that British pizza just won't be the same now.

We're so glad the group had such a good time and for many the excitement at being able to travel independently made it all that more special.

We're looking forward to working with Seable in the future hopefully to run similar trips so do keep a look out for any info, if you'd like to be the first to hear about any upcoming plans then drop us an email and we'll keep you in the loop.

'We're looking forward to working with Seable in the future hopefully to run similar trips so do keep a look out for any info'

Regretfully, due to funding and other trip commitments we are unlikely to be able to run a Seable trip annually, but we know there's a desire for another group to gain the same memories as our first six did.

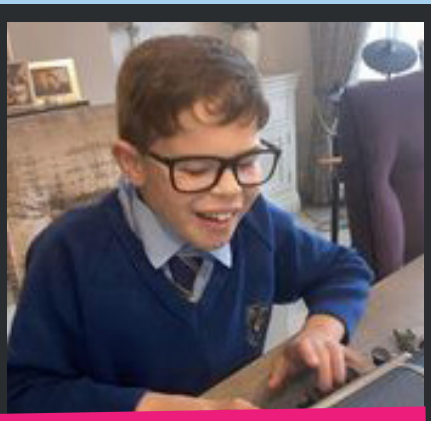
A special MACS thank you must go to Damiano who lead the trip and to Lucy who helped out with all the booking and planning. The group would also like to thank the guides – Carla, Miriam and Jacopo who did a fantastic job. We love collaboration here at MACS and this was definitely a great one.

MACS Members' Milestones

As MACS celebrates the big milestone of turning 30, our members are also celebrating their personal achievements...

AS PART of our Thriving at Thirty campaign, we've been sharing members' milestones and we've had so much great feedback from people whose hearts have been warmed when reading about these personal successes!

The MACS family truly understands that a 'milestone' can mean many things to many people. Our community is made up of people of all abilities and from many different walks of life, and we encourage each and every one of them to share (and shout about) the things they are proud of. We're thrilled that so many obliged, and are sure everyone will enjoy reading about these great achievements...



Nothing should get in the way of learning a new language. Frazer is blind and I have been teaching him for the last 4 years! His Spanish speaking and listening is outstanding so we thought we would step it up this year and do some reading and writing.
I have been learning Braille this year so I can support him and make sure he learns the same as all our other students (even though he's definitely no fan of writing!)

A brilliant start to the year Frazer- ¡bien hecho!

MACS adult (and now staff member) Becky's MACS-specific comic is being sold online!

Here is the impactful message extracted from the illustrations:

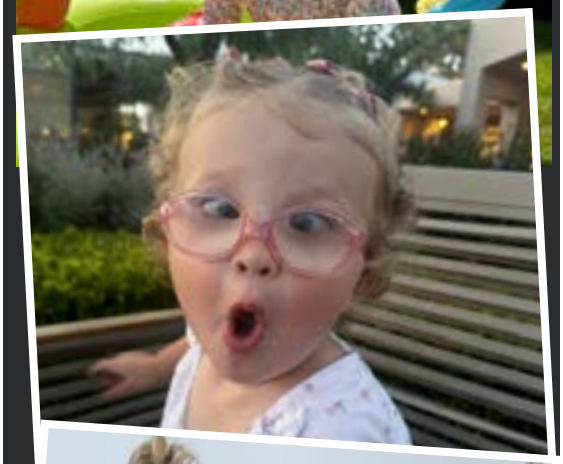
In June 0993 I was born with microphthalmia.

Microphthalmia is a developmental disorder of the eye in which one eye is abnormally small and has amniotic malformations.

The hospital wanted to leave my eye socket closed.

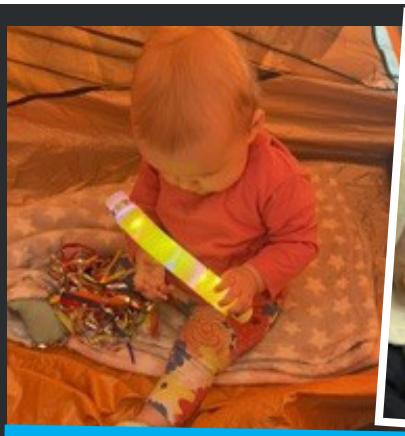
But after a long fight my parents got an artificial eye made for me. My parents taught me how to be brave and how to live with a disability.

Their love and support changed my life forever.



This is Freya, our happy and wild daughter who has bilateral coloboma, nystagmus, as well as microphthalmia in one eye.

She received her first pair of glasses this summer and in the couple of months that she's had them she's really shown what a difference they make to her life. She's now obsessed with books and loves to take them off the shelf and turn the pages.



Now nine months old, Daphne has learned to sit steadily by herself, and we have been working with a local visual impairment team to continue to assess Daphne's visual abilities and come up with techniques to nurture her skills. Daphne recently played in an orange sensory tent with light toys whilst the VI Teacher assessed her nine visual fields. We were delighted to find that Daphne was able to focus in all nine visual fields, which is such a positive step! Daphne surprises us every day with new skills, and we can already tell that she is a bright and curious little lady and will love learning as she gets older!

I have recently been working with a local occupational therapist who has been supporting me in becoming more confident with travelling with a baby. I've always found travel particularly difficult, but since having Daphne it was almost an impossibility at one stage. I've now been able to take multiple buses and even trains with a support of the occupational therapist and I'm slowly building my confidence week by week. Hopefully in the near future I'll be able to take these journeys by myself which will give me the freedom to travel outside of my hometown and give Daphne the opportunity to experience new things.

We are very happy to have MACS as a resource for fielding any questions we have around what we can expect her development to look like or questions around her care, but also for the future that she will be able to meet and talk with people who understand what it's like to be in her shoes.

The support from MACS has helped us very much in the early and worrisome days and has definitely made our outlook a lot brighter.

Jacks first day of Nursery

Jack started nursery in September and has spent the past few weeks settling in. He is becoming best friends with his 1:1 and growing in confidence as the weeks go by. We are so very proud of him and his determination to not let anything hold him back.

Jack has microphthalmia in his right eye with cataract, and he wears prosthetic. He also has Nystagmus in both eyes.

In September Bodhi started a new school following his autism and ADHD diagnosis... he was unsupported and drowning at his old school. Today he was awarded star of the week!

I'm as always so incredibly proud of his resilience and bravery! This Wednesday he's going on a residential trip with his school to take part in many physical activities (a lot like Calvert) this opportunity was denied by his old school. I'm so very proud of him!

Thea is 8 years old; she has a bilateral coloboma. Her milestone is completing a Junior Parkrun 2km, which she enjoyed as she is a keen runner!

If we had to pick one word to describe Amy it would be 'determined'. Amy was born in 2001 with an extremely rare genetic condition – oculofaciocadiodental syndrome (OFCD). She has a microphthalmic left eye (no vision) and partial vision in her right eye (due to cataracts). Amy has never been defined by her condition however, and has always had a 'can do' attitude. We still laugh about the time she insisted on going to Brownie camp with a broken arm (in plaster from finger-tips to shoulder). We arrived to collect her, only to find her triumphantly completing the camp assault course! I am grateful for people like her Brownie pack leader, who encouraged her to always try, and do her best. Amy loves nothing more than an adventure – from Duke of Edinburgh to MACS Ocean Youth Trust sailing weeks, which have been instrumental in boosting her confidence.

As well as the highs, there have inevitably been some lows. Including navigating the NHS with a virtually unknown syndrome of eclectic conditions. School was mostly supportive but also sometimes challenging and, in particular, I am ever mindful of the primary school SENDCO that informed us that Amy would never go to University. I am pleased to say, Amy completed her BEng Chemical Engineering degree last summer and is contemplating a Masters. She is a Research & Development Engineer for a global company (working on a hydrogen fuelled heating system) and is living independently in Hull. The company has embraced everything she has to offer and has put her forward as an ambassador to attract young women to Engineering. We are so very proud of Amy and the way she continues to challenge herself and embrace life.

I have recently completed my Psychology PhD, which explored the experiences of people living with visual impairment from several personal perspectives. Throughout my academic and general life journey as a visually impaired person, I have always been passionate about rights, accessibility, and overall improvement of wellbeing for persons with both visual impairment, and disability in general.

MACS has been an amazing source of support for my family and I throughout my life, and this support even extended to my PhD research. MACS very kindly helped me recruit participants for my study on the psychological effects of living with visual impairment on families. Without MACS, along with the families who shared their stories with me, a huge part of my research would not have been possible, so I am very thankful and grateful to you.

I am over the moon to have finally graduated as a Doctor of Psychology, (and using this title at every given opportunity never gets old!) I don't quite know what my next steps will be, but I hope I can continue making a difference in the disability world, and that I can keep on supporting and championing the lives of people who are living with a disability. Kirsty completed her PhD at Swansea University.

Darcy started school on September and whilst it was a huge adjustment and we had a lot of tears, she is smashing it!

Barney is nearly 2 and a half years old and has started nursery. He's impressed all the staff with his ability to do absolutely everything with vision in only one eye. It doesn't hold him back at all. He particularly looks forward to his sandwiches when he's collected!

Joseph started at nursery in September and is thriving. His speech is a lot better and he is enjoying socialising with lots of children his own age

Calvert

Nineteen very excited members aged from 10 to 18 attended Calvert this year with some first timers!

Most travelled a long way to attend and knowing what they would experience made it all worthwhile. Kelly's team did us proud and looked after them all and helped them get the very best from the trip.

The trip is very valuable, promotes confidence, independence and gives the opportunity to try things out in a welcoming, safe non- judgemental environment and get to experience it all with other MACS young people, hopefully as an introduction to what they are capable of and transitioning to other independent opportunities when they are older!

The activities are varied each year and cover things such as ghyll scrambling, canoeing, exploring underground caves and tunnels, traversing across zip wires and climb, then abseiling down an 8-metre wall!

The trip is open to members with a MACS condition aged 10-18, plus siblings in the same age range and is accessible to young people with all levels of needs, including complex needs.

Our care team manager Kelly would be happy to discuss your child's needs with you to help you decide if this adventure is right for them in 2025!

We get fantastic feedback about this trip every year:

"It was a great eye-opening experience for me and my child too. I never knew things she was capable of until we came on this trip."

"A really good opportunity to develop independence and socialise with like other children with the same rare conditions."

"It's amazing! Our son gets so much joy from it."

"Superbly organised, inclusive, fun and the children were always the focus- what do they need and what's best for them. Range of activities was excellent. Feedback from my child..." the best days of my life"!"

"From initially booking to collecting my child the whole team and experience has been exceptional. I honestly can't thank the MACS team enough for all they do and there understanding of each individual child's needs."

"AMAZING!! My child took part in so many activities that he just wouldn't at home. It's such an amazing trip and he gets so much out of it."

"My daughter had an amazing time, grew in confidence and made new friends. As per usual Kelly and team where amazing."

Please consider letting your kids go next year and experience something wonderful!

MACS Sailing

Our sailing trip with OYT this year was an experienced crew as several of our members have returned year after year: this is a fantastic annual opportunity for young people with MACS conditions to get together and have fun. They made a plan for the week, with a forecast of glorious sunshine....

IT was a week of sunshine, dolphins, gannets, fun and friendship. The weather on the south west coast is truly stunning. The crew all gelled well and looked after each other: there was a strong sense of family and kinship, they became very good at sail hoists and drops by the end of the week with some crew taking turns to lead them. They all had a fantastic time with big smiles. All in all they did 136 miles!

They sailed first from Brixham to Dartmouth and then on to Cawsand Bay near Plymouth. There they met another sail training vessel, Johanna Lucretia, the two crews enjoyed going round each others ships. From there, Prolific went on to Fowey, then back to Cawsand. Then a long passage back to Brixham.

The final stage of the voyage included picking up a tow – a vessel which had lost their propellor. Prolific towed her to the Brixham entrance where the harbour staff took her to a berth. A MACS experience where you can find and truly be yourself!

"Another amazing voyage! I loved leading sail drops and getting included in everything! I can't wait for many more years sailing and maybe even volunteering. Thank you Sea Staff - brilliant as always :)"

"Thank you for another amazing trip. The staff were welcoming and lovely. I have learned new things and had a laugh. Had a great time sailing and I didn't feel sick. Can't wait for next year."

"Seeing dolphins was magical!"

"The voyage was so cool and fun with great Sea Staff I had the best time ever with good weather and wind. I am so proud of myself about getting in the dinghy to go ashore."

"Seeing the young people step up to new challenges that they have not done in previous voyages was great - hoisting, leading drops and getting in the dinghy - thank you!"

"I loved this voyage so much! the staff and crew were so kind. I felt much more confident and knowledgeable. Thank you so much! :)"

"I love coming on these voyages and this year was no different! I really pushed myself to try new things which resulted in me going out on the bowsprit to help take in the jib sail and leading a mizzen drop which I am really happy about. Thank you very much! :)"

Due to the nature of this trip it is not fully accessible due to the space on board and the limitations of a boat. Please consider joining us in 2025 and do not hesitate to contact us if you would like to discuss any aspect of the journey or suitability.

Thank you as ever to our kind funders who make these trips possible.

We are always striving to offer new events and include as many MACS members as possible so read on for an exciting return to Mersea Island and some new projects coming your way in 2025, including Jamie's Farm, which promises to remind teens that there's a world out there away from tech!

MACs Meet-Ups Nottingham

A Day to Remember at the Nottingham MACS Meet Up

Despite the wild weather and flooding on the journey in, last weekend's Nottingham MACS Meet Up at the Holiday Inn turned out to be a delightful experience! The day was filled with laughter, creativity, and community, proving that a little rain can't dampen our spirits.

One of the highlights was a wonderful workshop led by Hayleigh from Creation Station. She inspired us all, nurturing our creative spirits and helping everyone—from the youngest to the oldest members—express themselves through art. It was a joy to see such a diverse group of MACS members coming together, each with unique talents and abilities.

> "The attentive staff made us feel truly special, serving us at our tables as we engaged in lively conversations. It was a feast for both the palate and the heart!."

The food was nothing short of exceptional. The attentive staff made us feel truly special, serving us at our tables as we engaged in lively conversations. It was a feast for both the palate and the heart!

For the first time, we introduced Nintendo Switches into the mix, and they were a huge hit! Members eagerly jumped into games and activities, adding an extra layer of fun to our gathering.

We were also touched by a special visit from Jeremy, a longtime member, who brought along a Braille book donation from his son, Matthew. It was a beautiful reminder of the support and generosity that defines our community.

As the day drew to a close, we couldn't resist packing up our things and heading outside to enjoy the unexpectedly sunny evening. The conversations flowed freely, and it was hard to say goodbye to such a wonderful day.
In the end, the Nottingham MACS Meet Up was a resounding success, filled with joy, creativity, and camaraderie. We can't wait for our next gathering!

REGIONAL Volunteers Programme

You may remember from our previous Focus issue that next year is the launch of our Regional Volunteers Program – or – for those of you who have been with MACS for some time, a slightly altered way to how things were.

We know how much being part of the MACS family matters to you all, and don't worry, we have no intention of breaking MACS down just into regions. Our adventure trips, annual get together and all those things you know and love won't be going anywhere.

But time and time again you tell us how meeting someone local is the changing point, for children it's the chance to meet someone a similar age, with a similar eye condition. The possibility of local meet-ups, even friendships leading to sleep overs and days out are all so much easier when people live nearby. For MACS adults it's friendship, someone nearby to have a coffee with and discuss work, relationships, families. For parents it's having someone nearby who "gets it" widening that MACS circle and cementing those all-so-important bonds.

Who better than to run these events than someone who knows the area? Someone who knows which café is welcoming to anyone with a disability, which soft play has a great range of equipment, which park has a nice safe path around the outside for skateboarding and bike riding. MACS members, of course.

Ultimately, we want each region of the UK to be represented by 2 people, one MACS adult and one MACS parent/carer/relative. That's not to say we intend any activities to be split, but it's all about representing as many MACS members as possible.

MACS staff will still be heavily involved, helping with bookings, providing training, always there to answer questions, setting up forms and so on. Some of you may question why MACS staff aren't just doing this as part of their roles? Events take a lot of organising, hours in fact for the kind of things we put on. We are a small, spread-out team, and it would not be possible to provide a MACS staff member at each event. At the moment our local events are generally on a Saturday, with a booking at a Holiday Inn or similar. We have little control other than over the phone. We know our members, but not in the same way you can by knowing people locally.

We want events that suit you, no matter how small. Events that suit each region depending on the demographic of that area. And as a staff team we can absolutely assist with all of this, but equally – we want you to be together, without one of us sat in the corner. The current format, while welcoming and gaining brilliant feedback, is still quite formal – because when organised by us, it has to be.

MACS is not pulling funding for regional events, in fact the availability of funds is likely to be higher. Often funders have available pots to put on events in certain areas – something that up until now we've not been able to take full advantage of, but you can.

Unfortunately, so far, we've not had as much interest as we'd hoped in becoming a regional volunteer, but to those who have we're very excited to start your training in January and get those first events lined up for the summer. There is, of course, a commitment required – but it's a few hours a month. All training, all funds provided. It's the ability to see what people around you want, welcome those new to the area, organise an event or two a year.

It could be as simple as meeting up in a local park – no multi-page forms to fill out, no receipts to file. Or it could be the local panto where you get the numbers, we buy the tickets. It will become what each region needs and wants it to be. If we, as a charity, organise events there are many, many rules and tick boxes we have to follow. For our members, having a regional program alongside this enables a greater choice of activities and the ultimate amount of freedom.

So please, if you'd like to join in, or simply want to talk through the idea, then **email enquiries@macs.org.uk**

Jamie's & Farm

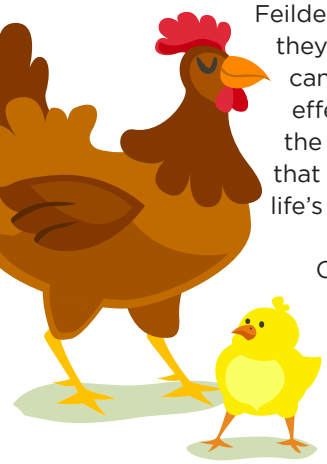
MENTAL WELLBEING

Mental health and wellbeing is so incredibly important for us all. But research has shown time and time again that anyone with a disability is more likely to experience poor mental health or wellbeing. While there are a range of resources out there, here at MACS we want to play our own part and support our members through any part of their journey.

NEXT YEAR, under the umbrella of mental wellbeing we're launching two new services.

The first is aimed at our teens, especially those still at school and will be a residential trip to Jamie's Farm.

Jamie's Farm was set up by Jamie Feilden and his mum, they believe teaching can often be more effective outside the classroom and that nature is one of life's greatest healers.



Often doing work with disadvantaged children and those who struggle at school, for MACS, they are excited to put together a program that primarily supports our visually impaired youngsters but will be opened up to siblings in the same age range if not oversubscribed.

We'll be sharing much more information in the new year but a residential at Jamie's Farm will include:

- **Growing veg, gardening and food preparation**
- **Feeding the animals**
- **Horse riding**
- **Chopping wood and farm repairs**
- **Walks**
- **Games**

The chance to be with others of a similar age and either having a MACS condition or being the sibling of someone who does.

So often we hear about young people being attached to games consoles and tech, this is a real chance to get outside, have fun, meet new people and try things that may not otherwise be available in a mainstream setting where groups are often larger and visual impairment isn't catered for.

For our project the main aim is self-esteem, socialisation and self-value. We want our young people to attend Jamie's Farm and realise just how much they can do and take that strength and knowledge back to their schools and home environments.

It is – of course – also a great opportunity to have some time away from parents!

The second part of our project is counselling. We know specialist counselling can often have incredibly long wait times and even then few counsellors can really understand what someone living with a visual impairment may go through. Be that adapting to losing vision or navigating a new phase of life and coming to terms with any limitations.

We will be supplying those eligible sessions with a fully qualified counsellor who also has a visual impairment. Someone who can listen and understand on both a professional and personal level. This project is aimed – due to licensing – at those over 16. We regret that we cannot offer multiple counselling types and this project may not be suitable for some, however when applications open all will be thoroughly discussed with each participant.

Mersea Island we're back!

You wanted more and in 2025 we'll be back at Mersea Island. This is a real family event, although unfortunately while under-eight's will be more than welcome, due to Mersea Island's rules they cannot take part. There is no upper age limit for this adventurous weekend and we hope to bring as many families together as possible.

Mersea has a fantastic range of activities and instructors meaning a range of things to take part in no matter your ability level.

So look out for the sign up form and let's hope the sunshine greets us for a weekend to remember.

Employability

Finding a job can be a nightmare for anyone, but statistically those with a visual impairment are far more likely to be out of work. With this, for many, comes the sadness at having to rely on benefits, the repeated disappointments of interviews and job applications that get nowhere, not to mention what can often feel like a constant battle making work accessible. Dealing with Access to Work, knowing what equipment is out there to help and what you're entitled to. For some, not even being sure what jobs you can do or what training is available. A good starting point is a CV – and it's not always the easiest document to write.

Next autumn we'll be running an in-person employability day. We aim to have demos from various tech companies alongside tips on interviewing, writing applications, how/when to talk about your disability and what you are entitled too. We want to showcase initially our MACS members who work in a wide range of jobs, but also those generally with visual impairments who are living successful working lives.

As this is a totally new idea, we will be seeking interest in January in order to meet a minimum number requirement – so do look out for that. The day is likely to be in Birmingham or London depending on interest levels and will be aimed at anyone from year 11 upwards.

So whether you're thinking about what to do after school/college, you're an adult but struggling to find a job, or even if you are working but want to look at alternatives we hope this day will be a fun, informative approach to reaching some employability goals.

MACS

Annual get together

We know how happy everyone was to be back at a bigger MACS event in Oxfordshire in September. The feedback has been invaluable and so we thank you for that. After running a poll it was very clear that the overwhelming majority were happy with a one-night event. So for now at least we will hold this, hopefully annually at the beginning of September with 2025's event planned to be in the midlands.

More details will follow in the New Year, but we're aiming to bring even more families together with a wider range of activities on offer.

Meet Sean: our new Access Tech Support Volunteer

As a direct result of member comments, we are delighted that **Sean** has offered MACS his time as a volunteer specialising in accessible technology.

SOME of you would've met Sean at our thriving at thirty event. He had been roped in to attending by Kim, our services manager, who he is lucky enough to be married to (Kim may have had a hand in writing this article)!

Kim promised Sean that giving up a day to help run the gaming section would be nice and quiet, and what else did he have to do on a Saturday anyway? Sean soon realised there was a real need for someone with the knowledge to answer questions about technology, and this has only continued through member comments.

> 'Sean grew up in rural Wales, where he spent his evenings programming and gaming online.'

Sean grew up in rural Wales, where he spent his evenings programming and gaming online. With no sight at all, due to being born very prematurely, he remembers some very old speech technology and the days when the only way to access a print book was to cut it up and painfully scan it into the computer.

After studying (and mostly failing) A-levels at a mainstream school, he hopped over to Hereford to try again. Here he met Kim, and 18 years later she's not yet managed to escape his awful jokes or the fact he can't do decent conversation until he's had at least 2 cups of coffee in the morning.

Sean's career has always been in access tech, most notably as a teacher of IT and access technology at a specialist school for over ten years. Alongside this he has always tutored privately as well as being involved in various tech-related projects. Having left teaching earlier this year to work as a digital accessibility specialist his priority and main love will always be education and improving the potential through tech for any visually impaired person.

Tech can open so many doors; it can foster a sense of belonging through online connections and the ability to carry out tasks independently. It can improve self-esteem, provide fun and relaxation, help with employment, living independently and further down the line help out with parenting tasks. We live in an age of tech, and visual impairment doesn't have to exclude anyone from that.

Sean has a range of knowledge encompassing screen reading software, typing, computer set ups, gaming, programming, braille technology, accessing employment... the list goes on. While it's fair to say his skillset is more suited to those in the lower vision range he will always do his best to help out regardless, and his years of teaching mean he has worked with such a variety of people, regardless of their technical ability.

Sean now lives in Worcester, and he and Kim have a sighted daughter, Lily and a cavalier king Charles spaniel, Millie! In what little free time he gets he's an avid reader (sci-fi) loves Star trek, thoroughly enjoys food as long as he's not the cook and looks forward to movie nights with his daughter. He's not so keen on his wife's need to discuss things at 2 AM though – but thankfully he has a great sense of humour and knows it's best to just listen.

'Sean has a range of knowledge encompassing screen reading software, typing, computer set ups, gaming, programming, braille technology, accessing employment... the list goes on.'

Alongside running some Zoom sessions Sean will be available to answer tech related emails, no matter how big or small. He is happy to provide guides in audio or written (Braille included) on how to use certain equipment, typing shortcuts or what games are suitable for someone with no sight. Anything you can think of, Sean will tackle. His students have always said he's incredibly approachable and has the talent of making someone feel completely at ease. With a love of education and making life as accessible as possible, be that learning to use a mobile phone and all the apps that make life easier, or looking at the most accessible websites for job-hunting.

He wants to help you bust those myths such as:

- **A blind person can't shop online/ manage banking/use job sites etc**
- **Blind people can't game**
- **They can't learn to set out word documents, use spreadsheets or read using a Braille display.**

Sean's heard it all and he wants to change perceptions.

Sean will also be doing home visits where required to provide one-one training or equipment set-up. He can't wait to be part of the MACS set up and share his love of technology with more people. His wife agrees he's pretty awesome, although his daughter is at the age where his coolness is questionable. We'll leave you to decide!

The First MACS Family

By Robbie & Caitlin Crow

In 1997, our two families met for the first time at a MACS Family Weekend. It was a gathering that would unknowingly plant the seeds of something much bigger than either of our families could have imagined.

A year later, in 1998, Caitlin's family attended another MACS event, this time with Sue was heavily pregnant with Caitlin. At that same event, Robbie and his family were also present, meaning that Caitlin's mum knew Robbie before Caitlin was even born! Every year after that, both of our families continued to attend the annual MACS family weekends, creating lifelong friendships and memories along the way.

We both grew up with MACS, but in slightly different ways. Robbie has two MACS conditions, became well known within the community, growing into a strong, independent adult and later taking on the role of Chair at MACS, navigating the charity through COVID-19, the toughest period in its history. His journey hopefully helps show what someone with a MACS condition can achieve, helping pave the way for future generations.

Caitlin, on the other hand, grew up as a MACS sibling. Watching her brother face the challenges of his own MACS condition, she learned early on the importance of celebrating differences and inclusion. Her role became one of unwavering support and advocacy.

Fast forward to 2017. Though we'd been crossing paths for years, we hadn't really gotten to know each other properly until that year's Family Weekend, a cornerstone of the MACS community.

Something just clicked, and from then on, our relationship took off. We exchanged phone numbers, started talking daily, and soon realised that what began as friendship had grown into something deeper.

By 2019, Caitlin had made the move to Glasgow to be with Robbie, and that's when the next chapter of our lives began – learning to live together. Navigating life as a visually impaired and non-VI couple came with its unique challenges. Whether it was Robbie's way of keeping things organized so he could find them or Caitlin's efforts to understand his day-to-day ways of doing things, we worked together, step by step. From disagreements about cooking methods to questions like, "Have you seen my telescope?" (a question that continues to pop up), we faced every challenge head-on.

We also weathered the COVID-19 lockdowns together, which was no small feat. During that time, we welcomed a new member into our home: Robbie's guide dog, Yogi. Little did Caitlin know, Yogi had a special role to play in the next step of our journey. Robbie cleverly used Yogi's guide dog training walks as cover to buy an engagement ring. And with Yogi by his side, he proposed!

In 2022, we tied the knot in what can only be described as the most perfect wedding. Our day was a true celebration of family – both our relatives and our MACS family. It even had Yogi walking us both down the aisle to say 'we do' and every guest left with a MACS memento.

Of course, planning a wedding with a blind groom had its own share of funny moments. Robbie's philosophy throughout the process was, "As long as we cut the cake with the Sword of Gryffindor, I'm happy." And yes, we actually did cut the cake with that sword – because when you marry into the MACS family, anything is possible. But if anyone knows what we can do with a full-sized Sword of Gryffindor, please let us know – we've still not found a use for it, 2 years on...

Later that year, in December, we received the life-changing news that we were expecting our first baby. Along with the joy came the inevitable questions: "What if she has a MACS condition?". We knew we would love her either way. After all, who better to raise a MACS child than a MACS adult and a MACS sibling? We felt uniquely equipped to provide her with all the love and support she might need, whatever her journey might hold. We knew that it's mostly parents' misconceptions that hold MACS children back, and we knew we could navigate that if we needed to, and make sure they grew up with a 'no limits' philosophy.

A few extra scans later, we learned that her eyes were developing in-line with expectations of her not to have a MACS condition. And on the 12th of August 2023, our beautiful daughter, Ailsa, made her grand entrance into the world. It was a moment of chaos and beauty all rolled into one. In true dramatic fashion, Caitlin didn't even make it to the delivery bed – Ailsa was in too much of a hurry! It was Robbie who ended up using the delivery bed, so he could get the first look at our little girl. In fact, the hospital staff said it was the first time they'd ever seen a dad in the delivery bed instead of the mum!

Getting to the hospital in time was another adventure. With Robbie unable to drive, it was our friend Dan – a fellow MACS dad – who swooped in to save the day, ensuring we arrived just in time for Ailsa's rapid arrival. Ailsa actually arrived before Dan managed to get himself home – we think he had a swift drink that night!

Now, Ailsa is a year old, and we're embracing the whirlwind that is parenthood. She's brought so much joy into our lives, but also the hardest challenges we've faced. Parenthood isn't easy at the best of times, and balancing our unique circumstances makes it even more complex. But every day with her is a gift, and we're so excited to see what the future holds for our little family.

We're already looking forward to the day we can take Ailsa to her first MACS Family Weekend and hoping they return again soon. We can't wait to show her where it all began – not just for us, but for the community that has shaped so much of our lives. MACS is not just a charity to us; it's a place of belonging, a support network, and, most importantly, a family. It brought us together, and now it will be part of our daughter's story too. She'll hopefully grow up being the girl who runs towards any disabled classmates to be their friend, not away from them, and MACS will – we hope – be a huge part in that.

As we look ahead to the future, we know there will be many more adventures, challenges, and joyous moments. We're ready for all of it, with Ailsa by our side and our MACS family cheering us on.

We know how lucky we are to be the first family made through MACS, and we thank the charity for that every single day.

Thanks to Robbie and Caitlin for sharing their amazing story, as more of our MACS adults enter the parenting journey we would like to take this opportunity to signpost anyone to Blind Parents UK – supporting anyone with a visual impairment, regardless of sight level or where they are on the parenting journey. BPUK is the only support network for VI parents in the UK and have their own qualified sling and breastfeeding supporters alongside a growing community, all of whom have a visual impairment. To find out more email **info@blindparents.uk** or search Blind Parents UK on Facebook. For full transparency our services manager, Kim, proudly leads the BPUK team.

MEET TEAM MACS 2025

In 2024, our 150 runners raised over £250,000 for MACS – **WOW**!! We're now thrilled to inform you that we have recruited our team of 155 runners for next year's marathon...and what a fantastic bunch they are!! Introducing them all would take a whole magazine, but here are a few of our runners and their reasons for choosing to run 26.6 miles for MACS...

ISOBEL CLARKE

'I'm excited to run the London Marathon 2025 in support of MACS. I chose to run for MACS because I want to make a difference. By raising awareness and funding we can ensure that MACS' incredible work helping children and supporting their families through the diagnosis and beyond can continue. Good luck to all of the MACS Charity runners through your training!'

TOM BEIRN

I am excited to be running the London marathon to help raise money for the amazing charity that is MACS. My son Rupert was born with microphthalmia and a congenital cataract in his left eye. The reassurance and support MACS provides has been invaluable and there meet ups have been a great way for Rupert and us as a family to get to know the MACS community.

NICOLE HUNTER BLAIR

Running has become a personal therapy for me, bringing structure to my life. Taking on a marathon has always been a dream, though a challenging one. Next year, I'm running to support MACS because I'm inspired by their work with children and adults born without or with underdeveloped eyes. Witnessing the resilience of those who face these challenges moves me, and I'm grateful to contribute to a cause that impacts lives so profoundly.

MACS reaches over 3,000 people from 1,000 families across the UK, providing practical and emotional support, organizing empowering events, and advocating for those they serve. With every mile I run, I hope to raise awareness and support for their vital work.

MUSTAFA MOHAMED

I began running May 2024 to stay in shape and spend more time outdoors. As my running progressed I needed a long term goal to keep me motivated which is when I decided to sign up for the London marathon 2025 and fundraise for Macs. Macs caught my attention as my grandmother had eye problems before her passing and the work carried out really resonated with me.

DAVID JACKMAN

MACS is a small national charity **'supporting children and adults born without eyes or with underdeveloped eyes'.**

When I read this, well it became apparent to me immediately that all of my own aspirations and ambitions dissipate to trivial when considered against the stark reality that people with these life conditions must face a greater challenge than I will likely ever know, every single day.

The privilege of reading or of writing a book would be so much more challenging, as would watching a movie, or driving a car, or....well so many things.

I thought in 2024 running TCM's London Marathon in a modest 4hrs 48 (injured and on one leg) was a thing, and I remember feeling awe on several occasions when blind runners

with their guides were out doing their own '26.2'.

It is virtually impossible to understand the challenges life presents if you are born without eyes or limited ocular evolution, but it is always possible to try and help.

Children are our future, everyone's future, the only possible tomorrow.

And so guess what, time to give something back methinks for this amazing and privileged life I have The people at MACS, and those they care for, deserve EVERYTHING I can give.

I hope everyone will donate as generously as they are able, and I promise to deliver 26.2 miles to aid in lighting in some small way, the path that lies before them all.

MARTIN SCHRANZ

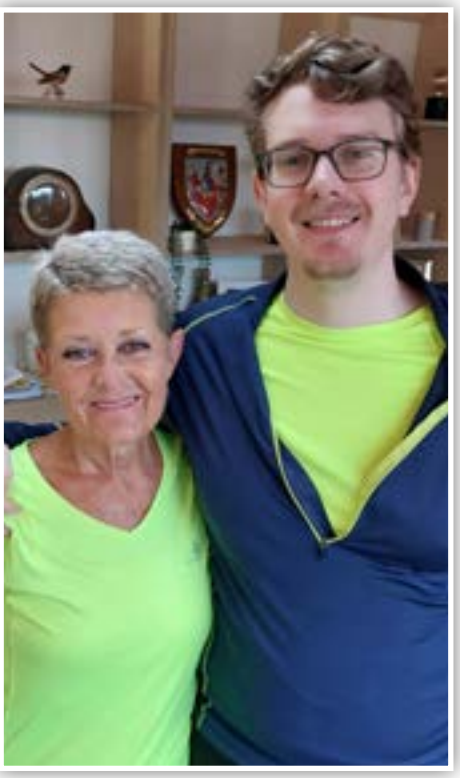
For me, marathon running is more than just a sport; it's a challenge, a passion, and above all, an opportunity to give something back. This year, I have the privilege of running the London Marathon for the charity MACS – an organisation dedicated to supporting children born with eye defects, offering hope and assistance to them and their families. Deciding to support MACS was easy, as their mission resonates deeply with my personal values.

In my life, I've had the immense fortune of raising three healthy children and enjoying success in my career. This journey, and the gratitude that comes with it, inspired me to establish my own foundation focused on children's education in Nepal. Through my work with the foundation, I've come to understand how vastly different the challenges faced by families around the world can be and how essential it is for some to have support. This insight has only reinforced my belief in the importance of taking responsibility and sharing one's good fortune with others.

That's why I consciously choose to run my marathons in support of organisations focused on helping families and children – like MACS. This charity does remarkable work by providing children with visual impairments and their families with a sense of hope and the essential support they need. MACS helps to break down barriers and offers these children the chance to live their lives to the fullest – a mission I wholeheartedly endorse.

Children are our future and the most precious asset we have. As I run through the streets of London, I'm not driven solely by athletic ambition; I'm motivated by a genuine desire to make a difference. Every mile I complete is a step towards a future where families can rely on support and children are empowered to reach their full potential.

By taking part in this marathon and raising funds, I hope to make a positive impact, however small, on the lives of many families. I truly believe that as a community, we are stronger together, and through our efforts, we can open up new opportunities for children and their families.



JULIE AND ROB FURZELAND: Myself and my son Rob are delighted to be running for Team MACS in the 2025 London Marathon.

We believe that MACS is an amazing charity helping babies, children and adults with severe eye problems and their challenges. We look forward to being part of the Team MACS family.

VINCE GREENAWAY

Our little Maeve was born on 8th April 2024, at 36 weeks. A few hours after Maeve was born, the doctor realised that Maeve hadn't yet opened her eyes. We'd hoped this was as Maeve was born premature, but deep down we knew something was wrong. Over the next few days Maeve had several tests and we were told the devastating news that our little girl was born with bilateral anophthalmia and will unfortunately never be able to see as a result of no optical nerves or eye development during pregnancy.

Hearing Maeve's diagnosis was a shock, followed by days of grief and worry about what the future may hold for our little Maeve. Maeve was just a tiny baby, and as family we felt helpless and has so many unanswered questions about her condition.

We were almost immediately introduced to a charity called MACS, who have been brilliant in showing us that we aren't alone, and provided huge comfort and support during what were tough weeks and months at the start of Maeve's life. Its been so reassuring being able to connect with other families in the same situation as us, and we are so grateful to MACS for providing us with the opportunity to be part of this community.

Fast forward five months and Maeve is thriving, she is the happiest little baby and she has her twin sister Orla with her every step of the way! She is hitting every milestone so far, and we know she's going to do amazing things. We couldn't be prouder of her.

Not only is this going to be the biggest physical & mental challenge of our lives, but it's also an incredible opportunity to raise money and awareness for MACS, a charity that is so close to our families hearts. Thank you for your support!

Continued over...

Acknowledging our regular givers

By John Leadbeater

At MACS, we are continually inspired by the dedication and generosity of our regular givers, whose steadfast support has been at the heart of everything we do. Thanks to you, our community is stronger, more connected, and better equipped to provide essential services to those living with Microphthalmia, Anophthalmia, and Coloboma. From the life-changing meet-ups to the guidance and resources provided to new families facing MACS diagnoses, every initiative is made possible by the kindness and commitment of our regular donors.

MACS currently has 20 regular donors, some of which have been giving on a regular basis since as far back as 2013.

Together our regular givers donate a collective £201 per month and £2,412 per year. Here are a few of our regular donors who would like to share their stories with the MACS community.

ZARA BOSWELL

My name is Zara and this year I turned 50 in July 2024. I have 2 children Ayesha 22 and Jav 27, a very supportive husband Wayne and our beautiful cocker spaniel Bonnie who is 13.

I have been a runner for years and done 7 marathons, lots of half marathons and 10ks. I am a regular Saturday morning park runner.

For my 50th year I wanted to run the London Marathon as I did it 10 years ago but also wanted to raise money for a charity.

I chose MACS as it's a small charity and the work they do is amazing.

I work with young people in care. Some with Autism, learning disabilities, Downs Syndrome and ADHD. I love my time with them making sure they enjoy life like the rest of us. Giving them help towards independence and getting them out into the community to feel a belonging.

I feel that's exactly what MACS does for the children and their families. Since I received a place to run the marathon the communication between me and MACs has been amazing and I feel part of the charity and raising funds to help is better than running London marathon. I hope I do them proud in which ever way I can get through 26.2 miles. Thank you MACS

JENNIFER BISHOP

I give regularly to MACS as it is such a supportive, comforting, inclusive and inspirational charity. We joined just after Ewan was born in 2007 and it has been a great support to all our family. I'm delighted to continue to support such a worthwhile charity which we have met some amazing people through.

CAROLE APPLEFORD

My interest in MACs began about 15 years ago. I was teaching a girl in mainstream school who had extremely poor vision due to her birth defect, her name was Marisa Sankar. Coincidentally there was a girl in my form whose younger brother Ben, had been born without eyes. The girls in the class did a fundraiser at the summer fayre. They organised an obstacle course which participants had to do with a blindfold. Since then I have been happy to support you as I discovered that both families were being supported by MACs. To this day I have a sticker in the back of my car.

NICOLE STANHOPE

I began giving a regular donation to MACS after my grandson Leo was diagnosed with optic disc coloboma as a baby. He is now nearly 8 and although the vision in his right eye is limited (or in his terms "a bit rubbish") he has good vision in his left eye. He can be rather clumsy which could be because his 3D vision is affected or because he is a 7-year-old who rushes about everywhere!

LAURA SINCLAIR

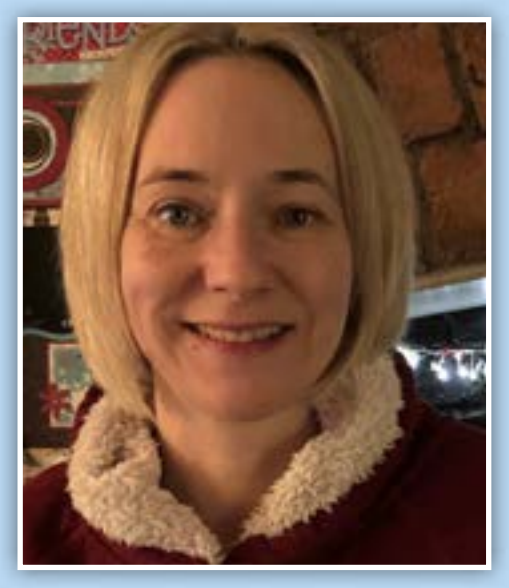
Before my daughter Penny was born, I had never heard the word coloboma. That quickly changed, when a few days after she was born and with the help of Dr. Google I noticed her iris coloboma. It was several weeks until her official diagnosis of left optic nerve and chorioretinal coloboma involving the macula.

I am forever thankful that I very quickly found MACS and the Facebook support group which put my mind at ease. Simply put, this is why I give to MACS: without this community, I don't think I would have been able to enjoy those early days with my baby and could have easily been consumed by worry and uncertainty. Plus, as Penny grows up (she's only 4) and has questions of her own, it's great to know there is a place she can turn to for support and a sense of inclusion to form her own personal connection.

JUDITH ACKERMAN

My name is Jude. In 2019 I was privileged to be a part of the MACS team to run The London Marathon. I did this in 4 hours 56 minutes and loved every single step of it.

I was grateful for the charity to put their faith in me to run for them. The support from MACS was overwhelming right from the beginning of the journey to the end. I knew that during this adventure I had chose a special charity. I was not wrong! Meeting the children and the families at the two designated tent areas en route during the marathon and meeting them at the end was so inspirational and emotional. They were just gorgeous, friendly, grateful, loving, courageous and they stole a little piece of my heart. It was at that moment that I decided that I would like to donate every month to this wonderful charity. I don't give a massive amount, but every penny helps the charity to be able to give support, experiences and respite which are invaluable. It's an absolute honour to be able to do this and I do consider myself to be a be part of the wider MACS family.



JULIE TIBBITS

10 years ago our grandson, Frazer, was born with left Anophthalmia and right microphthalmia. Initially we were all in a very dark place and we could see no future for Frazer, our first grandchild. Two things happened to pull us through. Firstly, a friend very firmly told me that I had no right to assume this and that Frazer would live his own life, we just needed to support him to be his best. Secondly, we found MACs.

Becoming a member of this wonderful charity meant I had access to a wealth of information about Frazer's conditions. By the time Frazer was 6 he'd had 64 operations on his micro eye and being able to ask questions and listen to the experiences of other MACs member was invaluable as we supported our daughter, a single parent, through it all.

Through hospital visits and the MACs Facebook group we've met other MACs families and being able to see some of the other kids achieving and thriving into adulthood has helped us overcome our fears. Frazer is totally blind and is a fabulously happy and sociable boy. He amazes us every day with his thirst for knowledge. He positively hates Braille reading and writing but is fluent in Spanish and plays the saxophone and piano. As a thank you to the organisation that helped us through some very bad times, I set up a standing order to give a small donation to MACs each month.

Inspired by our regular givers?

Become a regular giver and help fund friendship, confidence or even adventure for MACS members across the UK.

This year, around 114 families in the UK will be told their babies have no eyes (Anophthalmia), small eyes (Microphthalmia), or a cleft in the eye (Coloboma). Many of them will have additional needs or other health challenges. Some will be told there's no hope that their child will ever see. They may feel hopeless and alone, but because of support from generous people like our regular givers, they are not alone and there is hope.

JUST £4 A MONTH COULD FUND A WARM WELCOME OR BIRTHDAY WISHES...

A small monthly gift of just £4 could ensure that a new family enjoys a warm welcome and induction to MACS or it could help Macs the Monkey send birthday cards to three MACS kids each Month!

£15 A MONTH COULD FUND FUN WITH FAMILY AND FRIENDS...

A small monthly gift from you of just £15 could pay for a child to join all of their friends and MACS connections from across the UK at our annual MACS Get-together. If you've read about our Thriving at Thirty! event on pages 9-13, you'll understand what a valuable and enjoyable event this is for members.

£25 A MONTH COULD FUND FRIENDSHIP...

£25 a month could fund advice, guidance, and training for a MACS family on Access Technology. You'll have read about Sean, our new Access Tech Support volunteer, on pages 26 and 27; while he's kindly giving his time totally free of charge, we still need the funds to get him around the country to deliver these sessions.

£50 A MONTH COULD FUND ADVENTURE...

£50 a month could pay for a place for a younger MACS member to climb, zip-wire and row their way through our Adventure Weekend!

All amounts are examples only and based on twelve monthly donations. Donations can be allocated to specific services upon request.

Get in touch with **john@macs.org.uk** today to find out more about becoming a regular giver.

A MASSIVE THANK YOU! TO OUR SUPPORTERS...

AIDAN BENTHAM

On Wednesday, 11th of September, during MACS Awareness Week, 4-year-old Aidan Bentham gave a memorable presentation to his class. Aidan's teacher read aloud the book "What Makes You You," which he proudly shared with his classmates. Through this, Aidan helped his fellow pupils learn about MACS and MACS conditions. To make the day even more special, Aidan received a congratulatory letter from MACS the Monkey himself! Well done, Aidan – fantastic job!

JULIE AITCHISON & SHARON LEE
QUIZ NIGHT FRIDAY 1ST NOVEMBER

Brandshatch Place Hotel & Spa (Handpicked Hotels) chose MACS for their Charity Night for a very special reason— the organiser Julia's son, William, is a MACS young adult. William has been a member of MACS since he was very young and has greatly benefited from the charity's events and trips, particularly the sailing trips, which we're told he absolutely loves.

Julia tells us, 'I've worked for Handpicked Hotels for 18 years, and many of our members know William or have at least heard about him and his journey with MACS.' The charity evening proved to be a wonderful opportunity to raise awareness among those who may not have heard of MACS before. It was a fantastic event that brought new attention to the charity's important work.

Thanks to Julia and the generosity of those who attended, the event raised an incredible £461 for MACS, helping to support the ongoing efforts to benefit MACS members.

Can you help us reach more people who need us? There are thousands of people in the UK who have MACS condition but are not MACS members. A big part of the reason for this is that they simply haven't heard of us. Can you help by asking your local Eye Clinic to display this small poster?

Microphthalmia Anophthalmia & Coloboma Support

Every year in the UK, an estimated 114 babies are born with small eyes (Microphthalmia), no eyes (Anophthalmia), or a cleft in the eye (Coloboma). MACS is a small national charity supporting people with MACS conditions and their families.

www.macs.org.uk

Registered charity number UK: 1161897 Scotland: SC052711

Microphthalmia, Anophthalmia & Coloboma Support

Supporting People born without eyes or with underdeveloped eyes

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

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

FUNDRAISING REGULATOR