ISSUE 18
DECEMBER 2023

Microphthalmia, Anophthalmia & Coloboma Support
Supporting people born without eyes or with underdeveloped eyes

FOCUS MAGAZINE

Microphthalmia, Anophthalmia & Coloboma Support

Supporting people born without eyes or with underdeveloped eyes

Contents

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**

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MACS MAGAZINE | VOLUME 18
Thanks so much to all members and supporters who've contributed towards this edition. If you'd like to feature in the next edition, please do let us know!

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Chair's Welcome!

WELCOME FROM OUR CHAIR OF TRUSTEES

Welcome to the 18th edition of MACS' Focus magazine! As we turn 30 in 2024, we've been taking a look at our mission and purpose to better understand the impact we want to make on all of our members' lives.

What began as a charity for MACS children and their parents has evolved with our members. Many MACS children who were part of the charity's inception have now grown into adulthood, and those who followed are entering adolescence. This period has been incredibly important for us as we've listened to our members and worked together to establish a refreshed long-term goal:

All people with MACS conditions in the UK and their families are less isolated, better connected and have access to the advice, information and support they need to thrive and confidently lead a fulfilling life.

Our previous vision is of a world where all individuals with MACS conditions can enjoy the same opportunities as everyone else. Our mission had been to become the leading authority on MACS conditions and provide comfort and support to those affected by them.

In December, we took your feedback from a membership-wide survey to a workshop conducted by Insley Consulting as part of a resilience building initiative funded by CAF. We've refined our mission and vision statements to align them clearly with our new goal, and we're excited to share these updated statements with you soon.

Since the December workshop, we've also introduced new values that will be at the core of everything we do. We're also in the process of assembling a newly structured team that will embrace these values in all their work for MACS.

"It's an exciting time for MACS, with numerous accomplishments to celebrate and many more on the horizon"

As you may be aware, our CEO, Liz Bates, retired from her post in June. Along with this role, another position remained vacant as we took the time to review all roles in light of our members' needs. We've developed a new structure, and we've been recruiting from the ground up.

We've also welcomed Clare Jones to the team as she takes on the role of Member Services Coordinator, an evolved version of the previous Admin Officer role that Jess held. Clare will be joining newly appointed Member Services Development Manager, Kim Randall, and Sharon in the Member Services team. Kim and Clare are excited to start working with you all from January; in the meantime, you can read a short introduction from them both on page 5.

As well as recruiting to a full Member Services team, we have created a new hybrid role for our existing Fundraising and Communications Manager. This new role will be the Director of Charity Development and will report directly to me as I continue in my acting CEO role in a voluntary capacity. This step allows us time to identify the need for dedicated resources for income generation and secure the necessary funding. We have included our new organisational chart on the next page.

It's an exciting time for MACS, with numerous accomplishments to celebrate and many more on the horizon, including a full calendar of events for the year ahead and the launch of new services.

We hope you'll begin to experience the positive impact of these changes, and as always, my door is open for any feedback, whether it's good or bad.

Before we conclude, I'd like to take this opportunity to wish you a restful and enjoyable festive period, regardless of how you choose to celebrate.

Best wishes,

Teresa Gordon
Chair of Trustees

P.S. There have been some changes to the Board of Trustees and staff team, so please refer to the next page for up-to-date team and contact information.

Meet the Team

ORGANISATIONAL STRUCTURE

Board of Trustees

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Member Services Development Manager

Starts on 8th January

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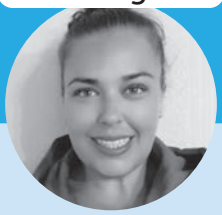

Communications Outreach Officer

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Clare Jones

Member Services Coordinator

Starts on 2nd of January

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Sharon Williams

Member Engagement Officer

sharon@macs.org.uk

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Meet our new Team Members

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

JESSICA MONTAGUE
COMMUNICATIONS AND OUTREACH OFFICER

You probably remember meeting Jess in our previous Focus magazine when we introduced her as our Admin Officer. Well, we're thrilled to share that Jess has now stepped into a brand-new role as our Communications and Outreach Officer, and we believe she's the perfect fit for it!

This role is quite exciting as it bridges the gap between our services and fundraising efforts. Its primary focus is to raise awareness about MACS, connect with new members, and rally support. Jess will take the lead on MACS' annual communications plan and mailing schedule, working closely with both the Member Services and Fundraising teams to gather heartfelt content and messages from our members.

As part of her new role, Jess will also champion accessibility, making sure that all our communications, publications, and promotions are as inclusive as possible. As someone who does not have a visual impairment, she's eager to upskill and learn more in this area and welcomes input from our members. So, if you have any insights or information that could contribute to Jess's accessibility mission, please don't hesitate to reach out. Your input is greatly valued!

CLARE JONES
MEMBER SERVICES COORDINATOR

We are delighted to welcome Clare Jones to the team in the role of Member Services Coordinator. Clare will look after bookings for venues, speakers and suppliers for member events and activities, as well as managing the booking system for members who wish to attend the events. She will also look after most of the general admin for the Member Services team.

Clare brings with her a wealth of administrative experience, with an NHS background. She lives in Southampton with partner Sam, son Leo and French Bulldog Mabel. Leo was born with Coloboma in 2021.

Clare tells us, 'I remember feeling so isolated and alone the first few months with the unknowns. We were directed to MACS and the support we have received from the charity itself and other members has been amazing and really made such a difference to us. I am excited to start my new role in the new year and to work with such an amazing team of people.'

KIM RANDALL
MEMBER SERVICES DEVELOPMENT MANAGER

Kim tells us she is delighted to be joining the MACS family. As a passionate and dedicated individual, she hopes to bring a unique combination of skills and experiences to the table.

While not having a MACS condition, Kim is blind from birth, married to Sean who is also blind. They live in the midlands with their daughter, Lily, almost 13, and cavalier King Charles spaniel Millie. In her spare time, Kim loves nothing more than cooking and baking, playing tennis, swimming, walking, watching comedies and decent dramas and spending time with her amazing family.

You'll often find Kim chatting, laughing, checking out the latest tech options or analysing the state of today's music! She hopes to bring a combination of lived experience and learned skills to the role, including from her previous employment as a Braille teacher and the many years she has been running Blind parents UK.

Kim has had the privilege of working with a diverse range of individuals, including vulnerable teens, blind and pregnant parents, and the elderly facing challenges related to the loss of their eyesight, and she hopes you'll find her approachable and fair whilst joining the MACS team.

AMY FRANCOMBE
DIRECTOR OF CHARITY DEVELOPMENT

In January 2024, our Fundraising and Communications Manager will step into this new and crucial role for MACS. Leading in the development and implementation of new strategies for both the diversification of sustainable funding streams and the development of member services, both with a priority of delivering the refreshed organisational objectives driven by MACS' revised theory of Change.

Amy has led in the review of the organisational structure, developing the existing roles and identifying skills and resource gaps to ensure capacity is maximised on both a strategic and operational level. Amy is excited to be driving forward the development and delivery of MACS' organisational priorities.

Calendar 2024

2024 EVENTS		
When	**What**	**Time**
10 February	MACS Meet Up Newcastle	10.00am
April TBC	MACS Adults Meet Up	TBC
1 June	Mersea Island Adventure Weekend	TBC
8 June	MACS Meet Up Newport	10.00am
27 July - 2 August	MACS Sailing Adventure Trip	TBC
29 July - 2 August	Calvert Activity Trip	TBC
24 - 25 August	Thriving at Thirty *(MACS birthday party)* event **NORTH**	TBC
7 - 8 September	Thriving at Thirty *(MACS birthday party)* event **SOUTH**	TBC
19 October	MACS Meet Up Nottingham	TBC

You'll notice two special events in our calendar for 2024: our Thriving at Thirty events! Through all of the work we've been doing to shape MACS' future, we've gathered lots of feedback from members around what works with our existing services and what doesn't, and a theme throughout these responses was the distance many members have to travel for our in-person events. Therefore, in 2024, we're taking what was our two-night MACS Family Weekend event in the North and creating two one-night events: one in the South and one in the North!

We're working hard to make these events as special as they can be and will update you all with the details as soon as we can. In the meantime, the general format will include some great opportunities to connect with fellow members throughout the Saturday, and a sit-down meal in the evening, followed by a big ol' birthday bash to celebrate MACS's 30th!

We hope to see you there!

New Members First Wednesday of the month	**8.00pm**
Quiz First Saturday of every second month commencing 6th January	**7.45pm**
Adults Social Zoom Last Wednesday of the month begins 31st January	**8.00pm**
Giving Members a Break opens 8th January 2024	**12.00pm**
Mini MACS Campaign #1 commences 8th January 2024	**8.00am**
MACS Teen Podcast #1 15th January 2024	**7.00pm**
Extended Family Coffee Evening 17th January 2024	**8.00pm**
Creative Writing Workshop 30th January 2024	**7.00pm**
Sailing Info Evening 6th February 2024	**7.00pm**
Wizard Workshop 12th February 2024	**4.00pm**
MACS Dads Zoom 14th February 2024	**8.00pm**
Children's Creative Writing Workshop 15th February 2024	**4.00pm**
Younger Sibling Workshop 21st February 2024	**4.00pm**
Younger Sibling Workshop 28th February 2024	**4.00pm**
MACS Teen Podcast #2 4th March 2024	**10.00am**
Younger Sibling Workshop 6th March 2024	**4.00pm**
Younger Sibling Workshop 13th March 2024	**4.00pm**
Creative Writing Workshop 26th March 2024	**7.00pm**
Mini MACS Campaign #2 1st April 2024	**8.00am**
Spy School 2nd April 2024	**4.30pm**
Kids Creative Writing Workshop 4th April 2024	**4.00pm**
Creative Writing Workshop 23rd April 2024	**7.00pm**
MACS Teen Podcast #3 6th May 2024	**10.00am**
Extended Family Coffee Evening 15th May 2024	**8.00pm**
Balloon Modelling Workshop 28th May 2024	**4.30pm**
Creative Writing Workshop 28th May 2024	**7.00pm**
Kids Creative Writing Workshop 30th May 2024	**4.00pm**
MACS Dad's Zoom 12th June 2024	**8.00pm**
Creative Writing Workshop 25th June 2024	**7.00pm**
MACS Teen Podcast #4 8th July 2024	**10.00am**
Creative Writing Workshop 23rd July 2024	**7.00pm**
Mini MACS Campaign #3 5th August 2024	**10.00am**
Fun Filled Disco 6th August 2024	**4.30pm**
Kids Creative Writing Workshop 15th August 2024	**4.00pm**
MACS Teen Podcast #5 2nd September 2024	**10.00am**
Older Sibling Workshop 11th September 2024	**4.00pm**
Extended Family Coffee Evening 18th September 2024	**8.00pm**
Older Sibling Workshop 18th September 2024	**4.00pm**
Creative Writing Workshop 24th September 2024	**7.00pm**
Older Sibling Workshop 25th September 2024	**4.00pm**
Creative Writing Workshop 22nd October 2024	**7.00pm**
Kids Online Workshop 29th October 2024	**4.30pm**
Kids Creative Writing 31st October 2024	**4.00pm**
MACS Teen Podcast # 6 4th November 2024	**10.00am**
Mini MACS Campaign #4 5th November 2024	**8.00am**
Creative Writing Workshop 26th November 2024	**7.00pm**
MACS Dads Zoom 11th December 2024	**8.00pm**
MACS Online Panto 14th December 2024	**TBC**
Kids Creative Writing Workshop 19th December 2024	**4.00pm**
Kids Online Workshop 23rd December 2024	**4.30pm**

HELLO To new members

IT IS OUR PLEASURE to introduce you to a handful of the many new members that have joined MACS since the last issue of our Focus magazine. We're sure you'll join us in giving them a warm welcome, and please do feel free to get in touch with the team if you have any advice or support you would like to pass on as these members start their journeys with MACS.

HENRY

This is Henry, he's almost 10 months old! He was born with right eye microphthalmia, bilateral coloboma and recently diagnosed with horizontal nystagmus and amblyopia to his right eye.

It was so difficult to adapt to the changes we had to make to help Henry as it's not something we have ever heard of, and we definitely didn't expect something like this, especially with him being our first born.

MACS have truly helped me as I now know I am not alone, and I absolutely love reading how the children and adults born with the same condition are now thriving in life. It gives me hope that Henry will be the same.

From Henry's mum, Katie

WILLOW

Our little Willow was born March 2023. Her Daddy instantly noticed something didn't look quite right. On completing the newborn checks, it was discovered that Willow's left eye had not developed, and her right eye potentially had a cataract.

Due to the local hospital not being specialists in this department, we were referred to Great Ormond Street Hospital. We attended an appointment three months later and discovered that Willow has anophthalmia in her left eye. Willow was required to undergo further assessments to investigate her right eye.

With recent appointments, it has been discovered that Willow does not have a cataract. It was also confirmed that she does not have sight in her right eye. This is a whole new journey for our family, us as parents and her two older siblings, but with the support from MACs and the Guide Dog Charity we have felt fully supported and ready for this journey. Willow is the happiest of little ladies who loves water, swimming, sensory toys and using her voice to get everyone's attention.

From Willow's mum, Vikki

FREYA

Our beautiful baby Freya was born in January 2023, and a few weeks later we noticed the shape of her pupils were not as we expected. Fast forward a few months and a fair few medical appointments, we now know she has bilateral chorioretinal coloboma and left microphthalmia. Freya is the happiest little girl who is always keen to smile, and she brings this positivity to everyone around her. She is developing so well and seems really motivated to work to have the best vision possible. We couldn't be prouder of her. It has at times been a challenging journey, where it has felt like for every answer we receive, we have five more questions. The MACS community has been so positive to reach out to where we have had questions, or wanted to see examples of what the future may hold for Freya, given we knew nothing about MAC conditions prior to Freya's diagnosis. We also couldn't be happier with the care that Freya is receiving at Moorfields hospital - every person we have seen there seems so invested in Freya's care, development and happiness.

From Freya's mum, Sarah

LENA

Our little Lena was diagnosed with microphthalmia of the right eye a few days after she was born in June of this year (2023). The diagnosis was quite shocking and frightening at first, especially as Lena was in the Neonatal ICU for a couple of weeks, and we were initially worried she had a more serious condition. Over time, some conditions have been ruled out and we have been able to watch this wonderful little human grow and develop at home.

We've been really happy with the care at King's College Hospital. During our initial stay at ICU Lena was seen by a neurologist, an occupational therapist, a speech and language therapist and physiotherapist which was very helpful in getting a better understanding of her condition. We've since had several follow ups with the ophthalmologist. After a VEP test at Great Ormond Street hospital we've learned that she has severely restricted vision in the right eye, the left eye supposedly has normal vision although she does have nystagmus. It took her much longer to smile than other babies her age, but started giving an enormous grin at around 15 weeks, which has us both melting into puddles. Parenthood has been a bit different than we expected, but the support we've had from all corners, including finding MACS, has made all the difference.

From Lena's mum & dad, Michal & Kyla

MACS Meet-Ups

Bradford

with thanks to Sovereign Healthcare Community Programme

Unpredictable July Weather didn't dampen our gathering in Bradford...

Despite the unexpected downpours, our members came together for a heartwarming day filled with connections, laughter, and the spirit of community. This special event, held in July, brought both our long-standing MACS members and newcomers closer, creating beautiful memories.

The day was packed with delightful surprises, as our younger MACS members wowed everyone with their limbo and dance skills during the kids' entertainment hour. Laughter and interaction were everywhere during the enchanting magic show, brilliantly hosted by Tanya from Non-Stop Kids. We'd like to give a special shout-out to Chris, the father of Arthur and Patrick, who joined the performance with infectious enthusiasm and good humor.

Our long-standing members, made up of families and four MACS adults, extended a warm welcome to the newer MACS families, fostering an atmosphere where experiences, advice, and understanding flowed freely. One member, reflecting on over 25 years of MACS membership, highlighted the significance of giving back:

"For us, MACS is not just about what we can gain, but what we can contribute to the charity and new families. We aim to share our experiences, knowledge, and celebrate the achievements of our child, who is now an adult."

Following the captivating entertainment, everyone gathered for a delicious buffet lunch, and our cheeky mascot, Macs the Monkey, brought additional joy to the occasion with hugs, games, and countless family photos.

Members shared their appreciation for the day, praising the warm welcome and the chance to make new friends and connections:

"What a delightful event that we thoroughly enjoyed. The team made us feel right at home, and our child had a blast playing with others."

"We're grateful for the opportunity to meet other members; it was so easy to get to know people, and we had an amazing day."

This event showcased the strong sense of unity and support within the MACS community, proving that not even unpredictable weather can dampen our spirits. We eagerly look forward to reuniting with our members in the future, as we continue to nurture connections and provide invaluable support.

Mersea Island Festival

In August, 30 of our members joined the team at the magical Mersea Island Festival. It's an annual adventure extravaganza in Essex that welcomes children, young people, and adults from all walks of life, with or without physical or learning disabilities. The event was packed with loads of thrilling activities!

This was our very first experience of the Festival, and we took a cautious approach, sponsoring a select group of members for a single day out of the event's nine-day fiesta.

Our members had a blast, and the feedback was off the charts. They raved about the experience, and it got us thinking. We heard you loud and clear! So, we're cooking up something special for you in June 2024, a bespoke MACS-only event. It's all about that cosy, community feeling and peer support.

But that's not all. We joined forces with the Mersea Island Festival organisers, who happen to be a registered charity too (Mersea Island Festival Trust, Registered Charity 1097455). The result? We've got Essex Outdoors all to ourselves on the 1st and 2nd of June 2024. Exclusive use, how cool is that?

We've got room for 50 adventurers each day. And boy, do we have a line-up for you! Picture this: accessible adventures and activities that might be tricky to find elsewhere. We're talking "It's a Knockout," archery, fishing, African drumming, circus skills, zip-lining, and quad biking, just to name a few. We've cooked up a storm of activities designed to boost confidence and show that having a visual impairment is no obstacle.

We've got a dream team of qualified instructors who set out to make every activity as inclusive as possible, so everyone can join in the fun.

One of our MACS parents summed it up perfectly: "The benefits of attending are greatly untold, and some you do not realise until months or years down the line. It benefits our MACS child, in that he can relax and be himself, it benefits our daughter who blossoms into our caring, inspiring girl, and it benefits us in that we reunite with special friends that we may only see once a year and we receive untold support through difficult times. Just a hug can tell you that someone else understands and cares."

So there you have it, folks! The MACS-exclusive event in June 2024 is going to be a whirlwind of adventure and community spirit. We can't wait to share it with you and make more heart-warming memories together.

Bury-St-Edmonds

In October, MACS members gathered at Ashlar House in Bury St. Edmunds for an unforgettable day. Ashlar House was a great venue and we can't say enough about Camilla, our gracious host, who received well-deserved praise for her fantastic support and unwavering attentiveness. And let's not forget the delightful buffet that made the day even more enjoyable.

We were delighted to have 26 attendees from 8 families, which truly reflects the dedication and spirit of the MACS community. Notably, one keen family of four, including two young children, embarked on an impressive 340-mile round trip to be part of this special gathering.

Our meet-up was a wonderful blend of familiar faces and new friends. Two families had previous experience with other MACS events, while six families were joining a MACS event for the very first time. One of the most touching moments of the day was when a 6-year-old member initially felt a bit shy about entering the room. With some encouragement, this young individual found the courage to join in the activities. Assured that there were others with similar experiences, including some without sight, this child had an amazing time. They connected with others and even stepped into the role of the assistant during the magical performance. The entertainment was provided by Tom from One Stop Kids, who traveled all the way from Derby to add some extra excitement to the day. After a delightful lunch, we took a moment to honor Brian for his recent fundraising run, recognising his dedication and commitment. Read more about Brian in the 'thank you' section.

The afternoon provided a more relaxed atmosphere, allowing our members to engage in conversations, build connections, and enjoy various leisure activities. Our younger members had a blast with balloons, Jenga, floor games, Duplo, Boppit, and the sensory tent, creating a wonderfully chaotic yet thoroughly enjoyable atmosphere. The Bury St. Edmunds MACS Meet Up was a heartwarming reminder of the power of unity and community. It showcased how people can come together to connect, support one another, and celebrate the joy of being part of a community. Expect more exciting updates from MACS as we continue to create opportunities for connection, support, and lasting memories.

A massive thank you to the masonic lodges of Suffolk for banding together to fund this event!

ADULTS Meet-Ups

Adult MACS Meet Up in Birmingham – September 2023

We facilitated the first ever Adults MACS Meet Up back in September and great fun was had by all!

We welcomed a mix of 14 members, some of whom were old friends through MACS and some had never even been to a MACS event before. The youngest attendee was 22 and the oldest was of an age at which, in their own words, 'you stop counting'.

It wasn't just voices speaking out through our annual survey and Focus Group that suggested an adult event was well overdue, but the distances travelled by some attendees also showed us just how much this was needed – some attendees travelled from mid-Scotland in the North and some from Plymouth in the South!

It was lovely and everyone enjoyed being able to get together and socialise with fellow MACS members. The group stayed in the Crowne Plaza, which was apparently a bit posher than we'd expected, and a fantastic and fully accessible venue. The staff were brilliant and massively accommodating to members' needs, and they were always at hand in case any assistance was required. This event was self-funded but we were fortunate enough to be able to have the funds to treat everyone to a meal on the Saturday evening, which went down a treat.

'The location was perfect and right next door to the resort centre, which was a few yards away. This worked really well as the group had wanted to do quite different things on their weekend,' said MACS' Member Engagement Coordinator, Sharon.

'The activities they chose were varied and included axe throwing, zip wiring, Bear Grylls Activity Centre, Coffin Museum, trip to Birmingham, Gaming, and Cocktails. There were a lovely choice of restaurants and several members of the group met up to eat during the afternoon.'

We are looking at the event for 2024 now and were hoping a few more members would come along. We would also like to have a few sighted buddies so that the members who need an escort to get about could be more independent. Please check your newsletters for the dates for the next event or come along to our MACS Adults zoom meetings.

Making Connections

Helping two strangers become "long lost twins"

Earlier this year, ten-year-old MACS member Fern, embarked on a journey that would connect her with an unexpected kindred spirit. As Fern navigated her final year of primary school, she had never encountered someone like her with the same MACS condition, until her mother, Lynsey, decided to take matters into her own hands.

Lynsey, eager to forge connections for her daughter, reached out to MACS to see if we could help, which of course we didn't hesitate in doing. We connected Lynsey with Donatella, mum of nine-year-old Gaia from London. The two families discovered an uncanny resemblance between Fern and Gaia, not just in their shared medical history but also in their appearance, leading them to affectionately refer to each other as "long lost twins."

The girls began their friendship with a Pen pal exchange, sending each other postcards. Fern's mum told us, "Fern read Gaia's postcards over and over. It was someone who gets her."

Lynsey felt Fern had never quite felt she had been able to make connections at in-person events for people with visual impairments or MACS conditions but thought Fern would benefit more from a one-to-one meetup. Lynsey arranged brunch with Donatella and Gaia to coincide with a trip to Moorfields for Fern's surgery.

Fern's mum, Lynsey, expressed the profound impact this connection had on both families. "We shared the same worries and same experiences – no other parents truly understand," she said. The newfound bond between Fern and Gaia served as a lifeline, providing comfort and understanding for both girls and their mums.

Gaia's mum Donatella added, "Gaia is so excited whenever a postcard from Fern arrives and she was delighted to meet and chat with her. It seemed that they felt an immediate bond with one another. Meeting Fern means a lot to Gaia, who has never met anyone with her condition before, as she knows that she has a special friend who really understands her experience."

> " We shared the same worries and same experiences – no other parents truly understand "

Lynsey, reflecting on the experience, expressed a wish that more parents knew about MACS' willingness to connect people on this one-to-one basis. "If parents knew there was a service like this that connects their children with others like them, it would be a big support," she shared. "I just wish I'd had the initiative to think of it myself ten years ago when we needed it most."

In a world where rare conditions can sometimes lead to MACS individuals and their families feeling isolated, MACS is here to help, through forging connections that transcend those boundaries. The story of Fern and Gaia serves as a testament to the power of shared experiences, demonstrating that sometimes, in the unlikeliest of circumstances, strangers can become long-lost twins, finding solace and strength in each other's company.

We urge any members wanting us to help connect them with their peers to get in touch – we're here to help!

Calvert 2023

Another adventure-filled trip to Calvert!

In an awesome summer adventure, 21 MACS members (aged 10 to 18) had a blast on our annual activity trip, all thanks to the amazing support from Trusts and Foundations that made their unforgettable journey possible. This year, our member services team made some cool changes based on what we've learned in the past.

We took a close look at our activity program and found some smart ways to save costs without sacrificing any of the trip's awesomeness. By skipping an extra night's stay, we managed to keep the trip just as impactful and fun for our young members. We also decided to skip the trip for the younger MACS kids this time, with costs and previous attendance in mind, so we could use our resources to make the best experience for our young people.

The trip filled up fast, and we were excited to see both familiar faces and new ones. Shoutout to the fantastic team from First Choice Care—they were total game-changers, as ever, making sure every child, no matter their abilities, got to join in sports with their friends. It was something we thought was impossible before!

Our excursion was carefully planned to be inclusive and cater to diverse needs. We were really pleased to welcome new members who hadn't been on a MACS activity trip before, a great reward for all of the efforts being made to break down those barriers that stop people signing up. We even provided one-to-one support for those with additional needs.

Before the trip, we had some Zoom meetings to create personalised care plans. It helped everyone get familiar with each other—participants, families, and support workers. We divided into three groups—physically able, low-level needs, and complex needs—and everyone got to join in on activities designed for inclusivity.

One of the coolest parts was a sensory-based ghyll scrambling activity, where groups tackled obstacles in the water, showing off their teamwork and problem-solving skills. Some groups conquered rock faces, while others had a blast with indoor climbing and swing equipment.

Canoes were both challenging and hilarious, promoting teamwork and communication. After canoeing to an island, a group enjoyed bushcraft activities, including lighting fires and toasting marshmallows. Our adventurers also took on a moderate cycling challenge, with various bike types ensuring everyone could participate and have a blast!

The success of the MACS activity trip, marked by strategic changes, inclusive planning, and unwavering support, serves as a testament to the MACS family's dedication to empowering and enriching the lives of members.

We can't wait for another fantastic trip in 2024!

MACS Awareness Week 2023

Raising awareness of your Local, National MACS charity.

AS we approach our 30th birthday, we couldn't help but make our MACS Awareness Week all about 'milestones'.

It's a special theme close to our hearts. When our Member Engagement Coordinator, Sharon, reached out to our wonderful members to share their milestones and photos, we were blown away by the incredible response.

Dozens of you sent in your personal milestones, and it was truly heartwarming to see such a diverse range of events and achievements that deserved celebrating. From first steps to toilet training, from the excitement of starting school to the adventure of moving into a new home, and even scaling heights like climbing 4,200 feet during a five-week expedition in Kyrgyzstan – every milestone was equally cherished and applauded by your fellow MACS members and supporters.

Reading through all the supportive comments from our MACS community was overwhelming. It's moments like these that remind us how understanding and compassionate our MACS family truly is. We're immensely grateful to everyone who contributed, showed their support, and shared our Awareness Week posts. Let's relive some of the highlights from that incredible week of milestones.

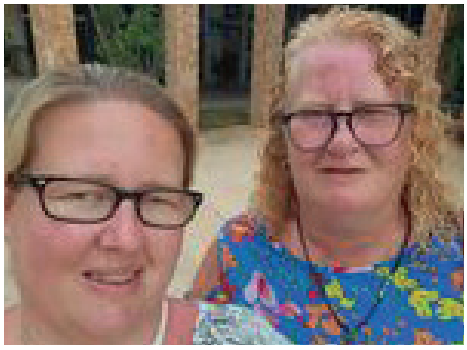
MACS Awareness Week 2023
Microphthalmia, Anophthalmia and Coloboma Support

ROSIE successfully climbed to 4,200 metres whilst on a five-week expedition to Kyrgyzstan.

ROBBIE and his wife Caitlin became first time parents to a beautiful daughter named Ailsa.

DYLAN attended Calvert where he put his head in a waterfall for the first time and completed ghyll scrambling by using his lip-reading skills as he was unable to wear his hearing aids.

HUGO started big boy school this year, made new friends and went on a bus for the first time. He also completed his first Superhero Triathlon in aid of MACS.



LOUISE finally found a community where she belongs and her mum, Sarah, put 37 years of guilt behind her after meeting some fellow MACS Mums when they attended their first MACS Meet Up.

FELIX is thriving and loves music, dancing and figuring out how things work.

More member stories can be found at https://macs.org.uk/member-stories

JAKE attended his first day of school and loved it!

MILLY started two new hobbies this year – the first being snowboarding and the second being another extreme sport.....crochet!

JESS is the first individual to have successfully completed the English Bar using Braille and is also the nations first black and blind barrister.

LAURA graduated Nursery and is looking forward to primary school with her new friend....the cane!

MATILDA not only mastered potty training but also started pre-school and cane training.

ESTOI overcame challenges in the water and now swims with a Swim England Club and is part of a Development Squad.

CARTER is meeting all of his milestones and now has his first prosthetic.

AVIYAH facilitated Childrens Mental Health Day workshops at her school with her Mum and Grandmother.

THADY started Nursery, is learning to ride his bike and has really picked up his running pace this year.

LAURA turned 42 and has a great quality of life despite several disabilities.

MATTHEW moved out of his family home in to his very own place.

FREYA is hitting all of her milestones and is now wearing her very first pair of glasses.

TYLER is loving his new Specialist College and has settled in amazingly.

ELLIE-MAE decided that 20 months was the perfect age to start standing and walking. She hasn't stopped since.

ARABELLA celebrates being two years seizure free and no more epilepsy medication.

MARNIE graduated from Sheffield Hallam University with a First Class Honours Degree in International Events Management.

HOPE celebrates a whole year of being qualified as a Small Animal Vet Nurse.

FREYA came in to the world this year and her family are enjoying every moment of watching her thrive.

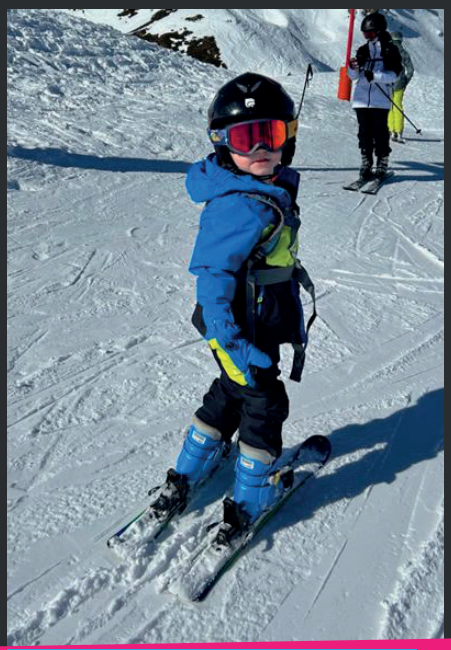
EVIE started her very own Podcast called 'Talking in the Dark' to help raise awareness about blindness, visual impairments and disabilities in general.

JACK got over his fear of the sea, mastered potty training, started trying new foods and doing more creative activities.

Here's some milestones that we didn't have an opportunity to include during MACS Awareness Week...

AVA

Ava has started walking around the house without her baby walker and has started repeating words very clearly now. Ava turns 2 in November!



ARTHUR'S SKIING TRIUMPH

MACS parents Jessica and Luke took 4-year-old son, Arthur, Skiing for the first time in La Plagne, France in February. Needless to say they were super nervous considering Arthur has bilateral Coloboma, is partially sighted and light sensitive to bright conditions. One coloboma affects Arthur's optic nerve and macula and so he has no sight in one of his eyes, the other coloboma affects the iris only and so is cosmetic only.

Arthur was amazing! He soon picked up the 'pizza slice' aka the snow plough and made his way down some pistes with style. He wore sunglasses and goggles for protection against UV rays which worked amazingly well given the sunny conditions! Jessica and Luke said it was heart-warming to watch him and even more so, enjoying himself.

'The world is Arthur's oyster! His resilience continues to amaze us everyday! For any other Skiing loving families out there, the slopes are calling!'

HUGO

At 10 days old Hugo was diagnosed with Unilateral Coloboma, ectopic pupil, corectopia, hypermetropia, anisometropic hypermetropia, astigmatism & amblyopia. Hugo wears glasses & aims to wear his eye patch for two hours a day (much easier before he learnt how to take it off). Hugo is very bright & articulate & being visually impaired certainly doesn't hold him back. He started pre-school in September. He is very bright and has learnt all of the colours and is currently learning shapes. Hugo struggles with bright light so always wears a cap and reactor glasses that go dark in sunlight to protect his eyes. He understands that he sees better with his glasses & he knows how to clean them & put them on himself. Hugo is an absolute superstar & nothing holds him back. Not forgetting the biggest milestone, he became a big brother in January to baby Theo & he loves helping look after him and sharing his monster trucks!

We will be including a member milestone in all future newsletters. If you would like to contribute to the newsletter, please let Jessica know by sending her an email at jessica@macs.org.uk

Thriving at

WITH THIS massive milestone approaching, we've been working hard to make sure the next thirty years are as good as the last – ensuring MACS is here for members in exactly the way (well, ways) we need to be.

As explained in Teresa's welcome message, our goal is for: ***All people with MACS conditions in the UK and their families to be less isolated, better connected and have access to the advice, information and support they need to thrive and confidently lead a fulfilling life.***

This is exactly what has inspired the theme for our 30th birthday: **'Thriving at 30!'**

Throughout the year we'll be sharing even more inspirational stories of members who themselves are thriving and, let's face it, if they're thriving so is MACS as the UKs dedicated charity for people with MACS conditions and their families.

We're not asking for cake or presents, but we would love for our members and supporters to join the celebrations in 2024! If you'd like to be a part of marking this special occasion by throwing a 30th birthday party for MACS, then please get in touch at **enquiries@macs.org.uk.** Whether you're a member or supporter, we have everything you need to help you throw a fantastically fun party.

If party-planning isn't your thing, there are lots of other ways you can get involved too. Get in touch today and we can discuss what you'll enjoy most.

You'll already have read on our calendar page that we'll be hosting two of our very own birthday bashes in the form of our 'Thriving at 30!' events ,and we hope to see you there! In the meantime, please feel free to get in touch with any suggestions of activities you'd like to be considered for the events.

Case Study A Helping Hand for Tyler's tech

TYLER is profoundly deaf. He is also visually impaired. He has a condition called Charge Syndrome which means that he's a wheelchair user and he's also tube fed. He primarily uses BSL to communicate. However, he also has a diagnosis of Autism which makes communication even harder. We have always looked for ways to increase his communication. It's been very limited. He didn't start to use sign language until he was around six years old and even then being in a full BSL environment it's still limited just because of his Autism it really hinders his communication. One of the things we were looking at, well we've always been looking at but especially so in his teenage years where he's found obviously a lot of emotions, hormones, a lot of things going on, the frustration for the lack of communication really has become apparent so I really wanted to find another way for him to be able to communicate. He was assessed by a speech and language therapist a little while back from the NHS but because he didn't meet their threshold we weren't able to access any AAC communication devices through them which is why I turned to MACS.

MACS have been a really supportive charity to us over the years. MACS really do take the whole child into consideration so we applied to the Helping Hands fund for some AAC software that we could install onto his iPad. It was super simple to apply, we just said what we needed, why we needed it and MACS were happy to help. We're really grateful for that.

We've had the software a couple of weeks now. It's still obviously a massive learning curve for Tyler but already he's been able to communicate through the AAC device so we use it for making choices as a really big thing for Tyler's as a way of keeping control of his life and keeping control of his day-to-day activities. We've been able to adapt the AAC so that we can give those choices through the AAC device.

Tyler finds interaction really difficult because of his Autism and sometimes when you're trying to communicate with him obviously with sign, you need for him to be looking at you and he really struggles with that sometimes. He doesn't want that human interaction with another person. With the AAC device already I can see a big difference because it allows him to just communicate with the device and I happened to hear that communication and then I communicate with the device and he happens to see that communication. That's a really big thing, a really big breakthrough for getting through those Autism barriers for him. We're still in super early stages but his College is really excited by it. They've adapted it into their day-to-day interactions with them as well.

> 'MACS have been a really supportive charity to us over the years'

With the software that we purchased you can also print off the grid choices so basically it gives you like on the screen you'll have you can choose a category so say you choose food you could have a whole list of foods on that you're able to print that off so that you don't have to have the communication device there with you. You can also have a print out of that on your table for you to choose food choices or for you to laminate and take with you. It's really interactive, is really adaptable and we are super excited that we've been able to have this software just to open up Tyler's world.

The fact that he's Deaf Blind, the fact that he has Autism, the fact that he's a wheelchair user - these are all things that are barriers to him that sort of control the amount of interaction that he has with the world and it's so wonderful for once to be able to have something like the AAC communication device which starts breaking down those barriers and really starts helping him interacting with the world.

Another really big plus point about the AAC is that it talks for you so Tyler would select the options on the screen and then it has a voice system on it so they will then voice whatever sentence you've made. This is a really big thing for Tyler if he goes into a shop he could actually go up to a counter and say I would like bread please and someone could help him find the bread because they can hear what he's saying. Before, obviously with sign, not everybody knows sign. Very few people know sign language and so it's just breaking through those barriers but is fantastic and we are super grateful for MACS for the opportunity to be able to use this with Tyler.

The fact that he's already started making progress with it in the short time that we've had there is proof that, unfortunately, the NHS threshold is way too high and in fact this is something that should be available to all children like Tyler and hopefully in the future that will be the case, but for now we are eternally grateful for MACS for having this opportunity to start smashing down barriers.

Thank you, **Tyler's mum**

Please note regional genetics services may differ in their service to patients.

Another Voyage Complete!

MACS members board the Prolific for another sailing adventure: Challenges, Camaraderie, and a Remarkable Encounter

A LETTER FROM CREW MATE, TORI...

This years MACS voyage saw a group of MACS people and siblings set sail from Brixham marina on a week of sailing adventure around the south coast! All but one of the crew members were returning sailors so many qualifications, awards and achievements were made across the week.

This year, unlike many of the other years, was met with lots of rain and a brewing storm, meaning that a few of the days were spent hiding in the harbour, completing theory for qualifications and exploring the seaside towns.

The first night on board was a windy one, meaning the boat and its crew had chance to practice man-overboard drills, fire safety drills and an abandon ship drill! The crew were very fast at the abandon ship drill, making it from bunks to deck, fully kitted out in under 5 minutes!

The second day, Prolific finally got sailing and we were all excited to put our theory to we covered yesterday to the test! It was a choppy journey which saw many of the crew with heads in buckets, but with the music playing and biscuits and juice flowing, everyone managed to work together to get to Cawsand for a BBQ on the beach.

Trying to take advantage of the good weather, we planned a passage to Falmouth and made it there after several hours of choppy but exciting seas. But again the weather was not on our side and another evening and day had to be spent inland. Although this was disappointing as we all wanted to get out sailing, this resulted in arguable the most exciting and memorable experience of the trip- we

The Queen's Award for Voluntary Service

were shown around the Royal Fleet Auxiliary ship named Argus which is a 100-bed hospital ship that gets deployed to areas of war. We explored the different hangers, the captains lookout on the Bridge, life board and even the different medical wings including the dentist and MRI machine! Falmouth was also particularly exciting as we were there during the Falmouth Music festival so we ended the most amazing day dancing the evening away with the locals!

The final few days consisted of a trip to Fowey where we hoisted the Mizzen sail without the help of the staff and also some of the crew starting their Watch Leader training.

Overall we sailed 167 nautical miles, with a few of us walking away with some sailing qualifications! Will, who was brand new to sailing achieved his Start Yachting and 3 returning crew members achieved their Competent Crew. I (Tori) also managed to qualify as a 3rd Mate during the voyage thanks to the help of the amazing MACS crew. Some of the returning sailors were also given Sea Staff recommendations to sail again in the future.

As always, thanks to MACS for this amazing opportunity offered to us each year- we learn so much and look forward to it each year. **Tori x**

Want to join the crew in 2024?

We're planning an information evening on Tuesday 6th February at 7pm.
Please drop us an email at **enquiries@macs.org.uk** for more information.

Research Update

Professor Nicky Ragge's research: the importance of families and networks in the quest to unravel the genetic causes of eye development conditions

2024 will mark the 25th anniversary of The Genetics of Eye Anomalies Study, which was started by Professor Nicky Ragge when she worked at Moorfields Eye Hospital, and has involved collaborations with clinicians and scientists worldwide.

Throughout this study Nicky and her team, initially at Oxford University and latterly at Oxford Brookes University, have worked to identify the genetic variants underlying Microphthalmia, Anophthalmia and Coloboma (MAC). Since 1999, over 450 families have joined the study through Moorfields, Southampton University Hospitals NHS Trust, Birmingham Women's and Children's Hospital Foundation Trust (Nicky's clinical base as a Consultant Geneticist) and Oxford Brookes University (the home of the research team).

The primary aim of our research is to identify the genetic basis of a family's MAC condition, which will lead to improved genetic testing for these conditions and ultimately bring genetic treatments one step closer. Our research would not be possible without the generous participation of families with MAC conditions.

Professor Nicky Ragge (bottom right) with the research team

The connection we have with family members brings a powerful dynamic to our research and to our long-term goal of advancing scientific progress in the field of eye development conditions. By collaborating with research groups worldwide, publishing research papers in renowned scientific journals and presenting at internationally acclaimed scientific meetings our work is constantly evolving and we are furthering our causes and providing answers for families.

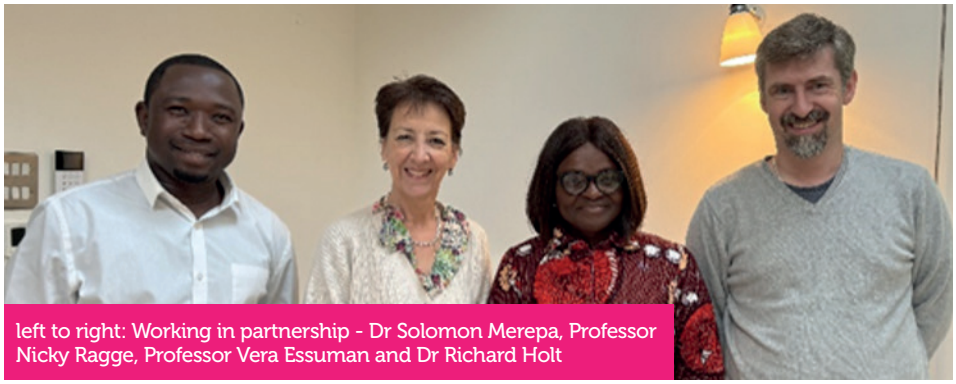
In June 2023 our communication with Sharon Williams from MACS, led to contact with 39 new families who were keen to find out more about our research. We were delighted by this response; it was a privilege to hear first-hand about the experiences of families living with a MAC condition and their quest to discover the cause. Several families are now taking part in the study and we are increasing the frequency of Nicky's research clinics to offer recruitment opportunities to more families.

SCIENTIFIC ADVANCES

Because the human genome is complex and very diverse, identifying a genetic variant thought to explain an individual's developmental eye condition is very challenging. Over the years, major advances in scientific technology have revolutionised our ways of working. We are now routinely using Whole Genome Sequencing (WGS) to look for 'spelling mistakes' in the genetic material (DNA). When existing methods do not provide an answer for a family we will continue testing when new genetic techniques become available. One new approach is Optical Genome Mapping (OGM) which aims to identify larger changes in DNA. These can be missing, or extra fragments of DNA, or fragments sitting in the wrong location; together they are called structural variants.

Dr Solomon Merepa with the Bionano Genomics OGM Saphyr

Not currently available through the NHS, OGM enables us to pinpoint and investigate the significance of these structural variations in an individual's DNA. With the help of OGM we were able to rapidly find genetic answers for two families; both had been participants in the study for nearly 20 years. In addition, this work significantly advanced our understanding of indicators of new genetic mechanisms which will help other families.


left to right: Working in partnership - Dr Solomon Merepa, Professor Nicky Ragge, Professor Vera Essuman and Dr Richard Holt

To date we have provided genetic answers to over 130 families and have presented our research findings at the following distinguished scientific meetings: European Society of Human Genetics (ESHG), UK Eye Genetics Group (UKEGG) and the Genetics of Ocular Development (GoOD). This work provides an example of how we are achieving our primary aim of identifying the cause of a family's eye condition and in doing so we are furthering the understanding of the causes of MAC conditions amongst the scientific community.

IMPORTANCE OF WORLDWIDE COLLABORATION

Earlier this year the fourth international GoOD (Genetics of Ocular Development) meeting was held in the beautiful city of Toulouse, France. This meeting was dedicated to eye development conditions and provided a fantastic opportunity for collaboration amongst clinicians, geneticists, ophthalmologists and scientists to determine future strategies for diagnostics, therapeutics and patient care. This event showcased twenty-four research presentations, including several from Nicky's team.

We have recently extended our collaborations into West Africa following funding awarded by Oxford Brookes University for a research partnership with Professor Vera Essuman, Ghana's first trained paediatric ophthalmologist working at the University of Ghana Teaching Hospital. This research will combine resources and expertise to establish genetic studies involving patients in Ghana with MAC. We anticipate that research study outcomes will lead to recommendations for improvements in genetic testing, diagnosis, treatment and care of Ghanaian families living with eye development conditions.

Closer to home, we are partnering with colleagues in the Psychology Department at Oxford Brookes University to develop a pilot study which will investigate the impact that MAC conditions have on the family unit. With the anticipated increase in the frequency of the research clinics held at Oxford Brookes, Professor Ragge is exploring the possibility of providing a specialist counsellor for families.

Thank you

A huge thank you to the many families who have contributed to our research. Without your help we cannot make the important advances that will improve the lives of families worldwide living with MAC conditions. We also thank all of the organisations who have funded our research through the years, including MACS, VICTA, Baillie Gifford and the individuals who have kindly made private donations.

Contact Us

Please note our telephone numbers are changing!

You can reach the research coordinators on:
01865 803045 (Fiona Watkins)
or
01865 534923 (Dorine Bax).

Alternatively, you can email Fiona and Dorine at **eye.genetics.study@brookes.ac.uk**. They are happy to answer questions and provide updates to families.

Meet the Team!

Meet MACS' **2024 TCS London Marathon** Runners

I'M DAN, 35, FROM EXETER, DEVON. After doing some research and looking for a charity place for London Marathon i stubbled across MACS and was very impressed with the work they do and the positivity they show! I cant wait to Race for them and raise as much money for this great Charity 😊

I'M CAROLINA MARTINES FROM SAO PAOLO, BRAZIL. I'll be running the London Marathon on my birthday in my favorite city in the world - and as an Ophthalmologist, doing it for MACS only makes it more special!

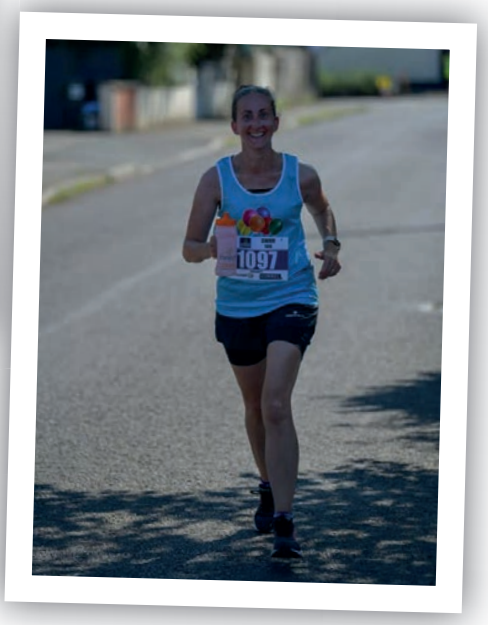
I'M DAVID SHAW FROM HUNTINGDON, CAMBRIDGESHIRE. I'm running the London Marathon for MACS to challenge myself and to help raise vital funds for children and adults with the Microphthalmia, Anophthalmia and Colomba eye conditions.

MY NAME IS SALAM ATASSI, 63 YEARS OLD, originally from Syria and a U.S. citizen for 35 years. I live in the Chicago suburbs. I chose MACS because it is an organization supporting children born without eyes and I believe every kid deserves a chance to see like most of us do and live a normal lives. Thank you for accepting my application!

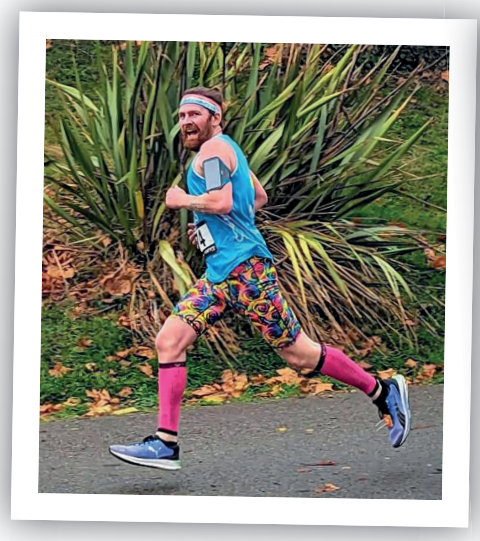
MY NAME IS GILSON JORDÃO. I AM 49 YEARS OLD, BRAZILIAN, married, and a father of two adult children. When my son was 24 years old, he was diagnosed with a rare orbital disease. We were devastated, but thanks to God, he was cured.

I will be running the London Marathon in 2024 as a donor to MACS, which provides support for people who are born without eyes and underdeveloped eyes. I want to thank God for my son's cure and to help others who are going through the same thing.

I believe that everyone deserves to live a full and happy life, regardless of their visual condition. MACS is working to make this a reality.

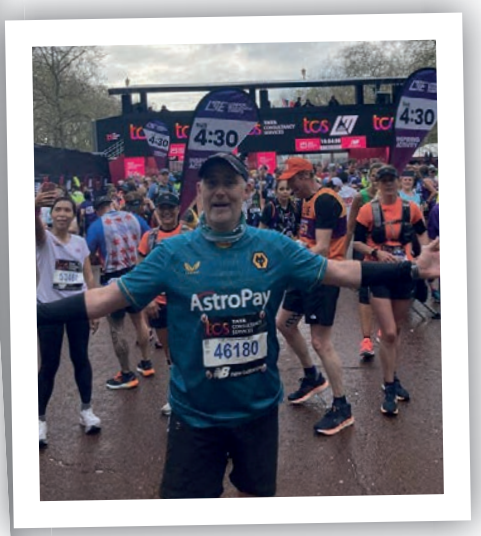


MY NAME IS TANYA AND I'M FROM DEVON. I'll be attempting to run my first ever marathon! I am a primary school teacher and am passionate about working with children. I feel privileged to be fundraising for MACS and support the fantastic work they do with children and their families and to be an advocate of equal opportunities.

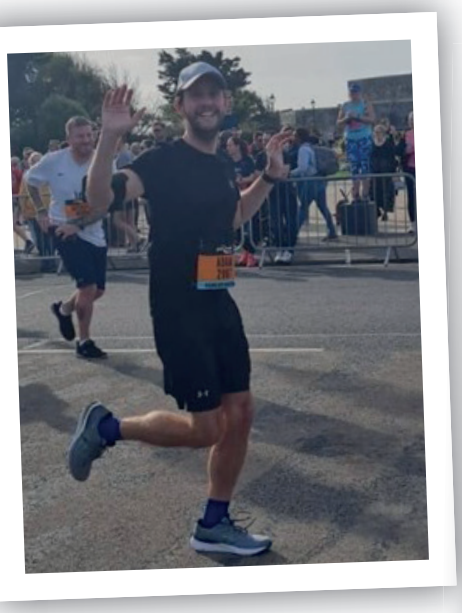


I'M SAMUEL CLARK, 34, FROM SITTINGBOURNE IN KENT. There are thousands of charities but it's the smaller ones that often get overlooked and that's why I picked MACS as my charity to run for. Running has helped me through some dark stages in my life and I'm now going to use this to give back and MACS is as good as cause than any other.

I'M LEE BRIDGES FROM WARWICKSHIRE. I'm always trying to keep fit as I get older and London Marathon has always been on the bucket list, and to do it for such a worthy charity...ideal combination!



I'M DAVID, 51, FROM MILTON KEYNES. I'm looking forward to my 10th London Marathon, an unmatched experience that never disappoints. I met MACS member, Ben Lupton maybe 10 years ago along with his parents Tim & Jenny who support Ben on his running journey & they introduced me to the work MACS do & I'm looking forward to raising funds & awareness for the charity.



ADAM BURT, AGE 41, BOURNEMOUTH. I competed in the Great South Run on 15th October as part of my training and am scheduled to run the South Downs off road Half-Marathon on the 25th November where I will be wearing my MACS t-shirt!

I'M SAM, 32, FROM AMPTHILL IN BEDS and I'm running with my dad Ian, 62, from Peterborough in Cambs. Dad and I decided to run the London Marathon for MACS this year after my Niece, Dad's granddaughter, was born with Microphthalmia in 2021. We would like to do our bit to help the charity with the amazing support they offer to the children and their families. We may not cross the line together, but you can bet a few celebratory drinks shall be shared soon after'.

GOOD LUCK TO ALL TEAM MACS RUNNERS, CLASS OF 2024!

Feeling inspired?

MACS still has places available! The deadline to register is on 22th August.

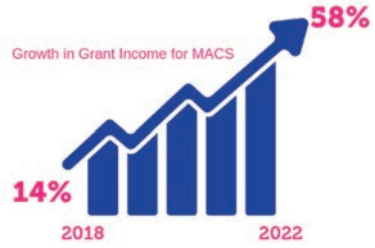
However, if running is not your idea of fun, how about inviting your friends or a family member? Any help spreading the word is really appreciated.

macs.org.uk/want-to-help/fundraise-for-us/run-london-marathon-macs/

Thank you, thank you, thank you!

We want to say a big THANK YOU to all of our past, present and future supporters.

MACS-IMISING GRANT INCOME



Before the Covid-19 pandemic, MACS received an average of 14% of its total income from grant funding.

Grants are financial donations, often large sums of money, that fund projects, events and ongoing charitable costs. Charitable grants are typically awarded through a competitive application process, with applicants required to submit proposals outlining their objectives, plans, and how the grant funds will be used. Grantmakers then carefully evaluate these proposals to ensure that the recipient's charitable goals and objectives align with their own. If approved, the funds must be spent in the proposed way, with funders often requiring feedback on the difference their donation has created.

When the pandemic hit, and events couldn't take place, grants became the main source of income for charities across the country, including MACS, representing an average of 44% of our overall income (2020 and 2021), when the London Marathon did not take place. In 2022, we employed our very first Trusts and Foundations Fundraiser to maximise grant income and help broaden our income streams with a view to fund 40% of all charity costs through grant funding (50% by 2026).

By the end of 2022, 58% of the total income for MACS was from grants. This included specific funds for Helping Hand, Calvert, Sailing, Giving Families a Break, Meet Ups and Pantomimes along with the unrestricted funds which allowed us allocate spend where it was needed most. Part of the strategy for grant funding moving forward is to secure multi-year grants, giving us greater confidence and reliability when planning future events, and we are delighted to tell you that already, we have secured £21,000 for initiatives in 2024 before the year has even begun.

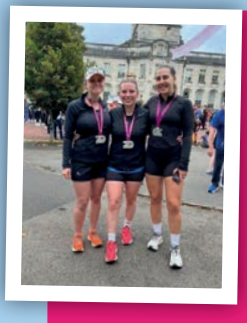
Local Community Fund

WE'RE thrilled to announce that from 11,000 applications nationwide to the Co-Op Local Community Fund, MACS has been chosen as one of the charities to benefit.

Only 3 charities per locality are chosen to benefit from this partnership which will last for twelve months to raise much needed funds for future MACS pantos. We have been partnered with food stores in the Dartford area but if you have a Co-Op members card, regardless of where you are in the country, once signed into your online account, you can choose MACS as your cause at: **https://membership.coop.co.uk/causes/80966.**

Then, for the next 12-months, 1p for every £1 spent on selected Co-Op branded products and services, will be donated to MACS. We are guaranteed a grant of £1,000 but the more members who select MACS, the more funds we will raise.

If you don't have a membership card yet, don't worry. They're free to get (just ask in store) and bring lots of benefits, whilst raising valuable funds for our charity.



MARI, EVANGE & SHANNON ran the Cardiff Half Marathon on the 1st of October for their little bestie Tirion.

Tirion was born in March with a rare condition on her left eye called PFV, as well as congenital cataracts and microphthalmia. It is not clear to why PFV occurs and therefore requires further research and testing. 1 in 100,000 babies are born with PFV where the eye is underdeveloped and essentially visually impaired or even blind. The group said they chose MACS it's 'a fantastic charity that provide extraordinary support to extraordinary children and their families'. Thank you to you all for you fantastic efforts and the whopping **£2,311** raised!

BRIAN took part in the great north run this year. Brian runs half marathons regularly but this time was a little different as he'd decided to raise money for charity, in particular MACS. And we're glad he did because he raised a brilliant **£855!!**

Brian told us, 'I'm doing this for my granddaughter who was born effected by MACS she's has a right microphthalmia choroid coloboma and retinal coloboma vision is nonexistent but she a little star and nothing stands in her way, this small charity needs funding to help support these young children and their families.'Thanks Brian, we're massively grateful for your support!