ISSUE 19
AUGUST 2024

MACS
Thriving at 30!

FOCUS MAGAZINE

Microphthalmia, Anophthalmia & Coloboma Support

Supporting people born without eyes or with underdeveloped eyes

@macsthecharity @MACSCharity @MACSCharity linkedin.com/company/macscharity

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

Contents

Welcome from Teresa	**Page 3**
Meet the Team and MACS Team Updates	**Page 4-5**
Meet Our New Trustees	**Page 6**
Calendar of Remaning events and activities 2024	**Page 7**
Hello to new members	**Page 8-9**
MACS Meet Ups	**Page 10**
Launch of Our New Volunteers Programme	**Page 11**
MACS History	**Page 12-19**
MACS Members Milestones	**Page 20-23**
Research Updates	**Page 24-27**
MACS' Plan to Thrive	**Page 28**
Team MACS Did it Again London Marathon Success	**Page 29-31**
Fundraising Thank Yous	**Page 32-33**
Tribute to Kelly Lehmann	**Page 34-35**
MACS Birthday Poster	**Page 36**

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**

Your MACS Contacts

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

Family support
& new member enquiries:
☎ 0800 169 8088

Information, fundraising
support & media enquiries:
☎ 0800 644 6017

General enquiries:
enquiries@macs.org.uk

Fundraising support:
fundraising@macs.org.uk

Running events:
marathon@macs.org.uk

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

X(Twitter): **@MACSTheCharity**
Facebook: **@MACSCharity**
Instagram: **@Macscharity**
LinkedIn: **linkedin.com/company/macscharity**

MACS MAGAZINE | VOLUME 19
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!

WELCOME FROM TERESA

Welcome to the very special 19th edition of MACS' Focus magazine, which we share with you as MACS turns 30! This milestone for MACS encourages me to reflect on when my family and I found the charity and were welcomed and embraced as part of the MACS family...

When my daughter Kara was born in 2008 with Microphthalmia, our world was turned upside down. The initial experiences were filled with uncertainty and fear, as every healthcare professional we spoke to seemed to focus on what she might not be able to do. Each visit to the hospital brought more daunting predictions, leaving us overwhelmed and disheartened.

In those early days, we were desperate for support and understanding. It was then that I discovered MACS (Microphthalmia, Anophthalmia & Coloboma Support) through an internet search. Words cannot fully express our gratitude for finding this incredible organisation. MACS became a lifeline, offering the connection and reassurance we so desperately needed.

Our first Family Weekend with MACS was a turning point. We walked into a setting where everyone understood each other, sharing a common bond through similar experiences. For the first time, we saw other children who were further along in their journeys, and we were overwhelmed with the positivity and potential of what was possible. The atmosphere was filled with hope and inspiration, replacing the isolation and devastation we had felt, and I am so pleased that more MACS members will once again feel that same feeling as they attend our Thriving at 30! party in September.

Connecting with other families early on was transformative. We no longer felt alone; instead, we were part of a community that offered support, advice, and encouragement. These early steps in our journey with MACS instilled a deep sense of purpose within me and my family. We knew that this connection and support were exactly what we needed.

"I hope you'll join me in celebrating as we truly are thriving at thirty!"

As we navigated the challenges of Kara's condition, the hope and inspiration we gained from MACS continued to guide us. The organisation provided not just practical advice but also emotional support, showing us that our fears could be replaced with optimism. Through MACS, we learned that Kara's potential was limitless, and we were empowered to face the future with confidence.

In reflecting on our journey, I am profoundly grateful for MACS. The community and support we found transformed our experience, turning what could have been a negative path into one filled with hope and possibility. For any family facing similar challenges, I cannot recommend MACS highly enough. It is through organisations like these that we find the strength to overcome and the inspiration to thrive.

I am delighted to bring you this special issue of Focus, in which you'll read inspiring stories from former Chairs of the Board as well as members who have joined the MACS family in more recent years. As we look back on the last 30 years and the milestones along the way, I hope you'll join me in celebrating as we truly are thriving at thirty!

I am also very excited to introduce you to two new Trustees who joined the Board this summer. You can read more about them on page 6, where you'll also sadly read that we've had to say goodbye to Jess, our Communications and Outreach Officer; may I take this opportunity to say a thank you to Jess for her hard work and dedication and wish her all the very best. While we are very sad to see Jess go, we were fortunate enough to have Llyr step in to keep things afloat with members' communications. We thank Llyr for helping out and now look to recruit our next Communications and Outreach Officer – see page five for a little more info!

I hope you enjoy reading this special issue of Focus and, as always, I am here if you need me.

Happy birthday MACS!

Best wishes,

Teresa Gordon
Chair of Trustees

Meet the Team

ORGANISATIONAL STRUCTURE

Board of Trustees

Lisa Jeffries

Trustee

lisa@macs.org.uk

Rory Hallas

Treasurer

rory@macs.org.uk

Teresa Gordon

Interim Chair & Acting CEO

teresa@macs.org.uk

Gary Murphy

Trustee

gary@macs.org.uk

Sarah Hiley

Trustee

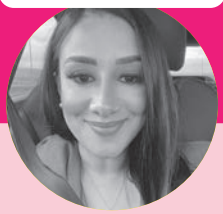
sarah@macs.org.uk

Dr Jessica Gates

Trustee

JessicaGates@macs.org.uk

Harvir Padda



Trustee

Harvir@macs.org.uk

Amy Francombe

Director of Charity Development

amy@macs.org.uk

07593 021 655

Kim Randall

Member Services Development Manager

kim@macs.org.uk

07517 861 107

Emily Murphy

Trusts & Foundations Officer

emily@macs.org.uk

07860 778 160

John Leadbeater

Supporter Relations Officer

john@macs.org.uk

07921 259 549

Recruiting Now

Please view page 5 for more information

Clare Jones

Member Services Coordinator

Starts on 2nd of January

clare@macs.org.uk

07921 259 635

Sharon Williams

Member Engagement Officer

sharon@macs.org.uk

07395 280 764

MACS Team Updates

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

WE'RE HIRING!

We're looking for a new Communications and Outreach officer to join MACS on a fixed-term 12-month contract.

This is a critical role that offers the chance to raise awareness of MACS, reach new members and galvanise support. You will work with the management team to deliver the strategic objectives for communications across the organisation, with a cohesion between both membership engagement, retention and growth, and supporter recruitment.

You will take the lead on the delivery of MACS' annual communications plan and mailing schedule, collaborating with both the Member Services team and Fundraising team to collate emotive content and ensure seamless delivery of effective communications across multiple channels, both amongst members and supporters and to our public audiences, as well as proactively seeking and engaging with new audiences.

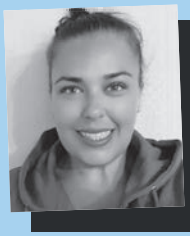
As Communications and Outreach Officer, you will be an ambassador for accessibility and the MACS brand, championing the cause through consistent and user-friendly communications, developing a recognisable brand to push MACS to the forefront of national charities.

For further details, please refer to the full job posting on our website here: www.macs.org.uk/jobs-and-volunteering or for an informal conversation about the role call Amy on **07593 021655**.

To apply, please submit your CV to **amy@macs.org.uk** by midnight on Sunday 22nd September. Interviews will take place online during the week commencing 30th of September.

CONGRATULATIONS TO CLARE & FAMILY!

Our Member Services Coordinator, Clare, welcomed a beautiful baby girl, Dulcie-Rose, into the world on April 4th at 4:32 pm. Weighing in at a petite 6lb 7oz, Dulcie-Rose was greeted with excitement by her big brother, Leo. The siblings share a unique bond as Dulcie-Rose was also born with Coloboma, making their connection even more special.



GOODBYE AND THANK YOU TO JESS

It is with regret that, due to personal health reasons, Jessica made the very sad decision to leave the MACS team at the end of May. While we're extremely sad to see her go, we fully support and understand her decision and are comforted in knowing that her and her family are still part of the MACS family as members themselves. A big thank you to Jess for everything she's done for MACS!

Meet our NEW trustees

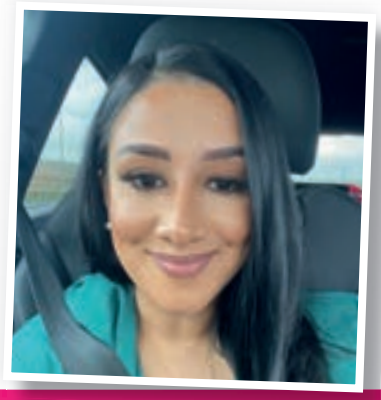
and learn about their roles in the team...

DR JESSICA GATES
Trustee

Jess lives with her husband Aidan and son Thady in Newcastle upon Tyne. Thady was born with unilateral microphthalmia, cataract and has no iris in his left eye. Thady was born in 2021 and since then MACS has been an incredible source of emotional and practical support for the family.

Professionally, Jess is an academic researcher based at Northumbria University in Newcastle with a background in health psychology and expertise in health services research. She works within the NIHR Applied Research Collaboration in the Knowledge Mobilisation and Implementation Science theme, which is all about using research and knowledge in innovative ways to improve health and care. Having had challenging healthcare experiences relating to Thady's care and knowing that this is a common theme among MACS families, her long-term professional goal is to drive forward MACS related research from applied health research perspective.

Jess brings these personal and professional experiences to MACS and is happy to be able to support the charity and help it grow.



HARVIR PADDA
Trustee

Harvir has two beautiful baby boys, Dylan and Dhian. Dylan, was born with anophthalmia, nystagmus, coloboma and a dermoid.

Harvir lives with her husband and children in Leamington and works as a Change Lead in the manufacturing/ construction sector.

Whilst initially in neonatal care, MACS was one of the first support networks they were advised of and accessed. Whilst navigating their new normal MACS became a fundamental part of their journey and so now Harvir is keen to reach those families going through similar and extremely difficult times whilst contributing towards driving forward the MACS vision.

In exciting news, we have a third new Trustee joining the Board who we'll introduce you to in the next magazine. **Watch this space!**

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.

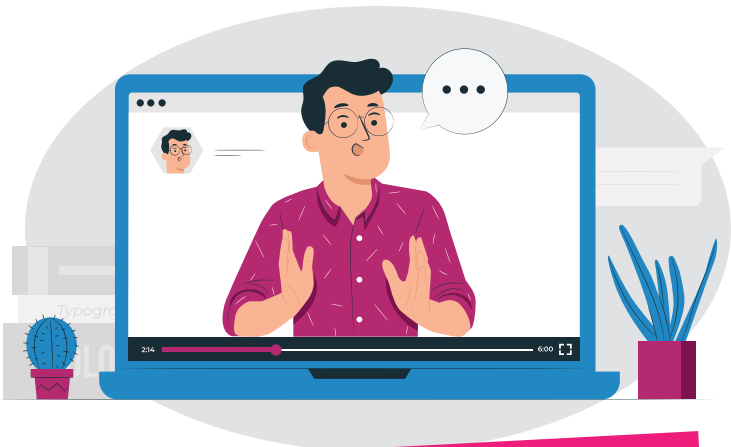
For an information chat with our Interim Chair, Teresa Gordon please email **teresa@macs.org.uk** and we will arrange a call.

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 2024

2024 EVENTS	
When	**What**
7 - 8 September	Thriving at Thirty *(MACS birthday party)* event **SOUTH**
13-18th October	Adults' Seable Trip to Sicily
19 October	MACS Meet Up Nottingham



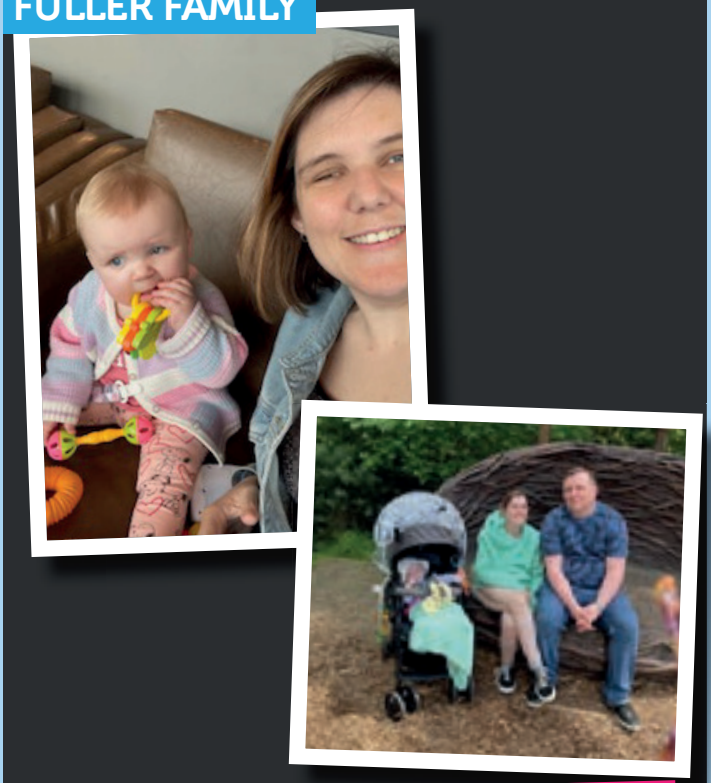
Online Events

New Members Meeting First Wednesday of the Month	**8.00pm**
Quiz First Saturday, every second Month	**7.45pm**
Adult Social Zoom Last Wednesday of the Montn	**8.00pm**
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**
Creative Writing Workshop 22nd October 2024	**7.00pm**
Adults' Seable trip to Sicily 13-18th October 2024	**-**
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**
Pantomimes Throughout December 2024	**TBC**

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.

FULLER FAMILY



Hello, we are the Fuller Family! I'm Laura (33) and I have right eye Microphthalmia and left eye Coloboma.

I have a beautiful 9-month-old little princess called Daphne, who has left eye Microphthalmia and bilateral Coloboma. We have a loving husband and Daddy - Louis (33), who is fully sighted.

We hope to find support in those difficult moments, and know that we are not alone, and I hope that we can support, encourage and cheer on everyone in the MACS community in turn!"

From Laura

CHLOE

Chloe has microphthalmia and morning glory disc, in her left eye. She recently celebrated her first birthday in June and is the happiest little girl and loves clapping her hands to "If you're happy and you know it."

She is very loud and bubbly and always has a smile on her face. As a family we are coping well with Chloe's diagnoses and will look on the positive side to any challenges we face in the future. We are happy to of found MACS and look forward to meeting others alike.

From Chloe's mum & dad

LUNA

This is our beautiful miracle girl Luna.

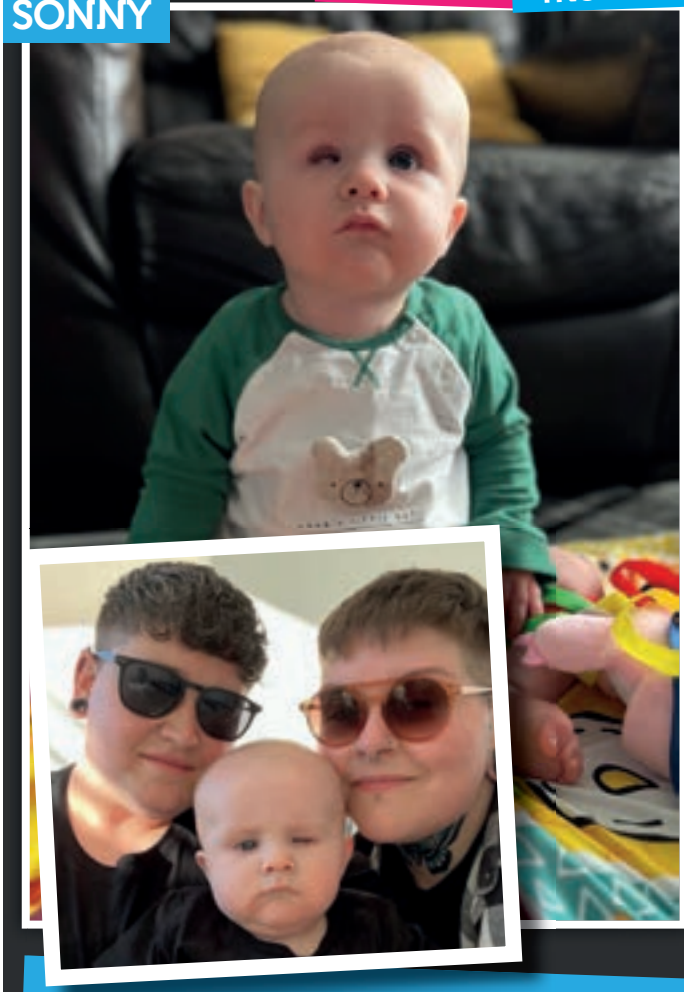
Luna was born in September 2023. When Luna was born we noticed straight away there was something different with her right eye but I was told it's just because of how small she is (she was 4lbs 8oz).

Luna spent a week in the NICU where we questioned this with her consultant and the multiple doctors that saw her whilst she was there but we were told it's just the way she is and it will change as she gets bigger. As we had never seen a baby like Luna we trusted what we were told , it was only when Luna was 6 months old I took a picture of her and she didn't have the red reflection in her right eye so i contacted my GP who referred to see ophthalmology at our local hospital and it was there she was diagnosed with right eye Microphthalmia with esotropia , right eye iris coloboma and posterior retina choroidal coloboma with no vision in her right eye.

We haven't been given much information from our hospital so we will be going private for Luna's care going forward but myself and my partner would have been absolutely lost if it wasn't for MACS. Especially when we first were going through the stages of getting her diagnosis the hour long phone call with Sharon gave me more information, guidance and hope in that hour than what I'd been fighting for since Luna was born. We wouldn't change our girl for the world her little eye just makes her even more special and unique. We are very grateful to be part of MACS and so thankful that MACS exists.

From Luna's mummy and daddy

SONNY



Our little boy, Sonny was born in October 2023. When he was born one of his eyes wasn't open and we knew something wasn't right. At 10 days old Sonny was diagnosed with Microphthalmia in his right eye, since this he has also been diagnosed with PFV and Peters Anomaly in his little eye.

It was a frightening time full of confusion and we felt very alone but we found MACS which helped answer many questions and let us see that we weren't alone at all.

At the beginning of the year we attended a MACS meet up which really helped us again to see that we weren't alone, and it was great to be able to share experiences and get advice from families. It also allowed us to realise that there was nothing that Sonny couldn't do, and he was just the same as everyone else.

We recently decided to create an Instagram to raise awareness of the MACS condition by allowing people to follow Sonny's journey, this can be found **@mylittleeyeandme**

From Sonny's parents

Meet-Ups

Newcastle

A Heartwarming Gathering

The MACS Meet Up in Newcastle turned out to be a delightful event, set in a charming venue with marvellous food. The February weather was kind, sparing us from snow. The highlight was the attendance of Creation Station, a visit from MACS the monkey, and a wonderful mix of MACS members, both old and new, each with their unique stories and conditions.

It was particularly touching to meet a newer family whose daughter was diagnosed with a rare form of epilepsy after finding matching symptoms on our member support page. This connection highlighted the crucial role of our community in providing support and information.

> "It was lovely and welcoming with a nice atmosphere. Both adults and children were catered for, and we felt extremely welcome and at ease after meeting parents in similar situations."

One new family, travelling from Scotland, attended their first meeting with some initial nervousness. Their experience was so positive that they are now active members, eagerly anticipating their next MACS event.

Established members warmly welcomed the newcomers, sharing tips and stories that forged new bonds and ensured everyone felt included. Creation Station added to the fun with activities like the proposed Guinness Book of Records attempt for the longest straw challenge and creative projects using crepe paper.

Despite the absence of adult MACS members, the event was a testament to the inclusive and welcoming spirit of our community, catering to both adults and children.

One attendee summed up the day perfectly: "It was lovely and welcoming with a nice atmosphere. Both adults and children were catered for, and we felt extremely welcome and at ease after meeting parents in similar situations."

EXCITING LAUNCH OF OUR Volunteers Programme

At MACS, we pride ourselves on our warm, friendly vibe. We always look for ways to improve and involve you more in what we do. After listening to your feedback and reviewing our recent events, we're excited to announce some big changes starting now and fully launching next year.

KEEPING OUR LOVED EVENTS

We've always hosted fun MACS Meet Up events where members can meet, share, and support each other. These events have helped build lasting friendships. While we won't stop having these big events, we also see the need for more local, smaller gatherings.

You may have noticed we've had to cancel some events this year. We know this is disappointing, so we want to explain why.

WHY WE'VE HAD TO CANCEL SOME EVENTS

You may have noticed we've had to cancel some events this year, like our north Thriving at 30! Party event. We know this is disappointing, so we want to explain why.

Most of our events are funded by trusts or foundations. Emily works hard to get this money, but funders have strict rules on how it's spent. When we book venues, food, and entertainment, we need a minimum number of people to attend. If we don't hit these numbers, we either face high costs or can't run the event at all. For example, the north event had only 20 sign-ups but needed at least 75. Cancelling events isn't easy for us, as we know you look forward to them.

INTRODUCING OUR VOLUNTEERS PROGRAMME

We're not stopping our larger events, but we think it's the right time to give you more control with our support. Imagine planning local events with other members in your area—zoo trips, coffee mornings, theatre shows, park picnics, trampoline parks, summer barbecues, or Christmas parties. As a regional volunteer, you'll connect with local members and plan events based on what they want, with our help, funding, and training.

This new approach aims to offer more events and build stronger local friendships. We want new members to feel welcome in their local community and the wider MACS family. We've already done something similar with our panto meetups, and it's been successful.

HOW YOU CAN HELP

We're in the early stages of this project and aim to launch fully at the start of 2025 with a calendar of regional events.

Volunteers are crucial for us, and those with MACS conditions or their families know best what they need. Our job is to support you in making it happen. We want one big regional MACS Meet Up each year, plus smaller events throughout the year for all age groups.

We're looking for MACS members over 18, with or without a MACS condition, to help out.

WHO WE'RE LOOKING FOR

We're looking for MACS members over 18, with or without a MACS condition, to help out. If you're interested, email us at enquiries@macs.org.uk with your name, location, connection to MACS (e.g., parent, MACS adult, grandparent), and a brief paragraph about yourself. This isn't formal; we just want to know who you are and what you can bring to your area. If you'd like to chat more about our plans, let us know.

Join us in shaping the future of MACS events. Your involvement can make a big difference, and we're excited to see what we can achieve together!

OUR HISTORY

A timeline of MACS' milestones, achievements and success stories from the past 30 years. That's over a quarter of a century of fun, friendships and support. We share some best moments and our favourite photos here.

1993

A series of articles published in the Observer investigating the little-known eye conditions.

First get-together in Battersea Park.

1994

MACS becomes an official charity.

Juveria Memon elected as Chair.

1995

First Family Weekend & AGM at Skegness Butlins.

1996

Family weekend & AGM at Cirensester.

1997

Family Weekend & AGM at Haven, Mablethorpe
Peter Attenborough elected Chair.

1998

MACS' first time at the London Marathon! We received our first Golden Bond places and registered first runners.

Family Weekend & AGM at Butlins, Pwllheli

1999

First Family weekend at Park Hall, Lancashire. We have been back most years since, now totalling 20 annual weekends there!

Regional network was launched.

2001

John Karvaski elected as Chair.

MACS MEMORIES FROM OUR CHAIRS, PAST AND PRESENT

Recollections and proudest moments

Jonathan Attenborough

In memory of his Dad, Peter Attenborough (Chair 1997-2001)

As some of you will know my dad sadly passed away in November 2010. He was a past Chair of MACS in the early years of the charity and it was something he was extremely proud of. He spent a lot of his time working on spreading awareness of MACS and introducing newly diagnosed families to MACS. He always spoke about how much he enjoyed the Family Weekend and seeing all the MACS families having such a great time at Camelot!

One of the things my dad always said his vision for MACS was that it would someday be led by MACS adults who grew up with the charity as MACS children, so I know he would be bursting with pride to see that is exactly where the charity is today. I know that he would love to see MACS continue to grow and reach every family that has child born with a MACS condition in the UK.

MACS MEMORIES FROM OUR CHAIRS, PAST AND PRESENT

Recollections and proudest moments from 25th anniversary edition of Focus

John Karvaski *(Chair 2001 – 2006)*

What was your fondest memory of leading MACS?
My fondest memory of MACS was helping and supporting new families especially when meeting them at the MACS weekends, for them to be able to meet others and speak with parents was so fulfilling, to see the children grow up each year.

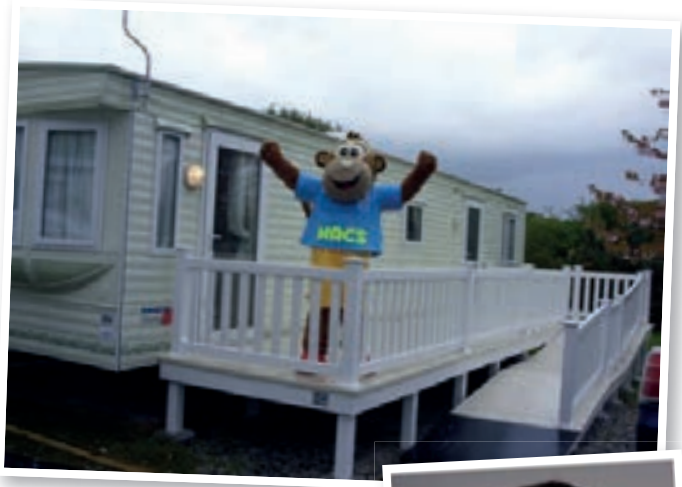
What was your proudest moment as a Chair?
My proudest moment as Chair was enabling the charity to move forward, bringing on board the London Marathon from a small fundraiser to over 100 places, enabling us to purchase our caravans for respite care. Also it was personally running the London marathon for MACS and being able to raise money and awareness to help the charity. Getting Ican involved as a sister charity and being able to see how their children were doing in America.

What's the best thing about MACS?
The best thing about MACS is the support and help provided either at the MACS Family Weekend or over the phone from parents who have been through the same experiences.

2002

First Charity Ball in London

First caravan purchased.



Lord Blunkett becomes Patron.

2006

£1 Million raised by MACS in total.

Anna Cannings elected as Chair – the first MACS adult to hold the position.

MACS MEMORIES FROM OUR CHAIRS, PAST AND PRESENT

Recollections and proudest moments from 25th anniversary edition of Focus

Anna Cannings
(Chair 2006 – 2007)

What is your fondest memory of MACS?
The launch day in London – so many families gathered together to support one another and mark the start of something special. Also, how this collaborative spirit has lived on through the annual AGM weekends and other local meetings. What was your proudest moment as Chair of MACS? The committee agreeing to extend the number of caravans available for families, thereby increasing opportunities for vital holidays. Affordable, home-from-home environments are so important for MACS young people, their siblings and parents, to make regular breaks possible.

What is, or was, the best thing about MACS?
The way in which the charity is evolving to facilitate more peer support and confidence building opportunities. The increase in integration provides many benefits to prepare MACS young people for life in the real world, but it can also be isolating and is often a less-than-ideal environment for developing specialist coping skills. MACS is helping to bridge this gap – something I think its trustees and patrons should be very proud of.

MACS MEMORIES FROM OUR CHAIRS, PAST AND PRESENT
Recollections and proudest moments

Debby Clark *(Debby stepped up to act as Chair twice during the early 2000s and whilst her tenure was short, on both occasions she helped steady charity through some challenging times)*

What is your fondest memory of MACS? There are many fond memories, it's hard to pick just one! They all have the same theme though, watching how MACS makes a difference to the lives of its members.

Seeing parents brave the sometimes scary experience of coming along to a family weekend or a regional event for the first time and then witnessing them realise there are other families who understand their fears, worries, desperation, and their joys at each small progression their child makes was always wonderful. I loved seeing them at future events as their friendships grew, watching them change and become more confident and happier, and in turn watching them welcome and help other families. My fondest memories are watching others, as we ourselves did, realise there is hope for our children, that they will be able to achieve their own potential although it might be tough along the way, knowing that there are others who have gone on to achieve amazing things, safe in the knowledge that there are other parents who they can turn to for advice, support and help.

I have been so fortunate to have watched the MACS child or their sibling, shy at first, then joining in with their peers, feeling comfortable in their own skin, forming friendships and then not wanting to go home because they made friends and didn't want to leave them! To have watched grandparents, who worry about their grandchildren and their own child, and also extended family members all of whom I saw attend events. They entered feeling out of their depth, unsure of what to say or do for their loved ones. Meeting other families helped provide them with answers to their questions and they left with hope for their loved ones future.

As Chair of MACS what was your proudest moment?
I was Chair for only short amounts of time when MACS was in difficult periods. I'm proud of the fact that MACS continued, that it learnt from its experience, and put safeguards into place to ensure that MACS members were always at its heart.

I am not only proud of my times as chair but am proud of all the time that I was a Trustee and part of the MACS committee. Although it does take time and can involve lots of work, it's very rewarding. I wanted to give something back to MACS and my initial personal aim was to help others never to feel the pain my family felt when our child was born. As he and his brother grew and we got to know more MACS members, I realised that there were many other issues that families needed support with and so my aims were then to extend the services MACS offered.

What is, or was, the best thing about MACS? For me and my family MACS has been there for us since our second son, who was born with micropthalmia and coloboma in his right eye, was 2 and he's 28 now!

I think that the best thing about MACS was, and still is, the knowledge, comfort, support and friendship it brings.

At first for us as parents, we felt totally isolated and alone and back then without the internet we had little information about the eye conditions and had no one around us who could understand the pain and worry we were feeling about our baby. Attending our first AGM weekend was very nerve wracking but we left feeling, after meeting older MACS children, that we had positive hope for our son's future. We had answers that we needed and felt like we were now part of a big MACS family. The many friendships we made 28 years ago at our first AGM meeting have lasted through the years and we are so thankful for those.

MACS went on to help both of our sons. Our eldest son struggled with people and his peers looking at his younger brothers differences and it was there for our MACS child as he began struggling with issues surrounding his appearance and self-esteem. Participating in the sailing voyages gave them both the confidence to deal with these issues and we saw the changes in them after they left the boat.

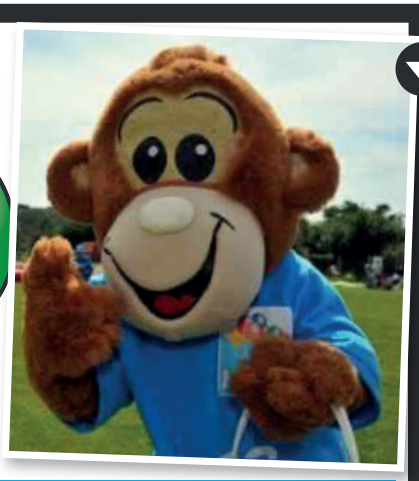
2007

Barry Stickings becomes Chair in November.

MACS started collaborations with Professor Nicky Ragge.

2009

First MACS sailing trip in Scotland.



MACS MEMORIES FROM OUR CHAIRS, PAST AND PRESENT
Recollections and proudest moments

Barry Stickings MBE *(Chair 2007 – 2015)*

What is your fondest memory of MACS?
Kelly, Toby and I were at a Family weekend in May 2001. As everybody knows when you walk into that room for the first time with your child it's overwhelming. You know nobody and as you enter you do feel slightly nervous. At this event, in walked Mary and Phi McEvilly with Eoghan, who was less than a year old. He had the same condition as our son Toby, Bilateral Anophthalmia. I saw them standing there alone, so we walked over and made our introductions. Kelly took Eoghan in her arms and proudly with love introduced him to everybody, walking around the hall, whilst telling everyone to go and say hello to Mary and Phil. This memory has been with me since that day. Kelly loved bringing new families into the MACS world at these events over many years. Giving them the encouragement to break the ice and become part of an extended family. We have never looked back, our friendship began and continues to this day with Phil and Mary.

What is, or was, your proudest moment as Chair of MACS?
There are so many its hard but one will remain with for me forever. I was nominated by my peers to receive an MBE for the work that I had accomplished working with the visually impaired, which is a passion, even now with my own support group BAAM for Bilateral Anophthalmic members it consumes me every day with new ideas and new members.

The MBE was was not about me, it was about the families. The presentation of my MBE at Buckingham Palace in February 2018 made me feel very humble, but I was part of a team, a team who made MACS happen. All of those trustees I worked with over the years made it happen. There is no I in team. To this day I feel honoured to have been able to help in part take MACS forward in my time I spent as Chairman, observer, trustee and volunteer. For me having the chance to help others fulfilled me then and still does to this day.

What's the best thing about MACS?
Being able to bring families and friends to a group that not only understood why they were part of it, but could genuinely empathise with them. We had been there, on that path from the moment of birth to now having our family. MACS, through its amazing families, was there to help. Through MACS I have met the most wonderful people whom I have shared laughter, tears, heartache and joy. I have made friendships for life. When just one person said thank you to us we as a team I knew we had done our work. It was worth a thousand thank you's.

I remember attending the meeting organised by the Observer and lord Jack Ashley in 1993. It was the first time for some families we had meet somebody else outside of hospital appointments with our Childs similar conditions. Its where the seed was planted making families there like myself want to do something to help. There was nothing for us, no other way of meeting, sharing, helping or just been able to say hello. That meeting made several people who attended start what is now MACS.

Attending that meeting and later being Chair, observer, trustee and volunteer it made me proud that I was part of it. Remember, it's not just a group. It's a family, and one where you feel comfortable and have no fears, just knowing that you and your children will make friends for life and have support. You were and are now no longer alone.

2010

MACS the Monkey is born! The beloved mascot comes on board to represent MACS.

£2 Million raised by MACS in total. Pictured here are our marathon runners wearing the old style running vest.

MACS hosts the first fundraising ball 'Ice Ball'

First MACS' Got Talent show.

2011

Another successful Family Weekend at Park Hall Hotel near Preston.

Autumn Ball.

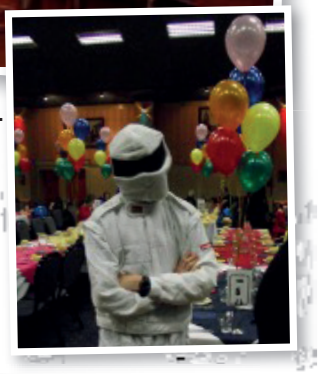
2012

£3 Million raised by MACS in total.

MACS Rebrand launched.
We have been blue ever since!

MACS takes part in the Tall Ships Races.

Night of Glamour Ball.



MACS Activity breaks begin.

Another successful Family Weekend at Park Hall.

MACS the Monkey completes the London Marathon!

A successful regional trip to the Harry Potter World.

2013

MACS recruits its first member of staff to manage the development of the charity. Two more staff members soon follow to coordinate fundraising events.

Family Weekend 2013.

Another successful sailing trip.

August - MACS participating in Ride London for the first time.

Masquerade Ball.

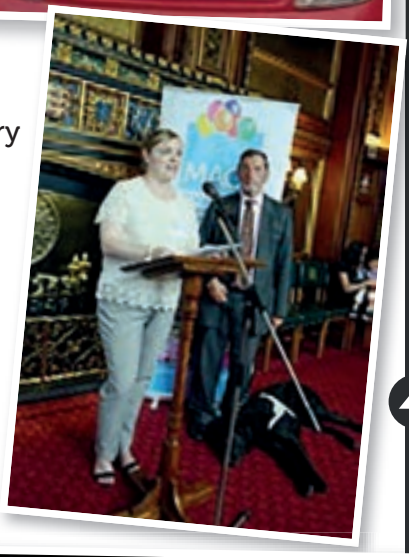
Skydiving event for MACS teens & adults took place.

2014

A MACS Fundraiser takes on the Mongol Rally! This most unusual fundraising challenge was undertaken by Magic Matt, an entertainer present at many MACS.

October

MACS celebrating its 20th Anniversary at a Westminster reception.



MACS member giving a speech sharing her story with the Patron Lord Blunkett in the background.

Roaring 20's ball.

2015

Robbie Crow became Chairman.
Microphthalmia, Anophthalmia & Coloboma Support is born - MACS changes its name from Micro and Anophthalmic Children's Society to Microphthalmia, Anophthalmia and Coloboma Support, and structure to a CIO (charity incorporated organisation).

MACS MEMORIES FROM OUR CHAIRS, PAST AND PRESENT

Recollections and proudest moments

Robbie Crow
(Chair 2015 – present)

What is your fondest memory of MACS?
My fondest memory of MACS is every single one of the family weekends that I have attended. From my first in 1996 to my most recent in 2019, every single one has been special to me. When I was younger, I used to count down the days from Christmas until the next Family Weekend where I could see my MACS friends. The 'MACS Weekends', as I used to call them, were the highlight of my year because they were one of the few times when my parents let me go alone with my friends. Whether that was just running around Park Hall or Camelot, that little bit of time alone with my MACS friends made me feel independent. MACS was the first place I felt independent and the first place where I felt 'normal'.

What is, or was, your proudest moment as MACS Chair?
My proudest moment as Chair of MACS was when I retired at the end of 2022 and realised I'd successfully led us through a global pandemic, with our minimum reserves still in the bank. Many charities struggled during the COVID-19 pandemic, and some no longer existed because of that.

I'm proud that I led MACS through the pandemic and ensured that the charity was there for generations to come. I know how important MACS was to me growing up and if it had disappeared because of the pandemic, the blindness sector would've lost one of its best organisations.

Although it was stressful and emotional for 24+ months, I'm proud that I led the organisation through its toughest time and that it came out the other side thriving.

What's the best thing about MACS?
I think the best thing about MACS is that we offer a safe environment where people can receive support from each other, support which is gained from lived experience of the MACS conditions. No-one can offer emotional understanding to someone with a MACS condition (irrespective of age) except another person with a MACS condition; and no-one can understand what it's like to be told that your child has a MACS condition except another parent who has been through that. Especially in teenage years, both the MACS young person and the MACS parents need support from others who have been through similar life experiences. That's what MACS does.

I don't know what it's like to be told my child will never see; but what I do know, all too well, is what it is like to feel alone, to feel scared, and to ask 'why me?' - all because of something none of us ever asked for. The MACS conditions force everyone to ask those questions and feel like that at some point in their lives, no matter how the conditions affect you, MACS is the only place in the world that can help people work through that.

CONTINUED

2016

MACS' first ever strategy is created.

2017

- £5 Million raised by MACS in total.
- Family Weekend format changes to sessions.
- Members can now attend sessions that interest them.
- MACS begins collaboration with Mariya Moosajee and Moorfields.
- MACS wins the 'Small Charity Big Impact' award.
- We were delighted to receive this award from FSI as well as the prize that was a professionally made video promoting MACS.

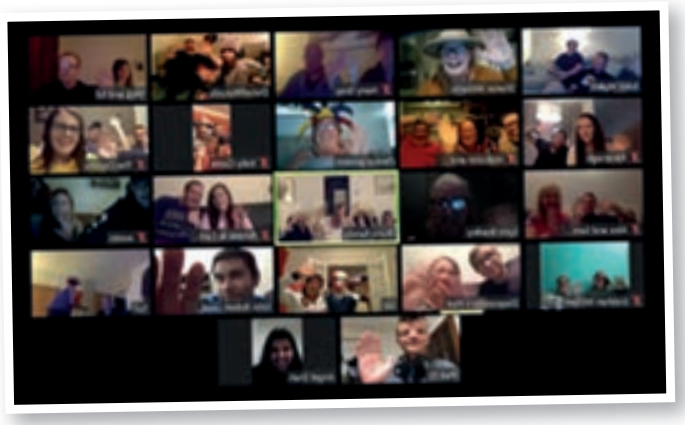
2018

MACS Achievement Awards 2018. We loved receiving all the contributions and only regret that we couldn't reward everyone!

First full time CEO appointed. £6 million raised in total.

MACS celebrates its 25th anniversary!

- MACS first digital event takes place
- MACS Adults and Siblings Facebook page launched April 29th, now with 87 members



- 1st Zoom meeting started April 2020

2020

Another successful activity break at Caldecotte Xperience.

Confident & Connected Launched – we publish the document setting out our goals for the next four years.

Fundraising Manager appointed.

2019

CONTINUED

2021

Income surpasses £7 million since beginning of MACS

2022

- MACS welcomes its 1,000th family in April
- Services and Events Facebook page launched June 24th

2023

1st MACS adults meet Up - Birmingham 16th September 2023

We facilitated the first ever Adults MACS Meet Up 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. 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.

£7,891,000 raised to date!

2024

New Plan to Thrive three-year strategy launched

Plans underway to develop Regional Volunteers Programme

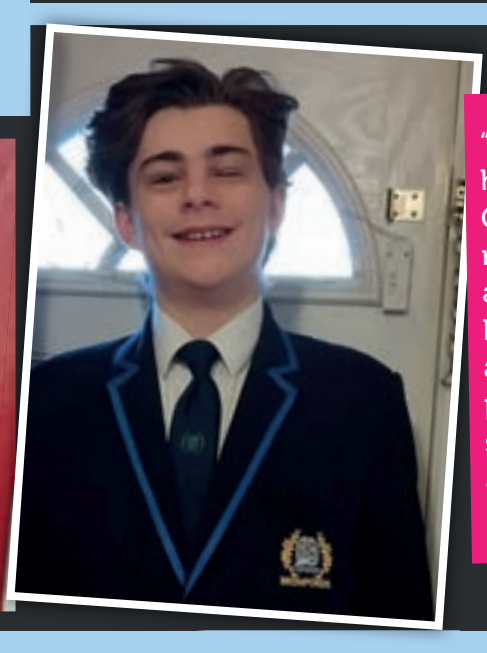
New events and services on the horizon

MACS Members' Milestones

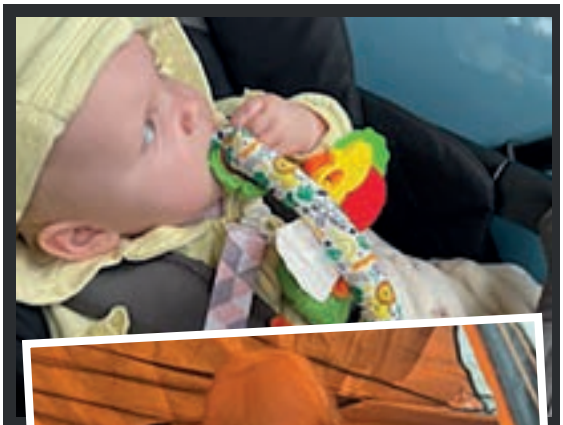
You all loved reading about big milestones being celebrated by MACS members in the last issue of Focus, so we have even more to share with you! We hope you'll be as proud as we are of your fellow MACS members and invite you to share your milestones with us for the next magazine...

"Recently I have had a big milestone in my life. I became a first-time mum to my daughter Violet."

"India-Rose has achieved so much considering the obstacles she's had in the way. She's just about to finish reception ready for year 1 of school. She's excelled in everything at school without any additional support, in reading, writing, dancing with only one eye. Nothing has been an obstacle. Her confidence has increase and it's hard to believe she the same girl. Even though we've just ordered her red glittery shell, she's still adamant that she doesn't want to wear it. She's adapted well to her glasses but she's so fiercely independent maybe one day she'll wear it or maybe she won't."



"Todd has just finished school having managed to sit ALL his GCSE exams, which given his recent struggles with crippling anxiety which affects the sight he does have is an amazing achievement. We are all so, so proud of him. In September he starts at a construction course at College which he is really excited about."

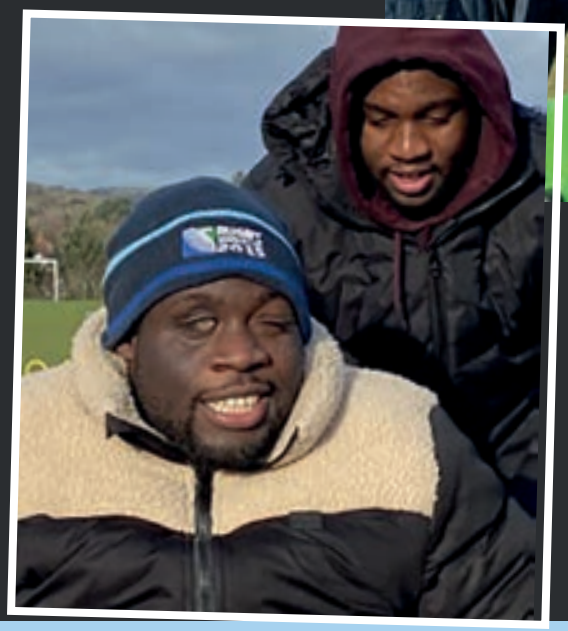


Now nine months old, Daphne has learned to sit steadily by herself, and we have been working with a local visual impairment team to continue to assess Daphne's visual abilities, and come up with techniques to nurture her skills. Daphne recently played in an orange sensory tent with light toys whilst 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 her 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.

After a year of 1:1 SEN lessons Leo achieved his 20m badge. Leo has bilateral chorioretinal coloboma and autism. Leo's autism was identified thanks to MACS linking us up with Dr Moosajee at Moorfield who invited Leo to a genetics clinic where he was assessed by a developmental paediatrician. Without this diagnosis he wouldn't have been able to access SEN lessons so would not have learnt to swim as he'd been asked to leave mainstream lessons.

Felix's first time in the swimming pool.



Where have the years gone?! It was great to be able to reflect on how life has changed since Matthew was born 28 years ago (21st May 1996) in Eastbourne. Matthew was born with micro and anophthalmia and severe learning difficulties as a result of his Peter's plus anomaly condition. Looking back from the vantage point of so many happy birthdays, I wish I could have told my younger self that life would have been alright! Maybe harder than I envisaged but perhaps richer and more fulfilled as we have met so many wonderful people along our life journey.

Matthew now lives away from us in a residential home in Henley on Thames and it is really great to hear news from the centre of how he is enjoying life and receiving regular pictures of him doing so many activities. Even though Matthew has taught me and our family so many things, our primary objective has always been to make sure he has a meaningful, protected and productive life. Although the initial dream may not be the same, a new reality has emerged of a young man who makes us and other people laugh, who shows us how to live simply and teaches us what it means to be human; loving, living and laughing. So we're enjoying the moment of seeing him develop each year, recognising that his life is a gift that we really cherish and celebrating the fact that he has brought life and joy into so many other people's lives as well. A big thank you to MACS who provided so much helpful advice along the way and for the opportunity in the early days to meet with families to hear and learn from their experience.

Caleb will be flying alone to the Netherlands to attend a music festival in July. It isn't the first time he's been to the festival but it will be the first time he's travelled alone with support at the airport.

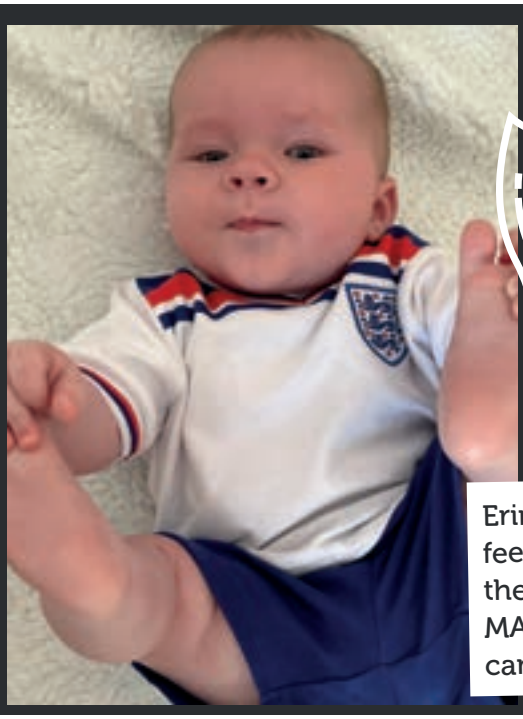
Aurora is learning braille and is doing amazing.

"Milly is working towards her Bronze Duke of Edinburgh Award this year. She recently did a two-day practice hike, camping overnight. In their group they must be self-sufficient carrying everything including tents and stove. They also must cook a main meal and breakfast. They walk for about six hours, following a route on a map, both days. it is quite a challenge, especially carrying the backpack. Milly has the qualifying expedition in a month, which is the same requirements in a different area.

To complete the award you also must undertake a skill, physical and volunteer section. They are all for an hour a week. One is for six months and the others for three months. Milly volunteered at a local chapel, which runs arts courses for the community. She helped at a stop motion animation course for youngsters. Helping them make their animations. Making drinks, serving, and washing up. She walked for the physical section, exploring our local area, and walking Pumpkin our dog. She also completed a Five Peak Challenge in aid of the RNLI with friends. Walking five local hills. Milly is learning to play guitar for the Skill. Her dad is teaching her and a few months in she is progressing nicely. Already playing the piano has helped.

We are very proud of Milly, as this has pushed and challenged her in different ways. It is a great scheme and would encourage others to give it a go if they have the opportunity. Our MACS kids constantly show us that they are resilient and up for a challenge!! MACS help encourage and build that can do attitude and many role models are visible within the group. Thank you to MACS and all the fantastic members."

Ben recently took part in the London Youth Games para swimming event, representing Wandsworth in the VI with severe learning disabilities category. He won an individual silver medal for backstroke, and Wandsworth Boys won the Gold overall. Ben was thrilled to hear his name called out and to have his medal presented by the Lord Mayor.



Erin has found her feet and is ready for the football!(Sent into MACS before it almost came home!)

Research Update

Professor Nicky Ragge's research: new findings and the importance of international meetings to advance better diagnosis and care for families

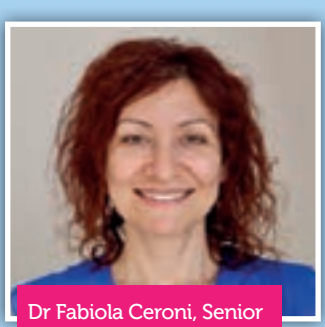
Attending conferences enables us to share ideas and approaches with medical and scientific colleagues, to build strong collaborative networks and to embrace new state-of-the-art technologies to shape our research methods. Keeping pace with, and contributing to, advances in the field of human genetics and specifically ocular genetics has been a privilege and enabled our group to make significant progress.

This article features our recent presentations at the European Society of Human Genetics (ESHG) Conference and the preparations for the upcoming 5th Genetics of Ocular Development (GoOD) meeting in September 2024.

The 2024 ESHG Conference, Berlin, Germany

The ESHG recently held their prestigious annual conference in Berlin, Germany. International geneticists, clinicians and academics convened to present their innovative research and latest clinical findings in talks, seminars, workshops and posters. An exhibition hall hosted stands from companies showcasing the latest technological advances.

Dr Fabiola Ceroni, Senior Research Fellow, and Dr Solomon Merepa, Post-doctoral Researcher, from Professor Ragge's group were selected by ESHG to present our research.



Dr Fabiola Ceroni, Senior Research Fellow, Oxford Brookes University

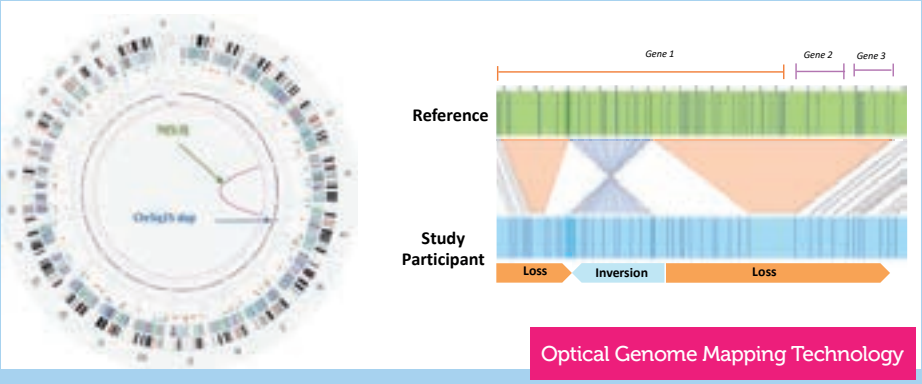
Dr Ceroni's experience of the ESHG Conference 2024

"The conference was packed with inspiring talks from the major experts in the field: four days of buzzing ideas and discussion about the latest methods and innovative technologies used to understand human genetic conditions.

As part of this exciting "meeting of minds", I had the fantastic opportunity to present our latest research on a gene called Wnt Ligand Secretion Mediator, better known as WLS. Until recently, geneticists were uncertain about the range of developmental disorders resulting from changes in WLS, because very few cases had been reported. Our study describes the genetic alterations in WLS in two unrelated individuals who have coloboma, microphthalmia / microcornea and additional features. It shows that MAC conditions can occur among individuals

"The conference was packed with inspiring talks from the major experts in the field: four days of buzzing ideas and discussion about the latest methods and innovative technologies used to understand human genetic conditions"

Genetic alteration in WLS leads to coloboma in humans and zebrafish



Optical Genome Mapping Technology

who carry changes in WLS. Moreover, Dr Hande Tunbak, Post-doctoral Research Scientist within our team, demonstrated that when this gene is altered in fish, they develop eye conditions similar to humans.

Therefore, our findings have showcased the gene WLS and described the clinical condition, thus adding to our knowledge of MAC conditions. This will enable healthcare professionals to provide accurate diagnosis and genetic counselling for affected patients and families".

Dr Solomon Merepa: Using new state-of-the-art Optical Genome Mapping technology in diagnosing MAC families

To help the many Microphthalmia, Anophthalmia and Coloboma (MAC) families still searching for a genetic diagnosis, the Ragge team recently installed a new state-of-the-art technology called "Optical Genome Mapping" (OGM).

Dr Solomon Merepa, Post-doctoral Researcher, Oxford Brookes University, loading OGM samples onto the Bionano Saphyr System

Although it has long been known that chromosome alterations can interrupt MAC genes, the main focus in NHS genetic testing has been on sequencing genes and using standard techniques to look for chromosome alterations, called arrays. But often the DNA can be rearranged in a very complicated way, with insertions, deletions, duplications of DNA, or a combination of all of these. However, by studying very long pieces of DNA using Bionano technology the actual alterations can be identified to a very precise level and reconstructed, so it is clear which genes might be affected. With the help of 60 families with MAC, we obtained new samples which we processed in a very specific way and then used this technique to identify new diagnoses.

I was delighted to showcase the significant progress we have made with the OGM technology at this year's ESHG Conference; particularly how the OGM technology has enabled us to provide important new diagnoses for more families. In several other families, the OGM technology has revealed complicated and very rare genetic changes that could affect the smooth working of certain nearby eye genes - which we are continuing to explore.

Thanks to this new and exciting Optical Genome Mapping technology, we have been able to identify brand new, previously hidden, changes in genes and inform more families of the genetic cause of their MAC conditions; finally making a diagnosis in some cases after many years of research.

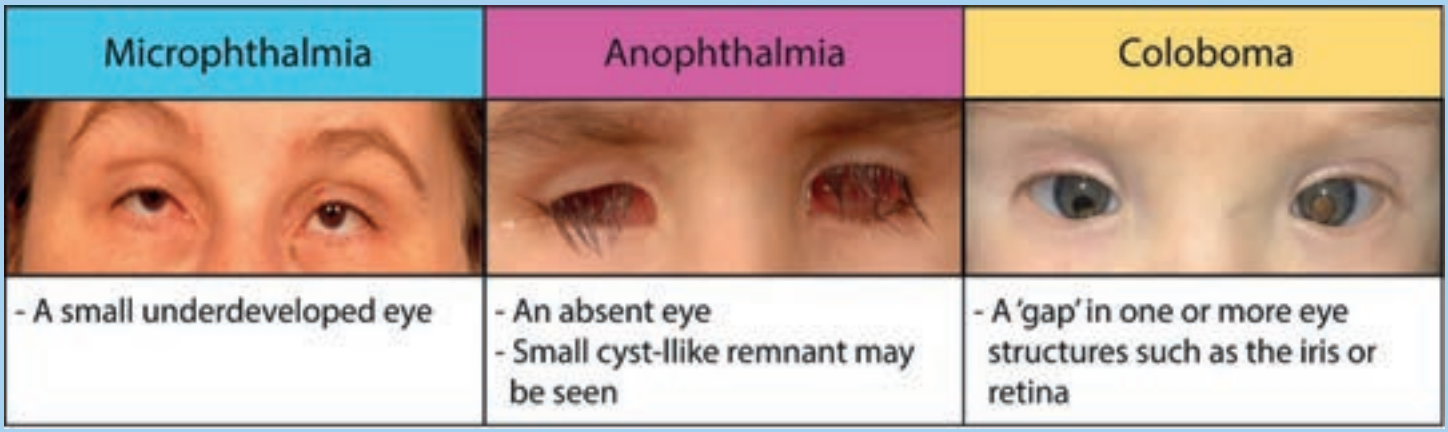
Genetics of Ocular Development (GoOD) Meeting, Oxford, UK, September 2024

Following the success of the previous Genetics of Ocular Development (GoOD) meeting held in Toulouse in 2023; the fifth GoOD Meeting will take place in Oxford in September 2024.

Gradel Quadrangle, New College, University of Oxford

Research Update

Dr Jonathan Eintracht and Prof. Mariya Moosajee share an update on some of their exciting MAC research at the UCL Institute of Ophthalmology and Moorfields Eye Hospital:

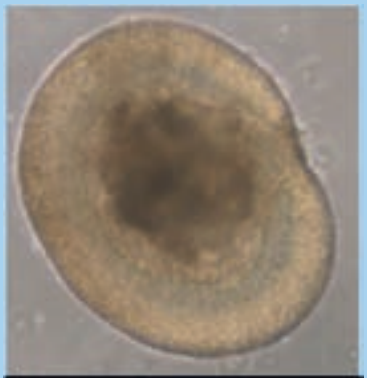


Microphthalmia, Anophthalmia and Coloboma (MAC) are a spectrum of eye conditions where the eye does not form correctly during pregnancy.

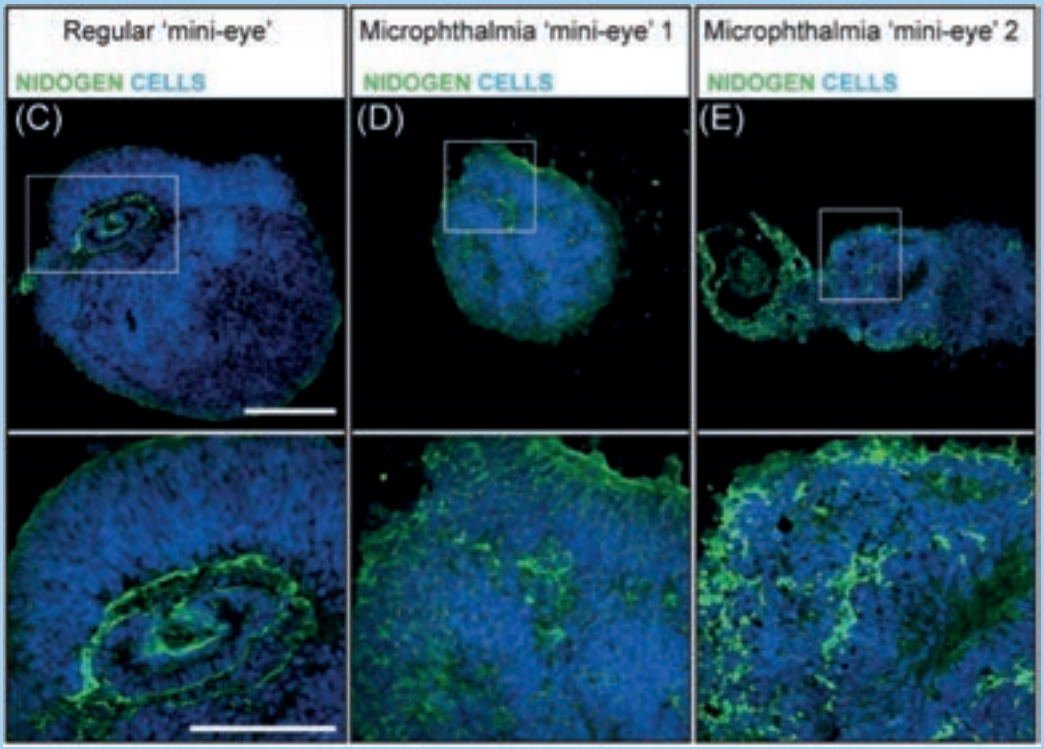
Genes are portions of DNA that provide instructions to cells telling them how to work. These instructions range from how organs, such as the eye, should form during pregnancy to making sure all the cells in our body function correctly throughout our whole life! Approximately 80% of MAC cases are caused by genetic mutations, meaning there is a change (which is like a spelling mistake) in the DNA code that tells the body how to form eyes. This results in either one or both eyes not developing as they should, thus falling somewhere along the MAC spectrum. Despite most cases being genetic, only one third of MAC patients who undertake genetic testing actually find out which gene is responsible for their condition. This is because there is a lot still to be learned about MAC genes and how they work and there are also likely to be many new MAC genes still to be discovered.

Researchers have found mutations in over 100 genes that have different roles in eye development. However, no one has found any changes to eye development processes that are common across MAC patients with different genetic causes. This is important as it would show new pathways in eye development that could be affected in MAC cases and could help us to identify new candidate genes involved with MAC. This could improve our ability to find a genetic answer for MAC patients who have previously had an 'unsolved' genetic test result.

In our study recently published in the journal Stem Cell Reports, we aimed to find common disruptions to eye development in two microphthalmia patients. First, we created a cell model in the lab that mimics the first 6 weeks of eye development, as we know that the genetic mutations that cause MAC disrupt development in the first 6 weeks of pregnancy. We did this by converting skin cells taken from these patients to stem cells, and then we turned these stem cells into 'mini-eyes'.



An example of a lab-grown 'mini-eye' grown for 5 weeks



We then compared the 'mini-eyes' which had been created from the cells of MAC patients to those from non-affected controls and found a few interesting things.

1) Even in the lab-grown mini-eyes, the MAC patient mini-eyes were smaller than the non-affected controls. This tells us that the 'small eye' effect of microphthalmia can be observed in lab-grown eyes too.

2) We found an increase in the formation of the 'extracellular matrix' which is an important part of all organs. Essentially, this is a network of proteins that surround organs and tissue in the body and is crucial for their structure and development. They also pick up on any signals from other cells that can form part of a larger message chain. It is possible that too much 'extracellular matrix' means the eye cannot develop as it should in pregnancy, resulting in microphthalmia.

3) We found more dead cells and less dividing cells in the microphthalmia 'mini-eyes'. It's possible that more dying cells and less growth cause the 'small eye' effect seen in microphthalmia.

4) We treated the microphthalmia 'mini-eyes' with a chemical designed to prevent cell death and measured its effectiveness in cells provided by one patient. The reduction of dying cells in the lab-grown eyes of this patient may suggest a new route to develop treatments for MAC and other developmental conditions.

We look forward to the next stages in our research into MAC conditions and their genetics!

How to get involved:
At Moorfields Eye Hospital, we have several research studies and genetic testing opportunities for patients with MAC and their families. These include:

- Whole genome sequencing – this is genetic testing where all of someone's DNA is analysed to try and find a cause of their MAC diagnosis. This involves getting over 3 million letters of DNA code per person onto computer - this is over 20,000 genes! This could either find a genetic spelling mistake in one of the MAC genes we know about, or it could help us to pinpoint new genes

- The National Institute for Health and Care Research (NIHR) BioResource for Rare Diseases is a large national project and anyone with MAC can take part in this. Signing up to the BioResource involves providing a blood or saliva sample for genetic testing. This project allows you to become part of a large national group of patients who are happy to be part of future MAC-oriented research.

- At Moorfields, we are also running a project called the "Genetic Study of Inherited Eye Disease" that any MAC patient can sign up to. This allows patients to join our large genetic database of patients and for our researchers to analyse your DNA at the UCL Institute of Ophthalmology.

- If you are interested in having genetic testing, taking part in research, or have any questions at all about this, please do not hesitate to contact Samantha Malka, Genomics Research Manager, on samantha.malka@nhs.net

MACS' Plan to Thrive

In 2023, MACS embarked on an exciting journey to assess and enhance the impact of our charity, driven by the enthusiasm and input of our vibrant community. This comprehensive evaluation, guided by feedback from our members, has been pivotal in shaping the future direction of MACS. We've uncovered heartening insights into the significant benefits our work brings to our members, and this feedback has been instrumental in refining our vision and strategies.

Our new strategy focusses on four key areas...

OUR COMMUNITY: BUILDING CONNECTIONS AND AWARENESS

We know that there are thousands of people in the UK at this very moment who have a MACS condition but may not even know we exist! That's why we are committed to building a positive and supportive network, aiming to increase our membership by 10% annually. This growth will be supported by a refreshed MACS brand and our "Thriving at 30!" campaign, which celebrates the achievements and possibilities of living with a MACS condition. Through this campaign, we aim to raise awareness and showcase the incredible stories within our community.

OUR SUPPORT: COMPREHENSIVE AND ACCESSIBLE

Supporting our members means providing access to the best information and resources. We're enhancing our advice and information services, ensuring that they are age-appropriate and reflect the latest research. Our events programme is also set for an upgrade, with plans for adventure trips and large-scale gatherings that foster connection and support. We're expanding our network of regional volunteers, making it easier for members to access help and build local connections.

Peer support is another cornerstone of our strategy. We're developing new activities to boost resilience and well-being, and we're committed to helping members navigate their rights, entitlements, and employment opportunities. Our "Helping Hands" grants will continue to provide crucial financial support, enabling members to fully participate in society.

OUR INCOME: SUSTAINABLE AND DIVERSE

To sustain and expand our work, we're focusing on diversifying our income streams. Building strong relationships with supporters and funders will be crucial, as we aim to cover 100% of our charitable costs. This financial stability will ensure that we can continue to offer essential services to our community.

OUR PEOPLE & SYSTEMS: STRENGTHENING OUR FOUNDATIONS

Behind the scenes, we're working on improving our IT systems and internal controls. These enhancements will equip us to better deliver our strategy and communicate our impact effectively. By capturing and sharing the stories and successes of our members, we can **learn, grow, and continue to meet the needs of our community.**

The future of MACS looks brighter than ever. With a clear plan, a supportive community, and a dedicated team, we're ready to take on the challenges and opportunities ahead. We look forward to celebrating many more successes with our members and partners as we work towards a more inclusive and supportive world for all.

Team MACS Did it again!

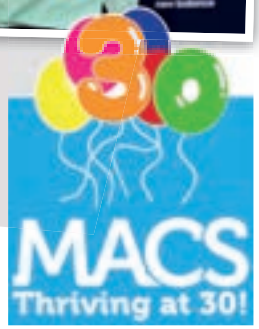
A TEAM of 142 dedicated supporters embarked on the 26.2-mile journey of a lifetime, all in support of MACS! Our London Marathon runners showed incredible determination and spirit as they collectively covered an astounding 3,720 miles in April's race. Their unwavering efforts have resulted in raising over £250,000 to support MACS.

This remarkable achievement would not have been possible without the tireless dedication of our runners. Each step they took represented not just physical endurance but a deep commitment to a cause close to all our hearts. Their journey through the streets of London was fuelled by the knowledge that they were making a real difference for individuals with MACS conditions.

We also want to extend a heartfelt thank you to everyone who supported our runners. Whether you contributed through donations, shared words of encouragement, or cheered from the sidelines, your support has been invaluable. It is your generosity and enthusiasm that help us bring together people with MACS conditions, providing them with life-changing support and creating a community of hope and resilience.

The funds raised will go a long way in continuing our mission to support and connect individuals and families affected by MACS conditions. Your contributions will help us offer essential services, organise events, and create resources that make a tangible difference in people's lives.

Once again, thank you to our extraordinary runners and to everyone who has been part of this journey. Together, we have achieved something truly special.

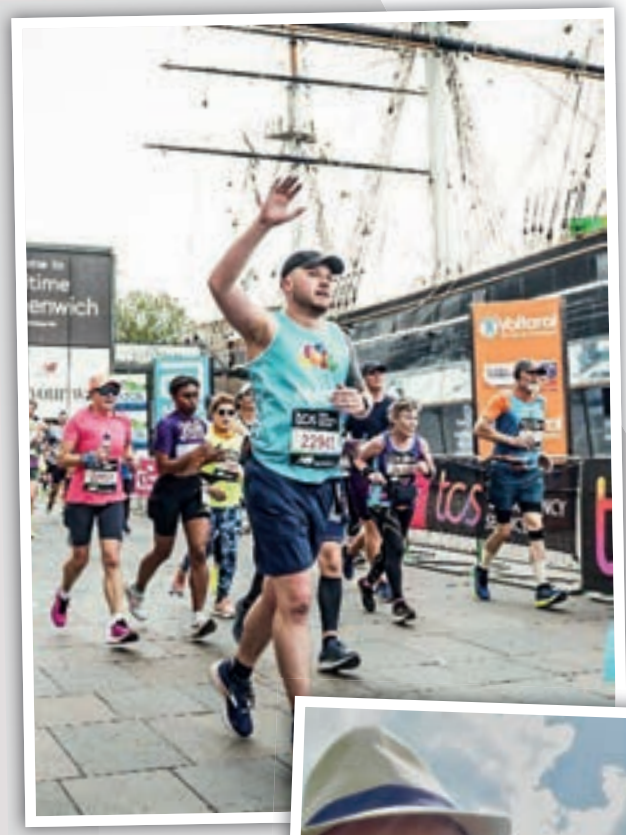


"I was delighted to run for MACS in this year's marathon and the shout out at the seventeen mile mark was welcome encouragement.

I choose MACS because it is one of the less well known charties that does amazing work.

It's brilliant to run the London marathon but all the more satisfying when supporting a great cause."

Gerard Boyle



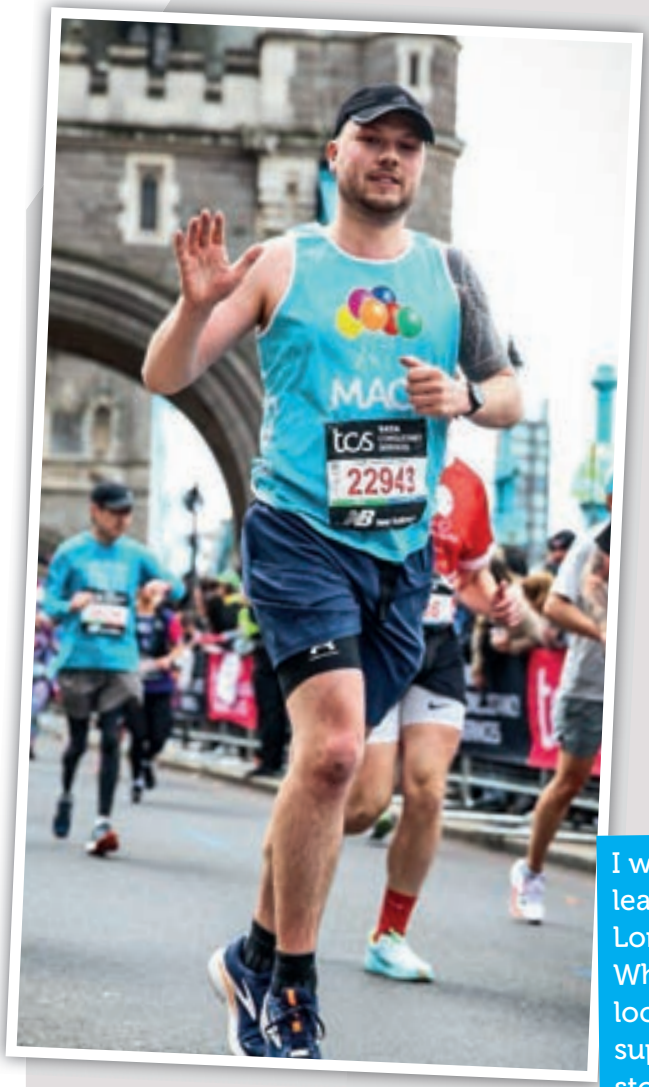
London was a magical experience running for MACS & I got to see so many friends at both the Expo & on the run & that's not to mention in the pub rehydrating afterwards.

I was inspired to take on the challenge by Ben Lupton & his parents Tim & Jenny who are so inspirational.

My customers were so very generous with their sponsorship which bought in over £1500 for the charity & I owe them a big thank you.

Running in my Wolves shirt gave me so much inspiration from football fans along the course & we had some wonderful banter, it would appear they don't all support my team !

David Bayley - Milton Keynes



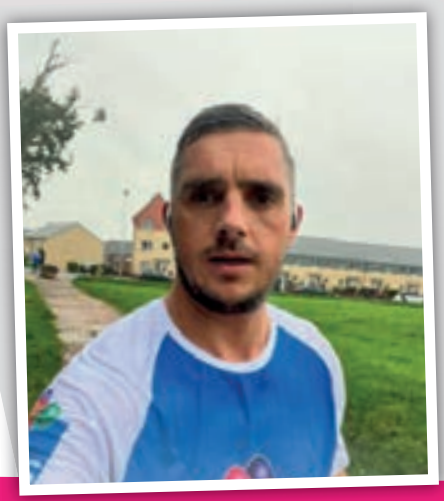
I will admit I hadn't heard about MACS previously but after learning about the charity, I decided to apply to run the London Marathon for them and raise much needed funds. What convinced me was reading a story about a little boy, local to me, who had no eyesight and reading how MACS had supported him and his family. I ended up reading all of the stories on the MACS website and spent most of it in tears. I couldn't imagine how hard it must be for these families to deal with their children having no eyesight.

So the training began and the fundraising started. I live in the north east of Scotland so most of my training was done in the dark with the wind, rain, ice and snow playing a huge part. Most of my fundraising money was raised by selling a calendar. I'm a keen amateur photographer so I put a calendar together of local views which I sold to friends, family and at Christmas fairs too.

For me, running the London Marathon is a huge challenge. After being diagnosed with cancer almost five years ago and having had treatment which means I can no longer feel the balls of my feet or underside of my toes, I find running extra difficult. But I never let these things stop me and it was a joy to be able to take part. Running the marathon is such an amazing experience and it was great to be wearing a MACS charity top.

Hopefully this will of also raised awareness as we ran through the streets of London. There were certainly plenty of people cheering us on and the atmosphere was electric!

Diana Thomson – Insch, Aberdeenshire



Although it was really hard for me due to the painful foot blister at mile 7 the thought of being able to finish and raise the money for your wonderful charity kept me going and so glad you gave me the opportunity to do so.

Malcolm Marchant - London

THANK YOU!

TO OUR FUNDRAISERS

Running for a Cause: The Inspiring Journey of Ruth Wilkinson and Friends

ON MOTHER'S DAY, 10 March 2024, Ruth Wilkinson from Crick, Northamptonshire, alongside her friends Sally Watts and Yogen Patel from Rugby, Warwickshire, took on the Retford Half Marathon to raise funds for MACS (Microphthalmia, Anophthalmia & Coloboma Support). This run was a deeply personal journey fuelled by love and the quest for a better future for children like Ruth's daughter, Betty.

Ruth's journey with MACS began in November 2022, when her youngest daughter, Betty, was born and diagnosed with bilateral coloboma at two days old. The news came as a heavy blow, leaving Ruth and her family in shock and uncertainty. "I noticed something different in Betty's eyes," Ruth recalls, "and the diagnosis meant she would likely see only light and shade."

The early days of Betty's life were a whirlwind of medical appointments, tests, and emotional turmoil. The family struggled with the unknown, lacking a clear path forward. During this difficult period, Sally, Ruth's close friend, discovered MACS while searching for support resources. Ruth signed up her family as members, and immediately, the warmth and support of the MACS community enveloped them.

Ruth vividly remembers her first post in the MACS Facebook group. She was seeking advice on how to support Betty in her early months. The response was overwhelming, filled with positive stories, practical advice, and a profound sense of belonging. "I learned so much about the MACS conditions and how to give Betty the best possible start," Ruth shares. The support from the community was instrumental in those challenging times.

With guidance from fellow MACS members, Ruth and her family transformed their home to stimulate Betty's vision. They filled their space with flashing lights and shiny objects, following the advice of those who had walked a similar path. Today, Betty is 18 months old, a happy, cheeky, and thriving little girl who continues to amaze doctors with her developing vision.

Running a half marathon had been a long-time goal for Ruth since she joined a local informal running group in 2015. However, it was Betty's diagnosis that provided the perfect motivation to turn this goal into a reality. Sally and Yogen joined Ruth in this endeavour, driven by a shared purpose and the desire to give back to the organization that had given Ruth's family so much.

Training for the half marathon was no easy feat, especially for Ruth and Sally, both mothers of young children. Finding time to train amidst their busy schedules was challenging. However, Yogen's organisation and motivation kept the group on track. "Yogen was a fabulous organiser and motivator when we were struggling," Ruth notes, "providing lots of breakfasts and Yorkie bars!"

The Retford Half Marathon was more than just a race; it was a celebration of resilience, community, and the power of support. Ruth, Sally, and Yogen's efforts culminated in a successful run, raising significant funds for MACS. "The sense of achievement in completing our run and raising funds to benefit our MACS family will stay with me forever," Ruth reflects.

For anyone considering taking part in similar activities, Ruth's message is clear: the support from MACS and the sense of accomplishment are invaluable. The funds raised not only help families like hers but also foster a community where no one feels alone in their journey.

Ruth's story is a testament to the incredible impact of community support and the power of determination. It's a reminder that with the right support, even the most daunting challenges can be overcome and that every step taken for a cause brings us closer to a brighter future for those in need.

CHARITY WALK RAISES OVER £2,500 FOR FIVE CHARITIES

The recent sponsored walk was a resounding success. With perfect weather—not too hot and no rain—the event was enjoyable for everyone involved. Balloons were handed out to the children, adding a festive touch as they were tied to their bags. Although all the sponsor money has not yet been collected, over £2,500 has already been raised. This impressive amount will be divided among five deserving charities, making a significant impact.

The day was incredibly busy, so there weren't many photos taken. However, a few special moments were captured: a Year 3 student holding a MACS flag and a photo of Florence and her supporter. "When asked which charities to support for the sponsored walk, MACS was the immediate choice. MACS was discovered shortly after Florence's Coloboma diagnosis and has been an invaluable source of support.

Sharon at MACS has been fantastic, staying in touch and providing essential information when Florence was later diagnosed with Aicardi Syndrome. Attending a meet & greet in Newcastle in February left the family feeling happy and hopeful. Thank you, MACS, for everything you do!"

The success of this walk is a testament to the generosity and enthusiasm of all participants and supporters. The team looks forward to continuing their support for these wonderful charities in the future.

RUN FOR A CAUSE: JOIN TEAM MACS!

Feeling inspired?

We now have a 134 runners running as Team MACS in the 2025 TCS London Marathon and we look forward to introducing them in the next edition of Focus. We're still operating a holding list as we usually see a number of dropouts as the event draws nearer, so please do apply if you're keen to get on the Team! If you can't wait, here are some other events we have places for...

Great Scottish Run Half Marathon | 6th October Registration Deadline: **20th September**

Great South Run Half Marathon | 20th October Registration Deadline: **4th October**

Join us and make a difference with every mile!

Tribute to Kelly Lehmann: A Champion for MACS

We would like to use this opportunity to give thanks and pay tribute to **Kelly Lehmann**, a remarkable supporter of MACS, who inspired us all with his unwavering dedication and spirit.

KELLY'S journey with MACS began with a personal challenge that turned into a lifelong commitment to support others. In April 2012, the year of the London Olympics, Kelly ran his first and only marathon. Motivated by his grandchildren's innocent question about his ability to participate in 'Go Ape,' he began exercising and entered the London Marathon to spur himself on. His determination was unstoppable, and he completed the marathon with pride.

> Kelly made it his mission to stay active and raise money for MACS whenever possible

Since then, Kelly made it his mission to stay active and raise money for MACS whenever possible. His efforts were not just about running; they were about making a difference, inspiring others, and showing that age and circumstances are no barriers to achieving great things. Fast forward 12 years, and Kelly set his sights on a new challenge. At the age of 70, with the Paris Olympics on the horizon, he decided to take on the "Marathon Pour Tous" (MPT). This

unique public marathon, held during the Olympic Games, would see 20,024 runners racing overnight on the official Olympic Marathon Course.

Kelly earned his place in the MPT by participating in a 5km race on the Champs-Élysées in October 2022. Competing against Eliud Kipchoge, the first runner to complete a marathon in under two hours, Kelly finished the race in 30 minutes and 42 seconds, securing his spot among the lucky 1,000 who beat Kipchoge to the finish line.

The MPT challenge required Kelly to run from the centre of Paris to Versailles and back again, covering 42.2km with significant elevation changes. Despite the daunting task, Kelly's training was underway, fuelled by his desire to continue supporting MACS. He reached out to his community, inviting them to recognise his efforts and contribute generously to his cause.

Kelly Lehmann's story is one of perseverance, generosity, and a heartfelt commitment to helping others. His legacy lives on in the hearts of those he inspired and in the ongoing support for MACS. We honour Kelly's memory by remembering the incredible impact one person can have on a community.

Thank you, Kelly, for your enduring spirit and for being a true champion for MACS. Your memory will continue to inspire us all.

MARTIAL ARTS EVENT

On Saturday, April 20th, a charity event took place at the MJM Stadium, raising an impressive £72,634 for various charities. Among the contributors, Robert made a significant impact by raising £460 for MACS. We extend our heartfelt thanks to him for his support.

We hope you'll join us in celebrating our 30th birthday by displaying the below poster where lots of people can see it

Happy 30th Birthday MACS

Microphthalmia, Anophthalmia & Coloboma Support

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

Scan the code and find out more or visit www.macs.org.uk

UK registered charity number: 1161897 **Scotland registered charity number: 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