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MACS

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

FOCUS MAGAZINE

Microphthalmia, Anophthalmia & Coloboma Support

Supporting children born without eyes or with underdeveloped eyes

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

Contents

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

MACS

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MACS MAGAZINE | VOLUME 15
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 to the summer edition of Focus!

In this issue we are delighted to share some fantastic stories from members, including the 1,000th family to have joined our community earlier this year! This is a fantastic milestone for MACS and we couldn't be prouder to have reached it. You can also read about our plans for the MACS Awareness Week, opportunities to get involved in the Ambassador scheme, and fundraising events. Last but not least, you can get inspired by our Ride London and Kiltwalk participants, and meet the London Marathon runners who are getting ready for their event in October.

There have been few changes to the team behind the scenes. We were sad to say farewell to our Chair Naomi Bowman, who has reluctantly stepped down due to family reasons. Naomi made a huge impact in her time as Trustee and I'm pleased that she's staying on as an advisor to the board when required.

We've also said farewell to Trustees Lisa Jefferies and Mariya Moosajee, both of whom are still closely linked to the charity. Until we appoint a new Chair I have taken up the positon of interim-Chair at the request of the board and will be working to appoint a new permanent chair and several new trustees before the end of 2022. I'd like to thank Naomi, Lisa and Mariya for your time on the board during my time. If anyone reading this is interested in joining our board and becoming a Trustee or the next MACS Chair, do get in touch. You can email **recruitment@macs.org.uk**

While our board of trustees is a small but mighty team, the staff team has continued to grow to meet our ambitions over the next few years. Emily Murphy has joined us as Trusts & Foundations Fundraiser and, thanks to a very generous grant from CAF, Ian van der Heyden will be our new Service Development Manager. Emily has already made great strides, having secured lots of new funding for MACS in such a short period of time. Ian's start has been delayed for family reasons but we look forward to introducing him properly in the next edition. Liz, our Chief Executive, is taking an extended leave of absence for health reasons, and I will be taking the steer as the interim Chair in the meantime, supported by an interim CEO.

We wish Liz and Ian all the best and look forward to welcoming them both back as soon as possible. It's my priority to ensure we support our staff as well as we support our members and they will both have our full support to return to their roles when it's best for them.

We are so pleased to see that our activity breaks and sailing adventure trip have all been fully booked up by our young people and we hope they have a fantastic time this summer. Similarly, the Giving Families a Break scheme was a huge success and we hope everyone taking a break with MACS enjoys some much-needed respite.

While the Covid restrictions have eased, we are facing more troubled times due to the cost of living crisis and global instability. Remember that the MACS family is here for you if you need us. I would also like to wholeheartedly thank all our fundraisers and donors who continue to support MACS throughout those turbulent times. With your help, MACS is as strong as ever, and here for every child, adult and family who need us.

I hope you enjoy this summer edition of Focus! If you'd like to write an article or submit a story for the next edition, please let us know.

All the best,

Robbie
MACS Interim Chair

Welcome to new staff members

EMILY MURPHY, TRUSTS AND FOUNDATIONS FUNDRAISER.
Emily joined MACS in April 2022 as the Trusts and Foundations Fundraiser. Emily brings a wide-range of experience having worked for her local hospice for nearly nineteen years, across various roles within the Fundraising department, but latterly as the Trusts Fundraiser.

Emily is excited to take on this new role at MACS and is looking forward to boosting the grant income from trusts and foundations to maintain and develop member services.

Meet the Team

The Trustees & Staff

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Update your preferences

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

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Meet our 1,000th family

In April we achieved an incredible milestone – we welcomed the **1,000th family** to the MACS community.

Tommy with mum Sophie, Dad Paul and big sister.

THE 1,000th family to become members of MACS are a family of five from Birmingham, made up of parents Sophie and Paul and their three children. The youngest child, Tommy was born in September 2021 and was six months old when they discovered the charity. Sophie said:

"Our son, TOMMY was three months old when he was found to have Bilateral Coloboma as part of a rare genetic condition he has. It is still early days and we don't yet know the extent to which his vision will be affected. At the moment, not knowing is the hardest part for us but we are happy to have found MACS to help us through this journey."

Welcoming the 1,000th family is a fantastic milestone for MACS and all our members. Since MACS was first formed in 1993, we have been working hard to reach everyone who needs us. We are very proud to be reaching such a vast number of families and would like to thank you all for helping us to spread the word, supporting MACS and helping us get here.

HELLO To new members

MACS is growing! We have several different types of memberships. Full membership for families and adults, Professional memberships for organisations, Extended Family Membership for wider family members, and Friends of MACS membership for those who are outside our UK remit but want to stay in touch.

We recently reached our 1000th family but that is not the full picture! Our members come in many forms and join at different stages of their lives. If we include extended family and those who've moved out of the family home to live independently, we have over 1155 households with more than 3251 people in the UK alone.

In the past 12 months we have had more than 308 people join MACS, including 274 full members from 91 households. So far this year and since our last copy of Focus magazine, we have had more than 131 people join MACS, of those, 113 are full members from 39 households.

Meet some of our new members below!

Martha with parents Rob and Amy

Leo

Braydon

Fenn with sister Eevie dad Joseph

Rosie

William

Evelyn

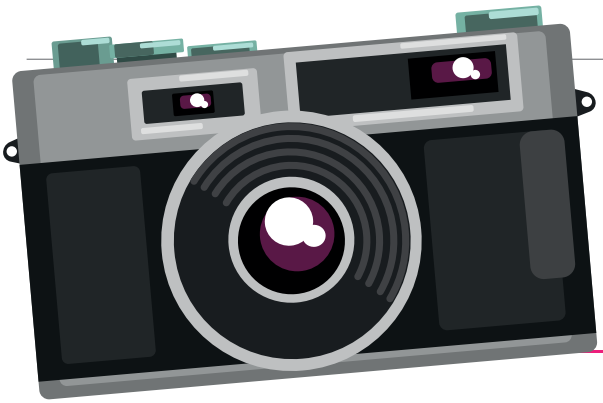
Lorraine, Jason and twins

"Having twins who both have eye issues, we felt so alone and isolated; the hospitals gave very little information. Being left alone to do nothing but Google made us more scared for the future than necessary... and then we came across MACS. Finding others in the same boat as us, experiences similar to ours, and information that we otherwise haven't been able to find has already been invaluable. We are so pleased and relieved to have found such a charity that is helping us come to terms with the boys' conditions and I'm sure will help them as they grow and develop to know that they are not alone and that they can be surrounded by others just like them.

I'm so grateful to MACS already and can't wait to join regional and national meet ups and get to know the other families and people that have already supported us."

Lewis

"This is Lewis who's 13yrs old. He has coloboma and is also autistic, he was diagnosed when he was around 6 weeks old and we weren't given any information except a leaflet and told that it was rare. He hates going for check-ups because the dye they put in his eyes hurts. Lewis is very talented playing his keyboard by ear and is wanting to learn the bass guitar. He also loves gaming he has loads of games for PlayStation 2,3 and 4 he has the VR too."



Cassidy's Photo Adventure


Cassidy

MACS' Helping Hands scheme offers subsidised equipment and services to members with a MACS condition, and we receive between 30-40 applications each year. As you may know, visual impairment equipment is notoriously expensive, so a helping hand with these purchases can go a long way for our members. Our grants don't just cover equipment. Earlier this year, we were delighted to be able to give a Helping Hand to fund a once-in-a-lifetime educational photography trip to Iceland for seventeen-year-old member, Cassidy from Dudley.

CASSIDY is studying a BTec photography course at college and has a natural talent, excelling in her course and already winning awards. Her college recognised that talent and invited her to take part in a photography trip to Iceland. This exceptional opportunity was going to cost £1,000 and despite her college's best efforts to find sponsors, there was only a month left before the trip. Neither Cassidy nor her family had the money available. That's when MACS came in, with a Helping Hand...

"MACS really was our last chance to attempt to get funding for this trip. My mum had emailed multiple different companies & charities for help, I had emailed Icelandic Air, the company I'll be flying with, and my college tutor had contacted multiple Nordic Banks in attempt to get funding for me. All of these we had no luck with, which is when my mum decided to get in touch with someone she knew who used to work for MACS, who then referred us to Demi Powell who has been absolutely amazing and helpful with everything we have enquired about.

"My photography means a lot to me because I have full creative freedom with what I choose to photograph and how I photograph it "

My photography means a lot to me because I have full creative freedom with what I choose to photograph and how I photograph it. Even with college projects where I have a brief to follow, I'm able to create photos that mean something to me on a more personal level. For example, I recently had a landscape project where I got to photograph anything as long it was classed as a landscape image. I took this idea and decided to morph it into something more.

I own a photography lens ball and decided to photograph sunsets through the lens ball. When the photo has been taken, the image through the middle of the ball is perfectly clear while the outside is completely blurred. This represents my vision when it's affected by nystagmus, where majority of my field of view goes blurred.

Using post-production skills on Photoshop, I desaturated the colours on my images to make them look dull, boring, and less colourful. This is to represent one of the main symptoms of cataracts which is how I lost the vision in my left eye when I was born.

Photography is a visual based artform, and most photographers are fully sighted. However, I have challenged myself to break this stereotype. The opportunity for me to go to Iceland is one that I am incredibly grateful for, and I'll forever be appreciative of MACS for enabling me to take part in this amazing trip. Going to Iceland means that I can develop my photography further than 12-year-old me would have ever imaged when I took my first landscape photograph.

Being a visually impaired teenage girl comes along with many struggles, including mental illness, low self-esteem, and little confidence. This trip will aid me in each of those things - being in a completely different country doing something that I'm passionate about.

It's fast and easy to apply for a grant and everyone at MACS involved with the Helping Hands scheme is extremely helpful and kind. They do their best to accommodate YOUR needs. I would encourage members to apply if they need help with funding something!"

MACS Meet ups

After the disruption of the pandemic, the MACS Meet Ups have resumed!
Our first event this year was held at Warrington Woolston Play and Sensory Centre.

THE majority of attendees were first timers at a MACS event. One family made a round trip of over 320 miles to meet other MACS members! Everyone had a wonderful time meeting other MACS families.

These events are so valuable. They are all about making contact with others who have common experiences and sharing your journeys. Our events are open to all abilities and age ranges and completely free to attend.

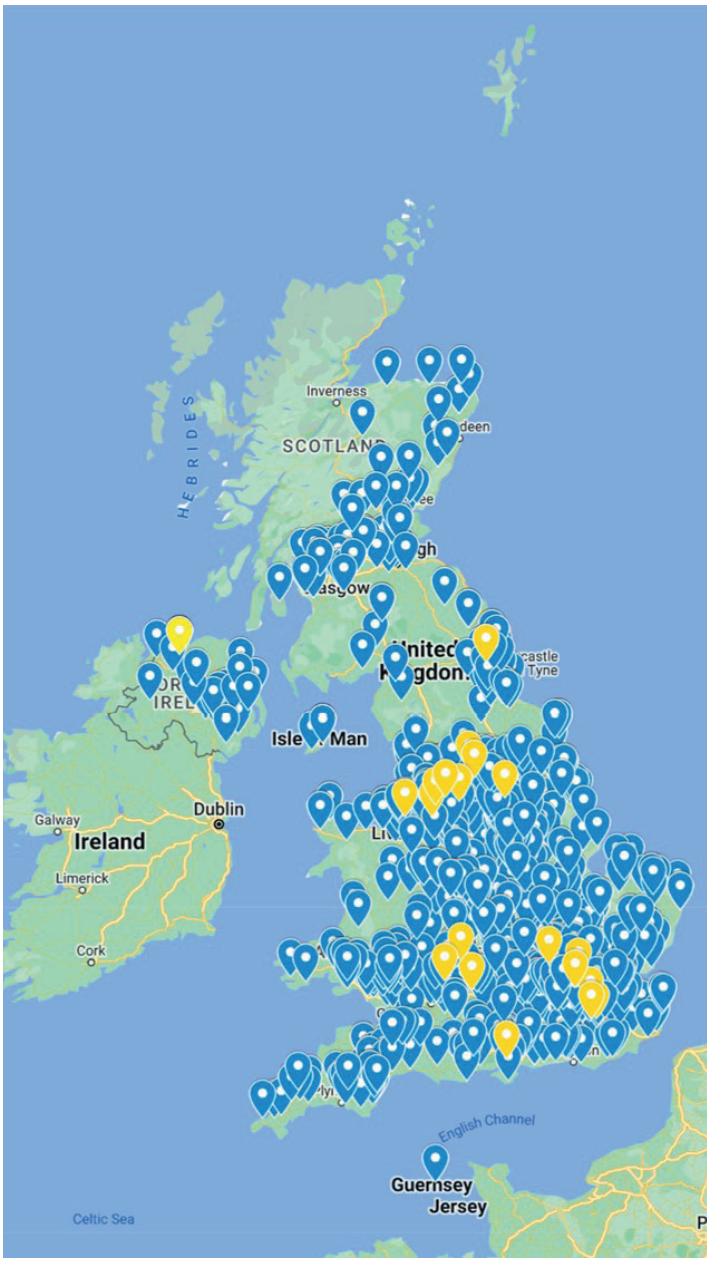
Local social groups

We are so pleased to update you that we now have 24 Local Social Groups volunteers, taking the lead on organising activities for members in their local area. We can't wait to see what they come up with, and very much hope for many of you to attend a local activity.

The map pictured here shows where the volunteers are located (indicated by yellow pins), as well as the density of our membership.

Can't see a location near you? Why not become a volunteer yourself!

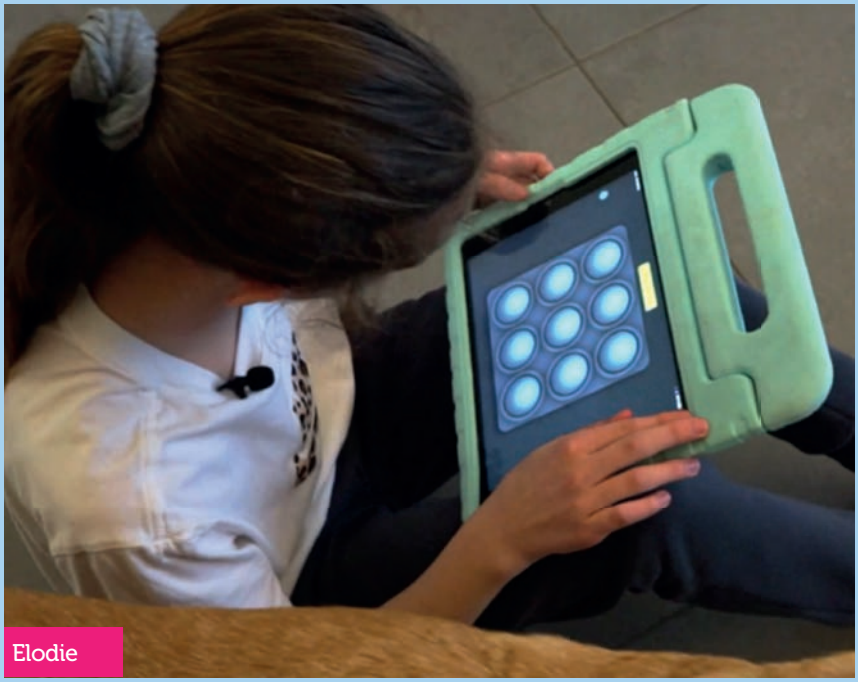
Local Socials are a great chance for you to meet other MACS members in your local area. You could go to the cinema, for a walk, coffee or go to a soft play centre. You could do anything big or small, it's totally up to you and your Local Group!



The activities are hosted by MACS volunteers with seed funding provided by MACS. At this stage MACS is looking for volunteers to form local groups and would like to encourage everyone to give it a go!

To learn more, please visit
macs.org.uk/members-area/local-socials-events/

Elodie's Braillenote Magic



Elodie

Elodie with her mum

EVERY YEAR OUR HELPING HANDS SCHEME ENABLES MEMBERS WITH A MACS CONDITION TO ACCESS TECHNOLOGY, EQUIPMENT OR ACTIVITIES THAT THEY WOULD NOT OTHERWISE BE ABLE TO AFFORD. MICHELLE HAS KINDLY SHARED THE STORY OF HER DAUGHTER ELODIE AND HOW HELPING HAND HAS HELPED ENABLE HER TO PARTICIPATE IN EVERYDAY LIFE WITH HER FRIENDS AND TO DEVELOP HER SKILLS IN TECHNOLOGY.

Elodie is 11 years old and was born with bilateral microphthalmia, retinal coloboma and when she was a baby both her retinas detached. She is completely blind in one eye and light perception in the other. Elodie has been reading Braille since she was three years old, she is a brilliant Braillist and is at a mainstream school in Northern Ireland. Her greatest joy however is using technology. Our technology journey started when she was two years old – we bought her an iPad as she enjoyed listening to nursery rhymes. She quickly mastered the iPad and voice over commands. As she got older she really wanted to try refreshable Braille and to be able to read and write in Braille, she loves writing stories and poems and writes in her own diary every night.

> 'Having access to this technology has been lifechanging for Elodie! She loves playing text adventure games and chatting to her buddies'

Part of Elodie's technology journey has been possible because of MACS. Her Braillenote was kindly donated to Elodie by a wonderful lady who was part of the MACS community. Through the Helping Hands Scheme MACS also recently funded a software upgrade for the Braillenote. Having access to this technology has been lifechanging for Elodie! She loves playing text adventure games and chatting to her buddies on Google Hangouts. She loves writing stories on her Braillenote and has joined the MACS creative writing group. She is learning so many vital life skills through access to technology.

An amazing thing happened in Elodie in 2021. The BBC news ran a short story on her ability to use technology to do all the things her friends could do. She was able to show others all the cool things that blind kids could do on the technology she used. So many things are possible when our kids have the tools to all the things that they both want and need to do. We cannot thank MACS enough for all their help in making Elodie's technology dreams happen.

The photos above show Elodie with mum, as featured on BBC News.

Sky is the Limit

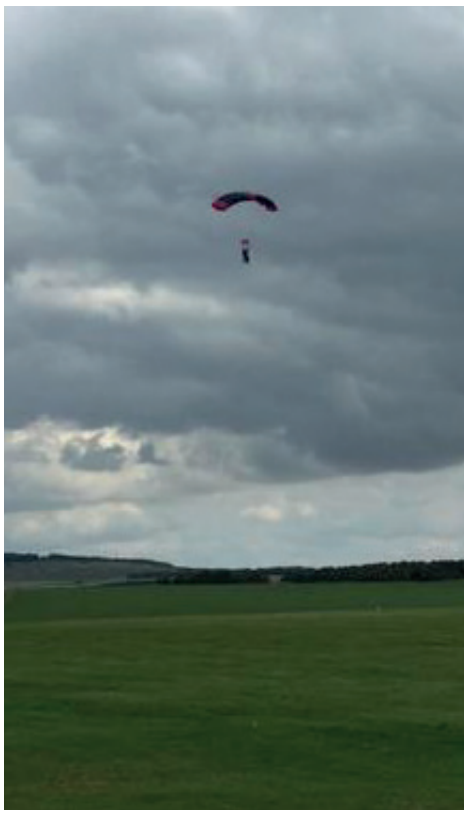
Becky's Story: skydiving and illustrating

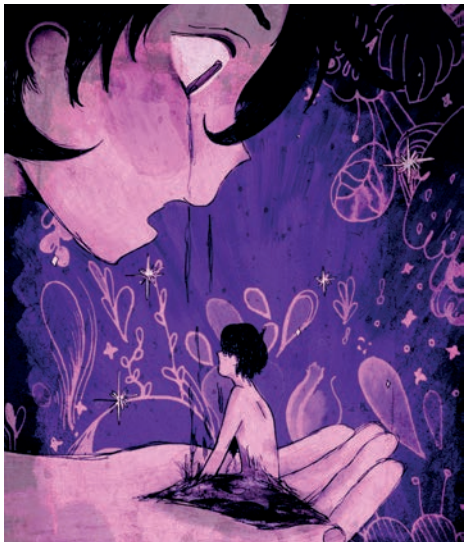
MY NAME is Becky Bell and I was born in June 1993 with Microphthalmia in my right eye.

When I was born, the hospital just wanted to keep the eye socket closed but my parents fought for me to have an artificial eye made. As a child I hated wearing it but I am so grateful that they continued to encourage me to wear it. I have now been doing this since I was just 13 months old. During my time growing up I was always super self-conscious and felt embarrassed about my eye but as an adult it doesn't affect me in the same way, in fact I have learnt to love it and have recently had made an all-black artificial shell (Which I love!).

I have always been a highly creative person. I have been drawing for my entire life and recently went back to university as a mature student to get my bachelor's degree in illustration where I graduated with a first-class

Becky pictured with her cousin and sister on the day of the skydive





Becky's illustrations.

degree. I currently work as a freelance illustrator. My art practice consists of a lot of comic style work and I have made a few comics and self-portraits about my eye and my experiences in life because of it. I find making work about something so personal can be really engaging for an audience and also helps point a spotlight at something they might not be aware of.

Like I said, growing up I didn't always feel very confident or comfortable about my eye so I didn't engage in any of the MACS activities up until 2015 when I did a Skydive! This is something I did with my older cousin and younger sister and I think we managed to raise about £1000. While at the skydive I have a memory of a young girl that had Anophthalmia doing a skydive and I remember thinking to myself about how brave and inspiring she was to me.

The skydive itself was very overwhelming and frightening but I am so glad it is something I accomplished. I am pleased I could raise the money for MACS and share this experience with my cousin and sister who inspired me to be brave.

Using my art work, joining in with the MACS events and having my family's support have all helped me be more myself and increase my confidence and not hide away over something that I have no control over.

Becky

A Partner's Perspective

I have something to tell you but, you might not like me anymore

HI,
My name is Declan, I'm 23 years old and on the 4th of January I celebrated my first MACS-iversary. Exactly a year before this date, my girlfriend Tori first told me that she lives with Microphthalmia in her left eye and wears a prosthetic shell. Having dated her for just over a year now, I do at least feel as though I understand what Microphthalmia means for her and her everyday life – the perks and challenges, and how incredible she is at not letting it define or limit her aspirations on a daily basis.

Being one of the only people in Tori's life that knows about her Microphthalmia, I feel blessed that she felt safe enough to confide in me with the knowledge that I wouldn't judge her or treat her differently once I knew. These days, this now continues in our regular pillow fights – we both set out to win against each other! But that's not to say that opening up about her condition wasn't a big deal for us both, because it absolutely was. In fact, it felt afterwards like a MASSIVE moment in our relationship.

These are the reasons I wanted to write this article, because being told about my girlfriend's visual impairment (whilst not a complete shock because let's face it, anyone would have to be at least partially blind to agree to date me) was an emotional experience and MACS stories such as ours are rarely shared from a partner's perspective. This made me think about how useful and comforting herself, her family and myself may have found hearing similar experiences of how other fully sighted people discovered and reacted to their spouse's visual impairment.

How did my girlfriend first tell me about her Microphthalmia?

It was the morning of Monday the 4th of January 2021 and I was sat at my desk trying hard to finish one of my 6,000 word assignments that was soon due in (which is unusual for a university student) when my phone vibrated on the table. It was Tori, which wasn't unusual because we speak every day, but the message wasn't the normal "have a good day" or "I miss you", instead it read: "I have something to sort of tell you but, it makes me scared to tell you in case you don't like me anymore".

Now, anyone who knows me well will know that I'm an overthinker at the best of times, so receiving a cryptic text message like this made all kinds of scary thoughts come into my head, ranging from breakup to illness. Seconds later, I received another message that read: "I don't mean to make you feel nervous. Can I ring you to tell you?".

Either she was psychic or she just knew me well enough to know how my mind works, because shortly after that she attempted to FaceTime me. I was petrified of answering

her phone call the first time she rang, so I deliberately let it ring out. This is something that I now deeply regret, knowing how much courage it took for her to even think about calling me. Nevertheless, with my nerves still going into overdrive, I accepted her call the second time and was greeted by her sat on the sofa...

She appeared composed and together but the redness around her eyes and cheeks gave me the impression that she'd been crying. We said our hellos and there was an awkward silence before the moment finally came when she had built up enough courage to disclose her condition too me. In the immediate seconds afterwards, the only emotion that I felt was an overwhelming sense of relief followed by pride. In a strange way, all the anxieties that I had allowed to build up in my head about losing her since her initial text message did, in a strange way, seem to make hearing about her visual impairment not a big deal – LIKE, AT ALL.

After I took a slight pause to calm myself and express my relief at the whole situation, I responded by saying "oh okay, and...?". Now this clearly came as both a welcomed surprise and a relief to Tori because she then began to cry and her amazing mum (who'd unbeknown to me had been sat on the sofa for moral support) appeared in view of the camera. She explained that because not many people knew about Tori's condition, they both feared that I might not be supportive of her once I knew about it.

My girlfriend then opened up further about her Microphthalmia, telling me it's a condition that she was born with, and how her childhood involved regular visits to the eye specialists. She also explained how it affects her depth perception and how, particularly during her school years, adaptations such as coloured paper to help her read made her feel different in comparison to her fully sighted peers (all things that my girlfriend herself wrote about in a previous issue of **MACS's Focus Magazine**).

Having heard all of this, I came off the FaceTime call feeling incredibly proud of what she'd just done. Although this whole conversation must have only lasted around 10 minutes, I do believe, as I did back then, that it was a very special moment in our relationship and added a unique layer of trust and understanding.

"She explained that because not many people knew about her condition, she feared that I might not be supportive once I knew about it"

How I've tried to be a supportive boyfriend since she told me about her Microphthalmia...

After the emotional event, my thoughts quickly turned to what my role was as Tori's boyfriend in supporting her and ultimately, will she find my support any good? (Something which you'd have to ask her to know if I've truly succeeded or not).

Therefore, in an attempt to show her that I am by her side, that evening I asked her if she knew of any useful sources of information that could help me to find out more about Microphthalmia. However, different to what I thought at the time, Tori doesn't expect me to know all the answers, come up with all the solutions or treat her any differently; all I need to do is be a good listener and let her know that I'm by her side no matter what.

I decided to get involved in MACS Charity events such as the virtual

creative writing workshops, quizzes, and MACS Family Weekends – all of which I consider to be opportunities for me to show my support for her. Another thing that I have started to do (which I first noticed done by a MACS sibling) is I now include a written description of any images that I upload to social media, so that those with a visual impairment can use audio transcription aids to visualise the images. Okay so yes, this may only be a small addition to my daily habits that largely goes unnoticed by others, but I don't do it for others I do it so that my girlfriend is reminded on a regular basis that I accept and support her 101% (I was never very good at Maths don't judge haha!).

Without the unconditional love and support from the MACS Charity that Tori has been lucky enough to access throughout her childhood and continues to have in adulthood, I believe she wouldn't have had the confidence nor strength to tell me about her condition. Therefore, from the bottom of my heart, I can't thank MACS enough for what you have done and continue to do for her and her family. You have helped to shape her into the beautiful woman that I know and fell in love with!

I would love to connect with other partners of MACS members in the same position as me and hear your stories of dating your better half so, please feel free to get in touch! Please contact* enquries@macs.org.uk *and the MACS team will forward your message to me.

Ambassadors and Champions

COULD YOU CHAMPION OUR CAUSE?

We are looking for MACS Champions and Ambassadors to help us continue to try and raise awareness and reach everyone who needs us. We're keen to have a wide-spread variety of champions and ambassadors, hopefully with someone representing MACS in each of our thirteen regions. There are three distinct roles for which we would like volunteers, each with the ultimate goal of helping to raise awareness and encourage support through engaging with lots of different communities. Here's a bit more information on each of these roles...

COMMUNITY ENGAGEMENT AMBASSADORS

Our Community Engagement Ambassadors will meet with different community groups and organisations, sometimes giving presentations and other times simply attending an event as a MACS representative, attending cheque presentations for example.

We'll also be looking out for community events and opportunities at which a MACS presence will be beneficial, so manning a MACS stand at a fete or supermarket may also be on the agenda.

Our Community Engagement Ambassadors need not be MACS members but will need to be confident public speakers with lots of passion for the cause.

ONLINE ENGAGEMENT AMBASSADORS

As well as Community Engagement Ambassadors, we'd really like to round up a handful of Online Engagement Ambassadors, who will act as representatives of MACS and identify online community groups and organisations to engage with. The Ambassador will network with these online communities in the same way a Community Engagement Ambassador would but just not in-person.

This voluntary role will also look out for audiences to which we can promote our activities e.g. online running groups for promotion of running events, as well as helping to gather and share external relative online content.

MACS CHAMPIONS

Last but not least, we're appealing for MACS Champions; people who can speak from the heart and from experience about the support of MACS. We would not expect Champions to make presentations, but rather support Ambassadors in their presentations by sharing their stories to help us really get the message across of what being a member of MACS is all about. Being a member is therefore essential for this role.

We'll also be looking to our Champions to help with content such as vlogs and social media posts to support the work of the ambassadors and MACS in general.

If you're interested in any of the above roles or perhaps a combination of two, then please get in touch with the team to find out more. Just drop us an email at enquiries@macs.org.uk and we'll be happy to arrange an informal chat with you and provide a more detailed role description.

MACS Awareness Week 2022

THROUGHOUT the week commencing 12th September, we'll once again be driving forward our annual awareness raising campaign. We'll be using each day of the week to shine the spotlight on different MACS regions and the members who live within them, with a theme of 'Your local, national MACS charity'.

The aim of this year's campaign is to achieve four great things for MACS and our families:

1. To introduce members to other MACS families living locally, in the hope that we'll open new doors for close-to-home connections and support.

2. To reach out to people who need us that may not have heard of us. How great it'll be for them to see the faces of their MACS neighbours and know that, even as a small national charity, we're right on their doorsteps and so widely spread!

3. To raise awareness of MACS, both as a charity and as a group of conditions that many people may not have heard or have the knowledge of.

4. To hopefully raise much needed funds towards our work.

CAN YOU HELP US ACHIEVE THIS?

For MACS members, it's not too late to be involved in this campaign. We'd like to gather some members' stories to share throughout the week with videos or photos, so please do let us know if you if you 'd like to be involved in this way.

For members and supporters alike, we're looking for community groups and individuals to help raise awareness and funds throughout the week. This can simply be through a flyer hand-out to raise awareness, or perhaps a coffee morning or bucket collection to help raise some money.

Perhaps your child's school would like to hold an assembly on MACS? We have everything you need for any of these activities, so please get in touch if you'd like to help.

You can also help throughout the week by sharing, sharing, sharing! Please watch our social media channels and like and share as much of our MACS Awareness Week content as you can. This really will help us to spread the word.

THE CHOICE IS YOURS!

Please get in touch with us by emailing **enquiries@macs.org.uk** if you'd like to be involved.

Featured here are photos from members who will be representing the various regions as per the 'Your local, national MACS charity' theme.

We hope you'll be as excited about this as we are, and we look forward to hopefully hearing from you soon!


Amy, Rob and daughter Martha representing Shropshire


Aidan representing North West


Clare, Sam and son Leo representing South East.


Fenn representing Scotland


Ryan representing Scotland

Meet team MACS

The TCS London Marathon takes place on 2nd October and preparations are in full swing! Good luck to all the runners taking on this challenge for MACS.

Sarah and Steve

"I HAD always wanted to run the London Marathon (once) so Steve and I decided to do it before we were 50. We decided to look for a charity place. I work with children who have SEND so this was our reason for applying for a place with MACS.

We are the class of 2020 and because of the postponement of our original event we have now run 1 virtual and 1 London Marathon!

To all the people who are starting their first marathon journey enjoy, it's amazing!" **Sarah and Steve**, pictured here in their 2021 Finishers' t-shirts.

"This will be my third marathon for MACS and I am so proud to be running for such a fantastic cause. I had always wanted to run the London Marathon ever since I was small boy watching the event on TV. I missed out on the ballot in 2019 although MACS were the first charity to offer me a spot and I couldn't now imagine running for any other cause. I love being part of the MACS family!

The support and encouragement over all the events has been incredible! The biggest motivation boost I received by far was when watching all of the recordings of good luck from the MACS children posted on Facebook the night before the event. I watched them all with my family. I was having doubts that evening whether I could actually run the marathon distance although after watching those kind clips of best wishes from those lovely children, I knew I would be crossing that finish line!! Thank you Team MACS and all the very best to my fellow runners!" **Toby**

Toby pictured at the Virtual London Marathon 2020.

Good luck to Andy Roberts

Good luck to Andy Roberts for his action packed year. In the run up to London, he will have completed multiple ultramarathons including the Viking 100 mile race, Endure 24 hour race, Hever Castle 50 miler, and a sub 3 hour attempt at the Berlin Marathon. When it comes to the London Marathon itself, Andy will be attempting a Guinness World Record! Andy says:

"I cannot wait for London, it's the most exciting race of the year and I love going for a Guinness World Record as it just adds to the fun and enjoyment of the day! This year I'll be going for fastest badminton player to run a marathon, 3:29:24 to beat. Must carry a racket and shuttlecock at all times plus carry 4 additional rackets in a bag and run in badminton shoes! I will of course be adding the MACS logo to my outfit, the bag and sweatbands.".

GOOD LUCK TO ALL TEAM MACS RUNNERS, CLASS OF 2022!

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/

"THIS will be my fourth time running for MACS! I couldn't ask for a better Charity, so supportive! I will be so happy to raise more funds for such a very good cause." **Kelly**

"When looking for a charity to run for, MACS caught my eye and I couldn't believe that there are 90 babies every year who were born without eyes or defected vision. I feel so moved that there is a group of people who CARE enough to set up the charity and do something for those 90 babies and their families each year and not leaving anyone behind. I am a mum of 3 healthy girls and it makes me feel humbled by what you do. I am hoping through my humble efforts to spread awareness and fundraise as much as I can." Xiaofang

"My daughter has coloboma in both eyes so I can't wait to run for MACS" **Clare**

"In 2015, my daughter Eloise was born. At around a week old, she was diagnosed with micropthalmia in her left eye and we joined MACS. It was particularly important in the very stressful early years of Eloise's life. She is now a perfectly happy and healthy girl in every other way, and we know we are the lucky ones.
At the same time, I weighed 15 stone and was obese. I hired a trainer and began to get fit, and lost 3 stone. Running the London Marathon to me is the ultimate fitness goal. It will mean so much to me to be able to do so in support of a charity that has made mine, and Eloise's lives so much better. I desperately want to do something to raise money for MACS, and help other families afflicted." Ed

"I have run the London marathon for MACS for many years and I'm back for more! I found this charity by chance and thought it was a great charity with not enough awareness. I have been happy to help raise money for the children affected by this condition and hope I can still continue to do this!" **Joey**

"I have run for MACS on a number of occasions now and feel part of the team! You are a great charity and I am so happy to be running for you again this year" Vicky

"I have always wanted to run the London marathon but wanted to run it when I found a charity which would give me the determination to take part and also finish. I think due to MACS being such a rare condition in the UK I wanted to do my part in helping and supporting those children and their families." **Aimee**

"It has always been a dream to run the London marathon for and raise money for a deserving cause." Kath

"Always enjoy supporting charities that support children!" **Karl**

"I'm an avid runner and was looking for a worthwhile charity to run for and when I read about MACS I decided this must be the one! Hands up I had never heard of this condition before and just can't imagine what this must be like for the families involved. I'm very fortunate to have a happy healthy family and because of that I'd love to do whatever I can to make a difference to those less fortunate." Andrew

"My reason for choosing MACS is following a long pledge to a friend whose daughter Mia, and the family have benefitted from MACS' support. A friend of mine has run the marathon for MACS previously and I have always said that if I ever felt I could run the distance I would like to run alongside him and raise as much money as I could for the charity in Mia's name. Wanting to run the London Marathon has been a bucket list dream since I was around 13 years old and now at the age of 45 I feel able to be brave enough to attempt the journey for charity as previously I was scared of letting anyone down. I felt I needed to run for a charity that had a close meaning and I look forward to running for MACS" **Liz**

"When my daughter was 3 months old I knew there was something wrong with her eyes. I had to see three different doctors before someone agreed with me that I had a right to be concerned. Following this she was referred to Moorfields Eye Hospital and was diagnosed with ocular Albanism, which means she is unable to see in the sunlight, suffers from nystagmus abs will always have difficulty with her vision and focus. At that time it turned our world upside down. More so because we were unfamiliar with the condition and we have had to spend a lot of time educating ourselves on ways we can help our little girl. It has now been 16 months since she was diagnosed and we have come to terms with it and she is doing amazing, but I don't want people to go through what we did. I want to be able to help other parents who are facing the same and also make people aware of what it is. My daughter gets funny looks when her eyes move rapidly when she's trying to focus - I feel I have a responsibility to help others understand to protect my child and others like her from being viewed differently. Also, there has been very little research in this area and the more we can raise the subject and money the more chance there will be of helping others in the future." Carly

"It's a tiny charity doing god's work. This is the type of charity I'd like to run for!" **Gareth**

"MACS strikes me as a wonderful, small charity that I really think I can give life changing money for. Although I had never heard of MACS before, it strikes me as a great charity!" Matthew

"I'm very excited for the marathon and I have been training non stop despite the hot weather!" **Rohel**

Good luck to all the Team MACS runners! All the best for your training and fundraising over the next few months. Thank you for supporting MACS!

Thank you to our fantastic supporters

It's not just the London Marathon keeping Team MACS busy! A huge well done to all the supporters who have been walking, cycling, and more! Here's what they've been up to this year

Menzies Distribution take on Kiltwalk

A massive well done and thank you to Emma Milroy and 7 colleagues from Menzies Distribution on completing their KiltWalk 15 mile challenge and raising an incredible £2,316 for MACS! The team were inspired to take on this challenge by Emma's 2 year old son who has Microphthalmia and Coloboma. MACS Trustee Robbie Crow was delighted to collect the cheque in June!

Emma says: "Knowing we have done something good gives me such pride to know this money will help the likes of my own son and all the other kids live a life more independent and enjoy everything they deserve even though they have challenges to overcome every day.

Again thank you for being an amazing support to my family in such a hard time where we were lost and needed that push to go forward there is light at the end of the tunnel for these inspirational children."

Once again, a big well done to the team on completing their challenge and achieving such a brilliant fundraising amount.

Team MACS at RideLondon – Essex 100

Well done to Team MACS riders who completed the RideLondon – Essex 100 sportive on 29th May. As a group the team have raised a fantastic £2,444 for MACS!

Maz and Birgitta

I saw on social media that MACS were offering charity places in the Ride 100. My cousin's grandson was born with a MACS condition and wanted to support this well deserved cause!

I needed to train for this as I had never ridden that far before! I also persuaded my friend Birgitta Whitaker to join me. Although on the day we were together for only about 20 miles out of the 100 - long story!

I had completed a 250 Mile Challenge for Maggie's charity at beginning of May and cycled 300 miles in Holland on a holiday. My good friend commented that "you can't count that as you were going to do it anyway because you're on a cycling holiday!" so I said, OK I'll do another 250 miles in May! All in all in the month of May I cycled 700 miles!

I noticed on the day that we didn't see any other MACS riders. I will be encouraging some of my cycling buddies to ride for MACS next year!

Dave

Back in 2015 I decided to enter into RideLondon, MACS gave me that chance to get a ticket into the event (a true win win 😉!) and this was now my fourth time riding for MACS!

I love the fact that MACS is not a large charity so every penny raised goes to good cause. MACS works really hard to make each pound raised go an incredibly long way; its positive effect on MACS children and their families is massive, so why would you not want to help and raise money for them?

Mark

I've been cycling, mainly in the warmer months for a number of years, but started to take my training more seriously last year, building up the miles on the indoor trainer over winter and getting out into the Hertfordshire countryside when the weather permits.

Always keen to have a challenge to work towards, I was delighted to get a place with MACS for Ride London. I have microphthalmia in my right eye, so MACS is a charity that is very close to my heart. I also ran the marathon back in 2014 raising funds for MACS, so I think that means I now just need to do the Serpentine Swim to complete the Classics Challenge clean sweep for MACS!"

Thanks to our Trusts and Foundations funders

GRANT FUNDING is essential to the ongoing provision of our member services, and we'd like to say a big THANK YOU to all the Trusts and Foundations that have supported so generously over the last year.

Every penny is enormously valuable in funding online and one-to-one support, local and regional meet ups, family weekends and the annual adventure trips.

In 2021, we received a magnificent £226,008 in grant funding – amazing! As our services start to get back on track this year following the pandemic, so our costs are starting to grow again and we remain forever grateful to all the Trusts and Foundations who continue to support our members', along with the new Trusts and Foundations who are joining us for the first time in making such a difference to **MACS** members lives.

Get Involved!

Support a child

A gift of as little as £12 a month could fund friendship, confidence or even adventure for a MACS child.

This year sees the launch of our new regular giving campaign, offering an easy, hands-off way of giving but still making a world of difference. Regular donations can be any amount you like but, to give you some food for thought, we've included some examples below of how different amounts could help...

£12 a month funds fun with family and friends...
A small monthly gift from you of just £12 could pay for a child like Indie (pictured here with older sister, Morgan) to:

- Join all of their friends and MACS connections from across the UK at our Family Weekend.

£25 a month funds friendship...
£25 a month could pay for a child MACS to:

- Meet with their MACS friends from their region on a monthly basis and
- Join their local MACS friends for a panto at Christmas time and;
- Join all of their friends and MACS connections from across the UK at our annual Family Weekend.

£56 a month funds adventure...
£56 a month could pay for two younger MACS children to:

- Climb, zip-wire and row their way through our Adventure Weekend and;
- Explore places they've never visited before on a funded holiday in the UK.

OR...

Your £56 a month could pay for an older MACS child to:

- Make waves on our annual Sailing Trip or;
- Push themselves to the limit at our Adventure Week.

To sign up to make a regular donation, please visit:
macs.org.uk/want-to-help/campaigns/support-a-child/

MACSIMISE YOUR MONEY CLUB

With the global cost of living increase, we completely understand that there are pressures on a lot of people's finances right now. As a charity that relies on donations, we're always trying to think of ways to support us that don't put a strain on those who may not have the spare money but still want to help. Because of this, we've started a new and exclusive club for MACS members and supporters; our MACSimise Your Money Club, or 'MYM Club' for short.

We'll be sending monthly emails to subscribers with discounts on a variety of things, from holidays to school uniforms, and the most brilliant thing about it is that you'll be supporting MACS as you save! That's right, for every purchase made, a percentage will be passed straight on to MACS as a donation.

There's no obligation for our MYM Club members, we just send you the regular emails and you pick and choose the discounts you'd like to take advantage of – simple.

To join the club today, subscribe to our newsletter and tick the MACSimise Your Money Club check box:

macs.org.uk/want-to-help/subscribe-to-newsletter/

FREE WILLS FOR MEMBERS & SUPPORTERS

Another exclusive we're offering to MACS members and supporters is FREE wills. Yes, that's right, a will writing service at no cost to you whatsoever. Did you know that over 54% of adults in the UK do not yet have a will written?

Without a valid will, assets will be distributed in accordance with the rules of intestacy, which means your wishes may not be reflected in the way your assets are given away.

We've partnered with Guardian Angel, a company providing free online wills, meaning you'll have the comfort and ease of mind that your affairs will be properly taken care of after your death.

As well as making your wishes known, here are a further three benefits of making a will:

1. Protect your children
If you have a child or children, a valid Will is necessary to make arrangements for the children should the parents die; for example, if the children are under 18 and would need someone to look after their inheritance or to have a guardian appointed for them.

2. Provide for those you choose
If you are not married or do not have a registered civil partnership but are in a relationship, your partner won't be able to inherit your estate without a valid Will in place.

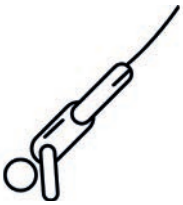
3. Reduce inheritance tax
Did you know that you could reduce the amount of inheritance tax payable by your beneficiaries after your death with a carefully drafted will?

Take to the skies for MACS

If you're after an adrenaline rush while you support MACS, then how about one of these sky-high challenges?

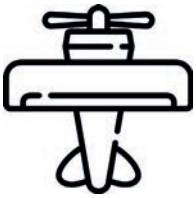
Jump!

Experience the thrill of jumping from 10,000 feet by taking part in a sponsored tandem skydive for MACS.
Our preferred skydive provider, Skyline, offers tandem skydives at over 20 airfields across the UK and a variety of dates throughout the year – so there is a skydive to suit everyone.



Leap!

Did somebody say bungeeeee?!
That's right, we're now offering bungee jumps as a new fundraiser for MACS. For those of you who'd prefer to be tied to something when you take the plunge, this one is the perfect opportunity.



Fly!

Is jumping not for you? How about flying instead?
Wing walking offers the ultimate thrill-seeking excitement experience that blows the socks off any other sponsored walk! Strapped to the top wing of a biplane, you'll be swept through the skies at speeds of over 100mph! Wing walking is THE once in a lifetime gift experience.

Take to the skies by contacting MACS airlines* on **fundraising@macs.org.uk** or simply visit **macs.org.uk/want-to-help/fundraise-for-us/skydive-for-macs/ to sign up today.**

**Disclaimer: MACS does not operate an airline, nor do any of the fundraising team consider themselves to be pilots.*

theBigGive.org.uk
CHRISTMAS CHALLENGE 2022

A pledge today could mean thousands of pounds for MACS next Christmas...

We're planning to take part in the Big Give's Christmas Challenge this year, which could raise thousands of pounds toward the work of MACS.

The Christmas Challenge is a campaign that runs for seven days throughout December and offers our supporters the opportunity to have their donations doubled!

How does it work?

First, we're trying to secure fifty pledges of a minimum of £50 each. These pledges make up the first half of a matching pot – that's the pot of money that will be used to match donations throughout the week the campaign is live in December 2022.

We'll then submit our application to The Big Give, where the campaign's champions (different philanthropic groups looking to support specific causes) can choose to add the other half to the pot – that's £5,000 of funds in total, ready to double donations made in December!

We then run a live campaign for seven days at the beginning of December, giving our supporters the chance to make a donation that they know will instantly be doubled!
We'd like to raise £10,000 and we can do this with your help...

Pledging

We've had a handful of generous pledges so far, but still need 44 people to please pledge a minimum of £50.00 each. These pledges will lead to an amazing gift to MACS this Christmas. If you'd like to donate more than £50 or if we receive more than fifty donations, that's fantastic! This means we can up the overall target for the campaign.

Fulfilment of a pledge is dependent on MACS receiving donations in the campaign; therefore, no donation needs to be made by pledgers until after the campaign is completed - this is usually in January. Pledgers may be asked to donate less than their pledge depending on the amount of donations received, but it will never be more than the original pledged amount.

If you can be one of our fifty pledgers and pledge to make a minimum donation of £50, you can find more on how to do so overleaf.

Let's make it a Merry Christmas for MACS!

Yes, I want to make a pledge towards MACS' matching pot for The Big Give's Christmas Challenge 2022.

To make your pledge online please visit: www.macs.org.uk/want-to-help/campaigns/the-big-give

Alternatively, you may like to complete the form below and send it back to us via post at:
Microphthalmia, Anophthalmia and Coloboma Support, 71-75 Shelton Street, London WC2H 9JQ

I would like to pledge to give £..... towards MACS' matching pot for The Big Give's Christmas Challenge 2022.

In pledging this amount, I understand that no donation is to be made by myself at this time. I agree to officialise my pledge via MACS' campaign page on The Big Give's website when requested to do so (usually around August time).

I will make this donation after the week-long live campaign in December 2022 and when contacted by the fundraising team.

Signature:..... Date:.....

Thank you very much for your pledge! You'll be updated on how the campaign is doing in our coming Focus newsletter but please do get in touch if you'd like updates from us on this as we have them.

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

If you would like to update how we contact you in the future please email **enquiries@macs.org.uk** or call us on **0800 644 6017.**

theBigGive.org.uk

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.
If you would like to update how we contact you in the future please email **enquiries@macs.org.uk** or call us on **0800 644 6017.**

Contacting us:

Family support:
0800 169 8088
enquiries@macs.org.uk

Fundraising and general enquiries:
0800 644 6017
fundraising@macs.org.uk

MACS

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