



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

ISSUE 14
December 2021



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)



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MACS MAGAZINE VOLUME 14

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**

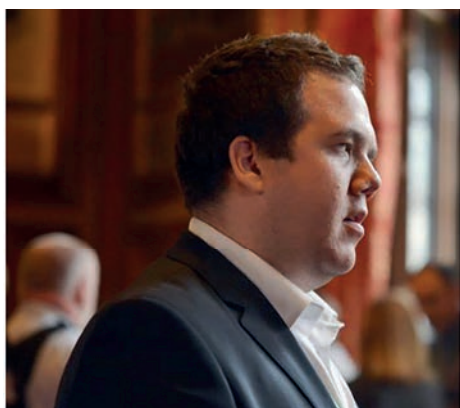
Design: **Southeastwest Design**
www.southeastwest.co.uk

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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**

Chair's Welcome!



WELCOME to the latest edition of Focus. There's no doubt that the last 20 months has been challenging for all of us. However, I'm honoured to introduce this edition to you all – my last as Chair – which is packed full of positivity and news of the future for MACS services.

Whilst the pandemic had a huge effect on all our lives, one thing stayed constant for us – the MACS family continued to grow. Coronavirus didn't slow the birth of babies born without, with small, or with underdeveloped eyes and it didn't change the fact that we would be here for those families, no matter what.

So far in 2021, we have welcomed 69 new families to the MACS family, bringing our total membership to 985 families. It really does make me proud, as a MACS adult and departing Chair, to know that we've been supporting people for over 25 years, and I know that the support will continue for generations to come. If you know a MACS adult who has lost touch with the organisation, or who isn't signed up as a member in their own right, please ask them to consider signing up or getting back in touch. I know how positive it was for me, as a young child with a MACS condition, to see adult role models with MACS conditions and I know this hasn't changed. MACS isn't only here for children, we're here for everyone irrespective of age or life stage.

It's safe to say that 2020 was all about 'going virtual' and I'm pleased that MACS adapted well, something that continued into 2021. This year, a total of 178 virtual events have been held with 1499 people attending; and we've even managed to host three 'in person' events as the

restrictions have eased alongside our annual sailing week with Ocean Youth Trust South and our activity week at Calvert Trust. We're hugely hopeful that the trend of 'in person' events will continue into 2022 and we can't wait to welcome you all to one of them soon. Nevertheless, MACS' main priority is and always will be the safety of our members, so we'll continue to operate in future on the cautious side of government restrictions across the UK.

Looking ahead to events in 2022 we'll be continuing to host a blended series of virtual and in person events, including seeing the return of our flagship event – the MACS Family Weekend! Sailing, activity breaks, local socials, regional events, and festive favourites are all planning to make a comeback too, as well as the plethora of online events including a monthly quiz, sign along with Jack, the creative writing workshops, and afternoon tea breaks. There's something for everyone and I'd encourage you all to sign up for something (especially the Family Weekend, which you can register for here: macs.org.uk/members-area/family-weekend-2022/).

The last couple of years have been a massive change for MACS. Not only because of COVID-19 but also because of the changes to the organisation's structure and governance. As a sailor, it's been my honour to captain the MACS ship through stormy waters, although I'd always prefer plain sailing, but I'd like to take this opportunity to thank a few people who added huge value to MACS but have sadly departed their roles. Liz has said farewell to Caitlin and Helen who were invaluable support to the day-to-day running of the organisation; and the Board of Trustees have been sad to see Jenny Lupton step down from her role as Trustee. Caitlin, Jenny and Helen all brought a huge amount to MACS and I wish them well in their future careers, however I'm pleased to say that both Jenny and Caitlin will still be involved as MACS family members!

There's no doubt that 2022 is going to be a huge year for MACS. With the fundraising team stronger than ever,

the staff team about to expand due to a £100,000 charitable donation (the charity's first of that size), the Family Weekend returning, and the inevitable growing of the MACS family, the future is nothing but bright.

As mentioned earlier, though, I am now coming towards the end of my tenure as Chair. I'll use the next edition of Focus magazine to write some thoughts on what the journey of Chair has looked like, and how much it has meant to me, but I'd like to say thank you. Thank you to each and every one of you for putting your faith in me to lead the best charity in the world. It has simply been the honour of my life to lead the organisation that made me into who I am today. MACS has given me more than I could ever ask – a positive outlook, friends for life, a fiancée, and one day (hopefully, as Caitlin and I plan for the future) a family of my own. I wouldn't be who I am today without MACS and hope I've done what I can to help repay those gifts. It gives me great pleasure to hand over the helm to another MACS adult member and Trustee, Naomi Bowman, who I'm sure will share more information about herself soon.

As I leave you, both in writing and as Chair, I ask one thing – if you ever know somebody who could fundraise for MACS, please ask them to consider doing so. MACS gets no government funding, and we rely on the generosity of our fundraisers – so whether someone could climb a hill, host a bake sale, run a marathon, or complete a sponsored silence, we would really appreciate any financial support they can give us. MACS is growing from strength to strength, there's no doubt about that, and the pandemic has proven that we can survive – but we will always need your help.

I hope you enjoy reading this edition of Focus, and please remember – if there's ever anything you want to contribute in future, we're only too happy to include it! With my warmest wishes and heartfelt thank you,

Robbie
MACS Chair

Meet the Team

The Trustees & Staff



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Welcome to new staff members!

Introducing Amy Francombe, Demi Powell and John Leadbeater



AMY FRANCOMBE FUNDRAISING AND COMMUNICATIONS MANAGER

Amy joined MACS in August 2021 as the Fundraising and Communications Manager. Before joining us, Amy worked for her local hospice as the Events and Community Fundraising Manager. Throughout her nine and a half years at the hospice, Amy covered various roles and remits within the fundraising team, including corporate, community, events, and legacy fundraising.

Amy is keen to harness her experience to create a fundraising strategy for the four years ahead. With MACS's great ambitions to expand our services and reach more families than ever before, Amy is excited to lead the fundraising team in growing our income to support these developments.



DEMI POWELL ADMINISTRATION OFFICER

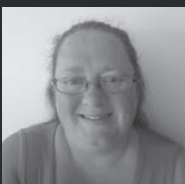
Demi joined MACS in August 2021 as Administration Officer. Demi lives in Scotland with her family, including son Ryan who has bilateral coloboma. They joined MACS in late 2019, just before the pandemic, and feel they have benefited a lot already from MACS services. Demi has worked and volunteered in small charities, predominantly in the disability sector, for twenty years in a variety of roles. She is enjoying being part of such a vibrant small charity and is now looking forward to getting to know MACS families.



JOHN LEADBEATER FUNDRAISING APPRENTICE

John joined MACS as the Fundraising Apprentice in September 2021, having been a member of MACS since 2015. Prior to joining the MACS team John had worked for six years at Bradford City Football Club Community Foundation, where he maintained records of community projects and compiled statistics for bi-annual reports. John is delighted to be part of the MACS team and work for the amazing organisation which has done so much to help him throughout his membership.

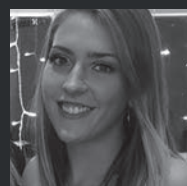
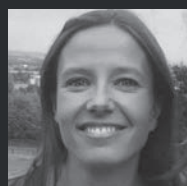
Farewell & goodbyes



IN FEBRUARY we said goodbye to Trustee, Jenny Lupton. Jenny had been a Trustee since 2010 and a volunteer

for many years before. Jenny has been a lifeline for many MACS families over the years, manning the MACS helpline and welcoming new families into the charity, as well as being a great support to our staff and Board. We would like to thank Jenny for

all her incredible hard work and for the countless hours she has put into MACS over the years. We're delighted that Jenny is staying a MACS member and we can't wait to see her and her whole family at future MACS events.

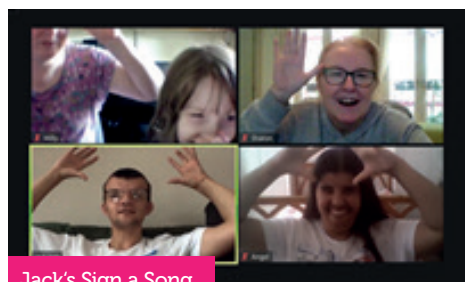


During 2021, we also said goodbye to two of our staff members, Helen O'Brien and Caitlin Brister. Helen was our Project Manager and had been with MACS since 2016. During

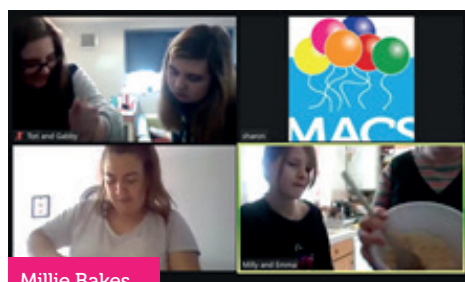
this time she helped deliver many of our major projects, most notably the member survey which resulted in our ambitions documents Confident and Connected. Caitlin joined the MACS staff team in 2019 and went on to become our Fundraising and Admin Officer. In addition to securing thousands of pounds of fundraising income Caitlin also had the daunting task of managing the MACS Giving Families a Break (*formerly the MACS Caravans*) scheme. Those of you who had a MACS holiday this year will know just how hard Caitlin worked over the last 12 months in some very difficult circumstances! We will miss them both and I'm sure you will want to join with us in wishing them well in their new roles.

VIRTUAL MEET-UPS

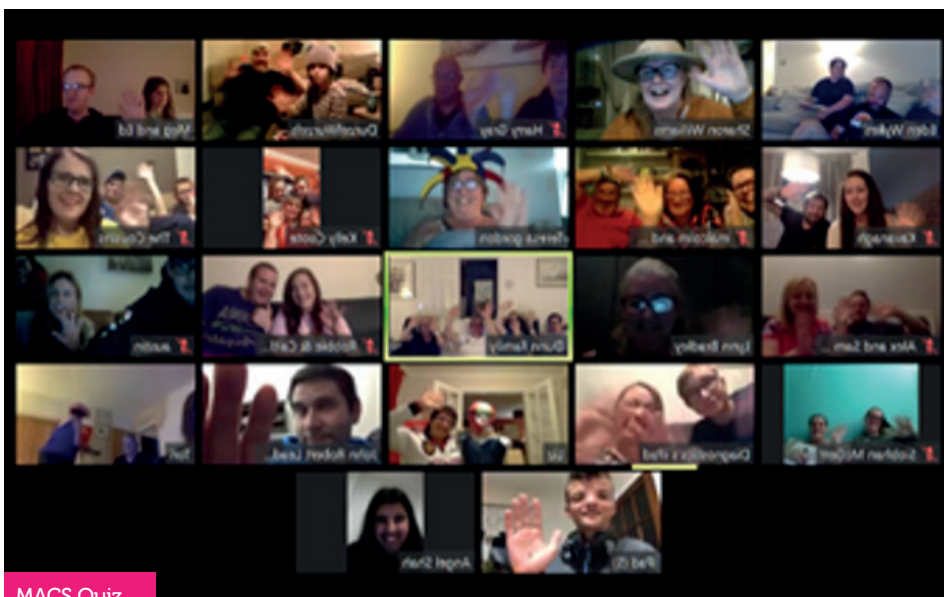
A series of virtual meetings & events for our members



Jack's Sign a Song



Millie Bakes



MACS Quiz

SINCE the pandemic started, we have held such a variety of events. Baking, pets' corner, tea breaks, magic, sleep studies, research updates, wellbeing, creative writing, quizzes and much more. If you came along, you will know how valuable and supportive they were during that time and since!

The zoom meetings offer a friendly place to catch up and are generally light-hearted and casual. We have had quite a few memorable moments! We have celebrated birthdays, football tournaments and held a Marathon after party. Our topics have been wide ranging and sometimes deep, ranging from duvet covers, curtain hanging, repairing showers, suicide, isolation and cake suggestions.

Since our last Focus magazine we have had several firsts! There was the first online AGM, we heard about research updates and PhD studies that our members are involved in, we had an adults and siblings' session when Theo told us about being youth mayor, pets' corner, magic, positive eye, sleep study, prosthetics from Sri Gore, MACS has talent, mindfulness, rambletag, Mariya Moosajee, Gene.Vision, UCAN, humanware, guide dogs. Here are a few quotes from those who have attended:

"These events have been an absolute lifesaver. They have saved me from feeling isolated during some very dark times during lockdown"

"Thank you so much for keeping us together as a community"

"These events have been an absolute lifesaver"

"These online meetings were one of the only things I had to look forward to during lockdown"

"After the AGM being cancelled, I was so sad I wasn't going to see my MACS family but these more than made up for it. It also gave my flatmates the opportunity to learn about MACS and more about me as a person. They love the quizzes and we all work together to answer them, even if we do bad!"

"The new members' meetings have been an invaluable support throughout these last few months"

Now that the pandemic restrictions have been eased, the virtual events programme has been reduced, as we have started getting out and about again and our in-person MACS Meet Ups have re-started. We are however, continuing with a monthly schedule for the famous big MACS quiz, new members, adults & siblings, and afternoon chat meetings. Creative writing workshops will continue running twice a month on the first and third Tuesdays. The virtual MACS Meet Ups schedule can be found on the members section of the website here: macs.org.uk/members-area/macs-virtual-meet-ups. If you would like to come along to any of our meetings you would find a warm welcome and leave with a smile!

Long may they continue! We hope you have gained something from the sessions and enjoyed them all as much as we have. I would like to take this opportunity to thank all of you who have supported the Virtual MACS Meet Ups with your contributions and attendance. **Thank You!**

MACS Meet ups

Our in-person events are back! We have held three events so far with many more planned so that every MACS family can attend an event in their region.



MACS Meet Ups have restarted and have been fantastic! So many of our attendees have been first timers at a MACS event, experiencing the MACS family hug for the first time. Due to Covid related constraints, this round of events has been very simple but uplifting.

Since restarting, we have held three MACS Meet Ups: Dudley, Durham and Cambridge. The events welcomed 64 people from 23 households and 16 of those households were first time attendees at any MACS event.

Our Regional Events Co-ordinator Sharon Williams says: "We had a room full of people who had never met each other before. Most of them have never even met another person with a MACS condition. The look of trepidation on some of those children's faces, transformed as they walked in and realised there were others just like them, is something that will stay with me for a long time. Soon we had people chatting with kids running everywhere with their new-found MACS friends".

Of course, it's not just about the kids. These events are suitable for all members. We have had a full age range of members attending, including MACS adults as well as parents and older children. It is so important for more established members to attend these events. As they have been through so much that the newer members are yet to experience and if they can remember the isolation, they can help the newer members find their feet and share their journeys.

The thought of going to a MACS event for the first time may be daunting but is so worth it. When you meet other families, you will soon realise that they are just like you and you can relax in each other's company knowing everyone is accepted and no explanations are needed.

The events are held approximately once per month, and we plan to have one MACS Meet Up event per region every year.

Look out for new events in the Members' Area:
macs.org.uk/members-area/macs-meet-ups

Just some of the feedback we have received from our recent MACS Meet Ups:

"We had a lovely time at our first MACS event. Would love to attend more and continue to meet other families"

"It was lovely to meet new MACS families we hadn't met before."

"Having the opportunity for our son to see other children like him."

"It was lovely and relaxed and we had the chance to speak to other parents."

Adventure Trips

We were delighted to be back at Calvert Trust and see how much the trip meant to the children and their families.

ARE BACK!

THE LAKE DISTRICT adventure trip took place from the 31st of July until the 7th of August 2021 with a total of 27 people attending. The first three-day part of the trip was a long weekend for children aged between five and ten who attended with a parent, the final five days of the trip were for children aged ten and over who attended without a parent.

Older children



19 young people took part in this five-night adventure and completed a wide range of activities including: ghyll scrambling, bushcraft, catamaran sailing, kayaking and a high ropes course. In the evenings they also participated in a wide range of social activities including a talent show, team challenges and finishing their stay with a celebratory disco.

In addition to MACS conditions, some of our young people also face additional health needs including autistic spectrum disorders, deafness, global development delay and CHARGE syndrome. The specialist support MACS provides on these trips means that everyone can actively participate in all the activities, have a fantastic time and benefit from attending. Throughout the week the young people overcame many physical and emotional challenges but showed each other tremendous support and many new friendships were formed.

"My son absolutely loved this trip; he hasn't stopped talking about it since he came back. He loved making new friends. Social skills are not a strength for him, but they seem to have been so well nurtured and supported by the fantastic care team. He also seems to have learned lots more about visual impairment and has met other children with significant issues. At home he is the most blind of everyone he knows and hates it. But now he can see that lots of people have similar or more challenging sight issues and that they are cool and doing fine in life. He's had a hard time this summer with a family bereavement and the MACS week has had a huge impact on his mental wellbeing at this difficult time for him."

"My son loved the week. He has a learning disability and social anxiety, and he was definitely NOT attending. He struggles with his behaviour and finds it hard to find an accepting social group. But he had a fantastic time, he hasn't stopped talking about it and is wearing his MACS hoody everywhere. He has made friends of a similar age and participated in every activity, which again is not like him. When I went to collect him, he seemed so comfortable and happy – it was so emotional to see."

We asked the parents of the young people to tell us about the impact of the trip:

78%

Told us their child was more confident

78%

Told us their child was more independent



We also asked the young people themselves how they felt they had changed over the course of the activity week - the top four areas of improvement were shown in the following behaviours:



- Feeling confident
- Working in a team
- Getting on with people
- Compromise and negotiation when living with other people

"My daughter came back more confident but more importantly more independent, this is the longest she's ever been away from home. I think she was nervous to start with, but she really got into the stride of it and loved every second. It's been so nice to hear her talking about it and we could never have provided her with that level of entertainment and all the amazing activities."



Our younger children

"I have wrapped her up in cotton wool, my boys as well. I am going to stop cutting up her food because now I know she can do it herself."

This year four children (aged 6, 7, 8 and 10) each accompanied by their parents, took part in our weekend adventure break. All took part in a wide range of activities including ghyll scrambling, a high ropes course and canoeing.

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

"My son was pushed physically and mentally to his limit. He needs this, as he is so driven. I am now finding that after our activity break I am now less scared and more confident to participate and push myself."

Everyone in the group completed every activity, and we found that the parents had at times struggled and worried about their own fitness holding back the children. Over several feedback sessions with the parents they reflected on common themes, they all shared the view that they were often over protective of their children and that they would consider these feelings going forwards.

"I'm going to make sure we do more fun stuff as a family."

We would like to thank all our supporters for making these adventures possible and encourage all members reading this to sign up for next year!

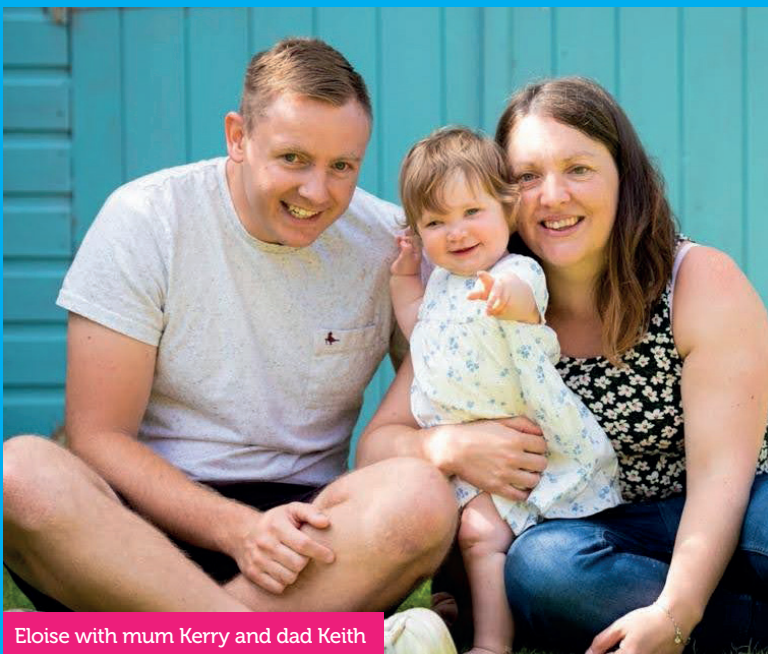
Book place for your child here:

macs.org.uk/members-area/adventure-trips

Hello to new members

THE MACS Awareness Week was held in September with informative content published to increase the profile of Microphthalmia, Anophthalmia and Coloboma. How fantastic to see that as a result of the week, 8 new households have found MACS.

So far in 2021, we have welcomed 69 new families to the MACS family, bringing our total membership to 985 families. We would like to say a very warm welcome to all the new families who have joined as members over the past 12 months! Here are just two of our new families.



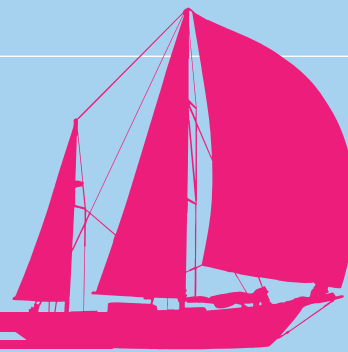
Eloise with mum Kerry and dad Keith



George and Frankie with dad Josh

Making waves

MACS Adventure Sailing Trip



Photos courtesy of Ocean Youth Trust South.

AFTER a year off due to the pandemic, last summer saw the return of our sailing trip and our MACS members were so excited to jump on board! The voyage, which took place during the last week of July, took our crew around the Devon coast aboard the Prolific – a sail training vessel brought to the water by our voyage providers, Ocean Youth Trust South. The crew, made up of five MACS

“As soon as we stepped on the boat, the smiles and giggles appeared – all the worries of the pandemic long gone”

young people (Jack, Angel, Phoebe, Pearl and Tori) two siblings (Caitlin and Zeenat) and one carer (Ruth), joined together on the Saturday and sailed from Brixham to Dartmouth on the first evening, then by Sunday morning everyone was ready to set off for a good voyage. The plan was for Plymouth, but the weather was so good and everyone was having such a great time that they kept going, and sailed all the way to Fowey! They did winch drills on the way and everyone got involved with hoisting sails.

As they left Fowey, they pretended they had an engine failure and needed to act very quickly by hoisting the staysail and mizzen – everyone did a brilliant job! It was then onto a man overboard recovery drill before starting to motor towards Mevagissey with the wind against them.

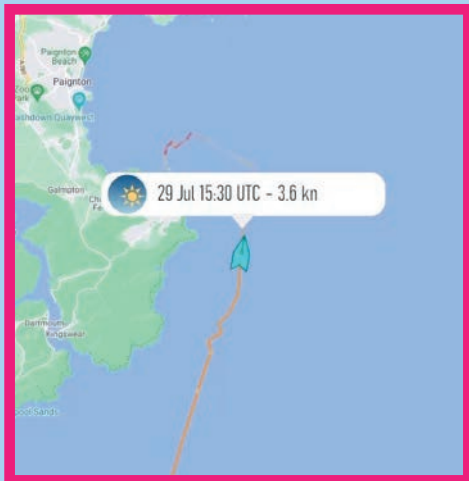
The following day Prolific sailed off the anchor with a MACS crew member on the helm. They had a

“I struggle to meet new people as I don’t have the confidence to start conversations or engage in them. The sailing voyages push me out of my comfort zone and make me build new relationships and trust other people”

good downwind sail to Cawsand, with people getting the hang of gybing – that’s changing course by swinging the sail across a following wind – while others took turns with bowsprit trips until they were anchored in Cawsand.

There was a huge achievement for Pearl who had sailed several times before, but this was the first time she was able to get out on the bowsprit! Angel helmed the boat whilst they sailed off the anchor, and later took the boat back into an anchorage at the helm – a triumph compared to previous years!





“What made it even better this year was seeing my sister truly become more confident and independent. In the past I always went as her buddy and helped her with quite a few things like getting on-board, but she’s truly amazing and was doing everything herself this year and even helping other crew members like Pearl get on-board”

After dinner in Cawsand they headed further into Plymouth Harbour for a nice evening/night sail, where some of the crew found that they could see the navigation screens more clearly



without the glare of daylight. They then spent Wednesday tucked safely in shelter while some bad weather came through, and enjoyed showers, shore leave and training towards their Royal Yachting Association certificates. They left Plymouth on Thursday morning and, with more bad weather forecast the next day, they headed straight back to Brixham and had a day of fun activities in harbour.



“My best part of the voyage was seeing everybody enjoying themselves and working as a team as always on OYT South, especially MACS members. I actually liked the night sail because I’ve never, ever sailed at night before, and so that was a new thing to me, and everything else was what I’ve done previously”

Overall, this voyage truly felt like respite for the crew, who fed back that this was exactly what they needed after a particularly difficult year of the pandemic. Some even felt that the trip brought them back to being and feeling themselves.

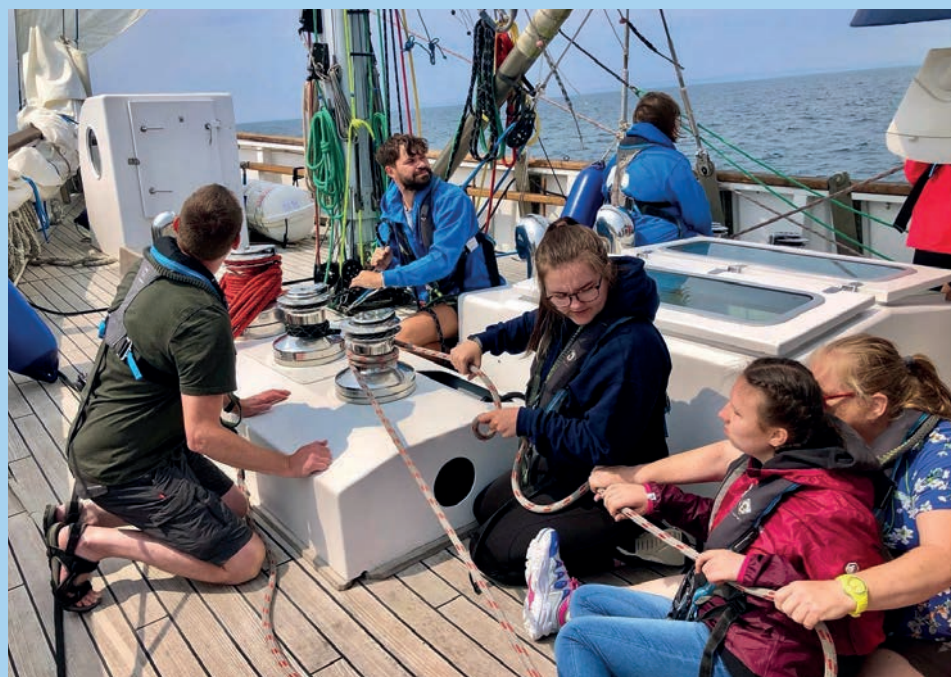
“Thank you for allowing me to be myself again. Also, thanks for giving me the best week of the past two years of my life. I will remember this week for ever.”

Two of our young sailors have even earned Royal Yachting Association Start Yachting certificates, which are recognised qualifications!

This year’s voyage was certainly one to be remembered and it would not have been possible without our generous funders. We’d therefore like to take this opportunity to say a big thank you to Sail Training International Youth Development Fund and The Annette Duvollet Trust for kindly granting us the funds to be able to send our members on such an incredible voyage.

If you’ve enjoyed reading about the sailing trip and see yourself as a potential MACS crew mate, bookings for 2022 are now open!

Visit: macs.org.uk/members-area/sailing-adventure-trip



MACS Family Weekend

After a 2 year break due to COVID-19 restrictions, we are so happy to be back hosting the MACS Family Weekend again in 2022!

2022



THE WEEKEND will be held at the Park Hall Hotel in Chorley, Lancashire and will run from Friday 29 April until Monday 2 May 2022.

Our MACS Family Weekend is a fantastic opportunity to meet with other families who all have experience of living with a MACS condition. Whether it's catching up with old friends, making new ones, giving the children a safe space to run around and experience new activities or just finding out more about MACS conditions, the Family Weekend has something for everyone.

For many new members, who have only had the chance to experience our online events, our Family Weekend is designed to be a great combination of informative content, exciting activities and social opportunities. We will have a range of speakers and exhibitors delivering content on lots of different aspects of living with a MACS condition. There are always great on and off-site activities for all the children and hopefully something special for our MACS adults this year!



The highlight of the weekend for most members are the social events, designed to help MACS members meet others in similar circumstances and build their own support networks. Most of our members come back year after year to enjoy the fun and see their MACS friends.

We know some members may be disappointed that the weekend is again in the North West and we want to reassure you that we remain committed to moving the Family Weekend around the country in future. However, finding suitable alternative venues for 2022 proved impossible as most are fully booked with weddings postponed from 2020 and 2021 and costings for venues have drastically increased. We will, of course, continue to search for alternative venues situated around the UK for future Family Weekends. We hope you understand and thank you for bearing with us.



The cost of attending the 2022 Family Weekend has been held at 2019 subsidised prices. They are:

- Adult with MACS condition (18+) – free;
- Adult Member and partners of adults with a MACS condition – £40 per person per night (for the first two adults, 18+ attending); and
- Child Member/Sibling (under 18) – free.

Additional adults, and children over 12 who do not have a MACS condition or are not siblings, will be charged at the full, non-subsidised rate.

We don't want cost to be a barrier to anyone. If you would like to attend but would struggle to pay the cost, or there are other issues such as transport, please contact liz@macs.org.uk for information on what support is available.

For more information, please see our website at: macs.org.uk/family-weekend-2022 or email events@macs.org.uk.

CALENDAR

Highlights of the year

When	What
April - May	
29th April – 2nd May	MACS Family Weekend
July	
30th July – 1st August	Activity breaks (5-10 year olds)
August	
1st – 6th August	Activity breaks (10-18 year olds)
3rd – 9th August	Sailing

Plus our regular activities:

Virtual Meet Ups:

Creative Writing Workshop – fortnightly

New Members' Welcome – monthly

MACS Virtual Quiz – monthly

Afternoon Chat – monthly

Adults & Siblings catch up – monthly

MACS Meet Ups – events in your region

The regional Meet Up events will be taking place once a month, taking turns to visit each region. Please keep an eye on our website to see when your local event will take place:

macs.org.uk/members-area/macs-meet-ups



Local Social Groups

Local Social Groups are events run by members for members.



THEY are a great chance for you to meet other MACS members in your area. These groups are designed to help members build a more local network and bridge the gap between our bigger events throughout the year.

Local Social Groups decide for themselves what they would like to do when they meet. You could go to the cinema, for a walk, coffee, soft play centre or plan a bigger trip for a special event. You could do anything big or small, it's totally up to you and your Local Group!

Local Socials are hosted by MACS volunteers with seed funding provided by MACS. Three of our Local Socials Facilitators in Dartford, Dunstable and Bristol have been busy organising festive pantomime trips for local members.

Kerry, one of our LSG facilitators said:

"I have been a Regional Supporter for about 7 years & have loved meeting new families along the way. I have been able to arrange events like the panto at Bristol & a visit to Longleat. More than the event itself, the value is in the support & friendship that the children & families give to each other. I have also been able to raise awareness of MACS conditions within our local community, as well as raising valuable donations from schools and local employers."

If you like the sound of Local Socials, we are currently looking for Facilitators and Volunteers to help grow the group network. Facilitating a MACS Local Support Group is a great way to use and share your personal experiences to support others in similar situations.

There is some great information about what is involved on our website.

macs.org.uk/members-area/local-socials-events

There are also lots of other ways to get involved in your local group – helping the facilitator, providing peer support, admin tasks, fundraising, etc. If you would like to get involved in your local group, please fill in the enquiry form: (**macs.org.uk/members-area/local-socials-events/volunteer-application**) and we will be in touch!

Tori's university story

University- the best experience I've ever had!



Tori and Declan in York

Hi, my name is Tori! I'm 21 years old and have microphthalmia in my left eye and wear a prosthetic shell. In 2018 I made the scary decision that lots of young people make, which is deciding which university I wished to attend, and I picked University of Huddersfield. I have been there for 4 years now. I am currently completing my primary teacher training and by the end of this year I will be a fully qualified primary school teacher!

The anxieties of not only starting university but also moving somewhere brand new and living with people I didn't know left me with a lot of fear and apprehension in the build up to starting university back in 2018. Living away from home, away from the safety net of my family was a big step for me, as it is for many, but I did feel extra worry about attending with my MACS condition. I had been part of mainstream education all my life and although it was, on the whole, a positive experience, bullies,



Tori with her boyfriend Declan and friends Chanel and Lauren at an escape room

name calling and the feeling of being different to everyone else always weighed over me. However, when I went to university that all changed! I flourished in the academic side of university as well as the social side, making a lovely group of friends, some of whom I still live with today.

Although the academic side of university has been a wonderful experience, the social side of university is something that I look back on as a highlight. Since beginning university I have tried baking clubs, archery, karaoke and even been to my first concert to see JLS this year with my flatmate Lauren! Some of these were with my wonderful university friends and others I had the confidence to go by myself. I also met my lovely boyfriend through university, Declan, who I am so grateful for. One thing I quickly realised at university is that everyone is in the same boat as you, everyone is nervous and just wants to settle in, so most people are happy to include you or be included by you. The friends I have made at university love me for who I am, and not only that, support me and my MACS journey completely. We regularly attend the Zoom quizzes and sometimes host them ourselves, normally in our matching Christmas pyjamas! My friends I live with love MACS as a charity and enjoy being a part of the MACS family as much as myself, some of whom are now 'friends of MACS' and get the newsletters.

To summarise my university experience, moving to university and meeting new people was the best decision I have ever made! I have a degree, new life and educational experiences and new loving friends for life. I know my friends will be reading this article and be super excited that I decided to write this, so hello to Chanel, Kian, Lizzie and Lauren! Thank you all for being there for me, MACS condition and all.

Could you be a MACS Ambassador?

If you've read Tori's story and think you might be able to put together something similar based on your own experiences – or perhaps you think you could talk to people about being a member of MACS – then you might like to find out a little more about becoming a MACS ambassador.

We are currently looking for members to help raise awareness of our work in several different way, including:

- Writing and promoting blogs about your experience of MACS
- Attending cheque presentations on behalf of the Charity to say thank you and a few words about how the money raised will help to make a difference
- Delivering talks to local community groups, schools, faith groups, Rotary Clubs, Round Tables, Women's Institute groups etc. about the work of the Charity and the ways in which they could help us achieve our goals
- Attending other events as a representative of MACS

If any or all of these the above are appealing to you then please do get in touch! We can then talk with you about the experience and skills you have and how we can put them to best use as an ambassador.

MACS Ambassadors will play an important role in helping us achieve our aims to reach new people, inspire new fundraising activity, and thank our supporters for the work they are doing.

If you'd like to find out more, please contact Amy Francombe at amy@macs.org.uk We look forward to hearing from you!

RESEARCH UPDATE

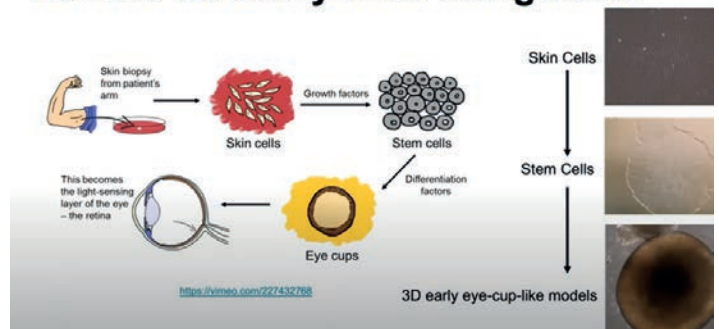
The latest studies on MACS conditions

AS PART of the virtual Family Day in June we were treated to two fantastic research updates: one from Pippa Harding, a PhD researcher in Professor Mariya Moosajee's team at University College London, and the other from Cerys Manning, a MACS parent herself and research scientist at University of Manchester.

Genetic causes of MACS conditions

Pippa started the session with an overview of the research Professor Moosajee's team have been carrying out over the last 3 years, investigating the genetic causes of MACS conditions.

How do we study MAC using cells?



What causes MAC?



She began with a helpful explanation of how eye development is controlled by a variety of different genes, which all work together to tell the eye how to form. If one of these genes is damaged through changes in its DNA or the environment, it can affect how the eye develops and lead to structural eye conditions such as microphthalmia, anophthalmia and coloboma. Pippa explained that MACS conditions tend to occur if the genes are affected early in the development of the eye, usually between 3-8 weeks of pregnancy. However, although scientists know there are over 100 genes that can cause MACS conditions, they don't yet know the steps between someone having changes in one of these genes and a MACS condition developing. It is those steps that Pippa and the team at UCL are studying. Knowing more about these steps will help to provide better clinical care to people with a MACS condition, perhaps through better treatments which can improve visual function.

Studying eye development using stem cells

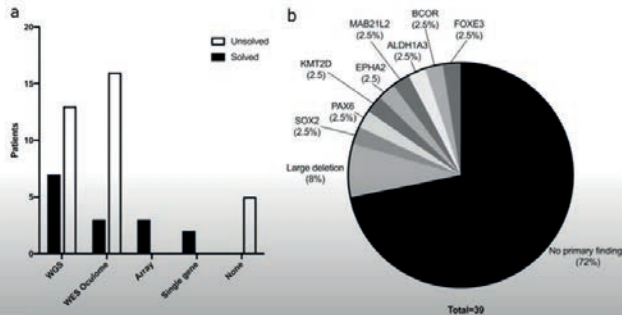
Researchers can study how the eye develops in early pregnancy by growing eye cups (early eyes) in the lab. This is done by taking stem cells, the special cells which have the potential to develop into many different types of cell in the body, from the skin of an adult with a MACS condition. From these eye cups, Pippa and the team can study the steps involved in causing microphthalmia, anophthalmia or coloboma when a particular gene is affected. They can also use these 'eye cups' to look at whether any new therapies or drugs can stop or reverse those changes happening.

'Researchers can study how the eye develops in early pregnancy by growing eye cups (early eyes) in the lab. This is done by taking stem cells, the special cells which have the potential to develop into many different types of cell in the body.'

Whole genome sequencing

A second study undertaken at UCL looked at a large group of patients with a wide range of MACS conditions and severity. Using a new technique called whole genome sequencing, the researchers were able to map the full genetic code of these patients to identify any genes that might be affected. Whilst in 90% of people with a bilateral (both eyes) MACS condition a genetic diagnosis can be made, for people with unilateral (one eye) MAC this falls to around 10%. With whole genome sequencing, the genetic diagnosis for people with a unilateral MACS condition increased to around 33%.

MAC patient cohort study



Genetic diagnosis for unilateral MACS conditions

The next stage of research is looking at why it is that people with unilateral MACS conditions are much less likely to have a genetic diagnosis. Early thoughts are that in these individuals, the genetic changes are only contained within eye cells and are not present in cells elsewhere in the body, such as blood cells. As genetic testing is usually carried out from a blood sample, this would explain why a genetic diagnosis cannot be made. The team are now looking at sending two different samples, one from the patient's blood and the other from cells taken from the affected eye for whole genome sequencing to see if there are any differences.

A new study on retinal detachment with coloboma

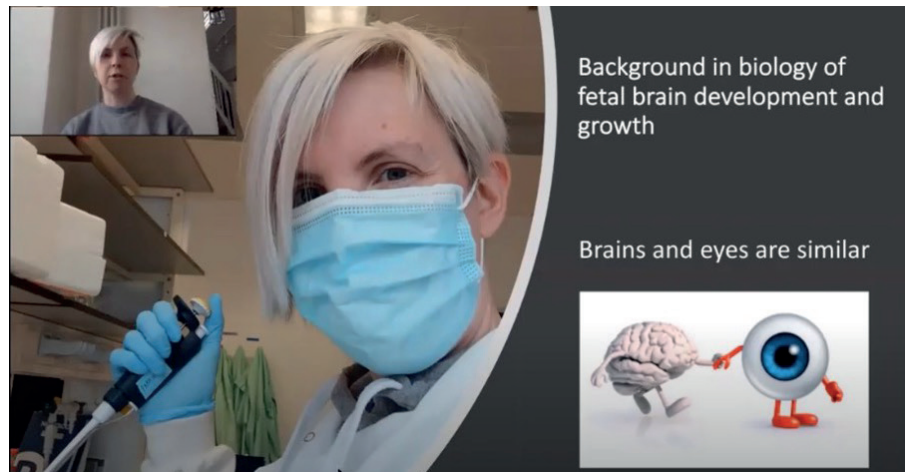
Another new area of research being planned is looking at why retinal detachment is more common in people with coloboma. This will involve studying a large group of people with colobomas to understand the mechanisms involved.

If anyone is interested in taking part in any research please get in touch with Pippa or Professor Moosajee

phillippa.harding.17@ucl.ac.uk or
m.moosajee@ucl.ac.uk

Eye development study using 'mini eyes'

The second research update was from MACS parent and research scientist Cerys Manning. Cerys told us about some exciting research she was about to start with funding from the Medical Research Council. Her research will concentrate on how the eye develops as well as the link between microphthalmia and coloboma. Working with mini eyes, grown from human stem cells, Cerys will continuously film the mini eyes as they develop so she can understand more about the complex process of eye growth and how it happens over time. We can't wait to hear how Cerys' research progresses and look forward to another update next year.



Questions & Answers with Orthoptist Vijay Tailor-Hamblin



WE WERE also very pleased to have Vijay Tailor-Hamblin talk to us about his role as an extended role orthoptist at Moorfields Eye Hospital working with MACS children. Vijay told us about the different types of strabismus or squints that can occur. Esotropia,

where one eye turns inwards, exotropia where one eye turns outwards and hyper or hypotropia where the eye turns upwards or downwards. Although squints are

commonly seen in children without a MACS condition, Vijay explained that MACS related squints are different as they are linked to the structural changes in the eye, the level of vision a child has or the size or position of the eye. Because of this, patching, where the eye with the better vision is covered to encourage the brain to maximise the vision received through the weaker eye, may not always be appropriate for children with microphthalmia or coloboma.

Each child needs to be assessed individually to see if patching or other treatments will provide any benefit. Vijay stressed that this is why some children with a MACS condition are patched and some are not. So, if your child has a squint and had not been offered patching, please don't think this is a mistake. If you are at all worried, talk to your consultant or orthoptist and they can explain why patching may not be right for your child.

Donna's Story

MY EARLIEST memory as a small child was being pushed in a buggy by my Mum to take my older sister to school and spending much of my second year of life in and out of hospital while they were trying to fit my right eye with a prosthetic by taking skin from my knee and doing a graft. My various aunties still recall fondly what a talkative two-year-old I was, and how I would ask if anyone was there when the sound in the hospital room became quiet.

Sadly, the operation wasn't successful, so I came home with a very small left eye socket, and a bigger right one where they had tried to build it up. My eyes were closed, and still remain so to this day.

As a child growing up, I knew that I was different from other kids, because I couldn't run about in strange areas without banging into something. But I didn't learn the actual name of my eye condition until I was 10 years old. A very conscientious teacher at the Royal School for the Blind in Wavertree Liverpool called John Dibble studied all our eye conditions when training for his teacher's exam for blind

children, and he very kindly told us all the names of them. That's when I learned that I had Anophthalmia, meaning no eyes.

I had incredibly supportive grandparents who minded me a lot, that I loved dearly, and who bought me my first Perkins Braille for £100, which was a lot of money then, a Mum who was hard at work much of the time, and a Dad who worked shifts but brought me up with lots of tough love. If he had showed me where something was in someone's house for example, and I later banged my head on it, that was my fault. But when he played football on a Saturday, he would call me when the half time whistle blew, and I would run towards him to be swept up into his arms. I still remember just how good that felt. He took me and my sister sledging and let us try anything that interested us which was in his power to organise, such as horse riding and piano lessons. Every year, we always went to a big bonfire where there were fireworks and had lots of fun. Mum worked hard, and so did he, but it was him I think who gave us a real childhood, while my Mum held the family together.

After a fantastic time at my primary school, where there were lots of outdoor things to play on as well as work to do, I moved to Chorleywood College, and then to RNIB New College Worcester the year before the two schools merged officially, as I was then in the first year of my GCSE's. I Loved Worcester but found the regime at Chorleywood a little strict and old-fashioned for my liking.

From there I did English at Swansea University, and then went to RNCB in Hereford to do a more vocational course, as I didn't really want to teach, and did English because it was what I happened to be good at in school without thinking how I might use it later.



I left RNC having already acquired my first job with RNIB, where I worked at the Western Eye Hospital in London as an Information and Advocacy Officer, now of course called an ECLO or Eye Clinic Liaison Officer. I went on to work later for the RNIB Helpline, and then as a Link Officer covering a wide area of the country, working directly with many of the Societies for the blind and meeting some great people on my travels, which were all done by train and public transport.

Since then, I've worked for Guide Dogs for the Blind in various roles such as Volunteer Development and Service Development, and I spent a short time working for HumanWare as a Sales Executive as well. However, my third Guide Dog Jack couldn't adjust to the job as my previous one had done, and so I changed to an office environment in order to give him some stability while I worked with him to iron out his various problems. This was with Action for Blind People, where I worked on their Helpline, and later as a Technology Officer.

It was through working with Jack and realising what a bad start he had in life compared to my previous Guide Dogs Abel and Olive that then encouraged me to take some time out and begin training my own. I returned him to Guide Dogs after 4 years of trying to sort him out, and then I trained and raised yellow Lab Alice and Chocolate Lab Hope from 8 week old puppies, thinking that if I was lucky, maybe one of them would work out. But as they both did, I kept them and shared what work I had between them for the next eight years.

Then 5 years ago, I began to train yellow Lab Kizzy, and whereas my previous owner-trained dogs were unqualified due to the fact that I couldn't find an organisation who would qualify us, Kizzy gained an



Assistance Dog qualification with Dog A.I.D. UK, and a guiding qualification with The Seeing Dogs Alliance, who are a small Guide Dog Organisation. This was a huge achievement for me, as I was the first totally blind person Dog A.I.D. had ever qualified, and we had to work hard to do 3 different tests before qualification, plus persuade them how an Assistance Dog could be of use to someone totally blind. It was a fantastic feeling to own a yellow book once again, which acts as a carte blanche if you are ever questioned in a restaurant or public place. That came a very close second to the feeling I got when I walked over the finish line at the Edinburgh MoonWalk in 2013, where I walked a full Marathon distance of 26.2 miles to raise £4,000 for breast cancer with a friend and sighted guide.

These days, I live in Eccles, Manchester with Alice and Hope who are 11 and 10 respectively, and my working dog Kizzy who is 5. I also have 3 pet Chihuahuas,

Poppy Peppa and Ava, and little Rita the pug who is just 17 weeks old. I volunteer for the RNIB Talk and Support Service, and I spend a lot of time walking dogs, reading dog training books, and learning about what makes them tick. I enjoy playing the guitar and singing, attending Glasgow Celtic matches when I can, and going to folk music concerts. My dream job would be to train dogs, or to work for a dog food company giving nutrition advice. All the same, I do keep my metaphorical eyes open for a job I could do mainly from home, or home based for part of the time to accommodate all my canine companions.

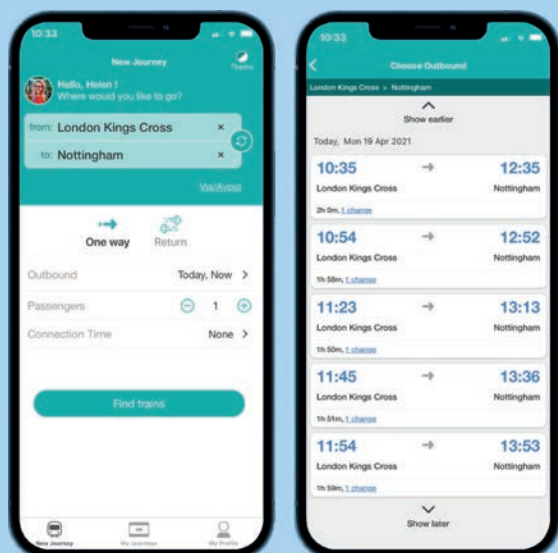
I am really looking forward to my first MACS weekend, and to finding out more about the organisation. I'm so pleased to have found a group for my eye condition that comes so highly recommended by friends. I look forward to meeting many of you in the future.

Donna

By Jonathan Attenborough

Tech Talk

Welcome to Tech Talk, a feature about the latest assistive technology that MACS members might find useful in their everyday lives.



Passenger Assistance

SINCE the COVID-19 lockdown ended you might, quite rightly, feel a bit nervous or anxious about travelling so that's why in this Tech Talk article I wanted to tell you about a new app that has recently launched called Passenger Assistance. This is an app that has been developed for disabled people to use to book assistance at train stations when travelling, and it is operational across every train station in the UK!

You can download the Passenger Assist app on the Google Play store for Android devices or the App Store for iOS devices, and it could not be simpler to use! Once you have downloaded the app to your phone, you can set up a profile where you can let the passenger assistance team know that you are visually impaired, as well as any other disability or impairment, and you can select what you need assistance with. Once your profile is set up all you need to do

from now on is select which train it is you will be getting and what you will need on the day. For example, I travel with my guide dog and there is an option to select extra room for assistance dog so that the assistance staff know to help you find a seat on the train with extra space for an assistance dog. Once you arrive at your destination a member of staff at that train station will be there on the platform to assist you off the train and out of the train station, if you have requested this in the app. You also have the option of letting them know in advance if you need a ramp for boarding, or if you are a wheelchair user that you will need the wheelchair space etc.

The app itself is also very accessible and for low vision users it allows you to customise the display with a colour contrast that best suits your vision – black writing on yellow background, black writing on white background

etc. It works really well for VoiceOver or TalkBack users as well.

I have used this app a few times to book assistance when I have been travelling on the train since the lockdowns ended and I have found that it makes journeys less stressful, and I feel a lot less anxious about travelling on the train knowing that someone will be there to assist me at each step of the journey. I also find this makes booking assistance on the train less time consuming as well as previously you would have to phone the train operator to book assistance which was quite time consuming. You can also book assistance with as little as 2 hours' notice of travelling so you don't have to give at least 24 hours' notice to book assistance like you did previously.

I hope that you have enjoyed this Tech Talk article and that MACS members will find the Passenger Assist app useful when deciding to travel by train.

If there are other accessible technology gadgets or apps you would like to feature on Tech Talk then please feel free to email enquiries@macs.org.uk

Get Involved!

Various up and coming MACS events.

#MACSimumPower



#MACSIMUMPOWER

WE'RE launching a brand-new campaign, filled with challenges and experiences that have been hand-picked by the MACS team with our supporter power in mind.

As a group, our supporters are a formidable force to be reckoned with; a collective of committed and determined individuals, pushing themselves to the max to achieve amazing things and raise incredible amounts of money towards the valuable work of MACS.

We've been inspired by the power of our supporters to select a series of national events, as well as something for the adrenaline seekers, which has been compiled to encourage our supporters to take it to the max for MACS in 2022.

Below, we've included an overview of each of these challenges. To find out more and to register for any of these events, just search #MACSimumPower on our website. Alternatively, get in touch with the fundraising team at fundraising@macs.org.uk



@macsthecharity



facebook.com/MACSCharity



We have the places. Do you have the power?

Manchester Marathon

3rd April 2022

The Manchester Marathon is one of the UK's premier running events, famous for its fast, flat and friendly route. Many regular runners find this the ideal event to get a personal best time, whilst everybody finds the incredible Mancunian support throughout the course unforgettable.

Hackney Half

22nd May 2022

East London's creative spirit inspires the second year of celebrating a festival of fitness with Virgin Sport Hackney! The Hackney Half is back, accompanied by the Go Fit Yourself line-up of classes to get everyone moving.

The Brighton Marathon

10th April 2022

The Brighton Marathon is one of the UK's favourite 26.2-milers. With a stunning backdrop of the sea in one of the country's most vibrant cities, the race gets bigger and better every year. Renowned for its buzzing atmosphere and roaring crowd support, the course winds through the city streets, finishing up on the spectacular Brighton seafront.

Edinburgh Marathon

Edinburgh Running Festival – 29th May 2022

You could be a part of Scotland's BIGGEST running festival!

This ever-growing festival of running is now a major event in the Scottish sporting calendar. Starting in Edinburgh, the course heads out through East Lothian, offering stunning views and an unforgettable running experience.

The marathon route is one of the fastest in the UK making that elusive personal best a distinct possibility!

Royal Parks Half Marathon

date TBC

This stunning central London Half Marathon takes in some of the capital's world-famous landmarks on closed roads, and four of London's eight Royal Parks - Hyde Park, The Green Park, St James's Park and Kensington Gardens.

TCS London Marathon

2nd October 2022

We also have places for the TCS London Marathon 2022. See more about this massive event and how to sign up on page 25.



RideLondon has announced that it will return on Sunday the 29th of May 2022 with a 100-mile sportive. The newly routed RideLondon-Essex 100 allows participants to ride on traffic-free roads through both London and Essex, starting and finishing in the capital while taking in 60 miles of rolling roads through Essex's countryside.

We have a limited number of places, so do get in touch as soon as possible if you'd like to take part.



With an experienced outdoor swimmer on our team, we're in the know when it comes to the best swimming events and challenges for our supporters. We'll guide you in choosing the perfect challenge to raise funds while you're in the water!



If you're an adrenaline junkie looking for that next white-knuckle thrill, then these activities will take you to a new high...

Skydive

Experience the thrill of jumping from 10,000 feet by taking part in a sponsored tandem skydive in aid of 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.

Wing Walk

For the ultimate thrill-seeking excitement, the wing walking experience simply can't be beat. 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.

Other ways to get involved



Play the MACS Lottery

Do you fancy winning up to £25,000 whilst supporting MACS?

Sign up to our Weekly Lottery, provided by The Weather Lottery, and you'll be given a unique 6-digit number. The more numbers you match in the weekly draw the bigger the prize - match all 6 numbers to win £25,000! Learn more and start playing today by searching 'lottery' on the MACS website.



Give while you shop

Did you know that when using Easy Fundraising when shopping online, you can help raise vital funds for MACS at no extra cost to you? Over 4,300 shops and sites will donate to MACS every time you shop online - so you can raise funds when you buy gifts, decorations, your festive food shopping or anything else! Please sign up and help us raise more at:

[www.easyfundraising.org.uk/ causes/macskidseyecharity](http://www.easyfundraising.org.uk/causes/macskidseyecharity)



Support via your workplace

We'd love to talk to your employer or company about MACS and what working with us can bring to the organisation and its employees. There are so many benefits of supporting a charity through your company, from team building to fulfilling your Corporate Social Responsibility aims. And the best thing? You'll be doing it all at the same time as making a difference to children with MACS conditions. If your company is interested in supporting MACS, please contact fundraising@macs.org.uk and we would welcome a chat with you about what you want out of a charity partnership.

Here are just a few ways businesses can get involved:

- You could nominate MACS as your Charity of the Year
- Make a financial donation
- Organise a workplace fundraising event or activity
- Sponsor one of MACS events e.g. a sailing trip, activity weekend, or you could even sponsor your local MACS Social Group.
- Promote MACS within your payroll giving scheme
- Donate gifts in kind



Calling all community groups

Are you a member of a sports, social or philanthropic group? Or perhaps you sit on the 'Friends of' or PTA group for a local school? If so, we would love to hear from you!

We're seeking opportunities to talk to as many groups and organisations in 2022 about MACS conditions and the work we do to support families living with them. If you think this would be beneficial to your group or school, then please do get in touch at **enquiries@macs.org.uk**



Do you have your own challenge in mind?

If you have your own idea for a challenge or a fundraising activity, we'd love to hear from you! We will be happy to assist in whatever way we can, cheer you on, and help you make your activity a success.

Please get in touch with us at **fundraising@macs.org.uk**. We await your call...



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.

London Marathon

Well done to Team MACS 2021!

What a day it was!

After a roller-coaster of postponements, cancellations and endless uncertainty, the London

Marathon finally took place on 3rd October 2021. It was an emotional day for many but Team MACS did incredibly well, getting to the finish and raising vital funds in the process.

Due to the pandemic restrictions, we were not able to meet for a team photo at the start of the race so asked our runners to submit photos for a digital version, and the result is below!



Here's what our runners said!



Kelly Hargreaves

What can I say, I'm still on a high! To have completed my 6th London Marathon and to have knocked 20 minutes off my PB, I'm still on cloud nine. All this would not have been possible without the help of all of you guys at MACS. It has been an absolute pleasure to run for MACS! I have raised £3500 so very happy with that. I just want to thank each and every one of you that has made this possible. I'm hoping I get the pleasure to run for this amazing charity next year. Stay safe everyone



Reuben Holt

Even after 2 years of waiting, the London Marathon 2021 still managed to exceed all my expectations! From the incredible support along the route to the amazing feats of endurance of every runner there! Running it as part of MACS made me feel part of a family and gave me a friendly face whenever you saw the balloons on someone's t shirt! I was lucky enough to find a fellow MACS runner in my starting wave and then again at mile 20 when I really needed a push! Thank you MACS for all your support before, during and after this unbelievable event!

London Marathon 2022

Are you feeling inspired? A limited number of places will be available in the 2022 event, which will take place on 2nd October. You can register interest on the MACS website. We also have a number of other events and activities happening – do take a look at page 24 and 25!

Well done!

Huge well done to all the amazing fundraisers!
Here's what MACS supporters have been up to this year.



Richard Yeo, James Lock and Tom MacTaggart

IN SEPTEMBER, Rich and his two friends, James and Tom, took part in the Torbay Half Marathon, raising a whopping £1,400!

During the first Covid lockdown, Rich's youngest daughter, Remi, was born and then diagnosed with Microphthalmia and Chorioretinal Coloboma when she was a few months old. This means she has almost no sight in her left eye.

Rich tells us: "Remi is completely smashing life and keeping us on our toes and hasn't let her condition affect her determination and love for life so far!". Well done to Rich and the guys for the fantastic fundraising total and all the effort you've put in!



Richard McKenna

In October, Richard completed the Royal Parks Half Marathon, not only reaching his goal time of under 2 hours, but also smashing his fundraising target, raising £1,330.01 for MACS! Richard was inspired to sign up by his son who was born with a MACS condition.



Hamish Devon

In June, Hamish ran the Goodwood Motor Circuit Marathon, inspired by his nephew who was born with a MACS condition. Hamish raised a brilliant £600.00!



Charlotte Heale Sandstone Trail

In September, Charlotte Heale completed the Sandstone Trail and raised an amazing £1,210! Charlotte says: "We completed this challenge for our gorgeous Nephew and son Arthur and all the families affected by this condition. We walked the Sandstone from Whitchurch to Frodsham. 55 Kilometres/31 miles! We set off from Whitchurch at 6am and ended at Frodsham about 13 hours later! There were blisters, sweat and tears but totally worth it for Arthur and this amazing charity, raising £1210. Thanks to MACS for supporting our family and everyone who donated!" Jess, Luke, Charlotte and Chris.



Captain Tom 100 Challenge

In April, MACS supporters took part in the Captain Tom challenge – a national campaign inviting the public to get creative with the number 100 in memory of Captain Tom Moore, who had famously walked 100 laps of his garden raising funds for NHS charities.

We saw some amazing ideas from MACS supporters! Natalie, Matt and children Sophia & Samuel, who are also MACS members, came up with the idea of walking 100 minutes per day while picking litter, aiming for 100 pieces – a double 100 challenge!

Natalie says: "We were so pleased to have successfully completed our Captain Tom fundraising challenge for MACS! We loved spreading the word about MACS to people who stopped and asked what we were doing. We smashed our target with £385 raised! Thank you to MACS for making so many families living with a MACS condition feel less isolated in their lives, and thank you to everyone who sponsored us! The funds make a huge difference to the people who need it most!"

A huge well done and thank you to all of our brilliant fundraisers!



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 next 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 need 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 next year, 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're asking for fifty people to please pledge a minimum of £50.00 each. These pledges to MACS this Christmas will lead to an amazing gift to us next 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 next December.

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 next year, you can find more on how to do so overleaf.

Let's make it a Merry Christmas for MACS!

The Big Give

www.macs.org.uk/want-to-help/campaigns/the-big-give

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

Or simply scan the QR code above.

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**.



We have used flowcode to create this QR code. If you want to know how your data will be used by them,
you can find our more here: privacy-flowcode.com

Microphthalmia, Anophthalmia & Coloboma Support

Supporting children born without eyes or with underdeveloped eyes

Contacting us:

Family support:

0800 169 8088

✉ enquiries@macs.org.uk

Fundraising and general enquiries:

0800 644 6017

✉ fundraising@macs.org.uk

@macsthecharity @MACSCharity @MACSCharity [linkedin.com/company/macsthecharity](https://www.linkedin.com/company/macsthecharity)

Registered Postal Address:

Microphthalmia, Anophthalmia and Coloboma Support, 71-76 Shelton Street, London, WC2H 9JQ

Registered charity number: 1161897

