



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

ISSUE 11
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FOCUS MAGAZINE

Microphthalmia, Anophthalmia & Coloboma Support
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WELCOME!



HELLO EVERYONE,

Welcome to our second newsletter of 2019! It's hard to believe that the year is almost over and that we're a couple of months to Christmas – where has the year gone?! So far this year: we've had our amazing #TeamMACS take

Chair's Introduction

part in both the London Marathon and Ride London events; we've held our annual Family Weekend, when we welcomed families back to the familiar surroundings of Park Hall; we've had our first MACS trip abroad to Portugal; and we've seen three amazing groups of MACS young people take part in our annual suite of confidence-building activity events. All of which you can read about here!

Since our last Focus we've had some exciting developments at MACS. We've planned some amazing 25th Birthday celebrations, and we've completed the recruitment for our first permanent Chief Executive Officer. I was so pleased to introduce Liz Bates to many of you at the MACS Family Weekend, but for those of you who missed the opportunity you can read all about Liz in this edition. Of course, I'd like to

say a big thank you to Fay for all she did for MACS during her time as interim CEO, she was a huge asset and I'm very happy that she'll be staying with us as a family member. Stay tuned for the Christmas edition of Focus featuring a round up of her achievements.

The Trustees have been busy throughout the year and I'm pleased to say that we really are in the best position to be pushing MACS forward, concentrating on delivering our *Confident and Connected* strategy for you, our members.

I hope you enjoy reading this edition of Focus and I know we can't wait to see you at a MACS event soon!

Robbie

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Thank you to donors

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Fundraising support: ✉ **fundraising@macs.org.uk**

Running events: ☎ **07734 954 976** or ✉ **marathon@macs.org.uk**

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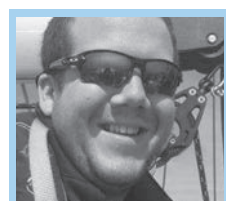


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The Trustees



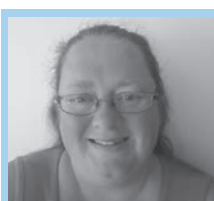
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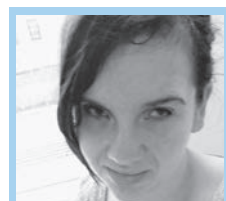
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**Microphthalmia, Anophthalmia
& Coloboma Support**

Supporting children born without eyes or with underdeveloped eyes

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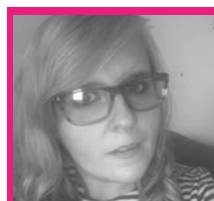
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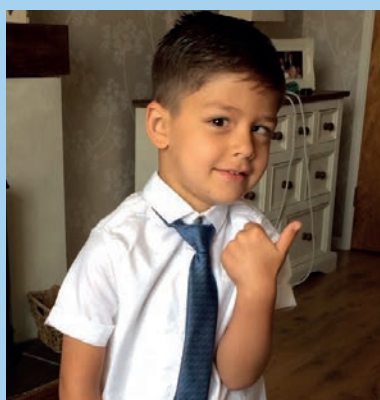
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Say 'HELLO' to some of our newest members!

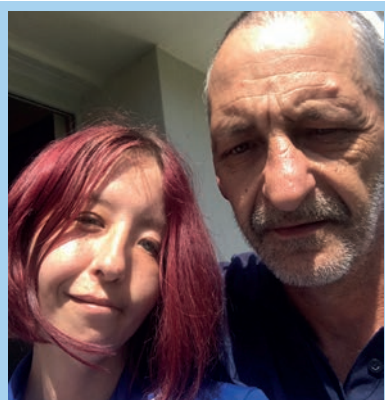
Welcome to all the new members who've joined MACS in recent months.



Amelia & guide dog Libby



Alfie



Leanne



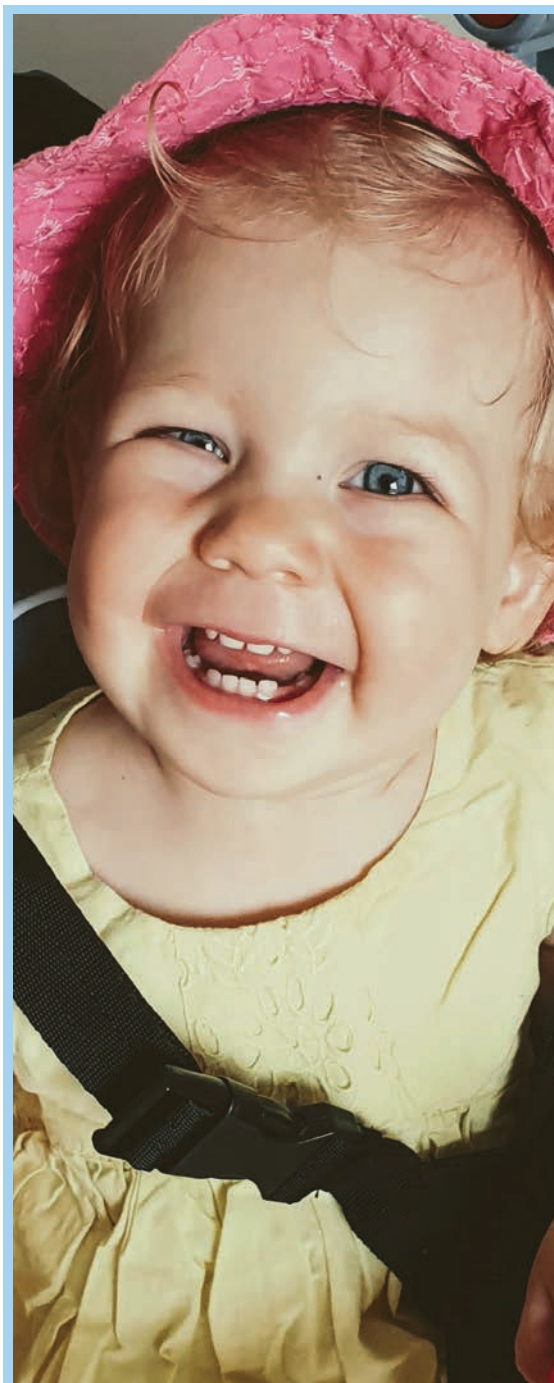
Jack



Griff



Ryan



Renie

Introducing Liz

Introducing our new CEO, Liz Bates



HELLO EVERYONE!

My name is Liz Bates and I am both proud and excited to have joined MACS as your new Chief Executive. Everyone has made me feel very welcome and I'm looking forward to spending the years ahead helping to grow and develop MACS in the way that you, our members, want and deserve. Although I've been in post for about three months now, everything still feels very new and there is so much more I have to learn about MACS and what the charity means for so many of our families.

Joining MACS as the charity celebrates its 25th birthday couldn't have been better timing and has provided me with the perfect introduction to the charity. I have just spent a fantastic month going to each of our 25th Birthday events and meeting so many of our wonderful MACS families. It has been a real privilege speaking to you and learning about how MACS has made a difference to your lives. Thank you all so much for sharing your stories with me and helping me understand what MACS can do to support you more in the future.

For those of you who would like to know a little bit more about me, I joined MACS after spending 7 years at Deafblind UK, initially as a trustee and more recently as their Chief Executive. Before that I worked for many years (more than I'd like to confess!) in the NHS where, amongst other things, I led the development and commissioning of VI services and was a member of the Department of Health's National Eye Services Steering Group. These experiences helped me understand the issues

facing people with VI and, more importantly, the impact those issues have on the everyday lives of families up and down the UK. All of which I hope will stand me in good stead for working with and for MACS families. In between working for the NHS & Deafblind UK, I also spent 5 years at Cancer Research UK, establishing their Health Professional Engagement department and working closely with GPs, hospital clinicians and researchers. Over the months and years ahead, I plan to build on these relationships and develop new opportunities for MACS.

The next twelve months are going to be incredibly exciting as we put forward our plans to deliver the ambitions set out in Confident and Connected. Obviously, we can't implement everything all at once but you should start to see one or two new MACS services and opportunities happening quite soon. Watch this space!

Finally, I would just like to say a huge thank you to Fay Skevington who did a brilliant job for MACS as your first Chief Executive. Fay has been incredibly supportive during my first few months and has left me with a fantastic platform to build on. I'm sure you will all join me in thanking Fay and wishing her well in her new job.

Best wishes

Liz

Please don't hesitate to get in touch with me at: liz@macs.org.uk

MACS Awareness Week



THIS YEAR we held our very first MACS Awareness Week to celebrate MACS' 25th anniversary! We aimed to get as many schools, workplaces, and hospitals involved in raising awareness and fundraising as possible. We have been incredibly impressed and grateful at how many of you were willing to help us with this campaign – thank you!

We were delighted that 29 schools got involved in awareness week, including 20 schools with a MACS child. Some of the schools also did some fundraising for us and we are incredibly grateful for your generosity. Thank you to Highworth pre-school who raised an incredible £228 by holding two MACS fundraising days! Also, well done to Hockcliffe Lower School who raised the fantastic sum of £135.45 by holding a blue day to raise awareness for MACS. Huge thanks to all the members who've encouraged the schools to get involved!

Almost every school with a MACS child as a pupil requested a goalball pack. We hope that you all had lots of fun playing the new all-inclusive sport with your friends! We received some excellent feedback from St James'

Thank you to St James' Academy for holding their MACS Awareness Day and sharing their photos! The school turned blue for the day as pupils donned different shades of the MACS colour and took part in activities while blindfolded to experience some of the daily

challenges faced by people with visual impairments. The children were really keen to get involved in both awareness raising and fundraising, with some of them donating their pocket money to MACS!



Academy telling us how the pupils enjoyed trying out the goalball kit to give their sighted pupils a chance to experience what school might be like for a visually impaired pupil.

Each school also received a pack of one-page tip sheets that can be taken into classrooms to help teachers set things up more effectively for a VI pupil and those with visible differences.

Awareness Week in workplaces

It is wonderful that 21 workplaces and 6 children also requested our general awareness pack – all of these came from recommendations, so thank you to everyone who helped spread the word! If you got your workplace involved, we would love to hear about it so please email helen@macs.org.uk to tell us how it went. Each of the adult packs included one-page tip sheets that MACS adults could take to their workplaces to help their employer set up things more effectively for VI workers and those with visible differences.

Awareness raising in hospitals

In addition, 21 hospitals and medical organisations signed up to receive information about MACS conditions. All of these centres received posters and leaflets as well as children's books for their waiting rooms. We know that for many members, doctors waiting rooms

can be worrying places, especially when their child is first going through diagnosis, so we really hope these resources will help them feel less alone and more hopeful during that time.



Resources

As a result of awareness week, we now have a range of new resources including: MACS the monkey masks, 'MACS means' bunting, lesson plans for all key stages, assemblies for schools, and brand-new posters. These packs are still available if you wish to receive one.

We also have a limited number of goalball packs available. Please note that members cannot request a pack, the request must come directly from a school email address.

If you'd like access to any of the resources mentioned above, please email helen@macs.org.uk

25th Anniversary Fundraising

It's been amazing to see so many people joining our fundraising campaign and getting creative with the number 25! Well done and thank you to each and every one of you!



Lewis

Helped his mum run a Stay and Play toddler coffee morning and raised £400!



Daniel and Kelly

Daniel and Kelly completed a tandem bike ride from Glasgow to Edinburgh and raised £925 and counting!



Chloe

Chloe ran 25 miles throughout the month of June



Joe

Joe held a coffee morning and raised £950!



Oscar and Ellis

Oscar and his brother Ellis have done a 12 mile hike carrying all their camping gear in the Forest of Dean and raised an amazing £162.50



Senior Street Sextet

Senior Street Sextet organised a Jazz concert and raised £2,187.25!



MACS members of staff

MACS members of staff have also been busy, with Kerry walking 25 miles in 5 days, Kaja completing 25km of outdoor swimming, and Liz swimming 25 miles in 25 days!

If you'd like to show your support to any of the above fundraisers you can view their individual pages here:

<http://uk.virginmoneygiving.com/fund/macs25anniversary>

It's not too late to create your own challenge! Get creative with the number 25 and join our campaign to celebrate 25 years of MACS!



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facebook.com/MACSCCharity

Family WEEKEND

2019 was our 20th year at Park Hall and as always it was an amazing weekend.



THIS YEAR was extra special as we celebrated MACS' 25th anniversary! 75 families joined us this year, including 8 new families who joined our MACS family for the first time. As it was our 25th anniversary, our theme this year was Glitz 'n' Glam - everyone was dressed in their best suits and dresses ready to party the night away. MACS' Got Talent - our annual talent show, the disco, and the chocolate fountain all returned, and new this year was the photobooth.

We also held several breakout sessions again this year, including Find Your Voice with David Roylance, Appearance Research, My MACS Journey, Treatment and Research, and 1:1 sessions with John Turnbull from Guide Dogs. These sessions allowed parents to find out the information they need relevant to their situation. If you have any sessions you would like us to hold next year, please let us know. enquiries@macs.org.uk

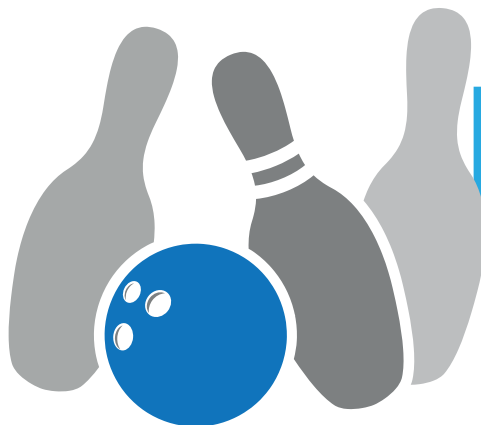
While the adults were taking part in the AGM and breakout sessions, the children visited Rock and River, taking part in a variety of sports. This gave them the opportunity to try new things and build new friendships - 83% of the young people made new friends by taking part in the activity. We also held our MACS Means sessions, where young people could express their feelings and tell their story as part of a podcast. 100% of the young people felt proud of what they achieved at their activity.

For the first time we held a taster session for Goalball, a VI inclusive sport. Several parents also participated to gain an insight into what their child experiences. Families thoroughly enjoyed this opportunity to try something new. Through lunchtime we held exhibitor stalls, where families could find information from different professionals on different aspects of living with a visual impairment.

"A life changing experience is how it feels. Something we will never forget and so look forward to doing again. Hard to find words to really express the experience and the effect it has. So emotional but in a good and inspiring way. We all felt very 'spoilt' by all the activities, events, evenings etc. The feeling of family and support was incredible.

We really came for our child but we both gained so much from it, which was unexpected. It filled a need that we didn't really realise was there for us! We cannot thank all the people who were involved in the organising and running of the weekend and the families we met enough. A very special group of people and weekend. We feel truly blessed to have found you."

Book your place: <https://macs.org.uk/family-weekend-2020-booking-form/>



BOWLING EVENTS

By our Regional Co-ordinator, Sharon Williams

I JOINED MACS in January and we have had a very busy year so far! This year we hosted our first core events at ten bowling alleys across the UK, in Glasgow, Manchester, Nottingham, Belfast, Cardiff, Cambridge, Gateshead, Bloomsbury, Birmingham and Exeter. We have been spreading the events to reach as many of you as possible. We held our first centrally arranged events in Wales, Scotland and Northern Ireland, in order to reach more of our members so thank you to everyone who attended!

We have built on this success and have planned MACS 25th Birthday Celebrations at 6 venues in Belfast, Edinburgh, Swadlincote, Park Hall, Bristol and Epsom. We have well over 300 members booked to come along and join in the fun at the events being held in September and October.

At the bowling events we had a total of 202 members and trustees from 67 families in attendance, which is a really great turnout! It was brilliant to see that 15 new families joined us at the events, it was lovely to see lots of new families and people of all ages joining in. A staff member or a trustee was present at every event to greet everyone, along with the support of our regional volunteers. I would like to thank Fay Skevington, Jenny Lupton, Robbie Crow, Teresa Gordon, Sarah & Ryan Ballentine, Anna Lloyd, Bev Wright, Dan & Kelly Coote and Clare & Adam Austin who helped out with the arrangements on the day. These were my first events, so it was great to jump in at the deep end and meet everyone and finally put faces to names. We're very grateful to all who came and to those who agreed to host the events.

Each bowling event consisted of 2 games with a diner meal and a soft drink. Accessibility is important to us,

so we ensured that each venue was within easy reach of a train station or bus stop and all had fully accessible parking outside. The feedback we received from the event was really positive. 81% of families who attended feel less alone with dealing with their / their child's condition as a result of attending the event. 76% of families who attended made new connections with other MACS families.

MACS 25th birthday celebrations will be great fun in wonderful locations, with MACS the Monkey, singing, face painting, exotic animals, a magic mirror and much more besides. I look forward to letting you all know how it went in the next issue of Focus!

Other regional events

We still welcome events organised by our wonderful Regional Volunteers and have had a Summer Mead Farm event from Mel Sharpe, a bowling event from Jenny Lupton and pantos coming up arranged by Mel Sharpe and Hayley Van Ommen – I would just like to thank you all for your input and work for organising these events. We look forward to more ideas and lovely events for MACS members in the future. If you think you might be interested in organising an event for MACS, please head over to page 11 to see how you can get involved.

We are really pleased with the outcome and attendance of the bowling events, thank you so much for coming! We are really looking forward to the 25th celebrations and more core regional events will be coming your way, throughout the UK next spring. We would like to involve all of the age ranges and abilities of our members. We are always open to ideas and suggestions for events. We hope you can join us at an event soon!



MACS Holidays

at Centre Algarve

For the first time this year MACS organised a trip abroad for our members to enjoy a break at a fully accessible resort and in the great company of fellow members

THE Centre was perfectly set up for people with additional needs and has some fantastic activities onsite which we knew our families would enjoy. We were delighted to hear so much positive feedback. Here's a report prepared by one of the attending parents, Hayley:

When I saw the Facebook announcement about the Algarve holiday, I thought 'wow this looks



"Amazing break for all the family with the extremely highly valued added bonus of sharing it with MACS families. Great to be able to share experiences knowledge and stories. Built great friendships, made friends with MACS families that we hadn't met before"



"My children keep asking when can they go back to Portugal to see their MACS friends"

amazing!' and a great opportunity to meet other MACS families. I registered my interest online and didn't think about it again until I received an email confirming that my family had been chosen to go! I told my husband and then the children, we were all really excited. Once I confirmed my place, MACS took a small deposit and I completed a few more forms. We booked our flights and looked forward to the week of fun in the sun with MACS.

The holiday came around quickly and before we knew it, we were

boarding flights and jetting off. On arrival at Faro airport the owner of the centre met and drove us back to the complex, showed us the accommodation and gave a quick tour. I was amazed to see how secure the venue was and the facilities that they had, especially for children. There was a fun games room, with a games console, art and craft, toys, pool table and table tennis, a sensory room that also turned out to be a good place to hold a disco, karaoke and children's shows for the parents to watch. There was a little petting farm, a swimming pool which was just the right size for the number of guests and a café that provided meals and refreshments.

Breakfast and evening meals were catered for, the choices for breakfast were similar each day but the evening meals were varied and always served with a salad. The accommodation was basic but met are needs with plenty of space in the rooms. The people that ran the complex were very friendly and went out of their way to help. There were three group outings planned for us. One to an amazing Aqua Park, another to a lovely beach

"Loved the planned trips out as a MACS group. Staff on site were friendly. I would highly recommend MACS holidays where groups of families can go together. Had so many benefits to all"



"For the first time my child spoke to other children about her eye. She told me she couldn't believe that other children had special eyes as well. Safe environment, loved that the children could chill out and play together without having to be watched constantly. They loved the freedom of being able to play in the park or the family room"

with restaurants, bars, and a few shops and a little train that takes you down to the beach, and the third to a local town with a huge fish market and a delicious pancake house. As we travelled to these destinations as a group, some families stayed together while others split off and then came back to re-group. It was up to individual families what they did on these outings and throughout the holiday as there was no pressure to stay together.

The best bit about the holiday was meeting and building great friendships with MACS families. All children played amazingly together, and everyone was included regardless of age. The days spent by the pool were fun and relaxing and this gave us time to bond as a group. We were able to discuss things regarding any of the MACS conditions openly and no one was judged by questions asked. We all spoke about our experiences of MACS and the last few days we started to reflect on the holiday. I think that everyone that attended would agree that the support of that week was amazing, also the children grew in confidence around the water, making friends and talking about their MACS conditions to each other. Emily keeps asking if we can now live in Portugal as we had such fun and she says she misses her friends. It was also the first time that Emily realised that others had an eye like hers. I would highly recommend this holiday break to anyone on the future. Thank you to MACS for giving my family this holiday experience which was greatly appreciated.

MACS NOTICEBOARD

Winter Lunches

Join us for winter festivities

Behind the scenes we are busy organising our annual Winter Lunches at two locations – North and South – and really hope we see lots of you there! The two venues are:

- **Holiday Inn Leeds - 7th December**
Queen's Drive, Ossett, West Yorkshire. Wakefield, WF5 9BE
- **Holiday Inn Reading - 14th December**
Basingstoke Road, Reading, Berkshire, RG2 0SL

Both events take place between 11:30 and 16:00, and include a delicious three course meal, children's entertainer, and lots of good fun catching up with other families and meeting new ones! The booking form will be available soon – look out for your invitation soon!

A Helping Hand

While technology can make life easier, many items can be costly and out of reach. MACS can help to make useful equipment and activities available to everyone. To date, we have helped to purchase Braille, talking microwaves and mobile phones, music therapy sessions and bike adaptations, and we are pleased that we will be able to continue providing this support for families this year.

In order to help us make the most of the limited funds we have available, we'll be helping our members to apply for funding from other charities, and using our funds for things that cannot be funded from others. If there's something you think you need a helping hand with, please fill in the form and Kerry will be in touch soon!

macs.org.uk/helping-hand-application-form

Opportunities to get involved

We are recruiting for the following volunteer roles. If you are keen to get involved or would like to find out more, please get in touch – we would be delighted to hear from you!

Peer supporter

Peer supporters offer empathy and a listening ear for other MACS members. Peer supporters should be able to commit to at least one phone call a month or more, to support other MACS families. Full training will be provided. Training is likely to take place over a weekend, all expenses, including travel, food, childcare and accommodation would be covered.

<https://macs.org.uk/peer-support-form/>



Local Event Organiser

Event organisers plan and host events for MACS families in their local area, to help members build networks and friendships, and know they are not alone. Training may be provided if deemed necessary. Training would be likely to take place over a weekend, all expenses, including travel, food, childcare and accommodation would be covered.

<https://macs.org.uk/event-organiser-form/>



Community Fundraiser

Community fundraisers come up with ways to raise money and awareness for MACS in and around their local area. They might get local organisations involved or work with other MACS families, or they might plan things for just themselves to do. Training may be provided if deemed necessary. Training would be likely to take place over a weekend, all expenses, including travel, food, childcare and accommodation would be covered.

<https://macs.org.uk/community-fundraiser-form/>



Sailing VOYAGE

By Caitlin Brister

What an amazing voyage!



ON MONDAY 25th August, 10 MACS young people set sail from Brixham on the boat Prolific for a week of adventure. Prolific is run by Ocean Youth Trust South and this year was our 10th year of running sail training voyages for MACS young people.

On the voyage we sailed to Cawsand Bay, Dartmouth, Anstey's Cove, and back to Brixham, sailing 108 nautical miles in total. Whilst on board, MACS young people learnt about sail handling, helming, anchoring, rope work, cooking and cleaning – every year we get consistently good feedback.

Below is a diary of what we got up to – if you think you or your child would be interested in going next year, please look out for announcements soon!

Day 1 Here we come!

Once everyone was safe and settled on the boat. The crew all got to know each other playing games around the table. Following the greeting, the young people were split into watches – small groups of people who would sail the boat at any one time – and began their sail training adventure. The crew learnt how to use the winches to pull up the sails and how all the equipment worked such as the gas for cooking and the heads, the toilets on board. As the crew couldn't sail out that evening, they headed to the beach to relax and skim rocks. The team climbed into bed for an early night ready for the adventure and enjoyed a wonderful WOM story, named because it was read by Will and Tom – two of our watch leaders!

Day 2 Ahoy!

At 7:30am the crew were full of enthusiasm ready for an adventure. Before they could sail the crew had to complete 'happy hour', where the boat is cleaned from bow to stern, including doing the washing up and cleaning the heads. With the boat and crew ready, they began the journey to Cawsand Bay. Out in the ocean the wind was blowing all over the place and the boat began to rock. This meant that several crew members were sick. However, the crew all pulled together and helped each other through the rough patch. Despite feeling ill, everyone worked as a team to hoist sails and get safely to our destination. Also swapping cooking shifts with those who were unwell. It was a tough day, but the crew made it through together.



Day 3 New adventures

The crew headed ashore on the dinghy to Cawsand Bay and enjoyed some chips and ice creams and tried out the kayaking that was available at the beach. Once everyone had had time to chill, they headed back to the boat. We sailed further along the coast to a place called Drake's island, unfortunately there wasn't enough facilities to anchor here and have a BBQ, so we headed back to Cawsand Bay where the team enjoyed a BBQ and a swim in the ocean (including a quick hair wash).

Day 4 Nothing in sight

With the wind blowing strongly, the forecast began to worsen with predicted wind speeds of up to 50mph (a gale force 9!). The crew had to sail somewhere safe to stay throughout the gale. They began the journey towards Dartmouth when fog surrounded the boat. The visibility was extremely low, the crew had to learn to listen for foghorns from surrounding boats. After an incredible team effort, the crew arrived safely into Dartmouth that evening.

Day 5 Ashore!

As the crew were now storm bound in Dartmouth, they needed something to help keep everyone entertained. The crew went ashore for a shower to refresh and then headed for a walk around the town. They all enjoyed some delicious fish and chips and also fudge from a local shop. Peta, the skipper, decided that whilst we were stuck on the boat we could do a baking competition and watch some films. We split into the watches and

each made a dessert, one team made a carrot cake, the other some chocolate chip cookies. By the time we were finished it was getting late, so we left the judging until the next day.



Day 6 Happy cooking!

With another day anchored in Dartmouth, the crew came together on deck and played games. However, once someone had become wet in the game, it turned into a big water fight. Everyone was soaked, mainly the staff. Once everyone had dried off, The Great Prolific Bake Off began, with the watch leaders dressed as the infamous Mary Berry and Noel Fielding, everyone tucked into the delicious food. The carrot cake won best presentation, and the cookies best taste. Everyone was awarded star baker! That afternoon the crew went ashore to explore the town and buy some souvenirs. Once everyone was ready, we met up and went for a lovely meal out. Everyone had a brilliant time, chatting and eating delicious food.

Day 7 Every cloud has a silver lining!

With one day left, the crew wanted to make the most of the adventure, so we stopped at a small beach called

Anstey's cove. The crew swam in the sea, explored the island, having lots of fun. Whilst people were swimming, others set up for a BBQ on the beach, enjoying hot dogs and burgers! Suddenly it began to rain. The crew worked together to cover the barbecue and keep the food cooking. Despite the rain, everyone had lots of fun at the beach and were soon back on the boat warm and dry. That evening, everyone settled down to watch The Lion King and shared lots of popcorn.



Day 8 Bye for now!

Time to say goodbye. The crew packed up all their belongings and scrubbed the entire boat ready for the next group. We sailed back into Brixham, ready to leave the boat. Everybody had a great voyage and it was an emotional goodbye. Until next year!



Caldecotte Adventure break

"It has been the best experience ever and I would recommend it to all MACS people. It was fun"

MACS Activity Week at the Caldecotte Xperience



"I also had a bit of a break which was invaluable during the long summer holiday"

EARLIER THIS summer, two groups of MACS young people attended our annual adventure trips at Caldecotte, Milton Keynes. The first trip, for 5 to 10-year olds, took place between 26th July and 28th July and MACS children took a parent with them. The second trip for 10 to 18-year olds took place between 28th July – 2nd August. Both trips were supported by our care providers, First Choice Care – thanks to Kelly and her team for another job well done!

The younger group enjoyed 3 days in a tent with a parent. Arriving on the Friday afternoon, everyone was raring to go – a weekend of fun was on the cards, with lots of new experiences to try. After setting up in their tents, the participants experienced caving, canoeing, and the children loved the sensory experience of zorbing on

water. In the evening, they sat round the campfire getting to know each other and eating toasted marshmallows. One parent said that they were grateful to spend 1:1 time with their child and getting to experience all the activities together.

"This being our first trip, we were surprised about how welcome we felt, and it was amazing how we were made to feel part of the group. It was wonderful to feel part of something and share this experience."

The older, independent group of 10-18-year olds attended for 5 days, some for the first time without a parent. Every year we always hear how much MACS young people value the opportunity to be

"The care staff are amazing. They went above and beyond to meet my child's unique needs and give him a fabulous week of fun and laughter"

amongst people who really understand and 'get it'. The week is an opportunity for MACS young people to not worry about having a MACS condition, because everyone is in the same boat (sometimes literally!). The young people tried lots of new activities such as sailing, crate stacking, and driving a speedboat! They even got to visit a local snow dome and go sledging in the snow!

On the final evening the young people showed off their talents in an open mic night talent show. Our MACS young



"I like doing all the activities because I don't get to do them at home"

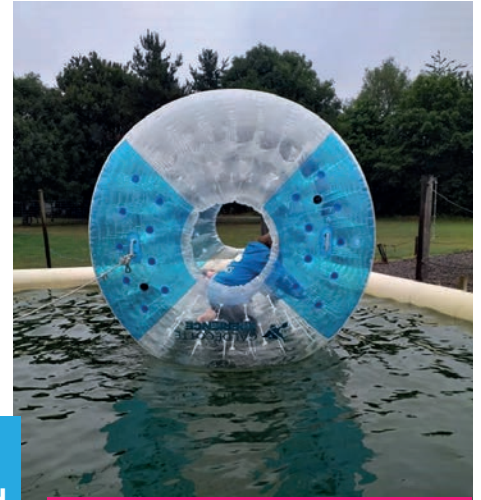
people sang their hearts out and even gave an incredible British Sign Language (BSL) performance, helping sign the song with their new friend from the week – a MACS young person who uses BSL. These trips benefit the young people in more ways than just trying new activities. They learn invaluable communication and teamwork skills, build friendships, and gives them respite from daily life.

- 100% of parents agreed that their child's confidence in making new friends had increased as a result of attending this trip.

We'll be releasing information on how you can book onto next year's trip soon – keep an eye out for the announcement!



"It was a wonderful trip that has given him friendships and experiences I never thought he would have. He absolutely loved every minute and didn't want to come home!"



"It was a wonderful weekend - my daughter did not stop smiling, which was amazing"



"His 1:1 supporter was excellent and the care team were exceptional. I knew he was in safe hands. He tried everything and really enjoyed himself"

"We felt so welcomed and it was amazing how we were made to feel part of the group. It was wonderful to feel part of something and share this experience."

CASE STUDY

Jen* was one of the youngest in the group and initially struggled to make friends due to issues with her social skills and the way in which she engaged with peers and staff. Our support workers worked with Jen to help her to improve her communication skills and discuss with her when she speaking in an abrupt manner. It became clear that this was due to her own personal insecurities. As the week progressed, we held an open mic night one evening and were delighted to see Jen shine as she sang beautifully and responded well to praise and encouragement. Jen was then able to go on and provide encouragement to her peers demonstrating the new interpersonal skills she had learned. (*name has been changed)



@macsthecharity



facebook.com/MACSCharity

Research UPDATE

From Dr Mariya Moosajee, MACS Medical Advisor



My name is Dr Mariya Moosajee, I am a Consultant Ophthalmologist at Moorfields Eye Hospital and Great Ormond Street Hospital for Children in London. I specialise in the genetics of developmental eye defects such as MAC. I also lead a research team at UCL Institute of Ophthalmology, London, where I am trying to understand the molecular mechanisms causing MAC and developing potential treatments that may be applicable in the future for patients and their families.

THIS HAS been an exciting year for our MAC research and I want to update you all about some of the projects my research group have been working on, and opportunities for you to get involved in our research on MAC.



Public Outreach

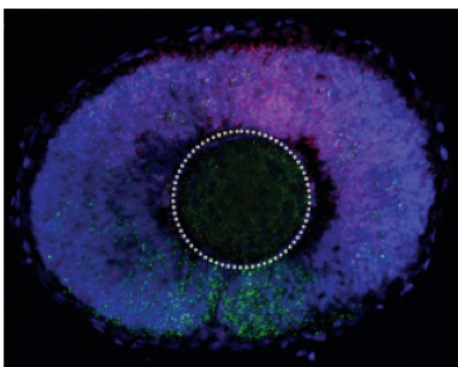
Communicating our research is vital for us to engage with patients, other researchers, and members of the public about the importance of MAC. This year we presented at Jeans for Genes day at a "Meet the Researcher" session at Moorfields Eye Hospital, as well as at the RARE summit 2019.



The NIHR Bioresource

The NIHR Bioresource is a national resource for researchers to gain a better understanding of the relationship between genes and clinical features of MAC. This research effort hopes to better understand the variation in the MAC spectrum, as well as develop new treatments. We would like to encourage you to be a part of this valuable resource. Everyone with MAC is eligible, and would need to provide clinical information and blood samples.

For more information, please contact Sam Malka on 0207 566 2265 or email: samantha.malka@nhs.net



Understanding genes that cause MAC

A coloboma forms when the eye does not fuse completely during early

development. To understand which genes are involved, our lab looked at which ones were switched on in the zebrafish eye. We found 181 genes were working in concert to help fuse the eye. Using this dataset, we identified a new gene called netrin (*ntn1a*) which when mutated resulted in a coloboma. The results of this work were published open access in Scientific Reports, and can be found at:

<https://www.nature.com/articles/s41598-018-38379-5>

Additionally...

we published a review paper which explores the current understanding of the genetic causes of microphthalmia and anophthalmia, and summarises current investigations, and promising new areas of research which may produce interesting results in the future. This review was also published open access in the Journal of Developmental Biology, and can be read at :

<https://www.mdpi.com/2221-3759/7/3/16>

Please contact us if you need genetic testing, want to get involved in our research or have any questions. We will be happy to help you!

Dr Mariya Moosajee

Consultant Ophthalmologist
Email: m.moosajee@nhs.net
Moorfields Eye Hospital
162 City Road, London, EC1V 2PD
Tel: 0207 566 2265

Please follow us on:



@MariyaMoosajee on Twitter



DrMariyaMoosajeeLab on Facebook

Professor Nicola Ragge

and her team at Oxford Brookes University

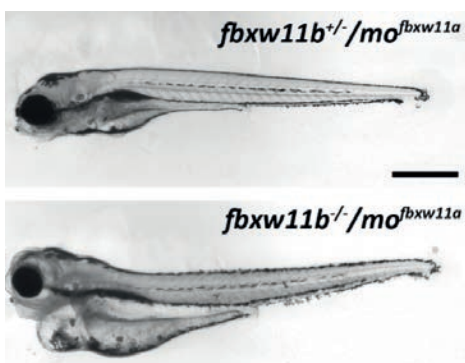
Professor Nicola Ragge has been conducting a world-leading research programme into the genetics underlying Microphthalmia, Anophthalmia and Coloboma conditions for 20 years, and has provided international level research that has led to the identification of several new genes and conditions.



2019 HAS been an exciting year for Professor Ragge and her team. In addition to her regular research work identifying the genetic basis to eye anomalies, and providing new

diagnoses for families with MAC conditions, since the last report in Jan 2019, she has published several new papers, including one describing a new gene, edited a Special Issue of a leading genetics journal (Human Genetics) dedicated to the genetics of eye anomalies, and hosted an international scientific conference, the GoOD (Genetics of Ocular Development) meeting, dedicated to MAC conditions. Professor Ragge's research is expanding rapidly and all of this work is co-ordinated by Dr Dorine Bax, who is funded by MACS.

In top news, our group has been involved in the identification of a new gene for eye, brain and the anomalies of the fingers and toes. Here, a study led by Professor Ragge, and involving 25 centres from 8 different countries (UK, USA, Italy, Netherlands, Denmark, Egypt, France and Australia, identified an important new gene, FBXW11, involved in the human development. The team demonstrated that the gene called FBXW11 drives the development of key structures, including the brain, eyes, hands and feet. Individuals with alterations of this gene showed developmental delay, brain and eye anomalies, and contractures affecting their fingers and toes. This study was published in the American Journal of Human Genetics, the top journal in the human genetics field, and generated press interest due to its high level of significance.



Experimental research on zebrafish that helped identify a new gene related to eye development

Another leading journal in the field, Human Genetics, commissioned Professor Ragge to be Guest Editor and her two collaborators from Toulouse, France, Patrick Calvas and Nicolas Chassaing, to be co-Editors to compile a Special Issue of the journal dedicated to the genetics of eye development. Professor Ragge and her co-Editors commissioned top clinicians and scientists from around the world to contribute articles to this Issue, and additional reviewed new papers on related topics. This resulted in an Issue that is a state-of-the-art resource compiled of 19 excellent papers covering many aspects of the genetics of eye development, including a discussion of classification of eye anomalies in the age of molecular science, summaries of genes that underlie MAC conditions, important pathways, animal models, and future therapeutic approaches. This Special Issue significantly furthers our knowledge on the genetic basis for anophthalmia, microphthalmia and coloboma in the most up-to-date way for the benefit of clinicians, scientists and affected individuals and their families worldwide. There is a special dedication at the start of the issue: 'This Special Issue is dedicated to the families affected by Developmental Eye Disorders, whose courage in living with these conditions is an inspiration to us all.'

This Special Issue was published at the beginning of September and to commemorate this event Professor Ragge, her team and her co-Editors from France organised an international conference, called the GoOD (Genetics of Ocular Development) meeting. The meeting was held on 5 and 6 September in Oxford and brought leading researchers on MAC conditions from Oxford, London, France (Paris & Toulouse), Spain (Madrid), the USA (Milwaukee and San Francisco), and Canada (Montreal), clinicians from the UK and France, as well as representatives of families together for a day-and-a-half of talks and discussion on the genetics of MACS conditions. The meeting proved to be a huge success, with new collaborations forged and existing ones renewed. All of this will benefit MACS families. As a result of the meetings, the attendees have determined to form a new society and to arrange another meeting in 2020

on similar lines to keep the collaborative network flourishing. Meanwhile, Professor Ragge continues to work as a Consultant Clinical Geneticist at the West Midlands Regional Genetics Service in Birmingham, where she sees MACS families referred to her in clinics in Birmingham and Rugby. Together with her research team and the West Midlands Regional Genetics diagnostic team she has developed two laboratory genetic tests specific for MACS conditions, and several families have received answers through these tests this year. These tests will be available until at least 2020, when NHS genetics testing throughout England, as a result of reorganisation of services, will take over this testing. This will be done through 3 national eye genetics diagnostic centres, of which Birmingham-Oxford-Southampton will be one, and Professor Ragge will be supervising the analysis at the lab in Oxford. This reorganisation will eliminate the postcode lottery of genetic testing, with similar testing available throughout every genetics service in England. Using the Birmingham tests as a basis, and as one of the national structural eye disorders experts for Genomics England, Professor Ragge has been leading the selection of genes to be tested as a standard throughout England. This has been done by carefully reviewing the scientific literature for over 500 genes and selecting the panel of genes to be analysed in individuals with anophthalmia, microphthalmia and coloboma in families providing the evidence needed to back up the testing scientifically.

Recruitment of MACS families

Professor Ragge will continue to recruit families into her research study; 434 families are now part of her study. Families interested in joining the study can contact Professor Ragge's Research and Family Coordinator, Dr. Dorine Bax on **01865 484413** or **bax@brookes.ac.uk**. Dr. Bax is part of Professor Ragge's research team in Oxford. This team also consists of postdocs Dr. Richard Holt, Dr. Fabiola Ceroni and Dr. Yesim Kesim, who was welcomed in June. The research team will continue to test every family that has joined the study since 2003 and has not had an answer, using the latest methods in genetics research. Professor Ragge's research benefits immensely from the generous grant provided by MACS, which funds Dr. Bax. We would like to extend enormous gratitude to the MACS families for taking part in the study, and who have contributed to the huge advances made in this area and to the funders for making this possible.

By Jonathan Attenborough

Tech Talk

Welcome to the latest edition of Tech Talk where we tell you about useful assistive technology that may be of interest to you.

IN RECENT editions of Focus I have told you about some very useful smartphone apps but in this issue I want to tell you about a wonderfully simple little gadget that I have been using called Tile.

TILE

I'm sure, like myself, you have at some point encountered the problem when you put your phone, wallet or keys down somewhere and then forget where you've placed them and then spend ages trying to find them again. This is especially an issue when you have a visual impairment as finding lost items is a lot more difficult. This little gadget called Tile helps you solve this issue. Let me tell you how it works. Tile is a small square piece of plastic with a hole in one corner so that



keys etc can easily be attached to it. Tile will help you locate any misplaced valuables by connecting each little square to a smartphone app that is accessible for iPhone and Android devices and will "ping" each Tile that you have placed either on your keys or in your wallet etc so that it will emit an audible sound to help you easily locate your misplaced

item within a 100m range. The great thing about Tile as well is that it works in reverse. So, if you have your keys or wallet handy and you have misplaced your phone, you can press a little button on the Tile device and it will "ping" your phone and play an audible noise so that you can find your phone.

Tile is available from many different online retailers, including Amazon and I have seen them for various prices depending on how many Tile devices you want, but you should expect to pay around £20 for one Tile.

I am only using one Tile at the moment that is attached to my keys, which I am always misplacing so I have found this device to be very useful.

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

VOCALEYES

Experience art and culture through audio description. Bringing theatre, museums, galleries and heritage sites to life for blind and partially sighted people.

VOCAL EYES is a charitable organisation whose aim is make arts accessible for people with visual impairments. Vocal Eyes strives to increase opportunities to enjoy the arts and make them as good as possible; ensure that as many blind and partially sighted people as possible are aware of them; and that the arts and heritage sector know

how to create them, and welcome blind and partially sighted people as a core audience.

There is a variety of audio-described performances coming up over the coming months. For the full list of events visit <https://vocaleyes.co.uk/whats-on/>



Leonardo Da Vinci: A life in drawing
Buckingham Palace, The Queen's Gallery, London
Tuesday 1 October 2019, 10:30 am
[Audio-described tour](#) [Workshop](#)



Amelie
Nuffield Southampton, Southampton
Saturday 5 October 2019, 2:30 pm
[Audio-described performance](#) [Musical](#) [Touch tour](#)

The SENSE Micro

An ultra-portable interactive sensory system

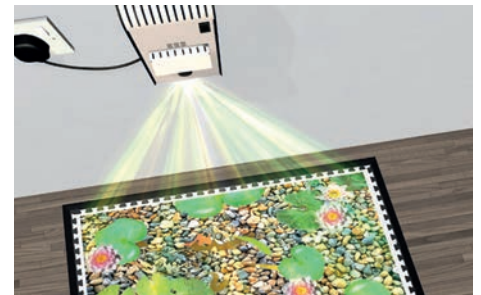
Try our new interactive floor mat at a MACS event near you!

THE SENSE MICRO is a portable interactive floor product designed by Integrex. The SENSE Micro creates colourful, stimulating and engaging floor projections that respond to, and interact with, body movement and touch. It is lightweight, easy to move from room to room, and offers an instant 'plug and play' operation with no set up required.

The Integrex SENSE Micro software and high brightness projector create multiple themes and images which are combined with in-built speakers for audio effects. The range of stimulating interactive and colourful themes includes 'Splat the

Balloons', 'Scatter the Flowers' and an interactive fish pond. With thousands of pictures and hundreds of videos and sounds on-board, any image or audio file can also be added to the many effects available enabling teachers or parents to customise programmes for individual users.

We had the pleasure of hiring this incredible product for our use at the 25th birthday events, and the response was amazing with all children enjoying the colourful content. We hope to be able to bring this amazing mat to many more future events so watch this space!



Support Group For Families Affected by Bilateral Anophthalmia

One of our past Trustees and former Chair, Barry Stickings, has founded a new support group specifically for people directly affected by bilateral anophthalmia.

BARRY WRITES: "In 1993 The Observer brought families together whose children were born with Anophthalmia. My wife Kelly and I were one of those families as our son Toby was born with bilateral anophthalmia. That meeting is how MACS started - we've been members ever since.

"Being told our son had no eyes was a life changing moment for us, one that continues to impact us to this day. For that reason, I have always believed that having a single support group, offering help and support to those specifically affected by bilateral anophthalmia, was important. I always wanted to do

more - not only for Toby and Kelly but for others, and not just in the UK but across the world.

"In February 2019, I decided the time was right to start such a group as I now have time to commit to it and so Bilateral Anophthalmia And Me (BAAM) was formed.

"BAAM exists to bring families affected by bilateral anophthalmia together, worldwide. It's important to us that we aren't only UK based as everyone needs support and borders should offer no boundaries in supporting one another. That's why we have families from Europe, USA, India, Saudi Arabia, Iran, India and more.



"If your child has bilateral anophthalmia, I'd like to invite you to join us. You can find us via any of the links at the end - we're also holding our first event in October, so if you are interested please email me for details."

Email: barry@baam.org.uk

Web: www.baam.org.uk

Facebook:
www.facebook.com/groups/BAAM2019

RideLondon

Join Team MACS for the biggest mass participation cycling event in the UK



THIS POPULAR 100 mile cycle sportive starts in the Olympic Park, runs through the Surrey Hills and finishes on the Mall, following the route of the 2012 Olympics road cycling race. RideLondon is the biggest mass participation cycling event and we were lucky to have such an amazing group representing MACS again. Here it is described in the words of one of our riders, Steve Lamb:

It's 5am on a cloudy Sunday morning; looking out on the London skyline, I'm now 2 hours away from rolling out, over the start line for the sixth time. This is the third consecutive year I've ridden for MACS and this time I'm joined by Nick, Noel & James, the latter two rode alongside me last year. Another three friends had

signed up to ride but had to pull out late on due to injury. One guy (Matt Hope) had amazingly raised £500 and put his disappointment to one side by posting his fundraising onto my fundraising page (thank you Matt!).

I know the route pretty well now, but have to admit the hills filled me with an amount of trepidation due to my lack of any serious training this year. That saying, the climbs up the hills were completed and we rolled across the finish line in a time of 5 hours and 50 minutes. Heading for Green Park, we were looking forward to meeting up with Teresa Gordon and other families who give up their Sunday each year to come and support us. It is very much appreciated and humbling in equal measures.

I know that all monies raised for MACS goes an awful long way to providing support and helping each child to grow socially in this ever-changing world of ours. So, on Sunday 16th August 2020, I'll be in my 61st year and pulling on my MACS jersey yet again; in support of a wonderful charity which ensures every pound is spent wisely.

If you're reading this and would like to make a difference for my charity of choice, come and join me on the start line next year. As the first person to register to ride for MACS in 2020, I'm in, my question is this... 'Are You'??

We are now recruiting for our 2020 team so if you, or anyone you know would like to take part, please get in touch.

Secure your place here:

<https://macs.org.uk/want-to-help/fundraise-for-us/cycle-prudential-ridelondon-surrey-100-macs>

London Marathon

On 28th April this year, 145 runners took on the 26.2 mile running challenge wearing the MACS colours at the 2019 Virgin Money London Marathon.

EARLY MORNING the team nervously gathered by the start area to take our annual team photo, which also gave them a chance to meet fellow team members and finally put names to faces having spent months sharing their progress via our MACS Team Facebook group. Our team consisted of all levels of experience and ability, but the camaraderie was second to none with everyone supporting each other and helping to ease the nerves. MACS the Monkey stole the show, as did our veteran runner Joey, who this time chose to dress up as a tub of margarine! Photos taken, it was time to count down the minutes to the start and off they went!

Along the route the team were cheered from two cheer points, led by Sharon and Kerry. We had a great turnout of volunteers, including a number of MACS members, which was much appreciated by all the runners. Our team did fantastically well, with the first runner finishing in 2hrs 41 minutes and the final runner in just over 7 hours. Our squad at the finish consisted of Jenny, Ben, Robbie, Caitlin, Teresa, Kaja and Kara and we all enjoyed welcoming our team back after they finished their challenge.

Registration for the 2020 event is now open! Head over to the MACS website for an application form. Alternatively, why not come and volunteer? We are always looking for some help on the day.



If it sounds like a good day out please do get in touch: marathon@macs.org.uk

Thank You

A big thanks to everyone who has supported MACS recently!



HUGE THANKS...

...to the Smith family for their support this year. Ted's school took part in the Awareness Week, while his dad and grandparents have secured two large donations for MACS!



We couldn't do it without you!

If you have any corporate connections you could share with us, or if you could introduce MACS to your employer, please do get in touch: lindsay@macs.org.uk

Thank You TO DONORS

WE WOULD LIKE TO THANK THE FOLLOWING INDIVIDUALS AND GROUPS FOR THEIR DONATIONS:

- UK Power Networks £900 from Pie the Manager and Staff BBQ
- Stretham Stores, Ely £100 (Charity of the Month)
- Ann's Fund £250
- St Paul's Column Freemasons £500
- Ferryside OAP Club £300
- Thorpe Park Golf Club, Lincoln £2,000 thanks to David Germaine
- Chris Conway-Hughes and the Senior Street Sextet £2,194.75 from their jazz concert
- Howe of Fife Rotary Club £500
- Trinity Toddlers £220
- Miskin Theatre, North Kent College £200
- 5th Hoddesdon Scouts £154
- 6th Hitchin Scouts £470
- Just For Fun Dancing £500 thanks to Brenda Mustill
- Music with Friends £480 thanks to Matthew Horspool
- Porsche Lockwood £402.50 from her quiz night
- Gemma Davies £180 from her disco

AND SPECIAL THANKS TO THE FOLLOWING FOR THEIR GENEROUS AND KIND SUPPORT:

- Claire Chebil
- Patsy Sharp
- Anna Batten
- Harriet Haynes-Coote
- Cheryl Smith and Linzi Pollard

WE'RE VERY GRATEFUL TO THE FOLLOWING CHARITABLE TRUSTS AND FOUNDATIONS FOR FUNDING OUR ACTIVITIES THIS YEAR:

- Jeans for Genes
- Tory Family Foundation
- Wallace Bell Charitable Trust
- Thomas Curtis Charitable Trust
- Will Charitable Trust
- Douglas Arter Foundation
- Lillie C Johnson Charitable Trust
- Wilmcote Charitrust
- Souter Charitable Trust
- Gordon Fraser Charitable Trust
- Webb Family Charitable Trust
- Sir Jules Thorn Charitable Trust (Ann Rylands Small Donations Fund)
- Constance Paterson Charitable Trust
- Hiscox Foundation
- Kobler Trust
- John Swire 1989 Charitable Trust





Join Team MACS!

Every year in the UK, around 100 babies are born without eyes or with underdeveloped eyes.

Cycle for MACS and help these children live their lives to the fullest.



MACS has places waiting for you!
Minimum sponsorship just £350



As a member of Team MACS you'll receive:

- ✓ fundraising support and materials
- ✓ training tips and advice
- ✓ access to an online support group
- ✓ supporters' packs for friends and family
- ✓ a unique MACS cycling shirt
- ✓ cheers along the route and at the finish

Apply today at www.macs.org.uk/cycle

Microphthalmia, Anophthalmia & Coloboma Support

Registered charity number 1161897 • Telephone: 07734 954 976 • Web: www.macs.org.uk • Email: cycling@macs.org.uk