



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

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FOCUS MAGAZINE

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

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MACS MAGAZINE VOLUME 13

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

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Microphthalmia, Anophthalmia & Coloboma Support

Supporting children born without eyes or with underdeveloped eyes

Charity number: 1161897

Chair's Welcome!



DEAR MEMBERS AND SUPPORTERS,
Welcome to the winter edition of Focus!

As 2020 is ending, it is not easy to reflect on what has been the toughest year in MACS' history. Like the rest of the world, we have been hit hard by COVID-19 but MACS is still here doing what it does best, supporting our members.

We started the year feeling confident about the future of MACS and our team had exciting plans to deliver a series of new in-person services for our members. Sadly, all that changed with the arrival of the COVID-19 pandemic. Faced with new essential restrictions, to safeguard not only us but the nation, we made the difficult decision to cancel the Family Weekend. It wasn't an easy decision to make as we know how valuable it is for our members, but it was the right one. The health and safety of our members will always be our priority. Unfortunately, the 2020 Family Weekend wasn't the only face-to-face MACS event that was cancelled.

While face-to-face events have been impossible during the pandemic, we quickly adapted and continued supporting our families with a brand-new suite of virtual member services. I can't say how proud I am of the committed staff team for initiating these successful events so quickly – I am proud of what we have achieved with limited resources. Since lockdown began we have launched new ways of supporting each other with online activities ranging from daily coffee breaks and quizzes through to creative writing workshops and sign language groups led by our members. In addition to our weekly services, we have also

hosted two online Family Days for our members and run our second successful MACS Awareness Week in July. Our virtual events have proved a great success with over 1,500 attendees so far and I'd strongly encourage you to attend one if you can.

It is not only face-to-face services that have suffered, our fundraising has also suffered more than ever before. The Virgin Money London Marathon, our largest income generator, was cancelled and turned into a virtual fundraising event. I'm pleased to say that our fantastic team of fundraisers responded to our call and embraced new ways of supporting MACS. In April we hosted our own version of a virtual marathon and October saw the official virtual London Marathon take place. The two events saw over 150 participants combined and raised over £23,000 for MACS. This tremendous effort by our fundraisers was fantastic and exceeded our hopes and expectations, 'thank you' really isn't enough.

Whilst next year's London Marathon isn't yet cancelled, only postponed, this will place a strain on MACS' cash flow at the beginning of 2021. Furthermore, London Marathon have informed us unexpectedly that we will be losing over 75% of our places in subsequent races. This is, of course, a huge disappointment and risk to MACS, but the decision reassures us that our commitment nearly 3 years' ago to invest in fundraising and staff resource was the right one.

To help combat the loss in income and prepare for a shift in fundraising activity for the organisation, we will launch our first emergency appeal this Christmas. This appeal will help MACS navigate the cash flow difficulties in early 2021 and start to build our fundraiser database for future appeals. If you can donate, or pass the request onto friends and family, it really would be hugely appreciated. It's appeals like this that will secure the future of MACS for generations to come.

Despite the challenges of 2020, there has been positive progress for MACS, in addition to our virtual member services. This year we have welcomed 57 new

families into MACS, meaning we now support over 2,700 members, from over 900 families. We have also welcomed three new trustees onto the Board of Trustees and we have formed a new partnership with five other charities to deliver more services in Scotland.

Looking ahead we are hopeful that next summer we will once again be able to meet each other again. We have provisionally booked in our adventure activities for MACS children and teenagers and we also hope that regional groups and national events will once again be possible. Regrettably, however, we have made the decision to not host a 2021 Family Weekend, although a virtual AGM and online activities will take place. The reasoning for this is two-fold. Firstly, it is unlikely social distancing restrictions will have been fully lifted by May to allow us to meet in large groups and sourcing another large venue for later in the year will be difficult. Secondly, Family Weekend is our biggest annual spend and with cash flow being difficult in the first half of 2021, it was considered too high a financial risk. We do hope, however, to have a bigger, better, and stronger Family Weekend in 2022.

In closing, I'd like to reiterate my thanks to the committed MACS Trustees and volunteers, and the dedicated staff team without whom MACS would not be here now. This year has been tough, but the dedication of the MACS team, and the support of our members, is what will secure the future of the organisation for years to come. After COVID-19 there is so much to look forward to. I cannot wait to see as many of you as possible in the years to come.

Stay safe, look after each other, and remember that MACS is here for you when you need us most.

Robbie

Meet the Team

The Trustees & Staff



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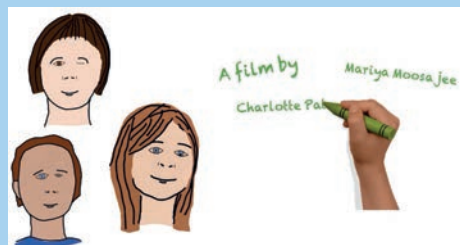
Family Day



The Covid-19 pandemic meant that the Family Weekend couldn't take place in its usual format, taking a virtual format instead. For the first time ever we held a virtual Family Day in May, and then again in November

OUR FIRST Family Day was held on 9th May 2020, with 100 families attending throughout the day.

We started the day with an update from Robbie and Liz, our Chair and CEO, updating everyone on MACS' recent activities and letting them know what to expect from the day. Following on from this, we welcomed all our new members. Members were able to hear all about what MACS is about and the support they can receive. Many of our new members hadn't had the chance to attend one of our regional events, so it was great to hear they enjoyed the new virtual set up, and still gained the support they needed.



Consultant Ophthalmologist and newly appointed trustee Mariya Moosajee held an extremely informative session on MACS

conditions. She took members through the process of how MACS conditions can arise.

We kicked off the afternoon with some magic. Magic Matt has been entertaining MACS children for many years now, and even virtually he didn't disappoint. Next up, young member Theo shared his story about life with a MACS condition and becoming youth mayor in his hometown. For a little break we held a session for members to talk and show off their pets. Sean Liddell (Mindfulness trainer) lead a calming session of mindfulness and training your mind to be positive and tips on relaxation.



Laura and Tom lead us through a presentation of their new guidance aid the Ramble Tag. We heard from MACS members who have tested the Ramble Tag and how it supported them to live a more independent life. We are delighted to now have Ramble Tags for sale in our online shop – www.macs.org.uk/shop.

Zoe and Giggles from Boogie Beats lead our younger members (and some adults) through songs and stories. We danced, sang, and listened to some wonderful stories!

Our annual talent show MACS' Got Talent closed our Family Day with lots of smiles. Patron Martin Pemberton compered the talent show, where we saw a variety of members showing off their talents. From singing and dancing, to Rubik's cubes and piano. Our members can do it all!

"It was a brilliant day and we loved that we could dip in and out and join the sessions that we felt applied to us. It was great to have the fun and informative aspects of the family weekend brilliantly put into an online day. Well done to everyone involved!"



All the sessions from the day were recorded so if anyone missed them, or just wants to watch again, simply head over to our website: <https://macs.org.uk/macs-family-day-2020-report/>

Family Day – the autumn edition

The autumn edition of the event took place on 7th November.

First off, we heard from Dr Iona Alexander who told us about a study on sleep and circadian rhythms in relation to visual impairment. Next, MACS member Kirsty Hill told us about her PhD work on the psychological impact of visual impairment. We were entertained once again by Magic Matt, as well as UCAN Productions who led a session on sound effects for our younger members. Ophthalmologist and Prosthetics Consultant Dr Sri Gore delivered a fantastic presentation on eye development and answered questions on prosthetics.

Dr Alex Yong told us all about the new website Gene Vision, a fully accessible website with an A-Z on genetic eye disorders, including information on MAC conditions, with the appropriate management pathways and latest research. You can read more about it on the next page. We then heard from Humanware who shared updates on the latest Braille technology.

Again, all the recordings from the day are on our website here: <https://macs.org.uk/family-day-nov2020/>

Future Family Days

With the current guidelines and financial implications of COVID-19, our events will continue to be held virtually for the foreseeable future. Upon reviewing your feedback, we would like to make this accessible for all our members, with all conditions. If you have any ideas for sessions or ways to make the day accessible for all, please get in touch with our CEO Liz at liz@macs.org.uk. We want all our members to benefit from our new support system.



@macsthecharity



facebook.com/MACSCharity

Meet the new Trustees

Introducing Dr Sylvanus Effiom, Naomi Bowman and Dr Mariya Moosajee



DR SYLVANUS EFFIOM

Please tell us a bit about yourself and your background.

My name is Dr Sylvanus Effiom. I am originally from Cameroon in Central Africa. I came to the UK in 1995 to study for a Master's degree in banking Law. Since then, I have lived, studied and worked in this beautiful country. I am currently married with 2 gorgeous children. My family and friends have been a source of real support for me in coping with my disability, and it is this degree of compassionate support that I hope to deliver to the MACS children.

Currently, I work in the Legal department of Moorfields Eye Hospital in London. However, my passion for equality has meant that

I do a lot of work in this area. I lost my sight after I obtained my Master's degree, and doing the PhD without sight was the most challenging period in my life. Sight loss has made me appreciate from a deep perspective the equal worth of each human being. I have experienced how disability could emasculate one of his/her personhood, and I want to make my own contribution in restoring this through MACS.

What made you want to become a trustee for MACS

For some reason, I have always felt that it is a duty incumbent on every disabled person to assist other disabled people to overcome the challenges of living with a disability. I applied to join MACS out of a sense of duty to the MACS members who deserve every opportunity to make their future as successful as possible. I intend to use my knowledge, skills and experience to this end.

How have you found the first few months of being in your new role?

It's been an exciting learning curve. Even though I had served in the Board of other disability organisations, the experience at MACS is very different. I attended the first Board meeting and was really captured by the spirit of

collegiality that reined in the meeting. The members were really very knowledgeable and very inquisitive. This is good for the organisation as it generates positive energy and candour as well as openness and accountability.

What would you like to see MACS achieve over the next few years. What do you look forward to the most?

I would like to see MACS become more inclusive in terms of its ability to reach out to other groups in the community. Currently, not many BAME families are engaging with MACS and enjoying the benefit of its services. I wish to see this situation changed in the next few years.

A large chunk of MACS service users are persons between the ages of 0-25 years, and I would like to work with MACS to develop a disability-focussed coaching and mentoring scheme to provide these children and teenagers with some skills on how to harness their education, skills and emotional intelligence to advance their career and self-development.

Finally, do you have a secret talent and if so, what is it?

Ah Ah..... secret talent? I am not certain I have a secret talent; any talent I may have is there in the public.



NAOMI BOWMAN

Please tell us a bit about yourself and your background.

I am a Partner at KPMG and I make complex transformation happen for global banks. I am also Mum to a very happy

2 year old boy - Elijah and wife to a sports mad medical lawyer - Mark. We live in Kent with our German Shepherd Dog and 5 rescue cats!

What made you want to become a trustee for MACS?

I was born with unilateral microphthalmia and optic nerve coloboma. I have almost no sight in my left eye. My husband and I have been supporters of MACS for a number of years and MACS has also been a great source of support to me and my family too - particularly in relation to gaining access to genetic testing.

How have you found the first few months of being in your new role?

I've really enjoyed it so far and am delighted to have been appointed to the Board of Trustees.

What would you like to see MACS achieve over the next few years?

I'd like to see MACS continue to grow and expand in order to support as many families as possible.

Finally, do you have a secret talent and if so, what is it?

My husband and I have played 50+ Escape Rooms around the world!



DR MARIYA MOOSAJEE

Please tell us a bit about yourself and your background.

I am a Clinician-Scientist, that means I spend half of my time as a Consultant Ophthalmologist seeing patients with genetic eye conditions like MAC in my clinics at Moorfields Eye Hospital and Great Ormond Street Hospital for Children; and the other half as a Professor of Molecular Ophthalmology researching eye development and related conditions in a science laboratory based at UCL Institute of Ophthalmology and the Francis Crick Institute, all based in London. I was awarded my PhD from Imperial College London, this was focused on understanding the genes that cause ocular coloboma and developing potential preventative therapies.

What made you want to become a trustee for MACS?

I have been a MACS medical advisor for a few years. Members of my team and I have attended the family weekend and just loved the experience. What struck me the first time I joined you back in 2017, was the positivity amongst members. I am committed to helping your community and when I saw this opportunity, I jumped at the chance to be involved. I feel I have a lot to offer from a medical and MACs-focused research background, especially as I look after a large number of families and can empathise with their emotional journey.

How have you found the first few months of being in your new role?

I have always been active in raising MACS awareness amongst professionals and the public, and I spent a few weeks over the lockdown offering "Ask the expert sessions," to our members. So there hasn't been much change in my energy and commitment since starting this role.

What would you like to see MACS achieve over the next few years

I think it's really important that we extend our reach to all families

with children affected by MAC conditions. I see a lot in my clinics who do not get in touch with the charity despite being given the information and contact details. MACS has invested work into issues around the diversity of its members, and I hope we can see a shift in the representation of those from various ethnic backgrounds in the future. This may require a different approach or strategy, which I am happy to help with. I think it's also important to identify new dynamic researchers across the UK committed to advancing our understanding of MAC conditions and forming a scientific board/panel to guide the direction of research priorities informed by our members.

What do you look forward to the most?

A cup of strong sweet tea at the end of the day and my favourite soap opera/reality tv show- I watch a lot of trashy tv!

Finally, do you have a secret talent and if so, what is it?

I love art, I'm a secret oil painter. I don't have much time for it at present- with work, my 7 year old twins and all the extras I do, but I used to sell my paintings for a fair price in the past!



Goodbye to Lindsay

WE WERE so sorry to see Lindsay leave her role as Fundraising Manager at the end of March. Lindsay had been with MACS for 2 years and brought a wealth of experience to help us develop our fundraising. Lindsay helped us grow our existing income streams and identified new ones, all which will stand us in good stead for the future. We will all miss her and wish her well in her new job!



VIRTUAL EVENTS

A series of virtual meetings & events for our members



ALONG with our Family Day we have held daily and weekly virtual events and will continue to hold for the foreseeable. These meetings have been invaluable for our members. They have helped members to reduce isolation, meet new people, and build confidence. All our virtual events are held on Zoom.

COFFEE BREAKS

Throughout lockdown, we held daily afternoon catch-up calls for all our members to share how they were feeling and just for a general natter. These calls are now held twice a week on Monday and Wednesday.

"Thank you to all the staff and trustees for all your hard work and bringing us all together throughout this difficult time. All the virtual events have really helped me to keep in contact with everyone and have some form of normality."

QUIZZES

During lockdown we held weekly quizzes which proved so popular we have continued them on a fortnightly basis. The quiz is held on alternate Saturdays at 8pm and is hosted by different MACS families each week. They are a lot of fun so please feel free to join us at any time. Or, if you have a burning desire to be the MACS quiz master for a week, please get in touch with Sharon (sharon@macs.org.uk) who will be happy to support you!

CREATIVE WRITING WORKSHOP

Hosted by MACS member Megan Paul, members can let their creative juices flow with this writing workshop. Focusing on different themes each week, you can learn more about writing

styles and see where your creativity takes you. These sessions are held at 6:15pm on alternate Tuesdays.

NEW MEMBERS' MEETINGS

Held on the first Saturday of each month at 4pm. This session is a chance for new members to meet up in a relaxed and informal way to discuss life with MACS conditions. This is a welcoming place for new members meet new people and gain peer-to-peer support, to express their concerns and share experiences. .

ADULTS AND SIBLINGS

Held on the last Wednesday of the month at 8pm. This is an opportunity for MACS adults and siblings to chat, connect with friends you may have lost touch with and to make new friends in the MACS community.

JACK'S SIGN SESSIONS

MACS member Jack has been holding sign sessions for members on a weekly basis at 11am Saturday morning. He teaches basic sign language, discussing signs such as alphabet, introductions, camping and nights out.

We are hoping to expand our sessions, including How To sessions, challenges, interests, and hobbies. If you have an idea you would like to share for a session, please get in touch!

"Thank you for bringing MACS closer through the virtual events such as the afternoon chats and quizzes. They've really helped my confidence in talking about my eye conditions, problems in education and a lot more. Roll on more of the MACS virtual events."



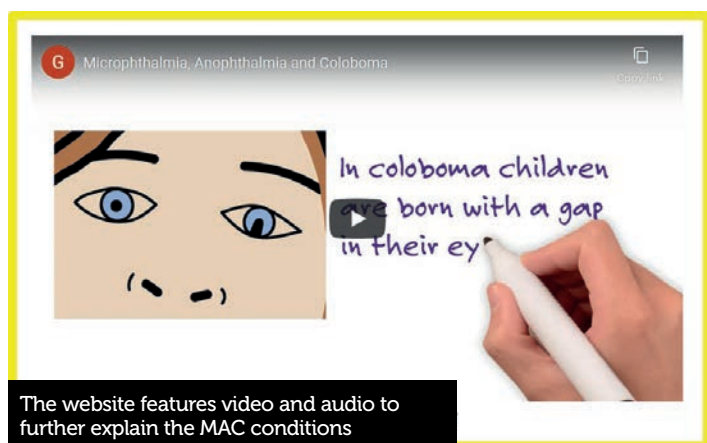
A fully accessible website on the A-Z of genetic eye disorders

OVER the past year, Professor Mariya Moosajee has been developing an accessible and mobile friendly website called Gene.Vision. This is an A-Z on genetic eye conditions, including information on MAC conditions, with the appropriate management pathways and latest research.

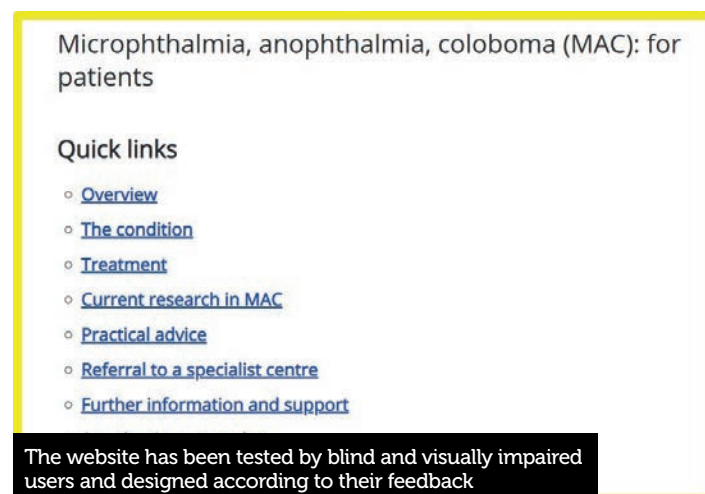
Her idea came from countless conversations with families struggling to find the information they needed on their condition, including the appropriate care pathways, latest research and accessing social support. Often patients would report never receiving an explanation on what their rare disease was and how it was caused.

She has held patient focus groups to ensure that both health care professionals and sight-impaired individuals could trial the website and comment on its usability. In addition, two professional digital accessibility consultants have reviewed the website. MACS has reviewed the content related to our conditions, ensuring the content is understandable and up to date.

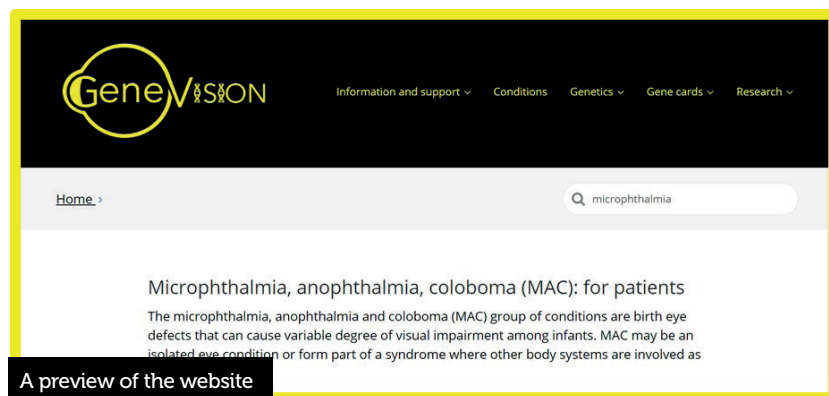
www.gene.vision was launched on 1st December 2020. Please do log on as it should be a great resource. You will also have the chance to register your interest for receiving updates on your condition and participating in research.



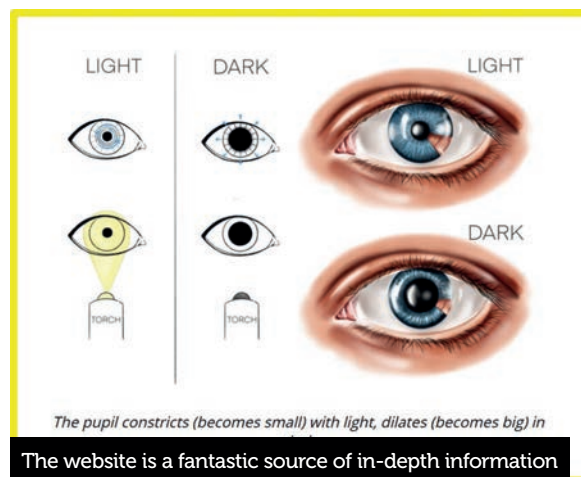
The website features video and audio to further explain the MAC conditions



The website has been tested by blind and visually impaired users and designed according to their feedback



A preview of the website



The pupil constricts (becomes small) with light, dilates (becomes big) in

The website is a fantastic source of in-depth information

MACS Services 2021

Join us online or at an event near you

WE ARE pleased to confirm that all virtual events outlined in the previous section will continue throughout 2021, while face-to-face events will resume as soon as it is safe to do so.

You can find an up-to-date schedule of our online events on our website:

<https://macs.org.uk/coronavirus-information-and-support/macs-virtual-meet-ups/>

Our virtual meetings are there for you to meet and keep in touch with others who are in a similar situation, with similar experiences and are a very supportive space. They are completely free to attend.



OTHER SERVICES

FAMILY WEEKEND

As Robbie said in his introduction, regrettably we have had to cancel our usual Family Weekend for 2021. However, we will be holding our Annual General Meeting (AGM) and another Family Day online in early May.

ACTIVITY BREAKS

Subject to Covid-19 restrictions, we hope to run our activity breaks (Calvert & Sailing) for younger members as usual in July and August. Members will be able to register their interest in attending these activities when booking opens in January and we hope to be able to confirm they will go ahead by April.

RESPIRE BREAKS (MACS CARAVANS)

We know that our MACS members are more in need of respite breaks than ever before. We are therefore prioritising our limited resources to provide access to respite breaks for more MACS families during 2021. We will publish more details shortly.

LOCAL SOCIALS

During 2021 we will be piloting a number of new local groups led by MACS members. Seed funding from MACS will be available to help these groups grow to provide much needed peer support and friendship in your local area. If you would like to get involved or simply find out about groups in your area, please contact Sharon at: sharon@macs.org.uk



MACS MEETS

MACS Meets is the new name for our regional events. We are hopeful that, subject to Covid-19 restrictions, we can restart our face-to-face regional activities from the summer with events taking place, where possible, in all four countries. We will be in touch in early 2021 with more information.

CALENDAR

When	Time	What	Who	Where
Throughout the Year				
Every Monday & Wednesday	2pm	Afternoon tea break	MACS Members	Online
First Saturday of the Month	4pm	New Members	Members who have joined MACS in the last 12 months	Online
Last Wednesday of the month	8pm	Adults and Siblings Group	Adults with MACS conditions or adult siblings	Online
First and third Saturday of the month	8pm	MACS Quiz Night	Everyone	Online
May				
1st May	9am	MACS Annual General Meeting	MACS Members	Online
1st - 3rd May		MACS Family Weekend	Everyone	Online
 				
July				
24th - 31st July		Sailing Trip	MACS young people & siblings	Brixham, Devon
31st July - 1 August		Calvert Residential Activity Break	MACS under 10s and Parent	Lake District
August				
1st - 6th August		Calvert Residential Activity Break	Over 10s	Lake District
August - December				
TBC		MACS Meets		Various





Awareness Week

The second MACS Awareness Week took place in July and was a great success. Over the course of the week, with your help, we flooded social media with some of your fantastic stories raising awareness of MACS and sharing your lived experiences with the public. Our campaign reached over 31,000 people and raised £3,450 to fund our future work. We would like to say a huge thank you to all the members for getting involved and helping us raise the profile of MACS.

A few of your inspiring stories are included over the next few pages, and even more stories can be found on our website here: <https://macs.org.uk/macs-awareness-week-2020>. You can also view the original videos on our website, the MACS YouTube channel and social media video library.

Ryan

"When your child is diagnosed with a visual impairment you have no idea what is possible. You don't know where to look for support, you don't know about technologies and services that can help. The young people are hampered by others' low expectations of their abilities. MACS is changing that for me and for Ryan and we are infinitely grateful for that."

RYAN is 13 and has bilateral coloboma. He also has a variety of other visual impairments, both ocular and cortical and therefore has significantly reduced vision. Ryan also has both learning and physical disabilities.

When Ryan was little it wasn't at all clear how he might develop. He didn't speak until he was nearly four and didn't walk till after his fifth birthday. He still used a frame or wheelchair to walk distances up until the age of about 10. It was always very clear he couldn't see well, because he always trips and falls and bumps into things, but we only really got an accurate picture of his vision when he was older.

Despite Ryan's difficulties, he has always worked really hard at everything. He attends a Learning Base within a mainstream secondary school. He particularly likes PE, cooking and Maths. He has always loved sports, but it's been really difficult to find things he can access locally because



Ryan Skiing



we live in a rural area and there isn't much accessible for people with significant sight impairment. He took up carriage driving when he was six and has competed all over the UK in competitions for people with additional needs. He loves driving fast, which can be a bit scary to watch!

When Ryan was ten we went sledging at a ski centre in Glasgow. Ryan saw people skiing and was desperate to try. I thought it was unrealistic as he can barely stand up on solid ground, but eventually we found out there was a branch of Disability SnowSport UK attached to the ski centre and we bought Ryan a couple of lessons for his 11th birthday. Little did we know where this would lead! Ryan loves skiing! He took to it straight away and with many many hours of hard work with his instructor he actually started to look the business. In 2019 we found out there was a small Special Olympics skiing club about 40 miles away from us and we took Ryan along for a trial. The team needed another member to compete and Ryan was keen to give it a try. The next thing I know it's 8 hour round trips to Lancashire for training and competitions!

Later last year Ryan was selected to represent Dumfries and Galloway at the Special Olympics GB National Alpine Skiing Championships in Switzerland! This was the chance of a lifetime for Ryan so we decided to accept and set about raising £10,000 to send the team. Every ounce of that hard work was worth it when Ryan skied into Gold Medal position in the Slalom and Giant Slalom in the Novice Class. He has now applied for Team GB for the World Winter Games!

"This was the chance of a lifetime for Ryan so we decided to accept and set about raising £10,000 to send the team. Every ounce of that hard work was worth it when Ryan skied into Gold Medal position in the Slalom and Giant Slalom in the Novice Class. He has now applied for Team GB for the World Winter Games!"

Ryan and I would like to say a massive thank you to MACS for helping Ryan with grant funding so that he could achieve his dream. We could not have made it to Switzerland without their kind donation and their faith in Ryan to succeed.

Despite Ryan being diagnosed with colobomas as an infant, we were simply told they were cosmetic and not a problem and sent away. We had no more information and no idea that there was a charity that could help us! We only found MACS last year when Ryan was almost 13 years old. We have been so glad to find the charity. We've been able to learn a lot about colobomas and meet lots of other families and young people who are affected. MACS has been really welcoming to us and although many activities have had to be cancelled this year due to COVID-19, MACS have created lots of online resources and support for us to use.

The most positive thing for us about being involved with MACS is meeting so many people living with visual impairments who have achieved so much in life. When your child is diagnosed with a visual impairment and you have limited experience with it, you have no idea what is possible. You don't know where to look for support, you don't know about technologies and services that can help. The young people often don't see others with the same difficulties and are hampered by others' low expectations of their abilities. MACS is changing that for me and for Ryan and we are infinitely grateful for that. Like any other teenager, Ryan needs role models to look up to, so he can be confident in saying **YES I CAN.**



Connor



Dreaming of becoming a skydiver!

MY NAME is Connor and I was born with Keyhole Coloboma in my right eye, meaning total blindness on my right side. Although I don't feel like it has held me back, it has certainly altered my perception of the world, and the way I have forged my path through it. I have decided to write this piece in the hope that I can offer some wisdom and encouragement to others with similar conditions.

Although I was too young to remember, my parents explained to me how upsetting it was for them when my diagnosis was made. Like all parents in their situation, they worried about how it might affect my chance to live a normal life and what limitations it would place on me. So this article is also for the parents out there who may be

worrying about what the future holds. You're doing great, trust me!

Although I was too young to remember, my parents explained to me how upsetting it was for them when my diagnosis was made. Like all parents in their situation, they worried about how it might affect my chance to live a normal life and what limitations it would place on me.

As I grew up and attended school, there were obviously questions about my eye from many of the other children; sometimes thoughtful, sometimes mean. It took me a little while to adapt to the natural curiosity that others had about my condition, but support from my family and friends helped me to develop ways of coping with this. Gradually, I came to realise that each of us is different, and each of us has something that sets us apart from the crowd. There will always be those who use others' differences to pull themselves up, to make themselves feel better. But, as difficult as it was, I stopped seeing my eye as a defect to be ashamed of, and began to realise that it was part of my identity. It makes me who I am. As I grew more comfortable with it, I realised there was power in self-deprecation. The jokes I've made about my eye are far funnier than anything I've heard anyone else say, and have often helped to make others more comfortable around me.

Gradually, I came to realise that each of us is different, and each of us has something that sets us apart from the crowd. There will always be those who use others' differences to pull themselves up, to make themselves feel better. But, as difficult as it was, I stopped seeing my eye as a defect to be ashamed of, and began to realise that it was part of my identity. It makes me who I am.

Later in my childhood, I began to worry less about the opinions of people around me and instead my attention turned to the physical limitations that my eyesight would place on the activities I wanted to take part in. Would I be

able to drive? How much independence would I have? From quite a young age, I dreamed of flying, and naturally wanted to grow up to be a pilot, just like my uncle. Unfortunately, this was one of the few jobs that wouldn't be possible for me to pursue. However, this would later turn out to be a blessing in disguise, and eventually turned me down the path of my chosen lifestyle. I was able to get my driving license, and have enjoyed the freedom of travelling - including a period driving around Europe living in a campervan. However, I kinda miss being chauffeured around all the time, as it's far more relaxing!

One of the less obvious effects of having only one functioning eye to view the world, is the effect on depth perception. People with two functioning eyes are able to create a 3-dimensional picture of the world



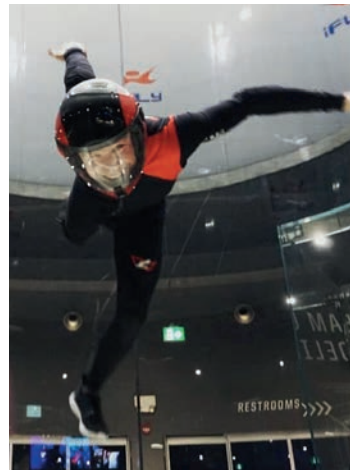
Connor at the International diving competition in Barcelona



as their brains stitch together the two images to assess how far away an object is. That is not something I'm able to do very well, so definitely never ask me to pour you a drink, unless you want it going all over the table! However, my brain has adapted to this, and I have found that whenever I am moving, I am able to use parallax from one moving eye, to create a 3D image. This has subtly led to me pursuing sports and activities to involve as much motion as possible.

I began training in gymnastics when I was 10 years old, and it taught me a great deal about my body and how to move it within a given environment. Then, when I was 14, I switched to diving. I found the split second that I was in freefall from the 10m platform was the closest thing I had ever felt to flying and I couldn't get enough! The high speed motion and rotation meant that visually, I was able to level the playing field and compete alongside my peers. I loved that sport, but as I left home to study engineering at the University of Southampton, I discovered a whole different passion: Skydiving.

I had dreamt of skydiving ever since I had watched my Dad do a jump for his birthday when I was 4. But I had never truly considered it as a sport until I joined the club at university in 2013. From that moment on, I was hooked. It was like every dream I had of flying as a kid; the freedom, the speed, the excitement. And my condition became less and less of a consideration. Eventually, I realised that I had found my calling in life. After having gained my Masters degree, I began to work full time in both outdoor skydiving, and indoor skydiving as an instructor and coach.



I was able to use my experience in gymnastics and diving to excel, and in 2019 I became the UK National Champion for Indoor Freestyle flying. After this, I was selected to represent Team GB at the World Championships in 2020.

Having Keyhole Coloboma has certainly had an impact on my life, but I can say with confidence that I wouldn't change a thing. It has opened my eyes (metaphorically speaking!) to a different path that has bought me so much joy and new experiences I never even thought possible. I now travel all over the world with my friends, teaching others the joy of human flight, and without my condition, I don't know if I would be where I am today.

Having Keyhole Coloboma has certainly had an impact on my life, but I can say with confidence that I wouldn't change a thing. It has opened my eyes (metaphorically speaking!) to a different path that has bought me so much joy and new experiences I never even thought possible. I now travel all over the world with my friends, teaching others the joy of human flight, and without my condition, I don't know if I would be where I am today.

It has been good to know that MACS has always been there to offer my family and I assistance at every turn should we need it. The work they do every day helps to ensure that families like mine have the support they need, and that every child with these conditions has every resource available to live their life to the fullest.

I, for one, am certainly doing that!

Mini MACS Goes on Tour

As part of the MACS Awareness Week, the mini-me version of our beloved mascot MACS the Monkey, went on tour around the UK to raise awareness of MACS in all corners of the country.



Thanks so much to all of our members and supporters for taking part in the MACS Awareness Week. Together, we've raised the profile of our small charity and raised some much-needed funds for MACS. Until next year!

Congratulations to Megan on becoming a MACS...

Ambassador



Megan's blog can be found at <https://macs.org.uk/macs-blog/> with new posts added monthly.

Would you like to share your writing or creative talents to help promote MACS? We always welcome any contributions from members. Whether you'd like to share your story, write an article for the website or shoot a video, we would love to have you on board to help us raise awareness of MACS! Any ideas are welcome. If you are tempted, please contact our communications officer Kaja at kaja@macs.org.uk.

WITHIN the last few months, I've been awarded my ambassador title! First of all, I'd like to thank MACS for giving me this opportunity and I hope to do the job with diligence and pride.

The ambassadorship is a big opportunity for me since 10 years ago I never could have imagined I'd be in a place mentally to actually handle talking about my MACS condition but I'm here and it's thanks to MACS for encouraging me and letting me grow. The positive attention I get from MACS staff, members, trustees and in fact some strangers really has done me the world of good. It has helped me turn my feelings about my condition full circle, making me a positive role model and a face of MACS rather than a lonely child with nobody to talk to. I've been writing a monthly blog for MACS and have found it quite therapeutic. Even though it can be a struggle to put down in words my troubled past I take solace in the fact it helps others. I have no qualms about people reading what happened to me, though some might find it over sharing, but if my words can help someone in the same position at the same age and avoid the pain I was in, then I've done my job and I can lay in my bed at night sleeping soundly knowing I've made a speck of a difference in someone's life.

I recently took part in the virtual Prudential Ride London challenge! Incidentally I had bought a bike about a week before I saw

the challenge on Facebook, my first thought was I'll kill two birds with one stone, I can do my bit for MACS and raise a bit of money and then I've got no excuse not to ride my bike! It's only 100 miles, I used to do that all the time when I was a kid! Then reality kicked in and I realised I'm 28 with my knees practically crippled with laying floors and my lungs are near enough made of concrete from breathing tile dust in for the last 10 years! But as I got closer and closer to my goal it got easier, I hit my donation target fairly early which spurred me on. My fitness got better bit by bit and by the end of it I was flying and doing ten miles was literally nothing but enjoyable!

One thing I will say to folk who want to try and do this sort of things themselves...for the love of God get a good bike and not a cheapy one like I did! (face palm).



Growing up with a MACS condition

by a MACS member Ella

I, I'm Ella, a 21-year-old Postgraduate student from East Anglia and I have Microphthalmia in my right eye. **Throughout my life I was told that I wouldn't be able to do things because of my eye and no one other than my parents encouraged me to try. This is my story of how I proved them all wrong!**

MY DIAGNOSIS AS A BABY AND FINDING MACS

I was diagnosed with Microphthalmia when I was 6 weeks old at my local hospital, though medical staff had suspected as much when I was 11 days old, yet didn't think this was something my parents needed to know at the time. From 6 months old I would begin to go to Great Ormond Street Hospital and Moorfields Eye Hospital in London at least once a year, sometimes a lot more, until I was 16. Talking to my parents now when they heard the news of my eye condition, they wanted to get as

much information as they could so they were as informed as possible on what my life could look like. The information they found didn't give them much hope. In 1999 the only articles they could find came from America and suggested that the eye was removed.

Fearing the unknown and not knowing what was instore for their new-born daughter and our family, we found MACS. It was through MACS that we were exposed to this new side of Microphthalmia and what it meant to me. A side with hope.

We met wonderful people who were just like me and found an amazing comfort in Dr Nicola Ragge who helped us to understand the medical side of Microphthalmia. We found that I had one of the mildest cases in the country at the time and the size difference between my eyes was not too severe but still required me to wear a prosthetic shell, and so we began that process.

notice that my right eyebrow seemed to be a little lower than my left and so began the process all over again, though this time I had an end date of when I didn't need to wear it anymore. I stopped growing at the age of 15 and one long year after that I was allowed to stop wearing my shell and that is exactly what I did. I have not worn my shell in over 5 years and have not been to Moorfields since I was 17 and have been discharged from their care. Yes, I am aware that this is not common at all, but it is how I feel most comfortable and since I do not wear my shell, I do not need to see the amazing staff at Moorfields. (Don't worry, I was discharged on the basis that I go to my opticians every 12 months and am currently being seen by surgeons at Addenbrook's hospital in Cambridge who check my eye health at every visit) I felt that it was important to remember that a shell was not only for medical purposes but aesthetic purposes too, and once those medical reasons were no longer there, along with my doctors approval I chose to stop wearing my shell altogether.

MY JOURNEY WITH A PROSTHETIC SHELL

Throughout my years wearing a shell there were many ups and downs. My face was very symmetrical when I was little, though they understood that I would need to wear a shell every day to encourage skeletal growth to remain this way. Though by the age of 8 or 9 they changed their mind and said I did not need to wear one if I did not want to. I jumped at this opportunity as I hated putting it in! This soon changed as just 3 years later they would

Thinking back I believe one of the reasons I stopped wearing it is because I didn't like how it made me feel, as well as the fact that I didn't recognise myself with it in when I looked in the mirror. I have light perception in my right eye and having that blocked out made me kind of uneasy. I am definitely more aware of that now then I was at the time. When I was young I hated flash photography because it gave me bright floaters and just made me feel uneasy, little did I know that this was because light was entering my right eye and stimulating a part of my brain that can go weeks without doing anything. Now, when light enters my eye it gives me something my mother and I call 'happy brain' and that is the only way



Ella now with her cat Alfie



Ella at 5 months

I know how to explain it. It makes my brain feel happy because it is getting that stimulation it doesn't normally ever have.

SECONDARY SCHOOL

During my primary and secondary school my mother fought tooth and nail for me to be treated like the other students and for them to overlook my condition, though this proved hard. Between taking me out of school for doctors appointments and a surgery when I was in year 3 and random visits by health workers at the school, it seemed to feel that they didn't think I belonged in their mainstream school, despite at the time not knowing I had any other issues that would cause them to think this. During year 9 I was found to have dyslexia and what they called 'a gap in my early years education', later when my parents would bump into my old teachers they would tell them this and they all replied with the same statement, 'I thought so', though never thought to help me. 3 years later this would be confirmed again officially, and I was also diagnosed with Dyspraxia tendencies. When it came to looking at our next steps after high school, everyone from my year was invited to go look around the local sixth form. Everyone except for 3 people. I was one. The school had come to the conclusion that I didn't need to be thinking about doing



Ella at 2 years old

A-levels or anything like that and I should be thinking about a vocational course. **They took away my option to choose my future for myself. So, I took it back.** I left high school with 7 GCSE's including English and Maths and went to sixth form where I did 3 A-levels and left with an unconditional offer to do a degree in Philosophy at Anglia Ruskin which I completed and am now working on my MA in History.

"I am planning on having the most 'normal' life possible! But my version of normal. Pushing boundaries, making my own limits and having a fun life with my partner and our families"

Throughout my life there have always been adults telling me that I wouldn't be able to do something because of my eye, and wouldn't even let me try to see if I could. All of those horrid

thoughts that I wouldn't be able to have a 'normal' life and that I would need to be in my parents' care all my life. I am sure many of you have heard the same about your child and I want you to know that it isn't going to be like following a macabre textbook. I went to mainstream schools all my life. (Did it suck? Of course, it's high school.) I passed my driving test when I was 17 with no provisions and I love driving. (I hate parallel parking with a vengeance!).

I have a degree in Philosophy and I am doing a Masters in History! (Yes I know I said I would never go back to education but it's like when you have a bad hang over and say you'll never drink again). I worked from the age of 16 to help me be independent and I have lived away from my family home for 4 years. I am planning on having the most 'normal' life possible! But my version of normal. Pushing boundaries, making my own limits and having a fun life with my partner and our families.

You or your child could have the life everyone is telling you you'll never have and push all the limits they place in front of you. You make your life how you want because you are the one who has to live it. I know I would have never had the confidence to be where I am today if it was for MACS and the support they gave me and my parents!



Apart but Together

The Ru Riders

1400 miles for MACS inspired by boy with Microphthalmia

THIS YEAR has been a very different year for us all but in the midst of the uncertainty my friend Jen pulled together a team of 25 willing cyclists to take part in a 100-mile challenge. Our team members ranged from 4 years to 40 something years and collectively cycled a total of 1400 miles across the UK in Aberdeenshire, Perthshire, Barra & Vatersay, Islay, Glasgow, Isle of Man, Lincoln, and London raising £2000 for MACs. I am not sure any of us realised at the start what we could achieve and how much we needed to do this.

Back in May, Jen mentioned that she was finding it hard to get on her bike during lockdown so I asked if the 100-mile challenge for MACs might be a good enough reason. As I had hoped, Jen was immediately on-board with the idea and went about recruiting not only members of her family but friends from around the UK to become members of The Ru Riders.

The boy behind the name is my son, Ru. He is a 2-year-old golden-haired boy born with Microphthalmia in both eyes – we are one of those families who have been told their child will never see. Back in 2018, the news that my 6-week old son was blind was a truly heart-breaking experience. Battling through the

grief, I picked myself up because Ru and my husband needed me and in time, I realised the grief was only ours (that is mine and my husbands but that is a story for another day) and I felt the joy in being Ru's mum.

So much joy comes from being a family, from marvelling at how our son learns, how he finds fun in the little things and in watching his interactions with those who selflessly support us. I want to thank those friends and family, the team members and our supporters with a special thank you to Jen for bringing us all together this summer. It is not easy to reach out or accept kindness when you are a 'determined do it yourself' type of person. I was honestly overwhelmed by friends and the friends-of-friends who took part in this challenge and by those who kindly donated to a charity they'd only learned about through my son. A person wiser than I once said at the start of our journey with Ru 'the best thing you can do for yourself and others is to let them help you'.

And so, in MACS Awareness Week we launched our challenge and the cycling began across the UK – some braving the winds of the Inner and Outer Hebrides, the rain of Perthshire and the heatwave in England. Our group updated and encouraged each other through messages on the WhatsApp group, photos, and Strava. The weekly 'Sat Stats' was born as we counted down the miles from 100 to 0. What started as a proposed virtual challenge became a real cycle around various cities, towns and some of the most remote and beautiful parts of the UK; familiar home territories or exploring somewhere new during a 'Staycation', apart from one Aberdeen teenager who clocked nearly all of his miles virtually locked in his garage! For some of us the miles were counted as a family giving them a goal over the





Getting out of Glasgow City and into the countryside. Our Ru Riders leader Jen spurred on by her MACS t-shirt.



These pals have waited until deadline weekend to pedal their way from zero to 100 miles and even further... Immense effort lads!



Our Aberdeen teenager released from his garage to explore the island of Islay



In the Isle of Man, Mum and Dad were struggling to keep up with the dedication of the 'Little Legs'



Fantastic maiden pedal on Barra - A trio of heroes



Well deserved smiles on finishing a full circuit of the island of Barra

school holidays and for others, the slightly fitter members, the 100-miles were simply blasted in one day. But it wasn't just the adults who got the miles in we had little legs cycling it out too in the Isle of Man, Lincoln and Glasgow.

So why did my friends say YES to Jen?

"Our primary motivation was our love for Ru! In a difficult situation it was something we could do that hopefully he will benefit from. But once we had started it gave us a summer focus when usually we'd discuss holidays with people, instead we'd talk about what we'd been doing, then say 'we'll send you a link, you can sponsor us!' I enjoyed the team spirit in times of disconnection. This spirit was so encouraging although it was tough at the beginning to keep going with 80 miles to go!!! But as we neared the end the sense of achievement that our cycling had raised money for this worthy cause was hugely satisfying."

"Our friendship with Ru's mum Lynsey has always had 'apart but together' at its heart as she moved from place



Our youngest rider about to join the rest of the Glasgow Team for the end of cycle socially distanced celebrations - Well Done Ru Riders!

to place over the years. Having this as our motivation to support a charity Ru, his Mum and Dad had stumbled on by chance (or maybe serendipity) meant that this challenge has brought us a practical and at times emotional means to support our good friends Lynsey, Jules and of course our handsome Ru"

We are a new MACS family and took part in our first MACS Family Day this year. I took comfort from knowing that

other families like us are out there. That Ru will get to know others like himself. Difference can be seen by some as frightening. Community is important. Feeling accepted and welcomed for difference will have a huge impact on his self-esteem. My hope for the future is that as a society we can continue to learn to accept and support each other and our differences. Sat in the park it can feel like you are the only family whose child is not running around like his sighted peers but we are not alone. I know that MACS will help us through the difficult times ahead.

It has been a huge accomplishment for us all not only in terms of raising money and awareness of MACS, but the physical challenge of getting on our bikes no matter the weather. Probably most importantly, was the opportunity to strengthen our friendship at such a difficult time. I know Auntie Jen can't wait to tell Ru all about the time we cycled Apart but Together for MACS.

Lynsey



@macsthecharity



facebook.com/MACSCharity

Well Done

A huge well done and thank you to Ru Riders and all of our amazing fundraisers who have taken on virtual events, challenges and fundraisers this year.



Huge thanks to all of our **virtual marathoners**, who completed the MACS Virtual Marathon organised in place of the cancelled London Marathon on 26th April this year. Despite the disappointment of having their event called off, the team showed some amazing spirit and raised £5,000 for MACS!

2.6 Challenge

On 26h April, the original date of the London Marathon, we participated in the 2.6 challenge – a nationwide campaign to fill the gap created by the cancelled marathon and raise some much needed funds for charities all over the UK. Pictured below are our fantastic fundraisers Sarah and Stephen.



Fast forward to October, and the London Marathon 2020 would now be held as a virtual event. The runners would complete the 26.2 miles of the event in their local areas while tracking the distance using a specially designed app. We had over 100 runners representing MACS in all corners of the country and abroad, raising an incredible £18,000!



Get Involved

Inspired? Why not take on your own challenge for MACS. We have a variety of virtual events, running and challenge events, skydiving and more!



The Everest Challenge

Climb 8,848m in 12 weeks

Have you ever wanted to climb Mount Everest, the highest point on Earth? That sounds great but is also very dangerous, expensive and difficult to do in line with social distancing! But we have a solution – can you climb the equivalent of Mount Everest in 12 weeks? In this challenge, you can go out to the hills on your daily exercise or simply tackle the stairs a couple of times every day....achieve 8,848m of elevation gain before the end isolation, and this well-earned medal can be yours!

More events can be found on our website here:
<https://macs.org.uk/want-to-help/fundraise-for-us/virtual-challenge-events>

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'd love to hear from you!

SKYLINE • E V E N T S •

Skydive for MACS!

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

Our preferred skydive provider, Skyline, offers tandem skydives at over 20 airfields across the UK and a variety of dates throughout the year - so there is a skydive to suit everyone.

To take part in a charity tandem skydive, all you need to do is pay a £70 registration fee (to Skyline) and raise a minimum of £395* for MACS. In return, we will pay for your jump and training.

**Please note that some airfields require a higher sponsorship level of £450.*

To book your tandem and for more information, please see here: <https://macs.org.uk/want-to-help/fundraise-for-us/skydive-for-macs/>

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 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: <https://www.easyfundraising.org.uk/causes/macskidseyecharity/>

Play the MACS Lottery

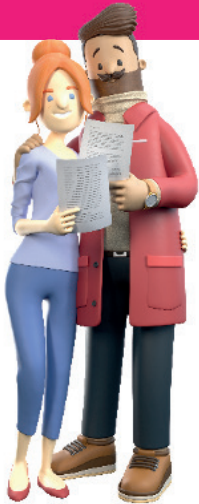


Do you fancy winning up to £25,000 whilst supporting MACS?

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: <https://macs.org.uk/want-to-help/weekly-lottery/>

Other ways to get involved



Leave a gift in your will

A gift in your Will could be one of the most important contributions you make to a cause you care about. It allows you to leave a lasting legacy and help MACS support all the children, adults and families who'll need us in the future.

MACS has partnered with Beyond to offer our supporters an online Will for free (RRP from £90.00). It is a quick and simple process which allows you to write a legally binding Will from the comfort of your home in as little as 15 minutes. Intrigued? Please visit our page here for more information:

<https://macs.org.uk/want-to-help/leave-a-gift-in-your-will/>



Support via your workplace

Could the company you work for nominate MACS as its Charity of the Year? There are so many ways in which businesses large or small can make a difference to MACS.

- 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 or activity weekend
- Promote MACS within your payroll giving scheme
- Donate gifts in kind

There are so many benefits of supporting a charity through your company. Fundraising in the workplace offers the staff members fun team building opportunities while at the same time 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 love to chat about how we could work in partnership.



Would you rather not receive the magazine?

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.



@macsthecharity



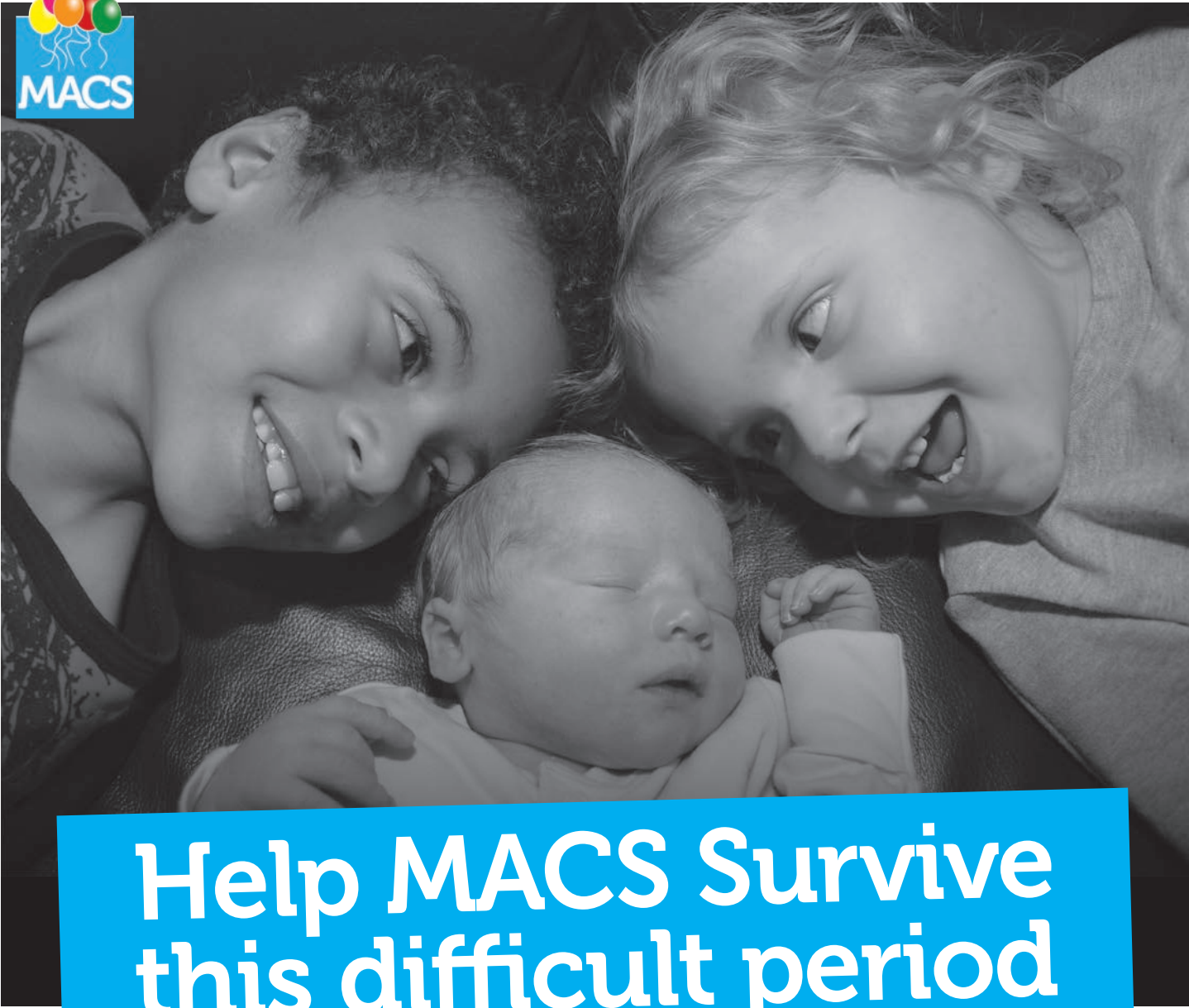
facebook.com/MACSCharity

Running, Challenge and Sporting events

As we are all eagerly awaiting the end of the pandemic, we now have a number of sporting events with places available. Marathons, half marathons, obstacle and mud events, as well as a wide range of distances of local events which you can browse by region. Head over to our website to see what we have an offer, and if anything looks appealing, you can secure your place with a few clicks of a button.

<https://macs.org.uk/want-to-help/fundraise-for-us/running-events-for-macs/>





Help MACS Survive this difficult period

2020 has been a year that none of us could have imagined. The cancellation of fundraising events and a loss of income leaves our small charity in a worrying position. We now need to ask our friends to donate to ensure that MACS can survive this difficult period and be there for future generations of MACS families.

This is the biggest crisis MACS has ever encountered and we must now ask for your support to ensure MACS can get through this tough period and be there for future generations of MACS.

We understand the times are tough for everyone and appreciate gifts of any size. If you'd like to invest in the future of MACS and donate, you can use the page overleaf or donate online at:

www.macs.org.uk/help-macs-survive

Yes, I want to help MACS survive

To donate online please visit www.macs.org.uk/help-macs-survive
Or use our QR code to donate securely



To donate via cheque please fill in this form and return to us to our registered charity address as specified below

I would like to give £..... and enclose a cheque made payable to MACS.

As a supporter we are currently writing to you by post no more than four times per year,
if you would rather not hear from us again, please tick below:

☐ I no longer wish to hear from you by post

☐ I would like to hear from you by email, and my email address is:.....

giftaid it

MACS can claim 25p of Gift Aid for every £1 you donate. Gift Aid is reclaimed by MACS from the tax you pay for the current tax year. Your address (overleaf) will be used to identify you as a current UK tax payer.

In order to Gift Aid your donation please tick, sign and date below:

☐ I want to Gift Aid my donation of £..... and any donations I make in the future or have made in the past 4 years to MACS. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Please notify MACS if you: want to cancel this declaration, change your name or home address or no longer pay sufficient tax on your income and/or capital gains.

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

If you pay Income Tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self-Assessment tax return or ask HM Revenue and Customs to adjust your tax code.

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.

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



facebook.com/MACSCharity

Registered Postal Address: MACS Charity, Reference 945998, 71-75 Shelton Street, Covent Garden, London WC2H 9JQ
Registered charity number: 1161897

