

Focus

*Issue 4
Autumn/Winter 2015*



Chair's foreword

Welcome to the latest issue of *Focus*, and my first as interim-chair of the charity.

2015 has been yet another year of change and development for MACS with our plans to change from a Registered Charity to a Charitable Incorporated Organisation finally coming to fruition.

We are officially now a new legal entity called *Microphthalmia, Anophthalmia and Coloboma Support*. Of course, we will remain known as MACS and our clear focus on providing support to children, young people, and adults with MACS conditions, will continue.

This is a relatively straightforward legal change, and as such, we plan to keep things low key. There will be a period of transition while the 'old' MACS is officially wound up (to take place at the 2016 AGM) and we fully embrace the 'new', but we hope that any disruption will be minimal. Behind the scenes, we are using this opportunity to review and develop our working policies, practices and overall strategy going forward.

Earlier this autumn, the committee was sad to say goodbye to MACS trustee Suzanne Hiley, who stepped down in order to focus on other commitments. The whole MACS team thanks her for her contributions and wishes her well for the future.

By now, you'll also be aware that in November, Barry Stickings stepped down as Chair of MACS. Barry has been a key driver at MACS for many years and, under his direction, the charity has gone from strength to strength. I'd like to personally thank him for his input over the years and officially welcome him to his new role as patron of MACS. I will serve as interim-chair until the 2016 AGM at Park Hall Hotel where you, the members, will have a chance to vote on the position of Chair. Please don't forget that the booking procedure for the Family Weekend has now opened and you are all invited to attend from Friday 29 April to Monday 2 May. I hope to see as many of you there as possible.

On behalf of the trustees, I wish you all a wonderful festive season!

Robbie Crow

Robbie Crow
Chair



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Please get in touch with any queries.



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New member gallery

The team at *Focus* would like you to meet some young members who have joined MACS since the last issue.

Lucy is 6 years old and has bilateral coloboma. She lives with her mum and dad in Sussex.

Minnie, from Edinburgh, is 5 months old and has bilateral microphthalmia.

Edward is 7 years old and has bilateral upper lid coloboma. He lives at home in Yorkshire with his sister Lola and his mum and dad.

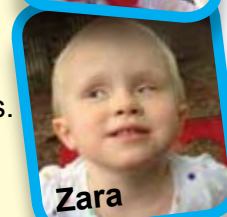
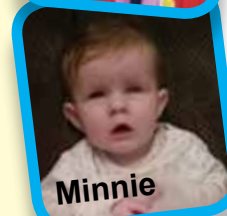
Zara is 2 and a half. She lives near Glasgow with her mum Kelly, dad Daniel and sister Bethan. Zara has bilateral microphthalmia, coloboma and nystagmus.

Adult member **John Leadbeater** is 34 years old and has bilateral microphthalmia and coloboma.

Five year old **Tilly** from Cheshire was born with left microphthalmia with PHPV and left colobomas as well as the rare condition Tracheo-Oesophageal Fistula.

Little **Roman** from the West Midlands is 14 months old and has microphthalmia and coloboma.

Buckinghamshire-based **Evie** is 2 and a half with anterior segment dygenesis and a microphthalmic left eye.



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Barry Stickings becomes patron of MACS

MACS trustees are very pleased that, despite stepping down as Chair, Barry has agreed to continue to support our charity as a patron. This is a fitting role for someone who has given so much time and energy to MACS and who remains passionate about providing the best support possible to you, our members.

Barry says:

I am very proud to have been asked to be a patron for MACS. I am pleased to accept this role because MACS is a part of my soul and always will be. I will do all I can to promote MACS and support it in this new role.

I have enjoyed being part of what is a unique support group. My goal has always been simple, if just one person has said 'thank you' then my work is complete. I'm happy to say that I have heard it a thousand times plus.

Without the support of my wife Kelly and son Toby, I would not have lasted as long as I have within MACS. They are what makes me. I now look forward to us having more time together and enjoying life, but still being part of the MACS family both as patron and family member.

Thank you all for making MACS a friendly, welcoming charity that gives support to new families, friends and supporters from the heart. Remember, we are all here because we have very special children who make us laugh, cry, feel proud, excite us, but most of all give us a reason to be the people we are. They inspire us.

With my love and best wishes

Barry



Barry and his family

Welcoming our new trustees

Say hello to **Gill Bramley**, **Aaron Eaton** and **Kerry Wykes**, who all became MACS trustees in July this year.

Gill joined MACS in 2013 as an adult member affected by bilateral microphthalmia and coloboma. A full time, London-based civil servant, Gill is keen to share some of her spare time with MACS and is currently sitting on our Grants and Fundraising sub-committees.

Aaron and his wife Jodie became members of MACS after their daughter Aurora was born with a microphthalmic right eye. As a health and safety professional, Aaron's knowledge will assist with event planning at MACS, but he is also supporting the work of our Finance & Governance, Grants and Marketing sub-committees.

Swindon-based **Kerry** joined MACS with her husband Tony after their second child Elijah was born with bilateral coloboma. Elijah also has Asperger's Syndrome. Kerry sits on the Family Weekend and Events sub-committees and is also your Regional Supporter for Wiltshire, Bristol and Gloucester.

Interested in becoming a MACS trustee?
We are looking for two new trustees! To find out more, submit your interest to jenny@macs.org.uk by 31 January.

Getting to know Aaron and Kerry

What made you want to become trustees?

Kerry: We've been members of MACS for more than 8 years, but attended our first Family Weekend in 2014. During those few days, we made new friends and our children had the best time. However, what hit us most was the sense of family. It made me want to get involved.

Aaron: After the birth of Aurora we became aware of MACS. My wife has been superb at fundraising but I felt I might be able to contribute in another way, and so when the opportunity arose I volunteered to become a Trustee. It was important to us both to be able to give something back to MACS, not only for the support we received, but for the future benefits that Aurora could find in the activities and support the charity offers.

What have your first few months as trustees been like?

Kerry: I have worked in a variety of roles during my working life - from sales to admin - but predominantly I have worked in Housing & Council Tax Benefits. It was quite nerve wracking attending my first meeting as a MACS Trustee in July. There are so many processes and procedures to learn - it can be quite daunting!

Aaron: It's been extremely interesting and quite hectic to even attempt to get up to speed with the different activities and challenges that the committee deals with. It's been very enjoyable and I think the committee will steer MACS in new and exciting directions in the coming months and years, to the benefit of all families.

How do you see MACS developing in the future?

Kerry: I'm a great believer that a problem shared is a problem halved. Support is the key to MACS, whether this is the sharing of experiences and solutions or whether it is knowing how and where to access professional advice and expertise.

Aaron: I think MACS can develop its profile as a recognisable charity and make more use of modern social media interactions. I am particularly keen on MACS developing a long-term plan to support its core aims.

What particular skills do you bring to the table?

Aaron: I'm someone with a keen eye for detail, and bring a wealth of experience from working for a large organisation providing professional health and safety advice. I hope that MACS can benefit from these skills by further improving governance and by running varied and safe events.

Can you share a nugget of information that may surprise us?

Kerry: I was a qualified dance teacher - teaching ballet, tap, modern and acrobatics - before snapping my cruciate ligament when I was 29!

Aaron: I discovered, thanks to my wife, that I actually really enjoy musical theatre! I loved Matilda and Wicked! Oh, and I am extremely keen on sharks.

What's your favourite book, film or piece of music?

Kerry: I love books (not kindles!), some of which are Richard Branson's autobiography; Harry Potter books; and Hunger Games.

Aaron: My favourite record is still Mellon Collie and the Infinite Sadness by The Smashing Pumpkins.



Left to right: Gill, Aaron with Aurora, Kerry



Spotlight

This month *Focus* has been chatting with some of its young adult members to find out more about living life with MACS conditions. Interestingly, the lives of full time university students, Bethanie Roughley and Jack Dignan have both taken on a sporty focus!

Spotlight on... Volunteering

Twenty year old Bethanie took a short break from her studies at Manchester University to fill us in on what she's been up to. This autumn, she started her third year studying for a BA Econ degree in Economics and Politics, which sounds like a lot of hard work to the *Focus* team.

It was great to hear that she also finds time to volunteer on a weekly basis for a Manchester-based club supporting children and adults to play blind football and tennis.

As part of her degree, Bethanie signed up to take an extra module called the Leadership Programme, which required her to take on some voluntary work.

"I really wanted to do something which would be helpful to others and have a positive impact. I searched around online and came across Manchester Blind Football Club; it really struck a chord with me and so I thought I'd give volunteering for the group a go."

Bethanie started volunteering a year ago and attends the club once a week. The club offers:

- **Visual impairment-specific sports sessions for children aged 4 to 9 years**
- **Blind and part sighted football training for children aged 10 to 15 years**
- **Blind and part sighted football for 16s and overs both for fun and National League competition**

Her tasks are varied and interesting; she could be helping out on the pitch, teaching football skills; supporting the club's leader who herself is registered as blind; undertaking administrative duties or helping to organise social days or



evenings out. She's also started helping out with a new activity; Blind Tennis.

Her experience shows how supporting others through volunteering can also provide personal benefits.

"It's helped me to put my own visual impairment into perspective and realise how I take things for granted. I have microphthalmia and wear a prosthetic eye, but life for those who are blind is undoubtedly very different."

"Working with children in particular, has helped me to become more aware of how I communicate and how to effectively deal with situations that may be difficult for them."

Manchester Blind Football Club is on the look-out for new members and volunteers.

If you, or someone you know, would like to join Bethanie and the group, please visit www.manchesterblindfc.co.uk

Blind football is from 7-8pm on Thursdays at Manchester Communications Academy, Manchester, M40 8NT. The cost is £2 per one hour session and is geared towards adults and children on alternate weeks.

Blind Tennis is currently for adults only and take place at 6-8pm on Tuesdays at Failsworth Leisure Centre, Failsworth, Manchester, M35 9HA. The cost is £3 per two hour session.

Spotlight on... Sailing

Jack, can you tell *Focus* readers about your introduction to sailing with MACS...

Back in May 2014, I stepped on board John Laing for the first time, about to embark on my first sailing voyage with a group of other MACS children. I had previously done a lot of dinghy sailing and racing but had never experienced yachts. I was anxious as to what it would be like to sleep on board, but excited for the challenge! After our first night on board, we got our first glimpse of what it was like to sail out on the sea. I felt a sense of freedom and pride and from this moment I knew this was for me!

Did you worry that your visual impairment might stop you sailing?

Part of the magic of sailing for me is that my visual impairment has never been a barrier. I find that other sports such as football or rugby, require good depth perception and vision, however sailing doesn't place emphasis on these skills. My eye condition didn't present any issues.

How did you become more involved in sailing?

I loved the first trip I did with MACS and at the end of the voyage I was asked if I wanted to train to become staff. I returned for two weeks of training over summer 2014 and qualified as a relief bosun, responsible for the maintenance and upkeep of the vessel. I continued doing many voyages in this role, using any opportunity I could to go sailing with Ocean Youth Trust South. After I turned 18, I was able to train to be a watchleader on board. I qualified as a 3rd Mate, meaning that I was responsible for half of the crew and running the boat during the times I was on deck. I am now close to completing my 2nd Mate's assessment. One year after my first voyage, I acted as watchleader on board the 2015 MACS voyage.

Has sailing changed you?

Involving myself with OYT South has opened so many doors for me. Not only have I become a better sailor and learnt many valuable seamanship skills, I have also had the privilege of working with an amazing and diverse range of young people. I get to witness young people



come out of their shells and unleash their adventurous spirit... as well as learn what they are really capable of.

Life is a little different for you lately... Can you tell us about it?

I have recently opened a new chapter in my life by starting at the University of Southampton. I am here studying Geography with Oceanography and am loving it so far.

Finally, what would you say to MACS youngsters considering going on a sailing trip in 2016?

I would strongly encourage everyone to give the voyage a chance. It is a once in a lifetime opportunity that is suitable for anyone, regardless of ability and experience. Throw yourself into it, and you won't regret it! **If you have any questions, I am always happy to help - please email jackmdignan@googlemail.com.**

MACS would like to congratulate Jack, who has recently been voted on to the Board of Trustees for OYT South. Well done Jack!

Fundraising Focus

"Thank you. My 6th marathon, but definitely the best in terms of support."

2015 has been a bumper year for fundraising, with supporters taking part in all manner of activities around the UK and further afield.

Our annual schedule of events started in March with the Reading Half Marathon, followed swiftly in April by the Brighton and London Marathons. In August, our cyclists took over for the Prudential RideLondon-Surrey 100, before passing the mantle to some very brave souls who were prepared to jump out of a plane at 13,000ft at our latest tandem skydive event.

We are so grateful to all MACS members, family, friends, schools, community groups, charitable trusts, and others, who have chosen to fundraise or donate their time or money to our special charity. You've participated in fun days, fashion shows, mud runs, ladies' nights, a bell ringing evening, football matches and much more, all in aid of MACS. A big thanks to you all.



"Unlike larger charities, I found MACS was more focussed on the individuals it supports and the people helping to raise funds."

Opportunity to run or ride for MACS in 2016!

We are currently filling our places in 2016 events, including the Virgin Money London Marathon, Prudential RideLondon and Brighton Marathon.

Our wonderful MACS members are always keen to take part in fundraising events and many of you have already signed up for next year's challenges.

We would love more blind MACS members to consider taking part in these events too. In 2016, Ben Lupton will be training for both the London Marathon AND Prudential RideLondon! Dad Tim, a prolific marathon runner himself, will act both as Ben's guide runner and tandem cycle partner.

Could you join them?

Lucky MACS has won two Green Start entries for the 2016 Virgin Money London Marathon! If possible, we'd like to use these for our blind and guide runners. As celebrities and fast runners set off from here, the area is less hectic than other start zones. A quieter and quicker start could help our blind runners and there's also a chance that MACS could be spotted by the media.



"Team MACS forever... my no 1 charity. I'll do my best to support them again in the future."



If you're interested in running with a guide runner, please contact fundraising@macs.org.uk by 31 December 2015. Also get in touch if you're interested in cycling RideLondon on a tandem!

MACS Members say ‘Thank you!’



"This arrived today. It's fab! Ben is a happy little soul."
Patsy and Ben



"I would just like to thank MACS for taking the time to buy me my braillenote. It has helped me so much and made everyday tasks much easier." Declan Webster

"Thank you so much for Luke's play equipment, he loves it and uses it every night (even in the rain)." Selina Bessant



"To MACS, thank you for my iPad. You are super. I love my iPad. Love Annie."

"Dear MACS, Thank you so much for funding my computer. I am using the computer frequently to do homework, revision and research. You have no idea how grateful I am!" Frazier



"Thank you so much for your very generous grant towards Ciara's smart brailer. She loves it so much and already she is a lot happier about the prospect of braille practice."
Caroline and Jim Gavigan



"I would like to say a huge thank you to MACS for making it possible for me to buy this wonderful trike for Ruby. Ruby is Deafblind and unable to walk independently. Having the trike... will increase her confidence and physical mobility."
Lesley Rogers

Would you like to get involved in MACS' grant making?

Involving members in decision-making is an important part of MACS' ethos. As our grant policy is under review, it's the perfect time to think about involving more members in the process of assessing grant applications.

Would you be interested in sitting on the grants sub-committee with trustees Aaron and Gill?

We are looking for three members to sit on the sub-committee for around a year, after which three different members will have the chance to take their seats. **If you think that you would be able to make decisions directed by our grants policy and would like to find out more, please register your interest by emailing grants@macs.org.uk.**

This is a great way of contributing to MACS and to your fellow members in a really positive way and we hope to hear from you!



Thank you so much for allowing me the grant for the computer, I love it." Daniel Mckinstry

MACS on film

Thanks to all members attending this year's Family Weekend who generously gave their time to be filmed for a series of MACS videos; you were all fantastic!

Your willingness to speak about your experiences on camera means that we now have an extremely useful set of professional videos at our disposal which will help MACS to reach out to more people, show them what MACS is about, and demonstrate the impact of what we do.

Keep a look out for the films on www.macs.org.uk and on social media.

MACS Family Weekend

Have you booked your 2016 tickets yet? Next year's event takes place from **Friday 29 April to Monday 2 May** and we are all set to give you a great time.

Here's a few snippets of what you can expect during the weekend...

Kids' favourite Magic Matt will amaze with his tricks, the Imajica Theatre Company will perform 'Down the Rabbit Hole' and host an interactive song and dance session after the show. The Sensory Fun Bus will also be in attendance and members of all ages will have a chance to demonstrate their skills via MACS has got Talent.

#IamABLE campaign

Earlier this year, MACS took part in the DM Thomas Foundation's #IamABLE campaign. The Foundation part-funded this year's sailing trip, so during the voyage, MACS young sailors produced a range of visual images capturing how they wanted to say 'I am ABLE' in spite of their visual impairments.

A case study about our young sailors was shared on the Foundation's website and the images were shared widely on social media platforms on 8 September helping to celebrate and raise awareness of the strength and tenacity of disabled young people.



MACS partner services

Blind Children UK supports parents of children with vision impairment with services including, Family Support, Education Support, Access Technology Support, Recreational Activities, Movement Matters (Habilitation) and CustomEyes books.

If parents have any concerns or worries about their child, please contact Hazel Russell or Sarah Taylor on 0800 781 1444 who are happy to talk to you how their services can help you. Please remember to let them know that you are a MACS member.



Dates for the diary

6 December 2015:

MACS North Christmas Party

Park Hall Hotel, Chorley

Contact: events@macs.org.uk

12 December 2015:

MACS South Christmas Party

Wokefield Park Hotel, Reading

Contact: events@macs.org.uk

18 December 2015:

Snow White & the Seven Dwarfs

Bristol Hippodrome

Contact: kerry@macs.org.uk

20 December 2015:

Nene Valley Railway Santa Experience

Contact: hannah@macs.org.uk

2 January 2016:

Snow White & the Seven Dwarfs

Princess Theatre, Torquay

Contact: louiseeggins@macs.org.uk

2 January 2016:

Cinderella

Manchester Opera House

Contact: lisapreston@macs.org.uk

3 January 2016:

Cinderella

Grove Theatre, Dunstable

Contact: melsharpe@macs.org.uk

16 January 2016:

Snow White & the Seven Dwarfs

Theatre Royal, Norwich

Contact: clare@macs.org.uk

29 April 2016:

MACS Family Weekend

Park Hall Hotel, Chorley

Contact: familyweekend@macs.org.uk

or book via www.macs.org.uk



LECTURES, EXHIBITIONS AND DEBATES



ABOUT THE SPEAKER

After studying undergraduate medicine at King's College, Cambridge and clinical medicine at New College, Oxford, Nicky initially specialised in paediatrics before entering ophthalmology. She specialised in medical, and surgical conditions of the eye particularly relating to children. She then additionally trained in genetics to become a dually accredited ophthalmic and clinical genetics specialist.

Did you know?

With collaborators nationally and internationally, Nicky has helped contribute to our collective understanding of over 300 genes that control eye development.



Born without eyes: understanding the genes that switch on human eye development

PROFESSOR NICKY RAGGE

For over 16 years, Professor Nicky Ragge has been researching the codes buried in our genes that control the development of one of our most extraordinary, complex and important organs: the eye.

First as a Consultant eye surgeon, and now as a Consultant clinical geneticist, Nicky has worked with many families who had babies born with missing or very small eyes and developed a national research program.

She continues to treat families and patients as part of a national eye genetics service, and to collaborate with scientists around the globe, to develop world-leading research in her lab at Oxford Brookes. Over the next few years, it is likely that the dream of developing treatments that can replace the function of missing or malfunctioning genes will be realised. As Nicky will explore in her lecture, this may enable therapies to grow the eye or preserve sight - bringing relief to many patients around the world.

WHEN Wednesday 20 April 2016, 6pm

WHERE JHB Lecture Theatre, Headington Campus

This free event is open to the public and MACS members aged over 18 are welcome to attend.

Date and Time: Wednesday, 20 April 2016, 18:00 to 19:00

Location: JHB Lecture Theatre, John Henry Brookes, Headington Campus, Gypsy Lane site

To Book: Phone: 01865 484864 Email: events@brookes.ac.uk

or online: <https://www.brookesalumni.co.uk/news-events/events-registration>

If individuals attending have special needs (e.g. visual impairment, mobility problems) and/or need parking they will need to please indicate this at the time of booking by contacting the organisers directly.



Microphthalmia, Anophthalmia & Coloboma Support

Registered address: MACS, Suite 472, Kemp House, 152 City Road, London, EC1V 2NX

Registered charity number: 1161897

www.macs.org.uk

T: 0800 169 8088 (Family Support)

T: 0800 644 6017 (Fundraising and General Enquiries)

E: enquiries@macs.org.uk