Focus

Issue 5
Summer 2016

Chair's foreword

Welcome to this summer issue of *Focus.*

It's been a very busy year to date at MACS. We held our first Family Weekend and AGM as *Microphthalmia, Anophthalmia and Coloboma Support* and I was officially voted in as Chair. This is a great personal honour and I intend to do my very best to ensure that MACS continues to benefit all members of our community.

The AGM saw us welcome two new trustees, Jonathan Attenborough and Fay Skevington, to the Board. A MACS member since childhood, Jonathan now works for RNIB Scotland and brings a great deal of useful experience to the table. Civil servant Fay, also has a wealth of knowledge to share and has already played an instrumental role in facilitating the Board's strategy meetings.

Reviewing MACS' strategic direction has taken the Board's focus for much of the year. Strategy planning takes time, but I'm delighted to report that our discussions have enabled us to positively hone and shape our ideas. We'll continue to work on this in the coming months and hope to have a clear plan of action to share with members in due course.

One thing I can now share is that a result of member feedback and Board discussions, we have decided to recruit a new trustee who will be able to represent the needs and views of individuals with Anophthalmia. Please visit page 7 for more information.

Representing and highlighting MACS wherever we can remains ever important and this issue of *Focus* shares information about our presence at events both home and abroad.

Enjoy the read!

Robbie Crow
Chair

Contents

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Please get in touch with any queries.

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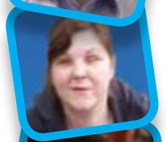

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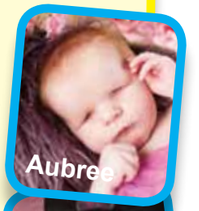
New member gallery

Say hello some of our newest young members…



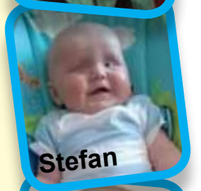
Aubree Burton is 19 months old and from Abergavenny in South Wales. She has bilateral Anophthalmia.

Annabella Higgins was born in January 2016 and is from Maidstone in Kent. She has been diagnosed with unilateral Microphthalmia.

Eric Kingston-Wills also has unilateral Microphthalmia, along with Nystagmus. Eric is two years old and from Beckenham in Kent.

One-year old **Harry Osmond** is from Wigan. He has right eye Microphthalmia and bilateral Coloboma of the retina.

Oliver Hall from Worcester is 3 years old. He has Microphthalmia, a Coloboma of the optical disc in his left eye, and 22q11.2 micro duplication syndrome. He loves farm animals!



Stefan Coll is one-year old and lives in West Dunbartonshire. Stefan has bilateral Microphthalmia.

Ryder Goddard from Merthyr Tydfil in south Wales is 9 months old. He has bilateral Microphthalmia.

Edward Smith has bilateral Anophthalmia. He's from Lincolnshire and is one-year old.

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MACS on tour…

MACS' trustee Jenny Lupton reports from Sight Village, 19 July 2016.

This is MACS' 5th year at QAC Sight Village in Birmingham. It's a very popular event in the VI calendar and is always worthwhile, with lots of exhibitors from technology companies, schools and colleges, to charities like MACS.

This year there seemed to be more ophthalmologists, orthoptists and nurses in attendance than usual. Happily, Teresa Gordon and I also met quite a few ECLOs (eye clinic liaison officers), who are the people that often signpost families to support groups like MACS.

ECLOs are an important resource and can help make sure that MACS' information is available in hospital eye clinics throughout the UK. We were told about a possible ECLO conference and are hopeful that MACS can attend in order to raise further awareness.

We also made contact with school teachers that have VI units or work within VI school settings.

They all loved our My Eye Man book and took copies back to their schools. A number of Rehabilitation Officers for the Visually Impaired (ROVIs) were also at the event and are another great resource for sharing information about MACS.

For me, the main point about attending Sight Village is the awareness we raise. If one or two people go away knowing about MACS and can pass on information to a family affected by one of the three conditions, we can prevent that family feeling alone or isolated.

MACS will also be attending the London Sight Village event on the 1st & 2nd November, so if you are in the area pop along and have a look around!

Out and about with Jonathan Attenborough

Firstly, thanks to the MACS members for welcoming me on board as a trustee at this year's AGM. I am very passionate about MACS and I promise you that I will give this role my all. Let me tell you a bit about what I have been up to recently:

Born Without Eyes Seminar, Oxford Brookes University, 20 April 2016

I attended Professor Nicky Ragge's seminar at Oxford Brooke's University with Robbie Crow, Gillian Bramley and MACS Patron Barry Stickings.

Nicky gave an overview of her genetic research into Microphthalmia and Anophthalmia. She explained that while there are no proven causes of these conditions, the most likely cause is disturbances of the morphogenetic pathway that controls the development of the eyes, either by a primary genetic defect (a carrier of the gene) or from external substances that could affect the smooth process of eye development, such as an infection or drugs.

Nicky touched on the fact that in the late 1980s there was an investigation into the possibility of fungicides causing babies to be born with Microphthalmia or Anophthalmia throughout the UK, however this has still not been proven.

Nicky has been working with researchers from all over the world, including Professor Steve Wilson who is an expert on Zebrafish at UCL. It was explained how zebrafish share a similar genetic structure and they were researching the possibility that, through stem cell research, if Anophthalmia was caught early they could grow a functional eye in place. However, human trials are obviously a very, very long way off!

Nicky wrapped up the seminar by sharing her vision of a national research and information centre in the UK where further genetic studies can take place. This national centre would also be a place for families to obtain more information relating to these specific eye conditions and information on charities and support groups available to them.

Vision UK 2020 *Expanding Horizons* Conference, London, 14 June 2016

As a member of Vision 2020, MACS (represented by myself and Victoria Samuel) attended this year's Vision UK 2020 Conference in London. The focus was on four main areas: Ageing and Sight Loss, Diabetes and Preventing Blindness, Children & Young People, Science & Technology.

The day started with a plenary session where Chair Professor Carrie MacEwan (Royal College of Ophthalmologists) welcomed everyone. Lesley-Anne Alexander (Chair UK Vision Strategy & CEO RNIB) then explained the theme of the conference (Expanding Horizons) and how this fits into the current UK Vision Strategy outcomes which are:

- Everyone in the UK looks after their eyes and their sight
- Everyone with an eye condition receives timely treatment and accessible support
- A society in which people with sight loss can fully participate.

We then broke off to attend one of the four morning streams: Children & Young People: Education & Inspiration. This interesting stream focussed on the issues that blind and partially sighted children and young people face in mainstream education and the difficulties that families face in getting the appropriate level of VI support for their children.

After lunch at the Children & Young People workshop we were asked to discuss areas of educational support and their surrounding issues. Our ideas were collected and will be used to put together a strategy of tackling educational issues.

Later, there was a chance to network with other professionals from the eye health and voluntary sectors and we made some contacts who could be very useful to MACS.

VINCYP Conference, Perth, 17 June 2016

VINCYP is the Visual Impairment Network of Children & Young People It's made up of a group of professionals who have developed a support pathway for children and young people with a visual impairment, from first diagnosis right through to educational support.

This conference had a particular focus on children and young people with a visual impairment but also with additional complex learning difficulties. The morning session looked at a form of visual impairment known as Cerebral Visual Impairment (CVI); it's a common cause of visual impairment and can often come with other eye conditions like Microphthalmia or Coloboma. It was explained that CVI can be difficult to detect and diagnose properly depending on the severity of the complex learning difficulties. Professor Dutton gave a particularly excellent presentation, sharing techniques that any professional could use when working with children and young people with a visual impairment to maximise the full use of the child's residual vision and their full potential.

After lunch, we shared thoughts on the role that professionals could play in children's development in relation to classroom support, environmental audit, playground support, lunch-time support etc. There were a wide range of professionals around the table and it was a fantastic opportunity for everyone to learn from one another.

VINCYP hold various different conferences and training events throughout Scotland and I hope to attend future events on behalf of MACS.

Focus on the Family Weekend

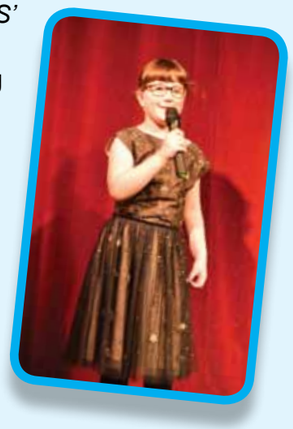
The last weekend in April saw a large group of MACS members enjoying another annual Family Weekend at the Park Hall Hotel in Lancashire. It was the first AGM for MACS as a new CIO and a key decision was taken by the membership to allow up to two external trustees.

The Board does not intend to rush into making external appointments, and will always seek to find appropriate individuals within the membership wherever possible. However, where skill gaps remain, it's wise to have the option to recruit externally to ensure that the charity's needs can be met. We thank the membership for recognising this and voting accordingly.

We also decided to incorporate a new element into the AGM: breakout sessions to discuss specific areas of interest. This seemed to be well received and we hope to develop this further next year!

We were all delighted to have ex-Chair Barry Stickings in attendance at the weekend. In thanks of his hard work and commitment to MACS for many years, Barry was presented with a framed photograph of the MACS community, along with a signed banner. We are sure that both will be given pride of place Chez Stickings!

Our younger members were catered for with activities such as swimming, bowling, a Sensory Fun Bus, a Battle of the 'Lip Sync' Bands, the *Imajica Theatre Company* performing *'Down the Rabbit Hole'*. Lots of fun was had by all.



Sunday evening's *MACS' Got Talent!* session yet again proved to be a big success! Thanks to all of the wonderful young people who performed for our enjoyment – you are all amazing!

We were also pleased to announce the well-deserved winners of our MACS Achievement Awards. Congratulations to:

Caitlin Brister (winner of sibling award)

Abigail Pike (winner of 7 to 12 age category)

Aiden Pryor (winner of 0-6 age category)

Thanks to all that attended the weekend and made it so special. This event is about having fun, but is also about creating new friendships and sharing support – something which our MACS community excels at time and again.

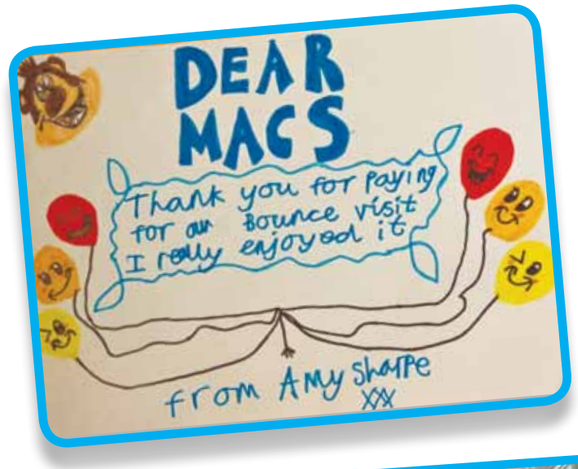
Regional events round up

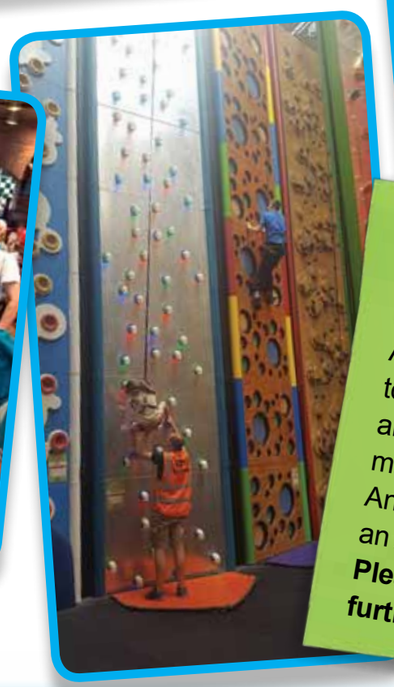
It's been another busy summer for our Regional Supporters with member meet ups place all around the country. We're pleased to see a wide variety of events being organised enabling our young (and older) members to bounce on indoor trampolines, scale climbing walls, play Laser Tag, visit sensory centres, and get your thinking caps on at Thinks Tanks and Science Museums.

Sue Brister is also looking forward to hosting a pottery painting event on 24 September at Skipton's *Coffee and Clay,* followed by dinner at *Billy Bob's Ice Cream Parlour.* Have fun everyone, we look forward to seeing your creations!

Regional Supporters required!

We have a number of areas where our regional support network could do with a boost. If you are interested in becoming a Regional Supporter or simply helping out by hosting or supporting an activity in your area, please let us know – we'd love to hear from you! **Please complete this online form or email events@macs.org.uk for further information.**





Could you be a MACS trustee?

Feedback from members has highlighted a lack of experience regarding Anophthalmia on MACS' Board. We'd like to rectify this and, in the first instance, are inviting expressions of interest from members who are directly affected by Anophthalmia or are parents or carers of an Anophthalmic child. Could this be you? **Please contact jenny@macs.org.uk for further information.**

How volunteering changed my world

MACS has existed for over 22 years in some way. During that time, we have done what we do best: offer support to families all over the UK who are affected by Microphthalmia, Anophthalmia, or Coloboma. At various times in MACS' existence we've helped some families and organisations abroad, but – for the very first time in the charity's history – in June 2016 we were invited to speak at the United Nations Office in Geneva. Our Chair, Robbie Crow, speaks about it below:

In May 2016 I was approached to see if I'd like to give a presentation at the UN office in Geneva as part of an international conference on volunteering, run by one of the biggest social movements in Russia, Vector of Friendship. Of course, I jumped at the chance, but there was a question in my head: 'what will I talk about?'. The only brief I had been given was to deliver a TEDx-esque type presentation as part of the UN Library Talks series which was entitled 'Getting More Than We Give: How Volunteering Changed My World'. I came to the conclusion that I would deliver a presentation on how volunteering allowed me to think differently about my visual impairment and about disabled people in general.

As a disabled person I believe two things to be true: the impairment defines the person, unless the right mind set is adopted; and the actions of disabled people who come before us can define the future successes of disabled people today.

Disabled people are defined by their impairment, arguably because it is the only thing that stays consistent throughout their lives. Age, location, education standards, relationship status… these all change, at some point, in a persons' life but their impairment (especially our impairments) stay with us forever. Due to this, it is my belief that, unless coupled with the correct mind set as a disabled person, impairments can negatively impact upon us from an early age. This is due, partly, to the fact that disabled peoples' perceived abilities are defined by the actions of disabled people who have come before them. Unless it has been achieved by someone else, it is believed to be impossible.

Disabled people, from an early age, are constantly faced with phrases such as "can't", "won't", "shouldn't", "mustn't", and "but" – all of these words are what I like to call clause words, meaning – in principle – that they always add a clause to something someone is about to say. Unless disabled people learn how to think about their disability in a different way, and learn that barriers (and beliefs!) are there to be broken, negativity can onset from an early age. Volunteering taught me this, and that's what I wanted to get across in my speech.

In my life I have volunteered with various organisations, two of which have – in different ways – helped me think about my impairment in a positive way. These organisations were MACS and OYT Scotland and both taught me different things.

Ocean Youth Trust Scotland is Scotland's national sail training charity and takes young people, between the ages of 12-24, to sea in order to experience an adventure under sail. By sailing with them as a young person, and later as a trustee and watch leader, OYT Scotland really explored my boundaries by teaching me to push my barriers as far as they can go. By learning to

work with people in a confined space, learning how to hoist a main sail in force 8 winds, cooking for 18 people or by watching people being sea sick, knowing that we need to carry on, I learnt resilience and that **everyone is different, everyone faces challenges.** The variance of characters that I encountered on my voyages was simply outstanding and it made me understand that everyone is on a journey and they don't know where their final destination is. It's not just disabled people who are different.

Similarly, MACS is a charity that I've grown up with and it has taught me important life lessons, too. As a young person it provided a peer support network of older and adult members with my condition who were doing the things that I had been told by society that I couldn't. It's important to note, here, that even though my parents told me I could do whatever I wanted, society had a different view – this is hard to cope with as a young person.

By having older people to look up to, I learn that **anything is possible** if you try hard enough. Now, as Chairman of the charity, I see that philosophy coming true every day. Whether it be by taking a group of our young people away on activity breaks, or by raising awareness of the conditions and delivering case studies, I am reminded how able each of our young people are, and how much they have to offer the world. That is what volunteering with MACS has taught me.

By simply saying "yes" to two volunteering opportunities when I was younger, my outlook on disabled people, and my own personal view of my impairment, has changed and the ability to believe in myself has increased.

That is the message I wanted to get across in my presentation at the UN. I hope it came across clearly.

The conference was full of other inspiring young people. I was introduced to a Maltese woman who is fighting for equality in her country; a German Ph.D. student who is fighting to make the voices of young people heard, worldwide; a Saudi Arabian who simply wants international peace; and an even more eccentric Scotsman than I who wants to help others be the best they can be. I now call them friends.

If I believe anything after the UN conference, it is the following…

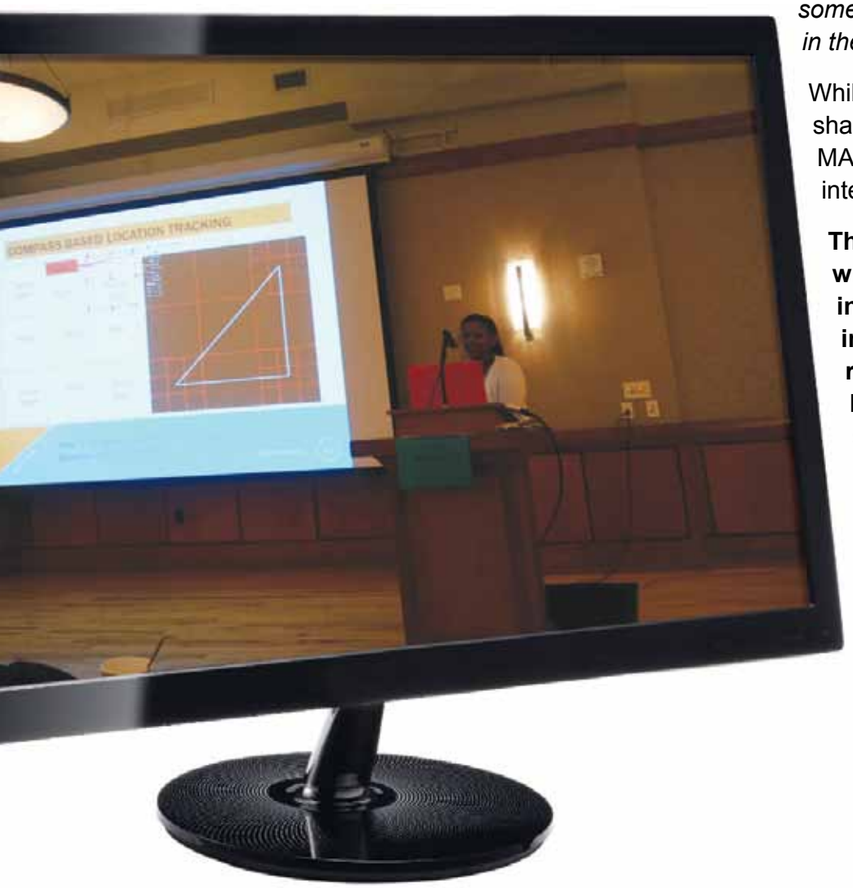
1. **Being disabled is not about ability, it is about society's barriers;**
2. **Everyone is different, not just those who are disabled;**
3. **Anything is possible – disabled people face barriers in life but barriers can be lifted; and**
4. **Anyone can change the world for the better if they truly believe in the cause.**

Blind drawing software update

We are looking for blind MACS members (children and adults) who have basic computer skills to help test some blind drawing software. Some may remember that the developer, Sandra Fernando (pictured, came to MACS Family Weekend in 2014 to share her ideas. You'd be able to help from home, but on one occasion you would need to be observed using the technology by Sandra at her base at Lewisham College / Goldsmith's University in London.

MACS member Toby Stickings has been working with Sandra for some time and recently went along to test out the software. Toby says:

"I used Sandra's drawing software to draw a stick man. The software is fantastic because you type in commands like 'zoom in N' which means that you zoom in on the north of the screen and then if you type circle it will be drawn. You can also draw lines as well from one compass direction to another. The software has a lot of potential and as it develops it will allow blind people to draw different shapes and pictures. Sandra also plans to implement voice commands so that you can tell the computer what you want to draw. With the use of 3d printing you will be able to print out what you've drawn and feel it too."



Sandra was recently proud to present her paper 'Drawing for Blind Learners: Assistive Technology for Graphical Design' at the 16th IEEE International Conference on Advanced Learning Technologies in Austin, Texas.

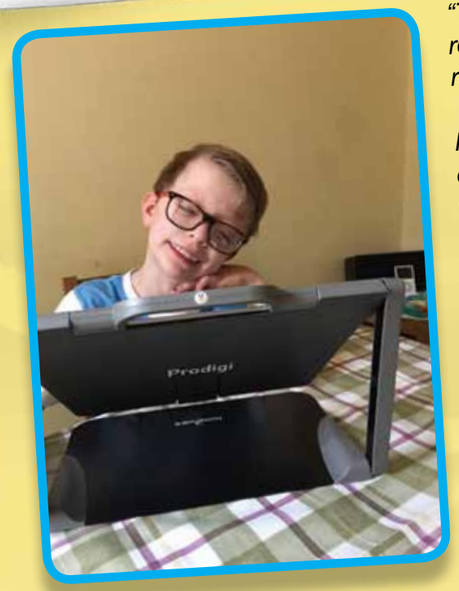
She says *"The conference went really well, people asked lots of questions and some suggested ways in which the picture validation could be done using Braille 2D - something I am looking into exploring in the near future."*

While in Texas, she made sure to share leaflets and information about MACS, again boosting MACS international presence.

This really is a unique project which is at an exciting stage in its development, but the input of blind MACS members really is crucial to its success. Please contact sandra.fernando@lesoco.ac.uk to find out more.

Making life better with MACS grants

It's always wonderful to hear from members about how MACS grants have benefitted their lives. Here's some feedback from some of our latest recipients…



"Thank you so much to all the trustees at MACS. Edward received his Prodigi connect 12 on Tuesday and the HumanWare rep came the next day to set it up for him.

In the first few hours it proved to be the life changing piece of equipment we thought it would. He has spent the day finding his way around all the functions and thinking about ways he can use them in everyday life. He is already able to use it easily!

Edward has been able to sit on the sofa and watch TV with the rest of the family for the first time, and we didn't have to watch around his head in the front of the screen!

We can't thank you enough for approving the grant to pay for it."
Sunny Freakley

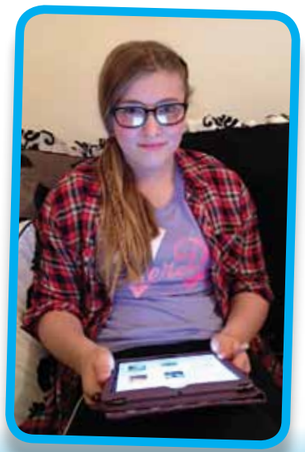
Edward says: *'Thank you MACS my connect 12 is brilliant, I can't believe I am so lucky to have one!'*

"Archie is getting on very well with his swimming lessons. Many thanks!"
Amanda Lerwill

A few words from Millie McGivney…
"Thank you so much to MACS for helping me get an iPad! I can now not only complete homework and school coursework wherever I go (mum is pleased with that!) but I can also research things of interest to me such as You Tube bloggers and authors of books I enjoy reading. The iPad also allows me to keep in regular contact with all the friends I see at the MACS yearly meetings, as well as those I get to spend great times with at Calvert and Bendrigg. I am so lucky to have made such good friends through MACS - children and young people who have similar eye conditions to mine, as well as sharing an understanding of what it feels like to have 'special' eyes.

Perhaps the most important thing of all, is that I have my iPad, I am able to Skype and Face time my brother Jordan who serves overseas in the Royal Air Force and who I miss so much when he is not at home.

Thank you MACS, for helping me communicate with those dear to me, and continue to learn every day."



Sportives

It's been yet another successful year for MACS, our marathon runners and Ride London cyclists. As usual, many of our MACS members stepped up to take part in these challenges alongside committed and new MACS supporters alike. We thank them all for their remarkable efforts in aid of our MACS community.

Kaja Kosla, MACS Fundraising Events Co-ordinator reports on London…

26 April saw 168 runners lining up at the start of the Virgin Money London Marathon to represent MACS in the 26.2 mile running challenge. The runners were supported by two cheering teams along the course, and greeted at the finish by MACS Trustees and a number of MACS members and their families. After a lot of excitement and nerves in equal measure in the run up to the event, the Team found it to be a challenging but rewarding experience, as reflected by numerous positive comments received afterwards.

The first MACS runner completed the course in an astonishing 2 hours 40 minutes while the last runner finished in 7 hours 25 minutes. A number of MACS members took part, including 18-year-old Ben and 20-year-old Conner, who were taking on their first marathon (and both enjoyed it!), as well as MACS dads Adam Williamson and Tim Lupton who completed the London Marathon having only finished the Brighton Marathon the week before.

Many runners commented on how they enjoyed the family atmosphere of the team and how they considered it an honour to be part of the team and help raise awareness of MACS. The event was also a fundraising success, with a record £266,000 raised to date.

Fundraising in Focus

So many people do so many wonderful things for MACS throughout the year. It's always impossible to name them all, but here's a snapshot to give you a flavour of our supporters' efforts…

The students of St George's Hospital Medical School in Tooting made MACS one of their RAG charities.

Maxine Scott organised a series of Shropshire Walks and a quiz night for family and friends raising £1,500! Great effort, thank you!

Thanks to Eden and Elijah Wykes and their school, the Lydiard Park Academy in Swindon, who have been fundraising for MACS for the second year running resulting in a donation of £1,100.

MACS was delighted to be chosen by M&S Simply Foods in Ruislip as their charity of the year for 2016/17. They've been busy gathering support in store and recently made a £1,300 donation raised via raffling hampers filled with £300 worth of prizes donated from local high street stores and a Euro 2016 sweepstake. Next up… a quiz night. Thanks and good luck to all the staff!

Three Peaks Challengers

MACS member Gary Clark reports on his experience of this very tough challenge. Thanks so much to team Three Peaks!

The idea of the Three Peaks Challenge first came up during a lunch break at work one-day last year when colleagues and I were discussing something that we could all participate in outside of work. We were all keen on the idea and so Robin contacted a company who provide guides and transportation between each location.

We all then decided that it would be nice to do it for charity and Adam and I knew straight away that we would like to do it for MACS! We were very pleased and honoured when our team members kindly offered to undertake the challenge for MACS too.

My wife Debby and I first became involved with MACS in 1997 after our youngest son Adam was born in 1995 with Microphthalmia and Coloboma in his left eye. Until then, we had never heard of such conditions, were totally devastated and did not know which way to turn. MACS not only gave us the support we needed but also enabled us to meet many other families who had children with similar conditions.

The team consisted of myself and Adam, Robin and his son Michael, Kevin and his Uncle William and Mark.

The objective of the three peak challenge is to climb the three highest peaks in the UK in 24 hours - namely Snowdon in North Wales, Scaffell Pike in the Lake District and Ben Nevis in Scotland.

On the day before the challenge in June, the team all met at The Queen Victoria Hotel in Llanberis, North Wales, where Robin had reserved rooms for us earlier in the year. This gave us all a chance to unwind from lengthy journeys and prepare us for the weekend ahead.

The following morning, we all enjoyed a hearty breakfast before meeting the guides a few yards from the Hotel. We were then given a short briefing before being driven to Snowdon.

The weather was warm and sunny as we started the challenge of what was to be a very hard and arduous climb before reaching the top at around midday. Then there was just time for a quick stop to take in the beautiful view and a group photo with the MACS banner before the long climb down.

Once down it was back in the minibus and then onto Scaffell Pike in the Lake District for an evening climb which we managed to complete in daylight.

After Scaffell Pike it was then on to Ben Nevis which was six-hour drive away, and at 3am we started yet another very challenging climb.

Once again, the views were spectacular and well worth the effort but with the additional bonus of walking through thick snow in the summer once we had reached the summit nearly four hours later.

It was an incredible experience, although a very tough one, which I enjoyed not only with my son but also with a great group of friends and with the added bonus of the team raising nearly £2,000 for MACS.

In need of technology help?

The Wilberforce Trust now offers a technology help and advice service for visually impaired users on a 1-1 basis via phone, email or within a drop in clinic.

Please contact Christine on 01904 760037 or at enquiry@wilberforcetrust.org.uk for help with:

- **Accessibility settings**
- **iPhones, iPads**
- **General technology advice**

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
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T: 0800 644 6017 (Fundraising and General Enquiries)
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