



ISSUE 9
JULY 2018

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



FOCUS MAGAZINE

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

WELCOME!



DEAR FRIENDS,

Welcome to another edition of our Focus magazine, where we update you on all things MACS. We have had quite a lot of staff changes over the last 6 months having brought on 2 new Trustees, Rory and Lisa (meet them on page 9), employed our first Fundraising Manager (read all about

Chair's Foreword

Lindsay on page 10) and we now have our first ever CEO in Fay Skevington (see page 8). We've also announced a lot of exciting changes to our services lately and you can read more about these and how you can get involved on pages 7 and 18.

The last 6 months has also seen us further developing some partnerships which we see benefiting our members over the coming months and years. On page 11 you can read about our inspiring 'Breaking Down Barriers' event in March with MACS Patron, Lord Blunkett. We are also pleased to feature a guest article by the charity Guide Dogs, who led an interesting and informative session at our Family Weekend and who we look forward to working with further in the future.

This Focus has Part 2 of our article about MACS adults' careers (pages 13 & 14) and Part 1 of a feature on toys of

VI children (pages 15, 16 & 17) which will be continued in the next edition. If you would like to submit anything on either of those topics, or indeed something entirely different that you think would interest MACS members, please email helen@macs.org.uk with your suggestion. We are pleased to feature articles by 5 MACS members in this edition and we'd love to feature you in the next one so please get in touch!

I hope you all have a wonderful summer and to see you at a MACS event soon.

With my best wishes,

Robbie

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Your MACS Contacts

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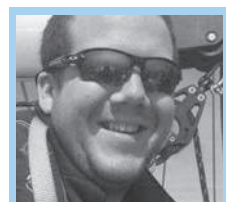


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The Trustees



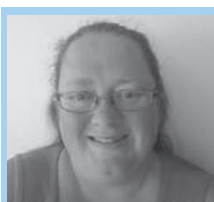
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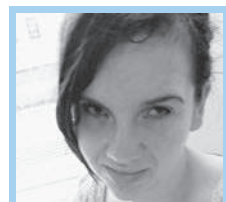
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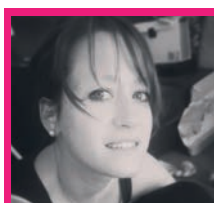
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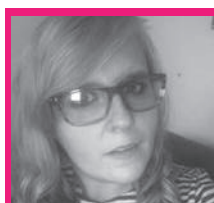
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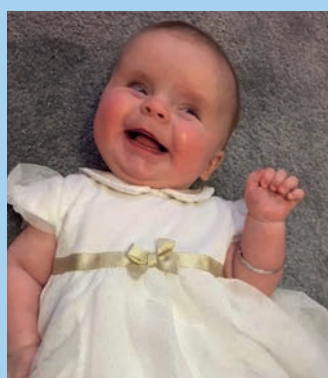


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Say
'HELLO'
 to some of our newest members!



Amelie



Aurora



Bella



Bodhi



Elanor



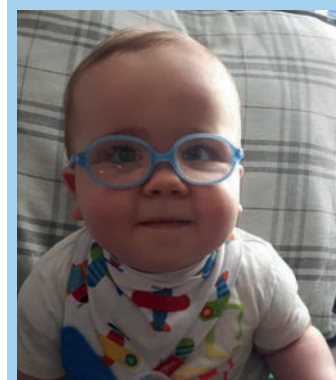
Freya



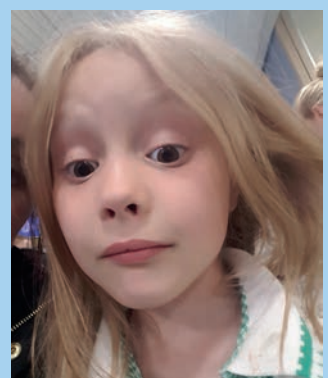
Isla Rose



Ivor



Jacob



Lauren



Maisie Mae &
 mum, Amy



Rayna



Stirling

MACS Remembers Mel Gordon

(1956-2018)

ON SUNDAY, 3rd June 2018 the MACS family lost a much-loved dad, Mel Gordon. Mel joined MACS in 2008 with his wife Teresa after the birth of their daughter, Kara, who was born with unilateral microphthalmia. Very quickly Mel and Teresa – along with their two older sons, Scott and Cole – became an integral part of the MACS family, reciprocating the support they received at the start of their MACS journey to other new MACS families when they needed it most. MACS was a lifeline to Mel and Teresa during Kara's early childhood and they were both only too happy to support others when they joined. It's safe to say, Mel was loved by hundreds of MACS parents, nationwide.

In 2010 Mel decided to take on his greatest challenge to-date, he decided he would complete the London Marathon for MACS. Little did Teresa know that this would be the start of something special for Mel. Not only did Mel go on to complete the London Marathon three times, he also completed the Chicago marathon twice, along with the New York and Berlin marathons – all seven marathons for MACS, raising tens of thousands of pounds along the way. As well as his marathon running, Mel founded two park runs in his local area and completed nineteen half marathons.

Mel was a running fanatic, lucky enough to have found a hobby he loved so much.

As we say our fond and emotional farewells to Mel, I'm humbled to announce the launch of Mel's MACS Marathon Place, in memory of the man himself. This annual place (which will run as long as MACS has golden bond London Marathon places) will be awarded to a MACS parent or adult, or to one of Mel's children, annually to complete the London Marathon on behalf of MACS in Mel's memory. More information on how to apply for this place will be announced in due course, but the first Mel's Place runner will run in the 2019 Virgin Money London Marathon.

We couldn't think of a better way to remember Mel, and we hope that you will all join us in supporting the first runner to run in Mel's memory.

On behalf of all the MACS Trustees and members, it leaves me with only one thing to say.



Mel Gordon

Mel Gordon, may you continue running through our hearts and minds forevermore. Rest In Peace, my friend, and know that Teresa, Scott, Cole, and Kara will be loved by the MACS family whenever they need it most.

Sleep well.



By Caitlin Brister

Family Weekend Review

ANOTHER WONDERFUL Family Weekend has passed, and things are already in preparation for next year! This year we held our Family Weekend at the stunning De Vere Beaumont Estate in Windsor. It was great to catch up with old friends, meet new ones, and share stories and experiences from the past year. Families described this weekend as *"A brilliant weekend, beautiful weather and time spent with amazing families! Really proud to be part of this amazing charity with the team that is driving it forward"*.

Following last year's success, the AGM was kept short (ending with, what we can all agree was, an emotional speech), this allowed time for breakout sessions including medical research with Professor Nicky Ragge and Dr. Mariya Moosajee's Moorfields team, blind drawing testing, and a session on employment and access to work with a visual impairment. We also held 1:1 sessions about EHCPs and Prof. Ragge's genetic research. These sessions allow parents to attend the sessions most suitable to their situation. 75% of attendees said that they felt more positive about their/their child's future as a result of attending this year's Family Weekend.

Whilst the adults were busy in the AGM, the children had lots of fun in their activities, including a drumming experience! Our older children ages 10-18 got to visit a local sports club, to try lots of new sports with all their old MACS friends and had the chance to make new ones. A new activity we tried this year was the pyramid club to try to help our shyer members aged 9-10, to make friends and



Soragia Vlachou

build their confidence. 82% of our members said their child had the opportunity to build friendships with people who understand them.

On Saturday night, things got spooky and the room filled with witches and wizards for our Harry Potter night! Our MACS children showed off their drumming skills that they learned from their activity and then got down to boogie at the disco (so did some of the adults!). On Sunday, we had our annual MACS' Got Talent contest, where we were once again amazed by the singing, dancing, and other fantastic acts our brilliant MACS children had to offer. Followed

"A brilliant weekend, beautiful weather and time spent with amazing families! Really proud to be part of this amazing charity with the team that is driving it forward"



Stacy Palmer

by our other firm favourite, getting covered in chocolate from the chocolate fountain!

Our new venue created mixed reviews with the hotel being a refreshing and different experience. The hotel was beautiful and modern;

however, several members felt the hotel was too large for the needs of our MACS event and created some difficulties for families. We are already excited for the 2019 Family Weekend, back for our 20th year at Park Hall. You can book your place at next year's Family Weekend at the URL below. We can't wait to see you all there!

Book your place at the 2019 Family Weekend here: macs.org.uk/fw19-booking-form

MACS Achievement Awards

Once again, in May we announced the winners of our MACS Achievement Awards. This year we received 22 inspiring nominations and it was very hard for the judges to pick just 4 winners.



THE WINNER in the sibling category was **Lola**, who collected her award in person while Lindsay Dunlop read out her mum's nomination. It was inspirational hearing about Lola's bravery in the face of her own health difficulties and about what an incredible sister she is. Lola's mum, Julie, said "I always knew Lola would make an incredible big sister but after everything she has been through I honestly believe she was chosen to be Estoi's big sister – to show her that even though you're slightly different that actually that's OK, to never give up on what your dreams are, to never take what the doctors tell you you'll be capable of doing at face value, to push boundaries and to never regret who you are or the way you were made!"

The other nominees in the sibling category were **Katie, Scarlett, Jack, Noah** and **Madison** all of whom deserve to be very proud of their achievements this year.



The winner of the MACS Child aged 0-6 years was **Aliyah** who was nominated by her mum, Stephanie. Stephanie told us that Aliyah is always pushing herself to learn and never lets her disability stop her. Aliyah can read and write in braille, speak French and Spanish and has just started learning Makaton to communicate with a good friend who is losing her hearing. Stephanie says, "Aliyah showed me that no matter what happens in life, things can always be overcome!" **Aurora, Roman** and **Cole** were also nominated in the 0-6 years category who are all little stars!

This year, **Isobel** was the winner of our MACS child aged 7-12 years. She was nominated by her dad for bravely facing everything that had been thrown at her which has included difficult operations, numerous health appointments and bullying. Her dad, Adam, says "My little (not so little) girl has overcome all this with no support in school until this school year but has continued to work hard (harder than we realised) to make sure she



is on target. She is so very kind and generous to everyone she meets and I am very proud to be called her Dad."

The other nominees in this category were **Macy-Rose, Ben, Rory, Amy, Oliver, Annie, Lewis** and **Grace** all of whom have achieved fantastic things this year!

The achievement award for MACS Person aged 13+ went to **Sarah** who was nominated for the incredible support she has given her whole family since her younger sister started having health problems. Sarah even had to call an ambulance for her sister while they were home alone one day. Her parents, Norma and Andrew, say "At 21 she should be out getting on with her social life, but she is a true friend and sister to Grace and a rock to us."

Also nominated in this category were **Abby** and **Olivia**, both of whom have done incredibly well in very tough circumstances this year and deserve to feel very proud of themselves.

Our Ambitions

AT THIS year's AGM, we revealed our Ambitions for 2018-2022 in a document that you can see here:

macs.org.uk/ambitions

These ambitions are based on a year's worth of research into what you, our members want and need from us. We are so grateful to the 200+ people who took the time to give us their opinions. Here is a top line overview of the ambitions.

AND HERE'S HOW YOU CAN GET INVOLVED:

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

macs.org.uk/become-a-peer-supporter

Become a local event organiser – Event organisers plan and host events for MACS families in their local area, to help members build networks and friendships, and know they are not alone. Sign up here:

macs.org.uk/become-a-local-event-organiser

Attend an anti-bullying workshop – this is for children/young people aged 9-16 and their parents/guardians and will be held in the October half term in Birmingham (we are likely to be able to cover some costs for attendees). Sign up here:

macs.org.uk/attend-the-zap-anti-bullying-workshop



We want to provide personalised and caring support, from a dedicated family support worker.



We'll invite members to participate in an engagement project, to shape our priorities for investment in research into MACS conditions.



We want to offer a listening and understanding ear, from trained volunteers in our peer support programme.



We'll give members the opportunity to participate in adult or youth advisory groups.



We will make sure members can get help with careers, confidence and life from a professional adult engagement and support worker.



We want to raise awareness of MACS conditions and improve attitudes and behaviours, with impactful campaigns run by a campaigns and outreach officer.



We'd like to give a wider range of options and opportunities for families to have a break.



We will deliver great services for our members through working in partnership with other organisations.



We've established a programme of events for members to connect around the country, with at least two events a year in each region.



We'll make sure our services are open and accessible to everyone who needs them.

Help shape our research and genetic priorities - We are looking for a team of volunteers (aged 12+) to take MACS' information and research services to the next level. No experience required – just a willingness to share your views, your thoughts and your time. This is your opportunity to shape research into MACS conditions, make new connections, and maybe even gain some valuable experience for your CV. Sign up here:

macs.org.uk/join-our-research-and-genetics-project

Shadow and interview a radio star - Emma from Absolute Radio's Breakfast Show ran the London Marathon for MACS in 2018. She's agreed to meet one lucky MACS member and share her experiences of working in the media. Our MACS member will interview Emma about running the Marathon, as well as telling Emma about the difference she has made by fundraising for MACS.

Open to those with a MACS condition, aged 12 or over. Under 18s will need to be accompanied by an adult. The interview will take place in London at a mutually convenient date. Closing date to register your interest, 30th September. Apply here:

macs.org.uk/shadow-and-interview-a-radio-star

Our new CEO and some goodbyes



Fay Skevington

Our first ever CEO Fay Skevington

By Robbie Crow

It gives me great pleasure to announce the appointment of Fay Skevington as MACS' first ever Chief Executive Officer, in a voluntary capacity. Directly responsible to myself and the MACS Board of Trustees, Fay will lead our dedicated MACS' staff team over the next 6 months to ensure that the services we're delivering to you - our members - are at the highest possible standard. After an interview process Fay was the clear best candidate for the role and she has the support of the entire Board of Trustees. I'm excited to work alongside Fay to make MACS even better and take it forward to its next stage of development. Please join me in congratulating Fay!



Caroline Hornby



Louise Eggins and family

Goodbye and Thank You

Sadly, since the last Focus magazine was released, Caroline Hornby has stepped down as Caravan Coordinator and MACS Trustee. Louise Eggins has also stepped down as Regional Coordinator but remains Regional Supporter for Devon. We'd like to thank them both for their hard work in support of our members.



@macsthecharity



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Meet our new Trustees



Lisa and family

Lisa Jefferies

HI, I'm Lisa and have recently become a MACS trustee. My eldest son was diagnosed with a microphthalmic right eye shortly after birth. He also has nystagmus and a large macular scar in his left eye which means his overall vision is 6/48, however most people can't even tell he has any vision issues when they meet him!

We were first introduced to MACS during one of our many visits to Moorfields and were impressed with how friendly and happy everyone was. At the time the world of prosthetics was all rather new to us and it was really reassuring to meet slightly older children completely comfortable with their prosthetics and getting on so well. Since then, we've always made an effort to talk to other people who seem less assured waiting for their appointments so that they know they are not alone.

I also have two other sons, including the youngest born April this year, so we're definitely kept busy at home! Despite that, I wanted to become a MACS Trustee as I think the work done in terms of building a community and supporting families is amazing and something I wanted to help develop even further.



Rory and family

Rory Hallas

HELLO, my name is Rory and I am one of the new trustees at MACS.

I remember sitting at work and receiving a text from my wife saying that our 2-week-old daughter's left pupil wasn't circular but oval. I replied 'Of course it isn't!'. That evening we prised open her eye and it was very obviously a different shape. After some frantic googling, we diagnosed a coloboma, but the journey of discovery and worry started then. We found and emailed MACS not long after. Jenny called back almost immediately – the support and reassurance she provided was invaluable.

When the call went out asking for new trustees, I thought my professional experience could be useful. I have ten years' experience as an accountant, having trained with Deloitte. My career has been varied (as much as an accountant's career can be!), but I have always worked for large listed corporates, most recently the FTSE100 listed property company Landsec. I hope that my commercial and financial experience will complement the strength of the Board and ensure that MACS continues to provide the support that so many of us rely on.

Introducing our new Fundraising Manager Lindsay Dunlop!

HELLO!

I'm Lindsay, and I joined MACS a couple of months ago to work on fundraising, so that we can continue to support many more MACS families into the future. I've been a fundraiser for almost 20 years, having worked mostly for children's and health charities, so I'm hoping I will be able to apply everything I have learnt to successfully raise money for MACS.

Being new to the charity, I have to say that, from day one, it really has felt like one big family! It's not like any other organisation I've ever worked for, and it is truly something to be cherished. From the support on the Facebook groups, to the volunteers, Trustees and staff – everyone has been so welcoming, and so full of passion for MACS. It's incredible to have so many inspiring people in one organisation.

I've been brought in to raise the money we're going to need in order to achieve all the ambitious plans that have recently been shared with you. I know MACS already has enormously successful running and cycling teams, and I'll be working with Kaja and Yvonne to see how we can build on that even further. We're also thinking about introducing some different kinds of activities for people who want to do something, but aren't runners or cyclists – making sure there's something for everyone. So if you have any ideas of things you'd like to see us doing, please let me know – I'm open to pretty much anything!

I'm also going to be looking at other ways we can raise money. We'll be writing to charitable trusts and foundations to tell them about our work and ask them to support us. I'm also looking for companies who might be interested in sponsoring some of our activities, or making donations, or offering their staff time and expertise in various areas – there are all sorts of ways businesses, large and small, support charities. So if you have any contacts you'd be willing to share, or can help make an introduction for MACS, again, please do let me know. A personal endorsement is worth so much!

Finally, I know that community spirit is extremely strong in MACS, and I know there are people fundraising for us



all around the country. If you'd like to join in, by doing something small, or something big – if you have ideas, or if you have no idea – please speak to me! I can guide and advise as much or as little as you'd like, and we can support you with fundraising materials and anything else you might need too.

I was so happy to meet so many lovely families at this year's Family Weekend, and look forward to meeting many more of you over the coming months and years.



By Abbie Clive

Breaking Down Barriers With Lord Blunkett

Abbie Clive



ON SATURDAY 24th March 2018, I went to Sheffield to interview Lord David Blunkett for a MACS charity video. It all started when one of the other MACS parents sent me a message on Facebook with an advert saying that MACS needed a young MACS person between the ages of 12 and 25 to come and interview David Blunkett. My interest was piqued and I decided to apply. I was over the moon to receive an email a few days later telling me that I had been chosen to do the interview!

I was put in touch with Selina Mills who is a visually impaired journalist, she helped me to compose a list of questions to use in my interview. When the day finally arrived, I was very nervous as I hadn't ever done anything like this before, but once the interview got under way I found my confidence was growing by the second, and Lord Blunkett was such an inspiration. He really helped me with my nerves. Overall, I felt that the whole experience was one of the most amazing experiences I have ever had, and I would like to thank MACS for giving me this opportunity.

David Blunkett and Robbie



Robbie Crow says:

"I think today has been good for MACS because it's allowed us to broaden the appeal we have to our older members. Historically MACS has been very focused on offering support and guidance to parents of visually impaired children and also to young visually impaired children themselves. I think this marks a change in that we are starting to offer advice and guidance to MACS adults, who after they have grown up with the condition, now have to go into the world and live with the condition.

To have Lord Blunkett address the MACS members on his life, his career in politics and the barriers he's faced, I hope will allow visually impaired adults, like myself, and other MACS adults to learn that nothing is impossible and to aim for the top"

By Jonathan Attenborough

Tech Talk

Welcome to the 4th edition of Tech Talk, the section where MACS Trustee Jonathan Attenborough reviews the latest accessible technology.

WELCOME to another edition of Tech Talk where we talk about all the latest technology that help make everyday tasks easier for visually impaired people. Today I want to tell you about 2 very useful pieces of technology that I have recently been using to aid my mobility.

HUMANWARE TREKKER BREEZE+

The Trekker Breeze+ is a handheld GPS device designed by Humanware. Last year I attended a technology open day and was very intrigued by the



Trekker Breeze+. I have recently been lucky enough to get one of my own. This handheld device uses GPS technology to find your exact location and will speak out loud to help you know where you are and how to get where you are going either by foot or in a vehicle.

Before you set off on your journey you can enter where you want to go and it will help you get there by letting you know what streets you are on, when you are approaching a crossing point and when you have reached your final destination.

I find this device incredibly useful when trying to get around an unfamiliar city. It's also handy if I am on a bus - I can program what street I would like to get off at and the device will alert me when I get there. Most bus drivers are very helpful in letting me know when

I reach my stop but there have been times where they have forgotten and having the Trekker Breeze+ ensures that I don't miss my stop.

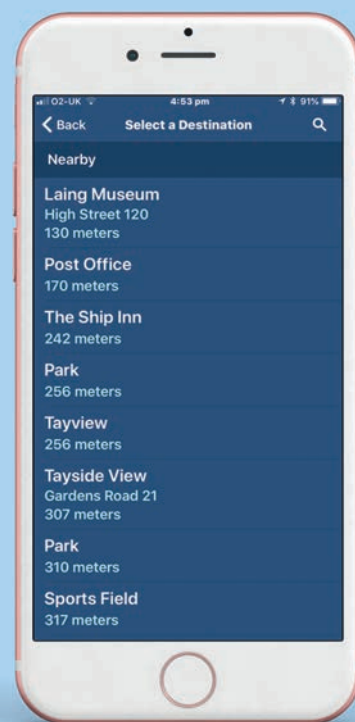
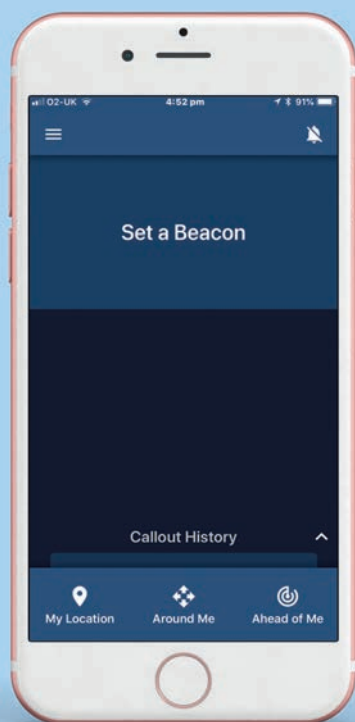
I believe Humanware have just discontinued the Trekker Breeze+ as they have brought out an updated version. However, they are still available to purchase from various retailers as well as second hand.

MICROSOFT - SOUNDSCAPE

Microsoft Soundscape is a new app created by Microsoft in collaboration with the UK charity Guide Dogs. Soundscape aims to give you a full audio map of your surroundings when you are out and about. This app was designed to give people with visual impairments more confidence to navigate and explore unfamiliar streets and environments. You have to use

headphones with the app to get the full 3D surround audio map. Guide Dogs recommend using a bone conducting headset so that it's not physically in your ear but I've been using the Bluetooth Apple AirPods. You can set a beacon as your destination and then you hear a sound as you travel so you always know which direction you should be going in. You could use it to find the location of certain shops, for example, in your right ear it might say "Tesco in 25 meters", or if it's on your left it will tell you in your left ear.

What I particularly love about this app is that it's compatible with the Apple Watch. This means that I don't have to take my phone out of my pocket to use any of the functions, all I have to do is tap the Apple Watch on my wrist. It's worth noting though that this app is currently only available for iPhone.



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

MACS Adults Talk Careers

Last November, we asked MACS Adults to tell us about their careers and were overwhelmed by the response. We featured 3 MACS adults in the December edition of Focus, and here is part 2 of that article, illustrating once again the different career choices our members are making and the ways that they are overcoming any barriers they face.



Sue Mustill Early Years Practitioner

I'VE HAD a long career, mainly in early years working with children in various settings. It nearly didn't happen though, the college I enrolled in "wasn't sure" if I'd be able to so the nursery nursing course I wanted to so put me on 6 months probation. However, all of the various workplaces I trained in had no problems with me at all and I gained my qualification, although I must admit in those days it paid to keep quiet about your disability – no legislation to protect you!

I've worked in private and local authority nurseries, as a private nanny and maternity nurse and run my own childminding business. In a Children's Centre and a Child Development Centre and with adults as a Healthy Eating Trainer, Volunteer Co-ordinator and a Childminding Network Co-ordinator. I would say that my lack of vision has not held me back at all, the only difficulties having been travelling in areas where public transport is poor and, while delivering the training, being unable to see people's faces to gauge their reactions – I might have been sending them to sleep!

As for the change in legislation since my career started, I wouldn't say that it has made things much easier. However, I will always take advantage if an employer is offering a guaranteed interview for disabled applicants that meet the essential criteria and I don't keep quiet about my disability any more. I think getting a job in the first place is the major hurdle, once you are there it's up to you to prove yourself. We all know how capable blind and visually impaired people are – it's others that need educating.



John Leadbeater

Views Administrator

I'M 36 and have bilateral microphthalmia and coloboma. I have a History degree and a postgraduate diploma in Medieval History.

After graduating in 2005, I struggled to find permanent paid work. Instead, I did temporary work, including some zero hours contract jobs, and 8 years of voluntary work. Luckily, in 2015 I did an employment programme through Incommunities - a housing group who help people facing barriers to employment. After completing their programme and passing an interview, I was offered a year-long placement at Football in the Community at Bradford Football Club. Happily, at the end of my contract the club took me on permanently.

My current role at Football in the Community is Views Administrator. It's not a graduate job but I enjoy it and it suits me well as I'm very organised and good at dealing with

deadlines. I'm also methodical and don't mind doing repetitive tasks. At present, I'm happy in my job but I'm frightened of being out of work in the future as my CV isn't as impressive as I'd like.

NEGATIVES

Unfortunately, I still don't have a graduate job or anywhere near a graduate's wage. Being out of work for so many years has meant that I haven't put as much into a pension as I would like. Although I've done lots of volunteering, this doesn't seem to impress employers as much as paid work would.

POSITIVES

In 2015, despite my qualifications, I thought I had no prospects - then I discovered MACS. Meeting other MACS adults who had fulfilling jobs, gave me the confidence to try again. Now, I have a job I enjoy with a good manager and colleagues who treat me no differently from anyone else. I see now that I have lots of potential. So, MACS helped me get into work!

Meg Reed

Wall and Floor Tiler

I'M MEG, I have Lenz Microphthalmia Syndrome. I was diagnosed at 2 days old and hardly knew a thing about my condition until I joined MACS except that it coincides with learning difficulties such as Asperger's Syndrome which I also have, unfortunately.

For the last 6 years I've been working with my father as a wall and floor tiler. My eyesight means I struggle to get certain cuts. It can be dangerous as well as I sometimes don't see things as I'm walking and often trip or misjudge distance.

I love my job; it's rewarding to make something with my hands and I like the freedom of being self-employed. Although it can sometimes be trying being female on a building site.



I have no interest in letting my condition rule my life as it did when I was a child; strength and

acceptance come with age. My condition will never stop me, and I hope it never stops others.





By Lisa Jefferies

Toys for VI Kids

8 Top Tips for Choosing Toys for VI Children

CHOOSING TOYS for any child, whether or not they have a visual impairment, can be a challenge. Often unexpected items prove popular and those we thought that they would love are complete ignored. Our son is completely blind in one eye and has a large macular scar in his other, impacting his central vision. His vision is 6/48. These tips and recommendations are based on what we have learnt with him.

1. TRY AS MANY TOYS AS POSSIBLE, BUT DON'T BE AFRAID TO THROW AWAY

Previously, we made the mistake of buying quite expensive toys that sat unused but we didn't throw them away because of their cost. Now we buy toys second hand at a fraction of the price - if they aren't popular, they go to the local charity shop and no one minds. Top places for bargains include:

- eBay – especially good for bulk buying Lego/Duplo
- Gumtree
- Charity shops
- School/Church Fairs

Lots of areas also have toy libraries where you can borrow toys for a nominal fee. This is a great way to try different things without cluttering the house.

2. DON'T BE AFRAID TO BUY TOYS FOR YOUNGER CHILDREN

A lot of our son's favourite toys are aimed at slightly younger children, but he likes them as they tend to be bigger and less fiddly, e.g. he prefers Duplo to Lego. When we try to get age appropriate toys that might help his development (e.g. puzzles), they just get ignored.

3. AVOID TOYS WITH TOO MUCH DETAIL

It feels like common sense when I write it down, but avoid choosing toys with too much detail or fiddly parts as there's little enjoyment in what can't be seen.

4. SORT TOYS SO THEY ARE EASY TO SELECT BASED ON MOOD

One of the best things we have done is box all the toys so that each box relates to a different kind of play – a box of Duplo, one of puzzles, another of musical instruments etc that are always in the same place. This means the boys can easily find what they are in the mood for, taking the pressure off their vision. We have gone for the IKEA Trofast range (www.ikea.com/gb/en/collections/trofast-toy-storage) as it was relatively cheap and the boxes are light so even when filled with toys our boys can carry them.

5. HOMEMADE TOYS ARE ALWAYS WINNERS

Out of everything, I would say it's the toys we've made ourselves that he's enjoyed the most. Partly this is because of the effort invested by him in making them, but also because they usually come straight out of his imagination. Most of ours are made from cardboard boxes. The great thing is that making of them is as much fun as the resultant toy. It also doesn't matter when it's time to throw them away.

We usually base it on whatever he's into at the time and then I use Google (the cooler amongst you might use Pinterest!) to get ideas.

The photo opposite shows one of his all-time favourite homemade toys. It was a great project as it was large and simple, so he could join in and get good results.

6. IMAGINARY PLAY

Games and toys that involve imagination and simulating real world activities are a big hit with our boys. Every day they pretend to cook dinner, be a builder, put out fires etc. There are so many things to support this play even just using household items; laundry baskets become boats, chairs are train carriages, etc. One of our favourite charity shop finds was a tea party set which they loved.

The great thing is that it is not very dependent on vision. Our son can see the snapping sharks swimming round our feet just as well as we can!

7. DEVELOP THEMES

We find that planning play around a specific theme is a great way of keeping attention and interest going. For example, we recently listened to the audio book of Charlie and the Chocolate Factory on a long journey. Our son loved it, so we then watched the film (thank you Amazon Prime!) and have been playing games such as having our own chocolate shop, inventing sweets, etc. We're now planning a trip to Cadbury's World so he can see inside a real chocolate factory!

8. TREASURE HUNTS

Making our own treasure hunts is great but our first treasure hunt was a bit of a worry. We'd been invited to an Easter Egg Hunt and the organiser called to ask what adjustments we needed. It was one of the first times we were shown that our son couldn't do what was easy for others. As well as some adjustments (e.g. slightly bigger eggs, a colour that was specific to him so not collected by the other kids etc.), we prepared by doing practice hunts and he loved them!

We've successfully tried lots of different formats. One involved leaving picture clues all around the house. We've also hidden chocolate in various places for him to find and created treasure maps that we've helped him 'read' to locate the treasure. This inspired him to draw his own maps which was great for his drawing skills as it's usually an activity he shies away from. We also had a hunt where he had a list of items he had to find and photograph. We used this camera <https://amzn.to/2NzhgtY> which he really enjoys. It has survived a lot of rather hard knocks and still works well.

By Lisa Jefferies

Toys for VI Kids: My recommendations

These can all be bought through Amazon Smile. It doesn't cost you any extra, but Amazon will donate to your chosen charity. MACS is registered, so we can receive a donation for every purchase made!



Crayola 'sidewalk' chalks

These are the best we've tried. They are particularly good for VI kids as they have a range of bright colours that show up well on the patio. Marks with other chalks have been harder to see. They are quite chunky so easy to hold and less likely to break than smaller chalks. That said, our children have still managed to break them, but they also destroyed a stairgate within two weeks (amongst other things) so I'm not sure I can hold it against the chalks!

£8.95 with Amazon Prime
<https://amzn.to/2KXJwb8>



Learning Resources Super Sorting Pie

This was a surprise favourite with our son. I bought it as I thought it would be a good 'educational toy' given his vision, to help with sensory development in his fingers (early preparation for Braille) as well as fine motor skill and concentration. I thought he would only use it with a lot of persuasion, but I was very wrong. He loves playing with it and there was a stage where he asked for it every day. For each colour, there are two fruits which can make some of the sorting more challenging. For example, the hardest is the orange colour which has an orange and a peach as the two fruits – both about the same size, but the orange one is textured. It's a great way to get him to use his sense of touch to distinguish between objects as the detail was too small for him to rely on his vision. Unfortunately, the game has had to be put away as his little brother kept putting the pieces in his mouth and it is a choking hazard for smaller children so I would not advise for those under 36 months or those who put everything in their mouth.

£18.25 with Amazon Prime
<https://amzn.to/2ugp4bb>



Casdon Supermarket Till

Both our boys have had hours of fun playing with this. I think it's good for VI children as the buttons on the till are quite large so easy to read and it also makes some great, realistic sounds. It is a real calculator with add and subtract buttons that actually work, so it can help children with basic maths in a fun way too. However, the feature that we enjoy most (even mum and dad) is the microphone which distorts your voice so it sounds like a real shop tannoy! Again, it's well thought out for a child with limited vision as the microphone button is a different colour from the other buttons and so easy to locate. The only downside is that you have to practically put the microphone in your mouth for it to work.

£14.49 with Amazon Prime
<https://amzn.to/2ztADBw>

By Kerry Cousins
our Regional Coordinator

Regional Shake Up

As we announced at the Family Weekend and in our Ambitions document we shared in May, we are revamping our regional offering. We have lots planned for the coming months so I'm delighted to have this chance to update you all!

INTRODUCING OUR CORE REGIONAL EVENTS

OUR CORE regional events are arranged centrally by me, Kerry, the Regional Coordinator. For these events the UK is split into larger regions. They will run in addition to those already provided by your local Regional Supporters and will be held in spring and autumn. The focus for these events is to get people chatting and making new friends, to ensure they feel less alone and that they have support when they need it. These events will give you a chance to build friendships with MACS families from a wider area that you might not have met before.

All core events will be in fully accessible venues and will involve a guided tour or group activity led by the venue. Then everyone can have a cheap and cheerful lunch together with the emphasis on getting people talking and socialising. So please bring along a sandwich and drink and we will provide the cakes and crisps. Our Autumn 2018 core regional events have now all been booked, anyone from any region can attend any event so we hope to see you there!

SEPTEMBER

8th September

Gloucester - Museum of Gloucester

8th September

Yorkshire - Coal Mining Museum

15th September

Somerset - Museum of Somerset

29th September

Leicester - New Walk Museum & Art Gallery

OCTOBER

6th October

Reading - Reading Museum

7th October

Tring - Tring National History Museum

13th October

Edinburgh - National Museum of Scotland

13th October

Carmarthenshire - Wool Museum

27th October

Northern Ireland - Ulster American Folk Park

NOVEMBER

3rd November

Coventry - Transport Museum

11th November

Manchester - Museum of Science and Industry

17th November

London - Science Museum



Yorkshire Coal Mining Museum



Tring National History Museum



London Science Museum

IF YOU ARE INTERESTED IN ANY OF THE EVENTS ABOVE, PLEASE VISIT [MACS.ORG.UK/REGIONAL-EVENT-BOOKING-FORM](https://macs.org.uk/regional-event-booking-form) TO BOOK

Want to help?

IF YOU have some time and would like to volunteer for MACS we are recruiting for regional volunteers, especially in areas that may not be covered now.

You could become a Local Event Organiser. We have some lovely events going on that our current volunteers have planned, but there

is always room for more! Please sign up at the weblink below or email kerrycousins@macs.org.uk
<http://macs.org.uk/become-a-local-event-organiser/>

Alternatively, you could become a Peer Supporter. Peer Supporters offer understanding and a listening

ear for other MACS members. Please sign up at the weblink below or email kerrycousins@macs.org.uk
<http://macs.org.uk/become-a-peer-supporter/>

And if you're really keen, we'd love to welcome you on board as both a Peer Supporter **and** a Local Event Organiser!

Images have been taken from the venues websites with permissions granted, but should probably be credited/captioned as follows:

National History Museum Tring (The Trustees of the National History Museum, London ©)

Coal Mining Museum Yorkshire © | Science Museum, London ©



@macsthecharity



facebook.com/MACSCharity

Guide Dogs: helping children, young people and their families

Guide Dogs has been best known as the provider of the iconic guide dog service, however the work of the charity now encompasses much more.



IN THE UK, two in every 1,000 children and young people under 25 live with a vision impairment. Guide Dogs now provides a range of support to those children and young people with a vision impairment, to give them and their families the future they deserve. Guide Dogs' Children & Young People's services offer parents, guardians and carers information, advice and guidance from the moment their child receives a diagnosis of vision impairment, all the way through to adulthood.

SUPPORT FOR YOUR FAMILY:

Guide Dogs' Family Support team can provide support following your child's diagnosis, up to 25 years old. Drawing on many years of experience within the vision impairment sector, our specialist

team can sensitively explain terminology and the impact of a sight impairment, as well as help with accessing benefits.

The Family Support staff are on hand to provide active listening, emotional support, reassurance and refer on to any appropriate eye condition groups or other support organisations.

EDUCATION, HABILITATION & ACCESS TECHNOLOGY:

As your child grows, Guide Dogs' habilitation services can help them to achieve as much independence as possible in their daily lives. Qualified staff do this by providing personalised training and support in mobility, orientation and independence skills.

When it comes to your child's education, the charity can advise on issues such as your statutory rights and entitlements, Education, Health & Care assessments, plans and reviews and key transitional stages.

Also available is independent, expert advice and support on all accessible and standard technology and software, with a grants scheme that can provide 90% toward the total cost of funding for equipment and software, where no statutory funding is available.

Guide Dogs also offers CustomEystailor-made large print books for both educational and leisure purposes.

RECREATION:

Guide Dogs provides recreational activities, where families can take a break and meet others in a similar situation, whilst children and siblings have fun. Family Days Out are a great way for families to find out more about the variety of children and young people's services available to them.

ADULT SERVICES:

As well as provision for children and young people, Guide Dogs offers a range of services into adulthood, supporting people to achieve their personal independence goals and aspirations. As well as the guide dog service, with no minimum age requirement for this service, many more people now access the charity's wider range of adult services, which includes the volunteer-led sighted guiding service, "My Guide".

To find out more, please visit <http://bit.ly/CYPMACS>, contact the Advice Line on 0800 781 1444, or alternatively email: cypservices@guidedogs.org.uk

By Caitlin Brister

Activity trips to remember!



Sailing

ONCE AGAIN MACS is hosting an adventure of a lifetime sailing trip! If your child is aged 12-20, join us in Brixham, Devon on the 31st July for a 7-night adventure, returning to Brixham on the 7th August.

This trip gives young people the opportunity to visit new places, learn new skills, and make new friends. From hoisting sails, steering the ship, and navigation, to learning invaluable skills like cooking, cleaning, and teamwork - there's plenty to do throughout the week.

Due to the nature of this trip, it's essential the young people work as a team to be able to sail the ship. This improves their teamwork skills and also their confidence levels, 100% of the 2017 attendees agreed that their confidence levels increased as a result of the trip. There is constant support from qualified staff, but the young people also learn to support each other throughout the trip, resulting in brilliant friendships.

"I love sailing, I look forward to it every year! This trip is an amazing opportunity to do something different and exciting. I enjoy steering at the helm, making friends, and hoisting the sails!"

MACS young person, 2017

Our chosen provider, Ocean Youth Trust South, is widely regarded as one of the best sail trainers in the UK and puts safety at the heart of everything that they do. Young people are guaranteed to have an adventure of a lifetime whilst being safe and supervised.

Caldecotte Xperience

AFTER THE success of last year, MACS is running two trips to the Caldecotte Xperience in Milton Keynes. Caldecotte is a fully accessible activity centre, suitable for all ages, and for disabled and non-disabled people alike.

Children with MACS conditions aged 5-10 can join us on 10th August - 12th August for a weekend of fun-filled activities with an accompanying parent or guardian. Young people aged 10-18, whether they have a MACS condition or are a sibling, can join us on 12th August - 17th August for 5 days of action-packed outdoor fun. Those on the older trip will be supervised by qualified support staff, and 1-1 support workers are available if needed.

You will spend your time sailing, rock climbing, caving and trying lots more activities but most importantly making friends and working as a team. 75% of 2017's children agreed that they made new friends during the trip. It doesn't matter what your ability, all that matters is that you have fun and try things you've never done before. Joining your child on this trip will give you the chance to build an irreplaceable bond and see them achieve the most amazing things!

"My favourite thing was just seeing her do things I never in my wildest dreams would have thought I'd ever see her do."

MACS parent, 2017

"It was my first time on the adventure holiday and it was fantastic. Everyone was kind and friendly and all the activities were so much fun!"

Further Information

The cost for each event is £50 per person, this includes, all food, accommodation, and activities.

Don't worry if you missed the opportunity to join one of our 2018 trips, please visit macs.org.uk/affected-by-macs/adventure-trips to keep up to date with our 2019 adventures.



@macsthecharity



facebook.com/MACSCharity

Virgin Money London Marathon 2018



ON 22ND APRIL, 140 runners toed the start line of the London Marathon sporting their blue vests and t-shirts representing MACS. It was a brutally hot day, but despite the conditions our team did an amazing job at not only tackling the challenging run, but also in raising money and awareness for MACS in the process.

In the months leading up to the marathon, the runners engaged in all sorts of fundraising activities – raffles, head shaves, bake sales and many other events took place in workplaces and around local communities all over the UK, with individuals getting coverage in their local newspapers, and asking employers for their company's support.

They have raised an amazing £250,000 for MACS so far, with more still coming in! Well done to

all our runners! Every penny will be spent on improving life for children born with MACS conditions, and the many messages of support from the children and families who will benefit were testament to the tremendous value of each runner's efforts.

and to the fabulous families who turned up on the day to cheer our team on! We received some amazing feedback and heartfelt thanks from many runners who were very grateful for the support of our families and felt honoured to run in aid of MACS.

"Running the London Marathon for MACS was one of the most rewarding experiences of my life! It was a very tough day but raising valuable funds and awareness for the wonderful MACS children and families, who came out in force to support us, made it more than worthwhile. I'd do it again in a heartbeat"

Sandra, MACS team, 2018

Our grateful thanks to all of the runners, to the MACS families who took the time to post good luck and thank you messages to our team on Facebook,

If you are interested in taking part in or supporting next year's London Marathon, we are waiting to hear from you!

Here is an interview with one member of Team MACS, Nick, telling us how he found the experience of running for MACS.



WHAT MADE YOU WANT TO RUN THE LONDON MARATHON FOR MACS?

Firstly, the London Marathon is the ultimate opportunity to push myself and see what I'm capable of. Secondly, as a father, my children's happiness is paramount; they are everything to me. Therefore, to hear of children and families who feel alone and helpless as a result of something completely out of their control is heart-wrenching. Pushing myself to run 26.2 miles was far easier knowing that I was helping to make a real difference in children's lives.

Finally, on a purely selfish note, I wanted to beat my younger brother's London Marathon time of 4:05 and regain bragging rights at our family's dinner table!

HOW DID IT ALL GO?

The run itself went (largely) to plan. I took it quite a bit slower due to the heat and settled into a nice, steady rhythm for the first 13 miles, leading into the sharp right turn towards

"I don't think it's truly sunk in just how much of a monumental achievement this is – not just for me, but for all MACS runners"

Tower Bridge – a moment that I will never forget. When I got to the MACS cheering point at mile 21, the sight of the MACS families and supporters was just the boost I needed. Their encouragement was invaluable as I found myself hitting the wall. I'm not going to lie – the final 5 miles were a slog, but I forced myself to keep running (partly because I knew if I started walking I wouldn't actually get running again!). Seeing the finish line

as I came down the Mall, and running over it, is an experience that will stay with me forever – I couldn't be happier with how today went and I was over the moon to record a time of 3:12:29. Thank you, as well, to Robbie, Jenny and Ben who were there at Horse Guards Parade – Jenny and Ben's hugs were just what I needed after that gruelling race!

I don't think it's truly sunk in just how much of a monumental achievement this is – not just for me, but for all MACS runners. We haven't just run the London Marathon, we have completed the hottest London Marathon ever recorded! None of us will have trained in temperatures of 23° which only magnifies the brilliance of our achievement.

Finally, reading and watching the MACS families' messages of support on both Facebook and Friday's email was such a huge inspiration. They were what kept me going today: that knowledge that what I was doing was not only raising money to support this amazing charity, but also raising awareness of conditions that many people don't even know exist. I'd like to thank MACS for giving me the opportunity to run this year's London Marathon – it has been an ambition of mine for several years to run this most iconic race, and I cannot thank everyone at MACS enough. It has been a real honour to represent this charity and the wonderful work

it does – and I'm sure that's a view we all share. It feels completely surreal that it's all done and dusted... Even madder is the fact that I'm considering doing it all again for MACS next year... watch this space!

Thank you once again for letting me be a part of team MACS - Sunday was a day I will never, ever forget and, despite the intensity of the heat, I loved (almost) every moment of it!



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 Address: MACS, Suite 472, Kemp House, 152 City Road, London, EC1V 2NX | Registered charity number: 1161897

