



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

ISSUE 10
MARCH 2019



ANNIVERSARY

FOCUS MAGAZINE

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

WELCOME!



DEAR FRIENDS,

In this very special edition of Focus, the first of our 25th Anniversary year, I want to let you know our exciting plans for special new services, how you can get involved in our 25th Anniversary Campaign,

Chair's Foreword

as well as share our good news after a successful Trustee meeting held in January.

I'm delighted to see the organisation growing, as we welcome Caitlin and Sharon to the team. Sharon will be building on Kerry's great work on regional events, and we look forward to some really special events for MACS' 25th anniversary. Kerry will now be looking after another of our exciting 25th anniversary services, helping to organise a special trip to the Centre Algarve for our members. And Caitlin will be working to improve our administrative practices and making sure we comply with GDPR, by helping to put our new management system in place.

In terms of a positive start to the

year I don't think MACS has ever been in such a strong position. Thank you to everyone for making it happen!

In this edition of Focus, you will find updates on regional events, family and activity breaks, as well as our regular Tech Talk feature and an interview with one of our young members, Charlee. We are always looking for members willing to share their stories, so if you'd like to contribute to the next edition please let us know! Enjoy the read!

With my best wishes,

Robbie

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Thank You

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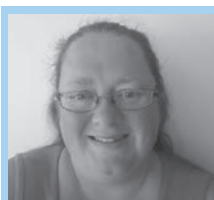
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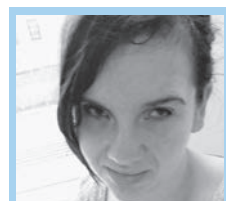
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& Coloboma Support**

Supporting children born without eyes or with underdeveloped eyes

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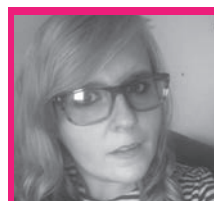
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Say

'HELLO'

to some of our newest members!

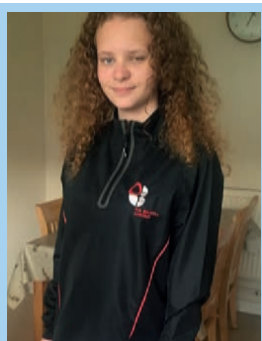
We are delighted to have been joined by many new members this year, including:



Kailo



Jax



Kitty



Polly



Annabelle

'HELLO' EVERYONE!



Caitlin

I'M CAITLIN. Some of you may know me from helping with the photographs at the Family Weekend throughout the years, and from supporting at Caldecotte 2018. I have been part of MACS all my life – since before I was born to tell you the truth! My brother Luke has unilateral microphthalmia and I have been brought up as part of the MACS family. I know how invaluable the support from MACS can be and will hopefully be able to pass this on.

I was thrilled to be given the opportunity of becoming the IT Administrator for MACS and am looking forward to giving back after all the support I have received. I will be helping to keep all of your data safe and up to date to ensure you receive all the support you need!

I hope to see you all at an event soon, Best wishes,

Caitlin



ANNIVERSARY

2019 marks the 25th anniversary of MACS officially becoming a charity. That's a quarter of a century providing life-changing support to families affected by MACS conditions! We are planning an array of exciting activities to celebrate this milestone throughout the year.

SAVE THE DATE!

We are delighted to announce that for our 25th anniversary, we're launching the first ever MACS Awareness Day. This will take place on Monday 1st July 2019 (aka MACS Monday!). We hope you'll be just as excited as we are to raise awareness of MACS conditions, showcase our inspirational members, and celebrate the support that MACS has offered over 25 years.

TIME TO CELEBRATE MACS' Big Birthday Bash

We're currently planning for a big day of family fun this summer. We'd love to see as many families as possible to celebrate 25 years of MACS together. We'll be sharing details soon, but we can promise that we'll have lots of activities for everyone, lots of birthday cake, and a certain MACS the Monkey making an appearance!



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Share Your Birthday With **MACS the Monkey!**

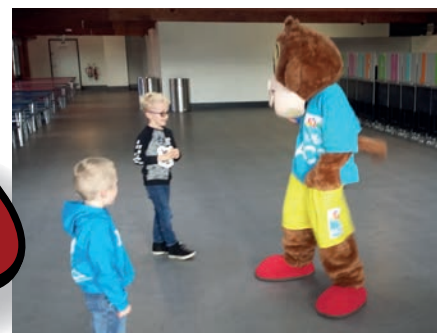
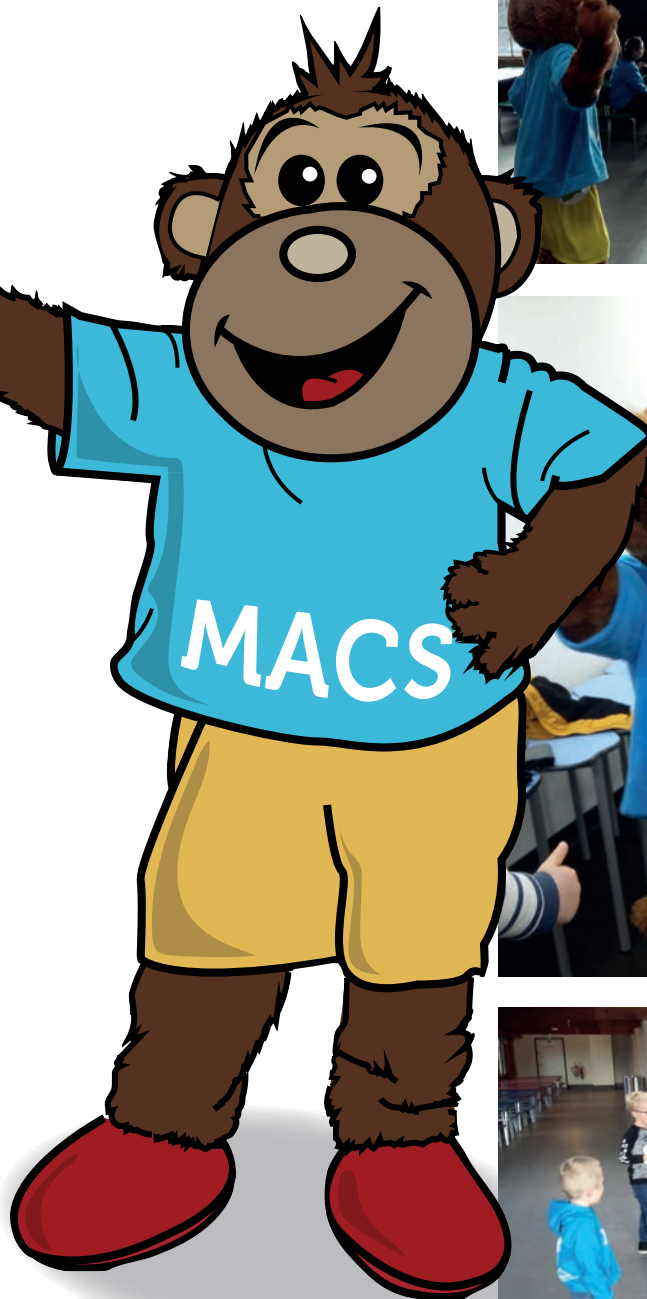
Share your birthday with **MACS the Monkey!**

In celebration of MACS' 25th birthday, we will be offering MACS members the chance to share their birthday with MACS the Monkey this year! Our party package will include:

- MACS balloons
- Party bags and contents, including a copy of 'What Makes You You' for each guest, and other MACS gifts and accessories
- MACS the Monkey party invitations
- Ideas for party games for children with VI and other disabilities
- Hire of MACS the monkey costume
- Support for those who would like to ask party guests for donations to MACS

If you'd like a MACS the Monkey Birthday Party, please email Sharon@macs.org.uk and let us know whose birthday it is and when the special day will be. MACS is a very busy monkey, so please book in early to avoid disappointment!

Fay Skevington, MACS CEO, says "For TJ's 5th birthday party in January '19, we asked for donations to MACS instead of presents (our little house can't take any more toys!). I was overjoyed that we raised £135 on Virgin Money Giving – and overjoyed that we didn't have to find space for more plastic in the cupboards!"



MACS Celebrates 25 Years!

2019 marks the 25th anniversary of MACS officially becoming a charity. That's a quarter of a century providing life-changing support to families affected by MACS conditions! We are planning an array of exciting activities to celebrate this milestone throughout the year.



Glitz 'n' Glam Family weekend Celebrating our Silver Anniversary.

There could be no other theme for a grand celebration of MACS' 25th anniversary! We're looking forward to an evening of Glitz and Glam so dust off your glad rags and get ready for a sparkly party full of fun with friends old and new!

If you haven't signed up already, please complete your booking form here: macs.org.uk/fw19-booking-form

Family Weekend is the heart of the annual MACS calendar, and this year will take place from the 3-6 May in Park Hall in Chorley. If you've never been before, please join us and we'll look forward to welcoming you into the MACS family! Many lifelong friendships have started at family weekend, and it's a great opportunity to be around people who know what you are going through, and meet people who will inspire you.

We've got some exciting new activities this year as well as our old favourites like MACS has got Talent, and a trip to Rock and River for our older kids. We're delighted to announce our keynote speaker is Gavin Neate, founder and creator of the Welcome app (which Jonathan Attenborough reviews on page 17). Gavin will be talking about how embracing digital technology can make lives easier.

Parents and adults:

Find your voice: Full day workshop aimed at young adults aged 16-35 (including adults with MACS conditions, siblings and parents, but open to adults of any age). Exciting programme includes:

- **Working with a professional voice coach**
- **Leadership training**
- **Find your purpose**
- **How to make your voice heard**
- **Awareness Ambassadors Academy**
(Social Media training - optional)

Scholarships (covering travel to and accommodation at Family Weekend) available for aspiring social media influencers who'd like to join our Awareness Ambassadors scheme.

Centre for Appearance Research: This year, we are delighted to introduce new research collaborators from the Centre for Appearance Research at the University of the West of England. In our 2017 survey, members told us that supporting their children around their appearance was something that they wanted MACS' help with. We're overjoyed that Claire Hamlet will be joining us to share her research on supporting young people affected by visible difference, and share early findings on what helps young people with visible difference thrive.

My MACS Journey: your chance to help new MACS families. We know families want more information about MACS conditions on the website, especially when they first receive a diagnosis. This workshop will allow you to share what you've learnt on your journey to help create an online resource for new families.

We'll also have a range of sessions offering support and advice, including:

- **Education**
- **Habilitation**
- **Prosthetics**
- **Dads and Lads session**

MACS Celebrates 25 Years!

Other exciting sessions we are planning to offer this year include:

Young people aged 8-18

"MACS means..." Creative podcast and animation workshop (onsite).

Working with Youth Leadership specialists Leaders Unlocked and creatives from communications agency COUCH, a team of MACS young people will work with

soundscapes and mood-boards to create a storyboard for a podcast and accompanying animation. Young people will have the chance to explain MACS conditions in their own words, and the work from the family weekend will turn into content that will have pride of place on the MACS website.

MACS Means

Experience

FUN

FRIENDS

Family Support

ADVENTURE Activities

Rock and River – offsite outdoor adventure:

A favourite for many MACS young people – your chance to try out a range of adventurous activities.

"This is me" dance workshop: Led by Caitlin and Tori this is a chance for a small group of young people to work on a choreographed routine which they'll perform later for Family Weekend Attendees.

Kids aged 0-10

We're happy to welcome back our children's activities providers from 2018, and look forward to another fun-packed day for our youngest MACS members. In the afternoon, we've got an extra-special sensory science session, so our kids can become little experimenters with activities that are accessible for all.

MACS Awareness Day

Bring MACS Awareness Day to your local school

FOR MACS awareness day, we'll be offering schools a fantastic pack full of activities and resources around MACS conditions, acceptance, anti-bullying, VI sports, and fundraising for MACS. This is a fantastic opportunity to help your school become a supportive environment for children with MACS conditions, or any other conditions which might make a pupil feel different.

We want to get MACS awareness day into at least 100 schools around the country – can you help us get in contact with your local school? Email helen@macs.org.uk with the subject line 'Schools Awareness', and tell us the name and location of the school, whether it's primary or secondary, and whether a MACS child attends the school.

Become an Awareness Ambassador

WE ARE looking for a team of aspiring social media influencers (aged 16+) to help us raise awareness of MACS conditions and help us build a buzz around our Awareness Day.

If you want to tell the world about your experiences with MACS conditions, whether that's through blogs, vlogs, podcasts, Instagram, Facebook or Twitter, please get in contact. We'll be offering professional training at Family Weekend, including a voice coach, technical training (sound and video), advice on building your brand and much much more. Scholarships (covering the cost of travel to and accommodation at Family Weekend) are available for those signing up to the Awareness Ambassador programme. Please contact kaja@macs.org.uk if you think you could be the next MACS Zoella!

SHARE YOUR STORY

To bring awareness of MACS conditions to a wider audience, we need families and individuals who want to share their stories, online, in print or on film. You might even get a free family photo-shoot! If you'd like to share your story, please contact kaja@macs.org.uk

A Helping Hand

WHILE TECHNOLOGY can make life easier, many items can be costly and out of reach. MACS can help to make useful equipment and activities available to everyone. To date, we have helped to purchase Brailers, talking microwaves and mobile phones, music

therapy sessions and bike adaptations, and we are pleased that we will be able to continue providing this support for families this year.

In order to help us make the most of the limited funds we have available, we'll be helping our

members to apply for funding from other charities, and using our funds for things that cannot be funded from others. If there's something you think you need a helping hand with, please fill in the form and Kerry will be in touch soon!

<https://macs.org.uk/helping-hand-application-form/>



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Introducing Sharon

My name's Sharon and I am the new Regional Co-ordinator. What an exciting time to join the MACS family in the 25th Anniversary year! I am really looking forward to working with the team and to meeting you all eventually.



HI EVERYONE!

My niece Grace has right side microphthalmia and coloboma. Grace was diagnosed when she was a few weeks old and is almost a teenager now. My sister Lynn and brother in law Keith got involved with MACS in 2006, so I have been on the periphery of the charity for many years. I have helped make costumes for Family Weekend many times, and I now look forward to being more involved with those events (and I imagine I will still be helping out with costumes!).

I am based in Liverpool. Amongst other things I have worked for the Royal National Institute for the Blind, the Prison Service and in a hostel for vulnerable people – quite varied,

but all involved working with and for people who needed support. I love meeting people and travel, so I hope to attend lots of MACS events and meet many of you soon.

If you would like to join me in planning events, if you have any ideas for new experiences and venues, or if there are any events that you particularly enjoyed and would like to revisit, please don't hesitate to get in touch with me at sharon@macs.org.uk. There's space for everyone and I'd love as many of you as possible to be involved in creating some wonderful, welcoming and inclusive events for all our MACS members!

I hope to see you soon

Sharon



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

Regional Events

UPDATE



WELL, 2019 will be a year of 25th Anniversary celebrations running alongside our events, so if you've never attended before this would be a wonderful time to start. I aim to have at least one event in all areas of the UK and I'll need your help and participation to achieve that.

We are still planning this year's regional events, but I think it's important to point out for those who haven't attended before the focus is not just having a fun day out.

THERE IS SO MUCH MORE....

MAKING CONNECTIONS - meeting others who know what it's like and you don't have to explain too much



SUPPORT - feeling less alone and knowing you will have support when you need it

BUILDING FRIENDSHIPS - making new friends, catching up with old friends

SHARING EXPERIENCES - of the day and of how to get through life with MACS conditions

SIBLINGS - meeting other siblings, sharing their support and experiences of coping in a MACS family and you get a lovely day out too!

"It was lovely meeting people who understood how we felt and what we were going through on a daily basis. It is nice to know we aren't alone with the daily struggle with the condition."

"We had a lovely time and we felt very welcomed. Appreciated the advice, friendship and wisdom from other members. And it was lovely to meet little ones with similar conditions for the first time."

All our MACS events will be in fully accessible venues and will involve a group activity and a picnic, lunch or dinner. Anyone from any region can attend any event so we hope to see you there!

We asked members for suggestions for this year's events and so far we've had: bowling, Lego Discovery, Bradford Science and Media Museum, Coombe Abbey Country Park and Herbert Art Gallery. If you have any other suggestions, please let me know.

If you would like to get involved, I'd love to hear from you on sharon@macs.org.uk

See you soon!

Sharon

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!

Alternatively, you could become a Peer Supporter. Peer Supporters offer

understanding and a listening ear for other MACS members. Please email sharon@macs.org.uk to ask for more information. And if you're really keen, we'd love to welcome you on board as both a Peer Supporter and a Local Event Organiser!

Featured MACS
Member:
CHARLEE JARVIS



GET IN TOUCH

Would you like to share your story in the next edition of Focus? Please let us know: kaja@macs.org.uk

Through my Eyes

Charlee Jarvis talks about education, job hunting and full time employment with VI

HELLO, MY name is Charlee. I was born with Microphthalmia and Coloboma. I am going to be turning 21 this month, and I really wanted to share with you some of my experiences.

Growing up with a visual impairment was challenging at the best of times. There is no 'one size fits all' when it comes to our eyes. Everybody looks, feels and sees things differently. When I was younger, I would read the articles in this magazine and I would search for the hope that when I grew up, everything would be okay, and that I would be able to live a normal and fulfilled life too. I would read the stories of MACS adults and I would aspire to become one of the courageous and inspirational people that they are. Now, I hope that it can be my turn to give back some of the courage, determination and pride that MACS installed in me, to the MACS children of today.

I have been through the "denial phase": I knew that I couldn't see, sure, but I didn't like admitting that I needed help. I didn't want to be different. I watched my friends passing their driving tests, finding employment and moving on with their lives, and I had the fear that I would never have these things because I couldn't see. But for every one "you can't" thrown my way, MACS families gave me 300 "yes you can"s. Being this way has made me resilient –

I learned that it doesn't matter how many times you fall, or how you fell in the first place, it just matters how you get back up again.

I studied at a mainstream school, I always have since playschool. Yes, it had its ups and downs. It's not fun when you swing the cricket bat before the ball was even thrown, or when you answer the teacher's question that was asked to somebody else because you couldn't see who she was looking at. But I soon learned the art of compromise, and started learning Braille during my PE lessons. I got to A-level years, and so many of my teachers told me that I wouldn't cope, that I should just take the easy path and study simpler subjects. So many days I would come home to my mum and just cry, and say that I couldn't do it. Luckily, I was blessed with 4 working pairs of eyes, in the form of my mum, my sisters and my little brother. Who needs a cane when you've got them guiding the way? I can remember revising for my English exams with my big sister in the waiting room of Ocular Prosthetics at Moorfields. Good things come to those who wait. I got A*ABB in General studies, Sociology, Theatre Studies and English Language.

I think that something all of us worry about is finding a job. It's not easy when you don't get first pick of them, and sometimes people see your eye condition before your personality and capabilities as a person. After school, I spent almost two years looking for work. I went for so many interviews, and had so many knock backs, when I just needed somebody to give me a chance. At points, I felt like giving up. If it hadn't been for my family, and

for the support of MACS, I probably would have. I kept going, because if there is one thing being a MACS baby taught me, it's that you can be blind, and still be a beautiful person inside and out. You are capable of doing anything a sighted person can do – you just do it better.

Now I work full time on the RNIB Helpline. I finally got to take all of my passion and my anger at being blind, and use it to help others. It is so important to remember that visual impairment doesn't have an age range, it doesn't have a gender or nationality, it comes in many forms.

As well as being a coloured cane specialist on the helpline, I am currently working on a community leadership project which involves bringing young visually impaired people together, creating relationships and building confidence. I am planning a telephone group for 18 -30's to create a safe space to just talk, share common experiences, and be a part of a group where everybody is equal.

I have been lucky enough to be blessed with two families, one of which is MACS.

Thank you all for supporting me as I learnt and grew. Thank you to my big sisters for making me strong and independent. My sister Bella is running the London marathon next year. She taught me to be the best me that I could be. My sister Danni taught me how to be accepting of the things I cannot change. And thank you to my mum, for raising me to be fearless.



Adventure BREAKS

Last year's adventure breaks were partially sponsored by the Alpkit Foundation.



Caldecotte Xperience A week of adventure

CALDECOTTE XPERIENCE is our annual adventure break featuring sailing, rock climbing, caving, and trying new things, but most importantly, making friends and working as a team. Last year, the first three days were aimed at children aged between five and ten who attended with a parent, with the final five days for children aged ten and over who attended without a parent. In total, 41 people got to experience this amazing week of adventure. All took part in a wide range of activities including canoeing, sailing, paddle boarding, power boat driving, climbing, caving, abseiling, archery, zorbing and a trip off site to the nearby Snow Zone to take part in sledging activity.

100% felt proud
of something they
achieved on the trip

"I am looking forward
to next year already!
Thanks"



"He loved all the activities and spending time with the other children. He's an only child and gets lonely at home."

The Older Children

19 CHILDREN aged 10+ took part in the five night adventure, which they attended without a parent. Last year saw the introduction of a pilot mentoring program for young people, with a view to helping them to develop skills for future employment. Three young adults with disabilities took part, (all had previously been attendees on our adventure week, and so were familiar with the types of activities) and were aiming to support younger members to get involved and develop new skills.

"She learned to look after herself. Showering and keeping clean and setting up for breakfast."

The Younger Children

11 YOUNGER children took part, each accompanied by a parent. At the start of the weekend, parents were asked to write down at least one objective they would like themselves and their child to achieve and place them in a jar. At the end of the weekend these objectives were revisited and parents were asked if they felt they had achieved their goal. Nine of the 11 parents reported they had achieved their original goal and the remaining two parents reported achieving more than just their original goal.

One of our parents described to the group how difficult it was for their child to make friends at school as everyone just wanted to mother them - the parent was overjoyed to see their child develop friendships and play and talk with the other children on the trip.

"My favourite part was seeing her interact with other children appropriately. That has never happened before and honestly it made me cry seeing her with the other girls playing games and become more confident with using her cane because it was second nature because her friends had them and her just having fun."

"The best things were the activities and making new best friends forever. Speed boat, climbing, everything."

The registration of interest form for this year's activities is already available on our website
macs.org.uk/adventure-breaks-2019-register-interest/



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facebook.com/MACSCCharity

EXTRA-SPECIAL

Family breaks programme for 2019

You may already be familiar with our caravans in the Lake District and Dorset, and these two locations will continue to be part of our family break options.

AT FAMILY Weekend 2018, we asked families whether MACS should arrange a trip abroad and the answer was a resounding 'yes' so we're delighted to say that our first overseas holiday is happening soon! We have arranged for around 10 MACS families to stay at the Centre Algarve in Portugal in the May school holidays. The centre is perfectly set up for people with additional needs and has some fantastic activities onsite which we know our families will enjoy. For example, they have an onsite petting zoo where children can interact with goats, exotic birds, tortoises, meerkats and plenty more exciting creatures! They also have a swimming pool with a hoist so everyone can enjoy a swim in the sun. Their gardens are set up to give visitors a wonderful sensory experience with amazing tastes, smells and sounds to enjoy. They also have their own sensory room which is the perfect place for our families to spend time when they've had enough sun.

MACS will be paying the majority of the accommodation costs for the families attending but many will be covering the costs of their flights themselves. Where families are unable to pay for flights though, we are going to work with them to try to get these costs covered by another charity. This means this really is a low-cost way for our families to get a break in the sun and we couldn't be more thrilled for them!

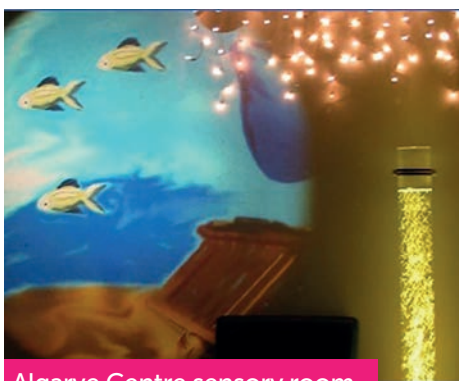
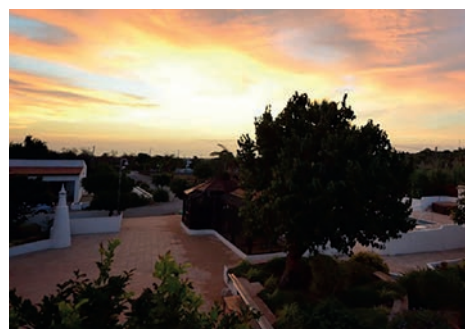
Our 2019 trip is now fully booked so but if you would like to go on a waiting list please email enquiries@macs.org.uk. We can't wait to hear how this year's trip goes and will share all the feedback with you in the next edition of Focus. Who knows, if it's a success we might be helping plan your family's trip to the Algarve next year!



Lake District caravan



Algarve Centre resort



Algarve Centre sensory room



Children stroking rabbits at the Algarve Centre

Photos: CentreAlgarve.org

By Jonathan Attenborough

Tech Talk

Welcome to the 5th edition of Tech Talk, the section where MACS Member Jonathan Attenborough reviews the latest accessible technology.

WELCOME to a new edition of Tech Talk where we tell you about the different technology and accessibility equipment available to help people with visual impairments in their every day life.

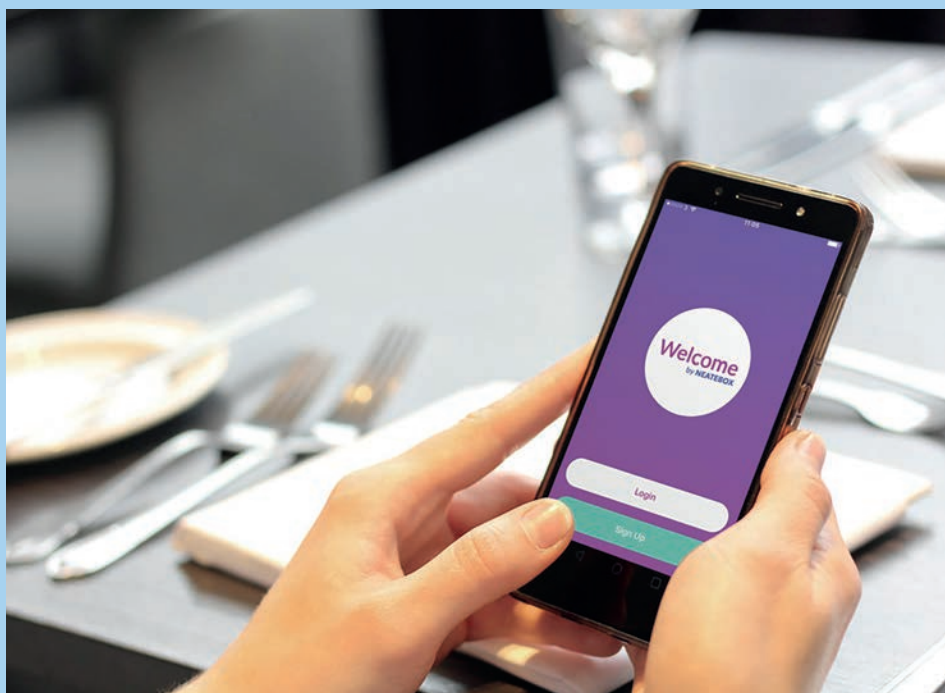
Today I would like to tell you about a small technology company based in Edinburgh called Neatebox that has been making big strides in improving the customer service experience for people with disabilities with their app called 'Welcome'.



WELCOME

Welcome App by Neatebox is available on both the Android and iOS store, and is an app designed to help retailers and businesses assist customers with disabilities. People can download the Welcome app and create an account. During the account setup process you can state what your disability is and how you would like to be assisted when you arrive, this way the venue knows in advance how they can help you when you arrive.

For example, I tested this when I went for lunch at the St. Andrews Clubhouse restaurant. The day before I went, I opened the Welcome app, looked up the venue and specified the time I was going, what I was going for and what I would need assistance with. This then notified the venue of my visit and they knew in advance that I had a visual impairment and would have a guide dog, and that I would like assistance through to the restaurant where I would be having lunch. The venue is also given



information such as not to interact with or distract guide dogs, to introduce themselves by name when greeting you, and to ask how they can best assist you. When I arrived at St. Andrews Clubhouse I was greeted at the entrance and taken through to the restaurant as requested through the app. Once I had finished lunch, a member of staff assisted me to the exit as well.

So how does this work? Well, venues that have been set up as 'Welcome venues' have their premises surrounded by what is called a geofence, which is a virtual boundary set by GPS. When you enter into the geofence boundary, the venue receives an automated phone call to let them know you are approaching. They then receive a second phone call once you enter the venue to let them know you have arrived. You don't even have to have the app open on your phone, as long as you have registered and notified the

venue in advance that you are coming, they will know when you arrive and how to assist you. Needless to say, this improved my customer experience massively by not having to try to find a member of staff to ask for assistance etc. It was also helpful that the staff knew not to distract my guide dog, and that they knew that I was looking for assistance through to the restaurant.

Welcome by Neatebox is available for both Android and iOS devices. Although most of the venues currently available are in Scotland, the company is live across the whole of the UK and Ireland, with some venues in London and Dublin signed up as well. If you download the app and register, you can see a list of the venues which are using the app.

I hope you have enjoyed reading this edition of Tech Talk, and hope that some of you will find the Welcome App by Neatebox as useful as I did!

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



@macsthecharity



facebook.com/MACSCharity

MACS Members tackling The 2019 London Marathon



Becca Grost

This is my second London Marathon, the first being in 1998 when I was a student at the University of Leeds. This time though, I am mum to two amazingly active children Seb (11) and Macy-Rose (8), a full-time police officer and wife to Simon.

Macy-Rose is a MACS child and my inspiration for doing the London marathon again, as she doesn't let her optic disc coloboma stop her doing anything she puts her mind to. This year she has taken part in surf lifesaving competitions, won medals at cross country, completed her first triathlon and taken up rugby. The very least I feel I should do is run the marathon and help to raise awareness and vital funds for the charity that offers Macy-Rose and those like her the opportunity to feel included, empowered and to meet children with similar conditions. To make this marathon super special I will be running alongside my little sister Lou who ran for MACS in the 2018 London Marathon. Together we will proudly wear the MACS vests and promote this amazing little charity. I can't wait.



Tim Lupton

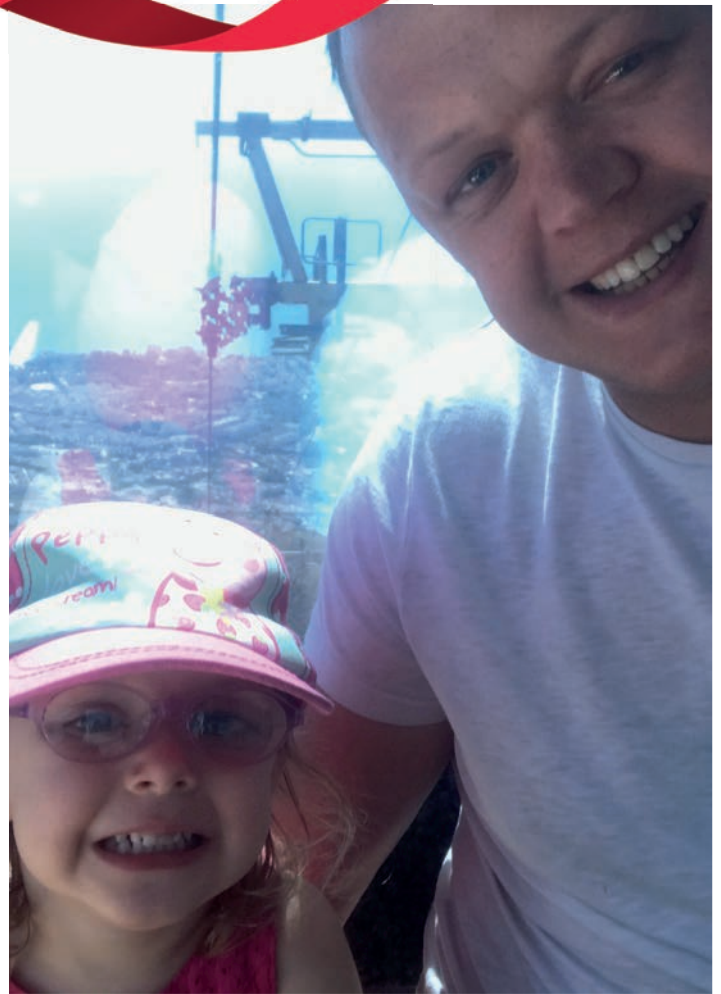
"I feel privileged to have been able to complete the London Marathon in the past 9 years - this was only made possible by MACS. Being a MACS dad to Ben, it is seeing all the MACS children and adults not let anything stand in their way that gives me the inspiration to run, and I always wear my MACS top with pride. In 2009 I had not even run for a bus, but decided to run and run and run, so running London Marathon in 2010 changed my life as it was my first (and only one I said at the time!!), but now looking back with pride on all 186 marathons I cannot thank MACS enough for giving me the chance for the first one!"

Tim is the first recipient of Mel's Place and will be running in memory of Mel Gordon, a much-loved MACS dad who passed away last year. This year, Tim is also going to celebrate his 200th marathon as well as tackle 10 marathons in 10 days!



May Evans

My family and I have been part of the charity since 1998, when I was born. MACS offered endless support and advice to my parents and helped us whilst I was growing up. I now want to give something back. This will be my first marathon!



Richard van Ommen

I got involved in running the marathon (my first ever) due to wanting to support the amazing charity that has been so helpful to me and my family after my daughter, Emily, was born with Microphthalmia. Without the support of this amazing charity, we would have continued to feel helpless and totally lost. MACS enabled us to see the light at the end of the tunnel, for which we can't show enough gratitude.



Ride London 2019



ON SUNDAY 29TH July last year, thousands of riders of all abilities, took to the streets of London to cycle 100 miles, in the pouring rain, to help raise money for charity. Amongst them was a very special team of people – a team of people who have worked tirelessly over the past year to raise over £22,000: the MACS 2018 Cycling Team.

The 100 mile bike ride follows the route of the 2012 Olympics, starting in the Olympic Park in London to pass through the City, down through the Surrey Hills and back in to London to finish on The Mall, all on closed roads. It remains one of the most popular and iconic annual rides.

Last year our team consisted of all levels of cyclists, male and female, young and old, those who had supported MACS previously and those who hadn't. It's a very special event for MACS and we'd love to smash the amount raised this year for our 25th anniversary in 2019 – do you want to help us do this?

We are now recruiting for our 2019 team so if you, or anyone you know, would like to take part, please get in touch. We only have 65 places available, so don't miss this opportunity!

We'd love to welcome you on to the team and will support you from the moment you register until you tell us to stop! The time, effort and support given by each and every member of the team is hugely valued and appreciated by all of the children with MACS conditions amongst our membership, and their families.

So if you're looking for a challenge and you think that raising £350 and cycling 100 miles on Sunday 4th August 2019 might be it, sign up today!

macs.org.uk/ride-london-2018-registration-form/



Join Team MACS!

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

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



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



As a member of Team MACS you'll receive:

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

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

Microphthalmia, Anophthalmia & Coloboma Support

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

25 for 25 Challenge

Could you help us raise £25,000 in our 25th year?

IT'S OUR 25th birthday, and we are challenging each and every one of our members, young and old, to raise £25 this year. Will you help us reach our team target of £25,000?

Let's join forces and achieve something amazing to celebrate 25 years of MACS!

It is up to you how you raise your £25 - You could bake, make, sell, cycle, walk or talk (or not talk!). Or you could take part in our 25km challenge, explained below.

Everyone who raises £25 will receive a personalised certificate, and if you go over and above and reach £100 you will receive a special 25th anniversary MACS medal.

To sign up, please complete our form here: <https://macs.org.uk/join-the-25th-anniversary-challenge/>



25km for 25 years of MACS Virtual Run

COULD YOU run or walk 25km throughout the year 2019 and set yourself a goal to raise £25? What's in it for me?!

- A certificate if you raise £25
- A special 25th anniversary medal if you raise £100
- You will be a part of Team MACS, collectively aiming to raise a whopping £25,000!

There is no specific timeframe -

you can do it at your own pace throughout the year 2019.

For example, to achieve a total of 25km you could

- Run 1km every other weekend
- Run 5km five times during the year
- Run 2 half marathons plus a 5km run
- Run or walk it all in one go

You could run or walk, and you can either do it in your own time, or attend an organised event such as

the free weekly 5km event, Parkrun.

To sign up, please complete our form here: <https://macs.org.uk/join-the-25th-anniversary-challenge/>

To keep yourself motivated, please keep in touch and send us your updates or tag us on Facebook and Twitter **#25yearsofMACS**

To receive your award, show us your kms (e.g. send screenshots of run tracking apps, watches, or fitness trackers).

Let's all get involved and raise £25k for 25 years of MACS!

Thank You

A big thank you to our donors and supporters! MACS is completely dependent on the generosity of donors, and the support of individuals and companies all over the UK makes what we do possible.

CHARITABLE TRUSTS, INCLUDING:

Ian Askew Trust, Sylvia Adams Charitable Trust, Pauline Meredith Charitable Trust, Tula Trust, Lowe CM Dec'd Charitable Trust, Roger Raymond Charitable Trust, Forte Charitable Trust, Chaldean Charitable Trust, Lynn Foundation, Dorothy Hay-Bolton Charitable Trust, Pennycress Trust, Awards for All, Joseph Strong Frazer Trust, G C Gibson Charitable Trust, Lewis Ward Trust, Taylour Foundation, Prudential plc Small Donations Fund, Lennox Hannay Charitable Trust, VTCT Foundation.

Between them, they have donated over £60,000 to MACS since September.

THANKS ALSO TO:



THE ALPKIT FOUNDATION donated an amazing £400 towards our Caldecotte activity breaks this year. All of our young members who attended said that they benefited positively from the trip!



WAITROSE LOCKS HEATH raised £296 for us through their Community Matters scheme this year, and invited us to join their tea party to celebrate ten years of Community Matters.



THE HOSPITAL SATURDAY FUND donated £3,000 to help fund our medical research into MACS conditions.

ALSO...

We received £10,000 from the **Big Lottery Awards for All** programme to help fund our Regional Support programme.

The **ITAM Review** raised over £5,000 from their annual gala dinner for MACS.

Lintstock Ltd donated £2,500, generated through their charity casino night.

Millie McGivney and the Students of Hagley/Stourbridge NCS Group 2018 raised a fantastic £512 for MACS last summer through the fundraising activities they organised.

The Worshipful Master and brethren of **Acacia Lodge** have made donations totalling £1,488 this year, raised through their summer barbecue and a Ladies' Night.

St John's Church, Great Sutton, sent us a cheque for £174, raised through their charity coffee morning.

The Rotary Club of Swindon Phoenix donated £106.33 to MACS, raised through their monthly prize draw.

Prudential Small Donations Fund awarded us a £3,000 Christmas Gift.

We are enormously grateful to all of the groups and individuals who have raised money and made donations to MACS over the past year, including:

Catriona Hill, who held a fundraising evening, raising a phenomenal £1,300 for MACS

All those who have chosen to request donations to MACS in lieu of birthday presents, raising valuable funds for our activities

Those who have encouraged their employers and schools to support MACS, including volunteer **Mel Sharpe** and **Elijah Wykes**

Everyone who has made a donation or regular gift to MACS, with a special thank you to **David Wilkinson**, grandfather of Rose.

We couldn't do it without you!

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



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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



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

