



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

ISSUE 12

March 2020

25th
Anniversary
Special Edition



FOCUS MAGAZINE

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

Chair's Welcome!



HELLO EVERYONE,

Welcome to this very special edition of Focus. It's incredible that MACS has existed for 25 years – a quarter of a century, and almost a lifetime

for some of us! In this edition, we reminisce about the early days, recent achievements and everything in between. We have contributions from some of our past Chairs as well as you, the members, sharing your stories and your favourite memories of MACS.

2019 was an extraordinary year, seeing us organise celebratory events across the country and welcoming almost 300 of you for a day of fun. Whether it's your 1st or 21st year as a member, we are so happy that you continue to participate in MACS events, meeting others in your area and building lasting friendships.

I would like to thank all the members who took the time to contact us and share their stories. We are always looking for members' contributions, as we know that others may read about your journey and recognise their own experiences, which can be

enormously reassuring. If you'd like to get involved in future editions please do get in touch, we would really love to hear from you and would encourage everyone to put pen to paper (or fingers to keypad!)

This year is already gearing up to be another exciting year for MACS, with a second MACS Awareness Week in the pipeline, another sailing trip, and an expansion of our regional events. Watch this space!

With best wishes,

Robbie

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'GOODBYE' to Fay

We'd like to say 'Thank You' to Fay Skevington, who moved on to new challenges in 2019

Having served first as a MACS Trustee, then as Charity Development Manager and latterly as our first Chief Executive Officer. Fay brought some fantastic skills to the charity and we wouldn't be where we are today without her support.

Fay's biggest accomplishment at MACS was the creation of our 'Confident and Connected' strategy which was launched in 2018. In creating this, Fay oversaw our largest ever member consultation, which included workshops at the Family Weekend, an online survey completed by almost 200 members, as well as telephone interviews. The finished document sets out our ambitions and goals for the future, and is a piece of work we are extremely proud of.

During her time as Charity Development Manager, Fay also submitted an application to the FSI

'Small Charity Big Impact' awards, which

we won! As a prize, we had a promotional video professionally made for us to publicise the charity, and this can now be seen on our homepage.

MACS Chairman, Robbie Crow, commented: "I'd like to take this opportunity to say a personal thank you to Fay. Together we set the foundations to allow us to appoint our first full time, permanent CEO and to expand our support services to a level that MACS has never had before. None of that would be possible without Fay. I'm so pleased she's staying as a MACS member and I can't wait to see her at future events!"

We were very sad to see Fay leave but would like to wish her all the best for future challenges.



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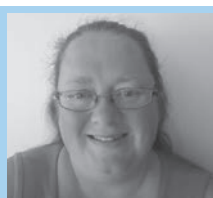
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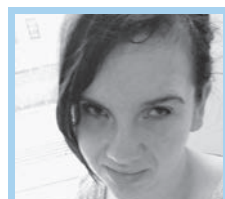
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& Coloboma Support**

Supporting children born without eyes or with underdeveloped eyes

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25 years of MACS



Anniversary Celebrations

We had a wonderful time at all six events, celebrating alongside nearly 300 MACS members

WE WERE delighted that our birthday celebrations were such a success! Thank you to all the families who attended and celebrated with us. We hope you had a lovely time playing games, dancing, face-painting, storytelling and handling the exotic animals, and that you enjoyed the Magic Mirror and the interactive mat. Most of all, we hope you met many MACS friends, old and new, and had a wonderful time together.

What we got up to!

We had similar activities taking place at each event.

• Singing and Storytelling

Boogie Beat is a franchise and provided interactive singing and storytelling at each event. They carried out special training just for our MACS events and were able to tailor their performances to the members at each event whilst using the same basic format. Their features consisted of games, movement, stimulation, colour, collaboration, storytelling, singing and dancing and were designed to involve all of the members who wanted to participate.

• Exotic animal visit

The venues enjoyed visits from different handlers of exotic animals (Ecomantella, Zoolab), as well as in-house talks by zookeepers at Edinburgh and Bristol.

• Face Painting

We were delighted to be able to find such talented local artists to attend each of our events.

• Magic Mirrors

Families at every event had fun posing with a selection of silly props in front of the 'magic mirror' which then took a snapshot of their best moves for posterity.

• SENse Micro Interactive Mat

as featured in the previous edition of Focus (<https://macs.org.uk/macs-focus-magazine-september-2019/>), this is an innovative interactive mat with lots of stimulating sensory content for eyes, ears and touch. Suitable for use by children and adults with a whole range of special needs, it proved extremely popular with everyone!



Our wonderful Regional Co-ordinator,
Sharon Williams, summarised each event:

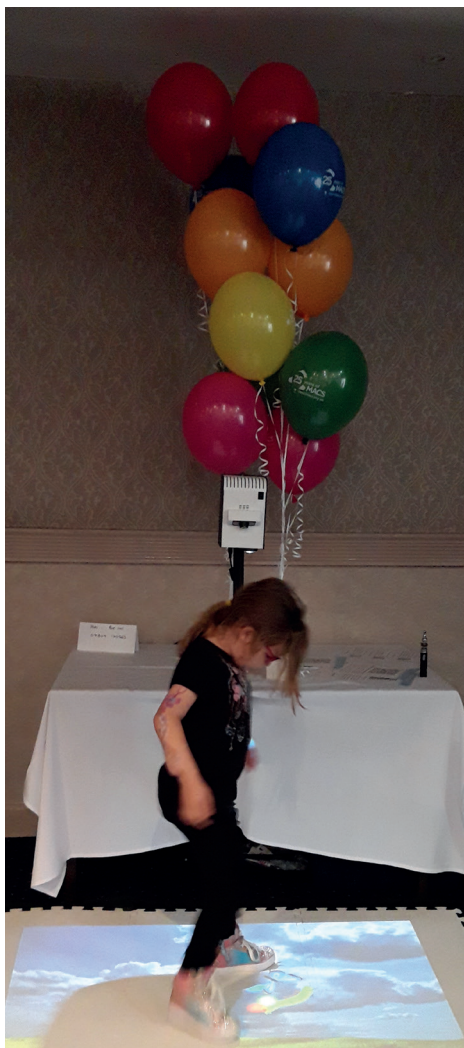
Park Hall



THIS event was held in the Eccleston Suite at Park Hall hotel, a very familiar place to lots of MACS members who know it from the Family Weekend. Robbie, Liz and I all attended this event, meeting up with 26 people from eight families.

Vicci started us off with some detailed and colourful face painting, before Rachel from Boogie Beat presented a really lovely, inclusive set for all of the children, incorporating colourful scarves, a parachute and instruments to involve everyone in the stories and songs.

We had a delicious, filling hot lunch, before Dave opened up his Magic Mirror with the very best selection of props. We had lots of fun with that! Lydia from Zoolab soon arrived with a large selection of exotic animals, telling us all the animals' names and how she came to them, as well as educating us about their natural habitats, which was all interesting and entertaining for all. This was the first outing for the SENSE Micro and we were delighted to see it in constant use throughout the day. MACS the Monkey had the best fun!



Swadlincote

OUR Swadlincote event was held in the Ashby Suite at Appleby Park Hotel. Our CEO Liz and I attended this event with 40 members from ten families.

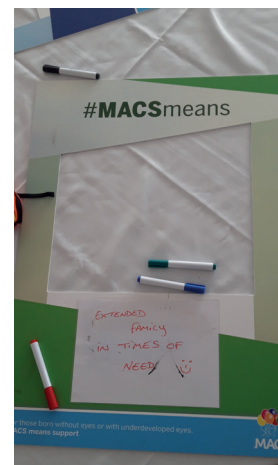
We had lovely weather with a bright and sunny day. Our room had direct access to a patio, with picnic tables and benches (a perfect space for Jenga!), and a nearby grassed area for the children to play on.

The day started with Jan from Fairy Tale, who did a wonderful job face painting. Then Emma from Boogie Beat gathered everyone together for a lively storytelling session, followed by singing and dancing with scarves and instruments, and games with a parachute. MACS the Monkey was there too, and even Bracken, Dylan's assistance dog, joined in. We had great fun.

The SENse Micro mat proved popular, with young member Ted having lots of fun on it, laughing at the noises he was hearing as he was hitting the mat with his hands and feet.

Lunch was lovely and plentiful. The

staff were attentive and friendly, even providing takeaway boxes so food would not be wasted. In the afternoon, we had Steve with the Magic Mirror, and Brandon from Zoolab came along with some very beautiful exotic animals.



Bristol

IN BRISTOL we were hosted in the beautiful Clifton Pavilion at the zoo. The wet weather didn't dampen our spirits, and the rain eventually admitted defeat in the afternoon. CEO Liz, Trustees Teresa and Jenny and I were all able to make it to this event, together with 66 people from 16 MACS families.

Several families arrived early and helped us out setting up balloons. The event then started with face painting from Lor at Colour Junkie, who did some really colourful work. Carrie from Boogie Beat started with a bang, and MACS the Monkey joined in on the Gingerbread Man story and the parachute game. The SENse Micro mat was again popular, as was the Jenga, which was made into several sets of furniture by Mya and Maisy!

It was then time for a delicious lunch, after which Shaun from Pink Giraffe opened the Magic Mirror and there

was an unusual queue of people all wearing props! Our exotic animals were brought in by 3 zookeepers who introduced the animals to families as they were sitting at their tables, which was fascinating to watch.



Belfast



IN BELFAST, our event was held at Queens University in the Isdell Courtyard. The glass roof made the room lovely and bright, and there was plenty of space for us all. We were lucky with the beautiful weather, which allowed the children to play in the gorgeous grounds. Again, our CEO Liz was there, along with me and 36 members from nine families.

The day started with face painting from Caroline at Face Mates, who did some lovely arm tattoos as well as face paint. Jackie from Boogie Beat got everyone involved with games, instruments, singing and scarves. Megan joined Jackie to lead the Okey Cokey and singing for the group.

The food was lovely with lots of choices for all. In the afternoon, Glen joined us with the Magic Mirror from Elite, and plenty of fun was had with the lovely props. MACS the Monkey was very energetic and did some dancing, and the exotic animals presented by Ecomantela were more unusual than ever - along with the reptiles we also had some beautiful birds. Jenga was, as ever, very popular, and the SENSE Micro again provided entertainment, even though the images weren't quite so clear against the overhead light from the beautiful weather and glass roof.



Edinburgh

IN EDINBURGH, our event was held in the auspicious Geddes and Gillespie Rooms in the Mansion house at Edinburgh Zoo. We had some miserable weather, but it really didn't dampen the day. Robbie, Liz and I attended this event, alongside 47 people from eleven MACS families. A professional British Sign Language interpreter attended the event. Leighanne Higgins from Lancaster University also came to talk to MACS members about an art project called 'The Marketplace and I', and invited members to get involved..

The event started with face painting from Laura, who was amazing and painted something on almost everyone in the room. I especially liked Bill's Unicorn horn and my own MACS tattoo! Zoe from Boogie Beat involved everyone with games, singing and movement with

her parachute, scarves and instruments. The children were enthralled – especially when MACS the Monkey also joined in! The SENSE Micro mat was popular with all ages and abilities, and Jenga was also used throughout the day.

Lunch was a delicious buffet that went down really well. After lunch, Leighanne told us about her art project, inviting members to submit art pieces for an exhibition. Later on, Scott brought along his Magic Mirror and numerous props, which were lots of fun. We were also lucky enough to have a visit from some of the zookeepers, who gave us a presentation and introduced us to some of their animals – including a beautiful owl and a snake. The energy of the day was infectious and there were lots of happy families joining in!

MEMORIES FROM THE DAY BY CAITLIN BRISTER

Even after attending MACS events for years, I really thought that the 25th anniversary event in Edinburgh was something special. As soon as we entered the room there were children smiling, laughing and having an amazing time singing and dancing with Boogie Beats. Whilst the children and some parents were joining in, other families were chatting and getting to know each other.

Everyone got so involved throughout the day, and most people (including adults) had their face painted. It's fair to say that all the activities were thoroughly enjoyed by everyone. As the event was held at the zoo, we got to meet some extraordinary animals that you would never normally meet up close. Kids and adults alike loved meeting snakes, owls and especially the armadillo.

Lunch was a great buffet, filled with delicious food (we loved the cupcakes especially!) Adults also enjoyed the constant flow of tea and coffee to keep up with the energy in the room.

Jenga was an absolute hit with the young people, who used their imagination and teamwork to build towers and bridges with the blocks. The magic mirror was also a hit with everyone (mainly Sharon!). From banana props to champagne bottles, there was everything you could imagine in those photos!

Due to the typical Scottish weather, the rain made it hard to explore the zoo after the event, but it gave us more time to spend with our MACS family. Another great event enjoyed by all!



Epsom



OUR EPSOM event was held in the Downs View Suite at Epsom Racecourse. The room was bright and spacious, and while the views from either end of the suite weren't apparent until much later in the day, they were worth waiting for! Teresa, Jenny and I were happy to attend this event along with 55 members from twelve families.

The day began with face painting from Jenny at ArtyCat Faces, who did some really intricate designs, before Julie from Boogie Beat took over, leading songs and stories with movement and dance to involve most of the room. I personally enjoyed watching everyone join in with Julie, and I have special

memories of watching the children of all ages and abilities play the statues game! The SENSE Micro mat was popular throughout the day, along with the Jenga and the Magic Mirror.

MACS the Monkey visited us before lunch, after which we enjoyed a buffet with lots of choice and attentive staff. After lunch, Shaun from Pink Giraffe opened the Magic Mirror and there was another unusual queue of people all wearing props!

Our exotic animals were presented in the most fantastic way by Rhys from Zoolab, who gave an entertaining introduction to each animal and then showed them around the families.



A friendly reminder to members.

We love organising these events and always hope to see as many of you as possible attending them. With this in mind, we strive to keep booking fees low to enable everyone to attend. Please keep in mind, however, that there is a cost involved to MACS and any no-shows cost the charity considerably. If you sign up and cannot make it, please do let us know as much in advance as you can, so that we can try to fill your place with another family or recover the funds.

OUR HISTORY

A time line of MACS' milestones, achievements and success stories from the past 25 years. That's a quarter of a century of fun, friendships and support.

We share some best moments and our favourite photos here.

1993

A series of articles published in the Observer investigating the little-known eye conditions.



First get-together in Battersea Park.

1994

MACS becomes an official charity.

Juveria Memon elected as Chair.

1995

First Family Weekend & AGM at Skegness Butlins.

1996

Family weekend & AGM at Cirencester.

1997

Family Weekend & AGM at Haven, Mablethorpe
Peter Attenborough elected Chair.

2001

John Karvaski elected as Chair.

1999

First Family weekend at Park Hall, Lancashire. We have been back most years since, now totalling 20 annual weekends there! Looking forward to number 21 in 2020.

Regional network was launched.

MACS MEMORIES FROM OUR CHAIRS, PAST AND PRESENT *Recollections and proudest moments*

Jonathan Attenborough

In memory of his Dad, Peter Attenborough (Chair 1997-2001)

As some of you will know my dad sadly passed away in November 2010. He was a past Chair of MACS in the early years of the charity and it was something he was extremely proud of. He spent a lot of his time working on spreading awareness of MACS and introducing newly diagnosed families to MACS. He always spoke about how much he enjoyed the Family Weekend and seeing all the MACS families having such a great time at Camelot!

One of the things my dad always said his vision for MACS was that it would someday be led by MACS adults who grew up with the charity as MACS children, so I know he would be bursting with pride to see that is exactly where the charity is today. I know that he would love to see MACS continue to grow and reach every family that has child born with a MACS condition in the UK.

1998

MACS' first time at the London Marathon! We received our first Golden Bond places and registered first runners.

Family Weekend & AGM at Butlins, Pwllheli

MACS MEMORIES FROM OUR CHAIRS, PAST AND PRESENT

Recollections and proudest moments

John Karvaski (Chair 2001 – 2006)

What was your fondest memory of leading MACS?

My fondest memory of MACS was helping and supporting new families especially when meeting them at the MACS weekends, for them to be able to meet others and speak with parents was so fulfilling, to see the children grow up each year.

What was your proudest moment as a Chair?

My proudest moment as Chair was enabling the charity to move forward, bringing on board the London Marathon from a small

fundraiser to over 100 places, enabling us to purchase our caravans for respite care. Also it was personally running the London marathon for MACS and being able to raise money and awareness to help the charity. Getting Ican involved as a sister charity and being able to see how their children were doing in America.

What's the best thing about MACS?

The best thing about MACS is the support and help provided either at the MACS Family Weekend or over the phone from parents who have been through the same experiences.

What would you like to see MACS achieve over the next 25 years?

I think MACS can achieve great things. It's achieved so much over the last 25 years that I know it can become bigger and better. Our children are now adults, so we have experiences we can pass on to new families. I feel that you need to do more for the children that have now grown up, such as Conner as there is nothing for him currently. This is an area you may wish to explore.

2002

First Charity Ball in London



First caravan purchased.



Lord Blunkett becomes Patron.



MACS MEMORIES FROM OUR CHAIRS, PAST AND PRESENT

Recollections and proudest moments

Anna Cannings
(Chair 2006 – 2007)

What is your fondest memory of MACS?

The launch day in London – so many families gathered together to support one another and mark the start of something special. Also, how this collaborative spirit has lived on through the annual AGM weekends and other local meetings.

What was your proudest moment as Chair of MACS?

The committee agreeing to extend the number of caravans available for families, thereby increasing opportunities for vital holidays. Affordable, home-from-home environments are so important for MACS young people, their siblings and parents, to make regular breaks possible.

What is, or was, the best thing about MACS?

The way in which the charity is evolving to facilitate more peer support and confidence building opportunities. The increase in integration provides many benefits to prepare MACS young people for life in the real world, but it can also be isolating and is often a less than ideal environment for developing specialist coping skills. MACS is helping to bridge this gap – something I think its trustees and patrons should be very proud of.

What do you think MACS could achieve in the next 25 years?

As the saying goes 'the possibilities are endless'. Many charities provide valuable online platforms for support, but the reach of MACS thankfully goes way beyond this and into something quite unique. Any initiatives that help to foster peer support, confidence building, specialist counselling, mobility and habilitation provision to help young people find work experience and employment would certainly get the thumbs up from me. Why these things specifically? Because they will help to reassure young VI people that they are not alone, help them make sense of the world, equip them with as many skills as possible to improve their life chances, and then inspire them to reach for the future they deserve.

2006

£1 Million raised by MACS in total.

Anna Cannings elected as Chair – the first MACS adult to hold the position.

MACS MEMORIES FROM OUR CHAIRS, PAST AND PRESENT

Recollections and proudest moments

Debbie Clark (*Debbie stepped up to act as Chair twice during the early 2000s and whilst her tenure was short, on both occasions she helped steady charity through some challenging times*)

What is your fondest memory of MACS?

There are many fond memories, it's hard to pick just one! They all have the same theme though, watching how MACS makes a difference to the lives of its members.

It might have been seeing a parent brave the sometimes scary experience of coming along to a family weekend or a regional event for the first time, watching as they realise there are other families who understand their fears, worries, desperation, desolation, and their joys at each small progression their child makes, and then seeing them at their next event having changed and becoming more confident and happier, in turn watching them welcome and help other families. Watching them as they realise there is hope for their children, they will be able to achieve their own potential, it might be tough along the way, but there are others who have gone on to achieve amazing things, and there are other parents who they can turn to for advice, support and help.

Or it could be watching the younger MACS child shy at first, but then join in with their peers, feeling comfortable in their own skin, forming friendships and then not wanting to go home because they've made friends and don't want to leave them!

It could be the grandparents who were devastated at their grandchild's diagnosis and they are coping with the worry of their grandchildren as well as their parents... Their very own grown children, or indeed extended family members; aunts, uncles who worry about the whole MACS family too. They may

feel out of their depth, unsure of what to say or do for the best, but just seeing others helps and gives them hope for their loved ones.

As Chair of MACS what was your proudest moment?

I was Chair for only a short period of time when MACS was in a difficult period. I'm proud of the fact that MACS continued as was, that it learnt from its experience, and put safeguards into place to ensure that MACS members were always at its heart.

I am proud of all the times that I have been part of MACS committee, not just as a Chair but as a committee member. I initially formed the regional groups 20 years ago and later returned to help re-establish them. I'm proud that these groups encompassed the needs of all family members, parents, child, siblings and extended family members.

I am most proud of how I helped transform MACS to ensure that the whole families' needs were supported.

I am proud that Robbie and I established the sailing trips and the adventure holidays and am so honoured to have watched the changes, in some cases complete transformations, in those who attended, not just in the MACS teens themselves, but the person that accompanied them.

I'm proud that I helped establish the caravans, and know that families are still enjoying and benefitting from their use. I am also proud of the comprehensive

literature that myself and ophthalmologists from Moorfields put together as part of the rebranding in 2000.

This was used to obtain a Children in Need grant as well as grants for the sailing and adventure weekends, and more importantly in raising MACS profile in hospitals, meaning that more people who were struggling knew about MACS.

What is, or was, the best thing about MACS?

For me and my family MACS has been there. Firstly it was for us as parents when our second child was born with microphthalmia. We really felt like we had found a family and the friendships we made 22 years ago at our first AGM meeting have lasted through the years.

It was there for us when our eldest son struggled with people and his peers looking at his younger brother.

Finally, it was there for our MACS child as he began struggling with issues surrounding his appearance and self-esteem.

What do you think MACS could achieve in the next 25 years?

I hope that as MACS grows it will never ever lose the knowledge that MACS strength is its members, the parents, the children themselves, the extended family members and friends who are passionate about the MACS conditions. They are the people who know best how to support each other, and new members who will be born in the future.

I hope that MACS will always be seen as a family rather than just another charity.

2007

Barry Stickings becomes Chair in November. MACS started collaborations with Professor Nicky Ragge.

2009

First MACS sailing trip in Scotland. As many as 14 successful sailing trips have followed, such as the one in 2017 pictured here.





2010

MACS the Monkey is born! The beloved mascot comes on board to represent MACS.

£2 Million raised by MACS in total. Pictured here are our marathon runners wearing the old style



MACS hosts the first fundraising ball 'Ice Ball'



First MACS' Got Talent show.

2011

Another successful Family Weekend at Park Hall Hotel near Preston



Autumn Ball.



MACS MEMORIES FROM OUR CHAIRS, PAST AND PRESENT

Recollections and proudest moments

Barry Stickings MBE (Chair 2007 – 2015)

What is your fondest memory of MACS?

One really stands out. Kelly, Toby and I were at a Family weekend in May 2001. As everybody knows when you walk into that room for the first time with your child it's overwhelming. You know nobody and as you enter you do feel slightly nervous.

At this event, I walked Mary and Phil M with Eoghan, who was less than a year old. He had the same condition as Toby, Bilateral Anophthalmia. I saw them standing there alone, so we walked over and made our introductions. We have never looked back, our friendship began. Kelly took Eoghan all around the room and introduced him to everybody, while telling everyone to go and say hello to Mary and Phil. This memory has been with me since that day. Kelly loved bringing new families into our MACS world, giving them the encouragement to break the ice and become part of extended family.

What is, or was, your proudest moment as Chair of MACS?

There is one and it will remain with for me forever. I was nominated by my peers to receive an MBE for the work that I had accomplished working with the visually impaired, which is a passion that still consumes every part of my day. It was not about me, it was about the families. Being presented with my MBE at Buckingham Palace in February 2018 made me feel very humble, but I was part of a team. To this day I feel honoured to have been able to help in part take MACS forward in the time I spent as Chairman.

What's the best thing about MACS?

Being able to bring families and friends to a group that not only understood why they were part of it, but also could genuinely empathise with them. We had been there, on that path from the moment of birth to now having our family. MACS, through its amazing families, was there to help.

When it started over 25 years ago, I remember attending the Observer meeting and thinking people here like myself want to do something to help. There was nothing for us, no way of meeting, sharing, helping or just been able to say hello. MACS changed that and in my 9 years as Chair I'm so pleased that I was part of it. Remember, it's not a group, it's a family, and one where you feel comfortable and have no fears, just joy that you and your children will make friends for life.

What do you think MACS could achieve in the next 25 years?

It is important that the families should play a far more important role as part of the Team where ideas can become a reality and achievable because MACS will be able make them happen.

Genetics is now linked to many MACS conditions and MACS must continue to encourage its members to be tested. I feel it is important to them but also the extended families that may have children in the future with a MACS condition. MACS must be at the forefront of this.

It would be good to see MACS expand its support and membership to families overseas. These conditions are global and, through expansion, knowledge and education, MACS will grow and be respected internationally.

The main goal for the future of MACS, is to be there. Bring families together. Be the point of contact for all MACS conditions, but also point people to other groups. Do not lose the personal, friendly and approachable group it is. MACS is unique, it is highly thought of and needs to continue its growth in a way that is of benefit to all.

Be brave, take risks, expand and become the leading point of contact for MACS conditions globally.

2012

£3 Million raised by MACS in total.

MACS Rebrand launched.

We have been blue ever since!

MACS takes part in the Tall Ships Races.

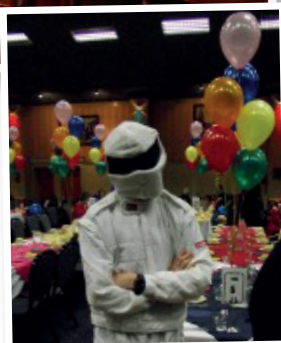
Night of Glamour Ball.



MACS Activity breaks begin.

Another successful Family Weekend at Park Hall.

MACS the Monkey completes the London Marathon!



A successful regional trip to the Harry Potter World.



2013

MACS recruits its first member of staff to manage the development of the charity. Two more staff members soon follow to coordinate fundraising events.

Family Weekend 2013.



Another successful sailing trip.



August - MACS participating in Ride London for the first time.



Masquerade Ball.



Skydiving event for MACS teens & adults took place.

2014

A MACS Fundraiser takes on the Mongol Rally! This most unusual fundraising challenge was undertaken by Magic Matt, an entertainer present at many MACS



October

MACS celebrating its 20th Anniversary at a Westminster reception.

MACS member giving a speech sharing her story with the Patron Lord Blunkett in the background.

£4 Million raised by MACS in total.

Roaring 20's ball.



2015

Robbie Crow became Chairman.

Microphthalmia, Anophthalmia & Coloboma Support is born - MACS changes its name from Micro and Anophthalmic Children's Society to Microphthalmia, Anophthalmia and Coloboma Support, and structure to a CIO (charity incorporated organisation).

MACS MEMORIES FROM OUR CHAIRS, PAST AND PRESENT

Recollections and proudest moments

Robbie Crow

(Chair 2015 - present)

What is your fondest memory of MACS?

My fondest memory of MACS is every single one of the family weekends that I have attended. From my first in 1996 to my most recent in 2019, every single one has been special to me. When I was younger, I used to count down the days from Christmas until the next Family Weekend where I could see my MACS friends. The 'MACS Weekends', as I used to call them, were the highlight of my year because they were one of the few times when my parents let me go off alone with my friends. Whether that was just running around Park Hall or Camelot, that little bit of time alone with my MACS friends made me feel independent. That's why - to this day - I still ensure that the weekends are in a closed, self contained and safe environment where parents feel content to let their children roam free, without fear of accidental injury or prejudice from others, because I remember how important that was to me as a MACS kid. MACS was the first place I felt independent and the first place where I felt 'normal'.

What is, or was, your proudest moment as MACS Chair?

My proudest moment as Chair was in 2018 when we launched MACS' first ever comprehensive strategy, Confident and Connected. Until 2016 MACS had never even thought about having a strategy. Within the space of 2 years we redefined a mission and a vision for the organisation, we developed our core values, and we carried out the charity's first ever extensive member engagement exercise, ensuring that the services we were offering were actually relevant to our members' needs. All of this has led to MACS becoming a very professional, well respected charity in the blind sector in the last 3 years. We already knew that the work we were doing was important, but now that's being acknowledged by outside people at top levels (including by the CEO of Moorfields Eye Hospital). I'm proud that I've steered MACS into a position where we're thinking two or three years ahead and that we have the ability to provide a really good proof of need to our future funders. We're now able to become less reliant on the London Marathon and, by doing that, the future of MACS is safer than it's ever been before. I'd never have imagined that possible when I was elected Chair.

What's the best thing about MACS?

I think the best thing about MACS is that we offer a safe environment where people can receive support from each other, support which is gained from lived experience of the MACS conditions. No-one can offer emotional understanding to someone with a MACS condition (irrespective of age) except another person with a MACS condition; and no-one can understand what it's like to be told that your child has a MACS condition except another parent who has been through that. Especially in teenage years, both the MACS young person and the MACS parents need support from others who have been through similar life experiences. That's what MACS does. I don't know what it's like to be told my child will never see; but what I do know, all too well, is what it is like to feel alone, to feel scared, and to ask 'why me?' - all because of something none of us ever asked for. The MACS conditions force everyone to ask those questions and feel like that at some point in their lives, no matter how the conditions affect you. MACS is the only place in the world that can help people work through that.

CONTINUED



@macsthecharity



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Robbie Crow

(Chair 2015 – present)

CONTINUED...

What would you like to see MACS achieve in the next 25 years?

The future is nothing but bright for MACS. MACS must make sure that, over the next 25 years, we never lose the MACS Family culture. What sets us apart from other, similar, organisations is that we're still governed by people who truly understand the personal, family, and life impact of a MACS condition – that's so important. However, I believe we can achieve a few tangible things over the next 25 years: become less reliant on the London Marathon income, so that it comprises 10-20% of our total income; reach 90-100% of all new births with MACS conditions per year (they don't have to sign up as members, but they need to know we're here when they need us); develop more services on a regional level, rather than a national level; implement and offer a counselling service for MACS members; and deliver an employment programme to support MACS adults into the next stage of their life journey. The future of MACS needs to be about support and empowerment, as it is now, but to do that we need to have experienced, professional staff in place to make sure that the services we offer are funded in the right way and delivered in the best, most efficient, and most reliable way possible for our members.

2016

MACS' first ever strategy is created.

2017

£5 Million raised by MACS in total.

Family Weekend format changes to sessions.

Members can now attend sessions that interest them.

MACS begins collaboration with Mariya Moosajee and Moorfields.

MACS wins the 'Small Charity Big Impact' award. We were delighted to receive this award from FSI as well as the prize that was a professionally made video promoting MACS.

2018

MACS Achievement Awards 2018. We loved receiving all the contributions and only regret that we couldn't reward everyone!



First full time CEO appointed.

£6 million raised in total.



MACS celebrates its 25th anniversary!

2019



Another successful activity break at Caldecotte Xperience.

Confident & Connected Launched – we publish the document setting out our goals for the next four years.

Fundraising Manager appointed.

Your stories

Remembering the beginnings and looking to the future.
Thanks to all members, old and new, for sharing your stories.

TERESA K

TWENTY FOUR years ago we were given the devastating news our son had bilateral Coloboma. They couldn't confirm at that stage (six weeks old) if he was totally blind or partially sighted but either way as a new mum, our lives had just been turned upside down. I wanted to shut myself away, but my husband wanted to face things head on. Even having a second opinion in London didn't make me feel that there was any future. The local hospital in Dudley gave us the number of the local VI team and he got in touch. The lady who ran the centre came to visit us a few days later



With my son on a MACS leaflet 24 years ago

with copies of information on bilateral coloboma and some invaluable advice.

We contacted the number on the photocopied info and my husband spoke with Maggie B. at MACS, who to this day has been a constant support and very good friend. We arranged to meet them at the MACS family weekend in Cirencester. We met Dawn and Rab C. who too are very good friends and were a massive support and gave us hope and knowledge of the condition. Although they may disagree as having to endure Robbie and Conner's driving on the gokarts at Camelot every year was rather nerve-racking.

We attended every MACS weekend and to this day are forever grateful for the support, memories and outlook each and every family have given us. Not only did my husband and I get support, but Conner got to meet other children and also made some very good friends, which includes Robbie. My husband became that passionate about MACS he even became Chair, and ran a marathon. Recently our daughter Charlotte who attends



My daughter raising awareness of MACS in her school in Switzerland

school in Switzerland completed a school project on charity and chose MACS as the charity she wanted to promote (pictured above).

Our son Conner is now 24. He has no vision in his left eye, and no distance vision in his right eye he is also photophobic. He attended Plymouth University completed a Mechanical Maths and Statistical Maths degree and now works and lives independently.

MACS will always hold a very special place in my family's heart.

PHIL AND SARAH

OUR SON Daniel was born with unilateral Coloboma and Microphthalmia and he was aged 3 when we found out about MACS during a routine examination at Moorfields Eye Hospital. We attended our first AGM at Park Hall when Daniel was 4 and continued to attend almost every AGM until he was aged 18. Before attending our first AGM neither we or Daniel knew anyone else with the same condition(s) so these annual events were really helpful for Daniel and us. It was great to get to know many other families over the years and learn from their experiences, knowledge, and general highs and lows of living and coping with these

and other MACS conditions. The guest speakers provided some valuable information too, and the weekend taking over Camelot Theme Park was an added benefit!

Attending the AGM's also allowed Daniel's sister (Lucy) and brother (Philip) to meet children with similar conditions to Daniel, and they also had a great time making new friends, some with MACS conditions and some without. Being involved in MACS has also enabled us to do things that we would never have otherwise considered; I (Sarah) ran the London Marathon and Lucy and Daniel went on a sailing trip. Lucy

also took part in the Tall Ships race a few years ago!

It's been great to hear over the years how some of the children we met all those years ago have progressed in life; Robbie and Angharad to name but a few. After leaving school Daniel gained a Travel and Tourism qualification and after a number of different jobs he is now working in a job he loves; project managing the design, build and commissioning of telecommunications networks.

We are sure MACS will grow on its success in the coming years and continue to provide valuable help to children and families.



Your stories

CONTINUED...

VICKY P

HERE GOES MY MACS TALE.

After a very traumatic birth with my first child I was lost in a world trawling the internet through pages and pages of Google's scary images. I tried to Google "child with one eye" after the local hospital were saying they didn't think he had a left eye, but we needed a referral for an ultrasound at Queen's Medical Centre in Nottingham. This appointment came through for the following week and confirmed what had been the hospital's first thought. The week after the appointment his consultant wrote to us and enclosed the URL for the MACS website along with some information about the Eyeless Trust.

I emailed MACS and got immediate positive response from both Barry S. and Debbie C. Their stories picked me up and inspired me. Toby has achieved so much and continues to do so, and at that time in a world of uncertainty, it sounded unbelievable. So that's my first contact through MACS and we continued to exchange emails for a while. I

couldn't believe that we were not alone and how supportive these strangers were.

They never tired of responding to my questions and provided support from a very early stage.

I then became a silent member for so long and looked forward to receiving the Focus magazines to see how amazing MACS members are and share their achievements. We felt supported as a family and never attended an event or met anyone until Aiden turned 2. We decided to attend the Christmas party in York at the Hilton hotel in 2012 and felt very welcome by Lynda R. and of course Angharad. We met a family from our own town as well as nearby cities and it was amazing. Aiden was in his element with the children's entertainer and he had a lovely time. We then booked on to the Family Weekend of 2013 and been every year since!

It was at this first Family Weekend where strangers became friends. This network of friendships just gets stronger

and bigger every year. As both adults and children, we all have MACS friends, and such great friends they are. We have exchanged numbers and we have had play dates and meets outside of MACS events. We have been a part of MACS for 9 years and have attended most Christmas parties, Family Weekends and local regional events as well as the 25th anniversary event.

My favourite thing about MACS are the people. The people who become friends, the people who support and guide you when you need it, the people who make it work (the Trustees and the volunteers and the staff). MACS is a wonderful charity who give directly back to their members.

I have such happy memories of MACS that it's so hard to have a favourite, but I just love the Family Weekend every year. It's the highlight of my year (even sitting through the AGM!). Obviously my first MACS event stands out along with the Family Weekend last year, the Cadbury world regional event, the Cbeebies Live event. And to any new families who are yet to join or who have recently joined MACS, there is nothing to lose and yet everything to gain from being a part of such an amazing organisation. We are a friendly bunch like no other, offering endless time, support and lifelong friends from people who totally get it.

MEGAN, 27

My name is Megan and I'm 27. I was born with bilateral Microphthalmia and although I had no sense of shape, I could see light and bright colours in my right eye. I grew up on a farm in the Yorkshire Dales with all the pets I could wish for, two sisters and a brother. After attending my little village primary school, I went onto a girls' grammar school before doing my A Levels at New College Worcester. Since then I have taught English on my gap year in Germany, worked for an energy company and my local council, and I have a degree and a Masters in Creative Writing.

I can't remember how my family came to hear about MACS. Perhaps this isn't surprising - I was only 2 when it was set up! We went on a MACS trip to Camelot Theme Park when I was 7, which sadly doesn't exist anymore. I had

one of my best childhood holidays on another MACS get-together at Center Parcs in the Lake District. I remember making great friends with some visually impaired girls on that holiday; we did a lot of swimming and zooming about on bikes. My parents had to drag me away. If MACS fancies putting on some trips to Center Parcs for the MACS adults who are still a child at heart, I'd be the first to sign up!

My family still has photos from the MACS outing to Ponda Rosa in the summer of 2001. Mum joked that she couldn't understand why I was so excited about visiting a farm when I already lived on one! This farm was different. They had lots of exotic animals for us to handle. My sister is terrified of snakes and now refuses to look at the snap of her with one wrapped around her neck.

These were great trips for me and my family. It was nice for my siblings to play with other children and for my parents to talk to others with similar experiences. Having friends who didn't go to my school was a real novelty for me and I loved ringing them up for long chats.

Even in the world of MACS, I didn't meet many children who were completely blind like me and a lot of them had additional needs. It meant that the friends I made were extra special because I could relate to them in a way I couldn't with other children. I hope the charity will continue to grow, showing that the MACS conditions aren't as rare as they seem. There are lots of blind children in the UK who grow up to be adventurous adults with stories to tell. I now live in Cheltenham with my boyfriend, guide dog Layla and two guinea pigs. This is a very exciting time for me as Ed and I are planning our wedding for next June.

IRENE B

I WOULD like to congratulate and thank MACS for 25 years of supporting families throughout the UK who have a child/children with eye defects.

My son, who is now 31 years old, was born with microphthalmia and choroid coloboma of the left eye (totally blind left eye, as optic nerve did not develop). He is extremely longsighted in his right eye so he requires quite a thick lens in his glasses. I feel fortunate though that he has vision in one eye.

Josh was born before MACS came into being and at a time when technology and the internet were not as advanced as they are today. For those reasons it was a very lonely experience with a child with a condition I had never heard of before. I'm sure many mums like myself felt some blame that their baby had a visual impairment, which little was known of at that time. I can't really remember how I found MACS, or if it found me, but it was a comfort to know that you're not the only mum who has a child with a visual impairment.

The early years of Josh's life were like any other child's, he was happy and healthy in every other way. The microphthalmia became more evident as he grew as there were some unkind comments from kids, but most people and children were respectful. I'm sure there are many children without any defect that have had the same experience.

Approximately two years before I found MACS Josh was referred to a local optician for a prosthetic shell for his left eye. I can remember to this day that the optician produced a shoebox full of these false eyes, all different colours and sizes. The idea was to find one that fitted, a little like Cinderella and the lost shoe. Thinking back now it was the most bizarre experience I had ever encountered, there were eyes everywhere as I tried to find the one that looked similar to his 'good' eye. I had to tell Josh to spit one out at one stage as he thought it was a sweet!

I wasn't aware that there was a procedure called moulding until I joined MACS that ensured a perfect 'made to measure eye'. However, the visits to the optician trying out various ill-fitting eyes, which was extremely painful for Josh put him off for life and he has refused to wear one ever since.

MACS has been a comfort over the years with information and support at the end of the phone. We, as a family have used their caravan in Bude and Cornwall which has been a fantastic break for us. It has been reassuring to speak to advisors/parents who have children with the same problems.

Josh has two siblings; Samuel aged 29 and a sister Emily, who is 20 years old. Josh works full time with Admiral as an insurance claims advisor. He is fortunate to be able to live an independent life. In the future, we will source genetic counselling for Josh and his siblings to see if the cause of his eye defect can be found. MACS is helping me with this now and we have, in the past taken part in research with Dr Nicola Ragge based in Oxford. Hopefully, as research develops the reason and causes of these eye defects can be established.

"I would like to thank MACS for being there for my family and wish them every success for the future. Here's to the next 25 years!!"



LINDA D

WE JOINED MACS approximately 23 years ago. I suppose we were lucky that we lived in the North as we were invited to Park Hall to the annual weekend meeting. It was wonderful to meet and be welcomed by such a wonderful group. Meeting people who understood what we were going through. It was through MACS that we heard about the DDD Genetic project.

At the age of 24 our daughter got the diagnosis of Charge syndrome. This is due to ongoing Genetic research. When she was younger we were told she didn't have Charge. But it is uncanny how alike they look.

Over the years we have attended the Annual Family Weekend and our sons have gone on adventurer weekends. We as a family have gone on Christmas shows and days out with our local area groups. Going forward, as all our children grow into adults, within this group they will be more and more adults who are going to need extra help. The Government needs to be aware of this. MACS is a wonderful group which has gone from strength to strength. The work that the committee does is amazing, the hours you must put in to MACS makes it what it is today.



My MACS Memory

Thanks to all our members for sharing their favourite MACS memories and best moments.

MY FAVOURITE MEMORY WAS... **THE ACTIVITY BREAKS**

THE ACTIVITY breaks are one of the best things the charity has to offer. It is an opportunity for the children to be with others just like them and not feel isolated.

MY FAVOURITE MEMORY WAS... **THE FAMILY WEEKEND**

IT WAS lovely meeting people who understood how we felt & 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.

MY FAVOURITE MEMORY WAS... **THE CALDECOTTE ACTIVITY BREAK**

I ENJOYED just seeing her do things I never in my wildest dreams would have thought I'd ever see her do. She loved zorbing and camping and wants to do it again. Just seeing her confidence with others was amazing, she seems to feel more comfortable being herself when she is at MACS events unlike when she's at school or out in the community.



Caldecotte activity break

MY FAVOURITE MEMORY WAS... **THE FAMILY WEEKEND**

WE HAD a lovely time and we felt very welcomed. Appreciated the advice, friendship and wisdom from other MACS parents. And it was lovely to meet little ones with similar conditions for the first time.

MY FAVOURITE MEMORY WAS...

MY CHILD enjoyed being with other children / friends that she has made through the charity and having the opportunity to be independent from her parents

MY FAVOURITE MEMORY WAS...

IT WAS wonderful seeing her with her friends and how she and a friend really helped a younger girl come out of herself. Also, my child was issued with a cane three weeks before the trip. At first she found using her cane on the rough grass on the site difficult and said she wouldn't use her cane there, even with a rough terrain attachment on the end of her cane. But when she saw her friends with their canes, she decided to give it another go, and became proficient at using her cane on rough ground by the end of the trip!

"It really makes a difference to her having other young friends at MACS who are cane users"

It really makes a difference to her having other young friends at MACS who are cane users, and this cannot be underestimated, as it gives her more independence and confidence. Parents also swapped experiences and ideas with each other about their children, and that was really helpful and supportive.

MY FAVOURITE MEMORY WAS... MY FIRST FAMILY WEEKEND

I TAGGED along with the Harris family, whom I had met earlier at a smaller MACS event. Nervousness was an understatement as I'd never been round so many people the same as me and I wasn't sure how to act and what to expect!

My original journey was one of terrible loneliness. Before I found MACS, I'd never met anyone else who was visually impaired, never mind with a MACS condition, so this weekend was a big thing for me. From the moment I arrived I was greeted with friendly, smiling faces, some from old friends I'd met on previous days out or new ones I made that weekend.

I had several parents asking me questions about growing up with a MACS condition and I was more than happy to answer. Even talking about it in general felt good because I didn't feel like I was banging on about it! It took me a few days to get used to that feeling.

My primary purpose going to the weekend was to build a bond with Aimee, and we did. We'll never be out of each other's lives now. I'll watch her grow into the force of nature she's already becoming, I'll be her friend so she's never alone in this. She'll be my purpose to be brave...

I saw something once that said "be who you needed when you were younger". Now I am that to Aimee.

I'll never forget that weekend because of the bond we cemented and the role model I became.



MY FAVOURITE MEMORY WAS...

MY CHILD loved the Zorbing but also spending time strengthening friendships she made last year and making more friends. She loved sharing her experience of using her cane with the other girls. I loved seeing my girl try new activities, building her confidence and challenging herself when frightened and nervous to just take a deep breath and do it but also when knowing she didn't actually want to do something, explain why and stand her ground despite my encouragement (only because she was tired). I also loved watching her play with friends she made and encouraging them in the activities. In truth, I loved it all!

MY FAVOURITE MEMORY WAS... **THE FAMILY WEEKEND**

THE KEY thing for us is seeing our children's confidence grow. We want both of them to realise that they can still take part and have that safe space. It is great for them to meet other children and for us to meet other families to talk about shared experiences, without defining the children by their conditions. All three of our girls enjoy the weekend and it's a good chance to spend a whole weekend together as a family.





Thank you

To all the members, volunteers, trustees, supporters, helpers who've been a part of MACS and have helped MACS become what it is today.

Here's to the next 25 years!





Join Team MACS!

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

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Microphthalmia, Anophthalmia & Coloboma Support

Supporting children born without eyes or with underdeveloped eyes

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Fundraising and general enquiries:

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