

# Focus on Funding

Celebrating grant funding at MACS in 2023



MACS



## Welcome

Hello! And welcome to the second edition of **Focus on Funding**; an annual newsletter dedicated to celebrating the impact of grant funding over the last year.



I am Emily Murphy, Trusts and Foundations Fundraiser at MACS. I created this newsletter, using a free online service, to summarise the wonderful achievements that we've been able to make over the last twelve-months, thanks to your kind support. We remain truly grateful for every grant and the real life difference this makes for MACS children, adults and their families.

This year has not been without its challenges but with a very healthy dosage of self-belief and determination, and a fantastic response from the grant giving community, we're moving forward at a rapid pace.

There has been a lot of behind the scenes working going on to make MACS bigger and stronger and we are now ready to start 2024 as we mean to go on.



It has been a pleasure getting to know you better and connect you with the impact your amazing support has had. The more stories I hear when collecting feedback, the more I'm inspired and determined to be successful. I hope after reading this, you feel the same and motivated to continue supporting MACS in the future.

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# Meet the members

MACS members are at the heart of everything we do. This section is dedicated to shining a spotlight on a few of the many people you have helped (we think that this is important!). They can't always say it to you directly, so hopefully this goes some way to showing you exactly who you are helping and how (and how grateful we all are!).

## Natalie & Esme



**ESME** is 5 months old and we joined MACS in August. So far, we have only had 2 appointments with the hospital and all I know is that she has coloboma in both eyes and microphthalmia in one. MACS has been a big support to me, since I feel I haven't had much information from the hospital appointments and most the things I have found

**"It's given me hope and stopped the conditions from robbing me from enjoying my baby"**

out are from the group and zoom meeting when I can get on. It's given me hope and stopped the conditions from robbing me from enjoying my baby. Being a member of MACS makes me feel less alone and I am sure it will be an amazing support for my daughter growing up.

## Rachel, Scott & Marnie



**MY NAME** is Marnie and I am 16 months old from the Scottish Highlands. My Mummy Rachel and Daddy Scott were told I'm the most northerly member of MACS! I have CHARGE\* Syndrome and that includes Bilateral Coloboma. I have around 60% vision and missing my upper field of vision, but I don't let that stop me being the cheekiest little monkey and keeping Mummy and Daddy on their toes!

## Charlotte and Darcy



The support from the Facebook group, being able to speak to someone at the charity that has a MACS family member and can provide guidance / advice has lifted the weight of my shoulders knowing we are not on our own!

Darcy is now 2.5 years old, thriving with the little vision she has in her left eye, but she is just a happy little girl and amazes us every day. She has achieved so much in her little life. I wish I joined MACS sooner, but I am glad we eventually did.

### \*DO YOU KNOW WHAT CHARGE SYNDROME IS?

- C**- ocular Coloboma
- H**- congenital Heart defects
- A**- choanal Atresia
- R**- Retardation of growth/development
- G**- Genital anomalies
- E**- Ear anomalies/deafness

## Emily, David & Eleanor



**THIS IS ELANOR**, she is 6 months old and loves our two dogs, Goose and Maddie. Eleanor has Microphthalmia in her left eye from a condition called PFV. Prior to her birth, we didn't even know these conditions existed. We've found the MACS webpage an invaluable source of information and have found the community to be so supportive. We find a lot of comfort in seeing older children and adults with the same condition doing so well. MACS has provided a lot of support for us in such a short space of time, we wish we'd joined sooner!

## Bethany and Daya

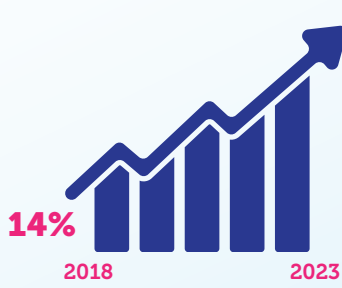


**DAYA IS THREE** years old and lives in West Sussex. At the beginning of 2022, we noticed white reflexes in her left eye. Daya was assessed by Queen Alexander Hospital and Southampton General Hospital. Consultants diagnosed Daya with coloboma of the optic nerve in both of her eyes with the left eye being more prominent. Daya is blind in her left eye and unknown what vision she has in her right eye. Daya regularly attends hospital appointments for her coloboma and is undergoing genetic testing. Daya is a loving and kind person who enjoys being outside and exploring her

surroundings and spending time with her younger brother Dexter.

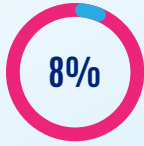
I found the MACS charity online when I was researching coloboma of the optic nerve. Unfortunately, I could not find much information online but the MACS charity supported me and provided information that I needed. I am grateful for the MACS charity because they provide a support system and you can communicate with other parents/caregivers that have children who suffer from coloboma, anophthalmia and microphthalmia.

# Charity Achievements



Before the Covid-19 pandemic, MACS received an average of 14% of its total income from grant funding - something we have been working hard to change, for a more resilient future.

Our three-year goal is to increase this to 50% (by 2026), and I am delighted to report that this year, thanks to your amazing response, we've reached that goal already! **Thank you all for your valuable contribution on our road to resilience.**



**313 new members**, representing **8% growth** in membership from 2022



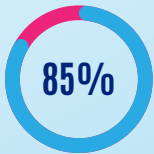
MACS now supports **3687 members** from 1369 households across the UK



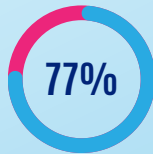
We were delighted to welcome **26 first time funders** to the MACS family, resulting in £93,354 new income

## Services Impact

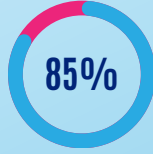
We have collated and evaluated the findings of a member-wide survey conducted at the end of 2022, to inform our next three-year strategy. The overriding theme is the desire to move back to in-person events, which we have been able to implement thanks to grant funding, hosting six in-person MACS Meet Up events across the UK. The outcomes and impact from our services were evaluated and we now know that



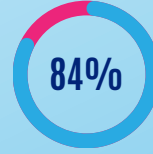
of parents say that they feel less alone and isolated



felt more able to help their child manage their condition



feel better informed about their condition



feel more connected to people who may be experiencing similar things



said they felt more prepared for the future

## Giving Families a Break

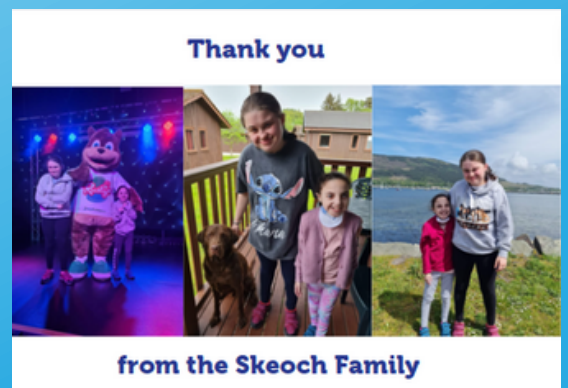


**Giving Families A Break** is a holiday voucher scheme that provides a relief of financial hardship for much needed respite with added physical and mental health benefits, for MACS families across the UK. Parents of MACS children may encounter added stress from managing the unique challenges of parenting a child with additional needs, so having a break becomes even more important and ultimately avoid carer burnout.

We've had some wonderful postcards this year from families who have benefitted and we know they'd want to say thank you to you directly if they could.

“ This holiday wouldn't of happened if it wasn't for MACS.

*We haven't had a family holiday in over 7 years so it was well needed. We had the best time. So much needed family time and time away from stress and hospitals. Both of the girls enjoyed it so much was lovely to see them both so happy... we made the best memories.* ”



# Staying Connected (Your local, national charity)

This year, we've had more regional funding than ever before which has been instrumental in supporting our response to members wishes and our desire to be their 'local, national charity'. Thanks to grant funding, we were able to host 6 MACS Meet Up events (MMU) this year across England. MMUs are in-person events that connect MACS families with each other and the charity. In total, 143 members attended events in Basingstoke, Staffordshire, Bradford, Mersea Island and Bury St Edmunds, and 14 attended our very first MACS adults Meet Up in Birmingham.



***"This was my first visit to a MACS group. I didn't know what to expect though it exceeded all my expectations and gave me a platform for me and my family to feel there is a community out there that is able to help us on our journey. Without them we would feel very isolated, and a lot of the care teams (community support) had no idea how to support us. We can't wait to come back next time."***

***"We have been with MACS for over 25 years, for us it is not what we want to get out of MACS, it is what we can give back to the charity and new families, with our experience and knowledge, and share what our child (now adult) had achieved."***



In March 2023, we collaborated with Headlines, CLAPA, Microtia UK and Changing Faces to put on a joint event in Scotland for members with a visible difference which is set to become an annual event.

THE COLLABORATIVE was established to help small charities like MACS run member events in areas where it would not be feasible to do so on our own, either because of small numbers of families, different age groups, costs of activities or geographical spread. All four charities in the Collaborative already have links with each other and provide similar services. Most importantly though, we all support families who have experience of conditions which involve visible differences to the face and head.

## Also in the last twelve months.....



We have set up 14 peer groups involving 275 members.



Our online support groups have grown 8% over the last year, now supporting over 885 people.



379 members connected with each other via 52 zoom meetings and events

***"I feel so connected without knowing you all that well and that's all thanks to this group."***

# Core - blimey!

In addition to the generous unrestricted grants that we have received this year, we have been overjoyed at the success of two new multi-year grants that have given us the resource and confidence to commit to the development of our services, allowing vital behind the scenes work to occur.

This includes our **Content Creative Collective**; a working group made up of MACS staff and volunteer members, who have collaborated with the WIG Future Leaders Programme (free resource for six months from civil servant professionals) and reviewed information/advisory resources evaluating accessibility and suitability, such as creating targeted leaflets for each life stage, to bridge existing gaps. This work has also initiated a website audit to improve accessibility and content and we are on track to start implementing the recommendations next year.

88p of every £1 is spent on charitable activities and services that **directly benefit our members**

# Oh Yes You Did!

Accessible Pantomime's are proving a very popular activity with our members. They are organised in conjunction with Local Social Volunteers and give MACS families the chance to enjoy the same opportunities as everyone else. Furthermore, they connect local families experiencing similar challenges for shared experience in an informal and enjoyable way, helping to foster a sense of community for reduced feelings of isolation and friendships for ongoing peer support.

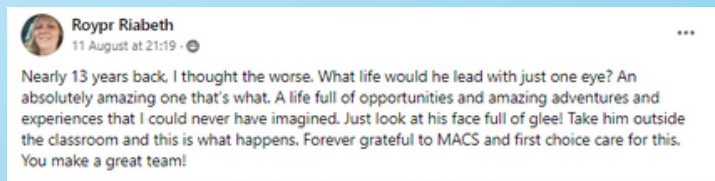


Grants have funded **4** accessible pantos in **Cardiff, Chesterfield, Canterbury and Dunstable** this year, benefitting **125** members

# Activity Trip

- 89% of attendees had an additional medical condition
- 20% of attendees had complex care needs
- 20% of attendees had 2+ co-existing MACS conditions

“ It was huge, his confidence has increased, he's come away with new friends who he's keen to talk to and he really struggles with social stuff normally. He hasn't stopped talking about the trip and what he did and being proud of the fact he did it! ”



<b>89%</b> of parents said the trip improved their child's confidence	<b>78%</b> of parents said the trip improved their child's independence	<b>100%</b> said the trip helped them feel more positive about themselves	<b>100%</b> of young people said they felt less alone and isolated
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# Making Waves



Our annual sailing trip was fully funded this year, enabling 10 MACS members, aged 17 - 24 years, to embark on a confidence building voyage like no-other!

One MACS member (aged 18) earned their RYA Start Yachting Certificate and three MACS members (aged 18, 22 & 23) earned their Advanced RYA Compete Crew Certificate. From the nine sailors who agreed to take part in the evaluation this year, we saw a marked change from the start to the end results, with overall scores for all the young people moving up 59 points from the start to the end of the voyage

***"I had the best time! I was able to learn new things and gained lots of confidence, thank you for all your help, the sea staff were very helpful and helped me understand everything."***

# Helping Hand

**Helping Hand** relieves financial hardship to support members in the most meaningful way possible. Members can apply for funding based on their own needs and **Helping Hand** subsidises the cost – from specialist aids or equipment to life changing experiences. This year, we've been able to fund **7** requests, including a **Helping Hand** of £200 opened up Tyler's world, connecting him to his family, education and the outside world in ways he's never experienced before.....

“ Tyler is profoundly deaf. He is also visually impaired. He has a condition called Charge Syndrome which means that he's a wheelchair user and he's also tube fed. He primarily uses British Sign Language (BSL) to communicate however, he also has a diagnosis of Autism which makes communication even harder.

*Now in his teenage years he's found a lot of emotions, hormones, a lot of things going on, the frustration for the lack of communication really has become apparent so I really wanted to find another way for him to be able to communicate.*

*We applied to the MACS Helping Hand fund for some AAC software that we could install onto his iPad. We've had the software a couple of weeks now and already Tyler has been able to communicate through the AAC device making choices and keeping control of his life and keeping control of his day-to-day activities. His college have adapted it into their day-to-day interactions with them as well.*

*It's really interactive, is really adaptable and we are super excited that we've been able to have this software just to open up Tyler's world.*



*The fact that he's Deaf Blind, the fact that he has Autism, the fact that he's a wheelchair user - these are all things that are barriers to him that sort of control the amount of interaction that he has with the world and it's so wonderful for once to be able to have something like the AAC communication device which starts breaking down those barriers and really starts helping him interacting with the world.*

*Another really big plus point about the AAC is that it talks for you so Tyler would select the options on the screen and then it has a voice system on it so they will then voice whatever sentence you've made. This is a really big thing for Tyler if he goes into a shop he could actually go up to a counter and say I would like bread please and someone could help him find the bread because they can hear what he's saying.*

*The AAC is breaking through barriers and we are super grateful for MACS for the opportunity to be able to use this with Tyler.*





# Focus on the future

Following our member-wide consultation (Dec 2022), we have now reviewed our organisational theory of change and finalised our sustained impact goal that **“All people with MACS conditions and their families are less isolated, better connected and have access to the advice, information and support they need to thrive and confidently lead a fulfilling life.”** This is now a guiding thread throughout the charity, helping shape service development and our new 3-year strategy.

2024 will represent 30 years of MACS. We've some celebratory events planned as well as some really interesting developments to achieve the outcomes on our refreshed theory of change and sustained impact goal.

From the start of 2024, we will be introducing a range of new services specifically for children/young people with MACS, as well as sibling carers under the age of 18 and progressing support for MACS adults. With age appropriate topics, content and communication channels, these fun and interactive activities, including teen podcasts, school holiday workshops and mini-MACS engagement campaigns, will offer the most meaningful support for our younger members, and continue to provide life-enhancing opportunities for our older members in a very cost-effective way.

This really is an exciting time to be part of the MACS family. We could not have reached this point without the outstanding support from the Trusts and Foundations community and thank each and every one of you for being the difference to families across the UK affected by these rare and irreversible conditions this year.

We really are privileged to have your support this year which has made a real life difference to so many people living with MACS.

We would be honoured if you would like to continue making a difference through your grant giving programme over the next twelve months.

Please do contact our Trusts and Foundations Fundraiser, Emily Murphy for more information on current funding priorities - [emily@macs.org.uk](mailto:emily@macs.org.uk) - or if you have been inspired enough to continue supporting MACS now, you can send payment to:

## **Cheques** (Payable to MACS)

Please send to:  
Microphthalmia, Anophthalmia and Coloboma Support  
71-75 Shelton Street, Covent Garden, London, WC2H 9JQ

**(Please include our full charity name on the envelope for the post to reach us)**

## **BACS**

CAF Bank Ltd  
Account Name: Microphthalmia, Anophthalmia and Coloboma Support  
Sort: 40-52-40  
Acct: 00029181

From everyone at  
MACS, the  
children, young  
people, and their  
families, thank you  
for your support  
this year.

## Acknowledgements



**The Calvert Trust**, Lake District for a successful adventure week

1st Choice Training, for providing excellent 1:1 care during the adventure trips, and evaluation of the week

**Ocean Youth Trust (South)**, for another successful sailing trip, and evaluation of the voyage

All the staff and volunteers who go the extra mile to make our events and services welcoming, successful and enjoyable

All our wonderful **MACS families** for making us proud

The **funders and supporters** who made all of this possible.

*We think that everyone deserves a shout out but have only been able to mention funders by name where specific promotion requests have been received. For GDPR reasons, we keep funders anonymous unless we hear otherwise, so please do let us know if you'd like a mention and we'll happily include you in future issues.*

**Microphthalmia, Anophthalmia & Coloboma Support**

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[www.macs.org.uk](http://www.macs.org.uk)

UK registered charity number: 1161897

Scotland registered charity number: SC052711