

Focus on Funding

Celebrating grant funding at MACS in 2024



Welcome

Hello! And welcome to the third edition of **Focus on Funding**; our annual newsletter that celebrates the impact of grant funding over the last year.



Following a comprehensive evaluation informed by member feedback, we entered 2024 with a sharpened vision, mission, and theory of change, culminating in our new three-year strategy, **Plan to Thrive**. Focused on four key areas - our **community**, our **support**, our **income**, and our **people and systems** - this strategy has been a guiding light for our efforts.

This year, we've made strong progress implementing **Plan to Thrive**, with regular reviews ensuring alignment with our mission and reinforcing the charity's sustainability and resilience. While unforeseen challenges, such as maternity leave and long-term staff sickness, caused minor delays, we are ending the year fully staffed and well-positioned to regain momentum.

Meanwhile, we've proudly celebrated our 30th anniversary (more on that later!) and remain deeply grateful for the grants that have strengthened our foundations and brought our mission to life.



It's been a pleasure connecting you with the MACS family and sharing the incredible impact of your support. Hearing these stories first-hand inspires and strengthens my resolve to make a difference. I hope this update leaves you equally inspired 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!).



We haven't been given much information from our hospital so we will be going private for Luna's care going forward but myself and my partner would have been absolutely lost if it wasn't for MACS. Especially when we first were going through the stages of getting her diagnosis the hour long phone call with Sharon gave me more information, guidance and hope in that hour than what I'd been fighting for since Luna was born. We wouldn't change our girl for the world her little eye just makes her even more special and unique. We are very grateful to be part of MACS and so thankful that MACS exists.

The MACS community has been so positive to reach out to where we have had questions, or wanted to see examples of what the future may hold for Freya, given we knew nothing about MAC conditions prior to Freya's diagnosis.



Hello, we are the Fuller Family!

I'm Laura (33) and I have right eye Microphthalmia and left eye Coloboma. I have a beautiful 9-month-old little princess called Daphne, who has left eye Microphthalmia and bilateral Coloboma. We have a loving husband and Daddy - Louis (33), who is fully sighted.

We hope to find support in those difficult moments, and know that we are not alone, and I hope that we can support, encourage and cheer on everyone in the MACS community in turn!

Chloe has microphthalmia and morning glory disc, in her left eye. She recently celebrated her first birthday and is the happiest little girl and loves clapping her hands to "If you're happy and you know it."

She is very loud and bubbly and always has a smile on her face. As a family we are coping well with Chloe's diagnoses and will look on the positive side to any challenges we face in the future. We are happy to of found MACS and look forward to meeting others alike.



Our little Lena was diagnosed with microphthalmia of the right eye a few days after she was born. The diagnosis was quite shocking and frightening at first, especially as Lena was in the Neonatal ICU for a couple of weeks, and we were initially worried she had a more serious condition.

It took her much longer to smile than other babies her age, but started giving an enormous grin at around 15 weeks, which has us both melting into puddles. Parenthood has been a bit different than we expected, but the support we've had from all corners, including finding MACS, has made all the difference.

Key Achievements

7

new services for more targeted support and engagement



134 new members
MACS now supports
3650 members from
1255 households
across the UK

25

We are delighted to have welcomed **25 first time funders** to the MACS family, resulting in £110,358.56 new income

Annual Member Survey Highlights

75%

Increased response rate in our annual member survey showing the positive impact of our engagement efforts



Online support groups on Facebook remain the most popular avenue of support for members, closely followed by in-person events

New heights for MACS Awareness

We made a significant impact for the rare disease community on **Rare Disease Day** (29 February 2024), sharing member stories across social media and reaching nearly **9,000** people and organisations. During **MACS Awareness Week** (23–29 September 2024), we launched a special 30th-anniversary Focus magazine and rolled out a hospital advertising campaign. Over four weeks, A1 posters and A5 leaflets were displayed in **21 hospital ophthalmology departments**, reaching an estimated **105,000 appointments** and generating **304,000 impressions** across the UK.



Thriving at 30

On 7th September 2024, MACS celebrated 30 years of community, support, and togetherness at our first major overnight family event since Covid! Families were welcomed with activities for all ages, including face painting, balloon modelling, and photos with MACS the Monkey. The day featured a tasty buffet lunch, gaming and circus workshops, and an evening of dancing to a live band. The celebration closed with a relaxed breakfast and swim session, leaving lasting memories and renewed energy for the future.

130 people from across the UK attended. **30%** were attending a MACS event for the first time. Many travelled over 50 miles to participate, but it was worth it. **90%** of participants felt more connected to others with MACS conditions, fostering community ties, and **85%** of parents agreed that their child felt more confident and accepted as a result of the event's support and information. **100%** said they would recommend MACS events to others, indicating high satisfaction and the perceived value of these gatherings.

The mix of new and long-standing members created the perfect balance, strengthening our sense of community and support. Through the shared experiences of others, new members gained insight into what MACS offers and received valuable tips that contribute to the overall mental well-being of everyone involved.

“It had an impact on me, I was advised on the importance of learning touch typing and how my daughter can learn to play games through this, and so first thing Monday morning and today I've had words with her QTVI and TA. Thanks for the empowerment.”

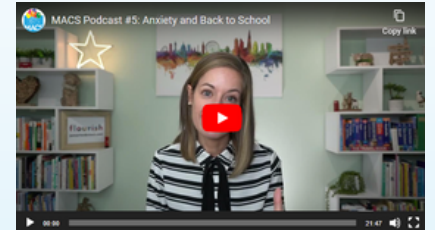


New for 2024!

Since its inception, MACS has dedicated its resources to supporting children and their families. However, after extensive research and community engagement, we've recognised the need for more targeted, age-appropriate services to support our members throughout different life stages. Alongside our existing online and offline service programmes, here are this year's key developments.

Online Services

We introduced a number of new services, delivered online for greater accessibility. These included **6 teen podcasts** (25 minutes) hosted by Jo Morton Brown - Accredited Counsellor and Young Persons Mental Health Practitioner, **6 interactive school holiday workshops** in partnership with Non-Stop Kids, **9 sibling workshops** delivered by Swings and Smiles (registered charity 1120598), **4 Dad's catch ups** - hosted by a volunteer Dad



Mini Macs

To engage with our younger members directly, rather than them experiencing membership via their parents, we introduced two initiatives.

1. We have sent **598** birthday cards to all children under 12 - a gesture that has been so warmly received that we'll continue it next year. Additionally, we'll introduce a special card for members turning 18, providing information on how they can join as independent members.
2. Mini MACS Travel Adventures encourages kids to take our mini-mascot, MACS the Monkey, on their travels and document the journey.



Regional Volunteer Programme

Thanks to generous funding from The Vinchel Foundation, we are expanding our regional volunteer network, making local support more accessible. This year focused on recruitment, with next year dedicated to onboarding and training volunteers to organise cost-effective, sustainable events. Building on the success of a local pantomime pilot, our aim is to have at least two trained volunteers in each of the UK's **12 regions**, enhancing engagement and sustainability through local support.



Data Dashboard

We were delighted to receive a one-off capital grant from the Clothworkers Foundation to advance our commitment to transparency, impact and continuous improvement by developing and implementing a new data dashboard. The dashboard will consolidate key data into a dynamic, real-time platform that enhances our ability to monitor, analyse, and respond to changing needs. These visual representations will be included in a new annual impact report which will be used to communicate impact to stakeholders including funders, members and the wider community.



Seable Sicily Trip

A new service for MACS adults, supporting our goal to develop transitional services. In partnership with Seable Holidays, we sent **6 MACS adults** on a bespoke, accessible holiday to Sicily in October. This project had a significant social impact, and for some, it was their first independent trip abroad giving them new and immersive experiences that may not otherwise be available, and was only possible because it was fully funded by grants!



Making connections

A fundamental aspect of our work is to connect MACS families across the UK to advice, information, support and each other to help them confidently lead a fulfilling life. We do this in a number of ways summarised below.

In-person Meet Ups

This year, we hosted two in-person meetups at Holiday Inns in Newcastle (February) and Nottingham (October). Established members warmly welcomed newcomers, sharing tips and stories that fostered inclusion and new bonds. In Newcastle, it was especially moving to meet a family whose daughter was diagnosed with a rare epilepsy after discovering matching symptoms on our online support page - highlighting the vital role of our community in providing connection and information.



“It was lovely and welcoming with a nice atmosphere. Both adults and children were catered for, and we felt extremely welcome and at ease after meeting parents in similar situations.”

Newsletters

Each month for the last year, **1,183** members have received our monthly e-newsletter, keeping them informed on a regular basis with updates, information and signposting. Furthermore, **1,992** hard copies of our printed members newsletter, Focus, were posted through members' letterboxes (braille copies are provided as needed).

Online Support Groups

Our members only groups continue to be a vital source of support and information. They are by far the most used service, with **78.57%** of parents/carers and **60%** of MACS adults regularly engaging on Facebook pages (with in person events following in second place with **54.3%** parents/carers and **20%** of MACS adults engaging).

“It helped us through the first through scary months when we didn't know anything about our daughter's condition. The Facebook group was a massive help to us.”

Clinical Networking

MACS has made great strides in building key connections and expanding support. Highlights include presenting at Alder Hey Hospital's Visual Impairment meeting, engaging with doctors, clinicians, QTVIs, RNIB, and local agencies to promote referrals into MACS. Our CEO, Teresa Gordon, spoke at the Hospital and Speciality Optometrists annual conference in Manchester (September 2024) and participated in the Vision Zone Southwest event to connect families with resources, and raising awareness at the Hospital and Specialty Optometrists annual conference in Manchester. We have initiated discussions with Vision for Good and taken on advisory role with the Centre of Appearance Research at Bristol University, helping develop a new resource hub for individuals with visible differences.



Accessible Pantomimes

Accessible pantomimes, featuring audio descriptions and tactile touch tours for visually impaired children, have become a hit with our members! Organised by local volunteers, these events offer inclusive entertainment while connecting MACS families. They provide a fun, informal setting to build friendships, reduce isolation, and foster ongoing peer support.



Also over the last twelve months....



Our online support groups have grown **7%** over the last year, now supporting over **950** people.



256 members connected with each other via **43** zoom meetings and events

“I feel so connected without knowing you all that well and that's all thanks to this group”

Building Confidence

Helping Hand

Helping Hand provides meaningful support to alleviate financial hardship, enabling members to engage more fully in society. Members can apply for funding tailored to their individual needs, with **Helping Hand** subsidising costs for everything from specialist aids and equipment to transformative opportunities. This year, we've funded **7** requests, including **£700** for Joseph. With this support, he received a TomCat Tiger Trike, opening up new possibilities and helping him connect with the outside world in ways he's never experienced before.



Joseph is a determined 19-month-old with severe visual impairment and developmental delays. Assessed at an 11-month developmental age, he faces challenges like low muscle tone, motor planning difficulties, and limited mobility - he isn't yet walking but can side-step around furniture. Joseph relies on support to interact with his environment during play and meals. Weekly visits from his occupational therapist and Qualified Visual Impairment Teacher, along with group sessions at Visibility Scotland, help his development.

A specially designed trike has been transformative for Joseph, allowing him to explore the outdoors and use his body actively. Unlike a pram, the trike engages his senses, builds awareness, and help him adapt to changing environments - essential steps toward independence and confidence.

Activity Trip

- 53% of attendees had an additional medical condition
- 32% of attendees had complex care needs
- 26% of attendees had 2+ co-existing MACS conditions
- 91% found the venue very accessible



91%

strongly agreed that their child feels more confident and accepted

73%

noted strengthened family relationships

100%

said the trip helped them feel more positive about themselves

100%

of young people said they felt less alone and isolated

“From initially booking to collecting my child the whole team and experience has been exceptional. I honestly cant thank the MACS team enough for all they do and there understanding of each individual child's needs.”



Making Waves



Our annual sailing trip was fully funded this year, enabling 10 MACS members, aged 19 - 25 years, to embark on a confidence building voyage like no-other!

This year's sailing trip was successful in fostering personal growth across various areas. evidenced by a marked change from the start to the end results, with overall scores for all the young people moving up 70.5 points from the start to the end of the voyage in areas like feeling confident, working in a team, learning new skills, dealing with setbacks, compromise and negotiation, and personal care. Each crewmate experienced personal growth, especially 19 year old WA who transitioned from limited speech at the start to full conversations by the end of the week.

“I really pushed myself to try new things which resulted in me going out on the bowsprit to help take in the job sail and leading a mizzen drop which I am really happy about.”

Core - blimey!

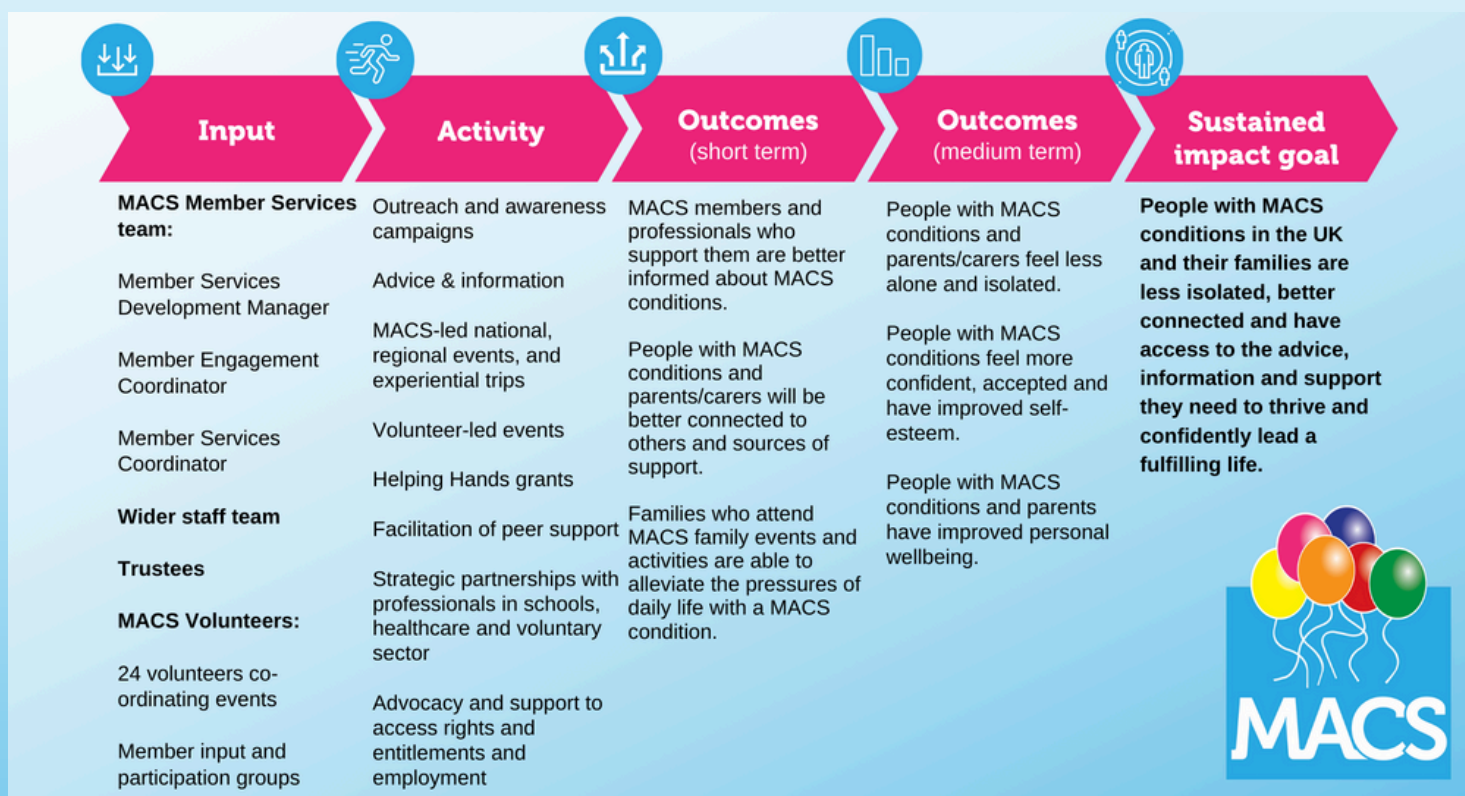
We've been so grateful for every unrestricted and core grant that we've received this year, helping to breathe life into our strategy by funding those 'hard to fund' elements. Salaries have been most successful area, and we are delighted to confirm that all member service salaries have been funded.

79p of every £1 is spent on charitable activities and services that **directly benefit our members**

Supporting our work in this way is invaluable and gives us the affirmation that what we're doing is worthwhile. It boosts morale and spurs staff on to do their very best for our members. Guiding them towards excellence is our Theory of Change; our framework that outlines how we achieve our intended outcomes. This year, we successfully completed a comprehensive review of our Theory of Change which now looks as follows.

Problem(s): MACS is a rare condition, which means that there aren't many other people with the same lived experience. Parents of newly diagnosed children can feel alone and anxious about the future for their child, have unanswered questions about the condition, and struggle to navigate the complex health, education and social care system. The impact of visible difference and people's negative perceptions can have a devastating impact on self-esteem and confidence of people with MACS conditions, particularly in adolescence and early adulthood. This can lead to isolation and mental health problems including depression and anxiety.

Primary benefiting group(s): Children and adults with MACS conditions, their parents and siblings.



Our **vision** is that all people in the UK with MACS conditions and their families are empowered to thrive and confidently lead fulfilling lives.



Our **mission** is to foster a vibrant, connected, and supportive community that is dedicated to empowering individuals and families with MACS conditions, helping them reach their full potential.



Our **values** collaborative, friendly over formal, and aspirational.



Focus on the future

Looking ahead: Continuing to Thrive Together in 2025

As we step into year two of our “Plan to Thrive”, we’re building on the tremendous progress made in the last year to strengthen our services and delivery for the MACS community. With 13 objectives spanning four key areas - our **community**, **support**, **income** and **people and systems** – this plan is designed to enhance our impact in a cost-effect and sustainable way.

In the coming year, we’re focusing on:

- Improving operational efficiency
- Raising awareness and support initiatives
- Increasing membership and engagement
- Expanding our volunteer programme
- Enhancing communication for outreach and accessibility for members
- Strengthening partnerships with clinicians and mental health professionals

To meet the evolving needs of our members, our Member Services Development Manager has crafted an comprehensive proposal to harmonise and expand our services. Exciting initiatives for 2025 include:

- **Parent carer talks** – recorded/streamed talks from subject matter experts, covering such topics as toilet training with disability, EHCP advice, transition to secondary school, benefits advice etc...
- **Employability programme** – supporting transitional services for young people. Conference style with demos and workshops including CV writing and access to work support.
- **Mental wellbeing** – including a targeted residential event for teens at Jamie’s Farm and build in specialist counselling by employing a part time counsellor (with visual impairment certificate).
- **Tech support** – responding to members’ needs for a bespoke activity to access society, gain independence, we would offer ‘at home’ support to set up equipment correctly to avoid wasted funds (from Helping Hand scheme) and best use for our members.

Your incredible support has made this progress possible, enabling real-life change for families living with MACS. We cannot thank you enough for being the difference this year.

As we look to the future, we would be honoured if you chose to continue this journey with us through your grant-giving programme. Together, we can reach even more families and ensure they have the resources and support they need to thrive.

Please do contact our Trusts and Foundations Fundraiser, Emily Murphy for more information on current funding priorities - emily@macs.org.uk

If you feel inspired to make a difference today, payments can be sent to:

Cheques

Please send to: (Payable to MACS)
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 all the MACS children, young people, adults and their families, thank you for making 2024 a year to remember, and for helping us shape a brighter 2025!

Acknowledgements



Non-Stop Kids, Swings and Smiles, Jo-Morton Brown, Ocean Youth Trust (South), 1st Choice Training, The Calvert Trust

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

UK registered charity number: 1161897

Scotland registered charity number: SC052711