

Focus on Funding

Celebrating grant funding at MACS in 2022



MACS



Welcome

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



I am Emily Murphy. I was delighted to join MACS back in April as the Trusts and Foundations Fundraiser. This is a new role, introduced as part of the strategic direction to become more service and fundraising led, and to diversify income streams.

The difference that the charity makes to people affected by MACS conditions is priceless and I feel privileged to be a part of that. Income from Trusts and Foundations is integral to MACS – constituting 60% of the overall income - and I feel it is an important part of your grant life-cycle to keep you informed, so you too can take great pride in the difference you have made this year.



I created this newsletter, using a free online service, to summarise the wonderful achievements that we've been able to make, thanks to your kind support. As I am learning more about the role, the charity and the people who benefit, it becomes all the more awe-inspiring and makes me more determined to be successful. I hope after reading this, you feel the same and inspired 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!).



Lorraine, Jason and twins

"Having twins who both have eye issues, we felt so alone and isolated; the hospitals gave very little information. Being left alone to do nothing but Google made us more scared for the future than necessary... and then we came across MACS. Finding others in the same boat as us, experiences similar to ours, and information that we otherwise haven't been able to find has already been invaluable. We are so pleased and relieved to have found such a charity that is helping us come to terms with the boys' conditions and I'm sure will help them as they grow and develop to know that they are not alone and that they can be surrounded by others just like them.

I'm so grateful to MACS already and can't wait to join regional and national meet ups and get to know the other families and people that have already supported us."



"Our son, **TOMMY** was three months old when he was found to have Bilateral Coloboma as part of a rare genetic condition he has. It is still early days and we don't yet know the extent to which his vision will be affected. At the moment, not knowing is the hardest part for us but we are happy to have found **MACS** to help us through this journey."



Martha with parents Rob and Amy



Martha is 11 months and joined with parents Amy and Rob.

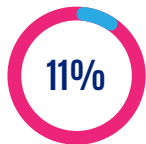
"MACS has been so wonderful to join! Seeing others who have been through the same thing made us feel less worried."



Lewis

"This is Lewis who's 13yrs old. He has coloboma and is also autistic, he was diagnosed when he was around 6 weeks old and we weren't given any information except a leaflet and told that it was rare. He hates going for check-ups because the dye they put in his eyes hurts. Lewis is very talented playing his keyboard by ear and is wanting to learn the bass guitar. He also loves gaming he has loads of games for PlayStation 2,3 and 4 he has the VR too."

Achievements



366 new members, representing 11% growth in membership on 2021



We welcomed our 1000th family

44 members benefitted from activity trips with demonstrated improvements in

1. Feeling confident
2. Working in a team
3. Getting on with people
4. Compromise & negotiation when living with others



812 members in our online Family Support Group, a growth of 10% from 2021



MACS now supports 3374 members from 1199 families across the UK



Activity Trips

Calvert (ages 5 - 18)

This year's activity trips took place at the Calvert Trust Centre in the Lake District. The centre is situated in a stunning location overlooking Bassenwaite lake.

We soon reached booking capacity and were delighted to see that a large proportion of children were new; having never engaged with MACS before. They were also children with severe complex needs. Where they may previously have felt this trip was not accessible to them due to their additional needs (many requiring 24hour one-to-one support), MACS staff have worked hard to bust this myth and are delighted to see such a positive response.



Grateful thanks to the Boshier-Hinton Foundation for their contribution to the activity trips.

In total, 60% of children attending had additional and complex needs. Each child had the chance to participate in a sporting activity, alongside their peers - something they never thought possible, but this did mean that we needed to fund additional specialist care support staff.

Grant funding contributed 40% of the overall costs for week. This is lower than expected due to the increased costs and being unfortunate in securing a regular grant which would have meant 88% of the overall costs would have been covered.

100%

of young people said the trip improved their confidence

88%

said the trip gave them a greater sense of independence

77%

said the trip improved their social & relationship skills

100%

of young people said they want to return again next year

"When your child has complex needs it is difficult to find any charity willing to include them on these types of trips. The care team were great with Josselin."

Giving Families a Break

25 holiday vouchers issued this year



Giving Families A Break is a holiday voucher scheme that provides much needed respite, with physical and mental health benefits, for MACS families across the UK.

Almost half of people in poverty in the UK are in a household with a disabled person/are disabled themselves so this service really does help make the impossible, possible. Each family receives £750 to be redeemed with our holiday partner who provide flexibility and choice for families enabling them to pursue the most accessible option for their circumstances.

Staying Connected



Our online support groups have grown 10% over the last year, now supporting over 812 people.

"Having a Facebook group with other families that we could ask questions was amazing and everyone is so supportive and helps in any way they can."

Away from the screen we were delighted to resume our **MACS MeetUps**. Our first event this year was held at Warrington Woolston Play and Sensory Centre. The majority of attendees were first timers at a MACS event. One family even made a round trip of over 320miles to meet other MACS members.

These events are so valuable. They are all about making contact with others who have common experiences and sharing their journeys. Our events are open to all abilities and age ranges and are free to attend.



On a more local level, we are so pleased to update you that we now have 24 **Local Social Group** (LSG) volunteers, taking the lead on organising activities for members in their local area. We've been delighted to see such a positive response from funders to progress these in their areas, including Sovereign Healthcare who donated a wonderful £4000 to help set-up two LSGs in Bradford.

The yellow dots on our members map shows where LSG volunteers are located. Our aim moving forward is to have at least one LSG in every county across the UK.

One seasonal get-together that always goes down well is the **pantomime**. MACS is organising a number of accessible trips this year for members to enjoy and is thrilled to receive £3000 funding from the National Lottery Awards for All (Wales) to fund our very first panto in Cardiff, which will fund 50 members for 2 shows.



The special pantomimes offer audio description and sign language enabling MACS children to enjoy the same opportunities as everyone else.



"This was my son's first time meeting another child with a MACS condition. My son has Microphthalmia, Autism and ADHD. His needs were both met, catered for and understood. He suffers with anxiety in social situations but never have I seen him adapt so well or be so at ease. From a child who didn't want to participate to a child who can't wait to come again. He now thinks of his eye as his superpower and doesn't feel so alone."

Your local, national charity

Local and Regional Funding

MACS is a national charity, yes! But we do operate at a local level and are able to ringfence your donation to a specific area if required. At this point, we'd like to thank the funders who have given so generously over the year to progress services in their local area.

The Eveson Trust for example has provided much needed funds to support members in the West Midlands (specifically Herefordshire, Worcestershire, Sutton Coldfield, Wolverhampton, Walsall, Sandwell, Dudley). We've also received funding specifically for South Yorkshire, Nottinghamshire, Derbyshire, East Lancashire and Cheshire.

If you have a specific request, do contact our Trusts and Foundations Fundraiser - emily@macs.org.uk - to see how we can accommodate this.

The Big Give

As part of our fundraising strategy to diversify income streams, MACS is taking part in The Big Give Christmas Challenge, and this year, we have approached Trusts and Foundations for the first time to support this initiative.

We are very grateful to the funders who responded so positively to this request keeping us on target to raise £9800 through this matched funding campaign.

All funds generated through this campaign will be directed towards supporting our members through our regional **MeetUp** events which connect local families for peer support.

theBigGive



Core - blimey!

As a remote working charity with 5.8FTE staff, overheads are kept to a minimum. However, they remain essential to the continued operation of the charity. Any **core funding** we receive to help cover these costs is hugely beneficial and gives us the flexibility to apply other funding towards the current greatest need/s.

Based on our latest audited accounts (year end December 2021), 70p of every £1 donated is spent on charitable activities and service delivery.

This year, we have been overjoyed at the success of two multi-year **core grants** (covering salaries) which help plan finances more efficiently and ensure the continuity and development of services for the benefit of MACS individuals.

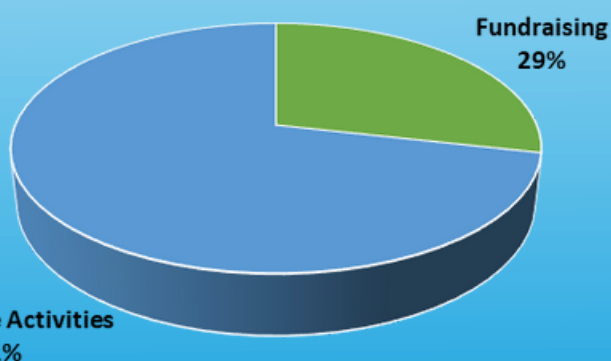
Thank you Pears Foundation and Masonic Charitable Foundation.

Pears
Foundation



Masonic
Charitable Foundation

MACS Expenditure 2021



Helping Hand



Helping Hand supports members in the most meaningful way possible. Members can apply for funding based on their own needs and **Helping Hand** subsidises the cost – be it specialist aids/equipment, life changing experiences, or medical needs. Whatever the reason, this initiative helps meet the extra costs associated with living with a disability, supporting people like Cassidy who received a **Helping Hand** this year.....

Cassidy is studying a BTEC photography course. She has a natural talent and even with her visual impairment, is excelling and winning awards. Recognising this, her college invited her to take part in a photography trip to Iceland but. A £1000 **Helping Hand** grant from MACS enabled Cassidy to participate in this trip which was otherwise unaffordable.

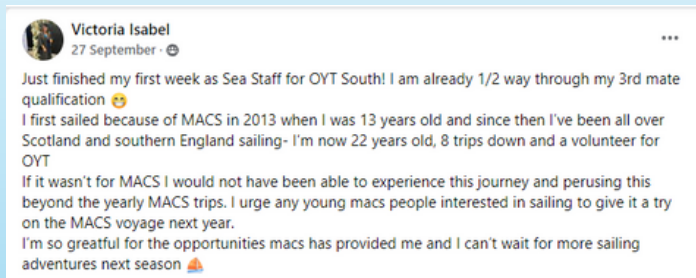
This extraordinary, life-changing opportunity helped develop Cassidy's skills so she can go on to thrive in a profession that she is so passionate about, whilst simultaneously boosting her self-esteem and the feeling of fulfilment. As she says herself, it will "develop my photography further than 12-year-old me would have ever imaged when I took my first landscape photograph."

With grateful thanks to the Hospital Saturday Fund, we can start 2023 with restricted funds specifically to give other MACS members a **Helping Hand** in 2023.



Making Waves

Our **sailing** adventure this year reached capacity with 15 MACS members aged 16 - 25 embarking on board the *Prolific* (managed by the Ocean Youth Trust) and sailing 151 nautical miles over the course of seven days. The group consisted of ten MACS young people and five carers, two of whom are sibling carers.



We use the outcomes wheel, developed by Children in Need and the Prince's Trust to measure how crew members felt about themselves at the start of the voyage and again at the end, giving themselves marks out of six in ten different areas.

We saw a marked change from the start to the end results, with overall scores for all the young people moving up 53 points from the start to the end of the voyage. These were evaluated in the following categories:

1. Feeling confident (+13 points overall)
2. Working in a team (+17 points overall)
3. Learning new skills (+10 points overall)
4. Coping with new experiences (+13 points overall)

More than that though, this trip provides opportunities for life as illustrated by Victoria (left).



Focus on the future

2023 is shaping up to be an exciting year with some new ventures in mind. The whole team and board are meeting on 24 January 2023 for a Strategic Development, Theory of Change, Impact and Evaluation Workshop. At this point, a member-wide survey will have been completed to better inform service design in line with member needs.

Our previous member-wide survey led to our 2018 Confident and Connected document, which mapped out our ambitions for the next four-years. Sadly, the impact of Covid and lockdowns meant a lot of this work had to be put on hold and needs reviewing. At this stage our key priorities remain to

- Diversifying and developing sustainable income streams
- Increasing awareness of the charity and expanding our reach to more people with MACS conditions.
- Developing our service offering to address need and reach more members.

We intend to maintain our **member-led** ethos throughout the year by organising more local/regional MACS **MeetUps** and will be inviting members to take part in a **focus group** at each meeting to better understand their changing needs. This will help us adapt our service programme for members as they grown up and their needs change.

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.

Microphthalmia

Born with one or both eyes being smaller



Anophthalmia

Born with one eye or no eyes



Coloboma

A cleft or gap in the eye structures



We really are privileged to have your support this year which has made a big difference, often leading to life-long impacts for our members and would be honoured if you would like to continue making a difference through your grant giving programme.

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

Cheques

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

(Please include our full name 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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Registered Charity Number 1161897