

Focus

*Issue 6
February 2017*



**Take a look inside to
meet Zorba, and find
out what's involved in
getting a Guide Dog**

Chair's foreword

Hello all, and welcome to our 6th edition of *Focus*, the first of 2017!

2016 was a fantastic year. MACS is now larger than it ever has been before and we continue to be there for our members, having the largest member base we've ever had. Year on year, MACS continues to grow yet still retain its core values, ensuring that member support is at the heart of what we do. That will never change.

This was my first full year as Chairman and I've loved every minute of it. From talking at the United Nations Office in Geneva to meeting members at our annual family weekend, it's been an absolute honour. I can't wait to see you all – my friends – in 2017.

This edition of *Focus* brings with it the most up to date and important information for you, our members. Our editorial team has enjoyed writing it, and we hope you enjoy reading it.

In late 2016 MACS welcomed a new staff member and said a fond farewell to another. Victoria Samuel, our Charity Development Manager of three years, has moved onto pastures new and we all wish her the very best. It is to my delight that Victoria has agreed to stay on as a volunteer and she

has edited this very magazine – a fantastic effort. Victoria really was a help to me in my first year as Chairman and I'm thrilled she's staying involved. Helen O'Brien joined us upon Victoria's departure and works with us as charity administrator. You'll find out more about Helen on page 6 and will no doubt meet her at future events so please don't hesitate to say hello! In addition, we've recruited new volunteers into new positions which has also seen the return of Debby Clark to become one of our Regional Coordinators, alongside Louise Eggins. The regional support network is one of MACS' strongest assets and I'm sure it will go from strength to strength with these two at the helm.

All that is left for me to say is – enjoy the read! **Remember that bookings are now open for the MACS Family Weekend** (as you'll read on page 14), **don't forget to book!**

I wish you all a wonderful and prosperous 2017 – I can't wait to see you all at some point!

Robbie Crow

Robbie



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New member gallery

Say hello some of our newest young members...

Daniel Johnson is 10 years old. He is from Oxfordshire where he lives with mum Maria and has bilateral Microphthalmia & Coloboma.



Eight-year old **Isaac Gwynne** from Lanarkshire has unilateral Microphthalmia and additional health issues. He lives with mum Miriam and twin sister Naomi.



Taliah Tanwala from Wigan, is just over 6 months old and has bilateral Coloboma. She lives with mum Anisa and dad Daniel.



Matthew Buggs and his mum Fay are from Essex. Matthew is nearly 4 and has Microphthalmia in his left eye and cataracts.



Eddison Brookes is 17 months old and lives with mum is Rebecca Williams and his older brother Toby. He has Microphthalmia and Coloboma in his right eye.



Cole Winfield was born in August 2016 with bilateral Coloboma. Cole is from Castleford, West Yorkshire where he lives with parents Laura and Oliver.



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Trouble at bedtime? Top tips for a silent night

With over 1,500 members around the UK, our MACS community contains individuals with lots of skills and expertise on a range of issues. One such member is Sunny Freakley, a sleep expert who is happy to share some top tips with our *Focus* readership.

Over to our sleep fairy, Sunny...

Let me introduce myself, I am Sunny and a proud parent to my fabulous MACS child Edward. Some of you may know him from the last family weekend... **he's the boy who can ROAR!**

I am by profession a Sleep Practitioner and work with families of children with disabilities or additional needs who struggle with sleep. Parents are often told that it is part of their child's diagnosis and so accept it, but it doesn't have to be like that! With a good routine and a little bit of insider information, many kids who have never slept well can have a good night's sleep.



Sunny and Edward

We all know that going without sleep is just plain awful. There is a reason sleep deprivation has been used as a form of torture, because it is just that, torture! It will affect a parent's judgement, ability to perform everyday tasks, and even make the mildest mannered parent irritable. Worryingly, sleep deprivation not only affects your child's learning, behaviour, mood and health, but also the parents and siblings physical and mental well-being.

Did you know?

- Up to 40% of children will experience a sleep problem in childhood.
- 27% of children aged 4-12 in mainstream schools have difficulties self-settling.
- Up to 86% of children with additional needs will suffer with sleep problems.
- Sleep deprivation is linked to obesity.
- Poor sleep patterns impact on cognitive ability; children who are sleep deprived often fail to meet their full potential at school.
- Parents who are sleep deprived are more at risk of family breakup.
- Sleep is as important as food and drink to the human body.
- Many sleep problems are behavioural and can be remedied by sleep practitioners rather than the use of medication.

Children with a disability or additional need can have sleep problems for a range of physical and behaviour reasons. And without specialist support, sleep problems can continue for years. Some sleep problems are common with certain impairments, so you need to take into account your child's individual diagnosis. Thankfully though, there is a lot that can be done to help.

Good bedtime routines are essential to promote good sleep. An essential part of any bedtime routine is to turn off all electronic devices, TV, Laptop, tablet and games console, at least 1 hour before bedtime as the white light these devices emit inhibit the production of Melatonin.

Nutrition is key and there are a variety of food groups which can assist with improving sleep. I recommend foods containing an essential amino acid called tryptophan which can only be produced through diet; this then converts in to the neurotransmitter serotonin, which is then converted to the neurohormone Melatonin. These foods include dairy, bananas, bread, cheese, seeds and nuts. It is a common misconception that cheese is to be avoided at bedtime as research shows it can actually have a positive effect on the ability to sleep.

The sleep fairy's top tips for a good night sleep.

- Get into a really good routine and make sure that you do the same thing at the same time each day. This includes waking your child at the same time every morning to strengthen their body clock. Yes, we know this is hard on a weekend but it is also very important!
- Switch off all screen activities an hour before bedtime, the light from them interferes with the production of melatonin which is the sleep hormone that helps us nod off.
- Activities that involve fine motor skills are generally relaxing so encourage your child to take part in these before bedtime. Colouring in, jigsaws, loom banding and threading activities all promote relaxation. You will need to plan appropriate relaxing activities in advance.
- If your child enjoys being bathed, then you should include this in your bedtime routine. A bath 30 minutes before bed is perfect for aiding sleep. The decrease in body temperature after getting out of the bath makes us feel sleepy around half an hour later.
- Give your child warning as bedtime is approaching, you can use a visual timetable to show them what is happening next.
- Using calming music and a more calming tone of voice as you begin to wind down.



What's the right amount of sleep?

The amount of sleep a child needs fluctuate at different developmental stages, of course each child is different.

The chart below can be used as a good indicator of sleep needs.

Average Sleep Needs by Age

1 -3 Years
3 - 5 Years
5 -9 Years
9 - 14 Years
15 -16 Years

Average Hours of Sleep Needed

12 -14 Hours a day (including naps)
11-12 Hours
10 -11 Hours
9 -10 Hours
8 Hours

Introducing our MACS Administrator, Helen!

I'm Helen O'Brien, MACS' newest staff member. I joined MACS as an Administrator in October 2016 and have absolutely loved my first 3 months! I really love working with the MACS trustees, staff and volunteers – everyone cares so much about the cause and their enthusiasm is not only awe-inspiring but it's also infectious; it's easy to see how people become life-long MACS supporters!

I've been asked to write a little about me, so here goes...

I live in Hemel Hempstead with my partner and 2-year-old son, Byron. Byron is a Bob the Builder and Fireman Sam fanatic and so I spend a lot of my spare time pretending to put out fires in my front room whilst singing "Can we fix it? Yes, we can!" Other than that, I enjoy playing tennis, Sunday roasts and board games.

I am going to be at Family Weekend this year so I hope to meet lots of you there if not before. I will be dusting off my pirate costume for the dinner and can't wait to see what sort of acts we have in 'MACS Has Got Talent'. When I worked in schools my favourite days were always towards the end of term when everyone wore fancy dress, had dancing competitions and played party games, so I'm sure you can imagine how much I am looking forward to Family Weekend! (Although I won't be dancing... the kids always outshine me!)

I think that's one of the things I love my role at MACS, it is so varied – one minute I could be attending a party dressed as a pirate, the next I could be sending out newsletters, or tinkering with the website, or cheering on Team MACS at an event. I think in that respect it makes use of a lot of the skills I have amassed through what has been a somewhat varied career. For example, in offices I have worked in customer service, finance and administration, whilst in schools I have worked with children aged 3 to 18 in various settings. I have also volunteered



in many different sectors— having worked with people with disabilities both in the UK and abroad, helped at homeless shelters and fundraised for various charities. So when I saw this job advertised at MACS which combined charity administration with a chance to help children all over the UK I knew I had to apply.

I look forward to meeting many of you at a MACS event soon. Please feel free to get in touch at helen@macs.org.uk whether it is just to say 'hello' or to ask for information or assistance, it would be lovely to hear from you all.

Best wishes,

Helen

Helen

Could you be a MACS volunteer?
If you are interested in becoming a volunteer for MACS or have ideas about events and activities in your area, please get in touch with events@macs.org.uk

MACS grants in action

Play equipment

We were recently granted a MACS' grant to help towards a play house for our son Charlie who has just turned 3 years old. Charlie was born with Peripapillary Staphyloma, optic nerve Coloboma in his right eye. He also has myopia in this eye and is very light sensitive. Charlie has been through so many tests and hospital appointments in his life and endures daily patching to try and get the best from his vision. The patching sessions are a nightmare. Charlie has an older sister and a twin brother so trying to explain that he has to wear the patch and his siblings don't is heart breaking. We asked for help towards the play house so that it would provide a distraction whilst patching and a safe play area for Charlie to play with his siblings, the added benefit of it being outside but allowing him, to play under cover when the sun is too much for his eyes.

The play house has been amazing. It has given Charlie so much joy and confidence. He calls it his present from MACS the monkey for being a brave boy and doing great patching! He said "MACS monkey gave me this because I've got super strong eyes and I'm really brave at the hospital". The house has allowed all three children Charlie, Alfie and Ruby to play happily together. It has been a real bonding gift and they have showed how proud they are of their brother. They also say "this is Charlie's house for being brave".

Thank you MACS for such an amazing gift and for always being there for Charlie and our family.
Donna Bennett

Music therapy

Calum Boyle has bilateral Anophthalmia and has benefited greatly from a music therapy grant. His therapist Lisa says: "Calum really enjoys music therapy - he loves playing different instruments to the rhythm of the music. His favourite part of the session is when he has a turn on the guitar, where he is allowed to strum. Calum's personal favourite is 5 little monkeys swinging in the trees. Music therapy allows Calum to have a personal sensory music experience."

Mum Xuxa adds: "A huge thank you to MACS for granting Calum one to one music therapy for the next school year! Calum really looks forward to his weekly sessions with Lisa!"



Aids to Accessible Living: Guide Dogs

In this first of a series of articles focusing on aids for blind and visually impaired people, trustee Jonathan Attenborough guides us through the Guide Dog Application and Matching Process.



The process of applying and being matched with a guide dog can be a long process, but is a very rewarding experience. Having said that, the process for me was surprisingly quick, taking only 5 months. It was pure luck that Guide Dogs had the right dog that matched what I needed, and that I was willing to travel for training. The average waiting time for a first guide dog is between 12-18 months, but could be longer or shorter depending on circumstances and the availability of dogs matching your specific requirements.

Shortly after I applied, I was contacted by a Mobility Instructor who came to visit to get some more information and carry out a mobility assessment which took us on a walk around my local village so that she could assess how well I travel, and how good my long cane skills were.

About a month later, a Guide Dog Mobility Instructor (GDMI) arranged my Guide Dog Assessment. The GDMI visits you at home to get more detailed information about your daily activities. This helps them to match you with the right dog. She also took more detailed information about our other pets - two pet greyhounds and a cockatiel!

The GDMI also brought a dog with her so that I could experience what it is like to have a guide dog and so that she could further assess if a guide dog was going to be right for me. I went for a walk with Frankie and it went very well. I was then officially placed on the waiting list for my first guide dog!

In July 2016 I got a phone call from a GDMI from the Guide Dogs Mobility Team in Belfast. She told me that she had a dog she thought could be a match for me and wanted to bring him over for a 'Matching Visit'. Two days later she arrived with a very handsome yellow Labrador x Golden Retriever called Zorba! We went out for a walk and I knew after the first few steps that I wanted this to be a match so badly! After about a 30-minute walk, the GDMI told me the best news that I had heard all year, that it was a match! We then introduced Zorba to our pets which he was fine with. I was then told I would have to go on a two-and-a-half-week residential training course in Belfast starting later in July.

I arrived in Belfast on the 26th of July and at my hotel I met the GDMI who done the matching visit with Zorba. I was taken round the hotel to find my bearings and later re-introduced to Zorba! I was given his bed, his food bowl, and his water bowl and was taken out to the back of the hotel to see where the spending (toileting) area for the dogs was.

The training

During the first week we learned the basic commands such as "straight on", "straight to the kerb", "find the crossing" etc., and put them all into practice. The first couple of days we went over crossings at right angled corners and then

after that we practiced rounded corners. The dog has a slightly different way of dealing with each of these kerb crossings so it was good to have the time to put these into practice.

I have been a long cane user for many years, so I was re-training myself to get around using totally different mobility techniques. I found quite difficult to grasp at first, but like with everything, the more you practice the more natural it becomes.

The benefit of doing the residential training is that it gave me time to bond with Zorba and really get to know him, both as a working dog and a faithful companion. It is away from any home distractions and it is just me and the dog, which in the beginning, is invaluable.

Throughout most of the day guide dogs are not working. Once they have taken their owner from A to B they are off duty until their services are required again, so a lot of the time the dog is just getting to be a normal dog. Mostly lazing about and sleeping!

The course also covered how to navigate around shops with the dog, how to safely get around off kerb obstacles such as a car parked on the pavement blocking the route and how to safely board and alight trains, buses and taxis. We also covered emergency stops as well.

On both Sundays that I was over in Belfast we took Zorba for a free run in the park. Guide dog owners are encouraged to give their dogs a free run once or twice a week to let their dogs have a burst of energy and give them a chance to mingle with other dogs and have a good time.

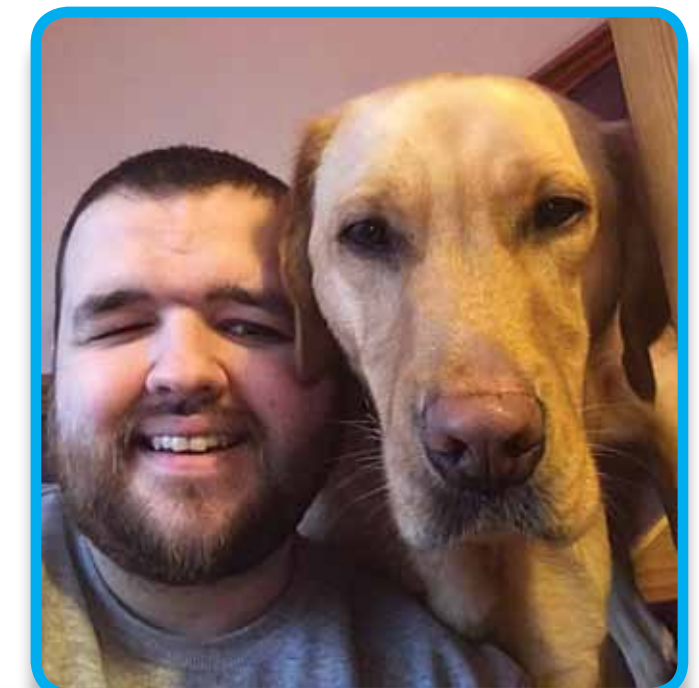
The residential training is physically and mentally exhausting but it is very worthwhile and beneficial. After the residential training I came back to Scotland with Zorba and the GDMI trainer. We got settled in and then we both chilled out for the rest of the evening as the next day we began the last part of our training from home.

The following week we covered all my home routes as well as my route to and from work to get Zorba familiar with them and to see if there was anything on the route myself or Zorba needed any extra support with. With the training now officially completed, I qualified with Zorba on the 10th August 2016 which was the best feeling in the world!

I always thought of myself as being very confident at getting around with my long cane, but since having Zorba, I feel a massive boost in confidence and I now find I have a spring in my step as I walk down the street with Zorba leading the way. I no longer have to worry about finding obstacles with my cane, as Zorba now guides me round them. It is an old cliché, but guide dogs really are life changing animals. It is really difficult to find the words to describe the sense of freedom they provide, and not only that, if you have a guide dog by your side you are never alone in the world.

Four months on, having Zorba has made such a massive difference to my life, in a positive way. Having a guide dog takes all the stress out of traveling if you have a visual impairment, and also makes you feel safe. Whilst I was a confident long cane user, I didn't particularly like it. I always felt that I had to think about, and plan each journey I was going to take even if it was just a walk down to the shops. With Zorba, I can be more spontaneous, and not have to worry about bumping into things or accidentally slipping off the edge of a kerb.

If you are considering applying for a guide dog, I would highly recommend that you get in touch with your local **Guide Dogs Mobility Team**. They would be more than happy to visit you to talk to you about the process and whether it would be the right thing for you. It has been one of the best decisions that I have made in my life!



Tech Talk... Audio Description

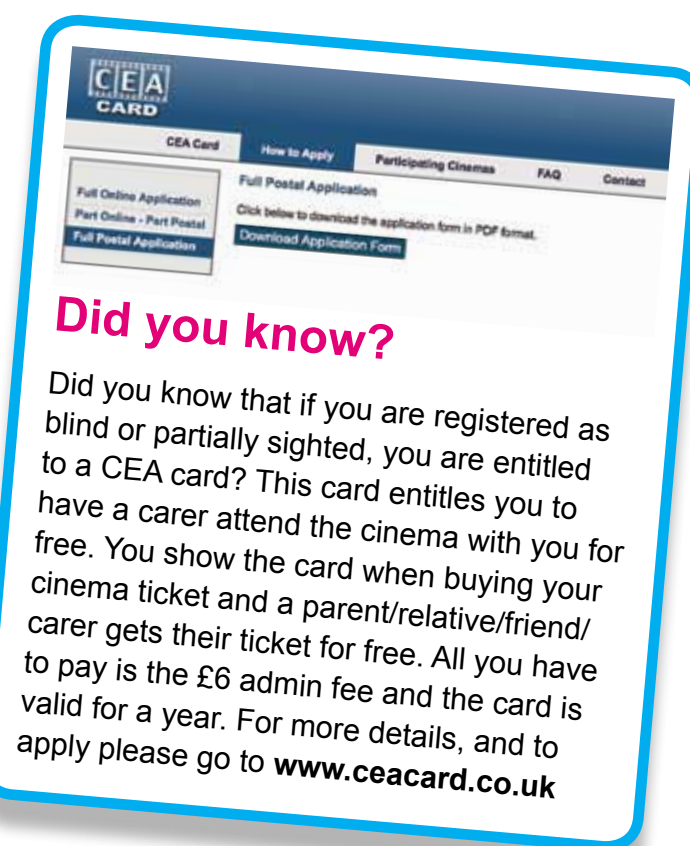
Welcome to another new section of *Focus* based on the technology available to help make everyday life easier for blind and partially sighted people.

Trustee Jonathan was eager to develop a technology section for *Focus* because he relies heavily on technology in his daily life, whether it be using the voiceover on his iPhone, screen magnification for his MacBook or portable video magnifiers for reading documents in smaller print - such as invoices, receipts, price tags, cooking instructions on packaging etc.

In this issue, Jonathan highlights his experiences with audio description. Thanks for your input Jonathan!

I have been using audio description for many, many years and it has helped me to enjoy movies and TV shows a lot more. What is audio description you may ask? Well, if you go to see a movie at the cinema, you can ask if they have audio description available for the movie you are wanting to see. They will give you a pair of headphones to put on and when the movie starts it will then describe to you what is happening on the screen, and pause when there is dialogue. So, if a character in a movie picked something up, or put something down, or made a certain facial expression it would tell you what they did in your headset. This greatly improves the cinema experience for me, as without it I would miss out on small details of the movie, and most likely key parts of the storyline. It is also very useful if there are parts of the movie that have subtitles as the audio description headset also reads out the text which is on the screen.

It is not only cinemas that use audio description. You can ask for audio description if you attend football matches or go to the theatre as well. I am also a big fan of Netflix and so pleased that they have recently added audio description to



mostly all their TV shows and movies. I have found that audio description services really have enhanced the enjoyment of watching movies and TV shows!

Why not check out *VocalEyes* – a website providing information on audio-described events around the UK! www.vocaleyeyes.co.uk

If you have your own experiences of using audio description that you would like to share, we'd love to hear your feedback and perhaps use some quotes in our next issue!

Please feel free to get in touch by emailing me at jonathan@macs.org.uk if you would like to share your thoughts, or if you have any ideas for future Tech Talk articles that you would like to see.

2017 MACS Family Weekend book your tickets now!

Come and join us for another weekend of fun from Friday, 28th April until Monday, 1st May at Park Hall Hotel, Charnock Richard, Lancashire.

As you may know, from 2018 we will be alternating venues for the Family Weekend between the North and South, so this will be our last weekend at Park Hall for a little while.

This year's event theme will be 'Pirates and Princesses' and we're looking forward to seeing what our members, old and young, make of it. We're expecting lots of sparkle and even more 'Aaaarrrrggghhhhs!'

Many more activities are yet to be announced, so please keep a look out on the MACS Facebook page for further updates.

A booking form for the weekend can be found online here:

www.macs.org.uk/family-weekend.html

Tickets costs £35 per person per night including dinner, bed & breakfast. Children or adult members affected by MACS conditions attend



free of charge and siblings can also attend free of charge if aged 18 years and under.

Any additional adults (friends, partners who are not MACS members, or extended family members) must pay the full price of £70.00 per night.

A deposit of £30 per booking is required, however if you are an adult member with a MACS condition and attending alone, no deposit is required.

We look forward to seeing you on the weekend! If you have any questions or suggestions please get in touch with the Family Weekend team on familyweekend@macs.org.uk

Holiday with MACS in 2017

For those who have already applied for a caravan holiday during peak season, you'll be hearing from us very soon with your allocations.

Applications for short breaks and extended family and friend bookings will open on 14th February. **Mark it in your diary so you don't miss out!**

Booking forms will be available here:
<http://macs.org.uk/book-your-holiday/>

This year, our MACS Caravan Coordinators are Caroline Hornby (Dorset & Cornwall) and Sarah Hornbrook (the Lakes). Thanks to both of them for their support.



Sailing the seas with MACS

MACS teenagers aged from 13-19 got to take part in another week long sailing trip during summer 2016 – this time setting sailing from Dartmouth and returning to Gosport. This is always an incredible experience for those taking part, and every child attained their competent crew certificate, learning to sail the boat, make knots, talk to the coastguard and plot a chart in addition to practical cooking and cleaning skills. Overall our young MACS people sailed 186 nautical miles, by day and by night – a huge achievement.

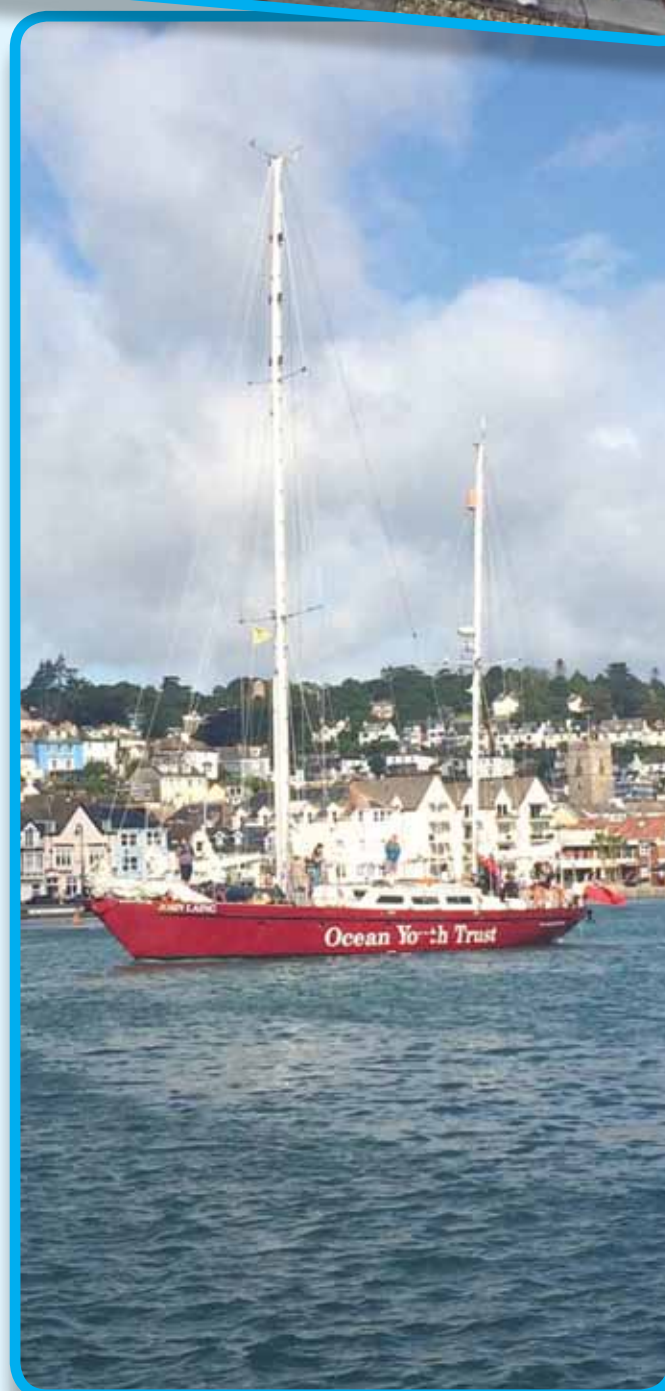
This particular trip however, contained a little extra 'special' with our MACS crew taking part in the ASTO Small Ships Race and being placed first in class! What an achievement!

MACS Chairman, and avid sailor, Robbie Crow said at the time:

"I've just got home from the crew party and prize giving of the ASTO Small Ships Race. All of the young people were having an absolute ball mixing with other young people from the other ships. The constant comment that I got from other sail trainers is how friendly, welcoming and slightly bonkers the MACS crew are. They really are amazing young people."

"As for race results? The old adage of 'it's the taking part that counts' still stands true, but it helps that they came first in their class, too! It's worth noting that the boat they were sailing on, John Laing, has only ever won first prize once before in her whole sail training life (roughly 30 years) and she's known in the UK sail training fleet as the boat that never wins, but always the friendliest boat in the race. It's very fitting that in her last ever race (she's being replaced and decommissioned in 2 months' time) is one that she won, all with MACS young people on board."

In 2017, MACS young people will have the chance to sail from Ipswich to Southampton on the new boat Prolific between the **24th to 30th August**. If you're keen to find out more, email events@macs.org.uk



Regional Round-up

As usual, there's was a lot going on within our MACS communities around the UK during the festive season - pantomimes, bowling, pottery painting, trampoline bouncing, and parties to name a few!

Take a look at the photos on this page and see if you can spot anyone you know!

Thanks to member Anna Batten who got to enjoy the company of the wonderful Treharris Male Voice while collecting a £400 donation raised at a local concert!

Regional Supporters required!
Make sure you look out for forthcoming events during 2017, we'd love to see as many old and new members as possible. If you are interested in becoming a regional supporter or have ideas about events and activities in your area, please get in touch with events@macs.org.uk



Adventurous Escapades at the Calvert Trust

Summer 2016 saw MACS return to the Calvert Trust in Cumbria with 37 MACS youngsters in tow (and a few parents).

Firstly, was our five-night adventure for children aged 10 and over. Many of the group had additional health needs on top of their visual impairment and so at Calvert, we made sure that the activities on offer were accessible to all.

New this year was Gyll Scrambling – which involves scrambling up and down gorges, with leaps into icy plunge pools – rather like caving but without the roof! Other activities

included canoeing, swimming, zip wire, giant swing, team activities, talent night, abseiling and archery.

We set each activity by ability rather than just mixing children together, which gave each child the chance

to achieve their full potential. This meant that those who had some experience in an activity could be challenged and those with limited or no experience were able to enjoy working at a pace that suited them and take on activities that enabled them to achieve greater outcomes.

When we asked our young people for feedback about the trip, 88% rated the trip with the highest star rating, 66% told us they felt more confident, and 90% told us they now wanted to try out new activities once they returned home. We'd call that a great success!

"Our daughter got so much from this residential stay. She is able to feel completely accepted by her peers there, and doesn't feel self-conscious of her appearance."

"She enjoyed having the experience of outdoor activities which she would not normally have access to. She enjoyed the week very much -

she would not normally try things like this but felt comfortable in doing so with the other visually impaired friends she was with."

Next up was a weekend for children aged between 5 and 10 years old, plus grown-ups.

The weekend started on Friday afternoon and over the weekend the children and their parents took part in activities that included archery, swimming, canoeing and rock climbing. We are pleased to report that every child took part in all of the activities and thoroughly enjoyed the experience – with 100% ranking the weekend with the highest star rating and 71% wanting to try new activities when they returned home.

"It enabled me to spend time with my child and encourage him out of his comfort zone."

"It's good to get together with other parents and see how our children can do things, not to worry that he's going to struggle or be different."

"It was great meeting other people who have an understanding of what we go through. I also met a MACS mum who was partially sighted and she was amazing. She had kids, worked, did everything. I could see my daughter being just like her in the future."

Are you interested in joining in with our activities in 2017? This year, we are bringing our activities south to the Caldecotte Xperience in Milton Keynes and hope this will enable MACS members new to these events to take part. Our 10 to 18 year-old group will kick off on 30 July and finish on 4th August, followed by our 5 to 10 year-old group weekend taking place between 4-6 August. The cost per child is £50. For more information, please contact events@macs.org.uk





Microphthalmia, Anophthalmia & Coloboma Support

Registered address: MACS, Suite 472, Kemp House, 152 City Road, London, EC1V 2NX

Registered charity number: 1161897

www.macs.org.uk

T: 0800 169 8088 (Family Support)

T: 0800 644 6017 (Fundraising and General Enquiries)

E: enquiries@macs.org.uk