Focus

Issue 1
December 2013

MACS
The Micro and Anophthalmic Children's Society

Welcome to *Focus*

Welcome to our newly renamed *Focus* magazine. There's such a lot going on within MACS and we felt that a new name for our magazine would reflect this.

2013 was a year of change for MACS. Victoria came on board and will soon be joined by two more members of staff. They will manage our places in the Virgin Money London Marathon, the Prudential RideLondon-Surrey 100 cycle race and other fundraising activities too. MACS trustees are still heavily involved in day to day operations and as a team we will take our charity forward.

Tina McKinstry, our new regional coordinator has taken on the role with gusto. She is leading a team of wonderful volunteers, our regional supporters, who arrange the fantastic events across the country. 2014 will also be a bumper year for events.

Our skydiving event was a great success and will be repeated next year. I would love to be able to involve more MACS members aged 16 and over. You can read more about our exciting day later in this issue.

Victoria has been working hard to get many of her projects off the ground and these are now starting to take shape.

Members are continuing to make use of our specialist volunteer supporters for help and advice around welfare benefits and prosthetic eyes. I'm really pleased to see these services being utilised. We hope to expand our specialist services further during 2014.

2013 has seen our funds and awareness of MACS ever increasing through the amazing support of our events, donations and our recent Masquerade Ball. These funds will enable us to further develop the services we can offer to you.

I am grateful for the support of the MACS team who have made this year outstanding, filled with successful activities for families and children, fundraising events and promotional exhibitions.

MACS is growing at a great rate and is now entering its 20th Anniversary year. Who could have believed that we would be saying that MACS is 20!

To celebrate, we are planning events across the UK and inviting former trustees to attend our Family Weekend and Ball. Our patron, the Rt. Hon. David Blunkett MP is also helping us to host a reception for MACS at Westminster in June.

Finally I would like to thank everybody who supported MACS financially or by giving your time during 2013.

On behalf of the MACS Team,
Happy Christmas and a prosperous 2014.

Barry Stickings, MACS Chairman

P.S. Enjoy your MACS Calendar!

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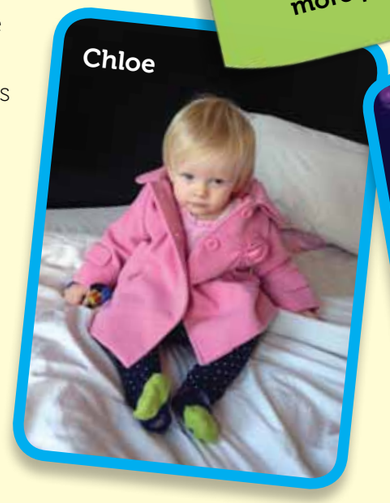
Please take time to visit our new Facebook group called MACS Support for Families. This is a closed group, open to MACS members only and gives you a private space to ask and respond to more personal questions.

New members

The Shawe family from Belfast have recently joined MACS. **Chloe** was one year old in October and she has Microphthalmia in her left eye.

The Merriman-Rex family are from Wigan. **Emily** is 13 and was born with unilateral Microphthalmia, Coloboma and Anophthalmia.



MACS is 20 in 2014!

What an achievement…
MACS started out in 1993 as a small parent support group and has grown into a vibrant and thriving charity supporting over 500 families and members around the UK. MACS offers its members everything from emotional and practical support services, to grants, respite holidays and the opportunities to get involved in sporting activities.

We've come a long way and in celebration of MACS 20th anniversary are planning a series of activities throughout the year. The key activities include:

Family Weekend

Some members have been joining us at Park Hall for this key annual event for many years, and a few for as long as it has been going! We look forward to seeing you all again and to welcoming some of our newer members too.

As it is a celebratory year, we are planning to make the event bigger and better than ever, so please come along from 1 to 5 May 2014! You should have recently received a Family Weekend booking form in the post, but if not, then just download it from **www.macs.org.uk** or email **lynda@macs.org.uk**.

MACS Family Fun Day

For those of you who are not able to make this year's Family Weekend there's another chance to celebrate! We are planning a family fun day in Milton Keynes on Sunday 17 August 2014. Please join us for an afternoon of fun, games, a BBQ and more with other MACS families. More information will follow soon, but please save the date in the meantime!

Reception at The Speaker's House, Westminster

Another event to mark the occasion of MACS 20th Anniversary will take place on 9 June 2014 at the prestigious Speaker's House at the Palace of Westminster. This reception event will give MACS the chance to highlight its work among MPs and others and raise awareness of the three eye conditions.

Timeline

1993 A group of parents meet and form a parent support network.

1994 MACS is officially born and registered as a charity with the Charity Commission.

1995 First MACS AGM / Weekend

1999 MACS supports its first London Marathon running team

2000 The inaugural MACS Ball takes place

2001 MACS grants scheme is initiated

2006 Lifetime funds raised for MACS reaches £1m

2009 MACS takes youngsters on its first sailing trip

2010 MACS the monkey is born!

2011 Our adventure weekends begin

2012 MACS new branding is developed

2013 MACS employs it first member of staff

2014 MACS celebrates its 20th Anniversary

Achievement Awards

Here at MACS we are keen to share our members' successes as a way of demonstrating that visual impairment doesn't mean that we can't achieve positive things in our lives. If your child, sibling or friend has achieved something positive in their lives too (however great or small), why not congratulate them by nominating them for a **MACS Achievement Award?**

Children with MACS conditions can be nominated in the following categories:

• 0-6 years • 7-12 years • 13 and over

Please email the name, age, condition and reason for the nomination to **barry@macs.org.uk** or **lynda@macs.org.uk**. Winners will be announced at the **MACS 20th Anniversary Family Weekend in May 2014.**

Technology; a vision for the future?

MACS has recently joined forces with researchers from Goldsmiths, University of London on a very exciting project. Our aim is to explore the ways in which blind and visually impaired people can access technology to express their thoughts for use in art, design and other forms of communication.

Just because a blind person cannot see, it doesn't mean that they don't visualise or imagine designs, diagrams and pictures in a similar way to a sighted person. It does mean, however, that they will need specific tools to help them transfer what they see in their mind's eye onto a screen so that they can share it with others.

Not having such a tool at their disposal, means that blind and visually impaired people's access to learning, and developing certain skills, may be reduced.

As MACS members (parents, adult members, young people and children alike), you could be instrumental in developing this project and we hope that you will share your thoughts and ideas with us. Sandra, the key researcher on this project, will be coming along to our annual Family Weekend in May next year to present information about her progress and to give you the opportunity to participate in the process.

In the meantime, we welcome your thoughts on the following questions. Please have a look and send your answers to **victoria@macs.org.uk** as soon as you can.

Remember, we want to hear any ideas that you have. Be imaginative if you can; anything goes!

Q1. Do you or does your child use technology and if so, what do you use and for what purpose? For example, what games do you play? Do you use software like JAWS or other applications?

Q2. Do you or does your child like to create picture, images or diagrams and how do you / they do this? Would you or your child like to be able to use technology to create images and designs?

Q3. What particular problems or barriers do you face in using technology generally?

Q4. If you could imagine a tool which would allow you to express yourself by getting the image in your mind onto a computer screen, what would it be like? What would work best? Would you prefer to use speech, touch, a keyboard or other methods to direct your ideas?

We asked Toby his thoughts on some of these questions. This is what he said...

'I'd like to have access to a screen reader that could read images and have software that would help me to draw images using speech recognition. You should be able to speak to create an image or object; so if I say circle, or top left circle, this should appear in the top left of the screen. It should also explain images with the size and colour.'

Sandra Fernando has ten years' experience in the software industry and as a teacher of IT and is now beginning a PhD investigating the development of a computer aided drawing tool for blind learners. Sandra was inspired by MACS member Toby Ott who she came across while teaching at Lewisham and Southwark College.

Dr James Ohene-Djan gained a PhD in computer science from Goldsmiths, University of London and is a senior lecturer in Assistive Technologies, Computing and Social Media. He founded the Assistive Technologies Research Group at Goldsmiths which specialises in designing tools and techniques for disabled people.

Jump!

Chairman Barry Stickings reports back on a wonderful day of skydiving arranged by MACS.

On Sunday 14 September, 17 very nervous people arrived bright and early at the Army Parachute Centre in Wiltshire ready to jump out of a plane for MACS! For many, this was their first experience of sky diving.

A germ of an idea which developed from an initial chat I had with MACS Dad Jason Franks had become a reality. We were giving MACS members and other supporters the chance to take part in a tandem skydive.

After registering, signing all the forms and importantly, eating breakfast, the names of the skydivers were called. Slowly, in groups of three and four, we made our way into the hanger to meet our tandem instructors and learn the key safety information. Our group was made up of six supporters, two MACS parents, three brothers of MACS members and six MACS teenagers.

Slowly the clouds began to clear and the call went out for the first group of skydivers to get into the plane. From below, over 50 supporters who had come along to cheer us on, watched in anticipation as, one by one, the brave skydivers jumped from the plane. After a long day of waiting, MACS Ambassador Amy Ottaway was the last to jump. The look on her face as she re-joined us on the ground, was worth the wait!

Our goal for this event was to raise awareness of MACS and at the same time raise the funds to help us plan more activities and develop support services for our members. Importantly, we also wanted to give our blind and visually impaired

Luke Brister and Adam Clark

Raf Galdeano

members the chance to do something out of this world, which they will remember for a long time to come. I know we achieved all these things and more.

Our MACS skydivers helped us to raise over £8,000 in sponsorship! I'd like to thank everyone who came along to jump, the fantastic instructors and all those who were there to support the event.

Our MACS Skydiving Team

Emma Allen, Charlie Kendall, Amy Ottaway, Jimbo Thompson, Jade Kendal, Andrew Fox, Scott Thompson, Laura Eggins, Nicky Galdeano, Raf Galdeano, Allison Winegarden, Lisa Murphy, Alex Nicholls, Rachel McMordie, Luke Bristow, Adam Clark and of course, MACS chair, Barry Stickings.

If any MACS members, family or friends would like to join us next year please contact barry@macs.org.uk to register your interest and obtain full details.

The proposed date is the 30 August 2014.

MACS MASQUERADE BALL

In October, 280 guests travelled from across the UK to enjoy MACS Masquerade Ball at the Grange Tower Bridge Hotel in London and help raise funds and awareness for MACS.

Guests wore masks of all varieties, colours, shapes and styles. They were met by the entertaining Lord and Lady Goldwyn who shuffled them into the reception area and, along with magician Jonathon Shotton, kept them amused and in order! Guests sipped some sparkling wine and were able to view the many items they could bid on during our live and silent auctions.

The main room was festooned in a blaze of colour with lit drapes and two huge Masquerade masks. Our MC Roger Dakin took to the stage to give an introduction to the evening, followed by a short welcome speech by MACS chairman Barry Stickings.

Guests feasted on a sumptuous three-course meal with wine, while our magician circulated among them displaying his close up magic skills. Between courses, our guests also had the chance to win a diamond valued at over £2000. The lucky winner was recently engaged Peter Southern!

After the meal, guests listened to Phil Harris give an insight into life as a parent of a visually impaired child; his beautiful daughter Aimee. His emotional speech led to a few tears from those in the room, followed by a roar of approval and thanks.

The live auction came next and offered guests the chance to bid on flights to New York, Epsom Derby days, Wentworth golf packages, Wing Walking experiences and signed books from David Walliams and Jeffrey Archer and so much more.

Towards the end of the evening, our band Junior Guevarra gave an energetic performance, keeping everybody on the dance floor until the final minutes of the evening.

Thanks to those who donated prizes to our auction; event organiser Jenny Hogg; the hotel staff; Andy and Teresa Mays and their team from Inspired Events; FunRaising Events; our MC Roger Dakin and our wonderful guests. You all made it an amazing evening.

In 2014, we'll be holding our 20th Anniversary Ball and details will be available soon. If you have any contacts for event sponsorship or would like to attend, please get in touch with barry@macs.org.uk.

The Making of Melody

For one young MACS member, the last few months of 2013 have been pretty remarkable! Ten year old Angharard Rhodes tells us all about it...

My mum heard about auditions being held for a new CBeebies programme called *Melody* through Jane & Bernie who run UCAN Productions (Unique Creative Arts Network) in Cardiff. Once a year for five days, UCAN comes to North Wales and puts on performing arts activities for blind and visually impaired children like me.

When my Mum had an email to say that *Wish Films* would like give me an audition, I was so excited! The audition piece was two pages long, but Mum helped me learn it off by heart.

We went to London for the audition. I was so nervous on the train but I practiced my audition piece and listened to music which helped me relax. My audition was at 11.30am and I was the only child there.

A couple of weeks later, the Production Manager rang to say 'Congratulations, you have got the part of Melody!' I was so happy and shocked, I nearly dropped the phone! I was jumping up and down so I gave the phone to my Mum.

When I found out I was going to be Melody it was really hard as I had to keep it to myself. I really wanted to tell all my friends, but I managed to keep it a secret. Just before going away for the 1st week of filming, we were allowed to tell people that I was going to be in a new CBeebies programme, but not what it was called. My friends in school were all really happy and cheered and clapped. All the teachers in the school wished me good luck for the filming too.

Before the filming, we had another trip to London so I could try on the clothes that Melody would be wearing. This was a lovely day and I got to meet most of the people that I would be working with, including my on screen Mum. The clothes I had to wear were usually a purple top (with a butterfly on it) and pink leggings, or a yellow top (with a butterfly on it) and purple leggings, both with white socks and pink sparkly shoes.

We had lots of phone calls with everyone who was doing the filming, so they could go over what was going to be happening and I could ask any questions. They also asked me questions about how I do things and, for the animation part of the programme, whether I dream with or without my long cane. My cane isn't with me when I dream, so this is why sometimes Melody doesn't have her cane in the animation either.

We filmed for two weeks in total; one week in September and another week in October. Mum and I stayed in a hotel. We were picked up in the morning and taken to where were needed to be for that day of filming. Sometimes, we had to go to two or three different locations! When I had my breaks, we sat sit in the green room so I could do my braille reading from school or just relax.

On the first day, I was really nervous in the car, but when I got there, we all sat down and talked and my nerves just disappeared. I loved the filming! I had so much fun and everyone was really kind. I had to act spilling the water over myself, playing in the sprinkler, trying on masks and eating cakes. It was funny and we had lots of laughs.

Because I'm registered as being severally sight impaired, I would tell them about the way I do things. Everyone would listen and they would change the part we were filming to help me.

On two days, I went to a recording studio to do a voice over for the animation part of the programme. This was also fun, especially when I got to do some different voices and the giggles.

When I was told that Melody was visually impaired like me, I felt really proud. I haven't seen any children's programmes with a child that is visually impaired or blind before and I hope it will help other children. When I found out that the programme was going to be audio described I was really pleased too.

On Monday 2 December, I was very excited when I got up as the first episode of Melody was being shown at 11.05am. I went to school and Mrs Grieves, the head teacher, arranged for the whole school to come into the hall and watch it together. I was very nervous and excited going to the hall. Everyone laughed at the part when I was eating my sandwich quickly and laughed even more when I spilt my drink. After the programme had finished the whole school clapped and I was asked to take a bow! It felt really strange to see myself on the TV. When I got home, I had lots of phone calls from friends and family and the people at Wish Films also phoned to congratulate me.

I hope that everyone who watches the programme enjoys it as much as I enjoyed taking part. I loved every minute of the whole experience!

Experience with education

MACS mum Michelle Bateson shares her thoughts on the nursery experience

My three year old daughter called Elodie has bilateral Microphthalmia, optic disc Coloboma and detached retinas. We live in Northern Ireland.

Since she was 12 months old, Elodie has attended a private day nursery. Arranging childcare for a visually impaired child can be daunting task but, her nursery was very supportive.

Elodie is registered blind although some residual vision, means that with lots of supervision, she can navigate about her environment. We are supported by a Qualified Teacher for Visual Impairment (QTVI) and a social worker.

Elodie settled well in to the nursery, but by two years old, she was struggling. Drop offs were traumatic and she found the noisy toddler room very frightening. Now, staff meet and greet her in the lobby and let her adjust so she is ready to go into the play room.

Elodie specifically needs extra help with her fine motor skills, as these are usually learned visually through imitation, refinement and practice. She enjoys art and craft activities, but needs more time to investigate and explore the materials. She also loves books and songs but finds it hard to concentrate on the pictures and the physical actions associated with the books and songs. This means she can quickly get distracted and disruptive to the group.

Elodie needs lots of verbal and physical cues to help shift her attention onto the next activity as she can't see what is happening next. She also misses out on non-verbal communication such as facial expressions. This can cause problems when, for example, she doesn't recognise that another child is angry with her.

Outside, Elodie has to avoid repetitive impact activities like the trampoline, which could cause her retina to completely detach. She needs help avoiding obstacles and staff need to spend extra time introducing her to playground equipment. Elodie's spatial awareness is also poor and she needs help with steps and uneven ground. Walking tires her out as she needs to concentrate harder than sighted children to keep safe.

Elodie is a happy three year old who has met her milestones in line with her sighted peers. She has some lovely little friends too. She now uses a white cane and although curious at first, the other children quickly came to understand why she needs it. Her friends help her by finding her dropped toys and she will also call out and ask them where they are so she can find them. Elodie and her little friends are developing good strategies for play together.

The QTVI uses her Developmental Journal for Children with Visual Impairment to support Elodie within the early years' framework. QTVIs can provide support in a range of settings, and can also advise about private childcare and nursery placements.

We initially looked at specialist childcare settings, but there was nothing suitable in our area. We fund her childcare place like any parent and the local childcare partnership provides the additional help. Elodie now has 12 hours per week of one to one support and sessional support from a pre-school teacher from our local education board. Staff provide close supervision to help develop her motor and social skills, confidence and stimulate her residual vision.

My advice to other parents would be to start talking to your QTVI or social worker about your child's needs as early as possible. I believe that specialist early years intervention from a very young age has really helped Elodie.

We feel positive about integrating Elodie into mainstream school and have realised that most problems can be overcome with the right support. Her early years' nursery placements have built strong foundations for her future development and education.

If you would like to talk further about how we arranged things, please email me at **michellebateson@macs.org.uk**

Daniel's new eye

Top: Daniel before the fitting
Above: Daniel after the fitting

15 year old Daniel McKinstry shares his experience of getting a new eye fitted.

I always said I didn't want a shell eye but after reading the *My Eye Man* book and leaflet a few times, I decided to try it. I went to Manchester to have it done and it was just like the book tells you. It doesn't hurt! I sat there and watched her paint my eye in front of me and the following week I went to have it fitted.

It took a couple of weeks to get used to, but now I wear it all the time. My dad was putting it in for me, but now I can do it myself.

I even go to basketball and forget to take it out - that's how comfortable it is. It was even better when I went to school and my friends' said *'Wow, you have an eye!'*

Epidemiology Study of MACS Conditions

Epidemiology is the study of how often diseases occur in different groups of people and why. We thought Focus readers would be interested in some key facts taken from a study published in 2011. Please let us know if you would like to read the full report.

Study name

Anophthalmos, Microphthalmos, and Typical Coloboma in the United Kingdom: A Prospective Study of Incidence and Risk; Shah et al.

The study's purpose was to determine incidence rate of MACS conditions diagnosed by ophthalmologists and to explore socio-demographic risks.

This study raises issues that may warrant further investigation. MACS is keen to keep track of issues which could interest members and so will let you know about any further studies or developments.

Key facts:

- 135 children were diagnosed over this period with an incident rate of 11.9 in 100,000
- Coloboma was the most common condition, with Anophthalmia being rare
- Both eyes were affected in 55% of children
- 41.5% of children had not seen an ophthalmologist by 3 months of age
- The incidence in Scotland was nearly double that in England and Wales.
- Children of Pakistani ethnicity had a 3.7 times higher risk than white children
- There was evidence to suggest higher incidences in socio-economically deprived areas
- Sibling risk ratio was low at 2.5%
- 58.3% of cases were identified by family member and only 29.3% by hospital paediatricians.

Thanks from our members

To all at MACS, I just want to say a big 'thank you' for my son's iPad. It's made a difference to our lives. He thinks he's playing but really he's learning.
Vicky & Tyrese

I like my iPad. I play Ninja games. I use mathletics numbers same as in school. Thank you, ***Tyrese***

Dear MACS,
Thank you so very much for my awesome iPad mini. I love it! My favourite things to do are play the CBeebies app, learn how to draw, play games and watch my favourite programs while I am at hospital. I give it a big thumbs up! With lots of love, from ***Archie*** xxx

Thank you MACS so much for the little Tiger trike for Elodie. Elodie's vision is very limited and needs full parental control on her bike at all times. The trike can be steered by myself and it has a pull cord brake option that can allow Elodie to independently pedal and steer the bike, to fulfil her toddler ambition of escaping from her parents. The trike has enabled us to ensure Elodie gets the same fun and adventures on her bike as her big brother.
Love from ***Elodie and the Bateson Family***

Thank you for helping us access the much needed grant for Esthers' therapy. We are ever grateful to you for enabling Esther to benefit from Music therapy that is helping her practice speech and language in a fun and relaxed way and she looks forward to her weekly sessions with the music therapist. She has become much more vocal as a result and loves to sing which is building her confidence and bringing out her voice. Many thanks to you and the whole MACS team, ***Rebecca***

A very big THANK YOU for your generous help in providing funds to help Berel's speech. He is definitely gaining from the one to one help and we hope he will only continue to improve. It is always heart-warming to know there is help out there. ***Aidel Hochhauser***

Hi MACS, I would like to say a big thank you to MACS for my new phone. This will help to develop my independence and the phone is easy to use so I can do it by myself.
Aiden Preston

Dear MACS, Thank you so much for the grant you made for Jacob, which enabled him to join in with the school residential programme this term. He is really enjoying his once a week "sleepover" and it gives him a chance to play with his friends, try new activities and also improve his independence skills!
The Tidcombe Family

Calling all cyclists; would you like to Ride London?

Back in the summer, after watching the inaugural Prudential RideLondon-Surrey 100 on the TV, MACS applied for places in the event in 2014. As a small, and relatively unknown charity, we weren't expecting to get a look in, so were extremely pleased when told that we had been given the opportunity to purchase a significant amount of places for the next three years!

This is a great opportunity to develop a new fundraising stream for MACS and to raise more awareness of what we do.

Taking place on **10 August 2014,** also the date of **MACS 20th Anniversary,** the 100-mile route will start in Queen Elizabeth Olympic Park in East London, then takes cyclists on a journey through the capital and into Surrey's stunning countryside. Cyclists will finish in style by cycling through Admiralty Arch on Trafalgar Square and onto The Mall in central London. This is the route made famous by the world's best cyclists at the London 2012 Olympics and will be a fantastic event for all involved.

Please help MACS by spreading the word about this event to your friends, families and colleagues. All information and an online application form is available at **www.macs.org.uk**. Those allocated a MACS place will have to be able to finish the race within 9 hours and raise a minimum basic sponsorship of £550.

Could this be your New Year's challenge?

MACS is recruiting

2013 has been a big year for MACS with the employment of our first full time member of staff. The committee did not foresee starting 2014 with even more staff, but that's what has transpired. RideLondon is a big event and will require a member of staff to carry out all of the related recruitment, administrative and fundraising aspects.

In addition, the administration of MACS Virgin Money London Marathon places, which to date has mainly been managed for us by VICTA, will be returning to MACS to administer in-house. VICTA has done a great job for MACS, but we now feel that it is the right time for us to manage this event ourselves.

Two new Fundraising Events Co-ordinators, Kaja Kosla and Charlotte Tobin will begin working with MACS in the New Year and we are very excited about having them on board. Not only will they be able to give their focus to these two major charity events, but they will also be able to help with the development of MACS fundraising capabilities in other areas. We hope that they will be able to join us during the Family Weekend to say hello.

MACS also has places in the **Brighton Marathon on 6 April 2014** and a waiting list for places in the **Virgin Money London Marathon on 13 April 2014.**

Dates for the diary

3 January 2014: Cinderella: A Fairytale,
The Unicorn Theatre, London
Contact:**teresagordon@macs.org.uk**

4 January 2014: Jack & The Beanstalk,
Princess Theatre, Torquay
Contact: **jenny@macs.org.uk**

4 January 2014: Sleeping Beauty,
Grand Opera House, Belfast
Contact: **tina@macs.org.uk**

5 January 2014: Dick Whittington Pantomime, Grove Theatre, Dunstable
Contact: **melsharpe@macs.org.uk**

7 January 2014: Deadline for caravan bookings,
Contact: **caravanbookings@macs.org.uk**

12 January 2014: Cinderella,
Theatre Royal, Norwich
Contact: **clareaustin@macs.org.uk**

18 January 2014: Music Therapy, Eltham
Contact: **victoria@macs.org.uk**

5 April 2014: CBeebies Live!
Wembley Arena, London
Contact: **tina@macs.org.uk**

13 April 2014: CBeebies Live!
Manchester Phones4U Arena
Contact: **tina@macs.org.uk**

1-5 May 2014: MACS Family Weekend,
Park Hall Hotel, nr Chorley
Contact: **familyweekend@macs.org.uk**

26 May 2014: Sailing voyage 1,
Southampton.Contact: **sailing@macs.org.uk**

9 June 2014: MACS Westminster Reception Contact: **victoria@macs.org.uk**

4 August 2014: Sailing voyages 2 & 3,
Scotland. Contact: **sailing@macs.org.uk**

17 August 2014: MACS Family Fun Day,
Milton Keynes. Contact: **tina@macs.org.uk**

27 August 2014: Wicked, Birmingham Hippodrome. Contact: **tina@macs.org.uk**

Sailing the seas

MACS members with children between 13-21 will know how popular and rewarding our sailing trips for young people can be. To meet demand during summer 2014, we will be organising not the usual two, but three week long sailing voyages!

The first trip of young blind and visually impaired people and their friends and siblings will set sail from Southampton on 26 May and return on 1 June 2014. The exact sailing route will be dependent on the weather.

Two further groups will depart from Scotland on 4 August 2014. One boat will start and finish in Oban and the other will start in Inverness, sail through the Caledonian Canal and Loch Ness and also finish in Oban.

If you are interested in joining the crew on one of these trips and would like more information about what's involved, please email **sailing@macs.org.uk.** An application form is also available from **www.macs.org.uk.**

Thanks to the Keith Coombs Trust and Genetic Disorders UK who have awarded funds towards these trips.

Travels to Gulliver's World

Gulliver's World Theme Park in Warrington opened its doors to a group of 21 MACS members and family in October. Organised by Regional Supporter Lisa Preston, a great time was had by all, as the photo suggests!

Star Supporters

Many of our MACS member do a great deal to support MACS via fundraising, regional support and other ways too. We feel that a special mention of MACS dads Mel Gordon and Tim Lupton is however, overdue. This running duo have probably covered the most of the UK in mileage over the past few years. Most weekends, they are out and about in their Team MACS running shirts raising awareness and funds for our charity. Tim has completed 12 half marathons in 2013 (plus a few full marathons) and Mel is planning to complete the 'big three'. He's already run the London and Berlin Marathons in 2013 and in September 2014 will fulfil his ambition by running New York. Well done Mel and Tim!

Fundraising update

MACS would like to thank all of the following supporters:

- Shirley Aird was one of the Team MACS runners who completed this year's Great North Run in aid of MACS and her grandson Lucas Hammond. Shirely raised **£282!**
- Mark, husband of MACS member Naomi Bowman, proved his mettle by competing in the Lake Tahoe Iron Man Challenge. This was an incredible achievement by Mark and not only did he swim 2.4 miles, cycling 112 miles and run a marathon in 14 hours, five minutes and seven seconds, he also raised **£3,464!**

- MACS parents Stacy and Luke Palmer and family continued their hard work helping MACS, this time, raising **£824** via a Family Fun Day. Thank you!

- MACS sibling Alex Lupton raised **£141.79** from cakes sales as part of a Young Apprentice project. Thanks Alex!
- Louise Rojas-Alvarez, mum of Luca, raised a massive **£1,434** with gift aid by completing the Bupa Birmingham Great Run in October. Well done Louise!
- Thanks to Heather Symonds, friend of Nick and Teresa Morgan, who managed to convince her employers at TK Maxx to make a **£2,000** donation to MACS!
- Thanks to Alli Winegarden who raised **£344** for MACS via a coffee morning at Upminster Methodist Church.

MACS would also like to thank the following and all other supporters:

Hilton in the Community Foundation, Lady Eileen Joseph Foundation, Dorothy Hay-Bolton Charitable Trust, Raymond and Black Lawson Charitable Trust, the Cowling Family and the Lynn Foundation.

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