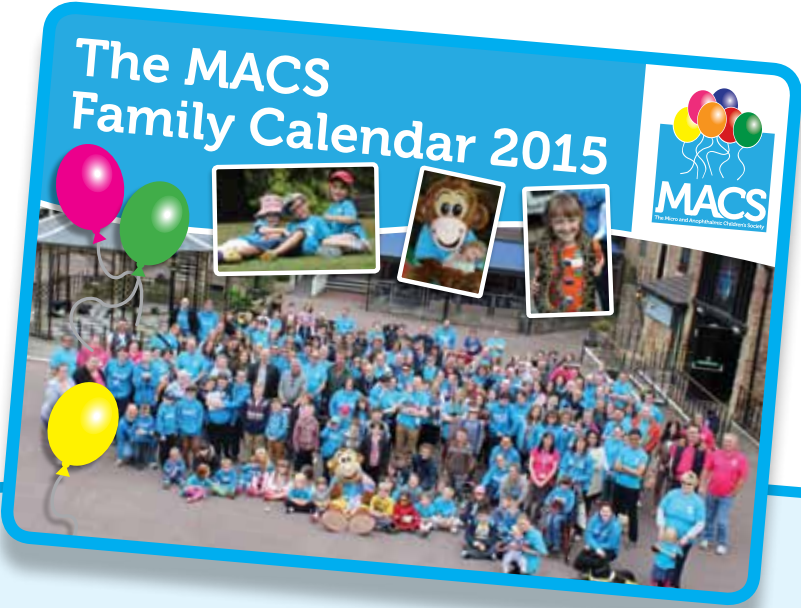


Focus

Issue 3
December 2014



Your 2015
MACS
calendar is
enclosed.
We hope you
find it useful!



Chair's report

This year has been one of amazing events, new steps forward, linking with new groups and most of all making lives better in many ways for MACS children.

We have hosted more events across the country than ever before and all of these make a difference to families old and new. In fact, we have had more new families join us over the last twelve months than in any other year and I am pleased that they have found us.

MACS fundraising has also developed with people from across the country taking part in some amazing events including the annual Ball, marathons, Prudential RideLondon-Surrey 100 and tandem skydiving among many other things. Thank you to every person, group and company who has generously donated to or otherwise supported MACS. I would also like to thank Kate Delaney for her expertise in writing the grant applications which have benefitted all our members.

This will likely be the last magazine where we are known as the Micro and Anophthalmic Children's Society as in the New Year we will be changing our charity structure and name (MACS will remain the acronym). This should only improve how the charity operates and as we develop will continue to provide to as many families and children as we can.

Thank you to everyone who helps to make MACS what it is.
We wish you all a very Happy Christmas and New Year.

Barry Stickings
Chair

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Who's who at MACS?

We'd love to hear from you, so please get in touch!



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Welcome to our new MACS members

Five month old **Emily Van Ommen**, lives with her mum Hayley in Sevenoaks, Kent. Emily has a microphthalmic left eye and cataract.



Roman Kopf is 10 years old has bilateral coloboma. He and his mum Sue are from Bagshot in Surrey.



Oxfordshire-based **Robert Murrell** is 13. He has bilateral coloboma of the retina, microphthalmia of the left eye, Charge Syndrome, and a passion for animals and books!



Ellen Wright is 16 and from Surrey. Ellen has right eye coloboma.



Max Hayden is 17 months old lives in Melton Mowbray with parents Stephanie and Robert. Max has bilateral microphthalmia.



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MACS' new charity structure

At our AGM in 2014 MACS members voted in favour of the charity restructuring from a Registered Charity to a Charitable Incorporated Organisation (CIO). This is a relatively new legal structure designed specifically for charities like ours.

As a CIO, MACS will only need to be registered with the Charity Commission and trustees will benefit from limited liability, rather than being burdened with personal liability as at present. The CIO is also a separate legal entity and as such can enter into contracts, hold property and employ staff, as opposed to staff being employed by trustees.

All this means quite a lot of work for MACS behind the scenes with new bank accounts, a new register of members, a revised logo and much more to organise. We will also receive a new charity number and will take on the new name agreed at the 2014 AGM. The new name of Microphthalmia, Anophthalmia & Coloboma



Support fully reflects what we do as a charity and allows us to continue to use the acronym of MACS.

We hope to have everything in place prior to our next AGM in May 2015 which will be the last official meeting in our current form.

Important information about transfer of membership

Through this process we are able to transfer MACS membership into the new structure. **If any member prefers not to become a member of the new charity, please advise us by letter or by contacting either gary@macs.org.uk or victoria@macs.org.uk by 31 January 2015.**

We also need to ensure that the details we hold for each adult member or MACS child member are accurate. If you have changed address or other contact details, please let us know by contacting victoria@macs.org.uk or completing our online update form in the members' area of our website at www.macs.org.uk/

Seeking answers through research



Professor Nicky Ragge

this research, and 28% of study participants have so far been given an answer as to why their eye condition has occurred.

Eye development is a complex process and we are yet to identify all the genes involved. Because these eye conditions are rare, as many families as possible are needed to participate in the research in order to stand the best chance of identifying all the genes that contribute to the development of a healthy eye.

Nicky and her team at Oxford Brookes University, in collaboration with the West Midlands Genetics Service, are in an exciting new phase of research. They are pioneering a new state-of-the-art genetic analysis technique that will allow a person to have over 500 of their genes screened at any one time. Nicky's team have used the knowledge gained from her ongoing research study with MACS families to select these 500 genes, which are thought to be involved in developmental eye anomalies.

Nicky recently presented her research at the MACS family weekend in May and many families who expressed an interest in the study are now recruited in this new phase, which will start early 2015. This new test will generate a huge amount of information. Although it will take time to analyse the test results, if an answer is possible, families should get results in weeks/months rather than years. Further analysis will continue for families with no answer after this test.

Professor Nicky Ragge has worked with MACS for over 15 years and, with fellow researchers around the world, has been responsible for the identification of many genes linked to Microphthalmia, Anophthalmia and Coloboma. Many MACS families have been part of

Through this research, the team is hoping to raise the percentage of families with a genetic diagnosis from 28% to over 50%. This will enable families to receive accurate information about recurrence risks. In addition, families participating in the study are helping to create a better understanding of eye development and to identify potential future treatments.

The team is happy to talk to anyone that is interested in finding out more about this research or participating in the study. Importantly, please update them if you are already a participant and your contact details have changed, or if you want more information on this new phase of the research.

Dr Suzanne Broadgate is the MACS funded research co-ordinator on this project. She has done an amazing job in providing all the essential co-ordination, including liaising with families, reconnecting with some, recruiting new families and supporting all the research activities. Without her support, the research would not be able to function and as such, MACS has agreed to continue to fund this post on a part time basis for the next three years.

Please contact Nicky's research coordinator Suzanne Broadgate (sbroadgate@brookes.ac.uk telephone 01865 484413) for more information.



Suzanne Broadgate, Research Co-ordinator



Research Scientist Dr Richard Holt

Member contribution: Ashley Wilkes

We featured **Ashley Wilkes** in the last issue of *Focus* after he gained his degree in Economics and Politics. Here, he shares with us how he has made the successful transition from university to the world of work!

"After successfully graduating from Lancaster University I was offered a job with Network Rail. My role with this organisation is as an Operational Planner. What that entails is that I plan the timetable to which the trains run. Sounds easy? Far from it! Read on..."

My favourite part of the job is deciding which platforms trains go into at the major stations as this is a lot more complex than people would think. You have to consider the length of the train compared to the length of the platform, where the train has come from, where it is going to and, of course, making sure that there are no other trains on the platform at that time! It's difficult at times but I relish the challenge.

Due to the amount of information we need to do our job successfully, we work with 3 monitors on the desk. I thought this might be a challenge with only having vision in one eye, but I have developed my own positioning for the monitors which allows me to not have to turn my head so much.

The area of the country which is my responsibility is called London North Eastern, so my area stretches from Berwick upon Tweed all the way to London King's Cross. I work in the Head Office in Milton Keynes with 2,000 people of which 450 are Train Planners like me. It's really great to work with so many different people. I find the diversity really interesting. This is my first full time job and despite my initial reservations and worry, I'm really enjoying it and I've met lots of amazing people.

So how did I get this demanding but rewarding job? The interview process at Network Rail is quite straight forward with an application followed by a Maths and English test, and then an interview with a Manager of the Planning Department. If you are successful at that stage

you are put into a pool and the wait begins for a Manager to decide whether they want to hire you. Luckily for me this wait wasn't too long.

Outside of work there are lots of different clubs available for Network Rail employees including football, cricket and singing! I have joined the Cricket Club and look forward to playing my first match for them.

To take up this job I had to move away from home. I decided to live in Leighton Buzzard. Apart from University where there were other people I could talk to, it has been a challenge to live by myself. I embrace new challenges so I think I'm coping quite well. Leighton Buzzard is a little too quiet for me so I'm looking to move again but I'm enjoying my time at Network Rail immensely. As I have always been told by my parents and MACS being blind or visually impaired doesn't mean that you can't achieve positive things in life."



Skydivers raise over £6,000 for MACS

On a warm Saturday morning in August a group of very excited people joined MACS at Netheravon Army Camp for our second tandem skydiving event.

The day started early with all of our skydivers meeting with their instructors, undergoing training and getting kitted out before waiting their turn to board the plane. Many filled the time, perhaps unwisely, by helping themselves to a big breakfast!

When their time came, each skydiver braced themselves, got into the plane and sat on the floor strapped to their instructor ready for take-off. For some, like MACS member Fran Condry, this was a rather unexpected experience. Fran came along only to support husband Dean and friends but she soon found herself stepping into the shoes of someone who was unable to take part. Her face told a thousand words, but

daughter Mia was laughing and singing all day and we know she was very proud of both her Mum and Dad.

As our MACS friends and families stood waiting on the ground the sky was suddenly full of skydivers, their parachutes opening after 40 seconds of free fall from 13,500 feet. During the day, our team, including many MACS teenagers, came down to earth with some very excited faces clearly having had a great experience.

Thanks to MACS member Jason Franks who, along with MACS Chair Barry Stickings, suggested this event three years ago. His support, and that of the instructors and staff at Netheravon, has been fantastic.

Thanks to all to our fantastic skydivers and supporters who have helped to raise over £6000 for MACS with funds still coming in.



Feasting and frolics at the MACS 1920s themed Ball



At our last major celebration of MACS' 20th anniversary, 300 guests descended on London's The Brewery for the MACS Roaring Twenties Ball.

Partygoers dressed in 1920s tasselled dresses and Gatsby-style suits were met by our security team who screened them for any contraband. Before dinner, a drinks reception, music from the IT Girls and tricks courtesy of magician Jonathon Shotton were enjoyed by all. The curtains were then pulled back to reveal the main dining room which had been given a full 1920s makeover.



Our MC Steve Warwick introduced Chair Barry Stickings who officially welcomed our guests on behalf of MACS. Barry also invited several guests to the stage, including MACS cyclists, runners and other fundraisers, to receive his personal thanks for the support they have shown to the charity.

Next up was the 'diamond game', something of a regular feature at MACS Balls. The game gives guests a chance to enter to win a fabulous diamond worth around £1,000 by correctly answering a series of random questions. This game raised over £6000 on the night for MACS.

After a delicious three course meal, MACS member Xuxa Boyle gave a very moving and emotional speech about her son Callum who has bilateral anophthalmia. Thanks to Xuxa who gave up her time to attend the event, despite her second child being due at any time!



It was then time for our live and silent auctions to take centre stage. A range of fantastic items resulted in over £18,000 of funds being raised on the night. We also asked guests to help raise funds for a Braille for a MACS child and the entire room generously responded by collectively providing donations totalling £3,500 in just five minutes.

Those in the know then headed down to MACS Speakeasy to dance the night away to the sounds of The Swinging Little Big Band.



Thanks to all those who made this such a special night including our guests, the helpers on the night and the Ball team made up of Barry Stickings, Gary Murphy, Jenny Hogg and Xuxa Boyle.



Member contribution: A poem about blindness by Charlee Jarvis

Charlee recently submitted this wonderful poem to the Christopher Tower Poetry Competition. We hope it resonates with our many MACS members. Thanks for sharing Charlee.

The Tooth Fairy is make believe and Santa's just the same
The Bible's just an ancient book and Jesus is just a name,
Mary rode to Bethlehem on an old man's steed
She stayed the night in a dampened building where the horses feed,

3,553 eggs are baked and brewed every single day
Millions of cells morph into children in exactly the same way,
He never wanted children but she persisted all the more
To have another beautiful child she was absolutely sure,

Meiosis made her possible meiosis made her real
3 months passed which went so fast then kicking she could feel,
Before she knew it Christmas arrived and snow had covered the trees
Although she worried labour would ruin the day her husband put her at ease,

On the 27th of December angel Gabriel returned
For a delicate tightly folded bud awarded them with a girl,
However, not everything appeared to be right something they soon learned
Her eyes were scarlet red and were closed up like a pearl,

To say the doctors could see what was wrong is frightfully unkind
Because soon they were informed their Christmas angel was born blind.

A healthily dividing embryo and they couldn't understand why
Out of the trillions of cells that compose a body the fault laid in her eyes.
7 colours of the rainbow they recognised them all
But the question still remained, - Would she ever see them at all?

She held her Christmas angel, whose eyes were very frail
With a burning question in her heart of how her eyes had failed,
Could she cope raising this girl whose sight was not yet stated?
Was this occurring madness something blood related?

They poked and prodded and their will power was tested
Eventually they realised that this problem shouldn't be messed with,
And so they raised their child as a normal human being
With 206 bones, 37 trillion cells and 5 senses without the seeing

Their girl grew up rode horses, bikes and even climbed a mountain
Now that girl who couldn't see's had 16 birthdays in counting,
Cells are a part of everyone whether they work or not
And if they're broken you get up you smile and give it your best shot



Fancy the adventure of a lifetime?

Following on from the success of our events over the last three years, this year MACS is again giving our young people a chance to take part in either a sailing activity or an adventure break – or both, should they so wish! Not only do MACS children get to take part, but a sibling or friend may have the chance to come along too! The dates for the events are as follows:

- Calvert activity 5 night break (age 10+): 26 to 31 July
- Calvert child and parent weekend (age 5-10): 24 to 26 July
- Scottish sailing (age 12-20): 3 to 9 August
- South sailing (age 12-20): 24 to 30 August

The cost for the events is £25 per young person, which includes all food, accommodation and safety instruction for the week. Also, for Calvert, we will provide fully-trained 1-to-1 carers for those young people who need it. The child and parent weekend is a brilliant opportunity for a parent to bond with their child in a new setting, and is a very unique experience. Some feedback from previous events...

"To see my son who lacks confidence be so independent is incredible. He struggles to talk about his condition and having time with peers with similar conditions helped him so much." MACS Dad, 2014

"Support team were amazing and had a great understanding of our kids needs whilst building and displaying a great rapport with kids and parents." MACS Mum, 2014

"I am more confident about trying new things. I really, really enjoyed it. I hope I can go again. I chose not to wear my shell because I wanted to look like others. I was very confident without my shell. I feel happy I have met other people with microphthalmia." MACS sailor, 2014

"I have made friends for life." MACS sailor, 2014

You can secure a place on next year's trips by emailing events@macs.org.uk and requesting a booking form.



The new caravan season will begin in March 2015. Get your applications in now and start planning your next holiday in Cornwall, Cumbria or Dorset!
Download a booking form from
<http://www.macs.org.uk/book-your-holiday/>

Regional update

It's been another bumper year for MACS events, with nearly 1350 members attending activities across the UK and keeping our Regional Co-ordinator, Tina McKinstry, and Regional Supporters very busy.

Events have ranged from trips to wild life parks and zoos to the theatre and of course, our Christmas parties!

Tina and our Regional Supporters do a great job making sure that members get a chance to meet up with people in their regions, talk to and support each other and have fun too.

Next year's events feature a tour of the Coronation Street set on 4 July 2015, a trip to Knowsley Safari Park on 21 June 2015, as well as theatre visits, including Calamity Jane and hopefully Charlie and the Chocolate Factory too!

If you would like to attend any of the above events or have any suggestions about events that you would like to see on the MACS calendar, please get in touch with Tina at tina@macs.org.uk



Regional Supporter vacancies!

Do you live in Norfolk, Oxfordshire or Sussex? If you would like to be considered for a Regional Supporter volunteer role in any of these areas, please contact tina@macs.org.uk for more information.

Tina says: "I love to help Regional Supporters plan events and help so many families get the chance to meet up and to talk to each other about their children. They all do a fantastic job and MACS could not hold these events without their input and support."



Vitality **READING**
Half Marathon
Sunday 22nd March 2015



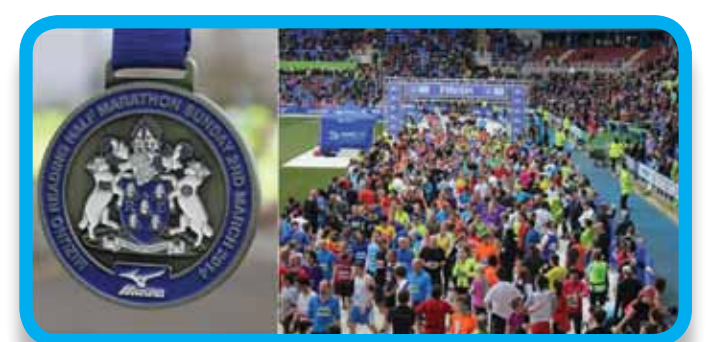
MACS needs you!

Could you run or volunteer for MACS at the Vitality Reading Half Marathon? MACS is delighted to have been chosen a Charity Partner for this event on 22 March 2015.

With 16,000 participants the Reading Half Marathon is one of the biggest running events in the UK. Huge crowd support and an incredible finish at the Madejski Stadium make it a fantastic event to take part in for experienced and novice runners alike.

It will be the first time MACS will be an official partner of a major running event and it will be a fantastic opportunity for us to increase awareness of MACS as a charity as well as raise interest in MACS amongst the running community.

We have been awarded a number of places which we can offer to enthusiastic MACS supporters passionate about the charity and its work. One of the runners who has already signed up is MACS member Ben Lupton, who will be running his first half marathon. Ben will be guided by his dad Tim and cheered by mum Jenny and a group of MACS volunteers.



Ben is very excited to be running the RHM and says: "I am really excited about my first half marathon at Reading, and being a MACS child I am looking forward to supporting other families like mine. Please join me for my exciting adventure!"

If your New Year's Resolution is to get more exercise, this event couldn't be better timed! Go on, join Ben in running the Reading Half Marathon and apply for a place at www.macs.org.uk

If running's not your thing you can still help. We need to provide official marshals for the event, plus volunteers to cheer runners along the route and at the finish. If you are able to help or spread the word the others, please contact Kaja at kaja@macs.org.uk for more information.

We hope you can join us and help us make it a fantastic day.

Thank you to...

Sonia Wilkes, Claire Croft, Coral Murphy and Matthew Horspool - MACS members who have recently given up their time to take part in speaking engagements or press calls on behalf of MACS. We are very grateful for your support and willingness to share your stories to help raise awareness of MACS! If you are interested in joining our list of volunteers and being linked to possible opportunities in your area, please contact victoria@macs.org.uk

Fundraising Focus!

It's been a great year for fundraising at MACS with many community groups, companies, charitable trusts, individuals and MACS members going all out to raise funds to allow the charity to provide its services and activities.

It's impossible to give everyone a mention, but we are continually thankful for the support we receive from far and wide!

Clockwise from right:

- Mel Gordon at the New York Marathon
- Gilliam Bramley ready to skydive
- Barney Tandy
- Triathlon Man Mark Bowman
- GKR Scaffolding at the Royal Parks Half Marathon
- Belinda Day at the Windmill 10km



New Forum Opens to Support People with Sight Loss



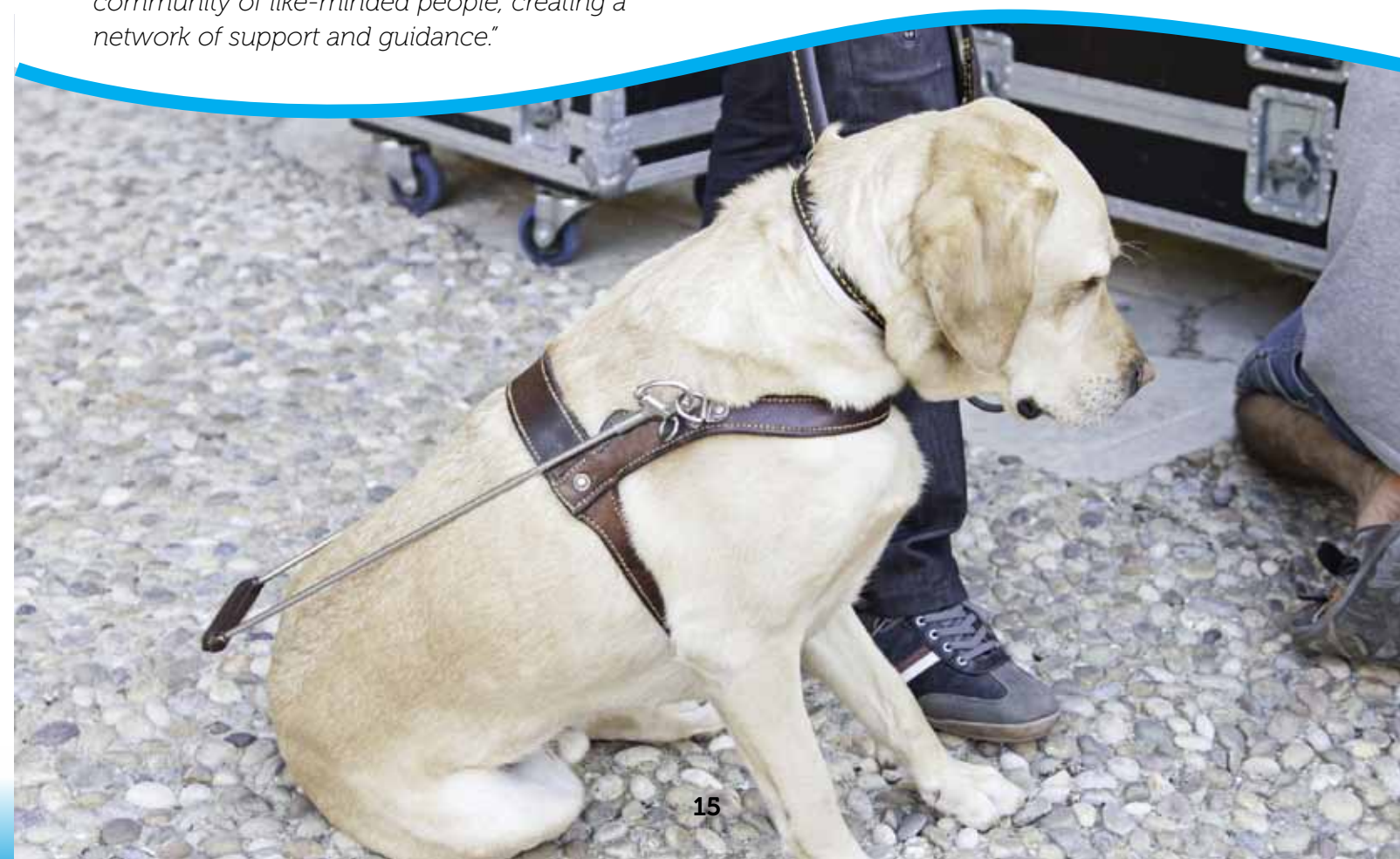
Our friends over at Guide Dogs have asked us to share information about a new community scheme giving people who are blind or partially sighted, and their loved ones, the opportunity to play a pivotal role in the charity's future.

The invite is extended to people all across the UK and asks anyone who is vision impaired to join *Friends of Guide Dogs*. In doing so they will benefit from a range of special offers from a variety of organisations, become a crucial part of on-going engagement taking place within their local community and have access to a flourishing online forum.

Chief Executive of Guide Dogs, Richard Leaman, said: "People are at the centre of everything that Guide Dogs stands for and everything we work for. Our new community scheme will help us connect with the people who are closest to our cause and in doing so build upon and improve the service we provide them. Not only this but by joining Friends of Guide Dogs, people with sight loss will get the opportunity to join a community of like-minded people, creating a network of support and guidance."

Friends of Guide Dogs will receive a welcome pack and pin badge when they sign up, as well as deals and discounts with organisations such as Travel Eyes, Vision Hotels, iCAN experiences, Dolphin Computer Access, Optelec and the Guide Dogs gift catalogue 'Dogalogue'. They will also be invited to attend local events and have the opportunity to be involved in Guide Dogs engagement with their local community, campaigning and shaping the way the charity works in the future.

If you or someone you know would like to sign up to *Friends of Guide Dogs* simply visit **www.guidedogs.org.uk/friends** or call your local team on **0845 372 7499** to find out more.





Micro & Anophthalmic Children's Society

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