

# LOOK FORWARD

ISSUE 178  
WINTER 2022

MARATHON




The cover of this edition celebrates the success of our amazing London Marathon team. Together they have raised more than £43,000.


Thank you to all of our London and Virtual marathon runners.

You can read more about them on pages 8-9.

Please pass this newsletter on to others when you've finished reading it

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## Welcome to our winter 2022 edition

Now that the nights are drawing in and the weather is less predictable, it's important for all of us to look after not just our physical health but also our mental health and wellbeing. Our free Discover Wellbeing resource is available to anyone living with sight loss and to their friends and family. Find out more at [RetinaUK.org.uk/wellbeing](https://RetinaUK.org.uk/wellbeing).

Our Helpline is a great resource if you need information or support. You can call them on 0300 111 4000 or email [helpline@RetinaUK.org.uk](mailto:helpline@RetinaUK.org.uk).

Some of you will have recently received a letter about our latest appeal. Thank you to everyone who has already made a donation. We are very grateful for any support you are able to give us, particularly during these challenging economic times. Find out more about our latest appeal on our website: [RetinaUK.org.uk/appeal](https://RetinaUK.org.uk/appeal).

Our Local Peer Support Groups are going from strength to strength with lots more planned in 2023. Find out

more about our volunteer facilitators on pages 16-17. If you would be willing to host a group, we'd love to hear from you.

Many of our members' annual fees are due in January. Please call our office on 01280 821334 to make a payment using a credit or debit card. Alternatively you can send a cheque made payable to Retina UK for £24. If you are not already a member but would like to be, you can join by calling our office or visiting [RetinaUK.org.uk/membership](https://RetinaUK.org.uk/membership).

You'll see from the enclosed card that there's another opportunity to donate to medical research this year, through the Big Give Christmas Challenge, where your donation will be doubled. We're so grateful for every single contribution we receive.



*Tina Garvey, Chief Executive*



*This newsletter has been funded through sponsorship by Janssen. Janssen has not been involved in the production, review or distribution of this material.*

**Retina UK** funds medical research into inherited sight loss and offers a range of information and support services to those affected.

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Retina UK is a Charitable Incorporated Organisation (CIO), registered charity number: 1153851

## The importance of a genetic diagnosis for research

**Do you know which gene contains the fault that is causing your sight loss? It could be any one of about 300! Identifying it could open up choices for you and your family, and possibly even enable access to a future treatment or clinical trial.**

We launched our Unlock Genetics resource in 2021 after our 2019 Sight Loss Survey revealed that only around 15% of respondents were aware of their genetic diagnosis. It is full of easy to digest information on genetics, inheritance and accessing a genetic test. Everyone with an inherited retinal condition (diagnosed by an ophthalmologist) is entitled to a free NHS genetic test. Many people are not made aware of this by their healthcare professional, which is troubling, because it could be putting the brakes on treatment development.

Scientists and the biotechnology industry simply cannot make progress towards treatments without the help of people living with inherited retinal conditions. They need to understand your experiences and the progression of your sight loss.

In many cases, your genetic diagnosis will be an essential part of the picture: it helps researchers explain what has gone wrong in your eye and find targets for treatment. A large proportion of new therapies currently undergoing clinical

trials are aimed at specific genetic faults. This means they can only be tested in individuals with a particular genetic diagnosis. If scientists and pharmaceutical companies can't find those people, then progress is hindered.

Retina UK is often asked to share gene-specific research participation opportunities, but identifying the right people can be challenging. Prof Mariya Moosajee from Moorfields Eye Hospital is investigating various therapeutic approaches, and recently led Moorfields' contribution to a clinical trial for a highly specific treatment. She told us: "We are always happy to support potential participants in getting their genetic diagnosis, but referrals and results take time and we can move things along so much faster when people already have their genetic test results to hand. Clinical studies often have a number of quite tight criteria that participants must meet, so it really helps if we can start screening with a reasonable number of people who already know they have the relevant diagnosis."

By the time we carried out our 2022 survey, 31% of you were able to share the name of your faulty gene, and we are so pleased when community members tell us that Unlock Genetics provided them with the understanding and confidence to ask for a genetic test. To find out more about reasons to consider a genetic test, as well as the limitations of testing, visit Unlock Genetics at [RetinaUK.org.uk/genetics](https://RetinaUK.org.uk/genetics).



## **“It’s all part of the journey” – How Discover Wellbeing**

**In July we launched Discover Wellbeing, a resource to support those affected by inherited sight loss to be able to recognise and better manage the impacts on their emotional wellbeing.**



The free-to-access course is designed as early intervention, to normalise the conversation and help people to feel confident to ask for support if they need it.

There are three pathways – Early Stages, Living with Change and Supporting Others (CPD accredited). Each comprises an introduction, pre-course questionnaire, five modules with

videos and guided practical activities to help embed the new knowledge or skill, followed by a post-course questionnaire.

We encourage people to complete one module and the related practical exercises per week, but they can work through the course in their own time.

We have also trained eight volunteers

# can help you

to offer guidance and support with regular calls throughout the course, if people choose an assisted journey.

## Shaped by experience

We wanted to include people living with inherited sight loss from the very beginning. We sent a questionnaire to our Lived Experience Panel asking about the impact of their sight loss on their emotional wellbeing and over 50 responses were received. We invited 21 people to take part in online focus groups and also had an in-depth conversation with someone living with Usher syndrome to understand the impacts of dual sensory loss.

*“As a blind person it is wonderful to know that there is a resource that visually impaired people can work through to help with the emotional impact of sight loss.”*

## Early feedback

In the first eight weeks, Discover Wellbeing had been accessed by almost 100 people.

Kirsty Jennings was one of the first people to work through the course.

She said: “I was diagnosed around nine years of age and didn’t really get much emotional and mental health support back then. As I’ve got older, and my sight has got worse, I’ve looked for self help. I found this course really helpful in showing me the stages that I’ve been

through – it’s all part of the journey.

“The course is very informative and interesting. I’m a screen reader user and it was fully accessible and easy to navigate.”

A range of professionals including from national and local sight loss charities, rehabilitation, and low vision support teams are working through the courses. Feedback from health and social care professionals has been really positive:

“I have just taken a look at the ‘Discover Wellbeing’ resource – such a great resource, thank you!”

“We have been waiting for something like this, what a great resource!”

## Why Discover Wellbeing?

When we conducted our 2019 sight loss survey, 92% of respondents said they had experienced negative emotional or psychological impacts. Anxiety, loss of confidence and stress were the biggest impacts. These statistics remain similar for our 2022 tracking survey. We want to change this.

## Find out more

Visit [RetinaUK.org.uk/wellbeing](https://RetinaUK.org.uk/wellbeing)  
Email [wellbeing@RetinaUK.org.uk](mailto:wellbeing@RetinaUK.org.uk)  
Phone 01280 821334.

Watch or listen to our conference presentations and webinar: [RetinaUK.org.uk/recordings](https://RetinaUK.org.uk/recordings).

## Research news roundup

**Despite the knock-on effects of the pandemic, there's been a lot going on this year in the world of research! Here are snapshots of a few stories that have appeared in the Research News section of our website in 2022.**

### Retina UK-funded discovery leads to \$2.5 million grant

In August, we were proud to share the news that Prof Alison Hardcastle, lead investigator on our UK Inherited Retinal Disease Consortium (UKIRDC) project, had received a \$2.5 million grant from US-based Foundation Fighting Blindness to build on her discovery of a new disease mechanism for RP17.

In 2020, Prof Hardcastle and colleagues at UCL Institute of Ophthalmology, alongside collaborators at Radboud UMC in the Netherlands, published their ground-breaking discovery that

RP17 is caused by complex structural re-arrangements of chromosome 17. That research was made possible by Retina UK as the major funder of the UKIRDC.

The researchers have now used the discovery as a springboard to success in the extremely competitive Foundation Fighting Blindness grant round. The new award will enable them to spend five years making a full exploration of underlying disease mechanisms and possible treatment strategies for RP17.

### Drug repurposing

Back in March, we reported that early stage clinical trials were underway to test whether drugs already in use for cancer and alcoholism might be helpful in treating retinitis pigmentosa (RP).

Methotrexate is a powerful drug already used to treat certain types of cancer and autoimmune disease, but scientists have also discovered that it can improve the function of faulty rhodopsin protein. Rhodopsin plays a key role in enabling light sensitivity in rod photoreceptors. US biotechnology company Aldeyra Therapeutics has started a small clinical trial of methotrexate for autosomal dominant

RP caused by a particular mutation in the rhodopsin gene, with the drug being injected into the jelly of the eyeball.

Meanwhile, knowledge of the biochemical targets of a drug normally used to treat alcoholism has led scientists to investigate whether it might be helpful in retinal disease. The drug, called disulfiram, helped restore some vision in mice with retinal degeneration, by dampening down nerve signal 'interference' from dying photoreceptors. The US-based scientists are planning a small clinical trial in people with advanced RP.

## Gene therapy without the specificity?

The gene therapies in development today are nearly always only suitable for those whose sight loss is caused by a particular genetic fault. However, with over 300 different genes potentially responsible for inherited retinal conditions, that leaves a huge number in our community without an option within reach.

Two biotechnology companies are now investigating the possibility of supplying the retina with gene therapies that may help overcome degeneration no matter what the causative gene.

US company Sparing Vision is focusing its efforts on preserving cone photoreceptors, which are concentrated in the centre of the retina and are responsible for detailed vision. Their treatment provides copies of the genetic instructions for

making a substance called Rod-derived Cone Viability Factor, (RdCVF), which nourishes cone cells and is essential for their survival. In late 2022, Sparing Vision will begin early phase trials.

Meanwhile, a company called Ocugen is hoping that one particular gene, called NR2E3, might have the power to stabilise retinal cells that have been damaged by a number of different underlying genetic faults. NR2E3 is what's known as a modifier gene, which can significantly affect disease progression and severity by influencing key biological networks. Studies in five unique mouse models of retinal degeneration, all with different genetic faults, showed that boosting the amount of NR2E3 gene in the retina rescued photoreceptors from further damage. Ocugen has now started in-human testing in the USA.

## Gene therapy for X-linked RP

In June, biotechnology company MeiraGTx announced encouraging news from its phase 1/2 clinical trial of a gene therapy aimed at X-linked RP caused by faults in the RPGR gene.

The primary aim of a phase 1/2 clinical trial is to establish the safety of the treatment. The therapy was found to be generally safe and well-tolerated.

In addition, MeiraGTx has announced that trial participants given the treatment experienced significant improvements in their retinal sensitivity

and vision compared to untreated 'control' participants.

MeiraGTx has now proceeded to a phase 3 trial, which will gather the larger amount of data needed to clearly establish the risk-benefit profile for the treatment. If the outcome is positive, it will enable the company to apply to regulators for licensing.

More information on X-linked inheritance can be found in our Unlock Genetics resource at [RetinaUK.org.uk/genetics](https://www.RetinaUK.org.uk/genetics).



# #TeamRetinaUK take on the TCS London Marathon

The sun was shining as #TeamRetinaUK stepped up to the city start line. As the cheering crowds came out in the capital, family and friends gathered in their neighbourhood to support our virtual race runners. Drawing on all of their training and the encouragement of well-wishers with every step, they each took on 26.2 miles to reach their finish line.



As our team, both in London and elsewhere, celebrated their triumph, and raising over £43,500 for Retina UK the race motto came to mind; engraved in both text and braille, the 2022 medal simply read 'we finished together'.

To our 2022 team, your family, friends and colleagues who supported you – we want to say a huge thank you. We've been humbled by your support. The fundraising amount you've raised together could fund over a year of a researcher's time, helping us to increase our understanding of inherited sight loss and search for treatments for the future.

### Thank you to:

Barry, Emily, Hannah, Chloe, Hugo, Chris and Sam, Ian, Chris and Yvonne, Isy, Claire, Jo, Dan, Jonny, Eileen, Matt, Emma, Raymond and Fenella.

### Five months to the finish line

In 2023, the TCS London Marathon returns to the traditional spring weekend. Join #TeamRetinaUK on 23 April 2023 and take steps to help people with inherited sight loss. You'll get dedicated support from our team all the way through to race day, with a personalised running vest, access to our exclusive Strava running club, fundraising tips and more!



*"It's hard to put into words and to do it justice what the incredible support has meant to me. Honestly, it could not have gone any better. Not just from the run side of things but also the whole process with being a part of #TeamRetinaUK – it's incredible ... Thank you so much for what you've done for me, it's given me the boost in life I wanted and made me think I'm able to go on and achieve so much more"*

*Chris – a member of #TeamRetinaUK 2022*



**LONDON** – Run the iconic route from Blackheath to The Mall, taking in the world-famous surroundings and cheering crowds.

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Minimum fundraising: £2,000

To apply for a place visit:

[RetinaUK.org.uk/london](https://RetinaUK.org.uk/london)

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Registration: £14

Minimum fundraising: £165

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[RetinaUK.org.uk/virtual](https://RetinaUK.org.uk/virtual)

**VIRTUAL** – Whether it's the freedom to complete a marathon anywhere in the world, or a front door finish line that takes your fancy – next year you can

**Find out more**

Email [fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk) or call Simon, Community and Events Fundraising Manager, on 07736 925174.



## Researcher spotlight: Dr Nikolas Pontikos

**We typically associate the cutting edge of inherited sight loss research with laboratory-based scientists, but today, discoveries in medicine are as likely to emerge from a computer screen as from a pipette.**

Dr Nikolas Pontikos is a Senior Research Fellow at UCL Institute of Ophthalmology, and has been working on inherited retinal conditions for several years. He is a bioinformatician, harnessing computing power to analyse vast amounts of healthcare and scientific data, generating answers in far less time than would otherwise be possible.

“Growing up with computer games in the 90s and witnessing the information revolution brought by the internet, I started getting really interested in maths and computers in my late teens, which led me to an undergraduate degree in computer science” Dr Pontikos told us. “Sadly, towards the end of my degree, my mother received a late cancer diagnosis and passed away. This made me realise how important it was to improve healthcare, and that I was in a position to contribute to this area with my computing knowledge.”

Dr Pontikos therefore married up his computing skill with biology and medicine via postgraduate qualifications (bioinformatics MSci at

Imperial College and PhD at Cambridge University) and work at the European Bioinformatics Institute, before arriving at UCL to work with Dr Vincent Plagnol on rare disease genetics. This led to an introduction to Prof Alison Hardcastle, who needed bioinformatics support for the UK Inherited Retinal Disease Consortium (UKIRDC) project, funded by Retina UK.

Dr Pontikos took charge of the UKIRDC’s bioinformatics pipeline, which processed the genetic data from everyone who had contributed a DNA sample to the project. “The computer systems originally refined by Dr Plagnol were able to identify different types of disease-causing genetic changes, and we used this to help us spot changes that had the potential to disrupt retinal function” Dr Pontikos explained. “Nearly everyone living with sight loss who took part in the UKIRDC had previously been screened for faults in genes already known to be associated with retinal disease, without success, and we were therefore often able to identify completely novel disease-causing genes. These discoveries can provide families with a clear genetic diagnosis and enable scientists to identify potential treatment pathways.”

Dr Pontikos and his team are now leading some large projects of their own, including an innovative endeavour called Eye2Gene, the idea for which grew directly from his work on the UKIRDC. The Eye2Gene project aims to



*Have you considered including a charitable gift to Retina UK in your will? Your generosity can help fund future medical research projects, and make a life-changing difference to others in our community in the years ahead [RetinaUK.org.uk/legacies](https://RetinaUK.org.uk/legacies)*

develop an artificial intelligence system that can use retinal scans alone to identify the likely disease-causing gene, making genetic diagnosis more readily and rapidly available to everyone with an inherited retinal condition.

Dr Pontikos has been awarded a significant grant by the National Institute for Health Research (the research arm of the NHS) to develop Eye2Gene. “The Eye2Gene AI system needs to learn from the retinal scans of people with a known genetic diagnosis” he explained. “So far, it has only been trained on genes for which at least 10 people’s scans were available, covering a total of the 36 most common inherited retinal disease associated genes. In order to optimise its performance and extend it to more genes, we will need to increase the amount of data to at least 20 patients per gene. This requires us to gather data from several sites in the UK and internationally.

“Our grant runs until 2024, and by

that time we will have developed the technology and tested it sufficiently to prove its performance and utility, so I would expect it to be used as a research tool in the next three years. It will take more extensive testing over an extra couple of years before it can be used day-to-day in the clinic.”

Dr Pontikos acknowledges that working with rare conditions is not without its challenges. “From a practical perspective, the datasets are relatively small, and in addition, rare disease does not necessarily attract the same level of research funding as other conditions. That’s why the support of charities like Retina UK is really important” he said.

However, there are plenty of positives too. “One of the most exciting moments was finding out that Eye2Gene performed very well on external datasets, showing that the algorithm is able to generalise” he told us. “In addition, the interest and support from the inherited retinal disease community, and the motivation of my team, is truly inspiring. We are very grateful to all those living with sight loss who have provided DNA samples and retinal scans”

To learn more about genes and genetic diagnosis, visit [RetinaUK.org.uk/genetics](https://RetinaUK.org.uk/genetics). You can find out more about Eye2Gene at [eye2gene.com](https://eye2gene.com) and Dr Pontikos’ other projects at [pontikoslab.com](https://pontikoslab.com).



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## Giving in memory – celebrating a life well lived

**Kevin Lucy's family wanted to honour his life after he sadly passed away in early 2022. They set up an online tribute page on the MuchLoved website ([muchloved.com](https://muchloved.com)) in aid of Retina UK and asked those who knew and loved him to make a donation in his memory.**

Kevin was diagnosed with congenital deafness aged seven, closely followed by his brother Desmond. Upon diagnosis, both brothers had hearing aids fitted, and continued to adapt to life as they went along; playing football with their friends, spending time with their two other siblings, and coping

as best they could throughout their school years.

When he finished school, Kevin joined British Aerospace following an apprenticeship, where he worked as an aircraft engineer. It was then that he started to lose his sight, and was diagnosed with Usher syndrome type 2. Desmond was later diagnosed with the same condition, and both brothers were told they'd be blind by the time they were 60.

Kevin loved his work as an aircraft engineer; he was able to travel the world, and even commissioned planes for the Royal Air Force. He continued until he was no longer able. He enjoyed pursuing his passion for dancing – particularly Rock n' Roll and Lindy Hop!

All donations made in Kevin's honour will help fund medical research which could make the challenges he faced on a daily basis a thing of the past. In addition, Desmond's support group are matching the funds raised through MuchLoved to further honour Kevin's memory and maximise the amount raised.

Retina UK is hugely grateful to the Lucy family, and to everyone who donated in celebration of Kevin's life.

For more information about giving in memory, email [fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk) or call Kimberly, Individual Giving Manager, on 07590 425644.



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## Festive Fundraising



### Retina UK's Great Bake

Rustle up some festive feel-good treats for your family, friends or colleagues. We've mixed together lots of ideas and resources to help you rise to the challenge. So whether it's a mince pie bake sale at work or a Christmas coffee morning at home, sign up today and get your free pack. Visit: [RetinaUK.org.uk/great-bake](https://RetinaUK.org.uk/great-bake)

### Charity Christmas cards



With artwork painted by artist Tina Wray, who has retinitis pigmentosa and glaucoma, these beautiful cards feature

snow-capped buildings surrounding a magnificent Christmas tree. Inside, they read 'Seasons Greetings'. Each pack contains six cards measuring 21 x 15 cm and costs £2.75. The cards were designed and printed free of charge. Visit our store for these cards, more designs and stocking fillers: [RetinaUK.org.uk/shop](https://RetinaUK.org.uk/shop)

This Christmas, join #TeamRetinaUK and raise funds as you celebrate.

### Santa Dash

This virtual 5k is sure to get you feeling festive. Pick a playlist of Christmas hits, run a route past the best decorated house or ask a friend to join you. However you decide to run, put on your Santa hat and raise funds.

*Registration Fee: £10*

*Minimum Fundraising: £100*

*Date: Anytime until 25 December*

All runners receive a Retina UK t-shirt or running vest (it's up to you) and a Santa Dash medal. Visit: [RetinaUK.org.uk/santa-dash](https://RetinaUK.org.uk/santa-dash)



### Support us as you shop

As you buy gifts this Christmas, you can raise funds for Retina UK at no extra cost with AmazonSmile, EasyFundraising and more. Get the details: [RetinaUK.org.uk/give-as-you-shop](https://RetinaUK.org.uk/give-as-you-shop)

## Meet a volunteer: spotlight on Joe



**Our amazing volunteers are diverse in age, background and ethnicity. The one thing they have in common is that they are all living with, or directly affected by, an inherited sight loss condition.**

Joe joined us as a volunteer fairly recently. He is a writer and teaches creative writing and English language both online and in university and community settings. He also has a background in publishing and editing.

Joe was diagnosed with retinitis pigmentosa at the age of 12, which led to his parents contacting our charity for information and support via the Retina UK Helpline. As a young adult, he first came across us at an event in London, which was also the first time he'd met someone else with his condition. He is registered as severely sight impaired

and whilst his central vision is still good, he has very little peripheral vision.

There is no family history of the condition and despite taking part in the 100,000 genome project, Joe doesn't currently have a genetic diagnosis. He is upbeat and optimistic about the future.

His first volunteering task for the charity was providing feedback on the Unlock Genetics project to ensure the written information was accessible and easy to understand. This type of informal volunteering is a great way to provide a 'lived experience' perspective, without having to commit to a regular role. You can find out more about the Retina UK Panel at [RetinaUK.org.uk/more-info](https://RetinaUK.org.uk/more-info).



Joe moved on to a more formal volunteering role on the Retina UK Helpline and attended his first Volunteer Training Weekend in 2022, which he describes as “intense”.

*“I’ve done a few volunteer telephone shifts but it made such a difference to actually meet the people who were also on the shifts with me. I had a lot of fun and really enjoyed chatting and laughing with them. It made me feel part of something. The warmth and energy of the group was quite something. There’s a huge sense of solidarity and shared vision and purpose.”*

He said: “They are a very warm and welcoming group of people who are all facing in the same direction when it comes to what they believe should

be happening in terms of supporting people with a retinal dystrophy.

“I feel really well supported by Retina UK. It’s clear that the whole team are there if I have questions or need help. The training materials are comprehensive and very easy to access and understand. I am looking into perhaps becoming a volunteer on the Retina UK Discover Wellbeing assisted journey in the future (see page 4-5). I’m very passionate about that project. Emotional and mental wellbeing resources are just as important as research into treatments and cures, in my view, because they help us live well in the present.”

If you are interested in becoming a Retina UK Volunteer we would love to hear from you. Please email Clair on [volunteering@RetinaUK.org.uk](mailto:volunteering@RetinaUK.org.uk) or call our office on 01280 821334.





# Thankyou <sup>#TeamRetinaUK</sup>



Clair, Richard, Carl and Karen, all climbed Snowdon, raising a fantastic £1,349 in memory of Linda Pritchard.



Lucy ran 5K every day for a month raising an amazing £600! Lucy is shown here with her running buddy Merlin.



Jo took on the Great North Run in preparation for the TCS London Marathon, reaching her target time and even spotting 'Elvis' running the route!



Rhea and Tim cycled the Leeds Liverpool canal over two days, covering 127 miles! They raised a fantastic £1,342 – thank you so much!

Diana ran the Big Half to cheering crowds and raised a brilliant £1,000 in sponsorship. Thank you!



Anisha and Sheena walked the Thames Path Challenge together and raised an amazing £2,800!

Thank you to everyone who has fundraised for Retina UK over the last few months.



Phil and Sarah took on the Chiltern 50, having a great time tackling the fantastic route and raising £1,780!



Penny took on the 100km Yorkshire Challenge with James, raising an incredible £5,255 and lots of awareness in their local newspaper.



The Hospital Saturday Fund kindly gave a grant of £2,000 to help support our exciting new gene therapy project!

Eileen and Alan McIntyre held an Open Garden fundraiser, and Alan donated proceeds from the sale of his artwork, raising £1,210 from the event!

The Retina UK staff team have been raising some dough with cakes in the office! We raised £30 with a Great British Bake Off sweepstake.



The team at Coventry based TBL and LDM Scanning Ltd hosted a customer Golf Day. Despite playing on the hottest day of the year, everyone completed the course, raising £1,200.

Please share your photos with us at [fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk)

## Regional volunteer facilitators needed



**2023 is going to be a busy year for our Local Peer Support Group Network.**

From Carlisle to Scarborough, Merseyside to Cambridge, Cardiff to Brighton and everywhere in-between. We are starting new groups and need volunteer facilitators!

If you enjoy engaging with others and could be proactive in developing a group with our office team, then we need you to help us support people in your local area.

Here is what some of our new facilitators have to say about their role with us:

*"It was such a beautiful meeting. Thank you so much for all your hard work. Everybody here just loved it. Such a brilliant organisation. We have done a wonderful thing tonight; thank you for all your help for so many people" – Belfast*

*"I already feel part of the team, the energy and enthusiasm is wonderful and I'm so glad that Retina UK are doing this" – Perm, West Midlands*



Our local peer support group meetings are available to anyone living with an inherited sight loss condition and their friends and family. Details of



meetings and locations can be found at [RetinaUK.org.uk/groups](https://RetinaUK.org.uk/groups). Some of our recent attendees have told us how useful they found the group:

*"I found the meeting extremely helpful and I have just this week been referred by my GP to the Moorfields Eye Hospital that you mentioned to me!" – Peer group member*

*"I found the talk at the peer support group informative and interesting" – Peer group member*

For more information on joining our amazing volunteer team and to have an informal chat please contact Clair, our Volunteer Coordinator, on 01280 821334 or email [volunteering@RetinaUK.org.uk](mailto:volunteering@RetinaUK.org.uk).

## West Midlands group visit Victorian factory

The West Midlands Local Peer Support Group recently visited the Newman Brothers' Coffin Works in Birmingham for a touch tour. The Coffin Works is a purpose-built Victorian coffin furniture factory, dating from 1894. Birmingham was once the centre of coffin furniture, and Newman Brothers' supplied the fittings for the funerals of Joseph Chamberlain, Winston Churchill and the Queen Mother.

The group were able to experience the sights, sounds and smells of factory life on the visit, with much of the working machinery still operational.

The visit concluded with a very enjoyable pub lunch at The Shakespeare Inn.

Denise, a regular attendee of the West Midlands group said: "I learnt

so much! There were some things that we weren't able to touch, understandably if it's not safe. But there were other things we could touch and listen to and smell.

"I'd like to thank everyone involved for such a wonderful day out. As a visually impaired person you don't get to go out as much as a fully sighted one, because of all the worry and anxiety of getting there, feeling safe and included etc. Thanks very much for a memorable day out!"

West Midlands Local Peer Support Group facilitator Perm said: "It was engaging, enlightening and absolutely inspiring. We all got together with a vision impairment but disability didn't come to the forefront, there were no barriers as we were all in it together. We enjoyed it thoroughly and also brought a smile to everyone's faces".

## Peer support for young people from LOOK

**We regularly work with sector partners, where their expertise complements our work. LOOK provide invaluable support for young people living with sight loss. In the following article they describe their mentoring scheme, which is available to children and young people aged 11-29.**

At LOOK we believe that nobody should have to cope alone. Experience has shown us that those who have personal experience of living with a visual impairment (VI) are best placed to support young people.

LOOK offers structured peer support for our young people through our pioneering mentoring programme connecting VI people to VI people, for guidance and support.

Our mentors are matched with a mentee based on their life experiences, eye condition, interests and ambitions, enabling mentors to create a positive bond with their mentee.

The mentor/mentee partnership can be hugely rewarding creating positive support for young people, whilst boosting self-development and confidence.

By creating community and connection amongst young people and their

families, we aim to empower them and increase access to social, employment and education opportunities, supporting blind and partially sighted people to thrive.

Want to find out more about our mentoring services? Visit [look-uk.org](http://look-uk.org) and click on 'Mentoring'.

### Emily Lamb

"I was diagnosed with the genetic eye condition, retinitis pigmentosa when I was 11 years old. Shortly after, my younger brother was found to have the same condition. This came as a shock to my family as we weren't aware of any family history of the condition, nor did we have much understanding of visual impairment.

"It wasn't until I was older, around 16, I noticed changes in my vision. Having stayed in mainstream education I had always wanted to attend university but began questioning if this was something that I'd be able to do.

"Thankfully, around this same time of what felt like an existential crisis, my mum came across a charity called LOOK UK.

"I was intrigued by LOOK's mentoring service, which provides young people who are navigating the struggles of sight loss with a mentor who they correspond with on an online platform.

# LOOK

“LOOK mentors have themselves experienced the difficulties surrounding visual impairment, and are specially trained to advise and support their mentees. I signed up to be a mentee with apprehension about how someone else’s experience could help my own. However, I was pleasantly surprised with how helpful I found it talking to someone that had already been through the issues that I was currently confronting.

“My mentor gave me invaluable practical advice on applying and going to university, but more importantly, she inspired the confidence that made me believe I could do it!

“After such a positive experience, I wanted to do the same for someone else. So I went from mentee to mentor, and I now connect

with my own mentee who shares her struggles with visual impairment.

“LOOK UK provided me, my brother and our family the support and guidance we needed to navigate the trying times of living with a visual impairment.

“Having a mentor, and talking to someone that could empathise with my experiences made me feel heard, valued and included.

“The guidance that I received from the charity as a whole, aided me on my journey of discovering and fulfilling my potential. Despite my worries, I graduated from York University this summer with a degree in English”.





# Help us find treatments for all!

Our new research strategy aims to find treatments for everyone living with inherited sight loss. But, as a charity, we can't do it without your help.

Donate today to fund ground-breaking medical research.

Thank you so much for your support.

Complete this form and return to: Freepost RETINAUK, or:

- **Donate online at [RetinaUK.org.uk/donate](https://RetinaUK.org.uk/donate)**
- **Call 01280 821334 or scan this QR code:**
- **Or double your donation by visiting [RetinaUK.org.uk/biggive](https://RetinaUK.org.uk/biggive) between 29 November - 6 December**



**£20**

helps fund everyday research materials.

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would provide the use of a state of the art microscope for a week.

**£100**

could go towards nurturing specialist stem cell cultures for half a year.

I enclose a cheque for £\_\_\_\_\_ payable to Retina UK

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We love being able to update you with what we're up to and we will continue to contact you in the same way we always have. To change your preferences please call 01280 821334.

It is often cheaper to contact you via email - please tick the box if you're happy for us to contact you via email

**Gift aid your donation and give an extra 25p for every £1 you donate, at no extra cost to you!**

I confirm that I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts in that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand that the charity will reclaim 25p of tax on every £1 that I give.

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