



LOOK FORWARD

ISSUE 182 SPRING 2024



Inside: Set yourself a challenge in 2024, plus find out about our brand new lottery

This edition includes a great article about cataract surgery for people living with inherited sight loss, the usual research news round-up and an introduction to our (almost) brand new fundraising team.

Don't forget, Look Forward is available as a hard copy, by email, audio (CD or memory stick) and in Braille. Get in touch if you'd like to receive a copy in one (or more) of these formats.

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



RetinaUKcharity



RetinaUK



Retina_UK

So much to look forward to in 2024

This is the first edition of Look Forward in 2024 and there is so much happening.

Before I move onto that, I would first like to reflect on 2023 and say thank you to everyone who attended a Local Peer Support Group or a Webinar, listened to one of our Podcasts, raised money for the charity in one of a host of different ways, donated to an appeal, read our newsletter or volunteered your time. You all contribute to making Retina UK the amazing charity-team we are!

We were proud to receive the Royal National Institute of Blind People (RNIB) Visibly Better Employer quality standard in 2023. Diversity and inclusivity is key to building a successful workforce. We are proud to employ a number of visually impaired staff and delighted to be awarded this quality standard as part of our commitment to supporting all of our team to grow and thrive.

Our Fundraising Team are back to full strength after a series of changes in

2023. Meet them on pages 22-23. They are excited to be launching a new way to support us in 2024 (pages 4-5) as well as encouraging our community to sign up for a challenge event (page 9).

We are often asked about cataract surgery and if it's worthwhile if you are living with an inherited sight loss condition. We spoke with two cataract specialists on pages 6-7, which we hope will answer that question.

As always, if you have any queries or suggestions about our work, please email me on chiefexec@RetinaUK.org.uk or call our office on 01280 821334.



Tina Garvey, Chief Executive



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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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What's on in 2024

We are planning a series of Webinars for 2024. Information will be available on our website very soon with details included in our e-Newsletters and on social media. You can find out more and register at RetinaUK.org.uk/webinars. Topics include:

- *In conversation with our latest research grantees*
- *Fitness, blisters and fundraising – being part of the #TeamRetinaUK TCS London Marathon 2024*
- *Ask the Expert*

If there are any topics you'd like us to cover, please get in touch. Email Jane on communications@RetinaUK.org.uk.

Our Local Peer Support Groups continue to grow with the launch of a new North East group (pages 10-11). Details of our upcoming Groups can be found on our website: RetinaUK.org.uk/groups.

Save the date

You told us you'd like us to move our Conference(s) north and we've done just that this year. We are excited to announce our Annual Conference and AGM will be held both in-person, and online on Saturday 28 September in Manchester. The in-person venue is the Pendulum Hotel, Manchester (M1 3BB).

Our Professionals' Conference will be held on Friday 27 September at the same venue and also online.

We are planning a fantastic line-up of speakers and topics for both events. Please save the date and, if you would like us to notify you when full delegate registration opens, complete our short registration form:

- RetinaUK.org.uk/annual-conference
- RetinaUK.org.uk/prof-conf

e-Newsletter now available in audio format

Our e-Newsletter is published every month (other than the months when Look Forward is published). It is sent via email with a plain text and audio copy also available. If you would like to subscribe to the e-Newsletter, please call us on 01280 821334 or email info@RetinaUK.org.uk. We are also happy to send it on CD or memory stick. Just get in touch to let us know your preference.

Feel the Friday Vibes

Join the Retina UK Lottery for a weekly dose of good fortune and good deeds!

Buckle up for a fantastic adventure!

WIN up to £25,000

and feel good about supporting people with inherited progressive sight loss.



Embark on a heart-pounding journey as we unveil an electrifying lottery experience that goes beyond just winning prizes - it's about sparking joy, making a difference, and leaving an indelible mark on our community!

Get ready for a lottery experience like never before - where excitement meets community impact, and everyone's a winner!

The stage is set, the lights are on, and the countdown has begun!



Have fun, help us to unlock the secrets of inherited sight loss by supporting life-changing research and support:

- Our Helpline - an essential beacon for people navigating the hurdles of visual impairment. It provides crucial

assistance for every step of their journey.

- Our peer support groups, Talk and Support, Unlock Genetics and Discover Wellbeing. These initiatives pave the way for people navigating the challenges of sight loss, ensuring no one walks this path alone.

By entering the Retina UK charity lottery we can continue our search for treatments and provide support, so everyone with inherited sight loss can live their best lives.

“Thank you so much. You don’t realise how much it helped me to talk to someone who knows what I’m going through. I don’t feel alone anymore. You have given me a lot to think about in terms of what I can do in the future.”
Talk & Support service user

How to play



Embrace your lucky streak: Choose five numbers or entrust destiny to make the call with a Lucky Dip. Each line costs £1.



Magnify the excitement with up to five lines - each line boosts your chances to win, making a bigger difference for good.



Seamless payments through Direct Debit - a quick and secure setup ensures swift transactions, and if luck favours you, we'll eagerly share the joyful news!

Over 50% of each £1 comes directly to Retina UK

Sign up now, set the ball rolling and be a catalyst for change!

Just visit **RetinaUK.org.uk/lottery** or scan the QR Code and join the Retina UK Weekly Lottery.



What would you do with £25,000?

"I would take my family on a luxury holiday".

"I would pay off my mortgage and make a donation to Retina UK".

"If I won £25,000 I would definitely give some back to the charity to help support the logistics of an international trekking challenge to celebrate our 50th Anniversary".

Responsible gambling

We're all about fun, but also about ensuring a safe and responsible gaming environment. Know the signs, play smart, and let's make every moment thrilling and enjoyable.

To help you enjoy the fun, we've put together some information about gambling responsibly on our website: **RetinaUK.org.uk/lottery**.

An expert view on cataract surgery

There are a number of misconceptions around cataracts, and many people struggle with the decision of whether or not to have surgery. We talked to experts Simon Keightley and Kanmin Xue about cataract surgery, specifically with regard to people living with inherited sight loss. Both hold extensive experience of treating cataracts in individuals with inherited sight loss.

Cataracts are a very common problem. Simon describes cataracts

as a cloudiness of the lens inside a camera (the eye), preventing light from reaching the film (the retina). They are caused by dead cells, which are pushed towards the centre of the eye and are not shed like other cells in a human body. In people with inherited sight loss, cataracts tend to develop at an earlier age, possibly due to low-grade inflammation in the eye.

Cataract surgery is the most common and oldest procedure performed in the world. It involves removing the affected lens and replacing it with a plastic lens. The procedure usually takes between



Kanmin Xue

15-20 minutes. This new lens allows more light to enter the eye.

Simon said: “It’s like removing a closed curtain, which creates a clear path for light to get through and hit the retina.”

Patients with retinitis pigmentosa (RP) with mild cataracts respond very well to surgery with a positive change in levels of vision in 70-80% of people. The main reported benefit for patients with RP is improved clarity.

However, if the retina has completely degenerated, it can be difficult to

assess if cataract surgery would be beneficial. Kanmin's advice is to see an expert who can assess how much function remains in the affected eye and discuss your options in more detail.

Cataract surgery is a straightforward procedure, but with all medical procedures, there will always be a degree of risk. The chances of complications arising from cataract surgery are very rare – around one in 10,000 operations. For those with RP, there is a slightly higher incidence of inflammation, which requires additional

treatment, but overall the risk is very low.

Both doctors stressed the importance of having regular check-ups either with your ophthalmologist or high street optician to monitor overall eye health.

Listen to our interview with Simon and Kanmin on our website: [RetinaUK.org.uk/resource/podcast-cataracts/](https://www.RetinaUK.org.uk/resource/podcast-cataracts/).

Find out about Sharron's experience of cataract surgery on page 8.



Simon Keightley

Cataract surgery – a personal perspective

Sharron is living with RP and recently underwent cataract surgery. She describes her experiences as follows:



Was it a difficult decision to go ahead with the surgery?

No, it was quite easy because my sight was deteriorating. My consultant was very positive and explained everything clearly, including the risks. He was sure that having the surgery would improve my vision. This gave me the confidence to go ahead.

What was your overall experience of the surgery?

It was very positive. Before, during, and after surgery all the staff told me exactly what would happen, and regularly checked I was comfortable. The operation itself was painless. At times, I felt uncomfortable, staring into a bright light and being prodded and poked around my eye. However, the background music made the atmosphere in the operating theatre less daunting and it was over in 20 - 25 minutes.

What was your vision like before and did the surgery improve it?

On sunny days, glare made it difficult to see when out walking. My tunnel vision had worsened, making me clumsier indoors and I had to wear glasses for watching television.

After surgery, my distance vision on the right was better, along with my peripheral vision on the left. I also had less sensitivity to glare and my tunnel vision improved. Overall, the results have been far better than I ever hoped.

My husband and I volunteer for Sea Watch Foundation, monitoring the local population of harbour porpoises. This means I spend a lot of time outdoors, scanning the sea. Since the surgery I have noticed a big difference. I now have a slightly wider field of general vision and better distant vision.

Did you experience any side effects?

I do have some intermittent double vision on the left, which clears when I blink. My local optician said it was a side effect of the surgery and reassured me it was common.

I was very lucky to have fantastic support from my husband, particularly with the various eye drops he had to administer four times a day for a couple of weeks after surgery!

Learn more about cataract surgery for people living with inherited sight loss on pages 6-7.

Join #TeamRetinaUK in 2024



As 2024 gets underway, our challenge events portfolio is growing, giving you, our amazing supporters, even more opportunities to join #TeamRetinaUK this year! Your contributions help us raise vital funds, so that we can continue investing in research and providing our vital information and support services.

We offer a range of events to suit all abilities, including hikes, treks, swims, runs, skydives, wing walks and much more. You'll receive regular encouragement from our team,

including lots of fundraising top tips throughout!

Whatever the challenge, we're here for you every step of the way. Nicola, one of our TCS London Marathon 2024 runners, said:



“The support I’ve received from Retina UK has been amazing. Everything that I have asked for help with, I have got, so thank you!”

Alternatively, you could challenge yourself by organising your own fitness challenge! Perhaps a charity spin like Kieran (page 18), yoga or an exercise class.

Get in touch with James, Events and Community Fundraising Manager, to discuss your challenge event ideas and goals: james.clarke@RetinaUK.org.uk.



Research news round-up

Study to access the safety and efficacy of OCU410ST for Stargardt disease

Biotechnology company Ocugen is conducting a phase 1/2 clinical trial to test the effectiveness of a gene therapy called OCU410ST for the treatment of Stargardt disease. US-based Ocugen will enrol 42 individuals living with Stargardt disease, aged between six and 65. The trial will take place in the United States across five study centres. It consists of two phases. In phase 1, the dosage of the gene therapy (OCU410ST) will be tested on 18 people. Then in phase 2, the remaining 24 people will be split into one of two groups, one of which will be a control group. The estimated completion date for this trial is October 2025.

Curing genetic blindness with space-enhanced artificial retinas

A start-up company, LambdaVision are working with Space Tango to develop a protein-based artificial retina. The artificial retina will utilise a light activated protein called bacteriorhodopsin. These artificial retinas will be manufactured in space where the reduced gravity will help the production quality.

The aim is for the artificial retinas to restore functional sight to individuals living with retinitis pigmentosa (RP).

SparingVision reaches final dose escalation step in trial of SPVN06 for retinitis pigmentosa

SparingVision is conducting a Phase 1/2 clinical trial for SPVN06, a therapy for the treatment of retinitis pigmentosa (RP) which aims to preserve central vision. In January 2024, SparingVision announced that the clinical trial had safely reached the final step of the dose escalation phase, which determines the best dose of a treatment.

SPVN06 is aimed at slowing disease progression in people with rod-cone dystrophy, regardless of their genetic diagnosis. The treatment provides copies of a gene that aids survival of the cone photoreceptors responsible for central vision. SparingVision is initially focusing on mid-stage RP.

President and CEO of SparingVision, Stéphane Boissel said the company was “encouraged by the strong safety and tolerability profile of SPVN06 demonstrated so far.”

Ascidian Therapeutics moves forward with RNA editing for Stargardt disease

Ascidian Therapeutics is to go ahead with in-human trials of their new treatment of Stargardt disease. The treatment, called ACDN-01, will begin phase 1/2 safety and efficacy testing in the first half of 2024.

ACDN-01 uses editing techniques which aim to compensate for harmful mutations

by changing the sequence of RNA, a molecule that copies and transfers genetic code from DNA to a cell's protein building machinery. This will allow normal proteins to be produced to replace the defective ones. Unlike edits to DNA, any changes made to RNA are transient, which potentially gives RNA editing a safety advantage over DNA editing approaches like CRISPR.

The condition will particularly benefit from an editing approach because it's caused by a very large gene which is more difficult to treat with traditional gene replacement therapies.

Alkeus Pharmaceutical announces positive interim data showing gildeuretinol halted Stargardt disease progression

Alkeus Pharmaceuticals announced positive interim data from their ongoing TEASE-3 clinical trial evaluating gildeuretinol (ALK-001) as a treatment in early stage Stargardt disease. The findings showed that ALK-001 stopped the progression of Stargardt disease for up to six years.

Stargardt disease occurs as a result of the ABCA4 protein being defective, leading to accumulation of toxic by-products, which irreversibly damage the retina.

In pre-clinical studies, gildeuretinol prevented retinal degeneration and

blindness in animals with Stargardt disease.

TEASE trials consist of four independent studies and TEASE-3 is the first clinical trial in early-stage Stargardt disease. The first three teenage patients who enrolled in the trial and were treated with oral gildeuretinol acetate, remained unaffected and free of disease progression for their treatment duration.

jCyte outlines plans to start pivotal trial of jCell for retinitis pigmentosa in second half of 2024

jCyte has announced plans to begin their much-anticipated phase 3 trial for jCell in the second half of this year. jCell is a stem cell-like treatment which is injected into the jelly (vitreous) of the eyeball, with a local anaesthetic. Unlike most gene therapies, jCell isn't designed to treat a specific genetic fault, which means it could be beneficial for a large proportion of people living with RP, especially in cases where genetic testing hasn't produced a definitive result. In phase 2 trials, jCell produced significant improvements in people with RP who still had a reasonable level of vision, and is thought to work by nourishing and supporting the survival of remaining photoreceptors. jCyte is committed to starting the phase 3 trial in the second half of 2024 but has not announced where the trial sites will be – it's unknown if any will be in the UK. Retina UK will provide updates as soon as we have more information.

New local peer support group in Tyne & Wear

Our new Tyne & Wear Local Peer Support Group, in collaboration with Northern Alliance VIPs, launched in October.

We are working hard to grow our peer support group network, and are pleased to introduce our new volunteer group facilitator Colin Hetherington, for the Tyne & Wear area. The group will work alongside Colin's established Northern Alliance group.

Colin introduces the group as follows:

"I'm the founder of the Northern Alliance VIPs group based in the North East of England. The group started after I attended a meeting at the Centre for Life in Newcastle some nine years ago. I had just finished working and as my condition worsened, I found my world falling apart, with no one to talk to or turn to. I found answers with Retina UK.

"At the meeting I talked about my journey, the shame, the struggles, the heartbreak, only to realise the tears in my eyes were shared by my audience.

"My occupational health officer had mentioned me starting a peer support group so I asked if anyone would be



"I am extremely aware of how much tech I have to learn, which I am finding difficult. However listening to Mark and all the friendly people at the meeting, I feel sure I will eventually start to pick things up and be able to ask relevant questions. I do enjoy being at the meetings which are so helpful. Well done."

Talking Tech Peer Support Group attendee

interested. I suddenly found I was not alone and others wanted change too. A month later the Northern Alliance was born.

“We are a different kind of group. When we meet in-person, we have a bar, guest speakers, a raffle, a singsong, a band and even a comedian. The room is filled with like-minded people and their partners. It’s a happy day full of facts about science, the benefits of guide dogs and what’s on in the North East. Most of all it’s about enjoying yourself without anybody judging you. We really do make friends for life. We also raise money for Retina UK, because ultimately we all want inherited sight loss to be a thing of the past.”

The next meeting will be held on **Saturday 23 March 2024, 1.00pm – 7.00pm** at The Bridges Hotel (upstairs function room), Castle Garth, Newcastle upon Tyne, NE1 1RQ.

Itinerary highlights include:

- Retina UK Information & Support Coordinator, Mark Baxter, will talk about our work and his own sight loss journey.
- Stephen and Joanne talk about their achievements with CURE Usher.
- The latest information on genetics and stem cells.

- Hazel Hyndland from RNIB discusses community work, connecting and supporting groups and getting involved.
- Gavin Neate introduces his app WelcoMe, a customer service tool putting disabled people first.

For more information about this and other local peer support groups, please email services@RetinaUK.org.uk or call Mark Baxter on 07889 595783.

If you would like to know more about our peer support group network and upcoming meetings and events, visit RetinaUK.org.uk/groups.

Why not get involved and either set up a peer support group in your area or support our existing groups by emailing volunteering@RetinaUK.org.uk or call 01280 821334.



“I thank and appreciate the teams who are working so hard to reach out to support and help people like me. Joining the group helped me gain knowledge of how to get help.”

London Peer Support Group attendee

Leading our best lives

Thanks to your ongoing support, at Retina UK we continue our search for treatments and provide support every day, so that everyone with inherited sight loss can live their best lives.

That support includes connecting people with others with lived experience, for example via our Helpline, Talk and Support service and our Local Peer Support Groups. Alongside that we offer a wide range of tools such as our website, podcasts, webinars and our Discover Wellbeing courses.

We also signpost to other organisations that can support people to manage the practical and emotional aspects of inherited sight loss.

Bobby grew up in a family who never spoke about their inherited sight loss. As a result he suffered trauma for many years. But since reaching out to Retina UK says he is better able to manage his emotional health and has taken up new interests.

“As many of my family live with retinitis pigmentosa (RP) I had grown up all my life seeing it, but there was a massive stigma in my family, we didn’t talk about it. Sight loss was taboo.

“I thought my life was done at 31 and there was no help for me. While working



as a Prison Officer I fell into a very dark place. RP was the main factor of the stress, fear and doubt clouding my mind and dragging me further and further down a horrible path.

“My ever-supportive partner Lou gave me Retina UK’s helpline number and said ‘here is the answer’. I’m really glad she did.

“After a few weeks I called and spoke to Mark, a helpline volunteer who also lives with RP. He gave his time to let me vent and air my fears, frustrations and emotional burden. Those hours changed my mind-set.

“I have now found ways to channel my grief. I had been living a lie all my life but now I’m taking responsibility for my own physical and mental health.

“Since ‘coming out’ as living with sight loss I’ve learned that people are often so friendly and helpful. I have started competing as a visually impaired

strongman and I'm now able to talk honestly and openly and feel better for it.

“Retina UK’s team of volunteers are a life saver. I no longer feel alone and have been inspired to prove my sight loss should not impact my life for the worse.”

Bobby spoke about his sight loss journey at our Professionals’ Conference in 2023. You can access the recording on the ‘Resources’ section of our website, along with previous issues of Look Forward: **RetinaUK.org.uk/resources**.

Katie was diagnosed with RP at the age of 39. She volunteers part-time for an organisation in Oxford, which helps adults with learning disabilities to gain life and work skills.

Katie says volunteering has helped her develop a more positive outlook, and explore new interests.

She said: “The positivity I see from others has helped me appreciate the small things in life, and to not focus on the things I can’t do but the things I can do. Writing poetry is new to me and I really enjoyed a recent six-week expressive writing course. I found it very relaxing and felt inspired to write about my sight loss journey.”

What do you see?

I shut my eyes and breathe,

I see my past, my future and my present,

Of course, I can’t see them really but I feel their presence,

A past which was joyful, a visual and striking rainbow,

full of noise, risks, laughter and tears,

The future I see less joyfully, a darker, smaller, safer space,

Secluded and quiet, planned and cushioned,

Like a new canvas, my view might be filled with ideas and wonderment,

Endless corridors of imaginings, some which will be fun and novel, others

dangerous and treacherous,

Mind the gap and I now see my present, a whirl of beauty and ugliness,

The constant treading of water to protect what I see,

the fear of loss, and independence,

the here and now, and live for the moment, reassuring words from friends,

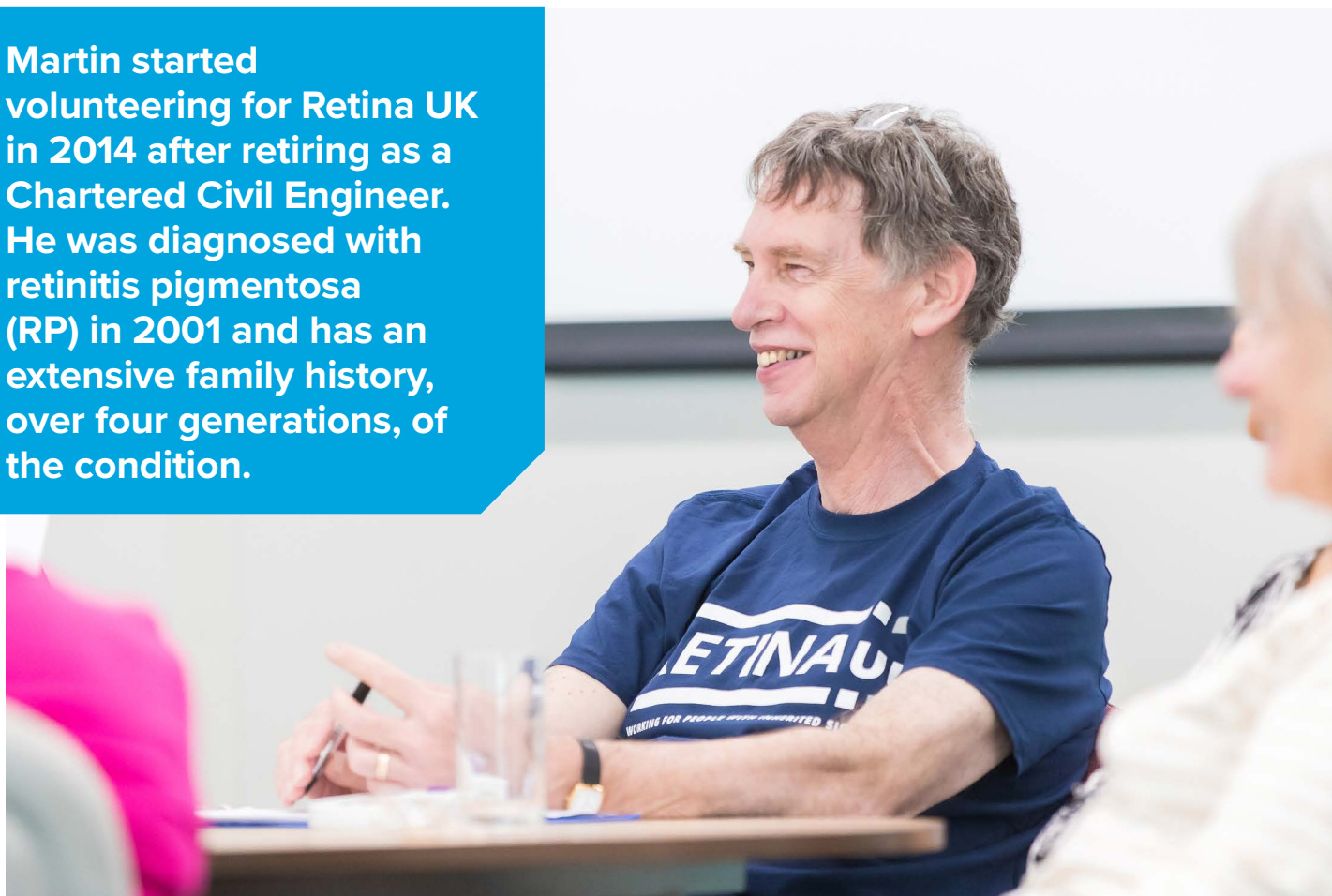
then the rapid disappearance of what I thought I saw

So what do I see now?

I see blind faith, I hear a warm laugh and a jump into the unknown

Spotlight on Martin Hills

Martin started volunteering for Retina UK in 2014 after retiring as a Chartered Civil Engineer. He was diagnosed with retinitis pigmentosa (RP) in 2001 and has an extensive family history, over four generations, of the condition.



Since 2017, he has overseen the day-to-day administration of the email Helpline service and has given more than 1,700 hours of his time to the charity. He monitors and manages helpline emails, triages them to the most appropriate team member, as well responding to many himself.

He has dealt with numerous different questions over the years, from people all over the country. He describes volunteering for the charity as ‘very rewarding’ and highlights one case which for him was particularly memorable.

“We received a message from someone who couldn’t talk to any of their family members about RP at all, because they were scared to do so and they didn’t think their family wanted to know about it. This person was really desperate to go abroad for what I considered to be a questionable treatment. We had many, many interesting conversations about that!”

The retired Chartered Civil Engineer creates reports to inform common subject areas, identifies training needs and keeps a record of feedback from service users to enable Retina UK to

continuously improve the service and demonstrate impact.

Martin has also shared his lived experiences as a key member of the Patient Advisory Committee for a biotechnology company, giving up significant time to help guide the company's patient information development and clinical trial design, and to ensure that they understood the needs of those living with inherited retinal conditions. He spoke about this at the Retina UK Annual Conference in 2023, helping our community to understand the value of engagement with industry and researchers. The recording of this can be found on our website: [RetinaUK.org.uk/resource/annual-conference-2023/](https://www.RetinaUK.org.uk/resource/annual-conference-2023/).

He has spent time completing detailed surveys about the impact of his sight loss condition, in order to support a Genetic Alliance submission to the HFEA pre-implantation genetic testing licensing committee. He also encouraged members of his wider family to complete the surveys.

His top tech tip is the good old-fashioned torch! He carries a small (but powerful) torch with him and uses it in dim light: "I can't begin to tell you how useful that is."

A few words from our community:

"I just wanted to thank you so so much for your reply. It is so appreciated, the time and effort you put in to your email and all the information, I can't thank you enough."

"Omg that is so helpful. Thank you so much."

"Thank you very much Martin for your detailed reply, there's a lot of extremely useful information there for us to pursue. With many thanks for your help, and all the best."

And from a fellow volunteer:

"Special thanks to Martin for his regular phone calls, his encouragement and his humour, this really makes me feel part of the Retina UK family."

To express an interest in future volunteering opportunities with Retina UK email volunteering@RetinaUK.org.uk.

THANK YOU

#TeamRetinaUK



A huge thank you to Kieran Ivers who raised £500 by organising and teaching a spinning class, which saw 16 family members and friends take part!



Jason Fernandes organised a quiz for Retina UK and raised an incredible £4,000 in the process! A huge thank you to Jason and everyone who took part.

Nicola Daly, one of our TCS London Marathon 2024 runners this April, organised a coffee morning and a curry night as part of her marathon fundraising. Nicola has raised over £2,300 and has already smashed her target!



Thank you to Tina Wray, our Christmas card artist for helping us to reach our biggest Christmas cards sales in 10 years!

Our TCS London Marathon 2024 team is our biggest in four years. They have already raised a staggering £30,000 with over a month still to go!



Thank you to Josie Grist and the office team from Costello Medical for raising £185 from their recent Souper Tuesday event.

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

Thank you to Worksop's Got Talent for another hugely successful event in aid of Retina UK, which raised an incredible £13,000.

We'd like to say a huge thank you to Sandra, David and Clare who took to the skies for a Bonfire Night skydive! They faced their fears and collectively raised £2,000 for Retina UK!



Thank you to Monica Arnold, who raised £300 from the Barcelona Half Marathon in February.



We'd like to thank Adrian Paternoster (Just Be Youu) for his continued support and for his recent donation of £250 from the sale of his incredible artwork!

A huge thank you to all of our incredible #TeamFinlay runners who are currently training and fundraising for the upcoming Bristol Half Marathon, in memory of Finlay Macleod. The overall fundraising total is currently £45,000!



If you would like to get involved in 2024, we'd love to hear from you. Call James on 01280 815900 or email fundraising@RetinaUK.org.uk. Details of all of our upcoming challenge events can be found on our website: RetinaUK.org.uk/challenge.

Please share your photos with us at fundraising@RetinaUK.org.uk or tag us on social media.

New pathway aims to transform eye care support

Retina UK has worked with other leading organisations in the eye care and sight loss sector to create a UK-wide Eye Care Support Pathway.

The Pathway is a new framework to ensure those diagnosed with sight loss have timely access to information, advice and support throughout their eye care journey.

Over the past two years, Retina UK staff and community members have shared their knowledge and lived experience during the development of the pathway, to ensure it specifically reflects the unique needs of those living with inherited sight loss conditions. For example, this includes access to genetic counselling and testing, wellbeing support and the opportunity to get involved in research activity.

The over-arching ambition for the Eye Care Support Pathway is that from the moment someone realises that “something isn’t quite right” with their sight, through to diagnosis and being able to live confidently – and independently – with their condition, they have access to the information, and support they need. We believe those living with inherited sight loss should be able to actively participate and take control of their eye care journey.

The project, led by RNIB, provides a great example of the sector collaborating with the NHS, social care, people with lived experience and the Third Sector. It was informed by detailed research, the insight of more than 500 people with lived experience and more than 30 bodies who represent professionals and patients across the sector.

More than 20 organisations have already endorsed the Eye Care Support Pathway, including NHS England, College of Optometrists, Royal College of Ophthalmologists and the Royal College of Nursing.

Paula McGrath, Deputy Chief Executive at Retina UK said the Pathway, which was launched in November, is a significant step towards working together to create positive change for those diagnosed with inherited sight loss conditions.

She added: “We are delighted that members of our community and our staff have had the opportunity to share their knowledge, expertise and, most importantly, their lived experience to help shape this new Pathway. This means the specific needs of those with inherited sight loss are acknowledged in the Pathway. For example, the opportunity to access genetic testing and counselling, to get involved in research activity, and to access timely emotional and practical support to

Eye care support pathway

Supporting you at every stage of your journey



enable them to make informed choices and live their best lives.”

Louisa Wickham, National Clinical Director for Eye Care for NHS England, said: “Success in transforming the way eye care services are provided to meet the increasing demand on the NHS will require the whole sector to transform its approach to improving patient care. The Eye Care Support Pathway puts the person at the centre of their eye care and sight loss journey. When the Eye Care Support Pathway is implemented, we must seize the opportunity to truly transform services, empower patients and improve outcomes.

We are now working with other leading sight loss organisations, the NHS and social care bodies and those with lived experience to implement the Eye Care Support Pathway with professionals.

A second version of the Pathway will be published later this year for those living with sight loss, to empower them to advocate for themselves.

This work will continue to be a priority for Retina UK until we can be confident that everyone who is diagnosed with inherited sight loss gets the right support at the right time throughout their eye care journey.

Read the Eye Care Support Pathway report RetinaUK.org.uk/news/ecsp.

“I’m grateful to our VI sector charity partners for collaborating in developing and publishing the Eye Care Support Pathway and in bringing people together to embed the framework into services and ensure that every person gets the right support at every stage.”

Get to know our Fundraising team

The past 12 months have seen significant changes to our fundraising department. Get to know the new team and find out which luxury item they'd choose if they were stranded on a desert island! Do please get in touch if you're interested in getting involved.

Jo Faulkner-Harvey, Head of Fundraising

jo.faulkner-harvey@RetinaUK.org.uk
07841 004564

Jo joined Retina UK in September 2023 and is thoroughly enjoying being part of our amazing charity. She has worked in the sector for 28 years for various organisations, including Macmillan Cancer Support, GB Wheelchair Basketball, Dogs for Good and Homeless Oxfordshire.

Luxury item: "My king size bed, fluffy quilt and 'hotel' pillows!"



"As the Head of Fundraising, it is my role to inspire and empower the fundraising team to raise much-needed income for Retina UK, to fund research and the variety of support we offer to our community. I take the lead on fundraising strategy and planning, contributing to the sustainability of the organisation. It's also my job to keep the team topped up with cake!"

Clare Bailey, Fundraising Team Administrator

clare.bailey@RetinaUK.org.uk
01280 815900

Clare's role is to assist and support the whole team in Fundraising. She is also the person you're most likely to speak to from the team if you call our office.

Luxury item: "A solar shower with shampoo and shower gel."



"I love to spend time with my family, I have five grandchildren - they keep me pretty busy! I also really enjoy going to the gym, trying new recipes and indulging in a glass of rosé or two!"

**Amelia Burton,
Trusts and Foundations Fundraiser**

amelia.burton@RetinaUK.org.uk
07841 481423

Amelia applies to trusts and foundations for support for our research projects, and for our information and support services. She also communicates with supporters from trusts and foundations and reports back to them on the impact their gift is having.

Luxury item: “A bowl of my favourite almond and raisin granola.”



“I love reading and listening to history podcasts, having a chai latte, charity shopping and cooking with my partner.”

James Clarke, Events & Community Fundraising Manager

james.clarke@RetinaUK.org.uk
07736 925174

James supports our incredible fundraisers with challenge events (ranging from runs to hikes to swims and so much more), or their own community event.



He loves listening to podcasts, eating yummy food and going on holiday!

Luxury item: “A sun lounger!”

Lily Powell, Individual Giving & Corporates Manager

lily.powell@RetinaUK.org.uk
07842 013440

Lily looks after individual supporters, as well as our corporate partners. She loves crochet, reading, camping holidays and windy beach walks with her very spirited Bearded Collie, Florrie.

Luxury item: A cheeseboard selection, complete with crackers and chutney!



“I love getting to work with a wide range of supporters who have a shared passion for this small but mighty charity!”

Support us to help more people on their sight loss journey.

Text donations – a simple and quick new way to give!

Text LFFIVE to 70560 to donate **£5**.

Text LFTEN to 70560 to donate **£10**.

Text LFTWENTY to 70560 to donate **£20**.

Text donations will be added to your monthly phone bill and will cost your donation plus one standard network rate message.

Complete this form and return to Freepost RetinaUK.

Or donate online at RetinaUK.org.uk/donate

Call 01280 815900 or scan this QR code:



I enclose a cheque for £_____ payable to Retina UK

I would like to donate £_____ by debit/credit card

Debit/Credit card details

Account holder name: _____

Card number:

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Expiry date:

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CV number:

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Contact details

Title: _____

Name: _____

Address: _____

Postcode: _____

Telephone: _____

Email: _____

Tick here to be contacted via email

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.

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

Yes, I'd like to gift aid my donation.

I confirm that I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Signature: _____

Date: _____



£25 could pay for two calls to our Helpline, supporting callers who feel isolated and alone.

£50 could pay for two hours of medical research into potential treatments for people with inherited sight loss.

£95 could pay for one PhD student for a day.