



LOOK FORWARD

ISSUE 188 WINTER 2025



This is the final edition of Look Forward this year and what a year it has been! We've had some very positive feedback about our Conferences (pages 4-5) and the Big Give Christmas Challenge (page 15) is back - a great opportunity to double your donation at no extra cost to you!

We've included a handy 'What's on' article (pages 22-23) which outlines some of our plans for 2026. We would like to take this opportunity to wish all of our readers a very Merry Christmas and a happy and fulfilling New Year.

A fantastic start to our Anniversary year

I would like to start my regular page by paying tribute to our incredible founder, Lynda Cantor who passed away in August. She truly was a remarkable woman and she is sorely missed by us all.



and the launch of our Gala dinner, which marks the end of our anniversary year in June 2026.

Finally, thank you to our amazing Sahara trekkers and congratulations to them on a successful expedition. Between them, they have

raised more than £40,000 for Retina UK and pushed way beyond their comfort zone to complete this monumental challenge!

We will continue to live the values of our fantastic organisation and look ahead to 2026 with passion and enthusiasm.

*Tina Garvey,
Chief Executive*

I hope those of you attended our Conferences (pages 4-5) this year enjoyed them as much as I did. It was an incredible couple of days, with more of you joining us than ever before. Thank you to our sponsors, our speakers, our volunteers, Trustees and our delegates. We are already starting to plan for 2026 and will share updates in our newsletter as soon as we can.

These final few months of the year are busier than ever, with our BBC Lifeline appeal on 16 November (available on BBC iPlayer bbc.co.uk/lifeline), The Big Give Christmas Challenge (page 15)

Look Forward is available as a hard copy, by email, audio (CD or USB) and in Braille. Get in touch if you'd like to receive a copy in one (or more) of these formats. If you no longer wish to receive Look Forward, please let us know by emailing info@RetinaUK.org.uk.

Retina UK is a charity searching for treatments and giving support every day, so everyone with inherited sight loss can live their best lives.

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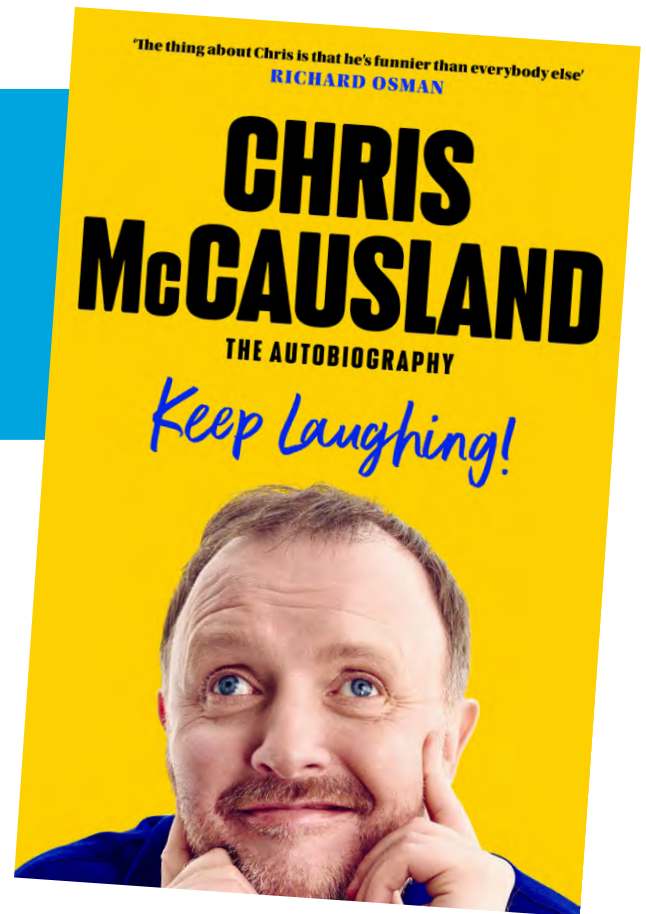
W: RetinaUK.org.uk · **E:** helpline@RetinaUK.org.uk

Keep laughing

Many of you will remember our interview with Chris McCausland in the spring edition of Look Forward. His autobiography “Keep Laughing” was released in October and we’re delighted to include this short review.

Keep Laughing is a great read / listen with so many anecdotes from Chris’s life – he sounds like he was a right handful as a child! It is honest, funny, sad and at times somewhat shocking. The following extract from the book may resonate with Look Forward readers.

“If you lose your sight in an instant, there is one single moment that you have to deal with, the loss of everything happening at the same time. I can only imagine that this would be incredibly difficult and painful, but the flipside here is that you do just have two distinct identities: the sighted you that is lost in that moment, and the new blind you, which you must try to come to terms with. My loss was drip-fed to me over such a long period of time that my identity was constantly being forced to change and I lost many different versions of me along the way. I would find that I was always playing catch-up and never really allowed to settle. The loss was constant, and as a result I think I developed coping strategies to protect myself against its relentless intrusion and probably against any sadness that all that loss might have caused me to feel.”



The book is widely available in bookshops. You can also borrow the audio version from our friends over at Calibre Audio. Visit their website for more details: calibreaudio.org.uk/.

We are very excited to be teaming up with 30+ theatres around the UK for bucket collections during Chris McCausland’s UK tour in 2025 and 2026! If you would like to volunteer for Retina UK during our 50th anniversary year and raise vital awareness and funds at various tour dates across the country, please get in touch to find out more. Email fundraising@RetinaUK.org.uk or call 01280 815900.

An incredible couple of days!

A huge thank you to everyone who joined either our Annual Conference or our CPD accredited Professionals' Conference in London in September.



Both days were jam packed with fantastic speakers, including our amazing lived experience panel on Friday who spoke candidly about their inherited sight loss condition and the importance of signposting to Retina UK. This session was incredibly thought-provoking and emotional for both the speakers and our delegates.

For the first time our Professionals' Conference featured role-specific sessions for ECLOs, Rehabilitation specialists and eye care professionals. Our online attendees were treated to a round-up of the opportunities that technology presents for people living with sight loss by Davinder Kullar of

"To meet people in the same situation as me. I am a nurse who has RP. I have never met anyone outside my family with RP. I spent a lot of the day crying, so was glad I was online...looking forward to tomorrow. The speakers were engaging and easy to understand. Thank you for changing my life."

Palliative care nurse

"I am thankful for the conference reminding me of all the great support that Retina UK have to offer. I have watched how you have grown and can honestly say your work has supported many of my service users of all ages over many years."

Rehab Officer

“Great day. I’ve been involved since 2001 and I know the charity and medical community have managed expectations with regard to treatments very carefully. It was remarkable that this year’s tone moved from ‘cautiously optimistic’ to ‘optimistic’. I know full well how long these things take, and there are many bumps along the road, but it must have given people more hope.”

Retina UK community member

“Really excellent thank you. I know what hard work it is to organise an annual conference and I’m really grateful. I think the best thing for me is just feeling much more connected to other people with inherited sight loss because of the team at Retina UK. I feel very confident to live my life and to get help when I need it. I always enjoy hearing about current tech as well. The venue and catering were amazing - all that makes you feel very cared for!”

Retina UK community member

Personaleyes. Deepening collaboration with our professional colleagues will undoubtedly have a positive impact on experiences and outcomes for our community.

Our Annual Conference saw more than 250 people join us in London. As part of the charity’s 50th anniversary, we took the opportunity to reflect on our progress so far with a really entertaining session from Professor John Marshall MBE. He was followed by a more general inherited sight loss research roundup from Professor Michel Michaelides, before being brought right up to the present day with Retina UK funded research evaluating the use of a micro-engineered photoreceptor patch implant from Professor Jane Sowden.

Both days were filled with smiles. Connections were made, friendships were forged and a real sense of community was felt around the room and online. Thank you so much to our

speakers, our volunteers, our exhibitors the Retina UK staff team and to everyone who attended. We really are #StrongerTogether!

The recordings from both days are available on our website in both video and audio only formats. If you would like to receive the audio recording on CD or USB, please email **info@RetinaUK.org.uk** or call us on 01280 821334 and we’d be happy to send these to you.

- **RetinaUK.org.uk/resource/annual-conference-2025/**
- **RetinaUK.org.uk/resource/professionals-conference-2025/**

Thank you to our headline sponsor Johnson & Johnson and our other sponsors Aavantgarde, Alkeus Pharmaceuticals, Beacon Therapeutics and Octant Inc for their support in delivering the Retina UK Annual and Professionals’ Conferences in 2025.

Research news round up

Sepul Bio doses first participants in phase 3 clinical trial

Sepul Bio has dosed the first two participants in its Phase 3 HYPERION trial of sepfarsen for CEP290 associated LCA10.

LCA10 is one subtype of Leber Congenital Amaurosis (LCA) caused by mutations in the CEP290 gene, leading to photoreceptor degeneration.

Sepfarsen is an antisense oligonucleotide (AON) which aims to improve visual function in patients with LCA10. Sepfarsen works by 'silencing' a specific damaging mutation in the CEP290 gene, allowing retinal cells to produce a functional protein and potentially restore some visual function.

Participants must be aged 6+ and have LCA10 due to the c.2991+1655A>G (p.Cys998X) mutation in CEP290 (see 'Genetic diagnosis mutation code explained'), which would be shown in a genetic test report. Sepfarsen cannot work for other CEP290 mutations.

HYPERION will evaluate the efficacy, safety and tolerability of sepfarsen in 32 participants over 2-years. The treatment is administered via intravitreal injection every 6 months. The eye is numbed with anaesthetic drops before the procedure.

The first two patients have been dosed in this clinical trial, with centres in

various locations including a UK site in Moorfields Eye Hospital.

To learn more or inquire about participation, email [**contact@sepulbio.com**](mailto:contact@sepulbio.com).

Cell-ibrating the dosing of patients with jCell in a phase 2 clinical trial for RP

jCell, a cell therapy designed to sustain vision in patients with retinitis pigmentosa (RP), is now in a Phase 2 clinical trial to assess safety and efficacy.

Delivered via an intravitreal injection, jCell releases neurotrophic factors that may reduce photoreceptor death and support cell health. Due to its mechanism, jCell is a gene-agnostic treatment, meaning that it could potentially work for patients with any genetic form of RP. This marks a significant milestone in non-gene specific treatment development!

The current trial involves testing an increased dose of jCell in a larger group of patients than in the Phase 1 trial. It will take place in California and enrol up to 60 participants with any genetic form of RP. Participants will receive either jCell or a sham (placebo) control and will be assessed over a 6-month period for safety and vision changes.

jCyte also plans an extension study for longer term follow up and to offer jCell to sham-group patients after this trial.

Genetic diagnosis mutation code explained

c.2991+1655A>G:

The numbers here refer to the exact position of the mutation within the genetic code.

A>G signifies a single nucleotide change from Adenine (A) to Guanine (G) at that position.

p.Cys998X:

This part of the description shows what the mutation does to the resulting protein.

In this case, the mutation causes a premature stop to protein production at the 998th amino acid in the sequence, which is a cysteine. The overall protein molecule ends up too short.

Predicting genetic diagnosis from scans

A study has recently been published describing how artificial intelligence (AI) can predict the genetic cause of inherited retinal diseases (IRDs) from retinal scans alone. Retina UK is proud to have supported the UK IRD Consortium, which helped pave the way for this groundbreaking innovation.

The AI algorithm, Eye2Gene, was developed using one of the world's largest datasets of individuals with an IRD genetic diagnosis, curated over 30 years at Moorfields Eye Hospital and involving over 2,500 records.

Eye2Gene can effectively predict causative genes from retinal scans for up to 63 IRDs, something even human experts struggle to do. Eventual implementation of Eye2Gene in the clinic could vastly increase the speed and efficiency of accurate diagnosis.

Clearing a path to retinal regeneration

Cells in the retina of cold-blooded animals called Müller glia are able

to regenerate retinal tissue into new photoreceptors after damage.

Mammal retinas contain Müller glia but they do not proliferate and reprogramme in response to damage, meaning that once photoreceptors and other retinal cells are lost, the degeneration is permanent.

Researchers at the Korea Advanced Institute of Science & Technology have identified a protein called PROX1 which inhibits retinal regeneration in mammals. Blocking this protein led to sustained retinal regeneration and vision restoration for over six months in animal models. The findings are encouraging and the team aims to continue development with the hope of moving to human trials in 2028.

The full content for these articles can be found at **RetinaUK.org.uk/research-news**.

You can keep up to date with further developments via our e-news, Look Forward newsletter, social media, website, webinars and podcasts.

Take on a challenge and help change lives

There's nothing quite like the feeling of crossing a finish line, reaching the summit, or completing a goal you never thought possible. When you do it for Retina UK, that achievement goes even further – because every step, pedal and jump helps support people living with inherited sight loss and funds vital research into treatments for the future.

We are proud to offer event places across the UK and around the world, giving you the chance to take part in something amazing, no matter where you are or what you're into. Maybe you've always dreamed of running a marathon, tackling a mountain trek, or taking part in an overseas cycle challenge. Or perhaps you'd rather stay closer to home and join a local run,

walk, or community event. However you want to get involved, we'll be there to support you every step of the way.

Our challenge events calendar (pages 22-23) includes a huge range of opportunities – from iconic runs like the TCS London Marathon and the Great North Run, to adventurous treks in some of the world's most breathtaking



Inspired by childhood visits to Cornwall, Alex set out to run from Land's End to London. On paper, it seemed straightforward, but the reality was far tougher. Over 12 days, he covered the equivalent of 17 marathons, averaging 55km per day across steep coastal paths and battling harsh weather. The challenge was gruelling, and five days in, a stress fracture in his shin forced him to adapt. He switched to cycling, which, he says, at first felt like a failure, but quickly proved just as difficult - especially with broken bike pedals and the unexpected physical toll of long-distance riding. Throughout, the support of family, friends, and the Retina UK community kept him going.



locations. We also offer charity skydives, cycling events, obstacle courses, and virtual challenges for those who prefer to take things at their own pace.

Taking on a challenge for Retina UK isn't just about the event itself. It's about being part of something bigger – a community of people who believe in a brighter future for everyone affected by inherited sight loss. The money you raise helps us continue offering vital support services, such as our Helpline, peer support groups, and information resources, while also funding pioneering research into treatments that could transform lives.

“It was the hardest thing I’ve ever done in my life and I wanted to give up so many times, but it was for a great cause so that kept me going!”

Maria, Manchester Half Marathon

Whether you raise £50 or £5,000, it all makes a difference. You'll be helping people find answers, support, and hope.

If you've already got a personal challenge in mind, we'd love to hear from you. From mountain climbs and long-distance walks to bake sales and fitness goals, any event you take on in aid of Retina UK will make a real impact. We can provide advice, fundraising materials, and Retina UK branded kit to help you show your support proudly.

“The free-fall is a massive adrenaline rush and it’s more like flying than falling, but it’s exciting and intense! After the parachute goes up, there’s a sense of calm and weightlessness, along with breathtaking views. I feel a real sense of achievement that I did it and raised some money for a charity close to my heart.”

Hazel, Skydive

Ready to get involved?

Visit **Retinauk.org.uk/challenge** or email **joe.clark@RetinaUK.org.uk** to learn more about all our upcoming events, overseas adventures, and challenge opportunities.

Top tech news

Do you find it hard to keep up to date with the advances in technology? If so, this article is for you! Each of the following tips is accompanied by a short audio clip which explains the features. These can be accessed by following the relevant link or scanning the QR code.

Meta Oakley smart glasses

bit.ly/4o6M5XC



Launched in June 2025, these sleek specs combine style with smart features, including:

- 3K video recording
- Open-ear speakers for calls & music
- Voice control with “Hey Meta” assistant
- Up to 8 hours battery life
- IPX4 water resistance

Robbie the robo guide

bit.ly/48urYhj



Robbie is a four-legged robot “guide dog” powered by 5G and advanced sensors that has been designed to support blind and partially sighted users.

The Robo-Guide will be used for indoor navigation such a museums, shopping centres and airports. This mobility tech is being developed by the James Watt School of Engineering at the University of Glasgow, supported by the VI community from RNIB Scotland and The Forth Valley Sensory Centre.

Wayve driverless vehicle technology

bit.ly/42MsmUK



Wayve is a London-based startup that’s redefining autonomous driving with ‘embodied AI’ – a smart system that learns from human behaviour rather than relying on detailed maps. The goal is safer, smarter, more adaptable self-driving vehicles that can handle real-world unpredictability.

For those who are blind or partially sighted, this tech could mean truly independent travel, without the usual barriers and frustrations of public transport.

Wayve has already raised over \$1 billion (led by SoftBank) and is partnering with Uber to trial these vehicles across London by 2026. A step closer to inclusive, accessible mobility for all.

Glide: The world’s first intelligent guide

bit.ly/3KXCXpG



Glide is an innovative AI-powered mobility aid designed for individuals who are blind or have low vision, providing

autonomous navigation and obstacle avoidance. Using advanced sensors and AI, it intelligently steers users along safe paths, identifies landmarks like doors and stairs, and offers real-time environmental descriptions, aiming to enhance independence and confidence in navigating both indoor and outdoor spaces.

VoiceVista navigation app

bit.ly/496xpDg



VoiceVista is a powerful, free iPhone app transforming navigation for people with vision impairment. Using immersive 3D audio cues and accurate location services, it helps users explore their surroundings with confidence. It allows them to set markers, create routes, and receive real-time information about their location and nearby points of interest.

Samsung Galaxy watch 8

bit.ly/4oiFNE6



The Samsung Galaxy Watch 8 and Samsung Galaxy Watch 8 Classic were released in July 2025 along with the updated version of the Galaxy Watch Ultra.

Meta Hypernova AI glasses

bit.ly/47AjQdd



The Hypernova glasses from Meta appear to be a considerable upgrade to the already available Meta Ray Bans.

Luna Glasses

bit.ly/48ALyLL



The Luna Glasses have been designed by Dutch startup company Angstone to assist those with night blindness.

Envision Ally Solo Smart Glasses

bit.ly/4ooHUGs



Ally Solo smart glasses from Envision combine AI software, which can be downloaded as a smart phone app assistant, with stylish smart glasses.

Navis

bit.ly/4n9njFO



TouchPulse is developing Navis, an AI-powered navigation app for blind and visually impaired users that provides precise, real-time, personalised, step-by-step voice and haptic guidance for independent travel.

Google and Amazon Smart Home devices

Discover the top 10 accessibility features for Google and Amazon smart home devices, as recommended by our community!

bit.ly/43l7XpZ - Google

bit.ly/4omWtdw - Amazon

Inclusion in this article does not constitute an endorsement from Retina UK.

THANK YOU

#TeamRetinaUK

Whatever you can do to support Retina UK, from organising a bake sale to taking on an epic challenge, it is hugely appreciated by us all. We are pleased to shine a light on some of our fantastic supporters in these pages. We quite simply can't do it without you.

We have been holding bucket collections across the country on Chris McCausland's UK tour. A huge thank you to everyone who has supported us so far.



Max Mountstevens was one of our fabulous fundraisers on our second Retina UK Day in October and raised a huge **£270** through his school bake sale.



Our friends at Your Training Partner in Worksop raised over **£100** on Retina UK Day by organising a 'wear it blue' run.



The 9th Worksop's Got Talent took place on Halloween and 700 people, including famous faces, supported the annual talent show in Nottinghamshire.

In the summer, Kylie Bryan from Essex took to the skies for Retina UK and raised a fabulous **£805** for our vital work.

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



Matt Stump organised a community strongman event for us in Gloucestershire and raised a fantastic **£405**.



In September, Debbie Gordon raised an incredible **£1,584** by taking on the Kilimanjaro trek!



Rose Earnshaw, an inspirational eight-year-old from Lancaster, completed a running challenge every day in August and raised a phenomenal **£2,326** for Retina UK research projects.

Specsavers Poole organised a non-uniform day on Retina UK Day. As well as raising money for us, they spread the word about our charity on World Sight Day.



Phoebe Bowsher was part of our Big Half team in London in September. She raised a wonderful **£654**.

If you would like to get involved, we'd love to hear from you. Call James on 07736 925174 or email james.clarke@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.

Navis – More Than an AI. Your Guide to the World



Join our Beta programme

Imagine stepping outside knowing you'll always find your way. The right turn, the right door, the safest path. That's what Navis is built for.

Navis isn't just another app. Designed with and for the visually impaired, it combines advanced technology with human support to make travel easier, safer, and more independent.

With Navis, you can:

- Arrive with confidence by identifying exact house numbers.
- Stay oriented with HALO haptic feedback acting like a sixth sense, guiding your direction.
- Explore nearby places with ease such as restaurants, shops, or landmarks
- Call a trained human guide when you need extra support.
- Save your routes in advance and use them again later.

We've tested Navis across the Netherlands and now we need your feedback to make it even better. Join our beta program to help shape the future of navigation for people with visual impairments.

Sign up today at www.touchpulse.nl/navis

Double your donation to Retina UK!

For the 10th year, Retina UK will be taking part in the Big Give Christmas Challenge and in our 50th anniversary year we are striving for our biggest total to date. Between midday on **2 December** and midday on **9 December**, you can double your donation and make twice the impact with your incredible generosity – **at no extra cost to you**. Donations will support medical research to make the challenges of living with inherited sight loss, a thing of the past.



Big Give

“Retina UK is at the forefront of research and by doubling my donation, it felt fantastic to be a part of their vital mission to find a treatment. I would encourage others to get behind this wonderful charity.”

Simon, Retina UK community member

The Big Give is a registered UK charity that operates as a matched funding platform. If you or someone you know is considering donating, or taking part in fundraising for Retina UK, please save the date and make twice the difference. Donations must be made through the Big Give website. Visit our website for a link directly to the Big Give site: **RetinaUK.org.uk/big-give**.

This Christmas, we hope that you will consider making a generous donation. Anything you can spare will make such a huge difference to those living with inherited sight loss. Thank you for all of your amazing support in 2025.

If you have any questions about the Big Give or would like help to make your donation, please call our friendly team on 01280 815900.



You don't have to be held back

The last edition of Look Forward focused on one of our longest serving volunteers. This time we are featuring one of our newest!

Charlotte is living with retinitis pigmentosa. She is a mum of two and is currently working on her PhD, the highest level of academic degree. Her sight loss condition has not held her back.

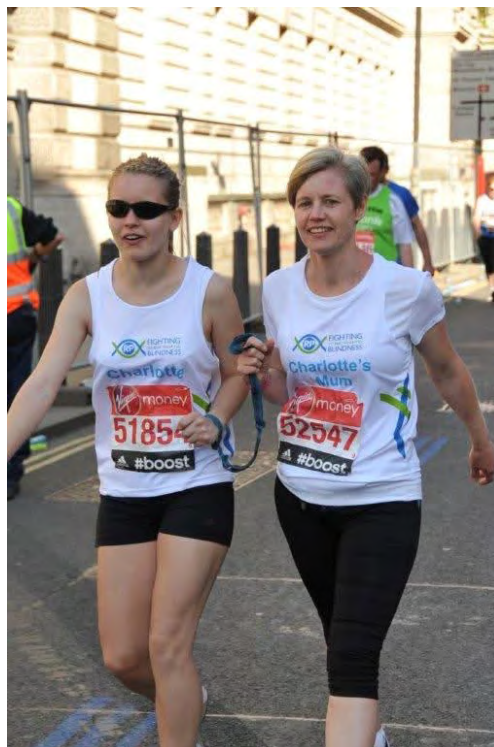
Her parents started to suspect that there was something not quite right with her vision when she was three, but she didn't receive a formal diagnosis until she was 11 or 12 because her presentation didn't follow the usual pattern. She was registered blind at the age of eight and by 14, had lost a lot of her useful sight. She does have light perception and can sometimes see colour, depending on the light conditions, but has no depth perception. She is completely night blind and remembers being very surprised when she discovered that there were stars in the sky, because she had never seen them!

She relies on assistive devices, whether that is her cane, screen readers or her mobile phone. She has also had a guide dog in the past but doesn't have one currently.



Her parents were in touch with RP Fighting Blindness, as Retina UK was known then, when Charlotte was younger and she ran the London Marathon for the charity in 2014 with her mum as her guide runner. She said “never again. It turns out I hate running.”

Charlotte signed up to be a Talk & Support volunteer with Retina UK in spring 2025. She said: “It felt like a nice fit. I like talking, I’m quite chatty and I’m quite open to talk about my experiences to help someone who may be struggling.



She went on to say “I didn’t know a lot of blind people like me when I was growing up. I had quite severe sight loss at a young age and the expectation at school was that I probably wasn’t going to go on to work and I would live on benefits. That’s not remotely what I’m doing. I think it’s quite important for the next generation of blind people to see someone who is still fairly young, managing to parent and in the highest form of education. You don’t have to be held back. There just needs to be adaptation.”

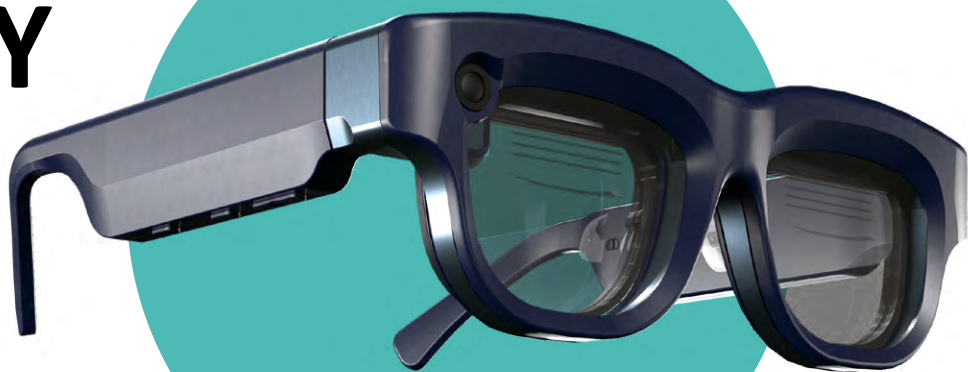
Talking about her volunteering experience, she said: “I feel very supported and I can ask if there is anything I am unsure about. The points of contact are quite clearly signposted so if I have a question, I can easily get in touch. You don’t have to have a huge amount of time. That’s the lovely thing about volunteering. It can be as much or as little as you want it to be. That kind of flexibility works for me.”

If you are interested in volunteering for Retina UK, please visit our website to find out more: **RetinaUK.org.uk/get-involved/volunteer-for-us/**.

“I’ve always done a lot of volunteering throughout my life. I was part of a local charity when I was a teenager and I was on a youth committee. A least once a year I go into my son’s school and do a blindness awareness assembly. I’ve always wanted to be quite active in the blind community. For me, awareness and understanding can’t ever be a bad thing.

TURN NIGHT INTO DAY

Luna.



See Clearly After Dark with Luna Glasses

Luna Glasses are an innovative solution for people with night blindness and related conditions. Using advanced near-eye display technology, Luna enhances vision in low-light settings - helping you move more safely and confidently after dark.



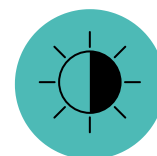
Prescription lenses

Luna is fully compatible with prescription lenses. These can be fitted by any optician.



Customisable fit

Like a regular pair of glasses, Luna can be customised for a comfortable fit, they are both stylish and lightweight.




Adjustable Brightness

Luna provides full control over brightness to suit a wide range of lighting conditions.



To find out more about Luna glasses please get in touch with our UK partner:

 0800 085 6055



info@sightandsound.co.uk



www.sightandsound.co.uk

Get behind us during our 50th anniversary year!

We are almost half-way through our 50th anniversary year and we still have so much more to come. As a new year approaches, can you get behind #TeamRetinaUK in 2026 and accelerate the search for treatments, whilst also providing our vital support services?



To make a generous one-off donation to Retina UK today, text ANNIVERSARY to 70560 to donate £10 (plus one standard network rate message) or please visit our website, RetinaUK.org.uk/appeal.

you will be invited to vote in our AGM, empowering you to have your say and shape the future of our charity. To find out more, visit RetinaUK.org.uk/membership.

Why not organise an event in your local community, school or workplace? From bake sales to non-uniform days, challenges to talent shows; however you choose to support us, we will be here every step of the way with advice and resources. Occasions like Christmas and Easter are a great time to fundraise.

Become a member

We are looking for more community members to join us as Retina UK members and receive regular updates on the difference you are making. In return for your £24 annual donation,

Play the Retina UK Lottery

Our Retina UK Lottery has created 35 winners so far and you could be next! Visit RetinaUK.org.uk/lottery to sign up and you could start 2026 with a bang with weekly prizes up to £25,000 for £1 a line! What would you spend your winnings on?

To have a chat with our friendly Fundraising team about your 2026 fundraising goals, please either call 01280 815900 or email fundraising@RetinaUK.org.uk. We would love to hear from you.

Every experience counts: Insights from our Sight Loss Survey 2025

A huge thank you to everyone who completed our 2025 sight loss survey. This year we received over 600 responses. It follows similar surveys in 2019 and 2022 which led directly to the introduction of our Unlock Genetics and Discover Wellbeing resources, as well as shaping our work with the professional community who support people with inherited sight loss.

The 2025 results provide a valuable insight into the continuing challenges faced by people living with inherited sight loss. They highlight where progress is most needed and help us shape Retina UK services and priorities so that we can respond effectively to current needs within our limited resources, recognising that it may not always be possible to meet everyone's expectations. As a relatively small team, we know that collaboration is essential and we join forces with others across the sector to strengthen our collective voice and where appropriate we will signpost to other sources of information and support. We also recognise the importance of reaching under-represented groups within our community and acknowledge that more work is needed in this area.

Genetics

Over four in 10 respondents (43%) said they have received a genetic diagnosis for their sight loss condition. A slight increase on 2022 (39%).

Since 2019 there has been a considerable increase in the proportion

of respondents who were able to name their specific genetic diagnosis with 29% of respondents in 2025 able to provide the name of a gene.

Quality of life

Half of respondents (43%) say their sight loss has a severe or very severe impact on their quality of life – slightly higher than in 2022.

People who'd had contact with Retina UK were far more likely to say they knew how to manage their sight loss and had support (76% compared with 61% of those not in contact).

Diagnosis

Experiences of receiving diagnosis appear to have returned to a positive upward trend, following a dip during the pandemic. The proportion offered emotional and psychological support at diagnosis is increasing. This is very encouraging.

Almost four in 10 (38%) of those diagnosed in the past five years were told about the support available from Retina UK, compared with a low of

oss Survey

18% for those diagnosed 5-10 years ago. We will continue our work to encourage referrals in the future.

Technology

Respondents use a wide range of aids, in particular, in-built accessibility features of smartphones and tablets, as well as flashlights and illumination devices.

When it came to the barriers for accessing aids 38% said cost is a significant cause and 25% reported they were not confident to use it.

Research

Retina UK remains the top source of research information. As with previous surveys, awareness of research is much higher among those who have engaged with Retina UK compared with those who haven't (49% compared with 28%).

There was a small increase in the proportion who said they had participated in research – 24%, compared with 20% in both 2022 and 2019.

Join the Retina UK Lived Experience Panel to hear about opportunities to take part in research-related activities. Visit RetinaUK.org.uk/lived-experience or call our office on 01280 821334.

Mental health

Anxiety (77%) and loss of confidence (73%) continue to be the biggest emotional or psychological impacts of sight loss, though more people reported anger than in 2022 (47%).

While half referred themselves for support, the proportion referred by a healthcare professional increased to 40% from 33% in 2022. Respondents reported shorter waiting times, with one in four receiving treatment within two weeks of referral.

Attitudes to Retina UK

Online search continues to be the main way recently diagnosed respondents find their way to Retina UK, though signposting from health professionals remains an important referral route.

Most agree Retina UK is approachable, trustworthy and ambitious on behalf of people with sight loss.

Retina UK's services and support were rated as 'good' or 'excellent' overall by 83% of respondents.

Regular newsletters, Website, Annual conference and Webinars all scored over 90% satisfaction.

The full report is available on the Retina UK website in PDF, plain text and audio formats: RetinaUK.org.uk/resource/sight-loss-survey.

Dates for your diary

Make a note in your diary and join one of our upcoming events.

Details of all of our events can be found on our website RetinaUK.org.uk/events.

NOVEMBER

Sahara Desert Trek (6-11 November)

QAC Sight Village: London (18-19 November)

BBC Lifeline appeal (16 November)

DECEMBER

Big Give Christmas Challenge 2025 (2-9 December)

FEBRUARY 2026

RP Awareness Month 2026

MARCH 2026

Spring Skydive Campaign

Sight Village Scotland, Glasgow (18 March)*

Paris Half Marathon (8 March)

APRIL 2026

Paris Marathon (12 April)

Adidas Manchester Marathon (19 April)

London Landmarks Half Marathon (12 April)

TCS London Marathon (26 April)

Milano City Marathon (12 April)

Virtual TCS London Marathon (26 April)

Sight Village South-West, Exeter (14 April)*

MAY 2026

5K A Day In May

Charity Day at Woburn Golf Club (27 May)

JUNE 2026

Sight Village North-East, Leeds (2 June)*

Retina UK Gala Dinner (6 June)

JULY 2026

Sight Village Central, Birmingham (7-8 July)*

Annual General Meeting (22 July) - tbc

SEPTEMBER 2026

Great North Run 2026 (13 September)

Retina UK Professionals' Conference
(18 September) - tbc

Retina UK Annual Conference (19 September)
– tbc

Sight Village North Wales, Llandudno
(22 September)*

OCTOBER 2026

Retina UK Day 2026 (8 October)

NOVEMBER 2026

Sight Village South-East (London) –
date and venue tbc*

Great Wall of China Trek (8-16 November)

Sahara Desert Trek 2026 (11-16 November)

DECEMBER 2026

Big Give Christmas Challenge
(1-8 December)

50th Anniversary Gala Dinner

To mark the end of our 50th Anniversary year, we will be holding a gala dinner on Saturday 6 June 2026 at the world-famous London Hilton on Park Lane.

The event will bring our community and supporters together, to make new connections and raise vital funds and awareness. We anticipate a glamorous and impactful evening with the inherited sight loss community at its heart.

With spectacular performances, unforgettable moments, exquisite food and an enviable guest list, our gala dinner is set to be an unmissable evening of fun and fundraising.

To find out more, please visit our website: **RetinaUK.org.uk/gala-dinner**.

All dates are subject to change. Please visit our website for up-to-date information:

- Peer support groups: **RetinaUK.org.uk/groups**
- Webinars: **RetinaUK.org.uk/webinars**
- Challenge events: **RetinaUK.org.uk/challenge**

*Retina UK has not yet confirmed our attendance at Sight Village.

Donate to Retina UK this winter

Phone donations

If you would like to make a donation via telephone, please call our team on 01280 815900.

Your generosity will enable us to accelerate the search for treatments, whilst also providing vital support services.

Text donations

A simple and quick 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.

Cheques

If you would like to donate by cheque, please complete the form (below) and return it to us at Freepost Retina UK.

Join the Retina UK Lottery

Be in with the chance of winning £25,000 every Friday - for just £1 a go.

35 supporters have won a cash prize so far and you could be next! Sign up today:

RetinaUK.org.uk/lottery.

£10 could pay for the primers required for the DNA analysis that detects disease causing mutations that result in RP.

£50 could pay for one hour of super resolution microscope imaging, allowing scientists to visualise how light sensing photoreceptors are damaged in RP.

£100 could pay for one PhD student for a day.

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.

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. If you no longer wish to receive Look Forward, please let us know by emailing info@RetinaUK.org.uk.