



LOOK FORWARD

ISSUE 185 SPRING 2025



Inside: We speak to Strictly star Chris McCausland about his success in the show and challenging himself (page 12-13).

This edition of Look Forward includes the very latest news about an experimental therapy by Retina UK funded researchers, an article about one of our PhD students (page 8-9), a calendar of events in 2025 (page 10-11), the usual research news round-up (page 14-15) and lots more. Please take the time to complete our Sight Loss Survey, enclosed with this edition. You can find out more about the Survey on page 3.

There are lots of ways you can support Retina UK in 2025, from volunteering (page 18-19) to corporate fundraising (page 4) or why not set yourself a challenge and take part in a walk, trek or run (page 16-17).



Tell us about you

A very warm welcome to this edition of Look Forward! I imagine, like me, you are looking forward to warmer weather and longer days.

This edition of Look Forward includes a copy of our 2025 Sight Loss Survey (page 3). It is so important that as many people as possible complete the survey, as it helps us tailor our work to what you want and need. Information from previous surveys has a huge impact on decision-making. Everyone's input is hugely valuable so please, please find the time to take part.

A special thank you to everyone who donated to the Big Give Christmas Challenge. Your very generous contributions resulted in a massive £65,290.

We will be marking our 50th Anniversary between June 2025 and June 2026 (page 5) so do please share your memories and messages with us.

This edition also includes an interview with Strictly Come Dancing winner, Chris McCausland. I know that many of you were cheering him on, so I do hope you find it interesting.

Finally, please 'save the date' for our Annual Conference in London on Saturday 20 September. More information will be available on our website very soon and we'll include details in the next edition of Look Forward, due out in June. In the meantime, register your interest at RetinaUK.org.uk/annual-conference.

Hang on in there – longer warmer days are on their way!



*Tina Garvey,
Chief Executive*

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.

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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You can influence positive change

This edition of **Look Forward** includes a copy of our latest **Sight Loss Survey** which takes place every three years.

We want to ensure our current and future activities are relevant and that they respond to your needs. The only way we can be confident of this is to ask about your experiences, views and what matters to you. Every response is important to us, but we are particularly keen to hear from a more diverse group, including young adults and those from a variety of ethnic backgrounds.

The information we gather through the Survey is powerful and can influence positive change. We have used it to develop new support services, raise funds for vital projects and even influence decision makers to make Luxturna, the first treatment for an inherited sight loss condition, available on the NHS. We want to hear from even more people in 2025, so if you have completed the Survey in the past, it is vital that you take part again, so that we can track changes.

Anyone living with inherited sight loss can complete the Survey. If they are under 18, it can be completed by a parent or guardian on their behalf.



We hope that you will also take the opportunity to tell us a little more about yourself so that we can contact you with information most relevant to you in the future. Those who wish to respond anonymously can of course do so.

You can either fill in a hard copy survey and return it in the Freepost envelope provided, complete it online by visiting **RetinaUK.org.uk/survey**, or call our office on 01280 821334 to book an appointment with a member of our team to complete the survey on your behalf over the telephone. The survey will take around 40 minutes to complete (longer if using assistive technology), so grab a cuppa.

The deadline for completed surveys is Friday 25 April 2025. If you have any questions, Vanessa Davis, Data and IT Manager, would be happy to answer them. She can be contacted at **vanessa.davis@RetinaUK.org.uk** or on 01280 821334.

A golden opportunity for your workplace

2025 marks an exciting milestone for Retina UK as we enter our 50th anniversary year. To help us to achieve our mission, could you or someone you know nominate Retina UK to a company or organisation for support?

By partnering with Retina UK, your workplace team can support a well respected and vital national charity. Your company could have a direct, tangible impact on the lives of people with inherited sight loss, and drive forward cutting-edge research that will move us closer to finding treatments. Your workplace can rally the team together for a life-changing cause and create a lasting positive legacy of support.

“The team at Retina UK are great. I have worked closely with them as an organisation for over five years supporting the inherited sight loss community. I have always found the team to be professional, fast responding, and informed.”

Andy Bolan, Sepul Bio

Find out more:

Contact Amelia Burton, our Grants and Partnerships Manager, who will be delighted to help you in your corporate fundraising journey: 07841 481423, amelia.burton@RetinaUK.org.uk.

Retina UK also offers meaningful and rewarding volunteering opportunities for companies, including at our conferences. Corporate fundraising is a great way to make a positive difference and raise awareness of Retina UK.

You can get involved by:

- Nominating Retina UK to be ‘charity of the year’ at your workplace.
- Asking if your company offers payroll giving.
- Hosting a fundraising event at work, like a bake sale, golf day, or coffee morning.
- Finding out if your employer offers match funding for any fundraising events you do.
- Seeing if your work might be interested in offering Retina UK *pro bono* support.
- Asking if your organisation might sponsor one of Retina UK’s exciting events, such as our Professionals’ and Annual Conferences.



Marking 50 years of Retina UK

We are marking our 50th anniversary between June 2025 and June 2026; a momentous milestone in the history of Retina UK.

We are 50 years on from the formation of the charity and whilst we have made significant progress, there is still a lot to do because we don't have a treatment or cure for the vast majority of inherited sight loss conditions.

We were founded by an incredible woman called Lynda Cantor MBE in 1975, following her diagnosis of retinitis pigmentosa (RP). She was driven by the impact of the condition on her life and frustration at the lack of knowledge and information that existed in those early days. The organisation she originally founded was called The British Retinitis Pigmentosa Society (BRPS) which became a registered charity in 1976. It was subsequently known as RP Fighting Blindness and became Retina UK in 2018.

We are one of only a few charities in the sight loss sector which funds medical research (more than £17 million since we were formed), as well as providing information and support so that people affected by inherited, progressive sight loss can live their best lives.

We have come a long way, but there is still a lot to do and we have ambitious plans for the future. We are facing the next 50 years with passion and

positivity and are committed to a future where people living with inherited sight loss no longer have to fear the progression of their condition.

Share your memories

We want to hear from you, our community. Whether you have a memory about the charity you'd be willing to share or if you'd like to say thank you to our volunteers or our staff team for support you have received, please tell us.

If you use a mobile phone, you can record an audio or video message and send it to us on WhatsApp **07719 967368**. Remember to start your recording with your name. If you prefer not to appear on camera, could you please share a photograph to accompany your message.

Alternatively, call our dedicated 50th Anniversary hotline on **01280 733190** where you'll be invited to record your voice message.

Terms & conditions

Please note that by recording your message, you give your consent for Retina UK to use the video / audio or a transcript of your message in promotional material in relation to the charity's 50th anniversary. This may be in podcasts, online and in social media. We may telephone you to confirm the spelling of your name or ask for more information. Please visit our Privacy Policy: [RetinaUK.org.uk/privacy-policy](https://www.retinauk.org/uk/privacy-policy) to find out more.



Experimental therapy by Retina UK-funded researchers leads to ‘life changing improvements’



Researchers who received funding from Retina UK have carried out experimental gene therapy that is reported to have led to ‘life changing improvements’ to sight for four children with inherited sight loss.

Doctors injected healthy copies of a defective gene into the back of the eye, very early in life, to treat a severe form of Leber congenital amaurosis (LCA4) caused by a mutation to a gene called AIPL1.

Before the therapy, the children were registered legally blind and were only able to distinguish between dark and light. After the infusion, all parents reported improvements - with some of their young children now able to begin to draw and write.

Scientists at University College London (UCL) Institute of Ophthalmology, who had received funding from Retina UK through the charity’s Gene Team project, developed the innovative procedure.

Professor Robin Ali led the Gene Team along with James Bainbridge and Michel Michaelides.

He said: “This is a significant step forward in our search for treatments which has been made possible, in part, thanks to Retina UK’s supporters who provided vital funds towards this innovative work through the charity’s Gene Team campaign in 2014.”

Healthy copies of the gene were injected into the retina at the back of the eye through keyhole surgery.

These copies are contained inside a harmless virus, which goes through the retinal cells and replaces the defective gene. The healthy, working genes then kick start a process which helps the cells at the back of the eye work better and survive longer.

Unlike traditional scientific trials, families were offered this experimental therapy under a special licence designed for compassionate use, when there are no other options readily



This work demonstrates the importance of UK clinical academic centre manufacturing facilities and UK Medicines and Healthcare products Regulatory Agency Manufacturer's 'Specials' Licences in making advanced therapies available to people with rare conditions."

available and when the condition is very rare.

Children had one eye treated each - a measure taken in case the treatment had any adverse effects.

According to doctors, the results of the tests they completed, alongside the parent's reports of their improvements, give "compelling evidence" that all four benefited from the treatment and were seeing more than would be expected with the normal course of the disease.

The team plans to monitor the children to see how long-lasting the results are.

Tina Garvey, Chief Executive at Retina UK, said the news was incredibly exciting.

"This hugely encouraging news will bring hope to all those living with inherited sight loss conditions and their wider families. The genetic and progressive nature of these conditions leave those affected living with the knowledge that they may eventually lose their vision but not knowing how

quickly changes will occur, causing anxiety, feelings of isolation and uncertainty about the future.

"We are proud to have provided funding to the team whose work led to this experimental gene therapy trial through our Gene Team fundraising campaign. This was only made possible thanks to the generosity of our charity's supporters.

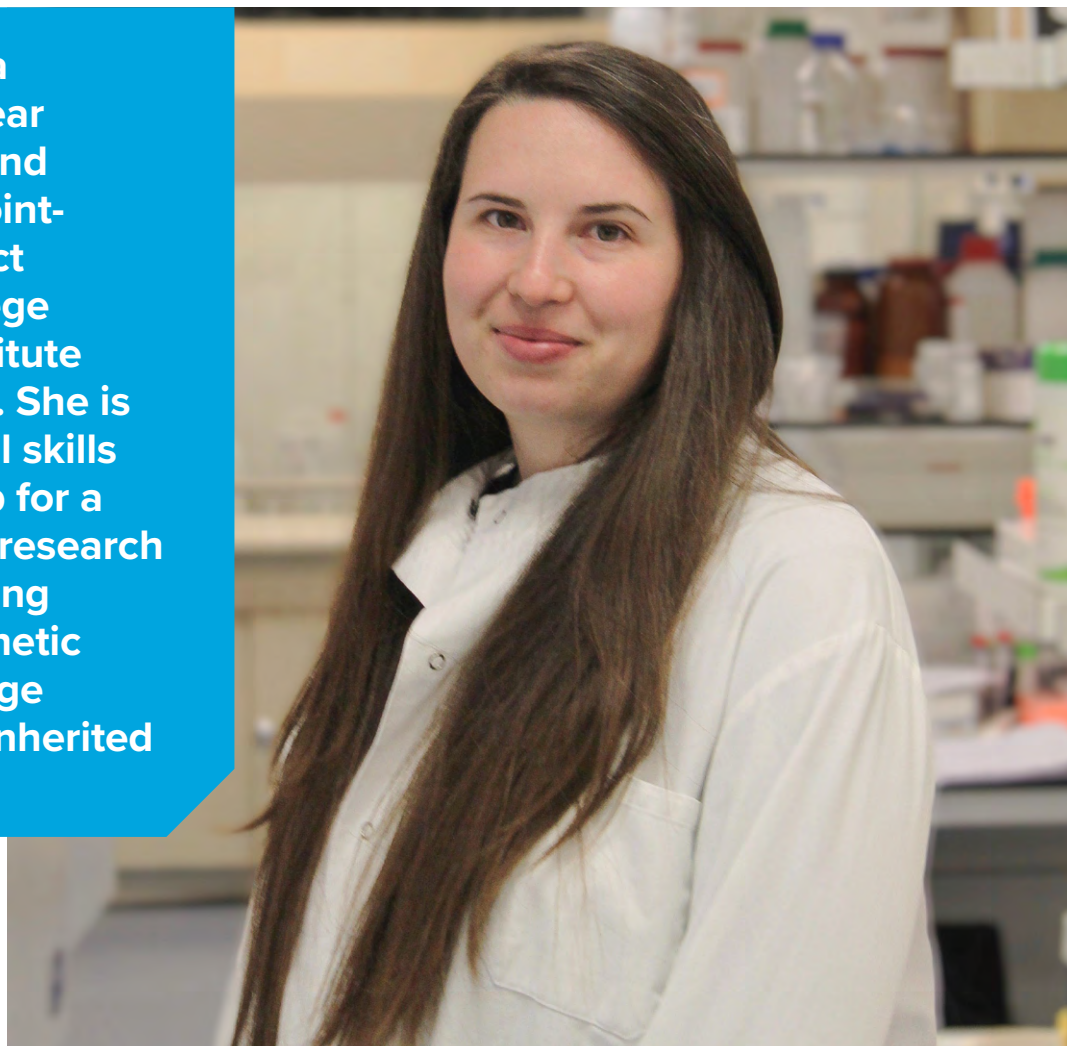
"While this trial brings great optimism, there is still much work to be done. At Retina UK we remain committed to supporting research into treatments until everyone who hears the devastating news that they have an inherited sight loss condition is also told a treatment is available."



Moorfields Hospital

A passion for genetic engineering

Gabriel Velichkova is in the second year of her Retina UK and Macular Society joint-funded PhD project at University College London (UCL) Institute of Ophthalmology. She is acquiring essential skills that will set her up for a future career as a research leader, while refining a cutting-edge genetic technique with huge potential to treat inherited retinal conditions.



“After gaining my MSci in genetics, I worked as a research technician, learning how to use a variety of techniques, including these amazing molecular scissors called CRISPR / Cas9 that allow us to snip out and correct specific bits of genetic code” Gabriel tells us. “This ignited my passion for genetic engineering, so I was really excited to undertake a PhD project focused on refining gene editing so that it might one day become a treatment with real impact for people with inherited sight loss.”

Gabriel is working on Stargardt disease, caused by faults in the ABCA4 gene that result in the accumulation of toxins in retinal cells and loss of central vision. One approach to treatment might be to provide healthy copies of ABCA4, so called ‘gene replacement therapy’, but this comes with a significant challenge.

“The problem we have is that ABCA4 is absolutely massive” Gabriel explains. “It won’t fit inside the harmless viruses typically used for delivering gene replacement therapies. Researchers

are looking at splitting it into smaller pieces for reassembly inside the retina, but as you can imagine, there are potential pitfalls.”

Gabriel is working with a relatively recent innovation called prime editing, which aims to permanently correct a genetic mutation, allowing the cell to produce healthy, functional protein from the corrected gene, thereby halting disease progression in the edited cells.

“A great advantage of the prime editing system is its precision” she says. “The original CRISPR / Cas9 approach involves breaking both strands of the DNA double helix, but there is a reasonably high risk of incorporating mistakes, or that bits of DNA will get lost. With prime editing, a guide molecule brings the prime editor to the exact DNA location you are targeting, snips just one of the strands, and then provides the template for correction of the DNA error. That limits the potential for mistakes at the target location. Another advantage of prime editing systems is that they can work in adult cells that have stopped dividing, like cells in the brain or retina.”

The aim of the project is to find the most efficient version of the prime editor, which will be tested in the laboratory in a disease relevant model: living, miniature models of the human retina called retinal organoids, which

can be grown in the lab from cells derived directly from a patient.

Retinal organoids are small 3D structures that have all the cell types found in a human retina and that need to be handled with a lot of care. “A fully developed retinal organoid takes at least 220 days to develop; often they are grown for longer!” Gabriel tells us. “In addition, there are a huge number of technically demanding experiments to run because multiple different combinations need to be tested to maximise the efficiency of the correction. There are plenty of challenges along the way.”

But Gabriel is driven to make a difference for those living with inherited sight loss. “As a child, I would sometimes close my eyes and imagine what life would be like without the ability to see. It was so scary, but then I could just open my eyes again. There are so many people who don’t have that option, and we need to put all the effort we can into supporting people and working towards disease prevention and treatments.”

Retina UK is able to fund projects like Gabriel’s thanks to the generosity of our supporters. You can find out more about ways to support Retina UK on page 22-23.

Dates for your diary

We have a packed year of events lined up, including the start of our 50th Anniversary year in June (page 5).

Details of all of our events can be found on our website RetinaUK.org.uk/events. You can also call our office for more information 01280 821334.

MARCH

'Talking' Tech peer support group (19 March)

Webinar: Genetic testing – what can I expect? (20 March)

National peer support group spring meeting (25 March)

South Yorkshire local peer support group (26 March)

Cambridgeshire local peer support group LAUNCH (27 March)

Edinburgh local peer support group (29 March)

APRIL

'Talking' Home & Garden peer support group LAUNCH (2 April)

Tyne & Wear local peer support group in collaboration with Northern Alliance VIPs (5 April)

Young adults peer support spring social (7 April)

QAC Sight Village: Wales (8 April)

Webinar: Miles for vision – behind the scenes at the London Marathon 2025 (17 April)

TCS London Marathon (27 April)

MAY

5K a day in May 2025

South Yorkshire local peer support group (3 May)

Men's peer support group (6 May)

Women's peer support group (8 May)

'Talking' Tech peer support group (13 May)

Cambridgeshire local peer support group (15 May)

QAC Sight Village: Scotland (21 May)

London & South East local peer support group (23 May)

'Talking' Creative Arts peer support group (29 May)

JUNE

50th Anniversary events start

Look Forward summer 2025 edition

National peer support group summer meeting (26 June)

JULY

Jump in July 2025

Retina UK summer raffle (1 July)

Women's peer support group (3 July)

QAC Sight Village: Central – Eastside rooms
Birmingham (7 July)

Men's peer support group (9 July)

Retina UK AGM (30 July) - Online

SEPTEMBER

Look Forward autumn 2025 edition

Great North Run (7 September)

QAC Sight Village: Blackpool (16 September)

Retina UK Professionals' Conference
(19 September) - London

Retina UK Annual Conference (20 September)
– London

Raffle draw (20 September) - London

National peer support group autumn meeting
(25 September)

OCTOBER

Retina UK Day 2025 (9 October)

NOVEMBER

Look Forward winter 2025 edition

Sahara Desert Trek 2025 (6 – 11 November)

QAC Sight Village: London (11 November)

Women's peer support group (13 November)

'Talking' Tech peer support group
(19 November)

Men's peer support group (26 November)

DECEMBER

Big Give Christmas Challenge 2025 (2 – 9 December)

Dates are subject to change. Please check 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

With opportunity, support and determination, anything can happen

If, like us, you cheered on Chris McCausland and Dianne Buswell in *Strictly Come Dancing* at the end of 2024 then read on! Chris recently took a short break from his very busy schedule to talk to Retina UK about his *Strictly* journey, living with sight loss and what's next.

Inherited sight loss runs in Chris's family on his mother's side. He doesn't remember his grandmother being able to see and his mum lost her sight later in life. He lost his central vision before his peripheral vision and whilst he can tell if it's a sunny day, Chris is no longer able to see anything else.

Despite taking part in the 100,000 Genomes Project, the family's causative gene has not been identified. Chris has been told at various appointments that he has macular degeneration, retinitis pigmentosa, cone-rod dystrophy and reverse cone-rod dystrophy.

He is optimistic about stem cell research, which would not require a genetic diagnosis. Asked whether he'd go ahead with having a treatment if it could restore his sight, he said "I can't speak for people who are born blind because I think you're a completely different animal, because you've never known any different. If you were able to restore your sight back to the point where you had mobility and independence, then yes. It'd have to be enough to really make a difference,



because those years of losing your sight are difficult and it actually becomes easier when you can't see."

Chris is a big fan of Apple technology and has used it for the past 15 years. He does have a symbol cane but says he doesn't use it often because he doesn't tend to travel independently.

Chris describes Strictly as "100% the thing he is most proud of". But says it could have been a disaster.

me', that's inspiring people. I don't think that means you're inspirational. It's nice to rub off on people in some way. For me, disability and blindness doesn't come into that. It's very easy to write people off. It's very easy to underestimate what is possible. To think that we can't do the simple things and certainly can't do the complicated things. So really it was about saying 'give people professional opportunities in the workplace', because we are more valuable and more capable than you might think.

"Strictly took a hell of a lot of work. It was the hardest thing I've ever done. We put the hours in. It was consuming in all ways, emotionally, mentally, physically. "



"I think part of the message that we sent out on Strictly was that more is possible than people might think. Sometimes, as a person with a disability, you can have low expectations of yourself. I wasn't on Strictly to inspire blind people. Everyone can do with being inspired."

"People have always done something in their life that they probably don't think they could do, or that's out of their reach. Anybody, who watched me on Strictly and says 'I'm going to try something that scares

Never one to rest on his laurels Chris is currently writing a book whilst he's on tour which is due out in October. He is also doing a Podcast "Winning isn't everything" with Dianne Buswell. His tour 'Yonks' continues throughout 2025 and into 2026 all over the country.

We wish him every success.

Research round-up

SB-007, we've been expecting you!

In December 2024, Splice Bio announced that the US Food & Drug Administration (FDA) had authorised treatment SB-007's progression to phase 1/2 clinical trial, passing the investigative new drug stage. This clinical trial, known as ASTRA, will begin enrolment in early 2025 and aims to evaluate the safety and efficacy of SB-007, a revolutionary protein splicing therapy looking to “transform the lives of Stargardt disease patients”.

SB-007 is a type of adeno-associated viral vector (AAV) gene therapy. Most gene therapies for IRDs work on the premise of delivering an entire new gene to replace the mutated one. However, the whole ABCA4 gene is too large to deliver in one viral vector. Splice Bio look to overcome this problem by delivering the ABCA4 gene in two halves, using dual viral vectors, through a one-time injection into the eye. Once in the cells, each half of the gene will make half of the desired protein. SB-007 then uses a process known as protein splicing to bond each half of the protein together to make it functional.

Progress in Charles Bonnet Syndrome (CBS) research

We recently received an update on the latest research into Charles Bonnet Syndrome from Dr Jasleen Jolly as part of a Retina UK podcast about visual hallucinations.

Jasleen reported that a measurable brain signal for CBS has now been identified. This clear physiological sign will support the education of the wider healthcare community to ensure that CBS is taken more seriously.

Now that a target has been identified in the brain, there might be an opportunity to develop therapies in the future. However, Jasleen stressed that social interaction does help to reduce hallucinations. She also suggested increasing the lighting level or reaching out to touch the hallucination as ways to stop them.

Jasleen encourages the Retina UK community to take part in CBS research studies, if invited, to help her and other scientists to demonstrate accurate prevalence rates and understand more about CBS.

To listen to the full podcast, head to RetinaUK.org.uk/resources or search Retina UK on Spotify, Apple Podcasts and more.

Mirugen – unlocking the power of retina regeneration

Mirugen hope to develop a treatment viable for a variety of conditions where vision loss is caused by faulty light sensing photoreceptors in the back of the eye. This broad approach looks to provide hope to those with conditions such as retinitis pigmentosa and Stargardt disease.

Mirugen are working to unlock a regenerative ability, normally only seen in animals such as chicken and fish, by injecting reprogramming genes into the eye. This may prevent and reverse photoreceptor damage.

The treatment has not yet reached human clinical trials, but Mirugen report promising results from preclinical and animal studies.

Sepul Bio begins clinical trial of ultevursen for USH2A-associated RP

Sepul Bio has shared the exciting news that its phase 2b clinical trial of ultevursen for USH2A-associated retinitis pigmentosa (RP) has got underway, with the first participant receiving treatment in the USA. Trial sites are expected to open in the UK in the coming months.

The new clinical trial, known as LUNA, will enrol 81 adults and children over the age of eight years across sites around the globe.

Ultevursen will only work for those individuals whose condition is caused by mutations in exon 13 of the USH2A gene. This can be confirmed by a genetic test.

Potential drug targets identified for RP

A recent study revealed shared disease mechanisms in inherited sight loss, suggesting potential drug treatments that could be effective across different genetic causes.

The research team discovered that two RP models displayed a huge number of commonalities, suggesting various critical pathways that could be targeted by drugs in order to slow or stop disease progression, regardless of the underlying genetic mutation.

The researchers caution that the mouse models have limitations and that lots of further work is needed, but some of their findings are supported by results from other studies.

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.

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.



From bake sales to challenges – get involved in 2025!

Easter is almost here and spring and summer are finally on the way! There are lots of opportunities for you, or someone you know, to take on a challenge or organise your own fundraiser for Retina UK!

Our website has been updated with a wide range of events to choose from and we always love hearing your own ideas too.

To chat with our friendly Fundraising team, please email **fundraising@RetinaUK.org.uk** or call 01280 815900. These are some of the ways you can support Retina UK in 2025.

Run locally

Are you a keen runner? Thanks to our partnership with Run For Charity, we have access to thousands of places in races across the UK and beyond. From local 5Ks and 10Ks to marathons home and away, you can join #TeamRetinaUK in all corners of the UK! Visit our website to choose your race today, including the Great North Run, where we are assembling our 50th anniversary team.

Hikes & treks

Could you and a team of family members, friends or colleagues take on a hike or trek in the UK this summer? With events in Scotland, Wales and England, including iconic routes such as Snowdon, Ben Nevis and the

Yorkshire Three Peaks, there's lots to choose from. Turn your miles into pounds and support our vital cause this year!

The Big Half

London's The Big Half is back for another year on 7 September 2025 and you could be there with #TeamRetinaUK! The 13.1-mile course takes runners from Tower Bridge to the Cutty Sark in Greenwich and you will receive not only an official medal, but an exclusive New Balance t-shirt too.

Tough Mudder

Are assault courses your thing? Could you or someone you know take on a Tough Mudder for Retina UK? With events taking place in Scotland, the Midlands, Yorkshire and London, this lively day out really puts the fun in fundraising! Events are taking place in May, June, July, August and September so it's a great way to bring a group together over the summer.





Extreme challenges

If you are a daredevil, could you take on a skydive or a wing walk for Retina UK this year? With our skydives, you will be strapped to your expert instructor and you'll exit the aircraft at 10,000ft, freefalling at speeds of up to 120mph! Then at 5,000ft, your parachute will open and the high-octane thrill of the freefall will become more relaxed and inspiring. You'll slowly descend to the ground, landing back at the airfield with a huge smile on your face, knowing you've completed an incredible challenge for Retina UK. Tick off a bucket list goal in 2025!

Retina UK shop

Have you visited our online shop recently? We are always adding new shop items, including watches, caps, mugs, recipe books, notebooks, pens and so much more. We also stock cards and e-cards for every occasion, so you can support Retina UK whilst also celebrating your loved one's special day. Browse our shop: RetinaUK.org.uk/shop.

Easter bake sales

Easter is coming and you could make the most of the occasion by organising

a bake sale in your local community or workplace. Stock up on some mini eggs and enjoy some relaxing baking time in the kitchen and give back to Retina UK at the same time. Get in touch to find out how we can help you decorate and promote your bake sale.

Birthday fundraising

With your upcoming birthday, you could organise a Facebook fundraiser so your loved ones and followers can contribute to Retina UK whilst sending you their best wishes. If you need some help setting one up, our Fundraising team would be happy to assist.

Complete a Gift Aid declaration

Did you know that for every £1 you donate to Retina UK, we can claim back 25p at no extra cost to you? By completing our short Gift Aid declaration form, your donations can go even further in 2025 and we can claim previous donations (within the last four years) and any future donations you may make. The short form can be found here: RetinaUK.org.uk/gift-aid.

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Finding a place to thrive



Ryan is living with rod-cone dystrophy. He was diagnosed at age seven and has a family history of inherited sight loss. He was a keen footballer in his early teens and was Head Boy at his High School with excellent academic results. He did start a university degree in Philosophy at the University of Glasgow but chose not to continue after four months.

Ryan joined the 'Lets Get Employed' trainee programme at Lochvale House in July 2024 aspiring for better opportunities than his previous role working in a factory. He said "When my registration changed from partially sighted to legally blind I knew I had to find somewhere that could help me thrive and give me the tools to reach my potential." He was appointed as a Lochvale Mentor in October 2024.



Ryan said: “Being given this job has really shown that working towards a goal and being surrounded by people who care about you achieving it fills you with self-belief and confidence. If I hadn’t found the programme, I am not sure where I would now be mentally. Structure and routine has allowed me to develop faster. It also gave me hope and belief that I could become successful despite me becoming registered blind.”

“I live in a fairly isolated location and hadn’t really spoken to anyone else with my condition before. Following a conversation with Mark, I really feel that I’ve now found my people. By volunteering for the charity, I can support other young people and show them that sight loss is not a barrier to success.”

Ryan first got involved with Retina UK in 2024 and is now an active member of the Young Adults peer support group. The group share tips, hints and information on subjects like further education, employment, leaving home and first-time buying as well as connecting you with others and forming long term friendships.



In recognition of the skills he has developed at Lochvale and the support he received from Retina UK, he has now become a volunteer on the Retina UK Talk & Support service providing the opportunity for a regular catch up with another young person.

Details of our Young Adults peer support group can be found on our website: [RetinaUK.org.uk/groups](https://www.RetinaUK.org.uk/groups). For more information about our Helpline and Talk & Support services, please visit [RetinaUK.org.uk/information-and-support](https://www.RetinaUK.org.uk/information-and-support).

The Talk & Support service links people who may be feeling isolated or lonely with a trained volunteer for regular contact. This service offers a social link on a more personal and longer-term basis than the Retina UK Helpline, with regular calls being made by the volunteers for as long as they are welcomed.

We have a wide range of volunteer roles available at Retina UK, including recording our newsletter, packing bags for our events, facilitating our local peer support group meetings and more. If you would like to find out more, please email Sadia on volunteering@RetinaUK.org.uk or call her on 07856 907463.

THANK YOU

#TeamRetinaUK

We rely on generous donations and funding from our community and our grants and corporate sponsors. Because of you, we are able to continue funding ground-breaking research projects and vital support services. Through our Thanks To You pages, we want to shine a spotlight on some of our recent fantastic supporters!

February was Retinitis Pigmentosa Awareness Month and lots of our supporters shared their stories, made a donation and organised a fundraiser – thank you! It's not too late to support the campaign. You can donate £10 by texting RPTEN to 70560. Texts will cost your donation plus one standard network rate message.



Leon Richardson chose to support Retina UK as one of his charities at a boxing match in South Yorkshire. He raised **£70** for us and won his fight! Go Leon!



We'd like to send our best wishes to our biggest ever team of runners at this year's TCS London Marathon, which is taking place on 27 April. #TeamRetinaUK have been training and fundraising for months now and the finish line is almost in sight. Thank you for the difference you are already making!

Back in December, our Gene Team Christmas Appeal saw us ask you, our community, to join forces with Retina UK to help fund our exceptional Gene Team of scientists around the UK who are working hard on finding treatments for inherited sight loss. We'd like to say a huge, heartfelt thank you to everyone who gave generous gifts to support our upcoming research projects.

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



Long-term supporters, The Voice Academy, organised two Christmas charity concerts in Sheffield in December and raised **£1,575** for Retina UK. They also kindly invited us to speak at their event so we can continue raising awareness as well as funds.

A thank you to the Garfield Weston Foundation who have awarded us a grant towards our vital support services, helping us ensure that no one with inherited sight loss need feel alone.

Thank you to D'Oyly Carte Charitable Trust for kindly supporting our Helpline. It means that we can provide important emotional support and practical advice to people reaching out to Retina UK when they need us most.

Our annual Big Give Christmas Challenge in December saw us raise a staggering **£65,290** for our research projects! A huge thank you for doubling your donation and impact through our annual match funding campaign. Save the date for our 2025 campaign: 2-9 December.



In Essex, our long-term supporters, Bodkins Haberdashery, organised several in-store fundraisers. They recently donated **£500** from their latest fabulous activities.



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.

Help us raise awareness and vital funds in 2025

As 2025 gets underway, we would love you to get involved and help us to raise vital awareness and funds for our work. We always love hearing your ideas on giving back, so please reach out to our Fundraising team on **fundraising@RetinaUK.org.uk** or call 01280 815900 to have a chat. The following are a handful of ways you can give back to Retina UK.

Make a single or monthly donation

As well as generously making a one-off donation to Retina UK via text, telephone, cheque, bank transfer or on our website, you can also set up a monthly direct debit donation. Don't forget to consent to Gift Aid to make it go even further. Visit **RetinaUK.org.uk/donate**.

Play the Retina UK Lottery

18 lucky Retina UK supporters have won a cash prize so far and you could be our next winner by signing up to play today! It

costs just £1 per line each week to be in with a chance of winning cash prizes, including the weekly jackpot of £25,000. One



of our recent winners commented: *“The more money that gets ploughed into research, the more hope there is. I would definitely recommend signing*

up today.” Play now: **RetinaUK.org.uk/lottery**.

Organise your own fundraiser

Is 2025 the year that you decide to organise a fundraising event for Retina UK? Quiz nights, concerts, bake sales, football tournaments and non-uniform days are just a handful of ways that you can bring your community together, whilst having fun and contributing to our cause! Contact us to chat through your ideas.



Become a Retina UK member

This year, we are looking for new individuals to become members of Retina UK. Anyone is welcome to join; whether you are living with a sight loss condition yourself, related to somebody who is, or if you are working as a sight loss professional. Membership is just £24 per year and this fee goes directly to supporting and maintaining our vital medical research projects and

extensive support services. Find out more: RetinaUK.org.uk/membership.

Display a collection tin

Collection tins are a great way to not only raise funds, but also to raise awareness in your local community. Whether you are a business owner

yourself, or know someone who runs a local salon, shop, pub, restaurant or other venue, we would love your support in distributing our remaining collection tins all over the UK. Contact our Fundraising team to order your free collection tin today or visit RetinaUK.org.uk/collection-tin.

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.

£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.

Cheques

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

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.



HOLIDAYS FOR BLIND AND PARTIALLY SIGHTED

ACCESSIBLE TAILORED AND GROUP HOLIDAYS FOR THE VISUALLY IMPAIRED COMMUNITY



Discover the world with Seable Holidays, a UK-based award winning social enterprise for the blind and partially sighted. Seable's mission is to provide accessible, tailored and group holidays for the visually impaired community, with inclusive trips that can improve your well-being with our trained local sighted guides and tailored activities to suit your needs.

EXPLORE OUR INCREDIBLE HOLIDAY OPTIONS

Group Holidays: Journey to incredible destinations such as Ecuador & Galapagos Islands, Rome, and Skiing in northern Italy with fellow VI travellers in a safe, accessible environment. Perfect for making new friends and exploring new cultures! With set dates, prices and itineraries, all you have to do is sign up and join.

Tailored Holidays: Craft your dream trip with us! We'll handle all the details, whether you want to indulge in Sicily's culinary delights, kayak in Lanzarote, or feed elephants in Thailand; this option caters to your unique preferences and is ideal for solo travellers, couples, or friends. It's your holiday designed how you want when you want.

WHY SEABLE IS SPECIAL

Our trained local sighted guides: From the moment you arrive at the destination to the moment you depart, our highly trained Seable local sighted guides will support you and your companions to ensure a stress-free holiday.

Putting You First: Engage in unique activities such as tactile museum tours, accessible sports, and food and wine-tasting sessions designed explicitly for VI travellers. The VI community has tried and tested each activity and excursion, ensuring they are accessible and will leave you smiling.

Receive an Alexa with every 2025 holiday booking: T&Cs apply.

Ready for an unforgettable journey? Visit www.seable.co.uk, call us on 020 3375 6947, or email lucy@seable.co.uk to secure your next adventure.



2025 GROUP HOLIDAYS AVAILABLE

Scottish Highlands 7-11 April

Lanzarote Relaxing 23-28 April

Bologna 8-11 May

Berlin 29 May - 2 June

Edinburgh 11-15 July

London 23-28 July

Cambodia & Vietnam 14-30 Aug

Sicily 2-7 Oct

Disneyland Paris 3-7 Nov

Ecuador & Galapagos 13-30 Nov

And more destinations to be released soon.

