



# LOOK FORWARD

ISSUE 184 WINTER 2024



Our incredible  
volunteers at  
our Annual  
Conference 2024.

Welcome to the winter edition of Look Forward. It's packed full of news from our Conferences (pages 3-5), the latest research news (pages 14-15) and an interview with Hassina Zeriri, one of our funded PhD students (pages 8-9).

We have also included details of lots of ways you can get involved with Retina UK over the coming months, along with some suggested festive fundraising for the Christmas period.

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



RetinaUKcharity



RetinaUK



Retina\_UK

## A landmark anniversary on the horizon

Many of you will know that Retina UK (The British Retinitis Pigmentosa Society as it was then) became a registered charity on 6 June 1976. In recognition of this landmark 50th anniversary, we will embark on a series of events to mark this milestone. More information will be included in the spring 2025 edition of Look Forward.

This edition includes an article about our Christmas appeal (pages 6-7) which will help us to fund the search for treatments quicker, so please consider supporting us. To increase the value of your gift, The Big Give Christmas Challenge offers you the opportunity to double your donation from 3 – 10 December. Find out more on page 7.

I hope you found our Conferences uplifting and inspiring. I thoroughly enjoyed meeting so many of

our community, supporters and collaborators. You can read a full round-up on pages 3-5.

We rely on your input and we will be repeating our successful sight loss survey in the spring of 2025. I urge you to take part, give your opinion – we really do listen and frame our work to what you, our community wants and needs. Find out more on page 19. This really is your chance to influence the future direction of our charity.

As always, if you have any questions or suggestions, please email me on [chiefexec@RetinaUK.org.uk](mailto:chiefexec@RetinaUK.org.uk) or call our office on 01280 821334.



*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](mailto:info@RetinaUK.org.uk).

**Johnson & Johnson**

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**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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## Time for learning and connecting



**Our Professionals' and Annual Conferences headed north to Manchester in September and what a welcome we received! Our Conferences are the highlight of the year and provide a fantastic opportunity to get together in person and chat with others living with similar conditions. We hope that you enjoyed the day and that you learned something new.**

Our speakers covered some of the important work taking place within the sector and the value of connecting with others. They included Helen Doyle, Strategic Engagement Manager, RNIB, who introduced the new Eye Care Support Pathway, with a focus on how it can guide and inform people living with inherited sight loss (and their families).



*“Honestly, I had such an amazing time at the conference. It was extremely informative, I got talking to lots of people and found out some great information.”*

We also heard from our lived experience panel who spoke candidly about their experiences of peer-to-peer support and the difference it had made to their lives.

Our PhD students, Chloe, Hassina and Gabriel talked passionately about their individual projects and their hopes for the outcomes. Read more about Hassina and her project on pages 8-9.

Some of our community will have heard Professor Graeme Black speak at our events in the past but for many this was the first time. He provided us with a broad overview of the latest progress in research which was followed by our ever popular Q&A session. We had so many questions it was impossible to answer them all but we did cover as many as time permitted.

We would like to thank all of our delegates and speakers for joining us in Manchester. We're already planning 2025 and we hope to see you then.

*“It was an excellent day. Really interesting and inspiring. All the topics covered were so relevant and I could really identify with the experiences of a number of the speakers. It’s great to hear about the progress of research, especially when I’ve had a condition for many years. I can see how valuable the peer support groups are, having just recently joined one.”*

The recordings for both days are available on our website **RetinaUK.org.uk/resources** in both video and audio only formats. We can also send it on CD or memory stick, just let the office know.

We have received some really positive feedback so far. If you did attend and you haven't submitted your feedback form, it's not too late. These insights really do shape our events so make sure you tell us what you think.

**RetinaUK.org.uk/feedback-annual-conf24** or **RetinaUK.org.uk/feedback-prof-conf24**.

*“This was the first event I have attended about sight loss since I started losing my sight. I came on my own and it was very daunting. I have nothing but praise and thanks for all the staff and volunteers who made the conference happen. I was met at the station and made to feel so welcome and comfortable and was looked after all day. I can’t thank you all enough. I have hopefully made some good contacts and now have the confidence to join in other events. It was a very emotional day for me, meeting other people with sight loss for the first time. I don’t feel so alone now. It has also given me the confidence to apply for a guide dog. Honestly, attending was the best thing I could have done. Thank you all.”*



*“The lived experiences were very powerful in showing how much support is required and how important it is for people to be able to make informed choices and take control of their lives.”*

### Supporting our professional colleagues

We welcomed a huge number of professionals to our CPD accredited Conference on Friday and we’ve already seen an increase in the number of referrals made to Retina UK.

Our new dedicated professionals area of our website is now available **[RetinaUK.org.uk/for-professionals](https://RetinaUK.org.uk/for-professionals)**. It includes an overview of the services available from Retina UK, condition

specific leaflets, a referral form and details of how to order hard copies of our printed materials.

We have ambitious plans to work more closely with our professional colleagues in 2025. Our team have delivered sessions about Retina UK to ECLOs and Rehabilitation specialists in the past few months. To chat about the options available to speak at your event, please email **[services@RetinaUK.org.uk](mailto:services@RetinaUK.org.uk)**.



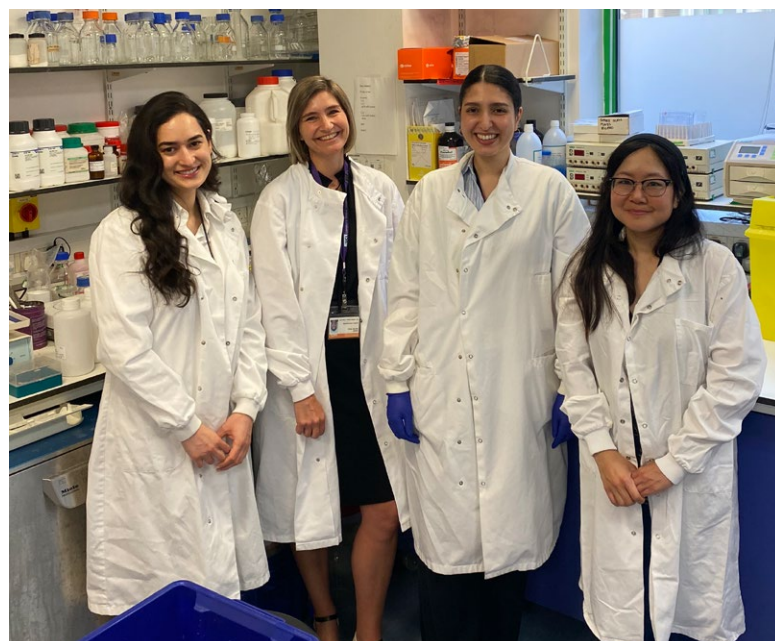
*Thank you to our headline sponsor, Johnson & Johnson. Johnson & Johnson provided part funding for the Retina UK conferences, but had no influence or involvement in the content, design or its development.*

## Join our Gene Team this Christmas

This Christmas, join our Gene Team and help us to raise vital funds for ground-breaking medical research. Together, we can foster hope for a happier tomorrow for the thousands of people across the UK living with inherited sight loss. **Donate today to support our team of exceptional scientists who are leading important translational medical research.**

Current funding includes innovative projects in areas such as gene therapy and photoreceptor stem cell patches, at institutions like University College London (UCL), Kings College, Edinburgh University and Newcastle University. With your support this winter, we can increase the momentum of this important research.

We have achieved so much together over the past 50 years, but we need

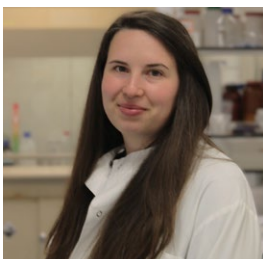


your help. Your donation will drive transformational research and give hope to people living with inherited sight loss, now and in the future.

These examples highlight our current projects and the impact they are making.



Professor Jane Sowden, University College London (UCL) Great Ormond Street Institute of Child Health, is tackling the challenge of restoring some vision at the later stages of sight loss. At advanced stages of RP and other inherited retinal conditions, most of the light sensitive cells (photoreceptors) across the retina have died. A potential route to restoring vision is to generate new photoreceptors from stem cells and place these at the back of the eye.



Gabriel, a PhD student under the supervision of Professor Van der Spuy, UCL Institute of Ophthalmology, is exploring the novel use of prime editing as a potential route to treating Stargardt disease.



### Angie's Story

"I was diagnosed with retinitis pigmentosa 24 years ago, just after the birth of my beautiful daughter. Retina UK recognises the importance of research in overcoming inherited sight loss and stories like mine inspire them to invest in research. Your support will help to contribute towards medical advancements that have the potential to transform lives."



To support the appeal, please visit [RetinaUK.org.uk/gene-team](https://RetinaUK.org.uk/gene-team) or call our friendly team on 01280 815900. You can also double your impact by making your donation via The Big Give Christmas Challenge.

### How your gift could help

- **£25** could fund one hour of medical research by a principal investigator.
- **£50** can buy 16 sequencing vouchers, required for investigating the human genetic code.
- **£100** buys a bottle of medium that can be used to grow "mini retinas" for RP research.
- **£500** buys a bulk RNA sequencing experiment that allows us to measure the activity of thousands of genes at the same time.

## The Big Give Christmas Challenge

If you would like to **double your donation\*** and **double your impact**, why not give online through the Big Give from midday 3 December to midday on 10 December. We've enclosed a postcard with this edition of Look Forward so pop it on your fridge and get involved when the appeal kicks off at midday on Tuesday 3 December.

Our community have helped us to raise more than £250,000 since 2017 through The Big Give. This year, with your help, we're aiming to raise an additional £60,000.

Find out more at [RetinaUK.org.uk/big-give](https://RetinaUK.org.uk/big-give).

\*whilst the match funding pot lasts.

## A unique perspective

It's not very often that we come across a researcher working on a project inspired by their own lived experience of a sight loss condition.

Hassina Zeriri holds qualifications in pharmacy and pharmacology and started her career in genetics research laboratories. Nearly ten years ago, she was diagnosed with Stargardt disease, an inherited retinal condition that is principally associated with loss of central vision. However, Hassina experienced a disturbing additional symptom: seeing bright flashes of light that weren't really there, a phenomenon known as photopsia.



“The flashes could be really scary” Hassina tells us. “The sudden appearance of a glowing shape that obstructed my field of vision was so alarming.”

Her ophthalmologist dismissed the photopsia as having nothing to do with Stargardt disease. “That was so frustrating, and just added to my anxiety. I couldn't help but start wondering if this symptom was actually a sign of a different issue affecting the eye or brain” she said.

Hassina's professional interest and personal experience had drawn her towards eye research. Whilst working as a research assistant at the Visual Perception and Repair Lab at UCL's

Institute of Ophthalmology, she shared her experience of photopsia, describing just how frightening it could be.

Her colleagues were incredibly supportive and encouraged an investigation. They joined forces with Professor Omar Mahroo, consultant retinal specialist at Moorfields Eye Hospital, to conduct a pilot study to find out whether photopsia in Stargardt disease was a more widespread problem.

“With the help of Stargardt's Connected, we sent out a survey to people living with the condition” Hassina explains. “More than 90% of



participants confirmed that they were experiencing photopsia, and many gave moving testimonies about how relieved they were that this symptom was finally being considered and taken seriously.”

And so, a more in depth research proposal was born! This will now form Hassina’s PhD studentship project, funded by Retina UK and the Macular Society and supervised by Professor Mahroo and Dr Matteo Rizzi.

“I will conduct wider surveys to confirm the proportion of those living with Stargardt’s who experience photopsia and another debilitating symptom called photophobia, an extreme over-sensitivity to light” Hassina explains. “The questionnaires will gauge the extent to which these symptoms impact vision and daily life. I will then look at participants’ medical records to see if there are correlations with disease progression and other clinical and genetic factors. We will be investigating the mechanisms behind the symptoms too: a better understanding of this could suggest approaches for symptom management and even the underlying disease.”

A project like this couldn’t happen without the generous contribution of those living with sight loss. “It’s so important for people to share their experiences with researchers through participation in studies” Hassina said.

“Clinicians and researchers need an in-depth understanding of what people are going through at every stage of the condition.”



*“It can sometimes be emotionally challenging being connected to the disease I’m working on, including anxiety for the future. However, the benefits are significant; I have a personal motivation to find answers, I can bring a unique personal perspective, and I feel empowered knowing that my work could help others like me. This first formal characterisation of photopsia and photophobia will be interesting in its own right, but recognition of these symptoms by clinicians will provide validation for their patients and support communication on what to expect as the condition progresses.”*

Hassina will primarily be recruiting Moorfields Stargardt’s patients and those registered with Research Opportunities at Moorfields (ROAM) ([research.moorfields.nhs.uk](https://research.moorfields.nhs.uk)). If you are living with Stargardt’s and would like to take part, Hassina can be contacted via [smgxhhz@ucl.ac.uk](mailto:smgxhhz@ucl.ac.uk).

## Sharing stories and experiences



*“When I first joined the online groups, I didn’t say a word. In fact, I didn’t speak. So, don’t be shy, if you want to get in touch that way, that’s fine.”*

*“It really helps to talk to a person with shared experience.”*

In addition to our regional Local Peer Support Groups, we hold a number of online and focused interest groups. The current list includes a Men’s Peer Support Group, Scotland Peer Support Group, ‘Talking’ Tech, ‘Talking’ Travel, Young Adults and a National Peer Support Group. There really is something for everyone.

Steve was diagnosed with retinitis pigmentosa in his early 40s after noticing problems seeing at night and flashing lights. He previously attended a Local Peer Support Group in Woking but after that closed in the early 2000s he found himself feeling more isolated. He attended the first National Peer

Support Group meeting in 2022 and said he “felt connected to others with the same condition again.”

Steve has recently started volunteering as a facilitator in the Men’s group, with a focus on working with tools. His virtual room is called the “Tool Shed” and provides a safe space for group members to discuss useful products and the adaptations which can be made to allow you to continue to enjoy being creative.

He describes having contact with peers with lived experience of inherited sight loss as follows: “It lets me know I am not alone and that others are facing

similar problems. We can have a laugh by sharing our stories.”

Steve makes dragons out of scrap metal in his spare time as well as incredible pyrography art.

Future plans for focused interest groups include a ‘Talking’ Home & Garden Peer Support Group in 2025. If you’d like to join this or any of our other groups, please visit our website: [RetinaUK.org.uk/groups](https://RetinaUK.org.uk/groups).

If you are interested in volunteering for Retina UK, we would love to hear

from you. Email Sadia at [sadia.asghar@RetinaUK.org.uk](mailto:sadia.asghar@RetinaUK.org.uk). You can find out more about Sadia and volunteering with us on page 18.

There are so many ways to access information and support from Retina UK. Find out more on pages 16-17.

*“To families I would say that Retina UK is there to help. They will most likely have a volunteer that has gone through the same problems, and it really helps to talk to a person with shared experience.”*



# THANK YOU

#TeamRetinaUK



The incredible Alex Backhouse took on the epic challenge of running and cycling 700KM, from Land's End to London, over 12 days at the end of September, including a very special guest appearance via video link at our Annual Conference. His fantastic fundraising, thanks to his supportive friends, family and colleagues, raised over £30,000 for Retina UK's vital research projects.



Our first ever Retina UK Day took place on World Sight Day (10 October) and raised not only thousands of pounds but also much-needed awareness for the work of Retina UK. A huge thank you to everyone who took part across the country. Retina UK Day will be returning in 2025 on 9 October.



Worksop's Got Talent, which has raised over £165,000 (including match funding) for Retina UK, returned on 8 November and high-profile celebrities including Suzanne Shaw (Hear'Say) and Coronation Street's Jude Riordan supported the annual fundraiser. The show, in its 8th year, saw 700 people come together to raise money and awareness for Retina UK.



In June, Martin McKibbin and Vernon Long from St James's Hospital in Leeds, completed the Great North Swim and raised a fantastic £572 for Retina UK.

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



Tina, James, Vanessa, Mark, Judy, Laura and Jay – a mixture of Retina UK staff and supporters – took on the 20-mile Thames Path Challenge in London in September and raised a staggering £3,000. Well done, #TeamRetinaUK!

September saw the Great North Run take over Newcastle. Professor Lako rounded up her research colleagues to form a team for Retina UK and they collectively raised an amazing £2,500.



Earlier this year, daredevil Roger Hill took on the Spinnaker Abseil in Portsmouth and raised an amazing £655 from his daring fundraiser!

A huge thank you to the National Lottery Community Fund for their generous grant which will be spent on our support services, including our popular Peer Support Groups.



In August, Joyce Huda organised a coffee morning and gave a personal talk about the work of Retina UK, from her perspective as a parent. Her fabulous event in Buckingham raised £402.



Hannah Grogan inspired us all back in June when she swam the English Channel for Retina UK, raising £1,189 in the process!

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](mailto:james.clarke@RetinaUK.org.uk). Details of all of our upcoming challenge events can be found on our website: [RetinaUK.org.uk/challenge](http://RetinaUK.org.uk/challenge).

Please share your photos with us at [fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk) or tag us on social media.

## Research round-up

### Recent Luxturna developments

Retina UK is delighted that the Scottish Medicines Consortium (SMC) has accepted the gene therapy Luxturna (*voretigene neparvovec*) for ongoing use by the NHS in Scotland.

Luxturna is designed specifically for retinitis pigmentosa (RP) and Leber congenital amaurosis (LCA) caused by mutations in the RPE65 gene. The treatment will not work for inherited retinal conditions associated with any gene other than RPE65.

Retina UK was actively involved in the SMC decision-making process, representing the inherited sight loss community and highlighting the urgent need for effective treatments. The successful outcome of the reassessment means that Luxturna will now be permanently available for prescription in Scotland.

In other Luxturna news, researchers have discovered a method to reduce the injection-related inflammation that is sometimes associated with this treatment.

The new research, led by Prof Sylvain Fisson in Paris, clarified the immune system processes causing the unwanted inflammation. Based on this they then found a way to “distract” the immune system and dampen down the inflammatory response.

The team’s work was carried out in mice and their method will need further testing before it can be applied in humans.

### Significantly worse vision found in female carriers of X-linked RP and Choroideremia

A recent study has challenged the previous belief that female carriers of X-linked inherited retinal diseases (IRDs), such as X-linked retinitis pigmentosa (RP) and choroideremia, are largely unaffected by sight loss.

The study has found vision in female carriers was significantly worse than controls, and carriers aged over 50 years had significantly greater impairment across all domains except photosensitivity. Female carriers have a copy of the disease-causing variant, as well as a healthy copy. Affected males have only the disease-causing variant.

### Antabuse moves into clinical trial for people with RP

A drug called Disulfiram (also known as Antabuse) which is approved by the US Food & Drug Administration (FDA) for chronic alcoholism, has moved into a phase 1 clinical trial for potentially improving vision in people with retinitis pigmentosa (RP). The placebo-controlled trial will enrol 30 participants who are patients at the University of Washington in Seattle.

Previously, researchers from the University of California used Disulfiram to restore some vision in mice with advanced RP.

The study researchers note that while this approach could restore some vision, it isn't a cure and won't inhibit retinal degeneration. Rather, it helps patients make the most of their remaining photoreceptors.

### **jCyte release additional preclinical data regarding jCell**

jCyte have released additional preclinical data on jCell which shows that the intravitreal injections of retinal progenitor cells (RPCs) are effective in treating photoreceptor degeneration in rats. Specifically, the treatment demonstrated substantial preservation of both retinal structure and visual function. This data provides further supporting evidence as jCyte move ahead with clinical testing.

RPCs work by releasing neurotrophic factors which are needed to maintain the health and function of retinal cells, and as such, jCell is predicted to be most effective if given at a reasonably early stage of photoreceptor degeneration.

### **A new approach to treating inherited sight loss**

Epic Bio have developed a new approach using epigenetic editing for

rare diseases. They have called this platform Gene Expression Modulation System (GEMS). Epigenetic editing is a unique approach which can change the expression of genes without making any permanent changes to the gene itself.

This approach has the potential to treat diseases that are unable to be treated using traditional gene therapies. Epic Bio is developing this technology for various conditions, one of them being retinitis pigmentosa type 4 (RP4) which is caused by mutations in the RHO gene.

### **New stem cell treatment gains approval to enter US clinical trials**

Biotechnology company Blue Rock Therapeutics has been given clearance in the USA to go ahead with in-human testing of a new type of stem cell therapy for retinal conditions like RP.

Many of the researchers and companies exploring this approach are using cell lines originally derived from human embryonic stem cells, but Blue Rock is pioneering the use of stem cells created from adult skin or blood.

The first phase of clinical testing will focus almost entirely on safety, involving a very small number of people in the US, and will probably take around 12 to 18 months.

## Information and support in a way that works for you



When it comes to accessing information and support we appreciate that one size doesn't fit all.

To ensure we are inclusive, we offer a wide range of formats so that you can choose and access what you need, when you need it and in a format that works for you.

While some of you will prefer digital communication, we know others like print, or audio. Online meetings might be great for some, others will welcome the opportunity to meet face-to-face or speak on the phone.

Mindful that many of you are working or busy with other responsibilities during the day, most of our groups and meetings are held during the evening.

Here are some of the many ways you can connect with us.



### Website – [RetinaUK.org.uk](https://RetinaUK.org.uk)

A wealth of information on inherited sight loss, available support and current research. It's also the place to find a wide range of videos, podcasts and audio recordings (see resources section) – from research news to day-to-day living, including sports, make-up and haircare.



### Helpline: 0300 111 4000

[helpline@RetinaUK.org.uk](mailto:helpline@RetinaUK.org.uk)

Our Helpline team can answer your questions and signpost to condition-specific information, benefits, employment and education or offer a listening ear. We will put you in touch with a volunteer who has lived experience.



### Talk and Support

Talk and Support offers the opportunity to have a chat with a volunteer with a similar background or interests on a regular basis at a time that suits you, daytime or evening. Request a referral via our Helpline.



### Peer Support Groups

Our local peer support groups provide a welcoming, safe and friendly place for people to share experiences, tips and information and form friendships.





Online



Email



Print



Phone



In person



Audio

Some groups bring together people from a local area, but we also offer a national group online.

Other groups bring together people with a shared interest such as tech and travel. We also have groups just for men, parents, and young people. Find out more on pages 10-11.

Our online peer support groups can be joined by telephone if that is better for you and most meetings are held in the evening. **RetinaUK.org.uk/groups**



### Sight Village

Why not pop along and say hello to our friendly team at the Sight Village events. They are free to attend and are packed with exhibitors. The 2025 schedule will be published at **qac.ac.uk/exhibitions** or call our Helpline for details.



### Discover Wellbeing

Our online Discover Wellbeing course helps people affected by inherited sight loss to develop an awareness of emotional wellbeing and the practical skills to adapt to life's ups and downs. **RetinaUK.org.uk/wellbeing**



### Unlock Genetics

Our Unlock Genetics resource provides clear, trustworthy and balanced information on genetics, inheritance patterns, accessing a genetic test and genetic counselling.

**RetinaUK.org.uk/genetics**



### Events

We hold events online and face-to-face, including our Annual Conference and Professionals' Conference and our Webinar series.

Our webinars can also be joined by telephone. **RetinaUK.org.uk/events.**



### Newsletters

Sign up to receive the latest news from Retina UK, including our Look Forward magazine. Look Forward can be provided online, large print, Braille, or an audio file on a memory stick or CD.



### Social Media

You can find us on LinkedIn, Instagram, TikTok and Facebook, as well as YouTube (@RetinaUK). Our Podcasts are available on Spotify, Apple and Google.

## Connect with us

Interested in finding out more? Visit **RetinaUK.org.uk**, email **services@RetinaUK.org.uk** or phone 0300 111 4000

## Join our wonderful team of volunteers

Sadia joined Retina UK in April 2024 as Volunteer Development Coordinator. She said “I feel so privileged to be part of a wonderful team of dedicated staff and volunteers all striving to improve the lives of people affected by inherited sight loss.

“I have always worked in the charity sector in roles where I support volunteers. I have huge respect for individuals who give their free time and personal experiences to improve the lives of others.

In the last six months I’ve been working to standardise the volunteer recruitment process and improve the volunteering experience for new and existing volunteers. I have enjoyed getting to know our volunteers and listening to individual stories – you guys are truly inspirational!

“I am very excited about the future of volunteering here at Retina UK, including plans to develop more opportunities in wider areas of the charity. I am also working on recruiting a more diverse group of volunteers from different cultures, and who can speak other languages, so that we can help more people.”



*“If you are interested in becoming a volunteer or finding out more about the different opportunities, please get in touch. I am always available for a chat over the phone to discuss options and help you decide how you can get involved and join our wonderful team of volunteers.”*

Volunteers support us in a variety of different ways including recording our newsletter, facilitating our Local Peer Support Group meetings, answering questions on our Helpline, packing bags for our events and much much more. If you would like to join our volunteer team, get in touch with Sadia. You can email her on [sadia.asghar@RetinaUK.org.uk](mailto:sadia.asghar@RetinaUK.org.uk) or call her on **07856 907463**.

## Make your voice heard

We are currently planning our third sight loss survey. Held every three years, starting in 2019 YOU have the power to tell YOUR charity about your experiences and what you want our focus to be in the future.

It is vital that as many of our community members as possible complete the survey. We are #StrongerTogether. It not only shapes the future of Retina UK but the results provide vital evidence of the day-to-day impacts of inherited sight loss to a much wider audience.

From our first Sight Loss Survey in 2019 we have used what we learned to improve our support. This includes the launch of our [Unlock Genetics](#) and [Discover Wellbeing](#) resources.

The survey will be launched in the next edition of Look Forward at the start of March 2025. It will be available in hard copy and online.

If you would like to take part, simply subscribe to our newsletters **RetinaUK.org.uk/subscribe**.

## The end of an era

In October 2024 we said goodbye and happy retirement to our former Office Manager and Finance Administrator, Margaret Williams after 20 years and numerous changes at The British Retinitis Pigmentosa Society (BRPS), RP Fighting Blindness and Retina UK.

Many of our community will no doubt remember Margaret, or Marg as she is known by some. Her calm and unflappable manner along with her dedication to Retina UK over the years is hugely appreciated. We are sure you will join us in wishing her every happiness in her retirement.



## Sign up for an adventure of a lifetime!



We are pleased to announce the return of our international treks, starting with the Sahara Desert in November 2025, as we mark our 50th anniversary.

The six-day adventure in Morocco will give you an insight into this vast and diverse landscape as well as the Berber way of life. Chris Baily, who took part in a group international trek for Retina UK 10 years ago, lives with retinitis pigmentosa (RP) and took part because he not only wanted to achieve something fantastic, but also wanted to connect and network with others who understood his sight loss condition. Chris made lots of friends and unforgettable memories on the trip and he remembers fondly the positive mindset of the other adventurers that he met.

Chris, who raised over £3,000 for us in 2014, said:

*“It’s an incredibly rewarding experience and the friendships you make and the sense of achievement you feel afterwards is indescribable. You won’t regret it – you learn so much about yourself and you’re giving back to Retina UK at the same time. By fundraising for the charity, it allowed me to have more open conversations about my motivation for supporting Retina UK with my friends, family members and colleagues and to open up more than before!”*

To find out more, visit [RetinaUK.org.uk/event/sahara-trek-2025](https://www.RetinaUK.org.uk/event/sahara-trek-2025) or contact our Senior Fundraising Manager, James Clarke, on [james.clarke@RetinaUK.org.uk](mailto:james.clarke@RetinaUK.org.uk) or 07736 925174.

# Join #TeamRetinaUK in 2025!

If you feel inspired after reading about our Sahara Trek, could 2025 be the year that you join #TeamRetinaUK?

Start by signing up to a challenge and work towards your goal. You'll not only raise money for us to continue supporting our community but you will also raise awareness and shine a light on the work that we do.

There is something for everyone, whatever the challenge. You could walk, hike, swim, run, cycle, skydive, wing-walk, take part in a Zumba class, abseil or something else! We will support you every step of the way.



## Our most popular challenges

### January 2025 – Jog in January

Could you jog every day in January and raise money for Retina UK?

### April 2025 – TCS London Marathon

Take part in the virtual TCS London Marathon 2025 and run in your home town or why not join our 2026 waiting list now!

### May 2025 – 5K a Day in May

Donate £5 and complete 5K a day of exercise every day in May!

### July 2025 – Jump in July

Take to the skies and jump out of a plane with a summer skydive!

### September 2025 – Great North Run

Head to Newcastle for the world's biggest half marathon in 2025!

### November 2025 – Sahara Desert

Take on an adventure of a lifetime for Retina UK!

Visit our website to find out more about our challenge events [RetinaUK.org.uk/challenge](https://www.RetinaUK.org.uk/challenge) or have a chat with our Senior Fundraising Manager, James Clarke, on 07736 925174 or email [james.clarke@RetinaUK.org.uk](mailto:james.clarke@RetinaUK.org.uk).

# Talking Watch Shop



VMRC-407LBK



VLRC-407LBK



### 'His & Hers'

New AI male voice Radio-controlled talking watch. A choice of straps, genuine leather or stainless steel expander. **£55.00**

**2 Year Warranty on ALL Verbalise Products**



### New 'Easy-adjust' Apple style 'Loop straps'

Ladies classically styled 9ct gold-plated radio-controlled talking watch, clear English male voice.

**£59.99**



VLRC-208CF

VLRC-208EXP



VLRC-22SLW



VLRC-21GWF

30g lightweight easy-to-see radio-controlled talking watches, clear English male voice stylish watch case with gold or silver bezel & buttons, choice of strap styles. **£32.99**



A choice of watch straps available



## FREE CLOCK\*

Worth £16.99 with all Verbalise branded watches.  
TC-100 Top Button Radio Controlled Talking Clock

\* Offer subject to availability



Suppliers to



Telephone  
**0345 00 40 100**  
[www.talkingwatchshop.co.uk](http://www.talkingwatchshop.co.uk)

All prices exclude VAT - Verbalise Ltd VAT no. GB849283094

## Festive fundraising

This festive period, there's plenty of ways you can support us whilst you enjoy your mince pies!

### Christmas cards

This winter, add a touch of magic to your festive traditions with our stunning Christmas cards and new for 2024, our personalised clear baubles.



With four exquisite cards to choose from, including two that were designed by members of our community, you can support Retina UK whilst spreading some festive cheer. You will not only be sharing the joy of the season, but also directly supporting people affected by inherited sight loss.

To purchase a pack, please visit [RetinaUK.org.uk/shop](https://RetinaUK.org.uk/shop) or call 01280 815900. We've also introduced a range of new shop items recently, so please have a browse.

### Stamps

As you receive cards this festive season, please keep the stamps for our appeal. If possible, cut them out, leaving 5-10 mm of envelope and post them to us. Simply write 'FREEPOST Retina UK' on the package. To keep appeal costs as low as possible, please only use

FREEPOST once you have collected approximately 200g of stamps.

If you have a smaller quantity of stamps and would like to send them, please pop them in a stamped envelope to Retina UK, Whiteleaf Business Centre, 11 Little Balmer, Buckingham, MK18 1TF. Why not ask your friends and neighbours to collect stamps too? It's an easy way to get involved and support us.

### Online shopping

Did you know that you could earn donations for Retina UK as you do your online shopping, at no extra cost to you? Big stores including eBay, Marks and Spencer, Argos, Tesco, Sainsbury's, Trainline, Waitrose, Boots and thousands more are part of the 'Give As You Live' scheme. Visit [giveasyoulive.com/join/retinauk](https://giveasyoulive.com/join/retinauk) and support Retina UK this winter – by simply doing your online shopping.

### A perfect Christmas present for your loved one!

We're pleased to share an exciting recipe book that has been created in aid of Retina UK, by long-term supporter Gwyneth Boyes AKA The Blind Baker!

The recipe book is available to purchase via our online shop, with all proceeds kindly being donated to our vital work: [RetinaUK.org.uk/shop](https://RetinaUK.org.uk/shop) or call 01280 815900.

# Transforming research, transforming lives

Make a donation between 3 December - 10 December and it will be **doubled\*** at no extra cost to you as part of **The Big Give Christmas Challenge**. Find out more on pages 6-7.

**Complete this form** and return to Freepost RetinaUK.

**Or donate online** at [RetinaUK.org.uk/donate](http://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:

Expiry date:  /

CV number:

## 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.

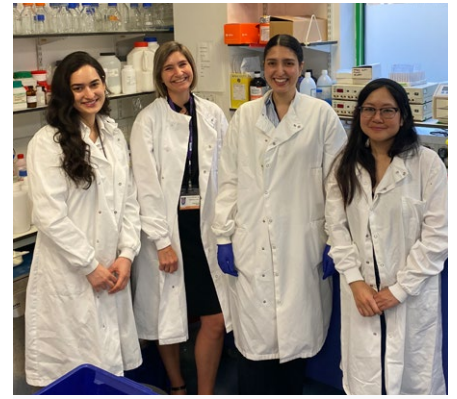
**Gift aid your donation and give an extra 25p for every £1 you donate, at no extra cost to you!**

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: \_\_\_\_\_



**£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.