# OUR IMPACT IN 2024

## THE DIFFERENCE WE MADE

RETINA UK

Volunteers are the foundation of everything we do at Retina UK. The charity started in 1976 with a small passionate group of individuals who were determined to support people living with inherited sight loss and to fund research into treatments and cures. Volunteers remain a big part of the charity; we couldn't do the work we do without them.

We welcomed 24 volunteers to our annual conference in 2024, a significant uplift on previous years. This development and learning opportunity was followed by an evening of networking and celebration.

This is what they said about volunteering with Retina UK:


"It's rewarding in so many different ways. You are part of something and talk to people who are on the same wavelength, who understand. Retina UK is all about people."

*Cindy Peacock*

"By volunteering for the charity, I can support other young people and show them that sight loss is not a barrier to success."

*Ryan Taylor*

“It is a tremendous privilege and honour to be involved in helping others, however small or large the contribution is.”

*Hilary Jones*


“Retina UK, formerly RP Fighting Blindness and BRPS has been part of my life for over 46 years and I’m very proud of what we’ve become.”

*Stephen A Goulden, MBE*

“I remember the support I got from other volunteers and the kindness they showed me and I wanted to do something similar for someone else, to give back.”

*Khadeja Ali*

# WHO WE ARE & KEY ACTIVITY IN 2024

We support people affected by inherited sight loss to lead better lives today, and fund medical research to accelerate the search for treatments for the future.

Retina UK supports people with conditions including:

- Retinitis pigmentosa (RP)
- Leber congenital amaurosis (LCA)
- Stargardt disease
- Cone-rod dystrophy
- Achromatopsia
- Choroideremia
- Usher syndrome

and many other Inherited Retinal Dystrophies (IRDs).

These conditions cause progressive and unpredictable loss of vision and are the leading cause of blindness in the working age population of the UK.

In 2024, we:

- Held our Annual and Professionals' Conferences in Manchester:
  - 368 people registered for our Professionals' Conference
  - 364 people registered for our Annual Conference.
- Launched our new practical information pack in Manchester for professionals who support people affected by inherited sight loss, which has resulted in an increase in the number of referrals received from the professional community.

- Saw a notable increase in the number of registrations for our Peer Support Groups (more on pages 16-17).
- Awarded four new research grants (more on pages 6-8).
- Increased our income despite significant challenges in the environment and changes to the team.
  - Successful applications to Trusts generated an income of £966,418.
  - Our 2024 appeal also performed very well with income of £105,500.
- Presented evidence to the Scottish Medicines Consortium (SMC) regarding the continued approval of Luxturna. It was initially offered for a limited period and was reassessed in 2024 based on evidence of its impact.

**“The lived experiences shared were very powerful in showing how much support is required when people are going through the difficult journey of sight loss.**

**“It was highlighted so clearly that people need accessible information and that everybody is included when it comes to getting an eye test and follow up appointments.**

**“It was a very insightful and informative conference.”**

***Helen Kidd,***
***Vision Rehabilitation Specialist,***
***Cambridgeshire County Council***

# THE SEARCH FOR TREATMENTS

Thanks to the support of our generous individual donors, project grants and trusts and foundations, we were pleased to award four new grants and one PhD studentship in 2024.

## Investigating photopsia and photophobia in Stargardt disease

A PhD studentship inspired by a scientist living with Stargardt disease co-funded by the Macular Society and supervised by Professor Omar Mahroo and Professor Andrew Webster at UCL. The project's focus will be on two under-recognised symptoms in Stargardt patients: photopsia (phantom light flashes) and photophobia (sensitivity to bright light), which disrupt daily life. The research will examine the prevalence and characteristics of these symptoms, explore their relationship with standard clinical measurements, and investigate whether they are linked to specific stages of retinal degeneration. The goal is to understand the biological mechanisms behind these symptoms and their potential use in prognosis and disease monitoring.

## Investigating cone photoreceptor starvation in retinitis pigmentosa using stem cell derived retinal organoids

Dr Jörn Lakowski and colleagues at Southampton University are investigating the mechanisms

behind cone cell death in retinitis pigmentosa (RP), which is initially caused by mutations in rod photoreceptors. It is believed that the loss of rods deprives cones of essential nutritional support, leading to their degeneration, but this survival signaling is not well understood. Using human stem cell-derived “mini-retinas” with a genetic mutation in BASIGIN-1 (BSG1), a key gene in cone survival, the team aims to explore the mechanism of cone starvation and identify potential drugs to prevent cone cell death, offering hope for protecting against advanced central vision loss in RP.

**“It’s so important for people to share their experiences with researchers through participation in studies. Clinicians and researchers need an in-depth understanding of what people are going through at every stage of the condition.”**

*Hassina Zeriri*

## Pre-clinical evaluation of a micro-engineered photoreceptor patch implant for retinal repair

Professor Jane Sowden and Robert Henderson at UCL's Institute of Child Health are developing a stem cell-based approach to restore vision in late-stage RP and other inherited retinal conditions. Since most photoreceptors are lost at this stage, their team is engineering a tiny photoreceptor cell patch to be implanted into the retina. This scaffold is designed to support cell survival and organisation. The project will test whether the patch can be successfully implanted in animal models, assess its compatibility with living tissue, and evaluate how the new cells behave - marking an important step toward a potential therapy for advanced RP.

## cGMP analogues for understanding and targeting early pathological changes in LCA4

Professor Jacqueline van der Spuy at UCL's Institute of Ophthalmology is leading a three-year study on the toxic buildup of cGMP, a molecule linked to Leber congenital amaurosis type 4 (LCA4) and other inherited retinal conditions. Working with teams in Germany and Turkey, the researchers will use advanced cell-based models to explore how excess cGMP contributes to cell death and identify potential treatment targets. They will also test a refined drug compound to see if it can reduce cGMP's toxic effects, with the goal of accelerating progress toward clinical trials for LCA4.

## An optimised human retinal organoid model for the study of inherited retinal diseases: application of biomaterials to support improved inner retinal circuitry and optic nerve formation

Scientists are using lab-grown retinal organoids (hROs) to study inherited retinal diseases (IRDs), but these models have limitations - specifically, the inner retinal structure breaks down before photoreceptors fully mature. Professor Rachael Pearson's team at King's College London has developed nano-scale fibres to act as a scaffold for retinal ganglion cells, helping them survive longer and form a pseudo-optic nerve. A new research grant will support further development of this approach, improving hRO models for IRD studies.

# OUR COMMUNITY SUPPORTERS


- Our TCS London Marathon 2024 team made history in April, raising over £65,000 to become our biggest team in eight years! We're so proud and grateful to our 22 runners for joining #TeamRetinaUK and taking on such an iconic race!
- 5K A Day in May, our new virtual campaign, raised over £7,500. A huge thank you to all of our participants for raising funds whilst staying active during National Walking Month.
- Max Mountstevens, a seven year-old supporter from Plymouth, organised a presentation about the work of Retina UK to his school classmates and raised £310 for us by taking on a 50-mile cycling challenge.
- Hope To Seaview, the annual walk on the Isle of Wight, has raised over £40,000 for Retina UK over the years. The 2024 event, organised by Colin and Linda McArthur, formed part of their 50th wedding anniversary celebrations. Congratulations and thank you for your fabulous continued support!
- Hannah Grogan inspired us all back in June when she swam the English Channel for Retina UK, raising £1,189 in the process!
- 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.

# FUNDING

> “I was diagnosed with retinitis pigmentosa not long after I got married. It really took a toll on my mental health, and I was struggling as my vision deteriorated - it was affecting so many aspects of life, including work, and my hobby of making art. I called the helpline, and I can honestly say that call saved my life.”
>
> *Adrian Paternoster*

We would like to thank all of the individuals, companies and trusts and foundations who supported our work in 2024. They include:

### The National Lottery Community Fund

We were fortunate to receive vital funding for our peer group networks and volunteer training; helping to bring our community together and foster connections and friendships.

### The Garfield Weston Foundation

The Garfield Weston Foundation awarded us a generous grant towards our support services, helping us to deliver on our mission that no one with inherited sight loss need feel alone. We are committed to being there for our community and making a lasting positive impact on the lives of people affected by inherited sight loss.

## Sepul Bio

Sepul Bio is a business unit within Thea exclusively focused on developing treatments for inherited retinal diseases. Sepul Bio has played an important role in supporting us with our work in patient advocacy projects.

“The team at Retina UK are great. I have worked closely with them as an organisation for over five years, supporting our ongoing clinical research in inherited retinal disorders (IRDs). I have always found the team to be professional, fast responding, and informed across a range of topics affecting clinical development. As a central voice of the community, Retina UK acts as a key focus point for companies to access direct IRD community perspectives. The Retina UK team really are true representatives of the IRD community in the UK.”

*Andy Bolan, Patient Advocacy Director, Sepul Bio*


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

# COMMUNITY ENGAGEMENT WITH RESEARCH

During 2024, we continued our efforts to promote engagement between members of our community, researchers and industry.

We shared seven participation opportunities to our Lived Experience Panel, which now has around 550 members. These opportunities included membership of a biotechnology company's advisory panel, a clinical trial for those with X-linked RP and a research study on Charles Bonnet Syndrome.

We also continued to keep our community updated on research progress via podcasts, webinars, features in each edition of the Look Forward newsletter, and research sessions at both our Annual and Professionals' Conferences.


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

## 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 (**RetinaUK.org.uk/resources**).

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.


Worksop's Got Talent, which has raised over £165,000 (including match funding) for Retina UK, returned for another year. The show saw 700 people come together to raise money and awareness for Retina UK.

# OUR 2024 IN NUMBERS

**£1.6 million**

**Total charitable spend**

**11** Research projects supported

**1,218**

**New people began accessing our information and support**

**£720K**

**Invested in medical research**

**£575K**

**Spent on providing information and support**

**We are in touch with 9,058 people affected by inherited sight loss**

**£740K**

Committed to ongoing research projects

**633 Helpline calls and 282 emails responded to**

**66**

**people registered onto our Discover Wellbeing portal**

# 1,206

**People registered for our local group meetings...**

**23** active groups, including three new local groups and two new online groups

**85** peer support group meetings

**17** physical locations, 1 national and 5 special interest groups

# 17

**active volunteers**

supporting **35 service users** on our Talk and Support service

# 2,923

**Podcast listens on our podcast channel on Spotify**

Spotify®

# 7

**Lived experience panel participation opportunities**

# 75%

increase in subscribers to our YouTube channel

+547% of views

YouTube

# 6,473

**Facebook support group members**

# 22,869

**Copies of Look Forward shared**

# 33,358

**Copies of our e-Newsletter shared**

# LIVING WELL TODAY

> “Thank you so very much for being there for me today and for everything that you have managed to put in place for me so far.”

Our Helpline underwent significant change in 2024 following a review of the service over the previous 12 months. As a result:

- Our helpline hours were updated to better reflect when calls were received
- Dedicated helpline co-ordinators were brought in to answer and manage calls;
- We are able to provide a greater consistency of service and better manage follow ups.

The changes have enabled us to make the service more tailored to the caller. As well as providing specific information, we can signpost to appropriate services both internally and externally and match the caller with a volunteer who has specific knowledge and experience of the subject concerned.

Volunteers have more time to prepare for calls and can provide support on areas they have an interest and experience in.

Both volunteers and service users have provided positive feedback on the new process. The email helpline service remained unchanged.

## Talk and support

As of 2024, the Talk & Support service has 17 active volunteers. In 2024 we supported 35 service users with regular calls, 32 of whom are still receiving support. This was an increase of 29% on the previous year.

Complimenting this service, our CBS Buddies have supported a further eight people specifically around their Charles Bonnet Syndrome experiences.

## Peer support

The Peer Support Group network continues to see a positive growth. We have introduced a number of new online support groups that have been popular as well as increasing the overall number of attendees at meetings, both online and in person.

New online groups in 2024 are:

- Talking Travel
- Young Adults Peer Support (18-30 years)
- Parent and Carers Peer Support.

We now have 17 physical group locations, one national online peer support group and five special focus online groups.

In 2024 we held a total of 85 peer group meetings, either online or in-person

There were 1,206 total registrations (an increase of 17% on 2023). Of these, 1,139 took part on the day (an increase of 22%) with others receiving the recordings of the online meetings to watch later.

This area continues to be a key focus for us based on feedback from our community and the positive impacts that we see and hear.

# OUR COMMUNITY SUPPORTERS: ALEX

Alex Backhouse's family has retinitis pigmentosa (RP). His grandmother and father both have the condition, and while he did not inherit it, his brother and sister did. Seeing their vision deteriorate over time, particularly their loss of peripheral vision and difficulty navigating in low light, brought home the reality of living with RP. Wanting to make a difference, Alex has supported Retina UK in various ways over the years, including running a marathon with his dad. But he wanted to take on a bigger challenge—one that would truly push his limits.

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.

Alex's goal was to raise funds for research into inherited retinal conditions. His uncle, an eye surgeon, pointed him toward Retina UK, recognising it as a leader in groundbreaking research. Knowing there is currently no cure for RP, Alex wanted his efforts to contribute to meaningful progress. The generosity of those who followed his journey reaffirmed why he had taken on such an ambitious challenge.

Reflecting on his experience, Alex credits his success to having a strong team around him, holding himself accountable by publicly sharing his goal, and regularly updating supporters to keep them engaged. Now that the challenge is over, he has a new focus—fatherhood. His wife, who was seven months pregnant while supporting him during the challenge, gave birth to their daughter, Freya. For Alex, this is the next big adventure.

More information about our running events and other physical challenges can be found on our website **RetinaUK.org.uk/challenge**.

# WORKING IN PARTNERSHIP

We accepted seven invitations to raise awareness of our work to relevant professionals including the UK Ophthalmology Association (UKOA), National Eye Care Liaison Officer (ECLO) seminar, Aston University, Doncaster Qualified Teacher of the Visually Impaired (QTVI) team and RNIB ECLO meeting.

We launched a new practical information pack for professionals working in health, social care and education to use when supporting people affected by inherited sight loss. It includes information on how Retina UK can help, how to make a referral to our charity, and where to signpost to our free-to-access support.

We continue to be an active member of the VI Partnership (previously the VI Charity Sector Partnership) a collaboration between RNIB, Guide Dogs, Macular Society, Visionary, Blind Veterans and Thomas Pocklington Trust.

We know we can have a bigger impact when we collaborate with organisations that have a shared purpose and values. Ongoing areas of collaboration include political influencing, developing an evidence base, independent living, rehabilitation and prevention and medical research. We have also worked together on projects relating to mental health and wellbeing, technology and the development of sight loss pathways.

Planned activity for 2025 includes the development of an inherited sight loss pathway in partnership with the RNIB.

# ADVOCACY AND CAMPAIGNS

Retina UK was invited to present evidence to the Scottish Medicines Consortium (SMC) regarding the continued approval of Luxturna, a treatment for individuals with a specific type of inherited sight loss. Our involvement highlighted the challenges faced by those living with Inherited Retinal Dystrophies (IRDs) and the transformative potential of access to effective treatment.

We will continue to enhance the tailored practical and emotional support we provide for our community so that they can make informed choices. We will carry out an Equality, Diversity, and Inclusion (EDI) audit and create an EDI strategy/ action plan. We will increase our engagement with young adults and improve the support we provide to this group to ensure equitable and inclusive access to our charity. We will also increase our engagement with the wider family, specifically parents, and improve the support we provide to this group.

Team Finlay, made up of 100+ friends and family members of Finlay Macleod, took on the Bristol Half Marathon and 10K in May. They raised a staggering £100,000+ for Retina UK in memory of Finlay. We are so thankful for their fantastic support.

# LOOKING TO THE FUTURE

RETINA UK 50 YEARS

WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

We will start a year-long series of events and activity to mark the 50th anniversary of Retina UK in June 2025.

A key focus will be to create and publish the first Inherited Sight Loss Support Pathway, a unique opportunity to transform the experiences of families affected by these conditions. We will deliver this ground-breaking work in collaboration with the RNIB.

While doing so we will continue to grow our tailored approach to practical and emotional support, with a specific focus on young adults and parents, including through peer-to-peer support. We will continue to offer information and support in a number of accessible formats. We will deliver a hybrid annual conference in September.

We will further develop our offering for the wide range of professionals who support those affected by inherited sight loss and will explore opportunities to deliver new CPD-accredited training. We will deliver a hybrid professionals' conference in September.

In spring 2025 we will carry out our third three-yearly tracking survey to identify how we make the biggest difference for those affected by inherited sight loss, measure our performance and identify opportunities for improvement.

Our people remain one of our biggest assets and we will invest in them to ensure that Retina UK is a happy and healthy place to work and volunteer, and an organisation where everyone can thrive and is valued. We will employ another Development Team intern with lived experience of sight loss.

We will seek to invest in our infrastructure to future proof IT systems, grow our database, and ensure our policies are up to date and remain fit for purpose.

# 2024
# IMPACT REPORT

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