

RETINA UK

# OUR IMPACT IN 2023

THE DIFFERENCE WE MADE





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. In 2023, we:

- Grew the number of people we are in touch with to 19,913. We are in contact with 3,258 more people than in 2021.
- Committed to funding three new PhD studentships and three new project grants. Two of the studentships were underway by the end of the year. The Gene Team project, led by Robin Ali, was completed and ongoing projects continued to make progress.

- Initiated a consultation to investigate the potential for a UK-based Inherited Retinal Dystrophy (IRD) registry to meet the needs of researchers, industry and community.
- Delivered hybrid Annual and Professionals' Conferences. More than 420 delegates registered for the Annual Conference and 336 for the CPD-accredited Professionals' Conference.
- Launched our new website in the spring. Since then the time people are spending on our website has almost doubled.
- Delivered nine webinars on a wide range of topics from research to day-to-day living.



“Peer support is invaluable. I cannot tell you how much it changed my life to just know there were other mums losing their sight and they had done just fine. I would say that referring people on to peer-to-peer support services is just as important as helping them clinically, if not more. I had nothing like that growing up and I only wish a professional had encouraged me to seek support. There is more available now than ever.”

*Michelle Tomlinson*



Retina UK supports people with conditions including:

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

and many other 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.



**“I know everyone can say they understand it, but nobody understands it like someone who has it and for me it was major. Being able to speak to someone and having long conversations with somebody who has the same eye disease and can really relate, that was a brand-new experience for me.”**

*James Moore*

# BUILDING MOMENTUM IN THE SEARCH FOR TREATMENTS



Thanks to generous donations from our supporters, we were able to award grant funding to one new project and two PhD studentships in 2023. We also approved funding for three further project grants and one additional PhD studentship starting in 2024. The PhD studentships are in collaboration with the Macular Society.

We continued to fund existing research projects, including The UK Inherited Retinal Dystrophy Consortium (UKIRDC), a PhD Studentship on the Development of CRISPR gene therapy for Stargardt disease, The Gene Team Project and a project led by Professor Majlinda Lako at Newcastle University to use stem-cell derived laboratory models to develop and refine a gene therapy

for RP associated with the PRPF31 gene.

In 2023 we started to fund an exciting project, thanks to the generous commitment from the AT Capital Charitable Foundation, into the treatment of sight loss associated with mutations in the USH2A gene.

Two new PhD studentships also commenced in 2023. The first, supervised by Dr Roly Megaw at Edinburgh University will investigate how particular mutations in the RPGR gene impact cone photoreceptors. The second project, supervised by Professor Jacqueline van der Spuy, will investigate if prime editing can efficiently correct one of the most common genetic changes causing Stargardt disease.



“I love learning more about science, but I’d also love to talk to people affected by inherited sight loss, to really learn the impact it has on their lives, and develop my skills and knowledge in order to help more people in the future.”

*Chloe Brotherton, a PhD student funded by Retina UK and the Macular Society*



# RESEARCH FUNDING

Our research is funded by our generous community through donations and also by our incredible Trust supporters like The Grace Trust.



“The Grace Trust has been pleased to make a substantial grant to Retina UK, to help provide funding to research potential treatments and advance Retina UK’s important work.

The Grace Trust is funded by donations from businesses and individuals, mostly who are members of the Plymouth Brethren Christian Church and who share the Grace Trust’s vision of helping and supporting others.”





# COMMUNITY ENGAGEMENT WITH RESEARCH

During 2023, we continued our efforts to promote engagement between members of our community, researchers and industry. We shared 16 opportunities to get involved with research to our Lived Experience Panel, which now has around 500 members. These included clinical

research studies for those with a particular genetic diagnosis, lived experience surveys in support of pre-implantation genetic testing license applications, presenting at a pharmaceutical company staff meeting, and a survey on attitudes to retinal implants.





# BRINGING TREATMENTS TO THE CLINIC



Securing NHS funding for new therapies is the essential final step in enabling those living with IRDs to access life-changing treatment. We held an industry round table event in 2022 which identified the lack of accessible patient data to be a key barrier to market access. In late 2023, Retina UK initiated a consultation to investigate the potential for a UK-based IRD registry to meet the needs of researchers, industry and community.

Luxturna was accepted for use by the NHS in England, Wales and Northern Ireland in 2019, but at that point was placed under review by the Scottish

Medicines Consortium (SMC) as part of its special framework for very rare conditions. This meant that it was initially offered in Scotland for a limited period only, and required reassessment this year when further data on its impact was available.

Retina UK was actively involved in the recent 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.

# OUR 2023 IN NUMBERS



**£1.5 million**

Total charitable spend

**9**

Research projects supported

**748**

New people began accessing our information and support



**£712,656**

Invested in medical research



**£574,378**

Spent on information and support

We are in touch with 8,900 people affected by inherited sight loss



**£809,912**

Committed to research projects



**600** Helpline calls and **230** emails responded to

**92**

people registered onto our Discover Wellbeing portal



**1,027**

People registered for our local group meetings...

21 active groups, including three new local groups and two new online groups

81 peer support group meetings

15 physical locations and 4 virtual groups

**14**  
active  
volunteers



supporting **27** service users, giving **325** hours of their time

**3,067**

Podcast listens on our podcast channel on Spotify



(75% increase on 2022)

**16** Lived experience panel participation opportunities

**↑ 65%**

increase in subscribers to our YouTube channel

**+99%** of views

**6,292**



Facebook support group members

**21,799** Copies of Look Forward shared

**29,338** Copies of our e-Newsletter shared

# LIVING WELL TODAY



We continue to grow our information and services offering practical and emotional support so that everyone with inherited sight loss can live their best lives.

That support includes connecting people with others with lived experience, for example via our Helpline, Talk and Support service, Local Peer Support Groups and online special interest groups. We provide a wide range of information including through our website, podcasts, webinars and our Discover Wellbeing courses.

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

Bobby grew up in a family who never spoke about their inherited sight loss.





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

“I thought my life was done at 31 and there was no help for me. While working as a Prison Officer I fell into a very dark place. RP was the main factor of the stress, fear and doubt clouding my mind and dragging me further and further down a horrible path.

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

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

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

“Since ‘coming out’ as living with sight loss I’ve learned that people are often so friendly and helpful. I have started competing as a visually impaired strongman and I’m now able to talk honestly and openly and feel better for it.

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



Listen to Bobby’s story and find a wide range of resources at [RetinaUK.org.uk/resources](https://RetinaUK.org.uk/resources).

# OUR GENEROUS TRUST SUPPORTERS

## **The D'Oyly Carte Charitable Trust**

The D'Oyly Carte Charitable Trust has been generously donating towards our Helpline for the last few years. Thanks to them and other kind supporters, we can continue to offer a friendly, compassionate listening ear to people facing challenges because of the loss of their sight. Through our helpline, we can ensure that no one with inherited sight loss need feel alone, and make a tangible positive difference to people's lives. Thank you to the D'Oyly Carte Charitable Trust for your valued support of our Helpline, it is greatly appreciated.



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# WE COULDN'T DO WHAT WE DO WITHOUT OUR INCREDIBLE VOLUNTEERS

In 2023 we published our very first Volunteer Impact Report. It is based on the feedback we received from our volunteer team in our three-yearly survey. Last year 100% of volunteers who completed our survey told us Retina UK supports them 'very well' in their role and 100% said they were 'very satisfied or satisfied' with their volunteering experience.

In 2023 we welcomed eight new volunteers into our Information and Support volunteer team, in roles in our Talk & Support service and Local Peer Support Group network. We provided regular online meetings for both training and social opportunities to the team and 23 volunteers attended our face-to-face training event.

**For the full report visit our website:**  
[RetinaUK.org.uk/resource/volunteer-impact-report](https://RetinaUK.org.uk/resource/volunteer-impact-report).

# OUR COMMUNITY SUPPORTERS



Colin and Linda McArthur have been married for 50 years, after first meeting when they worked together at British Gas. They are the proud parents of five sons.

Originally from Fulham and Battersea, the couple later moved over to Isle of Wight where they now live. Colin first realised that something was different with his eyes at nursery when he was drawing. Night blindness came next and he was diagnosed with glaucoma at Moorfields. This was followed by a diagnosis of retinitis pigmentosa (RP) in 1964 in Belgium. Subsequent visits to Moorfields in the UK confirmed the diagnosis.

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The couple first found Retina UK (then the British Retinitis Pigmentosa Society) after reading an article in their local newspaper. They went along to an event where they met Lynda Cantor, John Marshall and others with the condition.

Colin and Linda started fundraising for Retina UK in 1981 with a fundraising evening which featured a UK snooker champion. Various other events followed, including fun days, variety shows, the national Three Peaks Challenge, the Olympic torch relay and raffles – all to raise vital funds for medical research projects at Retina UK. Their hugely successful annual fundraising coastal path walk, Hope to Seaview, which takes place every year on the Isle of Wight, has raised over £40,000 to date.

As well as facilitating our Peer Support Group on the Isle of Wight, Colin re-joined our board of Trustees in 2024 after serving as a Trustee between January 2008 and September 2019. He adds great value with his lived experience and fundraising background.

The couple would love to see more people with lived experience getting involved in fundraising and they say:

**“It’s in our hands to get our eyesight back, so anything you can do support the work of Retina UK would be fantastic. We’ve got the power to do this – we’ve come so far but we still need to keep the researchers busy, so for your own wellbeing and for a sense of purpose, we’d recommend getting involved and supporting the charity. Our children and grandchildren could be affected by RP so that keeps us passionate about fundraising and raising awareness.”**

# WORKING IN PARTNERSHIP WITH OUR SECTOR COLLEAGUES AND THE PROFESSIONAL COMMUNITY



We collaborated with sector partners to develop an Eye Care Support Pathway, endorsed by more than 20 organisations and professional bodies, including the Clinical Council for Eye Health Commissioning. The Pathway is a new framework to ensure patients have timely access to information, advice and support throughout their eye care journey.

Another priority in 2023/4 is to increase the level of awareness amongst health and social care professionals of the information and support that Retina UK provides. We also want to increase the level of signposting that takes place, both at point of diagnosis and at other stages in the patient journey, by introducing a clear referral process.

Our aim is to improve outcomes for our community by ensuring that they are referred to Retina UK promptly for access to the support we provide, and all of the useful information we can share about topics such as genetic testing and counselling. This will enable them to make timely informed decisions.

We conducted a survey and focus groups with members of the professional community in the last quarter of 2023 to understand how we can best achieve this aim.

The results of this scoping exercise will inform phase two of the project in 2024.

We were invited to deliver information and training to professionals in 2023, including:



“Retina UK was a godsend for me. An amazing and incredible organisation that is packed to the rafters with amazing and incredible people.”

*Rishi, Croyden*

- Discover Wellbeing webinar for Visionary
- In-person session at the Visionary Conference
- Rehabilitation Workers Professional Network Study Day
- VICSP Meeting Retina UK Showcase

We will continue to deliver sessions in 2024, including a session to QTVIs in February.

# ADVOCACY AND CAMPAIGNS



During the last quarter of 2023 we started work on a strategy to set out how Retina UK best understands and evidences the views and needs of the inherited sight loss community and how we use this insight to bring about positive change to their lives. Including, but not limited to, how we:

- Create momentum in the delivery of treatments and therapies from clinical trials to clinic.
- Effectively campaign and influence to bring about improvements in health and social care.

- Ensure the needs of those affected by inherited sight loss are recognised and understood by wider society.

Angie felt very emotional for a long time following her diagnosis. She didn't speak to anyone and became quite isolated. After finding out about Retina UK she couldn't believe how much work they've put into people's lived experiences. she said: **"I didn't feel like I was on my own. Retina UK are an amazing charity. They do so much for the visually impaired community."**

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# LOOKING TO THE FUTURE

We will increase our investment in pioneering medical research and improving information and support for those living with inherited retinal conditions around the UK, their friends, family and the professionals who support them.

We have invested more than £17 million into cutting-edge research since we were founded in 1976 and we are determined to build on the progress made to date.

Through our Project Grants we will continue to support medical research projects of varying length that seek to explore new ideas or test theories. We awarded three new project grants in 2023.

We will hold our Annual and Professionals Conferences in

Manchester and continue to offer the opportunity to attend online. Our webinar series continues to be popular and will continue in 2024 with a wide range of topics.

We will further enhance the tailored practical and emotional support we provide for our community so that they can make informed choices. We will focus on increasing referrals from professionals so that everyone affected by inherited sight loss can live their best lives.

We remain committed to providing employment opportunities for those with inherited sight loss and will employ a Research Intern and a Development Team Intern with lived experience.



# 2023 IMPACT REPORT



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