



OUR IMPACT IN 2022

THE DIFFERENCE WE MADE FOR OUR COMMUNITY



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 2022, we:

- launched our Discover Wellbeing resource (page 8)
- held our conferences in a hybrid format, allowing those who were able to attend in person to do so, and those not able to travel, to join us online.
- delivered 10 webinars (online via Zoom) on a wide range of topics.
- held three face-to-face

information days in Bristol, Hull and Manchester.

- increased our Local Peer Support Groups to include 14 physical group locations and two virtual groups (online only).

Calls to the helpline decreased by 25% but were still up on pre-pandemic (2019) figures by 10% whilst email helpline queries increased by 20% against 2021.

“A brilliant webinar, I learnt a great deal today and feel I have come away with more confidence and knowledge which I can share with others.”



Retina UK supports people with inherited retinal dystrophies (IRDs), including:

- Achromatopsia
- Choroideremia
- Cone-rod dystrophy
- Leber congenital amaurosis
- Retinitis pigmentosa
- Stargardt disease
- Usher syndrome

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

Our charity's values represent how we behave and work together.

- **Approachable:** We are respectful, caring and considerate
- **Honourable:** We are open, professional and act with integrity
- **Collaborative:** We value all those who support us
- **Ambitious:** We are innovative, passionate and always do our best

"It really gives you hope that one day RP can be cured. I am really pleased I found your organisation/website and I'm sure it will be a useful tool for us as a family."

SEARCHING FOR TREATMENTS



Your donations make progress possible

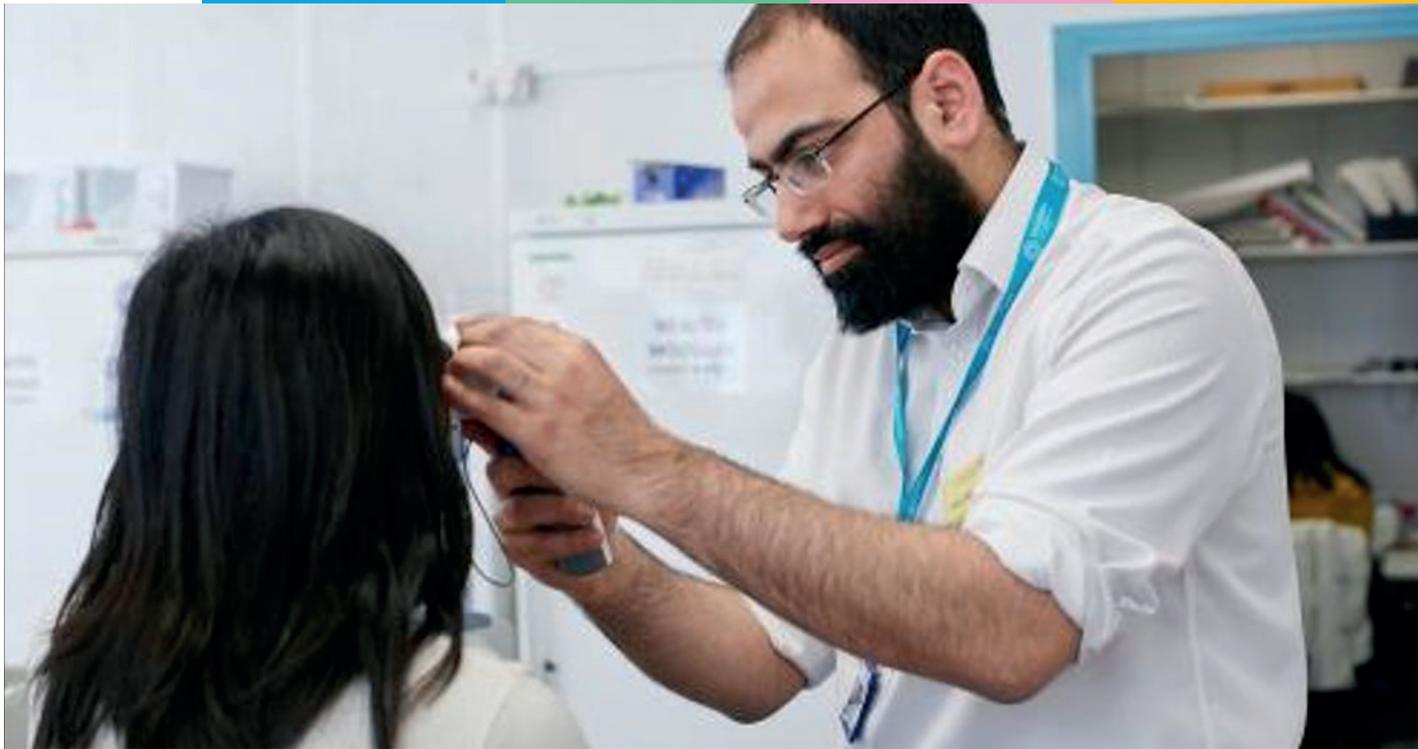
Your generous support allows Retina UK to fund the work of leading scientists who are increasing understanding of inherited sight loss and moving us closer to treatments.

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 and The Gene Team Project.

In 2022 we were delighted to award funding to 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. We also opened a call for applications for PhD Studentships in the autumn, which resulted in three promising proposals.

“From a practical perspective, the datasets are relatively small, and in addition, rare disease does not necessarily attract the same level of research funding as other conditions. That’s why the support of charities like Retina UK is really important.”



Community engagement with research

In 2022 we continued our efforts to facilitate engagement between members of our community and researchers. We publicised eight research participation opportunities, as well as directly emailing community members who have expressed a wish to take part in such activities. Our lived experience panel now includes over 450 members.

Bringing treatments to the clinic

Securing NHS availability for new therapies is the essential final step in enabling those living with IRDs to access life-changing treatment as they

become available. In 2022, Retina UK joined the Charity Medicines Access Coalition (CMAC) to add our voice to those of other organisations in challenging and influencing policy around licensing and reimbursement.

“This funding will enable us to use state-of-the-art technologies to understand whether it will be possible to rewrite the genetic code in patients with Stargardt’s disease. In doing so, this would permanently ‘repair’ or ‘correct’ the genetic change that causes the disease within the affected cells of the eye, thereby permanently curing the disease.”



LEADING BETTER LIVES TODAY

Learning from your experiences

We repeated our Sight Loss Survey in spring 2022, to learn what has changed since 2019 and to understand the current experiences faced by our community to enable us to shape our future plans. Key findings included:

70% of those who knew about research cited Retina UK as the source.

We appointed Kate Arkell as our first Research Development Manager in 2019 to improve our research communication and we will continue to grow this important area of our work.

54% of people would like to participate in a clinical trial or some other kind of research, but haven't yet.

We continue to make our community aware of opportunities to get involved in research, including through our Lived Experience Panel.

93% reported they have experienced one or more of the biggest emotional or psychological impacts of inherited sight loss; anxiety, loss of confidence and stress.

Through our new Discover Wellbeing course (page 8) we aim to enable our community to better manage emotional impacts.

31% of respondents could name the gene or genetic disease type causing their sight loss – this is twice the percentage in 2019, and suggests a positive increase in the number of people who are given a genetic diagnosis

We are delighted our Unlock Genetics resource is helping people to understand their choices and is having a positive impact.



"It was so rewarding; meeting people in person, chatting and engaging on a personal level, swapping stories and real life changes that are needed."

"The telephone befriending service is brilliant. It makes such a difference being able to chat to someone who understands what it's like, I've never had that before."

"The first chance I ever got to meet someone like me was at a local group meeting These people just 'got' me in a way no one else had and I felt so accepted. It was a massive confidence boost at a time when I really needed it."

"I was in a terrible state, but they were always so understanding and they always listened and were patient with me, despite the fact that I called so many times over that initial period. Just speaking to the Helpline team, knowing they are living with sight loss but are able to live confidently and do everyday things, it was so reassuring. I felt like I could actually face the future."

"We met lovely people, and the staff made me feel very at ease and welcome. The Speakers and Researchers were amazing, caring and so passionate about helping others."



DISCOVER WELLBEING



When we conducted our 2019 sight loss survey, 92% of respondents said they had experienced negative emotional or psychological impacts.

This confirmed the anecdotal evidence that we had gathered for some time from discussions with people on our helplines and at various events.

Our response was to develop our innovative Discover Wellbeing resource.

We worked with Arthur Ellis Mental Health Support and Dr Mhairi Thurston, a Senior Lecturer in Counselling at Abertay University, who also lives with a sight loss condition,

to develop modules. As well as encouraging an exploration of impacts and feelings, the modules provide a range of tools to empower the user to manage their own emotional wellbeing, improve their resilience and prepare for the future.

Denise Rawden, Information and Support Manager, said “We want to encourage open conversations about emotional health alongside the physical impacts of living with an inherited sight loss condition.

“Our Discover Wellbeing course will give people the tools they need to become more aware of their emotional health and



practical skills to maintain positive wellbeing.”

There are three courses to choose from and all are free to access:

Early stages – understand your feelings of apprehension and take positive practical steps to prepare for the future.

Living with change – understand your feelings of loss, adapt to a reduction in sight and take practical steps to live a positive life today.

Supporting others – learn practical skills and access tools to look after yourself whilst learning how to support others. This is designed for family members and professionals.

The modules can be completed independently, or members of our community can request the support of a specially trained wellbeing volunteer, who will contact them regularly for encouragement and support.

More information on the course, and a link to register can be found at RetinaUK.org.uk/wellbeing or email wellbeing@Retinauk.org.uk.

“I was diagnosed around nine years of age and didn’t really get much emotional and mental health support back then. As I’ve got older, and my sight has got worse, I’ve looked for self help. I found this course really helpful in showing me the stages that I’ve been through - it’s all part of the journey.”

“I have recently started the Living with Change Wellbeing Course and wanted to tell you that I think it is a brilliant thing devised specially for the sight loss community.”

“The course is very informative and interesting. I’m a screen reader user and it was fully accessible and easy to navigate.”

“As a blind person it is wonderful to know that there is a resource that visually impaired people can work through to help with the emotional impact of sight loss.”

OUR 2022 IN NUMBERS



£1,562,632
Total funds raised



£624,853
Invested in medical
research



£615,141
Spent on information
and support



We are in touch with
8,300 people
affected by inherited
sight loss



902 new people
began accessing our
information and support



575 people
registered for our
local peer support
group meetings



1090 Helpline
calls and emails
responded to



50,752 copies of
Look Forward shared



6,148 online
support group
members

VOLUNTEERS



Our volunteers are highly valued members of the Retina UK team and their roles are essential to help support people affected by inherited sight loss and enable them to live fulfilling lives.

Our charity was founded by volunteers in 1975 and they have been the lifeblood of the organisation ever since. They are involved in a wide range of activities across the charity.

In 2022, our helpline volunteer team responded to over 1,000 calls and emails, providing emotional, life-changing conversations while offering practical help, ideas, support and relevant signposting.

Collectively they give around 400 hours of their time to the helpline service each month. Our 11 Talk & Support volunteers supported 21 individuals via regular telephone contact and gave around 240 hours of their time.

Volunteers are critical to the success of our rapidly growing local peer support group network. In 2022 our volunteer facilitators led 59 in-person and online meetings enabling around 600 people affected by inherited sight loss to meet others with lived experience in their local area. This will increase in 2023.



WORKING IN PARTNERSHIP

At Retina UK we believe partnership working is key to success. Collaboration is one of our charity's values as we know it can have a huge positive impact for our community.

We regularly involve other organisations in our research, information and support, and awareness-raising activities because we know we are stronger when we work well together.

As well as collaboration on research with pharmaceutical companies and other charities in the sector, we partner with other like-minded organisations and charities actively working with people living with a visual impairment and improving people's lives. We are a founding member of the VI Charity Sector Partnership, a collaboration of charities working towards similar goals including local sight loss organisations, RNIB, Guide Dogs, Macular Society and Blind Veterans UK.

Through the partnership we are working to improve care and support by creating a Sight Loss Pathway. Our involvement,

which has included consulting with members of our local peer support groups, means we can ensure the pathway is reflective of the unique experiences of those with inherited sight loss.

Awareness raising and influencing

By working together we can strengthen the voice of all those living with sight loss, including inherited conditions and get tangible outcomes sooner. In 2022 we joined with over 25 other charities to urge the Government to put disabled people and those with sight loss at the heart of its response to the cost of living crisis.

Together we can reach a larger and more diverse audience to raise awareness of the impacts of sight loss. We can educate the public to enhance their understanding, which could lead to a change in attitudes and behaviour. This in turn would lead to a positive change for all.

We can make your voice heard so you can influence change. Join our lived experience panel RetinaUK.org.uk/more-info.



THE FUTURE

We will continue to invest in pioneering medical research and in 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 new theories. We invited applications for research grants in 2022 with 15 preliminary submissions. A decision on these applications will be made in 2023.

We will also 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. Ultimately, we

want 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.

Other plans for 2023 include:

- to further develop resources to support our community to manage their wellbeing
- to further grow our Local Peer Support Group network around the UK,
- to develop how we support professionals who work directly for the IRD community
- to appoint a Communications Intern via the TPT Get Set Progress programme
- to hold our Conferences in London, including CPD accreditation for the professional community
- to launch a brand new website, with a Resources section where content can be filtered to find audio, video and written information. We will also have an event calendar, which can be filtered based on the type, distance, location and date.



“Retina UK has been part of my life since 1976 and I’m so proud to see how it has grown into a modern, inclusive and community based charity thanks to our brilliant volunteers and dedicated hard working staff.”

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