



WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

THE DIFFERENCE WE MADE IN 2021

WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

We are the only UK-based charity dedicated solely to working for people affected by inherited retinal conditions that cause progressive sight loss.

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.

We responded to the COVID-19 pandemic by adapting and taking a more innovative approach to our information and support provision.

- Our Annual Conference and Professionals' Conference went ahead online rather than in person with very positive feedback.
- We launched our innovative Unlock Genetics website.
- We introduced a series of webinars.

- We launched a suite of online wellbeing modules for our information and support volunteers.
- We expanded our online local peer support group meetings with more than 244 people registering to attend.
- We were delighted to hold our volunteer training weekend in-person in September 2021.



"Thank you so much for all your hard work; everybody here just loved it. My partner has been depressed about a huge loss in vision and she feels so inspired right now. Such a brilliant organisation. We have done a wonderful thing tonight. Thank you for all your help for so many people."

A local peer support group meeting attendee

A man with a beard and glasses, wearing a dark shirt, a blue bow tie, and a grey patterned vest, stands in front of a backdrop of blue and silver balloons and large illuminated letters. The letters appear to be 'WGT' for 'Workshop's Got Talent'.

Retina UK supports people with conditions including:

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

“Organising a show for a charity that you care so deeply about spurs you on and I love the sense of achievement when I stand there and see hundreds of people enjoying something that I have worked on. I can’t recommend fundraising enough and the support that Retina UK provides towards the events is invaluable.”

James Clarke (pictured), Founder and organiser of Workshop’s Got Talent which has so far raised more than £40,000 for Retina UK.



Elena Piottter is a PhD student at the University of Oxford. She has been funded by Retina UK and the Macular Society and is investigating a potential Stargardt disease treatment which could also be relevant for other inherited retinal conditions.

SEARCHING FOR TREATMENTS

Your support has kept research on track at a crucial time.

In line with medical research across the UK, the majority of projects funded by Retina UK experienced delays in 2020 due to the COVID-19 pandemic and associated lab closures, which had knock-on effects on project timings in 2021. We have been pleased to provide extensions as required so that grantees can achieve the aims set out in their original project proposals.

Despite the challenges many researchers have faced, they continue to work with energy and determination to develop new understanding and therapies and this gives us great hope for the future.

In 2021, Retina UK contributed to the NICE Methods and Process Review consultation and we continue to engage with sector partners and the pharmaceutical industry to ensure that future therapies are made available to our community. Recent progress in clinical trials for gene-agnostic cell-based therapies for retinitis pigmentosa (RP) has been of great interest to those living with inherited sight loss.

We continued to facilitate engagement between members of our community and researchers. We publicised six research participation opportunities via our social media channels and e-newsletters, and engaged with community members who have expressed an interest in taking part in such activities. Our

research participation panel now includes 311 members.

Participation has included industry-led activities to learn more about lived experience, and questionnaire-based studies on the impact of the pandemic on the wellbeing of people with a visual impairment. Interaction between those living with inherited sight loss and the research community is essential for progress; it also provides our community with choices about participation, and opportunities to influence the direction of research.

"I support Retina UK because they are a charity whom I trust and whose purposes I believe in. They set their goals based on the needs and desires of those they are supporting."

LEADING BETTER LIVES TODAY

Information and support activity dominated our work in 2021 to meet the growing demand of those reaching out for support.

The delivery of our Information and Support services in 2021 involved a real digital transformation. The UK was again subjected to numerous lockdowns and changes to COVID-19 guidance and we adapted to focus on the ways we could reach those living with or affected by inherited sight loss, as well as the professional community that supports them, in a remote way. The insights gained from working in this way during 2020 proved invaluable and allowed us to expand our provision.

In 2021, 762 new contacts told us they were happy for us to stay in touch, including 587 individuals, 31 companies and 136 organisations.

At the start of 2021 we made the difficult decision to move our Annual

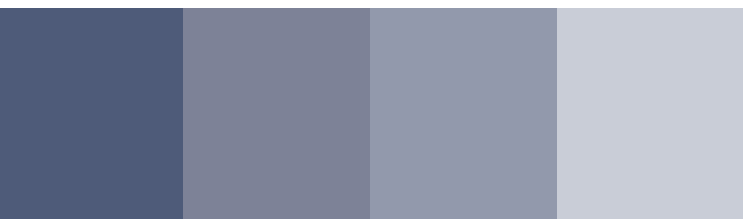
Conference, AGM and Professionals' Conference fully online with over 500 attendees.

We introduced a series of monthly webinars in August 2021 with a focus on research. These were very well received by our community and the professionals who support them. Recordings of the webinars were made available on our YouTube channel and our Podcast channel (audio only).

We continue to provide accurate and trustworthy information and updates in a variety of accessible formats through our regular newsletters which are available in print (*Look Forward* only), Word, PDF and audio format (CD and memory stick). We were able to continue

with our planned schedule of *Look Forward* in 2021, publishing it three times during the year. A total of 19,780 copies of *Look Forward* were distributed and 25,536 copies of the e-newsletter.

"I have been a member since 1979 and I have never been to a conference because of the distance and not having anyone to accompany me. But this time I was able to attend online and I really enjoyed it and thought the presentations were outstanding."



Mark completed his fourth skydive (from 15,000 ft) in 2021. He has raised more than £20,000 for Retina UK over the years.



"I feel better now that I have gained a better understanding of genetic forms of retinal eye conditions. I will be able to better signpost others now that I know what services are on offer."

"Amazing that Retina UK are available as a first point of call. As when I was registered in 1999 there was nothing available for me, my husband and family."

"I have read through the various sections of the Unlock Genetics website, and was very impressed by the clarity and comprehensiveness of its content as well as the ease with which one can find and move between the sections."

UNLOCK Genetics

Discover Your Choices

Genetic testing may help you and your family learn more about your inherited sight loss and how to unlock choices.

RETINA



"Congratulations to the team for building this excellent site. I enjoyed looking over it and listening to the audio recordings, especially of experiences of having genetics testing. I think there are going to be a wide range of experiences so it helps to understand how it has been for other people."

We held 14 online **local peer support group meetings** in 2021 for those living in London, Scotland, Birmingham and Somerset. More than 244 people registered – a 49% increase in attendance on 2020. The meetings were recorded and shared with group members who were not able to attend on the day.

Our phone and email **Helpline and Talk and Support** services experienced a significant increase in demand in 2021 compared to 2020.

Daily Living – 39% of callers had queries about daily living (increased from 24% last year), including concerns about driving and having to give up a driving license; employment queries, benefits and mobility training.

Emotional support – 27% of calls required specific emotional support (increased from 20% in 2020), 5% of people had been newly diagnosed, and others were struggling for

many reasons, in particular a recent deterioration in vision.

Information about RP/retinal dystrophies – 22% of callers were seeking information about their eye condition including symptoms.

Research and genetic testing – 18% of callers wanted information about research, clinical trials, genetic testing and counselling. This figure reduced in comparison to 2020 (25%)

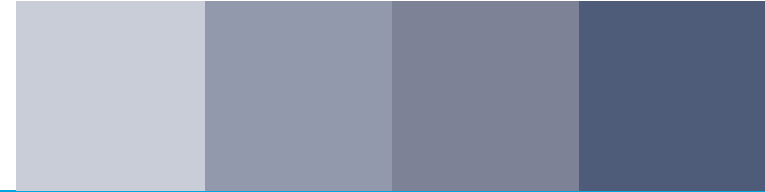
Of those who responded to our short post-call questionnaire:

- 100% of people said they were likely, or very likely, to use the helpline again or recommend it to someone else
- 100% felt it was either helpful, or very helpful, speaking to someone else living with an inherited retinal dystrophy

Our **Unlock Genetics** website was launched at our conferences in April 2021 thanks to a grant from Novartis Pharmaceuticals UK. The site aims to increase the level of awareness of genetic testing and genetic counselling amongst people living with inherited sight loss conditions, empowering them to make fully informed decisions about their lives, healthcare and family planning. It provides clear, trustworthy and balanced information and has been developed with significant input from experts in the field and also those who live with inherited sight loss.

Plans for 2022 include the development of a new website resource to support our community to manage their wellbeing; grow our local support group network around the UK and gain further insight into our community's experiences through our sight loss tracking survey.

OUR 2021 IN NUMBERS



Total funds raised



£1,239,135



£163,051

Invested in medical research



£343,775

Committed to research projects



£470,847

Spent on information and support



Nine

Research projects supported

We are in touch with



7,877

people affected by inherited sight loss



762

New people began accessing our information and support



1,345

Helpline calls and emails responded to



244

People attended our local group meetings



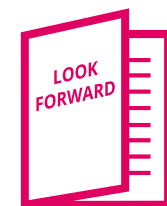
2,014

Podcast plays



10,966

Online support group members



32,453

Copies of *Look Forward* shared



708

New Followers on Social Media

VOLUNTEERS

Volunteers founded our charity 45 years ago and they continue to be at our heart.

Our volunteers have continued to support our work throughout the pandemic. Their contribution is incredibly valuable and allows us to deliver our services, particularly the helpline, from a 'lived experience' perspective. We are hugely grateful for all they do.

Volunteers attended bi-monthly online information evenings and buddy support groups, initiatives set up during 2020. We are seeking feedback from our volunteers to inform future development.

Our volunteer training weekend went ahead face-to-face in September 2021. Sessions included wellbeing training delivered by Arthur Ellis Mental Health Support

in response to a rise in emotional support calls to the Helpline.

In 2022 we will further develop our induction and training programme for volunteers.

When asked for feedback, 100% of our helpline and talk and support volunteers told us they felt well supported by staff over the past 15 months.

100%
of our volunteers felt well supported in their role



Supporters Colin, Linda and their families and friends joined over 70 walkers for Hopefully to Seaview 2021 and took on a fantastic five mile route on the Isle of Wight, raising over £5,000.



“This organisation was built on volunteering by an extremely committed and determined group of people. I am humbled and amazed by all that you do for us in your spare time. We are all eternally grateful.”

Tina Garvey, Chief Executive

COLLABORATIVE WORK

We believe collaboration is key to making a lasting difference and we bring together charities and industry partners to achieve our shared goals.

We are proud to be a founding member of the VI Charity Sector partnership and our relationships with other charities supporting those living with sight loss continue to grow. We regularly collaborate with our partners in a number of key areas including: mental health and wellbeing; insight gathering; information sharing; access to technology; awareness raising and campaigning.

We believe by working together our voice is stronger and we can have a bigger impact for those we represent.

Legacies are an important source of income for Retina UK. Over the last four years, gifts in Wills and in memory totalled more than **£2.5 million.**



“We started supporting Retina UK in 2019, and have raised over £10,000. New inter-departmental relationships were developed and existing teamwork strengthened as employees from different areas of the company pulled together, competed against each other (good naturedly) and found out more about themselves and their colleagues, which was an unexpected and very welcome benefit from getting involved. I can honestly say that we got so much out of the experience and the support from the charity was second-to-none ...”

THE FUTURE

We have ambitious plans for the future, which are only possible thanks to the contributions we receive from our fantastic supporters. They include:

Research: We will continue to support medical research projects that seek to explore new ideas or test new theories. We invited applications for research grants in 2021 and received 12 preliminary submissions. Six of those projects have been invited to submit full applications for grants in the region of £200,000 - £250,000. A decision on these applications will be made in spring 2022.

We will publish a new research strategy to inform our future direction and involve our community and other key stakeholders in its creation.

Information and support: We responded to the COVID-19 pandemic by adapting and delivering more of our information and support provision online. This success has informed our decision to hold our 2022 conferences in hybrid form to enable delegates to join us in person or online. We continue to have an agile approach to events, offering digital alternatives wherever possible alongside our traditional face-to-face activity. We will continue to run monthly webinars and deliver a number of face to face information days around the UK.

Sight loss survey: To ensure we continue to meet our community's needs we will carry out a sight loss survey, tracking against our 2019

survey, to include new questions on wellbeing. The insight gained will inform our priorities for the second half of 2022 and 2023.

"Grants from trusts, foundations and corporate foundations are a vital source of income for us at Retina UK, they enable us to invest more into ground-breaking medical research and new and vital projects for our community."

"We are so grateful to each and every funder who has supported our work."

RETINAuk

WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

More than **25,000** people
in the UK live with inherited
retinal conditions.

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Retina UK is a Charitable Incorporated Organisation
(CIO), registered charity number: 1153851



"Thank you for organising such an excellent conference. It is wonderful to realise how much progress you are all making to help the VI community. It was a pity we were not able to meet in person, but it was good to be able to sit in the comfort of my lounge and listen in! Thank you to you and all the team."