



# THE DIFFERENCE WE MADE IN 2020

# 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.

The COVID-19 pandemic meant that doing things differently was a theme for 2020 and the whole Retina UK staff and volunteer team pulled together to ensure that our community was not alone.

- We prioritised the use of digital technology to connect with our community at a time when restrictions made face-to-face contact impossible.
- We contacted all those in our community who are happy to hear from us to remind them of

the information and support we provide, including our upgraded helpline.

- We updated our helpline and can now capture statistical information to help us continually improve the service.
- We expanded the audio content available through our podcast channel and now record all e-newsletters as well as our hard copy newsletter, *Look Forward*.

We rely entirely on the generosity of our supporters to fund our vital work. We are so grateful to everyone who found a way to contribute during a challenging year.

Retina UK supports people with conditions including:

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

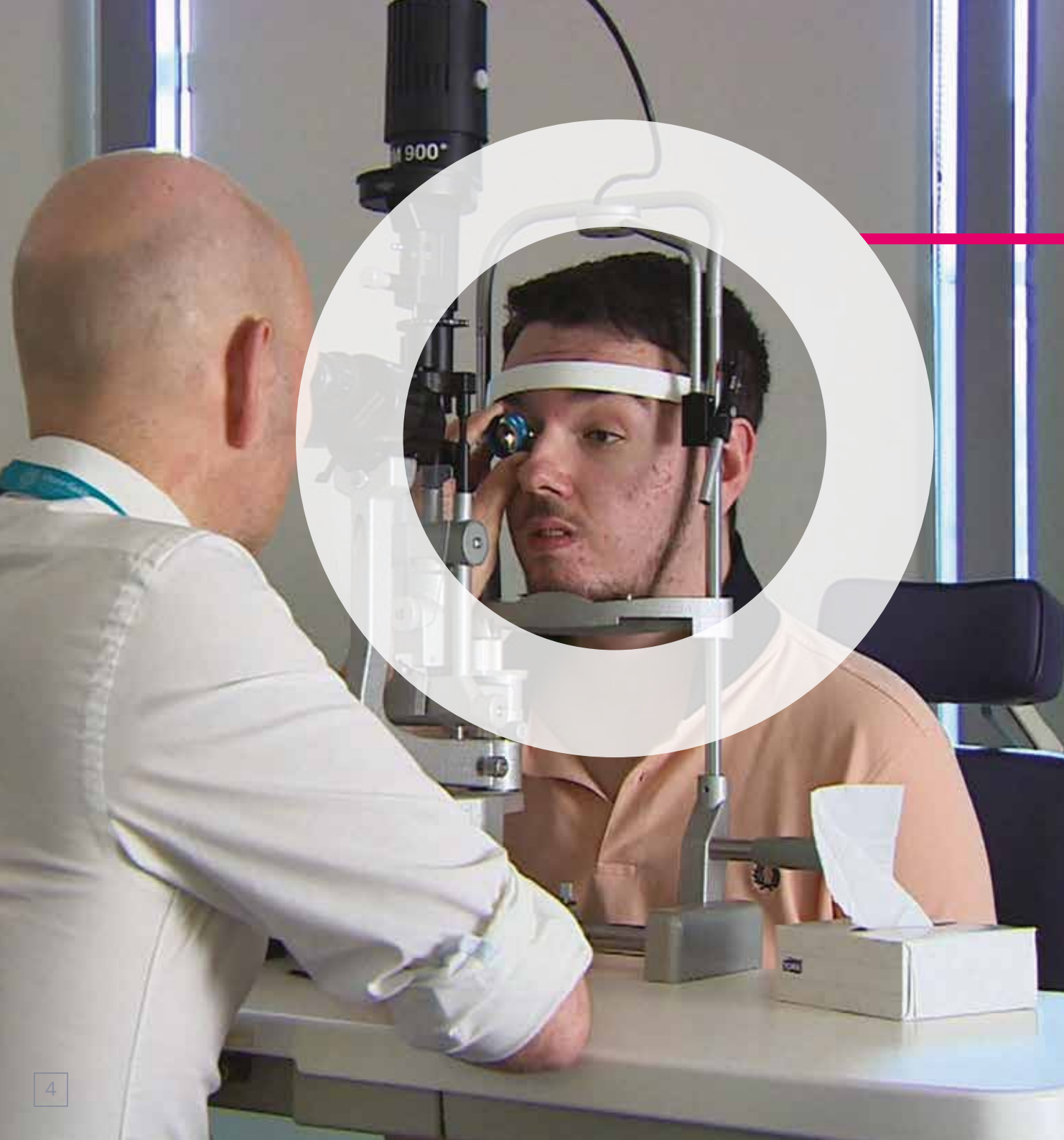
and many other inherited retinal dystrophies (IRDs).

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



***“I was at an extremely low ebb when I rang and a lady on the talk and support service spoke to me over the course of several weeks. I am certain without that support I would not have got through that horrible time and her words stay with me to help me through today. It is an absolutely brilliant and well needed service. I thank Retina UK with all my heart.”***

Jan – now training to be a volunteer on our helpline and talk and support service.



***"I never imagined in my lifetime there would be a treatment available on the NHS. 2020 was such a difficult year for everyone, but for me it was also the best year of my life."***

Jake Ternent, the first person in the UK to be treated with Luxturna on the NHS.

In 2020 we invested

**£610,000**

in medical research

## SEARCHING FOR TREATMENTS

The pace of progress in research into inherited retinal conditions is increasing.

As the UK locked down in March 2020 many researchers, including those working on Retina UK projects, were midway through research that had been making excellent progress. Although they carried on analysing data and writing papers at home, their experimental work was severely disrupted. We are determined to continue to support our fantastic researchers as they get things back up and running, so that they can make the breakthroughs our community needs.

The results of our sight loss survey in spring 2019 were presented to the National Institute for Health and Care Excellence (NICE) committee later that year as part of the evaluation process to offer the gene therapy, *voretigene neparvovec*

(Luxturna) on the NHS. Their evaluation document specifically quotes our findings on mental health impact and concludes: 'The committee acknowledged that RPE65-mediated IRD is a rare, serious and debilitating condition that severely affects the lives of patients, families and carers'.

In January 2020 Jake Ternent became the first person in the UK to be treated with Luxturna on the NHS.

In 2020 we spent £610,000 on medical research, continuing to fund the very best scientists working on 11 ground-breaking research projects.

### RESEARCH FUNDED IN 2020

The focus of our research in

2020 was understanding the mechanisms of disease along with the identification of causative genes to help to inform the development of future treatments.

Research funded by Retina UK has also investigated innovative gene therapy delivery systems and gene-editing technology.

We also put members of our community in touch with scientists, an important part of our work. Interaction between those living with inherited retinal dystrophies (IRDs) 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.

## HELPING PEOPLE TO LEAD FULFILLING LIVES

Families affected by inherited retinal conditions may experience emotional, physical and psychological challenges. We ensure no one need face these alone.

The COVID-19 pandemic seriously disrupted our planned information and support activity in 2020 and the theme for the year became 'doing things differently'. It did, however, accelerate our plans to connect digitally with our community, including many people who have never attended our face-to-face events.

In 2020 892 new contacts told us they were happy for us to stay in touch, including 785 individuals and 43 companies.

We were in touch with 7,219 people affected by inherited sight loss.

We held six online / phone local peer support group meetings in 2020 for those living in London, Scotland,

Birmingham and Somerset. The meetings were recorded and then shared with group members who were not able to attend on the day.

Our volunteers, all of whom are affected by progressive sight loss, provided emotional and practical information and support through our helpline and talk and support services. They responded to more than 1,800 helpline calls and emails in 2020. This was more than 20% higher than in 2019. Call lengths also increased.

- 100% of our callers who gave feedback would use the service again and / or recommend it to others
- 100% of our callers who gave

feedback were very satisfied / satisfied with the service.

Our e-newsletters keep our community up to date with news and information. We sent out 43,230 copies of our newsletter, *Look Forward*, in print, email, CD, memory stick and braille in 2020.

***"The information you provided was of the highest quality. The empathy and understanding you showed and the level of service was outstanding."***

Telephone helpline service user



***“Retina UK can offer something that patients need which I can’t provide – being able to talk to someone else living with the condition. It’s invaluable to me to know I can give your number and whenever they need it, they know someone is there.”***

Eye Clinic Liaison Officer

***“Thanks so much for hosting the London group meeting today! It was fantastic to come together and share experiences, now more than ever given how the restrictions have made travelling and socialising harder.”***

Joe, local peer support group member

## OUR FANTASTIC SUPPORTERS

In 2020, thanks to the ongoing commitment of our supporters, we raised £2,128,000 to fund our work. This included significant legacy income received late in the year.

Our amazing supporters continued to train and fundraise as part of challenges that were postponed / delayed. They raised money for us in a COVID-19 safe way with virtual challenges and online quiz sessions.

We also applied for and secured a BBC Lifeline appeal in 2020, which not only raised a considerable amount of money but also helped to raise awareness of inherited sight loss conditions.

In 2020 we were fortunate enough to receive gifts in wills kindly left to us by 14 generous supporters. Their contributions made a huge difference to the activities we have been able to carry out for the inherited sight loss community and the research we can invest in.

### HIGHLIGHTS OF 2020

- Despite the global pandemic, our community still managed to support us to the tune of £201,905
- Our community took part in a range of fundraising events and challenges, raising £134,381
- Our corporate supporters contributed £129,151
- Grants from charitable trusts and foundations totalled £264,494
- Our three appeals raised:  
£35,521 BBC Lifeline Appeal  
£45,816 The Big Give  
£17,040 Christmas Raffle

***“Close friends of mine have retinitis pigmentosa and I’ve witnessed first-hand the amazing work Retina UK does to fund ground-breaking research. I’ve really enjoyed this challenge, with everyone confined to their own houses it’s been a great way to fundraise.... my family and friends have been extremely supportive, despite many a joke about how I might get a bit dizzy!”***

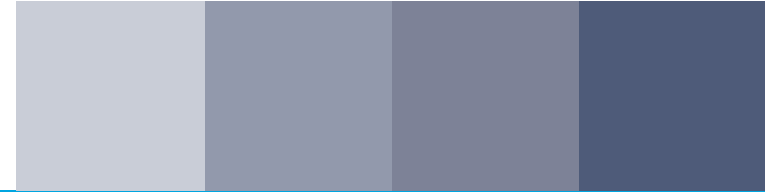
David, who ran 50 miles in his garden





*Sophie took on a wing-walking challenge*

# OUR 2020 IN NUMBERS



Total funds raised



**£2,128,494**



**£610,000**

Invested in medical research



**£327,049**

Committed to research projects



**£460,702**

Spent on information and support



**11**

Research projects supported

We are in touch with

 **7,219**

people affected by inherited sight loss

 **892**

New people began accessing our information and support

 **1,805**

Helpline calls and emails responded to

 **125**

People attended our local group meetings

 **1,714**

Podcast plays

 **10,921**

Online support group members

 **43,230**

Copies of *Look Forward* shared

 **1,021**

New Followers on Social Media

## VOLUNTEERS

**Volunteers founded our charity 44 years ago and they continue to be at our heart.**

We simply could not deliver our information and support services without our dedicated volunteers. Our helpline, talk and support service and local peer support groups rely on their commitment.

We developed new wellbeing training for our volunteers to support them to maintain their own wellbeing and to enable them to better support our community. This was rolled out in the autumn via video / audio modules on:

- Wellbeing in general
- Identifying how you are feeling
- Using protective and maintenance factors to balance / improve your wellbeing.

While we were unable to run our face-to-face training weekend, we maintained regular contact with our helpline volunteers through two new initiatives.

- Our bi-monthly group Zoom provides an opportunity to update on organisational activity, share information and offer support.
- Our buddy support groups. Five small groups of volunteers meet bi-monthly to share how they are feeling, discuss how they are using the new wellbeing modules, and offer peer-to-peer support.

***“Our volunteers are so upbeat, cheerful and hard working. We couldn’t wish for a better group of people to support us during these incredibly challenging times. From the very bottom of my heart, thank you.”***


Tina Houlihan, Chief Executive

***“I’ve never felt more welcome and part of a team than I do with Retina UK.”***

A Retina UK volunteer

# 100%

of our volunteers who gave feedback felt well supported in their role



***“I actually cannot believe I’ve raised £2,000 (my original target was £300!!). I am truly grateful for the sheer generosity of everyone who donated and supported me. By doing this challenge it has raised awareness amongst my family and friends of the incredible work Retina UK does – this makes it doubly worthwhile.”***

Miri - who took on a John O’Groats to Land’s End virtual cycle around her neighbourhood

## WORKING IN PARTNERSHIP

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

By working together our shared communities will reap the rewards of these partnerships.

A new Visually Impaired Charity Sector Partnership has been formed. The founding partners are:

Retina UK

Blind Veterans UK

Glaucoma UK

Guide Dogs

Macular Society

RNIB

Thomas Pocklington Trust

Visionary

The partnership will build on the work of Vision UK which closed in July 2020.



## 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 strategy:** We will create a new research strategy in consultation with our community and other key stakeholders in 2021. Research into the causes of, treatment for and impact of inherited sight loss is evolving. Our research strategy will reflect these changes to provide the best possible return on investment.

**Mental health support:** We will build on our existing modules and offer further volunteer training and a suite of wellbeing modules for our community in accessible formats.

**Supporting our volunteers:** We will continue our bi-monthly online information evenings and buddy support groups which started

during the pandemic. We are seeking feedback to inform future development.

**Supporter journeys and process mapping:** We will audit our processes and communications with supporters across the whole charity and identify opportunities for improvement.

**Unlock Genetics:** We will provide high quality information on genetic testing and counselling for families affected by inherited sight loss, empowering them to make fully informed decisions about their lives, healthcare and family planning. The project was initiated as a direct result of our 2019 Sight Loss Survey, in which 43% of those

who responded said they were 'not aware' of genetic testing or they were 'aware of it but it is not available to me'.

**A hybrid approach:** We will continue to develop our digital information and support provision in 2021. We will explore offering a hybrid approach, with face-to-face events where possible, supported by online provision for those who are not able to, or do not wish to, travel.

**Sight Loss Survey:** We will carry out a second audience insight survey in spring 2022 (three years since our first sight loss survey). It will include additional questions on mental health to help shape our planning and delivery.



WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

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

#### OFFICE

PO Box 350, Buckingham,  
MK18 1GZ (UK)

**01280 821 334**

**info@RetinaUK.org.uk**

**RetinaUK.org.uk**



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

*Martin from Euroglaze  
cycled 1,000 km from  
his garage*

