



**RETINA** UK

# Are you supporting someone with inherited sight loss?

A guide for professionals

**We are here to help**

[RetinaUK.org.uk](http://RetinaUK.org.uk)



## Quick guide:

Website:

**[RetinaUK.org.uk](https://RetinaUK.org.uk)**

Helpline:

**0300 111 4000**

**[helpline@RetinaUK.org.uk](mailto:helpline@RetinaUK.org.uk)**

Discover Wellbeing:

**[RetinaUK.org.uk/wellbeing](https://RetinaUK.org.uk/wellbeing)**

Unlock Genetics:

**[RetinaUK.org.uk/genetics](https://RetinaUK.org.uk/genetics)**

Newsletters:

**[RetinaUK.org.uk/resources](https://RetinaUK.org.uk/resources)**

Recordings:

**[RetinaUK.org.uk/recordings](https://RetinaUK.org.uk/recordings)**

Local groups:

**[RetinaUK.org.uk/groups](https://RetinaUK.org.uk/groups)**

Contact details:

**[RetinaUK.org.uk/contact](https://RetinaUK.org.uk/contact)**



Sign up to receive regular updates at:

**[RetinaUK.org.uk/subscribe](https://RetinaUK.org.uk/subscribe)**



**“Thank you to Retina UK for supporting people with inherited sight loss so fantastically on their journeys and for educating the rest of us to commit to making our corner of the world a more understanding and inclusive place.”**

## **Who are we?**

Retina UK\* is a national charity. We offer information and support to people affected by inherited sight loss to enable them to lead better lives today and fund medical research to accelerate the search for treatments for the future. We also support professionals working with them.

### **We are here for you. You could be:**

- An Ophthalmologist
- An Eye Care Liaison Officer
- A Vision Rehabilitation Specialist
- A Qualified Teacher of the Visually Impaired
- A Dispensing Optician or Optometrist
- A Genetic Counsellor

\*Retina UK was previously known as RP Fighting Blindness and the British Retinitis Pigmentosa Society (BRPS).



## What is inherited sight loss?

Inherited progressive sight loss is caused by a range of rare genetic conditions. We specialise in those which affect the retina, including:

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

... and many more inherited retinal dystrophies.

Inherited retinal dystrophies (sometimes called IRDs) are the most common cause of sight loss in the working age population of the UK\*, affecting tens of thousands of people. Diagnosis can be made at any age and leads to partial or full loss of sight.

## Diagnosis

Early signs of an inherited retinal dystrophy are sometimes picked up during a routine eye test. The optician will refer on to an ophthalmologist at an eye clinic for further tests, leading to a formal diagnosis.

The cause of these conditions is genetic and they cannot be prevented. Progression can vary from person to person. Some people are affected as children and others as adults. Everyone's experience is different.

\*<https://bmjopen.bmj.com/content/4/2/e004015>



## How we can support you in your role

Whether you are a professional looking for practical information for yourself, or practical or emotional support for your clients, online, by phone or face-to-face, we're here to help. All of our services are free to access and offered in a range of accessible formats. These include:

### **Website – [RetinaUK.org.uk](https://www.RetinaUK.org.uk)**

A wealth of information on inherited sight loss, available support and current research. This includes a section specifically for professionals.

### **Helpline: 0300 111 4000 | [helpline@RetinaUK.org.uk](mailto:helpline@RetinaUK.org.uk)**

Our Helpline team are here to support you and your clients. They can answer your questions and signpost to other sources of information. Those affected by inherited sight loss can speak with our volunteers with lived experience.

### **Discover Wellbeing – [RetinaUK.org.uk/wellbeing](https://www.RetinaUK.org.uk/wellbeing)**

Our online course helps people affected by inherited sight loss to develop an awareness of emotional wellbeing and the practical skills to adapt to life's ups and downs. It includes a CPD-accredited course called Supporting Others, designed specifically for professionals.

### **Unlock Genetics – [RetinaUK.org.uk/genetics](https://www.RetinaUK.org.uk/genetics)**

Our Unlock Genetics resource provides clear, trustworthy and balanced information on genetics, inheritance patterns, accessing a genetic test and genetic counselling. It also provides information on how to make appropriate referrals for genetic counselling and testing.



## **Events – [RetinaUK.org.uk/info-events](https://RetinaUK.org.uk/info-events)**

We hold events online and face-to-face, including our Annual Conference and Professionals' Conference. We also organise webinars for professionals and those living with inherited sight loss.

## **Newsletters – [RetinaUK.org.uk/resources](https://RetinaUK.org.uk/resources)**

Sign up to receive the latest news from Retina UK, including our emails specifically for professionals. Choose which format is best for you.

## **Talks and presentations**

Our staff and community members with lived experience are happy to share their knowledge and expertise. We regularly deliver presentations for groups of professionals online and in person. Interested? Email [services@RetinaUK.org.uk](mailto:services@RetinaUK.org.uk).

## **Peer Support Groups – [RetinaUK.org.uk/groups](https://RetinaUK.org.uk/groups)**

Groups meet in person or virtually and are a welcoming, safe and friendly place for people to share experiences, tips and information and form friendships.

## **Other resources**

- YouTube (@RetinaUK)
- Podcast on Spotify, Apple and Google podcasts,
- Facebook groups:
  - [facebook.com/groups/retinuklocal](https://facebook.com/groups/retinuklocal)
  - [facebook.com/groups/therpgroup](https://facebook.com/groups/therpgroup)

Sign up to receive our information [RetinaUK.org.uk/keep-in-touch](https://RetinaUK.org.uk/keep-in-touch), email [info@RetinaUK.org.uk](mailto:info@RetinaUK.org.uk) or call 01280 821334.



**“The conference was well organised and presented, and had a very interesting range of knowledgeable, engaging speakers. I have been inspired to explore the issues raised further, so that I can better support my clients.”**

## **Our research**

Retina UK has invested more than £16.5 million into cutting-edge research since we were founded in 1976. We are proud to support some of the best scientists and clinicians in the fields of ophthalmology and genetics and we are committed to driving forward high quality research into causes and treatments.

We will keep you up-to-date with the latest research news via our website, newsletters and events.

We are determined to build on the progress that has already been made, maintaining momentum and driving forward the best and most promising research into inherited retinal dystrophies and possible treatments. Our ability to do so depends entirely on the contributions we receive from our fantastic supporters.

Retina UK is the voice of the inherited sight loss community.



**"I have attended a few webinars now and I find them very interesting and informative. The speakers are great and always relevant topics."**

**We are here to help**



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Retina UK is a Charitable Incorporated Organisation (CIO),  
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