



**Are you affected by
inherited sight loss?**

We are here to help
[RetinaUK.org.uk](https://www.RetinaUK.org.uk)



Quick guide:

Website:
RetinaUK.org.uk

Helpline:
0300 111 4000
helpline@RetinaUK.org.uk

Local groups:
RetinaUK.org.uk/groups

Discover Wellbeing:
RetinaUK.org.uk/wellbeing

Unlock Genetics:
RetinaUK.org.uk/genetics

Newsletters:
RetinaUK.org.uk/publications

Recordings:
RetinaUK.org.uk/recordings

Contact details:
RetinaUK.org.uk/contact



“Since my diagnosis of Retinitis Pigmentosa four years ago, I have reached out to Retina UK several times and have always been moved by their compassion and understanding.”

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 are here for you. You could be:

- Recently diagnosed
- Living with inherited sight loss for a while
- Someone with a family history of the condition
- A family member or friend of someone affected
- A professional providing support.

*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

Whether you are looking for practical information or emotional support, 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

A wealth of information on inherited sight loss, available support and current research.

Helpline: 0300 111 4000 | helpline@RetinaUK.org.uk

Our Helpline is run by volunteers with lived experience of inherited sight loss. They can answer your questions and signpost to condition-specific information, benefits, employment and education or offer a listening ear.

Talk and Support

Our Talk and Support service links people who may be feeling isolated or lonely with a volunteer for regular contact. Request a referral via our Helpline.

Local Peer Support Groups – 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.

Discover Wellbeing – 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.



Unlock Genetics – 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.

Events – RetinaUK.org.uk/info-events

We hold events online and face-to-face, including our Annual Conference and Professionals' Conference and our Webinar series.

Newsletters – RetinaUK.org.uk/publications

Sign up to receive the latest news from Retina UK, including our Look Forward magazine. Choose which format is best for you.

Other resources

- YouTube (@RetinaUK)
- Podcast on Anchor FM (<https://anchor.fm/retina-uk>). It is also available on Spotify, Apple and Google podcasts,
- Facebook groups:
 - facebook.com/groups/retinauklocal
 - facebook.com/groups/therpgroup

Sign up to receive our information RetinaUK.org.uk/keep-in-touch, email info@RetinaUK.org.uk or call our friendly team on 01280 821334.



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 will also provide you with opportunities throughout the year to ask questions directly to the researchers that are working hard to find future treatments.

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 our inherited sight loss community. By joining our Lived Experience Panel, you can get involved in focus groups, surveys and research projects. Make your voice heard! RetinaUK.org.uk/more-info



“Armed with this new knowledge that there are people like the volunteer support at Retina UK, I no longer want to retreat, I want to advance.”

We are here to help

RETINA UK

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RetinaUK.org.uk



Retina UK is a Charitable Incorporated Organisation (CIO),
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