



WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

# THE DIFFERENCE WE MADE IN 2018



**RETINAUK.org.uk**

Registered charity number: 1153851

# 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 fund medical research to understand these complex conditions and speed up the search for treatments and we provide information and support services to help more people lead fulfilling lives.

In 2018, in consultation with our community, we changed our name from RP Fighting Blindness to Retina UK.

Our new brand is more relevant, recognisable, accessible and inclusive. It is enabling us to raise our profile, reach more people

and grow income to achieve our vision of a world where everyone with inherited sight loss is able to live a fulfilling life.

In the first six months from launch, the number of new people asking to be added to our database quadrupled and we recorded a 12% increase in income.

We rely entirely on the generosity of our fundraisers and partners to fund our vital work. A heartfelt thank you to all those who support us.

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.



***“Without this charity I wouldn’t have any passion or get-go in life. I’m always finding ways to help and promote it.”***

Emily Millichip, who lives with retinitis pigmentosa



***“A huge thank you to supporters of Retina UK who donate time and money so that researchers like me can receive funding. Their generosity allows me to work on this project and pays for essential laboratory equipment, all of which is critical to gaining new insights into the development and progression of diseases.”***

Dr Jenny Dewing, Retina UK-funded postdoctoral researcher

## SEARCHING FOR TREATMENTS

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

The first licenced gene therapy treatment for an inherited retinal condition won European approval in 2018. We are determined to build on this momentum, to find more treatments and make these available as soon as possible.

In 2018 we spent £450,000 on medical research, continuing to fund the very best scientists working on eight ground-breaking research projects. We also agreed to invest in four new projects with a total commitment of £679,000.

This included researchers hunting for new genes and scientists probing more deeply into those already identified. Their discoveries are

leading to the creation of new potential therapies and real hope for future treatments.

We continued to fund work to explore gene therapies and the testing of these in the lab and on patients. This includes how to overcome the challenges of delivering therapies, so that a larger number of our community can benefit.

Scientists we fund have developed new ways to screen promising drugs. Their work is leading to a better understanding of the unique characteristics of retinal cells and the causes of inherited retinal conditions.

In 2018 our first joint-funded PhD student began work as we strive to develop early career researchers, to harness their talent and enable them to grow their careers in retinal dystrophies research.

We also put members of our community who want to get involved in research in touch with scientists, an important part of our work.

In 2018 we spent

**£450**

**THOUSAND**

on medical research

## HELPING PEOPLE LEAD FULFILLING LIVES

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

During the year, we were in regular contact with 6,069 people affected by inherited sight loss, including 906 people who were new to our charity.

Membership of our online support groups grew to almost 6,000. These provide a positive place for families to share their knowledge and experiences and offer mutual support.

We know a diagnosis can be isolating, that's why we connect people. In 2018, 547 people who live with, or support those with, inherited sight loss attended our annual conference and information days and we met 471 more at other sight loss events.

Our growing number of volunteer-led peer support groups enabled people to meet others in their local areas.

Volunteers affected by progressive sight loss provide emotional and practical information and support through our helpline and talk & support services. They responded to 961 helpline calls and emails in 2018.

We launched our fantastic new website in October 2018. It hosts a wealth of information about research news, inherited sight loss conditions, and where to find support. We also gained 833 new followers on Facebook and Twitter.

Our e-newsletters keep our community up to date with news and information. We sent out 17,257 copies of our members' newsletter, *Look Forward*, in print, email, CD and braille in 2018.



We were in touch with

**6,069**

people affected by inherited sight loss.



***“It was so great to meet others who knew exactly what my own issues are, and who could offer some really helpful tips. This was the first time I had got to meet other people with retinitis pigmentosa. I wish I hadn’t waited so long.”***

Local peer support group attendee

## OUR FANTASTIC FUNDRAISERS AND PARTNERS

**In 2018, thanks to the ongoing commitment of our supporters, we raised £1,732,000 to fund our work. We receive no statutory funding.**

Our amazing fundraisers baked, sang, played, danced, cycled, collected, swam, ran and found all sorts of other innovative ways to raise money towards our vital work.

We are hugely grateful for all of their efforts. We were also humbled to be named as a beneficiary in the wills of committed and generous supporters, who have together helped to secure the future of our charity.

We developed meaningful relationships with a number of businesses. These not only supported us financially but also enhanced the experience of those who attended our events and enabled our community to get involved in developing new technologies and possible future treatments.

### HIGHLIGHTS OF 2018:

- Individual donations from our community totalled £686,000
- We were grateful to be remembered in the wills of several supporters, who donated £392,400
- Our community took part in a range of fundraising events and challenges, raising £229,900
- Grants from charitable trusts and foundations totalled £186,200

We believe that **collaboration is key to achieving success.** In 2018 we worked in partnership with **around 50 organisations** and charities that share our aims and values.

During 2018 we received significant contributions from the following funders, partners and corporate supporters:

- Cllr Terry Waters & Mrs Elizabeth Waters, Mayor and Mayoress of North Warwickshire (2017-2018)
- Fighting Blindness Ireland
- Fight for Sight
- G C Gibson Charitable Trust
- G W Cadbury Charitable Trust
- Hospital Saturday Fund
- International Steel Trade Association
- MeiraGTx
- Nineteen Eighty-Nine Charitable Trust
- OxSight
- The Peter Stebbings Memorial Charity
- Thomas Pocklington Trust

***“The race was hard, but seeing the Retina UK team made me so happy - the sense of belonging and my purpose for raising money. I felt like I gained a second breath. This experience has been great, I never realised how generous people are.”***

Big Half marathon runner Rita Pakalniskyte, who lives with retinitis pigmentosa



# OUR 2018 IN NUMBERS

Total Funds Raised



# £1,732,000



# £450,000

Spent on medical research



# £696,000

Committed to research projects



# £420,869

Spent on information and support



# 12

Research projects supported

We are in touch with

 **6,069**

People affected by inherited sight loss

 **906**

New people joined our charity

 **961**

Helpline calls and emails responded to

 **547**

People attended our information events

 **100**

Volunteers supported our work

 **6,000**

Online support group members

 **17,257**

Copies of *Look Forward* shared

 **833**

New Followers on Social Media

## OUR DEDICATED VOLUNTEERS

Volunteers founded our charity 43 years ago and they continue to be our lifeblood.

Those members of our team who donate their time and skills are highly valued and work closely with staff to enable us to make the biggest difference together.

While some support us for a one off activity, other volunteers have made a long-term commitment. Everyone's contribution is greatly appreciated.

Volunteers support with many of our activities including our helpline, talk & support service and local peer support groups, which meet around the UK. All those involved in these services have personal experience of inherited retinal conditions.

We are hugely grateful to all those who generously give their time and enable us to benefit from their wide range of skills and experiences.

***“The talk & support service is brilliant. It makes such a difference being able to chat with someone who understands what it's like. I've never had that before.”***

Talk & support service user

- 85% of Retina UK volunteers feel supported in their role
- 81% of Retina UK volunteers told us they get a sense of personal achievement through volunteering
- 85% of Retina UK volunteers told us they get satisfaction from seeing the result of outcomes from giving their time

# 100

Volunteers supported our work



***“It’s been brilliant to watch us grow from the British Retinitis Pigmentosa Society, to RP Fighting Blindness and now Retina UK. I have made many friends and been glad to help newly diagnosed families.”***

Stephen, Retina UK volunteer

## LEADING THE WAY

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

Our unique Working Age Group Project aims to better understand the challenges people with inherited sight loss face in their working lives and identify gaps in services they would benefit from.

During 2018, hundreds of people contributed their views and experiences to this project, which was led by Retina UK, funded by Thomas Pocklington Trust and supported by Visionary and RNIB. We are using this evidence to improve our information and support services and sharing our findings with others to influence them to do the same.

In 2018 we founded IRD COUNTS, a consortium of charities and industry partners aiming to establish the prevalence, financial cost and impact of inherited retinal dystrophies in the UK and Republic of Ireland.

The findings of this project will prove invaluable as we build evidence to prepare society and the NHS for a new generation of highly-specialised cutting-edge treatments such as gene therapy.



## THE FUTURE

We are innovative, passionate and proud to be at the forefront of a number of ground-breaking projects.

We are ambitious. We want to do more of what we do best – providing information and support and funding research.

Our community is at the heart of everything we do. We listen to families affected by inherited sight loss to understand their needs and ensure we make the biggest difference.

In 2019 we will survey our community and use the findings to create a strategy to set out our priorities for the next five years.

With the continued support of our fundraisers, partners and volunteers in 2019 we will:

- Fund new research projects to continue to search for causes and treatments
- Raise awareness of our charity to enable more families to access our support
- Ask our community what matters to them so that we can best meet their needs
- Grow our relationships with relevant professionals to encourage them to signpost to us
- Enhance the practical information we provide to enable people to live more fulfilling lives
- Hold more events around the UK to provide information and enable people with inherited retinal conditions to get together
- Involve volunteers in new areas of our work to enable us to do more.



***“As a family we actively fundraise and donate to Retina UK, a positive way to make a difference for Thomas.”***

Hannah Baker, mum of five year old Thomas who lives with Usher syndrome

# RETINA UK

WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

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

**HELPLINE**  
0845 123 2354  
[helpline@RetinaUK.org.uk](mailto:helpline@RetinaUK.org.uk)

## OFFICE

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

**01280 821 334**

[info@RetinaUK.org.uk](mailto:info@RetinaUK.org.uk)

