

THE DIFFERENCE WE MADE IN 2017



WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

We are Retina UK - the leading UK charity dedicated solely to working for people affected by inherited retinal conditions.

Our vision is a world where everyone with inherited sight loss is able to live a fulfilling life.

By stimulating and funding medical research, we increase the understanding of inherited retinal conditions and accelerate the search for treatments for the future.

The information and support we provide helps people lead better lives, today. We aim to ensure no-one with inherited sight loss need feel alone.


We are in the unique position of being small enough to listen and respond to our community's needs but with a big enough reputation to make our voice heard by those who matter.

While we are proud of the difference we made in 2017, we want to do so much more; with our passion and hard work, and the ongoing support of our amazing community, we will make our vision a reality.

Retina UK is the new name for RP Fighting Blindness. Our aims remain unchanged.

“Our new name marks a pivotal moment in our history. The team and I have ambitious plans for the future, to do even more of what we do best - funding cutting-edge research and supporting families living with inherited sight loss conditions.”

Tina Houlihan,
Chief Executive, Retina UK



“We are more positive about what’s ahead. We feel less isolated and alone. It has made us more determined to help others.”

Information Day attendee



“Researchers like myself quite simply wouldn’t be able to carry out many of our exciting projects without the funding we receive from Retina UK. We are hugely grateful to the charity’s supporters who make our research possible.”

Dr Mariya Moosajee, clinician scientist and Retina UK-funded researcher

In 2017 we invested

£612

THOUSAND

in research.

SEARCHING FOR TREATMENTS

We want to find treatments for inherited progressive sight loss as soon as possible – that’s why we bring together the very best scientists and fund ground-breaking research projects.

During our 42-year history we have invested over £16.6 million in medical research. In 2017, our total spend on research was £611,842. We provided ongoing funding to eight promising projects and approved funding for four exciting new ones.

The UK Inherited Retinal Dystrophy Consortium, a hugely successful consortium of the University of Leeds, London’s UCL Institute of Ophthalmology, Manchester Royal Eye Hospital and Oxford University Eye Hospital, has continued to gather momentum. The team has identified five new disease-causing genes and mutations, found the genetic basis for disease in more than 230 families and published 17 papers.

Other researchers we fund are exploring the potential application of existing drug therapies, progressing the use of gene therapy and furthering our understanding of, and potential treatments for, Stargardt disease and Usher syndrome.

Our rigorous peer review process means we are confident we only fund the highest quality research, while our size means we can be flexible and quick to respond to exciting new research opportunities.

We also play an important role in facilitating conversations between our community, scientists and clinicians, including raising awareness of opportunities to take part in clinical trials and be part of the discovery of future treatments.

HELPING PEOPLE LEAD FULFILLING LIVES, TODAY

While we search for treatments for the future, we provide information and support for today.

In 2017, we were in touch with 4,719 people affected by inherited sight loss, an increase of eight percent on the previous year.

We brought together 436 people at our popular Annual Conference and Information Days. This included our first Families' Conference which was attended by 135 people, including 13 families who were new to us. The event was a great success and many people told us they left feeling more positive about the future.

Our phone and email helpline volunteers all know what it's like to be affected by sight loss, as do our volunteer befrienders. They responded to 1,046 helpline calls and emails in 2017.

More than 65,000 people visited our website in 2017, which hosts a wealth of information about inherited sight loss conditions, how to access support, and published and current research. We also gained 943 new followers on our growing social media channels.

Our online support groups provide a positive place for people affected by inherited sight loss to connect with others, share knowledge and experiences and offer mutual support. Membership of these groups reached 5,286 in 2017.

Look Forward, our members' magazine, and regular e-newsletters keep our community up to date with the latest news and information.

We sent out 16,751 copies of *Look Forward* in print, email, CD and braille in 2017.

We could not provide the support we do without the dedication of our amazing volunteers - we are so grateful to them all.



We were in touch with

4,719

people affected by inherited sight loss.



“My family and I met some truly wonderful and inspirational people... I can honestly say it’s changed the way I feel about retinitis pigmentosa. I don’t feel so alone having met, face to face, other people who actually understand my condition.”

Families’ Conference attendee

OUR AMAZING SUPPORTERS

In 2017 we raised £1,152,733 and, as always, our dedicated supporters went to incredible lengths to raise these funds.

Across the country, amazing people braved the elements to hold bucket collections, baked up a storm in the kitchen and partied the night away at fundraising galas and dinners to raise the vital funds we need for our research and services.

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

We developed meaningful relationships with a number of businesses that not only supported us financially, but also enhanced the experience of those who attended our events.

FUNDRAISING HIGHLIGHTS OF 2017:

- 11 intrepid trekkers tackled the West Highland Way to raise £22,666
- More than 85 amazing donors raised £25,319 through our first ever participation in the Big Give Christmas Challenge!
- 15 dedicated runners pushed themselves to the limit to complete the Virgin London marathon, raising £43,995
- 600 enthusiastic audience members attended 'Workshop's Got Talent', raising £6,574
- Our wonderful community got into the festive spirit, raising £19,163 through our Christmas raffle
- Our generous corporate supporters contributed £26,330.

We believe that **collaboration is key to achieving our success**. In 2017 we worked in partnership with **more than 40 charities** and organisations that share our aims.

We received significant contributions from the following funders, partners and corporate supporters:

- Allergan International Foundation
- The Carmen Butler-Charteris Charitable Trust
- The Desmond Foundation
- The Hospital Saturday Fund
- The Inman Charity
- Network Rail
- Nineteen Eighty-Nine Charitable Trust
- Second Sight
- Sir Samuel Scott of Yews Trust
- Spark Therapeutics
- The Tedworth Charitable Trust
- The Thomas Pocklington Trust

“The London marathon is the perfect place for fundraising and, for me, knowing that I am running the race for such a worthwhile cause, and with all the support of my sponsors, really does motivate me to keep going and get to the finish line!”

Tim Robinson, marathon runner, inspired by his grandmother



OUR 2017 IN NUMBERS

Total Funds Raised



£1,152,733



£26,330

From Corporate Sponsors



£25,319

From the Big Give Christmas Challenge



£19,163

From our Christmas Raffle



£611,842

Invested in Medical Research



£555,205

Spent on Services



12

Research Projects Supported

We are in touch with

 **4,719**

People Affected by Inherited Sight Loss

 **40**

Active Collaborations

We are in contact with

 **264**

Healthcare Professionals

 **15**

London Marathon Runners

 **5,286**

Online Support Group Members

 **943**

New Followers on Social Media

 **1,046**

Helpline Calls and Emails

 **3,460**

Twitter Followers

THE FUTURE

We have ambitious plans for the future. We want to do more of what we do best - supporting people affected by inherited sight loss and funding pioneering research.

WITH THE ONGOING SUPPORT OF OUR FUNDRAISERS, PARTNERS AND VOLUNTEERS IN 2018 WE WILL:

- Establish our new brand, Retina UK
- Launch our new website
- Adopt a regional approach to service provision
- Increase the number of people we are in touch with
- Set up our first Pioneering Research Centre
- Grow our volunteer numbers
- Publish the findings of our Working Age Group Project.



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

“This is the most encouraging time for our charity. We have a very dedicated team working hard to achieve our goals and I believe we are ever closer to an effective treatment for inherited sight loss.”

Don Grocott, Chair of the Board of Trustees

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