



**Retina UK**

**A Charitable Incorporated Organisation**

**Annual Report & Financial Statements**

**Year Ending 31 December 2018**

**Registered Charity Number 1153851**

## Retina UK

### Reference and administrative details

For the year ending 31 December 2018

---

<b>Charity number</b>	1153851
<b>Registered office and operational address</b>	Retina UK PO Box 350 Buckingham MK18 8GZ
<b>Telephone</b>	01280 821334
<b>Email</b>	info@RetinaUK.org.uk
<b>Website</b>	www.RetinaUK.org.uk
<b>Honorary President</b>	Mrs Lynda Cantor MBE
<b>Trustees</b>	Trustees who served during the year and up to the date of this report were as follows:  Mr Don Grocott (Chairman) Mr Roger Backhouse Mrs Lynda Cantor MBE Ms Janet Crookes FCA (Treasurer) Dr Elizabeth Graham Mr Stephen Jones (until 23 June 2018) Mr Colin McArthur Prof John Marshall MBE Mrs Rachael Stevens Mr Keith Valentine Dr Lucy Withington
<b>Ambassadors</b>	Mrs Bhavini Makwana Mr Steven Bate MBE  Mrs Seema Flower Mrs Victoria Claire
<b>Chief Executive Officer</b>	Mrs Tina Houlihan
<b>Principal Bankers</b>	Lloyds Bank PLC 187 Watling Street Towcester NN12 6BX
<b>Auditors</b>	Baldwins Audit Services Statutory Auditors Pillar House 113 - 115 Bath Road Cheltenham GL53 7LS

This document is laid out in size ten font, but can be magnified if you are using an electronic version. If you are visually impaired and would like a copy of this document in large print, please contact us stating the font size most appropriate for your own use and we will be happy to provide this.

## Retina UK

### Chairman's Report

#### For the year ending 31 December 2018

---

2018 proved a productive, exciting and thoroughly satisfying year for our charity. Our core aims remain unchanged: funding pioneering medical research related to inherited retinal dystrophies and providing much-needed information and support to those affected with such sight loss. Serving our community through research and support means that we are able to provide care for today and hope for tomorrow.

2018 saw us fund a number of ground-breaking projects that further extend the understanding of inherited sight loss conditions. Notable examples are the RDH12 Project which is a three year project investigating Leber's congenital amaurosis caused by faults in the RDH12 gene, and a project based at the University of the Netherlands studying the identification and functional characterisation of the missing ABCA4 gene variants in Stargardt disease. You can learn more about these and the other medical research projects funded in 2018 later in this report.

The unique Working Age Group Project which is led by Retina UK, funded by Thomas Pocklington Trust and supported by RNIB and Visionary, completed its evidence gathering exercises in December 2018. This ground-breaking project is the first of its kind and is examining how our charity and others can assist in keeping those affected by inherited sight loss in employment as their condition progresses. We will be using the information gathered to formulate a collaborative cross-sector approach to tackle this very important issue.

Perhaps our most 'visible' achievement is our rebrand. This was no vanity exercise. The decision was over a year in the making, taking counsel from our members, the scientific community and various experts. We recognised that our old name was becoming outdated and so we were being missed by some members of the inherited sight loss community. It was essential that we resolved this. Retina UK was adopted as our new name. I am delighted at how well it has been received and feel sure it was the right decision for the future of the organisation.

The charity has a highly dedicated Trustee board with a wide range of talents. Around the table are people with strategic planning experience, scientific understanding, financial expertise and, especially important, people with insight to the issues faced by the visually impaired. Our engaged team of staff in Buckingham ably manage the charity's activities. They fundraise for our work, administer our medical research grants programme, provide information and support services, and communicate our achievements and progress to our members and to the wider public to further raise our profile. We are also fortunate to attract a great many volunteers who help us with our work across the UK - these people are vital and are the foundation upon which the charity has been built; without them we would not be here today.

I am excited for the future of Retina UK - we are seeing the fruit of earlier endeavours as the first treatments for inherited sight loss come to market. We continue to work closely with our partners in the sight loss sector and are delivering our services, information and support to more people than ever before. 2019 promises to be a significant one in our proud history and I am confident that we will make even greater progress in this coming year.



DJ Grocott  
Chairman  
8 May 2019

## **Retina UK**

### **Report of the Trustees**

#### **For the year ending 31 December 2018**

---

The Trustees are pleased to present their annual report together with the financial statements of the charity for the year ending 31 December 2018. The financial statements comply with the Charities Act 2011, the constitution, and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

### **Structure, Finance & Governance**

#### **Governing document**

Retina UK is a Charitable Incorporated Organisation (CIO). The charity's constitution was registered on 18 September 2013 as charity number 1153851 and amended on 19 June 2018. The charity was originally registered as the British Retinitis Pigmentosa Society, formed in 1976, and subsequently known as RP Fighting Blindness until June 2018. All the assets and liabilities of the original charity were transferred to the current Charitable Incorporated Organisation on the date of incorporation.

#### **Appointment of Trustees**

When appointing new Trustees the Board discusses the Trustees' skills requirements and seeks suitable potential candidates to match those needs. Candidates are interviewed by the Chairman and considered by the Board as a whole, sometimes after attending a Trustee meeting as an observer. If the Board approves the candidate and the candidate is willing to serve then they are appointed. The Board of Trustees will always include people affected by an inherited retinal dystrophy or with a family member who is affected. This ensures that the organisation remains focused on the charity's objectives. The Board however is also conscious of the need to include a range of appropriate skills.

#### **Trustee induction and training**

Trustees are responsible in law for financial and strategic management and this responsibility is taken very seriously. New Trustees complete an induction process based on briefings by staff, researchers and existing Trustees. When further training needs are identified these are met by attendance at external courses or by bespoke internal workshops. Trustees are expected to attend most Trustee meetings and the charity's annual conference, and to act in accordance with good practice guidance issued by the Charity Commission.

#### **Organisation**

The Board of Trustees comprises a minimum of three and a maximum of twelve members. The Board normally meets quarterly and is quorate for making decisions with a minimum of three fifths of Trustees present. At its meetings the Board reviews financial performance, the awarding and management of research grants, fundraising, and exposure to risk. The day to day management of the charity is delegated to the Chief Executive. The Board approves an annual operating budget and measures operational performance against this. Significant expenditure outside the budget must be authorised by the Board. The Board is supported by two sub-committees: the Remuneration Committee and the Audit Committee. These committees carry out reviews on behalf of the Board and report to the Board.

#### **The Executive Team**

The Trustees agree the operational plan and budget and delegate responsibility for day-to-day operations to the Chief Executive who is supported by staff and volunteers bringing valuable skills and experience to the charity.

#### **Membership of professional bodies**

The charity is a member of the Association of Medical Research Charities, Retina International and VISION 2020 UK and abides by each organisation's principles of best practice at all times.

## Retina UK

### Report of the Trustees

#### For the year ending 31 December 2018

---

##### Related parties

Trustees are required to declare details of related parties and if the charity considers purchasing goods or services from, or awarding a grant to, an organisation in which a Trustee has an interest, the potentially conflicted Trustee withdraws from any discussion on the awarding of the contract. The value of any contract subsequently awarded would be disclosed in these accounts.

##### Key Management Remuneration

The remuneration of the Chief Executive is set by the Chairman of the Board of Trustees in consultation with the Remuneration Committee.

##### Financial Review

Our income and expenditure for the year ended 31 December 2018, as shown in the Financial Statements, reflects the results of our efforts over recent years to develop our capability to grow income from a wider range of channels, collaborating with individuals, trusts and other organisations who share our aims. In an external environment that shows no signs of becoming less challenging we have been able to increase our total income to £1,732,373 (2017: £1,152,733).

Much of the additional income has been restricted to specific projects or areas of research. Some grants have already been awarded out of this income and the remainder is held in Restricted Funds at 31 December 2018. We expect to be able to release more of these funds in 2019.

In 2018 we made awards to medical research totalling £395,588 (2017: £390,553). Additional awards of £146,969 were delayed due to the late running of research projects but these will be progressed in 2019 when we expect to see significantly more funds being awarded both to new and ongoing projects.

Fundraising and support costs continue to be monitored and controlled in order to enable us to pursue all our objectives in the short and medium term using as little of the income raised by our hardworking staff, volunteers and fund-raising supporters as possible.

Our net increase in funds for the year of £414,776 (2017: decrease of £144,890) was after absorbing a reduction of £32,704 in the valuation of our small equity portfolio due to the condition of the equity markets at 31 December 2018. Total funds also reflect the further movement to holding restricted as opposed to unrestricted funds. We are working to ensure sufficient unrestricted income to support our operations and be able to support relevant medical research that would not otherwise attract funding.

At 31 December 2018 our Balance Sheet shows total funds of £982,878 (2017: £568,102). The Board is satisfied that this, together with our budget for 2019, will enable us to continue to deliver our charitable objectives.

##### Principal Funding Sources

The majority of our income is from voluntary sources, the key elements of which are the donations and fundraising efforts of individuals and groups across the UK. In addition to this we receive vital funds from corporate and trust donors, and are also privileged to receive a number of legacies. The Trustees are aware of the unpredictability of all these sources of income. The charity continues to develop all the income channels and very much appreciates the efforts of those who give us support.

##### Investment Policy and Objectives

The charity's investment policy remains unchanged: for any funds surplus to short term requirements we consider using secure deposits on fixed terms of up to one year. The charity holds equities in a CAF Balanced Growth Fund with the objective of gaining a return in excess of that available on short term deposits. This investment forms the core of the amount held under our Reserves policy and so is held for the long term.

## **Retina UK**

### **Report of the Trustees**

#### **For the year ending 31 December 2018**

---

We do not plan to increase our investment in equities as we will continue to seek to spend our income on suitable medical research projects and on information and support programmes.

#### **Reserves Policy**

The Trustees consider it appropriate to maintain unrestricted funds to cover six months budgeted essential expenditure which we see as adequate in the event of the charity being forced to wind up. At 31 December 2018 the target level of unrestricted funds remained unchanged at £280,000. Any additional unrestricted funds may be designated by the Trustees for research grants. At 31 December 2018 the general unrestricted funds were £280,111 (shown in Note 21).

#### **Risk management**

The charity has carried out a risk management review and has a risk register which identifies the risks to which the charity is exposed. These are evaluated and action taken to mitigate any significant risks. The Trustees review and update this register each year.

#### **Going Concern**

The Trustees review the financial position of the charity at each Board meeting. Budgets are prepared and approved annually and the Trustees are satisfied that there are no material uncertainties about the charity's ability to continue as a going concern.

#### **Future Plans**

While our charity adopted a new name in 2018, our objectives remain the same. We will continue to invest heavily in pioneering medical research and in improving service provision for those living with inherited retinal conditions around the UK.

We have invested approaching £15.5 million into cutting-edge research since we were founded in 1976 and we are determined to build on the progress made to date. We firmly believe it is a matter of when, not if, treatments are available.

Through our Innovation Fund we continue to support projects of varying length that seek to explore new ideas or test new theories.

In 2019 we will launch the Oxford Centre for Inherited Retinal Diseases, a new dedicated pioneering research centre within Oxford Eye Hospital at the John Radcliffe Hospital. This is the result of an innovative collaboration between Retina UK, Oxford University Hospitals NHS Foundation Trust and the Medical Sciences Division at the University of Oxford. We will invest up to £200,000 in the centre each year over three years, matching a commitment from the Trust to provide staffing and infrastructure. This will provide stable, long-term, flexible funding to support Oxford to retain talented staff and allow its research teams to maintain all-important momentum and maximise progress.

We will strive to increase the number of families we support. We will organise and attend events around the UK to build new relationships and continue to provide high quality, trustworthy and accessible information and support to enable people to live fulfilling lives.

We will continue to grow our collaborations and build relationships with relevant education, health and social care professionals to encourage them to signpost to Retina UK. This year we will hold our first conference for professionals to enable them to better understand the unique challenges faced by those living with or affected by inherited retinal conditions and help them to provide the best support.

During the first half of 2019 we will undertake a community insight project to inform our future plans and strategies and ensure these are rooted in the lived experiences, views and aspirations of people in the UK living with inherited sight loss. The findings from this survey will inform the development of Retina UK's longer-term strategy, and provide a baseline against which to measure our progress in the future.

## **Retina UK**

### **Report of the Trustees**

**For the year ending 31 December 2018**

---

#### **Objectives & Activities**

##### **Our Mission**

We are the only UK charity dedicated exclusively to working for people affected by inherited sight loss. Our vision is a world where everyone with inherited sight loss is able to live a fulfilling life.

We stimulate and fund medical research to increase the understanding of these conditions and accelerate the search for treatments for the future.

We continue to invest in the very best medical research, as reviewed by our independent Medical Advisory Board. This panel consists of expert world-respected scientists and researchers. In 2018 Professor Susan Downes, Consultant Ophthalmic Surgeon and an Honorary Senior Lecturer at the University of Oxford took over the chair from Professor Andrew Lotery who retired at the end of his successful term in the chair.

Retina UK is committed to collaborative working within the field of medical research. We partner with leading research and other sector-leading charitable organisations with similar aims and objectives to accelerate progress.

We provide information and support to help people lead better lives and to ensure no-one with inherited sight loss need feel alone.

##### **New name and brand**

In June 2018 the Charity Commission approved our change of name to Retina UK and careful planning meant the transition was a smooth one.

A suite of new materials were produced along with our first impact-style report, demonstrating the difference Retina UK makes for those affected by inherited sight loss conditions.

We also launched our new website, which is easier to navigate and features new and enhanced functionality and content.

#### **Achievement & Performance**

##### **Research grant funding**

The charity is a member of the Association of Medical Research Charities and abides by its principles of best practice in peer review when prioritising which research applications demonstrate the best scientific merit and likelihood of patient benefit. These principles include the use of a completely independent Medical Advisory Board which makes recommendations to the Board of Trustees regarding the best research applications.

##### **Medical Research**

The following project summaries give an overview of the medical research work funded by the charity, which was underway in the year ending 31 December 2018.

##### **The UK Inherited Retinal Dystrophy Genome Project**

We are the lead funder of this project which has received small contributions from two other organisations and has been in operation since late 2014. The project brought together the four largest research groups in the UK specialising in inherited retinal dystrophies: Manchester Royal Eye Hospital, University of Leeds, London's UCL Institute of Ophthalmology and Oxford University Eye Hospital.

## Retina UK

### Report of the Trustees

#### For the year ending 31 December 2018

---

It was the first project of its kind in terms of the level of collaborative working required for its success. Four further sites were added to the study, widening the scope for collaboration and the availability of data and resources. The consortium has become a Genetics England Clinical Interpretation Partnership (GECIP) associated with the widely publicised UK 100,000 Genome Project. This allowed the team to ensure that ophthalmic genetics are well positioned among the 100,000 genomes being sampled and one of the consortium investigators has been chosen to lead the GECIP in the field of ophthalmology. The progress that the consortium has made in terms of the gathering, analysis and sharing of data has been impressive, and their position as part of the GECIP kept IRDs on the national agenda at a crucial time for research. Importantly, their work has also led to discoveries that would not have been possible without this project, including the identification of five novel disease-causing genes, advancing our knowledge of IRDs and informing the development of future treatments for those facing visual impairment. The consortium is currently pursuing continuation funding in order to extend this pioneering work.

#### **DNA Damage as a Driver of Photoreceptor Loss in X-linked retinitis pigmentosa**

This is being studied by Dr Toby Hurd of the University of Edinburgh. Mutation of the RP2 gene causes retinitis pigmentosa but the mechanism by which this happens is still not fully understood. Current data suggests that a reduced ability to deal with oxidative stress and DNA damage may be the issue, and this project aims to explore whether this is the underlying cause. It will also test whether drugs which target DNA repair pathways and / or antioxidant therapies represent a suitable treatment option.

Dr Hurd's team has been able to demonstrate that loss of the RP2 gene does not impair a cell's ability to detect DNA damage; however cells appear to be intrinsically more sensitive to DNA damaging agents. Data has been generated indicating that this may be due to disruption of a critical organelle in the cell known as the Golgi, which regulates the delivery of proteins to specific regions of the cell. Furthermore, the team has begun to test whether inhibitors of a protein called DNA-PKcs can restore Golgi function, with some preliminary success. Together, this data expands on a novel emerging role for DNA-PKcs in regulating Golgi function independent of its role in dealing with DNA damage, and provides a novel mechanism to account for defects observed in photoreceptors. Additionally, this provides a new avenue of research, investigating if the inhibition of DNA-PKcs represents a novel strategy to slow or halt photoreceptor degeneration in RP patients.

#### **Aberrant RNA processing in Retinal Dystrophies: understanding mechanisms and developing therapies**

Prof Mike Cheetham at the UCL Institute of Ophthalmology is leading this project. Using an artificially produced retina, the team discovered that photoreceptors maximise the information in their genes by splicing them together in complex ways to produce specialised proteins. This helps them to fulfil their highly complex function of detecting light, but it does make them more vulnerable to mutations. Sometimes they mistakenly splice in the wrong information, disrupting their function. A method called RNAseq has been used to identify the complex splicing events and which parts of the genes the photoreceptors stick together during the process. The team has also identified the time window during which the splicing process occurs, and has used stem cell technology to create retinal cells with intentionally disrupted splicing factors to test whether they affect photoreceptor function. A number of individuals with potential splicing faults have been identified to study in more detail in the future.

#### **Identification and functional characterisation of the missing ABCA4 variants in Stargardt disease**

This is a project being run by Prof Frans Cremers at Radboud University Medical Centre, in The Netherlands. ABCA4 mutations affect the majority of people with recessive Stargardt disease and about 30% of those with cone-rod dystrophy. The vast majority of the ABCA4 gene actually consists of non-coding regions, known as introns. These sections are 'edited out' during protein construction



## Retina UK

### Report of the Trustees

#### For the year ending 31 December 2018

---

by a process known as splicing. However, mutations within introns can still have a significant influence on how the coding regions are edited and interpreted by the cell's protein-building machinery, often resulting in a faulty protein. During the first year of this project, Prof Cremers' team has developed an ultra-cheap method for examining the sequence of the entire ABCA4 gene, including all of the introns, which costs around ten times less than other techniques (around €40 per sample). The researchers have used a small set-up of this method and found mutations in 158 out of 412 STGD1 cases that were previously unexplained, including 70 genetic variations within introns. Prof Cremers has also completed design of a test, known as a splice assay, to investigate how ABCA4 introns are edited out during protein construction. The development of the test has made a significant contribution to a high impact paper in the journal *Genome Research* (Sangermano et al., 2018). The test itself has also been used to examine the impact on editing of seven newly discovered intron variants. The team will now go on to examine a greater number of samples and gain a deeper understanding of how ABCA4 intron mutations damage the retina.

#### **Non-viral gene therapy using S/MAR vectors for Usher Syndrome**

Dr Mariya Moosajee from the UCL Institute of Ophthalmology began this project in 2018. Usher syndrome is the commonest cause of deaf-blindness worldwide with USH2A being the most prevalent causative gene. The team is adapting a non-viral gene delivery system, containing a human DNA element called scaffold / matrix attachment regions (S/MAR) to encase USH2A. They will be treating human-derived retinal cells from an Usher syndrome patient with a USH2A mutation and zebrafish disease models. The team will then assess the therapeutic response by looking at retinal structure, toxicity, visual function and long-term gene expression. Non-viral S/MAR vectors may revolutionise the treatment of inherited retinal disorders by providing a safer and more applicable form of gene therapy.

#### **Modelling effects of TIMP-3 mutations in RPE- insights into Sorsby disease and night blindness in retinal dystrophies**

Dr Arjuna Ratnayaka of the University of Southampton commenced work on this project. Sorsby fundus dystrophy (SFD) is a dystrophy where changes in the protein TIMP3 cause patients to lose night vision and to eventually go blind. Earlier work using cell-lines, mouse models and donor eyes have shown how mutated TIMP3 behaves differently to normal TIMP3 proteins. TIMP3 proteins are made by a carpet of cells under the retina called the Retinal Pigment Epithelium (RPE). However, very little work has been done to understand how exactly RPE cells become damaged by mutant TIMP3. For the first time, Dr Ratnayaka's team has successfully grown RPE cells directly from SFD patients using their own skin cells, allowing them to study how mutant TIMP3 damages RPE cells in SFD. Gene-editing technology will then be used to correct mutated TIMP3 and study how damaged RPE cells can be rescued by 'restored' TIMP3. The team will use retinal scans from patients to study gradual sight loss, and identify new ways of recognising / tracking SFD. By providing these retinal images as well as their skin cells, these SFD patients allow us to link any cellular changes with disease changes in their eyes. The findings could help design effective future treatments.

#### **Investigating the role of alternative splicing in autosomal dominant retinitis pigmentosa using a PRPF31 patient specific induced pluripotent stem cell disease model**

Following on from a small seed-funding grant from Retina UK, Prof Majlinda Lako at Newcastle University was able to begin work on her larger project. A major form of RP is caused by defects in components of the "spliceosome", an important and complex structure within cells. The spliceosome edits unwanted or nonsensical passages out of a set of genetic instructions so that only intelligible code remains for the cell to use. A fault in a group of genes that regulate this process is one of the most common causes of RP, but despite this defect residing in all cells of the body, the retina is the only tissue affected and the reasons for this are not fully understood. Prof Lako's team has generated retinal cells from patients with mutations in a key gene involved in the splicing process (PRPF31) and has already provided preliminary data to explain how retinal cells are much more affected by mis-splicing when compared to other cell types. They will use state-of-the-art cell biology to further this understanding, and also look at developing gene therapy approaches to correct the defect.

## Retina UK

### Report of the Trustees

For the year ending 31 December 2018

---

#### **Understanding the disease mechanisms and developing new therapies for RDH12-related Leber congenital amaurosis**

Dr Mariya Moosajee has started work on this project at UCL Institute of Ophthalmology. It aims to increase knowledge of the molecular basis of this type of LCA and accelerate development of an effective treatment. Dr Moosajee will develop new disease models, one using stem cells derived from patients with LCA and one in zebrafish, so that both can be used to increase understanding of the effects of the disease-causing mutation in the RDH12 gene. The models will also be used for high-throughput screening of drug compounds that have shown promise in other retinal dystrophies, to see if these can also slow retinal degeneration in LCA.

#### **Natural exon skipping in ABCA4 mRNA and its modulation as a novel generic therapy for Stargardt disease**

A PhD student supervised by Dr Rob W J Collin at Radboud University in The Netherlands has begun studying the different genetic mutations which lead to Stargardt disease – a macular dystrophy which affects people from childhood and for which there is no cure. The project has been funded by Retina UK in conjunction with the Macular Society. Stargardt disease is usually caused by mutations in the ABCA4 gene. Patients with two severe variants of ABCA4 develop sight loss early, as their code only contains the instructions to make harmful versions of the protein. Other people with a combination of severe and mild mutations produce a mixture of harmful and normal proteins and so tend to avoid symptoms until later. In some people with later-onset Stargardt, bits of the genetic code are mistakenly “skipped”. So like a recipe with steps missing, the resulting protein doesn’t turn out like it is supposed to. This project aims to understand how and why bits of the gene are “skipped”, and prevent the misreading of the gene that causes damaging protein versions to be produced. The studentship is enabling this promising young scientist to lay the foundations for a future career in inherited sight loss research.

#### **The Gene Team Project**

This high profile study has been led by Prof Robin Ali at the UCL Institute of Ophthalmology since 2011. It has been establishing the viability of gene therapy for retinal disorders as a potential treatment and has developed a therapeutic pipeline for at least 11 forms of early-onset severe retinal dystrophies, making excellent progress towards its aim of building a programme of clinical trials. In 2018, the team has optimised vectors for delivery of gene therapies for LCA4 and LCA13, continued clinical trials in LCA2, Achromatopsia and XRP3, and used animal and stem cell-derived models to develop therapies for other conditions including LCA5, RP2, Stargardt disease, and Usher and Bardet Biedl syndromes. As Retina UK’s funding comes to an end, Prof Ali and colleagues intend to secure substantial funding from other sources for future clinical trials.

Funding was secured to deliver the first phase of a health economics and epidemiology project seeking to establish the incidence and prevalence of inherited retinal dystrophies, as well as the impact on individuals and the cost burden to the UK and Irish economies. This piece of work will be vital when evidencing the need for treatments of the future, and our consortium approach has enabled us to collaborate with sector partners as well as representatives from the pharmaceutical industry.

#### **Information and Support Services**

The services team continued to grow our partnerships in 2018, laying the foundations for future collaborative working in line with the regional services delivery model introduced in 2017.

The Regional Managers in the two established regions (North West & Northern Ireland and North Wales & Midlands) continue to build collaborative working relationships with local representatives from national sight loss charities including Guide Dogs and RNIB. Excellent relationships have also been developed with many local visually impaired support charities and eye health, education and social care professionals. These collaborations have seen the team present on Retina UK’s work, share information, signpost and undertake joint activity on a local level.

## Retina UK

### Report of the Trustees

#### For the year ending 31 December 2018

---

During the year, 1,615 new contacts told us they were happy for us to stay in touch including 1,262 individuals and 191 organisations.

2018 saw us support the Esme's Umbrella helpline for people living with Charles Bonnet Syndrome (CBS) when the helpline faced closure. We worked together to find a solution that would ensure continued support for those with the syndrome. Calls to the helpline are now answered by the RNIB and we respond to requests for peer support from someone who has lived experience of CBS. We also supported the first CBS Information Day in November, organised by Esme's Umbrella, which had 70 attendees. We also worked closely with Usher Kids UK, providing opportunities for this support group to promote its activities and helping with its plans to deliver a family event for the Usher community in June 2019.

The team delivered information days in Birmingham, Leeds, Falkirk and London. These brought together sight loss professionals and people living with inherited retinal dystrophies. Attendees were able to find out about the latest research, how Retina UK can support them and what can help with day to day living while networking and sharing experiences. Over 300 people attended, around 100 of who were new to the charity.

We attended Sight Village Events in Exeter, Birmingham, Leeds and London and 105 of the family members and professionals we met asked us to stay in touch.

We welcomed more than 200 delegates to our annual conference in London in June. We received excellent feedback from delegates including that 80% felt better informed about the work of the charity; 100% felt better informed about research into inherited sight loss; 76% felt more connected to the inherited sight loss community and 76% felt better informed about how to access information and support.

The team maintained our much-valued helpline and befriending services and our committed helpline volunteers responded to 961 enquiries in 2018.

Our unique Working Age Group Project, funded by Thomas Pocklington Trust and supported by RNIB and Visionary, completed its data capture exercises in December 2018. This ground-breaking project is examining how Retina UK, and other charities and organisations, can assist in keeping those affected by inherited sight loss in employment as their condition progresses. We will be using the data gathered to formulate a cross-sector approach to tackle this very important issue in 2019.

We continue to provide accurate and trustworthy information and updates in a variety of accessible formats, including on our website and through our regular newsletters.

#### **Our volunteers**

At the end of 2018 we had almost 100 volunteers supporting our activities including 40 helpliners, befrienders and local group facilitators.

We currently have volunteer-led local groups in the East of Scotland, Glasgow, London and the Isle of Wight and we are proactively working to grow this number in 2019.

We will also involve volunteers in more areas of our work and ensure they feel valued and have the best possible experience while volunteering with us.

## Retina UK

### Report of the Trustees

#### For the year ending 31 December 2018

---

##### **Fundraising**

It has been a busy year for the fundraising team, who have achieved income of £1,732,373 thanks to support from our amazing community and a range of corporate and charity-sector funders and partners.

Highlights include significant growth in individual donations from £226,304 in 2017 to £686,141 in 2018, due in part to contributions restricted to a particular research project. Income from trusts and foundations also increased from £80,623 to £166,239, and corporate income from £26,330 to £64,755. We have developed excellent working relationships with new and existing corporate partners, including OxSight and Network Rail.

The team worked with Through Vicky's Eyes to deliver the hugely successful Eyes on the Future Gala Dinner in London in October, raising more than £240,000 for a project researching the RDH12 gene, which causes Leber congenital amaurosis and retinitis pigmentosa. This project also receives funding from Candle In The Dark and the RDH12 Fund for Sight. Another prestigious event was our gathering at Speaker's House, House of Commons, which brought together supporters of all kinds and MPs to celebrate the charity's change of name from RP Fighting Blindness to Retina UK.

Our splendid London Marathon runners raised £47,000 this year, the Hope to Seaview walk on the Isle of Wight raised £15,000, and the ever popular Worksop's Got Talent event continued to grow, with 700 attendees raising £8,500. In total, supporters participating in challenge events and organising their own activities up and down the country raised in excess of £220,000.

Individuals who generously chose to make gifts to Retina UK in their wills, and those who kindly made donations to our charity in memory of loved ones, donated a significant £407,986, which enabled us to invest in a greater number of medical research projects.

All fundraising in 2018 was carried out by Retina UK's in-house fundraising team and by supporters engaged in their own activities in aid of the charity. Retina UK subscribes to the Fundraising Regulator and Fundraising Preference Service, is licensed by the Gambling Commission and adheres to the Fundraising Code of Practice. We did not receive any requests via the Fundraising Preference Service to cease contact with any of our supporters.

We always aim to fundraise in a fair and transparent way. We respect the privacy of our supporters, and our privacy notice is available to view on our website. We did not carry out any door to door fundraising, or cold donor acquisition through face to face or telemarketing approaches in 2018.

##### **Supporter experience**

We continue to work hard to ensure all our supporters have the best experience with us.

All staff attended a workshop on enhancing supporter care and all our communications with supporters have been reviewed. The whole staff team were involved in developing and agreeing new organisational values that set out how we act and ensure people affected by inherited sight loss are at the heart of everything we do.

##### **Ambassador Programme**

We were delighted to appoint a new ambassador in 2018 to help us spread the word and further raise our profile. Victoria Claire was diagnosed with retinitis pigmentosa at the age of 19 and registered blind at the age of 29. She is an inspirational speaker and a professional sculptor who has exhibited throughout the UK, as well as a keen surfer, skateboarder and musician.

## **Retina UK**

### **Report of the Trustees**

#### **For the year ending 31 December 2018**

---

#### **Acknowledgements**

The support we have received in 2018 from individuals, groups, companies and organisations has been outstanding, and has enabled us to continue funding some of the most promising medical research and delivering vital services to our community.

We would like to take this opportunity to thank the following trusts and foundations for their generous support during 2018:

- The A F Wallace Charity Trust
- The Albert Van Den Bergh Charitable Trust
- The Arden Trust
- BE Rodmell Trust
- The Catherine Cookson Charitable Trust
- The Champniss Charitable Trust
- The David Fryer Charitable Trust
- David Killick Trust
- DG Marshall of Cambridge Trust
- Dixie Rose Findlay Charitable Trust
- The Doris Field Charitable Trust
- Dorothy Bayles Trust
- The Felicity Wilde Charitable Trust
- G C Gibson Charitable Trust
- The G W Cadbury Charitable Trust
- The Gertrude Gourvitch Charitable Trust
- Gilbert Edgar Trust
- The Grace Trust
- Hospital Saturday Fund
- John Laing Charitable Trust
- Lillie Johnson Charitable Trust
- Mrs L J Walkers Charitable Trust
- The N Smith Charitable Settlement
- Nineteen Eighty-Nine Charitable Trust
- The Payne-Gallwey Charitable Trust
- The Peter Stebbings Memorial Charity
- R S Brownless Charitable Trust
- St James's Place Foundation
- Tennant Southpark Charitable Trust
- The Wallace and Edna Davis Charitable Foundation
- The Wyseliot Rose Charitable Trust

**Retina UK**

**Report of the Trustees**

**For the year ending 31 December 2018**

---

**Trustees' responsibilities in relation to the financial statements**

The charity Trustees are responsible for preparing the Trustees' annual report and financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales requires the charity Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing the financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP 2015 (FRS 102);
- Make judgments and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011 and the Charities (Accounts and Reports) Regulations 2008 and the provisions of the charity's constitution. They are also responsible for safeguarding the assets of the charity and taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the charity and financial information included on the charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.



DJ Grocott  
Chairman  
8 May 2019

## **Independent Auditor's Report to the Members of Retina UK**

**For the year ending 31 December 2018**

---

### **Opinion**

We have audited the financial statements of Retina UK (the 'charity') for the year ended 31 December 2018 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2018, and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

### **Basis for opinion**

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### **Conclusions relating to going concern**

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the Trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charity's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

### **Other information**

The Trustees are responsible for the other information. The other information comprises the information included in the Trustees' annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

## Independent Auditor's Report to the Members of Retina UK

For the year ending 31 December 2018

---

### Matters on which we are required to report by exception

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 require us to report to you if, in our opinion:

- the information given in the financial statements is inconsistent in any material respect with the Trustees' report; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records; or
- we have not received all the information and explanations we require for our audit.

### Responsibilities of Trustees

As explained more fully in the Trustees' responsibilities statement, the Trustees are responsible for the preparation of financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

### Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with regulations made under section 154 of that Act.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our auditor's report.

### Use of our report

This report is made solely to the charity's Trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

### Baldwins Audit Services

Statutory Auditor  
Pillar House  
113/115 Bath Road  
Cheltenham  
Gloucestershire  
GL53 7LS



Date: 8.5.19

Baldwins Audit Services is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.



Retina UK

Statement of Financial Activities

For the year ending 31 December 2018

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2018 £	Total Funds 2017 £
<b><u>INCOME FROM:</u></b>					
Donations & legacies	3	767,729	928,222	1,695,951	1,138,793
Charitable activities					
<i>Medical research grants</i>	4	-	30,000	30,000	-
<i>Information, support &amp; engagement</i>	5	-	-	-	75
Investments	6	6,422	-	6,422	13,865
<b>Total income</b>		<b>774,151</b>	<b>958,222</b>	<b>1,732,373</b>	<b>1,152,733</b>
<b><u>EXPENDITURE ON:</u></b>					
Raising funds	7	358,335	54,938	413,273	352,355
Charitable activities					
<i>Medical research grants</i>	8	55,163	395,588	450,751	412,840
<i>Information, support &amp; engagement</i>	9	389,313	31,556	420,869	555,205
<b>Total expenditure</b>		<b>802,811</b>	<b>482,082</b>	<b>1,284,893</b>	<b>1,320,400</b>
Net gains (losses) on investments		(32,704)	-	(32,704)	22,777
<b>Net movement in funds</b>	10	<b>(61,364)</b>	<b>476,140</b>	<b>414,776</b>	<b>(144,890)</b>
<b>Funds at 1 January 2018</b>	<b>21/23</b>	<b>408,675</b>	<b>159,427</b>	<b>568,102</b>	<b>712,992</b>
<b>Funds at 31 December 2018</b>	<b>21/23</b>	<b>347,311</b>	<b>635,567</b>	<b>982,878</b>	<b>568,102</b>

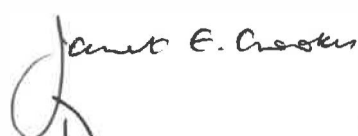
Retina UK

Balance Sheet

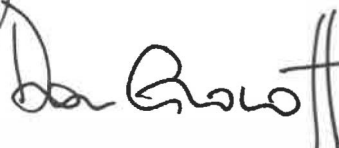
At 31 December 2018

	Note	2018 £	2017 £
<b>FIXED ASSETS</b>			
Tangible fixed assets	14	5,480	6,549
Investments	15	229,225	261,929
<b>Total fixed assets</b>		<b>234,705</b>	<b>268,478</b>
<b>CURRENT ASSETS</b>			
Debtors: Amounts falling due within 1 year	16	234,148	135,419
Cash at bank and in hand	17	1,283,037	1,169,248
<b>Total current assets</b>		<b>1,517,185</b>	<b>1,304,667</b>
<b>LIABILITIES</b>			
Creditors: Amounts due within 1 year	18	<u>(769,012)</u>	<u>(1,005,043)</u>
<b>Net current assets</b>		<b>748,173</b>	<b>299,624</b>
<b>Net assets</b>		<b>982,878</b>	<b>568,102</b>
<b>FUNDS</b>			
Unrestricted	21	347,311	408,675
Restricted	23	635,567	159,427
<b>Total funds</b>		<b>982,878</b>	<b>568,102</b>

Approved by the Trustees and signed on their behalf by:



**J E Crookes**  
Treasurer  
8 May 2019



**D. J. Grocott**  
Chairman  
8 May 2019

Retina UK

Cash Flow Statement

For the year ending 31 December 2018

<b>Cash flows from operating activities:</b>	<b>Note</b>	<b>2018</b>	<b>2017</b>
		<b>£</b>	<b>£</b>
<b>Net income / (expenditure) for the reporting period</b>		<b>414,776</b>	<b>(144,890)</b>
<b>Adjustments for:</b>			
Depreciation charges	14	3,397	1,600
Unrealised losses <del>es</del> (gains) on investments	15	32,704	(22,777)
Dividends and interest from investments	6	(6,422)	(13,865)
(Increase) <del>es</del> decrease in debtors	16	(98,729)	580,176
Increase <del>es</del> (decrease) in creditors	17	(108,608)	85,250
Increase <del>es</del> (decrease) in grant creditors	17	(127,423)	(221,289)
<b>Net cash used in operating activities</b>		<b>109,695</b>	<b>264,205</b>
<b>Cash flows from investing activities:</b>			
Dividends and interest from investments	6	6,422	13,865
Purchase of tangible fixed assets	14	(2,328)	(5,538)
<b>Cash flows from investing activities</b>		<b>4,094</b>	<b>8,327</b>
<b>Change in cash and cash equivalents in the year</b>		<b>113,789</b>	<b>272,532</b>
<b>Cash and cash equivalents at 1 January 2018</b>	17	<b>1,169,248</b>	<b>896,716</b>
<b>Cash and cash equivalents at 31 December 2018</b>	17	<b>1,283,037</b>	<b>1,169,248</b>

## Retina UK

### Notes to the Accounts

For the year ending 31 December 2018

---

#### 1. Legal status of the charity

The charity is a Charitable Incorporated Organisation (CIO) registered in England and Wales, registered number 1153851. The address of the registered office is given in the reference and administrative details on page 2 of these financial statements. Each member pays an annual subscription, is entitled to vote at the AGM, and has a duty to exercise his or her powers as a member of the CIO in the way he or she decides in good faith would be most likely to further the purposes of the CIO. If the CIO is wound up, the members of the CIO have no liability to contribute to its assets and no personal responsibility for settling its debts and liabilities.

#### 2. Accounting Policies

##### Basis of preparing the financial statements

The charity constitutes a public benefit entity as defined by FRS 102. The financial statements of the charity have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland', and the Charities Act 2011. The financial statements have been prepared under the historical cost convention except where investments held as fixed assets are held at market value. The financial statements are prepared in £ sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

##### Going concern

There are no material uncertainties about the charity's ability to continue as a going concern.

##### Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Income from government and other grants is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received, and the amount can be measured reliably.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the Trust that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

Dividends, donations and fund raising receipts are taken to income on a received basis. Membership subscriptions are allocated to income in the year to which they relate. Any funds raised but not remitted are accounted for appropriately within the balance sheet. Membership and other income received in advance is deferred until the criteria for income recognition are met.

##### Donated services

The charity benefits from the donated time and services of many individuals across a wide range of roles. These are not normally accounted for as it is not practicable to attribute a value. Where services are donated, and a reliable estimate of the cost can be made, this is included as donated income and as expenditure under the appropriate headings.

## Retina UK

### Notes to the Accounts

#### For the year ending 31 December 2018

---

##### **Interest receivable**

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the Bank.

##### **Expenditure**

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources as set out in the notes to the financial statements. Irrecoverable VAT is charged against the category of expenditure expended for which it is incurred.

##### **Grants**

Grants payable are accounted for on an accruals basis. The charity's policy on research is to limit grant funding commitments to one year. Subject to a satisfactory review of progress and funds being available, grants are then approved for funding on a year-to-year basis.

##### **Allocation of support costs**

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Support costs include office costs, finance, personnel, payroll and governance costs which support the charity's projects, programmes and activities. These costs have been allocated between the categories of expenditure on charitable activities. The bases on which support costs have been allocated are set out in the notes to the financial statements and the weighting is revised on an annual basis.

##### **Investments**

Investments are included in the financial statements at bid-price. Gains or losses arising on revaluation or disposal of investments are recognised in the Statement of Financial Activities in the period to which they relate.

##### **Tangible fixed assets**

Individual fixed assets costing £500 or more are capitalised at cost and are depreciated over their estimated useful economic lives. Cost is defined as purchase cost less any residual value.

Depreciation is provided for on all tangible fixed assets (office equipment) at a rate of 33% straight line.

Net book values are regularly reviewed by the Trustees and any appropriate adjustments are made to carrying values.

##### **Financial instruments**

###### ***Financial assets***

Basic financial assets, including trade and other debtors and cash and bank balances are initially recognised at the transaction price. At the end of each reporting period financial assets are assessed for impairment and any impairment loss is recognised in the Statement of Financial Activities.

Financial assets are derecognised when either the contractual rights to the cash flows from the asset expire or are settled.

## Retina UK

### Notes to the Accounts

For the year ending 31 December 2018

---

#### ***Financial liabilities***

Basic financial liabilities including trade and other creditors are initially recognised at transaction price. Trade creditors are obligations to pay for goods and services that have been acquired in the ordinary course of business from suppliers. Trade creditors are classified as current liabilities if payment is due within one year or less. Financial liabilities are derecognised when the liability is extinguished, that is when the contractual obligation is discharged, cancelled or expires.

#### **Cash at bank and in hand**

Cash at bank and in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

#### **Taxation**

The charity is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or section 256 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects.

#### **Pension costs**

The charity contributes towards personal pension plans for employees. The cost of these contributions is accounted for as a defined contribution and is included on an accruals basis.

#### **Fund accounting**

Unrestricted general funds - these are funds which can be used in accordance with the charitable objects at the discretion of the Trustees. Designated funds represent monies allocated by the Trustees to specific charitable objectives or projects, notably but not limited to the future commitment to medical research projects.

Restricted funds - these are funds that can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

#### **Operating leases**

Rental charges under operating leases are charged to the SOFA on a straight line basis over the term of the lease.

## Retina UK

### Notes to the Accounts

For the year ending 31 December 2018

#### 3. Donations and Legacies

	2018 £	2017 £
Membership subscriptions/donations	40,308	40,842
Individual donations	686,141	226,304
Trusts	186,239	80,623
Donated services	-	109,500
Corporate	64,755	26,330
Legacies/In memoriam	407,986	315,460
Fundraising	229,908	232,532
Prize draw/appeals/mailings	25,590	52,075
Gift Aid	55,024	55,127
<b>Total</b>	<b>1,695,951</b>	<b>1,138,793</b>

#### 4. Medical research grants

	2018 £	2017 £
Research funding	30,000	-
<b>Total</b>	<b>30,000</b>	<b>-</b>

#### 5. Information, support & engagement

	2018 £	2017 £
Event sponsorship - PID	-	75
<b>Total</b>	<b>-</b>	<b>75</b>

#### 6. Investments

	2018 £	2017 £
Share dividends	5,474	5,083
Bank interest	948	8,782
<b>Total</b>	<b>6,422</b>	<b>13,865</b>

## Retina UK

### Notes to the Accounts

For the year ending 31 December 2018

#### 7. Raising funds

	2018	2017
	£	£
Event costs	107,861	84,225
Materials & equipment	2,702	10,507
Collection fees	11,119	11,936
Travel expenses	1,898	3,009
Training, consultancy & campaigns	6,483	4,189
Donor development including trusts & corporates	6,416	15,095
Other	885	12,626
Support costs (see note 11)	275,909	210,768
<b>Total</b>	<b>413,273</b>	<b>352,355</b>

#### 8. Medical research

	2018	2017
	£	£
Annual grant awards	395,588	390,553
MAB expenses	435	226
Support costs (see note 11)	54,728	22,061
<b>Total</b>	<b>450,751</b>	<b>412,840</b>

#### 9. Information, support & engagement

	2018	2017
	£	£
Publications, DVDs, leaflets etc	16,540	15,473
Annual conference	18,571	16,553
Helpline support	9,316	6,958
Patient information and engagement events	7,121	42,392
Helpline training	-	4,897
Non-medical research	30,955	-
Travel expenses	12,079	8,820
Retina International	4,659	10,101
Brand and website development	27,101	-
Other	3,687	9,016
Support costs (see note 11)	290,840	440,995
<b>Total</b>	<b>420,869</b>	<b>555,205</b>



## Retina UK

### Notes to the Accounts

For the year ending 31 December 2018

---

#### 10. Net movement in funds is stated after charging

	2018	2017
	£	£
Auditor's remuneration (audit)	6,720	5,534
Auditor's remuneration (accountancy services)	-	1,000
Depreciation	3,397	1,600
Trustees' expenses	2,314	1,576
Lease payments	13,500	13,500

Trustees' expenses, incurred on travel and accessibility support, represent amounts reimbursed to two Trustees for expenses incurred (2017 - 2).

No Trustee received any remuneration during the year (2017 - none).

---

#### 11. Analysis of support costs

	Total	Fund-raising	Research	Information, support & engagement	Basis of apportionment
	£	£	£	£	
Office administration	95,883	38,270	10,359	47,254	Staff time or actual
Human resources/ Remuneration	490,197	223,480	40,829	225,888	Staff time
Governance	35,397	14,159	3,540	17,698	Staff time or actual
<b>Total</b>	<b>621,477</b>	<b>275,909</b>	<b>54,728</b>	<b>290,840</b>	
Governance costs in 2017	45,746	11,436		34,310	

---

## Retina UK

### Notes to the Accounts

For the year ending 31 December 2018

---

#### 12. Staff numbers and costs

	2018	2017
	£	£
Wages and salaries	455,618	387,970
Social Security costs	40,410	32,183
Pension costs	12,628	7,837
	<u>508,656</u>	<u>427,990</u>
Miscellaneous staff related costs (including donated services)	-	105,176
<b>Total</b>	<u><b>508,656</b></u>	<u><b>533,166</b></u>

The number of persons employed by the charity during the year was 17 (2017 - 16).

There were no donations of staff resource in 2018 (2017 - 2 persons).

No termination payments were made during the year (2017 - £25,000).

Total remuneration (including employers NIC) for key management personnel in the year was £77,346 (2017 - £68,956). The number of employees with remuneration (excluding employers NIC) between £60,000 - £70,000 was 1 (2017 - 1).

---

Retina UK

Notes to the Accounts

For the year ending 31 December 2018

13. Comparative information for Statement of Financial Activities

	Unrestricted Funds	Restricted Funds	Total Funds 2017
	£	£	£
<b><u>INCOME FROM:</u></b>			
Donations & legacies	813,537	325,256	1,138,793
Charitable activities			
<i>Medical research grants</i>	-	-	-
<i>Information, support &amp; engagement</i>	-	75	75
Investments	13,865	-	13,865
<b>Total income</b>	<b>827,402</b>	<b>325,331</b>	<b>1,152,733</b>
<b><u>EXPENDITURE ON:</u></b>			
Raising funds	337,290	15,065	352,355
Charitable activities			
<i>Medical research grants</i>	213,435	199,405	412,840
<i>Information, support &amp; engagement</i>	543,231	11,974	555,205
<b>Total expenditure</b>	<b>1,093,956</b>	<b>226,444</b>	<b>1,320,400</b>
Net gains / (losses) on investments	22,777	-	22,777
<b>Net movement in funds</b>	<b>(243,777)</b>	<b>98,887</b>	<b>(144,890)</b>
<b>Funds at 1 January 2017</b>	<b>652,452</b>	<b>60,540</b>	<b>712,992</b>
<b>Funds at 31 December 2017</b>	<b>408,675</b>	<b>159,427</b>	<b>568,102</b>

## Retina UK

### Notes to the Accounts

For the year ending 31 December 2018

#### 14. Tangible fixed assets

	Office Equipment £
<b>Cost</b>	
At 1 January 2018	35,636
Additions	2,328
<b>At 31 December 2018</b>	<u><u>37,964</u></u>
<b>Depreciation</b>	
At 1 January 2018	29,087
Charge for year	3,397
<b>At 31 December 2018</b>	<u><u>32,484</u></u>
<b>Net book value</b>	
<b>At 31 December 2018</b>	<u><u>5,480</u></u>
At 31 December 201 <del>7</del>	<u><u>6,549</u></u>

#### 15. Investments

	2018 £	201 <del>7</del> £
At 1 January 2018	261,929	239,152
Unrealised (losses)/gains	(32,704)	22,777
<b>As at 31 December 2018</b>	<u><u>229,225</u></u>	<u><u>261,929</u></u>
	2018 £	201 <del>7</del> £
Included within investments are the following:		
CAF balanced growth fund at valuation	228,837	261,541
Shares in Taylor Woodrow	275	275
3% City of Liverpool stock	113	113
	<u><u>229,225</u></u>	<u><u>261,929</u></u>

All investments are held in the UK.

## Retina UK

### Notes to the Accounts

#### For the year ending 31 December 2018

---

##### 16. Debtors: Amounts falling due within one year

	2018 £	2017 £
Accrued income	220,273	121,496
Prepayments	13,875	13,923
<b>Total</b>	<b>234,148</b>	<b>135,419</b>

---

##### 17. Analysis of cash and cash equivalents

	2018 £	2017 £
Cash at bank and in hand	1,283,037	1,169,248
<b>Total</b>	<b>1,283,037</b>	<b>1,169,248</b>

---

##### 18. Creditors: Amounts falling due within one year

	2018 £	2017 £
Trade creditors	124,948	227,503
Tax and social security	12,904	12,031
Accruals and deferred income	6,720	13,646
Grant liability	624,440	751,863
<b>Total</b>	<b>769,012</b>	<b>1,005,043</b>

---

##### 19. Contingent Assets & Liabilities

There is a contingent liability of £883,795 at 31 December 2018 (2017 - £583,781) in respect of research grants authorised subject to annual review. This money falls due in years 2019 onwards.

---

##### 20. Financial commitments

	2018 £	2017 £
Total future minimum lease payments under non-cancellable operating leases are as follows:		
< 1 year	13,500	13,500
1 - 5 years	27,000	40,500



## Retina UK

### Notes to the Accounts

For the year ending 31 December 2018

#### 21. Unrestricted Funds

	<b>General Fund £</b>	<b>Designated Research Fund £</b>	<b>Total Unrestricted Funds £</b>
Balance at 1 January 2018	280,834	127,841	408,675
Transfer between funds	60,641	(60,641)	-
Net incoming resources	(61,364)	-	(61,364)
<b>Balance at 31 December 2018</b>	<b>280,111</b>	<b>67,200</b>	<b>347,311</b>

Designated Research Fund: This general unrestricted fund has been designated for medical research by the Trustees in view of the contingent liabilities in respect of grant expenditure.

#### 22. Comparative information of Unrestricted Funds movement at 31 December 2017

	<b>General Fund £</b>	<b>Designated Research Fund £</b>	<b>Total Unrestricted Funds £</b>
Balance at 1 January 2017	405,452	247,000	652,452
Transfer between funds	(72,000)	72,000	-
Net incoming resources	(52,618)	(191,159)	(243,777)
<b>Balance at 31 December 2017</b>	<b>280,834</b>	<b>127,841</b>	<b>408,675</b>

Retina UK

Notes to the Accounts

For the year ending 31 December 2018

23. Restricted Funds

	Research Fund £	Innovation Fund £	Usher Fund £	Awards Fund £	RDH12 Fund £
Balance at 1 January 2018	-	27,786	29,774	1,275	-
Transfer between funds	30,250	-	-	-	-
Net incoming resources	9,788	(27,786)	19,055	(125)	308,963
<b>Balance at 31 December 2018</b>	<b>40,038</b>	<b>-</b>	<b>48,829</b>	<b>1,150</b>	<b>308,963</b>

	Pioneering Research Fund £	H E & E Fund £	Regional Services Funds £	Specified Restricted Fund £	Total Restricted Funds £
Balance at 1 January 2018	-	-	-	100,592	159,427
Transfer between funds	50,000	-	-	(80,250)	-
Net incoming resources	27,500	41,409	7,900	89,436	476,140
<b>Balance at 31 December 2018</b>	<b>77,500</b>	<b>41,409</b>	<b>7,900</b>	<b>109,778</b>	<b>635,567</b>

**Research Fund:** These are donations restricted to use for medical research, the specific nature of which is decided by the Trustees.

**Innovation Fund:** This fund was created for new and innovative research projects.

**Usher Fund:** These donations were specifically allocated by the donors for research into Usher Syndrome. The largest contribution (£10,000) was received from The Peter Stebbings Memorial Charity. The Trustees accepted these monies on that understanding.

**Awards Fund:** This donation was given to fund the John George Memorial Award for Volunteering, and other awards, at the discretion of the Trustees.

**RDH12 Fund:** This fund was set up for a targeted medical research project, and has been funded by specific donations.

**Pioneering Research Fund:** This fund is for pioneering research.

**H E & E Fund:** This funding is for a project to establish the incidence and prevalence of inherited retinal dystrophies, the impact on individuals, and the cost burden to the economy.

**Regional Services Funds:** These donations are to be used to fund regional events held to promote further information and support available.

**Specified Research Fund:** This fund is for specified research.

Transfers between funds occur when the original donors redirect the use of donations in consultation with the Charity.



Retina UK

Notes to the Accounts

For the year ending 31 December 2018

24. Comparative information of Restrictive Funds movement at 31 December 2017

	Specified Research Fund	Innova- tion Fund £	Usher Fund £	Awards Fund £	Sponsor- ship Fund £	Total Restricted Funds £
Balance at 1 January 2017	50,592	-	3,616	1,332	5,000	60,540
Net incoming resources	50,000	27,786	26,158	(57)	(5,000)	98,887
Balance at 31 December 2017	<u>100,592</u>	<u>27,786</u>	<u>29,774</u>	<u>1,275</u>	<u>-</u>	<u>159,427</u>

25. Analysis of net assets between funds

	Tangible Fixed Asset £	Fixed Asset Investment £	Current Assets £	Current Liabilities £	Total £
Restricted Funds	-	-	1,072,053	(436,486)	635,567
Unrestricted Funds	5,480	229,225	445,132	(332,526)	347,311
	<u>5,480</u>	<u>229,225</u>	<u>1,517,185</u>	<u>(769,012)</u>	<u>982,878</u>

26. Comparative analysis of net assets between funds 2017

	Tangible Fixed Asset £	Fixed Asset Investment £	Current Assets £	Current Liabilities £	Total £
Restricted Funds	-	-	266,718	(107,291)	159,427
Unrestricted Funds	6,549	261,929	1,037,949	(897,752)	408,675
	<u>6,549</u>	<u>261,929</u>	<u>1,304,667</u>	<u>(1,005,043)</u>	<u>568,102</u>

## Retina UK

### Notes to the Accounts

For the year ending 31 December 2018

---

#### 27. Grants awarded - 2018

Institution	Grant Holder	Amount £
UK Inherited Retinal Dystrophy Consortium	GR586 - *	20,000
Institute of Ophthalmology	GR589 Prof M Cheetham	70,176
Radboud University, The Netherlands	GR591 Dr F Cremers	78,950
UCL	GR594 Dr M Moosajee	118,989
Newcastle University	GR595 Prof M Lako	79,502
Radboud University, The Netherlands	GR596 Dr R Collin	36,820
<b>Total</b>		<b>399,437</b>
Opening creditor for grant commitment		751,863
Grant payments - 2018		(523,011)
Adjustments on completion of grant projects		(3,849)
Closing creditor for grant commitment		<b>624,440</b>

\*The four UK Inherited Dystrophy Consortium centres this refers to are: University of Leeds, UCL Institute of Ophthalmology, Manchester Royal Eye Hospital and Oxford University Eye Hospital

---

#### 28. Related party transactions

There are no related party transactions requiring disclosure in the Financial Statements (2017 - none).

---