



**Retina UK**

**A Charitable Incorporated Organisation**

**Annual Report & Financial Statements**

**Year Ending 31 December 2019**

**Retina UK is a Charitable Incorporated Organisation, registered charity number: 1153851**

## Retina UK

### Reference and administrative details

For the year ending 31 December 2019

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<b>Charity number</b>	1153851
<b>Registered office and operational address</b>	Retina UK PO Box 350 Buckingham MK18 1GZ
<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 Colin McArthur (until 28 September 2019) Prof John Marshall MBE Mrs Rachael Stevens Mr Keith Valentine (until 23 March 2020) 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  113 - 115 Bath Road Cheltenham GL53 7LS  Pillar House

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## Retina UK

### Chairman's Report

#### For the year ending 31 December 2019

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2019 has been a busy and successful year. We invested £841,080 in 9 medical research projects.

Simply investing in research is not, however, enough. There is an important need to support the research and its outcomes with more than just money. One major project undertaken this year with this aim was the Sight Loss Survey launched in the Spring and completed by almost 1,000 people. The findings have given a unique insight into the experiences of those living with inherited retinal conditions. It has helped us set a number of our 2020 priorities - in direct response to the findings.

One major step forward in the treatment of inherited retinal disease was the NICE recommendation that Luxturna (voretigene neparvovec) is made available on the NHS. Whilst Luxturna, a gene therapy, is only for the treatment of Leber congenital amaurosis type 2 (LCA2) and severe early-onset RP caused by mutations in a specific gene called RPE65, this is very significant progress. Retina UK materially assisted the NICE decision-making process bringing insight from the community perspective. The committee's evaluation document specifically quotes the Sight Loss Survey's findings on mental health impact.

The Retina UK Annual Conference was held in Milton Keynes in September 2019 - the first time outside London for many years. On the previous day our first Professionals' Conference was convened. More than 400 people attended our Conferences in 2019 and from the feedback reports, it is clear that both days were hugely successful.

Another supportive project initiated by Retina UK was the pilot study into the burden of Inherited Retinal Disease (IRD) on wellbeing and productivity. The report was commissioned by IRD COUNTS, a patient-led multi-stakeholder consortium managed by Retina International. It set out to estimate, using a cost-of-illness approach, the disease burden and economic impact of IRDs from a societal perspective for people in both the Republic of Ireland and United Kingdom. This type of data is essential for the development and commissioning of clinical services, treatments, and the planning and implementation of clinical treatment trials.

2019 was yet another successful year for our fundraising team, with growth achieved in a number of income areas. An addition to our fundraising events calendar was the Retina UK Tandem Cycle challenge, which saw 37 brave supporters pedalling 100 miles along Hadrian's Cycleway on tandem bicycles.

We said farewell to Trustee, Colin McArthur, at the AGM in September after 11 years. I would like to thank him and his wife, Linda, for the support they have provided to Retina UK - a massive contribution that is difficult to measure. Happily, Colin continues to fundraise on the Isle of Wight as a very active supporter of our charity.

None of the work we deliver would be possible without the wonderful community who support us in so many ways. May I, on behalf of the charity's trustees, express thanks to all our supporters.

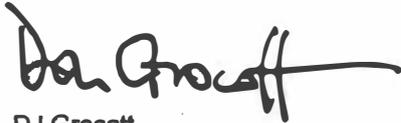
**Retina UK**

**Chairman's Report**

**For the year ending 31 December 2019**

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When this report was drafted, it ended with the hope that 2020 will be an even better year for progress for those with IRD. Sadly, Covid-19 has diminished the chance of fulfilling that hope. We have had to find new ways of working, to be even more imaginative in our fundraising and to accept the reality that to continue the great work to support IRD research and the IRD community, survival of the charity is our vital aim. More than ever, we look to our community – in the widest sense – to dig deep so that, on the other side of the devastation caused by the virus, Retina UK will continue to be the dynamic and successful charity it has grown to be.



DJ Grocott  
Chairman

12 August 2020

## **Retina UK**

### **Report of the Trustees**

#### **For the year ending 31 December 2019**

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The Trustees are pleased to present their annual report together with the financial statements of the charity for the year ending 31 December 2019. The financial statements have been prepared in accordance with the accounting policies set out in the notes to the accounts and comply with the Charities Act 2011 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 published in October 2019.

#### **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 of 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 UK and abides by each organisation's principles of best practice at all times.

**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 2019, as shown in the Financial Statements, demonstrates how we have been able to deliver activities to support our charitable objectives. We have continued to work across a number of income-generating channels and due to a significant legacy we have been able to achieve total income of £1,687,502 (2018: £1,732,373).

As expected, we have been able to utilise some of the Restricted Funds remaining at the end of 2018, in addition to new grant spending in 2019. As a result, our charitable spending has increased to £1,538,022 (2018: £871,620) enabling vital support to be given to researchers and to our community as a whole.

In order to achieve the results we are looking for we have continued with focussed investment in our team and its work. However, fundraising and support costs continue to be monitored and controlled. We spend as little as possible of the income raised by our hardworking staff, volunteers and fundraising supporters on these costs to enable us to pursue all our objectives in the short and medium term.

At the end of the year we had a net decrease in funds of £136,837 (2018 increase of £414,776), reflecting the level of our activity spend, and we have a more equal balance between Unrestricted and Restricted funds which helps us support relevant medical research that would not otherwise attract funding.

Our Balance Sheet at 31 December 2019 shows total funds of £846,041 (2018: £982,878). At the start of 2020 the Board was satisfied that this, together with our budget for 2020, would enable us to continue to deliver our charitable objectives. The onset of the Covid-19 pandemic, as discussed elsewhere in this report, has meant that our expectations of income and our plans for expenditure have both changed but the Board remains confident that we will be able to support existing research awards and other vital work for our community.

**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 and the onset of the Covid-19 pandemic has had a significant impact on many areas of fundraising. The charity is reviewing the possible short to medium term effects of this changing situation in planning how to continue to develop all the income channels. As always, we very much appreciate 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. 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 2019 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 2019 the general unrestricted funds were £280,550 (shown in Note 20).

#### **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. The experience of the current pandemic has resulted in additional risks needing to be added to the register. Short term management of key risks has been undertaken by the Chief Executive and her senior management team, with regular oversight from the Board of Trustees.

#### **Going Concern**

The Trustees review the financial position of the charity at each Board meeting. Budgets are prepared and approved annually. The UK government's response to the Covid-19 pandemic has resulted in a significant curtailment of the charity's operations and the ability to generate income from some fundraising channels. Action was taken in March 2020 to limit expenditure, pursue new sources of income, and to reorganise the staff team to work remotely where possible. Claims are being made under the government Job Retention Scheme where appropriate.

Financial information is being reviewed more frequently with forecasts of funds and cash updated on a rolling basis. Board meetings are being held monthly for the time being, in order to provide scrutiny and oversight of operational decisions. Planning is taking place to establish the possible range of impacts on the remainder of 2020 and 2021. Whilst some uncertainty will continue for much of that period, the Trustees are satisfied that the necessary actions are being taken and that the charity continues to be a going concern.

#### **Future Plans**

We will continue to invest heavily in pioneering medical research and in improving information and support for those living with inherited retinal conditions around the UK, their friends, family and the professionals who support them.

We have invested approaching £16.5 million into cutting-edge research since we were founded in 1976 and we are determined to build on the progress made to date. The first treatment for an inherited sight loss condition, Luxtuma (voretigene neparvovec) was recommended by NICE for use in the NHS in England in early September 2019 which brings great hope to our community. We believe that this is just the start and that other therapies will soon be discovered for a range of inherited retinal dystrophies and made available on the NHS.

Through our Project Grants we will continue to support medical research projects of varying length that seek to explore new ideas or test new theories.

## **Retina UK**

### **Report of the Trustees**

#### **For the year ending 31 December 2019**

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Our Sight Loss Survey 2019 surveyed almost 1,000 individuals to ask about their experiences of living with inherited sight loss. We have set a number of our 2020 priorities in direct response to the findings.

In 2020 we plan to launch a project to increase the level of awareness and understanding of genetic testing and genetic counselling among people living with inherited retinal dystrophies, empowering them to make fully informed decisions about their lives, healthcare and family planning. Despite the Covid-19 crisis, funding has been secured for this project.

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 further develop the high quality, trustworthy and accessible information and support we provide to enable people to live fulfilling lives. The pandemic has halted all face to face interaction for the time being. 2020 events have been postponed and, where possible, online and telephone activity has replaced these.

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. In 2019 we held 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. The feedback received was overwhelmingly positive and we will hold a further professionals' conference.

#### **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 (MAB). This panel consists of expert world-respected scientists and researchers.

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.

The Trustees have paid due regard to guidance issued by the Charity Commission on Public Benefit in deciding what activities the charity should undertake.

## **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 2019.

#### **The UK Inherited Retinal Dystrophy Consortium (UKIRDC) Started 2014 / Ends 2023**

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.

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 joined the 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 were well positioned among the 100,000 genomes being sampled and one of the consortium investigators was 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 six novel disease-causing genes, advancing our knowledge of IRDs and informing the development of future treatments for those facing visual impairment. The consortium has been granted continuation funding for another three years.

#### **DNA Damage as a Driver of Photoreceptor Loss in X-linked retinitis pigmentosa Started 2015 / Ended 2019**

Dr Toby Hurd at the University of Edinburgh completed this project in spring 2019. He set out to better understand the mechanism via which mutation of the RP2 causes Retinitis Pigmentosa. Previous data suggested that a reduced ability to deal with oxidative stress and DNA damage could be key, and this project aimed to explore whether this was indeed the underlying cause.

During the course of the project, the researchers established that, in photoreceptors, a protein called DNA-PKcs, known to defend against DNA damage and the toxic by-products of energy production (oxidative stress), actually has a distinct role in regulating special cellular structures called Golgi apparatus. When Golgi become fragmented, protein trafficking is disrupted, which is known to be a contributory factor in photoreceptor degeneration.

Through a series of careful experiments, Dr Hurd and the team established that the absence of RP2 does not diminish most of the normal effects of DNA-PKcs, so they have been able to hypothesise that DNA-PKcs controls the activity of RP2, rather than the other way around. They propose that DNA-PKcs regulates Golgi morphology through RP2, and that if RP2 is missing or dysfunctional, then this might result in Golgi fragmentation.

## Retina UK

### Report of the Trustees

#### For the year ending 31 December 2019

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The project has indicated a clear direction for further studies to work out if RP2 regulation of Golgi is a potential drug target and could be restored to slow retinal degeneration. Further understanding of the role and regulation of DNA-PKcs is also needed to clarify how modifying its activity might help to maintain proper Golgi structure and function.

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

**Started 2017 / Ends 2020**

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 precisely identified the time window during which the splicing process occurs. They have also disrupted the function of a candidate factor that controls this process and tested the effect on splicing in retinal organoids generated via stem cell technology.

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

**Started 2017 / Ends 2020**

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 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.

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). They have used their method to examine the entire ABCA4 sequence of 1,054 samples. Prof Cremers has also completed design of a test, known as a splice assay, to investigate how ABCA4 intron variations influence the editing of the genetic code during protein construction.

By employing these two techniques, the team has found 14 known and 13 new disease-causing variants deep within the non-coding sections of ABCA4 in 117 samples. This work has contributed to two publications, with a further large paper currently being written.

Using a molecular "patch", known as an antisense oligonucleotide, the researchers were able to block the effects of the non-coding mutations in a stem cell-based disease model, providing promise that this could be employed in future approaches to treatment.

**Non-viral gene therapy using S/MAR vectors for Usher Syndrome  
Started 2018 / Ends 2021**

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. A gene therapy approach that supplies healthy copies of USH2A is a potential route to treatment. However, for most gene therapies, the healthy gene is packaged into a virus for delivery into the diseased cells; this is not possible for USH2A because it is a very large gene and simply will not fit into a virus.

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. During the first year of the project, they have worked out how to successfully package USH2A into the S/MAR backbone by breaking the gene up into fragments and slotting them in one by one. The researchers have also begun the process of developing and characterising both zebrafish and human cell disease models so that they can test the therapeutic response to the S/MAR packaged therapy.

**Modelling effects of TIMP-3 mutations in RPE: insights into Sorsby disease and night blindness in retinal dystrophies  
Started 2018 / Ends 2020**

Dr Arjuna Ratnayaka of the University of Southampton is working on this project. Sorsby fundus dystrophy (SFD) involves changes in the protein TIMP3, which cause patients to lose night vision and 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. They have started to use gene-editing technology to correct mutated TIMP3 and study how damaged RPE cells can be rescued by 'restored' TIMP3.

The team will go on to use retinal scans from patients to study gradual sight loss, and identify new ways of recognising / tracking SFD. The findings could help design and test 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  
Started 2018 / Ends 2021**

Prof Majlinda Lako at Newcastle University is leading this project, which follows on from a smaller study "seed funded" by Retina UK. 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). They have used this model to establish that the mutated protein is found only in retinal pigment epithelium (RPE), not in photoreceptors, and have identified a number of proteins and key cellular pathways that are impacted upon by malfunctioning PRPF31. They have also discovered that affected RPE cells contain large clumps of protein (aggregates), suggesting that the cells are struggling to clear debris. This could provide a potential target for treatment.

## Retina UK

### Report of the Trustees

For the year ending 31 December 2019

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#### **Understanding the disease mechanisms and developing new therapies for RDH12-related Leber congenital amaurosis Started 2018 / Ends 2021**

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. So far, Dr Moosajee has developed effective cellular models to show how genetic changes impact protein function. Her team has also begun the generation and characterisation of a zebrafish disease model that will allow them to study the impact of mutations on the whole eye in a living system, as well as test the effects of drug compounds that may slow retinal degeneration.

#### **Natural exon skipping in ABCA4 mRNA and its modulation as a novel generic therapy for Stargardt disease Started 2018 / Ends 2021**

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 Started 2011 / Ends 2022**

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 aims.

So far, the team has instigated three early phase clinical trials and is considering expansion of one of these into a phase 3 trial. They have also amassed considerable expertise in the development of gene therapy delivery systems (vectors) and are applying this to the preclinical development of a number of therapies for retinal conditions and related syndromes. This includes work on the IMPG2 gene, modelling this particular type of retinal disease in cells and mice and starting to assess the viability of an IMPG2 gene therapy vector.

#### **IRD COUNTS**

The first phase of this health economics and epidemiology project, instigated by Retina UK, sought 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. The project was managed by Retina International and funded by the multi-stakeholder IRD COUNTS consortium (of which Retina UK is a member), with the cost-of-illness report being produced by Deloitte Access Economics.

The project showed that wellbeing costs, which refer to the years of quality of life lost due to IRDs, were responsible for 38.4% (£196.1million) of total IRD costs in the UK. Productivity costs, which refer to reduced workforce participation, absenteeism and presentism, were the second highest cost burden due to IRDs in the UK, amounting to £114.1million.

## Retina UK

### Report of the Trustees

#### For the year ending 31 December 2019

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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.

#### **Community engagement with research**

2019 saw Retina UK increase its efforts to facilitate engagement between members of our community and researchers. We have publicised nine research participation opportunities via our social media channels and e-newsletters, as well as directly emailing community members who have expressed a wish to take part in such activities. As a result, over 100 people affected by IRD have given their explicit consent to make contact with researchers.

Participation has included a survey for IRD COUNTS (see above), industry-led focus groups and patient committees, and questionnaire-based studies on mental health and information provision. Interaction between those living with IRD and the research community is essential for progress; it also provides our community with choices about participation, and opportunities to influence the direction of research.

#### **Bringing treatments to the clinic**

Securing reimbursement for new therapies is the essential final step in enabling those living with IRD to access life-changing treatment. In 2019, we ensured that our community's voice was heard during the NICE and Scottish Medicines Consortium technology appraisals of Luxturna, the first disease-modifying treatment for IRD. Our submissions to both organisations relied heavily on feedback from our Sight Loss Survey 2019 to provide insights into the impact of these conditions, and multiple references to these in NICE's Final Evaluation Document suggests that they played a significant part in securing the recommendation that Luxturna be made available through the NHS.

We will continue to work with NICE, SMC and industry partners to ensure that the unique profile of wellbeing and productivity burden in IRDs, as illustrated by IRD COUNTS, is appropriately considered in future cost-benefit analyses.

#### **Providing Information and Support**

The information and support team continued to develop collaborative partnerships in 2019, including working with a number of sight loss organisations during the year.

In 2019, 2,378 new contacts told us they were happy for us to stay in touch, including 1,032 individuals, 54 companies and 41 trusts/press media.

We delivered a collaborative family event in the North West in March with Henshaws, Royal Society for Blind Children and St Vincent's School for the Blind. More than 50 people attended.

We also worked with Usher Kids UK and Sense to deliver a family event in Birmingham in June where we welcomed over 70 people. We are very grateful to Apple, Birmingham City FC and Cadbury World for their support in delivering fun activities for the children whilst parents heard from professionals.

The team delivered information days in Newcastle, London, Brighton and Belfast. 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 help with day-to-day living while networking and sharing experiences. Over 227 people attended, around 106 of whom were new to the charity.

We attended Sight Village Events in Exeter, Birmingham, Leeds and London and of individuals affected by IRDs and professionals we met for the first time, 71 asked us to stay in touch. We also re-connected with people who are already on our database.

## **Retina UK**

### **Report of the Trustees**

#### **For the year ending 31 December 2019**

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We welcomed more than 230 delegates to our annual conference in Milton Keynes in September. We received excellent feedback from delegates including the fact that 100% would recommend future Retina UK events, 86% had a greater awareness of the support available to them, 94% felt more connected to the inherited sight loss community.

We also delivered our first professionals' conference in Milton Keynes in September. More than 180 education, health and social care professionals joined us. Feedback was overwhelmingly positive and we plan to repeat this successful event.

The team maintained our much-valued helpline and talk and support services. Our committed helpline volunteers responded to 759 calls and 152 emails in 2019. The Talk and Support service is in touch with nine people and our Charles Bonnet Syndrome Buddy service supported 25 people in 2019.

We ran a Helpline Training Weekend in June, which gave us the opportunity to bring our volunteers up-to-date with safeguarding, GDPR, the latest research and more.

We were delighted to congratulate volunteer Elizabeth Baio who was awarded 3rd place in the Volunteer of the Year awards at the Helplines Partnership Conference in November.

We surveyed all of our members in 2019 and had almost 1,000 responses. These have helped the charity understand the real-life experiences, challenges and expectations of those living with inherited sight loss conditions. Over half (53%) said their sight loss has a severe or very severe impact on their quality of life and loss of confidence, anxiety and stress are the biggest emotional or psychological impacts of sight loss.

We continue to provide accurate and trustworthy information and updates in a variety of accessible formats, including on our website, through our regular newsletters which are available in Word, PDF and audio format.

#### **Our volunteers**

In 2019 we engaged with 40 new volunteers who supported us in many ways such as, taking photographs at the London Marathon, entering data from our Sight Loss Survey, reading for our audio recordings, guiding and guide dog support at our events and much more. In addition, we continued to support our helpline and talk & support volunteers through training, recognition and appreciation.

We increased our local peer support groups to seven, with new meetings now established in Merseyside, Oxford and Somerset. We know from our Sight Loss Survey that respondents benefit from informal meetings with others that are affected by sight loss. Where possible, we have worked in collaboration with regional sight loss organisations so that resources are shared and a varied agenda can be delivered. We plan to start six more support groups in 2020.

We will continue to engage with volunteers to work us in a variety of roles and will strive for their positive well-being and enjoyment whilst supporting us.

## **Retina UK**

### **Report of the Trustees**

#### **For the year ending 31 December 2019**

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##### **Fundraising**

2019 was another successful year for the Retina UK Fundraising Team. £1,678,361 was raised thanks to the incredible support we have received from our community and a number of funders, corporate supporters and partners.

Highlights include growth in trusts income from £186,239 to £236,179, growth in corporate income from £64,755 to £119,936, and growth in appeals/prize draw income from £25,590 to £68,350. Regular events continued to perform well, with more than £52,000 raised by our amazing London Marathon runners, more than £6,200 through the Hope to Seaview walk on the Isle of Wight and £14,994 at the annual Worksop's Got Talent event, including match funding accessed through the Big Give Christmas Challenge. In total, supporters across the UK taking part in challenge events and community fundraising raised £234,651. This included £21,993 from our very first Retina UK Tandem Cycle Challenge, which saw 37 intrepid supporters taking on a 100 mile route along Hadrian's Cycleway on tandem bicycles.

Individuals who generously chose to make gifts to Retina UK in their wills, and those who kindly made donations to the charity in memory of loved ones, contributed £757,243 to help fund our vital work.

All fundraising in 2019 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 the Fundraising Preference Service, is licensed by the Gambling Commission, and adheres to the Code of Fundraising Practice.

We did not receive any requests via the Fundraising Preference Service to cease contact with any of our supporters, and received no complaints about our fundraising in 2019. We aim to fundraise in a fair and transparent way, in line with our values, and we respect the privacy of our donors. 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 2019.

**Acknowledgements**

We have received tremendous support in 2019 from individuals, groups, companies and organisations, enabling us to fund pioneering medical research into inherited sight loss and vital information and support for our community.

We would like to take this opportunity to thank the following trusts and foundations for their generous contributions in 2019:

- The Albert Van den Bergh Charitable Trust
- Allergan International Foundation
- The Annett Trust
- The Arden Trust
- BE Rodmell Trust
- Bosphorus Foundation
- The Champniss Charitable Trust
- The David Fryer Charitable Trust
- David Killick Trust
- The Doris Field Charitable Trust
- Edgar E. Lawley Foundation
- The Frogmal Trust
- G C Gibson Charitable Trust
- The G W Cadbury Charitable Trust
- The Gertrude Gourvitch Charitable Trust
- Gilbert Edgar Trust
- The James Wise Charitable Trust
- John Laing Charitable Trust
- Lillie Johnson Charitable Trust
- Mrs L J Walker's Charitable Trust
- Nineteen Eighty-Nine Charitable Trust
- Oakdale Trust
- Sir Samuel Scott of Yews Trust
- St James's Place Foundation
- Stella Symons Charitable Trust
- Tennant Southpark Charitable Trust
- The W.E.D. Charitable Trust
- Tom and Thelma Wilson Trust
- The Wallace & Edna Davis Charitable Foundation
- The Wyseliot Rose Charitable Trust

**Retina UK**

**Report of the Trustees**

**For the year ending 31 December 2019**

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**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 2019 (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  
12<sup>th</sup> August 2020

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

**For the year ending 31 December 2019**

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### **Opinion**

We have audited the financial statements of Retina UK (the 'charity') for the year ended 31 December 2019 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 2019, 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.

### **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*

### **Baldwins Audit Services**

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

Date: 19<sup>th</sup> August 2020

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 2019

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2019 £	Total Funds 2018 £
<b>INCOME FROM:</b>					
Donations & legacies	3	579,218	1,099,143	1,678,361	1,695,951
Charitable activities					
Medical research grants	4	-	-	-	30,000
Investments	5	9,141	-	9,141	6,422
<b>Total income</b>		<b>588,359</b>	<b>1,099,143</b>	<b>1,687,502</b>	<b>1,732,373</b>
<b>EXPENDITURE ON:</b>					
Raising funds	6	213,154	104,338	317,492	413,273
Charitable activities					
Medical research grants	7	33,384	858,197	891,581	450,751
Information & support	8	294,001	352,440	646,441	420,869
<b>Total expenditure</b>		<b>540,539</b>	<b>1,314,975</b>	<b>1,855,514</b>	<b>1,284,893</b>
Net gains / (losses) on investments		31,175	-	31,175	(32,704)
<b>Net movement in funds</b>	<b>9</b>	<b>78,995</b>	<b>(215,832)</b>	<b>(136,837)</b>	<b>414,776</b>
<b>Funds at 1 January 2019</b>	<b>20/22</b>	<b>347,311</b>	<b>635,567</b>	<b>982,878</b>	<b>568,102</b>
<b>Funds at 31 December 2019</b>	<b>20/22</b>	<b>426,306</b>	<b>419,735</b>	<b>846,041</b>	<b>982,878</b>

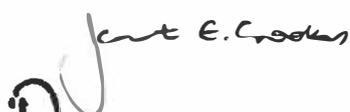
Retina UK

Balance Sheet

At 31 December 2019

	Note	2019 £	2018 £
<b>FIXED ASSETS</b>			
Tangible fixed assets	13	4,120	5,480
Investments	14	260,400	229,225
<b>Total fixed assets</b>		<b>264,520</b>	<b>234,705</b>
<b>CURRENT ASSETS</b>			
Debtors: Amounts falling due within 1 year	15	832,612	234,148
Cash at bank and in hand	16	847,352	1,283,037
<b>Total current assets</b>		<b>1,679,964</b>	<b>1,517,185</b>
<b>LIABILITIES</b>			
Creditors: Amounts due within 1 year	17	<u>(1,098,443)</u>	<u>(769,012)</u>
<b>Net current assets</b>		<b>581,521</b>	<b>748,173</b>
<b>Net assets</b>		<b>846,041</b>	<b>982,878</b>
<b>FUNDS</b>			
Unrestricted	20	426,306	347,311
Restricted	22	419,735	635,567
<b>Total funds</b>		<b>846,041</b>	<b>982,878</b>

Approved by the Trustees and signed on their behalf by:



J E Crookes  
Treasurer  
12<sup>th</sup> August 2020



D J Grocott  
Chairman  
12<sup>th</sup> August 2020

Retina UK

Cash Flow Statement

For the year ending 31 December 2019

Cash flows from operating activities:	Note	2019 £	2018 £
<b>Net (expenditure)/income for the reporting period</b>		<b>(136,837)</b>	414,776
<b>Adjustments for:</b>			
Depreciation charges	13	3,574	3,397
Unrealised (gains)/losses on investments	14	(31,175)	32,704
Dividends and interest from investments	5	(9,141)	(6,422)
Increase in debtors	15	(598,464)	(98,729)
Decrease in creditors	17	(69,814)	(108,608)
Increase/(decrease) in grant creditors	17	399,245	(127,423)
<b>Net cash used in operating activities</b>		<b>(442,612)</b>	109,695
<b>Cash flows from investing activities:</b>			
Dividends and interest from investments	5	9,141	6,422
Purchase of tangible fixed assets	13	(2,214)	(2,328)
<b>Cash flows from investing activities</b>		<b>6,927</b>	4,094
<b>Change in cash and cash equivalents in the year</b>		<b>(435,685)</b>	113,789
<b>Cash and cash equivalents at 1 January 2019</b>	16	<b>1,283,037</b>	1,169,248
<b>Cash and cash equivalents at 31 December 2019</b>	16	<b>847,352</b>	1,283,037

### 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 have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued in October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued in October 2019 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

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

The Covid-19 pandemic and the resulting changes to planned fundraising and operational activities initially created significant uncertainties around income and cash forecasts. The actions taken by the charity in response to this challenge have mitigated the level of ongoing risk. Recent notifications of legacies, together with ongoing fundraising efforts, mean that 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.

**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 reviewed 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.

***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 2019**

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**3. Donations and Legacies**

	<b>2019</b>	<b>2018</b>
	<b>£</b>	<b>£</b>
Membership subscriptions/donations	<b>35,728</b>	40,308
Individual donations	<b>162,949</b>	686,141
Trusts	<b>236,179</b>	186,239
Corporate	<b>119,936</b>	64,755
Legacies/In memoriam	<b>757,243</b>	407,986
Fundraising	<b>234,651</b>	229,908
Prize draw/appeals/mailings	<b>68,350</b>	25,590
Gift Aid	<b>63,325</b>	55,024
<b>Total</b>	<b><u>1,678,361</u></b>	<b><u>1,695,951</u></b>

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**4. Medical research grants**

	<b>2019</b>	<b>2018</b>
	<b>£</b>	<b>£</b>
Research funding	-	30,000
<b>Total</b>	<b><u>-</u></b>	<b><u>30,000</u></b>

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**5. Investments**

	<b>2019</b>	<b>2018</b>
	<b>£</b>	<b>£</b>
Share dividends	<b>7,039</b>	5,474
Bank interest	<b>2,102</b>	948
<b>Total</b>	<b><u>9,141</u></b>	<b><u>6,422</u></b>

Retina UK

Notes to the Accounts

For the year ending 31 December 2019

6. Raising funds

	2019	2018
	£	£
Event costs	58,029	107,861
Materials & equipment	1,372	2,702
Collection fees	6,670	11,119
Travel expenses	-	1,898
Training and conferences	1,129	6,483
Donor development including trusts & corporates	1,696	6,416
Other	801	885
Support costs (see note 10)	247,795	275,909
<b>Total</b>	<b>317,492</b>	<b>413,273</b>

7. Medical research

	2019	2018
	£	£
Annual grant awards	840,403	395,588
MAB expenses	215	435
Support costs (see note 10)	50,963	54,728
<b>Total</b>	<b>891,581</b>	<b>450,751</b>

8. Information & support

	2019	2018
	£	£
Publications, DVDs, leaflets etc	16,429	16,540
Annual conference	17,537	18,571
Helpline support	6,083	9,316
Information events	9,569	7,121
Non-medical research/projects	179,802	30,955
Travel expenses	17,602	12,079
Retina International	4,945	4,659
Brand and website development	3,284	27,101
Sight Loss Survey 2019	10,512	-
Volunteering	9,666	-
Other	1,608	3,687
Support costs (see note 10)	369,404	290,840
<b>Total</b>	<b>646,441</b>	<b>420,869</b>

**Retina UK****Notes to the Accounts****For the year ending 31 December 2019**

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**9. Net movement in funds is stated after charging**

	<b>2019</b>	<b>2018</b>
	<b>£</b>	<b>£</b>
Auditor's remuneration (audit)	<b>7,000</b>	6,720
Depreciation	<b>3,574</b>	3,397
Trustees' expenses	<b>2,057</b>	2,314
Lease payments	<b>13,500</b>	13,500

Trustees' expenses, incurred on travel and accessibility support, represent amounts reimbursed to three Trustees for expenses incurred (2018 - 2).

No Trustee received any remuneration during the year (2018 - none).

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**10. Analysis of support costs**

	<b>Total</b>	<b>Fund-raising</b>	<b>Research</b>	<b>Information, &amp; support</b>	<b>Basis of apportionment</b>
	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>	
Office administration	94,969	37,987	9,498	47,484	Staff time or actual
Human resources/ Remuneration	539,243	196,228	38,070	304,945	Staff time
Governance	33,950	13,580	3,395	16,975	Staff time or actual
<b>Total</b>	<b>668,162</b>	<b>247,795</b>	<b>50,963</b>	<b>369,404</b>	
Governance costs in 2018	35,397	14,159	3,540	17,698	

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**Retina UK**

**Notes to the Accounts**

**For the year ending 31 December 2019**

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**11. Staff numbers and costs**

	<b>2019</b>	2018
	<b>£</b>	£
Wages and salaries	<b>502,184</b>	455,618
Social Security costs	<b>43,346</b>	40,410
Pension costs	<b>14,403</b>	12,628
	<u><b>559,933</b></u>	<u>508,656</u>

The number of persons employed by the charity during the year was 19 (2018 - 17).

Total remuneration (including Employer NIC) for key management personnel in the year was £85,349 (2018 - £77,346). The number of employees with remuneration (excluding Employer NIC) between £70,000-£80,000 was 1, between £60,000-£70,000, 0 (2018 – between £70,000-£80,000, 0, between £60,000-£70,000, 1).

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Retina UK

Notes to the Accounts

For the year ending 31 December 2019

12. Comparative information for Statement of Financial Activities

	Unrestricted Funds	Restricted Funds	Total Funds 2018 £
	£	£	£
<b><u>INCOME FROM:</u></b>			
Donations & legacies	767,729	928,222	1,695,951
Charitable activities			
<i>Medical research grants</i>	-	30,000	30,000
Investments	6,422	-	6,422
<b>Total income</b>	<b>774,151</b>	<b>958,222</b>	<b>1,732,373</b>
<b><u>EXPENDITURE ON:</u></b>			
Raising funds	358,335	54,938	413,273
Charitable activities			
<i>Medical research grants</i>	55,163	395,588	450,751
<i>Information, support &amp; engagement</i>	389,313	31,556	420,869
<b>Total expenditure</b>	<b>802,811</b>	<b>482,082</b>	<b>1,284,893</b>
Net losses on investments	(32,704)	-	(32,704)
<b>Net movement in funds</b>	<b>(61,364)</b>	<b>476,140</b>	<b>414,776</b>
<b>Funds at 1 January 2018</b>	<b>408,675</b>	<b>159,427</b>	<b>568,102</b>
<b>Funds at 31 December 2018</b>	<b>347,311</b>	<b>635,567</b>	<b>982,878</b>

Retina UK

Notes to the Accounts

For the year ending 31 December 2019

13. Tangible fixed assets

	Office Equipment £
<b>Cost</b>	
At 1 January 2019	37,964
Disposals	(26,944)
Additions	2,214
<b>At 31 December 2019</b>	<u>13,234</u>
<b>Depreciation</b>	
At 1 January 2019	32,484
Disposals	(26,944)
Charge for year	3,574
<b>At 31 December 2019</b>	<u>9,114</u>
<b>Net book value</b>	
<b>At 31 December 2019</b>	<u>4,120</u>
At 31 December 2018	<u>5,480</u>

14. Investments

	2019 £	2018 £
At 1 January 2019	229,225	261,929
Unrealised gains/(losses)	31,175	(32,704)
<b>As at 31 December 2019</b>	<u>260,400</u>	<u>229,225</u>
	2019 £	2018 £
Included within investments are the following:		
CAF balanced growth fund at valuation	260,012	228,837
Shares in Taylor Woodrow	275	275
3% City of Liverpool stock	113	113
	<u>260,400</u>	<u>229,225</u>

All investments are held in the UK.

**Retina UK****Notes to the Accounts****For the year ending 31 December 2019****15. Debtors: Amounts falling due within one year**

	2019 £	2018 £
Accrued income	812,972	220,273
Trade debtors	5,303	-
Prepayments	14,337	13,875
<b>Total</b>	<b>832,612</b>	<b>234,148</b>

**16. Analysis of cash and cash equivalents**

	2019 £	2018 £
Cash at bank and in hand	847,352	1,283,037
<b>Total</b>	<b>847,352</b>	<b>1,283,037</b>

**17. Creditors: Amounts falling due within one year**

	2019 £	2018 £
Trade creditors	23,661	123,362
Tax and social security	12,108	11,722
Accruals and deferred income	34,000	6,720
Grant liability	1,023,685	624,440
Other creditors	4,989	2,768
<b>Total</b>	<b>1,098,443</b>	<b>769,012</b>

**18. Contingent Assets & Liabilities**

There is a contingent liability of £551,213 at 31 December 2019 (2018 - £883,795) in respect of research grants authorised subject to annual review. This money falls due in years 2020 onwards.

**19. Financial commitments**

	2019 £	2018 £
Total future minimum lease payments under non-cancellable operating leases are as follows:		
< 1 year	13,500	13,500
1 - 5 years	13,500	27,000



**Retina UK****Notes to the Accounts****For the year ending 31 December 2019**

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**20. Unrestricted Funds**

	<b>General Fund £</b>	<b>Designated Research Fund £</b>	<b>Total Unrestricted Funds £</b>
Balance at 1 January 2019	280,111	67,200	347,311
Transfer between funds	(100,437)	100,437	-
Net incoming resources	100,876	(21,881)	78,995
<b>Balance at 31 December 2019</b>	<b><u>280,550</u></b>	<b><u>145,756</u></b>	<b><u>426,306</u></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.

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**21. Comparative information of Unrestricted Funds movement at 31 December 2018**

	<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><u>280,111</u></b>	<b><u>67,200</u></b>	<b><u>347,311</u></b>

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Retina UK

Notes to the Accounts

For the year ending 31 December 2019

22. Restricted Funds

	Research Fund	Usher Fund	Awards Fund	RDH12 Fund	Pioneering Research Fund	H E & E Fund	Regional Services Funds	Scottish Research Fund	Macular Research Fund	CJ Legacy Fund	Specified Research Fund	Total Restricted Funds
	£	£	£	£	£	£	£	£	£	£	£	£
Balance at 1 January 2019	40,038	48,829	1,150	308,963	77,500	41,409	7,900	-	-	-	109,778	635,567
Transfer between funds	8,340	-	-	-	-	-	-	(8,340)	-	-	-	-
Net incoming resources	(39,026)	(46,284)	-	(87,187)	3,600	(41,409)	(7,900)	11,000	1,697	71,649	(81,972)	(215,832)
<b>Balance at 31 December 2019</b>	<b>9,352</b>	<b>2,545</b>	<b>1,150</b>	<b>221,776</b>	<b>81,100</b>	<b>-</b>	<b>-</b>	<b>2,660</b>	<b>1,697</b>	<b>71,649</b>	<b>27,806</b>	<b>419,735</b>

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

**Usher Fund:** These donations were specifically allocated by the donors for research into Usher Syndrome.

**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 (IRD Counts):** 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.

## Retina UK

### Notes to the Accounts

For the year ending 31 December 2019

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#### 22. Restricted Funds (continued)

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

**Scottish Research Fund:** This fund contains donations for research within Scotland

**Macular Research Fund:** This fund contains donations for macular research.

**CJ Legacy Fund:** This legacy cannot be used to support vivisection (research on animals) but can be used for any other expenditure.

**Specified Research Fund:** This fund is for specified research, funded by specific donations.

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#### 23. Comparative information of Restricted Funds movement at 31 December 2018

	Research Fund	Innovation Fund	Usher Fund	Awards Fund	RDH12 Fund	Pioneering Research Fund	H E & E Fund	Regional Services Funds	Specified Research Fund	Total Restricted Funds
	£	£	£	£	£	£	£	£	£	£
Balance at 1 January 2018	-	27,786	29,774	1,275	-	-	-	-	100,592	159,427
Transfer between funds	30,250	-	-	-	-	50,000	-	-	(80,250)	-
Net incoming resources	9,788	(27,786)	19,055	(125)	308,963	27,500	41,409	7,900	89,436	476,140
Balance at 31 December 2018	40,038	-	48,829	1,150	308,963	77,500	41,409	7,900	109,778	635,567

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Retina UK

Notes to the Accounts

For the year ending 31 December 2019

**24. Analysis of net assets between funds**

	<b>Tangible Fixed Assets £</b>	<b>Fixed Asset Investment £</b>	<b>Current Assets £</b>	<b>Current Liabilities £</b>	<b>Total £</b>
Restricted Funds	-	-	833,888	(414,153)	419,735
Unrestricted Funds	4,120	260,400	846,076	(684,290)	426,306
	<u>4,120</u>	<u>260,400</u>	<u>1,679,964</u>	<u>(1,098,443)</u>	<u>846,041</u>

**25. Comparative analysis of net assets between funds 2018**

	<b>Tangible Fixed Assets £</b>	<b>Fixed Asset Investment £</b>	<b>Current Assets £</b>	<b>Current Liabilities £</b>	<b>Total £</b>
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>

## Retina UK

### Notes to the Accounts

For the year ending 31 December 2019

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#### 26. Grants awarded - 2019

Institution		Grant Holder	Amount £
UCL	GR576	Prof R Ali	100,000
UK Inherited Retinal Dystrophy Consortium	GR586A	*	136,179
Institute of Ophthalmology	GR589	Prof M Cheetham	72,541
University of Southampton	GR590	Dr A Ratanyaka	63,343
Radboud University, The Netherlands	GR591	Dr F Cremers	69,687
UCL	GR592	Dr M Moosajee	91,675
UCL	GR594	Dr M Moosajee	117,342
Newcastle University	GR595	Prof M Lako	130,313
UCL	GR598	Dr M Moosajee	60,000
<b>Total</b>			<b>841,080</b>
Opening creditor for grant commitment			624,440
Grant payments - 2019			(441,158)
Adjustments on completion of grant projects			(677)
Closing creditor for grant commitment			<b>1,023,685</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

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#### 27. Related party transactions

There are no related party transactions requiring disclosure in the Financial Statements (2018 - none).

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