



Retina UK

A Charitable Incorporated Organisation

Annual Report & Financial Statements

Year Ending 31 December 2020

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

Retina UK

Reference and administrative details

For the year ending 31 December 2020

Charity number	1153851
Registered office and operational address	Retina UK PO Box 350 Buckingham MK18 1GZ
Telephone	01280 821334
Email	info@RetinaUK.org.uk
Website	www.RetinaUK.org.uk
Honorary President	Mrs Lynda Cantor MBE
Trustees	Trustees who served during the year and up to the date of this report were as follows: Mr Don Grocott (Chair until 17 April 2021) Dr Martin Kirkup (Trustee from 24 February 2021, Chair from 17 April 2021) Mr Roger Backhouse Mrs Lynda Cantor MBE Ms Janet Crookes FCA (Treasurer) Dr Elizabeth Graham Prof John Marshall MBE Mrs Rachael Stevens Dr Lucy Withington Mr Keith Valentine (until 23 March 2020)
Ambassadors	Mrs Bhavini Makwana Mr Steven Bate MBE Mr Amar Latif Mrs Seema Flower Mrs Victoria Claire
Chief Executive Officer	Mrs Tina Houlihan
Principal Bankers	Lloyds Bank PLC 187 Watling Street Towcester NN12 6BX
Auditors	Azets Audit Services Churchill House 59 Lichfield Street Walsall West Midlands WS4 2BX

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Retina UK

Chairman's Report

For the year ending 31 December 2020

I am honoured to have the opportunity to take on the role of Chair of the Board of Trustees. Having a son with Stargardt's disease has made me acutely aware of the critical need to drive forward the search for cures for inherited sight loss and the equally important need to support all those affected by sight loss in their everyday lives.

2020 has proven a tough year for the whole of the charity sector, especially those involved in funding and carrying out research. Experiments that were cut short had to be re-started with months of expensive research lost. The AMRC (Association of Medical Research Charities) is estimating it will take 4.5 years for the sector to recover.

At Retina UK we have been inspired by the tenacity and resilience of the research teams we fund. Applying speed and agility they have already started to recover some of the time and momentum lost.

Notwithstanding the challenges of the pandemic, underlying income (income excluding legacies) has remained stable thanks to continued project funding from sector partners and the hard work of community. The addition of significant legacy income received late in the year has taken total income to £2,128,000. We are very fortunate to have secured this uplift at such a difficult time but we remain cognisant of the fact that legacy income is an unpredictable source of funding in the longer term.

Whilst taking a necessarily cautious approach of reducing spend and retaining income, we have nevertheless managed to invest £610,000 on medical research and £461,000 on directly supporting our community, recognising that the community needed us more at this time and not less.

By accessing the furlough scheme and tightly managing expenditure, the charity was able to finish the year in a more positive position than our early forecasts had anticipated.

I am delighted to report that, far from standing still in this difficult year, important progress was made and there were some stand out achievements:

- Funding was secured to upgrade and increase the capacity of helpline services which enabled the team to respond to a 68% increase in calls.
- Funding was secured to complete the 'Unlock Genetics' project. The project reflects the importance of the community's need to understand both the process and importance of genetic testing / counselling. The project was launched in April 2021 before this report went to press.
- We have continued to support all of our current medical research projects and undertaken one new award.
- We have created online forums in place of our face-to-face meetings including a buddy system and local group meetings.
- We contributed to the NICE process and their methodology reviews in preparation for treatments to follow in Luxturna's footsteps over the next few years.

In line with charity commission guidelines, the necessary decision was taken during the year to delay our national conference and AGM until April 2021. Despite the limitations imposed by its 'virtual format' the events were extremely well attended and received positive feedback, but we look forward to meeting with our community face-to-face as soon as we can do so safely again.

In 2021-22 year we will seek to regain research momentum looking first to increase our financial resources to allow greater investment into research. Towards the end of 2021 we will be developing a research strategy to ensure that we remain aligned to the evolving status of research and the significant steps forward that have been achieved in recent years.

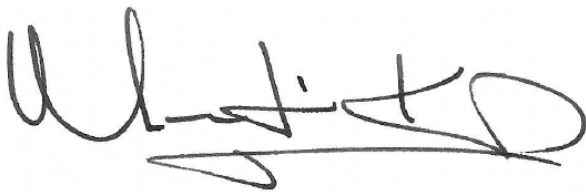
Retina UK

Chairman's Report

For the year ending 31 December 2020

Whilst the search for cures and treatments for IRDs continues to be our primary mission, the organisation will also continue to focus on the community's daily well-being and delivering the support they need from us as a charity. Our evidence shows that the mental health of our community has been negatively impacted by the pandemic and the likely effects that might continue for some time afterwards. Therefore we will be looking at ways to further support and enrich the lives of families living with IRDs.

Before this report went to press, at the April Annual General Meeting we wished Don Grocott a fond farewell. Don has served Retina UK as Chair for more than 10 years and we owe him an enormous debt of gratitude for his service both to Retina UK and to the sector as a whole and we wish him the very best in his retirement.

A handwritten signature in black ink, appearing to read 'M Kirkup', with a long horizontal flourish underneath.

Dr M Kirkup
Chair
14 July 2021

Retina UK

Report of the Trustees

For the year ending 31 December 2020

The Trustees are pleased to present their annual report together with the financial statements of the charity for the year ending 31 December 2020. 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 a panel of Trustees and then 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 (AMRC), Retina International, Visionary and Vision UK (closed on 31 July 2020) and abides by each organisation's principles of best practice at all times.

Report of the Trustees

For the year ending 31 December 2020

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 2020, as shown in the Financial Statements, shows that we concluded the year with income and funds in excess of those in the previous year. For the first three quarters of the year this was not the case, due to the impact of the COVID-19 pandemic and the restrictions on the activities we could carry out both for fundraising and in support of our community. Shortfalls in some areas of fundraising were mitigated by grants and donations from a range of organisations, for which we are very grateful. Confirmation of significant legacies later in the year meant that we achieved total income of £2,128,494 (2019: £1,687,502).

Given the uncertainties arising from the pandemic, expenditure was initially reduced to a minimum and then reinstated to the extent that work could be carried out under the various social distancing regulations. There is more detail on this elsewhere in this report. The area of our activities hit hardest overall was medical research. Many projects were paused and with the restrictions on laboratory work we did not feel it appropriate to call for new research funding applications. As a result our spending on medical research decreased to £610,119 (2019: £891,581).

At the end of the year we had a net increase in funds of £793,448 (2019 decrease of £136,837). Our Balance Sheet at 31 December 2020 shows total funds of £1,639,489 (2019: £846,041). Our plans for 2021 have taken into account the continuing restrictions in place in the first half of the year as well as the opportunities we hope will arise before the year end to award new medical research grants, and to continue working to support our community.

Principal Funding Sources

The majority of our income is usually 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. In 2020 we were fortunate to receive more funding from corporate and trust donors to assist during the pandemic emergency. The Trustees are aware of the unpredictability of all these sources of income and the need 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

For several years we have considered it appropriate to maintain unrestricted funds to cover six months budgeted essential expenditure which we have seen as adequate in the event of the charity being forced to wind up. The experience of the COVID-19 pandemic over the course of 2020 and into 2021 showed that this approach, maintaining £280,000 of unrestricted funds, was sufficient for us to have time to modify our expectations of income and to control expenditure. Significant uncertainties have continued in 2021 and so the Trustees have decided to retain additional funds in unrestricted funds at 31 December 2020, whilst still intending to release some funds into new research projects to be identified before 31 December 2021. In addition, the Trustees have designated £307,000 to cover amounts shown as contingent liabilities which may arise on medical research projects that have already started.

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 COVID-19 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 resulted in a significant curtailment of the charity's operations in the spring and summer of 2020 including some fundraising channels. Actions were taken to keep the charity on a sustainable basis, and the frequency of Board meetings was increased to monitor the situation.

Planning for 2021 covered a range of scenarios and, whilst some uncertainty will continue for much of this year and into 2022, 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 more than £16 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, Luxturna (*voretigene neparvovec*) was recommended by NICE for use in the NHS in England in early September 2019. In January 2020 the first patients in the UK received this treatment. 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. As detailed later in this report, the majority of projects funded by Retina UK experienced delays to their work streams in 2020 due to the COVID-19 pandemic and associated lab closures. We have been pleased to provide no-cost extensions as required so that grantees can achieve the aims set out in their original project proposals.

The COVID-19 Pandemic has forced us to be more innovative with our information and support provision with face-to-face events not possible because of restrictions and periods of staff furlough. Whilst we were forced to be more reactive to the needs of our community at the start of the year, we were able to proactively encourage, support and innovate during the second half of the year.

Retina UK

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For the year ending 31 December 2020

Zoom has been used widely to maintain relationships with our community and our volunteers and whilst 2020 was not the year that any of us expected it to be, our staff, volunteers and community have become more adept at using technology than we would have been otherwise.

Our new Helpline system and updated number have never been more needed and we were very grateful to Allergan for the funding of this project.

We hope to reinstate face-to-face information days in the latter part of 2021. 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. 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.

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 2020.

The majority of projects funded by Retina UK experienced delays to their work streams in 2020 due to the COVID-19 pandemic and associated lab closures. We have been pleased to provide no-cost extensions as required so that grantees can achieve the aims set out in their original project proposals.

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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 seven novel disease-causing genes and further understanding of the role of nine other genes. Consortium members also contributed to a 2020 publication describing a brand new disease mechanism involving structural changes to chromosome 17. Overall, the consortium has played an important role in advancing our knowledge of IRDs and informing the development of future treatments for those facing visual impairment. The consortium successfully applied to Retina UK for a new grant to continue their work and allow further investigation of the genome sequences from the original project. This began in December 2020.

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

Started 2017 / Ended 2020

Prof Mike Cheetham at the UCL Institute of Ophthalmology led 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. Although this factor was crucial for splicing, it actually had little effect in a particular LCA disease model, leading the team to conclude that other factors were likely to be more important.

The team's investigations as part of this project have also increased understanding of how a particular variant in the *DYNC2H1* gene causes retina-specific symptoms through its effects on splicing. They found that, although this change was within a non-coding section of genetic information, it was in fact resulting in changes to the protein produced in retinal cells, because the retinal splicing process treated it as a small coding sequence (micro-exon).

The project has moved understanding forward in this area and identified potential targets for future treatment development. The team has also used their expertise in stem-cell derived retinal models to contribute to the development of antisense oligonucleotide therapy, now being taken through clinical testing.

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

Started 2017 / Ended 2020

This was a project 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 several new disease-causing variants deep within the non-coding sections of ABCA4 in 117 samples. This work has contributed to some important publications. The team has also collaborated with clinicians across Europe, offering testing and providing genetic diagnoses to families across the continent.

The researchers also discovered a gender imbalance (more females than males) in people carrying two ABCA4 mutations, suggesting that inheritance is multifactorial, and that other factors are needed for Stargardt's to occur. This is a novel and potentially significant factor for consideration.

Looking ahead to therapy development, the researchers used a molecular "patch", known as an antisense oligonucleotide, 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.

This project has also played a role in training promising young scientists, with one of Prof Cremers' PhD students winning a prestigious Young Investigator award for her work.

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

Started 2018 / Ends 2021

Prof 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, the researchers 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. They have also refined the S/MAR system to contain specific signals (promoters) that switch the therapeutic gene on in retinal cells.

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The researchers have also made progress in developing and characterising both zebrafish and human cell disease models so that they can test the therapeutic response to the S/MAR packaged therapy. During the project's second year, they have delivered the S/MAR-packaged gene to human skin cells from Usher syndrome patients and have some evidence that the cells are using the gene to produce usherin protein. The patient skin cells will be cultured to create stem cell-derived retinal models for further, more sensitive testing of the new delivery system.

The team has optimised microinjection delivery of the S/MAR vector to the single developmental cell of the zebrafish model and has also completed detailed characterisation of the fish to enable accurate testing of the effects of the therapy.

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

Started 2018 / Ends 2021

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. This work has generated a wealth of new knowledge, which has been submitted for publication. The researchers have also started to use gene-editing technology to correct mutated TIMP3 and study how damaged RPE cells can be rescued by 'restored' TIMP3. They are comparing the effects on different TIMP3 mutations.

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 in RPE that are impacted upon by malfunctioning PRPF31. The team is now using bioinformatics approaches to better understand how and why the RPE splicing machinery edits the genetic code in such a dysregulated way.

The researchers have also discovered that affected RPE cells contain large clumps of protein (aggregates), suggesting that the cells are struggling to clear debris. These aggregates may trap mutant PRPF31 protein and some of the substances that are necessary for the visual cycle to work, suggesting that therapies aiming to clear the aggregates could be worthy of investigation.

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This project has experienced delays due to pandemic-associated lab closures and, when the initial lockdown was instigated, the researchers were also forced to discard retinal organoids that had been cultured over many months. Retina UK has awarded a cost extension to support the replacement of these organoids. Despite the delays, Prof Lako's team is making good progress and has produced a number of publications.

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

Started 2018 / Ends 2021

Prof Mariya Moosajee is leading this project at UCL Institute of Ophthalmology and the Francis Crick Institute. It aims to increase knowledge of the molecular basis of this type of LCA and accelerate development of an effective treatment.

So far, Prof Moosajee has developed effective cellular models to show how genetic changes impact protein function, although some of this work has been delayed by pandemic-related lab shutdowns and retinal organoids will need to be regrown.

Prof Moosajee's 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. The fish did not show signs of retinal degeneration at the very early stages of their development, so are being allowed to grow to 6 month and one year time points, when they will be re-examined.

The researchers have detected high levels of cellular stress in the RDH12 mutant cell lines, so have selected three drugs for testing that have the ability to reduce cellular stress. Two other drugs have been selected that may help restore RDH12 function for some types of mutation. All of these drugs will eventually be tested in cell lines and retinal organoids.

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 is 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 sections (exons) 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.

Using human retinal specimens, the researchers have identified various different forms of altered ABCA4 and has discovered that one of these, lacking a section known as exon 15, is the commonest form that undergoes exon skipping. They have also looked in more detail at two gene regions that might regulate exon skipping, which has enabled them to start designing a molecular “patch” (antisense oligonucleotide, or AON) to block these regions and prevent skipping. The AON has had mixed results so far, so the researchers are looking to optimize it further.

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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; in 2020 Prof Ali and the team moved to King's College London to establish a Centre for Cell and Gene Therapy there. The project 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 treated several infants with a rare form of LCA under a local special license.

The team has 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.

Understanding NR2E3-retinal disease pathways and identifying therapeutic targets

Started 2020 / Ends 2021

This project is being led by Prof Mariya Moosajee at UCL Institute of Ophthalmology and the Francis Crick Institute. The gene NR2E3 functions in the light-sensing cells (photoreceptors) of the retina. We have two types of photoreceptors, rods (which aid vision in dim light and detect movement in our peripheral field of vision) and cones (of which we have 3 subtypes red, green and blue and these control our fine detail and colour vision). NR2E3 is active in early retinal development during pregnancy to signal more rods to develop and suppresses cone development (in particular green and blue cones) in a very controlled manner so we get the correct proportion of both in the correct place.

Mutations in NR2E3 causes retinitis pigmentosa (RP), characterised by progressive loss of rods followed by cones. It also causes enhanced S cone syndrome, where patients have increased sensitivity to blue light, mediated by the S (short wavelength, blue) cones. This project aims to increase understanding of NR2E3 retinal disease by using a zebrafish model to study the direct effects on cone and rod development. The researchers will investigate how disruption of NR2E3 affects other genes in the retina in order to identify a potential treatment target.

Development of CRISPR gene therapy for Stargardt disease

Started 2020 / Ends 2023

This PhD studentship, co-funded with the Macular Society, is being supervised by Prof Robert MacLaren at Oxford University.

Stargardt disease is a juvenile-onset macular dystrophy, usually caused by mutations in the ABCA4 gene. ABCA4 is a large gene, too long to fit inside the viral delivery systems most commonly used for gene replacement therapy, and so requires innovative approaches to treatment. This project will investigate the feasibility of using a CRISPR-based gene editing approach to correct faults in the genetic code. In particular, the researchers will look at editing the intermediary genetic molecule known as RNA, which exists only temporarily inside the cell and potentially provides a safer, more flexible target than the original DNA blueprint.

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Community engagement with research

2020 saw Retina UK continue its efforts to facilitate engagement between members of our community and researchers. Despite the slow-down in research activity caused by the pandemic, we have publicised six 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 300 people affected by IRDs have given their explicit consent to make contact with researchers.

Participation has included industry-led interviews and patient committees, and questionnaire-based studies on auditory processing with visual impairment and attitudes to gene therapies. 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 2020, Retina UK contributed to the NICE Methods Review consultation, emphasising our community's unique profile in terms of the healthcare vs. wellbeing costs incurred by inherited sight loss and endeavouring to ensure that this is considered in future cost benefit analyses.

Information and support

The COVID-19 pandemic seriously disrupted our planned activity for 2020 and the theme for the year became 'doing things differently'. It did however provide an unexpected opportunity to connect digitally with our community, including those people who have never attended face-to-face events.

In 2020 892 new contacts told us they were happy for us to stay in touch, including 785 individuals, 43 companies and 27 trusts/press media.

Our Annual General Meeting (AGM), Annual Conference and Professionals' Conference were all postponed because of the ongoing restrictions regarding public gathering. They have now taken place (April 2021).

Helpline

We had already planned to update the functionality of our helpline system in 2020 but the increase in calls to the Helpline during the early days of the pandemic highlighted the urgency of this project. The helpline system was upgraded in April 2020, which included the introduction of a local call number.

We wrote to our community advising them of the change of number and reminding them of our other information and support services, encouraging them to reach out to us if they were in need of support.

Call volumes have been high throughout but the new system makes it much easier for our volunteers to access and the enhanced reporting function has provided valuable insights. Contact on the email helpline has also increased.

- Email queries: 154 (vs 152 in 2019)
- Phone calls: 931 (vs 759 in 2019)
- Average call length: approx. 20 minutes (vs approx. 9 minutes in 2019)
- Talk and support service in touch with 12 people (9 in 2019)
- Charles Bonnet Syndrome Buddy service 17 people (25 in 2019) – we now only take referrals for people living with the conditions for which the charity provides support.

Retina UK

Report of the Trustees

For the year ending 31 December 2020

Local Peer Support

We held six online / phone local peer support meetings in 2020 for those living in London, Scotland, Birmingham and Somerset. More than 125 people attended. The meetings were recorded and then shared with group members who were not able to attend on the day.

“Thanks so much for hosting the London group meeting today! It was fantastic to come together and share experiences, now so more than ever given how the restrictions have made travelling and socialising harder.”

Look Forward & e-Newsletters

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. Thanks to sponsorship secured from Janssen, we were able to continue with our planned schedule of Look Forward in 2020, publishing it three times during the year. A total of 20,730 copies of Look Forward were distributed and 22,500 copies of the e-Newsletter.

The Fundraising team was able to secure funding from Janssen for memory sticks and pouches which has allowed us to offer audio material in both CD and memory stick formats for our community, particularly useful to those who use radios with a USB slot.

Podcast

Our podcast channel on Anchor FM has increased in popularity with 1,714 plays during 2020. The most popular content was the new MyEyeSite innovation and an interview with three Luxturna patients.

Unlock Genetics

Our Unlock Genetics website and awareness campaign (funded by Novartis Pharmaceuticals UK) aims to increase the awareness and understanding of genetic testing and genetic counselling among people living with inherited retinal dystrophies.

This innovative new resource was delayed from the original intended launch in September 2020 due to the pandemic and launched at our conferences in April 2021.

Gene Vision

Retina UK provided funding for Gene Vision, developed by Consultant Ophthalmologist Professor Mariya Moosajee and her team. Funding was also provided by The National Institute for Health Research (NIHR), Biomedical Research Centre (BRC) at Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology.

Gene Vision (www.gene.vision) is a website which provides in-depth information on the specific genes involved in inherited retinal dystrophies. It also includes information on the latest research and support available via specific charities. The site launched in December 2020.

Sector Collaboration

A new VI Charity Sector Partnership has been formed. The founding partners are: Blind Veterans UK, Glaucoma UK, Guide Dogs, Macular Society, Retina UK, RNIB, Thomas Pocklington Trust and Visionary. The partnership will build on the work of Vision UK which closed in July 2020.

The development team has nominated representatives for a number of working groups including Talent Development, Access to Technology, Crisis Response, Insight Hub and Campaigning and Awareness Raising.

Retina UK

Report of the Trustees

For the year ending 31 December 2020

Ask the expert: 1-1 Sessions

We facilitated a number of 1-1 informal phone calls with the Retina UK community and Consultant Ophthalmologist Professor Mariya Moosjaee in spring 2020. Mariya offered a number of appointments for a confidential informal chat (by telephone); community members were able to ask questions on a variety of different subject areas and did not have to be registered at Moorfields. A total of 11 members of our community were able to take part in this opportunity with a further six people who received an email from Mariya.

Volunteer support

- We maintain regular contact with our helpline volunteers through two new initiatives.
- Our bi-monthly group Zoom group provides an opportunity to update on organisational activity, share information and offer support.
- Our Buddy Support Groups see five groups of four/five volunteers meet bi-monthly to share how they are feeling, discuss how they are using our new wellbeing modules, and offer peer-to-peer support.

Our face-to-face volunteer training weekend is rescheduled for September 2021.

We have introduced a suite of accessible wellbeing and mental health training modules for our Helpline volunteers, in collaboration with the Arthur Ellis Foundation. These modules have also been made available to our staff team.

Fundraising

Working remotely, and with most events cancelled or postponed, the Retina UK Fundraising team faced many challenges in 2020. Income from Community and Challenge Event fundraising understandably reduced, as our amazing community was unable to take part in the many activities they had planned.

Our team worked hard to make up the lost income in many different ways. Highlights included a successful BBC Lifeline Television Appeal, raising £35,521, contributing (along with record Big Give Christmas Challenge income of £45,816) to growth in our Appeals and Prize Draw income from £68,350 to £98,377. We were able to secure additional support from Trusts and Foundations, including some COVID-19 emergency funding, generating growth in this income stream from £236,179 to £264,494. Contributions from our corporate partners also increased, resulting in growth from £119,936 to £129,151.

All of this, along with a very strong year for legacies and collaborative and government grant income, led us to achieve total income (excluding investment income and investment revaluation) of £2,123,268 for the year. This represented growth of £444,907 on the previous year's total of £1,678,361. This outcome, in the face of a hugely challenging climate, is testament to the wonderful commitment and support of our fantastic community of individuals, funders and corporate partners. We are so grateful for every contribution received during this challenging year.

All fundraising in 2020 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.

Retina UK

Report of the Trustees

For the year ending 31 December 2020

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 2020. 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 2020.

Acknowledgements

Despite the difficulties that everyone faced in 2020, we received tremendous support 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 2020:

- The Albert Van den Bergh Charitable Trust
- The Annett Trust
- The Anson Charitable Trust
- The Arden Trust
- BE Rodmell Trust
- The Champniss Charitable Trust
- The Coln Trust
- The David Fryer Charitable Trust
- David Killick Trust
- Dixie Rose Findlay Charitable Trust
- The Doris Field Charitable Trust
- Edgar E Lawley Foundation
- G C Gibson Charitable Trust
- The G W Cadbury Charitable Trust
- The Gertrude Gourvitch Charitable Trust
- Gilbert Edgar Trust
- The Grace Trust
- Green Hall Foundation
- John Laing Charitable Trust
- Lillie Johnson Charitable Trust
- Lloyd's Charities Trust
- Nineteen Eighty-Nine Charitable Trust
- The Samuel Storey Family Charitable Trust
- Sir Samuel Scott of Yews Trust
- St James's Place Charitable Foundation
- Stella Symons Charitable Trust
- The Tedworth Charitable Trust
- Tesco Bags of Help
- The Sir Jules Thorn Charitable Trust
- The Wallace & Edna Davis Charitable Foundation
- The Wyseliot Rose Charitable Trust

How we work with the pharmaceutical industry

We work with pharmaceutical companies in an open, transparent and ethical way, in line with the strict guidelines provided by the Association of British Pharmaceutical companies (ABPI). We ensure that our community has a voice by facilitating participation in surveys, focus groups and research, and we feed into the regulatory and reimbursement processes to evidence the impact of inherited sight loss. Pharmaceutical companies support our work by providing grants for projects that benefit our community, and by sponsoring certain events and activities. In 2020 we were grateful to receive the following support:

- Allergan – £15,000 to fund our Helpline upgrade
- Biogen – £50,000 towards our Information and Support services
- Janssen – £29,999 sponsorship of our *Look Forward* newsletter
- Meira GTx – £7,649 to support our work during the pandemic
- Novartis – £29,477 to fund our Genetic Testing and Counselling Awareness project

Retina UK

Statement of Trustees' Responsibilities

For the year ending 31 December 2020

The 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:

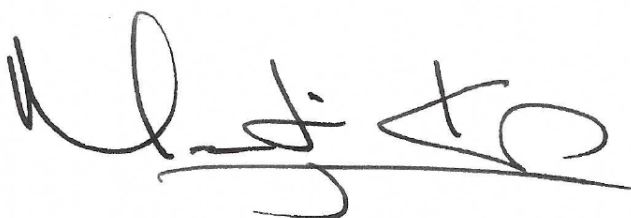
- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP 2019 (FRS 102);
- Make judgments and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material 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.

Auditor

On 7 September 2020, Group Audit Services Limited (trading as Baldwins Audit Services) changed its name to Azets Audit Services Limited. The name it practises under is Azets Audit Services and, accordingly, it has signed the Report of the Independent Auditors in its new name.



Dr M Kirkup
Chair
14 July 2021

Independent Auditor's Report to the Members of Retina UK

For the year ending 31 December 2020

Opinion

We have audited the financial statements of Retina UK (the 'charity') for the period ended 31 December 2020 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and the 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 2020 and of its incoming resources and application of resources, for the period 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

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and we do not express any form of assurance conclusion thereon. 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 course of 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 this gives rise to a material misstatement in the financial statements themselves. 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 2020

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 statement of Trustees' responsibilities, the Trustees are responsible for the preparation of the financial statements and for being satisfied that they 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 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 the Act and relevant regulations made or having effect thereunder.

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 is available on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

Extent to which the audit was considered capable of detecting irregularities, including fraud

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above and on the Financial Reporting Council's website, to detect material misstatements in respect of irregularities, including fraud.

We obtain and update our understanding of the entity, its activities, its control environment, and likely future developments, including in relation to the legal and regulatory framework applicable and how the entity is complying with that framework. Based on this understanding, we identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. This includes consideration of the risk of acts by the entity that were contrary to applicable laws and regulations, including fraud.

In response to the risk of irregularities and non-compliance with laws and regulations, including fraud, we designed procedures which included:

- Enquiry of management and those charged with governance around actual and potential litigation and claims as well as actual, suspected and alleged fraud;
- Reviewing minutes of meetings of those charged with governance;

Independent Auditor's Report to the Members of Retina UK

For the year ending 31 December 2020

- Assessing the extent of compliance with the laws and regulations considered to have a direct material effect on the financial statements or the operations of the entity through enquiry and inspection;
- Reviewing financial statement disclosures and testing to supporting documentation to assess compliance with applicable laws and regulations;
- Performing audit work over the risk of management bias and override of controls, including testing of journal entries and other adjustments for appropriateness, evaluating the business rationale of significant transactions outside the normal course of business and reviewing accounting estimates for indicators of potential bias.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

Other matters

Your attention is drawn to the fact that the charity has prepared financial statements in accordance with "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)" (as amended) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has now been withdrawn.

This has been done in order for the financial statements to provide a true and fair view in accordance with current Generally Accepted Accounting Practice.

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 auditors' 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.

Azets Audit Services

Azets Audit Services

15 July 2021

Chartered Accountants
Statutory Auditor

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

Azets Audit Services is eligible for appointment as auditor of the charity by virtue of its eligibility for appointment as auditor of a company under of section 1212 of the Companies Act 2006.

Retina UK

Statement of Financial Activities

For the year ending 31 December 2020

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £	
INCOME FROM:					
Donations & legacies	3	1,542,474	456,976	1,999,450	1,678,361
Charitable activities <i>Grants</i>	4	75,138	48,680	123,818	-
Investments	5	5,226	-	5,226	9,141
Total income		1,622,838	505,656	2,128,494	1,687,502
EXPENDITURE ON:					
Raising funds	6	202,636	45,310	247,946	317,492
Charitable activities <i>Medical Research</i>	7	126,873	483,246	610,119	891,581
<i>Information & Support</i>	8	276,291	184,411	460,702	646,441
Total expenditure		605,800	712,967	1,318,767	1,855,514
Net (losses) / gains on investments		(16,279)	-	(16,279)	31,175
Net movement in funds	9	1,000,759	(207,311)	793,448	(136,837)
Funds at 1 January 2020	20/22	426,306	419,735	846,041	982,878
Funds at 31 December 2020	20/22	1,427,065	212,424	1,639,489	846,041

Retina UK

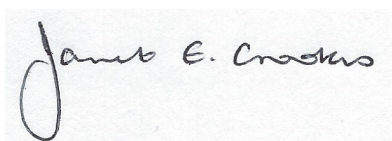
Balance Sheet

For the year ending 31 December 2020

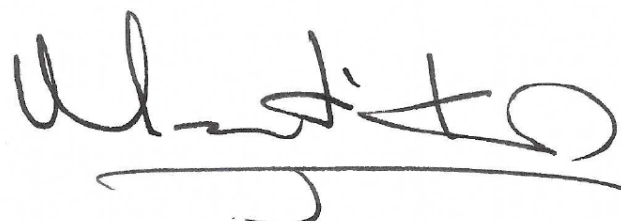
	Note	2020 £	
FIXED ASSETS			
Tangible fixed assets	13	7,650	4,120
Investments	14	244,121	260,400
Total fixed assets		251,771	264,520
CURRENT ASSETS			
Debtors: Amounts falling due within 1 year	15	1,227,530	832,612
Cash at bank and in hand	16	1,197,890	847,352
Total current assets		2,425,420	1,679,964
LIABILITIES			
Creditors: Amounts due within 1 year	17	(1,037,702)	(1,098,443)
Net current assets		1,387,718	581,521
Net assets		1,639,489	846,041
FUNDS			
Unrestricted	20	1,427,065	426,306
Restricted	22	212,424	419,735
Total funds		1,639,489	846,041

Approved by the Trustees and signed on their behalf by:

J E Crookes
Treasurer
14 July 2021



Dr M Kirkup
Chair
14 July 2021



Retina UK

Cash Flow Statement

For the year ending 31 December 2020

Cash flows from operating activities:	Note	2020 £	2019 £
Net income / (expenditure) for the reporting period		793,448	(136,837)
Adjustments for:			
Depreciation charges	13	3,466	3,574
Unrealised losses / (gains) on investments	14	16,279	(31,175)
Dividends and interest from investments	5	(5,226)	(9,141)
Increase in debtors	15	(394,918)	(598,464)
Increase / (decrease) in creditors	17	74,461	(69,814)
(Decrease) / increase in grant creditors	17	(135,202)	399,245
Net cash generated / (used) in operating activities		352,308	(442,612)
Cash flows from investing activities:			
Dividends and interest from investments	5	5,226	9,141
Purchase of tangible fixed assets	13	(6,996)	(2,214)
Cash flows from investing activities		(1,770)	6,927
Change in cash and cash equivalents in the year		350,538	(435,685)
Cash and cash equivalents at 1 January 2020	16	847,352	1,283,037
Cash and cash equivalents at 31 December 2020	16	1,197,890	847,352

Notes to the Accounts

For the year ending 31 December 2020

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 actions taken by the charity in response to the challenges arising from the COVID-19 pandemic have mitigated the level of ongoing risk. The Trustees are satisfied 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.

Retina UK

Notes to the Accounts

For the year ending 31 December 2020

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.

Notes to the Accounts

For the year ending 31 December 2020

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 2020

3. Donations and Legacies

	2020 £	2019 £
Membership subscriptions/donations	33,922	35,728
Individual donations	201,905	162,949
Trusts	264,494	236,179
Corporate	129,151	119,936
Legacies/In memoriam	1,095,391	757,243
Fundraising	134,381	234,651
Prize draw/appeals/mailings	98,377	68,350
Gift Aid	41,829	63,325
Total	1,999,450	1,678,361

4. Grants

	2020 £	2019 £
Medical research funding	48,680	-
Government grants	75,138	-
Total	123,818	-

Government grants comprise amounts in respect of the Coronavirus Job Retention Scheme ('CJRS').

5. Investments

	2020 £	2019 £
Share dividends	4,891	7,039
Bank interest	335	2,102
Total	5,226	9,141

Retina UK

Notes to the Accounts

For the year ending 31 December 2020

6. Raising funds

	2020	2019
	£	£
Event costs	28,105	58,029
Materials & equipment	69	1,372
Collection fees	5,605	6,670
Appeals	347	-
Training and conferences	416	1,129
Donor development including trusts & corporates	722	1,696
Other	800	801
Support costs (see note 10)	211,882	247,795
Total	247,946	317,492

7. Medical research

	2020	2019
	£	£
Annual grant awards	543,559	840,403
MAB expenses	187	215
Support costs (see note 10)	66,373	50,963
Total	610,119	891,581

8. Information & Support

	2020	2019
	£	£
Publications, DVDs, leaflets etc	17,765	16,429
Annual conference	55	17,537
Helpline support	8,598	6,083
Information events	425	9,569
Non-medical research/projects	18,684	179,802
Travel expenses	3,067	17,602
Retina International	5,443	4,945
Brand and website development	850	3,284
Sight Loss Survey 2019	-	10,512
Volunteering	1,845	9,666
Other	5,881	1,608
Support costs (see note 10)	398,089	369,404
Total	460,702	646,441

Retina UK

Notes to the Accounts

For the year ending 31 December 2020

9. Net movement in funds is stated after charging

	2020	2019
	£	£
Auditor's remuneration (audit)	7,940	7,000
Auditor's remuneration (non audit)	1,390	-
Depreciation	3,466	3,574
Trustees' expenses	1,580	2,057
Lease payments	13,500	13,500

Trustees' expenses, incurred on travel and accessibility support, represent amounts reimbursed to one Trustee for expenses incurred (2019 - 3).

No Trustee received any remuneration during the year (2019 - none).

10. Analysis of support costs

	Total	Fundraising	Research	Information & Support	Basis of apportionment
	£	£	£	£	
Office administration	86,537	25,961	8,654	51,922	Staff time or actual
Remuneration	547,194	173,137	53,458	320,599	Staff time or actual
Governance	42,613	12,784	4,261	25,568	Staff time or actual
Total	676,344	211,882	66,373	398,089	
Governance costs in 2019	33,950	13,580	3,395	16,975	

Retina UK

Notes to the Accounts

For the year ending 31 December 2020

11. Staff numbers and costs

	2020	2019
	£	£
Wages and salaries	516,480	502,184
Social Security costs	48,281	43,346
Pension costs	15,511	14,403
Total	580,272	559,933

The number of persons employed by the charity during the year was 20 (2019 - 19).

Total remuneration (including Employer NIC) for key management personnel in the year was £87,056 (2019 - £85,349). The number of employees with remuneration (excluding Employer NIC) between £70,000-£80,000 was 1 (2019 - 1).

Retina UK

Notes to the Accounts

For the year ending 31 December 2020

12. Comparative information for Statement of Financial Activities

	£		
INCOME FROM:			
Donations & legacies	579,218	1,099,143	1,678,361
Charitable activities			
<i>Investments</i>	9,141	-	9,141
Total income	588,359	1,099,143	1,687,502
EXPENDITURE ON:			
Raising funds	213,154	104,338	317,492
Charitable activities			
<i>Medical research</i>	33,384	858,197	891,581
<i>Information & Support</i>	294,001	352,440	646,441
Total expenditure	540,539	1,314,975	1,855,514
Net gains on investments	31,175	-	31,175
Net movement in funds	78,995	(215,832)	(136,837)
Funds at 1 January 2019	347,311	635,567	982,878
Funds at 31 December 2019	426,306	419,735	846,041

Retina UK

Notes to the Accounts

For the year ending 31 December 2020

13. Tangible fixed assets

	Office Equipment £
Cost	
At 1 January 2020	13,234
Additions	6,996
At 31 December 2020	<u>20,230</u>
Depreciation	
At 1 January 2020	9,114
Charge for year	3,466
At 31 December 2020	<u>12,580</u>
Net book value	
At 31 December 2020	<u>7,650</u>
At 31 December 2019	<u>4,120</u>

14. Investments

	2020 £	2019 £
At 1 January 2020	260,400	229,225
Unrealised (losses)/gains	(16,279)	31,175
As at 31 December 2020	<u>244,121</u>	<u>260,400</u>
	2020 £	2019 £
Included within investments are the following:		
CAF balanced growth fund at valuation	243,733	260,012
Shares in Taylor Woodrow	275	275
3% City of Liverpool stock	113	113
	<u>244,121</u>	<u>260,400</u>

All investments are held in the UK.

Retina UK

Notes to the Accounts

For the year ending 31 December 2020

15. Debtors: Amounts falling due within one year

	2020 £	2019 £
Accrued income	1,187,828	812,972
Trade debtors	28,205	5,303
Prepayments	11,497	14,337
Total	1,227,530	832,612

16. Analysis of cash and cash equivalents

	2020 £	2019 £
Cash at bank and in hand	1,197,890	847,352
Total	1,197,890	847,352

17. Creditors: Amounts falling due within one year

	2020 £	2019 £
Trade creditors	125,101	23,661
Tax and social security	12,926	12,108
Accruals and deferred income	8,950	34,000
Grant liability	888,483	1,023,685
Other creditors	2,242	4,989
Total	1,037,702	1,098,443

18. Contingent Assets & Liabilities

There is a contingent liability of £327,049 at 31 December 2020 (2019 - £551,213) in respect of research grants authorised subject to annual review. This money falls due in years 2021 onwards.

19. Financial commitments

	2020 £	2019 £
Total future minimum lease payments under non-cancellable operating leases are as follows:		
< 1 year	13,500	13,500
1 - 5 years	60,750	13,500

Retina UK

Notes to the Accounts

For the year ending 31 December 2020

20. Unrestricted Funds

	General Fund £	Designated Research Fund £	Total Unrestricted Funds £
Balance at 1 January 2020	280,550	145,756	426,306
Income	1,606,559	-	1,606,559
Expenditure	(531,465)	(74,335)	(605,800)
Transfer between funds	(235,579)	235,579	-
Balance at 31 December 2020	<u>1,120,065</u>	<u>307,000</u>	<u>1,427,065</u>

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.

21. Comparative information of Unrestricted Funds movement at 31 December 2019

	General Fund £	Designated Research Fund £	Total Unrestricted Funds £
Balance at 1 January 2019	280,111	67,200	347,311
Income	619,534	-	619,534
Expenditure	(518,658)	(21,881)	(540,539)
Transfer between funds	(100,437)	100,437	-
Balance at 31 December 2019	<u>280,550</u>	<u>145,756</u>	<u>426,306</u>

Retina UK

Notes to the Accounts

For the year ending 31 December 2020

22. Restricted Funds

	Research Fund	Usher Fund	Awards Fund	RDH12 Fund	Pioneering Research Fund	Info & Support Fund	Specified Project Fund	Scottish Fund	Macular Research Fund	CJ Legacy Fund	Specified Research Fund	Total Restricted Funds
	£	£	£	£	£	£	£	£	£	£	£	£
Balance at 1 January 2020	9,352	2,545	1,150	221,776	81,100	-	-	2,660	1,697	71,649	27,806	419,735
Income	96,965	5,482	-	16,558	-	200,249	31,707	-	48,725	-	105,970	505,656
Expenditure	(105,970)	(5,482)	-	(119,695)	(80,000)	(158,159)	(6,726)	(102)	(50,377)	(71,649)	(114,807)	(712,967)
Transfers	-	-	-	-	-	250	-	-	-	-	(250)	-
Balance at 31 December 2020	347	2,545	1,150	118,639	1,100	42,340	24,981	2,558	45	-	18,719	212,424

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 to support Usher Syndrome-related research and activities for those with 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 to support a dedicated centre for inherited retinal dystrophy research.

Information & Support Fund: This fund is made up of specific donations for Information & Support projects. In 2020, specific projects funded include the new helpline and Look Forward.

Specified Project Fund: This fund contains funding for specific projects. In 2020, this was for Unlock Genetics.

Retina UK

Notes to the Accounts

For the year ending 31 December 2020

22. Restricted Funds (continued)

Scottish Fund: This fund contains donations for research and/or other expenditure 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.

23. Comparative information of Restricted Funds movement at 31 December 2019

	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 Restricted 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
Income	86,687	30,006	-	38,925	3,600	96,871	1,250	11,000	1,697	730,000	99,107	1,099,143
Expenditure	(125,713)	(76,290)	-	(126,112)	-	(138,280)	(9,150)	-	-	(658,351)	(181,079)	(1,314,975)
Transfer	8,340	-	-	-	-	-	-	(8,340)	-	-	-	-
Balance at 31 December 2019	9,352	2,545	1,150	221,776	81,100	-	-	2,660	1,697	71,649	27,806	419,735

Retina UK

Notes to the Accounts

For the year ending 31 December 2020

24. Analysis of net assets between funds

	Tangible Fixed Assets £	Fixed Asset Investments £	Current Assets £	Current Liabilities £	Total £
Restricted Funds	-	-	730,842	(518,418)	212,424
Unrestricted Funds	7,650	244,121	1,694,578	(519,284)	1,427,065
	<u>7,650</u>	<u>244,121</u>	<u>2,425,420</u>	<u>(1,037,702)</u>	<u>1,639,489</u>

25. Comparative analysis of net assets between funds 2019

	Tangible Fixed Assets £	Fixed Asset Investment £	Current Assets £	Current Liabilities £	Total £
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>

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Notes to the Accounts

For the year ending 31 December 2020

26. Grants awarded - 2020

Institution		Grant Holder	Amount £
UCL / KCL	GR576	Prof R Ali	100,000
University of Southampton	GR590	Dr A Ratanyaka	65,703
UCL	GR592	Dr M Moosajee	79,802
UCL	GR594	Dr M Moosajee	118,289
Newcastle University	GR595	Prof M Lako	19,850
Radboud UMC, The Netherlands	GR596	Dr R Collin	39,400
Oxford University	GR599	Prof R MacLaren	40,580
Oxford University	GR600	Oxford Centre	80,000
Total			<hr/> 543,624
Opening creditor for grant commitment			1,023,685
Grant payments – 2020			(678,760)
Adjustments on completion of grant projects			(66)
Closing creditor for grant commitment			<hr/> 888,483 <hr/>

27. Related party transactions

There are no related party transactions requiring disclosure in the Financial Statements (2019 - none).
