



Retina UK
A Charitable Incorporated Organisation
Annual Report & Financial Statements
Year Ending 31 December 2021

Retina UK

Reference and administrative details

For the year ending 31 December 2021

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: Dr Martin Kirkup (Chair from 17 April 2021) Mr Don Grocott (Chair until 17 April 2021) Mr Roger Backhouse Mrs Lynda Cantor MBE Ms Janet Crookes (Treasurer) Dr Elizabeth Graham Prof John Marshall MBE Mrs Rachael Stevens Dr Lucy Withington Mr Simon Keightley (Trustee from 26 January 2022) Mr Paresh Makwana (Trustee from 26 January 2022) Mr Ashley Grist (Trustee from 26 January 2022) Ms Vanessa Forster (Trustee from 26 January 2022)
Ambassadors	Mrs Bhavini Makwana Mr Steven Bate MBE Mr Amar Latif Mrs Seema Flower Mrs Victoria Claire
Chief Executive Officer	Ms Tina Garvey
Principal Bankers	Lloyds Bank PLC 187 Watling Street Towcester NN12 6BX
Auditors	Azets Audit Services Epsilon House The Square Gloucester Business Park Gloucester GL3 4AD

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Retina UK

Chair's Report

For the year ending 31 December 2021

The past year has been challenging and the charity has necessarily contained its activity and its spend in a cautious manner to reflect the continued uncertainty that has affected research, fundraising and the economy in general. However, I am proud to say that the charity has once again risen to the challenge of supporting its community by responding impressively to a significantly higher level of demand for support from people living with an inherited retinal dystrophy (IRD) who have found the year every bit as challenging as the last with the continuing impact of COVID-19. Consequently, there is a significant focus in this year's annual report on the important information and support work carried out by the Retina UK team.

During the year, research funding has continued to be particularly hard hit by the pandemic. This has been reflected across the charity sector and is far from unique to Retina UK. As has been the case across medical research, the majority of projects funded by Retina UK experienced delays and lab closures. Notwithstanding the difficult economic context, the charity generated a total income of £1,239,135. We are enormously grateful for the support we received from the community and from individuals, trusts and corporates.

Despite the challenges many researchers have faced, they continue to work with energy and a determination to find new understanding and therapies and this gives us great hope and promise for the future. We were pleased to provide no-cost extensions as required so that grantees could achieve the aims set out in their original project proposals and, despite the impact of the pandemic, we still funded nine research projects.

In 2021, Retina UK also contributed to the NICE Process Review consultation and continues to engage with sector partners and the pharmaceutical industry to ensure that future therapies are made available to our community. Moreover, recent progress in clinical trials for gene-agnostic cell-based therapies for retinitis pigmentosa (RP) has been of great interest to those living with IRD.

Looking forward, the charity is determined to drive forward in 2022 and take every opportunity to reinvigorate fund raising activities working with our community, individuals, trusts and corporates.

The number of applications received for our 2021/22 grant round brings much positivity. The proposals include substantive projects to investigate treatment approaches that are either independent of the specific underlying genetic cause of sight loss or address a group of similar genetic causes, offering hope to a large proportion of the Retina UK community. We look forward to providing updates on new awards later in the year.

I am particularly excited that the Board of Trustees has been joined this year by four new members, Ashley Grist, Simon Keightley, Vanessa Forster and Paresh Makwana who bring valuable experience in the fields of ophthalmology, law, business development and pharmaceuticals. Their appointments will be submitted for ratification by the membership at the AGM.

Ashley Grist will be taking over as Treasurer from Janet Crookes who will be retiring in the course of 2022 after long and valuable service. On behalf of Retina UK I would like to express my deep gratitude to Janet for her service, her dedication and her wise counsel over many years and wish her the very best for the future.



Dr M Kirkup
Chair
11 May 2022

The Trustees are pleased to present their annual report together with the financial statements of the charity for the year ending 31 December 2021. The financial statements have been prepared in accordance with the accounting policies set out in the notes to the accounts and comply with the Charity's governing document, 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 (FRS102) (effective 1 January 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 and Visionary and abides by each organisation's principles of best practice at all times.

Report of the Trustees

For the year ending 31 December 2021

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

The disruption caused by the pandemic and the attendant restrictions on activities continued to have a significant impact in 2021. Despite this we raised income from fundraising activities, trust and corporate donors and government grants at similar levels overall to 2020. After higher than average legacy income in 2020 (£1,095,391) we received £219,531 in 2021 so our total income for the year ended 31 December 2021 was £1,239,135 (2020: £2,128,494).

We continued to provide information and other support activities for our community, spending £470,847 on these activities (2020: £460,702). We awarded grants and donations of £95,867 for medical research (2020: £543,559) which was a significant reduction from our expected levels of research funding in pre-pandemic years. This was in line with our decision to wait until the research community had returned to full-scale activity before making new awards.

As a result, we had an increase in funds of £383,853 (2020: £793,448) and at 31 December 2021 our total funds were £2,023,342 (2020: £1,639,489). This will enable us to make new medical research grants in 2022 in line with our core strategy.

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 2021 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

The Trustees want to maintain sufficient unrestricted reserves to enable the charity to deal with any events that challenge our financial position and ultimately be able, if necessary, to wind up the charity in an orderly way. The experience of the COVID-19 pandemic over the course of 2020 and 2021 has showed that our approach of maintaining £280,000 of unrestricted funds is sufficient for these purposes and so we retain that level as a minimum and have regard to this when preparing budgets and taking significant decisions on expenditure.

It is our intention to utilise any additional unrestricted reserves as soon as possible to further our charitable objectives. Sometimes this will result in the Trustees designating amounts of unrestricted funds for specific purposes such as medical research projects.

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. Although the impact of the COVID-19 pandemic continued to be felt throughout 2021 and into 2022 we continued to operate the charity on a sustainable basis.

Whilst planning for 2022 and beyond is focussing on moving forward, the Trustees remain mindful of the risks of future disruption. The Trustees are satisfied that the charity continues to be a going concern.

Future Plans

We will continue to invest 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. Significant progress is being made in the causes of and treatments for Inherited Retinal Dystrophies (IRDs) and there is good reason to be hopeful.

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. We invited applications for research grants in 2021 with 12 preliminary submissions. Six of those projects have been invited to submit full applications for grants in the region of £200,000 - £250,000. A decision on these applications will be made in spring 2022.

We responded to the COVID-19 pandemic by adapting and being more innovative with our information and support provision. Our Annual Conference and Professionals' Conferences went ahead online rather than in person with very positive feedback. This has resulted in a decision to hold the 2022 Conference in hybrid form to enable delegates to join us in person or online. We also introduced a series of webinars in the last quarter of the year which were recorded and made available for people to view after the event; these have proven very popular and will continue monthly in 2022.

Other plans for 2022 include to develop new resources to support our community to manage their wellbeing; grow our local support group network around the UK and gain further insight into our community's experiences through our sight loss tracking survey.

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 were underway in the year ending 31 December 2021.

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, which had knock-on effects on project timings in 2021. 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 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. 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. 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 with the recruitment of a new bioinformatician to support continued data analysis. Other post-doctoral research assistants were appointed later in 2021 to look into variants flagged by the bioinformatics pipeline. One bioinformatician has also developed algorithms to comprehensively mine all of the UKIRDC data for structural variants, following on from the chromosome 17 discovery.

The project has recruited almost 600 people with IRD and has solved 116 previously intractable cases, providing these families with better understanding of their condition and opening up choices. 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.

Non-viral gene therapy using S/MAR vectors for Usher Syndrome Started 2018 / Ended 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.

Prof Moosajee's team has been investigating use of a non-viral gene delivery system, containing a human DNA element called scaffold / matrix attachment regions (S/MAR), to encase USH2A. During the course 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.

The researchers developed and characterised both zebrafish and human cell disease models so that they could test the therapeutic response to the S/MAR packaged gene. They delivered the vector to HEK cells, as well as skin cells from Usher syndrome patients, and have obtained evidence that the vector is successfully driving usherin protein production in these cells. The team then went on to create stem cell-derived retinal models from the skin cells. It has proved challenging to test the vector in this retinal organoid model, as the gentle electrical pulses used to help the vector enter the cells were found to be causing damage. However, Prof Moosajee will continue to work on finding better methods of vector delivery.

The team optimised microinjection delivery of the S/MAR vector to the single cell stage of the zebrafish embryo and also completed detailed characterisation of the USH2A mutant fish to enable accurate testing of the effects of the therapy in this fish. The treated fish demonstrated successful expression of the USH2A gene for up to 12 months of age.

This has been a successful project with a number of key outputs, including fully characterised disease models as well as the vector itself. The project has provided an ideal springboard for the continued translational development of the S/MAR vector approach to addressing diseases involving large genes.

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

Started 2018 / Ended 2021

Dr Arjuna Ratnayaka of the University of Southampton worked 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 was published in 2021 in the highly regarded Journal of Pathology. The team has also studied how TIMP3 mutations affect the lining of the blood vessels that supply the outer retina, and the findings are being prepared for publication.

The team has also gathered retinal scans from patients to study gradual sight loss and identify new ways of recognising / tracking SFD. They have generated a database of these images, which they plan to publish. The researchers have also been investigating a possible link between TIMP3 mutations and lung damage by referring SFD patients at Southampton for lung function tests. So far, no lung abnormalities have been detected, but monitoring will continue.

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

Started 2018 / Ended 2021

Prof Majlinda Lako at Newcastle University led this project, which followed 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 generated retinal cells from patients with mutations in a key gene involved in the splicing process (PRPF31). They used this model to establish that the mutated protein is found particularly in retinal pigment epithelium (RPE). They found that PRPF31 mutations reduce active spliceosomes and alter the structure of the cell's splicing machinery, which has a knock-on effect on the splicing needed to maintain normal structure and function of retinal cells and RPE. The team also discovered that affected RPE cells contain large clumps of protein debris.

The researchers investigated how other genes, proteins and key cellular pathways are impacted by malfunctioning PRPF31. They found that several affected pathways are involved in protein degradation and waste disposal, which ties in with the discovery of the protein clumps. RPE cells play an important role in recycling worn out photoreceptor components, so the team investigated whether drugs that help eliminate debris could be a potential therapeutic approach and found that the cancer drug rapamycin showed potential in cultured RPE cells.

This project has shed significant light on splicing-related disease mechanisms and highlighted potential therapeutic approaches.

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

Started 2018 / Ended 2021

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

During the course of the project, Prof Moosajee generated cell lines transfected with normal and mutated RDH12 to show how genetic changes impact protein function. She and her team also generated patient-derived retinal organoids, and developed a zebrafish disease model. The cell models have been used to increase understanding of how faulty RDH12 causes disease and help the researchers to identify appropriate drugs for testing. The zebrafish has demonstrated suitability as a model of late-onset retinal degeneration, and will be available for further experimentation as required.

The researchers detected high levels of cellular stress in the RDH12 mutant cell lines, so selected three drugs for testing that have the ability to reduce cellular stress. One of these, pregabalin, showed promise when tested, and as this works in a mutation-independent manner, it will now go on to be tested in the retinal organoids. Two other drugs were selected for their potential to restore RDH12 function for some types of mutation, with one, amlexanox, proving successful in the cell lines.

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

Started 2018 / Ended 2021

A PhD student supervised by Dr Rob W J Collin at Radboud University in The Netherlands has studied 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 aimed 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.

Using human retinal specimens, the researchers have identified various different forms of altered ABCA4 and have discovered that one of these, lacking a section known as exon 15, is the commonest form that undergoes exon skipping. They also looked in more detail at two gene regions that might regulate exon skipping, which enabled them to design five different molecular “patches” (antisense oligonucleotide, or AON) to try to block these regions and prevent skipping. These AONs produced mixed results when tested in HEK293T cells and healthy fibroblasts, including when the researchers tried different pair combinations of AONs. Although one of the AONs did have some efficacy in increasing exon 15 retention, none of the AONs produced a significant impact. The researchers concluded that a greater pool of AONs that cover more of the key gene regions need to be tested.

The studentship has enabled a promising young scientist to lay the foundations for a future career in inherited sight loss research.

The Gene Team Project

Started 2011 / Ends 2023

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 / Ended 2021

This project was 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 suppress 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 aimed to increase understanding of NR2E3 retinal disease by using a zebrafish model to study the direct effects on cone and rod development. The researchers investigated 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.

The student made excellent progress during the first year of the project, carefully selecting clinically-relevant ABCA4 mutations to target. She has created plasmids (short strands of DNA) containing these mutations, and has then inserted the plasmids into cultured human cells (HEK293T cells), which use the newly introduced genetic code to produce ABCA4 protein. These cells can now be used to test and optimise the CRISPR constructs the student has designed.

2021/2022 grant round

After a pandemic-related hiatus in 2020, the charity was delighted to be able to open a call for new research grant applications in autumn 2021. This has resulted in shortlisting of six promising proposals. They include exciting projects to investigate treatment approaches that are either independent of the specific underlying genetic cause of sight loss or address a group of similar genetic causes, offering hope to a large proportion of the Retina UK community. Meanwhile, one application considers the members of our community for whom genetic testing has so far failed to return a result: the proposed project would use advanced genomic analysis to unearth those genetic errors that are very hard to detect with current diagnostic techniques. Our Trustees will decide which projects to fund as far as our financial position allows, based on scientific merit and the recommendations of our Medical Advisory Board, in spring 2022.

Community engagement with research

2021 saw Retina UK continue its efforts to facilitate engagement between members of our community and researchers. We 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. Our research participation panel now includes 311 members.

Participation has included industry-led activities to learn more about lived experience, and questionnaire-based studies on the impact of the pandemic on the wellbeing of people with visual impairment. 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 2021, Retina UK contributed to the NICE Process Review consultation and continues to engage with sector partners and the pharmaceutical industry to ensure that future therapies are made available to our community.

Information and support

The delivery of our Information and Support services in 2021 involved a real digital transformation. The UK was again subjected to numerous lockdowns and changes to COVID-19 guidance and as such, we adapted to focus on the ways we could reach those living with or affected by inherited sight loss, as well as the professional community who support them, in a remote way. The insights provided from working in this way during 2020 proved invaluable and allowed us to expand our provision.

In 2021, 762 new contacts told us they were happy for us to stay in touch, including 587 individuals, 31 companies and 136 organisations.

Conferences

At the start of 2021 we made the difficult decision to move our Annual Conference, AGM and Professionals' Conference fully online.

Many of the speaker presentations were filmed in advance with the same speakers being available live online for the Q&A sessions. This proved to be enormously successful; more than 400 delegates registered to attend the Annual Conference; almost 200 registered for the Professionals' Conference. The theme for 2021 was genetics and included the launch of our new Unlock Genetics website.

"I have been a member since 1979 and I have never been to a conference because of the distance and not having anyone to accompany me that might be interested enough to attend the conference. But this time I was able to attend online and I really enjoyed it and thought the presentations were outstanding."

The AGM voting process was completed in advance with eligible members offered the opportunity to vote online, in writing (hard copy) or by telephone to ensure accessibility. The online AGM offered members the opportunity to ask questions.

We plan to offer a hybrid option for our conferences in 2022 where those who wish to attend in person can do so and those who are not able to, or prefer not to, can attend online.

Unlock Genetics

Following our sight loss survey in 2019 we identified that of the 1,000 people who responded, 43% said they were 'not aware' of genetic testing or that they were 'aware of it but it is not available to me'. We estimate 85% of our community do not currently have a genetic diagnosis. Our response was to develop our innovative Unlock Genetics resources.

The Unlock Genetics website was launched at our Annual and Professionals' Conferences in April 2021 thanks to a grant from Novartis Pharmaceuticals UK. The site aims to increase the level of awareness of genetic testing and genetic counselling amongst people living with inherited sight loss conditions, empowering them to make fully informed decisions about their lives, healthcare and family planning. It provides clear, trustworthy and balanced information and has been developed with significant input from experts in the field and also those who live with inherited sight loss.

The site has been promoted amongst our existing community and externally, with appearances on RNIB Connect Radio, BBC Radio 4 InTouch and various sector press. We sent hard copies of the resource to 296 eye clinics and with postcards to give to patients and presented at events including

Retina UK

Report of the Trustees

For the year ending 31 December 2021

the Edinburgh Institute of Genetics and Cancer's 'Shining a Light on Genetic Eye Conditions'.

Since launch, the site has had almost 20,000 page views with visitors from around the world. Content is available in a number of formats.

"Congratulations to the team for building this excellent site. I enjoyed looking over it and listening to the audio recordings, especially of experiences of having genetic testing". A member of our community

"This is a brilliant resource that will make a big difference to our community." A retinal specialist

Webinars

We introduced a series of monthly webinars (online via Zoom) in August 2021 with a focus on research. These were very well received by those living with inherited sight loss and the professionals who support them. Recordings of the webinars were made available on our YouTube channel and our Podcast channel (audio only).

	Registered to attend	YouTube (to date – 2/2/22)	Podcast (to date – 2/2/22)
Dec 21: Dr Salwah Rehman – clinical trials process	96	199	78
Nov 21: Michael Gilhooley - Optogenetics	104	178	57
Sept 21: Roly Megaw Inflammation and retinal degeneration	65	159	45
Aug 21: Elena Piotter DNA and RNA base editing tools	51	131	66

"Excellent quality webinar. Fantastic speaker and host. Very impressive."

"As a layperson suffering from RP and not an academic, I found the presentation well-constructed and easy to follow."

Information days

Our intention was to hold two face-to-face information days in 2021 coinciding with Sight Village events. However, because of uncertainty around restrictions and public confidence in visiting large events, we decided to hold these events online.

Our first information evening featured some of Northern Ireland's top medical, ophthalmic and healthcare professionals with presentations on genotyping, inheritance patterns, Unlock Genetics and navigating towns and cities with sight loss. This was followed on 13 October with a similar information evening with a focus on Wales.

These events were also recorded and shared on our YouTube and Podcast channels.

	Registered to attend	YouTube (to date – 2/2/22)	Podcast (to date – 2/2/22)
Northern Ireland	43	76	47
Wales	29	51	46

Retina UK

Report of the Trustees

For the year ending 31 December 2021

Podcast channel

Our podcast channel on Anchor FM has seen growth of 14.4% on 2020 with more than 2,000 listens in 2021. Our content is syndicated across nine platforms, which include Spotify, Apple podcasts and Google podcasts.

We have listeners world-wide, including more than 20% from the USA. We will include a reference to our charitable status and encourage donations from listeners in 2022 and broadcast more frequently.

YouTube channel

Our YouTube channel saw a more than 40% increase on 2020 with 3,300 viewers in 2021 with an overall click through rate (from impressions) of 5.7%. The average across that channel varies greatly depending on the type of content but would suggest that we are performing slightly higher than the average given of 4-5%.

For our charity, the YouTube audience is primarily UK-based with 85% in the UK and 6.6% in the United States (the next largest audience).

Look Forward and e-Newsletters

We continue to provide accurate and trustworthy information and updates in a variety of accessible formats, through our regular newsletters which are available in print (Look Forward only), Word, PDF and audio format (CD and memory stick). Thanks to sponsorship secured from Janssen, we were able to continue with our planned schedule of Look Forward in 2021, publishing it three times during the year. A total of 19,780 copies of Look Forward were distributed and 25,536 copies of the e-Newsletter.

We worked collaboratively on content with guest features from Thrive, British Blind Sport and RNIB in 2021 with an article from Guide Dogs planned in the first edition of 2022. We also have introduced a regular guest slot on apps which is written by a long standing supporter of the charity who is living with RP.

Local Peer Support

We held 14 online / phone local peer support group meetings in 2021 for those living in London, Scotland, Birmingham and Somerset. More than 244 people /registered – a 49% increase in attendance on 2020. The meetings were recorded and shared with group members who were not able to attend on the day.

In recent months we have shared local group meeting recordings on YouTube in a dedicated playlist (previously they were shared via Google docs).

Attendance varied through the year, with some groups more active online than others. We are grateful to the volunteers who co-ordinate our local groups.

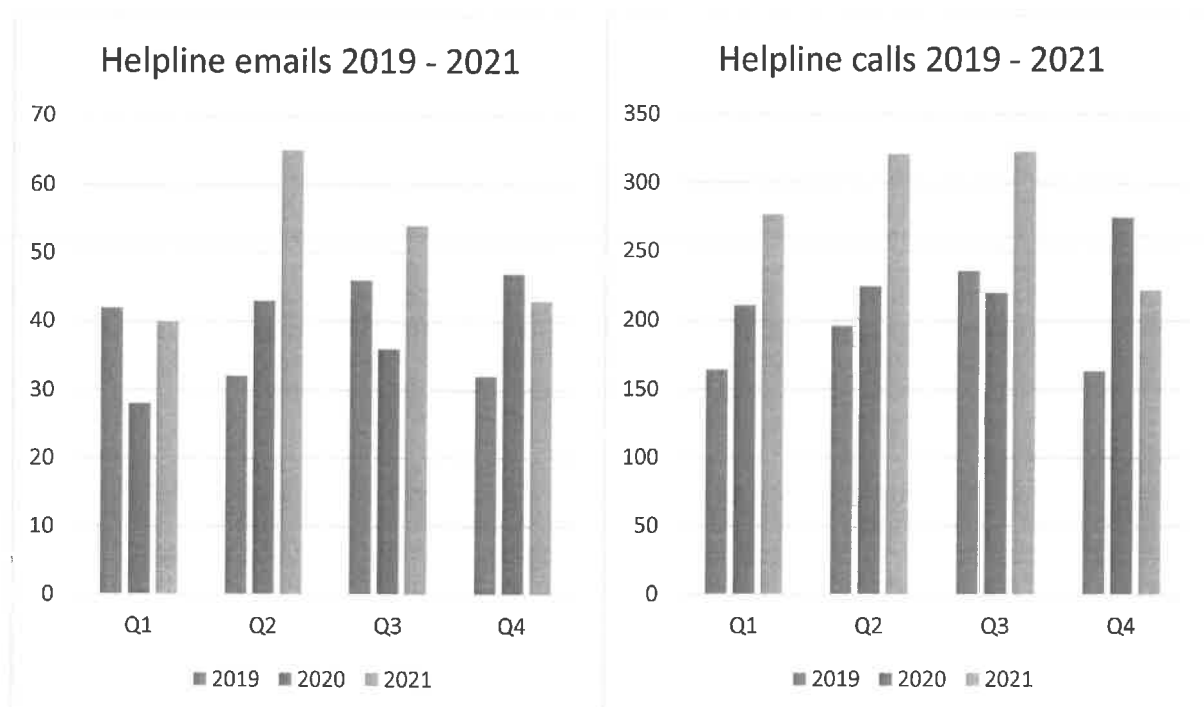
Helpline

Our phone and email Helpline and Talk and Support services have experienced a significant increase in demand.

The additional data that we receive through our service providers, Windsor Telecom, have given a further insight this year. Subject areas included:

- **Daily Living** – 39% of callers had queries about daily living (increased from 24% last year), including concerns about driving and having to give up a license; employment queries, benefits and mobility training.
- **Emotional support** – 27% of calls required specific emotional support (increased from 20% last year), 5% of people had been newly diagnosed, and others were struggling for many reasons mostly struggling with a recent deterioration.

- **Information about RP/retinal dystrophies** – 22% of callers were looking for information about their retinal dystrophy including symptoms, to ask whether other people experienced a certain issue such as floaters or colours, to discuss cataracts and the considerations for these being treated given their retinal dystrophy, questions to ask at appointments etc.
- **Research and genetic testing** – 18% of callers wanted information about research, clinical trials genetic testing and counselling. This figure has dropped in comparison to last year (25%)



Of those who responded to our short post-call questionnaire:

- 100% of people said they were likely or very likely to use the helpline again or recommend it to someone else
- 100% felt it was either helpful or very helpful speaking to someone else living with an inherited retinal dystrophy

“Excellent service, the answer was specific to me. Concise and relevant. I was also grateful for the speed of getting back to me.”

“Thank you for you and your colleagues for such prompt and helpful advice. I will certainly be able to do some research now and make an informed decision. Many thanks.”

This service will be reviewed in 2022 with a view to extending the reach and increasing the number of volunteers and service users receiving support.

Volunteers

Our volunteers have continued to support our work throughout the pandemic. Their support is incredibly valuable and allows us to deliver our services, particularly for the helpline, from a 'lived experience' perspective. We are hugely grateful for all they do.

Volunteers remain engaged with our bi-monthly online information evenings and buddy support groups, initiatives set up during 2020. We are seeking feedback from our volunteers to inform future development.

Our volunteer training weekend went ahead in face-to-face September 2021. Topics discussed included emotional wellbeing training with presentations from Arthur Ellis Mental Health Support.

In 2022 we will further develop our induction and training programme for our volunteers.

When asked for feedback, 100% of our helpline and talk and support volunteers told us they felt well supported by staff over the past 15 months.

Wellbeing resources

We are working with Arthur Ellis Foundation to develop innovative new wellbeing resources for our community which we plan to launch in July 2022 at our conferences. We want to encourage conversations about the emotional, as well as practical, impacts of inherited sight loss.

We will also further develop our new volunteer and staff wellbeing modules to train our volunteers to be 'wellbeing champions'.

Sector collaboration

We are proud to be a founding member of the VI Charity Sector partnership and our relationships with other charities supporting those living with sight loss continue to grow. We regularly collaborate with our partners in a number of key areas including: mental health and wellbeing; insight gathering; information sharing; access to technology; awareness raising and campaigning.

Fundraising

The ongoing impact of the coronavirus pandemic made 2021 another challenging year for the charity. Our fundraising success in 2020 meant that we were no longer eligible for many emergency COVID-19 funds, and there was a significant drop in our legacy income. However, our core income streams held up well, and our income for 2021 was £1,239,135.

Highlights included another hugely successful Big Give Christmas Challenge, with £53,752 raised – the most we have ever achieved through this annual match funding campaign. We were also delighted to see recovery beginning in those areas most impacted by the pandemic – namely community and events, with growth in community income of 9% and growth in events income of 43%.

This included the return of the most popular road races including the world-renowned Virgin Money London Marathon. From Blackheath to Ballymena, 27 supporters completed 26.2 miles, receiving their medals and raising £60,827 for Retina UK. From 5ks to full marathons, virtual challenges to skydives and wing walks, #TeamRetinaUK achieved amazing things.

Although lockdown restrictions continued to limit our community's ability to hold events and fundraising activities, £12,750 was raised by guests who had planned to attend Jennifer's Eye Ball, Hopefully to Seaview on the Isle of Wight raised a fantastic £5,269 and Worksop's Got Talent rounded off the year with £7,046 raised on the night, £6,941 of which was doubled through the Big Give Christmas Challenge.

We were able to secure funding for two important new projects – £17,599 for a suite of online resources to support our community with their mental health and wellbeing, due to be launched at our Annual Conference in 2022, and £14,000 to repeat our Sight Loss Survey and gather vital data to inform, evidence and support our work.

Significant funding was also secured towards medical research - £110,850 from the UK Government COVID Medical Research Charity Support Fund, £100,000 from a donor to complete a three-year project investigating the IMPG2 gene, and AMT to further RDH12 research. The Macular Society contributed £41,100 towards our collaborative projects.

We are so grateful to everyone who supported Retina UK in 2021. With your help, we have been able to continue delivering vital information and support during these challenging times, and have not only maintained our investment in our current medical research projects, but launched a call for new projects to be selected in spring 2022.

All fundraising in 2021 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 as well as the General Data Protection Regulation.

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 2021. 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 2021.

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 2021 we were grateful to receive the following support:

Biogen	£5,000 to support our Annual and Professionals' Conferences
Janssen	£9,514 to support our Annual and Professionals' Conferences
	£7,099 to support our Mental Health and Wellbeing Project
	£28,531 sponsorship of our <i>Look Forward</i> newsletter
Novartis	£5,000 to support our Annual and Professionals' Conferences
	£10,500 to support our Mental Health and Wellbeing Project
ProQR	£4,993 to support our Annual and Professionals' Conferences
Santen	£14,000 sponsorship of our Sight Loss Survey

Trusts and Foundations

We would like to take this opportunity to thank the following trusts and foundations for their generous support of our work in 2021. Their contributions have enabled us to continue supporting our community during challenging times, and to invest in pioneering medical research into inherited sight loss:

- The Albert Van den Bergh Charitable Trust
- The Anson Charitable Trust
- The Arden Trust
- Arnold Clark Community Fund
- BE Rodmell Trust
- The Carmen Butler-Charteris Charitable Trust
- The Champniss Charitable Trust
- The Coln Trust
- The David Fryer Charitable Trust
- David Killick Trust
- DG Marshall of Cambridge Trust
- The Doris Field Charitable Trust
- The D'Oyly Carte Charitable Trust
- The Edgar E Lawley Foundation

Report of the Trustees

For the year ending 31 December 2021

- G C Gibson Charitable Trust
- The G W Cadbury Charitable Trust
- The Gertrude Gourvitch Charitable Trust
- Gilbert Edgar Trust
- Hospital Saturday Fund
- Jack Petchey Foundation
- John Laing Charitable Trust
- Lillie Johnson Charitable Trust
- Nineteen Eighty-Nine Charitable Trust
- The Roger and Jean Jefcoate Trust
- The Tedworth Charitable Trust
- Tennant Southpark Charitable Trust
- Tom and Thelma Wilson Trust
- The Wallace & Edna Davis Charitable Foundation
- The Wyseliot Rose Charitable Trust

Statement of Trustees' Responsibilities

For the year ending 31 December 2021

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.



Dr M Kirkup
Chair
11 May 2022

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.

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 2021

- 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

Chartered Accountants
Statutory Auditor

Azets Audit Services

12 May 2022
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Epsilon House
The Square
Gloucester Business Park
Gloucester
GL3 4AD

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 2021

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £	Total Funds 2020 £
INCOME FROM:					
Donations & legacies	3	607,719	443,078,	1,050,797	1,999,450
Charitable activities					
<i>Grants</i>	4	33,378	151,950	185,328	123,818
Investments	5	3,010	-	3,010	5,226
Total income		644,107	595,028	1,239,135	2,128,494
EXPENDITURE ON:					
Raising funds	6	245,982	7,136	253,118	247,946
Charitable activities					
<i>Medical Research</i>	7	11,946	151,105	163,051	610,119
<i>Information & Support</i>	8	345,417	125,430	470,847	460,702
Total expenditure		603,345	283,671	887,016	1,318,767
Net gains / (losses) on investments		31,734	-	31,734	(16,279)
Net movement in funds	9	72,496	311,357	383,853	793,448
Funds at 1 January 2021	20/22	1,427,065	212,424	1,639,489	846,041
Funds at 31 December 2021	20/22	1,499,561	523,781	2,023,342	1,639,489

Retina UK

Balance Sheet

For the year ending 31 December 2021

	Note	2021 £	2020 £
FIXED ASSETS			
Tangible fixed assets	13	6,336	7,650
Investments	14	275,742	244,121
Total fixed assets		282,078	251,771
CURRENT ASSETS			
Debtors: Amounts falling due within 1 year	15	925,059	1,227,530
Cash at bank and in hand	16	1,322,144	1,197,890
Total current assets		2,247,203	2,425,420
LIABILITIES			
Creditors: Amounts due within 1 year	17	(505,939)	(1,037,702)
Net current assets		1,741,264	1,387,718
Net assets		2,023,342	1,639,489
FUNDS			
Unrestricted	20	1,499,561	1,427,065
Restricted	22	523,781	212,424
Total funds		2,023,342	1,639,489

Janet E. Crookes

J Crookes
Treasurer
Date: 11 May 2022

Dr M Kirkup

Dr M Kirkup
Chair
Date: 11 May 2022

Cash Flow Statement

For the year ending 31 December 2021

Cash flows from operating activities:	Note	2021 £	2020 £
Net income for the reporting period		383,853	793,448
Adjustments for:			
Depreciation charges	13	3,677	3,466
Unrealised (gains) / losses on investments	14	(31,734)	16,279
Dividends and interest from investments	5	(3,010)	(5,226)
Decrease / (increase) in debtors	15	302,471	(394,918)
(Decrease) / increase in creditors	17	(81,105)	74,461
Decrease in grant creditors	17	(450,658)	(135,202)
Net cash generated in operating activities		123,494	352,308
Cash flows from investing activities:			
Dividends and interest from investments	5	3,010	5,226
Purchase of tangible fixed assets	13	(2,363)	(6,996)
Disposal of investments	14	113	-
Cash flows from investing activities		760	(1,770)
Change in cash and cash equivalents in the year		124,254	350,538
Cash and cash equivalents at 1 January 2021	16	1,197,890	847,352
Cash and cash equivalents at 31 December 2021	16	1,322,144	1,197,890

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.

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 initially measured at transaction price excluding transaction costs, and are subsequently measured at fair value at each reporting date. Transaction costs are expensed as incurred. 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.

3. Donations and Legacies

	2021 £	2020 £
Membership subscriptions/donations	31,422	33,922
Individual donations	287,171	201,905
Trusts	125,514	264,494
Corporate	99,042	129,151
Legacies/In memoriam	219,531	1,095,391
Fundraising	159,275	134,381
Prize draw/appeals/mailings	80,843	98,377
Gift Aid	47,999	41,829
Total	1,050,797	1,999,450

4. Grants

	2021 £	2020 £
Medical research funding	41,100	48,680
Government grants	144,228	75,138
Total	185,328	123,818

Government grants comprise amounts in respect of the Coronavirus Job Retention Scheme ('CJRS') £33,378 (2020: £75,138) and from UK Government COVID Medical Research Charity Support Fund £110,850 (2020: none).

5. Investments

	2021 £	2020 £
Share dividends	2,885	4,891
Bank interest	125	335
Total	3,010	5,226

6. Raising funds

	2021 £	2020 £
Event costs	22,807	28,105
Materials and equipment	-	69
Collection fees	6,403	5,605
Appeals	7,247	347
Training and conferences	193	416
Donor development including trusts & corporates	553	722
Other	800	800
Support costs (see note 10)	215,115	211,882
Total	253,118	247,946

7. Medical research

	2021 £	2020 £
Annual grant awards	4,584	543,559
Grant donation for medical research	91,283	-
MAB expenses	-	187
Support costs (see note 10)	67,184	66,373
Total	163,051	610,119

Grant awards in 2021 were offset by £78,690 (2020: none) of unused funds reclaimed from the original UKIRDC project, which will be used to fund awards in 2022.

In 2021, a grant donation of £91,283 (2020: none) was made from our restricted RDH12 Fund to Moorfields Eye Charity to fund relevant research as we had not been able to identify a suitable project to fund directly with remaining funds.

8. Information & Support

	2021 £	2020 £
Publications, DVDs, leaflets etc	19,389	17,765
Annual conference	4,306	55
Helpline support	8,169	8,598
Information events	1,170	425
Non-medical research/projects	27,125	18,684
Travel expenses	2,706	3,067
Retina International	5,360	5,443
Website development	570	850
Sight loss survey	2,613	-
Volunteering	4,558	1,845
Other	2,356	5,881
Support costs (see note 10)	392,525	398,089
Total	470,847	460,702

9. Net movement in funds is stated after charging

	2021 £	2020 £
Auditor's remuneration (audit)	7,050	7,940
Auditor's remuneration (non audit)	-	1,390
Depreciation	3,677	3,466
Trustees' expenses	14	1,580
Lease payments	13,500	13,500

Trustees' expenses, incurred on travel and accessibility support, represent amounts reimbursed to one Trustee for expenses incurred (2020 - 1).

No Trustee received any remuneration during the year (2020 - none).

10. Analysis of support costs

	Total £	Fundraising £	Research £	Information & Support £	Basis of apportionment
Office administration	77,218	23,165	7,722	46,331	Staff time or actual
Remuneration	555,869	179,429	55,288	321,152	Staff time or actual
Governance	41,737	12,521	4,174	25,042	Staff time or actual
Total	674,824	215,115	67,184	392,525	
Governance costs in 2020	42,613	12,784	4,261	25,568	

11. Staff numbers and costs

	2021 £	2020 £
Wages and salaries	531,264	516,480
Social Security costs	42,073	48,281
Pension costs	16,180	15,511
Total	589,517	580,272

The number of persons employed by the charity during the year was 19 (2020 - 20).

Total remuneration (including Employer NIC) for key management personnel in the year was £86,258 (2020 - £87,056). The number of employees with remuneration (excluding Employer NIC) between £70,000-£80,000 was 1 (2020 - 1).

12. Comparative information for Statement of Financial Activities

	Unrestricted Funds	Restricted Funds	Total Funds 2020
	£	£	£
INCOME FROM:			
Donations & legacies	1,542,474	456,976	1,999,450
Charitable activities			
<i>Grants</i>	75,138	48,680	123,818
Investments	5,226	-	5,226
Total income	1,622,838	505,656	2,128,494
EXPENDITURE ON:			
Raising funds	202,636	45,310	247,946
Charitable activities			
<i>Medical research</i>	126,873	483,246	610,119
<i>Information & Support</i>	276,291	184,411	460,702
Total expenditure	605,800	712,967	1,318,767
Net losses on investments	(16,279)	-	(16,279)
Net movement in funds	1,000,759	(207,311)	793,448
Funds at 1 January 2020	426,306	419,735	846,041
Funds at 31 December 2020	1,427,065	212,424	1,639,489

13. Tangible fixed assets

	Office Equipment £
Cost	
At 1 January 2021	20,230
Additions	2,363
At 31 December 2021	22,593
Depreciation	
At 1 January 2021	12,580
Charge for year	3,677
At 31 December 2021	16,257
Net book value	
At 31 December 2021	6,336
At 31 December 2020	7,650

14. Investments

	2021 £	2020 £
At 1 January 2021	244,121	260,400
Disposals	(113)	-
Unrealised gains / (losses)	31,734	(16,279)
As at 31 December 2021	275,742	244,121
	2021 £	2020 £
Included within investments are the following:		
CAF balanced growth fund at valuation	275,467	243,733
Shares in Taylor Woodrow	275	275
3% City of Liverpool stock	-	113
	275,742	244,121

All investments are held in the UK.

15. Debtors: Amounts falling due within one year

	2021 £	2020 £
Accrued income	836,351	1,187,828
Trade debtors	63,545	28,205
Prepayments	25,163	11,497
Total	925,059	1,227,530

16. Analysis of cash and cash equivalents

	2021 £	2020 £
Cash at bank and in hand	1,322,144	1,197,890
Total	1,322,144	1,197,890

17. Creditors: Amounts falling due within one year

	2021 £	2020 £
Trade creditors	44,082	125,101
Tax and social security	13,261	12,926
Accruals and deferred income	7,600	8,950
Grant liability	437,825	888,483
Other creditors	3,171	2,242
Total	505,939	1,037,702

18. Contingent assets & liabilities

There is a contingent liability of £343,775 at 31 December 2021 (2020 - £327,049) in respect of research grants authorised subject to annual review. This money falls due in years 2022 onwards.

19. Financial commitments

	2021 £	2020 £
Total future minimum lease payments under non-cancellable operating leases are as follows:		
< 1 year	13,500	13,500
1 - 5 years	47,250	60,750

20. Unrestricted Funds

	General Fund £	Designated Research Fund £	Total Unrestricted Funds £
Balance at 1 January 2021	1,120,065	307,000	1,427,065
Income	644,107	-	644,107
Expenditure	(561,906)	(41,439)	(603,345)
Transfer between funds	(4,451)	4,451	-
Unrealised gain on investment	31,734	-	31,734
Balance at 31 December 2021	1,229,549	270,012	1,499,561

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 2020

	General Fund £	Designated Research Fund £	Total Unrestricted Funds £
Balance at 1 January 2020	280,550	145,756	426,306
Income	1,622,838	-	1,622,838
Expenditure	(531,465)	(74,335)	(605,800)
Transfer between funds	(235,579)	235,579	-
Unrealised loss on investment	(16,279)	-	(16,279)
Balance at 31 December 2020	1,120,065	307,000	1,427,065

Retina UK

Notes to the Accounts

For the year ending 31 December 2021

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	Specified Research Fund	Total Restricted Funds
	£	£	£	£	£	£	£	£	£	£	£
At 1 January 2021	347	2,545	1,150	118,639	1,100	42,340	24,981	2,558	45	18,719	212,424
Income	246,510	275	-	105,262	-	99,646	-	-	41,790	101,545	595,028
Expenditure	25	-	-	(100,463)	-	(118,647)	(22,751)	-	(41,835)	-	(283,671)
At 31 December 2021	246,882	2,820	1,150	123,438	1,100	23,339	2,230	2,558	-	120,264	523,781

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 2021, specific projects funded include the helpline, Look Forward, the Sight Loss Survey and Mental Health project.

Specified Project Fund: This fund contains funding for specific projects. In 2021, this was for Unlock Genetics.

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

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

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

22. Comparative information of Restricted Funds movement at 31 December 2020

	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 £
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)
Transfer	-	-	-	-	-	250	-	-	-	-	(250)	-
At 31 December 2020	347	2,545	1,150	118,639	1,100	42,340	24,981	2,558	45	-	18,719	212,424

23. Analysis of net assets between funds

	Tangible Fixed Assets £	Fixed Asset Investments £	Current Assets £	Current Liabilities £	Total £
Restricted Funds	-	-	821,486	(297,705)	523,781
Unrestricted Funds	6,336	275,742	1,425,717	(208,234)	1,499,561
	6,336	275,742	2,247,203	(505,939)	2,023,342

24. Comparative analysis of net assets between funds 2020

	Tangible Fixed Assets £	Fixed Asset Investment £	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
	7,650	244,121	2,425,420	(1,037,702)	1,639,489

25. Grants awarded

Institution		Grant Holder	Amount £
Radboud UMC, The Netherlands	GR596	Dr R Collin	43,750
Oxford University	GR599	Prof R MacLaren	39,524
Total			83,274
Adjustments on completion of grant projects			(78,690)
			4,584
Opening creditor for grant commitment			888,483
Grant payments			(452,228)
Adjustment on grant rebate on project completion			(3,014)
Closing creditor for grant commitment			437,825

26. Related party transactions

There are no related party transactions requiring disclosure in the Financial Statements (2020 - none) other than those relating to Trustees' expenses disclosed in note 9.