RETINA UK

England & Wales · Charity number 1153851

Details

Other names	BRPS, RP FIGHTING BLINDNESS, RP FIGHTING BLINDNESS.
Status	Registered
Legal form	CIO
Registered	2013-09-18
Register	View on the Charity Commission register

Contact

Address	PO Box 350 Buckingham MK18 1GZ
Phone	01280821334
Email	info@RetinaUK.org.uk
Website	www.RetinaUK.org.uk

Activities

Objects: THE OBJECTS OF THE CIO ARE THE RELIEF OF PERSONS SUFFERING FROM ALL FORMS OF RETINITIS PIGMENTOSA, ITS SYNDROMES AND SIMILAR HEREDITARY RETINAL DYSTROPHIES, IN PARTICULAR BUT NOT EXCLUSIVELY, BY PURSUING MEASURES TOWARDS FINDING THE CAUSE, TREATMENT AND CURE OF ALL FORMS OF RETINITIS PIGMENTOSA, ITS SYNDROMES AND SIMILAR HEREDITARY RETINAL DYSTROPHIES AND PROVIDING INFORMATION AND SUPPORT FOR PEOPLE WITH THESE CONDITIONS.

Activities: We support people affected by inherited progressive sight loss and invest in medical research to ensure that people can lead a fulfilling life.

Classification

- **How:** Makes Grants To Organisations, Provides Other Finance, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body, Other Charitable Activities
- **What:** The Advancement Of Health Or Saving Of Lives, Disability, Economic/community Development/employment, Other Charitable Purposes
- **Who:** Children/young People, Elderly/old People, People With Disabilities, People Of A Particular Ethnic Or Racial Origin

Geography

- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£2,170,849	£1,656,344	£2,042,464	23
2023-12-31	£1,287,014	£1,793,801	£1,527,959	24
2022-12-31	£1,562,632	£1,535,942	£2,036,626	26
2021-12-31	£1,239,135	£887,016	£2,023,342	25
2020-12-31	£2,128,494	£1,318,767	£1,639,489	29

Trustees

Name	Role	Appointed
Ashley Grist		2022-01-01
COLIN MCARTHUR		2024-01-30
Dr ELIZABETH MARY Buckingham		2014-01-28
Dr Martin Kirkup		2021-04-07
Dr Samuel Nathan Godfrey		2026-01-01
Kathleen Evans		2024-09-18
Lucy Withington		2015-12-02
PROFESSOR JOHN MARSHALL MBE BSC		2013-07-31
ROGER CHARLES FRANCIS BACKHOUSE		2013-07-31
Robert William Halliwell		2026-01-01
Simon Keightley		2022-01-01
Vanessa Forster		2022-01-26

Accounts

RETINA UK

WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

Retina UK

A Charitable Incorporated Organisation

Annual Report & Financial Statements

Year Ending 31 December 2024

Reference and administrative details

For the year ending 31 December 2024

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	RetinaUK.org.uk
Honorary President	Mrs Lynda Cantor MBE (from 18 September 2024)
Trustees	Trustees who served during the year and up to the date of this report were as follows: Dr Martin Kirkup (Chair to 18 September 2024) Ms Kathy Evans (Chair from 18 September 2024) Mr Ashley Grist (Treasurer) Mr Roger Backhouse Mrs Lynda Cantor MBE (to 18 September 2024) Dr Elizabeth Graham (also known by her legal name, Elizabeth Buckingham) Prof John Marshall MBE Dr Lucy Withington Mr Simon Keightley Ms Vanessa Forster Mr Colin McArthur (from 30 January 2024)
Ambassadors	Mrs Bhavini Makwana Mr Steven Bate MBE Mr Amar Latif
Chief Executive	Ms Tina Garvey
Principal Bankers	Lloyds Bank 30 Market Place Brackley NN13 7BA
Auditors	Azets Audit Services Epsilon House The Square Gloucester Business Park Gloucester GL3 4AD
Solicitors	EMW Law LLP Seebeck House 1 Seebeck Place Knowlhill Milton Keynes MK5 8FR

Solicitors

Dutton Gregory Solicitors
Concept House
6 Stoneycroft Rise
Chandler's Ford
Eastleigh
Hampshire
SO53 3LD

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This is my first Annual Report as Chair of Trustees and I am looking forward to supporting and guiding such a fantastic, impactful charity. I would like to thank Dr Martin Kirkup for his significant contribution over the past three years. He remains as a Trustee for the charity.

I would like to thank all of our volunteers for their contributions during 2024. We simply couldn't do the work we do without them! I would also like to thank our ambassadors, our Trustees and the members of our Medical Advisory Board for so generously contributing their time and expertise to the work of Retina UK. We rely on a wonderful, dedicated staff cohort, led by Tina Garvey, and I pay tribute to them.

Four new research grants were funded in 2024, two at Newcastle University, one at UCL Institute of Ophthalmology and one at King's College London. More information about these is available in the 'Research grant funding' section of this report.

Our Conferences in Manchester were very well received, with 368 registrations for our Professionals' Conference and 364 for our Annual Conference. Our Annual Conference also saw 24 of our volunteers attending, an increase on previous years. I was only able to attend the Professionals' Conference in 2024, but I am looking forward to being part of both days in 2025 in London.

We launched our new practical information pack in Manchester for professionals who support people affected by inherited sight loss. It is available in both hard copy and digital formats and has resulted in an increase in the number of referrals we have received from the professional community.

Our Peer Support Groups have once again seen a notable increase in the number of registrations. We now have 17 physical groups, one national online group and five special interest groups (also online). I will be interested to learn if our 2025 Sight Loss Survey shows positive evidence of the effect of these groups on anxiety and depression levels within our community.

Despite significant challenges in the environment and changes to the fundraising staff team, income increased in 2024. Successful applications to Trusts generated an income of £966,418 compared to £140,760 in 2023. Our 2024 appeal also performed very well with income of £105,500 compared to £57,145 in 2023. However, more than 50 percent of this income is restricted funds.

As part of Policy, Influence and Campaigning, Retina UK was invited to present evidence to the Scottish Medicines Consortium (SMC) regarding the continued approval of Luxturna, a treatment for individuals with a specific type of inherited retinal dystrophy. Our involvement highlighted the challenges faced by those living with IRDs and the transformative potential of access to effective treatment.

I am looking forward to a packed calendar of activity in 2025 as we start our 50th Anniversary events to mark this milestone in the charity's history.

Kathy Evans

Kathy Evans
Chair

The Trustees are pleased to present their annual report together with the financial statements of the charity for the year ending 31 December 2024. 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 (FRS) 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 purpose. However, the Board 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 People Committee and the Audit and Risk 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), Visionary, the Fundraising Regulator, Chartered Institute of Fundraising, Information Commissioner's Office (ICO) and the Fundraising Preference Service. It is also a CPD Accredited Provider. Retina UK abides by each organisation's principles of best practice at all times.

Related parties

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

Key management remuneration

The remuneration of the Chief Executive is set by the Chairman of the Board of Trustees in consultation with the People Committee. Staff remuneration with regard to inflation is proposed by the Chief Executive and considered by the People Committee, on behalf of the Trustee Board.

Financial review

Income for the year (excluding legacies, grants and investments) closed at £1,664,577 which is more than double that achieved in 2023 (£637,139) due primarily to restricted trust income. Legacies were £367,947 which is broadly in line with the long term average each year, although lower than a strong 2023 (£542,476). Grant income was £86,376 and included a final amount of £51,527 from the UK Government Covid Support Fund. Interest income was £51,939 (2023: £36,174). Total income generation for year ended 31 December 2024 was therefore £2,170,849 and a marked increase over prior year (2023: £1,287,014).

Total expenditure for the year was £1,656,344 (2023: £1,793,801), including £716,144 for medical research (2023: £906,043). Fundraising costs of £364,726 represented 17% of income (2023: 23%). The balance of £575,474 was spent on Information & Support services and this was a 2% reduction versus prior year.

Retina UK had net assets of £2,042,464 at 31 December 2024 (2023: £1,527,959) which reflects an increase of £514,505 due to the excess of income over expenditure in the year.

The Charity had a cash balance of £1,887,763 at the year end. Of this, £1,158,770 was in a 32 day notice account to balance maximising interest income with the ability to withdraw funds from the remainder current account as required for grant spend and day to day operations. Cash flow forecasts are assessed regularly to establish if any should be placed on a longer fixed term deposit to optimise income generation from our cash over the coming period.

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. 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

For any funds surplus to short term requirements, we look to place secure deposits on fixed terms of up to one year.

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 and subsequent cost-of living challenges 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.

Restricted funds are spent in line with donor wishes.

At 31 December 2024, the charity had total funds of £2,042,464:

- Unrestricted funds of £629,539 (of which £248,875 designated for future medical research commitments)
- Restricted funds of £1,412,925

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. 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. We continued to operate the charity on a sustainable basis.

Whilst planning for 2025 and beyond is focussing on increasing charitable impact, 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 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 £18 million into cutting-edge research since we were founded in 1976 and we are determined to build on the progress made to date.

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. Four new research projects funded by Retina UK started in 2024.

We will start a series of events and activity to mark the 50th anniversary of Retina UK in June 2025, which will run through until June 2026.

Our Annual and Professionals' Conferences went ahead as hybrid events in Manchester. Our Conferences will take place in London in 2025. Our webinar series continues to be popular and will continue in 2025 with a wide range of topics. We will carry out our third three-yearly tracking survey in the spring of 2025.

We will continue to enhance the tailored practical and emotional support we provide for our community so that they can make informed choices. We will carry out an EDI audit and create an EDI strategy/action plan. We will increase our engagement with young adults and improve the support we provide to this group to ensure equitable and inclusive access to our charity. We will also increase our engagement with the wider family, specifically parents, and improve the support we provide to this group

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 feels 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 that demonstrate the best scientific merit and likelihood of patient benefit. These principles include the use of a completely independent Medical Advisory Board when prioritising 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 2024.

The UK Inherited Retinal Dystrophy Consortium (UKIRDC)
Started 2014 / Ends 2025

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 ten other genes. The project has recruited almost 600 people with IRDs and has solved one third of these previously intractable cases, providing families with better understanding of their condition and opening up choices.

Development of CRISPR gene therapy for Stargardt disease
Started 2020 / Ended 2024

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 investigated the feasibility of using a CRISPR-based gene editing approach to correct faults in the genetic code. In particular, the researchers looked at editing the intermediary genetic molecule known as RNA, which potentially provides a safer, more flexible target than the original DNA blueprint.

The project has encountered some challenges, but these were overcome successfully. RNA editing has proved challenging in living models, suggesting that this might not be such a promising alternative to DNA editing.

Establishing AAV.PRPF31 gene augmentation in PRPF31-deficient RPE and photoreceptor cells and assess its efficacy in restoring RPE and photoreceptor function
Started 2022 / Ends 2025

This project, led by Prof Majlinda Lako at Newcastle University, follows on from an earlier Retina UK-funded study of defects in the PRPF31 gene, which plays a key role in "editing" the genetic code during protein construction. Prof Lako and colleagues will now look into the development of a gene replacement therapy to overcome the effects of faulty PRPF31, using cutting-edge techniques to explore the impact of the therapy on cell-based models of PRPF31 disease. This will provide important proof of concept data as a first step towards treatment.

Generation and transplantation of hypoimmunogenic pluripotent stem cell derived photoreceptor precursors into a mouse model of advanced retinal degeneration: a proof-of-concept study for USH2A and retinitis pigmentosa (RP) treatment
Started 2023 / Ends 2026

“Pluripotent” stem cells have shown promising outcomes with respect to generation of rods and cones, which transform light into electrical signals that can be processed by the brain. Pluripotent stem cells can be generated from each patient and guided to give rise to rods and cones; however, this process is time- and cost-demanding and does not allow for immediate availability of off-the-shelf ready-made cells for transplantation. This project, led by Prof Majlinda Lako at Newcastle University, will look at making the pluripotent stem cells invisible to the patient’s immune system (so called hypoimmunogenic) and then differentiating them into rods and cones, to be safely transplanted into anyone with RP (including RP caused by USH2A mutations) without the risk of immune rejection.

The researchers believe that this gene-agnostic hypoimmunogenic photoreceptor transplantation approach has far-reaching impact as it could benefit a large proportion of the RP community. This project was funded thanks to a generous commitment from the AT Capital Charitable Foundation.

Deciphering RPGR’s role in cone-mediated disc formation
Started 2023 / Ends 2026

Retina UK and the Macular Society are co-funding this PhD studentship, supervised by Dr Roly Megaw at Edinburgh University.

The PhD student will investigate how particular mutations in the RPGR gene impact cone photoreceptors. Different mutations in RPGR can cause either retinitis pigmentosa (which first affects the peripheral ‘rod’ photoreceptors and therefore our visual field and night vision) or a Cone Rod Dystrophy (which first affects the macular ‘cone’ photoreceptors and therefore our central vision). Currently we don’t know why these different mutations cause different symptoms.
Using cutting edge techniques in collaboration with scientists in Geneva, the proposed project will mimic macular disease and investigate the mechanisms underlying cone damage. Finding out why different RPGR mutations cause different diseases could help identify future treatments and could even provide a springboard for preventative therapies.

Investigating Stargardt disease as a prime target for gene repair
Started 2023 / Ends 2026

This PhD studentship project, co-funded by Retina UK and the Macular Society, is being supervised by Prof Jacqueline van der Spuy at UCL Institute of Ophthalmology.

Prime editing is a cutting-edge technology in which a disease-causing genetic change is precisely and permanently repaired in an individual’s genetic code, restoring the normal function of the gene. In this study, the student will investigate whether prime editing can efficiently correct one of the most common genetic changes causing Stargardt disease. By establishing methods for safely and precisely editing these particular faults, the project could contribute to the subsequent application of the technique across a huge range of conditions, transforming future treatments for a wide proportion of those living with inherited sight loss.

Investigating photopsia and photophobia in Stargardt disease
Started 2024 / Ends 2029 (part time)

This studentship was inspired by a young scientist living with Stargardt disease, who will now undertake the project to gain her PhD. It is co-funded by the Macular Society and supervised by Prof Omar Mahroo and Prof Andrew Webster at UCL.

Preliminary research with Stargardt patients has uncovered two common but underappreciated symptoms: photopsia, which is the sudden appearance of phantom light flashes within the field of view, and photophobia, which is pathological aversion to bright light. These symptoms can be highly disruptive to normal visual processing and impair normal daily activities. This project will study prevalence and characteristics of photopsia and photophobia in patients with Stargardt's and will relate the incidence of photopsia and photophobia to the standard clinical measurements used in diagnosis, prognosis and disease monitoring. This will allow the researchers to establish if the symptoms are associated with a particular stage or aspect of degeneration and if they can be used to inform prognosis. Finally, the project will investigate biological mechanisms that link these symptoms to disease-related changes in the retina.

Investigating cone photoreceptor starvation in retinitis pigmentosa using stem cell derived retinal organoids
Started 2024 / Ends 2027

RP is primarily caused by gene mutations effecting rod photoreceptors, which mediate vision in dim lighting, however, cones, critical for high acuity and colour vision, start dying once most of the rods have been lost. Based on this, it has been hypothesised that the cessation of rod-derived nutritional support is a major contributor to cone cell death; however, the details of this survival signalling are poorly understood, and remain untested in the human context.

Taking advantage of recent advances in genome engineering and stem cell technology, Dr Jörn Lakowski and colleagues at Southampton University have established a novel human model system of RP by genetically disabling BASIGIN-1 (BSG1), a pivotal gene in the cone survival pathway. This project will now use human stem cell derived "mini-retinas" carrying this mutation to investigate the mechanism of RP associated cone starvation and identify drugs that can prevent cone cell death thereby protecting against the devastating end stages of central visual loss.

Pre-clinical evaluation of a micro-engineered photoreceptor patch implant for retinal repair
Started 2024 / Ends 2026

Professor Jane Sowden and Mr Robert Henderson from UCL's Institute of Child Health, will be tackling the challenge of restoring some vision at the later stages of sight loss. At advanced stages of retinitis pigmentosa (RP) and other inherited retinal conditions, most of the photoreceptors across the retina have died. A potential route to restoring vision is to generate new photoreceptors from stem cells and place these at the back of the eye.

To this end, Professor Sowden and her team will micro-engineer a photoreceptor cell patch to implant into the retina, creating a tiny millimetre dimension scaffold for the new cells to sit in. They are hopeful that this scaffold will aid the survival and organisation of the implanted photoreceptors. Over the course of the project, they aim to demonstrate that the patch can successfully be surgically implanted in an animal eye; they will assess its compatibility with the living tissues around it and evaluate the behaviour of the new photoreceptor cells. This is a first step towards development of a therapy for late-stage RP that could be helpful in a large proportion of cases, regardless of the underlying genetic fault.

cGMP analogues for understanding and targeting early pathological changes in LCA4
Started 2024 / Ends 2027

Professor Jacqueline van der Spuy at UCL's Institute of Ophthalmology will work with collaborators in Germany and Turkey to delve into the consequences of toxic accumulation of a molecule called cGMP. The three-year project will use cell-based models of a very severe form of Leber congenital amaurosis (LCA) caused by mutations in the AIPL1 gene (LCA type 4), but cGMP accumulation also occurs in a number of other inherited retinal conditions, so understanding how it contributes to cell death could have much wider relevance.

The team will use cutting-edge techniques to follow up on clues about how excess cGMP impacts vital molecular pathways, with the aim of finding targets for therapeutic intervention. They also aim to test whether a particular potential drug can dampen cGMP's toxic effects. The drug compound has already been extensively refined in other laboratory work, and Prof van der Spuy hopes that her project's use of highly sophisticated disease models, based on human cells, would allow for rapid progress into clinical trials in LCA4, should the drug show promise.

An optimised human retinal organoid model for the study of inherited retinal diseases: application of biomaterials to support improved inner retinal circuitry and optic nerve formation
Started 2024 / Ends 2027

Human stem cell-derived "retinal organoids" (hROs) are spontaneously forming, laboratory-grown retinal-like tissues that offer extraordinary potential to model and study inherited retinal diseases (IRDs). Current methods for growing hROs yield good, but imperfect, retinal structures, typically containing two layers, a well-formed photoreceptor layer and a combined inner / retinal ganglion cell (neuron) layer. However, before the photoreceptors fully mature, the inner structure breaks down and the retinal ganglion cells die, most likely because they lack a target &/or nutrient access.

Prof Rachael Pearson and colleagues at King's College London have generated nano-scale fibres to create a scaffold for retinal ganglion cell axons to grow along. These have been combined with hROs with very encouraging preliminary results, where retinal ganglion cells send axons along the fibre creating a pseudo-optic nerve, and, importantly, survive in large numbers for extended periods in culture. The current project grant will allow the researchers to further develop this approach to create a custom-designed platform to improve long-term hRO retinal ganglion cell structure and function for the study of IRDs.

Community engagement with research

During 2024, we continued our efforts to promote engagement between members of our community, researchers and industry.

We shared seven participation opportunities to our Lived Experience Panel, which now has around 550 members. These opportunities included membership of a biotechnology company's advisory panel, a clinical trial for those with X-linked RP and a research study on Charles Bonnet syndrome.

We also continued to keep our community updated on research progress via podcasts, webinars, features in each edition of the Look Forward newsletter, and research sessions at both our Annual and Professionals' Conferences.

Policy, Influence & Campaigning

Campaigning, influencing and policy

Advocating for continued access to Luxturna

Retina UK was invited to present evidence to the Scottish Medicines Consortium (SMC) regarding the continued approval of Luxturna, a treatment for individuals with a specific type of inherited retinal dystrophy. Our involvement highlighted the challenges faced by those living with IRDs and the transformative potential of access to effective treatment.

Key contributions and outcomes:
- **Evidence Submission:** Shared insights on the impact of IRDs on mental health, education, employment, relationships, and leisure activities.
- **Patient Testimony:** Introduced a patient who had undergone Luxturna treatment, demonstrating the life-changing benefits of improved vision.

- **Successful Outcome:** Luxturna received full approval for continued use in Scotland, ensuring ongoing access to this vital treatment for eligible patients.

Bringing treatments to the clinic

Securing NHS availability for new therapies is the essential final step in enabling those living with IRDs to access life-changing treatment. We held an industry round table event in 2022 which identified the lack of accessible patient data to be a key barrier to market access. In late 2023, Retina UK initiated a consultation to investigate the potential for a UK-based IRD registry to meet the needs of researchers, industry and community.

Information and support

We were pleased to secure funding for a Research Intern and a Development Team Intern through the Thomas Pocklington Trust (TPT) Get Set Progress scheme. These two Interns started with us in January 2024 and completed their Internships in September. We were then fortunate to be able to recruit another Development Team Intern who started with us in October 2024.

- **Professionals' Conference, Manchester, 27 September 2024** – 368 delegates registered to attend (in-person and online). 145 of people were new to the charity. Content included:
    - Working together to deliver the Eye Care Support Pathway
    - The role of peer-to-peer support in achieving good outcomes for clients
    - The importance of quality-of-life research: understanding the impact of inherited sight loss
    - Supporting you to deliver equitable, accessible and inclusive services
- **Annual Conference, Manchester, 28 September 2024** – 364 delegates registered (in-person and online). 98 people were new to the charity. Content included:
    - The Eye Care Support Pathway and what it means for you
    - Harnessing the power of peer-to-peer support
    - Supporting the next generation of research leaders: a discussion with Retina UK-funded PhD students
    - Progress at the forefront of Inherited Sight Loss research, followed by Research Q&A
- **Webinars** – We delivered a total of nine webinars in 2024 with combined registrations of 224. All Webinar recordings were uploaded to YouTube with 1,249 people watching them. Topics included: research, clinical trials, fundraising, young adults, challenge events and creativity.
- **Podcasts** – We delivered eight podcasts in 2024 with a total of 477 listens. Topics included: leisure activities, governance, fundraising, voting and cataract surgery.
- **Spotify** - our channel on Spotify had a total of 2,923 listens in 2024 with a roughly equal split between men and women. The highest age range at 34.6% was in the 45-59 category.
- **YouTube** - Our YouTube channel grew by 254 people, a 75% increase. Views were 69.5K (up by 547% on the previous year) and the watch time was 1.6K (76% more than in the previous year). This indicates that our channel is attracting a wider audience
- **Newsletters** – We distributed 22,869 copies of Look Forward and 33,358 copies of our e-Newsletter.
- **Professionals**
    - We accepted seven invitations to raise awareness of our work to relevant professionals including UKOA; National ECLO seminar; Aston University; Doncaster QTVI team; RNIB ECLO meeting.
    - We launched a new practical information pack for professionals working in health, social care and education to use when supporting people affected by inherited sight loss. It includes information on how Retina UK can help, how to make a referral to our charity, and where to signpost to our free-to-access support. We made contact with 260 new professionals.
- **Peer Support Groups** – We increased our offering to 17 physical groups, one national online peer support group and five special interest online groups. A total of 1,206 people registered to attend these groups (an increase of 17% on 2023).

- **Helpline** - We fully embedded changes to the telephone helpline. These have increased the percentage of callers being added to the database, ensured a more professional and consistent service, led to more referrals to other Retina UK services and improved satisfaction from volunteers who are now 'matched' with a service user. 2024 saw a 4% decrease in helpline calls and a 25% increase in helpline emails.
- **Volunteers** - We welcomed 24 volunteers to our annual conference, a significant uplift on previous years. This development and learning opportunity was followed by an evening of networking and celebration.
- **Database growth** - We grew the number of contacts on the database from 19,913 (December 2023) to 21,707 (December 2024).

Fundraising

As we reflect on the past 12 months, it continues to remain a challenging environment for third sector fundraising. With our 50th anniversary campaign coming up in 2025 and 2026, we are looking forward to engaging our community in supporting us through fundraising during this special occasion.

2024 highlights:

- Our Big Give Christmas Challenge in December 2024 raised over £65,000 – our most successful match-funding campaign to date.
- Our Challenge Events 2024 saw continued growth, increasing the stream by £55,000 year on year. Our London Marathon runners raised over £65,000 in April.
- Membership remained at a constant level during the year and a review and relaunch are planned for early-2025.

- Grants from Trusts and Foundations increased by over £100,000 year on year – including the award of a grant from the National Lottery Community Fund, which has been invested in growing our Peer Support Group network in England.
- The Retina UK Lottery launched in March 2024, as part of our work to grow our Regular Giving income stream. 16 Retina UK supporters have won a cash prize.
- We launched our first ever Thank-athon to thank and inform our supporters of their impact and the difference they've made.
- Our Christmas Appeal became our biggest in three years, alongside our record-breaking Big Give Christmas Challenge.

All fundraising in 2024 was carried out by Retina UK's in-house Income Generation 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 2024. 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 2024.

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 Industry (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 2024 we were grateful to receive the following support:

Johnson & Johnson	£10,000 to support our Annual and Professionals' Conferences £22,666 sponsorship of our *Look Forward* newsletter £50,000 towards Patient Registry £3,960 consultancy fees for recruiting patient public involvement panel

Trusts and Foundations

We would like to thank the following trusts and foundations for their generous support of our work in 2024, noting that some prefer to remain anonymous so are not listed below. Their contributions have enabled us to continue supporting our community during challenging times, and to invest in pioneering medical research into inherited sight loss:

- Garfield Weston Foundation
- Albert Gubay Charitable Foundation
- AMW Charitable Trust
- The Annett Trust
- Anthony and Elizabeth Mellows Charitable Settlement
- The Autumn Stone Foundation
- Benecare Foundation
- Bouttell Bequest
- The Carrington Charitable Trust
- Cecil Pilkington Trust
- Champniss Charitable Trust
- Crispa (Richard Cahn) Charitable Trust
- The David Family Foundation
- David Killick Trust
- David Lister Charitable Trust
- Dennis Alan Yardy Charitable Trust
- Dixie Rose Findlay Charitable Trust
- Dora Rebecca Fine Charitable Trust
- The D'Oyly Carte Charitable Trust
- E M Macandrew Trust
- Edgar E Lawley Foundation
- The Frank Litchfield Charitable Trust
- G S Plaut Charitable Trust
- Gilbert Edgar Trust
- Girdlers Company Charitable Trust
- The Gledswood Charitable Trust
- Grace Trust
- Hamamelis Trust
- Ian Askew Charitable Trust
- The Inman Charity
- R J Tijou Charitable Trust
- Jack Petchey Foundation
- Kathleen Beryl Sleigh Charitable Trust
- Lillie Johnson Charitable Trust
- The Lockett Trust
- Louis Nicholas Residuary Trust
- Marsland McAdoo Charitable Settlement
- Mason Bibby Trust
- Maurice and Rochelle Miller Foundation
- National Lottery Community Fund
- The N Smith Charitable Settlement
- The Percy Hedley 1990 Charitable Trust
- The Potel Charitable Trust

- Rest Harrow Trust
- Robert Luff Foundation
- Rockley Charitable Trust
- Sharegift
- The Sir Cliff Richard Charitable Trust
- The Sir James Roll Charitable Trust
- Spectacle Makers' Charity
- Tennant Southpark Charitable Trust
- Thistledown Trust
- Thomas Pocklington Trust
- Thomas Sivewright Catto Charitable Settlement
- Thriplow Charitable Trust
- Tom and Thelma Wilson Trust
- Vandervell Foundation
- The W E Dunn Trust
- The Westwood Charitable Trust
- WH Smith Group Charitable Trust

Retina UK

Statement of Trustees' Responsibilities

For the year ending 31 December 2024

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.

Kathy Evans

Kathy Evans
Chair
Date 28 May 2025

We have audited the financial statements of Retina UK (the 'charity') for the period ended 31 December 2024 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 2024 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;
- 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
.... 02 June 2025

Chartered Accountants
Statutory Auditor

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.

Statement of Financial Activities

For the year ending 31 December 2024

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £	Total Funds 2023 £
INCOME FROM:					
Donations & legacies	**3**	824,709	1,207,815	**2,032,524**	1,179,615
Charitable activities					
Grants	**4**	-	86,376	**86,376**	60,000
Investments	**5**	51,949	-	**51,949**	47,399
Total income		**876,658**	**1,294,191**	**2,170,849**	1,287,014
EXPENDITURE ON:					
Raising funds	**6**	(364,726)	-	**(364,726)**	(299,690)
Charitable activities					
Medical Research	**7**	(451,744)	(264,400)	**(716,144)**	(906,043)
Information & Support	**8**	(436,091)	(139,383)	**(575,474)**	(588,068)
Total expenditure		**(1,252,561)**	**(403,783)**	**(1,656,344)**	(1,793,801)
Net losses on investments		-	-	**-**	(1,880)
Net movement in funds	**9**	**(375,903)**	**890,408**	**514,505**	(508,667)
Funds at 1 January 2024	**21/23**	**1,005,442**	**522,517**	**1,527,959**	2,036,626
Funds at 31 December 2024	**21/23**	**629,539**	**1,412,925**	**2,042,464**	1,527,959

Balance Sheet

For the year ending 31 December 2024

	Note	2024 £	2023 £
FIXED ASSETS			
Tangible fixed assets	**13**	**9,411**	8,386
Investments	**14**	**275**	275
Total fixed assets		**9,686**	8,661
CURRENT ASSETS			
Debtors: Amounts falling due within 1 year	**15**	**959,165**	352,927
Current asset investments	**16**	**-**	600,000
Cash at bank and in hand	**17**	**1,887,763**	1,457,460
Total current assets		**2,846,928**	2,410,387
LIABILITIES			
Creditors: Amounts due within 1 year	**18**	**(814,150)**	(891,089)
Net current assets		**2,032,778**	1,519,298
Net assets		**2,042,464**	1,527,959
FUNDS			
Unrestricted	**21**	**629,539**	1,005,442
Restricted	**23**	**1,412,925**	522,517
Total funds		**2,042,464**	1,527,959

Ashley Grist
Treasurer
Date: 28 May 2025

Kathy Evans
Chair
Date: 28 May 2025

Cash Flow Statement

For the year ending 31 December 2024

Cash flows from operating activities:	**Note**	**2024 £**	**2023 £**
Net income/(expenditure) for the reporting period		**514,505**	(508,667)
Adjustments for:			
Depreciation charges	**13**	**5,290**	4,237
Losses on investments	**14**	**-**	1,880
Dividends and interest from investments	**5**	**(51,949)**	(47,399)
(Increase)/decrease in debtors	**15**	**(606,238)**	279,003
(Decrease)/increase in creditors	**18**	**(4,691)**	24,973
(Decrease)/increase in grant creditors	**18**	**(72,248)**	471,800
Net cash (outflow)/inflow from operating activities		**(215,331)**	225,827
Cash flows from investing activities:			
Dividends and interest from investments	**5**	**51,949**	47,399
Purchase of tangible fixed assets	**13**	**(6,315)**	(7,887)
Proceeds of disposal of investments	**14**	**-**	260,181
Cash from fixed term deposit	**16**	**600,000**	-
Cash flows from investing activities		**645,634**	299,693
Change in cash and cash equivalents in the year		**430,303**	525,520
Cash and cash equivalents at 1 January 2024	**17**	**1,457,460**	931,940
Cash and cash equivalents at 31 December 2024	**17**	**1,887,763**	1,457,460

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 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

	2024	2023
	£	£
Membership subscriptions/donations	**26,121**	28,474
Individual donations	**122,154**	101,882
Trusts	**966,418**	140,760
Corporate	**125,025**	65,769
Legacies/In memoriam	**367,947**	542,476
Fundraising	**241,763**	192,005
Prize draw/appeals/mailings	**105,500**	57,145
Gift aid	**77,596**	51,104
Total	**2,032,524**	1,179,615

Trust income includes £720,000 granted by one trust for medical research activity (2023: £nil), which will be settled in cash over 2024, 2025 and 2026. Also included in the above is £30,360 of donated services (2023: none).

4. Grants

	2024	2023
	£	£
Medical research funding	**19,739**	60,000
Other grant funding	**15,110**	-
Government grants	**51,527**	-
Total	**86,376**	60,000

Other grant funding comprises amounts from a collaborative venture towards our Young Adults project (2023: £0). Government grants comprise amounts due from UK Government Covid Medical Research Charity Support Fund (2023: £0).

5. Investments

	2024	2023
	£	£
Share dividends	**10**	11,225
Bank interest	**51,939**	36,174
Total	**51,949**	47,399

6. Raising funds

	2024 £	2023 £
Event costs	**26,081**	15,777
Materials and equipment	**135**	168
Collection fees	**12,067**	9,382
Prize draw/appeals	**12,041**	4,182
Training and conferences	**996**	200
Donor development including trusts & corporates	**5,653**	1,528
Other	**9,013**	4,139
Support costs (see note 10)	**298,740**	264,314
Total	**364,726**	299,690

7. Medical research

	2024 £	2023 £
Annual grant awards	**343,526**	712,656
Support costs (see note 10)	**372,618**	193,387
Total	**716,144**	906,043

8. Information & Support

	2024	2023
	£	£
Publications, DVDs, leaflets	**28,141**	20,682
Annual conference	**41,759**	30,551
Helpline support	**10,869**	8,281
Information events	**3,403**	3,633
Non-medical research/projects	**55,722**	14,093
Travel expenses	**6,185**	8,028
Website development	**5,558**	5,040
Volunteering	**11,454**	8,786
VI Sector Collaboration	**1,860**	-
Subscriptions	**6,521**	-
Other	**7,565**	4,023
Support costs (see note 10)	**396,437**	484,951
Total	**575,474**	588,068

Included in the above is £30,360 of donated services (2023: none).

9. Net movement in funds is stated after charging

	2024	2023
	£	£
Auditor's remuneration (audit)	**13,340**	11,500
Depreciation	**5,290**	4,237
Trustees' expenses	**1,256**	2,389
Lease payments	**3,982**	52,500

Trustees' expenses, incurred on travel and accessibility support, represent amounts reimbursed to three Trustees for expenses incurred (2023: 1).

No Trustee received any remuneration during the year (2023: none).

10. Analysis of support costs

	Total	Fundraising	Research	Information & Support	Basis of apportionment
	£	£	£	£	
Office administration	182,294	50,720	64,551	67,023	Staff time or actual
Remuneration	827,826	231,871	287,881	308,074	Staff time or actual
Governance	57,675	16,149	20,186	21,340	Staff time or actual
Total	**1,067,795**	**298,740**	**372,618**	**396,437**	
Governance costs in 2023	50,910	15,273	16,800	18,837	

11. Staff numbers and costs

	2024	2023
	£	£
Wages and salaries	**762,739**	647,124
Social Security costs	**71,398**	59,218
Pension costs	**34,515**	17,743
Total	**868,652**	724,085

The number of persons employed by the charity during the year was 23 (2023: 20).

Total remuneration for key management personnel in the year was £176,943 (2023: £171,062).
The number of employees with remuneration (excluding employer pension contributions) between:

£60,000 and £70,000 was 1 (2023: 1);
£70,000 and £80,000 was 0 (2023: 0);
£80,000 and £90,000 was 0 (2023: 1);
£90,000 and £100,000 was 1 (2023: 0).

12. Comparative information for Statement of Financial Activities

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
INCOME FROM:				
Donations & legacies	**3**	939,937	239,678	**1,179,615**
Charitable activities				
Grants	**4**	-	60,000	**60,000**
Investments	**5**	47,399	-	**47,399**
Total income		**987,336**	**299,678**	**1,287,014**
EXPENDITURE ON:				
Raising funds	**6**	(299,690)	-	**(299,690)**
Charitable activities				
Medical Research	**7**	(496,690)	(409,353)	**(906,043)**
Information & Support	**8**	(515,337)	(72,731)	**(588,068)**
Total expenditure		**(1,311,717)**	**(482,084)**	**(1,793,801)**
Net losses on investments		(1,880)	-	**(1,880)**
Net movement in funds	**9**	**(326,261)**	**(182,406)**	**(508,667)**
Funds at 1 January 2023	**21/23**	**1,331,703**	**704,923**	**2,036,626**
Funds at 31 December 2023	**21/23**	**1,005,442**	**522,517**	**1,527,959**

13. Tangible fixed assets

	Office Equipment £
Cost	
At 1 January 2024	**21,544**
Disposals	**(4,061)**
Additions	**6,315**
At 31 December 2024	**23,798**
Depreciation	
At 1 January 2024	**13,158**
Disposals	**(4,061)**
Charge for year	**5,290**
At 31 December 2024	**14,387**
Net book value	
At 31 December 2024	**9,411**
At 31 December 2023	**8,386**

14. Investments

	2024 £	2023 £
At 1 January 2024	**275**	262,336
Disposals	**-**	(262,061)
As at 31 December 2024	**275**	275

	2024 £	2023 £
Included within investments are the following:		
Shares in Taylor Woodrow	**275**	275
	275	275

All investments are held in the UK.

15. Debtors: Amounts falling due within one year

	2024	2023
	£	£
Accrued income	**939,701**	343,812
Trade debtors	**4,684**	-
Prepayments	**14,780**	9,115
Total	**959,165**	**352,927**

Accrued income includes £480,000 due from a Trust for medical research activity (2023: £nil), which will be settled in March 2025 and March 2026.

16. Current asset investments

	2024	2023
	£	£
Cash on fixed term deposit	**-**	600,000
Total	**-**	600,000

Fixed term deposit of £600,000 for one year ending 16 October 2024 at an interest rate of 3.6%.

17. Analysis of cash and cash equivalents

	2024	2023
	£	£
Cash at bank and in hand	**1,887,763**	1,457,460
Total	**1,887,763**	1,457,460

18. Creditors: Amounts falling due within one year

	2024	2023
	£	£
Trade creditors	**14,261**	15,009
Tax and social security	**4,420**	15,938
Accruals and deferred income	**30,463**	48,713
Grant liability	**737,664**	809,912
Other creditors	**27,342**	1,517
Total	**814,150**	891,089

19. Contingent assets & liabilities

There is a contingent liability of £976,442 at 31 December 2024 (2023: £1,020,116) in respect of research grants authorised subject to annual review. This money falls due in years 2025 onwards.

20. Financial commitments

	2024	2023
	£	£
Total future minimum lease payments under non-cancellable operating leases are as follows:		
< 1 year	**3,857**	2,884
1 - 5 years	**12,944**	10,278

At 31 December 2024, there was a rent commitment under licence totalling £51,478, due by the end of February 2026. (At 31 December 2023, there was a rent commitment totalling £18,036 due by the end of June 2024).

21. Unrestricted Funds

	1 Jan 2024 £	Income £	Expenditure £	Transfers £	31 Dec 2024 £
General Fund	281,466	876,658	(1,173,435)	395,975	**380,664**
Designated Research Fund	723,976	-	(79,126)	(395,975)	**248,875**
Total Unrestricted Funds	**1,005,442**	**876,658**	**(1,252,561)**	**-**	**629,539**

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

22. Comparative information of Unrestricted Funds movement at 31 December 2023

	1 Jan 2023 £	Income £	Expenditure £	Transfers £	Loss on investment £	31 Dec 2023 £
General Fund	1,028,400	987,336	(1,008,414)	(723,976)	(1,800)	**281,466**
Designated Research Fund	303,303	-	(303,303)	723,976	-	**723,976**
Total Unrestricted Funds	**1,331,703**	**987,336**	**(1,311,717)**	**-**	**(1,800)**	**1,005,442**

23. Restricted Funds

	1 Jan 2024 £	Income £	Expenditure £	Transfers £	31 Dec 2024 £
Research Fund	342,809	479,908	(126,173)	-	**696,544**
Specified Research Fund	-	568,056	(30,000)	-	**538,056**
ATCCF Fund	166,441	-	(88,489)	-	**77,952**
Macular Research Fund	-	19,739	(19,738)	-	**1**
Information & Support Fund	9,559	224,988	(139,383)	-	**95,164**
Awards Fund	1,150	-	-	-	**1,150**
Scottish Fund	2,558	1,500	-	-	**4,058**
Total Restricted Funds	**522,517**	**1,294,191**	**(403,783)**	**-**	**1,412,925**

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

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

ATCCF Fund: This is funded by a major donor grant and is for a specific research project on USH2A.

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

Information & Support Fund: This fund is made up of specific donations for Information & Support. In 2024, specific projects funded include volunteers (helpline & training), Look Forward, Conferences & Events, Young Adults. It also includes income and expenditure in relation to donated services.

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

24. Comparative information of Restricted Funds movement at 31 December 2023

	1 Jan 2023 £	Income £	Expenditure £	Transfers £	31 Dec 2023 £
Research Fund	430,676	118,918	(214,283)	7,498	342,809
Specified Research Fund	96,719	44,700	(135,021)	(6,398)	-
ATCCF Fund	166,441	-	-	-	166,441
Macular Research Fund	50	60,000	(60,050)	-	-
Information & Support Fund	3,999	76,060	(70,500)	-	9,559
Specified Project Fund	2,230	-	(2,230)	-	-
Awards Fund	1,150	-	-		1,150
Scottish Fund	2,558	-	-		2,558
Pioneering Research Fund	1,100	-	-	(1,100)	-
Total Restricted Funds	**704,923**	**299,678**	**(482,084)**	**-**	**522,517**

25. Analysis of net assets between funds

	Tangible Fixed Assets	Investments	Current Assets	Current Liabilities	Total
	£	£	£	£	£
Unrestricted Funds	9,411	275	1,117,702	(497,849)	629,539
Restricted Funds	-	-	1,729,226	(316,301)	1,412,925
	9,411	**275**	**2,846,928**	**(814,150)**	**2,042,464**

26. Comparative analysis of net assets between funds 2023

	Tangible Fixed Assets	Investments	Current Assets	Current Liabilities	Total
	£	£	£	£	£
Unrestricted Funds	8,386	275	1,617,715	(620,934)	1,005,442
Restricted Funds	-	-	792,672	(270,155)	522,517
	8,386	275	2,410,387	(891,089)	1,527,959

27. Grants awarded

Institution		**Grant Holder**	**Amount £**
Newcastle University	GR601	Prof M Lako	89,386
Newcastle University	GR602	Prof M Lako	88,488
UCL Institute of Ophthalmology	GR604	Prof J van der Spuy	39,479
King's College London	GR610	Prof R Pearson	126,173
Total			**343,526**
Opening creditor for grant commitment			809,912
Grant payments			(415,776)
Closing creditor for grant commitment			**737,664**

28. Related party transactions

There are no related party transactions requiring disclosure in the Financial Statements (2023: none) other than those relating to Trustees' expenses disclosed in note 9.

Abbreviations

AAV	Adeno-Associated Viral Vector
ABCA4	A gene associated with IRDs
ABPI	Association of British Pharmaceutical Industry
AGM	Annual General Meeting
AIPL1	A gene associated with LCA and other inherited retinal conditions
AMRC	Association of Medical Research Charities
ATCCF	Does this need a definition?
BASIGIN-1 (BSG1)	A pivotal gene in the cone survival pathway
CAF	Charities Aid Foundation
cGMP	A molecule which can accumulate to toxic levels in LCA
CIO	Charitable Incorporated Organisation
CRISPR	Clustered Regularly Interspaced Short Palindromic Repeats
DNA	Deoxyribonucleic acid
ECLO	Eye Care Liaison Officer
EDI	Equality, diversity and inclusion
FRS	Financial Reporting Standard
GECIP	Genetics England Clinical Interpretation Partnership
hROs	Human stem cell-derived “retinal organoids”
IRD	Inherited Retinal Dystrophy
LCA	Leber’s Congenital Amaurosis
LCA4	Leber’s Congenital Amaurosis type 4 (caused by mutations in the AIPL1 gene
MAB	Medical Advisory Board
MBE	Member of the Order of the British Empire
NHS	National Health Service
PRPF31	A gene associated with IRDs
QTVI	Qualified Teacher of the Vision Impaired
RHD12	A gene associated with Inherited Retinal Dystrophies
RNA	Ribonucleic acid
RNIB	Royal National Institute of Blind People
RP	Retinitis pigmentosa
RPE	Retinal pigment epithelium
RPGR	A gene associated with IRDs
SOFA	Statement of Financial Activities
SORP	Statement of Recommended Practice
TPT	Thomas Pocklington Trust
UCL	University College London
UKIRDC	The UK Inherited Retinal Dystrophy Consortium
UKOA	UK Ophthalmology Alliance
USH2A	A gene associated with IRDs
VAT	Value Added Tax

RETINA UK

England & Wales - Charity number 1153851

Accounts

Retina UK

A Charitable Incorporated Organisation

Annual Report & Financial Statements

Year Ending 31 December 2023

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	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) Mr Ashley Grist (Treasurer) Mr Roger Backhouse Mrs Lynda Cantor MBE Dr Elizabeth Graham (also known by her legal name, Elizabeth Buckingham) Prof John Marshall MBE Mrs Rachael Stevens (until November 2023) Dr Lucy Withington Mr Simon Keightley Mr Paresh Makwana (until November 2023) Ms Vanessa Forster Mr Colin McArthur (from January 2024)
Ambassadors	Mrs Bhavini Makwana Mr Steven Bate MBE Mr Amar Latif Mrs Seema Flower (until November 2023) Mrs Victoria Claire (Until November 2023)
Chief Executive	Ms Tina Garvey
Principal Bankers	Lloyds Bank 30 Market Place Brackley NN13 7BA
Auditors	Azets Audit Services Epsilon House The Square Gloucester Business Park Gloucester GL3 4AD

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2023 saw a level of income that, whilst down on 2022, was considerably buoyed by strong legacy income. Total expenditure on medical research was £906,043 as the charity was able to finally restart substantial funding of research.

Fundraising will be a major focus for Retina UK in 2024 with the strengthening and expansion of the fundraising team that will allow us to accelerate our funding ambitions. To this end the team will focus on developing major donor, trust, and corporate sponsorship.

Our ongoing strategy review has already set a clear focus to drive research into cures and treatments of inherited retinal dystrophies. 2023 represented an excellent start to the process with the launch of three new PhD projects and three new project grants.

2023 also saw the charity share 16 opportunities for involvement with trials with our 500 strong Lived Experience Panel. The Retina UK team continued to deliver vital information and support to its community through a broad range of channels and initiatives.

We are indebted to our major donors and corporate supporters for their vital support throughout 2023. I wish to highlight the efforts of those who give regularly to the charity, and those that fundraise tirelessly through their own physical exploits and through the mobilisation of others who remain the core of our funding base.

I would like to recognise the very considerable achievements of all of the Retina UK staff team who have worked phenomenally hard to deliver on fundraising, on an expertly curated programme of research stewardship and on an impressive programme of information and support to the community.

I wish to thank our volunteers who have once again delivered great service to our community. I also wish to thank our ambassadors, our Trustees and the members of our Medical Advisory Board for so generously contributing their time to the work of Retina UK.

The membership of the Board of Trustees saw some changes at the end of 2023. Paresh Makwana and Rachel Stevens took a step back from their roles as Trustees to focus on activities outside of Retina UK. The Board of Trustees have shared their appreciation to Paresh and Rachel for their invaluable contributions and expressed a hope that they would be willing to return to the Board when circumstances allow. We also welcomed back a new, past Trustee, Colin McArthur, who previously served on the Trustee Board. Colin's nomination is presented for ratification by members at the 2024 AGM.

At the end of 2023 I personally took the decision not to continue at Chair of Trustees of Retina UK and initiated a process to attract and appoint a new Chair. The Board of Trustees were delighted that after an open call for candidates, Kathy Evans was selected by a panel of Trustees and accepted the invitation to join as the new Chair. Her nomination is also being put forward to members for ratification at the 2024 AGM. Kathy is a Chartered Accountant and law graduate and served for 19 years as the CEO of the Royal College of Ophthalmologists. We are confident that she will make an excellent Chair and wish her many years of success in her new role.

I wish to take this opportunity in my final contribution to the Annual Report to thank my fellow Trustees for their support and collaboration over recent years. I wish to extend my thanks to Tina and the staff team, volunteers, supporters, members, donors and representatives for making my term such a memorable and enjoyable one and to wish each and every one a successful future.

Dr Martin Kirkup
Chair of the Board of Trustees

The Trustees are pleased to present their annual report together with the financial statements of the charity for the year ending 31 December 2023. 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. However, the Board 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) and Visionary, and abides by each organisation’s principles of best practice at all times.

Related parties

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

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. Staff remuneration with regard to inflation is proposed by the Chief Executive and considered by the Remuneration Committee, on behalf of the Trustee Board.

Financial Review

2023 was a tough year, given the cost-of-living challenges and vacancies within the fundraising team, which are now filled.

Non-legacy, non-investment income generation for the year therefore closed at £697,139, about 22% lower than the level foreseen in the budget. However, both investment income (mainly interest) and legacy income were significantly higher than budget, £47,399 and £542,476 respectively.

Total income for the year therefore closed at £1,287,014, which, though higher than budget, is £275,618 down on 2022 due mostly to no major donor grant (within individual donations, and totalling £250,000 in 2022) and no government grants.

Non grant expenditure for the year ended at £887,758. In 2023, the charity’s grant expenditure totalled £712,656, versus £531,622 in 2022 as research funding continues to pick up following the pandemic years.

Retina UK had net assets of £1,527,959 at the end of December 2023 (net assets at end December 2022 were £2,036,626), which reflects lower income generation and higher expenditure on medical research.

The Charity had a cash balance of £1,457,460 at the year end with a further £600,000 placed on a 12-month fixed term deposit to make the most of interest at a rate of 3.6%. Of the cash balance, £978,639 was in a 32-day notice account to balance maximising interest with the ability to withdraw funds if required, and the balance held in current accounts for day-to-day activities.

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. 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 has slightly changed; by the year end, we no longer held equities. For any funds surplus to short term requirements, we have placed secure deposits on fixed terms of up to one year.

The charity held equities in a CAF Balanced Growth Fund until June 2023 when CAF closed the fund. We do not plan to invest in further equities at this time, 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 and subsequent cost-of living challenges 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. We continued to operate the charity on a sustainable basis.

Whilst planning for 2024 and beyond is focussing on increasing charitable impact, 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 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 £17 million into cutting-edge research since we were founded in 1976 and we are determined to build on the progress made to date.

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 awarded three new project grants in 2023.

Our Annual and Professionals' Conferences went ahead as hybrid events once again and we plan to follow the same format in 2024 when we hold the Conferences in Manchester. Our webinar series continues to be popular and will continue in 2024 with a wide range of topics.

We will continue to enhance the tailored practical and emotional support we provide for our community so that they can make informed choices. We will focus on increasing referrals from professionals so that everyone affected by inherited sight loss can live their best lives.

We will again provide direct employment opportunities for those with inherited sight loss by employing a Research Intern and a Development Team Intern with lived experience.

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 feels 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 that 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 2023.

The UK Inherited Retinal Dystrophy Consortium (UKIRDC)
Started 2014 / Ends 2024

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 ten other genes.

Consortium members also contributed to a 2020 publication describing a brand-new disease mechanism involving structural changes to chromosome 17, and identified heterozygous deletion of an entire gene as the cause of late onset macular dystrophy in eight families.

As the original grant approached its end in 2020, 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 IRDs and has solved one third of these previously intractable cases, providing families with better understanding of their condition and opening up choices. By communicating their results through meetings and more than 35 publications, the team has also helped clinicians across the globe to interpret the genomes of those living with inherited sight loss. 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 Gene Team Project
Started 2011 / Ended 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's work has led to the instigation of four early phase clinical trials, supported by MeiraGTx. One further therapy is also under consideration for clinical testing. The researchers have also treated several infants with a rare form of LCA under a special licence.

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 and characterising this particular type of retinal disease in cells and mice and starting to assess the viability of an IMPG2 gene therapy vector. The researchers have demonstrated that this therapy can improve photoreceptor structure in a mouse model, although there was minimal impact on visual function, perhaps due to challenges with replicating human phenotype in the mice used. A new CRISPR-based model may prove more useful.

The team has also conducted an in-depth study of the IMPG2 disease phenotype in five people living with the condition, which will help inform future clinical trials and development of disease models.

Development of CRISPR gene therapy for Stargardt disease
Started 2020 / Ends 2024

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 has made good progress, 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 were used to test and optimise various CRISPR constructs the student designed, with some constructs successfully correcting the code and enabling production of full length, healthy ABCA4 protein. This provided proof of concept, but there have been some challenges with off-target effects. Attempts to resolve these will be a key part of the final months of the project.

Establishing AAV.PRPF31 gene augmentation in PRPF31-deficient RPE and photoreceptor cells and assess its efficacy in restoring RPE and photoreceptor function
Started 2022 / Ends 2025

This project, led by Prof Majlinda Lako at Newcastle University, follows on from an earlier Retina UK-funded study of defects in the PRPF31 gene, which plays a key role in “editing” the genetic code during protein construction. Prof Lako and colleagues will now look into the development of a gene replacement therapy to overcome the effects of faulty PRPF31, using cutting-edge techniques to explore the impact of the therapy on cell-based models of PRPF31 disease. This will provide important proof of concept data as a first step towards treatment.

During the first year of the project, Prof Lako and her team have optimised their gene therapy vector at various doses in retinal pigment epithelial cells, and have moved onto testing in retinal organoids derived from the cells of individuals living with PRPF31-related RP.

Generation and transplantation of hypoimmunogenic pluripotent stem cell derived photoreceptor precursors into a mouse model of advanced retinal degeneration: a proof-of-concept study for USH2A and RP treatment
Started 2023 / Ends 2026

Thanks to a generous commitment from the AT Capital Charitable Foundation, Retina UK was able to conduct an additional grant round in 2022. The foundation committed to fully funding one project that would be relevant to the treatment of sight loss associated with mutations in the USH2A gene, and this project was successful after the usual peer review process.

Mutations in the *USH2A* gene cause Usher syndrome type 2 (USH2A), characterised by early bilateral hearing impairment and later onset of night blindness and visual loss. USH2A is the most common cause of deaf-blindness and the most frequent form of recessive Retinitis Pigmentosa (RP). The *USH2A* mutation spectrum is heterogeneous; moreover, the *USH2A* gene is too large to be packaged into gene therapy vectors.

A type of stem cells named “pluripotent” has shown promising outcomes with respect to generation of rods and cones, which transform light into electrical signals that can be processed by the brain. Pluripotent stem cells can be generated from each patient and guided to give rise to rods and cones; however, this process is time- and cost-demanding and does not allow for immediate availability of off-the-shelf ready-made cells for transplantation. Prof Lako’s proposed approach is to make the pluripotent stem cells invisible to the patient’s immune system (so called hypoimmunogenic) and then differentiate them into rods and cones, to be safely transplanted into anyone with RP (including RP caused by USH2A mutations) without the risk of immune rejection.

The researchers believe that this gene-agnostic hypoimmunogenic photoreceptor transplantation approach has far-reaching impact as it could benefit a large proportion of the RP community.

Deciphering RPGR’s role in cone-mediated disc formation
Started 2023 / Ends 2026

Retina UK and the Macular Society are co-funding this PhD studentship, supervised by Dr Roly Megaw at Edinburgh University.

The PhD student will investigate how particular mutations in the RPGR gene impact cone photoreceptors. Different mutations in RPGR can cause either Retinitis Pigmentosa (which first affects the peripheral ‘rod’ photoreceptors and therefore our visual field and night vision) or a Cone Rod Dystrophy (which first affects the macular ‘cone’ photoreceptors and therefore our central vision). Currently we don’t know why these different mutations cause different symptoms.
Using cutting edge techniques in collaboration with scientists in Geneva, the proposed project will mimic macular disease and investigate the mechanisms underlying cone damage. Finding out why different RPGR mutations cause different diseases could help identify future treatments, and could even provide a springboard for preventative therapies.

Investigating Stargardt disease as a prime target for gene repair
Started 2023 / Ends 2026

This PhD studentship project, co-funded by Retina UK and the Macular Society, is being supervised by Prof Jacqueline van der Spuy at UCL’s Institute of Ophthalmology.

Prime editing is a cutting-edge technology in which a disease-causing genetic change is precisely and permanently repaired in an individual’s genetic code, restoring the normal function of the gene. In this study, the student will investigate whether prime editing can efficiently correct one of the most common genetic changes causing Stargardt disease. By establishing methods for safely and precisely editing these particular faults, the project could contribute to the subsequent application of the technique across a huge range of conditions, transforming future treatments for a wide proportion of those living with inherited sight loss.

Further projects approved during 2023

Further to recommendations from our Medical Advisory Board, in late 2023 Retina UK Trustees approved funding of one further co-funded PhD studentship worth £120k, and three project grants worth £870k in total. All of these will start in 2024.

Community engagement with research

During 2023, we continued our efforts to promote engagement between members of our community, researchers and industry.

We shared 16 participation opportunities to our Lived Experience Panel, which now has around 500 members. These opportunities included clinical research studies for those with a particular genetic diagnosis, lived experience surveys in support of pre-implantation genetic testing license applications, presenting at a pharmaceutical company staff meeting, and a survey on attitudes to retinal implants, amongst others.

We also continued to keep our community updated on research progress via three webinars, including “Ask The Experts” sessions, two research podcasts, features in each edition of the Look Forward newsletter, and research sessions at both our Annual and Professionals’ Conferences.

Bringing treatments to the clinic

Securing NHS availability for new therapies is the essential final step in enabling those living with IRDs to access life-changing treatment. We held an industry round table event in 2022 which identified the lack of accessible patient data to be a key barrier to market access. In late 2023, Retina UK initiated a consultation to investigate the potential for a UK-based IRD registry to meet the needs of researchers, industry and community.

Information and support

Our new website was launched in early June 2023. Feedback has been very positive, with information much easier to find. Particular areas to highlight include the new Resources section, where content can be filtered to find audio, video and written information. We also now have an event calendar which can be filtered based on the type, distance, location.

We were pleased to secure funding for a nine-month Communications Intern through the Thomas Pocklington Trust (TPT) Get Set Progress scheme. This scheme is designed for people living with sight loss to jump start their career and included support through TPT with their CV, interview techniques and more. Our Intern joined us from February to November 2023. She was a great asset to the charity and as a result of such a positive experience, and thanks to continued support from TPT, we have appointed two Interns in 2024.

Conferences

We were delighted to deliver our Annual Conference and Professionals’ Conference in a hybrid format in 2023.

The majority of our speakers were able to be with us live in London. More than 420 delegates registered to attend the Annual Conference; over 330 registered for the Professionals' Conference, which included CPD accreditation.

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 hybrid nature of the AGM offered members the opportunity to ask questions.

We will offer a hybrid option for our conferences again in 2024, 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.

Webinars

We delivered a popular series of monthly webinars (online via Zoom) throughout 2023 on a number of topics. Recordings of the webinars were made available on our YouTube channel and our Podcast channel (audio only).

	Registrations	YouTube (to date 7/2/24)	Podcasts (to date 10/1/24
Harnessing the power of AI	48	474	87
Support through Access to Work – a World Sight Day special	43	90	94
Ask the Expert with Samantha de Silva	57	141	55
Hair care and styling with Anna Cofone	47	156	55
Getting involved with Retina UK, the value of volunteering	4	42	77
Low vision services, aids and equipment	42	139	49
Ask the expert with Simon Keightley	43	116	57
Supporting Retina UK and what it can do for you	4	70	54

Podcast channel

Our podcast channel on Spotify had 3,067 listens in 2023. This is a more than 75% increase on 2022 (1,749 listens). Our content is syndicated across nine platforms, which include Spotify, Apple podcasts and Google podcasts.

YouTube channel

Our YouTube channel saw significant increases in engagement as follows:

- Subscribers +65%
- Views +99%
- Watch time +64%

Our click through rate from impressions decreased slightly to 3.7% (from 4.4%).

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 2023.

A total of 21,777 copies of Look Forward were distributed and 29,338 copies of the e-Newsletter.

We worked collaboratively with VICTA with a guest feature in our Spring 2023 edition.

Eye Care Support Pathway (ECSP)

We worked with sector partners to develop an Eye Care Support Pathway, endorsed by more than 20 organisations and professional bodies, including the Clinical Council for Eye Health Commissioning. The Pathway is a new framework to ensure patients have timely access to information, advice and support throughout their eye care journey.

Working with the professional community – phase one

We conducted a survey and focus groups with members of the professional community in the last quarter of 2023 to:

- Map out all the professionals who interact with our community.
- Understand how and when those interactions occur.
- Establish which professionals we should target to achieve the greatest impact.
- Understand how they enter their profession and how they access training.
- Identify any professional bodies they belong to.
- Understand the barriers which currently prevent referrals or signposting to Retina UK.
- Establish what we can offer to each category of professional that will add value from their perspective.
- Identify how we can reach them most effectively, and what materials or resources we may need to create.
- Establish a clear referral process which can be monitored and evaluated.

The results of this scoping exercise will inform phase two of the project (in 2024) which aims to increase the level of awareness amongst health and social care professionals of the information and support that Retina UK provides and increase referrals to the charity.

Campaigning, influencing and policy

During the last quarter of 2023 we started work on a strategy to set out how Retina UK best understands and evidences the views and needs of the inherited sight loss community and how we use this insight to bring about positive change to their lives. Including, but not limited to, how we:

- Create momentum in the delivery of treatments and therapies from clinical trials to clinic
- Effectively campaign and influence to bring about improvements in health and social care
- Ensure the needs of those affected by inherited sight loss are recognised and understood by wider society.

Delivering training to professionals

We were invited to deliver information and training to professionals in 2023, including:

- Discover Wellbeing webinar for Visionary
- In-person session at the Visionary Conference
- Rehabilitation Workers Professional Network Study Day
- VICSP Meeting Retina UK Showcase

We will continue to deliver sessions in 2024, including a session to QTVIs in February.

Local Peer Support

The Local Peer Support Group network has once again seen a positive growth over the past year, as a result of our focus on expansion.

In 2023 we increased the number of active peer support groups from 16 to 21. This includes three new local groups and two new online focus groups.

- A total of 81 peer group meetings, both online and in-person were held. An increase of 37% on 2022.
- There were 1,027 total registrations - a 79% increase on 2022.

Two new national groups were launched in 2023:

- ‘Talking’ Tech had five meetings. We have seen returning members and attracted new attendees both community and professional alike.

- Gents Support Group - This group had a successful launch as part of Befriending Week and Men’s Mental Health Awareness Month and, although it was only a soft roll out to a small number of our male community, it had a positive response and we will focus on continued growth next year.

We are, as always, grateful to the new and existing volunteers who facilitate our local groups.

Helpline

Calls to the helpline this year have decreased again, this year by 32% and are now 18% lower than pre-pandemic levels of 2019.

July was the only month that saw a significant number of calls. This often occurs in the month following the conference as we are at the forefront of both the community and professionals’ minds. August, however, was the lowest number of calls received since 2014. April, June and December were also quiet.

We received a total of 639 calls in 2023.

Email enquiries are down slightly on last year at 230, a 5% decrease.

A review of the helpline was undertaken in 2022 / 23 and proposed improvements to increase use and consistency of the service will be implemented in 2024.

From the information recorded the subject matters are as follows:

	Telephone	**Email**
Daily living (inc mobility and tech)	21.4%	10.1%
Emotional support	20.1%	-
Information about their condition	15.3%	20.5%
Medical information	12.7%	-
Genetic testing and counselling	10.9%	8.3%
Research	10.5%	22.3%
Benefits and employment	9.2%	3.9%
The Charity (joining, volunteering, collaboration etc.)	-	9.5%
Retina UK services	-	24.5%

Given the reduction in call numbers specifically to the helpline, there is a need to ensure that we are promoting the number in the appropriate places to ensure those that need us know how to reach us.

As we implement the new proposals, we will also be increasing our marketing of this valuable service including with professionals supporting those with inherited sight loss.

Talk and Support

During 2023, the Talk & Support (T&S) service had 14 volunteers who supported 27 active service users.

We also trained four new volunteers who have been matched with a number of service users.

This saw the service increase its volunteers by 27% and service users by 28%.

During the year we saw more cross over engagement with many of those being supported, actively taking part in other services and activities, such as online local groups.

This service has also evolved to support individuals with a wider range of inherited retinal dystrophies and specific conditions, such as Charles Bonnet Syndrome (CBS). We have two further volunteers who specifically support this initiative, both with lived experience of CBS. During 2023, they supported five people experiencing this condition.

Retina UK has been invited to the Charles Bonnet Information Day being held in Manchester in March 2024. This will be a good opportunity to raise the profile of the service we offer to people living with inherited, progressive sight loss.

Volunteers

In 2023 we welcomed eight new volunteers into our Information and Support volunteer team, in roles in our Talk & Support service and Local Group Network. We provided regular online meetings for both training and social opportunities to the team and 23 volunteers attended our face-to-face training event.

We also produced our first Volunteer Impact Report in 2023.

Fundraising

As we reflect on the past 12 months it remains a challenging environment for third sector fundraising, with the continued cost of living crisis, and other macroeconomic challenges. With the departure of the previous Head of Fundraising (HoF) in December 2022, the subsequent 12 months witnessed a significant turnover of Fundraising (FR) staff. To navigate this transitional phase, the workload was distributed among existing team members.

James Clarke, Community and Events Manager joined in May 2023 and Clare Bailey, Fundraising Administrator, August 2023.

Head of Fundraising, Jo Faulkner-Harvey joined the team in September.

Upon joining, the staffing landscape revealed key vacancies across critical areas:

- Trusts & Foundations (from October 2023),
- Corporate, and Individual Giving – encompassing Major Donors, Legacies, In memory donations, and Regular Giving.

Further recruitment means in 2024 fundraising will once again be a fully functioning team of five.

We ran another successful Big Give Christmas campaign, which saw us hit our target within four days – raising £58,323 in total, smashing the target. This is most we have ever raised via the match-funded campaign.

2023 also saw continued growth in fundraising from challenge events. Income was enhanced by £41,293 raised by Team Finlay for the Bristol Half Marathon in 2024 in memory of Finlay McNicol.

There were signs of recovery in certain income streams although it is still early days in an unpredictable market. 2023 experienced the highest Regular Giving income since 2014 according to organisational trends with a 6.45% growth. Single individual donations saw an 86% growth, returning to pre-Covid levels.

More of our supporters took on fundraising in their community this year (67 people vs 52 in 2022). It's crucial for engagement in community fundraising to remain adaptable, stay connected with our supporters, and assess the evolving needs of our communities. Open communication, transparency in fundraising activities, and a focus on demonstrating the impact of donations will contribute to rebuilding and sustaining community support. Whether they return to pre-Covid levels remains to be seen, more likely in a different format.

Despite the challenges faced, the fundraising efforts concluded the year with an admirable outcome, with a shortfall against the annual target. The resilience demonstrated in fundraising reflects the dedication and adaptability of the team in navigating the hurdles encountered throughout the year.

Membership remained at a constant level during the year. A review and relaunch are planned for 2024.

As we reflect on the challenges and triumphs of the past year, the FR Team look forward to the positive impact and growth that the new team can bring to Retina UK in the upcoming year and beyond.

Highlights for 2024 include:

- The launch of the Retina UK Lottery
- Major Donor Event with the support of the Board of Trustees
- Launch of a Legacy Program and event
- Corporate Partnerships Retina UK awards
- A Thank-a-thon
- 2 Big Give Campaigns
- “On the couch” with Fundraising Podcasts

All fundraising in 2023 was carried out by Retina UK 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 2023. 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 2023.

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 2023 we were grateful to receive the following support:

Janssen	£10,000 to support our Annual and Professionals’ Conferences £36,596 sponsorship of our *Look Forward* newsletter £10,000 market access

Trusts and Foundations

We would like to thank the following trusts and foundations for their generous support of our work in 2023. 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 G W Cadbury Charitable Trust
- G C Gibson Charitable Trust
- Tom and Thelma Wilson Trust
- G S Plaut Charitable Trust

- David Killick Trust
- Hospital Saturday Fund
- The Albert Van Den Bergh Charitable Trust
- Sir Samuel Scott of Yews Trust
- The Champniss Charitable Trust
- The D'Oyly Carte Charitable Trust
- The Samuel Storey Family Charitable Trust
- Robert Luff Foundation Limited
- Tennant Southpark Charitable Trust
- The Edgar E Lawley Foundation
- The Frognal Trust
- The Doris Field Charitable Trust
- Cecil Pilkington Charitable Trust
- The Coln Trust
- The William Leech Charity
- Lillie Johnson Charitable Trust
- Christos Lazari Foundation
- Gilbert Edgar Trust
- James Ellis Charitable Trust
- Girdlers' Company Charitable Trust
- Astor Foundation
- The Alan Brentnall Charitable Trust
- The Frederick Arthur Alford Charitable Trust
- Hasluck Charitable Trust
- The Barbour Foundation
- The David Fryer Charitable Trust
- The Stella Symons Charitable Trust
- BE Rodmell Trust
- Jack Petchey Foundation
- Robert and Margaret Moss Charitable Trust
- The Ardwick Trust

Retina UK

Statement of Trustees' Responsibilities

For the year ending 31 December 2023

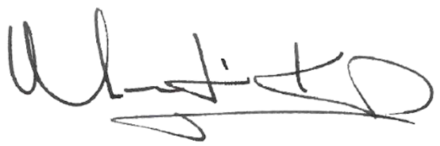
The Trustees are responsible for preparing the Trustees' annual report and financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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
16 July 2024

We have audited the financial statements of Retina UK (the 'charity') for the period ended 31 December 2023 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 2023 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;

- 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

24 July 2024

Chartered Accountants
Statutory Auditor

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.

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £	Total Funds 2022 £
INCOME FROM:					
Donations & legacies	**3**	939,937	239,678	**1,179,615**	1,350,667
Charitable activities					
Grants	**4**	-	60,000	**60,000**	205,309
Investments	**5**	47,399	-	**47,399**	6,656
Total income		**987,336**	**299,678**	**1,287,014**	1,562,632
EXPENDITURE ON:					
Raising funds	**6**	(299,690)	-	**(299,690)**	(295,948)
Charitable activities					
Medical Research	**7**	(496,690)	(409,353)	**(906,043)**	(624,853)
Information & Support	**8**	(515,337)	(72,731)	**(588,068)**	(615,141)
Total expenditure		**(1,311,717)**	**(482,084)**	**(1,793,801)**	(1,535,942)
Net losses on investments		(1,880)	-	**(1,880)**	(13,406)
Net movement in funds	**9**	**(326,261)**	**(182,406)**	**(508,667)**	13,284
Funds at 1 January 2023	**21/23**	**1,331,703**	**704,923**	**2,036,626**	2,023,342
Funds at 31 December 2023	**21/23**	**1,005,442**	**522,517**	**1,527,959**	2,036,626

Retina UK

Balance Sheet

For the year ending 31 December 2023

	Note	2023 £	2022 £
FIXED ASSETS			
Tangible fixed assets	**13**	**8,386**	4,736
Investments	**14**	**275**	262,336
Total fixed assets		**8,661**	267,072
CURRENT ASSETS			
Debtors: Amounts falling due within 1 year	**15**	**352,927**	631,930
Current asset investments	**16**	**600,000**	600,000
Cash at bank and in hand	**17**	**1,457,460**	931,940
Total current assets		**2,410,387**	2,163,870
LIABILITIES			
Creditors: Amounts due within 1 year	**18**	**(891,089)**	(394,316)
Net current assets		**1,519,298**	1,769,554
Net assets		**1,527,959**	2,036,626
FUNDS			
Unrestricted	**21**	**1,005,442**	1,331,703
Restricted	**23**	**522,517**	704,923
Total funds		**1,527,959**	2,036,626

Ashley Gri

A Grist
Treasurer
Date: 16 July 2024

Dr M Kirkup
Chair
Date: 16 July 2024

Cash Flow Statement

For the year ending 31 December 2023

Cash flows from operating activities:	**Note**	**2023 £**	**2022 £**
Net (expenditure)/income for the reporting period		**(508,667)**	13,284
Adjustments for:			
Depreciation charges	**13**	**4,237**	3,678
Losses on investments	**14**	**1,880**	13,406
Dividends and interest from investments	**5**	**(47,399)**	(6,656)
Decrease in debtors	**15**	**279,003**	293,129
Increase/(decrease) in creditors	**18**	**24,973**	(11,910)
Increase/(decrease) in grant creditors	**18**	**471,800**	(99,713)
Net cash from operating activities		**225,827**	205,218
Cash flows from investing activities:			
Dividends and interest from investments	**5**	**47,399**	6,656
Purchase of tangible fixed assets	**13**	**(7,887)**	(2,078)
Proceeds of disposal of investments	**14**	**260,181**	-
Cash on fixed term deposit	**16**	**-**	(600,000)
Cash flows from investing activities		**299,693**	(595,422)
Change in cash and cash equivalents in the year		**525,520**	(390,204)
Cash and cash equivalents at 1 January 2023	**17**	**931,940**	1,322,144
Cash and cash equivalents at 31 December 2023	**17**	**1,457,460**	931,940

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 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

	2023	2022
	£	£
Membership subscriptions/donations	**28,474**	30,667
Individual donations	**101,882**	338,101
Trusts	**140,760**	111,944
Corporate	**65,769**	91,175
Legacies/In memoriam	**542,476**	535,255
Fundraising	**192,005**	140,892
Prize draw/appeals/mailings	**57,145**	64,933
Gift aid	**51,104**	37,700
Total	**1,179,615**	1,350,667

4. Grants

	2023	2022
	£	£
Medical research funding	**60,000**	60,010
Government grants	**-**	145,299
Total	**60,000**	205,309

There were no government grants received in 2023 (in 2022, these comprise amounts from UK Government COVID Medical Research Charity Support Fund (£145,299)).

5. Investments

	2023	2022
	£	£
Share dividends	**11,225**	2,190
Bank interest	**36,174**	4,466
Total	**47,399**	6,656

6. Raising funds

	2023	2022
	£	£
Event costs	**15,777**	23,399
Materials and equipment	**168**	211
Collection fees	**9,382**	6,942
Appeals	**4,182**	8,684
Training and conferences	**200**	482
Donor development including trusts & corporates	**1,528**	3,331
Gift aid	**-**	1,293
Other	**4,139**	1,242
Support costs (see note 10)	**264,314**	250,364
Total	**299,690**	295,948

7. Medical research

	2023	2022
	£	£
Annual grant awards	**712,656**	402,702
Grant donation for medical research	**-**	128,920
Support costs (see note 10)	**193,387**	93,231
Total	**906,043**	624,853

There were no grant donations in 2023 (in 2022, a grant donation of £128,920 was made from our restricted RDH12 Fund to the charity ' Eyes on the Future' to fund relevant research as we had not been able to identify a suitable project to fund directly with remaining funds).

8. Information & Support

	2023	2022
	£	£
Publications, DVDs, leaflets	**20,682**	20,819
Annual conference	**30,551**	32,996
Helpline support	**8,281**	13,735
Information events	**3,633**	7,005
Non-medical research/projects	**14,093**	12,767
Travel expenses	**8,028**	7,029
Website development	**5,040**	49,439
Sight loss survey	**-**	12,056
Volunteering	**8,786**	7,912
Other	**4,023**	6,825
Support costs (see note 10)	**484,951**	444,558
Total	**588,068**	615,141

9. Net movement in funds is stated after charging

	2023	2022
	£	£
Auditor's remuneration (audit)	**11,500**	10,860
Depreciation	**4,237**	3,678
Trustees’ expenses	**2,389**	1,529
Lease payments	**52,500**	16,542

Trustees' expenses, incurred on travel and accessibility support, represent amounts reimbursed to one Trustee for expenses incurred (2022: 1).

No Trustee received any remuneration during the year (2022: none).

10. Analysis of support costs

	Total	**Fundraising**	**Research**	**Information & Support**	**Basis of apportionment**
	£	**£**	**£**	**£**	
Office administration	204,113	61,234	67,357	75,522	Staff time or actual
Remuneration	687,629	187,807	109,230	390,592	Staff time or actual
Governance	50,910	15,273	16,800	18,837	Staff time or actual
Total	**942,652**	**264,314**	**193,387**	**484,951**	
Governance costs in 2022	46,347	13,904	4,635	27,808	

11. Staff numbers and costs

	2023	2022
	£	£
Wages and salaries	**647,124**	609,287
Social Security costs	**59,218**	57,138
Pension costs	**17,743**	18,434
Total	**724,085**	684,859

The number of persons employed by the charity during the year was 20 (2022: 20).

Total remuneration for key management personnel in the year was £171,062 (2022: £96,828).
The number of employees with remuneration (excluding employer pension contributions) between:
£60,000 and £70,000 was 1 (2022: 0);
£70,000 and £80,000 was 0 (2022: 0);
£80,000 and £90,000 was 0 (2022: 0);
£90,000 and £100,000 was 1 (2022: 1).

12. Comparative information for Statement of Financial Activities

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
INCOME FROM:				
Donations & legacies	**3**	868,167	482,500	**1,350,667**
Charitable activities				
Grants	**4**	-	205,309	**205,309**
Investments	**5**	6,656	-	**6,656**
Total income		**874,823**	**687,809**	**1,562,632**
EXPENDITURE ON:				
Raising funds	**6**	(287,018)	(8,930)	**(295,948)**
Charitable activities				
Medical Research	**7**	(233,860)	(390,993)	**(624,853)**
Information & Support	**8**	(508,397)	(106,744)	**(615,141)**
Total expenditure		**(1,029,275)**	**(506,667)**	**(1,535,942)**
Net losses on investments		(13,406)	-	**(13,406)**
Net movement in funds	**9**	**(167,858)**	**181,142**	**13,284**
Funds at 1 January 2022	**22/24**	**1,499,561**	**523,781**	**2,023,342**
Funds at 31 December 2022	**22/24**	**1,331,703**	**704,923**	**2,036,626**

13. Tangible fixed assets

	Office Equipment £
Cost	
At 1 January 2023	**24,671**
Disposals	**(11,014)**
Additions	**7,887**
At 31 December 2023	**21,544**
Depreciation	
At 1 January 2023	**19,935**
Disposals	**(11,014)**
Charge for year	**4,237**
At 31 December 2023	**13,158**
Net book value	
At 31 December 2023	**8,386**
At 31 December 2022	**4,736**

14. Investments

	2023 £	2022 £
At 1 January 2023	**262,336**	275,742
Disposals	**(262,061)**	-
Unrealised loss	**-**	(13,406)
As at 31 December 2023	**275**	262,336

	2023 £	2022 £
Included within investments are the following:		
CAF balanced growth fund at valuation	**-**	262,061
Shares in Taylor Woodrow	**275**	275
	275	262,336

All investments are held in the UK.

15. Debtors: Amounts falling due within one year

	2023 £	2022 £
Accrued income	**343,812**	610,854
Trade debtors	**-**	5,246
Prepayments	**9,115**	15,830
Total	**352,927**	**631,930**

16. Current asset investments

	2023 £	2022 £
Cash on fixed term deposit	**600,000**	600,000
Total	**600,000**	600,000

Fixed term deposit of £600,000 for one year ending 16 October 2024 at an interest rate of 3.6%.

17. Analysis of cash and cash equivalents

	2023 £	2022 £
Cash at bank and in hand	**1,457,460**	931,940
Total	**1,457,460**	931,940

18. Creditors: Amounts falling due within one year

	2023 £	2022 £
Trade creditors	**15,009**	6,658
Tax and social security	**15,938**	14,573
Accruals and deferred income	**48,713**	33,671
Grant liability	**809,912**	338,112
Other creditors	**1,517**	1,302
Total	**891,089**	394,316

19. Contingent assets & liabilities

There is a contingent liability of £1,020,116 at 31 December 2023 (2022: £488,745) in respect of research grants authorised subject to annual review, falling due in years 2024 onwards

20. Financial commitments

	2023	2022
	£	£
Total future minimum lease payments under non-cancellable operating leases are as follows:		
< 1 year	**2,884**	15,412
1 - 5 years	**10,278**	35,236

At 31 December 2023, there was a rent commitment under licence totalling £18,036, due by the end of June 2024 (2022: £nil).

21. Unrestricted Funds

	1 Jan 2023 £	Income £	Expenditure £	Transfers £	Loss on investment £	31 Dec 2023 £
General Fund	1,028,400	987,336	(1,008,414)	(723,976)	(1,880)	**281,466**
Designated Research Fund	303,303	-	(303,303)	723,976	-	**723,976**
Total Unrestricted Funds	**1,331,703**	**987,336**	**(1,311,717)**	**-**	**(1,880)**	**1,005,442**

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

22. Comparative information of Unrestricted Funds movement at 31 December 2022

	1 Jan 2022 £	Income £	Expenditure £	Transfers £	Loss on investment £	31 Dec 2022 £
General Fund	1,229,549	874,823	(888,645)	(173,921)	(13,406)	**1,028,400**
Designated Research Fund	270,012	-	(140,630)	173,921	-	**303,303**
Total Unrestricted Funds	**1,499,561**	**874,823**	**(1,029,275)**	**-**	**(13,406)**	**1,331,703**

23. Restricted Funds

	1 Jan 2023 £	Income £	Expenditure £	Transfers £	31 Dec 2023 £
Research Fund	430,676	118,918	(214,283)	7,498	**342,809**
Specified Research Fund	96,719	44,700	(135,021)	(6,398)	**-**
ATCCF Fund	166,441	-	-	-	**166,441**
Macular Research Fund	50	60,000	(60,050)	-	**-**
Information & Support Fund	3,999	76,060	(70,500)	-	**9,559**
Specified Project Fund	2,230	-	(2,230)	-	**-**
Awards Fund	1,150	-	-	-	**1,150**
Scottish Fund	2,558	-	-	-	**2,558**
Pioneering Research Fund	1,100	-	-	(1,100)	**-**
Total Restricted Funds	**704,923**	**299,678**	**(482,084)**	**-**	**522,517**

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

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

ATCFF Fund: This is funded by a major donor grant and is for a specific research project on USH2A.

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

Information & Support Fund: This fund is made up of specific donations for Information & Support. In 2022, specific projects funded include the helpline and volunteer training, Look Forward, our Professionals' and Annual Conferences and some funding towards our Professionals Project.

Specified Project Fund: This fund contains funding for specific projects. In 2022, this was for Unlock Genetics.

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

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

Pioneering Research Fund: This fund is to support a dedicated centre for inherited retinal dystrophy research.

24. Comparative information of Restricted Funds movement at 31 December 2022

	1 Jan 2022 £	Income £	Expenditure £	31 Dec 2022 £
Research Fund	246,882	266,777	(82,983)	**430,676**
Specified Research Fund	120,264	77,415	(100,960)	**96,719**
ATCCF Fund	-	249,944	(83,503)	**166,441**
Macular Research Fund	-	50	-	**50**
Information & Support Fund	23,339	84,859	(104,199)	**3,999**
RDH12 Fund	123,438	109	(123,547)	**-**
CJ Legacy Fund	-	8,930	(8,930)	**-**
Usher Fund	2,820	(275)	(2,545)	**-**
Specified Project Fund	2,230	-	-	**2,230**
Awards Fund	1,150	-	-	**1,150**
Scottish Fund	2,558	-	-	**2,558**
Pioneering Research Fund	1,100	-	-	**1,100**
Total Restricted Funds	**523,781**	**687,809**	**(506,667)**	**704,923**

In addition to the funds disclosed above, the following had nil balances from the end of 2022 and are no longer in use:

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

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

Usher Fund: These donations were specifically allocated by the donors to support Usher Syndrome-related research and activities for those with Usher Syndrome.

25. Analysis of net assets between funds

	Tangible Fixed Assets	Fixed Asset Investments	Current Assets	Current Liabilities	Total
	£	£	£	£	£
Restricted Funds	-	-	792,672	(270,155)	**522,517**
Unrestricted Funds	8,386	275	1,617,715	(620,934)	**1,005,442**
	8,386	**275**	**2,410,387**	**(891,089)**	**1,527,959**

26. Comparative analysis of net assets between funds 2022

	Tangible Fixed Assets	Fixed Asset Investment	Current Assets	Current Liabilities	Total
	£	£	£	£	£
Restricted Funds	-	-	857,714	(152,791)	704,923
Unrestricted Funds	4,736	262,336	1,306,156	(241,525)	1,331,703
	4,736	262,336	2,163,870	(394,316)	2,036,626

27. Grants awarded

Institution		Grant Holder	Amount £
UK Inherited Retinal Dystrophy Consortium	GR586A	*	68,090
University of Oxford	GR599	Prof R MacLaren	53,430
Newcastle University	GR601	Prof M Lako	125,320
Moorfields Eye Hospital	GR603	Prof O Mahroo	41,932
UCL Institute of Ophthalmology	GR604	Prof J van der Spuy	38,300
University of Edinburgh	GR605	Dr R Megaw	59,564
University of Southampton	GR606	Dr J Lakowski	79,868
UCL Institute of Ophthalmology	GR607	Prof J Sowden	148,732
UCL Institute of Ophthalmology	GR609	Prof J van der Spuy	97,420
Total			**712,656**
Opening creditor for grant commitment			338,112
Grant payments			(240,856)
Closing creditor for grant commitment			**809,912**

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

28. Related party transactions

There are no related party transactions requiring disclosure in the Financial Statements (2022: none) other than those relating to Trustees’ expenses disclosed in note 9.

Accounts

Retina UK

A Charitable Incorporated Organisation

Annual Report & Financial Statements

Year Ending 31 December 2022

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) Mr Ashley Grist (appointed 26 January 2022; Treasurer from 22 June 2022) Ms Janet Crookes (Treasurer until 22 June 2022) Mr Roger Backhouse Mrs Lynda Cantor MBE Dr Elizabeth Graham Prof John Marshall MBE Mrs Rachael Stevens Dr Lucy Withington Mr Simon Keightley (appointed 26 January 2022) Mr Paresh Makwana (appointed 26 January 2022) Ms Vanessa Forster (appointed 26 January 2022)
Ambassadors	Mrs Bhavini Makwana Mr Steven Bate MBE Mr Amar Latif Mrs Seema Flower Mrs Victoria Claire
Chief Executive	Ms Tina Garvey
Principal Bankers	Lloyds Bank 30 Market Place Brackley NN13 7BA
Auditors	Azets Audit Services Epsilon House The Square Gloucester Business Park Gloucester GL3 4AD

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

As was the case last year, 2022 saw little change with regard to the immense challenges associated with fundraising in a continuing adverse economic climate. Non-legacy income for the year was £815,412, lifted to £1,562,632 thanks to significant legacy income and a major donor grant. This was against expenditure of £1,535,942, of which £624,853 was for medical research (versus £163,051 in 2021).

We never lose sight of the fact that the very same economic conditions that affect our ability to raise funds, also places additional stress on the community we serve.

Therefore, we, at Retina UK, have once again raised our game in supporting the wellbeing of our community, increasing accessibility to support and information. The number of innovations that have been introduced to support our community are legion. Of particular note in 2022 was the launch of the webinar series which is proving particularly popular.

In 2022 we re-energised our research funding with total grant expenditure being five times higher than in 2021. Our net assets are little changed from 2021 offering substantial potential for driving forward an exciting programme of research going into 2023.

During 2022, applications were invited for a number of research grants to be awarded in 2023 for which we have received 15 preliminary submissions.

2022 saw the launch of a new study by Prof Majilinda Lako at Newcastle University of the efficacy of restoring RPE and photoreceptor function. Prof Lako will also lead a project funded by a generous commitment from AT Capital Charitable Foundation to investigate the development of a hypoimmunogenic cell-based therapy starting in 2023.

The UK Inherited Retinal Dystrophy Consortium (UKIRDC) grant concludes in 2023. Retina UK is the lead funder of the project and the Consortium has played an important role in advancing our knowledge of inherited sight loss and informing the development of future treatments for those facing visual impairment. Also concluding in 2023 is the Gene Team Project and our PhD studentship on the development of CRISPR gene therapy for Stargardt disease.

Much of the research being undertaken has been made possible by the considerable success achieved by Retina UK's executive team, in building effective and enduring partnerships with funders, charities and research teams. These efforts deserve particular recognition.

I want to express my heartfelt appreciation to all those that support the work of the charity; the fundraising efforts and the generosity of our community, of individuals, trusts and corporates who continue to sustain the charity, despite the difficult economic situation.

I would like to recognise the considerable achievements of the Retina UK Team who have worked hard to deliver on fundraising; on an impressive programme of support to the community; and on an expertly curated programme of research stewardship.

I wish to thank our volunteers, who have once again delivered great service to our community, attracting much well deserved positive feedback. I also wish to thank our ambassadors and trustees for generously contributing their time to the work of Retina UK.

Four new Trustees joined us in January 2022. Their skills and experience will be enormously beneficial to Retina UK as we approach our 50th anniversary. Finally, we said goodbye to our excellent Treasurer, Janet Crookes, in 2022. Janet played a very active hands-on role in the charity including stepping in to support the office team prior to Tina's appointment in 2015. She has handed over the reins to the very capable Ashley Grist.

The independent Medical Advisory Board (MAB) also said a fond farewell to its Chair, Professor Susan Downes of Oxford University, to whom we owe an enormous debt of gratitude for her excellent contribution and stewardship of the MAB since 2018. We are privileged and honoured that Professor Tara Moore of Ulster University has agreed to join as the new Chair, and I would like to extend her a very warm welcome on behalf of Retina UK. Tara is joined in an expanded MAB by Professor Paulo Stanga, Professor Andrea Cusumano, Professor Luminita Paraoan and Professor Jod S Mehta.

Dr M Kirkup
Chair
4 May 2023

The Trustees are pleased to present their annual report together with the financial statements of the charity for the year ending 31 December 2022. 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) and Visionary and abides by each organisation's principles of best practice at all times.

Related parties

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

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. Staff remuneration with regard to inflation is proposed by the Chief Executive and considered by the Remuneration Committee, on behalf of the Trustee Board.

Financial Review

In December an amount of £145,299 was received from the Medical Research Council. This is slightly more than we received in 2021. Other income was also strong due to a positive Big Give Appeal. Non-legacy income generation for the year therefore closed at £815,412, about 10% lower than the level foreseen in the budget. However, once the £250,000 major donor grant for USH2A is added on, the non-legacy income level was broadly in line with 2021.

Legacy income was £535,255, which is above the average amounts received over the past five years. Total income for the year therefore closed at £1,562,632, which is £323,497 better than 2021, due mostly to the increased legacy income.

Non grant expenditure for the year ended at £911,089. In 2022, the charity's grant expenditure totalled £531,622, versus £95,867 in 2022 as research funding picked up following the pandemic years.

Retina UK had net assets of £2,036,626 at the end of December, which is broadly in line with prior year (£2,023,342 at December 2021).

The Charity had a cash balance of £931,940 at the year end with a further £600,000 placed on a fixed term (12 months) deposit to make the most of interest at a rate of 2.3%. Of the cash balance, £501,033 was in a 32-day notice account to balance maximising interest with the ability to withdraw funds if required, and the balance held in current accounts for day-to-day activities.

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. 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 and subsequent cost-of living challenges 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. We continued to operate the charity on a sustainable basis.

Whilst planning for 2023 and beyond is focussing on increasing charitable impact, 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 £17 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 2022 with 15 preliminary submissions. A decision on these applications will be made in 2023.

We responded to the COVID-19 pandemic and beyond by adapting and being more innovative with our information and support provision. Our Annual and Professionals' Conferences went ahead as hybrid events (rather than in-person or fully online) with very positive feedback. This has resulted in a decision to hold the 2023 Conferences in hybrid form, in London, to enable delegates to join us in-person or online. We also introduced a series of webinars in the last quarter of 2021 which were recorded and made available for people to view after the event; these have proven very popular and were held monthly through 2022 and will continue into 2023.

Other plans for 2023 include further developing resources to support our community to manage their wellbeing, grow our local support group network around the UK, and further develop how we support professionals who work directly for the IRD community.

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 2022.

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 ten other genes.

Consortium members also contributed to a 2020 publication describing a brand new disease mechanism involving structural changes to chromosome 17, and identified heterozygous deletion of an entire gene as the cause of late onset macular dystrophy in eight families.

As the original grant approached its end in 2020, 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 IRDs and has solved one third of these previously intractable cases, providing families with better understanding of their condition and opening up choices. By communicating their results through meetings and publications, the team has also helped clinicians across the globe to interpret the genomes of those living with inherited sight loss. 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 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's work has led to the instigation of four early phase clinical trials, supported by MeiraGTx. One further therapy is also under consideration for clinical testing. The researchers have also treated several infants with a rare form of LCA under a special licence.

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 and characterising this particular type of retinal disease in cells and mice and starting to assess the viability of an IMPG2 gene therapy vector. So far, the impact of the therapy in the mice has been minimal, but the team will try testing the intervention at an earlier stage.

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 has made good progress over the first two years 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 were used to test and optimise various CRISPR constructs the student designed, with some constructs successfully correcting the code and enabling production of full length, healthy ABCA4 protein. This has provided proof of concept, and will enable the student to progress to testing in other models during her final PhD year.

Establishing AAV.PRPF31 gene augmentation in PRPF31-deficient RPE and photoreceptor cells and assess its efficacy in restoring RPE and photoreceptor function
Started 2022 / Ends 2025

This project, led by Prof Majlinda Lako at Newcastle University, follows on from an earlier Retina UK-funded study of defects in the PRPF31 gene, which plays a key role in “editing” the genetic code during protein construction. Prof Lako and colleagues will now look into the development of a gene replacement therapy to overcome the effects of faulty PRPF31, using cutting-edge techniques to explore the impact of the therapy on cell-based models of PRPF31 disease. This will provide important proof of concept data as a first step towards treatment.

2022 grant round for proposals directly relevant to USH2A-mediated disease

Thanks to a generous commitment from the AT Capital Charitable Foundation, Retina UK was able to conduct an additional grant round in 2022. The foundation committed to fully funding one project that would be relevant to the treatment of sight loss associated with mutations in the USH2A gene, and Retina UK therefore conducted a grant call that stipulated these parameters.

After the usual peer review process, in autumn 2022 the grant was awarded to Prof Majlinda Lako at Newcastle University, who will investigate the development of a hypoimmunogenic cell-based therapy. This project will start in 2023.

2022/2023 PhD studentship grant round

Retina UK is pleased to be continuing its co-funding relationship with the Macular Society for PhD studentship projects related to inherited macular dystrophies. We opened a call for applications in autumn 2022, which has resulted in the shortlisting of three promising proposals.

In spring 2023, the Trustee Boards of Retina UK and the Macular Society will agree on one project for funding, based on recommendations from the Medical Advisory Boards of both organisations.

Community engagement with research

2022 saw Retina UK continue its efforts to facilitate engagement between members of our community and researchers. We publicised eight 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 over 450 members.

Participation has included industry-led activities to learn more about the lived experience of those X-linked RP, questionnaire-based studies on the impact of Charles Bonnet Syndrome, and a clinical trial. Interaction between those living with IRDs 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 NHS availability for new therapies is the essential final step in enabling those living with IRDs to access life-changing treatment. In 2022, Retina UK joined the Charity Medicines Access Coalition (CMAC) to add our voice to those of other organisations in challenging and influencing policy around licensing and reimbursement.

Information and support

We surveyed all of our members in 2022 and had almost 700 responses. These have helped the charity understand the real-life experiences, challenges and expectations of those living with inherited sight loss conditions. Almost half (49%) said their sight loss has a severe or very severe impact on their quality of life and once again, loss of confidence, anxiety and stress are the biggest emotional or psychological impacts of sight loss. Almost a third (31%) can now name the gene or genetic disease type causing their sight loss – this is twice the percentage in 2019 and suggests a positive increase in the number of people who are given a genetic diagnosis. This will, in part, be due to the launch of Unlock Genetics in 2021.

Conferences

In line with our values, and following feedback from our community, we made the ambitious decision to not only return to holding our conferences face-to-face, but to deliver them in a hybrid format, allowing those who were able to attend in person to do so, and those not able to travel, to join us online.

We were delighted that most of the presenters were able to be with us live in Birmingham. 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 2022 was Wellbeing and included the launch of our new 'Discover Wellbeing' website and resources.

Following feedback from previous events, the 2022 Professionals' Conference was also fully CPD accredited.

Following the success of the 2021 AGM, the 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 hybrid nature of the AGM offered members the opportunity to ask questions.

We will offer a hybrid option for our conferences and AGM again in 2023 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.

Discover Wellbeing

When we conducted our 2019 sight loss survey, 92% of respondents said they had experienced negative emotional or psychological impacts. This confirmed the anecdotal evidence that we had gathered for some time from discussions with people on our helplines and at various events. Anxiety, loss of confidence and stress were the biggest impacts. These statistics remain similar for our 2022 survey. This issue is recognised by professionals supporting those with sight loss, NHS leaders and politicians. However, while there has been much discussion about the need for improved support, this has not been forthcoming.

We realised that people needed support early on to be able to recognise and better manage the negative impacts on their emotional wellbeing. Our response was to develop our innovative Discover Wellbeing resource.

We worked with Arthur Ellis Mental Health Support: https://www.arthurellismhs.com and Dr Mhairi Thurston, a Senior Lecturer in Counselling at Abertay University, who also lives with a sight loss condition: https://www.abertay.ac.uk/staff-search/dr-mhairi-thurston, to develop modules as part of a fully consultative process with our community. Three online training modules in a mix of accessible video, audio and written content supporting those in the early stages of their sight loss journey; those living with change and those supporting someone living with a condition. As well as encouraging an exploration of the impacts and feelings associated with each of the three situations, the modules provide a range of tools to empower the user to manage their own emotional wellbeing, improve their resilience and prepare for the future.

The modules can be completed independently or, if they so wish, members of our community can request the support of a specially trained wellbeing volunteer, who will contact them regularly for encouragement and support.

The Discover Wellbeing modules were launched at our Annual and Professionals' Conferences in July 2022 thanks to a grant from Novartis Pharmaceuticals UK and Janssen.

The resource has been promoted amongst our existing community and externally, with appearances on RNIB Connect Radio, and various webinars with sector partners.

In the first 6 months following launch, the Retina UK Discover Wellbeing page had received 1,044 unique page views and the portal had been accessed by 142 people excluding our administrators.

“I feel so lonely. My RP has progressed to a stage that I can no longer see to go out with my girlfriends for things like shopping trips. My husband now does all the food shopping as I cannot see labels or food. I feel sad I cannot see the new things on offer to buy. Whether it be clothes, food or even gifts for Christmas for relatives. I have a great circle of friends but I am finding I am becoming more inclined to refuse offers of going out as I feel such a burden. I hope this course gives hope.”

“I have recently started the Living with Change Wellbeing Course and wanted to tell you that I think it is a brilliant thing devised specially for the sight loss community.”

Webinars

Following the successes of the 2021 webinars, we delivered a series of monthly webinars (online via Zoom) throughout 2022 on a number of topics. 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).

	In Attendance	YouTube (to date 13/4/23)	Podcasts (to date 13/4/23)
Visual Hallucinations and Charles Bonnet Syndrome	67	461	67
Get Active with British Blind Sport	16	62	42
Medical Images and what they show	20	186	55
"Mini Retina" A tool to unlock the future of restored vision in retinal blindness	32	1,242	72
Usher Syndrome mini series (Part One)	59	269	62
Technology Solutions with VisionAid	20	111	50
Usher Syndrome mini series (Part Two)	50	195	40
Wellbeing	27	85	49
Make Up with Bhavini	13	54	51
Maximising your income – social security support for people living with sight loss	18	35	90

Information days

Our intention was to hold five face-to-face information days in 2022 (Aberdeen, Manchester, Hull, Bristol and Oxford). However, because of uncertainty around restrictions and public confidence in visiting large events, we had to be dynamic in the approach to these events.

Regrettably we had to cancel the event in Aberdeen and move the Oxford event to an online evening session (18 attendees), however we were able to hold physical events in Bristol (32 attendees), Hull (17 attendees) and Manchester (26 attendees).

Podcast channel

Our podcast channel on Spotify (previously Anchor FM) had 1,749 listens in 2022. Our content is syndicated across nine platforms, which include Spotify, Apple podcasts and Google podcasts. We will be maximising this content on our new website and reviewing the type of content to maximise this channel.

YouTube channel

Our YouTube channel saw a more than 63% increase on 2021 with 5,394 viewers in 2022 with an overall click through rate (from impressions) of 4.4%.

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 2022, publishing it three times during the year. A total of 21,803 copies of Look Forward were distributed and 28,722 copies of the e-Newsletter.

We worked collaboratively on content with guest features from VocalEyes, Look and Guide Dogs UK.

Local Peer Support

The Local Peer Support Group network has seen a positive growth over the past year due to the appointment of a dedicated Information & Support Coordinator role in September 2021.

In 2022 we were able to increase our Peer Support Groups to include 14 physical group locations and two virtual group locations (online only) - with the introduction of a Wales and Northern Ireland group to accompany our existing online Scotland regional group.

- A total of 59 peer group meetings, both online and in-person were planned and carried out.
- There were 575 total registered/attendees (an average of 10 people per meeting) - this is a 60% increase over 2021.
- Local peer group meeting growth up 76% from the end of 2021.
- 11 out of 14 groups returned to in-person meetings (the remainder were new groups where an in-person meeting is planned for early 2023).
- A total of 25 in-person meetings were held by the end of 2022.

As a result of our Peer Groups returning to in-person, this has brought our community together by giving them the opportunity to explore the world of museum touch tours, dining out, getting hands on with home smart tech and a steamboat trip.

"It was good to meet people like me with a visual impairment and to have the chance to access a museum like fully sighted people."

With the continuation of online meetings, running alongside in-person peer group events, this has allowed group facilitators to invite a variety of inspirational, motivational and informative speakers to their meetings such as Paralympians, assistive tech companies, ECLO/ROVI support and local sight loss organisations.

"It was such a beautiful meeting. Such a brilliant organization. We have done a wonderful thing tonight thank you for all your help for so many people".

In June 2022 we saw the launch of our National Peer Support Group which will host four seasonal meetings per year. This has been an encouraging method of inviting our community across all of the UK to join an online meeting, proving beneficial to those that are unable to join an in-person local group or that do not have a group in their area. With just a summer and autumn meeting in 2022 our National Peer Support Group has seen a growth of 76 followers who have attended or expressed interest. The launch of this group gives our community the opportunity to hear from speakers and engage with each other about subjects from across the UK.

"It was an excellent session which was very informative. It was practical advice which could be easily implemented which was what I really appreciated."

"It was a good session! Very well organised and professional."

Over the past year we have shared local group meeting recordings on YouTube in a dedicated playlist.

Attendance varied through the year, with some groups more active online than others. We are grateful to the new and existing volunteers who facilitate our local groups.

Helpline

Calls to the helpline this year have decreased by 25% but are still up on pre-pandemic (2019) figures by 10% whilst email helpline queries increased by 20% against 2021.

In 2022 just over 50% of telephone calls were looking for emotional support sometimes alongside other practical help and sometimes as the only focus of the call. Daily living queries, including concerns about mobility; benefits; employment and driving accounted for 39% of calls. Other calls were people asking for information about their condition, research and genetic testing and counselling.

“I have been a member for many years but not felt need to use the helpline until today. I had a few questions which were all answered by a very helpful chap. I am very proud of the service you are supplying to those of us with inherited sight loss. Thank you so much.”

This year again the largest number of enquiries to the email helpline were about Research and Genetic Testing and Counselling but this was very closely followed by enquiries about Retina UK services, what was available and how to access them. Many people had seen articles in Look Forward, E-bulletins and on our website as well as quite a few being referred from professionals.

- Research and Genetic testing 25%
- Retina UK services 24%
- Information about RP/Retinal dystrophies 20%
- Daily Living 14% (to include mobility, tech, benefits and finance and glasses – prescription tints, sunglasses and sim specs)
- Emotional support 11%

“I wanted to take the opportunity to send you a message to let you know how grateful I am to you and your whole foundation for assisting me on all my concerns.”

“Thank you for such prompt helpful advice. I have now followed the links and all the info is very helpful.”

Talk and Support

As of 2022, the Talk & Support (T&S) service has 11 active volunteers who support 21 active service users. To expand and grow this service we are currently recruiting and training new Talk & Support volunteers throughout 2022 who will then await being paired with a potential match.

This service has also evolved to support individuals with other inherited retinal dystrophies and specific conditions such as Charles Bonnet Syndrome (CBS).

During 2022, the T&S service has shown a change to the number of volunteers that have been matched or have an existing service user. We have seen the departure of three of our volunteers however we have also introduced four new volunteers that have been matched or are awaiting a match with their first service user.

At the end of 2021, we had 13 volunteers but during the summer this number fell to 10 due to retirement, transferring over to the Wellbeing team and becoming a member of staff. For the second half of 2022 we saw this number increase to 14 with the introduction of the new volunteers which is an increase of 7%.

In 2022 the T&S service was supporting 17 active service users which are matched with a volunteer with three service users pending due to personal circumstances.

Since June, there have been 10 members of our community who have directly contacted Retina UK through our Helpline or who have been referred by another organisation such as RNIB or local sensory team. Four have been successfully matched with a volunteer, three have been contacted by telephone and awaiting a response, two are awaiting a match and one has been referred to the Discover Wellbeing service.

Two existing service users had been successfully re-matched with a new volunteer as they wanted to continue using this service after their volunteer stepped down.

The T&S service has seen an overall growth of 35% over 2022. This includes those who have contacted Retina UK regarding this service, those who have been matched and those who are awaiting a match.

"I talk to my volunteer on a fortnightly basis and I think this service is extremely beneficial. I decided to use the Talk & Support service as I thought it would be a good way of connecting with like-minded people and improving my confidence."- Talk & Support Service User

"Being alongside and offering a listening ear to others is such a privilege, having walked a similar path of sight loss myself. Knowing from experience how speaking things out helps enormously, I wanted to give others that same opportunity, being that friendly voice at the end of a phone." - Talk & Support Volunteer

Volunteers

In 2022 we welcomed 12 new volunteers into our Information and Support volunteer team, in roles in our telephone helpline, Talk & Support service, Local Group Network and Discover Wellbeing service. We provided regular online meetings for both training and social opportunities to the team and 24 volunteers attended our face-to-face training event.

In 2022 we produced all our training documentation in audio format.

We also circulated our volunteer feedback survey, which is done every three years.

Fundraising

Fundraising has remained challenging, with the cost of living crisis creating further waves for the Fundraising team. Nonetheless, we ran another successful Big Give campaign, which saw us hit our target within two days – raising £52,700 in total. We were also able to introduce an online raffle option, making it quick and easy for our supporters to buy tickets and make an additional donation. We hope to build upon this in the future, saving both mailing and administrative costs in turn.

2022 saw continued growth in fundraising from challenge events. #TeamRetinaUK took on challenges from seaside treks to cycling the streets of the capital. Through the Ultra Challenge series, our supporters stepped forward to raise over £11,000 and our inaugural RideLondon 100 team raised over £6,000. From Woolwich to Whitby, the sun shone as our team ran the virtual and city route TCS London Marathon, raising over £50,000!

More of our supporters took on fundraising in their community this year (52 in 2022 vs 35 in 2021). We were delighted to be supported by such a range of events! In 2022, Worksop's Got Talent returned to the North Notts Arena for another sell-out show. The organiser, James Clarke, surpassed £100,000 in overall fundraising for Retina UK! We also returned to the Isle of Wight for the annual sponsored walk, Hopefully to Seaview, hosted by Colin and Linda where over £4,000 was donated.

Significant funding was also secured towards medical research – including £145,000 from the UK Government Medical Research Charity Support Fund and £250,000 from a major donor to fund a three-year project.

All fundraising in 2022 was carried out by Retina UK 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 2022. 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 2022.

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 2022 we were grateful to receive the following support:

AbbVie	£4,000 to support our Annual and Professionals' Conferences
AGTC	£3,993 to support our Annual and Professionals' Conferences
Janssen	£10,000 to support our Annual and Professionals' Conferences
	£20,660 sponsorship of our *Look Forward* newsletter
	£10,000 as an Information and Support grant
	£4,000 to support our Professionals' Project
Novartis	£10,000 to support our Annual and Professionals' Conferences
	£3,206 for CPD accreditation for our Professionals' Conference
ProQR	£5,000 to support our Annual and Professionals' Conferences
Santen	£5,000 to support our Annual and Professionals' Conferences

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 2022. 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 Annett Trust
- The Anson Charitable Trust
- Arnold Clark Community Fund
- BE Rodmell Trust
- The Catherine Cookson Trust
- The David Fryer Charitable Trust
- David Killick Trust
- The Doris Field Charitable Trust
- The D'Oyly Carte Charitable Trust
- The Edgar E Lawley Foundation
- G C Gibson Charitable Trust
- The Girdlers' Company Charitable Trust
- The G W Cadbury Charitable Trust
- Gilbert Edgar Trust
- Grace Trust
- The Hospital Saturday Fund
- The Inman Charity
- The James Wise Charitable Trust
- John Laing Charitable Trust
- Lillie Johnson Charitable Trust
- The Orr Mackintosh Foundation

- Nineteen Eighty-Nine Charitable Trust
- The Oakdale Trust
- The Samuel Storey Family Charitable Trust
- The Spectacle Makers' Charity
- The Spectris Foundation
- The Stockwell Cliffe Charitable Trust
- Tennant Southpark Charitable Trust
- Tom and Thelma Wilson Trust
- The WO Street Charitable Foundation

Statement of Trustees' Responsibilities

For the year ending 31 December 2022

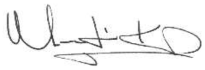
The Trustees are responsible for preparing the Trustees' annual report and financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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
4 May 2023

We have audited the financial statements of Retina UK (the 'charity') for the period ended 31 December 2022 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 2022 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;

- 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

11 May 2023

……………………………………………………….

Chartered Accountants
Statutory Auditor

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 2022

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £	Total Funds 2021 £
INCOME FROM:					
Donations & legacies	**3**	868,167	482,500	**1,350,667**	1,050,797
Charitable activities					
Grants	**4**	-	205,309	**205,309**	185,328
Investments	**5**	6,656	-	**6,656**	3,010
Total income		**874,823**	**687,809**	**1,562,632**	**1,239,135**
EXPENDITURE ON:					
Raising funds	**6**	(287,018)	(8,930)	**(295,948)**	(253,118)
Charitable activities					
Medical Research	**7**	(233,860)	(390,993)	**(624,853)**	(163,051)
Information & Support	**8**	(508,397)	(106,744)	**(615,141)**	(470,847)
Total expenditure		**(1,029,275)**	**(506,667)**	**(1,535,942)**	**(887,016)**
Net (losses) / gains on investments		(13,406)	-	**(13,406)**	**31,734**
Net movement in funds	**9**	**(167,858)**	**181,142**	**13,284**	**383,853**
Funds at 1 January 2022	**21/23**	**1,499,561**	**523,781**	**2,023,342**	**1,639,489**
Funds at 31 December 2022	**21/23**	**1,331,703**	**704,923**	**2,036,626**	**2,023,342**

Balance Sheet

For the year ending 31 December 2022

	Note	2022 £	2021 £
FIXED ASSETS			
Tangible fixed assets	**13**	**4,736**	6,336
Investments	**14**	**262,336**	275,742
Total fixed assets		**267,072**	282,078
CURRENT ASSETS			
Debtors: Amounts falling due within 1 year	**15**	**631,930**	925,059
Current asset investments	**16**	**600,000**	-
Cash at bank and in hand	**17**	**931,940**	1,322,144
Total current assets		**2,163,870**	2,247,203
LIABILITIES			
Creditors: Amounts due within 1 year	**18**	**(394,316)**	(505,939)
Net current assets		**1,769,554**	1,741,264
Net assets		**2,036,626**	2,023,342
FUNDS			
Unrestricted	**21**	**1,331,703**	1,499,561
Restricted	**23**	**704,923**	523,781
Total funds		**2,036,626**	2,023,342

A Grist
Treasurer
Date: 4 May 2023

Dr M Kirkup
Chair
Date: 4 May 2023

Retina UK

Cash Flow Statement

For the year ending 31 December 2022

Cash flows from operating activities:	Note	2022 £	2021 £
Net income for the reporting period		**13,284**	383,853
Adjustments for:			
Depreciation charges	**13**	**3,678**	3,677
Unrealised losses / (gains) on investments	**14**	**13,406**	(31,734)
Dividends and interest from investments	**5**	**(6,656)**	(3,010)
Decrease in debtors	**15**	**293,129**	302,471
Decrease in creditors	**18**	**(11,910)**	(81,105)
Decrease in grant creditors	**18**	**(99,713)**	(450,658)
Net cash from operating activities		**205,218**	123,494
Cash flows from investing activities:			
Dividends and interest from investments	**5**	**6,656**	3,010
Purchase of tangible fixed assets	**13**	**(2,078)**	(2,363)
Disposal of investments	**14**	**-**	113
Cash on fixed term deposit	**16**	**(600,000)**	-
Cash flows from investing activities		**(595,422)**	760
Change in cash and cash equivalents in the year		**(390,204)**	124,254
Cash and cash equivalents at 1 January 2022	**17**	**1,322,144**	1,197,890
Cash and cash equivalents at 31 December 2022	**17**	**931,940**	1,322,144

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

	2022	2021
	£	£
Membership subscriptions/donations	**30,667**	31,422
Individual donations	**338,101**	287,171
Trusts	**111,944**	125,514
Corporate	**91,175**	99,042
Legacies/In memoriam	**535,255**	219,531
Fundraising	**140,892**	159,275
Prize draw/appeals/mailings	**64,933**	80,843
Gift aid	**37,700**	47,999
Total	**1,350,667**	1,050,797

4. Grants

	2022	**2021**
	£	**£**
Medical research funding	**60,010**	41,100
Government grants	**145,299**	144,228
Total	**205,309**	185,328

Government grants comprise amounts from UK Government COVID Medical Research Charity Support Fund (£145,299 (2021: £110,850)). There were no amounts in respect of the Coronavirus Job Retention Scheme (‘CJRS’) (2021: £33,378).

5. Investments

	2022	**2021**
	£	**£**
Share dividends	**2,190**	2,885
Bank interest	**4,466**	125
Total	**6,656**	3,010

6. Raising funds

	2022	2021
	£	£
Event costs	**23,399**	22,807
Materials and equipment	**211**	-
Collection fees	**6,942**	6,403
Appeals	**8,684**	7,247
Training and conferences	**482**	193
Donor development including trusts & corporates	**3,331**	553
Gift aid	**1,293**	-
Other	**1,242**	800
Support costs (see note 10)	**250,364**	215,115
Total	**295,948**	253,118

7. Medical research

	2022	2021
	£	£
Annual grant awards	**402,702**	**4,584**
Grant donation for medical research	**128,920**	**91,283**
Support costs (see note 10)	**93,231**	**67,184**
Total	**624,853**	**163,051**

Grant awards in 2022 had no significant adjustment on completion of projects (2021: offset by £78,690 of unused funds reclaimed from the original UKIRDC project).

In 2022, a grant donation of £128,920 was made from our restricted RDH12 Fund to the charity ' Eyes on the Future' (2021: £91,283 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

	2022 £	2021 £
Publications, DVDs, leaflets	**20,819**	19,389
Annual conference	**32,996**	4,306
Helpline support	**13,735**	8,169
Information events	**7,005**	1,170
Non-medical research/projects	**12,767**	27,125
Travel expenses	**7,029**	2,706
Retina International	**-**	5,360
Website development	**49,439**	570
Sight loss survey	**12,056**	2,613
Volunteering	**7,912**	4,558
Other	**6,825**	2,356
Support costs (see note 10)	**444,558**	392,525
Total	**615,141**	470,847

9. Net movement in funds is stated after charging

	2022 £	2021 £
Auditor's remuneration (audit)	**10,860**	7,050
Depreciation	**3,678**	3,677
Trustees' expenses	**1,529**	14
Lease payments	**16,542**	13,500

Trustees' expenses, incurred on travel and accessibility support, represent amounts reimbursed to two Trustees for expenses incurred (2021 - 1).

No Trustee received any remuneration during the year (2021 - none).

10. Analysis of support costs

	Total	Fundraising	Research	Information & Support	Basis of apportionment
	£	£	£	£	
Office administration	90,904	27,271	9,090	54,543	Staff time or actual
Remuneration	650,902	209,189	79,506	362,207	Staff time or actual
Governance	46,347	13,904	4,635	27,808	Staff time or actual
Total	**788,153**	**250,364**	**93,231**	**444,558**	
Governance costs in 2021	41,737	12,521	4,174	25,042	

11. Staff numbers and costs

	2022	2021
	£	£
Wages and salaries	**609,287**	531,264
Social Security costs	**57,138**	42,073
Pension costs	**18,434**	16,180
Total	**684,859**	589,517

The number of persons employed by the charity during the year was 20 (2021 - 19).

Total remuneration (including Employer NIC) for key management personnel in the year was £96,828 (2021 - £86,258). The number of employees with remuneration (excluding Employer NIC) between £80,000-£90,000 was 1; £70,000-£80,000 - 0 (2021: £80,000-£90,000 - 0; £70,000-£80,000 - 1).

12. Comparative information for Statement of Financial Activities

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
INCOME FROM:				
Donations & legacies	**3**	607,719	443,078	**1,050,797**
Charitable activities				
Grants	**4**	33,378	151,950	**185,328**
Investments	**5**	3,010	-	**3,010**
Total income		**644,107**	**595,028**	**1,239,135**
EXPENDITURE ON:				
Raising funds	**6**	245,982	7,136	**253,118**
Charitable activities				
Medical Research	**7**	11,946	151,105	**163,051**
Information & Support	**8**	345,417	125,430	**470,847**
Total expenditure		**603,345**	**283,671**	**887,016**
Net gains on investments		31,734	-	**31,734**
Net movement in funds	**9**	**72,496**	**311,357**	**383,853**
Funds at 1 January 2021	**22/24**	**1,427,065**	**212,424**	**1,639,489**
Funds at 31 December 2021	**22/24**	**1,499,561**	**523,781**	**2,023,342**

13. Tangible fixed assets

	Office Equipment £
Cost	
At 1 January 2022	**22,593**
Additions	**2,078**
At 31 December 2022	**24,671**
Depreciation	
At 1 January 2022	**16,257**
Charge for year	**3,678**
At 31 December 2022	**19,935**
Net book value	
At 31 December 2022	**4,736**
At 31 December 2021	6,336

14. Investments

	2022 £	2021 £
At 1 January 2022	**275,742**	244,121
Disposals	**-**	(113)
Unrealised (losses) / gains	**(13,406)**	31,734
As at 31 December 2022	**262,336**	275,742

	2022 £	2021 £
Included within investments are the following:		
CAF balanced growth fund at valuation	**262,061**	275,467
Shares in Taylor Woodrow	**275**	275
	262,336	275,742

All investments are held in the UK.

15. Debtors: Amounts falling due within one year

	2022	2021
	£	£
Accrued income	610,854	836,351
Trade debtors	5,246	63,545
Prepayments	15,830	25,163
Total	**631,930**	925,059

16. Current asset investments

	2022	**2021**
	£	**£**
Cash on fixed term deposit	**600,000**	-
Total	**600,000**	-

Fixed term deposit of £600,000 for one year ending 16 October 2023 at an interest rate of 2.3%.

17. Analysis of cash and cash equivalents

	2022	**2021**
	£	**£**
Cash at bank and in hand	**931,940**	1,322,144
Total	**931,940**	1,322,144

18. Creditors: Amounts falling due within one year

	2022	**2021**
	£	**£**
Trade creditors	**6,658**	44,082
Tax and social security	**14,573**	13,261
Accruals and deferred income	**33,671**	7,600
Grant liability	**338,112**	437,825
Other creditors	**1,302**	3,171
Total	**394,316**	505,939

19. Contingent assets & liabilities

There is a contingent liability of £488,745 at 31 December 2022 (2021 - £343,775) in respect of research grants authorised subject to annual review. This money falls due in years 2023 onwards.

20. Financial commitments

	2022 £	2021 £
Total future minimum lease payments under non-cancellable operating leases are as follows:		
< 1 year	**15,412**	13,500
1 - 5 years	**35,236**	47,250

21. Unrestricted Funds

	General Fund £	Designated Research Fund £	Total Unrestricted Funds £
Balance at 1 January 2022	1,229,549	270,012	**1,499,561**
Income	874,823	-	**874,823**
Expenditure	(888,645)	(140,630)	**(1,029,275)**
Transfer between funds	(173,921)	173,921	**-**
Unrealised loss on investment	(13,406)	-	**(13,406)**
Balance at 31 December 2022	**1,028,400**	**303,303**	**1,331,703**

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

22. Comparative information of Unrestricted Funds movement at 31 December 2021

	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

23. 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 £	ATCCF Fund £	Total Restricted Funds £
At 1 January 2022	246,882	2,820	1,150	123,438	1,100	23,339	2,230	2,558	-	-	120,264	-	523,781
Income	266,777	(275)	-	109	-	84,859	-	-	50	8,930	77,415	249,944	687,809
Expenditure	(82,983)	(2,545)	-	(123,547)	-	(104,199)	-	-	-	(8,930)	(100,960)	(83,503)	(506,667)
At 31 December 2022	**430,676**	**-**	**1,150**	**-**	**1,100**	**3,999**	**2,230**	**2,558**	**50**	**-**	**96,719**	**166,441**	**704,923**

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. In 2022, specific projects funded include the helpline and volunteer training, Look Forward, our Professionals' and Annual Conferences and some funding towards our Professionals Project.

Specified Project Fund: This fund contains funding for specific projects. In 2022, 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.

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.

ATCFF Fund: This is funded by a major donor grant and is for a specific research project on USH2A.

24. Comparative information of Restricted Funds movement at 31 December 2021

	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

25. Analysis of net assets between funds

	Tangible Fixed Assets	Fixed Asset Investments	Current Assets	Current Liabilities	Total
	£	£	£	£	£
Restricted Funds	-	-	857,714	(152,791)	704,923
Unrestricted Funds	4,736	262,336	1,306,156	(241,525)	1,331,703
	4,736	**262,336**	**2,163,870**	**(394,316)**	**2,036,626**

26. Comparative analysis of net assets between funds 2021

	Tangible Fixed Assets	Fixed Asset Investment	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

27. Grants awarded

Institution		**Grant Holder**	**Amount £**
King's College, London	GR576	Prof R Ali	100,000
UK Inherited Retinal Dystrophy Consortium	GR586A	*	136,179
Newcastle University	GR601	Prof M Lako	84,185
Newcastle University	GR602	Prof M Lako	83,503
Total			403,867
Adjustments on completion of grant projects			(1,165)
			402,702
Opening creditor for grant commitment			437,825
Grant payments			(502,415)
Closing creditor for grant commitment			**338,112**

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

28. Related party transactions

There are no related party transactions requiring disclosure in the Financial Statements (2021 - none) other than those relating to Trustees' expenses disclosed in note 9.

Document Activity Report

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Date	Activity

Accounts

RETINA UK

WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

Retina UK

A Charitable Incorporated Organisation

Annual Report & Financial Statements

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.

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 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 prevalentcausative 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 deliveryinto 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 nightblindness 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 supress 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 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

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).

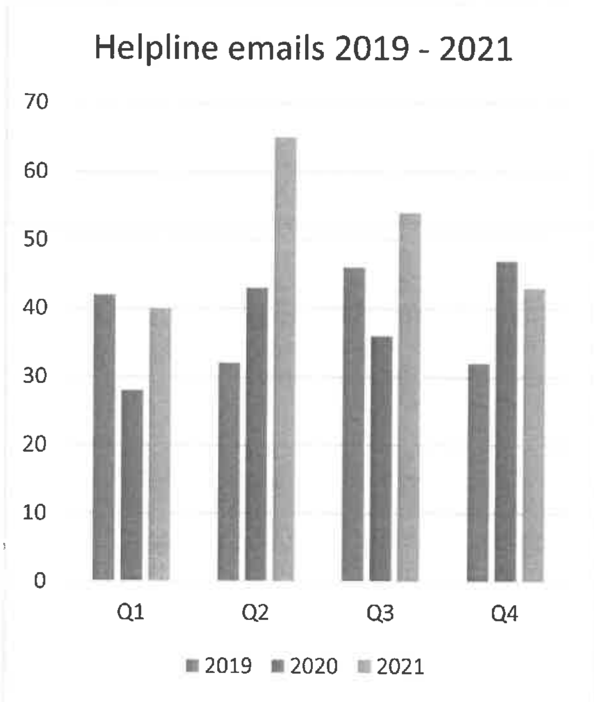
Attendance varied through the year, with some groups more active online than others. We are grateful to the volunteers who co-ordinate our local groups.

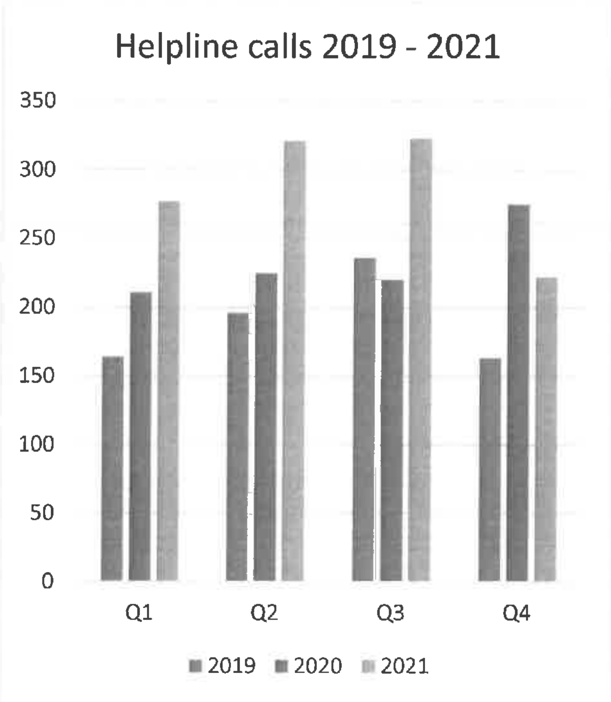
Helpline
Our phone and email Helpline and Talk and Support services have experienced a significant increase in demand.

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 *Look Forward* 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

- 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

Retina UK

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;

- 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 12 May 2022

Chartered Accountants
Statutory Auditor

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					
Grants	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					
Medical Research	7	11,946	151,105	**163,051**	610,119
Information & Support	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
Chair
Date: 11 May 2022

Retina UK

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			
Grants	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			
Medical research	126,873	483,246	**610,119**
Information & Support	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

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.

Accounts

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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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.

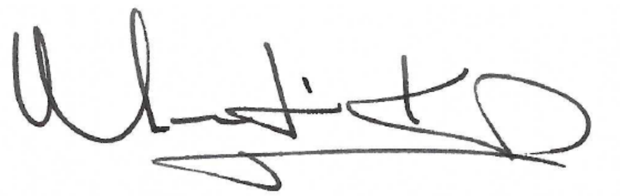
Retina UK

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.



Dr M Kirkup
Chair
14 July 2021

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.

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 £136,83**7**). 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.

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.

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.

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.

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.

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.

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 specials 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 supresses 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.

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.

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.

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.

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

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;

- 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

Chartered Accountants
Statutory Auditor

15 July 2021
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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 £	Total Funds 2019 £
INCOME FROM:					
Donations & legacies	**3**	1,542,474	456,976	**1,999,450**	1,678,361
Charitable activities					
Grants	**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					
Medical Research	**7**	126,873	483,246	**610,119**	891,581
Information & Support	**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 £	2019 £
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

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

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

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

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

Financial instruments
Financial assets
Basic financial assets, including trade and other debtors and cash and bank balances are initially recognised at the transaction price. At the end of each reporting period financial assets are assessed for impairment and any impairment loss is recognised in the Statement of Financial Activities. Financial assets are derecognised when either the contractual rights to the cash flows from the asset expire or are settled.

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

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

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

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

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

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

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

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

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

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

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	

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).

12. Comparative information for Statement of Financial Activities

	Unrestricted Funds £	Restricted Funds £	Total Funds 2019 £
INCOME FROM:			
Donations & legacies	579,218	1,099,143	**1,678,361**
Charitable activities			
Investments	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			
Medical research	33,384	858,197	**891,581**
Information & Support	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**

13. Tangible fixed assets

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

14. Investments

	2020 £	2019 £
At 1 January 2020	**260,400**	229,225
Unrealised (losses)/gains	**(16,279)**	31,175
As at 31 December 2020	**244,121**	260,400

	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
	244,121	260,400

All investments are held in the UK.

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

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	**1,120,065**	**307,000**	**1,427,065**

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	280,550	145,756	426,306

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.

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

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
	7,650	**244,121**	**2,425,420**	**(1,037,702)**	**1,639,489**

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
	4,120	260,400	1,679,964	(1,098,443)	846,041

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			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			**888,483**

27. Related party transactions

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