



Retina UK

A Charitable Incorporated Organisation

Annual Report & Financial Statements

Year Ending 31 December 2024

Retina UK

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

Retina UK

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For the year ending 31 December 2024

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

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.

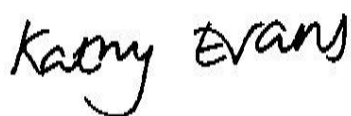
We launched our new practical information pack in Manchester for professionals who support people affected by inherited sight loss. It is available in both hard copy and digital formats and has resulted in an increase in the number of referrals we have received from the professional community.

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
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:

Report of the Trustees

For the year ending 31 December 2024

Johnson & Johnson	£10,000 to support our Annual and Professionals' Conferences
	£22,666 sponsorship of our <i>Look Forward</i> 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
- Champriss 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

Statement of Trustees' Responsibilities

For the year ending 31 December 2024

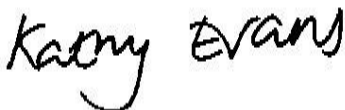
The Trustees are responsible for preparing the Trustees' annual report and financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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
Chair

Date 28 May 2025

Independent Auditor's Report to the Members of Retina UK

For the year ending 31 December 2024

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:

Independent Auditor's Report to the Members of Retina UK

For the year ending 31 December 2024

- 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

Chartered Accountants
Statutory Auditor

Azets Audit Services

.....

Epsilon House
The Square
Gloucester Business Park
Gloucester
GL3 4AD

..02 June..... 2025

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.

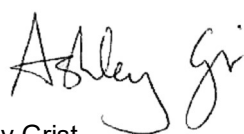
Retina UK

Statement of Financial Activities

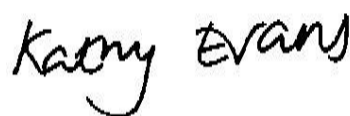
For the year ending 31 December 2024

	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					
<i>Grants</i>	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					
<i>Medical Research</i>	7	(451,744)	(264,400)	(716,144)	(906,043)
<i>Information & Support</i>	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

	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:		2024	2023
	Note	£	£
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.

Notes to the Accounts

For the year ending 31 December 2024

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

		Unrestricted Funds	Restricted Funds	Total Funds
	Note	£	£	2023 £
INCOME FROM:				
Donations & legacies	3	939,937	239,678	1,179,615
Charitable activities				
<i>Grants</i>	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				
<i>Medical Research</i>	7	(496,690)	(409,353)	(906,043)
<i>Information & Support</i>	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