



Retina UK
A Charitable Incorporated Organisation,
Registered in England and Wales
Annual Report & Financial Statements
Year Ending 31 December 2025

Retina UK

Reference and administrative details

For the year ending 31 December 2025

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 (d 21 August 2025)
Trustees	Trustees who served during the year and up to the date of this report were as follows: Ms Kathy Evans (Chair) Mr Ashley Grist (Treasurer) Mr Roger Backhouse Dr Elizabeth Graham (also known by her legal name, Elizabeth Buckingham) Prof John Marshall MBE Dr Lucy Withington (to 31 December 2025) Mr Simon Keightley Dr Martin Kirkup Ms Vanessa Forster Mr Colin McArthur Dr Samuel Godfrey (from 1 January 2026) Mr Rob Halliwell (from 1 January 2026)
Ambassadors	Mrs Bhavini Makwana Mr Steven Bate MBE Mr Amar Latif Mr Colin Hetherington
Chief Executive	Ms Tina Garvey
Principal Bankers	Lloyds Bank 2 George Row Northampton NN1 1DJ
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 2025

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The start of the charity's 50th anniversary year is a hugely momentous milestone in the history of Retina UK. However, this achievement is tinged with sadness following the loss of our founder and Honorary President, Lynda Cantor MBE, in August 2025.

I would once again like to thank all of our wonderful volunteers, Trustees, Ambassadors and members of our Medical Advisory Board for their contributions to the charity in 2025. Their dedication, expertise and hard work mean that we can achieve far more than would otherwise be possible. My thanks also go to our Chief Executive, Tina Garvey, and the committed staff team.


In March 2025 we conducted our three-year tracking survey. The results really do shape our current and future activities ensuring that our work remains relevant and responsive to the needs of our community. Most respondents agreed that Retina UK is approachable, trustworthy and ambitious on behalf of people with sight loss. This is very positive news.

Our conferences in London were packed with fantastic speakers. More than 250 people joined us in person for our Annual Conference, the highest number of delegates we have ever welcomed. We held role-specific sessions as part of our Professionals' Conference for the first time. We also held our volunteer training and celebration events during the conference weekend. It was an inspiring, informative and innovative few days.

Our Peer Support Groups continue to go from strength to strength, with 104 meetings held in 2025 and a 25.4% increase in the number of people attending.

Fundraising continues to be challenging, but despite this difficult environment, our Income Generation Team secured income totalling more than £1.7 million. Highlights include The Big Give Christmas Challenge, which raised more than £113,600, and our BBC Lifeline Appeal, which also raised vital awareness of inherited sight loss conditions. We are incredibly grateful to all those who have chosen to remember us in their will, with gifts totalling £750,239 in 2025. This represents a significant increase and highlights the importance of legacy giving in sustaining our ability to fund research. We are deeply thankful for the generosity and foresight of our supporters.

I am looking forward to the culmination of our 50th anniversary year and another packed year of events.



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 2025. 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), registered in England and Wales. 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 Chair 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 Scientific and 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 Chair 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 £872,069 which is less than in 2024 due primarily to significant restricted trust income received in that year. 2025 was a successful year for legacies and we received £750,239, which is more than twice the amount received in 2024 (£367,947). Grant income was £89,633, of which £50,000 was restricted towards our Patient Registry. Interest income was £37,183 (2024: £51,939). Total income generation for year ended 31 December 2025 was therefore £1,749,159 (2024: £2,170,849).

Total expenditure for the year was £2,092,362 (2024: £1,656,344), including £1,038,837 for medical research (2024: £716,144). Fundraising costs of £410,285 represented 23% of income (2024: 17%). The balance of £643,240 was spent on Information & Support services, a 12% increase compared to prior year.

Retina UK had net assets of £1,699,261 at 31 December 2025 (2024: £2,042,464) which reflects a decrease of £343,203 due to the expenditure on grants.

The Charity had £600,000 in a fixed term deposit account (March 2026 maturity) and a further cash balance of £1,164,112 at the year end, of which £679,629 was in a 32-day notice account to balance maximising interest income with the ability to withdraw funds 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 at least £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 2025, the charity had total funds of £1,699,261:

- Unrestricted funds of £507,217
- Restricted funds of £1,192,044

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 2026 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

Our central strategic objective for 2026 is to re-energise and clarify our research agenda while reinforcing organisational resilience, strengthening income generation capacity, and sharpening our priorities. We will strengthen our role as the leading charity for inherited retinal conditions by completing a structured and comprehensive reset of our research agenda.

Our 50th anniversary events will conclude in our planned Gala Dinner on 24 October 2026 at the London Hilton on Park Lane.

We will continue to expand our peer support groups and strengthen support for young adults and families. Conferences will take place as hybrid events in Birmingham in 2026. Our Professionals' Conference will once again include role-specific sessions, expanding our offering to include professionals working in the education sector. We also hope to hold a volunteer event in 2026.

Following the appointment of our new Volunteer Manager, we plan to launch our first volunteer strategy and improve volunteer communications.

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 Scientific and Medical Advisory Board (SMAB). 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 demonstrate the best scientific merit and likelihood of patient benefit. These principles include the use of a completely independent Scientific & 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 2025.

The UK Inherited Retinal Dystrophy Consortium (UKIRDC)

Started 2014 / Ended 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.

Establishing AAV.PRPF31 gene augmentation in PRPF31-deficient RPE and photoreceptor cells and assess its efficacy in restoring RPE and photoreceptor function

Started 2022 / Ended 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 have now looked 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.

The results have been encouraging: the gene therapy has improved many aspects of cell health, including better waste clearance, longer and healthier cell structures (called cilia), and improved responses to light. These results are being collated into a manuscript that the team intend to submit for publication. This will provide important proof of concept data as a first step towards treatment.

Generation and transplantation of hypoinmunogenic 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

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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. So far, they have successfully produced hypoimmunogenic stem cell-derived photoreceptors and established that these do not produce a response from immune cells *in vitro*. They will now move on to testing in a mouse model of retinal degeneration.

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 is investigating 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 the Netherlands, the project is using macular disease models to 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.

So far, the student has established that cone photoreceptor problems are likely to start at a molecular level rather than a physical one. Experiments suggest that RPGR protein helps to control photoreceptors' internal scaffolding, which is crucial for building the part of the cell that detects light.

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 is investigating 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.

The student has already designed prime editing tools and selected those that appear most efficient to take forward for testing in retinal organoid models of Stargardt disease.

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.

During year 1, scaffolds have been built, quality-checked and optimised. The researchers have worked with the Dutch Ophthalmic Research Centre to develop a special device to implant the patches into the retina with minimum disruption to the surrounding tissue and have been testing this in the animal eye.

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 is working 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 is using 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 and/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.

Dissecting the impact of ageing on in vitro models of IRDs to support the development of gene-agnostic therapeutic approaches

Starts 2026 / Ends 2026

The biological and clinical implications of the natural ageing process on IRD progression, epidemiology, severity and, most importantly, the molecular mechanisms underpinning their pathology, have yet to be investigated. With an increasingly ageing population, a propensity towards late diagnosis, and IRD-related clinical features shown to deteriorate with age in progressive forms, the objective necessity of studying this interaction becomes particularly significant and it is critical for enabling the development of novel and effective gene-agnostic therapeutic approaches. The current project, led by Prof Luminita Paraoan at Manchester Metropolitan University, aims to deploy high throughput CRISPR-Cas9 genomic screening to identify molecular processes at the interface of IRDs and ageing that can be leveraged to develop gene-agnostic therapeutic approaches.

Innovative Proteomic and Phosphoproteomic Profiling to Identify Regenerative Pathways for treatment of Inherited Retinal Dystrophies

Starts 2025 / Ends 2026

Inherited retinal dystrophies (IRDs) cause irreversible vision loss due to photoreceptor degeneration. In mammals, this damage is permanent because the retina cannot repair itself. In contrast, zebrafish, which share a high degree of genetic (~70%) similarity and have the same retinal cell populations as humans, exhibits remarkable regenerative capacity (1). In the zebrafish, the Müller glia (MG) can transform into new neurons to replace the lost tissues. This divergence presents a critical question: Can mimicking zebrafish regenerative processes offer a therapeutic pathway for human IRDs?

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This project, led by Dr Tess McCann at University College Dublin, will investigate whether the zebrafish retina activates unique, regeneration-specific signalling pathways following damage that are absent or repressed in the mammalian retina, thereby limiting IRD regeneration. Dr McCann will work with collaborators in Dublin, London and the USA.

Community engagement with research

Throughout 2025, we continued our efforts to promote engagement between members of our community, researchers and industry.

We shared ten participation opportunities to our Lived Experience Panel, which now has around 710 members. These opportunities included several patient and public involvement (PPI) discussions, clinical trials/studies for USH2A-associated RP, X-linked RP and Stargardt Disease and several research surveys looking at a variety of topics.

We shared the first opportunity with our newly formed Community Research Review Panel, which currently has seven members. We shared further research opportunities to different groups such as our Young Adults group, volunteers and wider community through social media, E-newsletters and email. These included surveys on young people's social support and psychological wellbeing and PPI focus groups.

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

- Jim Shannon MP sponsored a Backbench business debate on rare inherited retinal disorders in January 2025 and produced an article for the parliamentary magazine.
- We attended the first Eye Health and Vision Impairment APPG in January which had a focus on employer attitudes to employing VI people and barriers to work.
- We took part in the AMRC Charity Showcase event in Westminster.
- We attended the Rare Disease Day Reception in February.
- We attended a lived experience sector round table with Sir Stephen Timms (Minister for Social Security and Disability) to discuss various areas affecting blind and partially sighted people (Built environment, Access to Work, Additional cost of disability (PIP) and Accessibility Standards.
- We attended the House of Lords reception to launch "Tomorrow's science, Today's NHS" report on cell and gene therapies". The report aims to accelerate the introduction of cell and gene therapies to patients, particularly in the rare disease space.

Patient Registry

Work to establish a national registry for people living with inherited retinal dystrophies progressed significantly in 2025. A secure "sandbox" environment was developed as a proof-of-concept, demonstrating that the registry and access tool can operate safely and effectively as the foundation for future scale-up. The system was populated with simulated data to test functionality, data validation and reporting capability while ensuring no real patient information was used.

Alongside the technical development, work focused on simplifying disease classification and ensuring the registry can balance patient-entered information with clinician-verified data. The testing phase was successfully completed in August 2025, confirming that the system can support both patient-reported and clinical data within a secure governance framework.

The next milestone is to secure the necessary ethical approvals and confirm governance arrangements to enable the next stage of development.

Subject to trustee approval and securing the necessary funding, the next phase planned for 2026 will begin the pilot stage of the registry, testing its use in clinical settings and refining how patient and clinician data can support research, improve clinical care and enable access to emerging therapies.

Information and support

We surveyed our community in 2025 and received over 600 responses. These have helped the charity understand the real-life experiences, challenges and expectations of those living with inherited sight loss conditions.

Work to mark the 50th anniversary of Retina UK started in 2025 with the official launch of the anniversary year in June 2025. Our logo was updated to reflect the milestone. We also held a celebration dinner for our volunteers on the evening of our Annual Conference.

Thanks to funding from the Thomas Pocklington Trust (TPT) Get Set Progress scheme, our Development Team Intern successfully completed her placement in July. We were able to offer her a full-time permanent role which started immediately following the completion of her internship.

- **Professionals' Conference, London, 19 September 2025** – 458 delegates registered to attend (in-person and online). 144 of people were new to the charity. Content included:
 - From vision to reality: 50 years of progress
 - Learning from lived experience: In conversation with our community
 - Current developments in Inherited Retinal Dystrophy (IRD) research
 - CPD-accredited workshops for in-person delegates:
 - ECLOs: An overview of the causes, symptoms and stages of inherited progressive sight loss
 - Rehabilitation specialists and Habilitation specialists: Exploring some of the challenges of delivering vision rehabilitation with ethnically diverse clients
 - Optometrists: Low vision strategies: Advice and services for people with Inherited Retinal Dystrophies (IRDs)
- **Annual Conference, London, 20 September 2025** – 546 delegates registered (in-person and online). 177 people were new to the charity. Content included:
 - The journey so far: genes, machines, misses and marvels
 - Restoring the retina: a project at the cutting edge of treatment research
 - Iterative innovation and accessible technology
 - Together we thrive: Exploring new possibilities
- **Webinars** – We delivered nine webinars in 2025 with combined registrations of 192. All Webinar recordings were uploaded to YouTube with 521 people watching them. Topics included: research, clinical trials, fundraising, young adults, challenge events and creativity.
- **Podcasts** – We delivered nine podcasts in 2025 with a total of 452 listens. Topics included: research, volunteering and Charles Bonnet Syndrome (CBS).
- **Spotify** - Our channel on Spotify had a total of 2,636 listens in 2025 with a roughly equal split between men and women. The majority of listeners, 36%, were aged 35-44.
- **YouTube** - Our YouTube channel saw slower growth in 2025 with 71 new subscribers. Views were also lower at 7,873.
- **Newsletters** – We distributed 34,412 copies of Look Forward and 32,738 copies of our e-Newsletter.
- **Professionals**
 - We gave a presentation on the support services we provide at the Bardet Biedel Syndrome conference, and spoke to parent/carers about inherited, progressive sight loss conditions thanks to an invitation from LOOK, a charity that supports visually impaired young people.
 - We distributed 53 copies of our Professionals' Pack, our practical information pack for professionals working in health, social care and education to use when supporting people affected by inherited sight loss.

Peer Support Groups – We were pleased to introduce two new physical location-based groups, continued with our national online peer support group and increased our special interest online groups to seven. A total of 104 meetings took place in 2025 with 1,522 people attending (an increase of 25% on 2024).

- **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 (approx. 62 referrals in 2025 compared to approx. 32 referrals in 2024) and improved satisfaction from volunteers who are now 'matched' with a service user. 2025 saw a 7% increase in helpline calls and a 20% increase in helpline emails.
- **Volunteers** - We welcomed 10 new volunteers to our Retina UK service provisions in 2025 and 40 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 21,707 (December 2024) to 23,806 (December 2025).

Fundraising

As we reflect on the past 12 months, it continues to remain a challenging environment for third sector fundraising, but we are pleased to have ended the year above target.

2025 highlights:

- Our annual Big Give Christmas Challenge raised £113,639 (including Gift Aid) – up by £45,723. 15% of the 263 donations were new to us.
- Bucket collections at Chris McCausland's tour raised £10,000 and added 30+ new volunteers to our database.
- Our Challenge Events income stream was our biggest area in 2025, boosted by another successful London Marathon in April (£64,890), our annual 5K A Day in May campaign in May (£7,725) and our return to the Sahara Desert in November (£47,851).
- Our Lottery continues to grow, ending the year on 200 weekly players.
- We were thrilled to collaborate with brand new Corporate partners, including Bupa in Epsom, Specsavers in Poole, Evolve Estates across the country and Bristol Airport.
- We secured £37,000 of funding towards our Conferences from existing supporters in the pharmaceutical space and also monetised our exhibition space for the first time.
- Our BBC Lifeline Appeal in November raised £14,881.

All fundraising in 2025 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. We support our volunteer fundraisers with their fundraising goals, and we did not work with any external professional fundraisers. 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 use the Code of Fundraising Practice to train and support our internal fundraising staff and our external fundraising volunteers. We pay an annual Fundraising Levy.

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 2025. There were no compliance issues with any schemes or fundraising standards. We aim to fundraise in a fair and transparent way, in line with our values, and we respect the privacy of our donors. We have a vulnerable donor policy in place, and this has been reviewed in March 2026. 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 2025.

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 2025, we were grateful to receive support from the following companies:

- AAVantgarde: £5,000 – conference sponsorship
- Alkeus Pharmaceuticals: £10,000 – conference sponsorship
- Beacon Therapeutics: £5,000 – conference sponsorship
- Janssen: £15,000 – conference sponsorship
- Octant Bio: £2,000 – conference sponsorship
- Sepul Bio: £20,000 – £15,000 Patient Registry / £5,000 Sight Loss Survey.

Trusts and Foundations

We would like to thank the following trusts and foundations for their generous support of our work in 2025, 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:

The Ardwick Trust
Arihant Charitable Trust
B-C H 1971 Charitable Trust
Belvedere Trust
Benecare Foundation
Cecil Pilkington Charitable Trust
Christos Lazari Foundation
Dalgleish Trust
Doctor Munshi Foundation
Dora Rebecca Fine Charitable Trust
Fight for Sight
G C Gibson Charitable Trust
George A Moore Foundation
Gilbert Edgar Trust
Girdlers' Company Charitable Trust
Heart of Bucks Foundation
Jack Petchey Foundation
Macular Society
Masonic Charitable Foundation
Maurice & Rochelle Miller Foundation
N Smith Charitable Settlement
Sir Samuel Scott of Yews Trust
Stavros Niarchos Foundation
The Stockwell / Cliffe Charitable Trust
Sylvia Waddilove Foundation UK
Tendril Trust
The Annett Trust
The Anson Charitable Trust
The Anthony and Elizabeth Mellows Charitable Trust

The Basil Brown Charitable Trust
The Carrington Charitable Trust
The David Fryer Charitable Trust
The Doris Field Charitable Trust
The E M MacAndrew Trust
The Frank Litchfield Charitable Trust
The General Charity Fund
The Grace Trust
The Liddell-Simpson Charitable Trust
The Michael and Anna Wix Charitable Trust
The Ormonde Charitable Trust
The Patrick Rowland Foundation
The Pharsalia Charitable Trust
The Potel Charitable Trust
The Rockley Charitable Trust
The Samuel Storey Family Charitable Trust
The Serendipity Foundation Limited
The Tedworth Charitable Trust
The Treeside Trust
The Vandervell Foundation
The Wallace and Edna Davis Charitable Foundation
Thomas Pocklington Trust
Thomas Sivewright Trust
Tom and Thelma Wilson Trust
Ulverscroft Foundation
Walter Lees Foundation
Ward Family Charitable Trust
William Howarth Charitable Trust

Statement of Trustees' Responsibilities

For the year ending 31 December 2025

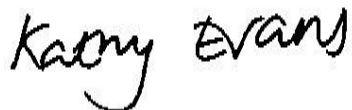
The Trustees are responsible for preparing the Trustees' annual report and financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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;
- 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 hence for 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: 18 June 2026

Independent Auditor's Report to the Members of Retina UK

For the year ending 31 December 2025

We have audited the financial statements of Retina UK (the 'charity') for the period ended 31 December 2025 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 2025 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 2025

- 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

23 June 2026

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 2025

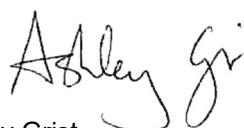
	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2025 £	Total Funds 2024 £
INCOME FROM:					
Donations & legacies	3	824,903	797,405	1,622,308	2,032,524
Charitable activities					
<i>Grants</i>	4	-	89,663	89,663	86,376
Investments	5	37,188	-	37,188	51,949
Total income		862,091	887,068	1,749,159	2,170,849
EXPENDITURE ON:					
Raising funds	6	(410,285)	-	(410,285)	(364,726)
Charitable activities					
<i>Medical Research</i>	7	(98,169)	(971,499)	(1,069,668)	(716,144)
<i>Information & Support</i>	8	(475,959)	(136,450)	(612,409)	(575,474)
Total expenditure		(984,413)	(1,107,949)	(2,092,362)	(1,656,344)
Net movement in funds	9	(122,322)	(220,881)	(343,203)	514,505
Funds at 1 January 2025	20/22	629,539	1,412,925	2,042,464	1,527,959
Funds at 31 December 2025	20/22	507,217	1,192,044	1,699,261	2,042,464

Retina UK

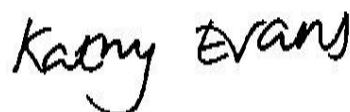
Balance Sheet

For the year ending 31 December 2025

	Note	2025 £	2024 £
FIXED ASSETS			
Tangible fixed assets	13	9,227	9,411
Investments	14	275	275
Total fixed assets		9,502	9,686
CURRENT ASSETS			
Debtors: Amounts falling due within 1 year	15	745,009	959,165
Cash at bank and in hand	16	1,764,112	1,887,763
Total current assets		2,509,121	2,846,928
LIABILITIES			
Creditors: Amounts due within 1 year	17	(819,362)	(814,150)
Net current assets		1,689,759	2,032,778
Net assets		1,699,261	2,042,464
FUNDS			
Unrestricted	20	507,217	629,539
Restricted	22	1,192,044	1,412,925
Total funds		1,699,261	2,042,464



Ashley Grist
Treasurer
Date: 18 June 2026



Kathy Evans
Chair
Date: 18 June 2026

Cash Flow Statement

For the year ending 31 December 2025

Cash flows from operating activities:	Note	2025 £	2024 £
Net income/(expenditure) for the reporting period		(343,203)	514,505
Adjustments for:			
Depreciation charges	13	6,226	5,290
Dividends and interest from investments	5	(37,188)	(51,949)
Decrease/(increase) in debtors	15	214,156	(606,238)
Increase/(decrease) in creditors	17	11,863	(4,691)
Decrease in grant creditors	17	(6,651)	(72,248)
Net cash (outflow)/inflow from operating activities		(154,797)	(215,331)
Cash flows from investing activities:			
Dividends and interest from investments	5	37,188	51,949
Purchase of tangible fixed assets	13	(6,042)	(6,315)
Cash from fixed term deposit		-	600,000
Cash flows from investing activities		31,146	645,634
Change in cash and cash equivalents in the year		(123,651)	430,303
Cash and cash equivalents at 1 January 2025	16	1,887,763	1,457,460
Cash and cash equivalents at 31 December 2025	16	1,764,112	1,887,763

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 2025

Dividends, donations and fundraising 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

	2025 £	2024 £
Membership subscriptions/donations	28,195	26,121
Individual donations	133,975	122,154
Trusts	168,789	966,418
Corporate	107,137	125,025
Legacies/In memoriam	750,239	367,947
Fundraising	227,585	241,763
Prize draw/appeals/mailings	129,782	105,500
Gift aid	76,606	77,596
Total	1,622,308	2,032,524

Included in the above is £36,194 of donated services (2024: £30,360).

4. Grants

	2025 £	2024 £
Medical research funding	39,663	19,739
Other grant funding	50,000	15,110
Government grants	-	51,527
Total	89,663	86,376

Other grant funding comprises amounts from a collaborative venture towards our Patient Registry project (towards our Young Adults project in 2024 - £15,110). In 2025, no government grants were received (2024 from UK Government Covid Medical Research Charity Support Fund, £51,527).

5. Investments

	2025 £	2024 £
Share dividends	5	10
Bank interest	37,183	51,939
Total	37,188	51,949

6. Raising funds

	2025	2024
	£	£
Event costs	44,820	26,081
Materials and equipment	624	135
Collection fees	11,889	12,067
Prize draw/appeals	6,990	12,041
Training and conferences	615	996
Donor development including trusts & corporates	9,999	5,653
Other	5,966	9,013
Support costs (see note 10)	329,382	298,740
Total	410,285	364,726

7. Medical research

	2025	2024
	£	£
Annual grant awards	525,048	343,526
Market access project	30,831	-
Support costs (see note 10)	513,789	372,618
Total	1,069,668	716,144

8. Information & Support

	2025	2024
	£	£
Publications, DVDs, leaflets	39,821	28,141
Annual conference	69,957	41,759
Helpline support	11,122	10,869
Information events	6,830	3,403
Non-medical research/projects	41,462	55,722
Travel expenses	2,189	6,185
Sight Loss Survey	14,661	-
Website development	7,841	5,558
Volunteering	21,279	11,454
VI Sector Collaboration	5,216	1,860
Subscriptions	7,497	6,521
Other	8,777	7,565
Support costs (see note 10)	375,757	396,437
Total	612,409	575,474

9. Net movement in funds is stated after charging

	2025	2024
	£	£
Auditor's remuneration (audit)	21,198	13,340
Depreciation	6,226	5,290
Trustees' expenses	1,184	1,256
Lease payments	4,598	3,982

Trustees' expenses, incurred on travel and IT support, represent amounts reimbursed to three Trustees for expenses incurred (2024: 1).

No Trustee received any remuneration during the year (2024: none).

10. Analysis of support costs

	Total £	Fundraising £	Research £	Information & Support £	Basis of apportionment
Office administration	214,224	57,624	90,439	66,161	Staff time or actual
Remuneration	955,420	258,451	402,651	294,318	Staff time or actual
Governance	49,284	13,307	20,699	15,278	Staff time or actual
Total	1,218,928	329,382	513,789	375,757	
Governance costs in 2024	57,675	16,149	20,186	21,340	

11. Staff numbers and costs

	2025 £	2024 £
Wages and salaries	866,277	762,739
Social Security costs	91,285	71,398
Pension costs	21,907	34,514
Total	979,469	868,651

The number of persons employed by the charity during the year was 23 (2024 - 23).

During the year a total of £37,395 (2024: nil) was paid in respect of termination payments.

Total remuneration for key management personnel in the year was £192,944 (2024 - £176,943).

The number of employees with remuneration (excluding employer pension contributions) between:

£60,000 and £70,000 was 1 (2024: 1);

£90,000 and £100,000 was 1 (2024: 1);

12. Comparative information for Statement of Financial Activities

		Unrestricted Funds	Restricted Funds	Total Funds
	Note	£	£	2024 £
INCOME FROM:				
Donations & legacies	3	824,709	1,207,815	2,032,524
Charitable activities				
<i>Grants</i>	4	-	86,376	86,376
Investments	5	51,949	-	51,949
Total income		876,658	1,294,191	2,170,849
EXPENDITURE ON:				
Raising funds	6	(364,726)	-	(364,726)
Charitable activities				
<i>Medical Research</i>	7	(451,744)	(264,400)	(716,144)
<i>Information & Support</i>	8	(436,091)	(139,383)	(575,474)
Total expenditure		(1,252,561)	(403,783)	(1,656,344)
Net movement in funds	9	(375,903)	890,408	514,505
Funds at 1 January 2024	21/23	1,005,442	522,517	1,527,959
Funds at 31 December 2024	21/23	629,539	1,412,925	2,042,464

13. Tangible fixed assets

	Office Equipment £
Cost	
At 1 January 2025	23,798
Disposals	(2,250)
Additions	6,042
At 31 December 2025	27,590
Depreciation	
At 1 January 2025	14,387
Disposals	(2,250)
Charge for year	6,226
At 31 December 2025	18,363
Net book value	
At 31 December 2025	9,227
At 31 December 2024	9,411

14. Investments

	2025 £	2024 £
At as 1 January 2025 and at 31 December 2025	275	275
	2025 £	2024 £
Investments comprise the following:		
Shares in Taylor Woodrow	275	275

All investments are held in the UK.

15. Debtors: Amounts falling due within one year

	2025 £	2024 £
Accrued income	732,066	939,701
Trade debtors	70	4,684
Prepayments	12,873	14,780
Total	745,009	959,165

Accrued income includes £240,000 due from a Trust for medical research activity (2024: £480,000), which will be settled in March 2026.

16. Analysis of cash and cash equivalents

	2025 £	2024 £
Cash at bank and in hand	1,764,112	1,887,763
Total	1,764,112	1,887,763

Includes fixed term deposit of £600,000 for one year ending 27 March 2026 at an interest rate of 2.54% (2024 - nil)

17. Creditors: Amounts falling due within one year

	2025 £	2024 £
Trade creditors	34,071	14,261
Tax and social security	17,830	4,420
Accruals and deferred income	27,400	30,463
Grant liability	731,013	737,664
Other creditors	9,048	27,342
Total	819,362	814,150

18. Contingent assets & liabilities

There is a contingent liability of £551,394 at 31 December 2025 (2024: £976,442) in respect of research grants authorised subject to annual review. This money falls due in years 2026 onwards.

19. Financial commitments

	2025	2024
	£	£
Total future minimum lease payments under non-cancellable operating leases are as follows:		
< 1 year	4,845	2,884
1 - 5 years	12,297	10,278

At 31 December 2025, there was a rent commitment under licence totalling £7,140, due by the end of February 2026 (2024: commitment totalling £51,478, due by the end of February 2026).

20. Unrestricted Funds

	1 Jan 2025 £	Income £	Expenditure £	Transfers £	31 Dec 2025 £
General Fund	380,664	862,091	(984,413)	248,875	507,217
Designated Research Fund	248,875	-	-	(248,875)	-
Total Unrestricted Funds	629,539	862,091	(984,413)	-	507,217

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.

21. Comparative information of Unrestricted Funds movement at 31 December 2024

	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

22. Restricted Funds

	1 Jan 2025 £	Income £	Expenditure £	31 Dec 2025 £
Research Fund	696,544	598,987	(542,049)	753,482
Specified Research Fund	538,056	156,504	(311,835)	382,725
ATCCF Fund	77,952	-	(77,952)	-
Macular Research Fund	1	39,663	(39,663)	1
Information & Support Fund	95,164	91,914	(136,450)	50,628
Awards Fund	1,150	-	-	1,150
Scottish Fund	4,058	-	-	4,058
Total Restricted Funds	1,412,925	887,068	(1,107,949)	1,192,044

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 2025, specific projects funded include volunteers (helpline & training), Conferences, Sight Loss Survey. 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.

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

23. Comparative information of Restricted Funds movement at 31 December 2024

	1 Jan 2024 £	Income £	Expenditure £	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

24. Analysis of net assets between funds

	Tangible Fixed Assets £	Investments £	Current Assets £	Current Liabilities £	Total £
Unrestricted Funds	9,227	275	995,487	(497,772)	507,217
Restricted Funds	-	-	1,513,634	(321,590)	1,192,044
	<u>9,227</u>	<u>275</u>	<u>2,509,121</u>	<u>(819,362)</u>	<u>1,699,261</u>

25. Comparative analysis of net assets between funds 2024

	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
	<u>9,411</u>	<u>275</u>	<u>2,846,928</u>	<u>(814,150)</u>	<u>2,042,464</u>

26. Grants awarded

Institution	Grant Holder	Amount £
Newcastle University	GR602 Prof M Lako	77,952
University of Edinburgh	GR605 Dr R Megaw	59,763
University of Southampton	GR606 Dr J Lakowski	73,015
UCL Institute of Ophthalmology	GR609 Prof J van der Spuy	98,217
UCL Institute of Ophthalmology	GR610 Prof R Pearson	116,101
Manchester Metropolitan University	GR611 Prof L Paraoan	50,000
University College Dublin	GR612 Prof T McCann	50,000
Total		525,048
Opening creditor for grant commitment		737,664
Grant payments		(531,699)
Closing creditor for grant commitment		731,013

27. Related party transactions

There are no related party transactions requiring disclosure in the Financial Statements (2024: 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
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
CPD	Continuing Professional Development
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"
ICO	Information Commissioner's Officer
IRD	Inherited Retinal Dystrophy
LCA	Leber's Congenital Amaurosis
LCA4	Leber's Congenital Amaurosis type 4 (caused by mutations in the AIPL1 gene)
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
SMAB	Scientific and Medical Advisory Board
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