

# Retina UK A Charitable Incorporated Organisation Annual Report & Financial Statements Year Ending 31 December 2023

#### Reference and administrative details

#### For the year ending 31 December 2023

Charity number 1153851

Registered office and operational address

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Honorary President Mrs Lynda Cantor MBE

**Trustees** Trustees who served during the year and up to the date of this report were as follows:

Dr Martin Kirkup (Chair) Mr Ashley Grist (Treasurer) Mr Roger Backhouse Mrs Lynda Cantor MBE

Dr Elizabeth Graham (also known by her legal name, Elizabeth Buckingham)

Prof John Marshall MBE

Mrs Rachael Stevens (until November 2023)

Dr Lucy Withington Mr Simon Keightley

Mr Paresh Makwana (until November 2023)

Ms Vanessa Forster

Mr Colin McArthur (from January 2024)

Ambassadors Mrs Bhavini Makwana

Mr Steven Bate MBE

Mr Amar Latif

Mrs Seema Flower (until November 2023) Mrs Victoria Claire (Until November 2023)

Chief Executive Ms Tina Garvey

Principal Bankers Lloyds Bank

30 Market Place

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**Auditors** Azets Audit Services

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#### **Chair's Report**

#### For the year ending 31 December 2023

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

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

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

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

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

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

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

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

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

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

Dr Martin Kirkup

Chair of the Board of Trustees

#### For the year ending 31 December 2023

The Trustees are pleased to present their annual report together with the financial statements of the charity for the year ending 31 December 2023. The financial statements have been prepared in accordance with the accounting policies set out in the notes to the accounts and comply with the Charity's governing document, the Charities Act 2011 and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2019).

# Structure, Finance & Governance

#### **Governing document**

Retina UK is a Charitable Incorporated Organisation (CIO). The charity's constitution was registered on 18 September 2013 as charity number 1153851 and amended on 19 June 2018. The charity was originally registered as the British Retinitis Pigmentosa Society, formed in 1976, and subsequently known as RP Fighting Blindness until June 2018. All the assets and liabilities of the original charity were transferred to the current Charitable Incorporated Organisation on the date of incorporation.

#### **Appointment of Trustees**

When appointing new Trustees, the Board discusses the Trustees' skills requirements and seeks suitable potential candidates to match those needs. Candidates are interviewed by the Chairman and a panel of Trustees and then considered by the Board as a whole, sometimes after attending a Trustee meeting as an observer. If the Board approves the candidate and the candidate is willing to serve, then they are appointed. The Board of Trustees will always include people affected by an inherited retinal dystrophy or with a family member who is affected. This ensures that the organisation remains focused on the charity's objectives. However, the Board is also conscious of the need to include a range of appropriate skills.

#### Trustee induction and training

Trustees are responsible in law for financial and strategic management and this responsibility is taken very seriously. New Trustees complete an induction process based on briefings by staff, researchers, and existing Trustees. When further training needs are identified these are met by attendance at external courses or by bespoke internal workshops. Trustees are expected to attend most Trustee meetings and the charity's annual conference, and to act in accordance with good practice guidance issued by the Charity Commission.

#### Organisation

The Board of Trustees comprises of a minimum of three and a maximum of twelve members. The Board normally meets quarterly and is quorate for making decisions with a minimum of three fifths of Trustees present. At its meetings the Board reviews financial performance, the awarding and management of research grants, fundraising, and exposure to risk. The day-to-day management of the charity is delegated to the Chief Executive. The Board approves an annual operating budget and measures operational performance against this. Significant expenditure outside the budget must be authorised by the Board. The Board is supported by two sub-committees: the Remuneration Committee and the Audit Committee. These committees carry out reviews on behalf of the Board and report to the Board.

#### Report of the Trustees

#### For the year ending 31 December 2023

#### The Executive Team

The Trustees agree the operational plan and budget and delegate responsibility for day-to-day operations to the Chief Executive who is supported by staff and volunteers bringing valuable skills and experience to the charity.

#### Membership of professional bodies

The charity is a member of the Association of Medical Research Charities (AMRC) and Visionary, and abides by each organisation's principles of best practice at all times.

#### Related parties

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

#### **Key Management Remuneration**

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

#### **Financial Review**

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

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

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

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

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

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

#### For the year ending 31 December 2023

#### **Principal Funding Sources**

The majority of our income is usually from voluntary sources, the key elements of which are the donations and fundraising efforts of individuals and groups across the UK. In addition to this we receive vital funds from corporate and trust donors and are also privileged to receive a number of legacies. The Trustees are aware of the unpredictability of all these sources of income and the need to continue to develop all the income channels. As always, we very much appreciate the efforts of those who give us support.

#### **Investment Policy and Objectives**

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

The charity held equities in a CAF Balanced Growth Fund until June 2023 when CAF closed the fund. We do not plan to invest in further equities at this time, as we will continue to seek to spend our income on suitable medical research projects and on information and support programmes.

#### **Reserves Policy**

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

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

#### **Risk Management**

The charity has carried out a risk management review and has a risk register which identifies the risks to which the charity is exposed. These are evaluated and action taken to mitigate any significant risks. The Trustees review and update this register each year. The experience of the COVID-19 pandemic has resulted in additional risks needing to be added to the register. Short term management of key risks has been undertaken by the Chief Executive and her senior management team, with regular oversight from the Board of Trustees.

# **Going Concern**

The Trustees review the financial position of the charity at each Board meeting. Budgets are prepared and approved annually. We continued to operate the charity on a sustainable basis.

Whilst planning for 2024 and beyond is focussing on increasing charitable impact, the Trustees remain mindful of the risks of future disruption. The Trustees are satisfied that the charity continues to be a going concern.

#### **Future Plans**

We will continue to invest in pioneering medical research and improving information and support for those living with inherited retinal conditions around the UK, their friends, family and the professionals who support them.

#### For the year ending 31 December 2023

We have invested more than £17 million into cutting-edge research since we were founded in 1976 and we are determined to build on the progress made to date.

Through our Project Grants we will continue to support medical research projects of varying length that seek to explore new ideas or test new theories. We awarded three new project grants in 2023.

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

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

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

# **Objectives & Activities**

#### **Our Mission**

We are the only UK charity dedicated exclusively to working for people affected by inherited sight loss. Our vision is a world where everyone with inherited sight loss is able to live a fulfilling life.

We stimulate and fund medical research to increase the understanding of these conditions and accelerate the search for treatments for the future.

We continue to invest in the very best medical research, as reviewed by our independent Medical Advisory Board (MAB). This panel consists of expert world-respected scientists and researchers.

Retina UK is committed to collaborative working. Within the field of medical research, we partner with leading research and other sector-leading charitable organisations with similar aims and objectives to accelerate progress.

We provide information and support to help people lead better lives and to ensure no-one with inherited sight loss feels alone.

The Trustees have paid due regard to guidance issued by the Charity Commission on Public Benefit in deciding what activities the charity should undertake.

# Achievement & Performance

# Research grant funding

The charity is a member of the Association of Medical Research Charities and abides by its principles of best practice in peer review when prioritising which research applications that demonstrate the best scientific merit and likelihood of patient benefit. These principles include the use of a completely independent Medical Advisory Board which makes recommendations to the Board of Trustees regarding the best research applications.

#### Medical Research

The following project summaries give an overview of the medical research work funded by the charity, which were underway in the year ending 31 December 2023.

#### For the year ending 31 December 2023

#### The UK Inherited Retinal Dystrophy Consortium (UKIRDC)

Started 2014 / Ends 2024

We are the lead funder of this project which has received small contributions from two other organisations and has been in operation since late 2014. The project brought together the four largest research groups in the UK specialising in inherited retinal dystrophies: Manchester Royal Eye Hospital, University of Leeds, London's UCL Institute of Ophthalmology and Oxford University Eye Hospital.

It was the first project of its kind in terms of the level of collaborative working required for its success. The consortium joined the Genetics England Clinical Interpretation Partnership (GECIP) associated with the widely publicised UK 100,000 Genome Project. This allowed the team to ensure that ophthalmic genetics were well positioned among the 100,000 genomes being sampled, and one of the consortium investigators was chosen to lead the GECIP in the field of ophthalmology. The progress that the consortium has made in terms of the gathering, analysis and sharing of data has been impressive, and their position as part of the GECIP kept IRDs on the national agenda at a crucial time for research. Importantly, their work has also led to discoveries that would not have been possible without this project, including the identification of seven novel disease-causing genes and further understanding of the role of ten other genes.

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

As the original grant approached its end in 2020, the consortium successfully applied to Retina UK for a new grant to continue their work and allow further investigation of the genome sequences from the original project. This began in December 2020 with the recruitment of a new bioinformatician to support continued data analysis. Other post-doctoral research assistants were appointed later in 2021 to look into variants flagged by the bioinformatics pipeline. One bioinformatician has also developed algorithms to comprehensively mine all of the UKIRDC data for structural variants, following on from the chromosome 17 discovery.

The project has recruited almost 600 people with IRDs and has solved one third of these previously intractable cases, providing families with better understanding of their condition and opening up choices. By communicating their results through meetings and more than 35 publications, the team has also helped clinicians across the globe to interpret the genomes of those living with inherited sight loss. Overall, the consortium has played an important role in advancing our knowledge of IRDs and informing the development of future treatments for those facing visual impairment.

#### The Gene Team Project

Started 2011 / Ended 2023

This high-profile study has been led by Prof Robin Ali at the UCL Institute of Ophthalmology since 2011; in 2020 Prof Ali and the team moved to King's College London to establish a Centre for Cell and Gene Therapy there. The project has been establishing the viability of gene therapy for retinal disorders as a potential treatment and has developed a therapeutic pipeline for at least 11 forms of early-onset severe retinal dystrophies, making excellent progress towards its aims.

So far, the team's work has led to the instigation of four early phase clinical trials, supported by MeiraGTx. One further therapy is also under consideration for clinical testing. The researchers have also treated several infants with a rare form of LCA under a special licence.

The team has amassed considerable expertise in the development of gene therapy delivery systems (vectors) and are applying this to the preclinical development of a number of therapies for retinal conditions and related syndromes. This includes work on the IMPG2 gene, modelling and characterising this particular type of retinal disease in cells and mice and starting to assess the viability of an IMPG2 gene therapy vector. The researchers have demonstrated that this therapy can

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improve photoreceptor structure in a mouse model, although there was minimal impact on visual function, perhaps due to challenges with replicating human phenotype in the mice used. A new CRISPR-based model may prove more useful.

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

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

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

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

The student has made good progress, carefully selecting clinically relevant ABCA4 mutations to target. She has created plasmids (short strands of DNA) containing these mutations, and has then inserted the plasmids into cultured human cells (HEK293T cells), which use the newly introduced genetic code to produce ABCA4 protein. These cells were used to test and optimise various CRISPR constructs the student designed, with some constructs successfully correcting the code and enabling production of full length, healthy ABCA4 protein. This provided proof of concept, but there have been some challenges with off-target effects. Attempts to resolve these will be a key part of the final months of the project.

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

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

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

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

Started 2023 / Ends 2026

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

Mutations in the *USH2A* gene cause Usher syndrome type 2 (USH2A), characterised by early bilateral hearing impairment and later onset of night blindness and visual loss. USH2A is the most

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common cause of deaf-blindness and the most frequent form of recessive Retinitis Pigmentosa (RP). The USH2A mutation spectrum is heterogeneous; moreover, the USH2A gene is too large to be packaged into gene therapy vectors.

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

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

# Deciphering RPGR's role in cone-mediated disc formation

Started 2023 / Ends 2026

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

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

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

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

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

#### Further projects approved during 2023

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

#### For the year ending 31 December 2023

#### Community engagement with research

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

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

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

#### Bringing treatments to the clinic

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

# Information and support

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

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

#### **Conferences**

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

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

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

We will offer a hybrid option for our conferences again in 2024, where those who wish to attend in person can do so and those who are not able to, or prefer not to, can attend online.

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#### Webinars

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

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

#### **Podcast channel**

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

#### YouTube channel

Our YouTube channel saw significant increases in engagement as follows:

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

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

#### Look Forward and e-Newsletters

We continue to provide accurate and trustworthy information and updates in a variety of accessible formats, through our regular newsletters which are available in print (Look Forward only), Word, PDF and audio format (CD and memory stick). Thanks to sponsorship secured from Janssen, we were able to continue with our planned schedule of Look Forward in 2023.

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

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

#### **Eye Care Support Pathway (ECSP)**

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

#### Working with the professional community - phase one

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

#### For the year ending 31 December 2023

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

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

#### Campaigning, influencing and policy

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

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

#### **Delivering training to professionals**

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

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

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

#### **Local Peer Support**

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

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

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

Two new national groups were launched in 2023:

• 'Talking' Tech had five meetings. We have seen returning members and attracted new attendees both community and professional alike.

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

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

#### Helpline

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

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

We received a total of 639 calls in 2023.

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

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

From the information recorded the subject matters are as follows:

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

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

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

#### **Talk and Support**

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

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

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

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

This service has also evolved to support individuals with a wider range of inherited retinal dystrophies and specific conditions, such as Charles Bonnet Syndrome (CBS). We have two further volunteers

#### Report of the Trustees

#### For the year ending 31 December 2023

who specifically support this initiative, both with lived experience of CBS. During 2023, they supported five people experiencing this condition.

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

#### **Volunteers**

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

We also produced our first Volunteer Impact Report in 2023.

#### **Fundraising**

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

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

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

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

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

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

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

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

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

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

#### Report of the Trustees

#### For the year ending 31 December 2023

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

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

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

Highlights for 2024 include:

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

All fundraising in 2023 was carried out by Retina UK in-house fundraising team and by supporters engaged in their own activities in aid of the charity. Retina UK subscribes to the Fundraising Regulator and the Fundraising Preference Service, is licensed by the Gambling Commission, and adheres to the Code of Fundraising Practice as well as the General Data Protection Regulation.

We did not receive any requests via the Fundraising Preference Service to cease contact with any of our supporters and received no complaints about our fundraising in 2023. We aim to fundraise in a fair and transparent way, in line with our values, and we respect the privacy of our donors. Our privacy notice is available to view on our website. We did not carry out any door-to-door fundraising or cold donor acquisition through face-to-face or telemarketing approaches in 2023.

#### How we work with the pharmaceutical industry

We work with pharmaceutical companies in an open, transparent and ethical way, in line with the strict guidelines provided by the Association of British Pharmaceutical companies (ABPI). We ensure that our community has a voice by facilitating participation in surveys, focus groups and research, and we feed into the regulatory and reimbursement processes to evidence the impact of inherited sight loss. Pharmaceutical companies support our work by providing grants for projects that benefit our community, and by sponsoring certain events and activities. In 2023 we were grateful to receive the following support:

Janssen £10,000 to support our Annual and Professionals' Conferences

£36,596 sponsorship of our Look Forward newsletter

£10,000 market access

#### **Trusts and Foundations**

We would like to thank the following trusts and foundations for their generous support of our work in 2023. Their contributions have enabled us to continue supporting our community during challenging times, and to invest in pioneering medical research into inherited sight loss:

- The G W Cadbury Charitable Trust
- G C Gibson Charitable Trust
- Tom and Thelma Wilson Trust
- G S Plaut Charitable Trust

#### **Report of the Trustees**

#### For the year ending 31 December 2023

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

#### Statement of Trustees' Responsibilities

#### For the year ending 31 December 2023

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

The law applicable to charities in England and Wales requires the charity Trustees to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing the financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP 2019 (FRS 102);
- Make judgments and estimates that are reasonable and prudent;
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011 and the Charities (Accounts and Reports) Regulations 2008 and the provisions of the charity's constitution. They are also responsible for safeguarding the assets of the charity and taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the charity and financial information included on the charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Dr M Kirkup Chair

16 July 2024

#### For the year ending 31 December 2023

We have audited the financial statements of Retina UK (the 'charity') for the period ended 31 December 2023 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and the notes to the financial statements, including a summary of significant accounting policies.

The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102; the Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2023 and of its incoming resources and application of resources, for the period then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

# **Basis for opinion**

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

# Conclusions relating to going concern

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

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

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

#### Other information

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

# Matters on which we are required to report by exception

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 require us to report to you if, in our opinion:

- the information given in the financial statements is inconsistent in any material respect with the Trustees' report; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records; or
- we have not received all the information and explanations we require for our audit.

# **Responsibilities of Trustees**

As explained more fully in the statement of Trustees' responsibilities, the Trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error. In preparing the financial statements, the Trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to cease operations, or have no realistic alternative but to do so.

# Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

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

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

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

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

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

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

#### Independent Auditor's Report to the Members of Retina UK

#### For the year ending 31 December 2023

- 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

Alet Audit Perser 24 July 2024

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 2023

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

#### **Balance Sheet**

# For the year ending 31 December 2023

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

A Grist

Treasurer

Date: 16 July 2024

Dr M Kirkup Chair

Date: 16 July 2024

# **Cash Flow Statement**

# For the year ending 31 December 2023

Cash flows from operating activities:  Note	2023 £	2022 £
Net (expenditure)/income for the reporting period	(508,667)	13,284
Adjustments for: Depreciation charges 13 Losses on investments 14 Dividends and interest from investments 5 Decrease in debtors 15 Increase/(decrease) in creditors 18 Increase/(decrease) in grant creditors 18	4,237 1,880 (47,399) 279,003 24,973 471,800	3,678 13,406 (6,656) 293,129 (11,910) (99,713)
Net cash from operating activities	225,827	205,218
Cash flows from investing activities:Dividends and interest from investments5Purchase of tangible fixed assets13Proceeds of disposal of investments14Cash on fixed term deposit16	47,399 (7,887) 260,181 -	6,656 (2,078) - (600,000)
Cash flows from investing activities	299,693	(595,422)
Change in cash and cash equivalents in the year	525,520	(390,204)
Cash and cash equivalents at 1 January 2023 17	931,940	1,322,144
Cash and cash equivalents at 31 December 2023 17	1,457,460	931,940

# 1. Legal status of the charity

The charity is a Charitable Incorporated Organisation (CIO) registered in England and Wales, registered number 1153851. The address of the registered office is given in the reference and administrative details on page 2 of these financial statements. Each member pays an annual subscription, is entitled to vote at the AGM, and has a duty to exercise his or her powers as a member of the CIO in the way he or she decides in good faith would be most likely to further the purposes of the CIO. If the CIO is wound up, the members of the CIO have no liability to contribute to its assets and no personal responsibility for settling its debts and liabilities.

# 2. Accounting Policies

#### Basis of preparing the financial statements

The charity constitutes a public benefit entity as defined by FRS 102. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued in October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued in October 2019 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

The financial statements have been prepared under the historical cost convention except where investments held as fixed assets are held at market value. The financial statements are prepared in  $\pounds$  sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest  $\pounds$ .

#### Goina 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 2023

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.

#### **Notes to the Accounts**

#### For the year ending 31 December 2023

#### **Financial instruments**

#### **Financial assets**

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

#### Financial liabilities

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

#### Cash at bank and in hand

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

#### **Taxation**

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

#### **Pension costs**

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

#### **Fund accounting**

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

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

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

#### **Operating leases**

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

# 3. Donations and Legacies

	2023 £	2022 £
	L	1
Membership subscriptions/donations	28,474	30,667
Individual donations	101,882	338,101
Trusts	140,760	111,944
Corporate	65,769	91,175
Legacies/In memoriam	542,476	535,255
Fundraising	192,005	140,892
Prize draw/appeals/mailings	57,145 54,404	64,933
Gift aid	51,104	37,700
_ , .		
Total	1,179,615_	_1,350,667
	2023	2022
	2023	2022
A. Grants  Medical research funding	2023 £	2022 £ 60,010
I. Grants  Medical research funding Government grants	2023 £	2022 £
I. Grants  Medical research funding	2023 £	2022 £ 60,010

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

6. Raising funds		
3	2023	2022
	£	£
Event costs	15,777	23,399
Materials and equipment	168	211
Collection fees	9,382	6,942
Appeals	4,182	8,684
Training and conferences	200	482
Donor development including trusts & corporates	1,528	3,331
Gift aid	-	1,293
Other	4,139	1,242
Support costs (see note 10)	264,314	250,364
Total	299,690	295,948
7. Medical research		
	2023	2022
	£	£
Annual grant awards	712,656	402,702
Grant donation for medical research	· -	128,920
Support costs (see note 10)	193,387	93,231

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

906,043

624,853

**Total** 

# 8. Information & Support

2023	2022
£	£
20,682	20,819
30,551	32,996
8,281	13,735
3,633	7,005
14,093	12,767
8,028	7,029
5,040	49,439
-	12,056
8,786	7,912
4,023	6,825
484,951	444,558
588,068	615,141
	£ 20,682 30,551 8,281 3,633 14,093 8,028 5,040 8,786 4,023 484,951

# 9. Net movement in funds is stated after charging

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

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

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

# 10. Analysis of support costs

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

## 11. Staff numbers and costs

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

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

Total remuneration for key management personnel in the year was £171,062 (2022: £96,828). The number of employees with remuneration (excluding employer pension contributions) between:

£60,000 and £70,000 was 1 (2022: 0);

£70,000 and £80,000 was 0 (2022: 0);

£80,000 and £90,000 was 0 (2022: 0);

£90,000 and £100,000 was 1 (2022: 1).

# 12. Comparative information for Statement of Financial Activities

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

# 13. Tangible fixed assets

13. Tangible fixed assets	ı	Office Equipment £
Cost At 1 January 2023 Disposals Additions		24,671 (11,014) 7,887
At 31 December 2023	_	21,544
<b>Depreciation</b> At 1 January 2023 Disposals Charge for year		19,935 (11,014) 4,237
At 31 December 2023		13,158
Net book value At 31 December 2023	_	8,386
At 31 December 2022		4,736
14. Investments		
	2023 £	2022 £
At 1 January 2023 Disposals Unrealised loss	262,336 (262,061) -	275,742 - (13,406)
As at 31 December 2023	275	262,336
	2023 £	2022 £
Included within investments are the following: CAF balanced growth fund at valuation Shares in Taylor Woodrow	- 275	262,061 275
	275	262,336
All investments are held in the UK.		

15.	Debtors:	Amounts	falling	due	within	one	year

13. Debicis. Amounts failing due within one y	Gai	
	2023	2022
	£	£
Accrued income	343,812	610,854
Trade debtors	-	5,246
Prepayments	9,115	15,830
Total	352,927	631,930
16. Current asset investments		
	2023	2022
	£	£
Cash on fixed term deposit	600,000	600,000
Total	600,000	600,000
17. Analysis of cash and cash equivalents	2023 £	2022 £
Cash at bank and in hand	1,457,460	931,940
Total	1,457,460	931,940
18. Creditors: Amounts falling due within one	voar	
10. Orcators. Amounts family due within one	2023	2022
	£	£
Trade creditors	15,009	6,658
Tax and social security	15,938	14,573
Accruals and deferred income	48,713	33,671
Grant liability	809,912	338,112
Other creditors	1,517	1,302
Total	891,089	394,316

# 19. Contingent assets & liabilities

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

20.	Financial commitments		
		2023	2022
		£	£
	al future minimum lease payments under non-cancellable rating leases are as follows:		
< 1	year	2,884	15,412
1 - 5	o years	10.278	35.236

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

# 21. Unrestricted Funds

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

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

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

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

#### **Notes to the Accounts**

#### For the year ending 31 December 2023

## 23. Restricted Funds

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

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

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

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

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

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

#### **Notes to the Accounts**

#### For the year ending 31 December 2023

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

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

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

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

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

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

#### **Notes to the Accounts**

#### For the year ending 31 December 2023

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

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

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

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

# 25. Analysis of net assets between funds

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

# 26. Comparative analysis of net assets between funds 2022

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

#### 27. Grants awarded

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

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

# 28. Related party transactions

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