



**Retina UK**  
**A Charitable Incorporated Organisation**  
**Annual Report & Financial Statements**  
**Year Ending 31 December 2022**

## Retina UK

### Reference and administrative details

#### For the year ending 31 December 2022

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<b>Charity number</b>	1153851
<b>Registered office and operational address</b>	Retina UK PO Box 350 Buckingham MK18 1GZ
<b>Telephone</b>	01280 821334
<b>Email</b>	info@RetinaUK.org.uk
<b>Website</b>	www.RetinaUK.org.uk
<b>Honorary President</b>	Mrs Lynda Cantor MBE
<b>Trustees</b>	Trustees who served during the year and up to the date of this report were as follows:  Dr Martin Kirkup (Chair) Mr Ashley Grist (appointed 26 January 2022; Treasurer from 22 June 2022) Ms Janet Crookes (Treasurer until 22 June 2022) Mr Roger Backhouse Mrs Lynda Cantor MBE Dr Elizabeth Graham Prof John Marshall MBE Mrs Rachael Stevens Dr Lucy Withington Mr Simon Keightley (appointed 26 January 2022) Mr Paresh Makwana (appointed 26 January 2022) Ms Vanessa Forster (appointed 26 January 2022)
<b>Ambassadors</b>	Mrs Bhavini Makwana Mr Steven Bate MBE Mr Amar Latif  Mrs Seema Flower Mrs Victoria Claire
<b>Chief Executive</b>	Ms Tina Garvey
<b>Principal Bankers</b>	Lloyds Bank 30 Market Place Brackley NN13 7BA
<b>Auditors</b>	Azets Audit Services Epsilon House The Square Gloucester Business Park Gloucester GL3 4AD

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## Retina UK

### Chair's Report

#### For the year ending 31 December 2022

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

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

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

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

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

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

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

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

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

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

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

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

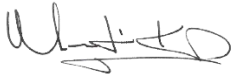
**Retina UK**

**Chair's Report**

**For the year ending 31 December 2022**

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



Dr M Kirkup  
Chair  
4 May 2023

The Trustees are pleased to present their annual report together with the financial statements of the charity for the year ending 31 December 2022. The financial statements have been prepared in accordance with the accounting policies set out in the notes to the accounts and comply with the Charity's governing document, the Charities Act 2011 and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (effective 1 January 2019).

## **Structure, Finance & Governance**

### **Governing document**

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

### **Appointment of Trustees**

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

### **Trustee induction and training**

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

### **Organisation**

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

### **The Executive Team**

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

**Membership of professional bodies**

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

**Related parties**

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

**Key Management Remuneration**

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

**Financial Review**

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

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

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

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

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

**Principal Funding Sources**

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

### **Investment Policy and Objectives**

The charity's investment policy remains unchanged: for any funds surplus to short term requirements we consider using secure deposits on fixed terms of up to one year. The charity holds equities in a CAF Balanced Growth Fund with the objective of gaining a return in excess of that available on short term deposits. This investment forms the core of the amount held under our Reserves policy and so is held for the long term. We do not plan to increase our investment in equities as we will continue to seek to spend our income on suitable medical research projects and on information and support programmes.

### **Reserves Policy**

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

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

### **Risk management**

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

### **Going Concern**

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

Whilst planning for 2023 and beyond is focussing on increasing charitable impact, the Trustees remain mindful of the risks of future disruption. The Trustees are satisfied that the charity continues to be a going concern.

### **Future Plans**

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

We have invested more than £17 million into cutting-edge research since we were founded in 1976 and we are determined to build on the progress made to date. Significant progress is being made in the causes of and treatments for Inherited Retinal Dystrophies (IRDs) and there is good reason to be hopeful.

Through our Project Grants we will continue to support medical research projects of varying length that seek to explore new ideas or test new theories. We invited applications for research grants in 2022 with 15 preliminary submissions. A decision on these applications will be made in 2023.

## Report of the Trustees

### For the year ending 31 December 2022

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

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

## Objectives & Activities

### Our Mission

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

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

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

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

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

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

## Achievement & Performance

### Research grant funding

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

### Medical Research

The following project summaries give an overview of the medical research work funded by the charity, which were underway in the year ending 31 December 2022.

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

Started 2014 / Ends 2023

We are the lead funder of this project which has received small contributions from two other organisations and has been in operation since late 2014. The project brought together the four largest research groups in the UK specialising in inherited retinal dystrophies: Manchester Royal Eye



## Retina UK

### Report of the Trustees

#### For the year ending 31 December 2022

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Hospital, University of Leeds, London's UCL Institute of Ophthalmology and Oxford University Eye Hospital.

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

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

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

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

#### **The Gene Team Project**

Started 2011 / Ends 2023

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

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

The team has amassed considerable expertise in the development of gene therapy delivery systems (vectors) and are applying this to the preclinical development of a number of therapies for retinal conditions and related syndromes. This includes work on the IMPG2 gene, modelling and characterising this particular type of retinal disease in cells and mice and starting to assess the viability of an IMPG2 gene therapy vector. So far, the impact of the therapy in the mice has been minimal, but the team will try testing the intervention at an earlier stage.

**Development of CRISPR gene therapy for Stargardt disease**

Started 2020 / Ends 2023

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

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

The student has made good progress over the first two years of the project, carefully selecting clinically-relevant ABCA4 mutations to target. She has created plasmids (short strands of DNA) containing these mutations, and has then inserted the plasmids into cultured human cells (HEK293T cells), which use the newly introduced genetic code to produce ABCA4 protein. These cells were used to test and optimise various CRISPR constructs the student designed, with some constructs successfully correcting the code and enabling production of full length, healthy ABCA4 protein. This has provided proof of concept, and will enable the student to progress to testing in other models during her final PhD year.

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

Started 2022 / Ends 2025

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

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

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

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

**2022/2023 PhD studentship grant round**

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

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

### **Community engagement with research**

2022 saw Retina UK continue its efforts to facilitate engagement between members of our community and researchers. We publicised eight research participation opportunities via our social media channels and e-newsletters, as well as directly emailing community members who have expressed a wish to take part in such activities. Our research participation panel now includes over 450 members.

Participation has included industry-led activities to learn more about the lived experience of those X-linked RP, questionnaire-based studies on the impact of Charles Bonnet Syndrome, and a clinical trial. Interaction between those living with IRDs and the research community is essential for progress; it also provides our community with choices about participation, and opportunities to influence the direction of research.

### **Bringing treatments to the clinic**

Securing NHS availability for new therapies is the essential final step in enabling those living with IRDs to access life-changing treatment. In 2022, Retina UK joined the Charity Medicines Access Coalition (CMAC) to add our voice to those of other organisations in challenging and influencing policy around licensing and reimbursement.

### **Information and support**

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

### **Conferences**

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

We were delighted that most of the presenters were able to be with us live in Birmingham. This proved to be enormously successful; more than 400 delegates registered to attend the Annual Conference; almost 200 registered for the Professionals' Conference. The theme for 2022 was Wellbeing and included the launch of our new 'Discover Wellbeing' website and resources.

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

Following the success of the 2021 AGM, the voting process was completed in advance with eligible members offered the opportunity to vote online, in writing (hard copy) or by telephone to ensure accessibility. The hybrid nature of the AGM offered members the opportunity to ask questions.

We will offer a hybrid option for our conferences and AGM again in 2023 where those who wish to attend in person can do so and those who are not able to, or prefer not to, can attend online.

### Discover Wellbeing

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

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

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

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

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

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

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

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

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

### Webinars

Following the successes of the 2021 webinars, we delivered a series of monthly webinars (online via Zoom) throughout 2022 on a number of topics. These were very well received by those living with inherited sight loss and the professionals who support them. Recordings of the webinars were made available on our YouTube channel and our Podcast channel (audio only).

Report of the Trustees

For the year ending 31 December 2022

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

**Information days**

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

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

**Podcast channel**

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

**YouTube channel**

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

**Look Forward and e-Newsletters**

We continue to provide accurate and trustworthy information and updates in a variety of accessible formats, through our regular newsletters which are available in print (Look Forward only), Word, PDF and audio format (CD and memory stick). Thanks to sponsorship secured from Janssen, we were able to continue with our planned schedule of Look Forward in 2022, publishing it three times during the year. A total of 21,803 copies of Look Forward were distributed and 28,722 copies of the e-Newsletter.

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

**Local Peer Support**

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

### Report of the Trustees

#### For the year ending 31 December 2022

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

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

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

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

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

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

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

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

*“It was a good session! Very well organised and professional.”*

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

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

### Helpline

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

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

## Retina UK

### Report of the Trustees

#### For the year ending 31 December 2022

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were people asking for information about their condition, research and genetic testing and counselling.

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

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

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

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

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

#### Talk and Support

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

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

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

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

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

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

## Retina UK

### Report of the Trustees

#### For the year ending 31 December 2022

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

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

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

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

### Volunteers

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

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

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

### Fundraising

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

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

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

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

All fundraising in 2022 was carried out by Retina UK in-house fundraising team and by supporters engaged in their own activities in aid of the charity. Retina UK subscribes to the Fundraising Regulator and the Fundraising Preference Service, is licensed by the Gambling Commission, and adheres to the Code of Fundraising Practice as well as the General Data Protection Regulation.



### Report of the Trustees

#### For the year ending 31 December 2022

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We did not receive any requests via the Fundraising Preference Service to cease contact with any of our supporters, and received no complaints about our fundraising in 2022. We aim to fundraise in a fair and transparent way, in line with our values, and we respect the privacy of our donors. Our privacy notice is available to view on our website. We did not carry out any door-to-door fundraising or cold donor acquisition through face-to-face or telemarketing approaches in 2022.

#### How we work with the pharmaceutical industry

We work with pharmaceutical companies in an open, transparent and ethical way, in line with the strict guidelines provided by the Association of British Pharmaceutical companies (ABPI). We ensure that our community has a voice by facilitating participation in surveys, focus groups and research, and we feed into the regulatory and reimbursement processes to evidence the impact of inherited sight loss. Pharmaceutical companies support our work by providing grants for projects that benefit our community, and by sponsoring certain events and activities. In 2022 we were grateful to receive the following support:

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

#### Trusts and Foundations

We would like to take this opportunity to thank the following trusts and foundations for their generous support of our work in 2022. Their contributions have enabled us to continue supporting our community during challenging times, and to invest in pioneering medical research into inherited sight loss:

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

## Retina UK

### Report of the Trustees

#### For the year ending 31 December 2022

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

**Statement of Trustees' Responsibilities**

**For the year ending 31 December 2022**

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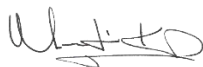
The Trustees are responsible for preparing the Trustees' annual report and financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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

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

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

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



Dr M Kirkup  
Chair  
4 May 2023

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

**For the year ending 31 December 2022**

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We have audited the financial statements of Retina UK (the 'charity') for the period ended 31 December 2022 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and the notes to the financial statements, including a summary of significant accounting policies.

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

In our opinion, the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2022 and of its incoming resources and application of resources, for the period then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

### **Basis for opinion**

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

### **Conclusions relating to going concern**

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

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

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

### **Other information**

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

We have nothing to report in this regard.

## **Matters on which we are required to report by exception**

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

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

## **Responsibilities of Trustees**

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

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

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

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

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

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

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

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

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

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

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

### For the year ending 31 December 2022

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- 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

.....  
Epsilon House  
The Square  
Gloucester Business Park  
Gloucester  
GL3 4AD

Azets Audit Services is eligible for appointment as auditor of the charity by virtue of its eligibility for appointment as auditor of a company under of section 1212 of the Companies Act 2006.

Retina UK

Statement of Financial Activities

For the year ending 31 December 2022

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

Retina UK

Balance Sheet

For the year ending 31 December 2022

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



A Grist  
Treasurer  
Date: 4 May 2023



Dr M Kirkup  
Chair  
Date: 4 May 2023



## Cash Flow Statement

For the year ending 31 December 2022

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

## 1. Legal status of the charity

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

## 2. Accounting Policies

### Basis of preparing the financial statements

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

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

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

### Going concern

The actions taken by the charity in response to the challenges arising from the COVID-19 pandemic have mitigated the level of ongoing risk. The Trustees are satisfied that there are no material uncertainties about the charity's ability to continue as a going concern.

### Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Income from government and other grants is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received, and the amount can be measured reliably.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the Trust that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

Dividends, donations and fund raising receipts are taken to income on a received basis. Membership subscriptions are allocated to income in the year to which they relate. Any funds raised but not remitted are accounted for appropriately within the balance sheet. Membership and other income received in advance is deferred until the criteria for income recognition are met.

#### **Donated services**

The charity benefits from the donated time and services of many individuals across a wide range of roles. These are not normally accounted for as it is not practicable to attribute a value. Where services are donated, and a reliable estimate of the cost can be made, this is included as donated income and as expenditure under the appropriate headings.

#### **Interest receivable**

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the Bank.

#### **Expenditure**

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources as set out in the notes to the financial statements. Irrecoverable VAT is charged against the category of expenditure expended for which it is incurred.

#### **Grants**

Grants payable are accounted for on an accruals basis. The charity's policy on research is to limit grant funding commitments to one year. Subject to a satisfactory review of progress and funds being available, grants are then approved for funding on a year-to-year basis.

#### **Allocation of support costs**

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Support costs include office costs, finance, personnel, payroll and governance costs which support the charity's projects, programmes and activities. These costs have been allocated between the categories of expenditure on charitable activities. The bases on which support costs have been allocated are set out in the notes to the financial statements and the weighting is reviewed on an annual basis.

#### **Investments**

Investments are initially measured at transaction price excluding transaction costs, and are subsequently measured at fair value at each reporting date. Transaction costs are expensed as incurred. Gains or losses arising on revaluation or disposal of investments are recognised in the Statement of Financial Activities in the period to which they relate.

#### **Tangible fixed assets**

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

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

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

### **Financial instruments**

#### **Financial assets**

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

#### **Financial liabilities**

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

#### **Cash at bank and in hand**

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

#### **Taxation**

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

#### **Pension costs**

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

#### **Fund accounting**

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

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

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

#### **Operating leases**

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

### 3. Donations and Legacies

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

### 4. Grants

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

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

### 5. Investments

	2022 £	2021 £
Share dividends	2,190	2,885
Bank interest	4,466	125
<b>Total</b>	<b>6,656</b>	<b>3,010</b>

**6. Raising funds**

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

**7. Medical research**

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

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

In 2022, a grant donation of £128,920 was made from our restricted RDH12 Fund to the charity 'Eyes on the Future' (2021: £91,283 to Moorfields Eye Charity) to fund relevant research as we had not been able to identify a suitable project to fund directly with remaining funds.

**8. Information & Support**

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

**9. Net movement in funds is stated after charging**

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

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

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

**10. Analysis of support costs**

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

**11. Staff numbers and costs**

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

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

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



## 12. Comparative information for Statement of Financial Activities

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

**13. Tangible fixed assets**

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

**14. Investments**

	2022 £	2021 £
At 1 January 2022	275,742	244,121
Disposals	-	(113)
Unrealised (losses) / gains	(13,406)	31,734
<b>As at 31 December 2022</b>	<u>262,336</u>	<u>275,742</u>
	2022 £	2021 £
Included within investments are the following:		
CAF balanced growth fund at valuation	262,061	275,467
Shares in Taylor Woodrow	275	275
	<u>262,336</u>	<u>275,742</u>

All investments are held in the UK.

**15. Debtors: Amounts falling due within one year**

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

**16. Current asset investments**

	2022 £	2021 £
Cash on fixed term deposit	600,000	-
<b>Total</b>	<b>600,000</b>	<b>-</b>

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

**17. Analysis of cash and cash equivalents**

	2022 £	2021 £
Cash at bank and in hand	931,940	1,322,144
<b>Total</b>	<b>931,940</b>	<b>1,322,144</b>

**18. Creditors: Amounts falling due within one year**

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

**19. Contingent assets & liabilities**

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

**20. Financial commitments**

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

**21. Unrestricted Funds**

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

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

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

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

## Retina UK

### Notes to the Accounts

For the year ending 31 December 2022

### 23. Restricted Funds

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

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

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

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

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

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

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

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

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

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

## Retina UK

### Notes to the Accounts

For the year ending 31 December 2022

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

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

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

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

	Research Fund	Usher Fund	Awards Fund	RDH12 Fund	Pioneering Research Fund	Info & Support Fund	Specified Project Fund	Scottish Fund	Macular Research Fund	Specified Research Fund	Total Restricted Funds
	£	£	£	£	£	£	£	£	£	£	£
At 1 January 2021	347	2,545	1,150	118,639	1,100	42,340	24,981	2,558	45	18,719	212,424
Income	246,510	275	-	105,262	-	99,646	-	-	41,790	101,545	595,028
Expenditure	25	-	-	(100,463)	-	(118,647)	(22,751)	-	(41,835)	-	(283,671)
At 31 December 2021	246,882	2,820	1,150	123,438	1,100	23,339	2,230	2,558	-	120,264	523,781

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**25. Analysis of net assets between funds**

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

**26. Comparative analysis of net assets between funds 2021**

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

**27. Grants awarded**

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

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

**28. Related party transactions**

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