



**RP Fighting Blindness**  
**A Charitable Incorporated Organisation**  
**Annual Report & Financial Statements**  
**Year Ending 31 December 2017**

## **RP Fighting Blindness**

### **Reference and administrative details**

**For the year ending 31 December 2017**

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<b>Charity number</b>	1153851
<b>Registered office and operational address</b>	RP Fighting Blindness PO Box 350 Buckingham MK18 8GZ
<b>Telephone</b>	01280 821334
<b>Email</b>	info@rpfightingblindness.org.uk
<b>Website</b>	www.rpfightingblindness.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:  Mr Don Grocott (Chairman) Mr Roger Backhouse Mrs Lynda Cantor MBE Ms Janet Crookes FCA (Treasurer) Dr Elizabeth Graham Mr Stephen Jones Mr Colin McArthur Prof John Marshall MBE Mrs Rachael Stevens Mr Keith Valentine (from 1 February 2017) Dr Lucy Withington
<b>Ambassadors</b>	Mrs Bhavini Makwana Mr Steven Bate MBE
<b>Chief Executive Officer</b>	Mrs Tina Houlihan
<b>Principal Bankers</b>	Lloyds Bank PLC 187 Watling Street Towcester NN12 6BX
<b>Auditors</b>	Davies Mayers Barnett Audit Services Statutory Auditors Pillar House 113 - 115 Bath Road Cheltenham GL53 7LS

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## **RP Fighting Blindness**

### **Chairman's Report**

**For the year ending 31 December 2017**

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When this charity was set up just over forty years ago, the plan was to raise money to spend on research that would aid our understanding of retinitis pigmentosa, to stop or, better, reverse its progress in those who have inherited RP and move us nearer to finding ways of eliminating it. You will see in this report, on our website and in many of our communications that real progress is being made on all those fronts.

Almost all of the projects we fund step us along the way. Our most ambitious, the UK Inherited Retinal Dystrophy Consortium, is identifying relevant genes and bringing us ever nearer to achieving our aims. We have a great deal to be proud of because we have initiated unique cooperation and exemplary data sharing across four primary hub institutions and a growing number of other centres working with people who have inherited retinal disease. And they are getting results. Dr Lucy Withington, one of our trustees, attends the consortium's quarterly meetings at which scientists, clinicians and informatics experts share results, exchange views and report progress. I attend those meetings when I can and both Lucy and I are enormously encouraged by the effectiveness and energy of all those participating.

Many other strands of research are progressed with funding from us - you can learn about the broad range of projects we support on pages seven to ten.

There are now competing commercial companies developing gene therapies specifically for RP. Some of these companies were spun out of academic and clinical research institutions where we sponsored the initial work. Other companies are pioneering devices to bring vision back to those who have lost it.

As all this progresses, we realise that what might have seemed simple - a single aim - is extraordinarily complex because so many other factors and related conditions affect RP. That has prompted the Board of Trustees to think very carefully about how wide or how narrow should be our focus. An obvious question about a particular research proposal might be: is it clearly and directly looking at RP and, if the answer is no, should we automatically not support it? You will see the results of that thinking as we adapt our charity to such developments.

This is the most encouraging time for our charity. We have a fully engaged Trustee Board with appropriately diverse talents. We have a highly effective Chief Executive leading a very dedicated and hardworking team to deliver our goals. Many expert academics, clinicians and scientists support us by helping to assess research applications, by speaking at Information Days and Members' meetings and by looking out for what will help us achieve what we want. Like everyone engaged with this charity, I am enormously grateful to them, to the researchers we support, to the Board, to the team in Buckingham and to you. And next year, through all these efforts, I believe that we will come ever closer to an effective treatment for inherited sight loss.



DJ Grocott  
Chairman  
2 May 2018

## **RP Fighting Blindness**

### **Report of the Trustees**

#### **For the year ending 31 December 2017**

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The Trustees are pleased to present their annual report together with the financial statements of the charity for the year ending 31 December 2017. The financial statements comply with the Charities Act 2011, the constitution, 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 (FRS 102) (effective 1 January 2015).

### **Structure, Finance & Governance**

#### **Governing document**

RP Fighting Blindness is a Charitable Incorporated Organisation (CIO). The charity's current constitution was registered on 18 September 2013 as charity number 1153851. The charity was originally registered as the British Retinitis Pigmentosa Society, formed in 1976. All the assets and liabilities of the previous charity were transferred to the new 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 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 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 delegate responsibility for day to day operations to the Chief Executive and agree an operational plan and budget. The Chief Executive is supported by staff and volunteers who bring various skills and experience to the charity.

#### **Membership of professional bodies**

The charity is a member of the Association of Medical Research Charities, Retina International and VISION 2020 UK and seeks to abide by each organisation's principles of best practice at all times.

## **RP Fighting Blindness**

### **Report of the Trustees**

**For the year ending 31 December 2017**

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#### **Related parties**

Trustees are required to maintain 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, that Trustee withdraws from any discussion on the awarding of the contract and the value of any contract subsequently awarded would be disclosed in these accounts.

#### **Key Management Remuneration**

The remuneration of the Chief Executive is set by the Chairman of the Board of Trustees in consultation with the Remuneration Committee.

#### **Financial Review**

In our last Annual Report, we stated that we were looking to improve our work on information and support services, and to embrace the opportunities for collaborative funding for specific areas of vital research. 2017 has also been a year in which the charity sector faced further challenges in respect of fundraising methods and effectiveness.

All these factors impacted on our financial position at 31 December 2017. Income for the year of £1,152,733 was down on 2016 (£1,613,502) with substantially less being received in legacies and from community and challenge events. This was not surprising as 2016 was our 40th Anniversary year which boosted fundraising by our supporters. Our focus on collaborative fundraising gained momentum although this will not be reflected until 2018 when we will be able to further support ongoing vital research.

We continued to pay close attention to all areas of expenditure whilst seeking to fulfil our charitable objectives. Expenditure on information and support services was £555,205 (2016: £315,176). Grant awards for medical research totalled £390,553. This was a reduction from the previous year (£687,581) as some significant projects came to an end, but with our new awards our contingent liabilities for future grant funding have increased to £583,781.

We ended 2017 with a decrease in total funds and a further shift from unrestricted to restricted funds as shown in the Financial Statements. Internal systems are being improved to help us manage the different income and expenditure streams. Overall, the Board continues to be satisfied that the balance sheet provides a strong platform to support the work of the charity as we move through 2018.

#### **Principal Funding Sources**

The majority of our income is 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. The charity continues to develop all the income channels and very much appreciates 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 continue to use 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. The value of 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, as well as on information and support programmes.

## **RP Fighting Blindness**

### **Report of the Trustees**

**For the year ending 31 December 2017**

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#### **Reserves Policy**

Our Reserves Policy has been amended slightly. The Trustees consider it appropriate to maintain unrestricted funds to cover six months budgeted essential expenditure which we see as adequate in the event of the charity being forced to wind up. At 31st December 2017 the target level of unrestricted funds was decreased to £280,000 reflecting this change. Any additional unrestricted funds may be designated by the Trustees for research grants. £72,000 was therefore transferred to designated funds leaving £280,834 as general unrestricted funds (shown in Note 21).

#### **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 have been evaluated and action taken to mitigate any significant risks. The Trustees review and update this register each year.

#### **Auditors**

During the year the Audit Committee undertook a review of the appointment of the external auditors, using best practice guidance. As a result of this review the Board confirmed the appointment of Davies Mayers Barnett LLP. Due to organisational changes at the firm of auditors, Davies Mayers Barnett LLP resigned as auditors on 30th October 2017 and were replaced by Davies Mayers Barnett Audit Services, a trading name of Baldwins Audit Services Limited. This is essentially a continuation of the previous service.

#### **Going Concern**

The Trustees review the financial position of the charity at each Board meeting. Budgets are prepared and approved annually and the Trustees are satisfied that there are no material uncertainties about the charity's ability to continue as a going concern.

#### **Future Plans**

RP Fighting Blindness will continue investing heavily in pioneering medical research, and in improving patient service provision across the whole of the UK. We are in the process of creating a new research funding model which will see us working collaboratively with leading institutions to increase investment in Inherited Retinal Dystrophy (IRD) research at a crucial time in the mission for delivering treatments. We want to accelerate research and recognise an important way forward is for us to work in partnership with other charities and research organisations. Our new regional approach for patient support and services will continue to be rolled out across all areas of the UK, transforming the way in which we offer practical assistance in providing a lifeline to children, young people and adults who are in the process of losing their sight. This local approach brings our services closer to the community and allows for more tailored, effective service provision.

The charity is aware of the need to remain relevant as scientific understanding increases, and public perceptions change. 2017 has seen work undertaken to explore the possibility of a rebrand for the organisation, to ensure the charity is futureproof and as visible as possible within the sector. The Trustees expect this process to be complete by mid-2018 and will be consulting with key stakeholders during this review and implementation process.

#### **Objectives & Activities**

##### **Our Mission**

RP Fighting Blindness stimulates and supports high quality medical research with the aim of increasing scientific understanding of progressive sight loss and provides information, support and services to those affected. The Trustees consider the Charity Commission's guidance on public benefit when planning and reviewing activities and when approving applications for research grant funding. The Trustees include several people who either have an IRD or have a close family member with an IRD.

## **RP Fighting Blindness**

### **Report of the Trustees**

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The charity aspires to a world in which anyone affected by progressive sight loss conditions is fully supported and has ready access to treatment, and so does not need to fear the loss of their sight. Whilst working towards this, RP Fighting Blindness is committed to focusing on its objectives, to transparency in all matters, to collaborating with other organisations, to fair business practices and equal opportunity.

RP Fighting Blindness works on the principle of providing care for today and hope for tomorrow for those affected by an IRD. It is achieving this by funding more pioneering medical research than ever before which will provide an effective and readily available treatment for progressive sight loss, and it continues to improve its patient services provision through the rollout of its regional delivery model. This ambitious programme is seeing the charity working in partnership with local service providers and national organisations to offer better support for the whole patient community.

The charity continues to invest in the very best medical research, as reviewed by our independent Medical Advisory Board. This panel consists of expert world-respected scientists and researchers. Our medical research programme has invested over £14.5m into research since the charity's inception in 1976. RP Fighting Blindness is committed to collaborative working within the field of medical research, and is developing partnerships with leading research institutions and other high profile charitable organisations with similar aims and objectives to accelerate progress.

#### **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.

#### **Acknowledgements**

The Trustees and staff are extremely grateful to everyone who has supported RP Fighting Blindness during 2017. We rely on those individuals, groups, companies and organisations who support our work so generously and know that without their contributions we would be unable to deliver vital services and fund pioneering research.

We received a number of legacies in 2017, as well as in-memoriam income; we must express our thanks to those people who remembered the charity in their wills and to the many families who honoured their loved ones with generous gifts in their memory.

We would like to take this opportunity to thank the following charitable trusts and foundations for their generous support during 2017:

- A and S Graham Charitable Trust
- The Albert Van Den Bergh Charitable Trust
- Allergan International Foundation
- The Annett Trust
- The Arden Trust
- BE Rodmell Trust
- Bosphorus Foundation
- The Carmen Butler-Charteris Charitable Trust
- The David Fryer Charitable Trust
- The Desmond Foundation
- The Dixie Rose Findlay Charitable Trust
- The G C Gibson Charitable Trust

## **RP Fighting Blindness**

### **Report of the Trustees**

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- The Gertrude Gourvitch Charitable Trust
- The Gilbert and Eileen Edgar Foundation
- The Hospital Saturday Fund
- The Inman Charity
- John Laing Charitable Trust
- The Lady Eileen Joseph Foundation
- Masonic Charitable Foundation
- The Mildred Duveen Charitable Trust
- Nineteen Eighty Nine Charitable Trust
- The Samuel Storey Family Charitable Trust
- Sir Samuel Scott of Yews Trust
- St. James's Place Charitable Foundation
- The Tedworth Charitable Trust
- Thomas Pocklington Trust
- Woolton Charitable Trust
- The Wyseliot Rose Charitable Trust

### **Achievement & Performance**

#### **Medical Research**

RP Fighting Blindness is supporting ground breaking research from some of the world's leading scientists in an effort to develop treatments for inherited retinal dystrophies. In 2017 the charity supported eight ongoing scientific research projects and approved funding for four new ones.

The work being supported seeks to identify novel drug targets to slow retinal degeneration as well as supporting replacement of faulty genes via gene therapy. Stem cells are also being used to help understand why certain gene changes lead to disease.

All of this work has been rigorously peer reviewed and is of a very high standard. As retinal research is generally underfunded it is vital RP Fighting Blindness supports this work as in the long term it will give the best hope for treatment of these sight threatening conditions. The following project summaries give an overview of the medical research work funded by the charity in the year ending 31<sup>st</sup> December 2017.



## RP Fighting Blindness

### Report of the Trustees

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Our joint partnership project, *The UK Inherited Retinal Dystrophy Genome Project* which we are managing in conjunction with Fight for Sight, has been in operation since late 2014. Lead by Prof Graeme Black, 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. Three further sites have been added to the study since its inception, widening the scope for collaboration and the availability of data and resources. A further research site is currently under consideration to join the group. The consortium has become a Genetics England Clinical Interpretation Partnership (GECIP) associated with the UK 100,000 Genome Project. This allows the team to ensure that ophthalmic genetics are well positioned among the 100,000 genomes being sampled and one of the consortium investigators has been 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 will keep 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, advancing our knowledge of IRDs and informing the development of future treatments for those facing visual impairment. The project is running until September 2018, and the consortium is currently pursuing continuation funding in order to continue this ground-breaking work.

A further high profile study, *The Gene Team Project*, has been led by Prof Robin Ali at the UCL Institute of Ophthalmology since 2011. It has been establishing the viability of gene therapy for retinal disorders as a potential treatment and its aim is to build a programme of clinical trials for various forms of retinal dystrophy. The team is currently conducting the world's first ocular gene therapy trial for Leber's congenital amaurosis (LCA2) associated with the gene RPE65. The first results of this trial demonstrate improvements in vision and, along with the results of two other trials, have established proof of principle for gene therapy in inherited retinal disease. The team has also demonstrated proof of concept of gene therapy in animal models of several other forms of LCA, and developed a therapeutic pipeline for at least 11 forms of early-onset severe retinal dystrophies including nine of the 16 different forms of LCA. In addition to therapy for RPE65 deficiency, the project has developed four more therapies to the point at which they are almost ready for human application in clinical trials. The team plans to maintain its current clinical studies, complete preclinical development of gene therapy for LCA4 gene therapy and help secure substantial funding from other sources for a broad programme of clinical trials of gene therapy for inherited retinal disorders.

Prof Robin Ali at the UCL Institute of Ophthalmology is also leading the study *Maintaining Effective Antioxidant Capacity in a degenerating Retina: A Generic approach to treatment in RP*. Gene therapy can restore function in many forms of RP, but it may not prevent further degeneration unless treatment begins early. Many different RP genes directly or indirectly cause reduced photoreceptor function, but these may lead to an abnormal retinal state which causes the disease to progress. Targeting the factors driving rather than initiating the degeneration could form the basis for a generic and widely applicable therapy for RP. Degenerating retinas show high levels of oxidative stress, which Prof Ali suggests drive the degeneration. This project is thoroughly investigating the major antioxidant pathway (PRDX3) in retinal mitochondria, the powerhouses of the cell, which are a major site of oxidative stress. This study examines this pathway in depth in a mouse model of RP and deliver PRDX3 and / or its re-cycling components by sub-retinal gene therapy in order to slow photoreceptor loss, as a step towards a generic treatment for RP.

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Prof Mike Cheetham is leading the project *Pharmacological therapies for rhodopsin retinitis pigmentosa* at the UCL Institute of Ophthalmology. This project aims to advance pre-clinical development of these drugs, quantifying their efficacy and suitability for the various rhodopsin mutations present in the UK patient population. Ultimately, this study will facilitate the future translation of these promising pre-clinical findings to the clinic trials stage. The team has now shown that some drugs can delay the death of these photoreceptor cells and prolong vision in the animals. This application aims to extend these recent findings to identify the most effective drugs that offer the best protection to photoreceptor cells. The project will also examine the range of rhodopsin gene changes found in the UK and test which ones might be treatable with these drugs. This approach could lead to the development of pharmacological treatments for rhodopsin retinitis pigmentosa and potentially other forms of retinitis pigmentosa.

*The development of human iPSC-derived ex vivo models of retinal degeneration and their analysis in splicing-factor RP* is being investigated by Prof Andrew Webster at the UCL Institute of Ophthalmology. A recent innovation allows the creation of stem cells from human skin and the transformation of these into retinal cells for use in the laboratory. The team has undertaken detailed analysis of a number of patient samples to identify the root genetic cause of the mechanisms by which the retinal cells are damaged, and it has also investigated samples from carriers of a disease-causing mutation, some of whom show symptoms of RP and some of whom do not, in an attempt to identify why this might be.

Dr Jacqueline van der Spuy of the UCL Institute of Ophthalmology investigated Leber congenital amaurosis (LCA) patients for *AIPL1-targeted gene therapy through functional validation of uncharacterised and novel AIPL1 variants*. The team has been able to establish conclusive evidence confirming the disease-causing status of AIPL1 variations detected in patients with Leber congenital amaurosis (LCA) recruited at Moorfields Eye Hospital. These findings are critical for supporting the accurate diagnosis and effective triage of LCA patients with these mutations.

*DNA Damage as a Driver of Photoreceptor Loss in X-linked retinitis pigmentosa* is being studied by Dr Toby Hurd of the University of Edinburgh. Mutation of the RP2 gene causes retinitis pigmentosa but the mechanism by which this happens is still not fully understood. Current data suggests that a reduced ability to deal with oxidative stress and DNA damage may be the issue, and this project aims to explore whether this is the underlying cause. It will also test whether drugs which target DNA repair pathways and/or antioxidant therapies represent a suitable treatment option. The team has been able to demonstrate in vitro, loss of the RP2 gene does not impair a cell's ability to detect DNA damage, however cells appear to be intrinsically more sensitive to DNA damaging agents. Data has been generated indicating that this may be due to disruption of a critical organelle in the cell known as the Golgi, which regulates the delivery of proteins to specific regions of the cell. Furthermore, the team has begun to test whether inhibitors of DNA-PKcs can restore Golgi function. Very preliminary data suggests that two DNA-PKcs inhibitors can restore Golgi morphology. Together, this data expands on a novel emerging role for DNA-PKcs in regulating Golgi function independent of its role in dealing with DNA damage, and provides a novel mechanism to account for defects observed in photoreceptors. Additionally, this provides a new avenue of research investigating if the inhibition of DNA-PKcs represents a novel strategy to slow or halt photoreceptor degeneration in RP patients.

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Prof Mike Cheetham at the UCL Institute of Ophthalmology is leading the project Aberrant RNA processing in Retinal Dystrophies: understanding mechanisms and developing therapies. This project is building upon previous research to better understand why gene mutations that might be tolerated elsewhere in the body can cause disease in the retina when this splicing process goes wrong. It is also testing potential treatments using stem cell technology. Using an artificially produced retina the team discovered that photoreceptors maximise the information in their genes by splicing them together in complex ways to produce specialised proteins. This helps them to fulfil their highly complex function of detecting light, but it does make them more vulnerable to mutations. Sometimes they mistakenly splice in the wrong information, disrupting their function. A method called RNAseq has been used to identify the complex splicing events and which parts of the genes the photoreceptors stick together during the process. The team has also identified the time window during which the splicing process occurs, and has produced stem cells with intentionally disrupted splicing factors to test whether they affect photoreceptor function. A number of individuals with potential splicing faults have been identified to study in more detail in the future.

*Identification and functional characterisation of the missing ABCA4 variants in Stargardt disease* is a project being run by Frans Cremer at Radboud UMC. ABCA4 mutations affect the majority of people with recessive Stargardt disease and about 30% of those with con-rod dystrophy. This project aims to develop a cost-effective sequencing method for the entire ABCA4 gene, sequence 1,000 Stargardt's cases worldwide and finalise a process for testing the effects of mutations. Ultimately the diagnosis of people with an ABCA4 mutation will be improved, and the identification of those suitable for participation in future clinical trials made easier.

In the 2017 call for grant applications Dr Mariya Moosajee from the UCL Institute of Ophthalmology had her project *Non-viral gene therapy using S/MAR vectors for Usher Syndrome* approved. Usher syndrome is the commonest cause of deaf-blindness worldwide with USH2A being the most prevalent causative gene. The team plan to adapt a non-viral gene delivery system, containing a human DNA element called scaffold / matrix attachment regions (S/MAR) to encase USH2A. They will be treating human-derived retinal cells from an Usher syndrome patient with a USH2A mutation and zebrafish disease models. The team will then assess the therapeutic response by looking at retinal structure, toxicity, visual function and long-term gene expression. Non-viral S/MAR vectors may revolutionise the treatment of inherited retinal disorders by providing a safer and more applicable form of gene therapy.

Another approved project in the 2017 call for grant applications was that of Dr Arjuna Ratnayaka of the University of Southampton; *Modelling effects of TIMP-3 mutations in RPE- insights into Sorsby disease and night blindness in retinal dystrophies*. Sorsby fundus Dystrophy (SFD) is a disease where changes in the protein TIMP3 cause patients to lose night vision and to eventually go blind. Earlier work using cell-lines, mouse models and donor eyes have shown how mutated TIMP3 behaves differently to normal TIMP3 proteins. TIMP3 proteins are made by a carpet of cells under the retina called the Retinal Pigment Epithelium (RPE). However, very little work has been done to understand how exactly RPE cells become damaged by mutant TIMP3. For the first time, Dr Ratnayaka's team has successfully grown RPE cells directly from SFD patients using their own skin cells, allowing them to study how mutant TIMP3 damages RPE cells in SFD. Gene-editing technology will then be used to correct mutated TIMP3 and study how damaged RPE cells can be rescued by 'restored' TIMP3. The team will use retinal scans from patients to study gradual sight loss, and identify new ways of recognising and tracking SFD. By providing these retinal images as well as their skin cells, these SFD patients allow us to link any cellular changes with disease changes in their eyes. The findings could help design effective future treatments.

## **RP Fighting Blindness**

### **Report of the Trustees**

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##### **Fundraising**

The Fundraising Team worked hard to sustain income levels following our successful 40th Anniversary Year in 2016. It achieved income of £1,152,733 thanks to the enthusiasm and generosity of our fantastic supporters.

Particular highlights included growth in major donor income to £132,570, plus £40,295 secured in sponsorship of our events and activities, growth in our appeals income to more than £50,000 thanks to a successful Christmas campaign and raffle, a Virgin London Marathon Team which collectively raised more than £30,000 and an amazing trek along the West Highland Way which raised £19,500 for the charity.

Plans to expand the department's size and scope were implemented, with investment in the corporate, major donor and community fundraising income streams. The team looks forward to building on these foundations in order to fund the exciting developments planned for 2018 and beyond.

A collaborative research funding partnership was agreed with the Macular Society, which will fund projects specifically into macular conditions such as Stargardt disease, Sorsby fundus dystrophy and others. We also started negotiations for our first Pioneering Research Centre, which aims to increase investment into research at a crucial time through collaboration with a leading UK institution.

All fundraising at RP Fighting Blindness is carried out by the charity's own fundraising team, or by supporters engaged in their own activities in aid of the charity. There was one exception to this during 2017, when a fundraising consultant was contracted to research and approach corporate prospects whilst an internal member of staff was recruited.

RP Fighting Blindness subscribes to the Fundraising Regulator, and adheres to their Fundraising Code of Practice. We have received no complaints about our fundraising activities in 2017, and no requests via the Fundraising Preference Service to cease contact with any of our supporters.

We place our community and supporters at the centre of everything we do, and are committed to protecting them from unreasonable intrusion into their privacy, excessively persistent approaches or undue pressure to give. We have not carried out any door to door fundraising, or cold donor acquisition through face to face or telemarketing approaches during 2017.

##### **Services**

2017 was a busy and transformational year for the Services team, starting as the Engagement Department and evolving into the Services Department; this change reflects the deeper community work the team is now undertaking, directly offering and facilitating more support and patient services.

The team delivered a mixed programme of events including regional Information Days and the first ever RP Fighting Blindness Families' Conference. The department also represented the organisation at five Sight Village roadshow events and a number of local partner events, plus maintained the RP Helpline, Befriending Service and various patient resources.

The Families' Conference was held centrally, in Milton Keynes, specifically for families affected by IRDs. It saw 150 people attending from across the UK for a three day programme of speaker presentations, interactive workshops, fun activities and Q&A sessions. It was developed as a fully-inclusive way to provide affected families the opportunity to meet and socialise in an informal setting, and to learn more about the services and support available to them. The conference was a great success and the feedback gained from attendees is helping shape the future direction of the charity's support services.

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The Services team also contributed to a successful Information Share session at a Stargardts Day run by Moorfields Hospital; the event brought 150 patients and professionals together to learn more about Stargardt disease and the range of support services available to people living with the condition.

2017 saw our Services Department contact over 360 organisations providing eye health services, plus social care and education specialists working with people affected by IRDs or related syndromes. Contacts were encouraged to sign up to a newly devised scheme which will provide free professional membership to the charity and associated benefits.

In August the charity's first Professionals e-Bulletin was sent to 191 professionals who had signed up following recruitment at events throughout the year. The Professionals e-Bulletin contains information about events, reminds key workers about the services and resources provided by the charity and ensures the organisation always remains in mind. The Professionals e-Bulletin distribution list had swelled to over 300 by the close of the year.

At the end of 2017 we started a new way of delivering services to people affected by IRDs introducing a new regional services delivery model. This will eventually lead to the creation of five regions developed across the UK, each having a Regional Service Manager delivering and facilitating local services and working closely with partner organisations on collaborative projects. The development of the first two regions is well under way in the Central & North Wales and North West & Northern Ireland areas. In these initial areas a Regional Service Manager has been recruited, both of whom are networking in their regions and attending meetings with other organisations and sight loss professionals, laying the foundations for future working.

#### **Ambassador Programme**

RP Fighting Blindness has two volunteer Ambassadors who represent the organisation for fundraising and awareness purposes. An RPFBA Ambassador is someone with a strong interest in supporting our work, an understanding of and interest in fundraising and excellent communication skills. This will usually be someone of standing or profile either within our own community, or in the wider public.

Bhavini Makwana joined the organisation as an Ambassador in 2016 and has run a number of events ranging from interactive workshops to charity dinners. She works with the charity South East London Vision (SELVIS) and set up her own group for support and socialisation called SocialEyes.

Steven Bate MBE joined RP Fighting Blindness as an Ambassador in late 2017. A double gold Paralympic medallist, he presented at the charity's annual conference as an inspirational speaker to great admiration. Steven looks forward to helping promote the charity in 2018 and beyond.

#### **Trustees' responsibilities in relation to the financial statements**

The charity 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 2015 (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;

## **RP Fighting Blindness**

### **Report of the Trustees**

**For the year ending 31 December 2017**

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- 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 Charity (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.

A handwritten signature in black ink, appearing to read 'DJ Grocott', followed by a long horizontal stroke and a period.

DJ Grocott  
Chairman  
2 May 2018

## **Independent Auditor's Report to the Members of RP Fighting Blindness**

**For the year ending 31 December 2017**

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### **Opinion**

We have audited the financial statements of RP Fighting Blindness (the 'charity') for the year ended 31st December 2017 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and 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).

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 auditor's 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.

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31st December 2017, and of its incoming resources and application of resources, for the year 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**

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the Trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charity's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

### **Other information**

The Trustees are responsible for the other information. The other information comprises the information included in the Trustees' annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, 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 audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a

## **Independent Auditor's Report to the Members of RP Fighting Blindness**

**For the year ending 31 December 2017**

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material misstatement of the other information. 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 Trustees' responsibilities statement, the Trustees are responsible for the preparation of financial statements which 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 liquidate the charity or to cease operations, or have no realistic alternative but to do so.

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

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 for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our auditor's report.



### **Davies Mayers Barnett Audit Services**

Statutory Auditors  
Pillar House  
113/115 Bath Road  
Cheltenham  
Gloucestershire  
GL53 7LS

Date: 2/5/18

Davies Mayers Barnett Audit Services is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.



# RP Fighting Blindness

## Statement of Financial Activities

For the year ending 31 December 2017

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2017 £	Total Funds 2016 £
<b><u>INCOME FROM:</u></b>					
Donations & legacies	3	813,537	325,256	1,138,793	1,511,289
Charitable activities					
Medical research grants	4	-	-	-	82,296
Information, support & engagement	5	-	75	75	6,500
Investments	6	13,865	-	13,865	13,417
<b>Total income</b>		<b>827,402</b>	<b>325,331</b>	<b>1,152,733</b>	<b>1,613,502</b>
<b><u>EXPENDITURE ON:</u></b>					
Raising funds	7	337,290	15,065	352,355	349,650
Charitable activities					
Medical research grants	8	213,435	199,405	412,840	700,647
Information, support & engagement	9	543,231	11,974	555,205	315,176
<b>Total expenditure</b>		<b>1,093,956</b>	<b>226,444</b>	<b>1,320,400</b>	<b>1,365,473</b>
Net gains / losses on investments		22,777	-	22,777	15,667
<b>Net movement in funds</b>	<b>10</b>	<b>(243,777)</b>	<b>98,887</b>	<b>(144,890)</b>	<b>263,696</b>
<b>Funds at 1 January 2017</b>	<b>21/23</b>	<b>652,452</b>	<b>60,540</b>	<b>712,992</b>	<b>449,296</b>
<b>Funds at 31 December 2017</b>	<b>21/23</b>	<b>408,675</b>	<b>159,427</b>	<b>568,102</b>	<b>712,992</b>

# RP Fighting Blindness

## Balance Sheet

At 31 December 2017

		2017	2016
	Note	£	£
<b>FIXED ASSETS</b>			
Tangible fixed assets	14	6,549	2,614
Investments	15	261,929	239,152
<b>Total fixed assets</b>		<b>268,478</b>	<b>241,766</b>
<b>CURRENT ASSETS</b>			
Debtors	16	135,419	71,595
Cash at bank and in hand		1,169,248	896,716
<b>Total current assets</b>		<b>1,304,667</b>	<b>1,612,314</b>
<b>LIABILITIES</b>			
Creditors: Amounts due within 1 year	18	(1,005,043)	(1,141,082)
<b>Net current assets</b>		<b>299,624</b>	<b>471,229</b>
<b>Net assets</b>		<b>568,102</b>	<b>712,992</b>
<b>FUNDS</b>			
Unrestricted	21	408,675	652,452
Restricted	23	159,427	60,504
<b>Total funds</b>		<b>568,102</b>	<b>712,956</b>

Approved by the Trustees and signed on their behalf by:

*Janet E. Crookes*  
*D J Grocott*

**J E Crookes**  
Treasurer  
2 May 2018

**D J Grocott**  
Chairman  
2 May 2018

## RP Fighting Blindness

### Cash Flow Statement

For the year ending 31 December 2017

<b>Cash flows from operating activities:</b>	<b>2017</b>	<b>2016</b>
	<b>£</b>	<b>£</b>
<b>Net income / (expenditure) for the reporting period</b>	<b>(144,890)</b>	<b>263,696</b>
<b>Adjustments for:</b>		
Depreciation charges	1,600	863
Unrealised gains on investments	(22,777)	(15,667)
Dividends and interest from investments	(13,865)	(13,417)
(Increase) decrease in debtors	580,176	(456,436)
Increase (decrease) in creditors	85,250	(1,110)
Increase (decrease) in grant creditors	(221,289)	(73,333)
<b>Net cash used in operating activities</b>	<b>264,205</b>	<b>(295,404)</b>
<b>Cash flows from investing activities:</b>		
Dividends and interest from investments	13,865	13,417
Purchase of tangible fixed assets	(5,538)	(3,154)
<b>Cash flows from investing activities</b>	<b>8,327</b>	<b>10,263</b>
<b>Change in cash and cash equivalents in the year</b>	<b>272,532</b>	<b>(285,141)</b>
<b>Cash and cash equivalents at 1 January 2017 (Note 17)</b>	<b>896,716</b>	<b>1,181,857</b>
<b>Cash and cash equivalents at 31 December 2017 (Note 17)</b>	<b>1,169,248</b>	<b>896,716</b>

## **RP Fighting Blindness**

### **Notes to the Accounts**

**For the year ending 31 December 2017**

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#### **1. Legal status of the charity**

The charity is a Charitable Incorporated Organisation (CIO) registered number 1153851. 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 of the charity have been prepared in accordance with the Charities SORP (FRS 102) '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) (effective 1 January 2015)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland', the Charities Act 2011. The financial statements have been prepared under the historical cost convention except where investments held as fixed assets are held at market value.

##### **Going concern**

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.

## **RP Fighting Blindness**

### **Notes to the Accounts**

**For the year ending 31 December 2017**

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#### **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 revised on an annual basis.

#### **Investments**

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

#### **Tangible fixed assets**

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

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

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

#### **Financial instruments**

##### ***Financial assets***

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

## **RP Fighting Blindness**

### **Notes to the Accounts**

**For the year ending 31 December 2017**

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#### ***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 cash 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.

## RP Fighting Blindness

### Notes to the Accounts

For the year ending 31 December 2017

#### 3. Incoming Resources

	2017 £	2016 £
<b>Donations &amp; legacies</b>		
Membership subscriptions/donations	40,842	29,425
Individual donations	226,304	116,251
Trusts	80,623	191,081
Donated services	109,500	-
Corporate	26,330	29,675
Legacies/In memoriam	315,460	653,905
Fundraising	232,532	414,263
Prize draw/appeals/mailings	52,075	13,585
Gift Aid	55,127	66,104
<b>Total</b>	<b>1,138,793</b>	<b>1,514,289</b>

#### 4. Medical research grants

	2017 £	2016 £
Research funding	-	82,296
<b>Total</b>	<b>-</b>	<b>82,296</b>

#### 5. Information, support & engagement

	2017 £	2016 £
Event sponsorship - PID	75	6,500
<b>Total</b>	<b>75</b>	<b>6,500</b>

#### 6. Investments

	2017 £	2016 £
Share dividends	5,083	5,547
Bank interest	8,782	7,870
<b>Total</b>	<b>13,865</b>	<b>13,417</b>

## RP Fighting Blindness

### Notes to the Accounts

For the year ending 31 December 2017

#### 7. Raising funds

	2017 £	2016 £
Event costs	84,225	116,919
Materials & equipment	10,507	2,188
Collection fees	11,936	14,446
Travel expenses	3,009	5,134
Consultancy & campaigns	4,189	2,400
Major donor development	15,095	6,353
Other	12,626	3,781
Support costs (see note 11)	210,768	198,429
<b>Total</b>	<b>352,355</b>	<b>349,650</b>

#### 8. Medical research

	2017 £	2016 £
Annual grant awards	390,553	687,581
MAB expenses	226	300
Support costs (see note 11)	22,061	12,766
<b>Total</b>	<b>412,840</b>	<b>700,647</b>

#### 9. Information, support & engagement

	2017 £	2016 £
Publications, DVDs, leaflets etc	15,473	16,189
Annual conference	16,553	12,015
Helpline support	6,958	343
Patient information events	885	6,889
Helpline training	4,897	6,400
Engagement events	41,507	5,457
Engagement expenses	8,820	5,322
Retina International	10,101	7,144
Other	9,016	2,248
Support costs (see note 11)	440,995	253,169
<b>Total</b>	<b>555,205</b>	<b>315,176</b>



## RP Fighting Blindness

### Notes to the Accounts

For the year ending 31 December 2017

#### 10. Net movement in funds is stated after charging

	2017 £	2016 £
Auditor's remuneration (audit)	5,534	5,500
Auditor's remuneration (accountancy services)	1,000	1,400
Depreciation	1,600	863
Trustees' expenses	1,576	970
Lease payments	13,500	13,250

Trustees' expenses represent amounts reimbursed to two Trustees for expenses incurred (2016 - 2)  
No Trustee received any remuneration during the year.

#### 11. Analysis of support costs

	Total £	Fund- raising £	Research £	Info, support & engagement £	Basis of apportionment
Office administration	214,548	41,572	1,193	171,783	Staff time or actual
Human resources/Remuneration	413,530	157,760	20,868	234,902	Staff time
Governance	45,746	11,436		34,310	Staff time or actual
<b>Total</b>	<b>673,824</b>	<b>210,768</b>	<b>22,061</b>	<b>440,995</b>	
Governance costs in 2016	28,815	11,526	-	17,289	

## RP Fighting Blindness

### Notes to the Accounts

For the year ending 31 December 2017

#### 12. Staff numbers and costs

	2017	2016
	£	£
Wages and salaries	387,970	314,034
Social Security costs	32,183	25,876
Pension costs	7,837	7,810
	<u>427,990</u>	<u>344,720</u>
Miscellaneous staff related costs (including donated services)	105,176	3,405
<b>Total</b>	<u><b>533,166</b></u>	<u><b>348,125</b></u>

The number of persons employed by the charity during the year was 16 (2016 - 13).

The services of two persons were donated during the year.

During the year a total of £25,000 was paid in respect of termination agreements.

Total remuneration (including employers NIC) for key management personnel in the year was £68,956 (2016 - £63,120).

The number of employees with remuneration (excluding employers NIC) between £60,000 - £70,000 was 1 (2016 - 0).

## RP Fighting Blindness

### Notes to the Accounts

For the year ending 31 December 2017

#### 13. Comparative information for Statement of Financial Activities

	Unrestricted Funds	Restricted Funds	Total Funds 2016
	£	£	£
<b><u>INCOME FROM:</u></b>			
Donations & legacies	1,129,868	381,421	1,511,289
Charitable activities			
<i>Medical research grants</i>	-	82,296	82,296
<i>Information, support &amp; engagement</i>	-	6,500	6,500
Investments	13,417	-	13,417
<b>Total income</b>	<b>1,143,285</b>	<b>470,217</b>	<b>1,613,502</b>
<b><u>EXPENDITURE ON:</u></b>			
Raising funds	349,650	-	349,650
Charitable activities			
<i>Medical research grants</i>	172,445	528,202	700,647
<i>Information, support &amp; engagement</i>	308,676	6,500	315,176
<b>Total expenditure</b>	<b>830,771</b>	<b>534,702</b>	<b>1,365,473</b>
Net gains / (losses) on investments	15,667	-	15,667
<b>Net movement in funds</b>	<b>328,181</b>	<b>(64,485)</b>	<b>263,696</b>
<b>Funds at 1 January 2016</b>	<b>324,271</b>	<b>125,025</b>	<b>449,296</b>
<b>Funds at 31 December 2016</b>	<b>652,452</b>	<b>60,540</b>	<b>712,992</b>

## RP Fighting Blindness

### Notes to the Accounts

For the year ending 31 December 2017

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#### 14. Tangible fixed assets

	Office Equipment £
<b>Cost</b>	
At 1st January 2017	30,098
Additions	5,538
<b>At 31st December 2017</b>	<b>35,636</b>
<b>Depreciation</b>	
At 1st January 2017	27,487
Charge for year	1,600
<b>At 31st December 2017</b>	<b>29,087</b>
<b>Net book value</b>	
<b>At 31st December 2017</b>	<b>6,549</b>
At 31st December 2016	2,611

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#### 15. Investments

	2017 £	2016 £
At 1 January 2017	239,152	223,485
Unrealised (losses)/gains	22,777	15,667
<b>As at 31 December 2017</b>	<b>261,929</b>	<b>239,152</b>
Included within investments are the following:	2017 £	2016 £
CAF balanced growth fund at valuation	261,541	238,764
Shares in Taylor Woodrow	275	275
3% City of Liverpool stock	113	113
	<b>261,929</b>	<b>239,152</b>

All investments are held in the UK

## RP Fighting Blindness

### Notes to the Accounts

For the year ending 31 December 2017

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#### 16. Debtors: Amounts falling due within one year

	2017 £	2016 £
Accrued income	<del>121,496</del>	680,938
Prepayments	<del>13,923</del>	34,657
<b>Total</b>	<b><u><u>135,419</u></u></b>	<b><u><u>715,595</u></u></b>

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#### 17. Analysis of Cash and cash equivalents

	2017 £	2016 £
Cash in hand	<del>1,169,248</del>	896,716
<b>Total</b>	<b><u><u>1,169,248</u></u></b>	<b><u><u>896,716</u></u></b>

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

	2017 £	2016 £
Trade creditors	<del>239,534</del>	159,668
Accruals and deferred income	<del>13,646</del>	8,262
Grant liability	<del>751,863</del>	973,152
<b>Total</b>	<b><u><u>1,005,043</u></u></b>	<b><u><u>1,141,082</u></u></b>

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#### 19. Contingent Assets & Liabilities

There is a contingent liability of £583,781 at 31 December 2017 (2016: £207,911) in respect of research grants authorised subject to annual review. This money falls due in years 2018 onwards.

There are no contingent assets at 31 December 2017 (2016: £100,000).

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## RP Fighting Blindness

### Notes to the Accounts

For the year ending 31 December 2017

#### 20. Financial commitments

	2017 £	2016 £
Total future minimum lease payments under non-cancellable operating leases are as follows:		
< 1 year	13,500	13,500
1 - 5 years	40,500	54,000

#### 21e Unrestricted Funds

	General Fund £	Designated Research Fund £	Total Unrestricted Funds £
Balance at 1 January 2017	405,452	247,000	652,452
Transfer between funds	(72,000)	72,000	-
Net incoming resources	(52,618)	(191,159)	(243,777)
<b>Balance at 31 December 2017</b>	<b>280,834</b>	<b>127,841</b>	<b>408,675</b>

Designated Research Fund: These general unrestricted funds have been designated for medical research by the Trustees in view of the contingent liabilities in respect of grant expenditure.

#### 22. Comparative information of Funds movement at 31 December 2016

##### Unrestricted Funds

	General Fund £	Designated Research Fund £	Total Unrestricted Funds £
Balance at 1 January 2016	270,271	54,000	324,271
Transfer between funds	(193,000)	193,000	-
Net incoming resources	328,181	-	328,181
<b>Balance at 31 December 2016</b>	<b>405,452</b>	<b>247,000</b>	<b>652,452</b>

## RP Fighting Blindness

### Notes to the Accounts

For the year ending 31 December 2017

#### 23. Restricted Funds

	Inno- vation Fund £	Usher Fund £	Awards Fund £	Sponsor- ship Fund £	Specified Research Fund £	Total Restricted Funds £
Balance at 1 Jan 2017	-	3,616	1,332	5,000	50,592	60,540
Net incoming resources	27,786	26,158	(57)	(5,000)	50,000	98,887
<b>Balance at 31 Dec 2017</b>	<b>27,786</b>	<b>29,774</b>	<b>1,275</b>	<b>-</b>	<b>100,592</b>	<b>159,427</b>

*Innovation Fund:* This fund was created for new and innovative research projects.

*Usher Fund:* These donations were specifically allocated by the donors as being for Usher Syndrome related research. The Trustees accepted these monies on that understanding.

*Awards Fund:* This was initiated by a donation in 2010 to fund the provision of the John George Memorial Award for Volunteering for an indefinite period, and other awards at the discretion of the Trustees.

*Sponsorship Fund:* This fund was set up to fund a Families' Conference as part of information and support remits.

*Specified Research Fund:* This fund is for specified research.

#### 24. Comparative of Restricted Funds 2016

	Anniversary Research Fund £	Specified Research Fund £	Usher Fund £	Awards Fund £	Sponsor- ship Fund £	Scottish Research Fund £	Total Restricted Funds £
Balance at 01 January 2016	104,524	14,246	3,616	1,494	-	1,145	125,025
Net incoming resources	(104,524)	36,346	-	(162)	5,000	(1,145)	(64,485)
<b>Balance at 31 December 2016</b>	<b>-</b>	<b>50,592</b>	<b>3,616</b>	<b>1,332</b>	<b>5,000</b>	<b>-</b>	<b>60,540</b>

*Anniversary Research Fund:* This fund was created as part of our fortieth anniversary year and was designated for medical research in 2016.

**RP Fighting Blindness**

**Notes to the Accounts**

**For the year ending 31 December 2017**

**25. Analysis of Net Assets between Funds**

	<b>Tangible Fixed Asset £</b>	<b>Fixed Asset Investment £</b>	<b>Current Assets £</b>	<b>Current Liabilities £</b>	<b>Total £</b>
Restricted Funds	-	-	266,718	(107,291)	159,427
Unrestricted Funds	6,549	261,929	1,037,949	(897,752)	408,675
	<b><u>6,549</u></b>	<b><u>261,929</u></b>	<b><u>1,304,667</u></b>	<b><u>(1,005,043)</u></b>	<b><u>568,102</u></b>

**26. Comparative of net assets analysis between Funds 2016**

	<b>Tangible Fixed Assets £</b>	<b>Fixed Asset Investments £</b>	<b>Current Assets £</b>	<b>Current Liabilities £</b>	<b>Total £</b>
Restricted funds	-	-	290,938	(230,398)	60,540
Unrestricted funds	2,611	239,152	1,321,373	(910,684)	652,452
<b>Total</b>	<b><u>2,611</u></b>	<b><u>239,152</u></b>	<b><u>1,612,311</u></b>	<b><u>(1,141,082)</u></b>	<b><u>712,992</u></b>



## RP Fighting Blindness

### Notes to the Accounts

For the year ending 31 December 2017

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#### 27. Grants awarded - 2017

Institution		Grant Holder	Amount £
Institute of Ophthalmology	GR576	Prof ReAli	93,103
UK Inherited Retinal Dystrophy Consortium	GR586	- *	11,008
Western General Hospital, Edinburgh	GR588	Dr T Hurd	65,194
University of Southampton	GR590	Dr A Ratanyaka	59,635
Radboud University, The Netherlands	GR591	Dr F Cremers	68,096
Institute of Ophthalmology	GR592	Dr M Moosajee	78,517
Newcastle University	GR593	Prof M Lako	15,000
<b>Total</b>			<b>390,553</b>
Opening creditor for grant commitment			973,152
Grant payments - 2017			(611,842)
Closing creditor for grant commitment			<b>751,863</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

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#### 28. Related party transactions

There are no related party transactions requiring disclosure in the Financial Statements (2016 - none).

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