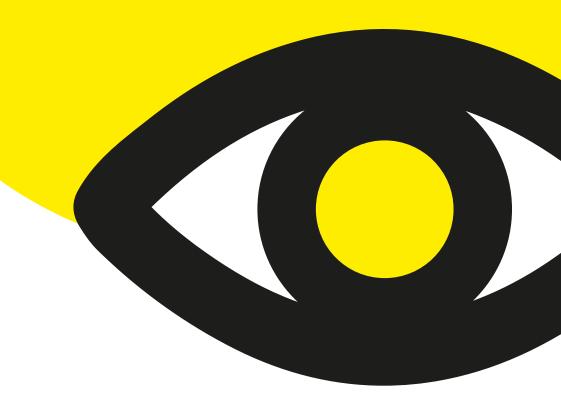
# Macular Society Beating Macular Disease

The Macular Disease Society operating under the name The Macular Society

### Report and Accounts 31 December 2021



# Macular Society Report and Accounts for year ended 31 December 2021

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for year ended 31 December 2021

President	Timothy ffytche, LVO, FRCS, FRCOphth
	(from 9 February 2021)

Patrons Henry Blofeld OBE \*

Gemma Craven \*

Gwyneth Dickinson MBE \*

Patricia Greene \*

Vince Hill\*

Maggie Norden

Zac Shaw \*

The symbol \* indicates visual impairment.

# Macular Society Report and Accounts for year ended 31 December 2021

Auditors	Clifford Fry & Co, St. Mary's House, Netherhampton, Salisbury, Wiltshire SP2 8PU
Bankers	Barclays Bank Plc, South West London Corporate Banking, 1 The Causeway, Teddington, Middlesex TW11 0HB
Legal Advisers	Furley Page LLP, Admiral's Offices, Main Gate Road, The Historic Dockyard, Chatham, Kent ME4 4TZ
Investment Managers	Rathbone Investment Management Ltd, 8 Finsbury Circus, Finsbury, London EC2M 7AZ
Registered Office (and actual office address)	Crown Chambers, South Street, Andover, Hampshire SP10 2BN
Contact	Tel 01264 350 551 – Office
information	Tel 0300 3030 111 – Advice & Information
	Email info@macularsociety.org

for year ended 31 December 2021

The Directors of the Macular Disease Society submit their annual report and audited financial statements for the year ended 31 December 2021. The Directors of the Company are also Trustees of the Society and are known collectively as the Council. This report includes as separate statements, the Directors' Report and the Directors' Strategic Report, as required by the Companies Act 2006 (Strategic Report and Directors' Report) Regulations 2013, given in their capacities as Directors/Trustees. The term Trustee is used throughout this report.

### History and Objectives

The Society was founded as a membership body in 1987 by a group of patients and medical professionals.

They recognised that macular disease was a growing public health problem. However, there was little awareness among the general public about the disease the impact of which was too often underestimated by medical professionals.

Consequently patients received little emotional or practical support to cope with a devastating condition. Policy makers did not prioritise eye care and little research funding was allocated to finding treatments.

Macular disease is now the biggest cause of sight loss in the developed world and the third biggest globally. In the UK it is responsible for as much registered sight loss as all the other conditions combined: being the dominant reason for registration in children, working age people and older people. As such it is a major public health challenge.

for year ended 31 December 2021

To meet the challenge, the Society's objectives are to support medical research to find a cure for macular disease, and to provide information, advice and other services to improve the lives of people living with macular disease. We summarise these aims in this way:

### **Beating Macular Disease**

#### Our vision:

An end to macular disease.

#### Our mission:

Beating macular disease with world class research and the best advice and support.

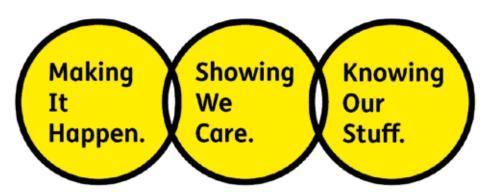
#### Our strategic aims:

- Finding a cure
- Providing the best advice and support
- Educating the public that 'vision matters'.

### Our values

Everyone at the Macular Society aims to live its values in all we do.

#### We <u>will</u> Beat Macular Disease by



for year ended 31 December 2021

We are Ambitious.

We will Beat Macular Disease.

We are committed to be brave in our actions to make the progress that people need.

We will fundraise to find a cure, empower our team, be progressive yet supportive and dedicated in our belief...

#### ...to Beat Macular Disease.

We are Supportive and Caring.

We provide a caring, approachable, and supportive environment for each member, supporter, volunteer, and all members of our team.

We act with empathy in all that we do. We listen to each other and we all work together...

#### ...to Beat Macular Disease.

We have Integrity and we act honestly.

We are trusted for our supportive, open and collaborative approach, our professional expertise and our dedication to be the best we can be to do more...

#### ...to Beat Macular Disease.

for year ended 31 December 2021

### Structure, Governance and Management

The Society is a Company Limited by Guarantee, without Share Capital, incorporated on 13 October 1987 and registered as a Charity on 10 December 1990.

At the end of 2021, the Society had 15,304 members – 12,972 voting members and 2,332 six months free trial members.

There were 410 peer support groups at the end of 2021. The majority, 359, operate under the Society's charity number. Fifty one groups are 'affiliated', operating under the auspices of other organisations such as local societies for visually impaired people.

Each group that operates under our charity number is required to submit an annual financial return at the year-end. These returns are combined into the Society's own financial statements.

Owing to the continuation of lockdowns and social isolation guidance, few groups met. However c. 7,000 people remained registered as group members.

The majority of groups have used teleconferencing facilities provided by the Society to keep in touch with their members or have done so on a one-to-one basis.

for year ended 31 December 2021

The Society is granted exemption from Income Tax under s.505 ICTA 1988 and exemption from Capital Gains Tax under s.256 TCGA 1992. The Charity and Company number are shown on the back page of this document.

The Company was established under a Memorandum of Association which confirmed the objects and powers of the Company and is governed under its Articles of Association.

Under the Articles, the Trustees are appointed by the Council to serve a maximum period of six years, with a reappointment requirement after three years. The exception to this is the Hon. Treasurer who may serve up to three consecutive three-year terms.

Vacancies for Trustees are advertised widely in Sideview (the members' quarterly magazine) and elsewhere.

Applications are reviewed by the Governance and Appointments Panel. Selected candidates are invited to a meeting with the Chief Executive for a briefing on the Society and discussion of the role and responsibilities of Trustees. Trustee training takes place by means of the initial briefing and study workshops.

The Council of Trustees meets four times a year. In addition to the top-level decision making undertaken by Council, preparatory work takes place in committees comprising a combination of Trustees, Society members, salaried staff, and external advisers, as required.

for year ended 31 December 2021

These committees are:

#### • Finance and Fundraising

Reviews the annual budget, monitors financial and fundraising performance and provides risk management oversight.

#### • Research

Allocates research funding and monitors output from research projects.

#### • Governance and Appointments Panel

Oversees governance and appoints Trustees and key employees. Sets the remuneration of key management personnel.

#### • Ethics Committee

Reviews the Society's policies and activities to make sure the organisation operates to the highest ethical standards.

• **Public Policy and Government Affairs Advisory Group** Provides expert advice and guidance on the Society's work to represent the views of patients to policy makers.

In all its activities, the Macular Society Trustees and staff pay due regard to the Charity Governance Code.

The Trustees present their report and the financial statements for the year ended 31 December 2021.

### Trustees' Responsibilities Statement

The Trustees are responsible for preparing the Strategic report, the Trustees report and the financial statements in accordance with applicable law and regulations.

Company law requires the Trustees to prepare financial statements for each financial year. Under that law the Trustees have elected to prepare the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'. Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the Company and of the surplus or deficit of the Company for that year.

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies for the Company's financial statements and then apply them consistently;
- make judgments and accounting estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis, unless it is inappropriate to presume that the charity will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the Company's transactions and disclose with reasonable accuracy at any time

## **Trustees Report**

for year ended 31 December 2021

the financial position of the Company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the Company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

### **Results and Dividends**

The surplus for the year, after taxation, amounted to £1,703k (2020 - £134k).

#### Trustees

The Trustees who served during the year were:

Cecilia Bufton BSc (Hons) MBA – Chair Paul Ryb BA(Hons) \* – Vice Chair Alison Guthrie MCOptom – Vice Chair Richard Piller FCA, CTA – Honorary Treasurer William Best BSc (Hons) \* Tim ffytche LVO, FRCS, FRCOphth (resigned 9 February 2021) Anna Fletcher LLB \* Dr Sheena George, FRCOphth Robin Hamilton, FRCOphth Charles Griffith ACII, CFA (appointed 11 May 2021, resigned 8 February 2022) Frances Luff BA (Hons) Anthony MacQuarrie M Ed, B Phil, DASEC, Cert Ed \* (resigned 11 May 2021)

## **Trustees' Report**

for year ended 31 December 2021

Patrick McGeough Eng MIIE (Mech), RAF Rtd \* James Potter LLM \* Amanda Rowland LLB \* Sobha Sivaprasad, FRCOphth Stephen Stacey MA, DPhil Elaine Latham Christopher Strutt (resigned 11 February 2022)

Catherine Yelf – Chief Executive and Company Secretary

\* This symbol indicates visual impairment

#### **Future Developments**

Future developments are set out in detail on pages 14 to 43 in the Trustees' Strategic Report. There are no going concern issues, which may affect the Company's ability to continue its activities for the foreseeable future.

#### Disclosure in the Strategic report

The company has chosen in accordance with Companies Act 2006, s414c(11) to set out information required under sch7 to be disclosed in the Trustees report within the Trustees Strategic report.

### Disclosure of information to auditors

Each of the persons who are Trustees at the time when this Trustees' report is approved has confirmed that:

so far as the Trustee is aware, there is no relevant

## **Trustees' Report**

for year ended 31 December 2021

information of which the Company's auditors are unaware, and

the Trustee has taken all the steps that ought to have been taken as a Trustee in order to be aware of any relevant audit information and to establish that the Company's auditors are aware of that information.

#### Post balance sheet events

The impact of COVID-19 and Brexit has been considered by the Trustees within their Strategic Report.

#### Auditors

The auditors, Clifford Fry & Co LLP, will be proposed for reappointment in accordance with section 485 of the Companies Act 2006.

Approved by the Council of Trustees on 10 May 2022.

Calia. Ul. Bulla.

Cecilia Bufton Chair of the Council Macular Society

for year ended 31 December 2021

#### **Responsibilities of Trustees**

Trustees responsibilities are set out in the Code of Conduct ('The Code') for Trustees. The principal duties are these:

Trustees must, with the help of the Chief Executive, formulate and review regularly the Society's vision, values, and strategy as well as policies for their fulfilment.

With the assistance of the Chief Executive and appropriate professional advisers, Trustees must make sure that the Society complies with all regulatory and statutory requirements and must exercise overall control over the Society's financial affairs. In addition to compliance with statutory requirements, Trustees should have a commitment to the development and implementation of good practice in charity operations and in good governance.

Trustees must make sure there is a clear understanding of the scope of authority delegated to the Chief Executive.

The Code also sets out the relationship between the staff and Trustees. It is the role of the Chief Executive to implement the Society's vision, values and strategy through a combination of salaried staff and volunteers.

### Assessment of Public Benefit

The Trustees have complied with the duty in Part 1 Chapter 1 s4 of the Charities Act 2011 to have due regard to public benefit guidance published by the Commission. The Trustees have had regard for the guidelines when reviewing the Society's aims and objectives and in planning for future

for year ended 31 December 2021

activities. The public benefit of the charity is in finding a cure for macular disease, providing best advice and support for those living with the conditions and educating the public that 'vision matters'.

The Trustees consider how planned activities will contribute to the aims and objectives they have set with the executive team. The Trustees consider that the Macular Society satisfies the public benefit test.

The day-to-day management of the Macular Society is led by the Chief Executive on agreed authority delegated by the Council of Trustees.

### **Financial Review**

The financial statements show a surplus for the year of £1,703k (2020: £134k). Total funds at the year-end were £5,483k (2020: £3,780k).

The measures taken in 2020 to protect our financial position during the COVID-19 global pandemic were successful and our fundraising continued to be effective. As a result we felt confident in setting a deficit budget for 2021. The pandemic continued to have a significant impact on our plans in several income streams such as events and community fundraising, but many areas of our fundraising showed growth in the year. There are still delays in HM Courts and Tribunals Service, meaning that some legacy gifts have not been paid to us. However, a large bequest of £1.5m ensured that overall legacy income was in excess of that forecast.

for year ended 31 December 2021

### **Reserves Policy**

Unrestricted reserves at the year-end amounted to £3,758k (2020: £2,946k). Each year the Trustees consider the financial and other risks associated with our income and expenditure streams. Our policy is to hold unrestricted reserves representing a minimum of four months of our costs budgeted for 2022. This amounts to £1,692k for 2022 and represents the costs of executing an orderly winding up of the Society if such were required. In addition, we aim to hold a level of reserves necessary to protect the Society from variances outside our immediate control. We also seek to ensure that our planned expenditure over the coming years can be covered by reserves while our Great Fundraising income generation plans come fully to fruition and our fundraising investment sees the forecast returns

The impact of COVID-19 will be felt into 2022 and, coupled with high inflation rates and a still unquantifiable impact of the UK leaving the EU, will continue to require a cautious approach to spending. For these reasons we have retained the designated fund in anticipation of continuing exceptional and unpredictable circumstances.

### **Investment Policy**

We invest funds not required in the short term with Rathbone Investment Management Ltd (Rathbones). The Portfolio performance is reviewed regularly by the Finance Committee, which reports to Council. Rathbones are instructed not to invest in tobacco stocks owing to the strong evidential link between smoking and macular disease. There is a strong Environmental, Social and Governance thread to the investments in the Portfolio, in line with Rathbones' own approach in these areas.

for year ended 31 December 2021

The total fund started the year at £1,410k and ended the year at £1,579k. During the year COVID-19 had an impact on capital growth and investment returns, especially in quarter two. Performance finished strongly, delivering investment income of £33k. Overall, this result was in line with the investment objectives set when Rathbones were engaged as Investment Managers in 2019.

The Society's policy is to invest remaining cash reserves in bank deposits or similar instruments. Of the £5,273k at the year-end (excluding cash held by local groups), £321k was on deposit with Nationwide, £401k with NatWest and £1,000k with Lloyds TSB. The remaining cash is held with Barclays. Interest income for the year amounted to £1k (2020: £3k).

### **Research Grants**

Research grants are awarded by Trustees on the recommendations of the Research Committee which is comprised of clinical and research experts in relevant fields and is chaired by an independent Chair.

In May 2021 the Chair, James Bainbridge, Professor of Retinal Studies at University College London and Consultant Ophthalmologist at Moorfields Eye Hospital, stood down as his term of office had ended.

He was succeeded by Luminita Paraoan, PhD (Gen), PhD (Mol Biol), FARVO, FRSB, FHEA, Professor of Molecular Cell Biology and Leader of the Ocular Molecular Biology and Mechanisms of Disease Group, Eye and Vision Science, Faculty of Health and Life Sciences at the University of Liverpool.

for year ended 31 December 2021

The full Committee membership can be found at Appendix A.

The Committee invites applications for funding of research projects within research area priorities set by the Trustees.

Applications are independently peer-reviewed and assessed by the Committee. Selected projects are formally approved by the Council.

The progress of projects (which may last up to three years) is monitored by the Research Committee with periodic reports to Council.

#### **Executive Team**

The executive team comprises:

Catherine Yelf, Chief Executive

Emma Malcolm, Director of Fundraising and Marketing

Stephen Scowcroft, Director of Services (from May 2021)

Karen Noble, Head of Finance

Rebecca Ward, Head of HR

John McKay, Head of IT and Data Insight

Their pay is reviewed annually by the Governance and Appointments Panel and is set having regard to market information in respect of charities of equivalent size with head office operations located outside London.

for year ended 31 December 2021

### **Risk Assessment**

The Trustees have reviewed the major risks that the Society faces and believe the Society has sufficient resources to cope with any foreseeable adverse conditions. The major risks that might impact the Society have been assessed and we are satisfied with the actions taken to mitigate exposure to these risks.

The most significant of these risks are:

- a reduction in our income generation, especially during the period of the COVID-19 pandemic; protected by holding of a minimum reserve and other funds;
- protection of our bank deposits and investment portfolio; protected by setting maximum deposit holdings with individual banks and spreading risk through our investment portfolio holdings;
- computer failure; protected by six monthly computer disaster recovery exercises;
- data protection failure; protected by a comprehensive data protection policy. This includes an Information Security Incident Management Policy, a review of data retention and annual staff and volunteer training;
- hurt to vulnerable adults; protected by two safeguarding officers, policies covering the expectations of staff and volunteers, the safeguarding of vulnerable adults, whistleblowing and the use of the Disclosure and Barring Service.

for year ended 31 December 2021

### Our Approach to Fundraising

Everyone who supports us may be assured that we comply with the regulatory standards for fundraising. We are registered with the Fundraising Regulator and are committed to the Fundraising Promise and adherence to the Code of Fundraising Practice. Several members of the fundraising team, including the Director, are Institute of Fundraising members.

It has cost us £4,174k to provide our services and fund our research programme, all of which came from fundraised income.

Our fundraising includes our membership programme, encouraging donations and gifts in Wills, running events working with trusts and corporates and operating a weekly lottery\* and raffle. (\*All profits from the weekly lottery go to the Macular Society. Of the £359,814 received in ticket sales from January to December 2021, 20% was spent on expenses, 20% on prizes and 60% was used to fund our important work. From the proceeds of all tickets sold in the two raffles during 2021: 12% was spent on expenses, 13% on prizes and 75% was used to fund our important work). We have an annual Groups' Research Appeal. Via this Appeal, we invite groups to undertake fundraising and to secure donations for a specific research project.

We monitor and evaluate the impact of internal and external factors on fundraising performance against our strategy and our wider aims and objectives. We review and adapt/amend timescales, expenditure and income targets and the content of fundraising plans designed to achieve our objectives. We seek a wide range of feedback

for year ended 31 December 2021

and also benchmark against the market and our key performance indicators.

During 2021, our fundraising increased, most notably from Legacy income, as the HM Courts and Tribunals delays began to improve.

We also launched our first regular giving campaign 'Fund a Cure' via Face to Face fundraising.

We work with carefully selected third parties to raise money to Beat Macular Disease, including professional fundraisers. We work closely with all our third party suppliers to make sure they deliver a high quality experience for our supporters through training, monitoring and contractual arrangements. We also carry out mystery shopping and have robust systems in place for receiving and addressing feedback, which we are always pleased to receive.

Our website carries our complaints policy for the public and explains clearly how an individual may complain. We received three complaints in 2021 (2020: nine) from 31million fundraising contact points.

We responded to all complaints within five days. Complaints are dealt with in line with our fundraising complaints policy. The most serious complaints are escalated to our Chief Executive and Trustees so they may review our activities in the light of the complaint. We report the number of complaints we have received to the Fundraising Regulator.

for year ended 31 December 2021

We are registered with the Fundraising Preference Service so that individuals are able to opt out from receiving fundraising communications from us. We actioned 11 requests from this Service in 2021.

In addition to our general fundraising policy, we have an agreed operating procedure to protect vulnerable people. The policy is based on the framework recommended by the Direct Marketing Association and developed by the DMA's Vulnerable Taskforce Committee. Our staff are trained in how to put this policy into practice with all our contacts. The full policy can be found on our website. https://www.macularsociety.org/about/policies/vunerable-people-policy/

#### Environmental responsibility

The Macular Society's aim is to deliver the overall objectives of the organisation while also developing, maintaining and delivering an environmental and social responsibility impact.

The Macular Society accepts that some of our operations have a detrimental effect on both the local and global environment and is committed to reducing them further.

We have a role to play and a duty of care to staff, volunteers, members and wider society with regard to climate and environmental change. There is an increasing expectation from all of these stakeholders that we are doing what we can, as well as encouraging our wider audience through leading by example.

for year ended 31 December 2021

We will have choices as to what we do in order to get the balance right between achieving our mission while also limiting our environmental impact and being sustainable.

A group of staff, known as the Green Group, has been established to help the Macular Society to develop policy and practice to reduce our carbon footprint.

# Beating Macular Disease by finding a cure 2021

Key Evaluation Question:

How effectively is the Macular Society supporting research and progressing us towards cures for macular disease?

The amount of research grant funding awarded by the Society each year continues to rise. The UK has some of the finest academic and clinical research scientists in the world in macular disease and the Society's funding in this under-resourced area is critical. The knowledge generated by Macular Society-funded research is key to developing future new therapies.

We operate a two-stage application process starting with an outline application that must be accompanied by a lay summary. Applicants shortlisted by the Research Committee submit a full application which is peer reviewed before being assessed again by the Committee. The Committee's recommendations are considered by the full Council for approval.

for year ended 31 December 2021

Research Committee members may serve up to two terms of three years. Two Macular Society Trustees are members of the Committee and represent the Council.

We received 27 grant applications for our 2021 funding programme. 26% were considered 'fundable'.

In July 2021 we launched the new 'seed corn' grant programme and received 11 applications, three of which were considered fundable.

Our seed corn funding grants are for up to £25,000 for one year projects designed to acquire data to support promising projects to the next stage of funding.

Three projects were approved in 2021 for funding in 2022.

Some of the new 2020 projects had recruitment related delays due to the pandemic, which meant that they were not able to start until early 2021. However the projects already underway were able to continue their research through the lockdown period at the start of the year, so no further significant delays were incurred.

The new 2021 projects were able to start on time but one project is slightly delayed because the lead researcher is in the process of changing universities.

for year ended 31 December 2021

The following research grants, to the value of £1,219,671 were awarded in 2021:

#### **Project grants:**

#### Professor Andrew Webster, University College London 2 years £109,432

Identifying genetic factors responsible for adverse clinical outcomes of ABCA4 mutation in macular disease; interrogation of large genomic datasets

#### Professor Andrew Dick, University of Bristol 3 years £243,732

Manipulating immune regulators that maintain retinal pigment epithelial health and metabolism as a therapeutic strategy for age-related macular degeneration (AMD)

#### Dr Jamie Ellingford, University of Manchester 3 years £249,950

METR-GT: The Manchester Eye Tissue Repository Genome-Transcriptome Project

#### Professor Luminita Paraoan, University of Liverpool 3 years £220,670

Elucidating the role of mitochondrial dynamics and endoplasmic reticulum-mitochondrial communication in ageing retinal pigmented epithelium: towards new therapeutic interventions for macular disease

for year ended 31 December 2021

#### Professor Dulcie Mulholland, University of Surrey 3 years £196,338

Novel homoisoflavonoids for the inhibition of ocular angiogenesis

#### **PhD Studentships:**

#### Dr Linda Troeberg, University of East Anglia 3 years £99,573

Does aberrant extracellular trafficking cause both age-related and genetic forms of macular degeneration?

#### Dr Keziah Latham, Anglia Ruskin University 3 years £99,976

Assessing the costs and benefits of innovative low vision aids

In addition:

- We now have 26 live research projects underway with a combined value of £3,510,133.
- Seven scientific papers from projects we fund were published this year.

The Society contributes to the research environment in multiple ways in addition to our grant funding programme.

• We held an international conference on Artificial Intelligence in AMD at Harris Manchester College, University of Oxford.

for year ended 31 December 2021

This 'hybrid' event (part in-person, part online) was chaired by Professor Alistair Denniston and Professor Pearse Keane.

- As a member of The Association of Medical Research Charities (AMRC) we continued to campaign for government support for medical research charities whose income, and so ability to fund medical research has been severely affected by the pandemic. A sum of £20m was allocated to charities in the 2021 Spending Review, specifically for the funding of early-career researchers. The Macular Society applied to this fund and will receive funds in 2022 Our CEO, who is a member of the AMRC Executive Board, has also been involved in discussions with senior NHS leaders on the use of patient data in research.
- We are the lead charity funder supporting the National Institute for Health Research's UK Ophthalmology Clinical Research Strategy. This includes the setting up of five Clinical Study Groups to co-ordinate and develop clinical eye research. The funding will provide three years of support for a post within NIHR to co-ordinate the work of the strategy. Our Research Manager, Geraldine Hoad, sits on the Executive Board and on the Retina Clinical Study Group.
- We now have over 4,000 registrants to our research participant database. We connect these volunteers with research teams who need to recruit patients as trial participants, trial steering committee members or in other patient advisory roles.

for year ended 31 December 2021

#### **Action Against AMD**

Action Against AMD (AAAMD) was created as a specialised charity collaboration between the Macular Society, Blind Veterans UK, Sight Scotland and Sight Scotland Veterans. It is focused on tackling AMD as early as possible, specifically to identify a potential new therapy that may prevent early AMD developing into late-stage disease and taking it to early stage clinical trials by 2028/9.

We believe this is the most rational way to address the forecast increase in the incidence of AMD in an ageing population. AAAMD's strategy is to:

- Seek for existing therapeutics that could be usefully re-purposed to treat AMD
- Identify new markers of early-stage disease to facilitate the design of affordable clinical trials in early AMD
- Leverage more funding into macular-related research

Despite the challenges caused by COVID, AAAMD made strong progress in 2021.

AAAMD and the University of Birmingham continued their pharmaco-epidemiology collaboration to analyse anonymised medical records from 20+ million UK patients. The aim is to identify drugs which might be protective against AMD. Several possibilities have been found and AAAMD and the University will next work to validate the

for year ended 31 December 2021

results. If this is successful, AAAMD will aim to take them into clinical trials. AAAMD is also engaged in discussions with an US biotech company to secure access to a novel and potent antioxidant to be tested against AMD.

AAAMD's CEO sits on the steering committee of the Scottish Collaborative Optometry-Ophthalmology Network e-research (SCONe) project based at the University of Edinburgh. This project aims to study images of the retina to improve care and support research.

In a separate project, AAAMD has also secured an initial investment in principle of £1m from two Scottish charities to progress a project to access community-level eye scans. AAAMD entered discussions with two other organisations (one UK, one US) with a view to securing further investment.

The aim of this project is to acquire and analyse eye scans obtain from the patients of community optometrists. These patients have early or no disease and such scans are important in being able to identify the first stages of AMD. AAAMD will take this work forward within a fully-owned trading subsidiary called Foresight.

To further strengthen the offering of Foresight's ophthalmic data and to promote the need for focus on eye research, AAAMD has been working closely with the UK government's Our Future Health (OFH) initiative. This project is to genotype five million Britons in the next three years. OFH is chaired by Prof Sir John Bell and AAAMD is

for year ended 31 December 2021

one of 16 charities endorsing the initiative (alongside much-larger organisations such as Cancer Research UK, the British Heart Foundation and Alzheimer's Research UK).

In addition to endorsing, AAAMD's CEO Dr Wen Hwa Lee has worked with OFH successfully to include sight loss in their launch statement and to ensure eye disease is investigated as part of this project. https://ourfuturehealth.org.uk/the-uks-largest-everhealth-research-programme-to-transform-theprevention-detection-and-treatment-of-diseases/

#### Looking ahead

In November the Trustees met to discuss how the Society might diversify its research funding as our income grows. We are presently a 'response-mode' funder of academic research. Our 10 year research strategy, published in 2020 identified a need to expand the ways in which we fund research.

The meeting introduced a range of possible new avenues to explore. These included creating new funding streams for more directed or commissioned research, technology development, business accelerator grants, 'action' research in the community and even direct investment in promising early stage commercial start-up companies. Trustees agreed to investigate these options further in 2022.

for year ended 31 December 2021

# Beating Macular Disease by finding a cure – 2022 targets

- Fund £1.5m of new research into macular diseases.
- Hold an international seminar on the potential of gene therapies in the treatment of macular disease.
- Sponsor a workshop to develop a 'virtual eye' using mathematical modelling techniques.
- Appoint a Director of Research who will lead the Society's ambitions to fund more research and diversify our funding streams. The Director will develop an evidence base to support our decisions on where our investments will have most impact and bring us closer to achieving our strategic aim of finding a cure for macular disease.



for year ended 31 December 2021

# Beating Macular Disease with the best advice and support 2021

Key Evaluation Question: Is the Macular Society effectively supporting people with macular disease?

#### Supporting more people

2021 was a remarkably successful year for the Society's services in spite of the continuing pandemic. Using the lessons learnt during 2020 we continued to expand our digital services delivery in our aim to double the number of people we support, or our 'reach', between 2019 and 2023. In some services we mean doubling the number of individuals supported. In others we mean the number of occasions on which we provide support.

For example, we know how many individuals are referred to the counselling service and we count those rather than the number of counselling sessions given. However, we historically have not identified how many individuals call the Advice and Information service more than once in year so, for that service, we count the number of times the service provides advice. We take that as a proxy measure to indicate whether we are reaching more people. We now count attendance figures for virtual group meetings and webinars as they are significant 'in person' events, albeit delivered online or by teleconference.

for year ended 31 December 2021

While this does not provide complete data, we have been consistent in reporting in this way for several years and believe that, as long as the process is transparent, it is an adequate means of demonstrating growth in our service delivery. We will refine this process over time.

Throughout the second year of lockdown our staff, once again, worked with great energy, dedication and professionalism to stay in touch with, and motivate, our volunteers and provide more services to as many people as possible.

As a result we won two awards for our response to the pandemic:

- Charity Association of Excellence Award for Best Covid Response (Bronze) due to our immediate transformational change in services when the pandemic hit the world
- Visionary's National Partner award, which recognises our commitment to making a positive difference to people who are visually impaired.

for year ended 31 December 2021

#### Our support groups

Only a handful of our local support groups met in person during 2021 and then only in the second half of the year when restrictions were relaxed.

In spite of the long shutdown of groups they have shown great resilience. At the year-end 410 groups were still operating in a viable way. This compares with 430 before the start of the pandemic and 420 at the start of 2021. This is a result of dedicated work by staff to maintain the groups and also the extraordinary efforts and loyalty of the many hundreds of volunteers who have been determined to keep their groups intact. We congratulate them and humbly thank them all.

#### Virtual communities

In the absence of face to face meetings, we have accelerated the growth of virtual 'communities'. Most groups continued to meet, usually by teleconference. In the course of the year the regional team facilitated 2,790 hour-long calls – the equivalent of 372 working days. The calls had 19,801 attendees. Among the teleconferences were the Winter Warmer calls, held monthly for the second year between October and February. The calls are in the evenings and are designed to offer entertainment and companionship. These alone attracted 601 attendees.

Many local support groups now want to maintain these alongside their physical meetings. The virtual groups are accessible by people, who would otherwise not be able to

for year ended 31 December 2021

benefit from this sort of peer support, perhaps because of mobility or transport problems or because they just do not have a group near them.

Video conferencing is also gaining ground, even with older people and we will support the expansion of the webinars to include other practical and emotional educational or personal experience topics

We continued to hold our 'Virtual Clinic' webinars on a range of topics. The Chief Executive hosted monthly events aimed at an AMD audience. Colin Daniels the Working Age and Young People (WAYP) Services Manager hosted monthly events for people affected by other macular conditions and on subjects that affect people of working age. The webinars are available online after the live event.

The webinars attracted a total of 16,191 attendees, either at the live events or as viewers of the recordings.

We held our annual conference online again. As in 2020, the morning was devoted to macular dystrophies and other macular conditions such as diabetic macular oedema and the afternoon to AMD. These sessions focused on science and research progress. We added a parallel stream that ran in both the morning and the afternoon called Macular and Me. This strand was carefully devised for people wholly new to macular disease, their family and friends and people keen to learn more about living with a macular condition. The feedback from all these strands was extremely positive. My Macular and Me will be the overarching title of our webinar series in 2022.

for year ended 31 December 2021

### Working age and young people

Face to face groups for younger people are moving away from physical meetings. Where they are working well we will continue to support them. However, we do not plan to develop new communities in any particular locality or region. Macular conditions are relatively rare in young people and so face to face meetings in a locality are often poorly attended.

The emphasis is now on building communities around specific conditions or topics. We have established communities on diabetic macular oedema and myopic maculopathy. We will also focus on topics such as going into or staying in employment.

The WAYP Facebook page continues to grow its membership and is a vibrant and dynamic community itself. It now has 700 members and has seen over 3,700 interactions where people are asking and answering questions, supporting others with advice and experience.

We have directly supported 138 individuals with specific employment and benefit related advice, information, mentoring and support and continued to build this community focussing on providing condition specific content and employment related topics.

In order to support parents and teachers of children affected by macular conditions, we have refreshed and republished a suite of materials for teachers of visually impaired children and launched them at the start of the autumn term.

for year ended 31 December 2021

### Peer support and volunteer strategy review

In common with many charities, we have found that attendance at face to face peer support groups has been falling in recent years and it has become increasingly difficult to recruit volunteers. Some of our volunteers felt the demands of running a formal group were too great and others felt that, although they wished to stand down from their role with the group, they were not able to as there was no one to take over from them.

We conducted a survey of our volunteers in 2020. It demonstrated that that volunteering is an enjoyable experience (94.2%) for our volunteers and that they feel valued and appreciated by the Society (91.2%), which results them in wanting to recommend it to others (97.8%). However, the review highlighted that there is more that we can and should be doing.

In 2021 we completed a wide ranging review of our peer support services and our volunteering.

### Peer support groups

We concluded that our groups are changing organically and we need to change to support them. It is more helpful now to regard our 'groups' as 'communities' so that we can embrace a more flexible and loosely organised model. It is clear that a formal, perhaps bureaucratic, model is less popular than it was. The structure of a committee, comprised of a Chair, Treasurer and Secretary was originally designed to share the workload of running a group among several people and not just one volunteer.

for year ended 31 December 2021

Many groups adopted the formalities of taking minutes of meetings and holding an AGM for the election of officers. We encouraged groups to sign our constitution and to have a bank account if they were handling anything more than petty cash. These structures, originally intended and seen as supportive, are now viewed as a burden by many volunteers.

Many groups meet in community venues but there is an increasing demand for groups of people to meet in public spaces such as cafes and bars which are often more flexible, accessible, cost effective and do not have the burden of needing to be managed.

The existing model for groups assumes that they form part of our 'educational' services by having formal talks at meetings. Many newer groups are focused on the social interaction and peer support. And of course formal 'talks' are not possible in public spaces.

Although our groups have had multiple purposes, providing social, educational, practical and psychological support, what emerged from the review, and from the wider sector, is that the groups primarily provide a social focus, with information and support secondary. The review showed that we need to be clear in the purpose and focus of a group or 'community' so they achieve what we and the participants need them to do. We intend to focus on the social aspects of these communities in future. This makes clear what the group primarily is for and where it sits in the wider peer support services we provide. With this approach, signposting to other services becomes key.

for year ended 31 December 2021

This reinforces that the group does not stand alone and is part of a wider organisation that is beating macular disease and making things happen. Covid-19 has also highlighted that the growing area of concern and greatest need is on tackling isolation.

### Supporting volunteers

Our volunteers are critical to the success of many of our services. We are grateful to and humbled by the commitment, dedication and generosity of our volunteers. We recognise the importance of good recruitment, training and support for our volunteers.

Having reviewed our volunteer strategy we have set out our vision for our volunteering and set our priorities. The vision is that through a supportive and empowering volunteer experience, our volunteers will make the greatest positive impact for everyone affected by macular disease.

The three key priority areas are:

- Strengthening the volunteering infrastructure to create a consistent approach to volunteer management across the organisation.
- Making the Macular Society a meaningful place to volunteer by providing an enriching volunteer experience
- Expanding our volunteering opportunities and recruitment activity to extend our reach in communities across UK and achieve our organisational goals

for year ended 31 December 2021

In order to achieve and deliver on the priority areas we:

- Reviewed and created clear and consistent role opportunity descriptions, including new opportunities to get involved.
- Created a Volunteer Agreement to set out expectations of a role and what we will do to support it.
- Reviewed and updated our volunteer handbook and welcome pack.
- Implemented a consistent introduction to the Macular Society, our approach to volunteering, key messaging and a role specific training approach.
- Reviewed and enhanced ongoing support and supervision.

We communicated with our volunteers in a variety of ways; through specific volunteer updates, newsletters and messages to thank, recognise volunteers and ensure they feel part of a wider team and organisation that is beating macular disease.

### National and telephone services

Many of our services are designed to be delivered remotely and these have continued uninterrupted throughout the pandemic.

Our advice and information service saw a fall in contacts

 the first in memory. It is possible that fewer patients
 were made aware of our services by their eye clinic as

for year ended 31 December 2021

infection control measures have led to a streamlining of clinic appointments with less time available for wider conversations between patients and clinicians and, frequently, a complete ban on the display of patient information leaflets.

- However, referrals to our telephone counselling service continued to rise with a total of 550 referrals in the year compared with 488 in 2020. Distress arising from Charles Bonnet syndrome remains a common reason for referral.
- Our befriending service supported 311 people, a slight fall on 2020 resulting from a fall in volunteer numbers. This has led to a waiting list for this service.
- 163 people were given IT and technology support via our telephone Tech Talk service.

### **Effective support**

We measure the effectiveness and impact of our services by surveying a representative group of 300 service users each year. The results show a significant increase in appreciation scores on 2020 in nearly every area.

for year ended 31 December 2021

## Beating Macular Disease with the best advice and support – 2022 targets

- We will continue to develop information, support and educational resources through a wider variety of channels, expanding our reach and reflecting the diverse needs of people affected by macular conditions
- We will support and manage the transition back to face to face support where appropriate and deliver new ways of working to ensure that our services are sustainable.
- We will learn from the experience as a result of COVID and continue to develop and support digital services and interactions in order to expand our reach and meet the needs of a wider community of people affected by macular conditions.
- We will facilitate the voice of people affected by macular conditions in order to raise awareness and ensure that this is at the heart of any decisions or developments.
- We will continue to work with Eye Care Professionals so that they can work with and support people affected by macular conditions.





for year ended 31 December 2021

## Vision matters – Beating Macular Disease by improving eye health 2021

Key Evaluation Question: Is the general population aware of macular disease and the Macular Society?

The rise in conditions such as age-related macular degeneration means that, in the NHS, ophthalmology is now the biggest outpatient specialty with around 11m outpatient appointments in 2021. Even before the pandemic, health and care services in many parts of the country were struggling to cope with demand. This had led to unnecessary sight loss for patients who suffered delays to their treatment.

Sadly, there is no doubt that the COVID-19 pandemic has had a significant impact on the nation's eye health.

We have worked to influence the NHS Restoration and Transformation work to make sure that the whole needs of people with macular disease are considered as the NHS reconfigures its services. There are many welcome innovations developing in the reshaped delivery of care. However, we remain concerned that the streamlining of the pathways will mean that there is no resource for the holistic care of the patient; their emotional and practical needs beyond the eye clinic and the medical treatment itself. As part of this we significantly increased our focus on influencing public policy on eye health. A Public Policy and Government Affairs Advisory Group of Trustees helped develop our approach.

for year ended 31 December 2021

We partnered with the pharmaceutical company Roche and the research charity Fight for Sight on a joint parliamentary campaign called The Eyes Have It. The campaign included the development of a website and eye disease simulator headset as well as a very successful Westminster Eye Health Day which was attended by around 50 Parliamentarians.

We jointly campaigned for a National Clinical Director for Eye Health in England to provide the leadership that we believe is necessary to transform eye health and protect the interests of patients. In the autumn it was confirmed that such a role would be created.

The campaign also achieved:

- A wider awareness among key ministers and policymakers of the shortfalls in eye care services.
- Publicity in national, trade and regional media.
- Engagement from Macular Society members who wrote to their MPs to invite them to the Parliamentary event.
- Social media activity around the Parliamentary day, with interaction from MPs.

We continued to work with national bodies, both statutory and voluntary to improve eye care. These included the Clinical Council for Eye Health Commissioning and the UK Ophthalmology Alliance.

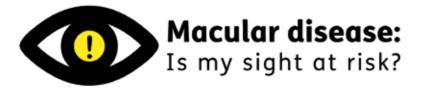
for year ended 31 December 2021

In October 2021 we launched our Macular Risk Checker, which was advertised via Facebook between 14 October and 3 December.

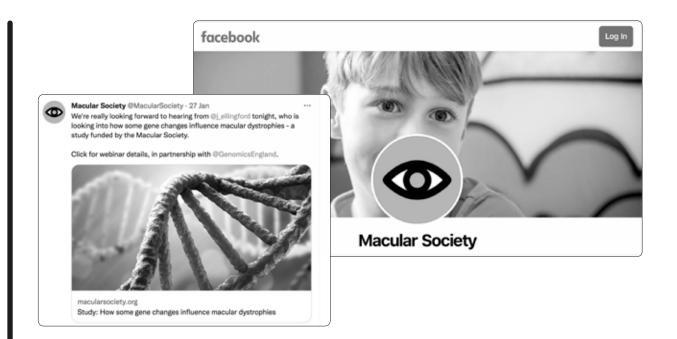
Based on a product from the Macular Disease Foundation Australia, the risk checker is available through our website and takes the form of a short quiz. Relevant content, based on the answers given to the quiz is provided and based on the potential risk of developing AMD. The user is given the option to stay in touch with us.

The risk checker has enabled us make ourselves relevant to new audiences (including the 'at risk' group), to engage with them, to stay in touch to help them look after their sight and keep them informed about progress in research that may make the difference to them in the future. In addition, this gives us an opportunity to grow our supporter base and help generate incremental income for research and support services so that future generations do not have to live with the devastating effects of macular disease and can be supported right now.

This all contributes to delivering our Vision Matters strategic pillar. Almost 33,000 people checked their risk between 14 October and 31 December. Ten per cent opted to continue receiving communications from us. Over October and November the Risk Checker doubled the traffic to our website.



for year ended 31 December 2021



## Vision matters – Beating Macular Disease by improving eye health – 2022 targets

- We will continue to prioritise messaging about urgent eye care to minimise the amount of avoidable sight loss caused by the pandemic.
- We will continue to campaign for eye health to be a higher priority and for improvements in existing health and social care for people with eye disease as well as greater investment in eye research.
- We will continue to budget for marketing campaigns to promote our services, especially the Advice and Information line as this is the 'gateway' to all our services.
- We will undertake a patient insight exercise to ensure we are providing what particularly hard to reach patients need in terms of support.

for year ended 31 December 2021

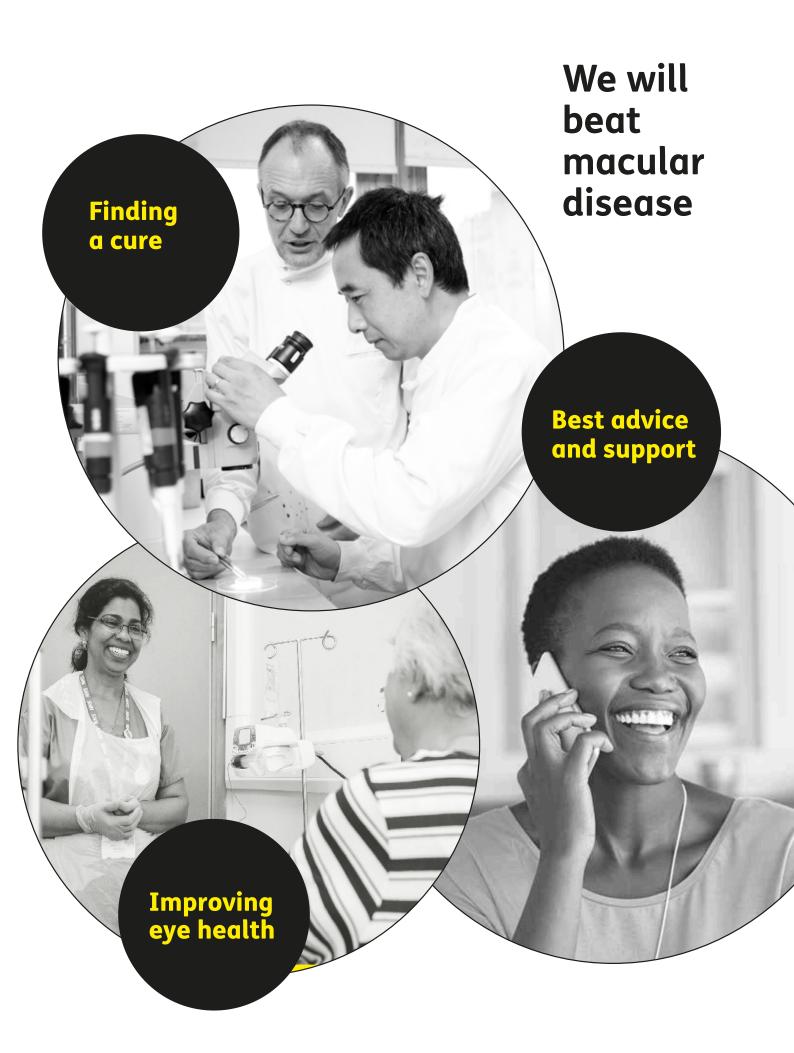
- We will continue to develop our digital presence to increase our reach including the use of additional social media platforms.
- We will use all our communications channels to promote eye health; encouraging healthy lifestyles and the benefits of regular eye health examinations.

The Trustees wish to express their thanks to all our donors and supporters without whom none of our work is possible.

Approved by the Council of Trustees on 10 May 2022

Calia. U. Bulla.

Cecilia Bufton, Chair of the Council, Macular Society



to the Members of the Macular Disease Society

## Opinion

We have audited the financial statements of The Macular Disease Society (the 'Company') for the year ended 31 December 2021, which comprise the Statement of Financial Activities (incorporating an income and expenditure account), the Balance sheet, the Statement of cash flows and the related notes, 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 Company's affairs as at 31 December 2021 and of its profit 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 Companies Act 2006.

### 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

to the Members of the Macular Disease Society

described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the Company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the United Kingdom, including the Financial Reporting Council'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.

### Conclusion 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 Company'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.

to the Members of the Macular Disease Society

## Other information

The other information comprises the information included in the Annual Report other than the financial statements and our Auditors' 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, except to the extent otherwise explicitly stated in our report, 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.

# Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

• the information given in the Strategic report and the Trustees' report for the financial year for which the

to the Members of the Macular Disease Society

financial statements are prepared is consistent with the financial statements; and

• the Strategic report and the Trustees' report have been prepared in accordance with applicable legal requirements.

# Matters on which we are required to report by exception

In the light of the knowledge and understanding of the Company and its environment obtained in the course of the audit, we have not identified material misstatements in the Strategic report or the Trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of Trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

to the Members of the Macular Disease Society

### **Responsibilities of Trustees**

As explained more fully in the Trustees' responsibilities statement set out on page 11, 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 Company'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 Company or to cease operations, or have no realistic alternative but to do so.

# Auditors' 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 Auditors' 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

to the Members of the Macular Disease Society

the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

We gained an understanding of the legal and regulatory framework applicable to the company and the industry in which it operates, including obtaining details on how they identify and comply with laws and regulations and whether they were aware of any non-compliance, how they detect and respond to the risks of fraud and whether they have knowledge of any actual, suspected or alleged fraud and finally the controls they have in order to mitigate risks of fraud or non-compliance with laws and regulations.

We designed audit procedures to respond to the risk, recognising that the risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting from error, as fraud may involve deliberate concealment by, for example, intentional misrepresentations.

As a result of these procedures, we considered the opportunities and incentives that may exist within the

to the Members of the Macular Disease Society

organisation for fraud and identified the greatest potential for fraud in the following area: revenue and profit recognition.

We focussed on laws and regulations which could give rise to a material misstatement in the financial statements, including, but not limited to, the Companies Act 2006, Charities SORP (FRS102) and UK tax legislation.

Our tests included agreeing the financial statement disclosures to underlying supporting documentation, performing analytical procedures to identify any unusual or unexpected relationships that may indicate risks of material misstatement due to fraud, reviewing minutes of meetings and enquiries with management.

We did not identify any key audit matters relating to irregularities, including fraud. As in all our audits, we also addressed the risk of management override of internal controls, including testing journals and evaluating whether there was evidence of bias by the Trustees that represented a risk of material misstatement due to fraud.

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/auditors responsibilities**. This description forms part of our Auditors' report.

to the Members of the Macular Disease Society

### Use of our report

This report is made solely to the Company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the Company's members 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 Company and the Company's members, as a body, for our audit work, for this report, or for the opinions we have formed.

S M Allenby FCA (Senior statutory auditor)

for and on behalf of Clifford Fry & Co LLP

St Mary's House Netherhampton Salisbury Wiltshire SP2 8PU

10 May 2022

## **Statement of Financial Activities**

(incorporating an income and expenditure account). For the year ended 31 December 2021

		£'000 Unrestricted Funds	£'000 Restricted Funds	£'000 Total 2021	£'000 Total 2020
	Notes				
Income from:					
Donations and legacies	2(1)	4,004	2,743	6,747	4,182
Charitable activities	2(2)	-	723	723	996
Other trading activities	2(3)	65	58	123	112
Investment income & interest	2(4)	34	-	34	31
Total income		4,103	3,524	7,627	5,321
Expenditure on:					
Raising funds	3(1)	1,885	-	1,885	1,422
Charitable activities	3(2)	1,541	2,633	4,174	3,845
Total expenditure		3,426	2,633	6,059	5,267
Net income before Gains/(lo on investments	sses)	677	891	1,568	54
Net gains/(losses) on investments	8	135	-	135	80
Net income/(expenditure) & net movement in funds		812	891	1,703	134
<b>Reconciliation of funds</b>					
Total funds brought forward		2,946	834	3,780	3,646
Total funds carried forward		3,758	1,725	5,483	3,780

There are no recognised gains or losses other than those disclosed above. All income and expenditure derives from continuing activities.

## **Balance Sheet**

As of 31 December 2021

		2021		202	0
	Notes	£'000	£'000	£'000	£'000
Fixed assets:					
Tangible assets	7		45		32
Investments	8		1,579		1,410
			1,624		1,442
Current assets:			,		,
Stocks	9	3		6	
Debtors	10	732		317	
Cash and bank balances		5,273		3,581	
Cash held by local groups		360		365	
		6,368		4,269	
<b>Current liabilities:</b>		·		·	
Creditors: amounts falling					
due within one year	11	1,814		1,449	
Net current assets			4,554		2,820
Total assets less current liabilities			6,178		4,262
Creditors: amounts due					
after more than one year	12		695		482
Net assets	16		5,483		3,780
Funds	45		0 750		1.0/6
Unrestricted funds	15		2,758		1,946
Designated funds	15		1,000		1,000
Restricted funds	14		1,725		834
Total funds			5,483		3,780

The notes on pages 61 to 80 form part of these accounts.

The financial statements were approved and authorised for issue by the Council of Trustees and were signed on its behalf on 10 May 2022.

Q. Bulla. Dalia.

Cecilia Bufton, Chair of the Council

K Llen

Richard Piller FCA, CTA, Hon. Treasurer

The Macular Disease company registered number: 2177039

## **Statement of Cash Flows**

For the year ended 31 December 2021

Cash flows from operating activities	2021 £'000	2020 £'000
Net income for the year	1,703	134
Adjustments for: Depreciation of fixed assets (Gain)/loss on disposals of investments Decrease/(increase) in debtors Decrease/(increase) in stock Increase/(decrease) in creditors	34 (135) (415) 3 578	34 (80) 122 1 572
Investment income and interest	(34)	(31)
Net cash from operating activities	1,734	752
Cash flows from investing activities		
Proceeds from sale of investments Purchases of investments Purchases of fixed assets Investment income Interest received Decrease in cash held for investment	221 (281) (47) 33 1 <b>26</b>	333 (344) (20) 28 <b>3</b> -
Net cash from investing activities	(47)	0
<b>Net increase/(decrease) in cash and cash equivalents</b> Cash and cash equivalents at beginning of year	<b>1,687</b> 3,946	<b>752</b> 3, 194
- Cash and cash equivalents at end of year	5,633	3,946
<b>Analysis of cash and cash equivalents</b> Cash in hand	5,633	3,946
Total cash and cash equivalents	5,633	3,946

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For the year ended 31 December 2021

### **1. Accounting policies**

The Macular Society is a private charitable company, limited by guarantee and incorporated in England, which is a public benefit entity under FRS102.

### (a) Basis of preparation

The net income of the Society arises solely from continuing activities. The accounts have been prepared on the accruals basis and combine the financial activities of the Society and local Groups. They have been prepared in  $\pounds$  sterling and rounded to the nearest thousand.

### (b) Accounting convention

The accounts have been prepared under the historical cost convention and in accordance with the applicable United Kingdom Accounting Standards, the Charities Statement of Recommended Practice (FRS 102) and the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended).

### (c) Going Concern

After reviewing the Charitable Company's forecasts and projections, the Trustees have a reasonable expectation that the Company has adequate resources to continue its activities for the foreseeable future. The Company, therefore, continues to adopt the going concern basis in preparing its financial statements.

### (d) Tangible Fixed Assets

Tangible Fixed Assets are stated at historical cost less accumulated depreciation. Historical cost includes expenditure directly

For the year ended 31 December 2021

attributable to bringing the assets into use.

### (e) Depreciation of Tangible Fixed Assets

Depreciation is charged on a straight line basis by reference to the expected useful lives of the assets concerned. The rates used are 33<sup>1</sup>/<sub>3</sub>% for IT and film equipment and 20% for office equipment. Fixed assets purchased by local Groups are written off in the year of purchase.

### (f) Investments

Investments are stated at market value. Unrealised gains and losses are recognised in the statement of financial activities.

### (g) Stocks

Stocks are valued at the lower of cost and estimated realisable value.

### (h) Legacies

Legacies are accounted for when it is probable that they will be received and the amount can be reliably ascertained.

### (i) Debtors

Debtors are measured at amortised cost less any impairment.

### (j) Creditors

Creditors and provisions are recognised where the Charitable Company has a present obligation resulting from past events that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts which may be due. For the year ended 31 December 2021

### (k) Cash and Cash Equivalents

Cash is represented by cash in hand and deposits with financial institutions payable without penalty on notice of not more than 24 hours.

Cash equivalents are highly liquid investments that mature in not more than three months from the date of acquisition and that are readily convertible to known amounts of cash with insignificant risk of change in value.

### (I) Financial Instruments

The Charitable Company has financial assets and financial liabilities of a kind which qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at amortised cost using the effective interest method. Financial assets held at amortised cost comprise cash at bank and in hand, together with trade and other debtors. Financial liabilities held at amortised cost comprise bank loans and overdrafts, trade and other creditors.

Investments, including bonds, held as part of an investment portfolio are held at fair value at the Balance Sheet date, with gains and losses being recognised within income and expenditure.

#### (m) Donated services

Donated services are included at estimated valuation.

#### (n) Volunteers

The Charitable Company has in the region of 1,400 volunteers. The financial value which these volunteers make is not incorporated

For the year ended 31 December 2021

within these financial statements.

### (o) Local Groups

In order to reflect correctly the stewardship of the Charitable Company over activities of its local support groups, their results are included in the SOFA and their cash balances at the year end are included in the Balance Sheet as restricted funds. The amounts have been incorporated based on returns received by the Charitable Company by 21 February 2021.

### (p) Grants received

Where related to performance and specific deliverables, grants are accounted for when the Society earns the right to the consideration. UK Government assistance for COVID-19 is accounted for in the period in which it is received.

### (q) Expenditure

Expenditure includes irrecoverable VAT.

### (r) Research grants Unconditional research grants payable in future years are accrued for in the year awarded.

### (s) Unrestricted Funds

Unrestricted Funds comprise income received without restriction as to its use.

### (t) Designated Funds

Designated Funds comprise funds set aside by the Trustees out of Unrestricted Funds to create a COVID Recovery Fund to address exceptional and unpredictable circumstances from COVID-19, particularly around legacy and trust income.

### (u) Restricted Funds

Restricted Funds comprise income received for the purposes specified by the

For the year ended 31 December 2021

donor. Expenditure, which meets these criteria, is applied to the related Fund.

### (v) Resources expended

Resources expended are allocated to the particular activity where the cost relates directly to that activity. Payroll and support costs are apportioned to these activities on the bases set out in Notes 4 and 5. Restructuring and redundancy costs are recognised when the Company has an obligation to pay the benefits and they can be measured reliably.

(w) Income tax recoverable in relation to donations received under Gift Aid is recognised at the time of production of the claim and allocated to the appropriate income stream.

### (x) Expenditure on raising funds

Expenditure on raising funds relates to the costs of attracting income and those incurred in trading activities that raise funds.

For the year ended 31 December 2021

2. Analysis of incoming resources	2021 £'000	2020 £'000
(1) Donations and legacies		
Donations, appeals and unrestricted grants	1,464	1,968
Membership subscriptions	283	270
Fundraising events	701	513
Legacies (Note 18)	4,299	1,431
	6,747	4,182

£3,166k of the 2020 income was unrestricted and £1,016k restricted.

(2) Income from charitable activities		
Grants for specified charitable activities	672	911
Job Retention Scheme Grant	-	36
Other – donated services	51	49
	723	996
(3) Income from other activities		
Local group income (restricted)	58	48
Trading income (unrestricted)	65	64
	123	112
(4) Income from Investments and Interest		
Interest received	1	3
Investment Income	33	28
The income for 2020 was all unrestricted.	34	31

For the year ended 31 December 2021

3.	Analysis of resources expend	ed			2021 E'000	2020 £'000
	(1) Costs of raising funds (unr	estricted	)			
	Employee remuneration (N	lote 5)			759	593
	Support costs (Note 4)				156	161
	Direct costs				930	625
	Trading costs				28	33
	Investment management	costs			12	10
				-	1,885	1,422
				-	,	,
					2021 £'000	2020 £'000
		Direct costs £'000	<b>Staff</b> <b>costs</b> <b>£'000</b> (Note 5)	Support costs £'000 (Note 4)		
	(2) Charitable activities		. ,			
	Publications	80	12	3	95	89
	Educational information	180	147	28	355	362
	Advice & Information & Counselling	151	198	41	390	385
	Groups & Volunteers	42	885	179	1,106	1,203
	Low Vision	93	212	42	347	256
	Conferences	14	20	4	38	31
	Research	1,411	306	62	1,779	1,440
	Support to professionals	1	-	-	1	42
	Local group activities	63	-	-	63	37
		2,035	1,780	359	4,174	3,845

2020 charitable expenditure was charged as to £2,288k to restricted reserves and £1,557k to unrestricted.

For the year ended 31 December 2021

4. Support costs	2021 £'000	2020 £'000
Rent and rates	79	86
Postage and office supplies	37	36
Telephone and IT	143	133
Depreciation	44	34
Recruitment	43	10
Bank charges	24	27
Governance	27	22
Other expenses	118	79
	515	427

The support costs allocated to charitable activities have been allocated pro rata to the apportionment of staff costs allocated to those activities. The resulting allocation is shown in Note 3(2). Governance costs include the audit fee and taxation return fee totalling £12,000 (2020: £8,500).

#### 5. Employee remuneration

The average number of full and part-time employees in the year was 74 (2020:73). The average number of employees calculated on a full-time equivalent basis, analysed by function was:

	2021	2020
Management, governance and administration	6	6
Customer care and membership administration	5	4
Fundraising	18	17
Group development & volunteer coordination	15	15
Advice & Information and treatment advocacy	5	5
Low vision	5	5
Research	2	2
Education and awareness	8	8
Sideview and Digest	1	1
	65	63

For the year ended 31 December 2021

	2021 £'000	2020 £'000
Salaries	2,210	2,213
National insurance	208	210
Pension costs	121	122
	2,539	2,545

The number of employees whose emoluments\*, as defined for taxation purposes amounted to over £60,000 in the year and to whom retirement benefits are accruing under money purchase pension schemes are:

	2021 Number	2020 Number
£60,000-£70,000	1	1
£70,000-£80,000	1	2
£80,000-£90,000	1	-
	3	3

The total emoluments paid to the three key managers amounted to £202,000 (2020: 3 key managers £234,000)

\*Emoluments for these purposes exclude pension contributions

The cost of staff that are involved in specific activities has been allocated to those activities; the balance of the payroll has then been allocated pro rata to the direct cost allocation. The central finance raising payroll costs have been allocated to specific activities pro rata to the funds raised for those activities.

	2021 £'000	<b>2020</b> £'000
Cost of fundraising	759	593
Cost of charitable activities	1,780	1,952
	2,539	2,545

The payroll costs allocated to individual charitable activities is as set out in Note 3(2).

Included here (2020) are Restructuring and Redundancy costs of £101,159.

For the year ended 31 December 2021

#### 6. Pension scheme

The charity operates a defined contribution pension scheme. The pension charge for the year £121k (2020: £122k) represents contributions payable by the Company to the scheme. These costs are allocated on the basis of head-count of staff within each category of expenditure. Contributions totalling NIL (2020: £21,246) were payable to schemes at the year-end and are included in Creditors.

#### 7. Tangible fixed assets

	IT & film equipment £'000	Office equipment £'000	Total £'000
Cost:			
As at 1 January 2021	140	29	169
Additions	47	-	47
Disposals	(89)		(89)
As at 31 December 2021	98	29	127
Depreciation:			
As at 1 January 2021	115	22	137
Charge for year	31	3	34
Disposals	(89)	-	(89)
As at 31 December 2021	57	25	82
Net book amounts:			
As at 31 December 2021	41	4	45
As at 31 December 2020	25	7	32

For the year ended 31 December 2021

		2021 £'000	<b>2020</b> £'000
8.	Investments	2 000	2 000
	Market value as at 1 January 2021 Acquisitions at cost* Disposals at carrying value Net realised gains Net unrealised gains	1,343 281 (221) 58 77	1,066 530 (333) 36 44
	Total investments at market value at 31 December 2021	1,538	1,343
	Cash held for investment	41	67
	Total investments	1,579	1,410
	Total investments at market value	1,579	1,410
	Total investments at historical cost	1,394	1,316
	Revaluation unrealised gain	185	94
	Investments are further analysed as follows:		
	Listed equities (UK £478k, Overseas £465k)	943	841
	Listed fixed interest and index linked Investments (UK £317k, Overseas £89k)	406	364
	Other investments	400 189	138
	Cash held for investments	41	67
		1,579	1,410

\*Acquisitions include donated shares valued at £13,125 (2020:NIL)

For the year ended 31 December 2021

	2021 £'000	2020 £'000
9. Stocks comprise diaries & cards for sale	3	6
10. Debtors & prepayments		
Legacies (Note 18) Gift aid Prepayments Other debtors	580 51 101 - 732	207 41 69 - 317
11. Creditors & accruals: amounts falling due within one year		
Research grants committed not yet paid Trade creditors Accruals & other payables Taxation and Social Security	1,446 228 134 6 1,814	1,163 107 111 68 1,449
12. Creditors: amounts falling due after more than one year		
Research grants committed not yet paid	615	412
Accruals and other payables	80	70
	695	482

For the year ended 31 December 2021

#### 13. Analysis of research grants

Grant payments have been made or accrued during the year for the following research projects, all of which are with universities and other medical institutions:

- University of East Anglia Does aberrant extracellular trafficking cause both age-related and genetic forms of macular degeneration?
- **University of Liverpool** Elucidating the role of mitochondrial dynamics and endoplasmic reticulum-mitochondrial communication in agening retinal pigmented epithelium: towards new therapeutic interventions for macular disease.
- University of Surrey– Novel homoisoflavonoids for the inhibition of ocular angiogenesis.
- University of Manchester METR-GT: The Manchester Eye Tissue Repository Geneome-Transcriptome Project.
- University College London Identifying genetic factors responsible for adverse clinical outcomes of ABCA4 mutation in macular disease; interrogation of large genomic datasets.
- Anglia Ruskin University Assessing the costs and benefits of innovative low vision aids.
- **University of Bristol** Manipulating immune regulators that maintain retinal pigment epithelial health and metabolism as a therapeutic strategy for AMD.
- **Moorfields** to fund a study of the impact of COVID-19 on the mental health of medical retina patients.
- **AAAMD** for the purposes of facilitating or funding AAAMD's mission to create convenient, affordable and accessible solutions that stop age-related macular degeneration in its early stages before it causes sight loss.

For the year ended 31 December 2021

13. Analysis of research grants (continue	d)
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	Charged t	to reserves
	Restricted £'000	Unrestricted £'000
University of East Anglia	100	
University of Liverpool	221	
University of Surrey	196	
University of Manchester	250	
University College London	109	
Anglia Ruskin University	100	
University of Bristol	244	
Moorfields	5	
AAAMD	74	
Salary, support and other costs	480	
Total charge to reserves	1,779	
Total research expenditure – Note 3(2)	-	1,779
	£	2'000
Research grants committed but not yet paid b/f 1 January 2021	-	1,575
Grants directly paid in the year to institutions		732
Research grants committed but not yet paid c/f 31 December 2021	_	(246)
	:	2,061
* Excludes attributed indirect costs calculated in accordance with the apportionment in Note 1(t)	_	

For the year ended 31 December 2021

#### 14. Restricted funds

The Society's Restricted funds, into which are paid amounts received with a specific request that the income should be used to fund specified activities, comprise:

- A Research fund for research activities
- A National Lottery Community Fund People and Communities for practical and emotional support for people with sight loss
- A Groups and Services fund for support to local groups and services
- A Counselling fund to support the provision of the counselling service
- A Local Groups fund representing cash and deposits held by local groups to fund their future activities
- A National Lottery Community Fund for practical and emotional support for people with sight loss

As at 1 Jan 2021 £'000	Moveme Income £'000		As at 31 Dec 2021 £'000
405	2,739	(1,779)	1,365
34	-	(34)	-
-	562	(562)	-
30	9	(39)	-
365	58	(63)	360
-	156	(156)	-
834	3,524	(2,633)	1,725
	<b>1 Jan 2021</b> <b>£'000</b> 405 34 - 30 365 -	1 Jan 2021 £'000Income £'0004052,7393456230936558-156	1 Jan 2021 £'000Income £'000Expenses £'0004052,739 $(1,779)$ 34- $(34)$ -562 $(562)$ 309 $(39)$ 36558 $(63)$ -156 $(156)$

For the year ended 31 December 2021

#### 14. Restricted funds (continued)

Restricted income includes:

- £31,271 from The Albert Gubay Charitable Foundation for treatment research for dry age-related macular degeneration.
- £36,600 from The Albert Gubay Charitable Foundation for developments of a stem cell model for early onset macular degeneration.
- £10,000 from Bill Brown's Charitable Settlement of 1989 for AAAMD.
- £60,000 from the Linbury Trust towards the development of digital infrastructure.
- £10,000 from the Kirby Laing Foundation for online eccentric viewing training.
- £25,000 from The City Bridge Trust, the funding arm of the City of London Charity, Bridge House Estate (1035628) for support services in London.
- £35,000 Unrestricted funding from Sharegift.
- £12,000 from The RS Macdonald Charitable Trust, for providing a range of practical and emotional support services in Scotland
- £39,750 from the National Lottery Community Fund for practical and emotional support for people with sight loss in Scotland.
- £80,000 from the National Lottery Community Fund for practical and emotional support for people with sight loss in Northern Ireland.
- £36,000 from the National Lottery Community Fund for practical and emotional support for people with sight loss in Wales.
- £10,000 from Steel Charitable Trust towards stem cell research into age-related macular degeneration.

For the year ended 31 December 2021

#### 15. Unrestricted and designated funds

	As at 1 Jan 2021 £'000	Income £'000	Expenses £'000	Transfer £'000	As at 31 Dec 2021 £'000
Unrestricted	1,946	4,238	3,426	_	2,758
Designated	1,000	-	-	-	1,000
	2,946	4,238	3,426	-	3,758

The Company transferred (2021:NIL) (2020:£1,000k) from its Unrestricted funds to a Designated fund, to create a COVID-19 Recovery Fund in anticipation of any exceptional and unpredictable circumstances from COVID-19 particularly in relation to Legacy and Trust income.

#### 16. Analysis of net assets between funds

	Unrestricted funds £'000	Designated funds £'000	Restricted funds £'000	Total funds £'000
Fixed assets & Investments	1,624	-	-	1,624
Net assets	1,134	1,000	1,725	3,859
	2,758	1,000	1,725	5,483

#### **17. Trustee remuneration**

The Trustees received no remuneration during the year (2020: nil).

During the year 6 Trustees (2020: 3) were reimbursed for travel and out of pocket expenses amounting to £1,096 (2020: £445).

For the year ended 31 December 2021

#### **18. Legacies**

Legacies of an estimated £1,920,000 (2020: £892,700) have been excluded from income as the criteria for recognition had not been met.

#### **19. Commitments**

As at 31 December 2021 the Society had the following annual office rent commitments under non-cancellable operating leases:

	2021 £'000	2020 £'000
Payable within one year Payable from one year to five years	66 61	66 127
rayable from one year to five years	127	193

#### 20. Analysis of changes in net debt

	As at 1 Jan 2021 £'000	Cash flows £'000	As at 31 Dec 2021 £'000
Cash and cash equivalents			
Cash	3,946	1,687	5,633
Borrowings	(1 / / 0)		(1.01/)
Debts due in under 1 year	(1,449)	(365)	(1,814)
Debts due after 1 year	(482)	(213)	(695)
	(1,931)	(578)	(2,509)
Total	2,015	1,109	3,124

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For the year ended 31 December 2021

#### 21. Share capital and members' guarantees

The Company is limited by guarantee and has no share capital. Each member, whilst a member or within 12 months of ceasing membership, undertakes to contribute on a winding up such amount, not exceeding £1, as may be required.

#### 22. Ultimate controlling party

The Society was controlled throughout the current and previous year by the Board of Trustees.

#### 23. Financial Instruments

At the balance sheet date the Company held financial assets at fair value of £5,633k (2020: £3,946k).

#### 24. Related Party Transactions

During the year a grant payment was made to Action Against AMD amounting to £74,000 (2020: £22,000).

The Macular Society and Action Against AMD are related by virtue of Catherine Yelf (CEO) being a Trustee of Action Against AMD, together with the CEOs of the other founding charities plus three independent Trustees. No balance was owing to AAAMD at the year end.

During the year Richard Piller, Honorary Treasurer and Trustee Director, acquired a minority shareholding in Okulo Ltd (also know as OKKO Health) a company with which the Macular Society transacts on an arms-length basis.

During 2020 it was agreed in principle to make a small grant of £5k to Professor Sobha Sivaprasad and others to fund a study of the impact of COVID-19 on the mental health of medical retina patients. This grant was paid in 2021. Professor Sivaprasad is a Trustee/Director of the Company.

During 2021 a grant of £220,670 was agreed to be paid to the University of Liverpool, with lead Professor Luminita Paraoan, to fund a study into new therapeutic interventions for macular disease.

There are ten members of our Research Committee: eight are distinguished academics from UK universities and two are Trustee Directors. The Committee

For the year ended 31 December 2021

#### 24. Related Party Transactions (continued)

is supported in its work by the Society's Research Manager and a Research Officer. Grant applications for projects falling within research priorities set by the Trustees are invited annually and are reviewed by members of the Committee using specific assessment criteria.

In a second stage those applications that have been selected are peer-reviewed and then assessed by the Committee's members with funding decisions being consensed in discussion. Committee members absent themselves from assessments in which they have a conflict of interest. The Committee's final selection is approved formally by the Trustees. Each research project is monitored by the Committee's officers with regular progress reports being submitted.

### **Professor James Bainbridge**

**CHAIR** (resigned April 2021) Professor of Retinal Studies, University College London and Consultant Ophthalmologist, Moorfields Eye Hospital

#### Professor Luminita Paraoan

**CHAIR** (appointed April 2021) Eye and Vision Science, Institute of Ageing and Chronic Disease, University of Liverpool

### **Professor Tariq Aslam**

Professor of Ophthalmology and Interface Technologies, University of Manchester Consultant Ophthalmologist, Manchester Royal Eye Hospital

#### **Bill Best**

Macular Society Trustee and lay member

### **Dr Michael Crossland**

Specialist Optometrist & Hon Senior Research Associate University College London and Moorfields Eye Hospital NHS Foundation Trust

### **Professor Alexander Foss**

Consultant Ophthalmologist, Department of Ophthalmology, Nottingham University Hospitals NHS Trust

### Dr Imre Lengyel

Senior Lecturer, Centre for Experimental Medicine, School of Medicine, Dentistry and Biomedical Science, Queen's University Belfast

### **Professor Astrid Limb**

Professor of Retinal Biology and Therapeutics, Institute of Ophthalmology, University College London

### **Professor Tom Margrain**

(resigned April 2021) Cardiff Centre for Vision Sciences, College of Biomedical and Life Sciences, Cardiff University

#### Professor Sobha Sivaprasad

Macular Society trustee Medical Retina Consultant Ophthalmologist Moorfields Eye Hospital NHS Foundation Trust and Professor in Retinal Clinical Research University College London

### Professor Adnan Tufail

Consultant Ophthalmologist, Moorfields Eye Hospital NHS Foundation Trust & Professor of Ophthalmolgy, University College London

## Macular Society Beating Macular Disease

Macular Society Crown Chambers, South Street, Andover, Hampshire SP10 2BN

**Company Registered Numbers:** England and Wales 2177039 Isle of Man: 005738F

Registered Charity Numbers: England and Wales: 1001198, Scotland: SC042015, Isle of Man: 1123