

The Macular Disease Society operating under the name The Macular Society

Report and Accounts

31 December 2020

# Macular Society Report and Accounts for year ended 31 December 2020

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for year ended 31 December 2020

**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 2020

=	) 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 information	Tel 01264 350 551 – Office Tel 0300 3030 111 – Advice & Information Email info@macularsociety.org

for year ended 31 December 2020

The Directors of the Macular Disease Society submit their annual report and audited financial statements for the year ended 31 December 2020. 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.

The objectives of the Society 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'.

for year ended 31 December 2020

#### 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 2020, the Society had 13,452 members -13,244 voting members and 1,194 six months free trial members.

There were 430 peer support groups at the start of 2020. The majority, 381, operate under the Society's charity number. Forty nine 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 COVID-19 pandemic, no groups have met face to face since March 2020. As a result, we are not able to ascertain reliably how many non-voting members continued to be members of the group network. In 2019, that number was c. 4,000.

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. Only around 36 groups have not operated in any way during the pandemic. It is not clear how many groups will restart face-to-face in 2021.

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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 Society's 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. We were delighted to welcome six new Trustees during 2020 and a new Chair from the last quarter of the year.

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.

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#### 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.

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

# **Trustees' Report**

for year ended 31 December 2020

The Trustees present their report and the financial statements for the year ended 31 December 2020.

#### 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 profit or loss of the Company for that period.

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;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis, unless it is inappropriate to presume that the charity will continue in business.

### **Trustees' Report**

for year ended 31 December 2020

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 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 profit for the year, after taxation, amounted to £134k (2019 - £283k).

#### **Trustees**

The Trustees who served during the year were:

John Dunston MA, CF, FRSA, ACIL - Chair (resigned 12 September 2020)

Cecilia Bufton BSc (Hons) MBA, - Chair (from 12 September 2020)

Paul Ryb BA(Hons) \* -Vice Chair

Alison Guthrie MCOptom - Vice Chair

Richard Piller FCA, CTA -**Honorary Treasurer** William Best BSc (Hons) \* Timothy ffytche LVO, FRCS, **FRCOphth** Anna Fletcher LLB \*

Sheena George, FRCOphth Robin Hamilton, FRCOphth Frances Luff BA (Hons) Anthony MacQuarrie M Ed, B Phil, DASEC, Cert Ed (appointed 12 May 2020) Patrick McGeough Eng MIIE (Mech), RAF Rtd

(appointed 17 November 2020) Margaret Packham BSc (Hons), MCIPD (resigned 17 November 2020)

James Potter LLM (appointed 17 November 2020) Amanda Rowland LLB (appointed 1 September 2020)

### **Trustees' Report**

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Sobha Sivaprasad, FRCOphth Stephen Stacey MA, DPhil Elaine Latham (appointed 1 September 2020)

Christopher Strutt (appointed 12 May 2020) Catherine Yelf – Chief **Executive and Company** Secretary

#### **Future Developments**

Future developments are set out in detail on pages 12 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 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 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.

This report was approved by the Council on and signed on its behalf.

for year ended 31 December 2020

#### 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 activities. The public benefit of the charity is in finding a

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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 Disease 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 £134k (2019: £283k). Total funds at the year-end were £3,780k (2019: £3,646k). We set a deficit budget for 2020. The pandemic had a significant impact on our plans both for 2020 and subsequent years. The following income streams were affected very badly:

- Events and community fundraising largely stopped from the first lockdown to the year-end. This had an immediate in-year impact.
- Legacy income was severely reduced by delays in granting probate. This also affected income in 2020.
- Face-to-face fundraising also stopped within days of it starting and only resumed for a short period between lockdowns in the summer. This had some impact in 2020. It will have a greater adverse effect on our income in future years because important new relationships take time to be cultivated.

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Such was the concern in the first half of the year that we took action to reduce our costs. The measures we took were:

- A recruitment freeze.
- A voluntary redundancy programme among the Regional Managers.
- Postponement of some fundraising investment.
- A general reduction of costs across the organisation. Some consequential savings were COVID-19-related such as lower travel and subsistence costs.

We endeavoured to protect our income by seeking emergency grants from bodies such as the National Lottery and corporate partners. These measures taken together were successful in helping to produce a largely balanced budget. This helps provide protection for the Society in 2021 as the pandemic continues to have an impact on our ability to fundraise.

#### Reserves Policy

Unrestricted reserves at the year-end amounted to £2,946k (2019: £2,584k). 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 2021. This amounts to £1,503k for 2021 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.

The impact of COVID-19 will continue into 2021 for a number of reasons:

for year ended 31 December 2020

- Normal face-to-face, community and events fundraising may not re-start until late in 2021, if at all.
- Continued delays in HM Courts and Tribunals Service over probate mean that legacy income could still be held up in 2021.
- The competition for other funding sources e.g., trusts and foundations, will be much greater.

For these reasons we have designated £1m extra as a further reserve against the exceptionally unpredictable circumstances, especially in respect of legacy and trust income.

#### **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.

The total fund started the year at £1,315k and ended the year at £1,410k. 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 £28k. Overall, this result was in with the investment objectives set when Rathbones was employed as Investment Managers in 2019.

The Society's policy is to invest remaining cash reserves in bank deposits or similar instruments.

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Of the £3,581k at the year-end (excluding cash held by local groups), £321k was on deposit with Nationwide, and £401k with NatWest. The remaining cash is held with Barclays. Interest income for the year amounted to £3k (2020: £9k).

#### **Research Grants**

Research grants are awarded by Trustees on the recommendations of the Research Committee which is chaired by an independent chair. The current Chair is James Bainbridge, Professor of Retinal Studies at University College London and Consultant Ophthalmologist at Moorfields Eye Hospital. 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 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
Tessa Barrett, Director of Services (to 31 July 2020)
Stephen Scowcroft, Director of Services (joins May 2021)
Karen Noble, Head of Finance
Rebecca Ward, HR Manager (maternity leave from February 2020)
Zaga Makhecha, HR Manager (maternity cover from March 2020)
John McKay, Head of IT and Data Insight

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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.

#### 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 annual 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.

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#### 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 £3,845k 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 lottery\* and raffle. (\*All profits from the weekly lottery go to the Macular Society. Of ticket sales from January to December 2020, 20% was spent on expenses, 20% on prizes and 60% 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 and also benchmark against the market and our key performance indicators.

During 2020, the number of individual donations showed a

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small increase. However, due to delays with HM Courts and Tribunals legacy income received was reduced.

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 nine complaints in 2020 (2019: five) from 3.3 million 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.

We are registered with the Fundraising Preference Service so that individuals are able to opt out from receiving fundraising communications from us. We actioned 17 requests from this Service in 2020.

In addition to our general fundraising policy, we have an agreed operating procedure to protect vulnerable people. Our fundraisers (both staff and agents) are familiarised with the procedure to make sure that it is applied properly. The procedure is published on our website.

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#### **Beating Macular Disease** by finding a cure

2020



#### Our Key Evaluation Question:

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

- We had 17 projects underway at the start of the year and all but one were suspended during the lockdown primarily due to university laboratories closing. By the end of September all the projects had re-started. However, all were behind schedule. To help the planned work to be completed, we granted no-cost extensions and we allowed funds to be re-routed to support the salaries of researchers. It is possible that we will receive requests for additional funding if the delays have increased costs. Existing grants, for two or three year projects, should not be under threat from reduction in our income in future years as we accrue for the full cost of our grants in the year they are first made.
- In January we published our new Research Strategy 2020-2030, which contains six strategic goals and sets out our ambition to grow and develop the research programme.
- We received 38 grant applications for our 2020 funding programme. 21% were considered 'fundable'.

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The following medical research grants were awarded in 2020:

Professor Chris Dickinson, University of Manchester £81,449

Creating a virtual personal assistant to support those with visual impairment.

This project aims to provide an interactive chat-bot for people with visual impairment which can give information and advice. The researchers will test whether technology can answer a range of questions, and how visually impaired people perceive and use the technology.

Dr Ruth Hogg, Queen's University Belfast

£113,860

Looking for factors associated with increased risk of developing AMD.

Finding gene, chemical and physiological associations that may be linked to an increased risk of developing AMD, and understanding which associations are more strongly linked with developing AMD.

Professor Majlinda Lako, Newcastle University £199,882

Producing a blood test to find markers of early AMD, and how these biochemical changes are associated with AMD.

It has been reported that people with AMD have changes in their exosomes, which remove waste from cells. This project aims to test whether these changes can be detected in the blood, and how these changes are associated with AMD.

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Dr Jacqueline van der Spuy, UCL £200,000 Testing a new form of gene therapy to treat juvenile macular dystrophy

The project aims to produce a model of the retinal pigment epithelium (RPE) using cells from patients with Doyne honeycomb dystrophy, a macular dystrophy. The researchers will test whether a new type of gene therapy can stop or slow the progression of the disease.

Dr Arjuna Ratnayaka, University of Southampton £100,000 Stopping the build-up of toxic waste in dry AMD.

In dry AMD and other macular conditions, toxic molecules build up in the RPE causing cell death and vision loss. This project aims to understand why such build up occurs and tests whether the RPE may be saved by increasing the removal of this waste.

Professor Jane Sowden, UCL £100,000 Improving the integration of stem cell derived photoreceptor transplants in the retina.

The project aims to identify molecules that promote photoreceptors creating new connections with neighbouring cells. These would allow better integration of stem cell derived photoreceptor transplants, which would replace dead cells and restore vision.

Dr Ashley Wood, Cardiff University £99,858 Can IRD be used as a testing for early stages of AMD?

A new technology called Imaging Retinal Densitometry (IRD) measures the ability of the retina to adapt to the

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dark, an early sign of AMD or macular degeneration. The researchers are testing whether this technique can be used to diagnose early AMD before other key markers, and to understand what causes loss of dark adaptation in AMD.

Professor Robert MacLaren, £119,610 University of Oxford (Joint funded with Retina UK)

#### Development of a gene therapy for Stargardt disease

Stargardt disease is the most common macular dystrophy affecting children and adolescents. It is caused by having two copies of a faulty gene called ABCA4. Prof MacLaren and his team are working to edit the gene code that leads to the ABCA4 creating a faulty protein. By fixing the gene code, the cells can produce some healthy ABCA4 protein. This can stop the damage to the cells which cause vision loss.

- We now have 24 live research projects underway with a combined value of £2,747,603.
- 13 scientific papers from projects we fund were published this year.
- Plans to introduce a seed-corn funding stream and to agree the outline proposal for a commissioned research funding programme were postponed owing to the impact of the pandemic on our income.
- We have co-funded a PhD student with Retina UK (a research and support charity that focuses on inherited retinal diseases and was formerly RP Fighting Blindness). This is the second PhD student we have funded with Retina UK.

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- We have increased the maximum value of our medical research grants for 2021 to £250k over a period of up to three years.
- We have agreed in principle to make a small (£5k) grant available in 2021 to Professor Sobha Sivaprasad to fund, with others, a study of the impact of COVID-19 on the mental health of medical retina patients. The other funders are the Moorfields Trust and Moorfields Eye Charity.
- We published an important report on the burden of wet AMD care for patients. The report was based on responses from more than 450 patients about their wet AMD care. Fear and anxiety about treatment remains common even in experienced patients. The report will be a useful tool in highlighting the challenges of current treatment and the need for new ways of treating these patients.
- Our research collaboration Action Against AMD has made further progress towards its strategic aim; to identify a new therapy or therapies to prevent the progression of early AMD to the late stages that cause sight loss, and to have it/them in early stage clinical trials by 2027.
- AAAMD is involved in three collaborative research programmes:
  - The INSIGHT consortium (with University of Birmingham, Birmingham NHS Trust, Moorfields Eye Hospital, Genentech and Google Health).
  - The SCONe initiative (with University of Edinburgh and Optometry Scotland, funded by the Royal College of Surgeons Edinburgh, The RS MacDonald Charitable Trust and the Scottish Government).
  - Repurposing research (with University of Birmingham).

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- Discussions with High Street optometry businesses regarding the acquisition of eye scans are progressing and AAAMD is now preparing an investment prospectus for the Foresight Research companies.
- Our plans to hold an international conference on Artificial Intelligence in macular research were postponed because of the pandemic (being rescheduled for 2021).
- We provided a submission to NICE as part of their technology appraisal of the new drug for wet AMD, Beovu® (brolucizumab).
- We lobbied Government both as the Macular Society and as part of The Association of Medical Research Charities (AMRC) for better support for medical research charities. AMRC are of the view that possibly 40% of charity-funded medical research is now at risk. To date, no Government support has been offered. UK charities fund c. £1b of medical research per annum, excluding Wellcome Trust funding.
- The Society is playing an increasingly important part in the national research arena:
  - We are 'patient representatives' on five clinical trial steering committees.
  - We are often approached to be a partner in projects, providing support for patient engagement to academic, NHS and commercial research teams.
  - We are the lead charity funder supporting the National Institute for Health Research's UK Ophthalmology Clinical Research Strategy.

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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.

- Our CEO, Cathy Yelf has been re-elected for a second term of office as a Trustee of AMRC on whose Nominations Committee she sits. She is also a member of the Steering Committee of the UK Spine, a Government-funded initiative to accelerate research across UK universities into diseases of ageing. She is a member the Roche Pharmaceuticals Global Patient Advisory Panel.
- We now have over 3,000 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.

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#### **Beating Macular Disease** by finding a cure

#### 2021 targets

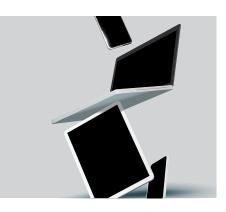
- Fund £1.25m of new research into macular diseases.
- Introduce a seed-corn funding stream.
- Hold an international seminar on the potential and applicability of Artificial Intelligence in macular disease.
- AAAMD's targets for 2021 include:
  - Continuation of the INSIGHT and SCONe projects.
  - Launch an investment pitch for the FORESIGHT initiative.
  - Launch communications strategy.
  - Create a US fundraising strategy, including contracting a Fundraising Intermediary in the US to enable us to fundraise legally there.
  - Agree a contract with the Macular Society to fundraise for AAAMD's core costs.



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#### **Beating Macular Disease** with the best advice and support

2020



All our services were affected by the pandemic, especially those we normally deliver face-to-face. The staff worked with great professionalism to stay in touch with, and motivate, our volunteers and provide more services to as many people as possible.

• Face-to-face services were suspended just before the general lockdown in March. We started the year with 381 Macular Society support groups and 49 'affiliated' groups. (Affiliated groups are managed by other organisations but are linked to us by way of a Memorandum of Understanding. By affiliating with us these groups benefit from the same support from our regional managers as our own groups).

Eighteen groups are specifically for working age people and are mainly attended by people with an inherited macular condition which appear in younger people. However, most support groups have older members who are in the category most at risk from COVID-19. Very quickly after the first lockdown, head office and regional staff set up and encouraged the use of telephone conferencing for groups. The majority of our groups made use of this facility. A few, mainly those groups for

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younger people, also used video conferencing. Many group leaders were quick to take up these methods of keeping in touch with their group members.

Although these platforms can be difficult for older people, especially those with hearing problems or lacking the equipment, the members who were able to join calls and video conferences greatly appreciated this approach to keeping in touch with friends in their group. Some people were able to 're-join' groups they left because they could no longer get to meetings.

From March to December we hosted more than 3,000 calls that had a combined attendance of more than 20,000 participants.

- We supported other, smaller sight loss organisations, to start similar services by explaining what we were doing and making our conferencing facility available to them.
- Our Skills for Seeing service was also suspended. Again, we encouraged volunteers to keep in touch with their service users by telephone. We discovered that some people can be coached in eccentric viewing techniques by telephone and that useful low vision advice can still be given in this way.
- The Skills for Seeing partnership, with other sight loss organisations, did not result in the engagement we hoped for and we intend to end the paid partnership. We will keep the referral pathways open with these partners so that a voluntary level of engagement can continue. We intend to keep our volunteer Skills for Seeing active, but do not anticipate training new volunteers. An online training course is being developed, aimed at people with

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- macular disease, to facilitate self-learning. This will launch in 2021.
- Many of our services are designed to be delivered by telephone and these continued seamlessly throughout the crisis. We saw a large increase in demand for our advice line, befriending and counselling services. We were able to secure additional 'emergency' funding for these services from a number of sources.
- Very many callers to the advice line were anxious about the virus and particularly the perceived conflict between the advice to stay at home and the advice that they needed still to attend hospital for their treatment. Many referred to having to make a choice between 'risking their life or risking their sight'. There were many very distressed callers.
- Our advisors were encouraged to have extra contact with our counselling team and the employee support service to help them manage their own emotions in the face of so many upsetting calls. In total the service responded to 18,214 requests for information and advice. (2019 total: 15,630).
- Monthly referrals to our counselling service increased from an average of 22 in 2019 to more than 40. Total referrals in 2019 were 264 against 488 in 2020. The service manager, Suzanne Roberts, worked with the sector to encourage external referrals but the pandemic was also a major driver of increased referrals. We started highly valued group counselling sessions for people with Charles Bonnet syndrome.
- Our befriending service was of enormous value to people

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who felt especially isolated during the pandemic. We have supported 320 people this year compared with 218 in 2019.

- Our Gadget Guide volunteers were also locked down but we combined this service with our Tech Talk volunteers to create a new Connect by Tech telephone service. It was designed specifically to help people use technology to connect with friends and family. Volunteers are commissioned via a closed Facebook page. The service supported nearly 200 people in 2020.
- Our new Working Age and Young People's service (WAYP) made good progress. The new WAYP Facebook page had more than 500 members. Colin Daniels (WAYP Engagement Leader) struggled to get a parents' forum working but is persisting and hopes to recruit more members by connecting with groups of teachers who are qualified to teach visually impaired students (QTVI).
- Colin recorded a series of 15 videos on Personal Independence Payments (PIP) and employment. He gave regular one-to-one advice to people facing challenges with their studies, at work, seeking work or claiming benefits.
- Much of Colin's work was to engage with other organisations in the sector to make sure that the specific needs of people with central vision loss were understood.
- We used telephony and digital platforms to enable us to continue to provide people with macular disease and their families with opportunities to hear from and connect with leading experts. Colin Daniels has held monthly webinars on Zoom on specific topics of interest

for year ended 31 December 2020

to his target groups such as myopic maculopathy and PXE. From August, the CEO held monthly webinars for people interested in AMD. Topics included AMD clinics during the pandemic, prospects of new treatments for dry AMD, Charles Bonnet syndrome (CBS), and nutrition and eye health.

- Regional managers held teleconferences with local leading clinicians for their groups and other people to join. These were in place of the planned patient information events in eye clinics which had to be postponed. However, as the pandemic continued, it was increasingly difficult to engage with senior clinicians for these sessions.
- Our annual conference was held virtually. The morning session was on inherited disease and Access to Work and the afternoon on AMD and CBS. Feedback was excellent.
- Although all these virtual events only began in August, they attracted more than 1,500 attendees and several thousand viewers after the live events on YouTube.
- We commissioned a series of nine information videos for our new website, based on our most popular information leaflets. Production was delayed by COVID-19. This was an especially important project as clinics largely stopped ordering paper leaflets when the lockdown started. This was because of the significant drop in numbers of patients in clinics but also a result of concerns about infection control.
- We used our new impact evaluation framework as the basis for an external survey of our beneficiaries.

for year ended 31 December 2020

The 300 people surveyed were a mix of group members, advice and information callers, befriending and Skills for Seeing clients. The results were very encouraging:

- 91.7% reported that they trust the Macular Society to provide them with the right information.
- Two thirds of people feel that they have acquired knowledge or a skill from the Macular Society that helps them manage their condition better.
- 69.7% believed that because of their contact with the Macular Society, they have the confidence to live life as they want to.
- 83.4% felt confident about managing their condition without the need to draw on health or social care.
- 92% would recommend the Macular Society to others.
- Just over half the people surveyed felt the Macular Society answered all their questions. In total, just over 90% felt that most of their questions were answered.
- Three-quarters of the people surveyed were of the opinion their contact with the Macular Society had improved their situation.

for year ended 31 December 2020

**Beating Macular Disease** with the best advice and support

#### 2021 targets

The months ahead are very unpredictable. It is likely that the effects of the pandemic will be felt for some time to come. Our gim is to double the number of people we reach between 2018 and 2023. Although we will expand our face-to-face and telephone services, much of the increased reach will be by developing digital services. COVID-19 has accelerated the progress of this work.

 We will re-start face-to-face services and events when it is safe to do so. and when the responsibility for COVID-19 security is not too onerous for our volunteers to manage. We can expect some groups not to reopen and some volunteers to fall away. We will have a reduced cohort of regional managers in England until our income is secure enough to consider further restructuring for the way our



for year ended 31 December 2020

regional managers operate. It is possible we may not be able to run groups where there are no volunteers or some very small groups that need a great deal of support. All to be considered as part of our revised approach to groups.

- We will conduct a review of all our peer support services to address the post-COVID-19 needs of our volunteers and beneficiaries as well as some of the longer-term challenges including:
  - Falling attendance at groups and the reasons for this.
  - Volunteer recruitment, induction and support.
  - New models and platforms for peer support to replace and/or supplement face to face meetings.
- We will review the use of information leaflets to determine if physical material is a viable means of reaching patients in the post-coronavirus era. We will explore alternative ways of delivering this information to patients.
- Our volunteer-delivered Skills for Seeing programme will continue with our existing volunteers but we will no longer train people from other organisations as this has not proved to be cost-effective. We will launch an online training course for people to coach them in eccentric fixation techniques (eccentric viewing/reading).
- We will research the validity of telephone coaching eccentric viewing.
- We will research the feasibility of introducing a new volunteer role that develops the very highly regarded low vision advice section of the Skills for Seeing programme.

for year ended 31 December 2020

- We will continue to expand our Befriending programme, our Counselling Service and the use of our Advice and Information Service by internal and external promotion.
- If funding allows, we will begin work to develop resources for the carers and family of people with AMD.
- Our work with working age and young people will continue to expand:
  - The support offered to people of a working age in all aspects of their life including employment, employment retention, welfare benefits and statutory entitlements will continue to expand through the promotion of the Advice and Information Service, on the new website, social media, and networking with partners.
  - The use of Facebook, virtual peer support and the network of WAYP support groups will also expand. The support groups will continue to meet either via telephone or video platforms until it is possible to meet face-to-face.
  - We will work with education providers in schools, colleges and universities to promote and offer support to students with central vision loss regarding Disability Student Allowance and student support services.
  - We will develop online training modules for QTVIs, TAs and student disability services.
  - We will continue to develop services for parents of children with a macular condition.

for year ended 31 December 2020

Vision matters – Beating Macular Disease by improving eye health

2020



This area of our work was also overtaken and dominated by the COVID-19 crisis.

- Our first priority was to help maintain attendance at eye clinics for those needing essential medical treatment for their eye conditions. Calls to our Advice and Information line demonstrated the acute fear many patients had, and that was reflected in the sudden, widespread (and very unusual) failure of many patients to attend their urgent injection appointments.
- We worked with the Royal College of Ophthalmologists to create a document to reassure patients that infection control measures were in place and to encourage them to attend. We have spread this message throughout the year in communications to members, via social media, on our website, in our email newsletters and in press releases and media interviews.
- We wrote to every health minister in the UK to stress the importance of continuing to maintain hospital eye services during the pandemic and keeping hospital transport services available to people with sight loss.

for year ended 31 December 2020

- The second priority area was to encourage people to see an optometrist if they had a change in their vision.
- There was evidence that new referrals into medical retina clinics had fallen substantially (from between 65% and 87% at the height of lockdown) and that this would translate to considerable loss of vision in patient groups. The fall in referrals was a result of patients not attending their routine eye examinations in High Street optometry.
- Later in the year, as optometry practices reopened for routine appointments, we encouraged people to go for routine eye examinations. The climax of this campaign was in September as part of the joint work with Vision Express.
- The Vision Express partnership led to:
  - A corporate donation to the Society.
  - Publicity in national newspapers.
  - Coverage on 20+ radio stations, reaching 12.5million people.
  - Social media activity on our channels and those of Vision Express.
- We continued to work with national bodies, both statutory and voluntary to improve eye care. The CEO and/or Research Manager represents the Society at:
  - Working groups of the NHS Restoration and Transformation programme that is re-designing services across the NHS to cope with the backlog of care created by the pandemic and create sustainable services for the future.

for year ended 31 December 2020

- The Clinical Council for Eye Care Commissioning. An important piece of work in which we are involved is the production of a report on how patients' needs can be met in the NHS 'outpatients transformation programme' and the post COVID-19 'eye care restoration roadmap' of remote consultations, virtual clinics, risk stratification and patient-initiated follow up.
- The UK Ophthalmology Alliance, similar to the above, led by the NHS.
- The Royal College of Ophthalmologists AMD guideline development group.
- The National Institute for Health and Care Excellence - we are a statutory consultee.
- A new grouping of third sector CEOs which started to scope how the sight loss sector can work together more effectively.
- We suspended our professional membership scheme as it was no longer fit for purpose. We are encouraging take up of a new, bespoke e-newsletter while we consider the future of our work with eye care professionals.
- We developed and launched phase one of our new website that we hope will be engaging, inspiring and informative. This forms part of our expanding suite of digital patient resources to deliver important eye health information and sight loss support to more people.

for year ended 31 December 2020

 We have been tracking levels of awareness of macular disease and the Macular Society. The first survey ran 29 Jan – 2 Feb 2016 and the latest survey ran in July 2020. All surveys have had c. 1,000 respondents and a confidence interval of c. 3%.

In 2016, spontaneous awareness of macular degeneration was 50% compared with 61% in 2020. Of those who were not aware of macular degeneration, 12% were aware when prompted in 2016. This figure rose to 22% in 2020. Awareness of us has remained static between 2016 and 2020 at 10%.

There have been no statistically relevant changes over this time. It is always difficult to ascribe causes of these trends, but we will use these data alongside those of our reach, levels of engagement etc. to provide a broader and more informed picture of our impact.

# Trustees' Strategic Report for year ended 31 December 2020

### Vision matters -**Beating Macular Disease** by improving eye health

### 2021 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 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 launch our online 'risk calculator'. The calculator is an idea adapted from work done by our counterparts at the **Australian Macular Degeneration** Foundation who have been willing to share it with us. (In return, we are sharing our online EV training.)
- We will continue to develop our digital presence to increase our reach including the use of additional social media platforms.



for year ended 31 December 2020

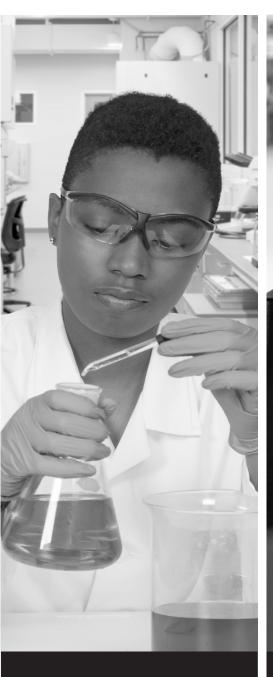
- We will use our fundraising activity, focussing on new audiences, to increase awareness of our services and our research.
- We will appoint a new Director of Services whose role will be to take a more strategic approach to our work with external organisations in this area of our work.
- We will establish a Public Policy and Government Affairs Committee to support the Director of Services and appoint a senior Public Policy Campaigns officer.

Approved by the Council of Trustees on 11 May 2021

Cecilia Bufton, Chair of the Council, Macular Society

Calia. Ul. Bulla.

# Trustees' Strategic Report for year ended 31 December 2020







**Finding** a cure

**Best advice** and support Improving eye health

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 2020, 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 2020 and of its profit for the vear 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 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

to the Members of the Macular Disease Society

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.

### 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

to the Members of the Macular Disease Society

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.



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 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.

to the Members of the Macular Disease Society

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.

### Responsibilities of Trustees

As explained more fully in the Trustees' responsibilities statement set out on page 9, 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

to the Members of the Macular Disease Society

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 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

to the Members of the Macular Disease Society

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 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.

to the Members of the Macular Disease Society

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.

### 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

to the Members of the Macular Disease Society

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

8 June 2021

# **Statement of Financial Activities**

(incorporating an income and expenditure account). For the year ended 31 December 2020

		£'000 Unrestricted Funds	£'000 Restricted Funds	£'000 Total 2020	£'000 Total 2019
	Notes				
Income from:					
Donations and legacies	2(1)	3,166	1,016	4,182	4,522
Charitable activities	2(2)	-	996	996	516
Other trading activities	2(3)	64	48	112	267
Investment income & interest	2(4)	31	-	31	17
Total income		3,261	2,060	5,321	5,322
Expenditure on:					
Raising funds	3(1)	1,422	-	1,422	1,049
Charitable activities	3(2)	1,557	2,288	3,845	4,034
Total expenditure		2,979	2,288	5,267	5,083
Net income before Gains/(lo on investments	sses)	282	(228)	54	239
Net gains/(losses) on investments	8	80	-	80	44
Net income/(expenditure) & net movement in funds		362	(228)	134	283
Reconciliation of funds					
Total funds brought forward		2,584	1,062	3,646	3,363
Total funds carried forward		2,946	834	3,780	3,646

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 2020

		2020	)	2019	9
	Notes	£'000	£'000	£'000	£'000
Fixed assets:					
Tangible assets	7		32		46
Investments	8		1,410		1,315
			1,442		1,361
Current assets:					
Stocks	9	6		7	
Debtors	10	317		439	
Cash and bank balances		3,581		2,840	
Cash held by local groups		365		354	
		4,269		3,640	
<b>Current liabilities:</b>					
Creditors: amounts falling					
due within one year	11	1,449		1,012	
Net current assets			2,820		2,628
Total assets less current liabilities			4,262		3,989
Creditors: amounts due					
after more than one year	12		482		343
Net assets	16		3,780		3,646
Funds					
Unrestricted funds	15		1,946		2,584
Designated funds	15		1,000		-
Restricted funds	14		834		1,062
Total funds			3,780		3,646

The notes on pages 55 to 71 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 11 May 2021.

Cecilia Bufton, Council Chair

Calia. Ul. Bulla.

Richard Piller FCA, CTA, Hon. Treasurer

# **Statement of Cash Flows**

For the year ended 31 December 2020

Cash flows from operating activities	2020 £'000	2019 £'000
Net income for the year (including interest received and investment income)	134	283
Adjustments for: Depreciation of fixed assets (Gain)/loss on disposals of investments Decrease/(increase) in receivables Decrease/(increase) in stock	34 (80) 122 1	29 (44) 52 1
Increase/(decrease) in payables	572	193
Net cash from operating activities	783	514
Cash flows from investing activities		
Proceeds from sale of investments	333	818
Purchases of investments	(344)	(1,158)
Purchases of fixed assets	(20)	(39)
Net cash from investing activities	(31)	(379)
Net increase/(decrease) in cash and cash equivalents	752	135
Cash and cash equivalents at beginning of year	3,194	3,059
Cash and cash equivalents at end of year	3,946	3,194
Analysis of cash and cash equivalents Cash in hand	3,946	3,194
Total cash and cash equivalents	3,946	3,194

For the year ended 31 December 2020

### 1. Accounting policies

The Macular Disease 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 £ 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) 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 33⅓% for IT and film equipment and 20% for office equipment. Fixed assets purchased by local Groups are written off in the year of purchase.
- (e) Investments investments are stated at market value. Unrealised gains and losses are recognised in the statement of financial activities.
- (f) Stocks stocks are valued at the lower of cost and estimated realisable value.
- (q) Legacies Legacies are accounted for when it is probable that they will be received and the amount can be reliably ascertained.

For the year ended 31 December 2020

- (h) Debtors Debtors are measured at amortised cost less any impairment.
- (i) 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.
- (j) 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.

- (k) Donated services donated services are included at estimated valuation.
- (I) Volunteers The Charitable Company has in the region of 1,400 volunteers. The financial value which these volunteers make is not incorporated within these financial statements.
- (m) 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 2020.

For the year ended 31 December 2020

- (n) 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.
- (o) Expenditure expenditure includes irrecoverable VAT.
- (p) Research grants unconditional research grants payable in future years are accrued for in the year awarded.
- (q) Unrestricted Funds -Unrestricted Funds comprise income received without restriction as to its use.
- (r) 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.
- (s) Restricted Funds Restricted Funds comprise income received for the purposes

- specified by the donor. Expenditure which meets these criteria is applied to the related Fund.
- (t) 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.
- (u) 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.
- (v) 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 2020

2. Analysis of incoming resources	2020 £'000	2019 £'000
(1) Donations and legacies		
Donations, appeals and unrestricted grants	1,968	1,205
Membership subscriptions	270	280
Fundraising events	513	571
Legacies (Note 18)	1,431	2,466
	4,182	4,522
£3,488k of the 2019 income was unrestricted and £	1,034k restrict	ed.
(2) Income from charitable activities		
Grants for specified charitable activities	911	463
Job Retention Scheme Grant	36	_
Other – donated services	49	53
	996	516
The income for 2019 was all restricted.		
(3) Income from other activities		
Local group income (restricted)	48	196
Trading income (unrestricted)	64	71
	112	267
(4) Income from Investments and Interest		
Interest received	3	9
Investment Income	28	8
The income for 2019 was all unrestricted.	31	17

For the year ended 31 December 2020

3. Analysis of resources expended	d			2020 2'000	2019 £'000
(1) Costs of raising funds (unre	stricted	)			
Employee remuneration (No		•		593	503
Support costs (Note 4)				161	103
Direct costs				625	395
Trading costs				33	40
Investment management c	osts			10	8
			- 1 -	1,422	1,049
	Direct costs	Staff costs	Support costs	2020 £'000	2019 £'000
	£'000	<b>£'000</b> (Note 5)	<b>£'000</b> (Note 4)		
(2) Charitable activities					
Publications	77	10	2	89	137
Educational information Advice & Infomation	205	135	22	362	458
& Counselling	190	169	26	385	324
Groups & Volunteers	46	1,001	156	1,203	1,353
Low Vision	25	200	31	256	278
Conferences	6	22	3	31	37
Research	1,036	384	20	1,440	1,211
Support to professionals	5	31	6	42	65
Local group activities	37	-	-	37	171
	1,627	1,952	266	3,845	4,034

2019 charitable expenditure was charged as to £1,737k to restricted reserves and £2,297k to unrestricted.

For the year ended 31 December 2020

4. Support costs	2020 £'000	2019 £'000
Rent and rates	86	77
Postage and office supplies	36	57
Telephone and IT	133	93
Depreciation	34	29
Recruitment	10	23
Bank charges	27	14
Governance	22	26
Other expenses	79	181
	427	500

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 £8,500 (2019: £7,200).

### 5. Employee remuneration

The average number of full and part-time employees in the year was 73 (2019:69). The average number of employees calculated on a full-time equivalent basis, analysed by function was:

	2020	2019
Management, governance and administration	6	6
Customer care and membership administration	4	6
Fundraising	17	15
Group development & volunteer coordination	15	14
Advice & Information and treatment advocacy	5	5
Low vision	5	5
Research	2	2
Education and awareness	8	7
Sideview and Digest	1	1
	63	61

For the year ended 31 December 2020

	2020 £'000	2019 £'000
Salaries	2,213	2,087
National insurance	210	198
Pension costs	122	108
	2,545	2,393

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:

	2020 Number	2019 Number
£60,000-£70,000	1	1
£70,000-£80,000	2	1
£80,000-£90,000		_1
	3	3

The total emoluments paid to the three key managers amounted to £234,000 (2019: 3 key managers £222,000)

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.

	<b>2020</b> £'000	<b>2019</b> £'000
Cost of fundraising	593	503
Cost of charitable activities	1,952	1,890
	2,545	2,393

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

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

<sup>\*</sup>Emoluments for these purposes exclude pension contributions

For the year ended 31 December 2020

#### 6. Pension scheme

The charity operates a defined contribution pension scheme. The pension charge for the year £122k (2019: £108k) 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 £21,246 (2019: £17,330) 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 2020	120	29	149
Additions	20	-	20
Disposals			
As at 31 December 2020	140	29	169
Depreciation:			
As at 1 January 2020	85	18	103
Charge for year	30	4	34
Disposals	-	-	-
As at 31 December 2020	115	22	137
Net book amounts:			
As at 31 December 2020	25	7	32
As at 31 December 2019	35	11	46

For the year ended 31 December 2020

8.	Investments	2020 £'000	2019 £'000
	Market value as at 1 January 2020 Acquisitions at cost* Disposals at carrying value Net realised gains (losses) on disposals Net unrealised gains	1,066 530 (333) 36 44	834 1,006 (818) (14) 58
	Total investments at market value at 31 December 2020	1,343	1,066
	Cash held for investment  Total investments	1,410	1,315
	Total investments at market value Total investments at historical cost	1,410 1,316	1,315 1,236
	Revaluation unrealised gain	94	79
	Investments are further analysed as follows: Listed equities (UK £451k, Overseas £390k)	841	504
	Listed fixed interest and index linked Investments (UK £316k, Overseas £48k)	364	358
	Other investments  Cash held for investments	138 67	204 249
		1,410	1,315

<sup>\*</sup>Acquisitions include an additional cash injection into the portfolio of £Nil (2019:£343)

For the year ended 31 December 2020

	2020 £'000	2019 £'000
9. Stocks comprise diaries & cards for sale	6	7
10. Debtors & prepayments		
Legacies (Note 17)	207	333
Gift aid	41	38
Prepayments	69	65
Other debtors	-	3
	317	439
11. Creditors & accruals: amounts falling due within one year		
Research grants committed not yet paid	1,163	760
Trade creditors	107	102
Accruals & other payables	111	150
Taxation and Social Security	68	-
	1,449	1,012
12. Creditors: amounts falling due		
after more than one year		
Research grants committed not yet paid	412	283
Accruals and other payables	70	60
	482	343

For the year ended 31 December 2020

#### 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 Manchester AIVI A virtual rehabilitation assistant to offer timely and relevant information and advice to individuals with visual impairment.
- Queen's University Belast Using data science to determine the best combination of factors for the diagnosis of AMD and to detect clinical change over time...
- Newcastle University Developing biochemical exosomal vesicle-associated markers for AMD and elucidation the role of exosomes in AMD pathogenesis.
- University College London Antisense oligonucleotide therapy for the treatment of dominantly inherited juvenile macular dystrophy.
- University of Southampton Rescue of dysfunctional lysosomes in the retinal pigment epithelium (RPE) as a new dry AMD treatment.
- University College London Tissue engineering using stem cell-derived photoreceptors for macular repair.
- Cardiff University High fidelity imaging densitometry: exploring the relationship between visual pigment kinetics, choroidal vasculature and sub-retinal drusennoid deposits in AMD.
- Macular Society/Retina UK PhD Studentship to joint fund a second PhD studentship on retinal dystrophies with Retina UK.
- AAAMD an additional grant towards research into repurposing drugs for use in treating macular disease.
- NIHR to fund a new post to co-ordinate eye research in the NHS.

For the year ended 31 December 2020

### 13. Analysis of research grants (continued)

ov / mayoro or research grants (commeta,	Charged to reserves		
	Restricted £'000	Unrestricted £'000	
University of Manchester	91		
Queen's University Belfast	114		
Newcastle University	200		
University College London	200		
University of Southampton	100		
University College London	100		
Cardiff University	100		
Joint PhD Studentship	60		
AAAMD	22		
NIHR	71		
Salary, support and other costs	382		
Total charge to reserves	1,440		
Total research expenditure – Note 3(2)	•	1,440	
	<u> </u>	E'000	
Research grants committed but not yet paid b/f 1 January 2020	•	1,043	
Grants directly paid in the year to institutions		1,058*	
Research grants committed but not yet paid c/f 31 December 2020	_	(526)	
	•	1,575	
<ul> <li>Excludes attributed indirect costs calculated in accordance with the apportionment in Note 1(t)</li> </ul>	_		

#### 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 for resources to increase the impact of services in Northern Ireland

For the year ended 31 December 2020

#### 14. Restricted funds (continued)

- A National Lottery Community Fund Improving Lives in Scotland
- A Groups and Volunteers fund for support to local groups and volunteers
- A Local Groups fund representing cash and deposits held by local groups to fund their future activities
- Special Project funds for specified current year activities

	As at 1 Jan 2020 £'000	Moveme Income £'000	ent in year Expenses £'000	As at 31 Dec 2020 £'000
Research	648	1,197	(1,440)	405
National Lottery Community Fund - People & Communities	-	120	(86)	34
Groups & Volunteers	-	601	(601)	-
Counselling	60	38	(68)	30
Local Groups	354	48	(37)	365
National Lottery Community Fund - Improving Lives in Scotland		56	(56)	
	1,062	2,060	(2,288)	834

#### Restricted income includes:

- £15,000 from the Blindcraft Charitable Trust for supporting people with macular conditions in Scotland.
- £45,000 from The City Bridge Trust, the funding arm of the City of London Charity, Bridge House Estate (1035628) for support services in London.
- £38,300 from the Masonic Charitable Foundation for Emotional Support Services, so that no one faces sight loss alone.
- £56,124 from the National Lottery Community Fund for practical and emotional support for people with sight loss in Scotland.
- £120,000 from the National Lottery Community Fund for support services in Northern Ireland.
- £12,000 from the RS Macdonald Charitable Trust for providing a range of practical and emotional support services in Scotland.

For the year ended 31 December 2020

#### 15. Unrestricted and designated funds

	As at 1 Jan 2020 £'000	Inccome £'000	Expenses £'000	Transfer £'000	As at 31 Dec 2020 £'000
Unrestricted	2,584	3,341	2,979	(1,000)	1,946
Designated	-	-	-	1,000	1,000
	2,584	3,341	2,979	1,000	2,946

The Company has transferred £1,000k from its Unrestricted funds to a new 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	1,442	-	-	1,442
Net assets	504	1,000	834	2,338
	1,946	1,000	834	3,780

#### 17. Trustee remuneration

The Trustees received no remuneration during the year (2019: nil). During the year 3 Trustees (2019: 8) were reimbursed for travel and out of pocket expenses amounting to £445 (2019: £3,439).

For the year ended 31 December 2020

### 18. Legacies

Legacies of an estimated £892,700 (2019: £890,200) have been excluded from income as the criteria for recognition had not been met.

#### 19. Commitments

As at 31 December 2020 the Society had the following annual office rent commitments under non-cancellable operating leases:

	2020 £'000	2019 £'000
Payable within one year Payable from one year to five years	66 127	60 175
Payable after five years	0	0
	193	235

### 20. Analysis of changes in net debt

	As at 1 Jan 2020 £'000	Cash flows £'000	As at 31 Dec 2020 £'000
Cash and cash equivalents			
Cash	3,194	752	3,946
D a was a single			
Borrowings			
Debts due in under 1 year	(1,012)	(437)	(1,449)
Debts due after 1 year	(343)	(139)	(482)
	(1,355)	(576)	(1,931)
Total	1,839	176	2,015

For the year ended 31 December 2020

#### 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 £3,946k (2019: £3,194k).

#### 24. Related Party Transactions

During the year a grant payment was made to Action Against AMD amounting to £22,000 (2019: £91,000).

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 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 will be paid in 2021. Professor Sivaprasad is a Trustee/Director of the Company.

There are nine members of our Research Committee: eight are distinguished academics from UK universities and two are lay members, both Directors/ Trustees. The Committee 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.

# Appendix A

Research Committee

### **Professor James Bainbridge** CHAIR

Professor of Retinal Studies at University College London and Consultant Ophthalmologist at Moorfields Eye Hospital

#### **Professor Bal Dhillon**

Professor of Clinical Ophthalmology, University of Edinburgh and Hon Consultant Ophthalmic Surgeon at Princess Alexandra Eye Pavilion

#### **Professor Phil Luthert**

Professor of Pathology, Head of Department of Eye Pathology, Institute of Ophthalmology, University College London

### **Stephen Stacey**

Macular Society Trustee and lay member

#### **William Best**

**Macular Society Trustee** and lay member

#### **Professor Tom Margrain**

Cardiff Centre for Vision Sciences, College of Biomedical and Life Sciences, Cardiff University

#### Professor Luminita Paraoan

Eye and Vision Science, Institute of Ageing and Chronic Disease, University of Liverpool

#### Dr Imre Lengyel

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

#### **Professor Alexander Foss**

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



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