

# Macular Society Report and Accounts for year ended 31 December 2022

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for year ended 31 December 2022

President Timothy ffytche, LVO, FRCS, FRCOphth

Henry Blofeld OBE \* **Patrons** 

Gemma Craven \*

Gwyneth Dickinson MBE \*

Patricia Greene \*

Vince Hill\*

Maggie Norden

Zac Shaw \*

The symbol \* indicates visual impairment.

for year ended 31 December 2022

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 BDB Pitmans,

Advisers One Bartholomew Close,

London EC1A 7BL

Investment Rathbone Investment Management Ltd,

Managers 8 Finsbury Circus,

Finsbury, London EC2M 7AZ

Registered Crown Chambers,

Office (and South Street,

actual office

address)

**Numbers** 

**Numbers** 

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Company England and Wales 2177039

Registered Isle of Man: 005738F

Registered England and Wales: 1001198,

Charity Scotland: SC042015, Isle of Man: 1123

for year ended 31 December 2022

The Directors of the Macular Disease Society submit their annual report and audited financial statements for the year ended 31 December 2022. 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 the biggest cause of sight loss in the developed world and the third biggest globally. In the UK it causes 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. Approximately 700,000 people in the UK have late-stage age-related macular degeneration.

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As we live longer that number will rise. Globally it is estimated that the population with all forms of AMD will rise from 196m in 2020 to 288m by 2040. There are many forms of rarer conditions that affect younger people; inherited macular conditions such as Stargardt disease, macular pathology caused by high levels of myopia (short-sightedness) and diabetic eye disease that affects the macula.

To meet this enormous public health challenge, the Society has three key objectives; to support medical research to find a cure for macular disease, to provide information, advice and other services to improve the lives of people living with macular disease and to campaign for eye health to be prioritised across society. 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:

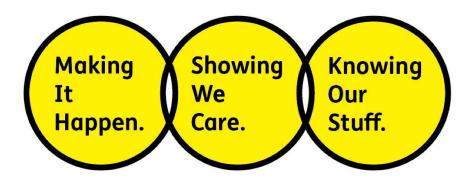
- Finding a cure
- Providing the best advice and support
- Making sure 'vision matters' to everyone.

for year ended 31 December 2022

#### Our values

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

We will **Beat Macular Disease** by



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.

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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.

#### Thank you

The Trustees are extremely grateful to everyone who has contributed to our work this year; our generous donors and supporters, our committed and dedicated volunteers, our partner organisations and our staff.

### 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 2022, the Society had 14,317 members – 12,585 voting members and 1,732 six months free trial members.

There were 330 support groups at the end of 2022, all of which operate under our charity number. Each group is required to submit an annual financial return at the year-end. These returns are consolidated into the Society's financial statements.

Approximately 7,600 people remained registered as group members.

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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 members' quarterly magazine) and elsewhere.

Applications are reviewed by the Governance and People Committee. 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.

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#### These committees are:

#### Finance and fundraising

Reviews the annual budget, monitors financial and fundraising performance and oversees the statutory annual audit.

#### Research committee

Recommends the allocation of research funding and monitors output from research projects.

#### Governance and people committee

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

#### Audit and risk committee

Oversees the Society's risk policy, framework and appetite statement. Provides internal audit supervision and advice, and risk management oversight.

 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.

# Trustees' Report

for year ended 31 December 2022

The Trustees present their report and the financial statements for the year ended 31 December 2022.

### 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 2022

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 £1,278k (2021: £1,703k).

#### **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) \*

Anna Fletcher LLB \*

Jayne George (appointed 10 May 2022)

Sheena George, FRCOphth

Charles Griffith (resigned 8 February 2022)

Robin Hamilton, FRCOphth

Elaine Latham

Frances Luff BA (Hons)

Patrick McGeough Eng MIIE (Mech), RAF Rtd \*

James Potter LLM \*

Amanda Rowland LLB \*

### Trustees' Report

for year ended 31 December 2022

Sobha Sivaprasad, FRCOphth Stephen Stacey MA, DPhil 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 15 to 44 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 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.

# Trustees' Report

for year ended 31 December 2022

#### **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 16 May 2023.

Cecilia Bufton

Chair of the Council

Calia. Ul. Bulla.

**Macular Society** 

for year ended 31 December 2022

### 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

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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 £1,278k (2021: £1,703k). Total funds at the year-end were £6,806k (2021: £5,483k).

The Society's reserve position at the end of 2021 was such that we felt confident in setting a deficit budget for 2022. The pandemic continued to have an impact on our plans in several income streams such as events and community fundraising. The economic crisis that began to emerge after the Russian invasion of Ukraine has shown signs of affecting the growth in individual giving. However, all areas of our fundraising grew in the year, especially income from trusts and foundations, corporate partners and legacies. Movements in the stock market led to an unrealised loss of some £223k from our portfolio invested with Rathbones.

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### Reserves policy

Unrestricted reserves at the year-end amounted to £4,302k (2021: £3,758k). 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 maximum of six months of our costs budgeted for 2023. This amounts to £3,017k for 2023 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. For two years in succession the Society has received unexpected legacy income at the very end of the year of c. £1m, leading to a better than forecast outturn in both 2021 and 2022.

The two large legacy gifts were from the same estate and are restricted to research expenditure. We now have significant restricted research reserves, which provides an opportunity to broaden our portfolio and invest in new areas of research and development.

We are committed to making the best use of these funds, so generously left to us by the late Mrs Agnes Pullen. We commissioned a research 'gap analysis' to guide our decisions on where we could have the biggest impact on the development of new treatments and a cure for macular disease. All our research investment to date has been in academia and it is clear from the analysis that we need to grow our support of basic science. However, we will now start to diversify into more translational areas where a lack of funding is hampering innovation. This is new to us and we need to build the

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capability to be effective and credible in this translational space. We have appointed our first Director of Research and are now creating the team that can deliver new research programmes. Meanwhile the funds remain in our Restricted Reserve, ready to be deployed when the new research funding streams are launched in 2023/4.

At the year end we are holding restricted reserves amounting to £2,504k (2021: £1,770k), of which £2,098k (2021: £1,365k) are restricted to research to enable the launch of major new and additional research funding in 2024.

Inflation will have a significant impact on our costs in 2023, although our energy costs are contained in a fixed tariff contract until 2025.

We remain cautious in our approach to spending in 2023 in the light of the economic situation. However, we are drawing down 50% of our £1m designated COVID Recovery Fund in both 2023 and 2024 to ensure that we can continue to deliver our strategic aims during a period of high inflation and a potential drop in charitable giving during the cost of living crisis.

### 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

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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 £1,579k and ended the year at £1,685k. This portfolio represents the Society's minimum reserve fund. During the year, the global economic crisis and the continuing impact of the COVID-19 pandemic had an adverse impact on capital growth and investment returns. In 2022, the Society invested an additional £300k to top up the minimum reserve fund. At the balance sheet date, the net unrealised losses amounted to £223k (2021:(£135k) unrealised gains). Investment income for the year totalled £42k (2021:£33k).

The Society's policy is to invest remaining cash reserves in bank deposits or similar instruments. Of the £6,946k at the year-end (excluding cash held by local groups), £402k was on deposit with NatWest and £321k was with Nationwide. The balance is held with Barclays Bank PLC. It was agreed by Council that we would deposit £2m of our cash balances across approximately 14 accounts via the cash deposit platform Flagstone, who are authorised by the Financial Conduct Authority. Interest income for the year amounted to £5k (2021: £1k).

#### Research grants

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

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The Committee membership can be found at Appendix A.

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. They are Professor Sobha Sivaprasad and Richard Piller. In 2022 Professor Jo Aldridge was appointed as a lay member of the Committee (resigned February 2023). A complementary lay panel was also established with the intention of it starting work in 2023.

The Committee currently 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:

(appointed February 2023)

Catherine Yelf, Chief Executive Emma Malcolm, Director of Fundraising and Marketing Stephen Scowcroft, Director of Services (resigned February 2023) Peter Bloomfield, Director of Research

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Karen Noble, Head of Finance Rebecca Ward, Head of Human Resources **John McKay**, Head of IT and Data Insight (resigned March 2023)

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 economic difficulties facing the UK; protected by a holding of a minimum reserve and other funds;
- protection of our bank deposits and investment portfolio; protected by diversifying our holdings across a greater number of accounts via Flagstone Investment Management and spreading risk through our investment portfolio holdings;
- data protection failure; protected by a comprehensive data protection policy. This includes an Information Security Incident Management Policy, a review of data retention, six-monthly disaster recovery exercises and annual staff and volunteer training;

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 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.

### 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 £5,100k 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 £477,405 received in Weekly Lottery ticket sales from January to December 2022, 20% was spent on expenses, 20% on prizes and 60% was used to fund our important work. Of the £121,463 received in tickets sales in the two Macular Society Raffles during 2022: 15% was spent on expenses, 14% on prizes and 71% was used to fund our important work). We have an annual Groups' Research Appeal. Via

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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, adapt and 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.

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 six complaints in 2022 (2021: three) from 14.6 million fundraising contact points (excluding legacy direct mail and individual giving stewardship communications). 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 the 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.

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We are registered with the Fundraising Preference Service so that individuals are able to opt out from receiving fundraising communications from us. We actioned 20 requests from the Service in 2022 (11 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 their 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.

We will make choices in the operation of the charity that aim to balance the requirement to achieve our mission with

for year ended 31 December 2022

limiting our environmental impact and the sustainability of our activities. A key element of this is reducing travel to work by offering staff flexible working arrangements and working from home options.

### Equality, diversity and inclusion

We are committed to treating people fairly and as equals. We know that to Beat Macular Disease for all we will need to work more proactively than to date to reach people who do not currently use our services.

- We will work together as employees, volunteers and partners to create an inclusive organisation and a culture of equality and diversity that informs everything we do.
- We will be clear about the change we want to see and why. We will reflect, learn and listen so that we can make meaningful changes the impact of which we can demonstrate.
- We will make fair and accessible services available to everyone affected by macular disease.
- We are committed to funding research that considers everyone affected by macular disease.

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# Beating Macular Disease by finding a cure 2022

#### Key evaluation question:

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

#### Our progress in 2022

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.

The Committee's recommendations are considered by the full Council for approval.

Our seedcorn 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 for funding in 2022. We received a total of 41

for year ended 31 December 2022

applications for our 2022 funding programme, 20 for research grants, nine for PhD studentships, 11 seedcorn funding applications and one ad hoc application. 26.8% were considered 'fundable'.

The start of some of the 2021 and 2022 funded projects was delayed owing to recruitment problems and the lack of applications for post-doctoral posts from EU citizens.

We had three funding streams in 2022:

- Research project grants up to £250k over a maximum of three years
- PhD Studentships for which the grant is up to £120k over three years
- Seedcorn grants of up to £25k over one year

The PhD studentships and the research project grants have a two-stage application process starting with an outline application. Applicants shortlisted by the Research Committee submit a full application, which is peer reviewed before being assessed again by the Committee.



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The following grants to the value of £1,209,656 were awarded in 2022:

#### **Project grants:**

#### Professor Maria Balda, University College London £249,450

Apg2 pathway in age-related macular degeneration

#### Dr Michael Crossland, University College London £134,280

Supporting Teenagers and young people to Overcome Macular Problems (STOMP): User-led vision rehabilitation for young people with inherited macular disease

#### Dr Adam Dubis, University College London £244,861

Differential staging and progression of age-related macular degeneration driven by genetic risk polymorphisms

#### Professor Reinhold Medina, Queens University, Belfast £242,783

Targeting cellular senescence in the choriocapillaris as a new strategy to treat dry AMD

#### Professor Robin Walker, Royal Holloway £37,178

Evaluating therapies for visual hallucinations in Charles Bonnet Syndrome: an on-line Randomised Control Trial (RCT)

#### Professor Rhiannon Tudor Edwards, Bangor University £24,867

A health economics bolt-on analysis of the Vitrectomy,

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subretinal Tissue plasminogen activator and Intravitreal Gas for submacular haemorrhage secondary to Exudative age-Related macular degeneration (TIGER) study

**Total project grants: £933,419** 

#### PhD studentships:

#### Professor David Kavanagh, Newcastle University £99,818

Interrogation of genetic variability in complement factor I for personalised patient management of geographic atrophy

#### **Dr Forbes Manson, Manchester University** £101,419

CRISPR-activation therapy for macular disease

Total PhD studentship grants: £201,237

#### Soodcorn grants

Seedcorn grants:	
<b>Dr Eleni Beli, Queen's University Belfast</b> The impact of misaligned daily light cycles on the progression of diabetic retinopathy	£25,000
<b>Dr Takeshi Yoshimatsu, Sussex University</b> The zebrafish high-acuity zone as a novel model for the human macula	£25,000
Professor Heidi de Wet, Oxford University The role of ABCC5 in diabetic macular oedema	£25,000

Total seedcorn grants: £75,000

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We invested £1,209,656 directly in research projects and supported our research collaboration, AAAMD, with £100k of funding for core costs.

We signed a Memorandum of Understanding with Diabetes UK, paving the way for joint funding of research into diabetic eye disease together with Fight for Sight and Moorfields Eye Charity.

We jointly fund early-career researchers with Retina UK and have agreed to fund two more PhD studentships on macular dystrophies. We received a grant of £383k from the Government, via the Medical Research Council, expressly to support our investment in early-career researchers. The grant was the result of discussions between the Association of Medical Research Charities, on behalf of organisations such as the Macular Society, and the Department for Business, Energy and Industrial Strategy.

We held two extremely successful scientific meetings; one on gene editing in ophthalmology and another on the development of a mathematical modelling pathway to create a 'virtual eye'.

We commissioned a research and development 'gap analysis' to identify areas along the therapeutic development pipeline where investment from the Macular Society has the potential to make a significant impact on the progress towards new therapies and technologies to Beat Macular Disease. The work will begin when our Director of Research joins in February 2023.

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We supported the wider research ecosystem. We part-funded a three-year post within the National Institute of Health Research (NIHR) to help plan and coordinate eye research across the NHS. We remain an NIHR non-commercial portfolio partner. Acceptance on this scheme gives relevant researchers access to NIHR support. We sit on the Executive Committee of the UK Clinical Eye Research Strategy and the new Retina Clinical Research Group.

We part-funded Phase 1 of the UK National Eye Heath and Hearing Study to provide data on the underlying burden of eye disease/vision impairment within the population.

Our CEO contributed to the national conversation about charity-funded medical research in her role as a Trustee of the Association of Medical Research Charities and as a member of the INSIGHT and UK Spine research initiative steering committees.

We contributed to many groups and committees, fulfilling the role of patient representative to ensure the patient voice is heard. This includes sitting on the steering committees of five clinical trials and inputting to the development of RCOphth Clinical guidelines on treatment of macular holes.

We contributed to several consultations on NICE technology appraisals on new treatments and tracked the progress of new drugs going through clinical trials and regulatory approval.

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The first RCOphth clinical audit of wet AMD treatment took place in 2022. We provided key funding to support early development work and have continued to work closely with the College by being on the advisory group and enabling the views of patients to shape the audit.

All this work has continued to drive our excellent and growing reputation as a leading research funder and innovator.

#### 2023 plans

Our first Director of Research will take up their role in early 2023. The Director will lead the development and diversification of our research portfolio to reach into new areas where we can help accelerate progress towards new treatments and cures for macular diseases.

We propose to budget £1.7m for direct research grants and the holding of scientific meetings in 2023. This figure includes £100k to support AAAMD and £24k to continue to support the co-ordination of the NIHR ophthalmology clinical specialty groups.

Much of 2023 will be taken up with developing our new plans for 2024 and beyond, including the further development of our collaborations and partnerships.

We now have over 4,100 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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#### **Action Against AMD**

Action Against AMD (AAAMD) is a charity collaboration between the Macular Society, Blind Veterans UK, Sight Scotland and Sight Scotland Veterans. Its challenge is to find ways of preventing early AMD progressing to the stages that cause sight loss. AAAMD's strategy is to:

- Find 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

In 2022, AAAMD made progress in identifying potential new therapies for AMD among existing medicines. These discoveries have led to a collaboration with the National Institute for Health in the USA.

AAAMD's wholly owned subsidiary, Foresight Research Ltd, was brought out of dormancy in readiness for the start of trading. Its primary focus is the aggregation of community-acquired OCT scans for analysis to identify early stage disease. Sight Scotland Veterans have invested £1m in Foresight as a programme-related investment. Bright Focus, a US charity have invested \$250k.

AAAMD has joined the Our Future Health programme; the world's largest-ever health research project. Our Future Health will use health data from five million UK citizens to help people live healthier lives for longer through the discovery and testing of more effective approaches to

for year ended 31 December 2022

prevention, earlier detection, and treatment of diseases. With the involvement of AAAMD, those diseases now include AMD and glaucoma. Among other benefits, the collaboration with Our Future Health is intended to enrich the eye data acquired by Foresight Research Ltd. These three projects will be developed throughout 2023.

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

Key evaluation question:

Is the Macular Society effectively supporting people with macular disease?

### Our progress in 2022

This year revealed the real impact of COVID-19 on our services. Although some have continued to flourish and grow, others have seen a contraction in their activities.

#### Peer support

Our peer-support group network in particular was hit by the pandemic. The groups did not meet at all for most of 2020 and 2021. It was only in the second half of 2022 that the majority of groups returned to regular face-to-face meetings. In the intervening time a significant number of volunteers stood down. At the end of the year 330 groups were still operating from a total of 410 that were, on paper, operational at the end of 2021.

for year ended 31 December 2022

At the end of 2022, 293 groups had returned to face-to-face meetings. In total, 102 groups were still holding only teleconference meetings. Some groups enjoyed their virtual meetings so much they continue to hold them as well as in-person gatherings. Tele-conferencing has allowed people to have the benefit of peer support even if they cannot attend a face-to-face group. Over the year, the regional team facilitated 1,070 one-hour calls with over 5,724 participants.

The regional staff supported their volunteers with great dedication during this difficult time and it is a testament to their work that so many groups remain vibrant and robust.

#### Virtual support

The pandemic accelerated our work to develop new virtual communities and these new ways of connecting people have been very popular.

In addition to the regular group tele-conferencing, we continued our telephone based Winter Warmer sessions to tackle isolation and loneliness during the winter months. The calls have seen 465 participants across 16 sessions, with over 100 people joining regularly.

We held monthly My Macular and Me webinar sessions. Each month the chief executive hosted events gimed at the AMD audience, and the working age and young people services manager hosted sessions for people affected by other macular conditions. The webinars attracted a total of 1,840 people at the live events and more than 31,000 views of the recordings.

for year ended 31 December 2022



We held our annual conference online again in 2022. As in the two previous years, we had two optional sessions for people to participate in. The My Macular and Me session was aimed at people newly diagnosed, as well as friends, family and carers. It ran in both the morning and the afternoon. The other slot had a morning slot devoted to macular dystrophies and an afternoon slot focussed on AMD. The speakers gave presentations on the recent progress in science and research. More than 2,553 people registered, with peak viewing figures on the day of 1,235 (plus 34 joining via conference call). Another 8,395 had watched the recording by the end of January 2023. We reached many more people than would be possible at a physical event.

#### Working age and young people

We know that people with macular disease value specific information about their own condition. We have therefore continued to developed our condition-specific online groups for people affected by diabetic macular oedema (DMO), myopic macular degeneration (MMD), Sorby fundus dystrophy and Best disease.

for year ended 31 December 2022

Our Facebook group for working age and young adults has over 800 participants sharing information and support. We supported 224 people with specific enquires about employment and access to benefits and support.

### Advice, information and support services

Our Advice and Information service received nearly 18,000 calls and emails and recorded more than 12,000 'significant' support actions on topics covering all macular conditions, treatments and low vision aids.

Practical and emotional support was provided through our Befriending service to 261 people. Our counsellors delivered care to 602 people by way of 2,057 individual sessions. We have expanded the counselling service to include groups on particular topics including employment, being newly diagnosed and Charles Bonnet Syndrome (the visual hallucinations often associated with sight loss).

We have developed alternative ways to deliver low vision support through our Skills for Seeing and Connect by Tech services. This year we have responded to 889 referrals through a combination of telephone support, our introduction to Skills for Seeing monthly webinars and by signposting 569 people to our eccentric viewing online programme.

### **Effective support**

Our annual quality of life survey provides feedback on the impact of our support services and how effective they are.

for year ended 31 December 2022

This year 95.9% (97% in 2021) reported that the Macular Society provides information that people can rely on. 86.9% (86% in 2021) of respondents feel that their connection to the Society has made things better.

In 2022 we conducted further research to understand the support needs of people affected by macular disease, both people with the condition and those who provide support and care to people with the condition.

Important findings were that people with low awareness of support services, such as those provided by the Macular Society, reported less good emotional wellbeing. The majority of eye care professionals reported that they 'always' or 'often' signposted patients to support services but only a small proportion of patients recalled that they had received this information. Caregivers have a range of emotional and practical support needs of their own, arising from the care they provide to a person with macular disease, that are unrecognised and unmet.

### **Volunteers**

The pandemic has had an adverse effect on the number of people volunteering for us. Many of our services, such as our peer support network and our befriending service rely on volunteers.

We continue to be extremely grateful, and humbled by the generosity and dedication shown by more than 1,200 people who continue regularly to give their time to support the Macular Society and people affected by macular disease.

for year ended 31 December 2022

All our staff greatly appreciate the work of our volunteers and want to support them in any way they can. We have appointed a dedicated Volunteer Manager to help us recruit and retain volunteers and to make sure we are providing valued volunteering roles.

We conducted our volunteer survey in order to continue to understand the impact and engagement that we have with our volunteers. We are pleased to report that 95% of our volunteers feel valued and appreciated as a volunteer and that their contribution is recognised. In addition, 96% feel that we use their skills and knowledge and 99% would recommend volunteering for the Macular Society.

We have improved our volunteering resources. We produced a new volunteer handbook incorporating a clear volunteer agreement that sets out expectations of our volunteering roles and how we support them. We have reviewed and created clear and consistent role descriptions and have developed a more consistent approach to induction and training for new volunteers. These have all been co-created with our volunteer community in order to ensure the materials are relevant and engaging.

We are planning a volunteer recruitment campaign for 2023.

### 2023 plans

Reflecting the information we collected from our research with eye care professionals, patients and caregivers, our service development plans will focus on three key areas.

for year ended 31 December 2022

- Expanding our marketing to different audiences in order to reach more people and more diverse audiences
- Continuing to develop our information and support through digital and face-to-face
- Expand our interaction with friends, family carers and eye care professionals as key channels to people affected by macular conditions

A Head of Services Development will take up their position in early 2023 to take this work forward.

We will expand our existing informative, emotional and practical support, ensuring our services have the resource they need to meet rising demand.

In our group network the priorities will be to stabilise the existing groups, rebuild the volunter base and reach into new and under-served communities.

# Vision matters – Beating Macular Disease by improving eye health

Key evaluation question:

Are our key audiences aware of macular disease and the Macular Society?

### Our progress in 2022

We have continued to build awareness of macular disease within the general population by our on and offline

for year ended 31 December 2022

presence. Our offline activity promoting our services, membership and fundraising has reached over nine million people. We have purposely increased our promotion of membership through offline channels, such as print, this year to reach people who aren't online.

Online we used our social media platforms to increase awareness and drive engagement, reaching over 2.75 million people on Facebook alone.

We promoted our Macular Risk Checker between September and November to help people rate their risk of age-related macular degeneration and receive information on driving it down. Over 55,000 people checked their risk in the three months it ran and 6% are continuing to receive communications from us.

In order to build awareness of macular disease across the general population, we collaborated with Bayer on their 'Don't Lose Focus' campaign. This featured a 30-second advertisement, fronted by Twiggy, which launched on World Sight



Day in October. Over a six-week period on social media, the campaign reached a total of 559,244 on Facebook and received 237,958 views on YouTube. The advert also featured on ITV3 for a two-week run and reached 2,163,000 adults. The campaign will continue in 2023.

for year ended 31 December 2022

The Macular Society partnered with a wide range of organisations to increase awareness of macular disease and eye health generally.

'The Eyes Have It' is an increasingly effective collaboration with the Royal College of Ophthalmologists, the Association of Optometrists, Fight for Sight, the RNIB and Roche Pharmaceuticals. The group successfully campaigned for the appointment of a National Clinical Director for Eye Health in England. In 2022, the work focused on the call for a national eye strategy for England. Jim Shannon MP led

a Westminster Hall debate in January during which several MPs called for a national strategy. This was reinforced at a second successful Westminster Eye Health Day in October. In November, Marsha de Cordova MP introduced a 10 Minute Rule Bill to establish a national eye health strategy.



The Society is part of the 'VI Sector Collaboration' of eight eye charities that is seeking to identify ways for the sector to work together more effectively. Projects are underway to increase employment among visually impaired people, improve emotional wellbeing in people with sight loss and increasing collaboration between charities on key campaigns, such as the impact of the cost of living crisis on people with sight loss.

for year ended 31 December 2022

The Society has continued to engage with the NHS in the redevelopment of eye care services.

### 2023 plans

We wish to address some key themes that emerged from our research with patient, carer and eye care professionals research, namely:

- A lack of awareness of the Macular Society often expressed as: "I didn't know" and "I didn't think it was for me."
- A need for knowledge: "I didn't understand my condition (or my family member's condition) or the support and treatment options." This is exacerbated by a lack of information at the point of diagnosis.

As a response to this, we have developed a programme of activities for 2023/2024 which will aim to:

- Engage patients who have low awareness of the Macular Society and available support/treatment at the point of diagnosis.
- Ensure the Macular Society's services are available to all by understanding the needs of people in more under-served areas of the UK.
- Revise our patient information support materials so they are more appealing to the target audiences and easier to understand.
- Promote support at the point of diagnosis.

for year ended 31 December 2021

- Develop strategic relationships across the eye care sector to amplify our voice, thereby ensuring swift signposting for patients and their support network.
- Provide increased specialist support through the Macular Society's Advice and Information Service.
- Develop and promote emotional and practical support services for carers.

Approved by the Council of Trustees on 16 May 2023.

Cecilia Bufton,

Chair of the Council,

Calia. Ol. Bulla.

**Macular Society** 



# We will **Beat Macular Disease**

# 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 2022, 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 2022 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 described in the Auditors' responsibilities for the audit of

to the Members of the Macular Disease Society

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 12 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

to the Members of the Macular Disease Society

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

to the Members of the Macular Disease Society

• 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 organisation for fraud and identified the greatest

to the Members of the Macular Disease Society

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.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance.

to the Members of the Macular Disease Society

The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. 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 Company's members, as a body, for our audit work, for this report, or for the opinions we have formed.

Simon Allenby FCA (Senior statutory auditor) for and on behalf of Clifford Fry & Co LLP

St Mary's House, Netherhampton Salisbury, Wiltshire SP2 8PU

16 May 2023

### Statement of Financial Activities

(incorporating an income and expenditure account). For the year ended 31 December 2022

		£'000 Unrestricted Funds	£'000 Restricted Funds	£'000 Total 2022	£'000 Total 2021
	Notes				
Income from:					
Donations and legacies	2(1)	5,237	2,181	7,418	6,747
Charitable activities	2(2)	-	1,296	1,296	723
Other trading activities	2(3)	79	91	170	123
Investment income & interest	2(4)	47	-	47	34
Total income		5,363	3,568	8,931	7,627
Expenditure on:					
Raising funds	3(1)	2,330	-	2,330	1,885
Charitable activities	3(2)	2,266	2,834	5,100	4,174
Total expenditure		4,596	2,834	7,430	6,059
Net income before Gains/(lo on investments	sses)	767	734	1,501	1,568
Net gains/(losses) on investments	8	(223)	-	(223)	135
Net income/(expenditure) & net movement in funds		544	734	1,278	1,703
Reconciliation of funds					
Total funds brought forward		3,758	1,770	5,528	3,780
Total funds carried forward		4,302	2,504	6,806	5,483

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 2022

		2022		202:	1
	Notes	£'000	£'000	£'000	£'000
Fixed assets:					
Tangible assets	7		27		45
Investments	8		1,685		1,579
			1,712		1,624
Current assets:			,		,
Stocks	9	6		3	
Debtors	10	596		732	
Cash and bank balances		6,946		5,273	
Cash held by local groups		302		360	
		7,850		6,368	
<b>Current liabilities:</b>					
Creditors: amounts falling					
due within one year	11	1,970		1,769	
Net current assets			5,880		4,599
Total assets less current liabilities			7,592		6,223
Creditors: amounts due					
after more than one year	12		786		695
Net assets	16		6,806		5,528
Funds					
Unrestricted funds	15		3,302		2,758
Designated funds	15		1,000		1,000
Restricted funds	14		2,504		1,770
Total funds			6,806		5,528

The notes on pages 55 to 73 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 16 May 2027

Cecilia Bufton, Chair of the Council

Richard Piller FCA, CTA, Hon. Treasurer

# Statement of Cash Flows

For the year ended 31 December 2022

	2022 £'000	2021 £'000
Cash flows from operating activities		
Net income for the year	1,278	1,703
Adjustments for:	20	27
Depreciation of fixed assets	29	34
(Gain)/loss on disposals of investments	223	(135)
Decrease/(increase) in debtors	136	(415)
Decrease/(increase) in stock	(3)	3
Increase/(decrease) in creditors	292	578
Investment income and interest	(47)	(34)
Net cash from operating activities	1,908	1,734
Cash flows from investing activities		
Proceeds from sale of investments	255	221
Purchases of investments	(563)	(281)
Purchases of fixed assets	(11)	(47)
Investment income	42	33
Interest received	5	1
(Increase) /decrease in cash held for investment	(21)	26
Net cash from investing activities	(293)	(47)
Net increase/(decrease) in cash and cash equivalents	1,615	1,687
Cash and cash equivalents at beginning of year	5,633	3,946
Cash and cash equivalents at end of year	7,248	5,633
Analysis of cash and cash equivalents		
Cash in hand	7,248	5,633
Total cash and cash equivalents	7,248	5,633

For the year ended 31 December 2022

### 1. Accounting policies

The Macular Society is a private charitable company, limited by guarantee and incorporated and registered in England and Wales, 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 negrest thousand.

### (b) Accounting convention

The accounts have been prepared under the historical cost convention and in accordance with the Financial Standard Reporting 102, the Financial Standard applicable in the UK and the Republic of

Ireland, the Companies Act 2006 and the Charities Statement of Recommended Practice (FRS 102) 2019 and 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

For the year ended 31 December 2022

accumulated depreciation. Historical cost includes expenditure directly 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\\% 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.

### (q) 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.

### (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.

For the year ended 31 December 2022

### (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.

### (l) 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 within these financial statements.

For the year ended 31 December 2022

### (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 6 March 2023.

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

For the year ended 31 December 2022

### (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.

attracting income and those incurred in trading activities that raise funds.

(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

For the year ended 31 December 2022

	2022 £'000	2021 £'000
2. Analysis of incoming resources	£ 000	£ 000
(1) Donations and legacies	1 67/	1 / 6 /
Donations, appeals and unrestricted grants  Membership subscriptions	1,674 291	1,464 283
Fundraising events	796	701
Legacies (Note 18)	4,657	4,299
Legacies (Note 10)		
	7,418	6,747
£4,004k of the 2021 income was unrestricted and £	2,743k restrict	ed.
(2) Income from charitable activities		
Grants for specified charitable activities	1,232	672
Other – donated services	64	51
	1,296	723
The income for 2021 was all restricted.	,	
(3) Income from other activities		
Local group income (restricted)	91	58
Trading income (unrestricted)	79	65
	170	123
(4) Income from investments and interest		
Interest received	5	1
Investment Income	42	33
The income for 2021 was all unrestricted.	47	34

For the year ended 31 December 2022

2 Anniusia of war areas				2022	2021 £'000
3. Analysis of resources exp	penaea				
(1) Costs of raising funds	(unrestricted	)			
Employee remunerati	·	•		854	759
Support costs (Note 4				154	156
Direct costs			1	,274	930
Trading costs				36	28
Investment managen	nent costs			12	12
_			_		
			2	,330	1,885
			_		
				2022	2024
				2022	2021
	Divoct	Chaff	Cummout	£'000	£'000
	Direct costs £'000	Staff costs £'000 (Note 5)	Support costs £'000 (Note 4)		
(2) Charitable activities		(	(11000 1)		
• •					
Publications	100	23	2	125	95
Educational informati		23 171	2 29	125 434	95 355
	on 234		_		
Educational informati	on 234		_		
Educational informati Advice & Information	on 234	171	29	434	355
Educational informati Advice & Information & Counselling	on 234 174	171 219	29 39	434 432	355 390
Educational information Advice & Information & Counselling Groups & Volunteers	on 234 174 118	171 219 1,090	29 39 195	434 432 1,403	355 390 1,106
Educational information Advice & Information & Counselling Groups & Volunteers Low Vision Services	174 118 139	171 219 1,090 241	29 39 195 43	434 432 1,403 423	355 390 1,106 347
Educational information Advice & Information & Counselling Groups & Volunteers Low Vision Services Conferences Research Support to profession	174 118 139 22 1,576 als	171 219 1,090 241 41	29 39 195 43 7	434 432 1,403 423 70	355 390 1,106 347 38
Educational information Advice & Information & Counselling Groups & Volunteers Low Vision Services Conferences Research	174 118 139 22 1,576 als	171 219 1,090 241 41	29 39 195 43 7	434 432 1,403 423 70	355 390 1,106 347 38 1,779
Educational information Advice & Information & Counselling Groups & Volunteers Low Vision Services Conferences Research Support to profession	174 118 139 22 1,576 als	171 219 1,090 241 41	29 39 195 43 7	434 432 1,403 423 70 2,086	355 390 1,106 347 38 1,779

2021 charitable expenditure was charged as to £2,633k to restricted reserves and £1,541k to unrestricted.

For the year ended 31 December 2022

4. Support costs	2022 £'000	2021 £'000
Rent and rates	79	79
Postage and office supplies	47	37
Telephone and IT	159	143
Depreciation	39	44
Recruitment	31	43
Bank charges	23	24
Governance	20	27
Other expenses	149	118
	547	515

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 tax return fee totalling £14,400 (2021: £12,000).

### 5. Employee remuneration

The average number of full and part-time employees in the year was 86 (2021:74). The average number of employees calculated on a full-time equivalent basis, analysed by function was:

	2022	2021
Management, governance and administration	7	6
Customer care and membership administration	5	5
Fundraising	22	18
Group development & volunteer coordination	19	15
Advice & Information and treatment advocacy	6	5
Low vision	5	5
Research	3	2
Education and awareness	10	8
Sideview and Digest	1	1
	78	65

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For the year ended 31 December 2022

	2022 £'000	2021 £'000
Salaries	2,655	2,210
National insurance	267	208
Pension costs	149	121
	3,071	2,539

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:

	2022	2021
	Number	Number
£60,000-£70,000	1	1
£70,000-£80,000	1	1
£80,000-£90,000	1	1
	3	3

The total emoluments paid to the three key managers amounted to £233,000 (2021: 3 key managers £202,000)

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.

	2022 £'000	2021 £'000
Cost of fundraising	854	759
Cost of charitable activities	2,217	1,780
	3,071	2,539

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

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

For the year ended 31 December 2022

#### 6. Pension scheme

The charity operates a defined contribution pension scheme. The pension charge for the year £149k (2021: £121k) 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 (2021: NIL) 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 2022	98	29	127
Additions	10	1	11
Disposals	(30)	(17)	(47)
As at 31 December 2022	78	13	91
Depreciation:			
As at 1 January 2022	57	25	82
Charge for year	26	3	29
Disposals	(30)	(17)	(47)
As at 31 December 2022	53	11	64
Net book amounts:			
As at 31 December 2022	25	2	27
As at 31 December 2021	41	4	45

For the year ended 31 December 2022

8.	Investments	2022 £'000	2021 £'000
<b>.</b>	Market value as at 1 January 2022 Acquisitions at cost* Disposals at carrying value Net realised gains Net unrealised (losses)/gains	1,538 563 (255) 16 (239)	1,343 281 (221) 58 77
	Total investments at market value at 31 December 2022	1,623	1,538
	Cash held for investment	62	41
	Total investments	1,685	1,579
	Total investments at market value Total investments at historical cost	1,685 1,735	1,579 1,394
	Revaluation unrealised loss	(50)	185
	Investments are further analysed as follows: Listed equities (UK £473k, Overseas £283k)	756	943
	Listed fixed interest and index linked Investments (UK £373k, Overseas £190k)	563	406
	Other investments	304	189
	Cash held for investments	62	41
		1,685	1,579

During the year the charity invested an additional £300k into the investment portfolio to represent the minimum reserve requirements \*Acquisitions include donated shares valued at NIL (2021:£13,125)

For the year ended 31 December 2022

	2022 £'000	2021 £'000
9. Stocks comprise diaries & cards for sale	6	3
10. Debtors & prepayments		
Legacies (Note 18) Gift aid Prepayments Other debtors	361 61 101 73 ———————————————————————————————————	580 51 101 - 732
11. Creditors & accruals: amounts falling due within one year	ar	
Research grants committed not yet paid Trade creditors Accruals & other payables Taxation and Social Security	1,649 167 137 17 1,970	1,446 228 89 6 1,769
12. Creditors: amounts falling due after more than one year Research grants committed not yet paid Accruals and other payables	696 90	615 80
	786	695

For the year ended 31 December 2022

#### 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 College London Apg2 pathway in age-related macular degeneration.
- University College London Supporting Teenagers and young people to Overcome Macular Problems (STOMP): User-led vision rehabilitation for young people with inherited macular disease.
- University College London Differential staging and progression of age-related macular degeneration driven by genetic risk polymorphisms.
- Queen's University Belfast Targeting cellular senescence in the choriocapillaris as a new strategy to treat dry AMD.
- Royal Holloway London Evaluating therapies for visual hallucinations in Charles Bonnet syndrome: an on-line Randomised Control Trial (RCT).
- Bangor University A health economics bolt-on analysis of the Vitrectomy, subretinal Tissue plasminogen activator and Intravitreal Gas for submacular haemorrhage secondary to Exudative age-Related macular degeneration (TIGER) study.
- Newcastle University Interrogation of genetic variability in complement factor I for personalised patient management of geographic atrophy.
- University of Manchester CRISPR-activation therapy for macular disease.
- Queen's University Belfast The impact of misaligned daily light cycles on the progression of diabetic retinopathy.
- University of Sussex The zebrafish high-acuity zone as a novel model for the human macula
- University of Oxford the role of ABCC5 in diabetic macular oedema.
- Anglia Ruskin University UK National Eye Health and Hearing Survey
- 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 2022

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

L3.	Analysis of research grants (continuea)		
		Charged Restricted £'000	to reserves Unrestricted £'000
	University College London	249	
	University College London	134	
	University College London	245	
	Queen's University Belfast	243	
	Royal Holloway London	37	
	Bangor University	25	
	University of Newcastle	100	
	University of Manchester	101	
	Queen's University Belfast	25	
	University of Sussex	25	
	University of Oxford	25	
	Anglia Ruskin University	10	
	AAAMD	100	
,	Technical meeting	20	
	Salary, support and other costs	747	
	Total charge to reserves	2,086	
,	Total research expenditure – Note 3(2)		2,086
		:	E'000
	Research grants committed but not yet paid b/f 1 January 2022		2,061
	Grants directly paid in the year to institutions		918
	Research grants committed but not yet paid c/f 31 December 2022	_	(634)
		_	2,345

For the year ended 31 December 2022

#### 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 Groups and Services fund for support to local groups and services
- 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 2022 £'000	Moveme Income £'000	ent in year Expenses £'000	As at 31 Dec 2022 £'000
Research	1,365	2,819	(2,086)	2,098
Groups & Services	-	449	(446)	3
Local Groups	405	91	(127)	369
National Lottery Community Fund for practical and emotional support for people with sight loss	-	209	(175)	34
	1,770	3,568	(2,834)	2,504

Included in the Local Groups balance above are amounts totalling £67k (2021:£45k) ringfenced on behalf of Local Groups and held by the Macular Society in their bank account.

#### Restricted income includes:

- £32,317 from The Albert Gubay Charitable Foundation for treatment research for dry age-related macular degeneration.
- £20,000 from The Albert Gubay Charitable Foundation for research to understand complement factor protein mutations in age-related macular degeneration.
- £25,000 from Blindcraft Charitable Trust for practical and emotional support services for people affected by sight loss in the Blindcraft catchment area.

For the year ended 31 December 2022

### 14. Restricted funds (continued)

- £1,000 from the David Family Foundation for the Advice and Information Service.
- £15,000 plus a further £375 in additional support from The City Bridge Trust, the funding arm of the City of London Charity, Bridge House Estate (1035628) for support services in London.
- £10,000 from Steel Charitable Trust towards research to establish a new disease model of age-related macular degeneration.
- £12,000 from The RS Macdonald Charitable Trust, for providing a range of practical and emotional support services in Scotland.
- £39,750 final grant instalment from the National Lottery Community Fund for practical and emotional support for people with sight loss in Scotland.
- £33,750 first instalment of a new grant from the National Lottery
   Community Fund to provide emotional and practical support for people affected by macular disease across Scotland. Grant to be carried forward and allocated to 2023 expenditure.
- £80,000 from the National Lottery Community Fund for practical and emotional support for people with sight loss in Northern Ireland.
- £55,400 from the National Lottery Community Fund for practical and emotional support for people with sight loss in Wales.
- £10,000 from the National Lottery Community Fund for the development of our volunteer strategy in Wales.
- £10,000 from the National Lottery Community Fund for the development of our volunteer strategy in England.
- £2,500 from the Welsh Government Connected Communities: Loneliness and Social Isolation Grant fund and Powys Association of Voluntary Organisations (PAVO) for emotional support for people with sight loss in Powys.

For the year ended 31 December 2022

### 15. Unrestricted and designated funds

	As at 1 Jan 2022 £'000	Income £'000	Expenses £'000	Transfer £'000	As at 31 Dec 2022 £'000
Unrestricted	2,758	5,363	4,819	-	3,302
Designated	1,000	-	-	-	1,000
	3,758	5,363	4,819		4,302

The Company transferred (2022:NIL) (2021:NIL) 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	Designated	Restricted	Total
	funds	funds	funds	funds
	£'000	£'000	£'000	£'000
Fixed assets & Investments Net assets	1,712 1,590 3,302	1,000 1,000	2,504 2,504	1,712 5,094 6,806

#### 17. Trustee remuneration

The Trustees received no remuneration during the year (2021:NIL). During the year 5 Trustees (2021: 6) were reimbursed for travel and out of pocket expenses amounting to £2,475 (2021: £1,096).

For the year ended 31 December 2022

#### 18. Legacies

Legacies of an estimated £1,082,000 (2021:£1,920,000) have been excluded from income as the criteria for recognition had not been met.

#### 19. Commitments

As at 31 December 2022 the Society had the following annual office rent commitments under non-cancellable operating leases:

	2022 £'000	2021 £'000
Payable within one year Payable from one year to five years	65 7	66 61
	72	127

### 20. Analysis of changes in net debt

	As at 1 Jan 2022 £'000	Cash flows £'000	As at 31 Dec 2022 £'000
Cash and cash equivalents			
Cash	5,633	1,615	7,248
Borrowings			
Debts due in under 1 year	(1,769)	(201)	(1,970)
Debts due after 1 year	(695)	(91)	(786)
	(2,464)	(292)	(2,756)
Total	3,169	(1,323)	4,492

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For the year ended 31 December 2022

#### 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 £7,306k (2021: 5,633k).

#### 24. Related party transactions

During the year a grant payment was made to Action Against AMD amounting to £100,000 (2021: £74,000).

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.

Richard Piller, Honorary Treasurer and Trustee Director, holds a minority shareholding in Okulo Ltd (also known as OKKO Health) a company with which the Macular Society transacts on an arms-length basis. For the year ended 31 December 2022 these transactions amounted to £9,611 (2021: £NIL).

There are ten members of our Research Committee: eight are distinguished academics from UK universities and two are Trustee Directors. The Committee is supported in its work by the Society's Research Manager and two Research Officers. 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.

For the year ended 31 December 2022

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 Luminita Paraoan **CHAIR**

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

#### **Professor Jo Aldridge**

(appointed October 2022) Lay member (resigned February 2023)

#### **Professor Tariq Aslam**

(resigned April 2022) Professor of Ophthalmology and Interface Technologies, University of Manchester Consultant Ophthalmologist, Manchester Royal Eye Hospital

#### **William Best**

(resigned April 2022) 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

#### **Richard Piller**

(appointed December 2022) **Macular Society Trustee** and lay member

### **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

### **Professor Yit Yang**

(apppointed October 2022) Consultant Opthalmologist The Royal Wolverhampton **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