Macular Society Research Strategy

Introduction

The Macular Society is the UK charity dedicated to supporting people affected by macular disease. Since we were founded in 1987 we have had twin aims: to provide information and support which improves lives today and to fund research so that one day we can overcome macular disease.

The impact of macular disease on the patient, their families and society is significant. It currently accounts for half of all registered sight loss in the UK and with an aging population, the impact will increase into the future unless new and better treatments are found. This is why our aim is to increase our research investment significantly over the next few years while maintaining and improving the quality of services we provide to people with macular conditions.

In contrast to the impact of sight loss, medical research in the eye sector is underfunded, eye health receiving <1% of the total research spend. Yet we have world leading research teams here in the UK and research into macular conditions is among the most exciting areas of medical research.

Such good progress has been made, we now have a number of drugs for the treatment of wet age-related macular degeneration (AMD) and the possibility of a drug to slow the progress of dry AMD. Advances in genetics offer the chance to understand more about risk factors for development of AMD and responses to treatment. Advances in stem cell research hold great promise that in the future we will be able to repair and replace damaged cells and therefore improve vision.
Our members and supporters donate generously to research so it’s important that we sponsor projects that are likely to lead to tangible benefits to people affected by macular disease. This strategy sets out how we ensure that every piece of research we fund moves us closer to our goals.

**How the charity funds research**

Over the last 15 years we have invested more than £2.8m in 54 research projects aimed at improving the treatment or quality of life for patients with macular disease. In 2015 we contributed £355,908 to 4 projects and in 2016 we have a research budget of half a million pounds.

The Macular Society operates response mode funding and has an annual grants round inviting applications for research grants and PhD studentships. It will consider applications for clinical or laboratory-based research projects aimed at improving the treatment or quality of life of patients with macular disease.

Projects must be able to demonstrate potential benefit to people with macular disease including AMD and macular dystrophies. This may include research into causes and prevention, early detection, treatments or improving the quality of life.

The Sight Loss and Vision Priority Setting Partnership set priorities for eye research in 2013 in 12 different areas. One of the areas was AMD where 10 priorities were identified.

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1 [www.sightlosspsp.org.uk](http://www.sightlosspsp.org.uk)

Helpline 0300 3030 111
Registered Charity Nos 1001198, SCO42015 Scotland, 1123 Isle of Man.
Macular Society is the trading name of the Macular Disease Society.
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All applicants who are invited to submit full applications are asked to specify, if applicable, which of the priorities their application addresses and how. This is then taken into account by the Research Committee when appraising the applications.

The Macular Society is a National Institute of Health Research non-commercial portfolio partner and a member of the Association of Medical Research Charities (AMRC).

**Research Grants**

Grants of up to £170,000 over three years are available for research at UK institutions only.

Applications for small grant awards of up to £15,000 for one year are also accepted.

We will consider applications for clinical or laboratory based research projects aimed at improving the treatment or quality of life of patients with macular disease.

**PhD Studentships**

Studentships of up to £100,000 are available to cover a stipend, fees and consumables over 3 years. PhD Students should be based at a UK institution and be a UK graduate in a relevant subject.

The scientific merit of the research project, its suitability as a PhD project and the research and training environment
provided by the host department are all taken into account when assessing the applications.

PhD studentships can focus on any of the following:

- basic research
- epidemiology
- clinical research
- gene therapy
- stem cells
- visual rehabilitation
- new technology

**Eligible costs**

For both research grants and studentships, eligible project costs may include:

- capital items (items over £2,500 require three written quotations once a grant is awarded)
- staff costs
- relevant consumables
- travel and communications – please justify any international travel costs
- administrative support
- computing costs
- open access publication

As a charity, we only support the directly incurred costs of research.
Ad hoc funding requests

The Society does not accept ad hoc requests for funding. Applications will only be considered within the context of the annual research grants round and within the deadlines set for receipt of applications.

Research Committee

The Research Committee includes a Trustee and five external representatives with relevant expertise. It meets twice a year having assessed, scored and ranked preliminary and then full applications for research grants and PhD studentships. Between meetings members receive updates and provide advice by e-mail. They also receive interim and final reports from all funded projects.
The application process

The Macular Society runs a two stage application process for both research grants and PhD Studentships.

Stage one – preliminary application stage

Preliminary application forms are reviewed and shortlisted by the Research Committee. Successful applicants are invited to complete a full application.

Stage two – full application stage

Full applications are sent for peer review to expert external reviewers. The Research Committee meet to consider the full application and peer review feedback. A final funding decision is made by the Trustees.

The Research Committee considers applications against the following criteria:

- scientific quality
- innovation
- potential benefit to people with macular disease
- relevance to Macular Society members (mainly patients), taking into account the Sight Loss and Vision Priority Setting Partnership priorities for AMD research
- value for money
- quality of proposed student training (PhD studentships only)
Peer review

It is important that the extent of peer review is in proportion to the amount of funding to be awarded.

- Grants worth less than £5,000 must be reviewed by the Chair of the Research Committee.
- Grants worth between £5,000 and £10,000 per annum must be reviewed by the Committee.
- Grants worth over £10,000 per annum must be reviewed by the Committee and externally peer reviewed.
- At least two external reviewers should be employed for all research grants worth over £25,000 per annum.

Terms and conditions

All successful applicants will be asked to sign and return a copy of our terms and conditions, which includes the following information.

- Use of funds
- Disbursement of funds
- Reports
- Presentation of reports
- Funded extensions and no cost extensions
- Monitoring
- Capital items
- Project modification
- Under-expenditure or over-expenditure
- Balance funds
- Cancellation
Indemnification
Remittance and receipt of grant funds
Dispute settlement

Where ethical approval is required, a copy of the approval letter must be received by the Macular Society before any funds are paid to the researcher.

Reports

The Macular Society expects to receive the following written financial reports and narrative accounts of the project from the grant holder.

- At 12 month intervals from the start of the project – an interim report for the Research Committee giving an update on the progress of the project.

- Each year the project is live - a report written for our annual scientific and professional journal Digest describing the project aims and objectives, progress made and anticipated outcomes.

- On completion of the project - a final narrative and financial report on the project and utilisation of the funds granted. This must be submitted within six months of project completion at which time the balance of funds will be released. A summary report for Digest should also be submitted.
The grant holder also agrees to take part in any surveillance which the Macular Society may undertake to monitor the impact of research funds.

**Dissemination**

We are keen to work with researchers to communicate the progress and outcomes of research in order to raise awareness of macular disease and promote the need for investment in the field. It is therefore the expectation that research will be published via at least one publication in an appropriate scientific journal.

We encourage publication in open access journals and will consider funding the costs of open access publication if funding cannot be accessed elsewhere.

We require researchers to notify us when a paper is accepted for publication. Publications should always recognise the support of the Macular Society.

Progress and the results of research projects are reported in our member magazine Sideview and in Digest, our annual scientific journal. They may also be featured on our website, in newsletters, press releases and on social media.

**Use of animals in research**

The Macular Society supports the principle of using animals in research when it is necessary to advance understanding of health and disease and to develop new treatments. This research only takes place where there is no alternative available.
A statement on the use of animals in research is available on our website.

**Stem cell research**

The Macular Society believes that stem cell research has the potential to bring great benefit to people with macular conditions. It therefore supports the use of all types of stem cells including embryonic, adult and induced pluripotent stem cells. A statement on stem cell research is available on our website.

**Research participant database**

The Macular Society launched a research participant database in 2015 based on feedback from our members and the research community in the UK. The database enables both Society members and non-members to sign up and receive information about research that they may be eligible to participate in.

The database is open to people with all forms of macular conditions, family members and healthy volunteers. The database will also be used to identify members who are willing to be contacted by the Communications Team as case studies for campaigns.

Signing up to the database is optional and only collects basic information about the person and their condition to enable assessment of eligibility for a study. If someone may be eligible, a letter is sent with more information from the research team and information about how to volunteer or find out more.
The Macular Society offers this service free for non-commercial research. If research is commercial a charge will be made.