



Macular Society
Beating Macular Disease

Research Strategy

2020 – 2030

Beating Macular Disease

Our Vision is to end macular disease.

Our Mission is beating the fear and isolation of macular disease by funding world-class research and providing the best advice and support.

We are one of the few sight loss charities that actively fund and support research into macular disease. Every year, the number of people losing their sight to macular disease rises – and as their sight fades, too many of them are overcome by frustration, grief, fear and isolation.

But our members tell us how hopeful they are that a cure will be found, to spare them and their children from the looming threat of blindness. That's why, in 2018, the Macular Society launched its new ambition – to Beat Macular Disease – and why funding research is so crucial to our mission.

I know that we are nearer to a cure than ever, and that every project we fund brings us closer to a world without macular disease.

By 2023, we will fund £6m of research a year, because without research, our ambition will remain just words. But intelligently funding high-quality, innovative research gives us the best chance of making it a reality – and the more research we can fund, the quicker we'll get there.

For the sake of the 1.5m people in the UK today with sight loss caused by macular disease, and for the others who will join their ranks in the years to come, we will not stop until we **Beat Macular Disease**. I hope you'll join us.

Cathy Yelf
Macular Society
chief executive





Introduction

Since the Macular Society was formed in 1987, we have funded 73 research projects with a total value of over £5.1m. Our pockets aren't as deep as those of bigger medical research charities, but we have ensured that our funding has been put to good use: it has gone to projects at a crucial time, giving them time to develop findings so that they can access the big funders' pots; it has supported researchers at early stages of their careers so that there are more people working to beat macular disease; and we have formed collaborations with other funders to multiply our money and make our support go further.

Our efficient research funding has generated some excellent impacts, which will make very real differences for people with macular disease, now and in the future.¹ This strategy sets out our priorities for funding in the next 10 years and how we will make the biggest possible impact for people with macular disease by 2030.

¹ Research Impact Report 1987 – 2019, macularsociety.org/research

Peer review

The Macular Society uses peer review to award grants so that the decision-making is independent and transparent. The validity of peer review is based on certain principles: for example, that there are no conflicts of interest, and that the expert scientific review is high quality, independent and unbiased.

The Macular Society has been awarded an Association of Medical Research Charities (AMRC) Best Practice in Medical and Health Research certificate. Peer review is an accepted means of assessing the quality of research, and the AMRC believes that it is the best way for medical research charities to decide what research to fund. The award confirms that the Macular Society uses robust methods to make decisions about which research projects to fund and that we support the best researchers and the highest quality research.

Scope

The 1.5 million people living with macular disease in the UK includes those with age-related macular degeneration (AMD), myopic macular degeneration, central serous retinopathy, macular dystrophies, macular hole, retinal vein occlusions and diabetic macular oedema. Researchers are welcome to submit grant applications to carry out research on any type of macular disease.



Strategic goals

1. To fund world-class research on macular disease which will have impact for patients and lead to improvements in our understanding of disease and potential new treatments.
2. To introduce new opportunities for funding research that are aimed at accelerating progress towards a cure.
3. To build clinical and scientific capacity in macular disease in the UK through the funding of PhD studentships and research fellowships.
4. To improve the quality of life for those with macular disease and their families through funding research which informs our services and supports campaigns.
5. To work collaboratively with other charities, research funders and patient organisations and build partnerships to beat macular disease.
6. To encourage and facilitate communication and collaboration across the research community, including patient and public involvement in research.



1. To fund world-class research on macular disease which will have impact for patients and lead to improvements in our understanding of disease and potential new treatments.

Our vision is to end macular disease. This can only be achieved through research to improve our understanding of the causes of macular disease. Through this knowledge, we can identify preventive measures and treatments to stop people losing their sight.

To make the most effective use of our resources and fund the highest-quality research, the Macular Society is a member of the Association of Medical Research Charities (AMRC) and follows best practice for peer review. This means that research projects applying for funding are scrutinised by independent experts on the Research Committee, as well as by international experts in the field.

Once projects are underway their progress is monitored and evaluated by the Research Committee through the submission of annual reports.

It is important that the results of the research are communicated to other scientists, the public and those with macular disease. Therefore it is a requirement of funding that the outcomes are published through presentations at scientific conferences and papers in scientific journals. It is also important that the results are communicated to those with macular disease through the Macular Society, explaining the impact for patients.

“There was no treatment for my dad, but my son’s injections have helped stabilise his vision and meant he can continue to work. For every generation there is more hope. I hope he doesn’t pass it onto his daughters, but by that time, with more research, there will hopefully be more treatment available.”

Josephine

Macular Society member





2. To introduce new opportunities for funding research that are aimed at accelerating progress towards a cure.

As our investment in research grows, we will have the scope to introduce new and innovative ways of funding research aimed at accelerating progress towards a cure.

As a first step, from 2020 we are increasing the maximum value of our research grants to £200,000 and from 2021 this will increase again to £250,000. We also plan to introduce a new seedcorn funding programme in 2020, which will provide small grants of £25,000 to researchers wishing to develop an idea and generate preliminary data. This data can then be used to underpin larger grant applications.

In our medical research programme, we will continue to have researchers submit applications based on their own research ideas, called response mode funding. However, we will consider the option to request applications in a particular area or on a particular macular disease.

“It has been 20 years since my diagnosis; 20 years and still no cure. How many more people have been diagnosed since then?”

Kate Macular Society member

3. To build clinical and scientific capacity in macular disease in the UK through the funding of PhD studentships and research fellowships.

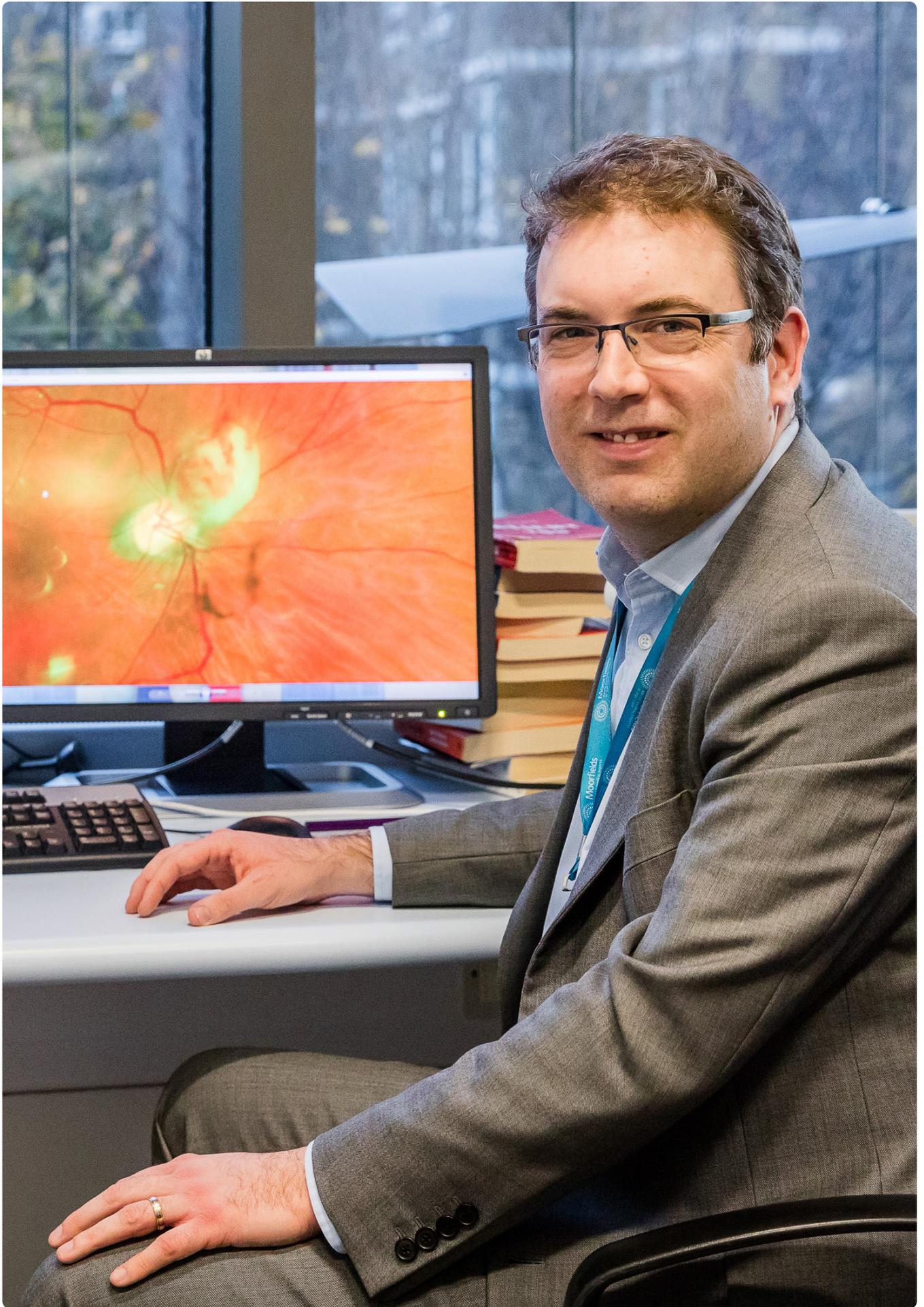
An important way to support research into macular disease is to build the future workforce researching the condition. This starts at the early stages of a research career, with PhD studentships. These grants help graduates to begin their careers in macular disease research, with the hope that they will continue this great work in their future careers.

The Macular Society has funded PhD studentships for a number of years to bring new young talent into the field and will continue to do so. We also plan to introduce a fellowship programme to enable those at a later stage in their career to undertake research on macular disease.

“I found out I am likely to develop macular disease one day. I’m passionate about making progress with genetic testing, not just for patients but also for myself. I want to be part of the solution as it will affect me too.”

Pearse Keane

consultant ophthalmologist, Moorfields Eye Hospital, and researcher, Institute of Ophthalmology, UCL





“I am so grateful for the research that’s going on. It might not mean a difference to my life because my eyes are really bad but it could change my children’s lives.”

Kelly Macular Society member

4. To improve the quality of life for those with macular disease and their families through funding research which informs our services and supports campaigns.

As well as medical research, the Macular Society has always funded research which studies aspects of living with macular disease. For example, projects on the eccentric viewing technique, which involves identifying and using the healthiest parts of the macula, have helped the Society to train and support those with macular disease to use their remaining vision most effectively.

More recently, we have funded work to identify how best to run our network of over 400 local groups, which provide valuable peer support. Meeting others with macular disease can help people to understand the condition, come to terms with sight loss, share information about support and treatment and ultimately stay independent.

In the future, we will fund research that increases our understanding of quality of life issues and builds evidence around potential new initiatives that could support those with macular disease and their families. This will include the use of technology, where new products such as apps and 'smart glasses' designed to help the visually impaired are being developed all the time. The projects can focus on any part of the patient pathway from diagnosis and treatment to living with macular disease. Research in this area may be commissioned to address specific issues where we see a requirement for research, or be part of our response mode funding.

5. To work collaboratively with other charities, research funders and patient organisations and build partnerships to beat macular disease.

By working collaboratively with organisations which share our vision to end macular disease, we can have a stronger voice and maximise our impact.

The Macular Society is already a partner in the collaboration Action Against AMD (AAAMD) with three other charities: Blind Veterans UK, Fight for Sight and Scottish War Blinded. AAAMD's main objective is to facilitate the funding of medical research aimed at finding an effective treatment for early-stage AMD and stopping sight loss. We will integrate any AAAMD outputs which are aligned with our own research programme, including strategic funding of appropriate projects.

We will also explore the potential for working with other charities and research funders where there are areas of mutual interest and where joining forces will bring added value to our research programme.





“Age-related macular degeneration is a devastating condition which is affecting more and more people globally as our population ages. Collaboration is essential to tackle the growing sight loss epidemic.”

Cathy Yelf Macular Society chief executive



“Research is the thing that people ask me about most frequently, particularly if they’ve recently been diagnosed: ‘When will there be a cure?’ From my point of view, I want to know that, if my children or grandchildren were affected too, there would be treatment or a cure.”

Nancy Macular Society support group leader

6 To encourage and facilitate communication and collaboration across the research community, including patient and public involvement in research.

We know that no one person, team or organisation can beat macular disease alone and that everyone's input contributes to achieving the vision. The Macular Society, as the patient voice, can work with the research community to facilitate communication and encourage collaboration across the UK and internationally.

We will do this through our charity collaboration Action Against AMD which has influencing as one of its goals², through sponsorship of scientific meetings and conferences and lobbying for greater research funding.

Patient and public involvement (PPI) in research is important and we will aim to develop and increase this area as a service to both patients and researchers. We will continue to offer PPI support to researchers developing grant applications and respond positively to requests to be on trial or study steering committees. Where invited we are also willing to be co-applicants on grant applications. We will continue to maintain and grow our patient registry which can assist with recruitment. It currently has over 2,700 people in the UK who would like to take part in clinical research and who can be contacted by the Macular Society with information on a study for which they may be eligible.

² INFLUENCING A thought leader and catalyst for effective collaboration between industry, academia, government, research councils and foundations.

Evaluating our impact

We have just published our first research impact report ³ and will continue to monitor the impact of our research, specifically:

- how much new knowledge is generated and new research is stimulated
- our impact in influencing policy and other stakeholders, facilitating collaboration and improving PPI
- progress in making new treatments accessible to patients, or improving their quality of life.

Applying for funding

For more information on how we fund research and the peer review process, see macularsociety.org/application-process

³ Research Impact Report 1987-2019, macularsociety.org/research



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