



Macular Society

Strategy 2019-2023



Introduction

Macular disease is the biggest cause of registered blindness in the UK in every age group; children, working age people and the older generation.

Our eye sight is precious. Many studies show that people fear sight loss more than serious illnesses like diabetes or the loss of a limb. The cost of sight loss to individuals and to society as a whole is vast. Yet eye research is a low priority and as a result is shockingly underfunded.

The Macular Society's strategy is to challenge that status quo to bring hope to people with macular disease and their families. We are the largest charity for people with these conditions. It is our duty and responsibility to work to find a cure for 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.



“I just remember going home and breaking down.”

At the age of 31 Katie had no reason to think there was anything wrong with her vision. But a routine eye test changed her life.

Katie’s optician spotted something wrong at the back of her eyes and referred her to hospital. Four days later Katie was told she had Stargardt disease, a juvenile macular dystrophy.

She said: “I just remember going home and breaking down, I cried so much I literally couldn’t breathe. I went into shock for a few days, I couldn’t eat or sleep and was really shaky. My mind was in overdrive, I was terrified and felt sick constantly. I sometimes wonder when I think back, how I got through those few days.

“My whole life had changed in a day and the life I thought I was going to have wasn’t going to happen.

“My biggest fear when I was first diagnosed was not being able to see my little boy’s face. I thought I was going to lose all of my vision completely and that blindness meant complete darkness. I worried about not being able to see my loved ones, losing my independence, not being able to drive and being a burden to everyone.”

Katie sought help from the Society’s counselling service.

“The counsellor calmed me down every week, listened to me cry, cheered me up, made me realise life will carry on and I’m so grateful for having her to talk to at that early stage. It gave me someone other than family to pour my heart out to.”

“Without the counselling service I really don’t know how I would have got through those first couple of weeks after diagnosis.”

Why we have developed this strategy?

Nearly 1.5m people¹⁻¹⁰ in the UK have a macular condition.

Most, nearly 700,000, have age-related macular degeneration (AMD). AMD is the biggest cause of visual impairment in the developed world and the third biggest globally with an expected 20m people with macular sight loss by 2040.

Our age and our genes are the biggest factors in whether or not we develop macular disease.

AMD is rare at age 60, affecting around one in every 250 people. But the prevalence roughly quadruples through the succeeding decades of life so that by age 90 AMD affects one person in every four.



A number of genes are linked to the development of AMD and so it is common for it to run in families.

There are lifestyle risks too; smoking, poor diet, high blood pressure and obesity all increase the risk of AMD.

There are many genetic forms of macular disease that affect children and young people, the most common being Stargardt disease. In addition there are other devastating macular conditions such as pathological myopia (shortsightedness), diabetes and retinal vein thrombosis that also affect hundreds of thousands of Britons.

The macula is the central, most sensitive part of the retina. People with macular disease do not lose all their sight but their central vision is destroyed, leaving only peripheral vision. This means that people with advanced macular disease cannot drive, read or recognise faces.

Macular disease is incurable and most is not even treatable. A few forms, including wet AMD can be slowed with drugs that are injected regularly into the eye but most people still lose significant vision.

Macular disease is devastating. It is associated with an increased risk of falls, social isolation, depression and suicidal feelings. Children struggle at school, often enduring years of problems before getting the right support. Working age people face unemployment and poverty.

Macular disease is a vast and growing public health issue.

But, inexplicably, vision is not a high priority for public health leaders or medical research funders. Barely one fifth of one percent of UK public funding of medical research is spent on the most common cause of eye disease, macular disease.

There is exciting and promising research work in progress, but it needs more funding.

We will campaign for others to invest in research, but we will also lead the fight by increasing our funding of macular research tenfold by 2023.

We will continue to provide support to people affected by macular conditions in their darkest hours. We will expand our practical and emotional support services, especially our growing network of peer support groups.

We will ensure that macular disease is a household word and that everyone knows what their macula is and how to look after their eyes.

None of our work is possible without the generosity and loyalty of our donors, volunteers, trustees and staff.

Thank you so much – together, we will beat macular disease.

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Library photo

Minnie tried to remain independent, but simple things became too hard for her to do on her own.

Sheila's mum, Minnie, was a keen golfer and even when she could no longer play she loved watching it on the TV.

Macular degeneration put an end to that and many other things that had given Minnie her quality of life.

"Everything gradually fell away and she became utterly depressed. AMD really, really messed up her life. It devastated her."

Minnie tried to remain independent, but simple things became too hard for her to do on her own. The most devastating moment for her was when she realised she no longer recognised her own children.

"She met me at the station one day and it wasn't until I was right in front of her and I said 'hello' and she broke down in tears. 'I didn't even recognise my own daughter' she said, 'Has it come to this?' She never ever went anywhere on her own after that."

Sheila saw her mum every day after work as Minnie spent all day inside, alone.

"It was awful watching her. I did everything I could to try to raise her spirits, but nothing would lift her. It was just so sad seeing that happen to her. She would ask 'why is this happening? Why isn't there more research?'"

Key strategic aims

Finding a cure

We will be the largest funder of eye research in the sight loss sector and be known for our commitment to finding a cure for macular disease. We will fund c. £6m of internationally important research per annum by 2023.

The best advice and support

Good information, advice and support helps people with macular disease and their families cope with such a frightening diagnosis. We will expand our services – face to face, telephone, digital and our membership – so that no one has to face macular disease alone.

Vision matters

Everyone in the UK will know what their macula is and understand how to protect their vision. Eye health checks will be routine for most families. Health policy makers will understand the significance of eye health and the importance of prioritising macular disease.



Making our vision a reality

Finding a cure

- By 2023 our annual gross income will have risen to £12m. Half of that, £6m, will be invested in medical research.

This represents a trebling of our current income and a tenfold increase in research funding. To achieve this we will become a more effective fundraising organisation.

- All our staff, our trustees and our volunteers will understand and be able to explain the values, vision and mission of the Society and why we need to raise a lot more money.
- We will make sure we understand what motivates our donors, how we can meet their needs and how to engage them in our work.
- We will establish a new Supporter Care Team whose role is to serve the needs of our supporters, from their first contact with the Macular Society to processing their donation and thanking them for their generosity. The Supporter Care Team members will also be the champions of our supporters, feeding back their views so that we are always in touch with what they think and feel about our work.
- We will improve and streamline our processes and our use of data so that we are better able to understand our donors and which fundraising methods are cost effective.
- We will invest in fundraising to grow our income, understanding that net income may

fall in the first few years before we see the return on our investment.

- We will test and employ traditional and new fundraising methods in a constantly learning environment.
- We will invest in research expertise in the Society and develop a research strategy that makes best use of our increased resource.
- We will maximise our impact by working collaboratively with other research funders, especially Action Against AMD to make sure that every penny spent on research moves us closer to a cure.

The best advice and support

- We will increase the number of our peer support groups, making sure we target the areas where there is most need. We will use independent research to help us learn and spread best practice in setting up and running our groups. We will increase our understanding as to why some people do not engage with peer support so that we can encourage them to experience the great benefits it can bring.
- We will review how we invest in and deliver all our services, so that we can understand the needs of the people who use them and meet the growing demand for practical and emotional support. This includes the development and improvement of our information and advice services and the provision of advice and peer support online and through social media channels.

- We will structure volunteering roles such as Gadget Guides to work with groups to broaden the groups' usefulness and appeal.
- We will make sure our volunteers are employed effectively and that their roles are satisfying and enjoyable. We will make sure we thank them properly for all they do for us.
- We will introduce a new membership offer, including an offer specifically for younger people to grow our membership.
- We will review our professional membership scheme and increase our portfolio of online learning resources for professionals so that we deepen our relationship with them.

Vision matters

- We will campaign to raise the profile of macular disease and lift it up the hierarchy of health priorities.
 - We will invest in communications expertise and acquisition strategies to grow our supporter base and increase our campaigning strength.
 - Our messages will be bold, honest and authentic. We will not scaremonger but neither will we hide the truth about macular disease and the impact it has. We know that, with the right support, people with macular disease can still enjoy a good quality of life. But we also know that sight loss is devastating and comes at a terrible cost to

people who have the condition, their families and our society as a whole. Macular disease needs to be a national health priority.

- Our messages will help people care for their own vision. The poor understanding of macular disease has serious consequences. These include not understanding the dangers of smoking and poor diet, failure to recognise symptoms in time and unnecessary distress caused by fear of total blindness or misunderstanding the cause of visual hallucinations. Encouraging the public to have regular eye health checks is an important part of this work.

For all our work

- We will have robust methods of evaluation so we can learn how to improve what we do and demonstrate its value to our Board of Trustees, our service users, charity regulators and our donors.
- Our policies and behaviours will reflect our values and our commitment to the highest standards of ethical behaviours in fundraising, data protection, equality and safeguarding.



“One minute I just thought I’d need glasses, the next I’m going blind.”

Sarah was 28 when she first found it difficult to see in the evenings. She booked an eye test, assuming she’d need glasses. Instead she was urgently referred to hospital where she was told her sight was too bad for her to drive herself home.

Sarah has Stargardt disease.

“I had never heard of it. The consultant tried to explain, but all I heard were the words ‘blind’ and ‘no cure’. It was all a blur.

“I felt confused; one minute I just thought I’d need glasses, the next I’m going blind.

“I felt angry, scared and hopeless. All of this was out of my control. I was frightened to death that I wouldn’t see my little boy grow up.

“I’m now registered severely sight impaired. I can hardly recognise anyone unless I see them often but I am hopeful that one day there will be a cure.”

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