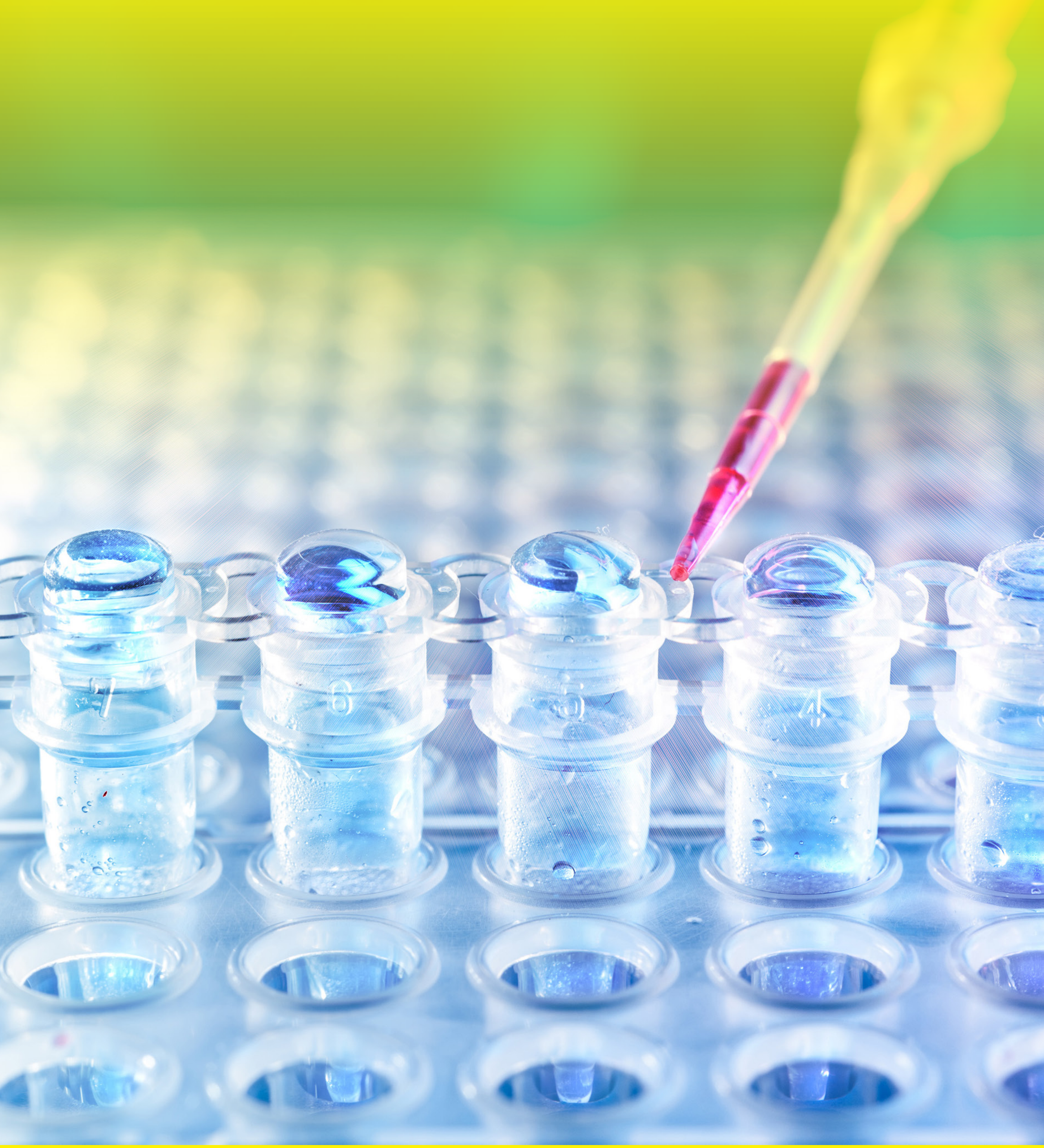


Macular Society

Strategy

Introduction

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

Our eyesight is precious. People fear sight loss more than serious illnesses like diabetes or the loss of a limb. And we know that the number of people losing their sight to macular conditions is increasing, not falling.

The cost of sight loss to individuals and to society as a whole is vast. Yet eye research in the UK is a low priority and as a result is shockingly underfunded.

There is no cure for macular disease and many forms are not yet treatable in any way. Too often people have to cope with the impact of macular disease without the right advice and support. Very often the first time they hear the word ‘macula’ is when they are told they have a 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.

“When I was diagnosed, I was in complete denial. I pretended I didn’t have it. That’s literally what I was doing. I didn’t tell anyone for about a year.”

Nilima was told she had macular disease in 2018, aged just 27 years old.

“It was a huge shock. I’d never heard of it before, and neither had anyone in my family. My doctor told me to stop doing this, stop doing that, and I ignored him, because I was so badly in denial. I wasn't taking it seriously. But I was struggling, really struggling – with work, with everything. And then I went to a Macular Society conference, and that was when everything changed for me."

I remember thinking at the time, "I don't want to be here." It was very overwhelming. But it was literally like a switch; the next day, I actually accepted I've got this condition, and I needed to do something about it. It was a big trigger for me, to think, "Okay, I need to get help, mentally, physically – and stop pretending this isn't happening.""

Nilima was worried she wouldn't be able to continue with her career – she was training to be a solicitor at the time of her diagnosis.

> "It was actually the Society that made me realise: "I've got macular disease, I'm going to get through this – I just need to know that I can get support."

It was Colin Daniels' talk at the conference which really helped me, learning about Access for Work. The next day, I called them up and they sorted out my computer, I've got a magnifier - it's made a huge difference for me at work. And I'd never have known about any of it if I hadn't gone to the conference."

Why we have developed this strategy?

This strategy is designed to tackle one of the biggest public health challenges in the developed world and one of the most devastating conditions that can affect a person.

We are the specialist charity for people with macular conditions. It is our duty and responsibility to work to find a cure for macular disease and to offer the best advice and support to everyone who needs us. It is also imperative that eye health is given a higher priority in public policy making and resource allocation, and that everyone knows how to care for their sight.

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.

Around 1.5m people[1-10] in the UK have a macular condition that is affecting their vision.

Around 700,000 of those people have age-related macular degeneration (AMD). AMD is increasing rapidly, primarily due to the number of people living into their 80s and 90s when AMD is much more common. Cases of AMD are expected to have doubled between 2010 and 2040, by which time there will be well over 1m people with AMD in the UK.

There are many other 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 (short-sightedness), diabetes and retinal vein occlusion that also affect hundreds of thousands of Britons.

Macular disease is incurable and most macular conditions are not even treatable. However, scientific research has provided some groundbreaking treatments. As a result, 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. Ophthalmology is the biggest outpatient specialty in the NHS, largely driven by macular disease[1]. Many clinics cannot cope with the demand for treatment even though only a minority of patients can be treated. Clinic delays lead to even more sight loss.

The cost of AMD is huge both to individuals and society as a whole. AMD is estimated to cost the UK £2.6 billion per annum[2].

Even so, public funding of eye research is low compared to many other conditions and the underlying biological disease processes are still not well understood. This has slowed the progress towards better treatments and cures.

We know that many patients are not provided with good quality advice on diagnosis or signposted to services that can support them. The availability of rehabilitation services is a postcode lottery. Provision of emotional support to cope with the grief of sight loss and the impact on daily life is rarely available.

Many people do not know the risks of macular disease or understand the importance of regular eye health checks to identify treatable conditions early.

The Macular Society's strategic aims are to change this.

We will Beat Macular Disease by:

- **Finding a cure**
- **Providing the best advice and support**
- **Making sure that vision matters**

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

“George was sitting closer and closer to the television, and said he was finding it difficult to read, that everything was wavy. We didn’t think it could be his sight, because his eye test at school had been fine.”

Sarah and Ollie’s son George was just 8 years old when he was diagnosed with juvenile macular degeneration.

"George's teacher thought he had a problem with his colour vision, but I taught him his colours, I knew he knew them. I took him to the optician who said he had some pigmentation on his macula. It was an 8 week wait to see a specialist, so I called the Macular Society and they told us to go straight to A&E. He was diagnosed that day."

Because of how quickly George's eyesight had deteriorated, he was tested for Batten disease (a fatal genetic disorder). The family were terrified.

"It was devastating. We just had to wait for the result to come back and luckily it was negative. When we got the call to say it wasn't Batten's we thought, "We can deal with his macular disease, it's going to be hard but he'll be alive." We decided we had to harness and embrace every bit of support we could.

The advice and guidance we got from the Macular Society was the best there was – where else would we have got that support from?"

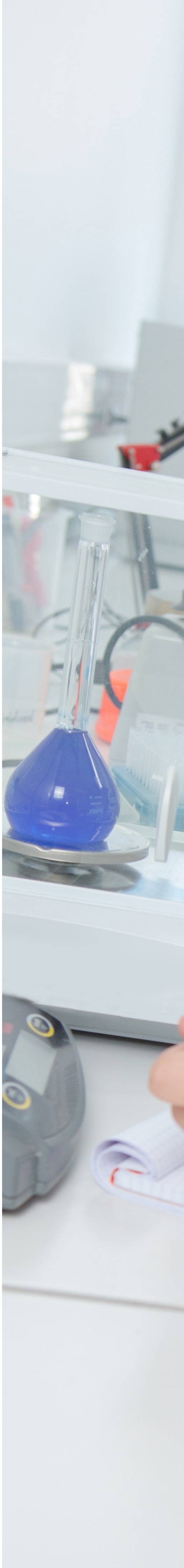
Sarah and Ollie's hope is that a cure can be found in George's lifetime; they don't want any other families to have to experience what they're going through.

"We're creating memory boxes for George filled with tactile things, so when we talk about places we've visited and things we've done as a family, he can touch those things and remember. He won't have visual memories."

Making our vision a reality

Finding a cure

- We will continue to invest in research until we Beat Macular Disease.
- We will fund where our support will have the most impact on the search for a cure.
- We will diversify our funding so that promising ‘action’ research and innovation is supported as well as vital basic research in academia. This may include support for early stage commercial ventures where our funding can accelerate progress towards bio-medical treatments, technologies or action that improves quality of life for people affected by macular disease.
- We will have a robust evidence base and processes for assessing and evaluating all our funding decisions to make sure we maintain the high quality of the work we fund and that we are spending the gifts of our donors in the best ways.
- We will maximise our impact by working collaboratively with other research funders, especially Action Against AMD, to leverage more resource into macular research to make a bigger difference.



- We will involve a diverse range of patients in our research decisions including priority setting and evaluation as well as in taking part in research projects as patient experts and trial participants.

Providing the best advice and support

- We will provide the best quality advice, information and support for people with macular disease because evidence shows that better informed patients are less likely to lose vision unnecessarily.

- We will understand more about the people who are affected by macular disease, how they feel, what support they need, where and when.

- We will ensure our services meet those needs. This means continuing to develop a wider portfolio of activities delivered in a broader variety of ways to reach more diverse communities. Everyone who comes to the Macular Society will find something of benefit.

By doing this **we will double the number of people we help** between 2023 and 2028.

- We will continue to value the unique role our volunteers play within the organisation. The skills and experiences they share enable us to achieve our vision: The experts on living with macular disease are the people who have it. We have more than 1,200 dedicated volunteers, nearly all with macular disease, who deliver many of our services. The bottom line is; we simply could not do what we do without our volunteer team.

- We will strengthen our volunteering infrastructure to create a consistent approach to volunteer management across the organisation.
- We will make the Macular Society a meaningful place to be a volunteer by providing an enriching volunteer experience.
- We will expand our volunteering opportunities and recruitment to extend our reach in communities across the UK and achieve our organisational goals.

Making sure vision matters

- We will campaign to increase understanding of the impact of macular disease, including with policy makers, so that it is given the priority it needs. Macular disease should be a UK health priority.
- We will make sure our messages are bold, honest and authentic. We will not scaremonger but neither will we hide the truth about macular disease. We know that, with the right support, people with macular disease 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.

- We will make sure our messages help people care for their own vision. Too little understanding of macular disease has serious consequences. These include not understanding the dangers of smoking and poor diet, inability to recognise symptoms in time and unnecessary distress caused by fear of total blindness or misunderstanding the cause of visual hallucinations.

- We will encourage the public to have regular eye health checks as this reduces unnecessary sight loss.

- We will engage with health and care professionals who work with people affected by macular disease. We will raise awareness of the need for better emotional and practical support for people affected by macular disease. We will encourage referral to our specialist services so that we can support more people when and how they need us.

For all our work

- We will have reliable methods of evaluation so we can learn how to improve what we do, as well as demonstrate its value to our service users, volunteers, supporters, donors, staff, Trustees and charity regulators.

- We will make sure our policies and behaviours reflect our commitment to the highest standards of ethical behaviours in fundraising, data protection, equality, diversity, inclusion and safeguarding.

Our values

Our values are a critical part of how we will achieve our mission to Beat Macular Disease.

We will Beat Macular Disease by Making It Happen. Showing We Care. Knowing Our Stuff.

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.

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.

“I have those hours in the middle of the night when I just can’t contemplate what’s ahead of me.”

Margaret’s life has been affected not only in the practical sense of knowing what macular disease is taking away from her, but also mentally as she struggles to come to terms with losing her eyesight.

“It’s always with me. It’s like a little thing sitting on my shoulder the whole time. Apart from when you’re asleep, you’re always using your eyes, so I’m constantly reminded that I have macular disease. It’s very isolating. You lose your confidence, not just your sight.”

“I was diagnosed in May 2016. But recently there’s been a major deterioration. My particular macular degeneration nearly always turns wet, and the doctors expect that I’ll almost certainly need injections in both eyes.”

“Nobody wants people sticking needles into their eyes, and before I went for my first injection, I was absolutely petrified. I could not imagine how I was going to deal with somebody sticking a needle in my eye. But at least there is the prospect that the injections will slow down the progression of the disease and maintain my vision for longer – hopefully.”

“It’s the loneliness of the condition that I think has the most impact, because every day, when you get up, you open your eyes and think, “What am I going to be able to see today?” I still wonder every morning if today is the day I’m going to wake up and not be able to see.”

References

AMD

1. Owen CG, Jarrar Z, Wormald R, Cook DG, Fletcher AE, Rudnicka AR. The estimated prevalence and incidence of late stage age related macular degeneration in the UK. *Br J Ophthalmol* 2012; 96(5):752-756.
2. Rudnicka AR, Jarrar Z, Wormald R, Cook DG, Fletcher A, Owen CG. Age and gender variations in age-related macular degeneration prevalence in populations of European ancestry: a meta-analysis. *Ophthalmology* 2012; 119(3):571-580.
3. Dr Alicja R Rudnicka, Professor Christopher G Owen, Personal Communication. Macular Society 2016

Myopic Macular degeneration

4. Impact of increasing prevalence of myopia and high myopia: report of the Joint World Health Organization – Brien Holden Vision Institute Global Scientific Meeting on Myopia, University of New South Wales, Sydney, Australia, 16 – 18 March 2015.

Central serous retinopathy

5. Liew G, Quin G, Gillies M, Fraser-Bell S. Central serous chorioretinopathy: a review of epidemiology and pathophysiology. *Clin Exp Ophthalmol* 2013; 41: 201–214.

Juvenile macular dystrophies

6. Puech B, Kostrubiec B, Hache JC, François P. Epidemiology and prevalence of hereditary retinal dystrophies in the Northern France. J Fr Opht almol. 1991;14:153–64.
7. Literature search on the prevalence/incidence and progression of diabetic maculopathy and juvenile macular dystrophy and the progression of age-related macular degeneration. Aggressive Research Intelligence Facility West Midlands Health Technology Assessment Collaboration, University of Birmingham. November 2007

Macular hole

8. Mitchell P, Smith W, Chey T, Wang JJ, Chang A. Prevalence and associations of epiretinal membranes. The Blue Mountains Eye Study, Australia. *Ophthalmology*. 1997;104(6):1033–40.
9. Rahmani B, Tielsch JM, Katz J, Gottsch J, Quigley H, Javitt J, Sommer A. The cause-specific prevalence of visual impairment in an urban population. The Baltimore Eye Survey. *Ophthalmology*. 1996;103(11):1721–6.

Retinal vein occlusion

10. Laouri M, Chen E, Looman M, Gallagher M. The burden of disease of retinal vein occlusion: review of the literature. *Eye*. 2011;25(8):981-988. doi:10.1038/eye.2011.92.

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