

Strategy 2016-2020

The Macular Society's charitable aims remain as important today as they were when the Society was formed in 1987.

Our vision:

Excellence in support now; a cure in the future.

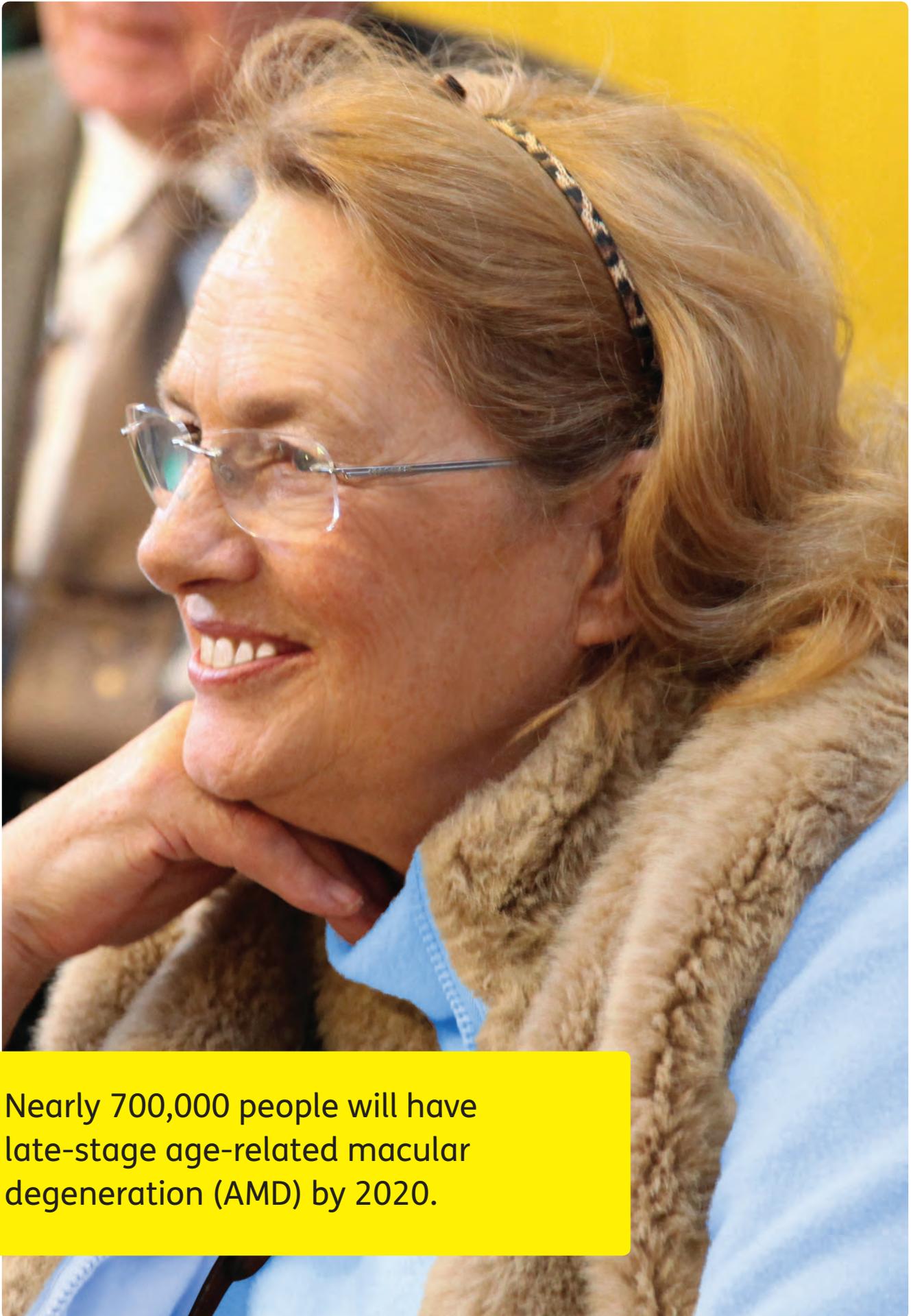
Our mission:

To promote independence, confidence and quality of life and to find a cure for macular disease.

Nearly 700,000 people will have late-stage age-related macular degeneration (AMD) by 2020¹ and many more will have early disease. Recent research suggests that 54% of people over 60 have early AMD². As more people live into their 80s and 90s late AMD will increase. Although our age and genes are the biggest factors in whether or not we develop AMD there are lifestyle risks too; smoking, poor diet, high blood pressure and obesity all increase the risk of AMD. In addition to AMD, a number of purely genetic forms of macular disease affect tens of thousands of younger people, including children. People with macular disease do not lose all their sight; their central vision is destroyed leaving only peripheral vision.

1. The estimated prevalence and incidence of late stage age related macular degeneration in the UK, Christopher G Owen, et al, BJO 2011

2. Prevalence of age-related macular degeneration (AMD) in an elderly UK population, the Bridlington eye assessment project (BEAP), W. Amoaku, Digest 2015



Nearly 700,000 people will have late-stage age-related macular degeneration (AMD) by 2020.

This means that people with macular disease cannot drive, read or recognise faces. Only a few types are treatable. Wet AMD is treated with a drug injected into the eye but the treatment can only slow the progress of the disease. Dry AMD and nearly all the genetic forms remain untreatable although new drugs are being trialled for dry AMD.

Macular disease is associated with increased risk of falls, social isolation, depression and suicidal thoughts. With the right support people with AMD can continue to live full and happy lives but without it macular disease can be devastating.

Our aims over the next five years are to support more people living with macular disease and to make progress towards a cure. To achieve that we must increase our reach, offer services that are valued and increase the effectiveness of what we do.

Objective 1: To increase awareness of macular disease and the Macular Society

Macular disease is the biggest cause of sight loss in the developed world but many people have never heard of it. This low awareness has a number of consequences:

- People do not know how to recognise the signs of macular disease and often present too late for treatment to be as effective as it could be.

- Many people who have the early stages of the disease don't know their sight is at risk and may not understand that some behaviours, such as smoking, are making late stage disease much more likely.
- Unnecessary distress and fear is caused by lack of knowledge of the condition including a lack of understanding of Charles Bonnet Syndrome.
- Insufficient planning and investment is put into developing services for people with macular disease.
- There is not enough investment in research to find ways to prevent, treat and cure macular disease.
- The needs of visually impaired people in society can be overlooked.
- Low awareness of the Macular Society means that too few people benefit from the support services we provide.

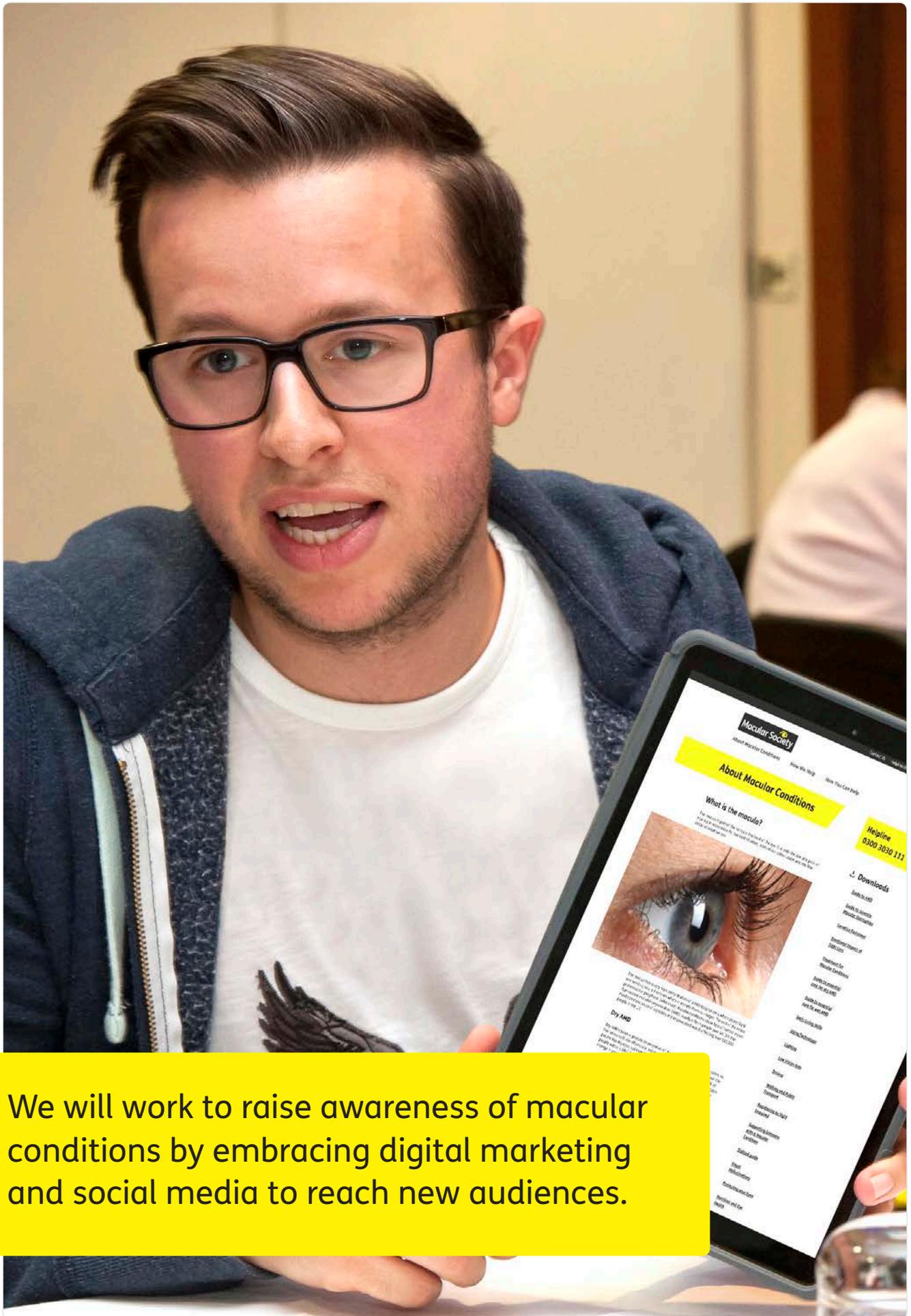
Over the next five years we will work to raise awareness of macular conditions so that they are better recognised and understood by the public and by decision makers.

- 'Macular disease' will be known by its name as well as dementia is.
- The Society's name will be relevant and clear to people who have no connection with macular conditions.
- More people with the condition will understand it so they can better manage it and get the right care.

- Wider awareness will make it easier for the Society to advocate on behalf of people with macular disease and to raise funds.

We will do this by:

- Improving our messaging so that we have a consistent narrative and an authoritative evidence base about the Society and the condition.
- Developing media relations as the trusted representative of the macular community.
- Leveraging groups and volunteers to grow through word of mouth and local awareness-raising.
- Embracing digital marketing and social media to reach new audiences.
- Collaborating where appropriate to spread messages cost-effectively and with authority.
- Creating effective campaign plans especially around our research agenda.
- Developing and strengthening our relationship with eye care professionals through our professional membership scheme.
- Influencing decision makers.
- Gathering high quality data and awareness tracking to measure progress and inform strategy.



We will work to raise awareness of macular conditions by embracing digital marketing and social media to reach new audiences.

Objective 2: To increase the provision of valued services for people affected by macular conditions across all ages

No one should face macular disease alone. We are dedicated to supporting people affected by macular conditions. We offer a range of services some of which are delivered by paid specialists others by many wonderful volunteers.

We specialise in offering peer support. Over the next five years we will expand and develop our support services to meet the needs of older people, working age people, young people, children and their families.

We will do this by:

- Listening to what our members and other people affected by macular disease want. Support services will be tested for their appeal, utility and cost-effectiveness before being expanded or introduced.
- Increasing the number of local peer support groups to make sure as many people as possible can attend if they choose to. Our aim is to have 400 groups by 2020. We will review our model to ensure it is as effective as possible. Some people may prefer ‘virtual’ groups to face to face meetings. If so we will expand these too.
- Improving the effectiveness and reach of all our services: our helpline, counselling service, befriending, daily living champions, and our eccentric viewing programme as well as our information services and our website.

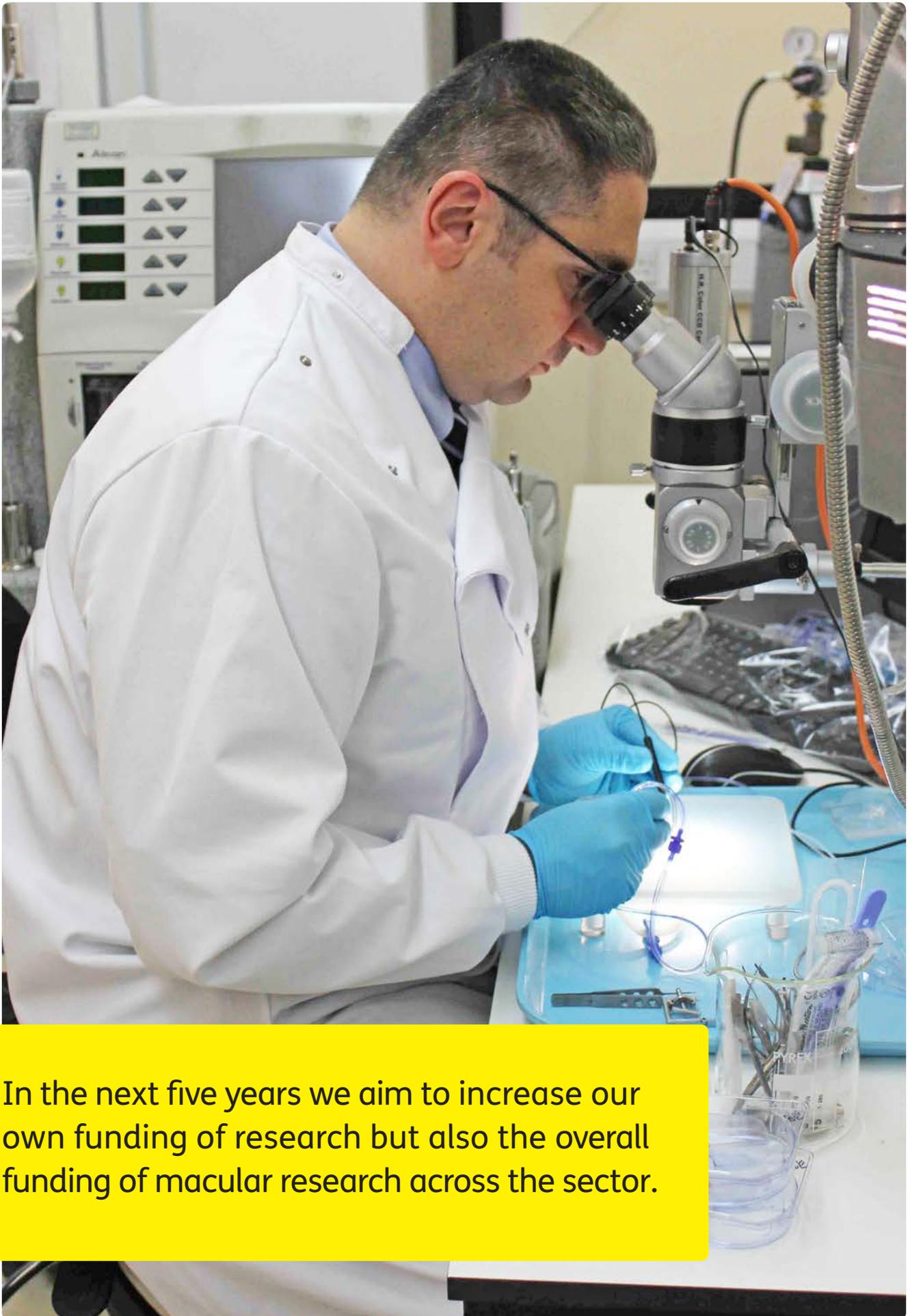
- Developing resources specifically for young people and their families including materials for use with schools and colleges to help inform educational establishments about the needs of students with macular conditions.
- Developing new ways of supporting our volunteers to make sure their work with us is as rewarding and effective as possible. This will include the further development of our regional structure to ensure volunteers are well supported in their area.
- Encouraging more corporate engagement with volunteering.

Objective 3: Building research capability

The Macular Society has funded £2.5m of scientific research since 2000. In the next five years we aim to increase our own funding of research but also the overall funding of macular research across the sector.

We recognise that we cannot make enough difference alone so we will do this by:

- Raising awareness of the lack of research funding for macular disease.
- Building alliances and establishing a collaborative research platform to increase the money available for research and focus it on agreed priorities.
- Taking responsibility for the macular stream of the James Lind Alliance Priority Setting Partnership.



In the next five years we aim to increase our own funding of research but also the overall funding of macular research across the sector.

- Helping research teams by expanding our database of people willing to participate in research.
- Strengthening our communications about our research programme and macular research more broadly.
- Supporting the wider work of the Association of Medical Research Charities of which we are a member.
- There will be no reduction in support services to fund our leadership in research, but new funding will be sought and made available.

Objective 4: Increasing our income to £5.4 million by 2020

We are enormously grateful to our members and supporters who give so generously to the Society. The Society receives no income from government or the pharmaceutical industry. All our income (except for a small amount derived from trading activities) is from voluntary donations. In the next five years we will increase our annual income to £5.4 million. Our members are very important to us; we will grow our membership to 30,000 patient and 6,000 professional members by 2020.

We will do this by:

- Upholding the highest standards of ethical fundraising.
- Developing a membership model that is attractive and beneficial to members, that continues to

provide a financial benefit to the Society and that increases our ability to represent people affected by the condition.

- Increasing our donor pool as a result of raising our profile.
- Developing stronger fundraising messages.
- Inspiring our staff and volunteers to play a part in spreading our fundraising messages and enlisting the help of our trustees to reach out to more audiences.
- Increasing donor engagement with improved donor care and stewardship (for example we will improve our welcoming and lapsing processes).
- Exploiting new methods of fundraising including a wider range of appeals, digital and social media.
- Making our website more effective for fundraising.
- Building on strong fundraising activities in legacies, in memory, trusts and community events and developing corporate fundraising.

Objective 5: An effective and efficient headquarters

We cannot achieve our ambitions without a strong staff and volunteer base. The Macular Society is committed to equal opportunities and diversity and this commitment extends to our volunteers. We will equip staff and volunteers with the right training and skills. We will seek to offer appropriate

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support and an organisational culture, ethos and environment that enable them to work effectively. Staff and volunteers should feel appreciated and appropriately rewarded.

We will do this by:

- Having an attractive working environment for staff and volunteers with well-designed induction processes, performance management and training and development plans.
- Recruiting and retaining staff, volunteers and skills to match the needs of the Society.
- Maintaining the service-focused, yet cost conscious, team ethos.
- Upholding best practice in the acquisition, protection and use of data.
- Ensuring our health and safety, insurance, confidentiality and complaints handling processes are robust.
- Having excellent internal communications that keep staff and Trustees informed and included.
- Improving our volunteer support so that every volunteer feels valued and able to perform their role well.
- Develop meaningful ways to evaluate the effectiveness and impact of our activities.

Enablers

There are three important factors that contribute to each of these objectives. They are needed to justify and manage the activities of the Society and without them we will fail to meet our objectives. They are:

- **Communications:** We must have the ability to communicate effectively with different audiences using the most effective channels. For example good internal communications are needed to maintain the ethos of the Society. External communications promote membership, encourage volunteers, increase awareness of the condition, build fundraising, influence decision makers and explain research programmes and goals.
- **Evidence:** Decisions will be made on the basis of evidence such as the value of support services to people who use them, the cost effectiveness of working practices, the effectiveness of membership offers, and the impact of campaigns.
- **Audit:** Measures will be put in place to determine progress and achievement of the objectives so that trustees and managers can adjust the resources and direction of activities to achieve the desired outcomes.

I am grateful to all our staff and trustees for their contributions to this strategy.



Cathy Yelf
Chief Executive
December 2015



Support throughout central vision loss

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Registered Charity Number 1001198, SC042015 in Scotland, 1123 Isle of Man.
Macular Society is the trading name of the Macular Disease Society.
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