Let’s Beat Macular Disease

“My project is investigating whether gene editing can be used to cure Best disease and other inherited macular conditions. We really hope to have treatments for people with macular disease within my lifetime.”

Dr Amanda Carr, UCL Institute of Ophthalmology, recipient of a project grant in 2018.
The Macular Society is the only charity determined to beat the fear and isolation of macular disease with world-class research, and the best advice and support. To help people affected by macular disease now, the Macular Society provides a range of support, information and services. Our research programme is focused on finding new treatments and a cure to Beat Macular Disease forever.

Macular disease is the biggest cause of sight loss in the UK, with around 300 people diagnosed every day.

In 2018, the Macular Society launched its new five-year strategy and our three strategic aims: Finding a cure; Providing the best advice and support; Making sure that vision matters. With this came bold new language and a new drive to Beat Macular Disease. It’s a huge ambition, but we hope you agree that it’s one worth fighting for.

You, our supporters, are already very generous and we are so grateful for all your continuing support. You also help inspire others to support us so please ask friends and family if they will join our campaign to Beat Macular Disease.

We cannot achieve our great ambition without you — but with you we cannot fail. Let’s Beat Macular Disease. Thank you.
When the Macular Society was founded more than 30 years ago, the prospect for people diagnosed with macular disease was bleak. No treatments were available and people felt isolated and abandoned. Now adaptive technologies are making every aspect of the world easier to access, and new treatments are preserving the sight of thousands of people every year.

But that’s not enough – the number of people with macular disease continues to rise faster than we can reach them, and for the majority there is still no treatment.

That’s why we are reaffirming our commitment to funding the best research we can.

Our Macular Society Support Groups, Advice and Information Service and other services do an incredible job at helping people live the best life they can with macular disease, but our dream is of a world where they don’t have to exist. Where macular disease is diagnosed early and cured before it can restrict people’s independence – or where it is prevented from ever striking in the first place.

We hope that you’ll join us in championing macular research.

“For the first time in eight years I am hopeful that one day there will be a cure.”
Sarah, Macular Society member

Research
In 2018, we invested £563,000 in research grants. This will support four research projects, including a PhD studentship that we are funding in collaboration with Retina UK.

We invested a further £50,000 in Action Against Age-Related Macular Degeneration, a collaboration between several sight loss charities that will pool resources to invest in cutting-edge research.

Macular Society Support Groups
Our 412 local groups enabled peer support for over 8,500 attendees.

Advice and Information Service
We had over 12,700 calls for advice, information and support to our dedicated phone service.
Digital support
We had over 200,000 visitors to our website in 2018, accessing a range of advice and information.
Our following on Twitter increased to over 9,700, and Facebook over 8,600. On these channels we share stories, advice and information.

Information leaflets
We distributed 322,000 information leaflets to anyone in need of advice. These leaflets cover a range of topics and are compiled with the help of our expert panels to ensure that the advice is helpful and accurate.

Counselling
Our team of accredited professional counsellors delivered more than 1,500 counselling sessions.

“The Macular Society was a great source of information and emotional and practical help to me and continues to be through the counselling. It helped me accept my condition and gave me hope for the future.”
Jessica, Macular Society member

In total, we helped people affected by macular disease over 500,000 times in 2018 with our services, support and information.

Volunteers
Our services rely on volunteers to provide the support that people with macular disease deserve. In 2018, 1,500 people volunteered their time with us in a range of roles. Between them, they provided nearly 12,000 hours of support for people with macular disease across the UK; that’s over 1,500 work days!

Gadget guides
Our gadget guides delivered 128 demonstrations around the country, introducing over 2,900 people to ideas, tips and technology to help them manage their sight loss.

Befriending
Our volunteer befrienders provided more than 5,000 hours of friendly phone conversations, helping to beat the isolation of macular disease.

Professional membership
Our professional membership programme welcomed even more eye care experts, researchers and low vision specialists. More than 7,900 professional members now help us to reach many thousands of people with macular disease across the UK.
London Project to Cure Blindness

In 2008 the Macular Society supported some promising research with a grant of £100,000. This project went on to become the London Project to Cure Blindness. This trial was testing the transplantation of retinal pigment epithelial cells (a type of cell that forms a layer in the retina that becomes damaged in macular disease), produced from stem cells, into the eyes of people with wet AMD as a treatment.

Although in a limited number of people and at an early stage, the results are promising and one of the first trials of stem cell-based therapy for macular disease.

“Research is important as the more research there is the more chance we have of finding a treatment or cure at some point and to help others.”

Hannah, Macular Society member

Action Against AMD – Collaborating to find a cure

In 2017, the Macular Society joined forces with other sight loss charities (Blind Veterans UK, Fight for Sight and Scottish War Blinded) to transform the funding of research to address age-related macular degeneration (AMD). The collaboration is called Action Against AMD (AAAMD).

In 2018, AAAMD partnered with a drug discovery company, BenevolentBio, in its first project. The company uses artificial intelligence (AI) to analyse vast amounts of research and filter out the most promising avenues for future research.

“The first therapy for macular disease was a drug already used for cancer. There may be more drugs in existence that would be effective. We are using AI to search the millions of clues in research data and speed up the hunt for new treatments.”

Cathy Yelf, Chief executive, Macular Society

Research is important as the more that’s invested in research, the faster successful treatments will be developed. Without your generous donations, fundraising, and gifts in memory and Wills we wouldn’t be able to conduct this important research.”

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Hannah, Macular Society member
Providing the best advice and support

Our Advice and Information Service offers information, advice and support through our telephone support line, via email, and also through online health forums to ensure that no-one with macular disease is alone.

“I feel like the Macular Society is my own telephone befriender.”
Audrey, Macular Society member and volunteer

Macular Society Support Groups

“The support I’ve had from the group has been a tremendous help. It really does make a big difference, being able to speak to others in the same position, who truly understand what it’s like to have sight problems.”
Bill, Macular Society member

Our Skills for Seeing programme works with individuals to help them better manage their condition and make the most of their remaining vision, maintaining independence and improving wellbeing. In 2018, our volunteers delivered Skills for Seeing training to 213 people.

“I get a lot of enjoyment from Skills for Seeing training especially. On one occasion, it enabled a lady to see a photo of her grandchildren for the first time, so it’s really satisfying to know that you’ve been able to help.”
Pat, Macular Society member and winner of the Chairman’s Award for Volunteering in 2018
Making sure that vision matters

**Macular Week 2018**

During Macular Week 2018, as well as fantastic fundraising and awareness events held around the country by our supporters, we launched two activities:

Our short film, ‘Five years through the eyes of a mum’ was made to help more people understand the impact of macular disease. ‘Five years through the eyes of a mum’ charts one woman’s changing relationship with her young son as her sight deteriorates.

We also launched our ‘Sight Matters’ packs, which included eye health tips, an eye test voucher and an Amsler grid. This was aimed at people who didn’t know about the Macular Society or macular disease.

During Macular Week, over 2,700 ‘Sight Matters’ packs were sent out.

**Scenes from our short film ‘Five years through the eyes of a mum’**

The film is 90 seconds long, and was viewed more than 800,000 times online. The film went on to win silver at the Charity Film Awards in 2019.

**Eye care professionals’ network**

In 2018, we launched our first online training module for eye care professionals, ‘An introduction to AMD’.

This training is accredited, and counts towards professionals’ mandatory training time.

It’s designed to support staff to develop a greater understanding of macular disease and the services and support available. One more module has been launched since, ‘The emotional impact of a diagnosis of AMD’, with a further two planned.

All modules are free to use and available to all.

We also hosted our third annual Professionals’ Conference. The event aims to encourage those in the sector to work together in order to reduce feelings of fear and isolation in patients by improving their experience upon diagnosis.
Four sisters, one wonderful gift

A generous gift from four sisters is helping our local support groups reach out to more people with macular disease. Isobel, Chrissy, Eleanor and Sheila McNab grew up in Fraserburgh, Aberdeenshire, where their family owned two local shops. When wartime bombing forced them out to the country, the older sisters worked for an engineering firm. Isobel trained in hotel management and later became bursar at the University of St Andrew’s. Isobel and Chrissy both experienced macular degeneration and Isobel, who lived to over 100, thoughtfully left a gift to the Macular Society in her Will, enhanced by inheritance from her sisters.

Our support groups are just one way that Isobel’s kind gift will help other people with macular disease.

Jaguar auction for Macular Society

In 2018, the Jaguar Enthusiasts Club raffled an F-Type Jaguar for us. The club toured the UK between February and November with the car to reach as many car enthusiasts as possible and give them the option to buy a raffle ticket. Graham Searle from the Jaguar Enthusiasts Club says, “Our Chairman, Mike Horlor, chose your charity to help raise the profile of the Macular Society and its work in tackling this dreadful disease.” The raffle was drawn on the 11th November at the Birmingham NEC Classic Motor Show. The raffle raised £25,000 for the Macular Society.

As an independent charity we receive no funding from government and rely on your voluntary support. Thank you again.
The financial statements show a surplus for the year of £340k (2017 deficit of £80k). Total funds at the year-end were £3,363k (2017 £3,023k).

We started the year in a strong position and we set a deficit budget once again for 2018. Owing to unexpectedly high income from legacies, we ended the year with a surplus. This allows us to accelerate investment in our services division and infrastructure development. In addition, we plan to invest a record £1m in research.

In 2019, we have budgeted for a deficit of £497,510.
Patrons
Henry Blofeld OBE*
Gemma Craven*
Gwyneth Dickinson MBE*
Denis Norden CBE* (died 19 September 2018)

Trustees
John Dunston MA, ACIL, FRSA – Chair
Paul Ryb BA(Hons) * - Vice Chair
Margaret Packham BSc(Hons), MCIPD – Vice Chair
Alan Walter* – Vice Chair
Richard Piller FCA, CTA – Honorary Treasurer
Toby Evans BA(Hons), ACA *

Timothy ffytche LVO, FRCS, FRCophth
Alison Guthrie MCOptom
Keith Arscott (retired 25 January 2018)
Bill Best * (appointed 11 April 2018)
Cecilia Bufton BSc(Hons)
Anna Fletcher LLB *
Lucy Howe FRCophth (retired 21 September 2018)
Alan Howell *
Steve Kendall * (appointed 11 April 2018)
Martyn Long CBE *
Frances Luff BA(Hons)

Alan MacFarlane * (retired 4 July 2018)
Stephen Stacey MA, DPhil

Executive team
Cathy Yelf – Chief Executive and Company Secretary
Emma Malcolm – Director of Fundraising and Marketing
Tessa Barrett – Director of Services

The symbol * indicates visual impairment.

Please support the vital work of the Macular Society: macularsociety.org/donate