

# 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.**



**Macular Society**  
Beating Macular Disease

**Annual Review 2018**

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

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.

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.



*John Dunston*  
**John Dunston**  
Chairman



*Cathy Yelf*  
**Cathy Yelf**  
Chief executive



# Beating Macular Disease

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

**Sarah, Macular Society member**



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.

## Highlights from 2018



### 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.

# Beating Macular Disease

## 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.



# Highlights from 2018

## 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.

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

## 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



## 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.

# Beating Macular Disease



## 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.



# Finding a cure



“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.”

Dr Amanda Carr,  
UCL Institute of  
Ophthalmology,  
recipient of a  
research grant  
in 2018.

## 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



## 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

# Beating Macular Disease

Professors Pete Coffey and Lyndon da Cruz





# 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**

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.

## 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**

# Beating Macular Disease



“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

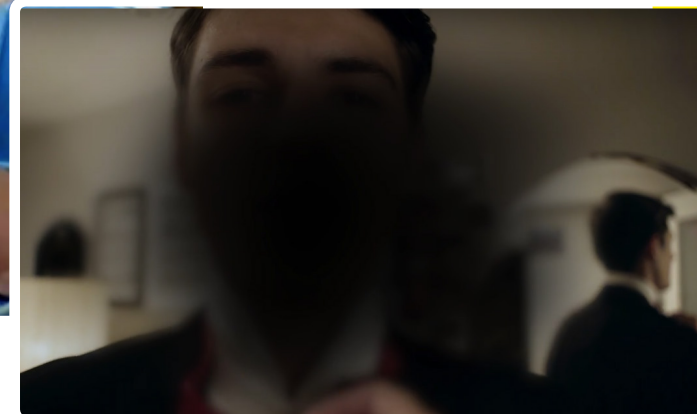


Scenes from our short film ‘Five years through the eyes of a mum’.

## 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.



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.

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.



## Eye care professionals’ network

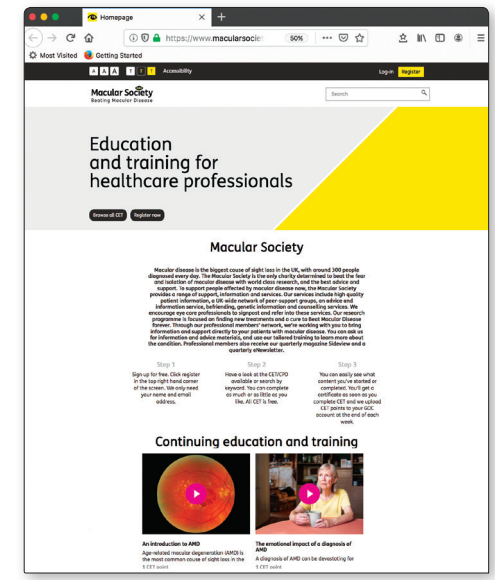
In 2018, we launched our first online training module for eye care professionals, ‘**An introduction to AMD**’.

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.



# Our grateful thanks

We would like to thank all our members and donors for their kind support in 2018, including those, sadly missed, who thoughtfully remembered us in their Will. We are especially grateful to the following whose generous gifts enabled so much of our work:

- Blindcraft Charitable Trust
  - The Carmen Butler-Charteris Charitable Trust
  - Elise Pilkington Trust
  - The Evan Cornish Foundation
  - Garfield Weston Foundation
  - G C Gibson Charitable Trust
  - Mr Gordon and Mrs Patricia Gilby
  - The Halifax Foundation NI
- The Kirby Laing Foundation
  - The Linbury Trust
  - The Mabs Mardulyn Foundation
  - Masonic Charitable Foundation
  - National Lottery Community Foundation (Wales)
  - National Lottery Community Foundation (Northern Ireland)
  - National Lottery players in Wales and Northern Ireland
- Robert Luff Foundation Ltd
  - The R S Macdonald Trust
  - Schroder Charity Trust
  - Simon Gibson Charitable Trust
  - Simplyhealth
  - Sovereign Health Care Community Programme
  - Thriplow Charitable Trust
  - Lady Margaret Wall and The April Trust

As an independent charity we receive no funding from government and rely on your voluntary support. Thank you again.

## 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.

## Beating 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.



Macular Society Summarised Accounts – year ended 31 December 2018

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.

	2018 £000	2017 £000		2018 £000	2017 £000		2018 £000	2017 £000
Income								
Subscriptions	291	290	Advice and Information Service and Counselling	310	293	Net income		
Legacies	2,443	1,520	Groups and volunteer co-ordination	1,096	1,039	- Unrestricted	144	75
Donations & unrestricted grants	1,270	1,225	Local Group activities	160	175	- Restricted	196	(155)
Grants for specified charitable activities	446	531	Low vision	199	160		340	(80)
Fundraising events	635	517	Research	995	913	Funds and net assets at 31 December		
Trading and other income	78	78	Other expenditure	108	133	- Unrestricted	2,310	2,166
Total income	5,163	4,161	Total charitable expenditure	3,714	3,394	- Restricted	1,053	857
Expenditure						Total funds carried forward	3,363	3,023
Charitable activities:			Costs of generating funds	1,045	864			
Side View and Digest	252	210	Net investment (gains)/losses	64	(17)			
Educational information	594	471	Total expenditure	4,823	4,241			



# Patrons, officers and trustees as of 31 December 31, 2018

## 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.

## Beating Macular Disease



Please support the vital work of the Macular Society: [macularsociety.org/donate](https://macularsociety.org/donate)



# Macular Society

Beating Macular Disease

## Macular Society

PO Box 1870, Andover SP10 9AD

01264 350 551

[macularsociety.org](http://macularsociety.org)

[info@macularsociety.org](mailto:info@macularsociety.org)

Macular Society is the trading name of the Macular Disease Society. A charity registered in England and Wales 1001198, Scotland SC042015 and Isle of Man 1123. A company limited by guarantee, registered in England No. 2177039. Registered Office: Macular Society, Crown Chambers, South Street, Andover SP10 2BN © Macular Society 2018.