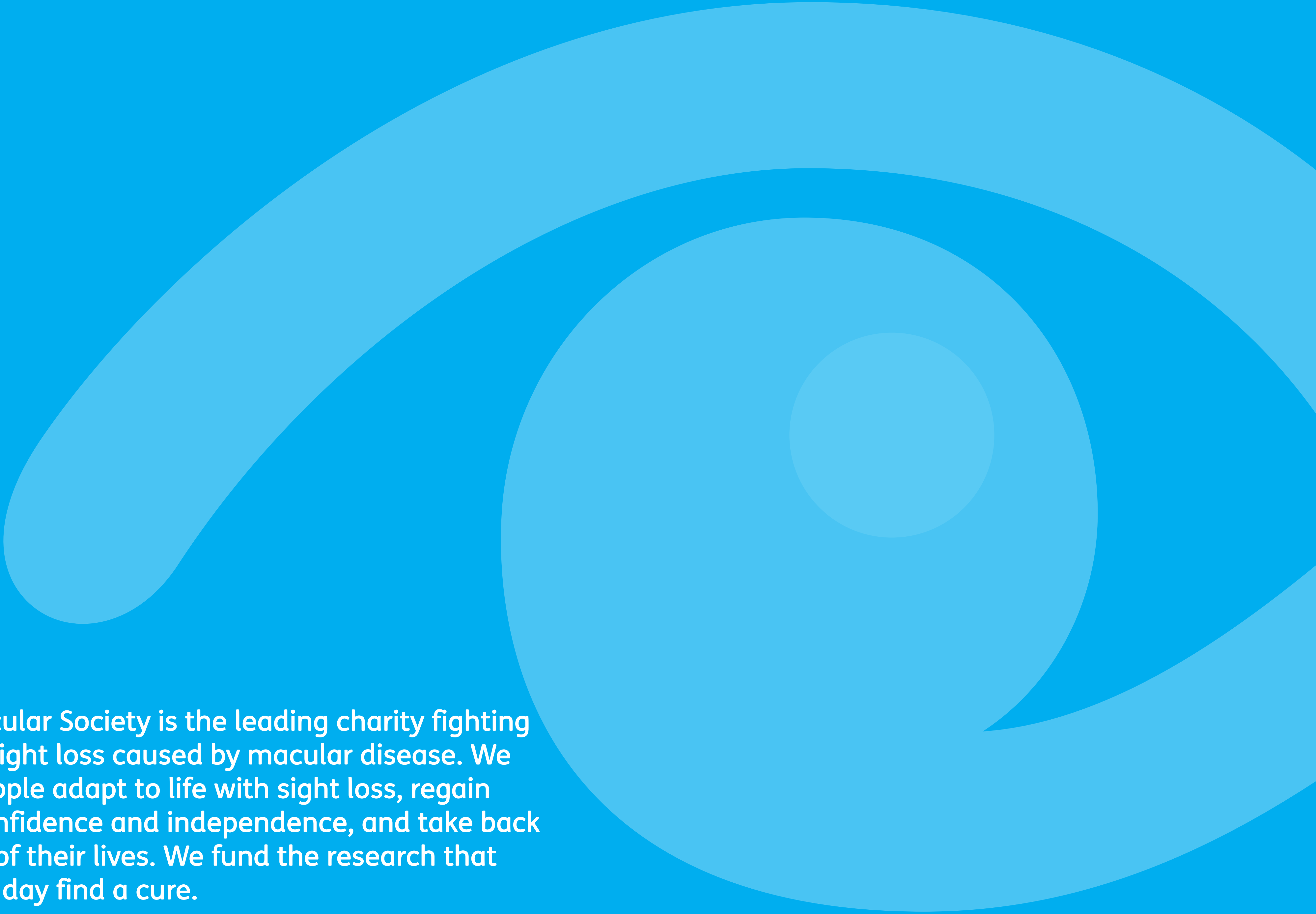
Macular Society

Annual Review 2017

> "I couldn't have gone back to work without speaking to the Macular Society. I felt lost and scared but the Society gave me information and someone to talk to, and made me feel I had someone in my corner."
>
> **Kristy, Macular Society member**

Dedicated to people with macular disease



The Macular Society is the leading charity fighting to end sight loss caused by macular disease. We help people adapt to life with sight loss, regain their confidence and independence, and take back control of their lives. We fund the research that will one day find a cure.

We won't quit

Macular Society

In 2017, the Macular Society celebrated its 30th birthday. And we have certainly come a long way since those first few patients gathered to support each other back in 1987. We now fund more research, support more local groups and answer more Helpline calls than ever before. Why? Because although technology and treatments have moved on, people still dread losing their sight more than any other sense.

Of course, we couldn't do any of it without our members, volunteers and donors – the people who share our vision of a world without central sight loss, and whose support will make it a reality sooner.

John Dunston

John Dunston
Chairman

Cathy Yelf

Cathy Yelf
Chief Executive Officer

Macular disease isn't backing down . . .

We are all living longer, but that means more of us are living with late AMD.

By 2050 it will affect one in fifteen people over the age of 65, and one in seven aged over 80 – around 1.3m people in total.

Patients with early age-related macular degeneration (AMD) generally still have much of their sight. But not knowing when their sight loss will worsen is agonising. There is no cure for AMD and no way to prevent early AMD turning into late.

That's why in 2017 we teamed up with Fight for Sight, Blind Veterans UK and Scottish War Blinded to launch a major program called **Action Against Age-related macular degeneration (AAA)** to stop early AMD getting worse.

AAA will:

- Help industry, government, academia and researchers work together better
- Raise the funds for vital research
- Test new treatments in clinical trials within 10 years
- Be the voice of AMD patients.

"The onset of advanced AMD can happen at any time, and not knowing when (or if) causes a lot of apprehension. My eyes have been stable for the last five years, but that doesn't relieve the fear I feel every morning."

Sandie,
Macular Society member

Find out more at www.actionagainstamd.org

And neither are we

To help people with sight loss take back control of their lives in 2017, we:

Research

Invested in **5** more research projects, which means we're currently funding **16** projects totalling **£1.7m** to understand the causes of macular disease, find a cure, and improve lives for those living with macular degeneration today.

Helpline

Advised **12,575** Helpline callers like Malcolm about all aspects of macular disease.

Malcolm benefitted from the Society's Helpline and is now running a group in Oswestry. He said: "I am most grateful for the invaluable support I received from the Helpline, so I wanted to give back."

Counselling

Provided **1,356** counselling sessions for people like Kristy struggling to cope with the emotional impact of sight loss.

"I felt lost and scared but the Society gave me information and someone to talk to, which made me feel like I had someone in my corner."

More highlights from 2017 ▸▸

More highlights from 2017

Support groups

Enabled peer support for **7,297** people at **383** local groups, including Gillian's group in Edinburgh.

"I have been inspired by the other local support group members, and gained strength from their example and fortitude."

Gadget Guides

Showed **4,432** people equipment to help with everyday tasks, from cooking to watching TV, so they can retain their independence.

Leaflets

Distributed **360,000** pieces of patient information to help people understand their condition, feel more confident at home and ask their healthcare professionals the right questions.

Befriending

Tackled loneliness for Rita and **350** other people with calls from telephone befrienders.

"What I find most useful about the befriending service is the friendship and reliability, the positivity and encouragement. I really do want to encourage people to use this scheme. It is like a safety valve."

Professional membership

Welcomed even more eye care experts, researchers and low vision specialists into our professional network. More than **7,300** professional members now help us reach many thousands of people with macular disease across the UK.

Campaigning

We campaigned to:

1. Tell more people that smokers are four times more likely to develop macular degeneration.
2. Demand that the Department of Health act to stop people going needlessly blind.
3. Reassure people that visual hallucinations are a common side effect of sight loss.
4. Bring people feeling isolated because of macular disease out of the shadows.

“It all started a couple of years ago when a great friend and long-standing group member announced that she had always wanted to go abseiling and zipwiring, so I took her along for her birthday. She enjoyed it so much, we decided a group visit was on!”

Patricia, group trip organiser

Services

Ambition 1: To make sure that no one faces sight loss from macular disease alone

"I train people with central vision loss to use their peripheral vision. For one of my learners, the most important thing was the sense of independence she regained from being able to open her own front door again. For another, it was seeing her six-month-old great-nephew for the first time, and being inspired to look through old photo albums."

Patricia, Eccentric Viewing trainer

"Jean, my befriender, is such a friendly and positive character. She always makes me feel better. She's had macular disease for yonks so she knows it inside out!"

Mary, befriending service user

"Twenty years ago, I couldn't have appeared on TV. I love being a group leader and I think that's what has given me the confidence."

Jane, support group leader

Research

Ambition 2: To find a cure for macular disease

"My father was diagnosed with AMD aged 47. I was 51 when my eyes started to deteriorate.

"There was no treatment that my dad could have, but for every generation there is more hope."

Josephine, Macular Society member

"Even if I can't save my own sight, I want to know that I've done what I can for my grandchildren. Somebody's got to test these new drugs: science can't advance without 'guinea pigs'."

Cynthia, research participant

"Our project is aimed at understanding how a genetic mutation affects eye tissue's ability to remove waste products. If we succeed, it will help current efforts to design drugs that could slow the progression of the disease.

"We have only been able to launch this project due to funding from generous donations, gifts in memory and Wills."

Majlinda Lako, PhD, Professor of
Stem Cell Sciences, Newcastle University

Professor Lako's research team, Newcastle University

Campaigning

Ambition 3: To make the 600,000 people with central sight loss impossible to ignore

In 2017 we:

- Made the most of Macular Week by encouraging members to spread the word that smoking is the largest preventable cause of sight loss

- Delivered a petition with **11,000** signatures to 10 Downing Street, demanding that the Department of Health act to end preventable blindness caused by NHS delays. Around **40,000** people saw our posts online and dozens shared their own stories

- Shone a light on the isolation experienced by many people with sight loss, especially at Christmastime

- Talked about Charles Bonnet syndrome – letting people know that hallucinations caused by sight loss are a common side effect, not a sign of dementia or mental illness. **54,000** people watched our video online and more than **350** downloaded our guide on living with hallucinations.

Right: One person’s experience of a visual hallucination.

Our grateful thanks

We would like to thank all our members and donors for their kind support in 2017, 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:

- 29th May 1961 Charity
- Big Lottery Fund
- The Carmen Butler-Charteris Charitable Trust
- Alice Ellen Cooper Dean Charitable Foundation
- Donald Forrester Trust
- G C Gibson Charitable Trust
- Simon Gibson Charitable Trust
- Mr Alastair Gunn
- Mr Gordon and Mrs Patricia Gilby
- The Hampson family in memory of Mrs Sylvia Hampson
- Dr Brigitte Hoffmann-Lundgren in memory of Mrs Aexel-Annelene Briggs
- Roger and Jean Jefcoate
- The Kirby Laing Foundation
- The Linbury Trust
- The R S Macdonald Charitable Trust
- The Mabs Mardulyn Foundation
- Millichope Foundation
- Pilkington Charities Fund
- Mr Rhys Revell
- Mrs Beryl Saunders in memory of Mr Edward James Wilmot Saunders
- Simplyhealth
- Three Oaks Trust
- Lady Margaret Wall and The April Trust
- Garfield Weston Foundation

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

The Dodkin family

When Ben and Sarah Dodkin's young son Finley was diagnosed with a juvenile dystrophy, the whole family rallied around to fundraise for us.

Sarah arranged a race night, raffles and an auction night, while her aunt Kate Singletary organised a bike ride. Chris and Jo Parker, Sarah's parents, completed the Peddars Way 50-mile walk and Ben took part in the Great North Run.

Sarah says: "The Helpline was really helpful and sent us lots of information after Finley's diagnosis."

And Ben adds: "We think the Macular Society does an incredible job and are proud to support you."

The family's amazing efforts raised almost £10,000 – a huge thank you to everyone involved!

John Digby Sutton

Two brothers who inherited from their uncle generously gave part of their gift to help people with macular disease. Their uncle, John Digby Sutton, did not have age-related macular degeneration (AMD), but their father David did. Because the Society had been "of significant assistance" to David, his sons Richard and Jon were keen to offer their support.

Sub-Lieutenant John Sutton (pictured) had a distinguished naval career, being twice awarded marks of gallantry. His brother-in-law David was a valued Skills for Seeing trainer who helped many people make better use of their peripheral vision.

Financial review

The financial statements show a deficit for the year of £80k (2016: deficit of £234k).

Total funds at the year-end were £3,023k (2016:£3,103k).

We started the year in a strong position and we set a deficit budget once again for 2017. Our unrestricted reserves now stand at a level at which we can embark upon our New Ambition plans.

Macular Society Summarised Accounts

	2017 £000	2016 £000
Income		
Subscriptions	290	291
Legacies	1,520	1,469
Donations & unrestricted grants	1,225	941
Grants for specified charitable activities	531	533
Fundraising events	517	432
Trading and other income	78	69
Total income	**4,161**	**3,735**
Expenditure		
Charitable activities:		
Side View & Digest	210	180
Educational information	471	821

– year ended 31 December 2017

	2017 £000	2016 £000
Helpline and counselling	293	241
Groups and volunteer coordination	1,039	936
Local Group activities	175	172
Low vision	160	132
Research	913	786
Other expenditure	133	129
Total charitable expenditure	3,394	3,397
Costs of generating funds	864	699
Net investment (gains)/losses	(17)	(127)
Total expenditure	**4,241**	**3,969**

	2017 £000	2016 £000
Net income		
- Unrestricted	75	(354)
- Restricted	(155)	120
	(80)	(234)
Funds and net assets at 31 December		
- Unrestricted	2,166	1,991
- Restricted	857	1,112
Total funds carried forward	**3,023**	**3,103**

Patrons, officers and trustees

Patrons

Henry Blofeld OBE*

Gemma Craven*

Gwyneth Dickinson MBE*

Denis Norden CBE*

Peter Sallis OBE*
(died 2 June 2017)

Trustees

John Dunston MA, ACIL, FRSA - Chairman

Alan Walter* – Vice Chairman

Margaret Packham BSc(Hons), MCIPD – Vice Chairman

Tom Wilson FCA – Honorary Treasurer (retired 21 June 2017)

Richard Piller FCA, CTA – Honorary Treasurer
(appointed 21 June 2017)

Moira Black CBE, MA, FCA
(retired 13 April 2017)

Toby Evans BA(Hons), ACA*

Timothy ffytche LVO, FRCS, FRCOphth

Alison Guthrie MCOptom

Lucy Howe FRCOphth

Martyn Long CBE *

Alan MacFarlane *

Paul Ryb BA(Hons) *

Anna Fletcher LLB
(appointed 15 September 2017)

Frances Luff BA (Hons)
(appointed 15 September 2017)

Keith Arscott
(appointed 15 September 2017)
(resigned 25 January 2018)

Stephen Stacey MA, DPhil
(appointed 15 September 2017)

Cecilia Bufton BSc (Hons)
(appointed 15 September 2017)

Chief Executive and Company Secretary

Cathy Yelf

The symbol * indicates visual impairment.

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

Macular Society
PO Box 1870, Andover SP10 9AD

01264 350 551
www.macularsociety.org
info@macularsociety.org