



**Macular Society**  
Beating Macular Disease

**One step closer**

Impact and Accountability  
Report 2022

# What is this report about?

This year we are filled with hope as, thanks to you, we are moving one step closer to **Beating Macular Disease**. It's time to reflect on a busy year for us all and to say a huge thank you for making it all happen.

The disruption of the pandemic seems to be easing and, thanks to the lessons learned, we have adapted our services so you can access them from home more easily. Being able to reach people both virtually and face-to-face is vital, as we continue to provide essential advice and support in as many ways as we can.

In this report you will find out how you've helped us reach more people than ever before,

and how you're bringing hope for the future for the millions affected by macular disease.

You'll hear from your fellow members Kenneth, Jessica and Sabina; all have been supported through their macular journey, and now feel more confident and independent so they can live their lives to the fullest.

Members like you are at the heart of the Macular Society and we hope you feel a great sense of pride in reading the stories of those you are helping.

**Together, we will Beat Macular Disease. Thank you.**



**Kenneth**



**Jessica**



**Sabina**

# “Your support is vital.”

**James Whiteford** (right) is a director of graduate studies at Queen Mary University of London. He leads a team of researchers which undertook a Macular Society grant-funded project investigating alternative treatments for wet age-related macular degeneration (AMD).

In 2022, his team investigated a group of proteins called syndecans, which are believed to be involved in cell movement and growth. They discovered the specific part

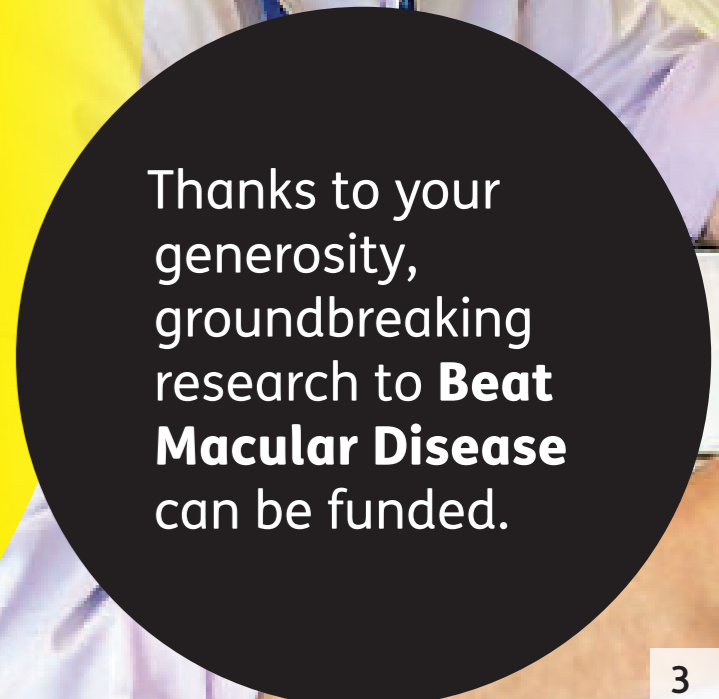
of the protein responsible for inhibiting new blood vessel formation, to create a therapy that works differently to current wet AMD treatments. This could be great news for people who don't respond well to anti-VEGF injections and it's likely to be able to be produced more cheaply and easily too.

The team's next step is working with a pharmaceutical company to continue this research and start clinical trials.


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**“We were incredibly grateful to receive funding from the Macular Society to further develop our novel therapies for inhibiting new blood vessel formation associated with macular disease.**

“This vital support enabled us to discover and refine our peptide-based therapies, which we hope will provide an alternative to anti-VEGF therapy.” **James Whiteford, Queen Mary University of London**



Thanks to your generosity, groundbreaking research to **Beat Macular Disease** can be funded.



**“Macular Society  
Counselling helped  
bring my confidence  
back.”**

**Kenneth**

**Macular Society  
Member**

I was first diagnosed with macular degeneration around seven years ago and I convinced myself that I wouldn't lose my sight.

However, last year, I started experiencing blurring and distortion and I was registered as partially sighted. The shock was bad and it took me a while to realise what was going on.

My first Macular Society Group meeting went well but by the time I attended again I had started 'seeing things' and felt scared. I didn't understand about Charles Bonnet hallucinations back then and at my second meeting I just broke down. I couldn't stop crying.

My group leader put me in touch with Macular Society Counselling, which really calmed me down. Within two sessions I started to think more about what was happening to me. I had vision that still allowed me to do some things; and the counsellor explained that I wasn't the only one going through this.

Without a doubt, counselling helped bring my confidence back. Before it was like trying to run a steam train without any coal. My counsellor was

fantastic. She understood where I was and what was wrong with me.

When you go through a life-changing situation like this, it is invaluable.

**I'm just thankful for all the support I've received from the Macular Society, especially in understanding my Charles Bonnet syndrome. I'm determined to help others like me and make a difference.**

**Thanks to your generosity, 602 people were helped with counselling in 2022. This is 52 more people than 2021.**

We have now expanded our counselling service to include groups on particular topics, including employment, being newly diagnosed and Charles Bonnet syndrome (visual hallucinations).

When I was told I had a macular hole in each eye I was in shock and I didn't have anyone to talk to. It was quite a lonely place to be, particularly when you're a younger person.

I feared I was never going to watch my nine-year-old daughter grow up and I wouldn't be able to see my future grandchildren. I thought I was a burden; a burden at work and a burden at home.

My GP said they could refer me for counselling, but there was a six-month waiting list.

In the meantime I'd been in touch with the Macular Society and the referral for the counselling service came through within weeks.

I worried about my job and I was advised by the Macular Society to

request an appointment via Access to Work. This helped me and my employer recognise my limitations and the adjustments that were required. I want to continue to work as I have done my job for 16 years and I love it. I need to maintain my independence as the macular holes have already caused so much disruption in my life.

I can never thank the Macular Society and Suzanne (my counsellor) enough for the amazing support – both practical and emotional. If I hadn't had counselling I would probably still feel like a burden.

**It was as if someone was holding my hand and guiding me as I moved forward.**

**“The Macular Society guided me as I moved forward with my life.”**

**Jessica**

**Macular Society Member**

**Our annual quality of life survey revealed that over 95% of people think that the Macular Society provides information that people can rely on.** In addition, almost 90% of respondents feel that their connection to the Society has made their life better.

**The Working Age and Young People's Service supports people who have other types of macular disease, rather than age-related macular degeneration (AMD).** It offers advice on employment, Access to Work, welfare benefits, entitlements and technology as well as peer support, mentoring and counselling. This year we have continued to develop condition-specific online groups too to provide information, support and an opportunity for people to discuss shared experiences.



**“The support the Macular Society has given me has been life-changing.”**

**Sabina**

**Macular Society Member**

After my macular degeneration diagnosis, I felt disillusioned, uninformed and fearful of the future.

However, when I called the Macular Society Advice and Information Service, I spoke with a lovely member of staff who really listened to me. Soon after I received a helpful information pack, which answered lots of my questions and included information about the upcoming Macular Disease Conference.

At the conference I felt so much more informed about my condition and meeting others in the same position gave me a sense of hope.

I think it's important for people with macular conditions to be aware and kept up to date with the latest scientific findings. Research is key in learning about the different variations and, ultimately, in finding a cure for macular disease.

I went on to join my local support group and started volunteering to help out. Through volunteering, I finally felt at ease with my condition. I met many amazing people, gained transferable skills and had a lot of fun!

It also gave me huge confidence to look for employment. The only downside to now being in full-time employment is that I am unable to regularly volunteer for the Macular Society!

The support that the Macular Society has given me has been-life changing in the way I have managed my life post diagnosis. I feel far more self-confident and independent now.

**In 2022, our Advice and Information Service received nearly 18,000 calls and emails on topics covering everything from treatment advice and macular condition queries to low vision aids.**

The annual Macular Disease Conference is a great place to learn more. 'My Macular and Me' session is aimed at people who are newly diagnosed, as well as friends, family and carers. There are also talks about macular dystrophies, age-related macular degeneration (AMD), the latest research and inspiring stories from people with macular conditions.

# Thank you

Looking back on 2022, it was another challenging year for many of us. We were confronted with the death of our longest-serving monarch, political uncertainty and a cost of living crisis which continues to touch all our lives.

Faced with these obstacles, I could not be prouder of the response shown by each and every one of our fantastic members, supporters and volunteers.


Thanks to your generosity, kindness and commitment to our common goal, you are bringing us one step closer to Beating Macular Disease. Because of you, the Society has been able to reach more people than ever and fund more groundbreaking research to find a cure.

Over the next few pages, I will explain everything we planned to achieve in 2022 and how we have risen to each of these challenges. I hope you will join me in celebrating our shared successes and, where we

have not yet achieved our ambitions, understand that our commitment to them remains as strong as ever.

I want to take this opportunity to thank you from the bottom of my heart for everything that you have done to help us to achieve our goals.

We simply can't do this without wonderful members, donors, volunteers, partners and supporters like you by our side.



**Cathy Yelf**  
Macular Society  
chief executive



# How we did it together

**2,057** telephone counselling sessions delivered



**261** people helped through befriending



**330** support groups continued to meet (with 293 meeting face-to-face)



**3** new 'seedcorn' early stage research projects approved



**30** live research projects underway



**32,840** views of our online webinars



**4,000+** people registered to our research participant database



**55,000** people used our Macular Disease Risk Checker from September to November



**1,070** hour-long support group calls with 5,724 attendees



**836** working age and young people supported each other in our Facebook group



**18,000** calls and emails to our Advice and Information Service



# Finding a cure

You are bringing us one step closer to Beating Macular Disease for all. Thanks to your support, we are funding groundbreaking research projects; gaining invaluable insights and understandings into macular disease and its treatments. Knowledge is power, and with your help, we will find a cure and bring hope to the millions of people affected by these terrible conditions.

**Our 30 current research projects on macular disease, kindly funded by you, have a combined value of £3,808,445.**

**In 2022, 11 scientific papers were published in high-quality, peer-reviewed journals from projects we funded.** These help increase worldwide awareness and accelerate progress towards a cure.

## In 2022, we said we would:

### **1 Invest £1.5m into new research on macular diseases.**

**Ongoing** We received 41 applications for our 2022 funding programme, of which 26.8% were 'fundable'. Thanks to our members and supporters, six grants, three seedcorn grants and two PhD studentships were awarded to the value of £1,209,656. We now have 30 research projects underway with a combined value of £3,808,445 and are funding 'gap analysis' research to identify new opportunities where investment could make significant steps towards Beating Macular Disease.

### **2 Hold an international seminar on the potential of gene therapies in the treatment of macular disease.**

**Success** We held an international

gene therapy conference at the University of Oxford in September 2022, bringing together several leading researchers from the UK, Europe and the USA.

The two-day meeting was chaired by Professor Andrew Lotery and Dr Jörn Lakowski and provided an opportunity for researchers to share their experience of using gene editing, exchange ideas and build collaborations to better understand and treat macular disease.

### **3 Sponsor a workshop to develop a 'virtual eye' using mathematical modelling techniques.**

**Success** In June 2022 a group of mathematicians and ophthalmologists came together to plan the development of a

'virtual eye'. The event, chaired by Dr Peter Stewart, devised a plan for a prototype and discussed potential clinical uses.

### **4 Appoint a director of research to lead the Society's ambitions to fund more research and diversify the projects we fund.**



**Success** Our first director of research, Dr Peter Bloomfield was appointed in late 2022 and took up the post in early 2023. Peter will lead the development and diversification of our research portfolio to reach into new areas where we can help accelerate progress towards new treatments and cures for macular disease.

# The best advice and support

Nobody should have to face macular disease alone, and thanks to your support, we can be there every step of the way. From initial questions and conversations to ongoing advice and guidance, our dedicated team of staff and volunteers are here to help.

**In 2022, we said we would:**

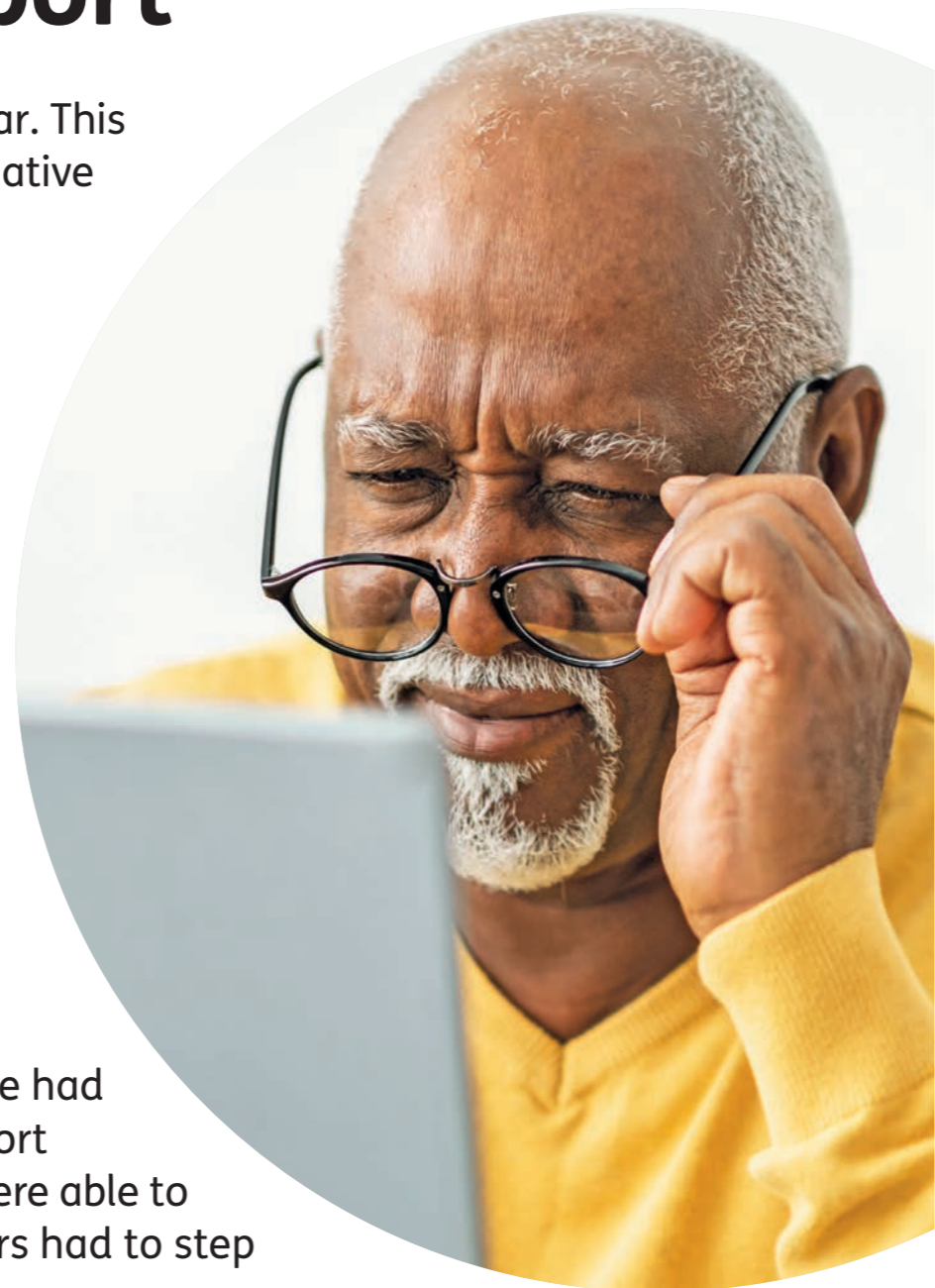
**1 Continue to develop information, support and educational resources through a wider variety of channels, expanding our reach and reflecting the diverse needs of people affected by macular conditions.**

**Success** The pandemic accelerated our work to develop new virtual communities and these new ways of connecting

people have proved popular. This includes developing alternative ways to deliver low-vision support through Skills for Seeing and Connect by Tech services, using a combination of telephone support, webinars and our Eccentric Viewing online programme.

**2 Support and manage the transition back to face-to-face support where appropriate and deliver new ways of working to ensure our services are sustainable.**

**Success** Pre-pandemic, we had more than 400 peer-support groups, but sadly not all were able to return and some volunteers had to step down in this period.



By the second half of 2022 the majority of our 330 groups had returned to regular face-to-face meetings, 102 maintained tele-conference sessions and some ran both formats. We know how valued our peer-support services are and are rebuilding our network.



**3 Continue to develop and support digital services and interactions in order to expand our reach and meet the needs of a wider community of people affected by macular conditions.**

**Success** We held monthly My Macular and Me webinar sessions,

attracting 1,840 people to the live events and more than 31,000 views of the online recordings. Our annual conference was again held online in order to reach more people. In total, 2,553 people registered and 8,395 had watched the recordings by the end of January 2023.

We have also continued to develop condition-specific online groups and our Facebook group for working age and young adults has over 800 members.

**4 Facilitate the voice of people affected by macular conditions in order to raise awareness and ensure that this is at the heart of any decisions or developments.**

**Success** We conducted research with members, patients, caregivers and volunteers in 2022 and have used these findings to help inform decision makers in trial steering committees and nationally as part

of 'The Eyes Have It' campaign and Westminster Eye Health Day.

**5 Continue to work effectively with eye care professionals.**

**Success** We are members of the National Ophthalmology Alliance and the Clinical Council for Eye Care Commissioning and sit on the National Ophthalmology Database AMD Audit Advisory Group and the Ophthalmology Specialty Group of the National Institute for Health Research. Patient research shows we need to improve communication with professionals and we will be putting more resource into building relationships in 2023.

As part of charity collaboration Action Against AMD (AAAMD) we are working with professionals to support and drive public engagement in the Foresight project, launching in 2023.



# Vision matters

Macular disease continues to affect millions of lives and, until there is a cure, we will fight for greater awareness and better care from those in charge of health policies. Thank you for helping us to spread the word, improving the nation's understanding of macular conditions and the need to Beat Macular Disease.

## In 2022, we said we would:

### 1 Continue to prioritise messaging about urgent care to minimise avoidable sight loss caused by the pandemic.

**Success** We continued to prioritise this messaging in national and regional press, as part of 'The Eyes Have It' partnership, including coverage on BBC Radio Four and in the Daily Express. We have purposely increased our promotion

of membership through offline channels, such as print, to reach people who may not be online.

### 2 Continue to campaign for eye health to be a higher priority and for improvements in existing health and social care for people with eye disease as well as a greater investment in eye research.

**Success** As part of 'The Eyes Have It' campaign, we successfully lobbied for the appointment of a National Clinical Director for Eye Health in England and are working towards a 'National Eye Strategy' for England.



The Society is now a member of the 'VI Sector Collaboration' of eight eye charities working together to improve the lives of blind and partially sighted people, and those at risk of sight loss across the UK.

### 3 Continue to invest in promoting our services, especially the Advice and Information Service.

**Success** To help people understand their risk and drive them to receive accurate information, we promoted our Macular Risk Checker online. In three months, 55,000 people signed up to find out more. Direct advertising in eye clinics and pharmacies also promoted our services to new audiences.

### 4 Undertake a patient insight exercise to ensure we are providing what particularly hard to reach patients need in terms of support.

**Success** Our research found that, while the majority of eye care professionals report that they 'always' or 'often' signpost patients to support services, only a small proportion recalled receiving this information. People with a low awareness of such services report lower emotional wellbeing and more needs to be done to provide emotional and practical support to caregivers. Patients told us of their emotional and practical challenges and explained the support they would like.

### 5 Continue to develop our digital presence to increase our reach, including the use of additional social media platforms.

**Success** Our social media platforms were used effectively to increase awareness and drive engagement, reaching over 2.75

million people on Facebook, and 393,000 views on Twitter.

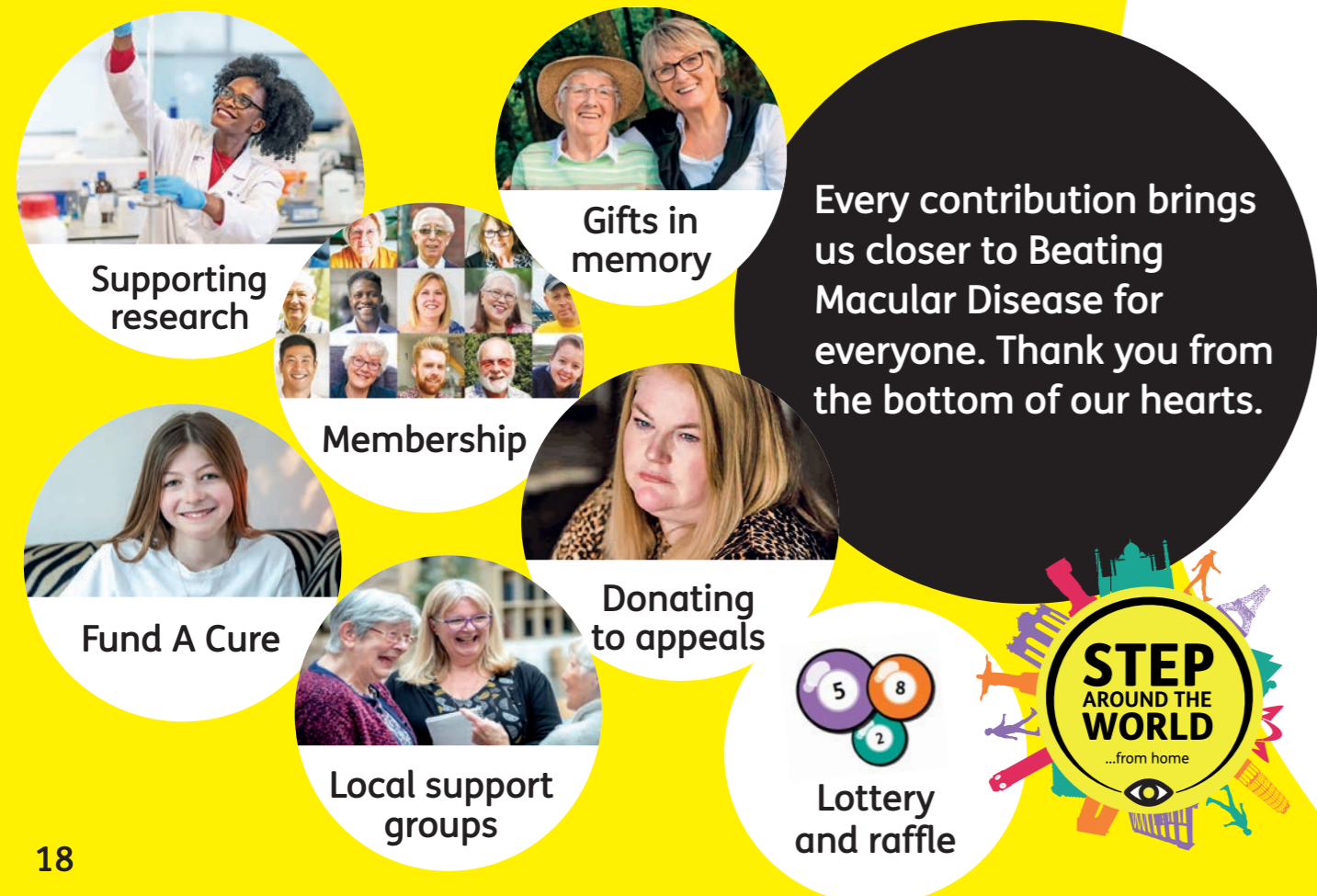
### 6 Use all our communications channels to promote eye health; encouraging healthy lifestyles and the benefits of regular eye health examinations.

**Success** To build awareness of macular disease and promote eye tests, we collaborated with Bayer on their 'Don't Lose Focus' TV advert campaign. Fronted by Twiggy, the ITV3 advert reached 2,163,000 people, with 237,958 views on YouTube and 559,244 people reached on Facebook. The campaign continues in 2023.



# How you made it happen

Every calendar bought from our shop, raffle ticket purchased or membership subscription brings us one step closer to Beating Macular Disease. Whether it's a donation to a local appeal, sponsoring someone to take part in an inspiring challenge or leaving a gift in your Will, your generosity is invaluable. We really appreciate your support; thank you.



## This is how you did it:

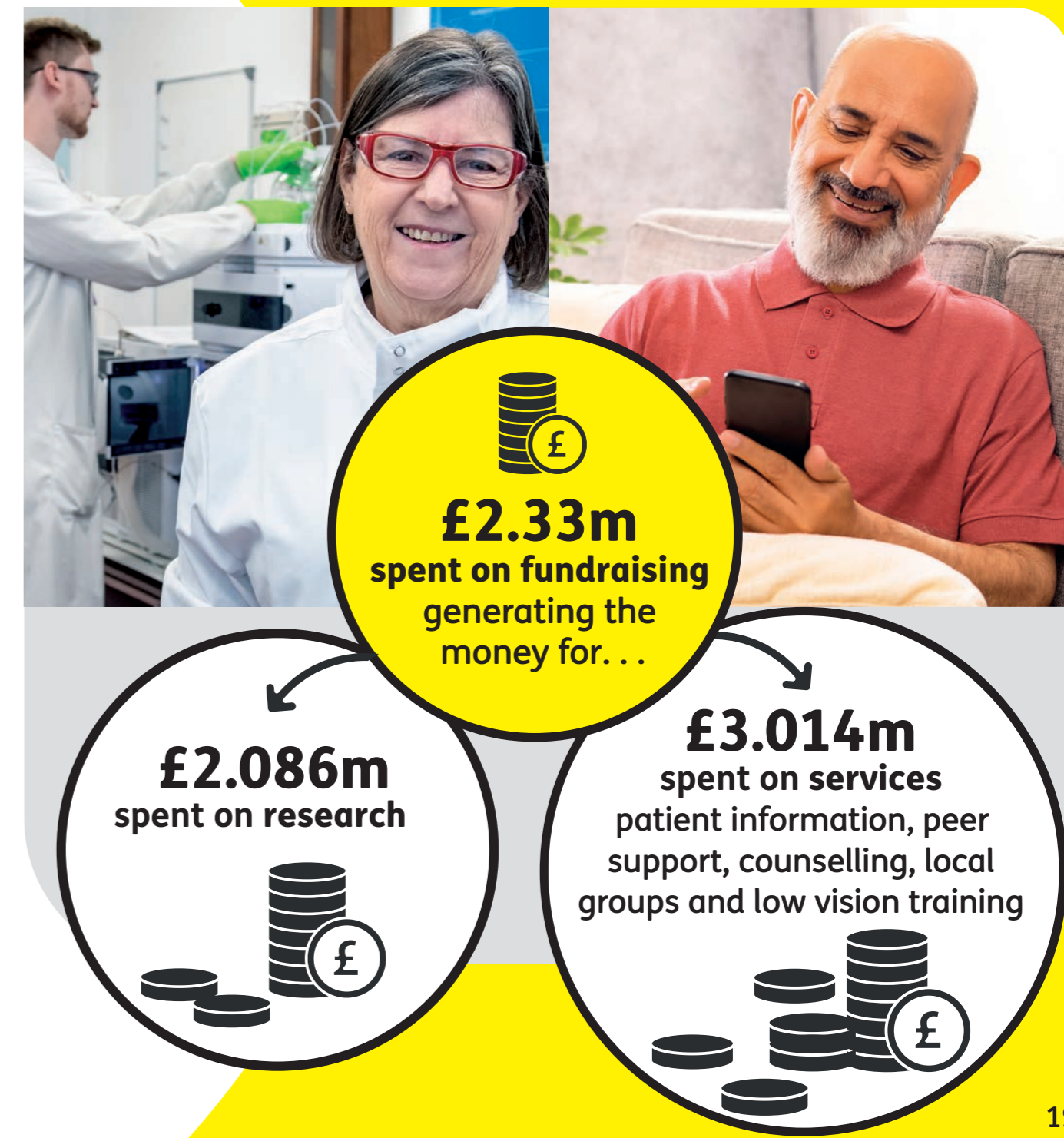
- **£4,657,000** – gifts kindly left in Wills
- **£1,674,000** – donations directly from our wonderful members and supporters, monthly donors, raffle and lottery players, small trusts and other organisations
- **£1,232,000** – grants from larger trusts, corporates and foundations
- **£796,000** – raffle and lottery players, and fundraised by thoughtful supporters like you
- **£291,000** – vital annual membership subscriptions
- **£111,000** – investment interest, emergency grants and other sources
- **£79,000** – items you generously bought from our shop
- **£91,000** – raised by our network of inspirational local support groups

# How we spent it

Every pound we receive funds our ambitious goal of Beating Macular Disease. Our fundraising activities make it all happen, allowing more money to be spent on research and vital services.

In 2022, for every **£1** we spent on fundraising, we brought in another **£4** in important funding.

The more funding we can generate the sooner we can develop life-changing treatments to save the sight of everyone affected by macular disease. This year, we have already seen new treatments and breakthroughs, bringing us one step closer to a cure.



# Patrons, officers and trustees (as of 31 December 2022)

Special thanks go to our patrons, for helping to spread awareness of macular disease in 2022, and to our trustees for ensuring we are working effectively towards our goal of Beating Macular Disease.

## Patrons

Henry Blofeld OBE \*  
Gemma Craven \*  
Gwyn Dickinson MBE \*  
Patricia Greene MBE \*  
Vince Hill\*  
Maggie Norden  
Zac Shaw \*

## President

Timothy ffytche LVO,  
FRCS, FRCOphth

## Trustees

Cecilia Bufton BSc (Hons)  
MBA – Chair  
Paul Ryb BA(Hons) \* – Vice Chair  
Alison Guthrie MCOptom –  
Vice Chair

Richard Piller FCA, CTA –  
Honorary Treasurer

William Best BSc (Hons) \*  
Anna Fletcher LLB \*

Jayne George  
(appointed 10 May 2022)

Sheena George FRCOphth  
Charles Griffith ACII, CFA  
(resigned 8 February 2022)

Robin Hamilton FRCOphth

Frances Luff BA (Hons)

Patrick McGeough Eng MIIE (Mech),  
RAF Rtd\*

James Potter LLM\*

Amanda Rowland LLB\*

Sobha Sivaprasad FRCOphth

Stephen Stacey MA, DPhil

Chris Strutt (resigned 11 February 2022)

## Executive team

Cathy Yelf – Chief Executive  
and Company Secretary

Emma Malcolm – Director of  
Fundraising and Marketing

Stephen Scowcroft – Director  
of Services

Karen Noble – Head of Finance

Rebecca Ward – HR Manager

John McKay – Head of IT  
and Data Insight

# We can't do it alone

Every one of our supporters makes a real difference to the lives of everyone affected by macular disease. Whether through your membership subscription, dedicated volunteering, donations, grant awards or important partnerships, you are ensuring we can reach more people who need us. We are especially grateful to the following for their commitment to Beating Macular Disease in 2022.

- AbbVie
- The Albert Gubay Charitable Foundation
- Apellis
- Association for Information Technology Trust
- Astellas
- The Barbour Foundation
- Bayer
- Blindcraft Charitable Trust
- The Harebell Centenary Fund
- The Evan Cornish Foundation
- Mrs Patricia Gilby
- The Linbury Trust
- The Mabs Mardulyn Foundation
- The National Lottery Community Fund
- Novartis
- OcuPlan

- OKKO Health
- Ora Clinical
- Oxsight
- The R S Macdonald Charitable Trust
- Red Dog Ads
- Roche
- Serious Readers
- Sharegift
- Siloton
- The Steel Charitable Trust
- The Syncona Foundation
- Vision Express

In 2022 we lost some of our most dedicated supporters, but the generous gifts they left in their Wills mean that they can help us keep fighting macular disease for many years to come.

We are enormously grateful to everyone who remembers the Society in their Will, but our particular thanks in 2022 go to:

- Kathleen Borland
- Janet Maud Briggs
- Norma Cartwright
- Sybil Hewitt
- Harold Thomas Lloyd
- Richard Charles Meyrick
- Norman Ernest Mumford
- Margaret Jean Murray
- Wilfred Robishaw
- Muriel Agnes Shaw
- Joy Wingfield

The symbol \* indicates visual impairment.

# Macular Society Summarised Accounts –

year ended 31 December 2022

The financial statements show a surplus for the year of £1,278k (2021: £1,703k). Total funds at the year-end were £6,806k (2021: £5,528k).

The Trustees have reviewed the major risks the Society faces and believe there are sufficient resources to cope with any foreseeable adverse conditions.

These risks include loss of income, cash deposits or data and hurt to vulnerable adults. Policies are in place to mitigate these risks.

The Trustees have approved the development of an ambitious new research strategy. Significant reserves are being held to implement that strategy from 2024.

	2022 £000	2021 £000		2022 £000	2021 £000		2022 £000	2021 £000
<b>Income</b>								
Subscriptions	291	283	Advice and Information Service and Counselling	432	390	<b>Net income</b>		
Legacies	4,657	4,299	Groups and volunteer co-ordination	1,403	1,106	- Unrestricted	544	812
Donations and unrestricted grants	1,674	1,464	Local Group activities	127	63	- Restricted	734	891
Grants for specified charitable activities	1,296	723	Low vision services	423	347		<b>1,278</b>	<b>1,703</b>
Fundraising events	796	701	Research	2,086	1,779	<b>Funds and net assets at 31 December</b>		
Trading and other income	170	123	Conferences and prof. support	70	39	- Unrestricted	3,302	2,758
Investment and other income	47	34	<b>Total charitable expenditure</b>	<b>5,100</b>	<b>4,174</b>	- Designated	1,000	1,000
<b>Total income</b>	<b>8,931</b>	<b>7,627</b>	Costs of generating funds	2,330	1,885	- Restricted	2,504	1,770
<b>Expenditure</b>			Net investment (gains)/losses	223	(135)	<b>Total funds carried forward</b>	<b>6,806</b>	<b>5,528</b>
Charitable activities:			<b>Total expenditure</b>	<b>7,653</b>	<b>5,924</b>			
Publications	125	95						
Educational information	434	355						

# Macular Society

Beating Macular Disease

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 @MacularSociety

 /macularsociety

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