Macular Society
Beating Macular Disease

A year like no other

Impact and Accountability Report 2021

What is this report about?

This year, we find ourselves a step closer to 'normal' and are seeing many 'green shoots' of opportunity, growing as a direct result of what we have all been through. So, it's time again for us to say a heartfelt 'thank you'.

Last summer, we sent all Macular Society members a report to tell them just how much they had made possible in 2020.

At that time, we were still in the midst of the pandemic, but our members and supporters were keeping us strong and there was a plan for our journey into the post-coronavirus world.

One year on, and we have much to be hopeful about and thankful for.

Thanks to members and supporters like you, thousands of people with macular disease have continued to receive a consistent level of contact and support that is so vital in uncertain times.

And by enabling us to deliver hybrid services, providing a mix of virtual and face-to-face programmes, you've helped us reach people who couldn't be reached before.

Margaret, Lisa and Scott are just three of the thousands of people you helped this year. I hope their stories make you proud to be a Macular Society member, donor or member of staff, and even more certain that together we will Beat Macular Disease. **Thank you.**

Margaret

Lisa

Scott

"We're all working together"

Only with your support can we fund the ground-breaking research that is needed to progress in the fight to Beat Macular Disease. Every new piece of knowledge gained and shared helps in understanding the causes of macular disease, enabling new treatments, and making it easier for people who live with it today.

Amanda Carr (right) is a Lecturer at the UCL Institute of Ophthalmology, London. She leads a team of researchers undertaking Macular Society grant-funded projects focusing on understanding macular disease.

In 2021 her team were working with stem cells to investigate the BEST1 gene and its influence on macular disease. Not only did the project reveal vital information, but all the cell lines created have been made available to researchers around the world. How wonderful that this new resource can now help other scientists progress in their work on macular disease.

"We would like to take this opportunity to thank the Macular Society and their supporters for generously funding our vital research into inherited macular disease, which has enabled us to increase our understanding of the impact of BEST1 mutations in the eye.

"This vital information will help us to develop new approaches for treating inherited macular disease." **Amanda Carr**

Dr Amanda Carr
UCL Institute of Opthalmology

“Macular Society research gives me hope of maintaining my vision”

Margaret

Macular Society member

Most people don’t know about, or don’t understand, macular disease and the impact it has on those of us who have it. A lot of people just see this as, ‘well you’re old, your eyesight is failing, you’re going a bit deaf, your joints ache... What do you expect?’.

As you get older, you have more things wrong with you, and you just can’t contemplate what’s going to be ahead.

Apart from when you’re asleep, you’re always using your eyes, so you’re constantly reminded that, ‘I have macular disease’. Macular disease is always with me and I think about what I will lose as my eyesight continues to worsen.

But the year before I was told about my age-related macular degeneration, I was diagnosed with breast cancer. I had an operation and radiotherapy, and I’ve been clear for five years. It showed me just how miraculous medical research can be.

The scientific brains are out there finding out about things and making improvements, but they can’t do it if the money isn’t there.

Thanks to the work of scientists, there is a prospect that the injections will slow down the progression of my disease and maintain my vision for longer.

I am so grateful to all who have dedicated themselves to improving our lives and for working tirelessly to find a cure for everyone with macular disease.

Every member and supporter can be proud that they are funding the research bringing us closer to a cure. Thank you!

We now have over 4,000 registrants to our research participant database. We connect these volunteers with research teams who need to recruit patients as trial participants, trial steering committee members or in other patient advisory roles.

It was just over two years ago that I was diagnosed with Diabetic Macular Oedema. I'm a type one diabetic, and have been for over 23 years, but my macular condition came about during pregnancy.

They're not allowed to do injections while you're pregnant, so I had laser treatment to try and stop the bleeding behind my eye.

The last few years have been a massive rollercoaster, and I think the reason I approached the Macular Society was because I realised that this was probably going to be with me for the rest of my life.

Losing my sight has been the biggest thing. It impacts my work, it impacts my driving, it impacts everything I do – the way I feel, how I am around other people… It's massive.

The counselling has helped my anxieties. I do try and think about the things it has taught me. And I try not to think about what might happen with my sight.

I'd already spoken to counsellors through my doctor, but it just wasn't the same.

The Macular Society counsellor knew about my condition and what I was going through, and it just instantly made me feel better, knowing that. She gave me tools to deal with it.

"Macular Society counsellors gave me the tools I needed"

Lisa

Mother with Diabetic Macular Oedema

In 2021, 550 people were referred for counselling, up 10% on 2020. And June was our busiest month ever, with 63 referrals. Thank you to all those who have trusted in our counselling service.

We now have nine counsellors ready on call – up from seven in 2020. Thank you to all those who have had the courage to share with us how they feel.

“Macular Society information helped me understand”

Scott

Macular Society member

I was always quite proud of my 20/20 vision and the fact I could see a long way, but when I turned 40, I became aware that my sight was changing.

I am a nurse and had moved from hospital-based working, where you’re on your feet all day, to working from home during COVID. I was getting a lot of screen time, which made me realise that my eyes were really struggling. I was bothered a lot by the light and glare, and my eyes started feeling tired.

I went to the optician who told me I had signs of macular degeneration, despite being quite young. I came away not really knowing a lot about it.

Being the type of nurse that I am, I wanted to find out more. I am quite a positive person and I try not to go down the negative pathways. I went on to Google and just searched ‘macular degeneration’, and the Macular Society came up.

I just started on the website, having a read, and before I finished that session I’d signed up to be a member. I got my pack in the post that had some great information, even for me as a healthcare professional. It explained things in a way that was easy to understand and gave me a sense of the support that was out there. The research the charity helps the clinicians deliver is also brilliant.

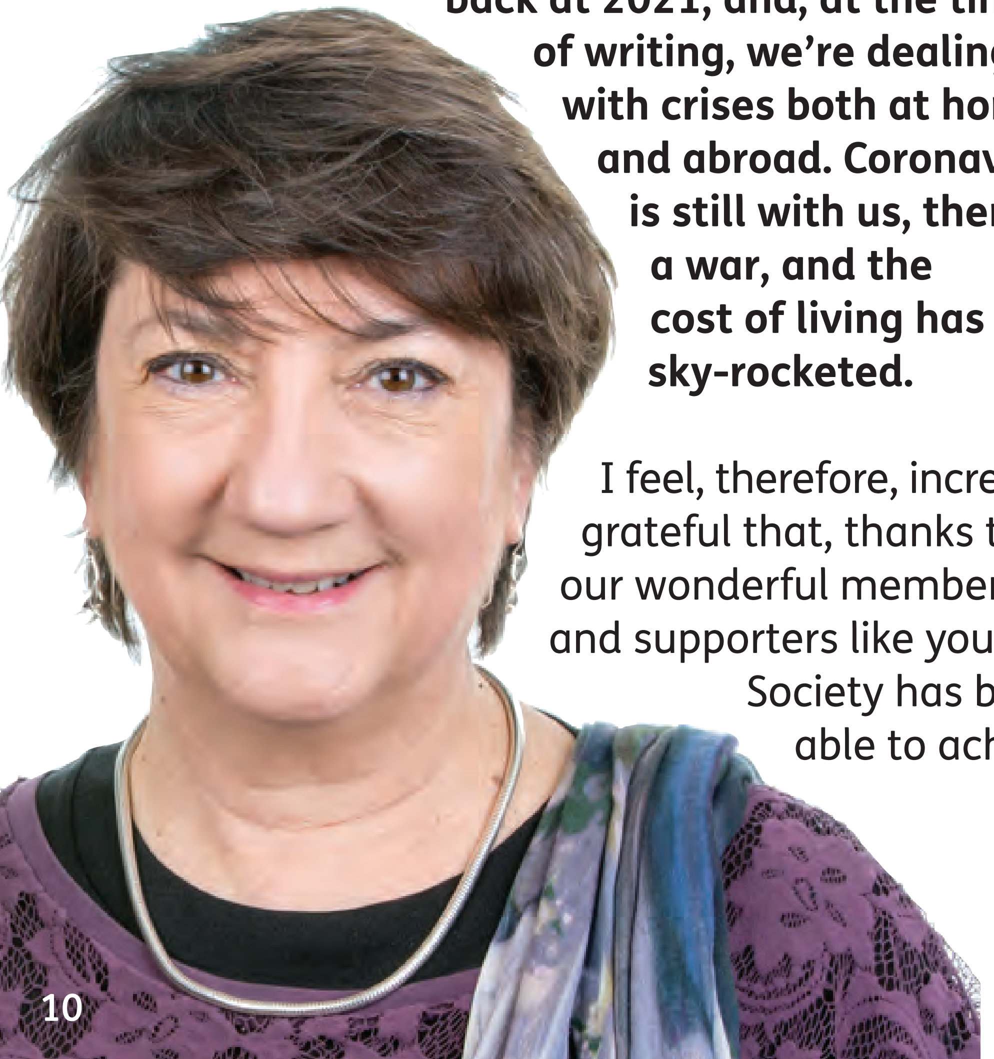
Being plugged into the kind of information the Society provides is great. It’s reassuring, knowing that you’ve got access to that kind of expertise and knowledge should you require it.

Thanks to your generosity, 138 people were helped with employment and benefit-related advice in 2021.

We take pride in developing clear information, so that people can feel better supported on issues relating to macular disease. But it doesn’t stop with our own communications. We have called for urgent steps to be taken to improve the up-take of the NHS’s Accessible Information Standard (AIS) among health and social care providers to provide patient resources in formats which are more suitable.

Thank you

I don't think any of us could have known when we sent last year's report that 2021 would present almost as many challenges to our day-to-day lives as 2020 did. And now here we are, looking back at 2021, and, at the time of writing, we're dealing with crises both at home and abroad. Coronavirus is still with us, there's a war, and the cost of living has sky-rocketed.



I feel, therefore, incredibly grateful that, thanks to our wonderful members and supporters like you, the Society has been able to achieve so much in 2021. In spite of everything going on around us, your commitment and generosity has not wavered. It's really quite remarkable.

Over the next few pages, I'll set out everything we planned to do in 2021, and how successful we were in doing so. We are always ambitious, because we won't Beat Macular Disease without ambition – but please don't be disheartened where we haven't managed to meet all our targets. Instead let's celebrate everything we've achieved together.

We are so lucky to have your continued support; thank you so much. Our members and donors are integral to everything we do, now more than ever. Together we will Beat Macular Disease.

Cathy Yelf

Cathy Yelf
Macular Society chief executive

How we did it together

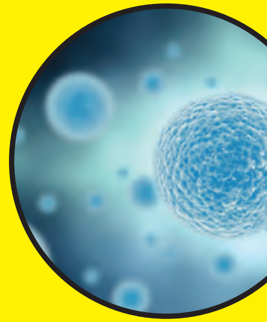
1,699 telephone counselling sessions delivered (plus 32 group calls)

311 people helped through befriending

410 groups continued to operate in the face of the pandemic

3 new 'seed corn' projects approved

26 live research projects underway



16,191 people watched our online webinars

4,000+ people registered to our research participant database

33,000 people used our Risk Checker within three months of launch

2,790 hour-long group calls, with 19,801 attendees

700 working age and young people support each other in our Facebook group

Finding a cure

One day, no-one will lose their sight to macular disease. Because of you, the hope for a cure becomes more real every day with each new research project funded. Every piece of knowledge gained teaches us more about the workings of these terrible conditions and helps us along the path to discovering new ways to slow, stop and reverse its effects. You are making every day look brighter and brighter.

Our 26 research projects currently underway have a combined value of £3,510,133.

In 2021, seven scientific papers were published from projects we funded.

In 2021, we said we would:

1 Invest £1.25m into new research on macular diseases.

Success We received 27 grant applications for our 2021 funding programme of which, 26% were 'fundable'. Thanks to our members and supporters, seven grants were awarded to the value of £1,229,272. We now have 26 research projects underway with a combined value of £3,510,133.

2 Introduce seed-corn funding: small grants for one-year projects designed to acquire data for the next stage of funding.

Success Our seed-corn grant programme launched in July 2021 and received 11 applications. Three projects were approved for funding in 2022 and granted £25,000 each.

3 Hold an international seminar on the potential and applicability of Artificial Intelligence in macular disease.

Success We held an international conference on Artificial Intelligence in Age-Related Macular Degeneration (AMD) at Harris Manchester College, University of Oxford. This 'hybrid' event (part in-person, part online) was chaired by Professor Alistair Denniston and Professor Pearse Keane.

4 Reach targets as part of the Action Against AMD (AAAMD) group:

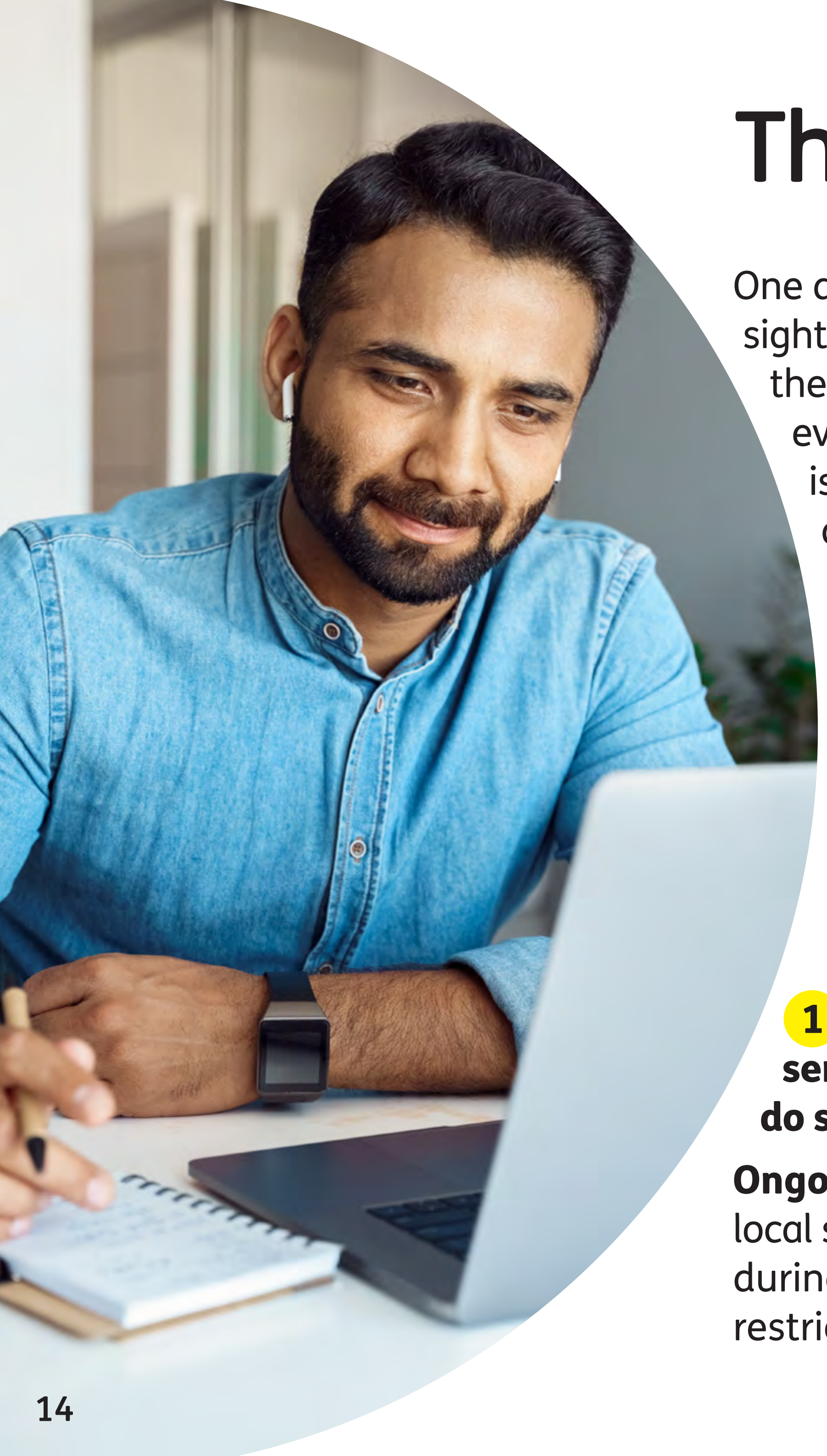
- Continuation of the INSIGHT and SCONe projects.
- Launch an investment pitch for the FORESIGHT initiative.
- Launch communications strategy.
- Create a US fundraising strategy, including contracting a Fundraising Intermediary in the US to enable us to fundraise legally there.
- Agree a contract with the Macular Society to fundraise for AAAMD's core costs.

Ongoing

Despite the challenges caused by COVID, AAAMD made strong progress in 2021.

The group has:

- continued their pharmaco-epidemiology collaboration with the University of Birmingham to identify drugs which might be protective against AMD.
- engaged in discussions with a US biotech company to secure access to a novel and potent antioxidant to be tested against AMD.
- secured an 'investment in principle' of £1m for the FORESIGHT initiative from two Scottish charities. These funds will help progress a project to acquire eye scans from high-street optometrists for identifying the first stages of AMD.
- worked with the UK government's Our Future Health (OFH) initiative to genotype five million Britons in the next three years.
- A legal fundraising operation has been set up in the US, and fundraising strategy work is underway.



The best advice and support

One day, no-one will lose their sight to macular disease. Until then, we will be by the side of every person affected by this isolating condition, to provide an understanding ear and the best guidance we can to make every day that bit more manageable. Thanks to your support, thousands of people are not facing this alone.

In 2021 we said we would:

1 Re-start face-to-face services when it is safe to do so.

Ongoing Only a handful of our local support groups met in person during 2021 once pandemic restrictions were relaxed. In the absence of face-to-face meetings, the growth of virtual 'communities' were accelerated and, at year-end, 410 groups were still operating in a viable way compared with 430 at the start of the pandemic.

2 Conduct a review of all our peer support services to address the needs of our volunteers and beneficiaries.

Success Our 2021 review revealed that it is more helpful now to regard our 'groups' as 'communities', so that we can embrace a more flexible and loosely-organised model. We need to be clear in the purpose and focus of these communities so they can achieve what they need to. We will put more focus on social aspects of these communities, with a priority of tackling isolation.

3 Explore alternative ways of delivering information to patients.

Success Video conferencing gained ground and included monthly 'Virtual Clinic' webinars on a range of topics with focus. The webinars, made available to watch online after the event, attracted a total of 16,191 views. And of course, our flagship conference was hosted online, bringing the experts live into our living rooms. Our new 'Macular and Me' session was a particular success.

4 Expand our Befriending programme, our Counselling Service and the use of our Advice and Information Service.

Varied success Our befriending service supported 311 people, a slight fall on 2020 resulting from a fall in volunteer numbers. This has led to a waiting list. Referrals to our telephone counselling service continued to rise with a total of 550 compared with 488 in 2020. And we welcomed new counsellors, growing our team from seven to nine.

Our Advice and Information service saw a fall in contacts. This could be due to the decreased opportunity for appointments and conversations between patients and clinicians during the pandemic and, frequently, a complete ban on the display of patient information leaflets.

5 Expand our work with working age and young people (WAYP).

Success Our WAYP service continues to build virtual communities around specific conditions or topics related to employment. In 2021, new groups were launched for diabetic macular oedema and myopic maculopathy. And 138 individuals were supported with specific employment-related advice.

The WAYP Facebook page increased to over 700 members and saw over 3,700 interactions, mixing questions to the Society with peer-to-peer support. Also online, our monthly WAYP webinar kept the community up to date with subjects affecting people of working age.

A suite of materials to support parents and teachers of children affected by macular conditions was refreshed and republished for the start of the autumn 2021 term.

Sight matters

One day, no-one will lose their sight to macular disease. Until there is a cure, we will keep shouting from the rooftops to get our voice heard by those who need help caring for their sight and those who are in charge of making health policies. Thank you for being here with us.

In 2021 we said we would:

1 Prioritise messaging about urgent eye care to minimise the amount of avoidable sight loss caused by the pandemic.

Success We significantly increased our focus on influencing public policy on eye health, working to influence NHS Restoration and Transformation as they reconfigure NHS services.

As part of this, we partnered with the pharmaceutical company Roche and the research charity Fight for Sight on a joint parliamentary campaign called The Eyes Have It. Together, we campaigned for a National Clinical Director for Eye Health in England, and in the autumn, the creation of this role was confirmed.

We continued to work with national bodies to improve eye care, including the Clinical Council for Eye Health Commissioning and the UK Ophthalmology Alliance.

2 Launch our online 'risk calculator'.

Success We don't yet know why some people develop macular disease and others don't – but there are things everyone can do to lower their risk of sight loss. In October 2021 we launched our Macular Risk Checker to help people rate their risk and receive information on driving it down. Almost 33,000 people checked their risk in the first three months and ten per cent are still receiving communications from us.

3 Appoint a new Director of Services to take a more strategic approach to our work with external organisations.

Success By maintaining our income in 2020/21 we unfroze this post and, in May 2021, we welcomed our new Director of Services, Stephen Scowcroft.

4 Budget for marketing campaigns to promote our services, especially the Advice and Information line as this is the 'gateway' to all our services.

Success We allocated budget for marketing campaigns to promote our services in 2021. This allowed us to implement a strategy to reach multiple audiences, on a variety of channels with different messages. We aimed to increase awareness and drive engagement for people living with macular disease, boosting website visits and calls to our Advice and Information line.

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

Success While we haven't used any new platforms, we have continued to increase our reach on social media channels such as Instagram, Facebook and Twitter. In 2021 we reached more than 3.4m people on Facebook alone, helping them to access essential support and information. We have increased our activity on Instagram, introducing takeovers of the platform to give those living with macular disease the chance to share their experiences more widely.

6 Use our fundraising activity, focussing on new audiences, to increase awareness of our services and our research.

Success Our fundraising activity created over 31 million opportunities for people to engage with us both on and offline. We received over 200,000 "engagements" from new audiences on Facebook in 2021– meaning that twice as many people liked, shared or commented on our content compared to 2020. This led to 10,000 people previously not known to us donating, calling or registering online.

7 Establish a Public Policy and Government Affairs Committee to support the Director of Services and appoint a senior Public Policy Campaigns officer.

Not yet We are still looking to appoint a senior Public Policy Campaigns officer and the Committee has become an advisory group. We have worked hard on activities to promote and champion eye health amongst Parliamentarians and policy makers through our The Eyes Have It partnership and Westminster Eye Health day in October 2021.

How you made it happen

A pack of Christmas cards or a diary bought from our shop. Donations from a local support group's bake sale. Sponsorship money from a Step Around the World (... from home) challenge. And, of course, your membership subscriptions and gifts in memory, raffle tickets and lottery chances... Every generous gesture of support is much appreciated and so precious.


Supporting research


Gifts in memory


Membership

Local group support

Lottery and raffle


Donating to appeals

Every pound brings us more hope of **Beating Macular Disease** for good. We thank you with all our hearts.

STEP AROUND THE WORLD ...from home

This is how you did it:

- **£4,299,000** – gifts kindly left in Wills
- **£1,464,000** – donations directly from our wonderful members and supporters, raffle and lottery players, small trusts and other organisations
- **£672,000** – grants from larger trusts, corporates and foundations
- **£701,000** – fundraised by thoughtful supporters like you
- **£283,000** – vital annual membership subscriptions
- **£84,000** – investment interest, emergency grants and other sources
- **£65,000** – items you generously bought from our shop
- **£58,000** – raised by our network of inspirational local support groups

How we spent it

Over the years, we have learnt that investing in fundraising is the best way for us to realise our ambitious plans to Beat Macular Disease. By spending more, we can make more happen.

In 2021 we did spend more and each £1 we spent on fundraising brought in another £4 in vital funding.

That means millions of pounds going directly towards supporting people whose sight is being stolen by macular disease; and more funding to enable the research that is bringing us better treatments and the hope of a cure.

£1.855m
spent on fundraising generating the money for. . .

£1.779m
spent on research

£2.61m
spent on services
patient information, peer support, counselling, local groups, and low vision training

Patrons, officers and trustees (as of 31 December 2021)

Our special thanks to our patrons, for using their profile to get more people talking about macular disease in 2021, and to our trustees, for making sure that everything we do gets us closer to 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 *
Sheena George FRCOphth
Charles Griffith ACII, CFA (appointed 11 May 2021, resigned 8 February 2022)
Robin Hamilton FRCOphth
Frances Luff BA (Hons)
Anthony MacQuarrie M Ed, B Phil, DASEC, Cert Ed * (resigned 11 May 2021)
Patrick McGeough Eng MIIE (Mech), RAF Rtd*
James Potter LLM*
Amanda Rowland LLB*
Sobha Sivaprasad FRCOphth
Stephen Stacey MA, DPhil
Elaine Latham (appointed 1 September 2020)
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 (from May 2021)
Karen Noble – Head of Finance
Rebecca Ward – HR Manager
John McKay – Head of IT and Data Insight

The symbol * indicates visual impairment.

We can’t do it alone

Every one of our supporters powers our mission – whether that’s through their membership fee, organising events, volunteering, or partnerships that help us reach more of the people who need us. We are especially grateful to the following for their commitment to Beating Macular Disease in 2021.

- The Albert Gubay Charitable Foundation
- Apellis
- Bayer
- The Bill Brown 1989 Charitable Trust
- Boehringer Ingelheim
- The Charles Wolfson Charitable Trust
- Mrs Patricia Gilby
- The Linbury Trust
- Masonic Charitable Foundation
- The National Lottery Community Fund
- Next plc
- Novartis
- Ora Clinical
- Oxsight
- The R S Macdonald Charitable Trust
- Red Dog Ads
- Roche
- Santen
- Sharegift
- Simplyhealth
- The Steel Charitable Trust
- The Syncona Foundation
- Vision Express

In 2021, we lost some of our most dedicated supporters, but the generous gifts they left in their Wills mean we can keep fighting macular disease for many years to come.

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

- Betty Patricia Clydesdale
- Joyce Greenwood
- Ursula Ruth Gruhn
- Mary Bathia Morrison Harris
- Vivien Patricia Jeffreys
- David Hubert Ladd
- Nigel Francis Philip Lloyd
- Agnes Pullen
- Josephine Rees
- Peggy Smith
- Richard William John Turner

Macular Society Summarised Accounts –

year ended 31 December 2021

The financial statements show a surplus for the year of £1,703k (2020: £134k). Total funds at the year-end were £5,483k (2020: £3,780k).

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

The most significant of these risks are a reduction in income generation since the COVID-19 pandemic; protection of our bank deposits, our computer systems and our data; and hurt to vulnerable adults, mitigated by safeguarding officers and policies.

	2021 £000	2020 £000
Income		
Subscriptions	283	270
Legacies	4,299	1,431
Donations & unrestricted grants	1,464	2,016
Grants for specified charitable activities	723	996
Fundraising events	701	513
Trading and other income	123	112
Total income	**7,593**	**5,321**
Expenditure		
Charitable activities:		
Sideview and Digest	95	89
Educational information	355	362
Advice and Information Service and Counselling	390	385
Groups and volunteer co-ordination	1,106	1,203
Local Group activities	63	37
Low vision	347	256
Research	1,779	1,440
Other expenditure	39	73
Total charitable expenditure	**4,174**	**3,845**
Costs of generating funds	1,885	1,422
Net investment (gains)/losses	(135)	(80)
Total expenditure	**5,924**	**5,187**

	2021 £000	2020 £000
Net income		
- Unrestricted	812	362
- Restricted	891	(228)
	1,703	134
Funds and net assets at 31 December		
- Unrestricted	2,758	1,946
- Designated	1,000	1,000
- Restricted	1,725	834
Total funds carried forward	**5,483**	**3,780**

Macular Society

Beating Macular Disease

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