



**Macular
Disease
Foundation**
AUSTRALIA



MACULAR DISEASE FOUNDATION AUSTRALIA

ANNUAL REPORT

2023

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Pillars of work



Macular Disease Foundation Australia acknowledges the traditional custodians of country throughout Australia and their continuing connection to land, sea, and community.

We pay our respects to them and their cultures, and to the Elders both past, present, and emerging.

Macular Disease Social Impact Survey

This year, 2000 people took part in our second Social Impact Survey. The purpose of this survey and longitudinal study is to gain a deeper insight into the impact macular disease has on a person's life, and to uncover the factors that may assist them to better cope with and manage their condition.

The first Social Impact Survey was launched in 2020 at the height of the COVID-19 pandemic. Many of the people involved in the first study have participated in this next survey.

Our aim is to carry out this

study every two years and track changes in people's vision status, support needs, well-being, and mental health.

This year's survey looked at specific health areas:

- low vision aids
- nutrition supplements
- anti-VEGF eye injections
- use of an Amsler grid to monitor for changes in vision
- routine eye healthcare.

The survey also looked at other aspects of macular disease including other eye conditions, competing health issues, falls, and mental health.



ANTI-VEGF EYE INJECTIONS

84% of people with wet AMD were receiving ongoing eye injections

13% of people previously had injections but had stopped.

9% of people said they could not afford eye injection treatment.



HIGHLIGHTS



LOW VISION AIDS AND TECHNOLOGY

62% use vision aids regularly

18% use vision aids some of the time

9% have not tried using vision aids.

Issues reported included knowing where to obtain vision aids, distance to services, the costs, and not knowing how to use low vision aids and technology.



REGULAR ENGAGEMENT WITH AN EYE HEALTH PROFESSIONAL

93% of people said they regularly engage with an eye health professional.



USE OF AMSLER GRID

Only **29%** of people use an Amsler grid regularly.



ASSESSING MDFA SERVICES

65% of respondents rated our National Helpline as good or excellent.

71% rated the Vision Voice newsletter as good or excellent.

64% rated our resources and website as good or excellent.

Message from the Chair

This year's Annual Report demonstrates the very positive year it has been for Macular Disease Foundation Australia.

The Board appointed a new CEO, Dr Kathy Chapman in July 2022. Kathy's background in public health and research has seen many instrumental developments for the Foundation in her first year, including the introduction of the Community Review Panel into the Research Grants Program which you will read about within the pages of this report.

The Board has also welcomed three new Directors, Susan Williams, Gillian Shea and Emma Cleary, who have brought additional skills to the governance of the organisation, including fundraising and financial expertise.

Recognising that more needs to be done to address Australia's largest cause of blindness, the Board reset our Strategic Directions to ensure our support and care of people with macular disease is at the centre of our work. Our other strategic pillars include research to help us move toward better treatments and a cure, as well as advocating for treatment to be more affordable and accessible. The Board has also committed to growing our fundraising efforts.

We are extremely fortunate to have the support of the community, our government partners, and sponsors, who allow us to provide quality services and support to those living with a macular disease diagnosis and their families.

Volunteers play a significant role driving our service delivery, extending our reach across the country, and leading our governance functions. Over the past year, we have tripled our volunteering capacity. Many of our volunteers have lived experience, and bring valuable insights on what it means to live with macular disease, low

vision, and who undergo regular eye injection treatment to retain their sight. We also have many skilled volunteers who help build capacity within our organisation to make it stronger, including members of our Board, Medical, Research, Financial Audit and Risk, and Fundraising and Engagement Committees.

We were also pleased to end the year in a financially strong position. While we had initially anticipated a financial deficit, we were pleased to end with a surplus of \$649,645 due to investment gains, positive fundraising returns and sound financial management.

Thank you to all the people who contribute to our Foundation's sustainability and impact. My special thanks to my fellow Board Directors and the staff of Macular Disease Foundation Australia.



Graeme Head AO
Chair of the MDFA Board

Message from the CEO

2023 has been my first full year leading Macular Disease Foundation Australia, and it has been a real privilege to get to know so many people within our community, their carers, and our healthcare partners. I'm extremely proud to work alongside our staff and volunteers, who come to work with a strong commitment to support our community every day.

In 2023, the Board of Macular Disease Foundation Australia reaffirmed our strategic intent and directions for the next three years. As part of this process, we considered our progress against the National Action Plan for Macular Disease. The National Action Plan was endorsed by the Australian Government when it was first developed in 2019, and recommended 44 actions across prevention, treatment, support and research.

Pleasingly, Macular Disease Foundation Australia has seen some significant areas of progress over the last four years, including:

- Raising community awareness of the risk factors and symptoms of macular disease, ways to reduce risk and detect it earlier – more than 200,000 people have completed the Check My Macula quiz since its launch, and now know their individual risk factors and what actions they should take.
- Four in five (82%) Australians between the ages of 50-70 have heard of age-related macular degeneration.
- Improving the understanding and knowledge of a range of health professional groups including optometrists, orthoptists, pharmacists and diabetes

educators through our online education modules.

- Building the evidence base on policy opportunities to assist people to persist with sight-saving intravitreal injections.
- Developing the first independent, personalised support service for all people living with age-related macular degeneration.
- Investing in \$5.9 million in 35 research projects.

However, this review of the National Action Plan has identified areas where we still need to see change, such as:

- Improving access to public hospital services for people with disease, especially those requiring intravitreal injections.
- Improving the affordability of sight saving eye injections and improving persistence with treatment.
- Improving accessibility to low vision aids and technology.
- Bridging the gaps between the health, aged care and disability sectors.
- Boosting research funding to eye health.

These are areas that are strongly the focus of our new Strategic Intent, as well as ensuring we are truly a national organisation.

It has been a great first year leading Macular Disease Foundation Australia and I extend my thanks to our Board, staff and volunteers, who share with me the same strong commitment to reducing the impact of macular disease.



Dr Kathy Chapman
CEO

Investing into Australia's leading research for macular disease

More than \$700,000 in research funding was awarded to six promising projects building the knowledge bank to better understand macular disease. This year's funding round now brings our commitment to macular disease research to \$5.9 million across 35 projects since 2011.

This round of funding is supporting three projects examining atrophic age-related macular degeneration, also known as geographic atrophy, for which there are no currently approved treatment options in Australia. Geographic atrophy is a significant cause of vision loss and blindness in Australia and has many unanswered research questions. One project includes a stem-cell derived modelling of geographic atrophy, and the second will address hyperspectral imaging for detecting and monitoring geographic atrophy. Other funded research programs seek deeper insights into sight-threatening diabetic macular

ischaemia, enhanced diagnostic approaches to reduce misdiagnosis of macular disease, and an evaluation of high-density lipoprotein levels that might identify people at high risk of developing age-related macular degeneration.

The quality of research applications was high, and subjected to a rigorous assessment process based on NHMRC criteria to ensure successful projects meet the highest scientific standards. Joining MDFA's Expert Review Panel and International Peer Reviewers in the 2023 grant selection process was our Community Review Panel comprising people caring for, or living with, macular disease.



“Progress towards effective therapies and treatment for both wet and dry MD is more extensive and advanced than I had realised. It was exciting to read about the breadth of current research and about proposed research while it is in the developmental stage. ”

– Dale Lowe

Research Grant Program Community Review Panel

Fourteen volunteers joined the Community Review Panel and - like the Expert Research Panel - reviewed and weighted the value of the applications according to a set of community-specific criteria. The Community Review Panel helped us to understand the areas of research people with lived experience considered the most important.

Our research grants program is funded through the generosity of our community, so it is very appropriate that our community has a say in how their funding is invested. MDFA is one of only a few organisations that actively involve our community members in helping to decide where research funding is directed.

Image: Members of the Community Review Panel and team from Macular Disease Foundation.

Left to right: Godwin Abela, France Pilavakis, Susan Falon, Chris James, John Simpson, Kathy Chapman, Kristina Ward, Dale Lowe, Ashley Chapman, Vicky Heaton, Deborah Chadwick.



Mrs Faye Grills, Dr Carla Abbott and His Excellency the Honourable David Hurley, Governor-General of Australia..

Honouring Richard Grills, AM

Macular Disease Foundation Australia celebrated the legacy and contribution of our friend, the late Richard Grills, by naming a research grant in honour of his dedication to eye health.

Richard was a valued Board member, advocate, and friend. Richard joined the Foundation’s Board in 2013 and had a lifelong commitment to those with low vision.

Richard’s wife Faye, daughter Alison, and son Bradley Grills joined us at Admiralty House, Kirribilli to award the Richard Grills Excellence in Research Award to Dr Carla Abbott.

Dr Abbott’s research project will investigate the links between lipids and macular disease, potentially paving the way for new treatments.



His Excellency the Honourable David Hurley, Governor-General of Australia, awards research grants on behalf of MDFA.

Congratulations to our 2023 research award recipients

Researcher: Dr Xavier Hadoux

Award: Grant Family Fund

Institution: Centre for Eye Research Australia, University of Melbourne

Project title: Evaluating the potential of hyperspectral imaging for detecting and monitoring geographic atrophy.

Researcher: Clinical Associate Professor Gerald Liew

Award: Research Grants Program

Institution: Westmead Institute for Medical Research, University of Sydney

Project title: Investigating mitochondrial dysfunction in macular degeneration – towards new treatments and biomarkers.

Researcher: Dr Alexis Ceecee Britten-Jones

Institution: Centre for Eye Research Australia, University of Melbourne

Award: Grant Family Fund

Project title: Redefining macular disease diagnosis to improve access to emerging therapies.

Researcher: Dr Carla Abbott

Award: Excellence in Research Award in honour of Richard Grills (AM)

Institution: Centre for Eye Research Australia, University of Melbourne

Project title: Composition and functionality of high-density lipoprotein in age-related macular degeneration and a high-risk disease phenotype.

Researcher: Dr Grace Lidgerwood

Award: Grant Family Fund

Institution: Centre for Eye Research Australia, University of Melbourne

Project title: A stem-cell derived model of geographic atrophy age-related macular degeneration for mitochondrial-focused drug screening.

Researcher: Professor Chandrakumar Balaratnasingam

Award: Research Grants Program

Institution: Lions Eye Institute, University of Western Australia

Project title: Spatial transcriptomics in diabetic macular ischaemia.

Research projects completed in 2023



Researcher: Dr Yvette Wooff

Award: Grant Family Fund (2021)

Institution: Australian National University

Project title: Treat yourself! The use of therapeutically loaded extracellular vesicles as a novel gene therapy for the treatment of age-related macular degeneration.



Researcher: Dr Ting Zhang

Award: Grant Family Fund (2021)

Institution: Save Sight Institute, The University of Sydney

Project title: Activating endogenous phosphoglycerate dehydrogenase (PHGDH) to treat age-related macular degeneration with the help of a Müller cell-specific lipid nanocarrier.



Researcher: Dr Anai Gonzales-Cordero

Award: Grant Family Fund (2021)

Institution: University of Sydney

Project title: Creating a macula in retinal organoids.

OUR STORY

Ashley and his daughter, Deborah, participated in Macular Disease Foundation's inaugural Community Review Panel.

Ashley lives with age-related macular degeneration, and Deborah has been right by his side as part of the family support unit. They both agree that involving people with lived experience into the Research Grants' assessment process was an invaluable initiative.

"People with lived experience provide insights only possible after experiencing deterioration and loss of vision. The needs and problems associated with macular disease can be successfully addressed by investment in research relevant to their experience. Some research, although seemingly important to researchers, may not have a

significant impact in the real world or be viable for those with macular disease", said Deborah.

Ashley and Deborah joined 12 other members on the Community Review Panel, reviewing the research applications alongside Macular Disease Foundation's expert research and academic peer reviewers – while looking at the proposals with a different lens.

Ashley stated "I found the whole experience interesting, challenging, and informative. I gained new insights into the quality and dedication of the academics who contribute so much to our research program".



"We look at research proposals through the filter of "is this research likely to contribute to an improved quality of life in the long/short term?" This is not to say that researchers don't consider this in their submissions, but macular disease patients bring their own perspective, when evaluating submissions, based on personal experience".

Investing to Save Sight

On 1 May 2023, as part of the Macula Month celebrations, we launched our economic modelling report, *Investing to Save Sight: Health and Economic Benefits of Improving Macular Disease Treatment Persistence* at the NSW State Library.

Macular Disease Foundation remains concerned that many people are missing out on sight saving injections and going needlessly blind. We hear from our community that issues of cost and needing to travel for treatment are barriers to staying on treatment. Therefore, we collaborated with PwC Australia to model the economic benefits to government of increasing treatment persistence for people with wet AMD.

Indeed, cost and access were identified as two of the main reasons why people with wet AMD stop treatment. These include the challenges in accessing affordable or bulk-billed treatment for low-income earners and pensioners, and difficulty accessing treatment for those living in rural and regional Australia.

The Investing to Save Sight report showed that by increasing treatment persistence by 25%, the sight of an additional 22,000 vulnerable Australians will be saved, and up to two billion dollars added to the Government's bottom line.

The launch of the report is the start of a much larger conversation to support an investment into systemic change to eye injection treatment for the macular disease community.

While a modest shift of 25%, or 22,000 patients, persisting with eye injection treatment may not sound like much, we know that the longer-term impact for those people living with AMD and their families is enormous – and for the government, the saving is significant.



Key recommendations

Investing to Save Sight recommended three key areas for the federal, state and territory governments to consider investment to increase treatment persistence by up to 25%. These included:

1. Increased affordability;
2. Increased access to treatment; and
3. Increased information and support to help people stay on treatment.

NSW State Election Agenda – A vision for a better NSW




In the lead up to the NSW State Election in March, we developed an election agenda that highlighted the priority issues affecting people with macular disease in NSW, primarily the need for greater access to public hospital and bulk-billed eye injections, and better support for regional and rural access to eye injections.

Our four recommendations were:

1. Conduct an audit of public eye injection treatment in NSW to improve resource allocation to address service gaps.
2. Increase the number of NSW public hospitals that provide eye injection treatment in high prevalence areas.
3. Increase access to the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) by changing the eligibility requirements.
4. Increase access to the IPTAAS scheme for people with vision impairment by improving the application process.

We reached out to 146 key election candidates and 93 elected NSW Members of Parliament with our recommendations.

The NSW Government has committed to:

-  Reviewing the provision of public eye injection treatment in NSW.
-  Introducing an IPTAAS phone application service for people with vision loss or blindness.
-  Improving the print accessibility of IPTAAS forms.

Prevalence Mapping Project – Atlas of Macular Disease

In June we completed a prevalence mapping project which culminated with the publication of the Atlas of Macular Disease.

The Atlas provides statistics on AMD across Australia, by federal, state and territory electorates. It also includes comprehensive geographic, demographic, health service distribution and socio-economic data for each electorate to assist with identifying the areas which require the greatest attention by their respective governments.

This project was supported by the Royal Australian and New Zealand College of Ophthalmologists, who will also use the Atlas to better understand treatment demand and ophthalmology workforce distribution.

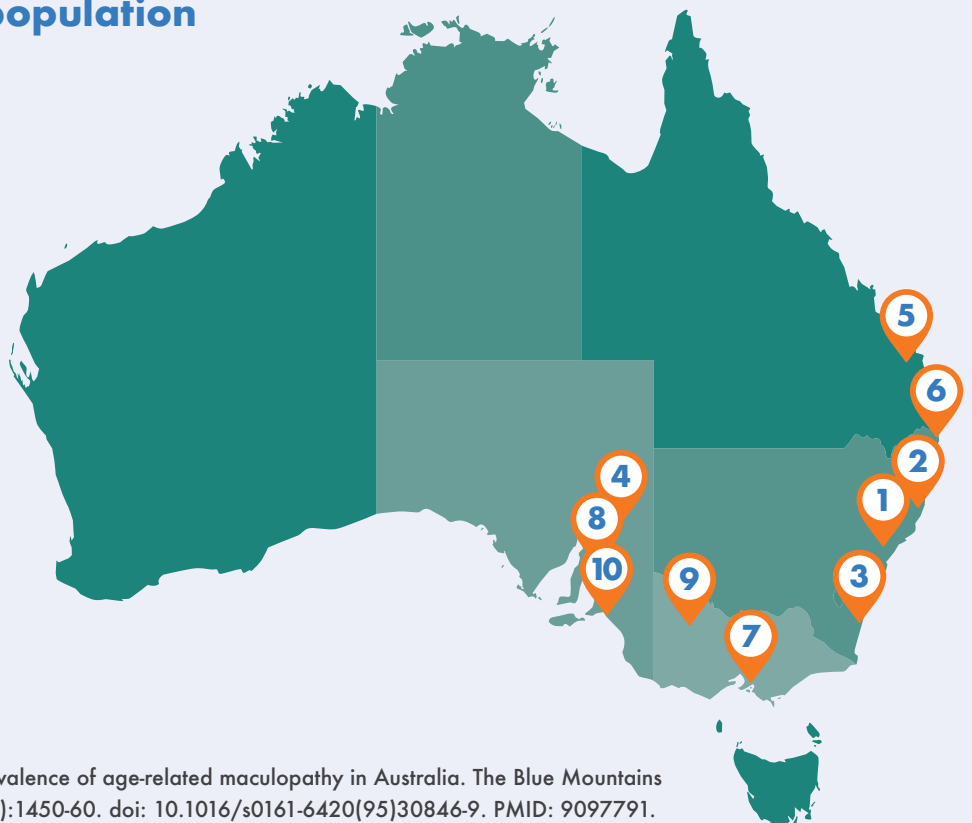
The following is a map of the Top 10 Federal Electorates with the highest AMD population, based on data from the Atlas. The AMD prevalence rates in the Atlas are taken from the Blue Mountains Eye Study, which was a large cohort study that provided evidence for the number of Australians living with age-related macular degeneration.

Macular Disease Foundation Australia will continue to advocate to the NSW Government for further reviews of the IPTAAS rebates and minimum eligible distance to improve treatment accessibility for the macular disease community, and we intend to make this issue a focus in other states and territories as well.



Top 10 Federal Electorates with the highest age-related macular degeneration (AMD) population

- | | |
|-------------|-------|
| 1. Lyne | 9,065 |
| 2. Cowper | 8,933 |
| 3. Gilmore | 8,889 |
| 4. Sturt | 8,439 |
| 5. Hinkler | 8,386 |
| 6. Richmond | 8,344 |
| 7. Flinders | 8,272 |
| 8. Boothby | 8,045 |
| 9. Mallee | 7,993 |
| 10. Mayo | 7,909 |



¹ Mitchell P, Smith W, Attebo K, Wang JJ. Prevalence of age-related maculopathy in Australia. The Blue Mountains Eye Study. Ophthalmology. 1995 Oct;102(10):1450-60. doi: 10.1016/s0161-6420(95)30846-9. PMID: 9097791.



Ita Buttrose calls on Government to do more through Macula Month in May

Patron, Ita Buttrose AC OBE celebrated this year's Macula Month and officially launched our new report, Investing to Save Sight.

Joining members of the community living with macular disease and carers, Ms Buttrose called on State, Territory and Federal Governments to do more for older Australians who are at risk of going blind.

We have been fortunate to have Ms Buttrose as our Patron and champion since 2011, lending her voice to raise critical issues that affect the macular disease community, such as access to affordable treatment highlighted in the Investing to Save Sight report.

Ms Buttrose shared the fact that 20% of people will stop treatment in their first year, and 50% of people will stop their eye injections within five years, citing reasons of affordability and access, particularly for those on pensions and people living in rural and remote areas of Australia.

Ms Buttrose shared the economic modelling of the Investing to Save Sight report with the members of the community, highlighting that modest Government investment to make treatment more affordable, services more accessible and more support for people on their treatment journey could save Government two billion dollars over a decade.

“By increasing treatment persistence by 25%, the sight of an additional 22,000 Australians will be saved,” said Ms Buttrose.

Ms Buttrose has continued to pledge her support to work on behalf of the macular disease community to champion this report with Government.

Macula Month

Macula Month is an annual campaign, raising awareness of macular disease. Each May we ask Australians over the age of 50 to book an appointment with their local Optometrist for a comprehensive eye examination and macula check, understanding that early detection will save sight.



Annual YouGov Galaxy Poll Highlights

Each May in Macula Month, we release the results of our annual YouGov Galaxy Poll.

These results have been trending since 2013 and allow us to understand of the general public's awareness and understanding of macular disease, risks, symptoms, and how to take preventive action to reduce impact of vision loss and blindness.

This year's survey findings included:

- Four in five (82%) Australians between the age of 50–70 have heard of the age-related macular degeneration/AMD condition. This has shifted from from 33% to 67% Australians being aware of AMD because of our awareness program.
- Awareness is higher among those aged 60-70 (88%) compared to the younger age group 50–59 (76%).
- Three in four (72%) Australians aged 50-70 have had an eye examination by an optometrist - including a macula check - within the last two years.
- Only one in ten (11%) Australians aged 50–70 think governments are doing enough to support the macular disease community.
- More than eight in ten (85%) Australians aged 50–70 believe that the Australian government should invest more to save sight.

Source: The YouGov poll was conducted online 31 Jan – 2 Feb 2023 with a nationally representative sample of 1,012 Australians aged 50 – 70, the data were weighted by age, gender, and region to reflect the latest ABS population estimates.

SUPPORT AND CARE

Eye Connect

Through the generous support from the Paskeville Foundation, we were able to expand our Eye Connect peer support program into Western Australia. With peer support already well-established in New South Wales and Victoria, this investment meant we could continue to increase our national reach and test the appetite of clients located in and around Perth.

We now have three Eye Connect groups across Perth, with new groups established in Tuart Hill, Willagee, and Cannington.

Our Eye Connect peer-to-peer groups cover multiple discussion topics and often have guest speakers to present on the interest areas of group members. Some of these have included Quantum presenting on the different vision technologies available, Guide Dogs presenting on the services they offer including vision assessments, Volunteer Home Support Western Australia to present on home care service in Perth, among others. Feedback from Eye Connect attendees has informed the guest speakers invited and the topics covered. We plan to invite more guest speakers to cover other topics, such as mental wellbeing and nutrition.

“I need to connect with others outside my family and friends. It’s hard for them to understand. Thanks to MDFA, I can attend the macular disease support group and talk about my macula.”

My Eyes

A new way of supporting people living with macular disease

My Eyes is our new patient support program which will be launching in 2024. To ensure the My Eyes service offering is relevant and accessible, we have spent the past 12 months working with members of the macular disease community to co-design what the program looks like and how it is to be delivered. Our Consumer Reference Group, people living with macular disease, carers, and volunteers, have all been involved in the review process as we develop content which will support people being diagnosed with macular disease. We have conducted in-depth interviews, focus groups, and surveys with member of the macular disease community to receive feedback on our ideas, all of which have informed the direction of My Eyes as it takes shape. Of significance, the research has highlighted the importance of mental health support through all stages of diagnosis. As such, we have put particular focus on embedding mental wellbeing support intrinsically into the My Eyes program.

Our Eye Connect group – Stirling, Western Australia



HIGHLIGHTS

- **271** people living with a macular disease have been involved in focus groups and surveys to provide feedback on the My Eyes program.
- **83%** of participants agree or strongly agree that attending peer support has improved their knowledge on low vision aids and technology.
- **67** participants across all our Eye Connect groups.
- **8** volunteer facilitators supporting our Eye Connect groups.

Supporting regional Australia

Regional Travel Bursary

In 2022, we launched a pilot travel bursary program with Dubbo Hospital and the Western NSW Local Health District. Fully funded through philanthropy, this program financially assists people who travel long distances to Dubbo Hospital for regular eye injection treatment. Our travel bursary program has been designed to address the gap not currently filled by the government's transport subsidy schemes, which MDFA believes could be more generous for people requiring ongoing treatment.

In 2023, we expanded this program into Victoria and are offering people financial assistance for their travel to and from Vision Eye Institute in Boronia. This expansion has facilitated a significant increase in sign-ups to the program, growing the program's active participants by more than 400%. Early reports on the program have provided case study data showing that some people are traveling upwards of 400km to receive their sight-saving eye injections. By offering the travel bursary, MDFA hopes we can demonstrate to governments the importance of helping people to get to their appointments, as we know treatment persistence is key to saving sight.

"I call the payments my little windfall. They pay for petrol and help me get to and from my appointments. It really helps." – Debbie, recipient of the Dubbo Travel Bursary

Raising awareness of diabetic eye disease in regional and remote communities

For another year, we have collaborated with Sight for All to deliver education sessions in regional and remote areas of New South Wales and South Australia where there are high rates of diabetes. People with diabetes are at heightened risk of diabetic retinopathy, yet our Community Survey earlier this year showed only 45% of people

living with diabetes know it can affect their eyes.

This year, our New South Wales sessions were delivered in Shoalhaven, Warren, Cootamundra, Nyngan, Gundagai, Berrigan, Dubbo, Coonamble, Werris Creek, Manilla, Quirindi, and Jervis Bay. In South Australia, sessions were conducted with Aboriginal Health Practitioners and community groups, reaching places like Coober Pedy, Mannum, Kadina, Bute, Moonta, Ardrossan, Clare, and Morgan.

This program works to address a lack of awareness of the risks of vision loss associated with diabetic eye disease. In these sessions, the significance of regular eye examinations for early diabetic eye disease detection is emphasised, highlighting the benefits of timely intervention in preventing or delaying vision loss.

These presentations delivered by the Sight for All team on our behalf encourage community members to explore the information resources and support we offer, including educational materials, and peer support groups, and access to specialised healthcare professionals. These resources aim to empower individuals in regional areas to stay informed about their macula health and benefit from effective management strategies and peer connections.



Engagement with eye health professionals

Healthcare professionals are on the front line of patient interactions and play a valuable role in early detection and management of macular diseases to prevent vision loss and blindness.

Over the past year, we have continued to foster relationships with key health professional stakeholders in the field of eye health. These partnerships are crucial to our mission of increasing awareness and improving detection, diagnosis, and management of macular disease.

We have strengthened partnerships with leading professional peak body organisations, including Optometry Australia, Orthoptics Australia, the Royal Australian and New Zealand College of Ophthalmologists (RANZCO), Diabetes Australia, and the Australian Ophthalmic Nurses Association.

These relationships offer continued opportunities to engage with frontline healthcare professionals.

Training and Education for Health Professionals on Macular Disease

As part of our strategy to increase awareness of macular disease among health professionals, we have developed a series of health professional education courses and actively engage with health organisations that have strong ties to healthcare practitioners and their communities.

Our initiatives have been supported by funding from the National Action Plan, including the Health Professional Education and Training and Consumer Populations at Risk grant.

The National Action Plan identified a need to create nationally consistent educational and training programs for key healthcare professionals. This ensures health professionals are kept up to date with the latest medical information on macular disease and helps them to better understand the free evidence-based support Macular Disease Foundation can provide to their patients.



Our educational courses on age-related macular degeneration and diabetic eye disease have achieved significant success, with over 13,000 Optometrists, Orthoptists, Pharmacists, GPs, and Diabetes Educators signing up to the education sessions. MDFA has also collaborated with the Brien Holden Foundation and Specsavers, focused on training health workers and connecting patients to support and resources for their condition. The partnership with Specsavers provides us with an additional avenue to reach healthcare professionals and reinforces the value of building trusted relationships to create effective referral pathways.

Pharmacy Engagement

Pharmacists have a valuable role to play in early detection and helping to reduce the impact of macular disease in our community. Recognising pharmacists' keen interest in enhancing their eye health knowledge, we have formed a new collaboration with TerryWhite Chemmart.

By leveraging the strong presence of these pharmacies in regional areas, this collaboration aims to improve access to eye healthcare and enhance patient knowledge in underserved regions.



KEY HIGHLIGHTS



13,718 health professionals have registered for MDFA health professional education courses since the education was launched.



97% of Optometrists told us they learnt new information to better manage patients at risk of AMD, or AMD progression.



Optometrists who completed the course are likely to see more than 439,000 patients per year who may have a risk or evidence of AMD or diabetic eye disease.



100% of Pharmacists told us they learnt new information to better manage patients at risk of diabetic eye disease or disease progression.



It takes a village

Marathon men, Simon and Andrew, raised over \$2000 for us at the Melbourne Marathon in October 2022.



These keen marathon runners were inspired to fundraise by the recent diagnosis of a family friend with Stargardt disease.

Stargardt disease is a genetic eye disease affecting central vision and is the most common childhood macular condition.

Thanks to their efforts and their generous supporters, they not only smashed their original target of \$1000 but both Simon and Andrew beat their previous personal best running times.

A huge thank you to Simon and Andrew and everyone who fundraises on our behalf – we couldn't do it without you.

Vale and thank you Giles

In June this year, Giles Cooper, and his 43-year-old Volkswagon, Clementine, set off on an adventure to journey around Australia in support research into macular disease and cancer.

Living on the Gold Coast, Giles bought his 1970 model VW Type 3 Fastback as a rolling wreck back in 2019 and spent the COVID lockdown months lovingly rebuilding Clementine – a salute to her VW paint colour, Clementine.

Giles and Clementine were to drive a lap of Australia, some 15,000 kilometres, not only to see more of our wonderful country, but also to raise both awareness and funds for research into cancer and age-related macular degeneration.

In 2007, Giles had a lengthy battle with throat cancer and received excellent care and treatment. He also has a sister as well as a best friend from his school days, who both live with age-related macular degeneration. As a result, he nominated MDFA and the Cancer Council as his two preferred charities to support in his fundraising efforts.



Upon arrival in Western Australia, Giles sadly passed away from health issues. While we were all shocked and so deeply saddened for Giles' family and friends, we wish to acknowledge his generous nature and his spirit of adventure.

Giles had a fundraising target of \$5000, and his fundraising contribution has now tipped over \$25,000 towards research into macular disease. This legacy is one we are truly grateful for, and we know that Giles would have been humbled by such generous support from his family and friends.

This amazing fundraising effort is supporting vital research into macular disease. Giles' legacy lives on.

VISION FOR LIFE

As her ophthalmologist, Dr Paul Beaumont enters her room in the nursing home, 102-year-old Norma Tory puts down her book – a biography of Australian poet Dorothea Mackeller – in anticipation of the eye injection that allows her to continue her passion for reading.

The centenarian, whose bookshelves and cupboards are crammed with biographies, literary classics and the odd Agatha Christie mystery, regards her regular eye injections as a lifeline.

Norma has wet (neovascular) age-related macular degeneration (AMD), and the treatment provided by Dr Beaumont over the past four years has helped her maintain functional vision.

It's because of these eye injections that she can still read, watch television, and see the faces of her two children, five grandchildren, and three great-grandchildren.

So, every six weeks, like clockwork, Dr Beaumont and his

ophthalmic nurse, pack a medical kit and travel from their Mona Vale surgery to Norma's nursing home in nearby Avalon, on Sydney's northern beaches.

Norma is bedbound. Visits to the ophthalmology clinic would require ambulance transport. So, the visits by Dr Beaumont are the only way she can continue to receive the sight-saving injections.

"I couldn't do without them, could I? It's very nice of him to come," Norma told us.

Norma's son David is present at her injections. "In the beginning, we would take Norma to Dr Beaumont in his surgery, but in September 2020, Norma unfortunately had to come in here (to the nursing home), so

Dr Beaumont decided to do the injections in her bed," David said.

Dr Beaumont, founded Macular Disease Foundation Australia in 2001, and says it is "critically important" to continue treatment. For someone like Norma, who is completely immobile yet still mentally sharp, "the alternative – blindness – is unacceptable".



Norma and her son, David.



Volunteers

Volunteers play a special role in supporting the macular disease community. We've had a bumper year of support, seeing our volunteer numbers triple in size and expand beyond New South Wales into Victoria, the ACT, Queensland, and Western Australia.

As our volunteer base has grown, we have paid particular attention to attracting skilled volunteers for targeted roles to help build capacity within our organisation. The diversity of skills now present among our volunteer team includes data analysis, project management, writing, design, psychology, optometry, law, photography, and policy.

Along with recruiting new skills and expertise into our organisation, there is also now wider representation of different cultures and languages including Korean, Mandarin, and Vietnamese. This has assisted in supporting the Culturally and Linguistically Diverse (CALD) members of our community.

The Australia Charities and Not-for-profits Commission (ACNC) recently reported a widely observed decline in Australian volunteering. We are pleased to report that we are reversing this trend following an increase in our volunteer base of 356% during the last financial year.

“As a future healthcare worker, I have really valued being able to connect with, and hear the experiences of, the older generation of volunteers at the Foundation. I know I will have older patients under my care in the future, and this unique experience will help colour the way I engage with this demographic.”

– Shayan

“Volunteering with Macular Disease Foundation Australia has been a great opportunity to give back to the community. I love leveraging my skills in project management and data analysis in a really positive and meaningful way.”

– Peter

HIGHLIGHTS



356% increase in volunteer numbers.



The national volunteer footprint now covers NSW, QLD, WA, ACT, and VIC.



788 hours of work contributed by volunteers.



Back: Shayan, Claire, Peter. Front: Tina, Sun.

Governance

Board Directors



Mr Graeme Head
AO FIPAA
Chair



Mr Neil Wykes
OAM BCom FCA AGIA ACIS



Ms Lisa Lusthaus
BSc App. Psych (Hons)



Ms Imelda Lynch
RN BN MHSN GAICD



A/Professor Alex Hunyor
MBBS (Hons), FRANZCO



Mr Peter Abrahamson
BAppSc, Dip. Business, FAICD

Welcome to our new Board members



Ms Susan Williams
BArgSc, MPH, CFRE
New (February 2023)



Ms Gillian Shea
B.Bus CA
New (February 2023)



Ms Emma Cleary
B.Bus CA GAICD
New (February 2023)

Committees

MDFA committees play a key role in advising management and championing our purpose to reduce the impact of macular disease. We are fortunate to have Australia's eminent research and retinal specialists and other professionals to inform our work.

Medical Committee

Associate Professor Alex Hunyor (Chair)
Dr Amanda Greaves
Dr David Hilford
Associate Professor Anthony Kwan
Dr Tharmalingam Mahendrarajah
Professor Paul Mitchell AO
Dr Grant Raymond
Associate Professor Peter van Wijngaarden
Dr Xia Ni Wu

Research Committee

Associate Professor Anthony Kwan (Chair)
Ms Imelda Lynch
Associate Professor Peter van Wijngaarden
Associate Professor Fred Chen
Associate Professor Samantha Fraser-Bell

National Research Advisor

Professor Paul Mitchell AO
MBBS MD PhD FRANZCO FRACS
FRCOphth FAFPHM

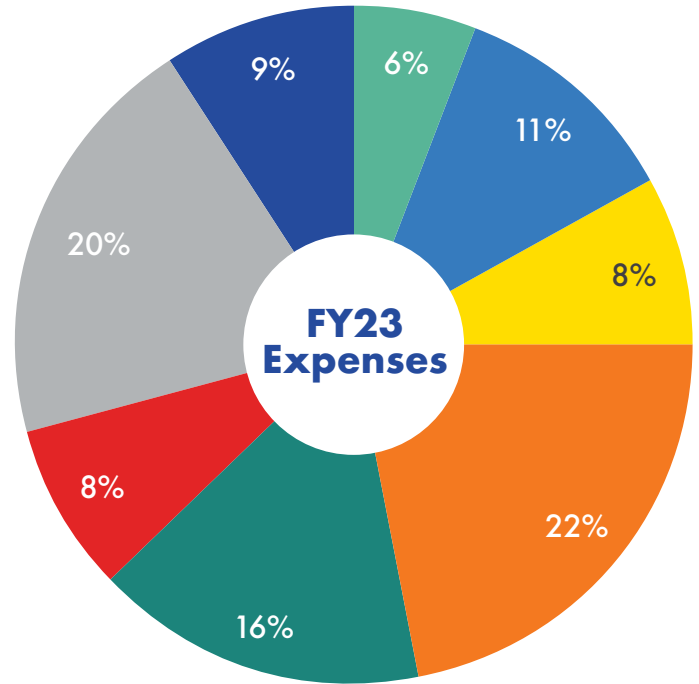
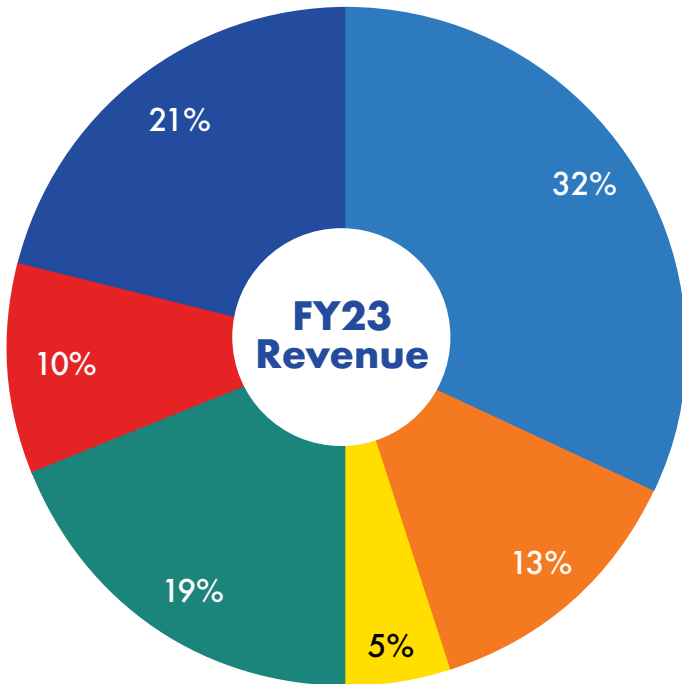
Finance, Audit and Risk Committee

Mr Neil Wykes OAM (Chair)
Mr Graeme Head AO
Mr Ashley Chapman
Mr Peter Abrahamson
Ms Gillian Shea
Ms Emma Cleary

Fundraising and Engagement Committee

Mr Peter Abrahamson (Chair)
Ms Lisa Lusthaus
Ms Susan Williams

Financials



Revenue (\$4,659,000)

- **Government Grants (\$1,507,000)**
- **Bequests (\$894,000)**
- **Donations (\$616,000)**
- **Sponsorship (\$445,000)**
- **Trust and Foundations (\$225,000)**
- **Investment Gains/Losses (\$972,000)**

Expenses (\$4,010,000)

- **Awareness and Early Detection (\$868,000)**
- **Services and Support to the Macular Disease Community (\$641,000)**
- **Research Grants (\$434,000)**
- **Healthcare Professionals (\$344,000)**
- **Advocacy (\$310,000)**
- **Other Research Projects (\$234,000)**
- **Operational Costs (\$794,000)**
- **Fundraising Activities (\$385,000)**

Our Supporters

Together we are working to reduce the impact of macular disease in Australia. Thank you enormously for your trust and support.

Individuals

Miss Denise Bramble
Mrs Lorraine Duthie
Mrs Dinie Gaemers
Mr James L'Estrange
Ms Natasha Lee
Dr David Morre
Mrs & Mrs Graeme & Lesley Parker-Reynolds
Pennay Family
Mr Alan Roberts
Ms Linda Sen Gupta
Mrs Joan Stevens
Ms Linda Thomas
Mr WL Turnbull
Mr Charles Vowell
Mrs Jan Waddington
Mrs Sally White
Mr Richard Williams
Dr KC Tang Midwest
Ophthalmology Orange

Estates

The Hughes Family Trust Fund
The Estate of the Late Alma Mary Bower
The Estate of the Late Josephine Simelius
The Estate of the Late Frederick Albert William Smith
The Estate of the Late Elaine Ruby Robinson
The Estate of the Late Kathleen Margaret Flanagan
The Estate of the Late Betty Bibb
The Estate of the Late Enid Marshall
The Estate of the Late Clarice Holly Smith
The Estate of the Late John Norman Williams

Trusts and Foundations

The McBriarty Family
The Mills Family Foundation
The Community Impact Foundation
Paskeville Foundation
Perpetual Foundation
Queensland Community Foundation
Fitzpatrick Sykes Family Foundation
Centenary Foundation – The Barbara Sherwood Legacy Fund
Graham and Pam Nock Foundation

Organisations

Club Burwood RSL
Hornsby RSL Club
Magpies Waitara

Visionary Partners

Mr Lindsay Allan

Mrs Robin Allardice

Mrs Mary Allen

Mr Ernest Athfield

Mrs Janina Bourke

Mrs Meryl Bowman

Mrs Betty Burgess

Ms Elizabeth Carr

Mrs Paddy Carter

Mrs Patricia Chisholm

Mr Alex Cleave

Mrs Faith Davidson

Mr Lloyd Davis

Mrs Kay De Graaf

Mr Victor Dobija

Miss Lorraine Edwards

Ms Lynette Elliott

Mrs Janet Fenwick

Ms Mary Fisher

Mr Neville Gallard

Mr Brett Gilles

Mrs Margaret Hamilton

Mr David Hamilton

Mrs Anne-Marie Harman

Mrs Diane Hobden

Mrs Christine Hooks

Dr Edith Horvath

Mrs Stephanie Joss

Ms Anne Keehan

Mr John Koivisto

Ms Wai Man (Connie) Kwong

Dr John Mayo

Mr Peter McDonald

Miss Lydia Miceli

Ms Bev Morris

Mr John Murphy

Mr John Ovenden

Mrs Christine Paris

Miss Marina Pitsonis

Mrs Maria Rosol

Mr Gregory Sachs

Mr Brian Schafer

Ms Nancy Scott

Mrs Jill Sedla

Mr Richard Shaw

Mrs Elaine Sinclair

Mrs Sue Smith

Mrs Margaret Snodgrass

Ms Pamela Taylor

Ms Jean Taylor

Mrs Bertha Tilley

Mrs Penny Tomlinson

Mrs Marjorie Vorsa

Ms Jennifer Wakeling

Mrs Jeanette Warne

Mrs Judith Wright

Ms Lorraine Young

Supporters

We are grateful for the generous contributions from the following organisations.

Government support

Macular Disease Foundation Australia received funding from the Australian Government.

Proudly funded by the
NSW Government in association
with Macular Disease Foundation Australia



Funding from NSW Health, supported by South Eastern Sydney Local Health District, contributes to the delivery of comprehensive education and awareness programs, as well as support services and evidence-based information to thousands of people in NSW, including those in regional areas.



The generous support provided by the following organisations enables the delivery of key initiatives and activities.

The logo for Apellis, featuring the word "Apellis" in a grey, sans-serif font.

Apellis continues to support the consumer research and strategy to develop our patient engagement initiative, which allows those living with macular disease to receive the right information at the right stage of their disease journey.



A key supporter since 2011, Bayer funding assists with key awareness, early detection, and prevention programs such as Macula Month and MDFA's growing digital footprint.

The logo for JBWere, featuring the word "JBWere" in a blue, serif font, with a horizontal line underneath.

JBWere manages MDFA's investments and supports with strategic advice for social return.

The logo for Novartis, featuring a stylized orange and blue flame-like symbol to the left of the word "NOVARTIS" in a blue, sans-serif font.

Novartis has been a contributor to our awareness and support services programs and is helping MDFA build integrated systems to support patient adherence and care.

The logo for Perpetual, featuring the word "Perpetual" in a blue, serif font, with a stylized blue flourish to the right.

Perpetual has supported MDFA with in-kind support as well as administering generous Trust and Foundation funds.

The logo for Profield Foundation, featuring the word "Profield" in a blue, serif font above the word "FOUNDATION" in a blue, sans-serif font.

Profield Foundation has been a long-time supporter and is working with MDFA to implement a travel bursary program in NSW and Victoria to help vulnerable people in rural and regional areas attend sight-saving medical treatment.



Roche is working with MDFA to enable research, strategy, technology development, and support for people undergoing treatment for macular disease.

The logo for Specsavers, featuring the word "Specsavers" in a white, sans-serif font inside a green, rounded rectangular shape.

Specsavers has collaborated with MDFA to trial a support program across selected stores to assist people with neovascular age-related macular degeneration. The program is aiming to increase appointment visitation and treatment adherence rates, enhancing eye health outcomes for people with macular disease.



MDFA has collaborated with the TerryWhite Chemmart pharmacy network to raise awareness of macular disease among pharmacy teams and community members, focusing on education and screening to improve detection and management in the community.



Macular Disease Foundation Australia

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W www.CheckMyMacula.com.au

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