

Seeing Change

25 years reducing the impact of
macular disease across Australia



Macular Disease Foundation Australia acknowledges the Traditional Custodians of country throughout Australia and pays our respect to Elders past and present. We honour their continuing connection to Country and community.

We also acknowledge people living with disability, including those affected by macular disease. We recognise the insight and strength that comes from lived experience and reaffirm our commitment to removing barriers, advancing equity, and seeing a future without limits.

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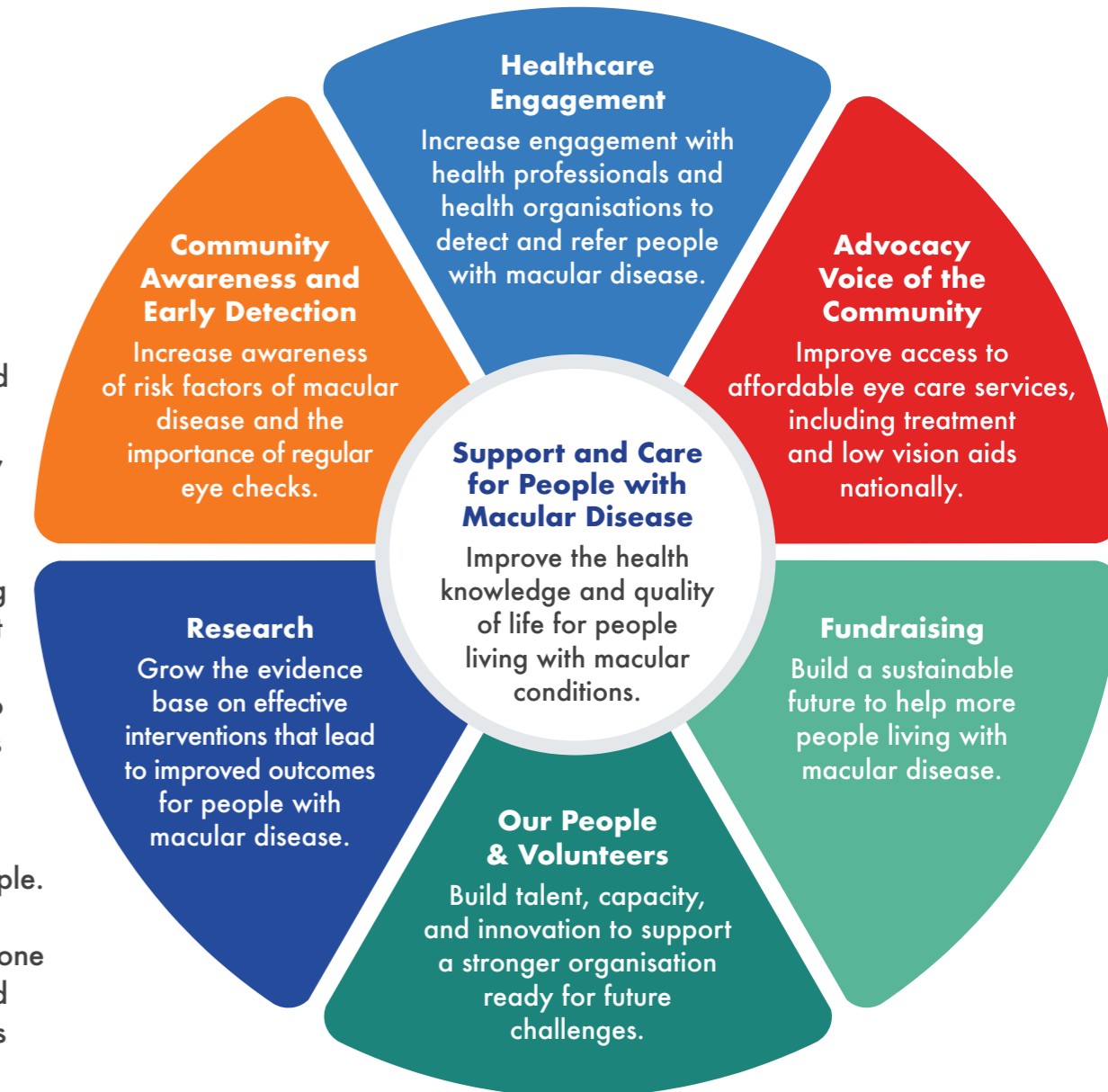
Our Purpose

From the very beginning, the macular disease community has been the driving force behind everything we do.

Founded in 2001 as the Macular Degeneration Foundation, the organisation's purpose was to ensure that people living with age-related macular degeneration were no longer left to navigate life alone following their diagnosis. Our early focus was to provide trusted education, meaningful support, and greater awareness of a disease that too often went unseen. Over the past 25 years, our remit has grown, expanding to represent all macular diseases, but our purpose has remained constant.

Today, we are a leading voice in advocacy, amplifying lived experience to influence change. Our commitment to research drives progress and hope, while our social impact evaluations make certain that everything we do is grounded in a deep understanding of the real needs of people affected by macular disease.

If there's one thread that weaves through our work across a quarter of a century, it is community. It is people. Those who have shared their stories with courage, volunteered their time with generosity, and supported one another with compassion. It is the donors who believed in our mission, and the collective strength of individuals determined to make a difference – and save sight.



Celebration

Twenty-five years is long enough to change lives – and Macular Disease Foundation Australia has done exactly that. When the Foundation was established, macular disease was poorly understood, rarely discussed, and too often accepted as an unavoidable part of ageing.

Vision loss was something people endured quietly, with limited information and little hope. Today, that picture has changed. Awareness has grown, treatments have advanced, research has accelerated, and people living with macular disease are no longer invisible.

As Patron, I have witnessed the extraordinary impact of this organisation – not just on policy and health systems, but on individuals, families and communities across Australia. This anniversary is an opportunity to reflect on how far we have come, and to remind ourselves why the work ahead remains so important.

For me, macular disease is deeply personal. My father, Charles, was an avid reader

and a former journalist. Newspapers connected him to the world, and he began each day immersed in words and ideas.

As age-related macular degeneration (AMD) gradually robbed him of his central vision, that connection faded. He would turn the paper at awkward angles, trying desperately to read with his peripheral sight. Eventually, he lost the ability to read, recognise faces, or follow the news – losses that were devastating in themselves, and even more so as he also lived with vascular dementia. At that time, effective treatments for wet AMD were not available, and his vision loss was irreversible.

My Uncle Gerald's story, however, tells a different and far more hopeful chapter.

Diagnosed early and treated promptly, he received regular eye injections that preserved his sight. Uncle Gerald continued to live independently, write, stay active, and – most importantly – see the faces of his family. His experience demonstrates what is possible when awareness, early detection, and access to treatment come together. Sadly, Uncle Gerald died in February this year when he was 102. He was listening to the opera Turandot and simply fell asleep.

These two stories – brothers affected by the same disease – capture the profound change that has occurred in just one generation, and why the work of Macular Disease Foundation Australia matters so deeply.

Over the past twenty-five years, the Foundation has transformed the national conversation about eye health. It has elevated macular disease to a recognised public health priority, driven sight-saving awareness campaigns, always ensuring that the voices of people living with vision loss are heard. As a result of this advocacy, Australia is now regarded as a world

leader in the management of neovascular, or wet, AMD, with breakthroughs in the pipeline for geographic atrophy or dry AMD. Australia is delivering some of the best patient outcomes internationally, and the Foundation has been a driving force in this pursuit.

Macular disease has real consequences. Vision loss is not merely an eye condition – it affects independence, mental health, mobility, employment, and social connection. It increases the risk of falls, depression, and early entry into residential aged care. By championing early detection, support services and treatment persistence, the Foundation has helped Australians retain not just their sight, but their quality of life.

Research has been another cornerstone of this impact. While there is still no cure for AMD, investment in research has grown significantly, bringing new therapies and technologies closer to reality. The Foundation's role in supporting and advocating for this research offers hope that future generations may face a very different outlook.

Yet anniversaries are not only about celebrating progress – they are also calls to action. Too many Australians still struggle to access timely, affordable treatment, particularly those in regional areas or on the Age Pension. As our population ages and macular disease becomes more prevalent, equity of access must be at the heart of our response. For twenty-five years, Macular Disease Foundation Australia has shown what is possible when compassion, evidence, and advocacy work together. This report, *Seeing Change*, tells that story – and points us toward a future where losing sight is no longer accepted as inevitable.

I am proud to support this Foundation, grateful to everyone who has contributed to its mission, and hopeful – because I have seen, in my own family, the life-changing difference that vision-saving care can make.



**Ita Buttrose AC OBE
Patron**



Chair & CEO Welcome

Welcome

An organisation like Macular Disease Foundation Australia does not exist because of one person, or even one idea. It takes a village.

At the heart of that village are our paid staff – people driven by far more than a pay cheque. Their work is shaped by empathy, professionalism, and a deep sense of purpose to their work.

Many have vision science and health backgrounds, some have personal experience caring for relatives with macular disease, but all want to make a significant contribution and change the outcomes for people living with macular disease.

We acknowledge and thank our past and present CEOs, dedicated staff, Board members and Chairs, whose stewardship, governance and long-term vision have guided our Foundation through 25 years of growth and change.

We are equally grateful to our medical and research committee members and expert advisers – leaders at the very top of their fields who so generously donate their time, insight and expertise to advance care, research and discovery.

Our volunteers give their time, wisdom and compassion freely, strengthening our connection to the community we serve. Standing alongside them is an often invisible, steadfast army of donors and Visionary Partners, together with our corporate and government supporters. Their belief in our mission makes progress possible.

This anniversary is not just a milestone. It is a tribute to every member of our village who make our work possible.



**Professor Sanchia Aranda AM
Chair**



**Dr Kathy Chapman
Chief Executive Officer**

Founding Director's Message

Our Beginnings

When the Foundation was established 25 years ago, the outlook for people diagnosed with macular degeneration was bleak.

At that time, there were no effective treatments and limited public awareness. Age-related macular degeneration was the commonest cause of blindness in Australia, yet only about 2% of people had heard of it.

As an ophthalmologist working at the frontline of care, I saw how profoundly macular disease affected people and their families. The community needed far more than clinical care alone. Yet beyond the clinic, opportunities for education, prevention and support were scarce.

One of my patients, recognised the urgent need for a dedicated, patient-centred organisation – one that could support individuals and carers, promote prevention through lifestyle and early detection, and engage governments to recognise macular disease as a national health priority.

The Macular Degeneration Foundation – now known as Macular Disease Foundation Australia – was created to meet that need.

Looking back, it is impossible to single out one achievement because the Foundation has delivered on its core purpose – to reduce the impact of macular disease through education, research, and advocacy. Our public awareness grew from almost nothing to becoming part of the national conversation, off the back of our 'How's your macula?' TV campaign. There's a lot to be proud of.

In the past 15 years we have witnessed extraordinary improvements in our ability to help prevent blindness in patients with macular disease. The introduction of new therapies – photodynamic therapy and intravitreal injections of anti-VEGF drugs – has been game changing.

There is now an enormous amount of research being carried out on better ways to treat macular disease. Looking ahead, I am optimistic that future treatments will be more effective, less burdensome, and increasingly able to preserve sight over a lifetime.

I'm relatively confident that the era of frequent eye injections will soon be over, and we will be able to control dry AMD with tablets and or gene therapy by the time the next 25 years are up.

We should look to the future with confidence and optimism.



**Dr Paul Beaumont AM
MBBS FRACS FRANZCO
Founding Director**

Celebrating 25 years of impact



Macular Degeneration Foundation Limited is established by Dr Paul Beaumont AM and Professor Paul Mitchell AO on 4 May.

The Foundation leased commercial premises to open its first offices and employed its first staff.

Ita Buttrose, AC OBE, joins the Foundation as Patron.

The first anti-VEGF drug is approved and listed on the PBS, revolutionising macular disease care; 8000 people attend our education sessions; our first Galaxy Poll puts awareness of macular degeneration at 57%.

Patron Ita Buttrose and dietitian Vanessa Jones publish the first Macular Degeneration Cookbook. Translated information resources are released; blindness is the same in any language.

The new Research Committee awards its first research grants to Professors Paul Mitchell AO and Robyn Guymer AM.

We become the Macular Disease Foundation Australia; the name change reflecting the need to support people with all forms of macular disease, not just AMD.

We are the major contributor to The Economic Impact of Diabetic Macular Oedema in Australia report published by Deloitte Access Economics.

Our first report reviewing the evidence of low vision aids and technologies, Low Vision, with The George Institute for Global Health is published.

Federal Health Minister the Hon. Greg Hunt launches the National Strategic Action Plan for Macular Disease.

2,000 people complete our first Social Impact Survey, telling us how macular disease impacts on their daily life; the Check My Macula online quiz and Grant Family Fund launch; the inaugural Ita Buttrose Oration at the National Press Club.

Our report, Investing to Save Sight, with PwC Australia provides powerful economic modelling on the benefits to government of increasing access to macular disease treatments.

We invest more than \$1 million into new research grants, taking total research funding to \$6.9 million since 2011. Eye Connect expands to diabetes-related eye conditions.



We attract our first government grant – from NSW Health – and first corporate sponsorship.

Our first national 'awareness week' is fronted by Patron, Thorn Birds author Colleen McCullough AO. Advocacy work begins with a roundtable conference on the cause, treatment and effect of macular disease.

The first federal funding is received, for education tours across Australia. A collaboration with Beyond Blue highlights the significance of depression in those living with AMD.

The iconic How's Your Macula? TV commercial airs for the first time.

Community awareness of macular degeneration rises to 85% of people aged 50+.

Our first economic report, Eyes on the Future, with Deloitte Access Economics providing the most comprehensive information on macular degeneration is published.

Jean Kittson AM joins the Foundation family as Ambassador. Our first partnership with Diabetes Australia to raise awareness of diabetes-related eye disease.

We log the 140,000th call to our National Helpline since initiation. Our Awareness Week campaign, featuring Ita Buttrose and Jean Kittson, targets Baby Boomers.

Macular Disease Foundation launches, Journey to See, a report showcasing Australia's world leading outcomes for AMD treatment.

We respond rapidly to the COVID-19 pandemic with public awareness and telephone campaigns highlighting the need to maintain eye injection treatment despite lockdowns.

After intense lobbying, we have a major win in the fight against a proposed cut to the MBS rebate for sight-saving injections.

Eye Connect, Australia's first macular disease support service, is launched to assist and care for people living with AMD.





“
The peer-to-peer service is beneficial to both me and the recipients. I am helping people with AMD, but I feel I’m also helping in a small way to make their day better.

– Clare, volunteer

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For two decades, Clare has volunteered with Macular Disease Foundation. In that time, she’s done just about everything – from attending events, to mailing out newsletters, and now supporting members of the macular disease community by phone as part of the peer-to-peer support service. Coming into the office every Tuesday, Clare built a strong connection with five other volunteers; the gang of six affectionately known as “the A team”.

“We all came from different backgrounds but enjoyed the company and had lots of laughs. Two of the group had AMD, the others had relatives or friends with macular disease.

“In 2020 I was diagnosed with AMD... I was shocked but I felt relieved knowing I would be supported by the Foundation. This was a great comfort to me and continues to be. “Being a volunteer for 20 years, I have had the privilege of seeing the Foundation staff at work, and their strong commitment to kindness, understanding, care and professionalism for the macular disease community.”

National Helpline

More than 3,700 calls to our Helpline each year. A woman from Perth, now 94, one of our first callers, recently reconnected to say the Helpline helped her to live focused on what she could do, rather than what she couldn’t.

Health Publications

The Foundation has produced over 60 publications – from one page fact sheets to comprehensive booklets – on the most prevalent macular disease conditions and topics including low vision aids, nutrition, treatments and supplementation. From Amsler grids to macula menus, low vision badges and our Vision Voice newsletter, these resources support people at every stage.

Education Sessions

What began in community halls has grown into a national education program, now delivered through live and recorded webinars, videos and podcasts. These sessions help people understand their risk, reduce it where possible, and learn how to live well after a diagnosis.

Mac Mates

Sometimes you just need to hear a friendly voice. Mac Mates began during COVID, when so many of us felt isolated. Instead of waiting for people to call us, we reached out. Today, trained volunteers with lived experience check in with community members, offering understanding and connection.

Peer Support Groups

We facilitate Peer Support Groups that meet face-to-face or online, usually every two months. Sessions are guided by skilled volunteer facilitators to ensure they are welcoming and informative. Sharing experiences with others who understand macular disease helps people feel less alone and better understood.

Eye Connect

Built on 25 years of listening and evidence-based learning, Eye Connect is our flagship support service. As needs evolve and treatments advance, it will continue to grow – embracing new ways to connect and helping ensure people living with macular disease are supported now and into the future.

Eye Connect: An Evolution in Support

“ It has been a helpful service that strengthened my understanding of the disease during a stressful time of change. The information shared was useful, helpful and informative.
 – Eye Connect member ”

For 25 years, Macular Disease Foundation has supported hundreds of thousands of people via our Helpline and written resources, helping them better understand and manage their diagnosis. But we wanted to know what more we could do. We began by listening to our community and learning directly from them about what support they needed most.

91% of Eye Connect participants say resources are both easily accessible, and easy to understand.

In response, we designed Eye Connect – an accessible service for people living with any stage of AMD or diabetes-related eye conditions, regardless of treatment status.

Eye Connect offers free, tailored support that considers a person’s diagnosis, any treatment they’re receiving, their vision status, and the real-world impact on daily life.

More than 1000 people with AMD or diabetes-related eye conditions have signed up to Eye Connect since May 2024.

As an evidence-based organisation, we partnered with experts and undertook a comprehensive series of research projects, including focus groups, surveys, and literature reviews.

What we found were significant gaps in support between appointments with eye health professionals.

81% of Eye Connect participants say they now better understand their AMD and how it affects them.

More than 2,200 phone calls each year by the Eye Connect team, checking in on community members and providing information and support.

The results have been encouraging, with Eye Connect members overwhelmingly endorsing the service. Crucially, while recent data show 20% of people discontinue intravitreal injections after one year – rising to 50% after five years – 95% of Eye Connect participants on intravitreal injection treatment have maintained their recommended treatment schedule while engaged in the service.

74% agree or strongly agree that these check-in phone calls help them feel more supported and heard.

The literature tells us only 56% of people with AMD recall receiving a clear diagnosis. In contrast, 81% of Eye Connect members report better understanding their AMD and its effects.

Importantly, Eye Connect is addressing the emotional impact of diagnosis. Three-quarters of participants say the service helps them feel more supported and heard.

Still in its infancy, Eye Connect will continue to evolve, expanding resources and finding new ways to support our macular disease community.

“ We need more than just treatment, we need support that sees the whole person, not just the condition.
 – Eye Connect member ”

“ I often had questions after I left the clinic, so I joined Eye Connect for support in between appointments. They listened to my emotions, and they listened to my questions and gave me answers. And I always come away feeling calmer because I’ve felt heard and understood.
 – Sue, Eye Connect member ”



“How’s your macula?”

It was a simple question – and a national TV campaign – that helped bring macular disease, and particularly age-related macular degeneration (AMD), into everyday conversation.

The campaign’s plain language and direct call to action proved powerful, marking a turning point in public awareness for what was then the Macular Degeneration Foundation.

Twenty-five years ago, awareness of the macula was pitifully low. Co-Founder Dr Paul Beaumont AM, estimated it at just 2%. In the early days of advocating for macular degeneration to be recognised as a national health priority, he recalls one senior politician repeatedly referring to it as “Immaculate D generation” – a telling reflection of just how little the condition was understood.

From those beginnings, awareness efforts evolved rapidly. What started as Macular Degeneration Awareness Week grew into Macula Month by 2018, and grassroots activities such as staff

handing out flyers to city office workers transformed into sophisticated, multi-channel public awareness campaigns. Alongside this evolution came a growing understanding of how to cut through with messages that were clear, credible and relevant.

At the heart of every campaign has been a consistent set of messages: that one in seven people over the age of 50 will show signs of AMD; that risk increases with smoking and family history; and that diabetes-related eye disease is the leading cause of irreversible blindness in working-age Australians.

Just as importantly, campaigns have focused on what people can do – the importance of regular eye checks, modifiable risk factors, and the simple truth that “early action saves sight”.



Hundreds of thousands of Australians have checked their macula risk.

Since launching in 2021, more than 275,000 people have completed the *Check My Macula* online quiz to better understand their risk of age-related macular degeneration.

Macula Month has become so embedded in the national calendar that it is now embraced by the eye health profession as if it were their own. Each year, we support healthcare professionals with free media toolkits, in-practice posters and digital resources, helping extend the reach of Macula Month messaging deep into communities across Australia.



Community awareness of age-related macular degeneration has grown significantly.

Awareness among Australians aged 50–70 increased from 57% in 2007 to 83% in 2025, based on our national YouGov/Galaxy polling.



A major step forward came with the launch of the *Check My Macula* online quiz, underpinned by the call to action “60 seconds could save your sight”. Promoted through a cheeky, irreverent television campaign voiced by Jean Kittson and Shane Jacobson, the quiz guides users through key risk factors and directs them to trusted information and practical next steps.

Every Macula Month is carefully coordinated around timely issues and media opportunities, supported by real-life stories from people living with macular disease, as well as the authoritative voices of our Patrons and Ambassadors. These stories have helped put a human face to the statistics, reinforcing why awareness matters in the fight for sight.

To measure impact, we have committed to regular YouGov/Galaxy polling, building a unique longitudinal picture of how community awareness and behaviour have changed over time. Together, these initiatives tell a powerful story: that sustained, evidence-based awareness can change conversations – and ultimately, save sight.



Regular macular checks are now routine for Australians at risk.

By 2016, 86% of Australians aged over 50 had undergone a macular check in the previous two years, up from 33% in 2007 and 69% in 2014. Today, in 2026, three in four Australians over 50 have had an eye examination in the past two years.

Awareness

How much of the family will you see in the future?

Macular Degeneration (MD) causes central vision loss and is now the leading cause of blindness in Australia. You could have Macular Degeneration in the early stages without knowing. If you're over 50 or have a family history of MD, have your eyes tested and make sure the macula is checked. Don't risk blindness. Visit your Optometrist or Ophthalmologist or call the MD Foundation on 1800 111 709.

Macular Disease Foundation AUSTRALIA

How's your macula?

Macular Degeneration (MD) is the leading cause of blindness* in Australia. You could have MD in the early stages without even knowing. If you're over 50 or have a family history of MD, early detection is vital. Visit your Optometrist or Ophthalmologist. Have an eye test and make sure your macula is checked.

Call the MD Foundation on 1800 111 709 for a free information kit.

Macular Disease Foundation AUSTRALIA

“Let's stop Australians going blind. For me, it's personal.”

“My father had macular degeneration”

4 ways to fight Macular Degeneration:

1. Get an eye test and make sure your macula is checked.
2. Eat a healthy diet.
3. Don't smoke or quit if you do.
4. Know your family history.

Check My Macula

Only a minute is all it takes to check your risks for macular disease. Get started at www.CheckMyMacula.com.au or call 1800 111 709.

Call 1800 111 709 for your FREE information kit.

Macular Disease Foundation AUSTRALIA

Treat yourself right to save your sight

Check My Macula

Only a minute is all it takes to check your risks for macular disease. Get started at www.CheckMyMacula.com.au or call 1800 111 709.

Macular Disease Foundation AUSTRALIA

You've got your mum's eyes

Do you have her macular disease?

Early action saves sight. Get your macula checked today.

Macular Disease Foundation AUSTRALIA

You've got your dad's eyes

Do you have his macular disease?

Early action saves sight. Get your macula checked today.

Macular Disease Foundation AUSTRALIA

Are you at risk of Macular Disease?

Early detection can save your sight. Free information kit available from Macular Disease Foundation Australia. Helpline: 1800 111 709

Macular Disease Foundation AUSTRALIA

Our focus is your vision

Don't let Macular Degeneration take away the centre of your world

MUST DO: Have an eye test and make sure my macula is checked

Call the MD Foundation on 1800 111 709 www.md.foundation.com.au

Macular Degeneration takes away central vision and is the leading cause of blindness* in Australia. You can have the early signs without knowing. Early detection is vital. How's your macula?

Macular Disease Foundation AUSTRALIA

Macular Degeneration Don't be blind to the risks.

- Are you over 50?
- Do you smoke, or have you smoked?
- Has anyone in your family had Macular Degeneration?

If you could tick any of the boxes above you're at risk of developing Macular Degeneration, the leading cause of blindness* in Australia. You can have MD in its early stages without knowing. Don't risk it. Have an eye test and make sure your macula is checked. Early detection is vital.

Call the MD Foundation on 1800 111 709 for a free information kit. www.md.foundation.com.au

Macular Disease Foundation AUSTRALIA

How's your macula?

Macular disease is the leading cause of vision loss and blindness in Australia

If you're over 50

- ✓ Have an eye test and macula check every two years.
- ✓ Never ignore any changes in your vision.
- ✓ Eat an eye friendly diet and maintain a healthy lifestyle.
- ✓ Know your direct family eye health history, you could be at risk.

Order a FREE information kit and Amsler grid today 1800 111 709

Macular Disease Foundation AUSTRALIA

I'd rather read the paper than go blind

One in seven have some evidence of AMD. So, are you at risk?

Take the Check My Macula quiz and, in one minute, you'll know your risk factors. www.CheckMyMacula.com.au

Macular Disease Foundation AUSTRALIA

I'd rather travel the world than go blind

You have 50% risk of developing AMD if you have a direct family history.

To learn more about your risks, go to www.CheckMyMacula.com.au

Macular Disease Foundation AUSTRALIA

“ You can be mentally and physically in good health but then you lose your sight, and you have to rely on others simply to drive down the street for milk, or to pay your bills. – Jean Kittson AM, Ambassador ”

Jean Kittson's connection with macular disease is deeply personal, profoundly inspiring, and vitally important to the eye health awareness message that Macular Disease Foundation Australia has championed for the past 25 years. As one of Australia's most loved entertainers and storytellers, Jean has brought humour, warmth, and lived experience to her role as an Ambassador. Both of Jean's late parents lost their vision to macular disease – her mother, Elaine, to age-related macular degeneration, and father, Roy, to macular dystrophy. Jean was open about the challenges – and joys – of caring for elderly parents with low vision, as well as her concerns about the hereditary nature of AMD.

“It bothers me that I might develop AMD because I have seen what has happened to my mother. If you lose your sight, you also lose so much of your independence,” Jean said. “Quite frankly, I don't manage my general health down to the last detail, but once a year, I make sure I have an eye exam.”

Jean's advocacy goes beyond sharing her family's story, literally lending her voice to national campaigns such as the Check My Macula initiative, inviting Australians over 50 to understand their risk factors for macular disease. Jean's courage in speaking openly about the impact of macular disease has helped raise awareness, deepening community understanding of macular disease.



Healthcare Engagement

“

Macular Disease Foundation fills the gap that we as clinicians may not have the expertise or the time to provide.

– Associate Professor Fred Chen, Lions Eye Institute

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From the beginning, Macular Disease Foundation has acted as a bridge between the clinic, and the everyday realities people face after a diagnosis of macular disease. We work alongside health care professionals to reinforce clinical advice and ensure patients feel informed, supported and connected. We are guided by the expertise of ophthalmologists, optometrists and other health professionals. Their input shapes the information we provide and ensures our resources reflect best practice and real-world clinical experience. We are grateful for their ongoing collaboration, enthusiastic adoption of our Macula Month awareness initiatives, and for referring their patients to Eye Connect, our flagship support service. Through partnerships with the eye health sector, we help improve health literacy for professionals. We deliver education programs and CPD opportunities across the health workforce, providing 13 online courses, regular webinars and in-person education sessions. Our reach extends to equipping the next generation of eye care professionals. Collaborating with universities, we deliver lectures to orthoptics, optometry and vision science students. Our university engagement also encourages students to educate patients, understand referral pathways, and consider non-clinical career paths that contribute meaningfully to patient wellbeing. Our work with students is about more than education – it’s about partnering with them to embed holistic care for people diagnosed with macular disease.

Together with the health care professionals of today and tomorrow, we will continue to strengthen care pathways and ensure no one faces macular disease alone.



Advocacy

Advocacy

Macular Disease Foundation Australia’s advocacy has been a defining force in delivering meaningful change for people living with macular disease.

By placing lived experience at the centre of policy discussions, we are helping to shape a health system that is more responsive, equitable and focused on the fight for sight. Our advocacy amplifies the voices of the macular disease community and translates them into action.

Central to this is the 2019 National Strategic Action Plan for Macular Disease, which firmly positioned macular disease on the national health agenda for the first time. The Plan outlines actions across prevention and early detection; treatment; support for people living with macular disease; and data and research. It provides a framework for coordination and targeting of limited healthcare resources across all levels of government.

Expanding Access

We’ve played a critical role in advocating for increased access to effective and affordable treatments. It’s a fight we’ll keep showing up for.

We were on the frontlines in 2006 and 2007, advocating for the first anti-VEGF eye injection treatment to be fast-tracked through the regulatory system and funded through the Pharmaceutical Benefits Scheme (PBS). This landmark success radically transformed the outlook for people with neovascular macular disease.

Today, we continue to advocate for approved treatments to be included on the PBS, ensuring timely and affordable access for all who need them.



Affordable Care

In 2022, we successfully campaigned to prevent proposed cuts to the Medicare rebate for eye injections. Had these changes gone ahead, an estimated 47,000 Australians would have been at risk of avoidable blindness due to unaffordable treatment. Our coordinated advocacy protected access to care for thousands of people who rely on ongoing treatment to preserve their sight.

Investing to Save Sight, released in 2023, highlighted cost and access to treatment as two of the main reasons for people discontinuing treatment. Barriers include limited access to affordable or bulk-billed care for low-income earners and pensioners, and challenges accessing treatment in rural and remote Australia.

Our economic modelling demonstrated that modest government investment could increase treatment persistence by 25%, saving the sight of an additional 22,000 vulnerable Australians and adding up to two billion dollars to the Government's bottom line. This evidence strengthens our case for reform and reinforces the

value of prevention over avoidable vision loss. Behind every statistic is a person trying to hold onto their sight. Quite simply, we can't accept that we have treatment to stop people from going blind, yet some Australians can't access eye injection treatment services. Most recently, we secured a positive outcome in advocating for changes to the

Medicare Benefits Schedule that would have prevented patients from claiming eye injection treatments through private health insurance in day surgery facilities and private eye hospitals. In a system where public injection services are limited or overstretched, this protects access to treatment and avoids significant increases in out-of-pocket costs.

“For me being part of the campaign to stop the proposed reduction in the Medicare rebate... was a lifelong highlight which assisted millions of Australians.”
– Rohan, Community Reference Group member, lives with wet AMD.



We must never forget that real people's lives depend on the Foundation's advocacy work. Community member Mike joined our 2022 campaign against the proposed Medicare rebate cut for sight-saving eye injections.

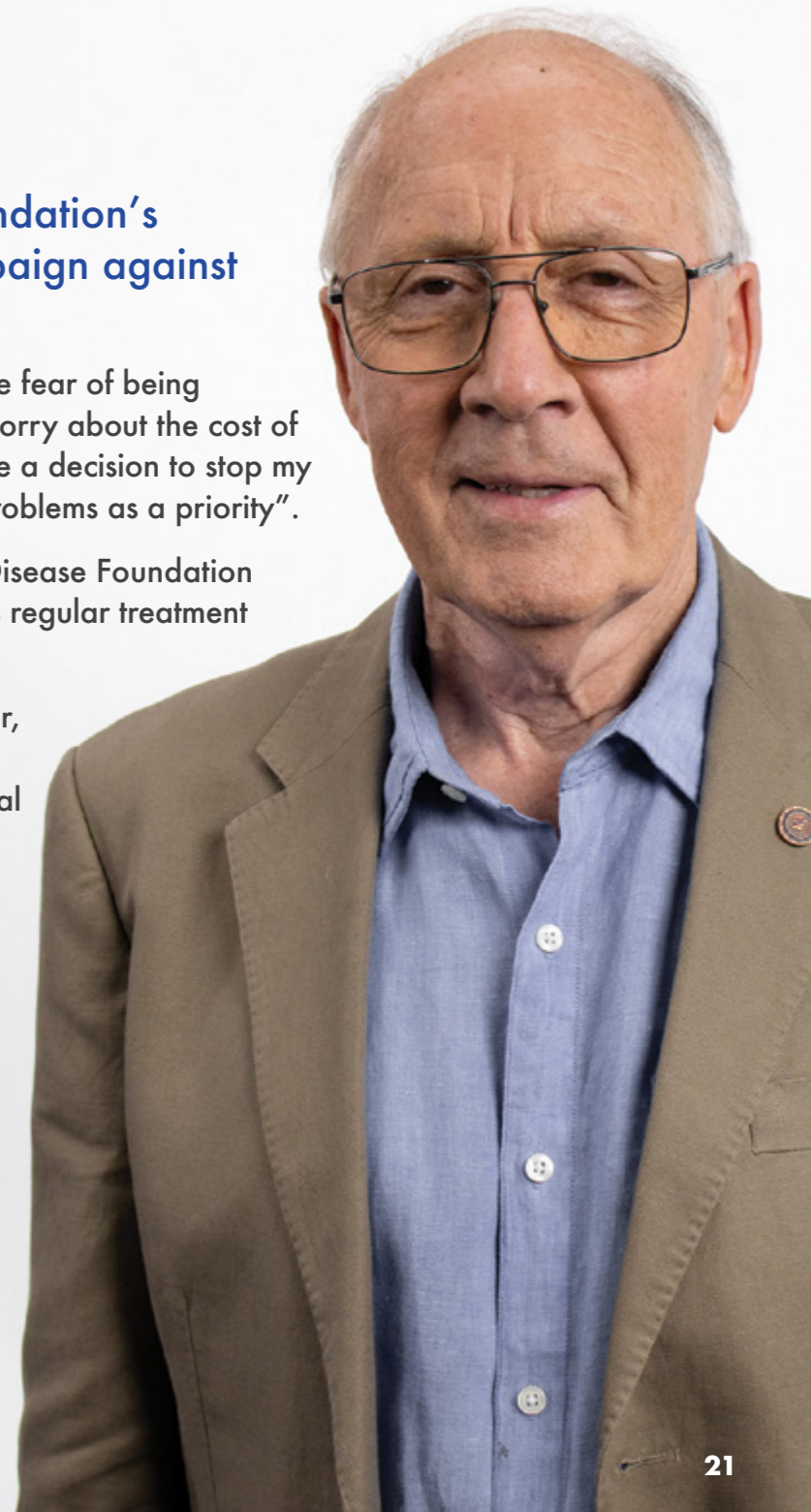
Our success in that campaign meant Mike, then approaching 80, could retire, without the fear of being unable to afford his sight-saving treatment. "I can now get on with life and not have to worry about the cost of maintaining my eyesight." Had the rebate been cut, "I would have definitely had to make a decision to stop my treatment when I stopped work, because I would have to look after my wife's medical problems as a priority".

Our strongest advocates are those with lived experience, like Mike – and like Macular Disease Foundation Ambassador, the Hon Jillian Skinner AM, former NSW Minister for Health, who receives regular treatment for wet AMD.

"These eye injections are sight saving for me as I'm already blind in my left eye. However, I am one of the lucky ones who benefits from access to excellent clinical care because I am based in metropolitan Sydney, and I receive affordable treatment." Despite the critical importance of preserving sight, many people living with AMD are struggling to afford essential treatments because the costs are simply too high... and access to affordable and consistent treatment is simply too difficult, particularly in rural and regional areas.



“The situation is critical for our older and more vulnerable Australians.”
– The Hon. Jillian Skinner AM, Ambassador



Research

For 25 years, Macular Disease Foundation Australia has stood at the forefront of the fight against macular disease; supporting people living with vision loss today while investing in discoveries that will change lives tomorrow. At the heart of this work is research: the engine that drives understanding, innovation and hope.

As an ophthalmologist, I've seen the profound impact macular disease can have on daily life, affecting the ability to read, drive and maintain independence. For many of my patients, it brings emotional, social and practical challenges that extend far beyond eyesight alone. While there is currently no cure, the past 25 years have seen remarkable progress that has transformed outcomes for many people, and reshaped what is possible.

Advances in treatments for conditions such as neovascular (wet) age-related macular degeneration have dramatically improved vision outcomes. At the same time, breakthroughs in diagnostic imaging now allow clinicians to detect disease earlier, monitor it more precisely, and provide tailored treatments. These tools have fundamentally changed the way macular disease is managed.

As a researcher, I'm excited by the growing momentum in scientific discovery, particularly in areas of high unmet need such as geographic atrophy. Promising therapies, including complement inhibitors, gene therapies and stem cell approaches, are expanding the global research landscape. Emerging technologies, including artificial intelligence, are opening new possibilities, helping researchers analyse complex data, predict disease progression and refine treatment strategies with greater accuracy than ever before.

What makes this progress possible is sustained investment in Australian research and the collaboration of scientists, clinicians and people living with macular disease. Through its Research Grants program, Macular Disease Foundation Australia has proudly supported leading and emerging

researchers to deepen understanding of macular and retinal diseases, explore innovative ideas, and improve quality of life for those affected – not only physically, but emotionally and socially.

Research is more than scientific discovery. It is a long-term commitment to preserving sight, restoring independence and building a future where macular disease no longer defines what people can see, do or hope for.



Professor Paul Mitchell
AO MBBS MD PhD FRANZCO FRACS
FRCOphth FAFPHM

National Research Advisor
Founding Director
Macular Disease Foundation Australia

Social Impact Research

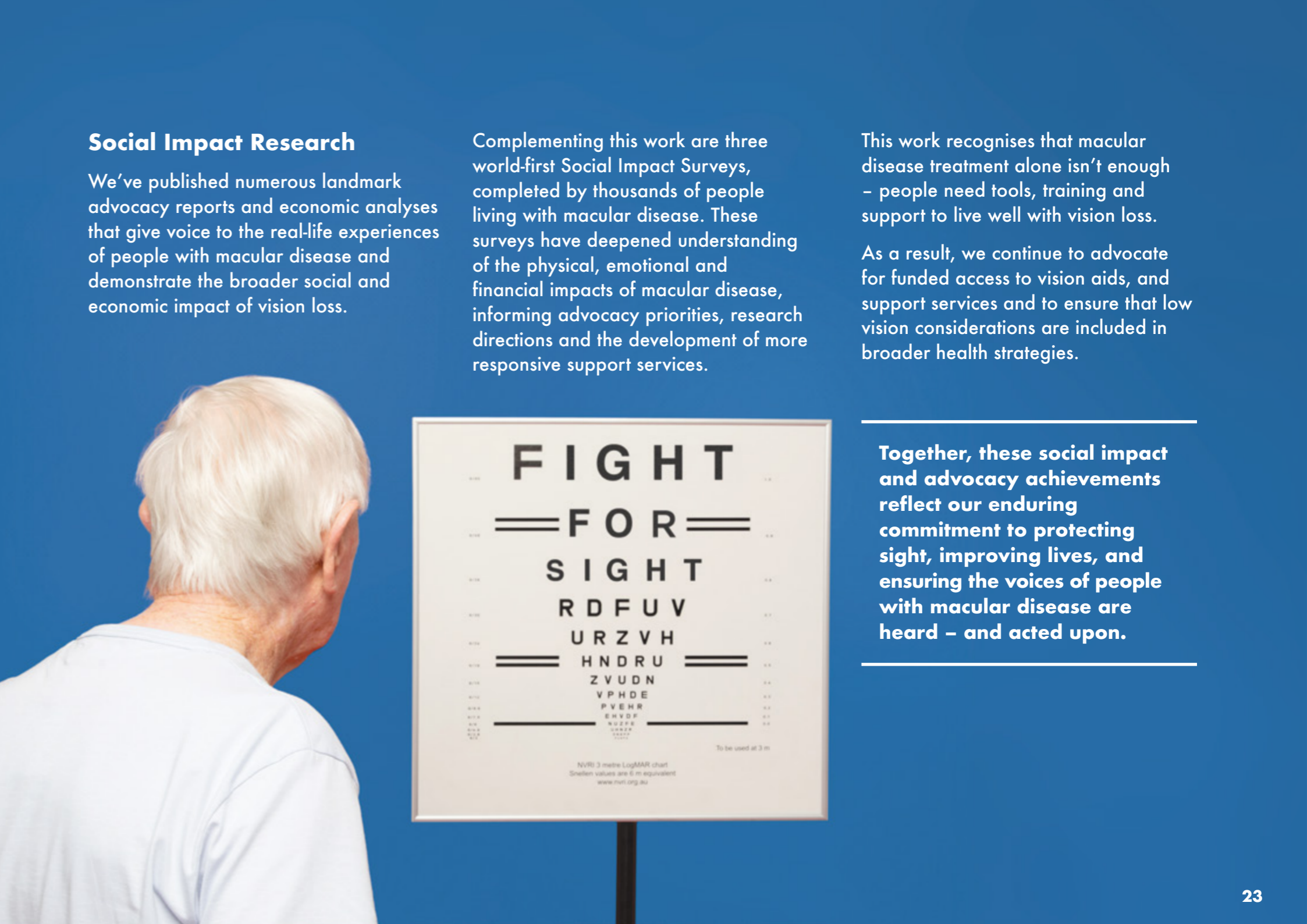
We've published numerous landmark advocacy reports and economic analyses that give voice to the real-life experiences of people with macular disease and demonstrate the broader social and economic impact of vision loss.

Complementing this work are three world-first Social Impact Surveys, completed by thousands of people living with macular disease. These surveys have deepened understanding of the physical, emotional and financial impacts of macular disease, informing advocacy priorities, research directions and the development of more responsive support services.

This work recognises that macular disease treatment alone isn't enough – people need tools, training and support to live well with vision loss.

As a result, we continue to advocate for funded access to vision aids, and support services and to ensure that low vision considerations are included in broader health strategies.

Together, these social impact and advocacy achievements reflect our enduring commitment to protecting sight, improving lives, and ensuring the voices of people with macular disease are heard – and acted upon.



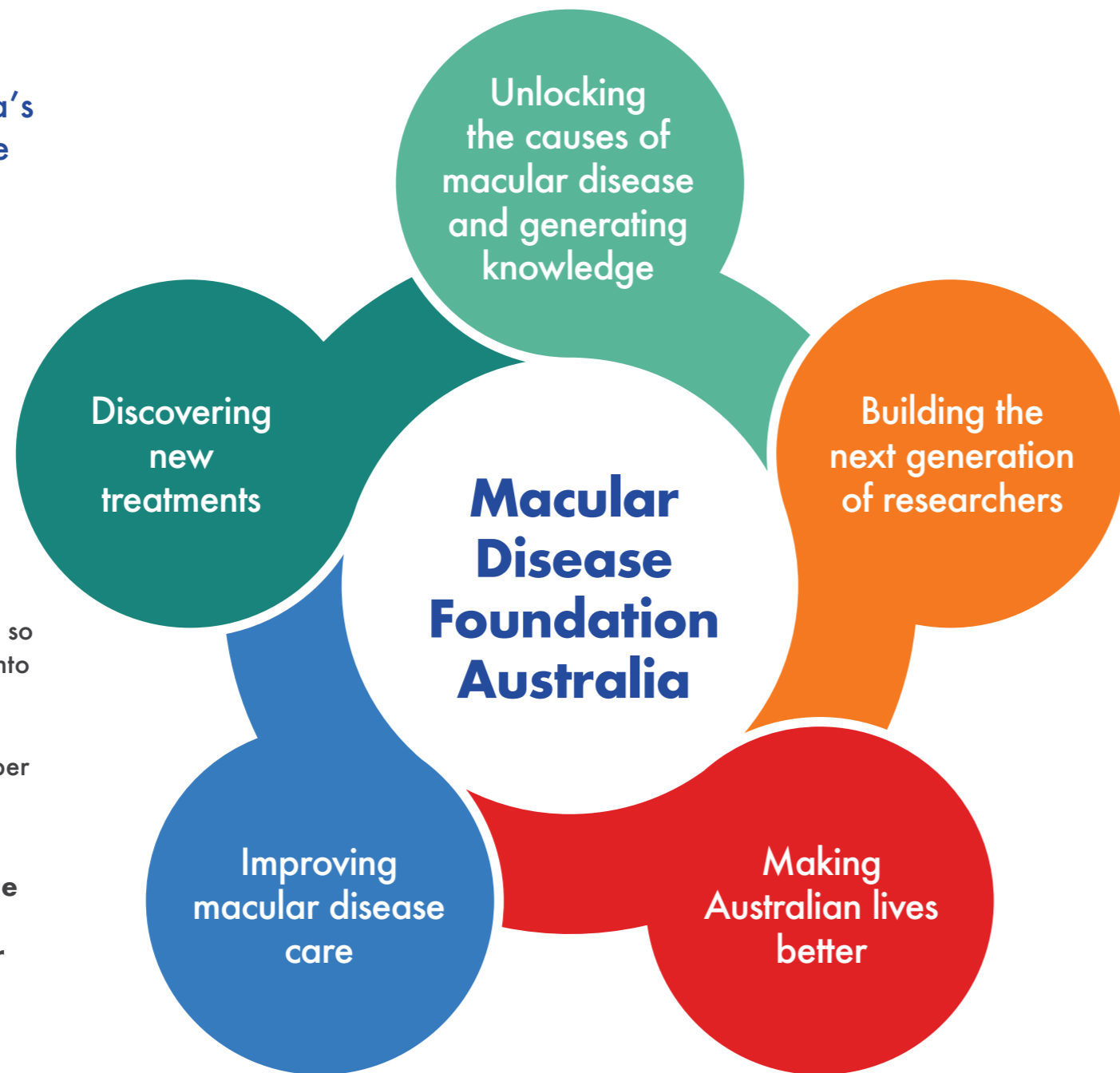
Research

Macular disease is Australia's leading cause of irreversible low vision and blindness, affecting around 1.9 million people – a figure that continues to rise.

As the only national organisation dedicated exclusively to reducing its impact, we're tackling a rapidly escalating health challenge that affects individuals, families and carers across the country.

With the support of our generous Visionary Partners and donors, we've so far invested more than \$6.9 million into Australian macular disease research. But the task ahead is far greater still. By 2030, we aim to double the number of research projects we fund – an investment of more than \$2 million.

In the fight for sight, knowledge is our strongest defence, and research the pathway to better treatments, prevention and, ultimately, cures.



Investing in Breakthroughs

More than \$6.9 million invested in groundbreaking Australian macular disease research, including \$1.7 million to discover new treatments and targets, \$3.7 million to improve diagnosis and identify risk factors, \$1.6 million to improve eye healthcare and support.

More than \$1 million of the \$6.9 million has supported our next generation of researchers.

Research with Global Reach

Over 15 years, 100% of funded researchers have presented their findings to the scientific community. Of the funded researchers, 29 have published more than 100 articles in leading scientific journals internationally. In addition, more than 50% of researchers reported innovative dissemination of findings (e.g. through social and mainstream media).

Building Momentum

50% of MDFA-funded Lead Researchers were awarded follow-on funding and achieved further grant success directly linked to the research we funded.

80% of researchers reported receiving a promotion or fellowship awarded as a direct outcome of the research funded by Macular Disease Foundation Australia.

Growing the Next Generation

20% of researchers funded by Macular Disease Foundation Australia are rising stars with fewer than five years' experience.

64% of the researchers we have funded are women.

Evidence That Drives Change

We commission and undertake our own research to expand the evidence base on macular disease. For example, our **economic modelling** and 2023 report, *Investing to Save Sight*, influenced health policy changes, helping to convince the Australian Government not to cut Medicare rebates for eye injections.

Giving Voice to Community

Since 2023, a 14-member Community Review Panel of people with lived experience of macular disease has helped shape our research funding decisions.

Working alongside expert reviewers, they ensure community priorities directly inform grant assessments.

Celebrating Inquiry, Innovation and Impact

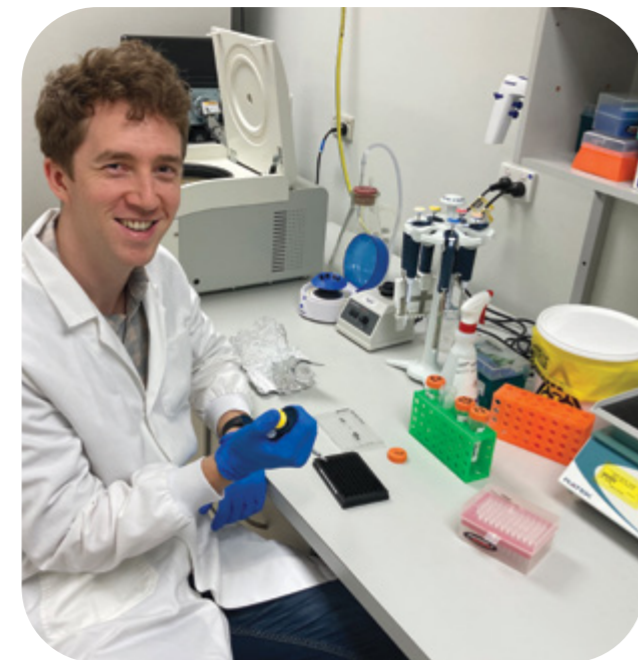
Macular Disease Foundation Australia champions research as the driving force behind the fight for sight.

We recognise that lasting change only comes through sustained investment in discovery and collaboration, and that authority comes through evidence. Our Research Grants Program supports research that advances knowledge today while shaping the breakthroughs of tomorrow.

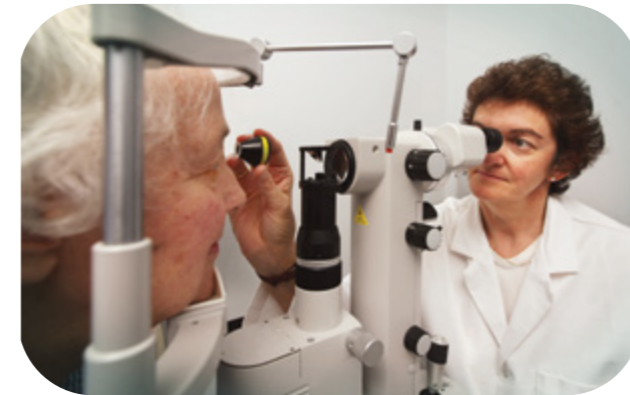
Deepening Understanding of Macular Disease

At the heart of our Research Program is a commitment to expanding understanding of macular disease – its causes, progression and impact on people’s lives.

The researchers we’ve supported have advanced knowledge across both common and rare macular conditions, uncovering critical insights into risk factors, disease mechanisms and early indicators of progression.



This foundational work has helped transform how macular disease is recognised and managed, laying the groundwork for more timely and effective care.



Discovering New and Better Treatments

A defining focus of our research investment has been the pursuit of new treatments, particularly in areas where options have historically been limited. We’ve supported pioneering research into dry age-related macular degeneration (geographic atrophy), diabetic macular oedema, inherited retinal diseases and other complex conditions. Innovative approaches – including stem cell and organoid models; regenerative medicine; biomaterials to repair retinal tissue; and the repurposing of existing medicines – are expanding what is possible and opening promising new pathways towards treatments that are more effective, durable and patient-friendly.

Improving Detection, Monitoring and Care

We’ve also funded research delivering meaningful advances in how macular disease is detected and managed. Research into imaging, risk assessment and disease monitoring has strengthened clinicians’ ability to identify vision-threatening changes earlier and tailor treatments more precisely. Large-scale registries and data-driven studies supported by our funding have contributed to improved standards of care, helping translate research findings into better outcomes for patients in real-world settings.

Advancing Equity and Access

Beyond the laboratory and clinic, we have invested in research that improves access to eye health care and promotes equity. Projects have explored innovative models of care for people living in regional and remote Australia, strengthened eye health services for Aboriginal and Torres Strait Islander communities, and improved diagnosis and support for children and families affected by inherited retinal diseases.

This work reflects our enduring commitment to ensuring research benefits reach all Australians.

Building Future Research Capability

Nurturing the next generation of researchers has been central to our vision. By supporting early and mid-career researchers and encouraging bold, innovative ideas, we’ve helped develop emerging leaders in eye health research.

Many have gone on to build influential research programs, mentor future scientists and contribute to Australia’s long-term research strength – amplifying the impact of our investment well beyond individual projects.

Shaping Policy and Lived Experience

We have always led the way in commissioning research that captures the lived experience of macular disease. Social impact studies, economic modelling and policy-focused research have deepened understanding of quality of life, mental health and treatment persistence,

while strengthening the evidence used to inform health policy. This work has helped ensure research drives meaningful, system-level change alongside scientific discovery.

As Macular Disease Foundation Australia celebrates its 25-year milestone, our research legacy stands as a powerful reminder of what sustained vision can achieve, as well as the growing possibilities ahead in the shared pursuit of preserving sight and improving lives.



A Legacy for Emerging Researchers

The Grant Family Fund was established through a generous bequest from the late Faye Grant, whose quiet dedication to her father, Ronald, shaped a powerful legacy for macular disease research.

When Ronald began losing his sight to AMD, Faye became his primary carer. She accompanied him to eye injection appointments, understood the importance of treatment, and enriched his final years with unwavering support. After her passing in 2019, Faye's generosity continued through a gift to MDFA – one that now fuels innovation for future generations.

First awarded in 2021, the Grant Family Fund is a biennial research stream within our Research Grants Program. It provides seed funding of up to \$50,000 to early-career Australian researchers pursuing bold, creative “blue sky” projects in macular disease.

The Fund is designed to challenge existing paradigms, explore new ideas and generate preliminary data that can attract larger-scale funding.

By investing in emerging researchers and high-potential concepts, the Grant Family Fund strengthens the pipeline of discovery, encouraging fresh thinking and accelerating progress toward better treatments and outcomes.

Through this lasting gift, Faye Grant's compassion lives on, advancing innovative research and offering hope to Australians living with macular disease.



FIGHT FOR
SIGHT



“

This type of blue-sky thinking is very hard to get funding for – it's seen as high-risk. But the Grant Family had vision. They wanted to fund novel ideas. This sort of creativity and new ideas and research wouldn't be funded otherwise.

– Associate Professor Anai Gonzalez Cordero, who received Grant Family funding in 2021 to help create a laboratory macula model for macular degeneration.

”



Investing to Support Impact

A strong research strategy must extend beyond laboratory discovery to include evidence that informs health systems and improves patient outcomes.

Since 2019, the Fitzpatrick Sykes Family Foundation has played a vital role in strengthening this arm of our internal research program.

Through targeted support of our social impact and economic modelling research, the Fitzpatrick Sykes Family Foundation has helped build a rigorous evidence base examining the broader consequences of macular disease, including the personal, social and economic burden on individuals, families and the healthcare system.

A landmark example was the commissioning of independent economic modelling in response to the proposed reduction in the Medicare rebate for intravitreal eye injections. By demonstrating that reduced access to treatment could result in up to 47,000 additional cases of avoidable blindness over five years, this

research helped convince the Australian Government not to cut the rebate. By investing in this critical research stream, the Fitzpatrick Sykes Family Foundation has strengthened our capacity to generate influential evidence that not only advances scientific understanding but protects access to sight-saving care.

Our ambition is to invest **\$1 million in macular disease research every year** – accelerating discovery, advancing treatments, and fast-tracking a cure. Your donation is not just a gift; it is an investment in ending vision loss for future generations.

Together, let's fight for sight.

Powerful Philanthropy

“ Her legacy lives on through this award, supporting sight-saving research and honouring her deep care for others.

– Kate Adams, Elisabeth's niece ”

A proud “bushie” from the Armidale region of New South Wales, Elisabeth Macdonald understood the risks of AMD. After witnessing her mother's experience, she remained vigilant with regular eye checks. Diagnosed with early AMD in 2005 and later wet AMD, timely treatment preserved her independence, allowing her to continue driving and reading music, activities that were central to her life.

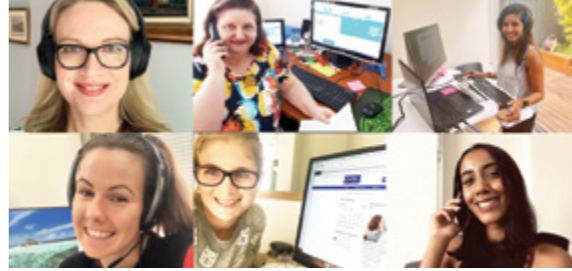
Throughout her lifetime, Elisabeth generously supported our research program, a commitment that culminated in a gift that became the Elisabeth Macdonald Memorial Award. The funding will be devoted to research that strengthens outcomes for regional and rural Australians with macular disease.



Advancing Understanding of Geographic Atrophy

The MDFA 25th Anniversary Award is a landmark investment of up to \$200,000 over three years to advance research and understanding of geographic atrophy, a late-stage form of dry AMD affecting an estimated 100,000 Australians. Informed by community and researcher feedback, this generous grant targets critical knowledge gaps, supporting work in genetics, risk factors, disease mechanisms, treatments and functional outcomes.

Together, these awards demonstrate how philanthropy powers bold research, accelerating discovery and delivering hope for Australians facing vision loss.



Thank you for your support

For 25 years, Macular Disease Foundation Australia has been guided by one enduring truth: we are our community.

From the beginning, people living with macular disease have shaped our purpose. They have shared their stories, challenges and hopes, ensuring our work responds to real needs and supports people at every stage of their macular disease.

Alongside them is an extraordinary group of staff and volunteers – at all levels. Through compassion, and lived experience, they ensure no one need face macular disease alone – offering reassurance, understanding and an empathetic ear when it matters most.

We are equally strengthened by working alongside healthcare professionals and researchers. Clinicians who see the value in the way we can extend care beyond the consulting room, while researchers pursue discoveries that drive progress towards better treatments, improved care and, ultimately, cures.

Together they ensure hope is matched with evidence and compassion with science.

None of this would be possible without the generosity of an army of faithful donors and the commitment of our corporate and government partners. Their belief in our mission fuels innovation, expands access to care and allows us to invest for the long term.

These distinct communities are woven together by a shared determination to protect sight and improve lives. As we mark 25 years, we do so with gratitude.

As we look ahead, we remain unwavering in our focus: standing with our community in the fight for sight.



Macular Disease Foundation Australia is supported by the generosity of individuals, corporations, trusts, foundations and government partners.

Many of the programs and initiatives we deliver across Australia are made possible thanks to the investment and commitment of our donors, bequestors, government, partners and social impact investors.

This anniversary publication has been generously funded by our partners



Support the Fight for Sight

Your support can be the catalyst for change as we work together to prevent and cure macular disease and to reduce the impact it has on the lives of millions of Australians. Together, let's fight for sight.

Visit: mdfoundation.com.au/donate



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To learn more about macular disease, join our Eye Connect service, or receive support for yourself or someone you care about, contact our National Helpline.

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