



Macular
Disease
Foundation
AUSTRALIA

VisionVoice

Spring Edition 2025



Join us in the *FIGHT FOR SIGHT*

Macular Disease Foundation Australia (MDFA) has welcomed a significant step forward in the fight for affordable, sight-saving treatment.

The Federal Government has postponed the reclassification of the Medical Benefits Schedule (MBS) item number for intravitreal (eye) injections, which would have barred many people from using private health insurance to pay for their treatment, from 1 July 2025 to 1 July 2026.

In a pre-election announcement, the Government has committed to further consultation with stakeholders including MDFA, to assess the impacts of these planned changes.

This decision is a relief for thousands of Australians. The proposed changes would have forced more than 12,200 people to pay out-of-pocket costs for their eye injections –

an essential treatment for several macular diseases – when delivered in private hospitals or day surgeries.

We heard from more than 100 distressed community members, worried about how they would be able to pay for these vital treatments if the Government's planned change was to go ahead. For many, these added costs would have made treatment unaffordable and continuing it nearly impossible, resulting in people unnecessarily losing their vision and going blind.

We are encouraged to see that the macular disease community has been heard on this issue, now we look ahead to what comes next.

Continued Page 2.

CEO Update

Macula Month in May was elevated by the Federal Election and our own election agenda, Fight for Sight. We took this opportunity to raise our concerns around the inequities of IVI treatment for neovascular AMD and speak to all sides of Government about affordable solutions that can help the most vulnerable in our society requiring treatment to save their vision.

Our recommendation is for the Government to introduce a new ophthalmology rebate on IVI treatment to help drive affordable and accessible eye injections for all. We have made headway but there is a long way to go, and we need your help to make these changes.

As mentioned in our lead story, you can help us stay front and centre in the Government's mind by writing to your local MP. Another way you can help is with a donation. MDFA receives only 30% of our funding from Government. You'd likely know that our services are free for all, and we can only do this with community support. A donation, big or small, will go a long way towards our work. If you're not in a position to support us now, a legacy gift in your Will is a very generous way you can help make macular disease a national priority and help us invest in Australia's leading research.

Generosity from our community, including an ongoing bequest gift, has made it possible to launch our largest round of research grants to date. These grants are a powerful investment in reducing the impact of macular disease, supporting a group of truly outstanding Australian researchers.

Congratulations to each of them, we're excited to see the meaningful impact their work will have in the years to come. You can read more about their projects in this edition of Vision Voice.



Thank you for your support.
We are very grateful.

Dr Kathy Chapman
Chief Executive Officer

Join us in the Fight for Sight Continued.

Beyond the pause: real, long-term reform is needed

While this pause in the decision about private health insurance is welcome, we are urging the Government to go further and address the fundamental issue: the lack of access to affordable sight-saving eye injections in Australia.

The current system is inequitable. We know that many people are faced with significant out of pocket costs for their sight saving eye injections. Treatment services in public hospitals are extremely limited, especially in regional and remote areas where people have to regularly travel for hours to reach more affordable options for treatment.

It's time for the Government to take action. Affordable and accessible eye injections must become a national priority to save the sight of the more than 108,000 people who need ongoing eye-injection treatment to save their sight. MDFA is part of the conversation, but we need your continued support.

Here's how you can help

Your voice matters. Help us keep up the momentum towards change by contacting your Federal MP. We've made it easy with a pre-written letter template you can download from our website today. Together, we can make sure saving sight remains a high priority in Australia's healthcare future.

Thank you to everyone who has already done so as part of our Fight for Sight advocacy campaign. MDFA's work isn't done. As the voice of the macular disease community, we'll continue advocating for meaningful, lasting change with the newly elected Federal Government.

Visit MDFA's website for our full recommendations to Government to make fair access to affordable treatments a reality for everyone.
www.mdfoundation.com.au

Sight preservation should be a national priority

As part of our ongoing advocacy efforts, an opinion editorial by The Hon. Jillian Skinner AM – former NSW Minister for Health and current MDFA Ambassador – was featured across the News Corp Australia Network in Macula Month.

As an advocate for the health of Australians, I am deeply concerned about the growing issue of access to treatment for those living with macular disease in this country. I am one of the 1.9 million Australians who lives with a macular disease diagnosis, and I am one of the more than 108,000 Australians with a treatable macular disease receiving anti-VEGF injections to preserve my sight.

Every six weeks, I receive eye injections in my right eye in a private clinic. 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, not because of a lack of options, but because the costs are simply too high.

The situation is critical for our older and more vulnerable Australians. According to new

research from Macular Disease Foundation Australia, nearly 1 in 10 people receiving eye injections to save their sight are forced to pay more than \$6,000 annually to manage their disease, including treatment costs, vision aids, support services, and travel. This is around 20% of the Australian aged care pension, a staggering amount for those already living on a fixed income. Self-funded retirees with restricted budgets are also greatly impacted.

I've seen the emotional and physical toll this disease takes on people. I'm living it too. The loss of vision is not just a health issue – it's an issue that robs people of their independence and their ability to live life on their own terms. Loss of vision forces people prematurely into aged care, and access to affordable and consistent treatment is simply too difficult, particularly those in rural and regional areas.

Yet, despite the growing prevalence of this disease, only a fraction of public hospitals and private clinics offer bulk-billed treatment. The reality is that for too many Australians, the cost of treatment is preventing them from saving their sight.

I have spent much of my life fighting for equitable access to essential health services. It is clear that the time for change is now. The Government has a

real opportunity to step up and make a difference by adopting a series of recommendations put forward by the Macular Disease Foundation. These measures, though ambitious, could make a world of difference to those living with macular disease.

A key recommendation is the introduction of a Neovascular AMD Treatment Incentive Program. This program would encourage ophthalmologists to bulk-bill pension card holders, who are often the most financially vulnerable, for sight-saving eye injections.

This initiative would cost the Government an estimated \$11.1 million a year but could save the taxpayer more than \$140 million annually by preventing more serious health complications that come with untreated macular diseases and blindness. It is an investment that would save the sight of thousands of Australians while ultimately reducing the long-term economic burden on our health system.

But it's not just about financial savings. It's about our respect for older Australians. No one should have to go blind simply because they can't afford the treatment that would save their sight. It's time to act, to make sight-saving treatments more affordable and accessible, and to ensure that no one is left behind in their fight for sight.

Macular Disease
Foundation Australia
Federal Election
Agenda 2025





Investing in sight-saving research

Macular Disease Foundation Australia (MDFA) is proud to announce that we have awarded more than \$1 million in funding to eight groundbreaking research projects in our 2025 funding round.

These initiatives aim to improve treatments, ease the burden on those living with macular disease, and help protect future generations from its impact.

This new funding brings our total research investment to \$6.9 million since 2011. MDFA remains the largest non-government funder of macular and retinal disease research in Australia. Supporting research is central to our mission to better understand and treat macular disease.

The projects we're funding are led by top researchers in their fields. They include studies that aim to predict and prevent the progression of age-related macular degeneration (AMD), research into new imaging techniques that could speed up diagnosis and treatment, and new gene therapy and targeted treatment for inherited diseases including Stargardt disease and Macular Telangiectasia (MacTel). The recipients of the MDFA Research Grants will be honoured at Admiralty House in Sydney – the official residence of the Governor-General – in August. You can learn more about the exceptional recipients and their vital work in this edition of Vision Voice.

"The calibre of research applications we received in this funding round was exceptionally high," said Associate Professor Anthony Kwan, Chair of Macular Disease Foundation Australia's Research Committee. "Applications for MDFA's Research Grants and Grant Family Fund awards

are assessed through a very rigorous process involving both national and international experts."

"In addition to expert peer review, we include a Community Review Panel of people living with a macular disease. This helps ensure that the projects we fund not only meet the highest scientific standards but also reflect the priorities of people directly impacted by macular disease. Keeping the voices of people with lived experience at the centre of our work is fundamental to our mission."

Looking ahead, we're aiming to double the number of research projects we fund by 2030. By doing so, we hope to empower even more Australian researchers to discover new ways to prevent or reduce the impact of macular disease. If you would like to be part of this important work, your support can make a real difference.

Help change the future for Australians living with macular disease

Your support can help fast-track vital research that brings hope to thousands of people affected by macular disease, now and for generations to come. To learn more or speak directly with our CEO, Dr Kathy Chapman, please email ceo@mdfoundation.com.au. Or, if you're ready to make a difference today, visit www.mdfoundation.com.au/donate-now to donate.

Driving into the future: new research grant to enhance driver independence

Driving plays a vital role in helping people stay independent and mobile, especially as they age. Losing the ability to drive can lead to isolation, loneliness, and a reduced quality of life.

Our latest Social Impact Survey of nearly 1,500 Australians living with macular disease found:

- 79% of those who stopped driving felt less independent
- 38% reported feeling socially isolated after giving up their licence
- 29% were less satisfied with life because they can no longer drive

That's why MDFA is proud to fund new research led by Dr Joanne Wood from Queensland University of Technology focused on enhancing independence for drivers with macular disease. This research will explore licensing options and the role of modern vehicle technologies.

In the past, many people with macular disease couldn't meet the vision requirements for driving due to central vision loss. But today, emerging treatments can help preserve or improve vision, allowing some people to drive safely for longer. Conditional licences and technologies like Advanced Driver Assistance Systems may also support safer driving – but we don't yet fully understand their impact.

Dr Wood's research will include:

- Focus groups with drivers who have macular disease to explore their challenges, treatment experiences, and use of driver assistance systems-equipped vehicles
- A national survey of drivers with macular disease to gather broader insights
- A second national survey of ophthalmologists to understand current practices around conditional licensing.

The research and survey findings will help shape strategies to help improve safety, mobility, and independence for people with macular disease, benefiting not only drivers, but also their families and communities.



Meet our 2025 research grant recipients



Dr. Sushma Anand, Centre for Eye Research Australia

Exploring new treatment delivery strategies for macular disease

Dr Anand's project will explore how exosomes – tiny, naturally occurring “delivery vehicles” – can be used to transport medicines and genes directly to the cells in the eye that need them to treat Stargardt disease, an inherited eye condition that affects about 1 in every 10,000 people in Australia, and Macular Telangiectasia (MacTel).



Professor Erica Fletcher, University of Melbourne

Predicting and preventing progression of AMD

Professor Fletcher will investigate reticular pseudodrusen, a type of waste material that deposits on the macula, that is associated with increased risk of late-stage age-related macular degeneration. She plans to create a special type of cell called microglia, a type of immune cell in the retina, to compare how effectively the microglia remove waste from the macula in people with and without AMD.



Dr Samuel McLenachan, Lions Eye Institute, University of Western Australia

Deepening the understanding of PRPH2-associated retinal dystrophy

PRPH2-associated retinal dystrophy is the third most common inherited retinal disease in Western Australia. Dr McLenachan and his team will study variations in the PRPH2 gene, along with other related genes, to determine how the different changes (mutations) in the gene influence the clinical features of retinal dystrophy. The outcomes of Dr McLenachan's research aims to improve diagnosis and predictions of progression for this inherited retinal disease.



Dr Danuta Sampson, Lions Eye Institute, University of Western Australia

Accelerating the development of new imaging biomarkers and therapies

Optical coherence tomography angiography (OCT-A) is an imaging technique that can detect vascular eye diseases, including neovascular AMD and diabetic retinopathy. Dr Sampson aims to standardise the computer software used to analyse OCT-A images, to enable faster, more accurate and consistent image processing and diagnosis reporting. This research will help support better monitoring of macular disease progression and ultimately improve the management of people with macular conditions.



Professor Mark Gillies, Save Sight Institute, University of Sydney

Reducing the risk of end-stage complications of neovascular AMD

About half of the people treated with anti-vascular endothelial growth factor (VEGF) eye injections for neovascular AMD will develop macular atrophy or subretinal fibrosis, both of which can cause irreversible vision loss. Prof Gillies' project aims to discover which of the six currently available anti-VEGF eye injection treatments are least likely to lead to macular atrophy or scarring beneath the macula.



Dr Jiang-Hui (Sloan) Wang, Centre for Eye Research Australia

Using next-generation gene therapy for Stargardt Disease

Dr Wang's research focuses on overcoming a major challenge in gene therapy for Stargardt disease: safely and efficiently delivering the large ABCA4 gene to the retina to repair the faulty gene involved in causing the disease. This work has the potential to advance gene therapy technologies and revolutionise treatment options for people affected by Stargardt disease and other inherited retinal conditions.



Professor Robyn Guymer AM, Centre for Eye Research Australia

Investigating unrecognised risk factors for neovascular AMD

Professor Guymer's project aims to determine how common nocturnal hypoxia – low blood oxygen levels that occur during sleep – is in people with neovascular AMD, compared to similarly aged people without the condition. The findings could confirm whether nocturnal hypoxia is an unrecognised risk factor for neovascular AMD, potentially enabling early screening and treatment to reduce the risk of disease progression.



Professor Joanne Wood, Queensland University of Technology

Discovering new strategies to enhance independence for drivers with macular degeneration

Professor Wood will conduct research to explore the experiences, challenges and needs of people with macular disease, to develop ways to enhance their driving performance, safety and independence through modern vehicle technologies and conditional licencing options.

Regional and remote Australians pay the price to fight for their sight

For Liz, a 76-year-old living in regional New South Wales, accessing sight-saving injections means an approximate 200km round trip every three weeks. "The injections are, to date, so effective I remain fully licensed to drive and live a fully independent life," she says.

For people in regional and remote areas, access to ophthalmologists delivering treatment to maintain their vision is extremely limited. Most ophthalmologists are based in major cities (~84 percent); the remaining 16 percent servicing the 28 percent of Australians living in regional and remote communities.

With no eye clinic close to her town delivering age-related macular degeneration (AMD) injections, Liz has no choice but to travel a considerable distance

every three weeks to keep her sight. Her injections could only be every six weeks but "having both eyes treated on the same day would result in me having to wait around for many hours for my vision to clear sufficiently to drive," Liz explains.

Liz lives alone with family very far away. "Asking a friend to provide transport is out of the question as it's up to five hours out of their day and leaves me very indebted," she says. "I rely on a partial pension, so the cost of travel and treatment is worrying, yet, maintaining my independence and minimising further cost to taxpayers is a priority."

In collaboration with the University of New South Wales, MDFA recently surveyed almost 1,500 Australians living with macular disease,

which revealed the disparity between the costs people in regional and remote Australia pay, compared to people in metropolitan areas.

The total annual median cost for people living in regional and remote areas is more than \$400 dollars higher per person compared with people in major cities. And the estimated indirect costs – such as time commitment and loss of productivity – related to unpaid carers of people with macular disease is more than \$600 higher for carers based in regional and remote Australia compared to carers in major cities.

"During my eye injection appointments I've enquired on many occasions as to how aged pensioners with no available funds can afford to have their AMD treated," said Liz. "To date, I have received no definitive answer. On most occasions the response is deflected or totally avoided. I find this very worrying as I may soon find myself in this position."

If you or someone you know is living with macular disease and needs practical or emotional support, please contact our free Eye Connect service on 1800 111 709.

This extract is a truncated article originally published on the Rural Health Alliance's online magazine Partyline and is republished here with permission.



Healthy choices

A Mediterranean feast for your eyes – introducing our new Macula Menu

We're excited to share our new Macula Menu cookbook which includes delicious and eye-friendly recipes from celebrity chefs Silvia Colloca, Luca Ciano and Rosemary Stanton.

Available for free on our website, this collection of delicious meals brings vibrant, fresh flavours inspired by the Mediterranean to your table while supporting eye health. Featuring nutrient-rich ingredients like fresh fish, leafy greens, and plenty of fruits and vegetables, these recipes are backed by the latest nutrition research to help care for your vision.

In addition to recipes from the talented chefs, our latest Macula Menu also features contributions from media icon and MDFA Patron Ita Buttrose AC OBE, MDFA CEO Dr. Kathy Chapman, community member Shane Somerville, and leading researchers Prof. Alice Pébay and Dr. Xavier Hadoux.

Take a step toward better eye health today. Download your copy of the Mediterranean Macula Menu from our website and start enjoying meals that are both nourishing and delicious.

For a taste, try creating Silvia Colloca's mouthwatering, macula-friendly Lemon and Caper Chicken Scaloppine with Cucumber and Avocado Salad.



Recipe by Silvia Colloca

Lemon and Caper Chicken Scaloppine with Cucumber and Avocado Salad

Reproduced with thanks to Essteele Cookware www.essteele.com.au

Serves 4

Ingredients

- 4 x chicken breast fillets, pounded to ½ cm thick
- 3 tablespoons of extra virgin olive oil
- 2 tablespoons of butter
- plain flour (or rice flour for a gluten free version) for dredging
- salt and pepper for seasoning
- juice and zest of 2 lemons
- 1 tablespoon baby capers in vinegar, rinsed

Salad

- 1-2 cucumbers cut into cubes
- 1 large Hass avocado cut into cubes
- 4 radishes, thinly sliced
- 2 tablespoons of extra-virgin olive oil
- juice of ½ lemon
- salt and pepper for seasoning



Instructions

1. Start by mixing avocado, cucumbers, olive oil, lemon juice, and radishes in a bowl, season with salt and pepper and set aside.
2. Dredge the chicken in flour and shake off the excess.
3. Heat up the oil and 1 tablespoon of butter over medium heat, add the chicken, season with salt, pepper, add capers and sear on both sides for 1–2 minutes or until golden.
4. Pour in the lemon juice and the second tablespoon of butter and cook over medium-low heat for 1 minute or until the sauce is thick.
5. Serve the scaloppine drizzled with sauce and with the avocado and cucumber salad.

Community insights help shape expansion of Eye Connect for diabetes-related eye conditions

We're committed to offering services that meet the needs of our community, so we're pleased to share an exciting update about our Eye Connect service. Recently, we completed four in-depth focus groups to help us expand Eye Connect to support people living with diabetes-related eye conditions, such as diabetic retinopathy and diabetic macular oedema.

These sessions included input from both people with lived experience of diabetes-related eye conditions and a range of health professionals, including ophthalmologists, optometrists, orthoptists, and diabetes educators. From those living with these eye conditions, we heard powerful stories about the emotional and psychological impact of managing their condition, and how important it is to feel supported and understood.

Participants also spoke about the need for:

- Flexibility and choice when it comes to the types and frequency of support
- Help navigating treatment and services
- Opportunities to connect with others going through similar experiences.

Health professionals offered valuable insights into the challenges people face in receiving holistic care, the kind of care that looks at your whole health, not just your eyes.

These valuable conversations will help us make sure Eye Connect's expansion to support for people living with diabetes-related eye conditions is relevant, easy to use, and meets real needs. We plan to launch the expanded service in the second half of 2025.



Connecting with the community in Queensland

It was a real pleasure to host a community seminar and lunch in Brisbane, where members of the macular disease community gathered to hear about the latest breakthroughs in treatment and research.

The event, held at the State Library of Queensland, featured updates on emerging therapies for age-related macular degeneration and geographic atrophy – conditions affecting thousands of Australians. Attendees also had the chance to learn more about the cutting-edge research our organisation is proud to fund.

Thank you to Dr David Hilford and Dr Audra Shadforth for their insightful presentations and dedication to advancing eye health.

We're grateful to everyone who joined us. It's your passion and support that continue to drive innovation and improve lives.





“It is a beautiful opportunity to connect with people.”

MDFA volunteer Levi reflects on his experiences supporting the macular disease community.

Volunteering with MDFA has allowed me to feel connected to the community in more ways than I could have ever imagined. Through presenting Volunteer Education Sessions, I’ve had the privilege of meeting hundreds of amazing, kind, and interesting individuals who are part of a wide range of organisations and community groups, all working towards supporting people from all walks of life.

In addition, my role as a Peer Support Group Facilitator has given me the privilege of bonding with a tight-knit group of individuals from the macular disease community. Supporting each other and engaging on a regular basis has been such a beautiful experience. I feel exceptionally grateful to be a small part of their lives.

Creating life memories

What stands out most to me are the deep and insightful conversations that happen after each education session. There are always so many thoughtful questions from people who have personal experiences with eye disease, and it’s incredibly moving to witness their engagement and care.

Regarding the Peer Support Group sessions, spending time with the group is always a highlight, and hearing the kind, positive feedback about how beneficial and supportive the sessions are truly means the world to me.

Volunteering at MDFA means a great deal

To me, it is a beautiful opportunity to connect with and support people experiencing a condition that, if left untreated, can deeply impact every aspect of their lives – including the lives of those around them. Visual difficulties bring profound life changes, and being part of an organisation that provides support through these challenges is absolutely priceless to me.

I am forever grateful for the experiences and opportunities MDFA has provided me over the last three years. Being an MDFA volunteer has given me so much happiness and purpose, and I truly wish everyone could experience the same joy and connection that this opportunity has given me.



Ready to make a difference?

Join Levi and our amazing team of volunteers today. Call us at 1800 111 709 or send us an email at info@mdfoundation.com.au. We look forward to hearing from you.

Connect and thrive: Join a peer support group near you

Living with macular disease can be challenging, but support is available and there are people who truly understand what you're going through.

Macular Disease Foundation Australia offers friendly, welcoming peer support groups across the country and online. These groups connect people with shared experiences in a warm and understanding environment.

Whether you prefer to meet in person or from the comfort of your home, we're confident there's a group for you. Sessions are led by trained volunteer facilitators and usually meet every two months.

Why join a peer support group?

- Feel understood and encouraged
- Share stories and helpful everyday tips
- Stay up to date on new treatments and research
- Make meaningful, lasting friendships

"It's valuable just being able to talk freely with people in the same situation."

– Peer Support participant



Interested in joining or learning more? Just give us a call on **1800 111 709**.
New members are always welcome – we look forward to hearing from you.

Contact Us: ☎ 1800 111 709 ✉ info@mdfoundation.com.au 📷 @maculardisease

📍 @MacularDiseaseFoundationAustralia 📍 Mezzanine level, 383 Kent Street, Sydney 2000