

**FIGHT FOR
SIGHT**



**Macular
Disease
Foundation
AUSTRALIA**

Macular Disease Foundation Australia Federal Election Agenda 2025



Executive summary

The next Australian Government has the opportunity to save the sight of thousands of Australians living with macular disease by adopting the recommendations put forward in this agenda from Macular Disease Foundation Australia.

What is macular disease?

Macular disease is the leading cause of blindness and severe vision loss in Australia.¹ In 2025, it is estimated there are over **1.9 million Australians with some evidence of macular disease.**^{1,2}

Macular disease is the collective term used for eye diseases and conditions affecting the macula, which is responsible for central vision.

Age-related macular degeneration (AMD) is the leading cause of blindness and irreversible vision loss in Australia among older Australians.^{2,3}

There are 1.5 million Australians with some evidence of AMD.²

Anti-vascular endothelial growth factor (anti-VEGF) eye injections are the game-changing, sight-saving treatment available for people with the neovascular form of AMD and other chronic conditions of the eye, including diabetic macular oedema and retinal vein occlusion.

Without this treatment, people with neovascular AMD, diabetic macular oedema and retinal vein occlusion will develop irreversible severe vision loss and blindness.

In Australia, there are currently **62,000 people with neovascular AMD, 18,000 with diabetic macular oedema and 11,000 with retinal vein occlusion** who receive sight-saving eye injection treatments.^{4,5}

Macular Disease Foundation Australia believes the Australian Government has a key role to play and an obligation in making the preservation of sight a national priority.

Every Australian should be able to access the support and treatments needed to fight for their sight.

Australia's shame – the lack of access to affordable sight saving treatment

Without treatment, vision loss caused by macular disease can have a devastating impact on the lives of people and their families. It can lead to a significant reduction in quality of life, the loss of independence, and premature need for aged care services.

However, across Australia, only a few metropolitan and larger regional public hospitals provide eye injection treatment.

Treatment is mainly provided by private ophthalmologists, with between 77% to 82% of them charging out-of-pocket fees.⁶

In addition, ophthalmologists providing eye injection treatment are extremely limited in regional areas. Most ophthalmologists are based in major cities (~84%);⁷ the remaining 16% of ophthalmologists service the 28% of Australians (7 million people)⁸ who live in regional, rural, and remote communities.

Limited access to public hospitals and bulk-billed private treatment has led to Australians being forced to access private eye injection treatment with significant out-of-pocket costs, and Australians living in regional, rural and remote areas having to travel long distances to major cities to access public hospital outpatient treatment.

Summary of recommendations

1. Improve access to and affordability of macular disease treatment

- **Recommendation 1:** Provide financial relief to lower the out-of-pocket costs for people receiving eye injection treatment through the introduction of a *Neovascular AMD Treatment Incentive Program* – \$11.1 million a year.
- **Recommendation 2:** Establish national access to, and stronger government oversight of, public treatment of macular disease in all states and territories.
- **Recommendation 3:** Invest in public-private partnerships to increase access to affordable eye injection treatment.

2. Partner with Macular Disease Foundation Australia to improve outcomes for people with macular disease

- **Recommendation 4:** Funding for continuing professional development for health professionals working with people living with macular disease – \$400,000 a year.
- **Recommendation 5:** Funding to support *Eye Connect* service delivery to improve outcomes for people living with macular disease – \$380,000 for Year 1, \$350,000 for Year 2 and \$335,000 for Year 3.

About Macular Disease Foundation Australia

Macular disease is the leading cause of blindness and severe vision loss in Australia.¹ The number of people with macular disease is growing. By 2030 we estimate this number will have increased from 1.9 million to 2.1 million people.²

Macular Disease Foundation Australia's purpose is to reduce the impact of macular disease – the country's leading cause of low vision and blindness. We do this through four pillars of work:

- 1. Support for people living with macular disease:** Our *Eye Connect* support service – Australia's first comprehensive support service for people living with the nation's leading cause of blindness – provides information, service linkages and advice to people living with macular disease and their family/carers. This free tailored service takes the form of education resources, psychosocial support, and practical guidance for navigating the health and aged care systems.
- 2. Advocacy:** we work to influence government policy on the health and social issues impacting our community so that people can have better access to affordable treatment, support, assistance and a better quality of life.
- 3. Research:** we invest in funding vital research working towards understanding the causes, better management, treatments, and cures for macular disease, and social impact studies.

- 4. Community awareness and early detection:** public awareness campaigns and education to promote early detection – including an annual awareness campaign in May called Macula Month.

We work with multiple partners in the eye health and low vision sectors, and governments to improve outcomes for people living with macular disease and their carers.

We currently directly engage with 60,000 members of the community nationally.

Macular Disease Foundation Australia is pleased to present this Election Agenda as our vision for the next Australian Government to address the important issue of macular disease, which touches the lives of many people across Australia.

One in seven Australians aged over 50 experience macular disease. With such high numbers of Australians living with macular disease, it is vital every Australian can access the support and treatments needed to fight for their sight.

About macular disease

Macular disease is the collective term used for eye diseases and conditions affecting the macula, which is the part of the retina at the back of the eye responsible for central vision.

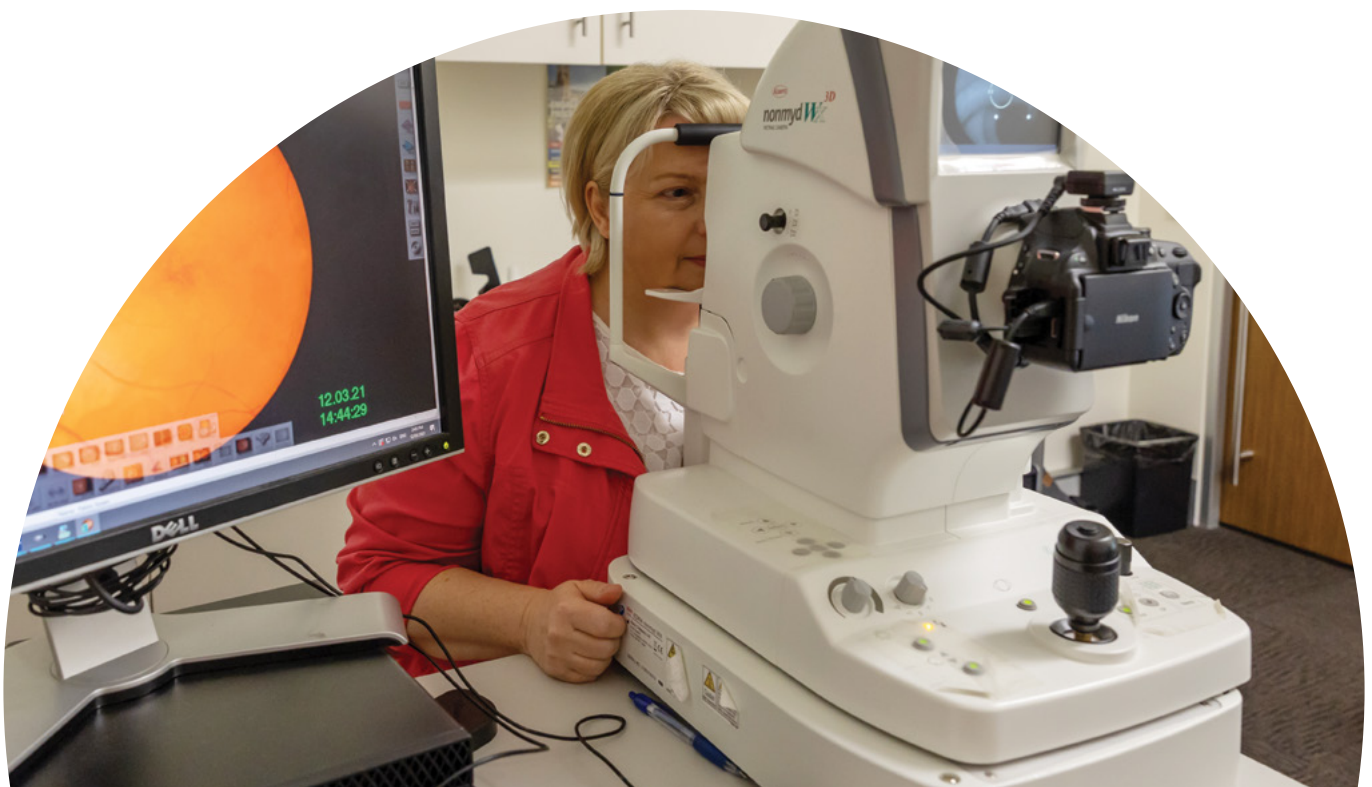
Age-related macular degeneration (AMD) is the leading cause of blindness and irreversible vision loss in Australia among older Australians.^{3,9}

There are 1.5 million Australians with some evidence of AMD.² This includes early, intermediate, neovascular AMD and geographic atrophy.

People with diabetes are at high risk of developing diabetic retinopathy.

Approximately 1.3 million Australians have diabetes, of whom about 300,000-400,000 people are affected by diabetic retinopathy, the leading cause of preventable blindness among working-age Australians^{10,11} which is rising rapidly due to the significant increase in the prevalence of diabetes.^{12,13}

Diabetic macular oedema is a serious complication of diabetic retinopathy that can cause the loss of detailed, central vision and legal blindness. It is estimated that there are 89,000 people living with diabetic macular oedema in Australia.¹⁴



Treatments for macular diseases

Anti-vascular endothelial growth factor (anti-VEGF) eye injections are the game-changing, sight-saving treatment available for people with neovascular (“wet”) AMD and other chronic conditions of the eye, including diabetic macular oedema and retinal vein occlusion.

People receive eye injection treatment for neovascular AMD every 4-16 weeks for an indefinite period to maintain vision, and unfortunately there is no definitive cure.

Without treatment, people with neovascular AMD will progressively develop severe vision loss and blindness.¹⁵

However, for people with diabetic macular oedema and retinal vein occlusion, eye injection treatment can in many cases reverse vision loss and may only be required for a defined period in some people.

In addition, the first-ever eye injection treatment for geographic atrophy (late-stage “dry” AMD) was recently approved in Australia in January this year, and more new therapies are expected to reach the market in the near future. This will enable a new population cohort to retain their vision.

In Australia, there are 62,000 people with neovascular AMD, 18,000 with diabetic macular oedema and 11,000 with retinal vein occlusion who receive sight-saving eye injection treatments.^{4,5}

“I am deeply concerned that we live in a country where people are needlessly going blind because they cannot access or continue to afford their sight saving treatments.

Reasonable investment will not only help reverse this unacceptable situation, but it will also generate huge cost savings for the Government. We must make it easier for vulnerable people who need eye injections to receive them.”

Patron, Ita Buttrose, AC OBE

Treatment burden and impact on people with macular disease

People receive an average of seven injections in one eye per year.⁶

Access to eye injection treatment is mainly limited to the private sector. Only a few metropolitan and larger regional public hospitals provide eye injection treatment.

Treating specialists set their own fees and only 18% to 23% of private ophthalmology clinics offer bulk-billing.⁶

A survey of people on eye injections undertaken in 2020 by Macular Disease Foundation Australia on barriers to treatment found:¹⁶

- **78% paid some out-of-pockets costs (after rebates).** Of those who paid out-of-pocket costs, 69% paid up to \$299 per treatment (after rebates), 20% paid between \$300 to \$599, and 6% paid over \$600.
- **69% of people had some difficulty paying their ophthalmologists' fees.** Of those who had difficulty paying fees, 29% considered delaying or stopping treatment due to **cost**, and of these **6% actually delayed or stopped treatment.**
- 11% considered delaying or stopping treatment due to **travel distance**, and of these 3% actually delayed or stopped treatment.



- 13% considered delaying or stopping treatment due to **lack of availability of community transport**, and of these 3% actually delayed or stopped treatment.
- 16% considered delaying or stopping treatment due to **lack of availability of a carer to provide transport**, and of these 4% actually delayed or stopped treatment.

People who delay or stop treatment risk irreversible vision loss or blindness.

Challenges to accessing eye injection treatment in Australia

Limited access to sight-saving eye injection treatment for macular disease is a national challenge.

Without treatment, people with macular diseases such as neovascular AMD (also known as wet AMD), diabetic macular oedema and retinal vein occlusion will lose their vision.

The total annual economic cost of vision loss in Australia is estimated to be \$16.6 billion or \$29,000 per person with vision loss aged over 40.³

Macular Disease Foundation Australia recognises that there is a role for both the federal and state/territory levels of government in addressing this critical eye health issue.

We acknowledge the role of the Australian Government in providing core funding for public hospitals, while the state and territory governments co-fund and administer this total funding individually within their own jurisdictions.

This document proposes clear and practical steps to address the eye health issues affecting Australians living with macular disease that fall within the direct responsibility of the Australian Government.

Across Australia, only a few metropolitan and larger regional public hospitals provide

eye injection treatment. Treatment is mainly provided by private ophthalmologists, with between 77% to 82% of them charging out-of-pocket fees.⁶

In addition, ophthalmologists providing eye injection treatment are extremely limited in regional areas. Most ophthalmologists are based in major cities (~84%);⁷ the remaining 16% of ophthalmologists service the 28% of Australians (7 million people)⁸ who live in regional, rural, and remote communities.

Limited access to public hospitals and bulk-billed private treatment has led to Australians depending on private treatment with significant out-of-pocket costs, and Australians living in regional, rural and remote areas having to travel long distances to major cities to access public hospital outpatient treatment.

Macular Disease Foundation Australia believes the Australian Government has a key role to play and an obligation in making the preservation of sight a national priority.

“I feel extremely fortunate to receive monthly sight-saving eye injections for my advanced neovascular AMD, but sadly this is not the case for all of us in Australia living with macular disease. Eye injections ensure that I can retain my vision, maintain my independence, and keep living life to the fullest.

As a former NSW Health Minister, I know how important it is that government supports the health and wellbeing of our community. We can’t stand by and let people lose their sight because they can’t afford sight-saving therapies. Tremendous gains have been made in Australia in tackling major health issues when we have taken a bi-partisan approach. I’m hopeful that all Members of Parliament, no matter their political allegiance, will support the recommendations of the Macular Disease Foundation.”

The Hon Jillian Skinner AM, Former NSW Health Minister.

Saving sight saves money

Recent research conducted by Macular Disease Foundation identified cost and access as two main reasons why people with macular disease stop treatment.¹⁷

This includes the challenges in accessing affordable or bulk-billed treatment for low-income earners, self-funded retirees, and pensioners and difficulty accessing treatment for those living in rural and remote Australia. The research highlighted that increasing access to treatment and the related persistence with sight saving treatment has cost benefits.

Government investment in more affordable and accessible treatment could, over the next decade, help 22,000 more people persist with their treatment, preventing severe vision loss and blindness, whilst saving the government more than \$2 billion, and reducing the financial impact on people with macular disease by more than \$1 billion.¹⁸

For a relatively small investment, preserving the vision of the community will go a long way to minimising the costs to the Australian Government of funding services that support

people with vision loss, including admission to hospitals due to falls and hip fractures,¹⁹ early transition to residential aged care facilities,¹⁹ and government funding for low vision organisations (e.g. Vision Australia and Guide Dogs) and the aged care system to provide low vision goods, equipment and assistive technologies.

With an ageing population and the advent of new eye injection treatments for geographic atrophy on the horizon, solutions to improve access to these treatments are needed before the increasing demand overwhelms the public health system and pushes the price of private treatment to unaffordable levels.

Macular Disease Foundation’s recommendations will help save the sight of Australians with macular disease, and we welcome the opportunity to work in partnership with the Australian Government to deliver on these sight-saving initiatives.

FEDERAL ELECTION ISSUE AND RECOMMENDATIONS

1. Improve access to and affordability of macular disease treatment

A unique problem

Neovascular AMD is a chronic medical condition that requires lifelong regular treatments, which can only be administered by medical specialists (ophthalmologists) and this is compounded as an equity problem when there is very limited public eye injection treatment providers.

The lack of access to affordable eye injection treatment for neovascular age-related macular degeneration and other similar macular diseases has been a longstanding issue. About 80% of eye injection treatments for macular disease are conducted in private ophthalmology clinics which is usually associated with out-of-pocket costs,⁶ where fees are varied with no assurance of affordability.

Out-of-pocket cost is a major barrier to treatment.²⁰ Treatment persistence is a significant problem, with about 50% of patients discontinuing treatment within five years of starting eye injections.⁵

Ensuring adequate access to eye injections for neovascular macular degeneration is a unique problem that demands unique solutions.

More barriers, less access to treatment

In addition, the Australian Government's planned policy change on 1 July 2025, which will reclassify eye injection treatment (MBS item 42738) from a Type B procedure to a Type C procedure, will result in most of the patients who currently receive eye injection treatment in private hospital and day surgery settings no longer being able to use their private health insurance to pay for their treatment.

While Macular Disease Foundation understands the reasons for this change, it is still important for the Australian Government to address the impact of this change on the overall access to and affordability of treatment.

With the existing cost barriers to persisting with treatment, future loss of eligible private treatment settings, and for the majority of people who currently use their private health insurance to cover the cost of their treatment being unable to do so, there is urgent need for the Australian Government to introduce new initiatives that target the most financially vulnerable patients to support them to continue treatment amidst the current cost of living crisis.

“RANZCO shares Macular Disease Foundation’s concern about the ongoing impact of macular disease on the Australian community and believes that more needs to be done to prevent vision loss for the estimated 1.9 million Australians with this condition.”

Professor Peter McCluskey, President of Royal Australian and New Zealand College of Ophthalmologists.

Recommendation 1: Provide financial relief to lower the out-of-pocket costs for people receiving eye injection treatment through the introduction of a Neovascular AMD Treatment Incentive Program.

Macular Disease Foundation recommends that the Australian Government establishes a *Neovascular AMD Treatment Incentive Program* to encourage ophthalmologists to bulk-bill pension card holders having eye injections for neovascular AMD.

Under this proposal, Medicare could provide registered ophthalmologists with an additional \$100 for eye injections performed on eligible neovascular AMD patients, on the condition that they are bulk-billed.ⁱ

This model is based on the Australian Government’s successful increase in the GP bulk-billing rate by increasing the bulk-billing incentives.²¹

This payment would not be counted towards the patients’ Original and Extended Medicare Safety Nets thresholds, as this program would only apply to bulk-billed patients.

By targeting the most financially vulnerable people who need sight-saving treatment and encouraging more bulk-billing, this program would cost the government an estimated \$11.1 million a year (see Appendix 1), and save government \$140 million a year (Appendix 2).

These savings will be from indirect health system costs of avoided expenditure on acute inpatient care; aids, modifications and equipment; carer welfare; emergency department admissions; mental health care; nursing home admissions; patient welfare; and primary health care.¹⁸

Recommendation 2: Establish national access to, and stronger government oversight of, public treatment of macular disease in all states and territories.

This recommendation aligns with the Australian Government’s *Pharmaceutical Reform Agreement (PRA) Review Report 2024*.²²

The Report recommended that the Australian Government negotiate with all eight state and territory governments to agree to a single unified PRA and incorporate it into the *National Health Reform Agreement*.

The current PRAs are all individualised and bilateral (between the Australian Government and the respective State/Territory). They are confidential agreements, and their details are not known to the public. In addition, **the NSW and ACT governments are not signatories to these agreements.**

Consistent with the recommendations in the *Report*, Macular Disease Foundation recommends the Australian Government establish interim PRA agreements with the NSW and ACT governments in 2025.

ⁱ For people requiring treatment for both eyes, 50% of this incentive will apply for the 2nd eye injection in the same service episode, consistent with the restrictions to the Medicare rebate (i.e. Note TN.8.2 - Multiple Operation Rule).

This will allow NSW and ACT public hospitals to access PBS-funded medicines, which are necessary to provide public eye injection treatments.

In the long-term, incorporating a unified *Pharmaceutical Reform Agreement* within the *National Health Reform Agreement* will ensure that all state and territory public hospitals can access and provide PBS-funded medicines in a nationally consistent approach. This will allow the supply of these medicines and indicated treatments to be inextricably linked with federal hospital funding, allowing the opportunity to establish national benchmarks that ensure equitable access to public hospital eye injection treatment for all macular disease patients who need them. Macular Disease Foundation recommends these outcomes be achieved as part of the Australian Government’s negotiations with the States and Territories a future national hospital funding agreement.

“I would like to be able to keep my eyesight. It is the greatest gift of all. There is so much I need to be able to do, for my husband and our family.”

Macular disease community member



Recommendation 3: Invest in public-private partnerships to increase access to affordable eye injection treatment.

Ophthalmologist-led public-private partnerships

In Australia, there have been some innovative public-private partnerships, organised by ophthalmologists, to create low-cost eye injection treatment arrangements for patients.

For example, in NSW, which is a non-signatory jurisdiction to the *Pharmaceutical Reform Agreement*, an example of such a partnership is between the public Sydney Eye Hospital and the private Save Sight Institute, where the Save Sight Institute provides the treating ophthalmologists and anti-VEGF medicine, and Sydney Eye Hospital provides the treatment facilities. Patients are bulk-billed for all diagnostic and treatment procedures, and only pay the PBS co-payment for the anti-VEGF medicine.

Another NSW example is the partnership between the public Westmead Hospital and the private Sydney West Retina clinic, headed by Professor Paul Mitchell AO. All Westmead patients requiring eye injection treatment for macular diseases are referred to Sydney West Retina. Patients are bulk-billed for all diagnostic and treatment procedures, and only pay the PBS co-payment for the anti-VEGF medicine.

An example in Victoria is the public Royal Victorian Eye and Ear Hospital, which only provides the first three eye injections for newly diagnosed patients, after which they are informally referred to private ophthalmology clinics to continue their treatment.

Overall, these examples and other public-private partnerships can be categorised into the following models:

- Facility sharing with private clinics (Sydney Eye Hospital)
- Outsourcing to private clinics (Westmead Hospital)
- Initial treatment in public facilities, with subsequent referrals to private clinics (Royal Victorian Eye and Ear Hospital)

Although a small number of these public-private partnerships exist, they are entirely ophthalmologist-led. There is no long-term guarantee that these arrangements will last beyond the tenure of the responsible ophthalmologists, and their treatment performance data are not captured or monitored by the respective State or Territory Health Departments. Furthermore, there is no government planning involved, so these arrangements are likely non-existent in regional and remote areas.

Meeting the imminent surge in demand for public and bulk-billed treatment

In addition, Macular Disease Foundation Australia has received increasing requests from patients seeking public and bulk-billed treatment, in the lead up to 1 July 2025 when eye injections (MBS item 42738) will become a Type C procedure and be highly restrictive for private health insurance patients to claim. As a result of this change in government policy, most of these patients will be forced to end their low or no-fee treatment at private eye hospitals and will instead have to seek treatment from an already stretched public hospital system.

However, this policy change also presents an opportunity for the Australian

Government to intervene and avoid a public health crisis and address the serious health inequities faced by people with macular disease, by leveraging the private health system to improve public access to treatment.

Based on the Australian Government's partnership with the private hospital sector to address the COVID-19 pandemic,²³ an Australian Government-led approach of contracting private eye hospitals and ophthalmology clinics to provide eye injection treatment to public hospital patients will improve treatment access and treatment persistence for patients, support the sustainability of private eye hospitals, and facilitate the collection of localised eye injection treatment data for better resource planning. This will especially benefit patients in regional and remote areas, where there is very limited access to public and bulk-billed treatment services.

Economic modelling shows that by expanding these transformative public-private partnerships to provide better access to intravitreal injection treatments and eliminating out-of-pocket costs for an additional 5,000 people who require neovascular AMD treatment, the government will save \$221 million over 5 years.^{ii,18} These savings will be from indirect health system costs of avoided expenditure on acute inpatient care; aids, modifications and equipment; carer welfare; emergency department admissions; mental health care; nursing home admissions; patient welfare; and primary health care.²⁹

The Australian Government can play a vital and heroic role in saving sight by enabling equitable access to treatment. The time to take action is now!

ⁱⁱ Based on "Model 2: Improved Affordability" of the Investing to Save Sight report: 10-year financial impact to government is \$442 million; 5-year financial impact to government is extrapolated to be \$221 million.

FEDERAL ELECTION ISSUE AND RECOMMENDATIONS

2. Support Macular Disease Foundation Australia

Since 2019, Macular Disease Foundation has prioritised addressing the gaps identified in the inaugural *National Strategic Action Plan for Macular Disease*. Addressing the inequities faced by people with macular disease is well aligned to the Department of Health and Aged Care's *National Strategic Framework for Chronic Conditions* and the principles of the *National Preventive Health Strategy 2021–2030*.

Macular Disease Foundation seeks government investment to deliver the following two recommendations under the *National Strategic Action Plan for Macular Disease*.

Recommendation 4: Funding for continuing professional development for health professionals working with people living with macular disease – costing \$400,000 a year.

Between May 2021 and March 2024, Macular Disease Foundation developed 10 online professional development courses on macular disease for a targeted group of health professionals. Content was produced on AMD and diabetic eye disease and was tailored for optometrists, pharmacists, ophthalmic nurses, orthoptists, diabetes

educators, and general practitioners. These courses were developed and disseminated as part of the *Health Professional Education and Training* program funded by the Australian Government's *National Strategic Action Plan for Macular Disease*.

Almost 3,000 people completed the course on AMD and over 3,000 completed the course on diabetic eye disease. Other content included a course on inherited retinal diseases and geographic atrophy. The content of each course was adapted for the specific needs of health professional groups identified as being best placed to detect and manage high risk patients in the community.

The *Health Professional Education and Training* program was externally evaluated. The report found key knowledge gaps in areas such as referral urgency for those with macular changes, and limited understanding about lifestyle modification and smoking cessation. Over 97% of all optometrists and pharmacists who completed the post-course evaluation stated that they had learnt new information that will help them better manage people at risk of macular disease or disease progression.

Macular Disease Foundation's focus on high quality, evidence-based education through this program has shown high

engagement with optometrists, ophthalmic nurses, orthoptists, and pharmacists, who have been receptive to improving their knowledge in eye health. The results of the evaluation demonstrate these courses filled an important gap that can improve detection rates, management and referrals for people with macular disease. It also extended the ability of key health professional groups to improve their knowledge about risk factors for macular disease and how they can promote and encourage early action.

Macular Disease Foundation is well placed to continue sharing its expertise with relevant health professional groups to improve the detection and management of people living with the condition. With the support of the Australian Government, existing courses will continue to be updated, accredited and promoted to reach more people in each profession. There is also scope to expand the library of content to include either new professional groups or new material as the treatment landscape and/or advice changes.

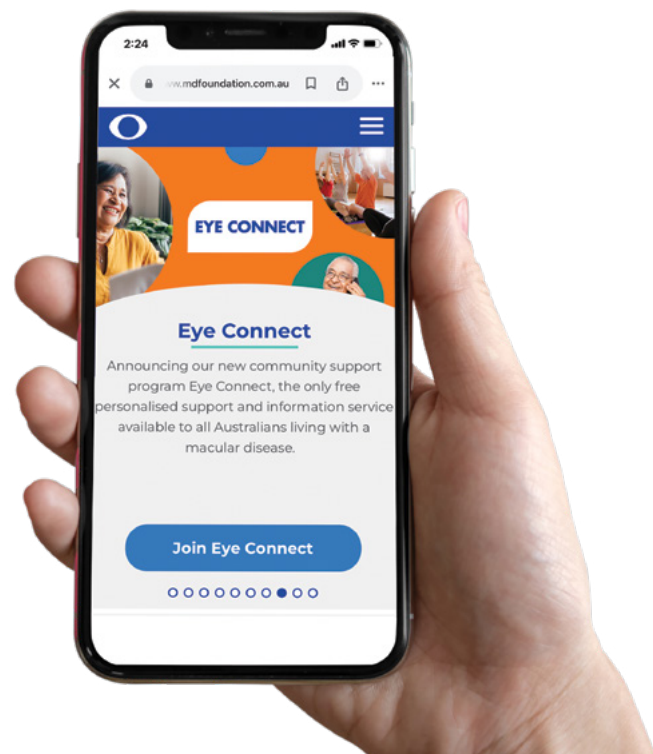
Recommendation 5: Funding to support *Eye Connect* service delivery to improve outcomes for people living with macular disease – costing \$380,000 for Year 1, \$350,000 for Year 2 and \$335,000 for Year 3.

Macular Disease Foundation Australia has been supporting Australians living with macular disease for the past 25 years by providing a Helpline service, community awareness and education sessions, and peer support programs.

In 2024, Macular Disease Foundation launched *Eye Connect*, a first of its kind service providing targeted personalised support for people living with AMD. The service is evidence-based, independent, and free of charge for the community.

Eye Connect was co-designed after two years of research with people living with macular disease, their carers, health professionals and with advice from behavioural science specialists. Research revealed:

- Limited patient knowledge and awareness of their condition and the associated risks
- Affordability and accessibility are significant barriers to treatment
- Patients experience inconsistent communication and don't always comprehend the information provided by their health professionals,
- The need for more practical support for people in between visits with a health professional, particularly emotional support.





Eye Connect was designed to improve an individual’s health literacy, deliver practical support for living with AMD and vision loss and offer psychosocial support by way of personal phone calls and peer support offerings, to improve mental health and well-being.

These services are delivered by qualified eye health professionals who receive referrals and follow up with a phone call to understand a person’s disease perceptions and learn how macular disease is impacting

their life. The person is then guided on their customised *Eye Connect* pathway, where they receive tailored information and support over many months, delivered in their preferred way to communicate.

Personal check-ins occur every six months to establish whether there have been changes to the person’s circumstance that might require more, or less, support.

A pilot evaluation in 2024 showed 98% of survey respondents would recommend *Eye Connect* to others. Even after being

in the program for a limited time, 75% of participants reported a positive impact on their general wellbeing and 90% of participants found the resources readable and accessible.

As a co-designed service, it is critical *Eye Connect* continues to adapt its approach and content to best serve the needs of the macular disease community. The key areas of focus for the next three years are:

- **Strengthening content and capability to provide psychosocial support:** Recent research undertaken by Macular Disease Foundation Australia investigated the social impact on people living with macular disease. Out of nearly 2,000 people surveyed, almost one in six respondents showed symptoms of depression and one in five showed symptoms of anxiety. This was also a finding of the evaluation, which recommended strengthening the connection between the components of the service (e.g. letters, calls and content of factsheets) to support the positive mental health of participants and to better support staff on the phones to facilitate mental health messaging and support. With investment, *Eye Connect* can design and include new evidence-based content developed from behavioural science research that promotes positive mental health behaviour and provide ongoing training and support for Helpline staff to use behavioural-based content when interacting with participants.
- **Increase the library of content for *Eye Connect*, including accessible content:** Rich, evidence-based content available in multiple formats is at the heart of the *Eye Connect* service.

Maintaining long-term engagement with participants requires us to continually review and update the resources included in *Eye Connect*. Further investment would ensure the ability to keep growing the library by identifying and translating new topics of interest into many accessible formats, and reaching culturally and linguistically diverse (CALD) communities.

- **Growing the groups served by *Eye Connect*:** *Eye Connect* is currently only available to people living with AMD. Further investment would enable the service to be expanded to support other macular conditions. In the next 12 months, Macular Disease Foundation Australia is adding diabetic eye disease to *Eye Connect*. The aim is to broaden the service to other kinds of macular disease over time, which will require new and updated content based on consultation with those living with the respective macular disease.

“The *Eye Connect* regular check-in calls and resources really helped me to understand my condition and helped my mental state.”

***Eye Connect* participant with AMD**

Macular Disease Foundation Australia’s Federal Election Agenda 2025 and its recommendations are endorsed and supported by the following supporters:



Together we can
FIGHT FOR
SIGHT



Appendices

Appendix 1

The full annual cost for *Neovascular AMD Treatment Incentive Program* is estimated to be **\$11.1 million**.

Calculation	Result
Estimated number of people who receive the age pension	2,600,000 people ²⁴
Estimated number of age pensioners who have AMD (1 in 7 people have AMD) ¹ 2,600,000 people/7	371,429 people
Proportion of people who receive eye injections for neovascular AMD out of all people with AMD: ^{2,4} 62,000 people/1,500,000 people x 100(%)	4%
Estimated number of age pensioners who receive eye injections for neovascular AMD: 4% of 371,429 people	14,857 people
Estimated number of age pensioners who receive eye injections in both eyes for neovascular AMD (bilateral AMD): 14% ⁵ of 14,857 people	2,080 people
Estimated number of age pensioners who receive eye injections for neovascular AMD in one eye: 86% of 14,857 people	12,777 people
Average annual number of service episodes per person ^{iii,5}	7
Annual cost of <i>Program</i> subsidy for age pensioners who receive eye injections in both eyes for neovascular AMD in both eyes (bilateral AMD): 2,080 people x 7 service episodes x \$150 (subsidy)	\$2,184,000 \$8,943,900
Annual cost of <i>Program</i> subsidy for age pensioners who receive eye injections in both eyes for neovascular AMD in one eye: 12,777 people x 7 service episodes x \$100 (subsidy)	
Annual cost of Neovascular AMD Treatment Incentive Program	\$11,127,900

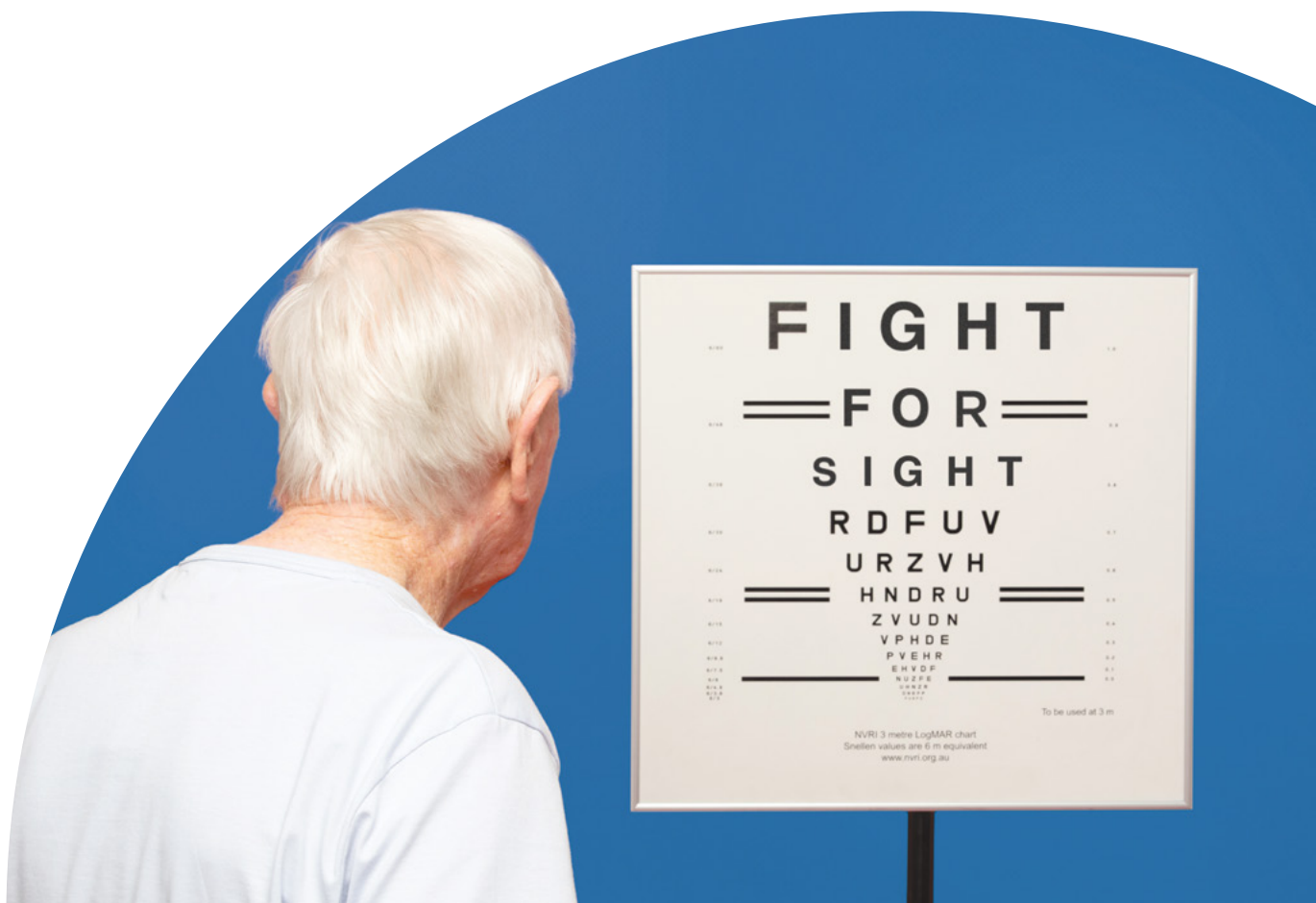
ⁱⁱⁱ Assumption of an annual average of seven service episodes is based on *Ranibizumab and Aflibercept: Analysis of Use for AMD, DMO, BRVO and CRVO* reference, as the annual average of seven eye injections does not differentiate between single eye or bilateral treatment in the same service episode.

Appendix 2

The annual financial savings to government from *Neovascular AMD Treatment Incentive Program* is estimated to be **\$140 million**.

Calculation	Result
Estimated number of age pensioners who receive eye injections for neovascular AMD (from Appendix 1)	14,857 people
Number of people treated based on Model 3 of <i>Investing to save sight</i> report, and associated 10-year financial savings to government ^{iv,18}	22,000 people, \$2.1 billion
10-year financial savings to government from <i>Neovascular AMD Treatment Incentive Program</i> : 14,857 people / 22,000 people x \$2.1 billion	\$1.4 billion
Annual financial savings to government from <i>Neovascular AMD Treatment Incentive Program</i>: \$1.4 billion over 10 years	\$140 million

^{iv} Based on “Model 3: Improved Accessibility” of the *Investing to Save Sight* report.



References

1. Australian Government Department of Health. (2019). *National Strategic Action Plan for Macular Disease*. Accessed at www.health.gov.au/sites/default/files/documents/2019/09/nationalstrategic-action-plan-for-macular-disease_1.pdf
2. Deloitte Access Economics and Macular Degeneration Foundation. (2011). *Eyes on the future – A clear outlook on age-related macular degeneration*.
3. Deloitte Access Economics and Vision 2020 Australia. (2010). *Clear Focus – The economic impact of vision loss in Australia in 2009*. A report for Vision 2020 Australia. Accessed at www.vision2020australia.org.au/resources/clear-focus-the-economic-impact-of-vision-loss-in-australia-in-2009/
4. The Hon. Mark Butler MP (2023, January 1). *Media release – Cheaper medicines from today*. Accessed at: www.health.gov.au/ministers/the-hon-mark-butler-mp/media/cheaper-medicines-from-today?language=en
5. Pharmaceutical Benefits Advisory Committee - Drug Utilisation Sub Committee (2018). *Ranibizumab and Aflibercept: Analysis of Use for AMD, DMO, BRVO and CRVO*. Accessed at https://www.pbs.gov.au/pbs/industry/listing/participants/public-release-docs/2018-05/ranibizumab_and_aflibercept_analysis_of_use_for_amd%2C_dmo%2C_b
6. Macular Disease Foundation Australia, Royal Australian and New Zealand College of Ophthalmologists and PwC Australia. (2019). *Impact of IVI rebate changes*.
7. Australian Government Department of Health. (2018). *Australia's Future Health Workforce – Ophthalmology*. Accessed at www.health.gov.au/resources/publications/ophthalmologyaustralias-future-health-workforce-report?language=en
8. Australian Government Australian Institute of Health and Welfare. (2024). *Rural and remote health*. Accessed at www.aihw.gov.au/reports/australias-health/rural-and-remote-health
9. Taylor H et al. (2005). Vision loss in Australia. *MJA*; 182:565-568. Accessed at pubmed.ncbi.nlm.nih.gov/15938683/
10. National Health and Medical Research Council. (2008). *Guidelines for the management of diabetic retinopathy*. Accessed at www.optometry.org.au/wp-content/uploads/Professional_support/Guidelines/nhmrc_diabetic_guidelines.pdf
11. Dirani M et al. (2013). *Out-of-sight – a report into diabetic eye disease in Australia*. A report for Baker IDI and Centre for Eye Research Australia. Accessed at baker.edu.au/-/media/documents/impact/outofsightreport.pdf?la=en#:~:text=On%20average%20one%20in%20three,3.3%25%20had%20diabetic%20macular%20oedema
12. Australian Bureau of Statistics. (2022). *Diabetes*. Accessed at www.abs.gov.au/statistics/health/healthconditions-and-risks/diabetes/latest-release
13. Keel S et al. (2017). The prevalence of diabetic retinopathy in Australian adults with self-reported diabetes: The National Eye Health Survey. *Ophthalmology*; 124:977-984.
14. Deloitte Access Economics and Bayer Australia. (2015). *The economic impact of diabetic macular oedema in Australia*. A report for Bayer Australia.
15. Wong T et al. (2008). The natural history and prognosis of neovascular age-related macular degeneration: a systematic review of the literature and meta-analysis. *Ophthalmology*; 115(1):116-26.
16. PwC and Macular Disease Foundation Australia (2020). *Estimating the costs and associated impact of new models of care for intravitreal injections*.
17. Macular Disease Foundation Australia. (2024). *Saving Sight Saves Money*.
18. Macular Disease Foundation Australia and PwC. (2023). *Investing to Save Sight: Health and Economic Benefits of Improving Macular Disease Treatment Persistence*.

19. Centre for Eye Research Australia and Access Economics. (2006). *Centrally focussed: the impact of age-related macular degeneration: a dynamic economic model and report*.
20. Vaze et al. (2014). Reasons for discontinuation of intravitreal vascular endothelial growth factor inhibitors in neovascular age-related macular degeneration. *Retina*. 2014 Sep;34(9):1774-8. doi: 10.1097/IAE.000000000000173.
21. The Hon. Mark Butler MP (2024, February 1). *Media release – Bulk billing on the rise*. Accessed at: www.health.gov.au/ministers/the-hon-mark-butler-mp/media/bulk-billing-on-the-rise
22. Australian Government Department of Health and Aged Care. (2024). *Pharmaceutical Reform Agreement (PRA) Review Report*. Accessed at: www.pbs.gov.au/info/reviews/pharmaceutical-reform-agreement-pra-review-report
23. The Hon. Greg Hunt MP (2020, April 1). *Media release – Australian Government partnership with private health sector secures 30,000 hospital beds and 105,000 nurses and staff, to help fight COVID-19 pandemic*. Accessed at: www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/australian-government-partnership-with-private-health-sector-secures-30000-hospital-beds-and-105000-nurses-and-staff-to-help-fight-covid-19-pandemic
24. Australian Government Australian Institute of Health and Welfare. (2023). *Income support for older Australians*. Accessed at www.aihw.gov.au/reports/australias-welfare/income-support-older-australians



Macular Disease Foundation Australia

Mezzanine, 383 Kent Street
Sydney, NSW, 2000

T 1800 111 709

E info@mdfoundation.com.au

W www.mdfoundation.com.au

W www.CheckMyMacula.com.au

ABN 5209 6255 177

If you agree with the recommendations presented by Macular Disease Foundation Australia in the Federal Election Agenda 2025: Fight for Sight, we hope that you will write to your local Member of Parliament.

For assistance and ease, please download this letter template provided.

Download template

Date:

MP name:

MP address:

Dear Member of Parliament,

As a resident in your electorate, I am seeking your support for the recommendations in Macular Disease Foundation Australia's Federal Election Agenda, *Fight for Sight*.

About macular disease

- Macular disease is the leading cause of blindness and severe vision loss in Australia.
- There are over 1.9 million Australians with some evidence of macular disease. Age-related macular degeneration (AMD) is the most common form of macular disease and the leading cause of blindness and irreversible vision loss among older Australians. There are an estimated 1.5 million Australians living with some evidence of AMD.
- Macular disease results in the progressive loss of central vision which affects the ability to recognise faces, read, drive, work and many other aspects of daily living.
- The current treatment for neovascular AMD is regular eye injections, with most treatment provided in private ophthalmology clinics with significant out-of-pocket costs. The median total cost of living for people with macular disease and receiving eye injection treatment is \$3,621 a year.
- Economic modelling commissioned by Macular Disease Foundation found that government investment in more affordable and accessible treatment could, over the next decade, help 22,000 more people persist with their treatment, preventing severe vision loss and blindness, whilst saving the government more than \$2 billion, and reducing the financial impact on people with macular disease by more than \$1 billion.

Macular Disease Foundation's recommendations

Macular Disease Foundation Australia is seeking your support to make the preservation of sight a national priority.

We ask that you support the macular disease community, by seeking commitments from a re-elected or new Australian Government to:

1. Provide financial relief to lower the out-of-pocket costs for people receiving eye injection treatment through the introduction of a *Neovascular AMD Treatment Incentive Program*.
2. Establish national access to, and stronger government oversight of, public treatment of macular disease in all states and territories.
3. Invest in public-private partnerships to increase access to affordable eye injection treatment.
4. Fund Macular Disease Foundation to deliver continuing professional development for health professionals working with people living with macular disease.

5. Fund Macular Disease Foundation to support its *Eye Connect* service delivery to improve outcomes for people living with macular disease.

These recommendations are outlined in more detail in Macular Disease Foundation's Federal Election Agenda, *Fight for Sight*, which can be found on Macular Disease Foundation's website at www.mdfoundation.com.au

As my Member of Parliament, I hope you will support Macular Disease Foundation's recommendations as they will save the sight of more Australians and have a positive impact upon Government expenditure.

Yours faithfully,

Signature:

Full name: