FIGHT FOR SIGHT

25TH ANNIVERSARY

Macular Disease Foundation AUSTRALIA

BETTER VISION FOR VICTORIANS:

Macular Disease Foundation Australia's Victorian Election Agenda 2026

About Macular Disease Foundation Australia

Macular Disease Foundation Australia is the national peak body fighting for sight and representing people living with macular disease and their carers. Our purpose is to reduce the impact of macular disease across Australia, as it is the largest cause of blindness and vision loss in Australia.

We work to achieve this through four core pillars:

1. **Community awareness and early detection**
   We deliver public awareness campaigns and education to promote early detection of macular disease, including our annual awareness campaign held each May, known as Macula Month.
2. **Support for people living with macular disease**
   We provide information, service linkages and support to people living with macular disease, as well as their families and carers. This support includes evidence-based information and education resources, psychosocial support, and practical assistance to help people navigate the health and aged care systems.
3. **Advocacy**
   We advocate to influence government policy on the health and social issues affecting our community, with the aim of improving access to affordable treatment and better quality of life for people living with macular disease.
4. **Research**
   We invest in vital research focused on improving the management and treatment of macular disease, advancing towards cures, and building the evidence base through social impact studies.

Macular Disease Foundation works in partnership with organisations across the eye health and low vision sectors, as well as with governments, to improve outcomes for people with macular disease. We currently engage directly with more than 60,000 people nationally, including 13,000 residents in Victoria.

Macular Disease Foundation Australia's Recommendations

Macular disease is the leading cause of irreversible blindness and severe vision loss in Australia, with more than **1.9 million Australians** estimated to have some evidence of macular disease.[1]

Macular Disease Foundation Australia is calling for targeted investments across key priority areas to prevent avoidable vision loss and improve outcomes for those living with macular disease.

These recommendations will reduce the treatment burden for people with macular disease, improve access to quality care, and deliver long-term savings to the Victorian health system.

Macular Disease Foundation Australia recommends that the Victorian government:

1. **Embed a statewide macular disease support service.**
   Partner with Macular Disease Foundation and invest in the statewide integration of the *evidence-based* Eye Connect support service across all public hospital ophthalmology macular disease outpatient services.

2. **Reduce the cost burden of transport for people receiving macular disease treatment in regional, rural and remote Victoria.**
   Increase the Victorian Patient Transport Assistance Scheme subsidy and remove the co-contribution requirement to ease the travel burden for people attending regular eye injection treatment.

3. **Strengthen public eye injection care in Victoria.**
   Develop and implement a Victorian Macular Disease Plan to establish a coordinated system for monitoring, planning and oversight of public eye injection services.

[1] Deloitte Access Economics and Macular Degeneration Foundation (2011). *Eyes on the future – A clear outlook on age-related macular degeneration*. Accessed at https://www.mdfoundation.com.au/resources/eyes-on-the-future/.

Why is macular disease important?

Macular disease is the leading cause of vision loss and blindness in Australia. Despite this, the scale of its impact remains under-prioritised.

Age-related macular degeneration (AMD) is the most common form of macular disease and the leading cause of irreversible blindness among older Australians. Around **1.5 million** people over the age of 50 have AMD nationwide,[1] of whom **377,000** people live in Victoria.[2]

People with diabetes are also at high risk of vision loss. An estimated **300,000–400,000 Australians** are living with diabetic retinopathy, the leading cause of preventable blindness among working-age adults.[3] Diabetic macular oedema, a complication of diabetic retinopathy, affects approximately **91,500** people and can cause permanent central vision loss.[4]

Eye injections are the sight saving treatment available for people with the neovascular form of AMD (wet AMD) and other chronic conditions of the eye, including diabetic macular oedema and retinal vein occlusion. For people with neovascular AMD, injections are required every four to sixteen weeks, often for life. Without consistent treatment, vision loss is rapid and irreversible.

Nationally, more than **117,000 Australians** rely on regular eye injections to maintain their sight.[5] **In Victoria, 16,000 people receive eye injection treatment for neovascular AMD, 5,400 people for diabetic macular oedema and 4,100 people for retinal vein occlusion.[5]**

Demand for treatment continues to grow due to population ageing and rising rates of diabetes, placing increasing pressure on public ophthalmology services.

Macular disease treatment burden

Access to affordable eye injection treatment can be challenging for people with macular disease, with most receiving treatment in the private sector and only a small number of public hospitals offering this care. Patients typically require around six injections per eye each year, placing a significant financial and logistical burden on individuals and families.

[2] Deloitte Access Economics and Macular Disease Foundation Australia (2014). *Age-related Macular Degeneration Across Australia: 2012-2030.*

[3] Baker IDI and Centre for Eye Research Australia (2013). *Out of Sight*. Accessed at: https://baker.edu.au/-/media/documents/impact/outofsightreport.pdf?la=en.

[4] Deloitte Access Economics (2015). *The Economic Impact of Diabetic Macular Oedema in Australia*. Canberra: Deloitte Access Economics, Barton, ACT.

[5] Services Australia. January 2026. Pharmaceutical Benefits Scheme, 10% data. Provided by Model Solutions Pty Ltd.

Treatment cost is a major barrier to care. Nearly **eight in ten** patients incur out-of-pocket costs, and **one in three** have considered delaying or stopping treatment because they cannot afford it.[6]

Affordability and access are significant barriers to treatment persistence. In Victoria, more than 25,000 people received eye injection services in 2023, yet only 36% were bulk billed.[7] Evidence indicates that approximately 20% of people with neovascular AMD discontinue treatment within the first year, and half stop within five years.[8]

Findings from Macular Disease Foundation's Social Impact Study found the median annual costs associated with living with macular disease were $3,621, with around 10% of people receiving eye injections paying more than $6,000 per year out of pocket.[9]

Travel and transport barriers further undermine access, particularly for older people and those living in regional and rural areas. **Eleven percent** of patients have considered delaying or stopping treatment due to travel distance, **13%** due to a lack of community transport, and **16%** because they could not access a carer to assist with travel.[6]

Delaying or discontinuing eye injection treatment places Victorians at high risk of irreversible vision loss and blindness. These barriers are preventable and highlight the urgent need for targeted, system-level action to protect sight, independence, and quality of life for Victorians.

[6] Macular Disease Foundation Australia and PwC. 2020. *Estimating the costs and associated impact of new models of care for intravitreal injections.*

[7] Services Australia. Data is for Medicare services for item 42738 delivered for the period 01/01/2022 to 31/12/2023 and processed up to 17 February 2025.

[8] 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

[9] Macular Disease Foundation Australia. 2024. *Social Impact Survey 3.*

Recommendation 1: Embed a statewide macular disease support service

Partner with Macular Disease Foundation and invest in the statewide integration of the evidence-based Eye Connect support service into ophthalmology outpatient services, ensuring consistent, automatic referral for eligible patients at the point of diagnosis or treatment commencement.

People with macular disease face complex diagnoses and long-term treatment, yet access to consistent education and support varies across clinics and regions. This contributes to anxiety, confusion, and reduced treatment adherence. *Eye Connect* is Australia's first support service providing tailored support for people living with macular disease.

Eye Connect is designed to improve an individual's health literacy, deliver practical support for living with AMD and diabetes related eye conditions, and offer psychosocial support by way of personal phone calls and peer support, to improve vision outcomes and mental health and well-being.

Launched nationally in 2024, the service is offered free of charge and available to all Australians living with AMD and diabetes related eye conditions.

Eye Connect demonstrates that structured, early support improves patient experience and engagement, with 98% of participants recommending the service to others.

Standardising referral to *Eye Connect* across all public ophthalmology services would ensure every Victorian with macular disease receives timely, reliable information and tailored support, regardless of location. Evaluation shows 95% of participants maintain their recommended treatment schedule, and 73% of those receiving eye injections feel more positive about their treatment.[10]

Eye Connect also improves health knowledge and self-management. 81% of participants report better understanding of their condition, and 79% feel able to talk about their macular disease with health professionals, family, or support people, with understanding increasing further after six months in the service.[10] Practical advice and support navigating changes resulting from their condition strengthen confidence and continuity of care.

Eye Connect delivers measurable psychosocial benefits, with 74% of participants reporting they felt more supported through regular check-in calls, alongside reduced worry over time.[10]

[10] Wu, Simon. 2025. *Evaluation of Macular Disease Foundation Australia's Eye Connect program for people with age-related macular degeneration.*

Improved understanding and confidence drive better treatment adherence, stronger engagement with care, and improved quality of life. Economic modelling indicates that improving health literacy in just 25% of treated macular disease patients could deliver treatment persistence and government cost savings of over $2 billion over the next decade. **Embedding this proven, free service within the public system would improve patient experience, reduce preventable vision loss, and support better long-term outcomes.**

Investment required

Eye Connect support service	2026-27
Project management and delivery	$50,000
Content delivery and distribution	$40,000
Promotion	$10,000
Total	**$100,000**

Noel, Korumburra VIC, living with dry age-related macular degeneration

"Age-related macular degeneration (AMD) has had a strong psychological effect on me and has been fairly hard to deal with. I can't see very well and it's hard to tell people about it. A lot of people are not aware of what it is and people I speak to don't really understand it - it felt like a nuisance.

Having a family history of AMD, I've been a long-time supporter of the Foundation; and when it was time I needed support, they were there to help. The service has significantly improved my understanding of AMD. The optometrist I attend is great, however the information and advice I get from the *Eye Connect* conversations keep me well informed about what condition I have, and the type and things I can do to slow it down.

I have the dry version of AMD, and Macular Disease Foundation informed me about new treatments for this, as well as introducing me to healthy eating for the macula. They also send me monthly resources that teach me about my condition, because the more you know about it, the better you can deal with it. Their information about the Mediterranean diet has completely changed my life for the better.

Overall, the psychological and emotional impact is the hardest part, and having experts to speak to at Macular Disease Foundation make me feel reassured and supported knowing I can ask them anything and they are happy to help and inform me. I receive monthly phone calls from the *Eye Connect* team and it's great to have that social connection with someone who understands what I'm going through.

I also receive letters from the Foundation to remind me about getting my eyes checked, or to remind me of getting a driver's licence check, although I don't drive anymore, I think this is great as it keeps people aware of these things."

Recommendation 2: Reduce the cost burden of transport for people receiving macular disease treatment in regional, rural and remote Victoria

Increase the Victorian Patient Transport Assistance Scheme (VPTAS) subsidy to at least 40 cents per kilometre and remove the $100 non-concession co-payment requirement.

People living in regional, rural and remote Victoria face significant barriers to accessing sight-saving eye injection treatment due to transport challenges and high travel costs. In areas with limited or no public transport, people with macular disease who are unable to drive because of vision impairment are reliant on carers or community transport services to attend treatment appointments.

These barriers make it difficult for regional, rural and remote patients to commence and maintain ongoing treatment – particularly for people with neovascular AMD, who require eye injections every four to sixteen weeks. Travel distance is a major risk factor for treatment discontinuation. Evidence shows that people who were required to travel more than 100 km to access care were 52% less likely to adhere to treatment than those living within 20 km.[11] Without regular treatment, people risk severe, irreversible vision loss and blindness.

While the Victorian Government provides travel assistance through VPTAS, the current private vehicle reimbursement rate of 21 cents per kilometre for journeys of 100 km or more one way falls well below actual transport costs and is the **lowest travel reimbursement rate of all equivalent transport subsidy programs across Australia.**

Another barrier for people with macular disease to access VPTAS is that it requires non-concession users to pay the first $100 without any reimbursements. This co-contribution barrier to accessing VPTAS should be removed to support better access to treatment for people who are already isolated from health care services due to the tyranny of distance, regardless of their financial circumstances.

Improving VPTAS reimbursement rates and removing co-contribution requirements would reduce financial barriers, support treatment adherence, and help prevent avoidable vision loss for regional, rural and remote Victorians.

Investment required

The Victorian Government will need to develop costings based on agreed VPTAS rule changes and usage. We hope the Victorian Government will acknowledge the need for this initiative and commit to funding it.

[11] Chang et al. 2021. Impact of a Patient Support Program on Patient Beliefs About Neovascular Age-Related Macular Degeneration and Persistence to Anti-Vascular Endothelial Growth Factor Therapy. *Patient Preference and Adherence. Accessed at pubmed.ncbi.nlm.nih.gov/33688173/*

Recommendation 3: Strengthen public eye injection care in Victoria

Develop a Victorian Macular Disease Plan to establish a monitoring and oversight system that helps the community know where services exist, identifies service gaps and ensures consistent treatment service provision across Victoria.

Access to public sight saving eye injection treatment is currently limited across Victoria, creating inequity and increasing the risk of delayed or discontinued care.

Macular Disease Foundation's study of public hospital outpatient eye injection services found only seven out of 86 investigated Victorian public hospitals provided eye injection treatment services.[12] Out of these seven public hospitals, six hospitals were located in metropolitan areas, and one hospital was located in a regional area.[12] A lack of outpatient clinics in public hospitals means most patients rely on private ophthalmology clinics, often facing significant out-of-pocket costs.

Currently, public hospitals across Victoria have a varied approach for macular disease treatment services. While some services provide lifelong eye injection care, others offer only a limited number of injections before referring patients to private ophthalmology services. In the absence of formal statewide referral policies and pathways, it is unclear whether patients receive treatment within clinically appropriate timeframes, are bulk billed, or incur out-of-pocket costs.

A state government *Victorian Macular Disease Plan* would establish more consistent and equitable public eye injection treatment standards across the different Local Health Service Networks, allowing public patients to have a fair expectation of treatment services within the Victorian public hospital system.

The *Plan* should also establish consistent public-to-private referral pathways across the state, ensuring that public patients who are referred out to private ophthalmologists receive timely and accessible care regardless of where they live and what they can pay.

Strengthening this public health safety net would reduce preventable vision loss, support independence and workforce participation, and deliver longer term savings by reducing demand on health, aged care, and disability support services.

Investment required

The Victorian Government will need to develop costings based on agreed frameworks with Victorian ophthalmologists. We hope the Victorian Government will acknowledge the need for this initiative and commit to funding it.

[12] Macular Disease Foundation Australia. 2025. *Public hospital eye injection treatment services mapping project*

Policy summary

Issue

Demand for sight saving eye injections is rising, but access remains inequitable.

Who is affected

377,000 Victorians with age related macular degeneration, plus thousands more with diabetes related eye conditions.

Cost of inaction

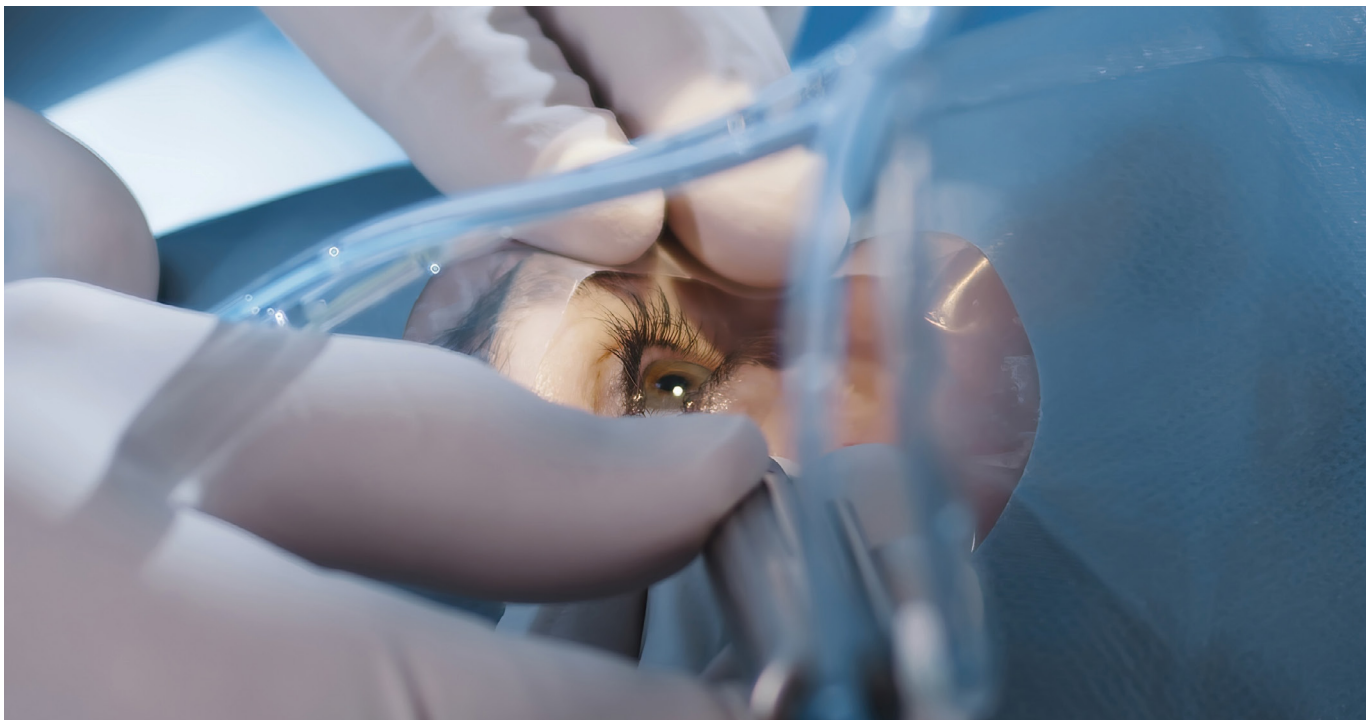
Avoidable blindness, higher hospital costs, and greater reliance on aged care and disability services.

What works

Removing barriers to timely care – especially cost and travel – and strengthening supports for people living with macular disease.

What we're asking

Three targeted, evidence-based reforms to improve support for people living with macular disease, reduce travel barriers for geographically isolated patients, and increase statewide access to public eye injection treatment.



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