



VisionVoice

Summer Edition 2025

Aged care system to provide low vision aids after years of advocating for your rights to equitable access

Since 2007, Macular Disease Foundation Australia (MDFA) has championed for all people with vision loss to be able to access affordable low vision aids and technologies.

However, when the National Disability Insurance Scheme (NDIS) was established, it excluded people older than 65 years who had acquired a disability. As the aged care system was not designed to deliver disability support services, this resulted in older Australians with vision loss due to macular disease being unable to access the low vision aids and technologies that they needed.

The Australian Government's new aged care program, **Support at Home**, represents a major step forward. While there is still more work to be done, these changes will help narrow the support gap between aged care system and the NDIS, by enabling Support at Home clients to access low vision aids and technologies as a key part of their care.

This outcome reflects 18 years of sustained advocacy by MDFA and the macular disease community – it's an issue that has been on our agenda for almost two decades. Through national campaigns, petitions, letters, and

federal election initiatives – including our 2013 Sight for Seniors campaign. We also raised the issue in government consultations and meetings with Ministers and Departments, ensuring the voices of people living with macular disease were heard. Thanks to everyone who contributed and supported us during this process.

How the Support at Home program will work

The Australian Government is reforming the in-home aged care system in response to recommendations from the Royal Commission into Aged Care Quality and Safety. The new program aims to provide a simpler, fairer, and more accessible system, enabling older Australians to live at home longer and more independently.

By November 2025, it will replace the Commonwealth Home Care Packages and the Short-Term Restorative Care Program.

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CEO Update

We were honoured to host our Research Awards at Admiralty House with Her Excellency, the Hon. Sam Mostyn AC, Governor-General of Australia. In her address, she spoke of making care the cornerstone of her term – “care for each other, care for those who care for others.” The Governor-General’s words deeply resonated with our community: people living with or caring for a person with macular disease, and the researchers dedicating their lives to finding a cure. You can read her powerful speech on our website.

Next year marks the 25th Anniversary of our Foundation. This milestone is both a time to celebrate our impact and to look ahead. We’ve launched our silver jubilee with the MDFA 25th Anniversary Award – a \$200,000 investment into geographic atrophy (the late-stage dry form of AMD) research – thanks to a generous family donation. We’re also proud to introduce the Elisabeth Macdonald Memorial Award, focusing on AMD’s impact in rural and regional communities – a fitting legacy from our dear friend, Elisabeth.

In our 25th year, we’ve set an ambitious goal to raise \$1 million to expand research and support services for people living with macular disease. We cannot do this without you. If you can give a special 25th Anniversary gift over the next year, your generosity will help change the lives for many in our community.

If you’re looking for a special gift for your Christmas stocking, our Patron, Ita Buttrose AC OBE, has just released her memoir

Unapologetically Ita, dedicated to her uncle Gerald – now 102 years old and still receiving sight-saving eye injections for wet AMD. Both Ita and Gerald are true inspirations.



Warm wishes for the season, Dr Kathy Chapman
Chief Executive Officer

Aged care system Continued.

On 1 July 2027, the Commonwealth Home Support Program will be integrated into **Support at Home** program, creating a single national in-home aged care program.

What this means for the macular disease community

For people with macular disease, the biggest change is that a new Assistive Technology Home Modifications Scheme will be established as part of the Support at Home program. This means that people becoming a Support at Home client can be identified, assessed and funded for low vision aids and technologies as part of their support needs from the beginning, which has not been possible with Home Care Packages.

Transitioning to the new program

If you are currently receiving a Home Care Package, you will transition to an equivalent Support at Home program funding classification, so there should be no disruption to your services.

If you are new to the aged care system, applying for an assessment to enter the program remains the same – contact My Aged Care through the website <https://www.myagedcare.gov.au/> or phone 1800 200 422.

Update on reclassification of eye injection treatment

The Australian Department of Health, Disability and Ageing has advised us that targeted consultations on the impact of reclassifying eye injection treatment procedures will be held with key stakeholders, including MDFA, before the end of the year. The Department of Health is looking at the Medicare Benefits item that relates to whether people can use their private health insurance for eye injection treatment in private day surgeries.

We will highlight your concerns that stopping the use of private health insurance to pay for eye injections will increase the financial burden of treatment. We will continue to keep you updated on this issue.



Not sure if Eye Connect is right for you or someone close to you?

Use our quick online Eye Connect Check assessment tool to see how the service could support your journey with AMD or a diabetes-related eye condition. www.mdffoundation.com.au/eye-connect-check

New Eye Connect support for diabetes-related eye conditions

Diabetes-related eye conditions affect between 300,000 and 400,000 Australians, with an estimated 91,000 living with diabetic macular oedema. These conditions are the leading cause of preventable blindness among working-age Australians.

To address this, we are expanding our free Eye Connect support service to include people living with diabetes-related eye conditions. This makes Eye Connect Australia's first national service dedicated to providing tailored information, practical advice, and emotional support for those affected by diabetic retinopathy and diabetic macular oedema, as well as AMD.

Many people with these conditions face challenges such as limited understanding of their diagnosis, access to lifestyle guidance, and feelings of emotional distress. Eye Connect aims to fill these gaps by offering support via phone, SMS, email, and printed resources. The service provides evidence-based health information, practical advice for daily living, and peer support.

MDFA worked closely with people living with diabetes-related eye conditions to develop the service. Focus group participants shared powerful reflections:

"It's not just the loss of sight, it's the loss of independence, confidence, and sometimes hope – connection makes all the difference," said one participant.

"We need more than just treatment – we need support that sees the whole person, not just the condition."

To ensure the service meets real-world needs, MDFA collaborated with Diabetes Australia and health professionals across eye care and diabetes management. Their insights helped shape resources that align with broader care strategies and reflect lived experiences.

"This expansion will help people better understand their condition and feel supported," said Dr Kathy Chapman, CEO of Macular Disease Foundation Australia. "Eye Connect is a place where people can feel truly understood and supported as they navigate life with a diabetes-related eye condition. If you or someone you know needs support, please reach out."



Celebrating 25 years of impact with two new research awards

We're proud to launch MDFA's silver jubilee celebrations with the introduction of two new research awards - a milestone that reflects 25 years of commitment to advancing knowledge, innovation, and patient-centred care in macular disease. These awards will support researchers whose work will help reduce the impact of macular disease and improve outcomes for people living with vision loss.

MDFA 25th Anniversary Award

Thanks to a large family donation, we are making a significant investment of \$200,000 over three years to support research into geographic atrophy, a form of age-related macular degeneration (AMD).

Also known as late-stage dry AMD, geographic atrophy is a progressive condition where retinal cells die, leading to patches of missing retina and central vision loss. It is estimated that around 100,000 Australians may be living with the condition.

This new grant responds directly to feedback from researchers and community members living with geographic atrophy, gathered during MDFA's recent Research Impact Evaluation.

The findings highlighted a critical need to prioritise research addressing key knowledge gaps in understanding and managing the condition.

Leaving a gift in your Will towards research is a way you can continue the fight for sight. If you would like to learn more how you can support MDFA, please contact Cecile Bill, Planned Giving Manager on 1800 111 709 or bequest@mdfoundation.com.au.

Elisabeth Macdonald Memorial Award

Living with a macular disease, and the associated vision loss, is an ongoing challenge particularly for people in regional and rural Australia, where access to specialist care and sight-saving treatment remains more limited.

To help address this, we have announced a new research grant of \$100,000 over a maximum of three years to support innovative solutions specifically focused on investigating aspects of vision health, care and support relevant to people living with a macular or retinal disease in regional and rural areas.

Created with our long-time supporter, the late Elisabeth Macdonald before she died, this final gift is to support research focused on people living with macular disease in rural and regional areas. The new award will fund research into macular and retinal diseases with a particular focus on improving access to diagnosis and treatment, and eye health care outcomes for people in non-metropolitan areas.

The grant aims to address critical knowledge gaps and address the practical and other care and support challenges faced by these communities.

Elisabeth moved to Armidale in 1969, where she lived on acreage outside of town and considered herself a die-hard "bushie." Following her AMD diagnosis in 2005 – and later with neovascular (wet) AMD in 2010 – she made the difficult decision to move closer to medical support in the town centre.

"My Aunty Elisabeth was generous in life – thoughtful, wise, and never one to invest foolishly," said Kate Adams, Elisabeth's niece. "Her legacy lives on through this award, supporting sight-saving research and honouring her deep care for others, especially those in regional communities."

The Elisabeth Macdonald Memorial Award and the MDFA 25th Anniversary Award build on the success of MDFA's Research Grants Program.

Established in 2011, the program has committed over \$6.9 million to 42 leading macular disease research projects in Australia, making it the largest source of non-government funded macular disease research in the country.



New MDFA-funded research advancing the fight against AMD



Could night-time oxygen levels affect AMD progression?

Professor Robyn Guymer AM, a leading retinal specialist and researcher at the Centre for Eye Research Australia, is investigating a potential new risk factor for neovascular AMD: nocturnal hypoxia, or low oxygen levels during sleep. A common cause of nocturnal hypoxia is a group of conditions called sleep disordered breathing, the most common of which is obstructive sleep apnoea.

Supported by MDFA funding, Professor Guymer's team is studying how common nocturnal hypoxia is in people with neovascular AMD compared to similarly aged people without the condition. They're also exploring whether those with nocturnal hypoxia experience more aggressive AMD, such as earlier onset, involvement of both eyes, or a need for more frequent eye injections.

If a link is confirmed, this research could open the door to new approaches for screening and treatment, potentially helping people reduce their risk of vision loss.

This project is part of a growing effort to understand the many factors that influence AMD and improve outcomes for those affected.



Reducing the risk of vision loss in advanced AMD

For people living with neovascular AMD, eye injections are essential to preserving sight. However, many people who receive eye injections still face the risk of serious complications – macular atrophy and subretinal fibrosis – that can lead to irreversible vision loss.

Professor Mark Gillies, a leading retinal specialist at the Save Sight Institute, is working to change that. His team's research focuses on improving treatment outcomes and reducing long-term risks for people with macular disease.

Through the Fight Retinal Blindness! (FRB!) Project, they've developed advanced software to track how treatments perform in real-world settings, beyond clinical trials.

Professor Gillies' new MDFA-backed research will explore which of the six anti-VEGF treatments are least likely to cause the death of photoreceptor cells in the macula that detect light (macular atrophy) or scarring beneath the macula (subretinal fibrosis). They also aim to determine whether less frequent injections, and tolerating fluid under the retina, may lower the risk of these complications.

The findings could help guide treatment decisions and protect vision for longer. If you or a loved one is receiving AMD treatment, this research could shape future care.

In our last edition of Vision Voice, we announced the recipients of our new round of research made possible by the generous donations and bequests from our community.

We thank everyone who has contributed to our research grants program. Here's a look at some of the exciting work your generous support is helping make possible.



Towards personalised AMD treatment: A new frontier in research

Professor Erica Fletcher, a leading retinal researcher at the University of Melbourne, is working to better understand how and why AMD progresses, and how we might stop it.

With support from MDFA, Professor Fletcher's team is investigating reticular pseudodrusen, a type of waste material that builds up in the macula and is linked to a higher risk of late-stage AMD. The team will create microglia – immune cells found in the retina – from blood samples of people with and without AMD. By comparing how well these cells clear waste, they hope to uncover why some people progress to advanced AMD while others don't.

They will also test around 3,000 compounds to find those that help microglia remove waste more effectively. The most promising compounds could lead to new treatments that slow or even prevent AMD progression.

This research brings us closer to personalised, targeted therapies, offering hope for better outcomes and a brighter future for people living with AMD.

Stay updated on the progress of these and other important MDFA-funded research projects via our website, Facebook and LinkedIn pages.



MDFA welcomes new board member

We are pleased to share that Professor Sanchia Aranda AM has joined our board of directors.

Professor Aranda is an experienced and well-respected senior executive and board director across national and international organisations, predominantly in the health, education, research, disability and for-purpose sectors. She has led the establishment of new and redesigned organisations, implemented robust governance frameworks, and led the transformation of ideas into actions to achieve greater impact.

Currently the Board Chair of Scope Australia, a disability service provider, and the Victorian Comprehensive Cancer Centre Alliance, Professor Aranda started her career in nursing and became the first nurse to lead Cancer Council Australia as its CEO.

Professor Aranda is driven by a desire to make a positive difference and ensure there is equity of access and outcomes for the most disadvantaged in our communities. She also has a personal connection to macular disease with both her parents having age-related macular degeneration.

We look forward to the valuable insights and leadership Professor Aranda will bring to MDFA's mission.



Her Excellency, the Hon, Sam Mostyn AC, the Governor General of Australia, celebrates the 2025 Research Grant Awards.

Research awards presented at Admiralty House

In August, we were delighted to have Her Excellency, the Honourable Ms Sam Mostyn AC, the Governor-General present new MDFA research grants at a special event held at Admiralty House.

MDFA Patron, Ita Buttrose AC OBE, also addressed the audience, adding her voice to a memorable occasion. The event was a fitting celebration of our ongoing commitment to research and innovation, and of the researchers whose work we proudly support.

As part of our 2025 Research Grant Program, MDFA is investing more than \$1 million in eight groundbreaking projects. Led by some of Australia's top researchers, these projects aim to:

- Discover new treatments for macular disease
- Reduce the burden of vision loss
- Protect future generations from its impact

We congratulate the successful researchers and extend our sincere thanks to the MDFA Community Review Panel, external peer reviewers, and Research Grants Panel, whose insights were invaluable during the grant selection process.

These projects have the potential to change the lives of people with macular disease, not just in Australia, but around the world.

Are you interested in macular disease research?

MDFA is launching two new research funds to support rural and regional communities, and research into geographic atrophy (often referred to as late dry AMD).

If you've been diagnosed with a macular condition and live in a rural or regional area – or if you're living with geographic atrophy or caring for someone who is – we'd love your help in shaping the future of macular disease research by joining our Community Review Panel.

To find out more, please visit <https://www.mdffoundation.com.au/community-reviewers>

Please email us at research@mdffoundation.com.au if you have any questions or would like to register your interest for our upcoming grants funding round.



Update on macular disease treatments

Geographic atrophy treatment being assessed for PBS listing

The most notable news this year was the registration by the Australian Therapeutic Goods Administration (TGA) of a new eye injection treatment for geographic atrophy (or dry AMD). The treatment is called Syfovre® (active ingredient pegcetacoplan).

Syfovre® is not currently listed on the Pharmaceutical Benefits Scheme (the PBS), however, the advisory body that recommends the listing of medicines on the PBS, the Pharmaceutical Benefits Advisory Committee (PBAC), will consider Syfovre® at its meeting this November.

We now understand who will be eligible for treatment with Syfovre® if it is PBS listed. The manufacturer has proposed that the treatment be listed for people with geographic atrophy in both eyes, where one eye has an intact fovea

(the centre of the macula) and vision is not yet affected but is threatened by the progression of the condition (the eye that can be treated), and the second eye has central vision already affected by geographic atrophy progression (the eye that can't be treated).

The outcome of the PBAC's decision is expected in late December 2025. We will keep you posted.

New cell-based treatment for macular telangiectasia type 2

In other news, a recent journal publication reported the results of a global clinical trial of a new treatment for macular telangiectasia type 2 (MacTel), an uncommon eye condition affecting one in 1,000 Australians.

MacTel Type 2, the most common form of macular telangiectasia, is associated with damage to the retinal

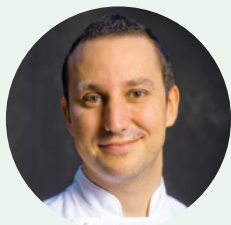
light sensing (photoreceptor) cells, decreasing the retina's ability to detect light, and changes in the retinal blood vessels that cause them to become "telangiectatic" and look like mini varicose veins in the macula, resulting in central vision loss.

The study, co-authored by one of MDFA's funded researchers Professor Mark Gillies, reports the effects of a new treatment that slows retinal cell death.

The surgically implanted cell therapy called ENCELTO (revakinagene tarorectel-lwey), releases a substance called ciliary neurotrophic factor that helps protect retinal photoreceptor cells, thereby helping preserve vision.

The US Food and Drug Administration (FDA) has approved the treatment based on the trial results. MDFA will follow further developments and provide updates as they become available.

Looking for a taste of summer



Celebrity chef Luca Ciano brings his signature Italian flair to macular health with a delicious, eye-friendly recipe: **Insalata di Tonno e Fagioli – a Borlotti**

Bean Salad with Tuna and Onion.

Good nutrition isn't just fuel for your body – it's protection for your eyes. Eating the right foods can help lower your risk of AMD and may even help slow its progression.

Find more delicious, eye-healthy recipes in our recently released Mediterranean Macula Menu, available now on our website.

Insalata di Tonno e Fagioli – a Borlotti Bean Salad with Tuna and Onion

Ingredients

- 250g dried borlotti beans or 400g tinned borlotti beans
- 1 onion, chopped
- 1 celery stick, chopped
- 1 carrot, chopped
- 1 garlic clove, bruised or slightly crushed
- 1 rosemary sprig
- 1 bay leaf
- 185g tin of good quality tuna in olive oil, drained
- 1 red onion, halved, thinly sliced, or in rounds
- 80ml extra virgin olive oil
- Oiled oregano leaves to garnish
- 4 - 5 slices lightly toasted bread, for serving

Instructions

1. If using dried beans, place beans in a large bowl, cover with water and soak for 6 hours, or overnight.
2. Drain beans and rinse well. Place in a large saucepan and add onion, celery, carrot, garlic, rosemary and bay leaf. Cover with water and bring to the boil on a high heat. Reduce heat to medium and cook for 40–45 minutes, until beans are tender. Drain, discarding vegetables and herbs.

OR if you're using tinned beans, drain and rinse under water. No need to cook them.
3. Place beans in a bowl. Add tuna, red onion and oil. Season and toss to combine. Let stand for 10–20 minutes to allow the flavour to infuse.
4. Scatter oregano over the top and serve with toasted bread slices.

Luca's Culinary Journey, Three Generations of Italian Family Cooking – by Luca Ciano, New Holland Publishers
www.newhollandpublishers.com

Elizabeth's journey with AMD, with daughter Amber Sherlock, by her side

We always love getting to know members of the macular disease community and hearing about the steps they take to live well with their diagnosis.

For Elizabeth, much of her approach involves staying connected with friends and family, including her daughter Amber Sherlock, who you might recognise from Channel Nine News.

Following a successful career in advertising and real estate, Elizabeth is now retired and lives with wet age-related macular degeneration (AMD) in both eyes. She first noticed symptoms while on holiday three years ago.

"I was reading and suddenly my vision in my left eye was blurred," she explains. "On my return, I went to my optometrist who informed me that I'd had a bleed and referred me to an ophthalmic specialist, where I now receive frequent injections in both eyes."

The support of friends and family and continuing to lead a full life has helped Elizabeth adapt to living with the disease, as well as her optimism.

"I have four other friends with macular disease; we meet regularly and discuss the adjustments we're making to our lives," she says. "What's really helped me is remembering to enjoy what is important to me – family, friends and entertaining – without focusing on the possibility that my eyesight may deteriorate."

"The achievements of my children and grandchildren and my inclusion in their lives also keeps me feeling positive and proud, despite my macular condition."



Amber says she has been particularly impressed by her mum's resilience. "Mum's attitude since her diagnosis has really reinforced to me the importance of accepting what can't be changed and focusing on the positives," she says. "Our relationship has always been strong; the diagnosis has not changed this."

For others supporting family members with macular disease, Amber says: "Learn all you can about the condition and offer love and support when needed. Since my mother moved from Sydney, the time we spend together has changed, so we try to spend quality time with frequent visits back and forth. Staying connected as much as you can is important."

A photograph of two women, one younger with dark curly hair and one older with white hair and glasses, both laughing joyfully. They are outdoors with colorful foliage in the background.

EYE CONNECT



**Macular
Disease
Foundation
AUSTRALIA**

**"I often had questions after I left the eye clinic, so I joined Eye Connect for support in between appointments. Now I have ongoing support and resources that are tailored to me."
– Sue, Eye Connect participant**

Eye Connect support services are now available for people living with diabetes-related eye conditions

Eye Connect has provided people diagnosed with age-related macular degeneration with the support and tools they need to navigate their condition.

98% of people using this free service would recommend it to others with a macular condition, and this is why we are expanding our support to those living with diabetes-related eye conditions.

Are you living with diabetic retinopathy or diabetic macular oedema?

You're not alone. Eye Connect is here to help you understand your condition and manage it with confidence.

Eye Connect offers:

- Tailored education on diabetic retinopathy and diabetic macular oedema
- Practical lifestyle and vision adaptation advice
- Emotional support via peer connection and counselling
- Multi-channel access (phone, SMS, email, print)

Join Eye Connect today.

Call: 1800 111 709

Email: eyeconnect@mdfoundation.com.au

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