



Macular  
Disease  
Foundation  
AUSTRALIA

# Vision Voice

Autumn Edition 2026



## Making sure the voices of people with macular disease matter in Parliament

The Federal Government recently considered changes to the Medicare Benefits Schedule (MBS) that could affect how – and how much – thousands of Australians pay for sight-saving eye injections. These changes relate to whether people can continue using private health insurance to help cover treatment costs, when the eye injections are performed in private hospital and day surgery settings.

If implemented, this change would impact more than 12,200 people, potentially increasing out-of-pocket costs for those receiving eye injections in private hospitals and day surgeries. MDFA is also concerned that this change may increase demand for private ophthalmology clinic in-

rooms treatment and the already overstretched and inadequate public hospital outpatient eye injection services.

This planned change highlights the broader issue of high treatment cost and lack of access to eye injection services for people living with a macular disease. No one should lose their vision because their treatment is unaffordable.

With treatment costs already high, MDFA is deeply concerned about the risk of people giving up treatment because they can't afford it. We know cost burden is one of the main reasons people stop having their sight-saving eye injections.

*Continued Page 2.*

I am very proud to welcome you to our first Vision Voice for 2026 – and our 25th year of operating as a Foundation. This milestone year gives us the chance to celebrate all that we have achieved together, while also recognising the important work still ahead of us.

In December, we officially welcomed Professor Sanchia Aranda AM as the new Chair of Macular Disease Foundation Australia. Sanchia is an outstanding leader who brings deep experience and expertise to the role. I would like to sincerely thank our former Chair, Graeme Head AO, for his significant contributions to our mission over the past four years. We wish him all the very best as the new CEO of the National Disability Insurance Agency.

As you're aware, an important part of our work is in advocacy. Recently, we launched our **Vision Loss is an Unacceptable Cost** campaign and called on the Federal Government to delay a planned change to the Medicare Benefits Schedule (MBS) that could affect how Australians pay for their sight-saving eye injections. The change could increase out-of-pocket costs for more than 12,200 people receiving treatment and use their private health insurance in private hospitals and day surgeries. We received over 400 letters from community members supporting our call for a delay until broader reforms ensure equitable, affordable treatment nationwide. We delivered these letters to Canberra to ensure your voices were heard at the highest level. We will keep you updated as the Government considers its decision.

Everyone at MDFA is energised and committed to making our 25th anniversary year a memorable and impactful one. Throughout the year we will be inviting our community to engage in activities and events showcasing our work. While we won't be able to make it to every state and territory in Australia, we will be hosting research updates in NSW, Queensland, Western Australia, Victoria and some regional centres.

We look forward to celebrating this milestone with you, and we thank you for your ongoing support.

Dr Kathy Chapman  
Chief Executive Officer



## Making sure the voices of people with macular disease matter in Parliament

Continued.

### Our position

As part of our **Vision Loss is an Unacceptable Cost** advocacy campaign, we have requested that the Federal Government further delay the planned MBS change until reforms can be made to ensure adequate and equitable access to affordable eye injection treatment across the country.

Treatment for AMD and other macular diseases is frequent and lifelong, and public eye injection services are often unavailable or overstretched, leaving most people reliant on the private system with significant out-of-pocket costs.

### What we've done

Over recent months, we invited the macular disease community to join our advocacy campaign – and you responded. We received more than 400 letters of support, which our CEO, Dr Kathy Chapman will share with Federal Health Minister Mark Butler. Thank you to everyone who contributed to this fight for sight.

Our concerns and recommendations have been echoed to government in our recent 2026-27 Federal Pre-Budget submission, with one of the priorities being to pause the Medicare reclassification of eye injections, so that people can continue to use private health insurance to cover the cost of this treatment when done in private hospital and day surgery facilities.

## We also recommended three new initiatives for the Federal Government to reduce the cost burden of people receiving eye injection treatment

First, to create a Neovascular AMD Treatment Incentive Program, which will encourage more private ophthalmologists to bulk bill eye injection treatment for age pensioners with neovascular AMD.

Second, to reform the Extended Medicare Safety Net, so that the threshold no longer resets at the start of every year, and continues to provide the additional 80% out-of-pocket cost rebate for concession cardholders who receive eye injection treatment for neovascular AMD.

Third, to integrate the Pharmaceutical Reform Agreements into the new national hospital funding agreement between the Federal Government and the state and territory governments, ensuring public hospitals are better resourced to deliver more outpatient eye injection treatment services.

### What's next

Regardless of the government's decision, MDFA will continue to advocate for affordable and accessible treatment for people living with macular disease. We'll keep pushing for solutions that ensure cost is never a barrier to saving sight – because vision loss is an unacceptable cost for our community.

**To read our full recommendations to Government and stay updated on this issue, visit [www.mdfoundation.com.au/eye-injection-typec-change](http://www.mdfoundation.com.au/eye-injection-typec-change)**



Dr Kathy Chapman, Professor Sanchia Aranda AM, and former NSW Minister for Health, The Hon Jillian Skinner AM.

## Meet the new Chair of MDFA

At the close of 2025, we had the pleasure of formally welcoming our new Chair, Professor Sanchia Aranda AM, following Graeme Head AO stepping down after four years of incredible leadership.

Already a member of our board, Sanchia brings a wealth of experience to the role and has a family history of age-related macular degeneration, which affected both parents. She is passionate about contributing to changing public understanding of macular disease.

“Stepping into the role of Chair is a privilege,” she said. “I extend my sincere thanks to Graeme for his outstanding leadership and steady stewardship of Macular Disease Foundation Australia.”

As we approach the Foundation's 25th anniversary, we honour a legacy built by a community supporting one another, empowering thousands of Australians living with macular disease. Together, we look ahead to new opportunities to strengthen this community, deepen our impact, broaden our research agenda, and ensure that every Australian has the best chance of preserving their sight.”

Mr Head's departure coincides with his appointment as the new CEO of the National Disability Insurance Agency (NDIA) in November last year.

Welcome to Sanchia, and a sincere thank you to Graeme for his outstanding contribution to our Foundation and the macular disease community.



## New findings: Eye Connect support is helping people manage AMD

People taking part in MDFA's free Eye Connect support service – which has reached a new milestone of over 1000 people – are telling us they feel more confident managing their condition and staying on track with their AMD treatment schedules while in the program.

### Why is this important?

In our first social impact survey, 75% of respondents told us that living with macular disease was impacting their daily functioning in some way, with around 1 in 6 people reporting a high level of impact to their lives.

This tells us there are a lot of people who could potentially benefit from support to help them manage their day-to-day life with macular disease. This is why we developed Eye Connect.

### Findings from our new Eye Connect evaluation

As part of this evaluation, conducted in collaboration with the University of New South Wales School of Optometry and Vision Science, we gathered feedback from Eye Connect participants.

- 81% said they now understand AMD better
- 74% felt more supported and heard thanks to regular check-in phone calls
- 91% found the resources easy to access and understand

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

Pharmaceutical Benefits Scheme data shows 20% of people stop treatment after one year of commencing eye injections, with a significant drop to 50% stopping by five years.

Against the backdrop of these national discontinuation rates, 95% of Eye Connect participants on eye injection treatment said they maintained their recommended treatment schedule whilst being in the Eye Connect service, and 73% said they feel more positive about their treatment.

These findings highlight the impact of tailored support in helping people manage AMD and stay engaged with treatment. This kind of positive feedback fuelled our decision to expand the service to people living with diabetes-related eye conditions.

**Find out more about Eye Connect and how it could support you by visiting [www.mdfoundation.com.au/eye-connect-check/](http://www.mdfoundation.com.au/eye-connect-check/) or calling us on 1800 111 709.**



## Community member Jo shares her journey with diabetic macular oedema

I was 29 years old when I was diagnosed with type 1 diabetes. I'd lost a bucket-load of weight – something like 10 kilograms in less than six months – but I'd put it down to stress. We were building a house at the time, and I was travelling statewide a lot for work. It was a busy time in my life.

After receiving my diagnosis, I remember bursting into tears with my partner. The shock was overwhelming.

At 46, I had a good handle on living with diabetes – it had been part of my life for 17 years. But that changed after a routine eye scan picked up some irregularities, and I was eventually diagnosed with diabetic macular oedema. This came as a shock because I hadn't been experiencing any symptoms, so I was grateful that I'd been diligent with frequent eye tests.

It wasn't until a couple of years ago that I began experiencing changes in my vision.

A blurry spot had appeared, I was squinting more to focus on things, and I had to increase the font size on my computer because it was becoming too small to read.

Being told that I'd eventually need injections in my eyes to keep my vision was very scary.

### Balancing health, family and everything in between

Living with diabetic macular oedema and type 1 diabetes is a lot to take on. It can be a juggle – working, family commitments, home life, on top of everything I need to do for my health, like exercising every day, making sure my diet is good, and receiving my eye injections every couple of months.

There's the emotional side of things too. I do worry about losing my eyesight, it's one of my biggest fears.

But I always try to stay positive and try not to let it get me down. I mean, I certainly have my moments, but I just ride the wave. If I feel like crying, I do, because I think it's important to let it out, knowing the next day is a new one. My family is super supportive, and I think it's so important to surround yourself with people that care about you.

### If you're going through something similar, MDFA can help

Staying on top of regular check-ups, leaning on the people around you, and taking things one day at a time has made all the difference for me. The team at MDFA have also been a wonderful help to me. I'd recommend getting in touch with them if you're looking for extra guidance or reliable information, like I was.

# Geographic atrophy or late-stage dry AMD FAQs

## **Q: What is geographic atrophy/late-stage dry AMD?**

**A:** Geographic atrophy – also known as dry age-related macular degeneration (AMD) – is a form of advanced or late-stage AMD.

It happens when retinal cells in the back of the eye gradually die (atrophy), leading to patches of ‘missing’ retina, which may cause gradual loss of central vision and the ability to read and see faces, if the macula is affected.

Some people with geographic atrophy may develop the wet (neovascular) form of AMD. It’s possible to have both geographic atrophy and neovascular AMD in the same eye.

## **Q: Is there any update on new treatments for geographic atrophy?**

**A:** Yes. Two eye injection treatments for late-stage dry AMD called pegcetacoplan (brand name Syfovre®) and avacincaptad pegol (brand name: Izervay™) have been registered and approved by the Therapeutic Goods Administration for use in Australia.

Pegcetacoplan has also been recommended for listing on the Pharmaceutical Benefits Scheme (PBS) but is not PBS listed yet. Avacincaptad pegol will be considered for PBS listing in March 2026.

Whilst the new eye injection treatments may help to slow down the progression of geographic atrophy, the treatments have not been shown to restore vision.

However, clinical research into new therapies and devices to help restore vision in people with geographic atrophy is also being conducted around the world.

## **Q: What should I do if I have been diagnosed with geographic atrophy?**

**A:** If you have been diagnosed with geographic atrophy, continue seeing your eye health professionals as often as recommended and don’t skip appointments.

Continue to have any tests (e.g. Optical Coherence Tomography or OCT) that your eye health professional recommends, to monitor the progress of your geographic atrophy.

Ask your eye health professional any questions you may have about your diagnosis, and your treatment options.

## **Q: What do I do if I experience an adverse event or reaction after an eye injection?**

**A:** In Australia, the Therapeutic Goods Administration (TGA) monitors the safety of all eye injection treatments and other medicines and therapeutic devices registered for use.

To do this, the TGA relies on patients and health professionals to report any information they have about adverse events, side effects and reactions they have noticed or experienced.

Anyone can report an adverse event to the TGA. You can also submit a report on behalf of someone else. You can make a report online or by phone. We encourage you to report any adverse events, side effects or reactions that you notice after an eye injection, or about any medicine you are taking.

**You can find out more here: [www.tga.gov.au/safety/adverse-events](http://www.tga.gov.au/safety/adverse-events)**



## An experimental implantable retinal device may help improve vision

We have been asked by community members for more information about a new device reported in the news recently as being able to help improve vision in people with geographic atrophy – also known as late-stage dry AMD.

The experimental system is called PRIMA (Photovoltaic Retina Implant Microarray). It consists of a tiny device which is surgically implanted under the retina, in the area where retinal cells are missing due to geographic atrophy.

The device is made from a special material that can convert light into electrical signals which can move to the brain where they are perceived as a visual image, replacing the role of the missing light-sensing retinal cells (photoreceptors) in the eye.

The system also involves wearing a pair of glasses with a tiny camera mounted in the frame. The camera captures images of what the wearer is looking at and sends the image to a portable processor that can be carried in your pocket, which is connected to the glasses. The processor changes the camera image

into light patterns and projects them onto the implant in the retina. The user can adjust the zoom and brightness of the glasses as needed.

### More research is needed

This new technology is experimental, and the results are based on a small, preliminary trial. More research is needed to determine the long-term safety and effectiveness of the implantation procedure and the device, which is not yet approved or available in Australia.

Geographic atrophy is a progressive condition, so this device, whilst potentially helping with vision, would not necessarily remove the need for eye injection treatment in eligible people to slow progression.

Reference: Holz F, et al. 2025. Subretinal photovoltaic Implant to Restore Vision in Geographic Atrophy Due to AMD. NEJM; DOI: 10.1056/NEJMoa2501396

# Could stem cell implants save vision in people with geographic atrophy?

Other recent news we have been asked about, reported the results of a clinical trial which involved implanting stem cells into the retinas of a very small number of people with geographic atrophy, with the aim of replacing the cells lost to the condition, and stopping – or even reversing – disease progression to restore vision.<sup>1</sup>

The stem cells were obtained from adult eyes donated to registered eye banks. The cells were taken from the layer of light-sensing cells called the retinal pigment epithelium in the donated eyes.

The cells were then grown in the laboratory to multiply the number of cells and then prepared for implantation into patients using an eye injection into the retina.

The study found that the cells were able to grow and become part of the retina, thereby improving vision in participants. This was particularly evident in participants who had worse vision at the start of the trial.

People who did not receive the stem cell implant showed a continued decrease in vision loss due

to the natural progression of their geographic atrophy. The stem cell implants were well tolerated and there were no significant safety concerns.

A new clinical trial conducted by scientists at the University of Southern California,<sup>2</sup> will test the safety of implanted retinal pigment epithelium cells and ability to improve vision in a larger number of people with retinal damage due to geographic atrophy.

In this study, the new implant, which is thinner than a human hair, will consist of cells created in the laboratory from embryonic stem cells – cells that can become any type of cell in the body. We will follow the progress of this trial and keep you updated.

#### References:

1. Rao R et al. 2025. Safety and tolerability of RPESC-RPE transplantation in patients with dry age-related macular degeneration: Low-dose clinical outcomes. *Cell Stem Cell*, 2025; 32 (11): 1659 DOI: 10.1016/j.stem.2025.08.012
2. University of Southern California - Health Sciences. "Scientists test a tiny eye implant that could restore sight." *ScienceDaily*. ScienceDaily, 9 January 2026. <[www.sciencedaily.com/releases/2026/01/260108231348.htm](http://www.sciencedaily.com/releases/2026/01/260108231348.htm)>.





## Could a magnifier make life easier for you?

The MDFA team was recently introduced to the Snow Pad – a portable electronic magnifier stand that turns your iPad or tablet into a powerful vision aid. It offers a range of features to help make life easier for people with low vision:

 **Near viewing:** Place reading materials, paperwork or other items under the stand, and they'll appear magnified on your iPad screen above. For example, you could put a cookbook or crossword underneath to see the text enlarged on the display.

 **Distance viewing:** A built-in high-definition camera lets you view and magnify objects up to 5 metres away, with up to 32x zoom. You might use it to check your TV program guide across the room or make text on a whiteboard clearer during a meeting.

 **Flexible and portable:** Lightweight and easy to move from the kitchen bench to the living room or dining table. Long battery life means you can use it anywhere.

If you don't own a tablet or are looking for a more affordable option, you might want to consider:

- Handheld electronic magnifiers: compact devices for reading labels or menus.
- Magnifier apps for iPad or smartphone: free or low-cost apps that use your device's camera for basic magnification.
- Simple optical magnifiers: lightweight, inexpensive solutions for quick reading tasks.

**Call our National Helpline on 1800 111 709 to discuss how assistive technologies might benefit you.**



Serves 4

Time to make  
20 mins

## Broccoli and pea soup

While it may not feel like it, the cooler months are on their way. Be prepared with this macula-friendly Broccoli and Pea Soup.

### Ingredients

- 1 tablespoon olive oil
- 1 large onion, finely chopped
- 2 garlic cloves, crushed
- 1 teaspoon lemon zest
- 2 large potatoes, peeled, chopped
- 350g broccoli, trimmed, chopped
- 2 cups frozen peas
- 2 cups reduced-salt vegetable stock
- ¼ cup reduced-fat sour cream
- 2 tablespoons chopped mint leaves, plus extra leaves, to serve
- 2 tablespoons pistachio nuts, chopped
- 4 slices toasted grainy sourdough, to serve

### Instructions

- Heat the oil in a large saucepan over medium high heat. Sauté the onion for 5 minutes, or until soft.
- Add the garlic and lemon zest, and cook, stirring for 1 minute more.
- Add the potatoes, stock and 2 cups of water, and bring to the boil.
- Reduce heat and simmer, covered, for 5 minutes. Add the broccoli and peas. Then simmer, partially covered, for 10 minutes, or until vegetables are tender.
- Set aside to cool slightly. Blend soup in batches until smooth. Return soup to a clean saucepan and reheat until hot.
- Season with black pepper. Combine sour cream and mint.
- Serve soup with a dollop of the mint sour cream, and sprinkle with the pistachio nuts and extra mint leaves.

# Vale Uncle Gerald

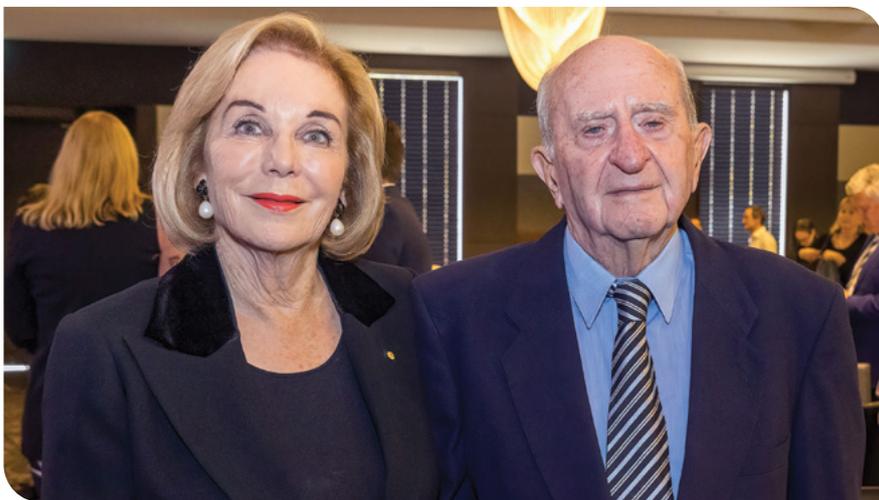
In February, we received the very sad news that our close friend, and uncle of MDFA Patron, Ita Buttrose AC OBE, Gerald Buttrose, died at the remarkable age of 102. Gerald was someone many of you would have read about over the years in Vision Voice.

Affectionately referred to as 'Uncle Gerald' by the macular disease community, he lost the sight in his left eye at age 79 after AMD was not diagnosed early enough for treatment. In 2008, he was diagnosed with wet (neovascular) AMD in his right eye, but this time it was detected promptly. Thanks to the availability of intravitreal anti-VEGF injections – which had become available to people with AMD only a year earlier – Gerald continued to receive sight-saving treatment right up until the end of his life.

Gerald often spoke about how different his experience was from that of his older brother and Ita's father, Charles, who lost his eyesight to wet (neovascular) AMD before treatment existed. Gerald's own journey served as a powerful reminder of the importance of early detection and timely intervention.

A positive and generous spirit, Gerald was always willing to give his time and energy to help raise awareness and understanding of macular disease, and to support MDFA's advocacy campaigns for positive change in the community. He was a warm presence at our events and never hesitated to share his story for the benefit of others – whether speaking in person or through the media.

**Macular Disease Foundation Australia extends our heartfelt sympathies to the Buttrose family. Uncle Gerald will be fondly remembered by all of us.**



Ita and Uncle Gerald at the National Press Club in Canberra.



## Congratulations Val

We're proud to celebrate Val, one of our longest-serving volunteers. Val recently marked her 15th year supporting MDFA.

From the beginning, she has been an important part of our community, starting her journey as many dedicated volunteers do - packing educational materials for community members.

Over time, Val's involvement with the Foundation has grown and evolved, drawing on her teaching background to contribute in many ways. She maintains strong ties with our community through our Mac Mates peer-to-peer support program, delivers insightful education talks based on her own experience to both students and community groups, and actively participates in our Community Reference Group.

**Val's enthusiasm and genuine approach have made her a treasured member of our community and organisation, building close friendships with staff and fellow members. We are delighted to celebrate her 15-year milestone. Thank you, Val.**

**EYE CONNECT**



**Macular  
Disease  
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**“My biggest worry when I was diagnosed with diabetic macular oedema was losing my vision and then losing the freedom that comes with that sense. And sometimes you don’t want to take up too much of your ophthalmologist’s time, so you don’t ask all the questions you have.”**



Ben’s experience is not unique. Many people feel uncertain and overwhelmed after their diagnosis. That’s why MDFA expanded its free Eye Connect support service to people living with diabetes-related eye conditions – the leading cause of preventable blindness in working-age Australians.

**Do you have concerns about living with vision loss? Want a better understanding of your condition? Or need answers between appointments?**

If you’re living with a diabetes-related eye condition – or age-related macular degeneration – Eye Connect is here to help.

Our qualified and friendly team can give you the support, information and practical advice you need to live confidently with your condition. This free support is available over the phone, via email or in the mail – whatever works best for you.

We are here to help so please get in contact with us.

**Join Eye Connect today:**

**Call:** 1800 111 709

**Email:** [eyeconnect@mdfoundation.com.au](mailto:eyeconnect@mdfoundation.com.au)

**Not sure if Eye Connect is right for you?**

Take our free online Eye Connect check at [www.mdfoundation.com.au/eye-connect-check/](http://www.mdfoundation.com.au/eye-connect-check/)

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