



**Macular  
Disease  
Foundation  
AUSTRALIA**

# VisionVoice

**Summer Edition 2023**

## **Celebrating our Centenarians**

**Norma and Gerald are two members of the macular disease community who are not losing sight of what's important – their vision**

What's unique about these two remarkable people is that they are both centenarians and are still receiving sight-saving eye injections to maintain their vision.

Norma is 102 years old and with the support of her treating Ophthalmologist and Macular Disease Foundation founder, Dr Paul Beaumont, she receives her regular eye injections in her aged-care facility. Norma has wet (neovascular) age-related macular degeneration (AMD), and the treatment provided by Dr Beaumont over the past four years has helped her maintain functional vision.

Norma is bedbound. Visits to the ophthalmology clinic would require ambulance transport so the visits by Dr Beaumont are the only way she can continue to receive the sight-saving

injections. So, every six weeks, like clockwork, Dr Beaumont and his ophthalmic nurse, pack a medical kit and travel from their Mona Vale surgery to Norma's aged care home in nearby Avalon, on Sydney's northern beaches.

"I couldn't do without them, could I? It's very nice of him to come," Norma told us.

It's because of these eye injections that Norma can still read two books a week, watch television, and see the faces of her two children, five grandchildren, and three great-grandchildren.

Norma's son David is present at her injections. "In the beginning, we would take Norma to Dr Beaumont in his surgery, but in September 2020, Norma unfortunately had to move in here (to the nursing home), so Dr Beaumont decided to do the injections in her bed," David said.

Dr Beaumont, founded Macular Disease Foundation Australia in 2001, and says it is "critically important" to continue treatment. For someone like Norma, who is completely immobile yet still mentally sharp, "the alternative – blindness – is unacceptable".



## In the words of Uncle Gerald

Gerald Buttrose, uncle of our Patron, Ita Buttrose AC OBE, celebrated his 100th birthday this year. It is only through sight-saving treatment that Gerald has retained his vision and his ability to read and use the computer. The following words have been penned by Gerald.

### Ninety-nine years plus one.

I was first diagnosed with macular disease at the age of 79 in 2002, when I lost the sight of my left eye through it not being diagnosed early enough to respond to any then available treatment.

AMD manifested itself in the right eye six years later when

it was promptly diagnosed and injected within 24 hours. However, a problem arose with its immediate subsequent treatment and when the Macular Disease Foundation became aware of this through my niece, Ita Buttrose, it recommended I urgently seek another opinion and offered the names of leading eye specialists.

Thanks to the Macular Disease Foundation I found myself in the hands of a leading Sydney eye surgeon who within a week or two restored sight to the eye after its vision had become greatly impaired.

From that point on and right up to this present day I have experienced near-normal vision. My distance sight is good, and I am able to cope with reading, writing, computer and television with little or no problem.

Upon recently reaching an age milestone, the question has cropped up as to how I will handle macular degeneration in my declining years and the answer is simply 'as before' because it demands no more than an injection of the sacred Lucentis every eight weeks or so. I calculate I have had over 120 of these treatments and can honestly say I have not experienced pain on any occasion.

I have not had a battle with AMD, rather a light, extended skirmish and for this I express my profound thanks to the two great doctors who treated me throughout and to the Macular Disease Foundation and Ita also because without their timely advice and assistance I would have had a far different story to tell.

- **Gerald Buttrose**



Ita Buttrose's five grandchildren (from left) Clare, Jack, Byron, Samantha and Elyse celebrating Gerald's 100th birthday.



# CEO Update



Thank you to the 2000 members of our community who took part in our second Macular Disease Social Impact Survey. The purpose of this study is to gain a deeper insight into the impact macular disease has on a person's life. Our aim is to carry out this study every two years and track changes in people's vision status, support needs, wellbeing and mental health. It also better informs the services we can offer people living with macular disease.

We are currently collating the data and will report back early in 2024. One result I can share is that that 74% of respondents rated our Vision Voice newsletter as good or excellent. I am sure this edition will continue to provide you with valuable information.

I recently had the pleasure of sitting in on our new Peer Support group in Stirling, Western Australia. Thank you to the participants of this group who allowed me the opportunity to listen to their stories and learn more about their lived experience. I was both moved by their difficult experiences and impressed by their strength and camaraderie by their strength. The Peer Support group showed how valuable it is to speak with others living with macular disease.

As we move towards the festive season, please reach out to our team if you need support. We're here for you.

**- Dr Kathy Chapman**

## RANZCO College Medal

A heart-felt congratulations to Associate Professor Alex Hunyor, Board member and Chair of the MDFA Medical Committee, who was awarded the prestigious College Medal at the most recent Royal Australian and New Zealand College of Ophthalmology (RANZCO) conference. The College Medal was presented to Alex by Professor Nitin Verma who is a previous Chair of our Medical Committee and a past Board member. Nitin was also a recipient of the College Medal, which attests to the quality and expertise of the ophthalmologists on our Board.







Kathy Chapman, MDFA CEO and Meera Chandra, Healthcare Relations Manager, visiting TerryWhite Chemmart Pyrmont

## MDFA partners with TerryWhite Chemmart for national campaign

Pharmacists have a valuable role to play in early detection and reducing the impact of macular disease in the community, which is why MDFA is partnering with TerryWhite Chemmart to raise awareness in pharmacies about the importance of monitoring for vision changes.

Despite over 1.9 million Australians having evidence of the disease, an estimated 25% of cases remain undiagnosed.

To tackle this, MDFA and TerryWhite Chemmart are providing people aged 50+ with a fast, easy way to understand and assess their general risk factors for macular disease.

As part of the partnership, TerryWhite Chemmart will be prompting customers to learn about their risk of developing AMD and diabetic eye disease, using the MDFA's Check My Macula online quiz.

In addition, the public can pick-up a free Amsler grid in store, allowing them to check for any changes to their vision in between eye tests.

"Our partnership with Macular Disease Foundation Australia has helped us to start conversations with patients and get these important tools into their hands," said Brenton Hart, Chief Pharmacist at TerryWhite Chemmart.

## AGM

We welcome members of the community to join us at the NSW State Library for our 2023 AGM. Our guest speaker is Professor Justine Smith, who is an ophthalmologist and researcher at Flinders University, SA.

**Date:** Wednesday 6 December 2023

**Time:** 10am to 12pm

**Venue:** NSW State Library  
Gallery Room  
1 Shakespeare Place, Sydney

Please RSVP to [info@mdfoundation.com.au](mailto:info@mdfoundation.com.au)  
or call 1800 111 709.



**Macular  
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# New developments in macular disease treatment

**November 2023**

## **New macular disease treatments approved in 2023**

For more than 15 years, anti-VEGF eye injections have helped preserve the vision of thousands of Australians living with neovascular (wet) age-related macular degeneration (AMD), and more recently, diabetic macular oedema, retinal vein occlusion and other sight-threatening macular diseases.

For Australians needing eye injections for either neovascular (wet) AMD or diabetic macular oedema, a new treatment option is now available with the listing of Vabysmo® (faricimab) on the Pharmaceutical Benefits Scheme (PBS) in January 2023.

Also in 2023, two new treatments for late-stage dry (atrophic) age-related macular degeneration, or geographic atrophy, were approved by the United States Food and Drug Administration (FDA) offering hope for tens of thousands of people living with this condition.

There is extensive research under way to better understand the causes of macular disease and to bring new treatment options to people living with macular disease. Read on for more about these important developments.





# Geographic atrophy treatments approved in the United States

For many years, treatment for late-stage dry (atrophic) age-related macular degeneration (AMD), also known as geographic atrophy, was limited to people participating in clinical trials.

This changed in 2023 when the United States (US) Food and Drug Administration approved two new eye injection treatments for geographic atrophy: Syfovre™ (active ingredient: pegcetacoplan) and Izervay™ (active ingredient: avacincaptad pegol).

The discovery of these two new treatments for late-stage dry AMD reflects the persistence and commitment of researchers to offer much needed hope to people living with this condition.

The two new treatments – pegcetacoplan and avacincaptad pegol – work by inhibiting the Complement system, a part of the immune system that specifically helps your body fight infections. Over time, the Complement system can cause small patches of cells in the retina to gradually die – these are called atrophic lesions. Late-stage dry AMD occurs when these lesions form at the macula, reducing central vision.

As the lesions grow and vision decreases, people's ability to continue their daily activities, including driving, reading, recognising faces, using public transport or doing household chores, is significantly impacted. The new treatments were approved in the US based on their effect in slowing the growth of these sight-threatening lesions. Slowing lesion growth helps to delay the progression of late-stage dry AMD.

Three clinical trials (named OAKS, DERBY and GALE) have studied the effects of pegcetacoplan eye injections and found that they slowed down lesion growth (by almost 40%) after 2½ years of treatment compared with "sham" eye injections that did not contain treatment. These beneficial effects seem to



Late-stage dry (or atrophic) age-related macular degeneration

increase over time with continuing treatment (injections monthly or every-other-month).<sup>1</sup>

The clinical trial (called GATHER2) testing the effect of a monthly injection of avacincaptad pegol, found that retinal lesion growth was slowed by 14% after 12 months of treatment, compared with no treatment.<sup>2</sup> Early results indicate this effect continues over 2 years with monthly or every-other-month injections.<sup>3</sup>

Neither pegcetacoplan nor avacincaptad pegol have been shown to reduce the size of lesions already present in the eye. Both treatments seem to be generally well tolerated, although they do slightly increase the risk of developing neovascular (wet) AMD in the treated eye.

Pegcetacoplan is being reviewed by the Australian Therapeutics Goods Administration with a decision expected in early 2024. It is unclear when avacincaptad pegol will be reviewed in Australia

If it's been more than 12 months since your last eye check, make an appointment today. An eye scan can help determine if treatment may be an option for you in the future.

## New findings bring a positive outlook for 2024

Following the successful listing of Vabysmo® (faricimab) on the Australian Pharmaceutical Benefits Scheme (PBS) in January 2023 for people living with neovascular (wet) AMD and diabetic macular oedema, Vabysmo® may also soon be available to treat people with macular oedema caused by retinal vein occlusion.

Retinal vein occlusion is when one of the veins in the retina becomes blocked, which can lead to vision loss, especially if it affects the macula, the central part of the retina.

New results from two clinical trials (called COMINO and BALATON) involving participants with retinal vein occlusion from 22 countries across the globe, compared the effects of Vabysmo® (faricimab) with EYLEA® (aflibercept) injections, one of the mainstays of treatment for neovascular AMD. Both treatments were found to be equally effective in improving vision.

## New high-dose version of EYLEA® approved in the United States

To increase the time between EYLEA® injections for people with neovascular (wet) AMD or diabetic macular oedema, the US Food and Drug Administration has approved a high-dose, longer-lasting new version of EYLEA®, known as EYLEA HD®.

Results from the PULSAR and PHOTON clinical

trials found that increasing the time between treatments from 8 weeks to 12 weeks and even up to 16 weeks in some people, resulted in similar improvements in vision. Longer intervals between injections may help to reduce treatment burden and cost for people with neovascular (wet) AMD, diabetic macular oedema and diabetic retinopathy.

Neither Vabysmo® for retinal vein occlusion nor EYLEA HD® are available yet in Australia. However, the Australian Therapeutics Goods Administration and Pharmaceutical Benefits Advisory Committee are expected to review both treatments in the coming months.

### What to look out for in 2024

- The Therapeutic Goods Administration is expected to decide whether to approve pegcetacoplan to treat late-stage (dry) AMD.
- The Therapeutic Goods Administration and Pharmaceutical Benefits Advisory Committee are expected to decide whether to approve and fund Vabysmo® (faricimab) to treat retinal vein occlusion.
- The Therapeutic Goods Administration and Pharmaceutical Benefits Advisory Committee are expected to decide whether to approve and list EYLEA HD® (aflibercept 8mg) on the Pharmaceutical Benefits Scheme to treat neovascular AMD and diabetic macular oedema.
- The Pharmaceutical Benefits Advisory Committee is expected to decide whether Byooviz® (ranibizumab biosimilar) should be listed on the Pharmaceutical Benefits Advisory Scheme.



<sup>1</sup> Press release: [investors.apellis.com/news-releases/news-release-details/syfovrer-pegcetacoplan-injection-continued-demonstrate](https://investors.apellis.com/news-releases/news-release-details/syfovrer-pegcetacoplan-injection-continued-demonstrate). Published 30 July 2023. Accessed 22 Sept 2023.

<sup>2</sup> Khanani et al. Lancet 2023. doi: 10.1016/S0140-6736(23)01583-0. Published 8 Sept 2023. Accessed 22 Sept 2023.

<sup>3</sup> Press release: [www.astellas.com/en/news/28506](https://www.astellas.com/en/news/28506). Published 19 Sept 2023. Accessed 22 Sept 2023.

<sup>4</sup> Hattenbach et al. Ophthalmology Science, 2023. doi.org/10.1016/j.xops.2023.100302. Published 8 Sept 2023. Accessed 12 Oct 2023.

<sup>5</sup> Press release: Aflibercept 8 mg two-year results from pivotal PHOTON trial in diabetic macular oedema presented at ARS. Published 29 July, 2023. Accessed 12 Oct 2023.

<sup>6</sup> Press release: Two-year PULSAR trial results for Aflibercept 8 mg demonstrate durable vision gains at extended dosing intervals in wet age-related macular degeneration. Published 10 Aug, 2023. Accessed 12 Oct 2023.

## In other developments...



### **Byooviz® (ranibizumab) approved by the Therapeutic Goods Administration**

A new entry into Australia is Byooviz® (ranibizumab), a biosimilar treatment, recently approved by the Therapeutic Goods Administration. Byooviz® may become available in 2024 after it has been evaluated by the Pharmaceutical Benefits Advisory Committee. It is an alternative to Lucentis® injections (also

ranibizumab) and can be used to treat retinal conditions including neovascular (wet) AMD, diabetic macular oedema and macular oedema caused by retinal vein occlusion.

### **US Food and Drug Administration rejects Lytenava™**

The US Food and Drug Administration rejected a new drug application for Lytenava™, a version of bevacizumab specifically designed for use in the eye as an alternative to Avastin® (also bevacizumab) to treat neovascular (wet) AMD and other retinal conditions.

#### **What is a biosimilar?**

You may be familiar with the 'generic' version of a medicine, for example a cholesterol-lowering or blood pressure tablet. Generic medicines have the same active ingredient and work in the same way as the original brand name medicine.

A biological is a treatment that is made from – or contains – human or animal cells or tissues and can be used to treat or prevent disease. A biosimilar is essentially the "generic" form of a biological treatment. As biological treatments are more complicated to produce, biosimilar treatments must also undergo clinical trials to prove they work the same way and are as effective and safe as the original biological treatment.

### **Tarcocimab (KSI-301) development stopped**

Clinical development of tarcocimab (KSI-301) was also stopped in June due to an unexpected increase in cataracts in people with diabetic macular oedema being treated with the drug. The future of both treatments is now uncertain.

MDFA does not accept liability for out of date, misinterpreted or incorrect information. This information is a summary only and further information is available from the MDFA. Mention of treatments and companies in this update does not constitute endorsement by MDFA.



### Raising awareness of diabetic eye disease in regional and remote communities

For over two years, MDFA has partnered with Sight for All to deliver education sessions in regional and remote areas of South Australia, and now NSW, where there are high rates of diabetes. People living with diabetes are at heightened risk of diabetic retinopathy, yet our Community Survey earlier this year showed 45% of people living with diabetes don't know it can affect their eyes.

This year, our New South Wales sessions were delivered in Shoalhaven, Warren,

Cootamundra, Nyngan, Gundagai, Berrigan, Dubbo, Coonamble, Werris Creek, Manilla, Quirindi, and Jervis Bay. In South Australia, sessions were conducted with Aboriginal Health Practitioners and community groups, reaching places like Coober Pedy, Mannum, Kadina, Bute, Moonta, Ardrossan, Clare, and Morgan.

These presentations delivered by the Sight for All team on our behalf work to address a lack of awareness of the risks of vision loss associated with diabetic eye disease. In these sessions, the importance of regular eye examinations for early diabetic eye disease detection is emphasised, highlighting the benefits of timely intervention in preventing or delaying vision loss.





### Slip, slop, slap on some sunnies!

Protecting your eyes from harmful UV radiation is crucial in a hot Australian summer where we have prolonged UV exposure. UV rays are a known risk factor for age-related macular degeneration (AMD), so to help safeguard your vision this summer, think about wearing sunglasses with 100% UVA and UVB protection and a high UV protection category (3 or 4). Wraparound styles and

those with blue light filtering can provide added protection. A wide-brimmed hat and seeking shade through the middle of the day is also essential to reduce UV exposure. When in doubt, consult with your eye health professional for specific recommendations tailored to your needs.



### Stay hydrated

As the summer months arrive, it is important to think about ways to stay hydrated. Dehydration can lead to serious health issues like heatstroke, urinary tract infections, and cognitive impairment. Below is our checklist to help you through the summer months.

1. Monitor your water drinking throughout the day (a common guideline is 8 to 10 cups a day if you're over 60 years of age)
2. Consume hydrating foods like watermelon and cucumber.
3. Avoid excessive caffeine and alcohol, which can dehydrate.
4. Set regular reminders to drink fluids.
5. Carry a reusable water bottle.
6. Monitor urine colour for hydration assessment.
7. Speak with your healthcare professional if you have any concerns or questions about staying hydrated.



Here's an easy and tasty way to stay hydrated this summer. All you need is an ice tray, some fresh juice (orange, apple, cranberry – whatever your pleasure). Fill the tray with the juice, freeze, then add the ice cubes to your water or pop them straight into your mouth.



# Vale and thank you, Giles

In June this year, Giles Cooper, and his 43-year-old Volkswagon, Clementine, set off on an adventure to journey around Australia to support research into macular disease and cancer. Living on the Gold Coast, Giles bought his 1970 model VW Type 3 Fastback as a rolling wreck back in 2019 and spent the COVID lockdown months lovingly rebuilding Clementine – a salute to her VW paint colour, Clementine.

Giles and Clementine were to drive a lap of Australia, some 15,000 kilometres, not only to see more of our wonderful country, but also to raise both awareness and funds for research into cancer and aged-related macular degeneration.

In 2007, Giles had a lengthy battle with throat cancer and received excellent care and treatment. He also has a sister as well as

a best friend from his school days, who both live with age-related macular degeneration. As a result, he nominated Macular Disease Foundation Australia and the Cancer Council as his two preferred charities to support in his fundraising efforts.

Upon arrival in Western Australia, Giles sadly passed away from health issues. While we were all shocked and so deeply saddened for Giles' family and friends, we wish to pay tribute to his generous nature and his spirit of adventure.

Giles had a fundraising target of \$5000, and funds raised in his honour have now tipped over \$25,000 towards research into macular disease. This legacy is one we are truly grateful for, and we know that Giles would have been humbled by such generous support from his family and friends.



**MY EYES**



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## My Eyes – a new way of supporting people living with macular disease



My Eyes is our new patient support program which will be launching in 2024. To ensure the My Eyes service offering is relevant and accessible, we have spent the past 12 months working with members of the macular disease community to inform what the program looks like and how it is to be delivered.

### What is My Eyes?

My Eyes is a service developed in collaboration with people with macular disease, carers, and eye healthcare professionals to ensure those living with the disease get the best care between visits to their optometrist or ophthalmologist.

My Eyes is free of charge, independent and endorsed by Australia's leading eye health professionals. The service focuses on three areas:

1. health information
2. practical advice, and
3. emotional support

My Eyes will help people to better understand and manage life with macular disease. Support is available through phone, email, and hardcopy, dependent on preference. If you join the My Eyes service, you will receive:

- Practical tips, including nutrition and lifestyle information, to help support your eye health
- Stories from other people with macular disease
- Advice on keeping a positive mindset
- Opportunities to connect with other people in the macular disease community.

## My Eyes is launching in 2024

If you'd like to learn more about the My Eyes service, you can chat to our friendly team by calling our National Helpline on 1800 111 709 during office hours Monday to Friday. You can also email us at [myeyes@mdfoundation.com.au](mailto:myeyes@mdfoundation.com.au)

Contact Us:  1800 111 709  [info@mdfoundation.com.au](mailto:info@mdfoundation.com.au)  @maculardisease

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