



Macular
Disease
Foundation
AUSTRALIA

VisionVoice

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Saving sight will save billions of dollars

A new economic modelling report, **Investing to Save Sight: Health and Economic Benefits of Improving Macular Disease Treatment Persistence**, was launched in May by Macular Disease Foundation Australia.

It shows that an investment to save the sight of thousands of vulnerable older Australians will save the Government up to two billion dollars – and it has the Australian public's support.

Currently, 80,000 Australians receive regular anti-VEGF eye injections to retain vision and prevent blindness. Since their introduction in 2007, eye injections have saved the sight of countless Australians living with neovascular age-related macular degeneration (AMD) and diabetic eye disease. For many, access and cost of treatment will become a barrier, and 50% of people will stop their eye injections within 5 years, putting them at risk of severe vision loss or blindness.

Macular Disease Foundation commissioned this report to model the economic benefits to government of increasing treatment persistence

for people with wet AMD. Cost and access have been identified as two of the main reasons why people with neovascular AMD stop treatment. This includes the challenges in accessing affordable or bulk-billed treatment for low-income earners and pensioners and difficulty accessing treatment for those living in rural and remote Australia.

The **Investing to Save Sight** report shows that by increasing treatment persistence by 25%, the sight of an additional 22,000 vulnerable Australians will be saved, and up to two billion dollars added to the Government's bottom line.

(continued on page 3).



CEO Update

Macula Month in May, our key awareness program for the year, showcased the launch of our **Investing to Save Sight** economic modelling report. We were thrilled to have Patron, Ita Buttrose, AC OBE, officially launch the report where we were joined by members of the macular disease community, including valued donors, volunteers, funding partners, and eye healthcare professionals at the NSW State Library.

Since launching the report, we have had a full schedule of meetings with politicians and health officials across the country. Each meeting has emphasised the importance of improving access and affordability for macular disease treatment in their jurisdictions.

Another key highlight of Macula Month was our next investment in research through the Research Grant Program and the Grant Family Fund. The \$700,000 investment across six outstanding research projects now takes our investment total to \$5.8 million since we launched the program in 2011. Once again, we were honoured to have this special award event hosted by His Excellency the Honourable David Hurley, Governor-General of Australia, and Mrs Hurley, at Admiralty House in Sydney.

Adding to the celebration, Mrs Hurley penned an original song about the importance of macular disease research.



With her permission, we have shared these words with you in our newsletter.

Please enjoy,

Dr Kathy Chapman
Chief Executive Officer

Advocating for better transport assistance

One of the areas Macular Disease Foundation raised in the lead up to the NSW State Election was better transport assistance for people travelling to have their sight-saving eye injections. One of the key factors in stopping treatment is having to travel long distances to the clinic. Research shows that those with significant distances to travel to their eye specialist (more than 100km) were 52% less likely to be adherent to treatment than those located within 20 km.

The NSW Government has the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) available to provide financial support for people travelling over 100km to receive medical treatment. Other states have similar assistance schemes. Transport subsidies can help people stay on eye injections, especially those in regional and rural areas. However, these transport schemes are not widely known and could be easier to apply for - and more generous.

Macular Disease Foundation detailed to the NSW Health Department some practical improvements that could be made to the IPTAAS scheme to improve accessibility. After the election, we were delighted to hear that NSW Health is introducing a print accessible version of the IPTAAS application forms with improved readability. As well, the service will now accept applications over the phone to better support people with vision impairment.

Macular Disease Foundation intends to continue advocating to State Governments as part of our work. The next state election campaigns will be in Queensland and ACT. If you live in these states, please let us know any key issues you think we should tackle on behalf of the community of people with macular disease.

If you need help with travelling for eye injections, please contact our Helpline on 1800 111 709 and we can advise you about the different government transport subsidy schemes and whether you may be eligible.

Saving sight will save billions of dollars cont.

Macular Disease Foundation is recommending three key areas for state, territory, and federal governments to consider investment to increase treatment persistence by up to 25%. These include:

1. Increased affordability of eye injections,
2. Increased access to treatment,
3. Increased health information and tailored support to help people stay on treatment.

Patron, Ita Buttrose says it is a tragedy that in 2023 Australians are losing their sight unnecessarily.

“Being able to see is a priceless gift that people take for granted until they lose it. So many older Australians are needlessly going blind when there are reasonable investments that Government can make now for a longer-term benefit.”

The investment has popular public approval with a recent YouGov survey finding that eight in ten Australians believe that government should invest in sight.

It also showed that 69% of people believed pensioners should be provided with free sight-saving eye injections.

**“Government can make huge savings, simply by making it easier for people who need eye injections to persist with their treatment.”
Ms Buttrose said.**

“Eye injection treatment saves people’s sight and maintains their quality of life. It reduces the reliance upon the aged care system, which we know is already under enormous strain.”

The *Investing to Save Sight* report was launched as part of the Macula Month awareness program. CEO, Dr. Kathy Chapman says the launch of the report is the start of a much larger conversation to support an investment into systemic change to eye injection treatment for the macular disease community.

“A modest shift of 25%, or 22,000 patients, persisting with eye injection treatment may not sound like much, but the longer-term impact for those people living with AMD and their families is enormous”, says Dr. Chapman.

You can download a copy of the Report Summary from the Macular Disease Foundation website at www.mdfoundation.com.au/news

The *Investing to Save Sight* report has highlighted the social and economic benefits of persistence for those people receiving eye injections. Health education is fundamental to this success.

Over the past two years, Macular Disease Foundation Australia has conducted research to hear directly from people with macular disease, the people who care for them, and the people who treat them.

We are using this information to develop a new patient support program for all people living with macular disease – based on their own needs and experiences. This new program is called **My Eyes**.

My Eyes focuses on three pillars of support – health information, emotional and practical – tailored to a patient’s own situation. Participants receive resources to live well with their macular disease and improve their health literacy.

Connecting to the program will ensure people with macular disease get the very best of care in between their visits to their eye health professional.

My Eyes will be piloted with community members and will officially launch in 2024.



We can and we must do better

The risk of blindness threatens 80,000 people currently receiving sight-saving treatment unless State and Federal Governments collaborate to reduce treatment costs and access issues for older Australians.

A new economic modelling report, **Investing to Save Sight: Health and Economic Benefits of Improving Macular Disease Treatment Persistence**, has been launched by Macular Disease Foundation Australia. It shows that an investment to save the sight of thousands of vulnerable Australians will save the Government up to \$2 billion over the next decade.

Since being introduced in 2007, anti-VEGF eye injection treatment has saved the sight of countless Australians living with AMD and diabetic eye disease. On average, patients need between 5-7 eye injections per eye each year, often for the rest of their lives.

However, 20% of people stop treatment in their first year and 50% within five years putting them at risk of severe vision loss or blindness.

If we can increase treatment persistence by 25%, the sight of an additional 22,000 Australians will be saved, and billions of dollars added to the Government's bottom line.

Research shows that cost and access to treatment are the main reasons people stop having eye injections. This includes being able to access affordable or bulk-billed treatment for low-income earners and pensioners, and treatment for those living in rural Australia.

I have seen first-hand the vast difference between someone having access to sight-saving treatment and someone who has not.

My father Charles lost his sight to the advanced wet form of AMD. He was diagnosed long before eye injection treatment was available and it was heart-breaking to watch things he loved so dearly, like reading and writing, quickly disappear for him.





His youngest brother by comparison, my 99-year-old Uncle Gerald, has lived with the same form of AMD for the past 17 years. He has received over 140 eye injections and to this day retains his vision and quality of life. I appreciate that my uncle is one of those lucky ones who has had access to excellent care and a support network which has allowed him to persist with his treatment program.

Many older Australians are not so fortunate. For some of them, it's a decision between having food on the table or receiving injections to stop going blind.

Based on the findings of the **Investing to Save Sight** report, Macular Disease Foundation is recommending three key areas for government to consider investment to increase treatment persistence up to 25%. This includes increased affordability, easier

accessibility, particularly for rural Australians, and education and support programs to help people understand the importance of staying on treatment.

If State and Federal governments were to absorb the cost for just one in four low-income earners and pensioners to stay on treatment, the government would benefit from overall net savings of up to \$2 billion.

It would reduce the reliance upon the health and aged care systems, which are under enormous strain. While the government is focused on savings in the May budget, preserving the sight of people with macular disease is a positive investment ready for action.

The Foundation's recommendations are sound. I urge government to review this new report and consider older Australians who are at risk of going blind. We can and must do better.



Source: Op-ed penned by Ita Buttrose, AC OBE, and published across the News.com network for Macula Month

ABC launches audio description across the ABC iview platform

In 2020, the ABC launched its audio description service across the broadcast television network, reflecting its commitment to inclusivity and accessibility to all Australians.

In July this year, the ABC is expanding the audio description service to ABC iview. So that viewers who are blind or visually impaired can enjoy their favourite shows, movies, current affairs and news on-demand and in a more inclusive way.

Audio descriptions are available on ABC iview across iOS (iPhone/iPad), Chromecast and Android devices from July.

The Governor-General of Australia awards the 2023 Research Grants Program

Macular Disease Foundation Australia has awarded more than \$700,000 in research funding to six promising projects building the knowledge bank to better understand macular disease.

The grants were presented to our latest cutting-edge Australian researchers, who are working to reduce the impact of macular disease, by His Excellency the Honourable David Hurley, Governor-General of Australia and Mrs Hurley, at Admiralty House in Sydney.

The latest funding round now brings our commitment to macular disease research to \$5.8 million across 35 projects since 2011. Macular Disease Foundation is Australia's largest source of research funding in the field of macular disease outside of government.

This year's funding round is supporting three projects examining atrophic age-related macular degeneration, also known as geographic atrophy, for which there are no currently approved treatment options in Australia. Geographic atrophy is a significant cause of vision loss and blindness in Australia and has many unanswered research questions.

One project includes a stem-cell derived modelling of geographic atrophy, and the second will address hyperspectral imaging for detecting and monitoring geographic atrophy.

Other areas of funded research seek deeper insights into sight-threatening diabetic macular ischaemia; enhanced diagnostic approaches to reduce misdiagnosis of macular disease; and an evaluation of high-density lipoprotein levels that might identify people with high-risk phenotypes of age-related macular degeneration.

The function of mitochondria, the energy-producing centres in our cells, are the focus of research by second-time funding recipient Dr Gerald Liew of the Westmead Institute for Medical Research, University of Sydney, and first-time recipient Dr Grace Lidgerwood of the Centre for Eye Research University of Melbourne whose research builds upon previous research funded by Macular Disease Foundation.

The quality of research applications was high, and subjected to a rigorous assessment process based on NHMRC criteria to ensure successful projects meet the highest scientific standards. Joining Macular Disease Foundation's Expert Review Panel and International Peer Reviewers in the 2023 grant selection process was our Community Review Panel comprising people caring for, or living with macular disease.

Fourteen people joined the Community Review Panel and – like the Expert Research Panel – reviewed and weighted the value of the applications according to a set of community-specific criteria. The Community Review Panel helped us to understand the areas of research people with lived experience considered the most important. At the end of the process, we found the researchers and the community members were very aligned in their recommendations, which is a testament to the quality of the funded projects.

Our research grants program is funded through the generosity of our community, so it is very appropriate that our community has a say in how their funding is invested.

You can read more about each of the researcher's work on the Macular Disease Foundation website at [**www.mdfoundation.com.au/news**](http://www.mdfoundation.com.au/news)



Left to right: Dr Xavier Hadoux, A/Prof Gerald Liew, Dr Alexis Ceecee Britten-Jones, His Excellency the Honourable David Hurley, Dr Carla Abbott, Dr Grace Lidgerwood, A/Prof Chandra Balaratnasingam.



Members of the Community Review Panel and team from Macular Disease Foundation. Left to right: Godwin Abela, France Pilavakis, Susan Falon, Chris James, John Simpson, Kathy Chapman, Kristina Ward, Dale Lowe, Ashley Chapman, Vicky Heaton, Deborah Chadwick.

Lyrics written by Her Excellency Mrs Linda Hurley to
celebrate the 2023 Research Grant Program recipients.



Her Excellency Mrs Linda Hurley

The Macular Disease Foundation Research Grants Awards

The Macular Disease Foundation does a mighty Job
It's funded by community Research Grants Awards are won
MDFA research funds from community for research
For 12 years now our researchers much support its brought

Thirty five great projects by 30 great researchers
Macular disease a collective term for eye diseases
Conditions affecting the macula severe vision loss may be
Sometimes leads to blindness a difficult place to be

For dedicated researchers Research Grants Awards are grand
Macular disease affecting the macula and blindness makes a stand
The Grant Awards are special our researchers work so hard
Their passion and commitment they go the extra yard

The Macular Disease Foundation we say thanks for what you do
Supporting our researchers giving sight the light shines through

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Healthy choices



Mediterranean

Ingredients

2 zucchini, trimmed,
cut into thick slices
2 small eggplant, trimmed,
cut into pieces
1 red capsicum,
cut into thick slices
1 red onion, thickly sliced
2 cloves garlic, sliced
finely grated zest
and juice of 1 lemon
1 tablespoon olive oil
400 gram can diced
tomatoes
1/4 cup kalamata olives
1/4 cup parsley leaves
1/4 cup chopped fresh dill
4 x 150g fillets firm white
fish fillets
Couscous, lemon wedges
to serve



This recipe has been nominated by Laura and Matthew who have been undertaking their research placement as part of their Masters in Nutrition and Dietetics under the guidance of the staff at Macular Disease Foundation.

Laura and Matthew shared their experience undertaking their research, working and learning alongside the Macular Disease Foundation team.



1. What have you been working on with Macular Disease Foundation Australia?

We were lucky enough to complete our research placement with Macular Disease Foundation, working on a systematic review to investigate the strength of evidence for diets, foods, nutrients and/or supplements and the prevention or progression of AMD. A systematic review looks at all published studies and pools their findings together.

2. What have you learnt about eye health and nutrition?

We found that following the Mediterranean diet pattern closely (this type of eating pattern has: lots of vegetables, fruit, wholegrains, fish, olive oil) and enjoying fish at least twice a week is likely linked with a lower risk of developing AMD and progressing to advanced stages. The Oriental diet pattern (lots of vegetables, plus rice, soy products, seafood) is also likely to be beneficial for reducing risk of developing AMD. Regularly eating foods high in omega-3 fatty acids as well as the antioxidants lutein and zeaxanthin are also associated with AMD prevention.

3. What have you gained from your placement at Macular Disease Foundation?

The team at Macular Disease Foundation has been so welcoming and supportive. We have had a first-hand insight into the amazing teamwork here, inspiring us while working together on our project. We have expanded our knowledge of AMD and the impact of AMD on the community, and with guidance from Dr Kathy Chapman, Victoria Heaton, and the staff we know our research will make a difference.

Watch for future updates soon on the nutrition project.

Method

Preheat oven to 180°C.
Spray a large baking dish with olive oil.

Combine zucchini, eggplant, capsicum, onion, garlic and lemon zest in dish. Season.

Pour over half combined lemon juice and olive oil.

Bake for 10-15 minutes until vegetables are just tender.

Stir tomatoes, olives and half combined herbs through vegetables. Nestle fish in mixture. Drizzle with remaining oil mixture.

Bake for a further 10-15 minutes until fish flakes when tested with a skewer.

Source: The Australian Woman's Weekly

MythBusters

1. Will cataract surgery cause my AMD to worsen?

Some studies and anecdotal reports suggest that cataract surgery may accelerate the progression of AMD. However, most major studies have shown no link. On balance, cataract surgery does not appear to contribute to worsening of AMD.

Firstly, both conditions are associated with age, and may occur at a similar time. Secondly, dense cataracts can mask the symptoms of AMD. When these dense cataracts are removed and replaced with new artificial intraocular lenses (or IOLs), the clarity of the final vision depends on the severity of any underlying AMD. In addition, the symptoms of AMD, such as distortion or blurring, can become more obvious once a cataract is removed. Because of this, some people have mistakenly concluded that the surgery made the AMD worse.

2. I have heard about a new wet AMD drug called Vabysmo. Who should be on Vabysmo treatment?

Vabysmo® (faricimab) is now available in ophthalmology clinics across Australia following news that the product is reimbursed on the Pharmaceutical Benefits Scheme (PBS) for the treatment of neovascular AMD and diabetic macular oedema from 1st January 2023.

As with all new treatment options, the decision to start or switch between anti-VEGF therapies requires careful consideration of risks and benefits. People who have been advised to start or are currently receiving eye injections for neovascular AMD should have a conversation with your ophthalmologist, who will be able to discuss whether the new treatment may be appropriate for you.

Focusing on Diabetic Eye Disease

Diabetes affects an estimated 1.5 million people in Australia. What's not so well known is that diabetic retinopathy, an eye complication of diabetes, is the leading cause of preventable vision loss in working age Australians, affecting between 300,000 and 400,000 Australians. The risk of developing diabetic retinopathy increases with the duration of diabetes, with almost all people with type 1 diabetes and over 60% of people with type 2 diabetes experiencing some form of retinopathy within 20 years of diagnosis. Regular eye examinations and optimal diabetes control are crucial in mitigating the risk of vision loss and preserving eye health.

Recognising this urgent need, Macular Disease Foundation in collaboration with the Australian Diabetes Educators Association (ADEA), has developed a new education course specifically designed for diabetes educators, thanks to funding from the Australian Department of Health.

Diabetes educators play a vital role in the multidisciplinary health care team for individuals with diabetes, empowering them through education, resources, and clinical support to successfully self-manage their condition and with enhanced wellbeing.

The newly created course aims to equip diabetes educators with the necessary knowledge and skills to effectively address the challenges posed by diabetic eye disease. It will provide diabetes educators with comprehensive training on diabetic eye disease, covering topics such as the importance of regular eye examinations, the impact of diabetes on eye health, strategies for effective patient education, and collaborative care between health professionals.

Excited about the benefits of the newly created course, Diyar Emadi, credentialed Diabetes Educator and ADEA team member said, "by enhancing their clinical understanding of eye-related complications associated with diabetes, diabetes educators can significantly contribute to the early detection, prevention, and management of diabetes-related vision loss."



Two survivors on a lap of Australia

Giles Cooper, 75 years young, and his 43-year-old Volkswagen will soon start on a 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. Between the two of them they have a combined age of 118 and would like to prove that age is no barrier to adventure.

Giles and Clementine are driving a complete 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 AMD.

In 2007, Giles had a lengthy battle with throat cancer and received such excellent care and treatment. He also has a sister as well as a best friend who both live with AMD. As a result, he has nominated Macular Disease Foundation Australia and the Cancer Council as his two preferred charities to support in his fundraising efforts.

Clementine will have the Macular Disease Foundation logo emblazoned on her side with a QR code people can scan to donate to our research program. Giles hopes to raise over \$5,000 for research. Just as importantly, he wants to start a conversation about macular disease and share health information with people he meets along the way.

We will keep you updated on Giles and Clementine's journey. And if he stops in your town, be sure to say hi and wish him well.

Lasting Legacy

Despite it being one of the most important things you should do, reports suggest that over 50% of Australians have not yet made a Will. An up-to-date Will allows you to ensure your wishes are fulfilled the way you intended and avoids the risk of incurring unnecessary cost and distress for your family.

Writing a Will is also an opportunity to help those causes that are important to you. In fact, around 20% of all charity revenue comes from gifts in Wills. Whether large or small, a gift in your Will creates a lasting legacy and can have a huge impact for future generations.

Generous legacy gifts pledged by our supporters have helped us invest over \$5.8 million into macular disease research and these gifts have enabled us to provide essential programs, services and support to people living with macular disease – and all free of charge. There are many reasons why you might consider leaving a gift. Mary, one of our **Visionary Partners**, who has confirmed with us that she has left a gift in her Will says,

“Over the last 60 years I have watched my mother and grandmother cope with the loss of sight from AMD. On being diagnosed myself it was enormously comforting to find that MDFA was there for me. It gives me pleasure that my bequest will help others in the future”

September 6th to the 12th is **Include a Charity Week**. Whether you have a Will or are yet to make one, we hope that when making or updating your Will, you might consider a gift to Macular Disease Foundation Australia to support our mission to reduce the impact of macular disease.

To find out more request a copy of our bequest brochure, call 1800 111 709 or email bequests@mdfoundation.com.au.

MyInteract – a new app to connect you with latest macular disease health information.



Macular Disease Foundation Australia has partnered with **MyInteract** to provide digital information and resources directly to people with early, intermediate and neovascular AMD, diabetic eye disease, and retinal vein occlusion.

MyInteract is a unique and free mobile application providing a single digital source for you to quickly access material relevant to your condition, as well as resources to help you live well with macular disease. This is an easy and paper-less way for people living with macular disease to connect with evidence-based information provided by Macular Disease Foundation's health experts.

People living with early AMD, intermediate AMD, wet AMD, geographic atrophy, diabetic eye disease, and/or retinal vein occlusion, and your families, can easily access the **MyInteract** app by scanning our QR code from your smart device or accessing a weblink

in their browser. You can download with confidence as all data is safely secured and will never be shared.

When you access MyInteract you will be presented with a registration page to input your disease and treatment information. The **MyInteract** app will automatically present you with folders of information personalised for your condition.

We believe this will be of great benefit for newly diagnosed people, or those who have family members or carers who would benefit from more information about your condition in an easy and accessible digital format.



**For any questions,
please contact our
National Helpline
on 1800 111 709.**