

Vision Voice

Summer Edition 2024

Early days, big impact: an update on MDFA's Eye Connect service

We are pleased to let you know that we have received overwhelmingly positive feedback from the people participating in our new Eye Connect community service.

Launched earlier this year, this free service offers people living with age-related macular degeneration (AMD) access to evidence-based health information, practical advice and emotional support in between appointments with their eye health professional.

The numbers are in

We recently surveyed the first 150 Eye Connect participants, which revealed:

- **98%** of respondents would recommend the service to their family or friends
- **75%** of respondents reported that the service positively impacted their general wellbeing.

We know that many people find it difficult to remember their eye professional's advice, which is why MDFA launched Eye Connect. This new service is here for people when they have questions or need support outside of the clinic.

It is very encouraging to see the service is having a positive impact. The evaluation has also helped us identify how we can improve the service going forward.

Currently, many of our early participants are women and we would like to encourage more men to join the service. If Eye Connect sounds like a service that you feel would benefit you, please call us for a chat.



Story continued on page 2

It has been an exciting year for the Foundation with the launch of the new Eye Connect service. People who have joined Eye Connect are benefiting greatly from the personalised support our qualified healthcare team are offering.

One member said to me recently, "I really wish I had this service earlier in my diagnosis, it would have changed the way I thought about my disease".

My response to this is, it's never too late!

If you've just been diagnosed with macular disease or you're now living with low vision, I can assure you that you will benefit from our support service. And remember, you can access this service free of charge over the phone, online, or we can share information in the post – anywhere in Australia.

Another way we continue to support you is with a strong advocacy agenda. As we head into an election next year, we will be speaking with both sides of government about ensuring our community has access to more affordable treatment, particularly for our most vulnerable age care pensioners. I look forward to sharing our election asks with you in early 2025.

Applications have now opened for our Research Grants. MDFA is proud to be the largest non-government funder of macular and retinal disease research in Australia. We look forward to funding some exciting projects in 2025 that will bring us better understanding and closer to more effective treatments.

As we near the festive and summer season, I urge you to connect with us if you need support. We are here for you. Thank you to everyone who has supported us this year.



Best wishes,
Dr Kathy Chapman
Chief Executive Officer

Early days, big impact: an update on MDFA's Eye Connect service cont.

Hear first-hand from participants

Aged 76 and happily retired, Eye Connect participant Helen was last year diagnosed with AMD in both her eyes.

"The Eye Connect program has been an absolute help," says Helen. "It has provided a complete understanding of my condition, describing multiple aspects like nutrition, supplements, healthy living, and low vision aids and technology. The team is fantastic, always there to answer my questions and keep me on the right track. I can't thank them enough!

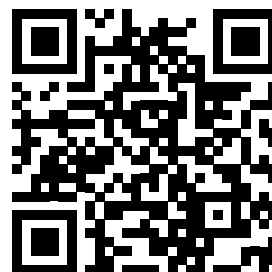
I feel like I have someone besides my doctor whom I can turn to and clarify my doubts," she said.

Kevin, who lives with dry AMD in both eyes, is another one of our Eye Connect participants. Visual changes have impacted his independence and lifestyle for two and a half years.

Kevin let us know that the service has given him a sense of reassurance regarding his experience with macular disease. It has provided him with a realistic understanding of the disease and its consequences. He not only appreciates the check-in phone calls he receives from the Eye Connect team, but also that there are people looking out for those who are living with macular disease.

Join Eye Connect

Helen and Kevin are two of the hundreds of people who are now benefiting from Eye Connect. MDFA plans to expand the service to support other macular conditions in the future.



If you're interested in joining too, please complete the contact form available at www.mdfoundation.com.au/join-eye-connect or call us on 1800 111 709.

A preview of our 2025 advocacy activities

As 2024 comes to a close, our preparations for the advocacy activities in 2025 are ramping up.

The Federal Government announced that from 1 July 2025, many people receiving eye injections in private hospitals and day surgery settings will no longer be able to cover the cost of their treatment using private health insurance.

MDFA will be advocating for measures that lower out-of-pocket treatment costs for ALL people with macular disease, by recommending incentives for more ophthalmologists to bulk bill, and increasing access to public treatment in our 2025 Federal Election Agenda and Pre-Budget submission.

Our full statement of our position on the reclassification of eye injections is available on our website at <https://www.mdfoundation.com.au/news/mdfa-responds-to-the-australian-governments-planned-mbs-change/>

To further support our community, we have started to identify all public hospitals that provide eye injection

treatment across the country, as there is currently no central source for this information.

The Federal Government also announced that by 1 July 2025, a new Aged Care Act will be in place, with a new Support at Home Program replacing the current Home Care Packages Program. The Federal Government has announced that fees will remain the same for people already on a Home Care Package.

After 2025, a new goods, equipment and assistive technology program will be established within the Support at Home Program. This will mean eligible older people with vision loss can use their aged care funding to purchase low vision aids and technologies. We've been advocating for this reform for over 10 years and are very happy that it will become a reality!

As the advocacy voice of the macular disease community, we regularly need up-to-date stories about the life experiences of people living with the disease. Please get in touch with us if you are interested in sharing yours. Email advocacy@mdfoundation.com.au

Join us for our Year in Review event

We welcome the macular disease community to join us at the NSW State Library for our 2024 Year in Review.

Our guest speaker is clinician-researcher Dr Ceecee Britten-Jones from the University of Melbourne.

Date: Monday 2nd December, 2024

Time: 10am for a 10.30am start

Venue: State Library of New South Wales

1 Shakespeare Place, Sydney NSW 2000

Please RSVP to info@mdfoundation.com.au or call 1800 111 709

You can review our latest Annual Report from 2 December at [mdfoundation.com.au](https://www.mdfoundation.com.au)



MDFA launches new Research Impact Report

For more than a decade MDFA has been funding vital macular and retinal disease research to advance knowledge and understanding, with the view to developing better treatments and achieving better health outcomes for people living with a macular disease, and hopefully, one day bringing us closer to cures.

Our Research Grants Program is now Australia's largest non-government source of funding for macular and retinal disease research, which has only been made possible through the support of donors and bequests. We thank everyone who has contributed to date – your generosity has helped improve the lives of people and future generations.

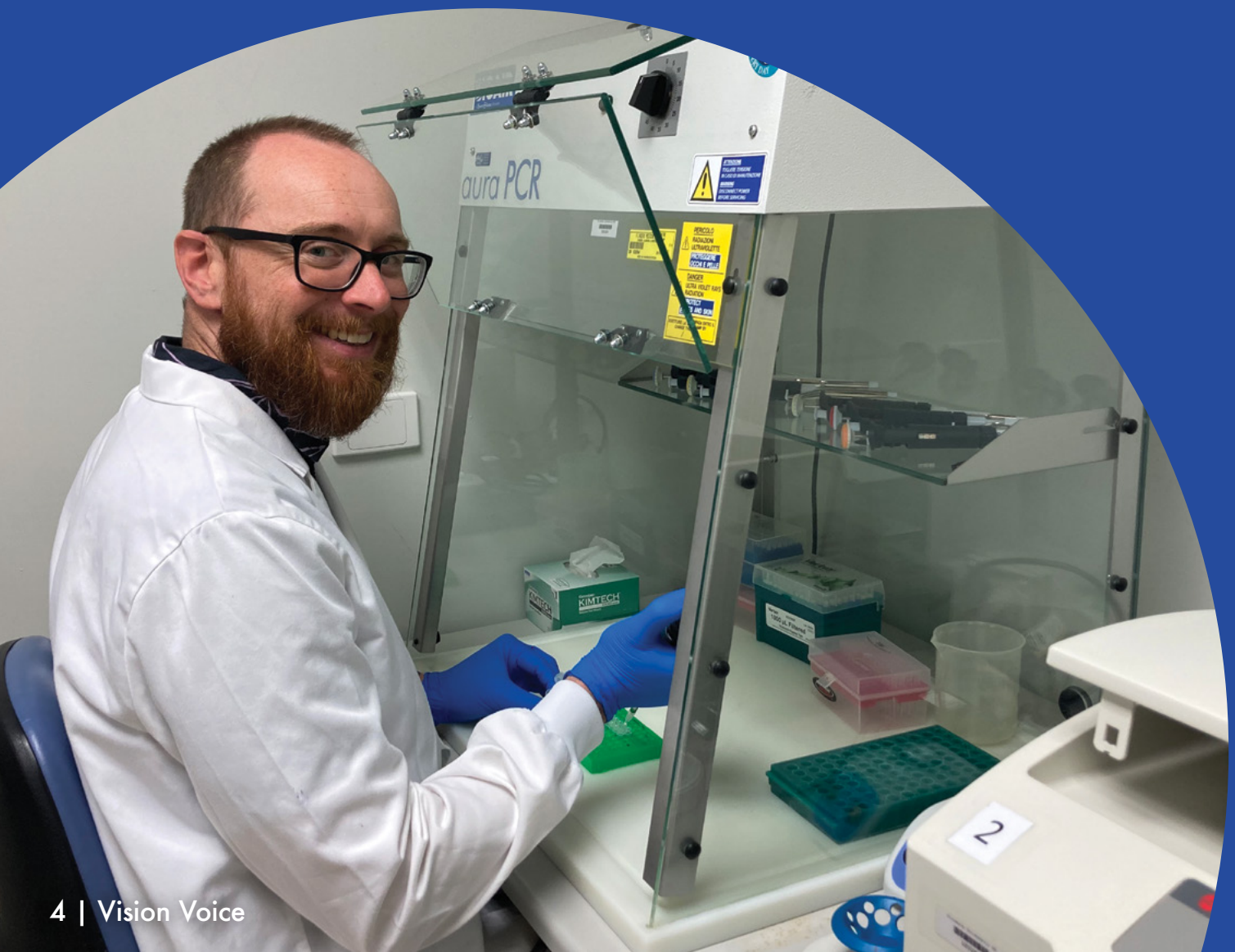
To demonstrate the value of MDFA-funded research we have released a new Research Impact Report.

In it you will find stories about some of the talented researchers we have invested in, and how their work has contributed valuable evidence to the macular disease knowledge base in Australia, and internationally.

MDFA looks forward to building on these achievements through our continued support of macular disease research to advance treatments and reduce the burden on people living with a macular disease, as well as their carers and families.



You can download the report on our website at mdfoundation.com.au





Macular Disease Research Update

Summer Edition 2024

We open the research focus of this edition of Vision Voice with an abridged foreword written by MDFA's National Research Advisor, Professor Paul Mitchell AO, which was published as part of our new Research Impact Report.



There is no denying the devastating impact macular disease can have on someone's life and their family. Macular disease limits functional activities such as reading and driving, and progressively causes loss of independence. In many older people this can lead to a premature need for supported care, including nursing home care. Overall, there can be a markedly reduced quality of life, with increasing depression, as vision loss becomes irreversible. As an ophthalmologist, I see this daily in my clinic.

Over the past 20 years, significant advances in AMD treatment include the pivotal development of anti-VEGF (vascular endothelial growth factor) therapies, which have dramatically improved outcomes for people with neovascular AMD. For geographic atrophy (dry AMD), research into gene therapies, complement inhibitors, and stem cell treatments have shown promise.

Improvements in diagnostic imaging, such as OCT (optical coherence tomography) and OCT angiography, have also enhanced early

detection and monitoring, leading to better management and tailored treatment strategies.

Ongoing randomised trials of potential therapies for geographic atrophy are crucial because current approaches to treatment are limited and often ineffective.

Artificial intelligence (AI) is likely to play an expanding role in AMD treatment opportunities in the future, by enhancing diagnostic accuracy through advanced imaging analysis, using datasets to predict disease progression, and potentially to personalise treatment plans and optimise drug delivery.

I have guarded hope for the future, particularly for treatments for geographic atrophy (GA), and advancing technologies using newer artificial intelligence possibilities.

As you read about the inspiring work into macular disease being undertaken by Australia's leading research minds, I hope you will join me in pledging your commitment to fight for sight in Australia.

New macular disease treatments assessed and approved in 2024



It's been a busy year for the Australian Therapeutic Goods Administration (TGA) and the Pharmaceutical Benefits Advisory Committee, with a number of treatments for macular and retinal diseases being assessed for registration and/or listing on the Pharmaceutical Benefits Scheme (PBS).

On 1 October 2024, Eylea® 8mg (afibercept 8mg) was PBS listed for treating neovascular (wet) AMD and diabetic macular oedema. This high-dose version of the original treatment (Eylea® 2mg) allows a longer time between eye injections, with the same clinical effects. This will help reduce the number of injections needed for eligible patients.

Vabysmo® (faricimab) eye injections were also recommended for PBS listing for macular oedema caused by retinal vein occlusion (where one of the retinal veins becomes blocked affecting vision). Vabysmo® is already PBS-listed for treating neovascular AMD and diabetic macular oedema.

Two new treatments for late-stage dry AMD or geographic atrophy, (pegcetacoplan and avacincaptad pegol), were submitted to the TGA for approval and registration. The assessment for both treatments is ongoing.

If you have any questions about the new treatments, or your treatment options, talk to your eye health professional.

In this issue, we answer your questions about the new treatments for geographic atrophy, and how MDFA is advocating for these on behalf of our community.

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 MDFA. Mention of treatments and companies in this update does not constitute endorsement by MDFA.

Geographic atrophy – your questions answered

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

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

Some people think that there are only two types of AMD, wet or dry. However, AMD is actually classified into three stages: early, intermediate and late AMD. Late-stage AMD can be either neovascular (wet) AMD or atrophic (dry) AMD/geographic atrophy.

Geographic atrophy happens when retinal cells in the back of the eye gradually die (atrophy), leading to patches of 'missing' retina (lesions). As the lesions grow, central vision may be affected.

Some people with late-stage dry AMD may go on to develop the wet (neovascular) form of AMD. It's possible to have both dry AMD and neovascular AMD in the same eye.

Q: Are there any treatments for geographic atrophy?

A: Yes, but they are not currently approved or available in Australia.

The two new eye injection treatments for geographic atrophy are pegcetacoplan (brand name Syfovre™) and avacincaptad pegol (brand name: Izervay™). These two treatments have been approved in America. The European Medicines Agency has not approved pegcetacoplan for

use in the European Union. We are awaiting decisions on both medicines from the TGA in Australia.

Both treatments are delivered as an eye injection, which need to be continued ongoingly, every 25 to 60 days.

Q: Will I be eligible for the new treatments?

A: It is currently unknown who will be eligible for the new treatments, or who will benefit most.

If they are approved and registered by the TGA in Australia, this doesn't necessarily mean that you will be eligible for treatment.

If the treatments are approved, it's important to talk to your ophthalmologist. They will need to determine if you are eligible and weigh up the benefits and risks to see if the treatments are suitable for you.

Q: How effective are the new treatments?

A: The clinical trials assessing pegcetacoplan and avacincaptad pegol found that eye injections every month, or every two months, helped to slow progression of geographic atrophy.^{1,2}

However, while the trials found that treatment can slow progression, neither treatment improved vision.

In addition, the pegcetacoplan trial found that some people experienced serious adverse events after treatment, including developing neovascular (wet) AMD and inflammation in the

injected eye that could further worsen vision.¹

Q: What can I do to prepare for if the new treatments are approved?

A: If you live with late-stage dry AMD, continue seeing your eye health professional as often as recommended.

Continue to have any tests (e.g. Optical Coherence Tomography or OCT) to ensure that the progress of your dry AMD is regularly monitored.

Ask your eye health professional any questions you may have about dry AMD or the new treatments.

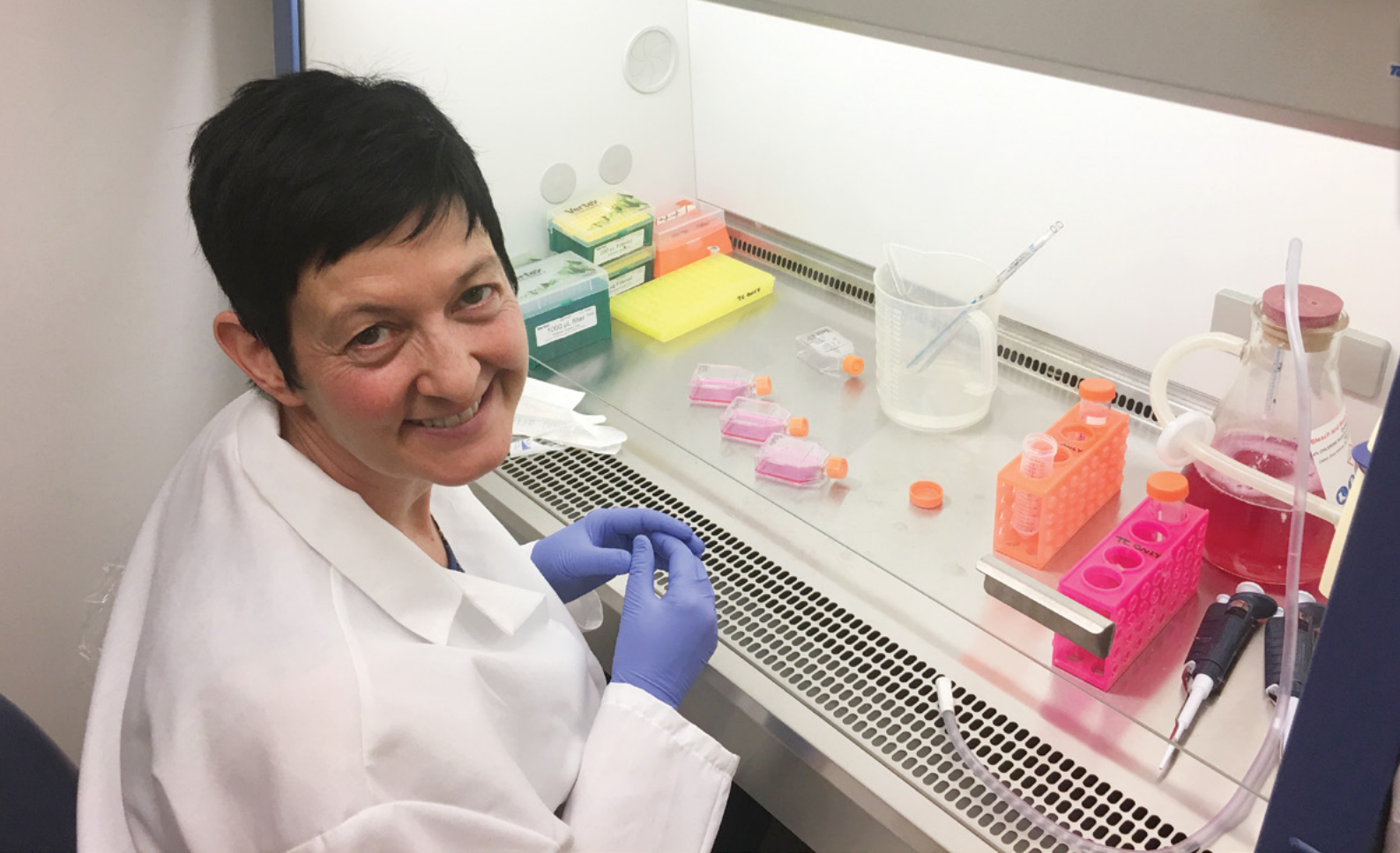
MDFAs advocate to ensure treatments are available quickly and affordably on the Pharmaceutical Benefits Scheme by highlighting the benefits of the treatments to our community and the impacts of delay or lack of access to the treatments.

We actively participate in public consultations for macular disease treatments once they have been approved as safe and effective by the TGA and are being considered for the Pharmaceutical Benefits Scheme.



References

- 1 Heier JS et al. 2023. Lancet; 402: 1434-48.
- 2 Jaffe GJ et al. 2021. Ophthalmology; 128(4):576-586.



Professor Justine Smith, AM.

Exploring new treatments for macular diseases – what does the research future hold?

Exploring innovative ways to treat, preserve or improve sight are the focus of two MDFA-funded researchers, Associate Professor Anai Gonzalez-Cordero and Professor Justine Smith.

Associate Professor Gonzalez-Cordero has made great strides towards developing and testing new treatments by creating a “mini eye” in a laboratory dish by using human stem cells. Cells from the mini eye could potentially be transplanted into the eyes of people with a macular or retinal disease to replace damaged or missing photoreceptor cells. As a double bonus, the mini eye can also be used to identify and test the effects of new candidates for medical treatment.

Professor Justine Smith is investigating existing factors called cytokines to see if they can be used to treat macular oedema, the swelling caused by fluid buildup in the macula that can lead to vision loss. Cytokines – small proteins important for sending signals between cells – help regulate inflammation in the body. But cytokines can also disrupt the movement of fluid away from the retina, causing fluid buildup. Using human eye cells in the laboratory, she is exploring the effect of blocking the action of a particular cytokine called Interleukin 1 β , which could help stop fluid buildup, thereby treating macular oedema.

If successful, both potential discoveries could lead to new avenues and pharmaceutical treatments to explore.

Healthy choices in summer

A mezze platter is an easy and elegant dish to celebrate the festive and summer season, as well as supporting your macula-friendly diet.

We suggest a smoked salmon platter loaded with fresh veggies like capsicum, tomato, radish, English spinach, as well as mediterranean flavours like olives, capers and marinated artichokes.

You can spoil yourself with a side of whipped feta or Labneh and serve with wholemeal pita bread. This dish can be made for one, two or 20 people.



Low Vision Life Hacks

Members of our community recently gave us some great tips about simple ways they are making their lives with low vision a little easier.

Challenge: Can't read the fine print on things like medicine and food packaging.

Hack: A jeweller's loupe could be useful. These small magnifying glasses can be worn around your neck and there are plenty of cheap options out there. A jeweller's loupe may not be suitable for everyone, so we encourage trying it before purchasing.

Challenge: Unable to differentiate between shampoo and conditioner.

Hack: Place a rubber band around the shampoo bottle. That way you can feel for the bottle that has the rubber band on it, rather than trying to read the small print on the bottle.

Challenge: Can't differentiate similar colours (such as red versus orange) of clothing in a dark wardrobe.



Hack: Hang a torch in your wardrobe and use it to shine light on clothing you're looking at. Or attach a battery powered light in your closet to light up the entire area.

Challenge: Can't place toothpaste on toothbrush.

Hack: Squeeze toothpaste on your finger and rub the paste on your teeth. Then grab your toothbrush and start brushing.

Challenge: Don't want to carry around a large magnifier in social environments.

Hack: Use your phone camera to zoom in (magnifier) or take a picture of the reading material, and then zoom into the picture.



Members of the Cootamundra Men's Shed.

Educating higher risk communities about Diabetic Eye Disease

MDFA has been working with Sight For All to educate regional and Aboriginal communities in South Australia and New South Wales about diabetic eye disease.

In 2021, MDFA was successful in a competitive tender for funding under the National Action Plan for Macular Disease funding stream to improve the wellbeing of people at higher risk of developing macular disease.

This led to us collaborating with Sight For All, an organisation whose purpose is to empower communities with the knowledge, skill and equipment required to detect and treat complex eye conditions that would otherwise go untreated.

The impact of this collaboration has been extremely positive, with more than 40 community eye health education sessions about diabetic eye disease successfully delivered to over 640 attendees during the funding period.

Over 95% of survey respondents agreed that the sessions had improved their knowledge of eye health and raised their awareness of the risks of vision loss associated with diabetes. They also learned about strategies they can take to reduce the risk of onset and progression of diabetic eye disease.

Another positive outcome was that most people indicated that they were more likely to attend regular eye examinations by an optometrist and take proactive steps to manage their diabetes after attending the education sessions.

MDFA is proud of this collaboration with Sight For All. This initiative allowed us to extend eye health awareness sessions into new communities and reach at-risk populations.

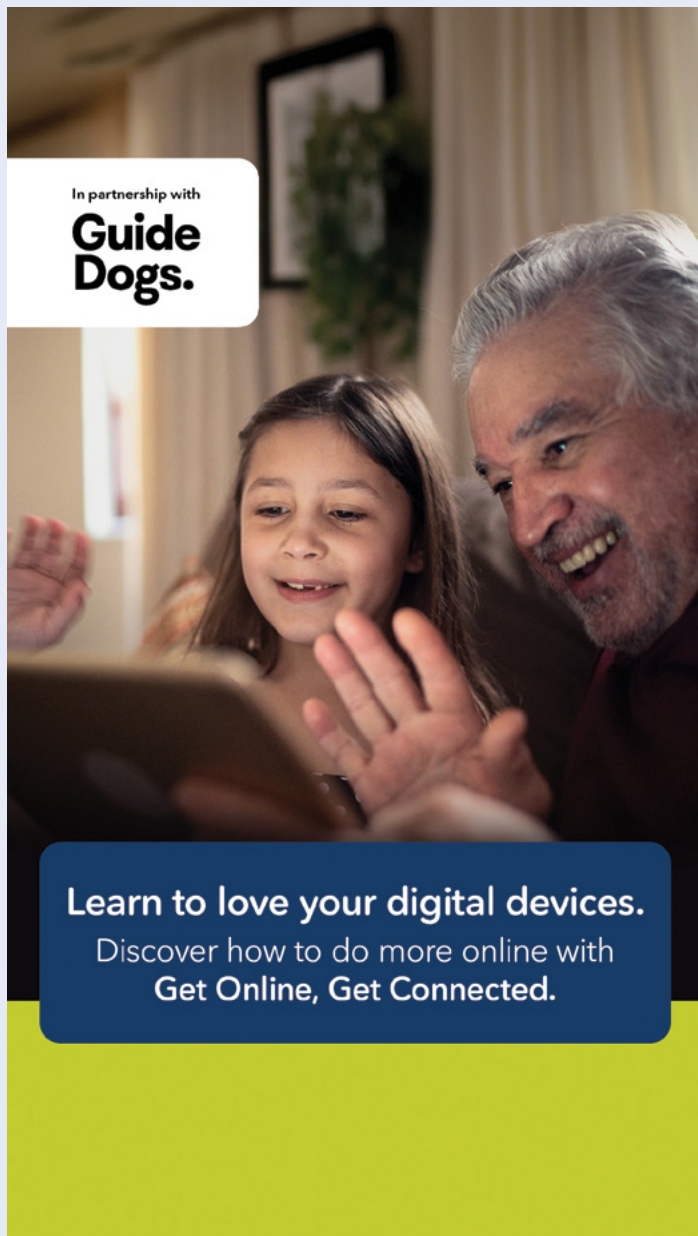
Representing MDFA at the Orange Ex-Services' Club annual Club Grant Presentation night were locals John and Jill Vant-Sand. John is a valued supporter and has participated in Eye Connect with MDFA. The Orange Ex-Services' Club have kindly donated funds to support our 'Check My Macula' online quiz which helps Australians over 50 years understand their risk of AMD.

Go to www.checkmymacula.com.au

Image: Orange Ex-services' Club Director, Lindsay Wright, with Jill and John.



Technology & You



In partnership with
Guide Dogs.

Learn to love your digital devices.
Discover how to do more online with
Get Online, Get Connected.

Let's get digital: support services you should know about

Accessing features on your smartphone or using a computer can be overwhelming when you're experiencing changes in your vision, but there is support out there to help with this.

One is Guide Dogs NSW's free digital skills training program called Get Online, Get Connected. Designed for people living with vision changes who are trying to navigate the digital world, the new program offers free training sessions, face-to-face or online.

These sessions assist people to stay in touch with their family and friends online, access online banking, and use features on their phone, like text enlargement. Contact Guide Dogs NSW to learn more about how the program could benefit you or someone you know.

Your local library can also help answer technology questions relating to your computer, smartphone, tablet, or connecting to the internet. Some run tutorials to help empower older internet users to stay informed and connected to their loved ones.

For more information, contact your local library or council.

Interested in the latest macular disease research? Join our Community Review Panel

As part of our research grant assessment process, we involve community members to review funding applications alongside our panel of experts.

Our Community Review Panel helps ensure the voice of people living with macular disease is heard and represented in our research funding decision-making.

Having launched our latest grant funding round, we are now looking for volunteers to join our Community Review Panel in 2025.

“People with lived experience provide insights only possible after experiencing deterioration and loss of vision,” explains Deborah, who participated in our inaugural Community Review Panel with her father Ashley, who lives with age-related macular degeneration.

“The needs and problems associated with macular disease can be successfully addressed by investment in research relevant to their experience.”

M DFA will train members of the community who are interested in joining our panel. **Please get in contact with us if you’re interested in finding out more: research@mdfoundation.com.au.**



“I found the whole experience interesting, challenging and informative. I gained new insights into the quality and dedication of the academics who contribute so much to our research program.”

– Ashley

M DFA events on the horizon

The following events are coming up over the next few months. Further information will be available soon.

When	What	Where
2nd December	2024 Year in Review celebration	Sydney
March	Will Writing Webinar	Nationwide (online)
April	M DFA Research Showcase Events	Queensland & Victoria
May	Macula Month	National

Contact Us:  1800 111 709  info@mdfoundation.com.au  @maculardisease

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