MY EYES

Macular Disease Foundation AUSTRALIA

Vision Voice

Special My Eyes Edition
Autumn 2024

Social Impact Survey 2: What did you tell us?

Macular Disease Foundation Australia (MDFA) is committed to understanding the impact of macular disease on the lives and health of people who live with the condition. One of the ways we do this is through our Social Impact research.

These studies are helping us identify new ways we can support you, and also help inform our advocacy activities and research priorities.

Our second Social Impact survey, launched in 2023, focussed on mental health, barriers to persisting with anti-VEGF injections, concerns about falling, and areas of advocacy you consider MDFA should act on.

Almost 2,000 people living with macular disease participated in our survey. An amazing response.

When it comes to anti-VEGF eye injections, 3% of people with neovascular AMD said they were not having injections, even though they were recommended. About 10% of people said the reason for not having injections was because of the cost of treatment. Unsurprisingly, the costs associated with anti-VEGF injections were consistently named as an area of advocacy by respondents. See Page 6.

'The injections are far too expensive but I always find the money. Because my eyesight is so very, very important to me' stated one survey participant.

Macular disease and the loss of vision can carry a high emotional burden and affect quality of life. It can also affect those around you. More than 15% of people told us they had been diagnosed with a mental wellbeing problem, with one in five people receiving support for their mental wellbeing.

These survey findings reinforced the need for comprehensive, supportive, and holistic care for people living with macular disease, especially considering the number of people experiencing mental health issues and lowered quality of life.

The insights we have obtained through the Social Impact surveys have now informed our new support service called **My Eyes**, which will launch this May.

My Eyes is a personalised service to help support you between visits to your optometrist or ophthalmologist. You will receive tailored support, information and resources, as well as regular phone calls to check how you're going and answer any questions. We want you to have the confidence to overcome any challenges you might be facing. My Eyes is completely free and you can opt out whenever you like. Call us on 1800 111 709 to find out more.

Our third Social Impact survey will also be launching soon – keep checking your mailbox.

CEO Update

We have an exciting year ahead of us with the launch of a new program co-designed by leading health experts and people living with macular disease. As you'll read in this edition of Vision Voice, the new **My Eyes** service is the first macular disease support service aimed at enhancing health outcomes by providing education, resources, and emotional support, leading to better adherence to treatment plans, improved self-management, and increased overall wellbeing. If you have a macular disease diagnosis, I urge you to join the My Eyes service. Like all our support services, My Eyes is free of charge and available to you no matter where you live.

Following an extensive piece of research, we will be updating our nutritional guidelines in May as part of our Macula Month awareness campaign. The research undertaken was a systematic review of published studies examining the links between age-related macular degeneration and dietary patterns, foods and nutrition supplements. For those of you who have ordered or downloaded a Macula Menu from our website, we will be publishing a new menu pack detailing fabulous new recipes which are in line with these updated guidelines. You might even see one or two celebrity chefs in the next Macula Menu, including a special recipe from our Patron, Ita Buttrose.

MDFA has been fortunate to receive government funding and we're working hard for this to continue, although we do also rely on community members to continue to generously support us. Thank you to everyone who gave so generously in our Christmas appeal.

Warm regards,

Dr Kathy Chapman
Chief Executive Officer

Social Impact research - what else did you tell us

In our recent Social Impact survey, we were very happy to hear that more than 70% of respondents rated our Vision Voice newsletter as good or excellent. We hope this edition is no exception.

Falls

Falls are a common problem for people living with vision loss. Unsurprisingly, there was a strong link between a high level of concern about falling and people who had fallen in the previous 12 months, with one in two people who were very concerned about falling reporting a fall in the previous 12 months.

The good news is many falls are preventable and we can provide you with information and tips on how to minimise your risk of falling.

Nutritional supplements

When we asked about nutritional supplements, almost 80% of people reported that they take one, with 2% unsure whether to take them. Some supplements might be good for your macular health, depending on your AMD diagnosis. We have a free fact sheet on supplements that you can order or download from our website.

An eye-healthy diet is important in reducing the risk of age-related macular degeneration (AMD), which could also slow the progression of AMD. You can read about our new evidence-based nutrition guidance for people with AMD in this issue. See page 6.

Using an Amsler grid

Our study also found that 30% of people said they rarely use an Amsler grid. An Amsler grid is a very simple low-cost way for you to monitor changes in your vision between visits to your eye health professional.

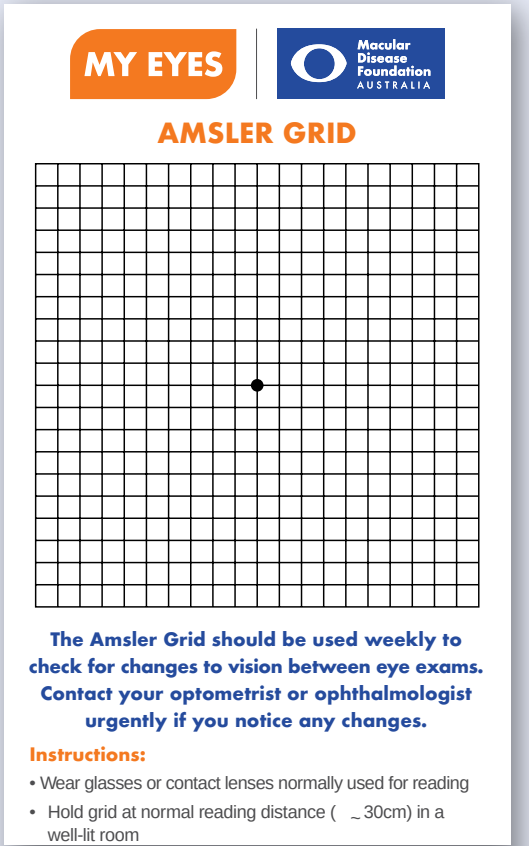
Early detection is key in preventing vision loss, so it's important to use an Amsler grid every week and to check each eye separately. You can order one for free on the MDFA website.

Low vision aids

When it comes to using low vision aids, 70% of people told us they believe that low vision aids and/or assistive technologies are beneficial. Using aids and technology can help you maintain independence and quality of life. The key is working out which ones are the best for your needs.

Some people told us that they don't know how to use them or where to get them. MDFA doesn't sell low vision aids, but we can point you in the right direction. You might also be interested in the article on page 10 which highlights new TV watching devices.

For assistance or free material, please call us on **1800 111 709** or visit our website to order resources or to sign-up for our My Eyes services.



Our first South Australian Peer Support group to launch in April

Connecting with other people who are going through similar health experiences can improve how you manage your own condition. Over the past years, we have expanded our Peer Support groups across Australia, and we are now launching our first group in Adelaide in April.

These free support groups are for people living with AMD. We aim to bring together people living with macular disease, so they know they are not alone. They are intended to complement, not replace, care from your eye health professional or formal counselling.

Groups meet face-to-face and online, and cover discussion topics like:

- Understanding your AMD
- Eating well with AMD
- Navigating life with AMD
- What's new in research, treatments, and low vision devices.

"The people in this program all have the same problem. We're able to talk about how things are going for us and also share helpful tips that might help each other. It's valuable just being able to talk freely with people in the same situation."

Peer Support member

Adelaide Peer Support meeting

Location: City of Adelaide Library

Start Date: Early April

Duration: Each meeting will last approximately 90 minutes, or as agreed to between facilitator and the participants.

Peer groups are limited to 10 participants and usually run twice a month or as the group decides.

If you're interested in joining this group or recommending another location, please contact us at **1800 111 709** or via email at **education@mdfoundation.com.au**

MY EYES

Your vision is as important to us as it is to you.

MDFA is piloting the first long-term support service for all Australians living with age-related macular degeneration (AMD). The service – called **My Eyes** – will be formally launched this May. We are currently working with some early registrants to test the content and processes and address any issues based on community feedback.

Why My Eyes?

We conducted research with people living with AMD and health professionals. It showed people were receiving high quality care in the clinic setting but there was an opportunity for MDFA to step in and provide more support and guidance in between visits with health professionals.

Another key learning from the research was that a person's needs and experiences when living with AMD change over time, so there was a role for MDFA to provide different support at different times over a longer period.

My Eyes has been designed to provide tailored and personalised support to people with AMD at various stages of their journey.

So, what exactly is My Eyes?

My Eyes is an opt-in service for people living with AMD. In time we will expand the scope to include diabetic eye disease and other retinal eye conditions.

The service starts with a phone call from one of our experienced team members to hear about your diagnosis and answer any of your immediate questions. You'll then receive a welcome pack in the post customised to your condition, vision, and whether you're receiving eye injections as treatment. We'll include a handy folder to store the information we send you.

Our team will then call you about four weeks later to check-in and hear how you're going. We'll also ask some questions to help us further customise your My Eyes experience. After the call, we'll dispatch your next pack of tailored content by mail or email – whatever your preference is. The information provided in the My Eyes service includes videos and we cater to those who prefer alternatives to written information.

Our team will continue to make contact around once a month with information and check in calls on topics designed to support you to live well with macular disease. We will reassess your My Eyes pathway every six months to see whether you need any changes – or you can let us know sooner if you need something different. And of course, if you decide My Eyes is not for you, you can stop at any time.

We are proud and excited to be launching the first service for all Australians with AMD and to be sharing this with you – our community – in advance of the launch in May.

My Eyes and your eye health professional

Leading to the launch in May, MDFA is working closely with optometrists, ophthalmologists, and orthoptists to ensure they are well-informed about the My Eyes service.

These healthcare professionals play a pivotal role in connecting their patients with the My Eyes service, extending support beyond the clinic setting.

A national awareness-raising campaign is set to launch in May 2024 to coincide with Macula Month. The campaign will encourage healthcare professionals to integrate My Eyes into their patient care practices, providing individuals with AMD access to additional support beyond the clinic.

My Eyes provides a variety of resources and guidance, including educational materials, lifestyle recommendations, and opportunities for community engagement.

As the My Eyes launch approaches, we encourage our community living with an AMD diagnosis to engage in discussions about the service with their eye health professional.

Cataracts and AMD

MYTH: Will cataract surgery cause my AMD to worsen?

FACT: 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.

QUESTION: Can I have cataract surgery at any time while receiving injections for wet AMD?

ANSWER: It may be considered appropriate to delay cataract surgery until any new blood vessel formation and leakage from wet AMD has stabilised. This will be determined by your ophthalmologist.

By joining **My Eyes,** you will receiving ongoing advice and guidance that will help you understand your disease and bust any myths you've heard.

Healthy choices

English Spinach & Cashew Dip

Prep 10 mins | Cook 1 mins | Makes 1½ cups

Ingredients

1 bunch English spinach, trimmed (about 150g trimmed leaves)

1 cup roasted cashews

1 tablespoon tahini

cup lemon juice

1 garlic clove, crushed

2 tablespoons extra virgin olive oil + extra for drizzling

2 tablespoons water

Fresh vegetable sticks, grissini or crackers to serve

Method

STEP 1: Wash spinach in cold water. Heat up a fry pan. Add a dash of olive oil and spinach, cover and cook for 1 minute or until just wilted.

STEP 2: Place spinach, cashews, tahini, lemon juice, garlic, oil and water into a food processor. Process until smooth.

Season with salt and pepper to taste.

STEP 3: Spoon dip into a serving bowl. Drizzle with extra virgin olive oil. Serve with fresh vegetable sticks, grissini or crackers.

Good for your eyes

Spinach is rich in an antioxidant called lutein, which is important for eye health.

Spinach is also rich in vitamins C, E, beta carotene (converts to vitamin A in the body), niacin (B3), folate, vitamin B6 plus its magnesium and potassium make it one of the most valuable vegetables. Spinach is high in iron, and it is best eaten with foods rich in Vitamin C to help our bodies absorb the iron.

Spinach is an excellent source of dietary fibre, which keeps our bowels functioning normally.

Your Voice

Federal Pre-Budget Submission

MDFA recently submitted our recommendations for consideration in the Federal Budget 2024-25. Preparing submissions like this is part of our advocacy efforts to shine a light on what actions the Australian government can take to reduce the impact of macular disease.

The main focus in our pre-budget submission was improving access to bulk-billed treatment for people with macular disease. MDFA hears frequently from our community about the challenges of affording sight-saving treatment, and we have again highlighted this to the government.

Our recommendations included:

1. Establishing a Medicare program to reduce the cost of eye injections for Pensioner Concession Card holders.
2. A national audit of public eye injection services.
3. Funding support to refresh our Check My Macula tool to raise awareness of risks and to detect macular disease early.
4. Ongoing funding support to assist MDFA provide education to eye health professionals.
5. Ensuring sufficient funding for low vision aids and technologies in the aged care Support at Home program.

Research

One of our key objectives is to support research into macular disease. MDFA's Research Grants Program is the largest non-government source of research grant funding for macular disease in Australia. In this edition of Vision Voice, we'd like to share two MDFA funded research projects working towards treatments and identifying who is at risk of late-stage AMD.

Shining a light on Stargardt disease

Stargardt disease is a form of macular disease caused by more than 1000 mutations, or changes, in the ABCA4 gene, affecting one in 10,000 people, often in childhood. It causes irreversible vision loss.

Ophthalmologist and 2017 MDFA Research Grant recipient, Associate Professor Fred Chen, has been working to find treatments and establish guidelines for the management of people with Stargardt disease.

MDFA funding allowed Associate Professor Chen to study Stargardt disease in more than 100 patients in his clinic at the Lions Eye Institute. The findings from his research, and collaborations with the Australian Inherited Retinal Diseases Registry, Genetic Services of WA and Murdoch University, has established a management plan for assessing and diagnosing Stargardt disease. People suspected of having the condition now receive genetic testing and counselling support.

Following Associate Professor Chen's project, Lions Eye Institute was chosen as a clinical trial site for Stargardt disease in Australia, testing a new treatment that may prevent progression. The trial is ongoing with updates due at the end of the year.

"My one wish as an ophthalmologist and researcher in macular disease is that one day I can tell my patients, who are affected by whatever form of macular degeneration, that we have the treatment to prevent them from going blind, or to restore their vision."

Associate Professor Fred Chen

OCT imaging to identify people at risk

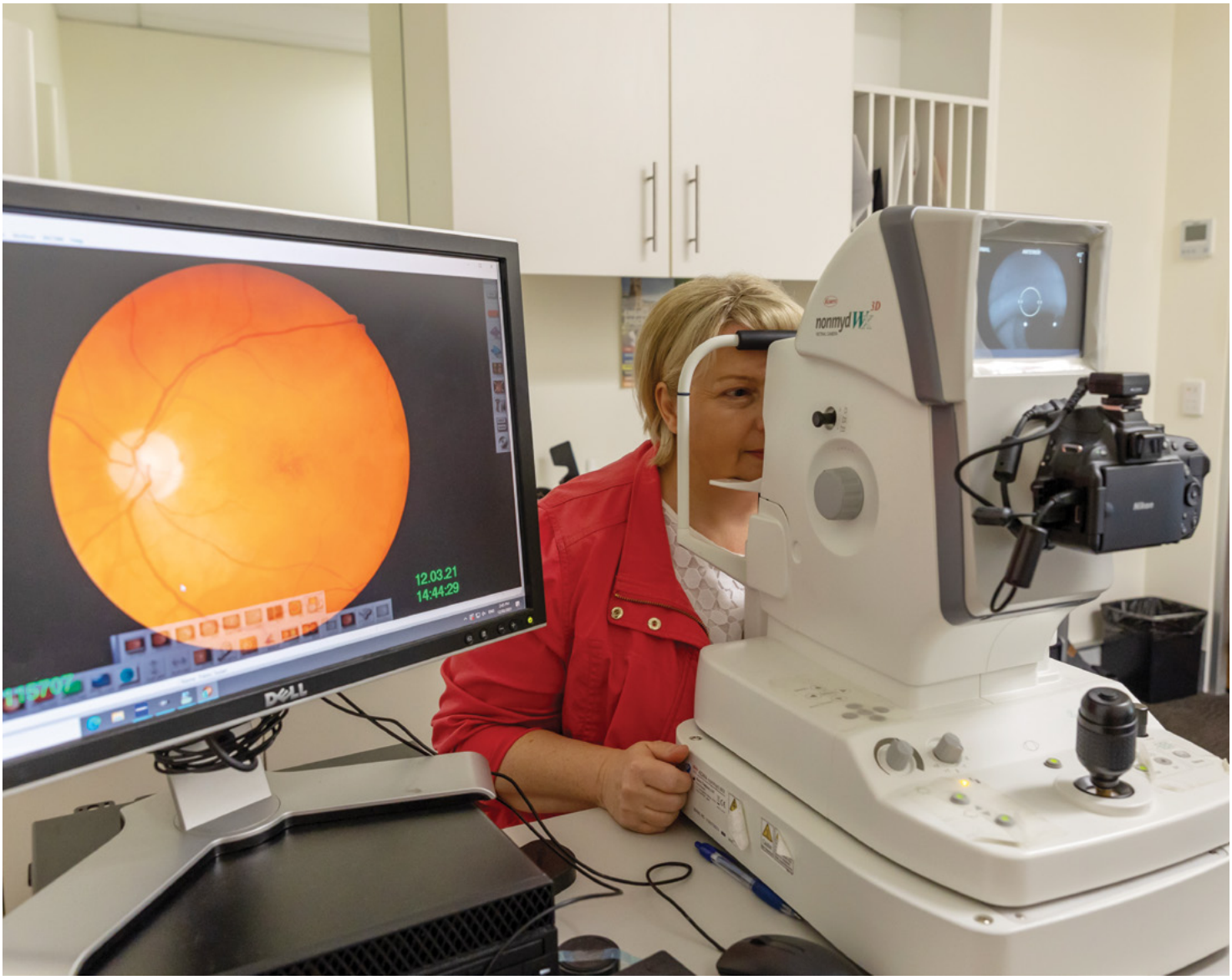
Associate Professor Zhichao Wu from the Centre for Eye Research Australia is investigating new imaging techniques to identify people at risk of progressing to sight-threatening late (neovascular, wet or atrophic, dry) AMD.

Predicting who will progress is challenging, and delays in detecting progression can lead to irreversible vision loss. Associate Professor Wu was awarded a 2019 MDFA Research Grant to identify high-risk individuals to improve their vision outcomes.

Associate Professor Wu says optical coherence tomography (OCT) shows promise as a powerful tool for identifying someone's likelihood of developing late AMD. OCT imaging shows the back of the eye 3-dimensionally, with each image holding information about the retina that is currently not understood.

Associate Professor Wu's team analysed OCT images looking for new predictive signs in people who progressed to late AMD. They found one of the strongest predictors was degeneration of the light-sensitive cells in the retina.

Associate Professor Wu is using these findings to contribute to guidelines for optometrists on managing AMD. His research is ongoing, examining how newer imaging techniques and artificial intelligence can further improve prediction of those at risk of late AMD.



Technology & You

Television Viewing Trial – what's next for people with low vision

MDFA and Quantum Reading Learning Vision (RLV) recently co-hosted a feedback session for people living with low vision. The aim was to trial low vision technologies to help people with macular disease have a better experience watching television.

We often hear that people with macular disease struggle to watch TV, so the purpose of the session was to see if people with central vision loss can benefit from alternative television viewing technology. Quantum RLV is a leading supplier of assistive technology for people with low vision and has identified some new approaches that could be of great assistance which were trialled with members of our community in this session.

We were motivated to host this session because of the interesting findings about low vision aids in our recent Social Impact Survey, see page 2, which highlighted the need to help people learn about different aids and vision assistance technology.

Our survey found while six in 10 people with fair to very poor vision use low vision aids and technologies when needed, there is still a high proportion who don't use them. About one in 10 people who could benefit from them had never even tried a low vision aid or technology because of reasons of complexity, access or cost.

During the television viewing trial, we were struck by the value of promoting some practical and free steps that can make viewing TV much better. Of the three people who tested out the range of devices, a simple iPad or tablet gave the best viewing experience.

Practical tips to improve your TV viewing experience

- Get up close – move a comfortable chair up close to the TV rather than sitting too far away. The trial participants were all surprised the effect this simple change had on viewing the TV screen.
- Consider using an iPad or tablet (remember to wear your reading glasses if you have them) – although this means watching catch up TV rather than live programs.

Quantum RLV have a range of devices that may assist people to watch TV better, including headset devices such as the Vision Buddy, the Max TV glasses, and the Cloverbook Pro which is a portable electronic magnifier. The phone number for Quantum RLV is **1300 883 853**, or you can find them online at **www.quantumrlv.com.au**

Overall, the results of this session showcased how MDFA and Quantum RLV can support our community with detailed information about different low vision services as well as helping people to navigate through the range of devices available. By calling our **Helpline on 1800 111 709,** we can also explain how you may be able to access government initiatives such as My Aged Care for financial assistance.

Our Community

Ita Buttrose thanks volunteers.

Celebration of our volunteer community

The 2023 Annual General Meeting end of year event was a celebration of our volunteer community. Guests were treated to two remarkable speakers, including our Patron, Ita Buttrose AC OBE, and MDFA funded researcher, Professor Justine Smith, AM.

The role volunteers play in supporting our community has expanded significantly over the past two years and allows us to meet the growing needs in the community. This expansion is not only in the types of roles undertaken by the volunteers but also geographically to help the Foundation be a much more national organisation.

The number of volunteers has increased three-fold and we now have volunteers represented in NSW, ACT, Victoria, Queensland, South Australia and Western Australia.

Our volunteer roles have also diversified to reflect new programs and unmet needs for the community. These roles include data analysis, project management, writing, design, psychology, legislation and policy, and language translation.

Ita Buttrose has volunteered her time as Patron of MDFA for 16 years. As she noted in her address, "volunteering is crucial in Australia. It fosters a sense of community, social cohesion, and empathy. Supporting people living with macular disease through volunteering is vital as it enhances their quality of life and independence."