



**Macular
Disease
Foundation**
AUSTRALIA

VisionVoice

Spring Edition 2021

Minister's message to our community

Health Minister Greg Hunt seeks to allay patient concerns over proposed Medicare rebate changes for eye injections.

As part of our ongoing campaign against a proposal to cut Medicare rebates for eye injections, Macular Disease Foundation Australia (MDFA) CEO Dee Hopkins and Medical Committee Chair Associate Professor Alex Hunyor met Minister Hunt at Parliament House in June.

The discussion centred on recommendations of the Medicare Benefits Schedule Review Taskforce, which last year proposed a 69 per cent cut in the eye injection rebate, despite strong opposition from MDFA, patients, and health professionals.

"My priority is to ensure that more people, rather than less, access treatment for macular disease. Patients' optimal health is central to decision making on this matter," Minister Hunt told MDFA.

The Health Minister also said he wants a decision on the rebate cut to be made as soon as possible to allay patients' concerns. Over the coming months, the Minister will establish a liaison group to guide the implementation process and ensure that recommendations don't have unintended consequences.

"MDFA will be part of this liaison group, which means the voice of the macular disease community will be heard. Your needs and best interests will inform the decision-making process," Ms Hopkins said.

(continued page two)



Greg Hunt

\$1 million awarded to new research

MDFA has awarded more than \$1 million to eight cutting-edge Australian researchers in a ceremony hosted by His Excellency the Honourable David Hurley, Governor-General of Australia, at Admiralty House in Sydney.

This funding will support promising projects on a range of macular conditions. Most projects are laboratory-based, but others investigate ways to improve quality of life for those with macular disease.

Celebrating MDFA's 20th anniversary and a decade of the MDFA Research Grants Program, this \$1 million investment brings our total commitment to \$5.1 million since 2011 – making us Australia's largest source of macular disease research funding outside of government.

Turn to page six to meet the researchers.

CEO Update

Since our last edition of Vision Voice, the team at MDFA continues to make inroads to tackle the issues that matter to the macular disease community.

As you have read on the front page, I recently met with Minister Hunt to discuss our concern regarding the proposed cuts to the MBS rebate for eye injections.

Minister Hunt welcomed our report, which contained costed solutions that would save sight for potentially thousands of Australians and offset any savings that might be initially derived from a cut in Medicare rebates. Read more about this in our leading article and in 'Your Voice' on page 11.

This meeting with Minister Hunt followed the inaugural Ita Buttrose Oration, which took place during Macula Month in May at the National Press Club.

As Patron, Ita vocalised MDFA's concern and position on the rebate cuts, highlighting the unacceptable ramifications of vulnerable Australians losing their vision if this MBS rebate cut were to be implemented. We thank Ita for her tenacity and her unfailing support for older Australians.

MDFA was thrilled to announce a \$1 million research investment as part of our 20th anniversary celebration. We continue to be so impressed by the quality of research being produced in Australia. Please enjoy reading about the new and innovative research – funded by you, our community.

As we go to print on this edition of the newsletter, Australia continues to grapple with the COVID-19 pandemic.

If you are receiving anti-VEGF eye injection treatment, it's important to continue your regular

eye injections with your ophthalmologist. If you're receiving anti-VEGF eye injections and have concerns about getting a COVID vaccination, please speak to your treating doctor.

Stay safe.



Dee Hopkins
Chief Executive Officer

Minister's message to our community cont'd.

"We've now presented the Minister with a detailed report outlining alternative costed models of care that would increase access for eye injections," Ms Hopkins said.

"The models include the establishment of more regional clinics, more healthcare professionals to provide injections under ophthalmologists' supervision, and improved transparency of treatment costs in private clinics to ensure patients access affordable care.

"We also included detailed calculations on the cost of doing nothing and the unintended consequences of cost shifting to other parts of the health and welfare systems."

MDFA will continue to advocate on your behalf for better access to vital sight-saving treatment. If you are experiencing financial difficulties with your treatment, please call our National Helpline on 1800 111 709. For a report on Ita Buttrose's national address on this issue, see page four.



MDFA CEO Dee Hopkins, Health Minister Greg Hunt, and MDFA Medical Committee Chair A/Prof Alex Hunyor.



New CPD courses for optometrists

MDFA has launched a new educational program for optometrists designed to help them deliver better care to you, their patients.

The free courses have been developed with Australia's leading retinal specialists – including world-renowned ophthalmologist and MDFA's National Research Advisor, Professor Paul Mitchell AO.

This new education is funded by the Federal Government under the National Strategic Action Plan for Macular Disease: a strategy that outlines how Australia's entire eye health ecosystem can work together to reduce the burden of macular disease.

One of the plan's key proposals is to improve health professionals' understanding of macular disease through better education.

This is why the Federal Government awarded MDFA \$1.5 million over four years to develop free educational courses for optometrists, general practitioners (GPs), pharmacists, aged care providers and Indigenous health workers.

We've launched the first two courses for optometrists – one on age-related macular degeneration and one on diabetic eye disease – and the program will roll out to GPs and pharmacists later this year.

The courses aim to improve the way optometrists communicate with you about macular disease, including how to manage your risk factors and where to find support services that can help you live well with your diagnosis.

Education

Join our digital learning centre!

Have you attended one of our free online education sessions? To register for a webinar, please call us on 1800 111 709, email education@mdfoundation.com.au, visit www.mdfoundation.com.au/education-sessions or scan this QR code.



Here are the webinars we've got coming up.

Topic	Presenter	Date and time
Understanding mental health and coping with vision loss	Dr Bonnie A Sturrock from Healthy Mind	Wednesday, 25 August at 2-3pm AEST
Early detection of macular disease: A research update	Elisa Li, Sharon Ho and Matt Trinh from the Centre for Eye Health	Wednesday, 15 September at 2-3pm AEST

For an up-to-date list of our upcoming webinars beyond September, please check our website.

You can also catch up on past webinars on YouTube. Watch the recordings at YouTube.com/MDFoundationAus or simply scan this QR code.





Ita shares her vision for a healthy ageing Australia

Our Patron, Ita Buttrose AC OBE, has used a nationally televised address to warn the Federal Government about a massive increase in the number of people going blind, if it approves a proposal to cut the Medicare rebate for eye injections.

Delivering the inaugural Ita Buttrose Oration to Canberra's National Press Club during Macula Month this May, Ita urged the Federal Government to reject a recommendation by the Medicare Benefits Schedule Review Taskforce to cut the patient rebate for eye injections by 69 per cent.

The tireless macular disease advocate said MDFA's economic modelling forecast the rebate cut would lead to an additional 47,000 people dropping out of treatment, suffering severe vision loss or blindness as a result.

"Eye injections are highly successful in saving sight," Ita said.

"Economic modelling commissioned by MDFA predicts the proposed rebate cut will result in out-of-pocket costs increasing from \$1,900 to \$3,900 a year on average – double for patients needing injections in both eyes.

"This translates to an additional 47,000 Australians experiencing severe vision loss and blindness within the next five years. Any resultant savings for the proposed cut would be offset by cost shifting to other parts of the health and welfare system costing \$2.6 billion in indirect costs and \$168 million in net direct costs due to increased vision loss."

Ita's remarks were made during the first ever Ita Buttrose Oration – a new MDFA initiative that aims to outline a vision for a healthy ageing Australia.

The inaugural Oration coincides with the 20th anniversary of MDFA and launched this year's Macula Month, MDFA's annual campaign to raise awareness of macular disease each May.

Ita's address called on the Government to reject the proposed Medicare cut for eye injections and consider MDFA's fully costed plans to improve access to sight-saving treatment.

MDFA's alternative models for treatment

- New low cost-regional clinics, so patients can access treatment without needing to travel to metropolitan clinics that are already at capacity
- Increasing the number of healthcare workers who can give injections under the supervision of qualified ophthalmologists
- Empowering patients to be better informed about fees so they can self-advocate if they can't afford ongoing treatment

Ita explained that although these models would need Government investment, the cost of doing nothing is much higher.

"We simply cannot accept an Australia where we have a gold standard treatment to stop people from going blind, yet there are some Australians who can't access it," Ita said.

"Australians at risk of losing their vision can't wait any longer – action is needed now."

Dr Muecke's Macula Month media blitz

MDFA Ambassador and former Australian of the Year spreads the word about diabetic eye disease – and how the *Check My Macula* quiz could save your sight.



Dr James Muecke AM spent Macula Month on media street raising awareness of diabetic eye disease.

Diabetic retinopathy (DR) is the leading cause of blindness among

working-age Australians, affecting between 300,000 and 400,000 people.

However, a YouGov poll commissioned by MDFA discovered that only 29 per cent of Aussies aged 50 to 70 had heard of DR, while only 26 per cent are aware of diabetic macular oedema (DMO), a complication of DR that threatens central vision.

Dr Muecke appeared on almost 300 radio stations across the country this May, encouraging Australians to not only learn the names of these conditions, but also take action to avoid vision loss.

"It's certainly concerning. There's a lack of awareness amongst the Australian public as to the sight-threatening complications of diabetes," the 2020 Australian of the Year told listeners located everywhere from Parkes to Port Lincoln.

"If you have diabetic retinopathy, regular eye checks will pick up sight-threatening disease in its early stages so that treatment can commence. Presently, over half of all Australians living



with diabetes are not having these sight-saving eye checks, and that's why it's become such a blinding problem in our society. If you have diabetes, please make sure you have regular eye checks at least every year."

Everyone with diabetes is at risk of diabetic eye disease. Almost every person with type 1 diabetes and more than 60 per cent of people with type 2 diabetes will develop some form of DR within 20 years of diagnosis.

But you can take steps to reverse your risk of vision loss through regular eye exams and managing your diabetes.

Dr Muecke urged Australians to visit **CheckMyMacula.com.au** to learn their individual risk factors, then book an eye exam – including a macula check – with a nearby optometrist.

"Anyone over the age of 50 or living with diabetes should visit **CheckMyMacula.com.au** and take the quiz. It could just save your sight," the Adelaide ophthalmologist said.

While awareness of diabetic eye disease still has some way to go, this year's YouGov poll showed that more Aussies are opening their eyes to the risks of age-related macular degeneration (AMD).

Over the past 20 years, our Macula Month campaigns have raised awareness of AMD from one in three Australians to two in three, resulting in more early detection and sight-saving action.

Check My Macula update

More than 50,000 Aussies have now discovered their individual risk factors for macular disease through **CheckMyMacula.com.au** since we launched the quiz last October.

Remember, if you have AMD, your immediate relatives – your children and siblings – have a one in two chance of developing it, too. So please share the Check My Macula quiz with your family and friends at **CheckMyMacula.com.au** or by scanning this QR code.



Eyes on Research

Meet the researchers

This May, MDFA awarded more than \$1 million of funding to eight exciting research projects.

The latest round of MDFA Research Grants funding has allocated \$935,000 to six projects, plus a further \$90,000 to two early-career researchers as part of the new Grant Family Fund.

CEO Dee Hopkins admits that MDFA didn't expect to finance so many projects when applications first opened, but said it's testament to the depth of talent among Australian researchers.

"This underlines the sheer volume of gifted researchers – particularly early-career researchers – that Australia is producing. MDFA is proud to play its part in supporting and funding these rising stars," Ms Hopkins said.

"All eight of these projects show great promise, but I'm particularly excited by the applications from younger researchers that aim to shift existing paradigms in macular disease research.

"MDFA funding is crucial and often leads to larger projects and larger investments from the Government and other funding bodies, resulting in significant advancements in treatment and better outcomes for the macular disease community."



The latest round of MDFA Research Grants funding was announced at Admiralty House – the official residence of the Governor-General in Sydney – during Macula Month this May.

Left to right: MDFA CEO Dee Hopkins, Associate Professor Chi Luu, Dr Yvette Wooff, Dr Ting Zhang, Dr Anai Gonzalez Cordero, His Excellency the Honourable David Hurley, Governor-General of Australia, Her Excellency Mrs Linda Hurley, Ms Diana Tang, Dr Sheela Kumaran, Associate Professor Matthew Simunovic, Professor Justine Smith.

Read more about the researchers

For a more detailed look at these eight research projects, scan this QR code to visit MDFA's website.



Our Research Grant recipients



**Associate Professor
Chi Luu**

**Centre for Eye
Research Australia
Investigating blood
supply and AMD**

A/Prof Luu's project will use an innovative imaging technique to investigate blood supply to the retina at the back of the eye, which will improve our understanding of the causes of AMD and help develop new treatment strategies.

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**Professor Justine Smith
Flinders University**

**Treating macular
oedema**

Prof Smith is looking
at the potential to use

existing drugs to treat macular oedema. This project will use human eye cells to create disease models in the laboratory, then use these to explore the possibility of treating macular oedema by blocking the actions of molecules called cytokines. Macular oedema is responsible for sight loss in diverse macular conditions, from diabetic eye disease to retinitis pigmentosa.

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**Associate Professor
Matthew Simunovic**

**Save Sight Institute,
University of Sydney**

**Gene therapy and
macular degeneration**

A/Prof Simunovic's project aims to eventually restore sight lost to macular degeneration using a type of gene therapy called optogenetics. Optogenetic gene therapy makes the ordinarily light-insensitive nerve cells that survive in advanced macular degeneration sensitive to light. Think of it as a biological equivalent of the bionic retina.



**Ms Diana Tang
Macquarie University
Wellbeing in AMD**

Ms Tang's study aims
to improve the mental
and physical health

of people living with AMD through the Movement, Interaction and Nutrition for Greater Lifestyles in the Elderly (MINGLE) program. MINGLE brings together social interaction, physical activity and nutrition education. The program is led by an accredited practicing dietician and a physical activity researcher.

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**Dr Sheela Kumaran
University of NSW
Quality of life
and AMD**

We know how AMD
affects your vision. But

what about your quality of life? Dr Kumaran's project aims to improve the way the impact of AMD on quality of life is measured. Technologically advanced questionnaires will help assess the effectiveness of various interventions, and improve our understanding of the economic impacts of AMD.

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**Dr Yvette Wooff
Australian National
University**

**New gene therapy
for AMD**

There is currently no

treatment for dry AMD, which occurs when retinal cells gradually die, leading to patches of missing retina and the loss of central vision. Dr Wooff's research will investigate cell particles called extracellular vesicles (EV), which could help develop novel gene therapies for dry AMD.



Faye and Ronald Grant.

A month for giving

Research shows that at least a third of Australians are considering leaving a gift in their Will but haven't yet done so. That's why September is **Leave a Gift in Your Will Month**.

After your financial commitments and loved ones have been looked after, a gift in your Will to MDFA is a meaningful way to leave a lasting legacy and impact on the eye health and lives of future generations.

Our webinar explains how a gift in a Will can be organised quite simply. The QR code will take you straight there. We're also available to chat. Just call the National Helpline on 1800 111 709 and ask for the donor care team.



Grant Family Fund

The latest round of MDFA Research Grant funding included the first allocation of the Grant Family Fund – a biennial grant opportunity made possible by a generous bequest from the late Faye Grant, which will support innovative 'blue sky' research in the field of macular disease.

Meet the inaugural recipients.



Dr Ting Zhang

**Save Sight Institute,
University of Sydney**

Understanding AMD at a cellular level

AMD is Australia's leading cause of blindness, but the exact causes aren't known. This is why Dr Zhang is looking at errors that occur in chemical reactions at a cellular level that may make the macula more vulnerable to stress and therefore more likely to develop macular degeneration. It's hoped the laboratory research will one day contribute to the development of a new treatment for AMD.



Dr Anai Gonzalez Cordero

University of Sydney

Creating the perfect laboratory macula model

One of the things that's hampered researchers studying macular disease is the lack of animal models that faithfully replicate the human retina. Dr Anai Gonzalez Cordero is hoping to change that, by creating an organoid – essentially a mini organ in a dish – with a macular structure. The macular tissue can be used as a source of cells for replacement therapies to help reduce sight loss of millions of people.



Janette Forrester – sister of the late Faye Grant, whose generous bequest established the Grant Family Fund and made this research possible – pictured here with Dr Anai Gonzalez Cordero and His Excellency the Honourable David Hurley, Governor-General of Australia.

Technology and you

Staying safe online

More and more older Australians are embracing technology. Sadly, cyber scammers have all sorts of tricks to try to steal your personal details, con you out of money, or damage your computer. But these simple steps can help keep you safe online.

Install anti-virus software

Malicious computer programs have many scary names, like viruses, trojans and spyware. But anti-virus software can protect your computer from all of them. Use a trusted comparison site like Choice to find anti-virus protection that's right for you.

Scammers change their tactics all the time, so check your antivirus software for updates regularly and install them when they're available.

Also, computers should be set to save to the cloud every day.

Create strong passwords

Conmen use computer programs to attempt to guess your online passwords, so you should use unique passwords that no one can guess.

Passwords to avoid:

- Simple words like 'password' or 'hello'
- Personal details like your name, birthday or address
- Sequences like 1234 or ABCD

Stronger passwords contain:

- More than eight characters
- Letters, numbers and symbols (#?!)

- Capitals and lower-case letters

Plus, use different passwords on different sites so that if someone steals one, they can't access all your other accounts.

But how are you meant to remember all these passwords? Most sites have a box saying 'remember me' or 'keep me signed in' when you log in, which you should tick if you're the only person who uses that computer.

Be wary of emails

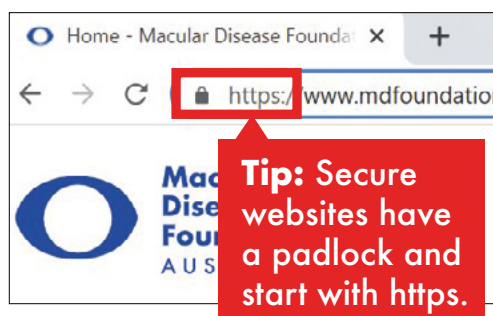
Your email provider automatically filters out suspicious messages to a junk or spam folder, but some might still sneak through to your inbox.

Bad grammar and spelling, plus words like 'win' and 'free' or offers of money, are obvious red flags.

However, some spam emails are more sophisticated, posing as trusted institutions – such as your bank, Medicare or the ATO – to trick you into clicking a dangerous link or attachment.

If you're suspicious, contact the institution by phone or in person to check if the email is legitimate. And if you have any doubts, it's safe to simply ignore or delete the email.

You also need to be particularly careful whenever you're buying anything online. The image below shows how you can spot a secure online shop.



Learn more about cyber security

Be Connected is a Federal Government program to help older Australians use technology safely.

The Be Connected website offers self-paced courses to build your online skills, training on internet security, and links to cyber support services. And it's free.

beconnected.esafety.gov.au

Look out for scams

For news and alerts, or to report a scam, visit the ACCC's Scamwatch website.

scamwatch.gov.au

Our commitment to you

MDFA takes great care to hold your personal information securely and complies with Australian privacy legislation.

We're committed to protecting your personal privacy and retain only necessary information that will help us to support you.

Read our full Privacy Policy at **www.mdfoundation.com.au/privacy-policy**

Our Community

New peer support groups in Townsville, Melbourne and online

MDFA has launched three new peer support groups for people living with age-related macular degeneration (AMD).

Our **Townsville** peer support group met for the first time in June, sharing their experience of macular disease and tips to live well with AMD under the guidance of MDFA's Programs and Services team.



"The most memorable thing about the first meeting for me was the fact that Natasha and Steve made the effort to come up from Sydney to actually spend that time with us, and they are supporting us through the future of the group," said the group's facilitator Lurna, who got the ball rolling by reaching out to MDFA.

"It's a great opportunity to be able to talk through problems, things that excite you, and opportunities with somebody who understands – because that to me is one of the hardest things.

"When you attend a peer support group, you get that opportunity to talk to like-minded people with no judgment."

Lurna was joined by four other people living with macular disease at the first meeting, and she's hoping to expand the group for their future monthly meetings.

"Now it's just a matter of trying to build on it to get it up to a good level. It's nice having five or six people but it would be much nicer having 10 or 15 people," Lurna said.

We've also started a new peer support group in **south-east Melbourne**, which met for the first time in Brighton in July, as well as a digital group called **At home with MDFA**, which began catching up via Zoom in June.



Plus, our peer support group in **Melbourne's east** continues to connect, and our volunteers are reaching out to members of the macular disease community through **peer-to-peer calls**.



Are you interested in peer support?

Would you like to join our groups in Melbourne or Townsville? Do you want to sign up for a peer-to-peer call or 'At home with MDFA'? Maybe you're keen to start a peer support group where you live? If so, we would love to hear from you. Please call our National Helpline on 1800 111 709 or email education@mdfoundation.com.au



Informed financial consent for macular disease patients

Australia's health care funding is complex. In Australia, health care operates in a free market. Within the eye health sector, less than 20 per cent of private ophthalmology practices offer bulk-billed services.

Treatments such as eye injections are funded from Medicare, Pharmaceutical Benefits Scheme (PBS), private health insurance (where available), and patient out-of-pocket expenses.

As treatment for conditions such as neovascular or wet AMD needs to occur regularly the accumulated out-of-pocket costs can be significant over time and become a barrier to treatment adherence.

In MDFA's recent poll of people receiving eye injections, 51 per cent of respondents told us they were uncomfortable asking their treating ophthalmologist to reduce fees. The survey also told us 49 per cent of patients are paying over \$200 in out-of-pocket costs per treatment and 29 per cent considered delaying or stopping treatment due to cost.

MDFA recently presented the Federal Government with a costed proposal for a national program to help patients better understand their ongoing treatment fees and build the confidence to ask for fee leniency.

The program also proposes that MDFA would work closely with Optometry Australia and the Royal Australian and New Zealand College of Ophthalmology to work collaboratively on

the initiative as part of a suite of initiatives to improve adherence to sight-saving treatment.

This proposed program could lead to reductions in out-of-pocket costs, help an extra 3,000 patients adhere to sight-saving treatment and save the government \$270 million over the next five years in NSW alone.

"When you scale the potential impact nationally, this is a low-cost investment and solution that can make a significant difference for patients who need ongoing eye injections," MDFA CEO Dee Hopkins said.

Reaching at-risk communities

MDFA has won a major grant to help bring the message about macular health to new at-risk communities. The \$500,000 grant was awarded as part of the National Strategic Action Plan for Macular Disease.

Ms Hopkins said the new campaign will leverage the trusted relationships that GPs and pharmacists already have with patients at risk of diabetic eye disease and age-related macular degeneration.

"Importantly, we'll also be reaching directly into Aboriginal and Torres Strait Islander communities with information about diabetic eye disease, starting in South Australia," Ms Hopkins said.

"The funding will allow us to develop and distribute new printed resources, but also reach more people with targeted education opportunities."



How we can help you

knowledge **health** **services** advice
awareness well-being patients
support empowerment welfare
education information learning expertise



Would you like to book an MDFA speaker?

Your community group could host a **free** AMD education session – either face-to-face or online.



Do you belong to a Probus, Rotary, Lions Club or U3A group? Are you a member of a retirement village or a men's group? Do you receive CHSP social support or centre-based respite services? Do you meet any other social clubs?

With one in seven Australians over the age of 50 at risk of AMD, the leading cause of severe vision loss and blindness, then your community might benefit from an MDFA education session.

As we return to face-to-face gatherings, we'd love to invite any group to book an MDFA speaker to deliver a presentation on AMD – as either an in-person seminar or an online webinar.

Our education sessions cover what is AMD, who is at risk, how you can control risk factors, which symptoms to look out for, and what you can do to reduce your risk and slow progression.

We provide free information packs for all attendees to take home – including an Amsler grid, nutrition booklet, AMD pamphlet and the latest newsletter – as well as the chance to grab a Macula Menu so you can whip up some macula-friendly meals at home.

All we need from you is a space to host the group and a projector screen or white wall to

display the presentation. MDFA can bring projecting equipment if you don't have any.

We can even hold sessions in languages other than English, or send you a pre-recorded presentation alongside info packs full of printed resources.

All MDFA speakers are qualified with a degree in either Vision Science or Optometry, and together have helped deliver more than 2,200 presentations to 100,000 Australians over the past 20 years.

Like all of our support services, these education sessions are free of charge.

To book an MDFA speaker, please email education@mdfoundation.com.au or call our National Helpline on **1800 111 709**.

Contact Us: 1800 111 709

info@mdfoundation.com.au

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