

MACULAR DISEASE FOUNDATION AUSTRALIA

20  
YEARS  
OF IMPACT  
2001-2021



Macular  
Disease  
Foundation  
AUSTRALIA

# ANNUAL

REPORT 2021

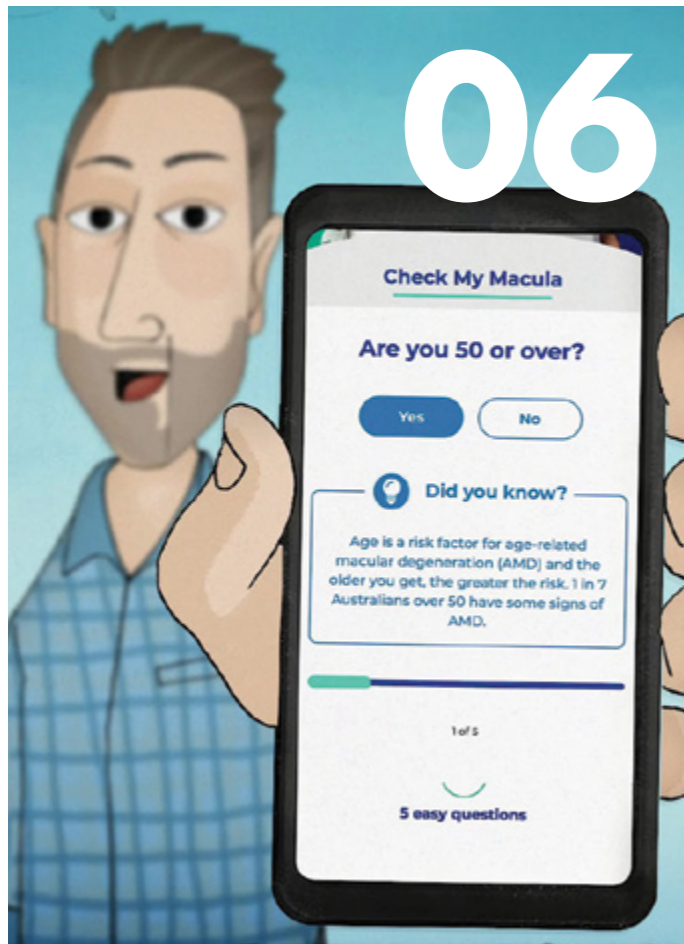
“

\$1 million plus  
invested into  
macular disease  
research

”

**HIGHLIGHT**

50,000  
Check My Macula  
quiz completions



06



10



12

Dee Hopkins, Greg Hunt and Alex Hunyor.



14

Justine Smith and Yvette Wooff.

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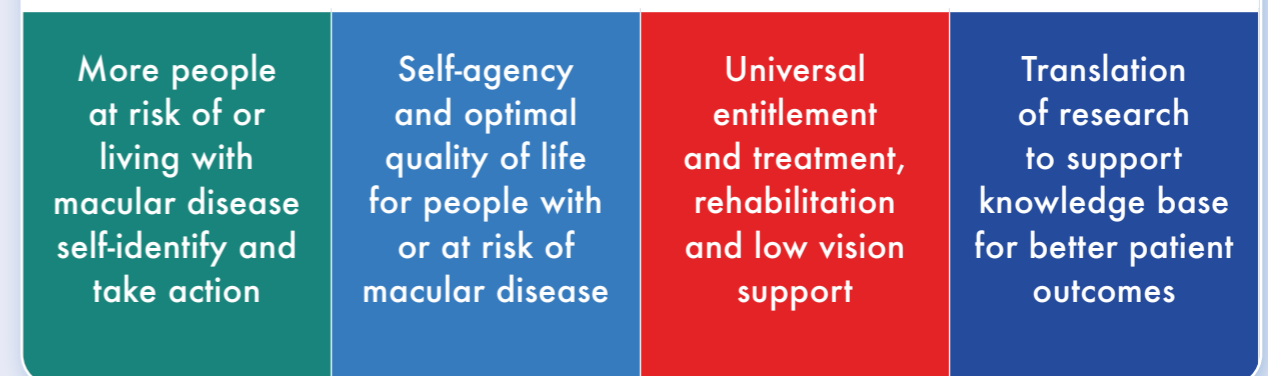
M DFA acknowledges the traditional custodians of country throughout Australia and their continuing connection to land, sea and community.

We pay our respects to them and their cultures, and to the Elders both past, present and emerging.

## PILLARS OF WORK



## IMPACT GOALS





**50,000** completions of the Check My Macula quiz



**Inaugural**

Ita Buttrose Oration at the National Press Club in Canberra



**Launch**

of the new Health Professional Education and Training (HPET) program



**2,733** attendees at online and face-to-face education forums



**5,851** National Helpline calls



**96** submissions to Government



**Met** Health Minister Greg Hunt to campaign against MBS cuts to eye injections



**\$1.1 million** awarded to eight Australian researchers by Governor-General David Hurley



**Inaugural** investment of the Grant Family Fund for 'blue sky' projects by early-career researchers



**Launch** of 10 Years of Research Report – how our community's investment is working to give hope

## 20 years of impact



**\$5.1 million** invested in 29 projects through the MDFA Research Grants Program



**2,200** community education sessions



**100,000** attendees at community education sessions



**175,000** patient and carer calls through the National Helpline



**Seven million** health publications distributed to the macular disease community



**More than 420** submissions to Government to advocate on behalf of the macular disease community

On behalf of the Board and staff we are delighted to present you with our 2020-21 Annual Report.

This year we celebrated our 20th year of promoting early detection to save sight and giving hope and support to those living with or at risk of macular disease.

Despite lockdown and working from home arrangements, the MDFA team has had another productive year in fulfilling its purpose of reducing the incidence and impact of macular disease.

We are particularly proud of the innovative Check My Macula digital quiz with over 50,000 Australians who now know their individual risk factors of AMD and have a pathway to get early and regular eye exams.

We have continued to advocate and campaign against proposed cuts to the Medicare rebate for sight-saving treatment. In the inaugural Ita Buttrose Oration at the National Press Club,

MDFA Patron Ita amplified our message of the importance of enhancing access to sight-saving treatment.

We have invested in compelling health economic reports to support this advocacy issue so we could provide the Australian Government with evidence-based advice about impacts on the macular disease community.

This year we were delighted to award more than \$1m in new research grants. We also launched the new Grant Family Legacy designed for early career researchers and blue sky research projects.

The 10 Years of MDFA Research Report outlined the numerous research projects funded through the generous support of our community, providing real hope for the current and future generations of Australians at risk of or

living with macular conditions. We thank the two thousand plus people who participated in our inaugural study and were delighted to launch the Impact of Macular Disease – Foundation Report. This important study and its findings will be an effective resource to inform our advocacy agenda to give voice to and improve the lives of those living with macular disease.

This report outlines the many activities and results achieved throughout the year – none would be possible without the generous investment by our community, sponsors and Government.

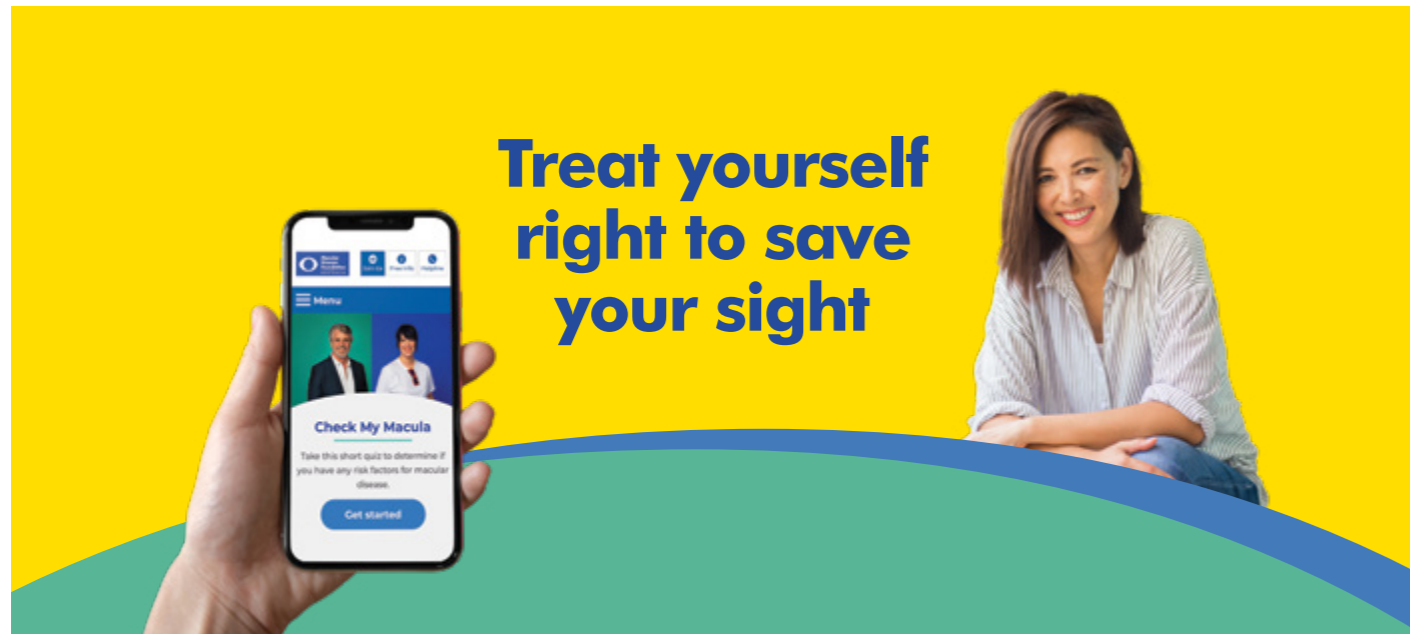
We take this opportunity to sincerely thank the hard work of our board, committees, staff and volunteers – driven by a collective passion to make a meaningful impact for our community.



**Neil Wykes OAM**  
Interim Chair



**Dee Hopkins**  
CEO



## 50,000 Australians complete Check My Macula quiz

One in seven Australians over 50 has the early signs of age-related macular degeneration (AMD) – Australia’s leading cause of blindness – but many don’t know it until it’s too late.

Our challenge has been not only to raise awareness of macular disease but to enable Australians to discover if they are at risk of AMD or diabetic retinopathy and take preventative steps.

A simple online quiz called Check My Macula has helped turn this problem around, and now more than 50,000 people over the age of 50 years have completed the quiz (25 October 2020 to 30 June 2021).

Check My Macula ([www.CheckMyMacula.com.au](http://www.CheckMyMacula.com.au)) is an online quiz developed by MDFA as an educational

tool and is based on known risk factors to help Australia’s over-50s quickly and easily identify their risk factors for key macular conditions.

Check My Macula targets Australians over 50 years – age is one of the key risk factors for AMD. In less than one minute, people can discover their specific risk factors and access relevant information. The tool also enables them to find their nearest optometrist and book an appointment for an eye exam via the relevant optometry booking platform. Check My Macula was

launched to much media fanfare alongside a new television campaign, which showcased the talents of actor Shane Jacobson and long-term MDFA Ambassador Jean Kittson.

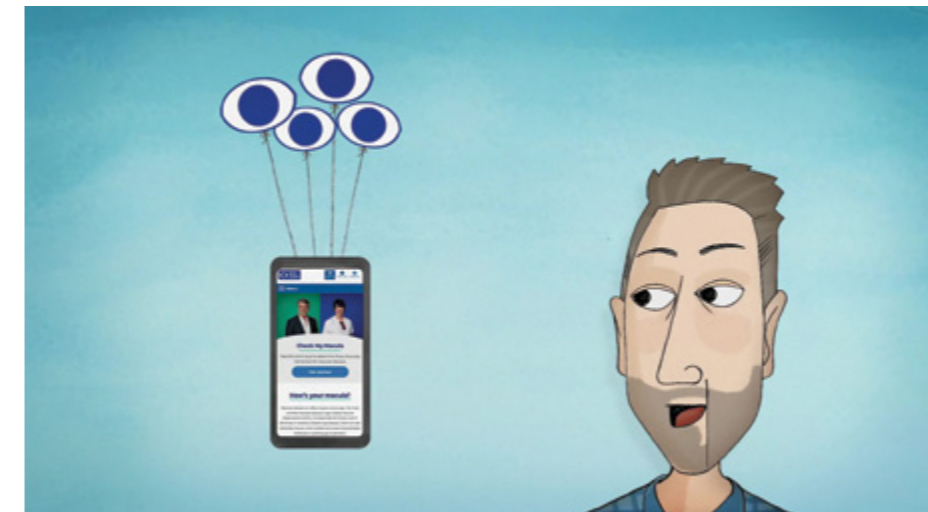
The advertisement addresses the check list of life-saving medical examinations all Australians should be taking from the milestone age of 50 and beyond. It aims to bring eye examinations into the commonly known list of bowel, breast, prostate and heart checks, to name a few. “Many Aussie blokes have a ‘you’ll be right’ attitude

towards their health, and they tend to bury their heads in the sand when it comes to routine check-ups like an eye exam. But your vision is far too precious to gamble with,” said Shane Jacobson, the popular actor, writer and entertainer. A Galaxy Poll conducted by MDFA showed that among Australians between the ages

of 50 and 64, only 6% say that an eye exam is their top health check priority. In the same study, only 10% could correctly identify the main risk factors: age, family history, smoking and lack of regular eye exams – making the need for a simple online quiz even more of an imperative.

“You are risking your vision if you don’t have regular eye exams, including a check of the macula. Early diagnosis is imperative for treatment, so my key message for everyone is get your macula checked, especially if you have someone in your family with AMD”

– MDFA Ambassador Jean Kittson



### HIGHLIGHTS

**50,000** quiz completions – and counting!

 Check My Macula nominated for the best health campaign in the 2021 Prime Awards.

**3,000** Free Mac Pack orders to deliver crucial health information including an Amsler grid for home monitoring of vision change.

**250,000** A quarter of million page views of the Check My Macula website.



### Check My Macula Ambassadors



**SHANE JACOBSON**  
Actor, writer, entertainer



**JEAN KITTON**  
MDFA Ambassador



**CHRIS SMITH**  
TV host, radio broadcaster



**BRENDAN JONES**  
Radio presenter



**MELISSA DOYLE**  
TV journalist



**NELSON ASPEN**  
Entertainment reporter



**ANDREW VOSS**  
Rugby league commentator



# MDFA launches education for healthcare professionals

In May 2021, MDFA unveiled the Health Professional Education and Training (HPET) program, as part of the Prevention and Early Detection initiatives in the National Strategic Action Plan for Macular Disease.

Funded by the Australian Government, the goal of the three-year HPET program is to reduce the incidence and impact of macular disease by strengthening training, education and awareness of macular disease for health professionals in Australia.

The program will target optometrists, pharmacists and general practitioners as a priority, as well as orthoptists, Aboriginal health workers and practitioners, and aged-care workers.

The program is being delivered by a consortium of organisations, led by MDFA.

### Lead agency

- Macular Disease Foundation Australia (MDFA)

### Consortium partners

- Royal Australian New Zealand College of Ophthalmology (RANZCO)
- Optometry Australia (OA)
- Pharmaceutical Society of Australia (PSA)
- Australian College of Rural and Remote Medicine (ACRRM)
- Orthoptics Australia
- Vision 2020 Australia (V2020A)
- Oculo

The first self-paced online course for optometrists launched in May. This OA-accredited course on age-related macular degeneration (AMD) was developed with the support of our consortium partners, as well as contributors Professor Paul Mitchell OA, A/Prof Alex P Hunyor and the Centre for Eye Health.

Optometrists can access this free CPD through MDFA’s website, Optometry Australia Institute of Excellence, Luxottica Institute of Learning, Specsavers MyCPD portal and mivision magazine.

By June 30, 126 optometrists had completed the course. The post-course evaluation survey analysis highlighted the intent of many participating optometrists to change their practices in future, to better align with the recommendations in the online course:

- 98% of survey respondents said they learnt new information through the AMD course that will help them to manage patients at risk of AMD or AMD progression
- 84% said it's likely they will discuss smoking cessation with at-risk patients in future; a change in current practice for 43% of participants
- 81% said they will recommend AREDS2 supplements in future for patients with intermediate AMD or late AMD in one eye; a change in current practice for 43% of attendees

**“Loved it. Very interactive and interesting. Fun and easy to follow”**

– optometrist after completing MDFA CPD course



We will launch modules on AMD and diabetic eye disease for optometrists, pharmacists and general practitioners over the next 12 months.

**“The course was informative and engaging. Very easy to follow”**

– optometrist after completing MDFA CPD course

### CPD webinars

Leading ophthalmologists Prof Paul Mitchell AO and A/Prof Wilson Heriot featured in our new educational webinar series for optometrists on the management of AMD.

Held in May as a part of the Macula Month awareness program, these webinars received Optometry Australia Quality Assurance and were accredited as one hour of CPD learning.

Almost 90% of optometrists who attended Prof Mitchell’s webinar said the content was relevant to their study or practice, and 100% said they were interested in attending future CPD activities.

### Macula Matters e-newsletter

MDFA created a new quarterly e-newsletter specifically for eye healthcare professionals (HCPs) in July 2020. Macula Matters updates HCPs on the latest news related to macular disease and the work of MDFA.

### Highlights



**Launched** Health Professional Education and Training (HPET) program.

**2,647**

subscribers to Macula Matters, MDFA’s new email newsletter for HCPs.

**100%**

of optometrists who attended CPD webinars said they were interested in future MDFA CPD activities.

**125,523**

free patient resources distributed to health professional practices.

**Consumer awareness**

M DFA won competitive tenders to deliver important preventative health initiatives in the National Action Plan for Macular Disease. A key part of this work is to collaborate with other organisations to increase the number of people undertaking comprehensive eye exams and increase the number of people diagnosed in early stages of macular disease.

The grant will enable us to do more with rural and Indigenous communities, people living with diabetes and diabetic eye disease, as well as those at risk of developing AMD.

**“I appreciate you taking the time to talk to me about my injection fears. It’s useful to understand why it’s important that I continue to receive them”**

– eye injection patient on a National Helpline outreach call



**Education and webinars**

As pandemic restrictions persist, we have continued to look for innovative ways to ensure we maintain engagement with our communities.

We were unable to deliver our traditional face-to-face education forums due to public health orders, so earlier in 2020 we introduced a new series of educational webinars.

Between 1 July 2020 and 30 June 2021, we presented 21 public webinars and six community webinars. Webinar forums have enabled us to expand the range of topics of most interest to our community. And it is delivered to them in the comfort of their own home.

This year we have included a wide range of guest speakers such as leading retinal specialists and nutrition and mental health specialists so that our community can ask questions of the experts.

These virtual education sessions have ensured people who are unable to attend their community groups or meet with their social clubs remain connected to their peers while engaging with pertinent content to maintaining vision.

**Peer support**

Acknowledging the increased potential for loneliness and social isolation as a result of the pandemic, we prioritised the creation of three new peer support groups for people living with AMD.

We created face-to-face groups in Melbourne and Townsville, as well as a digital group via Zoom, called ‘At Home with MDFA’.

We established these groups so people living with AMD can share their experiences and support each other, particularly when opportunities for social connection are low.

The MDFA team travelled to Townsville for the first meeting to connect with attendees and help guide the discussion. Group members totalled five, and numbers continue to grow. Our staff also attended the first meeting of the Melbourne group. We plan to launch a second group in the south of Melbourne this year.

Our digital peer support group was developed alongside our face-to-face groups and has provided an opportunity for people living in lockdown regions or without the means to travel to feel connected and to share their stories.

This group has proven particularly popular, with numbers tripling since its inception. Feedback from attendees has been overwhelmingly positive.



**National Helpline**

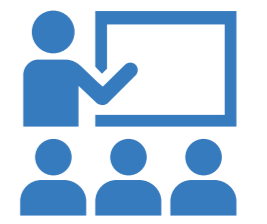
We have continued our tele-health campaign with a continued focus on ensuring our communities are keeping on top of their health and wellbeing.

With lockdown guidelines continually changing, our focus has been on outreach calls to ensure people in areas of concern are aware of the rules surrounding their travel, particularly those who need to receive eye injections.

**“During this lockdown time, I think it’s very important to connect with others outside your own home environment. I look forward to hearing how other members use their time during lockdown. Thank you for all you are doing for those of us who have AMD”**

– member of MDFA’s digital peer support group

**Launched** peer support groups in Melbourne, Townsville and online.



**2,733**

attendees at education forums.



**95%**

of participants rated our webinars as excellent or good.



**5,851**

National Helpline calls.

# Advocacy

In 2020, the Medicare Benefits Schedule (MBS) Review Taskforce published its ophthalmology report recommending cutting Medicare rebates for eye injections by 69%. These injections are used to deliver sight-saving treatment for people with a range of macular conditions.

While MDFA supports a number of the Taskforce’s 19 recommendations, we have run a sustained and strategic campaign against the Medicare rebate cuts.

Our campaign included the National Press Club address by MDFA Patron Ita Buttrose AC OBE, who gave voice to the concerns of the macular disease community in a nationally televised address.

Speaking to a crowded National Press Club and televised live on the ABC, Ms Buttrose warned that many older Australians will no longer be able to afford this vital treatment if the Government adopts this recommendation, and instead asked for the Government to consider alternative models – developed and fully costed by MDFA – to improve access to sight-saving treatment.

“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. Australians at risk of losing their vision can’t wait any longer – action is needed now,” Ms Buttrose said.

MDFA commissioned PwC to

co-develop a costed business case to improve access to sight-saving treatment.

The report includes new low-cost regional clinics, more healthcare workers giving injections under ophthalmologists’ supervision, and better and more consistent treatment fee transparency with support for patients to self-advocate for affordable treatment and improve treatment adherence rates.

## Your voice in Canberra

CEO Dee Hopkins, together with MDFA’s Medical Committee Chair Associate Professor Alex Hunyor, met with Minister Hunt to present our costed business case and to impress on the Minister the impact the proposed cut would have on the macular disease community.

In the months ahead, Minister Hunt will establish an Implementation Liaison Group (ILG) to guide the process of implementing the MBS Review Ophthalmology recommendations and ensure that they don’t have unintended consequences for patients. MDFA has been invited by Minister Hunt to be part of the ILG and represent our community’s best interest.

## 96 policy submissions and representations

After four years of persistent representations, we welcomed the final report of the Royal Commission into Aged Care Quality and Safety, which incorporated MDFA’s recommendation to make low vision aids and technologies more accessible for older Australians.

We believe everyone living with vision loss in the aged care system (over 65 years) should receive daily living support such as assistive technologies, aids and equipment – at the equivalent level to people with vision loss receive under the National Disability Insurance Scheme for those under 65 years.

The Government has released a response committing to redesign the aged care system to include aids and equipment but has not yet committed to providing them for people over 65 years at the same level as those under 65 years in receipt of an NDIS package.



Ita Buttrose, AC OBE, at the National Press Club

**“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 Greg Hunt

## Submissions and representations

In addition to MDFA’s representations to the Federal Health Minister to stop cuts to the MBS item for eye injections, we also met with the Federal Regional Health Minister and Shadow Health Minister and shared our costed report. We also met and briefed the majority of the state and territory Health Ministers on the impact this cut would have on constituents. They agreed to make direct representations to

the Federal Health Minister on this matter.

MDFA made 96 Government policy submissions and formal representations including:

- MDFA submission on the draft National Preventative Health Strategy
- Submission to the Royal Commission into Aged Care Quality and Safety
- House of Reps Inquiry into approval processes for new drugs and novel medical technologies
- Federal Pre-Budget submission for ongoing investment in recommended actions in the National Action Plan for Macular Disease
- We made representations to a number of aged care providers in several states, seeking to revise restrictive practices that made it difficult for some residents to attend sight-saving treatment during the pandemic.

MDFA works in partnership with multiple organisations to ensure that the voice of the macular disease community is heard. We contribute to many collaborative public health policy submissions on national initiatives and Government processes. These include the National Aged Care Alliance, Consumer Health Forum, the National Patient Advocacy Alliance and Vision2020 Australia.

**“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. Australians at risk of losing their vision can’t wait any longer – action is needed now”**

– Ita Buttrose, AC OBE

# 2021 Research Grants

MDFA awarded more than \$1 million in research funding at a prestigious ceremony at Sydney’s Admiralty House in May 2021. His Excellency, General the Honourable David Hurley AC DSC (Retd). and Mrs Hurley presented research grants to eight Australian researchers working to reduce the incidence and impact of macular disease.

This year’s investment brings MDFA’s total funding commitment to \$5.1 million since our Research Grants Program began in 2011.



**A/Prof Chi Luu, Centre for Eye Research Australia**

A/Prof Luu’s project will use an innovative imaging technique to improve our understanding of the causes of age-related macular degeneration (AMD) and help develop new treatment strategies.



**Prof Justine Smith, Flinders University**

Prof Smith’s 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.



**Dr Yvette Wooff, Australian National University**

Dr Wooff’s project will investigate the possibility of restoring communication between cells by therapeutically supplementing the natural molecular message of retinal health as a therapy.



**Dr Ting Zhang, Save Sight Institute, University of Sydney**

Dr Zhang’s project will look at AMD at a cellular level, considering the role of an important enzyme in combating oxidative and mitochondrial stress to particular retinal cells.



**Dr Anai Gonzalez Cordero, University of Sydney**

Dr Gonzalez Cordero’s research will create macula-containing organoids – or ‘mini organs’ – that can then be used as a source of cells for replacement therapies and used to test the efficacy of potential therapies.



**Ms Diana Tang, Macquarie University**

Led by an accredited practising dietician and a physical activity researcher, Ms Tang’s project aims to improve the mental and physical health of people living with AMD through the online Movement, Interaction and Nutrition for Greater Lifestyles in the Elderly (MINGLE) program.



**Dr Sheela Kumaran, University of NSW**

Dr Kumaran’s study aims to improve the way the impact of AMD on quality of life is measured. This will help assess the effectiveness of various interventions and improve our understanding of the economic impacts of AMD.



**A/Prof Matthew Simunovic, Save Sight Institute, University of Sydney**

A/Prof Simunovic’s research 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: it can therefore be considered a biological equivalent of the bionic retina.

# Grant Family Fund

This year’s awards also included the inaugural investment of the Grant Family Fund, a biennial grant opportunity made possible by a generous bequest from the estate of the late Faye Grant.

First awarded in May 2021, the funding provides grants to early-career researchers for innovative and creative ‘blue sky’ research in the field of macular disease.

“Without you, we wouldn’t have been able to achieve what we have in macular disease... thank you very, very much ”

– Ms Diana Tang

# \$1.1 million

awarded to eight Australian researchers by Governor-General David Hurley AC DSC (Retd).

Inaugural investment of the Grant Family Fund for ‘blue sky’ projects by early-career researchers.

The launch of the new Macular Disease Impact Study, thanks to the Fitzpatrick Sykes Family Trust.

# 28-page

publication reflecting on 10 years of MDFA’s Research Grants Program.



# 10 years of MDFA’s Research Grants Program

To mark the 10th anniversary of the MDFA Research Grants Program, His Excellency, General the Honourable David Hurley AC DSC (Retd). formally launched a new publication showcasing the impact of our commitment to research.

This 28-page report profiles each of the 18 Australian researchers MDFA has supported over the past decade, to become Australia’s largest non-Government source of funding for macular disease research.

The cover features MDFA-funded researcher Prof Bamini Gopinath, an epidemiologist whose research has improved our understanding of the links between nutrition and AMD.

# Grant Family Fund: Inaugural investment in 'blue sky' research

The late Faye Grant included MDFA in her will. Now, her generous legacy gift is funding vital, innovative research into macular disease through the Grant Family Fund.

This new stream of research funding was awarded for the first time in May 2021, supporting two early-career researchers to undertake creative, 'blue sky' research in the field of macular disease.

The Grant Family Fund enabled MDFA to allocate more than \$90,000 to Dr Ting Zhang (\$45,000) and Dr Anai Gonzalez Cordero (\$46,360).

They are now working on projects that have the potential to shift current paradigms and have a major impact on macular disease research.

Faye's father Ronald Grant lived with age-related macular degeneration (AMD) for 15 years before he passed away in 2016. Faye was Ron's main carer in the final years of his life and understood what it was like to care for someone living with AMD.

Faye passed away, aged 59, in 2019. After discussion with her family, Faye's gift is now supporting research that promises to improve the eye health and change the lives of future generations.

Faye's sister and brother-in-law, Janette and Rod Forrester, attended the prestigious event



at Admiralty House in Sydney, where His Excellency, General the Honourable David Hurley AC DSC (Retd) presented the first Grant Family Fund awards to Dr Zhang and Dr Gonzalez Cordero.

These are the exciting projects the inaugural Grant Family Fund recipients are working on now.

## Dr Ting Zhang, Save Sight Institute, University of Sydney

*Project title: Activating endogenous phosphoglycerate dehydrogenase (PHGDH) to treat AMD with the help of a Müller cell-specific lipid nanocarrier*

While the causes of AMD aren't known, there is evidence that suggests stress in particular retinal cells – called

Müller cells – is related to AMD's development.

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.

This project will focus on a chemical function of the eye called the serine synthesis pathway and a particular enzyme, called phosphoglycerate dehydrogenase (PHGDH), and its importance in combatting oxidative and mitochondrial stress in Müller cells.

Dr Zhang will use a gene manipulation system to activate the PHGDH enzyme, which will be delivered by Müller cell-targeting lipid nanoparticles.

The findings will provide novel insights into understanding the role of serine synthesis in the way AMD develops.

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

*Project title: Creating a macula in retinal organoids*

The loss of light-sensing photoreceptor cells in the eye is the leading cause of blindness.

However, laboratory researchers lack animal models that faithfully replicate the human retina, which hinders their ability to study these degenerations and develop new therapies.

Researchers currently use patients' own blood cells or skin cells to create stem cells, which can form organoids – or 'mini organs' – containing photoreceptor cells in the dish.

But these organoids don't form a macular structure.

Dr Gonzalez Cordero is aiming to change that, by creating a macula-containing organoid that would be the perfect laboratory model for macular degeneration.



Rod Forrester



Janette Forrester, Dr Anai Gonzalez Cordero and His Excellency, General the Honourable David Hurley AC DSC (Retd).

This macular tissue can then be used as a source of cells for cell replacement therapies, and to test the efficacy of these potential treatments.

Dr Gonzalez Cordero says cell replacement therapies of healthy photoreceptors into the diseased eye provide a promising treatment option that could help reduce vision loss in millions of people.

## Peer support

The COVID-19 pandemic has reminded us of the value of social connections.

Over the past year, we began face-to-face peer support groups in Melbourne and Townsville, as well as 'At Home With MDFA', a group that meets remotely via Zoom.

Our volunteers also continued to reach out to people living with AMD through peer-to-peer phone calls.

Irene, a member of MDFA's Melbourne peer support group, said: "I'm really grateful that I was put in touch with this group. It's very encouraging to be with people who have the same problem and you don't have to worry about what you're saying."



# Board Directors



**CHAIR: MR NEIL WYKES**  
OAM BCom FCA AGIA ACIS



**BRIG JOHN FENWICK (RETD)**  
BA MBA GAICD AFAIM



**MR RICHARD GRILLS**



**MS LISA LUSTHAUS**  
BSc App. Psych (Hons)



**RETIRED (JULY 2020):  
PROFESSOR NITIN  
VERMA**  
AM FRANZCO MD  
MMed Dip NBE



**APPOINTED (OCTOBER  
2020): ASSOC PROF  
ALEX P HUNYOR**  
MB BS (Hons),  
FRANZCO



**MS IMELDA LYNCH**  
RN BN MHSM GAICD



## Thank you and farewell

**CHAIRMAN: MR ROBERT KAYE**  
SC LLM LLB MAICD Retired (May 2021)

We farewell and sincerely thank Robert Kaye who chaired the board for the past five years. We thank him for his passion and dedication in advancing MDFA's work in reaching and supporting more Australians at risk or living with macular disease. Robert will undoubtedly continue to be a strong advocate for our community and our quest to reduce the incidence and impact of macular disease.

**MDFA committees** play a key role in advising management and championing our purpose to reduce the incidence and impact of macular disease. We are fortunate to have Australia's eminent research and retinal specialists and other professionals to inform our work.

### MEDICAL COMMITTEE

- A/Prof Alex Hunyor (Chair)
- Dr Amanda Greaves
- Dr Alex Harper
- A/Prof Wilson Heriot
- Dr David Hilford
- A/Prof Anthony Kwan
- Dr Tharmalingam Mahendrarajah
- Prof Paul Mitchell AO
- Dr Grant Raymond
- Prof Nitin Verma AM
- A/Prof Peter van Wijngaarden
- New: Dr Xia Ni Wu
- Retired: A/Prof Dimitri Yellachich

### RESEARCH COMMITTEE

- New: A/Prof Anthony Kwan (Chair)
- Ms Imelda Lynch
- A/Prof Peter van Wijngaarden
- New: A/Prof Fred Chen
- New: A/Prof Samantha Fraser-Bell
- Retired: Prof Nitin Verma (Chair)

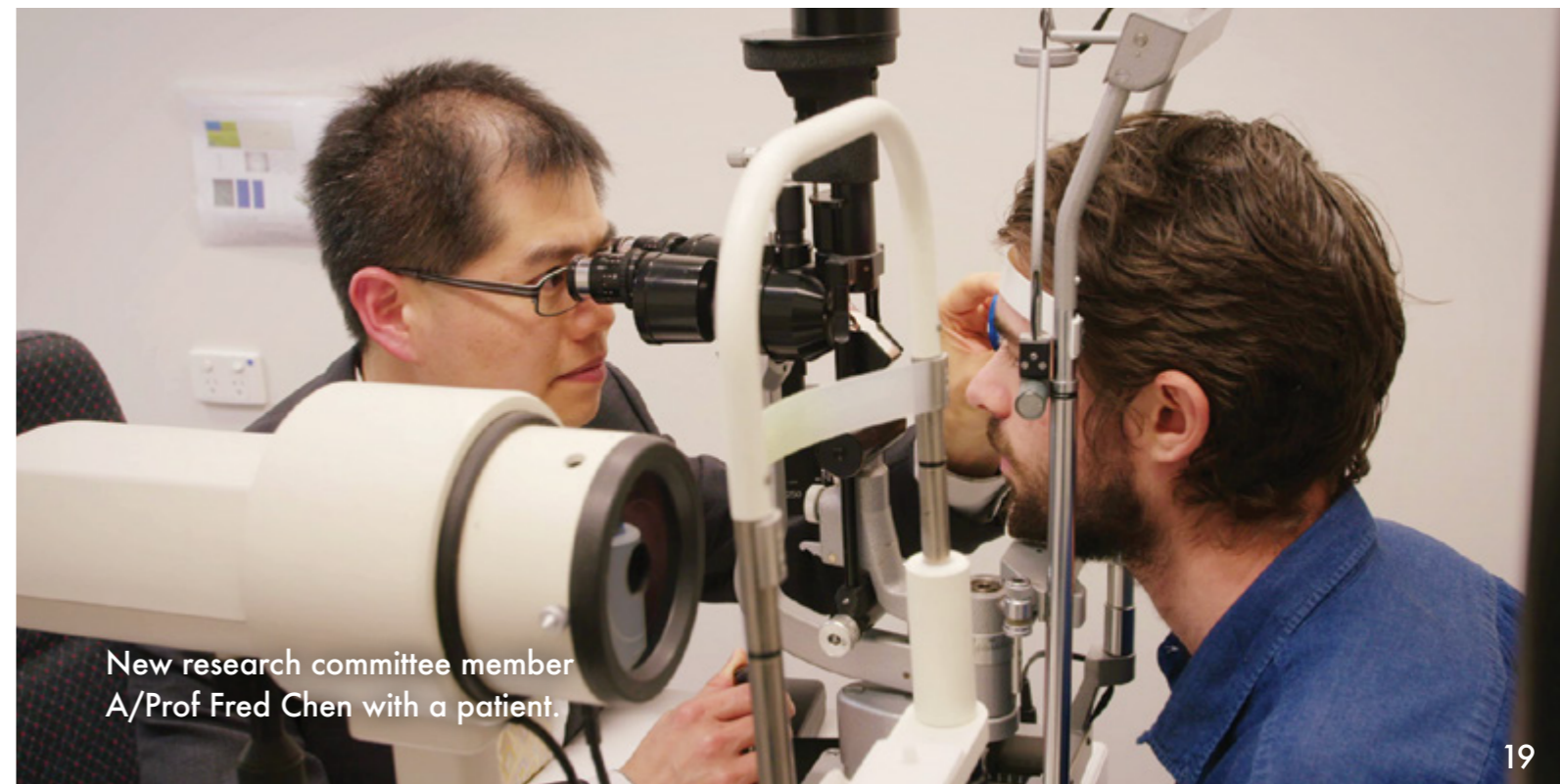
### AUDIT AND RISK COMMITTEE

- Mr Neil Wykes OAM (Chair)
- Mr Ashley Chapman
- Mr John Fenwick
- Retired: Mr Robert Kaye SC
- Retired: Mr Paul Rogan

### NATIONAL RESEARCH ADVISOR

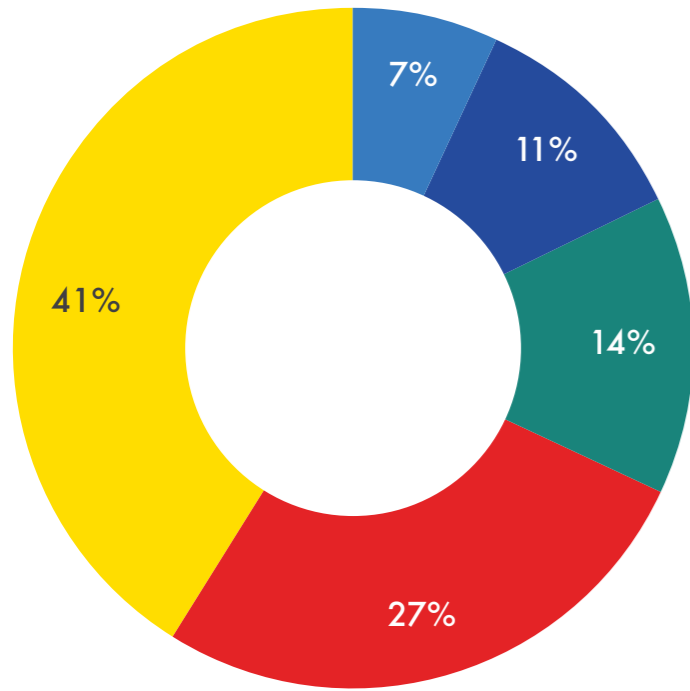


**PROFESSOR PAUL MITCHELL**  
AO MBBS MD PhD  
FRANZCO FRACS  
FRCOphth FAFPHM



New research committee member A/Prof Fred Chen with a patient.

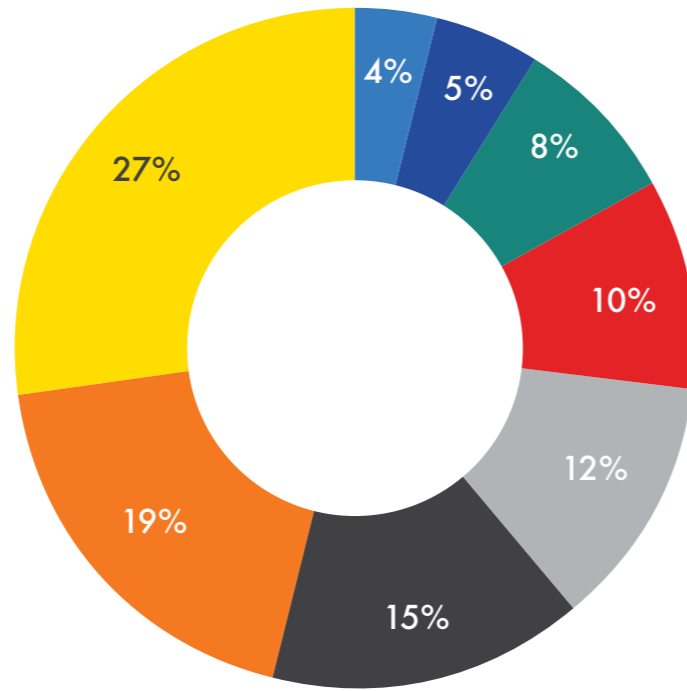
REVENUES \$000S



- Research donations and bequests \$300k
- Sponsorship \$518k
- General donations and bequests \$614k
- Investment gains \$1,232k
- Government grants \$1,835k

**Total \$4,499k**

EXPENSES \$000S



- Advocacy \$174k
- Research grants \$193k
- Research activities \$317k
- Fundraising activities \$385k
- Consumer education \$445k
- Services and community support \$559k
- Operational costs \$744k
- Prevention and early detection \$1,021k

**Total \$3,838k**

What have our volunteers been up to over the past year?



Val Nicholson

**Ita Buttrose Oration**

MDFA volunteer Val Nicholson, who attended the inaugural Ita Buttrose Oration at the National Press Club in Canberra: "I felt very proud to be representing the Macular Disease Foundation Australia and to be part of that group. I was delighted to be asked to attend, and excited to hear Ita advocate on all levels – from her family’s involvement and involvement in MDFA as a whole."



Jim Pringle

**Peer-to-peer phone calls**

MDFA volunteer Jim Pringle, who makes outreach calls to other people living with AMD: "It’s one of the best things MDFA has done because it builds relationships where they may not be able to elsewhere. They can talk to you about things they don’t talk about with their ophthalmologist, allowing people to open up even further. Every time I call, I get to talk to them about something different."



Peter Wilkinson OAM

**\$1 million in MDFA research funding**

MDFA Consumer Reference Group member Peter Wilkinson OAM, who attended the prestigious research announcement by Governor-General David Hurley at Admiralty House: "It was a great thrill to attend an afternoon tea with the Governor-General at his Sydney residence. To meet with the wonderful research scientists was quite a privilege. We were quite surprised when Mrs Hurley said it was a tradition that a song was sung at one of these functions, and were even more pleasantly surprised when she led us with her beautiful voice in a rendition of 'You Are My Sunshine', which all joined in with much gusto! It was quite a memorable afternoon, which left a memory that will last a long time."



Des Morton

**Thank you, Des!**

Much loved volunteer Des Morton has retired from his role with MDFA, bidding farewell to the many friends he made throughout his many years with us. Des became involved with MDFA through his wife Jean, who lived with wet AMD. When Jean passed away in 2015, Des honoured Jean’s memory by volunteering with MDFA. Thank you, Des, for your contribution – the contribution you have made to the wider macular disease community will never be forgotten.

## SUPPORTERS



Together we are working to reduce the incidence and impact of macular disease in Australia. Thank you enormously for your trust and support.

### Individuals

Ms Linda Sen Gupta  
Miss Leone Glynn  
Mr Ebrahim Gutta  
Mr Graeme Reynolds and Mrs Lesley Parker Reynolds  
Mr Lawrie Turnbull  
Mrs Sally White  
Mr Richard Williams  
Mrs Amy Young  
Ms Imelda Lynch  
Ms Elizabeth MacDonald

### Trusts and Foundations

The Fitzpatrick Sykes Foundation  
The Grant Family Foundation  
Profield Foundation  
Perpetual  
The Mills Family Foundation  
The McBriarty Family

### Visionary Partners

Mr Alex Cleave  
Mrs Anne-Marie Harman

Mrs Bertha Tilley  
Mr Brian Schafer  
Mrs Christine Paris  
Mr David Hamilton  
Mrs Diane Hobden  
Dr Edith Horvath  
Mrs Elaine Sinclair  
Mr Ernest Athfield  
Mrs Faith Davidson  
Mr Gregory Sachs  
Mr Ian Ferguson  
Mrs Janet Fenwick  
Mrs Janina Bourke  
Ms Jean Taylor  
Mrs Jeanette Warne

Ms Jennifer Wakeling  
Mrs Jill Sedla  
Dr John Mayo  
Mr Kevin Baldwin  
Mr Lindsay Allan  
Mr Lloyd Davis  
Ms Lorraine Young  
Miss Lorraine Edwards  
Ms Lynette Elliott  
Mrs Margaret Snodgrass  
Mrs Maria Rosol

Mrs Marjorie Vorsa  
Mrs Meryl Bowman  
Ms Nancy Scott  
Mr Neville Gallard  
Mrs Norma Schram  
Mrs Paddy Beatrix Carter  
Ms Pamela Taylor  
Mrs Patricia Chisholm  
Ms Penny Tomlinson  
Mr Peter McDonald  
Mrs Stephanie Joss  
Mrs Sue Smith  
Mrs Valery Holmes  
Mr Victor Dobija

### Estates

The Estate of the Late Ethel Hayden  
The Estate of the Late Enid Byrne  
The Estate of the Late Barbara Doreen Staples  
The Hughes Family Trust Fund  
The Estate of the Late Josephine Simelius  
The Estate of the Late Coralie Hillman

The Estate of the Late Irene Watson  
The Estate of the Late Anne Fenette Hartley  
The Estate of the Late Dolly Berwick  
The Estate of the Late Rodney Neale  
The Estate of the Late Valerie Jill Smith  
The Estate of the Late Ruth Beeson  
**Supporters**  
Dominican Sisters of Eastern Australia and The Solomon Islands  
Goulburn Workers Club Ltd

Goulburn Soldiers Club  
Magpies Waitara  
Lithgow and District Workmens Club Ltd  
Ramsgate RSL Memorial Club  
Hornsby RSL Club  
Club Forster  
Canley Heights RSL

## Government Support

Thank you to the Australian and NSW Governments for their continued financial support.



Australian Government



The Commonwealth's Peak and Advisory Bodies Program enables MDFA to provide input to public health policy and advice on what matters most to the macular disease community. NSW Health and the Federal Department of Health support the development and communication of relevant evidence-based information for the macular disease community, health providers, Government and other related stakeholders.

The Commonwealth's National Strategic Action Plan for Macular Disease funding supports important projects to deliver on its goals to manage, prevent and treat macular disease.

Funding from the NSW Government contributes to the delivery of comprehensive education and awareness programs, as well as support services to thousands of people in NSW, including those in regional and remote areas.

## Supporters

The generous support provided by the following organisations (in alphabetical order) enables the delivery of key initiatives and activities.

Apellis

A new partner in 2020, Apellis has supported the planning stage of our patient engagement initiative, which allows those living with macular disease to receive the right information at the right stage of their disease journey.

Perpetual

Perpetual has supported MDFA with in-kind support as well as administering generous Trust and Foundation funds.

Profield FOUNDATION

Profield Foundation has been a long-term supporter of MDFA, helping to fund front-line client services, including the National Helpline, MDFA's Vision Voice newsletter, and the delivery of awareness and education activities.



A key supporter since 2011, Bayer funding assists with key initiatives in the areas of client services, awareness, education and research.

JBWere

JBWere manages MDFA's investments and supports with strategic advice for social return.

NOVARTIS

Novartis has been a major contributor to our awareness and support services programs since MDFA's establishment. Novartis has assisted in the redevelopment of all MDFA health publications.

Specsavers

Specsavers is partnering to raise awareness of macular disease and develop a bespoke program to assist in patient adherence to sight-saving treatment.



**Macular  
Disease  
Foundation**  
AUSTRALIA

## **Macular Disease Foundation Australia**

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