



MACULAR DISEASE FOUNDATION AUSTRALIA

IMPACT REPORT 2018-2021



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MDFA 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 past, present and emerging.

VISION

To eliminate
preventable blindness
from macular disease.

PURPOSE

Reduce the incidence
and impact of
macular disease.

LETTER FROM CHAIR AND CEO

Macular Disease Foundation Australia (MDFA) has undergone significant change over the past three years. It has been a time of transformation to better align with the changing needs of our community and leveraging technology to work smarter.

In 2018, we adopted the Theory of Change model to better measure the impact of our work and the collaborative work we do with others to achieve better health outcomes for the wider macular disease community.

This outcomes-focused work helped to shape our 2018-21 Strategic Plan so we would focus on initiatives that can be better measured for impact for the community and in fulfilling our purpose of reducing the incidence and impact of macular disease. The key achievements include:

- The development of a Theory of Change Program Logic Map specifically designed for the macular disease community.
- The first National Strategic Action Plan for Macular Disease.
- Establishment of a Consumer Reference Group – so that MDFA's work is informed through structured and direct engagement with people who represent our diverse community.
- The ongoing transformation of our work to become a patient journey expert in addition to being a disease expert.
- New Government funded programs to reach and engage with more Australians at risk and living with macular disease and a new accredited education program for health care professionals.
- We have revised and developed a wide range of new evidence based information resources overseen by our Medical Committee.
- Recognition of the value of our work by social impact investors such as the macular disease community, philanthropists, corporate partners, and the Australian Government through the incremental increase and diversification of investment in our work over the past three years.
- We have formed a formal consortium with a number of health care professional peak bodies to work collaboratively to improve early detection of macular conditions. They include the Government, RANZCO, Optometry Australia, Orthoptics Australia, the Pharmaceutical Society of Australia, Vision2020 Australia, RACGP, ACRRM and many others.

We look forward to the next three years as we continue to grow and learn and continue being relevant and impactful.



Neil Wykes OAM
Chair



Dee Hopkins
CEO

“We’re so much better informed now than in my mother’s day. We just thought it was one of those things... I had no idea it was hereditary.

I’ve have seven children and 14 grandchildren. I hope there is a treatment for dry age-related macular degeneration or a cure by the time they’re over 50. That’s why research is so very, very important”.

– Rita, 90, NSW



THE MACULAR DISEASE COMMUNITY IS WHY WE EXIST

Macular Disease Foundation Australia (MDFA) is the national peak body for macular disease and exists to represent and support the macular disease community. Our community is at the heart of our work, decision making, continuous improvement and innovation. We conduct biennial evaluations so we can learn what's most important to our community and how we can improve and remain relevant and valuable.

In 2020, our community told us what they think about MDFA:

- 100% value MDFA's role as the voice of the community and advocacy activities
- More than 95% value MDFA's role in public awareness campaigns and prevention and early detection activities
- 94% value MDFA's work in funding Australian research into macular disease
- 92% value MDFA's work in providing information and support services
- More than 96% would recommend MDFA to a friend or family member

PILLARS OF WORK



**Prevention
and early
detection**



**Supports
and services**



**Voice of
the MD
community**



**Research
and data**

IMPACT GOALS

More people
at risk of or
living with
macular disease
self-identify and
take action

Self-agency
and optimal
quality of life
for people with
or at risk of
macular disease

Universal
entitlement
& treatment,
rehabilitation
and low vision
support

Translation
of research
to support
knowledge base
for better patient
outcomes

PILLAR ONE – PREVENTION AND EARLY DETECTION

Goal: Reach more Australians at risk or living with macular disease

Impact goal: More Australians at risk of macular disease self-identify and take action.

Strategic priorities – consumer development: Build better understanding of macular disease.

Increase consumer awareness of risk, prevention and treatment.

Key achievements:

- As of 30 June 2021, more than 50,000 Australians completed our new Check My Macula quiz – launched in October 2020 – 62.5% had identified two or more risk factors and almost 3,000 requested free information packs on AMD and diabetic eye disease.



- MyGov Galaxy poll results over the past three years showed an average awareness rate of 86% for age-related macular degeneration. In 2020 we asked about awareness levels of diabetic retinopathy with only 29% awareness rates. This is an area of priority in MDFA's 2021-24 strategic plan and in the National Strategic Action Plan for Macular Disease.
- Macula Month in May has become a key feature in the eye health calendar. In the past three years, we have generated a cumulative total of 648 media articles, television and radio interviews reaching an audience of 38 million through media outlets. In 2018, we introduced digital communication toolkits which are distributed annually to more than 5,000 optometrists, ophthalmologists, and other health care professionals.
- We have enhanced our social media, which has resulted in a 21% increase in Facebook followers, a 74% increase in Twitter followers, a 138% increase in Instagram followers, and a 163% increase in those engaging with us through LinkedIn.
- We launched our new website in 2021 which continues to provide our community with qualified and relevant content in an accessible and digestible format.

An advertisement for the 'Check My Macula' initiative. It features a smiling woman with long brown hair holding a smartphone that displays the quiz interface. The background is bright yellow. At the top is the Macular Disease Foundation Australia logo. The text 'Treat yourself right to save your sight' is prominently displayed. Below the woman, there is a QR code and contact information for the quiz.

Macular Disease Foundation AUSTRALIA

Treat yourself right to save your sight

Check My Macula
One minute is all it takes to check your risks for macular disease. Get started at www.CheckMyMacula.com.au or call 1800 111 709.

Check My Macula is an initiative of Macular Disease Foundation Australia (MDFA) and does not replace an eye examination or advice provided by a qualified eye health professional.



“My father was diagnosed with AMD and my 95-year-old Uncle Gerald lives with AMD now but has injections to keep vision loss at bay. I am at risk of losing my vision to this disease too so I maintain an eye-healthy diet, exercise, I use an Amsler grid to help me self-monitor my vision between eye checks, and I have my macula checked every two years.”

– MDFA Patron, Ita Buttrose AC OBE

Strategic priorities – Health care professional development:

Build collaborative partnerships with health care professionals to help us engage and support optimal numbers of Australians living with or at risk of macular disease.

Increase referrals from eye health care professionals (HCPs) to better support the macular disease community.

Key achievements:

- In 2021, and in collaboration with our Medical Committee and eminent retinal specialists and ophthalmologists, we developed accredited training resources for optometry in age-related macular degeneration and diabetic eye disease. Since its launch in May, 225 optometrists have completed the new AMD course. Three-hundred and sixty one people attended two other accredited CPD events for optometrists.
- We have delivered more than 30 educational forums through several universities over the past three years

for the next generation of eye health care professionals.

- We have experienced a slow, steady increase in the number of referrals from eye health care professionals with almost 1,300 referrals over three years.
- Macula Matters e-bulletin for health professionals was launched in 2020 with a subsequent 65% growth in its subscriber base.
- We are engaged in a raft of professional development conferences annually including RANZCO, Optometry Australia and others. We attended 35 key HCP industry events over the past three years.



PILLAR TWO – SUPPORT AND SERVICES

Goal: The macular disease community has accessible and timely support and information.

Impact goal: Self-agency and optimal quality of life for people with or at risk of macular disease.

Strategic priorities:

Increase access to MDFA and complementary services through new channels and initiatives.

Build on MDFA's position as the go-to expert for macular disease.

Key achievements:

- The results of new educational and community engagement activities resulted in incremental new registrations each year with more than 14,000 new members of our community.
- Our National Helpline continued to be of value with 20,880 assistance calls.
- COVID-19 restrictions impacted the numbers attending our consumer education forums. We had planned 150 education forums each year for FY20 and FY21 – most which were cancelled. Nonetheless, over the three-year period, we still engaged with almost 14,500 Australians through face-to-face and webinar educational forums. We are grateful to our webinar guest speaker experts including ophthalmologists, mental health experts and others who enhanced the interactive learning experience.
- Our education programs are highly valued by the wider community. Program evaluation showed that, prior to COVID-19, face-to-face sessions had a 99% rating of "Excellent" or "Good". The webinars were rated as "Excellent" or "Good" by 93% of respondents, and 71% rated the webinars as "Extremely useful" or "Very useful".
- An unintended consequence of COVID-19 lockdown restrictions was that some patients stopped attending appointments for sight-saving treatment such as intravitreal injections. We undertook two public relations campaigns reaching more than 2.5 million Australians. This included a national community service announcement by MDFA Patron, Ita Buttrose AC OBE, "Don't Let Coronavirus Fears Steal Your Vision."
- Throughout COVID-19 restrictions, we proactively reached out to the most vulnerable members of our community to:
 - check in on how they were managing during lockdown
 - promote the adherence of public health guidelines and the need to attend urgent and essential eye treatment
 - ensure people had resources to maintain eye health such as Amsler grids
- Many of our volunteers with a lived experience of macular disease have been trained to deliver peer-to-peer check-in calls to MDFA's community.





COVID-19 prompted a rise in our outbound calls to vulnerable members of our community.

- We have introduced some peer support group pilot programs in Victoria and Queensland and will continue to evaluate the models before testing more widely.
- Sign ups to our popular Vision Voice newsletter have increased to more than 40,000 subscribers in printed, electronic and audio formats - with 360,000 newsletters being distributed over the three-year period.
- Our inaugural Macular Disease Impact Study uncovered a range of factors including:
 - Most respondents were satisfied with their life but nearly one third had a satisfaction score of six or lower.
 - More than 10% of respondents experience high emotional impact from having a macular condition.
 - Primary impact of macular disease includes an inability to read labels, instructions and everyday print. For approximately 17% of people, their macular condition had a high impact on their daily functioning.



Dr James Muecke AM
Ophthalmologist
2020 Australian of the Year

PILLAR THREE – VOICE WITH AND FOR THE MD COMMUNITY

Goal: Our advocacy work is evidenced and co-developed with the community.

Impact goal: Universal entitlement for treatment, rehabilitation, and low vision support.

Strategic priorities:

Develop MDFA's position as a thought leader in detection, prevention and management of macular disease.

Key achievements:

- We co-developed the National Strategic Action Plan for Macular Disease (the Plan) in collaboration with the wider eye health sector and industry on behalf of the Australian Government. The Plan articulates a vision for macular disease in Australia and its goal is to reduce the social, human, and economic impact of macular disease by strengthening all sectors in developing, implementing, and evaluating an integrated and coordinated approach.



- A new Consumer Reference Group was established comprising consumers and carers with lived experience of macular disease to advise MDFA on policy issues, program and information development. We also conducted several polls and engagement with our wider community on issues such as out-of-pocket costs of sight-saving treatment.
- With input from the macular disease community, we developed 286 policy submissions, policy input and formal representations to the Federal Government and other key bodies to influence public health policy. We were pleased that several of our key recommendations on improving access to low vision aids and technology were included in the Royal Commission into Aged Care Quality and Safety Report (2021).
- We also worked with others such as Vision2020 Australia on more than 43 collaborative policy submissions.
- A key focus of our advocacy agenda was the proposed 69% cut to the MBS rebate for sight-saving intravitreal injections by the MBS Review Taskforce – Ophthalmology. We co-commissioned with RANZCO, PwC to develop an economic impact analysis of the proposed cut. The findings showed that any MBS and PBS savings would be offset by direct net costs of \$168m and \$2.6b in indirect costs due to resultant vision loss. Health Minister Greg Hunt MP facilitated MDFA's subsequent presentation of the report to the Ophthalmology Taskforce.
- We provided a copy of this report



Patron, Ita Buttrose addresses the National Press Club.

and briefed every state and territory health minister or their advisors.

Most state Health Ministers made direct representations to Minister Hunt requesting that the MBS be preserved due to the negative impact on patients.

- We independently commissioned PwC to develop a report to identify the costs and impacts of new models of care for intravitreal injection treatment, which was welcomed by Minister Hunt. The Minister has not yet made a decision on the MBS rebate. We have been invited by the Minister to be a member of his MBS Implementation Liaison Group to represent patients and to ensure decisions are not made that would have unintended consequences for patients accessing this critical treatment. His message to the macular disease community is clear: he wants to ensure there are no barriers to ensuring Australians get access to sight-saving treatment.
- In 2019, Minister Hunt launched MDFA's

Journey to See: A Model for Success in Parliament House. The report outlines how collaboration between Government, health care professionals, research agencies, the pharmaceutical industry and the Macular Disease Foundation Australia has delivered a continuum of care for Australians – from awareness and prevention to management and support of those living with AMD.



Dee Hopkins, A/Prof Alex Hunyor, Health Minister Greg Hunt MP

PILLAR FOUR – RESEARCH AND DATA

Goal: Diversify research program and enhanced data.

Impact goal: Translation of research to support knowledge base for better patient outcomes.

Strategic priorities:

Increased investment and diversification of MDFA's Research Grants Program.

Improve collection and analysis of global research and statistical data.

Key achievements:

- In 2021 we launched MDFA's Ten Years of Research – outlining research recipients success stories and the evidence that our research projects contribute to the detection, prevention, management, and elimination of macular disease. Projects have diversified to include diabetic eye disease prevention and some projects have been extended by securing larger National Health and Medical Research Council (NHMRC) funding.
- \$1.7m has been invested in research funds over the past three years. We increased the investment in research in the last round from \$600,000 to \$1m. This brings the total investment in the MDFA Research Grants Program to \$5.1m since it was established in 2011.



2021 recipients of the MDFA Grants Funding Program

“As our population ages and becomes more at risk of age-related macular degeneration, and with a rising prevalence of diabetic eye disease in working-aged Australians, the incidence and impact of macular disease will only increase and put additional strain on our health care system, which is why this research into understanding the disease and developing better treatments is so important.”

– Professor Paul Mitchell



National Research Advisor, Professor Paul Mitchell AO MBBS MD PhD FRANZCO FRACS FRCOphth FAFPHM

- We have sought to further diversify our research projects and recently funded research in diabetic eye disease for Aboriginal and Torres Strait Islander communities.
- A \$1 million Legacy Gift allowed us to establish the Grant Family Fund which provides \$100,000 every second year towards early career researchers for blue sky research projects.
- The launch of MDFA's inaugural baseline Macular Disease Impact Study in 2021 marked the start of a longitudinal study to better understand the impact of macular disease on people's lives, health literacy, motivations to reduce modifiable risk factors and more. The results will help shape improved policy and practice across the eye health system.



MDFA Grant recipient Prof Bamini Gopinath

PILLAR FIVE – BUILDING A STRONGER FOUNDATION

Goal: Wise capital investment for optimal social return.

Impact goal: MDFA activities grow in impact, cost effectiveness and quality.

Strategic priorities:

People, capital, footprint and capability, governance and compliance.

Key achievements:

- We have purposefully recruited skilled and experienced professionals across all areas of our work including people with Vision Science and Public Health qualifications, qualified optometrists, and other professionals with a track record in management and specialised skills.
- We have trained our volunteers to undertake new skills and leverage their lived experience to benefit members of our community.
- Our inaugural staff engagement survey shows an engagement index of 75% aligned with national benchmarks for all industries and despite extensive working from home arrangements since March 2020 due to the pandemic.
- MDFA secured \$3m in funding through a competitive tender process to implement many of the preventative health initiatives in the National Strategic Action Plan for Macular Disease.
- We expanded our fundraising team and were pleased to see significant growth in income from individual donors, Legacy Gifts, major gift givers and corporate investment in our work.
- While MDFA was established in Sydney, we are a national peak body. We now have staff also working in Melbourne and Canberra. We had eye health educators recruited for Queensland and WA but due to COVID-19 we have had to delay face-to-face education programs in those states.
- We have commenced a transformation program to upgrade our IT and business systems so enable us to scale our operations and support more Australians living with or at risk of macular disease.
- MDFA Board recently underwent a comprehensive skills audit. Recruitment is now underway to attract some skills gaps identified through this process that are needed to fully align with the new Strategic Plan.
- MDFA has consistently met our regulatory and legislative requirements.



Staff member Natasha Knopf



Our hard-working
volunteers



Jean Kittson,
Ambassador



Educating and engaging
with communities at risk
of macular disease

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