



MACULAR DISEASE FOUNDATION AUSTRALIA

ANNUAL REPORT 2019



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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 both past and present.

OUR VISION


Elimination of Preventable Blindness from Macular Disease

PILLARS OF WORK

Prevention & Early Detection



Supports & Services



Voice of the MD Community



Research & Data



IMPACT GOALS

More people at risk or living with MD self-identify & take early action

Self-agency & optimal quality of life for the MD community

Universal entitlement & treatment, rehabilitation and low vision support

Translation of research to support knowledge base for better patient outcomes

HIGHLIGHTS

HIGHLIGHTS 2018-19



Australia's first
National Strategic
Action Plan for
Macular Disease



8,500+ National
Helpline &
telecoaching calls



200,000 free patient
resources distributed to
community and health
care professionals



5,527 attendees
at 110 education
seminars



\$600,000 awarded to
three leading Australian
vision researchers and 5
completed projects



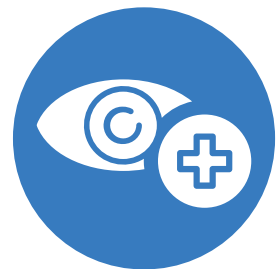
30 submissions
to government and
non-government bodies



1,500
volunteer
hours



Representation
at **36** advocacy
consultations



29 Eye health
professional conferences
and professional
development forums

PURPOSE

Reducing the incidence and impact of macular disease

On behalf of the Board and staff of MDFA, we are delighted to present this Annual Report for 2018-19, which outlines the numerous initiatives we have achieved for our community.

A major part of our work this year was the launch of Australia's first National Strategic Action Plan for Macular Disease. We thank our community and other stakeholders for their input to co-developing the Plan and look forward to working with government and others to implement the recommended actions.

Over the past 18 years, people with macular disease and their families have come to rely on MDFA as a trusted and independent expert for advice, support, information and resources. Our work is squarely focused on achieving positive impacts for our community.

In listening and working collaboratively with our community, we have undertaken several new projects across all pillars of our work including:

- A new Consumer Advisory Group – to inform and test new initiatives;
- Consumer survey to test and inform our representations relating to out-of-pocket costs for intravitreal treatment;
- A 'Peer to Peer' telephone check in service by volunteers with lived experience of macular disease;
- A refresh on our brand (look and feel);
- Real digital stories to reflect living optimally with a macular condition;
- New resources to enhance health literacy and better support people living with a macular condition;
- Training resources for Australian residential aged care providers and their staff to better detect and support residents with a macular condition.

We are honoured and privileged that Ita Buttrose, AC OBE, continues to be a generous Patron of MDFA. We also thank our partners and social impact investors in working with us in achieving our goals. Thank you for your support and passion and we look forward to the year ahead.



Dee Hopkins
Chief Executive Officer



Robert Kaye
Chairman

PREVENTION & EARLY DETECTION

Impact Goal: Improve health literacy and empower more people to self-identify and seek help when at risk of macular disease.

Enhancing Health Literacy – Changing Behaviour – Early Detection

Our outreach activities are designed to advance understanding of the risk, prevention and treatment of macular disease. We continue to raise awareness among families and carers as well as among those who are living with a macular condition.

Macula Month – family connections: are you next in line?

Macula Month is the centrepiece of our prevention and early detection activities and runs throughout May. Improved health literacy is proven to change behaviour in the over-50 age group. In 2007, one in three Australians were having an eye examination every two years. Now it's two in three. (YouGov Galaxy Polls 2016-19)

This year's national Macula Month campaign set out to address familial risk asking, "Are you at risk of macular disease?" If a parent or sibling has age-related macular degeneration (AMD), you have a 50% chance of developing it too – yet 63% of the general population don't even know that family history is a risk factor for AMD. MDFA commissioned a YouGov Galaxy poll again this year in addition to a survey of our own community.



The data revealed that only half of Australians diagnosed with AMD are aware of the hereditary connection. Of those, many underestimate the risk. A third of those with AMD who do understand the familial risk haven't told all relevant members. Just one in three patients recall being informed about the familial risk by their eye health professional.

Based on this evidence, MDFA set out to address these findings by sharing powerful stories and securing high-profile media coverage. We also teamed up with eye health professionals to increase awareness about the importance of regular eye examinations. Patron Ita Buttrose AC OBE shared her personal experiences in exclusive interviews with Sunrise, The Sunday Telegraph and 2GB. Top chefs, including Julie Goodwin, contributed recipes to our six-page 'Food for Eye Health' spread in The Australian Women's Weekly. Ambassador Jean Kittson featured in Woman's Day, also sharing her story in radio interviews and with online news outlets. MDFA also launched its first podcast series, 'See My World', with Ita as interviewer. The flagship episode, 'Jean's Genes', is available on iTunes and Spotify and details Jean's journey as a carer to her parents who live with macular disease.

Our new look and feel

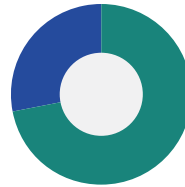
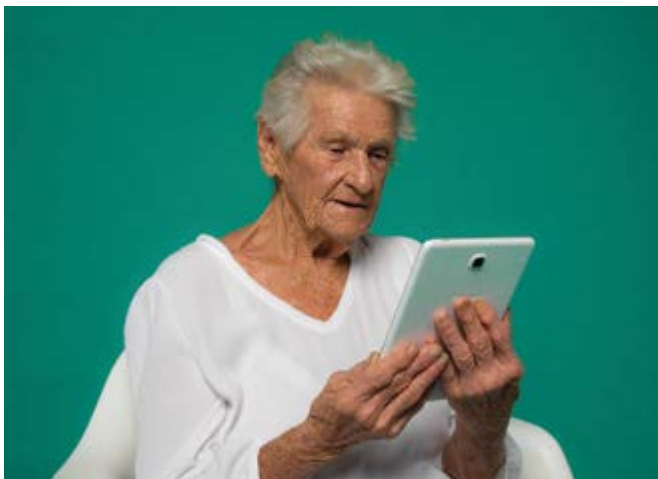
This year, we launched a new 'look and feel' to our communications and a refresh of the MDFA logo. We were delighted that members of our macular disease community participated in the photo shoot with their families and carers. The new colour palette is bright and bold to showcase that people living with macular disease can live well – especially with the right information and support at the right time.

Working Collaboratively with the Eye Health Sector

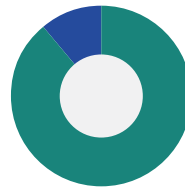
MDFA works across the ecosystem of eye health to promote early detection and to provide holistic support to those diagnosed with macular disease. By working collaboratively as part of an integrated care model, Australians with an early diagnosis can be better supported to improve their understanding of their condition, minimise vision loss and live optimally.

To promote the integrated care model, MDFA has invested in subscribing to Oculo – an online referral platform between optometrists and ophthalmologists and general practitioners. This enables health professionals to link consumers to MDFA when there is an identified diagnosis of a macular condition, for early support, free, relevant information and practical resources.

This year MDFA has delivered 29 presentations to eye health professional national and state conferences and professional development webinars including presentations to eye health professional student bodies. We also provided more than 154,000 free resources for patients of eye health professionals.



72% of Australians have heard of macular degeneration



89% of Australians aged 50 and over have heard of macular degeneration

"... people living with macular disease are extraordinarily stoic. They know their sight loss places a burden on their loved ones. I suspect that many people with AMD don't talk about the risk because they don't want the people they love to worry. But we must start talking about how this disease can run in families. My father had AMD. Two of his siblings were diagnosed with it. I'm at risk, which is why I am proactive about my eye health."

Ita Buttrose AC OBE,
MDFA Patron



154,000+ free resources to eye health professionals

SUPPORT & SERVICES

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

Optimal Quality of Life for Australians living with Macular Disease

Our supports and services aim to ensure Australians living with a macular condition can be equipped to adjust to changes in vision and live an optimal quality of life. Our 'support for life' services include:

- National Helpline and telecoaching service
- Navigation of government services
- Linkages to transport, low vision service options and community supports.
- Free information and resources
- Vision Voice newsletter
- Education seminars and events

Our telecoaching service via our National Helpline. It is designed to give people living with macular disease, their families and carers access to expert information and guidance throughout their journey. This year we supported more than 8,500 telecoaching calls.

Providing Australians with the 'right information at the right time' helps promote an optimal quality of life when living with a macular condition. We are delighted MDFA's National Helpline and telecoaching service support is highly valued:

"Thank you for all the information. I'm so happy I spoke with you. You do realise MDFA is lucky to have you as your tone, demeanour and professionalism are astounding. Brilliant!"

Improving Health Literacy

Understanding macular disease and improving health literacy can lead to better management now and in the future. We delivered education seminars across Australia with more than 5,800 attendees. Our seminars are designed to improve understanding of risk, living well with a macular condition and how to navigate optimal support and benefits from government and non-government agencies. We delivered 10 educational forums this year to 234 attendees from culturally and linguistically diverse groups including Cantonese, Mandarin, Portuguese, Greek and Vietnamese.

This year new outreach staff were appointed in Victoria and Queensland to reach more members of our community and to work collaboratively with eye health professionals in providing holistic support people living with or at risk of macular disease.





"On behalf of the Dural & District Prostate Cancer Support Group, I would like to thank you sincerely, for the most interesting talk you presented last night. It was indeed a most practical, candid and helpful presentation. The feedback from the group was enormously positive – all ticked 'extremely helpful' on the survey forms. Very good information, fluid, easy to follow. Excellent – thank you."

New Peer to Peer Tele Service

MDFA is fortunate to have more than a dozen loyal volunteers who have a lived experience of macular disease as a patient, carer or who have an interest in supporting MDFA's work. Most of our volunteers have now undertaken a training program to provide a new Peer to Peer telephone 'check in' service to members of our community – particularly to those who are socially isolated. The program aims to empower the community to live as optimally as possible with macular disease. Feedback to date has been very positive and we look forward to seeing this program grow in the coming 12 months.

Right Information – Right Time

The information and resources produced by MDFA are overseen and approved by our Medical Committee – comprising Australia's leading experts in ophthalmology and eye health. We assess individual needs so that information is tailored. This year there was a significant increase in requests for information in electronic format.

We produce and distribute more than 30 different booklets, fact sheets and resources in multiple languages. This year we distributed 45,000 free resources to the community.

MDFA's popular and informative Vision Voice newsletter now has more than 44,000 subscribers. This is distributed electronically, by post and in CD format.

VOICE OF THE MACULAR DISEASE COMMUNITY

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

Advocacy – Collaboration – Influence

MDFA is the national peak body for the macular disease community. As the representative voice, we influence Australian health, aged care and disability agendas to improve outcomes for patients, their families and carers.

We work with government and non-government organisations to tackle system change and champion quality of life, ensuring that sight-saving treatments and support are accessible and affordable.

Our representations are evidence based. We collaborate with a number of organisations to action changes that are important to our community, including the National Aged Care Alliance; NSW Agency for Clinical Innovation Ophthalmology Network Governing Body; NSW Non-Government Organisation Advisory Committee; and KeepSight Reference Group.

We work closely with Vision 2020 Australia, the peak body representing sector stakeholders, and serve as an active member of three sector committees: Aboriginal and Torres Strait Islander Eye Health Committee, Independence and Participation Committee, Prevention and Early Intervention Committee.

MDFA presented to the Medicare Benefits Schedule (MBS) Review Taskforce Ophthalmology Clinical Committee seeking more equitable and accessible anti-VEGF treatment options across Australia, including more affordable treatment options.

We proposed extended MBS rebates for Optical Coherence Tomography (OCT) to monitor ongoing treatment and address out-of-pocket expenses for patients.

MDFA made 25 submissions to the Commonwealth Government, including:

- Productivity Commission National Disability Agreement Review
- Medical Research Future Fund (MRFF) 2018-2020 Priorities Consultation
- Terms of Reference for the Royal Commission into Aged Care Quality and Safety Consultation
- Draft Charter of Aged Care Rights Consultation
- Joint Standing Committee on the National Disability Insurance Scheme (NDIS) Inquiry into Assistive Technology
- Federal Pre-Budget Submission
- Streamlined Consumer Assessment for Aged Care Consultation
- New National Disability Strategy Consultation

MDFA provided input and support to 19 submissions in collaboration with other peak bodies, including:

- Strong Eyes, Strong Communities – A Five Year Plan for Aboriginal and Torres Strait Islander Eye Health and Vision, 2019-2024
- Vision 2020's submission to the Royal Commission into Aged Care, Quality and Safety
- Data and costs associated with a proposed national vision aids and technology program, as outlined in the National Strategic Action Plan for Macular Disease
- A number of Vision 2020 policy submissions

We consulted with our community on the impact of out-of-pocket costs for intravitreal treatment by holding a focus group and conducting a survey.

The National Strategic Action Plan

MDFA developed the first National Strategic Action Plan for Macular Disease (Action Plan), aligned to the 2017 National Strategic Framework for Chronic Conditions. The Action Plan also builds on the World Health Organization (WHO) international action plan 2014-2019, which sets out a global target of reducing the prevalence of avoidable visual impairment by 25%.

Funded by the Australian Government, MDFA co-developed the Action Plan in collaboration with stakeholders including those living with macular disease, leading eye health professionals, researchers, other peak bodies and service providers.

Four areas for action lie at the heart of the Action Plan: prevention and early detection; treatment; support; and data and research. It acts as a roadmap to promote greater partnership and collaboration across the eco-system, ensuring limited health care resources are better targeted for optimum patient outcomes. There are 44 action points, which include:

- Advancing understanding of macular disease through targeted education campaigns, training and support for health professionals and the public
- Improving access to public hospital services by reviewing and increasing current services for macular disease in collaboration with State and Territory governments
- Creating a National Macular Health Patient Portal that will empower those living with macular disease to self-manage and access innovative, practical support, including care plans tailored to diagnoses; interactive e-education such as live webinars and Q&As; and online peer support forums
- Developing a national research agenda and increasing funding for eye health.

The Minister for Health, the Hon Greg Hunt MP, launched the Action Plan in March 2019 in recognition of the impact of macular disease in Australia. It is accompanied by a \$3 million funding commitment over four years. Governments will use the Action Plan to prioritise efforts to tackle macular disease as the leading cause of legal blindness and severe vision loss in Australia.

MDFA's National Research Advisor, world-leading ophthalmologist Professor Paul Mitchell AO said: "As our population ages... 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 healthcare system, which is why this Action Plan is so important."

The input from so many stakeholders from across the macular disease ecosystem is what makes this Action Plan so effective. MDFA thanks all those who contributed to the development of the Action Plan, including the advisory committee, encompassing leadership representation from: Optometry Australia; the Royal Australian and New Zealand College of Ophthalmologists (RANZCO); Vision Australia; and Vision 2020 Australia.



#1 national roadmap for macular disease



44 action points



\$3m committed by the Minister for Health

The launch of our Consumer Reference Group saw valued input from eight community members with lived experience of macular disease.

Thank you to Ashley Chapman, Des Morton, Gillian Prikulis, Jenny Solomon, Jim Pringle, Peter Wilkinson OAM, Richard Grills, Robert Prikulis and Val Nicholson, whose advice, guidance and feedback helps to ensure that our work reflects the needs of the macular disease community.



"It has taken me a while, but I'm not scared to ask for help now."

Elisabeth's story: Help is there when you need it

Learning has been a lifelong passion for 84-year-old Elisabeth, but one of her hardest life lessons came after her diagnosis of age-related macular degeneration (AMD).

She learnt to ask for help.

Initially diagnosed with AMD in her 50s, Elisabeth now has wet (neovascular) AMD in both eyes. Early detection, constant vigilance in monitoring her macula and regular anti-VEGF eye injections have allowed her to retain most of her sight.

"I have good days and bad days, but my sight is good. Honestly, I don't consider myself to be visually impaired... unless it is to my advantage, like getting a seat in the train," Elisabeth says with a laugh.

Despite her jokes, Elisabeth has made significant – and practical – changes to accommodate her AMD. She moved from a small hobby farm to town, near a bus stop, in case she lost her driver's licence.

She's never without sunglasses and a broad-brim hat when outdoors. She uses an identification cane when travelling so others know she has reduced vision. Elisabeth regularly turns to visual aids such as magnifiers. Although she can still read, she's learnt Braille – just in case. Importantly, she's also learnt to reach out when she needs help.

"It has taken me a while, but I'm not scared to ask for help now," Elisabeth concedes.

Elisabeth is in regular contact with MDFA and has occasionally joined MDFA's team for education seminars. By sharing the story of her journey with macular disease, she knows she is helping raise awareness and encouraging people to have regular eye exams.

MDFA provides information, advice and well-being coaching through its National Helpline on 1800 111 709. This is a free service available to people living with or at risk of macular disease, their families or carers.

RESEARCH & DATA

Impact Goal: Translation of research to support the knowledge base for better patient outcomes

Knowledge - Evidence - Impact

MDFA is the leading not-for-profit organisation funding macular disease research in Australia.

We conduct and invest in cutting-edge projects that help to further our understanding of macular disease and its causes and explore new treatment options.

We launched our Research Grants Program as a strategic priority in 2011. By supporting leading Australian researchers, we hope to help reduce the incidence and impact of macular disease - and, eventually, to find cures. To date, MDFA has committed \$3.6 million to 15 researchers and 18 studies. Up to \$600,000 has been allocated to the next round of funding with applications having opened in March 2019. The successful recipients were announced on World Sight Day in October 2019, outside this reporting period.

At the time of reporting, there were five ongoing studies: Professor Alice Pébay, (University of Melbourne), Professor Erica Fletcher (University of Melbourne), Dr Fred Chen (University of Western Australia), Associate Professor Bamini Gopinath, (University of Sydney) and Associate Professor Wilson Heriot (University of Melbourne).

Completed projects

Dr Laura Downie, University of Melbourne

Title: Advancing eye care for people with age-related macular degeneration (AMD) through integrating clinical research and its translation.

Project: Clinical audits improve care for patients by identifying practice patterns and shortfalls. Dr Downie recognised a lack of audit tools for optometrists and was allocated funding to enhance eye care for AMD patients. The project set out to develop an online self-evaluation tool that could be used by optometrists: the Macular Degeneration Clinical Care Audit Tool (MaD-CCAT). The aim was to capture data that could be analysed to identify AMD care patterns and inform optometric education programs. Dr Downie's pilot program is the first evaluation of current AMD practice patterns among Australian optometrists.

Outcome: In May 2018, the MaD-CCAT was launched at the Southern Regional Congress (SRC) in Melbourne. It is believed to be the world's first primary care clinical audit tool for AMD. The MaD-CCAT is now being piloted in optometry practices and has provided audit data for more than 300 patients in five Australian states, capturing important elements of clinical care, including the identification of modifiable risk factors, accuracy of diagnosis and referral timelines.

Going forward, the MaD-CCAT can be integrated into tertiary training programs, implemented in ophthalmology practice and expanded to enable clinicians to audit for other forms of macular disease. It also has the scope for its use to be expanded across Australia and New Zealand. This research resulted in a number of articles, in addition to seminars, presentations, webinars, exhibition booths and a peer-reviewed paper.

Professor Mark Gillies, University of Sydney

Title: How to get the best outcomes of treatment of neovascular age-related macular degeneration with vascular endothelial growth factor inhibitors: Real World Evidence

Project: Professor Gillies studied wet AMD treatment outcomes in order to identify the best options for managing the disease. The research was a continuation of the Fight Retinal Blindness! (FRB!) project, a clinical web-based registry that tracks retinal disease data.

Outcome: The FRB! Project has reported several real-world clinical findings for the treatment of wet AMD that are relevant for clinicians and patients, most notably a direct comparison of real-world outcomes of patients being treated with the two leading anti-VEGF drugs. The project also analysed treatment patterns and outcomes during the maintenance phase of treatment, and outcomes following various adverse and ocular events.

The project has provided a concise summary of the treatment journey over time for individual patients with wet AMD, to aid the decision making process. The extensive analysis from the large observational database has set an international benchmark for how the best outcomes for wet AMD can be achieved in real world clinical practice.

A high number of journal articles were produced to help establish best practices for treating AMD. Six have recently been accepted and a further 11 have been published. The FRB! project continues to expand internationally, acquiring data for other retinal diseases such as diabetic macular edema (DME) and retinal vein occlusion (RVO) as well as AMD. There is potential for global outcomes to be measured, comparing Australia to other participating countries.

Associate Professor Isabelle Jalbert, University of New South Wales (UNSW)

Title: Eye care practitioners and patients' perspectives on age-related macular degeneration (AMD): Identifying barriers and facilitators to optimal AMD care.

Project: This project explored the views, knowledge, attitudes and practices of eye care practitioners, people with AMD and their carers. Modifiable factors such as smoking and lifestyle have been shown to increase the risk of developing the disease and the speed at which it progresses. There are clear, evidence-based recommendations for patients and those at risk, but reports show that eye care practitioners' advice and patients' adherence to the recommendations can be poor. The research identified barriers and facilitators for optimal care, as well as knowledge and understanding of modifiable factors, and targeted health interventions that should be planned in the future.

Outcome: This project has progressed understanding of the effectiveness of translation of knowledge from research into practice, from the perspective of people with AMD and those involved in their care. It has also helped to identify the key barriers to appropriate AMD care and produced recommendations for change and improvements. The research resulted in a major publication and numerous research outputs.



Professor Steven Krillis AM, University of New South Wales (UNSW)

Title: Novel Mechanisms of Complement Control Protein Dysregulation Contributing to AMD Pathogenesis and Progression: CFH and Beta 2-glycoprotein I (B2GPI)

Project: Although we know that factors such as age, the environment and genetics cause the disease, treatments are limited and so further research into how damage occurs is required. Funding was awarded to study two proteins (CFH and B2GPI) found in the retina of AMD patients, with the aim of preventing damage and progression.

Outcome: CFH and B2GPI were found to be essential to the regulation of inflammation. If these proteins changed due to genetics or external influences such as ultraviolet light, their function is affected, resulting in an increased risk of AMD. The research identified an important in-vitro method for modifying the activity of these proteins in the same way that they change in the human eye and developing a test to measure the levels of the modified proteins in the blood of AMD patients. The findings will be useful when identifying patients at risk of developing the disease. Monitoring CFH and B2GPI levels could also provide a marker to establish whether treatment is effective.

Two journal articles were published in relation to this project. Further research into CFH and B2GPI in AMD is planned.

Associate Professor Gerald Liew, University of Sydney

Title: Deciphering the metabolomics signature of age-related macular degeneration to discover pathogenic pathways.

Project: This project was a pilot study analysing the systemic metabolites that are altered as a result of AMD. Metabolomics is a new area of medical research involving analysis of large amounts of data on metabolites from patients to generate hypotheses about the disease process, which can then be tested. The aim of the research was to investigate whether certain metabolites could enable the development of a simple blood test that could be used as an early marker for disease progression.

Outcome: This project has highlighted the role of dietary nutrients in the cause of AMD. New protocols for the collection, preparation, storage and analysis of blood for metabolomics experiments have been developed. Metabolites from the plasma of patients with AMD have been analysed for better understanding of their involvement in the cause and progression of disease. Two publications have resulted from the project, with further research planned to continue exploring the role of metabolites in the cause of AMD.

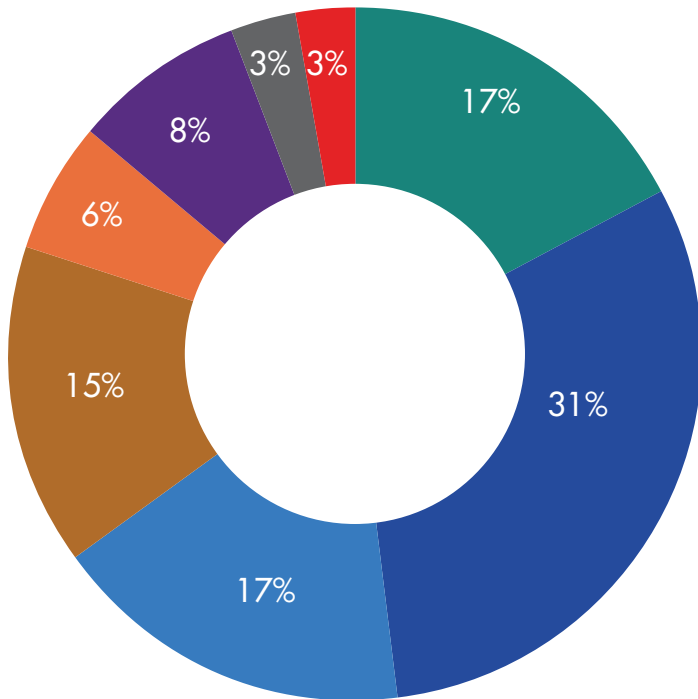


\$3.6 million allocated to Australian researchers since 2011



\$600,000 allocated to 2019 round of research grants

MDFA-funded research expenditure on AMD to June 2019



- Carers
- Improving patient care and treatment
- Causes
- Improving early detection and diagnosis
- Risk factors
- Retinal cell repair
- Stem cells
- Genetics

E-resources for Residential Aged Care Facilities

This year, MDFA released electronic resources for Residential Aged Care Facilities (RACFs). The digital training tools followed our landmark research report, 'Vision and Eye Healthcare Study in Residential Aged Care Facilities', which was funded by the Australian Government Department of Health and published in 2018.

Launched with a video featuring the Hon Ken Wyatt AM MP, former Minister for Senior Australians and Aged Care, the e-resources aim to help improve understanding of eye health and vision loss.

These include a video and resources for care workers, in addition to resources for management and health professionals, families and guardians. Their reach and effectiveness will be evaluated from a follow-up survey, to be conducted in the next financial year.



"It's important for aged care providers, important for aged care workers and important, fundamentally, to the many senior Australians living with vision loss."

Hon Ken Wyatt AM MP

OUR COMMUNITY

**Transparency –
Accountability –
For Purpose**

The support from generous funds received from donors, bequestors, Government and corporate partners is inspiring. This generosity supports talented researchers in their life-changing work and will continue to empower the macular disease community well into the future. Donations play a valuable role in the prevention, early detection and improved treatment of people with macular disease, and help prevent people from unnecessarily losing their sight. By working together, we can change the lives of those at risk or living with macular disease.



Roth Gair Golf Day

Now in its 12th year, the Roth Gair Golf Day has raised over \$125,000 for macular disease in memory of Roth Gair who lived with age-related macular degeneration.

Annual Report **2019**

Thanks to the Lions Club of Forest Hill, Ian Kennedy, the Gair family, and to all the volunteers and sponsors for their continued generosity and support.



Through Her Eyes

Australian jazz musician Dan Barnett was so grateful that his late mother Joan had access to sight-saving treatment for wet age-related macular degeneration that he is donating a portion of proceeds from his latest CD to MDFA.

Dan's 8th CD is called 'Through Her Eyes' and was recorded as a tribute to his late mother, Joan. It brings together Sydney jazz legends, with Dan leading the ensemble through a perfect selection from the Great American Songbook.

Dan describes recording the album as a "cathartic experience... I just wanted to put a positive spin on losing my mum. I thought 'what can I do that would make mum happy and I know she was so thankful that she could get treatment'."

Dan said his mother had regular eye injections and was able to maintain good vision until the day she died.

'Through Her Eyes' is available through Dan's website: www.danbarnett.com.au/cds/ or jazz music outlets.



Volunteers

MDFA volunteers just get on with the job at hand. While some of our trusted volunteers are living with low vision and legal blindness, it doesn't stop them from rising to meet the challenge of work every week. More than 1,500 hours of time were donated to support the work of MDFA. A new Peer to Peer program has sent our volunteers in a new direction, as they now provide a friendly follow up call to members of the community who have been newly diagnosed and who have requested information. Our Peer to Peer volunteers are a friendly voice at the other end of the phone checking in to see that everything's okay.



Photo courtesy of Whyalla News

Champion bowler breaking down barriers

After losing most of his vision to age-related macular degeneration (AMD), South Australian lawn bowler Bill Hunt almost gave the game away. But a year of sitting on the sidelines, while his wife continued to play the sport he loved, was enough to convince Bill that he didn't like missing out.

Now, 72-year-old Bill is once again a regular pennant winner at the Whyalla Bowling Club.

"It's a hard transition from seeing something to not seeing, but you have to adjust... if you can make it through that transition period, you will carry on."

With dark patches in his central vision and blurred side vision, Bill relies on other players to tell him where the kitty is on the rink.

"I picture that in my mind and I bowl to that. All the guys and ladies that I bowl with know what I need, and they tell me if I'm long or short and then I correct that," Bill explains.

Bill first noticed changes in his sight in 2004. An optometrist confirmed he had AMD, the leading cause of blindness and severe vision loss in Australia. The risk of AMD increases dramatically with age and there's a 50% risk of developing AMD if you have a parent or sibling with the disease. Bill says his mother "had bad eyes, but we didn't know about AMD in those days".

"Most bowling clubs are full of elderly people," Bill said, "and they are most at risk... get your eyes checked straight away. If you have macular degeneration, these are the cards you have been dealt with and you have to go out and make the best of it; make what you can out of living with it."

GOVERNANCE

Patrons & Ambassadors



Ita Buttrose AC OBE

Patron



Jean Kittson

Ambassador



Jan Utzon

Ambassador

National Patron since 2005, Ita has led the charge in reminding all Australians to have their maculas checked.

This year, Ita was joined by Ambassador Jean Kittson to record a powerful podcast titled, 'Jean's Genes'. Speaking to Jean's role as a carer for her mother Elaine, who lives with age-related macular degeneration (AMD), and her father Roy who has macular dystrophy – both of whom are in their 90s. Ita and Jean discuss the familial risk of macular disease and the journey as a carer for loved ones living with this condition.



Macular Disease Foundation Australia is grateful to Governors of Australia who, as MDFA's State Patrons, support our work to increase awareness of macular disease in their communities.

- **The Honourable Linda Dessau AC:**
Governor of Victoria. State Patron of MDFA in Victoria.
- **The Honourable Kim Beazley AC:**
Governor of Western Australia and State Patron of MDFA in WA.
- **Professor the Honourable Kate Warner AC:**
Governor of Tasmania and Tasmanian State Patron.
- **The Honourable Hieu Van Le AC:**
Governor of South Australia and MDFA South Australian Custodian of Vision.

GOVERNANCE

Board Directors



Mr Robert Kaye
SC LLM LLB AICD

Robert is a barrister, mediator and professional non-executive director and, as Board Chair, provides MDFA with a strong emphasis on Board governance and processes.



Mr Richard Grills

Founder of Designs for Vision, a Director of the Optical Distributors & Manufacturers Association and the Genetic Eye Foundation and Chair of the Essilor Vision Foundation.



Mr Neil Wykes
OAM BCom FCA AGIA ACIS

Neil is a senior executive with more than 50 years experience in the finance and accounting services sector. He recently retired from the position of General Manager, Audit & Risk for Ramsay Health Care and has been involved with MDFA since 2001.



Ms Imelda Lynch
RN BN MHSM GAICD

With a background in nursing, Imelda has extensive executive and health administration experience in both the public and private health sectors.



Associate Professor Nitin Verma AM FRANZCO MD MMed Dip NBE

A/Prof Verma is a leading ophthalmologist with a special interest in retinal disease. He holds several university appointments, is in private practice and is a board member and Fellow of RANZCO.

GOVERNANCE

Board Directors



Brigadier John Fenwick
BA MBA GAICD AFAIM

With a distinguished military career, John is a graduate of the Australian Institute of Company Directors and an Associate Fellow with the Australian Institute of Management.



Ms Lisa Lusthaus
BSc App. Psych (Hons)

Lisa is Council Secretariat at the Centre for Social Impact, UNSW. She has a background as a clinical researcher, as a Research Psychologist and as a publisher.

National Research Advisor



Professor Paul Mitchell AO
MBBS MD PhD FRANZCO FRACS
FRCOphth FAFPHM

Internationally renowned as a champion of ophthalmic research, MDFA's National Research Advisor Professor Paul Mitchell AO is Director of the Centre for Vision Research, Westmead Millennium Institute. He is a Professor of Sydney University, and Director of Ophthalmology at Westmead Hospital.

COMMITTEES

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
A/Prof Nitin Verma AM
A/Prof Peter van Wijngaarden
A/Prof Dimitri Yellachich

Research Committee

A/Prof Nitin Verma AM (Chair)
A/Prof Anthony Kwan
Ms Imelda Lynch
A/Prof Peter van Wijngaarden

Audit and Risk Committee

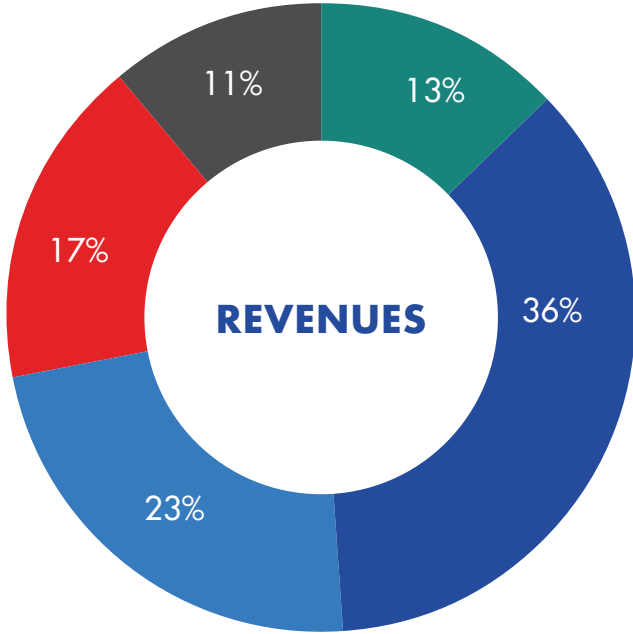
Mr Neil Wykes OAM (Chair)
Mr Ashley Chapman
Brigadier John Fenwick
Mr Robert Kaye SC
Mr Paul Rogan

State Chairs

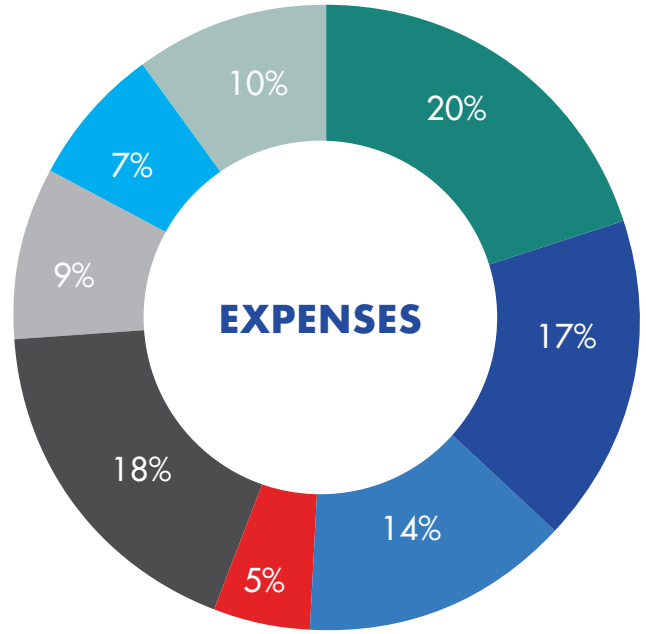
Dr Amanda Greaves (QLD)
A/Prof Wilson Heriot (VIC)
A/Prof Nitin Verma AM (TAS)
Ms Imelda Lynch (SA)
A/Prof Alex Hunyor (NSW)



FINANCIALS



- Sponsorship
- General donations & bequests
- Research donations & bequests
- Government grants
- Investments



- Services and community support
- Prevention and early detection
- Research grants
- Research activities
- Operational costs
- Education
- Advocacy
- Fundraising activities

Note: Investment income includes \$214,000 in unrealised gains on investment.

SUPPORTERS

Clubs - Club Grants

Goulburn Soldiers Club
Dubbo RSL Club

Estates

The Estate of the late :
Margaret Beaumont
Frank and Gwen McIntosh
Faye Grant
Lillian Margaret Johnson
Doris Walker

Organisations

Hobart Eye Surgeons
North West Eyes - Dr David Moore

Individuals

Richard Williams
Shirley Felsch
Beryl Percival
Peter Strang
Imelda Lynch
Barbara Douglas
Sarah (Sally) White
Jill Roberts
Janice Waddington
W.L. Turnbull
Helen Finn
Beverley and John Harvery
Linda Thomas
F Perez de la Sala
Sheryn Foord
Anthony David Corp
Sara Darling
Alan and Cecilia Calder
Colin and Feng Hall
Gregory Sachs
Owen and Judy Roberts

Trusts & Others

The McBriarty Family
Fitzpatrick Sykes Family Foundation

SUPPORTERS

Government Support

Thank you to the Commonwealth and NSW governments for their continued financial support through the following avenues:



Australian Government

Proudly funded by



The Commonwealth Department of NSW Health, Peak and Advisory Bodies Program, which supports the development and communication of relevant evidence-based information for the macular disease community, health providers, government and other related stakeholders.

National Action Plan funding, for the development of a strategic direction around the management, prevention and treatment of 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 enable the delivery of key initiatives and activities (in alphabetical order).



Science For A Better Life

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

BLACKMORES

A valued supporter over the past 14 years, Blackmores funds awareness, research and health promotion programs run by MDFA.

JBWere

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

SUPPORTERS



King & Wood Mallesons support MDFA's good governance with pro-bono legal direction.



Novartis has been a major contributor to our awareness and support services programs since MDFA's establishment.



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



Profield Foundation has been a long-term supporter of MDFA, helping to fund frontline client services, including the Helpline, MDFA publications, and awareness and education activities.



Quantum RLV, a founding supporter of MDFA.



We welcomed Specsavers as a new financial supporter in 2018. Specsavers funding will enable the development of new macular disease initiatives.



**Macular
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Foundation**
AUSTRALIA

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