

**MACULAR DISEASE FOUNDATION AUSTRALIA
ANNUAL REPORT 2018**



Our focus is your vision



TABLE OF CONTENTS

STRATEGIC GOALS	3
HIGHLIGHTS	4
GOVERNANCE	6
PREVENTION & EARLY DETECTION	12
SUPPORTS & SERVICES	18
VOICE OF THE COMMUNITY	24
RESEARCH & DATA	30
FUNDRAISING	36
FINANCIALS	45
DONATIONS	47

MACULAR DISEASE FOUNDATION AUSTRALIA

Our Vision: Elimination of Preventable Blindness from Macular Disease

Our Pillars of Work

Prevention
and Early
Detection



Supports
and Services



Voice of
the Macular
Disease
Community



Research
and Data



Impact Goals

More people
at risk 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
for treatment,
rehabilitation
and low
vision support

Translation
of research
to support
knowledge
base for
better patient
outcomes

INSPIRING INDEPENDENCE IN PEOPLE WITH LOW VISION



“There are some great services there that are provided. Don’t allow yourself to be trapped. Get out there in the community... Macular Disease Foundation can provide technical and qualified support for the various problems and challenges we face.”

Lorin Nicholson has made a living assuring people he meets that going blind “really isn’t the end of the world.” He’s living proof.

49-year-old Lorin has about five per cent vision due to retinitis pigmentosa, a genetic eye disorder that causes the retinal cells to stop working and die. Two of his five siblings also have the condition.

Despite the enormous challenges, Lorin has become one of Australia’s most inspirational motivational speakers, an award-winning

musician, a best-selling author and an experienced health professional.

In 2010, Lorin and his younger brother Dean created history, becoming the first blind people to ride more than 4,100 kilometres in an epic four-week journey from Perth to Sydney.

“The hardest challenge that you face going blind... is initially that fear of the future and a big part of that is the loss of independence.









“We live in a sighted world where we become so reliant

on what we are seeing that we forget there are some amazing other strengths and abilities that can compensate so well... it’s not until you are forced into that situation that you realise it really isn’t the end of the world,” Lorin said.

Lorin said a supportive home environment that didn’t wrap a low vision family member in cotton wool was important for encouraging independence. He urged people with low vision and their families to seek the support of the MDFA.

HIGHLIGHTS 2017-18



-  Funding received for a National Action Plan for macular disease
-  Launch of 'The Journey to See', a 10-year case study on the treatment and management of macular disease in Australia
-  Macula Month takes over May, replacing Awareness Week
-  6,727 inbound calls to the MDFA Helpline
-  21,393 information packs sent out to our community
-  446,935 resource materials sent to health care professionals, clubs and organisations
-  6,633 people attended 131 education seminars to community and health care professionals
-  \$600,000 in research grants awarded to three leading Australian vision researchers

PATRONS



Ita Buttrose AO OBE

Widely admired as one of Australia's most successful businesswomen and an accomplished communicator, Ita has been a tireless advocate in raising awareness of macular disease since becoming Patron of MDFA in 2005.

"I can't stress enough how important it is to get your macula checked, particularly for people with diabetes and baby boomers - it could save your sight."



Her Excellency the Honourable Linda Dessau AC

Governor of Victoria. State Patron of MDFA in Victoria.

"The impact of vision loss from macular disease on quality of life is equivalent to cancer or coronary heart disease. I am honoured to support the work of MDFA in Victoria."



Her Excellency Professor the Honourable Kate Warner AC

Governor of Tasmania and Tasmanian State Patron.

"I'm delighted to be able to help MDFA continue its vital work in Tasmania - eye tests are crucial for early identification of macular disease such as diabetic retinopathy and AMD."



His Excellency the Honourable Hieu Van Le AC

Governor of South Australia and MDFA South Australian Patron.

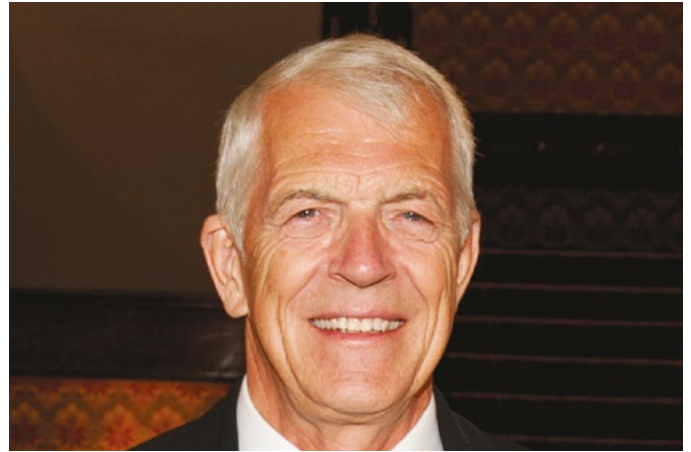
"As a Custodian of Vision, I'm honoured to support MDFA in its quest to raise awareness and find cures for the various macular diseases that can have devastating impacts on people's lives."

AMBASSADORS



Jean Kittson
**Celebrity performer, author and
 keynote speaker**

"I know how important it is to do everything we possibly can to keep our eyes healthy and also to support MDFA in the incredibly important work that they are doing."



Jan Utzon
**Architect and son of Sydney Opera House
 designer, Jørn Utzon**

"I can only urge everyone to have their macula checked and, very importantly, urge our society to make a greater effort to find a cure."

Thank you for your support



The Honourable Kerry Sanderson AC
**Governor of Western Australia and State
 Patron of MDFA [until May 2018]**

The Hon Mrs Sanderson became one of MDFA's Custodians of Vision soon after being appointed Governor of Western Australia. MDFA thanks her for participating in our awareness campaigns.

WORKING TOWARDS ELIMINATION OF PREVENTABLE BLINDNESS



Robert Kaye
Chairman



Dee Hopkins
Chief Executive Officer

We are delighted to present the 2017-18 Annual Report, which speaks to our position as Australia's representative body for the macular disease community.

This year we farewelled former CEO, Julie Heraghty and thank her for her terrific and tireless work for more than a decade.

We also thank retiring Board members Mr Paul Rogan and Mrs Suellen Tapsall as well as Dr Jim Runciman, who has retired from the Medical Committee.

In February, we conducted a large survey of our community to better understand needs.

The new CEO, together with the Board and staff, have developed a new Strategic Plan, which will work towards more engagement with our community and, over time, introduce better supports and

new initiatives with backing from our partners.

A highlight this year was the announcement by Minister for Health, Hon Greg Hunt, of funding for MDFA to develop a National Action Plan for Macular Disease.

This plan will be delivered to the Minister in December 2018. We thank the members of the community, our partners and industry leaders who are contributing to the development of this important work that sets some ambitious goals for the next five years for better data and research, preventative and early detection, treatment and support.

This year we extended our national awareness program Macula Month including the launch of 'The Journey to See' – a report showcasing Australia's world leading outcomes for the treatment of age-related macular degeneration over the past decade.

We look forward to progressing our new vision and goals through the next decade side by side with our community, donors, partners and government and thank them for their ongoing investment in our important work.

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.

Board Directors



Brigadier John Fenwick **BA MBA GAICD AFAM**

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, National Research Advisor Prof. Paul Mitchell was this year honoured as an Officer of the Order of Australia for distinguished service to ophthalmology.

He was typically humble about the recognition, instead preferring to draw attention towards the need for further research into macular disease.

Prof. Mitchell 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. As National Research Advisor, Prof. Mitchell provides the Foundation with expertise, support and guidance on the analysis of medical and research matters.

Committees

Medical Committee

A/Prof Alex Hunyor (Chair)
 Dr Amanda Greaves
 Dr Alex Harper
 Dr David Hilford
 A/Prof Wilson Heriot
 A/Prof Nitin Verma
 Prof Paul Mitchell
 Dr Tharmalingam Mahendrarajah
 A/Prof Dimitri Yellachich
 A/Prof Anthony Kwan
 Dr Peter van Wijngaarden

Research Committee

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

Audit and Risk

Neil Wykes (Chair)
 Paul Rogan
 Ashley Chapman
 Robert Kaye
 John Fenwick

Client Services Committee

Imelda Lynch (Chair)
 Richard Grills
 Ashley Chapman

State Chairs

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



PREVENTION & EARLY DETECTION

Increasing Awareness - Changing Behaviour - Impacting Lives

The focus of MDFA is to build a better understanding of the risk, prevention and treatment of macular diseases.

We are targeting not just those who are living with macular disease and vision loss but their families and carers. Our aim is to ensure more people at risk of macular disease self-identify and seek help.

In 2017-18, our outreach and public education activities included mass marketing campaigns, pitched to a national audience, and personalised face-to-face education sessions.

MDFA continues to capitalise on technology to expand our reach, developing robust social media campaigns to support specific initiatives as well as educate our online community. Our social media platforms are specifically aimed at growing a new audience and engaging with carers and families of those living with macular disease.

Macula Month

The centrepiece of MDFA's outreach program, held in May, is the annual awareness campaign, which asked 'Are you at risk of macular disease?' In 2017, the campaign was extended from a week to take over a whole month - Macula Month.

Over the past 15 years, the level of awareness of age-related macular degeneration (AMD) has changed behaviours in Australians over the age of 50.

In 2007, one in three Australians in the 'at risk' age bracket was having an eye test every two years. That's now increased to two in three, with 85 per cent of people over 50 aware of macular degeneration.

But there's more work to be done, particularly to shine the light on other macular diseases. A YouGalaxy poll, commissioned for MDFA and released as part of Macula Month, provided concerning statistics. It highlighted the disparity between those living with diabetes and those understanding that they are at risk of diabetic eye disease.

The polling also showed that awareness of macular disease and macular degeneration is driven by age.

"I have noticed a significant increase in public awareness of the need to get any sudden alteration in vision checked as a matter of relative urgency.

"This has applied not only to macular degeneration but also to other conditions that affect central macular vision such as retinal vein occlusions, retinal arterial blockages, macular holes and tractional syndromes etc.

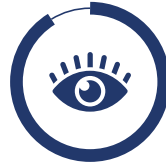
"The MDFA should receive credit for the significant role it has played in changing consumer behaviour. As an organisation it has made a valuable contribution in lifting people's awareness of macular disease and driving people at risk to get more comprehensive eye tests.

"This has enabled corrective treatments to be applied earlier in the course of the disease with consequent better outcomes."

Professor Ian McAllister, Lions Eye Institute, Western Australia



85% of people over 50 have heard of macular degeneration



91% of Australians are unsure or unaware of the function of the macula



13% of Australians wrongly attribute macular disease to muscles



60% of people diagnosed with diabetes do not know what the macula's function is



64% of diabetics are unaware that the eyes can be affected by diabetes



23% don't know what to do to reduce the risk of macular disease



Eating for eye health

One of the most popular initiatives to emerge from Macula Month was our e-cookbook, **Macula Menu**. The free booklet features a range of recipes, all aimed at either supporting a healthy macula or general wellbeing. Contributions were made by famous personalities, celebrity chefs and members of our community.

In Macula Month alone, more than 1,000 people downloaded the **Macula Menu** from our website. Importantly, almost half of these asked to stay in touch with MDFA.

mEYE World Photographic Competition

The MDFA received over 1,000 entries for the 2017 mEYE World Photographic Competition, which gave photographers the brief "In Your Own Backyard."

The distinguished panel of judges - MDFA Patron Ita Buttrose, internationally recognised photographer Rex Dupain and Australia's longest-serving news photographer Alan Pryke - selected Bettina Damme's image 'Pollen Face' as the Grand Finalist. Other winners were Dr Edwin Lim (Healthcare Professionals category); Jen Stocks (Macular Disease category); and Zara Jozsa (Junior category).



Public Education Seminars

The MDFA hosts macular disease and low vision education sessions across Australia via general public sessions and community group presentations. These education sessions are free and interpreters are used when needed. During the reporting period, MDFA education officers travelled to five states, visiting both metropolitan and regional areas.



111 public and community education sessions, with **5,684** attendees

Of these:



23 sessions were delivered to the general public, with **1,171** attendees



80 sessions were delivered to community groups, with **4,174** attendees



8 sessions were delivered to culturally and linguistically diverse (CALD) groups including Chinese, Greek, Vietnamese, Arabic and Italian, with **339** attendees



8 expos were attended in Sydney and Perth, with **2,168** attendees

"Very informative. Feeling confident for the future with all the help available."

Jan, public education seminar, NSW

"Thank you for the info, it is something I have not thought much about. I will now make an appointment for my husband and I!"

Maria, community talk, VIC

"Excellent talk - now aware of MD and will be taking up a check-up."

Anika, community talk, TAS

"As I caught my wet macular degeneration early and attended one of your seminars after my first injection, I feel very reassured that I am doing all in my power to keep my sight for as long as possible. I have given all of my family and friends an Amsler grid and use mine daily. Thank you for your help - you do a wonderful job."

Robert, education seminar, NSW



Shane Dunbar-Reid

Diabetes and Eye Health

Shane Dunbar-Reid has no doubts: without vigilance, regular monitoring of his macula and some hard lifestyle changes to control his diabetes, he would be blind.

Diagnosed with Type 2 Diabetes as a teenager, Shane “didn’t want to know” and made no effort to change his lifestyle. Then, in his 30s, he developed a diabetic ulcer.

“They put me on insulin... my diabetes got better but I nearly lost my big toe.”

By good fortune, Shane had a mate who was an optometrist.

“Every six months he would give me a full-on eye exam. He just kept telling me, ‘mate you’ve got to watch it, you’ve got to watch it’.

“I’d noticed some blurry vision when I was driving and... he found some spots in the back of my eye and sent me for treatment straight away.”

Shane had diabetic macular edema, a complication of diabetic retinopathy, which is the leading cause of blindness among working age adults in Australia. The longer a person has diabetes, the greater their risk of developing diabetic retinopathy.

Most people with diabetic retinopathy should keep most, if not all, vision providing it is diagnosed early. “My sight is good. But... if we hadn’t treated it so aggressively when we found it, I would be blind now. I’m still driving. Reading is fine. My diabetes is controlled... I have (regular) blood tests and I have a diabetic sensor, which scans my blood sugars 100 times a day.”

Shane’s advice? “Get checked. Don’t put it off. Visit the doctor as much as you can. Watch your day to day lifestyle.”

For access to MDFA’s range of information resources on diabetic eye disease and support, please call our Helpline ☎ 1800 111 709

SUPPORT & SERVICES

Timely - Relevant - Empowering

As the national peak body representing the interests of the macular disease community in Australia, MDFA offers accessible, timely support to those at risk of and living with macular disease and vision loss, as well as their family, friends and carers.

What we offer

Disease information: Latest information on risk reduction, treatment and how best to manage macular disease.

Navigating government support: Assistance in navigating government support, including Medicare, NDIS and My Aged Care, along with advice on rebates and cost of treatment.

Accessing low vision services: Information on the low vision services available to help maintain quality of life and independence.

Transport options: Information and assistance on how to access transport services.

Connecting with the community: Assistance in connecting people with support and community groups in their local communities.

Carer support: Assistance in directing carers to relevant support agencies.

Translation services: Information in other languages, including interpreters for Helpline calls.

Low Vision Advisory Service: Free low vision advisory service in collaboration with Guide Dogs NSW/ACT.



6,727 calls to the national Helpline



9,101 information kits packed by volunteers and distributed nationally



516,794 individual publications and resources distributed



Over **46,000** supporters asked for their feedback



'Vision Voice' newsletter distributed three times a year to over **40,000** people



Electronic Research Update distributed weekly to over **1,000** people

Helpline 1800 111 709



Behind the scenes of the National Helpline with Education Officer, Robyn

Who typically calls the helpline?

Robyn: Most of our Helpline calls are from people who are living with macular disease - but we also get a lot of calls from spouses, carers and family members. A lot of people ring more than once. They might first call when they or their loved one has been diagnosed, and then at different points along their macular disease journey.

What are the most common questions you are asked?

Robyn: The most common questions are usually around diet and lifestyle. Other big ones are the cost of treatment and injections and navigating government support systems such as Medicare, NDIS and My Aged Care. For many people, their questions are aimed at understanding macular disease, whatever form it takes for them. If someone has lost vision already, it is information about low vision aids and technology, or getting more help at home.

How many calls do you get to the helpline?

Robyn: It varies a lot. Some days the Helpline is running hot and we have phone call after phone call. We also make a large number of follow-up calls. On average we would spend about 15-20 minutes with a caller, but we're sometimes on the phone for an hour or more.

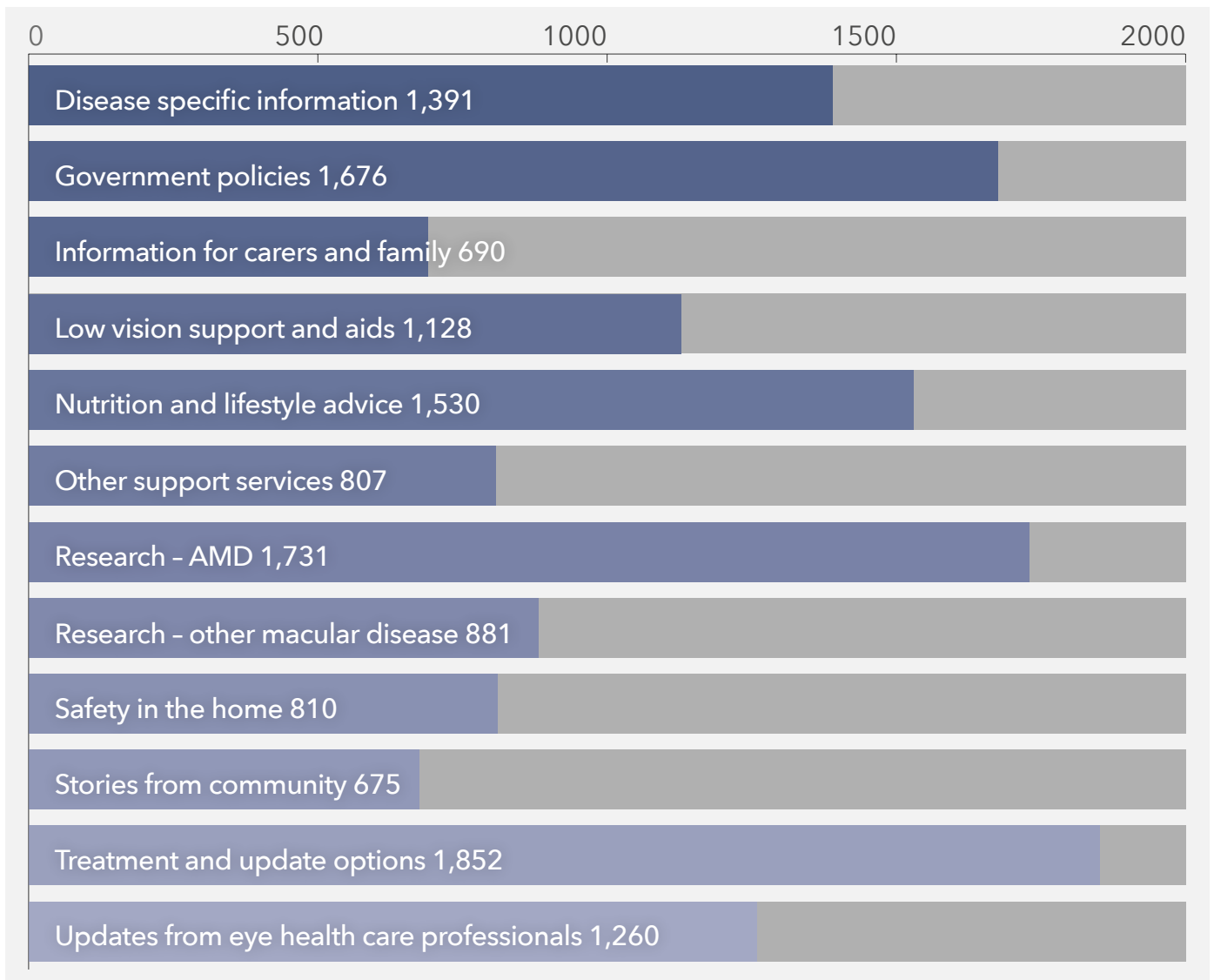
Thinking about the people who call, if you had one wish, what would it be?

Robyn: Would saying a cure be too obvious? If we can't say a cure, I want people to feel they are in the driver's seat, to know they have the information and help to feel empowered. I want them to feel 'there is so much I can do' rather than focus on what they can't do. I just want to help them on that journey.

Supporter Survey 2018

A supporter survey to better understand what information and services are most important to our community was undertaken in early 2018. The results will help us provide the most important and relevant information to the macular disease community.

Over 46,000 supporters were sent a survey for their feedback and we received a 10% response rate.



Informing the Macular Disease Community

One of the key supports provided by MDFA to its key stakeholder group - those living with or at risk of macular disease - is information.

Information is available via the Helpline, website, social media, fact sheets and publications.

Publications are available in electronic and hardcopy format. Selected key publications are available in audio in English and printed in eight languages (Arabic, Chinese, Greek, Italian, Portuguese, Spanish, Vietnamese and Italian).

In 2017-18, MDFA began a review of its publications and will develop new resources based on the changing needs of our community. The MDFA's newsletter, 'Vision Voice', which is distributed to over 40,000 people in electronic, large print or audio format, was reimaged. Now issued three times a year, the newsletter provides more relevant content, in a clear, contemporary format.

Work has begun on a digital strategy to provide timely, interesting and informative content to both our existing and new audiences online.



Engaging with Eye Health Professionals

MDFA works closely with eye health professionals to provide greater synergy between clinical care provided by optometrists, ophthalmologists and other eye care professionals and the care and support provided by MDFA.

MDFA attends conferences, provides targeted communications to - and for use by - eye health professionals, provides education and training sessions and organises regular meeting with key individuals and groups. Highlights in the reporting period included meetings with:

- Senior representatives of all the optometry groups and corporates
- Heads of Optometry Schools (UNSW, QUT)
- Orthoptic Schools (UTS, La Trobe)
- Presidents of Australian Ophthalmic Nurses in each State
- Optical Dispensing and Manufacturer Association
- Three major State hospitals



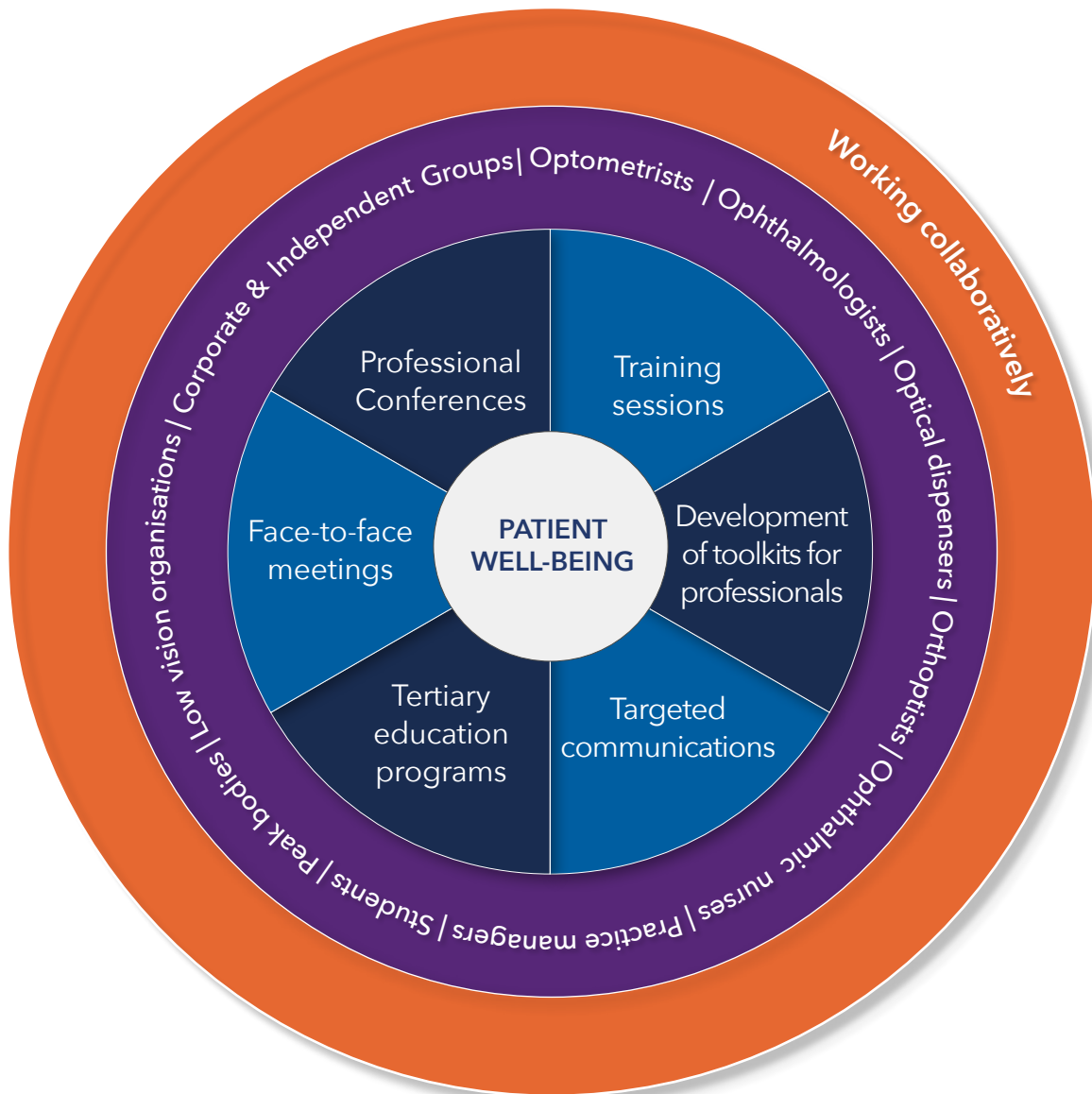
MDFA also met with over 200 optical healthcare professionals face-to-face in practices and at conferences; attended a number of staff/student in-practice training sessions; and presented at six relevant industry conferences.

MDFA has also developed toolkits for use by health care professionals, including a clinical audit tool about AMD for use by optometrists, developed by Dr Laura Downie and colleagues, through research funding from MDFA.

“Hobart Eye Surgeons is totally committed to providing the highest standard of professional ophthalmic care and treatment to our patients. To this end we regularly team with other practices and organisations to help us achieve our vision. MDFA is a valuable partner and resource in helping us achieve our goal of excellent patient outcomes in MD.”

Ray Andrew, General Manager, Hobart Eye Surgeons

MDFA Engagement with Healthcare Professionals



VOICE OF THE MACULAR DISEASE COMMUNITY

Advocacy - Collaboration - Influence

As the leading voice of the macular disease community, MDFA is influencing Australian health, aged care and disability agendas and driving improved outcomes for those living with macular disease. MDFA's efforts to date have led to affordable, registered, sight saving treatments for macular disease.

MDFA leverages key relationships - developed with a range of government and non-government organisations, covering areas of health, ageing and disability - to advocate on behalf of our community to ensure better entitlements and support.

This year, MDFA representatives were part of the Agency for Clinical Innovation Ophthalmology Network Governing Body; Non-Government Organisation Advisory Committee; National Aged Care Alliance; Australian Blindness Forum and Vision 2020 - Prevention and Early Intervention Committee, Preserve Sight Reference Group, Independence and Participation Committee.

National Action Plan Funding

Government funding for MDFA to develop a Strategic National Action Plan was announced by the Hon Greg Hunt MP, Minister for Health, in May 2018 as part of Macula Month.

The National Action Plan will develop a strategic direction around the management, prevention and treatment of macular disease to be incorporated into future government policies and budgets.

The development of the action plan, to be released in the next reporting period, has been led by MDFA as the national peak body and will provide a blueprint for key priorities and actions to reduce the incidence and impact of macular disease.

The announcement was made at a high-profile function at Parliament House, Canberra, at the launch of MDFA's report, 'The Journey to See: A Model for Success'.



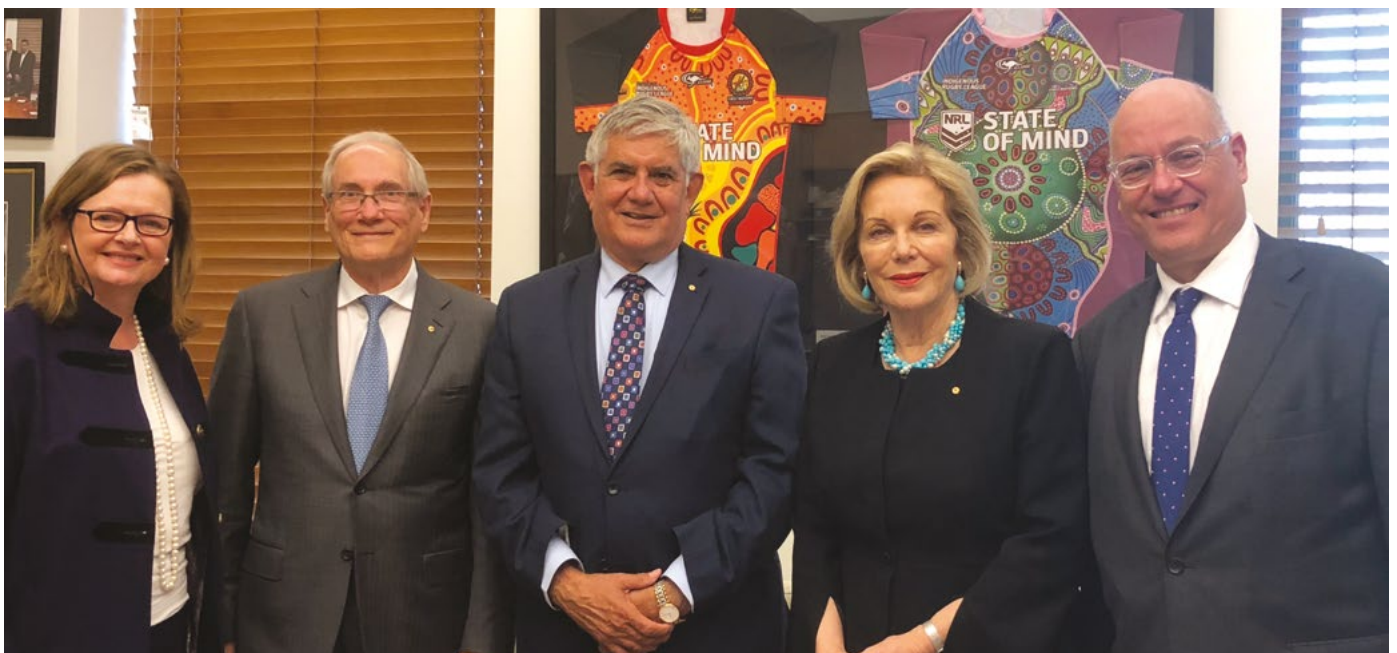
The Journey to See: A Model for Success

Over the past 10 years, Australia has become a world leader in the management of wet age-related macular degeneration. The MDFA's report, 'The Journey to See: A Model for Success' - launched by Minister Hunt, provides a fascinating case study of the collaborative effort that was needed to achieve this.

Once, most people diagnosed with wet AMD went blind due to the lack of an effective treatment. The arrival of anti-VEGF treatments changed this and rapid recognition of this across governments, health care professionals, and the eye health industry caused a monumental shift - from wet AMD being one of the leading causes of vision loss to a disease that could be managed. MDFA has been instrumental as a hub for those in need of ongoing support and information and the report outlines many of the MDFA's past initiatives and outlines key priority actions, including elevating macular disease to a national health priority; investment in education, awareness and support programs; greater investment in research; and the need for quality healthcare data.

High Level Representation and Advocacy

The MDFA's mandate includes advocating for the macular disease community. As part of May's Macula Month, a powerhouse MDFA delegation met with the Hon Ken Wyatt AM, Minister for Aged Care, to discuss issues relating to aged care and the needs of the macular disease community.



(L-R) Dee Hopkins (MDFA CEO), Prof Paul Mitchell AO (MDFA National Research Advisor), Hon Ken Wyatt AM MP (Minister for Aged Care), Ita Buttrose AO OBE (MDFA Patron) and Robert Kaye SC (MDFA Chairman).



39 submissions to Commonwealth Government inquiries, new programs and reviews



18 submissions in collaboration with other peak bodies



In July 2017, MDFA gave testimony at a Senate inquiry into the delivery of outcomes under the National Disability Strategy 2010-2020.

The strategy is a 10-year national plan for improving life for Australians with disability, their families and carers. This strategy has not delivered the outcomes required, especially in the equitable provision of government subsidies for low vision aids and technologies.

The MDFA's recommendations to the Senate Committee members centred on:

- The need for a Commonwealth-funded national aids, equipment and assistive technology program;
- The commissioning of a Productivity Commission inquiry on the decision to exclude those who acquire a disability after the age of 65 years from the NDIS, and the resulting difference in the levels of assistance and support between the NDIS and aged care system; and
- The amendment of aged care legislation, which does not appropriately support disability, to include "people with a disability" as a special needs group.

SUBMISSIONS BY MDFA

Productivity Commission's National Disability Insurance Scheme (NDIS) Costs Position Paper

Purpose: The Productivity Commission's Position Paper identified that the speed of the NDIS rollout resulted in poor participant outcomes and proposed draft recommendations to improve the quality of the NDIS.

Recommendation: MDFA recommended that the NDIS recognise and support all people with a disability, not just NDIS participants.

Joint Standing Parliamentary Committee Inquiry on transitional arrangements for the NDIS

Purpose: The Committee held an inquiry into the implementation, performance and governance of the NDIS during the current period of transition from state and territory disability programs to the NDIS.

Recommendation: The MDFA's key recommendations included the establishment of systems to ensure that people with a disability aged 65 or over have access to appropriate, adequate and equitable disability support services; and the establishment of a nationally funded, accessible, affordable and consistent low vision aids and equipment program.

Integrated care at home program to support older Australians

Purpose: A new integrated care at home program, currently under development, will merge the Commonwealth Home Support Programme (CHSP) and Commonwealth Home Care Packages.

Recommendation: MDFA supported the merger and highlighted the need for accessible and adequate disability support services in the new program.



Providing a Voice for our Community

Every 28 days, Val has regular eye injections, which are necessary to keep wet macular degeneration from stealing her sight.

“Being on a fixed income, the first few months of each year are financially tough until the Medicare Safety Net is reached. My out of pocket expenses starts at \$450 a month, gradually decreasing to about \$100 by year end,” Val said.

Part of MDFA’s mission is to be a voice for the macular disease community. As a regular MDFA volunteer, Val has been an active part of these advocacy campaigns, mailing thousands of letters on our behalf.

MDFA successfully campaigned for ocular coherence tomography (OCT) – routinely used in monitoring macular disease – to be reimbursed by Medicare. But currently, only one OCT per eye for diagnosis purposes is eligible for a rebate so continuing advocacy efforts are aimed at ensuring that rebates can apply to all OCT scans for macular disease diagnosis and treatment. MDFA is also concerned about the cost burden to patients caused by recent changes to Medicare item 105, which removed the rebate for consultations if a surgical procedure (such as an eye injection) occurs on the same day.

For Val, the out of pocket costs are onerous but she can’t skip a monthly injection or her sight deteriorates.

“I have to remind myself how fortunate I am that continual research makes it possible for me to keep my vision. The alternative is loss of sight and that is a huge incentive to keep having the injections,” Val said.

MDFA will continue to speak with community members like Val to ensure we understand the real-life issues facing people with macular disease and how we can best represent our community at the government level.

RESEARCH & DATA

Knowledge - Evidence - Impact

The strategic priority of the MDFA's research grants program is to increase investment and diversification of work to better understand the cause of macular disease, and pursue new treatments and, we hope, cures.

Collaboration with other Australian research bodies to avoid duplication is key and the impact of funding grants must contribute to better patient outcomes. In 2017-18, a further \$600,000 in grant funding was awarded to three leading Australian vision researchers.

This brings the total awarded as part of our research grants program since 2011 to almost \$3.6m, spread across 15 Australian researchers and 18 projects.

Associate Professor Alice Pébay - \$300,000 over two years Centre for Eye Research Australia, Melbourne



This project aims to better understand the mechanisms causing dry age-related macular degeneration (AMD).

A laboratory model will be developed using human retinal cells produced from induced pluripotent stem cells from 120 people with either dry AMD or control individuals.

The cells from AMD patients will include a wide range of the genetic variations that have been linked to an increased risk of disease. The aim is to help better understand the processes causing disease and to identify new targets for treatments.

Professor Erica Fletcher - \$180,000 over two years University of Melbourne



Building on previous research funded by MDFA, this study will examine whether measuring the function of certain cells can result in a diagnostic blood test to identify people at greatest risk of AMD progression.

Professor Fletcher will test a number of new proteins to determine if they can improve the ability of immune cells (monocytes) to remove waste products (drusen) and their potential for treatment which could slow or stop disease progression.

Dr Fred Chen - \$120,000 over two years Lions Eye Institute, University of Western Australia



Stargardt disease is the most common inherited form of childhood macular degeneration caused by over a thousand different types of mutations in a single gene. Clinical recognition and accurate genetic diagnosis of Stargardt disease within Australia must be improved given new treatments are on the horizon.

This grant will provide initial funding to investigate the varied presentation and natural history of Stargardt disease to identify suitable patients for future clinical trials. It will also support the infrastructure to discover mechanisms of new mutations in, and development of personalised treatment for, the Stargardt gene.



His Excellency General the Honourable Sir Peter Cosgrove, Governor General of Australia and Lady Cosgrove with the grant recipients at an official function at Admiralty House, Sydney in November 2017.



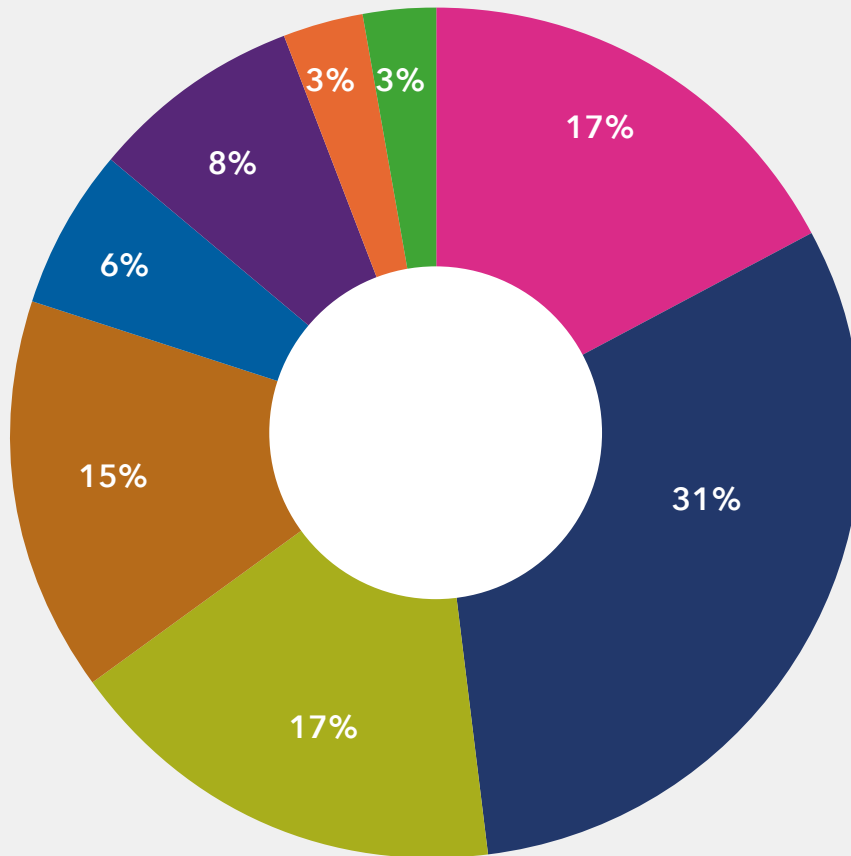
\$3.6 million allocated to 15 Australian researchers across 18 research projects since 2011.



\$600,000 awarded to three leading Australian researchers in 2017.

Recipients of MDFA grant funding published 14 journal articles and one journal abstract, with a further seven articles under review, and made seven conference presentations.

MDFA-funded Research Expenditure on Macular Degeneration to June 2018



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



The Value of Fundamental Research

To create anything worthwhile, you first need a firm foundation. It's as true in medical research as it is in building construction.

Fundamental vision research - that which helps scientists understand the basics of macular disease and how it develops - is a critical first step in developing new treatments and new ways of managing people with the disease.

But, as Professor Erica Fletcher explains, it is often difficult to attract funding, as it is seen as "too risky."

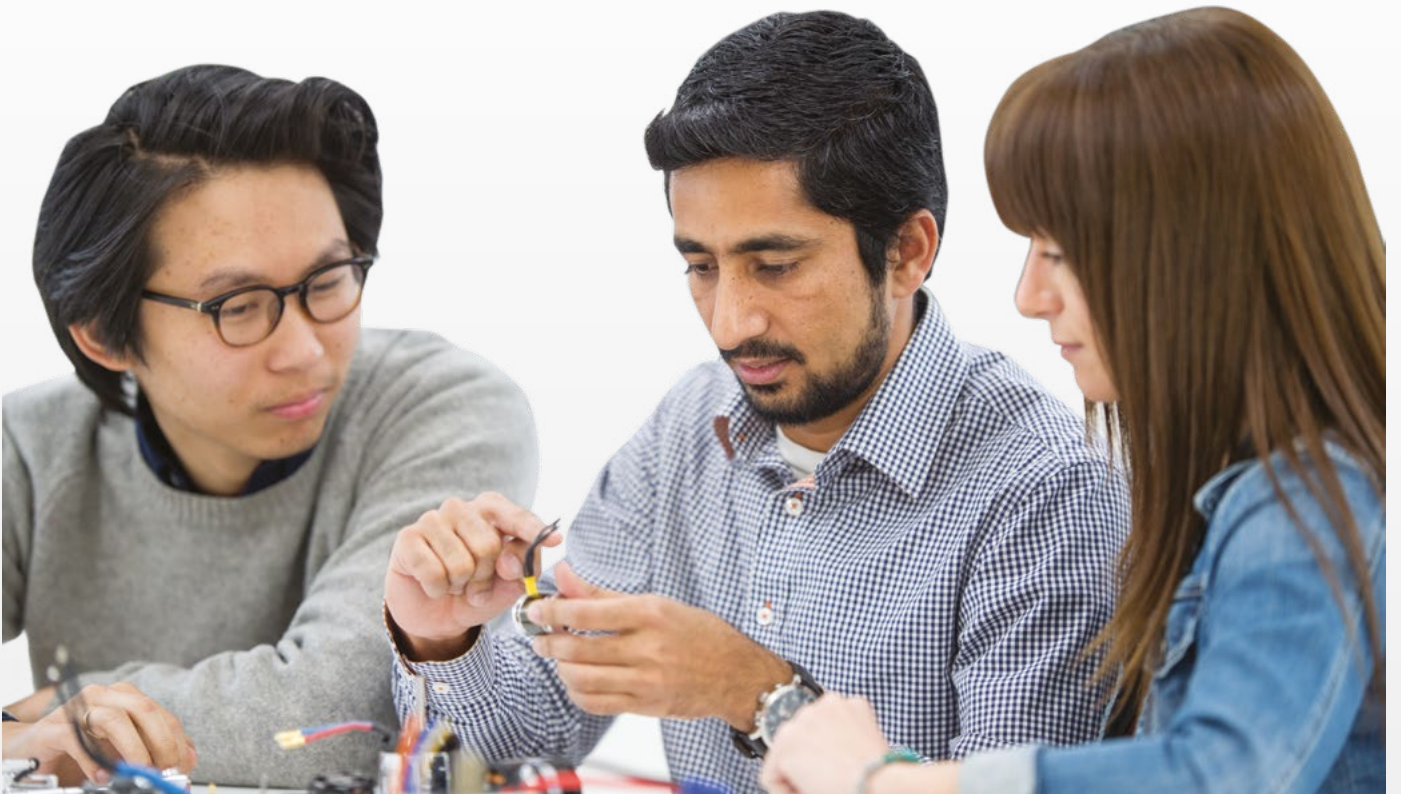
"Charities like MDFA are absolutely critical at funding these early stage results - we learn a huge amount about the disease, we learn a huge amount about why people develop the disease and we hope that by funding this research we can develop new treatments and new ways of managing people and that, in the end, is going to benefit hundreds of thousands of people in Australia."

Prof. Fletcher is currently working on an MDFA-funded project into AMD that she describes as "very promising."

"We are hoping to develop a blood test where we can predict, based on looking at immune cells, who is going to be at the highest risk of progression to late stage AMD. The second stage of the research is to look at why immune cells stop working in patients with AMD, why they stop working as well as they should, why they fail to remove cellular waste in our bodies... and whether we can tweak the process to make those cells work better."

While reluctant to put a timeframe on research due to the variables involved, Prof. Fletcher hopes the first stage - the blood test to identify those at heightened risk of progressing to late stage AMD - could be available in about five years.

Completed Funding



Associate Professor Chi Luu - Centre for Eye Research Australia

Project: A/Prof Luu's project aimed to determine if subtle changes in the function of the retina, able to be detected with a new Australian designed machine called the Dark Adapted Chromatic (DAC) perimeter, are an effective marker of disease severity and treatment efficacy. Study of retinal function using a DAC perimeter would also help identify AMD subjects with high risk of progression to advanced disease, and thus potential treatments aimed at slowing progression can be targeted to this high risk group.

Outcome: The study has identified the locations within the retina that have abnormal function in early stages of AMD. A testing protocol has also been developed to detect changes in the function of the retina over a short follow-up period. These findings will help to develop sensitive functional markers for monitoring disease progression and evaluating efficacy of new interventions for early stages of AMD.

Ongoing Funding

Seven funded grants have been progressing in 2017-18. These are being undertaken by Associate Professor Gerald Liew (Centre for Vision Research, Westmead Institute for Medical Research); Associate Professor Bamini Gopinath (Westmead Institute); Professor Mark Gillies (Save Sight Institute, University of Sydney); Professor Steven Krillis (St George Hospital, University of NSW); Dr Isabelle Jalbert (School of Optometry and Vision Science, University of NSW); Dr Laura Downie (Department of Optometry and Vision Sciences, University of Melbourne); and Associate Professor Wilson Heriot (University of Melbourne).

Eye Health and Vision Loss in Residential Aged Care Facilities

In 2017-18, MDFA finalised a comprehensive study which found high rates of eye disease - often under-diagnosed and untreated - in residential aged care facilities.

The 'Vision and Eye Healthcare Study in Residential Aged Care Facilities' report found more than 70 per cent of residents who took part in the study had some form of eye disease; almost 30 per cent had untreated cataracts and more than 60 per cent had some degree of AMD.

The report noted that vision loss in residents of aged care facilities could have many negative consequences, such as increased risk of falls and fractures, a reduction in social independence and quality of life and a huge increase in the risk of depression.

The MDFA study, which was conducted with funding initially allocated by the Australian Government Department of Health in 2015, also noted very low levels of low vision assessment and use of vision aids and technologies.

The study led to the development of a series of electronic resources, including a training video, for residential aged care facilities and their staff. That stage of the project fell in the 2018-19 reporting period.

"This... will assist staff from all of Australia's Residential Aged Care Facilities to better understand the care needs of residents who are blind or have poor vision.

"Recognising the signs of sight deterioration and the importance of early detection, diagnosis and treatment will benefit residents immensely and positively impact their independence and their quality of life."

Ciarán Foley, CEO of Allambie Heights Village Ltd

WITH YOUR HELP

Transparency - Accountability - For Purpose

The funding and donations provided by government, sponsors, donors, bequestors and community fundraisers allows MDFA to fulfil our purpose to reduce the incidence and impact of macular disease in Australia.

This support helps fund our client support programs, information and awareness initiatives, as well as research projects that will, we hope, one day find cures and better treatments for macular diseases. MDFA also receives invaluable non-financial support from volunteers and the wider community.

By working together, we can change the lives of those living with or at risk of macular disease.



“To the donors: A very sincere ‘thank you’. A great deal of work can be done with a small amount of money provided by donors. Sometimes fundamental research - work that is in the very early stages but is critical to our understanding of macular disease - is not funded because it is seen as a little bit risky.

I can't stress how important the research is and how important the donations are in financially supporting our work.”

Professor Erica Fletcher, MDFA research grant recipient



Community Fundraisers



We continue to be amazed at the efforts of our community fundraisers, who it seems will go to any lengths to challenge themselves and raise funds for MDFA in the process.

In its 11th year, the Roth Gair Golf Day on Victoria's Mornington Peninsula raised over \$11,000, bringing the total tally raised to \$125,000. This event is held in remembrance of the late Roth Gair, Past President of the Lions Club of Forest Hill in Victoria. Our heartfelt thanks to Ian Kennedy, the Gair family, the many volunteers

from the Lions Club of Forest Hill and Park Orchards, and the generous sponsors and golfers on the day.

In November 2017, the Melville Glades Golf Club hosted a Mixed Charity Day, raising more than \$16,000 for research for MDFA. Thank you to the Ladies Charity Committee for their generous support.

For the second year running, MDFA has been the recipient of the Wonthaggi Open Garden Day fundraiser, which has now raised \$8,000. The January event is hosted by Colin and Pam Willmot and

supported by the Lions Club of Wonthaggi. Although macular degeneration has stolen much of Colin's sight, he is still able to maintain a magnificent garden. More than 250 people attended the last Open Garden Day in January, drifting through the tranquil grounds.

MDFA thanks all involved for their ongoing generosity.

Tackling Kokoda for MDFA



The Kokoda Track is synonymous with pure physical challenge. Even for the fittest, most able trekkers, the 96km trek is gruelling.

Think, then, about what it would be like to do it the trek with a rare eye disease that has left you with less than 50 per cent vision in only one eye. That was the challenge Garvin Francis set himself.

Garvin was one of six life-long mates who in 2018 tackled the extreme version of the Kokoda Track, completing the trail in six days, rather than the usual 12. The "Kokoda Warriors", as they call themselves, dedicated the challenge to MDFA, raising over \$3,500.

Garvin has Rod Cone Dystrophy, an eye disease that he describes as being "right up there with the odd and rarer ones." Garvin is totally blind in his right eye and has a small amount of "foggy/blurry" vision in his left.

At the end of the day, Garvin said he knew he could rely on his mates to get him through.

"It was a personal challenge for all of us. My eyesight was just an extra curveball."

Looking for a Cure in the Cards

Joan doesn't spend much time thinking about what she can't do now she's legally blind. Instead she's focused on what she can do.

And there are two things she can do very well - make greeting cards; and inform people about the importance of macular health.

"MDFA sends me leaflets. If people stand still long enough, I give them a leaflet. The taxi drivers get leaflets. I had some people knock on the door to tell me about the Bible; they left with leaflets.

"People don't know about their macula. They don't understand macular disease just creeps up on you," Joan says.

MDFA leaflets are also slipped inside greeting cards, which she makes at home, then sells at the Ringwood East Market. Every cent is donated to MDFA.

"My right eye is gone. I had a big haemorrhage in my right eye this year, and now I've got a little bit of vision in the bottom left hand corner.

"I have always done craft. I've been fighting this disease now for 15 years and I got to the point where I was looking for something to do. So, I listen to my audio books, and I make cards. I trim the cards up with a guillotine (and no, I don't cut my fingers) but I couldn't make the cards if I couldn't blend the colours - I can still see colours.

Joan asks us to allocate her regular donations to research. Why?



"Because it's genetic. My mother had it; my elder sister has it. I have two children, eight grandchildren and three great-grandchildren - and that just tells you that I'm old.

"But research is important, and not just for my family. It is so, so important that people don't end up like me."

"People don't know about their macula. They don't understand macular disease just creeps up on you."

Volunteering

A wonderful group of volunteers, many of them long term, generously give their time each week helping to fulfil MDFA’s education and resource order requirements. Not only is their work vital to the efforts of MDFA, but it is done with great enthusiasm, camaraderie and joy.

We also appreciate those Friends of the Foundation who have generously allowed us to share their stories to raise both awareness and funds. MDFA would particularly like to thank Frank, who was the face of our May 2018 tax appeal.



12 regular volunteers



79 average age



1,774 packs prepared for education seminars



2,349 information packs sent out to the community



1,400 volunteer hours worked



MDFA volunteers with Patron Ita Buttrose and Ambassador Jean Kittson

Vale Neville Turnbull

Volunteers – many of whom attend community events, help spread the word about the importance of comprehensive eye tests and regularly assist with administration tasks at our office – are treasured as ‘family’ by MDFA. So it was with great sadness that MDFA said farewell to one of our long-time volunteers, Neville John Turnbull, who died aged 86 in August 2017.

Neville was a regular in the MDFA office for nine years and his contribution to the cause was much admired. He was the beloved husband of Margaret, who continues to volunteer with the MDFA on a weekly basis.

Government Support

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



Australian Government

The Commonwealth Department of 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.

The Aged Care Service Improvement Fund, to reduce the incidence and impact of vision loss associated with macular degeneration, and other eye conditions, in residential aged care facilities.

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.



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



Humanware provides support to MDFA through its attendance at our Low Vision Days.

Supporters

The generous support provided by the following organisations enable the delivery of key initiatives and activities.



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.



A founding and continuing supporter of MDFA, Quantum RLV supports our education events nationally.



We were delighted to welcome Roche to our supporter panel in 2017. Funding from Roche will be directed to supporting awareness through digital storytelling.



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

Community Supporters

ClubsNSW ClubGRANTS

Club Forster

Mounties Group

Club Jervis Bay

Orange Ex Services Club

Hornsby RSL Club

Lithgow & District
Workmen's Club

Dubbo ClubGRANTS
Committee

Community Fundraisers

The Lions Club of
Capalaba Inc

Melville Glades Golf Club

The Wollongong Doll
Club Inc

Donor Supporters

Mrs Beryl Jewell

Edwards Family

Ms Margaret Beaumont

In Memory of Brenton
Hawkes

The McBriarty Family

Mr William Service

Mrs Josephine Canals

Mrs Alison Mayfield

Mrs Beryl Percival

Mrs Helen Finn

Ms Linda Thomas

J and B Harvey

Mrs Rita Andre

Mrs Janice Waddington

Mr Richard Williams

Estates

The Estate of the Late
William McIntyre

The Estate of the Late
Ruby Burns

The Estate of the Late
Evelyn Thomas

mEYE World Photographic Competition 2017 Prize Donors

Adobe

Art Pharmacy

Bluethumb

FUJIFILM Australia

Jono Hennessy

Mainline Photographics

Manfrotto

Momento

Saxon

The Frame Shop

Wacom Australia

Professional Friend Program

Dianne Andrews
Menai Eye Care

Dr Jennifer Arnold
Marsden Eye Specialists

Sally Atkins
Atkins Optometrist

Dr Gayatri Banerjee
Nepean Valley Eye
Surgeons

James Baumgarten
Family Eyecare

Dr Paul Beaumont
Retina & Vitreous Centre

Geoff Blackwell
Clear Optometry

Rebekah Bormann
Vision Eye Health

Ian Brigden
Eyecare Plus Nelson Bay

Elaine Bryant
Lakes Entrance
Optometrists

Dr Guy Bylsma
Hobart Eye Surgeons

Mary-Rose Campbell
Optomize

Dr John Chang
Retina & Vitreous Centre

Andrew Christiansen
The Optical Superstore

Dr Augustino Clark
St Vincent's Hospital

Dr Sudha Cugati
Lyell McEwin Hospital
Ophthalmology
Department

Peter D'Arcy
Peter D'Arcy Optometrist

Cedric De Souza
Melville Optical Clinic

Maria Dimitratos
Icon Eyewear

Dr John Downie
Retina Consultants

Dr Cameron Dyson
Dyson & Long Optometrists

Fiona Eising
Eye Zing Optometrists

Dr Michael English
Cambridge Eye Clinic

Dr Adrian Fung
Retina and Macula
Specialists

Kylie Gough
Eyecare Plus Nambucca
Heads

Alan Greenhill
Alfred Nott Optometrists

Aaron Henry
Aaron Henry Optometrist

Dr David Hilford
Watkins Medical Centre

Graham Hill
Graham Hill & Associates
Optometrists

A/Prof Alex Hunyor
Chatswood Retina
Associates

Dr Girish Jamnadas
Ipswich Eye Centre

Dr Bradley Johnson
Northern Eye Surgeons

Susan Kalff
Freemasons Homes

Chris Katopodis
Canterbury Eye Care

Peter Kazacos
Eyecare Plus

Dr Gilda Kert
Darling Downs Eye

John Kingshott
Glenorchy Eyecare

Dr David Kitchen
CQ Eye

Jim Kokkinakis
The Eye Practice

Dr Vinithra Kumar
Specialist Medical Suites

Judy Kwan
Super Optical Optometrists

Dr Shish Lal
Hornsby Eye Specialists

A/Prof Christopher Layton
Greenslopes Specialty
Clinics

Dr Kuo Luong
Lee Eye Specialists

Dr Peter Macken
Dr Peter Macken and
Associates

Wayne McCarthy
Angelo Street Optical

Bruce Mellick
Bruce Mellick Optometry

Philip Milford
Philip Milford & Associates

Siobhan Murphy
National Vision
Optometrists

Dr Michael Newman
Miranda Eye Surgical
Centre

Judith Nicol
Optometrist

Harry Notaras
Eyewear Youwear

Brendon Pearce
Fernvale Optical

Lee Pepper
Vision Excellence

Dr Vivek Phakey
Waverley Eye Clinic

Dr Neroli Porter
Eye Care Queensland

Ray Proust
Ray Proust Optometrist

Dr Vignesh Raja
Joondalup Eye Clinic

Rick Ross
Forest Hill Optometry

Dr Jennifer Sandbach
Annandale Eye Care

Nicola Sawyer
Ballina Optometry

Glenda Schubert
Mooroolbark Eyecare

Lachlan Scott-Hoy
Innovative Eye Care

Dr Ashley Seawright

Dr Shanel Sharma
Eye and Laser Surgeons

Dr Jeremy Smith

Dr Brighu Swamy
South Eastern Eye Care

Dr William Talbot
William Talbot Eyecare

Dr Kong Tang
Midwest Ophthalmology

Dr Christine Tangas
Northcote Eye Clinic

Dr Brendan Vote
Launceston Eye Institute

Robert Webster
Webster Optometrists
Cowra

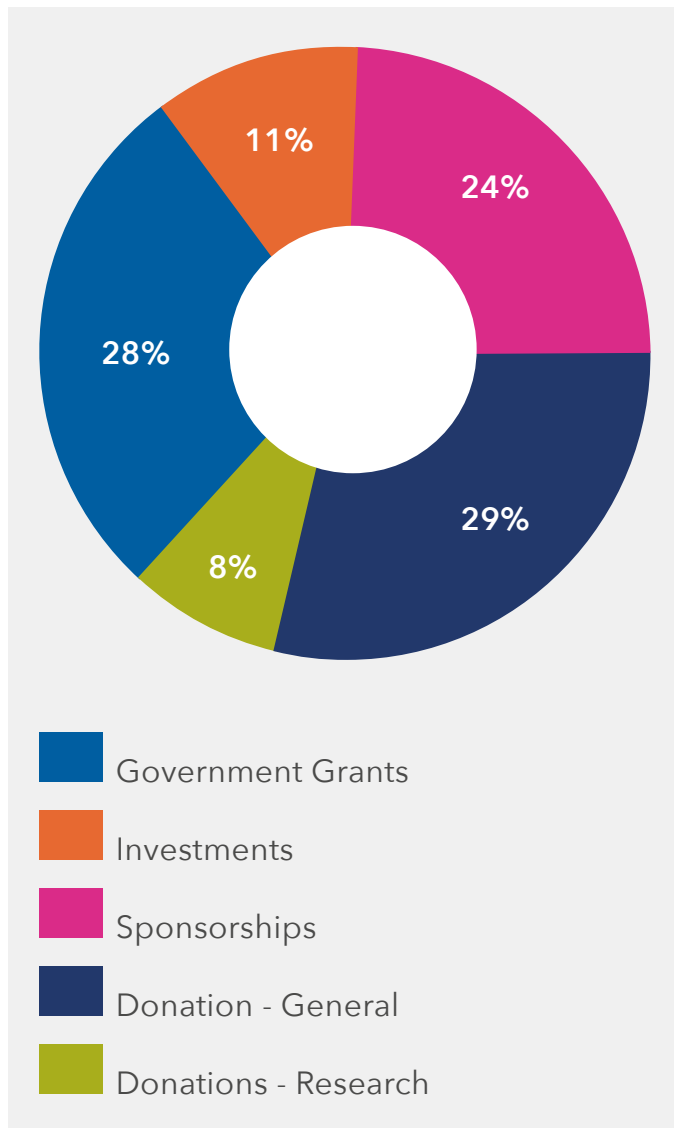
Dr Michael Wertheim
Perth Eye Clinic

David West
David and Carol West
Optometrists - Eyecare Plus

Dr Johnny Wu
WA Eye Specialists

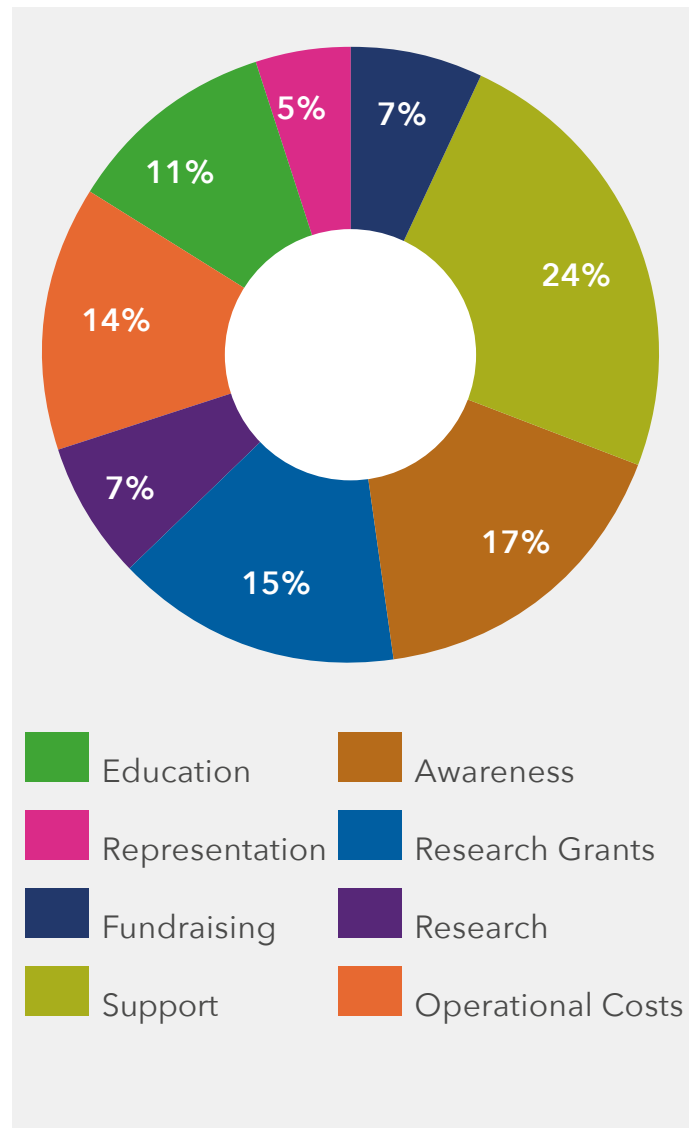
Robert Zent
Robert P Zent Optometrist

REVENUES



Total revenues = \$3,119 million.

EXPENSES



Total expenses = \$3,292 million.

The information on this page was extracted from the audited Financial Statements of Macular Disease Foundation Australia for the year ended 30 June 2018. The audited Financial Statements can be obtained free of charge on the Macular Disease Foundation Australia website or by contacting MDFA on 1800 111 709 or info@mdfoundation.com.au.

A LIFE WELL LIVED



Cliff has lived a life filled with family, music and travel. His most prized possession is his violin, which was given to him by his parents when he was a boy - and he's still playing, more than 90 years later.

Cliff, who this year turned 102, was very independent until age-related macular degeneration (AMD) robbed him of his sight.

His son Daryl has watched as his dad slowly lost things he treasured - his independence, his driver's licence and his ability to read music.

"Dad's had a very full and interesting life. He was a baker by trade, but also was

Chairman of the Board at Kaleeya Hospital (a small hospital in WA); he was also a Rotary District Governor in WA and was recognised by Rotary as a Paul Harris Fellow," Daryl said.

"About 20 years ago, his eyesight became problematic. He tried to hide it and pretend everything was alright. But eventually he was diagnosed with AMD. From then, his eyesight just slowly got worse.

"I had to tell him he needed to stop driving. He was quite upset about that, because it took away so much of his independence."

Daryl is aware that with the direct genetic link to a parent with the disease, he has a one-in-two chance of developing AMD.

MDFA is grateful to have the support of Cliff and Daryl in its fundraising appeals. They hope that by telling their stories, it will help MDFA to raise funds for research.

You can help MDFA continue its crucial work to reduce the incidence and impact of macular disease and fund research towards improved treatments and cures. MDFA's fundraising channels are highlighted opposite.

HELP MACULAR DISEASE FOUNDATION AUSTRALIA

Donate to Save Sight

Making a donation can help MDFA achieve its vision of reducing the incidence and impact of macular disease in Australia. All donations support the many activities undertaken in education, awareness, support services, research and representation. Every donation goes towards helping save sight. Joining MDFA's regular giving program provides a sustainable future for the work of MDFA.

Donate to Research

MDFA's Research Grants Program funds Australian research into macular degeneration. The aim is to save sight and reduce the impact of vision loss.

Bequest

A bequest can make a lasting impact on generations to come and is gratefully received by MDFA.

Corporate Partnerships

There are many opportunities for partnerships with corporations to support the work of MDFA in its activities in education, awareness, support services and research.

Sponsors

MDFA implements a range of programs across Australia. Sponsorship opportunities exist for organisations to support specific projects throughout the year.

Community Fundraising Events

MDFA welcomes contributions from the fundraising activities of community and service organisations, schools and clubs. The Everyday Hero and GoFundraise websites are available for people who participate in events to support MDFA.

Commemorative Gift

A donation to MDFA in lieu of a gift can help commemorate a significant occasion.

Memorial Gift

A memorial gift can be made in lieu of flowers in memory of a family member or friend.

Volunteering

MDFA welcomes and values volunteers who undertake a range of work to support its activities across Australia.

To donate or for more information, contact MDFA



1800 111 709



info@mdfoundation.com.au



www.mdfoundation.com.au

Macular Disease Foundation Australia is a registered charity.
All donations \$2 and over are tax deductible.



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