

# Seeing the future with your help...

Celebrating 15 years



Our focus is your vision

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# Macular Disease Foundation Australia

### Vision

Macular Disease Foundation Australia's vision is to reduce the incidence and impact of macular disease in Australia.

## Strategic Pillars

### **Knowing**

Recognised as the trusted expert on macular disease.

### **Engaging**

Regarded by the macular disease community as both highly relevant and engaging.

### Leading

The leading, authoritative voice of the macular disease community.

## **Values**

The Foundation's values are based upon creating a culture of respect, compassion, trust, integrity and excellence and we embed these values into our organisation and our everyday practice.

### Respect

Respect means respect for the dignity of the person in the work we undertake in the community, in our organisation and with our partners and stakeholders. The Foundation values and respects diversity and provides guidance and support for all in a non-discriminatory ethical manner.

### Compassion

Compassion means understanding and support. We acknowledge the unique needs of individuals, their families and carers by listening, caring and responding appropriately.

### **Trust**

Trust means honesty and reliability with the highest standards of ethical behaviour in an environment of total quality care.

### Integrity

Integrity means being equitable, consistent, transparent and accurate in our actions, decisions and communication. The Foundation is committed to empowerment of the macular disease community and opposes inequity and disadvantage.

### **Excellence**

Excellence means striving to be the best in all that we undertake and committing to excellence in all that we do. The Foundation strives to lead by example and actively supports personal and professional development of self and others, strengthening our organisation and our people. Excellence includes encouraging best-practice and valuing and encouraging critical thinking and innovation to solve problems and embrace change.

# **Guiding Principles**

### The Foundation:

- Places the macular disease community at the centre of all that is undertaken.
- Recognises and responds to the unique needs of those living with macular disease and vision loss.
- Is the voice for all Australians with, or at risk of, macular disease and represents their best interests at all times.
- Is the trusted lead expert on macular disease.
- Recognises that we are part of the larger health and social system and strives to ensure they respond effectively to macular disease.
- Creates a culture that values respect, compassion, trust, integrity and excellence and embeds these values into our work and workplace.
- Enables access to knowledge to help prevent vision loss and blindness.
- Supports equity and affordability in accessing treatment and rehabilitation.
- Supports those with vision loss or blindness to have the best opportunity to maintain quality of life and independence.

# Our Macular Disease Community

People with, or at risk of, macular disease are at the centre of the macular disease community. Their well-being is at the heart of everything the Foundation sets out to achieve. The community also includes: family and carers, health care professionals, service providers, researchers, local community and government.

Our support of the macular disease community is through our activities in education and awareness, providing strong representation, undertaking research, and outstanding client services delivered by capable and caring people. Our sustainability is underpinned by innovation, resourcefulness, diverse sources of funding and strong governance capabilities.

# Our focus is the vision of every Australian

# Supporting the Foundation's Work

Generous bequests fund support services as well as world leading Australian research.

Federal and State
Government funding
is critical to maintaining
services to support the
Foundation's work.

**Volunteers** provide valuable support to the Foundation, contributing **time and expertise** in many areas.

Corporate support
assists our vision to reduce
the incidence and impact
of macular disease

Every donation received makes an important contribution.

Dedicated eye health professionals support the Foundation with their expert knowledge.

Partner relationships are built on respect for each other's independence, integrity and autonomy.

Community fundraising supports the Foundation's sight saving work.

# Key Highlights of 2015-2016

Foundation celebrates

15 Years
of Sight Saving Work

6,600 members of the general public attend117 education sessions

Governor-General presents Foundation Research Grants totaling

\$1.3 million

Macular Degeneration
Awareness Week 2016
achieves outstanding results

1,000 eyecare professionals worldwide receive weekly

research e-newsletter

Entries to mEYE
World Photographic
Competition grow by

86%

10,000 information kits

packed by volunteers for national distribution

Almost **8,200** calls to national **Helpline**, bring total calls since initiation to almost

140,000

4

Foundation **studies**published in prestigious

peer-reviewed journals

**Foundation** 

survey highlights high financial

burden of treatment

99%

attendees rate Foundation education sessions as excellent or good

**37** 

Foundation submissions advocate for the betterment of client needs

Foundation reaches
out to culturally and
linguistically diverse
communities

# Ita's Story

My father was in his mid-eighties when he lost his central vision to macular degeneration. It changed his life. As a journalist and author he had always started his day reading a couple of newspapers. Suddenly this was no longer possible.

As a journalist and author myself I couldn't imagine not being able to ever read again. I was as devastated about Dad's fate as he was.

One of Dad's sisters also had macular degeneration and their youngest brother was diagnosed with it too. Fortunately the sight of one of my uncle's eyes has been saved with the help of a treatment now available for wet macular degeneration. He is able to read and still drive. This has been a major breakthrough in the management of the disease and my uncle's doctor has been able to stabilise his vision. If only this treatment had been around to help Dad, how happier the last years of his life would have been.

One thing I have noticed is how few people know that a family history of the disease brings with it a high risk of macular degeneration. When I tell them that I have a 50 per cent chance of getting it too, most people are usually shocked. My children are equally at risk and consequently we all do some kind of regular exercise, watch our weight and follow the eating program recommended by the Foundation.

I get my macula checked annually and when my ophthalmic surgeon tells me my 'macula is in pristine condition' his words are music to my ears!



# Ita Buttrose AO OBE Patron, Macular Disease Foundation Australia

Ita Buttrose is one of Australia's most admired businesswomen and an accomplished communicator, advising corporate as well as community and welfare organisations. She has a wealth of experience across a broad range of industry sectors and combines many roles as social commentator, businesswoman, journalist and author.

As Patron of the Foundation for ten years, Ita has been instrumental to its success in raising awareness of macular degeneration. A powerful voice within Australia, she shares her personal experiences to convey key health messages of risk factors, prevention, detection, treatment and rehabilitation.

In 2013 Ita was named Australian of the Year. She holds the appointment of Officer of the Order of Australia for her services to the community, particularly in the area of public health education. Ita is also the National Ambassador of Alzheimer's Australia and Emeritus Director of Arthritis Australia.

# Foundation State Patrons / Representatives

Macular Disease Foundation Australia is grateful to Governors of Australia who, as the Foundation's State Patrons and Representatives, support the Foundation's work and recognise its achievements over 15 years, in raising awareness of macular disease in Australia.



**Victoria State Patron** 

Her Excellency the Honourable Linda Dessau AM, Governor of Victoria

"Congratulations to Macular Disease Foundation Australia on 15 years of sight saving work. We know that diabetes is an enormous and rising challenge in Australia. This makes the Foundation's work to raise awareness of the risks of diabetic eye disease essential to save sight. I am honoured to be the State Patron and to contribute to the Foundation's awareness work in Victoria."



**Western Australia State Patron** 

Her Excellency the Honourable Kerry Sanderson AC, Governor of Western Australia

"I am very pleased to be the Western Australian State Patron for the Macular Disease Foundation Australia. Age is one of the major risk factors for macular degeneration. As a person over the age of 50, I understand the importance of undergoing regular eye tests, and encourage others to do the same. I commend the Foundation on its work to raise awareness in this area, which is vital to reducing the incidence of macular degeneration in Australia."



**Tasmania State Patron** 

Her Excellency Professor the Honourable Kate Warner AM, Governor of Tasmania

"Thanks to the Foundation's work over the last 15 years, Australians now know that early detection of macular disease and early intervention is critical to saving sight. I am delighted to be a State Patron and to help the Foundation continue its vital work in Tasmania to increase awareness of macular disease and to reduce vision loss."



**South Australia Custodian of Vision** 

His Excellency the Honourable Hieu Van Le AC, Governor of South Australia

With almost 100,000 residents of South Australia showing some evidence of macular degeneration, the Foundation's work to promote the importance of reducing risks by leading an active lifestyle, following an eye friendly diet, and not smoking is critical. The Governor is a 'Custodian of Vision' in South Australia.

# Report from the Chairman and Chief Executive Officer

In 2016 Macular Disease Foundation Australia celebrated the milestone of 15 years of work towards reducing the incidence and impact of macular disease in Australia.

The Foundation has been fortunate to have had the dedication and commitment of so many people to our cause over these 15 years, each of whom has contributed to saving sight and improving the quality of life for those with vision loss and blindness.

Once again, our education, awareness and activities reached out to thousands of Australians in cities and rural and remote areas, conveying our key health messages on prevention, early detection, treatment and rehabilitation. Our national helpline provided information, guidance and understanding to those in need and our extensive range of publications and resources supported our clients. In 2015-2016, the Foundation sought to bring our eye health messages to the culturally and linguistically diverse Australian communities. Our advocacy activities continued to drive accessibility and affordability of treatments and rehabilitation. ensuring equity of access for the macular disease community, especially in the area of treatment for diabetic eye disease and access to aids and technologies for those with vision loss and blindness.

A highlight of our year was the awarding of our third round of Macular Disease Foundation Australia Research Grants to outstanding Australian researchers. In 2015 \$1.3 million was awarded on World Sight Day, 8 October, by The Governor-General, His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd), bringing our total commitment to research since 2011 to almost \$3 million. The generosity of our supporters now places the Foundation as one of the leading sources in Australia of research funding for macular degeneration.



Robert Kaye SC, Chairman



Julie Heraghty, Chief Executive Officer

During the year the Foundation's financial position strengthened. This enables us to continue to meet the growing demand for our programs and services and increase our support of research. For the year ended June 2016 the Foundation generated a net surplus of \$1.0 million (2015: \$1.4m). Bequests and donations continue to be a significant driver of our result, reflecting the generosity of giving within our community. This is greatly appreciated.

As we celebrate 15 years of achievement we have, as part of good governance, dedicated time and resources to planning for the future of the Foundation. The environment in which we operate is one of ongoing change with significant challenges including government regulation, securing funding, increasing and changing needs of our clients and new modes of communication. Whatever the reason, we need to anticipate and plan for change, be responsive, meet the challenges and ensure that our work continues to meet the needs of our community.

To this end, the Board and senior management worked together throughout 2015-2016 to produce a new strategic plan. This plan will enable us to meet our vision by supporting the activities we undertake for the macular disease community and ensuring service delivery by capable and caring people in a sustainable financial environment. Our sustainability must be underpinned by innovation and resourcefulness and driven by diverse sources of funding and strong governance capabilities.

A principle of good governance is directors having a maximum term which ensures renewal and underpins diversity. The Board renewal program has continued this year with the retirement of two directors. Our Chair, Elizabeth Carr, retired in September 2016 having made significant contributions to the Foundation over more than 12 years, initially as an inaugural Director from 2001 to 2003, and then returning as Chair from 2006. Ophthalmologist, Dr Jim Runciman retired in December 2015, having served as Director

for almost 12 years from 2004. Both have given outstanding dedicated service, much valued expertise and steadfast commitment. On behalf of the macular disease community we thank you sincerely for your contribution to the Foundation.

In this 15th year, a special thank you to our supporters, partners, donors, funders and volunteers. Thank you to our Patron, Ita Buttrose AO OBE whose ongoing commitment to the Foundation is so valued, along with our State Patrons and Representatives. Thank you to all our dedicated Board members and our staff whose contribution is embodied in our values of respect, compassion, trust, integrity and excellence.

Robert Kaye SC Chairman

LLM. LLB. AICD

Julie Heraghty
Chief Executive Officer

BA DipEd, Assoc MAPS

# Governance

### **Board Directors**

Macular Disease Foundation Australia has a strong and experienced Board that represents the needs of the macular disease community.



Mr Robert Kaye SC, Chairman – LLM, LLB, AICD (appointed to Board 1 July 2016, appointed Chairman 7 September 2016)

Robert Kaye is a practising barrister and is also on the board of a number of ASX listed companies. He is chairman of Collins Foods Limited and Spicers Limited and a non-executive director of UGL Limited and Magontec Limited.

In 1978, Robert was admitted to legal practice and prior to this, was employed as a solicitor at Allen Allen & Hemsley. He pursued his legal career at the NSW Bar and was appointed Senior Counsel in 2003, practising in commercial law.

Robert has been extensively involved in an array of commercial matters, both advisory and litigious in nature, and has served on a number of NSW Bar Association committees including the Professional Conduct Committee.

Robert Kaye is the Chairman of the Board (from 7 September 2016) and is a member of the Audit and Risk Committee.



# Ms Elizabeth Carr, Chairman – BA (Hons), MPA, FAICD (retired 7 September 2016)

Elizabeth Carr was an inaugural board member of the Foundation and in October 2006 accepted the position of chairman. Elizabeth's background incorporates both the private and public sectors. She has worked in senior executive positions for IBM and Macquarie Group and within senior levels of politics and government in NSW, WA, PNG and the USA.

Elizabeth has been a board chair and board member for over 20 years. She is also Chair of South Metropolitan TAFE (WA), St Catherine's Aged Care Services (NSW), and Seton Villa (NSW). She is a director of the iCare (NSW) (and its associated Audit and Risk Committee and Remuneration and Nominations Committee), Kokoda Track Foundation and St Marys Anglican Girls School (WA) and a member of the Environmental Protection Authority (WA).

Elizabeth is chair of the Audit and Risk Committees for the Department of Family and Community Services (NSW), Urban Growth Development Committee and Australian Technology Park, a Member of the Harvard Club of Australia Council and a Facilitator for the Australian Institute of Company Directors.

Elizabeth Carr was the Chairman of the Board and a member of all Committees up to her retirement on 7 September 2016.



### Mr Ashley Chapman, Deputy Chairman - CPA, MACS

Ashley Chapman retired in 2004 after a career in information technology spanning over forty years. His experience includes fifteen years with IBM in a variety of roles covering systems engineering, programming and education. Ashley's industry experience includes banking and finance, airline, distribution and government utilities. After leaving IBM he became a partner in a CPA firm and then in 1978 he founded Management Control Systems, a company specialising in the development and marketing of financial systems for the distribution and manufacturing industries both in Australia and overseas.

Ashley Chapman is the Deputy Chairman of the Board and is a member of the Audit and Risk Committee, the Client Services Committee and the Board Nomination and Evaluation Committee.



### Colonel John Fenwick - BA, MBA, GAICD, AFAIM

John is a colonel and defence professional with over 27 years experience in the Army. His career spans being a helicopter pilot to leading and managing at numerous levels in the Defence Force in a variety of command and staff positions.

John is a graduate of the Australian Defence Force Academy and the Royal Military College at Duntroon. He holds an MBA specialising in Accounting and Finance from Deakin University and a BA in Economics and Information Systems from UNSW. John is a graduate of the Australian Institute of Company Directors and an Associate Fellow with the Australian Institute of Management.

Colonel John Fenwick is a member of the Audit and Risk Committee.



### **Mr Richard Grills**

Richard Grills is the previous Managing Director of Designs For Vision, a company which supplies ophthalmic and optometric products throughout Australasia. Prior to founding Designs For Vision in 1978, Richard was a clinical and dispensing optician specialising in visual handicap. He conducted low vision clinics throughout NSW at hospitals and ophthalmic practices. Since 1974 he has been a lecturer in ophthalmic optics at Sydney University and also teaches at UTS (orthoptics) and Notre Dame University (ophthalmic nurses).

Richard is a director of the Optical Distributors and Manufacturers Association (ODMA) and the Genetic Eye Foundation, and is the Chair of the Essilor Vision Foundation. He is a member of the visiting advisory board at both UNSW Optometry School and UTS Orthoptic School.

Richard Grills is a member of the Client Services Committee.



### Ms Imelda Lynch - RN, BN, MHSN, GAICD

Imelda Lynch has a nursing background with extensive executive and health administration experience having spent 25 years in leadership positions in both the public and private health sectors.

She was founding CEO of Bellberry Limited, the first provider of independent human research ethics committees in Australia, a position she stepped down from in 2014. She now holds a non-executive director role with Bellberry and Brain Injury SA.

Imelda Lynch is a member of the Client Services Committee and the Research Committee (appointed 31 March 2016).



### Mr John McCarroll - B.Ec

John McCarroll is a Director at JB Were Ltd - Private Wealth Management. John has more than 30 years experience in the finance industry, initially in Europe and for more than 20 years in Australia. John holds a Bachelor of Economics from Monash University (Vic), is a Diploma member of the Australian Institute of Company Directors and was a director of the Australian Stockbrokers Foundation for over 19 years.

John McCarroll is a member of the Audit and Risk Committee and the Board Nomination and Evaluation Committee.



### Mr Paul Rogan - BBus, FCPA, AICD

Paul Rogan is a senior executive with more than thirty years' experience in the financial services sector both in Australia and the United Kingdom. He is currently the Chief Executive, Distribution, Marketing and Research at Challenger Limited and is a Director of its subsidiaries. He has served as an Executive Director on subsidiary boards of the National Australia Bank and MLC group, including as CEO of the Wealth Management operations in the UK and MLC Building Society. Paul is also a past chairman of the Victorian Building Society Association and past Counsellor on the Association of Australian Permanent Building Societies.

Paul Rogan is the Chair of the Audit and Risk Committee.



### Dr Jim Runciman – FRACS, FRANZCO (retired 8 December 2015)

Dr Jim Runciman is a leading ophthalmologist with a special interest in retinal diseases and the support of those with vision impairment. He is a fellow and past SA state chairman of the Royal Australian and New Zealand College of Ophthalmologists, and has recently retired as a director of the Adelaide Eye and Retina Centre as well as from the board of the Royal Society for the Blind SA having served on it since 1995 including as a past president. He remains involved in ophthalmic research and is a consultant to Ellex Lasers Research and Development.

Dr Jim Runciman is the Chair of the Medical Committee and a member of the Research Committee.



### Ms Suellen Tapsall – BA, MA, FAIM

Suellen Tapsall is Director Custom Education at University of Melbourne. In this role she leads a team that works with the University's academics to develop and deliver open-enrolment and tailored programs in Australia and overseas. Suellen previously led a joint venture in Executive Education on behalf of the University of Western Australia and the Australian Institute of Management WA.

Suellen has extensive experience managing complex multi-stakeholder projects. Her career has been built around communications and stakeholder engagement, working as an academic leader and formerly in journalism and corporate communications. She is a past national president of the Journalism Education Association and has co-authored several books and major reports. Her current research is in consumer perceptions of value, with particular relevance to the cruise ship travel sector.

Suellen Tapsall is the Chair of the Client Services Committee and a member of the Research Committee.



### Associate Professor Nitin Verma – AM, FRANZCO, MD.MMed, Dip NBE

Associate Professor Nitin Verma is a leading ophthalmologist with a special interest in retinal diseases and has published and presented more than 100 papers. He is Head of the Department of Ophthalmology at the Royal Hobart Hospital, Clinical Associate Professor at the School of Medicine, University of Tasmania and Sydney, and is in private practice at Hobart Eye Surgeons.

He is a Board Member and Fellow of the Royal Australian and New Zealand College of Ophthalmologists (RANZCO), and Board Member of RANZCO Eye Foundation and the national Hospitaller for St John Ambulance Australia. Assoc. Professor Verma is also the Honorary Consul in Tasmania for Timor Leste. He was awarded the Order of Australia in 2010 for his service to ophthalmology.

Assoc. Professor Verma is the Chair of the Research Committee and a member of the Medical Committee.

### National Research Advisor



# Professor Paul Mitchell – MBBS, MD, PhD, FRANZCO, FRACS, FRCOphth, FAFPHM

Professor Paul Mitchell is a world renowned medical retinal specialist and director of the Centre for Vision Research, Westmead Millennium Institute. He is also a professor in the Department of Ophthalmology, University of Sydney and director of Ophthalmology at Westmead Hospital.

Professor Mitchell's clinical work focuses on the management of age-related macular degeneration, diabetic and other vascular retinopathies and on systemic diseases and their effects on the eye. His research has targeted the epidemiology of eye disease and clinical aspects of retinal diseases.

Professor Mitchell has made significant contributions in the fields of public health and ophthalmic epidemiology via the landmark Blue Mountains Eye Study, the first, large Australian population-based study of age-related eye disease, yielding almost 400 international publications.

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

### Chief Executive Officer



### Ms Julie Heraghty - BA, DipEd, Assoc MAPS

Julie Heraghty joined Macular Disease Foundation Australia as Chief Executive Officer in 2004. Under Julie's leadership the Foundation has evolved into a robust organisation serving the needs of the macular disease community. The activities of the Foundation over this time have resulted in Australia becoming a world leader in awareness of macular degeneration.

Prior to joining the Foundation, Julie spent over seven years as a Policy Advisor to NSW State Ministers, and also served as a director and manager in major government departments. She has served in local government as Deputy Mayor and worked voluntarily for many charitable causes. Julie's career began as a secondary school teacher and she is also a registered psychologist.

In 2013 Julie was awarded the Harvard Club of Australia Nonprofit Fellowship to attend the course *Strategic Perspectives in Nonprofit Management* at the Harvard Business School. The prestigious fellowship was a personal honour for Julie and supported the continued growth and development of the Foundation.

### **Board Committees**

### **Audit and Risk Committee**

Paul Rogan (Chair), Robert Kaye<sup>^</sup>, Elizabeth Carr\*, Ashley Chapman, Colonel John Fenwick, John McCarroll.

### **Client Services Committee**

Suellen Tapsall (Chair), Elizabeth Carr\*, Ashley Chapman, Richard Grills, Imelda Lynch.

# **Board Nomination and Evaluation Committee**

Elizabeth Carr (Chair)\*, Ashley Chapman, John McCarroll.

### **Medical Committee**

Dr Jim Runciman (Chair), Elizabeth Carr\*, Dr Amanda Greaves, Dr Alex Harper, Associate Professor Wilson Heriot, Dr David Hilford, Associate Professor Alex Hunyor, Associate Professor Anthony Kwan\*, Dr Tharmalingam Mahendrarajah, Professor Paul Mitchell, Associate Professor Nitin Verma, Dr Peter van Wijngaarden\*, Associate Professor Dimitri Yellachich.

### **Research Committee**

Associate Professor Nitin Verma (Chair), Elizabeth Carr\*, Dr Jim Runciman^, Suellen Tapsall, Associate Professor Anthony Kwan\*, Ms Imelda Lynch\*, Dr Peter van Wijngaarden\*.

### **State Chairs**

State Chairs assist the Chief Executive Officer with representation of Macular Disease Foundation Australia at a state level:

Queensland: Dr Amanda Greaves South Australia: Dr Jim Runciman^, Imelda Lynch#

Victoria: Associate Professor Wilson Heriot Western Australia: Suellen Tapsall

Tasmania: Associate Professor Nitin Verma New South Wales: Associate Professor Alex Hunyor#

<sup>^</sup> Appointed 1 July 2016

<sup>\*</sup> Retired 7 September 2016

<sup>^^</sup> Retired 8 December 2015

<sup>#</sup> Appointed April 2016

# Thank you

A principle of good governance is upholding a maximum term for directors. This ensures renewal and underpins diversity. The Board renewal program has continued this year with the retirement of two directors, our Chair, Elizabeth Carr, and ophthalmologist, Dr Jim Runciman. Both have given outstanding dedicated service, much valued expertise and steadfast commitment.

On behalf of the macular disease community we thank them sincerely for their contributions to the Foundation.

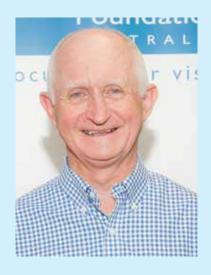


Elizabeth Carr Foundation Chair 2006 - 2016

Elizabeth Carr retired in September 2016 having made significant contributions to the Foundation over more than 12 years. She was an inaugural director from 2001 to 2003 and returned to the Foundation as Chair from 2006.

As Chair, Elizabeth implemented a review of the Foundation's governance needs and committee structures, to ensure best practices were in place for a robust and sustainable organisation.

In 2012 the Foundation changed its name to Macular Disease Foundation Australia. Elizabeth supported this change, using her skills and expertise to guide the Foundation to meet its strategic requirements within its expanded role. Elizabeth has been committed to the Foundation for 12 years, encouraging and supporting everyone to achieve the best results possible for the macular disease community.



**Dr Jim Runciman**Director 2004 - 2015

Ophthalmologist, Dr Jim Runciman, retired in December 2015 having served as a director for almost 12 years from 2004. During this time, Dr Runciman served on the Medical and Research Committees.

Dr Runciman embraced the values of the Foundation with his extraordinary passion for patients and his support for those with vision impairment.

Dr Runciman's commitment to the Foundation over many years was exemplified by the way in which he so generously shared his expertise as a long-standing member and chair of the Foundation's Medical Committee. His understanding of research, and his support in building the Foundation's understanding of research, helped shape our work to develop the Research Grants Program. Dr Runciman's commitment to educating staff on macular disease and low vision was invaluable, and has enabled the Foundation to deliver quality information in a meaningful way to all of our clients.

# Education

# Objective: To educate with accurate, specific, current and ongoing information.

The Foundation delivers education programs to members of the public as well as the health and aged care sectors. These programs are tailored to meet the needs of the audience and supported with relevant resources.

### **Education of the Public**

The Foundation delivered education sessions on macular degeneration to members of the public and community groups. These sessions included disease symptoms, risk factors, treatment options and the importance of nutrition and lifestyle. Sessions also covered low vision services, as well as aids and technologies available to help people with vision loss maintain independence and quality of life.

In 2015-2016 the Foundation conducted 117 education sessions for the general public, members of the Foundation's client base, and community-based organisations including seniors' groups, social groups, service clubs, vision-impaired groups, and groups for people from culturally and linguistically diverse (CALD) backgrounds.

Over 6,600 people attended these sessions. All received a comprehensive information kit and were asked to complete an evaluation form, which was used to inform further educational programs.

### **Public Education**

1,300 people attended 23 public education sessions held by the Foundation in metropolitan and regional locations across the country.

These sessions were promoted by invitations sent to people on the Foundation's mailing list, as well as invitations and posters sent to local ophthalmologists, optometrists, general practitioners, pharmacies, health and community centres, retirement villages and local clubs and groups. Advertising was placed in local newspapers.

### **Community Education**

In response to requests from community groups, the Foundation spoke to over 5,300 people at 94 community education sessions.

Participating community groups included Probus clubs, seniors groups such as RSL Day Clubs, Legacy War Widows, Combined Pensioners and Superannuants Association (CPSA), Men's Sheds, Computer Pals, University of the Third Age (U3A), service clubs such as Rotary, community centres, retirement villages and aged care facilities, and other health related support groups.

Additionally, the Foundation reached out to the Culturally and Linguistically Diverse (CALD) communities including Arabic, Chinese, Greek, Italian and Vietnamese communities, providing education sessions with the aid of an interpreter.

6,600 people attended 117 public and community education sessions held by the Foundation across Australia.



### Seniors Expos

Foundation educators engaged with over 1,100 people at presentations and exhibition stands at annual Retirement, Lifestyle and Travel Expos in Sydney, Melbourne and Brisbane.

Attendees received the Foundation's free self-monitoring Amsler grid as well as information on macular degeneration, diabetic eye disease, nutrition and low vision aids and services.

### **Ophthalmology Presentations**

The Foundation arranged for ophthalmologists to speak to the general public at education sessions around Australia. Dr John Downie (NSW), Dr David Hilford (QLD), Associate Professor Dimitri Yellachich (WA) and Associate Professor Nitin Verma (TAS) all delivered presentations.

"When my husband was diagnosed with age-related macular degeneration we decided to find out as much as we could about the disease so that we could try to slow down any vision loss.

Macular Disease Foundation
Australia provided us with
plenty of information and now,
understanding the importance
of diet, we try to make sure
dark green vegies and fish
are always on the menu."

Pat, NSW

# Educating Health Professionals

The Foundation delivered 20 education sessions and distributed free resources to almost 800 health professionals including ophthalmologists, optometrists, practice managers, ophthalmic nurses, orthoptists, psychologists and aged care workers.

Australia's ageing population continues to present increasing challenges for the health and aged care sector. Eleven tailored education sessions on macular disease and aged care were undertaken supporting the work of this sector.

Presentations were made to orthoptics students at the University of Technology Sydney and the University of NSW.

### **RANZCO**

The annual Royal Australian and New Zealand College of Ophthalmologists (RANZCO) Congress is a valuable opportunity for the Foundation to strengthen existing relationships with ophthalmologists and allied health professionals.

At the 2015 RANZCO Congress in New Zealand, the Foundation exhibited and Chief Executive Officer, Julie Heraghty presented two sessions to more than 120 allied eye health professionals, including orthoptists, practice managers and ophthalmic nurses.

### e-CPD Program

The Foundation continued to support general practitioners by providing resources on macular disease. A new e-CPD program was launched in May 2016 providing comprehensive information on macular degeneration including best practice referral pathways to ensure early detection and appropriate intervention.

# **APVRS**

The Asia Pacific Vitreo-Retina Society (APVRS) meeting involving over 1000 retina specialists from Australia, New Zealand and Asia was held in Sydney in August 2015.

In addition to the Foundation mounting a display of its educational resources, the Foundation's Chief Executive Officer Julie Heraghty chaired a special lunchtime symposium entitled 'Eyes, Body and Mind'.

An expert panel were invited to discuss important public health issues related to eye disease including smoking, obesity, ageing, and mental health.

The panel included, Professor Paul Mitchell, Professor John Dixon, Professor Matthew Peters, Dr Meredith Tavener and Dr Bridianne O'Dea.

This innovative and interactive Q&A session was designed to prompt thought

and discussion around a holistic, integrated approach across chronic diseases and related health areas.

It was a stimulating and informative session with the five guest panellist sharing valuable insights.



Dr Meredith Tavener, Professor Paul Mitchell, Professor John Dixon, Julie Heraghty, Professor Matthew Peters, and Dr Bridianne O'Dea.

## Where did we go?

### **COMMUNITY EDUCATION**

### **Seniors' Groups**

### **NSW**

**Asquith** Balgowlah Bankstown Baulkham Hills Black Head Blackheath **Brighton Le Sands** 

Burwood Campsie Canley Heights Carlingford Casino Castle Hill Chatswood

Cronulla Daceyville Dharruk Drummoyne **Dundas** Dural

East Maitland Gladesville Gordon Hornsby Killara

Leura Merrylands Mona Vale Mortdale North Manly North Turramurra Northbridge Parramatta Penrith

Penshurst Putney Rosehill Seaforth Seven Hills

Shoalhaven Heads

Singleton Sydney Sylvania Taren Point Tea Gardens Tenambit Thornleigh Wahroonga West Rvde Woy Woy

**ACT** Greenway Macquarie **QLD** 

**Bowen Hills** Caloundra Golden Beach

SA

Victor Harbor

**VIC** 

Caulfield Glen Waverley Ringwood Wendouree

WA

Bellevue Busselton Cottesloe Dianella Gosnells Medora Midland Nedlands Port Kennedy Rockingham Safety Bay Swan View

Yokine

NT

Darwin Wanguri

**Culturally and Linguistically Diverse Groups** 

**NSW** 

Auburn Burwood Chatswood Lidcombe Marrickville Riverwood

**VIC** 

Broadmeadows Doncaster **Lower Templestowe** Richmond

"I have the Amsler grid on my fridge at home and regularly check my eyes."

### **PUBLIC EDUCATION**

### **NSW**

Leonay

Casino Forster Katoomba Moss Vale Rosehill

Shoalhaven Heads **Terrigal** 

Tweed Heads South Wollongong

**QLD** 

**Bowen Hills** Toowoomba

Brooklyn Park

**TAS** 

Sandy Bay

**VIC** Ballarat Caulfield

WA

Crawley

NT

Wanguri

### **HEALTH CARE PROFESSIONALS**

### **NSW**

**Bondi Junction Hunters Hill** Kensington Kirrawee Lithgow Macquarie Park Mosman

Pymble St Leonards Sydney Ultimo

**VIC** 

Ringwood Melbourne

WA

Middle Swan

"Very informative and simple language that the average person can understand."

The Foundation delivered healthcare professional, community group and general public education sessions to almost 7,500 people.

To Macular Disease Foundation Australia,

Even though you must receive compliments from every venue at which you speak on 'MD' as we call it now, I doubt that you would have had a more appreciative audience and earned as many earnestly meant compliments as were flowing around the Killara Probus Club today after you had addressed our members.

On behalf of the President and all of the members, I write to thank you very much for the time you devoted to your talk today. If anything, the President's comment when you finished, to the effect that he had never heard anyone deliver a speech for 45 minutes without a glance at a note, might have sold you a bit short. Over and above that, there was not a pause to rephrase a comment, not an explanation of a technical condition that was not couched in simple terms comprehensible to all of your audience.

In short, we were treated to a masterly explanation of a complicated medical condition, which I can confidently say afflicts many in your audience and we are all greatly indebted to you for your delivery. You must have a great sense of satisfaction in the knowledge that you are helping many in the general community in a way that they could not ever expect to benefit otherwise.

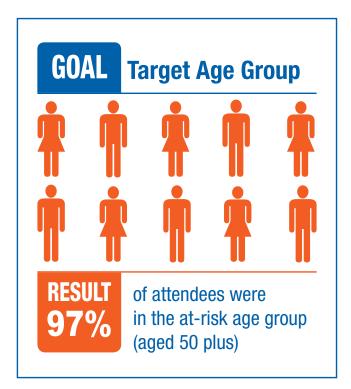
We wish you continued success in spreading a simple and comprehensive explanation of a condition that afflicts many in their senior years.

Yours sincerely,

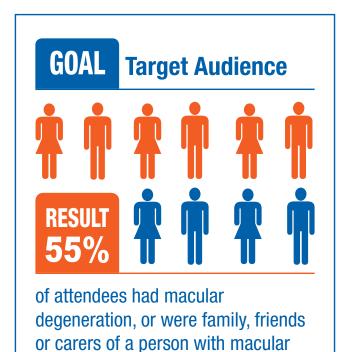
Barry Mahoney Speaker Convenor Killara Probus Club Inc

# **Achieving our Goals**

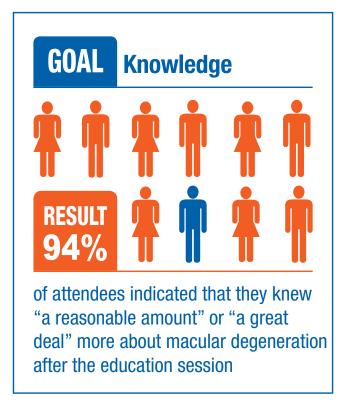
# **Education Sessions**







degeneration



# **Awareness**

# Objective: To increase awareness of macular disease

Australia leads the world in awareness of macular disease as a direct result of Macular Disease Foundation Australia's work over 15 years.

Independent national Galaxy Research surveys, commissioned by the Foundation since 2007, indicate that the majority of Australians at risk of macular degeneration (those over 50) are aware of this disease.

This is a result of the Foundation's work to promote the importance of:

- An eye test and macula check
- Positive changes to diet and lifestyle
- Early detection and treatment.

aware of macular degeneration (up from 58% in 2007)\*

86% had a macula check in the last two years\*

# Macular Degeneration Awareness Week 2016

Sunday 22 to Saturday 28 May

Themed "baby boomers at risk of macular degeneration", this year's Macular Degeneration Awareness Week was led by Foundation Patron Ita Buttrose calling for all those over 50 to have an eye test and macula check. The far reaching campaign included traditional media, online and social media, and direct mail.

### Voices of the Foundation

Ambassador Jean Kittson added her voice to Macular Degeneration Awareness Week media activities, along with CEO Julie Heraghty, Drs Alex Hunyor, David Hilford, Nitin Verma, and Friends of the Foundation Melvyn Byrne, Margaret Raynor and Lorna Rickert.

"All the baby boomers are now aged over 50 and that means they're at risk of macular degeneration. For this reason it is critical to have an eye test and macula check and adopt eye health diet and lifestyle practices."

Ita Buttrose, Patron

Macular Disease Foundation Australia

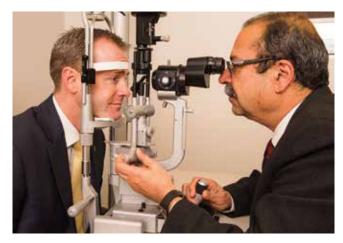
<sup>\*</sup> Australians at risk (over 50) of macular degeneration

### Politicians Support the Message

Federal and State Ministers who supported Macular Degeneration Awareness Week activities included:

- The Hon. Sussan Ley MP
   Minister for Health and Aged Care
   (Federal)
- The Hon. John Ajaka MP Minister for Disability Services and Ageing (New South Wales)
- The Hon. Cameron Dick MP Minister for Health (Queensland)
- The Hon. Zoe Bettison MP Minister for Ageing (South Australia)
- The Hon. Jill Hennessy MP Minister for Health (Victoria)
- The Hon. John Day MP
   Minister for Health (Western Australia)
- The Hon. Michael Ferguson MP Minister for Health (Tasmania).

# Tasmania Minister's Call to Action



The Hon. Michael Ferguson MP, Tasmanian Minister for Health, was filmed having an eye test and macula check by Foundation State Chair Associate Professor Nitin Verma AM. The video was used to communicate key messages on social media.



# **Key Media Outcomes**

## **Television**



2,349,821

National viewing audience

34 pieces of coverage across 33 regional and 5 metro markets

## Radio



3,372,381

**Estimated radio audience** 

271 pieces of coverage across 105 stations

### **Print**



2,610,655

Circulation across trade and consumer publications
112 articles across 93 publications

## Online



13,214,896

Online editorial
114 articles across 102 websites

### Online Advertising / Social Media

Online and social media engagement was undertaken across paid and the Foundation's own channels.

Material produced included advertisements and a number of short videos, including the personal story of Friend of the Foundation Melvyn Byrnes who lives with macular degeneration, and interviews with Foundation Patron Ita Buttrose and Ambassador Jean Kittson.





# Social Media



860,899

Potential audience on 3rd party social media platforms

### Reaching Out

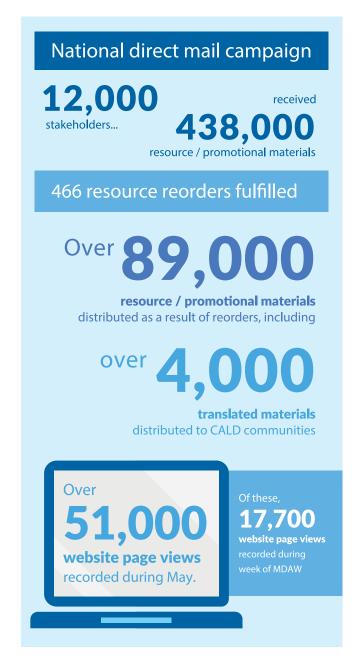
The Foundation reached out, communicating to Arabic, Chinese, Greek, Italian and Vietnamese people with key messages translated for radio and print media. Additionally, paid print adverts were produced to further spread the word.





### Information Distribution

A national direct mail campaign to 12,000 key stakeholders encouraged participation in Macular Degeneration Awareness Week through provision of resources, media engagement and social media promotion, to build awareness of macular degeneration and associated key health messages.



The Foundation welcomed Bayer as a new supporter of Macular Degeneration Awareness Week 2016 and thanks Bayer, along with long-term supporter Blackmores for their support. The Foundation also thanks Optometry Australia for its assistance.

# Melvyn's Story



As part of Macular Degeneration Awareness Week activities, Friend of the Foundation Melvyn Byrnes shared his experience of living with macular degeneration. His story was filmed and shared across multiple platforms.

Melvyn was diagnosed with wet macular degeneration in 2007 but considers himself fortunate. Aged 78 and a retired pharmacist, he is acutely aware that if he hadn't acted quickly upon recognising the symptoms of macular degeneration, he'd be telling a different story.

"One morning I woke up and noticed a black spot on the ceiling. I tested my vision with my Amsler grid and straight away noticed the lines, once straight, were wavy and blurry. The next day I saw a retina specialist who gave me an injection in the right eye and I've been having regular injections ever since. Those injections have saved my sight. My right eye hasn't deteriorated and because wet degeneration was picked up in my left eye, virtually before I had any symptoms, I still have good vision.

"I can still drive, I can still read, and I can look after my wife Robyn who, unfortunately, has developed frontaltemporal dementia in the last two years. I'd have been a different person now if these injections weren't available.

"My father was a soldier and when he came back from the war his eyesight deteriorated. It was all put down to something that happened in the war but looking back, I'm sure he must have had macular degeneration.

"I can only stress the importance of making sure that if you have macular degeneration, your immediate family is made aware of the need to have their macula checked regularly.

"I think a lot of the progress in treatment and services for people with macular degeneration comes down to the work of the Foundation.

"They are very proactive and are making the community aware of what a problem macular degeneration is, especially as the number of older people in the community continues to increase."

# mEYE World Photographic Competition 2015

The annual mEYE World Photographic Competition, initiated in 2011, raises awareness of macular disease and engages with the Australian community through the visual arts.

The 2015 competition ran from 14 July to 8 September 2015 and called for entries that captured the theme "See My World".

Promotional activities included a community service announcement campaign across radio and print; editorial coverage across radio, press, online and television; an online advertising campaign and other targeted engagement activities; all culminating to achieve an 86% increase in entries received on the previous year.

### **Key Outcomes**

- O 2,426 entries received, up 86% on 2015
- O Community Service
  Announcements reach potential audience of 21,000,000
- Online advertising reaches potential audience of 700,000 people, with 10,000 click-throughs to the competition website
- O 3,548 'Likes' on Facebook, up 200% in one month

### **Open Category Winner and Grand Finalist:** Rebecca Burton



"Golden morning light streaming into the kitchen and a box of shredded paper. My child was captivated by the dust motes dancing in the air; I got to peek into her magical world. We both saw magic that day. Celebrate the little details you see every day. It's all so precious."

Rebecca Burton

# Showcasing the Talent

mEYE World Photographic Competition entries were judged by Foundation Patron Ita Buttrose, and respected photographers Rex Dupain and Alan Pryke. Winners were announced by Ita Buttrose at an awards event on 12 November 2015.

A photography exhibition, held in the foyer of the newly opened Novartis Macquarie Park campus, showcased over 50 outstanding photographs from the competition and was open to the public.

A video showcasing the awards announcement event and exhibition was produced for the Foundation's website to further promote the competition and awareness of macular disease.

Thank you to judges Ita Buttrose, Rex Dupain and Alan Pryke, and competition supporters Novartis and Nikon Lenswear for Visionaries.

Thanks also to prize donors Nikon Australia, Adobe, Mainline Photographics, Wacom Australia, OPSM, Lindt, Officeworks, Manfrotto, Yaffa Publishing Group, Momento Australia, www.fotofast.com.au, New Holland Publishers, FUJIFILM Australia and Saxon.

# mEYE World Photographic Competition Winners 2015

Open Category Winner and Grand Finalist: Rebecca Burton

Healthcare Professional Category Winner:
Dr Kerry Boytell

Macular Disease Community Category Winner:
Di Lymbury

Junior Category Winner: Caitlin Dixon



Grand Finalist Rebecca Burton



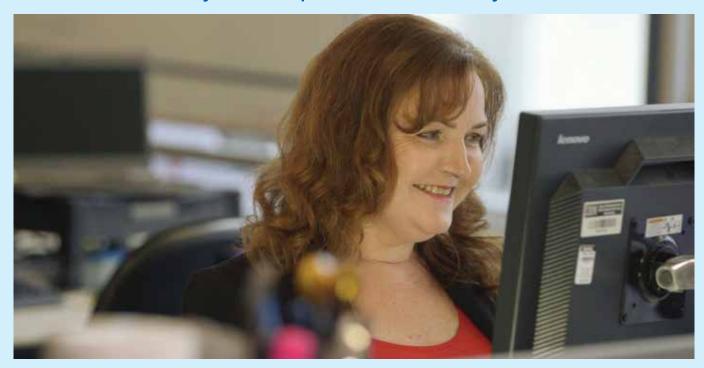
Judges Rex Dupain, Ita Buttrose and Alan Pryke



Judges Ita Buttrose and Rex Dupain with Junior Winner Caitlin Dixon



# International Day of People with Disability



On International Day of People with Disability, 3 December 2015, the Foundation launched a short video about Friend of the Foundation Alicia Thompson who lives with Stargardt's disease.

Alicia's story, which demonstrates how people can live well with a disability, was also told through editorial and inclusion on the Foundation's website, social media and newsletter.

Alicia's story strongly resonated with the community. People were inspired to call the Helpline to find out more about low vision aids and technologies.



# Alicia's Story

At 44, Alicia Thompson is a professional businesswoman with a husband, a teenage son and a love of knitting. Not much different from many women you'd meet on the streets of a busy city, except that Alicia has lost 95 per cent of her sight and, since the age of 19, has lived with loss of central vision now making her legally blind.

Alicia has Stargardt's disease, a hereditary eye condition that affects the macula, leaving a person with only their peripheral vision. She had perfect vision until 1990 when she was diagnosed and since then, her vision has progressively deteriorated. "My sight is still getting worse – I'll notice for a day or two that things aren't the same and then that

becomes normal. I don't really remember what I used to see."

### Technology is Everything

Alicia said her iPhone and iPad have given back her independence. "I can look up train timetables and plan trips using public transport, I can message people, read books, search the internet, look up recipes." Magnification too, has changed everything. "Using my portable magnifier, I can pretty much see anything I want to."

"I may not do things the way sighted people do, but I don't let that stop me. Different doesn't mean it's wrong. And hard doesn't mean you can't. It's more about finding a different way to do it."

### **Publications**

### **Trade Publications**

The Foundation was successful in gaining support from key media in the eye health sector to raise awareness of issues surrounding macular disease. Articles appeared in *mivision*, *Australian Optometry*, *RANZCO News* and *Insight*, ensuring health professionals remained informed of new developments as well as the important work of the Foundation.

### **Consumer Publications**

Full-page and half page advertisements promoting awareness of macular disease and the Foundation's services were published in the *NSW Seniors Directory*, which is distributed to almost one million people via post and email.

Awareness of diabetic eye disease was increased within the Vietnamese community with a double page spread in the South Australian publication *Viet Magazine*. Additionally, articles highlighting the importance of diet and lifestyle for good eye health ran in HCF's magazine *Fit and Well* and Australian Unity's magazine *LifePlus*.

### Social Media

Recognising the increasing power of social media to reach people of all ages throughout Australia, the Foundation supported all awareness activities with Facebook posts, Twitter feeds and YouTube videos.

## **Eating for Eye Health**

Eating for Eye Health - The Macular Degeneration Cookbook, co-authored by Patron Ita Buttrose and chef Vanessa Jones, and now in its 3rd edition, continued to generate awareness of the importance of eating eye-health foods.

# Friends of the Foundation

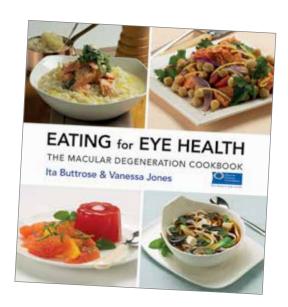
Friends of the Foundation continued to support the Foundation's work in advocacy, public relations, social media and fundraising.

This invaluable program enables the Foundation to capture inspiring personal stories from people living with macular disease, their carers, family members and healthcare professionals.

In this annual report you will find stories from Melvyn Byrnes, Alicia Thompson and Jacqueline Baxter-Cocks. The Foundation thanks all our Friends of the Foundation for so generously supporting in this way.

# Keep on Driving Safely

The Foundation successfully expanded its *Keep on Driving Safely* project to South Australia and Western Australia. The initiative involves a macular disease flyer being inserted into driver licence renewals. The program continues in the Australian Capital Territory. The Foundation thanks Lotterywest for supporting the program in Western Australia.





# Jean's Story

I remember the day my mother Elaine told the family she was losing her sight. She was in her early forties and had been to an ophthalmologist because she was having trouble with her vision. In particular the white lines on the road had become wavy. She wasn't told what her vision problem was, only that she would go blind one day and there was nothing she could do about it. Then she was sent home.

Without an understanding of her eye condition it was impossible to know how we could help or prepare for the future.

Nearly fifty years later mum is legally blind and many of the pleasures of her life have been greatly restricted; seeing movies, reading books, watching television. She now relies on her remaining senses. She still cooks an excellent fruitcake, conjuring by recollection, taste, smell and a fine mathematical mind. Dad is a great help to her, assisting when needed and being her constant, faithful chauffeur.

Much of their lives revolves around things they do with vision impaired groups, like walking, fitness and bowls. It is sad that mum can no longer read, drive or go to the movies – things she loved doing. She does have talking books, and a really big TV screen.

I have an uncle who also has macular degeneration so I am keenly aware that along with age, genetics puts you at risk. I care deeply about the eye health of my family and the possibility of my children getting the disease. I hope that one day, with enough support for research, we will have a cure for this disease.

At the moment, early diagnosis is imperative for treatment so my key message for everyone is get your macula checked, and if you have someone in your family with macular degeneration, contact the Foundation. They are warm, friendly and give invaluable information and great support. They make a huge difference.

### Ambassador Jean Kittson

Jean Kittson is a performer, writer and proud Ambassador of Macular Disease Foundation Australia. Jean is an engaging speaker and willingly shares her personal insight into the impact of macular degeneration on her family. Macular Disease Foundation Australia is very grateful to Jean for her ambassadorial work and dedication in promoting the Foundation's important messages.

# Celebrating 15 Years of Sight Saving Work



Annual
mEYE World
Photographic
Competition
raises awareness
of macular disease

78,000 people attended education sessions nationally over 10 years

Foundation
funded research
grants generates
25 published
peer-reviewed
articles

Annual Macular
Degeneration
Awareness Week
promotes eye
tests and macula
checks



Foundation
becomes a world
leader in raising
awareness
of macular
degeneration

Foundation's national **Helpline** takes **140,000 calls**since introduction

\$3 million in research grants awarded to leading Australian researchers since 2011



Foundation's
own research
published in
6 prestigious
peer reviewed
journals

Advocacy leads to affordable, registered, sight saving treatments for macular disease

Foundation
expands its
reach to include
all macular
diseases



Partnerships and alliances grow to support the work of the Foundation

"Congratulations on 15 brilliant years of supporting the Australian community. Here's to many more!" Jean Kittson "Congratulations to the Foundation for their ongoing work to save sight and on reaching this 15th year milestone."

Ita Buttrose

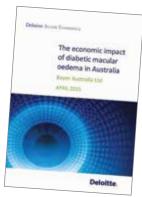
# Celebrating 15 Years of Sight Saving Work



Eating for
Eye Health
The Macular
Degeneration
Cookbook
launched

Over 5 million
people receive
macular disease
information with
drivers licence
renewals

The Economic
Impact of
Diabetic
Macular Oedema
in Australia
published



Global
engagement
program shares
Foundation's work
and expertise
with 16 countries

Professional
Friends
program engages
optometrists and
ophthalmologists



Friends of the
Foundation
share their stories
to increase
awareness of
macular disease

Thousands
support Sight for
Seniors campaign
for equity of
access to aids and
technologies



Key
publications
produced in
7 languages

Publication of
Foundation's carer
research **The Ripple Effect**of Vision Loss

Foundation

professional

education program

supports key health

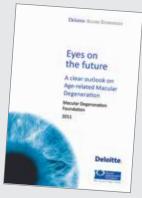
care providers

Health, ageing and disabilities become a key focus for the Foundation

The Vision Van initiative takes free eye tests and macula checks to **towns** across Australia



Eyes on the
Future Report
documents the state
of the nation of agerelated macular
degeneration



95,000 people receive information kits packed by volunteers

## Research

## Objective: To support and pursue research

## Macular Disease Foundation Australia Research Grants Program

Macular Disease Foundation Australia funds world-leading research which aims to reduce the incidence and impact of macular degeneration.

The Foundation's grants and fellowships make significant funding available for Australian medical, low vision and nutritional research into macular degeneration. They are awarded following rigorous evaluation based on the National Health and Medical Research Council (NHMRC) Guidelines. International peer review ensures successful applicants meet the highest standards.

## 2015 Research Grants Program

On World Sight Day, 8 October 2015, the Foundation awarded research grants to six Australian researchers totalling \$1.3 million.

The Governor-General, His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd) presented the grants on the Foundation's behalf at a ceremony at Admiralty House in Kirribilli, Sydney.

Guests included research grant recipients, representatives from the macular disease community, key supporters and Foundation Directors.



Governor-General Sir Peter Cosgrove and Lady Cosgrove with Research Grant recipients

## 2015 Grant Recipients

## Macular Disease Foundation Australia Research Grants

- Professor Mark Gillies
  Save Sight Institute
  The University of Sydney
  \$400,000 over three years
- Associate Professor Chi Luu
   Centre for Eye Research
   Australia, Melbourne
   \$200,000 over three years
- Associate Professor Gerald Liew Centre for Vision Research Westmead Millennium Institute The University of Sydney \$100,000 over one year

## Macular Disease Foundation Australia and Blackmores Combined Grant

Professor Steven Krilis
 St George Hospital
 UNSW Australia
 \$400,000 over three years

#### Blackmores Macular Disease Foundation Australia Research Grants

- Or Isabelle Jalbert
  School of Optometry and
  Vision Science, UNSW Australia
  \$100,000 over two years
- Or Laura Downie
  Department of Optometry
  and Vision Sciences
  The University of Melbourne
  \$100,000 over three years



Elizabeth Carr, Lady Cosgrove, Governor-General Sir Peter Cosgrove and Julie Heraghty



Governor-General Sir Peter Cosgrove



Dr Lesley Braun (Blackmores Institute), Professor Steven Krilis, Julie Heraghty, Christine Holgate (Blackmores)

Since launching the Research Grants Program in 2011, Macular Disease Foundation Australia has committed almost \$3 million to 13 leading Australian researchers.

### 2015 Researchers and their Funded Grants



Professor Mark Gillies MBBS, PhD, FRANZCO

Save Sight Institute
The University of Sydney

"The Foundation plays a very important role in helping people with macular disease in Australia. Its Research Grants Program is now one of the major support schemes for macular research."

Clinical trials can be very different from routine practice. 'The Fight Retinal Blindness Project' aims to establish if patients treated for eye conditions in the real world do as well as studies have indicated. This international collaboration will provide strong data on several questions about treatment. This includes the effects of duration between treatments. the effects of reducing treatment frequency, and recommendations that can be made to patients regarding longer term prognosis.



Associate Professor Chi Luu B.Orth (Hons), PGDipEpidBiostat, PhD

Centre for Eye Research Australia, Melbourne

"One of my hobbies is flying planes by simulation. I like it because it's challenging and exciting, and it took me years to master. I feel the same challenge and excitement in my research."

This study aims to validate a new instrument designed to detect people with high risk of macular degeneration at a much earlier stage.

If successful, this technology will enable trials on new treatments to be conducted more quickly and could also reduce the cost of trials, enabling more treatments to be studied.

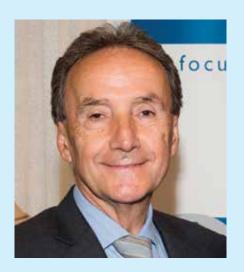


Associate Professor Gerald Liew MBBS (Hons), MMed (Hons), PhD, FRANZCO

Centre for Vision Research Westmead Millennium Institute, The University of Sydney

"Research is about trying to imagine what's possible in a future world and what can be done to make the future better. The Foundation's support of this research is critical to the continuation of work in metabolites."

This pilot study will investigate whether certain metabolites (small chemicals in the blood) that result from the age-related macular degeneration disease process may enable the development of a simple blood test which could be used as an early indicator for disease progression.



Professor Steven Krilis, MBBS, PhD, FRACP

St George Hospital UNSW Australia

"The thing I love about research is that it is creative – we are creating new ideas and knowledge that can be translated to help patients and families."

This study will link environmental risk factors such as smoking and a high fat diet with biological system changes that are involved with disease development.

The project is jointly funded by Macular Disease Foundation Australia and Blackmores.



Dr Isabelle Jalbert OD, MPH, PhD

School of Optometry and Vision Science, UNSW Australia

"The Foundation is a fantastic advocate for greater awareness of AMD and as such, a really good partner to help me ensure patients receive the information they need."

This project will identify obstacles faced by eye care practitioners in delivering the best care for people living with macular degeneration.

It will also assess knowledge and understanding of the role of diet, supplementation and lifestyle modifications so that health interventions can be directed where most needed.

The project is funded under the Blackmores Macular Disease Foundation Australia Research Grant.



Dr Laura Downie BOptom PhD, FAAO

Department of Optometry and Vision Sciences The University of Melbourne

"I feel passionate about this area of research. The work we are doing can lead to immediate improvements in the quality of clinical care."

This project will develop a standardised education program for optometrists based on best practice to deliver a more consistent level of early diagnosis, improved referrals and guidance from optometrists to patients and their families.

This project is funded under the Blackmores Macular Disease Foundation Australia Research Grant.

## Funded Research Grants Projects - Current

**Professor Erica Fletcher, The University of Melbourne:** examining a possible cause for the development and progression of early AMD. The aim is to develop new treatments and screening for people at greatest risk of disease progression.

Professor Damien Harkin, Queensland University of Technology and the Queensland Eye Institute: developing technology to enable healthy retinal pigment epithelium cells (RPE) to replace those damaged or killed during the progression of macular degeneration.

Associate Professor Bamini Gopinath, Westmead Millennium Institute, The University of Sydney: analysing diet and lifestyle of patients with late stage macular degeneration.

Associate Professor Wilson Heriot, The University of Melbourne: exploring a link between plaquenil and chloroquine retinal toxicity and blue light damage, and possible connections to other macular diseases.

# Research Grants Projects - Completed

Professor Robyn Guymer, Centre for Eye Research Australia, Melbourne: identification of several common characteristics found in some people with macular degeneration that progress more quickly than in others. Ten peer-reviewed papers published on the findings.

Professor Paul Mitchell, Westmead Millennium Institute, The University of Sydney: examining simple measures to reduce the risk of macular degeneration, or slow its progression. Findings from this project have informed key health messages.

Dr Liubov Robman, Centre for Eye Research Australia, Melbourne: examining dietary factors associated with age-related macular degeneration. The study reported that a primary diet comprising fish, chicken, grains, nuts, fruit and vegetables significantly lowered the risk of developing vision-impairing late stage macular degeneration.

Associate Professor Bamini Gopinath, Westmead Millennium Institute, University of Sydney: determining if consuming regular dairy foods lowered the risk of macular degeneration and whether vitamin B12 and folate supplementation impact risk factors. Further research is to be undertaken.

### Foundation Research

The Foundation conducts research independently and in collaboration with other researchers.

#### **Published Articles**

In 2015-2016 the Foundation had four peerreviewed articles published in prestigious journals. Peer-reviewed articles accepted for publication are those that exemplify the best research practices in a field.

The articles were:

- Predictors of psychological distress in caregivers of older persons with wet age-related macular degeneration. Aging and Mental Health, 2015,19:239-246.
- Current barriers to treatment for wet age-related macular degeneration: findings from the wAMD patient and caregiver survey. Clinical Ophthalmology, 2015;9:2243-50.
- Caregiver perceptions about the impact of caring for patients with wet age-related macular degeneration.

  Eye (London),
  2016;30:413-421.
- The emotional and physical impact of wet age-related macular degeneration: findings from the wAMD Patient and Caregiver Survey.

  Clinical Ophthalmology, 2016;10:257-267.

#### **Foundation Services**

The Foundation evaluates its services every year by surveying valued clients. The information collected is analysed and used to inform activities and services for the year to come. The Foundation surveyed 2,000 people from across the spectrum of the Australian macular disease community.

The Foundation studies this information to ensure we are providing the correct service to the community.

The survey identified:

- 90% of participants were 50 years or over
- 63% had macular degeneration or a family or friend living with macular degeneration
- 95% had accessed key services such as the national Helpline, newsletter, education sessions and website.

How satisfied were our clients?

- 93% were 'very' or 'mostly' satisfied with Foundation services
- 87% responded the Foundation 'mostly', 'fully, or 'exceeded' expectation
- 96% rated the Helpline, website and newsletter 'good' or 'excellent'

#### Low Vision Survey

Recent advocacy strategies were informed by a survey conducted in August 2015 of people registered with the Foundation who have vision loss. The survey showed 28% of respondents were prevented from purchasing some low vision aids due to cost. People with severe vision loss were significantly more aware of the availability of vision services than those with slight to moderate vision loss.

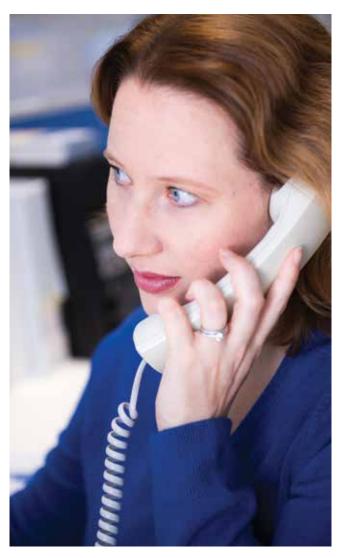
#### **Cost of Treatment Survey**

A further survey conducted in August 2015 on the costs experienced by people receiving injections for wet AMD revealed significant variations in treatment costs, and

that substantial numbers of people did not understand the reimbursement system. This led to the development of a new fact sheet on treatment costs and reimbursement which is now made available to all Foundation clients receiving injections and for distribution through ophthalmologists' clinics.

## Audit of State and Territory Aids and Equipment Programs

In 2015-2016 the Foundation audited the current availability of, and eligibility for, aids and technologies in each state and territory of Australia. Accessibility of low vision aids and technologies differs across Australia, with programs having different budgets, scope, eligibility requirements and levels of subsidy. This research highlighted inequitable access across the country and was used to inform the Foundation's advocacy work.



# Residential Aged Care Research

A Department of Health grant was awarded to the Foundation to conduct a study to 'reduce the incidence and impact of vision impairment' in residential aged care facilities. This study is to run over two and a half years.

The Foundation identified the need for this study, as there is evidence that aged care residents have more vision issues which are not being adequately managed, when compared to similarly aged people living in their own home.

Across the year the Foundation worked with eight participating aged care providers. This included a review of existing policies and procedures by the study's Project Officer, with vision and eye health assessments of residents being undertaken by a research orthoptist.

In the coming year this study will move into the next phase of data analysis, resulting in evidence based recommendations to guide the future management of vision and eye health care in residential aged care facilities.



Hazel Walden and Project Officer Jan Steen

## **Research Communication**

#### Macular Disease Research E-newsletter

Macular Disease Foundation Australia's weekly research e-newsletter is distributed to over 1,000 ophthalmologists and other interested eye care providers.

The e-newsletter summarises global published peer-reviewed research on key diseases of the macula. This important resource ensures eye health professionals remain informed of the latest developments in treatment, diagnosis, genetics, diet and other related issues.

#### Research Interpretation

The Foundation interprets the latest, typically complex research into key messages that are easily understood by the public to help them reduce their risks of macular disease, seek early diagnosis, treatment and/or rehabilitation.

Research is also interpreted so that clients can understand a diagnosis and maintain hope for the future.

#### **Annual Research Updates**

An easily understood Research Update, summarising promising research developments, is produced annually for the general public.

### **ARVO**

The Foundation attended the Association of Research in Vision and Ophthalmology (ARVO) in May 2016. ARVO is the largest gathering of laboratory and clinical researchers in the world and enables the Foundation to keep abreast of the current and future developments in drug development, diagnostics, genetics, stem cell treatments and other technologies.

## Jan's Story

For a considerable part of my life I was blissfully unaware of the existence of the disease known as macular degeneration.

When my grandfather, naval engineer and yacht designer Aage Utzon, gradually lost his sight in the late 1960's, it was accepted as something that could be expected when you grew older. Not until my father, Jørn Utzon, began to experience the same symptoms at the turn of the millennium, did the term 'macular degeneration' appear in the vocabulary of our family. Wet macular degeneration was the verdict. His vision steadily declined over the years until his passing in 2008.

My father was able to keep working on projects up until the end of his life. As he and I had been working together for almost 40 years, we had developed an architectural rapport as it were, where his ideas and directives, through my hands, could produce the documents and drawings needed for the refurbishment of the Sydney Opera House.

Because of his analytical approach to his own condition, the rest of the members of our family became acutely aware of the trauma that macular degeneration can have on a person's life. As you can imagine I have become very aware of macular degeneration, and must accept that I have a hereditary risk of being afflicted with the disease.

Witnessing my father's sight deteriorate from macular degeneration was heartbreaking. 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 for this disease, which unnecessarily disables many of our citizens, individuals who, if they could retain their eyesight, with their skills and knowledge could be of great benefit to our society.



### Ambassador Jan Utzon

Jan Utzon is a Danish architect and son of famed Sydney Opera House architect Jørn Utzon. Deeply influenced by his father's approach to architecture, the two worked closely together on several prestigious projects until Jørn's passing in 2008. Jan, through his own design practice, has undertaken many interesting projects. One of his most successful is the Performing Arts Centre in Esbjerg (1997) with its theatre and concert hall combined with the earlier art museum. Macular Disease Foundation Australia is grateful to have a strong and staunch advocate in Jan, and thank him for agreeing to be a champion for the cause.

## **Support Services**

## Objective: To provide and facilitate relevant support

Macular Disease Foundation Australia provides services in person, over the phone, in print and online to people who are living with, and at risk of macular disease, their families and carers.

## **National Helpline**

During 2015-2016 the Foundation's Helpline answered almost 8,200 calls from people around Australia who live with a macular disease, their family members, friends and carers.

The Foundation's Helpline team offered these people valuable information, guidance, understanding and support.

### Online Communication

The Foundation continued to increase its online presence to better meet the needs of people of all ages who seek information on macular disease.

The social media forums, Facebook, Twitter and YouTube were used to circulate information and engage in discussion among digital users.

The Foundation's website has become a powerful tool for the dissemination of information on macular disease, research and associated issues and the promotion of the Foundation's many activities.



## **Publications**

The Foundation produces publications in print, audio and online formats. These publications are critical to increasing awareness of risk factors and symptoms, and to giving guidance on diagnosis, treatment and rehabilitation. They are distributed nationally to individuals as well as to health care professionals to support their patients.

#### **Fact Sheets**

As well as producing publications on macular degeneration, diabetic eye disease and low vision, the Foundation produces fact sheets on other macular diseases and associated complications.

#### **New Fact Sheets**

The Foundation expanded its resources with fact sheets on:

#### **Eye Injection Costs and Rebates**

In response to the needs of the community, general information on the costs for eye injections for the management of wet macular degeneration, diabetic retinopathy and similar conditions. The fact sheet also gives general information on Medicare entitlements.

#### **Cataracts and Macular Degeneration**

Produced to increase awareness and resolve misconceptions about cataracts and macular degeneration, two common conditions that often occur at the same time.





#### **Guides for Low Vision**

The Foundation's low vision series assists people to live independently with low vision, and help carers and family to provide effective support.

The series comprises:

- Low Vision: A Guide A practical introduction to living with low vision
- Family, Friend & Carer: A Guide
  For people providing care to a person with low vision
- Slips, Trips & Falls: A Guide Practical advice on avoiding falls
- Low Vision Aids & Technology: A Guide Information on the different types of aids, equipment and technology which assists those with low vision.

## Reaching Out

Recognising Australia's diverse multicultural population, the Foundation provides key publications translated into Arabic, Chinese, Greek, Italian, Portuguese, Spanish and Vietnamese. These publications were made available in print and on the Foundation's website.

## **Audio Publications**

The Foundation produces a number of its information booklets as audio publications for use by people with low vision.

Publications including Age-related Macular Degeneration; Nutrition and Supplements for Macular Degeneration; Low Vision - A Guide; and Slips, Trips & Falls - A Guide, are available online via the Foundation's website and on CD.

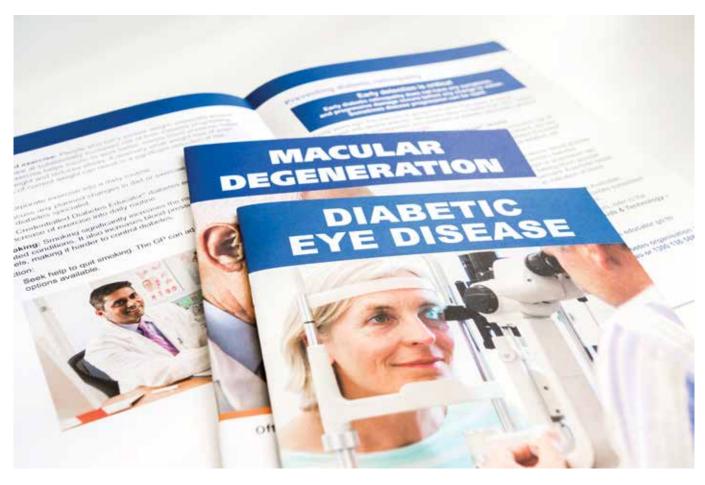


## **Information Kits**

Foundation volunteers packed over 10,000 information kits comprising publications about macular degeneration, diabetic eye disease and low vision.

Kits were distributed at education and awareness events and in response to calls to the Foundation's Helpline.

Over 900,000 individual publications and resources were distributed to the general public and health care professionals.



## **Newsletters**

The Foundation's quarterly macular degeneration newsletter focuses on issues related to macular disease.

It provides updates on projects and advocacy campaigns being undertaken by the Foundation and outlines key research. The newsletter remains a vital tool for communicating with, and educating, the community.

In 2016 the Foundation launched a newsletter on diabetic eye disease. Diabetic eye disease is the leading cause of blindness in Australia's working age population.

The first newsletter featured Australian music icon Marcia Hines who lives with diabetes. Marcia spoke about her personal lifestyle strategies to prevent the onset of diabetic eye disease.

#### Annual Research Updates

The annual *Research Update*, produced every December, summarises promising research developments over the year, in language easily understood by the general public.

The Foundation is especially grateful to the Medical Committee, which provides oversight and guidance on the Foundation's key messages.

"Thank you so much for the quality information provided by the Foundation. When your newsletter arrives, it's the first thing I open."

Gordon, NSW



### Low Vision Services

#### **Low Vision Information Days**

Low vision information days provide an opportunity for the Foundation to personally connect with the macular disease community, to provide advice and obtain feedback on different skills and equipment that can enhance quality of life and independence.

During 2015-2016 the Foundation organised and presented at low vision information days for members of the public across NSW. Low vision service providers were invited to present alongside the Foundation, including Vision Australia, Guide Dogs, Quantum RLV and Humanware.

#### Low Vision Advisory Service

The Foundation continued to provide its low vision advisory service in collaboration with Guide Dogs NSW/ACT. This service operates from the Foundation's national office and involves an orthoptist from Guide Dogs working closely with clients to assess individual needs and determine which aids and technologies can help to best maintain independence and quality of life. Clients are able to view, discuss and trial a wide range of low vision aids, equipment and technology during this consultation.

#### Navigator Audio Book Program

The Navigator is a hand-held portable device that reads books and newspapers aloud. The Foundation provides free access to the Navigator via two projects: the Navigator Library Access Project and the Navigator Home Access Project. These projects provide free access to audio book technology either through a local library or via download access from home.

"I've been an avid reader all my life and prior to developing macular degeneration I used to go to bed and sometimes read all night. Now I take the Navigator and when I go to sleep, it turns itself off. I couldn't imagine not having access to books.

Fortunately the Navigator gives me that access."

Val, NSW



## Kathleen's Story



At 85, Kathleen is an avid reader who loves to spend time reading the *Sydney Morning Herald* while her cat rests on her lap.

Kathleen has macular degeneration, and although she managed with deteriorating vision for many years, a year ago she began to lose the ability to read printed pages using only her spectacles.

A low vision consultation by Guide Dogs at the Macular Disease Australia Foundation alerted Kathleen to the need to increase her magnification and lighting in her home, however a few months later, she found herself back in the same situation. "There wasn't a lot I could do. I couldn't get out easily, I couldn't read and I couldn't even watch television because the remote control became too difficult to use," she said.

A home visit by Vision Australia provided the solution. "Vision Australia advised me on small changes I can make that will help me, including a large button remote control so

that I can get back to watching television.

They also gave me a new DAISY player which automatically downloads the Sydney Morning Herald each morning and enables me to access books. I was given a full demonstration of the DAISY and a large print out of the controls, which makes it very easy to use. There is also a Helpline available if I have difficulty or want to access more books.

"On the first day I had my DAISY, I read the Herald and then I started to read a book. I didn't move all day and the only complaint came from my cat who wasn't getting the usual attention.

"My DAISY has helped me get back in touch with what is happening in the world. I'm not feeling bored anymore and I have plenty to talk to my friends and family about. Now that I'm reading novels again, I'm even considering joining the book club at my local library."

## Representation

# Objective: To advocate for the best interests of the macular disease community

#### Government

#### Federal Budget 2016

The Foundation reviewed the 2016-2017 Federal Budget to assess the impact on the macular disease community.

Key issues identified included changes to Medical Benefits Schedule indexation for patients with macular disease, which could result in additional cost shifting to patients; tightened eligibility requirements for the mobility allowance; and changes to the carer allowance.

The Foundation welcomed the trial of the new 'Health Care Homes' program to better support those with chronic and complex conditions.

#### Federal Election 2016

The Foundation, along with many members of the macular disease community, wrote to candidates to request commitment to the Foundation's policy platform which comprised:

Establishment of an equitable, national, federally funded low vision equipment program to ensure affordability and accessibility of low vision aids, equipment and technologies for people with vision loss or blindness

- Support for affordability of health care for the macular disease community, including Medicare funding of OCT scans
- Funding for the Foundation's messaging for preventive health and chronic disease via continued national awareness, education and support services.

#### National Aged Care Alliance

## Ageing and Disability Interface Working Group

In chairing this group, the Foundation was highly active in the development of a position statement for the 2016 Federal Election, highlighting significant opportunities to improve aged care services to meet diverse needs of Australia's ageing population. Recommended improvements would also benefit carers, families and friends of elderly people, workers, professionals and aged care service providers.

In addition, a discussion paper was formulated, which aimed to reduce inequities and improve the interface between the aged care and disability sectors. This enabled the elevation of interface issues, and access and affordability issues for aids and equipment, to NACA's Federal Election 2016 agenda and position statement.



## **Advocacy Issues**

The Foundation made 37 submissions representing the interests of the macular disease community including:

#### **PBS Listing for Approved Treatments**

Successfully advocated for improved accessibility and affordability of additional registered anti-VEGF treatment for people living with diabetic macular edema (DME) and retinal vein occlusion (RVO), diseases that affect the macula and can cause vision loss and blindness.

In October 2015, aflibercept (Eylea) became the second anti-VEGF treatment to be listed on the Pharmaceutical Benefits Scheme for the management of DME and RVO.

## Medicare Benefits Schedule Item: Optical Coherence Tomography Reimbursement

Recommended a new Medicare Benefits Schedule item for reimbursement of optical coherence tomography (OCT), a non-invasive imaging test used to detect, diagnose and guide treatment for eye diseases including macular degeneration and diabetic eye disease. The Foundation continues to advocate for appropriate reimbursement of OCT.

## National Priorities for Clinical Practice Guidelines

Advocated for the development of clinical practice guidelines by the National Health and Medical Research Council to manage macular degeneration.

#### **Private Health Insurance**

Highlighted concerns at a consumer roundtable, particularly with respect to injections for wet macular degeneration, along with access to low vision aids and technologies for those with vision loss and blindness. This formed part of a review of private health insurance initiated by the Federal Government, chaired by Professor Graeme Samuel AC.

The Foundation also voiced concerns to the Australian Competition and Consumer Commission over changes by individual private health insurers in regard to treatment benefits.

## Pharmaceutical Benefits Advisory Committee Guidelines

Recommended amendments to the Pharmaceutical Benefits Advisory Committee Guidelines to support access and equity to treatment for macular diseases.

## Chronic and Complex Health Conditions – Primary Care

Contributed to the Federal Government's National Strategic Framework for Chronic Conditions being developed by the Primary Health Care Advisory Group. The Foundation highlighted the need for properly coordinated long-term management of chronic disease to ensure a smooth pathway between health, disability and aged care. This included accessibility of information and cost barriers to early diagnosis and treatment.

#### **Medicare Benefits Scheme Review**

In response to the Federal Government's Medicare Benefits Scheme review, the Foundation highlighted the need for affordable access to effective treatments for macular diseases, including intravitreal injections. This included concerns that any attempt to reduce costs may result in 'cost-shifting' with additional financial burden being placed on patients.

#### **Commonwealth Home Care Packages**

Actively supported proposed reforms to the Commonwealth Home Care Packages to improve consumer choice, provision of appropriate specialist low vision assessments and support services for people living at home.

## Independent Review of the National Disability Insurance Scheme Act

Strongly recommended the inclusion of people 65 years and over in the National Disability Insurance Scheme (NDIS). The advocacy included establishment of an independent and expert audit and risk group to advise the National Disability Insurance Agency on financial aspects and sustainability of the NDIS, and the impact on state and territory programs.

#### The Marrakesh Treaty

Reviewed and supported legislative changes to ratify the Marrakesh Treaty, which provides people around the world who are blind, visually impaired, or otherwise print disabled, with equal access to information and communications.

## Working Together

Macular Disease Foundation Australia worked with a range of organisations in the areas of ageing, health and disability including:

#### **National**

#### **National Aged Care Alliance**

A representative body of peak national organisations in aged care including consumer groups, providers, unions and health professionals.

#### **Australian Blindness Forum**

A forum that promotes effective functioning of blindness agencies by exchanging information and influencing the policy agenda of government.

#### Vision 2020

A global initiative of the World Health Organization and the International Agency for the Prevention of Blindness. The Foundation is represented on the Prevention and Early Intervention and the Independence and Social Participation committees.

#### State

The Foundation met with various state and territory ministers and departments in the portfolios of health, disability and ageing, highlighting key areas of concern affecting the macular disease community and the need for equitable access to treatment, services and low vision aids and technologies.

In New South Wales, the Foundation represents the macular disease community as an appointed member of the following NSW Ministry of Health organisations:

#### NSW Agency for Clinical Innovation Ophthalmology Network – Governing Body (Co-chair)

The Foundation co-chairs the Governing Body, which promotes equitable access to public sector ophthalmic services for the people of NSW. Representation is also undertaken on the Community Eye Care Steering Committee and Diabetic Retinopathy Working Group.

#### Non-Government Organisation Advisory Committee

The Foundation is a long-standing member of this committee which facilitates collaboration between NSW Health and non-government organisations (NGOs) on the development and implementation of NSW Health policy. The Foundation is also represented on the steering committee of Partnerships for Health, a program to support the transition to new procurement arrangements for health funded NGOs.

### Global Reach

The Foundation was also represented at major ophthalmic research meetings globally, throughout the year, including:

## Association for Research in Vision and Ophthalmology

The world's largest annual gathering of vision researchers where major new developments are presented.

#### **American Academy of Ophthalmology**

The world's largest ophthalmic clinical symposium where clinical outcomes from major new research projects are presented.

## Retina Australia Triennial Research Conference

A meeting with local and international low vision researchers and the retinal disease community.

## Supporting our Neighbours in the Asia Pacific

The Foundation continued its global engagement program, sharing best practice strategies, activities and experiences with ophthalmologists and representatives of macular disease organisations from the Asia Pacific.

As part of this comprehensive program, Macular Disease Foundation Australia was invited to attend Singapore's annual Age-related Macular Degeneration Awareness Week in September 2015. The Foundation's Chief Executive Officer, alongside Singapore's Health Minister, spoke to delegates at the launch of this important week.

Following this, the Foundation's Chief Executive Officer, supported by Foundation General Manager, led a two-day macular disease advocacy workshop, attended by twenty ophthalmologists from seven countries of Asia.







## **Best Practice Management**

## Objective: To ensure best practice management

## An Experienced Board

Macular Disease Foundation Australia has a strong, experienced Board to provide the overall direction, management and corporate governance of the organisation. Directors have valuable expertise and are committed to the interests of the macular disease community.

### Committees

The following committees operate as part of good governance and management throughout the year:

- Audit and Risk Committee: assists the Board in the effective discharge of its responsibilities for financial and regulatory reporting, internal controls, compliance and risk management, and the internal and external audit processes.
- Medical Committee: provides expert advice on macular diseases to ensure that, in all matters of a medical nature relating to macular disease, information is accurate, relevant, up to date and consistent with current evidence.
- Client Services Committee: provides input, guidance and support on client service related areas of the Foundation's work.

- Research Committee: provides expertise and guidance related to the Foundation's research activities, especially in relation to the Foundation's Research Grants Program.
- Board Nomination and Evaluation Committee: advises on Board appointments and performance, induction programs and continuing development, and committee membership.

### **Committed Staff**

Guided by the values of respect, trust, compassion, integrity and excellence, the Foundation's staff of 13 works from the national office in Sydney. Planning days, professional staff training and team development programs are regularly undertaken. Key performance indicators are set and achievements benchmarked to identify opportunities for continued growth and improvement.

### **Dedicated Volunteers**

Volunteers provide valuable support to the Foundation, contributing both time and expertise in many different areas of work. Many volunteers live with macular disease, others are carers, family members or friends, and others volunteer as part of their philosophy of giving to the community.



## Strategic Planning

All organisations need to dedicate time and resources to planning for the future. Ongoing challenges mean the Foundation must anticipate, plan and be responsive to change to ensure that its work continues to meet the needs of our community.

The Board and senior management worked together throughout 2015-2016 to produce a new strategic plan which has been built upon the three pillars of: centre for excellence; listening and speaking to our audiences; and being a strong voice for macular disease community.

This plan will enable the Foundation to continue to meet its vision of reducing the incidence and impact of macular disease in Australia. Our sustainability as an organisation is underpinned by innovation and resourcefulness and driven by diverse sources of funding and strong governance capabilities.





















## **Financial Report**

#### PROFIT & LOSS (FOR THE YEAR ENDED 30 JUNE)

\$000	2016	2015
Revenues		
Sponsorships	1,266	1,456
Donations/Fundraising	544	1,031
Donations - Research Grants Program	706	567
Corporate support	600	627
Government grants	698	516
Investment income	636	407
Total Revenues	4,450	4,604
Expenses		
Support services	636	876
Awareness	622	681
Research Grants Program	616	376
Research	347	204
Management	516	402
Education	387	345
Representation	232	226
Fundraising	114	136
Total Expenses	3,470	3,246
Net Surplus	980	1,358

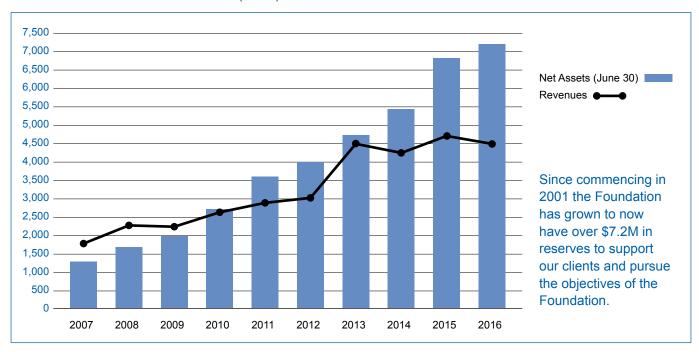
#### **BALANCE SHEET (AS AT 30 JUNE)**

\$000	2016	2015
Assets		
Cash and cash equivalents	1,118	1,365
Investments	5,666	5,672
Trade and other receivables	1,451	929
Property, plant and equipment	16	41
Total Assets	8,251	8,007
Liabilities		
Trade and other payables and provisions, current	924	1,203
Provisions, non-current	42	20
Total Liabilities	966	1,223
Net Assets <sup>1</sup>	7,285	6,784

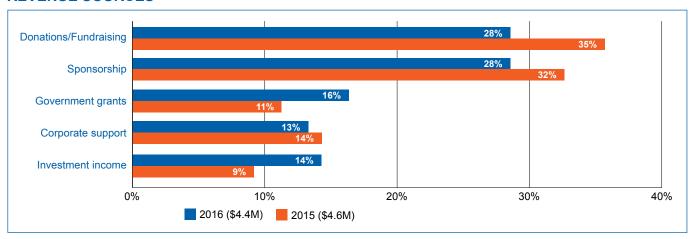
<sup>1</sup>As at 30 June 2016 the Foundation had \$1,165,000 (2015: \$2,000,000) set aside within the Net Assets to support future research initiatives. The difference between the movement in Net Assets and the Net Surplus for the year is attributable to movements in unrealised gains/(losses) on investments as required under Australian Accounting Standards.

The information on this page was extracted from the audited Financial Statements of Macular Disease Foundation Australia for the year ended 30 June 2016 and is presented in a management reporting format. The audited Financial Statements can be obtained free of charge on the Macular Disease Foundation Australia website or by contacting the Foundation on 1800 111 709.

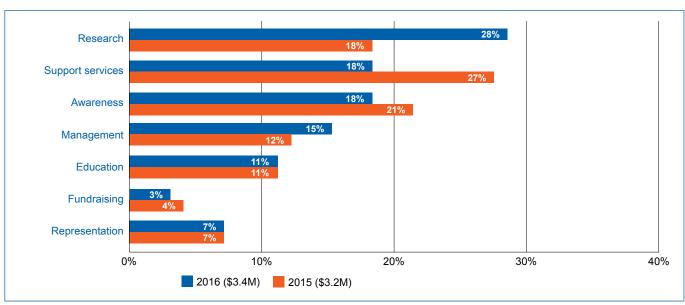
#### **10 YEAR FINANCIAL SUMMARY** (\$000)



#### **REVENUE SOURCES**



#### **EXPENDITURES**



## **Fundraising**

# Objective: To provide income to support the Foundation's services

The Foundation relies on financial support from government, organisations and individuals to meet the real needs of the macular disease community. Together we are reducing the incidence and impact of macular disease in Australia.

## **Government Funding**

Thank you to the Federal Government for its financial support since 2005, and the NSW Government, which has continued to provide funding since an initial establishment grant in 2002.

Federal Government funding further contributed to the Foundation's work, through:

- Funding over three and a half years under the Department of Health's Peak and Advisory Bodies Programme. This grant supports the Foundation's work including the development and communication of relevant evidence-based information for the macular disease community, health providers, government and other related stakeholders.
- Department of Health provision of funding for an aged care project aimed 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 contributed to the Foundation's 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.

## **Corporate Sponsorship**

Corporate sponsorship is integral to the Foundation's work, enabling the continuation of awareness campaigns, education, research and client service and support.

Thank you to all corporate sponsors who provided support during 2015-2016.

#### Bayer

Since 2011 Bayer has provided valuable support for numerous initiatives in the areas of client services, awareness, education and research. This has allowed the Foundation to expand its activities and services to assist the many people who require the Foundation's help.

Since 2013 the Foundation has also received support from Bayer's global organisation to expand its voice on the world stage.

In 2015-2016 Bayer furthered its support through Macular Degeneration Awareness Week 2016.



Adrian Dolahenty and Anna Karelas, Bayer

#### **Blackmores**

With a shared common value to reduce the incidence and impact of macular degeneration in Australia, Blackmores has been a long-term supporter of the Foundation's education, research and awareness programs.

In 2015-2016, in partnership with Macular Disease Foundation Australia, funding for new research grant/s was introduced to encourage and enhance research into the nutrition and/or lifestyle aspects of macular degeneration.



Marcus Blackmore with Foundation Ambassador Jean Kittson

#### **Novartis**

Generous support from Novartis since the Foundation's establishment has made a significant contribution to improving macular health in Australia.

In particular, Novartis supported the Foundation's first national television and radio awareness campaigns from 2008 to 2012, which helped Australia become a world leader in awareness of macular degeneration.



Brian Gladsden, Novartis

#### Mylan EPD

Mylan supported the Foundation's work to increase awareness and education of diabetic eye disease. This work, supporting both patients and health professionals, helped highlight the critical importance of eye health for those with diabetes.



Sylvain Vigneault, Mylan EPD

#### Quantum RLV

Low vision aids and technologies provider Quantum RLV is a founding and continuing supporter of the Foundation.



Tim Connell, Quantum RLV

#### Humanware

Low vision aids and technology provider Humanware became a new supporter in 2015-2016.



Jason Abrahams. Humanware

# Foundations and Trusts Profield Foundation

The Foundation acknowledges the support of the Profield Foundation since 2007, which has funded client services including the Helpline, publications, awareness and education activities.



Profield Foundation Board

## Community

#### ClubsNSW ClubGRANTS

During 2015-2016 the Foundation was a beneficiary of the NSW ClubGRANTS scheme, which encourages registered clubs in NSW to contribute directly to the provision of frontline services in their local communities.

Clubs that supported the Foundation in 2015-2016 were: Cabra-Vale Diggers, Campsie RSL Club, Club Central Hurstville, Club Maitland City, Club Rocky's, Cowra Bowling and Recreation Club, Dubbo RSL Club, Goulburn Soldiers Club, Goulburn Workers Club, Hornsby RSL Club, Lithgow Workies, Moree Services Club, Orange Ex Services' Club and Singleton Diggers.

#### Roth Gair Charity Golf Day

The 9th annual Roth Gair Charity Golf Day was held in February 2016 in memory of the late Mr Roth Gair, a long time member and past President of the Lions Club of Forest Hill, who lived with macular degeneration. This event was organised and hosted by the Lions Clubs of Forest Hill and Park Orchards in Victoria.

#### **Dedicated Community Members**

Every year people across Australia choose to fundraise for Macular Disease Foundation Australia by seeking financial support to undertake challenges and participate in events. Jacqueline Baxter-Cocks, featured on page 61, was just one of our supporters in 2015-2016.

### **Donations**

Donations from individuals and organisations, both large and small, are essential to the Foundation's ability to maintain and expand services to meet the needs of the macular disease community.

## **Bequests**

Bequests form an increasingly important part of the Foundation's funding. Bequests can be directed to support ongoing client services, or to the Foundation's Research Grants Program. The Foundation appreciates the very generous bequests made every year by members of the public.



## Jacqueline Baxter-Cocks: Painting for the Foundation



Jacqueline is 55 and has lived with wet macular degeneration in both eyes for the past three years. A fine artist from Western Australia, she said receiving her diagnosis was a life-changing moment.

"I was diagnosed with dry macular degeneration then one eye developed wet macular degeneration. My specialist told me to expect the other eye to turn within six months. He was right. I now have injections in both eyes every six to eight weeks to maintain my vision."

Once diagnosed Jacqueline decided to channel her artistic talents into raising money to support Macular Disease Foundation Australia's research. She set up a fundraising page on 'Everyday Hero' and got to work.

Jacqueline's fundraising concept is to create quick paintings in around ten minutes and video the process. The paintings and videos are uploaded to Facebook and auctioned off over a week with the starting price set at \$30.

Often a small bidding war takes place as the auction comes to its conclusion and the winning bidder is announced on Facebook.

"My favourite mediums for painting have always been watercolours, oils, and pastels. More recently I've turned to acrylics because they dry quickly, which makes them perfect for this project."

Jacqueline's art raised \$8,000 for the Foundation's research program in just six months and she continues to sell paintings and videos to support the cause. Her family also supports the Foundation, raising funds with their own campaigns.

This year Jacqueline's niece, Haylee Moyle and husband Shane raised almost \$7,000 by hosting a trivia night. In 2014-2015, her niece Alana Simmons raised funds by completing a 1,300 km virtual relay.

Thank you to Jacqueline and her family for their great support of the Foundation.

## Thank You

The Foundation thanks all sponsors, donors, volunteers and supporters whose generosity enables Macular Disease Foundation Australia to meet the real needs of the macular disease community. Together we are reducing the incidence and impact of macular disease in Australia.

## **Sponsors & Supporting Partners**

Australian Government



























## **Professional Friend Program**

The Foundation has enjoyed a strong and valuable relationship with optometrists, ophthalmologists and other eye care practitioners across Australia since its inception in 2001. Our combined efforts have saved the sight of thousands of Australians. By becoming a Professional Friend, eye care professionals demonstrate their ongoing support of Macular Disease Foundation Australia and show their commitment to being at the forefront of client support services.

#### Thank you to our Professional Friends:

Dianne Andrews, Menai Eye Care • Dr Jennifer Arnold, Marsden Eye Specialists • Sally Atkins, Atkins Optometrist • Dr Andrew Atkins, Victorian Eye Surgeons • Dr Gayatri Banerjee, Nepean Valley Eye Surgeons • James Baumgarten, Family Eyecare • Dr Paul Beaumont, Retina & Vitreous Centre • Geoff Blackwell, Clear Optometry • Garry Bormann, Vision Eye Health ● Deanne Bradford, Windsor Optometry ● Ian Breadon, Eyecare Plus Clifton Hill ● Ian Brigden, Eyecare Plus Nelson Bay • Elaine Bryant, Lakes Entrance Optometrists • Dr Guy Bylsma, Hobart Eye Surgeons • Mary-Rose Campbell, Optomize • Dr Derek Chan, Retina Consultants • Dr Jay Chandra, Jay Chandra & Associates Pty Ltd • Dr John Chang, Marsden Eye Specialists • Wai Yoong Chin, Wai Yoong Chin Optometrist • Andy Christiansen, The Optical Superstore • Dr Augustino Clark, Northern Rivers Eye Surgeons • Justin Clunas, Hansen Optometrists Eyecare Plus Orange • Janelle Coates, EyesWest • Judith Cooper, Judith Cooper Optometrist • Dr Sudha Cugati, Northern Eve Specialists • Peter D'Arcy, Peter D'Arcy Optometrist • Cedric De Souza, Melville Optical Clinic • Maria Dimitratos, Icon Eyewear Dr John Downie, Chatswood Grove Eye Clinic
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## Help Macular Disease Foundation Australia

### Donate to Save Sight

Making a donation can help the Foundation 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 the Foundation's regular giving program provides a sustainable future for the work of the Foundation.

#### Donate to Research

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

### A Bequest

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

### Corporate Partnerships

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

### **Sponsors**

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

## **Community Fundraising Events**

The Foundation 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 the Foundation.

#### A Commemorative Gift

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

#### A Memorial Gift

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

### Volunteering

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

To donate or for more information contact the Foundation

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.

## **OUR VISION**

To reduce the incidence and impact of macular disease in Australia

Celebrating 15 years



Our focus is your vision

Macular Disease Foundation Australia Suite 902, Level 9, 447 Kent Street Sydney NSW 2000

Helpline: 1800 111 709 www.mdfoundation.com.au ABN 52 096 255 177









