

Caring for our community with your help...



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# Macular Disease Foundation Australia

Macular Disease Foundation Australia is committed to reducing the incidence and impact of macular disease in Australia through education and awareness programs, research, provision of support services and representing the best interests of the macular disease community.

The Foundation is a national charity providing information, guidance and support on prevention, early detection, treatment and rehabilitation.

It is the voice of the macular disease community with the strategic goals of building healthy communities, development of effective public policy, a sound knowledge base, and strong relationships and partnerships.

The Foundation's work encompasses macular degeneration, diabetic eye disease, retinal vein occlusions and a range of other macular diseases.

# **Our Values**

The Foundation's strategic goals are achieved through the commitment to shared common values. These values are:

**Respect** – Respect for the dignity of the person

**Compassion – Concern, support and understanding** 

**Integrity** – Trustworthiness, honesty, loyalty, reliability and the highest standard of ethical behaviour in an environment of total quality care

**Competency** – Focus on effective, appropriate, high-quality care in the advocacy for, and administration of, services for people with macular disease, their family and carers



Ambassador Jean Kittson with parents Elaine and Roy. Elaine and Jean pictured on cover.

# **Our Vision**

To reduce the incidence and impact of macular disease in Australia

# Strategic Goals

Building healthy communities Building a strong position in the development of public policy

Building a sound knowledge base Building strong relationships and partnerships

# **Objectives**

#### **Education**

To provide accurate, specific, current and ongoing information

#### **Awareness**

To increase awareness of macular disease

#### Representation

To advocate for the best interests of the macular disease community

#### **Support Services**

To facilitate access to relevant support and support services

#### Research

To support and pursue research

# **Our Guiding Principles**

Macular Disease Foundation Australia's work as a charity aims to meet the real needs of the people it represents. It engages and depends upon the active support of volunteers, individuals and organisations and is guided by the following principles:

**Access and Equity –** The Foundation is committed to equity of access to treatments, care and rehabilitation

**Knowledge** – The Foundation values its knowledge and continues to develop expertise, drawing on its own and others' experience

**Social Justice** – The Foundation pursues social justice, works to empower the macular disease community and strives to oppose any disadvantage they may be experiencing

**Investment** – The Foundation invests in the future by using resources and knowledge to improve the future of the macular disease community. To undertake this task it is committed to strengthening the Foundation, its people and practices

**Change** – The Foundation is persistent in pursuing change and works creatively to make a real difference for the macular disease community

**Consideration** – The Foundation respects the client and all those with whom it relates in the meeting of its objectives. The Foundation treats others with respect at all times

**Participation** – The Foundation encourages the active participation of families, friends and communities

**Acceptance** – The Foundation values and celebrates diversity in its membership and in activities. It provides guidance and support for all people with macular disease, their family and carers in a non-discriminatory, ethical manner

**Standards** – The Foundation upholds the highest ethical standards in its daily work and its relations with all parties

**Appreciation** – The Foundation appreciates the contribution of governments, volunteers, advocates, other non-government organisations, and all those who work for the common good of the macular disease community

**Partnerships** – The Foundation values, supports and works with all partners including the medical profession, corporations and allied health care professionals in order to improve the quality of life of all people with macular disease

# Key Highlights of 2013-2014

- On World Sight Day 2013 the Hon Peter Dutton MP, Minister for Health, presented Foundation Research Grants totalling \$600,000 to two outstanding Australian researchers
- Research grants announcement event held against the backdrop of the Through
   His Eyes photo tribute to Sydney Opera House architect Jørn Utzon, who lived with
   macular degeneration in later life
- Foundation's overall commitment to the Research Grants Program now totals over \$1.5 million since 2011
- Over 13,000 calls to Foundation Helpline, with a peak of 5,000 calls achieved during May / June awareness activities
- Estimated audience reach of 26 million people achieved from media coverage of Macular Degeneration Awareness Week 2014
- 33,000 Amsler grids distributed as part of Macular Degeneration Awareness Week
- 92% awareness of macular degeneration among Australians over 50 following national television and radio campaign
- Over 7,800 people reached via education programs in metropolitan and regional Australia
- Shared key findings from The Ripple Effect of Vision Loss research with key healthcare professionals at RANZCO 2013 and at Vision 2014 congresses, highlighting the significant impact of wet age-related macular degeneration on carers and patients
- The Ripple Effect of Vision Loss research published in prestigious Aging and Mental Health journal
- Advocated across critical issues associated with all macular disease, including accessibility and affordability of treatment and rehabilitation
- Advocated on eye clinic capacity crisis at Royal Adelaide Hospital following major issues with access to timely treatment
- Thousands of people supported the Foundation's Sight for Seniors campaign advocating for no age discrimination in the National Disability Insurance Scheme, equal access to aids and technology, and increased Foundation funding
- In response to the Have a Cup of Tea with Your MP campaign, community members met with politicians around Australia to share their experiences of living with macular degeneration
- mEYE World Photographic Competition attracted a record 944 entries and achieved 16.9 million media impressions
- Professional Friend Program launched to further support relationships with eye health professionals
- Eating for Eye Health The Macular Degeneration Cookbook, by Patron Ita Buttrose and chef Vanessa Jones, relaunched to meet continued demand
- 95% of Foundation survey respondents reported being "mostly satisfied" or "very satisfied" with Foundation services

# 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 also diagnosed. 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. 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.

Ita was named Australian of the Year 2013 and 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 National Ambassador of Alzheimer's Australia and Emeritus Director of Arthritis Australia.

As Patron of Macular Disease Foundation Australia, Ita works tirelessly to promote the cause of macular degeneration across Australia.

# Report from the Chairman and Chief Executive Officer

In 2013-2014 we continued to build upon our internationally recognised work in macular degeneration while entering a new and exciting phase in working with other macular diseases including diabetic eye disease and retinal vein occlusions. We are delivering effective and impactful programs and activities across the Australian macular disease landscape in the areas of education and awareness, research and client services. We strive always to represent the best interests of the macular disease community.

A particular highlight of this year was the continued investment in Australian researchers via the Macular Disease Foundation Australia Research Grants Program. This program was launched in 2011 to fulfil the Foundation's objective to support research to reduce the incidence and impact of macular degeneration and ultimately to find a cure for this chronic disease. In 2013 the Foundation awarded grants to two outstanding researchers: Professor Erica Fletcher (The University of Melbourne) and Associate Professor Damien Harkin (Queensland University of Technology) to undertake innovative, high impact research.

The grants were awarded on behalf of the Foundation by The Hon Peter Dutton MP, Minister for Health, at an event at the Sydney Opera House. The event was set against the backdrop of the Foundation's unique photo tribute to the renowned Sydney Opera House architect Jørn Utzon who lived with macular degeneration in later life. The Foundation is indebted to his son and our Ambassador Jan Utzon for the gift and use of family photographs for the event and his ongoing commitment to the Foundation.

Since the Research Grants Program launch, over \$1.5 million has been committed to world leading Australian researchers. We thank all donors and benefactors who generously support our Research Grants Program.

Australia continued to be a world leader in raising awareness of macular degeneration, thanks to the work of the Foundation. Of the over 50 at-risk population, over 90% are aware of macular degeneration and almost two in three people report having had a macula check in the last two years. These awareness levels have a direct and substantial impact on early detection leading to saved sight.

The Foundation's awareness programs are multi-faceted, however, one of the major initiatives that has contributed to the awareness levels is the ongoing national television and radio advertising campaign. In May 2013, the Foundation continued this campaign airing a new advertisement which maintained the key message to have an eye test and macula check, as well as reinforcing the importance of seeking information and understanding from the Foundation. Our sincere thanks go to Bayer for their generous support of this campaign.

The television and radio campaign led up to and included Macular Degeneration Awareness Week. Now in its 14th year, the awareness week is a key fixture on the eye health calendar. This year the principle message was the promotion of the importance of self-monitoring one's eyes using an Amsler grid. With research showing that knowledge of the Amsler grid was low, it was an ideal opportunity to reinforce how a simple home test could save sight. Our continued thanks go to our partners Novartis and Blackmores for their ongoing support, along with assistance from Optometry Australia.



Elizabeth Carr, Chairman

Our Patron Ita Buttrose AO, OBE once again dedicated her time and expertise to the Foundation. She featured in media across Australia promoting risk reduction and early detection as well as the importance of nutrition for eye health through the relaunch of her popular cookbook *Eating for Eye Health - The Macular Degeneration Cookbook*. Ambassador Jean Kittson and her mother Elaine were also generous in their support of the Foundation, sharing their story of Elaine's challenges of being legally blind from macular degeneration.

This year, the impact of the national television and radio campaign as well as Macular Degeneration Awareness Week resulted in an unprecedented demand for the Foundation's services. Over the months of May and June, almost 5,000 Helpline calls were received and 4,000 information kits distributed.



Julie Heraghty, Chief Executive Officer

As part of our expansion into macular disease, this year the Foundation also directed its attention to diabetic eye disease. We signed a Memorandum of Understanding with Diabetes Australia and in October 2013 jointly undertook a media campaign on World Sight Day to highlight the frightening reality that diabetic eye disease is one of the most common complications of diabetes. More than a third of people with diabetes will develop some form of diabetic eye disease in their lifetime however up to 50% of Australians with diabetes do not undergo eye examinations at the recommended frequency of every two years.

Our comprehensive education program once again reached out to those with and at risk of macular degeneration, providing information, understanding and guidance to almost 8,000 people in cities and regional

areas across Australia. The program also engaged families and carers recognising the valuable, but often challenging role they have in supporting a person with reduced vision. The Foundation also provided education programs for health care professionals, with particular focus on how they can meet the needs of patients and carers.

In continuing our commitment to represent the best interests of the macular disease community, the Foundation is active in the eye health, disability and ageing sectors. We have fearlessly presented our community's key issues to policy makers, especially the advocating of equity of access to treatment and rehabilitation. Our goal is to improve the quality of life of those with macular disease, their family and carers.

Our major sponsors once again enabled us to deliver new projects, and maintain and improve our existing services. Our sincere thanks go to all our partners especially the Federal and NSW Governments, Blackmores, Bayer, Novartis, Profield Foundation and Perpetual Foundation. We thank Ernst & Young who so generously give their time and expertise as our auditors and to King & Wood Mallesons who support us with legal advice.

The Foundation is most grateful to the many donors, both individual and corporate, who give so generously in order that others may live better with macular disease. Thank you also to the people and organisations we work with including government and government departments, eye care professionals and their representative bodies, and low vision rehabilitation service providers.

Thank you to our staff and volunteers who work to ensure the delivery of quality services and outcomes. Good governance is a vital aspect of any organisation and we thank all the Foundation Board Directors for their guidance, commitment and expertise. Our robust fiscal disciplines, guided by the Board, help support our financial strength which enables us to continue to deliver our programs, plan for the future and grow to meet the increased demand for our services. Most importantly it enables us to achieve our vision to reduce the incidence and impact of macular disease in this country.

Elizabeth Carr

**FAICD** 

Chairman BA (Hons) UWA MPA Harvard University Julie Heraghty
Chief Executive Officer
BA DipEd, Assoc MAPS

"We are delivering effective and impactful programs and activities across the Australian macular disease landscape in the areas of education and awareness, research and client services. We strive always to represent the best interests of the macular disease community."

# Macular Disease Foundation Australia

#### **Our Board**

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



#### Ms Elizabeth Carr, Chairman - BA (Hons), MPA, FAICD

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 not-for-profit board chair and board member for 18 years. She is also chair of St Catherine's Aged Care Services, a director of the Kokoda Track Foundation, and St Mary's Anglican Girls School WA. She is a member of the Environmental Protection Authority (WA), a director of the Safety, Return to Work and Support Board (NSW) and its associated Audit and Risk Committee and Investment Funds, and also chair of the Audit & Risk Committee for the Department of Family and Community Services.

Elizabeth Carr is the Chairman of the Board and is a member of all Committees.



#### 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. Industry experience included 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 & Risk Committee, the Investment Sub-Committee, the Client Services Committee and the Board Nomination & Evaluation Committee.



#### Dr Paul Beaumont – FRACS, FRANZCO, AM (retired 10 December 2013)

Dr Paul Beaumont is a Founding Director of the Foundation and served the first Chairman's term. He is a regular speaker at international conferences and trains doctors worldwide in his approach to macular degeneration. He has had a particular interest in nutritional epidemiology and has been a pioneer in intensive counselling for patients with macular degeneration. He is a past chairman of the NSW Division of The Australian and New Zealand College of Ophthalmologists and of the Committee of Chairmen of the Australian College.

Dr Paul Beaumont was the Chair of the Medical Committee and a member of the Research Committee.



#### Mr Peter Brown

Peter Brown has spent thirty years in advertising and communication. He worked in London in consumer advertising and new product development before moving to Sydney in 1988, becoming Creative Director of a major healthcare agency. In 2005 Peter started his own company, spanning both consumer and healthcare advertising.

Peter Brown is a member of the Client Services Committee.



#### Mr Barry Clarke - FIPA

Barry Clarke has over 40 years experience in the financial services sector in both executive and CEO roles. He is currently a director of the Royal Society for the Blind of SA and serves on its Client Advisory Committee and the Finance and Investment Committee. Barry is legally blind, having experienced the onset of macular degeneration over 20 years ago, therefore he has a clear understanding of the needs of people with vision impairment.

Barry Clarke is a member of the Client Services Committee and the Investment Sub-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. He has been a lecturer in optics at Sydney University since 1974. Richard is the Chairman of the Optical Distributors & Manufacturers Association (ODMA) and a director of the Genetic Eye Foundation.

Richard Grills is a member of the Client Services Committee.



#### Professor Jill Keeffe - PhD, OAM

Professor Jill Keeffe is a member of the faculty of the L V Prasad Eye Institute in Hyderabad, India and has an Honorary Professorial position in the Department of Ophthalmology at the University of Melbourne. She is also a Technical Advisor to Lions Clubs International Foundation's SightFirst program. Her research focuses on the development and evaluation of eye care services that aim to prevent vision loss and blindness.

She was awarded the Order of Australia Medal for "services to public health particularly in the area of vision testing and as a contributor to the advancement of eye care education and practice".

Professor Jill Keeffe is a member of the Client Services Committee.



#### Mr John McCarroll - BEc, GAICD

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 Investment Sub-Committee and the Board Nomination & Evaluation Committee.



#### Mr Peter Reid - BA, LLB, FAICD

Peter Reid has practised as a lawyer since 1972, specialising in international law and the energy and resources sector. He served as an Australian diplomat for seven years including a posting to the Australian Mission to the United Nations in New York. He then spent nine years as the Senior Exploration Counsel for Esso Australia and the past 26 years in private legal practice. He is a frequent speaker at international industry and professional conferences and has lectured at The University of Sydney Law School. He has served as a non-executive director of companies in the private, public and not-for-profit sectors.

Peter Reid is a member of the Audit & Risk Committee, the Investment Sub-Committee and the Client Services 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 Product and Marketing, at Challenger Limited and is a Director of its subsidiaries. He has served as an Executive Director on subsidiary boards of National Australia Bank and MLC Group, including as CEO of the Wealth Management operations in the UK and MLC Building Society. He 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 & Risk Committee, the Investment Sub-Committee and the Research Committee.



#### Dr Jim Runciman - FRACS, FRANZCO

Dr 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 R&D.

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 the director of AIM WA - UWA Business School Executive Education. In that role she successfully and effectively works with public and private sector organisations (in Western Australia, interstate and overseas) to build their individual and organisational leadership capability.

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 former national president of the Journalism Education Association and has co-authored several books and major reports.

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





# 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.

His 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 300 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 more than seven years as a policy advisor to NSW state ministers, and also served as a director/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**

Board Committees meet quarterly and work with the Chief Executive Officer as part of good governance and management throughout the year.

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Mr Paul Rogan - Chairman

Ms Elizabeth Carr Mr Ashley Chapman

Mr Peter Reid

#### **Investment Sub-Committee**

Members of the Audit & Risk Committee form the Investment Sub-Committee along with:

Mr Barry Clarke
Mr John McCarroll

# **Board Nomination and Evaluation Committee**

Ms Elizabeth Carr - Chairman Mr Ashley Chapman Mr John McCarroll

#### **Medical Committee**

Dr Jim Runciman - Chairman
Dr Paul Beaumont (retired

10.12.13)

Ms Elizabeth Carr
Dr Amanda Greaves

Dr Alex Harper

Associate Professor Wilson Heriot

Dr David Hilford

Associate Professor Alex P Hunyor Dr Tharmalingam Mahendrarajah

Professor Paul Mitchell

Associate Professor Nitin Verma Associate Professor Dimitri

Yellachich

#### **Research Committee**

Mr Paul Rogan - Chairman

Dr Paul Beaumont Ms Elizabeth Carr Dr Jim Runciman Ms Suellen Tapsall

#### **Client Services Committee**

Ms Suellen Tapsall - Chairman

Mr Peter Brown
Ms Elizabeth Carr
Mr Ashley Chapman
Mr Barry Clarke
Mr Richard Grills

Professor Jill Keeffe

Mr Peter Reid

### State Chairs

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

Queensland:Dr Amanda GreavesSouth Australia:Dr Jim RuncimanVictoria:Associate Professor Wilson HeriotWestern Australia:Ms Suellen Tapsall

Tasmania: Associate Professor Nitin Verma New South Wales: vacant



# Jean's Story

I remember the day my mother told the family she was losing her sight. Mum 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.

It was hard to imagine what she must have felt at that moment, just as it was hard for her family to imagine mum without her sight. 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 fruit cake, 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 the family.

Macular Disease Foundation Australia is very grateful to Jean for her ambassadorial work and dedication in promoting the Foundation's important messages.

# Meeting our Objectives

# Education

To educate about macular disease by providing accurate, specific, current and ongoing information

## **Education of the Public**

Education sessions provide an opportunity for the Australian community to learn about macular degeneration including symptoms, risk factors, management and treatment. The sessions also cover the low vision services and aids available to help people maintain independence and quality of life.

The Foundation provides all those attending an education session with a comprehensive information pack which provides detailed information about macular degeneration and advice on support services. All participants are asked to complete an evaluation form.



The Foundation provided almost 6,700 information kits at education sessions



#### **Public Education**

Public education sessions are held across Australia at the Foundation's initiative. The sessions are widely promoted, including invitations 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 is placed in local newspapers and press releases are sent to local media including print, radio and television. In 2013-2014 people in cities and regional towns again expressed gratitude for the opportunity to have personal contact with the Foundation and for the information provided at the education sessions.

A total of 35 sessions were held nationally with over 2,200 attendees

"I now feel confident about recognising and handling a condition I'd previously had no knowledge of and steps, like diet, which I can take to try and prevent it."

#### **Community Education**

Community education sessions are presented following an invitation from community groups, such as aged care organisations, retirement villages, service clubs such as Rotary and Probus, vision impaired support groups, religious groups, nursing homes, aged care facilities and hospitals. In addition, the Foundation reached out to the Culturally and Linguistically Diverse (CALD) communities including Arabic, Chinese, Greek, Italian and Vietnamese communities by providing education sessions with the aid of an interpreter.

The Foundation spoke to over 5,600 attendees at 118 sessions

# Educating Health Professionals

The Foundation provided education and support to health professionals, including the supply of free resources and presentations at meetings and conferences throughout the year. Professionals included ophthalmologists and optometrists, as well as practice managers, ophthalmic nurses, orthoptists, pharmacists, carers and students. The Foundation continues to provide education to nursing and administration staff at the Sydney Eye Hospital, as well as courses for community based ophthalmic nurses.

#### Optometry

The Foundation continued to support the optometry profession with the ongoing provision of resources and professional education. The Foundation attended a key optometry expo which showcased the support the Foundation provides to optometrists for their patients, and also contributed to professional publications on topics such as research, new treatments, nutrition and supplements and awareness programs.

#### Health and Aged Care

Increasingly the Foundation is reaching out to health and aged care workers in order for macular degeneration to be better understood in these sectors. Foundation education officers supported the professional development of workers at retirement homes and senior care organisations. This education provides the opportunity for health and aged care workers to learn more about macular degeneration as well as how the Foundation can support their work and clients.

#### **Pharmacy**

With pharmacists and pharmacy staff being key providers of health information to the community, the Foundation ensures that they are well supported. Resources were distributed nationally to pharmacies for Macular Degeneration Awareness Week and the Foundation also attended and presented at the major pharmacy expo in Sydney. Here the focus was on providing information on the role of the pharmacist in macular degeneration care, diet and lifestyle modifications and supplements.

#### **Students**

The Foundation continued to support the education of students. The Foundation participated in the UNSW Low Vision Expo which is designed to introduce fourth and fifth year optometry students to the broad array of organisations involved in low vision care. The Foundation also provided ongoing support to Kingswood TAFE for its nursing program.

#### **General Practitioners**

The Foundation presented to general practitioners in Melbourne covering macular degeneration, risk reduction, diet and AREDS2 supplementation.

# Vision 2014 International Conference on Low Vision

The Foundation provided information to delegates attending the conference which presented leading research and information on low vision.

# Royal Australian and New Zealand College of Ophthalmologists (RANZCO) Congress

The Foundation attended the RANZCO Congress in November 2013, strengthening existing relationships with ophthalmologists and allied health professionals including orthoptists, ophthalmic nurses and practice managers.





Foundation educator discussing nutrition and supplements with an interested ophthalmologist.



Associate Professor Bamini Gopinath

Foundation Ambassador Jean Kittson and Chief Executive Officer Julie Heraghty presented at an evening symposium and dinner to over 100 professionals. Jean's talk was titled How macular degeneration affected me – my first hand experience. Her powerful story, conveyed with humour and sensitive insight, gave everyone a real understanding of the impact of vision loss on all the family. Julie spoke about the impact of macular degeneration on carers from the Foundation's ground breaking 2013 research, *The Ripple Effect of Vision Loss*.

Orthoptists and practice managers had the opportunity to hear the Foundation's Chief Executive Officer speak on the topic *The patient's journey - a team approach*. Orthoptists are an especially important partner in the Foundation's work as they play a crucial role in the detection, diagnosis and management of eye diseases. Practice managers ensure the smooth running of practices for timely treatment and seamless patient care.

The Foundation also presented to ophthalmic nurses, who have the important role of caring for patients with eye disorders.

Associate Professor Bamini Gopinath presented the results of her detailed analysis of the data from the Foundation's research *The Ripple Effect of Vision Loss*, which examined the impact of wet age-related macular degeneration on patients and carers.

# Where did we go?

#### **COMMUNITY EDUCATION**

#### **Seniors' Groups NSW**

Ashfield Auburn Ballina Bankstown Bardwell Park Baulkham Hills Beecroft **Belrose** Breakfast Point Burwood Cammeray Campbelltown Castle Hill Chatswood Chester Hill Coogee Cringila **Epping** Five Dock Galston Gladesville

Goulburn

Guildford

Harbord

Hunters Hill

Ingleburn

Kenthurst

Kingsford

Lalor Park

Lane Cove

Miranda

Liverpool West

Jannali

Mt Colah Narellan North Gymea Panania Parramatta Peakhurst Penshurst Regents Park Rooty Hill Sans Souci Seaforth St Marys Sydney Thornleigh Toongabbie Turramurra West Pennant Hills

#### **QLD**

Toowoomba

Woolooware

#### VIC

Kerang Nathalia Numurkah

#### WA

Applecross Gosnells Mandurah Medina Merriwa Mirrabooka Mundaring

Murdoch Rossmoyne Willeton Winthrop

#### **CALD Groups NSW**

Ashbury Cabramatta Crows Nest Earlwood Five Dock

#### OID

Kelvin Grove Sunnybank

#### SA

Para Hills Pooraka

#### VIC

Brunswick Hadfield

#### Service Clubs **NSW**

Cammeray Dural Sydney Warrawee

Retirement Villages **NSW** Cromer

#### QLD

Toowoomba

**Bull Creek** Murdoch

#### **Health Care Professionals NSW**

Camperdown

Earlwood Eveleigh Kensington Killara Kingswood Newcastle Randwick Strathfield Sydney Wetherill Park

#### QLD

Southbank

#### VIC

Melbourne

#### **TAS** Hobart

WA Nedlands Stirling

"I am now determined to have an eye examination more regularly."

"These sessions are a great way to learn more about macular degeneration and I feel better able to cope with it."

"Impressed by the open, practical, helpful attitude of your speaker."

5,620 people attended 118 community sessions nationally

#### **PUBLIC EDUCATION**

**NSW** Albury Ashfield Bankstown Baulkham Hills Belmont Coffs Harbour Griffith Lane Cove Leumeah

Lismore

Port Macquarie Rosehill Sydney Tweed Heads South Waqqa Waqqa West Gosford Wollongong

SA Marion QLD Bowen Hills Geebuna North Ipswich Petrie

Caulfield East Clayton

**TAS** Hobart

WA Crawley

**ACT** Woden

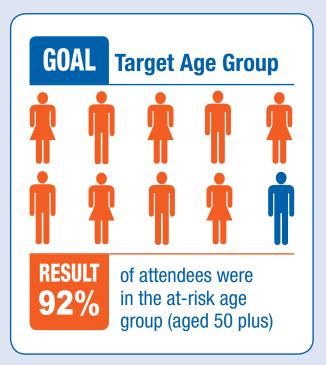
NT Wanguri

2,241 people attended 35 public information sessions nationally

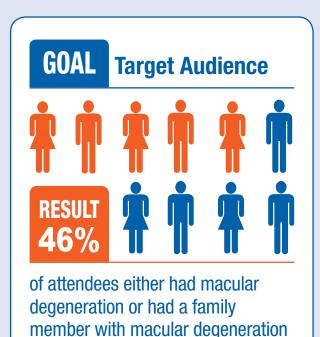
"I found the talk very interesting and I will alter my diet to lessen my chances of developing the disease."

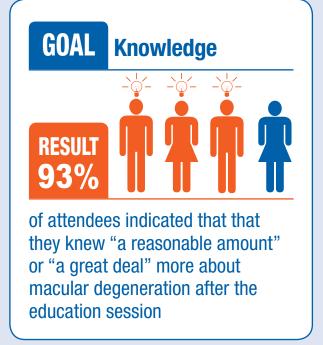
# **Achieving our Goals**

# **Education Sessions**









# Education session primed Fay to act quickly



Fay is thankful she attended a Foundation education session at her retirement village.

At the session she learnt about macular degeneration, the importance of early detection and how to use an Amsler grid.

Her knowledge of macular degeneration was put to the test when she noticed a sudden change in her vision after waking one morning. She initially thought it was just an "early morning thing" and went on with her day.

Later that day when her sight had still not returned to normal, Fay tested her eyes with her Amsler grid and saw there was distortion and a black spot.

Fay visited her GP the next morning who arranged an emergency visit to the ophthalmologist. Wet macular degeneration was diagnosed and a few days later Fay had her first injection.

The Foundation thanks Fay for sharing her story of how attending an education session primed her to act quickly when she noticed changes in her vision.

## Meeting our Objectives

# **Awareness**

# To increase awareness of macular disease

# Australia continues to be a world leader in raising awareness of macular degeneration

The Foundation undertakes a vast array of activities across the country to raise awareness of macular degeneration. It is a major focus of the Foundation's work to promote prevention, early detection and the importance of timely access to treatment and rehabilitation. Since 2007, the Foundation has been tracking awareness of macular degeneration in Australia.

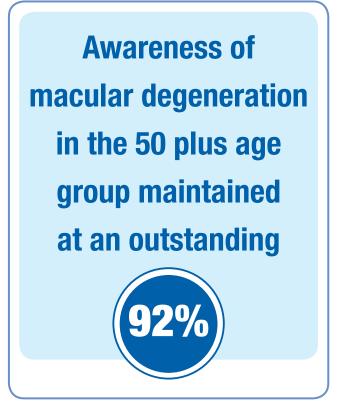
One of the key activities is a national television and radio advertising campaign, implemented over the last seven years. The primary goal from this is to ensure that those most at risk of macular degeneration have their eyes tested and macula checked.

The Foundation's promotion of the key eye health message of eye testing has benefited the Australian eye health sector overall. The allied preventative health messages of a healthy diet and lifestyle, exercise, healthy living, and anti-smoking have supported and promoted key public health messages. This work has had a multiplier effect in supporting and benefiting eye health and other chronic diseases, supporting the Foundation's strategic goal of building healthy Australian communities.

# **Measuring Awareness**

The advertising campaign was initiated following an independent national Galaxy poll in 2007 which showed only 47% of Australians were aware of macular degeneration; most thought it was related to muscles and few people claimed to have had their eyes tested and macula checked.

The Foundation has commissioned ten national Galaxy polls over the last seven years to independently measure awareness with outstanding results.



The Foundation's promotion of the key eye health message of eye testing has benefited the Australian eye health sector overall, building healthy Australian communities.

# Macular Degeneration Awareness Week

#### Sunday 25 May to Saturday 31 May 2014

Macular Degeneration Awareness Week is the premier awareness activity for the Foundation. The 2014 campaign focused on the message *Don't be in the dark about macular degeneration* and included a range of activities in media relations, direct mail, community engagement and education.

A Galaxy survey commissioned by the Foundation revealed only 1% of Australians over the age of 50 were familiar with the Amsler grid

The Amsler grid was central to all of the week's activities, with Australians over 50 urged to adopt the three-step approach of *test, monitor and respond* for early detection.



#### **Key messages:**

- O Australians over 50 to have their eyes tested and macula checked
- O Use the Amsler grid between eye tests to monitor for changes in vision
- O You can save sight through early detection
- O Know the risk factors
- O Macular degeneration is Australia's leading cause of blindness and severe vision loss
- O Information, guidance and support is available from the Foundation

# Excellent results across the country:

- An estimated audience reach of 26 million achieved through media coverage across Australia
- ✓ Over 14,000 information kits distributed including 512,223 resource materials, with a further 62,000 resource materials reordered
- 36,882 website page views recorded during Macular Degeneration Awareness Week
- 1,968 phone calls received over the period of the week, a 74% increase on 2013
- 3,000 requests for information kits during May 2014, up 287% on 2013

#### Media Activities

A media program commenced with a nutrition focus for long lead media concentrating on the relaunch of *Eating for Eye Health – The Macular Degeneration Cookbook* co-authored by Foundation Patron Ita Buttrose and chef Vanessa Jones.

National, state and regional print, along with television, radio and online media were targeted, as well as trade and industry publications.

Thank you to Optometry Australia for distributing the joint media release to optometrists nationally enabling promotion of the week in local media.

#### Media highlights:

- TV: 28 segments secured including Channel 7 Morning Show and Weekend Sunrise, Channel 9 Today Perth News, and extensive WIN coverage
- Radio: Widespread radio coverage including an Alan Jones 2GB interview of Chief Executive Officer, resulting in almost 1000 calls to the Helpline in just one day
- Print and online coverage: extensive consumer, trade and online coverage including Sydney Morning Herald and The Age

#### **Outstanding television coverage**



Julie Heraghty as seen on *The Morning Show* with Dr John D'Arcy



Channel 7 Weekend Sunrise coverage of macular degeneration



Channel 9 *Today* Perth News interview with Associate Professor Dimitri Yellachich

#### **Specialised SA focus**

The Foundation identified an opportunity to integrate Macular Degeneration Awareness Week with advocacy activities addressing the capacity crisis at Royal Adelaide Hospital. A specialised South Australian media approach secured key pieces of coverage including ABC News (TV) interview of Chief Executive Officer, case study Wanda Hibbard with her 90 year old mother Maria Herba, along with Professor Dinesh Selva, and radio interviews including 891 ABC Adelaide, 5AA Adelaide and Radio RPH.



#### Community Reach

Direct Mail Campaign: A national direct mail campaign involved over 14,000 information kits (containing over 500,000 resources) being sent to optometrists, ophthalmologists, orthoptists, pharmacies, health food stores, community health centres, libraries, NSW, QLD and VIC bowls clubs, federal and state parliamentarians. General practitioners in the NSW Newcastle Medicare Local region received kits as part of a pilot program.

Rotary Community Partnership: For a third year the Foundation issued a direct mail communication to over 1,000 Rotary Clubs Australia-wide, requesting their involvement in Macular Degeneration Awareness Week 2014. The communication included an offer to order macular degeneration information brochures and Amsler grids for distribution in their communities. 2,900 macular degeneration information brochures and Amsler grids and 62 posters were distributed to 29 clubs nationally in support of a range of promotional and fundraising activities.

**Sydney Action Day:** Foundation staff and volunteers engaged with the public in an action day in Martin Place, with 3,000 macular degeneration information brochures

distributed. To highlight the importance of an eye health diet, 3,000 cans of donated John West salmon were also given away to the public.

**Fundraising:** Over 40 Specsavers stores across Australia supported the campaign by including the Foundation in their community charity box program for the month of June and generating local media awareness.

Education: Leading retinal specialist Associate Professor Alex Hunyor, orthoptist and low vision consultant Marion Rivers, and Foundation Chief Executive Officer Julie Heraghty presented All about Macular Degeneration to 348 guests on Saturday 24 May at the Sydney Masonic Centre.



Associate Professor Alex Hunyor

# New National Television and Radio Advertising Campaign

In May 2014 the Foundation launched a new national television and radio campaign with the key message of *Have an eye test and macula check* while reinforcing that information, support and understanding was available from the Foundation through the 1800 Helpline.

#### Results as at June 2014:

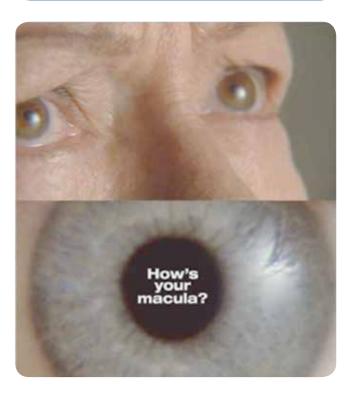
- Almost all (92%) Australians in the at-risk 50+ age group are aware of macular degeneration
- ✓ 83% of Australians aged 50+ are aware that macular degeneration affects the eyes
- ✓ 69% of Australians aged 50+ say their macula has been checked in the last two years
- ✓ 3,790 Helpline calls in May
- ✓ 3,985 information kits requested

"Getting plenty of comments and requests from patients to have their macula checked like it says on TV."

"This campaign is extremely effective. It has a flow on effect for improving early detection of all eye disease."

# An independent poll of optometrists in June 2014 found:

- 46% of optometrists said that patients had mentioned the campaign in the last two months. Of these 70% said that some patients had come for an eye test as a direct consequence of seeing the advertisements
- Virtually all patients who mentioned the campaign to their optometrist were aged over 50, indicating that the advertisement reached the at-risk age group
- An estimated 600 people would have been diagnosed with wet macular degeneration as a result of the campaign



"Excellent campaign - almost every patient over 50 will ask 'have you checked my macula?' Very powerful!"

# World Sight Day 2013

To mark World Sight Day (10 October) the Foundation engaged in a wide range of activities supporting research into and awareness of macular degeneration and diabetic eye disease.

#### Research Grants Announcement

The Foundation hosted an event on 9 October 2013 at the Sydney Opera House to announce two new research grants. The Hon Peter Dutton MP, Minister for Health, announced the successful recipients against the backdrop of the *Through His Eyes* photo tribute to Sydney Opera House designer Jørn Utzon. Jørn Utzon lived with macular degeneration in his later life and his son Jan Utzon is an Ambassador of the Foundation. Full details of the event on pages 32-35.



The Hon Peter Dutton MP, Minister for Health, announcing the Foundation's Research Grants

A media release highlighting the research grants announcement supported the event and featured Foundation Ambassadors Jan Utzon and Jean Kittson joining forces to highlight the enormous impact of macular degeneration in Australia by sharing the stories of their parents. The announcement generated extensive media coverage including print, online, radio interviews and trade publications.

#### Diabetic Eye Disease Awareness

World Sight Day 2013 marked the Foundation's entry into raising awareness of diabetic eye disease with a media release in partnership with Diabetes Australia. The release highlighted the importance of an eye test for all those with diabetes. This followed the release of the report Out of Sight - A report into diabetic eye disease in Australia.

#### Keep Your Eye on the Ball

The Foundation joined forces with Bowls Australia to knock macular degeneration out of play. The *Keep your eye on the ball* activity with Bowls Australia reached over 200,000 Australians with the key message of *have your eyes tested and macula checked*.

18,000 Amsler grids were inserted into Bowls Australia's *SHOT* magazine. Interviews with the Foundation's Chief Executive Officer appeared on Bowls Australia TV and radio, along with newsletter and website coverage.



A Keep your eye on the ball painted bowling green

In support of the campaign, two of the country's leading bowling clubs, Yarraville Footscray Bowling Club and Glen Eira McKinnon Bowls Club in Melbourne, held events engaging with the bowls community. Bowling greens were decorated to promote the Foundation's key eye health message.

# mEYE World Photographic Competition 2013

The third annual mEYE World Photographic Competition was launched by entertainer Monica Trapaga on 5 July at ODMA|2013 (Optical Distributors and Manufacturers Association trade show). The launch showcased a gallery of outstanding photographs submitted by entrants in past years.

The competition was established in 2011 to raise awareness of macular degeneration through the visual arts, engaging all age groups, the macular degeneration community and healthcare professionals.

Australians were invited to submit a photograph, along with a description of how their entry showed the appreciation of the gift of vision. A record 944 inspiring photographs were entered.

Winners were announced at The Royal Australian and New Zealand College of Ophthalmologists (RANZCO) Congress 2013 dinner on 4 November 2013. A gallery of 20 photos including the winners, runners up and a number of shortlisted entries were on display at this event.

Mr Denis Fitzgerald from Victoria was selected as the overall grand finalist from the four category winners.

Thank you to the judges of the 2013 competition, Foundation Patron Ita Buttrose and photographer Ken Duncan.

#### Media highlights:

- ✓ Estimated 16.9 million media impressions across the competition period (69% increase on the 2012 competition)
- ✓ Community service announcement advertisement on over 45 radio stations and interview with Chief Executive Officer Julie Heraghty aired on 13 ACE radio stations

A record 944 entries received in 2013!



Grand Finalist and Open Category Winner Denis Fitzgerald, Golden Square VIC



Healthcare Professional Category Winner Chris Barry, Sorrento WA

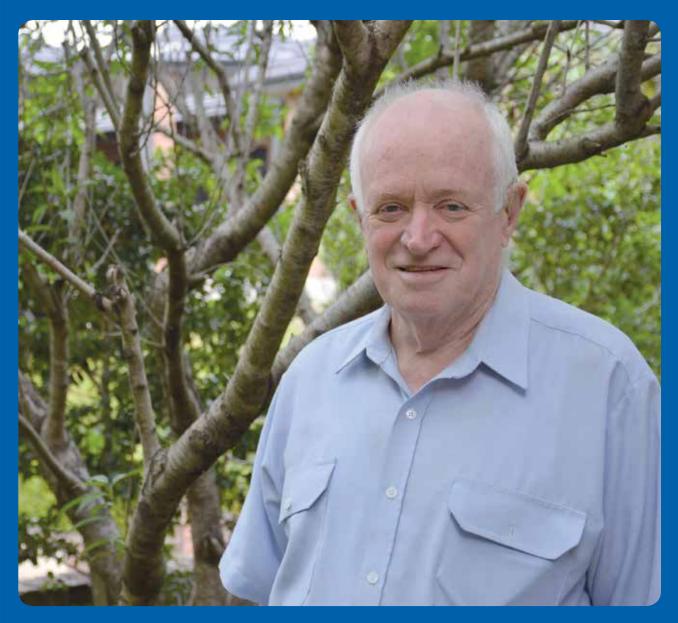


Macular Disease Community Category Winner M. Honeybun, Perth WA



Junior (Under 18) Category Winner Josh Nicol, Ruby VIC

# Retired pharmacist Melvyn helps raise awareness



Retired pharmacist Melvyn Byrnes' story of early detection appeared in the *Australian Journal of Pharmacy* to help raise awareness during Macular Degeneration Awareness Week.

Diagnosed with wet macular degeneration in 2007 Melvyn considers himself fortunate as he can still read, drive a car and continued to work part-time until about a year ago.

He is acutely aware that if he hadn't known about the symptoms of macular degeneration, which originally appeared overnight, and hadn't had an Amsler grid at home, he'd be telling a different story.

In the article Melvyn urged pharmacists to talk to customers about the risk factors, the importance of early detection and how using an Amsler grid can save sight.

The Foundation thanks Melvyn and the many Friends of the Foundation who shared their story and spoke to the media during Macular Degeneration Awareness Week.

# Public Relations, Marketing and Social Media

In addition to major awareness campaigns and promotional activities, the Foundation also secured extensive editorial across a range of media, and continued to increase its use of social media platforms YouTube and Facebook.

The Foundation's public relations activities ensured coverage on a wide range of topics and received outstanding support from Patron Ita Buttrose, Ambassadors Jean Kittson and Jan Utzon and many of our Friends of the Foundation who generously shared their stories to help raise awareness.

#### **Editorial highlights**

#### **News for Seniors**

As Australian of the Year 2013, Patron Ita Buttrose featured on the cover of Department of Human Services News for Seniors magazine in the July 2013 edition with a circulation of 2.1 million. This editorial generated a large volume of calls to the Foundation's Helpline requesting advice, information and an Amsler grid. A second feature in News for Seniors was secured in June 2014 and featured Foundation Ambassador Jean Kittson and her mother Elaine, who lives with vision loss from macular degeneration.



#### South Australian Hospital Crisis

The Foundation featured in South Australia's state pre-election media space, raising awareness of the South Australian Royal Adelaide Hospital capacity crisis which was impacting the delivery of timely treatment for macular diseases.

Channel 7 Adelaide news interviewed Professor Dinesh Selva and ABC Radio Drive interviewed Foundation Chief Executive Officer Julie Heraghty. The estimated combined coverage was 150,000.

#### In the Workforce

Major articles were printed in the *NSW*Teacher Federation Journal featuring retired teacher, volunteer and Friend of the Foundation Val Nicholson, and in *Police*News, which featured retired police officer and Friend of the Foundation James Boon.



#### **Trade Publications**

Key trade media strongly supported the Foundation's work in raising awareness including *mivision*, *Insight*, *Australian Optometry* and *RANZCO News*, ensuring health professionals remained informed of new developments as well as the important work of the Foundation.

#### **NSW Print Advertising Campaign**

25 advertisements were placed in local newspapers and seniors publications in NSW, reaching an estimated one million people.

# Keep On Driving – Safely

Since January 2009, the NSW Government has generously supported our *Keep on Driving - Safely* 

initiative, allowing a macular degeneration information brochure to be inserted into driver licence renewals. This five year program, completed in 2014, resulted in information reaching over 5.9 million people.



#### Friends of the Foundation

In 2013-2014 the Friends of the Foundation program, designed to capture inspiring stories from across the macular disease community, continued to support the Foundation's work in advocacy, public relations, social media and fundraising. These personal stories include people living with macular disease, carers, family members and healthcare providers, and are particularly important in gaining localised media coverage. It is a privilege to have so many people willing to share their stories including our Patron Ita Buttrose and Ambassadors Jean Kittson and Jan Utzon.

# Eating for Eye Health – The Macular Degeneration Cookbook Relaunched

Eating for Eye Health - The Macular Degeneration Cookbook, co-authored by Foundation Patron Ita Buttrose and chef Vanessa Jones, was relaunched during Macular Degeneration Awareness Week 2014 due to popular demand. The book generates awareness of the disease, provides critical eye health information and is a great way to encourage Australians to eat eye health foods.



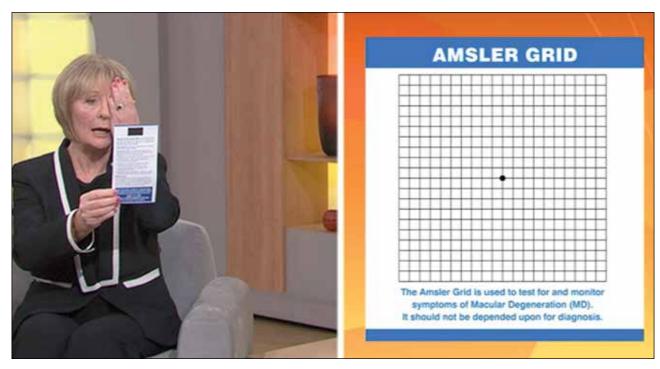
Patron Ita Buttrose promotes Eating for Eye Health - The Macular Degeneration Cookbook

#### **Amsler Grid Awareness**

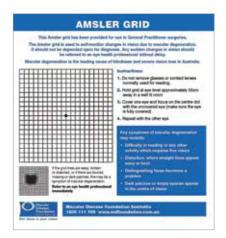
Throughout the year the Foundation has continued to promote the Amsler grid, a self monitoring tool used to test for and monitor symptoms of macular degeneration between professional eye tests.

Information on the Amsler grid featured extensively in the media, with copies inserted into targeted publications including Bowls Australia's *SHOT* magazine and Anglican Retirement Villages *SHINE* Magazine.

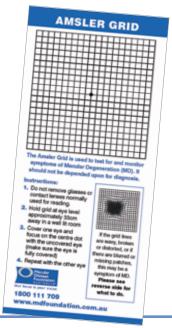
Specialised Amsler grids were developed for in-practice use by eye health professionals and general practitioners and were distributed as part of Macular Degeneration Awareness Week.



Chief Executive Officer Julie Heraghty as seen on The Morning Show

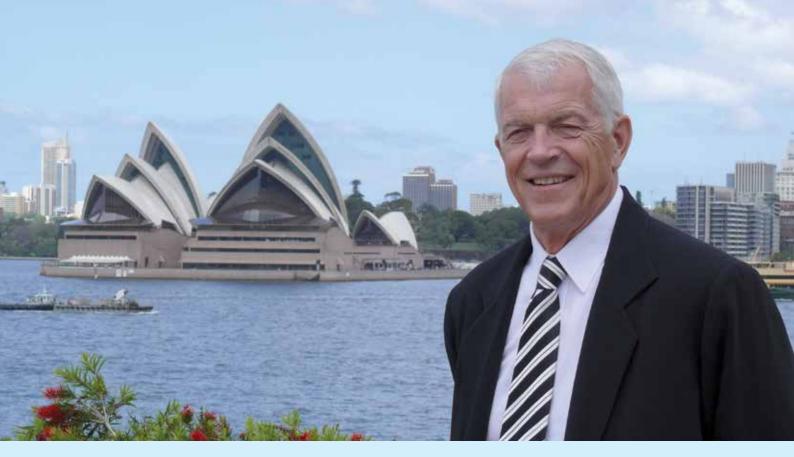


Specialised Amsler grid for eye health professionals and general practitioners



"It is our goal for all
Australians over
age 50 to have an
Amsler grid on their
fridge and to be using
it regularly."

Chief Executive Officer Julie Heraghty



# 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 of 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.

## Meeting our Objectives

# Research

## To support and pursue research

#### Research focus

In 2013-2014 the Foundation further strengthened its involvement in research by providing significant new funding to support the important work of Australian researchers and by conducting a number of its own projects.

# Research Grants Program

Since 2011, the Foundation has committed over \$1.5 million through its Research Grants Program. The grants support major research projects as well as fellowships and are funded by the Foundation's fundraising activities, supported by generous donations, bequests and corporate giving.



Already previous research grants and fellowships awarded in 2011 and 2012 have resulted in several important findings and numerous publications in highly regarded peer-reviewed medical journals, bringing us ever closer to understanding macular degeneration, and its causes, treatments and ultimately finding a cure.

# 2013 Research Grants Announcement

A highlight of the year was the Foundation's continued investment in Australian researchers with The Hon Peter Dutton MP, Minister for Health, awarding two Research Grants on behalf of Macular Disease Foundation Australia.

The grants were presented at an event held at the Sydney Opera House on 9 October 2013, to mark World Sight Day.

The event took place in the famous Utzon Room against the backdrop of the *Through His Eyes* photo tribute to Sydney Opera House designer Jørn Utzon, who lost vision from macular degeneration in later life. The photos and a pair of Jørn Utzon's glasses were generously donated by his son, Foundation Ambassador Jan Utzon.

Foundation Ambassador Jean Kittson, and her mother Elaine, who lives with macular degeneration, shared with guests the impact that the disease has had on their lives.

In 2013 the Foundation awarded \$600,000 over three years to two outstanding researchers.

# 2013 Research Grant Recipients



Associate Professor Erica Fletcher
Department of Anatomy and Neuroscience
The University of Melbourne

Associate Professor Fletcher's research project will examine how the removal of debris in the eyes changes as we age. This research will be a step towards identifying early markers for those people with a high risk of disease progression. The information gained from this project will be crucial for developing new treatments for macular degeneration.

Associate Professor Fletcher said, "The mechanisms that lead to the early stages of age-related macular degeneration remain to be determined. In this project we will examine a possible cause for the development and progression of early age-related macular degeneration. In particular, we will determine whether signalling of immune cells via receptors called purinergic receptors influences the removal of debris as we age, predisposing people to the disease and also its progression. The information gained from this project will be crucial for developing new treatments targeting immune cell function, as well as using the purinergic receptor as a way of screening those people at greatest risk of disease progression."



Associate Professor Damien Harkin School of Biomedical Sciences Queensland University of Technology and Queensland Eye Institute

Associate Professor Harkin's novel research project will look at a protein extracted from silk as a form of scaffold on which to grow new retinal tissue, with the view to replacing the damaged tissue that eventually leads to permanent loss of sight in macular degeneration patients. This project may help maintain or restore vision for people living with late stage disease.

Associate Professor Harkin said, "The ultimate goal of our research is to develop an effective, affordable and accessible treatment for patients afflicted with age-related macular degeneration. The novelty of our study is that we will use a protein extracted from silk as a form of scaffold on which to grow new retinal tissue, with the view to replacing the damaged tissue that eventually leads to permanent loss of sight in patients."

#### 2013 Research Grants Announcement

The Hon Peter Dutton, Minister for Health, awarded the Macular Disease Foundation Australia Research Grants on 9 October 2013, to mark World Sight Day.



"Like so many Australians mum witnessed the Sydney Opera House being designed and built. Little did she know that 40 years on she would no longer be able to see the Opera House due to her vision loss from macular degeneration."

Ambassador Jean Kittson with mother Elaine



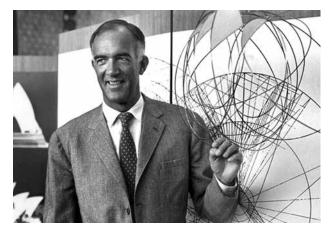






# Through His Eyes

At the 2013 Research Grants announcement a photo tribute to Jørn Utzon entitled *Through His Eyes* was displayed in the Utzon Room of the Sydney Opera House.

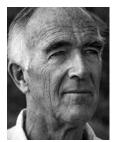


Foundation Ambassador Jan Utzon supports awareness raising of macular degeneration as his father Jørn lived with the disease in later life.

Jørn Utzon was an architect and famously designed the iconic Sydney Opera House. With his vision Sydney became an international city.



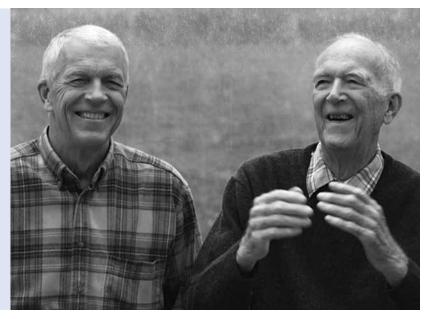






"My father, Jørn Utzon, was a visionary man and witnessing his sight deteriorate from macular degeneration was heartbreaking. The trauma the disease inflicts is enormous and I urge society to make greater efforts in research to find a cure."

Ambassador Jan Utzon



### **Amsler Grid Research**

To help develop media for Macular Degeneration Awareness Week and to support the promotion of the Amsler grid, the Foundation commissioned a Galaxy poll to survey 600 people aged 45 and over to assess awareness and knowledge of the Amsler grid. The poll was undertaken in March 2014.

### **Key findings:**

- Unprompted, only 1% of Australians aged 45+ knew an Amsler grid by name
- When shown a grid, 13% of people aged over 45 claimed to have used one in the last 12 months
- Less than 0.5% of people use the grid at least weekly

# The Ripple Effect of Vision Loss

In June 2014, the results of the Foundation's major research study *The Ripple Effect of Vision Loss* was published in the prestigious journal *Aging & Mental Health*. The study has also been presented at several scientific meetings including Vision 2014 and the RANZCO 2013 national conference.

The Foundation is grateful to Associate Professor Bamini Gopinath, Professor Paul Mitchell and Annette Kifley at Westmead Millennium Institute for their assistance with the data analysis and report writing to enable publication of this important research.

# Macular Disease Research E-newsletter

Each week, the Macular Disease Research E-newsletter is distributed to over 750 ophthalmologists and other interested eye care providers across the world.

The newsletter summarises global published peer-reviewed literature on macular degeneration and has now expanded to include other macular diseases. This important resource ensures eye health professionals are kept informed of the latest developments in treatment, diagnosis, genetics, diet and other related issues.

# **Translating Research**

A critical role of the Foundation is to translate the latest, typically complex, research on macular disease into key messages to encourage changes in behaviour to reduce risk, seek early diagnosis, treatment or rehabilitation. Research is also translated into understandable language so that clients can understand a diagnosis and maintain an appropriate degree of hope for the future.

# **Annual Research Update**

An annual Research Update is produced each December which 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.

Research is a journey of discovery, with the ultimate destination being a place where we can save sight.

Along the way we will learn a great deal that can yield major benefit.

# **Evaluating the Foundation**

Every year the Foundation evaluates its services by surveying a sample of its client base. In 2014 a questionnaire was sent to 2,000 clients from the Australian macular degeneration community, including:

- those with macular degeneration
- family and friends of people with macular degeneration
- those with a general interest in macular degeneration
- people working in a macular degeneration related field

# What do clients think of the Foundation's services?

The Foundation's flagship services - the Helpline, newsletter, education sessions and website - were given overwhelmingly positive ratings by clients, ranging from 91% for the website to 95% for the newsletter. Publications continue to be highly rated with over 90% indicating that they found these "helpful" or "very helpful".

# How satisfied are the Foundation's clients?

95% of respondents were "mostly satisfied" or "very satisfied" with the Foundation's services, up from 94% last year.

The Foundation continues to use client feedback to improve services to support the macular disease community.



of respondents were
"mostly satisfied" or
"very satisfied" with the
Foundation's services



A member of the public asks a question at a Foundation education session

# Meeting our Objectives

# **Support Services**

# To facilitate access to relevant support and support services

# Helpline - A Frontline Service

The Helpline is a key service provided by the Foundation to support the macular disease community. The Foundation responds to a range of calls but most particularly calls from those living with macular disease, their carers and family seeking information, guidance, understanding and support.

There is a great demand for phone support with over 13,000 calls received in 2013-2014. The Foundation has received over 121,000 calls to the Helpline since 2005.



95% of respondents who had used the Helpline rated it as "good" or "excellent"

### **Information Kits**

Comprehensive information kits, provided free of charge, are one of the main avenues for providing information about macular degeneration to the community. The information kits are available via the Helpline, at Australia-wide education sessions, expos, conferences and the Foundation website. The information kit includes an array of publications and helpful information on subjects related to macular degeneration, and living with low vision.

Over 6,500 information kits were distributed in 2013-2014

### Website

The Foundation's website continues to be a powerful information tool. The website is heavily promoted during national media campaigns and through all of the Foundation's materials and usage climbed to its highest ever.

91% if those who used the Foundation website rated it "good" or "excellent"

"It's nice to know there is so much help available if and when I may need it."

### Newsletter

The Foundation's quarterly newsletter focuses on issues relating to macular disease. It provides updates on projects and new research and remains a vital communication and education link with the community.





95% of respondents who used the newsletter rated it as either "good" or "excellent"





"I am a nurse working with clients who have macular degeneration. I like to read your newsletter as it helps me understand more about this disease."

# Helpline catches fisherman's sight



The important role the Helpline plays in giving sound advice and facilitating access to sight saving treatment was highlighted when a hardy fisherman called the Helpline in May 2014.

He'd noticed the horizon had become distorted over the past three weeks while out fishing on his boat. Foundation staff were very concerned about this distortion and delay in having an eye test and managed to have him seen by an optometrist that very day.

The fisherman was immediately referred to an ophthalmologist and by that evening had been diagnosed with wet macular degeneration and received his first injection in the affected eye. He continues to have treatment.

Since his diagnosis another direct family member has also been diagnosed and receives treatment for wet macular degeneration.

At the time he called the Helpline he was reluctant to take time out from his fishing to have his eyes tested, but agreed after some convincing from the Foundation.

This is just one example of how our Helpline assists those at risk of, or living with, a macular disease.

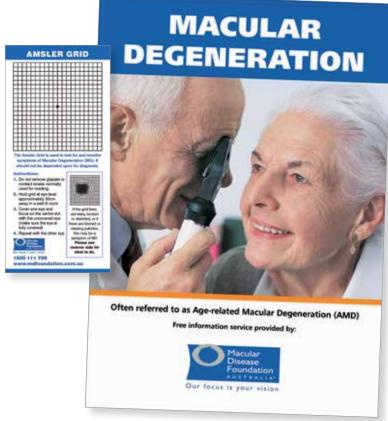
### **Publications**

The Foundation offers a comprehensive range of publications to meet the needs of the macular disease community. The publications are distributed broadly through the Foundation's activities, as well as via health professionals including optometrists, ophthalmologists, orthoptists and general practitioners. All publications are updated on a regular basis to ensure information is current and relevant to readers.

Integral to the range of publications is a series of four informative guides:

- 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

In 2013-2014 over 760,000 individual publications and resources were distributed to the general public and health care professionals





# **Special Projects**

### **Low Vision Information Days**

Low vision information days were held in Sydney, Canberra, Hobart, as well as regional NSW and QLD. These initiatives enabled the latest aids and technology to be viewed and trialled as well as providing an opportunity to hear how those with macular disease successfully use different skills or equipment to enhance quality of life and maintain independence. Presentations were given by the Foundation as well as Vision Australia, Guide Dogs and Quantum RLV.

### 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.

### Low Vision Equipment Display

The Foundation's national office displays a range of low vision equipment including magnifiers, daily living aids and assistive technology. Clients are able to learn about the aids and technology, trial the equipment and discuss their needs with Foundation staff.

### Low Vision Badges

The Foundation provides "I have low vision" badges to the macular disease community free of charge.



"When I wear my low vision badge the supermarket staff are so helpful."



### Meeting our Objectives

# Representation

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

# Sight for Seniors campaign and 2013 Federal Election

The Foundation's *Sight for Seniors* campaign continued in 2013-2014 and was the platform for advocacy during the 2013 Federal Election. With the support of thousands of registered campaign supporters, the Foundation raised three key issues with all major candidates in the lead up to the September 2013 Federal Election:

- No age discrimination in the National Disability Insurance Scheme for over 65s
- 2. A fair deal on aids and technology for people with low vision
- 3. Increased funding to support the work of the Foundation in macular degeneration

### Mapping Data

The Foundation's macular degeneration prevalence data mapped the estimated prevalence of macular degeneration by federal and state electorates for 2012 and 2030.

This valuable data was used to inform every Federal Member of Parliament of their respective electoral prevalence data. It was published on the *Sight for Seniors* website.

"Thank you to Foundation Patron Ita Buttrose for supporting the Sight for Seniors campaign."

# 1. National Disability Insurance Scheme Age Discrimination

The Foundation continued to advocate for the inclusion of people aged 65 and over with vision impairment or blindness in the National Disability Insurance Scheme (NDIS).

The Parliamentary Joint Committee on Human Rights Report (December 2013) acknowledged the Foundation's concerns regarding legislated and institutionalised age discrimination in the NDIS. The Committee rightly recommended that these issues be evaluated when the NDIS legislation is reviewed in 2015. Key issues, highlighted by the Foundation, were raised in the Committee's final report and included:

- The inequitable level of disability support in the aged care system in contrast to the NDIS, which would be further exacerbated by the legislated exclusion of the NDIS from the Age Discrimination Act 2004
- The aged care system may not be designed with the same comprehensive and holistic approach to disability that would underpin the NDIS.

### **NDIS Low Vision Severity Indicators**

The Foundation continued to support the implementation of the NDIS rollout, following the launch of the NDIS trial sites on 1 July 2013. The Foundation facilitated an expert panel and contributed to the development of NDIS's low vision severity indicators, which would be used to assist NDIS planners in matching the severity of participants' vision loss with the appropriate level of support package.

### 2. Low Vision Aids and Technologies

The Foundation continued to advocate on the importance of equity and access for all those in need of low vision aids and technologies. Following the 2013 Federal Election the Foundation made strong representations to Assistant Minister for Social Services, Senator Mitch Fifield, responsible for both the aged care and disability care systems.

In the aged care system, the Foundation advocated for improved policies to support people with vision impairment and their inclusion in the Commonwealth Home Support Programme (CHSP), to be launched 1 July 2015. The Foundation identified the CHSP as the most appropriate program in the aged care system to accommodate the needs of people with low vision. The goal is to ensure adequate access to low vision aids and technology to maximise independence and quality of life.

### 3. Supporting the Work of the Foundation

The Foundation submitted a federal pre-budget submission requesting Federal Government funding of \$6 million over three years to support the Macular Disease Foundation Australia Helpline.

The Helpline is a critical frontline service and is the only telephone Helpline in Australia that covers all macular diseases. The Federal Government does not presently provide any funding for the Helpline and the Foundation is strongly advocating for Federal Government support.

Representations were made by numerous Federal MPs on behalf of the Foundation to the Minister for Health. The support of so many people from the macular disease community was critical to the cause and gratefully received.

# Have a cup of tea with your new MP

As part of the *Sight for Seniors* campaign the Foundation encouraged individuals to have a cup of tea with their newly-elected MP. Foundation supporters shared their experience of living with macular degeneration, relevant issues associated with treatment and rehabilitation and the impact the disease has had on their lives. Madura Tea donated 72,000 tea bags to support the campaign.



Margery Stevens and husband Norm met with the Federal Member for Banks (NSW), David Coleman. From this meeting Mr Coleman made representations to the Hon Mitch Fifield, Assistant Minister for Social Services.



Foundation campaigners met with Sharon Claydon, Federal Member for Newcastle (NSW).

# Advocacy Across All Macular Diseases

PBS listing for registered anti-VEGF treatments for diabetic macular oedema and retinal vein occlusions

The Foundation made numerous submissions to the Pharmaceutical Benefits Advisory Committee supporting the Pharmaceutical Benefits Scheme (PBS) reimbursement of registered anti-VEGF treatments for diabetic macular oedema and retinal vein occlusions. These eye diseases are significant causes of major vision loss and blindness in Australia.

Anti-VEGF treatment has rapidly become the standard of care for most people with these conditions, with impressive evidence of safety and efficacy. The Foundation continues to advocate on behalf of the macular disease community to ensure accessibility and affordability of registered treatments.

### Out-of-pocket Healthcare Costs

There can be a substantial cost burden for patients' out-of-pocket payments for private specialist consultations, diagnostic testing, and treatment procedures.

The Foundation recommended the reduction of out-of-pocket healthcare costs to improve access to, and affordability of, treatment for patients with macular degeneration and other macular diseases in its submission to the Federal Parliament's Senate Standing Committee on Community Affairs.

The Foundation made over 14 major submissions on a range of issues to key government agencies and stakeholders to further the cause of the macular disease community including:

#### **National Commission of Audit**

**Key issue:** the lack of comprehensive analysis and economic modelling prior to the decision to exclude people who acquire a disability over 65 years of age from the NDIS on the basis of undetermined economics.

# **Commonwealth Home Support Programme**

**Key issue:** the inclusion of funding for low vision aids and technologies.

### National Eye Health Framework Implementation Plan

**Key issue:** ensuring a comprehensive document which reflected the needs of the entire Australian eye health community.

#### **National Construction Code**

**Key issue:** improving emergency egress from buildings for those with low vision.

In January 2014, the Foundation signed a Memorandum of Understanding with Diabetes Australia to work together on diabetic eye disease.

Diabetes Australia is the national body for people affected by all types of diabetes and those at risk.

# South Australian Eye Care Capacity Crisis

An ongoing advocacy campaign was launched by the Foundation in March 2014 to address a capacity crisis at the Royal Adelaide Hospital, Lyell McEwin Hospital and Queen Elizabeth Hospital public outpatient eye clinics which was causing serious delays in prescribed sight-saving eye injections.

The proposed plans for the redevelopment of the Royal Adelaide Hospital posed a further threat to accessible public treatment with plans outlining that the currently inadequate 24 rooms would be reduced to 11 rooms.

In response the Foundation raised these critical issues by undertaking a major media campaign including:

- Lobbying all major candidates prior to the 2014 March South Australian State Election.
- Meeting with the Hon Jack Snelling, South Australian Minister for Health
- Providing campaign letters for our SA macular disease community to communicate with their elected local State MP

The Foundation urged a collaborative approach with ophthalmologists at Royal Adelaide Hospital to find a sensible, practical and workable outcome.

The Foundation was grateful for the support of the Opposition and the Dignity for Disability Party. The South Australian Government's willingness to listen and respond to the concerns of the Foundation was appreciated.

Funding for an additional seven eye clinics per month was provided as a result of the Foundation's advocacy.

The Foundation continues to monitor the existing arrangements and advocate for a sustainable long term resolution to cater for the future eye health needs of all South Australians.





Foundation Chief Executive Officer Julie Heraghty and Professor Dinesh Selva AM appeared in South Australian media calling for action on the South Australian capacity crisis.

"I am writing on behalf of the staff and patients at the Royal Adelaide Hospital Eye Department to express our profound gratitude for the work that Macular Disease Foundation did to alleviate the macular degeneration injection crisis here in South Australia."

Professor Dinesh Selva AM, Chairman Ophthalmology Network Royal Adelaide Hospital

# Representing the interests of the macular disease community

In 2013-2014, the Foundation played a key role in representing the interests of the macular disease community in the areas of ageing, health and disabilities, while also supporting our New Zealand colleagues.

National Aged Care Alliance (NACA) is the representative body of peak national organisations in aged care working together to determine a more positive future for aged care in Australia.

#### Foundation activities:

- Ageing and Disability Interface Internal Working Group (chair)
- Commonwealth Home Support Advisory Group Service Group 5 Sub Group (member)

Australian Blindness Forum (ABF) is a not-for-profit organisation representing people who are blind or vision impaired in Australia.

### Foundation activities:

Australian Blindness Forum (member)

**NSW Health** is the government body covering all aspects of public health in NSW.

#### Foundation activities:

- Non-Government Organisation (NGO) Advisory Committee (member)
- NSW Health Agency for Clinical Innovation Statewide Ophthalmology Service Governing Body (member)
- (NGO) Advisory Committee Standard Contract Working Group (member)

**Vision 2020 Australia** is a global initiative of the World Health Organisation and the International Agency for the Prevention of Blindness.

#### Foundation activities:

- Prevention and Early Intervention Committee (member)
- Low Vision and Rehabilitation Committee (member)
- National Framework Implementation Plan for Action to Promote Eye Health and Reduce Avoidable Blindness and Vision Loss (major contributor)

# Macular Degeneration Foundation New Zealand

Macular Disease Foundation Australia's Chief Executive Officer facilitated a strategic planning day with Macular Degeneration Foundation New Zealand's Board to share knowledge and insights gained through activities undertaken in Australia. Additionally, the Foundation has assisted with ongoing support in the form of provision of resources which can be adapted for New Zealand. This supports Macular Degeneration Foundation New Zealand in reducing the incidence and impact of macular degeneration in New Zealand.



# Val has a cup of tea with her new MP

In November 2013 Val Sellars and her husband Roly met with their local MP Matt Williams as part of the Foundation's Have a cup of tea with your new MP campaign.

Val, who has had macular degeneration for 11 years and lives with vision loss, said she was keen to share her story with her local MP to ensure he understood how common macular degeneration is and how it affects so many older Australians.

Hindmarsh, which is Val's federal electorate, has the highest prevalence of macular degeneration in Australia.

The Foundation is grateful to Val and husband Roly for their support, along with all in the macular disease community who got behind this campaign.



Val Sellars with local MP Matt Williams

### Meeting our Objectives

# **Best Practice Management**

# Ensuring best practice in management

# A Dedicated and Experienced Board

Macular Disease Foundation Australia has a strong, experienced Board representing the needs of the macular disease community. The Board reflects the diversity in the macular disease community, particularly that of the macular degeneration community, and includes people living with the disease or who have a family member with the disease, ophthalmologists and people who bring to the governing body special skills in a broad array of areas.

The Board worked closely with the Chief Executive Officer throughout 2013-2014, setting a clear strategic direction to meet the vision and objectives of the Foundation.

# A Strong Committee Structure

Committees worked with the Chief Executive Officer as part of good governance and management throughout the year.

- Audit and Risk Committee: oversees and enhances the financial reporting, external audit, risk management and internal control frameworks. The Investment Sub-Committee oversees investments.
- Medical Committee: provides medical expertise, guidance and advice on medical matters related to macular disease.
- Client Services Committee: oversees and enhances the ability of the Foundation to provide the highest quality services to meet the needs of the clients.

- Research Committee: provides expertise and guidance in relation to the research program development.
- Board Nomination and Evaluation Committee: reviews Board appointments and performance.

### A Committed Staff Team

Julie Heraghty is the Chief Executive
Officer of the Foundation and leads a team
of 14 staff responsible for education and
awareness, marketing and public relations,
support services, research, finance and
administration. The national office is in
Sydney and provides Australia-wide services.

# Staff Development

Professional development of staff is an ongoing priority to help ensure that, through their individual roles, staff are able to contribute to the delivery of services to the macular disease community in the most effective and professional way.

### A Dedicated Volunteer Team

Volunteers provide valuable support to the Foundation, contributing both time and expertise in many different areas of work. Many volunteers live with a macular disease, others are touched by it in some way through a family member or friend, and others volunteer as part of their philosophy of giving to the community.

"Thank you to all our volunteers for their commitment and dedication to the work of the Foundation."





# Invaluable Vollies!

Susan (pictured left) has been a volunteer at the Foundation for more than four years and over that time has become an important member of the Foundation's ever willing and invaluable team of volunteers.

Susan uses her organisational skills to keep the Foundation's publication store in order and greatly assists the daily team of volunteers who collate the large quantity of information sent out to those requesting resources.

Susan's motivation to volunteer is to help make a difference in the macular disease community.

The Foundation is grateful to Susan and all her fellow volunteers for their hard work in helping to reduce the incidence and impact of macular disease in Australia.

# Financial Report

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

\$000	2014	2013
Revenues		
Sponsorships	2,003	2,249
Donations/Fundraising	525	800
Donations - Research Grants Program	290	280
Corporate support	610	575
Government grants	481	470
Investment income	319	269
Total Revenues	4,228	4,643
Expenses		
Awareness	1,446	1,563
Support services	649	541
Research Grants Program	370	283
Research	242	234
Management	408	426
Education	350	343
Representation	211	529
Fundraising	136	114
Total Expenses	3,812	4,033
Net Surplus	416	610

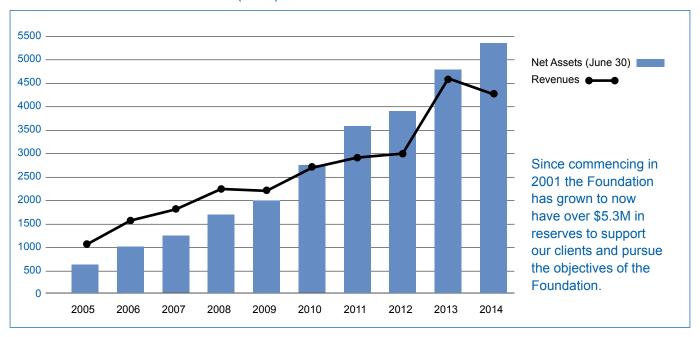
### **BALANCE SHEET** (AS AT 30 JUNE)

\$000	2014	2013
Assets		
Cash and cash equivalents	1,184	1,847
Investments	4,420	2,504
Trade and other receivables	1,078	1,476
Plant and equipment	62	88
Total Assets	6,744	5,915
Liabilities		
Trade and other payables	1,317	1,092
Provisions	42	22
Total Liabilities	1,359	1,114
Net Assets <sup>1</sup>	5,385	4,801

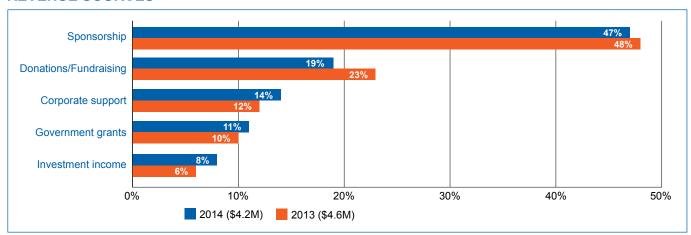
<sup>&</sup>lt;sup>1</sup>The Foundation has \$1,800,000 (2013: \$1,750,000) set aside within the Net Assets to support future Macular Disease Foundation Australia research initiatives.

The information on this page was extracted from the audited Financial Statements of Macular Disease Foundation Australia for the year ended 30 June 2014 and 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.

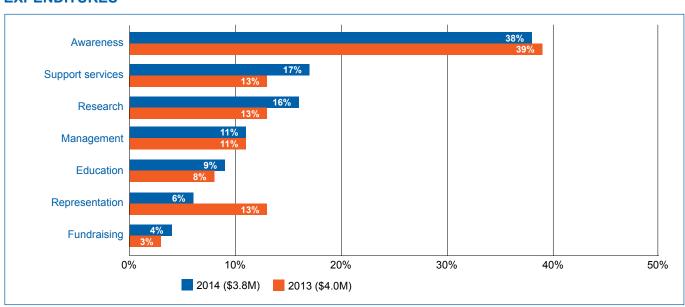
### **10 YEAR FINANCIAL SUMMARY** (\$000)



### **REVENUE SOURCES**



#### **EXPENDITURES**



# Meeting our Objectives

# **Fundraising**

# To provide income from fundraising to support the growth of the Foundation and its services

# **Government Funding**

The Federal and NSW Governments both provide financial support across many programs, especially education and awareness. The Foundation is most appreciative of the ongoing support of government.

### Department of Health

The Federal Government, through the Department of Health, has provided funding to the Foundation since 2005. This funding supports the continued delivery of the national education program which reached almost 2,200 people in 2013-2014, providing the opportunity for many people across Australia, especially in regional areas, to attend a detailed presentation on macular degeneration with a Foundation educator.

### **NSW Department of Health**

The Foundation was established with a NSW government grant provided in 2002. The ongoing funding from the NSW government has allowed the Foundation to deliver its comprehensive education and awareness programs and provide services to reach thousands of people in NSW, especially in regional and remote areas.

# Corporate Sponsorship

Corporate sponsorship is an integral part of the support for the Foundation and thanks go to all sponsors and supporters. The Foundation is grateful for such generosity and commitment to supporting awareness, education, research, and client service programs.

### **Blackmores**

With a shared common value to reduce the incidence and impact of macular degeneration in Australia, Blackmores remains a long term supporter of the Foundation's education, research and awareness programs. In addition to its generous ongoing support for the Foundation, Blackmores and The Blackmore Foundation provides funding for the Blackmores Dr Paul Beaumont Research Fellowship.



Marcus Blackmore with Foundation Ambassador Jean Kittson

### Bayer

Since 2011 Bayer has provided valuable support to a range of initiatives in the areas of client services, awareness, education and research. This generous support has allowed the Foundation to expand its activities and services to assist the many people who require the Foundation's help. In 2014 Bayer generously supported the Foundation's national television and radio awareness campaign, which enabled the Foundation to continue to maintain world-leading levels of awareness of macular degeneration.

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



Bayer General Manager Rene Klemm with Foundation Chief Executive Officer Julie Heraghty

### **Novartis**

Novartis has generously supported the Foundation since its establishment and this support has made a significant contribution to improved macular health in Australia.

In particular, Novartis supported the Foundation's first national television and radio awareness campaigns from 2008 to 2012, which resulted in Australia becoming a world leader in awareness of macular degeneration. This contribution is appreciated by the Foundation and the macular degeneration community.



Novartis Director Ophthalmics Business Franchise Jeff Martens and Managing Director Jason Smith

### **Foundations and Trusts**

Foundations and Trusts are important to the Foundation and give support across a range of activities. The Foundation especially acknowledges Profield Foundation for their ongoing support and funding, along with the generous support of Perpetual Foundation.

### **Profield Foundation**

The Foundation is indebted to the generosity of the Profield Foundation, which has been an outstanding supporter since 2007. Profield's commitment to the Foundation has funded client services including the Helpline, publications, and awareness and education activities.



**Profield Foundation Board** 

The Foundation is most grateful to the many donors, both individual and corporate, who give so generously in order that others may live better with macular disease.

### **ODMA**

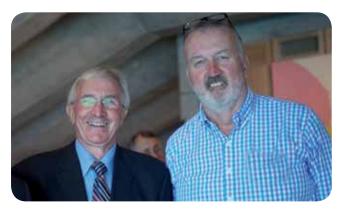
The Optical Distributors and Manufacturers Association (ODMA) was the primary supporter of the Foundation's mEYE World Photographic Competition in 2013. The competition introduces macular degeneration to a broad audience and reinforces the connection between sight and the visual medium of photography.



ODMA Chief Executive Officer Finola Carey with Foundation General Manager Lucy Walker

### Quantum RLV

Quantum RLV, provider of low vision aids and technologies, is a founding supporter of the Foundation's education programs.



Foundation Board Director Richard Grills with Tim Connell Managing Director Quantum RLV

### **Donations**

The Foundation relies on donations to ensure services continue and expand to meet the needs of the macular disease community. The generosity of so many people and organisations throughout the year has been remarkable and we thank all for their contribution.

# **Bequests**

Bequests form an increasingly important part of the Foundation's funding and we are most grateful to those who choose to support the Foundation in this way. Bequests can be directed to support ongoing Foundation programs, or directly to the Foundation's Research Grants Program, reflecting the desire to contribute to finding reasons and answers for this disease.

# Community

### Roth Gair Charity Golf Day

In February 2014 the Lions Club of Forest Hill in Victoria once again hosted the annual Roth Gair Charity Golf Day to raise funds for the Foundation, this year welcoming the support of the Lions Club of Park Orchards in assisting with event organisation.

The golf day is held in memory of the late Mr Roth Gair, a long time member and past President of the Lions Club of Forest Hill, who had macular degeneration.

Thank you to organiser Ian Kennedy, the clubs and event sponsors. Together they delivered a wonderful event, raising over \$14.000.



Roth Gair Charity Golf Day winning team - Oliver O'Callaghan, Mike O'Callaghan, Sharon Stewart, Paul Stewart

### ClubsNSW ClubGRANTS

Through the ClubGRANTS scheme, large registered clubs in NSW contribute directly to the provision of front-line services to their local communities.

Thank you to the clubs who supported the Foundation in 2013-2014:

Campsie RSL Club, Club Central Hurstville, Bankstown District Sports Club, Commercial Club Albury, Goulburn Soldiers Club, Goulburn Workers Club, Griffith Ex-Servicemen's Club, Griffith Leagues Club, Hornsby RSL, Murray Downs Golf and Country Club, Orange Ex-Services Club, Parkes Services & Citizens Co-Op, Rules Club Wagga.

### Rotary Clubs and District 9670

Rotary Clubs across Australia continued to support the Foundation through community fundraising in 2013-2014. A highlight of the year was the donation of over \$23,000 from Rotary District 9670, coordinated by Margaret Raynor.

During Margaret's husband's term as Rotary District Governor 9670, she chose to support the Foundation's Research Grants Program as her Partner's Project. See page 56.

Thank you to all Rotary Clubs who donated funds to support the Foundation's sight saving work.

# Great Priory NSW & ACT and Masonicare

The Foundation would like to extend a special thanks to The Great Priory NSW & ACT and Masonicare for their support of the Foundation. Through a joint effort \$11,000 was donated to the Foundation's Research Grants Program.

# Quota International Clubs of the 35th District

Thank you to Quota International Clubs of the 35th District for selecting the Foundation as their District Project for 2013-2014. The 12 clubs in the District each supported the project by organising fundraising events or making a donation, resulting in a contribution to the Foundation of over \$12,000.

### Everyday Hero and GoFundraise

Throughout the year many people chose to participate in an event or a personal challenge to raise money for the Foundation using websites Everyday Hero and GoFundraise.

Some of the outstanding efforts by supporters in 2013-2014 include:

- Andy who participated in the Five Dams Challenge (WA)
- Anne who ran City2Surf (NSW)
- Alison who cycled more than 800km from San Francisco to Los Angeles
- Tim and Kat who chose to support the Foundation instead of receiving wedding gifts



Andy participated in the five Dams Challenge and raised money for the Foundation

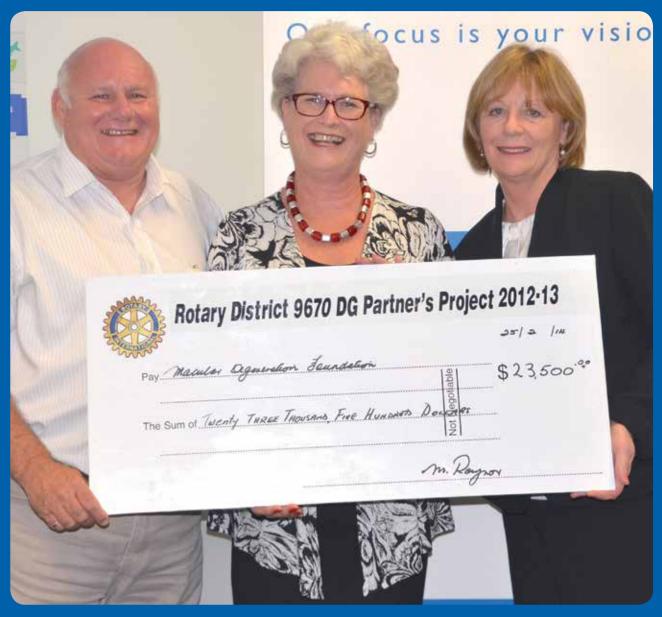
### Margaret's Rotary Partner Project raises \$23,500

Margaret Raynor chose the Foundation's research program to be the beneficiary of her Rotary District 9670 Partner's Project raising a total of \$23,500.

Margaret selected the Foundation as she had seen the impact of macular degeneration on her mother Betty's life. Margaret visited the Rotary Clubs in District 9670, sharing her personal story and encouraging members to consider the effect that vision loss would have on their own lives and calling on them to donate.

Margaret and husband Peter, Immediate Past District Governor of Rotary District 9670, visited the Foundation to present their giant cheque. It was a superb effort by Margaret and all the Rotary District 9670 Clubs who supported her project.

The Foundation thanks all community and individual fundraisers for their contribution. This financial support goes a long way to ensure all Australians can see a future.



Margaret and Peter Raynor with Foundation Chief Executive Officer Julie Heraghty

# Thank You

The Foundation thanks all sponsors, donors, volunteers and supporters for their assistance this year. The generosity, kindness, good works and spirit of giving shown by so many is highly valued. This support allows Macular Disease Foundation Australia to meet its objectives and realise the vision of reducing the incidence and impact of macular disease in Australia.

### Sponsors & Supporting Partners

Australian Government

























Thank you to all individual donors, corporate supporters, government and healthcare professionals for supporting the work of the Foundation to meet our objectives in education, awareness, support services, research and representation.

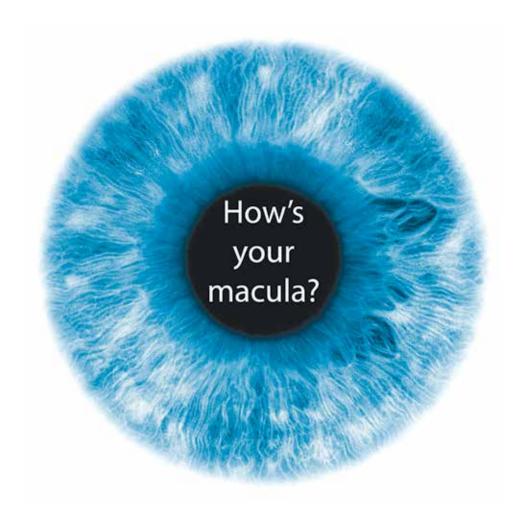
### Also thanks to...

- The Royal Australia and New Zealand College of Ophthalmologists
- Optometry Australia
- National Seniors Foundation Trust
- Buchan Consulting
- Galaxy Research
- Specsavers

- Simplot Australia
- Madura Tea
- Lisa Thompson Photographer
- Voss Design

### mEYE World Photographic Competition 2013 - Prize Donors

Adobe, Australian Geographic Retail, Foto Riesel, Frameworks, Fujifilm Australia, Jonathan Paul Eyewear, Ken Done Gallery, Ken Duncan Gallery, Momento Australia, New Holland Publishers, Safilo Australia.



# **Professional Friend Program**

Since the Foundation's inception in 2001 it has enjoyed a long and valuable relationship with optometrists, ophthalmologists and other eye care practitioners across Australia. Our combined efforts have saved the sight of thousands of Australians.

By becoming a Professional Friend, eye care professionals can demonstrate their ongoing support of Macular Disease Foundation Australia and show their commitment to being at the forefront of client support services.

To become a Professional Friend, contact Macular Disease Foundation Australia.

### Thank you to our Professional Friends:

Dianne Andrews, Menai Eye Care • Susan Ang, The EyeStore • Dr Jennifer Arnold, Marsden Eye Specialists • Sally Atkins, Atkins Optometrist • Odette Azzi, Belfield Optometrist • Dr Gayatri Banerjee, Nepean Valley Eye Surgeons • James Baumgarten, Family Eyecare • Dr Paul Beaumont, Retina & Vitreous Centre • Dr Peter Benecke, Northern Eye Surgery • Reg Bennett, Campbelltown Eye Care • Geoff Blackwell, Clear Optometry • Garry Bormann, Vision Eye Health • Dr Robert Bourke, Vision Eye Institute • 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, Retina & Vitreous Centre • Dr Christopher Chesney, Mentone Eye Specialists • Wai Yoong Chin, Wai Yoong Chin Optometrist • Andy Christiansen, The Optical Superstore • Dr Augustino Clark • Justin Clunas, Hansen Optometrists Eyecare Plus Orange • Janelle Coates, EyesWest • Judith Cooper, Judith Cooper Optometrist • Dr Sudha Cugati, Lyell McEwin Hospital • Dr Jenny Danks, Peninsula Eye Centre • Peter D'Arcy, Peter D'Arcy Optometrist • Cedric De Souza, Melville Optical Clinic • Maria Dimitratos, Icon Eyewear • Dr John Downie, Chatswood Grove Eye Clinic • Jane Duffy, Fitzroy North Eye Centre • Cameron Dyson, Dyson & Long Optometrists • Fiona Eising, Eye Zing Optometrists • John Farmer, L&F Eyecare Dr Adrian Fung, Retina and Macula Specialists • Russell Glasser, Eyecare-2-You • Dr Kai Goh, St John of God Murdoch • Kylie Gough, Eyecare Plus Nambucca Heads • Dr Tim Gray, Kingswood Eye Centre • Dr John Gregory-Roberts • Nicholas Hansen, Hansen Optometrists Eyecare Plus Orange • Mark Hansen, Hansen Optometrists Eyecare Plus Orange • Sean Hansen, Hansen Optometrists Eyecare Plus Orange • Jake Hansen, Hansen Optometrists Eyecare Plus Orange • John Harbison, Christensen Harbison Optometrists • Amanda Harkness, Moss Vale Optical • Dr Graham Hay-Smith, Moreton Eye Group • Sandra Heaney, Sandra Heaney Optometrist • Aaron Henry, Aaron Henry Optometrist • Graham Hill, Graham Hill & Associates Optometrists • Huy Ho, A+ EYECARE • Peter Ho, Peter Ho Optometrist • Associate Professor

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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 our activities in education, awareness, support services, and research.

### **Sponsors**

As the Foundation implements a range of programs across Australia, sponsorship opportunities exist for organisations to support specific projects.

### **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 to support the Foundation by participating in events to raise funds.

### 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 our 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



Our focus is your vision

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

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