

“For me it’s
personal.

My father
had macular
degeneration.”



Ita Buttrose, Foundation Patron
and Australian of the Year 2013

**Let's stop
Australians going blind
with your help...**

Annual Report 2012-2013

DID YOU KNOW?

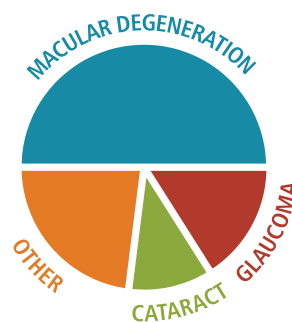
50% OF ALL
BLINDNESS*

IS DUE TO MACULAR DEGENERATION

By 2030 the number of those with evidence of MD **could increase by 70% to 1.7 million**

MACULAR DEGENERATION (MD) IS THE LEADING CAUSE OF BLINDNESS* IN AUSTRALIA

Causes of blindness in Australia



RISK FACTORS



Age

1 in 7 Australians over 50 show some evidence of MD



Family history

50% risk of MD if a direct family history is present



Smoking

Increases the risk of MD by 3 to 4 times

How's
your
macula?

HAVE YOUR EYES TESTED AND MACULA CHECKED

MACULAR DEGENERATION - THE FACTS

WHAT YOU CAN DO - HEALTH AND PREVENTION



Have your eyes tested and macula checked



Regular exercise and a healthy diet



Don't smoke

Eating for eye health

Eat dark green leafy vegetables and fresh fruit daily
Eat fish 2-3 times a week
Choose low GI carbohydrates
Limit intake of fats and oils



Cost

The total economic cost of vision loss associated with MD estimated at \$5 billion in 2010



Quality of life

The impact on quality of life is equivalent to cancer or coronary heart disease

Higher risk

Falls
Hip fractures
Depression
Social isolation
Earlier need for nursing home care



WHAT IS THE IMPACT?

Macular Disease Foundation Australia
www.mdfoundation.com.au | 1800 111 709

* legal blindness

Macular Disease Foundation Australia

The 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.

The Foundation is the voice of the macular disease community, building healthy communities through the development of effective public policy, a sound knowledge base and strong relationships and partnerships.

Macular Disease

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

Macular degeneration is the leading cause of blindness* and severe vision loss in Australia. One in every seven Australians over fifty (one million people) show some evidence of macular degeneration.

Macular disease and its associated vision loss can have a major impact on quality of life and independence.

Contents

Macular Disease Foundation Australia	I	Meeting our Objectives	
Macular Disease	I	○ Education	14
Our Vision	2	○ Awareness	20
Our Values	2	○ Research	32
Our Objectives	2	○ Support Services	38
Our Guiding Principles	3	○ Representation	42
Highlights of 2012-2013	4	○ Best Practice Management	50
Report from the Chairman		Financial Report	52
and Chief Executive Officer	6	Fundraising	54
Patron Ita Buttrose	9	Thank You	58
Macular Disease Foundation Australia	10	Working Together	60
○ Our Board	10	Help the Macular Disease Foundation	
○ National Research Advisor	12	Australia	61
○ Chief Executive Officer	13		
○ Board Committees	13		
○ State Chairs	13		

* legal blindness

Our Vision

To reduce the incidence and impact of macular disease in Australia.

Our Values

The Macular Disease Foundation Australia's Board, Committees, staff and volunteers have common shared values and commitments. These values and commitments underpin the Foundation's strategic plan.

These common 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

Our Objectives

The key objectives of the Macular Disease Foundation Australia are to represent the interests of the macular disease community by providing:

Education

Provide accurate, specific, current and ongoing information

Awareness

Increase awareness of macular disease

Research

Support and pursue research

Support Services

Facilitate access to relevant support and support services

Representation

Advocate for the best interests of the macular disease community

These objectives are realised through the provision of income from fundraising and ensuring best practice in management.

Our Guiding Principles

The 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

Highlights of 2012-2013

Education

- Delivered a comprehensive national education program
- 193 education sessions held nationally with over 7,500 attendees
- Distributed 7,000 information kits at education sessions
- 98% of attendees rated education sessions as either excellent or good

Representation

- Successfully campaigned to enable the switching of anti-VEGF drugs for wet macular degeneration, to improve choice and access for patients and doctors
- Contributed over 15 submissions on aged care policies and legislation and the development of the National Disability Insurance Scheme
- Represented the interests of the macular disease community at two Senate Standing Committee hearings on the National Disability Insurance Scheme and the aged care reform legislation
- Launched the Sight for Seniors campaign and website
- Mounted a major media drive to highlight the issue of discriminatory age restriction in the National Disability Insurance Scheme
- Convened the first-ever Global Ageing and Vision Advocacy Summit in partnership with the International Federation on Ageing
- Hosted the Australian Wet Age-related Macular Degeneration Summit in partnership with renowned international Angiogenesis Foundation

Support Services

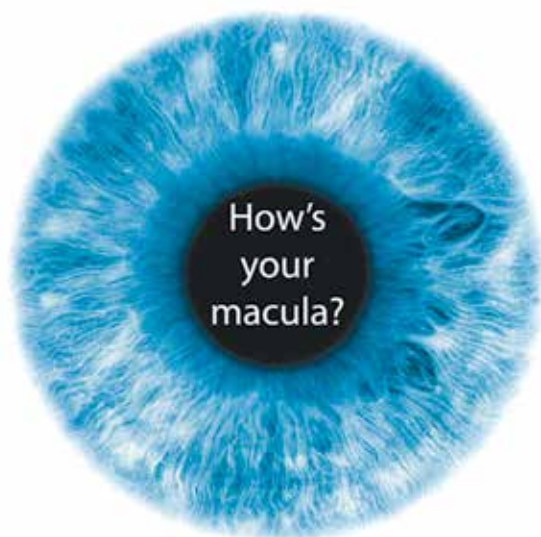
- Averaged 56 calls per day to the Helpline with over 14,000 calls in 2012-2013
- Over 700,000 individual publications and resources distributed
- Over 140,000 newsletters distributed
- Increased website visits by 20% on previous year with over 340,000 visits in 2012-2013

Awareness

- The Foundation continued to be a world leader in raising awareness of macular degeneration
- New national television and radio campaign produced a massive increase in symptom recognition, increasing from 20% in 2011 to 29% in the 50 plus age group
- Macular Degeneration Awareness Week 2013 estimated media impressions rose 8% to 53 million
- 'The Ripple Effect of Vision Loss' research generated extensive media coverage with over 500 media placements
- mEYE World Photographic Competition had a 36% increase in entries and recorded an estimated 10 million media impressions

Research

- Awarded the Blackmores Dr Paul Beaumont Research Fellowship 2013-2014
- Published the *Mapping the Landscape* report
- Major Foundation social research project completed, highlighting the 'Ripple Effect of Vision Loss'
- The prestigious American Journal of Public Health published the Foundation's peer-reviewed article on world leading work in raising awareness
- Foundation client survey showed that 94% of clients were satisfied or very satisfied with the Foundation's services



Report from the Chairman and Chief Executive Officer

The Foundation continues to work to protect the eye health of the Australian community. The Foundation's activities and programs are guided by a strong strategic framework which includes:

- building healthy communities;
- development and strengthening of national and international relationships; and
- a strong position in the development of public policy.

During the year the Foundation entered a new phase of its growth, extending its services to include all macular diseases, and changing its name from Macular Degeneration Foundation Limited to Macular Disease Foundation Australia. This change reflects the Foundation's commitment to servicing the needs of all those affected by macular disease, while recognising that macular degeneration is the leading cause of blindness and severe vision loss in Australia and the major focus for the Foundation's work.

The Foundation's strategic framework is underpinned by five key areas of focus: education, awareness, client services, representation and research. Building upon its work over the last 12 years, the expansion to service all macular diseases will be incorporated within these five pillars.

In January the Foundation's Patron, Ita Buttrose AO, OBE was awarded Australian of the Year 2013. This was a richly deserved recognition of Ita's extraordinary contribution to public life, including her commitment to older Australians and her various charitable causes. For over eight years Ita has tirelessly donated her time, energy and expertise to raising awareness of macular degeneration and the Foundation sincerely thanks her for her work and commitment.

Founding Director, Dr Paul Beaumont, was awarded the Member of the Order of Australia (AM) in the Queen's Birthday 2013 Honours List for his services to ophthalmology. The Foundation

congratulates Dr Beaumont on this award which recognises his significant contribution, particularly in the field of macular degeneration, and his vision in establishing the Foundation.

Australia continued to be a world leader in raising awareness of macular degeneration, thanks to the work of the Foundation. Ten years ago, the majority of Australians had not heard of macular degeneration, however today, according to Galaxy Research polling, over 90% of people in the age 50 plus at-risk population know of the disease and over 70% in this group report having had their macula checked in the last two years.

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. Again, in August - September 2012, the Foundation's campaign went to air nationally with a new symptom awareness advertisement. Our sincere thanks go to Novartis for supporting the campaign and for their outstanding contribution to eye health in Australia.

Since its beginnings in 2001, a key goal of the Foundation was to support Australian researchers to find reasons and answers for macular degeneration. As a result of the generosity of so many supporters, in 2011 the Foundation launched the Macular Degeneration Research Grants Program and funded two world famous Australian researchers. In 2013 the Foundation opened applications for the second major research grants awards to be announced on World Sight Day in October 2013. In December 2012 the Foundation awarded a two-year grant for the second Blackmores Dr Paul Beaumont Research Fellowship to Dr Bamini Gopinath, Senior Research Fellow at the Millennium Centre for Eye Research, Westmead and the University of Sydney. The Foundation sincerely thanks Blackmores and the Blackmore Foundation for their support for this fellowship.



Elizabeth Carr, Chairman

The Foundation is committed to representing the macular disease community and has developed a strong voice in the eye health, disability and ageing sectors. We continue to represent the key issues to policy makers and advocate for equity of access to treatment and rehabilitation to improve the quality of life of those with macular disease and their family and carers. One of the key challenges has been the proposed new National Disability Insurance Scheme and the Foundation continues to advocate for the terms to be amended to include those who acquire a disability over the age of 65. The 'Sight for Seniors' campaign is the key platform via which the Foundation, and the macular disease community, can convey their message to policy makers.

The Foundation continued to develop and strengthen its national alliances, but also expanded to forge new relationships internationally. In July 2012, the Foundation co-hosted with the US-based Angiogenesis



Julie Heraghty, Chief Executive Officer

Foundation, an expert summit on wet age-related macular degeneration which was attended by leading ophthalmologists from all over Australia. In April 2013 the Foundation co-hosted with the International Federation on Ageing, the inaugural Global Ageing and Vision Advocacy Summit in Barcelona, bringing together leaders in ageing and vision organisations from 12 countries to map a course for advocacy. Thank you to Bayer for their support of this initiative.

The Foundation is grateful for the generosity of its many loyal supporters and we extend our most sincere thanks for their dedication and ongoing commitment to the work of the Foundation. A special thanks to Foundation Ambassadors, Jean Kittson and Jan Utzon for their ongoing commitment and support of our cause.

Our major sponsors once again enabled us to initiate and implement new projects, and maintain and improve our existing services. Our sincere

thanks to all our funders especially the Federal and NSW Governments, Blackmores, Novartis, Bayer, Profield Foundation and the Optical Distributors and Manufacturers Association (ODMA). A special thank you also to 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 ensure 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
Chairman
BA (Hons) UWA
MPA Harvard University
FAICD



Julie Heraghty
Chief Executive Officer
BA DipEd UNSW
Assoc MAPS

A new frontier

In January 2013, the Macular Degeneration Foundation changed its name to the Macular Disease Foundation Australia.

This change reflects the Foundation's recognition of the need to champion all macular diseases including macular degeneration, diabetic retinopathy and retinal vein occlusions.

The Foundation is committed to providing information, understanding, guidance and support for the macular disease community.

The move to encompass and support all macular diseases will ensure those living with a macular disease will have an avenue for support as well as a representative voice in the community.

“The Foundation’s name change reflects the commitment to servicing the needs of all those affected by macular disease.”

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 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!



Patron and Australian of the Year 2013

Ita Buttrose AO, OBE

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. Ita combines many roles as social commentator, businesswoman, journalist and author. She 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 also National President of Alzheimer's Australia and Emeritus Director of Arthritis Australia.

Ita has continued her outstanding work as the Patron of the Macular Disease Foundation Australia in 2012-2013, working tirelessly to promote the cause across Australia.

The Foundation congratulates Ita on becoming Australian of the Year 2013 and thanks her for her truly remarkable contribution.

Macular Disease Foundation Australia

Our Board

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



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, and a director of the Kokoda Track Foundation, and St Marys Anglican Girls School WA. She is a member of the Environmental Protection Authority (WA) and a director of the Safety, Return to Work and Support Board (NSW) and its associated Audit and Risk Committee and Investment Funds.

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



Ashley Chapman, Deputy Chairman - CPA, MACS

Ashley Chapman retired in 2004 after a career in information technology spanning over 40 years. His experience includes 15 years with IBM in a variety of roles covering systems engineering, programming and education. Ashley's 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 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 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

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. Dr Beaumont 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 is Chairman of the Medical Committee and a member of the Research Committee.

Dr Paul Beaumont was awarded the Member of the Order of Australia (AM) in the Queen's Birthday 2013 Honours List for his services to ophthalmology. The Foundation congratulates Dr Beaumont on this award. This honour is a reflection of a long career dedicated to improving eye health, particularly in the field of macular degeneration.



Peter Brown

Peter Brown has spent 30 years in advertising and communication. He worked in London in consumer advertising and new product development before moving to Sydney in 1988 and 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.



Barry Clarke - FIPA

Barry Clarke has over 40 years experience in the financial services sector in both executive and chief executive officer roles. He is currently a director of the Royal Society for the Blind (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, and therefore 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.



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 New South Wales at hospitals and ophthalmic practices.

Since 1974 Richard has been a lecturer in optics at The University of Sydney. He is the chairman of the Optical Distributors and Manufacturers Association (ODMA) and a director of the Genetic Eye Foundation.

Richard Grills is a member of the Client Services Committee.



Professor Jill Keefe - PhD, OAM

Professor Jill Keefe 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.

Professor Keefe's research focuses on the development and evaluation of eye care services that aim to prevent vision loss and blindness. She was awarded the Medal of the Order of Australia 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 Keefe is a member of the Client Services Committee.



John McCarroll - B.Ec, GAICD

John McCarroll is a director at JB Were Ltd - Private Wealth Management. He has more than 30 years experience in the finance industry, initially in Europe and for the past 21 years in Australia. John holds a Bachelor of Economics from Monash University (Victoria), is a diploma member of the Australian Institute of Company Directors and was a director of the Australian Stockbrokers Foundation for over 19 years. He is fluent in German.

John McCarroll is a member of the Investment Sub-Committee and the Board Nomination & Evaluation Committee.



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.

Peter is a frequent speaker at international industry and professional conferences and has lectured at The University of Sydney Law School. In 2004 he established his own legal practice, Energy & Resources Lawyers Pty Ltd. 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.



Paul Rogan - BBus, FCPA, AICD

Paul Rogan is a senior executive with more than 25 years experience in the financial services sector both in Australia and the United Kingdom. He is currently the chief executive, distribution product and marketing, of Challenger Limited and is a director of its subsidiaries.

Paul has served as an executive director on subsidiary boards of the National Australia Bank and MLC Group, including as chief executive officer of the wealth management operations in the United Kingdom 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 Chairman of the Audit & Risk Committee, the Investment Sub-Committee and the Research Committee.



Dr Jim Runciman - FRACS, FRANZCO

Dr Jim Runciman is a fellow and past South Australian state chairman of the Royal Australian and New Zealand College of Ophthalmologists. He was appointed to the Foundation's Board in 2003.

Dr Runciman is a leading ophthalmologist with a special interest in retinal diseases and the support of those with vision impairment. He is a director of the Adelaide Eye and Retina Centre, has been a board member of the Royal Society for the Blind SA since 1995 and is a past president. Dr Runciman is also on the advisory boards of a number of ophthalmic drug companies and is a consultant to Ellex Lasers R&D.

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



Suellen Tapsall - BA, MA, FAIM

Suellen Tapsall is the director of AIM WA - UWA Business School Executive Education. In this role she successfully and effectively works with public and private sector organisations (in WA, 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 Chairman of the Client Services Committee and a member of the Research Committee.

National Research Advisor



Professor Paul Mitchell - MBBS, MD, PhD, FRANZCO, FRACS, FRCOphth, FAFPHM

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

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



Julie Heraghty - BA, DipEd, Assoc MAPS

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

Prior to joining the Foundation, Julie spent over seven years as a policy advisor to NSW state ministers, and also served as a director/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.

Audit and Risk Committee

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
Mr Ashley Chapman
Mr John McCarroll

Medical Committee

Dr Paul Beaumont - Chairman
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
Dr Jim Runciman
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 the Macular Disease Foundation Australia at a state level:

New South Wales: Dr Paul Beaumont

Queensland: Dr Amanda Greaves

Victoria: Associate Professor Wilson Heriot

Tasmania: Associate Professor Nitin Verma

South Australia: Dr Jim Runciman

Western Australia: Ms Suellen Tapsall

Meeting our Objectives

Education

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

What Did We Do?

Education of the Public

Education sessions provide an opportunity for the Australian community to learn about macular degeneration including the 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 7,000 information kits at education sessions

“The Foundation does a fantastic job helping people learn about macular degeneration as well as advocating for people with macular disease. Excellent presentation.”

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 2012-2013 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 54 sessions were held nationally with over 3,000 attendees



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 at 139 sessions to over 4,500 attendees

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.

Ophthalmology

The Foundation attended the 2012 Royal Australian and New Zealand College of Ophthalmologists (RANZCO) Annual Scientific Congress in Melbourne. The Foundation Chief Executive Officer was a guest speaker within the orthoptist and practice manager programs and the Foundation also supplied information to delegates at its exhibition stand and in delegate packs.

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 optometry for their patients, and also contributed to professional publications on topics such as research, new treatments, nutrition and supplements and awareness programs.

“I give the nutrition factsheet to my patients all the time.”

Health Carers

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 and also presented at the major health, aged care and disability expos in Sydney.

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.

Sydney Eye Hospital EyeCU

The Foundation was an active participant in the Sydney Eye Hospital's EyeCU Project group which was established to improve access to treatment for wet age-related macular degeneration in the public hospital setting. The Foundation's Research and Policy Manager continues to give education sessions to nursing and administration staff at the hospital and these talks are to be incorporated into the hospital's recently announced Ophthalmic Nursing course, to be developed in conjunction with the University of Notre Dame, Sydney.

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 of Eye Health

The Foundation continued to support the education of eye health students. Dr Paul Beaumont, Foundation Board Director, provided training to University of NSW optometry students on behalf of the Foundation. This included full day surgery observation for all fifth year students. The surgery observation included diagnostic testing, treatment procedures and patient counselling.

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. It also held an education session for orthoptist students at The University of Sydney.

Where did we go?

COMMUNITY EDUCATION		
SENIORS GROUPS	SERVICE CLUBS	
NSW Asquith Barrack Heights Belrose Berowra Birrong Blacktown Bondi Junction Burwood Camden Campbelltown Chatswood Dapto Dee Why East Sydney Emu Plains Ermington Gladesville Kogarah Lakemba Lane Cove Leumeah Lindfield Liverpool Marrickville Mona Vale Pennant Hills Penrith Picton Revesby Riverwood Rose Bay South Coogee South Hurstville South Penrith St Marys Sydney Turramurra Wagga Wagga West Ryde	NSW Baulkham Hills Budgewoi Camden Campbelltown Cheltenham Dural Five Dock Mt Colah Northbridge St Ives Wagga Wagga	Concord Croydon Darling Harbour Dulwich Hill Earlwood Greystanes Haberfield Kensington Kiama Kingswood Lidcombe Longueville Manly Marrickville Padstow Petersham Randwick Rosehill Strathfield Summer Hill Surry Hills Sydney
QLD Paradise Waters Wynnum	QLD Buderim Toowoomba	QLD Paddington
VIC Abbotsford Box Hill	VIC Botanic Ridge Dromana Mt Eliza Southbank	VIC Southbank
WA Bayswater Cambridge Gosnells Perth Rockingham Thornleigh West Perth Yokine	WA East Perth Osborne Park	WA Mount Claremont Nedlands
	RETIREMENT VILLAGES	CALD
	NSW Cherrybrook Erina Hammondville Kiama Pennant Hills Yowie Bay	NSW Ashbury Auburn Belmore Campsie Newtown Yagoona
	QLD Robertson	QLD Clear Island Waters Robina
	VISION IMPAIRED GROUPS	VIC Abbotsford Brunswick Dandenong Richmond St Albans
	NSW Drummoyne	VOLUNTEERS
	QLD Palm Beach	NSW Camperdown
	HEALTH CARE PROFESSIONALS	
	NSW Annandale Ashfield Bonnyrigg Campsie	

“A very informative and professional presentation. I was totally engrossed.”



“Informative. Delivered at a level easily understood. Best session of any nature I have ever attended.”

***“First class presenters.
Clear information. Very useful
to assist in looking after
mother and strategies to
reduce risk for myself.”***

**3,063 people
attended 54 public
information sessions
nationally**

PUBLIC EDUCATION

NSW

Batemans Bay
Blacktown
Bomaderry
Bondi Junction
Dubbo
Gladesville
Gosford
Kogarah
Liverpool
Mona Vale
Mudgee
Orange
Penrith
Rosehill
Rutherford
Sydney
Tuggerah
Ulladulla

ACT

Mitchell
Woden

VIC

Brighton East
Caulfield North
Cranbourne
Dromana
East Melbourne

QLD

Atherton
Bowen Hills
Bray Park
Cairns
Gympie
Hervey Bay
Ingham
Innisfail
Maroochydore
Southport
Toowoomba
Townsville

SA

Richmond
Wayville

WA

Crawley

TAS

Sandy Bay

NT

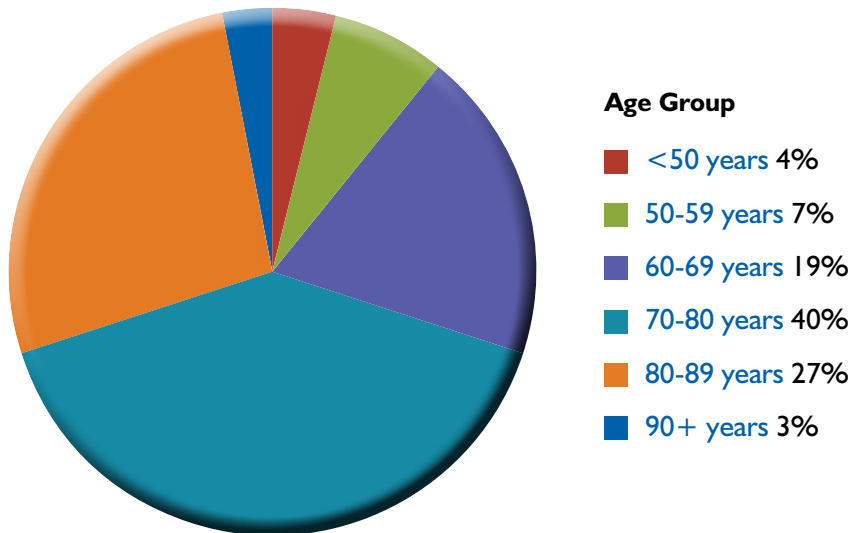
Alice Springs

***“Many thanks for this information. Although I have my
eyes tested and macula checked, I did not know anything
about recognition of symptoms and actions to take.”***

Achieving our Goals

Target Age Group

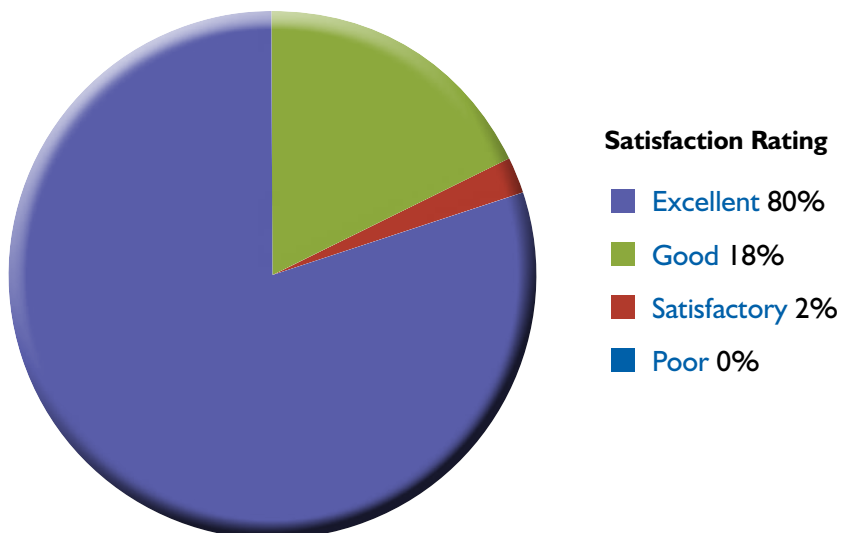
Goal: Ensure education sessions reach over 50s, at-risk age group



Result: 96% of attendees were in the at-risk group (aged 50 plus)

Satisfaction Rating

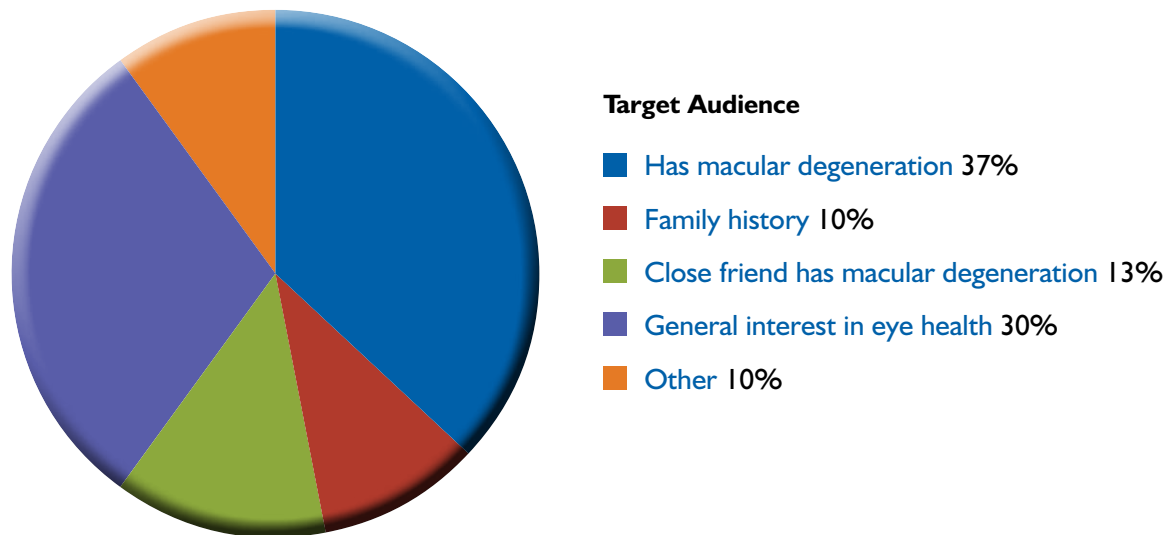
Goal: Attendees to have their expectations met in education sessions



Result: 98% rated the education sessions as either excellent or good

Target Audience

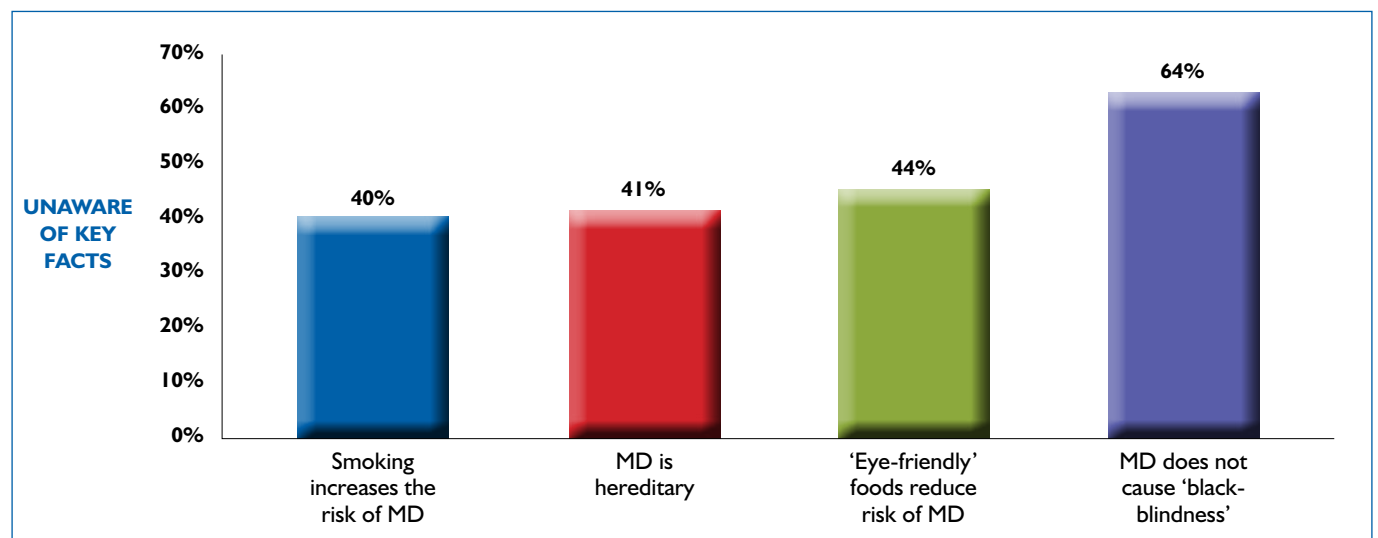
Goal: To reach the macular degeneration community and general public who are at risk



Result: 47% of attendees either had macular degeneration or had a family member with macular degeneration

Knowledge

Goal: To identify key gaps in knowledge about macular degeneration (MD) and provide education, support and resources



Result: An average of 47% of attendees were unaware of key messages prior to the education session. This highlights the importance of education sessions on macular degeneration

Awareness

To increase awareness of macular degeneration

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

Since 2007, the Foundation has been tracking awareness of macular degeneration in Australia to measure the effectiveness of the Foundation's vast array of awareness campaigns. Increasing awareness of macular degeneration is a major focus for the Foundation.

A highly focused approach, building upon layers of multifaceted work, has resulted in a massive increase in the awareness of macular degeneration in Australia.

A national television and radio advertising campaign has been implemented over the last five years with the primary goal being to ensure those most at risk of macular degeneration have their eyes tested and macula checked.

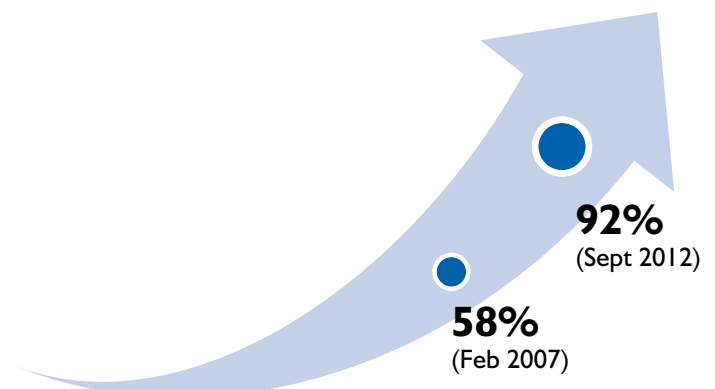
The advertising campaign was initiated following a 2007 national Galaxy poll which showed only 47% of Australians were aware of the disease; most thought macular degeneration was related to muscles and few people claimed to have had their eyes tested and macula checked.

The Foundation has commissioned nine national Galaxy polls over the last six years to independently measure awareness. The Foundation's work in raising awareness of macular degeneration has had a multiplier effect in supporting and benefiting allied key health messages for eye health and other diseases.

“Your Foundation creates awareness about the strategies to manage our eyes in the best way possible. I have not words to express my deep gratitude.”

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 healthy diet and lifestyle including nutrition, exercise, healthy living, and anti-smoking have supported and promoted key messages contained in the Federal Government's National Preventative Health Strategy.

Polling in September 2012 highlighted yet again the outstanding results of the national television and radio campaign and other awareness raising activities. Awareness of macular degeneration in the 50 plus age group reached an outstanding 92%.



Population awareness of macular degeneration in the 50 plus age group

Macular Degeneration Awareness Week 2013

Sunday 26 May to Saturday 1 June 2013

Macular Degeneration Awareness Week is the major annual awareness raising activity for the Foundation.

Ita Buttrose, Foundation Patron and Australian of the Year 2013, featured as the face of the 2013 campaign "Let's stop Australians going blind. For me it's personal."

The key messages were:

- **Have an eye test and make sure the macula is checked**
- **Never ignore any changes in vision**
- **Eat an eye friendly diet and lead a healthy lifestyle**
- **Donate to macular degeneration research**

Ita lent her powerful voice to call for the health of older Australians to be a priority for both the community and government, assisting the Foundation in achieving the estimated audience impressions of 53 million, the highest ever result for a Macular Degeneration Awareness Week campaign.

Excellent results across the country:

- **Estimated 53 million media impressions achieved, an increase on 2012 result of 49 million**
- **Over 59,000 information materials distributed from reorders**
- **Foundation Helpline calls soared with over 1,100 phone calls received during the week**
- **35,000 website visits during May, 24% increase on 2012 results**



Media activities

The Foundation implemented a comprehensive media program to promote Macular Degeneration Awareness Week 2013. Media activities focused on key eye health messages and the importance of eye health for older Australians. National, state and regional print, along with television, radio and online media were targeted, as well as trade and industry publications. Vast coverage emanated from a joint media release by the Foundation and Optometry Association Australia which was supplied to optometrists nationally for use in their local media.

Media highlights

- Channel 9 News Queensland interview with Friend of the Foundation Jill Falls
- body+soul feature interview with Patron Ita Buttrose and Associate Professor Alex Hunyor, syndicated nationally
- 2GB breakfast radio interview with Foundation General Manager Lucy Walker, syndicated extensively
- Online coverage on major media websites including The Australian and Victoria's Herald Sun

Community reach

Direct Mail Campaign: To complement the publicity generated through media, a direct mail campaign targeting eye healthcare professionals and associated groups was implemented. Over 12,000 Macular Degeneration Awareness Week kits were distributed nationally to optometrists, ophthalmologists, orthoptists, pharmacies, health food stores, community health centres, libraries and parliamentarians.

Community Service Announcement:

The Foundation secured extensive airing of its symptom recognition television and radio advertisements as a community service announcement in support of Macular Degeneration Awareness Week. Total impressions achieved (based on potentials per market) were over 15 million across major metro and regional markets.

Rotary Community Partnership: The Foundation continued its engagement program with Rotary Clubs nationally for Macular Degeneration Awareness Week 2013, issuing a direct mail communication to over 1,000 Rotary Clubs calling for their support. This resulted in the generation of local media and 12,000 brochures, 12,000 Amsler grids and 160 posters distributed to 47 clubs nationally in support of a wide range of promotional events. Activities included the distribution of brochures in local markets and shopping centres and invitations to local optometrists to address Rotary meetings.

Education: Leading retinal specialist Associate Professor Alex Hunyor and Foundation Patron Ita Buttrose were guest speakers at a special macular degeneration presentation in Sydney held by the Foundation as part of Macular Degeneration Awareness Week with over 200 guests attending.



Foundation Patron Ita Buttrose with Associate Professor Alex Hunyor

Sydney Action Day: Foundation staff and volunteers distributed over 3,000 information brochures and gold kiwifruit in Martin Place, Sydney.



Macular degeneration is leading cause of blindness

REGION - Macular degeneration is the leading cause of blindness in Australia, the latest findings from a survey of 10,000 people conducted by the Macular Disease Foundation Australia.

The survey, which was conducted by the Macular Disease Foundation Australia, found that 10 per cent of people aged 50 and over have some form of macular degeneration. This is a significant increase from the 5 per cent reported in a similar survey conducted in 2008.

Macular degeneration is a condition that affects the central part of the retina, the part of the eye that is responsible for central vision. It is a leading cause of blindness in Australia, and the number of people affected is expected to increase significantly in the coming years.

The survey also found that 10 per cent of people aged 50 and over have some form of macular degeneration. This is a significant increase from the 5 per cent reported in a similar survey conducted in 2008.

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Locals are urged to get eyes tested

LOCALS are being urged to have their eyes tested during Macular Degeneration Awareness Week, which runs from June 1 to June 7.

The Macular Disease Foundation Australia is urging people to get their eyes tested to check for signs of macular degeneration, a leading cause of blindness in Australia.

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mEYE World Photographic Competition 2012



mEYE World Photographic Competition winner Khang Ta with Foundation Chief Executive Officer Julie Heraghty

The mEYE World Photographic 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. The Foundation's second mEYE World Photographic Competition in 2012 resulted in over 560 inspiring photographs being entered. Australians were invited to submit a photograph, along with a brief description, which showed their appreciation of the gift of vision.

Winners were announced as part of World Sight Day activities on 11 October 2012 and photographs were judged by Foundation Patron Ita Buttrose and division editor Mark Cushway.

Mr Khang Ta was selected as the overall grand finalist from the four category winners and won an "Ultimate Sydney Experience" prize package.

Media highlights

- Estimated 10 million media impressions across the competition period (52% increase on the 2011 competition)
- Channel 9 Mornings interview with Foundation Patron and judge Ita Buttrose
- Extensive television coverage in Queensland through community service announcements

Entries for the mEYE World Photographic Competition increased 36% on the previous year, with over 560 entries.



Grand Finalist and Winner Healthcare Professionals Category
Khang Ta, Heatherton, VIC



Winner Open Category
Gary Brinkman, Broadbeach Waters, QLD



Winner Macular Degeneration Community Category
Helen Dugdale, Dalyellup, WA



Winner Junior (Under 18) Category
Georgina Flanagan, Coolamon, NSW

The Ripple Effect of Vision Loss

The Foundation undertook a major research project (SightSeer2) surveying Australians living with wet age-related macular degeneration and those who care for someone with this disease.

The objectives were to:

- Ascertain the key issues associated with the burden of disease and highlight relevant support services
- Raise awareness of the burden of wet age-related macular degeneration, not just on those living with the disease but also those who care for them
- Reinforce the importance of early detection and diagnosis

This new research revealed that the burden of wet age-related macular degeneration weighs heavily not only on the person living with the disease, but equally on those who care for them - the 'Ripple Effect of Vision Loss'.

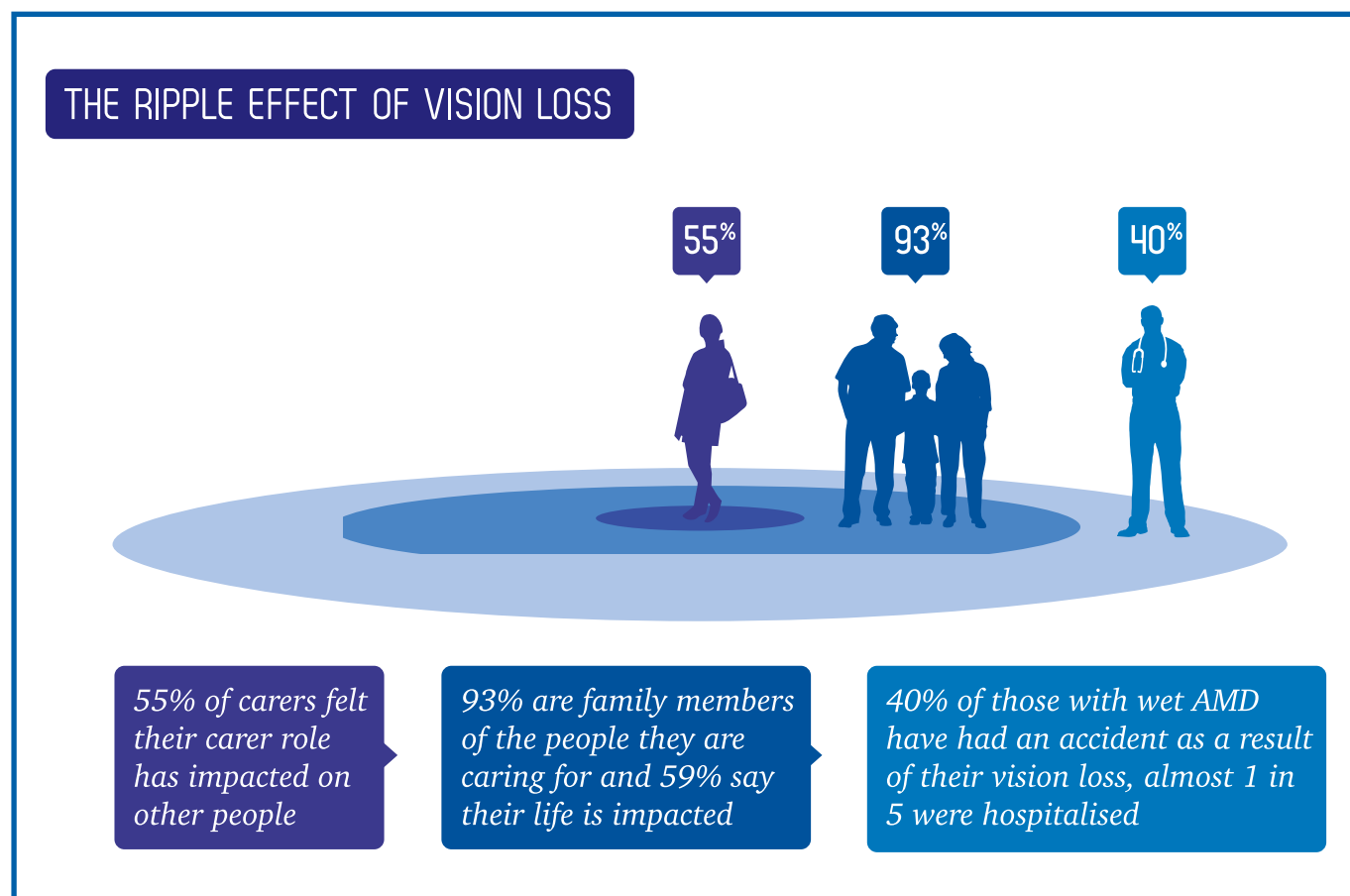
The key results:

- Depression rates tripled among those who care for someone with wet age-related macular degeneration when compared with Australians over 65 years of age
- Pressure of caring impacts relationships with children, grandchildren and partners
- Two-thirds of carers are contending with their own chronic conditions

Extensive media coverage was obtained with key spokespersons across Australia promoting the messages of early detection, depression, and carer entitlements.

Media highlights

The coverage included television, radio, print and online, securing over 500 media placements including SKY News Australia, Channel 7 4.30 News, ABC Radio National and The Sydney Morning Herald.



National Disability Insurance Scheme

The Foundation strongly advocated through many means, but especially the media, for changes to the National Disability Insurance Scheme (NDIS) in relation to the unjust exclusion of those diagnosed with a disability over 65 years of age. This would include almost all those with vision loss or blindness from macular degeneration.



National media releases

Two media releases were issued by the Foundation quoting Chief Executive Officer Julie Heraghty:

○ When age counts or doesn't count? MDFA calls on Government to rethink NDIS

"The Government has an obligation to accommodate older Australians who go blind. The older you get, the harder it gets, and we can't let this group suffer in silence."

○ National Disability Insurance Scheme continues to exclude over 65s. Australians say – it's just unfair!

"Letting people fall through the cracks of two Government reform agendas based on an arbitrary pension age cut off is unfair and unjust."

Media highlights

- ABC's 7.30 Program - November 2012
- The Australian - 19 February 2013

New National Television and Radio Advertising Campaign Symptom Recognition

In August 2012 a new national television and radio campaign was implemented maintaining the key message of "Have an eye test and make sure the macula is checked" but with a new focus on increasing symptom recognition.

The Foundation has undertaken national polling of symptom recognition since April 2010 and recognised the need to increase awareness of symptoms of macular degeneration.



Results of the campaign were outstanding. Symptom recognition within the 50 plus age group increased from 20% in 2011 to 29%.

Public Relations, Marketing and Social Media

Editorial

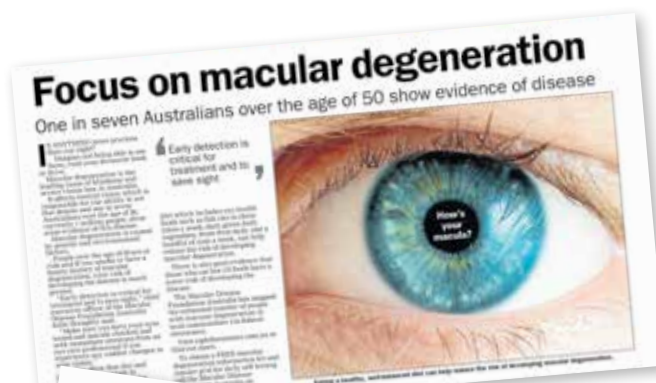
Along with major awareness campaigns, SightSeer2 research and National Disability Insurance Scheme media, the Foundation secured extensive editorial across television, radio, print and online. The Foundation also continued to increase its use of social media platforms YouTube and Facebook.

Features

The Foundation gained extensive editorial in a Daily Telegraph Vision and Eye Health feature insert in September 2012, which included Patron Ita Buttrose on the cover with the message "Are you at risk of macular degeneration? I know I am." Included in the feature was an interview with Ita Buttrose, key eye health messages, information on macular degeneration and promotion of the *Eating for Eye Health* cookbook.

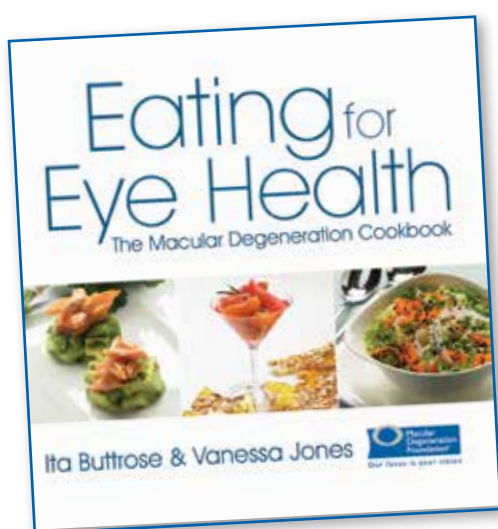
Trade Publications

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



Eating for Eye Health – The Macular Degeneration Cookbook

Following the successful launch in 2009 of *Eating for Eye Health - The Macular Degeneration Cookbook*, co-authored by chef Vanessa Jones and Foundation Patron Ita Buttrose, the cookbook has continued to be an outstanding success and is now in its third print run. It generates awareness of the disease, provides critical eye health information, and is a great way to have Australians eating good eye health foods.



Keep On Driving – Safely

In January 2009, the NSW Minister for Roads officially launched the 'Keep on Driving - Safely' project for the Foundation, with a macular degeneration information brochure being inserted into over one million driver licence renewals per year for five years. The brochure promotes an eye test and macula check and provides a tear-off response card for a Foundation information kit on macular degeneration.

Since January 2009, over 5.9 million information brochures have been placed in driver licence renewals and over 18,500 information kits requested and fulfilled.



Exhibitions and Expos

Across Australia, Foundation staff attended congresses, expos and exhibitions distributing information kits on macular degeneration, talking with attendees and presenting education sessions.

- **Retirement & Lifestyle Expos:** Sydney, Melbourne, Brisbane, Adelaide, Canberra
- **CAREX Expo:** a major health, aged care and disability services expo, Sydney
- **Men's Health Expo:** Sydney
- **Royal Australian and New Zealand College of Ophthalmologists (RANZCO) Congress:** Melbourne
- **NSW Premier's Christmas Gala Concerts:** Sydney
- **NSW Premier's Seniors Week Gala Concerts:** Sydney
- **Optometry Southern Regional Congress & Trade Expo:** Melbourne
- **NSW Pharmacy National Convention & Exhibition:** Sydney
- **Seniors Information Expo:** Toowoomba

Friends of the Foundation

In 2012-2013 the Friends of the Foundation program became central to supporting the Foundation's work in advocacy, public relations, social media and fundraising. The program was designed to capture inspiring stories from across the macular disease community. This includes stories from those living with macular disease, carers, family members and healthcare providers.

These personal stories were particularly important in gaining localised media coverage during Macular Degeneration Awareness Week 2013.

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.

Jill Falls

Jill Falls is a long term Friend of the Foundation and is passionate about spreading awareness of macular degeneration as she and four of her siblings live with the disease.

Jill lent her support to Macular Degeneration Awareness Week 2013, appearing on Channel Nine News (Queensland) to tell her story and reinforce the importance of self monitoring with an Amsler grid.

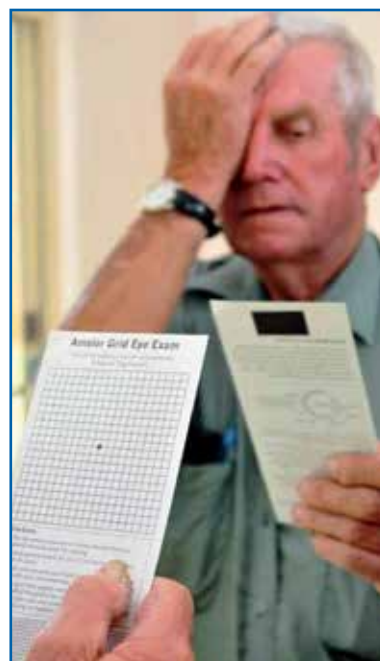
Jill admits the initial diagnosis of wet macular degeneration was shattering, however she maintains her independence due to treatment for the disease. She keeps herself busy and continues to do water colour painting twice a week.

Her story on the importance of early detection is invaluable and we thank Jill for her support and willingness to share her story.



“My advice to people is to make sure they go to the doctor as soon as they see any changes in their vision. Too often people delay and say, I’ll go next week. Don’t delay, have changes checked straight away, it could save your sight.”

Jill Falls



Abe Bos



Janet Waters



James Boon



Marion Pyne



Fay Bennett

Bill Murphy

As part of the Sight for Seniors campaign the Foundation mapped the prevalence of macular degeneration across Australia by federal electorate. Friend of the Foundation Bill Murphy featured in numerous media reports highlighting the importance of early detection and that his federal electorate of Hinkler ranked third highest in prevalence of macular degeneration in Australia.

Bill discovered he had wet macular degeneration in his right eye two years ago at his annual eye check up. Four weeks later his left eye received the same diagnosis. He now receives ongoing injections in his right eye to help maintain vision, independence and quality of life.

Knowing that there is a 50% chance of macular degeneration with a direct family link, Bill makes sure his four children get a regular eye test and macula check. He and his wife also ensure they eat an eye friendly diet and self monitor their vision using the Foundation's magnetised Amsler grid which they have on their fridge.

Thank you to Bill for his involvement in Macular Degeneration Awareness Week 2013 and helping to raise awareness in the federal electorate of Hinkler.



"I hadn't noticed that anything was wrong with my sight until I went to the optometrist. This really reinforced the Foundation's message about the importance of eye tests for both me and for my family."

Bill Murphy

Jean and Des Morton

Sight for Seniors has been a major advocacy campaign for the Foundation throughout 2012-2013 and Jean and Des Morton have been at the forefront, representing the Friends of the Foundation.

Jean and Des have helped the Foundation advocate for the removal of age discrimination in the National Disability Insurance Scheme through their support of the campaign.



Jean has had macular degeneration for over 20 years and lives with her husband and carer, Des. Together they are well aware of the daily challenges presented when a partner lives with vision loss.

The Friends of the Foundation program aims to not only tell the stories of those living with macular disease, but also inspire the many people who are affected including family, friends and carers. Thank you to Des and Jean for their invaluable contribution and the inspiration they bring to so many.

“I hope my story will highlight the importance of supporting the Foundation and funding research so that my children and grandchildren will be able to see a future without macular degeneration.”

Jean Morton

Ted Baker

Ted Baker has been a long time Friend of the Foundation and valued volunteer, narrating and recording the Foundation’s audio newsletter.

After witnessing his mother go completely blind in the last years of her life, Ted was prompted to volunteer by narrating talking books. Over the years, Ted has assisted many charities with their audio productions. He has kept up to date with the latest technology and has recorded so many audio newsletters for the Foundation that he has lost count! Ted was diagnosed with wet age-related macular degeneration eight years ago and due to treatment is able to continue his valuable volunteer work.

Many thanks to Ted for his warm manner, generosity and wonderful support.



“I’m really pleased to think I’m helping people, as well as enjoying a wonderful hobby.”

Ted Baker

Val and Doug Nicholson

Val Nicholson has been living with wet macular degeneration since 2009 and currently receives monthly injections. Val is definitely not one to sit around and volunteers at the Foundation once a week, where she has made enduring friendships.

Val is grateful that there is a treatment available to her and is aware that had she been diagnosed only a few years earlier, before treatment became available, she would have certainly lost her sight. Treatment has saved

Val's sight, but she does regret her delay in making an appointment with her eye specialist after noticing changes in her vision.

Val gave her number one tip of never ignoring any changes in vision when she and husband Doug appeared on Prime 7 News as part of the Foundation's 'Ripple Effect of Vision Loss' awareness activities in early 2013.

Our thanks go to Val and Doug for being such positive and proactive Friends of the Foundation.



“Knowing what I do now about macular degeneration, I regret not having my eyes checked as soon as I noticed changes in my vision.”

Val Nicholson

Professor Helen Beange

Professor Helen Beange has been a great supporter of the Foundation by drawing on her public health background. Previously Helen was in charge of a clinic for people with developmental disability and after being declared legally blind from wet macular degeneration she had to consider how this affected her professional role. “Losing my sight almost overnight changed my role dramatically from medical professional to someone living with a disability. I was devastated at the sudden turn of my circumstances,” said Helen.

Over the last nine years Helen has found ways to adapt to living with low vision with the use of aids and technologies. These aids allow her to continue to contribute to the health profession. She uses her computer with ZoomText for reviewing articles for medical journals, CCTV and magnifiers for reading and the Foundation's Navigator to play audio books.

Thank you to Helen for sharing her inspiring story and demonstrating that through aids and technologies those with low vision can live busy, stimulating and successful professional and personal lives.



“Visual disability affects quality of life and must not be seen as part of just getting old.”

Professor Helen Beange

Research

To support and pursue research

Research Focus

In 2012-2013 the Foundation continued to undertake its own social research and support the important work of Australian researchers to reduce the incidence and impact of the disease.

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.

Research Grants Program

The Foundation's grants and fellowships make significant contributions to Australian research into macular degeneration and are awarded following rigorous evaluation, based largely on the National Health and Medical Research Council (NHMRC) process, along with international peer review, to ensure that the successful applicants meet the highest standards.

The Foundation's Research Grants Program was launched in 2011 and later that year the inaugural recipients of the grants were announced by the Governor-General of Australia, Her Excellency Ms Quentin Bryce AC, CVO. Research grants totalling \$734,000 were awarded to:

- Professor Paul Mitchell, Millennium Centre for Eye Research, Westmead and the University of Sydney
- Professor Robyn Guymer, Centre for Eye Research Australia (CERA), Melbourne
- Dr Liubov Robman, Centre for Eye Research Australia (CERA), Melbourne - received the 12 month Blackmores Dr Paul Beaumont Research Fellowship

Both Professor Mitchell and Professor Guymer's three year project results are expected in 2015. Dr Robman's one year project was completed in 2012. Her finding was that people who have a diet consisting primarily of a combination of grains, fish, steamed or boiled chicken, vegetables and nuts had a significantly reduced risk of both early and late age-related macular degeneration. The research has been presented at a major conference and submitted for publication.

Blackmores Dr Paul Beaumont Research Fellowship 2013

In 2012, this fellowship was increased to a duration of two years and supported with an additional \$10,000 from the Foundation to a total of \$50,000 per year.

Dr Bamini Gopinath, senior research fellow at the Centre for Vision Research, Westmead Millennium Institute was awarded the Fellowship for 2013-2014. Dr Gopinath is working under the supervision of Professor Paul Mitchell, one of the world's leading experts in macular disease.



Neal Mercado, Blackmores Institute Director presents Dr Bamini Gopinath with the Blackmores Dr Paul Beaumont Research Fellowship 2013-2014

Dr Gopinath's research will improve knowledge of the nutritional and lifestyle risk and protective factors for macular degeneration, including dietary antioxidant and supplement intake, diet quality and food groups. It will also involve a detailed analysis of the 15-year data from the famous Blue Mountains Eye Study, which was the first large population-based study of age-related eye disease in Australia.

Age-Related Eye Disease Study 2 (AREDS2)

One of the major research priorities of the Foundation is to ensure the latest research is reviewed and translated into meaningful messages for the macular disease community. This is done under the guidance of the Foundation's medical committee.

The results of one of the largest eye studies in the world, the Age-Related Eye Disease Study 2 (AREDS2) was announced at the Association for Research in Vision and Ophthalmology (ARVO) meeting in the USA in May 2013. AREDS2 is a five-year study by the National Eye Institute in the USA involving 4,000 people and designed to test whether the original Age-Related Eye Disease Study (AREDS) formulation could be improved.

The original AREDS study, published in 2001, was a landmark clinical trial and other than AREDS2, is the only study for which there is good, long-term evidence for the benefits of high dose supplements for people diagnosed with age-related macular degeneration (AMD).

In May 2013 at the ARVO meeting, as a result of the AREDS2, a slightly modified version of the original AREDS formulation was announced which offers slightly better efficacy and improved safety.

The Foundation ensured that the results and recommendations of this important but complex study were quickly interpreted and effectively communicated to the Australian community.

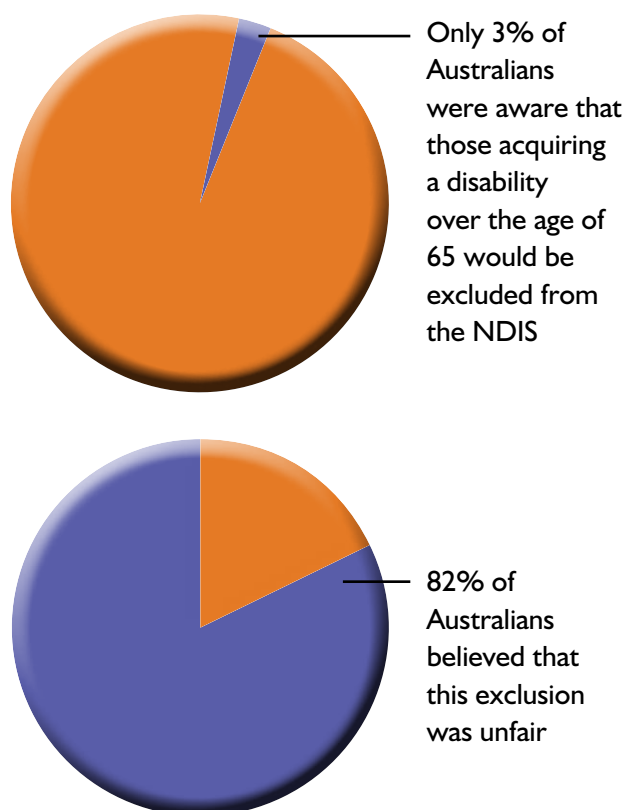
National Disability Insurance Scheme (NDIS)

The Foundation commissioned a national Galaxy poll in February 2013, to research the knowledge of the Australian community regarding the exclusion from the National Disability Insurance Scheme (NDIS) of those who acquire a disability over 65 years of age.

The research showed that only 3% of all Australians knew that those who acquire a disability after the age of 65 years were excluded from the scheme. When informed of this exclusion, 82% of Australians disagreed with the Federal Government's action.

The research enabled the Foundation to drive its strong advocacy on the exclusion from the NDIS in the media, with policy makers and in discussions with peak bodies and other organisations in the aged care and disability sectors.

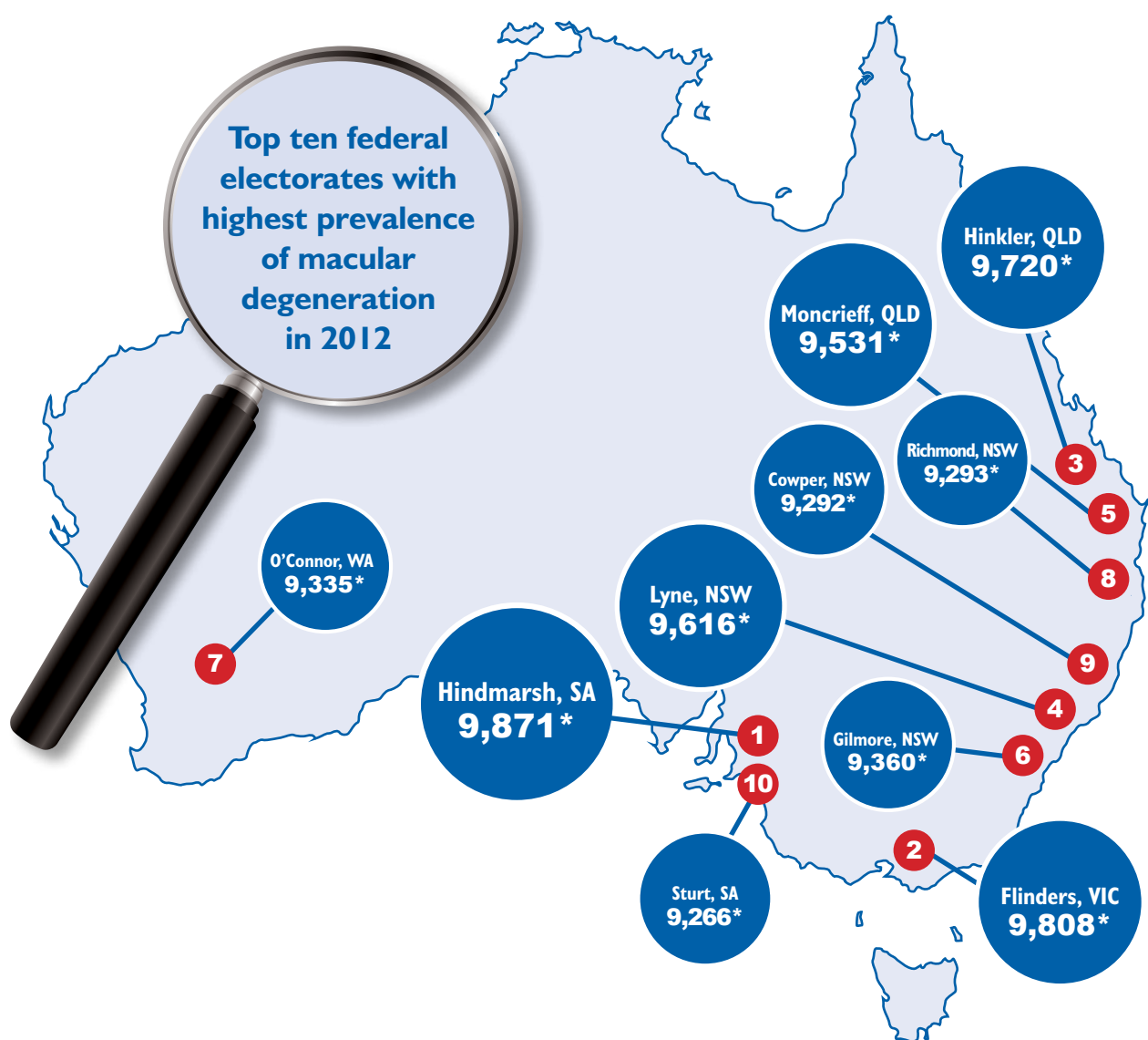
NDIS Galaxy Poll February 2013



Mapping the Landscape

The Foundation published its *Mapping the Landscape* report in 2012 which detailed the estimated prevalence of macular degeneration in 2012 and 2030, by federal and state electorate, and by Medicare Local. This report has been extremely valuable for planning and advocacy as it clearly highlights the enormity of the incidence and the potential impact of

macular degeneration in this country now and in 20 years time. The mapping project built upon the Foundation's publication in 2011, *Eyes on the Future – A clear outlook on age-related macular degeneration*, a landmark report on the epidemiology, management and economics of macular degeneration in Australia.



* Estimated number living with macular degeneration 2012

The Ripple Effect of Vision Loss

In early 2013, the Foundation undertook an extensive research project by surveying many people on our database to examine the impact of wet age-related macular degeneration (AMD) on various aspects of a person's life. The research had two components focusing on those who have wet AMD and the impact on the life of a person who cares for someone with wet AMD.

The response from our clients was outstanding with several thousand completed surveys received. Included were many additional comments that provided further insight and will help guide the Foundation in its work to assist those with macular degeneration and their carers.

This research revealed that the burden of wet AMD weighs heavily not only on the person living with the disease, but equally on those who care for them.

Key findings:

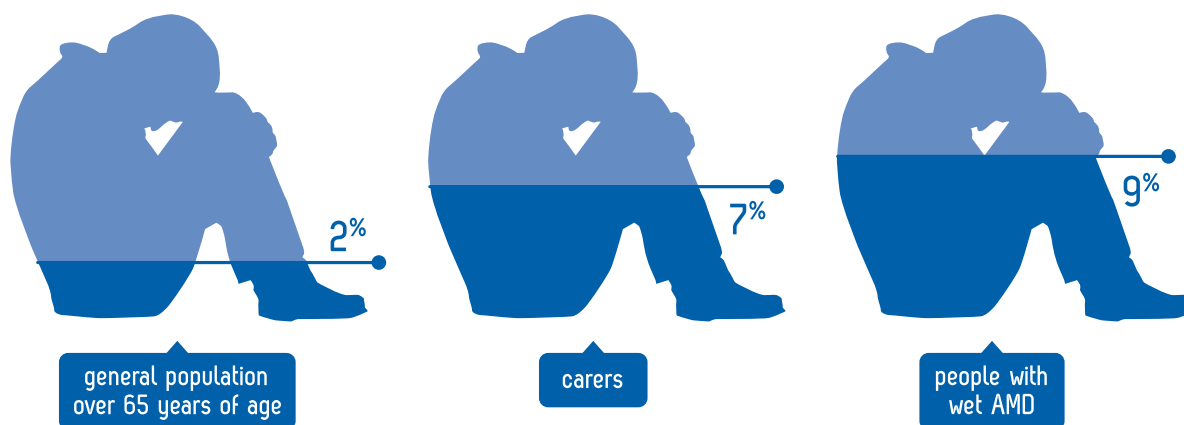
- Depression rates more than tripled among those who care for someone with wet AMD, when compared with Australians over 65 years of age
- The pressure of caring impacts relationships with children, grandchildren and partners
- Two-thirds (67%) of carers are contending with their own chronic conditions

- Retirement situations and future plans affect one in three
- 75% of those diagnosed with wet AMD never considered vision loss as a future health concern, and now living with the disease report feeling frustrated (49%), down (28%), isolated (18%) and sad (16%).

The Foundation mounted a large media campaign to raise awareness of the high levels of depression and anxiety in those with wet AMD and their carers, and the importance of seeking help and support. In addition, access to carer entitlements were promoted along with the importance of early detection to help reduce the incidence and impact of macular degeneration in Australia.

“When you become a carer it is a big responsibility. A special person, the person you are looking after, relies on you. A strong bond of trust and love builds up. I had 12 years of caring and would do it all over again. I still feel I am a carer.”

RATES OF DEPRESSION HIGH FOR THOSE WITH WET AMD AND THOSE WHO CARE FOR THEM



Evaluating the Foundation

Are we doing a good job?

Every year, the Foundation evaluates its services by surveying a sample of its client base. In 2013 a questionnaire was sent to 2000 of our clients. Amongst this group are people from across the spectrum of the Australian macular degeneration community:

- ☐ 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 our clients think of our services?

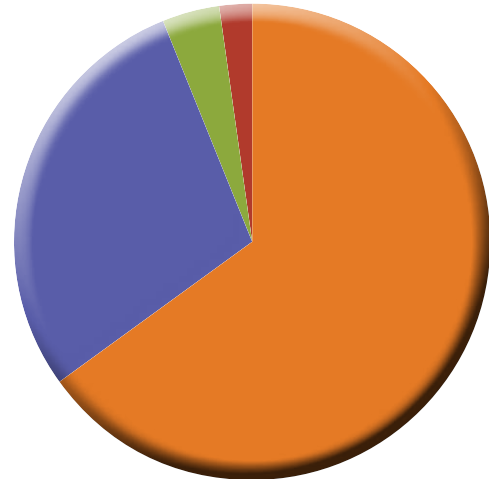
The Foundation's flagship services, the Helpline, newsletter, education sessions and website were given overwhelmingly positive ratings by clients, ranging from 91% for the newsletter to 95% for the Helpline. Utilisation of these services has also increased over the last three years. Publications were also highly rated with helpful or very helpful ratings between 87% and 93%.

How satisfied are our clients?

Clients are highly satisfied with our services. The great majority of respondents (94%) were satisfied or very satisfied with the Foundation's services. Our satisfaction rating also improved further over last year (90%). The Foundation will continue as always to use client feedback to improve services to support the macular disease community.

“The Foundation has been very supportive in every way and I am so very appreciative of having them at the end of the telephone.”

Satisfaction Rating



Very satisfied 65% Neutral 4%
Satisfied 29% Dissatisfied 2%

American Journal of Public Health publication

In September 2012, the prestigious American Journal of Public Health published the Foundation's first peer-reviewed journal article entitled *"A Layered Approach to Raising Public Awareness of Macular Degeneration in Australia"*. This article details the multiple layers of activities conducted by the Foundation to raise awareness of the disease and become a world leader in public health promotion.



Jean's Story

My mother was diagnosed with macular degeneration about 16 years ago at which time she wasn't told what it was, she was only told that she would go blind one day and there was nothing she could do about it. Then she was sent home.

Although my mother has lost so much of her ability to do things like reading, which she was passionate about, driving and seeing the faces of her family, she now borrows talking books and is involved in many wonderful groups; bowling for the visually impaired, exercise classes and walking groups.

Unfortunately my father has now been diagnosed and I have one uncle who also has macular degeneration. I am therefore keenly aware that along with age, your genetics also put you at risk. I am concerned about the eye health of my family and care deeply about my children getting the disease.

My key message for everyone is get your macula checked and if you have someone in your family with macular degeneration, contact the Foundation and discuss your situation as they are warm, friendly and give invaluable information and great support. They make a huge difference.



Ambassador Jean Kittson

Jean Kittson is a multi-talented performer, writer and proud Ambassador of the Macular Disease Foundation Australia. Jean is an engaging speaker and gives personal insight into the impact of macular degeneration on the family.

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

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 14,000 calls received in 2012-2013, an average of 56 calls per day. The Foundation has received almost 108,000 calls to the Helpline since 2005.

Information Kits

Comprehensive information kits, provided free of charge, are one of the main avenues for providing information about macular disease 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, as well as living with low vision.

“Keep up the good work. It is very comforting and reassuring to read your updates.”



“When I was told I had macular degeneration in my left eye I was very frightened. On contacting the Foundation I was sent booklets, information and best of all, encouragement and enthusiasm.”



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. 90% of clients said they used the newsletter, making it the most utilised service, of which 91% rated the newsletter as either 'good' or 'excellent'.

Website

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

In 2012-2013 there were over 340,000 website visits

Website visits continue to rise

253,400

2010-2011

284,200

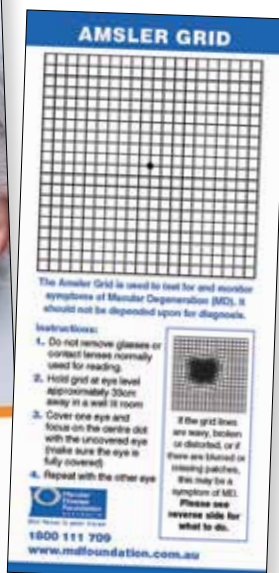
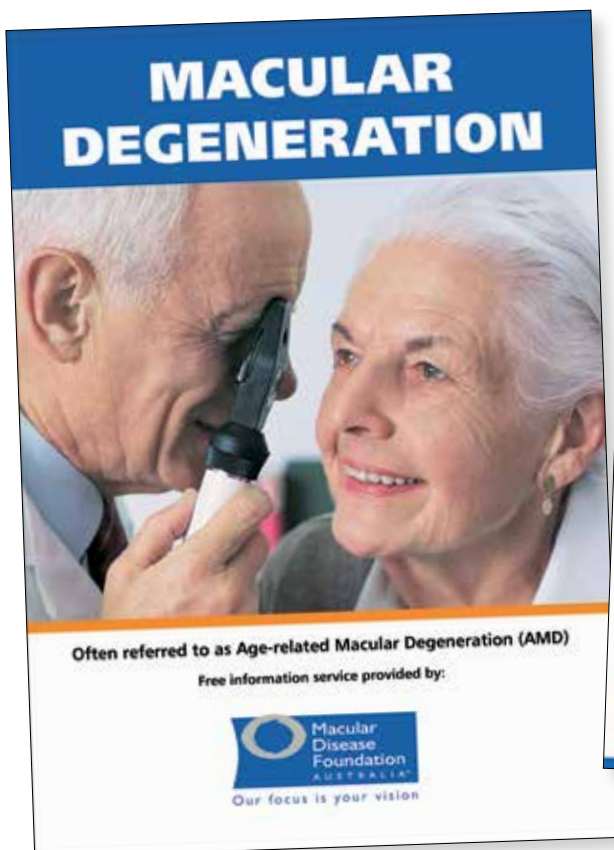
2011-2012

342,000

2012-2013

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 2012-2013 over 700,000 individual publications and resources were distributed to the general public and health care professionals.



“I have found the publications very useful, not only for myself, but to inform others about the work done by the Foundation. The publications are a positive source of information and facts. The staff at my nursing facility have been given copies and staff have used the suggestions in food planning as numerous residents have macular degeneration. Very supportive, friendly, understanding service. Thank you.”

Special Projects

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 free 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 Information Days

Low vision information days were held in Sydney as well as regional NSW and Tasmania. 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.

Low Vision Badges

In 2012-2013 the Foundation made available free of charge 'I have low vision' badges to the macular disease community through the newsletter. The response has been extremely successful with over 530 free badges distributed.



“People are so helpful when I wear my low vision badge.”



Representation

To advocate for the best interests of the macular disease community

National Disability Insurance Scheme and Aged Care Reform

In 2011, the Productivity Commission produced two major reports - *Disability Care and Support* and *Caring for Older Australians*. Both reports were highly relevant to the welfare of the macular disease community in Australia. The *Disability Care and Support* report found that the current disability support system is underfunded, unfair, fragmented and inefficient. The *Caring for Older Australians* report found that Australia's aged care system was not well placed to meet the future challenges of an ageing population.

In 2012-2013, the Commonwealth Government decided to adopt the overall recommendations of the two reports, resulting in the implementation of large-scale reforms to the disability and aged care systems.

In 2013, the Commonwealth Government established the National Disability Insurance Scheme (NDIS) to create a nationally consistent, person-centred disability system. The fundamental principle being that people with disabilities would be able to plan and manage their own support services to best suit their individual needs.

The *Living Longer Living Better* aged care reform program was implemented by the Commonwealth Government. It aims to build a flexible and seamless system with consumer choice, control and easy access to services for older Australians.

While acknowledging the beneficial outcomes from this reform process, the Foundation identified several major gaps in the reform agenda, leaving people who are vision impaired or blind highly disadvantaged. The primary gap was the exclusion of those who acquire a disability, such as blindness, at age 65 and over.

The Foundation's key advocacy issues for those with vision impairment or blindness were:

1. **An unjust, discriminatory age limit to access the NDIS.** People who acquire a disability aged 65 years or over are excluded from the NDIS and are required to seek services from the aged care system. In addition, the NDIS was unjustifiably exempted from the *Age Discrimination Act 2004*.
2. **The risk of failing an NDIS participant assessment due to the lack of a pathway for supporting specialist low vision knowledge and skills.**
3. **The lack of support pathways and mechanisms in the aged care system.** The aged care system is limited in expertise, capacity and resources to provide specialist disability support services for people who are vision impaired or blind.

The leading cause of blindness and severe vision loss in Australia is macular degeneration. Over 50% of all blindness is as a result of macular degeneration.

Almost everyone who loses vision from this disease does so after the age of 65 years old.

“Thank you for being our voice with government.”

What did we do?

- Contributed over 15 submissions on aged care policies and legislation and the development of the NDIS
- Commissioned a national Galaxy survey to ascertain the public awareness of the discriminatory nature of the NDIS for people aged 65 years and over
- Met with key ministers, policy makers and departmental representatives, pressing the case for fairness and equity for people who are vision impaired or blind
- Mounted a major media drive utilising the findings of the Foundation's national Galaxy survey to highlight the issue of discriminatory age restriction in the NDIS
- Proposed and participated in the Ministerial Roundtable on the NDIS
- Appeared as witness at the two Senate Standing Committee on Community Affairs inquiries, investigating the NDIS and the *Living Longer Living Better* aged care reform legislation
- Launched the Sight for Seniors campaign and website, advocating for the interests of older Australians with macular degeneration

“The Foundation welcomes the Federal Government’s approval of extended listings for macular degeneration medicines on the Pharmaceutical Benefits Scheme, which will now enable switching between treatments...

This will mean that ophthalmologists have the option to now assess patients for the most appropriate drug on an individualised basis to ensure the best outcome for the patient.”

**Julie Heraghty
Chief Executive Officer
Macular Disease Foundation Australia**

Access to Treatment Switching

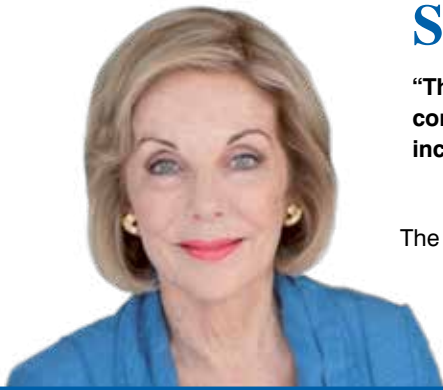
Prior to the listing of a second anti-VEGF drug for the treatment of wet AMD, Eylea (aflibercept), on the Pharmaceutical Benefits Scheme (PBS) in November 2012, it was announced that doctors would not be allowed to switch patients between drugs, even if it was believed that the patient may benefit.

Armed with over 6,000 letters of support, the Foundation made representations to the Chair of the Pharmaceutical Benefits Advisory Scheme (PBAC) for switching between approved drugs to be allowed. Shortly after the Foundation's representations, 'switching' was approved by the PBS in November 2012, enabling the decision about which drug is most appropriate to be made by the eye specialist in consultation with the patient.

The Foundation strives to ensure access to and affordability of treatment and rehabilitation in Australia. It is our privilege to be the voice of the macular disease community.



Julie Heraghty with just some of the 6,000 letters of support for the 'switching' campaign



SUPPORT SIGHT FOR SENIORS

"The day I was honoured with Australian of the Year, I made a public commitment to raise awareness of issues relating to older Australians, including macular degeneration."

Ita Buttrose – Australian of the Year 2013
Macular Disease Foundation Australia Patron

The Macular Disease Foundation Australia would like you to support

- ✓ No age discrimination in the National Disability Insurance Scheme for over 65s
- ✓ A fair deal on aids & technology for people with low vision
- ✓ Funding to better support the Foundation's work in macular degeneration

Sight for Seniors campaign

The Sight for Seniors campaign was launched on 1 May 2013 and was supported by Patron Ita Buttrose.

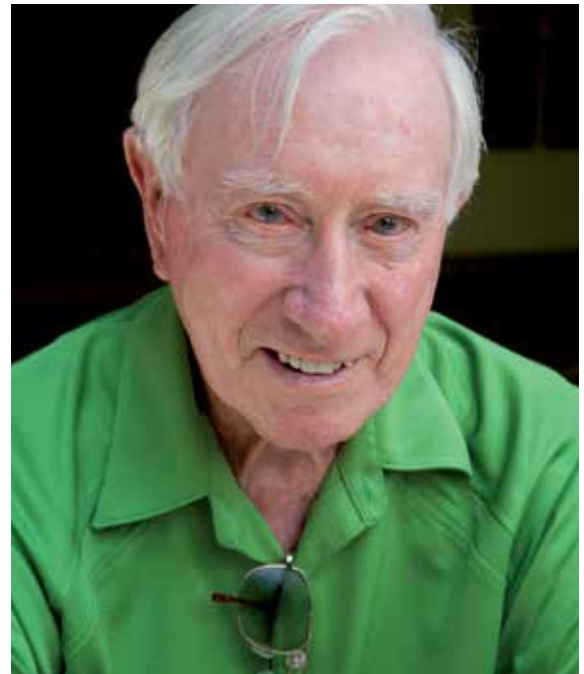
Sight for Seniors key issues

- 1. 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**

Along with thousands of registered supporters of the campaign, the Foundation raised the three key issues with all federal parliamentarians. The campaign informed and educated federal MPs, providing a platform for further advocacy surrounding the 2013 federal election. The Foundation worked with all major candidates and political parties to advocate for the Sight for Seniors issues.

The Foundation also mapped the estimated prevalence of macular degeneration by federal electorates for 2012 and 2030. This was an essential tool to highlight to MPs the enormity of the incidence of macular degeneration and the potential impact of this disease in their electorates now and in 20 years time.

Des' Story



"I have been caring for my wife, Jean, ever since macular degeneration started to affect her vision. We live a full life and are involved with family, friends and the community through our local Rotary Club. I hope you will support the Sight for Seniors campaign. The campaign is about removing age discrimination from the National Disability Insurance Scheme. It's about ensuring that every person with low vision has access to aids and technology. It's also about supporting the work of the Foundation in helping people with macular degeneration, their families, friends and carers. Let's stop older Australians going blind. Together, we can make a difference."

Australian Wet Age-related Macular Degeneration Summit

In July 2012 Australian and international experts met in Sydney to develop a road map for the management of wet age-related macular degeneration (AMD).

Hosted by Macular Disease Foundation Australia and convened by the US-based Angiogenesis Foundation, the summit brought together world experts in angiogenesis and AMD including researchers, clinicians, and scientists, to address barriers to timely and optimal care for Australian patients with wet AMD.



Delegates at the Australian Wet Age-related Macular Degeneration Summit

The Sydney summit followed meetings conducted by the Angiogenesis Foundation in Bogota, Colombia in 2012 and Berlin, Germany in 2011. These summits form the basis of a global campaign which identifies key issues, challenges and solutions related to the treatment of wet AMD.

Following the Sydney summit, a joint white paper was released by the two organisations, *“Advocating for Improved Treatment and Outcomes for Wet Age-Related Macular Degeneration.”* The report made specific recommendations aimed at informing national health services, the clinical and research community, and patient advocates. The white paper is an important tool to influence the management of macular degeneration in the future.

“We have taken the learnings of angiogenesis to develop a global campaign that unites the efforts of all countries to improve the outcomes for wet age-related macular degeneration.”

Dr William Li
President, Angiogenesis Foundation

“In a global village, partnering with world experts, learning from each other and sharing outcomes can bring us much closer to making a real difference in disease prevention.”

Julie Heraghty
Chief Executive Officer



Angiogenesis Foundation President Dr William Li with Foundation Chief Executive Officer Julie Heraghty

It was a special opportunity for the Foundation to work with the Angiogenesis Foundation and especially its president, Dr William Li, a world leading scientist.

Dr Li shared his valuable work in examining the role of new treatments, biomarkers and dietary factors to prevent diseases such as cancer, cardiovascular diseases, obesity, diabetes, Alzheimer’s disease and now macular degeneration.

Global Ageing & Vision Advocacy Summit

The Macular Disease Foundation Australia together with the International Federation on Ageing convened the first-ever Global Ageing and Vision Advocacy Summit in April 2013 in Barcelona, Spain, to address the previously unmet need for a new way of thinking and a new set of partnerships to connect the vision and ageing communities and achieve regional and global impact.

The summit brought together academic and advocacy leaders from the sectors of vision and ageing from 12 countries, with the goal of re-thinking, re-shaping and re-imagining the 21st century as a time when growing older with vision loss is not accepted as inevitable or the norm.

One of the most common and devastating diseases resulting in vision loss among older adults is age-related macular degeneration (AMD). Globally, AMD affects 30 million people and is the leading cause of vision loss and blindness in Australia.



The participants reframed the agenda on ageing and vision health around not only public health and ethical obligations, but also through the lens of economic and fiscal urgency, and created a pathway for targeted global advocacy and awareness efforts.

The summit provided a platform through learning and knowledge exchange to build the capability and capacity of the ageing and vision sectors to effectively advocate and represent the interests of citizens at risk of vision impairment.

The Foundation's Chief Executive Officer Julie Heraghty, and other leading key advocates presented their work on ageing and vision, exploring linkages and commonalities.

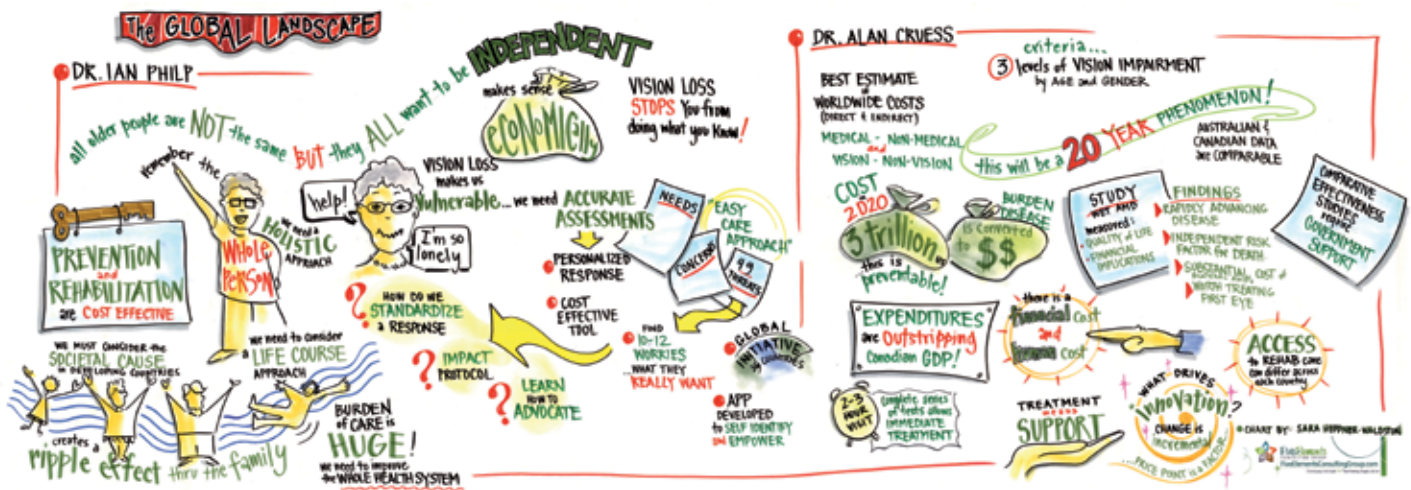
Many eye diseases and conditions, and the challenges that accompany them, are most pronounced among older adults. Beyond direct health costs, they present barriers to productivity and block the opportunity to maximise the economic growth potential of the global ageing population.

The Macular Disease Foundation Australia was honoured to lead this important international work, giving further strength to awareness and advocacy efforts for all Australians.



Delegates of the Global Ageing and Vision Advocacy Summit 2013





Mindmap - Global Ageing and Vision Advocacy Summit



Panel discussion with Dr Alan Cruess and Professor Ian Philip



Foundation Chief Executive Officer Julie Heraghty addresses the summit

“This summit constitutes the starting line for many of us... are we ready to act? The basic idea of the meeting is actually to transcend our silos and to build bridges because we all have pieces of a larger puzzle we cannot solve without each other.”

**Dr Michael Teit Nielsen
DaneAge Association,
Denmark**



Working Together

In 2012-2013, the Foundation worked with many organisations to represent the interests of the macular disease community especially in the areas of ageing, health and disabilities.

- **AMD Alliance International:**
AMD Alliance International generates awareness and understanding of macular degeneration at an international level. The Foundation's Chief Executive Officer sits on its Board.
- **Australian Blindness Forum (ABF):**
The ABF is a coalition of major blindness organisations, allied organisations and service providers. The Foundation is a member of ABF.
- **National Aged Care Alliance (NACA):**
A coalition of national organisations in aged care, including consumer groups, providers, unions and health professionals. The Foundation is a member of NACA.
- **Vision 2020:**
A coalition of Australian eye health organisations involved in local and global eye care service delivery. The Foundation is a member of Vision 2020, and served on the Low Vision and Rehabilitation Committee and the Prevention and Early Intervention Committee.



- **NSW Health's NGO Advisory Committee:**
The Foundation is a member of the committee which facilitates non-government sector input into health policy in NSW and assists in the administration of NSW Health's NGO Program.
- **National Seniors Australia:**
A national non-profit organisation that gives voice to issues that affect older Australians.
- **Blind Citizens Australia:**
A national consumer organisation representing the interests of blind and vision-impaired Australians.
- **Consumers Health Forum of Australia:**
A national organisation representing the interests of Australian healthcare consumers in order to provide safe, quality, timely healthcare for all Australians. The Foundation is a member of Consumers Health Forum of Australia.
- **Research Australia:**
An alliance for health and medical research. The Foundation is a member of Research Australia.



The Foundation continued to develop and strengthen its national alliances, but also expanded to forge new relationships internationally.

Jan's Story

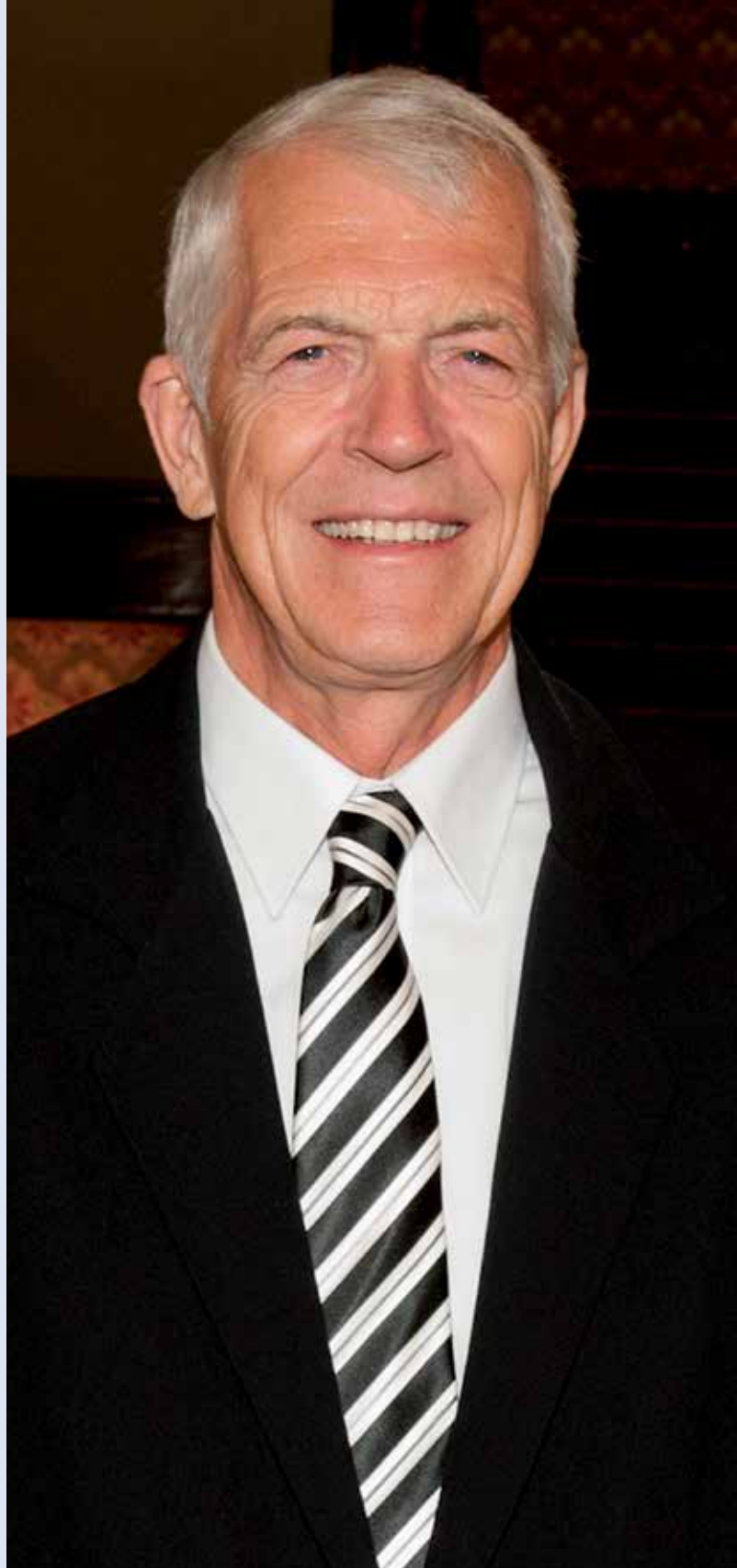
For a considerable part of my life I was blissfully unaware of the existence of the disease known as macular degeneration.

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, Jan worked closely with his father on several prestigious projects up until his 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. The 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.

Best Practice Management

Ensuring best practice in management

A Dedicated and Experienced Board

The 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 relative 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 2012-2013, 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 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.

Professional development of staff is an ongoing priority to help ensure that, through their individual roles, they 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 your great work.



Financial Report

PROFIT & LOSS (FOR THE YEAR ENDED 30 JUNE)

\$000	2013	2012
Revenues		
Government grants	470	459
Corporate support	575	595
Donations/Fundraising	800	449
Donations - Research Grants Program	280	183
Sponsorships	2,249	1,113
Investment income	205	191
Total Revenues	4,579	2,990
Expenses		
Education	343	294
Awareness	1,563	658
Research	234	325
Research Grants Program	283	154
Support services	541	499
Representation	529	230
Fundraising	114	94
Association management	362	353
Total Expenses	3,969	2,607
Net Surplus	610	383

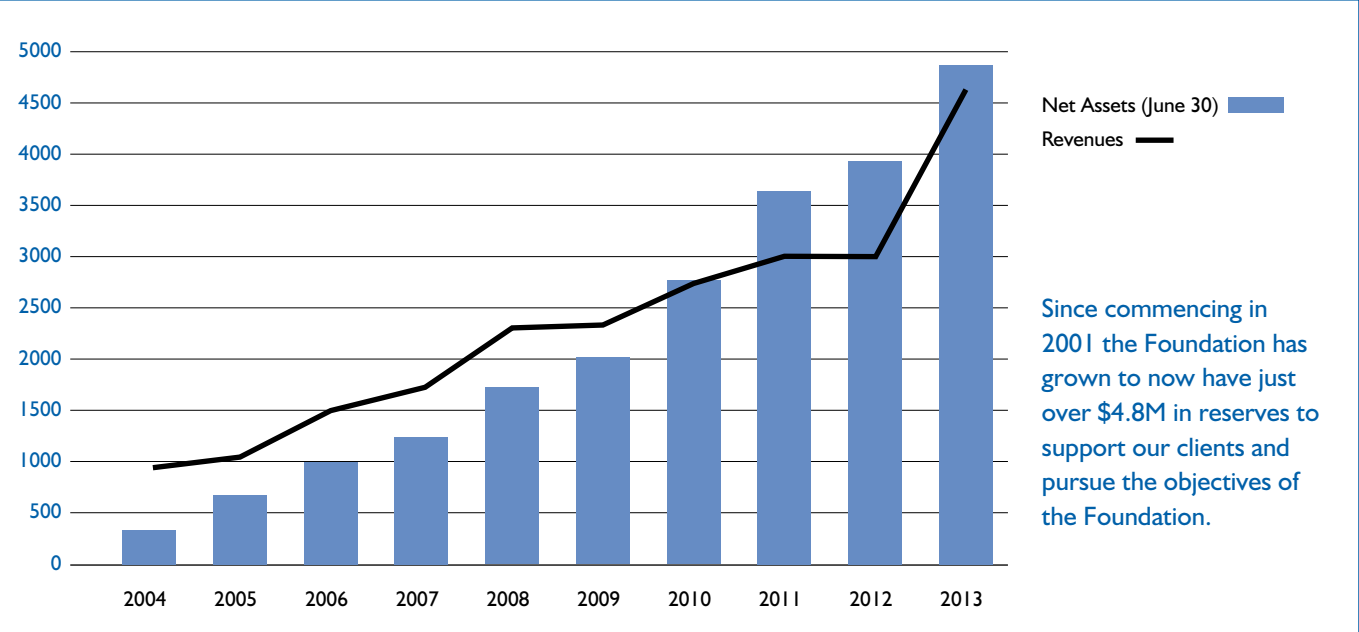
BALANCE SHEET (AS AT 30 JUNE)

\$000	2013	2012
Assets		
Cash and cash equivalents	1,847	2,479
Investments	2,504	1,835
Trade and other receivables	1,476	982
Plant and equipment	88	94
Total Assets	5,915	5,390
Liabilities		
Trade and other payables	1,092	1,408
Provisions	22	22
Total Liabilities	1,114	1,430
Net Assets¹	4,801	3,960

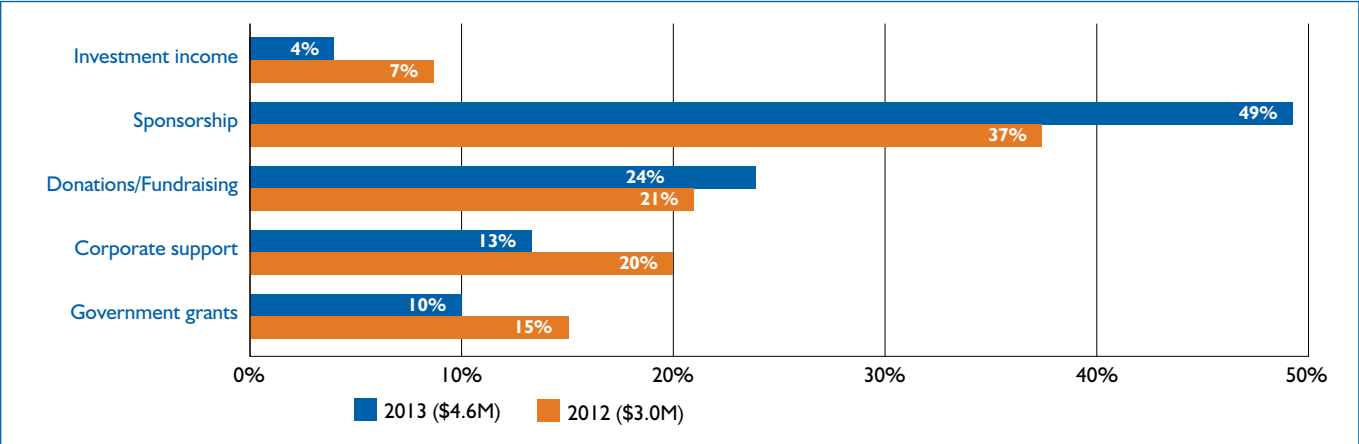
¹The Foundation has \$1,750,000 (2012: \$1,750,000) set aside within the Net Assets to support future Macular Disease Foundation Australia research initiatives.

The information on this page was extracted from the audited Financial Statements of Macular Disease Foundation Australia for the year ended 30 June 2013 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.

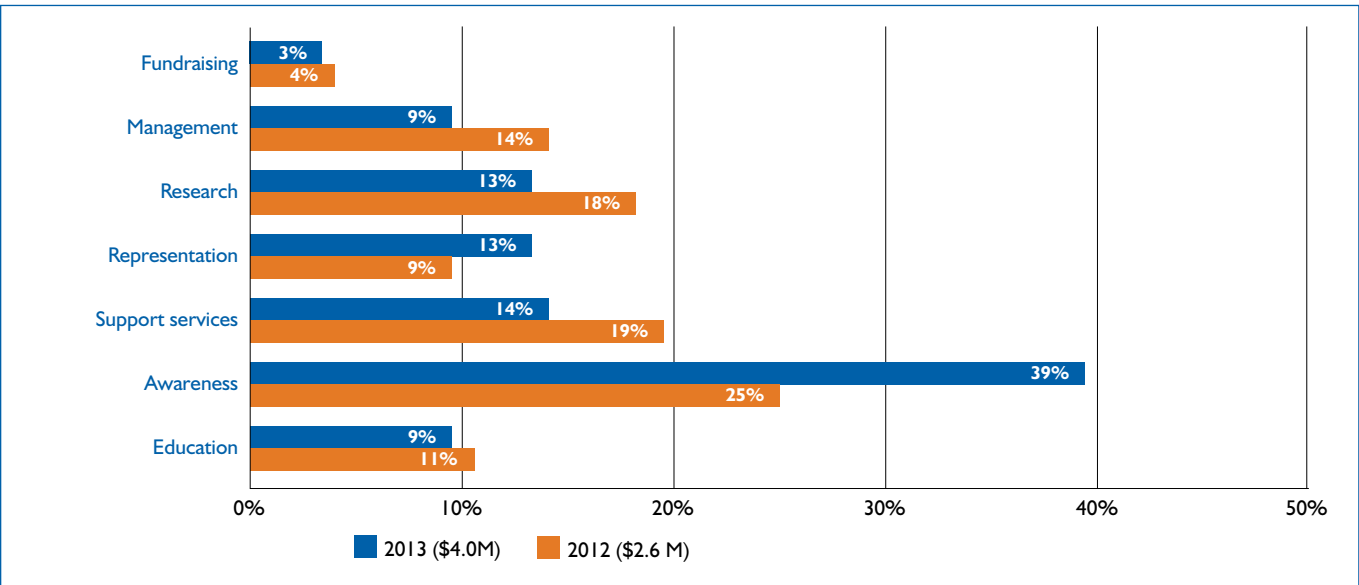
10 YEAR FINANCIAL SUMMARY (\$000)



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 2,600 people in 2012-2013, 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 by the then South Eastern Sydney and Illawarra Area Health Service. Since then, 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 provided funding for a macular degeneration research fellowship in recognition of the contribution of Founding Director Dr Paul Beaumont.



Marcus Blackmore with Foundation Ambassador Jean Kittson

Novartis

Novartis has supported the Foundation in a wide range of activities since the Foundation's establishment. In particular, Novartis has supported the Foundation's national television and radio awareness campaign since 2008, which has resulted in Australia now being a world leader in raising 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

Bayer

Since 2011 Bayer has provided valuable support to a range of initiatives in the areas of client services, awareness, education and most importantly the Ripple Effect of Vision Loss (SightSeer2) 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 2013 the Foundation also received support from Bayer's global organisation to deliver the first ever Global Ageing and Vision Advocacy Summit in Barcelona, Spain. This was an extraordinary honour and was a tribute to the status the Foundation has achieved on the world stage.



Bayer Healthcare Business Unit Manager Ashraf Al-Ouf and General Manager Rene Klemm with Foundation Chief Executive Officer Julie Heraghty

ODMA

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



Foundation Chief Executive Officer Julie Heraghty with ODMA Chairman Richard Grills and ODMA Chief Executive Officer Finola Carey

Quantum RLV

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

Foundations and Trusts

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

Profield Foundation

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



Profield Foundation Directors Michael and Angela Field with Foundation Deputy Chairman Ashley Chapman

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.

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. In particular, the Foundation acknowledges the substantial donation from ICAP, a global financial services company, which on one day each year donates all revenue and commissions globally to a range of selected charities.



ICAP Australia Chief Executive Officer Brad Howell with Foundation Chief Executive Officer Julie Heraghty

Bequests

Bequests form an increasingly important part of the Foundation's funding and we are most grateful to those who choose to support us in this way. Bequests can either 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

ClubsNSW

Local Clubs in NSW have been very supportive of the Foundation through the ClubGRANTS Scheme again this year. Funds received via ClubGRANTS assist the Foundation in delivering projects in local communities to help people live well with macular disease.

Roth Gair Charity Golf Day

In 2013 the Lions Club of Forest Hill in Victoria once again hosted the annual Roth Gair Charity Golf Day to raise funds for the Foundation. 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. Organiser Ian Kennedy and the Club delivered a wonderful event, raising a record amount.



Event organiser Ian Kennedy, John Gair (part of the winning team and Roth's son) and Lions Club of Forest Hill President Karen Young

Everyday Hero / GoFundraise Events

The Everyday Hero and GoFundraise websites enable people to raise funds for the Foundation as part of an organised activity such as a fun run or personal challenge. Heather Powrie participated in this year's HBF Run for a Reason in Perth and raised funds in memory of a friend who lived with macular degeneration. Thank you to Heather and all our other fundraisers.



Foundation supporter Heather Powrie

Pro Bono Support

The Foundation is most grateful to those organisations which provide support in the form of pro bono or discounted services. Particular thanks go to Ernst & Young for their pro bono auditing services and to King & Wood Mallesons for their pro bono legal advice.



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 the 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
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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.

Special thanks to

- Optometrists Association Australia
- The Royal Australia and New Zealand College of Ophthalmologists
- ClubsNSW ClubGRANTS supporting clubs: Campsie RSL Club, Club Ashfield, Club Central Hurstville, Club Forster, Dee Why RSL Club, Goulburn Soldiers Club, Goulburn Workers, Hornsby RSL Club, Orange Ex-Services' Club.

- Agency for Clinical Innovation
- Artarmon Masonic Centre
- Bluedesk
- B'nai B'rith Foundation
- Certatech Holdings Pty Ltd
- Chester Hill-Carramar RSL Sub-Branch
- Cornerstone Media
- Cube
- Davis Hull Foundation
- Deloitte Access Economics
- Dural Country Club Men's Bowling Club
- ES Wigg
- Everyday Hero fundraisers and donors
- Galaxy Research
- Ian Kennedy
- Insight
- Lions Club of Forest Hill
- Lutanda Manor staff and residents
- Macquarie Group Foundation
- mivision
- Optimed
- Perpetual Foundation
- Produce Marketing Australia
- RAAF Association Canterbury Bankstown Branch
- Rotary Clubs nationally
- Roth Gair Charity Golf Day sponsors
- Senate SHJ
- Ted Baker
- Toyo Tyres
- United Way Workplace Giving participants
- Voss Design
- Ward Family Foundation
- Zespri Gold Kiwifruit

Working Together

Who did we work with?

- AMD Alliance International
- Association for the Blind WA
- Association of Independent Retirees
- Atherton Hotel
- Australian Blindness Forum
- Australian Communications Consumer Action Network
- beyondblue
- Blind Citizens Australia
- B'nai B'rith Foundation
- Brothers Leagues Clubs
- Canterbury Multicultural Aged and Disability Support Service Inc.
- Carers Australia
- Centre for Eye Research Australia
- Centre for Vision Research
- Combined Pensioners & Superannuants Association
- Computer Pals for Seniors Groups
- Consumers Health Forum of Australia
- Culturally & Linguistically Diverse groups
- Deaf Society NSW
- Department of Family and Community Services, Ageing, Disability and Home Care
- Department of Health - Community Visitors Scheme
- Department of Veterans' Affairs Day Clubs
- Extended Community Help Organisation WA
- Federation of Ethnic Communities' Councils of Australia
- Greystanes Southern Cross Apartments
- Guide Dogs Australia
- Guide Dogs NSW/ACT
- Hellenic Club of Canberra
- Inner Wheel Clubs
- International Federation on Ageing
- Italian Co.As.It
- Kingswood TAFE
- Lions Low Vision Clinic Tasmania
- Local Council Libraries
- Local Government Councils
- Longueville Private Hospital
- Manly Waters Private Hospital
- Men's Shed
- National Aged Care Alliance
- National Seniors Australia
- Novartis Nurses & Support Staff
- NSW Agency for Clinical Innovation
- NSW Falls Prevention Network
- NSW Health's Non-Government Organisation Advisory Committee
- The Pharmacy Guild of Australia (NSW Branch)
- Optimed
- Optometrists Association Australia
- Pharmacy Guild of WA
- Probus Clubs
- Quantum RLV
- Research Australia
- Retirement Villages and Age Care Facilities
- Rotary Clubs
- Royal Australia and New Zealand College of Ophthalmologists
- Royal Guide Dogs Tasmania
- Royal Society for the Blind, SA
- RSL Day Clubs
- Salvation Army
- Senior Citizens Centres
- Seniors Groups
- Sir Charles Gairdner Hospital
- SMC Conference & Function Centre
- Superannuated Commonwealth Officers' Association
- Sydney Hospital/Sydney Eye Hospital
- The Pavilion Conference and Reception Centre
- Transport for NSW
- UnitingCare Ageing
- University of New South Wales - School of Optometry and Vision Science
- University of Sydney - Discipline of Orthoptics
- University of the Third Age (U3A)
- University of Western Australia
- VIEW Clubs
- Vision 2020
- Vision Australia
- Vision Impaired Person Support Groups
- Wesley School for Seniors - Wesley Mission
- Western Australian Self Funded Retirees
- Western Suburbs Leagues Club
- Women's Social Clubs
- Wrest Point Hobart

Help the Macular Disease Foundation Australia

We need your support to help us save sight!

How to Help Us

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 accepted 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 to find out
more contact the Foundation
1800 111 709
info@mdfoundation.com.au
www.mdfoundation.com.au**

**The 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

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