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# About Macular Degeneration

Macular Degeneration (MD) is the leading cause of blindness\* and severe vision loss in Australia. It affects central vision which is responsible for a person's ability to read, recognise faces, drive and see colours clearly.

One in every seven Australians over fifty is affected in some way and the incidence increases with age. It is primarily but not necessarily associated with ageing and is commonly called Age-related Macular Degeneration or AMD.

People over fifty, those who smoke or have smoked and those who have a family history of Macular Degeneration are most at risk of developing the disease.

It is a disease with multiple aspects which can affect quality of life and independence.

# About the Macular Degeneration Foundation

The Macular Degeneration Foundation is a charity. It is the national peak body in Australia formed in 2001 by those who felt there was a real need for an Australia-wide MD organisation that was primarily patient driven. The Foundation is committed to working on behalf of the entire Macular Degeneration community, specifically those with the disease, their family and carers. The national office is located in Sydney.

# **Our Vision**

## To reduce the incidence and impact of Macular Degeneration in Australia

## **Our Values**

The Macular Degeneration Foundation's Board, Committees, State Chairs, members, staff and volunteers have common shared values and commitments and these 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 Degeneration, their family and carers.

<sup>\*</sup> legal blindness

# About the Macular Degeneration Foundation

## **Our Guiding Principles**

The Foundation's work as a charity aims to meet the real needs of the people it represents and as such operates in the best interest of its client; the MD community. 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 and works to empower the MD 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 MD community and to undertake this task, is committed to strengthening the Foundation, the people and practices.

#### Change

The Foundation is persistent in pursuing change and works creatively to make a real difference for the MD 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 MD, 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 MD community.

#### **Partnerships**

The Foundation will value, support and work 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 Degeneration.

# Highlights of 2008-2009

#### Education

- Maintained the high attendance record of 19,000 people attending Education sessions, National Expos and Conferences across Australia
- Implemented Stage 2 of the special Veteran Education Project conducting 25 sessions with over 800 people in attendance
- Over 168 General Practitioners attended the Eye Health Workshop for General Practitioners
- O Distributed over 12,000 information kits to General Practitioners across Australia

#### **Awareness**

- National TV, radio and print advertising campaign contributed to awareness of MD increasing by 36%
- MD Awareness Week media reached an estimated 15 million people
- Launched the first ever Eating for Eye Health cookbook in March 2009 with 5,000 copies sold by June 2009
- Leading partner in the Australia-first mobile MD screening unit The Vision Van
- Launched Keep On Driving Safely project
- Successful final entrant in SBS Foundation grant program and awarded a share of \$2m of SBS TV airtime

## **Support Services**

- Over 150,000 MD information materials distributed across Australia
- Over 16,000 calls to the MD Foundation Helpline average of 64 calls per day

- Over 26,000 people on the MD Foundation database received newsletters and information
- Over 168,000 visits to the Foundation website
- Distributed a total of five newsletters to all those registered with the Foundation
- Distribution of over 11,000 key publications in Arabic, Chinese, Greek, Italian and Vietnamese
- Over 90% of participants on the Navigator Library Access Program reported that the Navigator had improved their quality of life and access to audio books

#### Research

- Commenced Project Vision III titled Living with MD to identify the needs and experiences of those with MD
- Supported key research projects with University and research centres including a partnership to design and trial an Australia first self-testing vision chart
- Maintained a robust research monitoring and reporting service to the MD community

## Representation

- Secured outcome with the Federal Government in progressing harmonisation of low vision aids and technology
- Presented Project Vision II results at Vision 2008 Montreal, Canada
- Represented the interests of the MD community at local, national and the international level

# Report from the Chairman and Chief Executive Officer

The year was an exciting one, providing the Macular Degeneration Foundation with new opportunities to elevate the understanding and awareness of Macular Degeneration in Australia to new levels.

Our key NSW and Federal Government grants were each renewed for three years. These will provide the Foundation with a solid base to move forward in delivering Australia-wide education. This program enables those with MD, their family and carers to hear first-hand about important information including nutrition, treatments and low vision technologies.

A key strategic goal in 2008/09 encapsulated the theme Blindness is the Same in any Language. We achieved this by having information translated and printed in five languages - Arabic, Chinese, Greek, Italian and Vietnamese. Relationships were also established with these communities enabling us to present education sessions with the assistance of a translator.

In addition, the MD Foundation was one of 23 successful charities to be supported by the newly formed SBS Foundation and awarded \$2 million of donated television airtime. This has given us the opportunity to target Australia's culturally and linguistically diverse communities through the powerful medium of TV advertising on SBS.

Our veteran education, supported by the Department of Veterans' Affairs (DVA), provided real engagement with the veteran community in Queensland, Victoria and NSW reaching over 800 veterans. Working with the RSL State Presidents and having the support of the National RSL has been a valuable partnership. The DVA recognised the value of this critical program and provided an additional grant to extend the program across Australia to fill the unmet need for veteran organisations.

Whilst our focus on education of professionals will always include Ophthalmology, Optometry, Orthoptics and student education, the challenge has been to expand this to General Practitioners (GPs) and Pharmacists. For the education of GPs, we gained funding from the Federal Government's Eye Health Demonstration Grant Program and undertook a pilot project in NSW to deliver comprehensive seminars to GPs on eye health and low vision. These seminars were accredited by the Royal Australian College of General Practitioners (RACGP). We also began our work with Pharmacists to extend their knowledge of, and involvement in, MD.

The MD Foundation is a relatively young organisation established in 2001, so the ongoing support of our major sponsors Blackmores and Novartis has enabled us to have certainty in growth and direction.

In May 2009 we recognised eight years of support from Blackmores culminating in \$2 million dollars worth of contributions. To symbolise the strength of this important relationship and to acknowledge our 'Growing Together', a native tree with commemorative plaque was planted at the new Blackmores facility in Warriewood NSW. With our shared common value to reduce the incidence and impact of MD in Australia, Blackmores remains a long term supporter of our education, research and awareness programs.

The ongoing support of Novartis meant that in 2008/09 our programs took a new and exciting direction that has changed the landscape of awareness of MD in Australia. We embarked upon an exciting initiative; the first ever national TV, radio and print advertising campaign. The awareness campaign was supported by Novartis through a direct investment of \$1.9 million. This resulted in Australia being the world leader in raising awareness levels of MD throughout the community.

We have undertaken four national Galaxy Polls since 2007 measuring MD awareness levels across metro and regional Australia. The number of Australians who have heard of MD increased from 47% (February 2007) to 72% (September 2009). The greatest acceleration in this increase took place as a result of the Novartis funded advertising campaigns during the year. Calls to the Helpline, website hits and requests for information packs all far exceeded expectations.

Several other unique initiatives in 2008/09 also highlighted MD across the country.

The Vision Van was launched in September 2008. This Novartis initiative was supported by the MD Foundation, Optometrists Association Australia and the Royal Australian and New Zealand College of Ophthalmology. This was the first Australia-wide mobile unit testing for MD. It travelled for 90 days throughout regional and urban areas nationally. It proved so successful it was repeated later in 2008/09.

Eating for Eye Health – the Macular Degeneration Cookbook was launched in March 2009. It was written by our Patron, Ita Buttrose, and leading Sydney chef, Vanessa Jones, in collaboration with the MD Foundation. Our Patron worked tirelessly to promote the publication, with the first print run of 5,000 copies sold out by June.

The significant media coverage around the cookbook launch, the TV and radio campaigns and the Vision Van ensured a strong media profile right up to MD Awareness Week (MDAW). The national public relations campaign around MDAW alone reached over 15 million people in May.

As a result of the massive awareness campaigns our Client Services team remained focussed on providing information and support for the thousands of callers to our Helpline. Newsletters, publications, Helpline support, website and client support all continued to help those in need across the country. Reaching the MD community is critical to saving sight and to ensuring those with the disease can live well with MD.

The Navigator Library Access Project continued to be a strong focus and provided hundreds of free talking book devices throughout NSW libraries. This initiative was possible through the generous support of the Profield Foundation and Vincent Fairfax Family Foundation.

Our social research Project Vision III commenced with a three part research focus:

- Wet MD: Barriers to treatment
- · Access to low vision aids and equipment
- MD Foundation service evaluation

The University of New South Wales School of Optometry and Visual Science generously donated time and expertise to work with us to design these three projects. The research will be completed in 2009/10.

In July 2008 we were honoured to be invited to present the results of Project Vision II to an international audience at the Vision 2008 conference in Montreal, Canada. This invitation was in recognition of the world leading results we have achieved in raising awareness of MD it and provided other MD organisations the opportunity to learn from our outcomes.

Representing our clients to Government and other agencies to ensure the best outcomes for the MD community continued to be a major focus. Of particular note was the advocacy work to address access to low vision aids and technology. This was achieved through representation on committees through the Australian Blindness Forum and Vision 2020. The MD Foundation also represents the Australian MD community on the world stage via a position on the executive of AMD Alliance International.

The MD Foundation's Board of Directors and various Committees met throughout the year to provide strategic direction and to oversee our work. The guidance and expertise of the Board has been invaluable in supporting the MD community.

Our sincere thanks go to Foundation Patron, Ita Buttrose AO, OBE, who gives her time, energy and expertise to the Foundation's activities throughout the year. A special thanks also to our staff and volunteers who work to ensure the delivery of quality services and excellent outcomes. This year Suncorp gave an outstanding commitment by providing 38 volunteers to support our work.

We appreciate and thank all our donors, supporters, partners and sponsors including the NSW and Federal Governments (and their appropriate departments), Novartis, Blackmores, Profield Foundation, Goldman Sachs JBWere, Australian Stockbrokers Foundation, the Brian Kirby Foundation, Vincent Fairfax Family Foundation, Quantum Technology, ANZ Staff Foundation, Mallesons Stephen Jacques, bluedesk, Optometrists Association Australia, Royal Australian and New Zealand College of Ophthalmology and Audio-Read.

We would also like to sincerely thank all those who made generous donations to ensure our services can continue; small or large this contribution is highly valued and appreciated.

We extend a special thank you to Ernst & Young who so generously give their time and expertise as our auditors. Thank you to all of the low vision service providers across Australia as well as other Foundations and Associations with whom we work to deliver comprehensive services for clients.

No organisation can exist without the support of the people it serves and we thank sincerely the entire Macular Degeneration Community, patients, families, friends and carers for their continued support.



Elizabeth Carr Chairman BA (Hons) UWA MPA Harvard University



Julie Heraghty
Chief Executive Officer
BA DipEd UNSW

# The Macular Degeneration Foundation

#### **Our Patron**



#### 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 made an Officer of the Order of Australia for her services to the community particularly in the area of public health education. She is also Vice President Emeritus of Arthritis Australia.

#### Our Board



#### Elizabeth Carr, Chairman - BA (Hons), MPA, GAICD

Elizabeth Carr is an inaugural Board member of the MD Foundation and in October 2006 accepted the position of Chairman.

She has had 20 years experience in the inter-relationship between employee productivity and the applications of technology to increase profitability in the IT & finance industries. Elizabeth is now focused on the growing inter-dependence of the private, public and not-for-profit sectors and undertook a Masters degree at Harvard University, specialising on issues of governance, accountability and strategic policy in this area. Elizabeth is currently a consultant on Public Private Partnerships.

Elizabeth is also a Council member of Kambala Anglican School for Girls, Honorary Vice-President of the International Management Organisation, and a council member of the Harvard Club of Australia.



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

Ashley Chapman retired in 2004 after a career in information technology spanning over forty years. His experience includes fifteen years with IBM in a variety of roles covering systems engineering, programming and education. Industry experience included banking and finance, airline, distribution and Government utilities.

After leaving IBM he became a partner in a CPA firm and then in 1978 he founded Management Control Systems Pty Ltd, a company specialising in the development and marketing of financial systems for the distribution and manufacturing industries both in Australia and overseas.

Ashley is the Deputy Chairman of the MD Foundation.



#### Dr Paul Beaumont – FRACS, FRANZCO

Dr Paul Beaumont is a founding Director of the Macular Degeneration 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. His clinic 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.

Paul is the chair of the Medical Committee and NSW State Chairman for the MD Foundation.



#### Peter Brown

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



#### Barry Clarke - PNA

Barry Clarke has over 40 years experience in the financial services sector in both executive and CEO roles. He is currently a Director of the Royal Society for the Blind of SA and other companies involved in the bio-medical field. He also serves on the Client Advisory, Finance, and Investment Committees for the Royal Society for the Blind of SA.

In 1990 he retired from his position as General Manager of the Police Credit Union in South Australia due to the early onset of Macular Degeneration. However, after a period of rehabilitation he returned to the workforce and went on to establish and successfully develop Mortgage Find as a national mortgage broking business. Having sold this business, he retired in 2005 to spend more time on his personal and investment interests.



#### Dr Peter Herse - DipAppSc, PhD, FAAO

Dr Peter Herse practiced Optometry for a number of years in Australia and Kenya. He entered academic life in 1984 and has held appointments in a number of Optometry schools around the world, the most recent being as Senior Lecturer at the University of NSW. He has been a Councillor for the Optometrists Association of Australia. He is a Fellow of the American Academy of Optometry and has a strong interest in international eye care. He has helped establish a number of low vision clinics in Sydney and around the world. He left academic life in 2007 and is currently Director of the Luxottica Institute of Learning in Sydney.

Dr Herse resigned from the Board of the MD Foundation on 5 December 2008, after serving four years as a Director. The Foundation is highly appreciative of the enthusiasm, expertise and commitment which Peter brought to the Foundation.



#### John McCarroll - B.Ec, GAICD

John McCarroll is a Senior Adviser at JB Were Ltd - Private Wealth Management. John has more than 29 years experience in the Finance industry, initially in Europe and for the past 19 years in Australia. John is fluent in German. John is a Director of the Australian Stockbrokers Foundation which holds two industry related functions each year and distributes the proceeds to 10 different charities. John holds a Bachelor of Economics from Monash University (Vic) and recently became a Diploma member of the Australian Institute of Company Directors.

# The Macular Degeneration Foundation



#### Peter Reid – BA, LLB

Peter Reid has practised as a lawyer since 1972 specialising in the energy and resources sector. He served as an Australian diplomat for seven years, spent nine years as the Senior Exploration Counsel for Esso Australia Ltd and the past 22 years in private legal practice. He has been a frequent speaker at international industry and professional conferences and was voted by his colleagues as one of the world's leading resources lawyers in 2002, 2004 and 2007. In 2004 he established his own legal practice, Energy and Resources Lawyers Pty Ltd. In 2006 he was appointed a non-executive director of Mosaic Oil NL an ASX listed company where he serves as the Chairman of its Governance, Nomination and Remuneration Committee.

Peter served as the inaugural Chairman of the Governance Committee of the MD Foundation before it was incorporated into the current Audit and Risk Committee.



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

Paul Rogan is a senior executive with more than twenty years experience in the financial services sector both in Australia and the United Kingdom. He is currently the Executive General Manager, Capital Risk & Strategy, of Challenger Financial Services Group and is a Director of its subsidiaries. He has served as an Executive Director on subsidiary boards of the National Australia Bank and MLC group, including as CEO of the Wealth Management operations in the UK and MLC Building Society. He is also a past Chairman of the Victorian Building Society Association and past Counsellor on the Association of Australian Permanent Building Societies.

Paul is Chairman of the Audit and Risk Committee for the MD Foundation.



#### Dr Jim Runciman - FRACS, FRANZCO, FAAO

Dr Jim Runciman is a fellow of the Royal Australian and New Zealand College of Ophthalmologists and the Royal Australasian College of Surgeons.

Appointed to the Macular Degeneration Foundation Board in 2003, Dr Runciman is a leading Ophthalmologist with a special interest in retinal diseases. He is a Director of the Adelaide Eye and Retina Centre, a Board member of the Royal Society for the Blind of SA and a consultant to Ellex.

Jim is the South Australian State Chair for the MD Foundation.



#### Suellen Tapsall – BA, MA, FAIM

Suellen Tapsall is the Director of the AIM-UWA Business School Alliance, a strategic alliance between the Australian Institute of Management WA and the UWA Business School, which provides senior executive leadership and organisational development programs and services. A former journalist (print and broadcast) who moved into academe in the 1990s, Suellen worked at Queensland University of Technology and Murdoch University in a variety of academic leadership and management roles. Co-author of two journalism books and a number of major research reports, Suellen's expertise and research interests include cultural diversity, technology policy, theories of journalism, borderless education and social and economic impacts of the internet. Suellen was diagnosed with myopia-related Macular Degeneration in 2001.

Suellen is Chairman of the Client Services Committee for the MD Foundation and the Western Australian State Chair.

#### National Research Advisor



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

Professor Paul Mitchell is a world renowned medical retinal specialist and Professor of Ophthalmology at the University of Sydney, and Director of Ophthalmology for the Sydney West Area Health Service. His clinical work focuses on the management of AMD, 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, already yielding almost 300 international publications including in the New England Journal of Medicine. The study examined prevalence, incidence, risk factors and impacts of the key causes of vision loss, vascular events, hearing, nutrition and other findings of systemic-ocular links, and key impacts of visual impairment on independent living and quality of life.

#### Chief Executive Officer



#### Julie Heraghty - BA DipEd

Julie Heraghty spent over seven years as a Policy Advisor to NSW State Ministers across three major portfolios. Her career began as a secondary school teacher and she later qualified as a registered psychologist working in schools with students, teachers and parents. Julie has served as a Director and Manager in major Government Departments across Education and Training, Fair Trading and Infrastructure, Planning and Natural Resources. She has also served in Local Government as Deputy Mayor and has worked voluntarily for many charitable causes.

#### State Chairs

New South Wales: Dr Paul Beaumont - Director Tasmania: Dr Nitin Verma

Queensland:Dr Amanda GreavesSouth Australia:Dr Jim Runciman - DirectorVictoria:Dr Wilson HeriotWestern Australia:Ms Suellen Tapsall - Director

#### **Committees**

#### **Audit and Risk Committee**

Mr Paul Rogan - Chair Ms Elizabeth Carr Mr Ashley Chapman Mr Peter Reid

#### **Medical Committee**

Dr Paul Beaumont - Chair Dr Amanda Greaves Dr Alex Harper Dr Wilson Heriot Dr Alex Hunyor (Jnr) Dr Jim Runciman Dr Nitin Verma Dr Dimitri Yellachich

#### Client Services Committee

Ms Suellen Tapsall - Chair Ms Elizabeth Carr Mr Ashley Chapman Mr Peter Brown Mr Barry Clarke Mr Peter Reid

# The Macular Degeneration Foundation

# **Our Objectives**

The key objectives of the Foundation are to represent the interests of the MD community by providing:

#### Education

O Provide accurate, specific, current and ongoing information

#### **Awareness**

Increase awareness of Macular Degeneration

#### Research

Support and pursue research

#### **Support Services**

Facilitate access to relevant support services

## Representation

Advocate for the best interests of the MD community

These objectives are realised through:

## **Fundraising**

 Provide income from fundraising and

## Best Practice in Management

Ensure best practice in management



# Meeting our Objectives

# Education

# Our Objective

To educate about Macular Degeneration 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 MD 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 MD Foundation provided over 9,800 information kits at education sessions.

#### **Public Education**

Public education sessions are held all across Australia at the Foundation's initiative. People on the MD Foundation's mailing list are invited to the session in their area. Invitations and posters are also sent to local Ophthalmologists, Optometrists, General Practitioners, Pharmacies, Health and Community Services, 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 2008/09 people in cities, regional towns and isolated communities again welcomed the MD Foundation with great enthusiasm and expressed gratitude for the opportunity to have personal contact with the Foundation and for the information provided at the education sessions.

A total of 94 sessions were held nationally with over 4,500 attendees.

#### Community Education

Community education sessions are held in NSW and WA on invitation from community groups such as aged care organisations, retirement villages, and service clubs, eg Rotary and Probus, vision impaired support groups, religious groups, nursing homes, aged care facilities and hospitals. All requests from community organisations for the year were accommodated.

The MD Foundation was invited to 140 sessions and spoke to 4,700 attendees.

#### **Veteran Education**

The MD Foundation was awarded a grant by the Department of Veterans' Affairs in 2007 to provide 40 MD information sessions to the veteran community in Queensland, NSW and Victoria. The Foundation is grateful to the National RSL and in particular to the National President Major General William J. Crews AO (Retd) for his support of the project. In addition, the Foundation expresses its sincere thanks to State Presidents Mr Don Rowe OAM (NSW), Mr Doug Formby (Qld) and Major General David McLachlan AO (Retd) (Vic) who have supported the program and given the MD Foundation great help and guidance.

In Stage 2 of the Project the MD Foundation conducted 25 sessions with over 810 people in attendance.

# Meeting our Objectives

# Education

## **Education of Professionals**

#### **General Practitioners**

# The Eye Health Care Partnership Initiative

The MD Foundation recognised the importance of the General Practitioner (GP) in early detection of eye disease and referral for diagnosis, treatment and rehabilitation. After successful application for Federal Government funding, the Foundation undertook a pilot project to provide GPs with a professional development program through a comprehensive Eye Health Workshop. The program was accredited by the Royal Australian College of General Practice (RACGP) at the highest level.

Key objectives of the GP Education Program (phase  $\,$  I) were to:

- Deliver a comprehensive, accredited Continued Professional Development (CPD) program for GPs
- Improve the skills of GPs in relation to eye health
- Improve GPs' knowledge of MD, especially prevention, early detection and disease management
- Outline and encourage clear and seamless referral pathways between GPs and eye health professionals
- Understand the physical, social, emotional and economic impacts of low vision

- Create awareness of the services the MD Foundation provides for GPs, their patients, family and carers
- Link and familiarise GPs with their local services for the vision impaired

The program was attended by over 168 GPs across six Divisions of General Practice in NSW with the highest number of over 50s population - Sutherland, Northern Rivers, Tweed Valley, Northside (Ryde), Illawarra and the Hunter.

The program evaluation showed:

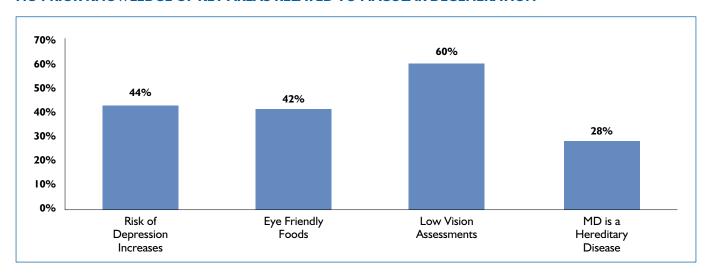
- Over 87% of GPs who attended the Eye Health Workshops believed it was entirely relevant to their practice
- All GPs felt that their learning needs were met with over 77% reporting their needs were fully met
- There was a high need for the program. On average over 40% of GPs had no knowledge of four key areas of MD before attending the workshop

#### SamplesPlus Project

In April 2008 the Foundation began participation in a GP "SamplesPlus" program whereby GPs are informed of the free MD Foundation materials and services and can request an information pack on MD.

Almost 12,000 information kits distributed during the nine month campaign.

# PERCENTAGE OF GENERAL PRACTITIONERS ATTENDING WORKSHOPS WHO HAD NO PRIOR KNOWLEDGE OF KEY AREAS RELATED TO MACULAR DEGENERATION



#### Eye Health Professionals

The MD Foundation continued to provide education and support to eye health professionals including Ophthalmologists and Optometrists as well as Practice Managers, Ophthalmic Nurses and Orthoptists by providing free resources and addressing meetings and conferences throughout the year.

#### Residential Aged Care Staff

The Aged Care Channel is Australia's leading training and education satellite TV channel for staff in residential aged care. It aims to engage, inform and inspire its audience to provide the best possible standard of care. The program Sensory Vision Loss was produced in June 2009. It was designed to educate staff about the psycho-physiological effects and practical difficulties associated with low vision, tools of detection and practical strategies to support people who have low vision.

The Foundation CEO Julie Heraghty was invited to be one of two interviewees in the program along with residents of Turramurra North Nursing Home in NSW. The program was designed to help staff develop their workplace competencies and promote person-centred care and demonstrate current best practice. Over fifty percent of all aged care homes in Australia receive the broadcasts by the Aged Care Channel with over 100,000 people watching the program live at any given time.

#### Eye Health Students

The Foundation extended its student education program in 2008/09 to include both students of Optometry and Orthoptics. A total of eighty Optometry and Orthoptic students visited the Foundation to learn about the work undertaken to meet the needs of the MD community. Importantly, students learnt about the role of the eye care professionals in achieving the best outcomes for patients in all facets of their wellbeing. Partnerships were established with the University of NSW School of Optometry and Vision Science and the University of Sydney, Discipline of Orthoptics, Faculty of Health Sciences.

#### Who Did We Work With?

In delivering education programs across Australia the MD Foundation works with a range of organisations for the blind and vision impaired, low vision equipment providers, Government agencies and community organisations. Our thanks go to the following:

- Association for the Blind of WA
- Australian Chinese Community Association of NSW
- Australian Greek Elderly Citizens Club of Oakleigh Victoria
- Australian Greek Welfare Society
- Victoria Chinese Association of Victoria
- · City of Armadale (WA) Council
- Co.As.It Sydney
- Co.As.It Victoria
- Council on the Ageing (COTA) NSW
- Council on the Ageing (COTA) WA
- Commonwealth Carelink
- Greek Pensioners Association Etsia Victoria
- Greek Orthodox Welfare Association of WA
- Guide Dogs NSW/ACT
- Guide Dogs Queensland
- Guide Dogs Association of SA & NT
- Guide Dogs Victoria
- Local Councils
- Local Libraries
- Muslim Women's Association
- NSW Department of Ageing, Disability & Home Care
- Optometrists Association Australia
- Quantum Technology
- Queensland Vision Initiative
- Royal Australian and New Zealand College of Ophthalmologists (RANZCO)
- Royal Australian College of General Practice (RACGP)
- Royal Guide Dogs Association of Tasmania
- Royal Society for the Blind of SA
- University of NSW School of Optometry and Visual Science
- University of Sydney Discipline of Orthoptics at the Faculty of Health Sciences
- Victorian Arabic Social Services
- Vietnamese Community in Australia
- Vision Australia
- Vision Impaired Persons Groups
- Vision 2020

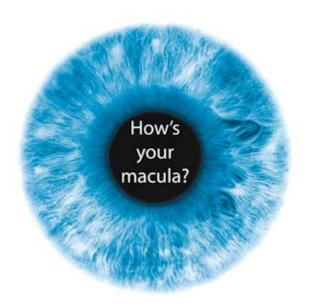
# MD Across Australia

# Where did we go?

WA
Ballajura
Bull Creek
Connolly
Cottesloe
Dianella
Doubleview
East Victoria Park
Ellenbrook
Falcon
Floreat
Hammersley
Joondalup ´
Kalamunda
Kelmscott
Kenwick
Leeming
Lesmurdie
Mandurah
Melville
Menora
Midland
Mt Lawley
Mundaring
Nedlands
North Beach
Osborne Park
Perth
Shenton Park
South Perth
Subiaco
Wembley Downs
Whitfords
Willagee
N N C P S S S V V

"I found the education session very beneficial and reassuring especially as I am newly diagnosed. Being at the presentation was so much better than just reading the information."

"Excellent presentation and a wonderful caring approach. Thank you."



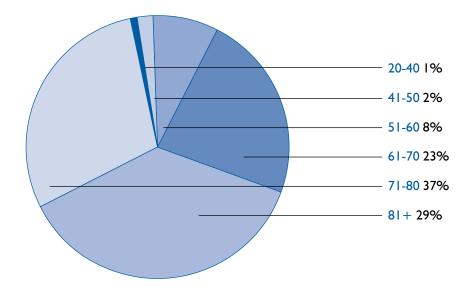
VETERAN EDUCATION				
NSW Batemans Bay Bowral Cowra Epping Gerringong Maitland Narrabeen	Parkes Parramatta Shoalhaven Heads South Tweed Heads Swansea Sydney Warilla	QLD Ipswich Mt Tamborine Tiaro Townsville	VIC Ararat Bairnsdale Beechworth Clunes Dandenong Warrnambool	

PUBLIC EDUCATION				
NSW	Leichhardt	Tweed Heads	Sunnybank	NT
Albury	Lismore	Wollongong	Toowoomba	Darwin
Armidale	Liverpool	Woy Woy	Yeronga	
Ballina	Maitland	Wyong	<u> </u>	TAS
Bankstown	Manly	, ,	VIC	Burnie
Baulkham Hills	Merimbula	QLD	Bacchus Marsh	Launceston
Bowral	Mona Vale	Beenleigh	Ballarat	
Cabramatta	Mosman	Bundaberg	Broadmeadows	SA
Caringbah	Mudgee	Caboolture	Frankston	Campbelltown
Cessnock	Nambucca Heads	Cairns	Geelong	Gawler
Chatswood	Nowra	Caloundra	Heathcote	Port Lincoln
Coffs Harbour	Orange	Cleveland	Kilsyth	St Marys
Epping	Penrith	Coombabah	Moreland	Victor Harbor
Forster	Picton	Hervey Bay	Narre Warren	
Gosford	Port Macquarie	Logan	Shepparton	WA
Goulburn	Randwick	Logan North		Hillarys
Granville	Soldiers Point	Maleny	ACT	Armadale
Gunnedah	Surry Hills	Maroochydore	Hughes	Victoria Park
Katoomba	Tamworth	Maryborough		Floreat
Lakemba	Taree	Southport		Crawley
Lakemba	Taree	Southport		Crawley

# Achieving our goals in education

Q. Is the Foundation reaching those in the 'at-risk' group in education sessions?

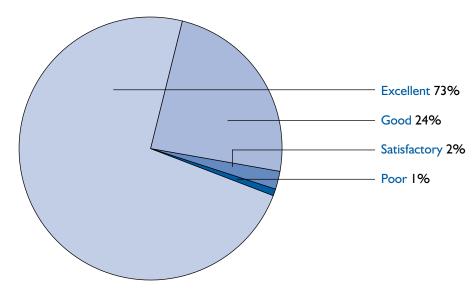
A. Yes. Almost all (97%) of attendees were in the at-risk group (aged 50+).





Q Are the education sessions meeting the expectations of the attendees?

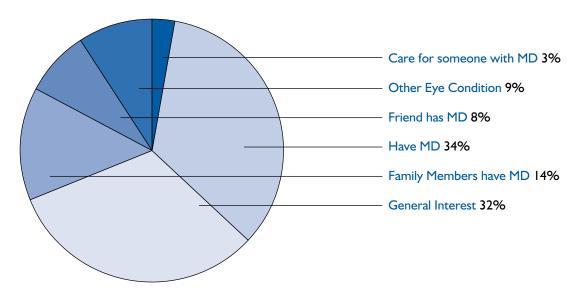
A. Yes. Almost all attendees (97%) rated the education sessions as either excellent or good.





#### Q. Is the Foundation reaching the target audience?

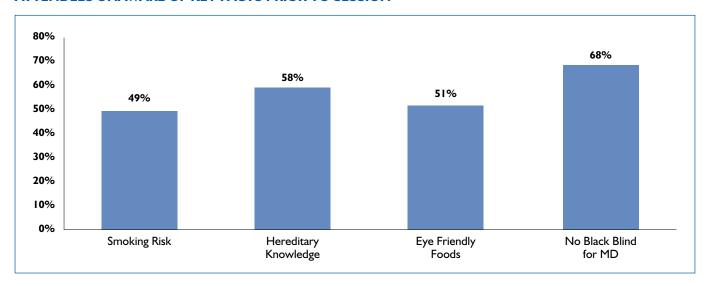
A. Yes. Attendees included both the MD Community (59%) and those wanting to learn about the disease in general (32%).



#### Q: Are the education sessions addressing key MD knowledge gaps?

A. Yes. Prior to the education sessions over 50% of attendees were unaware of key issues for MD.

#### ATTENDEES UNAWARE OF KEY FACTS PRIOR TO SESSION



# Meeting our Objectives

# **Awareness**

# Our Objective

To increase awareness of Macular Degeneration

#### What Did We Do?

# Macular Degeneration Awareness Week 2009

Macular Degeneration Awareness Week was held from Sunday 24 May to Saturday 30 May 2009. The release of Eating for Eye Health - the Macular Degeneration Foundation Cookbook in March 2009 extended the Awareness Week themes and media targets over a period of several months resulting in a significant impact.

The campaign's central theme for 2009 was 'Macular Degeneration – Don't be blind to the risks!' which was used on promotional materials and in media activities throughout Awareness Week. "How's your Macula?" remained an overarching message.

Over 11,500 MD Awareness Week kits were sent throughout Australia including to Ophthalmologist, Optometrists, Orthoptists, libraries, community health centres, pharmacies, health food stores and Parliamentarians.

The objectives of MD Awareness Week 2009 were to:

- Encourage people (especially those over the age of 50) to have their eyes tested and to be sure the macula is checked
- Promote the importance of early detection in order to save sight
- Increase awareness of the important role of nutrition and lifestyle choices through the Eating for Eye Health cookbook
- Raise awareness of MD in Australia
- Promote the work of the MD Foundation



#### Campaign Highlights

MD Awareness Week 2009 was highly successful, with the key messages reaching a potential audience of over 15 million Australians. TV coverage included *The Today Show* (Channel Nine), *Ready, Steady, Cook* (Channel Ten), and *Brisbane Extra* (Channel Nine Brisbane).

Other coverage included major metropolitan print and online media nationally, and extensive trade and consumer coverage of *Eating for Eye Health* cookbook, including *New Idea*, *Australian Optometry* and *Pharmacy Daily*.

Major events were held in Sydney (Martin Place) and Perth (a special education seminar at the University of WA).

# Eating for Eye Health Cookbook

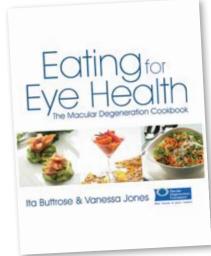
The publication Eating for Eye Health – the Macular Degeneration Foundation Cookbook was one of the most exciting projects undertaken by the Foundation. Our Patron, Ita Buttrose, generously donated her expertise and time over a year to produce, with Sydney chef Vanessa Jones, the first ever eye health cookbook in Australia. It was launched with an extensive media campaign and Ita personally conducted numerous interviews promoting awareness of MD and the importance of nutrition. Eating for Eye Health has been hugely popular with the initial print run selling out only three months after the release date and expanding to overseas markets.

"The Eating for Eye Health Cookbook is great and the meals are delicious." Ingrid NSW

# National Advertising Awareness Campaign

A multifaceted advertising awareness campaign across television, radio and print was undertaken. The need was clear following the low results of the December 2007 Galaxy poll showing that only 46% of Australians were aware of MD.





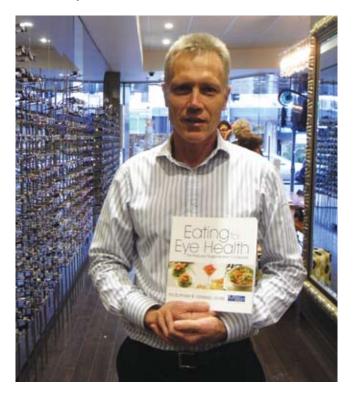
After the success of a pilot TV advertising campaign in 2007/08, the Foundation embarked upon a roll out of a national campaign. The campaign commenced in October 2008 via a combination of television and print advertising incorporating the Foundation's "How's your Macula?" theme. It included advertisements in publications such as Women's Weekly, Sydney Morning Herald's Good Weekend and Burke's Backyard as well as television advertising across metropolitan and regional networks throughout Australia in prime time.

In December 2008, the Foundation undertook its annual Galaxy poll to gauge the success of the campaign. The results of the poll were outstanding with a 36% increase in the number of Australians who had heard the term "Macular Degeneration" and a 63% increase in the number of Australians who are aware that MD affects the eyes. In addition, research with Optometrists recorded a 16% increase in patient flows and a doubling in patients specifically asking to have their macula checked (all for patients aged 50 plus).

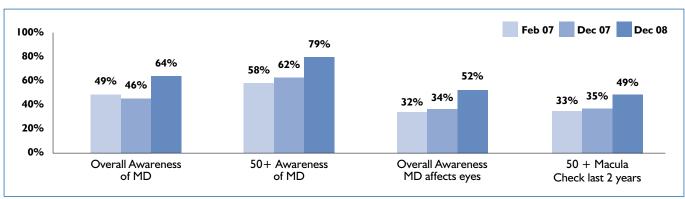
An additional campaign using television and radio was undertaken in March and April of 2009 with key indicators such as MD Foundation website hits, Helpline calls and requests for information kits increasing dramatically.

The dramatic rise in awareness of MD in Australia has earmarked the Foundation as a future world leader.

"Congratulations on the radio and TV awareness campaign. More patients are requesting their macula be checked and asking questions on MD. I believe this campaign is an effective way of educating the population about the importance of getting their eyes tested." Optometrist NSW



#### **GALAXY POLL AWARENESS**



# Friends of the Foundation





















# **Famous Faces**

#### Ita Buttrose AO, OBE

Ita Buttrose continued her outstanding work as the Patron of the MD Foundation, working tirelessly to promote the cause of MD across Australia. Her personal representation of the disease and her popularity as a famous Australian identity has contributed enormously to helping the Foundation achieve its goals.

#### Jean Kittson

Jean Kittson is a multi-talented performer and writer and one of Australia's best known and most popular comedians. Jean continued her outstanding support of the Foundation and attracted great media attention when she launched the first *Vision Van* tour on the NSW Central Coast with her mother who has MD. Both also appeared on the popular Channel 9 TV show *Mornings with Kerri-Anne*.

#### Vanessa Jones

Leading Sydney chef Vanessa Jones promoted her love of cooking, nutrition and eye health in the media and through her role as an outstanding Sydney chef.

## The Vision Van

The Vision Van is a mobile screening unit providing free tests for Age-related Macular Degeneration (AMD) to people aged 50 and over. The MD Foundation was a major partner with Novartis Australia in this Australia-first initiative. The project was also supported by Optometrist Association Australia and the Royal Australian and New Zealand College of Ophthalmologists.

The first phase of the Vision Van was launched at NSW Parliament House on 22 September 2008 and travelled for 90 days through the ACT, NSW, Qld, Vic, SA and WA screening 950 people. A second Vision Van tour took place from March to June 2009 travelling for 90 days through the Eastern states of Australia (Qld, NSW and Vic) screening 1,348 people.

The Vision Van initiative had the dual role of testing people for AMD as well as raising awareness of the disease. The widespread media coverage reached thousands of Australians with the message to have their eyes tested and to make sure the macula is checked. The MD Foundation supported the media campaign and conducted a series of MD education sessions in many of the locations where the Vision Van visited. The project generated worldwide interest and media attention.



Jean Kittson and her mother at Vision Van launch

# Keep On Driving - Safely

In January 2009 the NSW Minister for Roads the Hon. Michael Daley officially launched the Keep on Driving - Safely project for the MD Foundation. The project involves an MD Foundation flyer being inserted into over one million driver licence renewals per year for the next five years - totalling over five million insertions. The flyer encourages an eye test and macula check and provides a tear-off response card to request an MD Foundation information kit.

Over 2,300 information kits have been requested and fulfilled since January.

# Blindness is the Same in Any Language

The MD Foundation was one of the 23 successful charities awarded a share of \$2 million of donated television airtime by the newly formed SBS Foundation in January 2009. The Foundation has had its TV advertisement "How's your Macula" translated into five languages (Arabic, Chinese, Greek, Italian and Vietnamese) to be played during relevant community programs during the 2009/10 financial year.

# Public Relations and Marketing

The MD Foundation again strengthened its profile through targeted public relations campaigns. Editorial highlights included major articles on MD in *Health Workers Union*, *Fifty Plus Lifestyle*, *Women's Weekly*, *50 Something*, *Woman's Day* and *New Idea*.

Strong relationships were established with key trade media, such as *Australian Optometry* and *mivision*, to ensure health professionals remained informed on the risk factors and symptoms of MD, new developments and research and the important work of the Foundation.



A targeted campaign was established for each public education session across Australia focussing on local media. Advertisements were placed in local print media and in many cases complemented by editorial and coverage on local radio. Posters were also distributed for display in libraries, community centres and key promotional locations.

Educating those from culturally and linguistically diverse communities created opportunities for targeting non-English media through advertisements and editorial. Promotions in the *Oriental Post* in Perth alone reached a potential audience of 30,000 people in the Chinese community in Western Australia.

# **Exhibitions and Expos**

The MD Foundation secured stands at the following major exhibitions and provided a very public presence for the Foundation. Information kits were distributed and staff members were available to talk to attendees.

- Retirement & Lifestyle Expos (Melbourne, Canberra, Brisbane, Sydney)
- RANZCO Scientific Congress (Melbourne)
- Optometry Association Expos (Melbourne, Brisbane, Perth)
- Pharmacy Expo (Sydney)
- General Practitioner Convention & Exhibitions (Sydney, Melbourne)

# Meeting our Objectives

# Research

## **Our Objectives**

# To support and pursue research

#### What Did We Do?

# **Project Vision**

#### Promoting the Results of Project Vision II

The Foundation was invited to present the results of *Project Vision II* at *Vision 2008* - the 9<sup>th</sup> International Conference on Low Vision held in Montreal, Canada in July 2008. The results of the research were also presented and published in various media outlets across Australia including *Australian Optometry*.

Many of the findings of *Project Vision II* have been incorporated into the Foundation's education presentations. This was especially relevant in the professional development programs for General Practitioners and aged care staff. Key findings were published in the Foundation's newsletter.

#### **Project Vision III**

In 2008/09 the Foundation commenced a new research project titled *Project Vision III: Living with MD*. This project aims to build upon the previous two MD Foundation research studies (*Project Vision I and II*).

In *Project Vision III* three separate research projects have been scoped, designed and reviewed. In developing the aims and objectives of these three projects, extensive background work was conducted including literature reviews, research briefs, questionnaire design and consultations with external researchers and low vision specialists.

The three projects within Project Vision III are:

# I. Barriers to Accessing Wet MD Treatment in Australia: A Patient Perspective

This study examines the treatment pathways and outcomes for patients with Wet MD. It aims to identify barriers that may be preventing access to treatment. It also examines the impact of costs associated with receiving treatment for Wet MD.

Commencing October 2009

#### 2. Living Well with MD

This study examines the extent to which people with MD are utilising low vision aids and services, The study will identify barriers that may be preventing access and aims to determine if there is an association between the use of low vision aids and services and improved quality of life. Commencing January 2010

# 3. Evaluation of the Services Provided by the MD Foundation

Each year the MD Foundation evaluates the services it provides to ensure that the needs of the MD community are being met and to ascertain what improvements can be made, what gaps exist and how services can better meet the needs of clients.

Completed June 2009

The Foundation is grateful for the advice and support of the following:

- Or Mei Ying Boon: Associate Lecturer, University of NSW School of Optometry and Vision Science
- Ophthalmology, Massachusetts Eye & Ear Infirmary,
  Boston
- Professor Paul Mitchell: Professor of Ophthalmology, University of Sydney, and MD Foundation National Research Advisor



Professor Paul Mitchell reviews the Project Vision III research project with MD Foundation staff

- Or Paul Beaumont: Chairman MD Foundation
  Medical Committee
- Ms Suellen Tapsall: Chairman MD Foundation
  Client Services Committee
- Ms Elizabeth Carr: Chairman MD Foundation
- MD Foundation's Medical and Client Services
   Committee members

# Other Research Projects

#### Self-Testing Vision Chart

During 2008/09 the Foundation worked closely with Dr Mei Boon from the UNSW School of Optometry and Vision Science to design and trial a self-testing vision chart. This chart is the first of its kind to be developed in Australia and if the trials are successful the vision chart will be used as part of the Living Well with MD survey in Project Vision III.

#### University of NSW School of Optometry and Vision Science

The Foundation continued to support the UNSW School of Optometry and Vision Science and the Home Modification Information Clearinghouse with a study on how those with Macular Degeneration cope in the home. The study will be used to identify successful home modifications for those with central visual impairment.

#### Research and the MD Foundation Website

The research pages of the Foundation's website were continually updated with links to current scientific, social and Government reports related to Macular Degeneration.

#### Fight Retinal Blindness Research Project

The Fight Retinal Blindness Research Project aims to investigate and evaluate the clinical effectiveness, cost effectiveness and safety of the emerging therapies for treatment of MD, with the cumulative aim of developing strategies to reduce the incidence of retinal blindness in the Australian community. The MD Foundation supports the project as a member of the Project Advisory Committee.

#### **Evaluation and Reports**

The Foundation evaluates, measures and reports upon all major Government funded projects and any programs initiated by the Foundation or in partnership with funders and collaborators as part of reporting requirements, good practice and for forward planning.

In 2008/09 the research arm of the Foundation evaluated and provided sixteen detailed written reports on major programs.

## Meeting our Objectives

# **Support Services**

## **Our Objectives**

# To facilitate access to relevant support and support services

# The MD Foundation Helpline A frontline service

A range of calls are received on the MD Foundation Helpline. These include calls from those recently diagnosed and in need of information or answers to general questions, as well as callers responding to media activity and articles in the Foundation's newsletter. The callers frequently express their thanks and relief in having a Helpline for information and support. The Helpline is a key component of the Foundation's delivery of services.

In 2008/09 the Foundation received over 16,000 calls; an average of 64 calls per day. The National TV and radio campaigns saw the average daily Helpline calls rise dramatically:

- October 2008 104 calls per day
- November 2008 95 calls per day
- March 2009 147 calls per day
- May 2009 82 calls per day

## Newsletter

The Foundation's quarterly newsletter focuses on relevant issues affecting the MD community. It provides updates on MD projects and new research and remains a vital communication and education link with the MD community. *Project Vision III* showed that 74% read the MD Foundation newsletter and 85% rated it as either helpful or very helpful.

"Thank you for all the information we receive through your newsletter." Beverley WA

#### Information Kits

Comprehensive information kits provided free of charge are one of the main avenues for providing information about Macular Degeneration to the community. The information kit includes: an MD information booklet, Amsler Grid, Low Vision - A Guide, Family Friend and Carer - A Guide, Wet Treatment Options and Nutrition and Supplements Fact Sheets. The information kits are available via the Helpline, at Australia-wide education sessions, at expos and conferences as well as through the MD Foundation website.

Over 150,000 information materials were distributed across Australia. The 1,112 requests for information kits via the Helpline in October 2008 was the highest monthly number ever recorded by the Foundation.

"I wish to thank you for sending me the comprehensive information sheets on MD, which I have read and gained valuable information. I now discuss this with my specialist and Doctor. I now feel more confident." Gertrude SA

## **MD** Foundation Website

The MD Foundation website continued to be a powerful information tool. The website was heavily promoted during the national media campaigns and promoted through all of the Foundation's materials.

In 2008/09 there were 168,000 website visits with a massive peak in May and June of over 18,000 due to MD Awareness Week media coverage.



## **Foundation Publications**

#### Key Publications in Five Languages

In 2007/08 the Foundation had key publications translated and printed into five languages (Arabic, Chinese, Greek, Italian and Vietnamese). In 2008/09 the distribution of the information was accelerated ensuring that culturally and linguistically diverse communities are receiving key messages on Macular Degeneration. These were distributed through education sessions, health care professionals, clubs and organisations.

In 2008/09 over 11,300 translated materials were distributed to the general public and health care professionals.

#### **Review of Key Publications**

The following key publications were updated and revised:

### Wet Treatment Options Fact Sheet

With the guidance of the MD Foundation Medical Committee, the Foundation continued to update and expand the Wet Treatment Options fact sheet in response to changed treatment options. The fact sheet was again promoted through the Foundation newsletter and made available through the mail and the website.

#### The Guides

Low Vision - A Guide and Family, Friend and Carer - A Guide were both reviewed and updated. Both guides have continued to be popular and provide helpful information and support to not only the Macular Degeneration community but also for those requiring support and information across all major eye diseases.

"Thank you for Low Vision - A Guide which I received yesterday. I am 77 years of age and the booklet answered many of my concerns and has given me some comfort in knowing that there are ways to overcome difficulties." Ron NSW

#### **Nutrition & Supplements Fact Sheet**

The Nutrition & Supplements fact sheet was extensively revised and updated and included in the Winter newsletter. There was a great amount of positive feedback and thanks for the information highlighting the interest in nutrition by the MD community and the focus on nutrition during 2008/09.

# Special Low Vision Services Low Vision Display and Information Days

Two low vision information days were held in NSW at Port Macquarie and Baulkham Hills. These initiatives enabled the latest technology to be viewed and used and there were opportunities to hear how those with MD successfully used aids to enhance their quality of life and give increased independence. Presentations were given by Guide Dogs

NSW/ACT, Vision Australia and other low vision providers.

#### National Office Low Vision Service

The Foundation's Sydney office displays a range of low vision equipment including magnifiers, daily living aids and adaptive technology. Patients are able to learn about the aids and technology, use the equipment and discuss any questions or concerns with Foundation staff.



Special Projects
Navigator Library Access Program

The Navigator Library Access Project (NLAP) was successfully implemented by the Foundation in NSW in early 2007. The Navigator is a hand-held, portable device that reads aloud books and newspapers. NLAP is a unique and valuable client service program designed to help those with Macular Degeneration access audio technology through their local library. The Foundation has developed partnerships with around one third of NSW libraries who lend Navigators to library members who have Macular Degeneration. Over 430 people have access to Navigators through this project.

The project was evaluated in December 2008 and received an overwhelmingly positive response from the MD community and NSW libraries.

#### **Key Findings**

- 89% stated that the Navigator had improved their access to audio books
- 90% agreed that the Navigator had improved their quality of life
- 62% said that they spend more time reading with the Navigator
- 97% rated their enjoyment of the reading experience with the Navigator as good or excellent
- 81% reported that they preferred the Navigator over other audio book types such as CDs and cassette tapes

"My elderly mother was kindly directed to the Navigator program. If you could see her now compared to some months back, she is so much happier."

Family SA

"The newspapers are wonderful, like old times when I could read over the toast and coffee."

"I recently was loaned a Navigator from my local library made available by the Macular Degeneration Foundation. It has afforded me so much pleasure being able to hear books being read for me at any time of day. I thank you sincerely and assure you it is much appreciated." Bill NSW

"I love it and sleep with it every night. It makes reading stress-free at a time when my vision is failing. Thank you so much for this wonderful device."



## Meeting our Objectives

# Representation

## **Our Objectives**

# To advocate for the best interests of the MD Community

# National Representation

#### Low Vision Aids and Technology

In March 2007 the MD Foundation began the process of alerting Federal and State Governments to a major problem with accessibility and affordability of low vision aids and technology across Australia. The Foundation undertook a preliminary audit relating to the access and affordability of three major low vision aids across Australia which showed gross inequities - where you lived could determine how well you could access information.

During the Federal election campaign the now Prime Minister the Hon. Kevin Rudd MP gave a written commitment to consider developing a national aids and equipment strategy as a result of strong representation from the MD community. The Foundation continued to make representations to the Hon. Bill Shorten MP, Parliamentary Secretary for Disabilities and Children's Services, to ensure the matter was on the Federal Government agenda and to ensure speedy action on the matter.

In 2008/09 the Foundation achieved, through the support of the MD community, some significant movement on the critical issue of accessibility and affordability of low vision aids and technology across Australia.

In December 2008 Bill Shorten wrote to the Foundation advising that key decisions by the Commonwealth, State and Territory Disability Ministers had been made which put the pre-election commitment into motion with a new five year National Disability Agreement.

The Foundation will continue to monitor the harmonisation of the equipment schemes across Australia.

"Under the National Disability Agreement, work on creating greater consistency across State and Territory aids and equipment schemes will be undertaken. The audit on low vision aids that the MD Foundation provided will be used as part of the aids and equipment reform process. I envisage that negotiations (with States) would encompass a review of access criteria, equity of access and cost."

Parliamentary Secretary, the Hon. Bill Shorten MP, December 2008

#### **Print Disability Services**

Stakeholders were invited by the Department of Families, Housing, Community Services and Indigenous Affairs to comment on the shape of a new service delivery model for Print Disability Services. A new model is needed to support the production of print material in alternative formats to provide improved access to information and materials. The Foundation prepared a comprehensive submission to support modernisation, access and equity in the delivery of print disability services.

#### **Treatments**

As a result of a review into the Extended Medicare Safety Net (EMSN) the May 2009/10 Federal Budget contained measures to implement a cap on the EMSN rebate for certain Medicare items from 1 January 2010. In June 2009 the Foundation began a major review of the impact of this decision upon patients with Wet Age-related Macular Degeneration.

In addition, as of November 2008 changes to the Medicare Regulations for the treatment of Wet Macular Degeneration were implemented. These changes affected the Medicare rebates for some Wet MD treatments.



The Hon. Nicola Roxon, Minister for Health and Ageing with Julie Heraghty CEO

In April 2009 the Medical Services Advisory Committee's decision not to recommend public funding of Optical Coherence Tomography (OCT) scans for the assessment of macular disease was disappointing for the MD community. OCT scans form an essential part of the assessment and management of MD which means OCTs will continue to be an additional cost to patients.

Access to treatment in the public hospital system continued to be inconsistent and spasmodic across Australia.

On all matters, the Foundation has made strong representations to the Federal and State Governments for satisfactory outcomes which ensure equity and access to treatment for the MD community.

#### Australian Blindness Forum

The Australian Blindness Forum (ABF) is a peak body representing major blindness organisations bringing together both service providers and people who are blind or vision impaired and works closely with National Disability Services. On behalf of its members ABF also facilitates Australia's membership of the World Blind Union.

In 2008/09 the Foundation served on the Access to Equipment Committee to promote the timely harmonisation of equipment schemes across Australia and the National Vision Loss Committee which has provided input into the development of the Federal Government's National Vision Loss Strategy.

#### Vision 2020

Vision 2020 Australia is part of Vision 2020: The Right to Sight, a global initiative of the World Health Organisation and the International Agency for the Prevention of Blindness. It brings together Australian organisations involved in local and global eye care service delivery and other areas such as health promotion, low vision services and research. The Foundation is represented at its Member Forums and on its Low Vision Rehabilitation Working Group.

#### Memoranda of Understanding

The Foundation works with many parallel agencies that service the blind and vision impaired. Memoranda of Understanding acknowledge each organisation's role and formalises in a simple and concise way the positive relationship and collaborations. MOUs are established with:

- Glaucoma Australia
- Orthoptic Association of Australia NSW Branch
- Royal Guide Dogs Association of Tasmania
- Royal Society for the Blind of SA
- Royal Australian and New Zealand College of Ophthalmologists
- Vision Australia

#### Government

Throughout the year meetings and correspondence with State and Federal Ministers and Departmental officials were conducted to ensure that all were aware of Macular Degeneration and the various issues and needs of the MD community.



"The Foundation works to represent the best interests of the MD Community."

**Dr Paul Beaumont, founding Director** 

# International Representation AMD Alliance International

AMD Alliance International is the peak international body generating awareness and understanding of Age-related MD. It promotes the importance of education, early detection, knowledge of treatment and rehabilitation options, and improving the quality of life of those affected by the disease.

The Foundation sits on the Board and Executive of the AMD Alliance International holding the position of Secretary and Asia Pacific lead. The executive meets monthly by teleconference and yearly for board meetings. In 2008/09 members of the Alliance met from all over the world in Sao Paulo, Brazil to map the future direction of advocacy and support at an international level for those with Age-related Macular Degeneration.

#### International Conference on Low Vision

The 9th International Conference on Low Vision was held in Montreal, Canada in July 2008. The AMD Alliance International provided a panel presentation covering an overview of AMD epidemiology, new research, quality of life and the implications of Macular Degeneration on public health and rehabilitative systems. The presentation was attended by an estimated audience of 2000 people. The Foundation's CEO, Julie Heraghty presented the results of Project Vision II. Other panellists included world renowned identities Dr. Gregory Hagman, Carver Institute University of Iowa; Tara Cortes, CEO Lighthouse New York; Professor Mary Lou Jackson, Instructor in Ophthalmology Massachusetts Eye & Ear Infirmary; and outstanding patient advocate Betty-Anne Baker from Canada. The Foundation thanks the AMD Alliance International for the opportunity to showcase the Foundation's work on the world stage.

#### International Federation of the Ageing

The Foundation was invited to submit editorial on an ongoing basis in the e-newsletter of the International Federation of the Ageing. The e-newsletter is sent to 10,000 members internationally and will serve to further raise the profile of the MD Foundation in Australia as a world leader in meeting the needs of those affected by MD. The first article appeared during MD Awareness Week in May 2009.

#### New Zealand

The Macular Degeneration Foundation was asked by leading New Zealand Ophthalmologist, Dr Dianne Sharp to provide guidance to help establish a New Zealand organisation modeled on the Australian MD Foundation. In January 2009 the Foundation's CEO, was invited to Auckland to speak at the inaugural meeting of over twenty interested people including patients, family, Ophthalmologists, Optometrists and the Royal New Zealand Foundation for the Blind. The presentation outlined a road map to the establishment of an organisation dedicated to helping and supporting the New Zealand Macular Degeneration community.

# Meeting our Objectives

# Best Practice Management

## **Our Objectives**

# Ensuring best practice in management

# A Dedicated and Experienced Board

The Macular Degeneration Foundation has a strong, experienced and representative Board representing the needs of the MD Community. The Board reflects the diversity in the MD community including people living with the disease or who have a relative with the disease, Ophthalmologists, Optometrists 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 2008/09 providing sound strategic direction to meet the mission and objectives of the Foundation. It met quarterly and conducted a major Strategic Planning Day in April setting a clear strategic direction to maintain and grow the Foundation in the midst of the global financial crisis of 2008/09.

# A Strong Committee Structure

Committees met quarterly working with the Chief Executive Officer as part of good governance and management throughout the year:

- Audit and Risk Committee: oversees and enhances the credibility of financial reporting, external audit, risk management, internal control frameworks and reviews related party transactions
- Medical Committee: provides medical expertise, guidance and advice to the Foundation on medical matters related to Macular Degeneration
- Client Services Committee: oversees and enhances the ability of the Foundation to provide the highest quality products and services to meet the needs of the clients



General Manager, Lucy Walker with Directors at Strategic Planning Day

## A Committed Staff Team

Julie Heraghty is the Chief Executive Officer of the Macular Degeneration Foundation and leads a team of eleven full-time (equivalent) dedicated staff responsible for education and awareness, marketing and public relations, support services, research, finance and administration. All staff except for Western Australia are based in the national office in Sydney providing Australia-wide services to metropolitan and regional areas.

Staff attended a range of professional development courses throughout the year to ensure technical knowledge is maintained, new skills are developed and that there is constant review of best practice and good governance processes.

"A special thank you to the young lady who answered my telephone call, she was polite, informative and possessed extremely good telephone manner." Ron NSW

"I have had occasion to contact your staff for information and have been extremely impressed by their kindness and efficiency." Robert NSW



# A Dedicated Volunteer Team

Over sixty volunteers supported the Macular Degeneration Foundation in 2008/09 contributing both time and expertise in many different areas of work. Many volunteers have MD in various stages and others are touched by it in some way through a family member, friend or carer. This year, the Foundation was fortunate to be strongly supported by Suncorp as part of their corporate social program with 35 staff either working a day in the national office or at community events. To all our volunteers across Australia who have supported the work of the Foundation – thank you.

# Senate Inquiry for Not-for-Profits

In December 2008, the Senate Report on Disclosure Regimes for Charities and Not-for-Profit Organisations proposed fifteen recommendations highlighting governance, standards, accountability and transparency, models of regulation and legal forms that would improve governance and management given new emerging social enterprises and the use of public and Government funds. The Foundation attended Industry Association workshops and provided input to peak body submissions and has monitored and reviewed the impact of this important report into the future direction of the "third sector".

# Quality Improvement Program

In 2008/09 the Foundation undertook a self assessment through a desktop audit to see how well it met the Quality Improvement Council Standards and Accreditation Program in the *Health and Community Services Core Standards*.

The assessment covered 17 specific areas across three core standards:

- Building quality organisations
- Providing quality services and programs
- Sustaining external quality relationships

An independent Desktop Audit Report following completion of the Self Assessment Quality Improvement Pathway determined that of the seventeen areas of assessment ten were deemed to be fully met and four partially met.

The report by Quality Management Services stated:

"MDF is a well structured organisation with a highly qualified Board and good planning processes in place. Its strengths lie in the processes in place, such as the Client Services Committee and annual survey that maintains a close relationship with the MD community. The organisation is to be congratulated on the thorough preparation of the Quality Journal and the high quality of the website and 2007-2008 Annual Report."

# Best Practice Management

# **Evaluating the MD Foundation**

# Are we doing a good job?

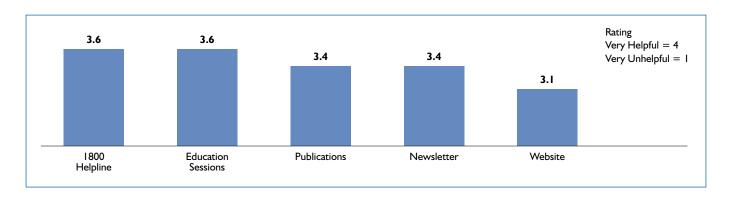
As part of the *Project Vision III* research, over 600 people on the MD Foundation database across all States were surveyed to evaluate the level of satisfaction with the Foundation's services. It is important for the Foundation to be providing services to the MD community that are relevant and of a high standard.

#### Q.Is the Foundation rated highly by users?

A. Yes. The results showed a very high level of satisfaction with the Foundation by the MD community with 90% of those surveyed rating the Foundation as excellent (48%) or good (42%).

#### Q. Is the Foundation providing a good service to the MD Community?

A. Yes. Those surveyed believed the Foundation was providing a very good service with an overall average rating of 3.4 out of 4 for all services and a very high level of satisfaction with the Foundation's individual services.



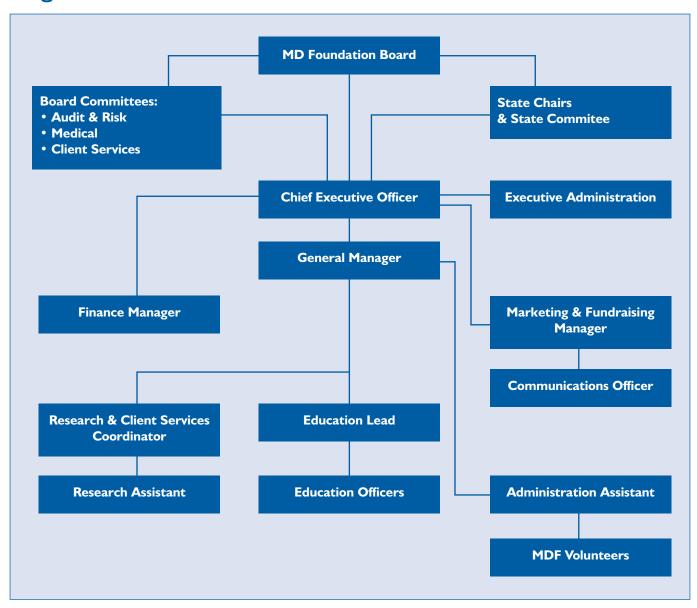
#### Q. What were the top three highly rated services?

A. The top three highly rated services were Newsletters (85%), Publications (73%) and Education Sessions (65%).

#### Q. Are the Foundation's publications rated well?

A. Yes. The results showed a very high level of satisfaction with the Foundation's publications. The average rating out of 4 for all publications was 3.5.

# **Organisation Structure**



"The Foundation provides a wonderful educative role regarding MD and a wonderful source of advice and assistance for individuals or for the families that care for them and have to deal with this debilitating disease."

**Joyce NSW** 

# Financial Report

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

\$,000	2009	2008
Revenues		
Government Grants	469	473
Corporate Support	505	481
Donations & Fundraising	349	487
Sponsorships	820	775
Investment Income	82	57
Total Revenues	2,225	2,273
Expenses		
Education	479	321
Awareness	641	552
Research	107	143
Support Services	245	321
Representation	32	70
Fundraising	98	121
Association Management	348	243
Total Expenses	1,950	1,771
Net Surplus	275	502

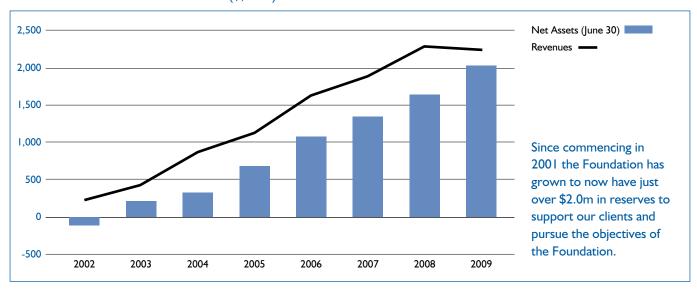
#### **BALANCE SHEET** (AS AT 30 JUNE)

\$,000	2009	2008
Assets		
Cash & Cash Equivalents	1,382	869
Investments	624	673
Trade & Other Receivables	188	272
Property, Plant & Equipment	51	80
Total Assets	2,245	1,894
Liabilities		
Trade & Other Payables	223	173
Provisions	10	40
Total Liabilities	233	213
Net Assets <sup>1</sup>	2,012	1,681

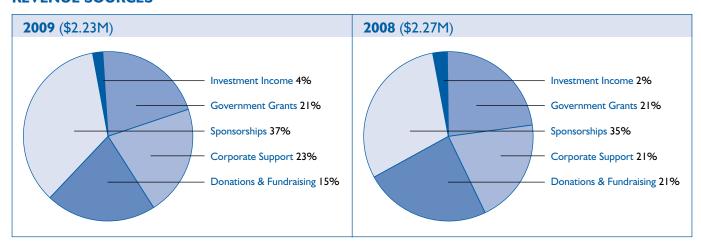
<sup>&</sup>lt;sup>1</sup> The Directors have set aside \$600,000 (2008: \$400,000) within the Net Assets to support future MDF research initiatives.

The information above has been extracted from the audited Financial Statements of the Macular Degeneration Foundation for the year ended 30 June 2009 and presented in a management reporting format. The audited Financial Statements can be obtained free of charge on the Macular Degeneration Foundation website or by contacting the Foundation on 1800 111 709.

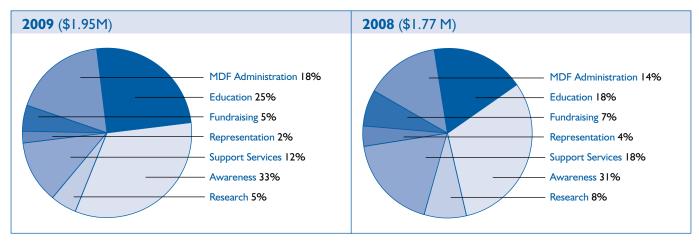
#### 8 YEAR FINANCIAL SUMMARY (\$,000s)



#### **REVENUE SOURCES**



#### **EXPENDITURES**



## Meeting our Objectives

# **Fundraising**

## **Our Objectives**

# Providing income from fundraising

# **Government Funding**

The Federal and NSW Governments both provide key financial support across all our programs, especially education and awareness. The MD Foundation is highly appreciative of the ongoing support of Government.

## Federal Government

In 2005 the MD Foundation received a first ever four year Federal Government grant through the Department of Health and Ageing. This grant enabled the education and awareness program to expand to include all States and Territories.

#### Department of Health and Ageing

Education of the public

In the 2009 Federal budget, the Foundation's grant from the Department of Health and Ageing was renewed for another three years. This enables the ongoing expansion of the education program which, based on the evaluation results, has a high impact across Australia.

Education of General Practitioners

The MD Foundation was awarded a two year Federal grant in June 2008 under the Eye Health Demonstration Grants program to undertake a project of professional development for General Practitioners.

#### Department of Veterans' Affairs

The Foundation was awarded a grant by the Department of Veterans' Affairs (DVA) in 2007 to provide 40 MD information sessions to the veteran community in Queensland, NSW and Victoria. In February 2009 the DVA renewed the funding to continue servicing Queensland, NSW and Victoria and to extend the veteran education program to Tasmania, Western Australia and South Australia.

#### **NSW Government**

The MD Foundation was established with a NSW Government grant provided by South Eastern Sydney and Illawarra Area Health Service in 2002. The ongoing funding from the NSW Government for the last six years enabled NSW to be the first State to implement a comprehensive and ongoing Macular Degeneration education program and provide services to reach thousands of people, especially in regional areas.

## NSW Department of Health

In 2008 the Foundation submitted a proposal for the renewal of funding to the South Eastern Sydney & Illawarra Area Health Service through the Non-Government Organisations Grants Program. The Foundation's funding application was successfully renewed for the next three financial years to 2011 for major education and awareness programs.

# Corporate Sponsorship

Corporate sponsorship is an integral part of the support for the Foundation and thanks go to all sponsors and supporters. The Foundation especially acknowledges the long standing major partners Novartis Australia and Blackmores for their outstanding commitment to raising awareness levels and supporting major education, research and client service programs. Thanks go also to Ernst & Young, Mallesons Stephen Jacques, bluedesk, Quantum Technology and Transitions for their continued support and commitment.

#### Novartis Australia

# Raising awareness of Age-related Macular Degeneration to new levels

Novartis Australia has been committed to supporting the Foundation in raising awareness of Age-related Macular Degeneration to ensure, those at risk has their eyes tested including the macula. The national TV and radio campaign, along with the Vision Van initiative, has helped placed Australia at the forefront of awareness of AMD and a key player in eye health.

#### **Blackmores**

#### Growing together - a special thank you

Strong, ongoing support from Blackmores has resulted in a total contribution of \$2 million to the work of the Foundation over the last seven years. In May 2009 the Foundation presented Blackmores with a plaque reflecting our 'Growing Together' at a commemorative tree planting at Blackmores' new premises in Warriewood, NSW.

## Foundations and Trusts

The MD Foundation is indebted to the generosity of Profield Foundation and Vincent Fairfax Family Foundation both of which have been outstanding supporters of major programs over the past years.

Our thanks go also to the Brian Kirby Foundation and Goldman Sachs JBWere Foundation which have again supported our work. In addition the Foundation has received support from the ANZ Staff Foundation, SBS Foundation and the Australian Stockbrokers Foundation which have all helped fund the vital services.

#### **Profield Foundation**

#### Supporting our clients in a very practical way

The commitment of the Profield Foundation has funded the provision of services to MD clients and also provided support for the Navigator Library Access Project, both of which directly improve quality of life and access to support and help for patients, family, friends and carers.

## Community

For the first time the Foundation has been fortunate to secure funds through the Community Development Support Expenditure scheme in NSW. These funds support projects in local MD communities covered by the scheme.

"With an increasing number of older people in our population the need for the work of the Foundation is unlikely to diminish." Joyce - NSW

#### **Donations**

The Foundation relies on the generosity of individual donors to ensure services continue and expand to meet the needs of the Macular Degeneration community. The generosity of so many people throughout the year has been remarkable and we thank all for their contribution.

"My husband is in a nursing home now with Macular Degeneration, dementia and various other problems. Our daughter has also been told she has MD. I am enclosing a cheque for \$100 from our small community group. Every bit counts." Hazel - NSW

## **Bequests**

The Foundation was also grateful to receive several bequests and is supporting this area with a special Macular Degeneration Bequest Program.

## **Events**

#### Roth Gair Charity Golf Day

In February 2009 the Lions Club of Forest Hill in Victoria held their second Roth Gair Charity Golf Day. The late Mr Roth Gair was a member of the Forest Hill Lions Club and had Macular Degeneration. Our thanks go to organiser Ian Kennedy, his committed team of helpers and local business sponsors.

#### Australian International High Power Association

Every year the Australian International High Power Association holds a fundraising function for a selected charity. This year the MD Foundation was the nominated charity recognising that eyesight is critical to this sport. A cheque was presented to the Foundation at the Association's Annual Sydney Cup competition.

# Thank you

The Foundation would like to thank all sponsors, donors, volunteers and supporters for their assistance this year. Without this valued support the education and awareness programs, support services and research could not be undertaken. The generosity, kindness, good works and spirit of giving shown by so many is appreciated and highly valued. The Foundation appreciates the contribution of so many dedicated people including health care professionals, patients and supporters who contribute their time and expertise.

The support of generous individuals, corporations, foundations and organisations allows the Macular Degeneration Foundation to meet its objectives and realise the vision of reducing the incidence and impact of Macular Degeneration in Australia.

## **Sponsors & Supporting Partners**























# Brian Kirby FOUNDATION





**ANZ Staff Foundation** 

#### SPECIAL THANKS TO

- Optometrists Association Australia
- Royal Australian and New Zealand College of Ophthalmologists
- NSW Department of Transport and Infrastructure

- Audio-Read
- Seeclear
- Working Tech

- bluedesk
- thurnhamteece

- Mallesons Stephen Jaques
- · Weber Shandwick

# How to help us

# How can you help continue the work of the Macular Degeneration Foundation and save the sight of Australians?

# Make a much needed donation

Making a donation can help the Foundation achieve its goals and support the Macular Degeneration community. All funds contribute to the Foundation's vision of reducing the incidence and impact of Macular Degeneration in Australia. A donation can be made by telephoning the Foundation on 1800 111 709. Every donation makes a real difference.

# Regular Giving

Become a regular giver by donating a set amount each month.

## **Sponsors**

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

# Corporate Partnerships

There are many opportunities for corporations to support the work of the Foundation. The Foundation welcomes new corporate partnerships which can support activities such as education, awareness, support services and research.

# Leave a Lasting Legacy

Planning an estate not only allows for the provision of family and loved ones but also gives the opportunity to support causes that are close to one's heart. Leaving a bequest can make a lasting impact on generations to come. A bequest will be acknowledged by the Foundation or if the donor wishes, can be made anonymously.

### A Memorial Gift

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

## A Commemorative Gift

Commemorate a significant occasion by asking family and friends to make a donation to the Macular Degeneration Foundation in lieu of receiving a gift.

# Community Fundraising Events

Participate in a local fundraising event with a community service organisation or hold your own fundraiser. The Foundation welcomes contributions from the fundraising activities of community and service organisations, schools and clubs.

# Volunteering

The Foundation relies heavily on the important work contributed by volunteers. Volunteering provides the opportunity to make friends, make a difference and be a part of the MD Foundation team. There are many different areas of work such as helping in the Sydney office with the organisation of education sessions, packing kits, fundraising work or data entry. The Foundation is always grateful for assistance.

## To find out more:

Contact the Foundation on 1800 111 709 or email info@mdfoundation.com.au

The Macular Degeneration Foundation is a registered charity. All donations over \$2 are tax deductible.

# **OUR VISION**

To reduce the incidence and impact of Macular Degeneration in Australia



Macular Degeneration Foundation Level 3, 447 Kent Street Sydney NSW 2000

Helpline: 1800 111 709 www.mdfoundation.com.au