

Dear Friends



Summer is here and the festive season has arrived. Firstly, I do hope that you have a joyous and safe time and one that brings peace and happiness.

At the end of the year it is a time for reflection and I do look back and think of you - the wonderful people with whom we have had the pleasure of serving in the macular disease community throughout the year. Given that macular degeneration affects older Australians we have the pleasure of meeting, talking with, and serving so many seniors. On behalf of the Board of Directors and the staff let me say it is such an honour and a pleasure to work for you.

We have had a very busy year continuing all of our key programs with the Helpline, publications, education and awareness activities. One of our key areas of work is advocating for your best interests in accessibility and affordability of treatment and rehabilitation. As part of our advocacy work this year we have made 40 submissions to government enquiries and commissions.

There has been one common theme in our submissions - the impact of cost shifting onto older Australians, both pensioners and retired superannuants. We have constantly highlighted how our constituency - those having treatment and those with vision loss

and blindness - are continually under stress as a result. The constant changes to benefits, the decision for over 65s to be excluded from the NDIS and the complexities and costs associated with aged care, are seriously impacting the health and welfare of older Australians.

It is acknowledged that there is an aging population and the demands this brings on the budget. However, the Foundation's position is that this must be balanced with fairness and equity for all, especially those with macular disease. We continue to put the case on your behalf.

This financial year saw the retirement of two board directors our Chair, Elizabeth Carr and ophthalmologist Dr Jim Runciman. Both have given outstanding dedicated service, much valued expertise and steadfast commitment. On behalf of the Foundation we thank them sincerely for their contributions.

The Foundation welcomes Mr Robert Kaye (SC, LLM, LLB, AICD) who was appointed to the Board on 1 July 2016 and appointed Chair 7 September. Robert is a practising barrister (commercial law) and has widespread experience on boards and great passion for our work in macular disease.

Julie Heraghty
Chief Executive Officer

Research Update Enclosed

Enclosed is the Foundation's annual Research Update which includes an overview of some of the latest research projects being undertaken into macular degeneration.



Research

Research Grants Program 2017

Macular Disease Foundation Australia is now a leading source of funding for macular degeneration research in Australia. The Foundation's Research Grants Program will open its next round of applications in early 2017, for research commencing in 2018. Grants will be open to researchers based in eligible Australian institutions to pursue research into medical, social, low vision, and nutritional research into macular degeneration.

2015 Funded Grants Update

In October 2015 the Foundation awarded grants to six Australian researchers for projects commencing in 2016. Below is an update on two of the funded projects:



Professor Mark Gillies
Save Sight Institute, The University of Sydney
Grant for \$400,000 over 3 years

Professor Gillies has established a large online database to be used by clinicians in everyday practice to record their outcomes of treatment for wet age-related macular degeneration. The Foundation's funding is to enable ongoing maintenance of this database and the analysis of data, to generate recommendations to maximise treatment outcomes. The research has shown that Australia is now leading the world with regard to treatment protocols and sight saving outcomes for wet age-related macular degeneration.



Dr Gerald Liew
Westmead Millennium Institute, The University of Sydney
\$100,000 grant over 12 months

This grant is in an exciting new field of research called metabolomics. In this pilot study Dr Liew is now looking at the metabolic waste products in the blood of people with macular degeneration, compared to those without disease. This could potentially result in a practical blood test for early identification of macular degeneration and new targets for treatment.

Donate to Research



Use the enclosed form and reply paid envelope



Call the Foundation on 1800 111 709



Donate online at www.mdffoundation.com.au

Research

Low Vision, Quality of Life and Independence Report

Earlier this year the Foundation commissioned The George Institute for Global Health to conduct a literature review of the current evidence relating to low vision aids and technologies.

As a result the Foundation has now produced a report 'Low Vision, Quality of Life and Independence' which, along with other issues, outlines the impact of low vision; the effectiveness of low vision aids; and examines future technologies. It also includes the cost of vision loss to society; cost-effectiveness of low vision interventions; low vision service access pathways; and the barriers to access low vision services in Australia.

A key recommendation of the report is the establishment of a nationally funded, accessible, affordable and nationally

consistent low vision aids and equipment program to ensure that all Australians with low vision can access aids and technologies to maintain independence and quality of life.

The report is being released in the lead up to International Day of Persons with Disabilities on 3 December 2016, and will be a valuable reference and advocacy tool for the Foundation to be able to continue its efforts on behalf of everyone with vision loss.



The report will be available on our website www.mdfoundation.com.au
(Limited hard copies available for researchers and healthcare professionals)

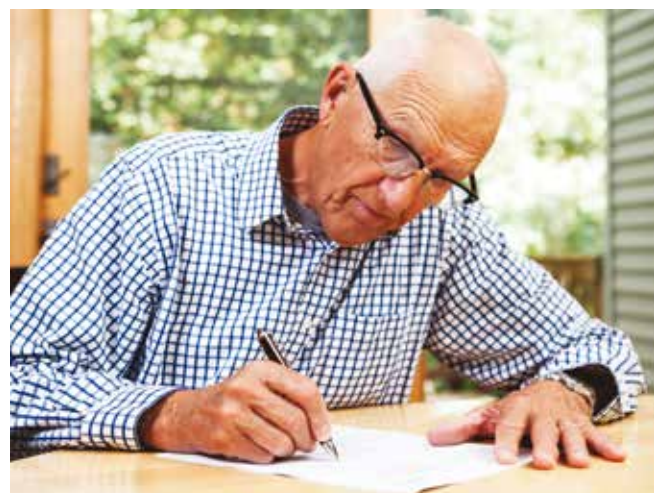
Understanding Your Needs

The Foundation is conducting broad reaching research to better understand the needs and experiences of the macular disease community. This includes those diagnosed with macular degeneration or other macular diseases, their family members and carers, and health professionals.

Through this research, the Foundation is seeking to ensure that it meets (and exceeds) the needs of our diverse macular disease community through its services, information, education, research and advocacy.

Over the next few months, the Foundation will be writing to a random

selection of our community. If you are contacted we would be most grateful for your participation. The Foundation values your thoughts and opinions.



Research

Foundation's Services

The Foundation evaluates its services every year by surveying a sample of its clients. Those surveyed gave overwhelmingly positive ratings to the Foundation's services.

93%

'very' or 'mostly'
satisfied with
Foundation services

87%

said the Foundation
'mostly met', 'fully
met', or 'exceeded',
expectations

95%

rated the Helpline,
education sessions,
website and newsletter
'good' or 'excellent'

Evaluation of the Foundation's Education Sessions

In 2015-2016, the Foundation presented comprehensive education sessions reaching almost 7,500 people. Thank you to those attendees who completed a survey at the conclusion of a session. Your comments are greatly appreciated.

If you are a member of a community group and would like a guest speaker on macular degeneration, call the Foundation on 1800 111 709.

GOAL Target Age Group



RESULT
97%

of attendees were
in the at-risk age group
(aged 50 plus)

GOAL Satisfaction Rating



RESULT
99%

of attendees rated the
education sessions as
"excellent" or "good"

GOAL Knowledge



RESULT
94%

of attendees indicated that they knew
"a reasonable amount" or "a great
deal" more about macular degeneration
after the education session

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Representation

OCT Medicare Rebate

From 1 November 2016 Medicare will provide a rebate for the use of an ocular coherence tomography (OCT) scan for the initial diagnosis of wet age-related macular degeneration, diabetic macular oedema and other similar conditions for new patients, when the procedure is performed by an ophthalmologist.

A maximum of one OCT will be funded per year, but only for the initial diagnosis prior to treatment. This means a maximum of two OCT scans will be funded in a person's lifetime - that is - one per eye.

While this new Medicare rebate is good news, the Foundation's position is that OCTs used to monitor ongoing treatment by eye injection should also be covered by Medicare.

The Foundation has been advocating for funding of OCT scans for many years, and will continue to make representations to Medicare and policymakers for a more appropriate rebate.

For further information call the Foundation on 1800 111 709.



Ozurdex PBS Listing

The Foundation welcomes the news that Ozurdex® (dexamethasone implant) has now been listed on the Pharmaceutical Benefits Scheme. The listing allows Ozurdex to be used in people with diabetic macular oedema who have already had cataract surgery or are scheduled to have cataract surgery, and have:

- A reaction (contraindication) to a VEGF inhibitor,
- or have failed to respond to a VEGF inhibitor,
- or where a VEGF inhibitor is otherwise unsuitable.

Ozurdex is a steroid that is delivered in a slow release implant placed inside the eye. Based on clinical trial data, the effect of each implant typically lasts between four and six months. Patients with diabetic macular oedema should talk to their ophthalmologist regarding treatment options.

Advocacy Update

Recent representations on your behalf:

- **Draft National Aged Care Advocacy Programme (NACAP) Framework consultation:** sets the key principles, priorities and outcomes to enable aged care advocacy providers to deliver effective, high quality, and nationally consistent services. NACAP will be aligned with the National Disability Advocacy Programme. The Foundation recommended that 'older people with a disability' be included as a NACAP target group for additional support.
- **Productivity Commission Inquiry into Human Services - Identifying sectors for reform:** identifying a number of sectors within Human Services which may benefit from increased competition and consumer choice. The Foundation highlighted that greater resources and funding were needed to increase the supply of ophthalmology services in the public hospital system.

Awareness

mEYE World Photographic Competition 2016

Winners of the mEYE World Photographic Competition 2016 were announced on World Diabetes Day, 14 November 2016. The outstanding winners were selected from over 2,400 photographs entered to celebrate the theme "See My World".

Tania Savona, of Ormond, Victoria, is this year's Grand Finalist and Macular Disease Community category winner. She captured the competition theme with a charming photograph of weary young ballerinas resting after a long day of dance.

In her description of the photograph Tania said, "After a hard day's work of dancing and prancing, these ballerinas were captured recharging their batteries and getting 40 winks. You cannot see their eyes, but they have a look of calmness and shared friendship. I'm not a dancer but I love to see my daughter dance and escape into her world of beautiful music and costumes."

Thank you to all who entered this year's competition, our long standing judges Ita Buttrose, Rex Dupain and Alan Pryke, and generous prize donors.

To find out more visit
www.mdfoundation.com.au



Macular Disease Community Winner
and Grand Finalist



Healthcare Professional Category Winner



Open (General Public) Category Winner

2016 Winners

Grand Finalist and Macular Disease Community Winner
Tania Savona, Ormond VIC

Healthcare Professional
Dr Kerry Boytell, Mosman NSW

Open (General Public)
Sharran Makin, Redhead NSW

Junior (Under 18)
Floyd Mallon, Maitland NSW

Living Well

Low Vision Aids and Technologies

'Low vision aids' is the term used to describe the range of devices and technologies that are increasingly being used by people with vision impairment to continue to live independently and perform a wide array of daily living activities. From lights that simulate daylight but stay cool to the touch and new square lenses for magnifying glasses; right through to high-tech electronic magnifying and reading solutions, low vision aids are now an integral part of many people's lives.

While they can be literally life-changing, people on low incomes and pensioners have often missed out on low vision aids because they could not afford them, and there have been very few funding options available. Some changes have occurred of recent times through discussion and advocacy with Government and relevant departments.

These changes enable low vision aids to be now eligible expenditures under two home based aged care programs - the Commonwealth Home Support Program and Home Care Packages.

Under **Commonwealth Home Support Program** up to \$500 can be spent annually on low vision aids, and this can be increased to \$1000 annually **if your home support provider is willing to make a case.**

Under **Home Care Packages**, low vision aids can be included when your package is being designed as part of **a range of supports you need, or if there are residual funds left over** as your package nears its end.

However, be aware that these benefits are not available from all providers and still offer less support than the NDIS.

If you have any questions on these and other avenues of support for low vision aids and technologies please phone the Foundation on 1800 111 709.



Photo: Quantum RLV

“My client was able to use funds in her Home Care Package to purchase a reading machine. She is very happy with it and it has given her a new sense of independence. She is able to read her Christmas letters and this is a great beginning.”

Cheryl Mutch, Registered Nurse
Home Nursing Group, Armidale, NSW

Fundraising

Golf Day – Register Now!

The 10th annual Roth Gair Charity Golf Day, sponsored by Lexus of Blackburn, will be held on **Sunday 5 February 2017**, at **Rosebud Country Club (VIC)**.

This annual event is hosted by the Lions Clubs of Forest Hill and Park Orchards, in memory of Lions Club of Forest Hill Past President Roth Gair, who lived with macular degeneration in his later life. Sponsorship packages and bookings are now available.



Please contact the Foundation on 1800 111 709 for more information.

Macular degeneration education seminars and low vision displays

Location	Date and Time	Address
Gold Coast, QLD	Monday, 6 February 2017 10.00am -12.00pm	Southport Sharks Event Centre Cnr Musgrave & Olsen Avenues, Southport
Wagga Wagga, NSW	Wednesday, 8 February 2017 10.00am -12.00pm	Commercial Club Wagga, 77 Gurwood Street, Wagga Wagga
Melbourne, VIC	Friday, 17 February 2017 10:00am -12:00pm	Windy Hill Venue, Essendon Football Club Cnr Napier & Brewster Streets, Essendon
Bega, NSW (incl. low vision display)	Monday, 27 February 2017 10.00am -12.30pm	Bega Valley, Commemorative Civic Centre Zingel Place, Bega
Batemans Bay, NSW	Tuesday, 28 February 2017 10.30am -12.30pm	Batemans Bay Soldiers Club Beach Road, Batemans Bay

All welcome - please register on 1800 111 709 if you wish to attend.

Donations

Thank you for supporting Macular Disease Foundation Australia. As a charitable organisation we rely on your generosity to service the macular disease community across Australia and fund our Research Grants Program.

If you are able to help us at this time a donation slip and reply paid envelope are enclosed for your convenience. You can also make a secure online donation using your credit card at www.mdfoundation.com.au or contact the Foundation to set up a regular donation.

All donations over \$2 are tax deductible. Bequests are gratefully accepted. Please call the Foundation for more information.

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