

Dear Friends



I do hope everyone has managed to stay cool given these long hot days and nights of summer. Very quickly, the cooler days will arrive bringing the wonderful season of Autumn.

2017 has begun in earnest at the Foundation and there is a great deal happening.

The Foundation launched an Australian-first report highlighting evidence of the benefits of aids and technologies for people with vision loss and blindness. A copy of this report has been sent to every federal MP and key Ministers in every State and Territory. Over the coming months we will use the findings from this report to urge Australia's new Federal Minister for Health to unlock access to the support that people with blindness and vision loss so desperately need and deserve.

Your Foundation is now a leading source of funding for age-related macular degeneration research in Australia and as such, we are proud to be opening the fourth round of applications to the Macular Disease Foundation Australia Research Grants Program in early March. With your support, we have committed over \$3 million to leading Australian researchers since the program launched in 2011 and this year we will commit a further \$800,000.

Research is a journey of discovery and it takes time, commitment and investment. In 2011 we set a lofty target of \$10 million to fund research over ten years and your support is vital to achieving this goal. Yes friends, it's a big target but at the Foundation we set the bar high in order to save sight.

We recently completed a survey to identify further opportunities to meet the needs of the macular disease community. Thank you to all those contacted by the Foundation, including health care professionals, who generously contributed to help us understand your needs and shape the delivery of our services.

One of our fundraising events, organised by members of the public in support of the Foundation, is the annual Roth Gair Golf Day. Now in its tenth year, the Golf Day has contributed almost \$120,000 to our work. In this newsletter we pay tribute to Roth Gair and the one decade of support by Lions Club and the organisers of this wonderful community event.

Please take care and know that it is always an honour for the staff to support and help you through the work we undertake every day.

Julie Heraghty
Chief Executive Officer

DIARY DATE

Macular Degeneration Awareness Week 2017 (Sunday 21 to Saturday 27 May)

To support the week we're keen to hear from family carers who are happy to share their story. Is this you? Call 1800 111 709 to find out more.

Representation

An Australian-First Report on Low Vision

The Foundation released an Australian-first report in January highlighting evidence of the benefits of aids and technologies for people with vision loss and blindness.

The report, titled 'Low Vision, quality of life and independence: a review of the evidence on aids and technologies' was produced by the Foundation in collaboration with The George Institute for Global Health. The key recommendation from the report is the establishment of a federally funded national aids and equipment program for those 100,000 older Australians with vision loss and blindness.

For over a decade, responsibility for a funded equipment program to ensure affordability of aids and technologies has been shuffled between state and federal governments, between numerous portfolios in health, ageing and disabilities, and finally falling between the gaps of aged care and disability reforms.

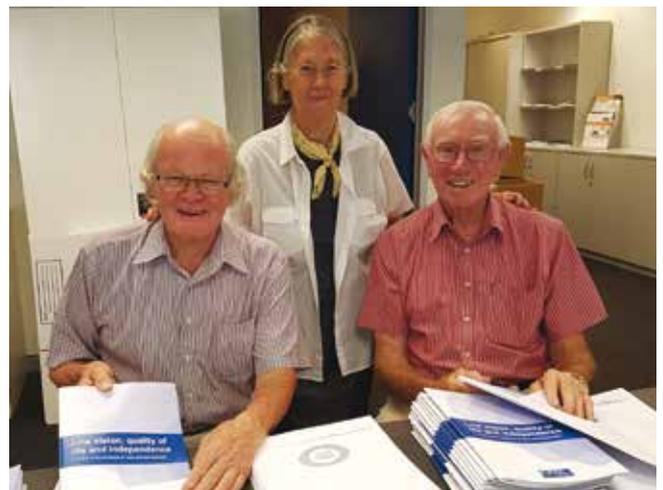


Recommendations proposed in the report are financially achievable and the Foundation is urging the new Federal Minister for Health to provide older Australians with access to the support they so desperately need and deserve.

The Foundation has estimated the initial cost to implement and evaluate a federally funded program could be as little as \$30 million per year with a suggested annual allowance of between \$667 and \$2,400 per person per annum, depending on vision assessment. Over the coming months, Foundation CEO Julie Heraghty will take this report to Canberra in the hope of prioritising this issue onto the national health agenda.

Not giving up!

- Since 2007 the Foundation has continually advocated with your support to successive governments for access and affordability of low vision aids and technologies.
- Prior to the 2016 Federal Election the Foundation wrote to every candidate, and following the election to every elected MP.
- The Foundation has now sent every Federal MP a copy of the 'Low Vision Report' requesting their support.



A team effort! Foundation volunteers Jim, Clare and Des packing low vision reports.

We will continue to advocate for those with low vision – we will not give up!

The report is available on our website www.mdfoundation.com.au and Facebook page
(Limited hard copies are available for researchers and healthcare professionals)

Representation

Disease Treatment Fast-Tracked

The Foundation has welcomed a decision by the Pharmaceutical Benefits Advisory Committee (PBAC) that will provide faster access to treatments for people living with a macular disease in rural and remote areas of Australia.

Previously, obtaining PBS approval for the use of drugs to treat wet age-related macular degeneration, diabetic macular oedema and similar conditions was a time-consuming process that had to be managed by the treating specialist ophthalmologist.

With the ophthalmologist having limited time in each remote or regional town, this had the potential to reduce time available to treat patients.

PBAC's new process allows another clinician, such as a junior registrar, to manage the administrative process, thereby freeing up the ophthalmologist's time.

The Foundation worked to support this change which could save sight by improving early access to treatment.

Advocacy Update

Recent representations on your behalf:

Aged Care Legislated Review: This investigates the impact of changes to aged care legislation since 2012 and the direction of future changes. The Foundation recommended greater integration of specialist disability support services and amendments to the Aged Care Act to recognise older people with a disability as a vulnerable group with special needs.

Consultation on the draft model of the new integrated carer support service:

This model aims to provide services to more carers in order to reach them earlier in their caring journey. The Foundation recommended that the new model integrate and improve on existing services, instead of replacing them, and supported the need for adequate funding and planned respite.

Draft model of the new disability employment services consultation: The model aims to improve user access to disability employment service providers and workplace assistance. The Foundation recommended there be no restrictions or limits placed on clients choosing or switching service providers, along with the need to regulate service providers through the establishment of a quality assurance system.

Pre-Budget submission: This submission highlighted the priorities of the macular disease community to the Commonwealth Government in preparation for the 2017/18 Federal Budget. The Foundation recommended the government carefully consider the impact of policies that shift health care costs to patients; increase Medicare subsidised ocular coherence tomography (OCT) scans for anti-VEGF injections; and for the Productivity Commission to investigate the benefits and costs of establishing a national low vision aids and equipment program.

Research

Research Grants Program 2017: Opening Soon

Macular Disease Foundation Australia's Research Grants Program will open its fourth round of applications on 1 March. Grants are open to researchers based in eligible Australian institutions to pursue research into medical, social, low vision and nutritional research into age-related macular degeneration.

Successful applicants will be announced on World Sight Day, 12 October 2017.

The Research Grants Program is supported by your generous donations. Together, we have committed over \$3 million to 13 leading Australian researchers since the program launched in 2011. Thank you also to Blackmores who support this program.

Further information is available on www.mdffoundation.com.au

Caring for the Carer Research - call for research participants

As reported in the Spring 2016 newsletter, the Foundation's Research Grants Program has committed to a three-year \$100,000 research grant to part-fund a new project aimed at improving support services and programs available to family carers of people with age-related macular degeneration.

The project, led by Associate Professor Bamini Gopinath from Westmead Institute for Medical Research, is a direct result of a large research study conducted by the Foundation in 2013 entitled "The Ripple Effect of Vision Loss". Many of you would have participated in this original study, which involved surveying those with age-related macular degeneration and their carers. It highlighted the dedication and



support of carers looking after someone with age-related macular degeneration, along with the impact this had on the carer's own health and wellbeing.

The research study will require volunteers to participate. The study is limited to people living in NSW, but the outcomes will have national implications for the betterment of the macular disease community.

NSW readers will find enclosed an insert with further information on this research study, including details on how you can participate. Please help by getting involved.

Fovista – latest research findings

The 12-month results of two large phase 3 (registration) trials involving over 1,250 patients with wet age-related macular degeneration have failed to demonstrate that combining Fovista with Lucentis results in any additional improvement in vision compared to using Lucentis on its own.

These results are disappointing given that an earlier phase 2 trial showed positive results. It is now very unlikely that this treatment will move forward in its current form for treating wet age-related macular degeneration.

Latest Research

A common question asked by people who have lost vision from late age-related macular degeneration (AMD) in one eye is: “What is the likelihood of it occurring in the other eye?”

An important new study combining the results from three other studies (including Australia’s Blue Mountains Eye Study) has been published in the British Journal of Ophthalmology and answers this important question.

The study found that people aged between 60 and 69 with late AMD in one eye had a 23.5% chance that they would get late AMD in the other eye within five years. For people aged 70 to 79, this risk increased to 47% within five years while for people aged over 80, the risk increased further to 52% within five years. Note that ‘late AMD’ means

either wet AMD or the end stage of dry AMD known as geographic atrophy. The study also found that smokers were twice as likely to have the disease progress to the other eye compared to non-smokers.

Key messages:

- If you have wet AMD in **one eye**, it is essential that you seek treatment as soon as possible as this gives you the best chance of preserving vision. As the risk is high that the **second eye** will eventually be affected, you should be alert to any change in vision and seek treatment immediately.
- If you, or a family member, smoke - then please seek help from your GP to quit. Smoking increases the risk of AMD by three to four times.

A Stamp-collector’s Legacy

Francis Cardinal Spellman said that, “the collecting of stamps brings untold millions of people of all nations into greater understandings of their world neighbours.” This is exactly what happened when Rita and Emmanuel Vidal donated the proceeds from the sale of an inherited stamp collection to support the Foundation’s research program.

Emmanuel has wet age-related macular degeneration and is undergoing treatment. When he and his wife Rita decided to sell the stamp collection they inherited from Emmanuel’s father 40 years ago, they wanted the funds to make a difference.

“The stamps have been in the back of the cupboard for forty years,” said Rita. “We wanted the money to go to a cause that was important to us, to help a little, and maybe make a difference for someone in the future.”



The collection was recently sold at auction to another enthusiast who will continue to build upon the 1,800 stamps from around the world which was started more than half a century ago by Emmanuel’s father. For the Vidal family, their donation will live on too through research to help us find better preventions and treatments, and ultimately a cure for macular degeneration.

If you are interested in leaving a sight-saving gift in your Will, please contact the Foundation on 1800 111 709.

Travel Tips to Smooth the Way

Travelling with vision loss can be daunting, but planning ahead, seeking information on available services, and making people aware of your (or your companion's) vision loss before you travel, will help smooth the way for a safe, relaxed and enjoyable journey.

Tips before travelling:

- Inform your travel agency and carrier eg. airline, that you or your travelling companion has a visual impairment and find out what facilities and services are available.
- Request priority assistance to help with check-in, disembarking, and going through the customs process if travelling internationally.
- If possible, only take carry-on luggage. If you are checking in luggage, attach a colourful sticker for easier identification.
- If travelling with medication, ask for a letter from your GP to outline what you will be travelling with in your hand luggage.
- Investigate the availability of transport, shuttle systems, people movers, moving walkways or curbside baggage check-in services that can help you continue your journey and move between parking, terminal buildings and gates.
- Be aware of any Guide Dog restrictions or special requirements.

Tips while travelling:

- Get to your departure point early!
- Ensure people are aware you have low vision by wearing your 'I Have Low Vision' badge (available from the Foundation) or carry your cane, whether or not you choose to use it.
- Ask for assistance from staff or other travellers if you cannot see a monitor, find a gate or need other help.

The Australian Government Civil Aviation Safety Authority (CASA) offers valuable travel tips for people who are blind or vision impaired and travelling by air.

Visit www.casa.gov.au



Branch Retinal Vein Occlusion

People with macular edema due to branch retinal vein occlusion now have a second anti-VEGF treatment option following the Pharmaceutical Benefits Scheme listing of Eylea (aflibercept) in late 2016. Anti-VEGF treatment involves

a series of injections into the eye and is generally very successful in preserving vision. A key function of the Foundation is to ensure patients have access to all available treatments and we welcome this listing.

For a factsheet on retinal vein occlusions, call the Foundation on 1800 111 709.

Fundraising

Roth Gair Golf Day Celebrates 10 Years

The 10th annual Roth Gair Golf Day on Victoria's Mornington Peninsula has raised over \$15,000 for the Foundation. The event, held in honour of Mr Roth Gair, has raised almost \$120,000 since its inception in 2007.

Roth Gair was just 18 when he was diagnosed with macular disease. He had already lost significant sight and, when he passed away in 2003, age 79, he had lost about 90% of his vision.

Roth's son Bill said vision loss didn't stop him from competing in golf at an international level and running successful businesses.

"Dad didn't really make it obvious that he had low vision however it was because of this that he always worked in his own businesses. One of these was a successful caravan sales and rental business he set up in Balwyn, Victoria.

"Dad had a strong network of friends and was a member of the Lions Club – he was president of the Forest Hill Lions Club. He joined the Blind Golfers Association in its very early days and competed around Australia and in Japan with a caddie to help him. He played in the World Blind Golf Tournament and it was at that stage that he became more public about being blind – he was proud of what he had achieved."

Three years after Roth's death, the Lions Club of Forest Hill decided to hold an annual golf day in his honour, which would also raise funds for the Foundation.

Ian Kennedy, Roth's nephew works closely with the Lions Club of Forest Hill as well as the Lions Club of Park Orchards to stage the golf day every year. What started out as a small event, attracting around 75 players and raising \$5,000, is now sponsored, attracts in excess of 110 players and raises around \$15,000 for the Foundation every year.

"Uncle Roth gave so much to many people over such a long time. It's great to be able to organise this event in his honour," said Ian.

Bill agreed. "It is fantastic to be part of this event in honour of Dad. It is also an opportunity to raise awareness of macular degeneration, encourage people to get an eye test and raise funds to support such a significant cause. We feel macular degeneration is an area where an investment can help bring about change, and we are very happy to support that."

The Foundation thanks all who are involved in the annual Roth Gair Golf Day for their significant and ongoing support.



Lions Club of Forest Hill (VIC) Past President the late Roth Gair

If you would like to arrange your own community fundraising event for the Foundation, call 1800 111 709 to discuss.

Fundraising

The Target: \$10 Million Investment in Australian Research over 10 Years

As the leading not-for-profit organisation funding research into prevention, diagnosis and better treatment options for age-related macular degeneration, we have set a lofty target of \$10 million to help fund Australian sight-saving research.

To date, \$3 million has been directed towards early detection and advances in treatments for people living with age-related macular degeneration.

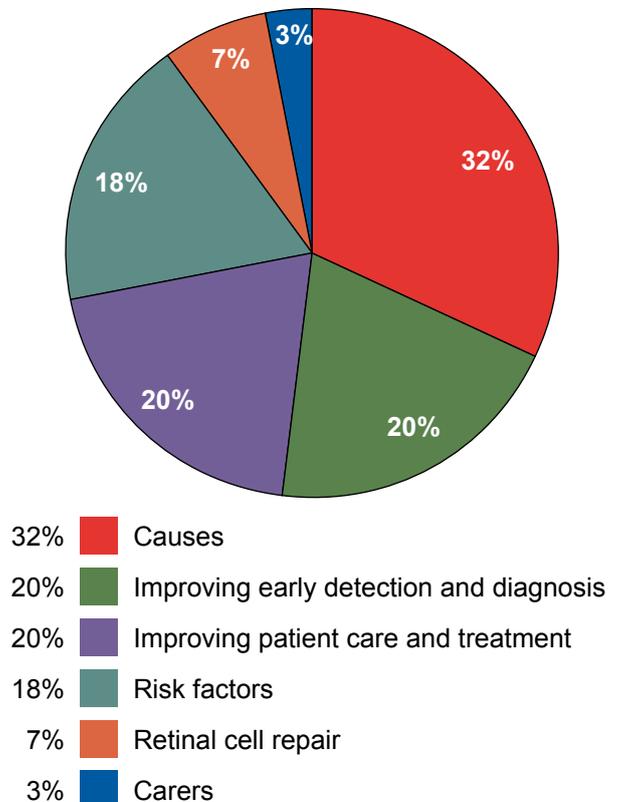
We have a long road ahead to achieve our target and we continue to need your help.

The chart shows the important research areas funded to date by the Macular Disease Foundation Australia Research Grants Program.

DONATE TODAY AND HELP SAVE SIGHT

In Australia today, 1.25 million people have some evidence of age-related macular degeneration. That's 1 in 7 over the age of 50 years. By the time a person is in their 70s, the prevalence of age-related macular degeneration increases to 1 in 4. Only an investment into leading research will help change these statistics. Donate today and help us to fund a cure for blindness from this disease. **YES! I want to help others see their future.**

Research expenditure on age-related macular degeneration to January 2017



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.mdffoundation.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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