

Dear Friends



There are some very serious issues which I need to convey in this newsletter. But firstly and most importantly I hope you are all rugged up for winter and keeping well and healthy.

Our pre-budget submission to have support for our Helpline was again not successful. This is not surprising since we now know of heavy cuts in health funding which may impact the Foundation.

I know that at some time, many of you would have attended a Foundation education session presented by one of our dedicated educators. These sessions provide a wealth of information and an opportunity to ask questions of a real live person! Our worst fears have now been realised with a massive cut of \$1 billion in the recent Federal budget impacting the Health portfolio's Flexible Funds Program, which will now make renewal of our grant very challenging.

At the most appropriate time, I will need your help as never before. I will outline what you can do to help in the next newsletter. At the moment we have a reprieve of 6 months but after that I suspect a submission will be needed, in a very short timeline, to the Department of Health and then we enter a lottery with very poor odds!

I thank our Patron Ita Buttrose AO OBE for having already communicated her serious concerns regarding our funding to the Minister for Health. We will never give up.

Survey on patient costs

Now I turn to your costs, which are always of great concern to the Foundation. Over the last 18 months there have been changes in the rules relating to the Extended Medicare Safety Net, which is of particular importance to people who are receiving injections for wet macular degeneration. As it has been some time since we have undertaken a survey of costs of treatment, we need to get a more accurate picture of the costs that many of you are now experiencing.

If you, a family member or someone you care for is receiving injections for wet macular degeneration, can you please ensure the enclosed survey is completed and returned to the Foundation by 20 June. We need to get accurate figures on the costs of treatment. If you do not have a copy of your latest invoice, you may need to contact the practice manager at your ophthalmologist's rooms. Thank you again for your help.

Finally, we will not let these challenges prevent us from maintaining our service to the macular disease community. You are our primary concern always and know that we are here working on your behalf every day.

Julie Heraghty
Chief Executive Officer

As always, your generous end of financial year donations are greatly appreciated. All donations made before 30 June will be processed promptly to assist with your year end taxation matters.

Representation

Federal funding - saving sight is now even harder!

In the last newsletter we addressed the lack of information surrounding the continuation of Federal Government funding for the Foundation's education program. This program has been in place since 2005 and provides important face-to-face public education sessions on macular degeneration across Australia in both regional and urban areas.

The Foundation was granted an interim 6 month extension on the existing grant while the Government assesses the future of this funding. Subsequently, it was announced in the May Federal budget that the Government will be cutting almost \$1 billion from health programs. The cuts will primarily be through the Health Portfolio's Flexible Funds Program under which the Foundation's education grant is funded.

These cuts, along with increased demand for funding, make the chances for renewal of the funding a great deal harder.

Macular disease is the greatest threat to the eyesight of Australians. Education supports prevention messages, awareness of risk factors, early detection and timely

treatment along with the importance of low vision services. The Foundation's ongoing evaluations have consistently shown the health benefits of this Australia-wide program with 47% of attendees stating that they were unaware of key eye health messages prior to attending a Foundation education session.

The Foundation will do all it can to convey to the Federal Government the need for the education program and our credentials in delivering positive outcomes for eye health.

Once we know the timeline, your help will be vital to show the Government and local MPs that the weight of the macular disease community is behind the Foundation for continued funding of the program.

"The government has said it will make nearly \$1 billion of its savings by 'rationalising and streamlining funding across a range of health programmes', primarily through cuts to the Health Portfolio Flexible Funds."

(Sydney Morning Herald, 13 May 2015)

Improving residential aged care for those with macular degeneration

While health funding for prevention and early detection continues to be a huge challenge for us, funding for the Foundation's work in aged care has been successful through the Department of Social Services.

In collaboration with several aged care providers including Estia Health, this grant will be used to work in aged care to identify best practice in the delivery of eye health in residential aged care facilities.

The Foundation will develop a guide on eye health for use in all residential aged care facilities. Again education is the key to ensure those at the front line of care in aged care facilities are fully informed and aware of prevention, treatment and rehabilitation needs for good eye health. This will include macular degeneration, the primary eye disease of residents in aged care, along with glaucoma, diabetic eye disease and other eye conditions. The Foundation will keep you informed of our work.

Research

Macular Disease Foundation Australia Research Grants Program

The Foundation is now offering the third round of grants under the Macular Disease Foundation Australia Research Grants Program. Already, this program has committed over \$1.5 million to world leading



Australian researchers since its inception in 2011. The current round will offer a further \$1.3 million across multiple grants. Your donations have made this level of investment possible. With your ongoing support we continue to fund research into this chronic disease.

Blackmores Macular Disease Foundation Australia Research Grant

Within the current round, the Foundation is pleased to announce the introduction of an additional grant in partnership with Blackmores for \$600,000 over 3 years to further research into the nutrition and/or lifestyle aspects of macular degeneration. Thank you to Blackmores for their support.

Promising research funded by Foundation grows new retinal cells

Funded by the Macular Disease Foundation Australia's Research Grant Program, a study led by Associate Professor Damien Harkin of Queensland University of Technology and the Queensland Eye Institute is developing a technology that will enable sheets of a type of healthy retinal cell to be implanted in the eye and integrate more successfully with the blood supply that lies underneath the retina. These cells, known as RPE cells, can be created from stem cells and are critical to the function of the retina. The implanted RPE cells replace RPE cells that are damaged or killed during the progression of macular degeneration. Dr Harkin's team has successfully created a three-dimensional scaffold from collagen and silk protein, and grown the required cells within the scaffold. This recreates a similar structure to that found within a healthy retina.

Due to the success of the program, Dr Harkin is hoping to commence clinical (human) trials earlier than planned and

has now received an additional \$519,000 NHMRC grant on the strength of the results achieved to date with Foundation funding.

Thank you to all those who have supported the Research Grants Program, your donations support the Foundation's commitment to investment in research.



CEO Julie Heraghty with Associate Professor Damien Harkin

Awareness

Macular Degeneration Awareness Week a great success!

Governors get an eye test and macula check

This year's Macular Degeneration Awareness Week (24-30 May 2015) went back to basics with the theme *How's your macula?* encouraging all Australians to get an eye test and macula check.

Thank you to the following State Governors for being *Custodians of Vision* during Macular Degeneration Awareness Week.

- The Hon. David Hurley AC DSC (Ret'd) (NSW)
- The Hon. Hieu Van Le AO (SA)
- The Hon. Kate Warner AM (TAS)
- The Hon. Alex Chernov AC QC (VIC)
- The Hon. Kerry Sanderson AO (WA)

Thank you to our dedicated ophthalmologists who tested the Governors' eyes and were Foundation ambassadors for the week:

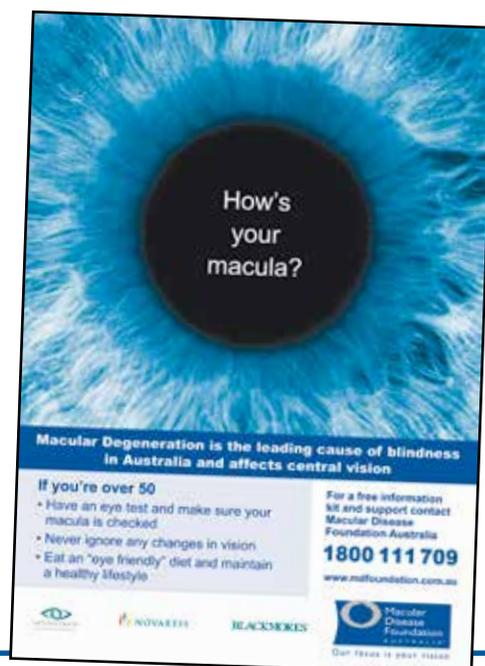
- Associate Professor Alex P Hunyor (NSW)
- Dr Grant Raymond (SA)
- Dr Jim Runciman (SA)
- Associate Professor Nitin Verma AM (TAS)
- Associate Professor Wilson Heriot (VIC)
- Associate Professor Dimitri Yellachich (WA)

Thank you to our Patron Ita Buttrose AO OBE for her ongoing support and tireless efforts to raise awareness of macular degeneration.

How's your macula?

A recent Galaxy survey commissioned by the Foundation found that almost half (47%) of Australians ranked loss of sight as their number one health concern, ahead of loss of memory (37%), loss of limb (7%) and loss of hearing (4%).

Despite this, and the high awareness levels of macular degeneration, one in four Australians over 50 still had not had their eyes tested and macula checked in the last two years.



Thank you to Blackmores, Novartis and Optometry Australia for supporting Macular Degeneration Awareness Week

BLACKMORES

NOVARTIS
PHARMACEUTICALS

Optometry
AUSTRALIA

Macula Menu

Thank you to all those who have sent in their eye-friendly recipes for our Macula Menu collection. Recipes will soon be showcased on the Foundation's website.

Enclosed with this newsletter is a delicious eye-friendly recipe submitted by Fusae from NSW.



Awareness

Dennis 'The Fisherman' shares his story of early detection



When fisherman Dennis Sutton started to see the horizon as a huge wave rather than a straight line, he didn't take his symptoms seriously. "I thought it would right itself," he said.

However, after seeing a Foundation advert in the local paper, he called the Foundation's Helpline. Despite Dennis' protests that it was a great day for mullet

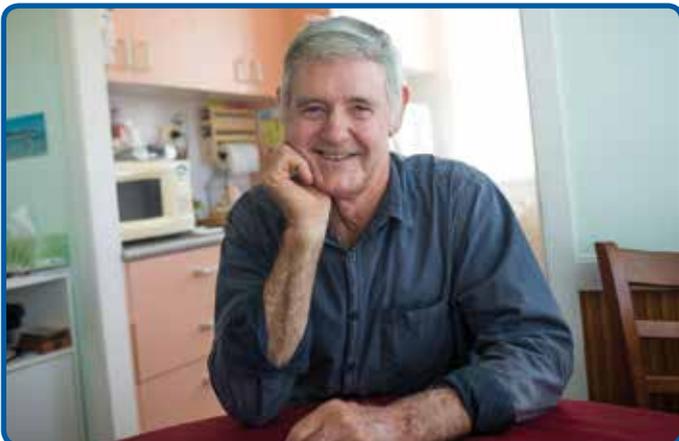
fishing, he was eventually persuaded by CEO Julie Heraghty that he needed to seek professional help urgently. "Julie told me, 'you've got to see an optometrist immediately' and she made the appointment for me," said Dennis.

Later the same day Dennis was diagnosed with wet macular degeneration in his right eye and received his first injection. Only recently did his ophthalmologist tell him just how lucky he was. "I'd have been blind in that eye if I hadn't seen him when I did," he said.

Thanks to this quick action and regular treatment, Dennis currently has perfect vision in his right eye, although he's been warned to watch for sudden changes in his left eye, again due to wet macular degeneration.

When Dennis was asked whether he had a message he'd like to pass on to other people at risk of macular degeneration, he had no hesitation. "Go and get your eyes checked. It's easy," he said.

Thank you to Dennis and all our Friends of the Foundation who shared their personal stories as part of Macular Degeneration Awareness Week.



Dennis Sutton acted quickly on noticing changes in his vision



Dennis and his wife Joy at home

Living Well

My Aged Care gateway

The Commonwealth Home Support Program will begin on 1 July 2015, and with this the My Aged Care gateway will formally open.

The Government's My Aged Care gateway is designed to help you access information about aged care, facilitate assessment for services, and provide easy access to a broad range of aged care service providers. It is only natural that growing older may mean there are times when you find day-to-day activities difficult and you, or someone you are caring for, need assistance. The Foundation is hopeful that My Aged Care will provide easy, streamlined services to people who need it.

Given that the Foundation has advocated strongly on behalf of those with vision loss to have appropriate information, advice and assessment through My Aged Care, we are very interested to receive your feedback on your experience with this new Government service. We can then use this feedback to

support our advocacy activities and advise the Government appropriately.

For more information about My Aged Care visit www.myagedcare.gov.au at any time or call 1800 200 422 (8am to 8pm weekdays and 10am to 2pm Saturdays).



Meet the Foundation's new ambassador - Mac de Gen!

Mac de Gen is the star of a new series of short animations about macular degeneration. These fun and informative videos are now available on the Foundation's website www.mdfoundation.com.au

Titles in the video series include:

- Risk factors for macular degeneration
- Reducing your risk of macular degeneration
- Eye testing for macular degeneration
- The Amsler grid
- Symptoms and early detection for macular degeneration
- Treatment for macular degeneration
- Living with low vision



Staying in control

Being diagnosed with any disease can be overwhelming and a source of concern and stress, especially in terms of any ongoing treatment and the burden of the disease on your own health, your partner and family. There are several key actions you can take when diagnosed with a macular disease which can help to keep you feeling in control.

Knowledge

In the first instance, it is important to understand your diagnosis and ask questions of your optometrist or ophthalmologist. Understanding can take time and no one has all their questions answered in the first visit. You can also contact the Foundation's Helpline to help understanding and to build knowledge.

It is normal to have to ask the same question over several visits. Having a family member or friend with you during consultations can help in becoming more knowledgeable, confident and reassured on the critical information you need.

Communication

Communication with your optometrist and/or ophthalmologist is paramount. Think about the questions and concerns you have prior to the consultation and if possible have them in written form ready to discuss. Flag right at the beginning of the consultation that you have some questions you need answered.

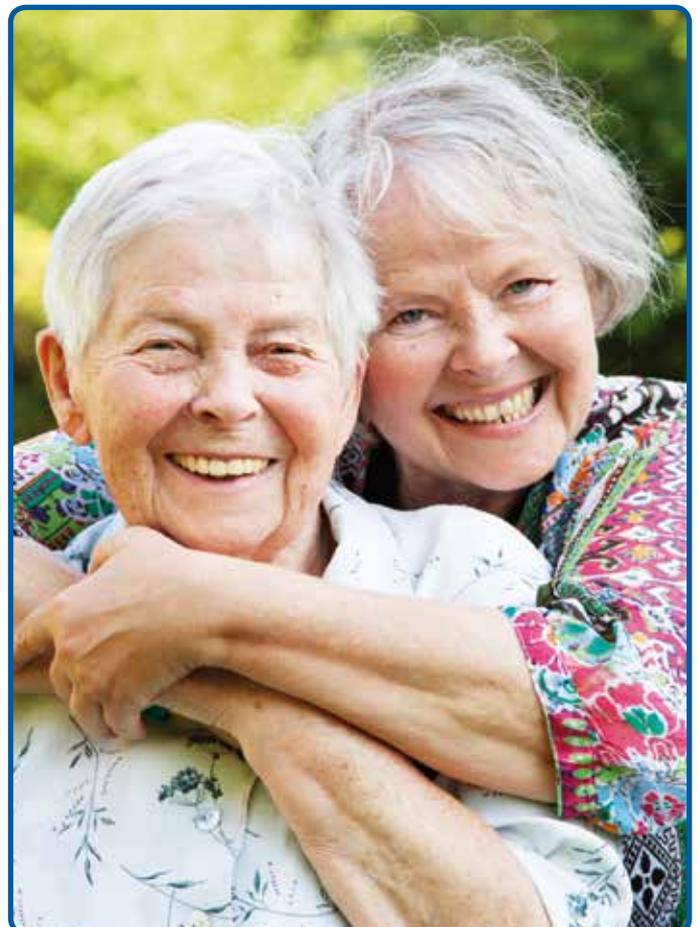
Understanding

It is important to recognise that emotional changes may occur for those with the possibility of vision loss or where vision loss has occurred. There can be concerns and fears about the future and how it will impact

independence and quality of life. Feelings of anger, anxiety and possible depression can occur. Support through health care professionals such as your GP, psychologists, counsellors and low vision specialists will make this journey easier.

The keys to success

- Acknowledge what is being experienced and seek skilled help to meet the challenges
- Maintain a positive attitude
- Explore and use new skills to support independence and quality of life
- Call the Foundation's Helpline on 1800 111 709 for information, guidance and support.



Fundraising

Thank you - end of financial year donations

The Foundation is so grateful to all who choose to donate towards our programs and Research Grants Program. For those wishing to make an end of financial year donation, please use the enclosed reply paid envelope. Alternatively you can donate securely on the Foundation website www.mdfoundation.com.au or over the phone by calling 1800 111 709.

Without your assistance we could not provide the programs and support services available to the macular disease community.

All donations made before 30 June will be processed promptly to assist with your year end taxation matters.



Get your workplace involved in Workplace Giving Month

June is Workplace Giving Month. You, or your family, can support the Foundation's sight saving work by signing up for workplace giving and making pre-tax contributions from your pay. There is no minimum amount to give and every dollar makes a difference.

Call the Foundation on 1800 111 709 to find out more about how to donate via workplace giving.

Diabetic Eye Disease Newsletter Now Available!

The Foundation is now producing a quarterly newsletter focused on diabetic eye disease. **Everyone with diabetes is at risk of diabetic eye disease.**

To subscribe to this FREE newsletter phone 1800 111 709.

A free publication on Diabetic Eye Disease is also available.

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 direct debit.

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

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DISCLAIMER: This newsletter is produced by Macular Disease Foundation Australia.

It is intended as a newsletter and its contents do not constitute medical advice and should not be relied on as such. June 2015