

## Dear Friends



Our dear Patron Ita Buttrose and Ambassador Jean Kittson cut our 15th birthday cake on your behalf at the Foundation's office in May. Thank you to everyone who

has supported our organisation – board directors, health care professionals, volunteers, donors, supporters and funders. Most importantly thank you for trusting in our work and allowing us to have the honour of serving the macular disease community.

The May Federal budget announced that the funding currently provided by the Department of Health's Flexible Funds will transition to a revised program,

commencing 1 July 2016. Once open for application the Foundation will apply.

For the forthcoming Federal election, we certainly want the needs of the macular disease community to be clearly articulated to all candidates. Our key issues are related to affordability and the ongoing cost shifting to patients. Support for access to low vision aids and technologies and the prevention of disease through government funding for our awareness and education programs are also key issues. Please support our campaign as outlined on pages 2-3.

Take care.

**Julie Heraghty**  
Chief Executive Officer

## Celebrating 15 years of serving the macular disease community

*"I have personally experienced the difference the Foundation makes by providing information and support to people, like my mum, who are living with macular disease, and their carers, like my dad, and their family members, like me. Congratulations on 15 brilliant years of supporting the Australian community, here's to many more!"*

**Jean Kittson**



*"I have been Patron of Macular Disease Foundation Australia since 2005. I'm proud of the results we have achieved in prevention and becoming a world leader in raising awareness of macular degeneration. Congratulations to the Foundation for their ongoing work to save sight and on reaching this 15th year milestone." Ita Buttrose*

## Help us celebrate by donating to the Foundation

Your generous end of financial year donations are greatly appreciated.  
All donations made before 30 June will be processed promptly.

# Representation

## Federal election 2016

The Federal election is now upon us and this provides an opportunity for our issues to be aired and our voice to be heard. Macular Disease Foundation Australia is calling on all candidates and political parties to endorse the following:

### 1. Establishment of an equitable, national, federally funded low vision equipment program to ensure the affordability and accessibility of low vision aids, equipment and technologies for people with vision loss or blindness.

This must include all those under 65 with vision loss who fall outside the National Disability Insurance Scheme (NDIS), and those diagnosed after the age of 65.

For ten years, successive governments and relevant ministers have promised to address this need. Unfortunately, the NDIS and aged care reforms and state systems have failed to provide a fair and equitable mechanism to support the equipment needs of many with vision loss. We cannot afford any more delays. The cost of such a program will be minimal in comparison to the enormous benefits in independence, productivity and quality of life for people with vision loss.



### 2. Supporting affordability of health care for the macular disease community. Shifting of costs onto the patient can result in poor outcomes and, at worst, failure to continue treatment, risking irreversible vision loss. Affordability and access to health care requires:

- Ensuring patients in need have access to affordable care by GPs, ophthalmologists, optometrists and other allied health care professionals
- Lifting the freeze on Medicare benefits for evidence-based procedures. The ongoing freeze on benefits only increases the likelihood of higher out-of-pocket costs
- Amending the Private Health Insurance Act to enable private health insurance rebates for in-rooms treatment of age-related macular degeneration, diabetic retinopathy and retinal vein occlusion
- Providing Medicare reimbursement for OCT scans which are now internationally recognised as standard of care for the diagnosis and management of a range of macular diseases

### 3. Funding Macular Disease Foundation Australia to continue our national awareness, education and support services to promote macular disease prevention, early detection and when required, early treatment or low vision rehabilitation.

## What will the Foundation do?

The Foundation will write to every MP and candidate in every electorate in Australia. All responses will be published on the Foundation website [www.mdfoundation.com.au](http://www.mdfoundation.com.au)

# Representation

## What can you do to help?

The Foundation has provided 2 copies of a *letter to candidates* with our key election concerns for you to send to chosen candidates. More pro forma letters are available for your use by calling the Foundation on 1800 111 709 or by downloading from the website.

**If you require more information on the campaign please contact the Foundation on 1800 111 709 or visit the website [www.mdfoundation.com.au](http://www.mdfoundation.com.au)**

## Letter to candidates: 3 simple steps

1. Complete the section:  
Name and address of candidate
2. Write your contact details in the space provided
3. Stamp and post the letter to your local Federal candidates.

**NOTE:** You have the option of including your name and address for a response or leaving this blank and just sending the form.

## Telephone voting

A voter who is vision impaired or blind will be able to cast a confidential vote for the Federal election by telephone, from any location.

### WHAT TO DO?

#### REGISTRATION

- You must first register to cast your vote by telephone
- Registration will be available from **Monday 13 June 2016** by calling the Australian Electoral Commission
- When you call to register, you will be asked questions to enable a check of the electoral roll and will also be asked to choose a PIN
- Once registered, you will be sent a registration number by email, SMS, postal mail, or through a phone call

#### VOTING

- Telephone voting will be available from **Tuesday 14 June 2016**
- You do not need to give your name when voting
- Your registration number and PIN will be used to mark your name off the electoral roll

**For more information, contact the Australian Electoral Commission on 13 23 26.**

## Advocacy update

The Foundation has made representations on your behalf on the following:

- **Development of the National Meal Guidelines**, by Meals on Wheels Australia
- **NDIS Information, Linkages and Capacity Building (ILC)**, by the National Disability Insurance Agency
- **The inquiry into chronic disease prevention and management in primary health care.** This is a critical review which will investigate options to provide better care for people with complex and chronic illness. Macular diseases are complex and most are chronic. In addition, many people in the macular disease community have multiple health conditions

# Awareness

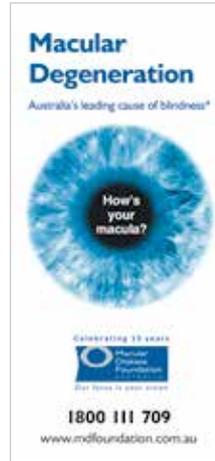
## Outstanding results for Macular Degeneration Awareness Week

### Thank you to supporters: Bayer, Blackmores and Optometry Australia

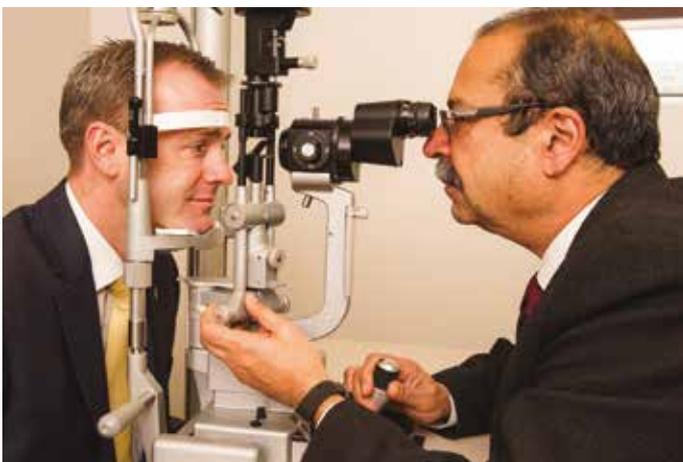
Macular Degeneration Awareness Week was held 22-28 May and achieved great results in reaching the Australian public and reminding everyone over 50 to have an eye test and macula check.

Federal Health Minister Sussan Ley and State Ministers supported the week and were quoted in media coverage. The Foundation also worked to inform non-English speaking groups, encouraging them to contact the Foundation for translated information about macular degeneration.

Special thanks to all our media spokespeople including Ita Buttrose, Jean Kittson, Associate Professor Alex Hunyor, Associate Professor Nitin Verma, Dr David Hilford, Mel Byrnes, Imelda Lynch, Margaret Raynor, Lorna Rickert.



Mel shared his story about living with macular degeneration



The Hon. Michael Ferguson, Tasmanian Minister for Health, had an eye test and macula check, conducted by Associate Professor Nitin Verma



Foundation Patron Ita Buttrose and Ambassador Jean Kittson reminded all baby boomers to have an eye test and macula check

# Awareness

## SA Governor joins the Foundation as a Custodian of Vision

Governor of South Australia the Honourable Hieu Van Le has agreed to be a 'Custodian of Vision' for Macular Disease Foundation Australia.

This follows Macular Degeneration Awareness Week 2015 when

His Excellency had an eye test and macula check and reminded South Australians over 50 to do the same. He joins the Governors for Victoria, Tasmania and Western Australia who became State Patrons for the Foundation in 2015.



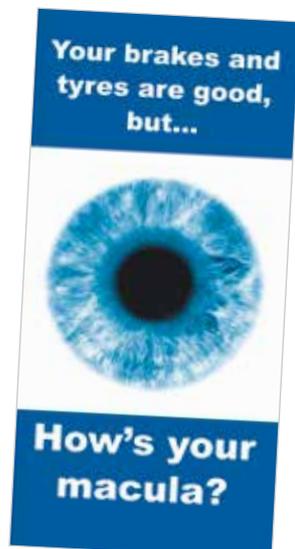
The Governor, Dr Raymond and Julie Heraghty



His Excellency, Governor of South Australia had an eye test and macula check

## Keep on driving safely

The Foundation has been successful in expanding the Keep on Driving Safely project to South Australia and Western Australia. The initiative, in collaboration with the SA and WA State Governments, includes a macular disease flyer inserted in driver licence renewals. The program continues in ACT. The Foundation thanks Lotterywest for supporting the program in WA.



## Low Vision Advisory Service – Sydney

Macular Disease Foundation Australia offers a free low vision advisory service in the Sydney CBD office. This service involves an orthoptist working closely with clients to assess individual needs and determine which aids and technologies can help to best maintain independence and quality of life. This free service is offered by the Foundation in collaboration with Guide Dogs NSW/ACT.

**Bookings are essential.**  
**Call the Foundation on 1800 111 709**

## Book club

The Foundation was recently visited by Vision Australia representatives who provided an update on their library service and the updated DAISY player. Many of you may be using (or have used) the original DAISY player which plays CDs.

DAISY (Digital Accessible Information System) players are a simple and common audio device. Vision Australia now has updated DAISY players that no longer use CDs. They have their own inbuilt technology so that audio books can be automatically sent to the DAISY player based on your reading preferences. Alternatively, you can make your own book selections on the library's online catalogue.

The DAISY player is simple to use and ideal for those with low vision and the elderly. It is designed to be easy to use to access books, newspapers and magazines.

The added benefit of the updated DAISY player is that it allows for accurate and easy bookmarking, so you can return to the correct passage in your book at any time. The players are designed to be used in a set location, so are best used at home.



The DAISY player

There are 2 types of DAISY players available for rent from the Vision Australia library:

- **3G player:** For those **without an internet connection**. The player delivers audio-content directly to the player via the OPTUS 3G telecommunications network. (Cost: \$12/month or \$136/year)
- **Wi-Fi Online player:** For those **with their own Wi-Fi internet connection**. The player delivers the audio-content directly to the player via a Wi-Fi internet connection. (Cost: \$9/month or \$99/year)

## Vision Australia's library service

The service provides the DAISY player and content for people with a print disability anywhere in Australia. It offers over 34,000 free DAISY titles, over 50 magazines and 350 newspapers.

**Contact Vision Australia library services on 1300 654 656 or email: [library@visionaustralia.org](mailto:library@visionaustralia.org)**

## Book review with CEO Julie Heraghty

Sometimes it is just a pleasure to re-read some of the old time classics, some I have not read since school days. While great movies are made of great classics, the written word can never be replaced.

Here are just a few of my favourites you may want to also revisit through your library service in audio or print. *Pride and Prejudice*, *To Kill a Mockingbird*, *Jane Eyre*, *The Great Gatsby*, *Emma* and that old favourite *Catcher in the Rye*.

# Awareness

## Mel's story

Retired pharmacist Mel Byrnes was diagnosed with wet macular degeneration in 2007. Thanks to sight saving treatment he can still read and drive and continued to work part-time up until a few years ago.

Mel is acutely aware that if he hadn't known the symptoms of macular degeneration and didn't have an Amsler grid at home, he could be telling a different story.

"I woke one morning and noticed a black spot had appeared in my vision overnight," he said. "I immediately checked my eyes with an Amsler grid and saw wavy lines and blurriness. By the next day I'd been referred to a retinal specialist and received an injection in my right eye. I've been having injections ever since."

"The injections have saved my sight. In my right eye, the vision hasn't got any worse. Problems in my left eye were picked up before I had any symptoms and as a result I still having 20/20 vision in that eye. I can still drive, I can still read, I can still do whatever I want to do."

"I've been married for 55 years. Unfortunately, in the past two years, my wife Robyn has developed frontotemporal dementia. If my eye sight wasn't what it is today, I couldn't do what I need to do for her."



Mel & Robyn on their 50th wedding anniversary



Mel and his wife, Robyn

Looking back, Mel says he realises his father probably had macular degeneration.

"Since my diagnosis my two brothers have also been diagnosed with the same problem so there is a family correlation," he said. "If you have macular degeneration, I can only stress the importance of making sure your family is aware of their increased risk."

**A short video of Mel is available on the Foundation's website.**

**Thank you to Mel, and all those who shared their story during Macular Degeneration Awareness Week.**



Mel working in the pharmacy

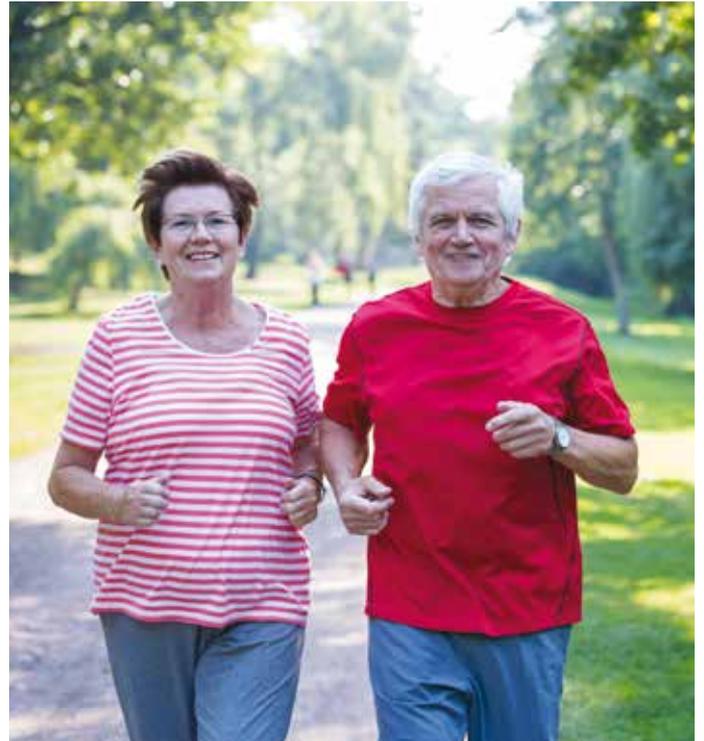
# Fundraising

## Running to see

Are you, or your family members, planning to participate in one of the many running events coming up around Australia? Why not put all that training towards a good cause and raise funds for Macular Disease Foundation Australia. Call 1800 111 709 to find out more.

### Upcoming running events around Australia

- **Sydney, Melbourne, Adelaide, Brisbane** - Stadium Stomp, June/July
- **Perth** – Swan River Run, 24 July
- **Sydney** – City2Surf, 14 August
- **Canberra** – Canberra Times Fun Run, 4 September
- **Melbourne** – City2Sea, 20 November



## Upcoming macular degeneration seminars Queensland

Hervey Bay Seminar  
Tuesday 16 August 2016  
1.00pm – 3.00pm

Masonic Hall,  
37 Watson Street  
Pialba, Hervey Bay

Bundaberg Seminar  
Thursday 18 August 2016  
1.00pm – 3.00pm

Brothers Sports Club  
130 Takalvan Street  
Bundaberg

**RSVP ESSENTIAL – CALL 1800 111 709**



## 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](http://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.

## Contact us

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**Helpline 1800 111 709**

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