

Dear Friends



Thank you to everyone who responded to our call and sent our key policy letter to their local candidate(s) in the lead up to the Federal Election.

Your support is greatly appreciated and is critical in highlighting to politicians and policy makers key issues which affect the macular disease community.

With the 45th Parliament decided, there is hopefully a genuine desire by all those re-elected and newly elected to support good policy and laws in the areas of health, ageing and disabilities. The macular disease community is depending on it.

The Foundation will be vigilant in making our position on key issues, especially those highlighted in the pre-election campaign, known to all in both Houses of Parliament.

Key issues include the establishment of an equitable, national, federally funded low vision equipment program; affordability of health care for the macular disease community; and funding for Macular Disease Foundation Australia programs in preventive health and chronic disease support.

One major concern is the gradual shifting of health costs onto the consumer, making health care unaffordable for some people, with the resulting emotional and social impacts on families and carers.

Governments investing in prevention, early detection and access and affordability of treatment and rehabilitation will always, in the long term, create savings. Our job as a

Foundation is to present this argument as clearly and strongly as possible in support of our macular disease community.

On a separate note, feedback received from our newsletter readers to the Foundation's Treatment Cost Survey, undertaken in 2015, highlighted the need for information on costs and rebates for eye injections. As a result we have developed a new publication that will assist those having eye injections understand the information on their ophthalmologist's bill. Read more about this new publication and how to order a copy on page 2.

Thank you for the generous end of year donations in June. Once again your support enables us to continue our work on your behalf.

Julie Heraghty
Chief Executive Officer

Annual General Meeting

Date: Tuesday 6 December 2016

Time: 12.00pm - 12.45pm

Location:

Macular Disease Foundation Australia
Suite 902, Level 9, 447 Kent Street,
Sydney

Following the AGM the annual Christmas celebration will be held until 2.00pm

RSVP: 25 November 2016 on
1800 111 709
(RSVP essential for catering purposes)

We hope you are able to join us.

New publication

Eye injection treatment costs and rebates

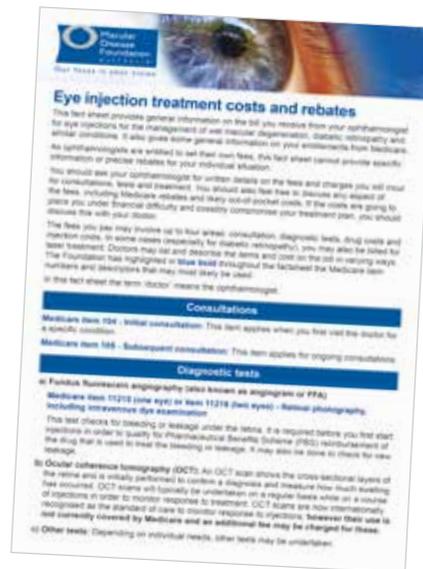
Feedback received from the Foundation's Treatment Cost Survey undertaken in 2015 highlighted a number of areas of concern. The Foundation has been using this valuable feedback to further support our advocacy efforts on a range of issues.

The survey also highlighted the need for information on costs and rebates for eye injections. As a result, the Foundation has developed a new publication to address this need.

The publication has been produced with the guidance of our Medical Committee to help those having eye injections (for wet macular degeneration, diabetic retinopathy and similar conditions) understand the information on the ophthalmologist's bill, including the various Medicare item numbers and their rebates as well as other entitlements such as the Medicare Safety Net.

A number of cost examples are also included to help illustrate the various costs and rebates.

To order a copy of the new publication call the Foundation's Helpline on 1800 111 709.



mEYE World Photographic Competition 2016

The sixth annual mEYE World Photographic Competition kicks off this month and promises to be yet another great awareness raising activity for the Foundation.

There are four categories for entry including one exclusively for the macular disease community.

In previous years we have received some wonderful entries from those with low vision.

We hope that all newsletter recipients will enter and in doing so, help raise awareness of macular disease.

For further details on the competition and to find out how to enter visit www.mdfoundation.com.au



Di Lymbury - Macular Disease Community Category Winner 2015

Representation

Marrakesh Treaty comes into effect

The Marrakesh Treaty, due to come into force on 30 September 2016, is an international agreement which will increase access to books, magazines and other printed materials for an estimated 285 million people with print disabilities.

This includes Australians with vision loss having greater access to books published in accessible formats such as large print,

Braille and audio. This greater access is due to the Treaty providing exception to copyright protection, and the ability to exchange accessible material across international borders.

For more information on the Marrakesh Treaty, visit the Foundation's website www.mdffoundation.com.au

Federal Department of Health

The Foundation recently met with Federal Department of Health officials to discuss issues with the aged care system. This included difficulties accessing funded low vision aids in the Commonwealth Home Support Programme (CHSP) and improving access and affordability of low vision support services in other parts of the aged care system. The Department is supportive in working through issues raised for those with low vision and

blindness, including when registering with My Aged Care gateway and will continue to work with the Foundation to resolve these issues.

If you have had difficulties accessing support through My Aged Care gateway in relation to low vision support we would like to hear from you. Please call us on 1800 111 709.

Increase in NSW Taxi Subsidy

From 1 July 2016, the NSW Taxi Transport Subsidy Scheme (TTSS) maximum subsidy for those with a disability increased from \$30 per trip to \$60 per trip. Transport for NSW's website states that the new \$60 docket books have been mailed to existing TTSS customers. You can find out more information on the NSW Taxi Transport Subsidy Scheme at:

TTSS Helpline: 1800 200 592

Email: ttss@transport.nsw.gov.au

Website:

transport.nsw.gov.au/customers/taxis/ttss



Representation

Your consumer rights: a guide for consumers with disability

The Australian Competition and Consumer Commission (ACCC) has published a consumer rights guide for people with disability.

The publication, “Your consumer rights: a guide for consumers with disability”, provides advice on people’s rights under the law when they make disability-related goods and services purchases.

The guide explains how to be a smart shopper, key issues when signing a contract/service agreement, and steps that can be taken to resolve problems with a good and/or service. It also provides letter templates. The Foundation provided feedback to the ACCC on the guide related to information on low vision.



A copy of the guide can be downloaded from www.mdffoundation.com.au, alternatively a print out can be requested by calling 1800 111 709.

Advocacy update

The role of a dynamic government is one of constant review and evaluation to ensure that the best possible, and most efficient, services are delivered to the community. An important aspect of the Foundation’s work is to help support and inform these ongoing improvements in Government services. Most particularly our focus is across the areas of health, ageing and disabilities.

The Foundation’s most recent representations to Commonwealth Government agencies have been:

- **Consultation on Increasing Choice in Home Care – Stage 1 reforms:** Changes to home care in the aged care system will allow greater ability for consumers to choose and change their home care provider.
- **Development of the National Strategic Framework for Chronic Conditions:** The Framework is being developed to

provide a national approach to guide planning, design and delivery of policies, strategies, actions and services to reduce the impact of chronic conditions in Australia.

- **Development of Short Term Restorative Care Programme Manual:** This new Programme is aimed at providing flexible packages of aged care services that are designed and approved by the consumer, and may be delivered in a home or residential setting, or a combination of both.
- **Productivity Commission Inquiry into Human Services – Identifying sectors for reform:** This Inquiry aims to identify sectors within human services that need reform, focusing on increasing competition, contestability and informed consumer choice.

Research

Research Grants Program - new research into carer support

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 entitled "The Ripple Effect of Vision Loss" conducted by the Foundation in 2013. This 2013 study involved surveying Foundation clients with age-related macular degeneration and their carers.

The 2013 study highlighted the dedication, unconditional love and support of carers looking after someone with wet age-related macular degeneration. However it also revealed some of the challenges including assisting with everyday tasks like cooking, getting dressed and doing the finances. In addition it was found that 7% of people

who care for someone with wet age-related macular degeneration report experiencing depression – more than triple the incidence seen in the general population over 65 years of age. Carers also reported feeling frustrated (38%), sad (28%) or down (25%).

The aim of the new research project now being funded is to enhance the health and wellbeing of family carers of people with age-related macular degeneration by improving the design and delivery of existing support services and programs.

The project, totalling \$440,000, is being co-funded by Macular Disease Foundation Australia and a National Health and Medical Research Council partnership grant. Carers NSW will also provide in-kind support.

The Foundation is proud to be supporting this new research which we hope will improve quality of life for those who care for a person with age-related macular degeneration.

Donate to research

Macular Disease Foundation Australia is now a leading source of funding for macular degeneration research in Australia. To date, the Foundation has committed almost \$3 million to fund Australian researchers.

Your generous donations support the Foundation's commitment to its Research Grants Program.

Donate today using the enclosed form and reply paid envelope, by calling 1800 111 709, or online at www.mdfoundation.com.au



Living Well

Embracing low vision aids - Shirley's story

A small investment in low vision aids has helped 85-year-old Shirley continue to be independent and participate in activities she has always enjoyed.

Shirley was really struggling with loss of sight and missed reading, especially the Sydney Morning Herald which she enjoyed every day with her beloved cat on her knee catching up on local and international news.

Shirley attended the free Low Vision Advisory Service at the Foundation's Sydney office and was provided with aids to assist with magnification and in-home lighting.

However a few months later, Shirley unfortunately had deteriorating vision and felt that there was not a lot she could do. "I couldn't get out easily, I couldn't read and I couldn't even watch television because the remote control became too difficult to use," she said.

The Foundation contacted Vision Australia to arrange for Shirley to access their DAISY player audio-book program. In no time at all Shirley had her new DAISY player and a large print out of the controls which makes it very easy to use. She was also provided with a helpline number for any difficulties or to access more books.

"On the first day I had my DAISY player, I listened to the Herald and then I started to listen to a book. I didn't move all day and the only complaint came from my cat that wasn't getting the usual attention," stated Shirley.

"Vision Australia also provided advice about small changes I can make to my home that will help me, including a large button remote control so that I can get back to watching television."

Shirley paid \$160 for her new magnifier and pays \$9 each month for her DAISY wi-fi online player. This small investment in aids and technology is giving a massive return to quality of life, keeping her engaged and independent. This is simple technology that anyone can use to connect with the world.



The DAISY player

Please ring the Foundation if you need help to connect with the world. There are always solutions to problems, you only need to ask!

Our last newsletter included details on Vision Australia's DAISY player service. If you missed this information, and Shirley's story has inspired you to find out more, please contact the Foundation on 1800 111 709 or visit www.mdffoundation.com.au

Living Well

Community lounge rooms

“What’s a community lounge room?” you ask. It’s a great description of how local libraries are becoming more than just a place to borrow books. Libraries are now community hubs where you can get involved in a raft of different social activities.

Your library might offer book clubs, movie screenings, author talks, knitting clubs, scrabble clubs, education talks, and even day trips.

It’s a great way to meet others, enjoy a hobby, and learn something new. More often than not, library activities are free.

Libraries are also well set up to assist those with low vision continue to enjoy books. Many popular new releases come out in audio books at the same time as printed copies, which makes activities like book clubs open to all.

Call your local library and find out what’s on offer in your area and take advantage of your “community lounge room”.



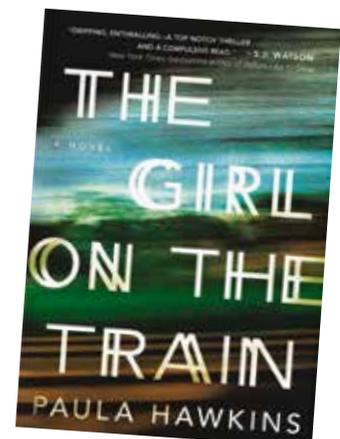
If you love reading why not join a book club at your local library. It’s a great way to meet people and socialise over a stimulating conversation about a book.

We want to hear from you!

Are you a member of a local book club? Do you listen to audio books? If so, we’re keen to share your story in the next newsletter. Please call the Foundation and let us know your story on 1800 111 709.

Book Review with CEO Julie Heraghty

The Girl on the Train (2015) is a psychological thriller novel by British author Paula Hawkins. It may not be everyone’s cup of tea but I did enjoy the way the author constructed the story and led you to a thrilling ending. Rachel takes the same commuter train every morning and night and stops at the signal that allows her to daily watch the same couple breakfasting on their deck. And then she sees something shocking. It’s only a minute until the train moves on, but it’s enough. Now everything has changed.



Fundraising

What a great idea

90 year old Tim, from Sydney, asked friends and family to donate to the Foundation in lieu of gifts for his 90th birthday. Their generosity raised over \$2,000. Thank you to everyone who donated and happy 90th birthday Tim!

Grazie Brisbane

The annual Festival of St Pantaleone Luncheon, a fixture in the Brisbane Italian community each July, raised over \$2,000 for the Foundation. Thanks to committee members David Cavallo, Sandro Cavallo, Paul De Luca, Paul Antonelli and all who attended.

Go the West!

Well done to Shane and Haylee Moyle whose successful WA trivia night raised over \$6,000 for the Foundation.

Upcoming events open for your support:

National: Great Southern Crossing virtual cycling challenge (Sept), **Sydney:** Blackmores Sydney Running Festival (18 Sept), **Adelaide:** City-Bay Fun Run (18 Sept), **NSW Southern Highlands:** Bowral Classic (23 Oct), **Noosa:** Noosa Triathlon Multi-Sport Festival (26 Oct), **Hobart:** Point to Pinnacle (13 Nov), **Melbourne:** City2Sea (20 Nov)

Call the Foundation to discuss your fundraising idea on 1800 111 709.

Macular degeneration education seminars NSW

North Shore (Sydney) Seminar and Low Vision Display

Tuesday, 18 October 2016
10.00am – 12.30pm

North Sydney Leagues Club
12 Abbott Street, Cammeray

Port Macquarie Seminar and Low Vision Display

Monday, 7 November 2016
10.00am – 12.30pm

Panthers Port Macquarie
1 Bay Street, Port Macquarie



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.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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