

Dear Friends



Easter occurs early this year so whether you receive this edition before or after Easter, I hope it is a restful and special time for you and your family.

This year is an exciting one for the Foundation. It is hard to believe but we are celebrating 15 years in 2016. We have grown rapidly to meet the needs of our macular disease community, to make a real difference to people of all ages. We are inspired by the people we speak to on a daily basis, like our eldest member who is 104! She lives in her own home and is highly independent doing her shopping and taking herself to the dentist. The wellbeing of our community underpins all the work we do and goals for which we strive. I hope that you will join us in celebrating this milestone by getting involved in some of the activities we will be running throughout the year.

The Foundation has continued to represent your interests on several levels over the last few months including in the areas of best practice guidelines, the ongoing issue of Medicare reimbursement for OCT and PBS listing of approved treatments.

I have for some time been advising you of the Federal funding gaps impacting

the Foundation, especially in regard to our national education program. While the education program funding has still not been addressed, the Foundation has been successful in its application for some funding over 3 years under the Peak Body and Advisory Bodies Programme. The grant will support some specified overheads for our role in this area. It is not applicable for education, advocacy or other Foundation services and activities. The Foundation is grateful for this grant, but requires ongoing funding to support our national education program for which the previous grant ended on 31 December 2015. We continue to consult with Government regarding this funding. We also once again submitted a detailed federal pre-budget submission and await the May budget outcomes.

I hope you enjoy Alicia's story on page 7 and the book club piece on page 4. Alicia, who lives with Stargardt's disease, inspired and educated me about accessing audio books on my iPad. I hope you will share your favourite way of reading and your favourite book with us.

Take care.

Julie Heraghty
Chief Executive Officer

The Foundation turns 15!

In 2016 we are celebrating 15 years as a charity dedicated to helping those at risk of, and living with, macular disease. Thank you for your ongoing support. We hope that you will join us in celebrating this special year.



Representation

The Foundation continues to represent the macular disease community...

Best practice care

Clinical practice guidelines are developed by the National Health and Medical Research Council to ensure health professionals are informed of best practice treatment and care options for patients. There are currently no clinical practice guidelines to manage macular degeneration. The Foundation has strongly advocated via a submission to Government for this to occur.

Commonwealth Home Care Packages Programme

The Government has proposed reforms to the Commonwealth Home Care Packages Programme which would allow clients more flexibility to choose and change their approved provider within the allocated home care package funding. If these reforms are passed they will begin February 2017. The Foundation has actively supported these reforms for improved consumer choice and made recommendations for the inclusion of specialist low vision assessments and support services.

The Government also announced plans to integrate the Commonwealth Home Care Packages Programme and the Commonwealth Home Support Programme into a single programme from July 2018 to simplify the way that services are delivered and funded. We will keep you informed.

PBS listing for approved treatments

In 2015, drugs Lucentis and Eylea were listed on the Pharmaceutical Benefits Scheme (PBS) for treatment of diabetic macular oedema (DME) and retinal vein occlusion (RVO). The Foundation supported these listings.

The Foundation is waiting for PBS listing of the drug Ozurdex to treat DME following its approval by the Therapeutic Goods Administration (TGA) for safety and efficacy.

Note: the Foundation does not endorse specific drugs. It is the role of the doctor to advise on recommended treatment in discussion with the patient.

Eye health in residential aged care facilities

Last year it was reported that the Foundation was successful in its application for a project grant funded by the Department of Social Services to improve the eye health of residents in residential aged care facilities. This two and a half year project is progressing well and has now gained ethics approval. The Foundation is now working with six aged care facilities from Estia Health, Presbyterian Aged Care and BaptistCare to assess the eye health landscape and ultimately develop resources for use in all residential aged care facilities across Australia.

Medicare reimbursement for OCT

Optical Coherence Tomography (OCT) is used to diagnose and monitor response to eye injections. The Foundation has lobbied for Medicare reimbursement for OCT for many years, with your help, to ease the financial burden of this testing required for ongoing eye injections. Recent advice has indicated possible reimbursement for only one OCT service per year, which is clearly unacceptable. We continue to represent you on this issue.

Research

Blue light and smartphones

Some recent media reports have suggested that blue light emitted by smartphones, computers and tablets may damage the retina.

The highly respected, peer-reviewed medical journal 'Eye' recently published the results of research into the level of blue light emitted by these devices. The research found that even under extreme long-term viewing conditions, none of the devices tested emitted enough blue light to suggest any cause for concern. They all produced only a small fraction of the blue light we are exposed to when we go outside.

Even though these devices do not damage the retina, if they are used regularly at or around bedtime, the emitted blue light can change the body's levels of melatonin, a chemical which can affect sleeping patterns.



It is worth noting that due to sunlight your exposure to blue light will be substantially higher when you go outside. It is therefore recommended to always use sun protection when outdoors including sunglasses (meeting Australian standards) and a hat, especially for children as they are more sensitive to blue light than adults.

*Reference: O'Hagan et al Eye 2016
Online 15 January.*

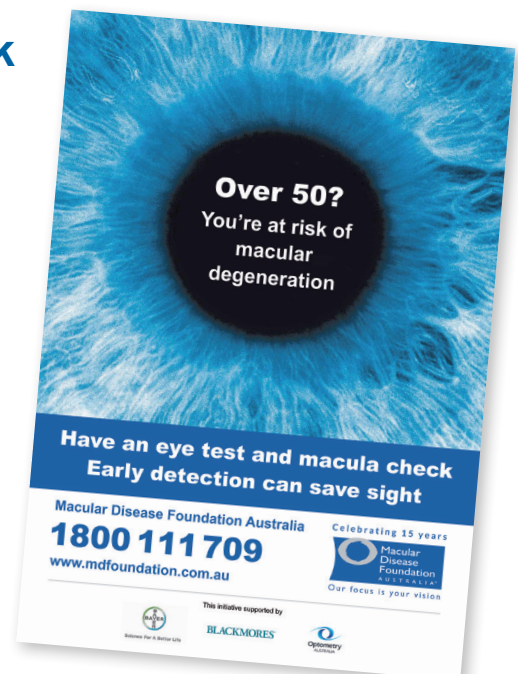
Macular Degeneration Awareness Week 22-28 May 2016

**“Over 50? You’re at risk
of macular degeneration”**

**Get involved: Spread the word to friends
and family about the importance of
“Having an eye test and macula check”**

You could save their sight

To get your community group involved
contact the Foundation on 1800 111 709



The Foundation thanks ongoing supporters of Macular Degeneration Awareness Week
Blackmores and Optometry Australia.

**Welcome to Bayer, our long-standing partner, as a new major
supporter of this important awareness activity.**

Book club with Julie Heraghty

So many people enjoy reading a book. I am not sure how you were introduced to the world of books but the teacher or parent who introduced you to the love of reading is a person that you do not forget. Does anyone recall the “Wendy, Sue, David” readers?

A cup of tea and a quiet place to immerse yourself in a good book is such a delight. However, how you read that book has changed dramatically in a very short time, due to technology. Now, whether you are sighted or whether you have vision loss you may well use the same device.

New technologies available to everybody, such as computers, smartphones, and tablets, have in-built features which can be used for many purposes. Your phone can talk to you, your computers can convert text to speech and your whole world can be stored on a very small device.

I know many people find new technology challenging. I know how you feel! But over the course of the next few newsletters we will review some of the technologies available and how you might use them to read books. One trick I have learnt is



CEO Julie Heraghty uses her tablet to access audio books

Reading a book using technology?

We would like you to share your review of the technology you used and a book you have recently read. Why does it work for you? What are the pros and cons?

Email to info@mdfoundation.com.au or post using the enclosed reply paid envelope.

to draw on children, friends and even neighbours for help!

I have an iPad and, inspired by Alicia (page 7), I decided to listen to books by downloading them through Amazon and then using an app called ‘Audible’. I purchase the books online (at a much cheaper price than hardcopy), then listen with my ear phones plugged into my iPad so as not to annoy all around me. Of course I fall asleep after a while, so I have learnt to use the in-built timer which automatically stops the book reading after a set time and bookmarks it so I can pick up where I left off. For those with an iPad, tablet or smartphone, audio books are just great.

If you don’t have one of these devices, there are many other options available. The Foundation offers the Navigator (a small handheld audio player which holds up to 5 books at a time), and other organisations such as Vision Australia, Guide Dogs, RSB, Quantum RLV and Humanware also offer alternatives. Some of these will be covered in upcoming newsletters. If you have a CD player, audio books on discs can be borrowed from many council libraries.

One book I recently enjoyed was ‘The Lake House’ by Kate Morton. See my short review over the page.

Book review

The Lake House by Kate Morton

Reviewed by: Julie Heraghty, Foundation CEO

Format: Audio format, listened via the mobile app 'Audible'

Where: Julie listened while in the car, cooking dinner and before going to bed

Cost: \$14.95



Julie's review:

I liked this book, it kept me guessing until the end. Fourteen year old Alice Edevane loves to write mysteries. Following a party held at their lake house, the Edevane family find themselves in the middle of their own mystery when their youngest son vanishes without a trace.

The case is never solved until 60 years later when Alice meets a young London detective and the mystery of her brother begins to unravel. It is an intriguing story, full of family secrets.

Australia ratifies treaty for greater availability of accessible books

Following the ratification of the Marrakesh Treaty in December 2015, Australians with vision impairment will have greater access to books and other published materials in accessible formats, such as large print, braille or audio. The treaty means copyright laws will be relaxed to allow more books to be produced in formats alternative to print.



Low Vision: A Guide now available in audio format

To order your free CD copy call the Foundation on 1800 111 709 or listen online at www.mdfoundation.com.au. The audio range now includes Low Vision: A Guide, Macular Degeneration, Nutrition and Supplements for macular degeneration, Slips, Trips and Falls: A Guide.



Taxi Transport Subsidy Schemes

Each state has a taxi subsidy scheme which allows eligible people to use taxis at a discounted rate. This service is available to people with a severe and permanent disability, who can't use public transport.

For more information or to apply for a taxi subsidy in your state contact:

- ACT Taxi Subsidy Scheme (02) 6207 1930
- Queensland Taxi Subsidy Scheme 1300 134 755
- NSW Taxi Transport Subsidy Scheme 1800 623 724
- Victorian Multi Purpose Taxi Program 1800 638 802
- Tasmanian Transport Access Scheme Taxi Subsidies 1300 135 513
- South Australian Transport Subsidy Scheme 1300 360 840
- Northern Territory Taxi Subsidy Scheme (08) 8924 7043
- WA Taxi Users' Subsidy Scheme 1300 660 147

Changes to the NSW Taxi Transport Subsidy Scheme

In December 2015, the NSW State Government announced an increase to the Taxi Transport Subsidy Scheme (TTSS). The subsidy increase will make taxis more affordable for the Foundation's clients who are legally blind. Under the scheme, people travel at half price and the government subsidises the other half of the fare, up to a cap. For people with a severe and permanent disability (including vision impairment) the TTSS cap will double from \$30 to \$60 per trip. There are eligibility requirements for the scheme.

To check if you qualify, call NSW Taxi Transport Subsidy Scheme on 1800 623 724 or visit www.transport.nsw.gov.au

WHO Report

The recent World Health Organization (WHO) report on ageing and health has noted the high prevalence and impact of macular degeneration, impact of vision loss and the role of aids and technology to maintain independence and quality of life, as well as the important role of the health system in catering for older citizens. These are the Foundation's key areas of work and recognition of their importance at an international level by WHO is highly encouraging.

“Timely diagnosis and comprehensive eye care and rehabilitation are extremely effective in reducing impairment.”

World Report on Ageing and Health, WHO 2015

Do you have diabetes?

Sign up for the Foundation's newsletter about diabetic eye disease in print, email or audio format. Call 1800 111 709.



Awareness

Inspired to Thrive: Alicia's Story

Alicia Thompson, 44, is a businesswoman, wife and mother with a love of knitting. Since the age of 19 she has lived with loss of central vision and is now legally blind having lost 95% of her sight.

Alicia has Stargardt's disease, a hereditary eye condition that affects the macula. Stargardt's disease causes the cells in the centre of the retina to die, leaving a person with only their peripheral vision.

"My brother has the same condition, although he was diagnosed much earlier, so when my vision started changing, I had an idea of what was happening," she said.

Alicia said she loves life and, with the help of technology, manages just like everyone else.

"One of my favourite things in the world is my iPhone, which has given me back a lot of the independence I thought I had lost forever. I can look up train timetables and plan trips using public transport, with my iPhone and iPad I can message people, read books, search the internet, look up recipes.

"Magnification too, has changed everything. Using my portable magnifier, I can pretty much see anything I want to. I use it to learn new settings on appliances, to read



the mail and to crochet and knit, which I really love to do.

Although fiercely independent and extraordinarily self sufficient, Alicia admits that having good people around her, both at home and in the office, makes an enormous difference to her quality and enjoyment of life.

"I may not do things the way sighted people do, but I don't let that stop me. Different doesn't mean it's wrong. And hard doesn't mean you can't. It's more about finding a different way to do it. It's something I have to do. If I still want to have a normal life and enjoy the things I do, then I have to find other ways to do them."

The Foundation captured Alicia's inspiring story in a short video which is available on the Foundation's website www.mdfoundation.com.au



Fundraising

A family affair

Given that a direct family history of macular degeneration means a 50% risk of developing the disease, it is no surprise there has been an increase in family members raising money for the Foundation in honour of their loved ones who live with vision loss. Jackie Cocks and her family from Western Australia are a great example.

Jackie, an artist living with wet macular degeneration, has set up a fundraising



'Everyday Hero' webpage to sell 'quick inspirational paintings' completed in 10 minutes. Proceeds from the sale of these artworks supports the Foundation's work.

Additionally, one of Jackie's nieces raised funds last year by completing a 1,300 km virtual relay, and another of her nieces is planning a trivia night to be held in June.

Thank you to all fundraisers and donors for your ongoing support.

This year is the Foundation's 15th year of providing ongoing information and support to the macular disease community. With your help, we will continue to build our community and provide services for years to come.

Together we will work to save the sight of our families and friends.

To discuss your fundraising ideas to celebrate the Foundation's 15th year, call 1800 111 709.

Another successful Roth Gair Golf Day!

Thank you to the Lions Clubs of Forest Hill and Park Orchards for organising the 9th Roth Gair Golf Day, held on 7 February. Approximately \$12,000 was raised on the day which will be used to produce information publications for distribution in Victoria.

The Foundation also thanks Jamie Kennedy, all sponsors including Toyo Tyres, Tyrepower Australia, OptiMed and David West from Eyecare Plus Cranbourne for doing eye tests on the day.



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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