

Dear Friends



Christmas is almost upon us and I wish you all a wonderful and safe time during the festive period. The New Year is a time to make resolutions and I cannot think of a better one than to make every day count and enjoy friends, family and loved ones.

Another year... the Foundation has been proud to work for you throughout 2013 by providing our Australia-wide education program, raising awareness and offering services to the macular disease community. This financial year the Foundation received over 14,000 calls to our Helpline, an average of 56 calls per day, and distributed 700,000 pieces of information.

It is heartening to learn that our annual evaluation of services survey, carried out on a sample of our client base, showed the Foundation's flagship services of Helpline, newsletter, education sessions, and website all achieved overwhelmingly positive ratings. We are pleased to be able to offer you these services.

We have also been relentless in our advocacy on your behalf and fighting for access to treatments and support for those with vision loss and blindness through the NDIS.

Research special... importantly we were able to support leading Australian researchers with \$600,000 to help us on the road to finding a cure for macular degeneration. This newsletter features the Foundation's special event "*Through his Eyes*" which was held at the Sydney Opera House and included the awarding of our grants to two outstanding Australian researchers.

The Foundation's annual Research Update is also included in this newsletter to bring you up-to-date on macular degeneration research worldwide. As always, none of this would be possible without your help and support and I thank you sincerely.

Have a cup of tea with your new MP...

we have had wonderful feedback from those who were able to meet with their newly elected or re-elected MP and provide the *Information Flyer* on the *Sight for Seniors* campaign, while at the same time telling their story of living with macular degeneration. If you were unable to visit please still send your federal MP the *Information Flyer*. You can phone us if you need to know your MP's name, address or need a new flyer.

The Foundation wrote to all MPs alerting them to your possible visit and one MP wrote to me saying: "As an MP, the better informed we are, the better decisions we will make. Your kind offer of information and contact is greatly appreciated and your information will be carefully considered. I will contact you if I require any assistance in any matters within your area of expertise." Change always takes time, but as you know, we will never give up.

Julie Heraghty
Chief Executive Officer



Living Well with MD

Centrelink pensions for people who are legally blind

Did you know that people who are legally blind are exempt from income and asset tests when applying for the Disability Support Pension (Blind) or the Age Pension (Blind) from Centrelink?

Centrelink has specific definitions of legal blindness and the vision assessment must be conducted or supported by an ophthalmologist. The Foundation encourages all eligible people to apply for the pension payments, as they can be substantial. (For a single person it can reach up to \$827 per fortnight.) To apply or find out more about pensions for people who are legally blind, contact Centrelink on 132 717 (Disability Support Pension) or 132 300 (Age Pension).

Centrelink payments for carers

Did you know that you are considered to be a carer if you provide unpaid personal care, support and assistance to a family member or friend who has a disability or medical condition, or who is frail or aged?

As a carer, you may be eligible for the Carer Payment, Carer Allowance and other Centrelink benefits. You may not need to live with the person you are caring for to be eligible.

The Foundation encourages all carers to contact Centrelink on 132 717 or the Carers Advisory Service on 1800 242 636 to find out if they are eligible for Centrelink benefits.

Why is registering for the Medicare Safety Net important?

The Medicare Safety Net provides an additional rebate for people who incur large expenses for Medicare items that are provided outside the hospital setting.

By registering for the Medicare Safety Net, Medicare will automatically keep a record of your total out-of-pocket costs for the calendar year which is covered under the Extended Medicare Safety Net. (Out-of-pocket expenses are the difference between the Medicare benefit and what your doctor charges you.)

This is especially important for those having injections for wet AMD and also if you have a large amount of medical bills associated with other health conditions, being doctor's visits and tests outside of the hospital setting.

Once your out-of-pocket costs for Medicare items exceed the threshold in any calendar year, Medicare will rebate you a further 80% of your out-of-pocket costs. The current threshold is approximately \$611 if you are a pensioner or concession card holder, or

\$1,222 for those without a concession card. The threshold increases slightly each year.

Note that certain procedures such as OCT scans that are not presently reimbursed through Medicare, do not count toward the threshold or the additional 80% rebate. Also, procedures performed in a hospital setting do not count towards the threshold or the 80% rebate.

Individuals should automatically be registered by Medicare for the Medicare Safety Net, but it is always wise to check. Families and couples need to register - you need to advise who is in your family, even if you are on the same Medicare card, so Medicare can track your combined medical expenses.

You only need to register once in your lifetime. To check if you are registered for the Medicare Safety Net, visit your local Medicare office or call 132 011.

If you have any further questions, please call the Foundation on 1800 111 709.

Research

AREDS2

One of the major priorities of the Foundation is to ensure the latest research is reviewed and translated into meaningful information. This is done under the guidance of the Foundation's Medical Committee. The results of one of the largest eye studies in the world, the Age-Related Eye Disease Study 2 (AREDS2) was announced at the Association for Research in Vision and Ophthalmology (ARVO) meeting in the USA in May 2013. AREDS2 followed the original AREDS study, a landmark clinical trial conducted by the National Eye Institute in the USA. The AREDS studies are the only studies for which there is good, long-term evidence for the benefits of high dose supplements for people diagnosed with age-related macular degeneration (AMD).

The original AREDS study showed that a supplement based on a specific formula of zinc and antioxidants reduced the risk of the disease progressing to the late stage (severe vision loss). For people in the intermediate stage of AMD (large drusen or many drusen) in one or both eyes, or in the late stage in one eye, the AREDS formula reduced the risk of progression of the disease by 20 to 25% and delayed vision loss. The AREDS study showed that the formula had no effect on those with no

AMD, or only very early signs of AMD (i.e. a few small drusen), or for those with advanced disease in both eyes.

The AREDS2 study recommended the continued use of the original AREDS formulation, but with beta-carotene removed, to be replaced by lutein/zeaxanthin. The AREDS2 formula (daily dose) is:

Zinc (as zinc oxide)	80 mg
Vitamin C	500 mg
Vitamin E	400 IU
Copper (as cupric oxide)	2 mg
Lutein	10 mg
Zeaxanthin	2 mg

People who have been diagnosed with AMD should consider taking a supplement based on the AREDS2 formula. However, the Foundation warns against self-prescribing supplements and advises that a doctor should always be consulted. Supplements are not a cure for macular degeneration. The AREDS study shows that taking the AREDS formula may reduce the risk of progression; it does not stop or reverse damage caused by the disease.

Research Update 2013

Enclosed is the Foundation's annual Research Update 2013 which includes an overview of many of the latest research projects being undertaken into macular degeneration that may one day provide the answers needed to eventually conquer this disease.



Research

Minister for Health Announces Grant Recipients

The Foundation was privileged to have the Hon Peter Dutton MP, Minister for Health, announce the recipients of the Macular Disease Foundation Australia Research Grants for 2013 at the Sydney Opera House on Wednesday 9 October.

The Minister awarded the grants, totalling \$600,000 over three years, on behalf of the Foundation to Associate Professor Erica Fletcher, Department of Anatomy and Neuroscience, University of Melbourne and Associate Professor Damien Harkin, School of Biomedical Sciences, Queensland University of Technology and the Queensland Eye Institute.

The event took place in the famous Utzon Room against the backdrop of the

"Through his Eyes" photo tribute to Sydney Opera House designer Jørn Utzon, who lost vision from macular degeneration in later life. The photos and a pair of Jørn Utzon's glasses were generously donated by his son, Foundation Ambassador Jan Utzon.

Foundation Ambassador Jean Kittson and her mother Elaine, who lives with macular degeneration, shared with guests the impact that the disease has had on their lives.

Julie Heraghty, Foundation CEO, highlighted the importance of funding future research through the Foundation's Research Grants Program and thanked all who have supported the efforts of the Foundation.



The Hon Peter Dutton MP with Assoc. Prof. Damien Harkin.



Julie Heraghty with Prof. Robyn Guymer (representing Assoc. Prof. Erica Fletcher) and Assoc. Prof. Damien Harkin.



Foundation volunteer Val Nicholson admires one of the tribute photos of Jørn Utzon.

Donate to the Foundation's Research Grants Program

We have a goal to have granted \$10 million to researchers by 2021.

There are several ways you can help:

- Tick the box "Foundation Research" on the enclosed donation form
- Call the Foundation if you wish to donate by telephone or donate securely online at www.mdfoundation.com.au

- Leave a bequest to support research
- Donate via direct debit, it's an easy way to support the Foundation on an ongoing basis without having to write a cheque or purchase money orders

Please call the Foundation on 1800 111 709 to donate, or for bequest, direct debit and general information on the research program.

Research

Research Grant Projects for 2013

Since 2011, the Foundation has committed over \$1.4 million through its research grants programs.

The grants support major research projects as well as fellowships and are funded by the Foundation's fundraising activities, supported by generous donations, bequests and corporate giving.

In October 2013 the Foundation marked World Sight Day by awarding a total of \$600,000 over three years to two highly regarded Australian researchers - Associate Professor Erica Fletcher and Associate Professor Damien Harkin.

Associate Professor Erica Fletcher, Department of Anatomy and Neuroscience, University of Melbourne.

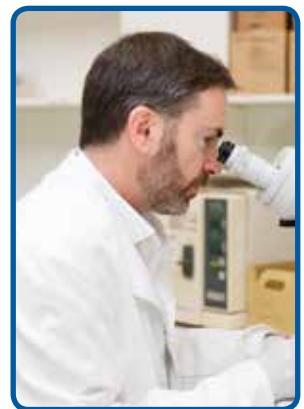
This research will examine how the removal of waste products in the eyes changes as we age and help identify those people with a high risk of disease progression. This will also be important for developing new treatments for macular degeneration.

Associate Professor Damien Harkin, School of Biomedical Sciences, Queensland University of Technology and the Queensland Eye Institute.

This research project will look at a protein extracted from silk to form a platform on which new retinal tissue can be grown, with the view to replacing the damaged tissue that eventually leads to permanent loss of sight in macular degeneration. This project may help maintain or restore vision for people living with late stage disease.



Associate Professor Erica Fletcher

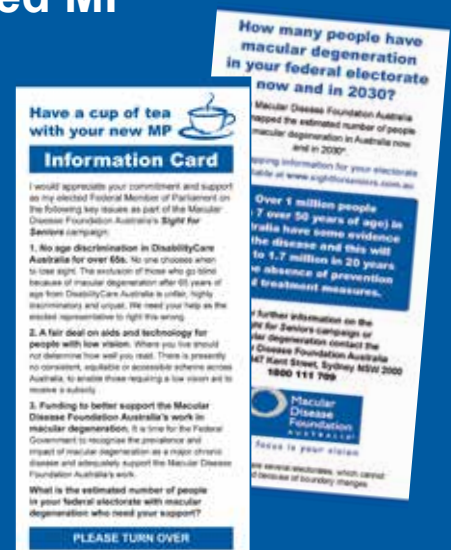


Associate Professor Damien Harkin

Have a cup of tea with your newly elected MP

Thank you to all who were able to meet with their newly elected federal MP in response to our spring newsletter. If you haven't met your MP as yet we encourage you to still do this.

We understand that not everyone will be able to meet with their local MP. If you are unable to arrange a meeting please send your MP the "Information Card" (pictured) which you received in the last newsletter. If you are uncertain of your electoral address or need another flyer please contact the Foundation.



Awareness

Celebrating World Sight Day

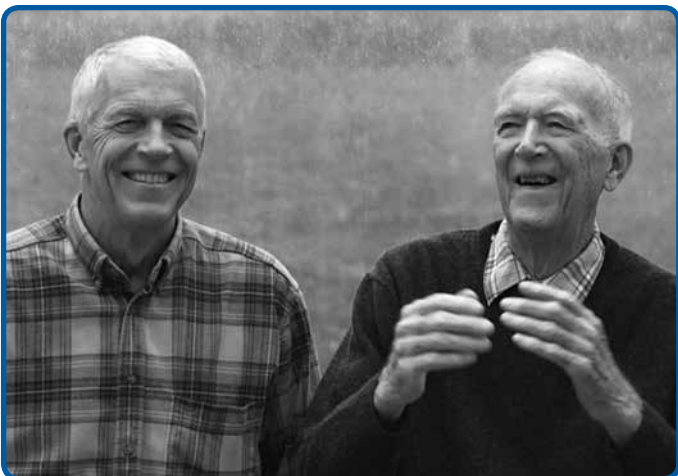
To celebrate **World Sight Day** on **10 October 2013** the Foundation engaged in wide-ranging activities supporting research and awareness into macular degeneration.

Foundation Ambassadors share their stories

As part of **World Sight Day** activities and the research grants announcement held at Australia's iconic Sydney Opera House, Foundation Ambassadors Jan Utzon and Jean Kittson highlighted the enormous impact macular degeneration has had on their parents' lives.

Renowned Sydney Opera House architect Jørn Utzon, had vision loss from age related macular degeneration in his later life.

"My father, Jørn Utzon, was a visionary man and witnessing his sight deteriorate from macular degeneration was heartbreaking. The trauma the disease inflicts is enormous and I urge society to make greater efforts in research to find a cure," said Foundation Ambassador Jan Utzon.



Foundation Ambassador Jan Utzon with his late father Jørn.

Jean Kittson's mother Elaine proudly witnessed the Sydney Opera House being built 40 years ago. Today Elaine has severe vision loss from macular degeneration and like thousands of older Australians has lost her central vision.

"Little did mum know that 40 years on she would not be able to see the world famous Sydney Opera House," said Foundation Ambassador Jean Kittson.

Over 1 million Australians show some evidence of macular degeneration and those who have a direct family history, like Ambassadors Jan and Jean, have a 50% chance of developing the disease.



Foundation Ambassador Jean Kittson with her mother Elaine.

"Research is a journey of discovery with the ultimate destination being a place where we can save sight. Through the generosity of the Australian community the Foundation is continuing to invest heavily in research to realise this important goal," said Julie Heraghty, Foundation Chief Executive Officer.

Awareness

Keep your eye on the ball

The Foundation partnered with Bowls Australia to help knock Australia's leading cause of legal blindness out of play.

The "Keep your eye on the ball" campaign, supported by Bayer Australia, was rolled out at Melbourne bowling clubs on **World Sight Day**.

The key message was "have your eyes tested and macula checked" and players were "bowled over" by the eye-catching stencils on club greens. If you are a bowler, encourage your club to participate in some awareness activities.



Bowls Australia CEO Neil Dalrymple with Foundation CEO Julie Heraghty

Make eye checks a priority for diabetes

As part of **World Sight Day** activities the Foundation, in representing the interests of all macular diseases, called on Australians who have diabetes to have an eye test.

Diabetic retinopathy is the eye disease resulting from diabetes. The disease may progress to advanced stages before any noticeable effects on vision occur, which is why the Foundation is encouraging those with diabetes to have an eye test and, most importantly, if any changes in vision occur to see an eye specialist immediately.

mEYE World Photographic Competition winners

Australians showed their appreciation for the gift of vision with 945 photographs entered into the mEYE World Photographic Competition 2013. Winners were announced on 4 November with Denis Fitzgerald from Victoria being announced as grand finalist for his very personal and stunning black and white photograph of his daughter.



The winners across all categories are:

- **Open Category and Grand Finalist**
Denis Fitzgerald, Golden Square VIC
- **Healthcare Professionals**
Chris Barry, Sorrento WA
- **Macular Disease Community**
M Honeybun, Perth WA
- **Junior**
Josh Nicol, Ruby VIC

The Foundation thanks judges, Foundation Patron Ita Buttrose and renowned Australian photographer Ken Duncan, for their involvement. Special thanks go to competition sponsor, ODMA, for their ongoing support.

Further information and all winning photos can be viewed on the Foundation's website.

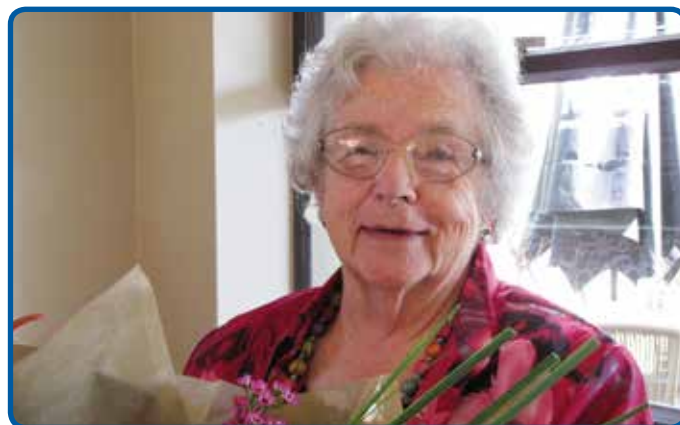
Education saved Fay's sight!

Fay Bennett is thankful she attended a Foundation education session at her retirement village. At the session she learnt about macular degeneration, the importance of early detection, and how to use an Amsler grid.

Her knowledge of macular degeneration has since been put to the test when she noticed a sudden change in her vision. "I woke one morning and could not see properly out of one eye. At first I thought it was just an early morning thing and went on with my day. When things were still not right later that day I tested my eyes with the Amsler grid and saw there was distortion and a black spot," says Fay.

Fay visited her GP the next day who arranged an emergency visit to the ophthalmologist that same morning. Wet macular degeneration was diagnosed and a few days later Fay had her first injection to treat the disease.

"Our eyesight is so precious. I am so grateful that I knew enough about macular degeneration to know to seek help right away. At the Foundation's education session they provided us with an Amsler grid and taught us all how to use it. It certainly confirmed to me that I had to act quickly," says Fay.



Mrs Fay Bennett

Book an education session

The Foundation's education team is available to speak at your community group or retirement village. If you are interested in arranging a speaker please contact the Foundation today.

Free Amsler grid

You can get your Amsler grid now! Call the Foundation on 1800 111 709 and we'll send you a free Amsler grid along with the latest *Nutrition & Supplements for Macular Degeneration* fact sheet.

Annual Report

The 2012-2013 Annual Report will be available mid December. To order a copy call the Foundation or visit the website to download.

Please note the Foundation will be closed from Christmas Eve and will reopen on 2 January 2014.

Donations

Thank you for supporting the Macular Disease Foundation Australia. As a charitable organisation we rely on your generosity to serve 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 donate by direct debit.

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

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It is intended as a newsletter and its contents do not constitute medical advice and should not be relied on as such. Dec 2013