

## Dear Friends



Happy Easter to everyone. I am sure an Easter bun and a little chocolate are allowed occasionally! That leads me (sort of!) into healthy eating and our new 'Macula Menu' project. I know many of you are wonderful cooks and have your

own healthy recipes, especially those which include eye health foods. So send us your favourite recipe for the 'Macula Menu'. We want to share your recipes with others on our new website to be launched in April.

I am seriously concerned about our Federal funding which provides for our education program across Australia. The lack of information about what will happen on 30 June 2015 at the end of our 3 year grant, is appalling. At this stage, Federal grants should be continued for another year while the grants program is reviewed. In the interim, I would be grateful for those donating to assign your donation to programs, if you so choose. I will keep you updated in the June newsletter and if I need your help, I will certainly let you know.

There are some very interesting items in this autumn newsletter. When you think about the fact that personal computers were not widely available until the 1980s and that the iPhone was not invented until 2007, it is easy to imagine that the driverless car is not far away. For those with vision loss, it could really be a pathway to supporting independence.

I also wanted to share with you that two lovely people who always had a smile, supported the Foundation and often appeared in the newsletter, both sadly passed away. Uncle Bruce, who supported our 'living well' column with all of his great tips, passed away just prior to Christmas. John Tatham, husband and carer for Pat Tatham, also passed away. He was so wonderful in telling the story of the role of the carer for our research on the ripple effect of vision loss. We are privileged to have known them both and grateful for the contribution they made to the macular disease community.

Stay safe, be positive and know that we are here to help you. Thank you to those who keep writing to me, I love reading your letters.

**Julie Heraghty**  
Chief Executive Officer



# Representation

## Left in limbo!

The Foundation's services are funded through donations, bequests, corporate and government funding. Since 2005 the Foundation has been successful in applying for and receiving 3 year grants for our national education program. We have received an average of only \$137,439 per year (excl. GST) in Federal funding for this valuable program, a small amount given the high prevalence and enormous impact of macular degeneration in this country.

Over the years many of you have attended an education session and know just how valuable it is to have the opportunity to hear our educators talk about the disease, the latest treatments and research.

Knowing that the funding agreements finish for many organisations on 30 June 2015, the Federal Government would normally have notified organisations of the next funding round. To date, the Government has not communicated its intentions. The Department of Health has stated that the future of funding for this program is "unknown at this stage". This lack of certainty around funding affects the forward planning of the Foundation and the sustainability and consistency of the education program to the Australian community. **We may need your support on this issue as securing this grant is critical to continuing these important education services to the public.**

**Over 9 years, 97% of attendees have consistently rated the sessions as "excellent" or "good"**

"I am now determined to have an eye test more regularly."

"I found the talk very interesting and I will alter my diet to lessen my chances of developing the disease."

"I'm lucky I attended your education session because I discovered symptoms of wet macular degeneration a few weeks later! I knew to act quickly and seek help."

**In 2013-14, 52 education sessions reached over 2,300 people.**

## Submission for Helpline funding

No Federal funding has ever been received for the Foundation's Helpline despite requests for support. Each year Treasury invites submissions for funding under the upcoming Federal Budget and each year the Foundation contributes a submission. This year, the Foundation has again requested adequate funding over 3 years to support the Foundation's toll-free national Helpline.

The Helpline is a vital frontline service providing information, guidance and support to thousands of patients of macular disease, their families and carers as well as healthcare professionals. Additionally the Helpline is available to the 8.5 million Australians at risk of macular disease in providing important information for prevention and early detection.

**We will keep you updated on the progress of this important submission.**

# Representation

## Access to low vision aids...

### via private health fund rebates

As reported in the last newsletter, the Foundation continues to lobby private health funds for provision of, or improved benefits for, low vision aids.

Recently, the Foundation contacted a private health fund on behalf of a client after he received confusing messages regarding availability of benefits for low vision aids. We were able to access accurate information on his behalf.

### via the Government aged care system

The Foundation has lobbied strongly for the appropriate inclusion of low vision aids and technologies in the Commonwealth Home Support Program (CHSP), to commence 1 July 2015. We await the outcome.

Further details about the CHSP are expected to be released soon, and an update will be provided in the June newsletter.

#### Contact the Foundation if you:

- a) are having trouble securing the information you need from your private health fund on benefits for low vision aids; or
- b) would like a copy of our summary of low vision aid benefits from major private health funds; or
- c) have vision loss and need advice on low vision services, aids and technologies available.



**We are here to help - phone 1800 111 709**

## Making a difference – we are your voice in the community

The Foundation has continued to receive positive feedback about the impact of our advocacy work to alleviate the capacity crisis at the Royal Adelaide Hospital (and Lyell McEwin and Queen Elizabeth Hospitals) public outpatient injection eye clinics.

**Thank you to those who have shared their experiences. If you have been affected by this issue, or have any difficulties with timely access to treatment, we are here to help – call 1800 111 709.**

*“A big thank you for your work to improve the waiting time at the Royal Adelaide Hospital retinal clinic in South Australia. It has improved dramatically. At one stage last year I waited nearly 3 times as long as recommended by my doctor for treatment. I am 85 and live alone. If I lose my sight, I lose my independence. I can’t say enough how much I appreciate the help you have made in RAH clinics. I personally have greatly benefited.”*

# Awareness

## Winning Photos capture a Sight Worth Saving

Congratulations to Dr Kerry Boytell, of Mosman NSW who took out the Grand Finalist prize in the 2014 mEYE World Photographic Competition. Dr Boytell was on a photography tour in Montana USA when



she managed to capture the image of the beautiful snow leopard before it sped off. "I only had a split second to get the shot before he disappeared," Dr Boytell said.

Thank you to our judges Foundation Patron Ita Buttrose, artist Ken Done and renowned photographers Rex Dupain and Alan Pryke. Congratulations also to the other category winners - Yvonne Hill, Paralowie SA (Macular Disease Community category), Corinne Le Gall, Vincentia NSW (Open category), Mikayla McCubben, Kingscliff NSW (Junior category).

**A gallery of the winning photos is available on the Foundation's facebook page**

## What's your story?

The Friends of the Foundation (FOF) Program was created to collect the stories of people living with macular disease, as well as their family members and carers. These stories are the human faces of macular disease. After all, nobody tells the story of macular disease better than the people who live with it every day.

We would be grateful if you would consider sharing your story. This collection of stories can then be drawn on when relevant media and awareness opportunities arise. We are interested in which macular disease you have, when you were diagnosed, the impact it has had on your life, activities that you enjoy, your career, and positive messages for living with macular disease.

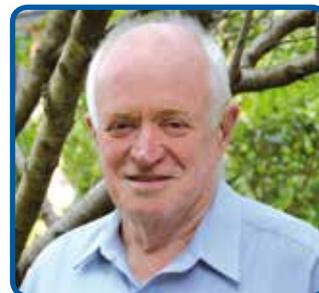
You can share your story by...

**Email:** [info@mdfoundation.com.au](mailto:info@mdfoundation.com.au)

**Mail:** Macular Disease Foundation Australia  
Suite 902, Level 9, 447 Kent Street  
Sydney NSW 2000

**Phone:** 1800 111 709

## Friend of the Foundation

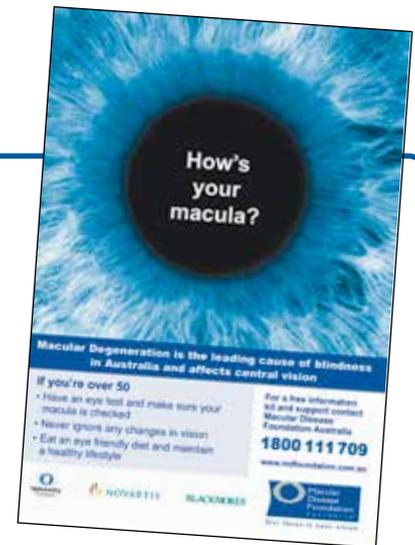


Retired pharmacist Mel Byrnes' story of early detection appeared in the *Australian Journal of Pharmacy* to help raise awareness during Macular Degeneration Awareness Week 2014. Diagnosed with sudden wet macular degeneration in 2007 he is acutely aware that if he hadn't known about the symptoms of macular degeneration and hadn't had an Amsler grid at home, he may not have been equipped to act immediately for the greatest chance to save his sight. Thank you to Mel for sharing his story.

# Awareness

## Macular Degeneration Awareness Week – 24 to 30 May 2015

This year the Foundation is back to basics with the theme *How's your macula?* which encourages those at risk to have an eye test and macula check.



**To highlight the importance of good nutrition during Macular Degeneration Awareness Week we are asking you to contribute a recipe to our 'Macula Menu'.**

We want to collect your healthy, eye friendly recipes to share with others on the Foundation website. To contribute your recipe to the 'Macula Menu' simply complete the recipe template included with this newsletter and send to the Foundation. Submitted recipes must reflect a healthy, well balanced diet, being one of our key messages.

We'd particularly like recipes which include eye friendly ingredients such as dark green leafy vegetables and fish. A healthy, well balanced meal is one which includes a variety of nutritious ingredients from any of the five food groups:

- Lean meats, poultry, fish, eggs, tofu, nuts and seeds
- Vegetables, legumes and beans
- Fruit
- Grain (cereal) foods, which are wholegrain and or high fibre varieties (low GI)
- Milk, yoghurt, cheese



### Method

1. Mix all ingredients in a bowl
2. Serve with a baked salmon fillet to make the dish extra eye friendly!

### Quick and Easy Tomato Salsa

Serves 2

- 4 large ripe tomatoes roughly diced
- 1 small red onion finely diced
- Handful fresh basil leaves roughly chopped
- 1 small chilli finely chopped (optional)
- Drizzle extra virgin olive oil

## How else can you get involved in Macular Degeneration Awareness Week?

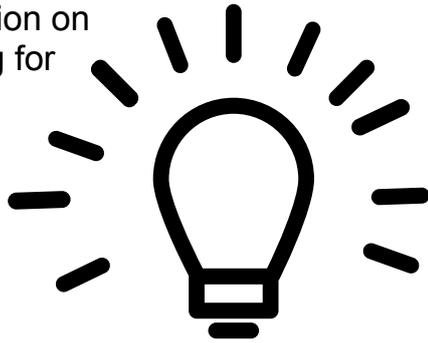
- ✓ Remind your friends and family over 50 to have an eye test and macula check.
- ✓ Encourage friends and family diagnosed with macular degeneration to contact the Foundation to ensure they receive ongoing information and support.
- ✓ Involve your community service group and distribute information materials to the local community (available from the Foundation).
- ✓ Organise a fundraising event through your local community or social club to raise money for the Foundation's work.

# Living Well

## Frequently asked questions...

### Q. Why is lighting so important?

Good lighting is important for everyone. For those with low vision, lighting is one of the most important and simple aids. Getting it right is not just about buying a brighter bulb, in fact that can be the wrong choice. A low vision assessment will include discussion on the right lighting for you and how it should be positioned.



### Q. Is there a way to go on a holiday and continue my injection schedule?

Yes there is a way to coordinate your injections and take a holiday. Discuss the options with your ophthalmologist and call the Foundation for information on available ophthalmology services in locations across Australia.



### Q. Are supplements really of benefit?

Certain people who have been diagnosed with macular degeneration should consider taking a supplement based on the AREDS2 formula in consultation with their doctor. The Age-Related Eye Disease Studies (AREDS) are the only studies for which there is good, long-term evidence for the benefits of high dose nutrients for people diagnosed with age-related macular degeneration.

#### The AREDS2 formula (daily dose) is:

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

### Q. What is kale and why is it good for my eyes?

Kale is a vegetable with green or purple leaves. It comes in a number of varieties, the most common being the curly leaved "Scots kale" and flat leaved "Lacinto kale".

Kale contains especially high levels of lutein and zeaxanthin, nutrients which are present in high concentrations in a healthy macula.

## New Low Vision Advisory Service – Sydney

A new free low vision advisory service is now available at Macular Disease Foundation Australia's Sydney 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. Those living in regional areas can also access the service when visiting Sydney, however bookings are essential.

#### Call the Foundation on 1800 111 709:

- ✓ To book an appointment at the Foundation's Sydney Low Vision Advisory Service
- ✓ For information on low vision services across Australia
- ✓ For a copy of the Foundation's publication *Low Vision Aids & Technology: A Guide*

# Research

## New research suggests a cause of drusen formation

It is well known that the early stage of AMD involves the build-up of drusen under the retina. Drusen are small yellowish deposits which contain fat and protein waste. It has not previously been known how or why drusen develop.

Researchers at the University College London have just published research which shows that drusen grow around microscopic spheres of a mineral called hydroxyapatite (HA), which is also found in bone. These spheres are found in most eyes but the more HA spheres you have, the more drusen you tend to have. It is not yet clear whether these spheres are a cause of AMD or just a symptom, but because it is possible to detect them at a very early stage using new diagnostic equipment, they may become a valuable tool to diagnose AMD much earlier than is currently possible.

Further research is planned to show if the HA spheres can be considered to be a cause of the disease. If so, it may be possible to develop new treatments aimed at the very earliest stages of the disease before any damage has occurred.

## Driverless cars may be closer than we think

Foundation research over the years has shown that reading and driving are the two areas that people with low vision are most concerned about. In recent years, the changing landscape of technology has brought many technologies and aids to assist in reading. This has made us consider what an impact the driverless car may have on the independence and mobility of those living with vision loss. Already some cars now include features of a driverless car, such as parking assist and collision avoidance, and it is reported that several companies are working towards a fully autonomous vehicle. Hard to imagine isn't it!

Conquering the challenge of driving for those with low vision will be yet another step in maximising independence and quality of life. Therefore we continue to watch the development of driverless cars with great interest.



## Research Grants Program - Opening soon

Macular Disease Foundation Australia's Research Grants Program will open its third round of applications in March 2015. Grants are open to researchers based in eligible Australian institutions to pursue research into medical, social, low vision, and nutritional research of macular degeneration. The successful applicants will be announced on World Sight Day - 8 October 2015. The Research Grants Program is supported by your generous donations.

**Since the program launch, over \$1.5 million has been committed to world leading Australian researchers.**

# Fundraising

## Lions helping all Australians keep their eye on the ball

On 2 February, the 9th Roth Gair Charity Golf Day was held at Rosebud Country Club in Victoria. The Lions Clubs of Forest Hill and Park Orchards hosted a very successful day, despite less than perfect weather! Foundation Professional Friend David West from Eyecare Plus Cranbourne, assisted by final year optometry student Flora Luk, provided digital eye examinations for players, with equipment provided by Optimed.

The Foundation is extremely grateful to everyone involved and thanks Ian Kennedy, Lions Club of Forest Hill, Lions Club of Park Orchards, David West, Flora Luk, and event sponsors including Toyo Tyres.

**Call the Foundation on 1800 111 709 to discuss how your club can get involved and help the Foundation in its sight saving work.**



## Calling all Bowls Clubs, Golf Clubs and Rotary Clubs!

In the lead up to Macular Degeneration Awareness Week (24-30 May) the Foundation is reaching out to all Bowls Clubs, Golf Clubs and Rotary Clubs and asking that they hold a fundraising event to support the Foundation's sight saving work. This could be a sausage sizzle, morning tea, bowls or golf competition – almost anything! The Foundation can support your fundraising event by providing posters, stickers and information flyers on macular degeneration.

**Call 1800 111 709 to discuss how your club can get involved.**

### A gift in your Will is a lasting legacy

For a copy of the Foundation's information booklet on bequests 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 direct debit.

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

## Contact us

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