

Dear Friends



Christmas is here again and I wish you all a happy Christmas and a wonderful New Year. May the festive season be filled with love and friendship.

I want to thank everyone for their support over the last year, for the lovely letters sent to us and your ongoing generosity to the Foundation.

This is my 10th Christmas with the Foundation. I know many of our readers have had a relationship with the Foundation for as long as I have, or even longer.

You are all our dear friends and with your help we continue to build upon our strengths and meet the challenges ahead.

I am constantly humbled by the enormity of the challenges so many of you face, from living with vision loss and other chronic diseases, to managing ongoing treatment.

On your behalf, I thank my dedicated Foundation staff who have throughout the

year fulfilled their role so well, guided by our values of commitment, compassion and respect. Every day they inform, guide and support those at risk of macular disease, patients, those with vision loss, and families and carers – offering real understanding.

Thank you to our amazing patron Ita Buttrose AO OBE and our wonderful ambassadors - Jean Kittson and Jan Utzon. They have given so much this year to our organisation in support of our work.

Over 13,000 information kits were packed and distributed by our dedicated volunteers, many of whom live with vision loss. Their donation of time and hard work contributes enormously to our efforts across Australia to save sight, and I thank them.

Take care, be safe and enjoy the festive season.

Julie Heraghty
Chief Executive Officer



Research Update - Enclosed is the Foundation's annual Research Update. The 2014 update includes an overview of some of the latest research projects being undertaken into macular degeneration. We hope research will one day provide the answers needed to conquer this disease. Your ongoing support has enabled us to fund renowned Australian researchers.

Research

Blackmores Dr Paul Beaumont Research Fellowship Recipient

On World Sight Day (9 October 2014) the Foundation was pleased to announce Associate Professor Bamini Gopinath as the successful recipient of the third Blackmores Dr Paul Beaumont Research Fellowship.

The proposed research will involve a detailed analysis of diet and lifestyle data currently being collected from 600 people with late stage age-related macular degeneration. It will link with a major study currently being conducted by Professor Paul Mitchell, funded by the Macular Disease Foundation Australia under our Research Grants Program.

The study aims to determine a detailed understanding of lifestyle risk factors which may assist to identify and change at-risk behaviour. It may also help in the



Associate Professor Bamini Gopinath

implementation of preventive strategies at a timely point in the disease course.

Blackmores Institute, Blackmore Foundation and Macular Disease Foundation Australia support the fellowship of \$100,000 over two years. It is one of the grants under the Foundation's Research Grants Program. The Foundation thanks Blackmores for their invaluable research support.

Foundation services feedback

The Foundation is constantly evaluating our activities so that we can best support the macular disease community. Thank you to everyone who has provided feedback at education sessions or through our yearly client feedback survey. We are proud to report the following results:

Education

98%

of respondents rated the Foundation's education sessions as either "good" or "excellent"

93%

of respondents indicated that they knew "a reasonable amount" or "a great deal" more after attending an education session

Client Services

87%

of respondents knew of our advocacy work and of these 97% said it was "good", "very good" or "excellent"

95%

were "very" or "mostly" satisfied with the Foundation's services

Representation

South Australian eye care crisis

After extensive lobbying by the Foundation on behalf of patients, their carers and families, SA Health has confirmed funding for an additional seven eye clinics per month to alleviate the capacity crisis at the Royal Adelaide Hospital (and Lyell McEwin and Queen Elizabeth Hospitals) public outpatient injection eye clinics.

This is a great win for South Australians living with wet age-related macular degeneration, and also for those living with other macular diseases such as diabetic eye disease, who should now receive timely treatment to save sight.

While the present response provides a short-term solution to the capacity issues, the Foundation will continue to monitor and advocate for a sustainable long-term resolution to cater for the future needs of eye health for all South Australians. In the interim if there is any change and people are delayed in receiving their treatment - please contact the Foundation immediately on 1800 111 709.

“I am writing on behalf of the staff and patients at the Royal Adelaide Hospital Eye Department to express our profound gratitude for the work that the Macular Disease Foundation did to alleviate the macular degeneration injection crisis here in South Australia.”

Professor Dinesh Selva AM
Chairman, Ophthalmology Network
Royal Adelaide Hospital

PBAC recommendation

After 18 months of Foundation advocacy the Pharmaceutical Benefits Advisory Committee (PBAC) has recommended that the drug Lucentis be listed to treat diabetic macular edema (DME) and retinal vein occlusion (RVO).

This is the first step to achieving access and affordability for registered treatment for these serious macular diseases, which can lead to vision loss and blindness. Diabetic retinopathy, which includes diabetic macular edema, is the leading cause of blindness in working aged Australians.

The Foundation continues to call on the Federal Government to fast track Cabinet approval for the listing to make the treatment quickly available to patients.

Ergon Energy

Several clients contacted the Foundation with concerns that Ergon Energy’s customer newsletter was difficult to read for those with low vision. The Foundation took these concerns to Ergon. The energy supplier responded quickly, indicating that they were previously unaware of the issue and would make font and colour changes to both their newsletter and suite of publications moving forward. Ergon Energy are commended for their swift response in addressing accessibility of information for all their customers.

Representation

Low vision aids campaign – private health fund benefits

Since 2010, the Foundation has advocated to major private health funds for the provision of fair and adequate subsidies for low vision aids and technology. Once again the Foundation has audited the six largest private health funds, which make up 86% of the private health insurance market, to ascertain if there has been any change in the provision of benefits. We also reviewed if benefits were listed in current health fund publications and on websites.

What did the audit show?

- 1. Benefits provided:** nib, HCF, Australian Unity and Bupa presently offer low vision aid benefits.
- 2. No benefit provided:** HBF and Medibank Private presently do not offer low vision aid benefits.

What is the Foundation doing on your behalf?

- 1. No benefit from private health fund:** Writing to the relevant health funds to encourage them to include low vision aids as a benefit (HBF and Medibank Private).
- 2. Existing provision of benefit:** Assessing if the benefit is reasonable and if there is room to provide a benefit that more fairly reflects the costs where appropriate (nib, HCF, Australian Unity and Bupa).
- 3. Listing of information:** Communicating with all private health funds that provide low vision aid benefits to ask that specific information on the benefits is clearly communicated in publications and on websites.

Thank you to nib for providing specific information on its website, listing “macular degeneration aids” as a benefit under one of its products - the “Health Aids (YAH)”. HCF has agreed to review its publications and website.

Please note: This information has been verified as correct by the relevant health funds at the time of going to print .

What can you do?

Contact the Foundation on 1800 111 709 if you would like:

A copy of the letter written by the Foundation to your health fund

and/or

A summary of low vision aid benefits offered by the six major private health funds (also available on our website www.mdfoundation.com.au)

or

To discuss the matter with the Foundation



Representation

Associate Professor Nitin Verma appointed to Foundation Board

Macular Disease Foundation Australia is pleased to welcome Associate Professor Nitin Verma AM onto the Board. Dr Verma is a leading Tasmanian ophthalmologist with a special interest in retinal diseases.



Elizabeth Carr, Chairman of the Macular Disease Foundation Australia says, "It is with great pleasure that I welcome Associate Professor Nitin Verma to the Board. He has been a long standing member of the Foundation's Medical Committee where his expertise and guidance has been of great benefit to the Foundation and the macular disease community for which we serve."



For those using a computer, the Foundation is now on Twitter!
Follow us @maculardisease

Donate to the Foundation's Research Grants Program

The Foundation has a goal to have granted \$10 million to researchers by 2021. There are several ways you can help:

- Donate using the enclosed donation form and tick the box "Foundation Research"
- Call the Foundation if you wish to donate by telephone or donate securely online at www.mdfoundation.com.au
- Leave a bequest in support of 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 a money order.

Please call the Foundation on 1800 111 709 to donate, or for information on bequests, direct debit and information on the Research Grants Program.

Bank PINs

In the last newsletter we reported on the Foundation's successful advocacy to ensure those requiring a signature option credit card are being assisted by the banks. Please note we are still assisting people. If you have a genuine need for a signature approved card due to low vision, and have not been able to get assistance through the appropriate avenues within your bank or financial institution, please contact the Foundation on 1800 111 709.



Awareness

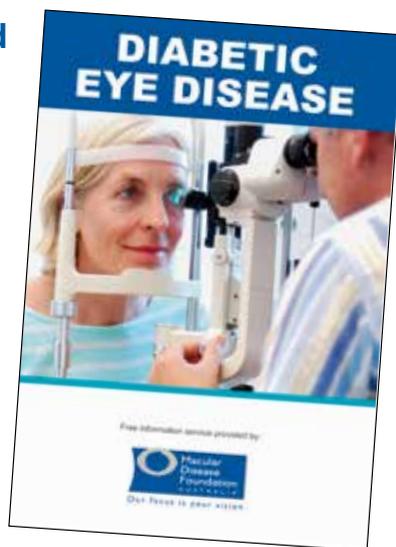
World Diabetes Day 2014

On World Diabetes Day (14 November) the Foundation and Senator Fiona Nash, Federal Assistant Minister for Health, issued a joint media release calling upon all with diabetes to have an eye test, to avoid irreversible vision loss.

Everyone who has diabetes should have a copy of our recently released free publication Diabetic Eye Disease.

If you have a friend or family member who has diabetes please encourage them to order their free copy – you could save their sight.

Order by phoning the Foundation on 1800 111 709



mEYE World Photographic Competition 2014

The mEYE World Photographic Competition closed on 12 November with a record 1300 entries received. We anxiously await the announcement of the winners by our renowned judges Ita Buttrose, Ken Done, Rex Dupain and Alan Pryke.

The winning entries will be announced on 9 December by Patron Ita Buttrose at the Foundation's Annual General Meeting. Winning photos will be posted on our website and published in our next newsletter. Thank you to everyone who entered a photo this year.

Summer is here!

With the warmer weather upon us, we're reminded how important it is to protect your eyes from sun exposure.

You might be surprised to know that rules for UV exposure for the skin and the eyes have recently been shown to be different. Skin is mainly affected by direct UV but the eye is affected by both direct and indirect UV. UV from the side, from behind and reflected from surfaces below eye height, all have significant impact on the eye.

Peak exposure times for the eyes is not between 10am and 2pm as for skin, but between 8am to 10am and 2pm to 4pm for most of the year because of the angle of the sun in relation to the eye at those times.

What can you do?

- ✓ Be sure to wear UV-blocking sunglasses and broad-brimmed hats whenever you're outside all year round
- ✓ Don't be fooled by clouds. The sun's rays can pass through haze and thin clouds.
- ✓ Never look directly at the sun. Looking directly at the sun at anytime, including during an eclipse, can lead to solar retinopathy, which is damage to the eye's retina from solar radiation.
- ✓ Don't forget the grandchildren, children and other members of the family. Everyone is at risk. Protect their eyes with hats and sunglasses.

Uncle Bruce

CEO Julie Heraghty recently asked her Uncle Bruce for his “Living with Low Vision” tip for this edition of the newsletter. His answer was “keep active, keep a sense of humour and make the best of what life throws at you”.

Uncle Bruce has lived up to his advice in the last month with a great positive outlook even though he quite suddenly added to his “most visited list” (along with the ophthalmologist) an oncologist.

However, he continues as he says, “to ride shot gun” one day a week delivering meals on wheels! He continues to use his aids and technologies to read. He gets



out and about always wearing his low vision badge and travelling confidently on public transport. He engages with his community and visits his local club occasionally for a “good old chat” with his buddies.



Our *Ripple Effect of Vision Loss Research* showed that 85% of the macular degeneration patients surveyed also suffered from other health conditions including arthritis (47%), heart disease (25%), diabetes (12%), cancer (10%), depression (9%), obesity (5%), and Alzheimer’s or dementia (1%). Carers also showed similar levels of chronic disease.

The Foundation is aware that many of our clients not only have vision loss but also other chronic conditions, which can be very challenging. Please remember that when things are tough don’t forget to call upon the support of those who love and care for you - friends and family - along with community services, health care professionals and the Foundation.

Please note the Foundation will be closed from Christmas Eve and will reopen on 5 January 2015.

Annual Report

The 2013-2014 Annual Report will be available from 9 December. To order a copy call the Foundation or visit the website to download.

Fundraising

Bowls clubs keeping their eye on the ball

To celebrate World Sight Day in October, a number of bowls clubs across Australia held fundraising events or made special donations to support the Foundation's Research Grants Program. Through the initiative over \$2,000 was raised. Our thanks go to all participating clubs.

If you, or someone in your family, are a member of any type of club and would like to hold a fundraising event please contact the Foundation on 1800 111 709.

Running to see

Throughout September and October Alana from Exmouth in Western Australia ran a virtual relay to raise funds for the Foundation. Alana's mum Jackie was diagnosed with wet macular degeneration earlier in the year so Alana decided to do something that will make a difference for people like her mum. Over 61 days Alana ran a total distance of 1300 kms, equivalent to the distance from Exmouth to Perth, and using Everyday Hero website raised more than \$2,000 to support the Foundation!

For more information about how you can be an Everyday Hero call 1800 111 709.

Education Sessions

Location	Date and Time	Address
NSW – Gymea Information Session and Low Vision Display	Wednesday, 4 February 2015 10.00am – 12.30pm	Tradies Gymea 57 Manchester Road, Gymea
TAS - Launceston	Saturday, 21 February 2015 10.00am – 12.00pm	Tailrace Centre 1 Waterfront Drive, Riverside
ACT - Canberra	Thursday, 26 February 2015 10.30am – 12.30pm	Hellenic Club of Canberra Matilda Street, Woden

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 direct debit.

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

Contact us

Suite 902, Level 9
447 Kent Street
Sydney NSW 2000

Helpline 1800 111 709

info@mdfoundation.com.au

www.mdfoundation.com.au

DISCLAIMER: This newsletter is produced by Macular Disease Foundation Australia.

It is intended as a newsletter and its contents do not constitute medical advice and should not be relied on as such. Nov 2014