Newsletter

SUMMER 4th Edition 2015

Dear Friends



Christmas has arrived so quickly and the festive season is here. On behalf of all at the Foundation we wish you every happiness for the holiday season and a very happy new year.

This newsletter is all about research. The generosity shown by so many including through donations and the kindness of bequests, has enabled the Foundation to award a third round of research funding totalling \$1.3 million to six outstanding Australian researchers. It was such a privilege to have our Governor-General award the grants on our behalf on World Sight Day (8 October) at Admiralty House in Sydney.

The researchers expressed their gratitude to the Foundation and stated that the reduction in Government funding in this area has been of great concern. The Foundation is now the main source of funding for Australian researchers in macular degeneration, which is a great responsibility.

Research will find the answers we need to find a cure. It provides hope for the future and for all Australians at risk or living with this disease. We will continue to build our research reserves, through the generosity of donations and bequests, and award much needed grant funding to outstanding

Australian researchers.
Enclosed is our annual Research Update providing the latest information on macular degeneration research.

Many of you will recall Ita Buttrose being appointed as our Patron in 2005. Ita has so generously been a champion of our work for 10 years. I cannot begin to describe the work Ita has undertaken on behalf of the Foundation including media interviews, guest appearances, producing the popular Foundation cookbook and as a great Friend of the Foundation. When Ita tells her story of her link with macular degeneration, it has a profound effect on so many and has helped to save the sight of older Australians. I thank our Patron on your behalf for one decade of outstanding service.

How quickly time goes and next year the Foundation will be 15 years old! We would like you to think of ways to celebrate and use this number to promote and support the Foundation. Check the back page for ideas.

Finally thank you to our Board of Directors and my amazing staff for their dedication and commitment and to you, for whom we serve, for your support and friendship. Take care.

Julie Heraghty
Chief Executive Officer

Research update enclosed

Enclosed is the Foundation's annual Research Update which includes an overview of some of the latest research projects being undertaken into macular degeneration.



Macular Disease Foundation Australia Research Grants 2015 \$1.3 million awarded

Macular Disease Foundation Australia Research Grants, totalling \$1.3 million, have been awarded to six outstanding Australian researchers to advance knowledge of macular degeneration. To date, the Foundation has committed over \$2.8 million to world leading Australian researchers.

The successful recipients were selected from 21 applications which were rigorously evaluated by international peer review, to ensure that they met the highest standards.

His Excellency General the Honourable Sir Peter Cosgrove Governor-General of Australia awarded the grants to recipients at a special event on World Sight Day (8 October) at Admiralty House, Sydney. Grants awarded included a new grant supported by Blackmores.

Video interviews with the grant recipients are available on the Foundation website www.mdfoundation.com.au



Professor Mark Gillies – awarded \$400,000 Save Sight Institute, The University of Sydney

This project will provide strong data on several questions about treatment including the effects of duration between treatments, the effects of reducing treatment frequency, and recommendations that can be made to patients regarding longer term prognosis. The project will provide strong, real-world evidence on these key clinical questions.



Associate Professor Chi Luu – awarded \$200,000 (represented by co-investigator Professor Robyn Guymer)

Centre for Eye Research Australia

This study aims to validate a new instrument designed to detect people with high risk macular degeneration at a much earlier stage. If successful, this technology will enable trials on new treatments to be conducted more quickly and could also reduce the cost of trials enabling more treatments to be studied.

Your generous donations support the Foundation's commitment to funding Australian research.

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



Dr Gerald Liew - awarded \$100,000

Centre for Vision Research, Westmead Millennium Institute, The University of Sydney

This pilot study will investigate whether certain metabolites (small chemicals in the blood) that result from the age-related macular degeneration disease process may enable the development of a simple blood test which could be used as an early indicator for disease progression.



Professor Steven Krilis - awarded \$400,000

St George Hospital, UNSW Australia

This study will link environmental risk factors such as smoking and a high fat diet with biological system changes that are involved with disease development.

Jointly funded by Macular Disease Foundation Australia and Blackmores



Dr Isabelle Jalbert - awarded \$100,000

UNSW Australia School of Optometry and Vision Science

This project will identify obstacles faced by eye care practitioners in delivering the best care for people living with macular degeneration. It will also assess knowledge and understanding of the role of diet, supplementation and lifestyle modifications so that health interventions can be directed where most needed.

Funded under the Blackmores Macular Disease Foundation Australia Research Grant



Dr Laura Downie - awarded \$100,000

Department of Optometry and Vision Sciences, The University of Melbourne

This project will develop a standardised education program for optometrists based on best practice to deliver more consistent level of early diagnosis, improved referrals and guidance from optometrists to patients and their families.

Funded under the Blackmores Macular Disease Foundation Australia Research Grant

Research Grants awarded on World Sight Day at Admiralty House



Grant recipients with the Governor-General and Lady Cosgrove.



Foundation Chairman Elizabeth Carr, Lady Cosgrove, Governor-General Sir Peter Cosgrove, Foundation CEO Julie Heraghty



Blackmores Institute's Dr Lesley Braun, grant recipient Professor Krilis, Foundation CEO Julie Heraghty, Blackmores CEO Christine Holgate

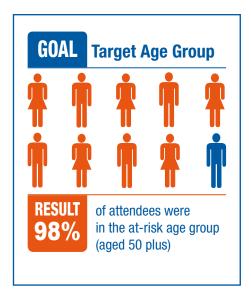
A video of the Admiralty House award ceremony, as well as videos of the Governor-General's and Foundation CEO's speech, are available to view on the Foundation's website www.mdfoundation.com.au

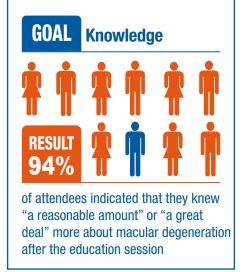
"Macular Disease Foundation Australia Research Grants Program is one of the major support schemes for macular disease research."

Professor Mark Gillies (grant recipient)

Evaluation of the Foundation's education sessions

The Foundation evaluates its education sessions by asking attendees to complete a survey at the conclusion of a session. We continue to achieve our goals!







Evaluation of Foundation's services

The Foundation evaluates its services every year by surveying a sample of its client base. Clients surveyed gave overwhelmingly positive ratings to the Foundation's services.

- √ 95% of all who had accessed the Foundation's services said the Helpline, newsletter, education sessions and website were "good" or "excellent"
- √ 96% of Foundation clients were "very" or "mostly satisfied" with Foundation services
- √ 99% of clients said the Foundation's advocacy work was "good", "very good" or "excellent"



Low vision survey results

A survey was sent in August to all members registered with Foundation as having vision loss. The purpose of this survey was to learn about peoples' experiences with low vision services.

The survey showed:

- 28% of recipients were prevented from purchasing some low vision aids due to cost. The Foundation continues to advocate for access and affordability of low vision aids and technology.
- People with severe vision loss were significantly more aware of the availability of vision services than those with slight to moderate vision loss. This is a concern as even with a moderate amount of vision loss it is worth seeing a low vision specialist. The best time to learn to use aids and technology is while vision is still good.
- Clients who used low vision services were highly satisfied with the time and service delivered. Especially useful was assistance on low vision aids (eg magnifiers) and reading support (eg audio books).

Awareness

A decade of support. Thank you Ita!

Ita Buttrose became the Patron of Macular Disease Foundation Australia in 2005 and this year marks 10 years of invaluable support. Over this time Ita has worked tirelessly to promote the cause of macular degeneration across Australia. We thank Ita for her commitment and generosity to the Foundation and the macular disease community.



In Ita's words

It was because of Dad that I became Patron of the Macular Disease Foundation Australia in 2005. He was in his mid-eighties when he lost his central vision to macular degeneration. It changed his life.

I was as devastated about Dad's fate as he was. Having seen the impact of the disease on him, anything I can do to help spread awareness about the preventative steps people should take to protect their eyes is a priority for me.

Unless you have witnessed a loved one or friend living with the challenges of vision loss, and appreciate how the simplest activities and joys of life can become great challenges, it is hard to believe "it could happen to me".

mEYE World Photographic Competition 2015

We had a huge response to the competition this year with over 2,400 inspiring photos submitted capturing the theme 'See My World'. Foundation Patron and head judge Ita Buttrose announced the winners



on 12 November. Thank you to all that entered, our judges Ita Buttrose, Rex Dupain and Alan Pryke, and supporters Novartis and Nikon Lenswear.

Open Category Winner and Grand Finalist Rebecca Burton

"Golden morning light streaming into the kitchen and a box of shredded paper. My child was captivated by the dust motes dancing in the air; I got to peek into her magical world. We both saw magic that day. Celebrate the little details you see every day. It's all so precious."

Representation

The Foundation continued to represent the best interests of the macular disease community with numerous submissions in response to government proposed reform as well as appearances at various consultations.

Private Health Insurance: On 28 October the Federal Minister for Health announced a review of private health insurance. Professor Graeme Samuel AC has been appointed to conduct a series of industry and consumer representative roundtables to identify reform options to enhance the value of private health insurance for consumers.

In the ACCC's annual report to the Australian Senate on anti-competitive practices by health insurers and providers in relation to private health insurance (Oct 2015), it stated "there are a number of market failures in private health insurance and there are increasing policy limitations and exclusions leading to an increased risk of unexpected out-of-pocket expenses and general dissatisfaction with the system."

The Foundation's CEO attended a consumer roundtable (20 November) and raised with Professor Samuel aspects of a "broken system" which certainly requires urgent fixing, especially with respect to injections for wet macular degeneration

and access to low vision aids and technologies.

Review of the National Disability
Insurance Scheme Act: A recent two year review enabled the Foundation to again highlight the discriminatory nature of the NDIS. The exclusion of those who acquire a disability aged 65 years, or over, means that the Act fails to comply with the UN Convention on the Rights of Persons with Disabilities. This was also previously raised by the Foundation with the Parliamentary Joint Committee on Human Rights and recognised in the Committee's report as a legitimate concern.

Medical Benefits Scheme Review:

The Federal Government is undertaking a comprehensive review of all Medicare procedures to assess their evidence base, relevance and costs. The Foundation has requested representation on the optometry and ophthalmology working groups to ensure our patient interests are fully represented to avoid any additional financial burden on patients.

New Board Directors



The Foundation welcomes two new members of our board - Ms Imelda Lynch and Colonel John Fenwick. Ms Lynch has a nursing background with 25 years in leadership positions in both the public and private health sectors. Colonel Fenwick is a defence professional with over 25 years experience in the Australian Army. Both bring skills and expertise to our organisation helping to guide and support the Foundation.



Fundraising

Donate this Christmas

A donation to the Foundation in lieu of a Christmas gift is a generous and thoughtful way to celebrate the festive season and help save sight. If you would like to make a donation, call 1800 111 709 and we will send your friend or family member a Christmas card letting them know that you've donated on their behalf.

Help us celebrate 15 years!

The Foundation will celebrate its 15th anniversary in 2016 and we want you to get involved by "Fundraising by the power of 15". Simply set yourself a challenge involving the number 15 and ask your friends and family to donate to the Foundation. You could run or walk 15km or invite 15 friends to donate \$15 to participate in a friendly card game.

To discuss your "Fundraising by the power of 15" idea call 1800 111 709.

Upcoming education sessions

To book your place at one of the below sessions call 1800 111 709.

Location	Date and Time	Address
Hobart, TAS Guest speaker: Assoc. Prof. Nitin Verma Includes Low Vision Display	Saturday 12 December 2015 10.00am – 12.00pm	Wrest Point 410 Sandy Bay Road, Sandy Bay
Forster, NSW Includes Low Vision Display	Wednesday 3 February 2016 10.00am – 12.30pm	Club Forster 19 Strand Street, Forster
Moss Vale, NSW Includes Low Vision Display	Tuesday 9 February 2016 10.30am - 1.00pm	Moss Vale Services Club Cnr Argyle & Yarrawa Streets, Moss Vale
Katoomba, NSW	Friday 26 February 2016 10.30am – 12.30pm	Katoomba RSL Club 82-86 Lurline Street, Katoomba
Melbourne Retirement & Lifestyle Expo, VIC	Friday 8 to Sunday 10 April 2016 One talk each day – times TBC	Caulfield Racecourse Station Street, Caulfield
Darwin, NT	Tuesday 31 May 2016 10.00am – 12.00pm	Tracy Village Social & Sports Club Cnr Tambling Terrace & Henbury Avenue, Wanguri

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

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