

Dear Friends



It is a busy period at the Foundation once again and spring is now upon us.

Firstly, a brief respite from the Federal Government funding challenge. We have secured the Federal education grant until

31 December 2015. In the interim, we have applied for other funding which has become available for peak bodies, such as the Foundation. I will keep you informed.

However, my immediate concern is the potential for cost shifting to patients. Firstly, the Government is currently reviewing the Medicare Benefits Schedule (MBS), which is a listing of over 5,500 medical services subsidised by the Federal Government under Medicare. This review is important because it could affect so many older Australians, not only for macular disease but also other health areas. The Foundation is engaged in the consultation process and will represent our clients' interests at all times.

Secondly, private health insurer NIB has ceased providing MediGap benefits for 224 items including 3 items for eye injections undertaken in a private hospital or day surgery setting, effective 17 August 2015. I am very concerned about this move by a private health insurer. I have been in contact with NIB and made representations through the Australian Competition and Consumer Commission and the Private Health Insurance Ombudsman.

Thank you to all who undertook the treatment cost survey, which has highlighted

the importance of ongoing support for our clients. On reading the responses it is clear that many patients are highly vulnerable to affordability of ongoing treatment if there is any "cost shifting" onto the patient. Some of the comments highlighted the stress and strain many of you are experiencing with injections and chronic disease, and the ongoing financial, emotional and physical challenges.

Maintaining independence and quality of life is the goal. I hope you are assured that the Foundation will always be your voice to government to achieve this outcome. More information on these critical issues is provided in this newsletter.

On a lighter note, spring will bring a new season to brighten us up, get out and about and enjoy life. My friends, take care, be healthy and meet every day with love and laughter.

Julie Heraghty
Chief Executive Officer

Annual General Meeting

Date: 8 December 2015

Time: 12.00pm - 12.45pm

Location:

Macular Disease Foundation Australia
Suite 902, Level 9, 447 Kent Street,
Sydney

**Following the AGM the annual
Christmas celebration will be
held until 2.00pm**

RSVP: 27 November 2015 on
1800 111 709

(RSVP essential for catering purposes)

We hope you are able to join us.

Representation

Survey on cost of wet macular degeneration treatment

Thank you to those who completed the treatment cost survey included with the last newsletter. Around 1,500 responses were received and data is now being collated and analysed. The final outcomes will be reported in the December newsletter. A top-line review of responses, however, has shown that many patients are under a great deal of financial strain from the cost of treatment and many patients also find invoices, treatment costs and Medicare item numbers difficult to decipher. Given the complexity of treatment bills and initial analysis of survey feedback, the Foundation has already begun to develop an easy-to-read item number guide for patients, family, friends and use by healthcare professionals.

Some preliminary observations:

- Many patients experience a great deal of financial stress from treatment costs
- Some patients are unsure whether they are registered for the Medicare Safety Net
- Some patients have considered stopping treatment due to cost and some had not discussed this concern with their doctor
- Overall, the burden of treatment can be very stressful in many ways

Why did we do this cost survey?

This survey will help us understand the range of costs associated with injections for wet macular degeneration and associated burdens of treatment. The data collected will be used to represent your interests in our ongoing advocacy work for equity of access and affordability of sight saving treatment.



Key Points for you to note:

- Never stop your treatment unless explicitly recommended by your ophthalmologist. If there is ever a situation where you feel you would stop treatment, please call the Foundation to discuss.
- To check if you are registered for the Medicare Safety Net call Medicare on 132 011 or visit your local Medicare office. Most single people should automatically be registered, while couples may be required to arrange registration. Medicare will also be able to tell you how much you have spent on medical bills and how close you are to reaching the yearly Safety Net threshold.

**Your participation has been very helpful and
your comments have been insightful.**

As one respondent wrote:

“My choice should not be to go broke or go blind.”

Representation

In addition to the survey on cost of wet macular degeneration treatment, several other surveys are currently being conducted by the Foundation. Thank you to everyone who has completed a Foundation survey in the past months. Your contributions help the Foundation to understand your needs and accurately represent the macular disease community.

Evaluation of Foundation services survey

Sent to a random sample of people each year who are registered with the Foundation.

Why did we do this survey?

This survey enables us to evaluate how well we are serving you and how we can improve our services provided to the macular disease community.

Thank you to all those who completed the survey. This survey has now closed and results will be reported in the December newsletter.

Low vision survey

Sent to all members registered with the Foundation as having some vision loss.

Why are we doing this survey?

To learn about peoples' experiences with low vision services. The results will be used to guide and inform the Foundation to improve our services as well as informing government, low vision agencies and others about the outcomes, so as to improve services.

Responses to the low vision survey are due by 4 September. However, we will do our best to include responses received after this date.

Call us on 1800 111 709 if:

- **You have low vision but did not receive the survey**
- **You would prefer to complete the survey over the phone and we can assist you.**

Governors become State Patrons of the Foundation

Following State Governors becoming 'Custodians of Vision' during Macular Degeneration Awareness Week, the Foundation invited Governors to become State Patrons of Macular Disease Foundation Australia. We are honoured that the following Governors have accepted this role:

- **The Governor of Tasmania,**
Her Excellency Professor the Honourable Kate Warner AM
- **The Governor of Victoria,**
Her Excellency the Honourable Linda Dessau AM
- **The Governor of Western Australia,**
Her Excellency the Honourable Kerry Sanderson AO



The Governor of Tasmania had an eye test and macula check during Macular Degeneration Awareness Week in May.

Representation

Two critical areas have arisen regarding cost of treatment (injections):

Medicare Benefits Schedule Review

The Medicare Benefits Schedule (MBS) is a listing of over 5,500 medical services subsidised by the Federal Government under Medicare. The Government has now initiated a review of MBS items.

Each service on the MBS is allocated an item number which is what appears on medical invoices. The items related to eye injections are items 42738 and 42739 and our concern is that the rebate on these items may be reduced. This follows the 2013 capping of the rebates payable for out-of-pocket costs under the Extended Medicare Safety Net.

While there may be legitimate reasons to review many items on the schedule, any proposed changes must not be a simple cost cutting exercise for government which shifts additional cost onto patients.

The Foundation is monitoring progress of this review on injection item numbers and has already represented the macular disease community at several government consultation days. We will be monitoring, assessing and contributing to this review wherever possible.

This review is important because it not only affects items for macular disease treatment but also covers a range of items that will affect all Australians, especially older Australians with chronic and multiple health issues.

We will keep you updated.



NIB cuts benefits for eye injections

Private health insurer NIB has ceased providing MediGap benefits for 224 items including 3 items for eye injections undertaken in a private hospital or day surgery setting effective 17 August 2015. The choice between the provision of injections in theatre or in rooms is between the doctor and the patient. However, if NIB customers decide to continue treatment in theatre they will now incur out-of-pocket expenses if the doctor charges above the scheduled fee for an injection.

Those affected by the **NIB changes** are largely older Australians, many of whom have been in health funds for many years with the understanding that these funds would provide financial protection in their older years when health conditions often occur.

Note that private health insurance (from any insurer) does not cover gap payments for procedures performed in ophthalmologists' rooms.

Representation

What is the Foundation doing to represent you on this issue?

The Foundation has discussed this issue with NIB in strong terms with no satisfactory outcome. We have subsequently raised our concerns with the Federal Department of Health and the Australian Medical Association. The matter is now being raised with the Australian Competition and Consumer Commission and the Private Health Insurance Ombudsman.

This is a serious issue and the Foundation is concerned that other health insurers may follow suit.



What you can do if you are an NIB customer affected by these changes:

- Call the Foundation and register your name so we are aware of the number of people affected - 1800 111 709
- Write to NIB - We can assist by providing a standard letter, if required
- Send a copy of your letter to your local MP. If writing your own letter, please send a copy of your letter to the Foundation
- Contact the Private Health Insurance Ombudsman to register a complaint

Address NIB letters to:

**Mr Mark Fitzgibbon
Chief Executive Officer
NIB
22 Honeysuckle Drive
Newcastle NSW 2300**

Register a complaint with the Private Health Insurance Ombudsman by:

Calling 1800 640 695 or emailing info@phio.gov.au
You will need to quote your health fund membership number, health fund name and your preferred contact phone number or email address

Representation

Low vision aids included in the Commonwealth Home Support Program (CHSP)

The Federal Government has announced that specific funding for low vision assistive technology is now included in the CHSP. This is a win for older people with low vision needs. The Foundation is very pleased with this outcome after several years of work on this issue for our community. The following has been included:

- ✓ CHSP clients are able to access up to \$500 per financial year for low vision assistive technology. This can be used for multiple items.
- ✓ Where a CHSP provider assesses it to be necessary, the amount can be increased to \$1,000 per client per financial year. This was a key recommendation by the Foundation.

Note: Victoria and WA have not transitioned to the CHSP. The Home and Community Care (HACC) program continues to operate in those states and are not included in these changes.

For more information contact the Foundation on 1800 111 709.

Australians with diabetic macular edema (DME) or retinal vein occlusions (RVO) now have access to sight-saving treatment on the PBS

In May 2015, the Federal Government listed Lucentis on the Pharmaceutical Benefits Scheme (PBS) for treatment of diabetic macular edema and retinal vein occlusions. This means that, like those with wet macular degeneration, people with these diseases now have affordable access to this registered treatment which has been fully evaluated and approved by the TGA for safety and efficacy.

The Foundation has and will continue to advocate strongly for accessibility and affordability of registered treatments.

DME is a common complication of diabetes which can lead to vision loss and blindness and RVO causes vision loss primarily in people over the age of 60.



Representation

Federal funding update

The Department of Health has provided a recurring grant since 2006. The last 3-year agreement ended in June 2015 and a 6 month extension to 31 December 2015 is now in place. A new grant is available called the Health Peak and Advisory Bodies Program and the Foundation has applied for funding from this grant but this will not incorporate our education program.

We await the other funding grants being opened for application for our education program. So keep those engines fired and ready to support our advocacy when we need it!

Please note that the NSW Government grant for education in NSW, continues with great appreciation.

Macular disease factsheets available

The Foundation has updated factsheets on a range of macular diseases including:

- Epiretinal Membrane (Macular Pucker)
- Macular Hole
- Macular Telangiectasia (Mac Tel)
- Myopic Macular Degeneration
- Posterior Vitreous Detachment
- Retinal Detachment
- Retinal Vein Occlusion
- Retinitis Pigmentosa
- Stargardt's Disease
- Vitelliform Macular Dystrophy (Best's Disease)

A factsheet on Charles Bonnet Syndrome is also available.



For a copy of any of these factsheets please call the Foundation on 1800 111 709.

Diabetic Eye Disease information kit

Everyone with diabetes is at risk of diabetic eye disease. If you have diabetes, call 1800 111 709 for a free information kit.



Research

Governor-General to announce Macular Disease Foundation Australia Research Grants

It is a great honour that the Governor-General of Australia Sir Peter Cosgrove will announce the recipients of the Macular Disease Foundation Australia Research Grants on World Sight Day (8 October 2015). The announcement will take place at an event hosted by the Governor-General and Lady Cosgrove at Admiralty House, Sydney.

With your help, the Foundation has committed \$1.5 million to Australian researchers to date. This round of grants will make up to a further \$1.3 million available and will include a new grant supported by Blackmores for \$600,000 over 3 years.



Research special

Our summer newsletter, due out in early December, will be one not to miss. It will include our annual research update and details of the recipient/s of the Foundation's Research Grants Program.

Media reports regarding Argus 2 implant 'bionic eye'

Extensive media coverage was given to a BBC report on the first case of a person with dry macular degeneration receiving the Argus 2 retinal implant, commonly referred to as a 'bionic eye'. This is a promising development in the quest to allow people

with significant vision loss a means to see their world. However, as with all early trials, there is still significantly more research and development required.

Almost everyone with macular degeneration will have much better vision than the limited images that the 'bionic eye' device currently provides. However, it is hoped that with further development, it will eventually allow the recipient to read, to see faces and watch TV. This will be quite some years away yet, but developments such as this continue to remind us of the extraordinary outcomes that investment in research can deliver. The Argus 2 is not currently available in Australia.



Awareness

mEYE Word Photographic Competition - record number of entries received!

Over 2,400 photos were entered into the 2015 mEYE World Photographic Competition which closed on 8 September.

Our judges now face the difficult task of deciding this years' winners. The judging panel includes Foundation Patron Ita Buttrose, internationally recognised photographer Rex Dupain and one of Australia's longest serving news photographers, Alan Pryke.

Winners will be announced on 12 November and highlighted in the December newsletter. Here are just a few of the fantastic photos received.



Open Category
Leanne Gibb



Open Category
Denis Fitzgerald



Macular Disease Community Category
Sarah Round



Junior Category
Joshua Heap



Healthcare Professional Category
Andrew Tsao

Living Well

Top tips for living well with low vision

Have a low vision assessment with a low vision service.

The assessment will test how much vision is remaining and provide advice based on your individual requirements. This may include recommendations for magnifiers.

For many, a low vision assessment is an important step in taking control of their vision loss and regaining confidence. Call the Foundation on 1800 111 709 to find relevant services in your state.



Seek help from low vision services before your vision has deteriorated too much.

It is much easier to learn to use aids and technology before significant vision loss has occurred.

Use accessibility features on your smart phone or tablet. Most models include a range of accessibility features including increasing text size, increasing contrast, changing colours and text-to-voice features.

These features are usually located within the 'settings' function.

Book an appointment with the Foundation's low vision advisory service at our Sydney CBD office.

To book, or for information on low vision services in other locations, call the Foundation on 1800 111 709.

Change text size when using a Windows based computer by holding the control (Ctrl) key and scrolling up or down with the mouse tracking wheel.

Learn computer skills by joining your local Australian Seniors Computer Club. Club locations can be found at www.ascca.org.au or call the Foundation for assistance to find a club near you.



Call the Foundation on 1800 111 709 for information, guidance and support and to obtain a copy of our free publications:

- Low Vision: A Guide
- Low Vision Aids & Technology: A Guide
- Family, Friend and Carer: A Guide
- Slips Trips and Falls: A Guide

Education

Upcoming education sessions

Bookings are essential - phone 1800 111 709

New South Wales

Location	Date and Time	Address
Shoalhaven Heads Seminar and Low Vision Display	Thursday 12 November 2015 10.30am - 1.00pm	Shoalhaven Heads Bowling & Recreation Club 76 Shoalhaven Heads Road Shoalhaven Heads

Queensland

Location	Date and Time	Address
Brisbane Retirement & Lifestyle Expo	Friday 16 October to Sunday 18 October 2015 One session delivered each day – times to be confirmed	Brisbane Showgrounds Gregory Terrace Bowen Hills

Western Australia

Location	Date and Time	Address
Perth Guest speaker: Associate Professor Dimitri Yellachich, Retinal specialist	Sunday 4 October 2015 2.00pm - 4.00pm	Wesfarmers Lecture Theatre Business School University of Western Australia Hackett Drive, Crawley

Tasmania

Location	Date and Time	Address
Hobart Guest speaker: Associate Professor Nitin Verma, Ophthalmologist Includes a Low Vision Display	Saturday 12 December 2015 10.00am - 12.00pm	Wrest Point 410 Sandy Bay Road Sandy Bay

**The Foundation holds education sessions across Australia.
Stay posted for upcoming sessions in your state.**

Fundraising

Keep your eye on the winning horse this Melbourne Cup!

If you, your friends or family members are holding an event for Melbourne Cup, and there is an opportunity to fundraise for charity, we would appreciate the Foundation being the charity of choice.

Donate an extra dollar when entering the sweep, or donate part of your winnings!

For more fundraising ideas, contact the Foundation on 1800 111 709.



Thank you to everyone who made an end-of-financial-year donation to the Foundation. Your generosity is greatly appreciated.

NSW Clubs support Foundation through ClubGRANTS Scheme

The Foundation is grateful to registered clubs in NSW for their continued support through the ClubGRANTS Program.

Thank you to supporting clubs: Campsie RSL Club, Cabra-Vale Diggers, Club Central Hurstville, Dubbo RSL Club, Orange Ex-Services Club, Commercial Club (Albury), Hornsby RSL Club, Maitland RSL Club, Lithgow Workies.



L-R: Robyn Mason, MDFA; Alf Briscoe, Director, Club Central Hurstville; Sandra Coogan, Director, Club Central Hurstville

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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