

Dear Friends



Winter came very late but let's hope spring is on time. I cannot wait to smell the wonderful scent of jasmine, for me it heralds the new season. I am reminded of 'Friends of the Foundation' who love gardening, some of whom

live with vision loss. They tell me of the enjoyment they get from being surrounded by lovely scented flowers, the native birds and the pleasure that gardening brings.

The amazing friends we meet at the Foundation, the thousands we talk to on the Helpline and the very special stories clients take the time to share, reinforce how privileged we are to serve you. In the last financial year over 8,000 people attended our education sessions and over 13,000 called our national Helpline. We distributed over 7,000 information kits and promoted our key messages in media across the country.

We are focused on the Foundation's vision to reduce the incidence and impact of macular disease in Australia and every day we are reminded of the importance of our work in prevention, early detection, access to treatments and supporting those with low vision.

One man, a fisherman, recently read our message on early detection and rang our Helpline. He had noticed that the horizon had become distorted over the

past three weeks while out on his boat. I was very concerned about this distortion and delay in a diagnosis. We managed to have him seen by an optometrist that very day who immediately referred him to an ophthalmologist. By that evening he had been diagnosed with wet macular degeneration and received his first injection in the affected eye. He continues to have treatment. Since his diagnosis another direct family member has also been diagnosed and also receives treatment for wet macular degeneration.



The horizon is back to normal and my fisherman friend has returned to his work. His sight has been saved. At the time he contacted us I was pretty determined to take him off his boat even though there were a lot of fish biting that day. Determined we are and determined you must be to never ignore any changes in your vision and to seek help immediately.

We are also determined to have Federal Government support for our Helpline so we can do even more to save sight.

The good news is that spring is coming and I understand that the fish are back biting. Take care as always.

Julie Heraghty
Chief Executive Officer

Representation

Federal budget update

Proposed changes to Medicare funded eye checks

The recent Federal Budget proposed two changes to the current Medicare rebate given for comprehensive eye examinations by an optometrist:

1. For people aged 65 years and over who do not have any symptoms, Medicare will provide a rebate for a comprehensive eye examination once per year (currently every 2 years).
2. For people under the age of 65, Medicare will only provide a rebate for people without symptoms once every 3 years (currently every 2 years).

While the Foundation supports the Federal Government's proposed changes to improve access to eye examinations for people aged 65 years and over, the proposed reduction in access to Medicare funded eye examinations for under 65s is not optimal.

The early signs of macular degeneration often appear well before age 65 and detecting the disease before symptoms occur can prevent irreversible vision loss. The Foundation is supporting the status quo of eye examinations on a 2 yearly basis for people aged between 45 and 65 who show no symptoms of an eye condition.

Note that these proposed changes have not been passed by parliament.

Ongoing representation on budget changes which may affect you...

The Foundation will continue to closely monitor other proposed 2014 budget changes that may impact our macular disease community in 2015. This includes proposed changes to Medicare, GP co-payment and private health insurance rebates.

Annual General Meeting

Date: 9 December 2014

Time: 12.00pm - 12.45pm
(followed by Christmas refreshments)

Place: Macular Disease Foundation
Australia Head Office
Suite 902, Level 9
447 Kent Street, Sydney

RSVP: 28 November 2014 on
1800 111 709 (RSVP essential
for catering purposes)

All welcome

Private health insurance rebates

Aids and technologies

The Foundation has, with your help, advocated strongly over the years for improved rebates from private health insurers for aids and technologies for those with low vision.

From this we did have improvements with some insurers. We are presently reviewing the status of these rebates once again with private health insurers. Hearing aids are covered (as they should be) in almost all policies and yet vision aids do not receive equivalent coverage.

If you have had an experience with your private health insurer regarding a rebate for an aid such as a magnifier or CCTV, which may assist in our advocacy work please contact the Foundation on 1800 111 709.

Representation

Government aged care reforms

'My Aged Care'

As part of the aged care reforms, 'My Aged Care' has been established as a single contact point to access the aged care system. 'My Aged Care' will provide you, your family and carers with information on, and referrals to, aged care services.

The Commonwealth Home Support Program (CHSP) is one of the key areas where people may be referred.

What is 'My Aged Care'?

'My Aged Care' is the new, central portal for information on, and access to, the aged care system. It consists of a website (www.myagedcare.gov.au) and a national call centre open between 8.00am and 8.00pm on weekdays and between 10.00am and 2.00pm on Saturdays.

Phone 1800 200 422



The Commonwealth Home Support Program (CHSP)

In the recent reforms to aged care, the Federal Government made changes that will introduce a single, streamlined home support program from 1 July 2015. The CHSP aims to support older people so that they may continue living in their own homes

for as long as possible. The CHSP will provide basic maintenance, care, support and respite services for older people living in the community. At this stage Western Australia is still negotiating their inclusion in this reform to the national program.

For many years, the Foundation has been advocating strongly at every possible turn to ensure people who develop vision loss over 65 years have access to affordable low vision aids, technology and support. Given the present access for this age group is denied through the NDIS, the only pathway is presently through the aged care system and the proposed CHSP.

Low vision aids and technology

An opportunity exists for the provision of low vision aids and technologies in the CHSP for older people with a disability.

In July 2014, the Federal Government released the draft Commonwealth Home Support Program (CHSP) for public comment. The Foundation provided a strong submission recommending the appropriate inclusion of low vision aids and technology in the CHSP and supporting a holistic approach to assessment and support. Assessment by an occupational therapist, mobility aids, home modifications, and personal assistance are all part of the CHSP.

If the Foundation's recommendations on the CHSP are accepted, it will be an important first step in securing support for older people living with low vision to enable independence, engagement with the community and enhanced quality of life.

Contact the Foundation if you require further information about 'My Aged Care'.

Representation

PIN-only credit cards – We have been fighting on your behalf

Since the beginning of the year the Foundation has been communicating with banks and major financial institutions surrounding the issues of the introduction of PIN-only authorisation credit cards from 1 August 2014. These changes have been introduced to increase security around transactions and will reduce the incidence of fraud.

The Foundation received a number of calls from members of our community who were frustrated with the lack of information and service provided by banks and financial institutions for people with low vision negotiating these changes. In response, the Foundation conducted a survey to assess the avenues for information and support available to those who required assistance or had genuine need to remain with a signature-approval credit card. This survey found that few major banks and financial institutions had knowledge of, or consideration for, these clients and hence had not established processes to assist them with the transition.



After a great deal of advocacy to alert various banks and financial institutions to the lack of service delivery, there is now reassurance that those who require a signature option credit card and have a genuine inability to use a PIN will be serviced appropriately.

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, contact the Foundation on 1800 111 709 and we will endeavour to assist.

South Australia's hospital crisis update

The Foundation has continued to lobby on the capacity crisis issue at Royal Adelaide Hospital (RAH) by writing to every SA politician on this issue. Thank you to all our South Australian readers who sent the campaign letter to their State MP.

SA politicians Rob Lucas, Stephen Wade and Kelly Vincent have asked helpful questions in Parliament and Estimates Committee meetings.

Foundation CEO Julie Heraghty met with SA Health Minister Jack Snelling to discuss the crisis and urged an immediate dialogue

between SA Health and ophthalmologists at RAH to work on practical, viable outcomes so that patients can receive timely treatment. Some progress has been made from this meeting but there are still many gaps in the service.

In addition to the current crisis, the Foundation has been advocating to address the reduction in outpatient eye treatment rooms at the new RAH site.

We won't give up. Access and affordability of treatment is essential for all Australians so that sight can be saved.

Research

Foundation research published in *Aging and Mental Health* journal

An article detailing the Foundation's 'Ripple Effect of Vision Loss' research has been published in the peer reviewed journal, *Aging and Mental Health*.

The Foundation is proud of the publication of this research which highlighted the unexpected burden and impact of wet age-related macular degeneration on both the person living with the disease and the person who cares for them.

The Foundation thanks Associate Professor Bamini Gopinath, Annette Kifley and Professor Paul Mitchell at the Westmead Millennium Institute for supporting the detailed analysis of the data and the writing of the paper. The original research was funded by Bayer.

Rehabilitation cuts depression in half

Depression is a common risk for people who have lost their vision from macular degeneration, however, a new study has shown some encouraging results.

The study found that rehabilitation methods which involve helping people to recognise that the loss of enjoyed activities could lead to depression, and then helping them to re-engage with those activities, reduced the risk of depression by 50% in study participants. The rehabilitation involved assisting people to use low vision aids effectively, make practical changes to their homes, maintain or increase social activities and set goals.

If you are concerned about depression speak with your GP.



Retinal imaging may provide an early indication of Alzheimer's disease

Preliminary results from an Australian study have suggested that retinal imaging could possibly be used in early detection of Alzheimer's disease.

Researchers found the level of beta-amyloid protein detected in the eye was significantly correlated with beta-amyloid in the brain and this allowed them to accurately identify those with Alzheimer's.

If further research supports the initial findings, it is hoped that that the process could become part of a regular eye check-up and provide a method for monitoring Alzheimer's progress and response to therapy.

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 Foundation's Blackmores Dr Paul Beaumont Research Fellowship recipient to be announced on World Sight Day, 9 October 2014.

Awareness

Diabetes and your eyes

Some of our readers may have diabetes as well as macular degeneration. It is important for these people to know that diabetes brings with it a risk of developing diabetic eye disease.

The early stages of diabetic eye disease usually have no symptoms. However once the disease reaches later stages, vision loss can occur rapidly and can be permanent. For this reason, it is critical that all people with diabetes get an eye test at least every two years (or more often if recommended by the optometrist or ophthalmologist) in order to detect the earliest signs.

A recently approved treatment (fenofibrate), which is taken as a tablet, has been shown to reduce the need for more extensive treatment (such as laser) in people who already have retinal damage due to type 2 diabetes. Any treatment, care or management for diabetes should be discussed with the GP or eye specialist.



A new publication on diabetic eye disease is now available. For a free copy call the Foundation on 1800 111 709.

A sight worth saving

Dust off your camera – the 4th annual mEYE World Photographic Competition has now opened!

This year's competition invites entrants to submit a photo along with 30-60 words explaining how their entry captures the competition theme 'a sight worth saving'. Foundation Patron Ita Buttrose will head up an impressive judging panel including iconic artist Ken Done, internationally recognised photographer Rex Dupain and one of Australia's longest serving news photographers Alan Pryke.

There are four categories for entry including one exclusively for the macular disease community. In previous years we have received some wonderful entries from those with low vision. We hope that all newsletter recipients will enter and in doing so, help raise awareness of macular disease.

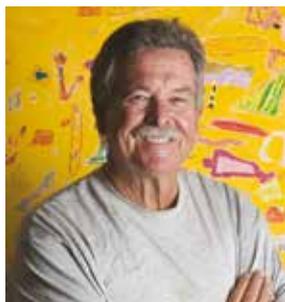
Entries can be submitted via the competition website www.meyephotocomp.com.au or if you are unable to use or access a computer, you can post your entry to the Foundation.

**Competition Period
2 September – 12 November**

The Judging Panel



Ita Buttrose



Ken Done



Rex Dupain



Alan Pryke

Always be prepared!

When living with low vision, it is important to be prepared for the unexpected and have relevant 'emergency plans' in place. Uncle Bruce, who has shared many of his experiences of living with vision loss, was relieved he had an emergency plan when Cyclone Ita came close to his home earlier this year.

There are many resources available to help you come up with emergency strategies. With a plan in place, you will be better equipped to stay calm and respond appropriately. Your safety is important.

Uncle Bruce's simple tips...

- ✓ **Create an emergency kit** - include torches, portable radio and spare batteries.
- ✓ **Compile an emergency contact list** - keep it on your fridge, near the phone or saved on speed dial. It should include family, friends and emergency services.
- ✓ **Make a plan** - in an emergency where would you go and how would you get there? Do you have any dependents or pets to consider?



Eating for eye health recipe - Fish cakes from a tin



- 150g (2oz) potatoes, diced
 - 200g (6½oz) tinned salmon, drained
 - Sea salt and freshly ground black pepper
 - 1 bunch parsley, washed and chopped
 - 2 tablespoons fresh parmesan cheese, grated
 - 1 cup breadcrumbs
 - 1 cup flour
 - 2 eggs, lightly beaten
 - 2 tablespoons light olive oil
1. Peel the potatoes and from a cold water start, boil until they are tender, drain and mash.
 2. Mix the salmon, potato, a little salt and pepper and half the parsley until combined. Mould the fish mix into round cakes.
 3. Mix the breadcrumbs, parmesan and the remainder of the parsley together.
 4. Roll the fish cakes in the flour and dip them in the beaten egg before rolling in the breadcrumb mix. Heat the oil in the frying pan and bring to a medium heat and gently fry the fish cakes for 4 minutes on each side or until golden brown.
 5. Remove from the pan and rest on absorbent paper before serving.

This recipe is taken from 'Eating for Eye Health - The Macular Degeneration Cookbook' by Ita Buttrose and Vanessa Jones. Cookbooks are available from selected bookshops or from the Foundation for \$27 + postage and handling.

Fundraising

Keep your eye on the ball

In celebration of World Sight Day on 9 October 2014, the Foundation is



inviting bowls clubs across Australia to hold an event during October to raise funds for the Foundation. Clubs can host a fundraising bowls day, BBQ or other event. All funds raised will go towards Macular Disease Foundation Australia's Research Grants Program.

If you or someone you know is a member of a bowls clubs and would like to participate, contact the Foundation on 1800 111 709.

Thank you Quota!

Thanks to Quota International Clubs of the 35th District for selecting the Foundation as their District Project. The 12 clubs in the District each supported the project by organising a fundraising event or making a donation to contribute to the overall amount which will go towards Foundation programs.

NSW Clubs give generously to Foundation programs

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

Thank you to supporting clubs: Cabra-Vale Diggers, Campsie RSL Club, Bankstown Sports Club, Club Central Hurstville, Orange Ex Services' Club, Griffith Exies, Griffith Leagues Club, Hornsby RSL Club and Petersham RSL Club.



Neville Moloney and Gordon Brian from Campsie RSL Club present Foundation Fundraising Manager Judith O'Hagan with their generous ClubGRANTS donation.

If you are a member of a community group and you would like to support the Foundation please 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 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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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. Sept 2014