

Dear Friends,



I hope that 2014 is bringing you good health and happiness.

The voice of the Foundation

I am very grateful for the support that you give the Foundation in many ways, so we obtain the best outcomes for the macular disease community. Your support of the Foundation's advocacy efforts makes our message more powerful when speaking to government.

This was well demonstrated by the wonderful feedback from the *Have a Cup of Tea with your new MP* campaign. Please read about Val, Roly, Margery and Norm who took the opportunity to have a cup of tea with their new MP and shared their experiences of living with macular degeneration.

Help the Foundation

I now have a very special and important request for everyone to help make our voice heard.

I would greatly appreciate your representation to the Minister for Health to support our submission in this year's Federal Budget requesting \$6 million over 3 years for the Foundation's Helpline.

Ours is the only national Helpline service providing patients, family, carers and health professionals with information, guidance and support on macular disease. This is despite the high prevalence and enormous impact of macular disease, primarily macular degeneration, in Australia.

While the Federal Budget constraints are acknowledged, the overall funding request is reasonable and fair, given the scale of this disease and the limited government funding allocated to the Foundation for its work.

The fact is the Foundation has received an average of only \$163,000 per year (excl. GST) in federal funding since 2005. No federal funding has been received for the Helpline.

To support the Foundation's funding request I ask that you sign the enclosed letter to the Federal Minister for Health and return it to the Foundation using the enclosed reply paid envelope by 1 April. We will deliver all the letters to Parliament House for you. See page 2 for more information.

Nutrition and Supplements

It is so important to eat an eye health friendly diet and to consider a supplement if appropriate. Enclosed is the updated fact sheet: *Nutrition and Supplements for Macular Degeneration*. Please call the Foundation if you have any questions or need clarification on any matters associated with nutrition and supplements.

Also, get ready for a re-launch of our *Eating for Eye Health* cookbook in early May.

Thank you

Finally, thank you to Uncle Bruce, who reminds me of the challenges for so many of our macular degeneration community living with low vision. Read about his latest encounter and make sure you have our booklet *Slips, Trips and Falls - A Guide*, which is now also available in audio.

Happy Easter, be safe, take care and thank you for your ongoing support.

**Julie Heraghty
Chief Executive Officer**

Representation

Help the Foundation

The Foundation has submitted a request for funding of \$6 million over 3 years as an allocation in the 2014-2015 Federal Budget. This funding will provide for Macular Disease Foundation Australia's national Helpline.

Since 2005 the Foundation has received an average of only \$163,000 per year (excl. GST) in federal funding despite the high prevalence and enormous impact of macular disease, primarily macular degeneration.

No federal funding has been received for the Foundation's Helpline. The current 3 year federal grant, ending in 2015, is for \$442,393 (excl. GST) which is \$147,464 per year.

The Foundation has prepared a campaign letter for you (enclosed) to support our funding submission, addressed to the Minister for Health, The Hon Peter Dutton MP.



How to help the Foundation

- ✓ Complete your personal details on the enclosed letter, sign and date in the space provided.
- ✓ Send the letter back to the Foundation in the enclosed reply paid envelope by 1 April. If you are also generously sending a donation, just use the envelope for both purposes.

The Foundation will ensure that all letters are delivered to the Minister for Health at Parliament House.

Q. What have we done on your behalf since the Summer newsletter?

1. Correspondence with Federal MPs (February 2014): The Foundation has written and thanked all MPs for taking the time to meet with older Australian's living with macular degeneration and to hear their special stories.

2. Prevalence of macular degeneration in Australia by state electorates: Macular Disease Foundation Australia published the map of the estimated number of people (prevalence) with macular degeneration in Australia for federal electorates in 2013. We have now published the prevalence data for state electorates on the *Sight for Seniors* website www.sightforseniors.com.au

3. NDIS exempt from Age Discrimination Act: The NDIS legislation was exempted from the *Age Discrimination Act 2004*. As a result, it is not possible to make a legal complaint against the NDIS on the grounds of age discrimination, for those acquiring a disability after the age of 65, such as blindness from macular degeneration.

The Foundation wrote to the Parliamentary Joint Committee on Human Rights in June 2013 to draw attention to this injustice. The report (released January 2014) expressed concern and referenced the Foundation's submission. The Foundation welcomed the Committee's recommendation that this issue be evaluated when the Act is reviewed in 2015.

Representation

Thank you everyone

Thank you to all those who were able to contribute to the *Have a cup of tea with your new MP* campaign. Whether you visited your MP, sent your MP the campaign information card or had a conversation with someone in your family or community about the key issues, your efforts are greatly appreciated. It adds to the education of our elected representatives and the wider community on our key concerns.

South Australian Val Sellars and her husband Roly met with their Federal MP Matt Williams, to explain the impact that living with macular degeneration has had on her life and her family. Val's electorate of Hindmarsh ranks number one in prevalence with an estimated 9,871 people

living with macular degeneration. They also spoke of the need for greater access to and affordability of aids and technology for people with low vision, the exclusion from the NDIS of those acquiring a disability after the age of 65 and the need for increased federal funding to the Foundation to match the scale of this disease in Australia.



Val Sellars and Mr Matt Williams MP



Val's story

In 2002 I noticed a blank spot in the vision of my right eye and was diagnosed with wet macular degeneration. With treatment, my sight held until 2013 when I started to lose a little more sight. After seeing my ophthalmologist I was told I had dry macular degeneration underlying the wet. I guess my sight will deteriorate, but hopefully slowly. Fortunately, I am still able to get around and do things that I like. I am still able to write, even

if untidily, but I can't read street signs or phone books. I do use a magnifier when I need to read and have glasses that I use to watch TV. I have found that binoculars are great to see close up. I found that by being in a group of other people going through the same thing you learn that you can still have a laugh. You can still get on with life. I must admit that I am apprehensive about losing more sight but like so many others, I will learn to cope.



Thank you also to Margery Stevens and husband Norm from NSW who met with the Federal Member for Banks, Mr David Coleman MP to speak about the key points of the Foundation's *Sight for Seniors* campaign. Mr Coleman has made representations to Senator the Hon Mitch Fifield, Assistant Minister for Social Services, on behalf of Mr and Mrs Stevens.

Norm and Margery Stevens

Awareness

Macular Degeneration Awareness Week 2014



Macular Degeneration Awareness Week will be held from Sunday 25 May to Saturday 31 May 2014.

How can you be involved?

- ✓ Remind friends and family that a direct family history of macular degeneration brings a 50% chance of developing the disease and that it is essential for those over 50 to have an eye test and make sure the macula is checked.
- ✓ Encourage friends and family diagnosed with macular degeneration to contact the Foundation to ensure they receive ongoing information and support.
- ✓ Address your local council or meet the mayor to discuss ways the local area could be improved for those with vision loss.
- ✓ Encourage local media to promote Macular Degeneration Awareness Week. You may like to share your story.
- ✓ Organise a fundraising event through your local community or social club.

- ✓ If you belong to a community service group, such as Rotary or Probus, hold a community event using information flyers available from the Foundation.
- ✓ Ask a local optometrist to speak about macula health at your community group meeting.
- ✓ Become an 'Everyday Hero'. The Everyday Hero website allows you to set up a fundraising event where friends and family can donate. For those using a computer, follow the link on www.mdfoundation.com.au

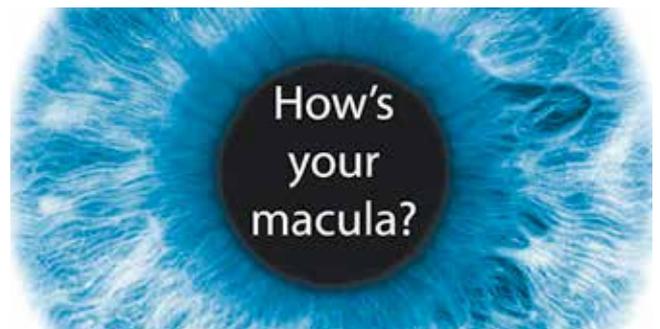


New TV and Radio Advertising Campaign

The Foundation will be running a major national television and radio awareness advertising campaign in May. Thank you to Bayer for supporting this initiative in 2014. These advertisements will highlight the importance of having an eye test and making sure the macula is checked.

The advertisements will also direct people to contact the Foundation to get their free information kit and Amsler grid. Please encourage friends and family over 50 to ring the Foundation. This is especially important for those diagnosed

with macular degeneration, whether they have vision loss or not, to ensure they receive ongoing information, guidance, support and understanding.



Our Founding Director



Founding Director, Dr Paul Beaumont AM, announced his retirement as director of the Foundation at the Annual General Meeting on 10 December 2013.

Dr Beaumont has given 12 years of outstanding service to the Foundation undertaking many roles including chairman of the Foundation's board and medical committee, NSW state chairman and a member of the research committee.

Chairman Elizabeth Carr, on behalf of the Foundation, thanked Dr Beaumont for his foresight and courage in establishing a Foundation to reduce the incidence and impact of macular degeneration in Australia.

Our Patron



The Foundation would like to congratulate Patron Ita Buttrose AO, OBE on completing her tenure as Australian of the Year 2013.

Over the year Ita has lent her powerful voice to many Foundation activities including Macular Degeneration Awareness Week, the *Sight for Seniors* campaign and as a judge of the Foundation's mEYE World Photographic Competition.

Ita's contribution as Foundation Patron over the past 9 years has been invaluable in raising awareness of macular disease and the Foundation is extremely grateful for her ongoing support.

Our Professional Friends



The Foundation has now launched the Professional Friend program.

The program enables ophthalmologists and optometrists across Australia to demonstrate their support for the Foundation.

Encourage your optometrist and/or ophthalmologist to join the Professional Friend program to show their ongoing commitment to the Foundation and its work.

Participating Professional Friends have already begun to display the Professional Friend logo at their practice. A list of participating Professional Friends can be found on the Foundation's website.

Please note: Participation in the Professional Friend program does not constitute an endorsement or recommendation from the Foundation.

Our Partners and Supporters

The Foundation could not provide the high standard of representation, awareness programs and client support services without our partners and supporters.

Our sincere thanks go to our current partners and supporters Bayer, Blackmores, Novartis, Profield Foundation, Optical Distributors & Manufacturers Association (ODMA), Ernst & Young, King & Wood Mallesons, Quantum RLV, participating ClubGRANTS Clubs and all our many business supporters for their contribution and support.

Living well - Staying safe

Slips, trips and falls

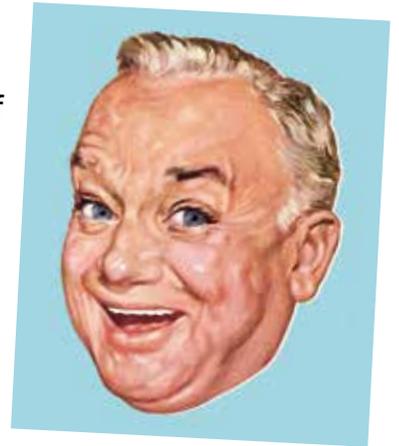
The Foundation began providing low vision badges after hearing about the travel experience of Foundation CEO Julie Heraghty's Uncle Bruce. Legally blind from macular degeneration, Uncle Bruce recently had a serious fall while shopping. This has reminded us how important it is for those with low vision to implement practical steps to avoid injury.

33% of those living with AMD have had a fall as a result of their vision loss – Sightseer Study 2013

Orientation and mobility training is available from low vision service providers and should be considered by anyone with vision loss. Training is tailored to your specific needs and can take place at home or out and about. It is important to learn the skills of low vision mobility early, while vision is

better, to maintain the highest levels of independence and confidence.

Call the Foundation for advice on low vision service providers offering orientation and mobility training and for a free copy of *Slips, Trips and Falls: A Guide*.



For those with low vision this guide is now available in audio format.

Of those who have had an accident as a result of vision loss, 19% were hospitalised – Sightseer Study 2013

Tips for avoiding a fall while out and about

- Plan ahead and allow ample time to travel and get to public transport.
- If you use a mobility aid, visual aid or glasses, always remember to leave them in the same place near the door.
- If catching a bus, ask the driver to wait until you are seated before they start driving and let them know which stop you require.
- Where possible, take the elevator and avoid stairs.
- Use hand railings when using stairs.
- Avoid routes around dangerous intersections.
- Take a moment to let your eyes adjust when switching from a bright environment to a dimly lit one.
- Wear your low vision badge so that others know to assist you where required. If you would like a free badge, call the Foundation on 1800 111 709.



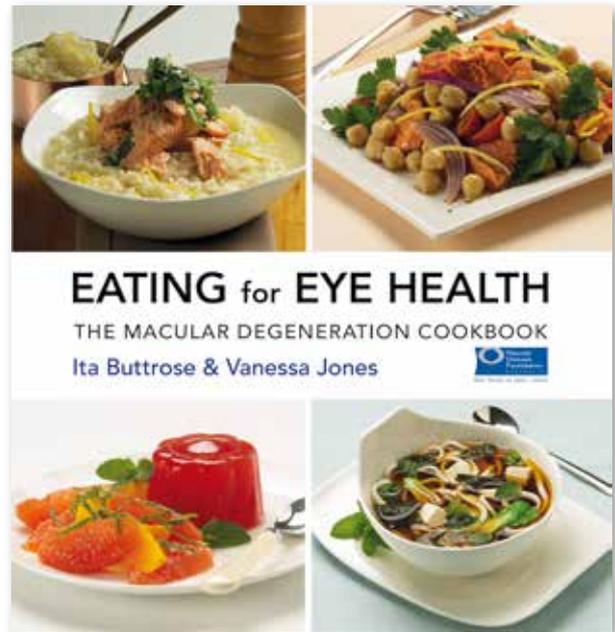
Living well - Staying healthy

Foundation Cookbook

The Foundation's original *Eating for Eye Health* cookbook, co-authored by Ita Buttrose and Vanessa Jones, is currently being reprinted and will be relaunched and available from early May for \$27 (incl. GST).

The cookbook features over 80 delicious recipes using eye friendly ingredients and makes a great Mother's Day or birthday gift!

To pre-order a copy of the cookbook call 1800 111 709. Payment will not be processed until stock is available.



Smoked Trout with Avocado

Serves 2



Instructions:

1. Remove the skin from the trout and break the flesh into fairly large pieces and put to one side.
2. Peel the avocado and dice into a bowl with the parsley, lemon juice and the extra virgin olive oil and mix together. Season to taste with salt and pepper.
3. Put equal portions of the trout on a plate and serve with the avocado.

Ingredients:

- 200g smoked trout fillet
- 1 avocado
- ½ bunch flat leaf parsley, washed and chopped
- Juice of 1 lemon
- 1 tablespoon extra virgin olive oil
- Sea salt and freshly ground black pepper, to taste

For a variation replace trout with smoked salmon or tinned tuna!

An updated *Nutrition and Supplements for Macular Degeneration* fact sheet is now available and a copy has been included with this newsletter. If you would like to know more about nutrition or supplements, call the Foundation on 1800 111 709.



Fundraising

Your help...

The Foundation relies on donations for the numerous activities and services provided to the macular disease community and for the research grants program. There are many ways you can support the Foundation.

Regular giving - Contributions on a regular basis are an easy way to support the ongoing services of the Foundation. This can be set up as a direct deposit to suit your individual wishes.

In celebration - A donation in lieu of a gift for a birthday, wedding, anniversary or other celebration is a thoughtful way to recognise a significant occasion.

In memory - Making a donation in memoriam is a considerate and meaningful way to honour a friend or loved one.

Bequests - An updated information booklet is now available. A bequest, big or small, can make a lasting impact on generations to come and is greatly appreciated.

For a copy of the booklet call the Foundation on 1800 111 709.



Roth Gair Charity Golf Day

Thank you to Ian Kennedy and the Lions Clubs of Forest Hill and Park Orchards for holding the 7th annual Roth Gair Charity Golf Day on Sunday 2 February. The day is held in memory of the late Mr Roth Gair, a long time member and past president of the Lions Club of Forest Hill, who had macular degeneration.

Thank you to all the sponsors, supporters, volunteers and participants for a wonderful event and making it their most successful golf day yet.

Donations

Thank you for supporting Macular Disease Foundation Australia. Easter is fast approaching, as is June 30, so if you are considering an end of financial year donation, please consider us in your generous giving.

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 donate by 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. March 2014