Macular Disease Foundation
AUSTRALIA™
Our focus is your vision

Newsletter

WINTER
2nd Edition 2014

Dear Friends

On budget night I anxiously opened up the budget papers on my computer while listening to the commentary. Like you, I am sure, I was very disappointed to see that we were unsuccessful in our request for funding for our national Helpline and additionally concerned for any budgetary impact on older Australians. I was humbled by the support so many of you gave to our campaign. What we were asking was reasonable, necessary and equitable. All your letters of support were delivered to the Minister's office. We will continue to ask - giving up on any issue for our macular disease community is just not an option.

Our new national TV and radio campaign has resulted in people at risk of macular degeneration having their eyes tested and macula checked. Many people have contacted our national Helpline to obtain information, guidance and support. We continue to lead the world in awareness raising of macular degeneration and hopefully saving sight.

The Foundation has been advocating strongly to the South Australian Premier and Minister for Health regarding the unacceptable situation at Royal Adelaide Hospital. In some cases, patients are waiting up to 12-16 weeks for ongoing injections for wet macular degeneration even though their doctor has prescribed injections for every 4 weeks. This places patients at serious risk of irreversible vision loss.

The current capacity crisis in the outpatient eye clinic at Royal Adelaide Hospital is at breaking point and there needs to be immediate action by the South Australian Government. In the longer term there is a viable and commonsense solution in establishing the *SA Eye Hospital* at the current Royal Adelaide Hospital site. SA newsletter recipients have received a campaign letter with this edition to send to their local SA Member of Parliament. We need the help of all South Australians to rectify this appalling situation.
(More on page 2)

I hope you enjoy our section on what to ask the eye health professional. It can be so easy to forget to ask those relevant questions, and also easy to forget the answers unless you are well prepared. I can certainly relate to that. Remember, we cannot give medical advice but we can help on many fronts, so just call the Helpline on 1800 111 709 and we will always do our best to guide and support you.

Take care everyone through the colder winter months. It's hard to believe it is June already. As always, your generous end of financial year donations are greatly appreciated. All donations made before June 30, will be processed immediately to ensure receipt in the 2013/14 financial year for taxation purposes.

Julie Heraghty
Chief Executive Officer

Representation

South Australia's hospital crisis

In South Australia, the vast majority of people receiving injections for the treatment of wet AMD will do so in private doctors' rooms. However, some people need to access the public hospital system.

The current redevelopment of the Royal Adelaide Hospital (RAH) will result in the already inadequate 24 outpatient eye clinic rooms being reduced to just 11. There is presently a capacity crisis at the hospital with patients being placed on long waiting lists and resulting in unacceptable delays for injections for treatment of wet AMD. The proposed reductions in rooms will only exacerbate the crisis and put patients at risk of irreversible vision loss.

In the short term, the Foundation is calling on the South Australian Government to act immediately on this crisis. In the longer term, to create a dedicated public eye hospital - the *SA Eye Hospital* - in the McEwin Building on the current RAH site. This is a viable and commonsense solution.

A call to action to our SA friends:

- ✓ **Contact the Foundation if you are having difficulty with obtaining an appointment for treatment at RAH in the recommended time period.**
- ✓ **Support the Foundation's campaign by completing the enclosed campaign letter to your SA State MP.**

  If you are unsure of your MP's name and/or address, please contact the Foundation and we will assist. (Note: only SA newsletter recipients have received this letter)

Low vision aids and technologies

For many years the Foundation has been advocating for better access to low vision aids and technology. Successive governments and ministers responded to the Foundation's lobbying promising that there would be an equitable solution and successive governments have failed to deliver.

The National Disability Insurance Scheme (NDIS) was to be the answer. However, an age limit was established and those aged 65 and over were excluded from the NDIS. As part of our *Sight for Seniors* campaign, the Foundation fought hard against this age exclusion. Despite our constant lobbying, the current Federal Government has decided to keep the NDIS age limit. This has not deterred us in finding a just and equitable outcome and we are now advocating hard in the aged care policy arena to ensure access to aids and technologies for those aged over 65.

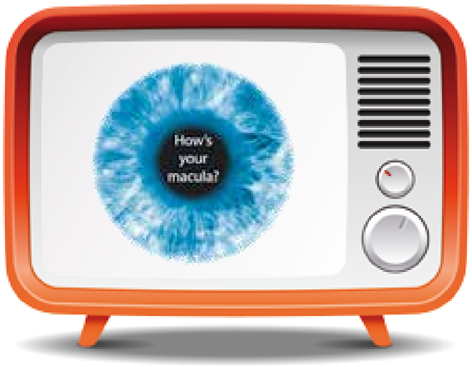
The *Commonwealth Home Support Program* (to be established 1 July 2015) is now the main mechanism for people in the aged care system to access goods and equipment. The Foundation is advocating strongly for a positive outcome for those with vision loss and blindness. We will work hard to ensure those with low vision are not left out again and have equitable access to the aids and services they deserve.

Awareness

National TV & radio awareness campaign

In May 2014 Macular Disease Foundation Australia launched a new national television and radio awareness campaign. The campaign urged people aged over 50 to "have their eyes tested and macula checked" and to access the Foundation for information, support and understanding. Our thanks to Bayer for supporting the 2014 campaign.

Australia is recognised as a world leader in raising awareness of macular degeneration, which has a direct impact on early detection and saving sight. We must be vigilant in maintaining the message as our population ages and the need for information, guidance and support rises.



Have a cup of tea campaign still rolling on

In April, in response to our "Have a cup of tea with your new MP" campaign, a wonderful group from our macular degeneration community shared their stories on living with macular degeneration with Federal Member for Newcastle, Ms Sharon Claydon MP. The group highlighted the critical issues of affordability of low vision aids and the need for Federal funding for the Foundation's national Helpline.

Ms Sharon Claydon MP with Nita, Joy, Ray, Noelle, Peggy, Terry and Victor (L to R)

Ita Buttrose featured in Good Food publication

Foundation Patron Ita Buttrose recently shared her most memorable meal and discussed the eye-health foods she always has on hand at home.

Ita also highlighted the Foundation's relaunched *Eating for Eye Health* cookbook which she co-authored with chef Vanessa Jones. The original cookbook is again available from selected bookshops or from the Foundation. An order form is enclosed.

Living Well

Communicating with your eye care professional

The relationship with your eye care professional, your optometrist or ophthalmologist, is very important. Clear, open and trusted communication with them will give you confidence and reassurance. This is especially relevant if you are having treatment such as injections for wet macular degeneration.

Diagnosed with macular degeneration

If you have been diagnosed with macular degeneration, it is important to feel comfortable asking questions. Information that provides you and your family with an understanding of the diagnosis, treatment options offered and avenues for rehabilitation, will make you feel more comfortable and reassured. Managing your eye health and any treatment or lifestyle changes you may need to undertake is a key priority.

It is quite normal not to recall all the things told to you by your eye care professional. Ask them to write down your diagnosis and any instructions you need to follow. Taking notes or having a friend or family member attend and take notes for you can be very helpful.

There may be special circumstances, such as when treatment is undertaken, that another person is not able to be present.

The Foundation is always here to support you. The following list of questions will help you to remember what to ask at the first or subsequent visits to your eye care professional.

Questions - about macular degeneration

- What type of macular degeneration do I have? Is it wet or dry?
- At what stage is my macular degeneration?
- If **both** eyes are affected, are they at the same stage?
- If **one** eye is affected, is the other eye likely to develop macular degeneration?
- How will it affect my vision now and in the future?
- What role do diet and lifestyle play? Are supplements appropriate for me?
- How can I get help to quit smoking?
- Would I benefit from getting some new glasses?

Questions - about low vision support services

- Do I need a low vision assessment?
- Do I qualify for any additional benefits?
- Could I benefit from low vision aids and technologies?

Living Well

Treatment for wet macular degeneration

Ophthalmologists are medical doctors who have completed extra training in eyes and can treat disease, prescribe medication and perform surgery. They provide treatment for wet macular degeneration.

You will be required to make an informed consent for treatment. This means you are provided with verbal and written information to ensure you understand the treatment, potential benefits, risks and side-effects.

Questions - about wet macular degeneration

- Can my wet macular degeneration be treated? What are my treatment options?
- When will treatment start and what does it involve?
- How many treatments may be needed?
- What are the benefits and how successful is it? What are the risks or side effects?
- What are the initial and ongoing costs associated for treatment?
- What rebate will I get from Medicare and/or private health insurance?
- Will I need assistance to get home after the treatment?
- Will I need assistance at home after the treatment?
- When and how should I contact you in case of an emergency out of surgery hours?

And remember, for both wet and dry macular degeneration...

1. **If you have any concerns or do not understand any aspect of your disease or treatment, don't be afraid to ask questions of your eye care professional.**
2. **If you have any sudden changes in vision, do not wait. Phone your eye care professional. Ensure the relevant phone numbers are easily accessible.**
3. **Use your Amsler grid in between visits to monitor for any sudden changes in vision for both wet and dry macular degeneration. Dry can turn to wet macular degeneration and requires immediate attention.**
4. **Ring the Foundation for information, support and understanding on 1800 111 709.**

Living Well - Staying Healthy

Charles Bonnet Syndrome

Up to 30% of people with significant vision loss will experience Charles Bonnet Syndrome which is characterised by seeing phantom images, or things which aren't real.

Research has shown that these false images may be the brain's way of compensating when it starts receiving fewer images, and it is important to remember that this is not an indication of mental health problems.

Uncle Bruce, who has shared many stories about living with vision loss, kindly told us about some of the images he has seen including geometric patterns on walls and a person waiting at the bus stop. He found this confusing at first, but now feels at ease after learning more about the syndrome.

If, like Uncle Bruce, you are concerned about Charles Bonnet Syndrome contact the Foundation on 1800 111 709. A fact sheet is available.

Our Story - Margaret and Betty

Margaret Raynor chose to fundraise for the Foundation after witnessing the impact macular degeneration has had on her mother Betty's life, who is now legally blind.

Given that several of Betty's siblings also lived with macular degeneration Margaret is aware of the increased risk to herself and her children of developing the disease as a direct family history means there is a 50% risk.

"I am committed to ensuring my family have their eyes tested and to doing all we can to avoid vision loss like my mother has experienced," said Margaret. "We eat eye-friendly foods, like fish and leafy green vegetables, and keep active."

"The right support, access to low vision aids, and a positive attitude have been vital to helping mum maintain independence. She's 91 and still cooks her own meals!" she said.

If you have macular degeneration, make sure your family members are connected with the Foundation. The Foundation is here to provide information, guidance and support to those living with macular disease, as well as family, friends and carers.

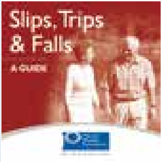
Read more about Margaret's impressive fundraising efforts on page 8.

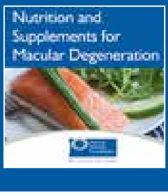
Audio publications now available

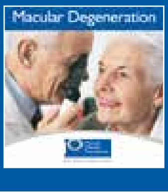
The Foundation is developing a series of audio guides on macular degeneration and low vision. To order any of these FREE audio CDs call 1800 111 709.

Currently available:

- **Slips, Trips and Falls: A Guide**
- **Nutrition & Supplements for Macular Degeneration**
- **Macular Degeneration**



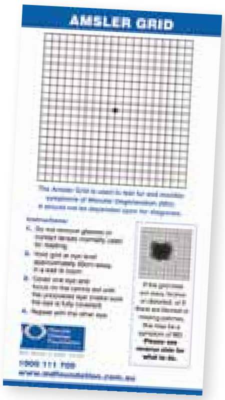




Macular Degeneration Awareness Week

Macular Degeneration Awareness Week was held 25 - 31 May and was again a great success, generating national media and spreading the Foundation's important eye health messages. The key messages of the campaign included:

- ✓ **Over 50? Have an eye test and macula check.**
- ✓ **Use the Amsler grid between eye tests to monitor for changes in vision.** All newsletter recipients, as well as family and friends over 50, should have a magnetised Amsler grid at home and be using it regularly. Call the Foundation for your FREE Amsler grid.



- ✓ **You can save your sight through early detection –** Never ignore any changes in vision.
- ✓ **Know the risk factors –** age, smoking and a direct family history.
- ✓ **Tell your family –** a direct family history brings a 50% risk of macular degeneration so an eye test is vital for all those over age 50.

- ✓ **Eat an "eye-friendly" diet and maintain a healthy lifestyle –** you may consider taking a supplement in consultation with your doctor.

Media Highlights

Julie Heraghty as seen on The Morning Show

Ambassador Jean Kittson and mother Elaine promote Macular Degeneration Awareness Week

Patron Ita Buttrose featured in Sydney Morning Herald and The Age

Our thanks to Novartis, Blackmores and Optometrists Association Australia for supporting Macular Degeneration Awareness Week 2014

Research

Rotary District 9670 raises $23,500 for Macular Disease Foundation Australia Research Grants Program

Thank you to Rotary District 9670 for their generous support of the Foundation's Research Grants Program.

Margaret Raynor co-ordinated the District 9670 Partner's Project 2012-13 and raised the grand total of $23,500. She selected the Foundation for the project because she has seen the impact of macular degeneration on her mother Betty. See Margaret and Betty's story on page 6.

Margaret and husband Peter Raynor, Immediate Past District Governor, visited the Foundation to present the giant cheque.

Blackmores Dr Paul Beaumont Research Fellowship 2015

The Foundation is grateful to Blackmores for supporting this Fellowship which will provide a two-year Research Fellowship of $50,000 per annum to Australian researchers to study nutritional and/or lifestyle aspects of macular degeneration.

Gene Therapy for wet AMD

Recent results of new gene therapy being developed in Australia for people with wet AMD offers the possibility of a highly effective, one-off, long term treatment for wet AMD. The treatment involves the new gene instructing the retina to continuously produce a protein which counters the cause of the leaking blood vessels that produce wet AMD. In a small number of patients assessed for 12 months, the new treatment appears to be safe and maintains vision. Several more years of research is needed to check that this therapy would work and is safe.

The Foundation attended *Vision 2014 International Conference on Low Vision*. Included with this newsletter is a summary of research covered.

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.

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