

Dear Friends – Have a cup of tea with your new MP



Spring is in the air and with it comes a federal election - both seem to have been a long time coming!

Thank you for your amazing and generous support of the *Sight for Seniors* campaign. The response to the request to send campaign letters to the Prime Minister and Leader of the Opposition was outstanding. After the federal election on September 7 we have an opportunity to educate and garner support from the newly elected representatives (whether re-elected or completely new to parliament) about the critical issues for macular degeneration.

The next phase of the campaign is exciting and is called *Have a cup of tea with your new MP*.

Enclosed is information on our **Have a cup of tea with your new MP** campaign as well as two tea bags. The Foundation is asking you to make an appointment with your newly elected Federal MP after the election and have a cup of tea with your new MP. The details on how to do this and the information to give to your MP are enclosed.

It would be wonderful if all Federal MPs, in every electorate in Australia, were meeting

to have a cup of tea with those who can best tell the story of macular degeneration - those who have the disease, their family, carers, friends and supporters.

Obviously many of you live remotely, are unable to travel, or may not feel comfortable undertaking this task. That is perfectly fine, the Foundation understands. But let's not waste the tea bags. Invite a neighbour, family member or friend to have "a cuppa" and give them the information. This will help spread the word about our three main objectives and raise awareness of macular degeneration.

We will not give up on the three important objectives – the inclusion of those aged 65 and over in DisabilityCare Australia, access and affordability to low vision aids and technologies and adequate funding to support the Macular Disease Foundation Australia's work. The journey is long but the determination is strong and with your help we will keep chipping away.

Thank you to those who donated in the lead up to the end of the financial year. Your support and overwhelming generosity allows the Foundation to continue its important work. We could not do it without your help.

Julie Heraghty
Chief Executive Officer

Annual General Meeting

The Macular Disease Foundation Australia's 2013 Annual General Meeting will take place in Sydney on Tuesday 10 December, followed by Christmas refreshments. All welcome.

Date: 10 December 2013

Time: 11.30 am - 12.30 pm (followed by Christmas refreshments)

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

RSVP: 29 November 2013 on 1800 111 709 (RSVP is essential for catering)

Media report on saffron and macular degeneration

There has been a recent media report regarding the use of saffron to prevent and treat macular degeneration. There is presently no robust evidence that saffron has any effect on the prevention or progression of macular degeneration or any other eye disease. The Foundation does not presently support or endorse the use of saffron to treat macular degeneration or any other eye disease.

The Save Sight Institute in Sydney is currently conducting a large study to determine whether saffron may have a role in the future. There is some preliminary data in a small number of patients. However, at this stage it is not currently clear whether saffron will have any influence on the development or progression of macular degeneration. The Foundation encourages patients to discuss all aspects of their care and treatment with their ophthalmologist.

Foundation Director awarded Order of Australia

Founding Director Dr Paul Beaumont was awarded the Member of the Order of Australia (AM) in the Queen's Birthday 2013 Honours List for his services to ophthalmology. The Foundation congratulates Dr Beaumont on this award which recognises his significant contribution to ophthalmology, most particularly in the field of macular degeneration.

It was Dr Beaumont's passion and vision that resulted in the founding of the Macular Degeneration Foundation in 2001, thus providing patients and their family a vital source of information and support. This honour is a reflection of a long career dedicated to helping to preserve our most precious sense, our sight.

Time to Get Snapping!

Entries for the third annual **mEYE World Photographic Competition** are now open! Submit your photo and include a description of how your entry has inspired you to appreciate the gift of vision. **There are great prizes to be won!**

We encourage all those with low vision to enter. One past grand finalist was legally blind, so have a go - you never know!

To get you enthused, here is one inspiring entry already received.

For more details visit
www.meyephotocomp.com.au



B. Keller, Marayong NSW

Representation

Sight for Seniors Campaign Update

The Foundation would like to thank everybody who registered their support for the *Sight for Seniors* campaign and sent the campaign letters to the Prime Minister and the Leader of the Opposition. The campaign now has over **5,000 supporters** registered, which is a great achievement in only four months. Please continue to spread the word and have your family and friends support the campaign objectives below. The next exciting part of the campaign **Have a cup of tea with your new MP** is about to begin. See page 5.



Patron Ita Buttrose supports *Sight for Seniors*

The campaign objectives

1. No age discrimination in DisabilityCare Australia for over 65s

Those who acquire vision impairment or blindness at the age of 65 or over will be excluded from DisabilityCare Australia and forced to access their support from an underfunded, ill-equipped and under resourced aged care sector. No one chooses when to lose sight, yet timing determines the level of support received. Everybody pays for DisabilityCare Australia through the taxation system so the exclusion of this group is plainly unfair, highly discriminatory and unjust. It was unjust the day it happened and it will be so until the day it is changed.

2. A fair deal on aids and technology for people with low vision

There is presently no consistent, equitable or accessible scheme across Australia that provides a subsidy to those who require a low vision aid. Where you live should not determine how well you read.

3. Funding to better support the Foundation's work in macular degeneration

It's time for the federal government to recognise the prevalence and impact of macular degeneration as a major chronic disease and adequately support the work of the Macular Disease Foundation Australia. Macular degeneration is the leading cause of blindness in Australia. However, since 2005 the Foundation has on average received approximately \$160k (ex. GST) per year to conduct limited education and awareness programs across Australia.

This funding is totally disproportionate to the incidence and impact of this disease which is well documented in our comprehensive *Eyes on the Future* report. The needs of the macular degeneration community have been well documented and communicated to federal funding agencies over the years, including the May 2013 Federal Budget submission that requested \$6.2 million over 3 years. The funding is required for the helpline, publications, website, representation, policy and advocacy work.

WE CONTINUE TO ADVOCATE FOR THESE 3 CAMPAIGN OBJECTIVES

Representation

How many people have macular degeneration and where are they?

The Foundation is proud to announce the results of its project to provide the estimated number of people with macular degeneration in Australia mapped by federal electorate for now and in 2030.

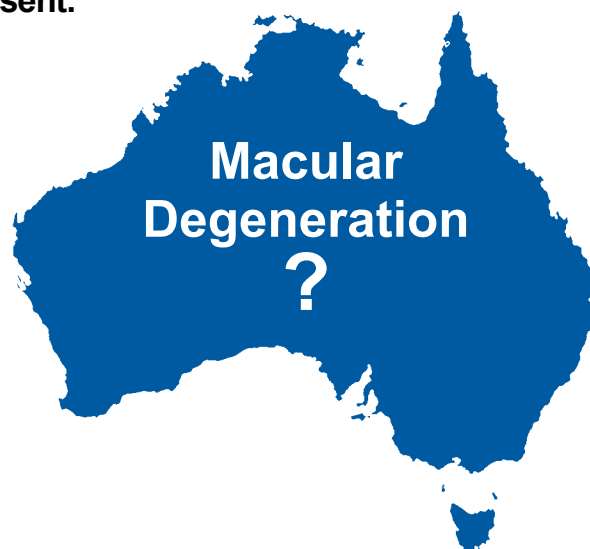
As an example, the electorate of Hindmarsh (SA) has an estimated 9,871 people with macular degeneration and this is projected to climb to 12,661 people by 2030. This is the highest ranking federal electorate. This information is available for other federal electorates.

The mapping information is available on www.sightforseniors.com.au/mapping or contact the Foundation on 1800 111 709 if you would like to know the estimated number of people with macular degeneration in your federal electorate.*

Why is this important?

We know there are 1 million people with some evidence of the disease and this will rise to 1.7 million in 20 years in the absence of prevention and treatment.

An elected representative is far more likely to take notice when he/she understands the incidence and impact on their constituents in their own electorate, the people they represent.



What has the Foundation done on your behalf since the last newsletter?

- ✓ **Made** Prime Minister Rudd fully aware of our campaign, given the change in Prime Minister.
- ✓ **Sent** campaign letters to every re-contesting Federal MP, Senator and all major candidates, asking them to review the exclusion from DisabilityCare Australia of people who acquire vision impairment or blindness aged 65 or over.
- ✓ **Placed** the estimated number of people with macular degeneration in Australia for federal electorates on the *Sight for Seniors* website.

* There are several electorates which could not be mapped following electorate boundary changes.

Representation

Have a Cup of Tea with your new MP

Following the September 7 federal election we want macular degeneration and the *Sight for Seniors* campaign to be top of your newly elected MP's agenda!



After the election the Foundation will write to all newly elected Federal Members of Parliament (MP) to remind them of the *Sight for Seniors* campaign, the estimated number of people in their electorate with macular degeneration and to notify them of the many "cup of tea" requests coming their way!

The Foundation would greatly appreciate if you, your family, friends, carers and supporters would have a cup of tea with your newly elected MP after the federal election! This includes existing MPs re-elected and brand new MPs.

What to do?

Enclosed in the newsletter is a **Have a Cup of Tea with your new MP Information Card** and a **Macular Degeneration Leaflet** for your MP and **your two tea bags!**

1. Your newly elected MP should have moved into their electorate office by early October. Look out for their contact number and address in your local newspaper or call the Foundation on 1800 111 709.
2. Phone your Federal MP's electorate office and request a meeting with your new MP.
3. Say you want to have a cup of tea with your new MP to discuss your concerns regarding macular degeneration. Let them know that you will bring the tea bags and the MP can provide the biscuits!

4. On the day of your meeting with your MP:

- ✓ **Take** your **Have a Cup of Tea with your new MP Information Card** and **Macular Degeneration Leaflet** with you.
- ✓ **Give** your MP both the **Information Card** and **Macular Degeneration Leaflet** to keep and ask that they read both and also visit the *Sight for Seniors* website.
- ✓ **Share** your story about macular degeneration with your MP. Your experience as a person living with the disease, as family, friend, carer or supporter and the impact the disease has had on your life, is the real story that needs to be told.
- ✓ **Tell** your MP that you want them to make macular degeneration a priority and to further support the work of the Macular Disease Foundation Australia.

Please note: Be assured that you do not have to talk expertly about the issues as the **Information Card** you hand to your MP directs them to our website for detailed information.

Thank you so much. We hope that every Federal MP will have many, many cups of tea in the next few months!

The Foundation is very grateful to Madura Tea for so kindly donating over 72,000 tea bags for you to share with your new MP.

“The ripple effect of vision loss”

Recent research undertaken by the Foundation examined the impact of wet age-related macular degeneration (AMD) on various aspects of a person's life, as well as the impact on the life of a person who cares for someone with wet AMD.

We promised to continue to update you on the results of the research in which so many of you so kindly participated. Here are just a few more of the outcomes, along with advice and insights you so generously shared with us. We have included some reminders about what actions you can take to ensure quality of life and independence.

Mobility

Research finding: The impact on activities for those with vision loss included driving a car (58%), travelling (43%), exercise/sport (38%), going for walks and using public transport (both 36%).



Being mobile and getting out and about is important for independence, socialisation and for varying our everyday environment. One of the most important things you can do if you feel your mobility is becoming increasingly restricted is undertake mobility training. It is so easy to learn the tricks of mobility and many wonderful organisations can help you. Don't be frightened or worried by undertaking mobility training. It can help you avoid falls and give you the confidence to go to the shops or, for some people, to run a marathon! Phone the Foundation on 1800 111 709 for your copy of *Low Vision - A Guide* or for a contact number for mobility training.

Hobbies, sports and activities

Research finding: Those with vision loss had to forgo hobbies (43%), or had their ability to do everyday activities impacted (37%) such as gardening and sport.



There are many activities in which to partake. It is wise to advise organisers of community activities that you are having some challenges with your vision and to wear your low vision badge (available free from the Foundation). It does not matter if what you are doing is not perfect. What is important is to have a go, have some fun and give it your best shot. Find something for “you” and share in the fun, whether it is working in your own garden or a community garden, playing bowls, blind golf or tandem bike riding! Such activities help you to get out of the house, change your routine, socialise and enjoy life. Local councils can sometimes advise you of local community activities.

Living Well with MD

Reading

Research finding: 69% of people with vision loss had to reduce or stop reading. Most commonly used aids include optical magnifiers (65%) and 10% reported use of desktop electronic magnifiers (CCTV), magnification software for their computer or low vision adaptive applications on the internet.

Make sure you have explored all the options to enhance your communication. A low vision assessment is a great way to begin and if you have been using the same aid for some time it may be worth a review of your needs. *Low Vision Aids and Technology - A Guide* is a great resource. Order a free copy from the Foundation 1800 111 709.



Telephone voting for people who are vision impaired or blind



If you are vision impaired or blind you can register and vote in the upcoming federal election via a telephone voting system. It is a 2 step process, so if you haven't done so as yet, call the Australian Electoral Commission's Blind and Low Vision Call Centre on 1800 913 993 to find out what is involved. **There is also a comprehensive video on the telephone voting process that can be viewed on the Foundation's website www.md.foundation.com.au. This may be useful for family and friends.**

Research special

Our summer newsletter, due out in early December, will be one not to miss. It will include our annual research update, information on nutrition, AREDS 2 results and details of the Foundation's Research Grants Program recipient to be announced on World Sight Day, 10 October 2013.

Still on offer

For a free low vision badge call the Foundation on 1800 111 709.

Chief Executive Officer awarded prestigious fellowship

The Foundation's Chief Executive Officer Julie Heraghty was awarded the prestigious Harvard Club of Australia's Nonprofit Fellowship for 2013 to undertake the course *Strategic Perspectives in Nonprofit Management* at the Harvard Business School, Harvard University, Boston in July. The fellowship was made available thanks

to the generosity of Harvard Club of Australia's founding patrons Mr William Ferris AC and Mrs Lea Ferris. The fellowship is an honour for Julie and the Foundation and will have far reaching benefits for the Foundation in its continued growth and development.

Education

Below is a list of locations and dates for upcoming education sessions.
If you would like to attend please call 1800 111 709 to RSVP (bookings essential).

Location	Date and Time	Address
NSW – Wollongong	Monday 16 Sept 10am	Illawarra Master Builders Club
NSW – Leumeah	Wednesday 9 Oct 10am	Western Suburbs Leagues Club
WA – Perth Assoc. Prof. Dimitri Yellachich	Sunday 20 Oct 2pm	University of Western Australia, Crawley
TAS – Hobart Assoc. Prof. Nitin Verma	Saturday 26 Oct 10am	Salvation Army Citadel, Hobart
ACT – Canberra	Monday 25 Nov 10am	Hellenic Club of Canberra, Woden

Thank you!

The Foundation would like thank the following NSW Clubs for donating over \$50,000 through the ClubGRANTS Scheme to support the Foundation's work in their community. Clubs include Bankstown District Sports Club, Campsie RSL Club, Goulburn Workers Club, Goulburn Soldiers Club, Griffith Leagues Club, Hornsby RSL Club, Club Central Hurstville, Orange Ex-Services Club, Australian Rules Club (Wagga Wagga). The Foundation also thanks The Great Priory NSW & ACT and Masonicare for their support with a combined \$11,000 donation to the Foundation's Research Grants Program.

Running to See

This year the Foundation was able to secure ten highly sought after Gold Charity Entries for the City2Surf held in Sydney on Sunday 11 August. Thank you to all our City2Surf participants for helping the Foundation continue its sight saving work.

If you would like to know more about how you, your community club or business can support the Foundation through donation and fundraising activities, please call 1800 111 709.



Donations

Thank you for supporting the Macular Disease Foundation Australia. As a charitable organisation we rely on your generosity to serve 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.

All donations over \$2 are tax deductible. Bequests are gratefully accepted. Please call the Foundation for more information.

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DISCLAIMER: This newsletter is produced by the 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 2013