

## Dear Friends,



We have two newsletters very close to each other so that we can communicate as much up-to-date information as possible on all of our advocacy work.

**Sight for Seniors Campaign:** Since the last newsletter the increase in the Medicare levy to pay for the NDIS was announced. The exclusion of those over the age of 65 years who acquire a disability, such as vision impairment, became even more paramount in our advocacy efforts.

A universal tax but no universal access for those over 65 years of age with macular degeneration, is plainly unfair and unjust. The economic argument against our inclusion does not stand up to scrutiny and in many cases older Australians who are blind from age-related macular degeneration will be paying the Medicare levy in addition to a co-payment for aged care.

Please continue to support our efforts on your behalf and we outline how to do this in this newsletter. Our sincere thanks to Ita Buttrose AO OBE our Patron and Australian of the Year 2013 for her support of our Sight for Seniors campaign.

If you sent the campaign letters from the last newsletter to the Prime Minister and Leader of the Opposition, thank you. We have also included a letter that you can sign and return to the Foundation that will support our advocacy work with all candidates over the next few months leading up to the federal

election. We need everyone to sign and send back to us. There is power in your voice and every letter counts.

**Funding:** The result of the Foundation's federal budget submission for funding of \$6.2m over three years to support our work was unsuccessful. Given the enormity of this disease and our very small level of funding of \$147,000 per year this is clearly unacceptable.

**AREDS2 results:** The long awaited results of the AREDS2 study have been released. We have given you an initial summary on page six, but as these results have only just been released, we will review further with the Foundation's medical committee and provide more information in future newsletters.

**End of year donations:** Thank you again for your ongoing support. As we draw quickly to the end of this financial year, please be assured that all of your generous donations made before 30 June will be processed immediately to ensure receipt in the 2012/13 financial year for taxation purposes.

**Thank you:** Your inspirational letters, your support and belief in our work on your behalf makes every day special at the Foundation and that is why we will never give up in working for the best outcomes for the macular disease community.

**Julie Heraghty**  
Chief Executive Officer

# Representation

## Sight for Seniors campaign - election fever!

The federal election is fast approaching. With less than three months until voting day on 14 September, it is time to move full steam ahead with the Sight for Seniors campaign. Our Patron and Australian of the Year 2013 Ita Buttrose, is supporting our campaign.



### SUPPORT SIGHT FOR SENIORS

“The day I was honoured with Australian of the Year, I made a public commitment to raise awareness of issues relating to older Australians, including macular degeneration.”

**Ita Buttrose** – Australian of the Year 2013  
Macular Disease Foundation Australia Patron

The Macular Disease Foundation Australia would like you to support

- ✓ No age discrimination in the National Disability Insurance Scheme for over 65s
- ✓ A fair deal on aids & technology for people with low vision
- ✓ Funding to better support the Foundation’s work in macular degeneration

## Campaign update

Since the last newsletter, the Federal Government has announced an increase to the Medicare levy by 0.5% to partly fund the National Disability Insurance Scheme, officially known as DisabilityCare Australia. However people who acquire a disability over the age of 65 will still be excluded.

This does not make sense. It is discriminatory, unfair and divisive to have a universal tax that denies benefits to one section of the community based solely on age. The myth that DisabilityCare will apply to any Australian with a permanent, severe disability, as cited by many, must be debunked.

Macular degeneration is the leading cause of blindness and primarily affects older Australians. 50% of vision loss in this country is caused by this disease. Over 95% of people who lose vision from macular degeneration do so after 65 years of age. The fear that the inclusion of over 65 year olds will be economically unviable is not justified. Out of four million people

with disabilities in Australia, there are only 167,000 older Australians who have vision loss or blindness from late stage macular degeneration, with an estimated number of 50,000 people being legally blind.

Most rehabilitation needs for vision impairment centre around maintaining independence and quality of life, with possibly some mobility training and low vision aids and technologies. A low cost investment from government will result in a high return for the taxpayer, with less falls, lower rates of depression and later admittance to nursing home care.

If you acquire a disability after the age of 65 years, you are presently excluded from the support of DisabilityCare and are expected to be catered for in the aged care system which has neither the funding, capacity nor expertise to provide the necessary support.

The age that you acquire your disability will determine the care and support you receive, turning disability care into a game of chance.

Imagine two brothers: One brother becomes blind at 64 years of age. He has been contributing towards DisabilityCare through general tax payments for his entire life, and recently through the increased Medicare levy. He can now access lifetime funded care and support via DisabilityCare.

The other brother becomes blind at 65 years of age. He has also been contributing towards DisabilityCare throughout his life through general tax payments and recently with the increased Medicare levy. Unfortunately he is not eligible for DisabilityCare as he acquired his disability at the age of 65. He is required to provide a co-payment for limited services in the aged care sector. To add insult to injury, he still has to contribute towards DisabilityCare through tax contributions and the increased Medicare levy, even though he cannot access it!

Research conducted by the Macular Disease Foundation Australia in February 2013 showed that only 3% of Australians knew of the 65 year age cut-off and 82% of people stated that the cut-off was unfair.

The Foundation recently appeared before the Senate Community Affairs Committee which was inquiring into aged care reform and stated that this exclusion was just plainly unfair saying, "Medicare does not stop at 65. DisabilityCare should not either."

The Foundation thanks everyone who has registered to be counted for the Sight for Seniors campaign, and sent the campaign letters to the Prime Minister and the Leader of the Opposition. We will not give up!

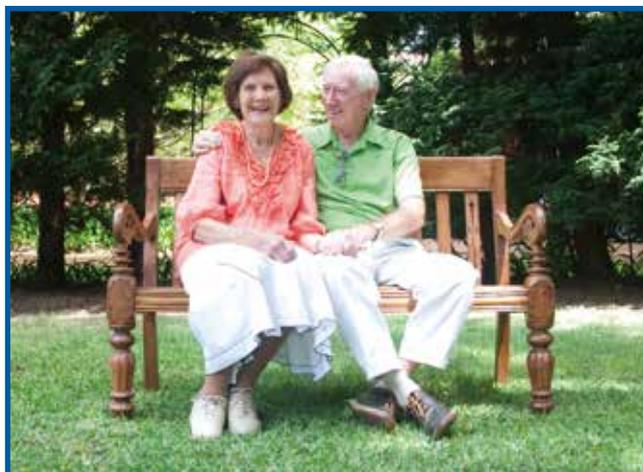
### What have we done on your behalf since last newsletter?

- ✓ Met with relevant MPs and Opposition spokespeople about these issues
- ✓ Appeared before the Senate Community Affairs Committee's aged care reform inquiry hearing on 2 May 2013
- ✓ Raised public awareness during Macular Degeneration Awareness Week 2013

### Be counted!

Friends of the Foundation, Jean and Des, have joined the Sight for Seniors campaign and have registered to be counted. Jean has macular degeneration and Des is her husband and carer. They are also sharing their stories in support.

**To read their stories and be counted visit [www.sightforseniors.com.au](http://www.sightforseniors.com.au) or call 1800 111 709 to register.**



# Representation

## We need your support for one final push before the election

The Foundation wants you, your family and friends to support the Sight for Seniors campaign.

**We ask you to do the following by 31 July:**

### Letter of support

- ✓ Complete the enclosed letter and return it to the Foundation. **We would like everyone who receives this newsletter to respond.**
- ✓ Photocopy the letter and pass it onto your friends and family to get their support.

The Foundation will then write to every sitting MP and candidate for the federal election on your behalf. With the weight of your support behind us we will call for action on the Sight for Seniors campaign.



The Foundation has mapped the estimated prevalence of age-related macular degeneration (AMD) in all federal electorates across Australia and can target the areas that have the highest prevalence of the disease. Below are the top 20 electorates. With a powerful and united voice we can make a difference.

### Top 20 federal electorates with the highest estimated prevalence of AMD

2012 rank	Electorate	2012 est prevalence	2012 rank	Electorate	2012 est prevalence
1	Hindmarsh, SA	9,871	11	Paterson, NSW	9,189
2	Flinders, VIC	9,808	12	Page, NSW	9,081
3	Hinkler, QLD	9,720	13	Robertson, NSW	8,919
4	Lyne, NSW	9,616	14	Boothby, SA	8,906
5	Moncrieff, QLD	9,531	15	Fisher, QLD	8,888
6	Gilmore, NSW	9,360	16	Barker, SA	8,804
7	O'Connor, WA	9,335	17	Farrer, NSW	8,715
8	Richmond, NSW	9,293	18	Fairfax, QLD	8,712
9	Cowper, NSW	9,292	19	Grey, SA	8,664
10	Sturt, SA	9,266	20	Corangamite, VIC	8,595

## New white paper - wet AMD

In May the Foundation welcomed the release of a white paper, “Advocating for Improved Treatment and Outcomes for Wet Age-Related Macular Degeneration”. The white paper is the outcome of an expert summit convened last year by the Foundation and the US-based Angiogenesis Foundation. The summit saw leading ophthalmologists from across Australia gather in Sydney to address barriers to timely and optimal care for Australian patients suffering from vision loss due to wet AMD.

The white paper provides an extensive analysis of the issues and needs of AMD patients in Australia’s healthcare system and makes specific recommendations aimed at informing national health services, the clinical and research community, and patient advocates. It will make an important contribution to influencing the management of AMD in the future.

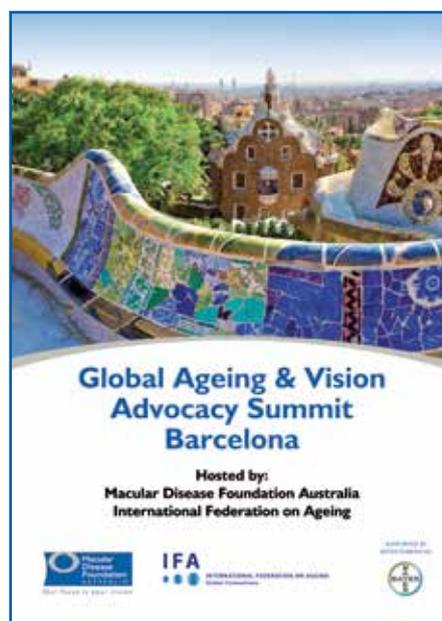
Australia is a global leader in providing affordable and accessible care to people with wet AMD, however there is still more that can be done for all those in need and to reduce the burden of treatment.

The expert summit was only the third international wet AMD summit presented by the Angiogenesis Foundation, and their partnering with us reflects the status of Australia on the world stage with regard to both the treatment of wet AMD and advocacy for patients.

The white paper can be downloaded from the Foundation’s website. For more information on the Angiogenesis Foundation go to [www.angio.org](http://www.angio.org).

## International Advocacy Summit

The Foundation co-hosted the inaugural Global Ageing & Vision Advocacy Summit in Barcelona, Spain on 17–18 April 2013. The summit provided a platform through learning and knowledge exchange to build the capability and capacity of the ageing and vision sectors to effectively represent the interests of citizens at risk of vision impairment. Leading international advocates from 12 countries lent a collective expertise and wisdom to the summit and Foundation CEO, Julie Heraghty, along with other leading advocates presented their work on ageing and vision. The Foundation’s participation in this summit is a reflection of its now world recognised reputation as a leader in representing the best interests of the macular disease community in Australia. A report will be released shortly and published on the Foundation’s website.



## AREDS2 results

The Age-Related Eye Disease Study (AREDS) is the only study for which there is good, long-term evidence for the benefits of high dose nutrients for people diagnosed with age-related macular degeneration (AMD). The original AREDS study demonstrated that a supplement based on a specific formula of zinc and antioxidants resulted in a reduction in the risk of progression of AMD by 20-25% for those in the intermediate stage of the disease in one or both eyes, or in the late stage in one eye.

Since 2006, the researchers have been conducting a follow-up study to AREDS. The initial results of the AREDS2 study were released on 5 May 2013 at the Association for Research in Vision and Ophthalmology (ARVO) conference in Seattle, USA.

In summary, during the presentation of the results at the ARVO conference, the AREDS2 study group recommended the continued use of the original AREDS formulation, but with beta-carotene removed, to be replaced by lutein/zeaxanthin. The recommended daily dose was therefore:

<b>Zinc</b>	<b>80 mg as zinc oxide</b>
<b>Copper</b>	<b>2 mg as copper oxide</b>
<b>Vitamin E</b>	<b>400 IU</b>
<b>Vitamin C</b>	<b>500 mg</b>
<b>Lutein</b>	<b>10 mg</b>
<b>Zeaxanthin</b>	<b>2 mg</b>

There is currently no single preparation in Australia which provides this exact combination, however, an AREDS2 equivalent would be to take a product compliant with the original AREDS formula (without beta-carotene) along with an additional lutein/zeaxanthin supplement.

The AREDS2 study also determined that fish oil at a daily dose of 1g did not have any benefit for AMD. (Note however that there is consistent evidence from several other studies that the consumption of actual fish 2 to 3 times a week does reduce the risk of AMD.)

The Foundation will further review the AREDS2 outcomes with its Medical Committee and provide additional advice in future newsletters. It is important to continue to eat an 'eye health' diet as recommended by the Foundation in the 'Nutrition for Macular Degeneration' factsheet. It is also important to talk to your ophthalmologist regarding taking appropriate supplements.

## Macular Degeneration Awareness Week 2013

**Sunday 26 May to Saturday 1 June**

The wonderful support of Foundation Patron Ita Buttrose guaranteed the success of Macular Degeneration Awareness Week 2013. We thank Ita for so generously giving her time and powerful voice to this year's campaign. We also thank Ambassador Jean Kittson and our medical spokespeople for their outstanding support.

Our thanks go to Novartis, Blackmores, Optometrists Association Australia and Bluedesk for their ongoing support which enables the week to be held each year.

Additionally, a large number of individuals and organisations support the week across the healthcare and community sector. The Foundation thanks all who participated in raising awareness in their local community.

# Awareness

## mEYE World Photographic Competition 2013

The Foundation's 3rd annual mEYE World Photographic Competition will be launched on Friday 5 July at ODMA Fair.

There are some wonderful prizes so whether you have a passion for photography or you just love to take happy snaps, you could be a winner!

Get involved and help raise awareness of macular degeneration. Don't forget to tell all your friends and family, as we want as many happy snappers from the macular degeneration community as possible!

If you have vision impairment do not let this deter you, as in past years we have received some wonderful photos from those with low vision.

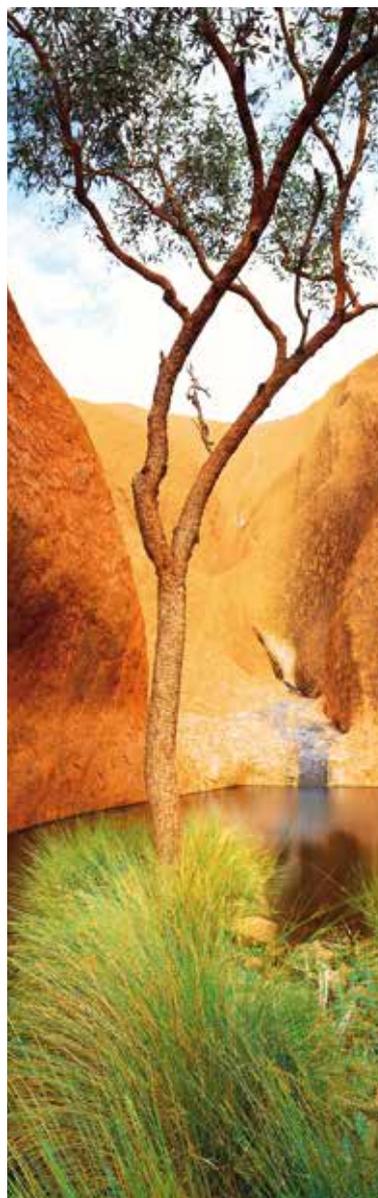
With a prize pool of almost \$10,000, our grand finalist will win, among other prizes, a limited edition framed photograph "Mutitjulu, Water of Life, Uluru NT" (pictured) generously donated by renowned Sydney photographer Ken Duncan, valued at \$5,800. We are also delighted to welcome Ken as one of our judges for this year's competition.

Photos are to be submitted via the competition's website with between 30-60 words on why this photo inspires you. To find out more go to the Foundation's website [www.mdfoundation.com.au](http://www.mdfoundation.com.au) or call 1800 111 709.

The Foundation thanks the Optical Distributors and Manufacturers Association (ODMA) for their ongoing support as competition sponsor.

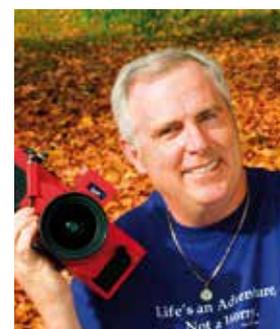


An initiative of the Macular Disease Foundation Australia



### Major Prize "Mutitjulu, Water of Life, Uluru NT"

generously  
donated by  
Ken Duncan



**Entries open**  
5 July 2013

**Entries close**  
2 October 2013

### Categories:

- Open (general public)
- Macular degeneration community (those with MD, family, friends and carers)
- Healthcare professionals (optometrists, ophthalmologists, GPs, orthoptists, pharmacists etc)
- Junior (under 18)

# Living Well with MD

## Telephone voting for people who are vision impaired or blind

For the federal election on 14 September, voters who are vision impaired or blind will be able to cast their votes using the telephone. This will enable voters to independently cast their votes from any location, including the comfort of their own home.

The telephone voting system will involve voters dialling into a call centre. The ballot paper will be read out by a call centre operator and voters will advise their voting preferences. A second person will be present at the call centre to verify that the preferences are recorded as per the instructions of voters.



In order to use this voting method, eligible voters must register for accessible voting by telephoning the Blind and Low Vision call centre which will be set up by the Australian Electoral Commission.

Once registered, voters will be issued with credentials, which will need to be quoted when the voter calls to vote. This allows the voter to be marked off the roll without disclosing their name. These credentials can be provided to registered voters via post, SMS, phone call or email. Voters can choose one or more of these options.

**The registration period begins on 26 August and closes at 12pm AEST on 14 September (election day). Once registered the voting period begins on 27 August and closes at 6pm AEST on 14 September.**

**To register and to vote call the Australian Electoral Commission on 13 23 26.**

**The end of the financial year is fast approaching! To ensure you have your tax deductible receipt in time to prepare your tax return please send us your donation using the enclosed donation coupon and reply paid envelope. Your gift will make a difference.**

## Donations

Thank you for supporting the 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](http://www.mdfoundation.com.au).

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

## Contact us

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[www.mdfoundation.com.au](http://www.mdfoundation.com.au)

**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. June 2013