

My Dear Friends,

I wish you all a Happy Easter, even though Christmas seems a short time ago. There is so much happening this year to ensure we achieve our goal of doing everything possible to reduce the incidence and impact of this disease in Australia. We want to help you as much as we can, and provide a good service for our MD community.

Funding: I sincerely thank all who supported our postcard campaign to help us renew our existing funding and to increase our funding overall. I would like to acknowledge and thank my staff who worked tirelessly, many giving up their holiday leave, to have the submissions ready for the 23 December deadline. Their commitment to the enormous task of submitting high quality, detailed funding proposals was truly outstanding and resulted in five submissions to undertake important and necessary work over the next three years. I am anxiously awaiting news from the Department of Health and Ageing.

Friends of the Foundation: I was overwhelmed by your generosity of spirit in sharing so many personal stories in our Friends of the Foundation project. Your stories are inspirational, and they help explain to others the real impact of this disease on people's lives and give hope when we hear about the stories of amazing fortitude in overcoming challenges. There is no better person to tell the story of living with MD than those who have the disease. I have the great pleasure of sharing various stories with you in our newsletter, with the kind permission of the authors, and we begin with Marion's story.

Low Vision Aids and Technology

Campaign: I am determined that there will be changes to support those with vision impairment in this country. There have been some further

wins on the private health fund front, which I am pleased about. However, on the broad government subsidy front, there is still more to do. We have continued to advocate in many forums and with federal ministers about the inequitable situation in this country. I have provided a comprehensive update for you as an insert to this edition of the newsletter.

Living Well with MD: We have some great information on living well with MD regarding phones, support for long distance travel to visit a specialist, trial audio description on the ABC and an opportunity to join our Navigator Program for audio books.

End of Financial Year Appeal

While it is only March, please remember the Foundation as we draw to the end of the financial year for tax deductible donations. Our next newsletter will be early June and our friendly reminder may not reach those who decide on their end of year charitable gifts a little earlier. Your donations are vital and enable us to do the much needed work for the MD community. Thank you so much.

Kind regards

Julie Heraghty

Chief Executive Officer



Funding Focus

Government Funding

Thank you to all those who supported our postcard campaign to help renew our existing funding and to increase our funding overall.

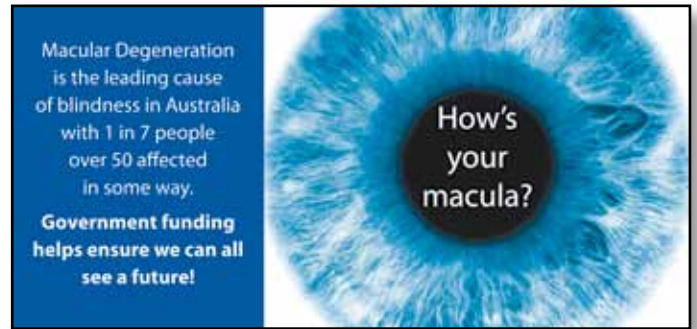
The Federal Government has introduced a new way to fund many of the nation's health priorities. Applications closed on 23 December 2011 with the Foundation submitting five high quality funding proposals.

In its 10 year history the Foundation has only received one Federal Government grant for education across Australia (\$142,000 annually). There is now an urgent need for funding that reflects the enormous amount of work to be undertaken by the Foundation to save the sight of many Australians. The prevalence of this disease is now four times that of Dementia and over half that of Diabetes.

In 2010 our major MD Foundation Deloitte Access Economics Report showed that 1 million people over 50 have some evidence of this disease and that this will rise to 1.7 million by 2030 in the absence of prevention and treatment measures.

As a result, the Foundation, under this new funding program requested funds (\$5 million over three years) which enable us to undertake necessary and valuable work. This funding request reflects the enormous size of the problem that we are facing with this disease in the next 20 years, unless we act now.

We now wait to be advised if your call to increase our funding is translated into support for these valuable projects. Notification will be before 1 July 2012 and we will keep you informed.



The projects applied for were:

- 1. Development of clinical guidelines for the risk reduction, early detection, management, and rehabilitation of MD** - to provide a solid evidence base to produce best practice clinical guidelines for the care of people with MD
- 2. Education Program** - to continue to deliver a national education and awareness program across Australia
- 3. Research & Support Services** - to develop and disseminate accurate and comprehensive information on MD, incorporating the latest global research
- 4. Aged Care and Vision Care Project** - to develop a successful model of eye health care for people living in residential aged care facilities
- 5. Raising awareness of key messages on MD** - to support a wide range of programs including the annual MD Awareness Week (MDAW), digital media, publications and distribution of information kits

Calling all Fundraising Heroes!

Fundraising online is easy through the Everyday Hero website. Visit our website (www.mdfoundation.com.au) for information regarding what's involved and how to register. This fundraising avenue is great if you (or a family member) are involved in an organised sporting event such as a fun run and want to raise money to help save the sight of Australians. It's an online version of the traditional walk-a-thon.

Community Spirit

Macular Degeneration Awareness Week 2012

Sunday 27 May to Saturday 2 June 2012

For details on MD Awareness Week, call the Foundation on 1800 111 709 or email info@mdfoundation.com.au

Keep your family in the picture is the theme of MD Awareness Week 2012, highlighting the fact that if a family member has MD there is a 50% chance of developing the disease.

Making sure your family members have their eyes tested and macula checked, along with adopting a healthy diet and lifestyle, will help reduce their risk of developing the disease.

Here are just a few ideas on how you can **be involved with MD Awareness Week**

- ✓ Contact your family and ask that they call the Foundation to obtain a free information kit
- ✓ Talk to young family members who smoke about the link with blindness
- ✓ Invite the family for a meal and ask them to each bring an eye health food
- ✓ Test your family on their knowledge with the quiz questions on this page
- ✓ Use the Foundation's Eating for Eye Health The Macular Degeneration Cookbook
- ✓ Ensure those over 50 have their Amsler grid on the fridge and test themselves everyday

You can also:

- ✓ Raise funds for the Foundation by becoming an "Everyday Hero" visit www.mdfoundation.com.au for more information
- ✓ Join the Foundation's Facebook community and spread the word - a link can be found on our website www.mdfoundation.com.au
- ✓ Promote on other websites, Facebook and Twitter pages
- ✓ Utilise your businesses, community and club connections

You could contact the following to encourage the display of posters, discussion, and promotion of the MD messages:

- ✓ Local newspaper
- ✓ Local council
- ✓ Local library
- ✓ Local member of parliament
- ✓ Optometrist
- ✓ General practitioner
- ✓ Ophthalmologist
- ✓ Pharmacist

How good is your knowledge of MD? Take our quiz and find out.

1. Is spinach good for your eyes?
2. Eating oily fish is recommended how many times a week?
3. How much does smoking increase the risk of developing MD?
4. Is a low glycemic diet recommended for eye health?
5. Does a family history of MD increase the risk of developing the disease?
6. What would you use to test for symptoms of MD at home?

Quiz answers on page 7.

Welcome Rotary

We Are So Proud to Have You as a Partner



The Rotary Club of Yea (VIC) has collaborated with the Foundation on behalf of Rotary nationally to become a special partner for our annual MD Awareness Week 2012. Our thanks to the Rotary Club of Yea for this wonderful initiative. It has long been a goal of the Foundation to partner with a major service club such as Rotary. This partnership will see distribution of thousands of MD information flyers and Amsler grids to over 1000 Rotary Clubs and over 30,000 Rotary members Australia-wide and to the broader public.

Rotary Club Raymond Terrace has approached the Foundation for promotional material as they are organising a stand at their local shopping centre during MD Awareness Week. They are working in conjunction with local optometrists to help raise awareness amongst those most at risk. Well done!

If you are a member of Rotary and your club would like to run a promotion, please contact the Foundation for further information.

2011 Annual General Meeting, Volunteer Christmas Party and Foundation Office Opening

The Foundation held its Annual General Meeting (AGM) 2011 on 13 December at its new national office. At the conclusion of the AGM, Foundation CEO Julie Heraghty, invited Jean Morton and her husband Des, long term Friends of the Foundation, to officially open the new office with the unveiling of a commemorative plaque.

As part of the celebrations, the Foundation's volunteers were acknowledged for their invaluable support throughout the year and guests were invited to trial the new low vision aids and technology display.



Jean Morton – officially opening new office



Foundation Low Vision Display



MD Foundation volunteers

Living Well with MD

Friends of the Foundation

The Foundation started the Friends of the Foundation program with the aim of encouraging people to share their stories of living with MD. Thank you to all of you who wrote to us, or phoned, to share your story, especially those stories on how you overcome the challenges of everyday tasks through determination and a positive attitude.

We are so fortunate to have so many incredible people engaged now with our Friends of the Foundation program. We are grateful for the gift you have given in sharing your inspiring stories. Please enjoy Marion's story below.

Tell us 'Your Story'

The response from the newsletter asking for 'Your Story' was amazing and if you haven't already, you are all invited to write or call the Foundation on 1800 111 709 to share your experiences.

"Laughter is the essential ingredient in our changed circumstances since MD arrived into our lives. Make every day an adventure!" John, whose wife Pat has Macular Degeneration.

Marion's Story

When I was diagnosed with Macular Degeneration some 17 years ago, my husband was still alive and was a great help to me. When he died very suddenly, I realised that I had to make a life for myself and try to overcome the disability of low vision.

I was invited to join a Widows Club, which I did, and in a very short time, I became the Social Secretary, arranging the bi-monthly bus trips for the members. I then heard about other social groups and joined them too. I have advertised fundraising activities for these clubs too. I applied to join even more clubs and within a year was elected President of one. I have also been a member of the RSL Women's Auxiliary for 44 years and until recently I was the Minutes Secretary.

Chairing the meetings and social functions is no easy task without proper vision but with the help of my computer which has Zoom Text, my CCTV which enlarges print and the hand-held magnifying glass, I have managed to overcome the difficulties.



As you can see, I have not let MD prevent me from living a full and interesting life at the age of 89. Where there's a will there's a way!

– Marion

Need to Travel Long Distances to See a Specialist?

Each state and territory has a scheme that pays some of the cost of transport and accommodation for people who need to attend a medical specialist a long way from home. The schemes provide financial assistance with the cost of transport and accommodation for the patient and, if deemed necessary, an escort. Rules vary depending on the state/territory you live in. If you would like to find out more about this service please call the Foundation on 1800 111 709.



Would You Like to Rediscover the Joy of Reading Books?

Do you have trouble reading books? Would you prefer to listen to books and newspapers in audio form? You may be eligible for a free Navigator talking book available through the Foundation's Navigator Home Access Program. The Navigator is a portable, easy to use device that reads books and newspapers aloud. The content is loaded onto the Navigator at home through an easy to use website that offers thousands of book titles and all major newspapers. In order to be eligible to receive a Navigator:

- you must have MD and have sight loss that makes reading difficult
- you, or a close 'support' person, must be able to use a computer and have a broadband internet connection in order to download audio content from a website

If you are interested in participating in this program, registration is online only via our website www.md.foundation.com.au/NHAP. The Foundation will review all registrations and then enrol as many eligible people as possible in the program. The program is made possible thanks to the generous support of the Profield Foundation. For more information call the Foundation on 1800 111 709.



Are You Having Trouble Using the Phone?

Telstra has a range of products and services available to assist people with disabilities to use their landline telephone. We have enclosed in this newsletter an information flyer on the products and services available. You can also contact Telstra to find out about their full range by calling the Telstra Disability Enquiry Hotline on 1800 068 424 or visit their website www.telstra.com.au/disability

Trial of Audio Description on the ABC

The Department of Broadband, Communications and the Digital Economy is going ahead with a trial of audio description on ABC1. The trial is set to take place mid-year, and will run for 13 weeks. Each day for 14 hours, the ABC will provide additional verbal commentary that complements the underlying soundtrack of drama and documentary content. The Foundation welcomes this trial and hopes that this will lead to a permanent commitment.

Roth Gair Charity Golf Day

The annual Roth Gair Charity Golf Day, held in Victoria on 5 February 2012, was another great success with over \$12,000 raised for the Foundation.

A big thank you to Ian Kennedy and his volunteers from the Lions Club of Forest Hill for their dedication and ongoing commitment in making this day a success.



Annual Report 2010-2011

If you would like a copy of the 2010-2011 Annual Report call the Foundation on 1800 111 709 or download from the website www.mdfoundation.com.au

Quiz Answers

- | | |
|----------------------|----------------|
| 1. Yes | 4. Yes |
| 2. 2- 3 times a week | 5. Yes |
| 3. By 3-4 times | 6. Amsler grid |

Latest Research

Family History

An important study just published in the British Journal of Ophthalmology has further confirmed that the risk of AMD is greatly increased by having an affected close relative. The researchers recommend that AMD patients should advise their brothers or sisters and children of this increased risk and to encourage them to seek prompt ophthalmological advice if they develop visual symptoms of distortion or reduced vision. The Foundation also encourages family members to have regular eye checks, as the early signs can be picked up by an optometrist or ophthalmologist even if there are no symptoms present. The earlier the disease is detected, the more that can be done to help slow it down by making diet and lifestyle changes (such as giving up smoking).



Early Results for New Treatment

Preliminary results in the first two humans treated with retinal pigment epithelial (RPE) cells derived from human embryonic stem cells have just been published in The Lancet. One patient, aged 51,

has Stargardt's disease (the most common form of MD in younger people) and the other, aged 78, has Age-related Macular Degeneration (AMD). These first two patients have shown no adverse effects, rejection or inflammation, and the cells are behaving as hoped. Some additional patients have now been entered into the trial due to this initial demonstration of safety. While this first study is not primarily designed to look at visual outcomes, the first two patients have already shown some slight improvement in their vision. It must be stressed that these results are preliminary, with a very short follow-up. Many more patients will need to be tested with larger doses of implanted cells with follow-up over several years before this treatment can be made more widely available. This study is being conducted in the USA, but has also just been expanded to the UK.

Education Across the Country

The Foundation has education sessions booked across the country in 2012 and you will be notified by invitation of any session being held near you. Don't forget, if you are a member of a community group and would like our Educators to attend your meeting, call the Foundation on 1800 111 709 to register your interest.

Donations

Thank you for supporting the Macular Degeneration Foundation. As a charitable organisation we rely on your generosity to service the MD Community across Australia.

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.

Contact us

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DISCLAIMER: This newsletter is produced by the Macular Degeneration 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 2012