

Dear Friends

Words cannot express my gratitude to you all for the enormous support you have given the MD Foundation over the last few months, especially the switching campaign and your generosity with donations as we signed off on the end of the financial year.

Treatment options for wet age-related MD “switching”

A few weeks ago I wrote to a great number of clients asking for your support in relation to the “switching” issue for anti-VEGF drugs for wet AMD. At that time I called on you to sign a letter to enable me to demonstrate to the relevant authorities the strong community support the Foundation has in relation to this issue. The timeline was short, but you were magnificent in your response with over 6,000 signed pro forma letters returned to the MD Foundation and 200 special letters of support. Further details on page 2.



CEO Julie Heraghty and Research Manager Rob Cummins take your letters to Canberra

Diagnosed with a disability after 65 years of age

I continue to advocate on your behalf in every forum possible on this issue, working with organisations for the blind and vision impaired, aged care, disabilities, and lobbying government. My concern is that a substantial group of older people, diagnosed with a disability after 65, will be in danger of falling through the cracks of two major reforms. Further details on page 3.

Funding

The MD Foundation relies heavily on a recurring grant from the NSW Government to support many of our activities in NSW. We have consistently met, and in fact exceeded, all of our funding requirements each year, with outcomes measured and reported. The NSW Government has recently advised they are reviewing the grants program with the view to budget savings. I am concerned that any funding decrease would significantly affect our activities in NSW, so I will keep you informed and call on you if I need your help. I also continue to advocate on your behalf for more funding from the Federal Government over and above our \$145K a year to run the entire national education program.

Nutrition & Supplements

Enclosed is the Foundation’s popular **Nutrition & Supplements** fact sheet. We have had many enquiries on supplements of late and have therefore included in this newsletter an outline of the evidence base for the MD Foundation’s recommendations and what products comply with this evidence. Also, make sure you look out for our **Reader Recipe** article, as we are calling for your very best “eye health recipe”. I am looking forward to reading, and sharing with our readers, some of your healthy and nutritious recipes.

The next newsletter will be our annual Research Update and then Christmas will be here again!

Kind regards

Julie Heraghty

Chief Executive Officer

Making the case on your behalf on switching

The MD Foundation's CEO met with Dr Suzanne Hill, Chair of the Pharmaceutical Benefits Advisory Committee in Canberra on August 27 and presented over 6,000 appeal letters and 200 personal letters of individual circumstances. Armed with your letters of support and our strong arguments, a very solid case was put to Dr Hill. The enormity of your response to our campaign and the impact of your personal stories enabled the strongest of representations. Dr Hill understood our case and the MD Foundation now awaits the formal outcome of our representations. One thing is certain, as you know, we will not give up!

In your letters, many people expressed thanks for treatment for wet AMD, which 5 years ago was not available, and how this has now meant saving sight for so many. The challenge however, so eloquently expressed in your letters, is the burden of treatment. This burden was repeatedly highlighted and covered such issues as age, treatment costs, coping with other diseases, travelling times in regional areas and associated costs such as petrol, accommodation and days off work for family. It was clear from your letters that husbands, wives, carers and relatives sacrifice so much to make sure their loved ones attend treatment to save sight. What is also evident is the enormous impact of the burden of treatment on the patient, their carers and family.

You can still help

Until we have a final positive answer the campaign does not end. Due to timing we were unable to contact all of our clients to sign and return our appeal letters. Please call the MD Foundation if you would like the information sheet, the pro forma letter to sign or to send a special personal letter. Again to those that responded to our call for help, thank you.



Dr Hill and Julie Heraghty



MD Foundation staff opening just some of your letters

Treatment options for wet age-related MD “switching”

The MD Foundation highlighted in the last newsletter that switching would not be allowed between anti-VEGF drugs for wet AMD. The Foundation's position is that switching should be allowed between both drugs Lucentis and Eylea (once available) and that, ultimately, the decision about which drug is most appropriate and potentially beneficial for the patient should be made on the recommendation of the eye specialist in consultation with the patient. For some people this may mean fewer injections and a lessening of the burden of treatment.

Your Questions ... answered!

Answering your questions is really important, keep them coming by phone or email. We are here to help! Here are a few Q & As you may find helpful.

Q: I've been diagnosed with dry AMD, can it turn to wet?

A: Yes, some patients who have dry AMD can develop the more aggressive wet form. That is why it is so important to use your Amsler grid every day, covering one eye at a time. If you notice any sudden changes in your vision you should contact your eye specialist immediately and arrange for a consultation without delay.

Q: I've heard about Eylea, when will it be available?

A: Eylea is a new drug for wet AMD. It has been registered for safety and efficacy by the Therapeutic Goods Administration (TGA) and is now on the Pharmaceutical Benefits Scheme (PBS). It is currently not available in Australia, but is expected to become available later in the year. Like other anti-VEGF drugs, Eylea is administered via an ongoing schedule of injections into the eye.

Diagnosed with a disability after 65 years of age

As highlighted on page one, the MD Foundation is working hard to ensure that those diagnosed with MD after 65 do not fall through the cracks of the two major reforms; the National Disability Insurance Scheme (NDIS), and the aged care reform announced by the Federal Government this year - Living Longer Living Better. The Foundation is especially concerned about access and affordability of low vision aids and technology for those with AMD and how this will be accommodated in aged care. CEO Julie Heraghty will continue to make representation through every means possible to make sure all Australians diagnosed with a disability after turning 65 will have a comparable level of services and equipment to those diagnosed before 65. There should be no discrimination based upon age.

Q: I am having difficulty reading the newsletter. Can I get it in another format?

A: Yes, we have a number of formats. It is also produced in audio, so you can listen to it on a CD player or your computer. It can also be sent to you as a Word document, for use with screen reading programs such as JAWS. Contact the MD Foundation to change your newsletter format.

Q: Why use the Amsler grid?

A: This is a simple tool you can use to check for symptoms and rapid changes in vision. Cover one eye at a time and use your normal reading glasses. Free Amsler grids are available from the MD Foundation.

All I want for Christmas...



Yes, we're talking Christmas already and it will be here before we know it! We're getting in early this year. Many people now choose to make a donation to their chosen charity in lieu of a gift at Christmas. So we're making this available so your family and friends can make a gift to the MD Foundation. Included in this newsletter is an "All I want for Christmas" donation card. All you need to do is hand this card to your loved ones for them to arrange a donation in your name. Helping to save sight... now that is a Christmas gift worth giving. Call the MD Foundation on 1800 111 709 for further information or to receive more cards.

Supplement Guide

Supplements are vitamins, minerals or other substances taken in tablet or capsule form. Supplements can play an important role in eye health.

One of the most common questions we are asked is “**Which supplement should I be taking if I have MD?**” The MD Foundation’s recommendations are based on evidence from large, randomised clinical trials which show that a supplement may help to reduce the risk of MD progressing.

Our information is provided through advice and recommendation from the MD Foundation’s Medical Committee which comprises ten of Australia’s leading ophthalmologists and retinal specialists.

What studies are there on supplements?

The AREDS Study: At this time, a supplement based on the Age-Related Eye Disease Study (AREDS) is the only one for which there is good, long-term evidence of benefit, but only for people who have already been diagnosed with MD.

The AREDS formula (daily dose) is:

Zinc	80 mg
Vitamin C	500 mg
Vitamin E	400 IU
Copper	2 mg
Beta-carotene	15 mg *

About Beta-carotene

*Beta-carotene has been omitted from most AREDS products because of concerns about it increasing the risk of cancer in smokers. This removal is strongly supported by the MD Foundation on the advice of the Foundation’s Medical Committee. People who smoke, or have smoked, or have asbestosis should not take a supplement that contains beta-carotene.

What were the results of the AREDS study?

The study showed that for people in the intermediate stage of AMD in one or both eyes, or in the late stage in one eye, the AREDS formula reduced the risk of progression of the disease by 20 to 25% and delayed vision loss. The study was not designed to show if the AREDS formulation is of any benefit for those with no signs of AMD, or for those with advanced disease in both eyes.

What products conform to AREDS?

There are a number of supplements available containing the AREDS formula. Check the label and ensure the product you buy contains the correct ingredients in the correct ratio from the AREDS study. The daily dose required to meet AREDS (minus beta-carotene) is: zinc 80 mg (or zinc oxide 100 mg), vitamin C 500 mg (also called ascorbic acid), vitamin E 400 IU and copper 2 mg.

Supplements and AREDS table

The MD Foundation has prepared the following table on some supplements known to the Foundation. The table shows if the product complies with the AREDS formula, the presence of beta-carotene and the required dosage of that supplement to meet the AREDS formula. If you are unsure whether a product not listed here conforms to the AREDS formula please contact the MD Foundation on 1800 111 709 and guidance can be given.

The correct dose to match AREDS formula

It is important to note that for products correctly matching the AREDS formula (with or without beta-carotene) you will need to take **two** tablets a day to match the dose used in AREDS, even though the bottle label will typically say “take 1 tablet per day or as professionally prescribed”. Please always consult your doctor first if considering a supplement or changing your dose.

Note: reference table has been removed

SUPPLEMENTS

For information on lutein, fish oil and other supplements please refer to our Nutrition & Supplements fact sheet enclosed.

Any changes in diet or lifestyle, including taking any supplement, should be undertaken in consultation with your doctor. Be sure to inform your doctor of your medical condition(s) and if you are taking any other medications, or vitamin or mineral supplements. When you purchase a supplement, check the label and be aware of the formula.

Declaration: The Macular Degeneration Foundation acknowledges that it receives financial support from Blackmores to support the Foundation's education, research and awareness activities. The MD Foundation's position on the use of supplements is determined by an independent Medical Committee comprising ten of Australia's leading ophthalmologists and retina specialists who receive no financial benefit from Blackmores.

Nutrition & Supplements fact sheet update

Enclosed is our updated **Nutrition & Supplements** fact sheet. Nutrition and supplements play a vital role in looking after your eye health. The benefits include reducing your risk of MD and slowing down the progression of the disease. Everyone can benefit from eating nutritious eye friendly foods, not smoking, and exercising regularly, but we are especially keen to promote the eye health messages to those over 50, those with MD, and importantly their families. Remember if you have a direct family member with MD there is a 50% chance of developing the disease.



MD Awareness

NEW! Symptom recognition TV and radio campaign

The MD Foundation has a new television and radio advertising campaign that is drawing attention to the symptoms of Macular Degeneration and emphasising the importance of early detection. At the same time our standard key message to people over 50 to "have an eye test and make sure the macula is checked" is still centrepiece of the eye health message. The advertisements can be viewed on the Foundation's website www.mdfoundation.com.au.



The MD Foundation thanks Novartis for their support of this public health campaign on symptom recognition for Macular Degeneration.

MD Awareness Week 2012 - thank you!

MD Awareness Week 2012, held in the last week of May, was a great success and included a large range of activities running under the theme "Keep your family in the picture" resulting in a huge amount of media. Our thanks go to MD Foundation Patron Ita Buttrose, Ambassador Jean Kittson and Founding Director Dr Paul Beaumont, who along with many others gave generously of their time. Thank you to ongoing sponsors Blackmores, Novartis and Optometrists Association Australia and a big thank you to Rotary clubs nationally who were a special partner in 2012.

Calling all Carers – we need your help!

Do you provide care and support for someone with Macular Degeneration?

If so, we would like you to phone the MD Foundation by 17 October on 1800 111 709 to register that you do undertake care and support of someone with MD.

The Foundation will be shortly conducting some valuable research on the role of carers and MD and it would be helpful for the Foundation to be aware of those people caring for someone with MD and to have this correctly recorded on our database.

To be a carer means you provide care and support for someone living with MD such as helping with daily activities, transport support, helping with bills and household chores, grocery shopping etc. You do not have to live with the person for whom you provide support, and it is not required to be every day or any fixed time.



Living well with MD

Calling all cooks

Do you love to cook? If so, we want to hear from you! We want you to send in your favourite "eye health recipe", that is if you're willing to share! We thought it would be fun to draw on the culinary talents of our readers by asking for your favourite recipes. Don't forget to include your name, address and phone number, and look out for our very first "Reader Recipe" in the next newsletter.



Aged care facilities ... it's ok to ask for nutritious food

Nutritious eye health food is back on a hostel menu after a call to the MD Foundation Helpline concerning the absence of poached eggs or green leafy vegetables on the menu, due to concerns about food safety. The MD Foundation discovered that it was now considered appropriate for these foods to be served in aged care facilities. Our caller approached her hostel to request a reintroduction of these foods and has since reported she is enjoying poached eggs and salads, including those all important leafy greens. Well done!

Reconnecting after 65 years!

When Beryl Godfrey saw Friend of the Foundation, Des Morton, in our last newsletter she called the MD Foundation and said that she and Des used to live next door to each other! After almost 65 years, two old friends have been put back in touch, thanks to the Friends of the Foundation program.

Volunteer Profile - Susan Harvey

Susan has been a volunteer at the Macular Degeneration Foundation for over two years. Susan comes three days every week to help in the office. Often called the 'Queen of the Storeroom', Susan knows where everything is to be found. She also helps to pack hundreds of information kits that are sent out each week.

"I enjoy being involved," Susan says. "When I see all the good work that the staff do, I just hope I provide enough support and help so they can do their hard work," Susan explains. "Everyone thanks me and is so friendly but I don't come here to get the thanks - I do it because I feel like I'm making a difference" she said.

The Macular Degeneration Foundation is grateful to Susan and all her fellow volunteers for their hard work and we look forward to forming many more joyful memories together over the years.



Susan Harvey
MD Foundation volunteer

Diary Date - Annual General Meeting

The MD Foundation's 2012 Annual General Meeting will take place in Sydney on Tuesday 11 December, followed by Christmas refreshments. All welcome.

Date: 11 December 2012

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

Place: MD Foundation, Suite 902, Level 9, 447 Kent Street, Sydney

RSVP: 30 November 2012 on 1800 111 709 (RSVP is essential for catering purposes)

Education

The MD Foundation has education sessions booked across the country in 2012 and you will be notified by invitation of any session being held near you. Below is a list of locations and dates for upcoming sessions. We will also be attending and giving daily talks at the Brisbane Retirement & Lifestyle Expo 12-14 October. Please call the Foundation to RSVP.

Location	Date
Canberra, ACT	25 October
Hobart, TAS*	27 October
Gosford, NSW	29 October
South Perth, WA	13 November
Penrith, NSW*	13 November

* The Hobart and Penrith sessions will feature comprehensive information and displays on low vision aids and technology.

IMPORTANT

Extended Medicare Safety Net changes commence 1 November 2012

In our last newsletter we explained to you the changes that will be taking place to the Extended Medicare Safety Net in relation to treatment for wet AMD and included a fact sheet for your information.

As this may have financial implications, dependent upon your doctor's fee, we urge you make yourself familiar with the changes before 1 November. In the first instance we encourage you to discuss any concerns with your doctor.

If you do not have this fact sheet and need a copy, or do not understand the changes to how people qualify for the Extended Medicare Safety Net, please call the MD Foundation on 1800 111 709.

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 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.

Contact us

Suite 902, Level 9
447 Kent Street
Sydney NSW 2000

Helpline 1800 111 709

info@mdfoundation.com.au
www.mdfoundation.com.au

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. Sept 2012