

Dear Friends

Christmas and the festive season have come again and another year has flown by so quickly. On behalf of all at the MD Foundation I send you best wishes for the holiday season and a very Merry Christmas and a Happy New Year to you, your family and friends. We have some great news to end our year.

We did it! Switching between treatments for wet Age-related Macular Degeneration

The power of your voice is very strong and effective, and I thank you all for your efforts and commitment to our work. In the last newsletter I reported on your response to my call asking for your support in relation to the "switching" issue for anti-VEGF drugs for wet Age-related Macular Degeneration (AMD). Your response was magnificent and as a result, there has been a great outcome for patients. Further details are on page two.

Diagnosed with a disability after 65 years of age

For some time now I have been raising my concerns over the fact that under the Federal Government's reforms in disabilities and aged care, those with vision loss or blindness from AMD, will be unfairly and inequitably accommodated. This is especially relevant in relation to access and affordability of low vision aids and technologies. You will recall how long and hard we have fought for change in subsidies for these aids and technologies. My major concern is that those diagnosed with a disability from AMD after 65 years of age will not be accommodated under the National Disability Insurance Scheme (NDIS). I recently decided to highlight this in the media with the ABC's 7.30 program and will be continuing this advocacy until the outcome is satisfactory. Read page two for more details.



Research

Enclosed is the MD Foundation's annual Research Update, which will bring you up-to-date on the latest in research and give us all hope for a cure. Included in this newsletter is the announcement of the successful recipient of the Blackmores Dr Paul Beaumont Research Fellowship for 2013-14. Details on page three.

The MD Foundation Research Grants Program is now clearly established through your generosity and support, so that we can find reasons and answers for this disease. I greatly appreciate your donations to enable the MD Foundation Research Grants Program to continue. It is also humbling to receive your enquiries on making a bequest to the Macular Degeneration Research Grants Program and I sincerely thank you for your generosity.

Annual Report

The MD Foundation's Annual Report 2011-2012 is now available detailing our activities in the past year. Call the Foundation on 1800 111 709 for your copy.

Have a wonderful festive season and best wishes to all.

Julie Heraghty
Chief Executive Officer

Representation

Switching between treatments for wet Age-related Macular Degeneration

The result... Following the representations made on your behalf, we are pleased to advise that switching will now be allowed between the anti-VEGF drugs, Lucentis® and Eylea®, which are listed on the Pharmaceutical Benefits Scheme (PBS) for wet AMD. This was conveyed by the Minister for Health, the Hon Tanya Plibersek, as part of an announcement on 24 October, regarding the listing of medicines on the PBS.

The Foundation's role is to ensure that patients have access to and affordability of treatment. In this case our representations have resulted in the right and proper outcome for patients.

This announcement is a win for patients and eye specialists. The decision means that ophthalmologists can now assess patients on an individualised basis for the most appropriate drug, to ensure the best outcome for the patient. The final decision on which drug should be used is a matter between the eye specialist and the patient. The Foundation knows that this excellent outcome is another step in supporting patients, families and carers in their treatment for wet AMD.

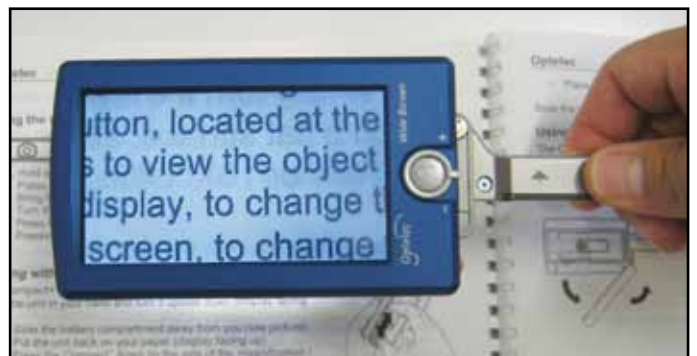
We did it!



Diagnosed with a disability after 65 years of age

The Federal Government's reform in disabilities involves the establishment of the National Disability Insurance Scheme (NDIS). However, this only covers those with a disability up to the age of 65 years. After 65 years those diagnosed with a disability, such as vision loss or blindness from Age-related Macular Degeneration (AMD), are to be covered in the aged care system. This means that almost all of those diagnosed with vision loss or blindness from AMD will be required to be supported in the aged care area. The MD Foundation has an ongoing concern that those affected were not included in the NDIS and now will not be fairly and equitably accommodated for in the Federal Government's aged care reform.

The Foundation continues to highlight this issue in all forums and in the media. On 15 November the ABC's 7.30 program reported on the issue and CEO Julie Heraghty and Friend of the Foundation Professor Helen Beange appeared. We sincerely thank Helen for her support to ensure all those with a vision impairment over 65 years are treated fairly, especially in relation to access and affordability of low vision aids. The Foundation will continue to advocate on your behalf on this issue. The 7.30 program can be viewed by following the links from the Foundation's website www.mdfoundation.com.au. Read Professor Beange's story on page six.



For further information on low vision aids, contact the Foundation for your free copy of Low Vision Aids and Technology – A Guide.

Research

Blackmores Dr Paul Beaumont Research Fellowship 2013-14

The Macular Degeneration Foundation is delighted to announce the recipient of the Blackmores Dr Paul Beaumont Research Fellowship for 2013-14 is Dr Bamini Gopinath, a senior research fellow at the Centre for Vision Research, Westmead Millennium Institute. Dr Gopinath will be working under the supervision of Professor Paul Mitchell, one of the world's leading experts in Macular Degeneration.

Her important research will improve knowledge of the nutritional and lifestyle risk for MD and protective factors particularly dietary antioxidant and supplement intake, diet quality and food groups. It will involve a detailed analysis of the 15 year data from the famous Blue Mountains Eye Study which was the first large population-based study of age-related eye disease in Australia.

The Macular Degeneration Foundation once again thanks Blackmores and The Blackmore Foundation for its support of this important Fellowship and congratulates Dr Gopinath as the successful recipient.



Dr Bamini Gopinath

MD Foundation Research Grants Program

The MD Foundation Research Grants Program was launched in 2011 with two major three year grants being awarded to Professor Paul Mitchell, Centre for Vision Research, Westmead and the University of Sydney and Professor Robyn Guymer of the Centre for Eye Research Australia (CERA). This research is progressing very well and now the Foundation is planning for the next round of research grants in 2013.

The goal is to provide \$10 million to fund world-class research projects by 2021 through the grants program and to eventually find a cure. Thank you to all those who support the MD Foundation Research Grants Program. It is only through the generosity of so many individual donations, bequests and our fundraising activities that we can fund such research. Every dollar donated to the Research Grants Program is allocated to research programs.

Research Update 2012

Enclosed is our Research Update for 2012 which includes reports on the latest research being undertaken into Macular Degeneration including research on wet and dry treatments, gene therapy and stem cell research.



Important Update: Extended Medicare Safety Net

As mentioned in the last two newsletters, a cap is now in place on benefits payable by the Extended Medicare Safety Net (EMSN) for out-of-pocket treatment costs for injections. The vast majority of people should be unaffected by this new cap.

The change means that if your eye specialist is charging **\$556.40** or less for item **42738** or **42739**, you will be unaffected by the capping of the EMSN and you will continue to receive an 80% rebate on out-of-pocket costs on the item from Medicare (once you qualify each year), in addition to the standard rebate. If your eye specialist is charging more than \$556.40 for item 42738 or 42739 (not including other fees such as a consultation) Medicare will no longer rebate any of the additional costs above this level.

If you are experiencing great difficulties with out of pocket costs, the first and most important step is to raise this matter with your eye specialist. One approach may be to say "Doctor, I now have some real concerns about my out of pocket expenses and I need to discuss this with you so that I can continue to receive my injections."

The most important thing is that you must not stop your treatment.

If you still have concerns after raising this with your eye specialist or wish to discuss concerns related to your ongoing treatment, please call the Foundation on 1800 111 709 to discuss the matter.

All I want for Christmas...



The Foundation's "All I want for Christmas" donation card makes it easy for your family to donate to the MD Foundation in lieu of a gift this Christmas. All you need to do is hand our donation card to your loved ones for them to arrange a donation in your name. Our spring newsletter included one of these cards for you, however more cards are available by calling the Foundation on 1800 111 709. Helping to save sight... now that is a Christmas gift worth giving.

Awareness Campaign hits the mark!

The Foundation's most recent national advertising campaign has been a great success!



Australia leads the world in terms of awareness of MD, in large part thanks to the ongoing national TV and radio campaign. However, alarmingly relatively few people could correctly describe a symptom of MD. The Foundation developed a new advertisement featuring MD symptom recognition. The outcome is an almost 50% increase amongst those in the 50+ at-risk age group being able to name a symptom of MD.

The Foundation sincerely thanks Novartis for their ongoing support of the Macular Degeneration national TV and radio campaign.

Awareness

Australians show their appreciation for the gift of vision

Australians answered the call of the Macular Degeneration Foundation and showed their appreciation for “the gift of vision” with over 560 inspiring photographs entered into the mEYE World Photographic Competition 2012.

Along with submitting a photograph, entrants were also required to submit between 30-60 words describing why their photograph showed their appreciation for the gift of vision. Thank you to our judges Macular Degeneration Foundation Patron, Ita Buttrose and mivision editor Mark Cushway.

Winners were announced as part of World Sight Day activities with optometrist Khang Ta from Melbourne the winner of the Healthcare Professionals category and selected as overall grand finalist from the four category winners.



Foundation CEO Julie Heraghty and Grand Finalist Khang Ta

The entries received have been truly inspiring and have told wonderful stories about the world in which we live and valuing our vision. The Foundation thanks all entrants in 2012, especially our successful winners and runners up.

The winners are:

Khang Ta,
Grand Finalist
and Winner
Healthcare
Professionals



Helen Dugdale,
Winner Macular
Degeneration
Community



Gary Brinkman,
Winner Open



Georgina Flanagan,
Winner Junior
(Under 18)

A special thank you to our sponsor the Optical Distributors and Manufacturers Association (ODMA) for their generous support of the mEYE World Photographic Competition 2012.

Winning photos and their inspiring supporting words can be seen on the Foundation's YouTube channel - go to www.mdfoundation.com.au and follow the links.

Living Well with MD

Professor Helen Beange's Story

I am a public health physician and I was in charge of a clinic for people with developmental disability. Eight years ago I had problems reading in low light and attributed this to getting old, I also ignored the flashes of light that came soon after. Then one day, the middle of the page I was reading suddenly went blank.

I was referred to a retinal specialist who told me that I had wet Macular Degeneration in one eye. He tried to save my sight, but it was unsuccessful. Sometime later I woke one morning seeing only a blur in my good eye. I had haemorrhaged and although I received treatment straight away, my sight could not be saved and I was declared legally blind.



Professor
Helen Beange

Having Macular Degeneration changes life on a very fundamental level. Losing my sight almost overnight changed my role dramatically from medical professional to someone living with a disability. I was devastated at the sudden turn of my circumstances.

My computer is my main aid as it is practical and lets me continue reading and reviewing articles for medical journals with the use of ZoomText. It also enables me to communicate with family, friends, and medical colleagues. I also use a CCTV reading aid, a handheld magnifier and listen to books on my hand held Navigator and a DAISY player. Technology makes it possible to take up new hobbies and I am currently revising my knowledge of Latin. These aids and technologies are a great help but are costly and older people need adequate access to training to be able to use them effectively.

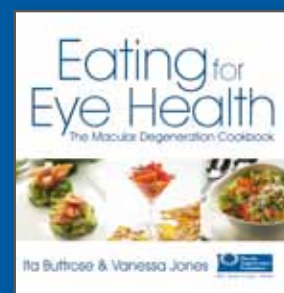
I believe the government needs to start improving rehabilitation for those living with low vision as it primarily falls to the private and not for profit sector. The Government needs to take some responsibility and I'm concerned that the current National Disability Insurance Scheme and Aged Care reforms are still not addressing this important issue. More needs to be done.

Uncle Bruce

Recently Foundation CEO Julie Heraghty accompanied a family member who has Macular Degeneration to the airport to catch a flight. He had on his vision-impaired badge, which was helpful to others to understand why he needed some assistance. This is a reminder that although it is sometimes difficult to ask for help, when we do ask, people are often very willing to assist. Please keep this in mind, especially if you are travelling in the busy holiday season. Take care and be safe.

Eating for Eye Health

The Macular Degeneration Cookbook is still available and makes a great Christmas gift. Call the Foundation to buy your copy on 1800 111 709.



Reader Recipe

Thank you to our lovely readers who sent in their "eye health recipes". The recipe below has been sent into us by Jean of Kiama, NSW.

Salmon Spinach Tart

Ingredients

2 sheets shortcrust pastry
1 tin 220 gm pink salmon - drained
3 or 4 leaves of English spinach
2 eggs
½ cup milk
½ cup coarsely grated cheese
A few chopped walnuts (if desired)

Method

- Grease a 9 inch (22cm) pie dish and line with pastry
- Prick and bake for 10 minutes
- Cook spinach lightly in boiling water, drain and stir in salmon. Add pepper to taste.
- Cool pastry a little then add spinach and salmon mixture (with the walnuts if using)
- Beat 2 eggs, add ½ cup milk and pour over the spinach mixture
- Cover with ½ cup grated cheese
- Bake in moderate oven for about 45 minutes to 1 hour

Grandma's Christmas Cake Recipe

Julie Goodwin was Australia's first Master Chef. The MD Foundation is thrilled to pass on her Grandma's Christmas Cake recipe for you to try at home as a treat this Christmas. Make sure you head over to Julie's website for more delicious Christmas fare – www.juliegoodwin.com.au

Prep time: 20 minutes

Cooking time: 2 hours 20 minutes

Ingredients

500g butter
500g sugar
500g plain flour
250g self raising flour
500g currants
250g raisins
60g mixed peel
8 eggs
Grated zest and juice of 1 lemon
Pinch salt
200g glace cherries, roughly chopped
200g blanched almonds
1 tablespoon brandy



Method

- Preheat oven to 200°C (180°C fan-forced). Grease a large cake tin and line with baking paper.
- Cream butter and sugar until thick and pale. Add eggs one at a time, beating after each addition.
- Add lemon zest and juice, fruit, cherries and brandy.
- Gently fold the flour through.
- Spoon the mixture into the cake tin.
- Arrange blanched almonds in a pattern on the top.
- Bake for 10 minutes, then reduce the heat to 150°C (130°C fan-forced) and bake for a further 30 minutes.
- Reduce the heat again to 120°C (100°C fan-forced) and cook for another 2 hours or until a skewer inserted comes out clean.

Education

The Foundation continues to deliver its education program around the country. The sessions cover symptoms, risk factors, treatment options, the importance of nutrition and lifestyle and latest research.

City	Location	When
Sydney, NSW	Kogarah Kogarah RSL Club	Tuesday 29 January 10.30am - 12.30pm
Sydney, NSW	Blacktown Max Webber Library Function Centre	Tuesday 12 February 10.00am - 12.00pm
Sydney, NSW (Low Vision Day)*	Bondi Junction Easts Bondi Leagues Club	Wednesday 20 February 10.00am - 12.30pm
Mornington Peninsula, VIC	Cranbourne Cranbourne Public Library	Wednesday 13 March 11.00am – 12.30pm

* The Bondi Junction session will also feature comprehensive information and displays on low vision aids and technology.

The Foundation has also arranged special presentations by ophthalmologists:

City	Location	When
Sydney, NSW Dr Paul Beaumont	Mona Vale Bayview Golf Club	Wednesday 6 February 2.00pm - 4.00pm
Brisbane, QLD Dr David Hilford	Bray Park Club Pine Rivers	Saturday 9 February 10.00am – 12.00pm

**If you would like to attend please call 1800 111 709
to RSVP (bookings essential).**

**Don't forget, if you are a member of a community group and would like our Educators
to speak at your meeting, call the Foundation 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 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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It is intended as a newsletter and its contents do not constitute medical advice and should not be relied on as such. Dec 2012