Macular Degeneration Foundation®

Our focus is your vision

Newsletter

WINTER
2nd edition 2012

Dear Friends

As always, I want to thank you all so much for your ongoing support.There has been so much happening in the last few months of great importance to the Macular Degeneration community.

One of the key critical issues is the Extended Medicare Safety Net capping. I deferred the delivery of this Winter newsletter in order to await the Federal Budget outcome on this matter. Other relevant issues for the MD community include:

- A Medicare review of the classification of item 42738 which is used for the injection of the treatment for wet AMD, which could affect privately insured patients.
- The introduction of a new treatment called Eylea (aflibercept) and switching of treatments.
- The outcome of the MD Foundation submissions for Federal funding (page 8).
- In addition, we want to introduce you to the "Merry Musicians" and another wonderful Friend of the Foundation – Nancy Little.

Spring Newsletter

Our next newsletter will include a special feature updating you on nutrition and supplements. The feature will deal with the new research about the benefits of a low GI (glycemic index) diet, give clarification on what supplements are appropriate for MD and discuss the evidence base that should guide the choice of supplement.

Extended Medicare Safety Net capping

In early April, I was concerned to hear media reports that there could be another attempt by the government to cap the Extended Medicare Safety Net payment to patients receiving injections for wet AMD. I immediately wrote to the Minister for Health requesting clarification of the matter and alerted other key parliamentarians and allied seniors' groups to the potential problem. A meeting was also held with senior officials in the Department of Health and Ageing where the Foundation's concerns were outlined based upon the 2009 Federal Budget scenario which would have left patients in dire circumstances. Please read the outcome on page 2 carefully. We have developed a Fact Sheet (enclosed) to guide you through the changes.

Rob Cummins (Research and Policy Manager) and Julie Heraghty (CEO) in Canberra.

Kind regards
Julie Heraghty
Chief Executive Officer

End of Financial Year Donations

We delayed this newsletter to include the information related to the Federal Budget, but hopefully there is still plenty of time for you to arrange your end of financial year donations. Any donations made before the 30 June will be processed immediately to ensure receipt in the 2011/2012 financial year.

Extended Medicare Safety Net capping

The 2012 Federal Budget did not include any changes to how people qualify for the Extended Medicare Safety Net. What has changed is the limit on how much the Government pays for some items, which is determined by the doctor's fee. The Government believes that capping of the eye injection items will address the issue of excessive fees charged by a very small number of doctors.

It is important to note - no patient who is charged less than $546.05 for an eye injection (item 42738) will be affected by the change. We believe that most patients will not be affected as most doctors charge under this amount.

The Foundation supports measures that reduce excessive fees charged by doctors, but we also must ensure that patients are not unfairly affected if there are high treatment fees. We will monitor the situation carefully to ensure patients impacted by this cap are able to access sight saving treatment and we will assist our clients wherever possible.

The MD Foundation has prepared a Fact Sheet (enclosed) which tells you everything you need to know, including: the detail of the changes, a table to calculate out-of-pocket expenses and information on what to do if you are being charged a higher amount. These changes do not take effect until 1 November 2012.

This information is also available on our website www.mdfoundation.com.au and please contact us if you have any questions or concerns on 1800 111 709. We are here to help and support you.

Classification of Medicare Benefits Schedule item 42738

Medicare is currently reviewing the classification of item 42738 which is used for the injection of the treatment for wet AMD. This review could affect where privately insured patients can be treated, and also whether privately insured patients can receive reimbursement through their health fund.

A change in the classification may mean that those patients with private insurance would no longer be able to receive a benefit from their private health fund when the procedure is performed in a private hospital or day care facility. Currently the majority of injections are given in doctors' rooms outside of a hospital setting.

In undertaking this review, the Department is seeking relevant views on the effect of classifying item 42738 in the Medicare rules as a Type C procedure and specifically what effect this would have on patients. On 19 April, discussions were held between senior officials of the Department of Health, Private Insurance Branch and the MD Foundation to discuss the potential impact on patients.

The Foundation is endeavouring to work with all interested parties to find a mechanism which will enable patients to access their private health insurance with an appropriate classification. We will keep you informed of the progress and outcome and call upon you for your help if required.

Access to Treatment
Lucentis and new treatment Eylea - "switching"

The anti-VEGF drug Lucentis (ranibizumab), used for the treatment of wet Age-related Macular Degeneration (AMD), has dramatically improved the outcomes for so many people. The registration of Lucentis by the Therapeutic Goods Administration (TGA) in 2007 and subsequent listing on the Pharmaceutical Benefits Scheme (PBS) changed the landscape of this disease. Lucentis continues to be used across this country to save the sight of so many people.

In April this year, another treatment called Eylea (aflibercept) was registered in Australia by the TGA. Eylea, which is also given as an injection into the eye, is not yet available in Australia but it is planned to be available for use by ophthalmologists later in 2012. Once available, it then needs to be placed on the Pharmaceutical Benefits Scheme as quickly as possible so it is not only accessible but also affordable. The MD Foundation will be advocating on your behalf to have Eylea placed on the PBS as soon as possible.

Clinical trial data indicate that Lucentis and Eylea produce very similar results, however the dosing regimen for Eylea is different. The committee that advises the Pharmaceutical Benefits Scheme has determined that switching will not be allowed from Lucentis to Eylea. Once you have started on the treatment, you will have to stay on the treatment.

The Foundation's position is that switching of treatments should be allowed between both drugs and ultimately, the choice of which drug is most suitable for the patient must be a decision made between the doctor and the patient.

The MD Foundation is now making representations on your behalf to the Minister for Health and the Department of Health and Ageing to produce an outcome which is in the best interests of the patient. If required, we will call on your postcard sending assistance to help provide the patient perspective on the need for switching of drugs.

NDIS and Aged Care Reform - Where is MD?

On behalf of the Macular Degeneration community, the MD Foundation CEO attended the launch of the aged-care reforms hosted by the Prime Minister and the Minister for Mental Health and Ageing at Parliament House on Friday 20 April 2012. During question time the CEO raised with the Minister the critical issue of the interface between the major reforms of the National Disability Insurance Scheme and Aged Care.

If a person has a disability acquired before pension age they will access funding and services (including low vision aids and technologies) through the disability system, but those acquiring vision impairment after pension age must rely upon the aged care system. The vast majority of the over one million Australians with Macular Degeneration are aged over 65. In fact, for those people who have late Age-related MD and experience serious vision impairment or blindness, virtually all are aged over 65.

This is one issue that is now caught up in the interfacing of these two reforms and could easily drop between the two reform packages. Currently there is no clear pathway to resolve the matter.

The CEO has written to the Minister recommending that an Interface Committee be established as a matter of urgency to address the issue. The purpose of this proposed committee is to recommend mechanisms by which the aged care and disability systems could interconnect seamlessly, so that a substantial group of older people with vision impairment do not fall through the cracks of the two major reforms.

Macular Degeneration Awareness Week 2012

Keep your family in the picture

Each year, we work extra hard to spread the sight saving messages of the Foundation in Macular Degeneration Awareness Week. This year the theme is **'Keep your family in the picture'.**

It is important to make sure Australians know that there is a 50% chance of developing the disease if a direct family member has MD. It is also important that Australians know what their family members can do to reduce their risk.

This year, for the first time the MD Foundation distributed 350,000 MD information flyers and Amsler grids through Rotary members Australia-wide. Thank you for the support of Rotary, and we look forward to growing this relationship in the years to come in MD Awareness Week.

Our sincere thanks once again to our sponsors Optometrists Association Australia, Blackmores, Novartis and bluedesk for their generous ongoing support.

National Galaxy Survey

As part of this year's MD Awareness Week the Foundation commissioned a national Galaxy survey. The results continue to show high awareness of MD amongst Australians (86% in the 50+ age group).

However the survey revealed some surprising results on knowledge of Australians on the role of genetics, nutrition and early detection of MD.

Results

These results were of concern and there is clearly more to be done!

- 71% of Australians (almost three quarters of the population) underestimate the genetic risks associated with MD.

  We need to spread the word on genetic risk.

- People over the age of 50 (particularly those over the age of 70) were less likely than others to identify any of the nutrients important for macular health.

  Eat that fish and munch those veggies!

- One in three believed that vision loss caused by Macular Degeneration is just a normal part of ageing.

  Never ignore any changes in vision at any age.

- Of those surveyed, 25% (in the 70+ age group) would mostly turn to their children if they lost their sight to MD, while 23% would mostly turn to a community health and welfare agency.

  Government and other service agencies need to plan for care in the community for those with MD, their families and their carers.

mEYE World Photographic Competition

An initiative of the Macular Degeneration Foundation

What inspires you to appreciate the gift of vision?

Following the success of last year's inaugural mEYE World Photographic Competition, the Foundation will be running the competition again in 2012.

This year we are asking you to submit a photograph which shows your appreciation of the **gift of vision**. It could be a person, landscape, event or any sight from your world.

Whether you have a passion for photography or you just love to take happy snaps, you could be a winner. Share your appreciation of vision through the lens of a camera and help raise awareness of Macular Degeneration.

How to enter the competition?

Submit your entry online through the competition website www.meyephotocomp.com.au

We're inviting you to submit your photograph online and tell us, in a description of 30-60 words, why your photograph is important to you.

If you are not sure how to submit online, ask someone who can use a computer to do this for you.

The photo must be in a digital format, submitted online. Call the Foundation on 1800 111 709 if you need any assistance.

The Foundation appreciates your help to spread the word about this competition. We need lots of entries as it helps raise awareness of Macular Degeneration.

We want happy snappers from the Macular Degeneration community!

Prizes include 'The Ultimate Sydney Experience': flights, accommodation and Sydney Harbour Bridge Climb; camera store vouchers; a telescope and more.

Categories

- Open (general public)
- Macular Degeneration community (those with MD, family, friends and carers)
- Healthcare professionals (optometrists, ophthalmologists, General Practioners, orthoptists, pharmacists etc)
- Junior (Under 18)

Competition Period

11 June -14 September 2012

An information flyer is included in this newsletter to give to your family or friends.

The Merry Musicians

We have done something quite different and entered the new world of social media with a real bang! The Merry Musicians of Coloundra in Queensland are an amazing group of talented older Australians with an average age of 79, the eldest is 91 and the junior of the band is 65!

They play at nursing homes, retirement villages and seniors events. They are "young at heart" and they will perform wherever there is a "free cup of tea and a willing audience." Stella, the leader of the group is nearing 90 and as piano player Ted says "we're just spring chickens"!

The Merry Musicians have agreed to team up with the superb Suncoast Social Dancers and record an amazing short video to show vibrant older Australians enjoying life. The video sends the message that you should never lose sight of your passion. Look after your health, have your eyes tested and macula checked and **you too could rock into your 90's!**

We intend for millions of people to view this amazing video on the internet and make the Merry Musicians as popular as Gracie Fields, Tony Bennett, Glenn Miller Big Band, Louis Armstrong and the Beatles.

To view this video you will need to use a computer. If you cannot do this ask family or friends to show you the video on their computer by visiting our website: www.mdfoundation.com.au or facebook site: www.facebook.com/maculardegenerationfoundation

If you have any videos or stories of yourself, your friends or your family "never losing sight of their passion," please share these with us on Facebook, email: info@mdfoundation.com.au or phone us on 1800 111 709.

Thanks to the Merry Musicians, Suncoast Social Dancers, Peter Brown (Artistic Director), Phil Carey (Film Maker) and the MD Foundation staff who worked so hard to make this project a reality.

Friends of the Foundation

The Vincent Fairfax Family Foundation Project

Vincent Fairfax Family Foundation (VFFF) is a philanthropic organisation that has been invaluable in supporting a number of the Foundation's important projects.

As part of their 50th anniversary celebrations this year, the VFFF generously provided the Macular Degeneration Foundation with a photographer to capture whatever we were most passionate about. We chose to have photographic portraits and personal stories written of some of our wonderful Friends of the Foundation. Through sharing their stories of living with MD they help us tell the MD story with passion and meaning and provide inspiration to others.

Thank you to Jean and Des Morton, Pat and John Tatham, Jill Falls, James Boon and Nancy Little and family for participating in the photography shoot at a beautiful home in Sydney donated by Mr and Mrs Seeto. It is our pleasure to share Nancy Little's story and photographs with you in this newsletter.

If you would like to be a part of the Friends of the Foundation program and help us with other fun projects, call the Foundation on 1800 111 709 and mention your interest.

Nancy's Story

I find life with Macular Degeneration can be frustrating at times. Tidiness and self discipline are two habits I have had to acquire. Without them, I might spend 10 minutes looking for my pen before I can start to write something down. I am forever getting out my torch for better light.

However, I do realise I can still do most of the things I enjoy. Reading is hard and sewing is impossible but I have been pleasantly surprised at the amount of help and support available to me. This reminds me that I am not the only one dealing with this disease so stop whining Nancy! My family is very helpful and supportive and I am very lucky to have them in my life.

I am grateful to the Macular Degeneration Foundation for all their help and information and their staff who are always lovely to talk to and very thoughtful. I encourage everyone to share their story with the Foundation because it is a special way to make a difference to our lives.

I was recently involved in the Vincent Fairfax Family Foundation Project and my photograph was taken! I was happy to be a part of this project as I know that the photos will be used to help tell the story of living well with Macular Degeneration.

Nancy Little and her family Photo by Helen Coetzee

MD Foundation Federal Government Funding

I regret to inform you of our great disappointment in the response to our recent funding submissions. Our education grant has been continued for three years but not one of our other four very worthy submissions was funded.

I will be writing to the Hon Tanya Plibersek, Minister for Health, to express my concern over this result. I will request a review of the processes that resulted in an unacceptable level of funding for this Foundation and the work we undertake. The Foundation clearly established the need for the funding towards areas that would help decrease the incidence and impact of MD. I thank you so much for your postcard writing efforts last year and do not worry - we won't give up.

Education

The Foundation's education sessions cover symptoms, risk factors, treatment options and the importance of nutrition and lifestyle and latest research. If you would like to attend please call 1800 111 709 to RSVP.

Location	Date and Time	Address
Darwin, NT	**Friday, 29 June** 10.30am-12.00pm	COTA (NT) Spillet House, 65 Smith Street, Darwin
Gladesville, NSW **with guest ophthalmologist** **Dr Andrew Kaines**	**Saturday, 4 August** 10.30am – 12.30pm	Gladesville RSL 4-6 Linsley Street, Gladesville

The Foundation is currently booking education sessions across the country for the next financial year. We will keep you updated when an education session is coming close to 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 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.

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