# The months really fly by and it is Autumn again, a lovely time of year with lots to tell you about in our newsletter

## **Treatment Update**

As at 1 March 2010, patients with wet Macular Degeneration (MD) who are receiving Avastin injections will again be entitled to a Medicare Rebate. The Government has decided that it is in the best interest of patients to re-install the Medicare benefit for Avastin injections used for a specific group of patients. The MD Foundation welcomes this decision by the Federal Government for those patients for whom it is intended.

It will benefit those patients who do not have age-related sub-foveal MD and are thus not eligible to receive Lucentis on the Pharmaceutical Benefits Scheme (PBS). Patients will still need to pay the full cost for the drug Avastin.

## **End of Financial Year Appeal**

While it is only March, I do ask that you remember us as we draw to the end of the financial year for tax deductable 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 more and more for the MD community. Thank you so much.

## Research

The Foundation is committed to supporting a major research project over the next few years. The Board of Directors of the Foundation has established a working group to oversee this exciting project. I will keep you informed of developments as we proceed.

**Julie Heraghty, Chief Executive Officer** 

# MD Foundation – Treatment Information

Patients should always have very clear information from their ophthalmologist as to what treatment they are receiving, the costs, safety and efficacy. In the first instance, if there are any concerns, the matter should be discussed with the ophthalmologist.

The Foundation has produced a free, comprehensive publication to help patients, family and carers regarding treatment for wet Macular Degeneration. The Wet Treatment Fact Sheet contains clear explanations regarding the drugs Lucentis and Avastin, a glossary of terms and questions you may wish to ask your ophthalmologist.

Call the Foundation for a free copy of the publication and for any further information on 1800 111 709.

## **Extra Special!**

Our next newsletter in early June will include an extra special publication titled 'Slips, Trips and Falls'.

As we age there are many reasons why our risk of falling increases such as weaker muscles and some health problems. Our vision is obviously a key part of this risk, so the Foundation has provided a range of ideas to help you reduce your risk of slips, trips and falls.

# Living well

# Thank you MDF Vollies!



Val and Neville voluteering at the MD Foundation

Last year over 15,000 information kits were packed by our wonderful volunteers in our national office in Sydney. In recognition of this we have printed on our envelopes "packed and prepared by volunteers". Thank you vollies, you are a valued part of our team. Here is an interview with Valerie and Neville, two wonderful volunteers.

### Do you have MD?

**Val:** "Yes. I was diagnosed six years ago and I am blind in one eye."

**Neville:** "Yes, I've got MD but I'm still driving but my wife tells me I don't drive as well as I used to!"

## Why do you volunteer with MDF?

Val: "I like to be positive and concentrate on what I can do rather than what I can't. It's a lot of fun and one of the highlights of my week!"

Neville: "My wife plays golf on Wednesdays so I had some spare time to help out. I feel like I'm doing something good for the wider community."

## What do you do here?

**Neville:** "We stick the address labels on the envelopes and pack them with invitations or education information to educate others about MD."

**Val:** "We also solve all the world's problems while we do it!"

### What do you like about volunteering?

Val: "I love all the young people that work here. I get along well with young people. What I like the most about volunteering with the MD Foundation is that the people are so kind. I think people who work in the caring professions or charities are generally good people."

Neville: "I agree. I like the bright cheerful atmosphere."

## **Extended Medicare Safety Net**

Foundation staff always advise clients to ensure they are registered for the Extended Medicare Safety Net (EMSN). So often people are unaware of this requirement and how important it is in terms of their out-of-pocket expenses.

The EMSN provides couples, families and individuals with financial assistance for out-of-pocket costs for out-of-hospital Medicare Benefits Scheduled Services. Once you meet the Medicare safety net threshold, you may be eligible for additional Medicare benefits for out-of-hospital services for the rest of the calendar year.

The out-of-pocket cost is the difference between the Medicare benefit and what your doctor charges you. Some examples of services where costs count towards the EMSN are GP and specialist consultations, blood tests, ultrasounds and x-rays and many more items.

Who should register? Couples and families do need to register; you only register once and it is free. Individuals do not need to register, but as a precautionary measure, make sure your contact details are up to date at Medicare Australia.

Make sure that you check you are registered and details are up to date for the EMSN by calling Medicare on 132 011 (call charges apply) or visiting your local Medicare office as soon as possible, as this is based on the calendar year.

# with MD

# **Jean's Story**

A visit by Carly from the Foundation to meet Jean Hogan was a truly rewarding time.

I was so thrilled to recently meet 83 year old Jean Hogan and to hear her story on living well with MD. Jean was first diagnosed with Macular Degeneration ten years ago, losing most of the sight in her right eye. She now has wet MD in her left eye and is currently being treated with Lucentis injections.

Jean attended a Macular Degeneration Foundation education session to gain a greater understanding of the disease. Knowing there is support from the MD Foundation is very important to her. (Hearing this put a great big smile on the face of the Foundation staff!)



Jean Hogan demonstrating her low vision aids

"When I was diagnosed with MD ten years ago I was devastated. I didn't know how it would impact my life. I sought all the information and support services around MD that I could. Today, I use aids and technology every day to keep active and continue living independently," Jean said.

When hand-held magnifiers stopped working for Jean she sought other technology and aids to suit her changed level of vision. She now uses a 'Compact Mini' to enable her to read whilst out shopping and around the house. A Compact Mini is a hand held electronic magnifier that enables the user to take pictures of objects and then enlarge the picture to a level that allows

the viewer to see it clearly. Jean has such a strong, positive approach to seeking and trying different and sometimes unfamiliar pathways to ensure quality of life and independence.

Jean is a wonderful example of a positive attitude, of carefully assessing various aids and technology which will support her everyday living needs and taking the challenge to using new technology.

"Don't be frightened of using new technology, after you see how easy it is and how much of a difference it makes, it can change your life", says Jean "and don't give up, there is always help available."

I left Jean, watching her cross the road to celebrate her 83rd birthday with her neighbours – busy, active and engaged in life.

## **Breaking Down the Barriers**

Thank you to everyone with Wet MD who participated in the recent 'Barriers to Accessing Wet MD Treatment' survey. There was a fantastic response and we will bring you the results as soon as we have completed the report.

In addition, the Foundation is conducting, in collaboration with the University of New South Wales, a survey on 'Barriers to Accessing Low Vision Services and Aids'. This survey will be mailed out to a random sample of our clients.

The results from the Foundation's research help us to help you. It supports our work in breaking down barriers to reduce the incidence and impact of this disease in Australia. Your participation in all studies we conduct is most important and greatly appreciated.

## **Fast Facts**

### **MD Awareness Week 2010**

This year MD Awareness Week is being held from Monday 24 to Sunday 30 May, continuing our successful theme 'How's Your Macula?' Remind your optometrist, ophthalmologist or library to display our poster and information flyers during the week.

During MD Awareness Week you can also help spread the word by promoting the key MD message "have your eyes tested and the macula checked" to your family, friends and local community.

## TV and Radio Campaign

Another major TV and radio campaign will run in April and May leading up to MD Awareness week, again reinforcing our key message on eye testing and the critical nature of early detection.

## **Research Update**

Thank you to so many who told us you loved our research update publication. We will most certainly do a yearly update for you each December after the major world ophthalmology conference.

# **Donations**

Thank you for supporting the Foundation. As a charitable organisation, we rely on your generosity of donations, bequests and sponsorship to serve the MD community across Australia.

If you are able to help us at this time, a donation slip and reply paid envelope is included for your convenience.

You can also make a donation online using your credit card. This secure method allows you to make a donation at any time. All donations over \$2 are tax deductible.

Thank you to all our wonderful supporters for their ongoing generosity.

## Not to be Missed...

Special talks across Australia on MD with special guest speakers.
Book now – 1800 111 709

#### **Sydney**

Special Guest Speakers: Dr Paul Beaumont and MD Foundation Patron, Ita Buttrose. Saturday 22 May, 10.30am –12.30pm Wesley Theatre, 220 Pitt Street, Sydney

### Parramatta (Sydney)

Special Guest Speaker: Dr Jennifer Arnold Saturday 17 April, 10.00am – 12noon Parramatta RSL, Macquarie Room O'Connell St, Parramatta

#### **Hobart**

Special Guest Speaker: Dr Nitin Verma Saturday 15 May, 10.30am – 12.00noon University of Tasmania, Centenary Theatre Grosvenor Crescent, Sandy Bay

#### **Perth**

Special Guest Speaker: Dr Dimitri Yellachich Sunday 30 May, 2pm – 4pm University of Western Australia Wesfarmers Lecture Theatre Business School Hackett Drive, Crawley

# Contact us We are here to help

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