4th edition 2010

## **Thank You**

Thank you once again for your ongoing support, generosity of spirit, your kind letters and your loyalty. On behalf of everyone at the MD Foundation I wish you all the very best for the festive season and a happy and safe new year.

**Julie Heraghty** 

Chief Executive Officer



# Ten years - one decade of service

Next year the MD Foundation will be 10 years old. It will be a very important year to celebrate together all that we have achieved. It will also be important to herald a new decade to launch a major appeal across Australia to raise \$10 million over the next 10 years. We need to support research projects to find reasons and answers for this disease. At the same time we must continue to fund and service all our other programs, so it will be a big challenge. However, it is a goal I am confident we can achieve to reduce the incidence and impact of Macular Degeneration in this country.

# What's happening in research?

What is happening in research and which areas are showing great promise? Included with your Summer newsletter is Research Update 2010, a summary of the latest in medical research on Macular Degeneration world-wide. Global research on the causes, genetics and treatment of Macular Degeneration continues at a hectic pace and no other area of ophthalmology is receiving as much attention at this time. Many Australian researchers are contributing substantially to the global effort, and the MD Foundation is very proud of their endeavours.





## **Annual Report 2009-2010**

The MD Foundation's 2009-2010 annual report has just been published and is now available. **If you would like a copy call 1800 111 709.** 

The report can be downloaded from www.mdfoundation.com.au.

## Low Vision Aids & Technology Campaign – not giving up!

Thank you to everyone who supported the MD Foundation's campaign on Low Vision Aids and Technology.

It seemed like Christmas did come early as the postman brought in the sacks of letters supporting our campaign. Your newsletter is delayed in an effort to give you the most up to date information possible on progress made on the campaign.

## What has happened?

- 1. Your campaign letters sent to the MD Foundation were photocopied, electorates checked and then over a thousand letters were mailed to the relevant federal MPs covering every electorate in Australia. This does not account for the many letters sent directly by you to the local member.
- We collected and collated incoming responses received from parliamentarians from all sides of politics.
- 3. We wrote to the heads of all major private health insurers requesting a meeting on your behalf.
- 4. We met with Senator the Hon Jan McLucas, Parliamentary Secretary for Disabilities and Carers on 18 November 2010 at Parliament House in Canberra and outlined the concerns of the MD community over this issue.

### What have we achieved?

#### 1. Government

Senator McLucas was very aware of our campaign and your letters to your local MPs. She reiterated her commitment to this area and outlined that Community and Disability Services Ministers in all states have agreed to:

- Give priority to a framework or "a road map" of measures to give people with disability more consistent access to aids and equipment by the end of 2012 via the National Disability Agreement.
- Compile a national list of existing core equipment that can presently be accessed in all states and territories by those with a disability to be completed by December 2010.
- Strengthen protocols to allow those who move between states/ territories to retain their access to core equipment required for their disability.

#### 2. Private Health Insurers

Several meetings have taken place and there is already an acknowledgement and a willingness by some providers to consider the issue. There is no doubt that your letters have had an impact. One health insurer made a real effort to understand the issue and visited our national office trialling the aids and technology.

## Where to now?

- 1. Keep those letters going to MPs.
  Do not underestimate the impact
  of your letters! It is not too late for
  you and your family and friends to
  send the campaign letter to your
  local federal member. Why not
  make an appointment to visit your
  local member? If you belong to a
  community club you may like to enlist
  their support for the cause.
- The MD Foundation will maintain a dialogue with the Senator's office and monitor the progress of the Governments intentions.
- **3.** The MD Foundation will continue to pursue the private health insurers and keep you informed.
- **4.** We will keep you informed of developments as we are in for the long haul on this one!

For more information call the MD Foundation on 1800 111 709 or visit our website www.mdfoundation.com.au.



CEO Julie Heraghty helping to compile letters to federal members across Australia. Special thanks to our new volunteer Dr Tim Nash, and staff for their help in collating and copying the responses.

## The EyePassport

The MD Foundation has developed a new client resource called the EyePassport. This will enable those living with MD to keep a clear, ongoing record of their diagnosis, including instructions from



the eye care professional and the estimated costs for treatment (if applicable). The cost estimate will help all patients have a clear idea of initial and potential ongoing costs.

Patients are often given information by their optometrist or ophthalmologist. Because there is no standard patient record for use by the patient (and carer and family), there can be confusion. Many patients can be unclear of their diagnosis and ongoing management.

The EyePassport is designed to help. For those already diagnosed please obtain a copy and take it with you on your next visit for completion. Keep it in a safe place and take it with you on each subsequent visit. You can also use it to show your GP your diagnosis and other aspects of your treatment. You may need one for your ophthalmologist and one for your optometrist if you are under the care of both.

This is all about communication and ensuring the patient has all the information to be in control of their own disease - to be in the driver's seat, to know where you are going and how you will get there and at what speed!

It has been designed to be as simple as possible for both the patient and the eye care professional using a tick box approach and it can be easily updated. This new resource will be available from the MD Foundation from late January 2011 but you can order the resource now on 1800 111 709.

## Fundraising Update - Blackmores Sydney Running Festival

The MD Foundation was thrilled to be part of the Blackmores Sydney Running Festival 2010 and wishes to thank Blackmores for including the MD Foundation as a benefiting charity.

Thank you to our wonderful runners and volunteers who helped on the day and in particular Suzannah Nicholson who raised over \$1,500 in support of the MD Foundation. Suzannah, with the help of her father Doug, put in a supreme effort in promoting her

involvement to all her friends, family and colleagues. Suzannah's mother Val, who is a regular volunteer with the MD Foundation, was there to cheer her daughter and team mate Emma over the finish line on the day.

Thanks to our wonderful volunteers who had a great deal of fun distributing water to the marathon and half marathon runners. Another great effort by a winning team! Thank you.



Left to right: Emma, Suzannah and Val



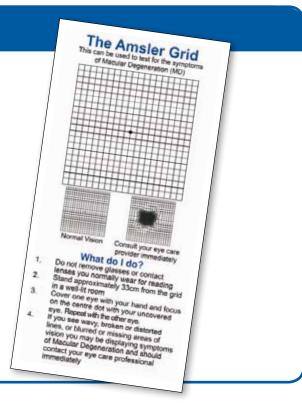
Volunteers Left to right: Gerry, Barbara, Pam, Susan, Janice and Paul.

## **Did you Know?**

### The Amsler Grid

Don't forget to test for sudden changes in your vision by using your Amsler grid daily. It is important to test each eye separately. Sometimes we may not realise there are changes in one eye without covering the other eye and doing the Amsler test.

Don't put any change in your vision down to old age, dirty glasses or a cataract ... Get it checked out urgently. Delay can lead to unnecessary loss of vision.



## MD Foundation Telesupport Program Dates for your diary!

The Telesupport Program is a support service that is provided over the telephone via teleconference once a month. It provides information on Macular Degeneration relevant topics as well as an opportunity for people with Macular Degeneration to be involved in a peer support group. Join in the session and discussion on the telephone in the comfort of your own lounge room.

Book your place at one of the upcoming Telesupport sessions by calling the MD Foundation on 1800 111 709.



| Date and Time                                 | Topic and Guest Speaker   |
|---|---|
| <b>Wednesday 12 Jan 2011</b><br>10.30am (est) | <b>Topic:</b> What low vision support services are available? The Low Vision Assessment and low vision rehabilitation. <b>Speaker:</b> Jane Ellis, Senior Manager Client Services, Vision Australia                       |
| <b>Wednesday, 9 Feb 2011</b><br>10.30am (est) | <b>Topic:</b> How can aids and technology help me? From magnifiers and daily living aids to assistive technology and support services. <b>Speaker:</b> The Royal Society for the Blind, South Australia                   |
| <b>Wednesday, 9 Mar 2011</b><br>10.30am (est) | <b>Topic:</b> When and where to ask for help? The role of family and carers, and the benefits and services available for people with MD. <b>Speaker:</b> Bronwyn Howlett, Executive Manager Regional Programs, Carers NSW |
| <b>Wednesday, 6 Apr 2011</b><br>10.30am (est) | <b>Topic:</b> How can computers and new technology help me? Opening up doors and staying connected via the internet. <b>Speakers:</b> Dr. Scott Hollier and Sarah Pulis, Media Access Australia                           |

Participants really found value in the sessions already held:

"I found the session was positive and enlightening. Julie was very welcoming and gave hope to people who were newly diagnosed." Connie (QLD)

"I really did not understand the importance of nutrition in slowing down my disease, Pam explained it so well." Jack (NSW)

Eating Well for Macular Degeneration – lifestyle, nutrition and supplements was presented by Pam Stone, Director of Education at Blackmores.

## **Christmas Card Orders**

There is still time for you to order your MD Foundation Christmas Cards, but you need to be quick! You have a choice of two pack options, each featuring three specially created Christmas recipes by chef Vanessa Jones and MD Foundation Patron Ita Buttrose, coauthors of Eating for Eye Health - The Macular Degeneration Cookbook. Packs retail for \$12.00 for a mixed pack of nine (plus postage and handling). Order forms are available by calling the MD Foundation on 1800 111 709 or download via our website on www.mdfoundation.com.au



### **Bequests**

We have recently received a few small but highly valued bequests after the sad passing of some of our dear clients. Many older charities receive a large level of income from bequests from loyal and constant supporters. The MD Foundation is conscious of the need to now develop bequests as an important component to fundraising, especially as we embark on our research project over the next 10 years.

Thank you to those who have advised us that the MD Foundation has been included in your will - your forethought is greatly appreciated. If you are considering leaving a bequest and would like to discuss the matter further, please contact the MD Foundation's General Manager Lucy Walker on 1800 111 709. A helpful bequest booklet is also available from the Foundation.

## **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 is 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

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

#### **Contact us**

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