

## Spreading the word about Macular Degeneration (MD)

The MD Foundation has had a busy start to the National Education Program for 2006. The education sessions are aimed at the over 50s and the MD Community. They focus on prevention, treatment and information on low vision services and aids.

### On the Road

This year education sessions have been held across Tasmania, South Australia and NSW. Launceston, Tasmania was a highlight with WIN TV covering the event. Over 400 people attended the sessions in Adelaide and regional centres in SA and the support of the Royal Society for

the Blind of South Australia was greatly appreciated. In NSW we have been very warmly welcomed in regional areas in Southern NSW and New England attracting over 700 attendees.

*"Most informative, it is great for people to come to the country and give us information on Macular Degeneration."*

- Attendee, Port Pirie SA

*"I had not previously been informed about using the Amsler Grid daily but now I am checking every day."*

- Attendee, Highbury SA

### Thank You

A big thank you to all of our partners and supporters including Quantum Technology, HumanWare, Carol Cane from the Hobart Support Group, Royal Society for the Blind of South Australia, Guide Dogs Tasmania, NSW and ACT and Vision Australia.

### Where to Next?

Queensland, Western Australia and the North Coast of NSW are our next locations. Phone the MD Foundation's helpline on 1800 111 709 for further information or to make a booking. Session details can also be viewed on the Foundation's website.



**Above - the Launceston Session**

## Macular Degeneration Awareness Week - June 5 to June 11 2006

MD Awareness Week is on its way again and the Foundation will be launching a thought provoking campaign in June. Get involved by making your local

community aware of this disease. Speak to a friend, phone a talk back show or write a letter to your local newspaper. Tell your story and spread the word!

## Marion's Story - Don't Delay!

When Marion (pictured right), visiting from Melbourne, walked through the MD Foundation's door, little did we realise how important her visit was. In the course of conversation Marion mentioned that she had experienced 'overnight' a dramatic change which included dark patches in her central vision. These were clearly symptoms of a 'bleed' indicative of wet MD.

The urgency of seeking immediate treatment from an ophthalmologist is critical in these situations. Marion later wrote to us and her following words convey an important message for us all:

"It was an expression of urgency that I sensed in your concern that motivated me to seek out a Retina Specialist on my return to Melbourne. He performed an angiogram which confirmed that I had Neovascular (Wet) MD. He explained that I needed the blood vessel treated immediately. Without the Photodynamic Therapy (Visudyne) I asked what would happen. My specialist promptly replied



'you will go blind.' So I agreed to go ahead. Had I waited and not sought treatment immediately, as I was advised to do, one can only imagine the possible extent of scarring and loss of vision. I am now using low vision aids including a CCTV in order to persevere with my Masters Degree through Macquarie University."

Marion was lucky; she spoke to the right people at the right time, received advice and acted immediately. Marion's story highlights the need for vigilance in detecting serious visual symptoms needing immediate attention.

## The Amsler Grid - Don't forget!

The Amsler Grid is used for detecting sudden changes in vision, which may be symptoms of Wet MD.

If you notice that your view of the Amsler Grid has become worse, parts are missing or lines appear more wavy, please contact your ophthalmologist for an urgent appointment.

Please remember to use the Amsler Grid every day. Contact the Foundation for a free grid on 1800 111 709.

## Our Research Says

Recent research conducted by the Foundation, with people who had Wet MD, showed that 40% of people did not receive appropriate treatment because it was "too late for treatment".

In 57% of cases the delay was as a result of being unaware of the symptoms or unknowingly linking them to something else.

The research also highlights the importance of using the Amsler Grid.

## The MD Foundation trials new exciting adaptive technology

### An invitation accepted

In late 2005 the Royal Society for the Blind of South Australia invited the Macular Degeneration Foundation to partake in a trial of a project called Books in The Sky (BiTs). This project uses technology that can make a real difference to the quality of life for the blind and vision impaired.

### How did the technology come about?

A gentleman recognised the difficulty his mother in law was experiencing with MD. Her main frustration was her inability to access newspapers and reading material of her own choosing. He set about inventing a device that was 'low tech' and sturdy with minimal buttons. He did so well he finally landed on the Inventors on ABC TV!

### So what is this technology and how does it all work?

The invention was called 'the Navigator' developed by a private company called Audio Read. It is approximately 15cm (six inches) long and 5cm (two inches) wide with 8 buttons and reads books, magazines and daily newspapers of your choosing.

The material is accessed through a local library connected to the program, a computer with broadband or through a small digital 'black box' installed in the home. The local library model is considered important to enable access and equity for the Macular Degeneration Community.

### What were the results of the trial in NSW?

The current six month trial has delivered outstanding results. People with MD in the age range 60 to 80 years have suddenly found that they have immediate access to books and magazines of their choice with

very little effort or technological know how. Several people have used it to assist with university courses.

### What can new technology mean for people with MD?

It is exciting that technology which is simple, user friendly and accessible can bring real improvement in the quality of life of those with MD. The next stage of this project for the Foundation, for which further funding has been sought from the Federal Government, is to increase the number of libraries involved with the program.

### For more information

For further information on the pilot project please contact the Foundation.

For enquiries on the product 'The Navigator' contact:

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Ultimo NSW 2007 Australia

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**Fax** 02 92125536

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[www.facs.gov.au/newsletters/disability/2005/issue45.htm#4](http://www.facs.gov.au/newsletters/disability/2005/issue45.htm#4)



**Technology such as 'the Navigator' can help to improve quality of life for the vision impaired.**

Our focus is your vision

## Contact Us

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## Low Vision Handy Hints

○ If you are going out for dinner, plan ahead by contacting the restaurant to receive a copy of the menu beforehand. This will allow you to make a decision without having to ask staff or other guests to read the menu for you on the night.



○ If travelling overseas, be sure to obtain customs forms well in advance. You can then fill them out in the comfort of your home with level of lighting you require.

## MD Foundation signs 'MOU' with RANZCO

The Macular Degeneration Foundation has signed an historic Memorandum of Understanding (MOU) with the Royal Australian and New Zealand College of Ophthalmologists (RANZCO). The MOU outlines ways in which both organisations can assist each other in reducing the incidence and impact of MD in Australia.

**Right - Leslie Lofthouse (MDF Chairman) with Dr Allan Rosenberg (RANZCO College President) at the signing.**

## Did you know?

### Low Vision Aids and Technology

The MD Foundation's National Office in Sydney has an area set aside for people to view CCTVs and daily living aids such as talking clocks and watches.

The Foundation does not sell these items but can refer visitors to providers of adaptive technology and low vision aids. Please phone the Foundation for an appointment to view the display.

## Donate to the Foundation

As a not-for-profit organisation the Macular Degeneration Foundation relies on donations and sponsorship to fund services to the MD Community.

A donation slip and reply paid envelope are included with this newsletter for your convenience. Donations can also be made by phone or in person.

All donations over \$2.00 are tax deductible. For more information on how to donate or if you are interested in leaving a bequest please contact the Foundation.



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