Newsletter

SUMMER 4th edition 2009

Our eyes are firmly on the future

with your help

What you said about us: In June 2009, as part of Project Vision III Research, over 600 people on the MD Foundation database across Australia were surveyed to evaluate their level of satisfaction with our services. The results showed 90% of the MD community had a very high level of satisfaction with the Foundation. Nearly half (48%) of those surveyed rated the Foundation as excellent and 42% as good.

What more can we do for you?

The main newsletter topic requests we had from you were for updated research.

We have listened and responded!

This newsletter contains a lift-out summary of presentations from the recent 2009 American Academy of Ophthalmology Meeting. More than 25,000 Ophthalmologists from around the world heard about the latest advances in MD, from anti-VEGF treatments to genetics and nutrition.

MD is a complex disease with many potential causes including genetic predisposition and a host of environmental factors. This provides both challenges for treatment as well as opportunities to target new pathways to track down the cause of the disease.

It is important to understand this research is ongoing and at different stages. Clinical trials are lengthy and conducted over three phases. New drugs and procedures do not become available to the public until they pass strict government regulations which



include the completion of Phase III trials conducted on thousands of participants to confirm effectiveness and safety.

What more can the Foundation do to find reasons and answers to MD?

In 2011 we will hit the big first decade – 10 years old. We have grown quickly and made great inroads into achieving our objectives.

It is now time to turn our attention to a key objective which needs our support: the funding of research. Our theme for the next year will be 'Finding Reasons - Finding Answers'. In the next newsletter I will outline how the Foundation proposes to meet our objective to find answers and reasons for this disease.

My best wishes to everyone for the festive season and a safe and happy 2010, when together we will focus our eyes firmly on the future. Thank you to my dedicated staff and Board of Directors, volunteers, supporters and friends. It has been a hectic but very rewarding year for our MD community.

Julie Heraghty CEO

Living well

Using low vision aids, technology, support

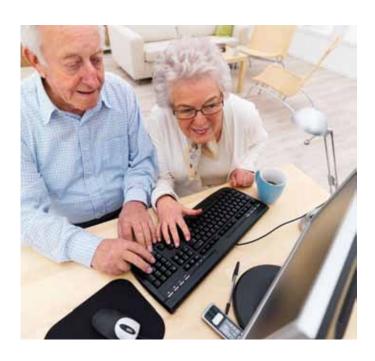
Listening to our MD community is so important. Your feedback stated that you wanted information on aids and helpful tips on low vision.

Rule number one is don't be frightened of the word 'technology'. Remember these words - smart, adaptable and organised. That's our MD community! Using low vision aids, technology, support and good practices can maximise quality of life and independence and that is what we want!

Ensure you have had an assessment at a Low Vision Clinic to determine your personal equipment solutions.

Some easy technology

- ✓ Electronic magnifiers desktop for reading bills, mail and medicine bottles and hand-held for reading when out and about in shops and restaurants
- Computer software providing magnification without speech
- ✓ Guide a great program for your computer making everything easier including reading emails and writing letters



For more information on Guide, call Quantum Technology on (02) 8844 9888.

The Navigator

The Navigator is a talking book device. It is easy to use and portable, so can be enjoyed either at home or when out and about.



The Foundation's new Navigator Home Access Program enables users to load content on to the Navigator at home via a website, giving easy access to thousands of book titles and major newspapers.

Participants are eligible for the program if they have access to broadband internet or a family member, friend or carer who can load content from the website onto the Navigator.

For more information call 1800 111 709 or register at:

www.mdfoundation.com.au/NHAP

Some simple aids for low vision

- ✓ Liquid level indicators, which beep when liquid reaches the top of the cup
- ✓ Large button telephones and calculators
- ✓ Talking clocks, watches and kitchen and bathroom scales

with MD

and good practices for your quality of life

Bruce – smart, adaptable, organised and doing it with attitude!

Bruce Moffat, a 66-year-old Cairns local, was diagnosed with wet MD two years ago. He now lives with low vision, but has never let it affect his quality of life or sense of humour.

"It's a real learning curve when you're first diagnosed with MD, but you adapt and develop little tricks. I'm coping well," says Bruce, who no longer drives and has trouble reading and recognising faces.

Bruce uses a variety of low vision aids and technology in his daily life to help him get around, including magnifiers, a CCTV (electronic magnifier), bright lighting, speed dial and audio books.

"My only fear is crossing roads because I can't see approaching cars. I've nearly been bowled over a couple of times. I think my sense of hearing has become more acute, but you have to watch out for hybrid cars, they're so quiet they can sneak up on you!"

But it's not all bad according to Bruce.

"One of the best things about having MD is that everyone looks like Nicole Kidman or Tom Cruise to me because I can't see them clearly!" he quips.

"Living well with MD is 99% attitude. If you fall victim to feeling like a victim, that's how you'll live. I don't advertise the fact that I have MD and I've never thought of myself as a victim," he says.



Bruce Moffatt with Julie Heraghty in Cairns, Qld

Good practices for low vision

Slips, trips and falls can happen to anyone, as our CEO found out when she tripped and fell down a flight of stairs a few weeks ago and crutches became her fashion item!

"I now always use the handrail, it is just not worth it. The risk of falling increases with age and we need to be extra careful with low vision," said Julie.

Some basic tips we should remember:

- Avoid rushing and allow plenty of time to get to your destination
- ✓ Place lighting in dark areas
- Allow time for eyes to adjust when walking from light to dark areas and vice versa
- Keep floors free of clutter and loose mats and rugs
- ✓ Always immediately wipe up spills

Never forget the golden rules of bigger, bolder brighter and good practices will ensure a 'no falls policy'! Our free publication 'Family, Friend and Carer - A Guide' has a comprehensive list of tips to prevent falls and accidents around the home.

Amazing fundraising achievement

Last month, legally blind Sydney man Matt Formston and his friend Scott Williamson cycled from Sydney to Melbourne to raise much-needed funds for the MDF. Matt, a 31-year-old business analyst, was diagnosed with MD at just five years of age and now has only 5% vision.

The pair raised an amazing figure of over \$15,000 for the Foundation and donations are still continuing to pour in.

"I have so much admiration for what Matt and Scott have achieved and I sincerely thank them both for their inspirational effort and amazing generosity," said MDF's CEO Julie Heraghty.

To see more photos of Matt and Scott's trip or to read their blog entries, visit: www.seeingbeyondbarriers.com.au



Matt Formston and Scott Williamson on the road during their epic journey

Annual Report now available

The 2008/09 Annual Report 'Our Eyes on the Future with your Help' is now available. If you would like a copy, please contact the Foundation on 1800 111 709.

Alternatively you can view it online at: www.mdfoundation.com.au

Low vision aids

One source for a good range of budget priced magnification and daily living aids is Royal Society for the Blind (SA). Their range includes talking watches, clocks, calculators and magnifiers.

For more information: call (08) 8232 4777 or visit www.rsb.org.au

How can you help the MD Foundation?

Thank you for supporting the Foundation. We rely on your generosity via donations, bequests and sponsorship to service the MD community across Australia.

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

You can also make a donation online using your credit card. This secure method allows you to make a donation at any time.

And remember - all donations over \$2 are tax deductible. We thank all our wonderful supporters for their ongoing support.

... but there's more!

Coming soon to meet the need of our MD community is the third in our Guide series 'Low Vision Aids and Technology – A Guide', thanks to recent grants received from the Department of Health and Ageing and the Trust Foundation.

This will be launched early next year.

Contact us

Suite 302, Level 3, 447 Kent Street SYDNEY NSW 2000 **Helpline** 1800 111 709 **Tel** 02 9261 8900 **Email** info@mdfoundation.com.au **Website** www.mdfoundation.com.au