

Need to know!



The results from the Foundation's recent *Project Vision II* research showed that many people living with low vision are not accessing the range of rehabilitation services available. Over 2,000 people completed the Project Vision II survey. Of those with MD, 85% were unaware of the services and aids available, and 53% were unaware of where to access services. It is important to meet and speak with a low vision professional. You can view the range of aids and technology available and discuss ways to improve quality of life and independence. If you are unsure of the appropriate rehabilitation service that could help you, please contact the Foundation to obtain a copy of *Low Vision – A Guide* or speak to one of our support staff who will be only too pleased to assist.

How can I make a Donation?

As a charity, the MD Foundation relies on donations, bequests and sponsorship to fund its operations. A donation slip and reply paid envelope is included with this newsletter for your convenience. The Foundation thanks contributors for their ongoing support. You can now make a donation to the MD Foundation online using your credit card. This secure method of payment allows you to instantly make a donation at a convenient time for you, any time of the year. For tax purposes, a receipt will be e-mailed to you on payment. And remember - all donations over \$2 are tax deductible.

Did you know?

Translated information about MD is available in five different languages. You can access information about MD in Arabic, Chinese, Greek, Italian and Vietnamese by contacting the MD Foundation on 1800 111 709.

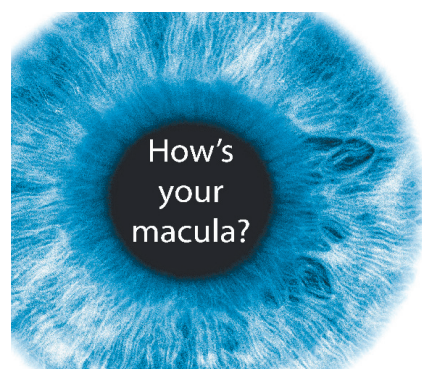
Upcoming Education Sessions

The Foundation will be conducting education sessions in South Australia and regional NSW from February onwards. Dates are yet to be confirmed, however if you would like more information please contact the Foundation on 1800 111 709. Alternatively, watch the Foundation website for regular updates on new education session times.

MD Foundation Annual Report

The 2007-2008 MD Foundation Annual Report is now available. To obtain a copy of the Report please call the Foundation on 1800 111 709.

Alternatively you can download the Report from the *About Us* section of the website: www.mdfoundation.com.au



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Our focus is your vision

Newsletter

SUMMER
4th Edition 2008

The Macular Degeneration Foundation wishes you all the very best for the holiday season!



National MD awareness campaign launches across Australia

In our recent *Project Vision II* research we surveyed over 2,000 clients on our database and asked the question: "What more could the Foundation do for those with Macular Degeneration?" The strongest recommendation from those interviewed was to increase awareness of the disease.

As the first step in fulfilling our MD community's wishes the largest ever MD awareness "How's Your Macula?" advertising campaign ran from October to December across television and print media. The Foundation received literally thousands of calls from across Australia asking for advice and information about MD. This three month intensive campaign highlighted the importance of getting your eyes tested and ensuring your macula is checked. Early detection can save sight, and this was a key message of our campaign.

Our sincere thanks go to Novartis for their outstanding support of the awareness campaign. Their commitment to the Foundation's aim to reduce the incidence and impact of this disease in Australia has really begun to make a difference in our fight against MD.

Television campaign

In October a three month MD awareness television advertising campaign was launched across Australia. The advertisements appeared in peak viewing periods. This campaign has allowed the Foundation to reach a record number of people in large metropolitan centres as well as both rural and regional communities. Advertisements reached a potential audience of over 5.5 million people in the 55+ age bracket alone.

Print campaign

The television advertising campaign was rolled out in conjunction with our print campaign. This included advertisements from October to December in publications such as *Women's Weekly*, *Sydney Morning Herald's Good Weekend* and *Burke's Backyard* to name a few. The print campaign reached a potential audience of almost 6 million people in the 50+ age bracket.

The Foundation received over 112 calls every working day during October as a result of this advertising campaign!

Education

Awareness

Support

Research

Representation

Keep On Driving – Safely

You wouldn't let your licence expire...what about your eye sight? This is the question our *Keep On Driving – Safely* campaign will ask millions of Australians over the next five years. There are over 8 million driver licence holders in Australia, the majority of whom will need to renew their licence in the next five years. The MD Foundation has partnered with the NSW and Queensland State Governments to provide MD information flyers in driver licence renewal notices as part of our extensive awareness campaign. The Foundation is currently working to extend this project to all remaining States to make this a national initiative. The Foundation would like to thank the NSW and Queensland State Governments for their willingness to support this exciting campaign.



Genetic advances in MD research

Dr Gregory Hageman (University of Iowa, USA) is the researcher who discovered the gene variant Complement Factor H and its protein, which is strongly associated with increased risk of developing MD. His discovery has the potential to change the way MD is treated and potentially cured. The identified gene, Complement Factor H (CFH), and its protein product are normally engaged in the control of a portion of the body's immune system. Normal levels of healthy CFH protein may protect against MD, while variants in the gene result in poor regulation of this system and can lead to the development of MD.

Dr Hageman is undertaking further research with liver transplant recipients as the gene Complement Factor H is produced in the liver. He recently spoke to US Congressional leaders, briefing them on dramatic advances in MD research since 2005, when he and his and three other research teams first identified the gene Complement Factor H. You can find more information on this research on the National Alliance for Eye and Vision Research (USA) website: www.eyereseach.org

Talk to the Family!

Genetics play an important role in the likelihood of developing MD. It is important to speak to your family members about MD and encourage them to have their eyes tested and ensure their macula is checked.

Professor Ron McCallum joins special UN committee

Our congratulations go to Professor Ron McCallum AO on his election to the UN committee as one of 12 independent experts that will monitor implementation of the UN Convention on the Rights of Persons with Disabilities. Professor McCallum is the former Dean of the Faculty of Law at Sydney University and an expert in industrial law. He is totally blind and is the only Australian currently serving on a UN treaty body.

The Committee plays a key role in considering reports by countries in the areas of non-discrimination; awareness-raising; accessibility of the physical environment, transportation, information and communication technology; and services to enable independence and full participation of people with a disability in society.



Pope Benedict XVI receives the Macular Disease Patient Charter

Representatives from Pro-Retina Deutschland and Retina Italia Onlus have had the unique opportunity to make His Holiness, Pope Benedict XVI, personally aware of the needs of people with macular disease. They presented him with the Macular Disease Patient Charter in October and were honoured for their efforts with a special blessing. The event marked the end of their awareness raising cycling tour that travelled through Europe and finished in Vatican City.



The Macular Disease Patient Charter is a bill of rights providing an essential road map for those living with macular disease. The Charter is supported by the MD Foundation and consists of four essential cornerstones: prevention and cure; timely diagnosis; universal access to proven treatment; and holistic care and support. A copy of the Charter is available by contacting the Foundation or via our website: www.mdfoundation.com.au

Volunteers

The Foundation is constantly on the lookout for passionate people interested in helping in the fight against MD. We run several events and expos throughout Australia that would not be possible without the dedication of the individuals that give up their time for our cause. If you are interested in volunteering, you can contact the Foundation on 1800 111 709 to register your details with us. We will send you a letter when an event is happening in your area to ask if you are available to assist us. Thank you for your support.

Living Well with MD – Your Story



The MD Foundation is about you – patients, family members, friends and carers. The staff and volunteers hear the stories you share with us every day on the helpline and are inspired by your strength and courage. The Foundation would like to share your *Living Well with MD* stories with the rest of the MD community. The stories might cover handy hints, a humorous event or how you overcame challenges associated with vision impairment. We would like to publish selected stories on our website, use them in presentations and in MD publications. Your consent would be obtained and your name changed before any reproduction of your story.

You can write your story or send in a tape or CD. You may like to ask a friend or family member to help you with the task. Grandchildren are a great help on these occasions as they are computer whizzes! Please send your story to:

MD Stories
Macular Degeneration Foundation
Suite 302, 447 Kent Street
Sydney NSW 2000

You can also email your story to: info@mdfoundation.com.au. There is no time limit, so we look forward to hearing from you at your leisure. Your story may change someone's life.