Macular Degeneration Foundation™
Our focus is your vision

Newsletter
4th Edition 2006

MD Foundation Annual Fundraising Dinner

This year's Annual Fundraising Dinner was held at the Shangri-La hotel Sydney on World Sight Day, Thursday 12 October. Over 250 people joined special guests the Hon Malcolm Turnbull, Parliamentary Secretary to the Prime Minister, the Foundation's Patron Ita Buttrose AO, OBE and Miss Universe Australia, Erin McNaught. Well known actor and comedian Jean Kittson generously donated her time to be Master of Ceremonies for the evening. Jean gave an entertaining and perceptive account of her parents' experiences living with MD.

A special thank you to all the generous sponsors, supporters and attendees who helped make the night a great success.

The MD Foundation would like to sincerely thank the organising committee for their tireless efforts in ensuring a wonderful evening. Well done on a great job!

Malcolm Turnbull, (right) with Patron Ita Buttrose AO, OBE

Left - The organising committee, (left to right) Pamela Healy, Grace Mirabella and Teena McQueen

2005-2006 Annual Report

The Foundation has recently published its 2005-2006 Annual Report which showcases many achievements over the last financial year. The Annual Report and Financial Statements are now available on the MD Foundation's website (www.mdfoundation.com.au). Copies of these publications can also be obtained by contacting the Foundation.

Charles Bonnet Syndrome (CBS)

The Foundation regularly receives enquiries from people experiencing 'phantom images'. People report seeing images that are in fact not really there. These images, called Charles Bonnet Syndrome (CBS), can be attributed to a side effect of vision impairment. Not everyone with MD experiences this syndrome. Learning about CBS can help allay fears and anxieties for those with MD and provide a measure of understanding for relatives and friends.

What is Charles Bonnet Syndrome?
CBS is a term used to describe phantom images or visual hallucinations experienced by some people with vision impairment. The images can take many different forms from patterns or lines to people or buildings. ***Quite simply this is your eyes playing tricks on you.***

Why do the phantom images occur?
Both eyes collect images which are then transferred to the brain. The brain interprets the images which allow us to see. If both eyes have vision loss the brain will often make up its own images as it tries to make sense of the damaged image received. ***This process causes phantom images to appear.***

Does everyone experience the phantom images?
Not all people who have low vision will experience phantom images. Some people will never experience CBS, while some may have symptoms for months or even years. The images may occur a few times a month, a few times a week or every day. ***When the brain adjusts to the vision loss the images will usually disappear.***

Do these images mean there is a mental health problem?
CBS is not a condition related to mental health, it is merely a side effect of low vision. These images generally occur when a person is fully conscious, often in broad daylight and the person is aware that the images are not real. They occur in combination with normal perception, for example you may be looking at your garden and you may see a lamp post that you are fully aware does not exist in your garden. ***The images do not appear in combination with sounds or other sensations.***

Examples of phantom images

Every time I sit in my lounge room I see six kittens playing in the middle of the floor.

When I water my pot plants the pots sometimes appear to have bunches of flags instead of plants.

I remember driving in the country through open fields but I kept seeing a skyscraper appear every few minutes which I knew certainly wasn't there!

I see a pink and yellow pattern on footpaths, floors and table tops. It happens for a little while, a few days a week.

What should I do if someone close to me is experiencing phantom images?
Friends and family members need to know that this can be a normal side effect of low vision. An understanding and supportive approach is required.
If persistent or disturbing images are experienced or combined with other senses, or if there are any concerns, then as a precautionary measure, a visit to the doctor should be scheduled as soon as possible.

A special thank you...

The Foundation thanks Leslie Lofthouse (pictured right) who has recently stepped down from her position as Chairman and Director.

Through her leadership and commitment the Foundation experienced a period of growth which saw the expansion of the education program and a dramatic increase in public awareness of MD.

Thank you and best wishes from the Macular Degeneration community.

Welcome to our new Chairman - Elizabeth Carr

Elizabeth Carr (pictured left) has joined the Board as a Director and kindly accepted the position of Chairman of the MD Foundation. Elizabeth has a family member with MD and is passionate about reducing the incidence and impact of the disease in Australia.

She brings to the Foundation valuable experience and expertise gained through a number of prestigious corporate and government appointments.

Dr Nitin Verma recognised with Distinguished Service Award

The Foundation's Tasmanian State Chair, Dr Nitin Verma (right) has received a Distinguished Service Award from the Royal Australian and New Zealand College of Ophthalmology (RANZCO). This award was presented to Dr Verma in recognition of his significant contribution to ophthalmology, especially in overseas and remote communities.

The Foundation congratulates Dr Verma on this award.

Blackmores - Over $1 million contributed so far

A sincere thank you to Marcus Blackmore and the team at Blackmores who have supported the MD Foundation from its inception in 2001. Over the last 5 years, Blackmores has contributed over $1 million to the Foundation's activities supporting education, awareness and research programs. Blackmores has also been a key partner in establishing Macular Degeneration Awareness Week.

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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

Donate to the Foundation

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.

An easier and quicker option is available by calling the Foundation to make a credit card donation. All donations over $2 are tax deductible.

The MD Foundation would like to say a big thank you to all who have donated in 2006.

Orion Expedition Cruises

Orion Expedition Cruises generously donated a discounted Kimberley holiday for auction at the Annual Fundraising Dinner.

As a thank you to Orion, a pamphlet is enclosed which showcases their many holiday adventures.

Seasons Greetings

The Foundation would like to wish the MD community, all donors, supporters, sponsors and partners an enjoyable break over the festive season and a happy new year.

Through your help, 2006 has been an enormously successful year for the Foundation. The combined efforts of so many have helped to reduce the incidence and impact of Macular Degeneration in Australia in 2006.

Thanks for your support.

New studies published on Ranibizumab (Lucentis®)

The results of two Phase III clinical trials of ranibizumab (Lucentis®) have been published in the *New England Journal of Medicine (NEJM),* demonstrating the drug's effectiveness in treating Wet Macular Degeneration.

The studies have shown that more than 90% of patients treated with ranibizumab maintained their vision over one and two year periods. Forty percent of patients experienced an improvement in vision, which was indicated by an increase in visual acuity by 15 letters or more.

For further details of these studies please visit the *New England Journal of Medicine's* website (***http://content.nejm.org/cgi/content/short/355/14/1419***). The Foundation will continue to provide updates on new treatments.