Macular Degeneration Foundation®
Our focus is your vision

Newsletter

SPRING
3rd edition 2011

Spring is here, and the gentle scent of the spring flowers, especially the jasmine, begins to remind us that summer is coming and, before we know it, Christmas!

Thank You

Please accept my sincere thanks for your generous response to our end of financial year appeal. We understand everyone has a preference for where their donations are directed and we are pleased to now offer you the option of supporting the Foundation's ongoing programs, or alternatively, to have your donation directed to our new Macular Degeneration Foundation Research Grants Program. Thank you to all for your wonderful support!

Research - Research - Research

There are many people with MD, their carers, partners and families whom I have the great pleasure of knowing and meeting. Recently one such wonderful person said to me, "Julie, I really look forward to the newsletter and I await the news that there is finally a cure". The comment brought home to me the importance of the work the Foundation has begun in research.

Applications for the Macular Degeneration Foundation Research Grants Program opened in June and there were some outstanding applications. The Foundation's research committee considered all applications and the Foundation's Directors supported the awarding of three outstanding research projects. The Governor-General Quentin Bryce announced the successful recipients on World Sight Day, 13 October 2011, at Admiralty House in Sydney.

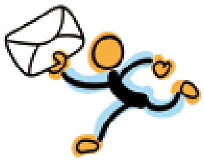
Our next newsletter will be a research special which will detail the three recipients and their work and provide a summary of the latest research across the world.

We need your help again - Federal Funding

It is hard to believe that almost three years have passed since I asked for your help to support the renewal of our funding from the Federal Government. The funding processes have changed and I have had initial discussions with the Department of Health and Ageing to outline the fact that we need to not only maintain but also increase our funding base.

Macular Degeneration covers the areas of health, disabilities, ageing and mental health. It is a chronic disease with four times the prevalence than dementia and almost half of that of diabetes. As the budget preparation takes place between now and the end of the year, I ask if you would again support us by sending the enclosed postcard to the Federal Minister for Health, The Hon Nicola Roxon. Every card sent is important, and you can acquire more cards for friends and family by contacting the Foundation on 1800 111 709.

This postcard will require you to affix a stamp. We thank you for your support.



Julie Heraghty
Chief Executive Officer

Representing your interests … so much is happening!

As reported in past newsletters, the Federal Government commissioned two major reports by the Productivity Commission in 2010. These were:

1. Disability Care and Support

2. Caring for Older Australians

Macular Degeneration has a strong place in both these areas. Prior to these reports the Foundation had embarked upon a campaign to make low vision aids and technologies more accessible and affordable. Your support in sending letters to local members and private health insurers has seen the matter on the government's agenda and some movement with private health funds. Meeting and correspondence with Parliamentary Secretary for Disabilities, Senator Jan McLucas resulted in the Foundation being encouraged to pursue this through the disability reform process.

The Foundation provided detailed submissions to both enquiries and further submissions when the draft reports were released for comment. The Foundation also appeared before both Commissions. Subsequently the Productivity Commission draft reports were released with strong recommendations to Government for an overhaul of the aged care and disability systems. The Foundation has throughout, all of the consultation processes, continually stressed the critical nature of accommodating all aspects of Macular Degeneration in the final recommendations, especially access to low vision aids and technologies.

The Foundation's Chief Executive Officer raised key aspects of the reports in recent meetings with the Hon Mark Butler, Minister for Ageing and Mental Health including:

1. Under the proposed systems, if you have a disability before 65 years of age you would access funding and services via the disability pathway (National Disability Insurance Scheme or NDIS).
2. If you have a disability post 65 years of age you would access funding and services under the proposed aged care system.
3. The most common form of MD (Age-related MD or AMD) and resulting blindness is usually diagnosed post 65 years of age.
4. The proposed National Disability Insurance Scheme may give better access to low vision services as well as aids and technologies but it is of concern that older people with vision loss will not have access to the NDIS and may risk falling between the cracks.
5. The aged care system may not be able to appropriately and adequately provide the services and the aids and technologies required by people with vision impairment.
6. The report, *Caring for Older Australians*, recommends a range of changes that may affect older people with vision impairment. The Foundation wants the government to ensure new systems recommended in the report incorporate the specific needs of people with vision loss including access to disability services, assessment, counselling, low vision aids and technology and the education and training of workers in the aged care and disability sectors.

> **"The Foundation is continually driving home the importance of eye health in the aged care system, in the community and in residential aged care."**
>
> **Julie Heraghty**

The Foundation's message to the government is simple: "It is critical that the services required by the MD community be positioned in the right place in both the disability and aged care systems so they are accessible and affordable."

Julie Heraghty

We will continue to represent your interests at every possible opportunity. To view the reports, go to www.pc.gov.au. To find out more about the Foundation's representations, phone Virginia on 1800 111 709.

Aged Care Reform – what could it mean for you?

Many of our clients are highly interested in aged care for their own future plans and for discussion with family and carers. The Federal Government is presently consulting the community across a range of matters regarding aged care. I know many of our readers will be interested in information related to potential changes and so we have adapted a summary kindly provided by the Council on the Ageing (COTA), which is enclosed for your information. This material does not represent the views of the Foundation, it is provided for your information as a service.

Proposed Aged Care Reform - What could it mean for me?

Background

Australia's current aged care system provides support and care at home for older people as well as providing residential care services.

The Federal Government makes funding available for these services that can be provided by state and local government bodies, non-government and private commercial organisations.

The Federal Government considers that the current system is facing many problems as it was designed for a different era. As a result, it is thought that many older people receive less support than they need, or miss out altogether.

Aged care services are frequently difficult to access and their flexibility, quality and affordability vary a lot.

These problems have been recognised in a recently released report "Caring for Older Australians" prepared by the independent Productivity Commission. This report recommends widespread reform.

The Federal Government is presently considering the report and deciding what it should do to reform aged care. The Minister for Mental Health and Ageing, the Hon Mark Butler, is holding a series of 'Conversations on Ageing' to hear from the community about what matters as you get older and the sort of support and services that will help most.

To assist this conversation the Council on the Ageing (COTA) produced a summary of key elements of the "Caring for Older Australians" report. The MD Foundation has adapted the information provided by COTA and provided a summary as a service to our clients. (See next page)

For further information about the upcoming consultation process, please call the Aged Care Consultation Information Line on 1800 057 618.

Please note that this publication is a summary of proposed reform of the aged care system by Government and in no way represents the views of the Macular Degeneration Foundation.

The Macular Degeneration thanks and acknowledges the information provided for this publication by
COTA Australia, 16 Hutt Street, Adelaide SA.

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Christmas Cards and Cookbook on sale now!

We have designed some new simple yet beautiful Christmas cards this year. Also available are our original cards which feature festive dessert recipes by chef Vanessa Jones and MD Foundation Patron Ita Buttrose, co-authors of *Eating for Eye Health: The Macular Degeneration Cookbook*.

We still have copies of this wonderful cookbook and it makes a beautiful Christmas present with over ninety delicious easy-to-follow recipes. All recipes have been developed with eye health friendly foods, ensuring good health comes with a great taste. This cookbook will certainly become a family favourite and retails for $25.00 (plus postage and handling).

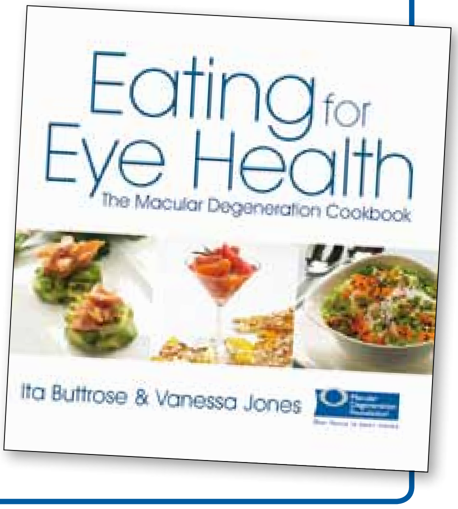
Place your order with the Foundation today! Please see the enclosed order form for further details.

Tuna is really a top food for eye health but what to do with it for variety? Here are some ideas from our Eating for Eye Health cookbook.

Three quick ways with tinned tuna, YUM!

Drain a 225g tin of tuna and:

- Toss in bowl with a squeeze of lemon juice, bean shoots and parsley leaves. Serve in a crisp iceberg lettuce leaf.
- Toss with diced red capsicum and Spanish onion. Coat with a little mayonnaise. Cut a round bread roll in half and put a few baby spinach leaves with tuna on top of one half of the bread roll. Place the other half on top. Grill (broil) in a sandwich maker.
- Blanch some green beans, refresh in iced water, and toss with kalamata and Sardinia olives. Top with tinned tuna, a little chopped parsley, and extra virgin olive oil.



Special December Summer Edition!

Our next newsletter will be a special research update that will review the latest research across the world being undertaken by both Australian and international researchers. It will also showcase the recipients of the Foundation's first research grants and the work they will be undertaking.

Your Story

Over the years, we have had the honour of so many people sharing their stories with us to help raise awareness of Macular Degeneration, including our wonderful Patron Ita Buttrose and amazing Ambassador Jean Kittson.

Every day at the Foundation we are in awe of the stories we hear from you, when phoning to seek advice or obtain help and information. They include personal and inspiring stories about overcoming the challenges of living with MD and the pride in the achievements of those with low vision in the home, workplace and community and wonderful stories from carers and family members. Your challenges with aids and technologies have included some wonderfully humorous stories, which you have so generously shared.

We think it would be wonderful to have a collection of "your stories" to raise awareness, promote the Foundation for support, to convey to politicians and potential funders and most importantly to inspire others who are challenged by this disease.

So please write and tell us your personal story and share your experiences about living with MD.

We have included a return page for you to write on but if you are unable to write your story, phone the Foundation and register for a call back so we can record your story over the phone. However, please be patient with us as there may be many calls and this may take some time.

We will compile the stories and then decide how we can best use your story to help others. Your story and contact details will be treated as confidential and will not be used in any way, or disclosed to any third party, without your written permission. By sending us your story you will start a personal conversation with us which could be the beginning of a wonderful journey to help, support and inspire others.

Community Fundraising

On Melbourne Cup Day, make the MD Foundation the winning charity by a good length!

We thank community groups across Australia who support us with community fundraising including **NSW Clubs 2011 Community Development Expenditure Scheme**; **Killara (NSW) Golf Club ladies golf day and bowlers bridge day; Roth Gair Charity Golf Day Victoria** and **The Salon on Asquith (WA).**

Running so Australia can see a future - There were many young participants in the *City to Surf* in Sydney, *Run Melbourne* and the *Gold Coast Airport Marathon* this year. Many of these young runners had parents or grandparents affected by MD and used their involvement to raise funds and awareness of Macular Degeneration through the *Everyday Hero* website. This is a great way for our younger family members to give support, while doing something they love. To find out more please call the Foundation on 1800 111 709.

Charles Bonnet Syndrome

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), is 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 brain playing tricks on you!**

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. It is a surprisingly common occurrence affecting about 30% of people who are legally blind or have lost a large amount of vision. The things people see can take all kinds of forms from simple patterns of straight lines to detailed pictures of people or buildings, which they know do not exist. The images can be very detailed and brightly coloured, but are not normally threatening or frightening. 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.**

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. Many people have told us that they did not ask or discuss it with anyone because of the strange nature of the experience. It is important to understand that these images are a result of losing vision, and are not associated with a psychological condition.

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.

Spring Notice Board

What you thought about us!

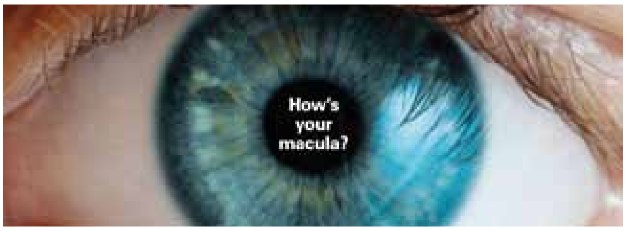
Thank you to everyone who completed our annual service evaluation questionnaire.

Every August, the Foundation evaluates its services by sending a questionnaire to a sample of over 1,800 clients on the database. Clients include people with MD, family and friends of people with MD, those with a general interest in MD and people working in an MD-related field. The great majority of respondents (87%) were satisfied or very satisfied overall with the Foundation's services. The newsletter was the most frequently used, and most highly rated, of the Foundation's services. All publications and services were rated positively by the great majority of those who had used them. The Foundation will use the information and suggestions to improve services for you, our clients.

PS: When returning surveys, a number of people requested Macular Degeneration publications and materials. Unfortunately, because the survey was anonymous, we do not know who requested these materials. If you requested information when returning your survey please call the Foundation on 1800 111 709 and advise us what publications you are waiting for and we'll get these posted to you ASAP!

National TV and Radio Campaign

The Macular Degeneration Foundation continues to lead the world in raising awareness of MD and yet another national TV & radio campaign will air from October to December. Thank you to Novartis who have been outstanding in their support of the MD Foundation and this campaign.



Bayer Joins the Foundation Team

Corporate sponsorship is vitally important to the Foundation's success and it is with great pleasure we now welcome Bayer to the team. Bayer has committed funding for a number of specific projects that will assist the Foundation's communications activities, including audio production of major publications. Rene Klemm, General Manager - Bayer Healthcare is pictured below with Julie Heraghty, celebrating signing of the partnership agreement.

Take care – a word of warning

A number of Australia's peak medical and patient advocacy groups are advising patients to be careful of alternative treatments that are advertised in newspapers or on the internet claiming dramatic success in the treatment of MD.

The Foundation's position on hyperbaric oxygen treatment aligns with that of the Australian & New Zealand Society of Retina Specialists (ANZSRS), the Royal Australian & New Zealand College of Ophthalmologists (RANZCO) and the Australian Medical Association (AMA). All these organisations urge caution as there is no compelling evidence-based research that hyperbaric oxygen treatment has a beneficial effect on either the wet or dry form of MD.

Before proceeding, patients considering such treatment or other alternative therapies claiming dramatic results are urged to discuss the evidence and potential risks with their ophthalmologist.

For more information, phone the Macular Degeneration Foundation (toll free) on 1800 111 709.

Announcing our New Board Director, Mr Richard Grills

The MD Foundation welcomes Mr Richard Grills to the position of Board Director. Richard is the Managing Director of *Designs for Vision*, which supplies ophthalmic and optometric products throughout Australasia, and is Chairman of the Optical Distributors & Manufacturers Association (ODMA). Richard has extensive experience as an optician and working in low vision clinics in hospitals and ophthalmic practices. He has also lectured in optics at the University of Sydney since 1974.

We Have Moved!

The Foundation has moved from level 3 to level 9 in the same building.

Our new address is:

Macular Degeneration Foundation
Suite 902, Level 9, 447 Kent Street,
Sydney NSW 2000

Our helpline number, fax and direct phones will remain the same and our mail is being re-directed with Australia Post. **Please be assured that your donations and correspondence will reach us on level 9.**

Diary Date

Annual General Meeting 2011

The Foundation's 2011 Annual General Meeting will take place in Sydney on Tuesday 13 December, followed by Christmas refreshments. All welcome.

Date: 13 December 2011

Time: 11:30 am - 12:00 noon

Place: MD Foundation, Suite 902, Level 9, 447 Kent Street, Sydney

RSVP: 28 November 2011 on 1800 111 709 (RSVP is essential for catering purposes)

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 are 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.

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