

Many Challenges – Great Outcomes

Firstly let me apologise for the lateness of our Spring newsletter. There are some very good reasons which I would like to share.

Proposed changes to the Extended Medicare Safety Net (EMSN)

The MD Foundation worked tirelessly on behalf of the MD community to reverse a decision from the May Federal Budget. This would have seen the maximum Extended Medicare Safety Net (EMSN) rebate on Item 42740 (injection of a therapeutic substance into an eye) capped at \$80.

This critical issue had the potential to heavily impact on the treatment for wet AMD. Our concern was patients would exit or not enter treatment based on affordability, therefore risking vision loss and possible blindness.

A compelling case must be based on information and facts. The Foundation gathered data with your help, undertook economic modelling and reviewed all available studies on the cost of blindness. Armed with a comprehensive submission we met with the Department of Health, the key advisor to the Federal Health Minister and Opposition Senators and cross benchers. We outlined the ramifications of this decision and the importance of removing Item 42740 from the proposed safety net changes.

On Wednesday 16 September 2009 the May Federal Budget decision was successfully turned around and Minister Roxon issued a media release.

On behalf of so many patients with wet AMD, their family and carers I would like to say thank you to

Media release extract:

“The Government has agreed that a cap on the benefits for the injection of a therapeutic substance into the eye **will not be implemented**. In recent years there have been significant advances in therapies to treat Macular Degeneration, which can hold dramatic results for patients – including saving sight. I’d like to acknowledge the important role the Macular Degeneration Foundation has played in securing these changes”. *Hon Nicola Roxon, MP, Federal Minister for Health and Ageing*

Members of Parliament from all sides of politics who listened to the Foundation, worked through the issues and came to a decision that was the right thing for the MD community in relation to the treatment of those diagnosed with wet Age-related MD.

I also sincerely thank the MD Foundation Medical Committee; especially Dr Paul Beaumont and Dr Alex Hunyor (Jnr); the Foundation’s Research Officer, Cherie Nay and all of you who responded so quickly to our letters seeking information.

This is your win, congratulations: **working together – we made a difference** on Wednesday 16 September 2009.

Julie Heraghty, Chief Executive Officer

Invitation: MDF Annual General Meeting

Date: 25 November 2009

Time: 10.00 - 11.00am

Place: City Tattersalls Club
Sydney Room (2nd Floor)
194-204 Pitt St, Sydney

RSVP: 9 November 2009 (essential)

Tel: 1800 111 709

Morning tea will be served after the meeting.
Nearest cross street is Market Street.
St James is the nearest railway station.

Federal funding renewed

Thank you for your support – every letter counted!

Earlier this year the Foundation asked you to write to the Prime Minister to ensure our Federal funding was renewed.

On 26 June, the Hon Nicola Roxon MP, Federal Minister for Health and Ageing, announced the renewal of the MD Foundation's Federal funding of \$457,600 over the next three years. This funding supports our national education program.

The announcement was made at a special event at the Tamworth Services Club, NSW during the last leg of the second Vision Van Tour.

The Foundation would like to offer our sincere thanks to everyone who supported this campaign. We could not have achieved this outcome without your support.



MD Foundation CEO Julie Heraghty with the Hon Nicola Roxon, MP

Re-discover the joy of 'reading' books in bed again

Do you have trouble reading books? Would you prefer to listen to books and newspapers in audio form? You may be eligible for a free Navigator talking book via the Foundation's new Navigator Home Access Program (NHAP).

The Navigator is a portable, easy-to-use device that reads books and newspapers aloud. For a number of years the Foundation has provided the Navigator to MD patients through NSW libraries and now it would like to extend this service.

Here's how it works. The content is loaded onto the Navigator at home via an easy to use website that offers thousands of book titles and all major newspapers. Participants are eligible to be part of the NHAP if all the following requirements can be met:

- Have Macular Degeneration
- Registered with the MDF
- Access to broadband internet connection
- A family member, friend or carer who can load content from the website onto the Navigator when you require (let's call them 'Nav Support'!)

If you're interested, register via a simple form on our website: www.mdfoundation.com.au/NHAP.

The Foundation will review all registrations and then enrol as many people as possible in the Program to meet the demand. We will provide the Navigator unit free and in the first year will cover the content license cost. After the first year there will be a small content fee to pay (outlined in online fact sheet).

This program is made possible thanks to the generous support of the Profield Foundation.

Ask your 'Nav Support' to register you today! Or for more information call the Foundation on 1800 111 709.



MDF volunteer Jean using the Navigator



Awareness of MD soars

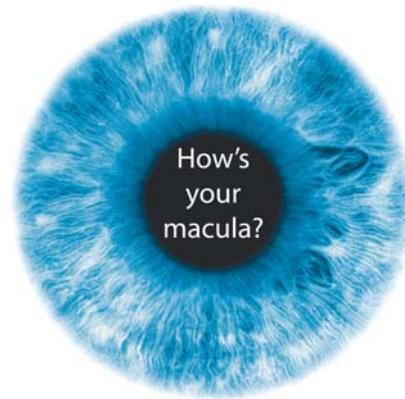
The Foundation's recent national Galaxy poll has placed Australia as a world leader in public awareness of Macular Degeneration.

The Foundation is proud to announce there has been a massive 53% improvement in the awareness figure over the last two years!

In February 2007, the Foundation commissioned a national Galaxy poll to gather data on MD given Australia's ageing population and the importance of early detection to save sight. The low awareness levels sounded alarm bells.

The Foundation was determined to turn this around and embarked upon a massive TV, radio and print campaign combined with other unique projects and awareness campaigns. We were supported by outstanding corporate partnerships and Government recognition of the importance of eye health.

Last month another Galaxy poll was conducted following the conclusion of the third *How's Your Macula?* national television and radio advertising campaign in July and August. The campaign had a strong call to action for people to have their eyes tested and to ensure their macula is checked.



Our sincere thanks to Novartis Australia for their outstanding contribution and commitment to raising awareness throughout Australia through this media campaign.

September 2009 National Galaxy Poll: highlights

- Overall population awareness of MD **53% improvement** (from 47% to 72%)
- Population awareness aged over 50 years **48% improvement** (from 58% to 86%)
- Awareness MD affects the eyes **90% improvement** (from 32% to 81%)
- Having the macula checked in the last two years for those aged over 50 years **75% improvement** (from 33% to 58%)

Federal support for publications

The Federal Government through the Department of Health and Ageing has awarded the MD Foundation a \$201k grant to produce core publications for the 2009/10 year.

This allows the Foundation to continue providing sight-saving information to the MD community. Our sincere thanks to the Federal Government for their ongoing commitment to reducing the incidence and impact of MD in Australia.

Supporting our Veteran community

In recognition of Veterans being in the high at-risk category for MD and the value of the MD Veteran Education Program; the Department of Veterans' Affairs (DVA) has expanded our funding to undertake further projects. The Foundation has already presented 40 education sessions in 2008/09 through RSL Clubs and sub-branches reaching nearly 1,500 people.

The Foundation met with the Minister for Veterans' Affairs, the Hon Alan Griffith MP, on 13 September in Canberra and conveyed our thanks to the Department for support of our work of the MD Foundation for the Veteran community.



Don't be Blind to the Risks

The annual MD Awareness Week (MDAW) campaign promoted sight-saving messages that reached over 15 million people across the nation.

Over 11,500 MD information kits were sent to eye health professionals, libraries, community health centres, pharmacies, health food stores and Parliamentarians.

Events were held all over Australia from a community action day in Martin Place, Sydney to a 'full house' seminar by leading Ophthalmologist Dr Dimitri Yellachich at the University of WA.

In conjunction with our Eating for Eye Health cookbook, our Patron Ita Buttrose was a celebrity cook on the TV program *Ready, Steady, Cook!* We also had great coverage in many national publications including *New Idea*, *Super Food Ideas*, *Australian Optometry* and *50 Plus News*.

The Foundation would like to extend its most sincere appreciation to Ita Buttrose, to those who shared their very personal MD stories in the media to help Australians understand the experiences of MD, and to the eye health professionals who acted as spokespeople throughout the week.

A very special thanks to our sponsors Novartis Australia, Blackmores, Optometrists Association Australia and bluedesk who have consistently supported MD Awareness Week 2009.



Ita Buttrose and Pam Stone (Blackmore's Director of Education) on the set of *Ready, Steady, Cook!*

Vision Van tour

Following the overwhelming success of the Vision Van's previous tours, the MD Foundation is thrilled to again be a partner in Vision Van 3.

The Vision Van is a mobile screening unit providing free tests for AMD to people aged over 50. In its third tour, the Vision Van will travel to Tasmania, Victoria, ACT, NSW and SA. Bookings for free AMD screenings are essential on 1800 176 255.

The schedule is included in the newsletter (back page).

Welcome aboard

The Foundation is pleased to announce that Professor Jill Keefe OAM has accepted the invitation to join the Board of the Foundation. Professor Keefe is Unit Head of the Centre for Eye Research Australia (CERA) Population Health Division at the University of Melbourne and also co-chairs the World Health Organisation Low Vision Working Group.

"I readily accepted the invitation to join the Board of MDF as my research at CERA has given me insights into the consequences of MD on adults and young people. I hope that my research experience will be of benefit" said Professor Keefe.



Professor
Jill Keefe, OAM

Encourage people to join our mailing list

Especially:

1. People you know who have MD
2. Your family members if you have MD (remember a family history means a 50% increased risk)
3. Carers, friends and supporters

Working together to make a difference

The Foundation relies on the support of thousands of wonderful individuals, organisations and corporations to provide our sight-saving support and services. Thank you.

MD in their sights

Driven by a love of their sport and the knowledge that vision impairment would severely limit participation, the Australian International High Power Association (AIHPA) recently presented the Foundation with \$3,600 cheque at their annual Sydney Cup competition.

AIHPA President, David Waters, said “in our sport many conditions can be overcome with the use of aids, but without your eye sight it is impossible to continue in this sport”.

“Also my mother, who has been a long time volunteer at the Foundation, has MD and I have seen the impact it has had on her life.”

Thank you to Janet, her wonderful son and his sporting club – truly inspirational giving.



Janet and Julie



Ian Kennedy

Victorian Lions lead the drive

The Lions Club of Forest Hill raised over \$8,000 for the Foundation at their second Annual Roth Gair Charity Golf Day at the Rosebud Country Club, Vic. The late Roth Gair has MD and was a member of the Lions Club of Forest Hill.

Organiser Ian Kennedy and his team have been inspirational with their fundraising golf day. The third Annual Roth Gair Charity Golf Day will be held Sunday 7 February 2010.

Contact Ian on 0419 325 780 or email: ian@hottopic.com.au for more information.

Riding blind

Matt Formston will cycle from Sydney to Melbourne with two mates to raise money for the MD Foundation. Matt, a 31 year old business analyst was diagnosed with Macular Degeneration at the age of five and has been legally blind ever since.

From 12 November the four mates will ride over 1,200 kilometres in only 13 days to raise much needed funds for the Foundation. Matt has never let his disability stop him achieving his goals and wants to share this with others to overcome life's challenges no matter how big or small.

For more information visit www.syd2mel.com

Growing together

Strong, ongoing support from Blackmores has resulted in a total contribution of \$2 million to the work of the Foundation over the last seven years.

We presented Blackmores with a plaque **Growing Together** and a commemorative tree was planted at their new premises in Warriewood, NSW.

The event was attended by MD Patron Ita Buttrose, Board Director Dr Paul Beaumont and CEO Julie Heraghty.



L-R: Dr Paul Beaumont, Ita Buttrose and Marcus Blackmore

Run to See

Recently six people who ran in the Sydney City2Surf nominated MDF as their charity of choice for fun-raising; here is one participant's story about why she decided to **Run to See**.

"Jessie Mavis Davies, my Nana, remains one of the most beautiful people in my life, despite her passing in 2006. It's not until now that I realise just how much MD affected her life.

She lost freedoms like reading a newspaper and cheering her favourite sports team on the TV (Hawthorn Hawkes).

I know Nana would be so appreciative to all my friends and family who donated generously. All I asked for was a donation equivalent to the cost of one coffee, however there are either a lot of coffee addicts out there, or truly generous people!" Meaghan Davies.

Meaghan set a target of \$400 – she raised over \$530! Thank you Meaghan and all her supporters.



L-R: Meaghan, Nana, brother Matthew, Mum Ellen, Dad Ken. and younger sister Sherryn

Giving hope to see the future

The MD Foundation touches the lives of tens of thousands of Australians each year. In 2004 Pamela Johnston was diagnosed with Macular Degeneration and her Optometrist recommended she contact the Macular Degeneration Foundation.

"At the time I was confused and upset. I had never heard of Macular Degeneration and it sounded like a life sentence," said Pamela. "My Doctor told me there was no cure and nothing I could do, so of course I became very distressed"

I immediately called the Foundation and everyone was so very helpful and caring. It seems like every question I have can quickly be answered by one of the lovely people there". Pamela said she totally

changed her life after being diagnosed. Thanks to information the Foundation provided she has modified her eating choices and has made sure her family is also more aware. "I suspect my father also had MD, but in those days we didn't know what it was".

Pamela said "I am ever so appreciative of all the support I receive from you; I am a pensioner so I wouldn't be able to pay for your services".

Pamela however has chosen to support the Foundation in a way that suits her. She has nominated the Foundation as a recipient in her Will – thank you Pamela for your generosity and kindness.

A lasting legacy

We were touched by Pamela's story at the Foundation and thought others may also be interested in information on bequests.

Some of our supporters include the Macular Degeneration Foundation in their Will because they share our vision; others see it as a natural extension of their support for the Foundation; and many tell us that leaving a bequest gives them the opportunity to make the kind of gift they could not afford to make in their lifetime.

Bequests often make a very significant difference to a charity's ability to grow and

develop and some of the most successful Australian charities can attribute their longevity to legacies from donors.

To assist with estate planning, we have a special booklet, **Giving Hope to See the Future**. It answers a number of questions people are likely to ask when making their Will.

If you would like to discuss this option, please call the Foundation's Marketing and Fundraising Manager, Monique Ryan on 1800 111 709.

Your enquiry will be treated with the strictest of confidence and sensitivity.

Surveys

Many patients with wet MD were recently sent a survey about their costs associated with receiving treatment. This information has been invaluable and we need to continue collecting this data. Please return this survey at your earliest convenience if you have not already done so. Your time and interest is greatly appreciated.

Recent research

Blue Mountains Eye Study

Ongoing research from the Blue Mountains Eye Study has revealed that a low GI diet may help slow down the progression of MD. The glycemic index (GI) is a measure of the effects of carbohydrates on blood sugar levels. Low GI foods digest slowly and release glucose more steadily. High GI foods break down faster and cause a more rapid rise in blood glucose levels. Talk with your Doctor about any changes in your diet.

Blocking the protein

A promising study by scientists in the USA has identified a new target that may block the activity of a protein known as CCR3 thus reducing the abnormal blood vessel growth associated with wet AMD.

“This is an exciting new discovery with the potential to detect and treat AMD in a whole new way,” said Alan Cruess, MD Chief of Ophthalmology, Dalhousie University.

How to make a donation

Thank you for supporting the Foundation. Your gift will ensure we can continue to grow and serve the needs of the MD community both now and into the future.

We thank all our wonderful supporters for their generosity. A donation slip and reply paid envelope are enclosed for your convenience.

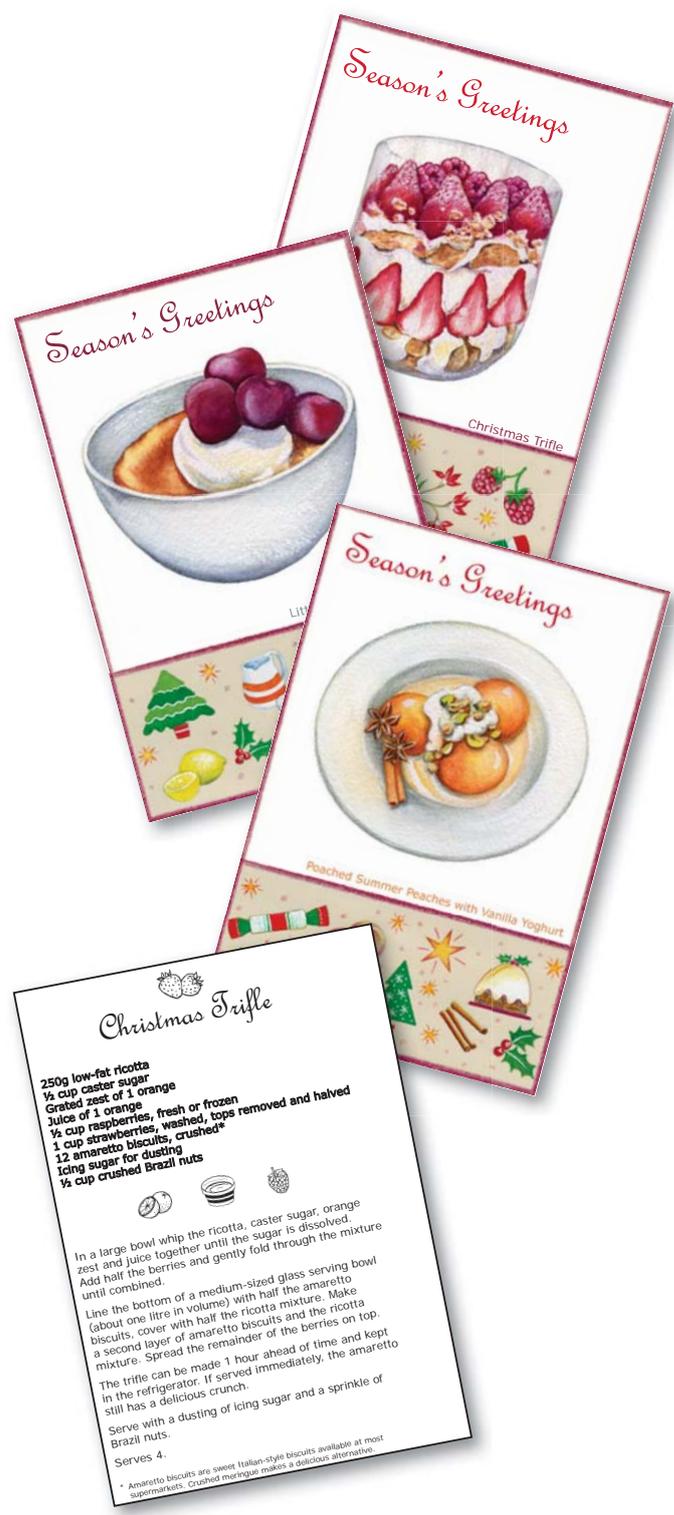
All donations over \$2 are tax-deductable.

Our first ever Christmas cards

These three beautiful designs each feature a specially created Christmas recipe by chef Vanessa Jones and MD Foundation Patron Ita Buttrose; chef and author of *Eating for Eye Health*.

The verse says ‘Wishing you all the joys of the Season and a Happy New Year.’ Give a gift that gives back. Cards retail for \$12.00 for a mixed pack of nine (plus postage and handling).

To order your cards call us on 1800 111 709.



Education and Vision Van timetable

Date	Place	What	Phone
9 Oct & 12 Oct	Lilydale, Vic	Vision Van	1800 176 255
13 Oct & 14 Oct	Wangaratta, Vic	Vision Van	1800 176 255
15 Oct & 16 Oct	Wagga Wagga, NSW	Vision Van	1800 176 255
19 Oct & 20 Oct	Belconnen, ACT	Vision Van	1800 176 255
21 Oct & 22 Oct	Kambah, ACT	Vision Van	1800 176 255
22 Oct - 10am	Whyalla, SA	MDF education session	1800 111 709
22 Oct - 2pm	Port Augusta, SA	MDF education session	1800 111 709
23 Oct 10am	Port Pirie, SA	MDF education session	1800 111 709
28 Oct - 2pm	Belmont North, NSW	MDF education session	1800 111 709
28 Oct - 10am	Terrigal, NSW	MDF education session	1800 111 709
29 Oct - 2pm	Adamstown, NSW	MDF education session	1800 111 709
05 Nov - 10am	Werribee, Vic	MDF education session	1800 111 709
9 Nov & 10 Nov	Port Lincoln, SA	Vision Van	1800 176 255
12 Nov & 13 Nov	Whyalla, SA	Vision Van	1800 176 255
16 Nov & 17 Nov	Port Augusta, SA	Vision Van	1800 176 255
18 Nov & 19 Nov	Port Pirie, SA	Vision Van	1800 176 255
23 Nov & 24 Nov	Mt Gambier, SA	Vision Van	1800 176 255
23 Nov - 2pm	Ulladulla, NSW	MDF education session	1800 111 709
24 Nov - 10am	Nowra, NSW	MDF education session	1800 111 709
24 Nov - 2pm	Shellharbour, NSW	MDF education session	1800 111 709
25 Nov & 26 Nov	Warrnambool, Vic	Vision Van	1800 176 255
27 Nov & 30 Nov	Wyndham, Vic	Vision Van	1800 176 255

Education sessions run approximately two hours.

Education program by leading Ophthalmologists

The Macular Degeneration Foundation is proud to have leading Ophthalmologists, Dr Alex Harper and Dr Paul Beaumont, present free information seminars on Macular Degeneration. Learn about the importance of nutrition and lifestyle as well as symptoms, treatment options and management of the disease from two respected Ophthalmologists.

Dr Paul Beaumont

7 Nov 10am
Macquarie University
Building W5A
Price Theatre
Western Road
Macquarie University,
NSW

Dr Alex Harper

21 Nov 10am
Parkview Hotel
Boulevard Rooms 1-3
562 St Kilda Road
Melbourne, VIC

See us at...

The Brisbane Retirement & Lifestyle Expo
Stand 120 – Hear us talk:
Friday 16 Oct: 2.15 - 2.45pm
Saturday 17 Oct: 2.00 - 2.30pm
Sunday 18 Oct: 3.00 - 3.30pm
RNA Showground

Can you volunteer with the MD Foundation for a few hours at the Expo? Please contact us on 1800 111 709.

Contact us

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