Macular Disease Foundation
AUSTRALIA™
Our focus is your vision

Newsletter
AUTUMN
1st Edition 2013

From the CEO's Desk

Dear Friends,

This has been a very busy time and there is a great deal to tell you.

The Foundation is your voice to government and in the wider community, and we have been shouting very loudly on your behalf over the last few months.

Our Patron: The Foundation was thrilled when our Patron Ita Buttrose AO OBE was named Australian of the Year 2013. We are privileged to have had Ita's support as our Patron over the past eight years, raising awareness of macular degeneration on behalf of the Foundation across Australia at every opportunity.

Funding: The Federal Treasurer invited organisations to make submissions for the May Federal budget in January. The Foundation submitted a request for $6.2m over three years. The Federal Government needs to provide the support the Foundation needs to save the sight of Australians and we anxiously await Budget night!

NDIS: The National Disability Insurance Scheme (NDIS) passed through the Federal Parliament on 21 March 2013. The exclusion of those who acquire a disability over 65 years of age has significant impact for those who have vision loss and blindness. This is discrimination and we fought very hard on this issue and will continue to do so with your help. This issue is also linked to our six year campaign to have equitable access to low vision aids and technologies. I ask that you, your family and friends support our ongoing campaign outlined in the newsletter. We will not give up! Your age or where you live should not determine the support you so rightly deserve.

Research: The Foundation undertook major research on those who have macular degeneration and the impact on the life of a person who cares for someone with the disease. Your advice and insights were invaluable. You were wonderful in sharing your thoughts and most importantly teaching us at the Foundation about your feelings and the challenges you have with the disease. Your comments with your good humour made us laugh, but your challenges also made us cry. We hope you know we are here to support you in whatever way we can.

Our name: The Macular Degeneration Foundation has made a name change and is now known, and formally registered, as the Macular Disease Foundation Australia (MDFA). This was approved at our Annual General Meeting in December 2012. Macular degeneration will remain our primary area of work.

Research Grants program: Our second round of research grants are now open and we are excited to offer $500K for a project (or projects) that help reduce the incidence and impact of macular degeneration in Australia. We have in this edition updated you on the inaugural research grants funded in 2011.

As the end of the financial year is fast approaching the Foundation is, as always, grateful for your donations. You may wish to consider the Foundation's research program for your donation.

Thank you for all you do to support our work, it is indeed a privilege to work for you.

Julie Heraghty
Chief Executive Officer

Sight for seniors campaign – we continue to fight

Since the Spring 2011 edition of the newsletter, the Foundation has been communicating with you about the progress of the National Disability Insurance Scheme (NDIS)* which passed through the Federal Parliament on 21 March 2013. The Government has determined that Australians who acquire a disability over 65 years of age will be excluded from the NDIS and will be required to access support for disabilities through the aged care system. The NDIS will provide lifetime funded care and support services, whereas aged care services require co-contribution payments. This raises the issue of age discrimination and inequity for those who have paid taxes all their lives. The aged care system lacks funding, capacity and expertise to deliver the support needed including low vision aids and technology, one of the key needs of people with macular degeneration.

Macular degeneration has fallen between the cracks of two reform agendas: disability and ageing. This is especially relevant to our ongoing Low Vision Aids and Technology (LVAT) campaign which first started in 2007. The provision of LVAT is low cost for the Government, yet yields high return for people with vision impairment or blindness in terms of improving quality of life and independence.

Your voice: what have we done in the last 3 months on your behalf?

- ✔ Initiated and held meetings with relevant Government Ministers and Opposition Shadow Ministers
- ✔ Submitted strong recommendations on changes to relevant legislation
- ✔ Issued media releases and gained good coverage
- ✔ Participated in Ministerial Round Table on 20 February 2013 on the NDIS
- ✔ Appeared before the Senate Community Affairs Committee’s NDIS inquiry hearing on 4 March 2013

What can we do now?

With the forthcoming Federal election on 14 September 2013, the Foundation would like your support for the Sight for Seniors campaign.

The campaign has three clear objectives:

1. **No age discrimination for over 65s in the NDIS**
2. **A fair deal on aids and technology for people with low vision**
3. **Funding to better support the Foundation’s work in macular degeneration**

There are three ways to support the campaign:

1. Tell the leaders

The Foundation has prepared two letters for you, one addressed to Prime Minister Julia Gillard and the other to Leader of the Opposition Tony Abbott. Simply complete your personal details in the space provided, sign and date, then post to their respective addresses provided at the top of the letters.

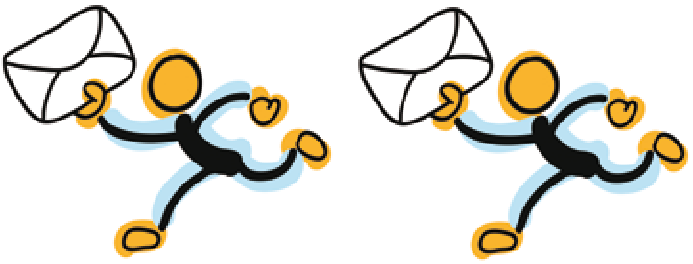
2. Be counted

There is also a website where we are counting the number of people who support our campaign **www.sightforseniors.com.au**
If you cannot use the website then complete the printed registration form, which has been included with this newsletter, and return to the Foundation in the reply paid envelope used for your donation. You will then be included in our count. This is just a permission to count you as a supporter of the campaign and your details will not be displayed or disclosed.

3. Tell your family and friends

Tell your family and friends that we need their support and encourage them to go online and be counted.

If you require more information, please feel free to call the Foundation on 1800 111 709 or visit the campaign website www.sightforseniors.com.au.



* The official name of the NDIS is DisabilityCare Australia.

Macular Disease Foundation Australia

The Macular Degeneration Foundation has made a name change and is now known and formally registered as the Macular Disease Foundation Australia (MDFA). This was approved at our Annual General Meeting in December 2012.

What does this mean? In the short term there are no significant changes. It is work as usual. In the long term we will be able to provide information and support to the less prevalent diseases of the macula such as diabetic retinopathy, macular dystrophies and retinal vein occlusions. The addition of the word "Australia" also highlights the Foundation as a national organisation.

Macular degeneration, the leading cause of blindness in Australia, remains our primary area of work. All general or research donations continue to be used for our work and research in the area of macular degeneration. Please rest assured that any bequests made in the name of the Macular Degeneration Foundation do not need to be re-written. Please call the Foundation on 1800 111 709 if you have any questions.

Macular Disease Foundation AUSTRALIA™

Our focus is your vision

Living Well with MD

“The ripple effect of vision loss” - Foundation’s new research

The Foundation undertook an extensive research project to examine the impact of wet age-related macular degeneration (AMD) on various aspects of a person’s life.

The research was twofold, focusing on those who have wet AMD and the impact on the life of a person who cares for someone with wet AMD.

In January we surveyed many people on our database. You were amazing in your response and thousands of surveys were completed. Thank you for the wealth of information, advice and insights so generously shared with us - it has been invaluable to help us help you.

The research has revealed far more than was expected and will assist the Foundation in understanding the impacts of wet AMD on carers and those with the disease so we can offer the best support and advocate for the needs of our macular degeneration community. There is so much information from the survey we want to share with you that we will need to do this over the next few newsletters.

Here are just a few learnings:

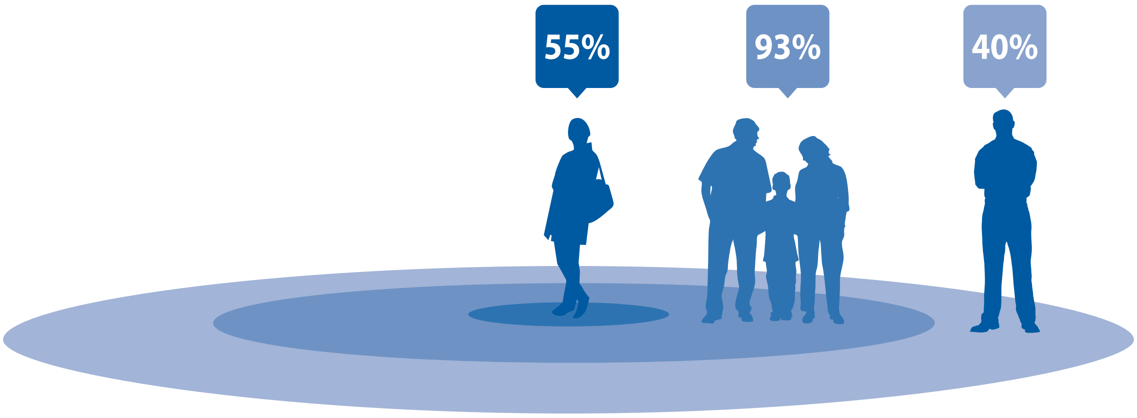
Emotions, depression and anxiety

Overall depression rates amongst those caring for people with vision loss from AMD were triple those seen in the Australian population over 65 years of age.

Being diagnosed with AMD can result in a range of emotions such as feelings of frustration (49%), feeling down (28%), isolated (18%), sad (16%), or pessimistic (13%).

If you feel anxious or depressed it is so important that you seek help. Make an appointment to see your GP. There is help available. Other services include Lifeline 13 11 14 and beyondblue 1300 22 4636.

THE RIPPLE EFFECT OF VISION LOSS



55% of carers felt their carer role impacted on other people

93% are family members of the people they are caring for and 59% say their life is impacted

40% of those with wet AMD have had an accident as a result of their vision loss, almost 1 in 5 were hospitalised

Support for carers

It is family, in particular spouses, who are bearing the impact of caring and many don't necessarily consider themselves a 'carer'.

The care you undertake may mean you are entitled to certain benefits and supports. This depends on many factors but if you need advice contact Carers Advisory Service 1800 242 636.

Chronic conditions

Almost nine in ten (86%) carers look after someone who has macular degeneration as well as other chronic diseases. The most prominent are arthritis (53%) and heart disease (33%). Two-thirds (67%) of carers report contending with their own chronic conditions: arthritis (54%), heart disease (25%), diabetes (11%) and cancer (8%).

Whether you have macular degeneration or are caring for someone with the disease, make sure you take care in all areas of your health. Taking your medication, keeping appointments with your health care professionals, eating well and enjoying life with friends, family and community are all important.

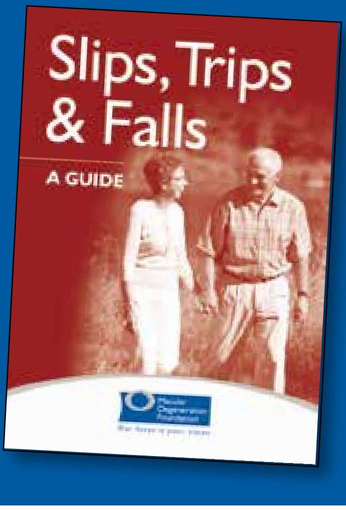
> **"As a carer I'm very conscious of the need to be alert to household and external dangers which may cause injury from trips and falls. I also strive to arrange intellectual and social stimulation, through outings and access to the internet."**
>
> ***Carer***

> **"I have tried, as far as possible, to keep up with my usual social and community activities since developing macular degeneration. I make sure I keep up with local and national news on the radio and keep engaged through studies, my grandchildren and other activities."**
>
> ***Person with wet AMD***

Accidents

Many people have had some kind of accident as a result of their vision loss (40%), most commonly a fall (33%). Other accidents include burns (9%) and car accidents (2%). Those who are legally blind in both eyes (57%), have had wet AMD for more than 6 years (48%), blind in one eye (46%) or over the age of 85 (43%) are most likely to have had a fall related to their wet AMD vision loss.

Make sure you have a copy of *Slips, Trips and Falls - A Guide* available from the Foundation to help reduce the risk of falls. Follow the tips and advice. Call 1800 111 709 for your free copy.



Research Grants Program

Our inaugural Research Grants Program…

In 2011 Her Excellency Ms Quentin Bryce AC, CVO, Governor-General of Australia announced the Foundation's inaugural Research Grants. Thus began an exciting journey to find reasons for macular degeneration, with the hope of a cure.

For the first round of grants, almost three quarters of a million dollars was awarded to two of Australia's world leading researchers in support of two major research projects. In addition, the first Blackmores Dr Paul Beaumont Research Fellowship was awarded. This fellowship is supported by Blackmores and The Blackmore Foundation and funds research into nutritional and/or lifestyle aspects of macular degeneration. The first Fellowship has been completed and second Fellowship was awarded at the Foundation's Annual General Meeting in December 2012 to Dr Bamini Gopinath. The results of her research will be available in 2014.

"Research is a journey of discovery with the ultimate destination being a place where we can save sight. Along the way we will also learn a great deal that can yield great benefit."

Our second round of research grants...

Following the awarding of two major research grants in 2011 the Foundation is again funding Australian researchers, allowing them to conduct major research that can help to reduce the incidence or impact of macular degeneration. The Foundation is offering a grant (or grants) of up to $500,000 over three years, commencing in 2014. Applications must be submitted by 3 June 2013. The successful applicant will be announced on World Sight Day, 10 October 2013. Instructions and application forms are available from the Foundation's website **www.mdfoundation.com.au** or call the Foundation for further information.

How can you help?

Thank you to all who support our programs and research. We have a goal to have granted $10 million to researchers by 2021. There are several ways you can help:

- You can tick the box "MDFA Research Grants Program" on your enclosed donation form
- Call the Foundation if you wish to donate by telephone or donate securely online at www.mdfoundation.com.au
- Leave a bequest to support research. Please call the Foundation on 1800 111 709 for bequest information and for general information on the research program

Donate before June 30 and we will send you your receipt in time for you to prepare this year's tax return.

Progress Reports - 2011 Funded Research Grants

Professor Paul Mitchell - Millennium Centre for Eye Research, Westmead and the University of Sydney. This research will allow better determination of those people who are at greatest risk of progression of the disease and for whom attention and regular follow-up may be needed. The study is one year into a three year program and is now analysing modifiable (eg diet) and non-modifiable risk factors (including genetics) of over 700 people with late stage disease, both wet and dry. The results will then be compared with the 15 year data from Professor Mitchell's historic landmark Blue Mountains Eye Study and the renowned US Beaver Dam Eye Study.

Professor Robyn Guymer - Centre for Eye Research Australia (CERA), Melbourne. This research identifies a range of new diagnostic tests and measures of visual function to be used to improve the identification of those people who are at greatest risk of progressing from early to late stage macular degeneration. This study is now one year into a three year program and has fully enrolled patients who are being measured and monitored regularly to check for progression. One new marker of disease severity has already been identified and published in a major journal.

Dr Liubov Robman - Centre for Eye Research Australia (CERA), Melbourne. The one year project funded by the Blackmores Dr Paul Beaumont Research Fellowship has now been completed. Data from over 21,000 participants in the Melbourne Collaborative Cohort Study were analysed to determine the eating patterns that reduce the risk of disease progression. It was found that people who have a diet consisting primarily of a combination of grains, fish, steamed or boiled chicken, vegetables and nuts had a significantly reduced risk of both early and late age-related macular degeneration. These findings are very consistent with the dietary recommendations of the Foundation.

The study also indicated that excessive consumption of red meat had a significantly increased risk of late age-related macular degeneration, so a balanced diet which includes fish and green leafy vegetables is important.

The Governor-General Ms Quentin Bryce with 2011 grant recipients Professor Robyn Guymer, Professor Paul Mitchell and Dr Liubov Robman

If you are interested in making a significant gift to research and being acknowledged by having a research grant in your name, or that of your company or someone you are endeared to, please contact Judith O'Hagan at the Foundation on 1800 111 709 for more information.

Macular Degeneration Awareness Week 2013

Sunday 26 May to Saturday 1 June

"Let's stop Australians going blind. For me, it's personal."

"My father had macular degeneration"

Ita

4 ways to fight Macular Degeneration

1 Have an eye test and make sure your macula is checked.

2 Never ignore any changes in vision.

3 Eat an "eye friendly" diet and lead a healthy lifestyle.

4 Donate to research.

www.mdfoundation.com.au

Call 1800 111 709 for your FREE information kit

Macular Disease Foundation Australia

Our focus is your vision

> ***"The day I was honoured with Australian of the Year, I made a public commitment to raise awareness of issues relating to older Australians, including macular degeneration."***
>
> ***Ita Buttrose***

Our sincere congratulations to Patron Ita Buttrose AO OBE in being named Australian of the Year 2013.

On her work with our Foundation alone Ita is so deserving of the honour bestowed upon her. Ita continually gives so much of her time and expertise to raise awareness of macular degeneration across the country, sharing her own family's personal journey with this disease, which we know primarily affects our older Australians.

"I want the health of older Australians to be a priority for both the community and government. It's a two way street. Older Australians need to take care of their health and not take good health for granted, and the government needs to look after this important group and treat them with the dignity they deserve," says Ita.

Ita is also supporting the Foundation's strong push to have those diagnosed after 65 years with a disability (eg. vision loss from age-related macular degeneration) to be included in the National Disability Insurance Scheme (now called DisabilityCare Australia) as it stands today (see page 2 for further information).

The Foundation has the powerful voice of Ita in support of our Macular Degeneration Awareness Week 2013 messages which will be spread across the country. Ita is encouraging all Australians to:

1. **Have an eye test and make sure the macula is checked**
2. **Never ignore any changes in vision**
3. **Eat an "eye friendly" diet and lead a healthy lifestyle**
4. **Donate to research**

Information, Guidance and Support

Tips, Tips, Tips!

The ripple effect of vision loss research project, which is discussed on pages 4 and 5 of this newsletter, asked both those living with wet macular degeneration and carers for their "key tips" on living with the disease and caring for someone with wet macular degeneration.

Here are just a selection, we hope they assist and inspire...

Patients

- ✔ Attend all medical appointments
- ✔ Stay positive and enjoy life
- ✔ Keep busy in mind and action
- ✔ It is important to have your eyes tested regularly
- ✔ Accept help from your friends and family
- ✔ If any changes occur with your vision, immediately contact your eye specialist
- ✔ Be optimistic, live your life to the fullest, let AMD make as little difference as possible to your everyday life
- ✔ Eat sensibly and include fruit and vegetables in your diet

Carers

- ✔ Have patience and understanding
- ✔ Plan your activities around or with the consideration of the person you care for
- ✔ Have a good knowledge of the disease to understand what the person is or will be going through
- ✔ Talk things over and plan ahead
- ✔ Respect independence at all times
- ✔ Ensure you give the person you care for the right to make their own decisions
- ✔ Assist with medical and other appointments
- ✔ Give dedication, devotion and tender loving care
- ✔ Keep yourself in good health and continue with own activities

Free Foundation Low Vision Badges

In our Summer 2012 newsletter we featured an article called "Uncle Bruce" which described how our CEO's Uncle Bruce wore a low vision badge at the airport and received extra assistance from the airport staff.

Following the printing of our newsletter, the Foundation was flooded with calls asking where to purchase low vision badges. In response the Foundation has created its own low vision badge that says "I have low vision" and shows the Foundation's new logo on the front and name and phone number on the back. Badges are available with either a pin or magnetic backing.

If you would like to receive a FREE "I have low vision badge" please contact the Foundation on 1800 111 709.

Information, Guidance and Support

Val's story, Foundation Volunteer

When I was first diagnosed with wet macular degeneration I was frustrated at having to deal with yet another health issue. I felt confronted and questioned "why me". After the initial shock of diagnosis, I realised I needed to accept that macular degeneration was now part of my life and continue with my many activities and volunteer work.

I'm definitely not one to sit around. I enjoy being active and have been involved in the community most of my life. I even met my husband Doug whilst volunteering when I was 21.

It was in early 2010 that I started to volunteer at the Foundation after attending an education session. I had been diagnosed in late 2009 and wanted to learn more. At the information session I discovered the Foundation needed volunteers, and after finding out what was involved, I signed up and have been a volunteer ever since. I receive a great deal of satisfaction from my volunteer work and have made enduring friendships with my fellow volunteers.

Knowing what I do now about macular degeneration I regret not having my eyes checked as soon as I noticed changes in my vision. It was a busy and challenging time in my life and although I had noticed straight lines appearing wavy, I delayed making an appointment with my eye specialist.

When I did have my eyes checked I was diagnosed with wet macular degeneration in both eyes and there and then was referred to a retina specialist for immediate treatment. After approximately eighteen months of treatment my specialist told me that my right eye was stable and would only require monitoring. This was a great relief as I was going every two weeks for injections. I now go once a month for treatment of my left eye and regular monitoring of my right eye.

I am grateful that there is a treatment available to me. If I had been diagnosed only a few years earlier, before treatment became available, I would have certainly lost my vision. I also appreciate the support and information that is available and am encouraged that there is a great deal of research taking place; and hope that eventually a cure will be found.

Thank you! The Foundation thanks Val and her husband Doug for taking part in a Prime TV interview in support of the ripple effect of vision loss research. Val and Doug spoke eloquently on their experiences and Val ensured she gave her "No. 1 Tip" of never ignoring any changes in vision. Well done and thank you!

The 'AREDS Supplements for Age-related Macular Degeneration' fact sheet has again been updated. If you would like a copy please phone the Foundation on 1800 111 709.

Thank you so much.....

ICAP Charity Day 2012

The Foundation's research grants program received a $50,000 boost from ICAP's Charity Day 2012. For just one day, international broker ICAP donated all company revenue and broker commissions to selected charities. Representing the Foundation were Patron Ita Buttrose and Ambassador Jean Kittson who both enjoyed the fun antics of the day.

Foundation Patron Ita Buttrose on the "wild west" brokers desk.

Roth Gair Charity Golf Day 2013

Thank you to **Ian Kennedy and the Lions Club of Forest Hill** for once again holding the annual Roth Gair Charity Golf Day (Victoria). The event is named after a past member of the Lions Club of Forest Hill, Roth Gair, who had macular degeneration. You are an amazing group of dedicated people and we thank you.

L-R: Ian Kennedy, John Gair and Lions Club of Forest Hill President Karen Young

"Run to See" with Everyday Hero

Put on your running shoes, put your best foot forward and run to save sight in 2013! Using Everyday Hero is a simple way to support the Foundation through your latest fitness challenge. You can sign up and so can your children and grandchildren, relatives and friends for the event of your choice and select Macular Disease Foundation Australia as your charity – it's that simple!

There are a number of events taking place across Australia in which you can participate whilst raising funds for the Foundation:

- HBF Run for Health (Perth, May)
- Brisbane Times City2South (Brisbane, June)
- The Age Run (Melbourne, July)
- City2Surf (Sydney, August)

Look for the Everyday Hero link on the Foundation website and follow the link to register.

City2Surf (Sydney) Gold Start Tickets

We have 10 gold start tickets available that will allow our runners to start at the front of the pack. This is a great opportunity for keen runners and fundraisers alike! Call the Foundation on 1800 111 709 or visit the Foundation's website.

Our Giving Program

The Foundation is grateful to so many people who give donations in lieu of gifts for birthdays and special events. Many people have also nominated a gift of a donation in lieu of flowers in the event of the loss of a loved one. The Foundation has a bequest program and this is a very private and special way to ensure the work of the Foundation is maintained throughout the coming years, especially in the area of research.

If you would like information on any of our giving programs, including our bequest program, please contact the Foundation on 1800 111 709.

Envision a future without Macular Degeneration

Give the gift of hope with a gift to the Macular Disease Foundation Australia in your Will

The Foundation relies on the generous support of the community to continue offering our services free of charge. If you, your club, school or organisation would like to host a fundraising event to benefit the Foundation please call Judith O'Hagan on 1800 111 709 for more information or to discuss your ideas.

The end of the financial year is fast approaching! To ensure you have your tax deductible receipt in time to prepare your tax return please send us your donation using the enclosed donation coupon and reply paid envelope. Your gift will make a difference.

Donations

Thank you for supporting the Macular Disease Foundation Australia. As a charitable organisation we rely on your generosity to service the macular disease community across Australia and fund our Research Grants Program.

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. Bequests are gratefully accepted. Please call the Foundation for more information.

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