

# Viewpoint

The MDNZ Newsletter Issue 2 - September 2015

0800 MACULA (0800 622 852)

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# What's been happening at MDNZ?

The demand for the services of Macular Degeneration New Zealand (MDNZ) has continued to increase. In 2014 we received four times the number of calls to the save sight helpline than were received in 2013 and we sent out three times the number of information packs.

We held 28 public seminars or community talks throughout the country, attended by a total of almost 3000 people. These statistics are good news, they mean the information and support this organisation can provide is needed in the community. However this increasing activity needs to be funded. As awareness increases so does demand. With the equivalent of 1.7 full time staff the MDNZ team are punching well above their weight in terms of service provision.

This year MDNZ Trustees met with several government representatives, seeking funding support in order to continue to meet these increasing demands. It is well recognised that raising community awareness of Macular Degeneration leads to earlier referral and treatment with fewer people losing vision. This message is being heard by our leaders.

We continue to seek assistance from donors, sponsors and supporters and to increase the variation of income sources as best we can. We have had some very generous donations from readers, professionals and businesses but MDNZ needs to offer an even better service, reaching more people with information, seminars and support.

We are also extremely grateful to our wonderful team of volunteers who work in the office, at events, as professional advisors and as ambassadors for MDNZ. These people are passionate about the need to save sight and support all those whose lives are affected in some way by MD. This edition of Viewpoint outlines a number of ways that you can help MDNZ as we seek to advance our mission, which is: *To reduce the incidence and impact of Macular Degeneration in NZ*.

Phillippa Pitcher, General Manager Macular Degeneration New Zealand





### MDNZ Awareness Week 2015

Thanks to the media and supporters who got behind MD Awareness week in May 2015.

It began with MDNZ Chairperson, Dr Dianne Sharp interviewed live on Newstalk ZB by Danny Watson. She answered callers' questions and the MDNZ phone began ringing!

Dr Sharp also appeared on World TV News (a Chinese TV channel) where Chinese sub titles were used to get the messages across.

The MDNZ website and Facebook pages were kept alive with information and the MDNZ website was visited four times the usual weekly visits over two weeks.

Internet and print media picked up the story extending the reach across NZ:

- Bay of Plenty Times
- Waikato Times
- Rotorua Daily Post
- Manawatu Guardian
- Wairarapa Times-Age
- Stratford Press
- Northern Advocate
- The Northland Age
- Horowhenua Chronicle

#### Plus:

- Super Gold Newsletter
- Grey Power newsletters
- www.scoop.co.nz
- www.stuff.co.nz
- www.pharmacytoday.co.nz
- www.voxy.co.nz

oOh! Media continue to display digital signage in malls around NZ for which we are very grateful.

### Meetings with government

Meetings with 20 cross-party MPs and officers of the Ministry of Health have successfully provided a greater understanding of the issues and concerns of MDNZ. These meetings began in April with Dr Dianne Sharp meeting with the Hon Dr Jonathan Coleman and Jamie-Lee Ross.





### **Lynette's Story**

Living with Sorsby's Disease (a genetic form of Macular Degeneration)

I have lived with Sorsby's disease now for 11 years having first being diagnosed at the age of 40.

Thanks to the immediate attention I was given when things started to deteriorate, treatment was not only able to restore, but maintain sight in my right eye to this day with intravitreal injections. Unfortunately my left eye did not receive the benefits of this treatment as the vision deteriorated before this was available, and received only laser treatment.

To this day I make regular trips to Auckland to receive my treatments from a great team of specialists, enabling me to continue living life to the full. Whilst reliant now on vision in only one eye I am still independent, working, driving etc but most importantly enjoying family time with my four beautiful grandchildren! I 'see' them playing sports, on stage at school functions, take them out for treats and going through their school work on Grandparents' day. This is everyday life that people take for granted, each day I am grateful that I can still see.

Vigilance is the key with regular eye examinations and as soon as anything changes or appears different/dull etc call your optometrist or ophthalmologist immediately. Delay could lead to permanent vision loss and be life changing.

### Advertise your business in the next Viewpoint newsletter.

The majority of the Viewpoint readers are those diagnosed with MD and their families and carers, plus medical professionals and MDNZ supporters.

For competitive advertising rates please contact: <a href="mailto:phillippa@mdnz.org.nz">phillippa@mdnz.org.nz</a>

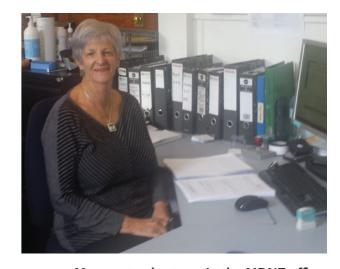
## MDNZ needs more volunteers

Do you have some time to spare and the skills and expertise to help us?

MDNZ welcomes volunteers in the following roles:

- Event co-ordination, required urgently
- Administration and general tasks
- Researching and populating database
- Preparing information packs
- Answering the phone
- Marketing and communications

All roles are to be based in the MDNZ office in Parnell. We would love to hear from you now.



Margaret volunteers in the MDNZ office.

# Need for urgent review of intervention strategies for AMD

Hamilton retina specialist and MDNZ trustee Dr David Worsley and his son, Andrew, a statistician, have published a paper in the February issue of the New Zealand Medical Journal. Entitled 'Prevalence predictions for age-related macular degeneration in New Zealand have implications for provision of healthcare services'.

The paper predicts the prevalence of age-related macular degeneration (AMD) in New Zealand from 2014 through to 2026 and highlights a need for New Zealand healthcare planners to review current strategies and funding of interventions that prevent vision loss from AMD<sup>1</sup>.

Dr Worsley said that with an ageing population the prevalence of AMD is expected to markedly increase from 2014 through 2026.

"The result will be a major healthcare burden for which we are not well prepared. By international standards New Zealand has a low level of investment in AMD healthcare; the lowest public funding of anti-VEGF treatment in the OECD, no specific funding for prevention strategies and a relatively small ophthalmic workforce and public infrastructure.

As such, there is an urgent need to plan for an increasing demand for AMD

intervention strategies and associated ophthalmic services. The alternative is a major increase in preventable blindness," said Dr Worsley.

	2014	2026
Any <85 years	184,400	208,200
Any >85 years	25,700	32,800
Any TOTAL	210,100	241,000
Late <85 years	7,600	8,600
Late >85 years	12,200	15,600
Late TOTAL	19,800	24,200

### The paper can be found at: www.nzma.org.nz/journal

 Worsley D., Worsley A. Prevalence predictions for age-related macular degeneration in New Zealand have implications for provision of healthcare services. N Z Med J. 2015 Feb 20;128(1409):44-55.





### Join the new MDNZ Professional Friend programme

Optometrists and Ophthalmologists across New Zealand can now feature on the MDNZ website listed as a Professional Friend of MDNZ. As a professional friend these practices will benefit from receiving all MDNZ brochures at no charge, feature on the website as a professional friend and receive and display a certificate in their practice identifying them as an MDNZ Professional Friend.

With increasing traffic to the MDNZ website, your listing will drive businesses to your eye care professional practice. Go to **www.mdnz.org.nz** to find out more and sign up to be an MDNZ Professional Friend.

### **Early Birds**

Thank you to the following eye care professionals who have become MDNZ Professional Friends.

#### **Optometrists**

Nigel Somerville, Glen Eden
Roger Apperley, Auckland Central
Kristine Jensen, Howick
John Adam, Remuera
Grace Lang, Ponsonby
John Mellsop, Whanganui
Jagrut Lallu, Hamilton
Peter Walker, Hamilton
Simon Rose, Hamilton
Richard Lobb, Invercargill
John Veale, Christchurch
Danielle Ross, Wanaka
Richard Newson, Nelson
Robert Dong, Wellington

#### **Ophthalmologists**

Dr David Worsley, Hamilton
Dr Dianne Sharp, Auckland
Dr Steve Mackey, Wellington
Dr David Dalziel, Whangarei
Dr Rachel Barnes, Auckland
Dr Andrew Thompson, Tauranga
Dr John Ah-Chan, Palmerston North
Dr Sean Every, Christchurch
Dr Phillip Polkinghorne, Auckland
Dr James Borthwick, Christchurch

These eye care professionals now feature on the MDNZ website as a Professional Friend of MDNZ. As supporters of the work of MDNZ, they will benefit from receiving MDNZ brochures for patients at no cost.

# Local Ophthalmologists & Optometrists assisting with Invercargill Seminar



### **Education Seminars 2015**

Thank you to Bayer NZ for again sponsoring MDNZ in 2015 to provide 12 seminars around NZ.

700 members of the public have attended ten seminars so far this year in Wanaka, Invercargill, Rotorua, Taupo, Kerikeri, Whangarei, Nelson, Blenheim, Timaru and Auckland with two planned in September in Levin and Wanaka.



85 people turned up in Nelson to hear Dr Sacha Moore speak

For more information phone **0800 MACULA (622 852)** 

### Evaluations received at Taupo Seminar - June 2015

names withheld for privacy

"Thank you for coming to Taupo. Very informative and encouraging."

"Please get the MD message out to the general public! I was diagnosed six months ago & had never heard of it. I like the idea of the grid on the back of buses."



### **Letter to MDNZ**

I am in my 50's and recently updated my will, making two big decisions. The first was to become an organ donor and the second to leave a bequest to the charitable trust 'Macular Degeneration New Zealand.'

With a Catholic upbringing becoming an organ donor is quite a hard decision to make. But after a very close friend died a few years ago I changed my mind. You see, he was a young guy in his 40's who tragically died in a motorcycle versus car accident but was an organ donor. A few months after he died, I read the letter his family received from Organ Donation New Zealand outlining how many lives his very personal gifts had saved, improved and even given renewed sight to. It was an incredible moment, and never felt more proud of my friend.

It seems to me we should leave what we can behind, to helps others.

It was in that vein, that I have also left a bequest to MDNZ. Macular Degeneration is an insidious condition and have seen the effects in my own family. People need to be more aware of the disease that effects 1 person in 7 over 50 years old. My father was a 1 in 7 and as a result is now blind. I know my bequest will help MDNZ do their amazing work for awareness, testing, early detection and treatment that will ultimately improve the lives of hundreds, maybe thousands of people.

As I have got to know the organisation through personal circumstances, I have come to understand how important their work is and how much work there still is to do.

For those contemplating a bequest, it is easy to do. And, it is comforting to know that one day my final gift will help many.





# Save the date! Saturday 20 February 2016

Join the fun at the annual MDNZ Charity fundraising event

How can you support this fundraising event that helps us save sight of thousands of New Zealanders?

Sponsor a race; purchase a table of ten guests where you and your friends, colleagues, family will have fun and enjoy a fabulous day out; or make a donation in lieu of attending. There will be celebrity guests, some fun auction and raffle items and a chance to watch superb horse racing on this important day of the racing calendar.

For more information contact <a href="mailto:phillippa@mdnz.org.nz">phillippa@mdnz.org.nz</a> or phone 0800 MACULA (622 852)

# Bayer NZ Macula Symposium

In May Bayer NZ hosted a Retinal Symposium at Sky City in Auckland. This was another great opportunity to engage with the ophthalmic community, with nurses, optometrists and technicians. Invited guest speaker was Assoc Prof Wilson Heriot from Melbourne and a number of other ophthalmologists contributed to the day. It was an opportunity not only to discuss management of retinal conditions and the use of Anti-VEGF therapies across several indications but also to showcase MDNZ and the work it is doing within the community.

The Bayer Symposium was followed by the Macular Degeneration Symposium. MDNZ is grateful for the support of Bayer NZ for making this possible.

# Who are the MDNZ Trustees?

We have a diverse group of trustees who are committed to progressing the work of MDNZ.



#### Left to right:

James Rangihika | Design/Communications
Mike Frith | Retired Low Vision Optometrist
Simon Rose | Optometrist
Sandra Budd | CEO Blind Foundation
Mark Darrow | Professional Company Director
Dr Dianne Sharp | Chairperson, Ophthalmologist
Dr Andrew Thompson | Ophthalmologist
Dr David Worsley | Ophthalmologist
Henry Ford | Financial Planning Consultant

# Online learning for all health professionals

A web-based professional education programme is now available to all health professionals, free of charge. This is being accessed by optometrists, pharmacists, nurses, technicians, aged care workers.

"Understanding Macular Degeneration" is available through the Goodfellow Learning catalogue of online learning opportunities and it is accredited for continuing professional development points.

One optometrist response received: "Great module, very informative and well worth the hour it took to complete". To find out more go to www.mdnz.org.nz

### **MDNZ Annual Meeting**

On 20 August MDNZ held its 4th annual meeting, when the Chairperson, Dr Dianne Sharp, summarised the board activities in 2015. The year began with strategic planning facilitated by Julie Heraghty, the CEO of the Australian Macular Disease Foundation.

A primary focus for 2015 has been an approach to MP's making them aware of MD, its prevalence and its impact on the lives of thousands of New Zealanders, with an emphasis on the cost of going blind vs the cost of prevention. Awareness is the key to saving sight. It is well recognised that increasing community awareness leads to earlier referral and treatment with better vision outcomes.

Dr Sharp has lead this approach and is delighted with the cross party responses. Their enthusiasm to raise awareness and address the issues of MD will make a difference to thousands of New Zealanders.

To read the full MDNZ Annual report for the 2014/15 year go to www.mdnz.org.nz

### We need your help!

Please help us help those with macular degeneration, their families and carers. MDNZ provides them with education, information and support.

#### **Donors**

Thank you to those who responded to the last issue of Viewpoint. Your donations have already made a difference. Your donation can be made by cheque or credit card using the tear-off form or online for direct payments go to www.mdnz.org.nz

#### **Bequests**

Please see the letter to MDNZ – this letter says it all. Thank you.

#### **Sponsors**

Check out the MDNZ website to see how you will be acknowledged with your logo should you become an MDNZ sponsor. Call Phillippa on 0800 MACULA to discuss ways in which you can sponsor specific activities of MDNZ.

#### **Eye Care Professionals**

Through early detection of MD, you can save sight and MDNZ wants to ensure that New Zealanders are having their macula checked, that they are aware of early symptoms of MD and are seeking your help. Join the MDNZ Professional Friends' Programme as we continue to work together.

Advertise in the Viewpoint newsletter. If you would like to know more about connecting with the varied MDNZ audience, please contact phillippa@mdnz.org.nz



#### Please donate to support those with MD

Title	Ar / Mrs / Ms / Miss / Other			
First name				
Last name				
Name to appear on tax receipt				
Street address				
Suburb				
City	Postcode			
Email				
Phone (hom	e)			
Phone (mob	ile)			
I would like to give a gift (choose one)  ☐ Single ☐ Monthly ☐ Annually  Amount ☐ \$200 ☐ \$150 ☐ \$100 ☐ \$50 or \$				
I would like to pay by (choose one)  ☐ Cheque (enclosed) ☐ Credit card VISA / Mastercard (circle one)				
Card number				
Cardholder's name				
Amount \$	Expiry date /			
Signature	. ,			
For online donations visit www.mdnz.org.nz				
Thank you				
☐ I would like to receive information about MD				
☐ I would like to receive the MDNZ newsletter				
☐ Please send me more information about leaving a gift/ bequest for MDNZ in my will				

Please complete this form and return to:

Macular Degeneration New Zealand, PO Box 137070, Parnell, Auckland 1151 or Fax 09 307 2021

For assistance phone 0800 MACULA (0800 622 852)

Donations over \$5 are tax deductible.

# Support MDNZ this Christmas



At MDNZ we are partnering with The Giving Tree to provide our supporters the opportunity to order their Christmas cards through The Giving Tree.

We look forward to receiving your support to this initiative now, as you think about connecting with those people important to you at Christmas time.

At MDNZ we have done our research and we consider these high quality colourful cards are a good deal – and for each card sold MDNZ receives 50 cents. The funds raised will support our sight saving work including sending information packs around NZ, continuation of our 'save sight' helpline, delivering free education seminars, providing understanding and guidance, support and awareness.

Make your order now by simply completing the order form alongside and sending it off to Ruth at The Giving Tree.



MDNZ has two significant goals to achieve to save the sight of more New Zealanders:

- 1. By 2017 to have awareness increased to 80% (currently 48%)
- 2. By 2018 to have 70% of people over 50 have had a macula check.



The Giving Tree's purpose is to connect smaller New Zealand based charities with business customers and the discerning card sender through the sale of high quality New Zealand designed and printed Christmas cards.

The Giving Tree and Macular Degeneration have collaborated to create a pack of ten Christmas cards for you to purchase. By doing so you are showing your support for an organisation whose goal is to reduce the incidence and impact of Macular Degeneration in New Zealand. For each pack of cards purchased \$5.00 will go toward this goal.



- Blank Inside
- NZ Post Standard Size
- Envelopes Included

Name:	
Address:	
Phone:	
No. of Packs Required:	@\$22.50
-	+ Postage: \$3.50

Send to: **PO Box 270, Matakana 0948 or** phone Ruth on the contact number below to place your order.