



MACULAR  
DEGENERATION  
NEW ZEALAND

# Viewpoint

The MDNZ Newsletter  
Issue 8 – August 2017

0800 MACULA  
(0800 622 852) info@mdnz.org.nz

## Contact your MP to make a difference

Elections are happening on 23 September. Aside from voting, how else can you have your say? We are asking you to make contact with your MP now, to speak to the candidates standing in your electorate and/or to make contact with an MP once new members are 'in the house' following the elections.

MDNZ has been working tirelessly over recent years to be heard in government and relevant ministries on behalf of the MD community. You may have read about these in past issues of Viewpoint. We are delighted to have started a conversation with a number of MPs and Ministry officials, but the work is not over yet. Funding is needed now to prevent increased costs later. We are asking for you to help get the message across to the decision makers in Wellington.

- ✓ Blindness from Macular Degeneration is a growing epidemic
- ✓ 1.5 million at risk individuals in New Zealand
- ✓ *"The total cost of vision loss from Macular Degeneration is estimated to be \$391 million in 2016. The costs of vision loss due to AMD comprise economic costs, as well as loss of wellbeing." \*\**
- ✓ *"\$2.8M in awareness funding will **Save \$70M a year.**" \*\**
- ✓ *"Investing in awareness and education would require substantial funding from other parties, including government and private sector." \*\**
- ✓ 59% of New Zealanders over the age of 50 know macular degeneration affects the eyes – **41% still do NOT know.** \*\*\*
- ✓ At the same time 82% of Australians know this. This is reflected in Australia leading the world in vision outcomes.
- ✓ Awareness is the key. It is well documented that an **increase in community awareness is reflected in earlier referral for treatment with fewer people becoming blind.**

\*\* Ref: Deloitte report Socio economic cost of macular degeneration in New Zealand, October 2016

\*\*\* Ref: Galaxy Poll, March 2016

# Postcards to MPs

Inserted with this newsletter are three postcards ready for you to add your message and send to your MP with options as listed:

1. Action immediately by sending to your existing MP **NOW – Freepost**. Parliament rises on 17 August pre the election date of 23 September so best sent as early as possible to catch an existing MP.
2. Send to an MP after the election at the end of September – **Freepost**.
3. Take a postcard to meet with any local person standing for election to introduce them to this subject (they may not know about MD) and to ask them what their stance is on committing funds to this cause – no post, no cost.

*Note: If you choose to post this to an MP at a local electorate address you will need to correct the address and affix a postage stamp before posting.*



## Your message

- This can be your story of how early detection saved your vision (or late detection has impacted on the advancement of MD lessening the effect of treatment).
- How you (or a family member) are living well with limited vision and early detection and treatment has prevented full vision loss.
- An encouragement to government to fund awareness campaigns so that those at risk are diagnosed early and treatment is accessed without delay, leading to better vision outcomes.
- 1,500,000 people are at risk now. This will increase to 1,800,000 by 2026.
- MD can progress within weeks or months causing rapid vision loss.

## MDNZ and the government in 2017

In May MDNZ posted a document to each MP updating them with facts from the Deloitte report of October 2016 and calling for action to fund awareness and education in New Zealand. An email version was also sent to all MPs the following week.

Following the postal and email campaigns, MDNZ met with a small group of MPs to talk through this subject further. Many MPs understand that managing MD is a health priority. We are being heard and need to keep up the momentum.

**MPs were invited to access further information, which is also available to you:**

- Socioeconomic cost of MD in NZ report by Deloitte's go to [www.mdnz.org.nz](http://www.mdnz.org.nz)
- One News video clip go to [www.mdnz.org.nz/onenews](http://www.mdnz.org.nz/onenews)

If you would like a copy of the update document sent to MPs, or the Deloitte document, please contact us on **0800 622 852** or [info@mdnz.org.nz](mailto:info@mdnz.org.nz).

# 2017 Awareness and Education Seminars

During April, May and June four public seminars were held around New Zealand. Thank you to the Ophthalmologists who gave their time and expertise to make informative presentations to audiences wanting to learn more.

In Gisborne, Dr Andrew Thompson delivered the presentation and local nurses Rachel and Kate were on hand to speak to the residents over a cup of tea. Eric Hoggins kindly offered his story to the Gisborne Herald prior to the event. The article is reproduced on page 8. Thank you to the Eastern & Central Community Trust for funding this seminar.



In Invercargill, Dr Mark Rudel presented and it was great to have Dr Nicholas Johnston and local Optometrist, Richard Lobb engaging with attendees. Local patient Mike Smith reassured the audience during his short address by saying that the needles in the eyes are not so bad.

Dr John Bowbyes, Ophthalmologist from Queenstown, gave the presentation to a smaller yet very interested and engaged audience at The Pavilion, a lovely location by Lake Hayes. The cheese scones provided by local Optometrist, Danielle Ross were a highlight! Sponsorship came from Queenstown Lakes District Council, waiving the fee for the venue, Shipleys Audio Visual discounting equipment hire and Ocula Optometry.



The New Plymouth seminar was held in June and is reported on page 5.

# Life doesn't end with common eye disease

## Jenny's story

One look at the list of books on Jenny Schlup's iPad tells you that being unable to consume books is not an option for the New Plymouth woman. But for four years that's what happened, as an eye disease called age-related macular degeneration slowly denied her the ability to read type in print. Now, she has access to online audio books and devours them at a rate that would make any book-worm proud.

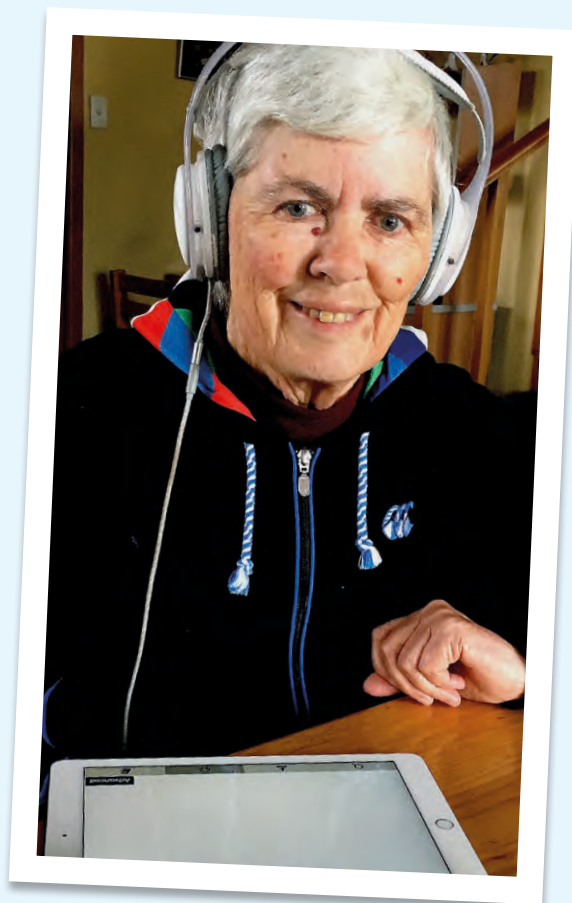
The four-year gap came after several years of gradual deterioration in her eyesight, to the point where she couldn't drive, read, or recognise people's faces.

"I went into denial," she says. "I didn't want to join the Blind Foundation – it just didn't seem like me. It took a while before I relented, and then of course I became aware of the wonderful array of services they have. I discovered this huge audio library."

She had to overcome another barrier, as well – a reluctance to adopt digital technology, devices like the iPad that have since become a central feature of her life.

The former principal of Waitara Central School says she was always short-sighted, but more than a decade ago noticed she could no longer easily discern her pupils' stories written in pencil. "I adopted a different approach for a while. I'd get them to read their work to me."

An optometrist diagnosed macular degeneration, a condition that damages the macular, the small spot near the centre of the retina needed for sharp central vision



and for looking at objects straight ahead. There are two versions – wet and dry – and Jenny has the latter with a gradual thinning of the retina. Nothing could be done to treat it. Her sight was destroyed little by little until she needed to retire in 2006, having led the school since 1991. Driving and reading printed books were out.

One of her greatest embarrassments was not recognising people she met in the street. "They must have thought I was the biggest snob. I began to wish people would say something like 'hi, my name is...' when I came across them."

She laughed when she thought of how she answered her grandson when he asked what she would want if she was granted one wish. "I think he thought I would say getting my sight back, and he was almost right. But there'd be a condition – I would want it to come back slowly because there are still so many wonderful books in the audio library that I still haven't read."

# New Plymouth seminar

Thank you to those who assisted the successful Awareness and Education seminar in New Plymouth in June. 161 people attended with 89% of evaluations rating the seminar as excellent or very helpful.

Local ophthalmologist, Dr Kevin Taylor provided a stimulating educational presentation which was very well received by the audience.

Lance Girling-Butcher rallied support through the various community organisations he is involved in and Positive Ageing New Plymouth promoted the event widely.



Lance Girling-Butcher addressed the audience in New Plymouth with his stories of life with no vision. Lance shared his many positive experiences encouraging the audience with the message that losing vision is not the end of the world. He is a great role model to the community, overcoming many barriers to achieve what he wants to.

## Community seminars coming up

<b>Tauranga</b>	Armitage Hotel	10am	Saturday 12 August
<b>Palmerston North</b>	Copthorne Hotel	10am	Saturday 19 August
<b>Hamilton</b>	Airport Hotel	10am	Saturday 30 September
<b>Christchurch</b>	Eye Hospital	9.30am & 1pm	Saturday 11 November
<b>Timaru</b>	TBC	10.30am	Sunday 12 November

Please call **0800 MACULA (622 852)** or email [info@mdnz.org.nz](mailto:info@mdnz.org.nz) to register your attendance.

# MDNZ Symposium July 2017

Leading retinal specialists and ophthalmic nurses came together in Auckland to attend the MDNZ Symposium, where they received updates on the activities of MDNZ and contributed ideas to the MDNZ reply to government. Challenging clinical cases were presented and discussed leading to further discussion on treatment availability in New Zealand.

MDNZ Trustee and marketing adviser James Rangihika discussed ways of engaging with government. The focus of MDNZ is to increase awareness of MD. In a Galaxy Poll in March 2016, awareness of MD was at 59%.

MDNZ's aim is to increase this to over 88% using a large-scale awareness campaign, including television advertising, emulating Australia's

success with such action. MDNZ creates awareness through an informative website, regular Facebook updates, Viewpoint newsletter and regular educational roadshows around the country, encouraging people to contact MDNZ through its **0800 'Save Sight'** help line, by email or through our website.



## MDNZ voice on the new Model of Care

MDNZ has worked for the past two years to ensure MD is a government health priority with a model of care established to ensure community awareness for early treatment and support for good treatment management.

Following a campaign by the Royal Australia and New Zealand College of Ophthalmologists' (RANZCO) to highlight the plight of many of the country's MD patients who were going blind while waiting for treatment, the government commissioned consulting firm Ernst and Young (EY) to develop a model-of-care report for age-related macular degeneration (AMD) from earlier this year.

Visionary and tireless advocate Dr Dianne Sharp, founding Chairperson of MDNZ, urged ophthalmology colleagues to offer their feedback before the report is put to government. "This is our chance to have our say – let's make it count!".

EY director Dr Gary Jackson led the audience through a draft version of a model for MD in NZ, followed by discussion. Key focus areas included prevention and early detection, intravitreal anti-VEGF treatments and low vision rehabilitation.

**The key objective was:** Timely diagnosis and the best use of professional skills, technology and infrastructure in the health system. Jackson also discussed early detection of MD and speed of treatment, with the aim to reduce time from diagnosis to the patient's first anti-VEGF injection to one week to reduce the damage to the eye caused by wet MD. Adequate and timely follow up is also essential.

Ophthalmologists gave feedback and there was lively discussion about anti-VEGF treatment options and availability, the potential of using other eye health professionals to administer injections and the administration challenges within the public health system. Everyone agreed the sessions provided many interesting talking points and useful feedback for EY.

We look forward to helping implement the final report with the Ministry of Health. We will keep you informed.



## MDNZ Professional Friends

We welcome recent new members to the MDNZ Professional Friend programme.

### Optometrists

Ian Buchanan, Bay of Plenty  
Phillipa Charteris, Taranaki  
Mike Jowsey, New Plymouth  
Roberta McIlraith, Christchurch  
Frederick Swain, Napier

### Ophthalmologists

Narme Deva, Auckland  
Nicholas Johnston, Invercargill

**Thank you** to the Optometrists and Ophthalmologists who have joined the MDNZ Professional Friend Programme. We are delighted to partner with you to save sight for the thousands of New Zealanders with Macular Degeneration. Professional Friends receive patient brochures at no cost, a certificate to display in their practice, and recognition in MDNZ's newsletter, website and Facebook.

Please support the eye professionals who support MDNZ and do tell them you saw them in our newsletter. A full list of Professional Friends is on our website.

**If optometrists or ophthalmologists would like to become a Professional Friend of MDNZ, please visit [www.mdnz.org.nz](http://www.mdnz.org.nz), or phone 0800 MACULA (622 852).**

## Vision for the future

Retired Gisborne cartoonist, graphic designer and sports historian Eric Hoggins has spent a lifetime creating fine art work. He considers himself more of a graphic designer than the cartoonist he is most renowned for. "I did very fine work, as well as drawing cartoons by hand, most of it in an era well before computers."

He is surprised that with the nature of his working life, he did not start wearing glasses until the age of 84. "I put on a pair of my late wife Mary's glasses one day," he said. "I could read a lot better. Everything was much clearer."

Mr Hoggins was surprised and had his eyes checked. He was surprised again. "They found I had a serious defect in my right eye." He had macular degeneration or MD, which is the leading cause of blindness in the country.

Mr Hoggins underwent "top notch" care and treatment at Gisborne Hospital. He estimates he had a dozen injections into his eye over 18 months. "I can't praise the Gisborne Hospital staff enough. They are the ultimate professionals."

Today Mr Hoggins describes reading the phone book as one of his biggest challenges. He can manage the Gisborne Herald if he has good light.

MD is the leading cause of blindness in NZ but the most severe form is treatable.

"It is important to get the word out about how important early detection is," Mr Hoggins said. He regrets not being aware of changes in his eyes before being diagnosed three years ago.

"It is important to get the word out about how important early detection is"





# Ambassador Profile

## John Adshead

John is one of the most important figures in the history of New Zealand football and is a Macular Degeneration NZ Ambassador.

John made his mark in New Zealand in 1979 when he was appointed coach of the New Zealand national football team. In 1982 the football world was shocked when the All Whites qualified for the FIFA World Cup in Spain. John led the team to honour as they were the only team not to get a yellow card and were at the top of the tables for good behavioural stakes throughout the first round of the tournament. John's influence goes well beyond taking the All Whites to Spain, especially in the football community. His coaching career extended for over 40 years as he guided many teams to success.

In 2013 John was appointed an Officer of the New Zealand Order of Merit for services to football.

MDNZ are appreciative of the support and work our ambassadors do. John is a staunch supporter of MDNZ fundraising events. Thank you John.



# Pharmacies spreading the word

A big thumbs up for Mary Bollard, from Bollard Pharmacy in Pahiatua who contacted MDNZ for brochures to display in the pharmacy to draw attention to macular degeneration.

Mary has identified that only 10% of people in Pahiatua have heard of MD and those who have heard of it either have MD or have a family member affected.

Thank you Mary for contributing to our awareness campaigning. The number of people who know about MD in Pahiatua is sure to increase thanks to you.



Don't forget!  
Contact  
your MP!

This is your chance to tell your MP your story using the postcards provided. Has early detection helped you? Should you have had your eyes checked earlier? The importance of awareness leading to early detection. Will your local MP commit to MD being a government health priority?

**For any further information please contact us on 0800 MACULA (622 852) or email [info@mdnz.org.nz](mailto:info@mdnz.org.nz) and view our website [www.mdnz.org.nz](http://www.mdnz.org.nz)**

# Frequently Asked Questions (FAQ's)

We receive many interesting and varied questions on the 'save sight' phone line and from time to time we will share some FAQ's in Viewpoint.

Q. Are there any support groups where I can engage with other people diagnosed with MD?

A. Retina NZ has support groups in locations around New Zealand which are open to anyone with sight loss or their family and friends. For more information or to start a group in your area contact Sue on **0800 569 849** (Ext 2).

Q. It is not easy to know which of the Blackmores macular health products to use – how does one choose between these products?

A. **Macu-vision + Lutein Defence** is recommended for someone who has moderate to severe signs of macular degeneration. To meet the full AREDS2 research formula you need to take 2 x Macu-vision each day + 1 Lutein Defence. Always advise your doctor that you are taking these supplements.

Lutein Defence is suitable for someone who has a family history of MD or needs to supplement their diet with Lutein. **Lutein-Vision Advanced** is also available which has Fish Oil and Selenium added to Lutein and Zeaxanthin. Lutein is a pigment that is concentrated in the macula and has been shown, in conjunction with vitamins and antioxidants, to slow the progression of macular degeneration.

Other supplements are available. Check with your Eye Care Specialist for what is the best for you.

## Blue Illusion raises funds for MD

In July, Macular Degeneration NZ was lucky enough to be invited to the Albany Blue Illusion store, where our volunteer Doreen and Intern Grace modelled the latest spring fashions on the catwalk while champagne and nibbles were enjoyed.

After the parade, Blue Illusion offered a 3-hour window where 15% of the total sales was donated to Macular Degeneration NZ.

This is a great contribution to our charity and we are very grateful to Blue Illusion for putting a fun spin on raising funds. We would like to thank those who participated in this event and we hope to do many more fashion shows with Blue Illusion in the future.

Thank you Georgina and the team at Blue Illusion, Albany.



# Your donation

**A very big thank you** to those who responded to our education appeal. Your donation has allowed MDNZ to deliver more community seminars and has enabled MDNZ to extend the hours of the '0800 save sight' phone line service.

Your donations contribute directly to the wellbeing of those with MD and their families and carers who seek advice or support through the phone line and by attending seminars.

We wish to recruit an educator to implement a wider community education programme. We will continue to grow this extension of our services and fundraise to make this happen.

If you missed the appeal in April, or did not get around to it, you can still donate today.

Be assured your donations and bequests will make a huge difference.

# Educate your neighbourhood

You can have a community awareness and education seminar near you.

If you are passionate about informing your local community about macular degeneration you could lead a local fundraising activity. Raising \$2,000 will enable MDNZ to have a seminar in your town. Send us your ideas and we will help make it happen.

Contact [events@mdnz.org.nz](mailto:events@mdnz.org.nz) or call us on 08000 MACULA (622 852).



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## Please donate to support those with MD

Title  Mr / Mrs / Ms / Miss / Other

First name

Last name

Name to appear on tax receipt

Street address

Suburb

City  Postcode

Email

Phone (home)

Phone (mobile)

### 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](http://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.*

## More photos from New Plymouth



### 20<sup>th</sup> Retina International World Congress 10 – 11 February 2018

Owen G Glenn Building  
University of Auckland

[www.retina2018newzealand.com](http://www.retina2018newzealand.com)

Bringing together people with a retinal disorder, their families, ophthalmologists, optometrists, scientists and rehabilitation professionals. Leading scientists, including Professors Elise Héon, Eric Pierce and Gerald Chader, and Associate Professor Andrea Vincent, will share the most up-to-date knowledge in retinal research. An event not to be missed!

Registrations now open.

For more information, or assistance with registration, contact the conference co-ordinator, Samantha Barrett:

Email: [s.barrett@auckland.ac.nz](mailto:s.barrett@auckland.ac.nz)

Phone: 09 923 4826



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