



MACULAR
DEGENERATION
NEW ZEALAND

Viewpoint

The MDNZ Newsletter
Issue 7 – April 2017

0800 MACULA
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Education is the key to reducing Macular Degeneration in NZ

Since inception, Macular Degeneration New Zealand (MDNZ) has been committed to reducing the incidence and impact of macular degeneration in New Zealand.

While we pat ourselves on the back for increased awareness measured bi-annually by a Galaxy Poll and we 'feel good' when large numbers register to attend the awareness and education seminars and 'even better' when the evaluation forms tell us the seminar was very helpful, we know we have a long way to go. This edition of Viewpoint will focus on education.

Feedback received from people attending the MDNZ education seminars tells us how important education is. Optometrists are noticing the difference the MDNZ education programme is making in their practices. Norma's story will tell you how 'by knowing what to expect and what to do' she has managed to maintain a quality of life overcoming limitations due to her reduced vision.

We remind all health care professionals that "Understanding Macular Degeneration" is an online learning programme available

to all medical professionals – 'education for the educated!' We acknowledge our Professional Friends who have made the commitment to support MDNZ and we introduce you to the new interactive map available on our website which will enable you to look at the predicted growth of the prevalence of macular degeneration in your area over the next ten years.

In this edition we profile MDNZ Ambassador, Dame Kate Harcourt DNZM, we introduce you to our intern, Grace and we share the success and photos from the Macular Degeneration Charity Race Day.

Education is the key to saving sight and living well with macular degeneration. MDNZ is calling for your help to reach the tens of thousands of New Zealanders who don't know about this disease and therefore may lose vision from it.

Read on to find out what you can do to make a difference.

Awareness is key

"An increase in awareness and education of AMD would lead to reduced burden of Macular Degeneration through timely and adequate provision of treatments."

Deloitte.

Living well with Macular Degeneration

– Norma Hopkirk



I noticed that there was something wrong with my eyesight about 16 years ago. My optometrist advised me to see an eye specialist who took photos of the back of my eye, told me I had dry (or atrophic) macular degeneration and that nothing could be done about it although I wouldn't go completely blind! Imagine my horror. I felt that my life had suddenly collapsed.

My optometrist suggested a second opinion. I made an appointment with not much hope of help – but instead of gloom I received an understanding and printed information on the problem, advice about my diet to include lots of green vegetables and fish and a combination of vitamins and minerals. While my vision has continued to deteriorate slowly over the past 13 years, I am still able to do so much more than I had originally believed would be the case!

I have had to make many modifications to my lifestyle. I can no longer read newspapers or books but I use a bright white light to help with essential reading, and amber sunglasses to reduce glare outside. I see crowds as a seething mass of colours and can't distinguish faces but friends wave to me to join them in a crowd.

I had to give up driving many years ago but I make full use of the bus service. I try to catch buses from stops where I know it

will be easy to know which bus to catch – it's embarrassing to hold your hand out for what you think is a bus only to find it is a concrete mixer truck!

Once a week I go on outings with Outdoor Tours, guided day trips around the wider Auckland area from Hamilton to Whangarei. I enjoy the company of the other people and they happily tell me what goodies are in the cabinets at the various cafes we visit.

I have always enjoyed knitting, crocheting and embroidery. Now I crochet simple woollen squares which I join together into blankets to donate to the Salvation Army. So life is pretty good and I enjoy it despite all the mistakes I sometimes make. Family and friends are always willing to help out for shopping, appointments or transport. At almost 90 I can still live in my own house with my own things around me – including all my knitting yarn and crocheted rugs!

Editor – Thank you for inspirational story, Norma.

Macular Degeneration Charity Race Day

Saturday 18 March was a glorious day in Auckland with the Ellerslie Racecourse gardens and surrounds looking their best and glistening in the sun. A fitting venue for the 290 MDNZ supporters who turned out in their race day finery for a great day of racing, a gourmet lunch in the Guineas Room and lots of fun.

MC, Stephen Stuart, kept the conversation flowing, gave out prizes for losing tickets, offered betting tips and encouraged the audience to buy raffle tickets and bid on the many items available in the silent auction.

With 38 silent auction winners, 5 raffles drawn, and a chance to win from a "losing betting ticket" everyone went home very satisfied.

Supporters had the chance to purchase

a visit to the commentary box as well as trackside at the race start. These unique race day experiences were a great hit.

MDNZ wholeheartedly thanks race sponsors, donors of auction items and prizes and all our supporters for their contribution to this event which raised \$25,000 net to provide services across New Zealand to those with macular degeneration, their families and carers.



Winner of best dressed man, Kenneth, from Tauranga.



Race sponsors Belinda & Kevin Way of OIC.



Simon Rose and the Visique Rose team.



Great to have the OPSM/Luxottica team join us.

An education appeal

“I am so glad that I knew to check each eye for early changes in my vision because this has saved my sight.”

Ross Legh was diagnosed with macular degeneration in his 50s. He knew he was at risk and had an Amsler Grid to check his eyes. When his eyesight deteriorated, he responded swiftly and was able to receive treatment that saved his sight.

Ross was well informed and took urgent action to prevent vision loss. For many people in previous generations, vision deterioration and associated loss of independence was part of growing old. Imagine the relief to discover that your vision problem can be treated. With new research and treatments for many people with macular degeneration the future is much brighter than it was 10 years ago.

Ross explained:

“Apparently I was very fortunate. Seeking treatment early meant the abnormal blood vessels that form wet macular degeneration did not have the chance to permanently damage my central vision. A few weeks’ delay in seeking treatment could have resulted in a very different outcome.”



Many New Zealanders still do not know about macular degeneration. They do not know to keep their eyes healthy by eating green leafy vegetables and lots of fish. They do not know to get their eyes tested regularly, nor do they know about the self-test Amsler Grid. They need to know to visit their health professional as soon as they notice changes and to get treatment as early as possible.

MDNZ’s goal is to reach thousands of people each year, so that people like Ross can be tested and won’t go blind needlessly. To do this we need community educators and we are calling on you to give those that don’t yet know about macular degeneration a chance to save their sight.

Your contribution today will help us raise \$100,000 to employ educators to engage with communities around New Zealand.

As a reader of this newsletter you are likely to be the one New Zealander in three that knows about this disease. MDNZ is asking for your support to reach the two thirds of New Zealanders that do not yet know about macular degeneration, so they too can take action to save their sight.

To find out how you can help to educate your neighbourhood see page 11.

We know education works. Two years ago, when delivering community presentations,

nobody knew about the Amsler Grid. Now, when we visit community groups, some people are familiar with the grid and show their friends how to take the test.

The community presentations talk about macular degeneration and give people confidence to take charge of their eye health. The presentations offer hope as people realise that it is possible to live a good life with macular degeneration and that going blind is not an inevitable part of growing older.

This is the most urgent need as we battle against this insidious disease in our bid to save sight.



Ross is grateful for the information he received. He reflects:

“Recognising macular degeneration’s early warning signs saved my sight.”

That is why through this appeal, we are determined to raise the funds needed to employ a community educator. MDNZ is reliant on supporters like yourself to provide education in the community.

Will you consider a gift to help others save their sight?

Please visit www.mdnz.org.nz/donate to donate now or fill in the donation slip at the end of this newsletter.

Whatever you are able to contribute will go towards raising awareness in the community. Your gift will help us win the battle to save sight.



What's up Doc? What do the Eye Professionals say?

At MDNZ, we believe that our seminars and public education presentations are making a positive difference. We think that people are now more aware of this disease and are more able to help themselves than they were previously. To gauge if we are on track with our education presentations, we approached the professionals to hear what they have to say.

MDNZ asked Simon Rose, a Hamilton optometrist and MDNZ Trustee for his thoughts: *"Not long ago people only found out they had Macular Degeneration (MD) when they went to the Optometrist or had a bad or adverse effect and went to the Ophthalmologist. Now people come in of their own accord wanting to know what chance they have of getting MD as their mum or dad has trouble with it, or have they got it, or even what can they proactively do to reduce their chances of getting it."*

Dr Andrew Thompson, Tauranga ophthalmologist and MDNZ Trustee reflects: *"I think MDNZ has had a huge impact on increased awareness of, and education about, the condition. Patients have often heard about the dry and wet forms of MD and are aware of available supplements that slow the progression of dry MD and treatments available for wet MD. For me,*

this makes discussion about the condition, treatments and the impact it may have on a patient's life much easier."

MDNZ seeks to start the conversation with the public by running education presentations and seminars, as well as providing comprehensive consumer resources. We aim to work collaboratively with optometrists and ophthalmologists to spread the word.

Both Simon Rose and Dr Andrew Thompson have noticed a difference since MDNZ's education campaign began. Simon Rose explains the benefits: *"By educating the public on MD they can be seen earlier and earlier detection means a better result. Remember early detection saves sight."*

Awareness and Education Seminars for 2017

We started the year with a Whangarei seminar in March, and we plan to get out and about in 2017. The following seminars are now confirmed:

Saturday 22 April	Gisborne
Saturday 27 May	Invercargill
Sunday 28 May	Queenstown
Saturday 17 June	New Plymouth
Saturday 12 August	Tauranga



Contact MDNZ to register your attendance and spread the word to others who may be interested. **Other possibilities this year are:** Palmerston North, Timaru, Wellington, Christchurch, Dunedin, Auckland. For details go to www.mdnz.org.nz



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Professional Friend

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 these eye professionals who support MDNZ and do mention you saw them in our newsletter.

Optometrists

Nigel Somerville, Glen Eden
Roger Apperley, Auckland
Kristine Jensen, Howick
John Adam, Remuera
Grace Lang, Ponsonby
John Mellisop, Whanganui
Jagrut Lallu, Frankton/Huntly
Peter Walker, Frankton
Simon Rose, Frankton
Richard Lobb, Invercargill
John Veale, Merivale
Danielle Ross, Wanaka
Richard Newson, Nelson
Robert Dong,
Wellington/Lower Hutt
Maira Ironside,
Palmerston North
Niall McCormack, Hastings
David Lee, Botany
David Haydon, Takapuna
Jayesh Chouhan, Wellington
Claire McDonald, Warkworth
Grant Watters, Auckland
Ian Finch, Bay of Plenty
Darryl Eastabrook, Auckland

Phil Donaldson, Hawkes Bay
Kevin O'Connor, Wellington
Philip Walsh, Auckland
Callum Milburn, Dunedin
Troy Cassidy, Auckland
Brian Naylor,
Palmerston North
Jeremy Wong, Auckland

Ophthalmologists

David Worsley, Waikato
Dianne Sharp, Auckland
Steve Mackey, Wellington
David Dalziel, Northland
Rachel Barnes, Auckland
Andrew Thompson,
Bay of Plenty
John Ah-Chan,
Palmerston North
Sean Every, Canterbury
Philip Polkinghorne,
Auckland
James Borthwick, Canterbury
Brian Kent-Smith, Northland
Jo Koppens, Auckland
John Bowbyes, Queenstown

Online Learning
for all medical
professionals

Understanding Macular Degeneration is an online learning tool available to optometrists, GP's, nurses, orthoptists, technicians, pharmacists. This programme has recently been reviewed and can be accessed and completed online at no cost.

Boost your CPD points and undertake this online learning NOW!

[www.mdnz.org.nz/
resources](http://www.mdnz.org.nz/resources)

www.goodfellowunit.org

New on YouTube

New to MDNZ is our YouTube channel where we'll post our latest news and research. What better way to kick off our YouTube channel than with a presentation by Prof Alan Bird, latest research on the cost of macular degeneration to New Zealand, and a patient's story about how early detection saved his sight.



The Treatment Revolution

British Ophthalmologist Prof Alan Bird, of the Institute of Ophthalmology at Moorfields Eye Hospital in London, is recognised as a pioneer in the field of Medical Retina.

Prof Bird delivered a presentation in Auckland in November 2016 where he discussed the latest advances in medicine in the last decade which have transformed the disease from progressive and disabling to one that can be tamed with medication.



Latest New Zealand Research

The "Socioeconomic cost of macular degeneration in New Zealand" is a Deloitte Access Economics Report published in October 2016. It is the first report in New Zealand to show the economic, social and personal cost of the disease. Dr Dianne Sharp, MDNZ Chairperson, delivers a summary of the report.

The full report is available on www.mdnz.org.nz

Ross Legh's Story

Macular Degeneration patient, Ross Legh, shares his inspirational story of his journey with macular degeneration – the importance of early detection, knowing how to identify changes and when to act.



If you missed Prof Alan Bird's presentation at the Treatment Revolution Symposium, want to hear the latest NZ research or a patient's story, you can find them at www.youtube.com/channel/UCTpME_f_AWA47QvurPZnwPg

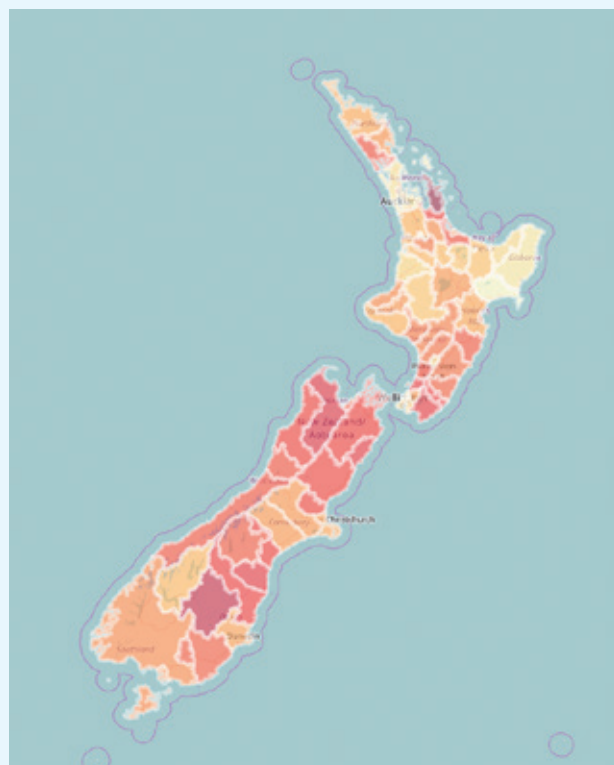
Mapping Macular Degeneration into the future

What is happening with macular degeneration in your district? An interactive map revealing regional statistics and predictions for macular degeneration has been developed by Andrew Worsley and Ethan Li.

To view the map, visit www.mdnz.org.nz
Click to view the map in detail for regions of New Zealand.

The map is derived from an article "Prevalence predictions for age-related macular degeneration in NZ have implications for provisional healthcare services" by David Worsley and Andrew Worsley, published in the NZ Medical Journal in 2015.

The idea of the map is to provide a visual tool to help planning for the future; where services will be most needed and where resources should be allocated. While it will be most relevant for policy and decision makers at a local and national level, MDNZ is keen to share this information with our supporters too.



Support the MDNZ Fundraiser,
Order your NEW 2017 | 2018 Entertainment™
Membership now!

MDNZ is grateful for the support of Old Grumpy's Gallery in Mt Maunganui who once again offers these books to support and raise funds for MDNZ, saving sight for thousands of New Zealanders. Order books for any region in NZ.

20% of every membership sold contributes to Macular Degeneration New Zealand. Help us achieve our goal by sharing this link with your friends and family.

www.entertainmentbook.co.nz/orderbooks/158x528

Thanks for your support!



OR



Contact: Bob Ricketts
Pickup address if you wish to:

Old Grumpy's, 276 Maunganui Rd, Tauranga 3116
Ph: 022 043 0862 Email: bob@oldgrumpys.co.nz

Ambassador Profile

Dame Kate Harcourt DNZM

Veteran actress Dame Kate Harcourt has had a long and distinguished career in theatre, television and film and is a great friend and ambassador for MDNZ. She has macular degeneration but does not let it stop her continuing with a demanding acting schedule and enjoying a full life.



Dame Kate has had a role in “Hen’s Teeth” as part of the Wellington Women’s Theatre Festival as recently as March 2017. She was in the original cast when Hens Teeth first premiered at Circa Theatre in 1988 and is one of a number of performers who have returned for the 2017 show (together with some new faces) which featured a feast of ‘side-splitting’ comedy.

In 2011 Dame Kate played a role in a NZ film, “Hook, Line and Sinker” about PJ (a truck driver) who failed his licensing eye test due to macular degeneration, when his life turned upside down. Dame Kate introduced MDNZ to the film production company and MDNZ hosted film premieres of the film in regional centres of New Zealand with two of the actors participating at each event. These film premieres were a ‘sell out’ and MDNZ awareness was launched to these audiences. Thank you Dame Kate.



Meet our intern

Grace Jones

Grace grew up in the small town of Paihia, Bay of Island. After graduating from school Grace took two years to travel abroad. She spent a year in London at a Prep School teaching Physical Education and coaching sports such as Cricket, Hockey, Swimming and Netball. She then ventured to France to spend 6 months at a ski resort where she learnt to ski. Before finally coming home she spent 6 months on Super Yachts in Turkey.

She is now in her final year of studying for a Bachelor of Communications at Unitec, Mt Albert. She has thoroughly enjoyed the course and makes the most of all opportunities. Grace is working for Macular Degeneration NZ in a role of Public Relations and Event coordination for the year and then she plans to set her career up in Sports Event Management.

“I love working in the office with the MDNZ team! They are very supportive in helping me develop my skills. I’m very excited to see what this year has to offer with MDNZ and see how we can really share awareness to a wider audience.”

Your donation

Your gift today will help us reach the thousands of people who will go blind from macular degeneration because they do not know about this disease.

We desperately need an educator to visit communities to tell people about this disease.

Your gift will ensure:

\$50 10 Information Packs mailed to people with macular degeneration

\$100 Information packs for attendees at a community seminar

\$3,000 Staffing the 0800 Helpline

\$10,000 Awareness & Education Seminars in communities across New Zealand

Educate your neighbourhood

You can have an 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.

Contact events@mdnz.org.nz or call us on **0800 MACULA (622 852)**.



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Please donate to support those with MD

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Amount \$200 \$150 \$100 \$50 or \$

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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.

Macular Degeneration Charity Race Day 2017

