



MACULAR
DEGENERATION
NEW ZEALAND

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Viewpoint

The MDNZ Newsletter
Issue 6 - December 2016

The Socioeconomic cost of macular degeneration in New Zealand

Macular Degeneration NZ (MDNZ) knew that macular degeneration-related vision loss costs this country a huge amount in health-care related costs, productivity loss, reduced personal well-being and all the associated costs with the burden of disability. We didn't know just how big these costs were. Nor did we know how much money could be saved by a greater investment in MD awareness and early treatment. With funding from the Rapanui Trust, MDNZ commissioned Deloitte to find out how much MD is costing this country.

We were surprised at just how high the costs were – an estimated \$391 million this year. This includes the economic costs as well as loss of wellbeing. Deloitte also uncovered that increasing awareness of MD is the key to reducing blindness. They identified that early detection and treatment could save New Zealand society an estimated \$75 million per year. Deloitte concluded that "an increase in awareness and education of AMD would lead to reduced burden of macular degeneration through timely and adequate provision of treatments".

MDNZ Chairperson, Dr Dianne Sharp describes such low awareness as "a tragedy that is costing the country a huge amount

of money, tying up health system resources and destroying lives".

"People mistakenly think that blindness is an inevitable consequence of getting old but that's no longer the case – provided that people know the warning signs of MD and seek treatment early," she says.

We cannot do this on our own. Collectively everyone needs to be part of the solution. The Government and private sectors must take a lead on this and together we can make a huge impact on this epidemic.

Please contact us at info@mdnz.org.nz if you'd like a copy of the report emailed to you.



Awareness message in Hastings

Dr John Beaumont, Hastings Ophthalmologist, addressed an audience of 130 at the MDNZ public seminar in Hastings in September. In addition to providing the latest information about MD, Dr Beaumont asked the audience to 'help to get the 'awareness message into the Community'.



Local resident Grant Thompson shared his story of being lucky to have his MD detected early and to have received timely treatment with the consequence of saving his sight and allowing him to live an active and full life as a result.



Seminars for 2017

Planning is underway for seminars around New Zealand in 2017.

We are dependent upon funding, availability of venues and a local ophthalmologist to offer seminars, and we hope to arrange a number of these in 2017.

Whangarei will start the year on Saturday 4th March at 10am. To register, please contact info@mdnz.org.nz or call 0800 MACULA (622 852).

Watch the MDNZ website www.mdnz.org.nz for further details, which will also be listed in the next issue of Viewpoint. We would like to get to Gisborne, Manawatu, Taranaki, Timaru, Otago, Wairarapa and Southland at some stage if we can.

MDNZ Ambassador Viv Jones spreads the word in the Bay of Plenty

A chain reaction is underway in the Bay of Plenty, which started some years ago when founding MDNZ Trustee, Viv Jones, was asked to tell her story of "life with MD" to a local community group. The demand for Viv's talks have increased many times over with clubs and senior groups asking Viv to speak. In 2016 Viv has spoken to 1,063 members of the Bay of Plenty community. Whenever possible, Bev Stowers (from the Blind Foundation) joins Viv to share services and low vision aids provided by the Blind Foundation. Together they are making a difference to awareness in the Bay of Plenty.

THANK YOU ladies.

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Letters to the editor

Charles Bonnet Syndrome

Thank you so much for sending me "Viewpoint" – Issue 5 August 2016. The article on Charles Bonnet Syndrome provided a "light bulb" moment for me. I have since been able to confirm that I do have Charles Bonnet Syndrome (CBS), but definitely (100%) do not have dementia. I have been through 12 months of distress and despair, but I am now extremely grateful to MDNZ and the Blind Foundation for their help.

I initially had been diagnosed with MD about 10 years ago and was well aware of gradual deterioration of the condition. I was taken by surprise at the sudden and drastic onset of visual hallucination and phantom imaging nearly one year ago. Luckily, I have always been aware that the imaging can only be considered as "unreal".

Since very recently being diagnosed with CBS, I have studied all information made available to me on this phenomenon and am concerned at the lack of knowledge on CBS amongst relevant health professionals and support people. My own experience over the last year has left me feeling degraded and ridiculed, and at times experiencing distress and despair.

Could health professionals and support people perhaps be encouraged to recognise and treat the existence of CBS more widely and seriously than in the past.

Gael

15 October 2016

Editor – Thank you for sharing your story Gael. I am sure it will resonate with many, and thank you to the original caller who prompted the article written in Issue 5.

Thank you

Thank you very much for the newsletters which arrived today. I have enjoyed reading them (in spite of difficulties) and look forward to keeping in touch. I wonder if you have published any articles on the tablets which are for the purpose of retarding MD, available from optometrists. One relevant question about them is whether they are compatible with blood thinners like Pradaxa and Warfarin, which would apply to quite a number of MD sufferers.

Desmond

21 October 2016

Editor – What a great matter to bring up Desmond. Your question will certainly ring a bell with many of our readers. Our recommendation is to always ask your GP for advice when taking supplements or any additional medication. They are the experts.

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.

The Treatment Revolution

400 people gathered at the Auckland War Memorial Museum in early November to hear Professor Alan Bird, a retinal specialist from the UK. Macular Degeneration NZ (MDNZ) took the opportunity to host this visit to New Zealand by Professor Bird where he educated guests about the treatment revolution for MD, which is regarded as one of the greatest advances in eye medicine in the past decade.

Professor Alan Bird is a British Ophthalmologist, internationally recognised as one of the pioneers of Medical Retina. He is a Professor and Consultant at the Institute of Ophthalmology at the Moorfields Eye Hospital in London, UK.



He has done incomparable work on MD, retinal dystrophies, and his international fellows have, over many years, become leaders in their field in many major centres in the world.

Professor Bird directs a multidisciplinary research team that investigates monogenic retinal disorders and age-related macular disease. This research resulted in the development of new technologies to define the clinical characteristics of retinal disease providing a clearer understanding of retinal degenerative diseases.

At the symposium MDNZ Chairperson, Dr Dianne Sharp, announced the arrival of the Deloitte report on the socioeconomic

cost of MD in New Zealand and highlighted the key points that are described earlier in this publication. She stressed the importance of awareness and early detection, timely treatment and suitable management and rehabilitation. "Funds must be found to slow the growth and impact of this debilitating disease". A relatively small amount spent now will save millions in the future.



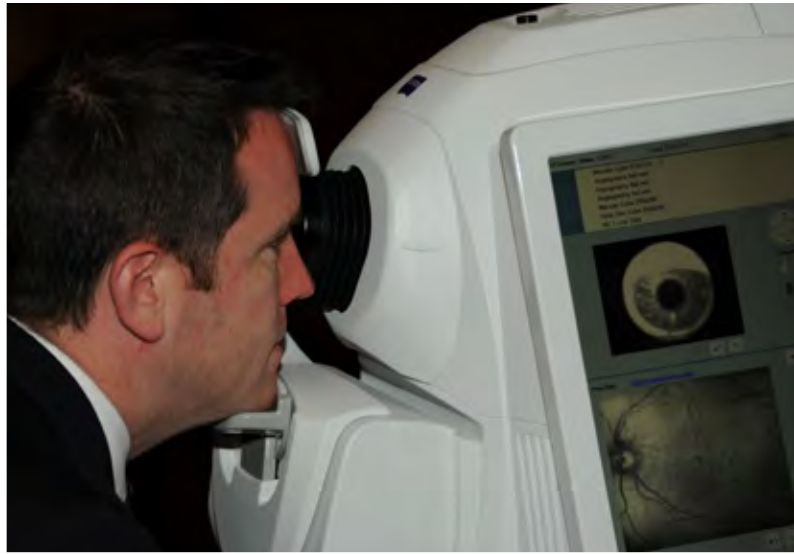
Businessman, Ross Legh addressed the audience with his story of diagnosis. A decade ago Ross was diagnosed with early stages of MD and given an Amsler Grid to regularly check his vision. Whilst working he noticed how similar an adjacent building's window mullions were to the Amsler Grid's lines. Out of curiosity, he checked his eyes one at a time to find wavy lines. Ross was very disappointed to find he had wet MD and treatment began immediately. Ross says "Recognising macular degeneration's early warning signs saved my sight. A few weeks' delay in seeking treatment could have resulted in a very different outcome".



The Treatment Revolution goes to Parliament

The day following the Kaikoura earthquake, MDNZ went ahead with plans to take the Deloitte paper and message to Parliament. In the Legislative Chamber MDNZ together with Zeiss undertook eye examinations. Chris examined 70 pairs of eyes of MPs and staff. This was a great awareness raising opportunity – thank you Zeiss.

MP and Chair of the Health Committee, Simon O'Connor, hosted the evening event attended by local medical practitioners, MPs, Ministry of Health officials and other decision makers. MDNZ offered copies of the Deloitte's document and Dr Sharp presented the financial facts of saving government funds later by investing now.



THANK YOU to the supporters of the Treatment Revolution events





Join us for a fantastic day at the track

On Saturday 18th February 2017 at Auckland Racing Club, Ellerslie

Join us from 12 noon in the Guineas Room, where you will be treated to drinks on arrival and a delicious buffet lunch, plus much more. Witness the extravaganza of horse racing including the prestigious Avondale Cup and Avondale Guineas races. Enjoy a great day, while fundraising for Macular Degeneration New Zealand and their work in the Macular Degeneration community.

A table of 10 package is \$1,250 (incl. GST) and includes:

- Table in the Guineas Room for 10 guests, including drinks on arrival, buffet lunch, afternoon tea and cash bar
- Entertainment throughout the day including tipsters, jockeys, celebrities and unique experiences
- Opportunity to display product and branded pull-up banners in the Guineas Room for the day
- Free carparking

A Unique Experience is \$100 (incl. GST) for 4 people for either option:

1. Experience the Commentary Box
2. Experience the Race Start

Book now to be on the inside!

**Individual tickets \$140 (incl. GST).
Earlybird tickets \$125 (incl. GST)
(before 31 December).**

Visit www.mdnz.org.nz to secure your tickets online.

1 in 7 people over 50 will get Macular Degeneration.

All funds raised on the day will gratefully go to support the Macular Degeneration community.

To take up this opportunity, please contact Alice McKinley at 027 634 0495 or events@mdnz.org.nz

Retina New Zealand

Retina NZ Inc is a volunteer-run patient support group of people with retinal disorders that lead to sight loss or blindness. Membership is open to anyone with a retinal condition, regardless of your degree of visual impairment, as well as family and friends or others with a professional interest.

Retina NZ offers peer support and promotes education about causes, treatments and prevention of retinal degenerative conditions.

Many of our callers to the MDNZ save sight helpline are looking to join a peer support group or at least talk to others who understand what they are going through. We invite those callers to contact Retina New Zealand to see if such a group exists in their area.

Phone: 0800 569 849
Website: www.retina.org.nz
Email: retina@reina.org.nz

Claire Turnbull's Christmas Chocolate Truffles

Claire Turnbull's Christmas Chocolate Truffles. "These delicious truffles are packed with nutritious ingredients so you can enjoy a little indulgence, and feel really good about it."

Ingredients

- 1 ripe avocado
- 12 Medjool dates
- 1 cup of raw almonds
- 1 cup of desiccated coconut
- Zest of 2 lemons
- 1 cup coconut thread (toasted)
- 1 cup pitted prunes

How to make:

1. Pulse the almonds in a food processor until they are the consistency of breadcrumbs.
2. Add the dates, avocado, prunes and lemon rind to the blender along with the almonds and blend together.
3. Take tablespoons of the mixture and roll into small balls.
4. Coat each ball with toasted coconut threads or ground almonds.

This recipe makes 50 small balls so half the

recipe if you would like less, or the bliss balls will keep for a week in the fridge.

Note: You can use 20 small dates instead of Medjool dates to save money! Just soak them for 5 minutes in $\frac{1}{4}$ cup of water to soften them and drain before adding to the blender. Save the soaking liquid as you may need to add a tablespoon or two to the mixture to get it to the right consistency.

Thank you Claire. For more of Claire's delicious recipes go to her website: www.claireturnbull.co.nz



Profile of an MDNZ Ambassador – Sir Peter Leitch

Sir Peter Leitch also known around the country as the Mad Butcher is a brand ambassador for Macular Degeneration NZ (MDNZ).



this year on an 'eye opening experience' of discovering the importance of eye care.

The pair visited ophthalmologist Dr Dianne Sharp to undergo a series of eye tests for macular degeneration, glaucoma and cataracts – three most common eye disorders that affect New Zealanders.

Sir Peter Leitch has put his name and face to the cause of Macular Degeneration NZ as an ambassador to help those New Zealanders who have MD and their carers, and to raise awareness of this hideous eye disease.

Thank you Sir Peter – you are an MDNZ Champion.

Although well known in New Zealand for his chain of butcheries, he is also well known for his charity, fund-raising work and his promotion of rugby league.

Sir Peter Leitch accompanied Monty Beetham, from The Kiwi Living Programme

STOPPRESS - MDNZ features on TV1 News on December 17

On the 17th of December, TV1 News featured Macular Degeneration referring to alarming statistics from the Deloitte report together with an interview with Dr Dianne Sharp. Two patients also shared their stories. To watch this segment, go to: <http://bit.ly/2i7wY37>



Bequests

Have you thought about leaving a bequest to support the future work of MDNZ and its aim to reduce the incidence and impact of MD in New Zealand? Contact us to find out more on info@mdnz.org.nz or 0800 MACULAR (622 852)

Your donation can save sight!

2016 has been a wonderful year, we have had an increase of donations and support within the macular degeneration community. We would like to thank those that have supported us throughout the year and welcome new people to our MDNZ community.

2017 is on its way and we have many exciting things ahead of including the Charity Race Day in February, the education Seminars and to continue in our endeavour with the Deloitte report.

Over 1.5 Million 'At Risk' New Zealanders



Please consider making a donation. Your donation will help us to help others save their sight. We are very grateful for the support. You can do this by completing the form opposite and sending it to us or alternatively going to our website www.mdnz.org.nz to donate now.



Please donate to support those with MD

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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.

To all of our supporters and friends



Thank you for your support during 2016. Wishing you and your families a happy Christmas and holiday season from us all at Macular Degeneration New Zealand. We look forward to working with you again in 2017.