

Viewpoint The MDNZ Newsletter

Issue 15 – December*2019

0800 MACULA (0800 622 852)

info@mdnz.org.nz

As the festive season draws near, in this issue we:

- reflect on the year past
- · share inspirational stores
- look at ways we can all improve our eye health
- · catch up with potential new drugs to watch out for
- discuss what is happening with cheques in NZ
- and we look to the year ahead

We wish you all a safe and happy festive season to be celebrated with your loved ones.

If you would like to receive a copy of the MDNZ Annual Report * please contact us on (0800 622 852 or) info@mdnz.org.nz

And it's not too late to order your Christmas cards, so make your order now...



With Christmas approaching, please purchase your personal and corporate Christmas cards with The Giving Tree. For each card purchased, The Giving Tree donates 50 cents to MDNZ to raise awareness and provide education and support to the macular degeneration community across NZ.

View this year's full range of cards at **www.thegivingtree.co.nz.** Let this Christmas truly be a time of giving.

Phone 09 378 9369



The Giving Tree: locally made and designed Christmas cards supporting MDNZ.

Letter to the editor, September 2019

I was very interested in your article on Charles Bonnet Syndrome, and if it related in any way to the Hugh Mearne poem, Antigonish. Antingonish is a small town in Nova Scotia, which, I believe, in Mearns poem had a history of ghostly events. Perhaps these are the reasons for the poem.

I was on holiday in Australia in August 2011, when I noticed a problem with my right eye. Friends told me that it was probably a cataract and that it would need to get worse before it could be removed.

On returning to New Zealand, I contacted my GP who said "You need to see an eye specialist immediately". Within two days I had received an injection of Avastin in my right eye. I now knew that I had macular degeneration. The injection didn't cure the problem but it and the succeeding injections stopped it becoming any worse.

Some months later, I was shampooing my hair in the shower, with my eyes tightly closed, when a little man, neatly dressed, very

a intue man, neurry arcsec, neurry realistic, and trying to smile, appeared before me. His smile showed only broken and missing teeth. I had to finish washing and rinsing my hair before I could open my eyes, when he disappeared.

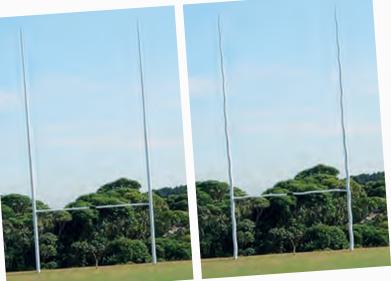
Future shampooing of my hair brought forth similar men, occasionally a woman, all very neat and realistic, but with an eye or an ear missing. A month or two later, I read in a Grey Power magazine of the Charles Bonnet Syndrome. These visions have now stopped.

Is this because my brain now knows of the syndrome and has corrected it? When my left eye also began to show slight signs of macular degeneration, it too had several

injections of Avastin, which has kept it under control. I find that when watching a game of rugby on TV, if a player is converting a try or kicking a penalty. I look at the goal posts or crossbar as they should not show any kinks or irregularities. If they do, see your eye specialist immediately. Many thanks to my team of professionals.

– Ted Falvey, Timaru

Thank you for sharing your story Ted, and for sharing a great tip for Kiwis who enjoy watching rugby.



Charles Bonnet Syndrome is a phenomenon of visually impaired people seeing things they know are not real.

Visual hallucinations or phantom images can be extremely vivid and realistic and can range from simple repetitive patterns to detailed images of people, animals or buildings. About 30% of people who experience major vision loss experience this.

The images are a consequence of losing sight whereby the brain attempts to compensate for the gap in vision.

What's happening to cheques?

Kiwi bank.

Kiwibank is going 'cheque-free'.

For some of us, receiving a cheque book was our first

banking experience and writing a cheque to pay accounts has been part of our lives for many years. Well, the time is coming when we will have to adjust to other forms of banking, making and receiving payments. Kiwibank is taking the lead and they have announced they will be cheque-free from 28 February 2020. They have already stopped issuing cheque books since the end of September. No other bank has announced such a move at this stage, but we can be assured this will become the norm in due course.

Cheque-free from 28 February means:

- Kiwibank won't cash cheques or accept cheques for deposit
- You can no longer write cheques to make payments from a Kiwibank account
- Kiwibank will stop issuing bank cheques

Like many charities, MDNZ receives cheques from our generous donors and this is greatly appreciated, so we realise this change in the ability to make payments will inconvenience our many supporters and friends over time.

So, what are the options?

- For now (from 28 February 2020) this will only affect those of you who use Kiwibank cheques
- If you are currently not using a computer or not familiar with online banking you

may be wise to ask family or a friend to help you set up internet banking and teach you how to make payments. You can also seek assistance from Kiwibank

- If you are familiar with internet banking you would seek the account number of the person you wish to pay and set them up on the internet, making payments when you wish
- You can save the details as a saved payee if you will be paying them again in the future
- Another option is to set up an automatic payment with your bank. The bank will make the payment regularly for the amount and frequency you have signed up for and you will not need to use internet banking
- If you are uncertain about the safety of internet banking contact your bank to find out about their internet banking guarantee. Banks want to assure you that your money is safe and they will be able to explain their policies to you.

If you are a donor to MDNZ and a Kiwibank customer contact us if you wish.

Call us on **0800 622 852** or

email us at info@mdnz.org.nz

We will be able to provide you with our account number to enable you to continue to make direct payments to MDNZ. We will provide you with your customer number and check your contact details with you which will enable us to identify your payment and issue you a tax-refundable receipt promptly.

New Anti-VEGF Drug promises to reduce frequency of injections for Wet Macular Degeneration

A new anti-VEGF drug called Beovu has just been given a tick of approval by the FDA¹ in the United States for the treatment of wet macular degeneration (MD). It is rumoured to be available in this part of the world in late 2020.

The major advantage will be that, for many patients, the time interval between injections will increase substantially yet without losing effectiveness. For currently used drugs, such as Avastin and Eylea, injections are needed every 4 to 6 weeks (although for a proportion of patients this can extend out to 8 or 10 weeks).

Beovu has been shown to be very effective at 12 weeks between injections, and it is claimed that potentially many patients could be extended out to 16 weeks. Also when compared to Eylea, it seems to be better at drying out the macula which in turn may lead to improved longer-term



preservation of vision.

The promise of less frequent injections and clinic visits is welcome news for both patients and for overburdened public health services. It may be that Beovu

will be funded for those who require very frequent treatments with the currently

available drugs. Pharmac and health insurers will be looking mainly at potential savings in the annual cost of treatment compared to Avastin and Eylea. Although there are considerable cost savings from fewer clinic visits the list price of Beovu in the USA is about NZ\$2,900 per dose.

Other potentially groundbreaking improvements in wet MD therapy are in the pipeline.

At an advanced stage of testing is a refillable Lucentis "port" implant providing months of drug delivery from a simple refill procedure.

Also being trialled are several new drugs targeting alternative aspects of wet macular degeneration which may give improved control, like in combinations with one of the current drugs.

Lucentis and Eylea copycats are waiting in the wings for patent expirations and with these we can expect major drops in drug costs.



^{1.} The Food and Drug Administration is a federal agency of the United States Department of Health and Human Services.

Boyd's story

Some 10 years ago my optician did a thorough test and found I had the beginnings of glaucoma. I was referred to a specialist and have regular checks. It was during one of these appointments in 2013 that he noticed the signs of macular degeneration.

I was pleased it was discovered at an early stage. He also did cataract operations on both my eyes. I feel it's just one of those things when you get to a certain age but I have not let it have any impact on my life – although I do need a strong light to read and sit closer to the TV now.

There are many things that could be stressful as you age such as Alzheimer's, which is a worry. However, it is necessary to try and be positive in mind and body. I swim regularly and go tramping, although I admit I have given up skiing now.

The injections are stressful for me, I must admit, but better than the alternative! I now see the specialist every three months, but if I see a wobble in reading lines, and a slow deterioration in my sight, then I see the specialist immediately. I'm comfortable having regular checkups, and reading tests put me well above the driving license line. I'm in my early 90's. When I asked my specialist if I'd still be driving at 100



the answer was positive, but he could not guarantee 110!

It is so important that it is diagnosed early. The sooner you consult an expert and start treatment the better. I know several people including my sister who are now blind or nearly blind because they left it too late.



explorē 8 THE BIG PICTURE IN A SMALL PACKAGE



The explorē 8 handheld electronic magnifier incorporates a high definition 8 inch screen with twin cameras for unsurpassed closeup and distance viewing clarity. Perfect when you're at a restaurant, the library, shopping, at school, travelling or at work. Large physical buttons and smart touchscreen technology make the explorē 8 intuitive and easy to use.

For further information, please contact 027 700 1674 humanware.com



2019 in focus

Seminars, conferences and senior expos have happened all over NZ in 2019, with fantastic participation, excellent feedback and we have showcased our collaborative approach working with funders, sponsors and partners.

Working with Blind + Low Vision NZ (formerly the Blind Foundation) at public seminars where they show people how they can help



L-R: Equipment display in Rotorua; Lots of interest in Orewa; Great service in Hamilton

We don't mind getting a little political if it helps raise awareness and save sight



Supporters assist us along the way



The crowds turn up to hear about macular degeneration



L-R: 192 in Orewa; Not a seat to spare in Rotorua; 170 in Ashburton

Awareness Week and media



L-R: Seven Sharp feature; Greenlane Eye Clinic display; Jim and his rug making helped us get media attention in Ashburton

In partnership



L-R: Sharing with Blackmores; Bayer hosted symposium; Sharing with Glaucoma NZ

... and ahead in 2020

Awareness, education, information and support remain our main focus for 2020 and with it being election year we will again express ourselves to potential MPs about how they can help save sight and save money in NZ.

Our community educator, Gaye, has already lined up 10 presentations through February and March. If you would like her to speak to your group please contact us to enquire.

We have commitment from funders and help from Ophthalmologists and Optometrists to deliver a number of larger public seminars around NZ. We continue to apply for funds to undertake more of these. If you would like a public seminar in your area please consider raising funds in your community and speak to us about how we can help.

We hope to get to:	
Oamaru	Henderson
South Auckland	Lower Hutt
Kerikeri	Tauranga
Whanganui	Thames
Christchurch	Westport
Taupo	and more

Contact us to find out more

() 0800 622 852

info@mdnz.org.nz

Mediterranean Diet: Healthy Eating for Healthier Eyes

Source: American Academy of Ophthalmology – www.aao.org/eye-health

These heart-healthy foods may lower your risk for advanced agerelated macular degeneration.

Eating the nutritious vegetables, fruits and fish of a Mediterranean-inspired diet can reduce your risk of developing age-related macular degeneration (AMD) or having it become more advanced.

A European study and a Portuguese study both show that a diet rich in plant-based foods and fish, with less dairy and red meat, may reduce your risk of developing age-related macular degeneration (AMD), or prevent it from becoming worse.

The Mediterranean diet generally includes:

- vegetables (especially leafy, green ones like spinach);
- fruits;
- nuts (like almonds, cashews, pistachios, brazil and walnuts);
- whole grains (such as complete grains of wheat, rice, oats, barley, rye, quinoa);
- fish (such as fresh or water-packed salmon, tuna, trout); and
- olive or canola oil instead of butter.
 Researchers found lower rates of macular degeneration among people who ate more vegetables, legumes (beans), fish, cereals, and especially fruits. In fact, one

study showed that people who ate at least 150 grams (just over 5 ounces) of fruits per day lowered their risk of developing AMD by 15 percent.

Conversely, people who had AMD, more frequently ate fast food, ready-made meals, dairy products and meat than those who did not have macular degeneration.

Other past research has shown that certain vitamin and mineral supplements play a role for some people in lowering their AMD risk. The studies examining specific diets help show that foods may also be protective in preventing vision loss from macular degeneration and highlight the possible vision-saving benefits of healthy daily eating habits.



If you would like to receive a copy of the Nutrition and Supplements brochure, or to discuss the Age Related Eye Disease Study #2 (AREDS2) contact MDNZ

🕓 0800 622 852 🛛 🖂 Email info@mdnz.org.nz 🕟 www.mdnz.org.nz

Great ways with greens and nuts – enjoy these summer recipes



Roasted greens with lemony dressing and hazelnuts

500 g	Brussel sprouts
1 head	Broccolli, cut into florets
3	Courgettes cut into thick strips on
	a slight diagonal
¼ cup	Hazelnuts, roughly chopped
¼ cup	Olive oil, for the dressing, plus 2
	Tbsp for roasting
1 tsp	Chilli Flakes
1	Lemon, zest and juice
1 bunch	Fresh mint, roughly chopped
1 bunch	Fresh parsley, roughly chopped
2 cloves	Garlic, peeled and finely chopped
1 tsp	Dijon mustard

Preheat oven to 190c. Place all vegetables in a roasting tray and drizzle over olive oil. Add salt and pepper, chilli flakes, hazelnuts and half of the lemon zest

Place the tray in top half of the oven and roast for 20 minutes

For the dressing, in a small bowl whisk together the ¼ cup olive oil, the juice and remaining zest of the lemon, salt and pepper, garlic and mustard. Stir through the herbs and whisk again.

Serve the vegetables hot out of the oven, or warm, with the dressing drizzled over.

www.bite.co.nz



Spinach Mandarin Salad

¼ cup	Pine nuts
2 tbsp	Orange juice
1 ½ tbsp	Balsamic vinegar
2 tbsp	Olive oil
1/8 tsp	Salt
1/8 tsp	Pepper
2 tsp	Honey
½ tsp	Brown mustard
4 cups	Fresh baby spinach leaves
1⁄4	red onion, sliced thin
1 can	Mandarin oranges, drained
	(or use 4 fresh)

Place the pine nuts in a small skillet that has been sprayed with nonstick spray. On medium-high heat, toast the nuts, stirring frequently, until they are lightly browned. Remove pan from heat and cool.

In a large bowl, whisk together the orange juice, vinegar, oil, salt, pepper, honey, and mustard. Add the spinach and toss until evenly coated. Add the onion, oranges, and pine nuts then toss to distribute evenly.

MDNZ Professional Friend Programme



We welcome a new Professional Friend in the last three months:

Ophthalmologist Dr Andrew Watts Eye Centre Primecare, Whangarei

MDNZ is extremely grateful for the commitment by Optometrists and Ophthalmologists around New Zealand who support our Professional Friend programme. We are working together to save sight.

If you would like to find a Professional Friend near you go to:

▶ http://mdnz.org.nz/resources

- Find an Optometrist
- Find an Ophthalmologist

Thank you for two great initiatives:

Thinking outside the square

A MDNZ supporter was grateful that the Amsler Grid saved his sight. He wanted others to have tools to save their sight too, so he came up with an innovative idea. While demolishing an old house, he made the pieces available to the public. He set up a postbox (pictured) for donations in exchange for the old materials. Thanks to his creative thinking more people will have an Amsler Grid...sight will be saved.

Thank you!



A generous resident's group

Following awareness and education presentations at Summerset Retirement Village at Monterey Park, Hobsonville the residents group decided they wanted to give back to the two charities involved in age related eye diseases. They held a casino evening to raise funds for the work of Glaucoma NZ and Macular Degeneration NZ.



Apparently they had a lot of fun on the night and successfully raised \$6,000 donating \$3,000 each to GNZ and MDNZ.

Congratulations to Evelyn and friends. You are making a great contribution to society with this initiative. **Thank you**



Your support will provide:

\$50	Information packs posted out to 10 people
\$150	Information packs for 36 seminar attendees
\$500	One week of the 0800 Save Sight Helpline
\$2,000	An Awareness and Education Seminar in your community
\$10,000	Help fund a Community Educator

Saving the sight of another is such a wonderful gift.

"No one has ever become poor by giving." Anne Frank

Bequests

Have you thought about leaving a gift 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 call **0800 MACULA (0800 622 852)**

> "Great things are done by a series of small things brought together "Vincent Van Gogh



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 t	o give a gift (choose one)		
Single	Monthly Annually		
Amount 🗌 \$2	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 / boguest for MDNZ in my will			
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			
For assistance phone			
	ce pnone ACULA (0800 622 852)		

Donations over \$5 are tax deductible. Issue #15



Display at Greenlane Eye Clinic, Awareness week



MDNZ team at Orewa



Stand at GP conference





Working with Blind + Low Vision NZ, Hamilton

For further information contact MDNZ

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

