



MACULAR
DEGENERATION
NEW ZEALAND

Viewpoint

The MDNZ Newsletter

Issue 16 – July 2020

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

From Lockdown to looking up

Wow, what a lot has happened since we last wrote to you. In early 2020, MDNZ was gearing up for a busy year in the community. Then in March it all changed as our country we went into lockdown to stop the spread of the Coronavirus.

There was much uncertainty and anxiety about how we could keep ourselves safe and what the future would hold. MDNZ was prepared and our staff continued to work from home providing support and information to anyone that needed it.

MDNZ's immediate concern was that if people did not maintain their eye treatments or seek help if their eyesight changed that NZ would be facing an epidemic of blindness later down the track.

MDNZ recognised the need to continue the 0800 Save Sight Helpline during lockdown. We received many calls from people unsure of whether to proceed with their

medical appointments, as well as people who had noticed recent changes to their eyesight and weren't sure what to do.

To help people know what to do during lockdown, MDNZ issued an advisory to thousands of people via email, on our website and social media. The advisory highlighted the importance of continuing treatment and what to expect when attending your medical appointment.

We heard back from a number of people who would have gone blind had they not received our emails or phoned our 0800 Helpline for advice and support.

In this issue, you can read about living with macular degeneration, MDNZ's new website, an ophthalmologist's perspective on the burden of treatment, new eye health initiatives and MDNZ's seminar schedule.

Life goes on and we are thankful to be living in NZ where we are restricting community transmission which hopefully will continue to keep us safe and well.




Thank you to T M Hosking Charitable Trust (managed by Perpetual Guardian) for contributing funds towards the MDNZ 0800 free helpline, which was well utilised during lockdown.



Sneeze
here.


A poem for a smile



*I am normally a social girl
I love to meet my mates
But lately with the virus here
We can't go out the gates.*

*You see, we are the 'oldies' now
We need to stay inside
If they haven't seen us for a while
They'll think we've upped and died.*

*They'll never know the things we did
Before we got this old
There wasn't any Facebook
So not everything was told.*



*We may seem sweet old ladies
Who would never be uncouth
But we grew up in the 60s -
If you only knew the truth!*

*There was sex and drugs & rock 'n roll
The pill and miniskirts
We smoked, we drank, we partied
And were quite outrageous flirts.*

*Then we settled down, got married
And turned into someone's mum,
Somebody's wife, then nana,
Who on earth did we become?*

*We didn't mind the change of pace
Because our lives were full
But to bury us before we're dead
Is like a red rag to a bull!*

*So here you find me stuck inside
For four weeks, maybe more
I finally found myself again
Then I had to close the door!*

*It didn't really bother me
I'd while away the hour
I'd bake for all the family
But I've got no bloody flour!*

*Now Netflix is just wonderful
I like a gutsy thriller
I'm swooning over Idris
Or some random sexy killer.*

*At least I've got a stash of booze
For when I'm being idle
There's wine and whiskey, even gin
If I'm feeling suicidal!*

*So let's all drink to lockdown
To recovery and health
And hope this bloody virus
Doesn't decimate our wealth.*

*We'll all get through the crisis
And be back to join our mates
Just hoping I'm not far too wide
To fit through the flaming gates!*



Unite
against
COVID-19

John's story

My name is John Patrick, I am in my 87th year and live in Warkworth.

In 1965 I was involved in a nasty accident which resulted in the loss of sight in my right eye. It was a fairly scary time as I was about to embark on two years of university-type study and I wondered what happened when you could only see out of one eye!

I learned a lot about sight/vision in the next few months including the fact that indeed, the eye is simply a camera and that the brain does all the interpreting of the images! Eventually I stopped pouring the tea down the side of the cup and managed to retrain my mind to make better calculations about distance. I was assured by my ophthalmologist that I was perfectly safe to drive.

Whew!

For the next many years I simply got on with my life without any vision issues except for the addition of reading glasses in my forties.

About ten years ago I became aware that my sight was not as it had been; I contacted the Blind Foundation, started using talking books and wondered whether I should be driving. I consulted an ophthalmologist and was told I needed an injection in my eye immediately as I had the wet form of macular degeneration.



Photo courtesy of Mahurangi Matters

I had the first three or four injections privately before getting into the public system. I would not have been able to continue the private treatment. Initially I had injections monthly but for the last several years I have received treatment every eight weeks. My vision improved with a few of the first injections and is now very stable and I had my license renewed at my 86th birthday. I have glasses for distance vision, for reading and for using the computer. I have now had 62 Avastin injections and have been fortunate to have been cared for by the same ophthalmologist for the whole time. The injections are painless, easy to cope with, and have about 48 hours of slight after effects which are not that much trouble!

We have a magnificent public health system with empathetic, professional and competent people working in it. If miracle is an appropriate word, then Avastin is a miracle!

Please check your vision and be unafraid.

Feedback received during lockdown

MDNZ was heartened to receive this email from Brian.



"Hi

You may recall we had an email exchange last week. I just wanted to pass on some feedback.

Firstly, a great big thank-you for your quick response and for 'someone' taking their time to call me, it was most helpful. The advice was spot on and prompted me to ring an ophthalmologist. He was superb, after mentioning my symptoms he asked me to come into his rooms the next day. I had a scan and received the devastating news that I had wet MD in both eyes and needed immediate treatment. He then administered the anti-VEGF drug into both eyes and said I had done exactly the right thing in contacting him; again a big

thanks for prompting me. He said he would write to the DHB to get me into the eye clinic. I think the focus in my right eye has improved a little so I am hopeful the treatment will be effective. I have viewed the video on your website a few times and find it very reassuring. Fortunately, I also have family support."

We are so pleased Brian acted quickly to enable him to get the best result. We provide support and advice over the phone and via email to many people. We love it when we hear back from you that we have made a positive difference.

Roasted greens with lemony dressing and hazelnuts

- 500 g Brussel sprouts
- 1 head Broccoli, 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 190°C. 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.

Thank you to bite.co.nz for this healthy recipe.

Burden of Treatment

by Dr Ainsley Morris, MDNZ Trustee and Ophthalmologist in Christchurch

'I don't want to be a bother' – it's a common theme amongst my patients with MD undergoing anti-VEGF treatment and one which I often discuss with them, as I know that better compliance with treatment will give better long term vision.

One of my patients is an accountant and he simply says he cannot afford NOT



to be treated. So let's consider AMD treatment as a return on investment – a Profit and Loss equation.

Treatment burden or Loss, is borne not only by the individual patient, but also by their whanau / caregivers, and society as a whole. Financial implications range from those on the patient (transport costs in attending appointments, insurance, lost productivity if employed) to their caregivers (taking leave to support and assist) and to society (productivity reductions, costs of medications and medical workforce). The emotional burden is significant. Moderate AMD causes a 32% decrease in the patient's quality of life – similar to severe angina or a fractured hip and very severe AMD results in a 60% decrease in quality of

life, akin to end stage cancer or a severe stroke⁽¹⁾. Depression amongst patients with AMD is significant, with rates as high as 40% quoted⁽²⁾. Family and whanau are negatively impacted also. Societal costs such as loss of individual engagement, reliance on social services and reduced community participation are significant.

Let's look at the Profit or benefits of treatment. Retaining or even improving sight, enables continued employment if applicable, giving financial value to the individual, their family and society via tax. Maintaining independence is vital for self-worth, mental health and community engagement. It reduces the need for support services and reliance on others.

A recent study in the US⁽³⁾ modelled the financial costs of treatment versus the economic benefits. It found the improved vision associated with MD treatments, specifically antiVEGFs, provided greater value to the patient and society as a whole.



It is understood that treatment comes with burdens, but perseverance is key and the benefits outweigh the costs. As my patients puts it "its an excellent return on the investment".

1. The burden of ARMD: A value based medical analysis. Brown et al. Trans Am Ophthalmol Soc 2005;103:173-84. 2. Anxiety and Depression in patients with advanced macular depression: current perspectives. Cimvulli V et al Clin Ophthalmol 2016;10:55-63. 3. Economic value for antiVEGF treatment for patients with wet ARMD in the US. Mulligan K et al JAMA Ophthalmol 2019; 138:40-47

David's story

(Macular Degeneration can move swiftly)

by Alison MacArthur Grant, Feb 2020

I was always fascinated with David's eyes; I had looked into them for nearly 60 years.

They were lovely soft, dark brown smiling eyes, and the pupils in both eyes were a different size. He didn't need to wear glasses, as one eye was long sighted and the other short sighted. He could read anything without glasses.

The saga of his eyes began in 2000 when he was diagnosed with Polymyalgia. He had to take big doses of drugs to counteract the polymyalgia; that led to Type 2 diabetes, about four years later. He got into the 'system' on our local doctor's advice and had regular monitoring through the DHB.

All was well until 22 November 2017 when suddenly it was found he had Macular Degeneration in his right eye. David had visited his optometrist regularly, and exactly a week before he was thrilled to know everything was all right. His older sister by 4 years had wet Macular Degeneration, but had left checking too late, and became legally blind as a result. Could it run in the family? His next sister, two years older, has since been diagnosed with dry Macular Degeneration. We don't know about his parents, as these checks were not available to them all those years ago. A younger brother is certainly keeping his eyes checked.

So it all happened within a week. We went straight away to his optometrist who confirmed that a week previously he had been clear. She phoned the Greenlane Eye Clinic and we saw a specialist the next day, when David had his first injection in the right eye. I marveled at the skill of the nurses who carried out the injections, which took only a few seconds following preparation. Thereafter, he had an injection every month, although after the first three, the doctor left it for two months. In that time the right eye did deteriorate, so it was back to monthly injections.

Overall, David had 13 injections until January 2019 when the left eye showed signs of deteriorating, although the right one was doing well. That meant two injections that day, one in each eye. By then, he had been diagnosed with Mesothelioma (asbestosis), a result of his exposure to asbestos while a building apprentice in the late 1950s; David passed on in June 2019.

We were both thankful that there was technology to help in this area. His eyes were so important to him; he spent over 30 years writing numerous studies, books and sermons, plus creating beautiful native wooden clocks, big and small, making furniture and building our homes, and driving thousands of miles in his working life. He had just spent six years researching a history of the area he grew up in – *We Gathered Here, A History of Matakana*, and the book launch was two days after his first injection.

Two weeks ago I drove my neighbour to the Greenlane Eye Clinic for his checkup. Unfortunately they cannot do anything for his right eye with Macular Degeneration as it is too late. It is imperative that people have regular monitoring of their eyesight.

AT LAST – Macular Degeneration seminars resume



Gaye

“I recently attended a talk at Senior Net. Gaye was amazing. Everyone was talking about how good she was. A lovely lady.”

– Gail, who called us for advice during lockdown

Post Coronavirus Lockdown and we are open once again receive your requests for an MDNZ speaker for your community group. We have also had a few calls asking “when are you planning a seminar in my city or town?”

MDNZ is pleased to report that the community presentations are underway with Gaye (above), our Community Educator, back on the road from July.

In August, we will restart MDNZ’s Public Seminars thanks to the support of sponsors, funders and local ophthalmologists (who give their time to deliver the presentation). In the coming weeks we hope to finalise locations, dates, and venues and aim to get to **Tauranga, Manukau, Kerikeri, Lower Hutt, Whanganui, Nelson and Blenheim** during the remainder of 2020.

Keep up to date with these as they are confirmed by checking regularly on our NEW website. www.mdnz.org.nz/seminars

NEW website – www.mdnz.org.nz

MDNZ invites you to visit our new website. During lockdown the creative juices flowed and we have developed a brand new website. There are a heap of resources that will be of interest to you, your families and carers and we are sure you will find the new site much easier to navigate.

Check out past newsletters, watch a video, sign up for seminars, find an optometrist or ophthalmologist, read patient stories, learn about macular degeneration, the treatments, and low vision services, and much more... Enjoy!





Eye Health Aotearoa is a collaboration of seven organisations who have come together to ensure that all New Zealanders can access equitable, quality eye health services and prevent avoidable vision loss.

This plan is affordable and achievable. It will significantly improve New Zealanders' eye health and reduce costs elsewhere in the health system.

The organisations involved are:

- Blind Low Vision NZ (formerly Blind Foundation)
- Glaucoma NZ
- Macular Degeneration NZ
- NZ Association of Optometrists
- Sight Support Trust
- The Royal Australian and NZ College of Ophthalmologists
- School of Optometry and Vision Science, Auckland University

In February Eye Health Aotearoa launched a seven-point plan in Parliament. You can read more at www.eyehealthaotearoa.org.nz and please share it with your local MP or candidates for the next elections too.

Elections coming up 19 September – What to ask your local candidates?

With Elections just around the corner, now is the perfect time to raise awareness of macular degeneration and eye health with your local candidates.

This NZ Herald article is a good piece to share with them and great way to start a conversation. www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=12331975



Here are also a couple questions and points you can raise with them:

- What will you and your party do to ensure the policy of 'one free eye check' is implemented quickly and effectively?
- Blindness from macular degeneration is a growing epidemic in NZ. 1.5 million people are at-risk, 160,000 people are diagnosed and 33,000 have vision loss. One in seven people over 50 years of age are affected. Awareness and early detection are the key to saving vision loss. How will you ensure people in our communities have the information and tools they need to save their sight?

Contact Macular Degeneration NZ if you want more information or resources to present to your local candidates.

 **Phone 0800 MACULA (0800 622 852) or**

 **Email info@mdnz.org.nz**

BUDGET 2020: SuperGold cardholders get free health/eye check-ups

NZ Herald, May 2020

In the budget announced by Hon Grant Robertson in May SuperGold cardholders will get a free annual health and eye check-up as part of health spending that mostly goes to District Health Boards that are tackling huge treatment backlogs caused by the Covid-19 lockdown.

New funding has been earmarked to roll-out a promised free annual health check-up for the country's more than 750,000 SuperGold cardholders, including an eye check (policy that was included in the New Zealand First-Labour Coalition agreement).

That will cost nearly \$13m in 2020/21, rising to an estimated \$61.6m a year from 2021/22. No start date has been determined, and the checks may not be available until next year.

This is great news for seniors.

Awareness and early detection lead to the correct advice being given and relevant treatment being implemented. These are the vital steps for saving sight.

Time lost is vision lost

The key to the policy's success is to have a sufficiently comprehensive eye check to pick up conditions such as macular degeneration. Macular Degeneration NZ is working closely with other eye organisations through the "Eye Health Aotearoa" (see

facing page). As a group we are calling on Ministry of Health officials to work together with all eye health organisations to determine what will be included in the 'eye health check'. We want to ensure the policy to be implemented in a way that will save sight for people over the age of 65.

NZ's Most Beautiful Views Competition

Ahead of Macular Degeneration Awareness Week 2-9 November 2020, we want you to share your most treasured views of beautiful New Zealand.

Upload your favourite view at www.mdnz.org.nz/competition to be in to **win an optometrist appointment, new glasses and lenses.**

Competition closes at 5pm on Sunday 9 August 2020 and you can enter as many times as you like.

Your view could be the face of MDNZ's national awareness campaign.

ENTER
AND BE IN TO
WIN!



Eight top tips to care for your eyes...



1. Healthy diet: green leafy veges, fresh fruit & oily fish



5. Stop Smoking



2. Take Supplements (AREDS 2 formula) as advised by your doctor



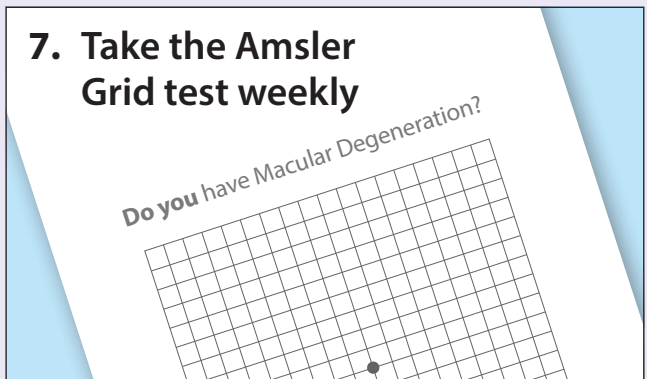
6. Wear Sunglasses



3. Healthy lifestyle: exercise regularly



7. Take the Amsler Grid test weekly



4. Keep having your injections for wet macular degeneration



8. Have an eye check with an optometrist every 2 years





Thank you to all our generous donors who have responded so positively to our requests for support through our recent campaigns.

New Zealanders can thank you for ensuring MDNZ can continue its valuable work during the lockdown and following COVID 19. Without you we would be in a vastly different position right now.

We can and will continue raising awareness, educating, and supporting those with macular degeneration.

With your continued support you will be assisting others as follows:

\$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.

Bequests

Have you thought about leaving a gift to support the future work of MDNZ? Contact us to find out more on info@mdnz.org.nz or call **0800 MACULA (0800 622 852)**



Please donate to support those with MD

Title Mr / Mrs / Ms / Miss / Other

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Phone (home)

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I would like to give a gift (choose one)

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

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Credit card VISA / MasterCard (circle one)

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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**

For assistance phone

0800 MACULA (0800 622 852)

Donations over \$5 are tax deductible.

Issue #16

People tell us they love to receive their Viewpoint newsletter

“I keep all the newsletters. I have a great big pile of them. You never know when you want to refer back to something that featured” – Judy

“Please let the person responsible for the newsletters know how much I enjoy receiving it. It is so good and I always pass it around to others. We were all particularly interested in reading about Charles Bonnet Syndrome and wondered how many dementia patients had been mistakenly diagnosed having this condition” – Verity

Lorraine wanted to tell us how much she enjoys our newsletters – she is President of a Retired Nurses group and circulates our newsletter to all members.

Back copies of Viewpoint can be found on our website at www.mdnz.org.nz/viewpoint

An informative ‘must see’ video to learn more about macular degeneration

To view the video go to our new website www.mdnz.org.nz and scroll down the home page until you get to “Watch Viv’s story” – it is an 18 minute informative video.

For further information contact MDNZ

 www.mdnz.org.nz

 0800 MACULA (622 852)

 info@mdnz.org.nz

