



MACULAR
DEGENERATION
NEW ZEALAND

Viewpoint

The MDNZ Newsletter

Issue 17 – October 2020

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

www.mdnz.org.nz

What's next?

As we take this edition of *Viewpoint* to print the 2020 election day is fast approaching.

Who will be in government and who will be out? Will they be able to govern alone or rely of minor party support? All sorts of questions are on our minds right now. We know many people will be satisfied with the outcome and many won't. That's democracy at work.

For our people we care deeply about action on eye health, and in particular accessibility to quality eye health checks and affordable eye care. At MDNZ we continue to raise this subject with officials at the Ministry of Health and, together with our colleagues around the table in the Eye Health Aotearoa (EHA) Trust, we will continue to raise these issues with whoever is in government. On page 8 you can catch up with what's happening in EHA. Not only is there a new term of government fast approaching, MDNZ has its own announcement of changes ahead. See page 10 for more details.

Before that there is much to be done. In this issue we will tell you about the Ocutech

glasses that you may have seen on Seven Sharp in August, we reveal the author of the poem and bring you more from 'poet Jan', our seminar update identifies the initial 2021 seminars being planned, and we tell you about Macular Degeneration Awareness Week planning for November.

More banks announce the removal of cheques

Both the BNZ and ANZ banks have joined Kiwibank in phasing out the issue and acceptance of cheques.

BNZ has stopped issuing cheque books and will stop accepting cheques by July 2021. Go to www.bnz.co.nz/personal-banking/everyday-banking/cheques

The ANZ will stop issuing cheque books after 30 November 2020 and stop accepting cheques after 31 May 2021. Go to www.anz.co.nz/comms/cheque-removal

If you use cheques to receive or make payments, you may need to find an alternative option.

Ocutech glasses

The MDNZ Save Sight Helpline rang hot in August after an article on TV3's Seven Sharp featured Ocutech glasses that can aid vision.

The news item showed a young mum whose life was changed after receiving Ocutech glasses. Wearing the glasses, she regained her central vision and could now see her young family playing in the garden, as she had never seen before.

Everyone wanted these, immediately!

MDNZ spoke with Peter Neuhauser of Bell Neuhauser Matthews Optometrists in Hamilton, who featured in the news item on Seven Sharp. Peter was forthcoming with the facts and at the top of that list was that these are not for everyone.

Peter advised MDNZ that Ocutech Bioptic visual aids are a very good optic system, but not everyone can be helped. He understands that people may be keen to try anything that might improve their vision but there is no miracle here. He felt it was important to caution people against getting their hopes too high.

He suggested this aid works better on younger eyes such as patients with Stargardt's disease and are less likely to work for anyone with advanced age-related macular degeneration.

www.ocutech.com

These glasses are expensive, costing around \$4,500, so a full assessment is vital to ascertain an individual's suitability



before making the commitment.

Funding for individuals who meet the criteria is available through **www.enable.co.nz**. The main aim of this funding is to get people with low vision into employment and to enable those already working to continue working if they encounter vision loss.

Revealed – ID of our Poet

We were delighted to receive an email from the poet who created “Let’s all Drink to Lockdown” – the poem we featured in Viewpoint Issue #16 calling it “A Poem for a Smile”.

Thank you Jan. See more delightful poems on Jan’s website.

jbpoerty.com



What Did You Do During Lockdown?

*What did you do during lockdown?
Did you do all you meant to get done?
Did you clean out your cupboards or sort
out your clothes
Or go out round the block for a run?*

*You didn't? I'm so disappointed
You had oodles of time to just do it
But, like me, I am guessing you just put it off
Because one day you knew you'd get to it!*

*So, like most of your friends and your family
You just kicked back and lay on the couch
And binge-watched those great Netflix series
And slowly morphed into a slouch.*

*The beer, wine and spirits were flowing
You tried to explain it away
When they said that you shouldn't be boozing
You said "They're my 8 glasses a day!"*

*It seems we were constantly hungry
And sadly it has to be said
That the most exercise I would get would just be
From the fridge to the couch to the bed!*

*Then suddenly it was upon us
Looked as if isolation would end
And we realised that none of our clothing would fit
Our habits we'd have to amend.*

*And we hoovered and dusted like crazy
There wasn't a real need before
As we knew that nobody was likely
To just turn up and knock on our door!*

*So now it is back to the real world
After idleness of some duration
And a bit down the track we will fondly look back
To that time of enforced hibernation!*

Bronwyn's message – Be informed

Bronwyn was overseas when she realised that her vision was not as good as it had been. On her return she received a card in the mail from her optometrist notifying her that she was due for her two-yearly check-up. Bronwyn promptly made an appointment.

She advised the optometrist that she was glad to receive the reminder as she was concerned about her eyes. The optometrist looked at her eyes, did the eye tests and a scan and told her that her eyes had barely changed since her check two years earlier.

Bronwyn challenged him on this as she felt her vision had changed. He said it was probably because she was not looking through her progressive lenses correctly. She thought this was odd and queried this to no avail. When she told her friends and family, they thought it was odd too.'

Less than two months later, Bronwyn woke up in the night, looked at the alarm clock and couldn't see it. She thought "that's weird", then thought nothing of it. The next morning when driving into work from Otaki to Wellington, Bronwyn remembered the alarm clock incident and checked her eyes. She closed one eye and she could see fine, she closed the other eye and couldn't see anything.

Bronwyn thought that maybe the tiny



cataracts had grown bigger, and busy at work, she did not pay it any more attention. About six days later, she decided to consult a different optometrist who showed Bronwyn that her eye was full of blood. The optometrist rang the eye clinic immediately and got Bronwyn an appointment with an ophthalmologist the next day.

The ophthalmologist did all the checks then asked her if she knew about Macular Degeneration (MD). She said "not really, just vaguely that it is a disease that can make you go blind." The ophthalmologist told her that she had MD. She said, "I can't have it, I have had a recent eye health test and they told me the retina was ok".

The ophthalmologist told her she had wet MD in one eye and dry MD in the other. She gave Bronwyn an injection immediately and then five days later she had another bleed and went back for another injection.

Because of the scar tissue from the bleeds, Bronwyn has permanent vision loss and is legally blind in one eye. She has dry MD in the other.

Bronwyn was very angry at first, as she feels if she had been told about MD, she would have been proactive. She would have used the Amsler Grid, she would have learnt about the disease and how to get the best outcome earlier to save her sight.

In retrospect, Bronwyn remembered that just before she went overseas, she was delivering a workshop and she looked down and couldn't read her notes. Because she didn't know about MD, she didn't really think anything of it. With hindsight, if she had known, she would have sought professional help and treatment.

Bronwyn has had to fight all along the way of her eye health journey. She had to fight to get her injections in time as they were constantly being delayed. At one stage she fell off the list of patients and had to fight to get herself reinstated.

Bronwyn realised that in order to get the help and treatment to save her sight, she would need to be proactive. "It makes me mad that you have to keep pushing and keep fighting to get the treatment you need".

At one stage when she was told that her treatment was going to be delayed for three months, Bronwyn rang MDNZ in despair. A phone conversation with an ophthalmologist ensued, the doctor immediately activated an appointment and Bronwyn got the treatment in time.

Bronwyn doesn't want others to go through what she did, so she is spreading the word. She spoke at her local Rotary club and everyone went home with an

Amsler Grid, well-informed and knowing what to watch out for.

Bronwyn says "MDNZ's information and support has been a life-saver for me". Bronwyn read all the information provided, took up MDNZ's suggestion of support networks and organisations such as Blind Low Vision New Zealand (BLVNZ) where she has become a member. They have been amazing, coming out to help Bronwyn with her computer, put her in touch with someone who helped with reading aids, and she can now access their audiobooks and the library.

As MD can be hereditary, Bronwyn told her son and daughter about the disease and got their eyes checked. Her son rang to tell her that he has an "immaculate macula". Thanks to Bronwyn, both now have Amsler Grids, are well-informed about the disease and what to do to prevent vision loss.

Bronwyn believes that all optometrists should make the Amsler Grid available for their clients and talk to them about what can be done.

She wishes she had known what to look for sooner and maybe she could have saved some of her sight.

Because of her vision loss, Bronwyn is no longer able to work in the city. However, she has a positive attitude and hopes her story will help others to be proactive about their eye health, to question if they feel something isn't right and to not delay in seeking help.



Macular Degeneration Awareness Week

2-9 November

This year MDNZ's Awareness Week (which is usually held in May) will take place from 2 to 9 November. This Awareness Week MDNZ aims to highlight what New Zealanders risk losing if they don't take their eye health seriously.

MDNZ launched a photographic competition asking people to enter their photo of their most "Beautiful New Zealand View". After months of lockdown, people were itching to get out and about and this theme fitted in nicely with New Zealanders wanting to travel around our beautiful country. The competition was publicised through NZ Herald Travel supplement, through Facebook and Instagram, and we received an amazing 503 entries.

Photos were shortlisted by the judging panel which included actress and TV presenter Shavaughn Ruakere, landscape photographer Rach Stewart and nutritionist Claire Turnbull, before being put to a public vote to find the top ten.

During Awareness Week, look out for the top ten photographs that will appear on billboards in Auckland, Hamilton, Wellington and Christchurch. They will also be promoted in newspapers, online news sites, Facebook and Instagram.

A photograph of Hooker Lake in Canterbury has been awarded New Zealand's most beautiful view. Images of Pouakai Tarns in Taranaki and Riwaka Resurgence in Nelson complete the top three. These top winners have won a free eye test, plus frames and lenses thanks to sponsors Essilor and the winners have been notified about their prize.

Check out and share MDNZ's Facebook (@MacularDegenerationNZ) and Instagram(@mdnz2013) leading up to and during Awareness Week to see a selection of the stunning photos entered into the competition. This could be a great opportunity to share and have a conversation with your friends and family about macular degeneration.

Optometrists and ophthalmologists around NZ will receive copies of the MDNZ Eye Map. If you have an appointment during or after Awareness Week make sure you ask them for a copy. This brochure highlights the eight top tips to care for your eyes and has an Amsler Grid that will enable you to check your vision frequently, one eye at a time. Remember, if you notice any sudden changes, you need to make an appointment with your eye professional promptly.

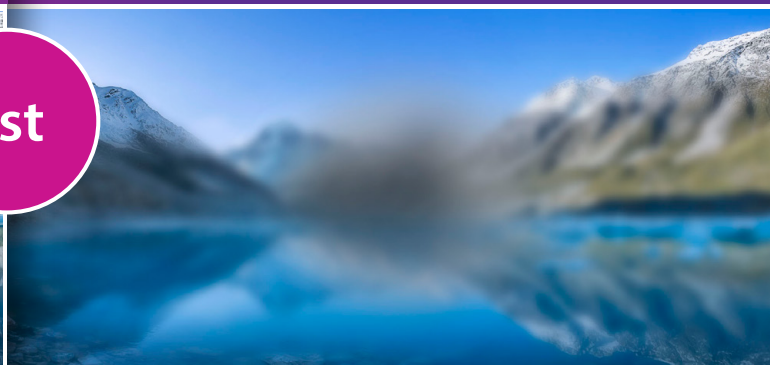
To see more photographs entered into the competition please go to our website www.mdnz.org.nz

**“Beautiful New Zealand View”
Competition TOP 3 photos**

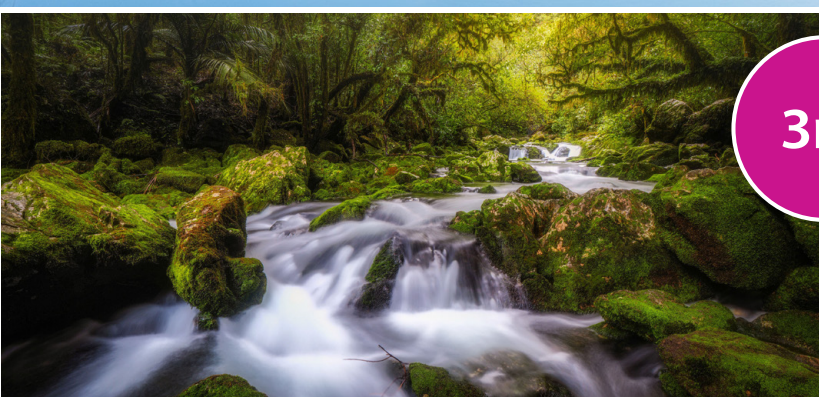
**Views with macular
degeneration**



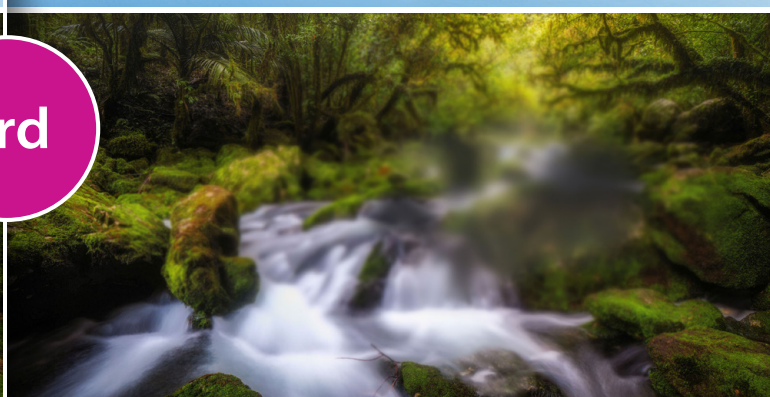
1st



2nd



3rd



The theme of Macular Degeneration Awareness Week 2020 is to protect your view from macular degeneration. See above what may happen if you don't. For more information go to www.mdnz.org.nz

COMPETITION WINNERS – 1st: Darren Patterson – Christchurch: Hooker Lake, Hooker Valley, in the Aoraki / Mount Cook National Park. **2nd: Delwyn Barnett** – New Plymouth: Pouakai Tarns, Egmont National Park, Taranaki region. **3rd: Aniell Esposito** – Nelson: Riwaka resurgence, Kahurangi National Park and Motueka area in the Nelson/Tasman region



Thanks to Essilor and supporting optometrists

Levodopa for AMD?

Arizona University researchers have found the common Parkinson's disease treatment, levodopa, stabilised and improved the vision of patients with neovascular age-related macular degeneration (nAMD).

In two proof-of-concept studies, published in the American Journal of Medicine, researchers tested 20 patients with newly diagnosed nAMD, who'd never had anti-VEGF injections, and 14 with nAMD who'd begun treatment. The results showed levodopa was safe, well tolerated and delayed anti-VEGF injection therapy while improving visual outcomes. Monthly injections of anti-VEGF decreased by 52% in the second group.



"Levodopa has a receptor (GPR143) selectively expressed on pigmented cells. This receptor can be supportive of retinal health and survival, which led to the development of our hypothesis that it may prevent or treat AMD" said lead investigator Dr Robert Snyder. Although this was a small study,

its positive findings support future studies into levodopa for nAMD and suggest it may be effective as an adjunct to anti-VEGF therapy, he said. "Using levodopa as an adjuvant therapy for nAMD could well alter the course of disease progression and save billions of dollars without sacrificing vision."

Source: *NZ Optics*



Once the new government is formed members of the Eye Health Coalition will continue to work with government on behalf of all New Zealanders with the ultimate goal of improving affordable and equitable eye health care in NZ.

The immediate focus will be on four of the seven priorities defined in the action plan presented to Parliament in February 2020.

These include:

1. Free eye check for SuperGold cardholders
2. First National Eye Health Survey
3. Inaugural National Eye Health Policy and Research Conference
4. National Mobile Eye Care Service Framework

Tell your local MP about the advocacy work of Eye Health Aotearoa and invite them to learn more through www.eyehealthaotearoa.org.nz

Macular Degeneration seminars

In June, we were delighted to resume and plan our calendar of public and community seminars as the whole country moved from lockdown to COVID 19 Level one. Then suddenly in August, there was an outbreak of community transmission which certainly challenged our planning as Auckland moved to level three and the rest of the country was at two.

With events in Auckland limited to a maximum of ten, the Manukau/East Tamaki seminar was cancelled. This left us focusing on Tauranga and Lower Hutt where gatherings of up to 100 were permitted with social distancing and contact tracing.

Over 150 people had registered for the Bay of Plenty Seminar and we were faced with a situation where we didn't want to turn people away but could only have 100 attendees. Some quick thinking, a few emails and phone calls to confirm that the venue was available and we had split the event into 2 events, one in the morning and a second event in the afternoon. Thank you to Dr Andrew Thompson who generously gave of his time to present two seminars, and thanks also go to attendees who agreed to move from the morning session to the afternoon session.

Our Community Educator Gaye, who organises the seminars, was in lockdown in Auckland and not permitted to leave

the city. Gaye called in a favour from her friend, Liz, of Papamoa who brought in her husband and another friend. Together with a retired optometrist we had four capable volunteers. Attendees were delighted to have the Mayor join the seminars and to meet MDNZ Ambassador, Viv Jones and her husband Allan who were both founding trustees and visionaries of the future for MDNZ. What a day!

Thankfully, Lower Hutt in early September also ran smoothly with 100 participants, all social distanced and signed in for contact tracing. Our Auckland based team was able to be present for organisation and logistics. Thank you to ophthalmologist Dr Neil Avery for delivering the seminar in Lower Hutt.

Seminars coming up in 2020:

Nelson	Sat 7 November	10am
Blenheim	Sun 8 November	1.30pm
Whanganui	Sat 14 November	10am

Register your interest in any of the following 2021 Seminars:

We hope to deliver seminars in **Manukau/ East Tamaki, Taupo, Cambridge, Christchurch, Palmerston North, Dunedin, New Plymouth** and maybe more.

Register online at

 www.mdnz.org.nz/seminars or phone

 **0800 622 852**

Call or email us on

 info@mdnz.org.nz if you would like a speaker at your group

We look forward to seeing you at one of our seminars soon.

Changes ahead at Macular Degeneration New Zealand

MDNZ Chairman, Henry Ford, has an important message for all MDNZ supporters and people that use our services.

Dear Friend,

I write to inform you of changes ahead in Macular Degeneration New Zealand.

After 8 years as General Manager of MDNZ, Phillippa has decided to retire at the end of November. She is looking forward to a change in lifestyle, freedom from the routine and the driving from Whangaparaoa, as well as spending more time with two little granddaughters.

Phillippa has been an outstanding leader of MDNZ and as General Manager she has driven the development of MDNZ to the professional organisation it has become. Phillippa will be missed greatly but it is time for her to transition to other pursuits and we wish her well. Her shoes will be hard to fill, and to achieve this we have conducted an extensive recruitment process.

We have recruited Anna Crane into the role of General Manager and this will enable a smooth transition. Anna has a diverse background in local government, community and the commercial sectors and shares our enthusiasm for making a difference for people with macular degeneration. "I am keen to use the skills I have gained from working in various roles to achieve MDNZ's goals" Anna says.

On behalf of the Trustees and staff, I would like to wish Phillippa a long, happy and healthy retirement. Phillippa, you leave MDNZ well placed to continue to grow and develop towards achieving MDNZ's vision.



Henry Ford
Chairman, Macular Degeneration NZ



MACULAR DEGENERATION NEW ZEALAND

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

New Zealanders can thank you for ensuring MDNZ can continue its valuable work throughout COVID 19 lockdown and beyond. 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 to give.

Bequests

Have you thought about leaving a gift to support the future work of MDNZ? Contact us to find out more.

- Email info@mdnz.org.nz or phone
- 0800 MACULA (0800 622 852)**



MACULAR DEGENERATION NEW ZEALAND

Please donate to support those with MD

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First name

Last name

Name to appear on tax receipt

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I would like to give a gift (choose one)

- Single
- Monthly
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Amount \$200 \$150 \$100 \$50 or \$

I would like to pay by (choose one)

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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/ bequest for MDNZ in my will

Please complete this form and return to:

**Macular Degeneration New Zealand,
PO Box 137070, Parnell, Auckland 1151**

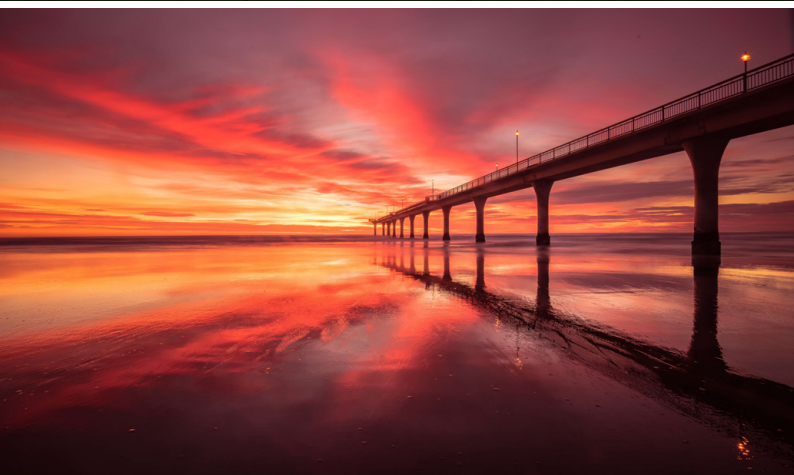
For assistance phone

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*More photos of
"Beautiful NZ Views"
from the Top 10
finalists*



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