



MACULAR
DEGENERATION
NEW ZEALAND

Viewpoint

The MDNZ Newsletter

ISSUE 22 – November 2023

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

www.mdnz.org.nz

Here's to a spring in your step!

With spring here and summer just around the corner, I hope your spirits have lifted as the days become longer and warmer. This seasonal change also signals the move toward the end of the year, a perfect time to reflect on what has been achieved and make plans for the year ahead.

In this issue of Viewpoint, you can read about our advocacy through Eye Health Aotearoa and the work we are doing to reduce avoidable blindness and inequities in eye health care. At time of print, the elections have not yet happened – we wish the incoming elected representatives the wisdom to govern and lead the nation in the face of challenges ahead... and to make sure they include eye health!

We provide you with an update on new and emerging treatments for age-related macular degeneration (AMD) from two medical retinal specialists who have a keen interest in this area. While it is still very early days for dry macular degeneration treatments, there is hope that further developments and research will lead to better and more reliable options for people with dry macular degeneration.

Brian shares his story of how his sight was saved using the Amsler Grid, his gratitude to MDNZ for steering him on the treatment path and his sincere thanks to the eye professionals who have treated him. The Amsler Grid is featured in this issue on page 5. If you don't have one, or you would like a fresh one, please contact us to get a free Grid with a magnet to stick on your fridge.

In this issue we introduce you to the Sight Support Trust (SST). The team at SST have vision impairment and they provide telephone support and practical guidance on how to manage with vision impairment. An article about Charles Bonnet syndrome should provide those experiencing the visual hallucinations with some comfort that they are not losing their marbles.

Get to know Deborah Gibson-Hardie as she introduces herself and shares her healthy smoothie recipe. Deborah is settling in very well to the MDNZ team and is making a amazing difference already.

Medical update

New and Emerging Treatments for dry AMD

One of the most exciting facets of being Medical Retinal specialists is the continued evolution of Age-related Macular Degeneration (AMD) therapies.

We have come a long way from the days of photo dynamic therapy and fledgling anti-VEGF treatments. We now have agents able to restore and maintain vision with wet (neovascular) AMD, such as Avastin, Aflibercept / Eylea and Faricimab. As well as agents potentially capable of stabilizing dry (atrophic) AMD. This article specifically looks at what is new in the field of dry (atrophic) AMD.

Several therapeutic approaches have been investigated for dry AMD and are in different stages of clinical trials, but as yet there is no agent that is shown to be a real “game-changer” in management. One of the main goals is to find treatments that prevent or limit geographic atrophy, the advanced stage of dry AMD. To support

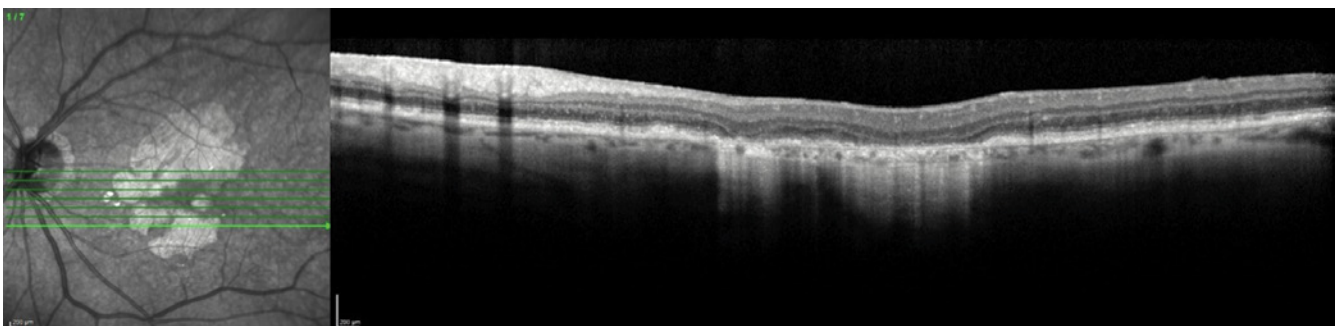
treatment, it is very important for patients with dry AMD to have good baseline data which will show the extent of the disease and monitor progression, including autofluorescence photography and OCT scans.

Some new treatments for dry AMD under development include those targeting the complement pathway and senolytic therapy.

One of the components of our immune system is the complement pathway. It is a complicated set of pathways, where one step cascades onto another, like a domino effect. AMD has been shown to be activated by immune pathways, especially the complement pathway and a lot of research is concentrating in this area.

One treatment that targets a complement pathway is Pegcetacoplan, administered by intravitreal injection (reported in Viewpoint #21). Study results for the complement inhibitor Pegcetacoplan (FILLY trial) show that geographic atrophy growth can be slowed. However, the benefits of treatment

Infra red and OCT images indicating cRORA in a 72 year old male with atrophic Age-related Macular Degeneration. (Images courtesy of Dr Oliver Comyn and the ARCHER trial group Christchurch.)



only became apparent after 18 months of monthly injections. Overall there was a ~30% reduction in progression from early dry AMD to severe dry AMD. There have been some significant adverse effects recently reported, including sudden, permanent vision loss and these are now under urgent review.

Other complement inhibitors are being studied. The GATHER study looking at avacincaptad Pegol, another intravitreal agent, has shown reduction in the growth of geographic atrophy by 30% after monthly injections. Other pathways for dry AMD research include senolytic treatments; treatments that slow the ageing process in the eye by removing ageing (senescent) cells.

While these treatments show promise, and it is exciting to have proof that the process of geographic atrophy can be slowed, the treatments are not currently funded nor readily available yet in New Zealand. What it does indicate however, is that there is significant current and ongoing research, so there is hope for the future.

Dr Jo Sims & Dr Ainsley Morris

GLOSSARY

AMD = Age-related Macular

Degeneration = MD

Neovascular AMD = wet MD

Atrophic AMD = Geographic

atrophy = advanced stage dry MD



Get your Christmas cards while supporting MDNZ

As we approach the holiday season here is a reminder that if you haven't already purchased your Christmas cards, The Giving Tree is the place to go.

They offer great festive cards for sale and proceeds from your purchase will be donated to MDNZ. What a wonderful way to connect with your customers, family and friends across the world this 2023 holiday season.

The Giving Tree has Christmas and Seasons Greetings cards with wonderful kiwiana themed scenes in bright and vibrant colours as well as

traditionally inspired cards.

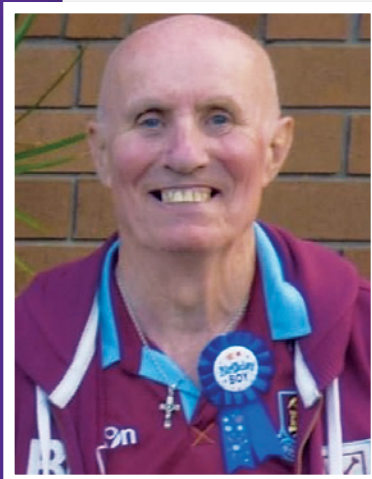
You can select any number of cards with a blank interior to write a personalised message to your family and friends. If you are ordering a large quantity, you may like to order a printed message that will appear on the inside of the card.

To view this year's range and place your order, visit www.thegivingtree.co.nz



Brian's story – Thank you MDNZ

Received by email in May 2023



I received an invite to a macular discussion by one of your team, at a local retirement village in New Plymouth. At the start she asked if anyone there had it and I couldn't believe the number

of hands that went up. After her talk we were handed out the chart which I used every time I thought about it.

Possibly a year later I was looking for something and came across the Amsler Grid chart and just casually checked it and much to my horror, my right eye showed the symptoms. I contacted my optometrist immediately. I saw him that afternoon and after examining me, gave me a number to phone the eye clinic. I did and saw a specialist the next day.

Since then, I went every four weeks for the injection which after a while went out to six weeks. Then one of the specialists decided, being as my eye was responding so well, that we should drop it back to four weeks to really get on top of it.

I checked my eye just before writing this and whereas originally, I had like a big blank thumbprint in the middle of the chart, with the rest of the squares

broken up, now I can see everything fine, with the thumbprint gone and just the tops of the squares wavy. The strength of the eye now seems to be the same as my other eye now.

I know I shuddered when I was told I would have a needle stuck in my eye, and so do people when I tell them, but I have had five different specialists do this and it is painless. The first time my eye was bloodshot for nearly two weeks and for some while it felt as if I had grit in my eye.

However, after that first injection, I bought an eye patch and before I leave the clinic each time, I put them on and they stay on until bedtime.

Doing this, I find that I don't end up with a bloodshot eye and no irritation next day.

I can't praise enough the specialists and staff I see, for their care and concern to put me at ease every time I attend. Or the fact, if I hadn't attended your talk & received the chart, it might have ended up being too late to save my eyesight. As I live alone and in my late 80s, having good eyesight is essential for my independence.

Keep up the good work.

Brian

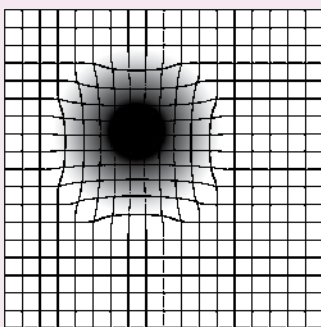
It's not a printing error, it's Macular Degeneration



Macular degeneration can cause different symptoms in different people and can be hardly noticeable in its early stages.

Symptoms include:

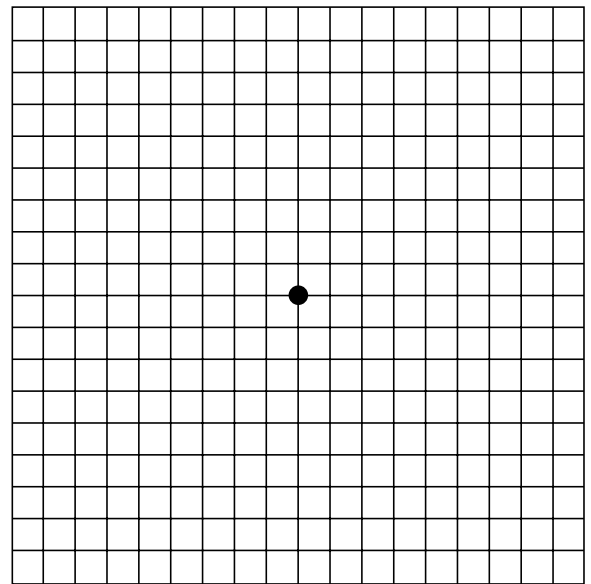
- Central or detailed vision being blocked with dark or empty spaces
- Images becoming blurry
- Straight lines appearing distorted or wavy
- Colours being hard to distinguish



Vision of a person suffering from Macular Degeneration

The Amsler Grid can pick up early signs of vision loss. Try the test with the grid on the right to see if you may be affected. Only an examination by a qualified eye care professional can properly diagnose macular degeneration, so please contact your doctor or optometrist if you notice symptoms of this condition.

The Amsler Grid



TAKE THIS SIMPLE TEST

- Wear the glasses or contact lens you normally use for reading.
- Hold this grid at eye level, about 35cm from your face.
- Cover one eye with your hand and focus on the centre dot with your uncovered eye.
- Repeat with the other eye.
- If you see wavy, broken or distorted lines, or blurred or missing areas of vision, you may be displaying the symptoms of Macular Degeneration. Contact your doctor or optometrist immediately.

Take this simple test regularly so that you become familiar with what is normal vision for you. If you see sudden or definite changes, contact your doctor or optometrist immediately.

To receive a copy of an Amsler Grid card with a magnet on the back to affix to your refrigerator please call us on **0800 MACULA (0800 622 852)**.

Advocating for Eye Health



MDNZ represents the macular degeneration community to government and decision makers as a trustee of Eye Health Aotearoa. Eye Health Aotearoa (EHA) is made up of key eye health organisations and our aim is to improve New Zealanders' eye health by highlighting issues and solutions to government and decision makers.

In June, the Co-chairs of EHA, John Mulka and Chrissie Cowan, made an oral submission to the Parliamentary Petitions Committee to recommend that the government fund the first Aotearoa Eye Health survey.

The Survey is essential to understand how many people in NZ live with a potentially blinding disease. These diseases must be carefully monitored, and treatment started as soon as possible. Early diagnosis and treatment have been shown to limit vision loss from some eye diseases.

While the Petitions Committee agreed a survey was a good idea in principle, it fell short of recommending a comprehensive National Eye Health Survey. You can

John Mulka from Eye Health Aotearoa presents the Petition to MPs Drs Liz Craig (Labour) and Elizabeth Kerikeri (Greens), in the presence of Minister of Health Hon Andrew Little, MPs Dr Anae Neru Leavasa MP (Labour), Toni Severin MP (ACT Party), Simon Court MP (ACT) [September 2022]

view the oral submission at <https://www.eyehealthaotearoa.org.nz/news>

EHA representatives also met with the health spokespeople from the Act, Greens, Labour, National and NZ First parties to highlight the issues of concern regarding eye health and share our solutions that will save sight.

The two primary solutions to addressing inequities and avoidable blindness are; appointing a Clinical Director of Eye Health within the Ministry of Health (Manatū Hauora), and funding a National Eye Health Survey.

As this article is written before the elections, we don't yet know who will govern Aotearoa New Zealand for the next three years. Eye Health Aotearoa has started to raise eye health issues with all the main political parties and will continue to do so once the new government is in place.

You can find out more at <https://www.eyehealthaotearoa.org.nz>

Charles Bonnet Syndrome

Charles Bonnet Syndrome (CBS) is a common condition among people with severe vision loss. It is characterised by temporary visual hallucinations. Up to half of all people with macular degeneration are thought to experience visual hallucinations at some time.

CBS is a condition specifically related to vision loss and it should not be mistaken for dementia or any other condition. It is a phenomenon of visually impaired people seeing things that they know are not real. Images can be extremely vivid and realistic and range from simple, repetitive patterns to detailed images.

Charles Bonnet hallucinations can be simple unformed flashes of light, colours or shapes. However, many people see more elaborate forms such as geometrical grids and lattices. Some people enjoy their hallucinations. However, they are more often an unwanted distraction, and can be frightening.

More research into Charles Bonnet syndrome is needed. For example, we do not know why only some people with sight loss have hallucinations. One thing that is certain is that hallucinations do not mean the person is mentally ill. However bizarre, frightening or funny their content, Charles Bonnet hallucinations are no more than a normal brain's response to reduced visual input.

While they may be an inconvenience, they are not a cause for concern. If you find your hallucinations upsetting, talk to your doctor or ophthalmologist.

The following exercises may stop some types of hallucinations:

- Imagine two points about a metre apart on a wall in front of you. Stand about a 1.5 metres away and look from one point to the other once every second or faster for 15–30 seconds. Do not move your head and keep your eyes open when looking left and right. Have a break of a few seconds.
- If your hallucinations are still there, try repeating the exercise.
- If they have not stopped after four or five attempts, the technique is unlikely to work. You may want to try again on another occasion.

Other ways to stop a hallucination:

- Shut your eyes or look away from the image.
- Switch on the room lights or, if in a brightly lit area, move somewhere darker.
- Simply get up and do something else.
- This can cause the hallucinations to disappear; however, they often continue.

Thank you to the Macular Society, UK for permitting us to reproduce this content.

What can you see...?

This is a question those of us with diminishing sight often get asked. How on earth do you answer a question like that? If it's a good day I might say "not much" but if I have been struggling to find an earring or I have just put toothpaste everywhere but on the toothbrush, it could lead to a sharp retort or worse tears of frustration.

We are all individuals that cope with our sight loss in our own unique way, although there are some common themes for all of us. Giving up driving is usually the biggest adjustment but there are plenty of others as well. Sadness and a sense of grief for all the books we will never hold in our hands to read, and photos we will never see, bring a sense of loss. Learning to use Talking Books becomes necessary if

reading is important to you and not always successful in the beginning, it is a learned skill so give yourself time.

For most of us, apart from driving, we can still do most things we have always done with some adaptation. Is it so bad if the odd seedling gets pulled out when you are weeding the garden, especially if it's a lovely day, the sun is shining, and the birds are singing?

Sight Support is a volunteer group of people that have experience of sight loss and awareness of what is available to solve some of life's frustrations when you can't see as well as you once did. If you would like to contact us phone 0800 555 577.


Thanks to our contact with the staff at MDNZ we hope to bring you an article in each of the Viewpoint Newsletters talking about practical, affordable, well tested aids and tips for coping with diminishing sight.



The team at Sight Support Trust provide practical assistance, knowledge, and support to those with vision loss. Macular Degeneration New Zealand frequently refers callers looking for support and assistance to Sight Support Trust no matter where in the country they are. Thank you to the Sight Support Trust for providing such an important service.

Sight Support Trust

 www.sightsupport.org.nz

 0800 555 577



Meet MDNZ's new Client Services Manager

Deborah Gibson-Hardie joined the MDNZ team in July and is well settled into her role, making a difference and responding to calls and queries from people all over New Zealand.

Deborah worked as a dentist in both private practice and hospital settings for over 20 years. Like many people lockdown allowed her to take a step back and consider it was time for a change.

On seeing the advertisement Deborah thought it's "not a big distance from the teeth to the eyes!" and this was a job that would utilise her medical knowledge, where she could enjoy working with people and continue to develop new skills.

"I have found it interesting to learn about Macular Degeneration and was amazed to discover how prevalent it is. Given the importance of early treatment for the wet type of MD, it feels very meaningful to be involved in raising awareness about this eye condition".

Deborah is looking forward to making connections with professionals in the eye world and learning more about eye health. "I am also enjoying the project management aspect of the role as I organise our Awareness and Education Seminars".

"Outside of work I love spending time with my family! My husband and our four children aged 16-21. I also love reading, walking, and playing the occasional game of golf".



Deborah's healthy eye smoothie recipe

70g (2 cup) kale
130g (1 cup) frozen blueberries
1 banana
1 tbsp chia seeds
1 tbsp linseeds (also known as flaxseeds)
Water

Combine all ingredients in a blender (a nutribullet or equivalent is ideal). Add enough water to cover ingredients. Blend for at least 2 minutes.

Serve and enjoy!

TIPS:

If you like it creamier you can use milk instead of water or half and half.

Halve the recipe if you have a smaller blender. This recipe is enough for 2 people.

Education and Awareness

MDNZ educators continued to raise awareness, inform, and educate people about macular degeneration through community seminars. In the quarter from 1st June to 30th September, nine presentations were made, with 231 people attending.

Comments from attendees confirms these seminars are valuable:

"To me, an unknown health issue. Thank you. Pleased to be aware now."

"More knowledge in the community is definitely needed."

Public Seminars are back with 80 people at the Taupo seminar in early October. The team from Rotorua Eye Clinic showed their full support with three ophthalmologists plus five staff turning up and were joined by local optometrist Ross Gordon. Thank you.

Dr Malcolm Naudé from Rotorua Eye Clinic gave a great presentation, and the audience agreed with the following comments:

"Clear explanation of what MD is and what is available to help. What we can do ourselves for early detection and through diet and supplements. Well done."

"Very informative and interesting. Glad I came."


"Good talk, hoping to see the new treatment for dry macular available in NZ sooner rather than later. Thank you!!"

In November 2023, we will deliver two more public seminars, one in Wellington and one in Waikanae, see back page for details. In 2024 we aim to return to a number of places across NZ including Timaru, Hawkes Bay, Whangarei, Queenstown.



Founding trustees and MDNZ Ambassador, Allan and Viv Jones joined educator, Philippa Pitcher at two community seminars in Mount Maunganui in early October.



 Go to www.mdnz.org.nz/seminars to register for a public seminar or to watch a presentation by Ophthalmologist, Dr Andrew Thompson.



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 continues its valuable work saving sight and providing support for people with macular degeneration. Without you many people would not get the help they need.

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.

Gifts in Wills

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)**



Please donate to support those with MD

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For donations by online banking, please email or call MDNZ.

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

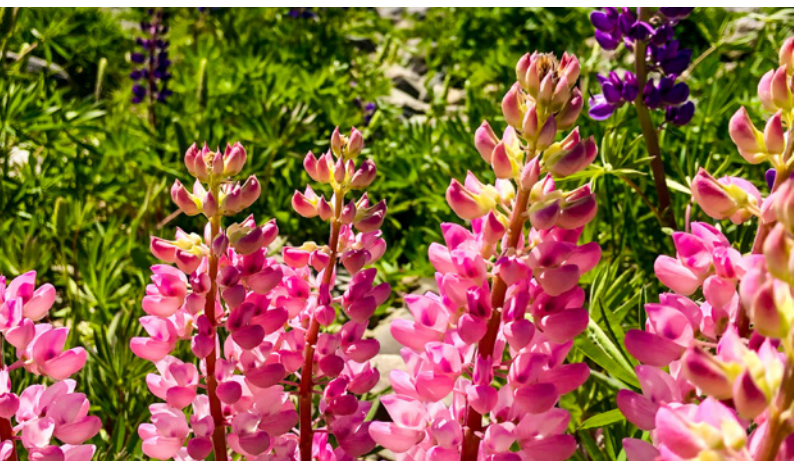
Please complete this form and return to:
Macular Degeneration New Zealand,
PO Box 137070, Parnell, Auckland 1151

For assistance phone
0800 MACULA (0800 622 852)

Donations over \$5 are tax deductible.
 We take great care with your personal information. Please see our Privacy Policy which is published on our website. See: www.mdnz.org.nz/privacy

It's Spring!

Enjoy a few entries from our *Beautiful NZ Views* competition of spring in bloom.



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Podcast of this newsletter is now available

We are very pleased to announce that *Viewpoint* will now be available on our website as a Podcast, and those who are Blind Low Vision NZ members can also access it on Blind Low Vision NZ platforms.

This link goes to the podcast on Macular Degeneration NZ website www.mdnz.org.nz/viewpoint-podcasts

To access it on BLVNZ platforms please search for Macular Degeneration New Zealand Viewpoint.

If you would like to in future receive the *Viewpoint* Newsletter by email only please do email info@mdnz.org.nz informing us of this, or call 0800 622 852.

For further information contact MDNZ

 www.mdnz.org.nz

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Macular Degeneration

Free Seminars

Learn about the impact of Macular Degeneration, medical research, treatments and resources available

Local ophthalmologists, Dr James Leong and Dr Neil Avery will share the latest information on treatments and offer advice about how to best manage Macular Degeneration.

Bring your friends and family to one of these free education seminars in your area.

WELLINGTON

10-11.30am, Sat 25 November 2023

Speaker: Dr James Leong
Cophthorne Hotel, 100 Oriental Parade
Oriental Bay, Wellington

WAIKANAЕ

10-11.30am, Sun 26 November 2023

Speaker: Dr Neil Avery
Waikanae Community Centre
28 Utauta Street, Waikanae

TO REGISTER GO TO

www.mdnz.org.nz/public-seminar-sign-up

or call **0800 MACULA (622852)** or email info@mdnz.org.nz