

Viewpoint

The MDNZ Newsletter

ISSUE 20 – September 2022

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

www.mdnz.org.nz

Here's to Spring!

While the winter cold isn't quite behind us yet, Spring is just around the corner, and we are pleased to be back with news and updates.

As it has been for many of you, Covid has made life difficult for MDNZ. No sooner had we planned seminars, than we went into lockdowns, with an especially long lockdown for Aucklanders in August last year. And just like many of you, MDNZ pivoted and found new ways to reach out to people.

In 2021 we saw the introduction of zoom Awareness & Education Seminars for MDNZ, enabling people anywhere in the country to attend. We heard back from many attendees who were grateful for the zoom sessions, as they would not have been able to attend if the seminar was face to face.

In this issue you can read about new treatments on the horizon; how Warren was saved by the Amsler Grid; and learn about MDNZ's new project to deliver Awareness and Education to the Chinese and Korean speaking communities.

Also in this issue, we say goodbye to Anna Crane, MDNZ's General Manager. Anna ably led MDNZ through a very challenging two years of Covid lockdowns and restrictions. Anna worked incredibly hard to ensure people with macular degeneration could still receive the same services and support from MDNZ. Her energy and leadership will be missed. We offer Anna our sincerest thanks for all her work, and we wish her all the best in her future endeavours.



We would like to introduce you to Sarah Berman, who will be stepping into the General Manager role in September. Sarah has

been MDNZ's Fundraising Manager for the past 6 years. Working behind the scenes, Sarah's has helped grow the organisation and the services we deliver. Sarah's many years in organisation development and leadership make her well placed to lead MDNZ in 2022 and beyond. We warmly welcome Sarah into the role.

Medical update

3 jabs a year, a possible new treatment?

A new drug for macular degeneration could reduce injections from monthly to only 3 times a year.

Faricimab has recently been approved in the UK for the treatment of wet macular degeneration. A recent phase-3 clinical trial, published in Feb 2022 in the Lancet Medical Journal showed that Faricimab lasted twice as long as other macular degeneration medications, meaning injections may only be required 3 times a year.

Cathy Yelf, chief executive of the Macular Society UK notes that for many people who have eye injections, going to monthly eye clinic appointments is arduous, often requiring help from family members or friends to get there. People sometimes need a day of rest after their treatment too.

The beauty of this potential new treatment is that patients who currently make monthly or 2 monthly trips to the eye clinic, may only need to make 3 visits a year!

Treatments that require less interventions make it easier for patients to stick with their treatments over time, meaning better vision outcomes in the long term. Less treatments per patient may also free up eye clinics to treat more patients, an important factor to consider as our society ages and macular degeneration becomes more prevalent.

Clinical trials with Faricimab are currently underway in Australia. Meanwhile, in New Zealand, Medsafe has recommended that Faricimab be added to the prescription schedule. This is the first step in the approval process, which does take time. Faricimab still needs to go through several stages before Medsafe approves it for use in NZ.

We will report on progress as we hear more.

Source: NZ Optics & Macular Society UK



A big thank you to these generous people



MDNZ was honoured to be the recipient of a \$3,000 donation from the Tauranga City Sunrise Lions Club.

Each year the Club organises a Magic Show and the proceeds from fundraising are donated to selected charities. In 2021, MDNZ was one of three charities under the "Vision Impaired" theme to receive this donation. The wonderful donation was used to provide much needed support for people living with macular degeneration.

MDNZ would like to offer a big thank you to the Tauranga City Sunrise Lions Club for their generosity!

MDNZ would also like to thank the family of the late James McClennan, who kindly donated a Topaz desktop magnifier, audio clock, and a large-faced watch to MDNZ.

The Topaz magnifier will be very useful for our low vision staff and volunteers. For our Auckland readers, if you were thinking of purchasing one and would like to see how it works, you are welcome to visit our office to try it out. You can contact us on 0800 622 852 or info@mdnz.org.nz to arrange a time.

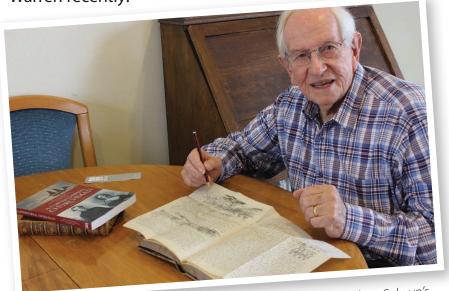
If you have low vision and would like access to a talking clock or a large-faced watch, please also contact us on

0800 622 852 or info@mdnz.org.nz



Credit where it's due! A letter bearing good news

We were delighted to receive this letter from Warren recently:



Warren consulting an 1848 letter of Bishop Selwyn's

Following Gaye from MDNZ's address on Macular Degeneration to the Remuera branch of U3A in 2020, I returned home and exclaimed to Elizabeth my wife what an illuminating, illustrated address Gaye had presented. I had listened carefully to the presentation as a cousin in the UK has been struggling with macular degeneration for years. I did not know how important it would soon become for me.

For 12 months or so since the talk I have occasionally taken MDNZ's advice, pulled the Amsler grid off my desk and with great self-satisfaction assured myself: "Well that's one thing I don't suffer from!"

I retired a few years ago, after 60 years of parish work, university teaching, historical

research and as Dean of a Cathedral in the Anglican Church. I now enjoy spending my time in historical research and writing.

I read and write a lot, and in September last year I noticed that my text was somewhat blurred, with wavy lines as well. Where was my little Amsler grid? That distortion, those

blurred patches, were not discernable six weeks earlier.

I remembered the advice, given at the presentation, not to delay and immediately called the clinic. My ophthalmologist's receptionist had a serious tone of voice, 'Come in first thing tomorrow even though it's Lockdown!'. By noon I'd received the first of three Avastin injections.

How did I manage self-diagnosis? Three strands had blended: MDNZ's talk to the U3A, the simplicity of the Amsler grid and my recollection of a distant cousin's woes in Bristol.

Thankfully, my macular degeneration was detected in time and my sight has not deteriorated significantly. I can still do all the things that I enjoy in life.

I have had a chance to reflect on what would have happened had I not recognised the disease and acted on it. Losing my sight would have made my historical research and writing extremely difficult, if not impossible.

I can now express my *gratitude for Gaye's timely* presentation as a U3A Visiting Speaker and as Macular Degeneration NZ's Educator.

With warmest good wishes, Warren

Thank you, Warren, for sharing your experience.

We welcome your stories and would love to hear how you are managing with macular degeneration.

Please be in touch on info@mdnz.org.nz and let us know.

Awareness & Education Seminars update

The past year was challenging as we all grappled with Covid-19 lockdowns and restrictions. MDNZ continued to be accessible to all in need and delivered seminars where possible.

Public seminars were cancelled due to the difficulty of holding in-person events. MDNZ moved to deliver seminars via zoom. We sincerely thank Drs Andrew Thompson, Ainsley Morris and Tracey Wong who presented Education and Awareness Seminars to over 380 people on zoom.

Many people appreciated the ease of zoom with one participant responding: "Zoom made the presentation much more accessible for my 94-year-old father-in-law, both from the convenience of watching in his own lounge and ... being easily able to hear both the presenter and the questions being asked."

Two in-person seminars were held in Thames, Coromandel and Invercargill. Thank you, Dr David Worsley and Dr Ainsley Morris for your support and time. MDNZ also delivered a zoom seminar on Living with Low Vision presented by Blind Low Vision NZ's Rehabilitation Instructor Mike Shaw.

Attendees shared: "Outstanding, practical, useful information and tips to make everyday living a bit easier, and help others understand how they can help."

MDNZ has also connected with community organisations, with 30 presentations to retirement villages, community groups and clubs in Auckland, Christchurch, Gore, Hamilton, Nelson, New Plymouth, Palmerston North and Rotorua.

If you would like us to speak to your group, please contact us on



(C) 0800 MACULA (0800 622 852)



info@mdnz.org.nz

Awareness and Education for the Asian Community

According to the 2018 census, New Zealand's cultural make-up is becoming more diverse. Asian ethnic groups (707,598) are the third largest, with 15.1 percent of the population identifying with at least one Asian ethnicity. More than a quarter of people within the Auckland region identify with an Asian ethnicity.

Research has also shown that the Asian Community is at a higher risk of macular degeneration than other ethnicities.

Thanks to the TM Hosking Charitable Trust (proudly managed by Perpetual Guardian), MDNZ engaged two Asian community educators, with one speaking Mandarin and Cantonese, and the other speaking Korean, to deliver community presentations within Auckland. To complement this, we also translated five of our brochures into Chinese and Korean languages. These are being distributed for free in the community.

We have made great progress in raising awareness in the Asian communities with 20 presentations to date, including one to a group of doctors in Botany.

MDNZ's community educator Ruth, who delivers talks in Cantonese and Mandarin, comments: "The audience tells me how glad they are to learn about macular degeneration and will now definitely go and



get their eyes checked." Ruth finds it very satisfying delivering these talks as she can see the difference it makes in people's lives.

Karen, MDNZ's Client Services Coordinator shares her thoughts: "We are pleased that elderly Chinese and Korean people now have access to key patient resources about macular degeneration, and support and advice in Mandarin and Cantonese through our 0800 helpline."

To order patient resources in Mandarin or Korean, or to book a talk for your community group in Mandarin, Cantonese or Korean, please be in touch on



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MDNZ is grateful for the support of The TM Hosking Charitable Trust, proudly managed by









Community presentations within Auckland.



当您第一次被诊断出患有黄斑病变时,尽可能获取详尽信息至关重要。

得知患有黄斑病变可能让人震惊失措,所以了 解清楚所患黄斑病变的类型以及所处的病程阶 段,对于您、您的家人与护理人员极具价值。 在处理您现在或将来可能需要的任何帮助服务 时,也具有很大的帮助意义。



咨询眼科专家时

- 如果您不明白眼科专家的解答,请专 家详细解释,直到您对答案感到确认
- 记录笔记或让朋友或家人为您做记录
- 请眼科专家为您写下有关的指引说明
- 尽可能获取一切可用的书面材料

与医生探讨您的黄斑病变的病程阶段和病变类型非常重要。了解这一点,将有助于您调整对自身有益的相关饮食和生活方式,以及可能的治疗士安迪四 方案选项。



眼睛健康检查清单

- 定期检查眼睛状况并确保对黄斑进行相应检查
- 戒烟
- 健康、均衡的饮食
- 每天吃深绿叶蔬菜和新鲜水果
- 毎周吃两到三次鱼
- 每周吃一把坚果
- 限制脂肪和油的摄入量
- · 保持健康的生活方式、控制体重和定
- 考虑与您的医生商讨服用补充剂

Above: Two samples of translated Macular Degeneration Brochures. Below: Educator on an Asian Website.





Eye Health Aotearoa: Love your Eyes Campaign

Eye Health Aotearoa (EHA) is a collaboration of eye health organisations working to ensure all New Zealanders can access quality eye health care through research and advocacy. Macular Degeneration NZ is a founding trustee.

EHA, in turn, is a member of the International Agency for Prevention of Blindness (a global initiative for eye health). Last year EHA participated in the international "Love Your Eyes Campaign" by gathering signatures from 4,500 New Zealanders who pledged to care for their eyes. In October 2021, World Sight Day was marked at Lands End, Bluff, where we hosted the southern-most eye testing

site in the world. An art competition for Southland youth was also held.

This year's Love Your Eyes Campaign focuses on parliament. In July, EHA ran partial eye testing sessions in parliament for MPs and parliamentary staff. MPs Dr Liz Craig and Dr Elizabeth Kerekere hosted the launch of the report "Eye Care in Aotearoa New Zealand 2022 – Eye Care Situation Analysis Tool (ESCAT)". The report is a snapshot of the eye care situation in New Zealand in 2022 and will support further conversations about improving access to quality eye care.

What can you do to help make a difference for eye health in New Zealand?

1. You can sign a petition calling on the government to fund an eye health survey.

Currently the government has no formal data on the frequency or causes of vision loss and no comprehensive eye health strategies, policies or frameworks to plan for and measure progress in eye health and vision care. We need to show the government that eye health matters to New Zealanders.

Please sign the petition at www.eyehealthaotearoa.org.nz

2. You can take part in a tactile art competition. The competition closes soon, so don't delay.

Visit <u>www.eyehealthaotearoa.org.nz</u> and look under "Take Action" to find the Love Your Eyes 2022 Tactile
Art Competition

Registration.

MDNZ offers a standing ovation to our funders and supporters for your generosity.

You have made a huge difference over the past year, **Thank you!**















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Warming and Nourishing Recipes

As the last of Winter fades and we look to the joy of Spring, here are some simple yet nourishing, and most importantly delicious recipes to see you through those occasional cold evenings, that may still hang around. Enjoy!



Moroccan roast pumpkin soup

Ingredients:

½ medium pumpkin, peeled, seeded, diced

- 1/4 cups canola oil
- 2 onions, chopped
- 4 cloves of garlic, crushed
- 1 tbsp ground cumin
- 1 tbsp smoked paprika
- 2 tsp ground sumac (optional)
- 5 cups vegetable or chicken stock
- 3 tbsp lemon juice
- Salt and pepper to taste

Method:

- 1. Preheat oven to 225 degrees Celsius
- 2. Toss pumpkin in half the oil and place in a roasting dish.
- 3. Roast in preheated oven until browned and cooked through. Once cooked remove from the oven.
- 4. Meanwhile place remaining oil in a large saucepan and sauté the onions until translucent.
- 5. Add garlic and spices and continue to cook for 1-2 mins
- 6. Add stock, lemon juice and roasted pumpkin to the sauce pan and cook slowly for 30mins
- 7. Remove from heat and blend until smooth.
- 8. Serve warm and enjoy!

Serves 4

Field mushrooms with soft herbs, lemon and feta

Ingredients:

50g butter

- 4 flat mushrooms, like portobello, peeled and stalks trimmed
- 1 tbsp balsamic vinegar
- 2 thick slices of crusty bread, like sourdough, toasted
- 100g low fat feta, crumbled
- ½ bunch of parsley, washed and leaved picked
- ½ bunch of dill, washed and leaved picked



Grated zest of 1 lemon Salt and pepper to taste

Method:

- 1. Melt butter in a frying pan.
- 2. Add mushrooms and cook for 3 mins.
- 3. Add balsamic vinegar and simmer for another 3 mins.
- 4. Remove the mushrooms (reserving the pan juices) and place them on the toast.
- 5. Spoon reserved the pan juices over the mushrooms and top with feta, parsley, dill lemon zest, salt, and pepper.
- 6. Serve warm and enjoy!

Serves 2



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

O800 MACULA (0800 622 852)



Please donate to support those with MD

Title	Mr	/	Mrs	/	Ms	/	Miss	/	Other		
First name											
Last name											
Name to appear on tax receipt											
Street addres	SS										
Suburb											
City						Pos	tcode				
Email											
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Phone (mobi	le)										
I would like to give a gift (choose one) Single Monthly Annually Amount \$200 \$150 \$100 \$50 or \$ I would like to pay by (choose one) Credit card VISA MasterCard Card number Cardholder's name Amount \$Expiry date / Signature For online donations visit www.mdnz.org.nz											
For donations by online banking, please email or call MDNZ.											
Thank you											
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,											

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We take great care with your personal information.

For assistance phone

Donations over \$5 are tax deductible.

Spring Days!

Enjoy the onset of spring with a selection of entries from our *Beautiful NZ Views* competition.











For further information contact MDNZ



(C) 0800 MACULA (622 852)

info@mdnz.org.nz



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.

Click on this link to head 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.