



MACULAR  
DEGENERATION  
NEW ZEALAND

# Viewpoint

The MDNZ Newsletter

ISSUE 21 – June 2023

0800 MACULA (0800 622 852) | [info@mdnz.org.nz](mailto:info@mdnz.org.nz)

[www.mdnz.org.nz](http://www.mdnz.org.nz)

## What's happening in 2023?

It has been a rather hectic start to 2023 – not only with 'mother nature' shaking us up with unheard-of weather and many challenging outcomes for people all over NZ, but also in Macular Degeneration NZ (MDNZ), with a reduced staff levels impacting on service delivery and available hours in the days/ weeks to get things done. There is no comparison between these really, and we wish full and strong recovery to those many families and businesses working through their challenges for some time yet.

**In this newsletter we bring you news of a new drug which holds promise for individuals affected by dry macular degeneration, offering hope for improved outcomes and vision preservation.**

We also profile MDNZ's Asian educator, Ruth, who is doing great work speaking to Chinese groups, either face to face or via Zoom. We have chosen some warming recipes for winter using ingredients that have those important vitamins and minerals that are good for your eye health. We also share our sadness at the passing of MDNZ Ambassador, Dame Rosie Horton. Rosie was

there at the beginning of MDNZ and she was always there to share her experience and wisdom with the team.

Led by our professional board we undertook strategic planning to re-prioritise our focus. Over the past few years, Covid restricted MDNZ's ability to engage with the public and connect with eye health professionals. We look forward to reactivating these areas this year.

We apologise to those of you who may have had difficulty in getting hold of us through the 0800 Save Sight Helpline. Our small team has been working at home with no direct access to receive those calls. Remedies are underway and we hope to catch you with every call very soon. Meanwhile messages are cleared each weekday, and we hope you will continue to call and leave a clear message with your name and phone number – WE WILL call you back.

**We are most grateful to the Lion Foundation for supporting MDNZ by funding the printing and distribution of this newsletter.**



## Farewell, Dame Rosie



With great sadness we acknowledge the passing of MDNZ's Founding Ambassador, Dame Rosie Horton.

Rosie was a highly regarded philanthropist and mentor for the charitable sector. She willingly gave her time to mentor and coach the MDNZ team and generously shared her experience and wisdom.

Our thoughts go to Michael and Dame Rosie's family at this time.

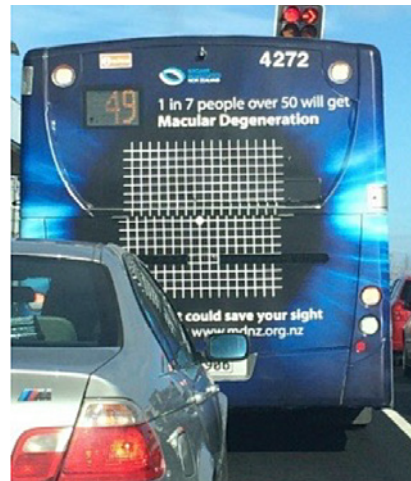
## Thank you to retiring MDNZ Trustee, James Rangihika



After 10 years of commitment to MDNZ by retiring Trustee, James Rangihika, we thank James sincerely for his invaluable contribution. James' dedication to enhancing the reputation and the success of MDNZ since 2013 has made a huge difference to raising awareness and supporting the people we serve.

As an advertising and marketing professional, James has shared his creative mind in a lead role in design and communications for MDNZ. He was responsible for leading several awareness

week campaigns during which many of you may have recalled seeing large electronic signage in shopping malls and airports. We are still reminded by people about how good the signage on the back of buses in Auckland in 2014 was.



James always had MDNZ on his mind, coming forth with great ideas and the ability to execute them, on numerous occasions, even when living overseas.

James and his wife Melanie and children now reside in Australia, and we wish them well with their ventures.

# A fabulous email sharing the benefits of the Amsler Grid

Macular Degeneration NZ (MDNZ) received this email just before Christmas. While it was lovely to receive thanks and appreciation of our work, the real thrill for us at MDNZ, is that the use of the Amsler Grid is increasing with many great stories of 'saving sight' as a result of using it, coming our way.

*Dear Sarah*

*Thank-you for your Christmas letter. It has spurred me on to write this email, which I've been meaning to write for many months.*

*I joined MD Group in Dunedin years ago because many of my father's family had had MD, and I wanted to get ahead of the game in case I ever developed it too.*

*Every so often I would use the Amsler grid from your very readable magazine. Nearly two years ago, I was horrified to see the lines, which had always been very clear, had become very distorted. Your recommendation was to immediately set up an appointment with my optician. I certainly did that.*

*My optometrist checked my vision and did find something amiss. She referred me to an eye surgeon. He confirmed her diagnosis of an epiretinal*



*membrane, which had grown to affect the macular of my right eye. My surgeon went on to successfully remove said epiretinal membrane, and my vision was restored.*

*So, your Amsler grid and advice on what to do if results were off, were very, very helpful to me.*

*You've run articles about people who discovered a macular condition and their subsequent treatment. Despite my reason for joining MD NZ, I had never thought I'd have a story of my own. But I do, and again, I am very grateful for MD NZ's part in discovering that.*

*Wishing you all at Macular Degeneration NZ a very Merry Christmas, and Happy New Year.*

*Fiona*

# Medical update

## New treatment for dry macular degeneration on the horizon

Dry macular degeneration, also known as atrophic AMD, is the more common form of macular degeneration (MD) and a frequent cause of vision loss in older adults. Traditional treatment options for dry MD have been limited, mostly centred on prevention and supportive measures, such as low vision aids, diet and nutrition.

**However, a new approach using pegcetacoplan, known as Syfovre, has emerged as a potential breakthrough in managing this condition.**

This new drug, intravitreal pegcetacoplan, represents a novel and innovative approach to treating dry MD. By directly targeting the alternative pathway of the complement system, this therapy aims to reduce inflammation and damage to the macula.

Like other treatments for MD, pegcetacoplan is an injection in the eye, given either 4 or 8 weekly. Clinical trials evaluating intravitreal pegcetacoplan have shown promising results. The phase 2 FILLY study and the phase 3 studies OAKS and DERBY confirmed that pegcetacoplan reduced the rate of progression of late MD. Additionally, improvements in visual function and quality of life were observed. These findings provide






evidence of the potential benefits of intravitreal pegcetacoplan in slowing disease progression and preserving vision in patients with dry MD.

While further research and clinical trials are needed to establish its long-term efficacy and safety, intravitreal pegcetacoplan holds promise for individuals affected by dry macular degeneration, offering hope for improved outcomes and vision preservation.

The drug has recently been approved for use in the USA (Nov 2022) and is currently being tested at trial sites in Australia. In NZ all medicines must first gain approval from Medsafe, to ensure the medicine is safe, appropriate and effective. Then Pharmac evaluate the medicine to determine if it will be publicly funded. Pegcetacoplan has not undergone either of these reviews in New Zealand at present, so it will be a while until it is available here. We will keep you posted.

### Remember:

-  [www.mdnz.org.nz](http://www.mdnz.org.nz)
-  Leave a message on **0800 macula (0800 622 852)**
-  Email us on [info@mdnz.org.nz](mailto:info@mdnz.org.nz)

# Advocating for Eye Health

MDNZ represents the macular degeneration community as a trustee of Eye Health Aotearoa. Eye Health Aotearoa is made up of key eye health organisations and our aim is to improve New Zealanders eye health by bringing the issue to the attention of government and decision makers.

Leading into the General Election this year, Eye Health Aotearoa has called for government to implement the following:

1. Appoint a **Clinical Director of Eye Health within the Ministry of Health**. A similar role has recently been appointed in the UK, and the role in NZ would provide leadership, advice, and support for eye health to the Health Ministry and wider health system.
2. Establish a **National Eye Health and Vision Loss Prevention Leadership Group** in the Ministry of Health. Groups like this already exist for other areas of health, and we are calling for eye health experts to have a voice around the Ministry of Health table.
3. **Identify barriers** to eye care services and treatments, and **apply effective solutions** universally. Eye health services differ from region to region and are not delivered equally throughout NZ. We are calling for barriers to be removed and equity of access for all.
4. Fund a **National Eye Health Survey**. Currently we don't have accurate data on the state of eye health in NZ. We can only estimate how many people have

eye diseases or vision loss. A survey would provide evidence which would inform services and actions to prevent vision loss and reduce inequities.

5. **Increase eye health awareness and education** through supporting groups such as MDNZ. Currently MDNZ receives no government funding, unlike our sister organisation in Australia (where eye health outcomes are significantly better). We believe the government should step up to fund this important sight saving work.
6. Establish a **referral system for patients** to access advice, information and support from organisations such as MDNZ when diagnosed with a disease or condition.
7. Finally, for the government to develop **an Eye Health Action Plan 2027-2035** and commit resource to implementing it.

Eye Health Aotearoa is speaking with politicians and political parties' health spokespeople. You can help raise this important issue too. As the general election is only a few months away, now is the time to raise these with your local MP and candidates, to put these important issues on the radar of our elected representatives.

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



# Healthy Eating

As the weather cools, we look for warm, hearty meals to cheer us up. These two recipes include capsicum, tomatoes, olives, broccoli, spinach, onion, celery and carrots. They are primary sources of lutein and zeaxanthin, antioxidants that may help reduce the risk of AMD or slow its progression. Broccoli is also a source of vitamin C, while spinach and carrots provide vitamin A, also beneficial to eye health.

We hope you enjoy these meals this winter.

## *Stuffed Capsicum*

### **Ingredients:**

2 large capsicum  
2 cups cherry tomatoes (3-4 medium tomatoes) diced  
2 cloves garlic, thinly sliced  
¼ cup chopped Kalamata olives (about 15)  
85 gr feta cheese, crumbled  
¼ cup chopped basil  
2 tbsp olive oil  
salt and pepper

### **Method:**

1. Preheat the oven to 200°C. Lightly spray a shallow baking dish with cooking spray.
2. Cut the capsicum in half lengthwise, removing the seeds and ribs, and leaving the stem. (The stem is not edible but helps the pepper maintain its shape

and looks good in this dish.) Place the peppers cut side up in the baking dish.

3. In a medium bowl, combine the tomatoes, garlic, olives, cheese, basil, and olive oil, and season with salt and pepper. Gently mix. Fill each half capsicum with the mixture, dividing it evenly. Cover the dish loosely with foil.
4. Bake for about 30 minutes. Remove the foil and continue baking for about 15 minutes more. The cheese will have begun to turn light brown and the capsicum will be tender. These can be served hot or at room temperature.

### **Recipe Notes**

Substitute goat cheese for the feta (could be an herbed one); change out the basil with fresh dill or oregano or a combination; could add some diced onion (2-3 tablespoons) or some sundried tomato slivers; can eliminate the olives; make it Mexican flavoured by substituting cilantro for the basil, omitting the olives, adding some diced jalapenos and red onion and substituting queso fresca for the feta.





## *Creamy Broccoli & Spinach Soup*

### **Ingredients:**

#### **What you'll need to generously serve 4:**

- 700 gr broccoli
- 2 tablespoons unsalted butter
- 2 tablespoons olive oil
- 1 small onion, diced
- 1 stalk celery, diced
- 3 cloves garlic, crushed
- 1 large carrot, diced
- Salt and freshly ground black pepper
- 2 teaspoons fresh thyme leaves  
(or ½ teaspoon dried)
- 5 cups of chicken or vegetable broth
- 2 cups packed fresh spinach leaves
- 2 teaspoons grated lemon zest  
(from 1 lemon)
- ½ cup cream (optional)

\*Homemade croutons (optional), Sour cream or crème fraiche (optional)

### **Instructions:**

1. Remove the florets from the broccoli stems and set aside. Peel the tough outer skin from the stems and trim off the fibrous ends. Cut the stems lengthwise into slices about 1.5cm thick

and then crosswise into 1.5cm pieces.

2. Heat the butter and olive oil in a soup pot over medium-high heat until hot. Add the onion, celery, and garlic, lower the heat to medium-low, and season with salt and pepper. Cook the vegetables slowly until tender, about 10 minutes. Keep the heat low so the vegetables cook without taking on colour.
3. Add the thyme and stir. Add the broccoli stems, diced carrots, and chicken broth and bring to a boil. Cook, uncovered, for about 3 minutes. Add the florets and continue to cook until very tender, about 5 more minutes once the mixture comes back to a boil.
4. Carefully puree the soup in a blender in small batches. Add some of the fresh spinach and some of lemon zest to each batch as you puree it. (The soup can be made to this point, covered, and refrigerated for up to one day or frozen for up to one month.)
5. When ready to serve, return the soup to the pan and reheat over gentle heat. Stir in the cream. Taste and adjust the seasoning with salt and freshly ground black pepper. Soup can be served with croutons and/or a dollop of either sour cream or crème fraiche.
6. \*Homemade croutons: Preheat oven to 180°C. Cut some day old day-old bread into large cubes and place in a large bowl. Drizzle cubes with olive oil, salt, pepper, and red pepper flakes. Toss well. Spread bread cubes onto a baking sheet and bake for about 15 minutes.

# Education and Awareness

**Since our last newsletter, we have continued to raise awareness and provide education by delivering seminars to reach wider into our communities.**

Coming out of lockdowns and with Covid restrictions removed, we have been able to deliver 16 seminars (in English) in-person and online to community groups to people in Christchurch and Auckland.

16 seminars have been presented to Chinese (Mandarin or Cantonese) and two to Korean audiences in Christchurch, Dunedin, and Auckland with two online.



We appreciate Auckland Council Libraries for welcoming us into the local libraries to deliver presentations in Chinese and Korean.

These seminars are funded through your generous donations. We want to share with you how your support makes a difference by sharing some of the feedback received

- *A well organised, well-presented talk. I had never heard of macular degeneration*

*before. I found your talk interesting and informative. At 84 years I will be on the lookout. Sight is so precious.*

- *Your talks are so worthwhile as I'm sure many people have not heard of this disease.*
- *Excellent. Very helpful for us.*
- *Excellent. Increased my knowledge.*
- *Very clear and concise Informative. Well presented with great illustrations/ presentation.*
- *Thank you so helpful to be more informed with dry so will be mindful of following up with eye care.*
- *Well-presented easy to understand and very informative.*
- *A very good talk by someone with a lot of knowledge and was very good.*
- *Presenter was great. Explained it so it was easy to understand.*

## Coming up in 2023

We hope to deliver public seminars in Taupo, Wellington, Timaru and Whangarei in the second half of 2023. If you are registered on our mailing list and reside in the area, you will receive a seminar notice with a message to register with a request spread the word to others who may be interested.

## Watch a recorded seminar on line:


[www.mdnz.org.nz/prerecorded-video](http://www.mdnz.org.nz/prerecorded-video)

While you are on the website check out a range of videos to watch online while you are inside keeping warm over winter. And don't forget to read the many patient stories too.



## 0800 save sight helpline update

Unfortunately, our service to you through the 0800 Save Sight helpline has been restricted. We acknowledge that many of you do not like leaving messages, yet this is the only way we have been able to manage this service recently. Remedies are underway and all will be normal again soon. Meanwhile please leave your message, your name and number and we will call you. The messages are checked daily.

 Leave a message on  
**0800 macula (0800 622 852)**

## Expos and Conferences

As part of MDNZ's goal to reach more people at-risk of macular degeneration, we hosted an information stand at the Retirement and Lifestyle Weekend Expo in Tauranga in March. The Expo attracted 3000 people, a good proportion of whom stopped to talk, asked questions and happily received brochures and a free pen. This Expo was targeted at people in retirement and great interest was shown in learning about macular degeneration.



The Goodfellow GP Conference (also in March) in Auckland gave us the opportunity to speak with doctors, nurses, registrars,

students and other health professionals. These primary healthcare professionals were keen to learn more about macular degeneration. Of particular interest was MDNZ's online learning module that can be completed anywhere and at any time, while earning professional development points.

A link to the learning module "*Understanding Macular degeneration*" can be found on <https://www.mdnz.org.nz/professional-development>



In May, MDNZ's General Manager Sarah Berman attended the Royal Australian & New Zealand College of Ophthalmologists (RANZCO) NZ branch Annual Scientific meeting in Wellington. With 280 participants Sarah was able to meet with ophthalmologists, nurses, technicians, students, practice managers and registrars. She gave a talk to around 100 people on collaboration between MDNZ and ophthalmology practices, which was very well received.

MDNZ will have a display stand at two upcoming GP Conferences, to keep the key messages about macular degeneration in front of the healthcare professionals. These are held annually in June in Rotorua and in August in Christchurch.

# Introducing Ruth Kuo

**Ruth brings an incredible background and set of qualifications and experience to her role as educator for the Chinese communities.**



Ruth came from China, she speaks, English, Mandarin and Cantonese. With a background in arts, business and education Ruth has

worked in the fields of communication, community, training and education. Using her Master of Business Management, Master of Global Marketing, NZ Certificate in Language Teaching and Mandarin Proficiency Test Certificate, Ruth's full time employment is with Auckland Council as Business Community liaison of Local Boards.

Ruth has assisted MDNZ with the translating to Chinese and she has led numerous seminars (both face to face and online) to Chinese groups in Auckland, Dunedin and Christchurch since the beginning of 2022.

The feedback from participants has been fantastic. Here are some examples:

*Thank you so much for providing Chinese sessions and Chinese education packs to us, we indeed need them, thank you for managing Chinese content for us Chinese community!*

*We would like to express our gratitude to MDNZ for sharing this vital information with us, and we sincerely appreciate the opportunity to organize the seminar with your support. We hope to have the chance to organize another educational session in the future.*

*I hope MDNZ can continue to promote this to the Chinese community.*

Ruth has presented talks in Auckland Libraries and this is proving an excellent partnership. Thanks to Ruth's great work, MDNZ is able to share vital information with older immigrants in their native language so they too can take care of their eye health.





**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:

<b>\$50</b>	information packs posted out to 10 people
<b>\$150</b>	information packs for 36 seminar attendees
<b>\$500</b>	one week of the 0800 Save Sight Helpline
<b>\$2,000</b>	an Awareness and Education Seminar in your community
<b>\$10,000</b>	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](mailto:info@mdnz.org.nz) or phone
- 0800 MACULA (0800 622 852)**



**Please donate** to support those with MD

Title

First name

Last name

Name to appear on tax receipt

Street address

Suburb

City  Postcode

Email

Phone (home)

Phone (mobile)

**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](http://www.mdnz.org.nz)**  
**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

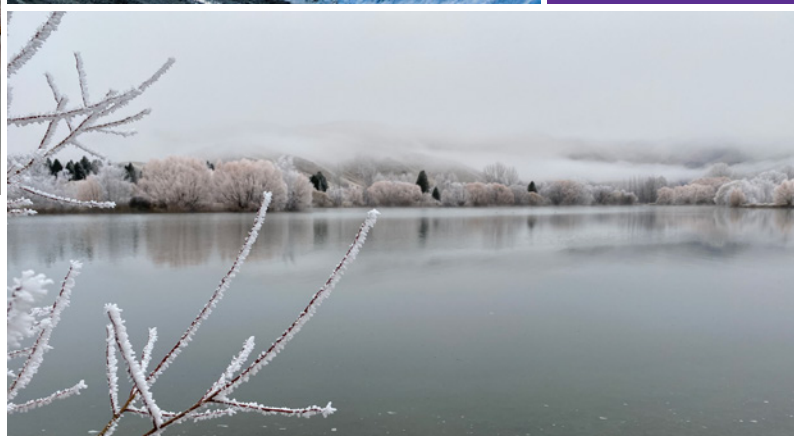
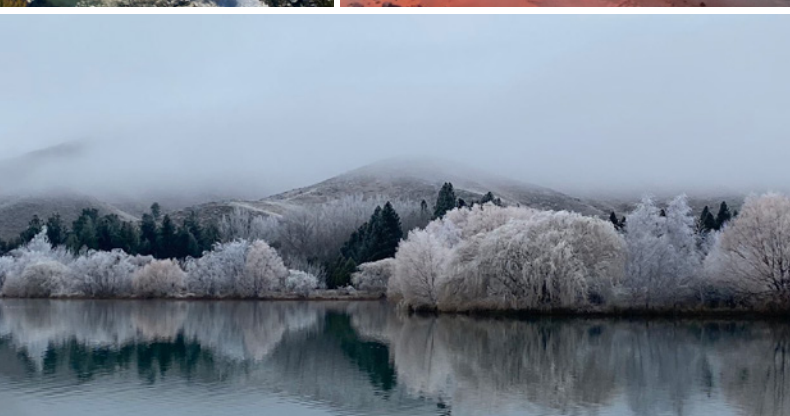
Please complete this form and return to:  
**Macular Degeneration New Zealand,**  
**PO Box 137070, Parnell, Auckland 1151**

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](http://www.mdnz.org.nz/privacy)

# Winter Days!

Enjoy a glorious winter wonderland of entries from our *Beautiful NZ Views* competition.



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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.

Click on this link to head to the podcast on Macular Degeneration NZ website [www.mdnz.org.nz/viewpoint-podcasts](http://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](mailto:info@mdnz.org.nz) informing us of this, or call 0800 622 852.

For further information contact MDNZ



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