



MACULAR
DEGENERATION
NEW ZEALAND

Viewpoint

The MDNZ Newsletter

ISSUE 18 – February 2021

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

www.mdnz.org.nz

Looking forward to 2021

We are now one month into 2021, and can imagine that like us you are hoping that it will be less difficult than 2020.



I am very proud to have joined the team of Macular Degeneration NZ as the General Manager and am looking forward to working with MDNZ's amazing team towards achieving our goals.

As I write this, we are currently in planning mode for the year ahead and in future Viewpoints we will update on what these are for 2021.

In this issue we introduce our new Client Services Coordinator, share with you details of our upcoming seminars and the story of Pamela Zane who suffers from aged macular degeneration.

If you are interested in possible future treatments for atrophic macular degeneration (also referred to as dry) then the article on page 10 will be of interest to you.

We also discuss macular degeneration in the Asian community and the Chinese New Year which is almost upon us.

Wishing everyone a very happy and healthy 2021.

Anna-Louise Crane

Pamela Zane Keys' story:

Living with Macular Degeneration

It came as a shock to Pamela Zane Keys to learn that she had macular degeneration. Unlike most people who have macular degeneration, it happened suddenly. It happened about three years ago and she has "kind of got used to it".

Her mother had very poor eyesight and Pamela Zane Keys would help her by reading signs (there is a strong genetic connection).

But her eyesight was good, needing glasses only when on the computer. It started as 'blob' on the page when she was reading and after going from the optometrists to the doctor to the hospital, she was faced with reality. It can't be cured but it can be slowed and even stopped for a time. However, this requires regular injections into the eye. In Pamela Zane Key's case it is every six weeks for one eye and eight weeks for the other. Not recommended for the squeamish and journalists, but she says, "You are given a local anesthetic and it just feels like pressing on a bruise".

Pamela Zane Keys is full of praise for the treatment and service she gets at our hospital (Whanganui).



Photo of Pamela Zane Keys and Warwick Keys at Macular Degeneration NZ's Whanganui public seminar on the 14th November 2020.

"They are professional, yet caring and very sensitive." She got over her nervousness about the treatment and now "honestly all I feel now is a depth of gratitude."

The problem is her central vision which be a blur but she explains, "The brain fills in that space and I have very good peripheral vision. I do have good and bad days though. I can still drive although I really concentrate on making my eyes work."

One side effect is, it has affected her sense of colour. "I will see blue when it is green. Fortunately, I know where the green/blue traffic light is."

Introducing Karen Chong

Pamela admits to cheating sometimes, although the eye specialists say, "I am just being resourceful. It is hard to identify water and clear glass. They are both transparent. So as I fill the glass up I put my finger into it."

Thank you to the River City Press, Whanganui and Pamela Zane Keys for permission to re publish this article.

Editors Note:

You may be aware of (and receive) the treatment that is detailed in this article which is given for neovascular (also referred to as wet) macular degeneration.

There is currently no medical treatment for atrophic (also referred to as dry) macular degeneration, however there are some life style changes that you might be able to do to reduce your risk or slow the progression of atrophic macular degeneration. Please contact us if you wish to learn more.

We are very pleased to welcome to the Macular Degeneration NZ's team Karen Chong.



Karen joined us just before the Christmas break as our new Client Services

Coordinator, and will be focused on continuing the excellent service that MDNZ supplies to all our friends. She is also the main organiser for our public and community seminars.

Karen says "I am excited to be able to utilise my marketing skills at MDNZ and getting to do what I like most – helping people! I am passionate about educating and raising awareness about vision loss as I myself am living with a genetic condition that is causing vision loss. I am a firm believer in positive thinking and I always say, I am losing my vision, but I am not losing my brain. I can still contribute a lot to society and the community. I look forward to adding value to MDNZ in any way I can."

Karen has significant skills and expertise with over 20 years of experience in branding, marketing and event management. She speaks English, Mandarin, Cantonese, Bahasa Malaysia and basic Japanese.

Some of you may have met Karen in her role with Blind and Low Vision where she has been volunteering for the last 7 years.

Macular Degeneration in the Asian community

Aged Macular Degeneration is more prevalent in some ethnic groups compared to others, people from a European background are at greater risk. Research has also indicated that Macular Degeneration is an increasing risk within New Zealand's Asian communities. This risk is impacted by changing risk factors including an aging demographic.

Concerned about this, one of Macular Degeneration NZ's focuses in 2021 will be to bring the message of awareness and education about Macular Degeneration to New Zealand's Asian communities.

We are currently looking at the best ways to achieve this.

If you would like to discuss this, offer support or suggestions please contact **Karen on our 0800 MACULA (0800 622 852) line, or email her at karen@mdnz.org.nz.**

CHINESE NEW YEAR



With the Chinese New Year being upon us we asked Karen Chong, our new Client Services Coordinator, to help those of us who only have limited knowledge about this special time of the year.

Chinese New Year is being celebrated on 12th February 2021, the first day of the Lunar Calendar, and it is celebrated over fifteen days.

I would like to share some idiosyncrasies of the Chinese community on how we celebrate Chinese New Year. Firstly, we do a big cleaning of our house before the actual day as it is taboo, especially to sweep the floor on the first day of Chinese New Year because it is thought that one will sweep all their wealth away. On the eve of the celebration, most families will come together to have a reunion dinner, where dishes that have significance and good meaning are served. For example, fish is a must have as the pronunciation of fish in Chinese sounds the same as the word that means "to have extra". Thus, eating fish means one will always have extras in life. Dessert usually includes

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round glutinous rice balls in a sweet syrup as this represents a sweet life ahead with no obstacles.

New clothes in bright colours like red, yellow, gold and green are worn on the first day of Chinese New Year, and some people even stay away from wearing anything black during the whole fifteen days of the celebration as black is the colour of mourning and is seen as bad luck. Red envelopes with money called "hong bao" are given to children or

those who are unmarried. I usually take the opportunity to visit family and friends during this time, always taking along a bag of Mandarins as the fruits represent "gold". Yes, as you can see, Chinese can be quite superstitious people!

Between 12 to 26 February 2021, you may wish your Chinese friends "Xin Nian Kuai Le", which is "Happy New Year" in Chinese.

Macular Degeneration seminars

Towards the end of 2020 we were able to deliver a few public and community seminars, after having cancelled or deferred some earlier ones due to Covid-19.



L-R: Phillippa Pitcher (outgoing General Manager of MDNZ) with Dr Heidi Eiseman.



Attendees at our seminar in Whanganui looking at the resources of and talking with Sight Support trust.

Gaye Stratton our educator was able to deliver several community seminars in Auckland, Phillippa Pitcher completed a number in the north of Auckland and even Anna Crane the new general manger got into the act, delivering two seminars to retirement homes.

Public seminars were delivered in Nelson, Blenheim and Whanganui.

Dr Antony Suter and Dr Connie Meredith completed the presentations in Nelson and Blenheim, respectively. These excellent presentations were very well received, and we are very grateful to everyone who attended these seminars, over 100 people in total, and to Sight Support Trust (who attended both) and Blindsided (who attended the Nelson seminar). Both organisations offer support and advice to people with low vision.

We were in Whanganui on the 14th November, where Dr Heidi Eiseman gave an great presentation to almost 100 people. Excellent questions were asked and it was a perfect opportunity for the community to meet Dr Eiseman who has recently arrived in the country.

It was really appreciated having Sight Support Trust and Blind Low Vision attend the Whanganui Seminar, again offering support and advice to anyone interested.

Seminars coming up in 2021

We are pleased to already have seminars planned in 2021. Thank you to the ANZ Staff Foundation who have kindly given funding for 5 seminars.

These seminars will be in:

Wanaka – 27 February 2021
3pm to 4.30pm (Lake Wanaka Centre)

Dunedin – 28 February 2021
1.30pm to 3pm (Toitu Otago Settlers Museum)

Dr Harry Bradshaw will be presenting these seminars.

Also confirmed are:

New Plymouth – 6 March, 10am to 11.30am (further details to be confirmed)

Albany, Auckland – 13 March, 10am to 11.30am (further details to be confirmed)

Waikanae – 10 April, 10am to 11.30am (further details to be confirmed)

Please register to attend these at

 www.mdnz.org.nz/public-seminar-sign-up or call us on

 **0800 MACULA (0800 622 852)**

There is also the opportunity to register an interest for attending seminars at Cambridge, Manukau/ East Tamaki, Taupo, Christchurch and Palmerston North.

Please go to  www.mdnz.org.nz/public-seminar-sign-up to register your interest.

We look forward to seeing you at a seminar this year.

Poached Salmon and Lemon Risotto

200g (6½oz) poached salmon, flaked
1 tablespoon light virgin olive oil
25g (1oz) butter
Sea salt
300g (9½oz) Arborio rice
Grated zest and juice of 1 lemon
600ml (1 pint) fish stock
2 tablespoons fresh parmesan cheese, grated
½ bunch flat leaf parsley, washed and chopped

Flake the salmon by gently pulling apart into bite-sized pieces. Heat a large heavy-based saucepan and then add the oil, half the butter, the onion and salt to taste. Cook

over a low heat until the onion is soft but not brown. Add the rice and stir for a few minutes to ensure all the grains are coated. Increase heat to high, add the lemon zest and juice. Heat the fish stock in a separate saucepan and gradually add to the rice, stirring continuously until all the liquid is absorbed. Add salmon and remainder of butter until melted and salmon is warmed through. The risotto should be quite wet and slightly runny. Sprinkle with parmesan and parsley and serve.

(Source: Eating for Eye Health, The Macular Degeneration Cookbook, Ita Buttrose & Vanessa Jones (Macular Degeneration Foundation, Australia))

Macular Degeneration New Zealand's Celebration

On the 23rd November 2020 Macular Degeneration New Zealand held an 11th birthday celebration at Foundation on George, Parnell.

Importantly it was also an opportunity to farewell Phillippa Pitcher who had been the General Manager of Macular Degeneration New Zealand for 8 years. During this time Phillippa oversaw the expansion of the organisation, always working to successfully deliver our core messages around awareness and

education of aged macular degeneration. Phillippa also had great success in securing the sustainability of Macular Degeneration New Zealand as a charity.

Our Chair Henry Ford, along with founding members Dr Dianne Sharp and Allan Jones all recognised the significance in Phillippa's work for Macular Degeneration New Zealand and thanked her for her passion and commitment to the cause.

The event was attended by current and past trustees, funders, volunteers and friends of Macular Degeneration.



L-R, Top to bottom: Phillippa Pitcher with Dinah Eichmann; Margaret and Ross Legh with Dr Dianne Sharp; Christie Murzello (Bayer New Zealand Limited), Diego Sonderegger (Device Technologies NZ Ltd) and Dr Andrew Thompson; MDNZ Trustees – Ross Legh, Steve Hayes and James Rangihika.

Life's a beach!

Some entries from our
"Beautiful New Zealand Views"
Competition



Top to bottom: Doreen Morrison (volunteer for MDNZ) and Niishahn Taan (Humanware); Helen Cisowski (MDNZ Designer), Phillippa Pitcher and Kat Day (Kindco); Everyone listening to the speeches; Shalini Raju (MDNZ Funding Support) and Ravneet Raju, with Chris Bradley (MDNZ Trustee); Jenny Springett (Eye Institute) with Lesley Springall (NZ Optics) and Anna-Louise Crane (new MDNZ General Manager).

Research Update on Treatment for Aged Macular Degeneration

Janssen Pharmaceutical, a Johnson & Johnson company, has bought the rights to Hemera Biosciences' gene therapy HMR59. This therapy consists of a one-time, outpatient, intravitreal (into the eye) injection to preserve eyesight in patients with geographic atrophy (Dry MD). Geographic atrophy is a late-stage, severe type of age-related macular degeneration (AMD).

“Geographic atrophy is a devastating form of AMD that impacts the ability to accomplish everyday tasks, such as reading, driving, cooking, or even seeing faces,” said James F. List, Global Therapeutic Area Head, Cardiovascular & Metabolism, Janssen Research & Development. “Our aim with this novel, single-administration gene therapy is to use our development expertise and deep heritage in vision care to help improve patient outcomes by intervening early, halting the progression to blindness, and preserving more years of sight.”

AMD patients often have low levels of CD59, a protein that protects the retina from damage caused by the body's natural complement immune response. In geographic atrophy, complement overreacts and destroys cells in the macula, the central part of the retina that handles central vision and fine details. This causes a “relentless progression to blindness.”


The gene therapy, HMR59, increases the ability of retina cells to manufacture a soluble

form of CD59. This helps prevent more damage to the retina and preserves eyesight.

Geographic atrophy affects about five million people around the world. It is the leading cause of blindness in people over 50 years of age.

Eye diseases are something of low-hanging fruit when it comes to gene therapies, because they can be directly administered to the eye, not systemically. Systemic gene therapies typically require being processed by the liver, which becomes a much more complicated mechanism of action and delivery.


To see original article* please go to:

 <https://www.biospace.com/article/janssen-pharma-buys-rights-to-hemera-s-macular-degeneration-gene-therapy>

Further from MDNZ

This possible treatment is in the early days of research and if it becomes available in New Zealand it is likely to be at least 18 months to 2 years (it will of course also need to go through the official approval process).

HMR59 is currently under FDA approved clinical testing for use in both dry and wet macular degeneration.

If you would like to know more about this, please go to  <https://www.hemerabiosciences.com/hmr59/>.

When we hear further updates on the trials, we will update you.

*Source: Biospace.com



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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)**



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For assistance phone

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Donations over \$5 are tax deductible.

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Beach Days!



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For further information contact MDNZ



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