



MACULAR
DEGENERATION
NEW ZEALAND

Viewpoint

The MDNZ Newsletter
Issue 11 – August 2018

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

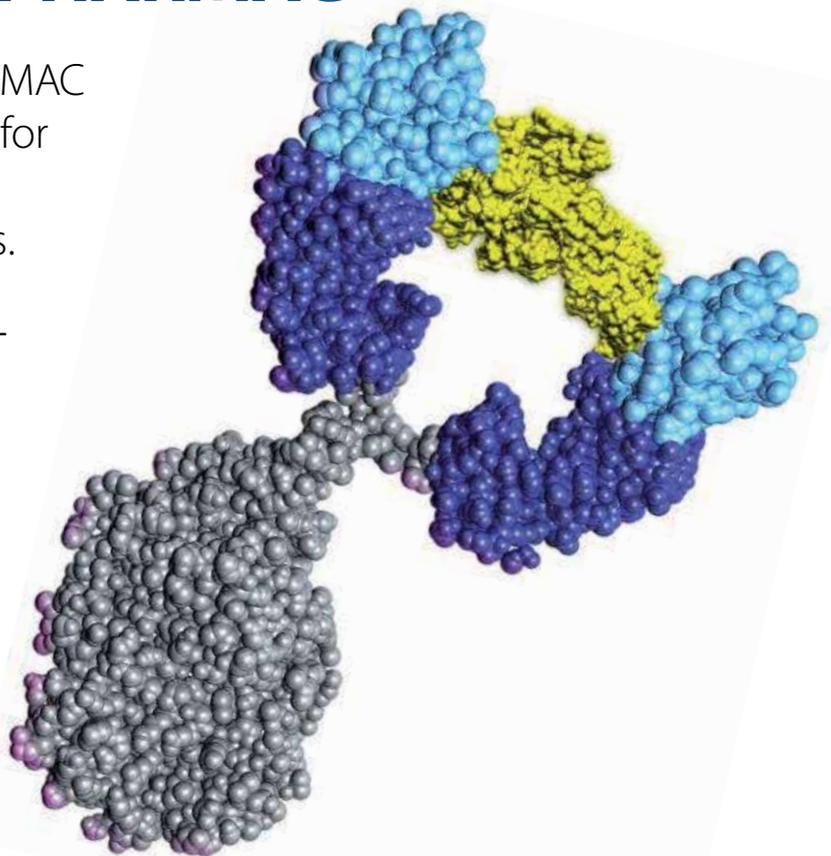
Good news from PHARMAC

Effective from 1 June 2018, PHARMAC has given the funding go-ahead for aflibercept (Eylea) for use in both hospital and community patients.

Aflibercept is a newer-generation anti-vascular endothelial growth factor (anti-VEGF) treatment that helps maintain and improve vision for people with wet age-related macular degeneration (wet AMD), diabetic macular oedema (DMO) and macular oedema secondary to retinal vein occlusion (RVO).

What is changing?

From 1 June 2018, aflibercept will be funded for patients in the community and hospital settings who meet specific criteria. PHARMAC fund aflibercept for use in wet AMD and DMO that is unresponsive to treatment with bevacizumab (Avastin). Aflibercept is not yet funded for the treatment of RVO. This means that patients who meet the funding criteria will be able to receive aflibercept treatment from DHB ophthalmology services or their private ophthalmologist.



Aflibercept requires less frequent administration than current treatments, such as Avastin, and is a funded treatment for both public and private patients. These factors will reduce the burden on DHB ophthalmology outpatient services in delivering sight saving treatment to patients with wet AMD and DMO and provide more flexibility for patients in terms of treatment options.

Seminars and Conferences

Demand for seminars continues and delivery of these depends upon us raising the funds to do so. Our Fundraising Manager, Sarah, is kept very busy applying for grants for seminars and all other activities that we undertake.

Whangarei Seminar

82 people came to hear local Ophthalmologist Dr David Dalziel make the presentation. He was accompanied by three of his Eye Centre – Prime Care staff and we were delighted to also welcome local Optometrist, Stephanie Wallen and GP, Dr Charlotte Foster from Whangarei Hospital.



Grey Power Howick/Pakuranga

76 people attended the branch AGM and a talk on Macular Degeneration was presented by General Manager, Phillippa Pitcher. Tracey Martin, Minister for Seniors, was also a guest speaker. Tracey advised us all of the launch of the Positive Ageing Strategy which was to take place later that day. This revision of the 2001 strategy is important as the world is a very different place today with a raft of changes in society, not least the increasing numbers of people over 65 and the predicted increases going forward. A discussion document has been prepared and individuals and groups are invited to attend public meetings and to submit their views.

Go to www.superseniors.msd.govt.nz/ageingpopulation to find out more and make a submission.



Pukekohe Seminar

Ophthalmologist, Dr Monika Pradhan addressed a large audience of 135 at the Pukekohe Anglican Church on 16 June. We were delighted to see so many people arrive and managed to find a seat for everyone. Support from volunteers, Kaye, Robyn and Doreen helped make the day a great success.

Dunedin Seminar

At the delightful Dunedin Art Gallery on a Saturday morning early this month local Ophthalmologist, Dr Harry Bradshaw, addressed 103 people who were eager to learn about macular degeneration. We welcomed a Pharmacist, an Orthoptist and two nurses – all keen to learn more so they can help their communities.



Retirement Village Presentations

We were very pleased to address a Ryman Retirement Village audience of 47 people at Lynfield, Auckland in July. They are patiently waiting to move in to their new village when completed and enjoy the Ryman lifestyle.

Also in July the Alandale Retirement Village in Hamilton invited us to make a presentation to 37 of their residents.

Bay of Plenty residents continue to be well informed about macular degeneration as MDNZ Ambassador and founding Trustee, Viv Jones, shares her inspiring story with the many groups who contact her. To read Viv's story go to the MDNZ website: www.mdnz.org.nz/stories/vivs-story

Coming up in 2018

Our new Community Liaison Educator will address the following local groups in Auckland:

- 11 September
Counties Manukau Grey Power at the Erin Park Retirement Village
- 9 October
Penrose Rotary Club at One Tree Hill College

Awareness and Education Seminars

Saturday 3 November	10am	Rutherford Hotel, Nelson
Saturday 3 November	2.30pm	Scenic Hotel, Blenheim
Saturday 10 November	10am	Copthorne Hotel, Masterton
Sunday 11 November	10.30am	East Pier Hotel, Napier
Saturday 24 November	10am	Katikati Community Hub, Katikati

To register your attendance please contact us on:
Our save sight helpline 0800 622 852 (MACULA)
Or email info@mdnz.org.nz



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VISION FOR
2020

Are you a star thrower?

"What is a star thrower?" you may ask. "What has this got to do with macular degeneration?" and "How do I know if I am a star thrower?"

To answer the first question, I would like to share with you a story..... Once upon a time, there was a wise man who used to go to the ocean to do his writing. He had a habit of walking on the beach before he began his work.

One day, as he was walking along the shore, he looked down the beach and saw a human figure moving like a dancer. He smiled to himself at the thought of someone who would dance to the day, and so, he walked faster to catch up.

As he got closer, he noticed that the figure was that of a young man, and that what he was doing was not dancing at all. The young man was reaching down to the shore, picking up small objects, and throwing them into the ocean.

He came closer still and called out "Good morning! May I ask what it is that you are doing?"

The young man paused, looked up, and replied "Throwing starfish into the ocean."

"I must ask, then, why are you throwing starfish into the ocean?" asked the somewhat startled wise man.

To this, the young man replied, "The sun is up and the tide is going out. If I don't throw them in, they'll die."

Upon hearing this, the wise man commented, "But, young man, do you not realise that there are miles and miles of beach and there are starfish all along every mile? You can't possibly make a difference!"

At this, the young man bent down, picked up yet another starfish, and threw it into the ocean. As it met the water, he said, "It made a difference for that one."

- adapted from *The Star Thrower*, by Loren Eiseley



What has this got to do with macular degeneration?

Vision for 2020 is an ambitious campaign to save the sight of the 615,000 people over 50 years old who are unaware of the disease. That is a lot of people and we appreciate that you are wondering how your contribution would make a difference?



We received this email the other day in the office that might answer your question.

"... I want to thank you very much for the information you sent me. I think it is important for you to know how much it meant to me. In fact as I read what was available with computers I was in tears with relief that I would be able to continue with the computer... Every time I have rung you have been absolutely wonderful and you should know you are making a difference for people."

How do I know if I am a star thrower?

Every time the young man threw a starfish back into the ocean, he made a difference to that star fish. Likewise, every bit of support you can give will make a difference to someone with macular degeneration.



Your support will provide:

- \$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.**

Meeting with the Minister of Health

In June, MDNZ Chairperson Henry Ford, Trustee and ophthalmologist Dr Andrew Thompson and General Manager Phillipa Pitcher met with the Minister of Health Dr David Clark in Wellington.

The meeting was part of a long-standing effort by MDNZ to obtain more support for macular degeneration awareness, early detection and treatment and the management of low vision in NZ. The Ministry of Health commissioned a report from Ernst & Young (EY) that was delivered to the government in August 2017. The purpose of the meeting was to pursue sign-off and action on the EY report and to highlight the inequity of access to anti-VEGF intravitreal injections that exists between and within district health boards.

There are several recommendations in the EY report that have already come to fruition, notably improved access to Eylea as a second-line agent for use when Avastin is ineffective in the treatment of wet macular degeneration. A national ophthalmology Expert Advisory Group (EAG), led by ophthalmologist Dr Stephen Ng, met in Wellington the same day as the meeting with the Minister of Health. The EAG is progressing initiatives to improve patient access to early diagnosis and treatment



of macular degeneration, an important aspect of the EY report.

Dr Thompson says, "There is no certainty around the signing off of the EY report, that is essentially a policy document on the model-of-care for macular degeneration in NZ. However, the meeting with the Minister of Health was positive. The Minister appeared receptive to the issue and our meeting was well-supported by a Ministry of Health representative".

MDNZ will continue dialogue with the Ministry of Health and Minister to ensure the report and its recommendations are actualised.

One free eye check annually for Gold Card Holders



This was an election promise of Hon Winston Peters of NZ First and features in the coalition agreement.

MDNZ, individually and collectively with the Eye Health Coalition, will follow this with interest to see that implementation follows best practice.



Professional Friends

We welcome new Friends:

Optometrists

Michael White, Whakatane & Opotiki
Tui Homer, Wanaka
Vanessa Cumming, Timaru
Cullen Szeto, Auckland

Ophthalmologists

Dr Oliver Comyn, Christchurch
Dr Ainsley Morris, Christchurch
Dr Peter Ring, Auckland
Dr Monika Pradhan, Auckland

To find a Professional Friend near you go to www.mdnz.org.nz

If optometrists or ophthalmologists would like to become a Professional Friend of MDNZ, please visit www.mdnz.org.nz, or phone 0800 MACULA (622 852).

Online learning for medical professionals in NZ



Understanding Macular Degeneration is a learning module available to all medical professionals.

Increasing numbers of professionals are registering and completing this module including nurses, optometrists, pharmacists, community health workers. CPD points are earned on completion.

Go to <http://www.mdnz.org.nz/resources> or to www.goodfellowunit.org

Eye Health Coalition (EHC)

MDNZ has joined with representatives of other "eye organisations" to work collaboratively and collectively on matters of common interest.

This group meets four times a year, making presentations in Parliament to the Parliamentary Friends of Eye Health, raising pertinent matters.

Members include representatives of:

- Ophthalmology
- Optometry
- Services Providers
- Academics
- Consumer organisations

EHC members meet with Parliamentary Friends of Eye Health in Parliament.



Volunteers

Where would the not-for-profit sector be without volunteers? Many thousands of hours work is undertaken across the world by individuals giving their time freely.

At MDNZ we are most grateful to have volunteers working with us in many ways. At each public Awareness and Education Seminar the local Ophthalmologist gives their time to make the presentation. At these seminars we often find staff from the local practice or hospital eye clinic come along to assist as well. These include practice managers, nurses, orthoptists – sure, they learn while they are there, but they are always willing helpers too. Many of these will have spent time with Kaye (our Client Services Administrator) in advance of the seminar,



Thursday volunteers, Margaret and Doreen.

providing us with valuable local information such as local media contacts, patients who are willing to have a story shared in the media and they help us identify local groups and places where we should send our flyers announcing the event.

MDNZ is also governed by a board of nine volunteers who meet four times a year to steer the ship and guide the direction of the charity.

Then we have the wonderful MDNZ Ambassadors who support us however they can, speaking to media, attending events and flying the MDNZ flag.

In the office we have three lovely volunteers - Margaret, Doreen and Vicky, who provide valuable help each week.

Thank you all.



Tuesday volunteer, Vicky.

Welcome to our Community Liaison Educator

In June we contracted Gaye Stratton to commence in the role of Community Liaison Educator. Gaye is involved in other contracted work and is able to undertake the 15 hours per week to get this role underway. She has a background in human resource management ranging from strategy to implementation and she has worked in a range of industries, coaching and leading professional development and career transition. Gaye is a certified toastmaster and as an experienced presenter she works with individuals to coach them in public speaking. The 15 hours per week will be variable with the aim to have around 60 hours per month dedicated to providing community seminars as well as representing MDNZ at conferences and the public seminars at which local Ophthalmologists make the presentation. Gaye has a relative with AMD and understands the difficulties of daily life with this eye disease.



Gaye shares a favourite recipe that is good for your eye health.

One-pan Garlic Butter Beans with Sumac, Kale & Feta

Ingredients

2 Tbsps olive oil	4 cups chopped kale
1 onion, chopped finely	1 tsp lemon zest
3 cloves garlic, sliced thinly	1/4 cup lemon juice
2 tsp sumac	Salt and pepper to taste
1 Tbsp finely chopped red chilli	100g crumbled feta
1 1/2 cups butter beans, rinsed	1/2 cup chopped mango (optional)

Method

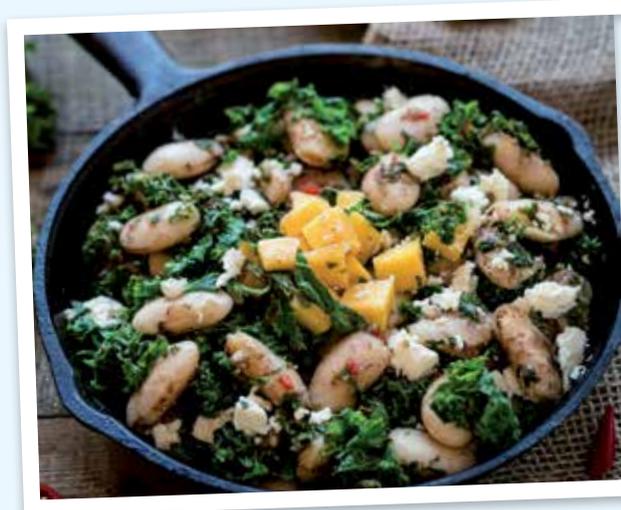
Heat the oil in a frying pan to a medium heat. Add the onion and garlic, cooking for 4 minutes to soften.

Stir through the sumac and chilli until fragrant. Add the butter beans and brown slightly.

Add kale, zest and juice and cook until wilted.

Season to taste with salt and pepper.

Crumble over the feta and serve warm, topped with mango, if using.

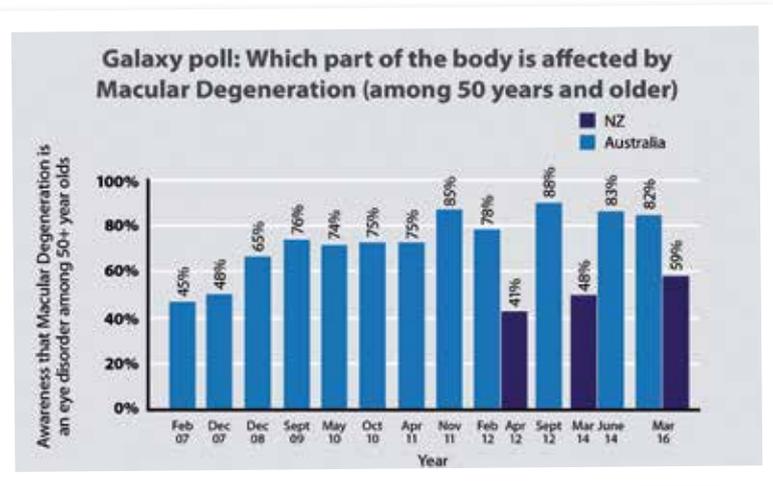


By Angela Casley: www.bite.co.nz (1 June 2018).
Image courtesy of NZ Herald.

How do we measure awareness in New Zealand?

Since 2012 MDNZ has undertaken a bi-annual Galaxy Poll to measure awareness. We have chosen the same research company as the Australian Macular Disease Foundation, which enables us to make comparisons and provides us with goals to achieve.

Australia is world renowned for its high levels of successful eye health outcomes, has a similar demographic to NZ and after all, they are our neighbours and we like to compete with them, don't we?



Our **Vision for 2020** campaign has a goal to reach 80% in the measure of people over 50 knowing what part of the body is affected by macular degeneration. You will see from this graph that we have done well in the past few years. We need to know where we are up to now in 2018 so that we know how big the 'reach' will be by the end of 2020.

Ideally we would like to continue to measure awareness using the same Australian company and therefore have access to the Australian results as a comparison. These results are useful to take to funders and sponsors of our services, to show what we are achieving. This research costs some thousands of dollars and unfortunately most NZ grantors do not fund outside of NZ.

Can you help us?

What we need is to find five or six individuals or businesses that will each donate \$1,000 to MDNZ to allow us to have an updated poll completed in September. Could this be you, or do you know of someone who would be willing to support this?

Donations can be made:

- Online at www.mdnz.org.nz/donate using your credit card
- Post a cheque in the mail to MDNZ, PO Box 137070, Parnell, Auckland 1151

Count down to Christmas

Can you believe it's just four months to Christmas?

Many of you will soon be thinking about sending Christmas cards to clients or friends – especially those overseas.

Once again The Giving Tree is providing MDNZ with the opportunity to raise funds by you selecting their Christmas cards and choosing MDNZ as your charity.

Why not get in nice and early this year by going to www.thegivingtree.co.nz





Thank you, thank you, thank you generous donors. You have responded to our call for support to raise awareness and educate people about this hideous eye disease. To date you have raised \$100,000.

You are our stars.

Your support by a single or regular donation means we now have an educator in the community raising awareness. Thank you also to those who have shown an interest in leaving a gift in their will.

You are making a difference. But we're not there just yet – your continued support will provide:

\$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 on info@mdnz.org.nz or call **0800 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 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)

Cheque (enclosed)
 Credit card VISA / MasterCard (circle one)

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
or Fax 09 307 2021**

For assistance phone
0800 MACULA (0800 622 852)

Donations over \$5 are tax deductible.

Seminars & Conferences



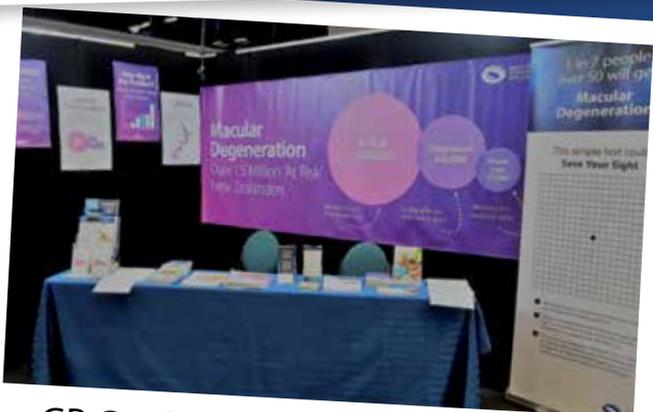
Whangarei



Dunedin



RANZCO NZ Conference, May 2018



GP Conference Rotorua, June 2018

Collaboration with Glaucoma NZ

Unfortunately many people in the age group that are prone to getting macular degeneration are also prone to getting Glaucoma and Viewpoint Issue #10 provided an article comparing these two eye diseases.

We are delighted to be working together with Glaucoma NZ (GNZ) when we can and in April GNZ invited MDNZ to share an exhibition stand at the Retirement and Lifestyle Expo in Ellerslie, Auckland for the weekend. MDNZ was represented by Sarah who worked with Ana (GNZ) to greet the many hundreds of people showing interest.



More about Charles Bonnet Syndrome

Many of you have commented on our previous articles about Charles Bonnet Syndrome.

A most interesting TED talk is presented by the Macular Society UK through the following link:

<https://youtu.be/UEgTNLAAngY>