



MACULAR
DEGENERATION
NEW ZEALAND

Viewpoint

The MDNZ Newsletter

Issue 14 – September 2019

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

DHB elections coming up in October



District health boards (DHBs) are the governing bodies responsible for overseeing the delivery of health and disability services in their districts.

They set strategic direction and monitor its performance. DHB elections are part of the local authority elections where voting takes place to elect members to DHBs.

When considering who to vote for in your region you might like to ask any of the following questions of the candidates:

- Do you know macular degeneration is the leading cause of blindness in the over 60 population, yet there are treatments available for it?
- Do you know about the waiting lists for macular degeneration treatment in your local DHB? Are they satisfactory?
- Are patients with macular degeneration having their appointments delayed?

- The same level of treatment should be available to all across all DHBs but unfortunately it isn't. Why? Ref: www.mdnz.org.nz/resources/news-and-media-releases

"Where You Live Determines How Well You Can See"

- Do you know if your DHB is on target to fully implement the national guidelines for treatment of macular degeneration within the expected timeframe?
- Why do some DHBs treat all retinal conditions that benefit from Avastin and other DHBs restrict treatment to only macular degeneration for example?

FACTS

48% of people over 60 have vision loss caused by macular degeneration.

1 in 7 people over 50 are affected by macular degeneration and 41% of that age group do not know about it.

Thank you

to our sponsors, funders and supporters in the last year

The work of Macular Degeneration NZ has been made possible in the last year due to the support and contributions from the following:



Science For A Better Life



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Cataracts can 'cloud' vision and 'hide' Macular Degeneration

Hamilton-man Stephen James, 89, was diagnosed with macular degeneration four years ago when he had cataracts removed from both eyes.

"I knew I had the dry form of macular degeneration, called Drusen," says Stephen, who notes that the cataracts may have prevented him from noticing the symptoms of the more aggressive wet macular degeneration and getting the early diagnosis so crucial to saving patient's central vision.

"It was a shock. Luckily my daughter was with me. She is a nurse, so she understood what Dr Worsley was saying and was able to explain to me anything I didn't understand about the diagnosis."

Stephen now has injections in both eyes every seven weeks. He has been able to preserve some of his sight through treatment although his independence has been affected.

"I do struggle to read, and need big print books – I can't read the newspaper at all," he says. "I often drop letters off the end of words. I worked in finance and I like to keep my books up to date, but when I go down the columns I might change columns or miss a figure."

He also voluntarily gave up driving two



years ago, which means he is more reliant on others.

"I didn't feel comfortable behind the wheel. If I had an accident, I couldn't stand the thought of it."

Stephen says that when he was first diagnosed with cataracts he was warned about MD.

"My specialist retired shortly after my cataracts were diagnosed, and it took me a while to find someone else," he says. "I should have gone to see someone sooner. Thankfully it was caught early enough to hold back some of the more severe symptoms, but early diagnosis and treatment are essential."

Charles Bonnet Syndrome

Charles Bonnet Syndrome (CBS) is a common condition among people with severe vision loss. It is characterised by temporary visual hallucinations.

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. Visual hallucinations or phantom images can be extremely vivid and realistic and range from simple, repetitive patterns to detailed images of people, animals or buildings. About 30% of people who experience major vision loss experience this. The images are a consequence of losing sight whereby the brain attempts to compensate for the gaps in vision.

The signs and symptoms of Charles Bonnet Syndrome include:

- Significant vision loss
- Visual hallucinations
- No control over the hallucinations
- A realisation that the hallucinations aren't real.

Antigonish is an 1899 poem by American educator and poet William Hughes Mearns. It is also known as "**The Little Man Who Wasn't There**".

Perhaps this poem is describing the experience of Charles Bonnet Syndrome.

*Yesterday, upon the stair,
I met a man who wasn't there!
He wasn't there again today,
Oh how I wish he'd go away!"*

*When I came home last night at three,
The man was waiting there for me
But when I looked around the hall,
I couldn't see him there at all!*

*Go away, go away, don't you come
back any more!
Go away, go away, and please don't
slam the door...*

*Last night I saw upon the stair,
A little man who wasn't there,
He wasn't there again today
Oh, how I wish he'd go away...*



Lions Club support in Hamilton



A seminar in Hamilton in May would not have been possible without the local Chartwell Lions club, who hosted the event and made a significant donation to awareness and support programmes delivered by Macular Degeneration New Zealand.

“Lions, traditionally, have been very involved in issues around sight,” says Lucie Armstrong from Chartwell Lions. “Not a lot of money in New Zealand is spent on the issue of vision awareness. I believe it’s important that people have the knowledge they need to preserve their vision as they age. Call it a community service, but I felt it was important Lions got involved and helped raise funds to make this event possible.”

“My optician is amazing!”

says Shirley Benton

In 2013 Shirley went to see her usual optometrist in Hamilton, thinking she might need new glasses. Her optometrist recognised the signs of macular degeneration straight away and he referred her to ophthalmologist, Dr David Worsley.

Shirley never developed wet macular degeneration, but it has progressed to a point where she is now visually impaired.

“People say, ‘oh! That’s terrible!’ but I think I’m lucky. I’m healthy and active with no other disabilities. I’m glad it’s happened now while I’m still able to

do things for myself and put things in place for the future.”



Dr David Worsley and Shirley Benton at our Hamilton seminar

Shirley got lots of offers of help from neighbours and friends, but is determined to maintain her own independence. “Dr Worsley helped get me registered with the Blind Foundation, who did an assessment at my home and supported me to use public transport as I can no longer drive.” With a bus stop right outside the door and regular services, Shirley finds she can go anywhere in Hamilton with only a short walk from the bus stop to her destination.

“My vision is very blurry with a black spot in the middle. I find I can only see the outline of things,” she explains. “But if I need to cross the road I just get my folding white stick out and stand at the side. Cars usually stop for me.”

Shirley remains active, walking frequently and going to Pilates.

“It’s a big change, but I’ve got a positive attitude. I decided when it happened I would not give up anything, and I haven’t. I’m coping well.”

Public seminars and GP Conferences

Since May 2019 Bayer NZ has sponsored the delivery of three very well attended public seminars across the country. Thanks to our willing Ophthalmologists for giving their time on a Saturday morning.

In Palmerston North Dr John Ah-Chan made the presentation to 134 people.

In Orewa Dr David Squirrell made the presentation to 192 people.

In Ashburton Dr Ainsley Morris made the presentation to 170 people.

We are attracting large numbers to these seminars which tells us that people want to know about macular degeneration – the risks, the treatment, diet and lifestyle choices, the support and management guidelines.

The medical professionals attending annual GP conferences are very interested in the developments in macular degeneration and thanks to funding from Bayer NZ we usually manage to get to two each year.

In June MDNZ and Glaucoma NZ shared a stand at the NZME GP conference (right) and in July MDNZ had a stand at the Royal College of GPs conference in Dunedin (far right)

Public seminars yet to come

31 AUGUST Rotorua Dr Neil Murray, sponsored by Rotorua Eye Clinic

30 NOVEMBER Auckland
Dr Dianne Sharp

2 NOVEMBER Waikanae –
to be confirmed


19 OCTOBER Oamaru –
to be confirmed



MISSED A SEMINAR?

Watch it online at www.mdnz.org.nz/awareness-and-education-seminar



Please call  **0800 MACULA (0800 622 852)** To register your attendance. Tell people you know who may be interested in those areas. Let us know how you can help us hold a seminar near you.



Picture supplied by the Ashburton Guardian.

Jim Kennedy – My story still reading and rug making

Two of my hobbies are reading and rug making, and both require being able to see clearly. For latch hook rug making I need to distinguish colours printed on the canvas and follow a graph with symbols representing different coloured yarns to produce the pattern. Five years ago, I started to notice changes in my vision.

The first sign something was wrong was lack of light, the room always seemed dim. Even on a bright sunny day I was finding it difficult to distinguish colours and book reading was becoming difficult. I started having difficulty recognising people and their faces seemed to be a blurry hole. Writing appeared as wavy lines. One time I was slicing vegetables and I was having trouble with co-ordination between the knife and the product, and judging distance was a problem. These symptoms all became apparent over a short time period of five or six weeks.

As luck would have it, I had an appointment booked with my optometrist for a regular

eye check. After checking my eyes, he told me I had macular degeneration. He rang the registrar of Dunedin Hospital's eye department and I had an appointment within three weeks. Treatment with Avastin commenced straight away. Initially the problem was only in my left eye which stabilised after eighteen months when MD started in my right eye, so treatment was started and continues to this day. My wife and I moved to Canterbury early 2017 and the care from the staff and treatment from both the Canterbury and Southland DHB's has been professional, caring and very efficient. I would highly commend the eye departments of both DHB's.

Macular degeneration is becoming more common especially in the older age group. One of the known causes is smoking, another could be hereditary. I was a smoker for a while. My mother also suffered from macular degeneration and went blind as in those days there was no treatment available.

Macular degeneration can occur rapidly. I would encourage anyone who notices any small changes in their eyesight to visit an optometrist or their doctor and get their eyes checked or have regular eye checks with an optometrist. We are very lucky to have a treatment for the most common form of macular degeneration. The treatment usually involves an eye test, eye scan and an injection with Avastin, it is painless and easy. Personally, I am grateful that my macular degeneration was detected and treated quickly and that I can continue to read, make Latch-hook rugs, drive a car, go to the movies and live life to the full.

VISION FOR

2020 REPORT CARD

Vision for 2020 Making a Difference in your Community

Many more people around New Zealand are benefitting from seminars and presentations about macular degeneration than ever before. Thanks to the Freemasons Foundation, MDNZ was able to engage a Community Educator as part of the Vision for 2020 Project. The Vision for 2020 Project aims to raise awareness to 80% of those at risk by the year 2020 to save sight.

In the past year, the Community Educator has organised and delivered many presentations throughout the country. Attendees reflect on how the seminars have benefitted them:

“Lots of interesting information. So pleased I came with my mother who is about to have her first injection. Thank you”

was feedback received from a Pukekohe seminar participant. For many people newly diagnosed with macular degeneration there are a lot of questions and often eye health professionals don't have time in clinic to go into detail.

This is where MDNZ steps in with a detailed presentation about macular degeneration and an opportunity for participants to ask questions at the end. *“I was aware, but this education has expanded my knowledge greatly and most usefully.”*

Seminar and Presentation Locations Aug 2018 – Aug 2019



Being diagnosed with macular degeneration can be a frightening experience and the fear of going blind is real. A Blenheim resident said they felt *“... great comfort & hope to learn about this challenge and the help available. Thank you so much for providing this seminar”*.

The seminars aim to demystify the disease and show people that it is possible to live a good life with macular degeneration. *“The talk has certainly alleviated some of my anxiety around MD. I have a better understanding of MD and the difference between wet and dry.”*

The seminars have also benefitted family members, who can better understand what their loved one is going through and that they too may be at-risk. A Dunedin participant explains *“Thank you, very helpful... helping my husband and passing on the hereditary facts to our children.”*

With 1.5 million people in New Zealand at-risk of macular degeneration and 615,000 of them unaware of the disease, there are many people still to reach. This is where MDNZ relies on health professionals to be proactive and spread the word.

Following a seminar in Nelson, a nurse recently said *“Thank you. I am a practice nurse and am involved in appointments for driving licence renewal. I will amend documents so we can add a test for MD into the nurse consultation.”* and an Invercargill participant adds *“Well presented facts. Invaluable information. I leave as a better-informed person, able to pass on this information. Thank you.”*

But most importantly the presentations have empowered people to take action to look after their eye health and save their sight. From Takapuna *“Good speaker with a message that was easy to understand. This has motivated me to have a long overdue eye test as soon as possible”*

..... to Palmerston North *“Extremely worthwhile. I don't know if I have MD but will go to the optometrist and have a check. Family member has it.”....*

....and down to Nelson *“Thank you for this informative presentation. I don't have MD in my functioning eye but have now a good awareness and will be proactive.”* ...the seminars are inspiring people to be informed and take action.



Thanks to the Freemasons Foundation, part of our work has been done and awareness has been raised, yet we still have much more to do, to stop avoidable blindness.

An Orewa Seminar Attendee understands the importance of awareness and education *“I wish more people could have come as the basic explanations were excellent and many people need to know more about it.”*

Please turn over the page to see what you can do to help make a difference for your community.

MDNZ Professional Friend Programme



We value the commitment and support to patients around New Zealand and to MDNZ made by Optometrists and Ophthalmologists who are members of the MDNZ Professional Friend Programme.

Check the MDNZ website to find one of these wonderful eye health professionals near you.

Currently there are 50 individual and

3 practice members of Optometrists, and 21 individual and 2 practice members of Ophthalmologists.

We welcome new Professional Friends since the April issue of Viewpoint:

Ophthalmologist Practice

Rotorua Eye Clinic

Optometrist Practices

Vivian Edgar Optometrists, Te Puke

Low Vision Services, various locations in Auckland

MDNZ continues dialogue with the Ministry of Health

Macular Degeneration New Zealand Trustee and Tauranga Ophthalmologist, Dr Andrew Thompson, and General Manager, Phillippa Pitcher, met with Ministry of Health officials in June.



The purpose of this meeting was:

- to seek an update from the ministry on progress with the implementation of the one annual free eye check for Supergold cardholders, which was a coalition policy introduced by NZ First,
- to seek assistance with supporting the work of MDNZ in raising awareness and saving sight.

¹The May 2018 government budget included a one-off contribution to develop and scope options for providing one free annual health check to Supergold cardholders (approximately 723,000 New Zealanders). This scoping will be undertaken by the Ministry of Health in 2018/19.

The complexities involved (and therefore costs) in providing a comprehensive and adequate eye test were providing a stumbling block to progress. We understand it has not gone away, although the update now on the MoH website says – ‘No further information about the check or anticipated start dates are available at this time’.

Suggestions were made to us of a variety of awareness activities we could ‘try’, with no sign of support to date. There is more work to do and 2020 being election year will be the time to ask of candidates who are standing for election what they will do.

¹ www.health.govt.nz

VISION FOR

2020

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.

"No one has ever become poor by giving." Anne Frank

Bequests

Have you thought about leaving a gift to support the future work of MDNZ and its aim to reduce the incidence and impact of MD in New Zealand?

Contact us to find out more on info@mdnz.org.nz or call **0800 MACULA (0800 622 852)**

"Great things are done by a series of small things brought together" Vincent Van Gogh



MACULAR
DEGENERATION
NEW ZEALAND

Please donate to support those with MD

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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.



Dr Ainsley Morris making presentation at Ashburton
Picture supplied by Ashburton Guardian



The Blind Foundation and Humanware support the MDNZ seminars by making low vision aids available for people to view and handle.



View of the crowd at Hamilton

For further information contact MDNZ



www.mdnz.org.nz



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