



MACULAR
DEGENERATION
NEW ZEALAND

Viewpoint

The MDNZ Newsletter

Issue 12 – December 2018



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

Founding Trustee and Ambassador, Viv Jones, receives Local Hero Award

Congratulations to founding Trustee and MDNZ Ambassador, Viv Jones, for being awarded a Kiwibank New Zealander of the Year Local Hero Award for the Bay of Plenty region.



Viv Jones is an amazing woman. She has overcome her own difficulties and has been committed to changing the lives of others for nearly ten years now. Viv has been speaking

to groups throughout the Bay of Plenty, highlighting the importance of regular eye examinations to check their eye health and recommending people share this information with their families and friends.

Viv tells her story of being diagnosed and losing vision, plus the shock and the impact

of living with vision loss due to macular degeneration, which she does every day with her extremely positive attitude.

People really relate to Viv's story and adhere to her advice about early detection. Thanks to Viv, the Bay of Plenty is streets ahead in awareness raised and people taking action to save their sight. 66% of Bay of Plenty residents get their eyes checked compared to 56% nationally, according to a Galaxy Poll conducted in October 2018.

Viv has worked tirelessly to help save people's vision. She has spoken to over 2,500 people in the past 3 years and as a result, awareness of macular degeneration in the Bay of Plenty is higher than the rest of the country.

Congratulations Viv for this well-deserved award.

Viv continues to work tirelessly to. She is an excellent role model of someone in our society who steps out of her comfort zone to educate others and to lead change in our society.



Artificial Intelligence and eye disease

Hailed as a “jaw-dropping” breakthrough, computers can use artificial intelligence (AI) to effectively diagnose eye disease such as macular degeneration. Moorfields Eye Hospital in London has been conducting research into the use of AI to assess OCT scans of patients with retinal disease.

AI is the imitation of human cognitive processes by a machine in which computer algorithms learn from data without human direction. It is already in use in various consumer technologies such as Apple’s Siri in the iPhone. Such advances are expected to continue and accelerate.

There are several research projects currently being undertaken internationally that are evaluating the use of AI technology in eye disease. One such recently completed study (De Fauw et al, 2018) used 14,884 high definition OCT

retinal scans to teach the computer how to spot features of eye disease. AI technology looks for signs such as haemorrhage and fluid leakage, and has the ability to adapt to different types of retinal scanners.

Scans were then taken from 1000 patients at Moorfields Eye Hospital and given to the computer to analyse. Results were compared to those read by 4 ophthalmologists and 4 specialist optometrists.

Both the computer and clinician groups were asked to decide whether a patient required urgent referral, semi-urgent referral, routine referral or observation. The results were incredibly accurate with the AI system achieving, and in some cases exceeding, expert interpretation by clinicians.

Benefits include earlier time to assessment and diagnosis for patients and the ability to prioritise patients for assessment at a much earlier stage than is currently the case.

AI is not going to replace consultant ophthalmologists. AI will not be used to simply recommend a patient for an injection into their eye on the basis of a machine-generated response. However, it will ensure patients see an appropriate specialist at the earliest possible point, get treatment early and result in better visual outcomes for patients.

AI is also being used to increase the speed and accuracy of diabetic retinopathy

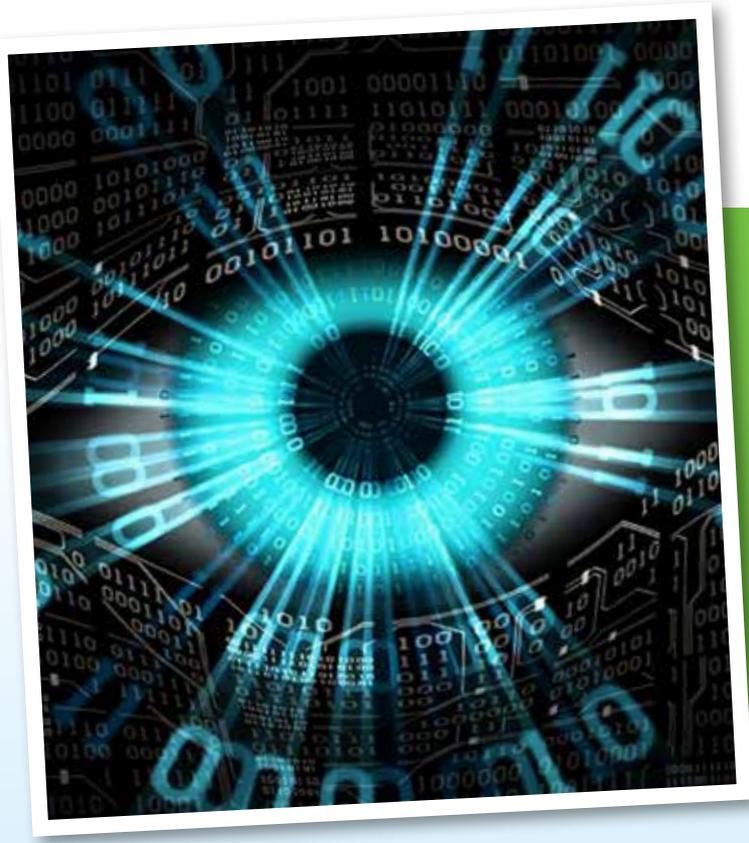
screening and will likely result in earlier detection and treatment (Fogel AL, *et al.* 2018).

Ongoing research into AI technology is necessary to ensure the technology is robust and continues to meet a standard comparable to clinical experts.

References

De Fauw J, *et al.* Clinically applicable deep learning for diagnosis and referral in retinal disease. *Nat Med.* 2018 Aug 13. [Epub ahead of print].

Fogel AL, *et al.* Artificial intelligence powers digital medicine. *npj Digital Med.* 2018 Mar 14. www.nature.com/npjdigitalmed



Wishing you all a very festive Christmas and happy holidays.

From all of the team at Macular Degeneration New Zealand: Trustees, staff and volunteers.



Video clips to view over the holidays

Awareness and education seminar (in case you missed a seminar this year)

Dr Andrew Thompson

www.mdnz.org.nz/awareness-and-education-seminar

A patient story – Ross Legh

www.mdnz.org.nz/rosslegh

What is Macular Degeneration?

www.mdnz.org.nz/what-is-macular-degeneration



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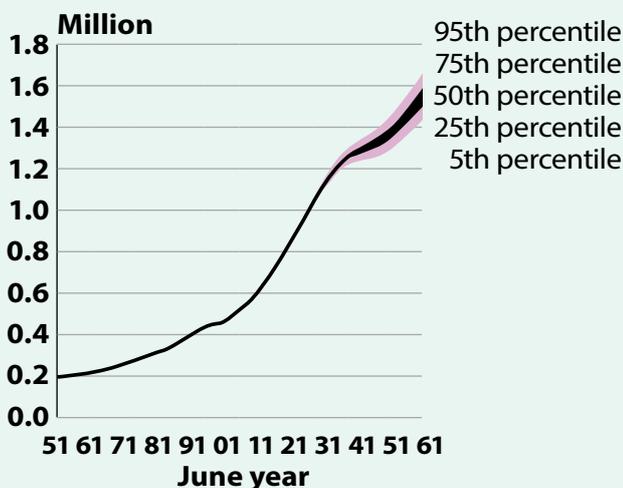
VISION FOR
2020

VISION FOR 2020: Reporting back, one year on

Just over a year ago, we came across a graph that really stunned us.

Population aged 65+ years

1951-2061



Source: Statistics New Zealand

We knew the statistics, and that as the population ages, the incidence of macular degeneration will increase, but this graph really hit home. We felt like we were standing near the bottom of an Awareness Raising Mountain that would require extra effort to scale.

That is when Vision for 2020 was born, the more people we could reach now to raise awareness of macular degeneration, before they turn 65, the more sight will be saved.

Early this year, we received the following email:



"Hello Kaye. I have both wet and dry MD. It was diagnosed the week before Christmas 2017 when I had a bleed in my right eye. (Up until then I had no idea I had MD). I am now legally blind in my right eye, and have dry MD in my left eye which is a real worry. I am 71 and still work part time. Many thanks, Lesley"

We needed to act now, so others would not be in Lesley's situation.

We knew we couldn't do this by ourselves. We set an ambitious target of raising at least \$150,000 per year devoted entirely to awareness raising and turned to you for your help.

Now at the end of the first year, we want to offer a huge thank you to all who responded to our call and gave your support. Thanks to you, we have raised \$130,000 in our first year. Your support means that we have been able to:

- 1. Engage Gaye Stratton as a community educator.** Gaye has been out and about in communities around New Zealand delivering seminars and presentations to over 800 people since June 2018.
- 2. Mailed out and distributed hundreds of free information packs and resources to people in need.**
- 3. Staffed the 0800 Save Sight Helpline** where every day we receive calls for assistance and support.

Thanks to your support, we were able to help people like Lesley:



"Hello Kaye. 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. Thanks again, Lesley."

We are now into the second year of Vision for 2020 and while last year we were able to help Lesley and many others like her, we still have a way to go.

MDNZ would really appreciate your support to reach people like Lesley before they lose their sight. If you are able to offer an annual or monthly contribution that would make a huge difference.

We are hoping in the coming year that we can afford to have more educators out and about reaching more people in more locations around New Zealand.

Every little bit helps, your contribution enabled us to reach \$130,000 last year. Please help MDNZ reach \$150,000 this coming year.

VISION FOR 2020

What we need to do

Amsler Grids in our community – This simple test could save your sight ...

- 1 Wear any glasses or contact lenses that you normally use for distance or looking at the TV.
- 2 Stand well back from the grid. Cover one eye with your hand and focus on the centre dot with the uncovered eye. Repeat with the other eye.
- 3 If you see wavy, broken or distorted lines, or blurred or missing areas of vision, you may be displaying symptoms of macular degeneration and should contact your eye care professional immediately.

What MDNZ is doing now

- New Zealand Awareness raised as funding allowed
- Bay of Plenty MDNZ Ambassador dedicated to raising awareness
- Awareness of Macular Degeneration in 2018 (Galaxy Poll Oct 2018): NZ 59%, BOP 68%
- Presentations in past 3 years (2016-2018): NZ 108, BOP 42
- Seminar attendees in the past 3 years (2016-2018): NZ 6,604, BOP 2,426

80% Awareness: Our Vision for 2020

* The sharp increases in Australia's awareness (2007-2011) was as a result of national TV Awareness Campaigns.

New Zealanders are getting older

Today, we are at the cusp of the most significant demographic change of the 21st century. **BY 2030, 1 IN 4 PEOPLE WILL BE OVER 65 YEARS OF AGE.**

This group will also be living for longer than previous generations. This bulge will not pass with time. We need to be proactive to save sight and ensure wellbeing in old age. This is one of New Zealand's most pressing issues.

What we do works, we just need to do more: The Deloitte Report concludes:

"An increase in awareness and education of Macular Degeneration would lead to reduced burden of Macular Degeneration through timely and adequate provision of treatments."

"...awareness campaigns were found to be cost effective based on World Health Organization benchmarks."

The Deloitte Report states that a \$2.8 million investment in macular degeneration awareness will save over \$70 million a year.

The Report clearly shows that the economic, social and personal cost of the status quo is too big to ignore.

MACULAR DEGENERATION NEW ZEALAND | **VISION FOR 2020**

Seminars and Conferences

Seminars continue to be the primary contact made by MDNZ to people in the wider community, spreading the awareness message far and wide. The pace of community seminars has increased significantly since Gaye has joined our team as our Community Liaison Educator.

Since August we have delivered 7 Ophthalmology led seminars in Dunedin, Nelson, Blenheim, Whangarei, Masterton, Napier and Katikati with a total of 642 attendees. Thank you to Drs Suter, French, Dalziel, Maslin, Beaumont and Thompson.

The Bay of Plenty has continued to be well catered for with Ambassador, Viv Jones, speaking to 216 people at 5 talks during that time.

Gaye has made 13 presentations around Auckland spreading the message to 221 people.

Open Day BUPA Wattle Downs



Penrose Rotary



Grey Power Manurewa

Awareness and Education Seminars

Coming up in 2019 we have public seminars planned for:

Greymouth Saturday 26 January 10am
Invercargill Saturday 23 March 10am

To register your attendance please contact us on:

-  Our save sight helpline **0800 622 852 (MACULA)**
-  or **email info@mdnz.org.nz**

Please tell people you know in these areas and invite them to contact us.

Watch for further details on the MDNZ website for other seminars as they are funded and confirmed. www.mdnz.org.nz



Routine eye check helps save sight after disease diagnosis...

Wendy's story

Blenheim resident, Wendy Reynolds was struggling to attend dog shows around the country as her eyesight deteriorated.

The white lines on the road seemed to wobble slightly as she drove, but Wendy put occasional problems with her sight down to age.

However, the elder care co-ordinator was experiencing symptoms of a disease that could have left her blind. A routine eye check uncovered the condition, macular degeneration, and Wendy wants to warn others to get regular eye checks.

"Just sometimes when I was driving, the lines on the road wobbled and seem to

split. I wear glasses and thought I just needed new ones.

"I went in for an ordinary eye test and the optician said he was sorry to tell me that I needed to see a specialist straight away. But even then I didn't really think anything of it," she said.

"I hadn't even heard of it before, I thought the optician was probably just being overly cautious. I was quite blasé about it really," Wendy said.

"I saw a specialist privately and he told me that I needed to have injections in my eyes for the rest of my life and that if I didn't, I could go blind. It was a shock."

Wendy was getting regular Pharmac-funded Eylea injections, which had improved the condition in one eye. But she said her left eye had proved more problematic.

The proud owner of a new \$120,000 mobile home, Wendy said she was worried that one day she would not be able to drive it.

The keen animal lover, who shows her pedigree poodles around New Zealand, said the disease had sometimes made it more difficult to attend events.

"Today, my eyes are clear but get worse when I'm tired. I remember one day grooming one of my poodles when it looked like the table was buckling but of course it wasn't."

"I don't know what's ahead with my eyes but I don't really have a choice if I want to keep my sight."

"All this from a routine check - it's just so important to see an optician," Wendy said.

Based on an article by courtesy of www.stuff.co.nz/marlborough-express

Blue light toxicity and the eye



Several studies have been published in medical literature regarding high-intensity blue light inducing retinal cell death.

This leads to questions regarding the effect of blue light emitted from displays of smart phones, monitors, televisions, and whether this blue light has the same effect on the health of retinal cells.

One study examined this question and investigated the effect of blue light emitted from various devices. It showed that blue light increased the production of reactive oxygen species (ROS), especially with a shorter wavelength of 449 nm. The study concluded that blue light hazard from display devices might be greatly reduced if devices contained less short wavelength blue light (Moon J *et al.* *Integr Biol (Camb)*. 2017;22: 436-443). Some smartphones can remove blue light from their display.

A difficulty with such studies is that they are laboratory based and not necessarily applicable to the body's natural state.

Another study concludes that exposure to blue light in the range of 470 to 480 nm for days to weeks should not significantly increase the risk of development of eye disease. However, this finding cannot be generalised to long-term exposure (months to years). More studies are required to

determine the effects of blue light on the eye (Tosini G *et al.* *Mol Vis*. 2016;22:61-72).

The natural crystalline lens of the eye grows larger and more yellow with increasing age, (i.e. a cataract forms). This results in decreased transmission of light, especially of short blue wavelength light. To address blue light toxicity, intraocular lenses commonly contain a blue light filter in the lens to mimic the natural crystalline lens absorption and transmittance properties of blue light. This prevents short wavelength blue light reaching the retina.

Controversy still exists around blue light toxicity in real life situations rather than laboratory science. Antioxidants, such as vitamin D, lutein and zeaxanthin, are useful free radical scavengers that offer protection against potential blue light induced retinal cell damage.

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MDNZ welcomes two new Ambassadors

Pic Picot

Pic is a well-known Nelson businessman of Pic's Peanut Butter fame, who lives with macular degeneration and has already become involved by promoting our recent seminar in Nelson.

He attributes much of his company's success to the imperative to delegate – forced on him by his macular degeneration, and his ability to move from a focus 'on detail' to taking an overall view of his companies' direction. He has joined MDNZ in the hope that his story might show others with the same condition that it need not negatively affect their quality of life.



Gordon Harcourt

Gordon joins his mother, Dame Kate Harcourt, as an ambassador for MDNZ.

He first became aware of MD because she had an Amsler grid on her bathroom wall, and he has a 50% risk of developing MD because of the family history.

He is best known as presenter of TVNZ Fair Go. After nearly 30 years in journalism in New Zealand and with the BBC, Gordon joined the Commerce Commission's communications team in 2017.

Gordon has already embraced his ambassadorial role as guests thoroughly enjoyed his MC'ing of the recent Vision for 2020 evening. We loved Gordon's checked suit as a homage to the Amsler Grid.



Macular Degeneration thanks our Professional Friends



These Optometrists and Ophthalmologists have made a commitment to support the work of MDNZ. We thank them all.

Optometrists

| | |
|-------------------|-------------------|
| Graham Jenkins | Auckland |
| Kristine Jensen | Auckland |
| Mike Jowsey | New Plymouth |
| John Kelsey | Pukekohe |
| Jagrut Lallu | Waikato |
| Grace Lang | Auckland |
| David Lee | Auckland |
| Richard Lobb | Southland |
| Niall McCormack | Hawkes Bay |
| Claire McDonald | Auckland |
| Roberta McIlraith | Christchurch |
| John Mellsop | Wanganui |
| Callum Milburn | Dunedin |
| Keith Miller | Tauranga |
| Rebecca Monteiro | Auckland |
| Kent Napier | Waikato |
| Brian Naylor | Palmerston Nth |
| Richard Newson | Tasman |
| Melinda Nordin | Auckland |
| Kevin O'Connor | Wellington |
| Simon Rose | Waikato |
| Danielle Ross | Central Otago |
| Lynley Smith | Tauranga |
| Nigel Somerville | Auckland |
| Frederick Swain | Napier |
| Cullen Szeto | Auckland |
| Noel Templeton | Blenheim/Westport |
| John Veale | Canterbury |
| Peter Walker | Waikato |
| Phillip Walsh | Auckland |
| Grant Watters | Auckland |
| Michael White | Bay of Plenty |
| Jeremy Wong | Auckland |

Ophthalmologists

| | |
|---------------------|----------------|
| Dr John Ah-Chan | Palmerston Nth |
| Dr Rachel Barnes | Auckland |
| Dr John Beaumont | Hawkes Bay |
| Dr James Borthwick | Canterbury |
| Dr John Bowbyes | Otago |
| Dr Oliver Comyn | Christchurch |
| Dr David Dalziel | Northland |
| Dr Narme Deva | Auckland |
| Dr Sean Every | Canterbury |
| Dr Nicholas Johnson | Southland |
| Dr Brian Kent-Smith | Northland |
| Dr Muhammad Khalid | Timaru |
| Dr Steve Mackey | Wellington |
| Dr Ainsley Morris | Christchurch |
| Dr Michael O'Rourke | Bay of Plenty |
| Dr Monika Pradhan | Auckland |
| Dr Peter Ring | Auckland |
| Dr Dianne Sharp | Auckland |
| Dr Andrew Thompson | Bay of Plenty |
| Dr David Worsley | Waikato |

To find a Professional Friend



near you go to

www.mdnz.org.nz

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

VISION FOR

2020

Help us to transform lives by supporting the Macular Degeneration three-year Vision for 2020 campaign.

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 act of kindness, no matter how small is ever wasted" Aesop

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)**

"Be the change you wish to see in the world" Mahatma Gandhi



MACULAR
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NEW ZEALAND

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.

At the Bay of Plenty Kiwibank Local Hero Awards



Viv Jones pictured with Dr Andrew Thompson, Ophthalmologist, Tauranga Eye Specialists and Trustee, Macular Degeneration New Zealand.



Allan Jones, John Adshead ONZM, Viv Jones, Vaughan Jones, Dr Andrew Thompson

Working in collaboration with the Blind Foundation

Masterton



Katikati



Nelson and Blenheim

