



MACULAR
DEGENERATION
NEW ZEALAND

Viewpoint

The MDNZ Newsletter
Issue 4 - Autumn 2016

0800 MACULA
(0800 622 852)

info@mdnz.org.nz

Welcome address by MDNZ Chairperson Dr Dianne Sharp at the recent Macular Degeneration Charity Race day.

Welcome to the MDNZ Race Day.

Thank you to Auckland Racing Club, to sponsors, to our MDNZ Ambassadors and to all of you for being here and supporting MDNZ.

In the past few years we have experienced a revolution in the way we treat Macular Degeneration. We now have the opportunity to treat some of the most severe forms and deliver some amazing results to people who would otherwise be experiencing significant troubles and hardship.

With these treatments now available, the key lies in an early diagnosis. We are at a point where Grandma Jill no longer needs to miss the expression on her grand-daughter's face as she walks down the aisle and Grandad Jack no longer needs to put chutney on his toast instead of jam! With public awareness and an early diagnosis we can prevent these problems from developing.



Timing is critical. At MDNZ we are working to seize the opportunity to save sight by raising awareness and ensuring good access to treatments.

Before us is a great moment in time to make a tangible difference on a leading cause of blindness in New Zealand

So I encourage you all to dig deep, have fun and be part of the vision!

A great day was had by 350 guests and they did dig deep to support the ongoing work of MDNZ, by raising \$45,000 on the day. THANK YOU to ALL contributors.

This edition of Viewpoint will bring you news of those treatment revolutions, photos of the fun at Race Day and will give you the opportunity to also dig deep with a donation that is tax-deductible for the 31 March 2016 year if you act quickly.

The Implantable Miniature Telescope is now available to help those with end-stage AMD

Dr. David Worsley, Hamilton Eye Clinic
2 March 2016.



A telescopic implant can be placed inside an eye to improve vision by reducing the impact of the central “blind spot” caused by end stage AMD.

There are three types available; IMT, ORIlens and the IOLAMD. The IMT is rigorously tested and FDA approved and is used worldwide. The other two are not rigorously tested and are not widely used. I cannot endorse the IOLAMD or ORIlens at this point in time. The IOLAMD needs to be discussed as some of you may have heard about it in the media due to a promotional campaign by the developer. The claims made for the IOLAMD are unrealistic and a serious concern to me. The bottom line is that the magnification of the IMT is X 2.5 Mag. The IOLAMD has only 25% magnification and this is rarely enough

for most AMD eyes. I have tried several times over the last year to get more information from the IOLAMD clinic surgeons in London but they have not replied – that means caution is required.

So I will talk about the IMT. It is a telescope the size of a pea placed inside the eye. The natural lens of the eye is removed and the telescope inserted where the lens had been.

Light entering the eye is enlarged (magnified) as it passes through the telescope. The result is improved vision because the image is larger when it reaches the cells in the macula. For example, prior to surgery, when looking at a family member there may be a dark hole where the entire face should be. With the telescope implanted, only the

nose or mouth may be missing, which will allow recognition of family members and expressions on their faces.

To be suitable for an implant you must have irreversible, end-stage AMD in both eyes, resulting from either dry or wet AMD, or where other treatments no longer help. So if you are currently having eye injections for wet AMD you aren't suitable. Lastly, previous cataract surgery in the eye in which the telescope will be implanted can be, but isn't always, a problem for implantation which the surgeon will need to evaluate.

Peripheral vision will be lost in the eye receiving the telescope. Therefore the telescope can be implanted in only one eye while the other eye provides peripheral vision to help with walking and other safety issues.

Before having an implant, several visits with a low vision specialist are needed to simulate the effect of an IMT and learn whether vision improvement is possible. After surgery, you need vision training with a low vision specialist to learn how to use the telescope image to attain the best possible vision.

As with any surgery, there are risks involved in the procedure, including making vision worse. Some patients may not adapt well to the new vision, or might find rehabilitation too stressful.

The telescopic implant and the surgery costs about \$25,000 (mostly the cost of the telescope) and unfortunately isn't yet government funded.

There are a small number of eye surgeons now offering this service in New Zealand. Ask your optometrist or ophthalmologist if you think this may benefit you.

What's up for 2016?

Education seminars are happening in areas of New Zealand where and when we are able to source the funding.

Let us know if you can assist us to prioritise a seminar in your area. Local input is vital to get a good result – contact with the local newspaper and your (or another) story to share, local clubs and societies that we can invite to attend, local venue and accommodation options.

Help us to help others to save sight.

Current plans are for seminars in:

- Whakatane
- Southland/South Otago
- Canterbury
- Hawkes Bay
- Wairarapa
- Nelson/Marlborough
- Waikato
- New Plymouth
- Northland
- Dunedin
- East Coast/Gisborne

To find out where and when these seminars are go to the MDNZ website www.mdnz.org.nz or call **0800 MACULA**.

Talks at community groups and retirement villages take place quite regularly in the Bay of Plenty and Auckland. This is due to our speakers being readily available in these areas.

Macular Degeneration Week

23 – 29 May 2016

Have you a story to tell?

How you manage positive daily living with macular degeneration may inspire others.

If you have a story to share we would love to hear from you. We may share your story during our annual awareness campaign.

Help us to help others - telephone us on 0800 622 852

- Plans are underway to promote awareness across New Zealand.
- Are you one of the 631,000 New Zealanders over 50 who use Facebook?
- Please look out for our dynamic facebook page during the campaign week
- LIKE and SHARE all our Facebook page posts
- The latest Galaxy Poll measuring awareness levels in NZ will be released
- Look out for stories in your local newspaper and on social media

The 2016 Awareness Week campaign is made possible due to the generous donation made by Pub Charity.



Entertainment Book sales support MDNZ

Once again Old Grumpy's Gallery is supporting MDNZ with the sale of Entertainment Books or Apps for the 2016/2017 year. These are available now through the website www.entertainmentbook.co.nz/orderbooks/158x528. Books or Apps are available for all regions of New Zealand

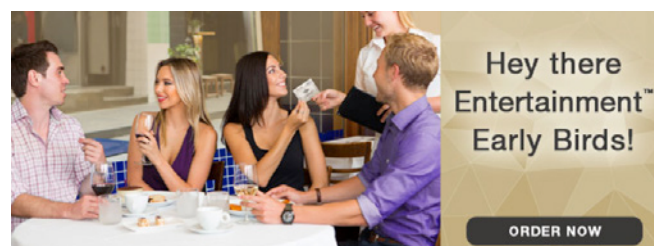
We're pretty excited about the arrival of the NEW 2016 | 2017 Entertainment™ Book as well as the Entertainment Digital Memberships that put all of the value of the Book on your phone. To celebrate, we're giving you the chance to not only receive your new Membership hot off the press come May, but also be rewarded for doing so!

Order your new Entertainment™ Book or an entertainment Digital Membership before 29 March 2016 and you will receive up to \$150 worth of additional offers that you can use right away - a nice little taster of what is to come!

Now that's something to tweet about!
#Entertainmentbook #EarlyBirdOffer

Purchase your Entertainment™ Membership from Old Grumpy's Gallery - Independent Fundraiser for Macular Degeneration New Zealand again to support their fundraising efforts.

For every Entertainment Membership sold, 20% helps community fundraising so tell your friends and spread the word so some much needed funds can be raised!



Eye Examinations – Test your Maculae

It is extremely important to have your eyes examined at least every 2 years and definitely after age 40 years as ageing changes in the eye become apparent. These changes may need an optical correction or further medical intervention.

One in seven people over the age of 50 years have some form of Macular Degeneration (MD). The earlier MD is detected the better the visual prognosis or outcome.

MD is initially detected by having a comprehensive eye examination by an optometrist or ophthalmologist, who can see if you have signs of the condition. They will review your medical and family histories and conduct a thorough eye exam to diagnose the condition. Examination of the back of your eye may show a mottled appearance caused by drusen. Drusen are yellow deposits that accumulate under the retina in people with MD.

An Amsler grid can be used to test for defects in the centre of your vision. You may have MD if some of the straight lines in the grid look faded, broken or distorted. A lot of patients report vertical lines like lamp posts, the edge of buildings or a window frame have a “kink” in them. This is a clue that MD may be present.

During the eye exam, retinal images such as a photo or an OCT (Optical Coherence Tomography) scan may be taken. The photo will qualify the amount of drusen present at the macula. The OCT takes a detailed cross sectional retinal image and identifies areas of retinal thinning, thickening or swelling. These are caused by fluid accumulation from leaking blood



vessels in and under the retina. In addition to its value in an initial evaluation, OCT is also often used to help monitor the response of the retina to macular degeneration treatment.

During your comprehensive eye examination a profile will be drawn up with your risk factors including age, family history, smoking history (previous or current) and the appearance of your retinae. The right treatment can then be tailored to you, including how often you will need to have your eyes tested in the future.

So, as you can see, **IT IS VITALLY IMPORTANT TO HAVE YOUR EYES REGULARLY EXAMINED BY AN OPTOMETRIST OR OPHTHALMOLOGIST.**

Simon has worked in Optometry for the last 32 years. He has a Diploma in Ocular Therapeutics which gives him insight to the current mechanisms involved in Macular Degeneration.

Seeing the effect of MD on people on a daily basis, Simon believes he has an honest empathy in wanting to make a difference to those who are affected and those who may be affected in the future.



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Professional Friend

MDNZ Professional Friend programme

We welcome the following Optometrists and Ophthalmologists who have committed to the MDNZ Professional Friend programme. These contributors to MDNZ are recognised on the MDNZ website and the Viewpoint newsletter, they receive all of the MDNZ patient brochures at no cost and they receive a certificate to display in the practice/s they work in.

We all play a part in the continuum of sight saving work. Awareness is increasing due to the work of MDNZ and more people are committing to have their eyes checked. Help us to help you save sight and join the Professional Friend programme now!

Optometrists

Nigel Somerville, Glen Eden
Roger Apperley, Auckland
Kristine Jensen, Howick
John Adam, Remuera
Grace Lang, Ponsonby
John Mellsop, Whanganui
Jagrut La lu, Frankton/Huntly
Peter Walker, Frankton
Simon Rose, Frankton
Richard Lobb, Invercargill
John Veale, Merivale
Danielle Ross, Wanaka
Richard Newson, Nelson
Robert Dong, Wellington/Lower Hutt
Maira Ironside, Palmerston North
Veeran Morar, Pukekohe
Niall McCormack, Hastings
David Lee, Botany
David Haydon, Takapuna
Jayesh Chouhan, Wellington
Claire McDonald, Warkworth

Ophthalmologists

Dr David Worsley, Hamilton
Dr Dianne Sharp, Parnell
Dr Steve Mackey, Wellington
Dr David Dalzeil, Whangarei
Dr Rachel Barnes, Parnell
Dr Andrew Thompson, Tauranga
Dr John Ah-Chan, Palmerston North
Dr Sean Every, Christchurch
Dr Philip Polkinghorne, Remuera
Dr James Borthwick, Christchurch
Dr Brian Kent-Smith, Whangarei

Advertise in the Viewpoint newsletter

The Viewpoint quarterly newsletter has a readership of 6,000.

If you would like to know more about the moderate rates to connect with the varied MDNZ audience, please contact info@mdnz.org.nz or phone 0800 MACULA (622 852) to receive the Viewpoint media kit.

Profile of an Ambassador



Sir Colin, Lady Verna and their granddaughters.

Sir Colin Meads – the mighty All Black

Sir Colin is the first person to say how important good vision is. "To see that ball being passed your way at speed while you are running at speed – there is no excuse for you not catching that ball and getting it over the line for a try" says Sir Colin. Sir Colin Meads has put his name and face to the cause of Macular Degeneration NZ as an Ambassador to help those New Zealanders and their families who are suffering from Macular Degeneration and to help raise awareness of this hideous eye disease.

Sir Colin is a horse racing enthusiast owning a number of horses (or part owning with his wife Lady Verna and with syndicates). One such horse "What's the Story" was the winning horse in the Rutherford Rede 2100 at the Macular Degeneration Race Day in February. Sir Colin and Lady Verna support the Macular Degeneration Charity Race day each year, bringing along their family and friends for a great day out. Sir Colin brought along two signed rugby balls for the auction. The first and second bidder received a ball and MDNZ received double the funds – Win, Win.

Thank you to funders in the 2015-16 year

- Alandale Charitable Trust
- Bay Trust
- David Levene Foundation
- Foundation North
- Four Winds Foundation
- Freemasons
 - Freemasons Foundation
 - Selwyn Lodge
 - ARA No 348 IC Charitable Trust
- Pub Charity
- Trust Waikato
- Perpetual Guardian
- TM Hosking Charitable Trust
- James Russell Lewis Trust
- W Duncan Bickley Trust
- Public Trust
- JBS Dudding Trust
- TM Hosking Charitable Trust



A day at the 2016 Ellerslie Races



Low Vision Rehabilitation Strategy Group

Contributed by Hamilton Optometrist and MDNZ Trustee, Simon Rose

Inexorably and up until recently, if you got Macular Degeneration (MD) whether it was Wet or Dry, you would progress to blindness. To be eligible to register and get support from the Blind Foundation (RNZFB) you had to have vision that was 6/24 or worse in the better eye or have a visual field no greater than 20 degrees at the widest point from central fixation. Over the last 10 years with new technology and treatments we are able to reduce the degree of visual loss dramatically. This is fantastic as a result but creates its own problems. Patients used to lose enough sight that they would become eligible to be registered with the RNZFB and hence get great support. Now that we can reduce the degree of visual loss, a lot of people with MD don't meet the RNZFB criterion to become eligible and hence don't get the support that they may need.

In 2015 the Ministry of Health (MoH) set up an initiative called The Low Vision Rehabilitation Service Reference Group. This group is comprised of numerous groups within NZ that are involved in dealing with people who have reduced vision that may support them in their daily lives. MD has a representative on this Reference Group as we see a lot of our members fitting into this Group. Low vision is thought of as anyone who has trouble with their vision in their day to day lives

which is better than the RNZFB criterion but still below normal – this still has yet to be defined properly

The initiative ultimately wants to establish a National pathway for people in this "Low Vision" category to have equal access to support which is extremely reduced currently. The initial diagnosis of Low Vision can be a frightening time for people so ensuring that the service is designed with the client at the centre is particularly important. Communication between health professionals and dedicated referral pathways will also ensure that people feel well supported when accessing low vision services.

MDNZ feels that this Strategic Group's initiative is very important because we know that we certainly haven't cured MD and we have a lot of members that fall within this low vision category. These people certainly need a clear and equitable level of support. The Strategy Group will carry on with developing this concept throughout 2016 and by the end of the year it may be in some closer form to be implemented into the community within NZ government's Health Strategy.

Simon Rose is the MDNZ representative on the Low Vision Rehabilitation Services National Reference Group

Would you like to reduce your taxable income?

Did you know that one-third of personal giving may be claimed as a tax refund and there is no threshold on that gift other than the amount claimed cannot exceed your taxable income for the year?

Please consider making a donation before 31 March 2016. You can make a donation by completing the donation form opposite and sending to us or going online to our website www.mdnz.org.nz to donate now. A tax-deductible receipt will be mailed or emailed to you to claim your tax refund.

All donations made to Macular Degeneration New Zealand contribute to our sight-saving work.

This can be any of:

- Information packs
- A seminar near you
- Calls to the 0800 save sight helpline
- Education, awareness and support.
- Research

Each year MDNZ provides information, education, support and advice to thousands of people around New Zealand. MDNZ is a charitable organisation and has NO government or outside funding to do this work. WE NEED YOUR HELP.

Some people who have MD recognise that there is a 50% chance that their children have the genes to develop MD, but many don't. How can MDNZ get the information out, increase awareness and educate the wider community without funding?

Thank you for your support



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Please donate to support those with MD

Title

First name

Last name

Name to appear on tax receipt

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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.



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