

Viewpoint

The MDNZ Newsletter Issue 10 – May 2018

0800 MACULA (0800 622 852)

info@mdnz.org.nz

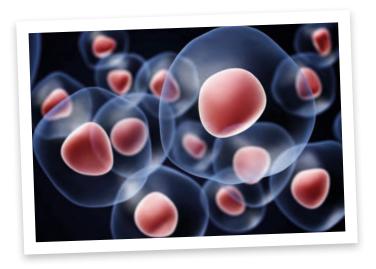
Bold claims from stem cell treatment but caution advised

A recent television news article hailed a stem cell treatment as a cure for macular degeneration. MDNZ has received many enquiries about the treatment. Here is an update on that treatment.

The treatment consists of incorporating stem cells from human embryos onto a synthetic backing membrane and surgically inserting this underneath the macula (central part of the retina). The stem cells had been allowed to develop into RPE cells and these cells support the photoreceptors (light capturing cells in the retina).

Two patients with advanced macular degeneration (MD) have already been treated and permission has been given for a total of 10 patients to undergo treatment. The 2 patients gained 21-29 letters on the vision chart effectively gaining 4-6 lines of vision. Whilst this gain is impressive the patients have reported troublesome distortion and dimmer vision.

The treatment relies on using immunosuppression in the form of local steroids inside the eye to prevent rejection. There were several adverse events that occurred, one of which was a retinal



detachment that required further surgery to correct. Fortunately, the patient retained their vision.

There are several risks with stem cell treatments such as rejection, tumour formation, uncontrolled proliferation of cells and the development of stem cells into different cell types that don't belong in the eye.

The trial results are encouraging but the reality of this as a routine treatment is still many years away. It is important to realise it is not a curative procedure, but it is encouraging to see new regenerative technology advancing the fight against sight threatening vision loss in MD.

Thank you to our sponsors, funders and supporters in the past year

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









The Rapanui Trust















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T.M Hosking Charitable Trust

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To see a full list of MDNZ Professional Friends go to www.mdnz.org.nz/resources/mdnz-professional-friends

This valued support made the following possible last year:

- 2,556 people attended seminars in 10 regions across NZ
- 13 presentations in the Bay of Plenty by MDNZ Ambassador, Viv Jones telling her story
- **1,262 enquiries** made to the 'save sight' 0800 macula helpline
- 9,857 resources issued
- **16 Ophthalmologists** volunteered their time to make presentations
- 21,000 Viewpoint newsletters sent

- **60 eye care professionals** attended the MDNZ Symposium in July
- **143 medical professionals** completed the MD on-line learning programme
- 187 people viewed the You Tube video "MDNZ awareness and education seminar" uploaded August 2017
- **120 Members of Parliament** received the MDNZ facts update
- MDNZ launched the Vision for 2020 campaign

Professional Friends

We welcome new Friends:

Optometrists

Brian Appleyard, Hamilton Kent Napier, Hamilton Melinda Nordin, Auckland John Kelsey, Pukekohe Michael Ferguson, Gisborne Graham Jenkins, Auckland

Ophthalmologists

Dr Muhammad Khalid, Timaru

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).

Missed a seminar in 2017? Watch now online.

Tauranga Awareness & Education seminar Dr Andrew Thompson, August 2017. www.mdnz.org.nz/awareness-and-education-seminar













Seeing well with the Vision for 2020 Campaign

Soon winter will be upon us, the perfect time for a get-together with family and friends over a hearty roast meal, followed by piping hot drinks. Fifteen people sitting around a table sharing food and drinks, talking and catching up. Two of the people in this room will get macular degeneration.

What will they do if they lose their sight? How will they manage their job, their home life, and their hobbies?

The good news is that they may not have to. With your help, MDNZ can spread the work and raise awareness so that your family and friends and others in your community can take the steps needed to save their sight.

What a wonderful gift to give.

MDNZ is calling on your support so that those who don't yet know about macular degeneration can get the tools needed to save their sight. To do this MDNZ needs to raise \$150,000 each year for the next 3 years. An ambitious goal but, with your help, it is achievable.

To date, your generous support has raised \$72,000, which has enabled us to engage a community liaison educator.

However, we are not there yet, to truly reach across New Zealand we need to raise \$150,000 each year for the next 3 years, so that we can engage a second community liaison educator, deliver more seminars, print more resources and continue to staff the 0800 Save Sight Helpline.

Please consider becoming involved, whatever you can contribute will have an impact.

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.

"If I cannot do great things, I can do small things in a great way."

- Martin Luther King Jr.

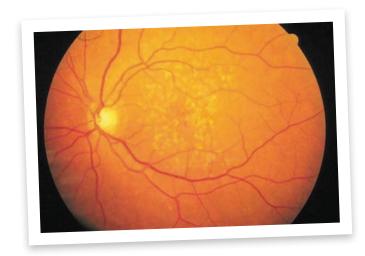
Glaucoma vs Macular Degeneration

Macular degeneration and glaucoma are very different but the similarities are; they get common with increasing age and secondly both are capable of causing blindness.

Macular Degeneration

The macula refers to the central area of the retina that is specialised for seeing fine details. It is 6mm in diameter and lines up with the direction of gaze, i.e. it lies on the visual axis. The eye chart with its letters of decreasing size tests how well the macula is working.

With increasing age the macula can wear out and the centre of the retina develops irregularities or blemishes. This is early

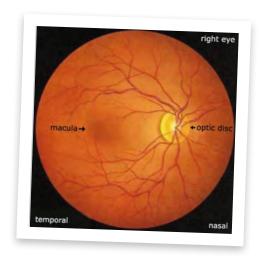


evidence of macular degeneration. In the early stages these are visible to the doctor but usually don't affect the vision at all. As macular degeneration worsens the vision becomes affected. This is experienced as difficulty with reading or distortion of straight lines or both.

The type of vision affected is central vision; the vision required for reading the eye chart that is recognising faces and all fine work. It is usually very obvious. Treatments are available for some types of macular degeneration once the vision is affected.

Glaucoma

Glaucoma affects the optic nerve, the nerve of sight. The optic nerve carries all the electrical impulses from the retina, including those from the macula, to the brain to create visual images. In glaucoma the optic nerve wastes away slowly. In all but the advanced stages the sufferer is not aware of this. This is because the vision lost first in glaucoma is side vision (and not central vision as with macular degeneration). The central vision nerve fibers are usually the last to be damaged in glaucoma.



Generally people are not aware of losing side vision. Even though you think your experience of vision is one integrated whole in actual fact it is not. Those with glaucoma who have lost side vision are not necessarily aware of it because the mind paints the world in. Take the blind spot for instance. Everyone has a blind spot and if you actively search for it you can find it, but you are otherwise not aware of the blind spot because the brain fills in the gap. Visual field tests are undertaken to determine the extent to which the side vision has been degraded and reference the effectiveness of glaucoma treatments.

Macular Degeneration Awareness Month

May 2018

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 is not a bulge that will pass with time.

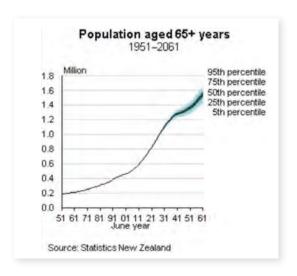
This group will also be living for longer than previous generations and 41% of them do not know about this eye disease.

To halt a potential epidemic of blindness, we need to be proactive to save sight so that New Zealanders can live well in old age.

How our society will cope with the health needs of a rapidly growing older population is **one of New Zealand's least known yet most pressing issues**.

5% of Eye Care sales goes to support MACULAR DEGENERATION NEW ZEALAND BLACKMORES EYE HEALTH WEIN-VISION ADVANCED WINS SUPPORTED BLACKMORES EYE HEALTH WACU-VISION DEFENCE Proudly supported by BLACKMORES BLACKMORES EYE HEALTH MACU-VISION DEFENCE PROUDLY SUPPORTED BLACKMORES EYE HEALTH MACU-VISION BLACKMORES EYE HEALTH BLACKMORES EYE HEALTH BLACKMORES EYE HEALTH BLACKMORES EYE HEALTH BLACKMORES EYE

Always read the label. Use only as directed, if symptoms persist see your healthcare professional. Vilamin supplements should not replace a balanced diet. Blackmores: Auckland, TAPSPP6714.



This year we welcome Blackmores NZ and Health 2000 to our campaign.

"Blackmores New Zealand is a long standing, proud partner of Macular Degeneration New Zealand and this year Blackmores is delighted to partner with Health 2000 and MDNZ to raise awareness and educate on macular eye health."

Blackmores will:

- Feature an article focusing on eye health on www.grownups.co.nz.
- Provide Amsler Grids for the 69 Health 2000 stores.
- Promote awareness on their website and in Facebook media.

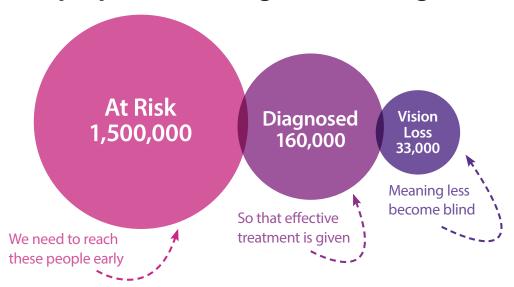
Health 2000 will:

- Promote macular degeneration awareness in the May Health 2000 magazine, now available on line www.health2000.co.nz/magazine.
 An informative article by Ophthalmologist and MDNZ Trustee, Andrew Thompson will feature.
- Distribute Amsler Grids in their 69 stores across NZ.
- Promote and recommend eye health checks to their customers.

MDNZ will:

- Invite participation from all Optometrists and Ophthalmologists in NZ.
- Publish a minimum of two Facebook posts each week. On Facebook please search Macular Degeneration NZ – MDNZ and Like/Share our notices.
- Highlight Awareness month in all email communications during May.
- Acknowledge our Professional Friends on the MDNZ Facebook page.

1 in 7 people over 50 will get Macular Degeneration



Advocacy update

- The Model of Care Assessment and Recommendations prepared by EY is now in the hands of the Ministry of Health awaiting sign off and implementation
- The Royal Australia and NZ College of Ophthalmologists (RANZCO) NZ branch appointed MDNZ founding chairperson, Dr Dianne Sharp to consult and prepare NZ National Guidelines for management of Neovascular AMD. Now complete, they have been ratified by Clinical Directors of DHBs and are ready for acceptance at the RANZCO NZ branch meeting in May. These guidelines represent the gold standard to achieve throughout NZ.
- MDNZ collaborates with other eye health professional representatives through the Eye Health Coalition, a voluntary coalition of eye health professionals, service providers and consumer organisations. The focus of the coalition is to increase access to quality eye health services in NZ and to work collaboratively with parliamentarians and ministry officials to improve NZ eye health services.
- In March the Eye Health Coalition members met with the Parliamentary Friends of Eye Health. The Parliamentary Friends group is made up of voluntary commitment by individual MPs through convenors Louisa Wall MP and Simon O'Connor MP.
- MDNZ representatives will meet with Health Minister, Dr David Clark in May.

Can eating chocolate improve your eyesight? Do Brussels sprouts really count as 'good greens'?



Well, it seems that eating dark chocolate and Brussels sprouts 'could' protect your eyesight according to Dr Google! Dark chocolate is considered to be high in antioxidants and Brussel sprouts are rich in Vitamin C.

These may not be scientific facts but as we head into Brussels sprouts season how about trying some recipes that could improve your intake of healthy greens.

Olive oil and garlic-roasted Brussels sprouts



Thank you Allyson Gofton www.allysongofton.co.nz

Ingredients

400-500 grams Brussels sprouts
½ cup virgin olive oil
6 cloves garlic, crushed, peeled and sliced
½ cup coarsely grated fresh Parmesan
¼ cup toasted pine nuts
Drizzle balsamic vinegar (optional)

Method

Preheat the oven to 200°C. Pour the olive oil into a large ovenproof dish and place into the oven to preheat.

Cut a cross in the base of each Brussels sprout and peel away any tough outer leaves. Blanch quickly in boiling salted water for 1 minute and then drain well. Transfer to the hot oil with the garlic.

Bake in the preheated oven for 20 minutes until lightly roasted and tender. Season well with salt and transfer to a serving plate. Garnish with the Parmesan, pine nuts and a drizzle of balsamic vinegar, if using.

Brussels sprouts, bacon and almonds

Ingredients

700g Brussels sprouts, halved1 Tblsp olive oil3 bacon rashers, diced¼ cup slivered almonds



Method

Steam Brussels sprouts until bright green and just tender.

Heat olive oil in a frying pan on medium heat and cook bacon until crispy (about 3-4 minutes). Add almonds and cook a further minute until lightly toasted.

Add steamed Brussels sprouts to the pan and toss with bacon and almonds. Delicious served with roast chicken and gravy.

Thank you Nadia Lim www.bite.co.nz

New Year's honour for MDNZ Ambassador Philip Sherry

In January Philip Sherry received well deserved recognition in the NZ Royal Honours for services to local government and broadcasting.

After spending his career in and out of newsrooms in both television and radio he moved into local body politics. He became a councillor for the North Shore City Council and the Takapuna Community Board, then represented the North Shore on the Auckland Regional Council. After moving to Papamoa he was promptly elected as a councillor for Environment



Bay of Plenty where he contributed for many years. He is appointed an officer of the New Zealand Order of Merit. Congratulations Philip.

For news that could save your sight go to www.mdnz.org.nz to catch macular degeneration awareness news read by Philip. Thank you Philip.

Awareness and Education Seminars 2018



To date 6 seminars have been held in 2018 as requested by local clubs, organisations and in retirement villages.

Planning is well underway for free public seminars around NZ.

Check our website and Facebook page for updates or phone us any time on **0800 MACULA** (**622 852**) or email us at **info@mdnz.org.nz** to find out when there is one near you or to register your interest.

Now open for registration

Waikanae 26 May, 10am to 11.30am Pukekohe 16 June, 10am to 11.30am

Other possible locations

Nelson, Greymouth, Wairarapa, Whanganui, Western Bay of Plenty, Dunedin, West Auckland.

Online AMD Toolkit

A global coalition of patient organisations concerned with vision health, ageing and avoidable blindness, led by Retina International, has launched a multi-stakeholder online toolkit designed to improve the understanding of Age-related Macular Degeneration – AMD. You can access this on **www.Retina-AMD.org**.

Retina International states that "although awareness of this condition has improved over the last decade, the various stages and complexity of the disease are not well understood. Early, intermediate and last stage AMD are complex conditions with differing signs and symptoms. Early diagnosis is critical to detect and treat the first signs of AMD successfully and to give all patients access to auxiliary aids and rehabilitation services that can improve their quality of life".

"Scientific research into AMD is leading to a much better understanding of the condition and so it is important that the most up to date information is delivered effectively to all stakeholders through a trusted source".

Online learning for medical professionals in NZ

Understanding Macular Degeneration is a learning module available to all medical professionals. Increasing numbers are registering and completing this module including nurses, optometrists, pharmacists, community health workers. CPD points are earned on completion. Go to www.mdnz.org.nz/resources or to www.goodfellowunit.org.



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

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One week of the 0800 Save Sight Helpline

\$2,000

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\$10,000

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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



Please donate to support those with MD

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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.

Macular Degeneration Awareness Month



This test could save your sight

1 in 7 people over 50 will get Macular Degeneration

