

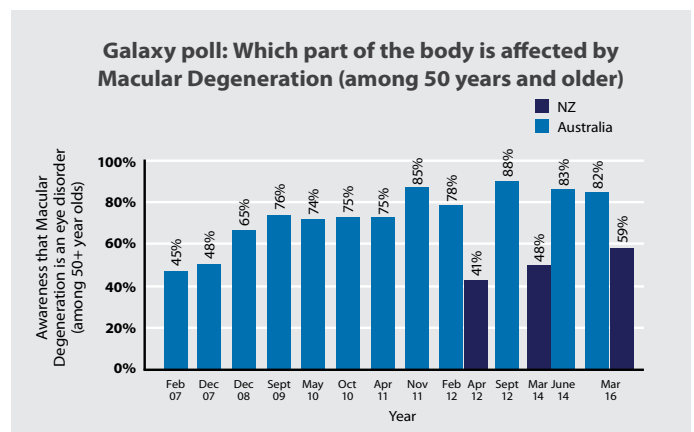
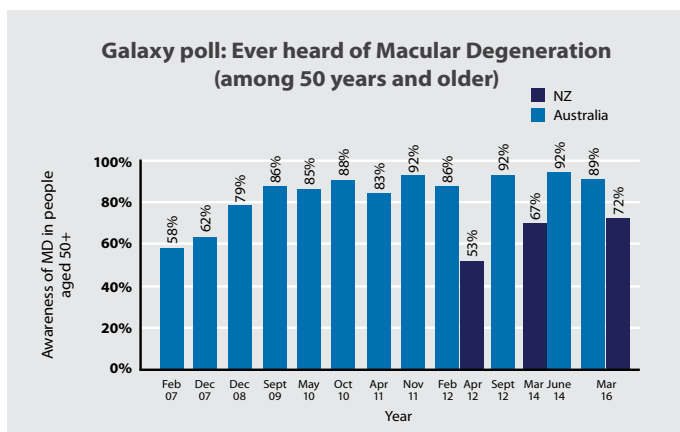


## Awareness → Eye Examinations → Early Detection → Saves Sight

If you are reading this you are likely to be in the 52% in New Zealand that have heard of macular degeneration (MD). A March Galaxy Poll of 750 New Zealanders, commissioned by Macular Degeneration New Zealand (MDNZ), brought good news that the level of awareness of MD in over 50 years olds has increased 11% in the past 2 years.

But the poll also showed that 28% of people over 50 have never heard of MD and 41% of over 50 year olds have no idea that MD affects the eye. So while MDNZ has succeeded in raising awareness levels, our job is far from done as we strive to save sight by reaching the 41% of people who are still unaware.

The graphs below show New Zealand still lags behind Australia who are world leaders in eye health and vision outcomes.



MDNZ remains committed to raising awareness to reduce the incidence and impact of MD through our highly-valued education programmes, continued advocacy for greater funding by policy and decision makers, and extensive awareness campaigns. Since the Galaxy Poll, MDNZ's Awareness Week in May will have increased awareness levels further; a key step towards our 2018 goal of 70% of people over 50 having had a macula check.

## Meet Anna Burns – MDNZ’s youngest volunteer

Volunteers are just gold to MDNZ, always willing and ready to help out with whatever is needed. Anna Burns is definitely gold: she stands out not only for her community spirit, Anna is MDNZ’s youngest volunteer. She has been helping in the MDNZ office weekly after school for almost three years. After meeting the



requirements for the Duke of Edinburgh Trust Award, she has stayed on, for which we are very grateful. “Seeing the difference the extra awareness makes is rewarding” says Anna “I also really enjoy working in the office because of the people”.

Anna applied this same level of commitment over the past four years as a rowing coxswain at Diocesan School for Girls. In March this year the senior crews were rewarded for their hard work and commitment by winning gold in both the Under 18 Coxed Four (Dawn Cup) and the Under 18 Coxed Eight (Levin Jubilee Trophy).

Well done Anna – we are very proud of you.



## Public Education and Treatment Seminars

MDNZ provides free seminars around New Zealand about macular degeneration, research, treatments and resources. The seminars are organised by MDNZ, with invaluable support from local communities that ensure their success. Local ophthalmologists make the presentation, local optometrists advertise events to their clients, local media get the word out, and trusts and foundations cover the cost. 2016 has seen seminars in Christchurch, Whakatane, Warkworth and Hamilton attracting 450 attendees who are now well informed about MD. Our thanks to Christchurch Eye Surgery, Bay Trust, Summerset Falls, WEL Energy and Trust Waikato for supporting their local events.



Plans are underway in Gisborne, Hawkes Bay, Whangarei and Manawatu. Check out [www.mdnz.org.nz](http://www.mdnz.org.nz) for dates and times, email [info@mdnz.org.nz](mailto:info@mdnz.org.nz) or phone us on **0800 MACULA (622 852)** to register your interest.

# Optometrist Naomi Meltzer answers your questions

Earlier this year Naomi Meltzer, who specialises in Low Vision Rehabilitation, travelled overseas to learn more about the latest technologies available to treat MD. These new applications include the Implantable Miniature Telescope (IMT) mentioned in our last newsletter, and advances in spectacle design for people with MD. She answers some of your questions:

## **Is LVR suitable for anyone with MD?**

No, there is selection process to ensure surgical and optical requirements are met. The eye which is implanted with the telescope must have had no previous surgery (including cataract surgery) or any type of laser surgery and no history of other conditions such as glaucoma or diabetic retinopathy in both eyes. The MD must be stable i.e. no further treatment required.

## **Is it best to have this done while my vision is still good enough for driving?**

On the contrary- IMT is only suitable for those whose vision has deteriorated significantly e.g. a person whose vision is bad enough to be accepted as a member of the Blind Foundation. The IMT will not enable anyone to resume driving due to the increased magnification and loss of peripheral vision the application provides.

## **Would it mean that I no longer need to use the low vision aids that I use at present?**

Generally you would still need to use spectacles to get the best distance and peripheral vision with the non-operated eye as well as additional reading aids. The IMT gives the best vision at about room distance such as recognising faces or walking the supermarket

aisles. Additional low vision aids are often still needed but less magnification is required.

## **I am really only using one eye to see with so how would that work?**

Most people have one eye worse than the other. The telescope is put in the eye which will give the best improvement in vision. The other eye usually still has peripheral vision so once the IMT is implanted the other eye is used for getting around and understanding where you are going. You need to learn to switch from using one eye for general seeing and other eye for more detail.

## **What else is new to help people with MD?**

Magnifying spectacles with three bright LED lights built into the front of the frame provide extra light which is so necessary for reading. This allows hands free viewing, the use of both eyes together at low magnification and provides a wider vision area than most magnifiers provide. These magnifying spectacles are suitable for those with low vision and for those working in jobs or hobbies which require close inspection of small details.

Another advance has been made through the use of a different type of lens which can improve vision for those who have a blank patch in the central part of their vision. The new lens works by shifting the point of viewing to a better part of the retina. Naturally this sort of advanced technology is not for everyone, but it is great to know that research and development is underway around the world to provide a variety of solutions for those suffering from MD to ensure they use their remaining vision more efficiently.

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**low vision  
services**

**Naomi Meltzer**

BSc, Dip Opt, PostGrad.Dip.Rehab.

Low Vision Consultant

Optometrist

# Macular Degeneration

Macular Degeneration, a growing epidemic.

MD Awareness Week 2016 was our most successful awareness campaign to date, enabled by high profile media opportunities, a stunning new-look campaign design, great personal involvement and a strong medical/optical presence.

The campaign focused on increasing awareness of the medical breakthroughs for treating MD and facilitating early diagnosis via regular testing. Our thanks to our media partner Cadence Communications for their excellent work which resulted in a marked increase in awareness of the Amsler Grid and people taking the test, an increase in visits to our website and phone calls to MDNZ.

told by people with MD from around New Zealand. People responded to the posts with “Worthy of FB space!” and “You keep on doing what you love... you have inspired me too”. The posts were shared over 800 times and 241,099 people were reached via Facebook during the campaign. We succeeded in generating high interest and engaging people!

## Television

TV One Breakfast featured an interview with ophthalmologist Dr Andrew Thompson, while TV3 NewsHub ran a story on MD with ophthalmologist Dr Dianne Sharp and a patient.

## Radio

Newstalk ZB interviewed ophthalmologist Dr Jim Borthwick on 20th May to kick off our week long campaign. Dr Dianne Sharp participated in three radio interviews; one with Heather du Plessis-Allan on RadioLive and two Radio NZ

## In case you missed Awareness Week 2016, this is what happened:

In addition to our regular focus on TV, radio, print and visual media, MDNZ moved into the social media space. Did you know that 631,000 New Zealanders over the age of 50 use Facebook the very people we need to reach.

## Social Media

Our social media campaign was launched with an Amsler Grid self-test, followed by 10 Facebook posts of personal stories



# on Awareness Week

22-29 May 2016

interviews, Nights with Bryan Crump and Nine to Noon with Kathryn Ryan.

## Print/Online

Regional newspapers featured 50 print and online articles nationwide about MD and the personal stories of people with MD. Coverage included feature stories in the New Zealand Listener, Verve Magazine, Grownups, Grey Power and

Age Concern magazines and articles in NZ Doctor Magazine and the Sunday Star Times.

MDNZ wholeheartedly thanks everyone who made Awareness Week 2016 a success; to the people who shared their stories, to the optometry practices and friends of MDNZ, and to Pub Charity who all supported this year's campaign.

## Grant Thompson

Five years ago when I visited my optometrist for a routine check-up I had no idea my life was about to change. I expected to talk about my glasses so was shocked when he told me that I could go blind because I had 'dry macular degeneration' – something I'd never even heard of. My sight had been deteriorating for a while and I thought that was simply an age related matter. It's scary to think there are lots of people out there who assume they have age-related eyesight problems when they actually have MD.

After getting the news I searched the net and read articles that confirmed my optometrist's view that I could go blind over time. It really bothered me and I suffered from depression for around six months following diagnosis.

Even though the news came as a shock, and my MD later changed from dry to wet (which is even worse) overall I feel that I've been really lucky. My MD was diagnosed early on and I have had regular treatment that has saved my vision.

MD is with you forever but early diagnosis and treatment prevented mine from getting any worse. I can still play tennis, table tennis, swim, drive and work. When I was diagnosed I was scared I would lose my vision and wouldn't be able to do those things, so I'm really glad the MD was spotted in time.

I can look forward to the future again now.



# Where you live can determine how well you can see!

Dr Andrew Thompson, retinal specialist at Tauranga Eye Specialists, recently completed a project as part of a professional development programme run by the Royal Australian and New Zealand College of Ophthalmologists. The following is a summary of the findings in his report- references are available on request.

The purpose of the project was to highlight the need for equitable access to Avastin for all New Zealanders living

and DHBs vary greatly in the number of Avastin procedures they fund. These range from between 40 and 140 treatments per 10,000 population and furthermore Avastin supplies do not currently meet demand. This situation may worsen as the prevalence of MD is expected to increase by 12.9% by 2026 due to demographic ageing.

DHBs currently loosely adhere to a Standardised Intervention Rate (SIR) of

40 injections per 10,000 population when funding Avastin treatment. Treatment numbers were obtained from each DHB under Official Information Act requests and the true SIR for each DHB was calculated using 2013 Census data. This highlighted a significant access inequity to Avastin treatment between DHB regions with the most overfunded at 3.3

and the least at 0.3 (adequate funding is represented by a value of 1.0).

Current funding arrangements fail to account for differences in the rate of MD between DHBs. Adjusting population for age and ethnicity yielded differences in MD prevalence per DHB ranging between 1 in 7 to 1 in 11.

Further analysis gives a population adjusted intervention rate (PAIR) that is far more appropriate than a standardised rate in determining the number of funded treatments required per DHB. The average number of treatments that an individual

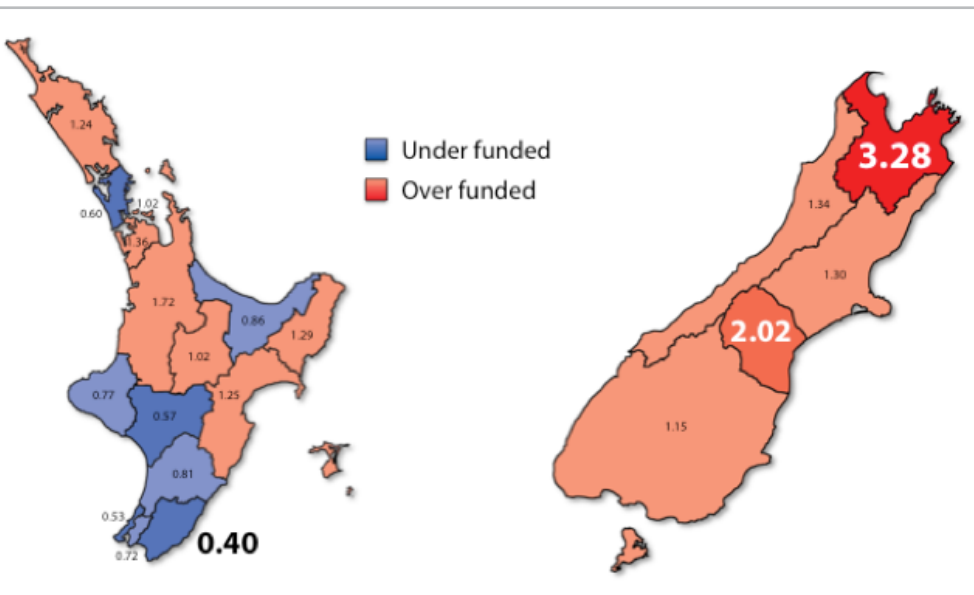


Figure 1. Standardised intervention rate of Avastin treatments per DHB within twenty District Health Boards (DHB) across the country.

New Zealand receives the lowest public funding of anti-VEGF drugs of all the OECD countries. The New Zealand Medicines and Medical Devices Safety Authority (Medsafe) does not approve the use of Avastin for use in the eye because manufacturer, Genentech, do not license this product for use in the eye.

This means Avastin funding is determined regionally by each DHB rather than nationally by the Ministry of Health

with wet MD typically requires over 12 months is 6 to 7 injections.

A patient presenting with wet MD typically requires six to seven injections over a one year period which is higher than the four treatments per patient per year assumed in the National Health Committee Report on MD, and necessitates additional treatments to be privately administered at significant cost to the patient, or worse not administered at all.

When all these factors are taken into account a significant inequity of access still exists between DHBs. In other words, where you live determines how well you can see.

Everyone affected by wet MD has the right to equal access to

Avastin treatment irrespective of the DHB in which they are domiciled. A national planning strategy is required to ensure fair access, and this can only come from the Ministry of Health.

These project findings have been disseminated to all DHBs, PHARMAC and the Ministry of Health.

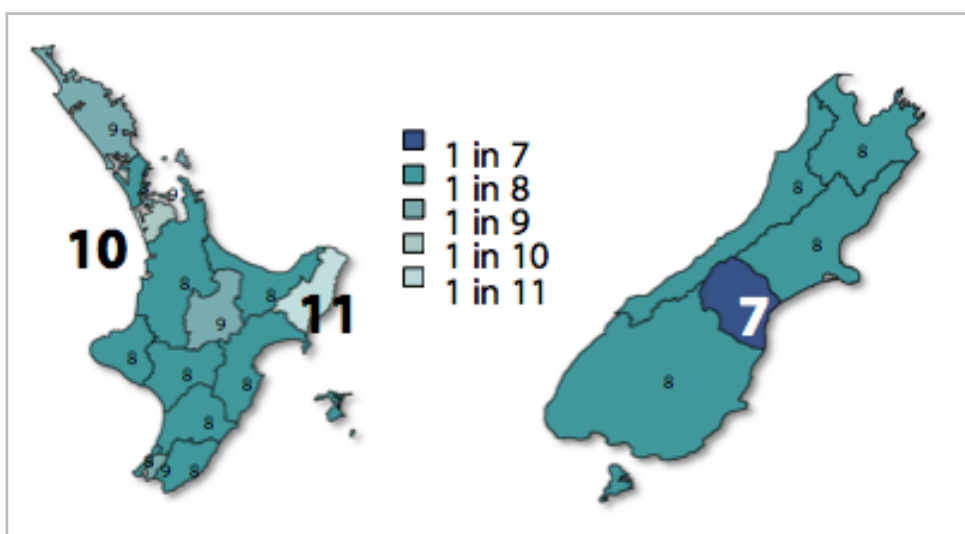


Figure 2. MD prevalence per DHB

## Save these dates:

<p><b>9 November</b> Evening Auckland</p>	<p><b>'The Treatment Revolution'</b></p>	<p>British ophthalmologist Professor Alan Bird, will discuss one of the greatest advances in medicine in the last decade.</p>
<p><b>October</b> <b>November</b> <b>December</b></p>	<p><b>Christmas Cards</b></p>	<p>If you are a business, you can thank your customers this year with a Christmas card from The Giving Tree. Talk to The Giving Tree about overprinting your Christmas message. Pack of ten available to individuals. <a href="http://www.thegivingtree.co.nz">www.thegivingtree.co.nz</a>.</p>
<p><b>18 February</b> Auckland</p>	<p><b>Ellerslie Race Day</b></p>	<p>Join MDNZ for a day out at the races at Ellerslie Race Course. Put your glad rags on and enjoy a fun day with entertainment, a gourmet lunch and more. Funds raised will help save sight.</p>

# Our Awareness Week Facebook Stories

MDNZ would like to offer a huge thank you to those who shared their personal stories. We know that your stories have informed, reassured and inspired others.

## Jenny Roxburgh

I had two haemorrhages in my right eye in my mid-thirties. Laser treatment caused scarring, which impaired my vision. I was recently diagnosed with MD in the same eye and the earlier scarring damage meant it wasn't possible to treat the eye.

Naturally I wanted to take special care of my left eye, so had regular eye check-ups for years and last May I was diagnosed with MD in my left eye. At first I was in shock and felt very emotional about the diagnosis as I knew there was a good chance I could lose my sight.

The initial treatment didn't work, which felt like another blow and my ophthalmologist suggested I try Eylea injections. I've had five injections and

these seem to have stabilised my vision with no further deterioration noted.

Pharmac does not fund the treatment and each injection costs \$2000.

I have regular treatments every four - eight weeks and am hopeful these will be funded by Pharmac because saving the vision in my good eye means I must receive this treatment every eight weeks for the rest of my life.



## Pic Picot

My mother had dry MD so to be safe, I went for an eye check-up in my twenties to find I also had signs of the disease.

My MD developed very slowly but by the time I was 50 I was having difficulty driving at night and had to stop. I then started having difficulty reading and my eye specialist said nothing could be done to help me so I can't drive, I can't read and I have trouble recognising faces.

Surprisingly, some good has come out of my diagnosis because MD has forced me to let other people help me run my Pic's Really Good Peanut Butter business. Previously I was a micro manager and the



business wasn't growing as a result. Now I've had to employ people to do the things that I can no longer do and they can do them better than I could have and my business has grown. I feel really fortunate. My employees tell me that my sight loss is ironic given they are guided by my vision for the business.

Do you have a story about your experience with MD that you'd like to share? Please email us at [info@mdnz.org.nz](mailto:info@mdnz.org.nz) or mail to **MNDZ, PO Box 137070, Parnell, Auckland 1151.**



# Does your diet include enough Lutein?

A recent study has found that a diet rich in lutein can help reduce the risk of MD and slow its progression. A good example of a lutein food source is Kale. You might like to check out the many recipes on this website devoted to Kale; [www.discoverkale.co.uk](http://www.discoverkale.co.uk).

## Similar recipe websites include:

[www.discoverleeks.co.uk](http://www.discoverleeks.co.uk)

[www.discoverspinach.co.uk](http://www.discoverspinach.co.uk)

[www.discovercavolonero.co.uk](http://www.discovercavolonero.co.uk)



Mexican Quinoa & Kale Bowl

## Portable Electronic Magnifying Aids

HumanWare have recently released the **explorē** family of portable electronic magnifying aids. The flagship product, **explorē 5**, providing a clear crisp image on a 5 inch display screen. The **explorē 5** is ready to use the moment you take it out of your purse or pocket. No instructions necessary. The large, bright buttons are intuitive and simple, and its key features are designed to help in every situation.

**explorē 5** has 3 modes of use: Straight out of your pocket, with folding handle or tabletop use. The long-lasting battery provides 3 hours of continuous use from a single charge.

Sántá & Maurice Sloane from Vision Associates – HumanWare have represented and supported HumanWare's products in New Zealand for over 25 years and welcome the opportunity to discuss client needs in order to match them with the correct product. They may be contacted on free phone 0508 22 55 734, or by email at [sales@vahumanware.co.nz](mailto:sales@vahumanware.co.nz)

### About HumanWare

For over 25 years, HumanWare's inspirational vision has resulted in a range of highly intuitive and intelligent solutions that empower people who are blind or with low vision by giving them the independence to participate effectively within a sighted world. [www.humanware.com](http://www.humanware.com)

Vision Associates Ltd

Phone 0508 22 55 734

 HumanWare™



# “I’ve been to London to visit the Queen” – a profile of MDNZ Ambassador Dame Rosie Horton DNZM, QSO, QSM

Dame Rosie Horton is a well-known philanthropist and mentor for many New Zealand charities, and MDNZ thanks Dame Rosie for giving her valuable time to act as an Ambassador for our organisation.



In March this year Dame Rosie was invited by Sir Don McKinnon to travel to London as New Zealand’s representative to the Queen’s Diamond Jubilee Trust celebrations.

Dame Rosie met Queen Elizabeth at a cocktail party marking Commonwealth Day 2016 held at Marlborough House, attended

the Jubilee Dinner and a banquet for Prince Charles and Camilla, Duchess of Cornwall.

Dame Rosie was invited to sit and chat with Queen Elizabeth and reflects that the Queen was genuinely interested in and cared about the people of the Commonwealth, with a perceived ‘soft spot’ for New Zealanders.

Despite Dame Rosie’s busy schedule and many engagements, she still has time to contribute to MDNZ. Dame Rosie says “through raising awareness of MD we can save sight and make sure our lives are filled with fresh memories” – thanks again Dame Rosie for your invaluable support of MDNZ.

## Charles Bonnet Syndrome – what is it?

Charles Bonnet Syndrome is a term used to describe the phenomenon of visually impaired people seeing things they know are not real. Visual hallucinations or phantom images can be extremely vivid and realistic and these can range from simple, repetitive patterns to detailed images of people, animals or buildings.

About 30% of people who experience major vision loss experience this syndrome which is a consequence of losing sight whereby the brain attempts to compensate for gaps in vision.

A Viewpoint reader recently shared her elderly father’s experience with Charles Bonnet Syndrome. Her father had suffered a stroke and lived with severe vision loss. He believed he saw frightening images on his food and would not eat until his

daughter was able to teach him behavioural coping strategies which needed to be regularly reinforced.

She guided her father to close his eyes and look away for a minute or two, then look back and refocus on his meal. This process needed to be repeated a number of times to build her father’s self-confidence.

Sadly Charles Bonnet Syndrome can be mistaken for dementia and often simple coping strategies can make a big difference.

# Your donation can save sight!

1.5 million New Zealanders are at risk of MD.

41% at risk are unable to identify which part of the body is affected by MD.

MDNZ still has much work to do to save sight.

With your support we can reach the '41%' and save sight.

The following items are most urgently needed to help us raise awareness, improve education and provide support to those with MD, their families and carers.

- Information packs
- Save Sight helpline
- Education seminars
- Newsletter and communications
- Awareness campaigns

**Time lost is vision lost, your donation will make a difference today.**

## Bequests

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

Contact us at [info@mdnz.org.nz](mailto:info@mdnz.org.nz) to find out more.



**Please donate** to support those with MD

Title

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](http://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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