Eyelights

July 2023

Glaucoma Symposiums

Eye bank

Sign our petition

GLAUCOMA NZ
TO SAVE SIGHT

You did it! Thank you!

You raised over $55,000 during our awareness campaign this year, and thanks to you, we can fund three FREE symposiums in Hawkes Bay, Christchurch, and Hamilton. Each event is two hours long and includes presentations from three or four eye specialists, a half-hour question time, and morning tea. They are an opportunity for you to hear about various topics, including eye drop instillation, surgical procedures, new treatments & some lifestyle tips.

The Hawkes Bay Glaucoma Group's first meeting will follow the inaugural Hawkes Bay symposium. This is our eleventh regional group which is only possible thanks to your generosity. Optometrist Hazel Wong and Practice Nurse Belinda Read will host the meetings at Havelock North Function Centre.

In this newsletter, we've highlighted three organisations we are proud to partner with - Vision Research Foundation, Eye Health Aotearoa, and the New Zealand Eye Bank. They support us in fulfilling our mission to advocate for glaucoma patients and advance research & awareness of eye health in New Zealand.

Ann and Roy kindly share their stories, demonstrating the importance of adhering to treatments and attending appointments to enjoy a positive lifestyle. Roy hosts a radio broadcast to share tips on retirement & enjoys the friendships he's made co-facilitating the Kapiti Glaucoma Group

We truly appreciate your donations which enable us to increase the education and support services we can offer you and your family. Whether you give a one-off donation, regular donation, or bequest, I can assure you that you are making a difference in saving sight in your community.

Our grateful thanks,

Pippa

Ann’s Story

Imagine a life where you live in a 5-star award-winning luxury lodge in a remote and picturesque part of New Zealand. Waipoua Lodge is nestled on a ridge overlooking the vast Waipoua Forest, where iconic kauri trees have been living for well over 3,000 years.

Recently I met Ann Sissons, who, with her partner, purchased the Lodge in 2020, just before Covid hit. Together they manage the property and prepare silver service cuisine for their guests, regaling the area’s unique history in a luxurious setting.

Ann is well-travelled and educated, dividing her time to support family in Melbourne, Auckland and Taranaki while juggling the demands of running a hospitality business. I got the feeling that Ann is pragmatic, tackles everything positively as part of life’s adventure, and loves helping others and learning, so it wasn’t surprising that her glaucoma diagnosis was dealt with in a similar way.

Her younger sister is an optometrist, and as such Ann knew to have regular eye tests every two years. She also knew glaucoma was a disease of the optic nerve but had little knowledge of what it would mean to live with until she was diagnosed by her sister following a routine eye test. Her vision was good, and there seemed little to no symptoms, so those regular eye tests meant Ann has been diagnosed early and this means she has less irreversible damage to her optic nerve.

At her first ophthalmology appointment, Ann had already established that there wasn’t glaucoma in her family, but she was keen to solve how she came to have it. Following gentle questioning from her ophthalmologist, Ann revealed she lived with migraines, which appears to be the key to solving her mystery. Migraine is a condition that causes painful and recurring headaches alongside other symptoms, including mild blurred vision and visual disturbances that are reversible (i.e. no lasting effects). The two most common types of migraine are migraine without aura and migraine with aura following the classification system by the International Headache Society.

Ann felt calm at the first appointment until the specialist suggested laser treatment. Ann said,

> **“it was just as well she didn’t give me a moment more to think about it, or I might not have done it, but I’m so glad I did. It was quick, painless, so easy and I’d highly recommend it.”**

She has a drop at night, and a couple of years on, she has added a drop in the morning, and none of this impacts Ann’s busy lifestyle.

She takes her drops religiously as she is aware that the early diagnosis and regular treatments are her best chance to maintain control over the disease. Despite being a confident person, she found that the first ophthalmology appointment was a little daunting, particularly as there is so much information to take in. She emphasised the importance of asking questions, and advocated for taking someone else with you to your appointments, or even asking your specialist if you could record the session on your phone so you can review their answers later.

If you would like to know more about glaucoma and migraines, please read the article on our website or contact us.

One Eye Donor can help up to four people

NZ National Eye Bank

The NZ National Eye Bank's mission is to restore sight through transplants. Since its inception in 1991, the New Zealand National Eye Bank (NZNEB) has not only served the community by providing eye tissues for transplantation but also non-transplantable eye tissues for research into blindness prevention.

Over 350 corneas are typically transplanted annually, but due to the COVID backlog, as many as 450 cornea transplantations per year are needed for a few years.

Unfortunately, presently the number of local eye donors is extremely low, and we all need to encourage greater awareness of eye donation in New Zealand.

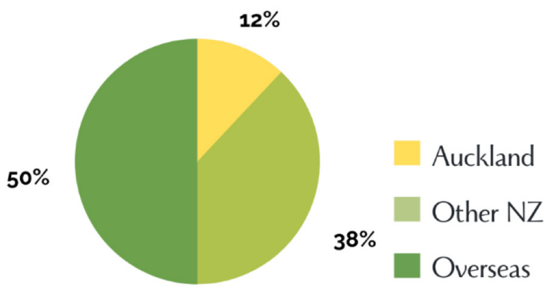
Ultimately, if it were not for the provision of tissue for corneal transplantation several thousand Kiwis would be blind! Therefore, if anyone is in doubt about the gift of donating their eyes after death, simply stated; your kind donation can make the blind see!

Professor Charles McGhee, Scientific Director & Chair NZNEB

Statistics & Challenges

Unfortunately, the number of eye donors in New Zealand is very LOW, with over 50% of donors from Australia. We now rely heavily on Australia (Figure 1) to provide corneas but the quantity is not guaranteed because it depends on the number of donors available in Australia, which has also reduced since COVID 19. Wait times for transplants in NZ average 2-3 years or even longer. Most waitlisted individuals are under 40, a critical stage in life.

Figure 1. Donor Location Jan-Jun 2022



Eye Donation Facts

- Eye donation is the precious gift of sight. You can choose to donate your eyes after you pass away.
- Corneal transplant is the last hope for people with cornea blindness. This sight-saving operation is only possible because someone chose to donate their eyes after their death. ONE EYE DONOR CAN HELP UP TO FOUR PEOPLE.
- Eye donation does not change the appearance or affect funeral arrangements. The process takes about 30-45 minutes.
- The cornea is a transparent "window" at the front of the eye. It must be transparent and regular in shape to focus light correctly.

Who can donate?

- The good news is that almost everyone can donate their eyes after their death.
- Eye donors can have different eye colours, blood types, and levels of eyesight.
- Most health conditions such as cancer, heart disease, and diabetes do not prevent eye donation. Cataracts, glaucoma, or LASIK surgery are not obstacles.
- Donor age is not as important as it is for other organs or tissues.

DON'T ASSUME YOU ARE NOT HEALTHY ENOUGH TO BE AN EYE DONOR.

How do I become an eye donor?

- The most important step is discussing your wishes with your closest family or friends (your 'next-of-kin'). Without their consent, no donation will occur. Talking to them in advance will help prepare them for this process.
- Being listed as a donor on your driver's license does not mean you will automatically become a donor after your death.
- For the eye donation to happen the Eye Bank needs to be notified as soon as possible after your death by hospital staff , GP, funeral director, family, or a referring donor agency.

Ron Tustin - Finding time to support others.

Ron Tustin is a Kapiti Glaucoma group facilitator and hosts a programme on Access Radio on tips when planning retirement. He is well qualified in both roles, having previously worked as a tutor and coach in retirement planning and public health prevention, encouraging people to manage their health through good nutrition, exercise, and awareness of early warning signs.

Ron advises how this period in our lives has changed radically since when our parents retired. We will likely have about a third of our lives in this period, likely to be much healthier and want to continue contributing. We all need something for which we will jump out of bed in the mornings.

Thinking carefully about what we want to do and how we balance our time among work, play, and family/friends becomes very important.

He kindly shares his journey with glaucoma with us and what makes him jump out of bed to remain actively engaged in his community and family life.

My only prior knowledge of glaucoma, apart from my mother living with it, was that I had been given glaucoma screening tests whenever I had been for an eye test. However, in 2019 I started to notice floaters. After a thorough test, the optometrist referred me to the public hospital for an acute appointment as he detected glaucoma needing urgent attention. Unfortunately, as we headed into Covid, that appointment did not happen for three months.

> **"I advise others newly diagnosed to seek information on evidence-based websites like Glaucoma New Zealand. Talk to friends and family about it and to others who have been diagnosed with eye disease. Join a support group!"**

The optometrist showed me the field test to explain what was happening with my peripheral vision. He also discussed the prognosis, and I felt reassured that if I kept to the treatment regime, I could control the disease.

We are fortunate in Kapiti to have three coordinators for our local glaucoma group. Carole organises the room, while Tony and I act like a 'tag team' facilitating meetings. I find it helpful to understand facilitation and being aware of how important it is to allow everyone to share stories and learn from each other.

I am a keen photographer, and although having glaucoma means I need to concentrate a little more on close-up work to have a well-focussed viewfinder, I still enjoy this hobby considerably.

As I spend much time giving others advice, I now know that with our life experiences, we can get the best advice from ourselves. As my daughter sometimes says, "What Dad does is not necessarily the same as what he says!"

Bring your friend(s) and family to join us at the Kapiti Glaucoma Group meets at Kapiti Village on the last Friday of alternate months.

See our website for details of our regional support group meetings. Or call Karon 0800 452 862

Follow Ron's facebook page– Revive And Thrive Channel, and listen to his show at **www.coastaccessradio.org.nz**

Disrupting conventional approaches to healthcare

Vision Research Foundation

Glaucoma New Zealand is proud to be a supporting partner of Vision Research Foundation and share its latest news.

Recently, new Senior Research Fellow William Schierding commenced work as part of the Vision Research Foundation Senior Fellowship. He is based at the Opthalmology Department at the University of Auckland and is supervised by Professor Helen Danesh-Meyer.

Dr Schierding's research investigates telomere length and age-related eye diseases using data from the UK Biobank database. Telomeres are structures made of DNA sequences and proteins located at the end of chromosomes that protect and organise them. They play a critical role in cell fate and aging.

Telomeres shorten with each cell replication, and when they reach a critical length, the cell dies. Telomere length is heritable, and shorter telomeres are associated with aging, mortality, and some age-related diseases. Telomerase is an enzyme that can lengthen telomeres. Research is ongoing to identify variables that can preserve or lengthen telomeres and to find treatments for telomere diseases.

Dr Schierding's research will explore the relationship between telomere length and major causes of blindness, such as age-related macular degeneration, glaucoma, cataract, and diabetic eye disease, using innovative big data analytical techniques and the UK Biobank. The study has the potential to enhance research and medical education and disrupt conventional approaches to healthcare.

"Loss of vision, including the development of glaucoma, can be a scary diagnosis – knowing that this is a debilitating disease with few treatment options. Earlier detection of risk factors can improve future diagnostics and power our understanding of disease pathology."

"My research will leverage large international genetic and clinical databases and use inexpensive, cloud-based computation to develop a tool which can show a comprehensive picture of how genetic, clinical, and environmental factors combine to increase the risk of diseases such as glaucoma. This project aims to find beneficial, cost-effective ways to screen individuals and reduce the burden on clinicians by removing some of the unknowns of diagnosis"

Dr William Schiedring

Dr Schierding is a Bioinformatician who received his Master's degree in Genetic Epidemiology in the United States. He moved to New Zealand in 2012 and completed his PhD at the University of Auckland.

With over 8000 citations of his work, Dr Schierding's research focus is on the intersection of genetic and epigenetic research with modern "big data" approaches (machine learning to determine the significance of molecular risk factors). His work involves the harmonisation of polygenic risk scores, epigenetic status, and clinical measurements in predictive computational models for better disease prediction.

You can save the sight of generations to come

Briefing MP Ricardo Menedez at Parliament House with Eye Health Aotearoa representatives, Jelena Zidov & John Mulka

Glaucoma NZ is a trustee of Eye Health Aotearoa (EHA), a multi-sector collaborative across the eye health sector. We have banded together to ensure that all New Zealanders can access equitable, quality eye health services and prevent avoidable vision loss.

New Zealand's eye health policy, planning, and programmes should be supported by high-quality research and data collection systems. But New Zealand has no formal data on the prevalence or causation of vision loss. Other countries like Australia have strategies, policies, and frameworks that give them up-to-date representative data on eye health conditions. As a result, New Zealand has no comprehensive eye health strategies, policies, or frameworks to plan for and measure progress in eye health and vision care. The first step in correcting this is to get truly representative and current New Zealand population-based data on the prevalence and causes of vision impairment.

One of EHA's strategic goals is for Government to commit to measuring the prevalence of eye health and access to eye health services, as good eye health supports overall health and well-being. Currently, vision loss in NZ costs taxpayers $3.74billion dollars each year.

Recently, the Chair of EHA, John Mulka, CEO of Blind Low Vision, and Chrissie Cowan, CEO of Kapo Maori Aotearoa New Zealand, made an oral submission to the Petitions Committee to recommend that the government fund the first Aotearoa Eye Health survey.

It is essential we understand how many people in NZ live with a potentially blinding disease. These diseases must be carefully monitored and treatment started as soon as possible. Early diagnosis and treatment have been shown to limit vision loss from some eye diseases.

A national eye health survey will reflect the national population, which is important to assess and respond to the needs of specific ethnic, age & socioeconomic groups. Many eye diseases, such as glaucoma, may be prevalent without presenting with vision loss or symptoms. For this reason, the national eye health survey must include a physical eye health examination, as many people completing a survey may not be aware that they are living with impaired vision.

Please support a national eye health survey by signing the EHA petition.
www.eyehealthaotearoa.org.nz

Eye Health
Aotearoa

Patient Symposiums 2023

Do you, or someone you know, live with glaucoma?

Complimentary morning tea to follow presentations from ophthalmologists & optometrists. Register now by calling Karon 0800 452 826 or email info@glaucoma.org.nz, or on our website.

Christchurch Symposium

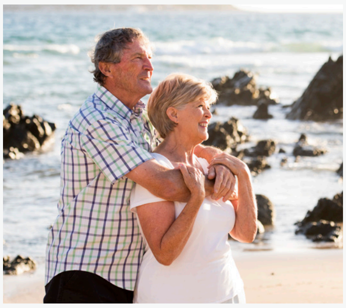
Saturday 9th September
9.30am – 11.30am

Commodore Airport Hotel
Head of Avon Room
449 Memorial Avenue,
Burnside, Christchurch

Hawke's Bay Symposium

Saturday 5th August
9.30am – 11.30am

Shakespeare Room
Toitoi – Hawke's Bay
Arts & Events Centre
101 Hastings Street South,
Hastings



Hamilton Symposium

Saturday 23 September
9.30am – 11.30am

Novotel Tainui
7 Alma Street,
Hamilton Central

Glaucoma Support Groups

If you would like to join a support group please contact Karon **0800 452 826**, or find our more on the website. **www.glaucoma.org.nz**

WARKWORTH

Summerset Falls, Warkworth

AUCKLAND NORTH

Glenfield Community Centre, Glenfield

AUCKLAND CENTRAL

Epsom Community Centre, Gillies Ave.

HAMILTON

Settlement Centre, Claudelands, Hamilton

TAUPŌ

Ross Gordon Optometrists– 66 Ruapehu St, Taupo

WELLINGTON CENTRAL

Penthouse Cinema and Café, Brooklyn.

TIMARU

Caroline Bay Lounge, Timaru

CHRISTCHURCH CENTRAL

Mary Potter Hospice or Mona Vale Homestead.

NEW PLYMOUTH

Muffin Break, Centre City Shopping Centre.

KAPITI

Card Room, Kapiti Village, Paraparaumu

HAWKE'S BAY

Havelock North Function Centre, Hastings.

Glaucoma Groups are an opportunity for members to meet regularly to gain peer support on living with glaucoma, hear from speakers to learn more about the disease, and make new friendships.

Glaucoma is a registered charitable trust and receives no government funding. Our education resources and support programmes are free with the generous support of Glaucoma NZ members. All donations of $5 and over are tax deductible.

Charities No. CC21421

Prefer to receive your newsletter by email?** Please provide an email address to Karon at **0800 452 826** or **info@glaucoma.org.nz

Always check with your health professional before trying alternative remedies or supplements.