

# Eyelights

November 2024

**Extending  
your care**

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**Who's who in your  
glaucoma family**

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**Is your family at risk?**

**GLAUCOMA NZ**  
TO SAVE SIGHT

# 2% Don't lose sight of family

Leaving a gift in your will is a powerful way to make a positive difference for your family for generations. 2% of Kiwis have glaucoma, with the risk of developing glaucoma 10 times higher if you have a close blood relative with the condition.

**A gift of just 2% of your estate to Glaucoma New Zealand leaves 98% for your family.**

GLAUCOMA NZ  
TO SAVE SIGHT



## Thank you for your support in 2024!

Welcome to your final Eyelights of 2024. Thank you for shaping everything we do. Your feedback, your engagement, your gifts of time, your donations and your experience are crucial to this charity.

You've helped to expand your network of regional groups to Tauranga, Palmerston North and Invercargill. More of you attended recent online seminars. You also attended 'Love Your Eyes' Symposiums in Taupō and Timaru. You help Glaucoma NZ do more.

In this edition of Eyelights, you'll find research from Esther, who provides a snapshot of new Glaucoma NZ member needs. You'll also read stories from Estelle, Clare, Sonia and Edith. They help you better understand the risk of glaucoma for your loved ones. And they show support that's here for you, no matter your age or stage of glaucoma.

As this newsletter was going to print, you reached a truly magnificent goal. You raised \$115,000 to proceed with a vital clinical trial! Thank you for paving the way to better eye health for NZ.

I would like to acknowledge very special members who have now passed away. Monetary gifts in their Will helped

you to achieve this goal. We feel honoured to be carrying their legacy through this significant study.

The evidence gathered will create a strong base for Glaucoma NZ to approach Pharmac. It will allow us to advocate for fairer access to preservative-free drops for you and your loved ones.

With Glaucoma NZ, you make sure that glaucoma care is extending well beyond clinics. You create awareness to save sight and education to build confidence. You empower others and provide a support network. Your passion for fairness enables advocacy, research, and so much more.

As the holiday season approaches, you'll spend time with loved ones and look to the new year. I'm excited for 2025 with the momentum you've built in 2024.

Thank you again for your support.

Warm regards,

*Pippa*





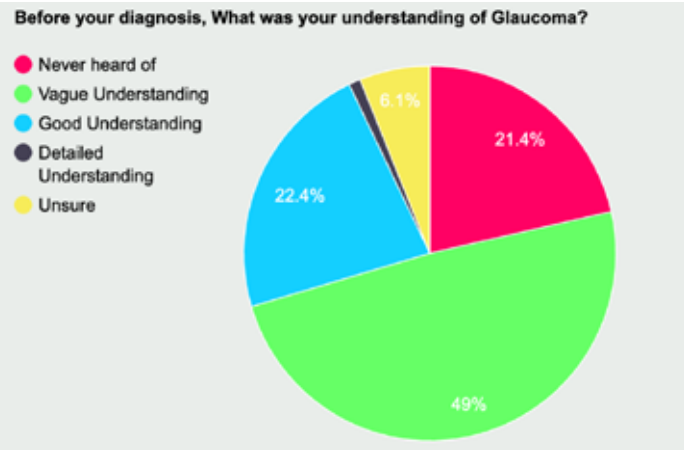
# Education & Communication in Glaucoma Care



Esther was Glaucoma NZ's 2022 research scholar.

Recent research by Glaucoma NZ Gordon Sanderson Scholarship recipient Esther Kim has highlighted key areas where we can all work together to improve understanding of glaucoma and treatment adherence.

In her study, Esther spoke with 90 new members of Glaucoma NZ. Alarmingly, over 76% of participants shared that they had little or no knowledge about glaucoma before joining, with only a vague awareness that it was an eye disease.



Many members also mentioned that, because glaucoma often shows no obvious signs in the early stages, it's easy to overlook or not discuss with others.

Furthermore, 66.3% of patients were not familiar with their specific glaucoma subtype, suggesting the need for clearer communication and education initiatives.

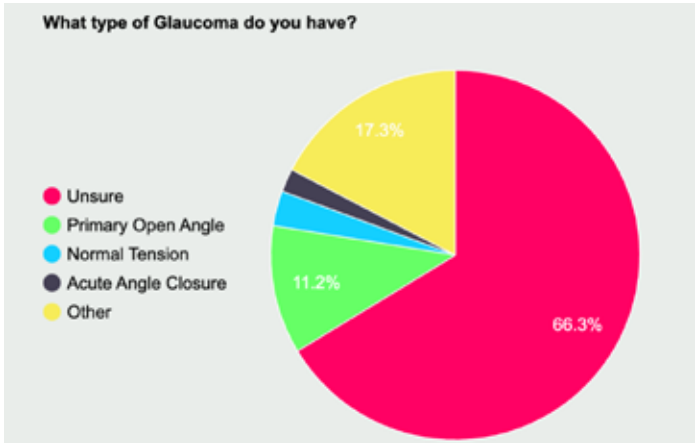
Esther also looked at common challenges that members like you face in staying consistent with treatment plans. She found that barriers such as forgetfulness, lack of motivation, treatment costs, and medication side effects can make it difficult to stay on track. These, combined with limited knowledge about the disease and difficulty accessing eye care, are areas where more support could make a real difference.

Glaucoma NZ offers the right resources and services to help, but more needs to be done. So, it's exploring new ways to provide direct educational support.

Phone calls from clinical educators to newly referred members offer chances for questions and getting guidance. Esther's findings suggest this tailored approach, with other education, could improve treatment adherence.

We're committed to supporting you by keeping open lines of communication. By staying connected—whether through phone calls, face-to-face meetings, or educational events—we extend your glaucoma care. You should have all the information and reminders you need to protect your vision for the long term.

*If you want to increase Glaucoma NZ's impact on new members, or support future research projects, **donate today at [glaucoma.org.nz](http://glaucoma.org.nz)**.*



## Estelle & SightScore™



Estelle (right) with her girls Michelle and Megan (L-R).

Estelle lives with severe glaucoma and she arranged for her daughter Megan to take a test. This test was to find her 'risk score' for glaucoma. It predicts if she might develop the disease in her lifetime.

"Neither of my girls have shown any signs of glaucoma" says Estelle. "And no one else in my family has it...I've sort of felt that my girls will probably be fine and won't get it. But in actual fact, it sounds like Megan could."

Estelle explains that the test results gave a score and showed a graph. "The left-hand side starts in a light colour, and it ends up red on the right-hand side. And it plotted her on that. She was at the beginning of the red".

As the score represents your likelihood over your whole lifetime, Megan still has a few more years till glaucoma is a concern. Megan's not too worried. She has total faith in her eye specialist who can leverage the risk score to treat her.

For Estelle's family, the score reminds them to keep up with their regular eye health checks. "It just means everybody will be a little bit more cautious."

"If someone in the family's got glaucoma, and they're worried about it, I would definitely recommend them getting the test" says Estelle. "And if they're anxious about losing their sight or they think there's something wrong." Find out more at [glaucoma.org.nz](http://glaucoma.org.nz).

## Extending Your Support Network

Earlier this year, sisters Clare and Jean attended Glaucoma NZ's Love Your Eyes Symposium. There they showed interest in a new Glaucoma group for Tauranga. A few months later they agreed to assist two others in setting up The Tauranga Glaucoma Support Group.

Clare has glaucoma but Jean doesn't. In fact, nobody in their family has glaucoma, but Clare. She was diagnosed when she was just 22 years old.

"My parents didn't have it. My cousins and so on don't have it" says Clare. "My mother was adopted as a baby, so there could have been something in that background, but I don't know that family history" she adds.

Like Clare, Jean is a member of Glaucoma NZ, staying up to date with the latest developments and updates on glaucoma. They are both happy to be

helping with Tauranga's new Glaucoma Group. "At the first meeting we had, there were some there who'd been recently diagnosed. And you know, it's quite a shock" says Clare.

**"It's always good to have a support group where you can talk to other people... you know you're not on your own"**

**The next meeting for the Tauranga Glaucoma Group is 10.00am on Saturday 23 November 2024 at the Parewaitai Village Community Centre, 718 Grenada Street, Papamoa Beach.**

**Visit [glaucoma.org.nz](http://glaucoma.org.nz) to find your local group.** If you want to set up a new group contact Jenna at [info@glaucoma.org.nz](mailto:info@glaucoma.org.nz) or 0800 452 826.

## Much-anticipated Children's Book Launches



*Children's book 'Lucas's Epic Adventure' is ready to provide courage to families affected by glaucoma.*

Sonia is Mum to a unique young man. Her son Lucas is the only confirmed genetic case to be born with severe myopia, glaucoma and Stickler syndrome\* (in all medical history!).

As Lucas was growing up, Sonia searched for a children's book. She wanted one that would inform and reassure him. And help him understand that he is special. A book like this could help family members and curious strangers. But Sonia couldn't find one.

So, what does this innovative Kiwi do? Write one herself of course. Sonia explains the book is now published after five years in the making. "I'm very excited for the book to get into the hands of our amazing families who need courage, support and inspiration!"

At the end of October, she attended the Parents of Vision Impaired NZ conference and launched the book. "I took 100 thinking I might sell 15-20, but I completely sold out" she says. "So many people are asking worldwide and eager to read it."

The book titled 'Lucas's Epic Adventure' goes through Lucas' journey. It shows his

positivity and resilience despite blindness in one eye and many surgeries on the other. And his passion for go-karts, tractors, farming and penguins!

Sonia is grateful for the support she and her family have received. She would like to acknowledge everyone who helped make this book a reality. She hopes that this book will inspire other children. And help them navigate their own eye health journey.

"I'd do anything to make the lives of other families like ours easier. We've had so much help so far. I really want to give back."

Glaucoma NZ General Manager Pippa Martin says "I appreciate the hours, effort, love and generosity that Sonia and many others have poured into this venture. An incredible gift to families of low vision children."

\*Stickler Syndrome is a connective tissue disorder. It leads to vision, hearing and movement difficulties.

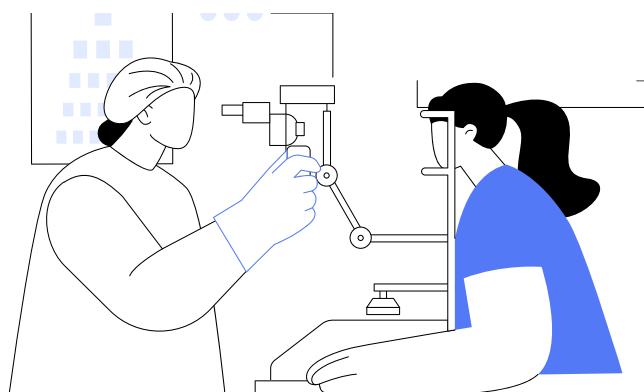
**Keep an eye on [glaucoma.org.nz](https://glaucoma.org.nz) to see how you can buy your own copy.**



# Who's in Your Glaucoma Family of Care?

Managing glaucoma can be overwhelming. Especially if you're not sure where to start or who to turn to for advice. Please know that there's a whole family of professionals supporting you on your individual glaucoma journey.

If you need, Glaucoma NZ is here to point you in the right direction. Here is a breakdown of your glaucoma family and when you might contact them:

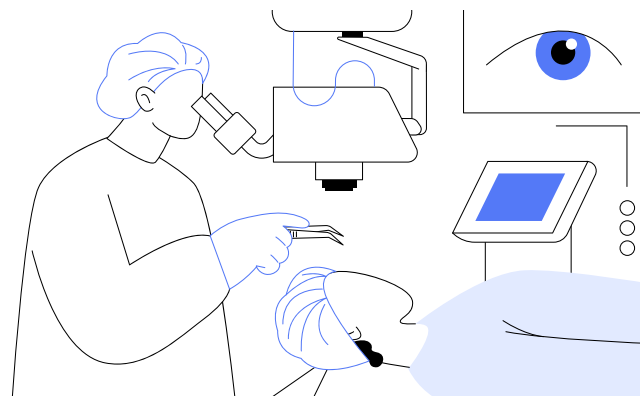


## 1. Optometrist (Eye Care Specialist)

Your optometrist is usually the first person you'll see for an eye check-up. They can examine your eyes, measure eye pressure, and check for signs of glaucoma. If they spot anything unusual, they'll refer you to a specialist for further investigation.

Some optometrists, known as **glaucoma-prescribing optometrists**, have advanced training and can prescribe certain medications for glaucoma, like eye drops, which may help with your treatment plan. A regular optometrist can help with the initial detection of glaucoma and general eye health, but a glaucoma-prescribing optometrist can manage more of the treatment alongside the eye doctor.

*Contact for: Routine eye checks, any changes in vision, questions about your glasses prescription, or general questions about your treatment if they're a glaucoma-prescribing optometrist.*



## 2. Ophthalmologist (Eye Doctor)

An ophthalmologist is a medical doctor specialising in eye diseases. They're the main person responsible for managing and treating your glaucoma. There are different kinds of ophthalmologists:

**General Ophthalmologist:** A trained eye doctor who can diagnose and treat many eye diseases, including glaucoma. They can prescribe medication and perform some surgeries if needed.

**Glaucoma Specialist Ophthalmologist:** An ophthalmologist who has done additional training specifically in glaucoma. They're experts in advanced glaucoma treatments and surgeries. If your glaucoma is more complex, you may be referred to a specialist.

Your ophthalmologist, especially if they're a glaucoma specialist, will create your treatment plan, which might include medications, laser treatments, or surgery to help manage eye pressure and protect your vision.

*Contact for: Major changes in your vision, detailed treatment questions, discussing new treatment options, or if you experience side effects from medications.*



### 3. Pharmacist

Your pharmacist is there to help you with the medications prescribed by your eye doctor. They'll show you how to use eye drops properly, explain any possible side effects, and remind you when it's time for a refill.

*Contact for: Questions about your eye drops, managing any side effects, and getting refills.*



### 4. General Practitioner (GP)

Your GP is your main contact for general health concerns, which can be especially important if you have other health conditions like high blood pressure or diabetes, as these can impact eye health. They might work with your eye doctor to ensure your whole health plan supports your glaucoma care, especially if you have side effects from glaucoma medications that impact your overall health.

*Contact for: General health questions, side effects affecting your overall health, or managing other health issues that might impact your eye health.*



### 5. Glaucoma NZ

Glaucoma NZ is a non-profit organisation dedicated to supporting Kiwis like you who are affected by glaucoma. Though they can't provide direct medical care or advice, they offer reliable information. And a community of support. You can hear from specialists and connect with others who have glaucoma.

As a member of Glaucoma NZ, you have access to a wealth of information, which can help you ask informed questions at your eye appointments. And understand any new treatments that might be suitable for you.

*Contact for: Understanding glaucoma, staying updated on new treatments, and finding community support for living well with glaucoma.*



*Did you know that you can watch past online education seminars?*

*Find Glaucoma NZ on YouTube or visit [glaucoma.org.nz](http://glaucoma.org.nz) and click on the 'Patient Education Seminars' banner.*

# Edith Robinson: High Intraocular Pressure

Edith loves her family. You hear the love in her voice as she speaks about her grandchildren. Even more when she speaks about her great grandchildren.

Her glaucoma journey has been long. It started by chance. Her friend's glasses had been stolen, so she was taking that friend to get a new pair.

Edith was asked 'Have you had your eyes checked lately?' Her answer was 'never'. She had just turned 50.

"I was lucky to be diagnosed with high intraocular pressures (IOP) back about 1997 and then asked to be on a new eyedrop trial in 1999 which was an interesting experience - especially when my eyelashes grew long and dark!" says Edith.

High IOP, also known as Ocular Hypertension (OHT), is different from glaucoma because there are no detectable changes in vision. There's no evidence of visual field loss, and no damage to the optic nerve.

OHT is not a disease on its own. And not everyone who has OHT will get glaucoma. But it puts you at risk of developing glaucoma. Sometimes this, in addition to other risk factors, can class you as a 'glaucoma suspect'.

Sadly in 2013, Edith's mother passed away. When putting her mother's affairs in order, she discovered that she unknowingly had a family history of glaucoma. Another risk factor.

"I didn't know that my mother was blind in one eye from glaucoma - she never told us. I was able to warn my siblings, and both my sisters have high eye pressures and are being monitored" she explains.

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Glaucoma NZ | Dept. of Ophthalmology, University of Auckland, Private Bag 92019, Auckland 1142, FREEPHONE 0800 GLAUCOMA (452 826) [info@glaucoma.org.nz](mailto:info@glaucoma.org.nz) | [www.glaucoma.org.nz](http://www.glaucoma.org.nz)



*Edith (77) has been a keen flyer since she was 17.*

Just one year later in 2014, Edith developed irreversible glaucoma damage. "The drops kept the pressure under control for quite a few years. Then suddenly they just started going up and up" she said.

Next was a trabeculectomy in each eye. There has been no more sight loss since. Though she had lost some sight, she could still do things she loved, like flying.

Edith is passionate about spreading awareness. She wants others to have an eye health check. So, she donates to Glaucoma NZ to make it happen.

**"It is my privilege and pleasure to be able to donate...If my donation helps towards preventing glaucoma in another person then it is worth every dollar."**

*If you or your loved ones have risk factors like family history or high intraocular pressure, you should have eye checks more often than those without them.*

*Do you want to raise awareness of glaucoma and its risk factors like Edith?*  
**Donate at [glaucoma.org.nz](http://glaucoma.org.nz) today.**

*Glaucoma NZ is a registered charitable trust (No. CC21421) that receives no government funding. Education resources and support programmes are free thanks to the generosity of everyday New Zealanders like you. All donations of \$5 and over are eligible for a 33.3% tax rebate.*