

## DON'T LOSE SIGHT OF FAMILY

What an unexpected year 2020 has been so far. It seems like so much has changed since our last Eyelights edition at the start of April. COVID-19 has been an unknown for everyone, and has provided challenges for all organisations and businesses in New Zealand.

But while things might have changed, Glaucoma New Zealand is more committed than ever to saving Kiwis' sight and to providing those with glaucoma the support and resources they need to preserve their vision.

Throughout lockdown, we were reminded of the importance of our family and looking out for one another. In a time when we couldn't meet in person, a phone call just to check in was so meaningful. Lockdown definitely gave us all a chance to reflect on what's important.

We hope that caring for others and looking out for our people continues long after COVID-19 is over. When it comes to glaucoma in particular, family and communities really matter.

July is our annual appeal month – this year our theme is 'Don't lose sight of family.'

One of the main ways we can look

out for our families is by looking out for one another's health. In this edition of Eyelights, we provide information on the link between genetics and glaucoma and why it's so important to be clued up on your own family and their eye health. We also share the story of a family who know better than most how much glaucoma runs in families! We encourage you to ask your family the important questions about their eyesight, and prompt them to get regular eye exams if you have glaucoma yourself.

I hope you will consider donating to Glaucoma New Zealand to help us to continue providing the valuable support we do. Please use the enclosed response coupon and freepost envelope or visit [glaucoma.org.nz](http://glaucoma.org.nz) to donate. Thank you so much.



PHOTOGRAPHY THANKS TO: @AWCREATIVEUT

We're looking forward to seeing you all soon. In the meantime, stay safe and well.

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# Genetics and glaucoma: Family matters

If a person has a family history of glaucoma, his/her risk of developing the disease increases markedly. But what is the risk? And what is the science behind it? Here, Associate Professor of Ophthalmology at University of Auckland Andrea Vincent shares her expertise on genetics and glaucoma.

Understanding your risk factors for glaucoma may allow for an earlier diagnosis, and for many people, one of the simplest, known risk factors is a family history.

In primary open angle glaucoma (POAG), 4-16% have a positive family history. However, this is unreliable as many cases of glaucoma are not diagnosed and some patients don't inform their family members that they are affected.

In the Ocular Hypertension Study, 42% had a positive family history in any relative, and in the POAAGG (Primary Open-Angle African American Glaucoma Genetics) study, >35% of subjects had a positive family history in a first degree relative (parent, sibling, child).

Looking at it another way, in one study first degree relatives of patients with POAG had a 22%

lifetime risk of developing glaucoma, compared with those in a control population, whose relatives only had a 2.4% risk. An Australian study showed a 9-fold increased risk compared with the general population for first degree relatives of POAG.

We also know that individuals with a family history are more likely to access screening for glaucoma, and at an earlier age.

The Australia and New Zealand Registry of Advanced Glaucoma (ANZRAG) looked at patients diagnosed with glaucoma genetically, vs. those diagnosed in

the clinic. In the genetic patients, 83% were unaffected, and the rest were glaucoma suspects. Compare this with the clinical cases, where 44% were glaucoma suspects, 28% had glaucoma, and 22% had advanced glaucoma. The IOP (intraocular pressure) was higher in the clinical cases, and the genetic group was on average 7 years younger than the clinical group.

This demonstrates that knowledge of disease in a family results in earlier screening, and earlier diagnosis.

Personalised medicine is an evolving field, with the potential to

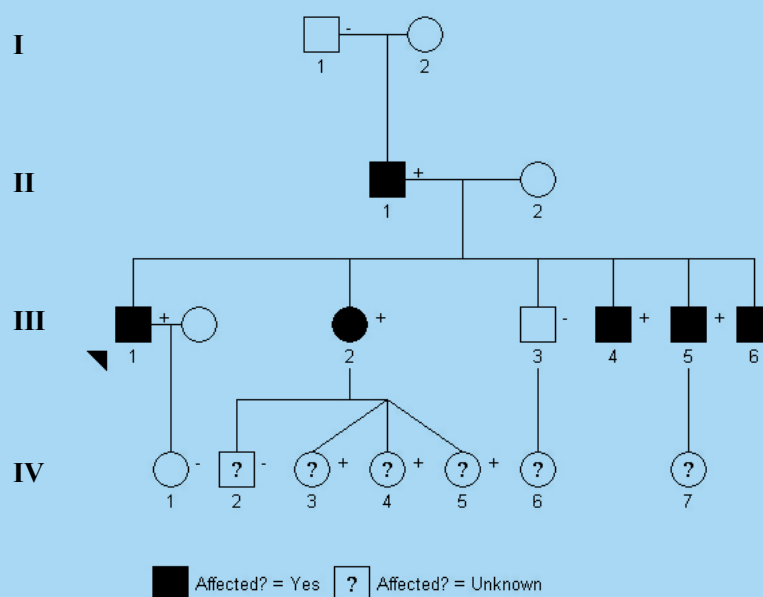


Figure 1. An autosomal dominant pedigree, as seen with Myocilin mutations in Juvenile-onset open angle glaucoma. Squares are males, circles are females. Filled symbols are affected individuals, empty symbols unaffected. The + represents a positive Myocilin mutation. The younger individuals who have tested positive for the mutation have not yet developed disease, but with regular screening can be detected early and treated appropriately.

use genetic information to predict disease development, and to tailor preventative intervention for an individual. Glaucoma genetics can allow family risk assessment, highlight optimal treatments, and provide new insights into the pathways leading to glaucoma. Ultimately, these genetic targets and pathways may provide opportunity for new treatments.

For juvenile onset open angle glaucoma (JOAG), which affects people under 40 years old, the first gene identified was Myocilin. Although Myocilin only accounts for 2.4% of overall glaucoma, it is responsible for up to 36% of people with JOAG, who often have higher

pressures at a younger age and more advanced disease when diagnosed.

Only a few genes like Myocilin exist, where there is a strong correlation between a gene mutation and developing glaucoma. The majority of over 100 glaucoma risk genes individually have a very minor effect on disease development.

Recent studies have summated these genetic risk factors to create a 'polygenic risk score'. This means that if you have an excess of risk variants, although individually they may not account for much, combined they can predict an earlier onset of disease and greater

risk of disease development, compared with those who have fewer risk variants.

So what are the practical considerations of this? Ask your family members if they have glaucoma, and if so, get your eyes checked sooner.

If you have been diagnosed with glaucoma, share this information and encourage your family to get their eyes checked.

Participation in the Australia New Zealand Registry of Advanced Glaucoma (ANZRAG) is free, and can be facilitated by your Eye Specialist, so ask them if you would like to become involved.



**Blindness from glaucoma is preventable.**

2% of New Zealanders over the age of 40 years are affected  
but only 50% know they have it.

## Update on patient symposiums and support groups

Because of what's happened with COVID-19 and changes in our circumstances, we are having to cancel the in-person version of our patient symposium this year. However, we will be asking speakers to produce the talks they were going to give as videos so that you can still learn from them.

These will be shared via our YouTube channel, on our website, and on our Facebook page. All talks should be available by the end of July.

We will hopefully be able to schedule another set of symposiums in 2021.

In regards to support groups, we are planning on continuing with these – however, we will give each group the ability to choose whether or not to hold a meeting in person or not. Contact your group coordinator to find out more about your group.





# A glaucoma diagnosis across generations: Anna-May and her family's story

Anna-May Martin wasn't the first in her family to be diagnosed with glaucoma. She wasn't even the second. Her grandmother, father, sister, and brother all have glaucoma, and have each dealt with the upset of diagnosis and ongoing treatment for the condition. For them, glaucoma is a family affair.

Anna-May's father was diagnosed in his thirties, when she and her siblings were still too young to fully understand what it all meant. "I can remember Dad having an operation and coming home with patches on his eyes," she says. "At the same time, his mother was going through her own glaucoma treatment as well."

Because of their father's glaucoma, Anna-May and her siblings were all tested regularly from the age of sixteen. Thanks to their vigilance, they've all been lucky in catching their glaucoma early.

After her sister's diagnosis at age 33 – the first among the siblings – glaucoma was always in the back of Anna-May's mind. When her daughter Niamh was born eight years ago, she began noticing an increase in strange headaches and decided to go and get checked.

"My doctor originally thought the headaches might've been due to being a new mum, but considering all of us in the family have experienced these headaches, I decided to take it further," Anna-May recalls. "When I was tested, my eye pressure was extremely high

and I was diagnosed with glaucoma right away."

When eyedrops couldn't immediately control Anna-May's eye condition, she underwent two surgeries and is now thankfully able to manage her glaucoma. "It can take time to find the right eye drops, but stick with it. I've been really lucky as my eyesight is still perfect, and I think that's due to getting tested regularly, catching it early, and maintaining regular treatment," she says.

Glaucoma has certainly had an impact on Anna-May's family, but thanks to catching the disease early, acting fast and listening to the advice of their amazing eye health professionals (Anna-May particularly credits the ophthalmology department at Nelson Hospital with incredible care), the whole family has learnt to manage their eyesight. "Blindness could be a reality for our family; that's why we are all so diligent with care.

"I've been living with glaucoma for the last eight years and it's all good



– there doesn't have to be fear if you catch it early and manage it well."

A family history of glaucoma is a very important risk factor. Glaucoma has a strong hereditary component, with approximately 40% of all individuals with glaucoma reporting a positive family history.

Having a first degree relative with primary open angle glaucoma increases your risk by 2-3 times the normal. If you have a sibling with primary open angle glaucoma then the risk is even higher.

More info can be found at: <https://www.glaucoma.org.au/articles/family-history-and-glaucoma-article/>

# BREAKING NEWS- AUSTRALIAN GLAUCOMA PATIENTS NOW HAVE ACCESS TO STAND ALONE MIGS

## Minimally invasive glaucoma surgery approved as a standalone procedure

After a long wait, minimally invasive glaucoma surgery (MIGS) has finally been approved as a standalone procedure for patients with open-angle glaucoma.



Glaukos iStent inject

Glaukos iStent inject actual size



The Xen Gel Implant, a tiny gel tube 6mm long is now available for the treatment of glaucoma in New Zealand. Photo/Copyright 2017 Allergan. Used with permission.

The Medical Services Advisory Committee has approved the new item number, ruling that MIGS has an acceptable safety profile and contributes to delaying or avoiding the need for a trabeculectomy in some patients.

The decision is testimony to the fact that advocacy can be successful. The Australian Society of Ophthalmologists (ASO) has been arguing and leading the case for over two years. They're thrilled that the previous severe limitations on clinicians' ability to use microsurgical technology has now been removed, meaning more people can access and receive this next generation surgery.

"This was always about people with glaucoma having access to the widest and most modern range of treatment options, and the injustice that arises when that access is denied," says Dr Ashish

Agar, the Australian Society of Ophthalmologists' Vice President.

The advocacy campaign and its success was thanks to an amazing collaboration of organisations across the Tasman. The dedicated team was composed of members from ASO, Thema, the Royal Australian and New Zealand College of Ophthalmologists, the Australian and New Zealand Glaucoma Society, Glaucoma Australia and industry representatives. Glaucoma New Zealand wants to thank them for their dedication and hard work over the past few years to make this ground-breaking decision happen.

It's not every day that a regulatory outcome gets behind new technology, so this decision is great to see. The decision means that more people with glaucoma will be able to receive this incredible surgery and save their sight.

## Thank you!

Thank you to Pub Charity for their continued support of the printing and mailing of Eyelights and to Foundation North for the translation of "Your Eyes" booklet into different languages.

  
**Pub Charity**  
THE HEART OF COMMUNITY FUNDING

# Glaucoma in your language

New Zealand is a diverse place, full of plenty of ethnicities and plenty of languages! Thanks to a generous grant from Foundation North, we're proud to be able to provide glaucoma information to more people – no matter the language they speak. Foundation North's recent grant has enabled us to translate our GNZ

brochure into 11 languages. We know that understanding glaucoma and knowing to get tested regularly is one of the most important ways to preserve sight. Allowing everyone to learn more about glaucoma is a crucial step towards ensuring that all Kiwis – wherever they are from and whatever language they speak –

have the best chance of preserving their vision.

Brochures are available in Te Reo Māori, Samoan, Tongan, Simplified Chinese, Traditional Chinese, Hindi, Punjabi, Japanese, Korean, Afrikaans, and French. Every version is available to download on the Glaucoma New Zealand website.

## For new readers

To those of you who have joined Glaucoma NZ since the last issue of Eyclights, we welcome you!

For your information here are some basic facts about glaucoma:

- People of all ages can get glaucoma.
- There are different types of glaucoma, but they all involve damage to the optic (sight) nerve, which is at the back of the eye.
- Glaucoma is not curable. If you have glaucoma it must be monitored for the rest of your life.
- A family history of glaucoma means you are at much greater risk of developing glaucoma.
- Current treatments for glaucoma aim to lower eye pressure and prevent further sight loss.
- Medication in eye drops can have side effects on other parts of your body. Tell your eye specialist if you notice any change in your general well-being since you started the eye drops.
- If you have glaucoma tell your relatives, especially close relatives like sisters, brothers, and adult children, to have an eye examination – they have an increased risk of developing glaucoma.

If you have not got a copy of our comprehensive booklet on glaucoma please let us know and we will send one out to you.

We are here to help and we care about your journey with glaucoma, so please reach out anytime you need by free phoning 0800 452 826 or emailing [info@glaucoma.org.nz](mailto:info@glaucoma.org.nz)



## Thank you!

Special mention to Bubble Design for the design and Digital Billboard Advertising for donating free billboard advertising to Glaucoma NZ. The advertising ran during Covid-19 level 2, at Wairau Park Auckland.



# WAYS YOU CAN SUPPORT GLAUCOMA NEW ZEALAND

## Making fundraising entertaining

Kiwis love our Entertainment Books – and what we can do with them! But did you know that you can support Glaucoma New Zealand when you buy yours?

Buy your Entertainment Membership at <https://www.entertainmentbook.co.nz/>

orderbooks/102253y and help raise funds to support us in our mission of saving sight. The Entertainment Membership has thousands of up to 50% off and 2-for-1 offers near you. Instantly available, valid year-round, gladly accepted. Get yours today and save.



Books are now completely digital and can be used in multiple cities during a 12-month period from date of purchase.

**A great gift for family and friends – something for everyone!**

## Eyedrop Aids

Using eye drops can be a challenge for many patients, young or old. AutoDrop<sup>®</sup> and AutoSqueeze<sup>™</sup> have been developed to make self-administration as simple as possible – helping to improve patient compliance and reducing reliance on others to help with this task.

Many patients who use eye drops have other conditions that affect their dexterity and ability to squeeze small eye drop bottles.

AutoDrop<sup>®</sup> and AutoSqueeze<sup>™</sup> are re-usable and provide a cost effective solution for simple eye drop application.

You can now purchase these from



Autosqueeze

Autodrop

Glaucoma New Zealand through our website [www.glaucoma.org.nz](http://www.glaucoma.org.nz) or phone 0800 452 826.

## Will you make a gift that lasts longer than a lifetime?

Including a gift (bequest) to Glaucoma New Zealand in your Will is a powerful way to make a positive difference to the outcomes of those with glaucoma and their families, far beyond your lifetime.

**Glaucoma is the leading cause of preventable blindness in New Zealand – this can be prevented with your help.**

People leave bequests of all sizes and no gift is too small. Whatever the size of your bequest, please be assured it will make a real difference to those with glaucoma, and the services Glaucoma NZ provide. **Contact us on [info@glaucoma.org.nz](mailto:info@glaucoma.org.nz) to find out more or request a bequest form.**

## Read your way to saving sight

Available on our website is the fantastic book *Glaucoma: How to save your sight*, written by Ivan Goldberg and Remo Susanna Jr. In it, you can learn about treatments, common myths, forms of glaucoma, and more. 50% of the proceeds from your purchase of the book are donated to Glaucoma New Zealand to continue our sight saving work.



**\$27\***



# Don't lose sight of family

**GLAUCOMA NZ**  
TO SAVE SIGHT

Start conversations. Get tested. Save sight.  
Donate now at [glaucoma.org.nz](http://glaucoma.org.nz)

## GLAUCOMA AWARENESS APPEAL 1 - 31 JULY 2020

As the leading cause of preventable blindness in New Zealand, glaucoma is a family matter. Having a first degree relative with primary open angle glaucoma doubles your chance of developing it yourself. Do you know when your family last had their eyes tested?

We all need to start the conversation. Talk with your family about their eye health, get tested, and give your loved ones the best chance of saving their sight.

About 50% of people with glaucoma don't realise they have the condition. But that's something we're working to change. Help us save Kiwis' sight – donate now to enable us to continue providing support to those with glaucoma throughout New Zealand.

### Not sure how to donate?

Fill in the response form that you received with Eylights, visit

[glaucoma.org.nz](http://glaucoma.org.nz) and click Donate or see below for how to set up an automatic payment.

If you're still giving to us via cheque, firstly thank you so much! Although we love receiving your donation cheques, the banks are now phasing out cheques and will soon stop issuing cheque books. To make sure you can still support Glaucoma New Zealand, why not set up an automatic payment instead?



### Setting up an automatic payment

Our bank details are below – you can set it up yourself online or at your bank, or contact us at [info@glaucoma.org.nz](mailto:info@glaucoma.org.nz) for more information or help to do so. Be sure to let us know when you've set it up so we can ensure you receive a receipt each year as well.

**GLAUCOMA NEW ZEALAND 12 3013 0180964 00**