The newsletter of Glaucoma NZ • Volume 17 • Issue 1 • April 2020

elights



The silent plague: Glaucoma and depression

Quality of life is key to a person's wellbeing – their ability to lead a fulfilled and contented life. From physical to mental wellbeing, social functioning to independence, the markers of quality of life may differ between countries, but vision is consistently listed as one of the core drivers of quality of life.

But what happens when that sight is compromised because of glaucoma?

In a recent study on glaucoma and depression, Dr Ivan Goldberg and Dr Simon Skalicky confirmed that factors such as progressive peripheral field loss, impaired visual function, and multiple treatments may contribute to depression – which in turn can affect a glaucoma patient's quality of life.

"We were some of the first to prove the link between depression and glaucoma – but it's not that surprising, considering that depression is linked with many chronic diseases," explains Dr Skalicky, who is also President of Glaucoma Australia.

Being diagnosed with glaucoma can be incredibly difficult. Loss of sight and having to deal with a change in lifestyle can be isolating and impact on a person's happiness, while having to consistently go through clinical appointments and occasionally treatments can be tiring and overwhelming. In particular, the risk of depression seems to increase as people grow older and as their vision gets worse.

"It's not only depression but also anxiety – there are a lot of unspoken fears out there about glaucoma. A lot of that comes down to knowledge, and to past experiences with glaucoma," shares Dr Skalicky. "For example, someone might be scared as they watched their mother go blind because of glaucoma – but today because they've been diagnosed early and treatments have improved since then, they will likely hold onto their vision."

"We can work against that fear and loneliness by improving people's understanding of what glaucoma is and how we can treat it. That's where organisations like Glaucoma New Zealand come in – they can provide a lot of psychological support, information and encouragement."

Ways to improve quality of life and reduce your risk of depression:

- Keep on top of treatment to prevent any further sight loss
- Talk to your doctor about how you're feeling and decide on a

plan of action (whether that's medication, therapy, or otherwise)

- Stay socially active spend time with friends and family
- Knowledge is power so get educated about glaucoma
- Connect with other people who have glaucoma (such as through Glaucoma New Zealand's support groups) so you know you're not alone

At Glaucoma New Zealand, we're passionate about saving sight because we know that retaining sight is key to retaining independence. Our goal is to connect you with a community, social services, and information that enable you to maintain your quality of life – so please, get in touch if you're feeling at all isolated or anxious.

Eyelights insights:

Mental Health & Glaucoma	pg 1
Isabella's Story	pg 2
Eye Health Advocacy	pg 3
Fundraising for Glaucoma	pg 4
Support Groups	pg 5
Genetics & Glaucoma	pg 6
How to help Glaucoma NZ	pg 7

Diagnosis out of nowhere: Isabella's story

Isabella knows the glaucoma journey well. She was diagnosed nearly a decade ago in her early 50s, and has dealt with the ups and downs of treatment every day since.

Visiting her daughter and new grandchild in Bristol ten years ago, Isabella was shocked to hear her daughter complaining about the hair Isabella had left all over the bathroom floor. For the life of her, Isabella couldn't see any of it. After an urgent visit to the local Specsavers, Isabella was told to visit her doctor as soon as she got back home to New Zealand. With a glaucoma prognosis, there was no time to lose.

"I had an absolutely sick feeling," says Isabella. "I kept on thinking – why had I let the cost of glasses put me off going to the optometrist for so long?"

Isabella had hoped for a speedy treatment upon returning home. However, over a six month wait, a misdiagnosis, and being bounced between Christchurch and Dunedin facilities meant that Isabella was robbed of three-quarters of her vision.

Even though she's undergoing constant treatment, everyday life can still be complicated for Isabella in a way that well-sighted people might take for advantage.

"I had always wanted to keep my independence... I remember feeling so frightened," says Isabella, who used to be an avid walker, enjoying an hour or so out on an evening. With a loss of depth perception, curbs and uneven pavements are a risk that she struggles to manage. Reading and writing are more difficult, so fonts need to be bigger and clearer to see.

"With glaucoma, you have dead spots in your eyes," she

explains. "In the bright lights of the supermarket, I can't see things; I can't read labels. It's a pain in the neck trying to read things."

Glaucoma can be an isolating experience without a helping hand along the way, and Isabella was looking for some comfort and information about her treatments after her diagnosis. She soon discovered the Glaucoma New Zealand website – as well as the Eyelights magazine, which quickly became a welcome wealth of information.

When Glaucoma NZ organised a public meeting in Isabella's town of Timaru, Isabella was on board immediately. "I could see that we



really needed the support here, like many other towns in New Zealand must do," says Isabella. "There's a sense of not being alone when you can hear about other people's glaucoma journeys and talk with one another."

"I was interested in the operations, how people were responding to the latest treatments. There were lots of hints on coping – things like how to shower and wash your hair, or how the post-treatment eyewear affects your sleeping. It's great to connect and learn what works well for others so that we can all live the best we can with glaucoma," she says.

"It means a lot to find friendly faces on your glaucoma journey."

Eye Health Aotearoa Trust

Glaucoma NZ is a trustee of Eye Health Aotearoa (EHA), and Glaucoma NZ's General Manager is currently Chair of this trust. EHA is a multisector collaborative of representatives from across the eye health sector.

We've banded together to ensure all New Zealanders can access equitable, quality eye health services and prevent avoidable vision loss. Representatives include Blind Low Vision NZ, Macular Degeneration NZ, New Zealand Association of Optometrists, The Royal Australian and New Zealand College of Ophthalmologists and the Auckland University School of Optometry and Vision Science. Supporting organisations are Retina NZ and the Optometrists and Dispensing Opticians Board.

On February 19th, in parliament, the EHA successfully launched its seven effective interventions to close the eye health and vision loss gap in Aotearoa New Zealand. These include plans to; conduct the first ever national eye health survey; run a national campaign to educate the public about the importance of taking care of their

eyes; provide funded eye examinations starting with super gold card users; establish a New Zealand vision bus to provide eye examinations in hard to reach





health

Are you with us? We've banded together

Parliamentary Friends Presentation

communities; provide timely access to quality treatment services; ensure rapid access to comprehensive vision rehabilitation, habilitation, and low vision services.

We thank 6 year old Lucas Kiser who has glaucoma and stickler syndrome, and his family, for attending and advocating for eye care for children. We also thank Glaucoma NZ ambassador Patrick Gower for his support.

We look forward to sharing with you how ministers of parliament and the ministry of health will effectively take up these seven interventions to prevent unnecessary blindness and hardship through vision loss.



Third in from the left MP Louisa Wall, and third in from the right MP Simon O'Connor with the Kiser Family.



First from the left Ana Lee, General Manager, GNZ, and trustees of EHA.

For New Readers

To those of you who have recently joined Glaucoma NZ, we welcome you!

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**



Auckland Garden Ramble Success

In November 2019, Albany Rotary held a garden ramble in picturesque Coatesville where six park-like gardens opened up for the day to raise funds for charitable causes. Glaucoma NZ was the main benefactor. A huge thank you to those of you who were able to join us for the day, and to all the volunteers who worked so hard even in the rain. Our General Manager Ana Lee was thrilled to receive a \$12,000 cheque at the cheque ceremony to charities involved. The funds will go towards our Community Education & Support Programme.



Ana Lee, General Manager with Albany Rotary President Grant Smith

Members' survey

At Glaucoma New Zealand, we're always working to support those with glaucoma and their families. Each year, we conduct a member's survey, which helps us learn what our members need and how best we can operate and communicate.

Your answers help us immensely and allow us to continue saving Kiwis' sight in the best way we can. By filling it in, you'll also be in the draw to win a \$100 Westfield voucher to spend and enjoy!

Please fill out the attached survey and return with the enclosed blue envelope.



Raising funds to save sight

Huge thanks to the Residents Group of Summerset at Monterey Park Retirement Village in Hobsonville for their recent casino evening, which raised funds for Glaucoma New Zealand and Macular Degeneration New Zealand. We are so appreciative of your efforts to support people living with agerelated eye diseases!



Ana Lee, General Manager GNZ (2nd from right) and Phillippa Pitcher General Manager MDNZ (left) each receiving a donation cheque from the Residents Group of Summerset.

Thank you!

Thanks to the following funders for their generosity: Pub Charity, for funding the cost of all newsletters for 2020



THE HEART OF COMMUNITY FUNDING

Thanks to all our members who have donated and the Freemasons Foundation, for funding towards our Education Project for one year to hire a Community Education and Support Coordinator.



Fellowship and guidance: Meet the Christchurch support group

Throughout the year, Glaucoma New Zealand support groups are busy giving those with glaucoma an opportunity to come together, learn from one another, and guide each other – as well as have a good chat. The tight-knit Christchurch group find comfort and advice from one another in their regular meetings. *Members of the Christchurch support group at the Positive Aging Expo*



Michaele, one of the group's coordinators, joined Glaucoma NZ not long after her own glaucoma diagnosis, after seeing some information in her ophthalmologist's office. Since then, she's been a frequent attendee of the support group and eventually put her hand up to be a volunteer coordinator.

For Michaele, the support group helps her feel less alone in her glaucoma journey. "Most people don't know anyone with glaucoma, and it's isolating to not know about other people going through a similar situation," she says.

Often, the group will find comfort in just being heard by one another. Michaele recalls a particularly good session dedicated to 'de-stressing', in which each member shared how they cope with stress. "Having glaucoma might lead to other stressful life events, so it was therapeutic to discuss how we cope with stress," she says. "One member mentioned meditation, which then led us to having a mindfulness coach visit the following month."

While the support group is a chance to be listened to and comforted, it's also an opportunity to learn about new ways of managing glaucoma and maintaining vision. The group share advice and pieces of wisdom with one another, like how to travel and manage glaucoma treatment or how to go about driving with glaucoma. The little bits of advice tend to make all the difference, and many members mention how much they'd never have known if they hadn't attended the support group.

Members often find the group gives them a bit of a confidence boost. Being newly diagnosed with glaucoma can be an immensely intimidating and confusing experience, but one that's easier to manage with the support of those in a similar situation. "I've seen some members appear like new people as they leave their first session," says Michaele.

Most of all, the support group is a source of joy for all those involved. "The group is always wonderful, and so warm and friendly," says Michaele. "The coordinators really feel like we've accomplished something when we see members so happy."

Find your local support group

Our support groups started up again in February. They're a fantastic opportunity to share your experience, build connections, and get support from people who understand. All dates and locations for the year can be found by going to our website **www.glaucoma.org.nz or free phoning our helpline 0800 452 826.**



Australian genetics study paves way for glaucoma blood test

Article is republished courtesy of Insightnews.com.au



Professor Jamie Craig hopes a simple blood screening test will one day determine a patient's glaucoma risk.

Australian researchers have identified 107 genes that increase the risk of glaucoma and developed a genetic test to detect people at risk of going blind from the condition.

The research team, led by QIMR Berghofer Medical Research Institute and Flinders University, now wants to recruit 20,000 people with a personal or family history of the disease for a Genetics of Glaucoma Study to discover other genes that play a role.

"We want to know who will get glaucoma, and for those who are susceptible, we want to be able to pinpoint at what age they're going to get it," Associate Professor Stuart MacGregor, lead researcher and the head of QIMR Berghofer's Statistical Genetics Group, said.

"That would allow us to develop a personalised approach for earlier treatment of high-risk individuals and means people at lower risk could have less intensive monitoring and treatment. This would have benefits for patients, doctors and the

health care system with reduced interventions and reduced costs."

At present, MacGregor said the newly identified genes have led to the development of a glaucoma polygenic risk score (PRS) that predicts a patient's likelihood of developing the disease.

"Our study found that by analysing DNA collected from saliva or blood, we could determine how likely a person was to develop the disease and who should be offered early treatment and/or monitoring.

"Importantly, unlike existing eye health checks that are based on eye pressure or optic nerve damage, the genetic test can

be done before damage begins."

Professor Jamie Craig, clinical lead researcher and chair and academic head of the Department of Ophthalmology at Flinders University, said the study results offer hope for mass screening for glaucoma in future.

"Early detection is paramount because existing treatments can't restore vision that has been lost, and late detection of glaucoma is a major risk factor for blindness," said Craig, who is also a consultant ophthalmologist.

"Glaucoma can arise at any age but most of those affected are in their 50s or older, so our ultimate aim is to be able to offer blood tests to people when they turn 50 so they can find out if they are at risk, and then hopefully act on it.

"In most cases, glaucoma can be treated easily using simple eye drops, but this test is likely to be helpful in identifying those who would benefit from more aggressive intervention such as surgery."

The study findings can be accessed on the Nature Genetics website.

AT ONCE

I'M FREE!

Glaucoma therapy in a simple surgical procedure.

iStent inject° is designed to reduce eye

pressure, which can help prevent the

progression of glaucoma and may

allow your doctor to reduce

your glaucoma medication.

****tent

SYSTEM

inject

TRABECULAR MICRO-BYPASS

Ask your doctor about iStent inject® today!

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.



We are Fundraising with

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!

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.

A States and the second second

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 to find out more or request a bequest form.**

Eyedrop Aids

Using eye drops can be a challenge for many patients, young or old. AutoDrop ® and AutoSqueeze ™ have been developed to make selfadministration 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 [®] and AutoSqueeze [™] are re-usable and provide a cost effective solution for simple eye drop application.

You can now purchase these from



Glaucoma New Zealand through our website www.glaucoma.org.nz or phone 0800 452 826.



YES! I would like to help Glaucoma NZ save sight
Title Mr Mrs Ms Miss Other
First Name
Last Name
Name to appear on tax receipt
Street Address
Suburb
City Postcode
Email
Phone (home)
Phone (mobile)
YES! I would like to become a regular donor
I would like to give a gift (choose one) Single Weekly Monthly Annually Amount \$200 \$150 \$100 \$50 or \$
I would like to pay by (choose one) Cheque enclosed
Credit Card VISA / Mastercard (circle one)
Cardholders name
Amount \$ Expiry Date /
Signature
I will give by direct Credit to:
Bank Act: 12-3013-0180964-00 REF: Name
I would like to receive more information about:
Donating on a regular basis by Automatic Payment
For online donations visit www.glaucoma.org.nz
Please complete this form and return to:
GLAUCOMA NZ Department of Ophthalmology The University of Auckland Private Bag 92019

How your donation helps

\$20 Will ensure three people receive initial support and information packs to assist them to answer their glaucoma concerns. \$50 Helps staff the Glaucoma New Zealand telephone support service (0800 452 826) for a month, to answer calls for information, and emotional support. \$75 Funds two support groups for a month. \$100 Assists to increase community glaucoma awareness and the need for regular optic nerve checks. Glaucoma NZ is a registered charitable trust and receives no government funding. We rely solely on donations, sponsorship, grants and fundraising. All the information available and provided to over 8000 members of Glaucoma New Zealand and the general public is free. Contact us to find out more on info@glaucoma.org.nz or call 0800 452 826 To donate on-line visit www.glaucoma.org.nz Content in 'Eyelights' is intended to help readers understand glaucoma. Every effort is made to ensure the

accuracy of this information. This information is not a substitute for the advice and recommendations of health professionals. Always consult a health professional prior to any decision regarding your eyes or other health concerns.

Auckland 1142, New Zealand

Donations over \$5 are tax deductible.