



## Governor-General Visits the Flinders Medical Centre for World Glaucoma Week

**His Excellency David Hurley AC DSC visited the Flinders Medical Centre on Friday, 13 March to attend the patient symposium hosted by Glaucoma Australia and undergo an eye test as part of World Glaucoma Week.**

Glaucoma Australia was delighted that the Governor-General and Her Excellency Mrs Linda Hurley attended the patient symposium, which offered glaucoma patients the opportunity to hear about the latest research

into genetic markers for the disease. A panel of experts across the disciplines of ophthalmology, optometry, pharmacy and orthoptics also discussed the benefits of collaborative care for people with glaucoma, and patients offered their perspectives on living with glaucoma.

The visit came at a crucial time in the national health calendar as Glaucoma Australia is encouraging all Australians over 50 and those with a family history of the disease, to get their

## From the CEO



Dear friends and supporters,  
As the outbreak of Coronavirus (COVID-19) continues to develop, I am thankful our

education team and digital capability can continue to provide a high standard of education and support over the coming months.

I am extremely thankful to our Patron His Excellency General the Honourable David Hurley AC DSC (Retd) and Ambassador Mr Kirk Pengilly (INXS), for being so actively involved in our World Glaucoma Week activities. Their public profiles dramatically extended the reach of our 'don't be blindsided' campaign which promoted eye health awareness and early detection. We are fortunate that the video broadcast of our Patient Symposium in Adelaide can now be accessed online.

It has been a delight to launch glaucoma support groups in most states as they provide a wonderful opportunity for people to learn, share and build new friendships. Highlights included the launch of our first Congenital Glaucoma Support Group in Sydney and a meeting at Queensland Eye Institute.

I am also pleased to see our campaigning to Government for standalone Minimally Invasive Glaucoma Surgery (MIGs) has been approved from 1 May. This means those needing stents inserted who do not have cataracts can now access this surgery. This is great news for many and I am thankful our advocacy work progressed to this outcome for you.

**Annie Gibbins**  
CEO

## Cover Story

### (continued)

eyes checked as part of our Don't be Blindsided campaign, timed to coincide with World Glaucoma Week.

The powerful campaign urges Australians to have their eyes checked by an optometrist every two years to prevent the irreversible damage caused by glaucoma if left untreated.

"We were absolutely delighted to have our patron, The Governor-General of the Commonwealth of Australia, David Hurley, as part of our patient symposium, and importantly undertaking an eye exam, which is our core call to arms for all Australians in our fight against the disease," said Annie Gibbins, CEO of Glaucoma Australia.

Presenting at the symposium was Professor Jamie Craig, who is working on a research project that is supported by funding from Glaucoma Australia. Professor Craig is working in the field of risk-profiling for glaucoma, to identify common genetic markers to better predict an individual's likelihood of developing the disease. It is at the forefront of early detection efforts.

"Glaucoma is the leading cause of irreversible blindness worldwide, affecting more than 60 million people. In Australia, there are more than 300,000 Australians suffering from some form of glaucoma. While one in 200 Australians over the age of 40 will develop glaucoma, the prevalence increases to one in 8 by age 80. Half of those in the earlier stages are undiagnosed, and tragically may present later with irreversible vision loss," Professor Craig said.

"These alarming statistics show that early detection is key in minimising vision loss – many people who have lost vision could have maintained their sight if the diagnosis and treatments were delivered sooner. This is why the work that Glaucoma Australia and eye health professionals are doing in the area of early detection is so important – and why the patient symposium was critical in improving patient outcomes and quality of life through collaborative care," Annie Gibbins added. ●

## Feature

# Kirk Pengilly: Return from the brink of blindness

*Written by Melanie Kell*

**Kirk Pengilly, of INXS fame, was just 29 when he came within millimetres of losing his sight to acute angle closure glaucoma. An integral member of the band, playing guitar, saxophone, and providing backing vocals, he had no knowledge of glaucoma. Although he'd had regular eye examinations, there had been no signs detected or symptoms to indicate that he was at risk of developing the disease.**

Now an ambassador for Glaucoma Australia, Kirk is helping create a greater awareness of the condition for all Australians.

"I was on tour with INXS, up the east coast of Australia, when I started seeing 'foggy halos' around street lights," says Kirk. "That was back in 1987 and I was 29. The halos were the only signs of anything going wrong and they were noticeable late in the evenings, usually after our performances."

The morning after the final concert of the tour in Darwin, Kirk woke up with excruciating pain in his eyes.

"I couldn't open my eyes. It was pretty frightening because I didn't know what was happening, so we called a



doctor to the hotel. He was unable to diagnose what was going on and he gave me painkillers."

Fortunately, the tour had come to an end and the band returned to Sydney.

"We flew back straight away, and I went to see my optometrist. She diagnosed acute angle closure glaucoma and fast-tracked me to see an ophthalmologist," Kirk said.

That ophthalmologist turned out to be none other than Professor Ivan Goldberg AM, who co-founded Glaucoma Australia in 1988 and has been integral to the organisation's

growth and development ever since. Prof Goldberg was awarded the title of 'Life Governor' of Glaucoma Australia in 2018, recognising his significant contribution.

Kirk said the diagnosis came as a complete shock to him. He had never heard of glaucoma, let alone acute angle closure glaucoma, which is relatively rare – 90% of people with glaucoma have primary open angle, which has strong genetic links.

"Back in the 80s, glaucoma was considered an 'old persons' disease', so I was an unlikely suspect. I was

extremely fortunate to have an optometrist and ophthalmologist who treated me with urgency and made a quick diagnosis. I went very close to going blind,” he said.

### Pioneering Laser Surgery

Kirk was initially treated with drops to relieve the pressure and soon after, he underwent laser surgery on both eyes. Despite being early days for this procedure, it was entirely successful, and no further surgery or medications have been needed.

As a result, Kirk was able to return to touring and get on with his life. As well as being one of the founding members of INXS, he has written, produced and performed on numerous other records and is the INXS archivist, logging daily entries in diaries that date back to the beginning of the band’s existence.

### Healthy Living

Today Kirk has a daughter, who is an actor, and he is married to seven times women’s world champion professional surfer, Layne Beachley AO, a partnership which encourages the healthy lifestyle recommended for great eye health.

“Certainly, looking after my health is something that I do much more now than I used to back in the old days, but mainly this consists of eating right, exercising regularly and

sleep is obviously important as well. So just maintaining a balance, keeping fit and watching what I eat,” he says.

Having worn glasses since he was a little kid, he says eye tests have always been part of life, however since being diagnosed with glaucoma they have become a priority.

“I believe people need to have their eyes checked regularly, and it’s just as important as going to the dentist or for check-ups with your GP,” he said.

With this thought in mind, Kirk was quick to agree to becoming an ambassador for Glaucoma Australia when CEO Annie Gibbins approached him in mid-2019.

Annie Gibbins said Kirk’s personal experience with glaucoma combined with his recognition as an Australian music legend put him in the perfect position to become an influential ambassador for Glaucoma Australia.

“Glaucoma Australia’s mission to eliminate glaucoma blindness focuses strongly on risk awareness, early intervention, and appointment and treatment adherence. This means we need to target our key message to a younger demographic than we did historically – primarily, people aged 40+ who are often difficult to engage but essential to reach,” she said.

“Kirk’s high profile and personal experience will resonate powerfully with this audience. The call to action is simple: ‘if you value your sight and are at risk, go and get tested’.

“He has demonstrated that his glaucoma diagnosis and management has not held him back in life and this makes him a fantastic ambassador,” added Annie.

For Kirk, his role with Glaucoma Australia is all about getting people into optometry practices for an eye test.

“When I got glaucoma it really hit home how important sight was to me and obviously to everyone. It was a real wake up call for me as I came within a millimetre of losing my eyesight. As a result, I’m certainly more aware of my eyes, my eye health and the importance of looking after my sight,” said Kirk.

He added, “I feel the need to encourage people to be aware of eye health and the importance of getting their eyes checked regularly. Most eye disease is preventable if you can get to it early so I’m keen to encourage ‘people at risk’ to get their eyes checked regularly.” ●

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# Acute Angle Closure Glaucoma

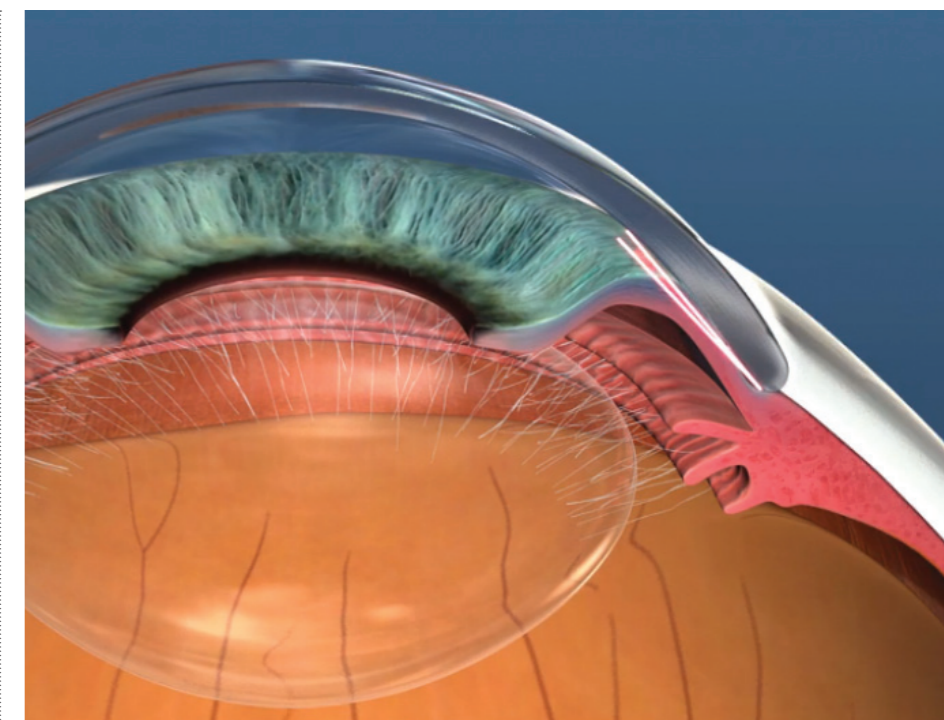
Written by Professor Ivan Goldberg

Angle closure glaucoma is caused by crowding of the front part of the eye. The words ‘angle closure’ refer to blockage of the fluid outflow pathways of the eye by the coloured iris tissue. This causes eye pressures to rise, which threatens the optic nerve at the back of the eye, thereby threatening vision. Blockage is most commonly gradual, although it can be intermittent or sudden, as was the case for Kirk Pengilly. Treatment is to re-open the drainage angle and to control eye pressures, thereby safe-guarding sight. Laser techniques can achieve this with the help of medications, but sometimes surgery becomes necessary. Although angle-closure glaucomas are less common than open-angle varieties, globally, they cause as much blindness and this highlights the importance of detecting them and treating them effectively.

Today we use lasers to re-open the drainage angle

### Onset, Signs and Symptoms

As with open-angle glaucoma, most angle-closure patients experience no warning signs. Those with intermittent closure might see coloured rings around lights at night and/or experience



an ache in and around the eye or eyes, which self-resolves. In the much rarer full-blown sudden attack, the person usually becomes very ill, with vomiting, and severe eye and head pain, along with very blurry vision.

### Treatment

Laser surgery has revolutionised the treatment of angle-closure glaucoma, which used to require an operation using scissors to open the wall of the eye.

Today we use lasers to re-open the drainage angle by making a small opening through the outer part of the coloured iris tissue. This creates a by-pass between the chambers in the front part of the eye, allowing the iris tissue to fall back away from the outflow drain, which

unblocks it and normalises the eye pressure.

This can be achieved in just a few minutes in an ophthalmologist’s rooms or in an outpatient clinic.

Our increased understanding of the mechanisms in the eye that lead to angle-closure, along with much better tools to make the precise diagnosis, and much safer and more effective treatments to achieve treatment targets, have changed the vision results for millions of patients world-wide. Kirk is one of these happy outcomes – saving his sight enabled him to continue his life without the constraints that visual disability could otherwise have forced on him. ●

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# 20,000 Volunteers Needed for Genetics of Glaucoma Study

**Australian researchers have identified 107 genes that increase a person's risk of developing glaucoma, and have developed a genetic test to detect those at risk of going blind from it.**

The researchers are now hoping to recruit 20,000 people who have been diagnosed with glaucoma or have family history of glaucoma to join their Genetics of Glaucoma Study so that they can identify more genes that play a role in the condition. Lead researcher and the head of QIMR Berghofer's Statistical Genetics Group, Associate Professor Stuart MacGregor, said identifying the new genes has allowed the researchers to develop a glaucoma polygenic risk score (PRS) that can predict who is likely to get the eye disease.

Although there is no cure for glaucoma, treatment can reliably slow or halt the rate of disease progression in most cases. Up to 50 per cent of people with the disease do not know they have it. "Glaucoma is a genetic disease and the best way to prevent the loss of sight from glaucoma is through early detection and treatment," Associate Professor MacGregor said.

**Early detection is paramount because existing treatments can't restore vision**

"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 so regular screening can be put in place. "Having a high risk score doesn't mean you will definitely get glaucoma, but knowing you could be at future risk allows people to take the necessary precautions."

Clinical lead researcher and Chair and Academic Head of the Department of Ophthalmology at Flinders University, Professor Jamie Craig, said the study results provided hope that mass screening for glaucoma could be offered in the future. "There are Australians who, if they'd had appropriate treatment a few years earlier, wouldn't have gone blind," said Professor Craig.

"Most people only find out they have glaucoma when they go to the optometrist because they are losing vision, or for a general eye check.

"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. "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.

Australians interested in taking part in the research can visit the Genetics of Glaucoma study website [www.qimrberghofer.edu.au/genetics-of-glaucoma/](http://www.qimrberghofer.edu.au/genetics-of-glaucoma/) phone 07 3845 3981 or email [Glaucoma\\_Genetics@qimrberghofer.edu.au](mailto:Glaucoma_Genetics@qimrberghofer.edu.au) ●

**The research has been funded by the National Health and Medical Research Council.**

**The research, led by QIMR Berghofer Medical Research Institute and Flinders University has been published in the journal Nature Genetics.**

# Berwick man wins the lottery of sight

**When Vernon Taylor, 62, from Berwick, Victoria, went to buy a lottery ticket at his local newsagency he never anticipated that he'd be winning big by having his eyesight saved.**

After feeling embarrassed that he was unable to read the fine print on the lottery ticket and needing the young newsagency employee to help, Vernon walked into an optometrist expecting a pair of reading glasses. Instead, Vernon walked out with a diagnosis of glaucoma and a prescription for eye drops.

"I thought I was far too young to have glaucoma," says Vernon. "My mother had it and I always thought it was something that only older people had. When I received a script for eye drops I was so anxious to start, I put them in at the shopping centre car park as I didn't want to wait until I got home... I didn't want to wait another minute."

Vernon continues to undergo treatments and using eye drops has become a ritual in his everyday life.

"Every morning I put my eye drops in. It's one thing I will never forget – I might forget car keys but not my eye drops.



It's the number-one thing I do in life because glaucoma causes irreversible blindness." Vernon will always be grateful to the optometrist who advised him to see a specialist, as he was able to detect the glaucoma before any further damage was caused. "I couldn't track him down... I just wanted to give him a big hug for what he achieved. I kick myself for not taking a photocopy [of the script]... I could've tracked him down and given him a big hug to let him know he changed my life. I

could've lost my job, could've not been able to drive my car at night – it would've been horrific," Vernon says.

Vernon hopes that Australians will be encouraged to get an eye test.

"Early prevention is key. I was so stunned by my glaucoma diagnosis. I had no signs before, and absolutely no pain, that's the scary part. Get in early and have an eye exam so you can live the rest of your life normally. You can't undo damage." ●

# Glaucoma Inheritance Study in Tasmania – 25 Years

Written by Professor David Mackey

**Glaucoma affects 3% of the population over 40 years of age and untreated, causes loss of peripheral (side) vision and eventual blindness. Anyone can develop glaucoma, however, if you have an immediate family member with glaucoma, you are at a much higher risk than the rest of the population.**

Since 1994, the Glaucoma Inheritance Study in Tasmania (GIST) has been working with families and individuals with glaucoma to help find the genes that cause glaucoma so that we can:

- Understand the disease better
- Predict those at risk of developing glaucoma, so that early detection and treatment reduces the risk of blindness
- Develop new treatments for glaucoma

Since starting the Glaucoma Inheritance Study in Tasmania (GIST) over 25 years ago, we have published over 150 papers describing major scientific discoveries relating to the genes that cause glaucoma.

In some families, we have been able to identify a specific glaucoma gene. Family members can then be tested if they carry the same specific glaucoma gene as their affected relative and help minimise blindness by regularly having their eyes examined.

Myocilin (MYOC), was the first gene associated with glaucoma and it was through our research that we were able to identify these genetic changes. To date (year 2020) we have identified over 100 genes that each contribute a small effect to the risk of developing glaucoma. This work has been part of the

International Glaucoma Genetics Consortium (IGGC) with the Australian team members as leading contributors.

In some cases, glaucoma can be influenced by several gene changes, as well as environmental factors. Therefore, glaucoma is referred to as a “complex” or “polygenic eye disease”. With the latest genetic discoveries, a new genetic risk scoring system has recently been developed for certain diseases. This system is called a polygenic risk score (PRS)<sup>1</sup>. This can help determine whether people are at high or low risk of developing glaucoma. High risk individuals could access treatment early to help stop vision loss.

**We are also retesting the original families we studied in the 1990s.**

We are continuing to test additional patients and families to find other glaucoma gene changes and improve the accuracy of the PRS. We are also retesting the original families we studied in the 1990s. We will continue to analyse all the glaucoma patients who were enrolled in the GIST in the last 25 years. The opportunity to have this testing performed by a US-based laboratory owned by the company Regeneron has arisen. As part of ongoing research, these results will be combined with that of other international research groups to better understand genetic risk factors for glaucoma. The ultimate aim is to identify potential new treatments for glaucoma. If you have any questions about this testing contact us at the details below.

We will be recontacting family members who were unaffected by glaucoma when they were seen as part of our research in the 1990s to find out whether they have since developed glaucoma. For the first time anywhere in the world, this will help us determine how useful the PRS can be in screening for glaucoma. If we check the accuracy of the PRS, then this offers the possibility of widespread genetic testing for glaucoma, not only for relatives of people with glaucoma, but also for the general population.

**The ultimate aim is to identify potential new treatments for glaucoma.**

One impact of the GIST is that visual field testing for glaucoma has increased in Tasmania.<sup>2</sup> The PRS will allow us to ensure that those at highest risk for glaucoma continue to undergo regular eye examinations, while individuals at lower risk are screened less often, conserving healthcare resources and saving clinician and patient time.

People who wish to learn more about the outcomes of the last 25 years of the GIST can read the attached articles.

We will be contacting many GIST participants again over the next 2 years and hope to be able to provide everyone with updates on their genetic test results.

For further information or any specific questions, contact us (03) 6226 4731 or by email at alex.hewitt@utas.edu.au or david.mackey@utas.edu.au ●

1. Craig JE, Han X, Qassim A, et al. Multitrait analysis of glaucoma identifies new risk loci and enables polygenic prediction of disease susceptibility and progression. *Nat Genet* 2020; <https://doi.org/10.1038/s41588-019-0556-y>.

2. Mackey DM, Craig JE, Hewitt AW. Seeing the impact of the Glaucoma Tasmania after 25 years (letter). *Clin Experiment Ophthalmol* 2019;47:677-9.

## Congenital Glaucoma Support Group



**Glaucoma Australia were thrilled to have hosted the very first Congenital Glaucoma Support Group Morning Tea, held in Sydney on Tuesday the 10th of March.**

Patients from our online community travelled far and wide to attend what was deemed a very special day. Patients and their families came together to share their stories and connect face-to-face, after becoming virtual friends in their Facebook community.

The event was also an opportunity for those living with glaucoma to hear of current and future research involving genetics, and find out how they can contribute to the future of congenital glaucoma studies.

At the event to present were special guest speakers;

Dr Emmanuelle Souzeau, Researcher and Genetic Counsellor in the Department of Ophthalmology, Flinders University; she has experience in medical research, genetic testing, patient counselling and support. Dr Souzeau shared the empirical knowledge that explains the role of genetics in Congenital Glaucoma.

Lachlan Knight, Orthoptist; who is currently undertaking a PhD with Professor Jamie Craig at Flinders University, discussed his research into childhood glaucoma and the psychosocial impact on the individual and their family, as well as genetics and clinical outcomes.

Lachlan's presentation illustrated the target group of the research and, explaining the importance of a whole family's journey.

Bronwyn Sheldrick, Coordinator of ANZRAG (Australian and New Zealand Registry of Advanced Glaucoma); currently working on research with Lachlan. Bronwyn's presentation provided a thorough explanation of the importance of this research, and expressing their understanding of the specific challenges that patients face.

Together, their research and insight will aim to develop new risk detection processes, as well as find answers to long awaited questions.

Bronwyn and Lachlan would love to hear people's stories, and to interview them formally (for research) and enrol the families into the ANZRAG project. ●

Further information on the research can be found at: [www.anzrag.com](http://www.anzrag.com), or contact Bronwyn Sheldrick, Registry Coordinator  
Email: [info@anzrag.com](mailto:info@anzrag.com)  
Phone: 08 8404 2035



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#### In Memorium

We acknowledge with gratitude gifts, from family and friends, in loving memory of:

Mr Giuseppe Skrezenek

Mr John Manfield

#### Bequests

The estate of the Late Joan Mackenzie

The estate of the Late Maurice Cassidy

The estate of the Late Barbara Chappell

#### Giving HOPE

A gift in your will can help eliminate glaucoma blindness.

If you would like more information about leaving a gift in your will please contact Glaucoma Australia on 02 9411 7722 or email [ceo@glaucoma.org.au](mailto:ceo@glaucoma.org.au)

## How can we help?

Glaucoma Australia offers FREE education and support to people living with glaucoma.

If you or someone you care for has been diagnosed with glaucoma we recommend you join our community to access free resources, guidance and support.

#### Join our community online

[www.glaucoma.org.au/registration](http://www.glaucoma.org.au/registration)

#### Call our free support line

1800 500 880

#### Contact details

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T: 1800 500 880 (Freecall)

F: 02 9413 4466

E: [glaucoma@glaucoma.org.au](mailto:glaucoma@glaucoma.org.au)

W: [www.glaucoma.org.au](http://www.glaucoma.org.au)

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## Your Questions Answered

# Q&A

## COVID-19 and Glaucoma

Written by Glaucoma Australia Clinical Committees

### Q Should I continue to attend appointments?

**A** Regular appointments with your ophthalmologist or optometrist are important for protecting your vision against glaucoma, and your need for eye health checks needs to be balanced against COVID infection risk. Before your next appointment your health care provider will advise you if any change to your appointment schedule is required. They will also advise you of any social distancing measures their practice has put in place to keep patients and staff safe.

**IMPORTANT:** If you have recently returned from overseas or have been in close contact with a confirmed case of COVID-19 you should self-isolate for 14 days. If you have flu-like symptoms you should wait until you are well before seeing your health practitioner, but if it is urgent or if you are unsure call your practitioner and they can advise you by phone.

### Q Will my eye surgery be cancelled?

**A** The national supply of personal protective equipment (PPE) remains of

great concern, therefore all non-urgent elective surgery has been temporarily suspended. It is recommended that only Category 1 and some exceptional Category 2 surgery proceed.

Your ophthalmologist will contact you to advise whether your surgery can be rescheduled based on your individual circumstances

### Q Will storing my eye drops in the fridge kill any potential germs?

**A** If you're worried about your bottles being contaminated then I'd wash them with soap and water, unfortunately refrigeration won't sterilise the bottles for you. I wouldn't be concerned about glaucoma drops being a source of infection, just wash your hands before you touch your face to instill each drop.

### Q Are optometry practices still open?

**A** As the Coronavirus (COVID-19) situation continues to escalate in Australia some optometry practices may choose to close their practice temporarily, while others will remain open for urgent and essential care. It

is recommended that you contact your local optometrist to see if they are open and what services they are currently providing if needed.

### Q Should I stock-up on glaucoma drops?

**A** To ensure there are enough medicine supplies for everyone, pharmacists will limit dispensing of glaucoma eye-drop medicines to a one-month supply at the prescribed dose.

Consider if there is a way to make fewer visits to renew your prescription to limit the risk of infection. Some practices are offering telehealth consultations (via phone or video link) to renew medication prescriptions.

As part of the temporary Home Medicines Service, vulnerable people and those in home isolation, will be able to order their PBS and RPBS prescriptions remotely and have these items delivered to their homes to reduce their potential exposure to COVID-19. Please call your local pharmacy to see if they are able to arrange home delivery.