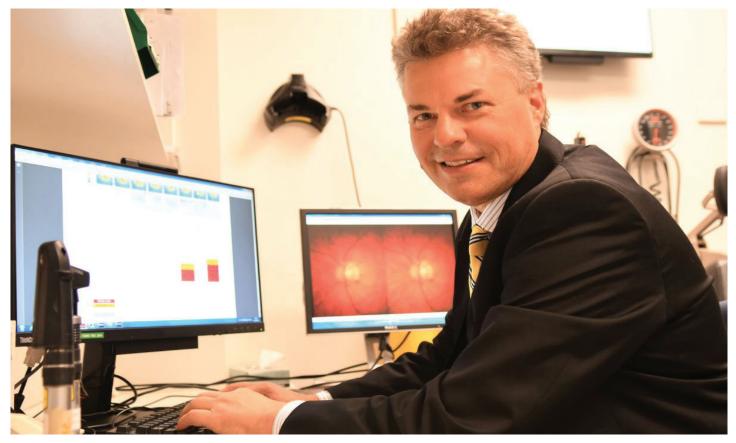


## Glaucoma News

Autumn 2022/ No.84

Our vision is for Australians to be free of glaucoma blindness



Professor of Ophthalmology Jamie Craig, who leads a major international glaucoma research program.

# New test for early-stage glaucoma set to roll out

Written by Flinders University

An innovative test developed by a world-leading research team has the potential to improve the management and early treatment of glaucoma patients and those at risk of glaucoma.

A \$304,000 South Australian State Government seed grant will be used to deploy the new test for use in clinical settings.

The polygenic risk score (PRS) test will enable health professionals to identify individuals at greatest risk of glaucoma, such that they can be prioritised in ophthalmology waiting lists and receive informed clinical care sooner.

Based on world leading research at Flinders University, the QIMR Berghofer Medical Research Institute, SALHN within SA Health, and the University of Tasmania, a blood or saliva sample

1800 500 880 glaucoma.org.au glaucoma@glaucoma.org.au PO Box 420 Crows Nest NSW 1585

## From the CEO



Dear friends and supporters,

As we wrap up World Glaucoma Week for another year, I am incredibly thankful for your continued support of our mission to eliminate glaucoma

blindness. Every conversation you have with friends and family raises awareness of glaucoma and the importance of regular eye exams which are vital for early detection and intervention.

That is why I was overjoyed to see so many people getting out and about in their local neighbourhoods to take part in Glaucoma Australia's first fundraiser The 7 Sights in 7 Days Challenge.

Every dollar raised will help take glaucoma blindness out of the picture and every photo snapped and shared during the month of March by our Sight Saving Champions is a wonderful reminder of how precious our eye sight really is. These funds will help us continue to support Australian families living with glaucoma, increase awareness and further improve treatment adherence rates and fund glaucoma research.

I'm almost lost for words looking at the incredible photos that were taken. Something that did stand out to me was the incredible diversity and beauty of our neighbourhoods all around Australia. I'm glad I'm not the one judging the best photo because there are so many great ones which I look forward to sharing with you in our next issue.

I would also like to thank our wonderful sponsors for supporting this important evehealth initiative. Thank you to MyHealth1st, NovaEye Medical, Shopper, Mivision, OPSM, Laubman & Pank, Specsavers and Bausch &

Wishing you all the very best

**Annie Gibbins** 

CEO

### **Cover Story**

### Continued from page 1

taken from a patient, the PRS test can be used to assess thousands of different genetic locations, known as single nucleotide polymorphisms (SNPs), to quantify a patient's genetic risk of developing glaucoma.

Glaucoma is an insidious disease that is asymptomatic in the early stages, with damage to the eye's optic nerve progressing gradually and unknown to the patient until irreversible vision loss occurs. Fortunately, glaucoma is a treatable condition if discovered early. Eye drops, laser and surgery are all effective interventions that can stabilise the condition, slowing or preventing disease progression.

However, detecting early-stage glaucoma is challenging using current technology, as is predicting which glaucoma patients will progress to severe vision loss. Some patients whose sight could have been saved are treated too late, while other patients who will never develop severe glaucoma are unnecessarily investigated, monitored and treated.

Our world leading research represents a step change in the clinical assessment of alaucoma risk.

Published in the prestigious international journal, Nature Genetics, the PRS is the first test able to estimate glaucoma risk sufficiently accurately for clinical use, says Lead author and ophthalmologist Professor Jamie Craia from Flinders University.

"Our world leading research represents a step change in the clinical assessment of glaucoma risk. A patient with a high risk (top decile) PRS is 15x more likely to develop glaucoma than a patient at low risk (bottom decile). Moreover, a glaucoma patient with a high risk PRS is significantly more likely to develop severe vision loss. Optometrists and ophthalmologists have been lacking tools to assess glaucoma risk, and our PRS has a significant role to play.

### News

## **CEO Annie Gibbins sets her sights on new** business opportunities



After a successful four and a half years as CEO of Glaucoma Australia. Annie Gibbins has announced she will be moving on to pursue other business opportunities and spend more time with her family at the end of June.

As a seasoned executive change manager, Annie led her team to deliver a range of innovative business transformation projects which have positioned the charity as a world leader in patient centred education and support for people with glaucoma.

Key highlights during her tenure include:

· Securing the Governor-General, His Excellency General the Honourable David Hurley AC DSC (Retd) as Patron and high-profile ambassador Kirk Pengilly (INXS) to help build our brand recognition and extend the reach of key messages to the Australian public.

- Creating a world leading patient support journey which educates and enables patients to confidently manage their eye health and improving adherence to their recommended treatment management plans to improve eye health outcomes and quality of life.
- Implementing a best-practice website, online support groups, clinical volunteers and tailored communication for patients. This has significantly improved the patient experience and tripled the number of patients Glaucoma Australia supports.
- Building collaborative referral networks and pathways to ensure newly diagnosed patients find their way to Glaucoma Australia at the earliest opportunity for ongoing education and practical and emotional support.
- Launching the new Glaucoma Australia brand and a variety of high impact campaigns that drive awareness and early detection among those Australians most at risk.
- Ensuring ongoing financial sustainability and growth of the organisation by securing new corporate sponsors, launching the new annual fundraising initiative the 7 Sights in 7 Days Challenge and sourcing future partnership opportunities that align with our mission to eliminate glaucoma blindness.

Annie leaves Glaucoma Australia with a strong brand and a highly motivated team who are well equipped to continue raising the benchmark of patient centred care for those we serve.

The board has commenced an executive search for a new CEO.



### Research

## Sleep Apnoea: A Risk Factor for Glaucoma?



Written by Samantha Sze-Yee Lee and Professor David Mackey AO

The question of whether sleep apnoea is a risk factor for glaucoma was recently debated in a session at the 2021 World Glaucoma Congress Virtual and listed as a 'Hot Topic' at the 2021 Association for Research in Vision and Ophthalmology Meeting.

This followed the publication of one key study arising from the Raine Study in Western Australia, published in the journal Ophthalmology, reporting that at 20 years of age, young adults with obstructive sleep apnoea (OSA) already have thinner retinal nerve fibre layers (RNFL) than controls. However, does this really mean that the risk of glaucoma is increased from young adulthood, or at all, in individuals with OSA?

Sleep apnoea describes a group of sleep-disordered breathing conditions in which individuals experience pauses in breathing (apnoea) or periods of overly shallow breathing (hypopnoea) during sleep.

There are three types of sleep apnoea:

 Obstructive, where the disruption in breathing is caused by a mechanical obstruction to the upper airflow,

- 2. Central, where the paucity in breathing is due to failure of the central nervous system to drive respiration, and
- 3. Mixed, which is a combination of the former

The obstructive variant, or OSA, is the most common type, comprising 90% of all sleep apnoea cases, and the focus of this article.

The gold standard for OSA diagnosis is with an overnight polysomnography (PSG), also known as a sleep study, which measures the amount of respiratory airflow along with a myriad of other bodily functions during slumber. OSA is diagnosed when the PSG-measured number of apnoea or hypopnoea episodes during sleep exceeds four events per hour.

A possible link between OSA and glaucoma was first described in the 1990s, when Mojon et al<sup>2,3</sup> noticed a "higher than expected" prevalence of open-angle glaucoma (OAG) among OSA patients. Several other studies have since been published supporting this observation.<sup>4-6</sup> However, more recent studies comprising large sample sizes<sup>7,8</sup> have failed to find such associations, especially after accounting for co-morbidities. A notable exception

is the findings from the United Kingdom Biobank and the Canadian Longitudinal Study for Ageing, comprising more than half a million participants, which found that incident glaucoma is 33% to 43% more likely in individuals with sleep apnoea (but not specific to OSA) compared to controls, even after adjusting for co-morbidities. (It is also worth noting that the study additionally found that participants with sleep apnoea were 39% more likely to have incident age-related macular degeneration. But this is a topic for another time).

### **How Might OSA Increase OAG Risk?**

One of the more plausible theories linking the two conditions is that the intermittent disruption in upper airflow during sleep in OSA results in hypoxia and hypoperfusion of the optic nerve, thus degrading the integrity of the retinal ganglion cells. This notion has been supported by observations of decreased peripapillary vessel density with more severe OSA.<sup>10,11</sup> By this assumption, treating any existing OSA should reduce the risk of OAG. Indeed, there have been case reports of continued glaucoma progression in spite of achieving the target IOP, and progression only halted after commencement of continuous positive airway pressure (CPAP) therapy for OSA.<sup>12,13</sup>

However, the use of CPAP therapy may pose an additional problem in patients with OAG or at high risk of OAG. CPAP treatment at night is known to elevate IOP during that time. If In a retrospective study, Chen et all failed to find that CPAP therapy use reduces the incidence of OAG. Thus, it is possible that the elevated risk of OAG in relation to OSA may not be due to the condition, per se, but rather due to the CPAP treatment.

On the other hand, the study<sup>15</sup> also found that patients who had undergone surgical intervention for their OSA had significantly lower risks of incident OAG. However, it is not feasible to recommend surgical intervention for all patients with OSA just to (possibly) reduce the risk of glaucoma. (This also remains a decision to be made by the sleep physician, and not optometrists or ophthalmologists).

But neither the vascular theory nor the IOP elevation effects of CPAP therapy explain why we found

significantly thinner RNFLs in patients with OSA as young as 20 years of age.¹ Both OSA and OAG are chronic, age-related conditions; thus structural and functional changes that occur in both diseases take a long time to manifest. The effects of any OSA or CPAP use (which is not commonly used by the young adults with OSA in the Raine Study), is unlikely to affect patients from the tender age of 20. This calls for a re-evaluation of our hypothesis that there is a causal link between OSA, or its treatment, and OAG.

### **Identifying Genetic Links**

One way to explore a causal link between two measures, in this case the measures being OSA and OAG, is to employ mendelian randomisation (MR). This method measures genetic variations to test for the causal effect of an exposure on an outcome. MR studies have allowed us to confirm that more intensive education results in myopia, rather than the other way around. However, MR studies are limited by the number of known genes associated with the condition of interest. While over 500 genes for glaucoma have been identified, genetic studies on OSA are lagging. Thus, before we can perform a well-designed MR study exploring the link between OSA and OAG, more genetic studies on OSA are warranted.

Even if no causal link exists between the two conditions, identification of more genes will help us to understand any shared processes between the two conditions. For example, several OAG genes have been identified as having other biological functions, information which has given us a better understanding of OAG pathophysiology (e.g. mutations in certain genes have been implicated in altered trabecular meshwork function and thus OAG).<sup>17</sup> Recently, shared genes between sleep disturbances and neuropsychiatric disorders, such as schizophrenia, have been identified.<sup>18</sup> Thus, it is conceivable that genetic links may also exist between OSA and OAG.

#### **Further Questions**

Clearly, further studies are required to explore the underlying mechanics of the relationship between OSA and OAG. First and foremost, we need to ascertain whether the use of CPAP has any





### Participate in research: Information for Prospective Patients

## Performance of vision-related everyday activities under low lighting conditions

### Continued from page 5

therapeutic benefit or adverse effects on the retinal ganglion cell. The Lions Eye Institute is currently investigating this as part of the West Australian apnoea and Vascular Endpoints Study (WAVES) in collaboration with the West Australian Sleep Disorders Research Institute (WASDRI), where we are testing the eyes of 500 patients with OSA, half of whom have been on long-term CPAP therapy.

Identification of genes associated with OSA (and OAG and its related endophenotypes) will also provide us with further avenues to explore causality or associations, including shared genes, between OAG and OSA.

#### In The Meantime

Although there is still a lot to learn about the link between OSA and OAG, it is still important for the eye specialist to be aware of their patient's history and treatment with sleep apnea, just as it is for other conditions such as hypertension and diabetes, as these are all risk factors of glaucoma. Given the potential for CPAP therapy to elevate IOP at night, it may be advisable for patients with OAG who are also on CPAP therapy to discuss their OSA treatment options with their sleep physician, and to bring up this issue with their treating ophthalmologist. This is important, even if the measured IOP appears to be meeting treatment targets, as IOP revert to baseline values after waking and the use of the CPAP device ceases in the morning. It is very important that patients with OSA and OAG who are on CPAP therapy to continue their therapy unless advised to stop by their sleep physician. CPAP therapy is highly effective in controlling upper airway collapse during sleep, and our patients' general health remains a priority.

References supplied. Visit glaucoma.org.au/news This article has been republished courtesy of www.mivision.com.au

#### Research team contacts

### **Principal Researcher:**

Dinesh Venugopal, PhD Stduent

#### **Associate Researchers:**

Professor Sharon Bentley, Principal Supervisor Professor Joanne Wood, Associate Supervisor Dr Alexander Black, Associate Supervisor

School of Optometry and Vision Science, Faculty of Health, Queensland University of Technology (QUT)

### What is the purpose of the research?

The purpose of this project is to develop a set of tasks to measure performance of vision-related everyday activities under low light levels and to compare performance for those with and without various eye conditions.

### Are you looking for people like me?

The research team is inviting people aged 18 years and above with either normal vision or an eye condition causing visual impairment and no walking/mobility/balance or cognitive/mental processing impairments to participate.



### What will you ask me to do?

Your participation will involve a visit which will require up to 2 hours at O block, School of Optometry and Vision Science, QUT Kelvin Grove campus. The visit will involve standard vision and eye testing, completing two questionnaires related to everyday activities performed in low light/night conditions and performing a set of everyday tasks (e.g. reading, locating familiar objects, recognising faces, walking,) under low and normal light levels in an indoor environment. You might also be invited to participate in an optional second study visit to repeat the set of everyday tasks, which will take up to an hour. If you agree, your performance on the everyday tasks will be video-recorded for additional analysis, but this is not a requirement of participation.

### Are there any risks for me in taking part?

The research team does not believe there are any risks beyond normal day-to-day living associated with your participation in this research. All vision and eye tests are used routinely in clinical practice. While there is a small chance of becoming fatigued, you will be given regular breaks during testing. Also, while there is a small risk of discomfort in sharing your thoughts about challenging activities performed under low light and in performing everyday tasks under low light, you will be supported and accompanied by a researcher at all times during the study.

It should be noted that if you do agree to participate you can withdraw from participation at any time during the research project without comment or penalty.

### Are there any benefits for me in taking part?

It is expected that this research project will not benefit you directly. However, the outcomes of the research can be potentially used to understand how low light is likely to affect

everyday activities, develop strategies to prevent injuries under low light levels and evaluate the real-world effectiveness of treatments for various eye diseases.

### Will I be compensated for my time?

We would very much appreciate your participation in this research. The research team will reimburse you with either a taxi voucher or a \$25 gift card per study visit to contribute toward any out-of-pocket expenses incurred during your involvement in this research (e.g. travel costs).

#### I am interested – what should I do next?

If you are interested in participating in this study, please contact one of the researchers:

#### **Dinesh Venugopal**

d2.venugopal@hdr.gut.edu.au 07 3138 2478

#### **Sharon Bentley**

sharon.bentley@qut.edu.au 07 3138 5738

### Joanne Wood

j.wood@aut.edu.au 07 3138 5701

### **Alexander Black**

aa.black@aut.edu.au 07 3138 5704

You will be provided with further information to ensure that your decision and consent to participate is fully informed.

QUT Ethics Approval Number: 2000000626



### Education

## **Tailoring Treatment for Compliance Success**

#### Written by Jessica Chi

Because the damaging effects of glaucoma are not always obvious, lack of treatment compliance is a major concern. Understanding patients, and tailoring treatment to ensure compliance, is paramount to their eye health.

Glaucoma is often called the 'silent thief of sight' because it causes irreversible damage to the eye before the subject is even aware. This disease, as we all know, first affects the peripheral vision, to which we are far less attuned than our central vision. People normally only become aware of the damaging effects in glaucoma's advanced

As a result, maintaining patient compliance with glaucoma medication has been poor. Many study results have reported that only a quarter to a half of patients maintain their medication regime for a vear.1-3

There are multiple barriers to compliance, with one study finding 71 different barriers. These barriers may be divided into regimen factors, i.e., the cost, complexity, availability and side effects; patient factors, i.e., their level of education, ability to remember to administer the treatment, motivation and any co-existing conditions; provider factors, i.e., the level of satisfaction and trust in their practitioner and environmental factors, i.e., their current situation, including other life events and access to support.4

The complexity of a treatment regimen plays a significant role in compliance - the more complex the treatment, the more compliance decreases. A patient on a single drop with once daily dosing will find it easier to adhere to their treatment than someone on multiple drops and multiple administrations per day. Increased age is associated with increased risk of glaucoma, but also of other comorbidities.

While a couple of drops a day may not seem difficult to recall, it may be overwhelming for a patient who already takes a plethora of other

medications. It is also important to be mindful of the patient's personal situation. For example, a patient who lives a stressful life, or is a carer for others, may fail to prioritise their own health, and may neglect adhering to their treatment plan, including returning for follow-up appointments.

The complexity of a treatment regimen plays a significant role in compliance – the more complex the treatment, the more compliance decreases.

A patient needs to understand the implications of glaucoma, including its irreversible nature. Patients that do not have this first-hand experience, or understanding of the disease, need to be adequately educated. However, it is not simply a matter of handing them information and expecting them to get it. Trust in the practitioner and the treatment regimen is paramount in maintaining compliance. Taking the time to develop rapport and a relationship is crucial as glaucoma is a chronic disease which requires lifetime monitoring and treatment.

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### My Glaucoma Story

## **Beryl's Story**



Redfern local, Beryl Ford, was diagnosed with glaucoma at 53 years old. She'd lost her glasses and inevitably visited her optometrist for a new pair when she stumbled across a terrifying diagnosis of glaucoma.

I was diagnosed with glaucoma in the late 1990s, and from then for a while, I felt I was carrying a heavy burden.

The thought of possibly losing my sight was to hard to accept. Having to have drops twice a day only hammered home this possibility.

Along with this was the cost. My husband had medication also, but I found my eye drops were much more expensive. Visits to the ophthalmologist were also costly. I was in a fortunate position of being able to afford this, but I do wonder how difficult it must be for some families.

As time went by, I accepted my condition, and did not feel the awful feeling of helplessness.

The Glaucoma News kept me informed, made me realise I was not alone, and gave me a feeling of having some control.

I have told you before that losing my glasses and having to be tested (I hadn't been for a few years), was the saviour for me.

I strongly believe testing for glaucoma should be free, there should be, like breast cancer, clinics that people could go to on a regular basis so that glaucoma is diagnosed in the early stages.

If you wish to share your glaucoma journey, go to: www.glaucoma.org.au/ share-your-story

OR email your story and a photo (optional) to glaucoma@glaucoma.org.au



### Education

### **Events**

Recently during World Glaucoma Week 2022, Glaucoma Australia hosted a series of Virtual Q&A events on popular glaucoma topics.

### **Available Treatment Options for People Living** with Glaucoma

with Dr Ridia Lim and Dr Kalliopi Giannopoulous

### **Earlier Surgical Intervention: Why This Might Be** the Best Option for You

with Dr Nathan Kerr

Living with Glaucoma - the Patient Experience with Shannon Davis

### Hear the Voice of Our Youngsters with Glaucoma

with Lachlan Knight

To watch these videos go to glaucoma.org.au/glaucoma-tv



### **Our Supporters**

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Many thanks to our wonderful supporters, you are greatly appreciated.



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### In Memoriam

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

Jessie Nokes

Chan Suet Ying

Mr Giuseppe Skrezerek

Mrs Jennifer Dawn Best

Mrs Rus Gaske

### Beauests

The Estate of the Late Marjorie Grace Lawn The Estate of the Late Jacqueline Gail Turner The Estate of the Late Vera Mary Coulthard The Estate of the Late Hazel Garret The Estate of the Late Anita McKenzie The Estate of the Late Joan Valmai Mackenzie

### **Giving HOPE**

Leaving a Gift in your Will is a generous act of love that can make a sight-saving difference to future generations of Australians with alaucoma.

To receive a Bequest Information Pack please contact ceo@glaucoma.org.au or call 02 9411 7722.

### 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/get-support

Call our free support line 1800 500 880

#### Contact details

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T: 02 9411 7722

T: 1800 500 880 (Freecall)

E: alaucoma@glaucoma.org.au

W: www.glaucoma.org.au

#### Follow us













Glaucoma News 10

### Your Questions Answered



### with glaucoma patient Shannon Davis

Glaucoma Australia interviewed glaucoma patient Shannon Davis during World Glaucoma Week to hear about his journey since being diagnosed with glaucoma. If you have any guestions about glaucoma, you can call our free support line 1800 500 880.

### What went through your mind at the time of diagnosis? How were you able to move forward to where you are today?

I was diagnosed two years ago when I was forty-three. I had no warning signs or symptoms, and like many who have been diagnosed, I was confronted with the shock that I had very advanced glaucoma in both eyes and had sustained irreversible damage to the optic nerves, as well as very severe visual field loss.

As someone who is very consultative, I went about getting second and third opinions early on in my diagnosis journey. After speaking with a few ophthalmologists to get their views on the situation, and having each of them say the same thing, I started to feel my diagnosis was validated, and it also allowed me to begin processing everything.

### Did you have periods of feeling overwhelmed by how it was going to affect you?

I was scared for what the future held, but I'm a verv positive person and I was determined to tackle this head on like any other challenge. Coming from a place of no knowledge at all to doing lots of research, I found myself reaching out to Glaucoma Australia.

I found the Glaucoma Australia website to be hugely useful in terms of building my knowledge about the disease, treatments, current research etc.

### What has your treatment journey been like?

Over a short period of two years I went on a range of different eye drop combinations, up to four times a day. In my case however, the drops were not getting my pressures down, and although I continued the drops, I underwent laser surgery on both eves multiple times, unfortunately for me I fell into the 20% that laser doesn't quite work for.

My eye surgeon started talking to me about trabeculectomy surgery for both eyes. I must admit, I was extremely fearful of this. There's a lot of misinformation around on the internet regarding that procedure, and there was a fair degree of risk regarding my surgery because I have very advanced glaucoma.

The combination of discussions with my eye surgeon, Sapna, and the other educators at Glaucoma Australia aot me comfortable with this pathway to treatment.

### You've now had to medically surrender your driver's license. How did you come to terms with this?

This is something that I find a lot of people like to ask me about. It is an important topic for those that need to get around every day. I've listened to people that live in the country and rural areas for example, or people that need their driver's license for their occupation, and I can understand those views and what that means for those people.

I would never have envisaged being in this situation (losing my license at such a young age), but when I consider the safety aspects it's a no-brainer for me.

The day that I failed the driver's test I drove to that appointment, which now that I look back, kind of shakes me up a bit to think that I was putting myself and my loved ones and members of the public at risk. For me personally, setting aside the pressure that it might be putting on others, including my wife, who is now the sole driver in our household. I am comfortable with where I've landed on it. as living here in Sydney the transition's been OK. There are ride share services, and we've got great benefits for the vision impaired in terms of transport.

### What is your outlook for the future? Do you have any advice for others with alaucoma and their loved ones?

I am a positive person, so my outlook reflects that. I am at peace with whatever comes my way with this disease. I am very focused now on my health and my family, and I am very confident that I will lead a very fulfilled enjoyable life, although it will be different.

If you're a glaucoma sufferer, or you know a glaucoma patient on this journey, I would say the number one thing I've learnt so far is to not let glaucoma define your life. Don't be limited by glaucoma, and don't let it stop you from doing anything you want to do. Also, many of you will be extremely glaucoma aware, but tell your family! It's on us as a community to build awareness, tell your friends, tell everybody to get their eyes checked.