

Winter 2020 / No.77

Glaucoma News

Our vision: Is for Australians to be free of glaucoma blindness

Quinlivan Research Grants

Can patients with glaucoma have regular monitoring of vision at home?

Research Grant Update by Dr George Kong

Glaucoma is the leading cause of irreversible blindness worldwide. Sadly, significant amounts of peripheral vision can be lost before a person with glaucoma notices symptoms. For patients with glaucoma, early detection of visual field deterioration is critical to their management. However the current practice of visual field testing in clinic is often not frequent enough, and some patient's vision can deteriorate before their next routine clinic visit.

This can lead to a delay in confirming any changes in clinical condition, and result in a delay in initiating new treatments.

During COVID-19 period, this problem has been exacerbated by many routine glaucoma reviews being postponed. Therefore it has been extremely valuable for Glaucoma Australia to provide the critical research funding to look into innovative Telehealth technology that helps patients with glaucoma to monitor their own visual field at home.

Previous research from my team showed that it is possible to test visual field using specially designed software, Melbourne Rapid Fields, running on computer/tablet devices that are found in most Australian households.¹⁻²The software is designed to allow self-directed visual field testing by following simple



Volunteer performing visual field test using a home PC running Melbourne Rapid Fields software

computer voice guidance. The Glaucoma Australia funding allowed our team to conduct the world's first long term (18-month) study to examine whether patients with glaucoma are able to perform visual field testing at home reliably and consistently. This follows an earlier pilot study that showed promising results.

To date, we have recruited more than 60 patients for this study and some patients have completed 12 months of monitoring. Our study showed that after a short learning curve, the visual field test results obtained from home

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

From the CEO



Dear friends and supporters,

The past few months of social isolation have resulted in significant

challenges for people with glaucoma adapting to changes in their treatment routines. To assist you in managing this period of change, our orthoptist educator continues to be available for phone support, our website is regularly updated and our Facebook live presentations are proving very popular. Please do not hesitate to reach out if you need additional information on new treatment management opportunities such as telemedicine appointments, electronic prescriptions and home delivery medications, we are here to help.

As we launch our Quinlivan Research Grants for 2020-2021, I wish to send a heartfelt thank you to those who support our research fund through bequests and donations. Your generosity has the potential to save sight well into the future and bring hope to those diagnosed with glaucoma.

Our patient referrals from Ophthalmologists, Optometrists and Pharmacists continue to rise which means our family link and risk awareness campaigns are reaching those who need to get tested. Our new website is being designed to enhance the education and support provided to patients throughout their glaucoma journey and I look forward to hearing feedback from our community on the improvements made.

Annie Gibbins CEO

(continued)

Cover Story

Can patients with glaucoma have regular monitoring of vision at home?



correlate strongly with test results performed in clinic. Importantly, during the COVID-19 period all participants were able to continue the study uninterrupted.

The results from visual field monitoring provide much more enriched information about a patient's vision for their

Dr George Kong

doctors during Telehealth consultations. This technology will especially benefit patients living in rural and remote locations, who would otherwise need to travel long distances for specialist care. It is hoped that this research could lead to earlier detection of glaucoma progression compared to standard clinic visits, allowing those most in need to receive specialist treatment in a timely manner; thereby increasing the likelihood of preserving sight for more patients with glaucoma.

References:

1. Kong YX, He M, Crowston JG, Vingrys AJ. A Comparison of Perimetric Results from a Tablet Perimeter and Humphrey Field Analyser in Glaucoma Patients. Translational Vision Science & Technology. 2016; 5(6):2.

2. Kong YXG. Visual field testing in the era of portable consumer technology, Clinical and Experimental Ophthalmology. May 2018.

Quinlivan Research Grants

Glaucoma Australia TARRGET Report 2020

Written by Bronwyn Ridge

The Targeting At Risk Relatives of Glaucoma patients for Early diagnosis and Treatment (TARRGET) study is a partnership project between Glaucoma Australia and the Australian and New Zealand Registry of Advanced Glaucoma (ANZRAG, based at Flinders University, Adelaide).

The importance of family history in risk assessment for glaucoma has been well documented and is an important message promoted by Glaucoma Australia. The TARRGET study aims to implement and evaluate an innovative educational program directed at family members of people with advanced glaucoma, and to encourage regular eye health checks. With a focus on early detection, the program is novel in providing personalised risk information to the family member to take with them to an eve health practitioner for a glaucoma screening appointment. All those who have received this information have an immediate relative with advanced glaucoma taking part in the Australian and New Zealand Registry of Advanced Glaucoma.

Family Tree forms, requesting contact details for first-degree relatives (FDRs) were mailed to 1919 advanced glaucoma cases



in the ANZRAG. 637 forms have been returned providing names and contacts details for 1922 FDRs, an average of 3 FDRs per advanced case. Details for an additional 311 FDRs have been provided directly to the ANZRAG resulting in a total of 2233 FDRs with contact details. 101 index cases are now deceased. however 27 of these had previously returned forms or forms were completed by family members. A TARRGET information pack, comprising a letter, personalised flyer and a newly developed Glaucoma Australia brochure, has been

Professor Jamie Craig

mailed to 2175 FDRs. 82 packs have been received back as "Return to Sender" so we estimate that 2093 FDRs have so far received personalised information about their risk. Feedback from FDR eye health checks has been received via reply-paid mail, email and an online survey.

Results have been received to date from 307 individuals indicating: 185 with no glaucoma, 51 glaucoma suspects, 11 ocular hypertension without glaucoma and 54 with glaucoma. These preliminary results suggest approximately 38% of FDRs have the disease or have suspicious signs and require close monitoring. Feedback of results continues to occur as we have follow up and reminder processes built into the study.

The TARRGET study continues to send Family Tree forms to all new, suitable advanced cases in the ANZRAG and to recruit their FDRs. Additional funding has recently been received from Glaucoma Australia which aims to broaden the study to include non-advanced cases of glaucoma as index cases and also to recruit family members into the ANZRAG so that their genetic risk can be assessed with a blood or saliva sample. The TARRGET study will also investigate the possible role of Polygenic Risk Scores (PRS) in determining care and treatment of patients with a mutation in the Myocilin gene. To assist in our investigations we will recruit 1,000 controls without glaucoma and assess their PRS.

Currently, FDRs in the study are assisting with a survey to gauge the interest of unaffected individuals in genetic screening for glaucoma related genetic susceptibility, which will further assess the risk of developing the condition.

Funded by the National Health and Medical Research Council (NHMRC), the TARRGET study is a partnership project between Glaucoma Australia, Flinders University, the University of Western Australia/Lions Eye Institute, the University of Tasmania and Sydney Eye Hospital and WA Country Health Service (Department of Health WA)

The Kath Holmes Scholarship Update

Congratulations to Dr Bigirimana Deus, Dr Bob Wang, Dr Sebastian Derham and Dr Alp Atik on being awarded Glaucoma Australia's "The Kath Holmes Scholarships" for 2020.

Miss Kathleen Holmes was the co-founder of Glaucoma Australia over 30 years ago and was awarded an OAM in 1996 in recognition of her dedication to the glaucoma cause.

Glaucoma Australia provides \$5,000 in scholarships to be awarded to the best presentations by a registrar at the Australian and New Zealand Glaucoma Society (ANZGS) annual conference.



2020 Kath Holmes Scholarship recipients: L – R: Dr Alp Atik, Dr Bigirimana Deus, and Dr Bob Wang (not pictured: Sebastian Derham).

Dr Alp Atik (pictured right) said "The scholarship will help fund my second glaucoma fellowship at the University of Alabama in Birmingham, Alabama. This is a part of the

US which has some of the most challenging glaucoma cases and I hope to learn as much as possible before coming home to Australia".

In the News

Al detects glaucoma 18 months earlier



A new test can detect glaucoma progression 18 months earlier than the current gold standard method. The technology, supported by an artificial intelligence (AI) algorithm, could help accelerate clinical trials, and eventually may be used in detection and diagnostics.

Lead researcher Professor Francesca Cordeiro (UCL Institute of Ophthalmology, Imperial College London, and Western Eye Hospital Imperial College Healthcare NHS Trust) said: "We have developed a quick, automated and highly sensitive way to identify which people with glaucoma are at risk of rapid progression to blindness."

Glaucoma, the leading cause of irreversible blindness worldwide, affects over 60 million people. Vision lost to glaucoma is caused by the death of cells in the retina, at the back of the eye, a process called apoptosis.

The test, called DARC (Detection of Apoptosing Retinal Cells), involves injecting a fluorescent dye into the bloodstream (via the arm) that attaches to retinal cells, and illuminates those that are in the process of apoptosis. The damaged cells appear bright white when viewed in eye examinations. One challenge with evaluating eye diseases is that specialists often disagree when viewing the same scans, so the researchers have incorporated an Al algorithm into their method.

In the Phase II clinical trial of DARC, AI was used to assess 60 patients, 20 with glaucoma and 40 healthy control subjects. The AI was initially trained on retinal scans of healthy subjects following the injection of the dye, and then tested on glaucoma patients.

Those taking part in the AI study were followed up 18 months after the main trial period to see whether their eye health had deteriorated.

The researchers were able to accurately predict progressive glaucomatous damage 18 months prior to what was seen with the current gold standard OCT retinal imaging technology, as every patient with a DARC count over a certain threshold was found to have progressive glaucoma at follow-up.

"These results are very promising as they show DARC could be used as a biomarker when combined with the Al-aided algorithm," said Professor Cordeiro.

Dr Eduardo Normando, (Imperial College London and Western Eye Hospital Imperial College Healthcare NHS Trust) said: "Being able to diagnose glaucoma at an earlier stage, and predict its course of progression, could help people to maintain their sight, as treatment is most successful if provided at an early stage of the disease."

The Al-supported technology has recently been approved by both the UK's Medicines and Healthcare products Regulatory Agency and the USA's Food and Drug Administration as an exploratory endpoint for testing a new glaucoma drug in a clinical trial.

Eduardo M. Normando et al, A CNN-aided method to predict glaucoma progression using DARC (Detection of Apoptosing Retinal Cells), Expert Review of Molecular Diagnostics (2020). DOI: 10.1080/14737159.2020.1758067



In the News

MIGS Approved as standalone procedure

The long-awaited new Medicare Benefits Schedule item for minimally invasive glaucoma surgery (MIGS) as a standalone procedure for patients with open-angle glaucoma has been approved.

The Medical Services Advisory Committee (MSAC) has approved the new item number, ruling that MIGS has an acceptable safety profile and may delay or avoid the need for trabeculectomy in some patients who are not adequately controlled with medical therapy.

The Australian Society of Ophthalmologists (ASO) has been at the forefront of efforts to argue the case for MIGS as a standalone procedure for over two years, ever since approval for use of the goniotomy item number for MIGS use was summarily revoked in May 2017. Revocation led to severe limitations on clinicians' ability to use this next generation microsurgical technology.

Advocacy Works

ASO Vice President Dr Ashish Agar said the decision is proof positive that advocacy works, and that the ASO was right to go into bat for glaucoma patients.

"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," he said. "It's a win for them first and foremost, and a concrete example of what your ASO and our partners can achieve for those who rely on us to save their sight."

Soon after the setback in 2017, and in response to ASO representation and lobbying, the Federal Health Minister Greg Hunt facilitated an expedited submission process, with the ASO as the principal applicant to MSAC to regain an item number for MIGS use.



Dr Ash Agar

A dedicated team comprising representatives from the ASO, Thema (health economics consultants), industry (led by Glaukos), the Royal Australian and New Zealand College of Ophthalmologists (RANZCO), the Australian and New Zealand Glaucoma Society (ANZGS) and

"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".

Glaucoma Australia then set to work. The following year a new item number encompassing combined cataract and MIGS surgery had been approved.

ASO says this achievement, in near record time for a new item number listing, was testament to the strength of the argument and also to Minister Hunt's support.

However the second part of the original submission, dealing with 'standalone' MIGS, where surgery is performed independent of concurrent cataract surgery, remained elusive.

Undaunted, the working group continued to engage with MSAC, which earlier this year hosted a meeting to discuss the group's concerns. MSAC requested special conditions and guidance on the use of MIGS be incorporated. In response another submission was developed, and again the team was fortunate to gain expedited processes for the re-submission.

Welcome News

Dr Agar says the announcement is very welcome news. "There are some details for us to work through from MSAC in terms of guidance for usage, as there are some limitations aimed at ensuring that the use of MIGS is in keeping with best-practice glaucoma management, and we shall begin the process with ANZGS in particular to develop these in coming weeks," he said. "It's not every day that we get a regulatory outcome supporting the use of new technology, given the inherent costs involved," he added.

"The ASO is grateful for the hard work and expertise of the working group, and in particular, I would like to extend my thanks to Dominic Tilden from Thema, Glenn Fawcett from Glaukos, A/Prof Paul Healy from ANZGS and Annie Gibbins from Glaucoma Australia.

This article first appeared in mivision.com.au. It has been reprinted with the permission of mivision (Toma Publishing).

My Glaucoma Story

Saskia's Story

While driving to work every day I would pass a huge billboard saying 'Have you checked your eyesight lately?'



After a month of reading this each day, I decided to go to the optometrist and have a sight test.

It was not what I had expected when I was told I had eye pressure of 18 in one eye and 30 in the other.

The optometrist couldn't ring the specialist fast enough, and I was seen by the end of that same week.

The specialist informed me I had glaucoma and said I would go blind if I did nothing, and I would probably have to stop driving; and it all just seemed doom and gloom.

I left there in tears, but after a while I decided to look into this and saw the Glaucoma Australia website which was very helpful. It helped me understand what was going on, and what options I had for treating glaucoma.

When my next appointment came around at the eye specialist, he realised that he had not even prescribed me any eye drops. I have since sought alternative specialist advice, and I am now a regular out patient at 'Eye and Ear on The Park' in Melbourne.



Research

Study shows glaucoma could be treated with a single eye injection

A new study led by the University of Bristol in the UK has shown glaucoma could be successfully treated with a single injection using gene therapy, which would improve treatment options, effectiveness and quality of life.

The research team led by academics at the Bristol Medical School: Translational Health Sciences tested a new approach to glaucoma treatment, which includes just a single injection that could provide patients with additional treatment options and benefits.

"A single long-term treatment...would improve the quality of life for many patients".

The treatment targeted part of the eye called the ciliary body which produces the fluid that maintains pressure within the eve. Using the latest gene editing technology, a gene called Aquaporin¹ in the ciliary body was inactivated leading to reduced eye pressure. Dr Colin Chu from Bristol Medical School, said: "We hope to



Histological section of a cillary body. Image credit: University of Bristol

advance towards clinical trials for this new treatment in the near future. If it's successful it could allow a long-term treatment of glaucoma with a single eye injection, which would improve the quality of life for many patients".

Academics are currently in discussions with industry partners to support further laboratory work and rapidly progress this new treatment option towards clinical trials. The study was funded by the National Eve Research Centre. T.F.C. Frost Charitable Trust, Above & Beyond, Fight for Sight, Elizabeth Blackwell Institute and the Medical Research Council (MRC).

1. Gene therapy for glaucoma by ciliary body Aquaporin 1 disruption using CRISPR-Cas9' by Jiahui Wui, Oliver H. Bell. David A. Copland. Alison Youna. John R. Pooley, Ryea Maswood, Rachel S. Evans, Peng Tee Khaw, Robin R. Ali, Andrew D. Dick, and Colin J. Chu in Molecular Therapy.

My Glaucoma Story

Harrison's Story

Written by Renee

Harrison was born on December 29th 2010, he came into this world two weeks late and 10 pounds 10 ounces. We were so overjoyed at this beautiful big baby boy!

As I held Harrison in my arms for the first time I noticed his eyes seemed very cloudy and swollen. I asked the nurse if his eyes looked okay, and she mentioned that most babies' eves will look like this when they are first born; already at this time I felt something was not right.

The next morning as I held Harrison the doctor on call came to visit. Once the doctor looked at Harrison's eyes I knew my thoughts were true, something was wrong. The doctor told us that it looked like Harrison had glaucoma, he had seen this once in residency but needed us to be transferred to a larger hospital to be examined.

We were then sent to a large city hospital in Boston, Massachusetts - at the time we were living in America. Harrison was diagnosed with primary congenital glaucoma on the second day of his birth. We were told that we would not know what sight he would have until his first operation, and because his pressures were so high and his case so



severe Harrison had a total of 6 operations within the first year of his life.

Harrison now has Ahmed Valve implants in both eyes, unfortunately due to the damage, Harrison lost sight in the left eye at the age of 7. Harrison has drops to keep his right eye healthy and we see his specialist here in Sydney and America on a regular basis.

Although this was such a surprising diagnosis for us at the time. I feel that my entire family now appreciates the privilege of seeing our world and the people we love every day. I will never forget the first time I took Harrison to see a movie and still to this day we all wake up grateful to see each other; there are so many small things during the day that bring us joy because we know Harrison is able to see them with us.

The doctor's we have met along this journey are heroes and the most inspiring people I have ever met.

Harrison is a healthy, active 9 year old, he loves coding and robotics and when he grows up he wants to be an Artificial Intelligence Engineer; I have no doubt this will happen!!



Volunteers

Celebrating Centenarian Thanks to our **Margaret Tanner**

We would like to take this opportunity to express our best wishes and gratitude to Margaret, one of our most beloved volunteers, who recently celebrated her 100th birthday.

Margaret has been a volunteer at Glaucoma Australia for 18 years. She enjoys volunteering for companionship and variety in her routine. She puts together welcome kits for people with glaucoma, and writes receipts and thank you notes to donors and supporters.

Happy 100th Birthday Margaret, and thank you for your very valuable contributions to Glaucoma Australia and our community.

If you would like to know more about volunteering please call 1800 500 880.



Our Supporters

Supporters

Many thanks to our wonderful supporters you are greatly appreciated.

Platinum 🔹 Allergan

William A Quinlivan Research Fund

Gold

Carr Family Trust

Silver

UNOVARTIS





Supporters

- · Anonymous
- · ASE IT
- Evolhope Family Trust
- · Glaukos
- Icare
- Specsavers
- The Angles Family Foundation

Media Supporters

- Insight Magazine
- mivision Magazine

Allied Health Partners

- Brien Holden Vision Institute
- · Centre for Eye Health
- · Healthdirect Australia
- Lions Eye Institute
- MedAdvisor
- MyHealth1st
- Oculo
- · Optometry Australia
- · Orthoptics Australia
- · RANZCO
- Vision Australia
- Vision 2020 Australia

In Memoriam

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

Ms Marjie Moore Mr Giuseppe Skrezenek Mr John Manfield

Bequests

The estate of the Late Maurice Cassidy The estate of the Late Lily Baker The estate of the Late Dr David Dick

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



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

Call our free support line

1800 500 880

Contact details

PO Box 420 Crows Nest NSW 1585 Suite 3.02 44 Hampden Road Artarmon 2064 T: 02 9411 7722 T: 1800 500 880 (Freecall) F: 02 9413 4466 E: glaucoma@glaucoma.org.au W: www.glaucoma.org.au

Follow us





glaucoma.org.au



Your Questions Answered

Q&A

Can a relative or friend get my glaucoma eye drops for me if they bring my script in?

A Yes, you can ask someone else to collect your eye drops for you. You can give your prescription to a relative, a carer, a next door neighbour or someone that you trust to take it to the pharmacy for you. Depending on what other prescriptions you have, the pharmacist might require some identification from them.

Q Can my medications be delivered to my house?

If you are having trouble getting your medicine or getting to the pharmacy, then telephone the pharmacy and have a conversation with the pharmacist. Most pharmacies do have arrangements to deliver medicines. If this is an ongoing thing for you, some pharmacies may charge you a little bit extra to cover their costs because there is no government subsidy for a pharmacy to do that for you every week or every second week.

Can my pharmacist give me the preservative free version of my glaucoma eye drop? Or do I need a specific script for that?

A There are many different kinds of drops to treat glaucoma. If you do not like the

with Helen Stone

Helen Stone is a pharmacist from The Pharmaceutical Society of Australia, she is also a member of Glaucoma Australia's highly skilled pharmacy committee.

drops you are on, your pharmacist can not prescribe different drops for you. Pharmacists will give you the drops that are on the prescription. If you want to change to preservative free eye drops then you need to go back and see your ophthalmologist or optometrist.

I finish my eye drops in less than 1 month and feel I may not be instilling it correctly.

If you are finishing your bottle in less than a month, it might mean you are having difficulties instilling the drops. There are dropper bottle aids that may be helpful and pharmacists can suggest aids that go with various types of droppers. Teaching someone else who lives with you to do the drops for you is a helpful method to assist in instilling drops. Another thing to look at is the setup for which you are instilling your drops. I find it easier to be sitting down in front of a mirror because it means I am stable and can put in the drops appropriately.

What happens if I still have eye drops left at the end of the month?

A If you find that when you get to the end of the month and there are still drops in that bottle, do not be tempted to use it until it is empty. Throw that bottle away and use the next one.

Q How many repeat scripts can I get for glaucoma eye drops?

A You can get six months at a time and that is a maximum. Now you might find that if you are newly diagnosed, for example, that you go to your ophthalmologist and they might only give you two months because they want to continue measuring your pressures.

Can my pharmacist help me with choosing lubricating eye drops and help with dry eye therapy?

Yes. When you go into a pharmacy you will see a large range of lubricating eye drops and ointments and it can be hard to choose between them. They differ because some have active ingredients, some have different preservatives and some have no preservatives at all. When talking to the pharmacist about lubricating eye drops, tell them that you have glaucoma and you are using drops every day and vou would like something that is less irritant. If it doesn't work then try something else. Keep a list of ones you do like and don't like. Eve ointments are a little bit different because they last a bit longer so if you find that your eyes at night and in the morning are dry. ointments could be the choice for you.