

The Glaucoma Issue

Written by Associate Professor Ivan Goldberg AM, Ophthalmologist

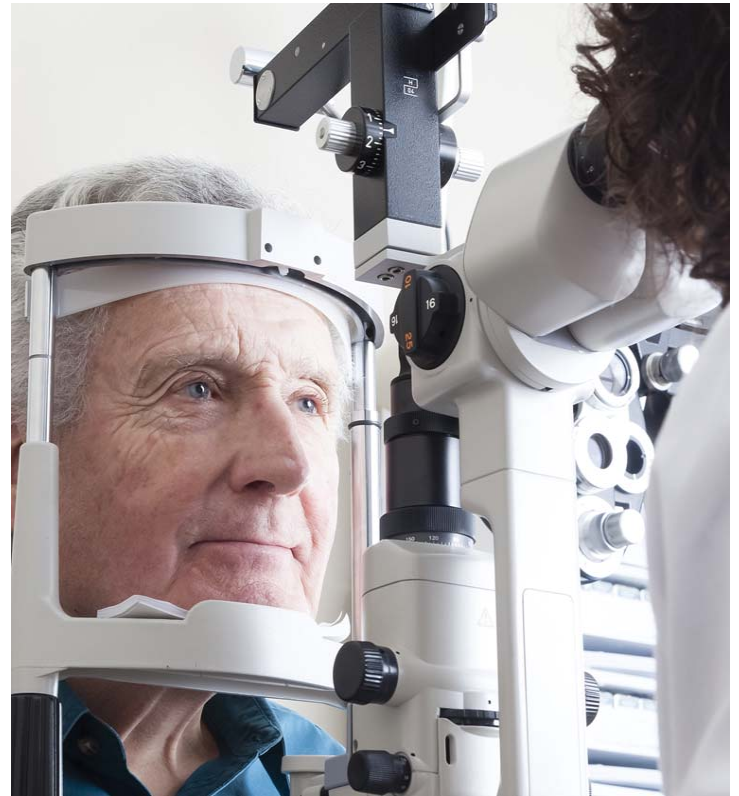
March 2018 marks 30 years of activity for Glaucoma Australia (GA) in pursuit of its mission to eliminate glaucoma blindness. Now blossoming as a digitally empowered organisation, GA forges ever-tighter bonds with health professionals across the spectrum of eye care in order to better serve people with glaucoma.

The glaucomas are progressive in the visual damage they wreak and the damage caused is irreversible. In early to moderate stages, this damage is only vaguely symptomatic and can be largely prevented with effective treatment strategies. This means earlier diagnosis and more effective treatment are essential to achieve GA's mission.

Yet in Australia, up to half of all glaucoma patients are unaware of their condition and on no treatment. Half of those on treatment are non-adherent to their drops or their follow-up appointments, non-persistent with their program, or physically unable to instil eye-drops effectively. The challenges are daunting, the urgency is real, however the good news is, opportunities are beckoning.

The goal of World Glaucoma Week (11–17 March) is to increase community awareness of glaucoma and encourage more frequent eye checks. This is being actively pursued in Australia with an emphasis on targeting high-risk first-degree relatives, which is where we believe our efforts will yield the greatest benefit.

Guiding and informing people who are being treated for glaucoma has a positive impact: adherence rates double with the knowledge of two facts: glaucoma can blind and treatment can save sight. You can play your part by looking for glaucoma, encouraging people to be tested regularly, and referring people with glaucoma to their lay organisation for information and support. Be involved actively in the elimination of glaucoma blindness.



300,000 Australians (approx)
live with glaucoma

Up to 50% don't know
they have the disease

50% of those diagnosed
don't comply with treatment

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Dear friends and supporters

Following a very busy World Glaucoma Week your Council and the whole Glaucoma Australia team wish you success in managing your glaucoma in 2018 and hope that this year we will make a further giant step towards reducing the huge number of as yet

undetected and untreated people in Australia with glaucoma.

Today, this is the central focus of our organisation. We know that if we have glaucoma, our direct relatives are 10x more likely to develop glaucoma - the silent thief of sight. The TARRGET study has revealed that if you have glaucoma, like me, our first degree relatives have up to a 50% chance of developing glaucoma as well which is simply staggering; and if left undetected and untreated they face irreversible vision loss or even blindness.

Glaucoma Australia is leading a national program to increase glaucoma awareness among all at-risk family members, alerting them to the increased risk of developing glaucoma and the need for regular eye examinations from the age of 40. In this we are grateful for the support of Australian Optometrists who are generally the first to detect the possibility of this disease. Progressively, their systems and Glaucoma Australia's are being integrated so that with patient agreement, we can work together to support people with glaucoma and encourage and facilitate regular eye checks for their families.

Welcome

As of February 1, our new CEO Annie Gibbins has replaced Geoff Pollard and is now responsible for the operations of Glaucoma Australia. Welcome Annie. Annie brings deep professional and life experience to her role having previously managed a myriad of complex challenges successfully. Her energy and enthusiasm is boundless and she has the total support of the whole glaucoma team in tackling our mission.

In addition to getting up to speed with GA, our detection mission and digital transformation, Annie has also learnt that our home for the last 5 years at St Leonards will soon be redeveloped requiring us to relocate to new premises. Annie has found an excellent alternative in the area and by the time you read this our team will have moved to new offices in Artarmon. This is on top of the always hectic World Glaucoma Week which ran from 11 – 17 March.

I am also pleased to welcome new Council Member and Chair of our Pharmacy Committee Suzanne Schultz to our team. Based in Canberra, Suzanne brings many years of experience to our Council, in health, as a company Director, and specifically as a prominent member of the pharmacy profession. Together with our Pharmacy Committee, Suzanne aims to encourage people with glaucoma to faithfully adhere to their prescribed treatment and save sight.

This month we are also welcoming two new staff members. Sofia Ettridge, Office and Accounts Administrator has replaced Kim Brady-Kells who is moving on to bigger things; and Jan Howlett, Patient Educator (Orthoptist) replaces Meegan McLeod who has moved to a well-earned retirement. We wish Kim and Meegan well and thank them for their support for people with glaucoma over their years with us. Both Sofia and Jan have now commenced and are already very active in supporting our work.

Council Update

Your Council met in February with full attendance and reviewed the progress of our many activities. Our special focus for this meeting was on the steps we need to take to strengthen our brand and communications as we seek to reach out to the many newly diagnosed people with glaucoma, and, very importantly, their families. We are indeed fortunate to have the support of top Australian marketers with this work – our thanks to the Sustainability Committee and to all our very active Committee members.

Glaucoma Australia is now midstream in our digital transformation with our systems and services increasingly available online.

Our longstanding loyal supporters will continue to receive this paper newsletter quarterly or have the choice of an online e-newsletter. Our support will continue to be available by phone or online as is today the choice of many.

As President and on behalf of people with glaucoma, I would like to thank the very large group of people who support our work both financially and with their efforts for all they do. GA can only exist with your support.

During World Glaucoma Week 2018 (11 – 17 March) Glaucoma Australia joined with friends, supporters, health professionals and business to highlight a sad and unacceptable statistic – 150,000 Australians are unaware they have glaucoma, and are at risk of suffering irreversible but preventable blindness.

Sadly, half of the 300,000 Australians with glaucoma are unaware they have the potentially blinding condition because they lack noticeable symptoms and have not had an eye examination.

Family Link

Of particular concern to Glaucoma Australia are the families of those people who are already diagnosed with glaucoma.

Considering you are 10x more likely to develop glaucoma if you have a direct family member with glaucoma, the message during World Glaucoma Week was loud and clear - if someone in your family has glaucoma go get your eyes tested, it's easy and it just might save your eyesight.

“Anyone from age 40 with a family history of glaucoma, or age 50 with no family history, should make an appointment for a comprehensive eye examination with an optometrist,” Glaucoma Australia CEO Annie Gibbins said.

Also, if you have glaucoma – one way you can help reduce vision loss from glaucoma is to talk to your family and make sure your first-degree relatives understand that they are at risk and should have a comprehensive eye exam.

B.I.G Breakfast

Thank you to our friends and supporters who hosted a B.I.G Breakfast during World Glaucoma Week. Your support helps raise awareness and funds for improved glaucoma detection, diagnosis, education, support and research.

You can donate any funds raised at your event online www.glaucoma.org.au/donation or call 02 9906 6640.

On Monday 12 March Glaucoma Australia hosted its own B.I.G Breakfast where guests heard from Andrew Voss and Sarah Martin who were both kind enough to share their glaucoma stories.

Sadly, Andrew Voss' mother and aunt both have glaucoma which was diagnosed after a significant

amount of their peripheral vision had already been lost. Fortunately though, Andrew's mother told him she had glaucoma and that the disease was hereditary so he should get his eyes checked regularly. Now Andrew is Glaucoma Aware and makes sure his three sons are Glaucoma Aware too; detected and treated early glaucoma blindness can be prevented.



Image: Andrew Voss, Sports Commentator and Glaucoma Australia Ambassador

Sarah Martin's mother was diagnosed with glaucoma at the age of 44 and was advised by her ophthalmologist to tell her direct relatives because glaucoma is hereditary. Speaking with relatives in Scotland, Sarah's mother quickly discovered her mother and sister both had glaucoma too.

Knowing that her grandmother, mother and aunt all have glaucoma Sarah has always been aware that she too is at risk and has had regular eye exams. Recently Sarah who is only 35, has discovered that she too has high intraocular eye pressure and is a glaucoma suspect. Sarah doesn't have glaucoma yet, but her ophthalmologist has advised her that it will develop at some stage.

“I want people to know that glaucoma is not just a disease your grandparents get” Sarah said at the Glaucoma Australia B.I.G. Breakfast.

The fact is, anyone may develop glaucoma, but the incidence increases with age. About 1 in 10,000 babies are born with glaucoma, by age 40 about 1 in 200 have glaucoma, rising to 1 in 8 at age 80.

If you missed the Glaucoma Australia B.I.G Breakfast you can watch it on YouTube. Visit <http://bit.ly/GA-YouTube>



Image: Sarah Martin, COO Vision Xray Group and Annie Gibbins CEO Glaucoma Australia

Glaucoma Australia Celebrates



Written by Geoff Pollard former National Executive Officer Glaucoma Australia

Thirty years on, Glaucoma Australia continues to make a significant impact on the lives of people at risk and diagnosed with glaucoma by delivering relevant communication and education, and funding valuable research.

March 2018 marked the 30th anniversary of the incorporation of Glaucoma Australia Inc. as the Peak Glaucoma Patient Organisation in Australia. The Glaucoma Association of Australia Inc. (as it was originally known), was started in 1986 by a group of volunteers who were keen to help people with glaucoma. Within two years the legal framework had been put in place recognising the organisation as a charity and work began to make a difference to the lives of those diagnosed by raising awareness of this potentially blinding disease in the Australian community. The first Steering committee included Professor (then Dr.) Ivan Goldberg AM and one of his patients, Kathleen Holmes OAM, who 'donated' her lounge room for many years to the large group of volunteers who came to help out.

While the first paid staff member had been employed by the end of 1995, the vast majority of work continued to be undertaken by volunteers, some of whom continue to provide their services, free of charge, today. In those early days, the Association gained traction with an interview on Ray Martin's 'Middy Show', a Dargie Family Benefit Concert and Margaret Whitlam, who accepted the role as the Association's first Patron.

Early Ambitions

With no lay organisation concentrating on glaucoma in 1988, the Glaucoma Association of Australia aimed to:

- Increase community awareness of glaucoma as a potentially blinding eye disease and stress the importance of regular eye tests;
- Provide information and support for glaucoma patients and their families, reinforcing advice and explanations given by eye care practitioners and improving adherence to therapy;
- Raise funds for Australian glaucoma research;
- Support eye and other health providers to maximise patient health outcomes, and;
- Advocate on behalf of the glaucoma community.

Although the marketing language and the communication channels have changed, the overall reason for Glaucoma Australia coming into existence still remains: to eliminate glaucoma blindness; in whatever form it takes.

The Association Today

Today, Glaucoma Australia employs five staff and has over 50 people working in a volunteer capacity to support glaucoma detection, treatment adherence and to help people live a better life while affected by the disease. The fact that there has only been four Presidents and three Executive Officers in its thirty year history is testament to the longevity of interest in improving the 'lot' of people with glaucoma... or maybe it signifies how much there is still to do? After all, it is estimated that only 50 per cent of people with the disease know they have it – such is the invisible nature of glaucoma that most people do not have signs or symptoms and need to be opportunistically diagnosed, unless they have significant damage.

Not An Old Person's Disease

Glaucoma Australia has helped the community understand what glaucoma is and to alter the perception that glaucoma, while a disease of ageing, is not an 'old person's' disease. Indeed, previous research undertaken by the Association found that 17 per cent of people with glaucoma were diagnosed before they turned 45 years of age. With an estimated 300,000+ Australians living with the disease, including approximately 11,000 blind from their glaucoma and a further 27,000 with glaucomatous vision loss⁽¹⁾ there is a long way to go before we can claim credit for realising the promise of preventing blindness and vision loss caused by glaucoma.

The Association does however, continue to disseminate glaucoma information via television, radio, newspapers, magazines and more recently, the internet and on social

media. The latter two are increasingly important as we work to involve younger people in looking after their eyesight, including undertaking a regular and comprehensive optic nerves check. Early detection, along with adequate treatment, remains the best way to improve those damning statistics.



Early Relationship Building

The website: www.glaucoma.org.au is rapidly becoming the most easily scalable way to engage our audience and to assist people to conduct an ongoing relationship with the Association. This is important as many who come to Glaucoma Australia for information don't yet have glaucoma or, if they do, will have widely varying needs over time.

While detection is the main emphasis, staying in touch and being relevant for a person at different stages of their disease is key to supporting those with a chronic asymptomatic disease that has such a variable outcome. A patient organisation like Glaucoma Australia that stays in touch with patients can assist eye healthcare professionals to increase medication persistence/adherence and increase the likelihood of patients returning for appointments.

This is important because treatment adherence, especially with topical medications is poor, with over half of those prescribed medication stopping within one year. Loss to follow-up is a main cause of stopping treatment, which in turns increases the likelihood of progressive vision loss and eventual blindness.

A recent Glaucoma Australia initiative is now seeing our organisation included as a referral destination for patients who are diagnosed with glaucoma/possible glaucoma. When an optometrist makes a specialist referral using the Oculo referral platform, the patient can also be referred to Glaucoma Australia for information and support that amplifies what the referring practitioner is hoping to achieve for the patient. This new program truly brings glaucoma education to the patient and in a seamless way.

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The Next 30 Years

A family history positive for glaucoma is an important risk factor and the Association has particularly invested in understanding what this means for the direct relatives of those with advanced glaucoma. After demonstrating what the burden of disease is, the important task is to do something with the data. Showing governments that cost-effective family testing programs are possible is something to occupy the Association in the years to come, along with other advocacy initiatives, such as equality of access to treatment choices and better collaborative health partnerships that benefit patient outcomes.

Glaucoma Australia will continue to offer multi-channel patient information, help deliver clinician education and partner with other research organisations to find better/easier ways to detect glaucoma, and to treat and manage it... all the time being sensitive to the needs of people with glaucoma, their families and the professionals who manage their condition.

Here's to the next 30 years!

Reference:¹ Clear Focus - the economic impact of vision loss in Australia in 2009. Vision 2020 Australia, 2010.



Articles in 'Glaucoma News' are 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 for other health concerns.

Sleep Apnoea and Glaucoma

Author: George Ploumidis is an optometrist and has both sleep apnoea and associated glaucoma



Glaucoma is not a singular disease. Current knowledge tells us that it is a result of both eye and systemic risk factors that cause progressive optic nerve damage and loss of vision. Systemic risk factors are those that compromise blood flow to the optic nerve, and include migraines, atrial fibrillation and reduced nocturnal blood pressure. Obstructive sleep apnoea (OSA) has also been identified as a risk factor.

In OSA, the upper respiratory pathway is repeatedly obstructed during sleep and results in daytime sleepiness. It also prevents the body from regulating properly. This results in lower perfusion (blood flow) to

the optic nerve and potentially loss of nerve cells and eventually loss of peripheral vision as the optic nerve struggles to recover. Where glaucoma is commonly thought of as being due to high eye pressure, this effect of OSA on the optic nerve can happen even in people with normal or low eye pressure.

To be clear, people with OSA are at a higher risk of glaucoma, not the other way around. Many studies have demonstrated a link between OSA and glaucoma. Early studies found that OSA was an indicator of poor health in general, but subsequent studies have identified OSA as an independent risk factor for glaucoma.

The exact mechanism for this association is still being researched. The message for people with obstructive sleep apnoea though is clear - have regular eye examinations to check for signs of optic nerve damage. As an optometrist with both OSA and associated glaucoma, I can tell you I had no idea I had glaucoma until I had it checked.

Reference: Faridi, O., Park, S. C., Liebmann, J. M. and Ritch, R. (2012), Glaucoma and obstructive sleep apnoea syndrome. *Clinical & Experimental Ophthalmology*, 40: 408-419.

In The News: Big Hopes for Humble Vitamin

Could an over-the-counter vitamin B3 supplement be the key to treating one of the biggest causes of irreversible vision loss in the world?

Researchers from the Centre for Eye Research Australia (CERA) in Melbourne are conducting a world-first human trial to see if vitamin B3 (nicotinamide) can help slow glaucoma.

Optometrist and Research Fellow Dr Flora Hui from the Centre for Eye Research Australia has been inundated with glaucoma patients wanting to take part in the 60-patient clinical trial.

She suggested that if other glaucoma patients wanted to start taking nicotinamide in the meantime they should consult their GP, as it was contraindicated in some conditions including pregnancy. They could also ask their optometrist or ophthalmologist about it, she said. "Currently, the use of nicotinamide in glaucoma is still experimental. But because the supplements are widely available commercially, people may still buy it. I recommend consulting your doctor to see if it is ok before starting nicotinamide," Dr Hui said.

In the 6 month clinical trial CERA researchers hope to prove that therapeutic use of high dosage vitamin B3 (nicotinamide) could be used to support existing therapies for glaucoma.

"Our study hopes to confirm that vitamin B3 can protect nerve cells from dying, in a similar way that adding oil to a faulty car engine can still allow it to run more smoothly" Research Fellow Dr Flora Hui added.

The trial follows previous promising research, reported last year, which showed nicotinamide can prevent glaucoma plus stop progression of existing disease in mice. The US study found that giving vitamin B3 to glaucoma-prone mice prevented optic nerve degeneration and glaucoma and reversed negative effects of ageing in the mouse eye.



Welcome Jan Howlett

Glaucoma Australia is delighted to welcome Jan Howlett as our new Patient Educator.



Jan is an experienced orthoptist and as an educator provides over the phone support and education to people with glaucoma, their families, carers and friends to help them to understand glaucoma and the treatment options available.

Jan's experience as an orthoptist spans decades working with patients of all ages and cultural backgrounds in hospital eye clinics and private ophthalmic practices.

Jan has a Masters in public health majoring in health promotion and has worked with Macular Degeneration Foundation, Atlantis Healthcare, UNSW, Sydney University and the Fred Hollows Foundation.

Involvement in a health promotion workshop to Cambodian and Vietnamese ophthalmologists gave Jan a unique insight into orthoptic education where language barriers exist. This experience emphasised how one seemingly simple message can be easily misunderstood if inadequately explained. This reinforced Jan's belief that one-on-one discussions with patients is necessary if misconceptions and misunderstandings are to be avoided and best practice treatment adherence for a given diagnosis is to be achieved.

Welcome to the team Jan. Glaucoma Australia is proud to be able to continue to offer a service that enables a one-on-one conversation to take place to educate and support people living with glaucoma.

If you would like to talk to a Glaucoma Australia educator please call our free hotline 1800 500 880

Thank You Meegan McLeod

Glaucoma Australia would also like to thank Meegan McLeod who retired last month after 11 years as National Educator. Meegan provided invaluable education and support to people living with glaucoma.

We wish Meegan all the very best in her retirement.

Many Thanks

Many thanks to the companies, clubs and organisations who provided financial and other support to the Association:

- Allergan Australia
- Anonymous
- Carr Family Trust
- Evolhope Family Trust
- Icare Finland
- Glaukos Australia
- Insight Magazine
- Mivision Magazine
- Marcus Quinlivan OAM
- Mundipharma
- Novartis Australia
- OKKO Eye Specialist Centre
- Pfizer Australia
- Specsavers



In Memoriam

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

Bequests

The estate of the Late Eileen Doris Gabriel
The estate of the Late Isabel Mary Tangie

You can now purchase your 2018 | 2019 Entertainment Membership! Not only will you receive 25 to 50% off and 2-for-1 offers at many of the best restaurants, hotels and attractions in your area but you'll be supporting us to eliminate glaucoma blindness.



www.glaucoma.org.au/help-us/entertainment-book

Follow us on



We've Moved

Glaucoma Australia has relocated to:
Suite 3.02 Level 3, 44 Hampden Road Artarmon 2064

Questions and Answers

Q. What is the difference between an optometrist and an ophthalmologist?

A. An optometrist is a primary health care provider, often being the first point of professional contact for people experiencing problems with their eyes or who have difficulty seeing. Optometrists have a unique role in providing accessible and vital eye care to the community. Apart from general practice, optometry is the only profession to have its consultations covered by Medicare without the need for a referral.

Optometrists are experts in: the optics of lenses, eye health and visual performance. They assess, diagnose and manage ocular diseases, injuries and disorders across a wide range of patients. Where clinically necessary, optometrists prescribe spectacles, contact lenses and devices for the visually impaired.

Practicing optometrists are registered health professionals who have undertaken a university degree in optometry and who are registered by the Optometry Board of Australia. The majority of optometrists have completed additional training to treat conditions of the eye requiring medicated eye drops. Complicated or unresponsive cases would be referred on to an ophthalmologist. An ophthalmologist would also be consulted at time of diagnosis of glaucoma, if pressure control with eye drops is not effective or if a surgical approach is to be considered.

An ophthalmologist is a medical specialist who has undertaken postgraduate medical training to specialise in eye health and vision. They “provide diagnostic, treatment and preventative medical services related to diseases, injuries and deficiencies of the human eye and associated structures” (ABS Australian Standard Classification of Occupations 2nd edition).

Ophthalmologists are trained and registered to provide total care of eyes, from performing comprehensive eye examinations to prescribing corrective lenses, diagnosing diseases and disorders of the eye, and carrying out the medical and surgical procedures necessary for their treatment. Their work includes prevention of blindness, promotion of eye health, and the rehabilitation of people with visual disability.

Ophthalmologists practice both medicine and surgery, providing both primary care as well as highly specialised treatment. They are the only providers of laser and surgical correction of eye disorders.

Q. What is an orthoptist?

A. Orthoptists are university trained eye healthcare professionals who specialise in the assessment, diagnosis and non-surgical management of various eye disorders.

Traditionally, orthoptists were involved in the management of patients with eye movement disorders and specifically with strabismus (squint), double vision and amblyopia (lazy eye).

Over the last several decades orthoptists have expanded their role and not only specialise in eye movement disorders but are now also involved in the care of patients with eye disease including glaucoma as well as cataracts, diabetic eye disease, age related macular degeneration, systemic or neurological vision disorders and low vision.

Orthoptists work across a range of settings including hospitals, private specialist practices and research centres. Whilst not many people know what an orthoptist is, many have been helped by one.

Q. Does Ginkgo Biloba have a role in the treatment of glaucoma?

A. Ginkgo Biloba is a tree native to China but also found in Japan and Korea. Its fan-shaped leaves contain a complex combination of chemicals including flavonoid glycosides and terpenoids. Pharmacologically, these can affect many processes in the body including influencing neurotransmitters in the brain and improving blood flow by reducing the action of platelets.

There is evidence both in animal models and in humans that Ginkgo is a beneficial treatment for glaucoma. Examples of such evidence includes increased survival of rat retinal ganglion cells in culture when exposed to Ginkgo and improvement in the visual field scores of patients with glaucoma after a course of treatment with Ginkgo Biloba extract. The mechanism behind such apparent benefits is not certain; improved blood supply to the eye (including optic nerve) has been demonstrated and may be important.

Ginkgo is generally safe and well-tolerated. As it can increase bleeding, it should be used with caution in individuals taking anticoagulants or in those with medical conditions associated with increased bleeding such as haemophilia, chronic liver disease or thrombocytopaenia.

It is important to appreciate that the benefit of Ginkgo for preventing glaucoma onset or progression is much less certain than other strategies such as lowering intraocular pressure. The latter has been extensively studied with consistent results whereas research of Ginkgo is much more limited. Currently Ginkgo is indicated for the glaucoma management in eyes where progression is detected despite low intra-ocular pressures.