IGA News

Autumn 2019

International Glaucoma Association

The Charity for People with Glaucoma



In this edition

Biggest ever research grants announced

New IGA Award for Excellence

Q&As from our Annual Meeting

The IGA Buddy Service

PATRON: DAME MAGGIE SMITH

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letter from the editor



Hello and welcome to your Autumn edition of IGA News.

Thank you to those of you who shared your thoughts about the virtual clinics featured in our Summer edition. What stood out was that the responses were overwhelmingly positive:

"I have not been to an actual clinic with a doctor for years. …. My first few years of attending a clinic were very stressful as it took nearly an afternoon to go through all the tests in various rooms scattered over Outpatients and wait for a doctor to check me out. Now I can go to the glaucoma unit and one or two ophthalmic technicians do all the eyesight/fields/pressure tests and the 3D imaging in about 40 minutes, all in one place. The best thing about this type of clinic is the speed at which all the tests are done, skillfully and competently by the staff, which does not stress me out at all compared to the earliest clinics with a doctor."

"The clinic is brilliant. You can be in and out having seen a specialised nurse practitioner … in well under an hour. I would thoroughly recommend their wider introduction. Obviously, there needs to be doctor back-up should there be anything of concern, but for most people glaucoma checks are just checks that everything is under control. Clearing such patients out from the ophthalmology clinic which is over-subscribed to a ridiculous extent, is very sensible. All pro and no cons."

It's obviously a very popular model of care, and I know your feedback will be heartening for the clinicians who've invested time and energy in setting up the clinics.

I'd also like to thank one of our members for suggesting that we include a glossary to accompany our more complex medical or surgical articles. It's an excellent suggestion, and one we'll certainly put into practice when terms or acronyms aren't fully explained in the main article.

The IGA is first and foremost a patient organisation and we really do like to hear from you. We had the

letter from the editor

opportunity to meet many of you face to face at the patient conference we held in Leicester in July, and it was so useful and encouraging to hear about your experiences and views.

When this edition hits your doormats we'll just have held our Bristol patient conference and I'm sure it will have been as entertaining and interesting as its predecessors. We're now planning our 2020 patient events, so if you feel we should hold a conference in your region please do get in touch.



Leicester patient conference

"Had a very interesting afternoon, thank you so much. Everyone did well to speak in a way that I and I'm sure everyone else, could understand! Look forward to more of the same."

"Found the talks very interesting and helpful. The Q&A discussion was even more useful and enlightening."

"It was good to be able to attend. I would not have done so if it had been in London. Felt more connected."

Next, I'm delighted to announce the launch of a new IGA award for professional excellence in glaucoma care. We invite you to nominate those people or teams who have really made a difference to you in the course of your glaucoma care or treatment. You can read all about it on page 3, and I look forward to reading your nominations!

Finally, this will be my last IGA News as stand-in Editor, as we've just recruited a new **Communication & Engagement Manager, Rachel Hughes.** Rachel joins us in September and she'll be editing your Winter edition. We welcome her to the IGA team on page 45.

I hope you enjoy the magazine, and as ever, do please get in touch with your views and tell us what topics you'd like us to cover in the coming months.



Karen Osborn
Chief Executive

IGA Excellence in Glaucoma Care Awards

We are delighted to announce a new award for excellence in glaucoma patient care. We'd like to recognise those professionals or volunteers who make a real difference to the lives of people living with the condition.

You can nominate an individual or team from any field of glaucoma care. It might be someone who runs a great Patient Support Group, someone who's made a breakthrough in glaucoma research, or whose new ways of working has had an impact on the care you've received.

It may be someone who provided you with the right information at the right time, or someone who gave you time and emotional support when you needed it most.



To nominate someone who has made a difference, please either write or email us and tell us:

- **Your name**
- **Your contact details**
- **The name of the person or team you are nominating**
- **Contact details of the person/team (name, organisation, address, email or phone)**
- **Why you are nominating them:**

How have they made a difference to patients, and what makes them stand out above the rest? (maximum of 300 words)

The closing date is ***Friday 1 November*** and the winner will be announced at the ***2019 UK & Eire Glaucoma Society Congress in Glasgow at the end of November*** and also in our Winter IGA News.

Please send your nominations to **Richenda at r.kew@iga.org.uk** or by post to our head office.

IGA news

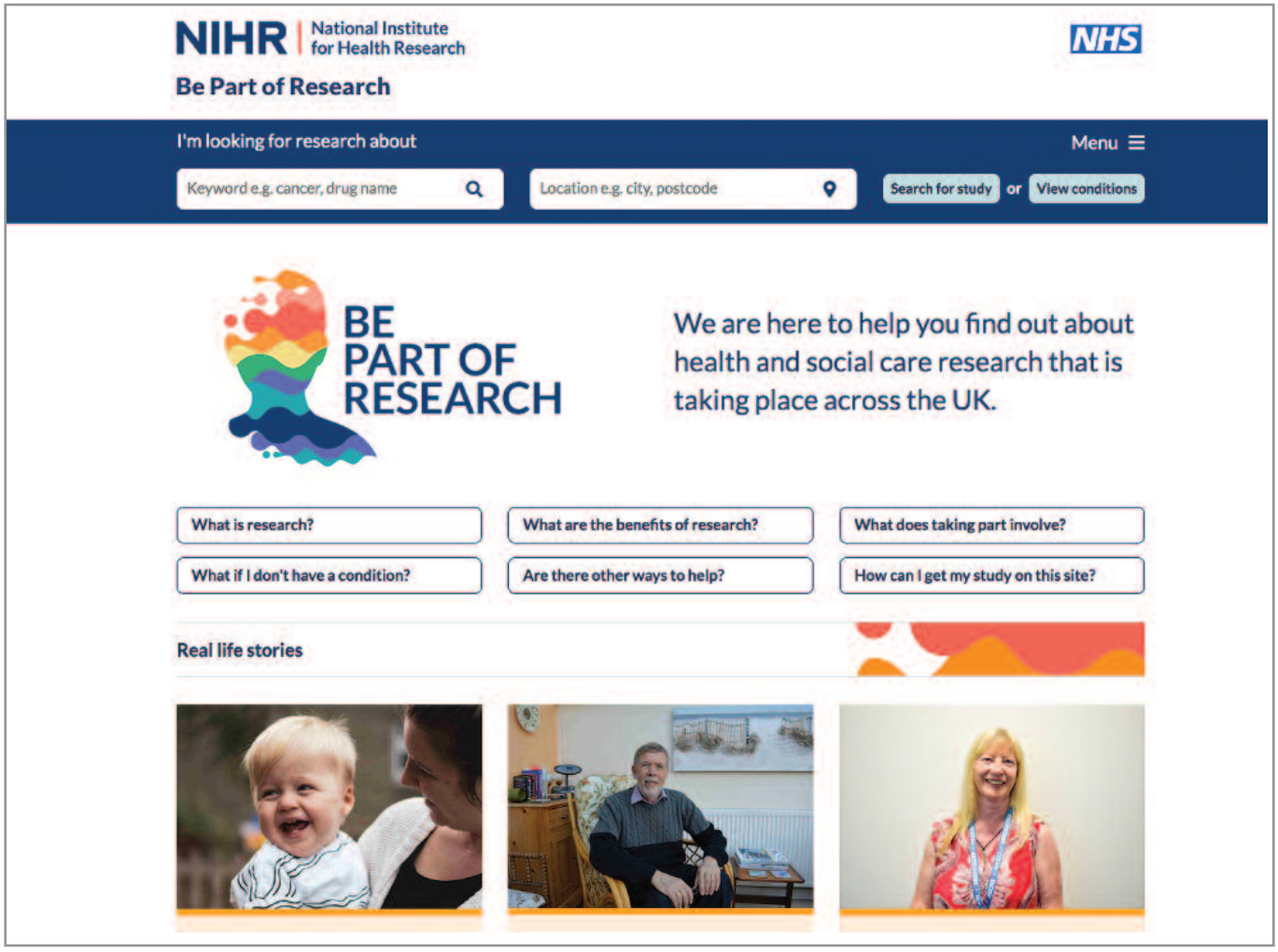
Research changes lives

According to the National Institute for Health Research (NIHR) an astonishing **870,000** people took part in health research last year.

They are keen to increase the numbers even further, and want to make it as easy as possible for the public to learn about UK research and to take part. To make this happen they have redeveloped their **UK Clinical Trials Gateway website.**

The new site will allow visitors to search for research studies by keyword, medicine, location or condition, use keywords to discover research findings, find out how to take part in trials, and give feedback on the usefulness of study information.

For details go to **www.bepartofresearch.nihr.ac.uk**



Welcome to the IGA's new Clinical Advisory Panel members

We are delighted to announce the members of our new Clinical Advisory Panel: a group of the UK's top glaucoma specialists who will provide the charity with clinical advice, help us refine our research priorities and strategy, write patient information, and promote our vision and mission.

The full list of members is:

Ophthalmologists

Mr Pankaj Agrawal (Edinburgh)

Mr Leon Au (Manchester)

Ms Laura Crawley
(Western Eye Hospital, London)

Mr Gus Gazzard
(Moorfields, London)

Mr Wojcieck Karwatowski
(Leicester)

Mr James Kirwan (Portsmouth)

Miss Joanna Liput (York)

Ms Rashmi Mathew (Moorfields)

Prof Andrew McNaught
(Cheltenham)

Mr Shabbir Mohamed
(Birmingham)

Prof James Morgan (Cardiff)

Miss Winnie Nolan (Moorfields)

Mr Alan Rotchford (Glasgow)

Miss Rani Sebastian (Bristol)

Mr James Tildsley (Derby)

Optometrists

Mr Robert Harper (Manchester)

Mr Paul Spry (Bristol)

IGA Trustee members

Mr Nick Strouthidis
(Moorfields, Chair)

Prof Anthony King
(Nottingham, Vice Chair)

Mrs Chris Wall (patient rep)

Mr Stephen Epstein
(optometrist and patient rep)

In the next few editions we'll introduce the Panel members, starting this edition with **Pankaj Agarwal** in Scotland…

IGA news

Pankaj Agarwal

Mr Pankaj Agarwal graduated from the University of Kolkata, India, in 1997 and underwent basic and higher specialist training in ophthalmology and then a Fellowship in Glaucoma at Glasgow. He has been a Consultant in Edinburgh since 2010 and now leads the glaucoma service in Lothian.



Pankaj Agarwal

Mr Agarwal is a clinical tutor and examiner in a number of ophthalmology programmes and is a member of the SIGN glaucoma Guideline Group (SIGN is the body that develops clinical practice guidelines for the NHS in Scotland).

He is active in glaucoma research and is a principal investigator in international studies such as **EAGLE and TAGS.** Mr Agarwal has over 25 peer-reviewed publications in international journals, has co-authored book chapters and is regularly invited to review papers for many leading ophthalmology journals. He also lectures nationally and internationally.

His main interest is shared care glaucoma services and patient awareness in glaucoma. He started the first patient support group meeting in Scotland with the IGA, and works for patient support and awareness not just in the UK but across the world.

We'd like to thank all our Panel members for agreeing to support us by sharing their professional expertise and advice.

Talking glaucoma
Questions, questions...

Do you have a question about glaucoma? **IGA's Sightline** and website are here for you all year round but once a year, after our AGM and Annual Lectures, a panel of top experts lines up to take questions live from an audience of members and guests. This year **IGA Chair, Professor Philip Bloom,** was joined on the platform by optometrist and **IGA trustee Dr Susan Blakeney, IGA Professor Ted Garway-Heath and Mr Gus Gazzard, Director of Glaucoma Services at Moorfields Hospital.**

As always in these sessions, the questions covered a great variety of topics. **Jacqueline Mitton** reports on what the experts had to say...

Delivering patient care effectively and efficiently

Several questioners picked up on changes to NHS policy and guidance that may affect the quality of care glaucoma patients receive.

In November 2017, **NICE** (the National Institute for Health and Care Excellence) revised its guidance on the diagnosis and management of glaucoma. One member thought the guidance is now suggesting longer intervals between check-ups, so how does this guidance impact on treatment?

In Ted's view the revised guidelines would not affect the intervals between check-ups very much. "Clinicians still have a lot a discretion to decide when each individual patient should have their next check-up," he said. "What has changed, though, is the guidance on when an optometrist should make a hospital referral. Under the old guidelines some optometrists were referring patients for suspected glaucoma just because they had an eye pressure of 21mmHg but that was not necessarily appropriate without any other signs of glaucoma."

In another change in policy, NHS England told GPs in 2018 not to issue prescriptions for ailments where remedies can be bought easily without a prescription. Blepharitis is one of the conditions affected by this ruling. "Is this an acceptable situation," a questioner asked, "and is NHS England putting patients at risk?"

Philip explained that his wife is a GP. He thought it was reasonable to expect people who can afford it to buy inexpensive medicines and other things they need for their treatment when these are easily available.

But he did think it was unfair where the cost was a burden for someone. In his opinion, it is a very complicated problem and one that needs more public discussion.

Gus Gazzard broadly agreed with Philip but added that the term "blepharitis" covers a multitude of symptoms from mild to very severe. Not everyone going to their GP is in great need but patients who are suffering a great deal of pain and discomfort are being denied treatment because of the general edict.

For example, people who have real problems with their ophthalmic medications because of blepharitis are being lumped together with people who have a little bit of relatively mild itching and red eye. The problem is how to target NHS treatment on those individuals who need it without spending an awful lot of money on people with lesser needs.

Another patient in the audience mentioned how helpful they had found the device called the Eyebag. After warming it in the microwave oven, you lay it over your eyes for a few minutes, then massage your eyelids. Philip agreed that it can be a useful part of treatment adding that what's being called "blepharitis" may be irritation of the eyelids related to



Eyebag
Image courtesy of The Eyebag Company Ltd

using glaucoma eye drops. Lubricating drops and eyelid wipes can help as well.

On a more positive development, one guest asked about the proposal to have optometrists monitor people with stable glaucoma. Susan said she wouldn't like to speak for the whole of her profession but she thought optometrists generally are well prepared for this. "There are far more optometrists in the country than there are ophthalmologists, they are easily accessible, and they open long hours – all good reasons for care being delivered more and more in optometric practices. Certainly the direction of the health service is, and has been for quite a few years, bringing care closer to home."

She went on, "I advise the College of Optometrists and the College awards

higher qualifications in glaucoma. There are a growing number of optometrists who are acquiring those higher qualifications. At the moment, there are optometrists working alongside ophthalmologists either in hospital or in the community.

Some work in optometric practice part time and take the expertise that they have developed alongside the ophthalmologist into that practice. So 'shared care' or 'co-management' is where we are going and I think we're looking forward to it."

Of course, if patient care is to be shared between more than one professional, there is a question about all those professionals having easy access to patients' notes. The panel was asked, "What are your views on patients holding their own medical records to take with them wherever they go for treatment – what is sometimes called a 'passport'?"

None of the panel members had had direct experience of such a scheme but Susan thought it would be extremely useful for optometrists if patients turned up with information about their medications, visual field test results etc. Philip agreed that it's a very interesting idea. At present it is NHS policy that patients should get copies of the letters their consultants send to their GPs although not every hospital is doing this. In some, you have to ask. But if you can get those letters and keep them, to some extent they can do the same job as portable notes. However, Ted's vision of the future was more technological – patients having access to their electronic records at home on their computer or smart phone. Gus agreed that this is the way things are going.

Problems with eye drops just don't go away

Invite questions on glaucoma and problems with eye drops are sure to be mentioned. One patient was having a real battle over supply. "Why are some eye drops difficult to get?" asked the questioner. "Most months I have to wait and almost fight to get mine **(Simbrinza)**."

Philip acknowledged that there can by supply problems, especially with the less common eye drops, and it's very frustrating for patients. Gus agreed. In his experience it's a perennial problem for his patients, especially where preservative-free versions are concerned. It seemed to him that, whoever you ask about the reasons, you are told that the problem is somewhere else in the supply chain. Philip pointed out that it might be possible to switch to more readily available drops that contain similar

drugs. But if somebody's on drops that suit them, it makes sense to try to stick with the same ones.

Gus went on to talk about the wider problem of generic (non-branded) versions of drops made by different firms coming in a great variety of different bottles. He and Philip agreed that it can be a big problem for patients but as yet no-one has a solution.

On a different matter concerning drops, Ted had mentioned that latanoprost eye drops may soften the cornea, leading to an underestimation of true eye pressure, so may not lower eye pressure quite as much as was once thought. Someone wanted to know whether patients should worry about that. Replying, Ted was very reassuring. "No-one should worry about latanoprost because it has been used very safely for many years," he said. "It is still very effective in stopping the progression of visual field loss."

Understanding the jargon

Many patients whose eye pressure is not reduced enough by drops go on to have a different kind of treatment, involving a laser or surgery. Just getting to grips with the names of the various procedures can be puzzling.

For a start, what is the difference between trabeculoplasty and trabeculectomy? Philip, Gus and Ted all contributed to answering this. There are actually three different procedures with similar names: trabeculoplasty, trabeculectomy and trabeculotomy. All of them act on the trabecular meshwork – the eye's drainage system – to increase the outflow of fluid from the eye.

Trabeculoplasty is a relatively gentle procedure, done with a laser. Gus had described Selective Laser Trabeculoplasty (SLT) in his talk earlier (see IGA News, Summer 2019).

Trabeculectomy is a surgical operation that involves making a small drainage hole in the wall of the eye, covered by a thin layer that acts rather like a trap-door. Fluid drains out through this 'trap-door' arrangement to a little reservoir on the surface of the eye, called a 'bleb.' A trabeculotomy is a less common operation that involves creating a small opening in the trabecular meshwork.

The panel was reminded, though, that SLT is not the only treatment for glaucoma involving the use of a laser. "Don't you think it would be helpful to the patients and the general public to use different names for different kinds of laser treatment?" commented someone. Philip agreed.

"I think it would help to be specific," he said. "Laser is a general term as there are at least four different types of treatment using a laser. I for one try to be specific when I'm talking about it."

One patient had been offered yet another procedure with a weird name. Could the panel explain the glaucoma treatment involving something called a Kahook dual blade?



Kahook dual blade
Image courtesy of New World Medical Inc.

Gus explained that it's a treatment more widely used in the United States than in the UK. It's a form of surgery that's more invasive than trabeculoplasty but less surgically invasive than trabeculectomy. However, to Gus's knowledge, it has not yet been subject to rigorous trials and, as he put it, falls into the category of "widgets for which we have little evidence." Philip confirmed the lack of trials but said that didn't necessarily mean it should not be offered. He is aware of a number of clinicians who do it.

Choosing the right treatment

Glaucoma patients and their consultants are faced with many alternative treatments and some questioners enquired about how choices are made. For example, the panel was asked, "For a patient with eye pressure that's not being controlled with medication, would you recommend a trabeculectomy or a **Santen MicroShunt** (previously known as the **Innfocus MicroShunt)**?"

Gus was quick to point out there isn't a simple answer. "It depends. It depends on what the target pressure is and on the level of risk for the individual patient," he said. In the previous 24 hours he had arranged trabeculectomies for three patients and had decided to put in a **MicroShunt** for a fourth patient. But he admitted that the medium- to long-term outcomes for **MicroShunts** are still uncertain.

"A lot of non-trabeculectomy surgeries come with lower success but at lower risk," he said, "so in

some cases they're worth it, particularly the ones done at the same time as cataract surgery. The **MicroShunt** is slightly different from other shunts because it is touching the conjunctiva. It involves lifting off the conjunctiva to gain access to the outside surface of the eye and this will inevitably have an impact on the success of a trabeculectomy if one is done later. I do believe it's worth trying in some individuals, though. A lot depends on what your target pressure is. I've got some colleagues who are very enthusiastic about it and other colleagues at Moorfields who really don't think it's the answer."

Ted came in too. "It's the same question we as clinicians ask and the only real way of getting the right answer is to do a clinical trial. It's to the credit of the company that makes the **MicroShunt** that they are sponsoring the clinical trial that will allow us to answer that question. So we don't have a definitive answer now but I think in a few years' time we will and we will be able to counsel patients with confidence."

"What about someone who has already had a trabeculectomy and a shunt inserted?" someone asked. "Could laser treatment prevent another shunt being needed?"

Gus explained that after extensive surgery to improve drainage of fluid from the eye, SLT was unlikely to succeed. His worry would be that it would just delay the surgery that was going to be necessary anyway and vision could be lost while waiting to see whether the SLT had worked.

Glaucoma patients and their consultants are faced with many alternative treatments and some questioners enquired about how choices are made.

In answer to a similar question, all three consultants agreed that someone can definitely have a trabeculectomy after having trabeculoplasty (SLT). Having the procedures the other way round, though, is not effective and none of them would plan to do that routinely.

A trabeculectomy problem

Trabeculectomies are generally very successful but occasionally a problem can crop up, and one patient in the audience explained what had happened to them. "I recently had an infection in one of my eyes and it

turned out that the 'bleb' from my trabeculectomy operation over 20 years ago was leaking. I had a successful operation to repair the bleb using tissue from a donor." The panel was asked how long the questioner could expect the repair to last. No-one had an answer.

However, Philip took the opportunity to say some more about trabeculectomies and the symptoms of a leaky bleb.

"I think your experience shows what a good operation trabeculectomy can be," Philip commented. "All of the advances over the last 20 years have refined it and made it even better and even safer. But rarely there are some complications and leakage from the bleb is one of them. Sometimes the tissue making the bleb becomes thin and then it can leak. That can cause an infection which can be serious. It's important that it's caught promptly but there are operations where tissue from the patient – including from another part of the body – or from a donor can be grafted on. If you've had a trabeculectomy and the eye suddenly starts watering, a leaking bleb is one of the things to think of, although it is very rare. Other symptoms can be pain, blurred vision, or dizziness. If you've had a trabeculectomy, always get a sticky eye looked at by an eye professional. But just to recap, a trabeculectomy is a very successful operation. It can have complications, but they are largely treatable."

Assessing the risks

People with glaucoma often have to think about risks: the risk of their vision getting worse and the risks of undergoing treatment as well as the potential benefits. So it's not surprising that several questions related to risks of one kind or another.

Even if glaucoma has not been diagnosed, "Shouldn't people with ocular hypertension (high pressure in the eye) be aware that glaucoma isn't the only danger and shouldn't the IGA mention this in its literature?" asked one person.

Gus guessed correctly that the questioner had had a problem with a blocked vein. "It is something that clinicians are taught about and one of the reasons for treating high pressure and trying to bring it down," he said. "It is one of the risks and it might help the public health message if people were aware that high eye pressure is linked to a number of problems, if only to encourage them to get a check at the optician more often." Ted agreed. "Blocked veins are relatively uncommon," he said, "and can happen to people with normal

eye pressure, but it should perhaps be discussed with patients in conversations about the pros and cons of treating high pressure in the eye."

Then, if someone has glaucoma diagnosed in just one eye, will it eventually affect the other one too? Ted replied that some people do have glaucoma in one eye only but it is more usual for both eyes to be affected. However, it is common for it to be worse in one eye than the other. "Certainly, if you have glaucoma in one eye, the other one should be monitored," was his advice.

Other questions related to the risks that go with surgery. One was about whether some people have a greater risk than others of getting scar tissue after glaucoma surgery because of their genetic make-up. Ted confirmed that some groups of people have a greater tendency to scarring than others – people with dark-coloured skin, for example. He explained that there probably are genes associated with the scarring response but it's uncommon for a single gene to be responsible for something of that kind. However, understanding the genetic connection does help in the search for new ways of dealing with such scarring.

Scarring can also be a risk for people who've had a trabeculectomy and go on to have a cataract operation later. This is the subject of a question people often ask. "Any surgical procedure after a trabeculectomy causes inflammation that may lead to scarring," Philip explained, "and that scarring may cause the trabeculectomy to work less well."

People with glaucoma often have to think about risks: the risk of their vision getting worse and the risks of undergoing treatment as well as the potential benefits

"Cataract surgery is the commonest procedure after trabeculectomy and, traditionally we wait between six months and a year before doing it. For people who have both cataract and glaucoma there is the question of whether we should address the glaucoma first or the cataract first. If the glaucoma is early and relatively mild, there are surgical procedures that can be done in association with cataract surgery. These can reduce the amount of drop treatment needed, although the hope that they would take away the need for trabeculectomy has yet to be realised. But if you have already had a

trabeculectomy, the answer is to leave a reasonable amount of time and take extra precautions. For example, sometimes we give more steroid drops to prevent the extra inflammation which may cause the scarring.

"But the most important fact is that it's perfectly safe to have a cataract operation after a trabeculectomy, although those operations should be done by specialists in glaucoma. Generally, the operations are very successful."

Gus summed up his approach very simply. "We have to take the cataract out to improve vision otherwise what was the point of the trabeculectomy? And then we work jolly hard to keep the trabeculectomy going, even if it takes a lot of visits and a lot of drops."

Phone a friend

So, many questions helpfully answered by the experts in the time available. But there are occasions when what helps most is just having a chat with someone who has gone through the same as you. And one patient in the audience spoke up about exactly that. "I'd love to find a buddy who has had the same problem that I've got," they said.

Philip thought it was a good idea too. Just knowing that other people have been through the same thing can be very reassuring. So how to find a buddy? Local patient support groups may be a way to find other people who have had similar experiences.

The IGA sponsors support groups at many hospitals around the country. Call to find out if there is one near you. The IGA also helps individuals find buddies.



Trish Ganszczyk, Sightline

Contact **sightline@iga.org.uk**
or phone **01233 64 81 70**

The phone line is open
9:30 to 17:00, Monday to Friday.

Talking glaucoma

Optical Coherence Tomography (OCT) explained

More and more of us are coming across optical coherence tomography, or OCT, in hospital eye clinics and optometric practices. But what is OCT and how does it work?

OCT is a medical imaging technique that uses light waves to generate images of the back of the eye. It allows the clinician to see a detailed three-dimensional view of the retina and look at the eye in very fine detail.



An OCT scanner

The OCT test itself is quick and non-invasive. The seated patient leans in to the OCT machine with their chin and forehead against a rest and focuses on a vertical blue light. The scan takes around 30 seconds per eye; nothing comes into contact with the eye itself, and there is usually no need for dilating eye drops.

OCT use in Glaucoma Assessment

The objective of OCT in glaucoma is to measure the thickness of the structures in the eye that are often affected by the condition and observe whether they are changing over time.

This can include measuring:

- **Neuroretinal Rim thickness**
- **Retinal Nerve Fibre Layer (RNFL) thickness**
- **Macular asymmetry analysis**
- **Ganglion Cell Layer (GCL) thickness analysis**
- **Progression analysis**

The changes caused by glaucoma tend to follow a characteristic pattern, most notably thinning of the neuroretinal rim, RNFL and GCL, which takes place slowly over time. Thinning is usually asymmetric, meaning there are differences in the

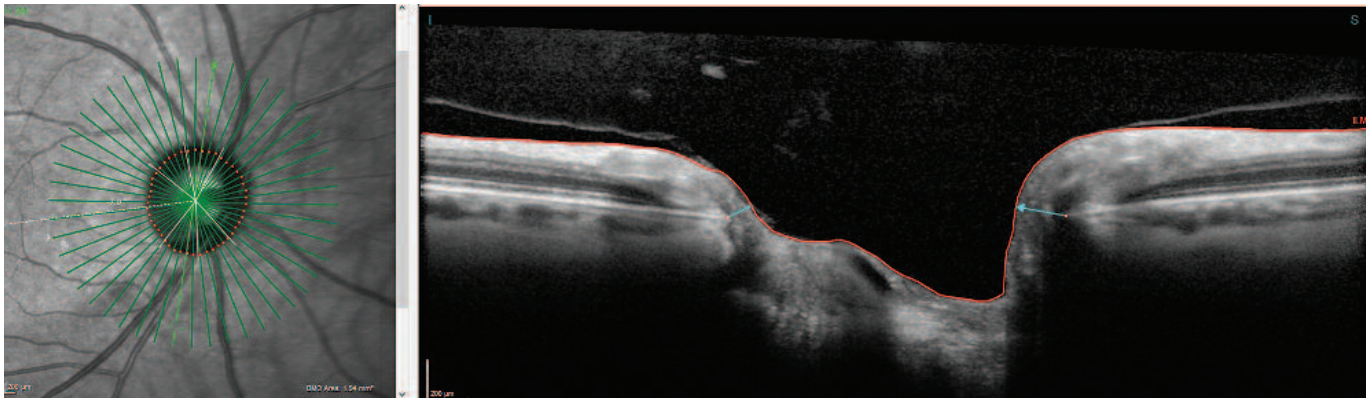


Figure 1. BMO-MRW from an OCT scan (right eye)

thickness of these structures between the upper and lower hemisphere of the eye, as well as asymmetry between the right and left eye.

When using OCT to assess a patient for glaucoma, the clinician is looking out for changes consistent with this pattern.

Neuroretinal rim thickness assessment
The optic nerve head, or optic disc, is usually round or slightly oval and contains a central cup. The tissue between the cup and the edge of the optic disc is called the neuroretinal rim. In normal individuals, the rim has a relatively uniform width.

The OCT provides the clinician with the thickness of the neuroretinal rim so that they can look for the rim thinning that is consistent with glaucoma.

To assess the thickness of the neuroretinal rim, OCT scans of the optic nerve head are taken (as visualised by the green lines like slices of a cake in figure 1, and the distance between the layers at the back of the eye are measured.

[1] Bruch's Membrane is the innermost layer of the choroid. The blue arrows in the right-hand image in figure 1 shows Bruch's Membrane Opening or BMO. The scan also captures the Inner Limiting Membrane, which is the boundary between the retina and the vitreous body. This measurement is referred to as Bruch's Membrane Opening - Minimum Rim Width (BMO-MRW) and gives the optic nerve head boundary and an accurate measurement of the neuroretinal rim.

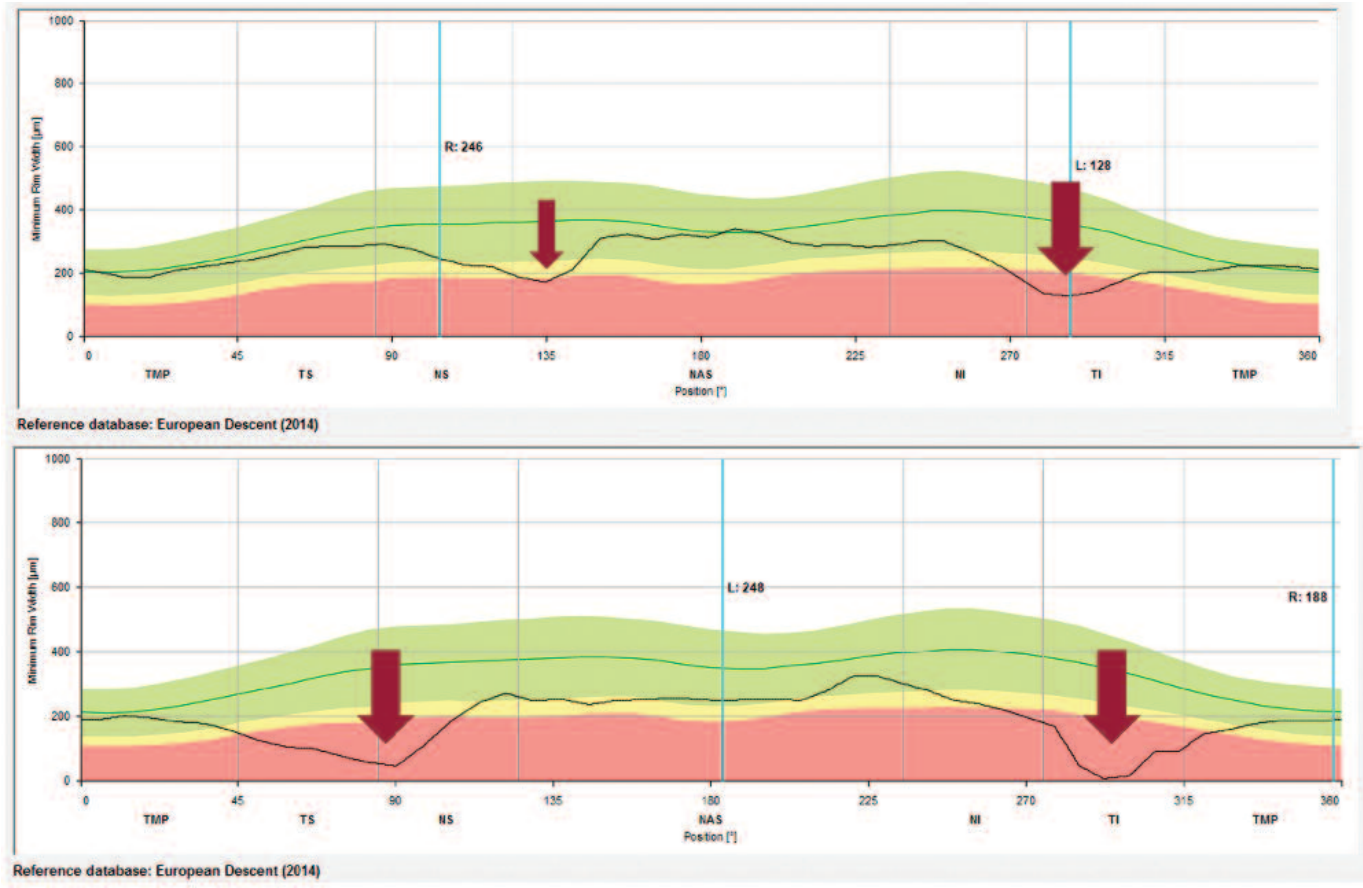


Figure 2. BMO-MRW thickness profiles (right eye top, left eye below)

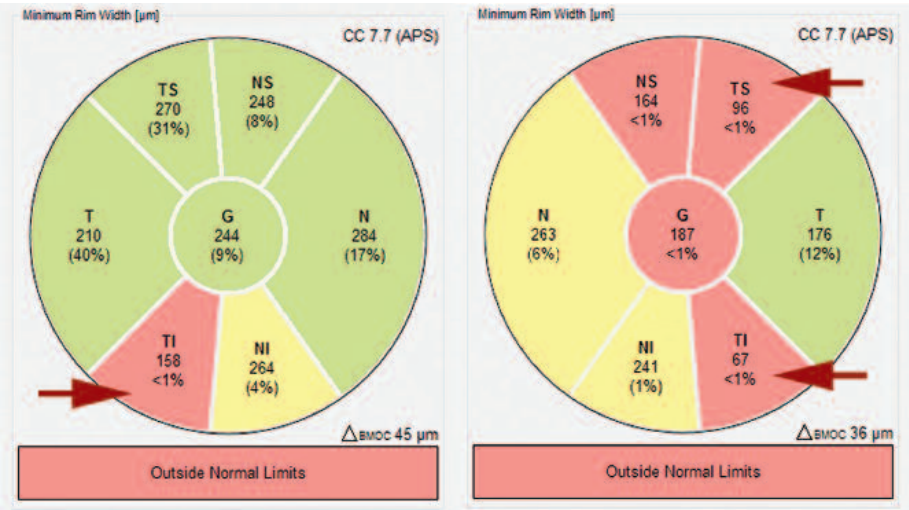


Figure 3. BMO-MRW classification charts (right eye on the left, and left eye to the right)

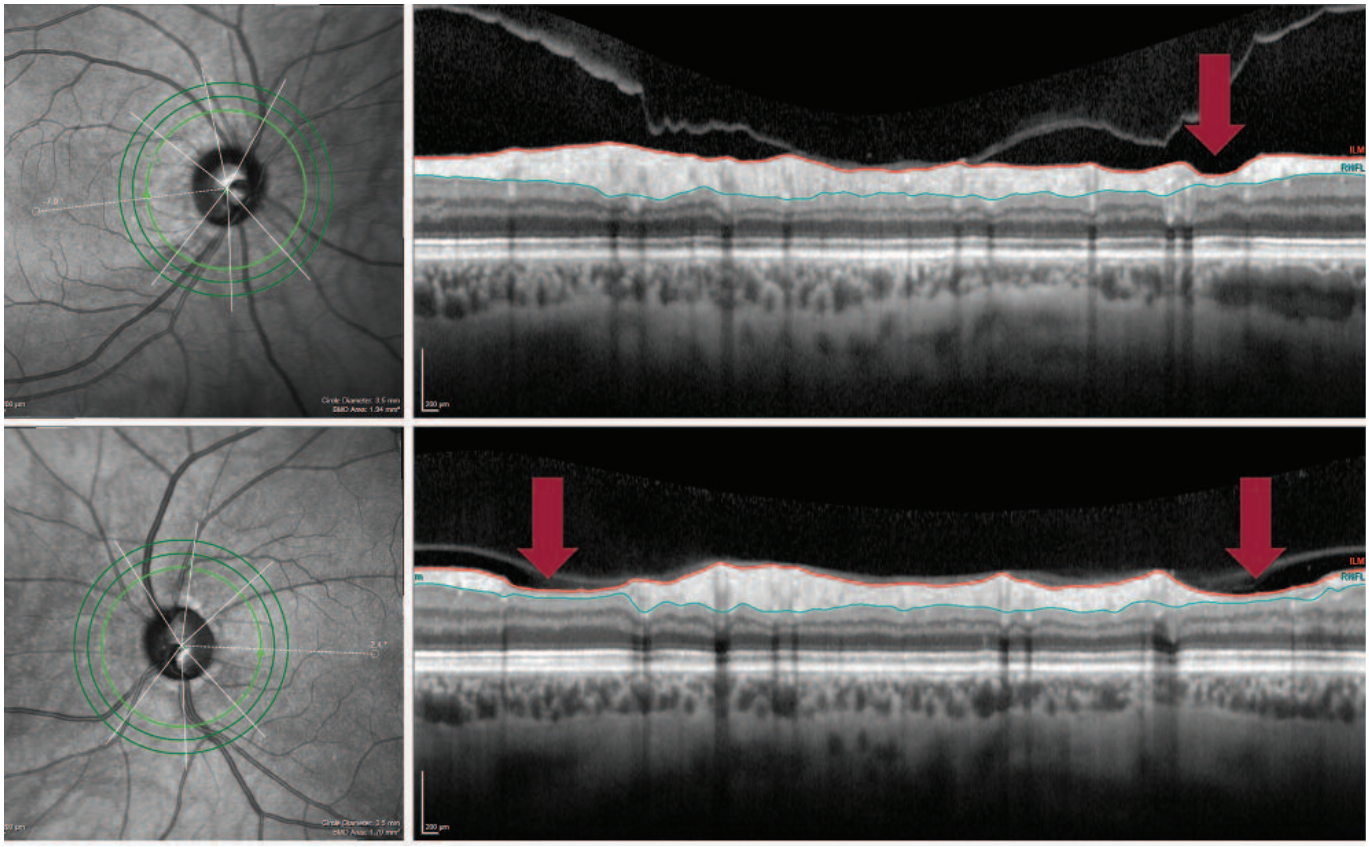


Figure 4. RNFL OCT scan (right eye top, left eye below)

Retinal Nerve Fibre Layer (RNFL) thickness assessment

An OCT scan of the RNFL is taken in a circular pattern (as visualised by the bright green circles in figure 4, bottom left). This circle is then "unrolled" and displayed as a horizontal OCT scan (below right). This allows the clinician to view the thickness of the RNFL around the optic nerve head in a single shot.

The thin RNFL in the right eye is shown by the red arrow (top right image). The left eye (bottom right, two red arrows) shows significant loss of the temporal RNFL, consistent with severe glaucomatous damage. This damage is also illustrated in figures 5 and 6, using diagrams very similar to those used to illustrate the neuroretinal rim thickness shown earlier.

Typically, a normal, nonglaucomatous eye has an RNFL thickness of 80 microns or more (a micron is one thousandth of a millimetre). An eye with an average RNFL thickness of 70 to 79 is suspicious for glaucoma, and an average thickness of 60 to 69

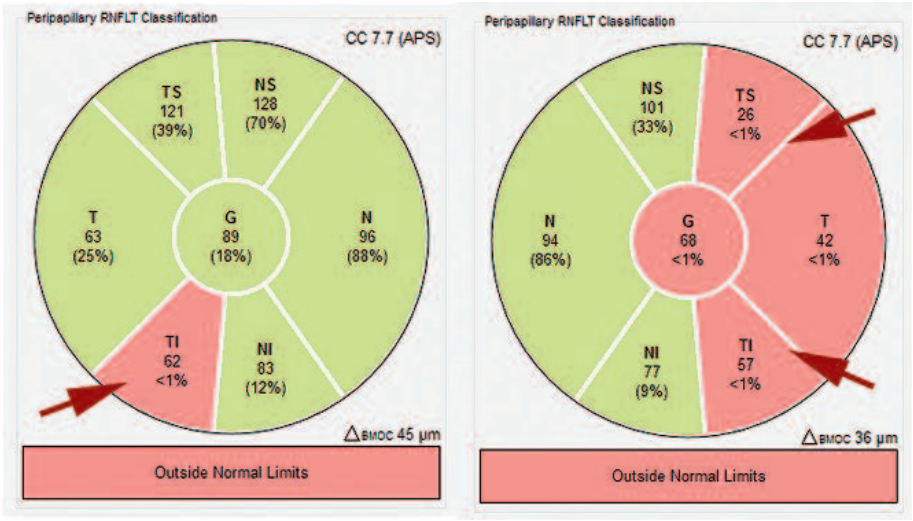


Figure 5. RNFL classification chart (right eye on the left, and left eye on the right)

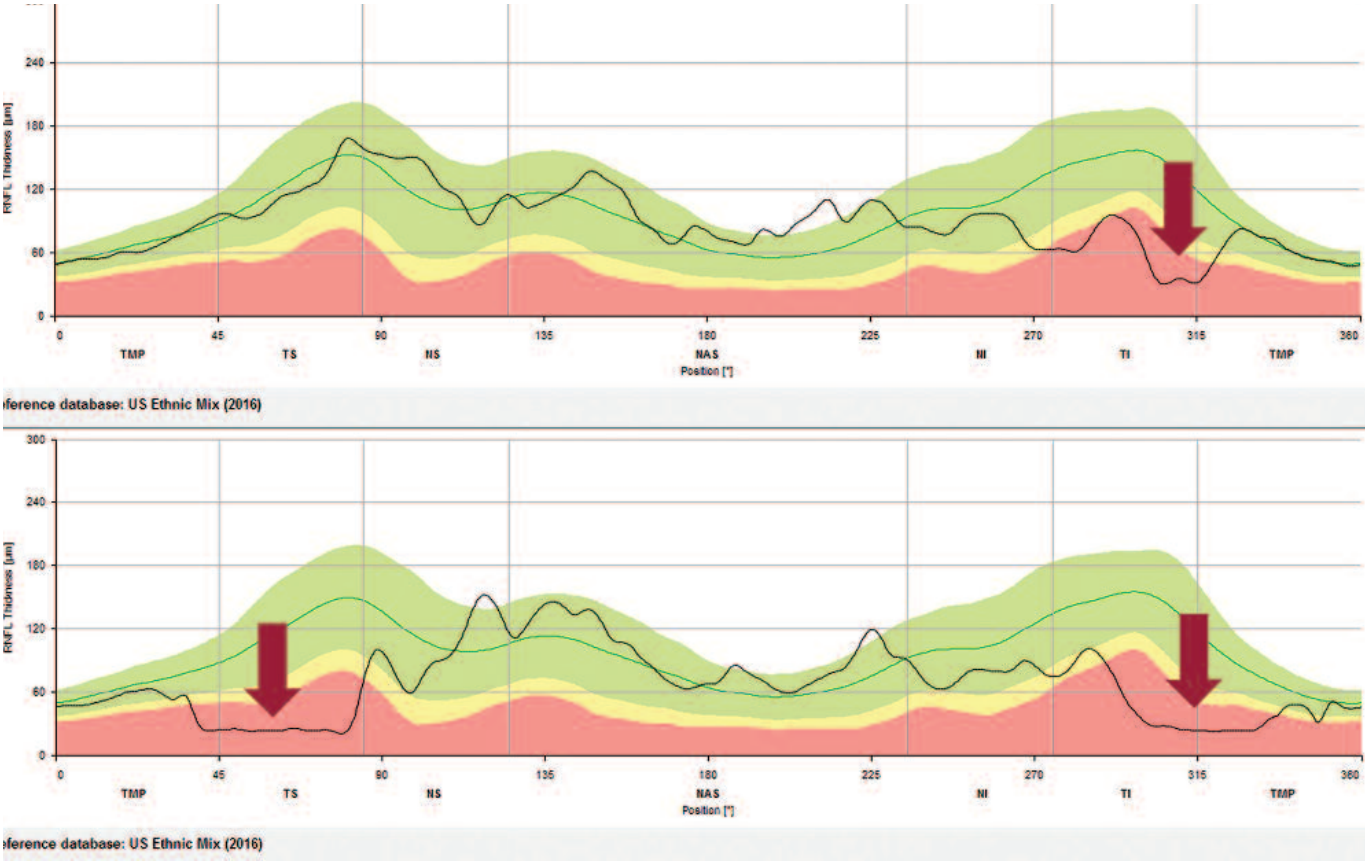


Figure 6. RNFL thickness profile (right eye above, left eye below)

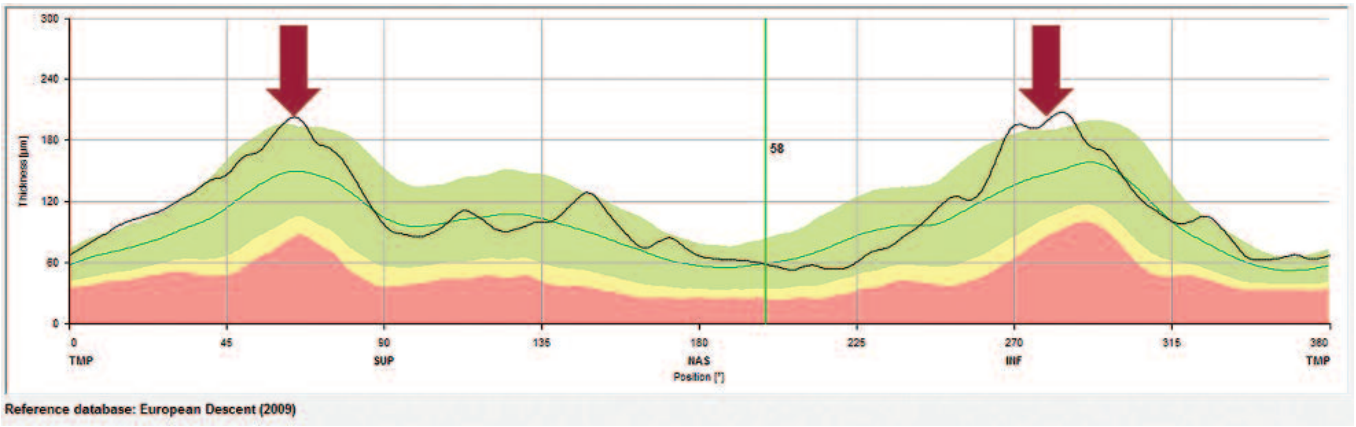
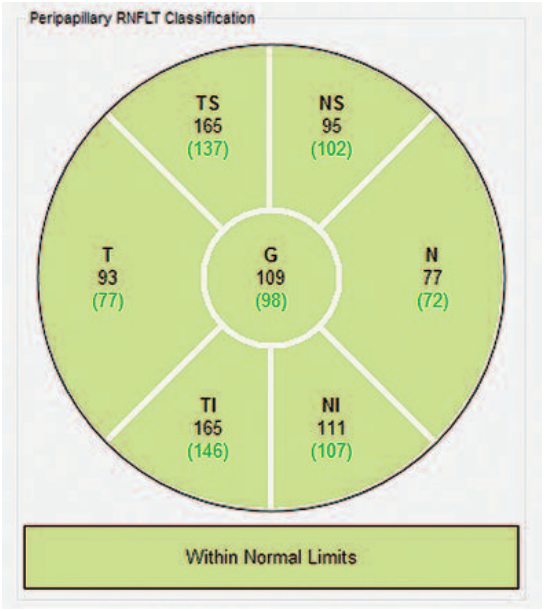


Figure 7 (above and below) RNFL thickness profile of a healthy eye



It's useful not just in hospital eye clinics but community optometric practice where stable glaucoma patients are increasingly being managed, or where further investigation is needed.

is seen in less than five per cent of the normal population and implies glaucoma.

The average thickness of the RNFL is calculated for each sector of the eye and can be displayed in a different kind of classification chart (figure 5) and thickness profile (figure 6). Again the red areas indicate measures outside normal limits.

In a healthy eye, the thickness profile shows as a "double hump" configuration, as in with two humps is indicated by the red arrows in figure 7. But in a glaucomatous eye, there is significant temporal inferior thinning in the right eye (figures 5 and 6 – red arrows).

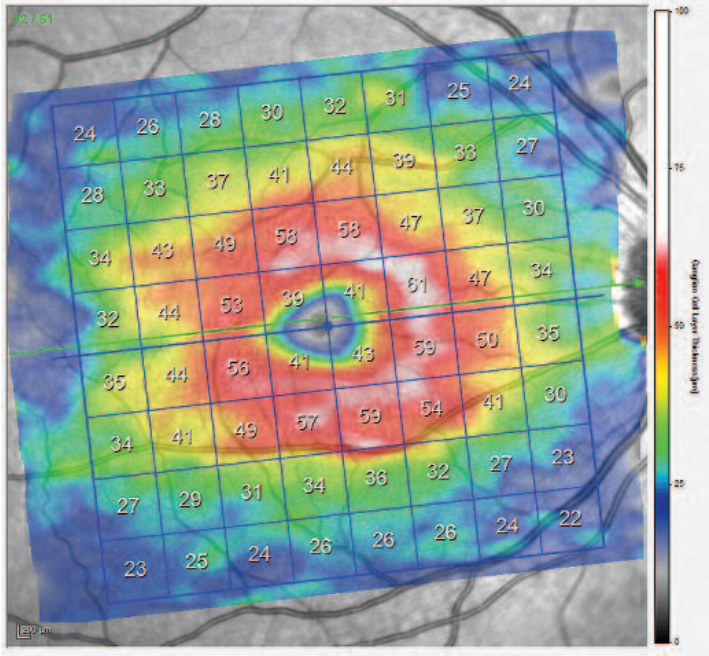


Figure 8. GCL thickness map of a healthy eye

Ganglion Cell Layer thickness assessment

The Ganglion Cell Layer (GCL) is located near the inner surface of the retina and is made up of retinal ganglion cells. Collectively, these cells transmit visual information from the retina to the brain along long axons that form part of the optic nerve. In glaucoma, the death of these retinal ganglion cells leads to optic nerve degeneration and ultimately to vision loss.

In a healthy eye, the GCL thickness is seen as a ring or doughnut pattern surrounding the fovea, which is where the GCL is thickest (figure 8 – red area).

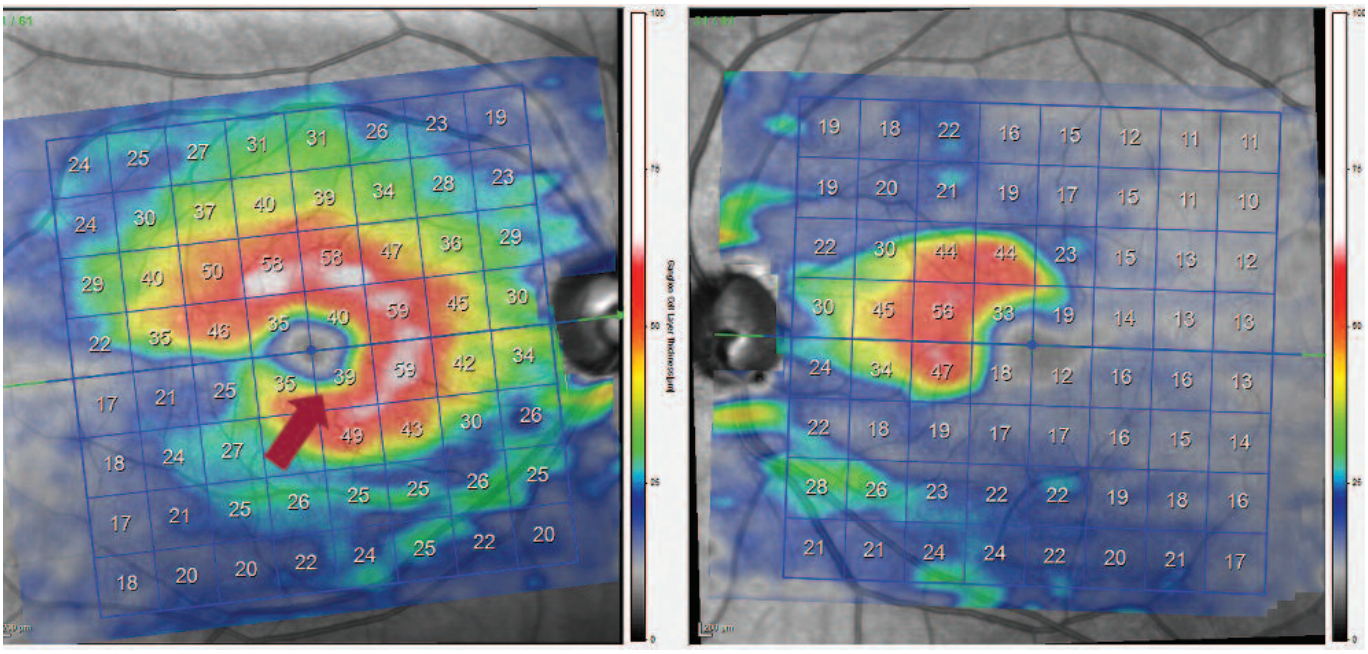


Figure 9. GCL thickness maps of a right and left glaucomatous eye

Ganglion cell damage can lead to a "snail shell" or "Pac-Man" pattern of atrophy (figure 9 – red arrow) and in this glaucoma patient, the GCL analysis shows early change in the right eye and more advanced change in the left eye (figure 9).

Progression Analysis

Progression analysis simply means mapping change over time. Glaucoma is a progressive disease and because OCT produces accurate measurements of change it is a vital step in monitoring treatment efficacy and helps identify rapid progressors.

It's useful not just in hospital eye clinics but community optometric practice where stable glaucoma patients are increasingly being managed, or where further investigation is needed.

But there is just one word of caution: some professionals have concerns about the routine use of OCT in primary care. They query why, in a routine eye health check you should need to measure retinal nerve fibre layer for example, if everything else is normal? The existing NHS-funded eye health check is usually sufficient to identify glaucoma suspects, and whilst OCT may have some value in detecting other eye conditions, its primary value to glaucoma patients is in monitoring progression.

Its role in identifying glaucoma is unproven, and some say there is a danger of people being sold a test they do not need.



Image courtesy of Heidelberg Engineering

Spectralis

Many thanks to **Heidelberg** for the images used here, which were taken by their SPECTRALIS with OCT machine with Glaucoma Module Premium Edition. Case study credit: Donald Hood, PhD and Robert Ritch, MD.

research

The IGA announces our biggest ever research awards for 2020!

Thanks to the generosity of our supporters we are absolutely delighted to bring you news of our highest ever level of annual research funding for the coming year.

£100,000 Ophthalmology research funding

This grant is awarded in the field of ophthalmology, and we are grateful to colleagues at the Royal College of Ophthalmologists for helping us to promote and judge this award.

Applications open on 1 October and close on 1 February 2020

The £100,000 2019 research grant went to Dr Victor Hu for his work on detecting glaucoma using a combination of low-cost, portable and easy to perform tests, and you can read our interview with Dr Hu on page 26.

£100,000 New PhD studentship award

This is a first for the IGA, and we are delighted to offer an award of £100,000 over three years to fund a PhD researching any aspect of glaucoma. The award is designed to encourage new and highly motivated graduates to take up a career in ophthalmic and vision research, and will be awarded on a fully competitive and peer reviewed basis.

The details of this new award are being finalised and we will bring you more news in our next edition.

£60,000 UK & Eire Glaucoma Society award

This award is primarily aimed at ophthalmologists, and is funded by £50,000 from the IGA and £10,000 from surplus funds generated by the annual UKEGS conference.

Applications are open now and close on 18 October 2019. The result will be announced at the UKEGS conference in Glasgow at the end of November.

£50,000 Allied healthcare award

This new award is open to any healthcare professional working in the field of glaucoma diagnosis, treatment or care. In the past the IGA has funded nursing and

optometry research grants; this new award replaces those funding streams, and is open to a wider group of professionals who haven't had the opportunity to apply until now – such as orthoptists and pharmacists.

Applications open on 1 October and close on 1 February 2020.

£100,000 for research into the development of digital support services for people living with glaucoma

This is another new departure for the IGA and we are very excited that this award will enable us to work with skilled researchers to develop and test new ways of supporting glaucoma patients, using digital technology.

Our **CEO Karen Osborn** says "This is a really exciting time. We've never designed a research brief before, but happily we'll be able to draw on the skills and knowledge of a host of professionals to help design the project and award the funding. We know that we need to start harnessing technology to deliver support services. The number of people with glaucoma is rising and that's going to continue for the foreseeable future, so we need to find ways to reach larger numbers of people, and to do that quickly and effectively, no matter where they live. This research will help us do that; it's safeguarding support for future generations."

In partnership with Fight for Sight, £15,000 small grants programme

We're delighted to be co-funding this small grant with Fight for Sight for the third year running. This small grants programme offers competitive funding to clinical or research scientists to conduct stand-alone projects for up to 12 months. The grants support small feasibility studies and facilitate the generation of preliminary data.

Applications are open now and the next deadline is 31 December 2019.

These research grants were made possible by the generosity of donors who left us gifts in their Wills and those who kindly gave to IGA appeals. We are tremendously grateful to them.

research

Detecting glaucoma using a combination of low-cost, portable and easy to perform tests.

The 2019 IGA Ophthalmology Research Grant of £99,960 was recently awarded to **Dr Victor Hu.** We met him at his office in the London School of Hygiene and Tropical Medicine (LSHTM) where he works two days a week, spending the other three as consultant ophthalmologist at Leighton Hospital in Cheshire. By happy chance we also met up with Dr Hu's collaborator **Dr Pete Jones**, Post-doctoral Research Fellow at the Crabb Lab at City, University of London.



Dr Victor Hu with our Fundraising Manager Jenny McCarthy

Dr Hu's team have a clear long-term goal: to develop a single device that is capable of performing all of the clinical tests, analysing the data, and producing a measure for the likelihood of glaucoma. Such a device would have the potential to aid glaucoma diagnosis and reduce the number of people presenting with advanced disease. The project should help determine whether such tests are feasible and accurate in a low-income setting and could in time provide better methods of glaucoma detection in Sub-Saharan Africa, a region with high glaucoma prevalence and a lack of conventional diagnostic equipment.

The global prevalence of glaucoma for the population aged 40-80 is estimated to be 3.5 per cent with over 60 million people affected. In the UK around two per cent of people over 40 are affected, but in low-income areas prevalence appears to be much higher and it is a far more common cause of blindness. Recent population-based surveys from Sub-Saharan Africa found a prevalence of four – eight per cent in those aged over 40, and a high proportion of severe vision loss in both eyes.

Dr Hu's team will test the feasibility and reliability of three low-cost tests in different field conditions - in the UK

and Tanzania - and use the results to develop an optimised algorithm for detecting glaucoma:

- **Optic disc photographs - using a Remedio hand-held fundus camera (see glossary) with a smartphone attached**

- **Eyecatcher visual fields - the Eyecatcher performs buttonless visual field testing by combining an ordinary table or laptop computer with an inexpensive eye-tracking device. The aim is to provide a cheaper and more intuitive test. As discussed in IGA News Spring 2019, the IGA is currently funding final stage trials of using the Eyecatcher in home monitoring of visual fields**

- **Contrast sensitivity - performed using a mobile phone**

As most IGA members will know, visual field examinations are a central part of diagnosing and monitoring glaucoma. The gold standard test uses the large and not-at-all-portable Humphrey Field Analyser (HFA), which costs around £20,000 - 25,000. But as Dr Hu told us "It also needs to be maintained, so the service agreement would often cost a lot, and in a place like Tanzania getting somebody to come out to service the machine or fix it might take months. And then once you have it of course you need a trained technician to run it. It's an automated test but there are personnel costs involved too."

The Kilimanjaro Christian Medical Centre (KCMC) in Moshi, Tanzania is one of the study sites. "KCMC is unusual for that region in that it does have a functioning Humphrey visual field machine but I don't think there are many others, certainly not in government-run services."

Dr Hu chose the KCMC as one of the trial sites as he did his PhD in Tanzania between 2008 and 2011. "That was on trachoma, caused by chlamydial infection in children. It's spread by close contact; they get scarring of the eyelids and eventually as adults they get in-turned eyelids, and it's quite a common cause of blindness in that part of the world. I know the hospital well so for me it's a practical and useful place to do research."
The other test site is the Leighton Hospital in Cheshire, where Dr Hu is a consultant ophthalmologist.

We asked how the experience of being diagnosed and treated might differ in Tanzania, compared to the UK. "Patients tend to present a lot later in Africa - only when they've noticed a problem - so they often



Sia Mbesi, who will work as research assistant for the next two years of the study, seen here in the eye clinic.

have either end-stage disease or a significant visual field defect. By contrast, in the UK a lot of patients get referred by the optometrist: they might have borderline high pressures or they might not have done the visual field test properly, so a lot of those will be false negatives or have very early disease. So the spectrum of disease is very different in Tanzania."

Dr Jones added "We looked at all the data that they've been collecting in Moshi and the striking thing is there's huge amounts of severe sight loss in relatively young people: working age people, and even children too. These are often people who are supporting entire family networks and are going to be living with their vision loss for 40-50 years. That's really scary, and also unnecessary when you think that we have the means to detect glaucoma far earlier. The current levels of late presentation are not surprising, but they are shocking."

Around 400 study participants will be recruited over the two sites, including a range from advanced glaucoma to healthy eyes. The three tests will be performed in addition to patient's usual tests. Dr Hu explained the process: "The patient will come in for their normal glaucoma clinic and they'll be approached while they're waiting for their appointment. If they're happy, they'll be recruited

to the trial, consent will be taken and then they'll be tested straight away. They'll have the Eyecatcher visual fields done first in a side room where it's a bit quieter. Contrast sensitivity will then be measured, which again is a very quick electronic test, maybe a couple of minutes, and then the fundus photograph. Ideally we'll ask the patient to repeat each test because we want to get an idea of comparability, but all of the tests are very quick so we're hoping patients won't mind doing that. They're all completely non-invasive tests."
So how will the researchers know if the tests work effectively?...

These are often people who are supporting entire family networks and are going to be living with their vision loss for 40-50 years

"The Eyecatcher visual field test is currently being validated in clinical and laboratory trials. The second test is digital photography of the optic disc and this study will use expert graders to grade the optic discs for glaucomatous damage. But the team anticipate that in the future machine learning will help to automate this process. Artificial intelligence-based automated software for detecting diabetic retinopathy from retinal images has reached an advanced stage, and similar work has begun on glaucoma detection."

.... and how will they develop an algorithm for detecting glaucoma?
"It's quite straightforward really. You'll have a group of people whom expert clinician says have glaucoma, and you've got a group who the clinician decides are healthy ('false positive referrals'). You then train the algorithm to replicate the clinician's decisions by statistically combining all the available data. In doing so, the computer might discover that it's better to base its decisions more on some information (for example the fundus image and the visual field test) than on others (for example contrast sensitivity measurement). The algorithm might even determine that some tests aren't required at all, in which case we could dispense with them in future. Whatever the outcome though, you'll have an objective way to synthesise all the clinical data into an instantaneous decision: in this case, whether or not to flag the patient as 'high risk'."

The trial is due to start in September and will run for two and a half years.
"I'm in the process of getting though

The new tests obviously have the potential to revolutionise glaucoma detection in low-income regions and save the sight of many people. But one day, could they replace the tests used in our own eye clinics?

all the ethical permissions which is quite complex. In the UK we've learnt that we need permission from the Medical Healthcare Regulations Authority. This was quite a surprise because our previous studies using these technologies didn't need to go through MHRA. But now the regulator's opinion is that because there's some software that interacts with the patient, all our tests need to be treated as 'medical devices' and so need to be regulated accordingly.

So that's another quite time-consuming and expensive step unfortunately. In Tanzania we also need permission from KCMC hospital and from the National Institute of Medical Research. So it's quite complex and time consuming. Then I aim to start recruiting in January, for one year in Crewe and for 18 months to two years in Tanzania."

The new tests obviously have the potential to revolutionise glaucoma detection in low-income regions and save the sight of many people. But one day, could they replace the tests used in our own eye clinics?

"Whether they could work in a clinic to replace other tests – maybe, but that certainly isn't our immediate aim. There's a huge number of people that never set foot in a clinic.

"Many adults don't go for regular eye tests. And some vulnerable groups simply can't attend traditional clinics, such as stroke patients and children with special needs. Similarly, you've got increasing numbers of cases where very elderly people have a spectrum of disorders, and it's often not suitable for them to attend regular glaucoma clinics.

"I think at optometry level it could definitely come in and I could see it working in primary care for GPs with an interest in glaucoma, and you're going to save the taxpayer money by having fewer false referrals. If it works in the rural outskirts of Moshi, then we could also give it to people to take home. Then you can be testing more often, getting more accurate data, fewer trips into the hospital; there's lots of different benefits that come from the same technology."

Dr Hu thinks that eventually all three tests could be carried out by one single piece of portable equipment.

Dr Jones adds "If there were the willpower and the money you could get all those three running on a mobile phone today. It is possible, and I very much hope it will happen. It's just about getting the right people together in the same room, with the money, the resources and the will to make a difference."

Glossary

Fundus photography involves photographing the back of the eye, also known as the fundus. The camera consists of a microscope attached to a flash enabled camera and is used to take pictures of the optic disc, central and peripheral retina, and macula.



Image courtesy of Remedio

Remedio hand-held fundus camera

A request for your help...
From the University of Nottingham Glaucoma & Exercise Research Group

One question often asked by people living with glaucoma is "Are there any lifestyle changes I can make to help my glaucoma?"

For some conditions evidence shows that exercise provides substantial benefits, particularly cardiovascular and mental health conditions. However, the potential gains of exercise specifically to the health of the eye are not as well understood. Regular exercise like cycling has been shown to produce long-lasting reductions in eye pressure[1] and a particular type of exercise, high intensity interval training (HIIT), has recently been shown to improve the eye's blood vessel structure[2]. However, we do not currently know the implications of this research for people with glaucoma.

At the University of Nottingham we have formed a collaborative research group to understand how HIIT may be able to moderate the course of glaucoma. HIIT has been shown to produce similar improvements in physical and metabolic fitness to traditional aerobic exercise training, but in much shorter periods of time.



Mark Burton

We believe it may be able to help with glaucoma control by lowering eye pressure and improving the eye's blood vessel structure. This could ultimately lead to reduced dependence on eye drops and better preservation of vision.

We are planning a study to investigate the effects of HIIT in a small group of Nottingham-based patients, and if our initial research shows a potential benefit, we propose expanding the project to include a wider group of people living with glaucoma.

To determine the acceptability of this potential future treatment we would be very grateful if glaucoma or ocular hypertension patients would share their thoughts about this research by completing our online survey.

(The survey also includes additional information on the design of the study).

www.surveymonkey.co.uk/r/XK59YKR

University of Nottingham
UK | CHINA | MALAYSIA

For further information please contact:
Dr Mark Burton at mark.burton1@nottingham.ac.uk

Thank you for your help

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[1] PASSO, M. S., GOLDBERG, et al 1991. Exercise training reduces intraocular-pressure among subjects suspected of having glaucoma. Archives of Ophthalmology, 109, 1096-1098.

QURESHI, I. A. 1996. Effects of exercise on intraocular pressure in physically fit subjects. *Clinical and Experimental Pharmacology and Physiology,* 23, 648-652.

VERA, J., GARCIA-RAMOS, A., et al 2018. Effect of a Short-term Cycle Ergometer Sprint Training Against Heavy and Light Resistances on Intraocular Pressure Responses. *Journal of Glaucoma,* 27, 315-321.

[2] SCHMITZ, B., NELIS, P., et al 2018. Effects of high-intensity interval training on optic nerve head and macular perfusion using optical coherence tomography angiography in healthy adults. *Atherosclerosis,* 274, 8-15.

One of our most valuable support services is one that involves you, IGA members and supporters...

The Buddy Service provides peer support by phone for people living with glaucoma. **Buddies** are people who have been through surgical and laser procedures and then share their experiences and thoughts with people who are facing those same treatments. Buddies can provide a truthful account of how it was for them: what they went through, what they wished they'd known or asked beforehand, and what helped or hindered them.



Marilyn and George

We know that everyone is different and a Buddy's experience won't necessarily mirror your own, but it can be reassuring to talk things through with someone who's been in your shoes.

We were delighted to receive this email from Marilyn, whose husband George recently faced a trabeculectomy, and was matched with his **Buddy, Alison** by our **Sightline** team.

Just wanted to say a HUGE thank you for arranging the 'Buddy' call for George. He said "don't know what I'm going to say" and nearly hour and a quarter later he and Alison said 'goodbye' to each other!

Her chat was a BIG help to George as the previous day he'd had a major wobble and more or less decided he wasn't going to go ahead seeing his sight had deteriorated so much. I'm a very positive, pro-active person, so you can imagine my feelings.

He needed to get his head back into a good place, and Alison, bless her did just that. It's knowing someone who 'sees' exactly as you do and understands what you are going through that makes such a difference, this is an invaluable support to fellow sufferers.

Alison, having been through it all herself, is an amazing asset, with all her undertakings on behalf of glaucoma sufferers.

If George has any other 'blips' then Alison said she will happily talk him through. Obviously, we all need other folks' help and sometimes as spouses we are too close, so it helps tremendously to speak freely to a comparative stranger.

So, many, many thanks to the **International Glaucoma Association** to both you and Alison and we'll keep in touch and let you know how George progresses.

Of course, once this operation is done, and we get back to normal, in a few months' time, we would very much like to offer to arrange a fundraising event here in Kendal, it won't raise masses but like with all charities, every single penny counts!

Marilyn

We'd like to thank Marilyn and George for letting us share their story.



buddy service

If you would like a Buddy or would like to be a Buddy, please call our Sightline team on 01233 64 81 70. You don't need to be a member to use the service, so if you know of anyone who might benefit from a little extra support, please encourage them to get in touch.

My life as a clinical volunteer

Ever wondered how it feels to be one of the volunteers for eye health professionals sitting practical exams? Then read on...

My name is Carol Gould and I live in Cardiff. I was diagnosed with glaucoma nine years ago when I was 58. I have had trabeculectomy in one eye and take two lots of drops in the other. Six years ago I became a volunteer for **WOPEC,** the Wales Optometry Postgraduate Education Centre at the School of Optometry and Vision Sciences, Cardiff University. I volunteer as a patient for postgraduate optometrists who are studying for higher qualifications in glaucoma.

The sessions I sit for are for clinical assessments of the optic nerve, the front of the eye and taking the intraocular pressure. I think my having had a trabeculectomy was interesting as in some sessions the optometrists were asked to look at all the anterior (front) of the eye.

A lot of them didn't look under my top lid. If they had they would have seen a large drainage bleb which is typical after a trabeculectomy. I do sometimes want to drop hints to look under the lid, but refrain – it's not always easy!



Carol Gould

I think my optic nerves are quite interesting as the left and right are very different - one being a lot worse than the other! They have to measure the cup to disc ratio which is different in the two eyes. In some clinical exam sessions I'm questioned on my eye disease and clinical history. I particularly like these as I like talking to the optometrists, who come from all over the world as well as the UK.

Most of them are nervous but some seem to show it more than others. I try to put them at their ease by

asking questions about their family and their workplace. But in the final examinations I don't say much and let them concentrate on the exam. They are all very grateful and thank me for being a volunteer. I wish them all good luck, but never know which ones pass the exams unfortunately.

I have also spoken to a group of optometrists about my experiences of being diagnosed with glaucoma to raise awareness and understanding of how to break the news to patients and how to offer them support to cope with their diagnosis.

These courses and examinations help optometrists to take on extended roles, to better refer patients and give the best and most up to date information to the hospitals on each patient's glaucoma.

I think my having had a trabeculectomy was interesting as in some sessions the optometrists were asked to look at all the anterior (front) of the eye.

It also allows community optometrists to manage and monitor more patients with ocular hypertension, glaucoma and suspect glaucoma.

There are quite a few volunteers at WOPEC. We all volunteer a few times a year and are all committed to help in any way we can.

Glaucoma is a terrible condition that can steal your sight before you notice that it is damaged.

Thankfully my surgery has halted my central vision loss in one eye, and the drops are keeping my other eye stable. I am very impressed that trained optometrists want to acquire more specialist knowledge about glaucoma, and will always continue to help WOPEC with the courses they run.

WOPEC pays a small fee every time I volunteer, and I donate mine to the IGA, of which I am a member.

To become an IGA member contact us on 01233 64 81 64 or email us at info@iga.org.uk

#glaucomasters take over our social media

National Eye Health Week runs from 23-29 September and our theme for this year is "Live Well with Glaucoma."

We wanted to share some positive stories of people with glaucoma. So far, so typical. But this time, it's via a social media takeover.

For those of you who don't know your Facebook Live from your Instagram Stories (i.e., most of the staff in the IGA office), this is where we hand over the controls of our social media accounts to some of our supporters, and let them tell their stories.

Why, I hear you ask? Because, people feel empowered when they tell their stories, our wider supporters love to hear more about others with the condition, and we get to increase our engagement and awareness by hijacking our supporters' followers. Win, win, win.

One of the stars for **National Eye Health Week is Cairen Bedward, age 33, from Birmingham.** Here, he tells his story to **Joanna Bradley, Head of Patient Support Services.**

Joanna Bradley (JB):
Hello Cairen, thanks for speaking to us today. So you've got several eye conditions. Can you explain a little bit about them?

Cairen Bedward (CB):
I have uveitis, which I had from the age of five, I was diagnosed with cataracts at the age of 12, and then I got glaucoma at the age of 19. The glaucoma has got progressively worse and I've now lost most of my sight to the condition, despite surgery.

I had two major surgeries, one on each eye, where I had a tube put in each eye. That allows the pressure to drain with help rather than my eyes doing it by themselves. I had the tubes cleaned last year, because my pressures had increased significantly. It was successful, because my pressures are reasonably low considering how high they were before. I also take five eye drops and a set of tablets. I've taken eye drops for so many years, taking them is second nature to me.

JB: Why would you like to share your story with the IGA?

CB: When I go to the hospital, I notice a lot of younger people being diagnosed with glaucoma, and the

younger they are, the more upset they are. I know glaucoma's not something you would choose or can help, but I believe you can still be happy with it. It doesn't stop you from doing anything that you want. There's got to be a way around it, with the right family, friends or support network to help.

JB: That sounds so positive. And what are your experiences of vision loss? When did it start?

CB: My vision was fine at school, I used to wear glasses and contacts and my vision was OK. However, when I was in college, soon after I was diagnosed with glaucoma, I just remember one morning I couldn't see properly even after I put my lenses in. I tried cleaning them again but the same thing happened. So I just remember calling my Mum and saying, "Mum, Mum, Mum, there's something happening, I can't see through my contact lenses." And then as a typical mum does, she said, "well maybe you haven't cleaned it properly." But I really couldn't see.

And I remember getting rushed to hospital, and it felt like they operated that same day. That's how it felt, everything just happened straight away. I think that was the first tube surgery - the pressures were over 40mmHg. And I was just panicking because it felt like I had a balloon in my head, everything just felt really hard. I didn't know what to expect, because nobody that I know suffers with vicious glaucoma, so I was just like, "what do I do, who do I talk to? What happens next?" And I was just really panicking.

JB: Scary. Did the surgery help?

CB: The tube surgery helped massively. I couldn't thank my professor enough, because I believe he's the one that saved my vision at that time. When I was given my diagnosis at the age of 19, I was given 10 years of sight. I'm 33 and I still have some sight, which I'm very grateful for.

JB: It sounds like you've had quite good experiences of eye care services?

CB: My Mum managed everything while I was growing up but as I've got older, I've started to notice issues. For example, I've gone for periods of up to a week without eye drops due to supply issues, even though I always get my prescriptions a week before I need the drops. I've had GPs send

over the wrong prescription when I've asked for a repeat prescription. I also had issues with appointments, where I had almost a year without an appointment. Despite repeatedly chasing the hospital, they tried to take me off the system because they said I'd missed three appointments, but I hadn't received any letters about any of them! This went on for about a year.

JB: And you're making a film documentary. How did that come about and what do you want to achieve?

CB: I train in a gym, which is like a family to me. They help me to do anything I want to do, give me support and give me ideas. So I decided to do a documentary to tell people about myself and that yes, you can do something if you really want to do it, even if someone tells you that you can't. I'm not just saying this to people with glaucoma, it could be any condition. If you want to do athletics, or boxing, you still can, your disease or disability might just slow you down slightly. No-one can tell you otherwise.

A lot of people don't do things because they're afraid of what people might think. When I first started going to the gym, I had the same perspective. If someone's going to laugh at you, they'll laugh regardless, even if you've got 20:20 vision. Just because I've got an eye condition, or anything else wrong with me, doesn't mean that I can't do something I love to do.

I want to be a spokesperson for glaucoma. I have a passion for doing what I want to do, with nobody telling me no, and I want to help other people feel the same.

JB: Agreed! And did I hear you did a skydive?!

CB: Yes! I've always wanted to do a skydive. I don't know what kept putting me off, but I was adamant that I've got to do a skydive. And I wanted to make sure I did it before I totally lost my eyesight, because I still wanted to see something. So I did it in July, and it was the most amazing thing I've seen. It was a very eye-opening experience.

Now I'd definitely say, if you want to do something, do it now, because you don't know what tomorrow has in store. I'm annoyed with myself that I put it off for so long, because obviously I would have seen a lot more if I'd have done it before. It made me feel like we don't have any problems. I know it's a bit

far-fetched, but it made me feel like there's no problem in the world that's too big to overcome.

JB: And what's next? Do you have plans for future projects?

CB: Yes. I want to do "life in the shoes of a visually impaired person." I want a videographer to follow me around for 24 hours, just to show people what people with glaucoma have to go through on a day-to-day basis, for example the challenges of getting on the right public transport. I want to show to people without visual impairments what this is like.

JB: So what do you want people to learn from you and your experience? If they remember only one thing, what should it be?

CB: Be passionate. I've overcome several things in my life, such as depression, with a strong support network. I see children and teenagers in the hospitals with glaucoma, and I want to show them that you can still be passionate, you can still hold your head up high because it's just a minor hurdle to overcome.

Acronym of the Month



The terms OD and OS are traditionally used on spectacle and contact lens prescriptions and in ophthalmological case notes. They appear like this in the notes – with the right eye to the left - as if they were your own eyes looking out of the page at you.

awareness

#glaucomasters

By the time you receive this, we'll have completed our social media takeover campaign. At the time of writing this in August, we hope to have four IGA supporters (we're calling them #glaucomasters) taking over our social media for one day each and sharing their stories. All have had glaucoma since childhood, and each has a different reason for wanting to share their story.

You may remember **Laura Tambin**, who featured in our summer appeal to help children and families affected by glaucoma. She's based in Newcastle and is really keen toincrease support for young people with the condition. She and our Development Manager in the North East, Hannah Morrow, are currently scoping demand for services specifically aimed at children and their families.

Alex Hanson lives in Hull and recently ran the London Marathon for RNIB, including hosting a charity ball which raised a whopping £3,500! She was diagnosed with juvenile open angle glaucoma in her teens.

Georgie Morrell lives in London and was diagnosed with juvenile arthritis aged three, which led to uveitis and glaucoma. She's now a comedian and uses her sight problems as the inspiration for her comedy performances. Her current project, **"Eyecon"** with the Theatre Wolsey explores disability and celebrity.

> ***We're really excited about this campaign – we've never done anything like this and it will be lovely to post more content online generated by our supporters.***
>
> ***This is all part of our move towards increased digital engagement. It's a step into the unknown, but we hope we can reach new audiences who want to learn more about glaucoma and living well with the condition.***

Thanks to our **#glaucomasters** for their support in this campaign.



Keith Barton (left), and colleagues

Past IGA Chair raises over £70,000!

Keith Barton, Consultant Ophthalmologist and Glaucoma Specialist at Moorfields Eye Hospital, Honorary Reader at the UCL Institute of Ophthalmology and Editor-in-Chief of the British Journal of Ophthalmology was an IGA trustee for 12 years and chaired the Board from 2012 to 2017.

Over the years Keith has undertaken several personal challenges to raise vital funds for the IGA and to support people with glaucoma. He has walked and cycled 100s, if not 1,000s, of miles, taken part in three 15-mile night time walks in London and recently completed the London to Paris 24-hour bike ride for the third year running. From these and other endeavours he has raised a fantastic **£72,000.** What an amazing achievement!

Thank you Keith!

Current IGA Chair Professor Philip Bloom said "We're hugely indebted to Keith – and rather in awe of him! Sums like this make a very real difference to the work the charity's able to do."

supporter news

Thank you - Moorfields International Glaucoma Symposium 2019 delegates

Earlier this year we were delighted to receive a **£2,500** donation from delegates who attended the **Moorfields International Glaucoma Symposium (MIGS) 2019,** which has been sponsored by **Laboratoires Théa** for five consecutive years.

The **MIGS** conference programme is developed by a group of glaucoma specialists from Moorfields Eye Hospital – including our own Keith Barton – and executed by an array of internationally distinguished speakers. It aims to provide an entertaining and sometimes irreverent agenda, as free of commercial bias as possible, where clinicians can discuss the topical issues they face in daily practice.

It is hosted at the **Royal College of Physicians by Vision Medical Events Ltd** and this year, for the first time, the proceeds from delegates booking fees were donated equally to three charities – the **IGA, the Andean Medical Mission and Moorfields Eye Charity.**

We are enormously grateful for their support.

Relay running raises cash!

Huge thanks go to all the members of the **Glaucoma Service Team at the Belfast Health and Social Care Trust.** Team members including **Susanna Beare, Katie Graham, Martin Branney, Jesa Protasio** and **Grainne Robinson** took part in the **Deep RiverRock Belfast City Marathon** in May to raise a magnificent **£928** for the IGA.

The team are pictured here at a coffee morning in April that contributed **£383** towards the total.



Glaucoma Service Sister, **Sarah Henderson,** said "We were really pleased to take part. Our Staff Relay Team ran for miles to raise money for the IGA because we care about sight loss. Thank you to everyone who gave and supported us but especially to each and every team member. Well done and congratulations."

Welcome to Rachel - our new Comms Manager

I am delighted to be joining the IGA in the capacity of Communications and Engagement Manager. A little about me, I am originally from Kent and only moved away for a few years in 2012 to Lancashire to study at Lancaster University. Since then I have worked in communications roles for several organisations in the charity sector. I am grateful to have worked towards some fantastic causes in this time from education to specialist support services for survivors of human trafficking. I have always been passionate about healthcare so when this position opened up at the IGA, I couldn't believe my luck and I knew I had to go for it.

In a nutshell, my role involves working with the communications team on implementing communication strategies and campaigns to increase awareness of glaucoma and meet the needs of people living with the disease and those who support them.

On a practical level, this includes overseeing the development and distribution of patient information publications, educational films and audio, website content, social media presence and, something I am very



Rachel Hughes

enthusiastic about, this magazine! I am excited to be joining the fantastic team at the IGA at a time of digital change and growth.

Discussions are taking place around how to maximise the impact of our digital communication channels including the website and social media. Throughout my career, digital transformation projects have been the foremost focus of my work. It is something I enjoy and I'm passionate about using technology to improve the accessibility of information. Having said that, I also recognise the importance and value of print media so we will be working hard to ensure

supporter news

that our digital and print communications do not compete against each other, but rather work together to reach as wide an audience as possible.

My priority will be ensuring our work reflects the needs of the people we support. So I am thrilled that within the first few weeks of starting with the organisation I will be joining the team at the Patient Conference in Bristol. It will be a great opportunity to meet some of you in person and gain valuable insights into your priorities.

So, until the next edition of IGA News, that's all from me. I'll be sure to let you know how the first few months go. I can't wait to get to work!

CHRISTMAS 2019

Grab a bargain - £3.50 for 3 packs of 10 cards

The message inside all cards reads: 'With Best Wishes for Christmas and the New Year'

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Mistletoe Christmas
Ref. 671 14 x 14cm



Happy Christmas inside

Polar Bear Fun
Ref. 665 15 x 15cm



Blank inside

Winter's Path
Ref. 667 15 x 15cm



Blank inside

support groups

Would you like to receive information about upcoming local patient support groups directly to your inbox?

If yes, we need your email address and your postcode. If we don't already have this, please call our membership line on **01233 64 81 71** to update our records.

Unfortunately, we will not be able to provide this information via post.

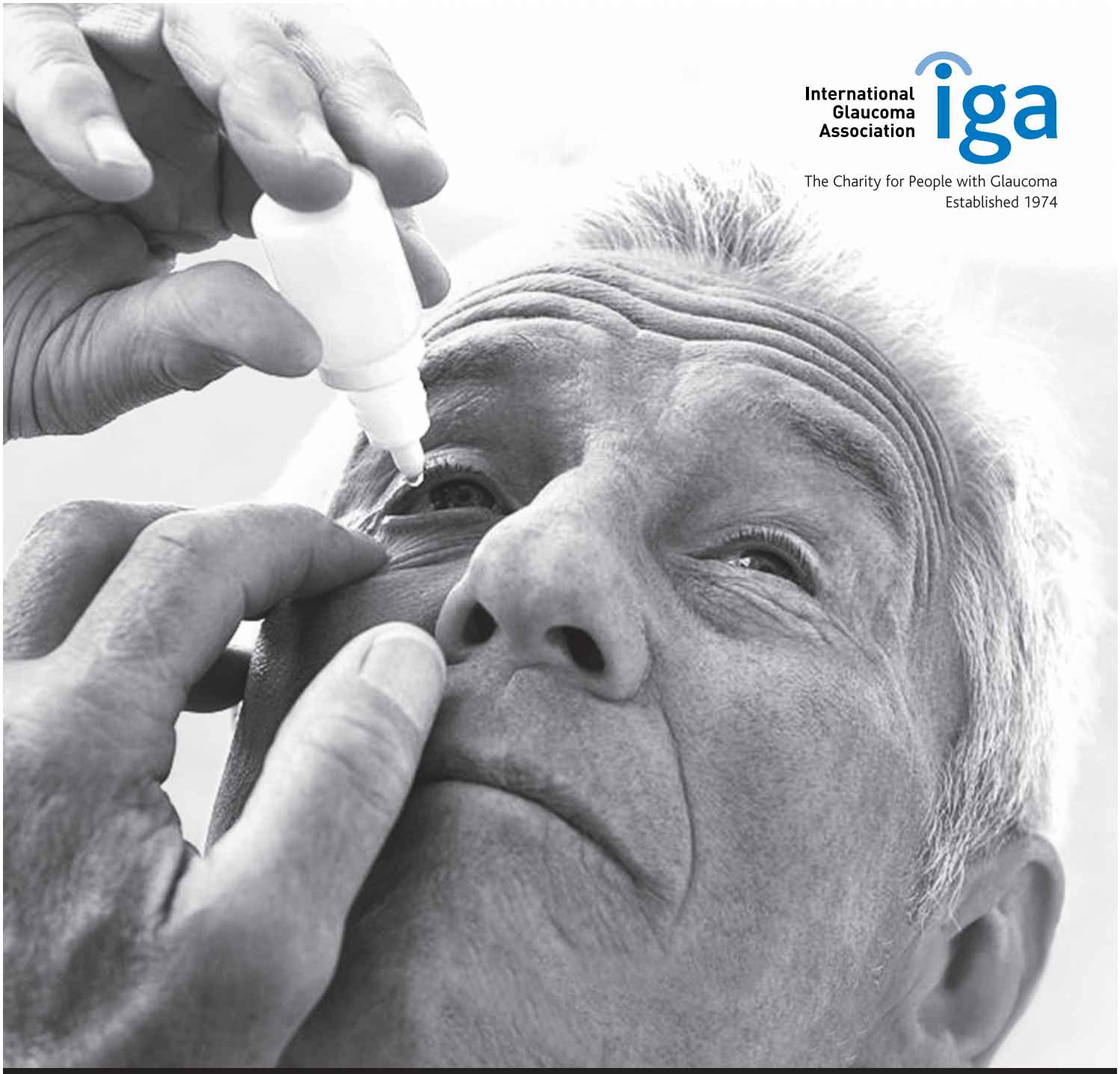
West Midlands	**Solihull Patient Support Group** John Palmer Hall, Union Road, Solihull B91 3DG Contact: **Carole Atkins** Email: **carole.atkins@heartofengland.nhs.uk**	**25 Sept 2019** 1.00-3.00pm
London	**St George's Hospital** Cranmer Terrace, Tooting SW17 Contact: **Subhash Suthar** Email: **s.suthar@iga.org.uk**	**9 Oct 2019**
East Yorkshire	**Hull and East Riding Glaucoma Group** Beech Holme, Beverly Road, Hull HU5 3HS Contact: **Kay Slingsby** Tel: **01482 34 22 97**	**11 Oct 2019** 11.00-1.00pm
West Sussex	**4 Sight Vision** QEII Room, The Shoreham Centre, 2 Pond Road, Shoreham BN43 5WU Tel: **01273 45 43 43** and leave a message	**14 Oct 2019** 11.00-1.00pm
Kent	**Folkestone Hospital** Burlington Hotel, 3 Earls Avenue, Folkestone CT20 2HP Contact: **Lynne Hadley** Tel: **07866 44 25 09** Email: **lynnehadley@nhs.net**	**17 Oct 2019** 2.00-4.45pm

support groups

Buckinghamshire	**Milton Keynes University Hospital** The Academic Centre, Milton Keynes University Hospital, Standing Way, Eaglestone MK6 5LD Email: **www.mkuh.nhs.uk**	**18 Oct 2019** 5.30-8.30pm
Derbyshire	**Cavendish Hospital** Buxton Methodist Church, Main Hall, Chapel Street, Buxton SK17 6HX Contact: **Norma Ayres** Tel: **01298 21 28 00**	**1 Nov 2019** 1.30-3.30pm
West Midlands	**Good Hope Hospital** Ophthalmology Department, Sheldon Unit, Good Hope Hospital, Rectory Road, Sutton Coldfield B75 7RS Contact: **Nicola Bennett** Email: **nicola.bennett@heartofengland.nhs.uk**	**6 Nov 2019** 2.00-4.00pm
West Lancashire	**Southport and West Lancashire Support Group** Royal Clifton Hotel, The Promenade, Southport Contact: **Pam Ladlow** Tel: **01772 81 36 15**	**27 Nov 2019** 2.30pm
Manchester	**Manchester Royal Eye Hospital** Outpatients Clinic B, Manchester Royal Eye Hospital Contact: **Karen or Rachel** Tel: **0161 70 14 819**	**11 Dec 2019** 2.30-4.00pm
East Yorkshire	**Hull and East Riding Glaucoma Group** Beech Holme, Beverley Road, Hull HU5 3HS Contact: **Kay Slingsby** Tel: **01482 34 22 97**	**13 Dec 2019** 11.00-1.00pm

No Patient Support Group in your area?

Talk to your consultant or nurse and ask for one!
Make sure they know the demand is there.
Alternatively, contact us on **info@iga.org.uk** or call **Jo on 01233 64 81 79,**
so we know where to focus our efforts.



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