INTERNATIONAL GLAUCOMA ASSOCIATION

pressure choroid drainage angle optic nerve blind spot primary angle closure canal of schlemm secondary blepharitis HAPPY compliance aids cataract 30TH central vision pigment dispersion eye drops goniotomy ocular hypertension glaucoma ophthalmology eye test tonometry optic cup retina ANNIVERSARY perimetry aqueous humour gonioscopy primary open angle trabecular meshwork psuedoexfoliation lamina cribrosa optic cup retina conjunctiva ciliary body cornea laser pressure canal of schlemm secondary blepharitis compliance aids cataract central vision pigment dispersion eye drops goniotomy ocular hypertension glaucoma ophthalmology eye test tonometry perimetry TO aqueous humour gonioscopy THE primary open angle trabecular meshwork psuedoexfoliation lamina cribrosa optic cup retina conjunctiva open angle trabecular meshwork psuedoexfoliation lamina cribrosa optic cup retina conjunctiva ciliary body cornea laser trabeculoplasty pachymetry iris sclera trabeculectomy acute schlemm secondary blepharitis compliance JANICE KRUSHNER intraocular pressure choroid drainage angle optic nerve blind spot primary angle closure choroid drainage angle optic nerve blind spot primary angle closure canal of schlemm secondary blepharitis compliance aids cataract central vision pigment dispersion eye drops goniotomy ocular hypertension glaucoma ophthalmology eye test tonometry perimetry aqueous humour gonioscopy primary open angle trabecular meshwork LECTURES psuedoexfoliation lamina cribrosa optic cup retina conjunctiva ciliary body cornea
Wishing all our members, friends and supporters a very Happy New Year.

From us all at the International Glaucoma Association.
Janice Krushner Memorial Lecture

**Date:** 8th March 2012  **Time:** 1.30 – 5.00pm

**Annual General Meeting 1.00 - 1.30pm**
All welcome to attend. Only IGA voting Members will be allowed to vote during this session. For more details, please contact us on 01233 64 81 64. Thank you.

**Address:** The Royal College of Pathologists, 2 Carlton House Terrace, London SW1Y 5AF • Tel: 020 7451 6700

**Keynote Speakers**
Richard Wormald, Consultant Ophthalmologist, Head of Epidemiology, Moorfields Eye Hospital

And

Katherine Binstead, Senior Optometrist, Moorfields Eye Hospital

**Venue information:**

**Nearest Underground Stations**

**Piccadilly Station (Piccadilly Line)** Take the exit marked – LOWER REGENT STREET – Walk down Lower Regent Street until you join Waterloo Place, walk to the far end and turn right onto Carlton House Terrace.

**Charing Cross Station (Northern and Bakerloo Lines)** Take the exit marked – THE MALL – go through the subway and come up the stairs, go to the left. Walk along the Mall until you come to Waterloo Place, turn left and walk to the far end and turn right onto Carlton House Terrace.

**Victoria (Circle and District Lines)** Join the Circle or District Line to St James’ Square and then it is a short walk through St James’ Park to the College. You could also walk direct from London Victoria to the College, which would take about 20 minutes.

**Car Parking**
There are parking meters outside run by Westminster council or you can also park at the Westminster car park around the corner (further details including prices can be found at www.westminster.gov.uk/services/transportandstreets/parking/masterpark/trafalgar)

Pre-registrations are not mandatory, but in order to help us organise the event, would you please confirm your attendance by phone on 01233 64 81 64 or by returning this part of the page to the IGA, Woodcote House, 15 Highpoint Business Village, Henwood, Ashford, TN24 8DH.

Name: ____________________________________________________________

Address: __________________________________________________________________________________________

__________________________________________________________________________________________________________________________________________ Post code: ________________

Number of people attending: ___________ Contact No: __________________________

Special requirements: __________________________________________________________________________________________
Directions From St James’s Park Station, St Ermin’s Hill
1. Head south on St Ermin’s Hill toward Broadway
2. Turn left at Broadway 187 ft
3. Turn left to stay on Broadway 217 ft
4. Turn right at Queen Anne’s Gate 0.3 mi
5. Continue onto Marlborough Rd 0.1 mi
6. Slight right at Pall Mall 66 ft
7. Turn right at Pall Mall/A4 0.2 mi
8. Turn right at Carlton Gardens 318 ft
Carlton House Terrace London, UK

The Royal College of Pathologists
2 Carlton House Terrace
London SW1Y 5AF
Tel: 020 7451 6700

MAP NOT TO SCALE
Welcome to the Winter 2011 edition of the IGA News. As the door opens on 2012, it is time for me to reflect on some of the achievements of 2011 and look ahead to the challenges 2012 will bring.

2011 was a busy year for the IGA team and saw many projects flourishing and moving forward. The year started with a key achievement for the team as the production of our patient information leaflets and booklets was accredited with the Information Standard quality mark, a standard set up by the Department of Health recognising the quality of the content and design of literature available to patients. Striving for high quality services, our team, with the participation of many patients (panel of readers) and professionals (authors and reviewers) has confirmed its commitment to ensure the information provided to people at risk of glaucoma, patients and carers is produced carefully with the sole objective in mind of offering the best support.

Our online presence has increased with a successful Facebook page welcoming new ‘fans’ each week (currently 307 as I am writing this article) and a Twitter feed with over 100 followers spreading our messages across the web. In addition, March saw the launch of the new IGA website, offering a new design and structure. Listening to patients’ and professionals’ feedback, our project team worked closely with a web team to improve the site, making it more accessible for visually impaired people, and introducing videos as well as an improved online shop and discussion area. This is a work in progress and all through 2012 you will see the website developing again and again to make sure that we make your visits as enjoyable as possible.

As part of the provision of our services, our constant battle for improved patient education has seen some great successes including the set up of 15 new support groups between January and December 2011, making it a total of 36 groups now in place around the UK (see pages 41-44). We have also been working with many more eye clinics around the UK introducing and implementing the ‘compliance briefcase’, an educational tool which ophthalmic teams can use to discuss the use of eye drops and educate newly diagnosed patients on the importance of treatment concordance to avoid further damage to the optic nerve. This project has been welcomed by healthcare professionals (79 briefcases were placed in 2011) and we will carry on working with them all through 2012 to ensure that all newly diagnosed patients around the country get the same opportunity to understand their condition and treatment and therefore do all they can to protect their sight and quality of life.
An increased focus on research has seen our Research Committee widening the types of grants awarded each year and now opening applications to not only ophthalmologists but ophthalmic nurses and optometrists as well. We hope this will allow us to welcome new projects of all sizes including practical projects on glaucoma awareness and patient education.

2011 also saw the start of the consultation on the vision standards for driving and the launch of the IGA awareness campaign 'Can U C 2 Drive’. Eye health and the impact on driving were recurrent themes in the media all through the year and a lot of work has been done by individuals and MPs, as well as campaigning, third sector and commercial organisations to bring the matter to the attention of the public and the Government to encourage regular eye tests. The launch of the Eyeway Code back in August created new opportunities for the IGA to represent patients, develop partnerships and get involved in campaigns which will continue in 2012.

Looking at the future now, 2012 will not be a year for us to rest as new challenges arise in three main areas: patient education, awareness and fundraising.

First of all, on the patient education front, our team has been watching carefully the increased number of generic eye drops introduced to the market over the past year and we know that this will be a new challenge for our patient education services in the coming months. It will lead to different bottle shapes, different names etc. which could all potentially confuse patients. But not to worry, Sightline is here to help and therefore please do not hesitate to ring us if your prescription has been changed and you feel concerned about it. The introduction of generics isn’t a problem in itself, but it is important for all patients to understand why their prescription has been changed and to raise the alarm if any side effects are being felt. Our team has recently published a new letter which we are circulating to ensure that pharmacists and GPs are aware of the questions and worries patients may have and are appropriately informed to support them.

Making sure more and more members of the public are aware of the importance of regular eye tests to ensure good eye health is a constant and difficult battle which we will carry on fighting for in 2012. World Glaucoma Week (11-17 March), National Glaucoma Awareness Week (June) and National Eye Health Week (tbc), are some key dates to add to your diary. I would like to take a minute to ask you to help us with our awareness activities. For example dropping leaflets or your copy of the IGA News, in your local pharmacy or GP surgery waiting room is a great way to make sure our materials reach those who may need them. Or perhaps you would be happy to share your story with others and become a case study and/or a media
contact. There is also another easy way to increase awareness of glaucoma: word of mouth. If each reader of this magazine was to talk to 1 person unaware of glaucoma and our services this year it would be over 5,500 additional people aware of it around the UK. Not bad, is it? And can you imagine if we all did this each year, as a ‘little personal challenge’, what we could achieve? So many more people would know about glaucoma, would be diagnosed earlier and be aware of the available support sooner. There is nothing more powerful than a patient ambassador talking to a patient, therefore please do not hesitate to get involved in our campaigns, we couldn’t run them without you.

Finally, turning to the future of the activities of the IGA, you may already know that your charity doesn’t receive Government or statutory funding and therefore relies solely on the generosity of its members and a variety of donors. We feel extremely lucky and grateful for each donation received as we know how, in these difficult economic times, each penny counts. Competition is fierce and the IGA will have to fight its corner next year to ensure that its services can remain free of charge to everyone in need of assistance for many years to come. Do you think you could help us? Maybe you know of a company looking to choose a ‘charity of the year’, or your children or grandchildren are thinking of taking on a challenge such as a marathon and would like to raise funds for a charity (for example by joining the second Carrot Night Walk in September, more details can be found on page 10), or maybe your local optician would be happy to ‘give a home’ to a collection box. There are many ways to raise funds for the IGA, therefore please don’t hesitate to contact us if you or someone you know, might be able to help and our team will be happy to discuss any ideas with you.

As I write these last few lines, I would like to take a moment to thank all staff, Trustees of the IGA as well as all of you, our dear readers, members and friends, all the patients and professionals I have worked with over the years, for making my time at the IGA so enjoyable. Starting over six years ago fresh out of University, I have learnt and grown with the team into a professional individual thanks to your support. I am so grateful to all patients who have been involved in the campaigns and projects I have worked on and have been so kind to me. It is with a little pinch to my heart that I am today working on my last edition of the IGA News, which I hope you will enjoy reading, and say goodbye to all of you, getting ready for the next chapter of my life on the other side of the World.

Once again, congratulations to the IGA team for working so hard all year around to be the voice of patients and provide the best support possible, and thank you to all of you, patients and professionals, for the incredible support we received from you each day.

Happy reading

Sarah Zerbib, Head of Marketing & PR
Thank you

Congratulations to George and Celia Plume on their golden wedding celebrations. What a wonderful milestone in their lives and our team would like to thank both George and Celia for sharing this very important time with us and raising £500 donations in support of the Association.

Thank you so much for your very kind and generous gift and we wish you many more years of blissful happiness together.

Sarah Zerbib  
Head of Marketing & PR

Hayley and Amy’s year of running

Amy and her mother Hayley took on two races this year, the Cardiff 5K in August and the great challenge of the Cardiff Half Marathon in October. Following the Half Marathon, which they completed in just over 3 hours, Hayley shared with us: “We actually really enjoyed the experience and I am considering another one. Yes, we have left our sanity at the finish line!”.

They took these challenges as opportunities to collect donations for the IGA and successfully raised over £590.00 (including Gift Aid)!

Thank you very much for your support, ladies, and congratulations on your achievement!

Sarah Zerbib  
Head of Marketing & PR
Anecdote from The World

“I have been putting my glaucoma eye drops in quite successfully for the past six years, but now age 71, it is starting to become more difficult. The problem is that it is not easy to look at the ceiling while standing up in front of the mirror and it is not easy to see in close up without glasses. So I have come up with my own solution: to use a magnifying make up mirror mounted on the brim of a hat and to instil my eye drops while lying down. This idea has been working well for me so I have made a few other samples and I am currently liaising with a couple of professionals to have other patients try it. It works for me, so, who knows, it could be a success and help many other patients in the future.”

John, Canada.

Comment from The Editor:

John has been in contact with us on his invention and sent us a sample. However, as far as we are aware there have been no published trials with this aid and we are, therefore, reluctant, at this stage, to endorse it but simply bring it to your attention as a matter of interest.

Did you get a new mobile for Christmas?

Don’t throw away the old one, contact us by phone on 01233 64 81 64 or by email at info@iga.org.uk and we will be happy to send you a recycling envelope.

The IGA gets a donation for each phone returned and it doesn’t cost you a penny!

Thank you very much
Calling all insomniacs and night owls
Date for your diary Friday September 21st 2012

“The Carrots Night Walk”

Raising Funds for Glaucoma Research.
Scenic walks planned for London, Cardiff, Norwich, Oxford, Cambridge and Manchester, starting at Midnight!!!

No need to get dressed up but it does add to the atmosphere!

Have a fun night with your friends and relatives in one of these cities and twist the arms of your friends, relatives, colleagues, patients, customers and acquaintances to sponsor you and raise much needed funds for glaucoma research.

For more information or to register please contact:
The IGA Sightline on 01233 64 81 70

Els’s Pounds for Pounds

My daughter Becky has glaucoma, so IGA is a charity close to my heart (and her eyes). She’s had four operations in the past year, and that’s only on the first eye. This is not normally something kids get, and it does not run in the family, so her diagnosis last year was a bit of a shock, and it is easy to worry about the future. Some people have asked if they can help... I’m hoping we can do this together.

What I am going to do is a sponsored slim (not swim). The idea is to focus on health, so don’t expect any crash diets. If you are willing to sponsor me you can either give a one-off donation or give a small amount now to encourage me and pledge something for every pound I lose - this may be quite a lot because Becky is on my back (not literally, that would add too much to the scales). I am putting an upper limit of 52 (in pounds...lbs) on it, so that you know what the maximum of money will be. Sounds optimistic, I know, but even if I only manage a couple of pounds, that’ll still be a couple of pounds.

Please visit http://www.justgiving.com/Els-Van-Geyte to donate.

Thank you
Els and Becky
Russell Young’s Bob Sleigh Run

On the 24th December 2011 an ever so slightly overweight graduate of the 1946 ‘baby boomer year’ will risk life and limb to raise research funds for glaucoma. I was inspired by the 1964 GB Olympic Gold medal two man bob team and it has taken me 47 years to reach this goal. So, a slightly manic, increasingly nervous, 65 year old ‘Saga Lout’ will, hopefully, launch himself down the bob run at St Moritz on Christmas Eve and a little financial commitment towards research might just be the stimulus I need to take those last few steps. Thanks in anticipation.

Please visit http://www.justgiving.com/RussellYoungIGA to donate.

Russell Young, Deputy CEO

Nigel’s Blue Hair Day

On January 5th 2012 my silver grey hair will be bright blue for the day! This is in support of the International Glaucoma Association. One of my work colleagues suffers from Glaucoma and the International Glaucoma Association have been very supportive to him and his family. They are committed to preventing unnecessary loss of sight through the condition, which is one of the most common eye disorders.

To support them in this work, I would like you to sponsor me in my Blue Hair day.

Please visit http://www.justgiving.com/Nigel-Nutting to donate.

Nigel Nutting

Say it with Charity Flowers

Do you send flowers to friends and family for special occasions?

Would you like the IGA to benefit?

Well, here’s how ..........

Order through Charity Flowers quote the charity source code “IGA” and we receive 15% of the retail value.

They publish a new brochure 3 times per year so they keep the options new and fresh.

The flowers can be ordered by phone 24 hours a day

HOTLINE 08705 300 600

or online at

www.charityflowers.co.uk
Words from Sightline

Why exercise is so important

We all know that we need to do a certain amount of exercise but I imagine we all would have done a lot more, had we known that it could affect our eyes in later life.

The EPIC-Norfolk Eye Study, published in September 2011, has been studying the link between moderate regular exercise and ocular perfusion pressure (intraocular pressure and blood pressure) looking at previous levels of physical activity and current perfusion pressure. The authors of the paper, including Professor Paul J. Foster of the University College London Institute of Ophthalmology, examined the relationship between physical activity and current ocular perfusion pressure in 5,650 men and women age 48-90 who live in Britain and were part of initial cohort from 1993 to 1997.

Professor Foster says: “It appears that ocular perfusion pressure is largely determined by cardiovascular fitness. (…). We cannot comment on the cause, but there is certainly an association between a sedentary lifestyle and factors which increase glaucoma risk.”

A number of studies have examined the effect of physical activity on the two components of ocular perfusion pressure before but this is the first study to look at the association between physical activity and OPP, according to the researchers.

“Before now, the only modifiable risk factor for glaucoma was IOP, altered by medication, laser or surgery,” Foster said. “We believe our study points toward a new way of reducing glaucoma risk, through maintaining an active lifestyle. This is a way that people can participate in altering their risk of glaucoma and many other serious health problems.”

It is important to note, though, that this is early stage and the authors acknowledged that more research is needed before anyone can rely on exercise to prevent or treat glaucoma.

As Professor Foster explains: “We don’t think these findings will ever mean that established glaucoma can be treated by exercise. The findings point more towards regular exercise over 1-2 decades helping to prevent the development of glaucoma. This is further evidence that a healthy lifestyle improves quality of life and reduces risk of disease”

Jini Gandolfo
Sightline Advisor
Peace of mind
In case of an emergency, healthcare professionals need to have rapid access to clear information about the patient’s health.

Here is a simple but very helpful programme run by Lions Clubs International which puts another slant to the phrase “message in a bottle”!

Quite simply it involves putting a written history of the medication you may be taking in a bottle provided and kept in your home. It is quite a comfort if you live alone to know that should anything untoward happen to you and the ambulance crew take you to hospital you then have written evidence of what you need to be on.

The patient completes the form which details their medical history and any medication, together with an emergency contact. You then place the completed form in the bottle which goes into your fridge; one green sticker is put on the door of the fridge and the other inside the front door (please be careful not to have it showing to the outside as this may place some people in a vulnerable position).

This is not a new idea by any means, as all the emergency services know about this scheme, but our team at the IGA has a number of bottles that we could let people have free of charge (all donations are most welcome)!

You can also contact your local Lions Club, GP Surgeries, Pharmacies, Neighbourhood Watch Co-ordinators and Social Services around the country to obtain your very own “message in a bottle”.

You can also contact the Lions Clubs International:
257, Alcester Road South
Kings Heath
Birmingham
B14 6DT

Telephone: 0845 833 9502
Email: mdhq@lions.org.uk

Office hours 8.30am to 5.00pm
Monday - Friday

For more information, please visit: www.lions.org.uk (Community section)

Jini Gandolfo
Sightline Advisor
Be aware: Pilogel 4% gel 5gm discontinued

Dear Patients,

We would like to inform you that Pilogel 4% gel 5gm has now been discontinued for sales and distribution in the UK.

If you have any questions or concerns, please contact:

- IGA Sightline on 01233 64 81 70 or
- Alcon Laboratories (UK) Ltd Customer Services Department on 01442 34 13 11 or
- your eye specialist, GP or pharmacist for further advice

IGA Sightline

New Drug Announcement

A new single dose preservative free eye gel named Tiopex has been launched by Spectrum. The formulation is 1mg/g (similar to timolol maleate) which is from a class of drugs known as beta blockers.

The therapeutic indication is reduction of the elevated intraocular pressure in patients with:

- ocular hypertension,
- chronic open angle glaucoma.

It is recommended, when using more than one medication, that there should be a 15 minute gap between using the first drop and inserting the Tiopex which should always be the last drop used.

In addition, Timolol eye gel has not been studied in patients using contact lenses, and therefore the wearing of contact lenses should be avoided while using TIOPLEX 1mg/g.

For more information, please contact Sightline on 01233 64 81 70 or by email at info@iga.org.uk

Jini Gandolfo Sightline Advisor
& Russell Young Deputy CEO
IGA Open Summer Patient Meeting 2011

The development and testing of an education programme delivered to a group of patients to improve adherence with glaucoma eye drops

Professor Heather Waterman & Jill Annis

Heather Waterman:

Thank you very much for inviting us here today. I am delighted to be here especially to talk to a group of patients. It’s the first time I have actually done this and so I’d really welcome your feedback at the end. I’m going to present a joint project between the University of Manchester and Manchester Royal Eye Hospital which we carried out to develop and test an education programme delivered to groups of patients to improve adherence to glaucoma eye drops.

Before I go into the details, I just would like to tell you a little bit about myself: I am a Professor of Nursing from the University of Manchester but long ago, in the distant past, I was a ward sister at Manchester Royal Eye Hospital and so that’s where my interest in this area came from and I would just like to introduce my partner here.

Jill Annis:

I am Jill, I am a community pharmacist and a glaucom patient hence why I’ve got an interest in this.

Why did we carry out this research?

Heather Waterman:

The aim of the talk is to give insight as to how we have used research to improve the nursing care of patients and to inform you on how patients may be involved in research. It’s well known that some patients have a tendency to not persist with their eye medication as this graph shows (Fig 1). After twelve months only about one third of patients are still collecting their prescriptions and even those who do carry on with their eye drops have been found to have ‘breaks’ from their eye drops, or they may not put them in at the time advised by the doctors.

This study was carried out in America, so we wanted to see what the situation was in the UK. We observed consultations between doctors and patients and between optometrists and patients, and we interviewed them as well. We found that patients told us that they weren’t putting in their eye drops and they seemed to have very poor knowledge of what glaucoma was. In addition, because of the busyness of clinics they weren’t given much
time to talk about any problems with putting in eye drops and nurses weren’t really involved in their care either.

I’ve got here a poem written by an ophthalmologist and I think it illustrates some of the issues shown by the graph (Fig 1):

![Graph showing Kaplan-Meier plot for time to discontinuation of ocular hypotensive therapies. The numbers of patients at risk are those who had not discontinued therapy or been censored by the start of each 3-month period.]

I am sure it’s not the case in all situations, just in some, but this is sufficient perhaps to make us think we want to do things better.

Jill is now going to share with you her experience of being a patient and what it was like when she was being diagnosed.

Jill Annis:

I first learnt about the study when I was approached by Fiona Spencer (Ophthalmologist), who told me

The Burdett Trust needed a pharmacist and a glaucoma patient, so I suppose I provided two for the price of one. I was interested to have the opportunity to learn more about glaucoma, how other patients were coping with it, and how their lack of knowledge could be rectified because as a pharmacist I come across a lot of it.

I was diagnosed with glaucoma about nine years ago after arguing with my optician that as my intraocular pressure was always at the upper limit of normal I should be referred. But by the time I saw an Ophthalmologist and was diagnosed with glaucoma I unfortunately had visual field defects in both eyes. I had a lot of questions to ask but the consultant kept looking at his watch, obviously not having much time to
spare. I was given no information at all, just a diagnosis and ‘here is your prescription, go and get the drops’. I was angry at first, then determined to learn as much as I could in order to help others. I used drops for about four years and then I had surgery on both eyes.

My role was to attend meetings and give input both as a patient and a pharmacist. I was only given a brief induction as I already had a medical background and was used to working with groups. I had to attend about six or seven meetings at the Eye Hospital where I was expected to put forward my perspective on patient education.

Next step: setting up an action research project

Heather Waterman:

We realised there were issues to do with patient support and patient education. We already had carried out some research on this subject and delivered education to some patients singly. We found it worked really well and that patients felt more educated and were putting in their eye drops more. So we thought let’s try and see if delivering education to patients in groups would work as effectively, because with the NHS being cash starved at the moment we thought it might be more...
The aims of the research were to find out how we should deliver the programme to groups of patients, what their learning needs would be, the content and duration of group education and then carry out a pilot study with real patients to see if it was feasible and acceptable. So to do this we felt it was really important to work closely with patients because after all they will be the recipients of care. We also wanted to work with staff because they would be delivering the programme if it was found to be any good. So we carried out what is called an ‘action research project’ where action researchers aim to work in partnership with patients and staff to understand and then improve an aspect of care. We formed an action research group, including patients, who kind of led the study by contributing to the design, conduct and analysis of the research. Jill was part of this group and is now going to share her experience as a member.

Jill Annis:

The group consisted of Heather, Ophthalmologists, Optometrists, GPs, Researchers, Nurses and patients. During the first year we covered our own experiences and views on patient education. Questionnaires were put to the patients, sometimes I felt the language was a bit too technical and should be made more user-friendly. I participated in the analysis of patient interviews, commented on their stories and reflected on my own and other experiences. I fed back to the group what the learning needs were and raised the importance of covering legal aspects, such as informing the DVLA and car insurance. I participated in the dummy run of the programme, which was practiced on three of us patients present at the meetings and offered advice on the use of the language. I attended the hearing of the first set of results and gave feedback on these. I have gained a lot from the experience and learnt about lifestyle issues which I didn’t know, for instance I now realise I’ll never go scuba diving with sharks. It was interesting to listen to other patients on the panel, some of whom were particularly well informed, and I enjoyed the interaction.
Finding out what patients want to learn

Heather Waterman:

We interviewed 27 patients from different ethnic backgrounds and with a range of glaucoma. We asked open ended questions which invited patients to talk about issues important to them, we recorded and transcribed the interviews then we examined the transcriptions to identify what patients needed to learn. The idea being that if we knew what patients needed to learn we could then build a teaching session from it. Figures 3 and 4 show you the learning needs identified. In the left hand column are quotes from patient interviews and in the right hand column are the patients learning needs that we found. There are ten altogether.

For example, for the first learning need it states that patients need to understand their diagnosis or understand the difficulties with giving our diagnosis and in the other column it shows you a quote.

Now there wasn’t just one patient who said this, there were several

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<th>Quotes from patient interviews</th>
<th>Learning Needs</th>
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<tr>
<td>‘...after that I was never really officially diagnosed...nobody actually sat down and explained to me what I had and why I had it’ Pt 04</td>
<td>To understand their diagnosis/understand the difficulties with giving a diagnosis.</td>
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<tr>
<td>‘...they didn’t warn me about the dangers, they did not warn me about ...what the glaucoma...do to you or whatever...like, I’ve got glaucoma and that’s it’ Pt 15</td>
<td>2 To understand glaucoma</td>
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<td>‘I just said the drug was no good...I wasn’t using it, but if I had enough information, I would be using that drug, even if my eyes are reddish’ Pt 13</td>
<td>3 To understand the implications of eye drops</td>
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<tr>
<td>‘I think there’s also, my biggest fear was actually putting drops in my eyes’ Pt 03</td>
<td>4 To understand the side effects of eye drops and tablets</td>
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<td>‘He said ‘...your pressure’s 17’ which didn’t particularly mean a lot to me at the time. [if] you haven’t a clue about the subject...you’ve no sensible questions’ Pt11</td>
<td>5 To feel confident to instil eye drops</td>
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<td>6 To be able to ask questions of the Doctors/Nurses/Optometrists involved in their care</td>
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### Quotes from patient interviews

<table>
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<th>Learning Needs</th>
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<td>7 To be able to challenge the system</td>
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<td>8 To understand their own reasons for non adherence</td>
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<tr>
<td>9 To put the condition into perspective - to know how to manage their risk</td>
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<tr>
<td>10 To know where to get other sources of information and support</td>
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| 'the main thing is...timescales between appointments. Quite a lot of time this concerns me...I did ring up and speak to the secretary, I wasn’t given an earlier appointment because she said it didn’t seem as if it was urgent. Now the consultant locally said it was urgent’ Pt 06 |
| 'It was just forgetting and then thinking 'oh it’ll be alright'. Erm, I think maybe for the first couple of months I’d be a bit...put it off...didn’t know how to do it, erm but it did it took a while, but again, understanding the implications...implications of not doing it’ Pt 03 |
| ‘you read books about it and it’ll scare the life out of you’ Pt 10             |
| ‘I found out more information, well that’s just by looking on the internet, the International Glaucoma Association...so I got more information from them that way than anywhere else’ Pt 04 |

and this is an example of a quote. Another example of a learning need was for patients to be able to challenge the system. This happens when, for example, there might be delays to appointments which are put back. Some patients were quite worried about this but felt awkward or didn’t understand how to ring up and challenge the fact that their appointment had been put back. From the quote in Figure 4, it also seems as if this patient received mixed messages as well.

Consequently, in this instance the learning need was about helping patients understand why appointments might be put back and therefore depending on circumstances how they can either accept it or if they really feel that it is the wrong thing to happen, what are the processes involved in trying to do something about it.

Note: More information about timescales between appointments can be found in the NICE Guidelines (CG85) published in 2009. Alternatively, patients are welcome to contact the IGA Sightline on 01233 64 81 70 to discuss their concerns.
Translating learning needs into a training programme

So we translated these learning needs into two sessions of two hours over two weeks. Patients were saying, they didn’t want any more than two sessions, that it would be enough. Interestingly a few patients actually said they wouldn’t come to a group education session and there was a lot of difference in opinion about when it should be put on, morning, afternoon or evening. This isn’t a worry because if you’re setting up a service in the hospital you can actually set up this programme at different times and slot in patients at the time that suits them.

Figure 5 shows the content of the first education session.

During session one, patients were first greeted, then they were put into groups of four and asked to share with one another their experiences of glaucoma and the questions they may have about their condition.

<table>
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<tr>
<th>Session 1</th>
<th>Content</th>
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| Patients’ stories (10 mins)                    | Why are you here today?  
What do you want to know about your condition? |
These were noted by Jane Ladditt, Glaucoma Nurse Specialist at Manchester Royal Eye Hospital, who ensured that during the course of the two sessions we addressed them all (if they couldn’t be answered straight away, research would be done and answers given during the following session). Then we moved on to explaining what glaucoma is using the model of an eye, the difficulties of giving a diagnosis, the different types of diagnoses, how glaucoma affects your sight and so on. Then we moved into a practical workshop where we actually taught patients how to put in eye drops using artificial tears, so we made sure that everybody there who could physically do so was taught how to do it. There was an elderly gentleman who was just absolutely sure he couldn’t put his own eye drops in but as a ward sister I remember teaching somebody aged 101 years old to put their eye drops in, so this gentleman left knowing how to do it. Then we talked about how eye drops work, side effects, storage and patients’ beliefs about eye drops and so on. We got them to talk about their adherence and tried to get them to talk about the reasons for not being adherent and what they might do in order to be adherent. For example one of the things you can recommend is making sure that the eye drop bottle is near the lamp beside your bed so it becomes part of your routine to put the eye drop in because one patient had said: ‘I keep them downstairs and sometimes I get into bed and I’d forgotten to put them in and then I’d think I can’t be bothered to go back down’. Another person said: ‘... but I go camping and I forget to take them camping and I’m worried about it’ therefore we discussed how this might be facilitated. We talked about how quite a few patients go away to Spain and places like that and don’t plan ahead to get the prescriptions in advance. We were just talking through some of these problems to make sure it is in people’s routine and because there was other people in the group they could hear what other people were doing as well.

Finally we talked about the IGA and we talked about Jane’s phone numbers so if anybody had any questions they could talk to Jane and then we did a brief evaluation.

Figure 6 shows the content of the second education session.

In session two, we reflected on the patients’ action plans to improve their adherence.

We gave advice on the DVLA and we actually helped patients to rehearse the kind of questions they might like to ask doctors. At the end of the session, they had the opportunity to talk to Jane about their own glaucoma if they wished.
Evaluating the sessions

You will recall we wanted to see how feasible and acceptable the programme is. We did this by looking at whether patients would come to the education session, their reactions to the sessions, and whether if there would be any difference to their adherence before and afterwards.

Attendance was great. In September 13 patients came (10 for the first session and 10 for the second). In November nine came and eight for the second. Most people who came were over 70 years old and had chronic open angle glaucoma. Most of them were retired but there was a fair proportion who were still working. Initial reflections on the programme were that patients liked the eye models, to be shown how to put the eye drops in and to be reassured. Incidentally, we found out that patients don’t like the Cosopt bottles, many of them were worried about the DVLA but felt reassured afterwards, and many of them voiced different reasons for non-adherence.

These are some of the quotes from the patients who evaluated the programme: ‘I thought the course was fantastic’, ‘didn’t expect to learn as much as I did’, ‘during the session you could interrupt and ask Jane questions which was very good’, ‘I liked the fact that they told us when you go to clinic don’t be afraid to ask questions, so when I go next time I shall be firing all sorts of questions’.

Regarding the before and after comparison; we compared the understanding of glaucoma, whether patients felt able to look after their eyes, the quality of life, what they thought about glaucoma, their beliefs about medicines and whether

<table>
<thead>
<tr>
<th>Session 2</th>
<th>Content</th>
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<tbody>
<tr>
<td>Feedback of action plans (30 mins)</td>
<td>Review of action plans by patients - did they help them to instil their drops?</td>
</tr>
<tr>
<td>Advice on DVLA</td>
<td>Information on the regulations concerning driving and glaucoma</td>
</tr>
<tr>
<td>Getting information (60 mins)</td>
<td>How to find out information they need in a consultation Group discussion</td>
</tr>
<tr>
<td>Individual chat with a health professional for advice (5 mins)</td>
<td>Opportunity to discuss treatment with specialist glaucoma nurse</td>
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<tr>
<td>Evaluation (10 mins)</td>
<td>Verbal evaluation</td>
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they put their eye drops in. We measured these by questionnaires given out before the education sessions, immediately after and three months after. We found that their level of knowledge was improved: before the programme only two patients scored 15 out of 19 on the knowledge questionnaire but immediately after 11 patients scored 15 or more and at three months the score had dropped slightly to nine patients who scored 15 or more. In addition, they felt more able to care for themselves with regard to their eyes, their perceptions about glaucoma were more realistic, their beliefs about medicines and need of medicines were better and their quality of life, health and wellbeing immediately after went up, but went down again after three months.

During the course of the programme patients were advised to administer eye drops within a four hour window, usually around 10 o'clock.

To measure how often patients were putting in their eye drops, we asked patients to place their eye drop bottle in a small white container, keep it in there and only open it when they were putting their eye drop in. Every time they opened it, it was electronically recorded in the lid. Unfortunately, this was not fail-safe because patients could still unscrew it and not put it in but it’s the best we could do. It was the first
time we used this device therefore we didn’t know whether patients would take to it or not, but luckily all 25 patients used it which was good. We said patients were adherent if they put their eye drop in at the four hour window every day and if they didn’t put it in using that four hour window we said they were non-adherent. The left hand side of Figure 7 shows patients level of adherence, that’s what they were doing before the educational programme. The right hand side is where it was when it finished. So the graph shows that we actually maintained their level of adherence but we didn’t improve it. You might think the programme hasn’t worked however considering previous research has shown a decline in adherence over time it may be that having maintained adherence is actually a positive effect. This needs to be tested in a larger trial with a control group to make proper comparisons.

In conclusion patients can be closely involved with the whole process of research and gain a lot from it. Group based education shows promise. Our educational programme not only targeted knowledge but motivation and behavioural skills.

The education programme was carried out by professionals with patients and part of the programme is suitable for standardisation but strategies to improve adherence need to be individualised.

Jill Annis:

I don’t think group education is for everyone. I think in some cases people will benefit more from one to one education but the group education can complement this.

One thing I feel very strongly about is that this programme should be rolled out and include all glaucoma patients not just the newly diagnosed because I come across plenty in my practice who’ve been diagnosed years ago and still don’t know how to adhere to their eye drops, what they’re for or how to use them properly.

Thank you.

We know that ease of instilling medication has a huge influence on compliance.

Many dispensers can be provided by your hospital, or alternatively, all of them can be purchased from the IGA. For more information on how to get hold of the dispensing aids please contact Sightline on 01233 64 81 70.
IGA Open Summer Patient Meeting 2011

Questions & Answers

Q1. When was the study actually carried out and over what period of time? How often did you see the patients?

A1. Two years but it was a pilot. We just wanted to see whether we could gain enough evidence for us to feel confident to go forward.

Q2. How many clients did you have in your pilot study?

A2. In the pilot study we had twenty five altogether.

Q3. I’ve had glaucoma for 10 years and I’ve been very happy with my Consultant but I haven’t never seen a nurse at all in clinics and there have been lots of little questions I’ve wanted to ask, but because I’m an ex-nurse people assumed I would have known. What are the chances of maybe involving your specialist nurses in clinics?

A3. Jane Ladditt: I’ve been a glaucoma nurse in Manchester for two years so it’s quite a newish post really and at the moment there is only one of me because of a funding issue, so for the near future there will continue to be only one of me. While I do try and see as many patients as I can, in a clinic of 100 patients I am limited as to how many I can see.

Q4. I think the IGA is marvellous and I’ve recently become a member and I’ve been able to ring up if I’ve been frightened, I’ve been upset or worried and it’s been brilliant to have somebody at the other end of the phone that’s been able to help and advise me. I do appreciate the shortages with only one of you and there’s hundreds and hundreds of people with glaucoma but it would be nice to be seen at some point, you know, like your people in your pilot study were.

A4. Heather We’re hoping to set the education programme up at Manchester. We’re sort of going through all the procedures; we’re very close to getting it off the ground.

Jane Yes, it’s almost ready and then what will happen is that any doctor in clinic will be able to refer a patient onto this course.
Heather

With the latest Research Grant that we have been attributed by the IGA, we’re planning on trying to roll the programme out to about five other hospitals and see how it works somewhere else.

Q5. Drops only have a limited lifetime, once they’ve been opened 28 days, I write on my box ‘started on Sunday evening at such a time’ and I know 28 days on from that. I know a lot of people who don’t do that and they haven’t ordered the prescription in advance so they throw the old bottle away or they carry on using that, or they run out of drops and they don’t bother. It could be something that you might consider when doing your studies.

A5. If you ever do run out of your drops that you use regularly you can always go to your pharmacist and they will give you an emergency supply. There’s always a date on the bottle, it’s not going to harm if you go a day over and we normally say ‘look at the date on the bottle and if it’s the 1st September throw them out on the 1st October. I don’t personally have a problem but I know people who do and they throw the bottle out and then they don’t bother getting a fresh supply. This is where compliance comes in.

Q6. I was diagnosed in 2007 and I was asked to take part in a programme which involved one interview with the nurse face to face and then a lot of telephone interviews in which she checked that I was taking the drops and I also had to keep a drop diary for about a month. I think the programme went on for at least a year and at the end of that I had a final interview on the telephone. I never heard whether it was decided that this nurse involvement at that stage was useful or not. Was it the precursor of the programme that you’re talking about?

A6. The study you are referring to has only just come to an end. I can confirm is that it worked. It is going to be published in the journal called ‘Eye’. It’s just been accepted.

Q7. I wanted to ask whether we can enrol for the next study?

A7. We’re going to be doing the next studies at different hospitals, it depends where you are.

Q8. I do always try and write on the bottles but sometimes it’s very difficult to write on the bottles so if you can get the manufacturers to put a bit (the date) on the actual bottle itself rather than the container.
A8. Actually getting manufacturers to do something like this is incredibly difficult. I know it seems obvious but the writing on most of these bottles is so small I for one would not be able to see them. Your pharmacist can give you large print labels. If you ask for them they will put large print labels on for you.

I thought I’d heard that it was good to keep your bottles in the cardboard containers that they arrived in and there’s plenty of room to write on. I’ve always kept my bottles in the containers that they arrive in, it’s probably a good idea and that will solve your problems.

Q9. There is one added nightmare. If you’ve got to take antibiotic drops as well for any period of time and they have to be kept refrigerated it’s really difficult on holiday. I’ve done things like leaving them in a kitchen in the hotel, I even had to go to the local Co-op store and ask if they’d put them in the fridge overnight, but there must be some better way of dealing with this.

A9. Certainly as far as the glaucoma drops are concerned the IGA sells a pouch, the Cool Wallet, in which you can put the drops. You soak it in cold water and it will keep them at a safe temperature right through a 48 hour period just because of the evaporation of water. Then you can just re-soak the pouch again.

Regarding individual antibiotic, you can take a little cool pack with the little gel insert that freeze and hotels or somewhere else may be able to freeze that for you rather than just storing your drops in their fridge. They may be happy to put the little chill pack in their fridge. I recommended that to people in the past. If you’ve got two or three of them you can have one freezing whilst one is in the pack and that’s what a couple of my patients have done while they were going abroad somewhere warm. I don’t know if that’s helpful. Camping stores sell very little ones as well.

Q10. I’ve met the glaucoma group at Henshaws Society for the Blind and ran a survey of the group which raised and matched the same issues than the ones highlighted by Professor Waterman’s study. I heard about Heather’s work and met with her. She agreed to run the course as part of a day we run called ‘Living well with glaucoma’. I have to say it completely mirrored this study: there were three people who it transformed their understanding and their use of the medication in particular and one person had an incorrect prescription. Fortunately they
had an appointment the next day and had their prescription changed the following day. It was very, very empowering I would say for those people and we now have a glaucoma support group that runs every two months. There is some education in all those groups but we are hoping to run the same day if we can and we might be begging Professor Waterman to run the same one. If anyone is interested in attending something like this we can actually set that up quite quickly in the New Year or sooner if possible. I would be very happy to take any details and it’s very easy to park where we are as well.

A10. Yes, I’ve got absolutely no problem at all with going back with Jane and doing one of these as part of Henshaws and if anybody here would like to attend you’ll be most welcome to attend.

Q11. I’ve had open chronic glaucoma for the last 26 years. I’ve had the most information and help that I could’ve had. I cannot fault the professionals who have taken care of me over the years. I’ve had every little bit of information and I’ve always been asked ‘any questions?’

A11. Yes, I agree some patients do have a very good experience but some people feel very shy and when asked if they’ve got any questions will say ‘no’ like that gentleman.

I don’t think all Consultants give you the time for questions.

It can be difficult to educate everybody singularly and that’s why we’ve done this group education in order to try and get across the essentials to groups of people because it seems to be a more efficient use of time.

Yes, The IGA is here to answer the questions that either you didn’t get an answer to or you forgot to ask when you were in the clinic because you only get that little bit of time with the healthcare professional, be it a nurse or a doctor or someone else. They have only a limited time to be able to answer you, although they are so much better than they were thirty odd years ago. The IGA is here to answer all your questions, whether you didn’t get an answer, didn’t get the time to ask or simply forgot the answer. It is well known that we often remember about a third of what we are being told when having conversations, with this simple fact in mind, as long as you get that third that’s fine, and we are here to complete the answer and make up the other two thirds therefore please do make use of
Q12. Why do opticians not always pick up on glaucoma? This has been my experience.

A12. There are a number of reasons why an optician may not pick up on glaucoma. One of them may be that they don’t perform all of the relevant tests to make the diagnosis. Of course all of our lives would be a lot easier if we had one test that gave us the answer ‘do you have glaucoma or not’ and it’s about how those pieces of information interact together.

The second thing is that our understanding of glaucoma has changed over the years and so optometrists nowadays are getting plenty of education on how glaucoma can present, what the appearance of the nerve in the eye can be like, what the pressure can be like and a number of other things. I know how much things have changed. I started in ophthalmology in 1988 and at the time somebody with normal tension glaucoma would have been so rare that everybody would have been called in to see them in the Consultant’s room. Now our understanding is that probably 40% of our glaucoma patients are within that bracket nowadays which means that we were probably missing 39% of them at least in those days so again that message has gone out to optometrists and they’re beginning to understand that. If it was very easy to diagnose, or there was one simple test, then obviously we wouldn’t be still missing people. Some of that is about general education and understanding and how that’s moved on over time. I think one of the results of the NICE guidelines in management and treatment has been that optometrists have looked differently at patients, although it’s not about diagnosis and referral. They’ve referred more people into the hospitals than they had before, and it has also made a difference to the number of people being picked up, so I think there’s a multi-factorial reason for that and some of it is just about change in our perception and our education which is improving.

Q13. I have narrow angle glaucoma and I heard recently that opticians cannot pick that up. This was a shock to me?

A13. I think that depends, narrow angles may be obvious at the microscope but may be less obvious when doing other tests. In some people who have sub-acute pressure rises, there can be symptoms that can alert you to thinking that’s the case but most optometrists don’t do gonioscopy so they cannot make the definitive diagnosis.
Anybody who is suspected of having narrow angles or whose pressure is high nowadays should be referred in for gonioscopy. Now that could be happening in the community, it doesn’t have to happen in the hospital eye service. It could be in a clinic of referral refinement in the community but gonioscopy should be done, it is mandatory really as part of the diagnosis of glaucoma, but optometrists can’t necessarily do gonioscopy. Things are changing though, there are a number of optometrists who are trained to do it now and any optometrist whose going to be working in a screening service generally does something towards the Diploma of Glaucoma Certificate in Diagnosis which at the moment involves gonioscopy. I’ve been involved in that and in the examination of it and I know that those optometrists have to be able to do gonioscopy and be able to diagnose narrow angles, so if you’re being referred in that should be picked up now by them.

Q14. Can you actually say how long glaucoma can be there for undetected? Can it go on for years and years and one goes to the opticians and each time is told everything’s fine?

A14. It depends on how much damage there is when it’s picked up as to what the prognosis may be in individuals. Certainly a number of people will have had glaucoma for quite a period of time before they’re referred in and it depends on whether they have a normal pressure range or a very high pressure range and what they’re referred for.

I know of one piece of work which looked at patients who had initially been referred and were then maybe lost to follow up. Their referral letter was sent in from the optometrist, but they never actually made it to the hospital eye service and then represented later on. There was a paper in the late 80s or early 90s (Murdoch J.R. & Jay M.L. (1993) The rate of visual field loss in untreated primary open angle glaucoma. Br J Ophthalmol. 1993 March; 77(3): 176–178) that looked at how much vision people appeared to have lost and how much change there was in the nerve in the eye when they represented and looked at the rate of change.

It was very clear that people with much higher pressure do deteriorate faster than people with normal or lower pressures generally, and that’s the only piece of evidence that we have. Therefore if somebody has very, very high pressure, we have to assume (if they still have got good functioning nerve and feel) they haven’t had it for a very long time when we see them. But you can’t tell on the day you meet somebody
in the clinic how long they’ve had glaucoma for.

Of course it is difficult to diagnose glaucoma because by definition it is a progressive condition. If you take a snapshot, so you look at somebody on one occasion you don’t know if it’s progressing because that’s what it is now, so we need to see some more snapshots later on and see if there’s change. It is quite possible to have a visual field defect that is not glaucoma and that’s why in some cases it can take months, maybe even one or two years to fully confirm a diagnosis of glaucoma.

Of course we don’t wait that long to start treating you because if it looks as if it’s glaucoma, and there’s all the signs and symptoms of glaucoma, there’s a very good chance it will be glaucoma so the consultant is going to give you the drops anyway.

Q15. If you’re actually told to have laser treatment, could there be a mistake in the fact that you might not have glaucoma but they think you’ve got glaucoma, and therefore if you have the treatment of laser surgery you’re putting yourself at risk.

A15. Yours is narrow angle glaucoma?

Is that different?

With narrow angle glaucoma you can see with gonioscopy you’ve got a narrow angle and it’s likely to close, so rather than let you have an acute attack, which is extremely painful and does do some damage, they will do the iridotomy, they will provide the little safety valve, the bypass and it won’t do any harm at all it’ll just stop you having a problem in the future.

The IGA would like to welcome our two new recruits

Alex Painter
Head of Marketing & PR,
a.painter@iga.org.uk

and

Emma Dexter
Senior Finance Officer,
edexter@iga.org.uk.
IGA-RCOphth 2011 Research Grants

Congratulations to the 2011 IGA-RCOphth Awards winners!

There were 13 applications for the 2011 awards. After a prolonged external peer-review process five applications were short-listed and three grants of £50,000 each were awarded. The awards were presented by Keith Barton, Chair of the IGA Research Committee, at the RCOphth Admissions Ceremony on Friday 9th September 2011.

The role of the IGA in supporting research was acknowledged at the Admission Ceremony by the President of the Royal College of Ophthalmologists, Professor Harminder Dua.

Mr A Bastawrous, International Centre for Eye Health, London School of Hygiene and Tropical Medicine

The five-year incidence and progression of glaucoma in Nakuru, Kenya and the validation of a glaucoma screening tool

This application was to fund a population-based study in Kenya that would actually determine incidence of disease and its progression, rather than prevalence, which is measured in most epidemiological studies. 4381 subjects were originally examined in 2007 in Nakuru, Kenya as part of the Nakuru Posterior Segment Disease Study. The application was to re-examine as many as possible of the original 4381 subjects to determine incidence of glaucoma and incidence of glaucoma progression as well as other risk factors.

This application was particularly well-presented and has the added attraction that the study would significantly enhance the information obtained from a previous study. Furthermore, the chance of a successful outcome from this study is improved by the fact that the investigators have already conducted a pilot study in January 2009, which has enabled the investigators to calculate the likely drop-out rate and incidence figures.
Miss R Mathew, Moorfields Eye Hospital

A randomised controlled pilot study to assess the safety and efficacy of subconjunctival bevacizumab as an adjunct to trabeculectomy surgery

Monoclonal antibodies such as Avastin and Lucentis are regularly injected into the eye for age-related macular degeneration. They also appear to have a significant effect on wound healing, and might therefore be useful in trabeculectomy surgery. There are many case reports and short-series using bevacizumab (Avastin) in trabeculectomy surgery. The purpose of this application was to fund a pilot study in advance of a full randomised controlled trial.

It is hoped that agents such as these might be used as safer alternatives to Mitomycin C after trabeculectomy surgery.

This is of interest to the IGA, as there is widespread interest in the use of Avastin in trabeculectomies in the ophthalmic surgical community. This study should provide some hard evidence as to the likely usefulness (or not) of Avastin.

Dr C Sheridan- Department of Eye and Vision Science, Institute of Ageing and Chronic Disease, Faculty of Life Science, University of Liverpool

Repopulation of the Trabecular Meshwork - a way ahead in IOP Control?

The single biggest risk factor for glaucoma is age. Mean IOP elevates with age and trabecular meshwork (the outflow channels, whose reducing function is believed to lead to high IOP in glaucoma) cell numbers decline with age. The purpose of this study was to examine the ability of cells in the vicinity of the trabecular meshwork to proliferate and differentiate into trabecular meshwork cells. This is in order to understand why they do not migrate and fill the void in situations where the trabecular meshwork becomes depleted of cells in glaucoma. Cell lines and tissue culture will be used to examine the function of these cells.

This study is attractive as it attempts to address a single question in a relatively simple fashion. In the original application, the investigators intended to use bovine eyes from an abattoir as a source of cells. The investigators reassured us however, that the study can and will be performed using human rather than animal tissue, given that the IGA does not fund research involving animal tissue.
2012 Diary

Our team would like to sincerely apologise for the inconvenience caused this year due to the withdrawal of the pocket diary from our yearly gift catalogue.

Unfortunately, despite many of you looking forward to this item each year, sales have decreased and we weren’t able to justify keeping this item in our catalogue this year.

We are currently looking for alternative items or suppliers and we are hoping to bring back a pocket diary again soon.

Thank you very much for your kind understanding.

Sarah Zerbib
Head of Marketing & PR

Remember your loved ones by saving the sight of others

Our lasting memories of those we have lost are priceless. A donation in their memory is a wonderful opportunity to free future generations from glaucoma.

Glaucoma is one of the leading causes of preventable blindness in the UK. By making a donation in memory, you can help us fund essential clinical research and provide the support people need to stop this thief of sight.

Thank you.

www.glaucoma-association.com
info@iga.org.uk

Charity Registered in England & Wales N°274681
and in Scotland N°SC041550
The Charity for People with Glaucoma, Est 1974

If you need any help or advice please contact
International Glaucoma Association
Woodcote House, 15 Highpoint Business Village
Henwood, Ashford, Kent TN24 8DH
Tel. 01233 64 81 64 • Fax. 01233 64 81 79
Inaugural meeting of the Edinburgh & Lothian Patient Support Group

The launch of the first glaucoma patient support group in Scotland took place at the lecture theatre of the Princess Alexandra Eye Pavilion in Edinburgh on 23rd September. The meeting, chaired by Dr Hilary Devlin, was well attended by patients, consultants and staff who were keen to get involved.

Dr Stephen McAtamney supported by Dr Pankaj Agarwal, kicked off with a lively interactive presentation on the nature of glaucoma and its treatment. This generated a host of questions and resulted in a wide ranging and free flowing session which, we hope, helped many to gain a much clearer understanding of their condition. Specialist eye care pharmacist, Angela James, then gave a very useful and informative presentation on glaucoma medication with a guided tour of the various types of eye drops, when and how they should be administered and looked after. This was supplemented by an excellent short video produced by Dr Agarwal on eye drop instillation technique and a demonstration of the new IGA ‘Compliance Briefcase’ by specialist nurse Zania McKenzie, stressing the need to adhere to the prescribed programme of treatment to maximise sight preservation. All of which stimulated further discussion as patients shared their own experience, tips and techniques that they had found helpful.

Following a short break, the meeting resumed with an inspirational talk by Jill Pain, a patient who has come to terms with her unusual form of glaucoma in her own individual way, helped wherever possible by gadgets, modern technology and a good helping of common sense. Finally, I gave the last lecture and outlined the charity’s vision for supporting patients, carers and health professionals in raising awareness, promoting research and helping to improve care for people with glaucoma throughout Scotland. We are fortunate in Scotland to have FREE NHS eye health checks available at most of our high street opticians which can greatly help in identifying the presence of glaucoma and other conditions, gaining early referral to a specialist, diagnosis and treatment.
The meeting concluded with discussions on the way forward for the group and the desire to have a Scotland-wide network of Glaucoma Patient Support Groups.

Early feedback indicated that 90% of attendees rated the meeting highly informative and useful and many would welcome the opportunity to attend further meetings of the group as well as recommending this to others.

The next meeting of the Edinburgh & Lothian Group will be held on Friday 10th February at St John’s Hospital in Livingston. Details will follow soon. Our grateful thanks to Dr Pankaj Agarwal, whose vision and enthusiasm helped drive this initiative, as well as all of the medical and clinical staff at Princess Alexandra Eye Pavilion and, of course all those who attended and whose input added greatly to the success of this first meeting.

John Hughes
*IGA Business Development Manager, Scotland*

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**New support group for Hull and East Riding**

A new glaucoma patient support group has been set up in Hull and East Riding. The inaugural meeting was held in November at the Hull and East Riding Institute for the Blind (HERIB) and attracted 15 people who were addressed by Mr Craig Burnett, the Glaucoma specialist at Hull Royal Infirmary. Mr Burnett gave an informal talk and responded to questions from members of the group.

The group was founded by Dr. David Pattison, who was recently diagnosed with Glaucoma. After his diagnosis Dr Pattison looked around his area unsuccessfully for some kind of support relating specifically to Glaucoma. Eventually he contacted HERIB who gave him assistance and advice and helped him to publicise the first meeting of the new group. The group has since been liaising with David Harris, IGA Business Development Manager, who has offered valuable help and advice to move things on.

A second meeting is planned for Friday 27th January 2012 at 11.30am at HERIB, Beech Holme, Beverley Road, Hull, HU5 3HS. A buffet lunch will be provided at a cost of £2. For further details ring Sue Pallister, HERIB, on 01482 34 22 97

Russell Young
*Deputy Chief Executive*
St Asaph Glaucoma Patient Support Group meeting 12th October 2011

The Support Group at HM Stanley Hospital, St. Asaph, meets on the 2nd Wednesday of the month between 3 - 4.30 pm in the board seminar room.
Address: Upper Denbigh Rd, St. Asaph, Clwyd LL17 0RS
It offers an opportunity for patients with glaucoma to meet on an informal basis to listen to speakers and discuss any problems or issues they may have in regard to their condition. Friends, carers and family are also welcome. Speaker topics are chosen by the group and tea and coffee are provided.

So far this year topics have included:
An update on Glaucoma by Mrs Divya Mathews, consultant
History of The League of Friends by Mrs. Edwina Owen
Lasers and Glaucoma by Linda Lewis, Ophthalmic Nurse Practitioner
Homecare and Repair by Mrs. Lynda Colwell

The Role of E.C.L.Os by Hazel Aspey, Eye Clinic Liaison Officer
Importance of Exercise by Noelle Watson, Physiotherapist

The most recent October meeting was attended by David Harris, who on behalf of the IGA, gave an interesting and thought provoking presentation on Driving and Glaucoma which was followed by a lively question and answer session. David also found time to talk through the new drop compliance aids suitcase which was very well received by all.

At the meeting a cheque for £500 was presented to the I.G.A. by the group from fundraising over the past 18 months, including a raffle, cake stall and ongoing bookstall. Thank you to all those who donated prizes, bought tickets or helped in any way.

Linda Lewis
Ophthalmic Nurse Practitioner, St. Asaph

The photo shows some of the members of the Support Group with treasurer Ted Edwards, 2nd from left, Ophthalmic Nurse Practitioner Linda Lewis and David Harris, far right, receiving the cheque on behalf of the IGA.
Glaucoma Patient Support Meeting - Cambridge - 12th October 2011

Twice-yearly support meetings in Cambridge for glaucoma patients were begun in 2009 at Addenbrooke’s Hospital by specialist glaucoma nurse Debbie Jankowski. Just nine people attended the first one but the numbers have since grown so much that, on the afternoon of Wednesday 12 October, some 40 patients, family and friends packed the rows of seats that replaced the normal layout in the eye clinic. As Debbie and other staff members made people welcome, IGA Development Manager Sue McGilveray set up her stand where she had IGA leaflets and samples of various aids to help manage eye drops.

At the very last minute, Consultant Ophthalmologist Mr Andrew White stood in for the two advertised speakers, who were not available. They had been due to talk on narrow angle glaucoma, dry eye and blepharitis, so he began by showing which part of the eye the ‘angle’ is and how it can become narrower than it should be so that pressure builds up in the eye. The good news though, was that there are safe treatments.

Mr White’s very clear explanations and friendly style soon had everyone relaxed enough to start asking questions, not just on narrow angle glaucoma but anything glaucoma-related. There was a great deal of interest in how it’s decided what an individual’s eye pressure should ideally be, the distinction between glaucoma and high pressure by itself, and when treatment should begin. Debbie explained that a single pressure measurement may not give a true picture, so sometimes it’s necessary to monitor how someone’s eye pressure changes throughout the day.

More questions ranged through the possible effects of diet and liquid intake on glaucoma and how different
As a helper to my wife, who has had glaucoma for some 14 years, I regularly attend the local support group at New Cross Eye Hospital Wolverhampton. Two delightful ladies, Sister Mary Stott and Sister Sharon Johns initiated and run the support group which has grown to a regular attendance of some twenty souls. All seeking assurances and aid in order to combat this deadly affliction.

Both Sisters regularly utilise your wonderful quarterly publication and we discuss all the new research information provided. They administer advice, give demonstrations and reassure all of those who attend. They do all this in addition to their already full agenda and together with all their staff at the hospital maintain a high level of efficiency and care. They are both angels, and need supporting as much as possible.

Keith
Glaucoma patient

New Cross glaucoma patient support group

After more discussion about the right way to put in drops, Mr White wound up with a final message: Keep up with the drops – it’s half the battle! When time ran out, the talking kept going as informal chat, while welcome tea and biscuits were served. Sue and Debbie were kept busy giving information and advice right until the chairs were being cleared away and the room was being turned back into a clinic. It had been a very successful and worthwhile afternoon.

Jacqueline Mitton
IGA Trustee
<table>
<thead>
<tr>
<th>Area</th>
<th>Location</th>
<th>Contact Details</th>
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</thead>
<tbody>
<tr>
<td>Cambridgeshire (East Anglia)</td>
<td>Cambridge Eye Unit Addenbrookes Hosp. Deborah Jankowski</td>
<td>To be advised</td>
<td>01223 274 600</td>
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<tr>
<td>Derbyshire</td>
<td>Cavendish Hospital to be held at Buxton Methodist Church Chapel Street Sister Norma Ayres</td>
<td>02/03/12 1.30-3.30pm</td>
<td>01298 212 850</td>
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<tr>
<td>Devon</td>
<td>Royal Devon &amp; Exeter Hospital Exeter Nurse Jane Kingett.</td>
<td>To be advised</td>
<td>01392 406 045</td>
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<tr>
<td>Seaton, Devon</td>
<td>St.Gregory’s Church Hall, Colyford Road Joan Ayres.</td>
<td>To be advised</td>
<td>0129 724 275</td>
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<tr>
<td>Dorset</td>
<td>Royal Bournemouth Hospital Staff Nurse Shelley Hankin and Elene Bizoumis</td>
<td>To be advised</td>
<td>01202 726 036</td>
</tr>
<tr>
<td>Essex</td>
<td>Essex County Hospital Colchester Jocelyn Murphy Senior Staff Nurse Lynn Barker <a href="mailto:Lynn.Barker@colchesterhospital.nhs.uk">Lynn.Barker@colchesterhospital.nhs.uk</a></td>
<td>To be advised</td>
<td>01206 744 672</td>
</tr>
<tr>
<td>Romford, Essex</td>
<td>Havering Group, Yew Tree Resource Centre Val Poole All meetings 2.00pm to 4.00pm Meetings 2nd Thursday of each month</td>
<td>To be advised</td>
<td>01708 434 392</td>
</tr>
<tr>
<td>Westcliff on Sea, Essex SSO OQF</td>
<td>The Steel Suite, St Peters Church Hall, Eastbourne Grove Jayne Harrison &amp; Geraldine Smith</td>
<td>To be advised</td>
<td>01702 435 555 Ext. 6979</td>
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<tr>
<td>Isle of Wight PO30 1DD</td>
<td>Isle of Wight Society for the Blind Newport I.O.W. John Lockley Group cancelled until further notice</td>
<td><a href="mailto:enquiries@iwsb.org.uk">enquiries@iwsb.org.uk</a></td>
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</tr>
<tr>
<td>Humberside</td>
<td>Hull and East Riding Institute for the Blind (HERIB) Beech Holme, Beverley Road, Hull, HU5 3HS Sue Pallister</td>
<td>To be advised</td>
<td>01482 342 297</td>
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<tr>
<td>Lincolnshire</td>
<td>Boston Pilgrims Hospital Lecture Hall, Education Centre Darralynne Stell <a href="mailto:darrylynne.still@ulh.nhs.uk">darrylynne.still@ulh.nhs.uk</a></td>
<td>24/02/12 at 1.30pm</td>
<td>01205 364 801</td>
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<tr>
<td>Kent, Sidcup South London</td>
<td>Queen Mary’s Hospital, Frognal Avenue, Sidcup Kent DA14 6LT Maria Moutsou</td>
<td>To be advised</td>
<td>020 8302 2678</td>
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<tr>
<td>Kent, Margate</td>
<td>QEQM Hospital Margate Nicola Anwar</td>
<td>To be advised</td>
<td>01843 225 544</td>
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<tr>
<td>Lancashire</td>
<td>Bolton Derek Meacher, Date and venue to be advised</td>
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<td>01204 651 792</td>
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<td>Hillingdon Hospital, Uxbridge</td>
<td>Pield Heath Road, Uxbridge, Middlesex UB8 3NN 23/04/12 4pm-6pm Talk by Professor Philip Bloom, Mr Inayat Khan and Dr Tom Kursey ‘Glaucoma, what is it?’</td>
<td>01895 238 292</td>
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<tr>
<td>London Whipsps Cross Uni. Hospital</td>
<td>Whipps Cross Rd Leytonstone E11 1NR Katy Sommersgill Orthoptic Department To be advised</td>
<td>020 8535 6710</td>
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<tr>
<td>Old Trafford Greater Manchester</td>
<td>Henshaws Society for Blind People 88-92 Talbot Road, M16 0GS Adrian Brooks To be advised</td>
<td>07925 962 184</td>
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<tr>
<td>Merseyside Ormskirk District Hosp.</td>
<td>Royal Clifton Hotel Southport Louise Couzens &amp; Mr Gonzalez Martin To be advised</td>
<td>01695 656 042</td>
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<tr>
<td>Northampton</td>
<td>Northampton General Hospital Cliftonville NN1 5BD Jane White &amp; Arnold Civil To be advised</td>
<td>01604 791 941 &amp; 07966 403 177</td>
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<tr>
<td>Sutton Hospital Surrey</td>
<td>Boardroom, 1st Floor, Sutton Hospital To be advised</td>
<td>020 8296 4445</td>
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<tr>
<td>Sussex Eastbourne Hospital</td>
<td>Eastbourne District General Hospital Lecture Theatre, Postgraduate Centre Eastbourne Sister Helen Coombs and Staff Nurse Annika Archer</td>
<td>Helen Coombs 01323 417 400 Ext. 4118</td>
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<tr>
<td>Sussex Eastbourne Blind Society</td>
<td>124-142 Longstone Road, Eastbourne BN22 8DA Sister Helen Coombs and Staff Nurse Annika Archer To be advised</td>
<td>Helen Coombs 01323 417 400 Ext. 4118</td>
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<tr>
<td>East Sussex Brighton</td>
<td>Audrey Emerton Building, Eastern Rd BN2 5BF Gaynor Paul</td>
<td>01273 606126</td>
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<tr>
<td>West Sussex Worthing Hospita</td>
<td>Eye Clinic First Floor East Wing Staff Nurse Annette Brampton Staff Nurse Julie State To be advised.</td>
<td>01903 205111 Ext. 5658</td>
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<tr>
<td>Tyne and Wear</td>
<td>Sunderland Eye Infirmary, Queen Alexandra Road Sunderland, SR2 9HP Staff Nurse Pauline Stores To be advised.</td>
<td>01915 656 256 Ext.46335</td>
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<tr>
<td>Wales (North) Denbighshire</td>
<td>St Asaph, Denbigh Linda Lewis Eye Clinic To be advised</td>
<td>01745 589 677</td>
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<tr>
<td>Wales (South) Bridgend Eye Unit Prince of Wales Hospital</td>
<td>Bridgend Residents Community Centre Karen Phillips Orthoptist Glaucoma Specialist Friday <a href="mailto:karen.phillips3@wales.nhs.uk">karen.phillips3@wales.nhs.uk</a></td>
<td>01656 752 179</td>
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<tr>
<td>Scotland</td>
<td>Edinburgh</td>
<td>EH3 9HA</td>
<td>Lecture Theatre Princess Alexandar Eye Pavilion</td>
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<td>Scotland</td>
<td>West Lothian</td>
<td>EH54 6PP</td>
<td>St John’s Hospital. Livingstone, West Lothian</td>
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<td>Scotland</td>
<td>Falkirk</td>
<td>FK1 4DD</td>
<td>Forth Valley Sensory Centre Redbrae Road, Camelon, Inaugural Meeting</td>
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<td>Paisley</td>
<td>PA2 9PN</td>
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<td>Bordesley Green, East Birmingham B9 5SS</td>
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<td>Good Hope Hospital Rectory Road B75 7RR</td>
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<td>West Midlands</td>
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<td>West Midlands</td>
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<td>Kidderminster Treatment Centre Bewdley Road DY11 6RJ</td>
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<td>Worcestershire</td>
<td>Royal Hospital</td>
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<td>Charles Hastings Way, Newtown Rd Worcester WR5 1DD</td>
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For further information on support groups, please contact our Sightline on 01233 64 81 70 or info@iga.org.uk. Information can also be found on our website: www.glaucoma-association.com
Glaucoma could take away your driving licence.

Regular eye health checks can protect your vision and your licence to drive.

DON'T LET GLAUCOMA STEAL YOUR SIGHT

Sightline 01233 64 81 70

www.glaucoma-association.com

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Henwood, Ashford, Kent TN24 8DH
Email: info@iga.org.uk

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