



UVEITIS INFORMATION GROUP

NEWSLETTER

Winter 2010

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Welcome to the 2010 'UIG News'

The UIG is still a very small organisation run by a very few volunteers, but we are making strides towards our goals of raising awareness about uveitis and taking patients' views and concerns to those that can make changes to the way uveitis patients are managed and treated.

We have been able to recruit a new treasurer this year, Karen Wilkinson, who has enabled us to move safely into developing essential areas such as Giftaid and online payments.

Annie Folkard, our secretary this year, has been involved in much of our development, especially our new website.

Rea Mattocks, our Chair this year, has drawn on her experience with Social Services to help ensure that uveitis is to the fore of the large organisations concerned with eye conditions and visual impairment. Both Rea and Annie suffer from Birdshot chorioretinopathy, a form of posterior uveitis and have set up a separate patient group within UIG, the Birdshot Uveitis Society (BUS), to support those with Birdshot and engage with Ophthalmologists with an interest in this field.

Phil Hibbert

Welcome to our Professional Panel

The UIG has always enjoyed a close working relationship with leading Uveitis Specialists and associated professionals in the UK and abroad. This year we have formalised and strengthened this arrangement by establishing our Professional Panel who consists of :

Professor Andrew Dick – Chair of Professional Panel

Mr Dara Kilmartin – Ophthalmologist

Professor Susan Lightman – Ophthalmologist

Professor Philip Murray – Ophthalmologist

Dr John Olson – Consultant Ophthalmic Physician.

Lead Clinician of Scotland's Uveitis National
Managed Clinical Network, NHS National Services
Scotland

Ms Angela James – Ophthalmic pharmacist

Dr Scott Mackie – Optometrist

Mr Alan Jones – (RNIB) Vision Impairment

Mr Mike Brace – Vision 2020 (UK)

Ms Annie Hinchcliffe – Uveitis Nurse

Dr John Curnow – Research Scientist

Chair of the panel, Professor Andrew Dick at Bristol, introduces the panel:

I am honoured to chair the Professional panel and serve and work with our patients via the Uveitis Information Group. My hope is that with your drive, and the needs you express, the

medical fraternity will act as brokers with NHS and health delivery services, to deliver what we do better and to encourage future research to ensure better outcomes. By engaging with your questions we can bring them to life, and most importantly incorporate them into research and routine practice. In this way we can make real improvements. Working together we can help to bring our services in line with your needs. The role of the professional panel, will I hope, remain dynamic and flexible and will develop in response to the questions you raise; the success of your lobbying will gain greater recognition of your needs, with health services, policy makers and research funders.

What could we achieve? Firstly, with your pressure, create and maintain a uveitis network for research trials; secondly, influence and improvement of NHS service delivery for your benefit in response to your consensus views. Questions raised in this Newsletter address some ways we can work towards this. These include the generation of specialist nurses as examples of best practice to be propagated through all eye units and incumbent on the professionals particularly, generating professional consensus for clearer guidelines and treatment algorithms, taking the Scottish Clinical Network further.

People in the UIG

President ● Professor John Forrester – Ophthalmologist

Management Team And Trustees ● Phil Hibbert – founder, Chief Executive
● Rea Mattocks – chair
● Annie Folkard – secretary
● Karen Wilkinson – treasurer
● Carri-Anne Walker – fund raiser

Other Trustees ● Fiona Smith
● Emma Strathdee
● Gill Ogden

Chairman of Professional Panel ● Professor Andrew Dick

NEWS

Thanks to some fundraisers

Fundraising will always be extremely important for the UIG. Not only does it help support people with Uveitis but it also helps raise much needed awareness of this 'Cinderella' eye condition. As we all know, uveitis has a low profile when it comes to awareness across the wider medical profession, and virtually no profile at all amongst members of the general public, who mainly have never heard of it.

There are many ways these days to fundraise and every penny raised for uveitis is significant. If you would like to raise money for UIG, we would be keen to help and advise. So please do get in touch about this if you would like our help with your fundraising effort.

These are just a few examples to demonstrate the sorts of ways funds can be raised for the UIG and we would particularly like to thank those involved:

- Ernest Walker and Helen Dollison who decided to ask for donations instead of wedding gifts at their wedding
- Nicola and Olivia Davis raised £100 at their school, Aldenham Prep School (Staff and Parents association)
- Maria Olivieri raised over £1000 pounds at a work charity event that she help organise.

Sponsored Cycle across the Pyrenees

Whilst on the subject of fund-raising, Phil Hibbert, founder of the UIG, would like to thank those who generously sponsored his cycle ride across the Pyrenees which he undertook this June. He raised £1,400 for the Uveitis Information Group and 18 year son Paul who cycled with him, also raised a substantial amount for a low vision centre in Shetland.

For those of you who are unaware, as many of you may be, Phil is registered partially sighted, with limited central vision. He clearly demonstrates to anyone who has lost functional vision that it does not necessarily hold you back as long as you can adapt.

The route crossed the Pyrenees from Hendaye on the Atlantic Coast to Cerbere on the Mediterranean Coast. It was 450miles long and climbed 7 vertical miles, taking in 18 high mountain passes. The pair completed it in less than 100 hours and found some very untypical June weather along the way encountering rain every day and even snow over the Col du Tourmalet.

FUNDRAISING OPPORTUNITIES

“Easyfundraising”

There is a very easy way to raise funds for the UIG and it needn't cost you anything! www.easyfundraising.org.uk is a website which provides a FREE service where you can shop with your favourite online stores and, at no extra cost, raise funds for any charity you want to support. UIG is registered so that we can be selected. First you have to register on the site, and then, having signed into your Easy fundraising account, you simply shop with each retailer as you would do normally, by using the links from the site to visit each online retailer. Each purchase you make will generate a cashback donation to your chosen charity. There are over 2,000 retailers involved including all the main online ones such as Amazon, Tesco, John Lewis, Argos, Insurance companies etc.

It is easy to register with the site by using the web address above and select the UIG as the charity to support. If members of the UIG, and our family / friends can get into this habit, the potential for raising funds for the UIG is great.

UIG Website Sponsorship, The Eyebag Company

We would especially like to thank Mr Teifi James of the Eyebag Company for kindly sponsoring our UIG website and also the website development for INTUPIA, the newly formed international association of national patient groups. The 'eyebag' was developed by Mr Teifi James, an Ophthalmologist in the UK with a special interest in uveitis for patients with dry eye.

“Health professionals frequently advise daily warm compresses for lots of common eye problems – Dry Eye, Blepharitis, Styes and Cysts. Hot wet flannels are ineffective and compliance is poor. The EyeBag is designed to treat these conditions. The EyeBag is a simple re-usable black and silver silk hot-compress. It is designed to be heated in a microwave for 20-30 seconds just before use and can be re-heated around 200 times. It is usually used twice a day for the first fortnight and several times a week thereafter.” The Eyebag Company has a website at www.eyebagcompany.com

We have had feedback from patients that the use of hot, or sometimes cold, compresses can give some additional relief to the symptoms of anterior uveitis (although, of course, this should never replace treatment or cause delay in seeking it).

Birdshot Patient Day

Birdshot chorioretinopathy is one of several types of posterior uveitis. Annie Folkard and Rea Mattocks, both Birdshot sufferers and now UIG Board members have set up a ‘sister’ group within UIG to advance the cause of Birdshot sufferers. Their immense hard work culminated in a very successful Patient Day in September. The conference which was put on with much assistance from consultant Narciss Okhravi and Moorfields Eye Hospital staff was sponsored by a large number of organisations including the following:



Without this generosity, the Birdshot Day would never have happened. The day brought patients and professionals together to learn from each other, hear about the latest treatments, build a Birdshot community, lobby for better treatment and agree to work towards supporting research for this very specific form of posterior uveitis which tends always to be a long term problem. Audio files of interviews from the day can be found on the Birdshot Uveitis Society’s website at www.birdshot.org.uk.

The Conference hopefully laid the foundations for a future Patient / Professional Day to cover the whole spectrum of uveitis types.

Smoking in Uveitis

We are sometimes asked if smoking has an effect on uveitis. Some recent research has suggested possible links although no absolute data exists to prove people who don’t smoke will do better but:

“If you smoke, you should consider stopping as some studies suggest macular oedema may be more common in people who smoke. There are lots of other good reasons for giving up too.”

John Olson, Consultant in Medical Ophthalmology, Aberdeen

NB Macular oedema is a relatively common sight threatening complication of uveitis

“Some patients will take systemic steroids and / or immunosuppressants. Patients on systemic treatments are increasing their risk of infection, and in some cases hypertension, hypercholesterolaemia and diabetes, and so having a healthy lifestyle, which includes giving up smoking, is to be encouraged”.

Dr Catherine Guly Specialty Registrar in Medical Ophthalmology, Aberdeen

Sight Loss. What can be done and what is Registered Sight Loss?

For people with uveitis, the risk of significant sight loss varies a great deal from very low to high. It is a good idea to get some sort of idea from your doctors which applies to you, so that apart from not worrying unduly you can appreciate what level of treatment and monitoring is best for you.

There are different types and degrees of vision loss of course, but it is apparent that many people who develop vision loss either are not offered this type of help, especially at an early stage when it is most needed, or do not know how to get the help they require.

One problem that exists in uveitis is that vision loss can be of a temporary or intermittent nature and this can be difficult to explain to employers, for example.

On a positive note, there are so many ways to adapt and cope with vision loss that it is hard to know where to start. Professional help in adapting to loss of vision is well worth taking up as early as possible even if your vision loss is of a temporary or intermittent nature. Low Vision Optometrists may be seen either in large eye clinics or in the community. Local voluntary organisations may also provide services in partnership with local health services. It should be possible to find out what exists locally by asking at your eye clinic, GP surgery or Optometrist. If you experience difficulty, we can usually help out. We would stress that anyone with a problem with their vision can make use of the professional services available to assist in adapting to life at work and home, without being registered.

Registration for Vision impairment

It is generally accepted now that the registration process for vision impairment is too slow and can delay tackling vision loss early on. However it is an important process to go through.

What is Registration?

To be registered, you need to be 'certified' as severely sight impaired (blind) or sight impaired (partially sighted) by a consultant ophthalmologist (eye specialist). If you are not currently seeing a specialist then your GP would need to refer you.

What vision is assessed?

- **visual acuity:** your central vision, the vision you use to see detail
- **visual field:** how much you can see around the edge of your vision, while looking straight ahead.

It is a combination of both of these which will determine if you satisfy the 'criteria for registration'. If you do then the Consultant will complete a form and, with your permission, this will be sent to the local social services who should contact you to see what may be done to help you. This will vary in England, Wales, N. Ireland and Scotland.

Benefits of registration:

1. It should trigger local access to services like Vision Workers, Low Vision Clinics etc
2. It records uveitis as a cause of vision loss which helps raise the profile of uveitis.
3. It may provide benefits, especially in Scotland where travel is assisted.

Anyone who wishes to go into this in more detail or ask advice should contact our helpline 0845 604 5660 or email us at info@uveiits.net. The RNIB also have many resources and information on the different aspects of helping with sight loss.

Keeping Healthy – for patients with uveitis

Patients with uveitis need to take care of their general health as well as their eye health. This is particularly important for those on steroid tablets (e.g. prednisolone) or immunosuppressive medication. This article will be covering some of the commonly asked questions but if you have any specific questions about your general health relating to uveitis you should contact your GP, ophthalmologist or uveitis specialist nurse.

Is diet important for patients with uveitis?

There is no diet that can prevent or control uveitis but you should aim to have a healthy, balanced diet. If you are taking steroid tablets your body does not process sugary foods as easily and so you should try and reduce the amount of sugar in your diet. Steroid tablets can boost the appetite leading to weight gain; having a low fat diet will help you to keep your weight stable. Eating foods rich in calcium such as dairy products and green leafy vegetables will help keep your bones healthy.

Can I drink alcohol if I have uveitis?

Yes, alcohol in moderation is fine. However, you should limit your alcohol intake if you are on methotrexate. The British Society for Rheumatology recommends that patients on methotrexate keep well within the national guidelines (no more than 14 units of alcohol per week for women and 21 units of alcohol per week for men).

Does smoking affect uveitis?

Yes, and it is advised that you give up smoking if you have uveitis. Recent studies have shown that smokers may be more

likely to develop complications of uveitis (such as macular oedema) and are more likely to have a flare-up of uveitis than non-smokers.

If you would like some help to give up smoking you could contact your GP or see <http://smokefree.nhs.uk>.

Does stress cause uveitis flares?

So far there is little scientific evidence that stress causes or triggers uveitis although we know that stress does have an effect on the immune system. However, many patients tell us that they feel that they are more susceptible to uveitis when they are under stress. It may be that there is a link between stress and uveitis but it is hard to prove as stress is difficult to measure.

I have heard that patients on steroid tablets and immunosuppression are more at risk of infections. Is there anything I can do to protect myself?

Steroid tablets and immunosuppressive medication do put you at a higher risk of infection although if you are otherwise healthy the chances of you having a serious infection are very low. You can help to protect yourself by making sure that you have a flu vaccine each year. If you are on steroid tablets and/or immunosuppressive medication you may also benefit from a pneumococcal vaccine which helps to protect you from pneumococcus infections (which include pneumonia and meningitis). Your GP can arrange for you to have these vaccines.

If you have not had chicken pox and you are in contact with someone who has either

chicken pox or shingles then you should contact your doctor urgently. Chicken pox can be more severe in patients on immunosuppression and so you may require a medication called immunoglobulin to give you protection from the infection.

Are there any vaccines that I can't have if I am on steroid tablets or immunosuppression?

You should not have live vaccines (such as yellow fever) if you are on steroids or immunosuppressive tablets. A live vaccine can actually cause an infection in someone who has a weakened immune system. Always tell your doctor which medications you are taking and they will check whether it is safe for you to have the vaccine.

I have been on steroid tablets for 3 months. How do I know if I am at risk of osteoporosis?

Steroid tablets can weaken your bones making you more prone to breaking a bone if you fall. This is called osteoporosis; having mild thinning of the bones is called osteopenia. Osteoporosis severe enough to cause a broken bone is rare in patients with uveitis, but osteopenia is quite common.

If you have been on (or are likely to require) steroid tablets for 3 months or longer you should be offered a bone scan (also called a DEXA scan) which is a type of x-ray that measures the thickness of the bones. This may be repeated (usually every 2-5 years) if you remain on steroids. If your bones show any signs of thinning you will be offered medication to help protect your bones. If you are over the age of 65 years you may be put on bone protection medication without having a bone scan as osteoporosis is more common as you get older.

Why is my blood pressure measured when I attend the eye clinic?

Your blood pressure may be increased if you are on certain medications like ciclosporin, tacrolimus and steroid tablets. Keeping your blood pressure controlled reduces the chance of you having a heart attack or stroke later in life. If your blood pressure is often high you may be advised to start blood pressure lowering medication.

Can I do exercise if I have uveitis?

Yes, exercise is good for your overall health, although you may prefer not to do anything too strenuous when your eyes are sore. Regular exercise has lots of benefits; it helps to keep weight steady, lowers blood pressure, helps control stress, and weight bearing exercise (like walking or running) helps to keep your bones strong.

If you have recently had eye surgery you should take advice from your ophthalmic surgeon as to when you can resume exercise.

Can I use alternative therapies or herbal medicines if I have uveitis?

There is no scientific proof that any of the alternative or complementary therapies are effective for treating uveitis. However, some patients feel that they benefit from these treatments when used in addition to regular medication. Just be wary about spending a lot of money on treatments that are essentially unproven. You should check with your doctor before trying any herbal medicines as these may interact with other medications.

Dr Catherine Guly
Specialty Registrar in Medical
Ophthalmology, Aberdeen

How good are we at taking our medicine?

Before we all say – “of course we take our medicines”, it is interesting and surprising to see the results of 2 recent studies. These have looked into how good patients are at taking their medicines and the results are dramatic.

Patients with uveitis often have to take more than one type of eye drop of varying strength and often different drops will be taken in each eye. A number of patients will also be on a combination of different tablets with or without drops. Because uveitis is potentially sight threatening, it is extremely important that the exact treatment/ advice is followed.

Adherence is a term used in medicine to describe ‘the active role of a patient in consenting to and following prescribed treatments.’ The following 2 studies looked into adherence, that is, at how well patients did what they were supposed to do in relation to the use of their prescribed medication.

Adherence to medication in a Uveitis clinic

Shabnam Sabah, Sadia Kalsoom, Philip I. Murray

*Academic Unit of Ophthalmology,
School of Immunity and Infection,
College of Medical and Dental
Sciences, University of
Birmingham, Birmingham, UK*

This first study was carried out in a major uveitis centre, and the staff were keen to make sure their patients were getting the best out of their treatment. They suspected that not all patients were taking their medicines as they should and decided to investigate.

A group of patients who were already on medication and had attended the clinic before were selected and asked:

- What was the name of their eye drop(s)?
- How often drop(s) were taken?
- Which eye(s) they were putting the drops in?

Patients also on oral therapy were asked about recall of medication name, dosage, and frequency.

Results:

- 30/63 (48%) patients did not know either the proprietary or non-proprietary name of their drops.
- 12/63 patients (19%) put their drops in the wrong eye.
- 24/63 patients (38%) used their drops at the wrong frequency.
- There were 26 patients (41%) who used their drops in the wrong eye and at the wrong frequency.
- Patients on more than one drop, and younger patients, were more likely to use their drops incorrectly i.e. either wrong eye or incorrect frequency
- Of those patients on oral medication (17/63, 27%), the vast majority knew the correct name, dosage, and frequency of their tablets.

Conclusions

Adherence to treatment with eye drops in uveitis patients was poor.

This in part may be due to the number of topical medications they are prescribed.

Patient education is paramount, and a written reminder containing instructions on how to use all medications should be provided for every patient that attends clinic.

The second study looks into the role of pharmacists and was carried out by the National Pharmacy Association this year.

A survey conducted by the National Pharmacy Association (NPA) has discovered that 29% of people in the United Kingdom, over the age of 50, admit they forget to take their prescribed medicine. While 22% stop taking their medicine before the end of the course if they feel better.

People who take prescribed medicines may take less than half the prescribed dose. Some forget, some misunderstand the instructions, and some refuse to believe they need medicines/ treatment at all.

John Turk, NPA Chief Executive said: "The statistics are not surprising as it is not always possible for GPs to enter into extended explanations about particular treatments, and even if they

do, patients may not remember or take in all the information provided."

"Most people associate their local pharmacy with the dispensing of prescriptions and see it as a place where they can also buy medicines over the counter. However, pharmacists should be seen as the first port of call for healthcare advice and the best source of advice on medicines."

The National Pharmacy Association is keen to encourage people to make more use of clinical services available from community pharmacy. Despite the fact that pharmacists have five years' training and are highly accessible many people are still unaware that they can discuss any aspect of their medicine related care with their pharmacist.

These 2 studies demonstrate a major problem and highlight the need for clear written instructions for ALL patients, detailing every patient's treatment, frequency and how long it must be taken for.

Where much is being done to research new treatments, it would be a shame if a simple way to improve outcomes for patients was overlooked.

In Scotland, as part of the Managed Clinical Network for Uveitis, this is hopefully being addressed.

We would be very interested to hear of people's (patients and healthcare professionals) experiences and suggestions on this.

The Role of the Specialist Nurse in Uveitis

The care of patients with certain medical conditions has been greatly improved in many instances by the introduction of Specialist Nurse Practitioners. They have important roles in the management of some chronic conditions such as diabetes and arthritis. A small number of Specialist Uveitis clinics benefit from the services of such nurses with a special interest and training in uveitis. Their main role is to directly support and counsel patients, provide information on treatment and drugs and increasingly to manage their overall care; that is, making sure that all relevant information on their past treatment, side effects, personal situation etc is all recorded and ready to hand.

Feedback from patients where this type of specialist uveitis nurse is present is predictably positive.

Having a post of uveitis nurse is usually seen as an extra cost and especially hard to justify these days. However, if the role of the uveitis nurse is carefully defined and developed, then the argument should be one of saving money. A recent article from the Journal of Nursing quoted below argues the case well.

"Specialists in the care of patients with rheumatoid arthritis save the NHS millions of pounds a year.

Nurses who are specialists in the care of patients with rheumatoid arthritis save the NHS millions of pounds a year, it was claimed last night.

In total specialist rheumatology nurses are already saving some £100 million a year, according to the Royal College of Nursing.

The nurses manage many of the out-patient appointments – allowing consultants to concentrate on new patients – and also reduce pressures on GPs by providing telephone support, the college said.

"We would ask you to think about your experiences at your eye clinic. There would be differences, of course, depending on whether you attend a dedicated uveitis clinic or not, but we would urge you to contact us with any thoughts you have on:

- whether there is a particular nurse who provides information and support
- if you think having a nurse supporting you with information on uveitis would make a difference to your experience in the clinic
- Any thoughts of what the role of a uveitis nurse should be.

The UIG, this year, is seeking to help make the case for the role of the Uveitis Nurse. Indeed in Scotland this role has been included in the Standards and Guidelines recommended for Uveitis management. Your feedback and views on this topic are essential to make the case and take this forward.

Annie Hinchcliffe is a specialised Uveitis Nurse at Bristol Royal Eye Infirmary and a member of our Professional Panel. She has developed a wide range of support services for patients and outlines the most important roles for a Uveitis Nurse Practitioner:

"The Uveitis Nurse Specialist has a pivotal role in the development of patient services to ensure patient safety, continuity of care, development of patient support networks and liaison between all agencies involved in a patient's care."

The UIG would like to hear from any nurses involved in eye clinics and with a role or an interest in supporting uveitis patients. We can help put you in touch with other nurses and hopefully develop a useful network.

“A Patient’s View”

We like to hear patient’s experiences and we know that people like to read them. Here, two of our members have kindly sent in their experiences and they describe situations we often hear through our helpline. Both these

stories raise the question of the possible need for better records which can follow the patient so that recurrences can be dealt with more consistently and some level of self management can be developed if appropriate.

1. By Yvonne Dingle, Cornwall.

I have had uveitis in my right eye caused by toxoplasmosis since 1980, when I was 33 years old. I did not experience any problems with diagnosis or treatment because I decided to attend Moorfields Eye Hospital A&E Dept where I was treated satisfactorily; I lived in London at the time and I moved to Cornwall in 1989. I did not experience a reoccurrence of uveitis until 1999 and to date I have had six flare ups the last one was in November 2007.

When the flare up occurred In 1999 I went to my G.P. who referred me to the Eye A&E at the local district general hospital, and I was seen on the same day by the duty Ophthalmologist who diagnosed posterior uveitis. She was concerned about my condition and asked the Consultant for her opinion. I was extremely fortunate that this consultant was on duty because she explained everything to me and I have been in her care ever since. I always feel involved in the decisions about my treatment and I have a lot of confidence in her.

However, since then my experiences at the Eye A&E Dept. have varied greatly. Although the Consultant always advises me to attend the dept. and obtain treatment as soon as the symptoms occur, the treatment greatly depends on the duty doctor’s willingness to listen to my history and to prescribe appropriate treatment. I always inform the doctor that the uveitis is due to toxoplasmosis and that the Consultant advises that oral steroids should be commenced straight away with clindamycin. Despite having posterior uveitis, I have been given steroid eye drops and an appointment

for two days later in the eye A&E Dept. to “see if it really is uveitis”. Once the doctor is convinced it is uveitis oral steroids have been prescribed, and an appointment given to see the consultant.

I find this situation very stressful which adds to the stress I am already experiencing because of being worried about further deterioration in my sight. I am not fully convinced the staff appreciates the way the vision is affected by uveitis. I am a registered nurse and I think I would show some empathy with a patient with any condition that compromised their sight. I am sure there is not a nurse in the Dept. that is experienced in uveitis or has a special interest in the condition.

However, when I attended the eye A&E Dept. in November 2007 I was relieved to find the duty doctor was very knowledgeable about my condition, and that he was interested in me as a person. He listened to my history and prescribed oral steroids and clindamycin, and I was given an appointment to see the consultant two weeks later. Therefore, I did not have endless visits to the eye A&E Dept before effective treatment was commenced.

I cannot fault my GP or the consultant ophthalmologist but I am not confident in the duty doctors as they vary greatly in experience and ability to diagnose and prescribe appropriate treatment. This is the part of my pathway that causes me most concern and stress to the extent that I have considered going to the consultant as a private patient for the first appointment to ensure getting appropriate treatment.

“A Patient’s View”

2. by Irene Houghton

I had my first attack of iritis in 1979. I had been suffering for about a week, being treated for conjunctivitis. I was alarmed when my doctor phoned the Eye Hospital and got me an appointment to see a Consultant that afternoon. I was told that I had iritis and that it was likely to recur. I was treated with atropine and steroid drops. I didn't have another attack for 10 years, but since then there have been several episodes, affecting both eyes. The latest was 4 years ago, immediately following surgery for breast cancer. The attacks rumbled on for 9 months, culminating in an injection of steroids because the inflammation was so severe.

I feel that obtaining treatment for my condition is far from satisfactory. The procedure here is that as soon as I suspect an attack I have to take myself off to the Acute Referrals Clinic at the hospital in

Shrewsbury 20 miles away. Although our local hospital is in the same Hospital Trust, it doesn't have an eye clinic. So every time I need treatment, there are 3 or 4 Consultations to check the progress of the condition, with a 40 mile round trip and a £2 car parking charge or train or bus fares each time. The first time I attended the clinic, no doctor was available, so a locum had to be summoned from an agency. When she arrived, she didn't give me the impression that she was really au fait with my problem.

Like one of the patients in the Uveitis magazine (UIG News), I get anxious when I'm going away on holiday in case I start an attack. The Consultant I saw after my latest episode said that he was happy for me to keep some steroid drops by me so that I could start treatment straight away, but that I should see an Ophthalmologist as soon as possible. How do I find such a person in a strange country or town?

How to Contact the UIG

Write to:

UIG
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Sweening
Vidlin
Shetland Isles
ZE2 9QE

Telephone:

0845 604 5660

e-mail:

info@uveitis.net

Website:

www.uveitis.net