



UVEITIS INFORMATION GROUP

NEWSLETTER

Summer 2009

Contents:

- Introduction ●
- News ●
- The Scottish Uveitis Managed Clinical Network ●
- European Uveitis Patient Interest Association ●
- Clinical Trials ●
- A Patient's View ●

Introduction

Welcome to this newsletter with apologies for the lateness of this issue. The UIG has been very active recently, notably taking up opportunities that are increasingly available for patient views to be represented. There will be reports on 2 such opportunities;

1. The involvement in a managed clinical network in Scotland, whose aim is to produce clinical standards and guidelines to improve uveitis treatment in Scotland.
2. Involvement in Scientific meetings of International Uveitis Societies putting across patient's viewpoints.

With additional volunteers becoming involved in the group recently, we shall be getting involved in promoting patient issues and be back to publishing an annual 'UIG News', and be mailing this out along with an issue of 'Uveitis', the journal produced for Patients and Ophthalmologists by EUPIA, the European Uveitis Patient Interest Association (see report on EUPIA below).

A lot of health information and correspondence is now in the electronic format, which is a good thing, but we remain completely committed to the printed word and indeed there are situations where it is still preferable.

Phil Hibbert

News

Membership:

Subscription and donations remain the prime means of funding the UIG. A subscription reminder form is enclosed for present members. If you have not yet subscribed to the UIG, then we would invite you to subscribe in 2 ways:

1. Fill out the membership form included with the newsletter
2. Go to our website: www.uveitis.net and click the link on the home page "print a subscription form". This can be filled out and posted to us.

We are looking at payment online and direct debits etc at the moment and will introduce this later this year as an option.

News for anyone affected by Birdshot Retinochoroidopathy (BR).

Rea Mattocks and Annie Folkard both have BR and have done a lot of work researching this form of posterior uveitis. Their interests include new treatments, finding out the number of people with this condition in the UK, and helping putting sufferers of BR in touch with each other. If you have BR, you can get in touch with us and we can send you up to date information on this form of uveitis.

Video boost for eye patients

A top eye specialist in Aberdeen has examined a patient in Dunfermline via a videoconference link.

It is the first time in the UK that a live tele-ophthalmology demonstration has been carried out on a patient with uveitis.

Video consultations for eye patients could rule out the need for a 220 mile round trip for some patients in Fife to the uveitis clinic in Aberdeen.

Professor John Forrester, an international authority on the disease, is head of the eye department at Aberdeen Royal Infirmary. Hospital eye specialists from the UK and around the world regularly consult him via the internet sending him images of patients' eyes.

For the demonstration Prof Forrester's clinic was linked to Queen Margaret Hospital, Dunfermline using videoconferencing equipment.

A special camera was linked to the video equipment and Prof Forrester could operate

the camera by remote control to examine the eyes of his patient sitting in Dunfermline, 111 miles away.

A video consultation with the patient took place allowing the consultant to outline fully informed treatment options and changes.

Dr Suzanne Brannan, a consultant eye specialist at Queen Margaret Hospital, organised the event. She said: "This is unique. It is the first time a videoconference consultation in uveitis has taken place. We are hoping to develop the system so that it becomes part of normal service delivery and helps to establish the managed clinical network in uveitis."

Dr Brannan said: "Overall, posterior uveitis is responsible for 10 per cent of all cases of blindness in developed countries. It is a very serious condition which has a major economic impact on the lives of patients."

Annual General Meeting

The UIG has always been run by a small committee based in the Shetland Isles. As we develop, it is now time to encourage more people to become involved in the group. Although a UK wide group, it is a Scottish Charity and an AGM will be held in the UK later in the summer. We would like to invite anyone who would like to attend the AGM, or to be involved with working with the UIG in any way, to get in touch with us. We can then keep you posted with dates and agenda etc. The AGM date once set will be posted on our website and the venue may depend on who wishes to attend.

The Scottish Uveitis Managed Clinical Network (MCN).

A major part of the group's work this year has been involved in the MCN in Scotland.

What does the MCN do?

It brings together Ophthalmologists, other related professionals and patients to work towards improving standards of care for uveitis and to enable that care to be patient centred

and available equally regardless of where the patient lives.

A patient focus group is one of the main parts of the MCN and is working to update patient information. It also makes a case for the provision of patient information, for ALL uveitis patients, to be a minimum standard of care.

What are Managed Clinical Networks?

“Managed Clinical Networks (MCNs) are linked groups of health professionals, patients and organisations working in a co-ordinated manner, unconstrained by existing professional and health board boundaries, to ensure equitable provision of high-quality, clinically effective services. Each MCN should be developed by a partnership of patients, clinicians and managers, and therefore should be effective in delivering care which is patient focused.”

The National Uveitis Managed Clinical Network (NMCN) was formed in the summer of 2008 under the auspices of the National Services Division of NHS Scotland.

Patient Pathways

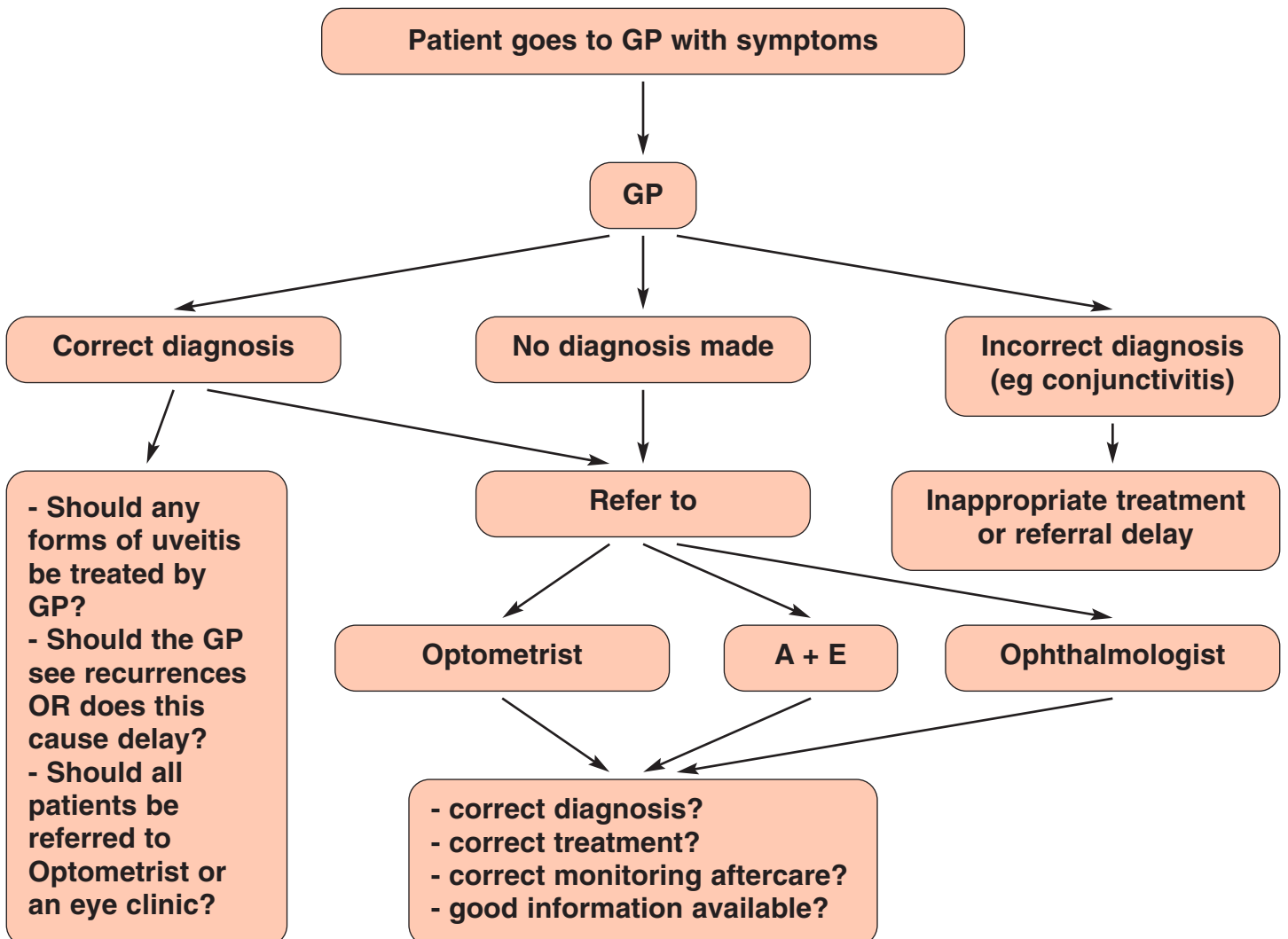
We are very interested, as always, in hearing about peoples’ experiences.

One of the things we are doing as part of the MCN is to try to map out ‘**patient pathways**’. That is, when someone first develops uveitis, who do they go to see first and what sort of pathways do they follow to get to see the “**right person, at the right place, at the right time**”?

Who do we go and see when we first develop symptoms of uveitis or when symptoms recur? Do we go to our GP, Optometrist, an Accident and Emergency Dept. or the Eye clinic?

Have a look at the diagram below and you should see there can be many ways that we can get lost along the way or become delayed in reaching the right person quickly enough.

An example is for a patient who visits their GP: The diagram serves to raise some questions



What can you do to help?

We have received very useful accounts of some peoples' problems with these pathways or just experiences in general (good or bad) and we would love to receive more because Uveitis Specialists are very keen to learn from them. They will prove very useful in developing clear standards and guidelines to improve the treatment of uveitis.

Please consider sending us some comments of your experiences, however short or long, by post, phone or email. Any information used / passed on will not involve names or places of treatment.

Uveitis Specialists frequently comment that one of the most important factors in a good outcome for uveitis patients is to get an early

diagnosis, early and correct treatment and to monitor closely for complications. This can be summed up by:

“Reaching the right person, at the right place, at the right time”.

The MCN will continue to work this year to provide standardised patient information which can be distributed to all eye clinics and hopefully all Optometrists in Scotland. They will form the basis of the UIG' s main leaflet available to all the UK. The clinical team of the MCN will, with patient input, draw up a 'patient centred' set of standards and guidelines to cover all aspects of uveitis care.

European Uveitis Patient Interest Association (EUPIA)

UIG has had contacts with other patient groups in Europe for some time, notably the patient group in Germany, DUAG. More recently groups have formed in France and Holland but there is very little help and support in most countries in Europe and elsewhere. As reported in the last issue, forming an association of patient groups could raise the profile of patient interest matters and achieve goals difficult for small national groups. Already interest has been expressed from specialists in India and Saudi Arabia who are keen to provide their patients with good information. The association will, no doubt, become an International Patient Interest Association.

EUPIA was officially founded in September last year at a meeting prior to the start of the International Uveitis Study Group's International Symposium on Uveitis at Constance in Germany. The group is open to national patient interest groups and the UIG is a founder member along with the patient

groups of Germany and France.

EUPIA is now present at the major scientific meetings of the 2 main Uveitis Societies, the Uveitis International Study Group (UISG) and the International Ocular Inflammation Society (IOIS).

These meetings offer a chance to get up to date information about current and emerging approaches to uveitis treatment and allows the national groups to develop good contacts with professionals working in the Uveitis field. It also offers a chance to get across patient's issues and to keep 'patient centred' approaches to uveitis to the fore.

Reports of these meetings will feature in future UIG News.

Clinical Trials and Uveitis

Clinical trials play an important part in developing new treatments for uveitis and also to see which of the current treatments work best.

But what exactly are clinical trials?

This article aims to explain what they are and how they may help some patients with uveitis. We recognise it is important to be able to find neutral information in this necessarily commercial area and so the UIG will work closely with Uveitis Specialists to make sure impartial information and good guidance is available.

The UIG currently has a section on clinical trials on our website and we will work with Uveitis Specialists to give news of as many specific clinical trials in uveitis and pass on guidance about how to become involved in new trials.

Our aim is to help people understand clinical trials and to give general background only.

For anyone considering taking part in a clinical trial, the aim would be to inform them of current trials and give them the necessary information regarding the specialist in charge of it and to allow them to discuss their participation with their doctors. We would make available the necessary forms and information for these trials in full. Any such information would have been prepared and approved by various ethics committees for that particular trial. It would include such things as benefits and risks of the trial, conditions for being accepted or leaving the trial and also things like travelling expenses etc.

Clinical trials can be initiated by drug companies or by research Institutes and uveitis specialists (researchers). In any of these cases, a specialist will be in charge of the study (chief investigator). These studies are submitted for approval by local ethics committees.

What is a clinical trial?

Clinical trials represent the best way of

demonstrating if a new therapeutic approach works and especially if it is safe to be routinely used in clinical practice. In a Clinical Trial the new approach is usually compared to the current one, and for it to be approved it has to be superior or at least equal, but with less side effects/toxicity.

They may be funded by drugs companies, government organisations eg NHS, or sometimes large charities.

What do clinical trials test?

We tend to think of clinical trials as testing a new drug to see if it works.

However, there are many more things which a clinical trial may be aiming to find out including:

- Is a new treatment actually better than an existing older treatment?
- It may want to compare two treatments which have been around for ages to see which is best
- It may be a drug which is tested but also may be a surgical procedure, a physical procedure, or even type of information or advice given to patients.
- It may be looking at 'alternative' or complementary treatments

How is a clinical trial planned?

Before treatments can be tested on humans, they will have already undergone extensive investigation in the laboratory and, where applicable, testing on animals.

If the results from these studies are positive, the next step is to seek approval to begin trials in humans. Approval has to be sought from the appropriate regulatory authority. In the UK this is the Medicines and Healthcare products Regulatory Agency (MHRA).

The researchers who will run the clinical trial must then draw up a **plan** (or **protocol**) which will include what the clinical trial is trying to find out, who and how many people will be recruited, information for those taking part and how results will be collected and published.

The plan then undergoes an independent scientific review and must also be approved by an ethics committee before the trial can go ahead. This is to ensure that the patient's best interests and safety will be looked after and that also the science and design of the trial is sound.

Once all this approval is received then the researchers can recruit patients to the clinical trial. **It is only at this stage that the official plans or protocol and how to apply will be**

published on this web site. From that stage onwards anyone interested in taking part in the trial must refer to the plan and contact the specialist / researcher conducting the trial, usually via their GP or Ophthalmologist.

News on current clinical trials can be found on our website and will be included in future newsletters. The UIG are happy to respond to any queries anyone may have about clinical trials.

“A Patient's View”

A Patient's View by Jean Briffet

I have had uveitis for at least 10 years with seeing problems for the past 5 or 6.

I thought it might be useful to give an account of my lens replacement operation because of cataracts caused by the steroid treatment for my uveitis.

It began last September when it was decided to replace the lens in my right eye because of cataracts forming in both eyes. My right eye is the best as my left has scar tissue due to wrong diagnosis about 10 years ago. I was quite apprehensive despite having had injections of steroids in both eyes over time.

I need not have worried, - it was better than going to the dentist.....they deadened and immobilized my eye by cutting the conjunctiva and inserting a small tube into the hole and squirting the anesthetic down the tube. The main challenge was keeping still for 45 mins. because my lens was coated with heparin and not bendy. This meant a larger cut and 2 stitches but I didn't feel a thing and felt very relaxed.

However after the op my uveitis kicked in despite having oral steroids before and after the op. I ended up taking "diamox" for high

pressure for 6 weeks which has very unpleasant side effects. This was followed by more oral steroids and eventually by injecting steroids into my eyeball - this was more scary than the op because they only used drops to deaden my eye and when the needle went in I jumped a mile off the operating table! It didn't really hurt - it was just unexpected as my actual operation was pain free and I expected the same as before.

Anyway it has done the trick and apart from a continual swirl (like my usual floaters really but a bit bigger), which is getting smaller and less dense, I can see again better than for years. I am still on steroid drops 4 times a day however.

Now though, I have to have my left eye done as the cataract is so bad I just see a white haze. I am hoping this eye stays settled with the oral steroids and drops, but if it takes 8 months like the right eye so be it. I can see leaves on trees again without being so close that I can touch them. Interestingly my new eye has different astigmatism 180 degrees different from the old one and it took about 6 weeks before I accepted that yes these were my new glasses and not someone else's! I have a slight tint in them which helps day to day work and of course I have sunglasses for all occasions, indeed I have a large handbag to

transport my 5 pairs of specs around and my shoulders ache!

I hope this helps any of you who are contemplating lens replacement, even with special lenses and uveitis it can work out for the good – eventually.

A Patient's View - Anterior Uveitis - My Story by Pauline Hoy

I had my first attack of Anterior Uveitis in my left eye about 11 years ago; unfortunately it was not recognised by my GP so by the time I took myself off to my local Eye Infirmary it was severe. I was prescribed a course of treatment and given a leaflet on the condition and told to go back if it didn't clear up. Luckily it did and I went another 5 years before my second attack, this time I recognised the symptoms and took myself straight to the Eye Infirmary. Again I was given a course of treatment and told to go back if it did not clear up. After the first attack I read up on the condition and so when I had the second attack I asked if they would investigate the cause but I was told they didn't until the third attack. I hoped I would not have another one but I did at the beginning of June 2005.

This time it did not clear up after the first course of treatment and I was not given the all clear until the beginning of September. As this was my third attack I asked about investigating the cause but this time I was told they didn't investigate unless the attacks were happening frequently, so once again I hoped I would not have another attack. A couple of days before Christmas the familiar symptoms were present so off I went again to the hospital and once again it had flared up. I was given the treatment and this time as it was a holiday period they asked me to return a few times so they could check on progress. When I asked about investigation the Doctor agreed. I had a chest X-ray and blood samples were taken.

At my follow up appointment a couple of

OTHER MATERIAL PRODUCED BY THE GROUP

- **Introduction Leaflet / subscription form**
- **Uveitis, a brief overview – an introduction; – good for interested organisations etc**

Fact sheets (including articles from previous newsletters).

- **What is Uveitis?**
- **Anterior Uveitis (Iritis)**
- **Intermediate Uveitis (includes the term Pars planitis)**
- **Posterior Uveitis**
- **Taking Steroids**
- **Complications of uveitis**
- **Keratouveitis, keratitis**
- **The treatment of uveitis**
- **Types of drugs used in the treatment of uveitis**
- **The need for patient information**
- **Uveitis and glaucoma**
- **A Glossary of terms**
- **Exercise: the benefits regarding uveitis and steroid use**
- **What is a vitrectomy?**

Note that most of these fact sheets are on the web site at www.uveitis.net

Fact sheets have been produced for the more uncommon forms of uveitis eg Birdshot Choroiditis and also for some of the more unfamiliar drugs used. Please ask for advice if you are not sure about the exact name of your condition.

weeks later I was told that the blood tests and chest x-ray were normal so I did not have any of the known causes. Good news but the cause therefore is not known. My eye was clear, so another week tapering off the drops and I could get back to normal. However that was not to be the case as I started to have symptoms in my right eye so off I went again and it was confirmed I had Uveitis in my right eye. Luckily I had caught it quite early therefore treatment was not so intense. So for a week I was using drops in both eyes. I finished treatment for both but then had to go back as my left eye had flared up again, but my right eye was okay. Another few weeks of medication then finally I stopped all drops. Brilliant for 4 days but by Thursday my left eye had flared up again, I received another course of treatment and a couple of weeks ago I was back again as

my right eye had flared up again. Last Thursday I was given the all clear in both eyes and I am still tapering off the drops

I am a 49 year old female, I was assaulted as a serving Police Officer 25 years ago when I received injuries to my neck resulting in cervical spondylosis. I have osteo arthritis in my hands and feet. I have problems with pain in my right hip, lower back pain, pain around my ears and inflammation in my heels I was diagnosed with temporomandibular joint pain some years ago.

I have recently seen my GP and she has referred me to a Rheumatologist.

Pauline Hoy

How to Contact the UIG

Write to:

UIG

South House

Sweening

Vidlin

Shetland Isles

ZE2 9QE

Telephone:

01806 577310

e-mail:

info@uveitis.net

Website:

www.uveitis.net