



Keratoconus Group

Newsletter Spring 2011

Next London KC Group guest speaker meeting

**Saturday 26th March
2011 10.30am**

*Clinical Tutorial
Complex, Moorfields
Eye Hospital (2nd
Floor) City Road, EC1*

*Any queries please
ring or email Anne.*

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2011 KC Group AGM on 26th March

Our guest speaker at the AGM will be our honorary president, Professor Roger Buckley who will talk about 'Keratoconus and the Eye Surgeon'.

The meeting starts at 10.30am in the Clinical Tutorial Complex on the 2nd floor of Moorfields Eye Hospital in City Road, London. All welcome, but if you like to come, please e-mail anne@keratoconus-group.org.uk or ring 020-8993 4759 so that we have some idea of numbers attending.

6th National Conference – 18th June 2011

The 6th KC Group National Conference will be held in London this year, in the Charity Centre close to Euston Station. Our last few conferences have covered the various treatment options currently available, so the main theme of the 2011 conference will be the help available for those with KC in employment, education and emotional support. We have booked speakers from Action for Blind People and from RNIB who will be able to update us on the help provided by disability staff in schools, colleges and universities, the Access to Work scheme and how far we are protected by disability discrimination legislation at work as well as talking about the services they provide to those with sight difficulties. As always, there will be plenty of opportunity for questions and also for talking to other people with KC and learning from one another's experiences.

The size of the venue means that places will be limited to 120 people but, funds permitting, we hope to record the event and produce a DVD that we can send to all our members in due course. Rising costs and dwindling income have also forced us to increase the suggested donation for attendance to £15 per adult though I hope you'll agree that this is still very good value for an all day event. If you would like to attend, please complete the booking form enclosed with this newsletter and return it to the KC Group.



Managing the dryness, the allergies and the discomfort of day after day contact lens wear in keratoconus

This is a summary of a talk given at a recent London KC Group meeting by Dr Sarah Janikoun, Associate Specialist in Ophthalmology at St Thomas's Hospital.

Dr Janikoun began by explaining that the front of the eye is crucial in terms of comfort and that there are many factors contributing to dry eye. The eye is coated in a layer of tears, consisting of three layers –

The top layer is the lipid layer, an oily layer produced by small meibomian glands on the eyelids

The middle layer is the watery aqueous made by the lacrimal gland

The inner layer of tears is the 'gluey' mucin produced by the squamous cells

If the tear film becomes thin, this can lead to problems – we need a thick cushion of tears for comfortable contact lens wear.

Dr Janikoun identified the following factors contributing to dryness –

- Blepharitis (a lid problem)
- Contact lenses (don't cause dryness but make it worse)
- London (pollution)
- Women are more prone to dryness than men
- Contact lens solutions (chemicals)
- Allergies (which people with KC are more prone to) Allergies thin the tear film and medication for allergies can add to the dryness
- Make up (powder in eye shadow gets into the eyes. Avoid powders near the eyes – perfume in make-up also makes things worse)
- Computers
- Driving
- Concentration

2009 Conference DVD

The DVD of our 5th National Conference, held in Glasgow in June 2009 is enclosed with this newsletter. The DVD includes a talk by an optometrist specialising in KC on managing contact lens wear successfully and talks from two ophthalmologists working in Scotland on corneal graft surgery, crosslinking, Intacs and intraocular lenses for KC as well as some members' stories. The DVD is being distributed free to all our mailing list members but of course, it wasn't free to produce!

Although we got a grant to fund the Glasgow conference from Awards for All Scotland, this didn't cover producing copies of the DVD. So do send a donation to the Group if you can so that we can continue to produce DVDs and other information in the future.

Remember you can download a Gift Aid form from the home page of our website to make your donation go further. And you can donate online by pressing the 'donate' button on the home page of our website www.keratoconus-group.org.uk

If you would prefer a booklet of the conference talks, please contact anne@keratoconus-group.org.uk.

The last 3 in the list all affect the blink rate – and people tend to blink less when wearing RGP lenses anyway. When we stop blinking, tears evaporate so we need to train ourselves to blink more often. Plants in a bowl of water on the computer desk will help to make the air less dry. And lubricating eye drops are helpful.

Blepharitis

This is a condition where the oil producing glands become blocked. There are many different types of blepharitis, which is basically an infection of the lid margins. The eyelids may become flaky.

If the blepharitis is really bad, then antibiotics and/or steroids are used. But the condition can often be controlled simple remedies such as –

- 1) Hot flannel massage – 2 minutes of pressing a hot flannel to the lids to dissolve the blocked oil
- 2) Dissolving some bicarbonate of soda or some baby shampoo in an egg cup of boiled water and using a cotton bud dipped in the solution gently along the base of the eyelid.

There are a number of proprietary ointments and drops which can help including Supranettes, Blephagel, Lid Care.

Cysts on the eyelid can also be helped by massaging with a hot flannel morning and night.

Contact lens solutions

Contact lenses need to be kept as clean as possible, but all chemicals need to be rinsed off before putting a lens in the eye. All contact lens cleaning solutions are detergents which dissolve oil, so need to be rinsed off with saline. Some people find inserting contact lenses with saline rather than soaking solution works for them.

Giant papillary conjunctivitis can be caused by ‘gungy’ lenses.

Antihistamines and steroids are used to treat GPC, but again simple measures will help avoid it occurring for example -

- Replacing contact lenses every two years avoids build up of deposits on the lens.
- Using preservative free cleaning systems
- Lens and lid cleaning with products such as Amiclear protein cleaner and Lid Care

These measures are worth taking even before there are any symptoms.

There are a number of useful lubricants for dryness. To avoid products with preservatives go for vials or minims rather than anything with a nozzle, which will contain preservatives. Jelly products tend to have preservatives. Lacrilube ointment does not and can be used at night,

Celluvisc comes in 2 types 'gloopy' and thin (the gloopy one is for use at night)

Other lubricants include Refresh Contacts, Systane, Visulube, Clinitas.

The range Hycosan, Hylocare is expensive but will last several months.

All these products have different viscosities, so it's a question of trying different ones to see which suit you.

Also important is keeping the contact lens case clean. After cleaning it should be dried with a tissue and then left to air dry.

Allergies

People with KC are more prone to allergies. Causes can be many including contact lens solutions, cats, pillows, washing powder, stress and life!

Remedies include – careful rinsing of lenses, care with use of make-up and moisturisers, avoiding too much sun, antihistamines.

Antihistamines in tablet form do not dry the eyes. Piriton and Cetrizine are available over the counter, Telfast is prescription only.

Eye drops over the counter include Opticrom (without preservative and used 4 times a day) and Allergic Eyes. Prescription only drops include Alomida, Rapitol and Opatanol. However, eye drops do dry the eyes and most contain preservatives so can't be used with soft lenses, piggybacking or hybrid lenses. Really bad allergies will need steroids.

Contact lenses

The fit, shape and material can all affect comfort e.g. a lens which lifts off and hits the edge of the eyelid, or a filmy scratched lens. Possible answers to greater lens comfort include –

- A new lens
- Steeper or larger lenses
- Changing the material to make it less gas permeable
- Making holes (fenestrations) in the lens
- Changing to a different type of lens eg Kerasoft; a hybrid lens such as Synergeyes or Clearkone; a lens such as SoClear or Slim/interlimbal lens, or piggybacking.

However, vision will always be better with RGP lenses.

In conclusion, Dr Janikoun made the following points –

- Oxygen permeability of the new lens materials, be they soft or hard, is greatly improved
- Soft lenses can be useful alone or under rgps
- There is now a huge range of new shapes and designs of lenses
- Surgery does not necessarily avoid contact lens wear.

Feedback forms on variable vision

Thank you to all the members who returned completed forms in response to the article on vision registration in the last newsletter. It's clear from the replies that a change to the rules on registration would help a significant minority of people with KC especially in terms of recognition for the condition and access to visual aids. While only a few people told us they had lost a job because of their vision or had been forced to take early or medical retirement, many more had times when they struggled at work, found little understanding from work colleagues and bosses and worried about time taken off work for hospital appointments or crises with lens wear. Similarly, a few members reported giving up or deferring a university course or getting a worse degree than expected because of the difficulties.

"I do not think of myself as disabled, but I have a problem which can sometimes be disabling"

Those members who had limited lens wear time told us that social life was often limited by the impossibility of wearing lenses long enough to cover both work and leisure time. Those with vision below driving standard also felt the deprivation of not being able to take children to activities or give as much help to elderly parents as they would have liked. All this led to some members experiencing loss of confidence and periods of depression and anxiety.

One of our members put the effects of KC in a nutshell –

"I do not think of myself as disabled but I would say that I have a problem which can sometimes be disabling".

We hope the 2011 conference will give us more information on how to manage KC at work and in education and deal better with times when it affects our lives. Meantime, don't forget that the KC Group has produced leaflets on 'Supporting Students with KC', 'KC at Work' and 'How the Law can help you at Work' which can either be downloaded from the website or obtained by contacting the KC Group.

Contact lens fitting workshops

From time to time, the KC Group is contacted by contact lens manufacturers who run workshops for optometrists in fitting different types of lenses for keratoconus. As there is often short notice of workshop dates, we tend to put information about these on the discussion forum of the website www.keratoconus-group.org.uk/forum There is currently a notice asking for volunteers

for workshops Ultravision is running this year for the fitting of Kerasoft IC lenses (special soft lenses that have been developed for KC). There was a similar notice for volunteers to act as 'guinea pigs' for a demonstration of the new SoClear lenses at a workshop a year or two ago. But we know that not all of our members have access to the internet and that those who do don't necessarily look at the forum regularly. So it would be useful to have a list of members who would be interested in volunteering for such workshops, and whom we could contact when we are approached for volunteers. By helping out at sessions like this, you would be helping manufacturers to produce better lenses for KC and ensuring that there are more lens options in the future. And you might benefit by finding there is a new lens that would suit you better than the lenses you currently wear!

If you'd be willing to have your name on a list of potential volunteers, please contact anne@keratoconus-group.org.uk or ring 020-8993 4759.

Research into KC in Glasgow

A Ph.D student at Glasgow Caledonia University (in the centre of Glasgow near the mainline railway stations and Buchanan Street bus station) is looking for people to take part in research at the Department of Vision Sciences. He is doing two studies.

Tear dynamics in Keratoconus RGP contact lens patients – the purpose of the study is to investigate the effect of RGP lenses on tear film dynamics of a group of KC contact lens wearers

Tear dynamics in post corneal graft soft contact lens patients – to investigate the change in tear film dynamics of post corneal graft soft lens contact lens patients and compare the results with normal soft contact lens patients.

Both studies involve just one visit lasting about an hour wearing your contact lenses.

Please support this research by volunteering if you can.

Evening slots are available for those working during the day.

You can contact the researcher by e-mailing

Raied.Fagehi@gcu.ac.uk or ringing 0141-331 3584.

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