Photochemical corneal collagen cross-linkage using riboflavin (vitamin B2) and ultraviolet light for keratoconus and other corneal ectatic disorders

This leaflet explains more about photochemical corneal collagen cross-linkage, including the benefits, risks and any alternatives, and what you can expect when you come to hospital. If you have any further questions, please speak to a doctor or nurse caring for you.

What is keratoconus?
Keratoconus is a condition that causes the cornea (the transparent dome in front of the eye) to get thinner and change shape, which results in reduced vision. It usually appears around puberty and progresses over the years. Keratoconus affects about 1 in 1,750 people, equally males and females, and occurs in all ethnic groups.

25 out 100 (25%) of all corneal transplants in the UK are carried out on patients affected by keratoconus.

What is photochemical corneal collagen cross-linkage with riboflavin (vitamin B2) and ultraviolet light, and why should I have it?

Riboflavin/ultraviolet corneal collagen cross-linkage (CXL) is a treatment that stabilises and strengthens the cornea, and stops the progression of keratoconus. Clinical studies have shown that the treatment stops the progression of keratoconus in about 95 to 98% of patients with up to six years of follow-up care, and improves the overall corneal shape in the majority of patients.

Your doctor has recommended that you have CXL with riboflavin and ultraviolet light because your keratoconus appears to be progressing and he/she believes you will benefit from the treatment.

What are the risks?
This is a fairly safe treatment but as with any procedure, there are some risks associated with it. They include:
- Infection and scarring of the cornea: this happens very rarely, in one out of every 100 patients, and can permanently reduce your vision which may require a corneal transplant.
• Progression of the condition: this can happen in two to five out of every 100 patients. Because the rate of progression of keratoconus is relatively slow, it will be a minimum of 12 months before we will know if the procedure has been effective. Improvements in vision and corneal shape do not usually occur until six to 12 months after the treatment.

The risks of this procedure will be discussed with you in detail. If you have any question about those risks or would like more information, please speak to a doctor or nurse caring for you.

Are there any alternatives?
There are no alternative treatments at present that have been shown to stop the progression of keratoconus. It is likely that without the treatment your condition will get worse.

How can I prepare for the treatment?
You can eat as normal before the treatment but you should only have a light meal.

You will need to organise for a responsible adult to accompany you to the hospital on the day of your treatment so they can assist you on your way home. They will also need to stay with you for at least three days after the treatment.

Please wear comfortable loose-fitting clothing.

Consent - asking for your consent
We want to involve you in decisions about your care and treatment. If you decide to go ahead, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

If you would like more information about our consent process, please speak to a member of staff caring for you.

What happens during the treatment?
The doctor will first apply anaesthetic drops to your eye to ensure you do not feel any pain. The central corneal skin (the epithelium) will then be removed and riboflavin (vitamin B2) drops applied to the eye for about 30 minutes. Once the B2 drops have soaked into the corneal stroma (thick, middle layer of the cornea), the ultraviolet light will be directed onto the cornea for about 10 minutes.

The whole treatment for one eye lasts 60 minutes. Usually, only one eye is treated at a time, with the second eye being treated a few months later.

Will I feel any pain?
You will not feel any pain during the treatment because of the anaesthetic drops used. Your eye will be painful for about for 24 – 48 hours after the procedure. To help relieve the pain, we will give you anaesthetic eye drops and painkillers to take by mouth.

What happens after the treatment?
You will be able to leave hospital, accompanied by a responsible adult, shortly after the treatment.

A contact lens bandage will be placed on your eye to help with pain relief and healing. It will be removed by your doctor at your first follow-up appointment a few days after the treatment.
Your vision will be blurred for one to two weeks and your will not be able to wear contact lenses for two to three weeks. You will be given antibiotic and anti-inflammatory eye drops to use for two weeks after the procedure. This is to minimise the risk of infection, and reduce the redness and inflammation in the eye.

**What do I need to do after I go home?**
Your eye will be painful for about 24 – 48 hours after the procedure and you will need to rest. The pain in your eye may be most severe for 12 – 18 hours but it will gradually get better.

If after this time your eye gets more painful, your vision gets worse, your eye becomes more red or you notice puss or discharge from your eye, you should come back to the Eye Department at St Thomas' Hospital or go to your nearest Emergency Department (A&E) immediately.

You should take 10 days leave from work and you should not resume any sporting activities for two weeks.

It is best that someone stays with you to help you for at least three days after the treatment.

**Will I have a follow-up appointment?**
A follow-up appointment for a few days after the procedure will be booked for you before you leave the hospital. It will take place in the Eye Department at St Thomas’ Hospital.
Contact us
If you have any questions or concerns about photochemical corneal collagen cross-linkage with riboflavin and ultraviolet light, please contact the anterior segment secretary on 020 7188 4331 (Monday to Friday, 9am to 5pm).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline
If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline. t: 020 7188 8748, Monday to Friday, 9am to 5pm

Your comments and concerns
For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.
t: 020 7188 8801 (PALS) e: pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) e: complaints2@gstt.nhs.uk

Language and accessible support services
If you need an interpreter or information about your care in a different language or format, please get in touch.
t: 020 7188 8815 e: languagesupport@gstt.nhs.uk

NHS 111
Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day. t: 111

NHS website
Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing. w: www.nhs.uk

Get involved and have your say: become a member of the Trust
Members of Guy’s and St Thomas’ NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.
t: 0800 731 0319 e: members@gstt.nhs.uk w: www.guysandstthomas.nhs.uk/membership

Was this leaflet useful?
We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, w: www.guysandstthomas.nhs.uk/leaflets, or e: patientinformationteam@gstt.nhs.uk

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