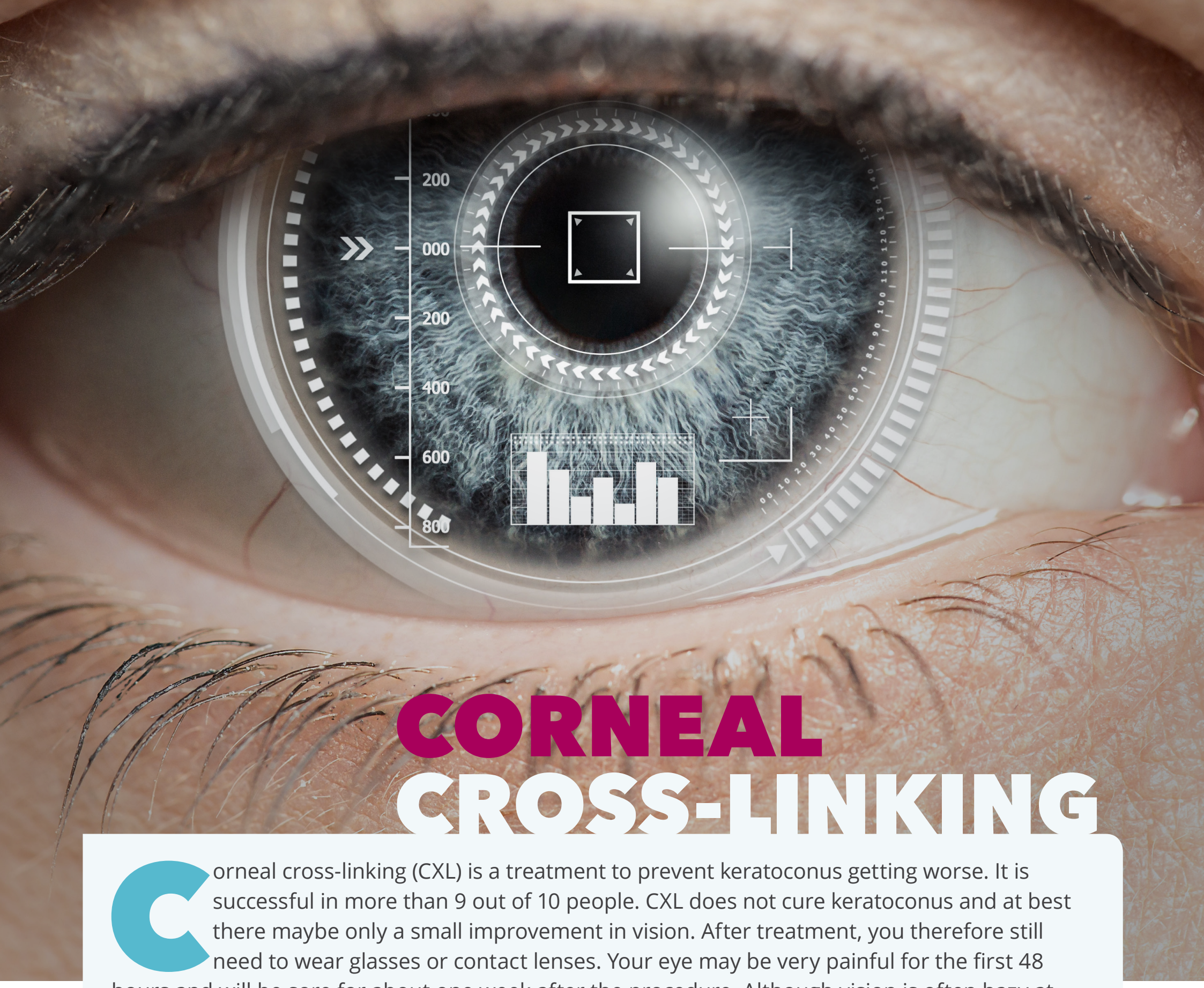

CORNEAL CROSS-LINKING

Corneal cross-linking (CXL) is a treatment to prevent keratoconus getting worse. It is successful in more than 9 out of 10 people. CXL does not cure keratoconus and at best there maybe only a small improvement in vision. After treatment, you therefore still need to wear glasses or contact lenses. Your eye may be very painful for the first 48 hours and will be sore for about one week after the procedure. Although vision is often hazy at first, most patients can resume contact lens wear and return to work after one week. As with all operations, there are risks: CXL is safe, but there is a small chance (about 1 patient in 30) of worse vision afterwards. As the treatment is not risk free, CXL is for patients whose keratoconus is progressing

What is Cross-linking?

Keratoconus gets worse because the cornea weakens and thins causing it to bulge into a cone. CXL, also known as C3R, uses ultraviolet light and vitamin B2 (riboflavin) drops to stiffen the cornea. Used together, they cause fibres within the cornea to cross-link – or bond more tightly. This treatment mimics the normal age-related stiffening of the cornea, which is known as natural cross-linking. Although there are several variations of CXL, the most commonly used and studied is the traditional method, called the Dresden epithelium-off technique and this is the method that we will refer to in this leaflet.

Will it work?

CXL is the only treatment currently available that appears to stop keratoconus from getting worse. Evidence from three big studies one year after CXL showed success in stopping keratoconus progression in more than 9 out of 10 patients, with more than 4 out of 10 people also gaining an improvement in corneal shape. Longer term results (up to five years) from a different study suggest a similarly high success rate in preventing keratoconus progression. Vision is slightly better after treatment than before in about half of the patients treated with CXL.

What are the risks?

In general, CXL is very safe, but like all operations your eye needs time to heal and problems do occasionally occur. About 3 out of every 100 patients having CXL will have worsening vision due to corneal haze, scarring, surface shape irregularities or infection. In the uncommon cases where the cornea becomes scarred affecting the vision, there are options to improve things. A transplant can be used to replace the cornea entirely if these complications occur, however, this is a much bigger operation with more risks and a long recovery.

Is it worth the risks?

Deciding to go ahead with an operation is a difficult decision for any patient. Studies on 'epithelial-off' CXL thus far have shown that CXL is effective at stopping keratoconus progressing. The complications from CXL appear largely minimal and temporary but it is still a relatively new procedure so long-term consequences are unknown.

An important part of weighing up if CXL is right for you is considering how fast your keratoconus is progressing and it is helpful to discuss this with your doctor to come to a decision.

Will I need to have both eyes treated?

Keratoconus typically affects both eyes. You may therefore need to have CXL on both eyes if the keratoconus is progressing in each eye. Treating both eyes in the same surgery however is not recommended due to the risks.

How will CXL affect my eyes long term?

CXL aims to stabilise keratoconus so in most cases your vision long term will remain the same. In a small proportion of patients their corneal shape improves after CXL resulting in a slight improvement in their vision. This small group who gains an improvement in their corneal shape may also notice their hard contact lenses fitting more comfortably onto their eye.

In some patients CXL will cause haze in their cornea, affecting the vision. This is usually at its worst after one month and remains the same until the third month when it begins to improve over the next year. The number of people who get corneal haze after CXL is unclear but has been found to be as high as 9 out of every 100 patients in some studies a year after the procedure.

What if I delay or do not have CXL?

Without CXL your keratoconus will progress as it would naturally. If your keratoconus is relatively stable it may be appropriate to monitor you instead of proceeding to CXL. This way you avoid unnecessary risks from the procedure for little gain. Even if you require CXL in one eye that is progressing, frequently the lesser affected eye is best just being monitored.

We know that keratoconus often stabilises after 30 years old so, if you are in this age bracket, again it may be more appropriate to monitor you instead of performing CXL.

If you do not require CXL or choose not to go ahead with it, it is important that you are still monitored regularly as if your keratoconus advances this decision may change. Crosslinking cannot be performed on a very thin cornea so regular reviews will ensure you are able to make up to date decisions on whether to have crosslinking before your cornea thins so much that it is no longer safe to have the procedure.

If your keratoconus is very advanced it may be too late for you to have CXL, but there may be other options such as a corneal transplant or specialised contact lenses.

Some patients may not be able to have CXL due to another eye condition such as herpes simplex keratitis, increasing the risk of complications.

THE CORNEAL CROSS-LINKING PROCEDURE

What are the different types of CXL?

There are many different ways, or "protocols", for doing CXL. One main variation is how the riboflavin is soaked onto the cornea. The surface skin of the cornea (epithelium) can be removed or left on (epithelium off vs epithelium on). The time that ultraviolet light is shone on the eye can also be varied - as rapid or classic. More experimental variations are being used in which other procedures such as laser or corneal ring operations are done at the same time as CXL.

Epithelium off cross-linking is considered the traditional method. Currently the National Institute for Clinical Excellence (NICE UK) has evaluated studies done for the different protocols. They only recommend epithelium-off as it has good evidence that it works, whereas epithelium-on and combined procedures do not have sufficient studies to back them up yet. What happens in the 'epithelial-off' treatment is described next.

What happens on the day of surgery?

CXL is performed as a day-case procedure in the operating theatre or consulting rooms. Although the procedure takes less than 60 minutes, there is usually some waiting time before treatment and you will also need to stay for a short while afterwards so we can check that you have everything you need to go home.

You will be asked to lie flat on the treatment table. Anaesthetic drops are used to numb the surface of your eye before a small clip is placed to keep your eyelids open. The surface skin of your eye (epithelium) is gently brushed clear and riboflavin drops are applied every few minutes for at least 10 minutes.

Following this, the ultraviolet light is shone at your eye. A soft contact lens may be placed on your eye at the end of the procedure and acts as a bandage.

RECOVERY AFTER CROSS-LINKING

What is the pain like?

The anaesthetic drops will wear off later on the day of your procedure, and your eye will be gritty, red and sensitive to light for several days. Everyone's experience of pain is different, with some patients reporting very little discomfort and others describing the first few days as very painful. Your eyes could be sensitive to light and many patients find sunglasses helpful.

What is it like straight after CXL?

You will be given eye drops to use after the procedure. The soft 'bandage' contact lens will remain in your eye until the surface has healed (usually in under seven days). If the bandage lens falls out during this time, please throw it away – do not attempt to reinsert it.

Your vision will be quite blurred at first, but will clear gradually over the first few weeks.

It is normal to experience fluctuating pain within the first two days after surgery. However, if you experience increasing pain three or four days after the procedure this could indicate infection and you should seek emergency assessment straight away. Please note that infection is rare, affecting fewer than 1 in every 100 patients.

What should I do, or not do, after CXL?

It is important to put the eye drops in regularly as prescribed. Wash and shower normally, but try to avoid getting water in your eyes. You may exercise, but should not swim before the surface of your eye has healed.

When can I drive again?

We will check your vision in the clinic within the week after your procedure to confirm if your vision is good enough to drive. It is normally safe to resume contact lens wear once the eye surface skin layer has healed. This typically happens around the end of the second week after your procedure.

Do I need to take time off?

Yes. You should allow at least one week off while most of the surface healing occurs, or two weeks if your job involves a lot of computer work, and the treatment is being done on your best eye. You will be putting eye drops in typically every four hours for the following days.

Day to day activities such as watching TV or using a computer will not do any damage to your eye, but you might find it more comfortable to rest with your eyes closed early on.

CORNEAL CROSS-LINKING IN CHILDREN

CXL is used less frequently in children and has been studied less than in adults. That being said some studies have performed CXL in children as young as 9 years old and have not found safety of the procedure to be any different from adults. However, how long CXL will last in children and side effects of the procedure are more uncertain than in adults. Although several studies have shown CXL to stop progression in a similar way to adults, some have found it is less effective with 1 in 4 children progressing despite CXL.

SAVE SIGHT KERATOCONUS REGISTRY

What is The Save Sight Keratoconus Registry (SSKR)?

The Save Sight Keratoconus Registry is part of the Fight Corneal Blindness! (FCB!) Project. It is a tool that allows you and your doctor to monitor your keratoconus and treatment journey including before and after CXL treatment as well as other treatments. Its innovative system collects data on your vision and eye shape at each clinic visit and stores it securely on a server at the University of Sydney.

A team comprised of clinicians and patients designed the Save Sight Registry and continually update and improve it with input from clinicians, patients and other stakeholders. The system is in use across Australia

How will the SSKR help you and your doctor?

The SSKR system can anonymously capture a lifetime record of your eye care. If CXL is needed, it then tracks your response to the treatment to determine if your eye remains stable as the effect of CXL may wear off over the years. It is also valuable for your safety as it can log any side-effects that you experience. SSKR is useful for your doctor; it assists them in tracking the progress and results of CXL for their patients, helping them improve the care they deliver. Only your doctor and their health care team can view your records to protect your privacy. The system also helps clinicians understand how keratoconus progresses and how it affects your day-to-day life. Understanding keratoconus and evaluating new treatments will help further research into finding a cure for keratoconus.

What can you do?

Ask your doctor if you can be a part of the registry to make sure you are receiving the best care.

Further information on the SSKR is available at

www.savesightregistries.org/registries/modules/fight-corneal-blindness

Save Sight Registries

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