Keratoconus Group

Newsletter Winter 2018

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Notice of Annual General Meeting

This year's AGM will be on **March 17th**. Much has happened in the last year and more is planned, not least the 2018 national conference in Birmingham. If you would like to hear more, help out, or even stand for our governing board, please do come along. If there are any board nominations or issues we should consider including, then details should be sent in as soon as possible. There is always lively discussion and we have a guest speaker as well, so please join us if you can.

The AGM is on **Saturday March 17th 2018** at 10.30am in the lecture theatre of the Moorfields Clinical Tutorial Unit which **is now located at 15 Ebenezer Street** (go up Provost Street which is across the road from the main hospital and you'll find 15 Ebenezer Street on the next corner).

Our guest speaker is **Dan Gore**, Cornea Consultant at Moorfields who will talk about his work on a CXL risk calculator.

All welcome - any queries to anne@keratoconus-group.org.uk

Lasers and Keratoconus

This is a summary of the talk given at the October meeting of the KC Group in London by **Mr Damian Lake**, corneal consultant at the Queen Victoria Hospital in East Grinstead. This was a wide ranging talk on the latest treatment options, in particular

Diary Dates

London — Join us at the AGM 17/3/2018.

Please see the story on page 1.

West Midlands

The next West Midlands meeting in Birmingham will be on **Saturday 12th May 2018**. More details will follow.

Sight Village events

Dates and venues for 2018 Sight Village events have been announced. Well worth a visit to see the latest in low vision aids and the latest IT technology to help those with sight difficulties, plus the help available from sight charities.

- Exeter 17th April
- Birmingham 10th & 11th July
- Leeds 25th September
- London 6th & 7th November

the role of the femtosecond laser (a specialist laser used for making precise and accurate incisions in eye surgery) and including a number of video clips of the procedures described.

Mr Lake began by showing Pentacam scans of eyes with KC. The average steepness of a normal cornea is about 40 dioptres and average thickness is about 550 microns (just over half a millimetre). In KC the steepness is greater than 45 dioptres and thickness is less than 500 microns with a value of above 400 microns needed for collagen crosslinking (**CXL**).

Keratoconus takes different forms and treatment was traditionally contact lenses or a corneal graft when lenses could no longer correct the vision.
The first corneal transplant was carried out over 100 years ago by Eduard Zirm using no stitches and no steroids. Currently, most transplants are done with a mechanical cutter (trephination) which does not produce a clean and regular cut and usually draws up the cornea slightly so that the edge surface is tapered giving a conical interface to the new graft. This then means that there is a small wedge to seal at the join so the stitching is almost bound to cause some distortion and, if sutures are too tight, this can cause astigmatism post graft. So how can transplant techniques be improved? In the 21st century, the use of a femtosecond laser to cut the cornea gives a more accurate and clean method and a more-even corneal profile post graft.

After a full thickness graft (Penetrating Keratoplasty or PK) there can still be an average of 4 dioptres of astigmatism and there is risk of rejection or blood vessels growing into the graft; in very rare cases (0.5%) there can be a bleed and total blindness. So surgeons are now trying to do less risky partial transplants such as DALK (Deep Anterior Lamellar Keratoplasty) which replaces the top layers of the cornea down to Descemet's membrane so leaving that and the endothelium intact. Mr Lake showed a video of a DALK operation using the femtosecond laser to cut the disc edge into and then go across the cornea to separate the layers

followed by a running stitch to hold the donor cornea. The laser can be precisely focussed at a specific depth in the cornea to create a microbubble (about 6 microns in diameter) and then a series of such bubbles can be joined up to make a vertical or horizontal cut. The femtosecond laser is so precise that it can even cut mortice and tenon type joints into the edge of the cornea leading to the intriguing possibility that an unstitched graft may be possible one day if suitable bio-compatible adhesives can be found! It was also noted that there is the Anterior Lamellar Therapeutic Keratoplasty (ALTK) which removes just the epithelium and top layer of the stroma.

Damian Lake

A meeting of corneal specialist from all over the world in 2015 in the United States produced a paper 'A global consensus on keratoconus and ectatic diseases' which set out the current pathways for treatment of KC. The flowchart from this paper is shown on page 5.
Collagen crosslinking was recommended for young KC patients who were suitable for the procedure and glasses where those could correct the vision. The next step was contact lenses, though not everyone is able to tolerate these. Where vision with contact lenses was unsatisfactory corneal rings should be considered if there was enough corneal thickness for successful insertion. Another suggested option was implanted lenses following CXL or in cases of stable KC or using laser to reshape the cornea. The 'last resort' treatment where there was corneal scarring would be a corneal transplant.

Collagen crosslinking was recommended for young KC patients who were suitable for the procedure

Collagen crosslinking has been carried out at East Grinstead since 2006. In 92% of cases the procedure stops progression, with 8% needing a repeat (children are more likely to need a repeat). The Royal Victoria is trialling a new machine which targets just the weak areas of the cornea to try to improve the vision. The main risk of CXL

The main risk of crosslinking is infection

is infection. Some people will get haze post CXL, which will usually clear up over time, or double vision.

Intra corneal rings aim to flatten the cornea and so improve the vision. They can be used alone or in combination with CXL. There is still no consensus as to which order is best – CXL first or rings first. They are made by several manufacturers. Intacs are 5 or 6 mm in size and there is now Intacs SK for more severe KC.

Kerarings come in different shapes and sizes. There was some resistance to using corneal rings because initially mechanical methods were used to create the channels for the rings. Using a femtosecond laser to make the channels gives much greater predictability.
Mr Lake quoted results of 80% of patients getting an improvement in unaided vision of 2 lines, 12% with no change and 8% with worse vision. The risks of corneal rings are infection and blood vessels growing into the cornea. Some people will get bothersome glare and may need the rings removed.

People can be refitted with contact lenses following the insertion of corneal rings. If the KC is stable, inserting an intraocular lens can improve the vision. The Artisan lens clips to the iris while another form of intraocular lens sits behind the pupil. Another option is to use laser to reshape the cornea (Lasik trimming).

KC Group conference

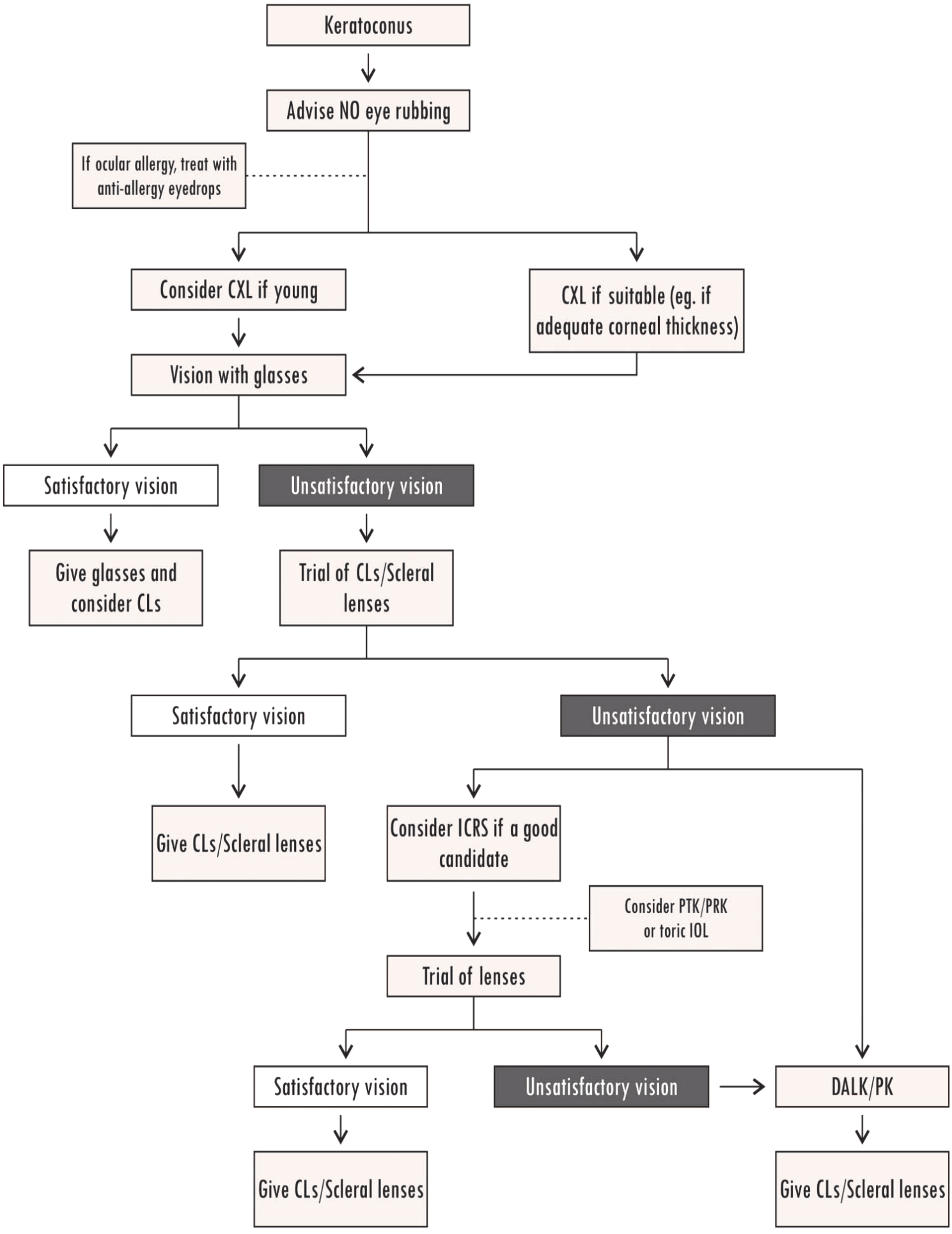
Another date for your diary—the 9th KC Group conference will be in **Birmingham** this year on **Saturday 15th September** so put this date in your diary if you are interested in coming.

As usual, the one day event will have a range of speakers - an ophthalmologist, optometrists, researchers and, of course, lots of other KC Group members to talk to and compare notes with. We will be sending further details and a booking form to all our members in a few months time. We hope to see lots of you there!

A Note from the Treasurer

Readers of this edition of our newsletter will see that we've included a Standing Order mandate which you can complete and return to us. A lot of our members already use this method of making a small but regular contribution. It is so helpful to have a regular source of income we can rely on (although of course we do very much appreciate ad-hoc donations of any size!) because it means we know we can cover fixed costs like the ones we have producing our newsletters.

We intentionally set the monthly amount at £1 because it is hopefully the sort of sum which many members can afford — without feeling bad that they're not giving a


Keratoconus
Advise NO eye rubbing
If ocular allergy, treat with anti-allergy eyedrops
Consider CXL if young
CXL if suitable (eg. if adequate corneal thickness)
Vision with glasses
Satisfactory vision
Unsatisfactory vision
Give glasses and consider CLs
Trial of CLs/Scleral lenses
Satisfactory vision
Unsatisfactory vision
Give CLs/Scleral lenses
Consider ICRS if a good candidate
Consider PTK/PRK or toric IOL
Trial of lenses
Satisfactory vision
Unsatisfactory vision
DALK/PK
Give CLs/Scleral lenses
Give CLs/Scleral lenses

larger amount. Because it is a Standing Order rather than a Direct Debit, you are in control of the amount. If once you've set up the donation you want to increase it, you can just ask your bank to up the amount to whatever Alternatively, you can cross out £1 and replace it with your chosen amount and initial your change.

Local Groups Contact Details

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The Charity's Policy on Data Protection

Data Protection law is changing on 25 May 2018 and as a charity we need to be ready for the new General Data Protection Regulation (GDPR).

We believe that the GDPR is a good initiative for the charitable and voluntary sectors because it confirms and enhances the rights of people who give their information to charities like ours – you'll have the right to be informed what data is held by a charity about you, for example, as well as the right to correct errors in the data held and the right to restrict what your data is used for (among many other provisions in the GDPR).

For our own compliance with the GDPR, we're sharing our own newly-written Privacy Policy. We'll also tell you here how you can make any changes to the data we hold about you – or even if you want us to remove any data we hold about you.

Our Privacy Policy

The charity will collect only the minimum data about you which we know is essential for us to provide our services to you. This data is used for the sole purpose of being able to communicate by us to you, our members. We will never sell your data to any third parties. We will never use your data to solicit individual donations directly – all our fundraising from our members is done as part of a general campaign such as the reminder you can donate to us by Standing Order which we've included in this edition of our newsletter. We will limit the data we collect about you to:

▫ Your name and postal address

▫ Your email address and/or telephone number, if you have chosen to advise us of them.

Unless compelled to do so by law, we will only share your data with a third party when it is necessary to produce our own communications to members (for example, to generate the mailing list for this newsletter where we send our printing company the current membership's names and postal addresses) or when necessary to carry out your specific instructions to us (for example, if you've asked us to reclaim Gift Aid and we need to notify HM Revenue & Customs).

You have the right to ask us what specific data we hold about you. You may want to do this to confirm we have the right information. You also have the right to request us to remove any of your data from our records at any time. If you want us to do this – or just want to make any enquiry at all about what data we hold about you – please do not hesitate to contact us by email at chair@keratoconus-group.org.uk or by post at the address shown below:

Keratoconus Self Help and Support Group
P O Box 26251
London
W3 9WQ

We will not make any charge for responding to these requests and we will respond within 30 days of our receiving the request.

Finally, our Data Protection Officer is the Chair of our Trustees. If we consider making any changes to this Policy in the future, our Data Protection Officer will consult with our members first, before making any changes.

Fundraising for research

While 10% of all NHS outpatient appointments are in hospital eye clinics, funding for research into eye conditions makes up only 1% of all funding for health conditions. That clearly has to change, and we'd like to encourage all our members to contribute to that change in any way they can. You will remember from a previous newsletter that the KC Group donated £4,000 to part of the large genetic study into KC being carried out at Moorfields and we hope to hear more about that at our London meeting in October. That grant was made possible by the efforts of one of our members, **Amy Musto**, whose employer, Barbican Insurance continues to support us as one of their charities of the year. In addition,

Get Involved

Barbican Insurance nominated the Keratoconus Group as the charity for last year's fundraising lunch organised by another insurance company, AON. That resulted in a wonderful donation of almost £8,000. We want to use this money wisely, and will be exploring a partnership with the largest charity that funds eye research in the UK, **Fight for Sight**. They have a scheme whereby they match fund with eye charities, doubling the value of the money raised. We hope to give members more news on this in the next newsletter.

Amy has now signed up to raise more money for research by taking part in the Eye to Eye Walk organised by the Moorfields Eye Charity on **March 4th**. We would love as many as possible of our members who live in or near London to join a keratoconus team on the walk. There is a 4 mile or 14 mile option and you can read more about the event at https://moorfieldseyecharity.org.uk/eye-eye-2018 where you will also find details of how to register. When you sign up, you'll find an option to register as a team - if you enter **keratoconus** in the team box, that will ensure that all money raised will go towards research into keratoconus. If you can't walk yourself, you can still raise funds by sponsoring one of our walkers - David Gable's Justgiving page is at kcgroup.org.uk/sponsor.

Although we are a small charity, run by volunteers, we can make a difference to the amount of money spent on research by teaming up with other eye charities. One of our members recently did just that - **Lesley Thompson** raised £600 towards the KC genetic research at Moorfields by abseiling down the Orbit monument at the Olympic Park - another event organised by the Moorfields Eye Charity. So thank you to Lesley.

We will, of course, continue to use our funds to produce newsletters, the KC Group leaflets that we distribute to hospitals and optometrists so that people with KC find us, to organise conferences and to subscribe to umbrella organisations such as Vision UK. But if there are gaps in what we provide, do let us know. It's your charity and we welcome feedback on how best we can help each other.

PO Box 26251, London, W3 9WQ. Telephone 020-8993 4759

A registered charity in England and Wales (No. 1057629), and in Scotland (No. SCO39552)