Keratoconus Group

Newsletter Summer 2022

Inside this issue

Keratoconus at Moorfields - Where we are and where we're heading

This was the topic of the talk given in London last March by Principal Optometrist Marcello Leucci. This was our first face to face meeting for members since before the pandemic. You'll find a video of Marcello's complete presentation on our website but this is a summary of his talk.

When people were referred for KC in the past, the hospital could only watch it get worse, provide contact lenses and monitor for future need for a corneal graft, with around 1 in 5 ending up needing a graft. Then came corneal crosslinking (CXL) and as treatments go, it's a silver bullet. It's 96% effective, it's cost effective and it's safe. In the past, 40% of grafts were done for KC - since CXL this has gone down to 11%. So CXL has really been a game changer.

The new KC service at Moorfields was set up in response to a lot more optometrists referring people and patients wanting CXL. In 2010 just 1 patient had CXL at Moorfields but since then numbers have climbed unbelievably, reaching a high of 867 in 2018. This would have overwhelmed the ordinary external disease clinic. In addition, NICE wanted the results of CXL audited to show whether it was effective and whether it would cause any problems in the future. At Moorfields, CXL is now carried out by nurse practitioners, with the service developing from a consultant led service in 2012 doing 5 eyes a month to nurse practitioners now doing roughly 100 eyes per month.

The outbreak of COVID in 2020 has had quite an effect. All clinics had to be stopped (1,300 appointments were cancelled between March and May 2020) and people's vision deteriorated. Another effect is that large numbers of people are failing to attend clinics (around 30% no shows for appointments). A young population with busy lives are putting KC on the back burner, not realising that their bad eye is getting worse because the 'good' eye takes over.

To clear the post-COVID backlog, new pathways have been developed. Previously the optometrists used to see all patients face to face. The current pathway is that optometrists see all new patients face to face to have a conversation about KC. They also see all patients for the first post -CXL appointment. But in between, KC is monitored by technicians performing scans and patients are only brought back to clinic if their KC is progressing. That means only 30% need to see the optometrist.

Marcello Leucci

"To clear the post-COVID backlog, new pathways have been developed"

Patients not eligible for CXL (for example because they need other surgical management or have uncontrolled atopic disease) are referred to the external disease clinic, and those that are contact lens dependent are referred to the contact lens clinic.

Vision and refraction are very unreliable indicators of progression. If you do two tests 45 minutes apart with a normal eye, you're likely to get different results. And in KC there is even less stability in refraction. So refraction is not used to inform decisions about eligibility for CXL except in very early KC. What does inform decisions is the scans that are done. The *Pentacam* machine has now been replaced by a new machine that does 3D scans of the front of the eye, which is far more accurate. An endothelial cell count is also carried out to make sure the back of the cornea is healthy and not at risk from the radiation of the UV

light. CXL is also only done with corneas of a certain thickness — if the cornea is too thin then CXL is avoided.

While tomography is far more reliable, it shouldn't be trusted without question. One pitfall is contact lens related corneal warpage. People are asked not to wear contact lenses for two weeks before a scan. But that's difficult and often patients won't tell you they haven't followed instructions. Another pitfall is the problem of eye movement; scanners don't have trackers to follow the eye. And the yellow dye used can make it seem that the cornea is thicker than it is. So a lot of training and effort is required to interpret scans properly. Scans are done at 6 month intervals; it was found that it was very rare to see change at 3 months, so the longer interval is more effective.

Clinicians are sitting on a mountain of data and now with the Electronic Patient Records, an audit of a treatment can be done at the click of a button. That has enabled research of the long-term treatment efficacy of CXL and redefining what progression looks like. Machine learning can figure out patterns, so this is the future of KC monitoring. *(This was covered in more detail in a talk given to the KC Group last year by Howard Maile, written up in the 2021 Summer newsletter, with the video on our website).*

From this, Moorfields has constructed a risk calculator to help clinicians make decisions. A combination of age at presentation and corneal shape (K_{MAX}, the maximum steepness of the cornea) are the best predictors of needing CXL at some point. If the patient is 16, it is highly likely they will need CXL whereas a 40 year old with a new diagnosis probably won't. (In response to questions, Marcello said the assumption that older patients will never progress is wrong - the chances are lower, but it can happen).

A paper on the five-year post CXL outcomes at Moorfields is due out shortly. It looks like about 2% need to have CXL repeated so it could be that patients don't need to be monitored for as long as five years after CXL, which is the current practice.

Find the KC group

On the web:
www.kcgroup.org.uk

On YouTube:
Keratoconus GroupUK

On Twitter:
@UK_Keratoconus

On Facebook:
Facebook.com/UK.keratoconus

We also recommend **facebook.com/groups/keratoconusGB** *[run by a member independently of the KC Group]*

"Vision and refraction are very unreliable indicators of progression"

Marcello ended by talking about some of the myths around contact lenses :-

1. *contact lenses stop KC getting worse* — not true.

2. *hybrid lenses are the best* — they have their place, but also have problems.

3. *if one eye sees well and the other badly, the good eye suffers* — No, it is the brain that does the seeing, not the eye. The brain creates two images, throws out the dodgy one and just uses the good one. So if a patient is happy with the vision they are getting without contact lenses, they shouldn't be forced down the contact lens route.

4. *soft lenses don't work in KC* — Soft lenses come in so many different powers now that they can be the right option post CXL.

For people who need rigid gas permeable lenses (RGPs), fitting those is an art that is dying or almost dead. So while there are still some High Street practices that fit them, most don't and most RGPs are fitted in hospital eye departments. Dan Ehrlich of Moorfields has recently had funding approved for research looking at using scanners to fit contact lenses. A standard contact lens fitting often means trying ten different lenses. Scanners could potentially select the most likely best first lens, reducing the time taken to find the optimum lens. (The idea of having the patient in clinic for less time is something that came out of COVID).

Selected Updates

That was the title of the talk given at the April West Midlands meeting by **Professor Martin Rubinstein**, Lead Optometrist at Leicester Royal Infirmary and lecturer at the School of Optometry, Aston University. Professor Rubinstein gave a potted history of keratoconus management from the first glass scleral contact lens fitted for KC by an American eye surgeon in 1888 to the present. He went on to talk about some of the exciting

RSVP

If you've had a corneal transplant at any time in the past, remember that there is always a risk of rejection.

Remember the "**RSVP**" danger signs:

- **R**ed Eye
- **S**ensitivity to light
- **V**ision change
- **P**ain

If you experience these symptoms get to A&E as soon as possible.

new research, new insights and new treatment possibilities for KC. So West Midlands members had a sneak preview of some of the topics Professor Rubinstein will be covering in his talk at our conference in September. Join us (see page 8) to hear about the latest developments.

Research News

Although the use of corneal crosslinking has meant that the proportion of transplants carried out for keratoconus has decreased, there are still people with KC for whom CXL came too late and who may need transplants now or in the future. There are also some who had transplants thirty or more years ago and who may need a regraft. And of course, there are other corneal conditions and injuries to the eye which may need a transplant. So when the KC Group was approached for a letter of support by researchers looking at ways of increasing the supply of donor corneas, we were happy to provide one. Historically, there has usually been a shortage of corneas (and, more recently, the pandemic has made this considerably worse).

A study looking at eye donation in hospice and palliative care settings has now been completed by a team from Southampton University, led by **Dr Tracy Long-Sutehall**. The research examined whether the availability of corneas could be improved by donations in these settings and what the barriers to donation were. The context of this is that the majority of cancer patients cannot donate organs or tissue, but **could** donate their corneas.

"Only 14 patients out of the 1,200 were approached to discuss the possibility of eye donation"

The research was carried out in three hospices and three hospital palliative care units in England representing different parts of the country. It involved several stages. First a retrospective review of 1,200 patient case notes was carried out to establish what percentage of these patients would have been eligible to donate their corneas. That demonstrated that 46% of the patients could have donated (the main factors that would exclude someone from donating were eye disease, eye surgery and neurodegenerative diseases such as Parkinson's or Alzheimer's). However only 14 patients out of the 1,200 were approached to discuss the possibility of eye donation. So potential donors were not

"95% ... were not aware that eye donation was an option"

being identified and the possibility of eye donation was never raised.

Two further stages of the research involved interviewing patients and carers about eye donation to establish how they felt about the subject, and sending an online questionnaire to health professionals in the selected hospices and palliative care units asking about current procedures. Both these stages were severely affected by restrictions and demands on hospital staff due to Covid.

But in spite of these limitations, the results were very clear. 95% of the 62 patients and carers interviewed were not aware that eye donation was an option and thought it should be raised as early as possible in end of life discussions. Patients felt donation should be their decision and that their views should take priority over their family's views. The survey of health professionals showed the majority had not had any recent training in relation to eye donation and didn't feel able to raise it with their patients.

The research has clearly shown potentially many more corneas would be donated if eye donation became a 'usual' option discussed with patients and carers. The study has developed an intervention STEPS - Support Toolkit for Eye donation in Palliative care Settings. When this is implemented by the Blood and Transplant-Tissue and Eye Service later this year, it should ensure eye donation is routinely discussed with patients, hopefully increasing the supply of corneas in the future.

KC and learning disability

People with learning disabilities are ten times more likely than the general population to have an eye condition. Latest figures suggest that as many as 1 in 10 of people with Down's Syndrome have keratoconus, but inequalities in eye care mean it often goes undiagnosed or is diagnosed very late. Seeability, the charity for people with learning disabilities and sight problems, wrote to the Health Secretary and the Chief Executive of NHS England urging them to legislate for everyone with a learning disability to be eligible for an annual NHS eye test as a 'high risk' group and to introduce an

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eye care pathway for all people with a learning disability. The Keratoconus Group was one of dozens of charities, organisations and individuals who signed the letter. You can find the full text here: www.seeability.org/news/joint-letter-calls-health-leaders-improve-eye-care-learning-disabilities.

A reminder for our members with a learning disability and their families that you will find excellent information about KC and how it affects this group of people on the Seeability website www.seeability.org/eye-care/eye-conditions/keratoconus.

Dates for your diary

Saturday September 24th 10am-4pm — The 10th **KC Group Conference** in the Moorfields Education Hub. More details on page 8 of this newsletter

West Midlands meeting Saturday 15th October 11am at the Priory Rooms, Birmingham. Details on page 8

Members Zoom meeting Saturday 5th November 11am with **Dr Tracy Long-Sutehall** talking about her research on eye donation (see Research News on page 5) To join, e-mail chair@kcgroup.org.uk for a link.

Sight Village events The KC Group will have a stand at the Leeds Sight Village on **Wednesday 21st September 9:30-3:30pm** at the Royal Armouries Hall, Armouries Drive, LS10 1LT and at the London event on **Tuesday 8th November 10am-6pm** at Kensington Town Hall, Hornton Street, W8 7NX. A great opportunity to see the latest technology for people with sight problems and see what other help is available.

Eye Contact Exhibition Wednesday 28th September 10am-4pm St Mary's Stadium, Britannia Road Southampton. Another event where you can look at all the latest technology to make life easier. www.opensight.org.uk/eye-contact-exhibition.

Definitions

CXL—Cornea Crosslinking

A procedure designed to slow KC progression

RGP—Rigid Gas Permeable

Small hard contact lenses, often used in early KC

Local Group Contact Details

West Midlands

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Our tenth one day conference

In-person or online

It's not too late to book for our tenth conference, postponed from June 2020. All members should have had details and a booking form. For the first time this year, there are two options - coming to the face to face event with the opportunity to meet the speakers and lots of people with KC, or joining the live stream (we successfully applied for a Lottery grant to cover the costs of this). As usual, there will be a variety of presentations — researchers and clinicians talking about the latest findings, optometrists suggesting practical solutions, and KC Group members talking about their experience of the condition, including the impact of the pandemic.

If you didn't receive the information or have mislaid it, you'll find full details of the programme and a booking form on our website. And if you don't have access to the internet, just ring the KC Group number **020-8993 4759** and we'll post you the information. The pandemic has meant our last conference was four years ago, so we'd love to welcome lots of you to the event.

West Midlands

The next West Midlands KC Group meeting will be held on **Saturday 15th October** starting at **11:00am** in The Priory Rooms, Birmingham (the same venue as April's meeting). There is no main speaker booked as this is planned to be more of a general meeting and information sharing opportunity. It will begin with a summary of the highlights from the National Conference in London that will have been held the month before and also to pick up on any points from that event which members want to discuss. It is quite likely that many from the West Midlands will attend the Conference virtually so this is the chance to follow up and for those who missed the Conference to learn more. Further details of the venue will be sent out nearer the time.

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Web: www.kcgroup.org.uk

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