



Keratoconus Group

Newsletter Spring 2022

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Notice of Annual General Meeting Saturday 19th March at 11am

We are very excited to be hosting our first live event for two years. Our AGM and speaker meeting is going to be held at the Moorfields Education Hub 1st Floor, 15 Ebenezer Street (the hub is opposite the main hospital). Cross City Road and go up Provost Street to the next corner and the Hub is facing you on the left.

Our guest speaker will be **Marcello Leucci**, Principal Optometrist and lead of the Keratoconus Monitoring Service at Moorfields Eye Hospital, London. Marcello will bring us up to date with the latest models of care for Keratoconus and other corneal ectasias, including an overview of his research and a look at how the KC service operates at Moorfields. He is well placed to answer our questions and no doubt will be just as interested in hearing from us, as we will be listening to him. We provide a free sandwich lunch which is always a good opportunity to meet other members and share stories. It is not necessary to register but it will be helpful if you let us know you are coming by sending an email to anne@kcggroup.org.uk so we can cater for numbers. For more information phone Anne on 020-8993 4759.

Please note that the Northern Line Bank branch is closed between Kennington and Moorgate, so people coming to Old Street from London Bridge should catch a 43 or 141 bus instead from the London Bridge bus station directly to Moorfields. From Waterloo, you should change at Euston or catch the 243 bus from Tenison Way.



Birmingham meeting

West Midlands KC Group live meetings resume on Saturday 23rd April at 11:00am at The Priory Rooms, 40 Bull Street, Birmingham, B4 6AF.

Professor Martin Rubenstein will present a talk entitled, 'Keratoconus 2022 - Selected Updates'

Young Patients and the Keralink Trial

This is a summary of the talk given by **Professor Frank Larkin** to the KC Group (via a Zoom meeting) in October 2021 on the Keralink Trial of corneal crosslinking in children aged 10-16. A video recording of the complete talk is available on our website.



Professor Larkin first gave the background to the Keralink trial, explaining that standard care for keratoconus has been spectacles, rigid gas permeable contact lenses when spectacles could not correct the vision, and corneal transplantation if contact lenses could no longer correct the vision or became impossible to wear. In the last ten years, crosslinking (CXL) has been advised for those in spectacles to avoid having to move to contact lenses, or for those in contact lenses to avoid further progression. There is often stabilisation of KC in the late 20s or early 30s.

CXL is normally done with local anaesthetic, but sometimes with sedation or general anaesthetic. It involves removing the epithelium (the top layer of the cornea) to allow riboflavin drops to penetrate the corneal tissue. The drops are administered for 10 minutes followed by UVA radiation for 8 minutes (this is the Avedro Rapid Protocol). A bandage lens is then applied for a few days and the first day or two can be very uncomfortable. CXL without removing the epithelium (known as epi on) is less painful but so far the evidence is that it is less effective.

“The Keralink trial involves 60 young people between the ages of 10 and 16 ”

Numbers of young patients with keratoconus referred to Moorfields have been steadily increasing in the last 10 years, with community opticians getting better at diagnosing the condition. For those whose KC starts in their teens, there is a risk of faster progression and of more severe KC. Professor Larkin showed slides of two 11yr old patients, both with hydrops (a tear in the back layer of the cornea) in one eye, while the other eye had no sign of KC or very minimal KC. He also showed a slide of a 14yr old who developed an infection of the eye after the CXL procedure. So one question for the trial was whether serious complications of CXL are more common in young patients. A slide of Pentacam scans of a 16yr old clearly showed the progression of KC over 29 months (Pentacam is the topography machine most often used for measuring the changes in KC eyes).

NICE gave approval for CXL in adults in 2014, but said there was not enough evidence for approval in children. Since then, CXL has been carried out in some youngsters, but there were no comparisons with those not receiving the treatment. There was also a wide disparity in availability of CXL across the UK. So Keralink was set up to answer the questions – is CXL effective in young patients and if so for how long; and is it safe in young people?

The Keralink trial involves 60 young people between the ages of 10 and 16 who were randomly allocated to receive either standard care or CXL. It is funded by the National Institute of Health Research (NIHR). Patients were recruited for the trial from Moorfields In London (the majority) and from Sheffield, Manchester and Newport. Recruitment started in October 2016 and continued until September 2018. The participants were then followed up every three months for 18 months, with the last follow up appointment of this first part of the trial in October 2020 (there were delays to follow up appointments due to Covid). Funding has been extended to allow for follow up of the youngsters for four years, so the trial will end in December 2022. There was no placebo in the trial, as it is not possible to do a 'mock' CXL. The investigators were masked *ie* the optometrists seeing the patients at follow up visits did not know who had had CXL and the

Find the KC group

On the web:

www.kcgroup.org.uk



On YouTube:

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[Facebook.com/UK.keratoconus](https://www.facebook.com/UK.keratoconus)

We also recommend
[facebook.com/groups/keratoconusGB](https://www.facebook.com/groups/keratoconusGB)
[run by a member independently of the KC Group]

“Funding has been extended to allow for follow up of the youngsters for four years”

“changes measured at 3 month intervals showed a steady increase in the standard care group, while the CXL group stayed broadly the same.”

ophthalmologists did not have access to the results of Pentacam scans. The main outcome for the trial was the K2 measurement (the steepest point of the cornea) from the scans, but other measurements included visual acuity (both corrected and uncorrected) corneal thickness, time to progression and quality of life measured by questionnaires completed by the youngsters.

Professor Larkin showed a slide of a flow chart of the trial showing that 240 patients were screened to arrive at the 60 needed (180 were not included for a variety of reasons including no progression at the start of the trial, previous eye surgery, consent not given). It was anticipated that parents giving consent for the trial would be concerned about what would happen if their child was randomised to the standard care arm of the study but showed significant progression during the course of the trial. For ethical reasons, to reassure parents and ensure that the best interests of the child were always followed, the protocol for the trial specified that in those circumstances, CXL would be offered, allowing for crossover to the other arm of the trial. A slide of the characteristics of the sample (eg age, sex, ethnicity) showed that 27 of the 60 were British Asian, a far higher proportion than in the community at large, so KC has a big impact in children of South Asian heritage.

A series of slides showed the main results. The changes in K2 measured at 3 month intervals showed a steady increase in K2 in the standard care group, while the CXL group stayed broadly the same. This was the key finding showing that CXL had halted progression. Graphs showing changes in corrected and uncorrected visual acuity similarly showed deterioration in the standard care group as against little change in the CXL group. After CXL, 2 of the 30 patients showed progression of their KC, as against 12 of the standard care group.

So the first random controlled trial of CXL in children confirmed the efficacy and safety of the treatment.

Should CXL be performed at diagnosis? 16 of the 28 youngsters in the standard care group did NOT progress and as CXL isn't a risk free procedure, Professor Larkin

felt CXL should be offered when there was evidence of progression. He ended his talk by summarising some of the problems of KC in young people: poor co-operation with topography, difficulty of wearing RGP lenses, rapid progression in some eyes, advanced KC in one eye at first presentation, CXL may require general anaesthetic, parental anxiety at diagnosis, higher prevalence of KC in young people with Down's Syndrome.

In the following question and answer session, Mr Larkin said the 1-4 scale which was used to classify the seriousness of KC has now been replaced by the accurate measurements of the Pentacam scan. On the effects of allergies, the Keralink trial was not set up to measure this, but in this small trial there was no significant difference. Eye rubbing was not asked about in the trial and is anyway very difficult to quantify. One parent asked about the likelihood of progression in the other eye (not possible to give an answer) and the effectiveness of epi-on CXL— scant evidence of any effect. On post CXL pain, Moorfields is getting better at managing this in patients.

Report on the Keratoconus Patient Day 27th November 2021

This was organised by the Moorfields Biomedical Research Council Patient and Public Involvement team, led by **Dr Helen Baker**. The main purpose of the day was to give feedback on the results of the Keralink trial to the youngsters who had taken part and their parents. But the day was also designed to disseminate the research findings wider, so the invitation was extended to other people with keratoconus, including members of the KC Group, and to optometry students at City University. It included talks about the latest research on crosslinking in adults and a session on what research we, the patients, would most like to see. Around 80 people came to this first 'in person' event since the beginning of the pandemic.

Professor Frank Larkin recalled that the first Moorfields Cornea Patient Day, back in 2013, gave support for a trial of crosslinking in younger patients. **Tulsi Parekh**, the optometrist who saw patients on the Keralink trial and **Kashfia Chowdhury**, statistician on the trial, then

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:

- Red Eye
- Sensitivity to light
- Vision change
- Pain

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

Definitions

CXL—Cornea Crosslinking

A procedure designed to slow KC progression

RGP—Rigid Gas Permeable

Small hard contact lenses, often used in early KC

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described how the study was set up and summarised the results at the 18 month point. The summary of Frank Larkin's talk to the Group in October covers this in detail. Tulsu went on to talk about the longer follow up which is now happening. Funding was obtained to follow up the participants for a total of four years to answer the question of whether the effects of crosslinking are long lasting in young people. There have been a number of challenges to the follow up, with appointments having to be cancelled due to Covid, resulting in patients not being seen in the right time frame, difficulties in contacting some participants who are now at university in another part of the UK and some not consenting to follow up. The requirement to remove RGPs a week before appointments proved impractical for some who were dependent on their lenses and has been dropped. Currently 39 of the original participants are being followed up. The questionnaire looking at the effect of KC on schoolwork has been replaced with a questionnaire more suited to adults.

The patient perspective

Carli and her son **Alfie**, who was in the CXL group, gave their experience of the trial. Alfie was pleased to have been in the CXL group, but described how painful the three or four days post treatment had been. (He has since had CXL in the second eye, which also painful for three or four days.) Alfie's mother spoke about schools not understanding the problems of having KC, appointments at specialist hospitals rather than the high street involving long journeys and time off school, lenses falling out and not being able to see the board. She hadn't come across the KC Group and so was unaware of the schools leaflet we have produced, explaining the condition to teachers. Alfie found it hard getting used to RGP lenses although he is happy with them now. CXL has stopped his KC progressing, though it didn't improve his vision. Like many people with KC, Alfie gets hay fever, but is proud to have finally learned NOT to rub his eyes. He described the importance of having the support of his family.

A Q&A session following Carli and Alfie's talk underlined a number of lessons we could draw. For hospitals, the transition from children's to adult services needs looking at. At the moment, there is an abrupt change at 16. For the KC Group, we need to make sure our leaflets, especially the schools leaflet, is available in children's clinics so that teachers know

how they can help any students with KC. Alfie was referred quickly to Moorfields by the High Street optician who suspected KC, but that wasn't the experience of all the youngsters in the trial. Community opticians need to be more aware of KC and of the importance of a hospital referral so that CXL can be offered to those who need it.

A mother's perspective

Catey Bunce, another of the statisticians involved in the Keralink trial, gave a personal perspective of the study. She began by thanking everyone who had taken part in the Keralink study, which had enabled her to feel confident in deciding on CXL treatment for her son when he was diagnosed with the condition. His experience contrasted with that of her half brother who experienced problems with his vision 20 years ago when he was an architecture student. After a series of misdiagnoses and no suggestions for treatment, he was eventually told he had KC and prescribed RGP lenses as his vision could no longer be corrected with glasses, and told he might need corneal transplants in the future. In fact, twenty years on his condition has stabilised.

Catey's son first mentioned problems with his vision when he was thirteen and an eye test at home showed that he couldn't see the chart with one eye. A visit to A&E gave a tentative diagnosis of KC, which was then confirmed in Frank's clinic in the children's hospital. The KC was already too advanced for CXL in one eye, but the other eye initially showed no sign of KC and was then regularly monitored. When progression was confirmed, CXL was performed in that eye. Catey summed up asking, so what has changed in the 20 years between the two experiences? There is more public awareness of KC now, but more still needs to be done. More High Street opticians now have scanning equipment, so KC can be picked up earlier. While most research proceeds in small steps, there are sometimes breakthroughs in treatment as with CXL, so there is always hope. And research now very much involves patients rather than medics deciding what is needed.

Frank Larkin summarised the effect of the Keralink trial on the future treatment of children at Moorfields. New referrals would have the diagnosis of KC confirmed with Pentacam



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scans. If no KC was detected, they would be referred back to their optician for 6 monthly checks. Moorfields would monitor those with KC for progression every 3 to 4 months and CXL would be offered in one or both eyes where progression was confirmed. He stressed the need to reach out to all opticians to refer children with suspected KC to a hospital clinic so that CXL could be offered where needed. Professor Larkin also reported on a study of corneal transplants in the under 16s which showed 97% doing fine 2 years post transplant, with good visual acuity and rejection free. These results suggest that, while in the past a transplant would not be offered while there was good vision in the 'good' eye, there is no benefit in delaying a transplant in this age group.

Dan Gore, the Moorfields consultant who runs the Early Keratoconus Clinic, talked about the current Moorfields pathway for newly diagnosed KC in adults. Since CXL was approved by NICE in 2013, treatments and referrals have increased year on year. In 2018, 880 CXL treatments were carried out in the Early KC Clinic. Follow up appointments to monitor any changes post CXL contributed to over 5000 outpatient appointments for KC in 2019. These numbers are a huge challenge. Dan then described the effect of the pandemic, when 1300 appointments were cancelled between March and June 2020. Overall in 2020, the number of CXL treatments dropped to 350, and KC outpatient appointments halved. The result has been some delayed diagnoses and missed progression.

This has resulted in a change to the way the clinic is organised. Technicians do the initial tests and scans and these are reviewed by an optometrist. For new patients, this is followed by a face to face visit to confirm the diagnosis, reassure the patient that the condition is not blinding and address any anxieties. There will also be a face to face visit following CXL treatment, but subsequent follow up scans are reviewed by an optometrist and followed up with a phone call. This



has resulted in a fourfold increase in efficiency and meant that it has been possible to catch up with some of the delays caused by Covid.

Dan went on to talk about the model that is being developed to predict who will need CXL, building on the research using artificial intelligence that Howard Maile told us about earlier in the year and reported on in the Summer 2021 newsletter (Howard's talk is also on our website). This will pave the way for personalised management of KC in the future. By inputting age, steepest corneal measurement, flattest corneal measurement, minimum corneal thickness, it is possible to compare similar patients and the time to progression. (While it would be useful to include ethnicity most patient notes do not record this). This will enable high risk patients to be identified (younger age, greater difference between the steepest and flattest corneal measurement, thinner cornea) allowing them to be prioritised and monitored more frequently, while low risk patients could be seen at yearly intervals. It will also enable better counselling of patients and their families.

Patient priorities

The day ended with an interactive session on our priorities for the future. The main points mentioned were:- promoting awareness and education about KC, with schools, high street opticians and other health professionals including GPs all needing to have more information; more research into the causes and trigger factors for KC eg hormonal, environmental, allergies; personalised contact lenses and more information on optimising lens wear; more research into the link with Down's syndrome and possible link with autism.

Coping during the pandemic

We all know the pandemic led to many cancelled appointments with eye clinics still playing catch-up. How has this and other Covid restrictions affected people with KC? Have you experienced delays to planned CXL or transplant surgery? Have you had issues with contact lenses which couldn't be addressed because appointments weren't available? Have there been positive effects, such

Moorfields Eye-to-Eye walk 2022

You are welcome to join our small KC team on the Moorfields Eye to Eye walk. We are doing the 15 mile route; there is also a five mile route if you prefer. See our website for details

The walk will be on **Sunday, 20 March 2022**. It is a new route exploring London's East End, starting and ending at Moorfields Eye Hospital

being able to work from home and the increased acceptance of at least part of the week out of the office in the future?

We would love to hear your KC related Covid stories and plan to have a session on this topic at our conference later this year. So please e-mail anne@keratoconus-group.org.uk or ring 020-8993 4759 to tell us about your experience.

Calling scleral lens wearers

Have you recently had replacement or new RGP scleral lens? Usually comfort and fit are pretty good. However, we hear there are a number of reports of discomfort, lens intolerance after a short time and poor visual outcome. These problems seem to arise even where the lens meets the prescribed parameters and/or has a similar specification to a previous lens.

Suggested causes include a problem with different materials now used, issues with manufacturing processes and/or some combination of both – or other causes as yet unknown. If you have any such or similar problems, please let us know by emailing info@keratoconus-group.org.uk or calling 020-8993 4759 so we can then highlight these concerns to manufacturers and practitioners. Many thanks!

December meeting

For our December Zoom members' meeting, we were joined by optometrist **Stephanie Campbell** (some of you will remember her from the Birmingham conference in 2018). She is one of the people advising on the new KC service in Wales now that cross linking is finally being funded there, and wanted to hear what KC Group members thought was important for people in a KC service.

Wales has been moving to a model of local optometrists taking on more of the monitoring of eye conditions, including KC, so there was some discussion about the advantages of services



close to home against people's desire to see an expert for diagnosis. Stephanie described a proposal for 12 specialist optometry practices across Wales which would have topography machines and be able to monitor newly diagnosed patients for eligibility for CXL.

Points members raised included :-

- the importance of clarity of explanations and options available
- signposting to other services such as assistive technology, work assessments, support in schools and colleges and, of course, the KC Group!
- the need to address the wide variation around the country as to what is available
- holistic care including awareness of co-morbidities and the implications for mental health of a KC diagnosis
- the need for expert contact lens fitters and a range of contact lens options
- the cost effectiveness of getting things right at the beginning, so avoiding more complex treatment down the line and avoiding the disruption of education and careers
- monitoring the children of people with KC given the possible risk of inheriting the condition
- co-operation between optometrists and ophthalmologists

Are there other aspects that are important that we missed?
Do e-mail your ideas to us info@keratoconus-group.org.uk.

2022 Conference

You may remember that we had a national Conference scheduled for 6 6 2020 but all our plans came to a sudden halt in March that year. We have been waiting for restrictions to end before reorganising the event and now that they have, we are going full steam ahead for September this year. We are currently checking out venues and speakers. As soon as we have a date, we shall post an announcement on our website and keep it updated with progress reports.

We are particularly excited about this conference as there have been many developments since our Birmingham

“Wales has been moving to a model of local optometrists taking on more of the monitoring of eye conditions”

Remember that you can watch videos of coffee morning and conference talks on our website or YouTube channel.

conference in 2018. So watch out for our flyer and booking form which will be posted around July, fingers crossed.

Coffee Mornings

Our Zoom coffee mornings have been a great success so we plan to keep them going even though Covid restrictions have been lifted and we are able to return to face to face meetings. They have proved to be a valuable means to connect with members throughout the country and we have learned a lot about what members need and want. Please check out our website for future dates or email david@kcggroup.org.uk if you wish to receive notifications of future Zoom meetings.

Sight Village Dates

- 26th April Sandy Park Stadium, Exeter. We plan to have a stand at this event, so come and see us!
- 28th - 29th June Birmingham
- 21st September Leeds

You'll find full details here:

<https://www.qac.ac.uk/exhibitions.htm>

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Did you know that you can raise funds for the KC group simply by shopping on Amazon as you would normally? All you need to do is start your shopping by visiting

<https://smile.amazon.co.uk/> (replacing the usual “www” with “smile”) and making a nomination of your preferred charity by searching for the word **keratoconus**.

Once set up, all future shopping using the Amazon shopping app, or at smile.amazon.co.uk will earn money for the charity; but remember that visiting the normal “www” site won’t. So far, we have received over £500 from Amazon through this scheme, and with your help, we’d like to get more members using this.

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Web: www.kcggroup.org.uk

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