Keratoconus Group

Newsletter Winter 2019

Inside this issue

Notice of Annual General Meeting

Saturday 23rd March 11am — London

Join us in the lecture theatre of the Moorfields Clinical Tutorial Unit at **15 Ebenezer Street** (go up Provost Street which is across the road from Moorfields main hospital on City Road and you'll find Ebenezer Street on the next corner).

Our guest speaker will be **Professor Alison Hardcastle**, who will update us on the Moorfields genetic research study which many of you will have contributed to either by taking part, or by supporting the grant of £4,000 we gave for some extra work on the study two years ago.

So come along to hear a fascinating talk plus updates on the activities of our charity in the last year and your chance to tell us what we should be doing in the future.

The meeting will end with a free finger buffet lunch and the opportunity to talk to lots of other people with KC.

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

Other dates for your diary

Saturday March 9th — West Midlands members' meeting

11am in the John Lewis Birmingham Community Hub (*above New Street Station*).

Speaker to be confirmed. Look out for mailings and website updates.

Saturday March 9th - Brighton members' meeting

A KC Group meeting at the Sussex Eye Hospital with corneal consultant **Mr Mayank Nanavaty**. Details to be confirmed - again look out for mailings and website updates

New local group in Bristol?

We are also hoping to arrange members' meetings in Bristol. Once we have a date and a venue, we'll update our website and mail members in the Bristol area.

Joint research grant with Fight for Sight

In our last newsletter, you will have read about our new partnership with Fight for Sight in their Small Grants Awards for research in eye conditions. This year we will be jointly funding a project at Nottingham University by a team led by **Dr Mouhamed Al-Aqaba** — "The *involvement of corneal nerves in the pathogenesis and progression of keratoconus*".

> *“corneal nerves are dramatically altered in KC”*

This research will run for a year from November 2018 with Fight for Sight and our charity each contributing £7,500. The research team has already identified that corneal nerves are dramatically altered in KC and will now be looking at whether these changes have a relation to the severity and progression of KC and identifying the types of nerves involved. This promises to increase the understanding of the condition, and may eventually lead to new interventions.

New and updated information sheets

We have updated our information sheets '***Supporting Students with Keratoconus***' '***Keratoconus at Work***' and '***Keratoconus - how the law can help you at work***' to reflect some of the changes in legislation and technology since they were first produced. These can all be downloaded from the 'publications' section of our home page. We have also added a new information sheet on '***how to get the most out of your contact lens appointment***' summarising the excellent talk given at our last conference by **Dr Waheeda Illahi**, Head of Optometry at the Birmingham and Midlands Eye Centre.

Collagen cross-linking

This is a summary of the talk given by Moorfields consultant **Dan Gore** at the London meeting for KC members in October.

Mr Dan Gore

Dan Gore called his talk "***Should everyone with KC have collagen crosslinking*** (CXL)?" to which the short answer was "No — we can be more targeted and clever at who gets it."

Dan gave a brief description of KC. The cornea does two-thirds of the focussing of the eye. So any distortion of the cornea affects vision and causes blurriness. Before CXL became available (although it is still not as available around the UK as it should be) the usual pathway for people with KC was spectacles followed by RGP contact lenses. Around 20% of people with KC would need a corneal transplant at some point.

A lot more is now known about graft survival rates, with an Australian study showing that 50% of full thickness (PK) grafts have failed by 20 years post graft. When a re-graft is done, that on average will survive for 10 years, while a 3rd graft will, on average, last half that time. While survival rates for partial grafts (DALK), which are now much more common, are predicted to be much better than for PKs, it is still important to find ways of avoiding the need for a graft for the majority of people with KC.

KC is usually diagnosed in the teens or 20s, so can affect education, work and career prospects. The effects are therefore potentially devastating for a young person starting out in life.

All that is changing with the advent of CXL, which can stop the progression of KC. So for newly diagnosed patients we now have a treatment which can stop KC getting worse and although there can still be a problem of access to the treatment or of late diagnosis, both are improving.

CXL involves applying anaesthetic drops followed by removing the front layer of the cornea (the epithelium) and applying vitamin B2 (riboflavin) drops and UV light. The whole procedure now takes around 20 minutes.

CXL is thought to strengthen the bonds of collagen in the cornea, although it is not known exactly how it works. It was first used in Dresden in Germany in 1997, with the first use of CXL in the UK in the 2000s. Moorfields Eye Hospital obtained funding to provide CXL on the NHS in 2012. Since then, the number of treatments carried out at Moorfields has steadily risen to around 1,000 each year.

> *“There is now greater acknowledgment that eye rubbing makes KC worse”*

Does CXL work? Success is defined as a stable corneal shape beyond 12 months. Results from Moorfields are:

	Mild KC	**Moderate KC**
6 months	91.7%	92.8%
12 months	93.8%	93.9%
24 months	92.5%	93.2%

Measuring the corneal shape with scans seems to be a better indicator than measuring vision, given how vision measured on the eye chart can vary from day to day or even during the day.

Moorfields monitor patients for up to 5 years before CXL and 5 years post CXL. This level of monitoring is very labour intensive.

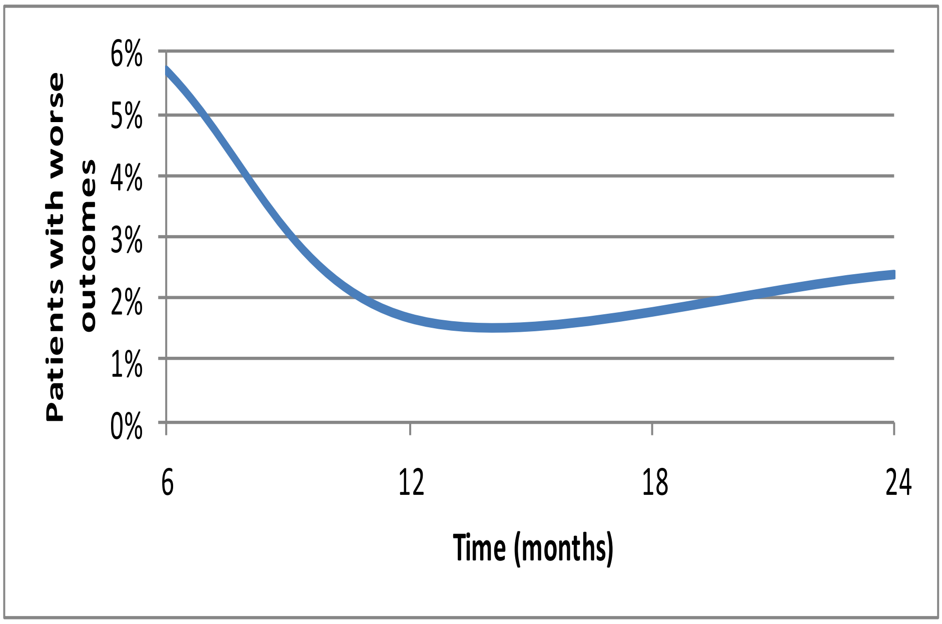
Clinical trials have shown 90% success with a single treatment, although the kinds of trials done in the past, where the control group were not offered treatment for the duration of the trial can no longer be done, as researchers can't just watch KC getting worse in a patient without offering CXL.

Moorfields 'Early Keratoconus Clinic' was set up in 2013 and has now seen 4,000 patients. Patients diagnosed are monitored for progression of KC and offered CXL where there is progression. If there is no progression in five years, the patient is discharged from the clinic.

So why not treat every patient?

CXL is still an operation and this means things can go wrong. The main risk is infection which could mean the patient ending up with worse vision than before. Corneal haze after CXL is common but temporary, usually lasting no more than 6-12 months when it does occur. But occasionally haze can persist and cause permanent damage. Infection can be very serious although very rare. Out of 4,000 patients seen, two needed an emergency transplant because of the infection. Recent research has also shown that there can be long term complications. 7% of eyes show continued flattening 10+ years after CXL. Although that may sound beneficial, the result is the need for constant changes of prescription.

Is CXL safe?



Safety is defined as the vision being no worse than pre CXL. Moorfields results are 5.7% worse at 6 months post CXL (mainly due to corneal haze) 1.7% at 12 months and 2.4% at 2 years.

Can we predict which patients are more likely to get worse and who would therefore benefit more from treatment? A study on risk factors for progression to corneal transplant was carried out in the late 1990s by **Stephen Tuft** of Moorfields. The main indicators were young age at diagnosis, race (with Black and Asian KC patients being four times more likely to progress), worse vision at diagnosis and finally eye rubbers. (There is now greater acknowledgment that eye rubbing makes KC worse.) Dan is currently developing a new risk calculator to predict progression of KC and identify those most in need of CXL.

The mathematical model used in the previous study used time from diagnosis to transplant as the measure, but this is not necessarily the best indicator, as it takes many years to progress to the point that a graft might be recommended and some patients may choose not to have a graft or to delay the decision. So current research is using the increase in steepness of the cone as the indicator. Another useful indicator for the future is to measure the strength of the cornea. The 'air puff' that is used by many opticians to measure eye pressure shows that a cornea that is weak will indent far more in response to the puff of air. This would be a very powerful tool to use at first assessment. However, the sophisticated machine that can measure this response accurately is currently only available in a couple of hospitals. In conclusion, a new risk calculator will use a combination of factors – age, race, vision, keratometry – to measure the steepness of the cone and corneal mechanics to measure the strength of the cornea.

In response to questions from members, additional points were -

- Approximately 40 patients so far (out of 4,000) have needed a repeat CXL procedure
- A number of modifications to the original CXL treatment have already been made and more are being tested *e.g.* duration of UV light treatment, concentration of riboflavin used, the possibility of not removing the epithelium (which would avoid the initial pain post CXL due to the cornea having more nerve endings than most other parts of the body). Another future possibility is replacing UV light with blue light (as currently used by dentists to fix fillings) which would have the advantage of being much cheaper and also safer.
- Moorfields is currently lowering the minimum corneal thickness below which CXL would not to be done to 375 microns (from the previous 400). This increases the number of people who would be able to have CXL.
- The link with eye rubbing and progression could be the explanation for the asymmetrical presentation of KC where one eye is usually affected more than the other.

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- The early KC clinic now does the scans to measure changes in the cornea without asking patients to stop wearing contact lenses for 2 weeks prior to the scan, recognising that this is unreasonable for those dependent on contact lenses.

2018 KC Conference

The setting was the majestic Priory Rooms at the Friends Meeting House, Birmingham. We were well served by the staff and an excellent sound and video team. The speakers were chosen by **Anne Klepacz** and **John Thatcher** and were asked to focus their contributions around the central theme of "***A Better Patient Experience***", which they did admirably.

Two of the speakers paid tribute to **Prof. Martin Rubinstein** in the audience, for his help and guidance in their early careers. I am pleased to say that he has agreed to speak at one of our West Midlands meetings next year. Videos of the talks are available on our website by following this link: tinyurl.com/kcconf18

The first speaker was **Mr Amit Patel**, Consultant Ophthalmologist at the University Hospital Birmingham NHS Foundation Trust. He gave a very insightful talk on his efforts to improve the patient pathway from diagnosis through treatment. The object to ensure that patients get appropriate treatment at important stages of their condition and early intervention of Cross Linking where appropriate.

He was followed by **Dr Waheeda Illahi**, Consultant Optometrist and Head of Optometry Services at the Birmingham & Midland Eye Centre (BMEC). This talk was

Mr Amit Patel

Dr Waheeda Illahi talks to David Gable

packed full of useful information to help get the most out of an eye clinic appointment. Waheeda clearly pointed out the compromises and difficult decisions that have to be made when assessing the most suitable contact lens. We have incorporated her ideas in a new Information Sheet which can be found on our website at tinyurl.com/kcfacts.

Mary Bairstow

The lunch break was a great opportunity for the audience to meet with the speakers and share KC experiences.

The afternoon kicked off with **Mary Bairstow**, a practicing optometrist, who now spends her time developing Vision UK’s national strategy for low vision services. She drew attention to the fact that there is a time, between finding contact lenses impossible to wear and receiving a corneal graft, when many of us are technically blind for all or

Dr Rubina Ahmed

part of the day and drew attention to the availability of low vision services.

Then followed **Michele Acton** (Chief Executive) and **Dr Rubina Ahmed** (Head of Research) at Fight for Sight, the leading charity that raises money for research into eye conditions. Michelle gave an overview of eye research and explained how her organisation had a commitment of £8m to research at 44 UK institutions. Rubina explained how they supported Keratoconus research through various schemes and partnerships.

Remember that you can watch videos of the conference talks on our YouTube channel or at tinyurl.com/kcconf18

The day was concluded by **Dr Stephanie Campbell**, a cornea optometrist in Bristol Eye Hospital. Stephanie has a passionate interest in the benefits of a strong relationship between primary and secondary care. She gave an update on her current project to integrate and create a multi team environment to serve the needs of KC patients.

The word ‘humbling’ was used several times by the speakers. The audience felt the same way, hearing how the professionals take our problems home with them and work tirelessly to make our lives better. It was clear that they recognise that as this condition strikes early, just as patients are starting to make

Dr Stephanie Campbell

their way in the world and with the right help, they can turn a disadvantage into a flourishing life.

Update on Clinical Development of an Ultrasensitive Optical Coherence Tomography (OCT) Device to Improve the Management of Eye Disease

Those of you who attended the KC National Conference will remember that the University of Liverpool were gathering feedback on a wooden mock-up of their new device which was in the breakout room at the conference venue. **John Thatcher** is a member of the Project Steering Committee and represents the KC Group as a Patient and Public Involvement voice.

John attended a meeting in November where the project reported progress and expressed great thanks to the KC Group for being able to attend our Conference and for all the comments received. The project has also taken the mock-up elsewhere and all the feedback obtained on it has been mostly positive. Suggestions and feedback from the public and patients have been incorporated into the ongoing design of the device and a working prototype is now nearly ready for initial trials. This new OCT device will be of direct relevance to keratoconus as high-resolution 3D maps of the cornea and its substructure will then be available benefitting understanding and diagnosis of the condition.

2018 'Visionary' Conference

'Visionary' is a membership organisation for local sight loss charities as well as involving the national organisations (RNIB, Guide Dogs etc). Its vision is for a world in which people living with sight loss can access the services they need at a local level where and when they need them and its mission is to develop a strong national network of good quality local sight loss organisations, covering all parts of the UK, to help achieve this. The KC Group is one of the 121 members making up Visionary (see https://visionary.org.uk for more info). Although very small in comparison with most other members, we are one of the few 'user' groups (as opposed to service providers) in Visionary and they are keen to have us involved.

The ninth annual conference took place in Aston in November with over 200 delegates present and John Thatcher attended representing the KC Group. The conference is an excellent way to develop links with other organisations and also provides the opportunity to raise the awareness of

KC and, more importantly, advise others of our existence as a body to provide help and support for the condition.

The conference involved a number of plenary sessions plus 28 workshops taking place over two days which provided networking and learning opportunities across the whole range of sight loss issues.

Moorfields Eye to Eye Walk - 10th March

David Gable, Chair of the KC Group, will again be doing this walk to raise funds for KC research at Moorfields this year. It would be great to have a KC team on the walk as we did last year. To join him, just register at www.moorfieldseyecharity.org.uk/eye-eye-2019 noting that you want to fundraise for keratoconus. And if you can't do the walk, but would like to sponsor David, just go to tinyurl.com/yccg46zt.

KC Group sponsors specialist training for optometrists

Many of you will know the name of **Ken Pullum**, Principal Optometrist at Moorfields from the talks he has given at KC Group meetings and conferences and will know of his tireless work over the years in developing scleral lenses for KC and promoting their use when corneal RGP lenses no longer work for an individual. This includes organising lectures and workshops through his own Hertford Optometry practice for optometrists who want to develop their skills in fitting KC patients.

Ken now organises a *'Keratoconus Symposium'* twice a year and this is attended by around 30 optometrists from around the UK and overseas, both in private and hospital practice.

> *“the KC Group sponsored two places for optometrists to attend the symposium held in October”*

With restrictions on NHS budgets, hospital optometrists are increasingly finding it difficult to obtain funding to attend such courses. So for the first time the KC Group sponsored two places for optometrists to attend the symposium held in October 2018. Several committee members also attended this symposium and one held earlier in the year, and saw for themselves how valuable this training was, covering all the different types of contact lenses used for KC and including practical fitting sessions to develop the optometrists' skills.

Huge thanks to our fundraiser

The concert in aid of KC research which we advertised in the last newsletter raised a splendid **£900**. We are immensely grateful to **Michelle Urquhart** and her fellow professional musician **Marco Van Pagee** for a wonderful evening of viola solos and duos. Michelle is the New South Wales representative of Keratoconus Australia, and had to give up her professional career when her eyesight was at its worst.

Following a second successful corneal transplant, she is back in the world of music and using her talent to support others with KC. The concert was held at the *Gallery Different* in London, where Michelle's artist sister was exhibiting her paintings. Our thanks to both of them and to the gallery for organising such a delightful event.

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