Keratoconus Group

Newsletter Spring 2023

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Emma McVeigh

Notice of Annual General Meeting

Saturday 18th March 2023 at 11am

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 optometrist **Emma McVeigh** who is going to talk to us about a new project led by **Dan Ehrlich** (retired Head of Optometry at Moorfields) who will also be there. They are looking at better contact lens design for KC, a topic close to many of our members' hearts. So do come along and hear about the latest lens developments. It's also a chance to give feedback about what is most important to us. We provide a free sandwich lunch which is always a good opportunity to meet other members and share stories. If you are coming please let us know by sending an email to anne@kcgroup.org.uk or phoning her on 020-8993 4759 so we can cater for numbers.

Before Emma's talk, there will be presentations of the chairman's annual report, the financial report and election of the committee. We are always looking for fresh ideas and new people to take the charity forward. If you're interested in getting involved, do contact Anne or David for a chat before the meeting.

West Midlands Regional Meeting

Saturday 25th March at 11am

If you can't make it to London then why not attend our West Midlands meeting which is held

at **The Priory Rooms, 40 Bull Street, Birmingham, B4 6AF**. The meeting will be hosted by John Thatcher and we are lining up a guest speaker who we cannot name at the moment. These meetings are an ideal opportunity to meet others with KC, socialise and share information. Please keep an eye on our website for updates.

Conference Summary

*"a recent Europe-wide study that suggests KC affects **1 in 350** people in Europe"*

In September 2022, we finally held our long delayed tenth one day conference, originally planned for June 2020. Although we had had to repay the Lottery grant we had been awarded for 2020, we were able to reapply, this time for an event that would not only be the usual 'in person' day, but that would also be live streamed. Our successful application meant that the conference was not only attended by around 50 people in the Moorfields Eye Hospital Education hub, but another 50 were able to take part online. And of course, the whole day was filmed as usual, so that everyone is now able to watch videos of all the talks online at bit.ly/KCconf2022.

We had a series of fascinating talks:-

Professor Stephen Tuft, corneal consultant at Moorfields, talked about the next steps in genetic research into KC and gave an update on the long running genetic research study that involves not only Moorfields patients but an international cohort of KC patients. It was a wide ranging talk which covered not only the search for the genes implicated in the development of KC, but also the increasing understanding of the biochemistry of the condition and of the environmental factors involved. He mentioned a recent Europe-wide study that suggests KC affects **1 in 350** people in Europe whereas the figure that used to be quoted was **1 in 2,000** (and the incidence is much higher in *e.g.* India or Iran). He pointed out that with collagen crosslinking (CXL) arresting the progression of KC, early detection of KC becomes very important, and rolling out techniques and methods for High Street optometrists to identify KC

is a priority. The genetic study has demonstrated that KC is a multi-gene condition, with over 30 sites of interest identified on the human genome. So more research is needed to find genetic markers for KC and the study is looking to recruit families which have 3 or more members with KC for this (see page 10). Professor Tuft thought it was likely that new treatments would replace CXL in the future and with better detection, it would be possible to stop KC before any visual loss had occurred.

Dr Sally Hayes, researcher at Cardiff University, talked about her investigations of the structural basis of KC. She explained that collagen is what gives the cornea its strength. In a healthy cornea, there are 250 interwoven layers of collagen. In KC there is less interweaving and the collagen layers slip and slide so the cornea is weaker and loses its shape. Her fascinating talk, illustrated with detailed images from electron microscopy and X-ray scattering, concluded with an explanation of how a cornea treated with CXL became four and a half times stiffer than an untreated one. She also explained how CXL also made the cornea more resistant to the enzyme attack that a KC eye is subject to, so avoiding the destruction of collagen which leads to KC progression in an untreated eye.

Professor Martin Rubinstein, Specialist Optometrist at Leicester Royal Infirmary, brought us up to date with developments in detection, measuring progression and therapies for KC. These included using photorefractive keratectomy (PRK) to fix the shape of the cornea before CXL and using a corneal implant called Xenia to stiffen the cornea (although there are currently reservations about the long term safety and stability of this procedure). Also mentioned were using stem cells to replace diseased keratocytes, and an eye drop now in stage 3 clinical trials called IV-Med. This is a copper based drop, designed to counteract the deficiency of the LOX enzyme in KC and is showing some promising results.

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]*

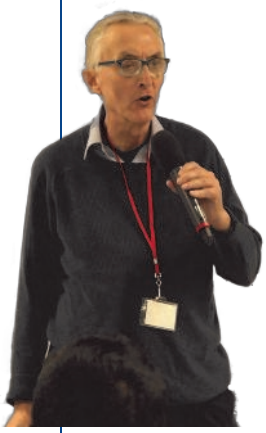
"a cornea treated with CXL became four and a half times stiffer than an untreated one"

"contact lenses only correct 65% of the aberrations in vision"

Over a buffet lunch, those attending had an opportunity to talk to other people with KC. It's so rare that we meet anyone else with the condition in our day to day lives, that the chance to find people who understand the issues is a really important part of our conferences and meetings.

Dr Trusit Dave, an independent optometrist with a practice in the West Midlands, opened the afternoon with a talk about his philosophy of fitting contact lenses for keratoconus. This included explanations for our poor night vision (the pupil becomes bigger, so we are seeing through more of the distorted area of the cornea) and explanations for why contact lenses only correct 65% of the aberrations in vision (the lenses can only correct the problems on the front of the cornea, not those at the back). Dr Dave now goes straight to scleral lenses for his KC patients and held out the promise of far more individualised fitting of lenses in the future with the new technologies now available.

Trustee and ex-chair of trustees, **Mike Oliver**, gave a moving personal account of how Covid prevented him getting much needed replacement lenses and then his emergency cancer surgery, still during the pandemic. The stress of that was increased by being literally 'in a fog', unable to put his lenses in and so effectively blind - not a condition a cancer ward was used to dealing with - and this led to talking about the importance of asking for help and the effect of physical problems on mental health.



Ken Pullum, Principal Optometrist at Moorfields, mentioned some positive effects on ways of working, with the use telephone consultations and looking at the potential of greater integration between hospital eye services and community optometrists. Points were raised

from the floor about possible delays to crosslinking treatments and corneal transplants due to Covid, though data on these is not yet available.

Ken also gave a talk about cataracts and KC and the day ended with a question and answer session. This is just a brief summary of the talks. Do watch the videos on our website if you'd like to know more about specific presentations. We are very grateful to all the speakers for giving up their time for us, and to staff at the Moorfields Education Hub for allowing us to use the venue for our conference.

In memoriam Professor Roger Buckley

It was with great sadness that we learnt of the death in October 2022 of **Professor Buckley**, who was the honorary president of our charity for most of our existence. Professor Buckley's support dates from its early days, when we were just a small group of Moorfields patients who met to talk about our experiences. It was Professor Buckley's encouragement that led the group to expand and become a national charity. He was unstinting of his time and wisdom, giving talks at several of our national conferences and at members' meetings in Moorfields.

Professor Buckley was Corneal Consultant at Moorfields from 1981 to 2004 and those of us who had the privilege of being his patients will be grateful not only for his skill, but for his caring and empathy. His understanding of the trials and tribulations of KC is illustrated by the fact that he also became Director of the Contact Lens department at Moorfields and made it his mission to ensure close working relationships between corneal surgeons and optometrists. This carried forward into his appointment as Professor of Ocular Medicine in the Optometry Department at City University in London, and subsequently at Anglia Ruskin University, so he was one of the pioneers of a multi-disciplinary approach to KC. He will be sorely missed.

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.

Definitions

KC—Keratoconus

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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Autism and me

by Martin Griffin, a KC Group committee member since 2020

My keratoconus coexists with autism; this is a lifelong, messy, real and complex neurodiverse condition. All my conditions are invisible: either disabilities or superpowers, limitations or strengths, depending on whom you talk to. To me these extreme reactions to autism, they are both sides of the same coin. The intersection of my conditions has shaped me, but they do not define who I am. Instead, they make me think and ask, what is considered normal and the uniqueness of all of us. Sure, my conditions and their interrelationships can drive me crazy at times but more importantly, they stir me to want to help and empower others at work and elsewhere.

Having a neurodiverse condition, is all part of neurodiversity, this is the way we think, process, move and act; our brains are all different. It is like comparing a manual to an automatic car; both are cars but driven in a different way. Therefore, neurodiversity addresses the concept that humans are not neurologically '*one size fits all*'. Our brains also change as a response to our environment either relaxing or stressful, and the things we do day to day. This means that it recognises everyone's unique abilities and considers neurological conditions and the associated differences, like autism, ADHD, and dyslexia, to be the result of variations in the human genome.

Autism is much more common than most people think. I am one of the fellow autistic people in the UK; there are around 700,000 in the UK, more than 1 in 100! There is much stigma associated with autism; it is not an illness or a disease. We who are autistic people share certain challenges but being autistic will affect us in different ways. Sometimes, the world feels overwhelming, and this can cause considerable anxiety. Some autistic people also have learning disabilities, mental health issues or other medical conditions, meaning there are different levels of support needed.

While autistic people share some similar characteristics, they are also all different from each other. The autism spectrum isn't linear from high to low but varies, just as one person

might vary from another. Some people with autism like myself, can live relatively independent lives but others may face additional challenges, which means each person's support needs are different. However, my autism has strengths, these being: unique sense of humour, honesty breeding trust, focus to complex tasks, detail orientated work, good and savant memory, intelligence and special interest.

A triad of impairments typically characterises autism: difficulty in communication, reciprocal social interaction and repetitive (obsessive) behaviours. With me, my autism also effects my mental process, memory, judgment and emotional process. Being an autistic person, I often find socialising and social interactions difficult. I, like many other people who are autistic, struggle with social and communication difficulties. There are lots of unwritten rules that humans use when talking to someone else, and these rules aren't always the same. Many times, I can find these rules difficult to remember or confusing because they aren't always applied in the same way. For example, I can find it harder to understand abstract concepts. Differences in social imagination can make it harder to cope with new, unfamiliar, or unexpected situations. Consequently, I hate uncertainty and like to know what is going to happen in advance and have set routines for the activities they do. I process sensory information differently and this can impact how I will interact with the environment and my ability to interact with other people. I can be 'under' or 'over' sensitive in any of the senses including balance, lightning, sounds and smells. All of which can be painful or very uncomfortable.

The impacts of my autism and its interaction with my keratoconus, initially as a university student, required one year out of my studies. This came as a complete shock to be told the diagnosis and adjusting my studying regime, for instance less reading of academic books. I needed a cornea transplant and graft including insertion of a fixed-length lens, as quickly as possible. I was a student without much support, thankfully most universities nowadays are well placed with dedicated staff and assistive technology to support those of us who are disabled. It was not easy completing my degree, but owning my conditions and understanding them gave me freedom to be my authentic self and provided me courage to

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speak up about what support I really needed via a Needs Assessment written by a specialist. Finally, claiming ownership of my keratoconus and autism at a early age, has provided me with much resilience to cope with stress and hardship. Then I transitioned into the world of work intertwined with periods of unemployment, bereavement, and disappointment, for instance not being and still unable to drive has closed many suitable positions. Thus, I am fully reliant on public transport (buses, trains, and the tube) and a sunflower lanyard (the symbol for hidden disabilities) to get from A to B.

Corrective options

My keratoconus offered to me require ongoing (about every five years) surgery to try to minimise its effects. Being a lifelong condition, KC has resulted in having partial eyesight (visual impairment) despite numerous operations (thank you NHS). Having a visual impairment, means I can see to a certain degree that causes problems not fixable by conventional means, such as glasses. Originally it was only my right eye was badly affected and in the last decade my left eye has shown some signs of the condition, enough to require additional surgery. It has meant travelling three hours each way to see my eye consultants, coupled with being very frustrated when trying to explain how I feel alone (my wife cannot get time off work) at the hospital. A hospital, a medical setting can be challenging because it is unfamiliar, necessitates a change in routines, and includes unique environmental stressors.

Martin Griffin

Over time, the NHS has been more accessible, welcoming and less scary. I feel all hospital staff should be sensitive and be made aware and trained in emotional intelligence, when dealing with patients who neurodivergent. Being people-centric, and the recognition of those

with special needs and better communication of individualized needs can have a significant impact on comfort, patient satisfaction and the patient experience. When preparing for hospital visits, to avoid excessive anxiety and overnight ruminations, I list down questions (health and social concerns) I would like answers to concerning assessment and treatment.

I also often have to ask staff to explain process, demonstrate equipment before using it; clinicians should clearly explain what they are doing and thinking and give clarity around clinical pathways. It helps if the importance of being seen on time and impact in terms of stress and anxiety when not seen on time is recognised, plus seeing the same clinician and ideally having some form of routine, *eg* having an appointment at the same time of day. It would help also, if I was offered longer appointments to allow time to process information but this rarely an option. Before operations, my wife and I recognise potential and actual stressors and help identify my individual needs as a patient with autism such as my pain threshold. Using bespoke coping strategies to me, I can calm myself down and manage my emotions to reduce the likelihood of adverse effects occurring such as having meltdown or a shutdown. But developing an effective patient to professional engagement means taking time to build engagement and rapport with the medical experts.

With all that said, forward the clock, from my initial keratoconus assessment approximately 30 years ago, I have a loving and caring family who accept me for all my neurological differences and oddities. I am very privileged to be working full time in an area very closely aligned to my interests and my university degree and working full time for a niche global consultancy within the mining engineering sector. Currently, I am working in London alongside a very supportive diverse team, acceptance and understanding by the senior leadership team, with a flexible working arrangement, and my reasonable adjustments such as speech-to-text software, scan pen are all thankfully in place. Therefore, with the right sort of support and others showing kindness, much can be done to help others to live more fulfilling lives of our own choosing.

Sight Village dates for 2023

- **Wales** (Cardiff)
  18th April 2023
- **Central**
  (Birmingham)
  17-18th July 2023
- **South West**
  (Exeter)
  26th Sept 2023
- **South East**
  (London)
  7th November 2023

KC stories

Do you have a KC story to tell?

We're keen to hear from our members - your experiences are just as important as the latest talk from a health professional!

Please send contributions to anne@kcgroup.org.uk

Do you have family members with keratoconus?

Professor Stephen Tuft writes

Our research into the genetic basis of keratoconus is ongoing. We know that genetic factors determine the risk of developing keratoconus, but environmental changes (e.g., eye rubbing, allergy) can then affect the rate of progression and the severity of the keratoconus.

In 2021 we published the results of the world's first large genetic study of keratoconus, which identified 39 genetic signals that influence the risk of developing corneal change. The study involved the participation of 4669 individuals with keratoconus, the majority from Moorfields Eye Hospital and the UK, and several other centres worldwide. We want to extend these studies and advance this research to learn more about the disease. One method is to enlist the help of families with multiple members affected by keratoconus.

Stephen Tuft

If you have **three or more** close family members diagnosed with keratoconus, such as parents, brothers or sisters, or children, we would be happy to discuss your participation. Participation would involve examining the eyes to confirm the presence of keratoconus and a small blood test to analyze your DNA. We hope that knowledge of the genetic changes that increase the risk of keratoconus could provide a way to identify patients at a stage where intervention could prevent visual loss and potentially lead to more effective treatments. For more information contact Professor Tuft (s.tuft@ucl.ac.uk).

Driving, DVLA and KC

Until recently, the DVLA website did **not** list keratoconus as an eye condition that specifically needed to be notified to them, so our advice to drivers was to let their insurer know they had KC (to make sure any claim would not be invalidated by lack of

disclosure) but not necessarily to tell DVLA. **This has now changed** and there is a long list of eye conditions that do need to be notified, and **KC is included if it affects both eyes**. The rules governing the level of sight needed to hold a driving licence remain the same. Full details at www.gov.uk/eye-conditions-and-driving.

In our experience, insurance companies only need to know that KC has been reported to DVLA and no adverse requirements or additional charges are usually made.

Drivers with KC in both eyes are now required to inform the DVLA

KC Coffee Mornings

We have held two Coffee Mornings since the last Newsletter. One in November where we were treated to a talk by **Doctor Tracy Long-Sutehall** from the University of Southampton, who informed us of her research into the shortage of donated corneas and how the supply could be helped by improved procedures in the hospice community. This led to a lively and interesting discussion.

The second zoom meeting was in January where we were joined by **Aneel Suri** one of the leading optometrists in the Moorfields Contact Lens Department. One question in particular took us down an interesting path. Our member was telling us about the problems he was having with new lenses and that he had to revert to a 15 year old lens. This reminded us of an article in our Spring 2022 Newsletter where we observed that a number of our members have experienced problems when supplied with new scleral contact lenses. Such was the concern that we asked members for feedback.

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

Aneel informed us of one solution to the problem; a new coating that can be bonded to some (but not all) hard contact lens materials. Its availability is increasing and hopefully by the year end it will be available for the majority of RGP and scleral lens materials in use in the UK.

The coating is called "**Hydra-PEG**" and was developed by a company called Tangible Science. You may want to draw your optician's attention to it if you are experiencing problems with lens wetting ability which can cause poor vision and

comfort primarily in scleral lenses. However, it will not address any discomfort caused by ill-fitting lenses.

You can read about it at
www.contamac.com/product/optimum-tangible-hydra-peg.

Find a Keratoconus Friendly Optician

Although most of our members get their contact lenses through a hospital eye clinic, some prefer to avoid the delays of the NHS by going to an independent optometrist who has an interest in KC and expertise in fitting KC eyes.

But finding a good optician who understands keratoconus and is prepared to put in the extra effort to fit appropriate lenses, is difficult. For this reason, we have on our website a database so members can search for their nearest one. This database has attracted more attention recently so we carried out an audit to make sure it is up to date. The database mainly includes opticians who responded to an advert 15 years ago so we are seeking ways to capture suitable candidates for inclusion. Consequently, if you are currently seeing a good optician or know of an optician with an interest in keratoconus please let us know their name so that we can contact them.

Moorfields Eye to Eye Walk

Sunday 5th March 2023

The Keratoconus Group team will be stepping out again to raise money for Moorfields. This year we plan to do the 5 mile walk. Why not join us, you will be glad you did. Full details on our website or join our Eye to Eye WhatsApp group by contacting David on **07927 178716**.

KC group walkers during last year's walk

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Web: www.kcgroup.org.uk

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