



Keratoconus Group

Newsletter Summer 2018

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KC Group AGM 2018

The KC Group AGM was held on 17th March. Our advertised speaker, Moorfields consultant **Dan Gore**, who was to talk on his work on a CXL risk calculator, unfortunately had to cancel at the last minute due to family illness (He will now present this talk in October, see sidebar on page 3). However we were fortunate that both **Ken Pullum**, principal optometrist at Moorfields and scleral lens guru, and **Professor Roger Buckley**, our Honorary President, were at the meeting and stepped into the breach to talk to us.

Ken presented the meeting with some thought provoking ideas, starting with the question 'should the NHS finance everything to do with keratoconus, given the financial and resource pressures on the NHS?' While Ken thought the UK was the best place to be for those with keratoconus, the NHS is not good at dealing with non-clinical urgency.

So, for someone with KC, a lost or damaged lens could mean them being off work until a replacement can be provided. For an RGP lens, that could be up to 3 weeks, for a more complex lens, it could be several months. Getting lenses privately can be very much quicker, but that involves the patient leaving NHS provision of lenses entirely, which for some types of lens can be very costly.

Keratoconus management is often very time consuming for the optometrist. Moorfields now have optometry assistants to help with



teaching new patients lens insertion, removal and handling which improves efficiency in the contact lens clinic, but the process of fitting the optimal lens can still be very clinically protracted.

So are there alternative ways of dealing with this? For example an 'NHS plus' where patients could be asked to make a contribution when they have a non-clinical urgent lens problem, rather than forcing them into private provision? Could optometrists expert in KC use their private practice for NHS patients? Private health insurance is a non-starter, as it doesn't cover contact lenses. Could loans to cover the cost of complex replacement lenses be a solution? Could employers contribute to the cost to avoid their employee being off work? Ken Pullum and Mike Oliver (from the KC Group committee) will be investigating these issues further.

The prospect of an alternative to the more invasive collagen crosslinking procedure of CXL is certainly very attractive.

Also at the AGM, Professor Roger Buckley told us about an exciting new development which could lead to non-invasive eye drops being used to stop the progression of keratoconus - a pharmacological version of CXL.

It is known that low activity levels of an enzyme called lysyl oxidase (LOX) is associated with KC. An American company called iVeena is developing a eye drop IVMED-80 designed to activate this enzyme in the cornea. Animal trials have demonstrated that the drop flattened the cornea and made it more rigid. The next stage is human clinical trials to test the safety of the drops, any long term effects, and to determine the right dosage and the length of time the drops would need to be used. These are planned for later this year, possibly also in the UK.

Clearly a lot of work needs to be done before any such drop could be generally available, and as with any new medication, it may prove not to be a viable option. But the prospect of an alternative to the more invasive collagen crosslinking procedure of CXL is certainly very attractive. You can read more about this research in this scientific journal <https://crstoday.com/articles/2018-feb/solo-eye-drop-treatment-in-development-for-keratoconus/>

New Partnership with Fight For Sight

As regular readers will know, continued sponsorship of the KC Group by Barbican Insurance (the employer of member **Amy Musto**, who originally nominated us as 'Charity of the Year' back in 2014) enabled us to make a grant of £4,000 towards part of the KC genetic research project at Moorfields, and to fund our anniversary conference in 2016. Last year, Barbican Insurance suggested our charity for a fundraising lunch organised by another insurance company AON. This resulted in a donation of a magnificent 8K to the KC Group. The committee decided that the best use for these funds was to double their value, by going into partnership with the major UK charity raising money for research into eye conditions, Fight For Sight.

Every year Fight for Sight (F4S) makes awards of £15K each for research into a variety of eye conditions. They invite charities like ours to make a contribution of £7.5K which they then match. F4S then puts out a call to researchers to submit applications for a grant.

<https://www.fightforsight.org.uk/apply-for-funding/funding-opportunities/small-grant-awards-schemes/>

Their experts, in consultation with the contributing charity, assess the applications to decide which projects to support. The closing date for applications is 31st July, so at the time of writing, we don't know what applications will come in for the KC grant. However, the Chief Executive of F4S, Michele Acton, will be speaking at our national conference in Birmingham in September, so we hope that by then, there will be more news on the research project we will be supporting. So do come to the conference to hear the latest. And of course, we'll keep members updated in future newsletters and on our website.

2018 KC Group conference in Birmingham

Our conference date (15th September) is fast approaching, but it's not yet too late to book your place.

Diary Dates

Conference , Birmingham 15th September

Please see more details on page 4.

London — 6/10/18

The next London meeting will be on Saturday 6th October at 11am 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

Sight Village events

- Leeds 25th September
- London 6th & 7th November

KC Group conference

A brief reminder of another date for your diary—the 9th KC Group conference will be in **Birmingham** this year on **Saturday 15th September** so send in your booking form 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 hope to see lots of you there!

Details of the conference and booking forms were sent out to all our mailing list members a couple of months ago. If you didn't receive these or have mislaid them, please contact anne@keratoconus-group.org.uk or phone **020-8993 4759** to get copies.

Moorfields Eye to Eye Walk 2018

This 14 mile walk, organised by the Moorfields Eye Charity, from Moorfields to the London Eye took place on 4th March. A KC Group team of **David Gable**, **Francis D'Silva**, **Amy Musto** and **Sian Browning** with several of her friends completed the walk to raise funds for research into keratoconus. Between them, they raised almost £2,000 so many congratulations to them all.

David writes:

Eight of us formed the KC team among the 500 walkers. We gathered in front of the piano in Moorfields reception ready for our 14 mile track.

After two of the coldest days in decades, the sun came out to send us on our way. It was a bright crisp morning with plenty of ice still floating on the canal. The route was perfect, we all found parts of London we had never seen before. It traced the Regents Canal, with a few detours through places of interest, to Little Venice. Then turned south to Paddington for our half way stop. The second section took us through the royal parks and Theatreland.

The temperature was ideal for walking, as was the company. We were so busy chatting that the miles flew by and after 5 hours we had completed our task and settled down to coffee, cake and a steel band. This is an annual event and I thoroughly recommend it for next year. Look out for dates. We raised almost £2,000 and are overwhelmed by the generosity of friends and family.



Our new Chairman David Gable with Amy Musto at the half-way point on the Moorfields Eye to Eye walk

New look website

How often do you look at our website www.keratoconus-group.org.uk?

Thanks to a huge effort by **David Gable** and our webmaster, **John Smith**, our website has a new look. And the new design means it can now be updated very easily with the latest news on our activities and the latest KC research news. So it's now definitely worth looking at it between newsletters to keep up to date. And do let us know if you come across interesting articles, exciting new developments in KC, or anything else that's worth sharing or putting links to on our site. We also welcome feedback on what you think of the new site and suggestions for what else should appear there. Of course the discussion forum is still there, a great way of talking to other people with KC and finding out how other people manage.

Introducing our new Chairman: David Gable

It is privilege to take over from **Mike Oliver** who is taking a rest after two very long stints as chairman.

Mike was there at the start 25 years ago, helping to turn Anne's idea of a self help group into a practical reality and developing the group into a formal charity. He has done a sterling job and his boots will be difficult to fill. Thank you Mike.

I would like to introduce myself by giving a brief background of my Keratoconus experience. The condition was first diagnosed in my 20's, I then progressed to glasses, contact lenses and grafts.

I am very fortunate in that after my grafts I was discharged and forgot about Keratoconus. Twenty years later I was wondering how technology had improved and whether modern laser surgery could correct my inconvenient astigmatism. The response from Moorfields was, 'don't push your luck'. However, it did make me aware of the Group and I went along to one of their excellent speaker meetings.

The thing that struck me was the ease with which everyone mixed. We all had a common interest and were there to learn. The talk was illuminating and the Q & A session lively and relevant. Each question opened up a new avenue of interest. I spoke to two parents that day who were greatly concerned about their teenage children's educational and employment prospects. Hopefully, they received some reassurance from the committee, all of whom have experienced difficulties coping with Keratoconus yet managed successful careers. After that experience, I joined the committee in May 2013.

Recently, I have been actively involved in helping our webmaster develop a new website for the Group and one of the pages lists the committee with a note about their

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Keratoconus condition. I hope this demonstrates why we are all so committed to the charity and although very small, are effective in our aims.

Boston K-Pro funding approved

The Boston Keraprotosis (K-Pro) is an artificial cornea which can be used where a conventional transplant is contra-indicated. In keratoconus, that would be the very rare cases where someone has had repeated graft failures. NHS Specialised Commissioning has now approved funding for this procedure so this may now be an option for a handful of our members where the corneal specialist feels it is appropriate, without the need for a special case having to be made.

3D printed human corneas

Scientists from Newcastle University have produced the first 3D printed human corneas in the world. Stem cells from a healthy donor cornea were mixed together with alginate (a gel derived from seaweed and already used in medicine in, for example, wound healing) and collagen to create a 'bio-ink' a solution that could be printed using a 3D bio-printer. This is 'proof-of-concept' research, published in the journal *Experimental Eye Research* so many years of further testing will be needed before this technique could be used in patients needing a corneal transplant. However, in the future, this could mean an unlimited supply of corneas for use in transplants, whether for KC or for other corneal conditions.

Another fundraising idea...

Charitable Bookings (charitablebookings.com) is a website and app which donates £1 to charity for each diner when you book a restaurant table from the wide selection of venues listed at no charge to you. The KC Group is one of the thousands of charities to benefit from this initiative. So have a look at their website and see what's on offer.

KC Group e-mails

We have recently suffered from some e-mail issues, so if you've got in touch but not had a reply, please get back in touch.

Amazon will donate to the KC Group when you shop!

Visit the link below and register the KC Group as your nominated charity, and from then on, the group will receive a 0.5% donation from most things you buy from Amazon!

Here's the link: <https://smile.amazon.co.uk/ch/1057629-0>.

If you have difficulty in finding us, just enter our charity number "1057629-0" in the search box.

All you then have to do is to visit smile.amazon.co.uk for us to earn a little on each of your purchases.

Concert in aid of KC research

Tuesday 9th October 6pm at
Gallery Different, 14 Percy
Street, London W1T 1DR
www.gallerydifferent.co.uk
020-7537 3775.

Michelle Urquhart and
Marco van Pagg giving a
solo viola and viola duet
recital.

Michelle is the NSW
representative for Keratoconus
Australia and all proceeds from
tickets/donations will come to
the KC Group to be used for
research into KC. Please come
and support this KC event
spanning two continents! You
can find more details on our
website.

VIOLA IN FOCUS

MUSIC AND ART IN SUPPORT OF SIGHT & THE KERATOCONUS FOUNDATION



MICHELLE URQUHART & MARCO VAN PAGEE

A UNIQUE ALL VIOLA PROGRAMME SHOWCASING ART BY TARA WINONA

TUESDAY 9TH OCTOBER - 6PM

GALLERY DIFFERENT

14 Percy Street, London W1T 1DR 0207 637 3775 www.gallerydifferent.co.uk

TICKETS £15 - TICKET SALES DONATED TO THE KERATOCONUS SELF-HELP AND SUPPORT ASSOCIATION UK
DOORS OPEN AT 6PM WITH ART AND WINE. PERFORMANCE AT 7PM

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A registered charity in England and Wales (No. 1057629),
and in Scotland (No. SC039552)