



KERATOCONUS GROUP

Autumn Newsletter 2026

WELCOME

Welcome to your August update from the Keratoconus Group.

We're here to support those living with Keratoconus, providing information, support and community.

Together, we are stronger.

Keratoconus and Other Health Conditions: Any Cause for Concern? by Dr Waheeda Illahi

Could there be a connection? We summarise Dr Illahi's talk from our recent AGM featuring the latest research and expert insights to help separate fact from fiction.

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Save the Date: Autumn Meeting

Join us this autumn in London for our next community meeting at our usual venue. Meet others living with keratoconus, hear from expert speakers and stay up to date with the latest news.

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A thank you to our Chairman

We say thank you to our outgoing Chairman for his dedication, leadership and unwavering support of the Keratoconus Group.

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Running for Keratoconus

Our fantastic supporters are taking part in charity runs all over the country to raise money for the Keratoconus Group.

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DATES FOR YOUR DIARY



London Speaker Meeting

Sat 3rd October



Drop-in Zoom Sessions

19th Aug & 12th Nov



AJ Bell Charity Runs

4th & 18th October



NEED SUPPORT?

You're not alone.

Visit our website for information, support and resources.

keratoconus-group.org.uk

Or check the back of this newsletter for our contact info.

Latest Research & Events

Catch up on our latest activities, community events and the newest developments in keratoconus research.

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Keratoconus and Other Health Conditions: Any Cause for Concern?

By Dr Waheeda Illahi

Based on Dr Illahi's talk at the Keratoconus Group AGM

For many people living with keratoconus, the focus is understandably on vision: diagnosis, contact lenses, cross-linking, hospital appointments, and trying to manage day-to-day life. But at this year's AGM, Dr Waheeda Illahi encouraged us to think more broadly about the person behind the condition.



Drawing on a two-and-a-half-year patient-centred pilot study involving 579 people with keratoconus, Dr Illahi explored an important question:

What other health conditions and life challenges are associated with keratoconus — and are there areas we should be paying more attention to?

Her talk combined clinical insight, practical advice, and a powerful reminder that understanding patients means understanding the whole person, not just the cornea.

Looking Beyond the Cornea

Dr Illahi explained that while huge advances have been made in keratoconus care over the past 30 years - including improved lens designs and materials, advances in surgical techniques, and the advent and development of collagen cross-linking - there is still more to learn about the lived experience of patients.

The study was developed after years of experience where many of the keratoconic patients seen over the years did not resemble the stereotypical personality often mentioned in medical publications, such as being “difficult” or “demanding”. These labels reflected a misunderstanding of patients’ with underlying struggles rather than their true character. It demonstrated they were struggling with anxiety, trauma, medication side effects, or life circumstances that had never been properly documented or understood.

The goal of the research was simple but important:

- Identify conditions associated with keratoconus
- Separate genuine causes for concern from those that are less significant
- Improve communication and support for patients
- Encourage wider future research

The Study at a Glance

The research involved 579 patients diagnosed with keratoconus, assessed during face-to-face contact lens appointments over a period of more than two years.

Some key findings included:

- Average age at diagnosis: 23 years old
- Most patients were aged between 20 and 40
- 69% were male and 30% female
- Only around 14% were members of a keratoconus support group
- Over 50% had degree-level or postgraduate qualifications
- 73% were employed

Dr Illahi said these findings challenge outdated stereotypes about keratoconus patients. Many are highly educated, professionally active, and making significant contributions across sectors including teaching, healthcare, business, and public service.

Mental Health: An Important Finding

One of the most striking parts of the study related to mental health.

Nearly 20% of patients reported a diagnosed mental health condition, including anxiety and depression, while almost 10% felt they had an undiagnosed condition for which they had never received support.

Dr Illahi noted that many patients only disclosed this information when specifically asked.

This matters for several reasons:

- Anxiety and depression can affect appointment attendance and communication
- Some medications can cause dry eye, blurred vision, glare, and light sensitivity
- Clinical teams may not be aware that symptoms such as blurred vision maybe related to other factors (e.g. medication side effects) rather than the contact lens itself

Her message was clear:

“Please inform your provider if you suffer from a mental health condition, diagnosed or undiagnosed. Support will be provided.”

She encouraged patients to inform their optometrist, ophthalmologist, GP, or contact lens clinic about any mental health concerns so that additional support and safeguarding measures can be put in place where necessary.

Eye Rubbing: A Major Concern

The study found high rates of allergies, eczema, asthma, and hay fever among patients, all of which can contribute to itchy eyes and rubbing behaviour.

Dr Illahi explained that repeated eye rubbing is now widely recognised as a significant contributing factor in keratoconus progression.

Using the analogy of repeatedly rubbing the same area of a woollen jumper until the fibres loosen and distort, she described how constant mechanical trauma can weaken the cornea over time.

Her practical advice included:

- Avoid rubbing eyes with palms or knuckles
- Use cool compresses instead
- Keep preservative-free artificial tears available
- Treat allergies proactively with antihistamines where appropriate
- Reduce pollen exposure during hay fever season
- Consider wraparound sunglasses outdoors

Importantly, she reassured patients that eye rubbing is usually driven by discomfort and allergies and not self inflicted.

Collagen Cross-Linking: Mixed Patient Perceptions

The study also looked at experiences of collagen cross-linking (CXL).

Of the patients surveyed:

- 38% had undergone cross-linking
- 54% felt it had been beneficial
- 45% did not feel it had helped

Dr Illahi suggested that patient expectations may play a role in these responses. Cross-linking is designed to stabilise the cornea and slow progression - not necessarily improve vision.

She also reflected on the feelings of some older patients who were diagnosed before advances in treatments such as cross-linking became available and who feel they may have “missed out”.

Her response was compassionate and thoughtful:

“I don’t think so. I think you are where you were meant to be in your journey.”

Contact Lenses: There Is No “Perfect Lens”

One particularly surprising finding was that nearly a third of patients used a different type of lens in each eye.

For example, one eye might need a corneal lens while the other works better with a scleral lens. Dr Illahi said this reinforced an important principle:

“The best lens is the one that’s right for you.”

Rather than searching for a single “holy grail” lens design, care should focus on what gives each individual eye and the patient the best combination of comfort, vision, and practicality.

Education, Work, and Daily Life

The talk also highlighted the importance of practical support in education and employment.

Dr Illahi encouraged younger patients to:

- Inform schools, colleges, and universities about their diagnosis early
- Discuss glare, dry eyes, or lens wear difficulties during appointments
- Plan ahead during exam periods (i.e. speak to your school about any additional support you may require).
- Seek support from disability and student support services where appropriate

For those in work, she advised patients to think carefully about the kind of adjustments they may need and to communicate clearly with employers where helpful.

Without contact lenses or spectacles, keratoconus patients may fall within the criteria for sight impairment, despite appearing fully functional day to day with visual correction.

A Need for More Research and Better Awareness

Dr Illahi described the study as a “pilot project” and emphasised the need for much larger research in the future.



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Questions remain about:

- Mental health prevalence compared with other eye conditions
- The long-term impact of allergies and eye rubbing
- Family history and genetics
- How clinics should better identify and support vulnerable patients
- Whether keratoconus services receive sufficient recognition within healthcare systems

She also stressed the importance of support groups (such as the Keratoconus Support Group), Eye Clinic Liaison Officers (ECLOs) and patient communities in improving awareness and helping patients feel understood.

Final Thoughts

Perhaps the strongest message from the talk was that keratoconus care is not just about corneal topography, lenses, or procedures. It is about understanding the individual.

Eye care professionals who often work in high volume clinics may not be aware of the challenges the individual patient is going through.

Patients may be experiencing anxiety, disrupted sleep, difficult working conditions, exam pressures, medication side effects, allergies, or simply the exhaustion of navigating a lifelong condition.

By improving communication between the patient and the eye care professional, and recognising these wider challenges, healthcare professionals and support organisations can provide more compassionate, personalised care.

As Dr Illahi concluded:

“The most important thing you can do to help yourself is inform your health care professional about your concerns and experience.”

Thank You

The Keratoconus Group would like to extend our sincere thanks to Dr Waheeda Illahi for taking part in our AGM and for her continued support of our regular West Midlands face-to-face meet-ups.

We are incredibly grateful for the time, expertise and enthusiasm she shares with our members. Her ongoing commitment to improving understanding of keratoconus and supporting our community is greatly appreciated.



Save the date: London Speaker Meeting



Email us if you'd
like to join us

We're delighted to announce the information for our usual Keratoconus Group Autumn Speaker Meeting in London this autumn.

These meetings are a fantastic opportunity to meet others living with keratoconus, hear from expert speakers, ask questions, and stay up to date with the latest developments in research, treatment and patient support. All are welcome, both people with KC and family members.

As usual, there will be a buffet lunch and therefore, please let us know by email or phone if you plan to attend so we can cater for numbers. **Email:** info@kcggroup.org.uk or **phone:** 020 8993 4759.



Speaker: Dan Ehrlich, former Head of Optometry at Moorfields, will talk about his continuing work on improving design and availability of specialist contact lenses.



Date: Saturday 3rd October



Time: 11am - 1pm



Venue: Moorfields Education Hub, 1st Floor, 15 Ebenezer Street, N1 7NP (the hub is opposite Moorfields main hospital – cross City Road and go up Provost Street to the next corner and the Hub is facing you on the left).



Save the date: Upcoming Drop-in Zoom Meetings



Email us if you'd
like to join us

Employment Special



Special Speaker:

Zsuzsanna Szabo, an Employment Specialist from Support4Sight, will explain the workplace support available to help you manage your job alongside living with keratoconus.



Date: Wed 19th August



Time: 7:00pm

Know Your Rights Special



Special Speaker:

Meg Pennycook, a barrister, will be speaking about disability discrimination law and the rights of individuals to reasonable adjustments - particularly those with sight impairments.



Date: Thurs 12th November



Time: 7:00pm

Thank you to our retiring Chairman: Steve Graham

From our interim Chairman David Gable

We are extremely grateful for the work Steve has done in his short tenure as chairman and hope that he will be able to play a significant part in our future, when circumstances permit. In the meantime, the committee has asked me to return to the role of Chairman until a suitable candidate can be found.

Steve has made a significant impact, most noticeably by employing the services of **Ellie Jarman** who has redesigned this newsletter and our website and is now acting as our Secretary.



He significantly raised our profile at the Hospital Optometry Conference in London where we were designated their charity of the year and benefited from the delegate donations. This flurry of activity brought in the following new members to our team:

Dr Sangeetha Rao who is working closely with Moorfields to develop a “Patient, Public Involvement Group”, for Keratoconus.

Rae Lovejoy who is well known for running the KeratoconusGB Facebook group and is now working with us on a suite of WhatsApp groups covering different aspects of life with KC. These are already proving very popular.

Paul Lupton who has an extensive experience working with government on disability benefits.

Ash Winter who is developing his role as “Patient Advocate”, which he performs for our counterpart organisation in America.

Steve came to us last year with **Peter Field** who is our resident expert of specialist contact lenses. Peter has extensive experience working with the country’s top experts to find solutions for their most difficult KC patients. He is very concerned that UK manufacturers are cutting back on their activities in this specialist market. He is also concerned at the lack of training given to opticians in fitting complex lenses. We hope to help Peter address these issues.



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Running for the Keratoconus Community

When new member **Tosin Adebajo** secured a place in this year's London Marathon through the public ballot, he decided to turn his achievement into an opportunity to support others by raising funds for the Keratoconus Group.

Having lived with keratoconus for the past 15 years, Tosin understands the challenges the condition can bring. From changes in vision and ongoing treatment to the emotional impact of adapting to sight loss, his journey has not always been easy. However, he says living with keratoconus has also taught him resilience, patience and the importance of both specialist care and support from others who understand.



By taking on the London Marathon, Tosin wanted to give something back, helping us continue to provide trusted information, raise awareness and support people affected by keratoconus so that no one has to face the condition feeling uninformed or alone.

"This marathon is a huge personal challenge for me, but it's one I'm proud to take on – not just for myself, but for everyone living with keratoconus."

On marathon day, Tosin made the challenge even more remarkable by completing the entire 26.2 miles in full traditional African attire while raising funds for the charity. Although he narrowly missed his Guinness World Record target by just 10 minutes, he was part of a record-breaking London Marathon, which saw the highest number of finishers in the event's history.

Thanks to his incredible efforts and the generosity of everyone who supported him, **Tosin raised £1,200** for the Keratoconus Group. Everyone at the Keratoconus Group is incredibly grateful to Tosin, and to everyone who donated, cheered him on and helped make the day such a success.



AJ Bell Great Scottish Run - 4th October

We're delighted to support **Johnny Sloss** as he takes on the AJ Bell Great Scottish Run in aid of the Keratoconus Group.

We'd like to say a huge thank you to Johnny for taking on this challenge and for helping to make a difference to the keratoconus community.

When asked why he chose to fundraise for Keratoconus Group, Johnny said:



"I wanted to run for Keratoconus Group as I was diagnosed with it when I was 12 years old and then quickly after had cross-linking surgery. Although my vision without my contacts is very poor, I'm able to live a normal life with my contact lenses. But it really does rule my life as I'm always having to carry my case and solutions with me everywhere I go. It's a bit of a running joke with everyone that knows me. I'm 29 years old and have always been quite a fit person but recently been enjoying running a lot more. I've only ran 10K before but did get a good time of 37 minutes, so hoping I can raise a lot of money for Keratoconus and get a good time!"

AJ Bell Great South Run - 18th October

Another supporter, **Carolyn Southall**, is taking part in the Great South Run to help raise the profile of the Keratoconus Group. Carolyn's son has KC and recently underwent crosslinking and she has appreciated the support of our members during this process. Let's continue to support her efforts.



Find ways to support our runners on our website

keratoconus-group.org.uk

Join Our WhatsApp Community

Connect with others living with keratoconus in our friendly WhatsApp Community. Ask questions, share experiences and receive support from people who understand, including volunteer eye care practitioners.

The community is moderated by **Rae Lovejoy**, founder of KeratoconusGB and a long-time keratoconus patient, helping to ensure the groups remain welcoming, supportive and informative.



Scan to Join

Latest Research: Landmark Dataset Set to Accelerate Eye Research

A groundbreaking new eye imaging dataset is about to transform research into diseases affecting the front of the eye, including keratoconus. By giving researchers access to one of the world's largest collections of anonymised anterior segment eye scans, the project will support the development of AI-powered diagnostic tools, improve understanding of eye disease and help shape future treatments.

This exciting initiative has the potential to speed up research, improve early diagnosis and ultimately deliver better care for people living with keratoconus and other anterior segment eye conditions.



Read the full article
on our blog

kcggroup.org.uk

Connecting with the Community in the West Midlands



It was a busy and rewarding few days for the Keratoconus Group as we attended Sight Village and hosted another successful West Midlands Meet-Up at Aston University.

Sight Village gave us the opportunity to meet members of the public, raise awareness of keratoconus and connect with organisations from across the sight loss sector.

It was great to see Prof. Martin Rubenstein at the meeting (pictured, furthest right).

Our Birmingham Meet-Up followed, bringing together people living with keratoconus for an afternoon of conversation, support and shared experiences. We were delighted to welcome back Dr Waheeda Illahi, who spoke further about her research involving people with keratoconus and answered questions from attendees.

Thank you to everyone who joined us. Our Birmingham Meet-Ups are again becoming a regular opportunity for people affected by keratoconus to meet face to face, share experiences and support one another, and we look forward to welcoming even more people to future events.



Thank you for taking the time to read this newsletter.

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