

DRY EYE AWARENESS

Do you experience a burning sensation in your eyes?

Do you feel there is sand or grit in your eyes?

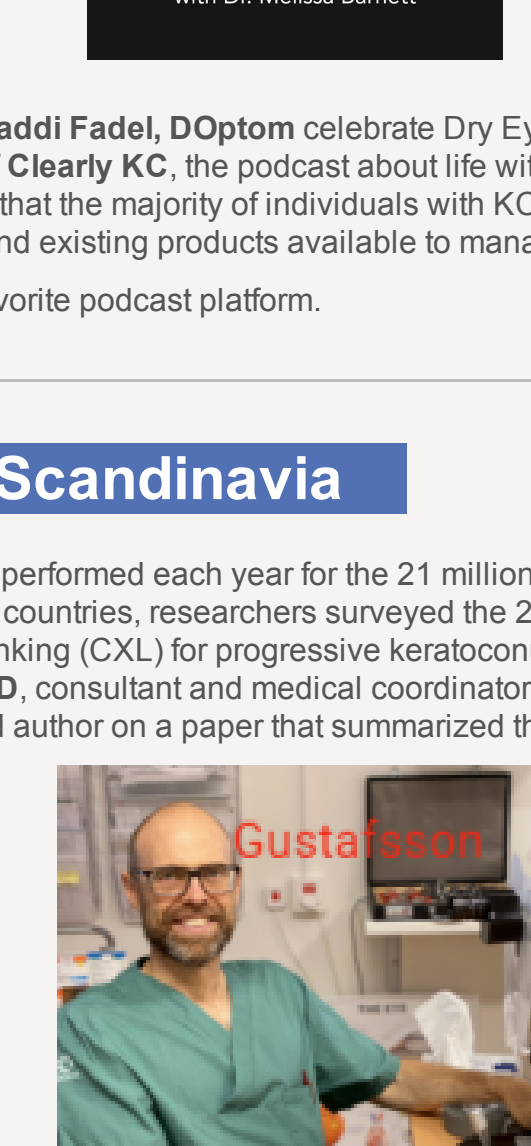
These are some of the common concerns of people who experience dry eye disease. July is Dry Eye Awareness Month and a good time to remind *Update* readers the symptoms and causes of dry eye and what is available to provide relief.

Dry eye is not a single disease, but an assortment of conditions that can result in irritation, redness, excessive tearing, and light sensitivity. The eye relies on the tear film to adequately lubricate the eye and coat the ocular surface. The tear film is composed of three layers, each with a different role. Blinking spreads the tear film evenly over the eye's surface. A problem in any of these alters tear composition and can lead to dry eye disease. **Dr. Melissa Barnett OD**, host of the *Clearly KC* podcast, lectures extensively on the many roles of the tear film. She observes, "dry eye disease is very complex and multifactorial. The tear film has hundreds of proteins that bathe and protect the cornea. It's the first refracting surface so it provides good vision."

* Sitting on the cornea is a **mucus layer**; proteins produced by goblet and epithelial cells. Its job is to cover the epithelium, and act as an adhesive for the other layers.

* Next is the aqueous or **watery layer** produced by lacrimal glands. This liquid nourishes the cornea and is responsible for the volume of tears.

* Finally, an **oily layer** of the tear film is produced by meibomian glands. This lipid layer prevents tear evaporation and provides a smooth surface for the tear film.



A common situation associated with dry eye disease is when the meibomian glands along the eyelid become blocked. MGD (meibomian gland dysfunction) can be treated by massaging the eyelids or applying warm compresses to release clogged oil. In severe cases, doctors can employ in-office treatments to heat and massage away blockages.

In other cases, the tears released by the lacrimal glands quickly drain, without providing the necessary nutrients to the eye. Lubricating eyedrops or artificial tears can be used to supplement tears and relieve dryness and irritation. In severe cases, the doctor may insert a punctal plug, a device about the size of a grain of rice to block tears from draining off the eye.

Dry eye affects about 1 in 10 Americans; the prevalence among those with keratoconus is even higher. In a 2021 publication, 197 individuals completed an on-line survey through National Keratoconus Foundation and SCOPE. **The authors found that 90% of patients who self-identified as having keratoconus reported symptoms of dry eye disease.**

If you experience burning, irritation, excessive tearing, or dryness, you may have dry eye disease. For many, artificial tears provide relief, but if symptoms impact comfort or vision, your doctor can help identify the underlying causes and prescribe an appropriate treatment.

Listen & Learn about Dry Eye



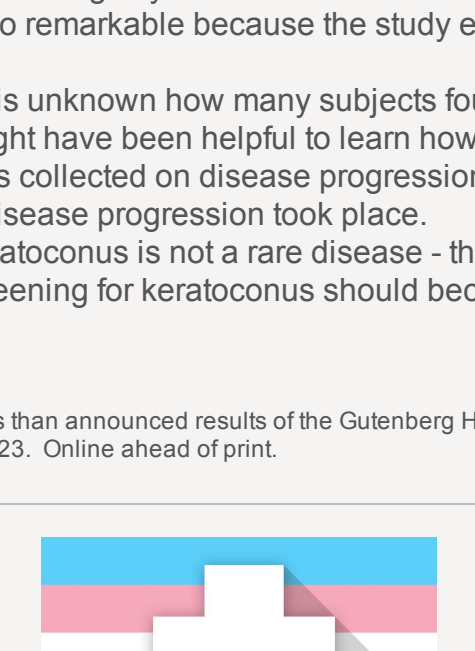
Dr. Melissa Barnett OD and **Dr. Daddi Fadel, DOptom** celebrate Dry Eye Awareness month by answering listener questions in **Episode 10 of Clearly KC**, the podcast about life with keratoconus. Dr. Fadel describes different types of dry eye and notes that the majority of individuals with KC have symptoms of dry eye disease. Dr. Barnett mentions several new and existing products available to manage dry eye.

Find **Clearly KC** [here](#) or on your favorite podcast platform.

Crosslinking in Scandinavia

About 1,200 CXL procedures are performed each year for the 21 million residents in Scandinavia. To compare clinical practices across neighboring countries, researchers surveyed the 20 centers in Norway, Denmark, Sweden, and Finland that offer corneal crosslinking (CXL) for progressive keratoconus; 19 centers responded.

Dr. Ingemar Gustafsson MD, PhD, consultant and medical coordinator for the cornea service at Skane University in Lund, Sweden was lead author on a paper that summarized the findings.

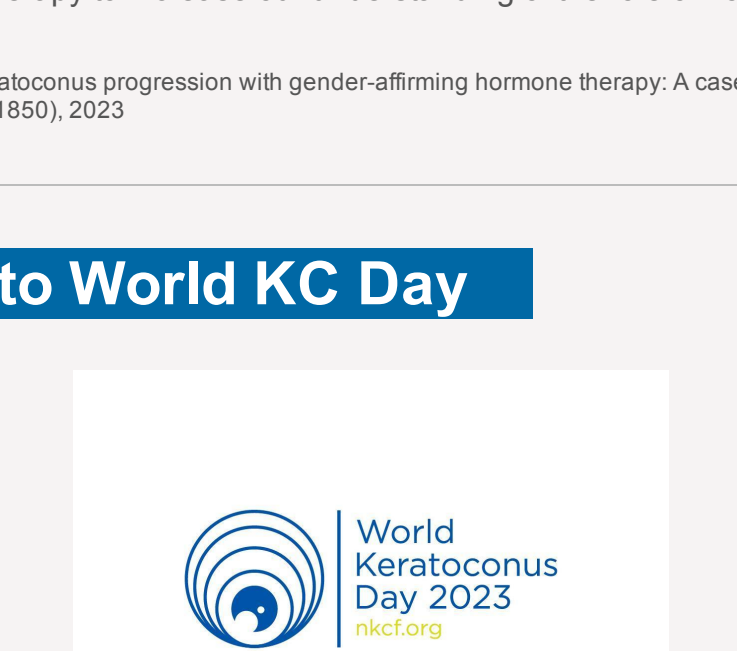


The Dresden protocol – an epithelium-off procedure – is the most common procedure performed. All 19 centers perform epi-off treatment always or most of the time. Three centers employ an epi-on protocol in select circumstances.

In 11 of 19 centers, adolescents and teens under age 18 are referred for crosslinking upon diagnosis without waiting for evidence of progression. In 18 of 19 centers, adults are followed for evidence of progression before a CXL referral is made. Crosslinking is covered by national health insurance in these Nordic countries. In a separate communication, Dr. Gustafsson notes that the CXL can usually be scheduled within 6-8 weeks, and always performed within 3 months of referral.

The survey respondents raised issues that are discussed by cornea surgeons globally. The most common concern is the lack of a standard protocol to define progression. Seventeen of the institutions during this center include progression by an increase in keratometric readings (K-max). Other methods employed at these centers include changes in corneal thickness, increase in astigmatism, changes in visual acuity, or patient complaints consistent with disease progression (e.g., worsening glare or halos, difficulty tolerating contact lenses, etc.).

Other CXL-related issues mentioned by survey respondents included understanding when (re-treatment (re-patch crosslinking) should be considered, and how to treat a cornea too thin to crosslink.



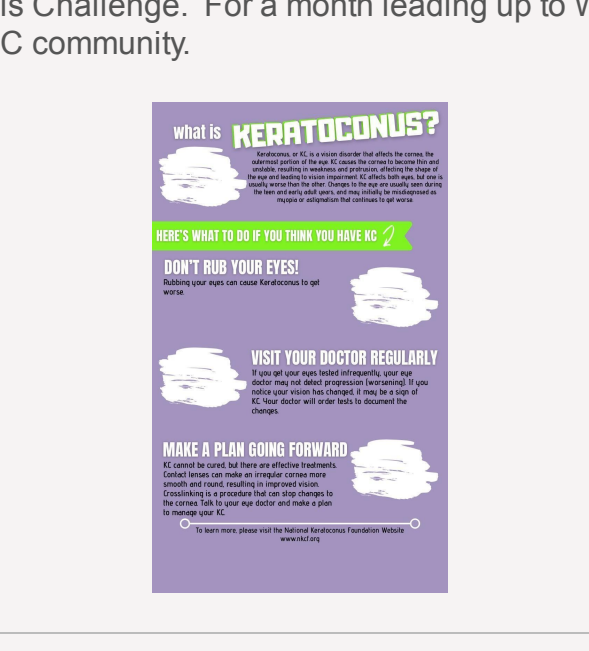
One of the noteworthy benefits of CXL has been the decline in the number of corneal transplants performed to treat advanced keratoconus. Dr. Gustafsson shared there has been a >80% decrease in corneal transplants for treatment of keratoconus since 2000.

Number of Corneal Transplants to Treat KC in Sweden by Year
Source: Swedish Corneal Transplant Registry

Reference: Current clinical practice in corneal crosslinking for treatment of progressive keratoconus in four Nordic countries, Gustafsson I, Vicente A, Bergstrom A, et al, Acta Ophthalmologica, 101:109-116, 2023.

German Study Provides Insight to Prevalence

The Gutenberg Health Study (GHS) is a long-term, population-based investigation following more than 12,000 adults living in the Rhine Valley. The study was developed at the Johannes Gutenberg-University of Mainz to learn more about age-related diseases and to promote healthy living. To that end, scientific



papers published from the GHS have been published in the areas of cardiovascular disease, brain activity, and cancer. Information about eye diseases like age-related macular degeneration and glaucoma have also been published using GHS data.

Beginning in 2007 residents living in Mainz and the surrounding rural area invited to participate were given a battery of medical and psychological tests, including a comprehensive eye exam with Scheimpflug imaging (tomography). 10,419 subjects between the age of 35 and 74 were enrolled. Follow-up testing was performed in 2012 and 2017 on study participants, now aged 45 to 84.

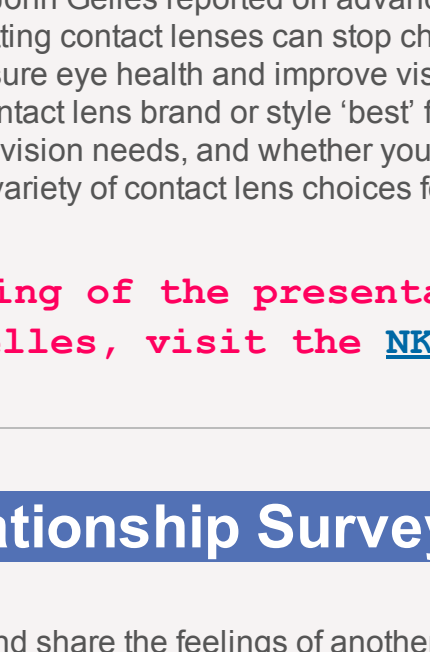
Reviewing corneal tomography data, researchers diagnosed keratoconus in 75 eyes (51 individuals). **The prevalence of disease was found to be 1:204, ten times higher than the often-quoted statistic of 1 in 2,000.** The 1:2,000 is based on a population study conducted in Wisconsin in the 1930s. At that time, keratoconus was diagnosed by observing clinical signs of disease, and many mild or subtle cases went undetected.

Most large-scale prevalence studies use registry data or insurance information rather than actual patient exams. The results of this study are also remarkable because the study enrolled a large cross-section of area residents.

One weakness in this study is that it is unknown how many subjects would have keratoconus had been previously aware of their disease. It might have been helpful to learn how many cases had been undiagnosed and untreated. Also, no information was collected on disease progression. However, since all study subjects were seniors, it is unlikely substantial disease progression took place.

This study adds to the reality that keratoconus is not a rare disease - the prevalence of keratoconus is much higher than is commonly believed. Screening for keratoconus should become part of a comprehensive eye exam.

Reference: Much higher prevalence of keratoconus than announced results of the Gutenberg Health Study, Marx-Gross S, Fiess A, Munzel T, et al, Graefes Arch Clin Exp Ophthalmol, June 14:1-4, 2023. Online ahead of print.



Hormone Therapy: Association with Keratoconus?

An interesting and timely case report was published in the *American Journal of Ophthalmology*. Doctors at the Naval Medical Center in Portsmouth VA reported visual changes in a male-to-female transgender 4 months after beginning hormone therapy.

The 28-year-old had a possible history of subclinical keratoconus although no topography or tomography studies had been performed. The patient complained of worsening myopia: an optometrist suspected keratoconus and referred to an ophthalmologist for additional testing.

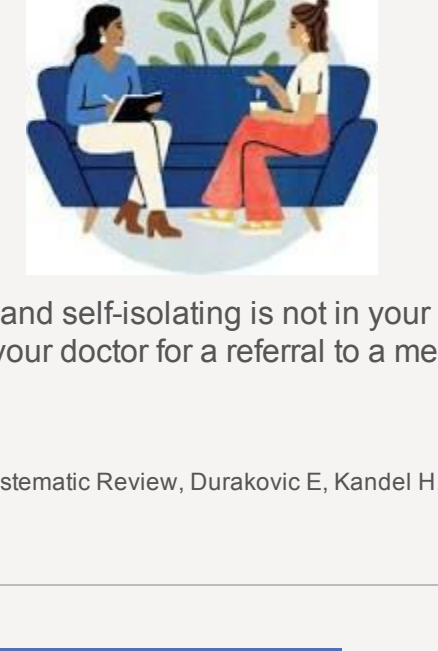
The patient was found to have corneal curvatures (K-max) of 58.3 in the right eye and 77.7 in the left eye. (Normal K-max is generally considered <48). The corneas in both eyes were thinner than normal and there was elevation of the posterior cornea. The patient was prescribed contact lenses and advised to return in 7 months. At the follow-up visit, vision had continued to deteriorate, and corneal crosslinking was recommended and successfully performed.

The doctors who offered this case report were unable to make a definite connection between onset or progression of keratoconus and rising estrogen levels resulting from the gender-affirming care the patient was receiving. There have been published reports of keratoconus being diagnosed or progressing during pregnancy, IVF (in vitro fertilization) or hormone replacement therapy (HRT). The authors note that because of the relatively young age of many who undergo gender-affirming therapy, there may be a higher risk of keratoconus progression.

The authors conclude this case may be another example of a connection between increased hormone activity and corneal ectasia. They suggest more studies looking at the corneal structure in transgender patients before and after receiving hormone therapy to increase our understanding of the role of hormones in keratoconus.

Reference: Possible association of keratoconus progression with gender-affirming hormone therapy: A case report, Deitel CM, Chen J, Kher UB, et al, Am J Ophthalmol Case Reports 30 (101850), 2023

Countdown to World KC Day



November 10 is World Keratoconus Day, recognized as the international day to raise awareness of keratoconus. Friends, family members, and eyecare professionals are encouraged to use World KC Day as an opportunity to educate others and to show support for those living with KC. Patients should take time all year, but especially on November 10, to congratulate yourself for another year of living with KC. Today, there are more options for improved vision and eye health than ever before. And next year will be even better!

For Individuals:

Think about how you can spread the word! Share your experience with KC, or the journey of a friend or family member with "KC" by posting on your social media platforms and using the hashtags **#worldkcday2023** and **#nkcf** and tagging us **@nkcforg**. We'll repost to your story goes global.

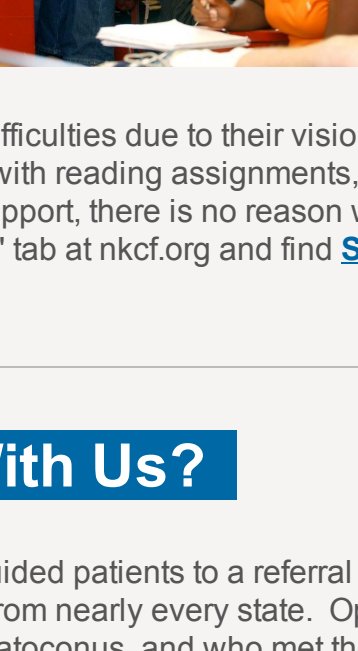
Check out our website, **nkcf.org** to participate in our annual photography contest, "KC:Through My Eyes". It's a chance to be creative and to show how KC impacts your view of the world.

For Eye Care Professionals:

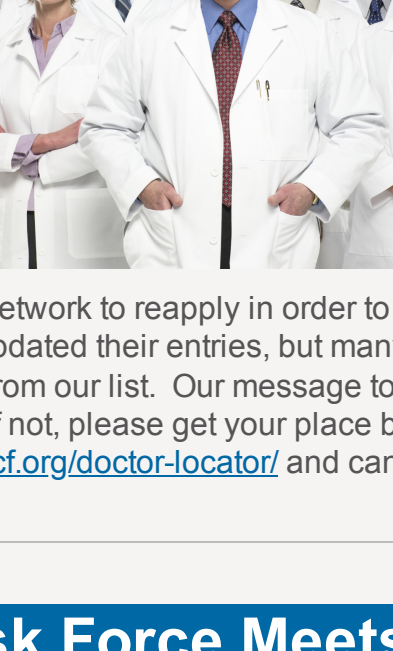
Display a "What is Keratoconus?" poster in your clinic. Click [here](#) to have one sent to you. Use it as a tool to start a conversation about keratoconus with your patients.

On the tab marked "For Doctors" on the nkcf.org website, you'll find a Social Media Tool Kit with ideas for you to use. Let your patients and the community know you are raising KC Awareness.

Participate in our Instagram Reels Challenge. For a month leading up to World KC Day, you can submit short videos that we will share with the KC community.



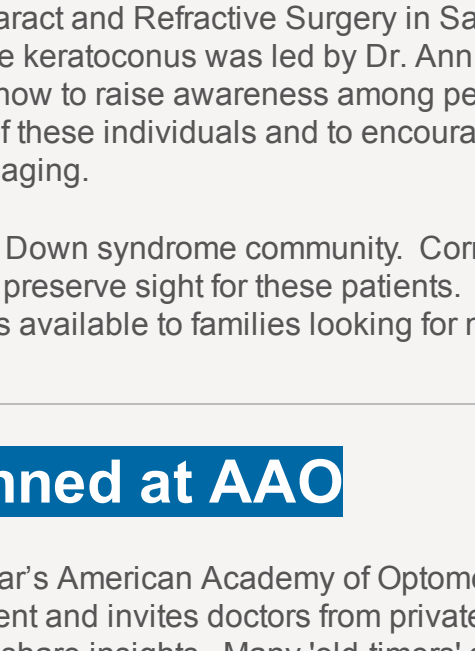
In Case You Missed It:



Addressing KC Vision Needs Throughout Life

Anyone looking for a comprehensive update on the state of keratoconus (KC) treatment should view July's Evening Webinar recording. The featured speakers, **Dr. Peter Hersh MD**, **Dr. Steven Greenstein MD**, and **Dr. John Gelles OD** are partners at the Cornea and Laser Eye Institute (CLEI) Center for Keratoconus in New Jersey. Dr. Hersh led the presentation, proposing keratoconus treatment is a 3-step process: stopping progression; improving topography or cornea steepness; and improving vision.

He said KC results from biomechanical weakness in the cornea. Eye rubbing causes wear and tear to the cornea exacerbating the disease and should be avoided. Dr. Hersh was medical monitor for the crosslinking studies sponsored by Glaukos (Avedro) and testified before the FDA on the results: CXL stopped progression in well over 90% of cases. He also gave an overview of some current clinical trials underway.



Dr. Steven Greenstein summarized surgical options for treatment of KC. He reviewed topography guided photorefractive keratectomy ("topo-guided PRK"), a technique where the surgeon uploads a patient's topographic map into a programmed laser and the map is used to select corneal tissue for removal, leveling the steepest areas. The result makes contact lenses wear easier and leads to improved vision.

Corneal Tissue Addition for Keratoconus ("C-TAK") was developed at the CLEI. Eye bank donor tissue is irradiated, and the resulting disc is used as an inlay adding volume to a cornea in the same manner as resection ring segments (Inlays). C-TAK can be cut into any shape and placed into a cornea with minimal risk of rejection. Dr. Greenstein noted his group has been performing C-TAK for six years and patients who undergo the procedure report significant vision improvement.

Corneal transplants replace damaged or badly scarred corneas with donor tissue. Dr. Greenstein noted the number of corneal transplants in the US has decreased at least 25% since the introduction of crosslinking, and he predicts the numbers will continue to decline as fewer patients progress to advanced KC.

In the final portion of the webinar, Dr. John Gelles reported on advances in contact lens options to improve vision. He dispelled the myth that tight-fitting contact lenses can stop changes to the shape of the cornea and said the role of contact lenses is to ensure eye health and improve vision, not slow disease progression. Dr. Gelles concluded there is not a single contact lens brand or style "best" for keratoconus. He noted that your doctor should consider your lifestyle and vision needs, and whether your keratoconus is mild, moderate or advanced, and should be able to offer a variety of contact lens choices for you to choose among.

To watch the recording of the presentation by Drs. Hersh, Greenstein, and Gelles, visit the [NKCF Video Library](#).

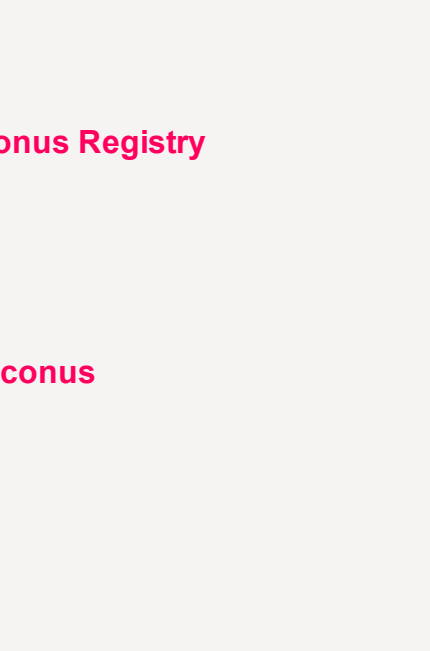
Doctor/Patient Relationship Survey: Finding the One!

Empathy is the ability to understand and share the feelings of another. One of the chief concerns of individuals with keratoconus is finding the right eye doctor. All doctors should be well-trained; most patients also look for their doctor to display empathy.

In the May edition of *Update*, we included a survey on Doctor/Patient Relationships. Forty-four people completed the poll. Thank you to those who shared their experience.

Most (76%) of the respondents were women and 80% were over age 46; 60% had been with their doctor for more than five years. Almost all of those who completed the survey had very positive comments concerning their doctor.

Asked to grade their doctor in a series of situations, patients found their doctor to be excellent (the top choice) in the following categories: answering questions (78%), friendly (76%), and provides a thorough exam (76%).



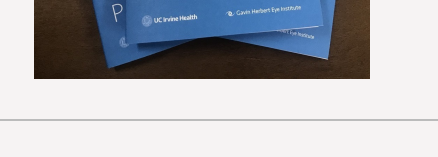
Patients were also given an opportunity to provide remarks. Responding to **something your doctor does well** patients generally stayed on the theme of listening with comments like "talks to me like a friend, not a patient", "never feels rushed", "is interested in what I have to say", "asks questions and looks at me when I answer", and "asks questions about how my vision is affecting my daily life".

Asked **what your doctor could do better**, a few believed their doctor could provide more details when explaining test results or treatment options, yet the overwhelming majority were more than satisfied with the doctor/patient relationship, responding with comments like "don't fix what isn't broken". From others, "I share all my concerns", "I can't think of anything", "can't say often enough how much more comfortable I am with my current doctor", and "Nothing. He's great and approachable". One patient admitted, "I find it hard to open up" and another observed, "opening up is not the goal of my appointments".

The perfect doctor for one patient may be precisely the wrong choice for another. The majority of patients who participated in our survey are extremely happy with their choice of caregiver. A key take-away is that **KC patients value being heard and having a doctor who listens**. If that isn't the case for you, try to communicate what you need while being respectful of your doctor's time and limitations. Patients and doctors working as a team can make navigating life with KC much more manageable.

Mental Wellness & KC

As the relationship between disease and mental wellness becomes more fully explored, NKCF has introduced new material on the NKCF website and in our patient resource packet. Mental health issues like depression are suffered by those with vision impairment at rates higher than those found in the general population; this is especially true of those living with keratoconus. These reactions are understandable - changes in vision are often accompanied by a shift in identity, feelings of isolation and trouble adjusting to changed circumstances.



Withdrawing from friends and activities and self-isolating is not in your best interest. Share your feelings of anxiety with someone you trust. And ask your doctor for a referral to a mental health professional if you think it will help.

Reference: Mental Health Impact of Keratoconus: A Systematic Review, Durakovic E, Kandel H, Watson SL, Cornea, doi:10.10971, 2023 online ahead of print.

Joey Gase Hero Cards Available

Did you know you can get a free **Hero Card** from NASCAR driver and NKCF Ambassador, Joey Gase? Hero cards are unique sports collectibles, like baseball cards. They include information about the driver, his team, and also information about KC. To get a card you can share with your racing fan friends, visit [here](#). (Sorry, *USA addresses only*). Follow him at [JoeyGaseRacing.com](#).

Listen to Joey Gase share his keratoconus story with Dr. Melissa Barnett on Clearly KC - Episode 8.
Find Clearly KC here or on your favorite podcast platform.

Find Tips for School on nkcf.org

Students living with KC can experience difficulties due to their vision. It can be very frustrating to not be able to see the classroom board clearly to keep up with reading assignments, or to have to interrupt studies to adjust contact lenses. With the right attitude and support, there is no reason why students with keratoconus cannot succeed academically. Visit the "For Patients" tab at [nkcf.org](#) and find **Students with KC**. Good luck in the new school year!

ECPPs: Are You Still With Us?

For most of the last four decades, NKCF guided patients to a referral network of keratoconus experts. The network had close to 400 eyecare providers from nearly every state. Optometrists, ophthalmologists, and ophthalmics with advanced training in management of keratoconus, and who met the guidelines for membership could join.

In 2022, we asked all members of the network to reapply in order to update practice resources. About half of the eyecare providers on the referral list updated their entries, but many keratoconus experts never completed a new application and have been dropped from our list. Our message to these doctors: *We miss you!* Check to see if you are still on our referral list, and if not, please get your place back by completing an application. You'll find our list of experts by visiting <https://nkcf.org/doctor-locator/> and can complete an application [here](#).

Down Syndrome Task Force Meets

A subgroup of the NKCF-sponsored Task Force on Keratoconus and Down syndrome met at the annual meeting of the American Society of Cataract and Refractive Surgery in San Diego. This group of eye surgeons who perform crosslinking for progressive keratoconus was led by Dr. Ann Ostrovsky MD of East Carolina University. The discussion focused on how to raise awareness among pediatricians and primary care providers who manage the overall health needs of these individuals and to encourage these healthcare providers to refer patients for topographic/tomographic imaging.

Keratoconus is very prevalent in the Down syndrome community. Corneal crosslinking can be an effective intervention to prevent progression and preserve sight for these patients. NKCF has produced a brochure, "Down Syndrome & Keratoconus" that is available to families looking for more information. Request one [here](#).

KC Roundtable Planned at AAO

New Orleans is the location for this year's American Academy of Optometry annual meeting and the Keratoconus Roundtable. NKCF hosts this annual event and invites doctors from private practices and those working in academic settings to compare notes and share insights. Many "old-timers" and newly graduated residents regard this unscripted lunch as a highlight of their Academy meeting. NKCF looks forward to seeing friends on October 12.

Evening Webinar Preview: Midday Fogging

The 2023-34 Evening Webinar Series kicks off with a discussion of one of the common complaints of contact lens wearers. **Dr. Maria Walker OD, PhD, FAAO, FSLs** will explain midday fogging – the causes and remedies. Midday fogging is the term used to describe how vision can become hazy after a few hours of contact lens wear. This is usually the result of a buildup of debris in the tears in front or behind the lens. **About one-third of scleral lens wearers complain of midday fogging.** Dr. Walker is Assistant Professor at the University of Houston College of Optometry and her research concentrates on the impact of contact lens wear on ocular surface diseases.

Dr. Walker will describe how your doctor can narrow down the source of midday fogging and what can be done to eliminate it. She will be joined by moderator Dr. Karen Lee OD, FAAO, FSLs, also of the University of Houston.

To attend the live broadcast, you must register in advance. If you are not available to hear Dr. Walker on September 12, a video recording will be available on YouTube and the NKCF website.

[Register for Midday Fogging Webinar](#)

NKCF Announces New Evening Webinar Series

Mark your calendars now to make sure you don't miss a single Evening Webinar. NKCF invites leaders in the field of medical and surgical keratoconus care and contact lens management to talk about issues of interest. These bimonthly lectures are live with speakers taped at their home or office and include Q&A from audience members. Recordings of past presentations are available at the NKCF Video Library.

September 12, 2023

What is Midday Fogging and How to Remedy it
Maria Walker OD, PhD
Houston Texas

November 14, 2023

Learning from the Save Sight Keratoconus Registry
(World KC Day Lecture)
Stephanie Watson MBBS, PhD
Sydney, Australia

January 9, 2024

Yes! There are Soft Lenses for Keratoconus
Susan Resnick OD
New York, NY

March 12, 2024

Cataract Surgery and Keratoconus
Jay Lustbader MD
Washington, DC

May 14, 2024

Systems and Solutions for your Contact Lenses
Susan Gromacki OD, MS
Fulton, MD

July 9, 2024

Ask Us Anything!
Uri Solberman MD
Baltimore, MD

Evan Kaufman OD
Charlottesville, VA

NKCF Resources - Share the Knowledge

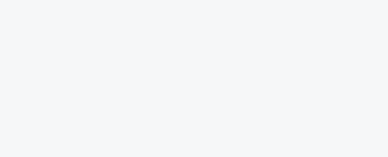
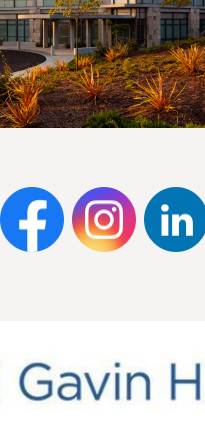
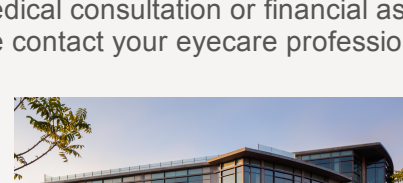
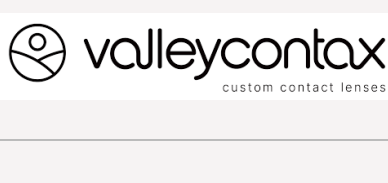
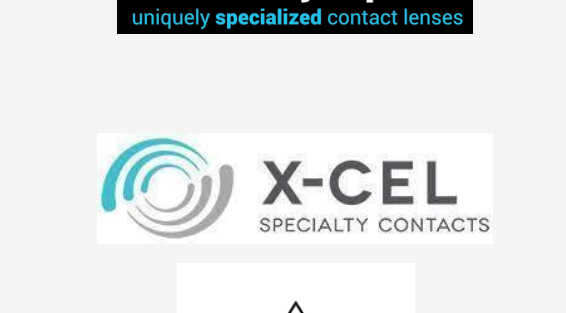
We hope you'll find the answers to your questions about keratoconus on our website, [nkcf.org](#). You can sign up for our Evening Webinars, and view our video library of more than 25 hour-long talks by experts. We have a Referral List with links to doctors expert in managing the disease. You can also find back copies of our newsletter, and information about World KC Day. If you are interested in receiving a copy of our Keratoconus Patient Guide, you can request one [here](#). You may want to share the book with teachers, employers, or family members to help them understand some of the challenges you face. If you still have questions, write to info@nkcf.org and we'll try to get an answer.

NKCF does not have financial resources to assist with the cost of contact lenses or medical care.

Your tax-deductible gift of any amount, to UCI Foundation, helps NKCF improve the quality of life for people with keratoconus through education and advocacy. Make an on-line gift today and join us to raise KC awareness.

I SUPPORT NKCF

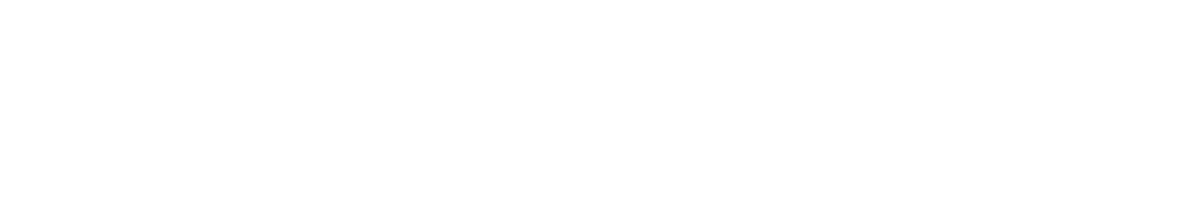
A heartfelt thank you to our brilliant corporate supporters.



NKCF Update is sent to you compliments of the National Keratoconus Foundation, an outreach program of the Department of Ophthalmology at University of California Irvine.

The mission of NKCF is to increase awareness of keratoconus and to provide information and resources to those living with the disease.

NKCF does not provide medical advice, medical consultation or financial assistance. If you have specific questions about your diagnosis, treatment or outcomes, please contact your eyecare professional.



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