

## KC Webinars for Friends & Family

NKCF has launched an evening webinar series where we invite experts to present current information about keratoconus. The live webinars are free to any resident of the US, and can be viewed by our international friends and US residents who miss the live broadcast on the NKCF website one week later. Jason Marsack, PhD, a researcher at the University of Houston College of Optometry moderates these webinars.

To register for the live webinar, look for the email invite sent to you a week before the webinar. You will be sent directions on how to enroll and will receive an email reminder prior to the event.

If you missed the first two webinars, you can view them through the links below:

**October 8, 2019:** Maria Walker, OD and Matt Kauffman, OD of the University of Houston College of Optometry discuss **"Roadmap to Treatment"**

**January 14, 2020:** S. Barry Eiden, OD, president and founder of International Keratoconus Academy and medical director of North Suburban Vision Consultants in Chicago discussed **"Early Detection and Defining Progression"**

Mark your calendar for these upcoming presentations:

**April 21, 2020:** Clark Chang, OD and Beeran Meghpara, MD from Wills Eye Hospital in Philadelphia will address the topic of corneal cross-linking with their talk, **"So You Think You Need CXL"**

**July 14, 2020:** Gloria Chiu, OD and Annie Nguyen, MD of the USC Roski Eye Institute in Los Angeles will present **"Update on Contact Lens Options"**

## Survey Results:

# Eye Rubbing & Cross-Linking



No scientific studies have been published linking corneal cross-linking (CXL) to variations in eye rubbing, but some doctors have remarked on changes to their patients' eye rubbing habits.

In the last *NKCF Update*, we asked readers who had undergone CXL if they experienced changes to in their eye rubbing habits. Thirty-eight individuals responded to the survey. They ranged in age from 16 to 67, 55% were women. All had undergone corneal crosslinking sometime between 2006 and 2019.

The survey participants were asked about their eye rubbing habits prior to CXL. Five (13%) described themselves as infrequent eye rubbers and 17 (45%) as moderate eye rubbers. One moderate eye rubber reported, *"I didn't notice that I rubbed by my eyes excessively, but other tell me I did."* Sixteen (42%) self-reported as frequent eye rubbers, describing their eyes as often itchy and painful and that eye rubbing brought relief.

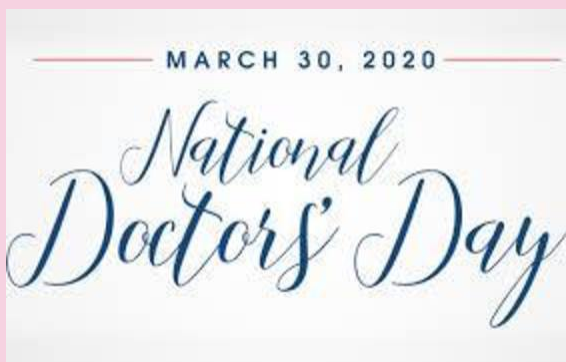
When asked about their habits after CXL, nine (24%) reported no change in their eye rubbing. These patients included those who described themselves as infrequent (4), moderate (2) and frequent (3) eye rubbers.

The rest of the respondents (n=29; 76%) reported changes after the procedure. Two individuals reported that they were rubbing their eyes more frequently since the procedure. One wrote, *"I started to rub my eyes even more, especially after removing the contact lens."* Another wrote, *"My eyes itch more so I rub them more; the eye that received CXL is very dry."*

However, a majority reported they had less of an impulse to rub their eyes since the procedure, *"My eyes are not as itchy and I am very aware of the habit,"* wrote one patient. Another noted, *"After CXL I could not rub my eye for a month (doctor's orders) so I think that helped to break the habit."* And another wrote, *"I don't rub my eyes now that I am educated about my condition."*

Thanks to the readers who participated in our survey. As more people undergo CXL, we will learn more about eye rubbing after CXL. We invite you to take this month's survey on Scleral Lens care. The link is found below.

# HONOR A CTOR



NKCF is again giving patients the opportunity to say **THANK YOU** to their eye doctor on National Doctor's Day.

Between now and March 30, go to the **NKCF website** and tell us how your doctor has

made a difference in your life. We'll send your doctor a special message on your behalf, and NKCF will print the names of all the nominated doctors on our website. We'll use your vote and your story to select our Top Doc of the Year. This program is only offered to friends of NKCF based in the US.



## Transcending Limitations of Keratoconus

If you are a loyal **America's Got Talent** fan, you know the name Tyce Nielsen. Tyce is a trapeze artist who, with his wife, Mary Wolf-Nielsen, performs aerial acts under the stage name **Duo Transcend**.

Tyce and Mary create and carry out daredevil performances, leaving their audiences holding their breath. While performing these maneuvers is difficult simply because they take immense physical strength and agility, Tyce faces an additional challenge: he has keratoconus. Tyce has been open about his condition, and advocates for living life to the fullest:

*"I was determined that I could still do trapeze with my wife even if I was blind. I trained daily as if my sight was gone and gained so much confidence in myself and truly learned that we can do anything we put our minds too. I was so blessed to be able to go on America's Got Talent and show the world that you still can achieve your dreams. Don't be afraid of*

*your challenges in life, be grateful you have them so that one day you can overcome them.*

*"Living with keratoconus is very much a life challenge as anyone with the disease will attest. The gift of eye sight is an incredible luxury that all who have it usually take for granted. Those of us who don't have it or have a blurred version of it usually cherish it like gem."*

Tyce and Mary perform internationally as Duo Transcend, and have been featured performers at Cirque du Soleil and on MTV and ESPN. To watch videos of their remarkable performances, visit [maryandtyce.com](http://maryandtyce.com).



GLAUKOS®

**Avedro is now  
Glaukos**

Glaukos Corp., an ophthalmic technology and pharmaceutical company, completed its acquisition of Avedro in November 2019. Based in San Clemente, CA, Glaukos is an established eye health company that previously focused on glaucoma treatments. Avedro, maker of the only FDA-approved crosslinking technology for progressive KC, will be the cornerstone of the new cornea division of Glaukos.

## **Epi-On CXL Clinical Trial Completes Enrollment**

Glaukos (formerly Avedro) reports they have completed enrollment in a Phase 3 clinical trial to evaluate an epithelium-on (epi-on) corneal cross-linking (CXL) procedure for progressive KC. 275 eyes will be tracked during the study.

The new epi-on procedure includes use of supplemental oxygen and a new drug formulation. This trial is the first Phase 3 epi-on study being performed to support an FDA approval filing (Study #NCT03442751 at [clinicaltrials.gov](https://clinicaltrials.gov))

Dr. George Waring, IV, MD is Medical Monitor of this clinical trial. He is looking forward to the opportunity to offer his patients with progressive KC

an epi-off or an epi-on treatment option. *"This new investigative procedure, which is designed to reduce post-op discomfort and enhance recovery time, has the potential to provide added benefits to both patients and ophthalmology practices."*

What is the next step? Now that this clinical trial has completed enrollment, study subjects will be treated and followed for 12 months. The results will be analyzed and submitted to the FDA. At the earliest, FDA review and approval for epi-on CXL is still a few years away.



Dr. George O. Waring, IV, MD, FACS, is founder and Medical Director of the Waring Vision Institute in Mt. Pleasant, South Carolina. For info, visit [waringvision.com](http://waringvision.com)

## Pacific Islanders Linked to KC

In an article published in the journal, *Cornea*, researchers in New Zealand conducted a study of students living in the capital city of Wellington (1). All 49 high schools in the city were invited to join and twenty schools, and a total of 1,916 students, participated. The study focused on students in year 9 (mean age 13.9 years) and year 11 (mean age 15.5 years). The three main ethnic groups that made up the study were white (60%), Maori (14%), and Asian (11%).



Each student was screened for evidence of disease using Pentacam tomography and an autorefractor to test vision. Ten students were found to have keratoconus: 7 males and 3 females. Seven of these ten students did not wear glasses or contacts for vision correction. Eight of the students were unaware of their diagnosis of KC before the screening. Seven of the students experienced atopy - hay fever, asthma or eczema, compared to 44% of the students without KC.

The researchers found that those with an indigenous Maori ethnic background had the highest rate of disease. While the Maori students made up 14% of the study subjects, they represented six of the ten students diagnosed with KC (for a prevalence of 1:45 vs. 1:191 for the total population of students screened).

This study gives more evidence that certain ethnic groups face an increased risk of disease. It also demonstrates that screening, even in the early teen years, can identify individuals with KC. Early diagnosis is important because adolescent-onset KC generally has greater severity and rapid progression.

(1) Paplil-Curtin AT, Cox R, Ma T, *et al*, **Keratoconus Prevalence Among high school students in New Zealand**, *Cornea*, 38: 1382-1388, 2019.

## Using Genetics to Predict KC

The role of genetics has been of interest among researchers and physicians as one of the factors that impact keratoconus (KC). Recent publications indicate genetic variants as well as membership in certain ethnic groups can influence who is likely to develop KC and experience disease progression.

Individuals with a family history of KC have an increased risk of developing KC. Children can be born to parents who carry an affected gene: these children can either be unaffected, or carry the gene mutation and have no evidence of KC (carrier), or can be diagnosed with the disease (affected). At this time, the majority of individuals with KC have no known family history of the disease. As genetic testing becomes more sophisticated, scientists may identify additional gene mutations that are potential links to the disease and will provide an answer to the question, "what causes KC?"

In order to identify patients at an increased risk due to genetic factors, Avellino Precision Medicine of Menlo Park, CA has developed the **AvaGen test**, the first commercially available genetic test that will help detect genetic mutations known to cause certain corneal dystrophies including KC. The AvaGen test uses a non-invasive cheek swab to collect cells and then sequences the DNA. It focuses on 75 genes known to impact corneal eye health, including the *TGFBI* gene that is linked to KC.

AvaGen test results will show if you carry any of the variants linked to KC and will provide a risk score. Your doctor or a genetic counselor can explain what this means to you and close family members.

Dr. John Gelles, OD, of the Center for Keratoconus at the Cornea and Laser Eye Institute (CLEI) in Teaneck, New Jersey warns that genetic testing cannot take the place of regular exams, "With the availability of new



*methods to treat keratoconus, early diagnosis has become ever more important. Tests like this give us a valuable new tool for KC diagnosis. However, such a test will not obviate the necessity of careful and regular clinical screening of at-risk patients, including relatives of KC patients, younger patients whose vision cannot be corrected fully with spectacles, and those with irregular astigmatism to name a few."*

The objective of the AvaGen test is to help physicians create individualized treatment plans for their patients, and help patients make informed decisions about their healthcare. Dr. Steven Greenstein, MD, also of the CLEI Center for Keratoconus noted, *"Although the concept of being able to diagnosis a disease prior to clinical manifestations is ideal, prophylactic treatment such as corneal crosslinking would not likely be performed without clinical evidence of disease. Nonetheless, testing like this will be valuable both in the clinic and for KC research in the future."*

To learn more about the AvaGen test, visit the **[Avellino website](#)**. The AvaGen test must be ordered by your doctor and is generally not covered by insurance. Ask your eye doctor if you believe you could benefit from this test.



Dr. John Gelles, OD, FCLSA, FSLC, is a member of the Hersh Vision Group's Cornea and Laser Eye Institute. He is a board member of the International Keratoconus Academy and a fellow of the Contact Lens Society of America and the Scleral Lens Society.



Dr. Steven Greenstein, MD is a fellowship-trained cornea specialist working at the Center for Keratoconus at the Cornea and Laser Eye Institute in Teaneck New Jersey. For more information, visit , **[vision-institute.com](http://vision-institute.com)**

## New Scleral Lens Product

Contamac, one of the world's leading contact lens companies, has launched Nutrifill, a new



insertion solution for scleral lenses.

Nutrifill is FDA-cleared and available only in the US. It is a preservative-free lens formula specifically designed for scleral lens wearers, and can also be used to rinse hybrid and gas permeable (GP) lenses.

Instead of a traditional sodium chloride solution, Nutrifill

contains additional useful nutrients for the cornea: calcium, magnesium, potassium and phosphate, and has a pH (7.4) and osmolality (300) that mimics the eye's tear layer as closely as possible.

Dr. Stephanie Woo, OD, of the Contact Lens Institute of Nevada, was the first optometrist in the US to offer Nutrifill to her patients. She notes that several of her patients have reported they are able to wear their scleral lenses for longer periods of time with this new formula. She adds, *"Many of my patients reported less fogging when they switched to Nutrifill."*

Talk to your doctor if you are interested in trying this new option to clean and fill your scleral lens reservoirs. Nutrifill comes in packs of 35 single use 10 ml ampoules. More information about this product can be found at [nutrifill.com](http://nutrifill.com) and at [dryeyeshop.com](http://dryeyeshop.com).



Dr. Stephanie Woo, OD, FAAO, FSLC is founder of the Las Vegas-based Contact Lens Institute of Nevada, a practice dedicated entirely to specialty contact lenses. Visit [clinevada.com](http://clinevada.com) for more info.

## Common KC Mistakes to Avoid

There are many misunderstandings surrounding managing keratoconus. Many individuals with KC fall into patterns that could actually be making their condition worse, or at the very least causing unnecessary discomfort. Are you guilty of any of these?

### EYE-RUBBING:



The first mistake to avoid is eye-rubbing. It is a common habit, characterized by rubbing eyes with the knuckles (instead of finger tips) for an extended amount of time. Many people with eye allergies rub their eyes to seek some relief, however in an individual with KC, it can aggravate and make the disease worse. Talk to your doctor about medications that might provide relief from allergies if you find you are tempted to rub your itchy eyes.

Dr. Francis Price, MD has been treating KC patients for more than 35 years. He notes, *"In my experience, eye rubbing is often associated with KC. Continued eye rubbing can negate the effects of both corneal transplants and crosslinking and, importantly, it is the one thing people can change (by not rubbing) that can influence the progression of the disease."*

### **INFREQUENT DOCTOR VISITS:**

Something that individuals with KC should do, but often put off, is visiting their eye doctor regularly. KC is a progressive disease: your eyes need to be consistently monitored to ensure that your vision is the best it can be. Your prescription for contact lenses or eyeglasses may need to be updated to account for vision changes. Even if you have undergone cross-linking, you need to continue to return to your eye doctor as advised.

### **INCORRECT CONTACT LENS CARE:**

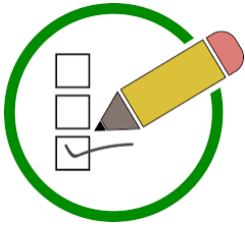
A final tip is to take proper care of your contact lenses. Most people with KC wear contact lenses on a daily basis, so it is important that they follow proper lens care. Lack of care, or improper use of supplies for your lenses can cause keratitis (inflammation of the cornea). Keratitis is caused by germs, and these germs can invade and infect your eye when lenses are worn past their replacement date or not cleaning them properly.

Some tips for caring for your lenses properly are:

- Wash and dry your hands before touching your contact lenses.
- Do not sleep in your contacts.
- Don't wear contacts in the shower or while swimming.
- Rub and rinse contacts with solution each time you clean them, not with water or saliva.
- Always use fresh disinfecting solution - don't "top off" by adding new solution to old.
- Never store your contacts in water.
- Replace your contacts as often as your doctor suggests.
- Wash your case every day with solution (not water!) and leave it to dry upside down with the caps off.
- Replace your case at least every three months.



Dr. Francis Price, MD, is founder and president of the Cornea Research Foundation of America and founder of Price Vision Group, a specialty ophthalmic practice located in Indianapolis. Visit [pricevisiongroup.com](http://pricevisiongroup.com) for more info.



## Take our Survey

Do you have good scleral lens habits? Take our quick survey to find out if you are guilty of some common practices that cause your doctor to despair. Please click the button below to be directed to our survey!

[Scleral Lens Survey](#)

## Columbus, we are coming for you!



NKCF and the Ohio State University College of Optometry will be hosting a [KC Family Symposium](#) on **Saturday, May 30, 2020.**

The KC Family Symposium is a day-long event where families affected by keratoconus can come together to learn and network with one another.

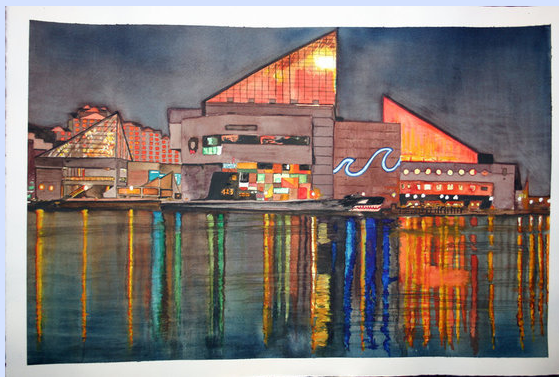
Presentations on topics such as diagnosis, cross-linking, contact lens options, and life with KC will be explored. If you are in the Columbus, Ohio area, plan on joining us for this event. Registration information can be found at [NKCF Family Symposium](#).



## Assistance for CXL Insurance Claims

Last year, Glaukos (Avedro), the company that offers the only FDA-approved CXL treatment, established a hot-line for physician offices to ask claim-related questions and receive assistance with insurance appeals. The program, Avedro Reimbursement Customer Hub (ARCH) has expanded and the billing experts are now accepting questions directly from patients about eligibility and benefits related to CXL. The program does not provide financial assistance for those in need, and cannot assist in securing insurance reimbursement for non-FDA approved CXL procedures.

If you, or your doctor's office, has questions about pre-approval, prior authorization, payment, or denial of claims related to FDA-approved CXL, this is a valuable resource. Learn more by visiting [livingwithkeratoconus.com](http://livingwithkeratoconus.com) or calling the ARCH hotline, 844-528-3311.



## Attention: KC Researchers

Scientists attending the annual meeting of ARVO (Association for Research in Vision and Ophthalmology) are invited to participate in the NKCF Roundtable. The Roundtable will take

place on **Wednesday May 6** at the Baltimore Convention Center. Researchers who are registered for the meeting are welcome. To receive an invitation, email [info@nkcf.org](mailto:info@nkcf.org).

## NEI's New Website Puts Eye Health Info at your Fingertips



The National Eye Institute (NEI) has redesigned its website making it easier than ever to get accurate, up-to-date eye health information that you can trust. Accessibility features make the site easier to navigate for people with blurry or low vision.

The site has information on a range of eye conditions and diseases, including keratoconus, and information about NEI-supported research and clinical trials.

Additionally, the site has useful resources that will help readers understand how the eye works, and free-to-use materials like fact sheets, videos, and photographs that can help educate and promote eye health.

Located in Bethesda MD, the NEI is part of the National Institutes of Health. Take a moment to explore the new and improved site at [nei.nih.gov](https://nei.nih.gov).



## Pham heads to San Diego

Major League Baseball outfielder Tommy Pham, who serves NKCF Ambassador, was traded to the San Diego Padres during the winter.

Pham recently shared his experiences of living with KC while playing baseball at the highest level with doctors attending the annual meeting of the American Academy of Ophthalmology at an event sponsored by Avellino Precision Medicine. Interviewing Pham was Dr. Eric Donnenfeld, MD of Rockville Centre, NY, NKCF Top Doc in 2018. Follow Tommy during the season on Instagram: [@tphamlv](https://www.instagram.com/tphamlv).

**MARK YOUR CALENDAR FOR THE NEXT  
NKCF WEBINAR**

**"SO YOU THINK YOU NEED CXL"**

**APRIL 21, 2020**

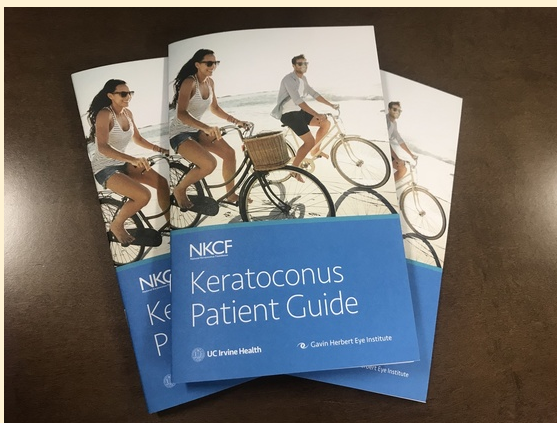
**MARK YOUR CALENDAR FOR  
RESEARCHER ROUNDTABLE AT ARVO\***

\*Association for Research in Vision and Ophthalmology

**MAY 6, 2020**

**MARK YOUR CALENDAR FOR  
OHIO NKCF FAMILY SYMPOSIUM**

**MAY 30, 2020**



**Share the  
Knowledge!**

Take the time to educate yourself and others. NKCF sends a free copy of the 22-page book, **Keratoconus Patient Guide** to US residents who request it. Many share the book with teachers, employers, or school

counselors to help them understand some of the challenges you are facing. If you are interested in receiving a copy of the Keratoconus Patient Guide, request one by visiting our website, [nkcf.org](http://nkcf.org).

**You can make a difference!**

We are so grateful to our friends and donors who help NKCF to be there when we are needed. Your tax-deductible gift of any amount helps maintain our educational and informational programs.

**Did you know that 100% of your tax-deductible gift to the UCI Foundation will be used exclusively for NKCF?**

Click the **I SUPPORT NKCF** button below to make a quick and very much appreciated on-line gift. If you prefer to send a check, payable to UCI Foundation, please send it to

**NKCF**  
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**Irvine, CA 92697**



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## NKCF Update

*is sent to you compliments of the National Keratoconus Foundation, a program of the Gavin Herbert Eye Institute at the Univ. of California, Irvine.*

Contact us with your general questions about keratoconus at [info@nkcf.org](mailto:info@nkcf.org) or call us at 800-521-2524.

*We do not provide medical advice. If you have specific questions about your diagnosis, treatment, or outcomes, please contact your eyecare professional.*



# UCI Health

National Keratoconus Foundation is a program of the Discovery Cornea Center at the Gavin Herbert Eye Institute, University of California, Irvine.

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