NKCF
National Keratoconus Foundation

July 2019 Update

Meet our 2019 TOP DOCs


In March, we asked readers to tell us about their eye doctor in celebration of National Doctors' Day. As in the past, NKCF selects one optometrist and one ophthalmologist to represent the entire group as the "Best of the Best". **Dr. Christine Sindt, OD** from University of Iowa *(left)* and **Dr. Erin Stahl, MD** from Children Mercy Hospital in Kansas City *(right)* have made treating individuals with KC an important part of their professional lives. Read more about these Top Docs **here.**

Top Doc Honor Roll

Read the names of the 179 optometrists and ophthalmologists on our 2019 Honor Roll. Congratulations to all the doctors who were nominated by our readers.

Keratoconus & Pregnancy:
a case for pro-active CXL

More than 25 years ago, doctors published a study of pregnant women who had successfully worn contact lenses. Several developed contact lens intolerance during their pregnancy or afterward while breastfeeding. By recording changes in the corneal curvature during the second and third trimester, the authors found that, for some women, pregnancy resulted in corneal steepening leading to contact lens discomfort. They concluded, "there is still much to learn about the complex changes that occur in ocular tissue during pregnancy."

None of these study subjects had been diagnosed or treated for keratoconus (KC), yet they experienced KC-like changes to their eyes during pregnancy. Estrogen receptors have been found on the cornea; with increased hormone levels during pregnancy it is not unexpected that some women experience changes that include increased steepening or reduced corneal stiffness or thickness.

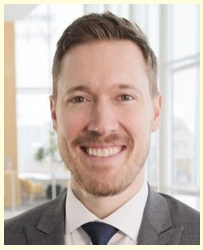
What does this mean for women with KC contemplating pregnancy?

Dr. Brandon Baartman MD of Vance Thompson Vision in Omaha recommends female patients with documented or suspected KC consider an evaluation by a corneal specialist for cross-linking (CXL) before considering pregnancy, especially if there have been signs of progression, such as a change in prescription or fit in contact lenses. Cornea specialists like Dr. Baartman are cautious about performing CXL on pregnant or lactating patients, as this population of patients was not included in any FDA clinical trials. While the benefits of CXL are well-established, the risks to both mother and baby are not fully known. Because pregnancy is a time of significant fluctuation in hormonal physiology, this may lead to progression in a previously stable cornea. Women with KC should be closely monitored by their eye doctors throughout the pregnancy.

Dr. Jeff Goshe MD of the Cleveland Clinic agrees. He also treats pregnant patients with a history of KC as well as those whose KC was diagnosed during pregnancy. He approaches treatment of these women conservatively and favors delaying CXL. Dr. Goshe notes that rapid progression of KC during prenancy is relatively uncommon. Some of the changes that occur may be transient and the result of pregnancy and not true progression of KC. He closely monitors these patients during their pregnancy, but believes that delaying CXL by 6-9 months will not impact their long-term visual prognosis

substantially. Women with KC of child-bearing age are counseled to think about CXL before considering pregnancy. Goshe reasons, "The risk of our treatment and postoperative medication to the unborn fetus is likely low, but definitely has not been studied and proven safe. I do not want to treat a patient and should they have any issues with the pregnancy be left with the fear/regret that the treatment impacted the life of their child."

Dr. Gloria Chiu OD of the Roski Eye Institute at Univ. Southern California notes that the management of KC during pregnancy is challenging given the lack of information on progression, reversibility, or stabilization after delivery. She recommends that women work with an eye doctor experienced in the management of KC during their pregnancy. While CXL may be deferred during this time, your doctor can offer tips to minimize any new discomfort caused by contact lens wear and, if necessary, can make corrections to your eyeglass or contact lens prescription that reflect pregnancy-related changes to your vision.



Dr. Brandon Baartman MD leads the Omaha office of Vance Thompson Vision, an ophthalmic practice with offices in 5 states. To schedule a consultation, visit Omaha.vancethompsonvision.com or call 402-204-8796.

Dr. Jeffrey Goshe MD is a member of the Cornea and External Disease service at the Cole Eye Institute, a part of the Cleveland Clinic in Ohio. To schedule a consultation, visit my.clevelandclinic.org or call 216-444-2020.

Dr. Gloria Chiu OD directs the specialty contact lens service at Roski Eye Institute, part of the USC/Keck School of Medicine in Los Angeles. To schedule a consultation, visit eye.keckmedicine.org or call 323-442-6335.

Mark your Calendar:

October 8

NKCF will offer four webinars in 2019-20 on topics of interest to the KC community. The series is free but you must pre-register and only available to those in the U.S. The first webinar is scheduled for **Tuesday, October 8** at 8 pm EST. Moderator **Jason Marsack, PhD** and speakers **Maria Walker, OD** and **Matt Kauffman, OD** from the University of Houston will present the KC Roadmap - what the newly diagnosed patient should expect over a lifetime. They will focus on treatments and answer some of the most common questions that KC patients and their families have. Watch for more information in the Fall about how to register and future topics and speakers.

Raising Awareness of Corneal Ectasia on a bike tour of Ireland

Born in Johannesburg, Boruch (Bruce) Len moved to the US as a young man and held a variety of jobs that relied on his vision.

Len wore thick glasses and decided in 2001 that LASIK surgery would make life easier. For a while, it seemed successful, but his vision never stabilized and gradually became much worse. After searching for several years, he was diagnosed with corneal ectasia resulting from the laser surgery. The symptoms of cornea ectasia are the same as keratoconus.

Len was advised to have a corneal transplant, but resisted. In his pursuit for a less radical option, he learned about corneal cross-linking. The procedure was not yet approved in the US, but it was being performed in Europe with good results.

His research led him to the **Wellington Eye Clinic in Dublin**, a leader in refractive surgery and treatment of KC. When he learned that the clinic's Medical Director was a fellow-South African, he was convinced that he had found the right place. He remembers, "So off I went, not being able to see a bloody thing." His treatment for corneal ectasia successful, he returned to a childhood passion: photography. Len now makes his living as a professional photographer.

During his visits to Ireland for treatment and aftercare, Len fell in love with the scenic Irish countryside. This summer, Len has returned to Ireland and is in the middle of a solo bike tour. He plans on cycling more than 1700 miles along the coastline and taking photographs along the way. He will use the bike tour to raise awareness of KC and corneal ectasia and plans on publishing his photographs when he returns to Florida.

You can follow his adventures by reading his blog posts and share the Irish experience by looking at some of the magical photographs he takes at **www.healingsight.com**. If you are interested in supporting Boruch Len on his journey, you can learn more and contribute at **www.gofundme.com/cycling-around-ireland-for-sight.**

Enjoy some of the beautiful shots from Borach's bike tour:

Corneal Transplant Survey

Thank you to those who completed the corneal transplant poll in our March newsletter. We had 41 responses from the U.S., including 20 men and 21 women from all parts of the country.

Among these individuals, there were 78 transplant procedures. The earliest transplant in this group took place in 1966 and the most recent was March 2019.

Twenty-two individuals (54%) underwent a corneal transplant in one eye only; 19 (46%) had bilateral transplants or operations to both their right and left eyes. The time between surgery for the first and second eye ranged from less than 1 year to 20 years, the average was 7 years and the median was 5 years.

We were interested in learning how long before patients required a replacement corneal transplant. There were 19 repeat surgeries reported, including four transplants (21%) that failed within 2 years of the initial surgery. The average time between replacement of a corneal transplant was 17 years. Removing the four early corneal failures from the survey moves the average time between the first and second transplant in the same eye to more than 21 years. The group responding to our survey included patients who went 32, 38, and 39 years before a repeat corneal transplant was required!

Asked to review the poll results, corneal specialist **Dr. Brian Alder MD** of the Shepherd Eye Center in Las Vegas noted, "Corneal transplantation surgery has been around for over 100 years, and techniques and therefore outcomes are constantly improving. Thankfully, when the reason for doing a transplant is keratoconus, grafts tend to survive longer. Looking over the on-line survey results, this looks to be confirmed, with some grafts lasting more than 30 years. As technology and surgical techniques continue to advance, we may see increasingly longer graft survival rates."

Dr. Beeran Meghpara MD, a cornea specialist working at the Wills Eye Hospital in Philadelphia, also found no surprises with the survey responses. "The results," he said, "are quite similar to what we notice at Wills Eye Hospital. It is not uncommon to see corneal transplants survive 15-20 years, or even beyond that. Corneal transplantation is major surgery and can be quite scary for patients to think about. But is important to point out that with appropriate post-operative care and follow-up, patients do quite well." His message to those individuals with KC who undergo a corneal transplant is to keep your follow-up appointments with your eye doctor and to contact your doctor right away if you notice any changes to your vision or to your eye's appearance.

Dr. Meghpara also noted that the number of transplants being done for KC may be on the decrease. He said, "Because of the success of cross-linking, less patients appear to be progressing to the point where transplantation is necessary. Also,

with improvements in contact lens technology and the availability of highly skilled contact lens fitters, even severe cones can be fit with a contact lens improving vision to the point where a corneal transplant is not necessary. This is an exciting time to be a corneal specialist who treats KC, we look forward to more advancements that will continue to help our patients."

Informal polls like this one offer a glimpse into what many individuals with KC experience. Your participation adds to our knowledge about this condition. While the number of individuals with KC who will require a transplant is decreasing, it appears that those who undergo a corneal transplant can expect many years of improved vision and eye health as a result.

Dr. Brian Alder MD practices at the Shepherd Eye Center, a group practice with five offices in the Las Vegas area. To arrange for a consultation, visit shepherdeye.com or call 702-731-2088.

Dr. Beeran Meghpara MD is a member of the Cornea Service at Wills Eye Hospital in Philadelphia. To arrange for a consultation, visit willseye.org or call 215-928-3180.

NKCF Poll: CXL & Eye Rubbing

Do individuals who have undergone cross-linking rub their eyes more or less? That is the question we want to answer this month. If you have had CXL, please take a minute and participate in this month's poll.

CXL & Eye Rubbing Survey

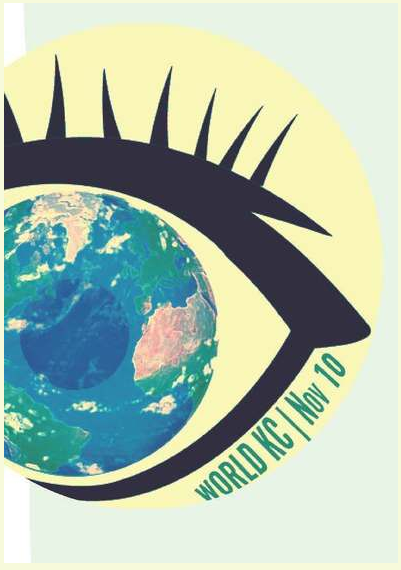
Raising Awareness in Tampa Bay

The Tampa Bay Rays organization hosted a keratoconus awareness

event after the game with the Oakland Athletics on June 12. Outfielder **Tommy Pham** met with more than 100 guests and shared his experience of living with keratoconus while playing Major League Baseball. Local eye doctors, **Dr. Vasilios Diakonis MD** from the Eye Institute of West Florida, **Dr. Roxanne Achong-Coan OD** from Coan Eye Care in Ocoee, from **Dr. Neeta Chhabra OD** from Anderson & Chhabra Eye Care in Tampa Bay answered questions about the latest treatments for KC. **Dr. Ed Bennett OD**, Professor of Optometry from Univ. of Missouri St. Louis moderated the event. In conjunction with the event, the Rays conducted an on-line auction of items autographed by Tommy Pham and/or worn during games, and the proceeds will be donated to NKCF to conduct more outreach events. Read more about Tommy Pham's remarkable story **here.**

What will you do?

World KC Day is **Sunday, November 10**. This is a day to spread the word in your community about early detection and treatment. Think about how you will help raise awareness - share your ideas with NKCF.



Who is Not a CXL Candidate?

Since crosslinking (CXL) was approved by the FDA in 2016, many individuals with KC have been encouraged to consider this treatment. While doctors are quick to point out that CXL is not a cure, in the majority of instances, disease progression halts and the resulting vision is no worse than it is on the day of surgery. For those who fear a lifetime of ongoing vision impairment, CXL is a welcome relief. **Dr. Annie Nguyen MD**, cornea specialist and Assistant Professor at the USC/Roski Eye Institute, has seen the value of CXL to her patients.

However, she notes, not everyone benefits from CXL. Here she names a few patient types who may not be good candidates:

The Stable or Older Patient: CXL is designed to be performed on those who have progressive KC. Dr. Nguyen notes that some individuals with mild cases can go their whole lives without knowing that they have KC. When they finally receive the diagnosis later in life, they are likely stable, having been 'naturally crosslinked' through a lifetime of exposure to UV light. Nguyen warns, "Patients over the age of 40 are unlikely to progress, however they should be monitored regularly. If progression is noted, these patients would be ideal candidates for CXL."

The Scarred Cornea: Individuals may have scarring on their cornea – perhaps from some infection or condition that can disfigure the cornea including poorly fitting contacts or other trauma to the eye. If the cornea is scarred, and you undergo CXL, you may have stopped disease progression, but it will not do anything to improve impaired vision. Individuals with significant scarring, particularly in the central cornea, are often advised to consider a corneal transplant to provide a 'clear window' for their eyesight.

The Thin Cornea: If your cornea is too thin, your doctor may not be willing to perform CXL. A cornea should be at least 400 µm thick so that the riboflavin solution and UV-light used during the procedure does not cause damage to the endothelium (the bottom portion of the cornea). There are pharmaceutical solutions that your doctor can use to temporarily thicken the cornea for the CXL procedure. Researchers are experimenting with other modalities to help treat thin corneas, including using a contact lens when crosslinking.

The Post-Transplant Patient: Individuals with KC may believe that they would benefit from CXL, even after they have undergone a corneal transplant. When a doctor performs a corneal transplant, the weak, keratoconic tissue is replaced with a donor cornea and the need for CXL is usually eliminated.

The Cataract Patient: For individuals with progressive KC who have cataract, Dr. Nguyen recommends CXL first and then waiting until the cornea is stable (about six months) to proceed with the cataract extraction and placement of an intraocular len. For patients who have had cataract surgery previously, she will

CXL if there are signs of disease progress. As with all decisions concerning CXL, the goal is to stabilize the cornea.

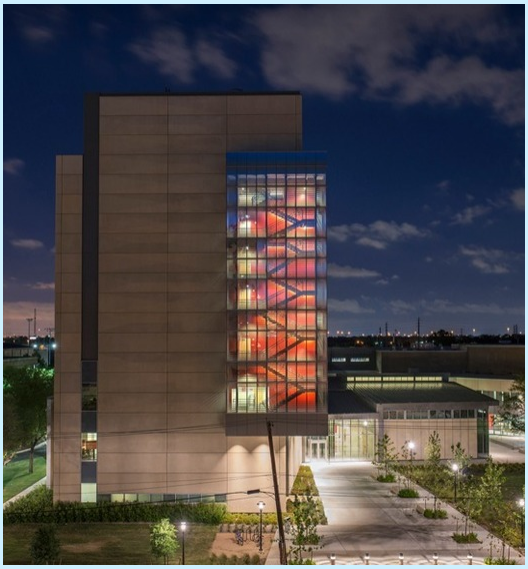
The Pregnant Patient: Since there is not research about the safety of CXL or the pharmaceutical solutions used during the procedure on unborn children or milk production, doctors will generally defer the procedure until after breastfeeding has ended. Women of child-bearing age who have progressive KC are encouraged to undergo CXL before they contemplate pregnancy.

The Squirmy Patient: Certain individuals may find they are unable to sit still for the procedure, or to fixate on the UV-light. While in a small minority of cases, this can mean that the procedure cannot take place, the doctor can usually offer a sedative to calm the uncooperative or extremely nervous patient. Patients with Down syndrome have a high rate of KC, and many doctors successfully perform CXL by having family members present during the treatment to help calm and direct patients. In some instances, CXL is performed under anesthesia.

In summary, Dr. Nguyen is a strong advocate for CXL for those who will benefit from the procedure. Yet not all individuals with a diagnosis of KC are ideal candidates. If your doctor recommends CXL for treatment of progressive KC, ask questions so that you understand how you will benefit from this procedure.

Dr. Annie Nguyen MD is a member of the Cornea Service at the USC/ Roski Eye Institute in Los Angeles. To arrange a consultation, visit eye.keckmedicine.org or call 323-442-6335.

Thanks to our good friends in Houston!



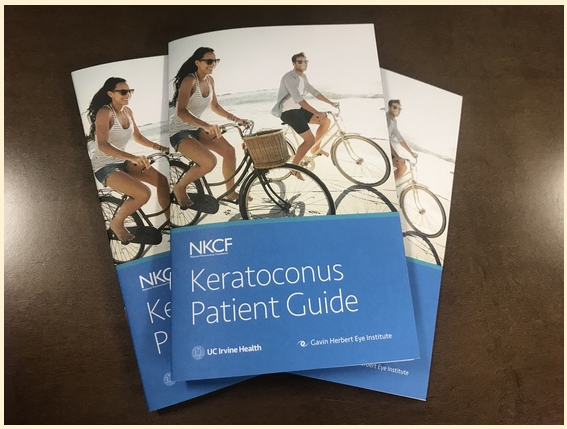
NKCF and the Univ. of Houston College of Optometry held a KC Family Symposium on Saturday, March 23. With more than 70 people in attendance, families had a chance to network with others, and learned about contact lens options, CXL, surgical treatments, insurance tips, and living with KC. We send our special thanks to the faculty: **Drs. Maria Walker OD, Matt Kauffman OD,** and **Jason Marsack PhD** from the Univ. of Houston, **Dr. Tom Arnold OD** of Today's Vision Sugar Land, **Dr. Sumitra Khandelwal**

MD from Baylor College of Medicine, **Rebecca Petris** from the Dry Eye Company and **Dr. Andrea Pihlaskari PhD** from Houston Psychology and Wellness.

Assistance for CXL Access

Last year, Avedro, the company that offers the only FDA-approved cross-linking device and treatment protocol, established a hot-line for physician offices to assist with CXL-related claims and appeals. The program, *Avedro Reimbursement Customer Hub* (ARCH) has recently expanded. Now patients who have questions about their insurance eligibility or benefits relating to CXL can contact the ARCH hotline directly and speak with a representative. Avedro's goal is to remove confusion about insurance coverage for CXL treatment. The ARCH program does not provide financial assistance for those who do not have insurance coverage, or assist in securing 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 CXL, this is a valuable resource. The hotline can also help you identify nearby doctors who perform CXL. You can learn more by visiting **www.livingwithkeratoconus.com**. The ARCH hotline is **844-528-3311**.



Get Ready for School

When school begins in the Fall, take the time to educate others. NKCF sends a free copy of the 22-page book, **Keratoconus Patient Guide** to those 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.** Regretfully, we cannot mail to addresses outside of the US.

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Contact us with your general questions about keratoconus at 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.

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