NKCF
National Keratoconus Foundation

February 2021 Update

It's time to Celebrate Your Doctor

Subscribers to *NKCF Update* can send a special **THANK YOU** to their favorite eye doctor before March 30. Share the story of how your optometrist or ophthalmologist makes a difference in your life. NKCF will send your doctor a special message on your behalf on Honor Your Doctor Day. Check our next newsletter for a list of all doctors nominated and our choice for Top Docs of 2021.

Submit a Top Doc Nomination!

HONOR A DOCTOR

Corneal Transplant Patients & COVID-19

This past year has presented a host of challenges, particularly for those with existing health concerns. A portion of individuals with severe keratoconus undergo one or more corneal transplants when options like specialized contact lenses can no longer help achieve the best possible vision.

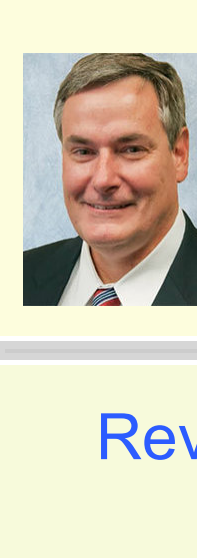
In the age of coronavirus, two common questions arise: Are individuals with corneal transplants at greater risk for contracting COVID-19? And, is it safe for someone with a corneal transplant to get the COVID-19 vaccine?

Dr. Christopher Sales, MD, MPH, Associate Professor of Ophthalmology at the University of Iowa reports that, "The average corneal transplant recipient is not at increased risk for contracting COVID-19 because of their use of steroid eye drops." Eye surgeons will normally prescribe maintenance eye drops for several months or even years after corneal transplant surgery to decrease the the unlikely rejection of donor tissue. The medication designed to offer systemic (or body-wide) suppression would provide a patient who has had a transplant where the organ shares a blood supply like a heart, kidney, or liver. Dr. Sales observed, "Only local immune suppression is required for corneal transplants because the cornea is relatively sequestered from the body's immune system. The tissue, a clear cornea does not contain any blood vessels. It is why your surgeon can transplant corneas without much, if any, concern for negative side effects on the rest of the body."

An individual who has undergone corneal transplant should take the same precautions as anyone to avoid the virus – practice social distancing, frequent hand washing, masking when appropriate, and avoid touching your face and especially rubbing your eyes.

A second concern is that the COVID-19 vaccine may trigger an immune response and cause rejection of donor cornea tissue. You and your doctor may have had a similar discussion about taking seasonal flu vaccines, and it is best to follow your doctor's advice. Evidence that cornea graft rejection has occurred due to vaccines is limited to a handful of case reports over the last forty years. The COVID-19 vaccine does not contain a live virus, and there have been no reported cases yet of rejection of corneal tissue from the COVID-19 vaccine.

Your doctor may recommend temporarily increasing the dosage of your steroid eyedrops to offer additional protection and offset any potential reaction. Contact your doctor if you have questions or concerns. To learn more about vaccines, visit the special COVID-19 CDC website.



Dr. Christopher Sales, MD, MPH is Associate Professor of Ophthalmology at the University of Iowa Carver School of Medicine in Iowa City, IA. A graduate of Tufts School of Medicine, he completed his ophthalmology residency at Stanford Univ. Medical Center and cornea fellowships in Portland, OR and at Lackland Air Force Base in San Antonio before joining the faculty at Cornell/Weill School of Medicine in NYC. Dr. Sales is active in state and national eye banking issues and is an expert in refractive surgery, advanced corneal transplant techniques and management of complicated ocular diseases like keratoconus.

Soft Lenses for KC

Did you know there are disposable contact lenses made especially for individuals with KC?

The majority of individuals with keratoconus are fit with rigid gas permeable (GP or RGP) lenses: the "go-to" lens for management of keratoconus. In a recent *NKCF Update* survey, 90% of readers reported they had worn GP lenses at one time or another. GP lenses offer crisp, clear vision but some find them uncomfortable and are unable to tolerate wearing them for extended periods.

For individuals with mild KC the solution may be soft contact lenses. In the same *NKCF Update* poll, a little less than half (47%) reported they had worn disposable lenses in the past, and 7% said they were currently wearing soft lenses.

A common story is that an individual is prescribed soft lenses for astigmatism or vision correction and when vision changes with conventional lenses continue, the diagnosis of keratoconus is finally made.

The disposable lenses favored by the general public may not be appropriate as KC progresses, but there are soft lenses or lathe-cut lenses manufactured especially for the keratoconus patient. Made with material similar to that found in standard soft contacts, these lenses are somewhat thicker to help smooth out cornea irregularities. Various parameters for height, curve and power are prefabricated and your doctor can prescribe a regular lens replacement schedule. These lenses have the ability to center well while correcting vision. The improved comfort and knowledge that replacements can be easily and inexpensively obtained make this a satisfactory alternative to GPs for many.

Dr. Dan Fuller, OD is the chief of the Cornea Contact Lens Clinic at the Southern College of Optometry in Memphis where he manages the treatment of many keratoconus patients. He finds that many of his patients with mild to moderate disease, and even some who have undergone corneal transplant surgery are successful in soft lenses. "Especially for newly diagnosed patients who have never worn contacts or those who have previously worn standard disposables, soft specialty lenses help the patient get used to the feel of something resting on the eye." Dr. Fuller generally fits NovaKone or Kerasoft IC, two brands of soft contact lenses made specifically for the keratoconus eye. These are conventional soft lenses replaced on a prescribed interval.

In the past, many individuals with KC could expect their condition to progress to the point where their options for clear, comfortable vision were limited. With crosslinking (CXL) slowing or halting changes to the cornea, more patients envision a future where their keratoconus remains stable and their vision needs can be realized with a soft disposable contact.

There are several new contact lens options for individuals with mild to severe keratoconus. Talk to your doctor about what types of lenses may work best for you.

Dr. Daniel Fuller, OD, FAAO, Dipl., FSLS, is a graduate of the Ohio State College of Optometry. He served as Officer in the US Navy Optometry Services and operated a multi-site private optometry practice. For more than 30 years, he has been a member of the faculty of the Southern College of Optometry in Memphis, currently serving as Professor and Chief of the Cornea Contact Lens service where he oversees the training of optometry students and residents in the care of patients with complex corneal disorders. Dr. Fuller is a member of the American Academy of Optometry and Diplomate in the AAO's Section on Cornea, Contact Lens and Refractive Technology Section.

Review of January Evening Webinar: SCOPE Wrap-Up

To kick off the first *NKCF Evening Webinar* of 2021, **Dr. Muriel Schonack, OD**, Assistant Professor at the Mayo Clinic in Rochester MN discussed results from the SCOPE (Scleral Lenses in Current Ophthalmic Evaluation) Survey.

More than 160 people tuned into the live event and more than 630 have viewed the webinar video since then. She summarized results of a survey completed by keratoconus patients concerning their contact lens history and current use. The study complements surveys she and a group of fellow clinician researchers have conducted of on the prescribing habits of eye doctors who treat patients with irregular corneas.

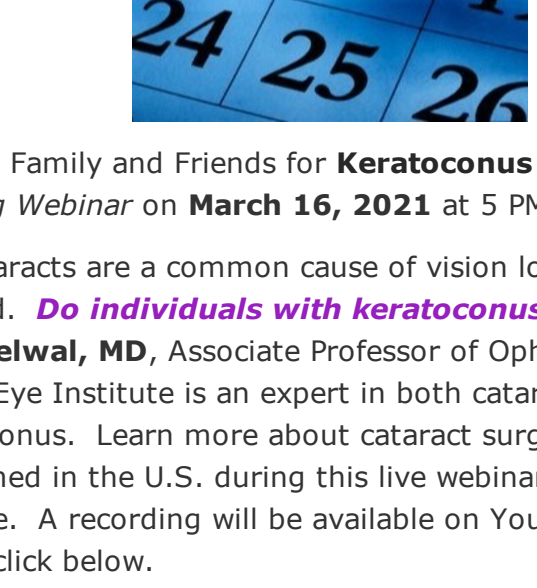
The essential point Dr. Schornack made during the presentation is that there is not one 'right' contact lens for all keratoconus patients, and sometimes there is not one 'right' contact lens for an individual patient. Dr. Schornack stated, "***There is no rule that says that one solution has to work for everything.***" When your doctor understands what are important work, home, or hobby demands, your doctor can make recommendations about achieving the best possible vision. While multiple types of vision correction may not seem reasonable for some, her underlying message is to learn about your options. Dr. Schornack noted, "You may find that one pair or one form of correction works best when you are at work, and a different form of correction works better for you when you are skiing or gardening. You may find that you really appreciate scleral lenses when you are going to your son's soccer game, but you might find that glasses give you perfectly functional vision when you're around the house cleaning. So that's just fine! Use both forms of correction!"

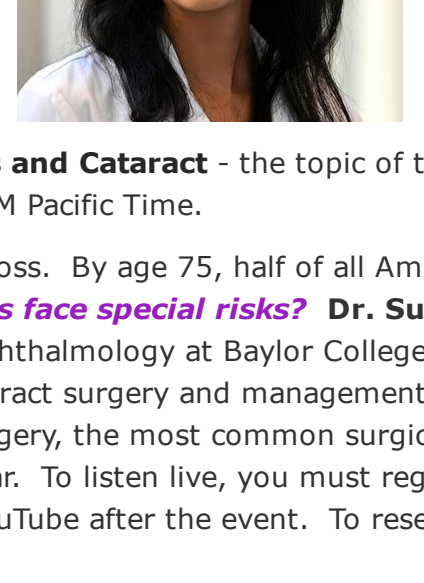
Be open and honest with your provider, and you may become aware of possibilities you didn't think of before. She added it is important to partner with your eye doctor, "***Finding a provider that you are comfortable with, and being willing to open up and share the concerns that you are having is critically important.***" To watch the full webinar, click below.

View Webinar Recording

Between 2010 and 2050, the estimated number of people who have or have had cataract will double from 24.4 million to 50 million.

Save the Date: Tuesday, March 16 Keratoconus & Cataract





Join Family and Friends for **Keratoconus and Cataract** - the topic of the next *NKCF Evening Webinar* on **March 16, 2021** at 5 PM Pacific Time.

Cataracts are a common cause of vision loss. By age 75, half of all Americans will be affected. ***Do individuals with keratoconus face special risks?*** **Dr. Sumitra Khandelwal, MD**, Associate Professor of Ophthalmology at Baylor College of Medicine / Cullen Eye Institute is an expert in both cataract surgery and management of keratoconus. Learn more about cataract surgery, the most common surgical procedure performed in the U.S. during this live webinar. To listen live, you must register in advance. A recording will be available on YouTube after the event. To reserve your space, click below.

REGISTER FOR WEBINAR HERE

Mark your calendar for these upcoming *NKCF Evening Webinars:*

May 18, 2021: Contact lens expert **Dr. Christine Sindt OD** of University of Iowa College of Medicine in Iowa City, IA will present "Deliberations and Considerations When I Treat Individuals with KC"

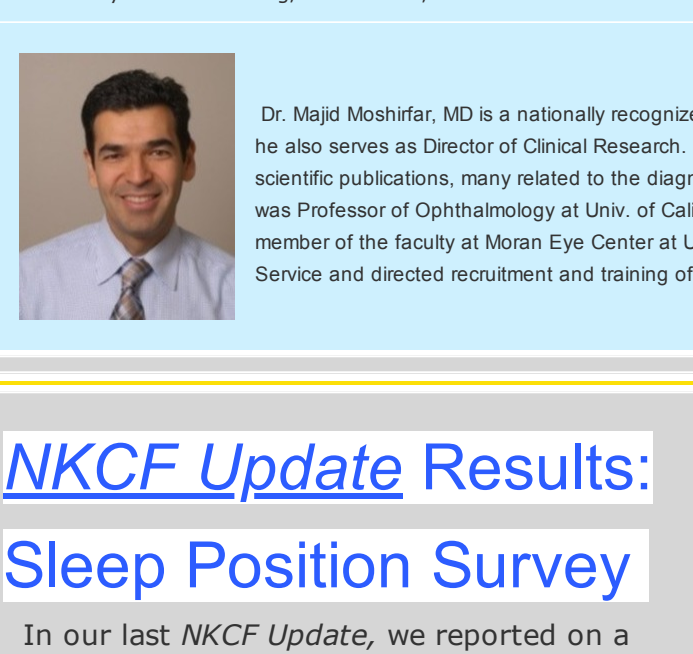
July 13, 2021: Eye surgeon **Dr. James Loden MD** of Loden Vision, Nashville, TN will recount his experience undergoing crosslinking for his own progressive keratoconus

Timely Treatment: Waiting for CXL

In countries with national health service, there can be a substantial delay between referral for service and treatment.

Doctors in New Zealand tracked keratoconus (KC) progression in 96 patients who had been given appointments for corneal crosslinking (CXL) at one of the country's specialty eye centers. Comparing topographic images of corneas taken when the referral was first made to images taken on the day of treatment, doctors were able to gather information about disease progression while treatment was postponed.

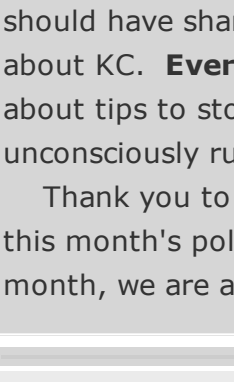
In this study, the waiting time was between 2 and 8 months, with an average delay of 5 months. The authors found that 40% of the patients showed progression, while 60% remained stable. Although not statistically significant, they found that younger patients were more likely to experience measurable progression during the wait period.



An earlier European study had also followed patients with keratoconus from the time of referral to treatment day. In that study, the authors found that 25% of the 104 patients had progressed during the wait list period. The average delay was about half the time (between 2 and 5 months) of the New Zealand study. They also found that the youngest patients were the subjects most likely to show evidence of cornea thinning and steepening. The authors in both studies suggested when there is a wait list for the CXL procedure, it may be worthwhile to give priority to younger patients to reduce their risk of further progression.

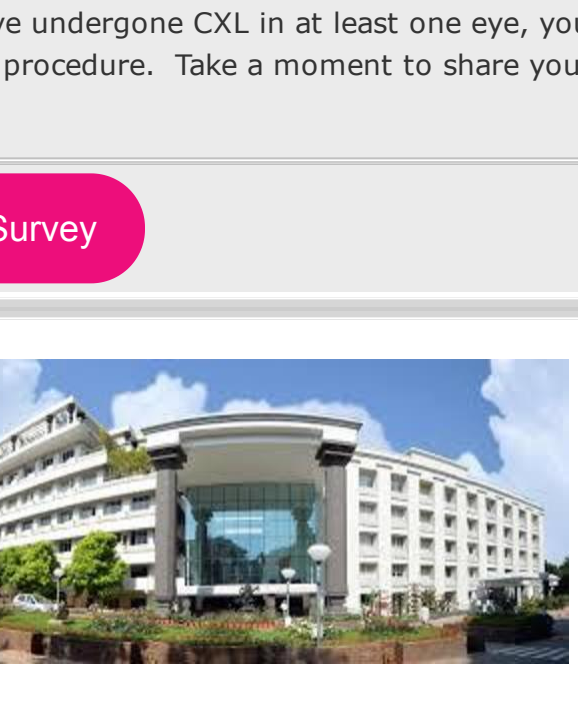
In the U.S., patients are less likely to encounter extensive wait times for CXL because of limited facilities, but there may be delays due to financial concerns, insurance verification, school calendars, seeking second opinions, or simply wanting to learn more about the procedure. In most cases, a delay of a few months may have minimal impact, but for patients with aggressive disease, the delay may lead to further progression. In particular, parents of adolescents referred for CXL should maintain regular contact with their child's eye doctor while the final decision to schedule CXL is under consideration. **Dr. Majid Moshirfar, MD** of Hoopes Vision in Utah, a noted clinician-scientist and expert in the treatment of corneal diseases, shared his perspective, "Corneal cross-linking is highly successful at any age for progressive keratoconus. For children and young adults who may have rapid progression, I advise that early intervention may be essential to prevent further progression. For older adults, I advise that since progression is variable, there may be some allowance depending on the changes in corneal topography."

References:
Goh YW, Gokul A, et al, Prospective Clinical Study of Keratoconus Progression in Patients Awaiting Corneal Cross-linking, Cornea, 39:1256-1260, 2020.
Romano V, Vinciguerra R, et al, Progression of keratoconus in patients while awaiting corneal cross-linking: a prospective clinical study. J Refract Surg, 34:177-180, 2018.



Dr. Majid Moshirfar, MD is a nationally recognized cornea surgeon at Hoopes Vision in Draper, Utah, where he also serves as Director of Clinical Research. He is a frequent lecturer and author of more than 300 scientific publications, many related to the diagnosis and management of keratoconus. Most recently he was Professor of Ophthalmology at Univ. of California, San Francisco, and for 18 years previously was a member of the faculty at Moran Eye Center at University of Utah, where he served as Chief of the Cornea Service and directed recruitment and training of cornea fellows.

NKCF Update Results: Sleep Position Survey



In our last *NKCF Update,* we reported on a publication from a Paris ophthalmology practice specializing in treatment of keratoconus (KC). Based on a survey of patients with advanced KC in only one eye, they concluded that 94% of their patients slept on their stomach or on their 'worse' side and proposed a connection between sleep position and severity of disease.

We conducted an unscientific poll to see if that was the case with *Update* readers. Eighty people responded: 36 were men. The mean age of the participants was over 50; the majority had been diagnosed with KC before the age of 30.

Ten people reported that their KC was equal on both sides and were excluded from the analysis. Forty reported their left eye was their 'bad' eye and 30 said that their disease was more advanced in their right eye.

Of the 40 reporting more advanced KC in their left eye, 17 slept on their left (42%). Ten reported sleeping on their right (25%), six on their stomach (15%), four on their back (10%), and three reported no preference (8%).

Of the 30 reporting more advanced KC in their right eye, 12 slept on their right (40%). Nine slept on their left (30%), six on their stomach (20%), two on their back (7%) and one with no preference (3%).

According to our survey, **there may be a slight tendency of individuals with KC to sleep in a way that applies pressure to their 'worse' eye.** However, our results are nowhere as compelling as the 90+% reported by the French authors. None of our readers could recall their eye doctor discussing sleep position with them. This is not surprising considering there is so little data available on this topic.

We also asked if people believed they rubbed their eyes with different intensity. The overwhelming response was that they rubbed both eyes with the same intensity, whether they self-reported as 'mild', 'moderate' or 'severe' eye rubbers. Of the 70 who reported that one eye had more severe keratoconus, 59 reported they rubbed their eyes with equal pressure, 9 said they rubbed their 'worse' eye more, and 2 said they rubbed their 'better' eye more forcefully.

The most disturbing bit of news is that 11 of the 80 who participated in the survey were unaware of the connection between eye rubbing and keratoconus. Your doctor should have shared the importance of avoiding eye rubbing when you first learned about KC. **Every effort should be made to avoid eye rubbing.** Talk to your doctor about tips to stop rubbing your eyes, and ask family members to tell you if you unconsciously rub your eyes.

Thank you to all who participated in this survey. Please take a moment to answer this month's poll. The more information we collect, the more we learn about KC. This month, we are asking questions of those who have undergone corneal crosslinking.

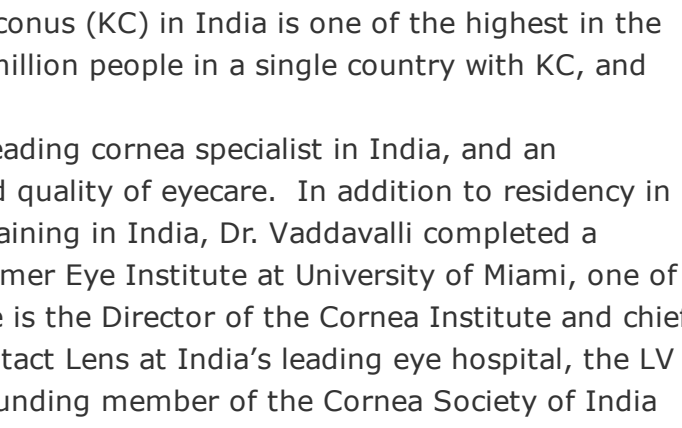
NKCF Update: What happens after CXL?

Take our poll to share your experience

You can increase our understanding of what happens after corneal crosslinking (CXL) by participating in our short survey. If you have undergone CXL in at least one eye, you can help us learn about the after effects of the procedure. Take a moment to share your experience.

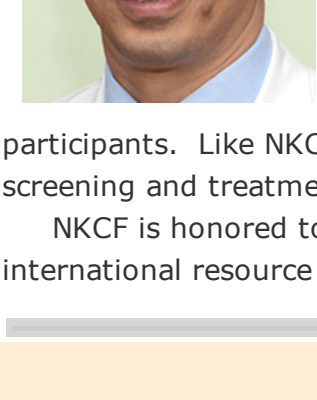
Take Our Survey

IKF: Important International Resource



With a population of 1.3 billion, India's eyecare challenges are considerable. Studies reveal the prevalence of keratoconus (KC) in India is one of the highest in the world, estimated at 2%. Consider 26 million people in a single country with KC, and the impact seems hard to imagine.

Dr. Pravin Vaddavalli, MBBS is a leading cornea specialist in India, and an advocate for improving accessibility and quality of eyecare. In addition to residency in ophthalmology and advanced cornea training in India, Dr. Vaddavalli completed a second cornea fellowship at Bascom Palmer Eye Institute at University of Miami, one of the top programs in the U.S.. Today, he is the Director of the Cornea Institute and chief of Refractive Surgery, Cataract and Contact Lens at India's leading eye hospital, the LV Prasad Eye Institute. Vaddavalli is a founding member of the Cornea Society of India and holds membership in many international societies.



Keratoconus is a disease that Dr. Vaddavalli has a special interest in, and in partnership with NKCF, he recently established the **Indian Keratoconus Foundation** (IKF). Located in the LV Prasad Institute in Hyderabad, the IKF is not exclusively associated with the Prasad Eye Institute, but the Institute generously provides resources for the massive effort to raise awareness of KC in India.

IKF's first effort was a virtual support group held in celebration of World KC Day that drew more than 300 participants. Like NKCF, the goal of IKF is to provide patient education and to encourage screening and treatment for those with the disease.

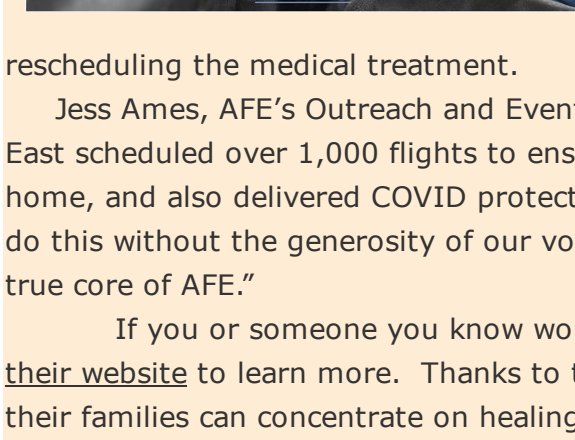
NKCF is honored to partner with IKF. We predict they will soon become a leading international resource and encourage our friends in India to visit their website here.

ANGEL FLIGHT EAST

Transportation for Medical Treatments

Angel Flight East (AFE) is a nonprofit organization whose mission is to provide free, non-emergency air transportation for individuals with medical conditions who require treatment far from home.

AFE serves the Northeast region of the United States. If you require medical care that is greater than 100 and less than 1,000 miles from home, AFE may be able to offer assistance or put you in contact with similar organizations in other parts of the country. Volunteer pilots use their personal aircraft and pay expenses for each mission, allowing the trip to be free-of-cost to the passenger.



Patients must be medically stable, and able to board and fly in a small, private aircraft. To request a flight, a physician or healthcare professional must verify the passenger's medical condition and confirm that the condition will not be affected by the non-pressurized cabin.

AFE requires advance notice, and flights cannot be guaranteed, so patients are urged to have a back-up travel plan or flexibility in rescheduling the medical treatment.

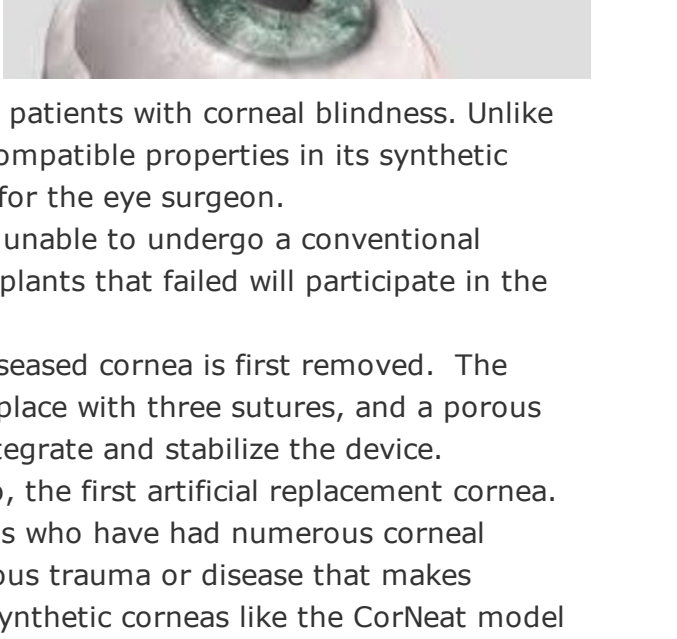
Jess Ames, AFE's Outreach and Events Director reports that last year, Angel Flight East scheduled over 1,000 flights to ensure patients had access to medical care far from home, and also delivered COVID protective gear to healthcare workers. "We could not do this without the generosity of our volunteer pilots. These men and women are the true core of AFE."

If you or someone you know would benefit from AFE services, visit their website to learn more. Thanks to the mission of this organization, patients and their families can concentrate on healing and not on travel to remote medical appointments.

In Case You Missed It

Did you see this infographic in our last issue of *NKCF Update*? If you are wearing a facemask these days, make sure it fits properly. Many of the symptoms of dry eye disease are similar to those for keratoconus. But if you are experiencing new or increased symptoms of eye fatigue, redness, and an itchy or gritty sensation, you may have MADE (Mask-Associated Dry Eye). Your doctor can recommend over the counter solutions, or in more severe cases, can prescribe medication that can provide relief.

New Artificial Cornea in Clinical Trials



CorNeat Vision, a medical device company based in Israel is conducting a clinical trial to test the safety and efficacy of their keratoprosthesis (KPro), an artificial cornea for patients with corneal blindness. Unlike currently available KPros, CorNeat utilizes biocompatible properties in its synthetic cornea and offers a simplified implant process for the eye surgeon.

Ten patients, blind from cornea disease, and unable to undergo a conventional corneal transplant, or who have had past transplants that failed will participate in the study.

As in a traditional corneal transplant, the diseased cornea is first removed. The CorNeat KPro is placed on the eye and held in place with three sutures, and a porous skirt encourages the patient's own tissue to integrate and stabilize the device.

In 1992, the FDA approved the Boston KPro, the first artificial replacement cornea. A keratoprosthesis is the last resort for patients who have had numerous corneal transplant failures, or who have sustained serious trauma or disease that makes transplant success unlikely. Easy-to-implant, synthetic corneas like the CorNeat model may someday prove valuable in parts of the world where corneal blindness exists because of lack of suitable donor tissue.

As a group, individuals with keratoconus usually have successful, long-lasting corneal transplants and are much less likely to need a keratoprosthesis than patients with other cornea diseases. Two test sites in the U.S., UCLA/Jules Stein Eye Institute in Los Angeles and Cincinnati Eye Institute are participating in the CorNeat preliminary clinical trials. To learn more, visit the CorNeat website.

CHANG REACTION: a New NKCF Production

CHANG REACTION

Beginning in April 2021, NKCF will record Chang Reaction, a monthly broadcast, featuring **Dr. Clark Chang, OD, FAAO** who will answer questions submitted by *NKCF Update* readers, and offer his expert opinion about all things keratoconus.

Dr. Chang is the Director of Specialty Contact Lenses on the Cornea Service at Wills Eye Hospital in Philadelphia. After graduating from Pennsylvania College of Optometry, he completed advanced training in ocular disease management and a cornea and contact lens fellowship at the Center for Keratoconus at the Cornea and Laser Eye Institute in New Jersey. He is a Fellow of the American Academy of Optometry and a member of the Glaukos Medical Affairs team where he focuses on research and professional training related to crosslinking. In 2020, Dr. Chang was named Top Doc by NKCF for his commitment to patient care and dedication to advancing awareness of keratoconus.

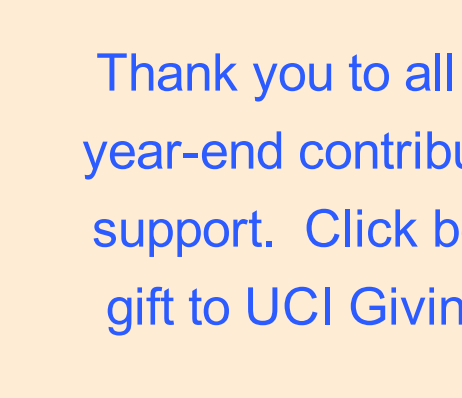
On the first day of each month, NKCF will upload a new episode of Chang Reaction on YouTube. If you have a keratoconus-related question that you'd like answered, complete the form found here on the NKCF website. Check back each month when a new episode is released.

NKCF is Proud to be a Part of AEVR

NKCF supports the work of the **Alliance for Eye and Vision Research** (AEVR), a 501(c)3 nonprofit that advocates for the value of federally funded vision research. In large part due to AEVR's efforts, the latest NIH budget includes $835 million for eye and vision research. It is estimated that between government, industry, philanthropy and foundations, support for vision-related research will be about $4 billion this year. Newly appointed Director of the National Eye Institute, Dr. Michael Chiang, MD announced one of his priorities will be to increase focus and funding for scientists investigating diseases and conditions affecting the cornea, including dry eye, ocular pain, ocular inflammation and keratoconus. AEVR shares patient narratives about the impact of vision research, and NKCF will be helping to collect these individual stories. Look for more details in our next *NKCF Update*. To learn more about AEVR, visit eyeresearch.org.

RESEARCH SAVING SIGHT, RESTORING VISION
an Initiative of the Alliance for Eye and Vision Research

NKCF Specialist List

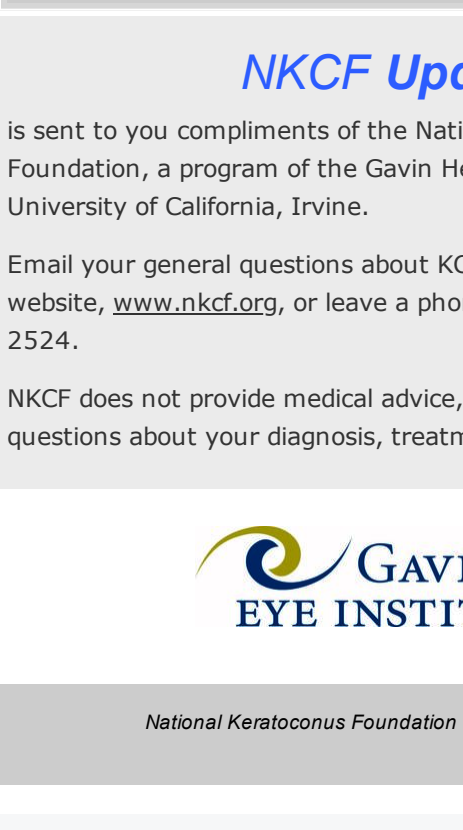


NKCF now offers links to the websites of the 380 eyecare professionals who meet our training and education standards and are members of our NKCF Specialist List. NKCF provides this resource without specifically endorsing any doctor or practice. Ophthalmologists, optometrists and opticians must enroll in this referral program. We encourage our readers to find local experts who ask directed questions and listen to their patients' answers to come up with a treatment plan. To view the NKCF Referral List, click here.

Thank you to all friends of NKCF who made a year-end contribution. We are grateful for your support. Click below to make an easy, on-line gift to UCI Giving. A gift of any size makes a difference!

I SUPPORT NKCF

Share the Knowledge



Take the time to educate yourself and others. NKCF sends the 22-page book, ***Keratoconus Patient Guide*** for free to U.S. residents. You may want to share the book with teachers, employers or family members to help them understand some of the challenges you are facing. If you are interested in receiving a copy, request one by visiting our website, **nkcf.org.** We are grateful to ***Glaukos/Avedro*** whose unrestricted grant supports printing and postage for these materials and whose ongoing support of the keratoconus community is appreciated. Visit their website, livingwithkeratoconus.com to learn more.

GLAUKOS

NKCF Update

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

Email your general questions about KC from our website, www.nkcf.org, or leave a phone message at 800-521-2524.

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

GAVIN HERBERT EYE INSTITUTE   UCI Health

National Keratoconus Foundation is an outreach program of the Department of Ophthalmology at UCI.
nkcf.org | 800 - 521 - 2524