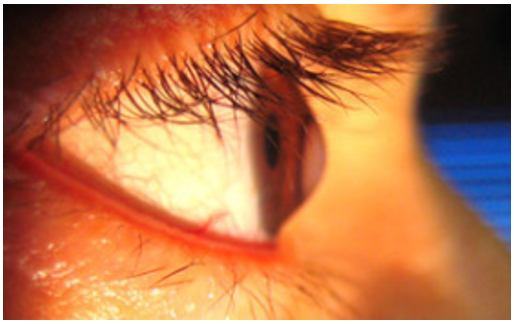
NKCF

National Keratoconus Foundation



Dry Eye & KC

Itchy eyes

Scratchy eyes

Blurry vision

Tired or Fatigued eyes

Sensitivity to Light

This list reads like symptoms someone with keratoconus may experience. They are also some of the most common complaints of those suffering from Dry Eye Disease.

Dry eye syndrome is a common condition affecting all ages and ethnic groups. The symptoms can be mild or moderate to quite severe. Dry eye develops when an individual does not produce enough tears, the tears evaporate too quickly, or they do not nourish the eye effectively. Tear film is composed of nutrients, electrolytes, proteins and lubricants. If the tears lack any of these components, the result is a lack of moisture or lubrication across the surface of the eye.

Certain medications like antihistamines (e.g. *Claritin*, *Benadryl*, or *Zyrtec*) or hormonal replacement therapy may cause dry eye. Smokers and those who face environmental challenges like a windy or dry climate often complain of dry eye. Certain diseases are also associated with dry eye: for example, individuals with keratoconus (KC) are at an increased risk of developing dry eye symptoms.

Because many of the complaints associated with KC and dry eye are identical, your eye doctor may need to determine which symptoms are the result of KC, and which can be relieved through available treatments for dry eye disease. Your doctor can discuss your medical history and lifestyle and test the composition of your tears to determine the reason for the dry eye sensation and discomfort. The variety of treatments available for dry eye expands as our understanding of this disease evolves.

Dr. Melissa Barnett, OD, FAAO, FSLS, of the University of California, Davis is a leading authority on the use of specialty contact lenses for the management of KC. In her clinics located in Davis and Sacramento, she also treats a number of patients suffering from dry eye disease. According to Dr. Barnett, her treatment plan generally begins with the following, "Initial management strategies may include over-the-counter artificial tears such as *Blink GelTears*, *Refresh Optive*, *Systane*, or *TheraTears*."

She continued, "I also stress eyelid hygiene including eyelid cleaners and warm compresses. Omega-3 dietary supplements such as *Science Based Health HydroEye* or *Physician Recommended Nutriceuticals Dry Eye Omega Benefits*, and foods rich in omega-3 fatty acid such as salmon, flax seed, or chia seed provide relief of dry eye symptoms for many patients."

"In more severe cases, punctal plugs – very small plastic pieces that close the ducts that drain tears out of the eye may be put into the eye." Dr. Barnett added that nighttime moisture goggles or daytime moisture release eyewear may be recommended.

Dr. Barnett has found that scleral lenses are beneficial to relieve the discomfort of dry eye while offering excellent vision to those with KC. She concluded that some of her dry eye patients will require prescription medications for relief, "For severe dry eye symptoms, I recommend certain prescription eyedrops such as *Restasis*, *Cequa*, *Xiidra*, autologous serum tears, or biologic eyedrops."

If you believe you have dry eye disease, visit your eyecare practitioner for an evaluation and discuss options to relieve your symptoms. You can learn more about dry eye syndrome by visiting All About Vision. More information about some products helpful in relieving dry eye symptoms can be found at the Dry Eye Shop.

Dr. Melissa Barnett, OD, FAAO, FSLS is a Principal Optometrist at the Univ. of California, Davis Eye Center, specializing in specialty contact lenses and dry eye disease. She is a lecturer, teacher, author and member of a number of specialty societies. Dr. Barnett is a Fellow of the American Academy of Optometry and past president of the Scleral Lens Education Society.

Several years ago, John Dalsey of Springfield, MA had a friend who complained about inserting his scleral lenses. A self-described tinkerer, Dalsey enlarged the hole in the plunger and with the aid of an LED light he found on a key chain, Dalsey developed a prototype that became the basis of the See-Green product line. Focusing on the light, his friend was able to guide the plunger and lens into place.

See-Green includes adaptive aids that makes it easier to insert and remove scleral lenses. Dalsey sought advice from the Boston Foundation for Sight (BostonSight) on the appropriate brightness and color for the LED guide light. The green, easy-to-spot LED light guides your eye to the lens and prevents misalignment. An optional stand is especially helpful to those who have unsteady hands or who need their hands to keep open stubborn eyelids. The See-Green insertion protocol allows close access to the lens and a short distance to the plunger, reducing the chance of air bubbles and the need to begin the process again. See-Green adaptive technology may make the experience of putting in your lenses every day less daunting and make wearing sclerals more enjoyable. To learn more about the See-Green products, visit Dalsey Adaptives.

Join NKCF for KC Evening Webinars for Friends & Family

The 2019-2020 Evening Webinar series concluded with Dr. Annie Nguyen, MD and Dr. Gloria Chiu, OD from the USC/Roski Eye Institute in Los Angeles discussing contact lens options. If you missed that talk, you can watch the video presentation here.

William Trattler, MD

Elise Kramer, OD

Our new academic year begins on **Tuesday, September 15** with the presentation, "*Understanding the Genetics of KC*" with **Dr. William Tratter, MD** from the Center for Excellence in Eyecare in Miami, FL and **Dr. Elise Kramer, OD** of the Miami Contact Lens Institute. Both are in-demand and engaging speakers with considerable experience diagnosing and treating keratoconus. Our understanding of the connection between genetics and KC is rapidly increasing. These experts will give us the current state-of-the-art overview. To reserve your space at this free webinar, click below.

REGISTER FOR WEBINAR HERE

And be sure to mark your calendar for the rest of the Evening Webinar Series:

November 17, 2020: Dr. Edward Bennett, OD will interview San Diego Padre outfielder Tommy Pham, who will talk about his career as a professional athlete living with KC

January 12, 2021: Dr. Muriel Schornack, OD of the Mayo Clinic in Rochester, MN will present The SCOPE (Scleral Lenses in Current Ophthalmic Evaluation) Survey - learning more about doctors who prescribe specialty lenses and the patients who wear them

March 16, 2021: Dr. Sumitra Khandelwal, MD of Baylor College of Medicine, Houston, TX will provide an update on cataract surgery for individuals with keratoconus

May 18, 2021: 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: Ophthalmologist Dr. James Loden, MD of Loden Vision, Nashville, TN, will recount his experience undergoing crosslinking for his own progressive keratoconus

Sleep Survey Results:

More individuals aware of link between KC and OSA

In our May newsletter, *Update* readers were invited to participate in an informal poll about obstructive sleep apnea (OSA). We had 88 people share their experiences. Thank you to all who completed the survey. The results give us insight into living with keratoconus (KC). Please take a moment and complete this month's survey on Contact Lens Options below.

The respondents included 56 women and 32 men. 44% (n=39) had been diagnosed with KC before the age of 21. Of the women, 71% reported that they snored, and 75% of that group reported that their snoring bothered others. 53% of men self-reported snoring, and 94% of this group said their snoring bothered others.

About 1 in 5 Americans have symptoms of OSA. Previous studies have concluded that individuals with KC have a higher than normal likelihood of being affected by OSA. While our survey was not a scientific sampling, these results seem to demonstrate a link between the two conditions.

We wondered if KC patients were referred to sleep specialists if they complained of daytime fatigue or loud or irregular snoring.

It has been suggested that the majority of Americans with OSA are never diagnosed because their doctor never asked them about their sleep symptoms. Close to 70% of our survey participants with sleep disorder symptoms have discussed their concerns with their doctor. This is encouraging news as it shows that primary care providers and even eyecare professionals are alert to the link between OSA and KC and are talking to their patients about their sleep symptoms. It also indicates that individuals with KC are aware that they are at risk for OSA and are sharing relevant medical history with their doctors.

Dr. Yarah Haidar, MD, a head and neck surgeon and sleep specialist at the University of California Irvine, noted that patients referred for sleep studies are routinely asked about their ocular history. "When we evaluate patients and we see that their sleep problems seem to be the result of a collagen disorder, we quiz them on other symptoms they might be experiencing." Dr. Haidar said that she first examines a patient's epiglottis and larynx using a flexible laryngoscope to determine if there is an anatomical cause for the sleep disturbances. "We usually follow an examination with a sleep study where we monitor the patient's movement, breathing and oxygen levels overnight, and then make a diagnosis of OSA." Although most cases of OSA are treated with the use of a CPAP machine, Dr. Haidar noted that sometimes a surgical repair can improve the symptoms of sleep apnea.

Dr. Yarah Haidar, MD is Assistant Professor in the Department of Otolaryngology / Head & Neck Surgery at UC Irvine. She has a strong interest in teaching and clinical research with a special emphasis on minimally invasive surgery and treatment of head and neck cancers.

Take Our *Update* Survey on Contact Lenses

600 people watched or listened to our July Evening Webinar on contact lens options. This month, we are asking some questions about what types of contact lenses you've worn, and what you are wearing today. Take a minute and share some information with us. The results will help us learn more about living with KC.

Take Our Survey

ScanFitPRO Offers Novel Method to Customize Scleral Lenses

Colorado resident Tricia* had been fit with close to a half dozen different gas permeable and scleral lenses in the six years since her diagnosis of keratoconus (KC). The lenses she had been wearing provided good vision, but left her eyes looking red, teary and painful. Now a teacher in her late 20s, Tricia often looked like she was at the end of a night of hard partying. She was self-conscious about the 'bloodshot' look of her eyes and, more than once, had heard comments about her appearance from co-workers.

She shared this concern with her eye doctor, **Dr. Swati Kumar, OD,** who concluded that the edge of her lenses irritated her eye and caused the redness. A lens that sat properly on her sclera would improve her eye's appearance and overall eye health. Tricia was fit into a ScanFitPRO lens and the results were immediate and impressive.

With the aid of comfortable, customized lenses, the angry, red eyes were gone.

As more doctors and patients appreciate the benefits of scleral lenses for treatment of KC, the technology is constantly advancing. By increasing the amount of data gathered, doctors have been able to customize lenses in ways that improve visual acuity and increase comfort and wear time.

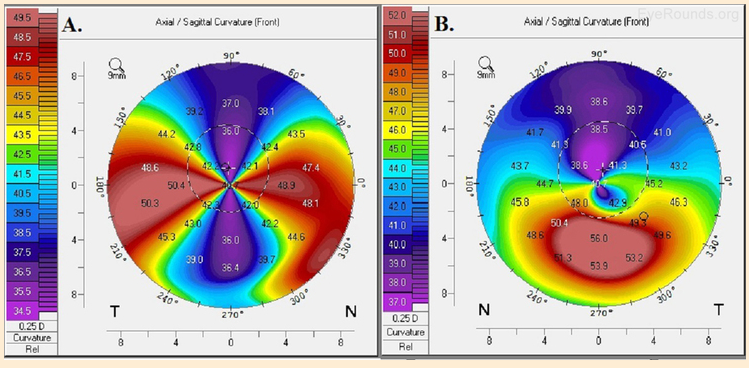
Most scleral lenses on the market start as prefabricated shells. The fitter is given options to modify the lens, including the size, the vault or how high over the cornea the lens sits, the alignment or edge, and the optics that provide the best possible vision.

ScanFitPRO, the latest innovation by the makers of EyePrint Prosthetics, takes the idea of a personalized lens to the next level. EyePrint Prosthetics was initially developed by optometrist and KC expert Dr. Christine Sindt, OD. To fit the flagship product, the EyePrintPRO, an eye doctor takes an impression cast of the eye and then sends the impression to the manufacturer who creates a one-of-a-kind lens that mirrors the eye's surface. EyePrintPRO is more costly and complex than traditional scleral lenses, but for people with damaged or highly irregular corneas, it offers a rare opportunity to achieve good vision and comfort.

ScanFitPRO, the company's new product, and the option offered to Tricia, presents an option between the impression method of the EyePrintPRO and the more common method of trying various diagnostic or trial lenses until the right fit is found.

Before

After ScanFitPRO



Keratoconus patients are evaluated regularly by their eyecare professional using a topography machine. As shown here, a 'map' of the cornea and sclera is captured, showing in color and numbers, the current state of disease. The Pentacam topography unit by the German company Oculus is the most popular machine used by KC experts.

Using special software, ScanFitPRO translates corneo-scleral elevation data from the Pentacam to create a 3-dimensional profile of the ocular surface. The eyecare professional uses this information and the ScanFitPRO software to design a custom lens and then sends the design to a state-of-the-art manufacturing facility. This new technique reduces the time a patient spends in the exam chair by eliminating the

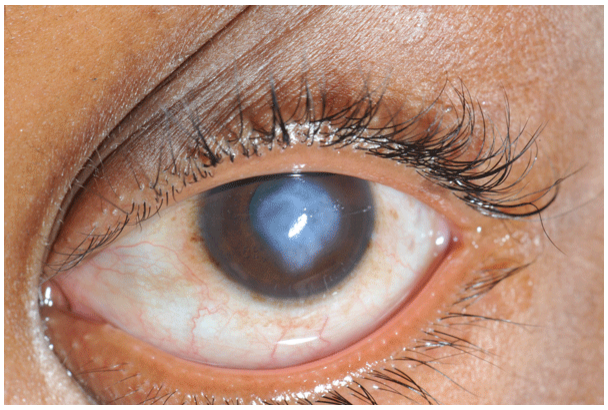
need for trial lenses, and introduces useful information about ocular surface elevation into the manufacturing process. The result being lenses than can be designed in a single visit with a minimal revision rate compared to traditional diagnostic scleral lens fitting.

Dr. Kumar has seen the results of this technology in several of her patients. "The ScanFitPRO provides a precise, glove-like fit for patients looking for more comfort and less time spent in the exam chair." To learn more, visit EyePrintPRO.com

* *Not the patient's real name.*

A Fellow of the American Academy of Optometry, Dr. Swati Kumar, OD, FAAO is a graduate of the New England College of Optometry. She completed a residency in cornea and contact lens at Nova Southeastern University in Florida and now practices at the Colorado Eye Center's offices in Eastlake and Thornton. She also works as consultant, designer, and clinical optometrist for EyePrint Prosthetics.

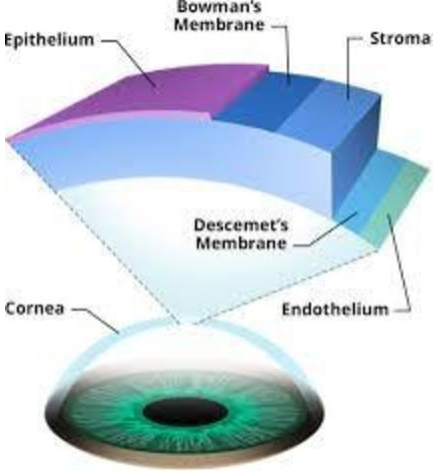
Acute Corneal Hydrops: A serious complication of KC



It happens in less than 3% of all individuals with keratoconus (KC), but it is a serious, vision threatening complication. Acute corneal hydrops occurs when there is a sudden break in the innermost portion of the cornea and aqueous fluid pushes forward. The break is considered spontaneous, but some patients recall prior to the event, they had been rubbing their eyes, or experienced a powerful sneeze or cough, or forceful nose blowing that may have temporarily increased pressure in the eye and caused a rip or tear in the endothelium and Descemet's membrane (DM).

Patients who suffer an episode of acute corneal hydrops describe suddenly blurry vision and extreme light sensitivity. While some patients do not complain of pain, others say the pain associated with the event is intense. These symptoms can linger for several weeks.

The look of hydrops is unique. As fluid enters the stroma from the break in the DM, an opacity develops, often in the area of the cone or steepest part of the cornea. The fluid appears as a pale, whitish shape.



The treatment for hydrops is to wait for the break in the DM to reattach and for the fluid in the stroma to reabsorb. **Dr. Tara McGeehe, MD**, a corneal specialist from the University of Virginia Department of Ophthalmology has considerable experience treating patients who develop hydrops. "The traditional treatment is to allow the healing to take place on its own. I may prescribe eyedrops that will reduce pain and swelling and promote healing, but I wait for the DM to heal itself."

Other doctors prefer to hurry the process along by introducing an air or gas bubble via an injection into the eye. The bubble pushes up against the DM, holding the tissue in place and closing off any leaks. While this treatment decreases the healing time, there are additional risks associated with this injection therapy and patients must hold their head a certain way (usually lying down) for a few weeks for the therapy to be effective.

Whichever method your doctor recommends, plan on several office visits during the healing period. Your doctor will want to closely monitor progress.

A significant problem during the 2-4 months it normally takes to recover from corneal hydrops is that, for many patients, contact lenses cannot be worn. A doctor may put a bandage contact lens over the eye in the beginning of treatment in order to quiet the eye, but may be reluctant for a patient to resume daily contact lens wear if there is a danger of causing additional trauma to the eye. For some individuals with hydrops, their eye is 'out of service' until it recovers.

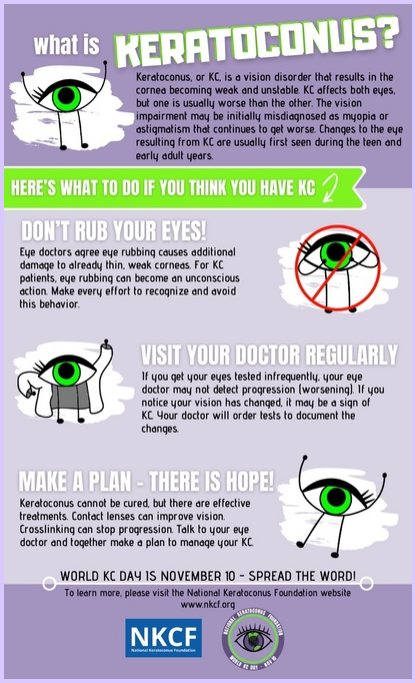
Dr. McGeehe explains that a major concern she has with her patients who develop hydrops is the location and density of the resulting scar. As the fluid reabsorbs, a scar may develop where the cornea was stretched; regaining clear vision may be impossible, even with custom contact lenses. "By 2-3 months, I have a general sense that surgery is likely to be required for vision improvement, but so much healing can happen with time it is impossible to accurately predict in the first several weeks after hydrops develops whether or not surgery will be needed."

She follows her patient closely, adding that she wants "to make sure symptoms are controlled: that corneal swelling (edema) is improving and that the top layer of the cornea (epithelium) is not getting swollen or breaking down as this can lead to an infection."

McGeehe noted that, "We still have a lot to learn about hydrops, like why it happens in some individuals with keratoconus and not others. She reports that those most likely to develop hydrops are those with a younger age of diagnosis, more severe KC (i.e., a weaker or steeper cornea), and those with poorer vision or a history of eye rubbing.

She noted that contact lens wear does not seem to increase the risk of developing hydrops. Dr. McGeehe urged patients who develop symptoms like sudden and extreme light sensitivity or eye pain to notify their doctor immediately.

Dr. Tara McGeehe, MD is an Assistant Professor at the University of Virginia in Charlottesville. She completed her ophthalmology residency at the University of North Carolina and her fellowship in cornea disease and at the University of Iowa. Dr. McGeehe specializes in eye surgery and the care of complex cornea diseases including KC.



World KC Day News

Awareness Poster

In honor of **World KC Day** on November 10, NKCF will be mailing informational posters and awareness ribbons to the doctors on our Specialist List, asking that they help spread the word about keratoconus. If you would like your own copy of the poster, you can download it here.

Wear a Ribbon

Tell your story on **World KC Day.** Help to increase awareness by posting a message on **social media** (and share with others at #keratoconusawareness; #WorldKCDay; #NKCF; #WorldKeratoconusDay; #keratoconus). **Wear an awareness ribbon**. When people ask what the ribbon signifies, educate them about KC. To get your own awareness ribbon, US residents can write us at info@nkcf.org.

Updated Specialist List on nkcf.org

For many years, NKCF has offered information about eyecare professionals who have special interest and expertise in treating KC. If you have moved to a new city, are newly diagnosed, or have recently changed health plans, you may find this list of experts helpful.

The NKCF Specialist List now includes a link so you can go directly to a practice website to learn additional details. While we make every effort to assure that the professionals on the list meet the educational and experience requirements we have established, NKCF provides this resource without specifically endorsing any doctor or practice. Also, providers must enroll in our program; there are many outstanding doctors who have chosen not to join this program. We welcome patient comments concerning the professionals on our list. To view the NKCF Referral List, click here.

Ohio Family Symposium is set for May 2021 . . .

Families living in the Columbus, Ohio area should mark their calendars for **May 15, 2021**. NKCF will be co-hosting a KC Family Symposium with The Ohio State University College of Optometry. For more information, or to register, **click here.**

. . . and look for us in St. Louis

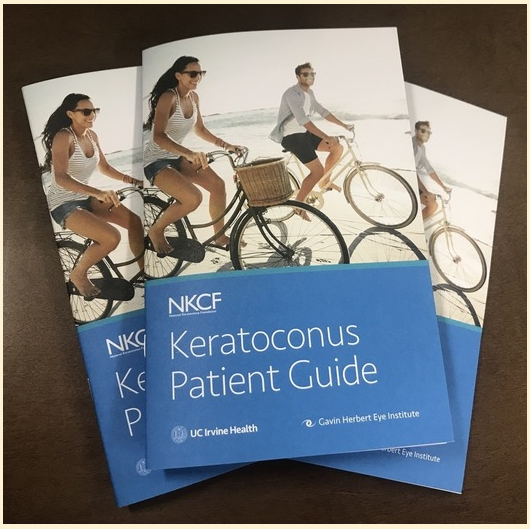
NKCF is working with the Univ. of Missouri-St Louis College of Optometry to host a KC Family Symposium in that city in 2021. Pandemic rules have prevented us from finalizing a date, but we hope to make it to the Gateway City next Spring.

Don't forget to mark your calendar and reserve your spot for the next NKCF Evening Webinar, ***"Understanding the Genetics of KC"***

with Drs. William Trattler & Elise Kramer

September 15, 2020

5:00 pm West Coast / 8:00 pm East Coast



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. You may want to 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.**

You can make a difference!

NKCF is there when families first learn about a condition they cannot pronounce and don't understand. We offer materials and information about keratoconus and let them know they are not alone. Your support, in any amount, makes it possible for NKCF to be there for the next family affected by KC.

Recognize a special event or person by making a gift *in honor of* or *in memory of* someone who has passed away. Your tax-deductible gift helps maintain our educational and advocacy efforts.

Click the **I SUPPORT NKCF** button below to make an online gift. If you prefer to send a check, payable to **UCI Foundation**, please send it to

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Irvine, CA 92697

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Support NKCF When You Shop

Here is an easy way to help NKCF. Register with **iGive** and you'll have access to retail stores, merchandise and special deals you may want to explore. if you make an on-line purchase through iGive, a donation is made to NKCF. It's an easy way to do good while you are staying home and spending more time shopping on-line. Join iGive, and make your cause National Keratoconus Foundation. For more information or to register, visit iGive.com.

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 or call us at 800-521-2524.

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

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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