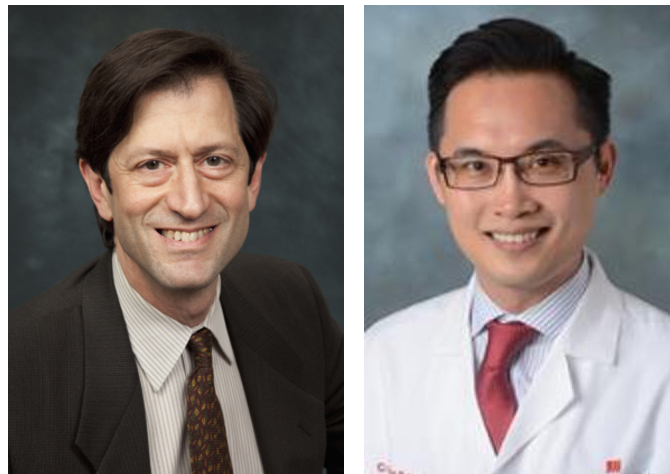


May 2020
Update



2020 TOP DOCS Named

For the fourth year, National Keratoconus Foundation asked **Update** readers to tell us what makes their eye doctor special. We compiled a list of doctors nominated by their patients for their compassionate care. NKCF selects the "Best of the Best" - an optometrist and ophthalmologist to represent the entire list. Learn more about this year's picks:



Dr. Michael Raizman, MD's patient nominated him as Top Doc, stating, *"Dr. Raizman not only gave me back my life, as other doctors may have done, he also stayed by my side and comforted me through it all."*

Dr. Raizman (photo left) is a graduate of the University of Michigan Medical School where he completed his ophthalmology residency. He then pursued fellowships in both cornea disease and immunology at Harvard's Mass Eye & Ear Infirmary. Tufts Medical School recruited him and he now is Associate Professor, director of the cornea fellowship, and co-chief of the cornea service at New England Eye Center. Dr. Raizman is also a member of the private practice, Ophthalmic Consultants of Boston.

He is an international leader in cornea clinical research and a leader in crosslinking clinical trials. He is a frequent lecturer and author of more than 100 peer-reviewed articles.

Of his selection as NKCF Top Doc for 2020, Dr. Raizman said, ***"The past decade has been one of the most gratifying times in my career, providing new vision-saving treatments to patients with keratoconus. I am especially honored that my patient nominated me for this recognition."***

When lists of keratoconus experts are made, **Dr. Clark Chang, OD, MSA, MSc, FAAO** (photo right) is regularly included. He is the Director of Specialty Lenses for the cornea service at Wills Eye Hospital in Philadelphia. The mother of a 21-year-old patient wrote to NKCF, *"My son was diagnosed with KC when he was 15; he never wore contacts so everything was completely new to him... Dr. Chang always takes his time and speaks directly to my son. He makes this disease bearable."*

Dr. Chang is a graduate of the Pennsylvania College of Optometry. He completed residencies in both primary care and cornea and contact lens. After this advanced training, he joined the staff of the Cornea & Laser Eye Institute in Teaneck, NJ and participated in keratoconus-focused research and clinical trials. Dr. Chang is a fellow of the American Academy of Optometry and serves on the executive board of the International Keratoconus Academy.

When informed of his selection as this year's Top Doc, he told NKCF, ***"It is an extraordinary honor to have patients take time out to recognize the care you provide, but I am only able to leave an impression due to a team effort by the entire Cornea Service at Wills Eye Hospital. They believe, as I do, that each keratoconus patient is unique and deserves customized treatment(s). This award belongs to my entire Wills Eye family."***

2020 Top Docs List

[Click here](#) for a list of all doctors nominated as Top Doc.

The CXL Redo: Retreatment after Crosslinking

No medical procedure can guarantee a desired outcome, but corneal crosslinking (CXL) offers a remarkable chance of success. [Read more](#) about what we've learned when disease progression continues after CXL.



Violet June

THE KERATOCONUS
AWARENESS CAMPAIGN



Two years ago, **Dr. Renato Ambrosio, Jr, MD, PhD** launched Violet June, a month-long campaign to raise keratoconus awareness in his native Brazil. NKCF is happy to help spread the message internationally. Dr. Ambrosio is a cornea surgeon who has authored more than 500 scientific articles and holds professorships at universities in Sao Paulo and Rio de Janeiro. He is the current president of the prestigious ISRS, the International Society of Refractive Surgeons. Dr. Ambrosio says the goal of Violet June is to focus on the simple message "**Do not rub your eyes**". He adds, "The color VIOLET is unique. Violet is the color of imagination and spirituality." We are lucky that such an advocate for KC exists.



KC Evening Webinars for Friends & Family

The 2019-2020 Evening Webinar series will conclude on **July 14, 2020** with Dr. Annie Nguyen, MD and Dr. Gloria Chiu, OD from the USC/Roski Eye Institute in Los Angeles. They will discuss Contact Lens Options for individuals with KC. These 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 one week later. Please check the NKCF webpage to view the recordings. **[Click the link to register here.](#)**

NKCF is pleased to announce the speakers and dates for the 2020-2021 Evening Webinar Series.

September 15, 2020: Dr. William Trattler, MD of the Center for Excellence in Eyecare in Miami, FL and Dr. Elise Kramer, OD of the Miami Contact Lens Institute present *Understanding the Genetics of KC*

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

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 present *Update on Cataract Surgery and 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: Dr. James Loden, MD of Loden Vision, Nashville, TN, will present *"The Ophthalmologist as Patient Undergoing CXL"*

Survey Results: Keeping it clean

Contact lens hygiene plays a vital role in the health of your eye. Studies reveal that some patients do not use proper techniques to wash and dry their hands before handling lenses, clean and disinfect lenses, or replace lens cases. Good hygiene for scleral lenses may be even more critical since these lenses cover a larger part of the eye and the solution can be a breeding ground for contamination if not properly cared for.



In March, we asked *Update* readers to complete a survey about their scleral lens care routine. Fifty-five individuals responded. About half were under the age of 26 and half over that age. 60% of those who replied were men.

All of those who responded to the survey had been prescribed scleral lenses. 53 wore their lenses regularly (at least 3 times a week); 2 individuals reported they did not wear their sclerals due to the challenge or hassle of wearing them.

We asked three questions and the responses showed that a majority of patients were practicing good scleral lens hygiene.

Do you ever wash your lenses with tap water?

79%	Never
13%	Sometimes
8%	All the time

Tap water can contain microorganisms and pathogens that can cause painful eye

infections. Instead, use nonpreserved saline solution to wash lenses.

Do you "top off" your solution?

- 91% Never
- 5% Sometimes
- 4% All the time

Always use fresh solution. Topping off, or adding new solution to the existing mixture, may contaminate the solution.

Do you clean and disinfect your lenses every night?

- 96% Yes, every night
- 2% Every few days
- 2% Once a week

Regular cleaning removes deposits and kills microbes that potentially cause eye infections.

Congratulations to those who responded to our survey. Overall, our readers have excellent scleral lens hygiene. To learn more about proper care of your contacts, ask your eye doctor. You can also refer to our [health tips page](#), view the patient informational videos at the [Scleral Lens Society](#), or read more on the subject at [AllAboutVision.com](#).

Cataract Surgery & Keratoconus

For most people, cataracts are a natural part of the aging process. More than 90% of those over the age of 65 show some evidence of cataracts. Are there special concerns that individuals with KC should have as cataracts develop?

[READ MORE](#)



A Caution about Eyelash Extensions

Eyelash extensions have become an increasingly popular cosmetic trend. They appear more natural and last longer than other forms of false eyelashes.

For individuals with KC, there is a temptation to having long, lovely lashes without



having to deal with a makeup mirror.

While these semi-permanent lashes may be beautiful, they can pose a potential threat to your eye health - eyelash extensions made of silk, mink, nylon or other synthetics are glued to natural lashes individually. Because of the close proximity to the eye, artificial extensions may cause certain kinds of ocular disorders.

The primary perpetrator seems to be the glue used to adhere the synthetic lashes to the natural lashes or the solvents used to remove them. Although the glue may not have direct contact with the eye, body temperature may cause changes to the adhesive. The chemical formaldehyde is a byproduct of the materials in the adhesive and can be the source of serious eye irritation. **Dr. Karen Lee, OD**, a contact lens expert at the University of Houston College of Optometry agrees, *"I do not recommend eyelash extensions for my patients with KC because the formaldehyde in the glue can be toxic to the ocular surface."*

A published report from Japan examined the complaints of 107 women whose eye irritation resulted from eyelash extensions. Some of the symptoms included keratoconjunctivitis (inflammation of the cornea and conjunctiva), blepharitis, and conjunctival erosion. Allergic reactions, contact lens discomfort, and dry eye have also been reported as a result of eyelash extensions.



It is important to be aware of the materials your eyelash technician is using, and to ensure measures are taken to maintain proper hygiene to prevent infections. Bacteria can exist on these artificial lashes and find its way into the eye. Dr. Lee notes this is another concern, *"These extensions also promote poor eyelid hygiene as patients are often afraid to clean them and this causes the lashes to fall out*

prematurely."

If you find that your eyes are red, teary, itchy, sensitive to light or painful, contact your eye doctor immediately, and if you have had eyelash extensions recently put on or taken off, share this information with your doctor.

Reference:

Amano Y, Sugimoto Y, Sugita M, Ocular Disorders Due to Eyelash Extensions, *Cornea* 31:121-5, 2012, PMID: 22134404



Dr. Karen Lee, OD, FAAO, FSLs is a graduate of the Indiana University College of Optometry and completed a residency in cornea and contact lens. She is Clinical Assistant Professor at the University of Houston College of Optometry and currently serves as President of the Scleral Lens Education Society.

Dramatic Weight loss affects Keratoconus



A recent case report in the journal *Cornea*, described how a patient experienced a regression in keratoconus (KC) after weight loss surgery. **Dr. Greg McCormick, MD** of Ophthalmic Consultants of Vermont described a patient he has been treating in his South Burlington office.

The patient was a 42-year old male with a diagnosis of KC. He did not rub his eyes, had no allergies, and no family history of KC. He did suffer from type 2 diabetes and was severely obese. He had undergone a successful corneal transplant in his left eye six years ago. Dr. McCormick intended to perform corneal crosslinking (CXL) to the patient's right eye as the KC was showing signs of progression. In 2016, the patient underwent bariatric surgery for weight reduction. As his weight loss increased and his overall health improved, Dr. McCormick noticed that his patient's right eye keratoconus seemed to be improving. In the two years following his sleeve gastrectomy, the patient's astigmatism improved and corneal topography documented more than 5 diopters of flattening.

Dr. McCormick notes, *"While the exact mechanism for the improvement in his KC remains uncertain, it gives reason to believe that managing risk factors can be effective at slowing or even reversing keratoconus in some patients."*

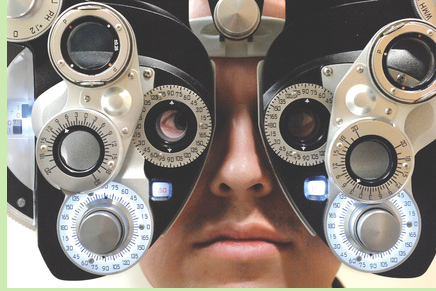
As a result of these changes, the planned corneal crosslinking procedure was cancelled. This happy and unexpected outcome after significant weight loss may be the unintended result of less stress put on the cornea by extreme body weight. Dr. McCormick observed that this dramatic result may encourage *"KC patients with sleep apnea or morbid obesity to aggressively manage these conditions to reduce their risk of vision loss."*

Reference:

Greenberg JR, McCormick GJ, Regression of Keratoconus After Gastric Sleeve Surgery, *Cornea*, PMID: 32068611, 2020



Dr. Greg McCormick, MD is a partner in Ophthalmic Consultants of Vermont, a multi-specialty eye practice located in South Burlington. He is a graduate of the University of Vermont College of Medicine and completed a fellowship in cornea diseases at Flaum Eye Institute at the University of Rochester.



Finding the Best Fit

Scleral lenses offer clear, comfortable vision, but you must find the right professional to work with you to get the comfort and fit just right. Expert contact lens fitters offer their insights into what qualities you should look for when making the transition to sclerals. [**READ MORE**](#)



COVID-19 & Keratoconus

NKCF hosted a special webinar on April 3 to address unique concerns of COVID-19 to the KC community. **Dr. Stephanie Woo, OD** of the Contact Lens Institute of Nevada and **Dr. Joseph Ciolino, MD** of Massachusetts Eye & Ear Infirmary shared observations and tips for keeping healthy. To review this webinar, visit [**here.**](#)

Could you have Obstructive Sleep Apnea?



Obstructive Sleep Apnea (OSA) is a condition that affects up to 22 million Americans.

Apnea is defined as not breathing for more than 10 seconds. OSA takes place when breathing stops because the throat muscles relax and temporarily collapse. As the oxygen level drops, brain signals awaken the person and breathing becomes regular again. In most cases, the sleeper is unaware of these interruptions because they don't trigger a full awakening. For some patients, this sleep disturbance cycle can happen hundreds at times during the night. Lack of a good night's sleep can result in symptoms including morning headaches, dry mouth, and daytime drowsiness as well as more serious medical conditions like high blood pressure, stroke, diabetes, and heart arrhythmia. Doctors who are sleep specialists can diagnose and treat OSA. Treatment is a machine called C-PAP (continuous positive airway pressure) which the sleeper wears at night that provides pressurized air to keep the airway open.

What is the connection to keratoconus?

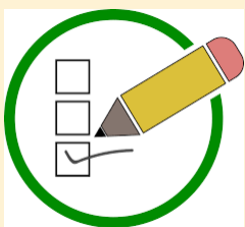
There are conflicting conclusions in studies involving patients with both conditions. The majority of people with OSA do not have KC, and most individuals with KC do not have OSA. However, someone with KC is nearly twice as likely to have OSA than someone in the general population.

There is a bond between the KC and OSA that is not fully understood, but researchers have put forward several theories. Some believe the activity of eye rubbing causes enzymes to be released that promote the weakening of the cornea; these same proteins are found in patients with OSA. Others propose that the nightly cycle of lack of oxygen followed by reoxygenation may damage cells in both KC and OSA. Still others suggest that the temporary collapse of the throat is due to a biomechanical instability. Weakened muscle tone is the result of the cellular matrix within the pharynx being improperly assembled. This can also describe KC, where 'improper' assembly of the cells within the cornea lead to thinning and bulging.

Although OSA can affect anyone, it is most common among men between the ages of 40-70, and individuals who are overweight. 80% of people with sleep apnea go undiagnosed. Since there is a higher risk of OSA if you also have KC, consider if you may exhibit symptoms. If you do, ask your doctor to refer you to a specialist for an evaluation. Here are two questions to consider:

- *Do you snore loud enough that people can hear you even if the bedroom door is closed?*
- *Has anyone ever observed you stop breathing during sleep?*

To learn more about OSA, visit [American Sleep Apnea Association](#) or [National Sleep Foundation](#).



Take our Survey

This month's survey consists of a few questions about Obstructive Sleep Apnea. We invite Update readers to take a few seconds to

complete this poll. Thank you for your participation. By sharing your experience, you are teaching us more about KC.

[Sleep Apnea Survey](#)

Ohio Family Symposium is rescheduled for May 2021



Due to the shutdown associated with COVID-19, the KC Family Symposium scheduled for May 30, 2020 has been postponed. The conference, co-hosted by the Ohio State University College of Optometry, is rescheduled for May 15, 2021. For more information, [click here](#).



World KC Day is November 10

NKCF and the Southern California College of Optometry are planning an educational event at Marshall Ketchum University in Fullerton in celebration of World KC Day in November 2020. Look for more information as details are finalized.

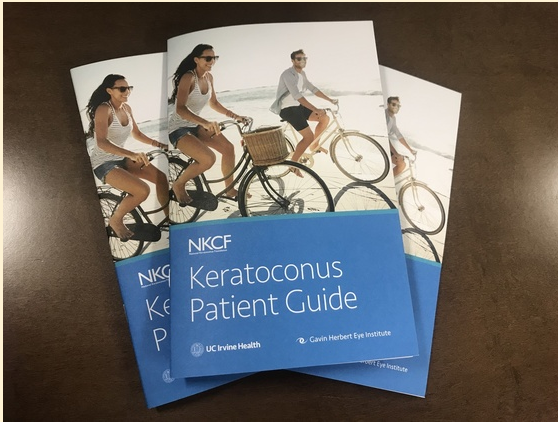
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**MARK YOUR CALENDAR FOR THE NEXT
NKCF WEBINAR**

"UPDATE ON CONTACT LENS OPTIONS"

JULY 14, 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. 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!

Support by our friends makes it possible for NKCF to be there when we are needed. Make a gift to NKCF **in honor of** a special event or a person, or **in memory of** someone who has passed away. Your tax-deductible gift of any amount to UCI Foundation helps maintain our educational and advocacy efforts and will help the next family affected by KC.

100% of your tax-deductible gift goes to NKCF

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

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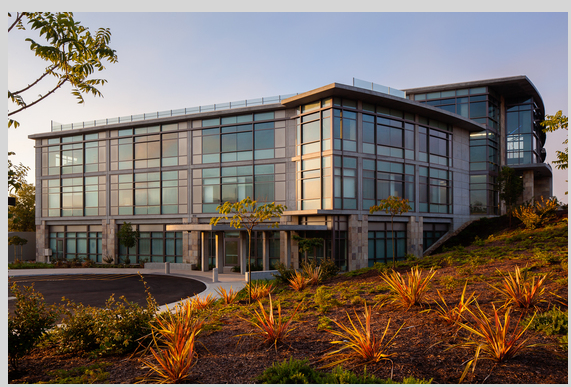
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Contact us with your general questions about keratoconus at info@nkcf.org or call us at 800-521-2524.

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



UCI Health

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