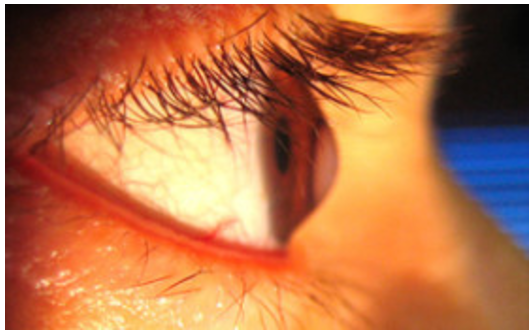
NKCF

National Keratoconus Foundation

December 2020 Update



Best wishes for a happy & healthy 2021 from your friends at NKCF

MADE: A New Coronavirus Concern

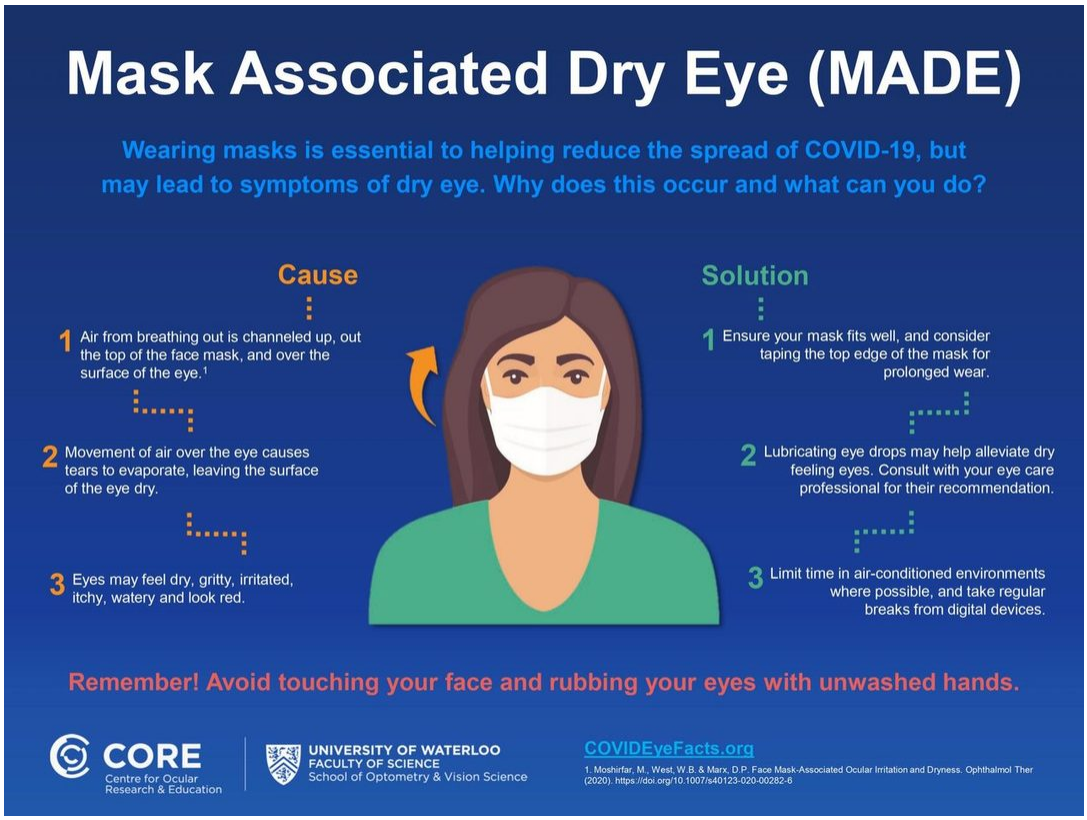
Just as the world is growing comfortable wearing facemasks, some are complaining about new or worsening symptoms of dry eye disease.

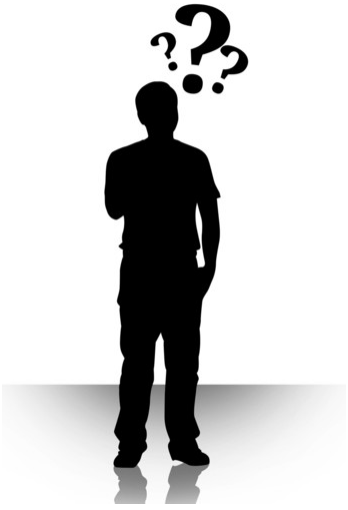
A Cleveland ophthalmologist recently blogged, "Even for a high-volume dry eye center, there sure were a ton of new cases coming in." He found the likely culprit hanging from the ears of his patients, and termed the condition MADE (Mask-Associated Dry Eye). Facemasks reduce the outward spread of air but if they do not fit properly, masks leave space either from the bridge of the nose or the sides that create a flow of air upward to the eyes. Mask wearers who notice their eyeglasses fogging are experiencing this diverted airflow. Exhaled breath may travel from under the mask across the surface of the eye, evaporating tear film. Individuals wearing contact lenses, like many KC patients, are especially likely to experience discomfort.

Dry eye disease is not the only concern. MADE encourages increased eye rubbing and face touching behaviors. Avoiding eye rubbing is especially important to those with KC as it can result in further damage to the cornea. Touching the face to adjust the mask or rub the eyes raises the possibility of unwashed hands for spreading

infection including coronavirus.

Doctors recommend a few tips to reduce the effects of MADE. Wear a mask with a pliable nose wire that conforms to the face. Use lubricating drops to lessen the effects of dry eye disease: your doctor can recommend a brand that will help. If you are wearing contact lenses or if you spend hours in front of a computer screen, take frequent "blink" breaks to replenish your eye's natural tear film. Ask your eyecare professional for more tips if you believe you have MADE.





What is your KC IQ?

In order to create a successful treatment plan, individuals with KC and their doctors must be able to communicate. A 2018 article in the medical journal *Cornea* observed "patients with keratoconus may feel they are not receiving attention and care to the level they feel the severity of their condition requires".

Patients complain their eye doctors do not fully explain their condition or hear their concerns. Eyecare professionals maintain they describe the risk factors, symptoms and treatment options, and answer patient questions.

Is anyone listening?

Last year, Swiss eye doctors were interested to learn how much their patients with keratoconus knew about the condition. They constructed a six-question survey and what they considered appropriate answers that displayed a minimal disease knowledge.

Rather than a multiple-choice test, study subjects were interviewed and had the opportunity to give as elaborate or simple an answer as they chose. In total, researchers

were looking for 21 'correct' answers to the six questions based on specific key words. **Click here** for the questions and answers.

The survey was given to 167 patients, with a mean age of 39, at five different eye clinics. In addition to answering the KC-related questions, interviewers collected information about the subjects' education, severity of disease, and health experience.

The authors were surprised to find that not one of the participants scored 100%. Average score was 35%, and the range was from 0–76%. Severity of disease and the number of years that the patient had lived with KC did not affect results. Educational level did not make a difference either. Participants with a medical or paramedical background scored no better than those who did not. They concluded there is a mismatch between what patients know about their condition and what their caregivers assume they know.

The lower than expected scores could be the result of a poorly designed survey, or perhaps some of the information that the doctors thought was essential to know was not considered important by individuals living with the condition. A patient-constructed survey would likely have different questions and answers in determining minimal keratoconus knowledge. The results of this research are interesting because they are another example of the communication gap that can exist between eyecare professionals and their patients with keratoconus.

Reference: *Do Patients With Keratoconus Have Minimal Disease Knowledge?* Baenninger PA *et al,* **Cornea**, Sept. 2020, epub ahead of print.

Mark your calendar for Evening Webinars for Friends & Family

Have you attended any of the 2020-21 Evening Webinars? Every other month, friends of NKCF have the opportunity to learn more about a topic of interest. Join speaker, **Dr. Muriel Schornack, OD** optometrist and researcher from the Mayo Clinic in Rochester MN on **January 12, 2021.** Her talk "The SCOPE (Scleral lens in Current OPhthalmic Evaluation) Survey" will highlight current contact lens research. Learn more about the doctors who prescribe scleral lenses and the patients who wear them.

To reserve your space at this live webinar, click below.

REGISTER FOR WEBINAR HERE

And be sure to mark your calendar for these upcoming Evening Webinars:

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

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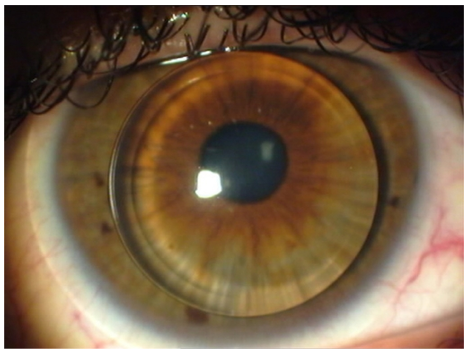
Update Results: Contact Lens Survey



One hundred thirty *Update* readers participated in the contact lens poll in the last issue: 1/3 of the respondents were male; 90% were over the age of 40, and most had worn contacts for several years.

We asked readers how many different types of contacts they tried and offered five choices: *soft lenses*, *gas permeables* (GPs or RGPs), *piggyback lenses* (a hard lens sitting on top of a soft lens), *hybrid lenses* (a soft skirt surrounding a hard lens), or *scleral lenses*. While people could describe the type of lens they were currently wearing, only 1 in 3 could recall the brand name or lens manufacturer.

Most had tried more than one type of contact lens (average = 2.4 different lens types). ***GP lenses are the overwhelming 'Go To' lens for treatment of keratoconus.*** Of the 130 who answered our survey, 90% reported they are currently wearing or had previously worn GP lenses.

On the other hand, scleral lenses seem favored among those who have tried and failed with other types: 75% (15 of 20) of those who reported wearing four or more of the different types of lenses were currently wearing scleral lenses.

We assumed most survey participants regularly replaced their lenses. Their response tells another story: 76% of those wearing scleral lenses and more than 2/3s wearing GPs had not replaced lenses in more than 12 months. This may be partially due to expense. Also, many patients who have good vision and comfort with a lens may be reluctant to replace it for fear the next one may not fit as well.

Another cost-related issue is that of a second set of contacts. Doctors recommend a spare set in the event a lens is damaged or lost. About 40% of those wearing GP lenses did not have a back-up pair and 60% with scleral lenses did not have a replacement.

Dr. Ellen Shorter, OD, Director of the Contact Lens Service at the Illinois Eye & Ear Infirmary noted, "During this pandemic, we have witnessed never before seen medical office closures and lens manufacturing delays. A back-up set of contact lenses has never been more important."

Thanks to the *Update* readers who took a few minutes to share their experiences. Please take a moment and answer this month's poll about sleeping position and KC.

Dr. Ellen Shorter, OD, FAAO is Assistant Professor of Ophthalmology at the University of Illinois in Chicago, Director of the Contact Lens Service and PROSE Clinic at the Illinois Eye & Ear Infirmary. She is a Fellow of the American Academy of Optometry and the Scleral Lens Education Society.

Can Sleep Position Affect your KC?

Multiple studies establish the relationship between eye rubbing and keratoconus. A group of cornea experts in Paris hoped to identify other risk factors that may lead to progression. They turned to a small subgroup of patients – those with severe KC in one eye and no evidence of disease in the other to learn more.

Thirty-three keratoconus and 64 control patients were given a comprehensive eye exam and survey with questions about their general health, allergies, dominant hand, eye rubbing, computer use, stress, and sleep habits.

They found most patients with KC admitted to vigorous eye rubbing: 81% reported eye rubbing in the morning, and 97% rubbed their eyes during the day, compared to 15% of the control patients.

In a significant finding not previously reported, 94% slept on the side of their 'worse' eye. The authors theorized that pressure from a hand or pillow may provide relief, just like eye rubbing, and could be causing trauma to genetically fragile corneas. Several hours each night of low-level biomechanical stress from 'pillow hugging' may have a cumulative effect and may be an overlooked risk factor.

Dr. Neda Nikpoor, MD, a cornea specialist in Honolulu found the study results compelling, "it stands to reason that sleep position could exacerbate keratoconus." She added that she asks her dry eye patients about sleep position, since those patients can show more irritation on their preferred sleeping side. "I would be very interested in a larger study to see if these results can be replicated. Until then, I plan to start asking my KC patients about their sleeping position to see if I notice a similar trend."

The authors further theorized that sleeping on the side or stomach may increase heat to the eye. A small change in temperature can cause biochemical changes resulting in corneal weakening. They also reasoned that direct and prolonged contact of eyelids against bed linen could increase allergens, triggering morning eye rubbing.

The good news about these findings is that sleep position is an adaptable behavior. Dr. Nikpoor concluded, "We are fortunate to live in a time in which we can offer CXL to our patients, yet there is still so much we do not know about KC. I look forward to more information like this on modifiable risk factors so we can better counsel our patients."

Reference: *Incorrect sleeping position and eye rubbing in patients with unilateral or highly asymmetric keratoconus: a case-control study,* Mazharian A *et al*, **Graefes Arch Clin Exp Ophthalmol** 2020, 258:2431-2439.

Dr. Neda Nikpoor, MD, is a graduate of the University of Oklahoma Medical School. She completed her ophthalmology residency and cornea fellowship at the University of Miami's Bascom Palmer Eye Institute, followed by a global ophthalmology fellowship at Stanford University where she worked with the Himalayan Cataract Project. Dr. Nikpoor is in private practice at Aloha Laser Vision in Honolulu, HI.

Take Our Survey on Sleep Position

This month, our poll asks about preferred sleep position. Some researchers believe that sleeping on your side may lead to KC progression (see story above). Do you sleep on the side of your 'worse' eye? Take a minute and answer our survey.

Take Our Survey

Research Continues on Eyedrop Therapy

Three years ago, *Update* ran a story about a Salt Lake City start-up investigating a novel treatment for progressive keratoconus. The company, Iveena Delivery Systems, was founded by ophthalmologists and eye researchers and developed the theory that eyedrops containing a copper-based enzyme, lysol oxidase, could accelerate crosslinking by stiffening and stabilizing the corneal collagen matrix.

Iveena just released promising results of its Phase I/II clinical trial. Thirty-one patients with progressive keratoconus were assigned to the placebo arm, or were treated for six or 16 weeks with a twice daily course of IVMED-80 eyedrops. All three groups were followed for 6 months after treatment ended.

Compared to the control group, both groups treated with the IVMED-80 eyedrops showed a measurable reduction in cornea steepness indicating this pharmaceutical intervention had achieved the desired crosslinking. These subjects also showed improvement in their visual acuity.

At the end of the six-month follow-up period, subjects treated with the shorter 6-week course started to show some reversal of the initially observed flattening of the cornea. Patients treated with a 16-week course

maintained the improvement with a mean reduction of 1.8D in Kmax at six months since the start of the trial.

Dr. Sarah Molokhia, RPh, PhD, Vice President of Research and Development at Iveena, was encouraged by the results, "We will be setting up a new clinical trial with an expanded number of patients to achieve optimal results by one year." Dr. Molokhia reported that no subjects involved in the Phase I/II study suffered treatment-related adverse events during or after the clinical trial.

She also reported that the company recently received a $1.68M Small Business Innovation Research (SBIR) technology grant from National Institutes of Health to advance this project. "Our Phase III clinical trial should start early next year and we hope to have some definitive results to bring to the FDA by 2022. This study proved the potential to develop an accessible pharmacological treatment for individuals with keratoconus."

This research is an exciting advancement for the KC community and has the potential to impact the way this disease is treated. For more information visit **iveenamed.com**

Cornea Donation News

Are your friends and family cornea donors?

EYE DONATION MONTH
NOVEMBER 2020

Consider this news from the Eye Bank Association of America: 68,759 people gave the gift of sight last year by donating corneas after their death. Recovered tissue was used for more than 85,000 corneal graft procedures in the U.S. and internationally, and more than 23,000 corneas were used for teaching, training and research.

The good news is that the need for corneal transplants for progressive keratoconus continues to decline. Improved contact lens technology and crosslinking are two of the reasons that fewer than 2,750 corneas were used to treat advanced keratoconus or corneal ectasia in 2019. While fewer individuals with KC received initial transplants last year, there are thousands of KC patients who have undergone corneal transplants in the past and need access to cornea tissue for replacement transplants. For all the members of the KC community, cornea donations remain critical.

People with keratoconus are not eligible to donate corneas but they can encourage others to register as organ donors. Sharing the value of the gift of sight is something you can do to help everyone with serious vision problems. To learn more visit **restoresight.org**.

World KC Day Wrap-Up

A few November 10 activities that raised public awareness of keratoconus

Webinar: Tommy Pham's Journey

As part of the celebration of World KC Day, San Diego Padre outfielder **Tommy Pham** was invited for a one-on-one interview with **Dr. Edward Bennett, OD**, Professor Emeritus at the University of Missouri-St. Louis College of Optometry. More than 100 people listened to the event live, and several hundred have viewed the video since then. Tommy opened up about his struggles and triumphs. In his role as NKCF Ambassador, he raises public awareness of this eye condition and inspires those affected by KC by proving that you can achieve your dreams.

Here is a sample:

Q: Tell us from the beginning about your diagnosis:

A: I was drafted out of high school at the age of 18 and played three seasons in the minors. I struggled. I had a vision issue and I didn't even know it. This ultimately led to my keratoconus diagnosis - I've been very lucky because we discovered the condition early and I was introduced to cross-linking.

Q: What lenses do you prefer for playing in baseball games?

A: I personally prefer RGPs (rigid gas permeable or hard lenses) from a sports performance perspective.

Q: What advice could you give to those individuals with keratoconus who feel like their condition is keeping them from achieving their dreams?

A: If there is a will, there's a way. I think about how much easier this game would be for me if I had 20/20 vision, but life always throws you some kind of punch, and it's how you react and what you do with it to get to where you want to be. You have to look at it like that. I

can't stress it enough how lucky I am that I've come across so many great people that have helped me and have been very instrumental in my career.

To watch the full interview, click here.

Social Media: TikTok Challenge

In honor of World KC Day, NKCF hosted a TikTok Challenge. We asked friends to use the TikTok app to create a short video to spread awareness of KC. Participants used the song "*Voyager Twins*" by **Gramatik** (a Slovenian hip-hop artist with KC). To view the submissions, go to our TikTok account, or visit our Instagram highlight reel titled "TikTok". Thank you to all who participated for helping to Spread the Word.

Video Lectures: Learn like an Eye Doctor

As part of World KC Day awareness, NKCF partnered with Marshall Ketchum University's Southern California College of Optometry (SCCO) to create "*Overview of Keratoconus for Optometry Students",* a four-part video series with information on diagnosis and management of KC.

The lectures are at an introductory level for doctoral students in optometry, but could be of interest to family members and patients who want to learn more about this condition. We are grateful to **Dr. Erin Rueff, OD, PhD**, Chief of the Cornea and Contact Lens Clinic at the University Eye Center in Anaheim, CA and her associates for putting together this educational series. The four videos can be found on YouTube.

Watch the Series Here

Updated Specialist List on nkcf.org

For many years, NKCF has offered information about eyecare professionals who have 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.

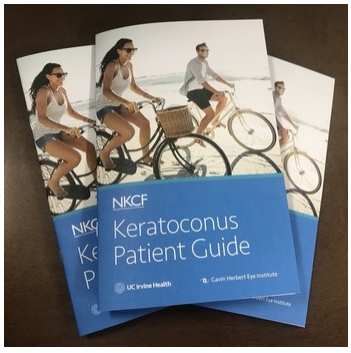
The NKCF Specialist List now includes a link so you can go directly to the practice website for additional details. While we make every effort to assure that the professionals on the list meet our educational and experience requirements, NKCF provides this resource without specifically endorsing any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

Ohio State Univ. Family Symposium postponed again

We've had to postpone our Family Symposium in Columbus again because of the continuing travel and group gathering restrictions due to COVID-19. NKCF and OSU College of Optometry will reschedule this event as soon as it is safe.

Thank you to all friends of NKCF who made a special gift in honor of World KC Day, or plan to give a year-end contribution to support our program. Visit UCI Giving to make an easy, on-line contribution. Your support makes a difference all year long.

I SUPPORT NKCF



Share the Knowledge

Take the time to educate yourself and others. NKCF sends the 22-page book, ***Keratoconus Patient Guide*** to US 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 free copy, request one by visiting our website, **nkcf.org.**

Thank you!

Printing and postage for many of the materials provided by NKCF, including the ***Keratoconus Patient Guide*** is possible through an unrestricted educational grant by Glaukos/Avedro. We appreciate their support.

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 at our website, www.nkcf.org, or leave a phone message at 800-521-2524. During this pandemic you may experience a delay in response. We apologize.

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.

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