
Letter to my Patients: What's Important to Know



Dr. Brian Chou, OD directs a busy Keratoconus clinic in San Diego at [ReVision Optometry](#). In Part One of a Letter to his Keratoconus Patients, Dr. Chou summarizes some important points to understand. [Read more here.](#)

Is there a Keratoconus Personality?

Eye doctors and others will sometimes comment on personality traits patients with keratoconus (KC) exhibit. Over the years, there have been a handful of articles written about the KC personality.

Dr. Mark Mannis, MD and **Dr. Melissa Barnett, OD** of the Department of Ophthalmology at [University of California, Davis Eye Center](#) recently published a paper searching for evidence of a unique KC personality. They conclude that caregivers may undervalue the degree to which KC impacts patients' lives, and also that KC is generally diagnosed at an age that is critical in the development of coping mechanisms. [To learn more, read here.](#)



Crosslinking Update: Epi-on v. Epi-off



All doctors and patients would like to duplicate the successful results of the FDA-approved crosslinking treatment without disrupting the epithelium. A recent paper published clinical trial results showing the trend toward epi-on CXL is gaining momentum. [Read more here.](#)

Diagnosing KC when screening for vision correction surgery



A recent article found that more than one in three patients screened for LASIK surgery at a center in Saudi Arabia were found to have symptoms of keratoconus. While the number of patients in the U.S. who are screened for refractive surgery and then diagnosed with keratoconus may not approach that level, it happens regularly.

Dr. Louise Sclafani, OD from [SoLo Eye Care](#) in Chicago reports that a lot of the patients with KC that she treats had hoped to 'get rid of their contacts'. [Read more here.](#)

Good News Continues for CXL Coverage



At the time of our last newsletter, we announced that 20 million lives enrolled in 49 local and national insurance plans were covered for cross-linking (CXL) for progressive keratoconus.

That number has grown significantly in recent weeks. Today, 61 commercial plans will cover the costs of FDA-approved CXL, a positive outcome **for more than 178 million Americans**. The recent addition of Anthem Blue Cross brought in an additional 31 million beneficiaries. **Our thanks to**

Anthem for providing this important benefit to their members! Now more than 90% of those insured by a commercial plan will have access to the procedure.

Your insurance company may have made changes to its medical policies, even if your eye doctor is unaware. It is important for you to know the status of your benefits and if there are specific criteria for coverage. Visit to your insurance plan's homepage directly and search for policy statements (use keywords *keratoconus* or *cross-linking*) or visit the website, [Living with Keratoconus](#), and see a list of all insurance companies offering coverage for CXL and see their written policies. Read more insurance tips for CXL in the following article.



Insurance Tips for Cross-Linking

NKCF has summarized information you may need if you or a family member will be undergoing cross-linking in 2019. Most importantly, you will want to know if your insurance considers CXL a covered benefit.

You will need to do some homework before you and your eye surgeon schedule the procedure. [Read our tips here.](#)

Military Update

Thank you to the several readers who shared their experience being denied the opportunity to enlist in, or their discharge from, the military because of KC. We have reached out to the Department of Defense to request that they reconsider their policy. If you would like to share your experience, please write us at info@nkcf.org and it will be added to the information we are collecting.



Mark your Calendar!



We are pleased to announce the first NKCF Family Symposium of 2019 will take place on **Saturday, March 23**. We are partnering with the **University of Houston College of Optometry** for our first patient event in the Lone Star State. Check our website and Facebook in January for more information and to register.

Do Scleral Lenses improve your Outlook as well as your vision?

Turkish doctors published the results of their research that evaluated changes in the quality of life of patients with keratoconus fitted with customized scleral contact lenses.

The doctors offered a survey that measures the impact of eye disease on daily activities to patients with KC before fitting them with scleral lenses. The participants were given the survey again three months after they were fitted with the custom lenses.



Scleral lenses are large diameter gas permeable lenses that completely cover the cornea and rest on the sclera, the white part of the eye. Their shape can be customized to accommodate the slope of keratoconus eyes, resulting in a smoother refractive surface and improved vision and comfort in most cases.



The doctors found patients reported a marked increase in scores after the contact lens treatment. Contrast sensitivity, near activities, and peripheral vision all improved, resulting in a higher quality of life. The average pre-treatment scores were 52/100, and post scleral lens fitting, the overall scores rose to 76/100.

The authors noted that despite the improved quality of life the lenses seem to offer, some patients opted to give them up because of handling difficulties and increased maintenance. The authors concluded that since scleral lenses have a positive

impact on quality of life, they should be considered as an effective option in cases of moderate-to-severe keratoconus.

Dr. Maria Walker, OD, a contact lens expert from [University of Houston Eye Institute](#) agrees, **“Scleral lenses yield the tremendous power to change the vision and quality of life for patients who would otherwise be left with no options other than corneal transplantation surgery. Time and time again, I see patients break down with joy after experiencing the comfort and vision of a scleral lens. They truly are a life-altering device for patients with keratoconus.”**

Reference: Ozek D, et al, Visual Performance of Scleral Lenses and their impact on Quality of Life in patients with irregular corneas. Arq Bras Oftalmol 81:475-480, 2018.



Dr. Maria K. Walker, OD, FAAO, FSLC is currently an Assistant Clinical Professor at The University of Houston College of Optometry and a fellow in Scleral Lens Society. She completed advanced training in Cornea & Contact Lens at Pacific University College of Optometry in Forest Grove, Oregon.

One-Fit care kit has a new Look

People who wear scleral lenses may find their vision improves, but the time they devote to daily lens care increases. Companies have started to offer larger carrying cases for scleral lenses.

Blanchard Lab, the makers of OneFit scleral lenses for individuals with keratoconus recently announced a new care kit and carrying case. Along with the lens case, the silver box contains tools to remove and insert lenses and individual packs of *LacriPure*, the popular rinsing and insertion solution. This new care kit may help you organize your ‘must have’ items when you leave home. Check with your eye doctor about the care kit or other tools that can make life with KC easier.

Useful items and information about scleral lenses can be found at the [Dry Eye Shop](#).



Join Us in Tampa Bay!

Plan on attending a Spring training event in Florida featuring KC Ambassador

Tommy Pham. The outfielder will be starting his second season as a member of Tampa Bay Rays and he'll share his story of success in professional baseball while living with KC. Follow Tommy on [Twitter](#) and [Instagram](#) and watch for event information on Facebook.



World KC Day



Raise Awareness
Advocate
Educate



Did you participate in World KC Day? Thank you to the hundreds of individuals who used November 10 to educate their colleagues, families and friends about life with KC. You are not alone!

#GIVING TUESDAY



We are so grateful for the friends who remembered NKCF on Giving Tuesday. This international day of generosity started in 2012 and in just six years has raised \$1 billion for charities and causes world-wide. NKCF was grateful to participate and we thank our supporters.

If you are still interested in making a tax-deductible donation in 2018, click the "I Support NKCF" button to make your on-line gift. If you prefer to send a check, payable to **UCI Foundation** (EIN: 95-2540117) for the exclusive use of NKCF, please send it to:

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

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

If you have specific questions about your diagnosis, treatment, or outcomes, please contact your eyecare professional.



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