



March 2019  
Update

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**Finding KC's TOP DOCS**

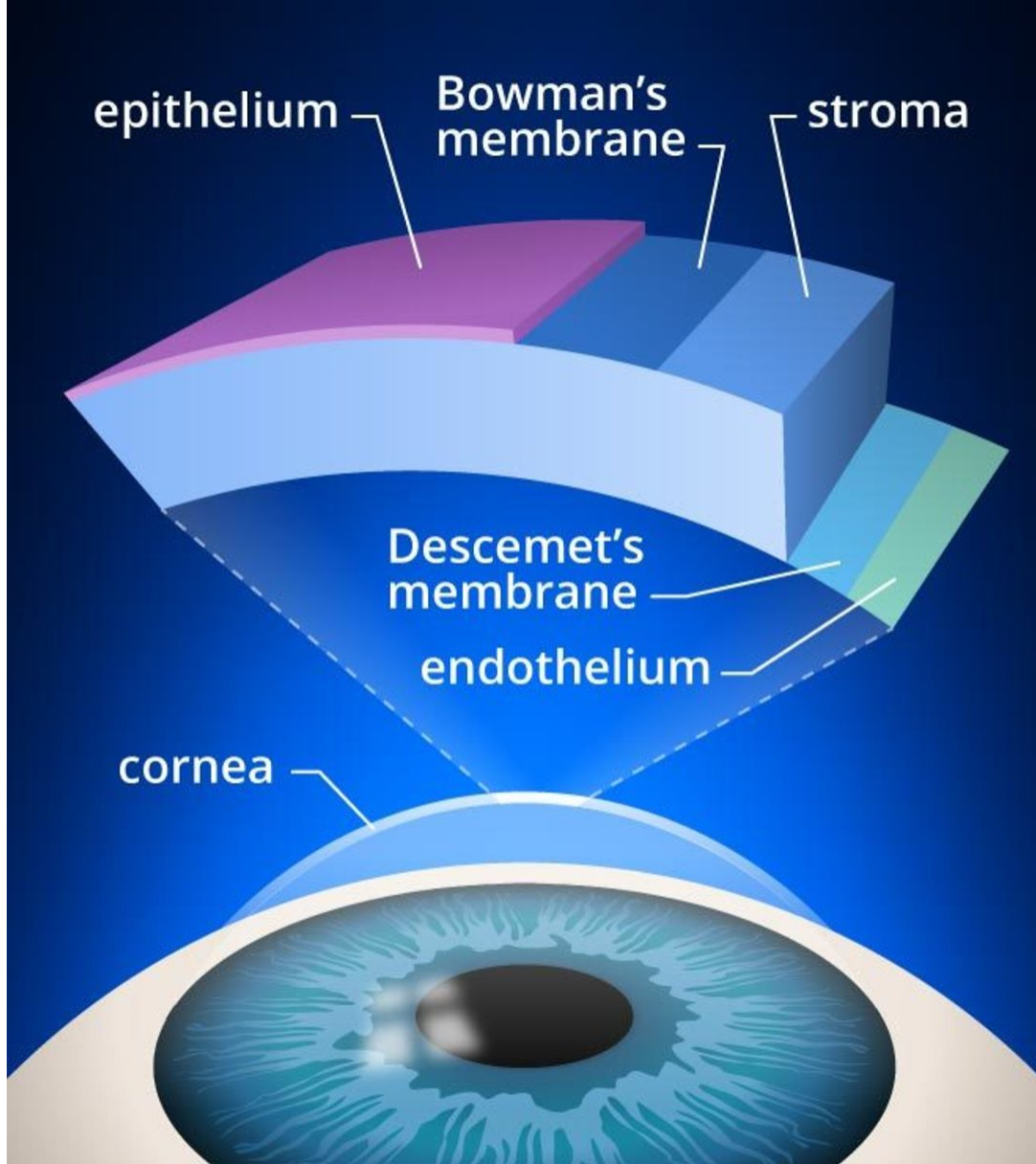
**Honor Your Doctor Day**

**HONOR A D♥CTOR**

NKCF is again giving patients the opportunity to say **Thank You** to their eye doctor on National Doctors' Day. Between now and March 30, go the [nkcf.org](http://nkcf.org) website and tell us how your doctor has made a difference in your life. We'll send your doctor a special message on your behalf, and NKCF will print the names of all the nominated doctors on our website. We'll use your vote and your story to select our **Top Docs of the Year**. This program is only offered to friends of NKCF based in the US.

[CAST YOUR VOTE](#)

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## Novel Surgical Treatment for Advanced KC

**Dr. Jack Parker, MD, PhD**, from the [Keratoconus Center of Alabama](#) is one of the few surgeons in the world who performs Bowman Layer Transplant (BLT).

**Watch** him describe the procedure to doctors, and **read here** about this procedure designed to stop progression, improve vision, and avoid corneal transplant for patients with advanced KC.

### NKCF Family

### Symposium:

### Join us in Houston

NKCF and [University of Houston College of Optometry](#) will be holding a KC Family Symposium on **Saturday, March 23**.



Anyone interested in learning more about keratoconus, and life with KC should make plans to attend. A copy of the final program can be found [here](#). To reserve your spot, [click here](#).



## Clinical Trials Progress

**Avedro**, the company that received FDA approval for its epithelium-off crosslinking treatment in 2016, has nearly completed enrollment of 275

participants in a new Phase 2 clinical trial. This study will evaluate the safety and efficacy of **epithelium-on** crosslinking to stop the progression of KC and steepening of the cornea. Study subjects are being treated at one of 13 centers in the US; they will be followed for one year after treatment. Data collected from this clinical trial will likely be presented to the FDA in 2021.

**Iveena Medical Devices**, another company we have been following, is scheduled to begin a Phase 1-2a study of its **eye-drop** for medical crosslinking of the cornea. 36 patients will be enrolled in this preliminary study being conducted outside the US. This study will focus on safety and dosage of the eye-drop and should have results by the end of 2019. Later, larger scale studies are planned to evaluate the eye-drop's effectiveness compared to current treatments for progressive KC.

## True Grit: Ash Winter's Story

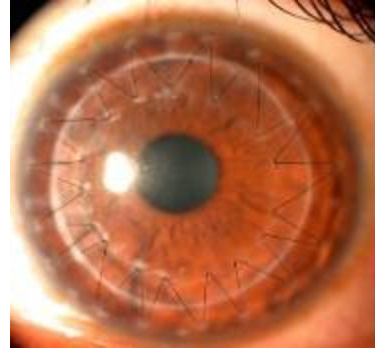
Ashley Winter, 2017 NKCF Film Festival winner has published an autobiography, "**Keratoconus and Me**" about his philosophy of prevailing over challenges that come with KC. [Read more about Ash's adventures](#), or [order](#) his new book from Amazon.



## Corneal Transplant Survey

Graduate students at UC-Irvine developing an artificial cornea would like to learn more about patients' perceptions of their transplant experience.

**If you have had a corneal transplant as a result of KC, and are interested in participating, please fill out the short survey below.** The researchers may contact a few participants with additional questions. Thank you for helping NKCF support research.



Corneal Transplant Survey

## NKCF offers Insurance Toolkit



When your insurance company denies payment for a treatment that you believe is covered by your policy, you will need to file an appeal. Visit a new section in the [NKCF website](#) that offers useful information about the appeal process, as well as a template and sample letter for denial of coverage for crosslinking.



## Identifying a KC Gene

Scientists searching for a single, simple genetic answer responsible for keratoconus have been disappointed, but as our understanding of genetic associations increases, researchers have been able to make the association between KC and a range of other diseases - some vision-related and

some related to other medical conditions. A thorough literature review was recently published in the journal, **Ophthalmology and Therapy**. The authors concluded that most cases of KC are likely the combination of a keratoconus-susceptibility gene and a secondary influence which could be environment, eye rubbing, allergies, or some other aggravating factor. For instance, the authors found locations with lots of sunshine and hot weather like India and the Middle East tend to be associated with a higher prevalence of KC, than locations with cooler climates and less sunshine: rates of KC range from 0.3/100,000 in Russia to 2,300/100,000 in Central India.



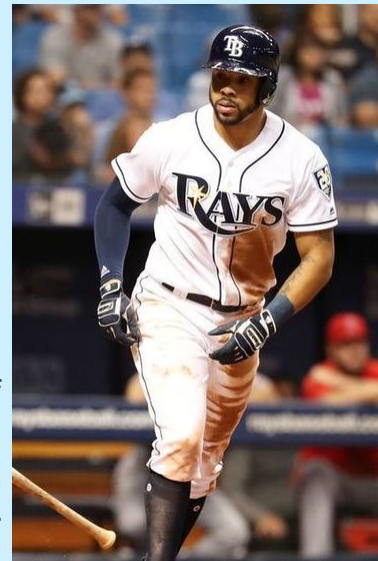
The authors identified 24 genes that are potential contributors to KC, and another 49 genes that had an association to KC symptoms, while primarily associated with other syndromes or diseases. Some of the strongest connections were between genes that also were linked to glaucoma, cataract, Down syndrome, connective tissue disorders, rheumatoid arthritis, mitral valve prolapse, and atopic disease like allergies or asthma.



The authors concluded that awareness of these potential co-morbidities should encourage doctors to monitor patients and refer them for evaluation of other conditions when appropriate. One important take-away from this paper is that due to the dominant pattern of inheritance, the increase in KC among close relatives is 15-60x higher than the general population. First degree relatives (parents, children and grandchildren) should be screened for KC and checked for symptoms at annual exams. Read the article, *Genetic Aspects of Keratoconus: a Literature Review Exploring Potential Genetic Contributions and Possible Genetic Relationships with Comorbidities* [here](#).

## Mark your calendar for June 12

The **Tampa Bay Rays** have offered NKCF a limited number of tickets for their June 12 outing against the Oakland A's. After the game at Tropicana Field, we'll have a chance to meet outfielder, **Tommy Pham**, who serves as NKCF Ambassador. He will be joined by a panel of eye doctors who will answer questions about KC. If you are in central Florida this summer, make plans to join us. To be added to our invitation list, please email [info@nkcf.org](mailto:info@nkcf.org).



## Science with Scarlett

***What Color Will It Be?*** is a new children's book that invites readers to engage in interactive experiments directed by Scarlett, a precocious scientist who is the focus of the story, and her assistant, Mr. Bear. The picture book is written by **Gary Abud**, an educational consultant and past Teacher of the Year in Michigan.



**What Color Will It Be?** explains how the eye sees color. Gary has a unique appreciation for eyesight: he has shared his experience of receiving two corneal transplants as a result of his keratoconus with the public and has presented to members of the KC community. To learn more about Gary's latest achievement, visit [Scarlett's Facebook page](#).

## Letter to my Patients: Part II



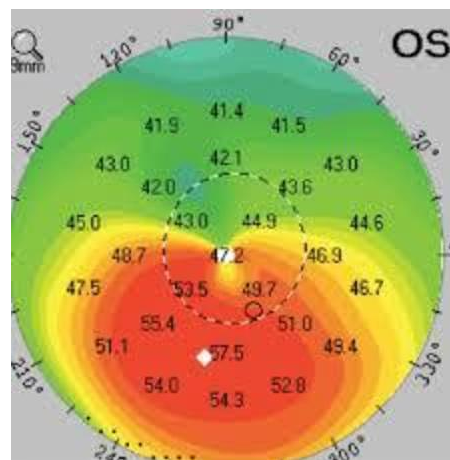
In our last newsletter, **Dr. Brian Chou, OD, FSLs, FAAO**, director of the Keratoconus and Scleral Lens Clinic at Revision optometry in San Diego shared information he wants his patients with keratoconus to understand. This month, Dr. Chou offers pointers about contact lens wear. To read more, [click here](#).



## International Keratoconus Academy Of Eye Care Professionals

### Research Update

NKCF is partnering with the [International Keratoconus Academy](#) (IKA) to determine the incidence and prevalence of KC in the US. IKA is a society of optometrists and ophthalmologists who promote professional education and effective strategies for treatment of KC. They have begun a research project with the [Illinois College of Optometry](#) (ICO). Students from the Chicago Public Schools who receive eye exams from the ICO-staffed clinic will receive a corneal



topography and the images will be evaluated by independent experts. This program will provide useful information about the number of affected individuals in an ethnically diverse U.S. city. Data will be collected this academic year, and preliminary results should be released in 2020.



APRIL 28 – MAY 2 | VANCOUVER

## For Eye Researchers & Vision Scientists

NKCF will again be hosting a KC Roundtable at ARVO, the annual meeting of the Association for Research in Vision and Ophthalmology. This year, our Roundtable will be moderated by Dr. Tim McMahon, OD from University of Illinois, with panelists Dr. Cynthia Roberts, PhD, from Ohio State Univ., Dr. Emilio Netto-Torres, MD from Univ. of Zurich and Dr. Jason Marsack, PhD from Univ. of Houston. If you are attending ARVO and would like to be included in this event, please email [info@nkcf.org](mailto:info@nkcf.org) to receive an invitation.

## You make a difference!

We are so grateful to our friends and donors. Your gift - of any amount - helps maintain our educational and informational programs.

***Did you know that 100% of your tax-deductible gift to the UCI Foundation (EIN: 95-2540117) will be used exclusively for NKCF?***

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

**NKCF**  
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## A Special Thanks

to all of our donors in 2018, and especially to the following major contributors:

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## NKCF E-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.*

*Contact us with your general questions about keratoconus at [info@nkcf.org](mailto:info@nkcf.org) or call us at 800-521-2524.*

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



# UCI Health

National Keratoconus Foundation is a program of the Discovery Cornea Center at the Gavin Herbert Eye Institute, University of California, Irvine.

[nkcf.org](http://nkcf.org) | 800 - 521 - 2524

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