#### THE NATIONAL KERATOCONUS FOUNDATION

A PROGRAM OF THE GAVIN HERBERT EYE INSTITUTE, UNIV. OF CALIF. - IRVINE

December 2016 E-Update



### **World KC Day Celebration**



#### Did you participate?

The response to the first World KC Day was remarkable. Industry, eye doctors, and patients joined together to increase awareness of keratoconus. In the weeks before November 11, there were thousands of visits to the website, and close to 200 individuals, living in all parts of the world, placed themselves on the KC interactive map. At the American Academy of Optometry annual meeting in Anaheim, CA, hundreds of optometry students sported World KC Day buttons.

On World KC Day, NKCF hosted a webinar, "*Crosslinking: It's finally here*" featuring Dr. Sam Garg, MD, of the Gavin Herbert Eye Institute.

Anyone investigating the procedure for themselves or a family member should take some time to **watch the webinar <u>here</u>**.

Thank you to all who participated in World KC Day. We hope you'll join us next year for a bigger and better celebration!







Some of the folks who helped celebrate World KC Day: Skip is still swinging at 81 years old, thanks to his clarinet and RGPs. Wendy Rose, who has had transplants in both eyes, sent a photo with her fiance - he also has KC! Dan, at work as a firefighter, a true KC Hero







Professional partners who took part in World KC events included <u>Dr. Brian Chou, OD</u> at EyeLux in San Diego, CA and <u>Dr. David Momnie, OD of Chicopee Eyecare</u> in MA. Our friends at <u>Cathedral Eye Clinic in Belfast, N. Ireland</u>, offered complimentary KC screening to young adults. Wow! Next year, get your eye doctor involved.



Our friends at <u>Avedro</u> posted a company photo and good wishes on World KC Day.

## Trends in Transplant Surgery

This month, the medical journal *Cornea* published an article looking at some trends in corneal transplantation. The authors looked at insurance data for more than 20,000 patients with keratoconus. What the authors learned is that there is a decreasing number of number of corneal transplants being performed. Read more about some of the reasons why this is the case.



## **International Update**

Our Amazing International Ambassador is in India connecting eye doctors and KC patients. Recent UC-Irvine graduate Gigi Sahota served as an intern at NKCF while completing her degree in Public Health.

Alarmed at the numbers of KC patients in India where there is no program to support and educate, Gigi is on a self-financed mission to set up NKCF- India. She has had several meetings with cornea and contact lens specialists in Delhi. To learn more, visit the



# **Caption Contest**

NKCF-India Facebook page.



Here's a way to express yourself and give some insight into life with KC. Create a caption for our lemur with a keratoconus twist. Submit your comment on our <u>Facebook page</u> or the <u>NKCF website</u>.

Best caption will get featured in the next e-update!

## Coaching deserves a closer look

The National Board of Medical Examiners and National Consortium for Credentialing Health and Wellness Coaches have joined to set up a certification process that sets education and training standards for health and wellness coaches. With this new professional credibility, can we expect to find more wellness coaches guiding keratoconus patients? Read more here...



". . . be aware that you are the one who will travel. The coach guides you, but doesn't do the work for you."

- Charlotte Terwolbeck, Life Coach

## **Contact Lens Hygiene**

National Handwashing Awareness
Week was celebrated the first
week of December. The start of
the flu season is a good time to
remind people that handwashing
can reduce the chances of
sharing germs.



Good handwashing technique is also essential to the majority of keratoconus patients who must wear contact lenses to improve vision.

An interesting report from the Centers for Disease Control and Prevention (CDC) summarized contact wearer demographics and behaviors that lead to contact lens-related eye infections. Forty million people in the US report that they wear contact lenses, either occasionally or regularly. That is one of six adults! Here is a more incredible statistic: 99% of wearers report at least one contact lens hygiene risk behavior. The study was based on an on-line survey of more than 4,000 contact lens wearers, most of whom wore soft lenses. Many of the same bad behaviors can occur wearing rigid gas permeables, sclerals or hybrids. Are you guilty of any of these? (includes % of those reporting this behavior at least once.)

- Rinsing your RGP lenses in tap water (91%)
- Napping in your lenses (87%)
- Showering in your lenses (85%)
- Using the same contact lens case for more than 3 months (82%)
- Swimming in your lenses (61%)
- Topping off solution\* (55%)
- Sleeping in your lenses (50%)

• Storing your RGP lenses in tap water (33%)

(\*Topping off is not replacing the fluid in your lens or lens case, but simply adding more solution to what is present.)

Compliance with contact lens hygiene is something that decreases over time. The greatest drop takes place in the first two years of wearing the lenses. After that, there is a slow but steady decrease in observing good practices. So continue to be alert with your CL hygiene! Experienced CL wearers may be less vigilant, but they also are more adept at handling the lenses and can reduce the potential for contamination using cleaning, insertion and removal techniques they have mastered.

If you find yourself admitting that you would also be on the above list, or even if you believe you are performing lens care correctly, take a few minutes to review your contact lens hygiene technique.

### Patient Education Events

Saturday, January 14, 2017 | Keratconus Patient
Seminar presented by <u>UC Davis Department of Ophthalmology</u>



Join us for this full day event in Sacramento, CA. This will be a wonderful opportunity to learn about the medical and surgical management of keratoconus, and to network with others living with KC. There is a cost to attend this conference, which includes parking, breakfast and lunch:

- \$25 for individuals (\$40 after January 10)
- \$25 for individuals (\$40 a)\$10 for family members.

To register or for more information about this event, <u>click here</u>.

## Time is running out!

## Have you completed the Patient Experience Survey yet?

Take less than ten minutes today and answer questions related to life with KC.



NKCF was a partner in developing this patient experience survey for the Mayo Clinic. Your responses are anonymous; taking part is completely voluntary. The more information we gather, the better the results! Help reseachers understand the KC experience.

Take our Survey!

## KC Link is our on-line support group



Last spring we changed the KCLink platform from a listserve
(one long strand of emails) to a
message board (different
folders with different topics).
Now visitors can read and
respond to comments made
during the past year, and
participate in several different
conversations. NKCF
recommends that newly

diagnosed families go to KC-Link to ask questions and voice concerns. We also encourage 'veteran' KC patients and professionals to weigh in with your own observations. You would be surprised how informative and inspiring your story could be to others! **To join KC Link, click**here.

## Thank you to our Donors



## Your Support makes things Happen!

A sincere and heartfelt thank you to those of you who made a donation to NKCF in honor of World KC Day or #GivingTuesday. Your gifts help us raise awareness of keratoconus. Remember, donations to NKCF through the UCI Foundation are used exclusively to support the programs of the National Keratoconus Foundation. **Thank you!!** 

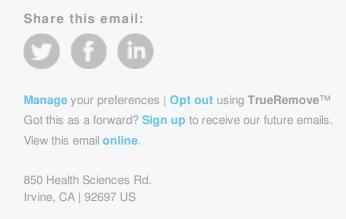
Give to NKCF

If you prefer to send a check, payable to **UCI Foundation** to support NKCF, please mail it to:

NKCF - GHEI 850 Health Sciences Rd 3rd Floor Irvine, CA 92697

## Holiday Greetings from the OC





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