March 2025 Newsletter



Awareness | Education | Research

Director's Desk

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Dear NKCF Community,

It is with immense gratitude and excitement that I introduce myself as the new Director of the National Keratoconus Foundation. As I step into this role, I am inspired by the extraordinary power of our community—patients, clinicians, industry and donors—working together to make a difference.

This newsletter is more than an update; it's a celebration of what we can achieve when we unite around a shared purpose. Together, we have the power to increase awareness and understanding of keratoconus, empower earlier diagnoses and proactive treatments, and drive groundbreaking research into the causes and management of this condition. Through these stories and updates, I hope you'll find inspiration, connection and ways to contribute to our mission.

I encourage you to share this newsletter with friends, family and colleagues. Let's grow this network of hope and action. If you're inspired to get involved or have ideas to share, I urge you to reach out and respond to the many opportunities you'll see highlighted each month. Together, we can achieve more than we ever imagined.

Your support—whether in time, expertise, or donations—fuels this foundation. Every contribution matters. Thank you for your continued engagement. I look forward to connecting with you.



Yours in progress and partnership,

Amy Hellem, PhD, FAAO Director, National Keratoconus Foundation

Expert Interview

What advice would you give to someone newly diagnosed with keratoconus?

The first thing I tell patients is to educate themselves about keratoconus, including treatment options and insurance coverage. Understanding the difference between regular contact lenses and medically necessary contact lenses is important, as insurance companies often have specific policies about coverage.

It's also essential to find an eye care provider with experience in keratoconus, particularly someone who fits scleral lenses. These specialists are well-versed in the full range of contact lens options and can help determine the best choice for each patient. The goal is twofold: slowing or stopping progression with treatments like corneal cross-linking and restoring vision with specialty contact lenses.



Maria Walker, OD, PhD Houston, Texas, United States Assistant Professor University of Houston College of Optometry

Read the full interview

Clearly KC Podcast



Episode 33: Keratoconus and Creativity: an Award-Winning Artist's Journey

In this episode of Clearly KC, Dr. Melissa Barnett features Rocky Kelley, an artist and passionate keratoconus advocate who won the senior category in our most recent World Keratoconus Day contest. The episode delves into Rocky's journey as an artist living with keratoconus and the inspiration behind

his winning artwork, Shattered.

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Clinical Trial Spotlight

A Different Approach to Crosslinking

Epion Therapeutics is conducting Phase 3 clinical trials for an investigational treatment called EpiSmart[™]. This minimally invasive procedure involves applying a riboflavin (vitamin B-2) solution to the cornea, followed by exposure to ultraviolet A (UVA) light. Unlike traditional methods, EpiSmart[™] preserves the cornea's outer layer, potentially reducing discomfort and speeding up recovery.

Click here to learn more

Research Update

Could Snoring Be a Risk Factor for Keratoconus? A New Study Says Yes

A new study suggests that snoring may increase the risk of developing keratoconus (KCN). Researchers used a genetic analysis technique called Mendelian Randomization (MR) to investigate whether snoring plays a direct role in causing keratoconus. Their findings, published in the journal *Cornea*, provide strong genetic evidence linking snoring to an increased likelihood of developing the condition.

Click here to learn more

Comfort and Fogging: Does Scleral Lens Size Matter?

If you wear mini-scleral lenses for keratoconus, you may have experienced issues like midday fogging (cloudy vision from debris in the tear layer) or lens settling (when the lens sinks into the eye slightly after wear). A recent study compared two different sizes of mini-scleral lenses—one 15mm in diameter and another 16.5mm—to see if size made a difference in vision, comfort, and fogging.

Click here to learn more

Support the National Keratoconus Foundation

The National Keratoconus Foundation (NKCF) is dedicated to educating, empowering, and advocating for individuals living with keratoconus. But we can not do it alone.

Your support is vital to sustaining our programs, raising awareness, and driving research for better treatments. With your generosity, we can continue to provide resources to patients, caregivers, and professionals, ensuring the keratoconus community gets the support it needs.

Please consider making a tax-deductible donation today. Every contribution—big or small—helps us move closer to a future where keratoconus is better understood and treated.

Thank you for believing in our mission and standing with the keratoconus community. Together, we can make a difference!



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