



DISCOVERY

THE DISCOVERY EYE FOUNDATION



Spring/Summer 2014

The Discovery Eye Foundation supports research, education and advocacy related to sight-threatening eye diseases and their treatments, improving the quality of life for patients and their families.

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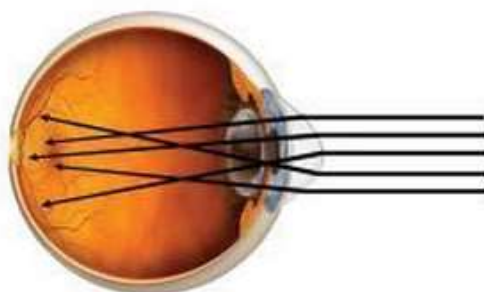
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For questions or comments about this newsletter, please [e-mail us](#).

Monumental Changes: KC and the National Keratoconus Foundation

The word *keratoconus* is formed from two Greek words: *kerato*, meaning cornea, and *konos*, meaning cone. It is pronounced kêr-â-tō-kō-nûs.

Keratoconus (KC) is a thinning disorder of the cornea, in which the normally round, spherical shape of the cornea is distorted, and a cone-like bulge develops, resulting in visual impairment. KC is a progressive condition that usually affects both eyes, though one eye may be affected more than the other.



The images entering through the irregular KC corneal surface create distortion and blurring.

Research, Diagnosis and Treatments

The human cornea has five distinct layers: the epithelium, Bowman's layer, the stroma, Descemet's membrane and the endothelium. "In the 1980s, we knew KC corneal stroma becomes thin, but the mechanism behind this thinning was not understood," explains Dr. M. Cristina Kenney, research director of The Discovery Eye Foundation (DEF). "In the '80s and early '90s, we identified an excess of degradative enzymes that cause breakdown of the extracellular matrix of the corneal stroma. Studies have been conducted to develop inhibitors that might block the degradative enzyme activities, but to date, these have not been successful. Future studies will continue to examine the regulation of these damaging enzymes in KC corneas."

Even 30 years ago, eye-care professionals had limited instruments with which to diagnose KC, and identification of early KC was almost impossible. "Now we have pachymetry instruments that quickly and reliably measure corneal thickness, automated corneal topography instruments to measure corneal curvature, and video-keratography to accurately detect KC at earlier stages, all of which mean patients can be treated earlier for KC," Kenney says.

[Keratoconus and the National Keratoconus Foundation cont'd...](#)

PROFILE

"Kerato-What?"

"I got keratoconus as a wedding present," Joanne Ciesluk says with a characteristic long laugh.

She was 35 and had been married for just two months. "Suddenly, my contact lenses didn't work. And my glasses didn't work. And I said, 'What the heck is going on with this?' I went to the eye doctor and was diagnosed with keratoconus," she says. "I asked my new husband, 'Do you want me anyway?' He said, 'Oh yeah, we already tied the knot, so I'll keep you.'"



While Ciesluk had worn glasses then contacts for nearsightedness since she was a child, she'd always considered her vision to be good. But the clinical nurse was forced to make an "abrupt" career change: "All of a sudden, I couldn't tell an 8 from a 3 from a 5. I was dispensing medications, and I realized, 'Oh my gosh, I can't do this.' I switched to administrative nursing, because I knew I could still make an appreciable difference. It was a U-turn for my career, but it worked out very well. With keratoconus, you can't plan on anything; you just have to go with the flow," she says.

[Joanne Ciesluk cont'd...](#)

Virtual Community

NKCF provides support and advice where you are

NKCF offers two online support groups that give those dealing with keratoconus (KC) a sense of community and the chance to interact with others worldwide who have the disease: KC-Link is an e-mail group, and KC Forum is a web-based bulletin board.

"A diagnosis of KC can leave people feeling isolated and alone," says Catherine Warren, director of NKCF. "Our online support groups provide a virtual community for those dealing with KC — no matter where they are. They can learn from others who are dealing with or have already dealt with the same issues. They can get advice, share stories, learn about treatments and tips, and most of all, find out they are not at all alone."

A paper in the December 2001 issue of [Health Education Research](#) reported numerous benefits associated with online support groups, including the following:

"With asynchronous communication, participants in online groups have access 24 hours a day, 7 days a week, at times most convenient to them. Asynchronicity allows individuals to carefully develop responses at their own speed. Geographic and transportation barriers are absent. People with mobility problems, speech and hearing difficulties or caregiving responsibilities can participate with ease. ... On the Internet, coverage spans the globe. This international scope permits group members to draw from a wide variety of perspectives, experiences, disabilities and points of view, while at the same time promoting a feeling of universality."

Indeed, the worldwide reach of online support groups is inarguable: One would be hard-pressed to “chat” with a doctor pioneering new techniques half way around the world, or “meet” someone from a different state or country who experienced the exact same symptoms in a local face-to-face group. For those who are lucky enough to have local groups to attend, online groups are excellent supplements. For those who have no such face-to-face groups, they can be life-altering.

[Virtual Community cont'd...](#)

DEF NEWS

DEF in the Blogosphere



DEF has launched its first-ever [blog](#), where you will find information from leading ophthalmologists, optometrists, eye researchers, low-vision specialists, nutritionists and other professionals who are interested in helping you keep your eyes as healthy as possible, and/or deal with eye disease and vision loss.

We are posting twice a week, with a guest post from an eye-care professional every Thursday addressing an issue important to our constituents.

We also want to hear from you. What information do you find useful? What topics are important to you? And while we will respond to general questions about eye diseases, we will not be able to address patient-specific questions that can best be answered by your own eye doctor.

Please visit and/or subscribe to the [DEF blog](#) and join us wherever you are online: We're on [Twitter](#), [Facebook](#), [Pinterest](#), [Google+](#), [LinkedIn](#) and [YouTube](#).

We're Grrreat!

Many people turn to independent sources when choosing recipients for their donations. A key source is www.GreatNonprofits.org, which is the only site based completely on donor experiences. DEF is listed with GreatNonprofits, and the more reviews we get, the fuller a picture prospective donors get about the lives we touch. We are very proud DEF has received a top-rated award every year since the site's inception.

Please log on to www.GreatNonprofits.org, and post a review of DEF. You will need to register for the site, or you may use your Facebook account to do so. It just takes a minute, and it means so much to those who rely on our services.

The Amazing, Evolving Contact Lens

Contact lenses give a person the ability to see without glasses. If you have keratoconus, they are essential, as regular glasses don't work with an irregularly shaped cornea. These relatively simple lenses have evolved beyond corrective lenses to measure blood glucose levels, dispense eye medication and even help the blind see.



Monitoring Blood Sugar

Google is currently working on a lens with tiny wireless chips and glucose sensors that are sandwiched between two lenses. They would monitor glucose levels once a second and use tiny LED lights, also inside the lenses, to flash when levels are too high or low. The electronics are no larger than a speck of glitter, with a wireless antenna that is thinner than a human hair. While they are still in development — Google has run clinical research studies and is in discussions with the FDA — they could make blood-sugar monitoring far less invasive than pricking your finger.

Drug Delivery for Glaucoma

Getting glaucoma patients to regularly use their eye drops to regulate the pressure in their eyes has always been difficult. They forget, don't want to be bothered or have a hard time getting the drops into their eyes. Two research projects are exploring the use of contact lenses to deliver medication for a prolonged period of time.

Researchers at Massachusetts Eye and Ear/Harvard Medical School Department of Ophthalmology, Boston Children's Hospital and MIT are working on a lens designed with a clear central area and a drug-polymer film made with the glaucoma drug latanoprost around the edge to control the drug release. These lenses can be made with no refractive power or made with the ability to correct the refractive error in nearsighted or farsighted eyes.

[Contact Lens cont'd...](#)

NUTRITION

Smoothie Sailing

Smoothies are an easy way to get antioxidants and other eye-healthy nutrients. They are also extremely versatile, with variations only limited by your imagination. Use frozen ingredients to make them more like a shake. Or add nuts or seeds for essential fatty acids, which are also important in preventing or slowing down eye diseases. Eye Cook's newest recipes feature [Kiwi-Banana](#), [Very Berry](#) and [Tropical Carrot smoothie varieties](#). Perfect for warm spring and summer.



GIFTS

Three More Easy Ways to Give

In the winter 2014 e-newsletter, we discussed the importance of your donations to The Discovery Eye Foundation, the Macular Degeneration Partnership and the National Keratoconus Foundation. We explored monthly credit-card donations, registering with shopping sites such as Amazon Smile or Supporting Pals, and making tribute gifts. Here are three more ways you can give to DEF:

- **Donor-Advised Funds:** Have a Fidelity, Charles Schwab or Greater Kansas City CF donor-advised fund? You can easily donate directly from your account using our [online tool](#).
- **Legacy Society:** Make a confidential pledge, bequest or other type of planned gift to continue your commitment to eradicating eye diseases and/or providing help for those who live with them on a daily basis.
- **Host an Event:** Do you want to have fun and raise some money for a DEF-supported program or research project at the same time? We can help you set up and solicit for an event or crowd-funding project.

Remember: Donors of \$250 or more per year receive 12 months of the *Harvard Health Newsletter* sent to their home. Donors of \$1,000 or more, plus all members of the Legacy Society, are invited to a hosted Donor Appreciation Dinner held in February.

If you have any questions about designating your giving, please contact Susan DeRemer at sderemer@discoveryeye.org or (310) 623-4466.

VISION LEGACY

Generosity and Planning

Do you have questions about estate planning? Planned giving? Your will? Each month, we feature new articles and interactive features that cover such topics. We hope it is a useful resource for you. Here are some articles we've just posted:

Chart Your Charitable Path

Whether you need to save on taxes, want the flexibility to change your mind, or wish to provide for loved ones and support our organization, we have an option for you.

[Charting your path...](#)

10 Important Questions to Ask Your Parents

Are you wondering if your parents have their estate and inheritance plans in order? Well, stop wondering, and just ask. Here's help posing the right questions in a sensitive way. [10 important questions...](#)

How Does Your Generosity Affect Your Kids?

Research reveals how your loved ones really feel about sharing a piece of their inheritance with a nonprofit. [Generosity and your kids...](#)

Think Twice Before Passing Assets to Loved Ones

For many of us, 401(k)s, IRAs and retirement plans constitute the bulk of our net worth, aside from our homes. Will these hard-earned dollars provide more comfort for the future of our loved ones? Maybe not. [Passing assets...](#)

If you have questions about creating or updating your estate plans, contact your estate-planning attorney. If you'd like to include DEF in your estate plans, contact Susan DeRemer today at (310) 623-4466 or sderemer@discoveryeye.org to discuss how you can leave a lasting legacy of vision.

www.discoveryeye.org | contactus@discoveryeye.org | 310-623-4466