

FALL 2013

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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RESEARCH

Is Corneal Crosslinking for You?

The good, the bad and the watched pot

Corneal crosslinking (CXL) strengthens the cornea using riboflavin eye drops and ultraviolet light to crosslink the cornea's collagen fibrils, making them stronger and more rigid and halting the progression of keratoconus (KC). The procedure has been approved in more than 450 medical centers around the world — none yet in the United States. Researchers, including those supported by DEF, are hopeful this will change within the next few years, as clinical trials of CXL across the country move forward toward FDA approval.

The good news for those with KC, post-LASIK ecstasia and corneal ulcers: The US trials are taking place in 26 states and are relatively easy to access. "Before 2008, when the clinical trials started, patients had to go to Canada or Europe for the procedure," says Cathy Warren, executive director of the National Keratoconus Foundation (NKCF). Read more.

PROFILE

Keracotonus, Chickens and the Pacific Coast Trail

The first thing Leslie Dow said when her middle son told her he couldn't see was, "Pull over."

It was three years ago, and Dow was visiting her son, Thelen, in Boulder, Colo. Twenty-one-year-old Thelen was driving them through the mountains when he said, "Mom, I can't see anything. Everything here looks like fluffy green clouds."

After she took the wheel, Dow immediately drove Thelen to LensCrafters. "They kept re-evaluating him; we were there for hours," she says. "Eventually the optical technician came out and said, 'We don't have the tools to figure out what his



vision is. It's that bad.' The optometrist said she thought he might have keratoconus, but she wasn't sure and told us to go to an ophthalmologist." The next thing Dow did was whip out her phone to look up *keratoconus*, since she'd never heard of it. The first website that came up was the National Keratoconus Foundation.



When Thelen moved back to Northern California nine months later, their family doctor referred him to an ophthalmologist, and he was quickly diagnosed with keratoconus.

"My oldest son was diagnosed with Type 1 diabetes during his first year in college," Dow says. "As bad as diabetes is for Philip, he has it completely under control. Everybody knows about diabetes. Because nobody knows about KC, it's very frustrating. Even when you try to explain it to someone, they just look at you like you're a bug. People don't understand how bad it is to not be able to see." Read more.

DEF NEWS

DEF Partners with UCI

New gift establishes Discovery Center for Eye Research

DEF has enjoyed many successes since its founding in 1970, from funding groundbreaking eye research, to developing internationally recognized patient education and outreach programs for agerelated macular degeneration (AMD) and keratoconus (KC). As a result of these successes, we expanded our collaboration with the University of California, Irvine, earlier this year. DEF invested \$3 million to establish the Discovery Center for Eye Research at the Gavin Herbert Eye Institute (GHEI).

GHEI will be able to leverage DEF's experience, success and reputation to help move research quickly toward treatment and cures and establish itself as one of the premier eye centers in the United States. In addition, DEF's program staff will be an integral part of increasing patient care and support at GHEI by providing guidance and information for patients with AMD and KC.

DEF will continue to work out of our Los Angeles offices, providing outstanding education and outreach, while seeking research-funding opportunities that will lead to new treatments and cures for eye disease.

New AMD Support Group in Orange County

The Macular Degeneration Partnership launched its third Southern California support group. The Orange County Support Group meets the second Monday of each month at the Michael Rodgers Senior Center in Huntington Beach. Attendance has been building, and several other organizations, including the Braille Institute and Enhanced Vision, have provided speakers to share tips for living with low vision and demonstrate assistive devices. For more information about AMD support groups, call (888) 430-9898, or visit www.amd.org.

EVERYDAY SOLUTIONS

Easy tips for dealing with vision loss

How to Apply Eye Drops in 12 Easy Steps

If you use eye drops or ocular ointments incorrectly, they may not help you. Here are 12 easy steps to ensure your eye medicines get where they need to go:

- Before using eye drops, wash your hands with soap and warm water. Dry them with a clean towel.
- 2. If you are putting in your own eye drops, lie down or use a mirror.
- 3. Look up to the ceiling with both eyes. Avoid touching the dropper tip or ointment tube against your eye or anything else; the applicator must be kept clean.
- 4. While tilting your head back, pull the lower lid of your eye down with your index finger to form a pocket. Hold the eye-drop bottle or tube in your other hand (if necessary, rest part of your hand on your forehead to keep it steady).
- 5. Place one eye drop or a small amount of ointment inside your lower lid. The tip of the medicine bottle or tube should not touch your eye.
- 6. Keep the eyes closed (without continued blinking) for two minutes to allow better penetration and effectiveness of the medication.
- 7. Blink and dab away any excess fluid with a tissue.
- 8. If you have trouble telling if you got the drops in, try refrigerating the bottle. That way you will feel the drop and know you got it in properly.
- 9. If you are prescribed both eye drops and an eye ointment, use the eye drops first.
- 10. If you have more than one type of eye drop to put in your eyes, wait about five minutes after the first medicine before putting in the second.
- 11. Replace and tighten the cap on the drop bottle or ointment tube. Do not wipe the tip or tube.
- 12. Immediately after using the eye drops, wash your hands to remove any medication that may be left on them.

If you have any questions about your medication, talk to your eye doctor.

TECHONOLOGY

Keep Track and Hangout

Keeping track of the where and when in your life has gotten easier for those with vision issues. Google Calendar has been enhanced to enable blind and low-vision users to view and edit the contents of their Google Calendar on the web with their existing screen reader. (Note: Google Calendar fully supports ChromeVox and Windows IE9/JAWS; other browsers *may* work.) Google Calendar can also sync with desktop programs such as Microsoft Outlook. No extra software is needed.

For more information on setup and navigating, please refer to the links below:

- Using Google Calendar with screen readers
- Google Calendar keyboard shortcuts
- Google Calendar sync for Microsoft Outlook

Another useful Google item for the visually and hearing impaired is the online chat feature "Hangouts," previously called Gmail Video Chat. Hangouts is also a great tool for sign-language speakers and is free to anyone with a webcam and a Gmail account; just download and install the Hangouts plugin. Group chats can include up to nine participants. If you don't have a webcam, you can still have a voice chat. For more information about setting up and using this feature, click here.

NUTRITION

White After Labor Day (and Before)

This issue brought to you by the color white

White fruits and vegetables are colored by pigments called anthoxanthins, which may help lower cholesterol and blood pressure. Onions also have the flavonoid quercetin, known for its anti-inflammatory properties and cardiovascular health benefits. Being heart-healthy is always eye-healthy.

Some members of the white group, such as bananas and potatoes, are also good sources of potassium. The hard-shelled coconut is considered a "superfood," because its natural water is loaded with vitamins, minerals and electrolytes, while the raw coconut meat (flesh) found



around the inside of a coconut shell contains high levels of lauric acid, which reduces cholesterol and promotes brain health.

For a great way to get in a double-whammy of whites, try our new recipe for <u>Cauliflower Pie in a Potato Crust at Eye Cook</u>.

Members of the white group include:

Bananas
 Cauliflower
 Coconut
 Garlic
 Ginger
 Jicama
 Mushrooms

Onions
 Parsnips
 Pears
 Potatoes
 Radishes
 Shallots
 Turnips

CULTURE CORNER

Theatre by the Blind Changes Perceptions



Changing Perceptions uses theater to educate the public about misperceptions surrounding the visually impaired. A program of CRE Outreach in Los Angeles, <u>Changing Perceptions</u> works with youth, teens and adults. CRE Outreach partners with local service agencies, helping participants overcome their disability through theater, "while promoting social skills, independence and confidence that can translate into an increased quality of life."

CRE's adult program, Theatre by the Blind, is the country's only theater group composed entirely of blind actors. Adults meet seven

hours each week to create an original play — from character and backdrop creation to writing songs to performing. Artistic director Greg Shane founded the company seven years ago as "a tool for empowerment" and a way to provide an opportunity to participate in theater for people who might not be able to access it otherwise.

Audience members often forget the performers are blind, Shane says. "The actors commit the stage to memory during the rehearsal process — where the couch is, where the table is — and we use a series of intersecting mats on the floor, so they can feel the texture, which helps guide them around the stage." They also find creative ways to write sound cues directly into the show: For example, an actor might put a glass down on a table, and that sound acts as a cue to a fellow actor.

"A lot of our audience is vision-impaired, as well, so we are very sensitive to creating detailed descriptions in the dialog when we write the plays, so those who can't actually see the performers can see the show in their minds," Shane says. "We've found that vision-impaired audience members get really into the performances. They're the ones who laugh at every joke!"

Theatre by the Blind stages two to three major shows — which usually sell out — plus shorter runs each year. Shows are performed in Los Angeles; for information about performances, click here.

VISION LEGACY

Today's the Day

These articles offer timely ideas and tips about estate and gift-planning options.

The Perfect Gift for 2013: Now is the Prime Time to Donate Appreciated Property

Do you have property you have owned for more than one year that costs more than you paid for it? If you sell that property, you will owe capital-gains tax on the appreciation. And with the 2013 capital-gains tax rate at the highest it has been since 1997, charitable gifts of appreciated property make sense more than ever before. Read more.

Do as They Did: Three Smart Celebrities

These famous folks have all earned A-list status, but they also deserve high marks for creating solid estate plans. Read more.

What Happens to Your Will After You're Gone?

You know it's important to have an up-to-date will so your wishes are carried out as you intend, but how exactly does that happen? Find out what steps are taken after you pass away ... from sending your will to court to dividing up your assets. Read more.

Young but not Immortal

Like many young couples, Kate and Brian Thompson kept putting off drawing up their estate plans ... that is, until her mother died unexpectedly, and they began pondering their own mortality. Don't let life's unexpected turns catch you off-guard! In five easy steps, you can put your estate in order today. Read more.

CONTACT US

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