



DISCOVERY

THE DISCOVERY EYE FOUNDATION



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.

CXL Trials

Collagen crosslinking (CXL) is the most promising technique to slow or stop the progression of keratoconus and post-LASIK ectasia. It uses riboflavin and ultraviolet light to strengthen the cornea by increasing the crosslinks within the collagen fibers. While CXL is used in many other countries around the world, it is still in the FDA approval process in the United States. Many clinical trials are evaluating CXL in the United States. For a list of trial sites, please visit www.nkcf.org.

Thanksgiving 2012

RP Trials as Soon as 2013

Treatment for RP moves forward, shows promise for AMD

A team led by DEF-supported researcher Dr. Henry Klassen, an associate professor in the Gavin Herbert Eye Institute at UC Irvine (UCI), is conducting pre-clinical work and preparing an FDA application for human clinical trials on a project called "Retinal Progenital Cells for Treatment of Retinitis Pigmentosa." The clinical trials could begin at UCI and collaborating centers as soon as late 2013. This is the next highly anticipated phase of this project, which began its discovery research stage in 2006, when DEF brought Klassen to UCI to begin this research.

"We're starting with treatment for RP, and we hope to expand it to dry AMD, then wet AMD."

Retinitis pigmentosa (RP) is a group of hereditary blinding disorders that begins with the loss of rod photoreceptors in the retina. Klassen's project shows rod photoreceptors can be replaced in the degenerating retina using a type of stem cell called a retinal progenitor cell (RPC). These cells also can rescue poorly functioning photoreceptors already present in the RP retina. RPCs can be grown in the laboratory from immature retinal tissue (Klassen's approach) or, under certain conditions, generated from embryonic or other stem cells. The goal is to use RPCs to slow the degenerative process and, hopefully, resuscitate photoreceptors that have stopped functioning but are still alive, and bring those back into a functional status to augment the RP patient's visual capabilities.

Those with RP are not the only ones who will benefit from this project. According to Klassen, this is exactly the same process that would be used to treat patients with age-related macular degeneration (AMD). "It's a progression: We're starting with treatment for RP, and we hope to expand it to dry AMD, then wet AMD," he says.

If all goes according to plan, clinical trials in humans may be under way for a treatment for AMD within the next two years. "The animal

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RP Trials as Soon as 2013

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models and all the testing we've done on these cells is the very same testing we would do to justify use in AMD or any other retinal degenerative disease that involves photoreceptors," Klassen says. "We think the cells we've developed and the animal testing we've done should qualify our cells for use in AMD directly. The only thing we need to do is ask the FDA to expand the scope to include folks with AMD. To do this work and to conduct specific AMD trials, we'll need FDA permission, AMD criteria — and money."

The project continues to move forward and provide hope for both RP and AMD patients, thanks, in part, to a grant this year from California Institute for Regenerative Medicine (CIRM) for \$17.3 million. If not for initial funding and ongoing support from DEF, however, this project might never have progressed or even been eligible for the CIRM grant.

As Klassen explains, grant money often comes with very strict constraints that can slow the progression of research. "In reality, we need more flexibility to move forward efficiently," he says. "DEF provides us with the flexible support we need to move toward cures."

Weisz Named Lifetime Trustee



Sylvia Weisz was named a lifetime trustee of The Discovery Eye Foundation. While Weisz (who turned 100 in 2011) was diagnosed with AMD only about a decade ago, she has been a member of the DEF board of directors since the organization's founding.

"Sylvia is part of the DEF family," DEF Medical Director Dr. Anthony Nesburn says. "She has been there since day one, and many of our great achievements in research and education never would have been possible without her support and dedication throughout the years."

Read more about Sylvia Weisz online in our winter 2012 newsletter.

Google's Little-Known Accessibility Extensions

Google introduced a new tool for people with low vision: ChromeVis. It's a free, customizable extension for the Chrome Web browser that lets you magnify and change the color of any selected text on a Web page. The magnified text displays in a separate lens and preserves the original page layout. You can change both the lens text color and the lens background color. ChromeVis is available at the Chrome Web Store at www.chrome.google.com/webstore (type "ChromeVis" in the search window).

Chrome offers a number of options and accessibility extensions for those with low vision. Some favorites:

Full-Page Zoom (in the Chrome Page menu): Page-zoom level will be remembered for each domain, so if you increase zoom for a website page, the zoom level

will automatically be increased for all pages on that site (with the same domain).

Adjusting Font Face and Size (in Google Chrome Options, choose Under the Hood, then click the Fonts and Languages button): This lets you set the minimum font size for Web pages, as well as colors and fonts.

ChromeVox (download through the Chrome Web Store): ChromeVox is a powerful screen-reader. Please note: It is still being developed, and at press time, it did not work in conjunction with desktop screen-readers, so disable your screen reader when using ChromeVox.

Stay tuned: Our winter e-newsletter will feature some cross-browser Internet tips and tricks for those with low vision. Make sure we have your e-mail address!



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The information published in the DEF newsletter is intended to help you better understand various eye diseases and available treatment options. DEF does not sell or endorse products, treatments or procedures. Every effort has been made to ensure the accuracy of the information presented. It is not intended to be a substitute for the advice and recommendations of your professional eye-care providers.

DEF 2012 Highlights

- Welcomed two new board members, Jim Hart and Wendy Seretan, and a new lifetime trustee, Sylvia Weisz.
- Honored director Arthur Hiller, who has AMD, with the screening of his war classic, *The Americanization of Emily*.
- Was instrumental in the Gavin Herbert Eye Institute at UCI, which started construction.
- Dr. Henry Klassen received \$17.3 million from CIRM to move his stem cell therapies for retinitis pigmentosa into clinical trials in 2013 (see front page).
- Dr. Cristina Kenney discovered a higher incidence of AMD in Ashkenazi Jews. She will investigate further through research partnerships in the United States and Israel.
- Expanded our worldwide reach with three Facebook pages, YouTube, Twitter, and the addition of Pinterest and LinkedIn pages.
- NKCF launched a new website; MDP and DEF will follow in 2013.

NKCF 2012 Highlights

- Awarded the Leonard Bronstein Award from the Arizona Optometric Association for service to the keratoconus community.
- Sponsored KC Patient Education Seminars in California, Florida and New Jersey.
- Distributed more than 2,600 KC information packets and 400 corneal-transplant booklets.
- Sponsored a roundtable of KC researchers at the Association for Research and Vision in Ophthalmology (ARVO).
- Expanded our virtual reach:
 - more than 200,000 visitors to www.nkcf.org.
 - sent E-News & monthly E-Updates to 10,000 subscribers.
 - 2,900 KC-Link subscribers.
 - 5,000 NKCF Forum subscribers.
 - 3,600 Facebook friends.

MDP 2012 Highlights

- Ran monthly support groups in Southern California, with Orange County to be added in 2013.
- Partnered with the Braille Institute, Center for the Partially Sighted and Enhanced Vision to present low-vision seminars throughout Southern California.
- Launched "Give Your Sight a Hand" campaign at the 2012 AARP Event and Expo during International AMD Week (see back page).
- Visits to www.amd.org increased 70 percent over 2011; visitors live in 187 countries and territories on six continents.
- 25 new people subscribed to AMD Update every week.
- MDP's Facebook likes increased by 200 percent.

contributors: Judi Delgado, Susan DeRemer, Lauren Hauptman, Melissa Juarez, Dr. Anthony Nesburn, Cynthia Ruiz, Catherine Warren

Set for Sight at the Beach

Aman Shastri likes basketball, swimming and the beach. Most of all, though, like many teenage boys, he likes video games. “I play video games with any extra time I get between doing my homework, going out with friends and spending time with family,” the 17-year-old says.

That’s not *entirely* true: There’s the time he spends organizing his very own annual fundraiser, “Set for Sight,” which raises money for the National Keratoconus Foundation (NKCF). Aman has had keratoconus (KC) since he was nine, but he is rather nonchalant about his condition, insisting it hasn’t changed his life much, other than having to sit in the front of the classroom in school, not being able to see underwater (he can’t wear his hard contacts while swimming) and “just a couple of minutes every day to put my contacts in, but really, that’s it.”

Aman comes from a very large, very close-knit family that both supports him and reminds him how important it is to help others. Before he had his first corneal transplant earlier this year, his Aunt Nimisha sat him down and said: “Aman, in life, we each have our own challenges to face, and this is yours, but something can be done. Eye-care specialists are better able to understand and treat KC because of research that is supported by organizations such as NKCF. Fundraising for NKCF is the perfect way for you to give back.”

“I wanted to put a positive spin on a difficult situation, and create an opportunity for him to make a difference,” Nimisha Shastri says. “Many years ago, there wasn’t



much that could be done. I wanted Aman to realize how lucky he is.”

She also suggested that, since Aman would be dealing with KC for the rest of his life, he should consider hosting a fundraiser that becomes a recurring event. And so began the planning for “Set for Sight,” Aman’s beach party, which took place on June 23 at Huntington State Beach Park in Southern California. He has raised nearly \$7,000 for NKCF and KC research.

In addition to volleyball, Frisbee and refreshments, the party included a short presentation by a family friend who is an optometrist — the person who first noticed Aman’s keratoconus several years ago. Dr. Arti Shah explained KC to some 75 attendees, mostly Aman’s friends and family.

“Arti really understands KC and what I’m going through, and she helped everyone there understand, too. She took a piece of Saran Wrap, folded it four times and had everyone put it over their eyes so they could see how I see. That was a pretty cool trick,” Aman says.

“I’ve had keratoconus since I was very young, and I always think about other people who are either less fortunate than me or don’t have enough money, so they don’t have treatment options. And there’s still no cure. I want to make this an annual event, so I can help NKCF make a change.”

To make sure you’re on the guest list for next year’s “Set for Sight” beach party, e-mail info@nkcf.org.

Threading the Needle Blind

There are two ways to thread a needle: The first is to try to maneuver a piece of thread directly into the eye of the needle; the second is to hide the end of the thread between your index finger and thumb, then slip the needle, eye perpendicular to the thread, down between those same two fingers until it just catches the thread. Montana jewelry artist Souther uses the second method, called “threading the needle blind.”

“For some reason, it almost always works,” she says. “I’ve always done it that way. I’ve never tried to look for the eye of the needle. Good thing, since I couldn’t find it now without a microscope!”

Souther is a bead-weaver who creates intricate, unique and beautiful jewelry from beads and thread. She has been diagnosed with age-related macular degeneration (AMD) twice — the first time when she was just 41 years old. Despite the drusen already present in her eyes, her then-ophthalmologist told her, “You don’t have anything to worry about until you’re really old.”

So, for 10 years, Souther didn’t even think about AMD. She’d forgotten about the first diagnosis when a new ophthalmologist told her she has AMD a decade later. He immediately sent Souther to a retinal specialist, who said she had maybe 2–10 years of good vision

left. Souther’s first thought: “I have to work as hard as I can and as fast as I can to get all my art accomplished.”

Souther’s AMD is dry, and her current ophthalmologist wants to be notified immediately of any vision changes, saying, “If it changes to wet, we can treat it right away.” This doctor also thinks her “good vision” could last much longer than her previous diagnosis led her to believe.

While that is a relief, Souther is still wasting no time. She now checks her Amsler grid every single day, one eye at a time, and is writing down all her beading patterns “so there will be a history, a legacy.”

In that spirit, she has been collaborating with her mother, author Diane Elliott, and photographer Linda Mitchell Griffith on a book called *Art & Inspiration*. It’s a memoir and exploration of Souther’s jewelry and inspiration. “It shows my art and my stories in juxtaposition,” she says of the coffee-table book. “I created it for two reasons: I have a short amount of time to be an artist, and at age 53, I need to become more known as an artist so people will be interested in my work; and I want to raise money for research on macular degeneration.

“The most important thing to me is to raise funds through the sale and promotion of the book for The Discovery Eye Foundation’s AMD



Jewelry artist Souther is raising money for DEF’s research on macular degeneration through the sale of her book, *Art & Inspiration*. For information, visit www.thesouthergroup.com.

research. I rely on DEF’s Macular Degeneration Partnership for information; I read their newsletters and often visit www.amd.org. If there’s a chance science can come up with a cure or a treatment that will prevent the loss of central vision, I want to help with that. Because, honestly, I’d just prefer not to be blind.”

"Give Your Sight a Hand" Launched at AARP

The annual AARP Event and Expo drew more than 15,000 people to New Orleans this past September. As usual, DEF's Macular Degeneration Partnership (MDP) was there to educate seniors all about age-related macular degeneration (AMD).

Visitors were drawn to the MDP booth by the chance to get a free souvenir photo postcard of themselves standing in front of one of New Orleans' iconic French Quarter balconies. Hundreds waited on line; the MDP booth was the highlight of the convention.

While there, visitors were asked to take another photo for MDP's new awareness campaign — "Give Your Sight a Hand" — which launched at



Incoming AARP President Robert Romasco and his wife, Audrey Romasco.

the expo. MDP is encouraging everyone to check their vision regularly one eye at a time. Since our two eyes help each other out, we may never notice a vision problem unless we check one eye at a time.

MDP took more than 700 pictures of seniors who chose to give their sight a hand by holding one hand over one eye. This is precisely

what you should do at home while looking at an Amsler Grid to check your vision every day.

These photos will be used with thousands of others of people checking their vision. During the next two years, the program will expand to include celebrities and people of all ages on a unique website, billboards and public-service announcements. You can participate, too. Just take a picture like the one shown here, and e-mail it to contactus@amd.org. Please be part of "Give Your Sight a Hand"; visit www.amd.org for updates.

This project is supported by an unrestricted educational grant from Genentech Inc. and by a grant from AMD Alliance International.

Visit our website: www.discoveryeye.org

New NKCF Website



The new NKCF website provides better access to unbiased keratoconus information for 20,000 monthly visitors. The site is easier to navigate and includes a new section for videos and interviews. A new format for the NKCF Forum online community

arranges topics in a moderated discussion-board platform. If you've been a member of the forum in the past, you'll need to sign on again the first time you use the new format. Visit us at www.nkcf.org.



and help millions of people dealing with eye disease.

Make a donation in honor of family, friends and business associates this holiday season with a contribution to The Discovery Eye Foundation.

To send tribute cards or order gift enclosures, please contact Susan DeRemer at (310) 623-4466 or sderemer@discoveryeye.org.