



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.

Board Members are "Best Doctors"

DEF board members Drs. Anthony Nesburn, David Boyer and James Salz were named as "Best Doctors in SoCal" in the *Los Angeles Times Magazine* on Oct. 4, 2009. Best Doctors is a peer-to-peer survey that identifies specialists "considered by fellow physicians to be the most skilled in their fields and most qualified for reviewing and treating complex medical conditions." Only five percent of doctors in the United States are included on Best Doctors lists nationwide.

Spring 2010

CXL Research Shows Promise

DEF supports important work on keratoconus treatment

In 2003, a group in Dresden, Germany, published preliminary studies demonstrating that a crosslinking (CXL) technique could increase the stiffness or rigidity of corneas and suggested this method might be helpful in treating thinning corneas and keratoconus (KC), which is a progressive corneal thinning that first shows up when patients are in their 20s and 30s.

Research has shown that keratoconus corneas have increased levels of degradative enzyme activity that make the cornea thinner. These corneas also have oxidative damage that causes breakdown of the cornea due to harmful free radicals and superoxides. More recent studies show KC corneas lack important structural supporting fibers, so the anterior cornea is destabilized, weakened and thinned.

Keratoconus corneas lack important structural supporting fibers.

CXL involves treating the thin cornea with Riboflavin and ultraviolet A light, which increases the crosslinking of the corneal collagens and makes the cornea more resistant to enzyme degradation. This treatment has been used in Europe, South America, Australia and Asia on hundreds of patients, delaying the need for corneal transplant in many. In the United States, there are ongoing clinical trials investigating the CXL treatment.

DEF is involved in furthering the research of CXL. DEF-supported researchers M. Cristina Kenney, MD, PhD, and James V. Jester, PhD, have shown there is a relationship between stretching corneal cells and oxidative stress that causes damage to cells and tissues. They have also shown that stretching corneal cells stimulates them to produce reactive oxygen species (free radicals), which can lead to increased activity of degradative enzymes and cell death. Scientists theorize that crosslinking makes the cornea more firm, as the cells are not stretched, and there is less enzymatic degradation and cell death. *To learn more about current CXL research, please read the longer version of this article (see below).*

Please visit www.discoveryeye.org/spring10.html for a longer version of this article.

6222 Wilshire Blvd., Suite 260
Los Angeles, CA 90048
(310) 623-4466
fax (310) 623-1837
contactus@discoveryeye.org
www.discoveryeye.org

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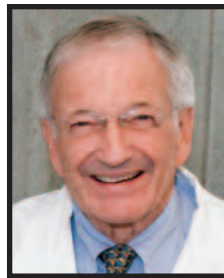
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* deceased



Anthony B. Nesburn, MD, FACS
Medical Director

From the Medical Director

Spring is a time of renewal and change, and we are making some subtle but important changes to our newsletters for 2010. As you may know, we will be publishing two print versions and two online-only versions of our newsletter this year (see the back page for more information). This will help ensure as much money as possible goes directly to our research and outreach programs. And as part of our ongoing

commitment to provide the most up-to-date and useful information for living with and preventing eye disease, we are also adjusting our content a bit, to include more about what is happening in the eyecare world at large, as well as key information about eye-healthy living. Additionally, we'll keep you updated about our work through our new "Funding Update" (below).

Change is also in the air for DEF's board of directors. As we welcome our newest board member, Cassie DeYoung, we also mark the departure of Dr. Allen Posner. Allen joined the board in 2001, and his hard work and dedication have been pivotal to DEF's continuing success. Thank you, Allen.

FUNDING UPDATE: 2010 DOCKET

In addition to providing funding for education and outreach through the National Keratoconus Foundation and the Macular Degeneration Partnership, DEF funds research in many vision-related areas. Key projects being funded for 2010 hope to:

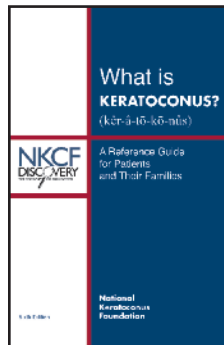
- identify and study how mitochondria affect vision loss in patients and families with AMD
- study the effects of Benzo Pyrene (a toxic smoking component) on an AMD model
- study factors that may lessen anti-VEGF injection frequency in AMD patients
- further develop clinical-grade human retinal progenitor cells (hRPCs), a type of stem cell, allowing us to optimize their growth, storage and clinical use
- prepare and use hRPCs for FDA clinical trials as part of the program of preventing vision loss in AMD and retinitis pigmentosa
- determine the interaction of two specific genes, IPOC and LAT, and how they might "lock" the herpes virus into the dormant state, preventing reactivation
- improve a test vaccine for immunization and treatment of ocular herpes prior to FDA review
- determine the potential of using human umbilical-cord stem cells to restore normal corneal structure and diminish scarring
- study the structure of the human optic nerve in relationship to the pressure-induced deformation from glaucoma, and how they both relate to vision loss in glaucoma



National Keratoconus Foundation Resources Open Eyes

The most important need people have when they are diagnosed with keratoconus is the need for information,” says Cathy Warren, executive director of NKCF. “Patients’ first question upon diagnosis is, ‘What is it?’”

That’s why NKCF is so important. “We provide unbiased and reliable information. From our *What is Keratoconus?* booklet to our website at www.nkcf.org — both of which will soon be available in Spanish — all our materials are presented in easy-to-understand, lay terms,” Warren says. “We provide patients with information and support that nobody else provides, free of charge.” Additionally, NKCF newsletters give updates on contact lenses and treatment options, and the toll-free “warm line” offers personal support, information and referrals.



Johanna Tooke was diagnosed with keratoconus seven years ago, but only recently discovered NKCF. “I have been beside myself that I never attempted to research KC on the Internet,” she says, calling her new experience with the organization “eye-opening.”

As her KC progressed, Tooke’s mother, who also has KC, urged her to call her doctor for advice. “The doctor’s assistant had an arsenal of ideas, and one of them was NKCF,” Tooke says. “I appreciated the clear, concise approach of the NKCF pamphlets. My education increased greatly with both the information and diagrams.”

Tooke also utilizes the NKCF website. “I research doctors who prescribe the contacts made by companies who sponsor NKCF. I’d had no idea there were contacts made especially for keratoconus,” Tooke says, adding her gratitude for another popular feature on the site: “There is a box at the top of the site showing how people with KC see. I was eager to show my husband to help him understand — *finally* — how I see the world.”

NKCF’s website offers a wealth of resources, from treatment information, to referrals to physicians with expertise in KC, to support programs and networks such as KC Link and KC Forum. The Resources menu even provides help with insurance reimbursement.

“Many patients find it is an uphill battle to get insurance benefits to cover their KC exams and treatment,” Warren says. “The site has a downloadable letter that explains KC to insurance companies, as well as a form for their eyecare provider to complete.” Patients can submit these to their insurance carriers when requesting reimbursement.



“I never would have known it was possible if I had not found it on the NKCF site.”

Jerilyn Glanzman Wyatt was diagnosed with KC more than 30 years ago. A member of KC Link, Wyatt was visiting the NKCF website when she

saw the link labeled “insurance reimbursement.” Having struggled with the expense of her KC exams and costly contacts, she was intrigued.

“According to the site information and the forms, health insurance should pay for my KC exam and contacts,” Wyatt says. But when she called her insurance company, she was told they would not cover her costs since she does not have eyecare insurance. Undeterred, Wyatt downloaded the forms from NKCF, filled them out, had her doctor fill them out, and sent them to her insurance company.

“They paid! They wound up paying for my whole exam and half my contacts,” she says. “I never would have known it was even possible if I had not found it on the NKCF site.”



Macular Degeneration Partnership Collaborates With Braille Institute

We all do better with a little help from our friends, and the Macular Degeneration Partnership (MDP) is no exception. A specialized organization, MDP has a much broader reach when partnering with other organizations, such as the Braille Institute.

MDP's expertise in medical information and research is a great complement to Braille's leadership in resources and techniques for dealing with low vision. The organizations have worked together for many years; recently, MDP Executive

Director Judi Delgado has been traveling around Southern California to senior centers, libraries and retirement communities, taking part in Braille's free four-week seminars on dealing with vision loss and daily living. MDP is the kickoff speaker at each location, with Delgado teaching attendees about macular degeneration, why they get it and what they can do about it.

"Many people just don't realize there are many daily steps that can help slow the progression of macular degeneration," Delgado says.

"Collaborating with Braille and participating in the seminars help us get the message out."

Sharon Zeigler, Braille's outreach coordinator, agrees: "We're glad to have partners such as MDP to help us spread the word in the community about free services available to people with low vision."

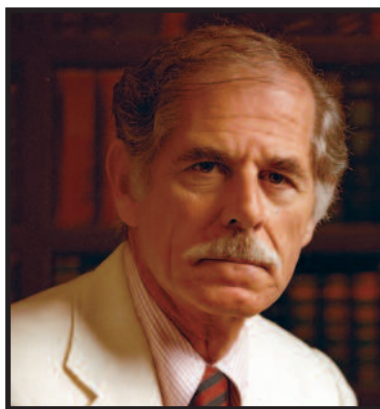
For more information, please call MDP at (888) 430-9898 or visit www.amd.org. To reach the Braille Institute, call (323) 663-1111 or visit www.brailleinstitute.org.

The Macular Adventures of the Lawyer-to-the-Stars

Ed Blau taught his kids to think of setbacks as new adventures. And that's exactly how he's approached his macular degeneration.

Blau discovered he has AMD in 2005 while looking at an Amsler Grid, something he does regularly to monitor his vision. In the years since, he's had cataract surgery and receives regular Lucentis injections in both eyes. He began attending MDP support groups and seminars, where he has learned about assistive devices and treatment updates; he also attended the DEF Los Angeles Vision Symposium.

Blau uses reading and magnifying glasses, as well as a Sapphire portable video magnifier, to minimize AMD's effect on his life. A prominent entertainment lawyer for many years, Blau seldom takes a vacation, spending his off time reading, watching TV and going



to the movies; losing his sight was not something he wanted to consider.

The Bronx, NY-born Los Angeles resident began his law career at the MCA talent agency in New York and has since represented such household names as Bobby Darin, Rock Hudson, Nat King Cole, Fred Astaire and Johnny Mathis (you can even find him at www.johnnymathis.com, under "Backstage"). Blau started his own entertainment-law firm several years ago; he currently represents The Caucus for Television Producers, Writers and Directors, and The Magic Castle, as well as many other people and companies in music, television and movies.

Blau has no plans to let his AMD — or anything else — slow him down, applying his lifelong philosophy to every bump in the road: "I look at these things as new adventures, as challenges."

FROM LAB TOUR TO BOARDROOM

Cathryn DeYoung went on a tour of DEF's Morris S. Pynoos Eye Research Laboratories at UC Irvine a year ago. "It's amazing — the amount and types of research being done in different areas is mind-boggling," she says. "I was so impressed, and I realized it's something with which I want to be involved and help."



"I hope to let people know this type of research takes time and financial commitment."

Indeed, DeYoung, who has been a DEF donor for the past few years, decided to take her involvement to a higher level: She is the newest member of the DEF board of directors, as of December 2009. The native Californian is a semi-retired litigator and former prosecutor who has served on myriad government commissions, committees and

boards. She was elected to the Laguna Niguel (Calif.) City Council in 1998, serving as mayor of the city in 2001 and 2006.

"I am very excited about the opportunity to be a board member and about contributions DEF will make to vision care in the future," DeYoung says. "I hope to help expand DEF's presence in Orange County and let people know this type of research takes time and financial commitment from the community."

"Sometimes people see these diseases as doomsday diagnoses," she says. "I want them to realize there is hope, but it takes time and commitment."

Smoke Gets in Your Eyes

Study supports link between smoking and AMD

Attention smokers: There's new ammunition in your fight to keep your New Year's Resolution for 2010 (and good for you if you've made it this long!). A recent study has found an additional link between smoking and age-related macular degeneration (AMD).

The findings of the study, which were published in the January 2010 issue of the *American Journal of Ophthalmology*, reported women who smoked had an 11 percent higher rate of AMD than women who did not smoke. They also found that women older than 80 who smoked were 5.5 times more likely to develop AMD than those who did not.

Led by University of California researcher Dr. Anne Coleman, who was a featured speaker at the DEF Los Angeles Vision Symposium in October 2009, UCLA scientists found that smoking continues to raise a person's risk of developing AMD, even after the age of 80. "The magnitude of the greater-than-additive effect of smoking on the age-adjusted risk of AMD reinforces recommendations to quit smoking even for older individuals," the study concluded.

"We've known for many years that smoking worsens macular



degeneration. Studies such as this are now revealing what a staggering impact cigarettes have on the level of risk," says

Judi Delgado, executive director of the Macular Degeneration Partnership (MDP). "In fact, if you have a family member with AMD and you smoke, you have an 8-fold increase in your chance of developing AMD."

For more information about lifestyle changes to improve your vision and reduce the effects of AMD, see "Bad Habits I Can Live Without" at www.amd.org.



6222 Wilshire Blvd., Suite 260
Los Angeles, CA 90048

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In This Issue:

Smoking and AMD

MDP's Lawyer to the Stars

DEF's "Best Doctors"

2010 Research Docket

The summer 2010 issue of
the DEF newsletter will be
ONLINE ONLY at
www.discoveryeye.org

Visit our website: www.discoveryeye.org

UPCOMING EVENTS

march 19

DEF Research-Lab Tour

Free guided tour of the Morris S. Pynoos Eye
Research Laboratories at UC Irvine, *noon-1:30 pm*

june 26

DEF Orange County Vision Symposium

Free seminar on AMD, cataracts for AMD/KC, dia-
betic retinopathy, glaucoma, KC and RP in Irvine

september 10

DEF Research-Lab Tour

Free guided tour of the Morris S. Pynoos Eye
Research Laboratories at UC Irvine, *noon-1:30 pm*

*In addition to these events, DEF, NKCF and MDP hold
various programs and support groups throughout the
year. For information about all programs and events, visit
www.discoveryeye.org, www.nkcf.org and www.amd.org.*

DO YOU WANT TO RECEIVE THE DEF NEWSLETTER?

ACTION NEEDED

The DEF newsletter is provided quarterly free of charge. Due to rising production and mailing costs, and to be environmentally responsible, **in 2010 there will be two hard-copy issues and two online-only issues of the newsletter.** While all newsletters are viewable as PDFs at www.discoveryeye.org, **the summer and winter issues will be only online.**

To ensure hard-copy newsletters reach only those who want them, we are updating our mailing list. If you made a donation to DEF in the past year, you will automatically receive the hard-copy versions. **If you have not made a gift and want to receive hard copies of the newsletter, you must do one of the following by June 1, 2010:**

- **Make a gift to DEF.** Use the enclosed envelope, or visit www.discoveryeye.org/you-can-help/donate.html.
- **Subscribe.** Visit www.discoveryeye.org/subscribe, e-mail contactus@discoveryeye.org, or call (310) 623-4466 to let us know you want to receive hard copies.