



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.

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Thanksgiving 2010

Report From AAO

Drug holds new hope of reducing progression from dry to wet AMD

Researchers at the annual meeting of the American Academy of Ophthalmology (AAO) in October reported progress in treating advanced dry age-related macular degeneration (AMD). Researchers from the New York University School of Medicine found that fenretinide, a synthetic derivative of vitamin A, nearly halved the risk of developing wet AMD in patients with dry AMD. The medication also appeared to slow the progression of dry AMD in some patients.

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AMD is a major cause of vision loss in the United States. While there are currently treatments for wet AMD, there have been no treatments available for the more common form, dry AMD. Either form can destroy the central vision used to recognize faces, read and drive. In wet AMD, abnormal new blood vessels develop under the retina, then bleed or leak fluid and form scars. Dry AMD can abruptly change to the wet form.

Fenretinide has anti-inflammatory properties, inhibits abnormal blood-vessel growth and reduces vitamin A-derived toxins. It has been used for years to treat cancers, rheumatoid arthritis and other diseases, and is considered safe and well-tolerated. The Phase 2 clinical trial included 246 patients at 30 sites in the United States; no adverse effects were found on patients’ visual acuity or eye health. ReVision Therapeutics is planning a Phase 3 clinical trial in 2011.

“We have been waiting for a long time for a treatment that could slow the progress of dry AMD,” says Dr. Anthony Nesburn, medical director of The Discovery Eye Foundation. “Through our Macular Degeneration Partnership, we work with thousands of people who struggle with AMD on a daily basis. If these findings are verified in the FDA Phase 3 clinical trial, it will make a potentially huge difference in their lives.”



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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 eyecare providers.

DEF 2010 Highlights

- Celebrated our 40th year
- Our second annual Vision Symposium, in Irvine, was attended by more than 400 people and raised more than \$155,000
- Best Doctors Inc. listed three DEF board members among the "Best Doctors in America": Drs. Boyer, Nesburn and Salz
- Received a Lincy Fdn. Grant of \$1.1. million for our Stem Cell Retina Regeneration Project
- Great Nonprofits named DEF a "top-rated health organization"
- DEF's Facebook page has more than 160 friends
- DEF is on Twitter. Follow us: @discoveryeye

NKCF 2010 Highlights

- KC-Link has 2,471 members worldwide
- KC Forum has 3,106 members
- 2,477 KC and transplant booklets were mailed to patients
- Published the sixth edition of our KC Booklet in English and Spanish
- NKCF's website is now available in Spanish: www.nkcf.org/es
- NKCF's Facebook page has more than 1,000 friends
- Recorded educational presentations are online at www.nkcf.org
- Spanish-speaking staff added to answer phone and e-mail
- Co-sponsored Patient Education Seminar in New Jersey
- Held NKCF Research Roundtable at ARVO
- Participated in two national conferences: GLSL and SECO
- Participated in LA Braille's El Poder Sin Ver Resource Fair

MDP 2010 Highlights

- Sent thousands of forwardable e-cards during AMD Week reminding members to get a dilated eye exam
- Presented more than 20 AMD seminars to community groups
- Provided patient-advocacy info at the California Association of Agencies on Aging, Retina Update meeting and South-eastern Council of Optometry
- Reached thousands of seniors at the AARP Annual Event and Expo (see p. 5)
- Shared AMD information with 14,000 people at California Women's Conference
- Increased online outreach and fundraising through Global Giving match campaign
- Launched Facebook page
- Held monthly support-group meetings in Los Angeles
- Provided real-time updates from the Retina Subspecialty Meeting at the American Academy of Ophthalmology



Creating Community Through NKCF and DEF

Jon Pynoos helps others with KC know they are not alone

When he showed up for his first cornea transplant at age 33, Jon Pynoos had never met anyone else with keratoconus (KC).

Pynoos, a Los Angeles native, had been experiencing eye problems as a college and graduate student at Harvard University, and his sight was deteriorating. It took several years and numerous doctors before he was diagnosed with keratoconus by Dr. Anthony Nesburn. It was 1965, and there was very little information available about the disease.

“When I showed up at the hospital for my first transplant, all of a sudden there were a lot of other people with keratoconus who understood what I was dealing with. Talking to people with a shared experience made me feel less alone,” Pynoos says.

“My parents realized how little was known and shared, in terms of information about how to cope with keratoconus and how little money was being spent by the government to understand the causes and find the cures,” he says. “They wanted to



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bring more attention to eye diseases in general, so they started DEF.”

Rita and Morris Pynoos founded The Discovery Eye Foundation (DEF) in 1970 as Discovery Fund for Eye Research to fund research into eye diseases. They also started the National Keratoconus Foundation (NKCF), now an outreach program of DEF, in 1986 to

serve as a forum where people could learn and share information about KC.

Pynoos, who is co-director of the Fall Prevention Center of Excellence at the Andrus Gerontology Center at the University of Southern California, continues his parents’ commitment to DEF, currently serving as vice president of the board of directors. And while he is involved with a number of charitable causes, his work with DEF is especially important to him.

“Of all the things I’ve done and really care about, this is the most meaningful, because it directly affects people’s lives in a very positive way,” Pynoos says. “Our research has come very far and is close to some breakthroughs. I just know there are cures out there.”

“NKCF provides a necessary forum for people to understand KC and exchange information,” Pynoos says. “And [Executive Director] Cathy Warren does an exceptional job helping people with KC and their families.

“I regularly monitor KC Forum and the listserv, and I see people learning from each other. They share all kinds of very useful information; that wasn’t there for me when I was diagnosed. Because of DEF, people with eye diseases don’t need to feel alone.”

Caffeine, Energy and Awareness Help E-Tailer Fight Macular Degeneration

Julie Adams has a lot of energy. Perhaps it's because the 52-year-old takes good care of herself. Or perhaps it's because she's been drinking coffee since the age of 2.

"My parents would invite people over to play cards, and I'd run around sipping coffee out of everyone's mugs when they weren't looking," Adams laughs. Her lifelong love of the drink led her to her dream job after she retired from nursing: She became a barista and opened a coffee shop with her husband in White House, Tenn.

While they sold the coffee shop several years ago, Adams has not kicked caffeine. Her latest venture is Java With Julie, an online coffee e-tailer. This business is more than meets the eye, though; she has an ulterior motive: raising awareness of macular degeneration.

With a long history of the disease in her family — 8 out of 10 of her grandfather's siblings, 4 out of 4 of her dad's siblings and her mom have had AMD — Adams was diligent about getting yearly eye exams.

"My doctor saw increasing drusen during the past 5–10 years, but I had no symptoms," Adams says. This past April, when she started seeing wavy lines while driving, she attributed it to her car window. "I kept making excuses," she says. "Until I looked out my back window, and the fence was wavy, too."

Avastin injections have been successful so far, and Adams has no plans to let AMD slow her down.

"My grandmother gave up. She said, 'I'm blind. I can no longer do anything,'" Adams says. "But my dad, who was a minister, didn't let AMD stop him from doing what



Adams gives \$1 from every product purchased at www.javawithjulie.com to DEF.

he loved. He continued to preach. He continued to travel. I was so proud of him, and that influenced me. I can't just let AMD take me over — I have got to be proactive about it. I've got to make more people aware about it."

Her site, www.javawithjulie.com, launched in July 2010 with the singular goal of raising awareness of AMD and a commitment to donate \$1 from the sale of every product to The Discovery Eye Foundation. Her Journey Blend, roasted in Tennessee, got a good response, and she's since added other flavors, as well as mugs and candles; she'll introduce gift baskets in time for the holidays. In addition to the e-store, the website includes

information on macular degeneration and nutrition.

In looking for a beneficiary for her new venture, Adams found the Macular Degeneration Partnership (MDP) after being unable to reach "actual humans" at other organizations. "Judi Delgado (executive director of MDP) has been a blessing to me. She is so warm, and she asked me about my own experiences," Adams says. "The information on www.amd.org is wonderful. I link there from my MD group Facebook page, and I use the newsletter to stay informed. Judi even told me I can watch recordings of physicians talking about AMD."

"We are so happy Julie found us and that we've been able to help her deal with her AMD," Delgado says. "We are also very excited she has dedicated herself and her business to supporting the work we do at MDP and to raising awareness of macular degeneration."

It's a no-brainer for the energetic Adams: "When I tell people I have AMD, they often say, 'What's that?' I've heard it too many times. That's just got to stop."

EVERYONE WINS AT AARP VISION PAVILION

The AARP Annual Event and Expo drew 22,000 active and engaged seniors, eager to learn and have fun in Orlando, Fla. The Macular Degeneration Partnership booth in the Vision Pavilion, which was generously sponsored by Genentech, drew them in with displays, games and demonstrations. Visitors played Spin & Win to claim sunglasses from FantasEyes and LiveEyeWear, digital magnifiers, lighted keychains and other prizes. Staff helped them with Amsler Grid screenings and distributed new brochures, which highlight the steps seniors can take to reduce their risk for AMD.

One lucky lady with AMD won the raffle for a portable magnifier

from Enhanced Vision — she was excited when she realized she could now read things she couldn't previously see — and others won a lamp from Berryessa Designs, Cocoon sunglasses and an iPod shuffle.

Perhaps the biggest winners were all the new friends we made for DEF. More than 1,500 people signed up to enter our free raffle and will receive an AMD Toolkit.

MDP Director Judi Delgado is already looking forward to next year's expo. "With AARP coming here to Los Angeles, we'll be able to include our local partners and grow the Vision Pavilion to teach even more people about eye disease," she says.



Medicare Now Covers Smoking Cessation

As part of the Affordable Care Act that was signed into law by President Obama earlier this year, Medicare will now cover smoking-cessation counseling as a preventative measure. Under the new coverage, all smokers with Medicare coverage can receive tobacco-cessation counseling from a qualified doctor or recognized clinician to quit smoking, regardless of whether they have a smoking-related disease. Previously, Medicare only offered this benefit to those who already had tobacco-related conditions.

In addition to its many health risks, smoking has been linked to age-related macular degeneration. In our spring 2010 newsletter, we reported on a recent study that found a significant increase of AMD in women who smoke. With Medicare offering extra help, now's the perfect time to quit.



Bad Habits = Bad Vision

Changing certain behaviors now can help you avoid macular degeneration in the future and improve your vision today, even if you already have AMD:

- Stop smoking
- Reduce high blood pressure
- Reduce cholesterol
- Avoid saturated fat
- Avoid processed foods

For more information about lifestyle changes to improve your vision and decrease your risk of AMD, visit "Bad Habits I Can Live Without" at www.amd.org.



Don't Miss Our Free Publications

For both financial and environmental reasons, many of our communications are now electronic — including this newsletter, which is published as an e-newsletter twice a year. **Are you signed up to receive our e-mail communications?** MDP sends monthly e-mail updates, and NKCF sends its e-newsletter in May, September and November, with additional periodic updates. DEF's 2011 publication dates below are subject to change; please be sure we have your e-mail address so we can alert you when they are available.

Your Gift Makes Our Work Possible

Please make your tax-deductible year-end donation to The Discovery Eye Foundation at www.discoveryeye.org

- February** DEF Spring E-Newsletter (electronic only)
- May** DEF Annual Report (online)
- May** DEF Summer Newsletter (print & online)
- September** DEF Fall E-Newsletter (electronic only)
- November** DEF Thanksgiving Newsletter (print & online)

Visit our website: www.discoveryeye.org

UPCOMING EVENTS

march 11

DEF Research-Lab Tour

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

may 14

DEF San Diego Vision Symposium

Free seminar on AMD, cataracts for AMD/KC, diabetic retinopathy, glaucoma, KC and RP

september 9

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.



Simplify your holiday gift giving, and help millions who deal 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.

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