# Support for DEF a Major Factor

n addition to being icons of the cosmetics industry, Max Factor and his family are icons in the philanthropy community. Through the Max Factor Family Foundation, descendants of the Oscar-winning makeup artist are generous donors to numerous causes, including medical research; scholarships for education in the fields of medicine, public health and computer technologies, particularly benefiting disadvantaged minorities and the disabled; and assistance to socialservice agencies in the Jewish and nonsectarian communities throughout Southern California.

The foundation has been among The Discovery Eye Foundation's most ardent supporters since 1986, an association that grew out of a relationship between the Factor family and DEF Medical Director Anthony Nesburn. "Tony was a personal friend of my grandfather, Davis Factor Sr., and was close friends with my father, Davis Factor Jr., for more than 60 years," says Dean Factor (pictured), a member of the board of the Factor Family Foundation.

The Factor Family Foundation has provided critical financial support to DEF for more than two decades, allowing it to



continue its groundbreaking work in research and education to combat eye disease.

"We are very proud of our association with everyone at Discovery Eye Foundation and the outstanding work they do in macular degeneration and keratoconus," Factor says. "DEF has made incredible strides in research, and their findings will help make life better for all people."



# **DEF Web Tip**

A yearly eye exam is among the most important things you can do to maintain your ocular health. If you need to find an eye doctor, the American Academy of Ophthalmology Web site, at www.aao.org/find\_eyemd.cfm, can help. (You may also want to ask your primary-care physician for a referral.)

## **Time to Review**

DEF joins GreatNonprofits Web site, solicits feedback

n an effort to garner feedback from constituents and provide information to others. The Discovery Eye Foundation has been listed on www.greatnonprofits.org.

According to its CEO, Great-Nonprofits is like an "online Zagat ... for nonprofits that collect[s] stories and reviews [by] people who have seen the impact of nonprofits up close and can speak personally and firsthand about it."

"We hope our patients, volunteers, donors - anyone who has an interaction with us - will take a moment to post a review," says

Susan DeRemer, vice president of development for DEF. "The more feedback we get, the better picture we have of what we are doing well and what we might be able to do better. It will also provide, from a constituent standpoint, a fuller picture of DEF for those who may not yet be totally familiar with us."

Visitors to the DEF Web site will eventually be able to link to the GreatNonprofits site from the DEF home page. To post and read reviews of DEF, NKCF and MDP, visit www.greatnonprofits.org, and type "discovery eye" in the nonprofit-finder window.



Los Angeles, CA 90048

#### In This Issue:

News From National Keratoconus Foundation & Macular Degeneration **Partnership** 

**Drug-Delivery Trial Shows Promise** 

DEF on GreatNonprofits Web Site

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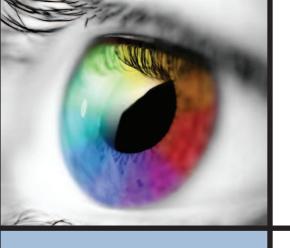
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#### **A Strong Foundation**

Financial support from foundations helps ensure DEF continues its fight against eye disease. The Allergan Foundation of Allergan, Inc. has been a consistent supporter of DEF's education programs, MDP and NKCF, since 2000. One of the largest philanthropic organizations in Orange County, CA, The Allergan Foundation supports innovative research conducted by local, national and international educational institutions.

Pictured: Allergan CEO David E. Pyott (center) presents a check to DEF Vice President of Development Susan DeRemer and Medical Director Anthony Nesburn.





Discovery Eye
Foundation exists
to facilitate the
development of cures
and improve patient
care through corneal
and retinal research
and educational
programs for
eye disease.

# **DEF Scientists at AMD Conference**

DEF-supported scientists Drs. Cristina Kenney, Henry Klassen and Anthony Nesburn were among 100 leading scientists invited to participate in a conference on age-related macular degeneration (AMD) in January. The conference was sponsored by the Arnold and Mabel Beckman Initiative for Macular Research and included sessions in which researchers from different fields collaborated and developed research plans to address new questions in the study of dry AMD.

Spring 2009

# **Neuroprotective Drug-Delivery System Shows Promise**

Brazil Safety Trial studies novel strategy

trial of a novel neuroprotective drug-delivery system aimed at slowing or halting the progression of retinal disease is under way in Brazil, and early indications are positive. In the new approach, microparticles are injected into the vitreous jelly of the eye where they slowly dissolve, preserving the retina in the face of damaging conditions or degeneration. "This strategy does not rebuild the retina the way stem cells hopefully will, but it is aimed at slowing or halting disease progression," says DEF—funded researcher Dr. Henry Klassen (meet him inside).

Klassen has been working with researchers at the University of Copenhagen on the drug-delivery system to combat optic-nerve degeneration in

animal models. They found the new method not only preserved the nerve cells that make up the optic nerve, but that those preserved cells remained functional. Researchers at the Vision Institute, Federal University of São Paulo, led by Prof. Rubens Belfort Jr.,

"Early indications suggest a modest but welcome regenerative influence."

were working with similar delivery systems for different retinal diseases. Using the technology developed by Klassen and his collaborators, the Brazilian team began a safety trial on patients with retinitis pigmentosa.

The trial is set to finish in mid-2009. "Early indications suggest a modest but welcome regenerative influence," Klassen says. If all goes well in the safety trial, researchers will look at moving to bigger trials to test efficacy and consider expanding the study to other retinal conditions.

"The expansion of this promising work will depend, in part, on finding funding," says Klassen, who is working with UC Irvine to explore the possibility of starting clinical trials in the United States.

Please visit www.discoveryeye.org/spring09.html for a longer version of this article.



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## From the Medical Director



Anthony B. Nesburn, MD, FACS Medical Director

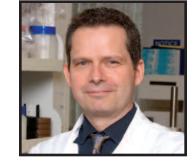
"People can make all the difference in improving the lives of their friends and loved ones with eye disease." he goal of the work we do at DEF is, of course, to help people with ocular disease. Luckily, we are not the only ones. As you'll read in the Macular Degeneration Partnership's (MDP) update, other people can make all the difference in improving the lives of their friends and loved ones with eye disease. It's not always easy to ask for help — or to give it, for that matter. Advising caregivers on how and when to offer assistance is one of the many charges of MDP and the National Keratoconus Foundation (NKCF).

We rely on help, as well, from those who fund our efforts and make our work possible. Among our most stalwart financial supporters are a number of charitable foundations. Included in this issue are stories about two of our generous benefactors, the Max Factor Family Foundation and The Allergan Foundation.

Like profilee Kevin Bosetti, we are very grateful to those who help us *and* for those we can help.

## **FOCUS:** DEF Researcher

**Dr. Henry Klassen** is assistant professor and director of the Stem Cell and Retinal Regeneration Program in the Department of Ophthalmology at UC Irvine.



**Degrees and Academic Credentials:** BA in neurobiology, UC Berkeley; MD and PhD

in neuroscience, University of Pittsburgh; medical internship, Cambridge Hospital, Harvard Medical School; residency in ophthalmology, Yale Eye Center; fellowship, Moorfields Eye Hospital/Institute of Ophthalmology.

**Areas of Expertise and Research:** development of regenerative strategies to treat diseases of the retina, optic nerve and retinal pigment epithelium.

Why DEF is Important to Your Work: "DEF has been instrumental in facilitating external funding, as well as in bringing people with specific diseases together with researchers to move research forward and get past obstacles."

**Research Goal(s):** "To bring the latest scientific technology to bear on retinal conditions and deliver new cures for people who would otherwise go blind."



# National Keratoconus Foundation Launches Web Site Poll

As part of the complete revamp it recently underwent, NKCF's Web site at **www.nkcf.org** now has a polling feature that will provide us with more information about the keratoconus community. The "Tell Us..." section in the lower left-hand corner of the home page will have a regularly changing poll.

"Our first poll is aimed at finding out about our visitors," Cathy Warren, NKCF's executive director, says. "The polls let us — and our constituents — know who is using the site. It's a great way for us to gather and disseminate information, and be responsive to site users."

In its first week, 173 people took the poll, "Please tell us a little about yourself." More than 80 percent of respondents are people with keratoconus, with the next largest group comprising those who know someone with the disease. Future polls will cover topics such as corneal crosslinking, diagnosis and progression of keratoconus, and contact lens wear.

The site offers a number of additional new features, including a monthly E-Update, past NKCF newsletters and a way to make a secure online donation to help NKCF continue its work for the KC community.

# Transplant Recipient Uses KC-Link to Give Back

evin Bosetti is grateful. He's grateful for the four corneas he's received. He's grateful for the help he's received from DEF and NKCF. He's so grateful, in fact, that he tries to give back to the keratoconus community every single day.

More than a decade after his second corneal transplant in 1994 due to keratoconus, Bosetti's vision started to rapidly deteriorate again. He found NKCF online, and soon had a list of doctors and a new way to learn: KC-Link, NKCF's e-mail-based support group. An interactive, worldwide list server, KC-Link welcomes people with keratoconus, as well as eye-care professionals, lens fitters, doctors and others.



Thousands of subscribers receive individual e-mails posted by others or a digest of them once a day.

"It's a fascinating place to learn about treatment options, types of contact lenses and practical advice on coping with KC," Bosetti says. "You can go to one place and be connected to people and doctors throughout the world and learn from their knowledge and experiences. It gives you the ability to educate yourself, so you can partner with your eye-care specialist and make the best decision for your treatment."

A bank auditor in Los Angeles, Bosetti reads KC-Link every day, looking to help others deal with the issues he's dealt with, especially those related to corneal transplants. "I learn something new on the NKCF Web site every day," he says. "I was so fortunate to have found NKCF, and KC-Link gives me the opportunity to give something back."

"KC-Link gives me the opportunity to give something back."



# Macular Degeneration Partnership to Caregivers: Understand, Advocate, Help

he diagnosis of age-related macular degeneration (AMD) rarely affects just one person. Caregivers need to understand the disease as much as the affected person. In addition, they need to learn new ways of dealing with their friend or loved one. And there are many ways in which they can help.

Asking for or receiving help can be difficult for some, no matter the circumstances. Among the many offerings of the Macular Degeneration Partnership (MDP) is its new Web site (see box), which has a section specifically targeted to family and caregivers (choose the link under "Living With AMD").

You can direct your helpers to the Web site; you may even want to save this article for the next time someone asks, "How can I help?" MDP has a three-step answer: "Understand, Advocate, Help."

#### Understand

It's difficult for a fully sighted individual to comprehend how another person sees. Because AMD affects the central vision, it takes away the most critical area of sight. We use our central vision to see faces, read books, watch television, cut our food. It's also our sharpest vision and has the best color.

No one goes blind from macular degeneration. People with AMD keep their peripheral vision — the

vision "around the edges" of the field of sight. That's why a person with AMD may see a shiny dime on the floor, but doesn't recognize her best friend standing in front of her.

To understand how people with AMD view the world, watch the video at **www.amd.org** (in the "For Family & Caregivers" section) that simulates the effect of macular degeneration and central vision loss.

#### **Advocate**

In the current healthcare environment, it is essential to have an advocate. The person dealing with a health issue is focused on the experience. You can help by being there to gather information, ask questions and make sure the patient gets what is needed.

Going to the doctor with a friend or relative can make a big difference. You can write down answers or remind your friend what he or she wanted to ask. There is a downloadable list of questions on our Web site you may want to take along.

#### Help

You can help your loved one deal with their diagnosis and disease in many ways. It's OK to ask, "How can I help?" It's OK to gather information and give it to them. Be guided by what you already know about the person: Some people appreciate a lot of help; others want to take care of everything themselves.



#### WWW.AMD.ORG

MDP's Web site at www.amd.org was redesigned with large type, high contrast, easier navigation and increased usability. There is a wealth of continually updated information about tools and resources — from medical research, to helpful devices and gadgets, to support groups — for anyone dealing with AMD.

Your relative or friend may be ready for help or may need more time. Learn how to offer help, when and how much. Find practical methods for the home, traveling, dealing with daily tasks. Locate resources and services that are available to the partially sighted.

The information you find will benefit both you *and* the person you want to help. Additionally, MDP's toll-free "warm line" at (888) 430-9898 connects callers to our professional staff, who can answer questions for both patients and caregivers.