The Corneal Dystrophy Foundation
"Focus on: Education • Inspiration • Vision"

November 2011

A Newsletter from The Corneal Dystrophy Foundation

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From the President's Corner

Monica Bellizzi, President

PATIENCE, TIME, SUPPORT ……

Patience: For the past three weeks I have been learning **Patience**. A car in the driveway and a broken bone in the right foot seem never to connect. **Time, Patience and Support** are my keys to connect with the car and a way to go out into the world...

It takes **Time, Patience and Support** when you talk about building a Foundation. To plan, build, reach those who are scared, looking for information. looking for the best way for them..

The thank you notes that the Corneal Dystrophy Foundation receives bring a lump to the throat. To allow people to ask questions and find out what they have, gather information, try to find the answers, to be comforted, to be able to share, truly makes a difference to those who find us.

In my world and I hope in yours, it is important to offer help, to bring a smile. So to in the Foundation's world, it is important to have the resources to accomplish much. Our volunteers are the keystone of this Foundation, whether you are on the Board of Directors, hosting a local group, talking on the support group's email. The digests show how each uplifts each other.

The Corneal Dystrophy Foundation is accomplishing more with firmer purpose. But we cannot do this without your support. Any monies given are spent on projects. This organization is run by volunteers without pay. Did you know that we have 14 websites?

The dollars you donate pay for brochures, Webinars, and allows us to dream.

Our wish list for 2012 is for

- A professional speakers bureau
- More webinars
- Newsletters published for those who do not have computers
- An increased Board of Directors
- More YouTube videos
- An Advisory Council of Doctors.

Patience, Time and Support. Working together with this formula causes us to accomplish our dreams and desires. Consider helping us to reach out to our "Customers", those who are scared, looking for information, and wanting to connect with anyone who can help. We can do that as long as you help and support the Corneal Dystrophy Foundation.

Inside This Issue

Physician's Corner

Natalie Afshari, MD FACS, Associate Professor of Ophthalmology, Director of Cornea and Refractive Fellowship, Cornea and Refractive Surgery, Duke University Eye Center, in collaboration with Molly Minear, Duke University Eye Center

Fuchs' endothelial corneal dystrophy (FECD) is a devastating disorder with no known cure other than to undergo corneal transplantation, a difficult decision for many patients living with this condition. FECD affects the back layer of the cornea, the endothelium, which is made of a single layer of cells whose primary function is to maintain proper ion balance in the cornea. These cells actively pump ions into the cornea and pump water out to keep the cornea relatively dehydrated in order to maintain clear vision. Although these endothelial cells naturally die as we age, these cells die off at an accelerated rate in FECD, causing the visual decline experienced by patients. Scientists are trying to figure out what causes these cells to die off more rapidly, but are still a long ways away from an answer.

Over the last decade, FECD researchers have turned to genetic studies to better understand this disease. By enrolling both patients and their family members, scientists can identify pieces of DNA that are passed down through the family along with the disease. By looking for DNA sequence differences between patients and their unaffected family members, researchers can identify which gene(s) may be important in causing the disease. So far, DNA mutations in three genes have been identified in a small number of FECD patients. The first gene, *COL8A2*, makes part of the collagen type VIII protein that is a major structural component of the corneal endothelium. Three mutations in *COL8A2* have been linked to a rare, early-onset form of FECD where patients have symptoms starting in their teens or twenties. The second gene, *SLC4A11*, makes an ion channel protein that is found on the surface of corneal endothelial cells. Although this particular ion channel is not well-studied, it seems like a good candidate given the importance of proper ion balance across the cornea. The third gene, *ZEB1*, makes a type of protein called a transcription factor. These types of proteins are responsible for turning on/off a variety of other genes in the genome, and although it is also not well-studied in the cornea the *ZEB1* protein could potentially affect the proper function of many other genes. Researchers have also identified four other DNA regions that may be important in FECD, but the causative mutation(s) have not yet been identified.

You can help advance our knowledge of FECD by considering participating in a genetic study. Scientists at several institutions, including our team at Duke University, are actively enrolling patients and their family members. The more people we enroll, the more successful we will be at better understanding this devastating disorder, which will hopefully lead to better treatments. Many of these studies do not require you to travel to participate; you can consent to participating in the study over the phone, the research team can examine your medical records to confirm your FECD diagnosis, and you can receive a free kit in the mail to have your blood sample (for DNA) taken the next time you visit your doctor. The success of future FECD genetic studies depends on enrolling large numbers of FECD patients, so please consider joining one of these studies today.

Genetic Research Studies

Duke Eye Center 919-681-9459
http://www.dukeeyecenterduke.edu/modules/eyectc_research

Wilmer Eye Institute at John Hopkins
http://www.hopkinsmedicine.org/wilmer/conditions/fuchs/

National Institute of Health
http://www.clinicaltrials.gov/ct2/info/understand

Mayo Clinic
http://www.mayoclinic.org/tcf4-fuchs-cornealdystrophy

- **Dr. Afshari, Chairman & Speaker 2009 CDF Symposium. DVD available – see attached Action Form**
- **Webinar "The Next 100 Years in Fuchs" www.cornealdystrophyfoundation.org**

Highlights of The 2011 Corneal Dystrophy Symposium & Conference (Portland, Oregon, July, 2011)

Bob Bellizzi, Executive Director

The 2011 Conference was another milestone in the growth of The Corneal Dystrophy Foundation and its mission to educate the public, patients and medical caregivers about corneal dystrophies.

We started with a Friday evening Reception at our hotel, The Crowne Plaza Portland, which included refreshments and snacks. It was a great place to meet and greet each other and to meet our speakers and exhibitors in a one on one setting. This also gave us a chance to view the sponsors and exhibitors.

One bright spot was the Story Booth where our videographers interviewed attendees who wanted to tell their journey through corneal dystrophy and the eventual bright outcome.

After a buffet breakfast on Saturday morning we spent the morning in session where two of our most talented corneal surgeon/researchers and others gave their time and talents with eye opening presentations covering:

Fuchs' The Next 100 Years; Implications of Recent Research
(Albert O Edwards, MD, PhD)

Pre-operative Evaluation and the Future of Non-Surgical Therapy
(Albert Jun, MD, PhD)

Some Questions About Donor Cornea Tissue Safety Answered
(Chris Stoeger, CDBT, CTBS Director of Operations, The Oregon Lions Eye Bank)

History of DSAEK
Techniques, Results and Complications
Future trends in DSAEK
(Mark A Terry, MD, FACS)

Eye Bank Assoc. of America Data Presentation
Signe Maximous, Board of Directors, The Corneal Dystrophy Foundation

The **Afternoon Panel Discussion** with all speakers resolved many questions from the audience. Unfortunately, it was limited to 1-1/2 hours which left some questions unanswered.

Signe Maximous contributed to our understanding of just how the 'partial transplant' (DSAEK/DSEK) has, in a short time, become the Standard of Care for people with endothelial dystrophy. Almost half of all donated corneas that qualify for transplantation were used for partial transplants, compared to next to none in 2005! A major change in surgery practices has occurred in a little over 5 years!

Saturday evening was spent with our group at dinner and strolling between tables to talk with our friends.

The entire day provided a comprehensive background and up to date knowledge base about corneal dystrophies, treatments and what to expect in the near and far future. These areas evolve over time just as any other well designed process does to meet new clinical, quality and patient care expectations.

How to Order a DVD from the 2011 CDF Symposium & Conference

The DVD has all five of the presentations that the speakers recorded from the podium and also includes the last day's panel discussions at the 2011 CDF Symposium in Portland, Oregon.

DVD cost is $50 for domestic and $60 for international orders.

The DVD will be shipped in an attractive black case with a picture of the Panelists on the front. We are receiving a limited quantity of DVD's this year. Orders will be filled on a first come, first served basis.

Four Easy Ways to Order:

1. Online on our homepage
   a. Go to our home page www.cornealdystrophyfoundation.org
   b. On left margin, click on blue box with "DVD 2011 Symposium"

2. Order by telephone
   a. 1-866-867-8965
   b. Select "order DVD information" from the audio menu.
   c. If you are asked to leave a message be sure to add your name and phone number so the volunteer can return your call.

3. Complete "Action Request Form"
   a. Complete form on page 7 and mail to us with a check made payable to The Corneal Dystrophy Foundation.

4. Order online at

   www.cornealdystrophyfoundation.org/html/2011_dvd_gift.html

What our Supporters are Saying about CDF…

"For all the hope and help you have given to others. For all the help and hope you have given to me. I am forever grateful."
Lydia

"Thank you for all of your hard work and support for people afflicted with Fuchs'. It is very beneficial to us all."
Jean

"I do want to say thank you for making this DVD possible for the people to learn from. Thanks for all that you do. It is all appreciated."
Elizabeth

"My sincerest thanks for all that you and the other board members do. I am so happy that the Corneal Dystrophy Foundation has continued to grow and support so many."
Diane

An Important Topic for Winter: Dry Eyes

Faye Liston, Vice President of Development

Did you know that just about everyone over 65 experiences some degree of dry eyes? Maybe that's why you've seen so many drug companies come to market with eye drops specifically targeted for dry eyes. Think back five years. How many types of eye drops did you see in Wal-Mart, Target, CVS, and Walgreens? Today, our choices are as diverse as our lifestyles.

Did you know that the symptoms of dry eyes increase with the winter months when we are indoors a lot more and the air is dry?

What causes dry eyes? If you are female and over 65, you are more likely to experience dry eyes. Some medications, including antihistamines, decongestants, blood pressure medications and antidepressants, can reduce the amount of tears produced in the eyes. Persons with rheumatoid arthritis, diabetes and thyroid problems are more likely to have symptoms of dry eyes. Also, problems with inflammation of the eyelids (blepharitis), inflammation of the surfaces of the eye, or the inward or outward turning of eyelids can cause dry eyes to develop. Environmental conditions such as exposure to smoke, wind and dry climates can increase tear evaporation resulting in dry eye symptoms. Failure to blink regularly, such as when staring at a computer screen for long periods of time, can also contribute to drying of the eyes. Long term use of contact lenses can be a factor in the development of dry eyes. Refractive eye surgeries, such as LASIK, can cause decreased tear production and dry eyes.

Here are a few commonsense tips that you can deploy to reduce the symptoms of dry eyes:

- Blink, blink, and blink regularly when reading or working on your computer.
- Increase the humidity level in the air around you.
- Wear sunglasses outdoors, particularly those with wrap-around frames.
- Consider adding more Omega 3 to your diet.
- Avoid becoming dehydrated by drinking plenty of water daily.

More information is available at: http://www.nei.nih.gov/health/dryeye/dryeye.asp.

Note From the Editor

Faye Liston, Vice President of Development, The Corneal Dystrophy Foundation

Great News! IRA Charitable Gift Transfers are Back! There is still time to make a unique contribution to the Corneal Dystrophy Foundation, but you must act by 12/31/2011. Congress extended the law allowing people who have IRA's and are age 70-1/2 or older to make gifts through their IRA's to qualified charitable organization such as the Corneal Dystrophy Foundation. To get detailed instructions, contact pres@cornealdystrophyfoundation.org.

In future issues, we will have regular columns featuring a note from our President, an update on the Corneal Dystrophy Foundation, topics on corneal dystrophies, a physician's column, and a column on new research and other changes that may impact the lives of those with corneal dystrophies and their loved ones.

If you have any questions or comments, please email us at:
newsletter@cornealdystrophyfoundation.org.

New Research on Dry Eyes

Now, with breakthrough technology from TearScience, it's possible to treat the root cause of Evaporative Dry Eye: a blockage of eyelid glands called Meibomian Gland Dysfunction. These blocked eyelid glands result in a deficiency in the tear film oil, which is responsible for preventing the tears from evaporating too quickly. If you have blocked eyelid glands and Evaporative Dry Eye, there's a clinically-proven treatment performed in your doctor's office that has the potential to help you maintain a normal lifestyle by reducing dry eye discomfort.

65% of patients with Dry Eye symptoms have meibomian gland dysfunction. If you're like many people with Dry Eye symptoms, your condition is related to obstructed meibomian glands and an inadequate protective layer of oils in your tears.

Tears are made up of three layers: (1) Lipid (oil) layer: lubricates and prevents evaporation; (2) Aqueous (water) layer: nourishes and protects the cornea; and (3) Mucin layer: adheres tears to the eye.

The eyelid glands called Meibomian glands create the lipid (oil) layer of the tear film. Evaporative Dry Eye disease is most often caused by a blockage or obstruction in the eyelid glands, which can lead to a lipid deficiency in the tears.

The LipiView® Interferometer

The LipiView® Ocular Surface Interferometer is a new tool approved by the FDA with which physicians can observe the tear film using digital images. This image can be captured during your office exam in about five minutes. A new and effective treatment using LipiFlow® treats the cause of Evaporative Dry Eye. The treatment involves relieving obstructions of blocked eyelid glands by applying a combination of localized heat therapy and pressure. LipiFlow's® single-use eyepiece provides controlled warmth to the inner eyelid surface, close to the location of the eyelid glands, and intermittent massage to the outer eyelid surface to facilitate release of lipid from the blocked eyelid glands.

The disposable LipiFlow® eyepiece fits around the lower lid and is shaped to prevent contact with the cornea. Once in place, you can simply recline in the exam room chair during the procedure, which takes approximately 12 minutes for each eye.

The LipiFlow® Thermal Pulsation System is a significant technological shift in evaporative dry eye treatment, effectively relieving blockage of the eyelid glands during an in-office treatment. Opening the blocked eyelid glands allows the body to resume the natural production of lipids (oils) needed for the tear film.

Ask your physician about this treatment. For more information, go to: http://www.tearscience.com.

[Information provided by TearScience]

The information published in this article is intended to help our readers become aware of new research and treatments. Every effort has been made to ensure the accuracy of this information. It is not intended to be a substitute for the advice and recommendations of professional eye care providers.

These Are Our Favorite Things

The Board of Directors: Monica Bellizzi, Bob Bellizzi, Signe Maximous, Faye Liston, Delores Axelrod, Shirley Landen and Mary Luby

- Our Donors. We are eternally grateful for your financial support. Thank you from the bottom of our hearts.
- Google, Inc. It all started with a simple Google search for most of us. What would we do without them! Thank you, Google for your generous support of our foundation through Google Grants for Nonprofits.
- The Oregon Lions Eye Bank, Portland, OR
- Nordic Naturals, Watsonville, CA
- S. KARGER AG Basel, Switzerland
- TEC-IT, Datenverarbeitung GmbH, Austria
- Almaden Super Lions, San Jose, California
- Our distinguished symposium presenters, all 23 of them at 5 events!
- Our Physicians and Their Staffs

To become a Sponsor for 2012, contact: execdir@cornealdystrophfoundation.org

Action Request Form

'X' Choices __Make a Contribution of $_____

___ In Honor of or __ In Memory of (please fill out Other Name section)

__ Ship to a Different Address (please complete info below credit card info)

DVD Order: ___ 2011 DVD ($50) __ 2009 DVD ($30) __ 2007 DVD ($20)

(All international DVD orders, add US$10)

___ Journeys with Fuchs' Dystrophy Booklet (US$5) (International, please add US$5)

Free Literature:

_____ "Visiting Your Doctor" _____ "Corneal Dystrophies" _____ "What People Say Brochure" _____ "Foundation Services Brochure"

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Country		

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The information published in this newsletter is intended to help our readers better understand their corneal dystrophy. Every effort has been made to ensure the accuracy of this information. It is not intended to be a substitute for the advice and recommendations of professional eye care providers.

To Give Hope Through Knowledge and Information

The Corneal Dystrophy Foundation

"Focus on: Education • Inspiration • Vision"

The Corneal Dystrophy Foundation supports education and advocacy related to sight-threatening corneal dystrophies. We are financed by donations from the public. Please donate.

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