

## SEASONS GREETINGS!

*A Newsletter from The Corneal Dystrophy Foundation*

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### Introduction

We thought that the holiday season would be a good time to update you on the many things that have taken place during the past year at The Corneal Dystrophy Foundation and the Fuchs' Friends online support group. We've been very busy this year; there is so much more to do and so few people to volunteer to do it all.

The first thing I want to tell you all is that we will be sending the 2009 contribution statements to all of you who contributed as soon after January 1, 2010 as we can get it done. If we have an email address for you we will email it to you. If the email bounces, we'll try your postal address. If we haven't got an email address we will mail the statement to the last postal address we have.

So here's just a quick look at what's happened in 2009, which we think was a very good year for The Foundation and Fuchs' Friends.

## 2009 Corneal Dystrophy Symposium

I think this is our most important news of the year. I am putting it at the top of the list of our accomplishments. As with almost all of the other accomplishments, we owe much to our original online Internet support group, Fuchs' Friends (FF). FF's members turn out at the drop of a hat to lend volunteer hands, be an appreciative and attentive audience and just an integral and necessary part of each Corneal Dystrophy Symposium.

This great event at Duke University's Eye Center, Durham, NC, was no exception. Almost half, if not more of the 135 attendees for the Saturday sessions were fellow FFs. Count on them to encourage the speakers, to ask pertinent and cogent questions, to selflessly volunteer not only to help with the workings of the weekend but also to join the NIH funded genetic study that Duke is doing on Fuchs' Corneal Dystrophy. In fact, they were so enthusiastic that they almost derailed the sessions when they insisted on remaining in line to give blood samples even when the break was over and the next speaker started his presentation. While we all came for the presentations, I'm sure most will admit that the Friday evening Reception was also a resounding hit. Roughly 125 attendees including not only conference attendees, Duke speakers but also significant staff and Dr. David Epstein, CEO of Duke Eye Center showed up for the festivities, refreshments and outstanding hors d'oeuvres prepared by the Millennium Hotel Durham's chef & staff. The reception served as a great kickoff for the official weekend.

Not to be outdone was the traditional post symposium dinner on Saturday night at the

Millennium Hotel Durham. With three entre choices, wine and NY cheesecake dessert, we had an engaging evening that included most of the speakers and some other interesting "Dukies".

We do owe many thanks to the professionals and staff of Duke Eye Center and the University. In particular, David Epstein, MD CEO of Duke Eye Center; Alan Carlson, MD, Professor of Cornea & Refractive Services and Natalie Afshari, MD, Associate Professor of Cornea & Refractive Services who served as Chairman of the Symposium. As Dr. Carlson mentioned to me more than once, "If Dr. Afshari thinks it should be done, it *will* be done." And so it was that weekend.

### 2009 DVDs available

Many thanks go to David Smith of Neo-Zaz, who again recorded, edited and negotiated a reasonable price for our DVD production. In mid-October, after several restarts on generating the final AV result from the Symposium, we made the newly minted DVD set of 3 disks available for a nominal contribution.

Notifications were sent to those who previously had contributed to receive one as a gift. We hope that you will take the opportunity to help us with our work and contribute so we can send you one and you too can see the 2009 Corneal Dystrophy Symposium on living DVD.

**A link to order the 2009 Symposium (or the 2007 Symposium) DVDs is in the order form at the end of this newsletter.**

Or, simply go to the end of the newsletter, print out the 2 page order form, fill it out and mail it with a check per the instructions.

Included on the DVD are files you can print off that contain each speakers' presentation slides. You can follow the speaker as he "works" his slides. It really is just like being there.

Where else can you get almost 7 hours of information and entertainment for the price of a couple of movies and also keep rerunning it so you miss nothing. The material is important if you have corneal dystrophy and the speakers are pretty riveting. I've attached a list of the subjects and speakers at the end of this newsletter.

## **Speakers at the 2009 Corneal Dystrophy Symposium**

### **Conference Chairperson & Speaker**

Natalie Afshari, MD, & Associate Professor of Ophthalmology, Duke University

### **Other Speakers**

Alan Carlson, MD, Professor of Ophthalmology, Duke University

Pratap Challa, MD, Assistant Professor of Ophthalmology, Duke University

Anthony Kuo, MD, Assistant Professor of Ophthalmology, Duke University

Diane Whitaker, OD, Assistant Professor of Ophthalmology, Duke University

Terry Semchyschyn, MD, Assistant Professor of Ophthalmology, Duke University

Evelyn Kelly, Health Care Administrator

Christopher Boehlke, MD, Assistant Professor of Ophthalmology, Duke University

## **Membership**

Membership in Fuchs' Friends, our online support message board group is at an all time high. We currently have over 2100 active people. To date, over 5500 people have, at one time, been members. They represent more than 70 countries.

## **Website:**

The Corneal Dystrophy Foundation's website is one of our major outreach activities and we invest a lot of time and energy into keeping it informative, fresh and inviting because it's kind of our front door and our billboard that advertises to the world who we are and what we do. "Hits" on the website have been increasing month by month. In the past four months we have had 10,000 plus visitors and for roughly 8,600 of them it was the first visit. What does this mean? Well, it says the word is getting around; The Corneal Dystrophy Foundation has the answers you want to help you with your vision problems.

## **Google Grants**

The biggest reason for the word getting out is thanks to Google, the hugely popular search engine and Internet Applications Platform. We applied for and were granted an advertising 'in kind' grant; this allows us to compete with thousands of other advertisers every time someone uses Google to search for sites that contain particular words or phrases. How much of the increase in activity is due to Google Advertising? 4,750 visitors clicked on one of

our Google ads that popped up in their search results. It didn't happen all at once, it was less than 1,000 in August, 1,050 in September, 1,300 in October and 1,300 in November. It takes constant 'tweaking' to get the most from the advertising campaigns and particular 'adwords' and we're due for another round of adjustment.

## **AAO and EKG Meetings**

In late October this year, the American Academy of Ophthalmologists held their annual conference in San Francisco. Concurrently, Dr. Mark A. Terry held his annual Endokeratoplasty Meeting (EKG Meeting) very early on the morning of "Cornea Day" for the AAO. about 125 of the top corneal surgeons are privileged to attend this meeting where they exchange ideas, statistics, case histories, etc. It's a unique group that is currently shaping AAO attitude about corneal transplants. And we were privileged to be invited. It was a perfect opportunity to apprise this select group of our work as patient-advocates and to let them see what we have to offer in the way of patient education. We now have the ability to interact with these surgeons and provide literature for their offices to give to Fuchs' and other corneal dystrophy patients.

## **National Organization of Rare Diseases**

In late 2008 we applied for and were accepted as a Genetic Registry for Corneal Dystrophies by NOORD. We are listed on their site complete with links that feed a steady trickle of people who are looking for support and information to our website.

## **National Institute of Health**

On October 1, 2009, we petitioned the NIH/NEI to list our foundation as a support and information resource for corneal dystrophies on their Genetic and Rare Diseases Organizations website. Listing by this prestigious US Government group tells the world that we are recognized as someone trusted to help people get help and answers to their medical questions. On October 28, 2009, we were informed that our foundation is now officially listed under support groups for corneal dystrophy.

## **Literature**

We are constantly updating our literature and looking for new outlets for it. We have committed to publish in two new areas, Ebooks and On Demand publishing.

**A link to order Free Literature is in the order form at the end of this newsletter.**

## **New Inspirational Booklet!**

We've just released a new booklet called "Journeys With Fuchs' Corneal Dystrophy". It is an expansion and update to my cofounder Dorothy Acton's informative booklet, "My Journey Through Fuchs' Corneal Dystrophy". We realized that Dorothy's story, while very important to all who have a corneal dystrophy, needed to catch up with the latest surgical procedures.

So we enlisted two people to add their stories. Deloris' story is a transitional one for she first had a traditional PK-style corneal transplant before she was aware of new surgical procedures. She takes us through both procedures and recovery. When she 'found' our group, she learned about the DSEK or partial transplant that replaces only the

endothelium, Descemet's Layer and a little of the stroma.

Healing is much quicker and usually no astigmatism is introduced by the surgery. So Deloris had a DSEK or EK for short. While still, after 3 or more years, trying to adjust to constantly changing vision on the PK eye, her EK eye healed within 4 weeks or so to a very usable level. She said she just wishes she knew about the EK before she had the PK.

The final story is about one of my own EK transplants which recovered very quickly and which I kept a log of day to day changes.

**A link to order Journeys is in the order form at the end of this newsletter.**

## Other Literature

You can browse our literature and DVDs on the order form at the end of this newsletter.

## We're looking at

Other ways to reach people with Corneal Dystrophies. Let us know what you think of the following

### Ebooks

Ebooks are electronic versions of paper books that can be read on electronic book readers such as the Amazon Kindle (my favorite), Sony's EReader and the new Barnes & Noble Nook.

The readers are about the size and weight of a pocket novel and can hold many books. A few, like the Kindle, have wireless connections that allow you to shop and download new books wherever you are, at the beach, the doctor's office or just in bed enjoying a read.

### On Demand Publishing

There are a number of publishers, mostly on the internet who accept books for publication and never print a single copy until it is ordered.

They have mystical, magical machines that do all of the work for one or a thousand books without requiring a single book in inventory.

I don't mean to run on about these new publishing methods but they represent new channels to reach other people with corneal dystrophies and therefore are possible opportunities for us.

## In 2010 We'll be?

We are currently working with a corneal specialist associated with a Southern California teaching institution to co-host a 2010 Corneal Dystrophy Symposium in the Los Angeles area sometime between 15 September and 15 October, 2010.

Let us know if this is newsletter was interesting for you.

## From the Board of Directors

We wish you a healthy and happy holiday season with a prosperous New Year.

Monica Bellizzi, President  
Michael Inlow  
Faye Liston  
Shirley Landen  
Mary Luby  
Signe Maximous  
Bob Bellizzi

## Contributions

may be made by:

- Personal Check to The Corneal Dystrophy Foundation
- Credit Card
- On Line at:  
<http://www.cornealdystrophyfoundation.org/html/contribute.html>

Through Paypal, GoogleCheckout or justgive.org

To make a contribution, fill out the form below and mail it with either a check or credit card information to:

The Corneal Dystrophy Foundation  
 6066 McAbee Rd  
 San Jose CA 95120

(X)	Please check the appropriate lines		
	Amount	\$	
	General Fund		
	In Honor of		
	In Memory of		
	I work for a matching gift organization and have enclosed their form.		
	Please Notify (for In Honor of or In Memory of)		
	Address 1		
	Address 2		
	City	State	Zip Country
	Please Charge my Visa MasterCard (circle one)		
	Card #	Security Code	
	Billing Address & Zip Code (exactly as on card statement)		
	Signature		
	City	State	Zip

The following items may be ordered by providing the information on the other side of this page and placing a check next to the specific items.  
 For professional discounts on quantity orders, call 866-607-8965 Extension 1

(X)	<b>Free Literature</b> You can order at <a href="http://www.cdfpubs.org">http://www.cdfpubs.org</a>
	What Is Corneal Dystrophy
	Information About The Corneal Dystrophy Foundation
	Visiting Your Doctor

**The following items are available as gifts for specific levels of contribution.**

(X)	Minimum Contribution	Item Title
	\$3.00	Small Note Pads (image below) 3 ½" X 7" 25 sheets
	\$5.00	Journeys With Fuchs' Corneal Dystrophy (The personal experience of three people, from diagnosis through different corneal transplant procedures to recovery.) Order at <a href="http://www.cornealdystrophyfoundation.org/my_journey_through_fuchs.html">http://www.cornealdystrophyfoundation.org/my_journey_through_fuchs.html</a>
	\$50.00	2009 Corneal Dystrophy Symposium Proceedings (set of 3 DVDs) Order at: <a href="http://www.cornealdystrophyfoundation.org/html/dvds.html#DVD2009">http://www.cornealdystrophyfoundation.org/html/dvds.html#DVD2009</a>
	\$20.00	2007 Corneal Dystrophy Symposium Proceedings (set of 1 DVD) Order at: <a href="http://www.cornealdystrophyfoundation.org/html/dvds.html#DVD2008">http://www.cornealdystrophyfoundation.org/html/dvds.html#DVD2008</a>

