

## APRIL 2010 NEWSLETTER

### Welcome

To April 2010 edition of The Corneal Dystrophy Foundation Newsletter. We want each edition to be interesting to you and invite your feedback; tell us what you liked or disliked about the newsletter and, if there's other articles you'd like us to cover and what other information you would like us to share with our readership.

### Bob's View

We are in process of writing the Annual Report, our first. I've realized that I have been concentrating on the bad rather than the good that we experienced in 2009. Many of us without jobs, contributions falling off, will it ever get better?

I began this issue of the Newsletter and was considering how to encourage more people to contribute. Somewhere in the process of gathering figures prove how down things were this year for us I suddenly realized that I was seeing an avalanche of caring rather than low numbers.

Over 200 people made about 260 contributions to The Corneal Dystrophy Foundation amounting to more than \$13,000! The contributions ranged from \$5 to almost \$1000. Thank you, from the bottom of our hearts for that outpouring of help. I would like to thank each and every one of you for that help. Since we are all volunteer operated, and have no office rent, we get much mileage from every dollar contributed.

The above numbers would have been about 10% larger but IRS rules require us to identify the Fair Market Value of gifts that we provide as incentives for you to donate.

***Thank you for your generosity***

### Meet the Board of Directors

Each newsletter will feature one member of the Board.

#### Signe Maximous,

Member of the Board of Directors, Vice President of Tissue and Transplant Information

Signe is a key force in the Foundation and also Fuchs' Friends (FF). She also initiated and moderates the Cornea Transplant message board. If you follow messages on the Fuchs' Friends board you'll see postings usually every day as she uses her wealth of experience with Fuchs' Dystrophy to support, inform and educate others.

Signe lives in Atlanta GA and is married to France, a chef, par excellence, as those who attended the 2005 Corneal Dystrophy Symposium know; they hosted a barbeque at their home for attendees. Her professional career is centered on marketing of computers and software. Signe has held senior management positions in Hewlett Packard, Compaq Computer Corporation and Digital Equipment Corporation.

Signe is a member of the Board of Trustees of The Georgia Eye Bank. Among corneal transplantees she is pretty unusual since she has one traditional PK full transplant and the other eye has a DLEK Partial transplant. She is one of a few who can compare results of both operations from their personal experience.



## What's New at the Foundation?

### Small Groups

Visit the website at  
<<http://www.cornealdystrophyfoundation.org>>  
Click on Meetings & Events in the left column.

### What are Small Groups?

People with corneal dystrophy who are located in the same general area and who meet on a regular basis. Two groups are currently operational, NOVA (Northern Virginia, DC and Maryland) and Dallas TX. The meetings are informal but take planning and work to set up,

### Why are we doing this?

There are many people with corneal dystrophy who either can't find us or are computer illiterate. These souls need a venue to talk one on one with others who have 'been there, done that' with corneal dystrophy, transplants, cataracts, etc. Our members can relate experiences that provide reassurance. Chatting and interacting with others who have been through the experience gives the attendee a sense of support and they become a better informed person and patient. These meetings can calm fears and shed light on the process from a patient's point of view .

### How do we support the groups?

- Provide notices on our websites announcing the area, location, date time and contact person for each group.
- We also publish short reports from each meeting.
- We send a 'care package' with literature, some DVDs, Volunteer Time sheet and Sign-in Sheet for the meeting.
- Set up special email address for each group leader to shield their personal email address from spammers.
- Each group may have a special 800 number that will send voicemail to the Group Leader.
- We soon will set up periodic web or teleconferences to discuss other needs with group leaders.

### Current Group Leaders

Atlanta, GA - Signe Maximous is having her first meeting in late April 2010. Since we've already talked about Signe on a previous page, I'll use her space to say that if you live within reasonable driving distance of Atlanta please register for a meeting. Northern Virginia (NOVA) - Currently Claudia Gibson is the lead. Previously, Ann Campany and Howard (Stitz) did the organizing of the group's meetings. This group has been a great success!

Central Florida holds their first meeting on April 24.

Dallas, TX group had their first meeting February 12, 2010. You can read about it on our website. Joyce Curtis is leading the Dallas group

### How can I start a group?

Call Bob at 866-807-8965 Extension 1 or email me at:  
[execdir@cornealdystrophyfoundation.org](mailto:execdir@cornealdystrophyfoundation.org) to discuss it. We're still working out our processes.

### Speakers' Bureau

We're starting a Speakers' Bureau. What, you might ask, is that? The Speakers' Bureau's purpose is to make available to other organizations speakers who are experienced and prepared to talk to service clubs such as Rotary, Toastmasters, Lions, etc. about Organ Donation, Corneal Dystrophy, Corneal Transplants and the way the Foundation, Fuchs' Friends and the Cornea Transplant message board work to help educate and support people on the road to better vision..

### How does it function?

We're working on this part. A list of people who are experienced in speaking to groups will be maintained. The Foundation will supply handout materials and a general outline to follow. We might even have specific subjects. When an opportunity presents itself to insert a speaker into a meeting and there is someone of our speakers available in the area contact the Speakers' Bureau. Most of the time an opportunity will have to be 'made' by a local person by offering to speak at a Lions' or Rotary meeting for example.

It's a challenge and quite intimidating to stand up in front of one or two dozen strangers in a strange setting and explain the reason for the Foundation and Fuchs' Friends, how they can help people in need of better vision through organ donation and giving the audience a better understanding of the needs. But by telling your story it will help the audience to understand what we do.

Often the audience doesn't have a clue about the difference between a cornea transplant and cataract and the speaker has to lead them through some tutorial information. The Speakers' Bureau is vitally important function because it can multiply our effectiveness by encouraging other groups to spread the message or even to team with us on projects.

As we develop this process we will keep you informed. Some of us have already spoken at other organizations. Information was shared about the Foundation & message boards, our outreach and literature programs, eye donation, transplants and cataracts. We hope others with speaking experience will volunteer and help us enlarge this program.

## Website:

Updating the Foundation's website is a never ending process. We spend a significant amount of time finding and reading research on best methods of information presentation, site navigation and other, more arcane subjects, finding how we have 'opportunities for improving' the site and then making those improvements. Thanks to Google, we have measurement tools that help us analyze the website's traffic and flow; where people enter, what they read, where they leave, how many read a page the first time and then how many read it again; how long do they spend on each page and what is their path through the site. All of this goes toward making a visit to our website easy to navigate, informative and educational. No roadblocks allowed!

## Google Grants

We have been awarded a one year use grant of Google Earth Pro that will allow us to generate a 'density overlay' for viewing on Google Earth. This

overlay will depict where we know people with Fuchs' Corneal Dystrophy live. This is anonymous data that we have gathered over the years. We hope it will help us understand where we can encourage speakers and small groups to operate. We have also been awarded a use grant for Google Apps (applications). This includes Calendars, on line groups, spread sheets and word processing, all on line

## DVDs

Sets of 2007 and 2009 Corneal Dystrophy Symposium DVDs are available. The 2007 minimum contribution is \$20 and the 2009 (set of 3 DVDs) has a minimum contribution of \$50. Because of IRS rules we are required to define a Fair Market Value for items given as gifts and that amount reduces your deductible contribution. The 2007 FMV is \$7 so your deductible contribution is \$13. The 2009 FMV is \$9 which gives you a \$41 deductible contribution. The support you show by contributing in this way gives us the financial resources to do more outreach.

## Literature

We are constantly updating our literature and looking for new outlets for it.

*To order, please use the order form at the end of this newsletter.*

## New informational booklet

### Corneal Dystrophies

The booklet contains a beautiful color cross sectional picture of the eye with labels, courtesy of The National Institutes of Health and clear and simple descriptions of six of the most common corneal dystrophies. We have been complimented on the booklet by one of our favorite corneal specialists. It's informative and easy to read. Surprise your doctor; give them a copy of the booklet!

## Helpful Hints

Shirley Landen - Board of Directors, London, KY

1. When the winter nights are cold and long and the covers slip down toward your feet, be sure that when you reach for them and pull them up that you have your hands way above your head. This happened to me one night and my right hand slid off the covers and my thumb hit me hard, right in the eye. This was before I had the DSAEK in my right eye, thank goodness!

I do not know if it exacerbated the Fuchs' or not as I was soon to have the DSAEK on that eye. I was really glad that it was the right hand that flew off the covers and not the left, which left eye had already had a DLEK. If I had already had the transplant in the right eye, the results could have been disastrous. Even though it has been nearly three years since the last transplant, I am still very careful to hold my hands above the level of my head when I tug at the covers.

2. I am ashamed to relate this but it happened to me recently and if it will help some other person be more careful, then I will share my stupid mistake. Since my transplants, I do not use Pred Forte regularly but I always keep a fresh bottle on hand and take it with me on trips. I use it if allergies act up or my eyes get really irritated. I recently picked up a new bottle and had it in my purse as I had been to visit family. I also had some antibiotic ear drops that I carry when away from home.

The eye drops are kept on a counter in the kitchen and the ear drops are kept in the cupboard. Being tired when I returned home, at some point, I took the ear drops out of my purse and placed them where the eye drops usually stay. One morning soon after, I got up and my eyes didn't even want to open as they were irritated. I thought, I will just put some Pred Forte in this morning, I grabbed the ear drops and inserted a drop in each eye.

I thought, Wow, I really needed this as it is burning. Immediately, I realized that there was no way that Pred Forte could sting that much and knew what I had done. I immediately grabbed the Refresh and kept using it until my eyes no longer burned. It took half a bottle to stop the burning. Fortunately I had no damage and did not have to go to the Dr. I guess we all make mistakes but I thought these were two of the more unusual ones and that they might keep someone else from making the same mistake.

The Board of Directors thank you for your help and support of The Corneal Dystrophy Foundation and those with corneal dystrophies.

Monica Bellizzi - President California	Michael Inlow - VP Group Membership - Maryland
Shirley Landen - Secretary Kentucky	Faye Liston - VP Development & Strategic Plans- California
Mary Luby - Publications Fulfillment - California	Signe Maximous - VP Transplants & Tissue - Georgia



Robert Bellizzi, Executive Director - California

## Do you enjoy reading this Newsletter?

### Give a copy to your doctor!

Let us know if this is newsletter was interesting for you. Tell us if you would like to continue receiving it. If you are on your computer you can do that by:

- Going to our website by pointing your web browser to [www.cornealdystrophyfoundation.org](http://www.cornealdystrophyfoundation.org) or click this link..
- Click on Newsletter in the left margin.
- Click on the Subscribe link in the right margin
- Fill out the form and Submit it.
  - Please select delivery method

If you wish to sign up by mail, fill out the information in the form near the end this newsletter and send it to us.

**Make sure** you checked the appropriate box indicating how you wish to continue receiving the newsletter and have given us your mail or email information.