

## AUGUST 2010 NEWSLETTER

Fuchs' Corneal Dystrophy Gene Found!

Meet Faye Liston

Making Your Medical Care Work for You By Faye Liston

Why I Contribute to The Corneal Dystrophy Foundation

Small Groups Initiative By Deloris Axelrod

In My View By Bob Bellizzi (Executive Director)

What's Happening?

What's New?

Website:

Google Grants

DVDs Available

Literature

Action Request Form

editorial may be read at the NEJM by clicking on the links below. Thank you!

[Abstract](#)

[Editorial](#)

We wish to thank the Almaden Super Lions Club of San Jose, CA for their generous contribution to The Corneal Dystrophy Foundation that helps us with the cost of this newsletter. The contribution from the Almaden Super Lions Club is a result of our fledgling Speakers' Bureau effort and the untiring efforts of Monica, our President, to ensure that the world knows about corneal dystrophies and that our Foundation is pledged to help get that message out. This grant helps make it possible for us to send this letter by the US Postal Service to those roughly 600 interested friends who don't have Internet service. Thank you for your generosity, Super Lions!



### **Fuchs' Corneal Dystrophy Gene Found!**

A link has been found to a specific gene that is thought to cause Fuchs' Corneal Dystrophy (FCD), a late onset genetic eye disease that is thought to affect 5% of the U.S. population over 40. A team of 13 scientists, lead by Albert O. Edwards, M.D., Ph. D. a molecular biologist at University of Oregon at Eugene, found the link as reported in The New England Journal of Medicine (NEJM) on August 25, 2010. Dr. Edwards said that understanding the genetic predisposition for FCD may be helpful in selecting patients for new studies of the disease. The full text may be read at the NEJM by clicking on this text

## Meet Faye Liston

Member of the Board of Directors, Vice President of Development and member of the Strategic Planning Committee, Faye has been a Fuchs' Friends member since 2003 and joined the Foundation board since April, 2008. Faye was one of the pivotal forces in securing our Google Nonprofit Adwords grant which allows us to capture so much traffic on the Internet.



## Making Your Medical Care Work for You By Faye Liston

I was diagnosed late with Fuchs' Corneal Dystrophy. For years, I tagged along with my husband on corporate transfers. Each new city meant new doctors and new climates and new surroundings. Sometimes my eyesight seemed OK. In Las Vegas, it seemed like I had razor sharp vision. The first indication that something was seriously wrong occurred after our move to Tulsa, OK. The humidity was high and I felt like my eyesight was quickly fading. I kept complaining about "eye strain" during my annual visits to yet another new ophthalmologist in Tulsa.

This was 16 years ago. When we transferred again, back to Southern California, I felt that my eyesight had deteriorated. I sought out another board certified ophthalmologist on my insurance provider's list. Unfortunately, I visited his satellite office and he did not have a complete set of tools at that office.

He was also developing a Botox practice to supplement his ophthalmology practice. Even though I was misdiagnosed as having macular degeneration, he did get me to one of the best retina specialists in Southern California for a consult. Dr. Lean recognized the symptoms and referred me to a corneal specialist at Doheny Eye Center.

If I hadn't been so persistent with Dr. Lean, he would've simply sent me back to the original ophthalmologist. I realized you have to become your own advocate before you completely lose your sight. I called and made an appointment with Dr. Irvine at Doheny myself, rather than wait for Dr. Lean. Then, I started searching the Internet for information on Fuchs', which is how I stumbled upon Fuchs' Friends and Dr. Mark Terry.

Dr. Irvine not only spent a lot of time with both my husband and myself on our first visit diagnosing that I did suffer from Fuchs' Corneal Dystrophy, but he explained the options for treatment and told me to think about it and let him know when I was ready. In hindsight, he didn't try to rush me into surgery, but let me absorb the shock and think about the alternatives.

Since both of my eyes were equally affected, time was of the essence. I knew that corneal transplants were not an option for me because I couldn't take that much time off from work. I contacted Dr. Terry myself and inquired about DLEK surgery. He was very forthcoming with information. At that time, a lot of people believed that DLEK surgery was untested and risky. I went back to Dr. Irvine and talked with him, then scheduled my first trip to Portland to meet with Dr. Terry.

Within six months, I had DLEK and cataract surgery on both eyes. This was a game changer for me. Everything went perfectly and I have been enjoying my vision ever since. I never looked back. After the surgery, Dr. Irvine did the follow-up care. He fussed over every broken blood vessel and loose stitch. He saw me on a moment's notice and instilled a lot of confidence in me.

Several years ago, with another corporate transfer, we moved to Charlotte, NC. and yet another corneal specialist. At the time, I wasn't comfortable with any of the corneal specialists in Charlotte, so I chose to go to Duke Eye Center in Durham. This began a wonderful friendship and

patient relationship with Dr. Natalie Afshari, one of the most caring and personable doctors I've ever had.

The object of my story is that I have had four unique and highly-qualified specialists and it has taken this team to get me where I am today. Each is different. Dr. Lean would be my "go to" specialist if I encountered retina problems. Dr. Irvine at Doheny Eye is the corneal specialist that I would go to for an assessment and as an advocate to help me select the best care. Dr. Terry would be my first choice for a corneal surgeon. Dr. Afshari, my current corneal specialist, is seeking a cure for Fuchs' Dystrophy through genetic research.

Always look for the best care. Don't hesitate to get a second opinion. Become comfortable with your primary corneal specialist because it will be a long-term relationship. Support your local eye banks and Lions Clubs because they provide the corneal tissue. Participate in research studies if asked. And, lastly, get at least one friend signed up to be a cornea donor.

### **Why I Contribute to The Corneal Dystrophy Foundation**

My relationship with The Corneal Dystrophy Foundation began with a Google search of symptoms for cloudy vision seven years ago. Once I was diagnosed and knew the name of the disease, I used Google to read everything possible on the subject. Sound familiar? Somewhere in my search, I found a link for Fuchs' Friends. Once I joined, I read all of the posts and knew that I had finally found my peers. The sense of not having to go it alone was priceless.

This was a short seven years ago! In such a short time the treatment for this disease has advanced from full corneal transplants to the DMEK surgery. When I read the posts on Fuchs' Friends now, those who are inquiring about DMEK surgery can be compared with those of us who inquired about DLEK surgery just a short 6-7 years ago.

I believe that none of this would have happened at such a quick pace, if Fuchs' Friends hadn't become viral in their advocacy for the latest in surgeries and up-to-date research. In short, we've become the cheerleaders for notable names like Terry, Price, Kozarsky, Afshari, Hwang, etc. We're known in the medical community as a leading patient advocacy group. We've changed the relationship that corneal specialists have with their patients. In 2009, for the first time in Duke's history, they partnered with us to present an educational program for patients and those suffering from Fuchs'. In the past, doctors presented to doctors and students only.

I had a happy ending. Dr. Terry did all of my surgeries and I now lead an active life with better vision than I can ever remember enjoying. I promised myself and others that I would do whatever I could to give back to those who helped me for the remainder of my life.

As a member of the Board of Directors of The Corneal Dystrophy Foundation I am utilizing the same skill sets that I developed in the corporate world. We are a 100% volunteer board. Even so, we do have operating expenses such as insurance, taxes, membership fees in research groups, costs to keep our website current, costs to keep our Fuchs' Friends and our Cornea Transplant support groups online with Yahoo, software, etc.

In 2010, we developed a strategic plan that will encompass the next five years. We have a lot of programs under development: educational webinars, regional meetings, and an annual symposium that is targeted for mid-2011.

Several years ago, we were honored with a legacy gift from our late co-founder, Dorothy Acton. The Board is determined to use these funds wisely for long term programs and we rely on new contributions for our ongoing programs and operating expenses.

Our fundraising goal is \$50,000 for 2010. We already have made remarkable progress towards that goal. As you are making your charitable contributions for 2010, please consider The Corneal Dystrophy Foundation. Your support keeps us working for you and for others. No amount is too small. Here is the link for more information: <http://www.cornealdystrophyfoundation.org/html/contribute.html>

Thank you for your continued support of The Corneal Dystrophy Foundation.

Faye Liston  
Vice President, Strategic Planning & Development  
The Corneal Dystrophy Foundation

### **Small Groups Initiative**

**By Deloris Axelrod**

This is an exciting time in the growth of The Corneal Dystrophy Foundation (CDF) as a service and educational organization. corneal dystrophy sufferers around the country are meeting one another and sharing their experiences through the CDF Small Groups Initiative. Scheduled meetings are posted online at <http://www.cornealdystrophyfoundation.org> as CDF is notified of them. Click the "Meetings and Events" heading for details.

Groups need not be more than a handful of lunch companions. The CDF's purposes include increasing levels of direct support and disseminating up-to-date corneal dystrophy facts covering every topic in the corneal dystrophy world. The CDF tracks and verifies the latest research, the best doctors and training and everything from the best place to get comfortable sunglasses to the latest surgical success rates as even newer techniques evolve. The intent is to make this personal, practical and knowledgeable information available to corneal dystrophy patients everywhere enabling us to live more comfortably, enjoy better vision, and make informed decisions about our ocular health care.

Anyone willing to form a Small Group has only to call our Executive

Director, Bob Bellizzi at the CDF 's toll free number 866-807-8965 and leave a message to get started. You will receive educational and informational supplies, invitation help, including a free set of DVDs from the 2009 CDF Patient Symposium. The DVDs are loaded with free medical information and practical coping tips from experts at Duke University and much, much more for you to share with your group. You can sample the publications for yourself and choose those fitting your group by reading them online at <<http://www.cdfpubs.org>> CDF will print them for distribution and get them to you prior to your group's meeting. Those of us who have corneal dystrophy understand corneal dystrophy like nobody else does. Try setting a meeting and see other "faces of corneal dystrophy" for yourself.

CDF Small Groups are currently active in several areas:

Atlanta, Signe welcomes us to share much more than a restaurant meal or coffee and dessert.

Northern Virginia and surrounding area, Claudia welcomes corneal dystrophy sufferers to the NoVA in-person support group.

Greater Dallas area is home to Joyce who has scheduled another meeting there.

Lakeland, centrally located in Florida, is the meeting place for Lorraine's group that is growing and gaining enthusiasm.

### **Deloris Axelrod**

#### **In My View**

**By Bob Bellizzi (Executive Director)**

We hope our articles strike a personal note with you as you begin to understand just what The Corneal Dystrophy Foundation means to those with corneal dystrophies. Corresponding with others who have the same problems eases the stress, finding a patient recommended corneal specialist, being able to ask questions of others on the support board,

are all part of our members' toolbox. Just knowing that you aren't the alone helps greatly.

### **What's Happening?**

Fuchs Friends, one of our Internet based support group is 10 years old! May 2000, Dorothy Acton and I founded the group as a place for 'Fuchsies' to come for hope, support and information about our rare disease. It is the jewel in the crown of The Corneal Dystrophy Foundation. It currently serves 2300+ active members and has served over 6500 members during its' lifetime. Fuchs' Friends is active, handling a daily traffic of 40 to 50 questions and answers that are visible to all current members

Over 105,000 messages have been posted and archived during the group's lifetime and all of these are available by a simple search that members can use at Yahoo's Groups websites **if they have a Yahoo ID**. You must be a member of the group to receive the messages on a daily basis (individual or digests of groups of messages). Of course there are many who help us maintain order in the group without whom it would be true chaos.

Fuchs' Friends 'morphed' into The Corneal Dystrophy Foundation when Dorothy and I, in late 2004, decided there was a need for an 'official' entity that would champion the needs of all those with corneal dystrophies.

Fuchs' Friends, UK is 8 years old, were founded by some of the original British members of Fuchs' Friends to better serve the needs of corneal dystrophy sufferers in the United Kingdom and have 235 members in their group.

### **What's New?**

We have started the speaker selection process for the 2011 Corneal Dystrophy Symposium. Once we have a set of candidate speakers and

we know their availability, we can start the site selection process. There's no sense selecting a site and not having available dates for selected speakers.

### **Website:**

We have redesigned the Join Fuchs' Friends process, making it more user friendly, clear and easier for the Moderators. Updating the Foundation's website is a never ending process. We periodically make changes based on Google Analytics which helps us determine optimum paths that people prefer through our websites. We have the ability to see how many people visited a web page, where they navigated from, how long they spent reading the page and where they went next. This data assists us in making the site ever more user friendly and inviting.

### **Google Grants**

We have several Google In Kind grants that provide us with various tools to work smarter and more efficiently.

**Google Analytics** helps us keep trim and attractive websites.

**Google Documents** gives us the ability to share documents within the Google 'Cloud' so teaming up on their creation and modification is a simple task. No emails required.

**Google Earth Pro** allows us to visualize where in the world our members and preferred doctors are located. We intend to use this map to determine where to encourage Informal Groups.

### **DVDs Available**

Consider giving one or both sets of the 2007 and 2009 Corneal Dystrophy Symposium DVDs to your eye professional. The presentations on these DVDs were specifically developed for The Corneal Dystrophy Foundation's Symposiums. The presenters are real specialists presenting real-life knowledge about research, genetics, current and future developments of great interest to our members. The 2007 minimum contribution is \$20 and the 2009 (set of 3 DVDs) has a minimum contribution of \$30. The support you show by contributing in this way

gives us the financial resources to do more outreach. Or do yourself a favor and get both sets. They are truly eye openers! (ouch!)

**Literature**

Is constantly being updated. We are continually looking for new outlets for it. You may interest your specialist to have some of our Free Literature on his display tables in Reception. Several of our Patient Recommended Doctors display our literature for their patients; UCSF's Beckman Vision, Chicago Cornea Associates, Duke University Eye Center in Durham NC and others.

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

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| Monica Bellizzi - President California                         | Deloris Axelrod - Informal Groups                          |
| Shirley Landen - Secretary- Kentucky                           | Faye Liston - VP Development & Strategic Plans- California |
| Mary Luby - Publications Fulfillment - California              | Signe Maximous - VP Transplants & Tissue - Georgia         |
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Use the form on the inside back page. Cut it from the newsletter and mail it in an envelope with any contributions to the return address on the back page. On the Internet, go to:

<http://www.cornealdystrophyfoundation.org/>

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| <p>The Corneal Dystrophy Foundation<br/>         6066 McAbee Rd<br/>         San Jose CA 95120<br/> <a href="http://www.cornealdystrophyfoundation.org">http://www.cornealdystrophyfoundation.org</a></p> |
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