The Power of Words

Monica H. Bellizzi, President

In cleaning out my Mom's apartment after her death, letters written in German were found. Some were worn, folded many times, some just put in a drawer. Unable to translate these they were again put in a drawer, until my cousin asked to read them. Her gift to me was a translation of these letters. They truly showed me the "power of words".

One was a final letter from my grandmother, to my mother, giving love, advice, and saying that this would be her last letter. Her last words were to care for her grandchildren and live life to the fullest.

The Corneal Dystrophy Foundation uses words. We tell of our members journey's through their experiences with Cornea problems. Scary is a common word and well used. Our words tell stories, give support and hope. We recommend that you keep a journal as you go through your experiences.

Journey's, our small book has been revised. Besides technical information it has four stories of people who are willing to share their corneal dystrophy journey to help others. This booklet shows the progression of the treatment of corneal dystrophies and surgical operations.

Publishing this small book is one of the ways we raise funds to help people cope with their eye condition. For a donation to The Corneal Dystrophy Foundation a copy will be sent to you. Please go online and fill out the request form.

Thank you for your help and support.

A Pakistan Connection

Deloris Axelrod & Bob Bellizzi

“Guide Me” was the subject line of an email plea recently received. The message echoed of despair, it was sent from the father of a 22 day old baby in Pakistan. His newborn child was born with a cornea issue called “tiny cornea”. Like any parent, the father desperately wanted to know if his son would have any chance of sight at all.

The biggest obstacle for this heartbroken father and family was that they live in Pakistan, half a world away from CDF and the medical experts who are so helpful to the foundation. As CDF volunteers often do, our volunteer made an internet search and learned that this condition is rare and usually accompanied by congenital cataracts, explaining the milky appearance of one of the baby’s eyes. Research seems to show this condition occurs in families of Indian and Pakistani origins.

A call to one of the Corneal Dystrophy Foundation’s friends, the Cornea Research Foundation of America, associated with famed surgeon Dr. Francis W. Price, had the answer we needed for this father. One of Dr. Price’s fellowship students had returned to his native Pakistan to practice a few years ago. Kindly Marianne Price provided the doctor’s name, phone number and email address.

Deloris, a Board Member, relayed this contact information to the worried father at once. As is often the case, the only response was a note from the father thanking us for the information. Should we learn the rest of the story, we will share it with our readers in this newsletter.
Dr. Natalie Afshari, Professor of Ophthalmology, and colleagues have been researching the therapeutic potential of agents known as ROCK inhibitors, in effort to treat patients with FECD more effectively, and with topical medications versus surgical intervention. To date, results have been promising. Application of ROCK inhibitor to corneal endothelial cells in vitro has led to significantly enhanced endothelial cell proliferation and endothelial cell migration, a finding that could contribute to restoration of corneal clarity and visual acuity otherwise lost in Fuchs corneal dystrophy. Furthermore, topical administration of ROCK inhibitors in animals has demonstrated a marked reduction of corneal edema and accelerated corneal thinning in treated eyes.

Collectively, these preliminary studies may demonstrate the efficacy of ROCK inhibitors as potential topical therapy for patients with FECD and other forms of corneal endothelial disease. Further research is ongoing.

Also, Dr. Natalie Afshari and colleagues have investigated the effect of corneal transplantation on corneal biomechanics in subjects with Fuchs corneal dystrophy who underwent DSEK. Eyes with Fuchs corneal dystrophy that underwent DSEK did not have dramatic changes in cornea resistance factor or corneal hysteresis (markers of corneal biomechanics) when compared to controls. This is understandable as in DSEK only a thin layer of cornea is replaced.
Inspiration…
Carole Vits

“Fuchs’ Corneal Dystrophy”…I had no idea what those words meant or what it would mean to me in the future. I had been given the diagnosis two years prior, but I certainly had no information.

During my computer search I found the Support Community of the Corneal Dystrophy Foundation, Fuchs’ Friends. After joining the online Support Community, I read the posts daily because this was a group who related to my situation. Now that I knew about my eye condition, I realized my symptoms were getting worse. In just weeks I had learned so much.

After my first transplant, I read the stories in Corneal Dystrophy Foundation publication, ‘Journeys’. Here again I found a written record so much like my own. Our surgeries were similar but each of us had a little different experience. Little did I think that my own story would be added to the latest edition of "Journeys Through Fuchs' Corneal Dystrophy".

Will That Be Me?
Advice from “The Doctors”, USA Weekend, April 2012

You watch a family member suffer with their eye problems, go to endless doctor’s appointments and you wonder, “Will that be me in later years?” The answer is maybe. Research has shown family medical history is an effective and accurate tool for assessing disease risk. Here are some tips to help compile your family medical history:

- Compile a list of your relatives
  Best history includes three generations.
- Prep your questions
  Ask a range of health conditions, and the age when problems started.
- Pick a good time to talk
  Over holidays or at family gatherings might be best.
- Keep your records up to date
  Store all your info online with surgeon general’s My Family Health Portrait, www.familyhistory.hhs.gov.

If you know which diseases hang from your family tree, you can reduce your risk.

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CORNEAL DYSTROPHY FOUNDATION – ORDER FORM

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- □ 2009 DVD $30  
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**Immobilizer Pillow**  
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Immobilizer Pillow

Many surgeons who perform corneal transplants and other surgical procedures require the patient to spend considerable time on their back in an 'eyes up' position. Since patients need postoperative rest, it is very difficult to ensure that they remain in this position while sleeping.

The Head Immobilizer Pillow, illustrated above, is a practical way for the patient to stay in an eye-up sleep position. It is easily adjusted to individual taste and can be padded by the patient for comfort and fit. Members who bought the Head Immobilizer Pillow found it easy and practical to use. The Head Immobilizer Pillow is a practical tool for patients. US$29.95 plus shipping & handling. Order online!

www.cornealdystrophyfoundation.org/html/ekpillow.html

Vision...

Bob Bellizzi, Executive Director

In my email inbox 2 weeks ago:

"Hello, my name is Charlotte. I am 52 years old and have been struggling with Fuchs dystrophy for several years. I had my cataracts removed a few months ago and now have severe Fuchs dystrophy. It is so bad in the mornings that I cannot see to drive to work safely anymore and I may not be able to keep my job because of my sight. I can't afford the corneal transplant; I have no insurance, had to give it up".

I made arrangements for her to get an evaluation from one of our advising surgeons who helped to "write the book" on partial corneal transplants. They brought her in for the evaluation and a few days ago I received this email from Charlotte:

“...my appointment went quite well...good news is that (they have) scheduled me for surgery...this summer, which means that I will not have to forfeit my job, which I love. THANK YOU...THANK YOU...THANK YOU...From the bottom of my heart! I WILL BE ABLE TO SEE AGAIN!...I have been so depressed, thinking that there was no hope for so long, and now this...I am SO happy and grateful. - Charlotte

The Corneal Dystrophy Foundation

Focusing 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. Thank you for your support.

We’re on the Web! Visit us at:
www.cornealdystrophyfoundation.org