President’s Corner
By Monica H. Bellizzi

Questions...

To find the direction....you need to ask questions

The Board of Directors, in re evaluating The Corneal Dystrophy Foundation's programs and policies, ask many questions. A strong, effective Foundation, using its resources wisely, is the goal of the Board, while also considering our effectiveness and developing new ideas.

The three questions listed on the right were answered by all Board Members in their own words and on their own time. The responses received were thought provoking and show passion and caring. The Board's answers were terrific and will help greatly in future planning. They will be shared with all. It is my great pleasure to have the answers given by Signe Maximous printed below.

We wish to thank The Art Institute of Milwaukee, who is collaborating with us as the audio/visual producer of the presentations. The Institute has set up credit courses. Student, under Instructor supervision will gain experience and course credit while producing our needed Audio Visual output. We look forward to working with them and being part of their continuing education program.

Answers...

Why are we here? We are here to provide support and education to people who suffer from diseases of the cornea and their friends and families.

What do we do? We gather and consistently provide information to people with diseases of the cornea. No other organization provides anything even close to the long-term consistent and accurate information for the person who has a corneal disease. We do not bombard people with medical jargon and, instead, do what we can to provide information in language that the person who has been diagnosed with a disease or members of their immediate family can easily understand. We provide definitions of commonly used terms and also provide the ability for members to share the names of their doctors and recommendations.

Doctors refer their patients to us because we provide a service that benefits both the patients and the doctors. And, because our information is not provided by a single medical source, we develop balanced materials and evaluate results that we see from various medical practitioners and the procedures that they use. We carefully observe what doctors are doing and exercise discretion in adding doctors to our recommended doctor list. We also may suspend display of a doctor on our list if we observe a pattern of less than optimal results.

Why do we do this? We are here to help. Each of us has been in the shoes of those people who come to us looking for help. We know that people are desperate for knowledge and we feel a real sense of responsibility to ensure that the knowledge we share will be for the benefit of the person and not just a way for us to make ourselves feel important. Dedication to our visitors and members is absolutely essential to those who choose to participate as members of this board of directors.

Signe Maximous, Vice President, Corneal Dystrophy Foundation
Rotterdam Mystery Still Not Solved

The plot thickens

Since 1998, NIIOS has introduced various concepts for endothelial keratoplasty for management of corneal endothelial disorders. A first concept was initially popularized as ‘deep lamellar endothelial keratoplasty’ (DLEK). A second concept in which an unsutured posterior graft is positioned onto the recipient posterior stroma after a descemetorhexis, is now worldwide adapted as ‘Descemet stripping (automated) endothelial keratoplasty’ (DSEK/DSAEK). Further refinement of the technique resulted in a third concept that allows for selective transplantation of a donor Descemet membrane, now referred to as ‘Descemet membrane endothelial keratoplasty’ (DMEK).

However, in recent years, clinical observation at NIIOS suggested that the entire concept of performing a ‘keratoplasty’ to manage corneal endothelial disease may have to be reconsidered. The objective of all keratoplasty procedures today - either penetrating or endothelial keratoplasty techniques - is to surgically replace diseased host tissue by healthy donor tissue, in the best anatomical fashion. However, eyes that showed graft detachment after DMEK for Fuchs endothelial dystrophy, consistently showed ‘spontaneous corneal clearance’. Despite the presence of a malpositioned and therefore non-functional graft, the transplanted corneas obtained complete transparency with pachymetry values returning to normal.

These findings indicate that the endothelium has the capacity for massive migration, in order to repopulate the denuded recipient posterior stroma (after initial descemetorhexis). Interestingly, spontaneous clearance does not seem to occur in eyes operated on for bullous keratopathy. If so, endothelial migration or regeneration depends on the indication for surgery. And if that is true, it would strongly suggest that the host endothelium is involved. This would in turn also correspond with the endothelial healing patterns observed (from the corneal periphery toward the center), and it would better explain the endothelial cell densities observed. If the host endothelium is capable of restoring corneal clarity in Fuchs endothelial dystrophy, this would allow for different surgical approaches, now tentatively referred to as Descemet membrane endothelial transferral (DMET) and graft mediated endothelial stimulation (GMES).


Editor's Note: NIIOS' Founder, Dr Gerrit Melles, has been continuously developing and refining new lamellar surgical techniques, from DLEK and DSEK to Descemet Membrane Endothelial Keratoplasty (DMEK technique since 2005). Dr. Melles’ research was responsible for the wonderful Partial Transplants which have helped so many to see so well in the 21st Century

Published with permission by Netherlands Institute for Innovative Ocular Surgery (NIIOS)

Notes From Our Donors . . .

I will forever be grateful to you and others in Fuchs' Friends (Online Support Group) who have so much encouragement for those in need of surgery.

- Hugs, Lana

I joined Fuchs' Friends about two years ago. Getting the right information and hearing the stories from all who participate has helped me realize I can cope with Fuchs' and get it fixed when the time comes.

- Joyce

Thank you so much for the education and support you provide. Because I knew what to expect, I was a better-prepared, less fearful cornea transplant patient.

- Margie
2013 Corneal Dystrophy Conference & Symposium
July 26 - 27, 2013
The Hilton Milwaukee City Center Hotel
509 W. Wisconsin Avenue, Milwaukee, WI 53203

Speakers:
Francis W Price Jr MD, Chairman, Price Vision Group, Indianapolis IN
Sanjay V Patel MD, Professor & Chair Ophthalmology, Mayo Clinic, Rochester MN
Dennis Siemsen OD, Rehabilitative Optometry, Mayo Clinic, Rochester MN
Signe Maximous, VP & Board Member Corneal Dystrophy Foundation, Eye Banking

Registration - 4 Different Options:
1) Go to www.cornealdystrophyfoundation.org, click on the Symposium link, click on the Register link, this will take you to the EventBright website.
2) Go to www.EventBright.com and search on Corneal Dystrophy, Milwaukee WI
3) Complete and mail form below, attach check or call with credit card information.
4) Phone 866-807-8965, please leave a detailed message and we will phone you back.

Hotel:
The Hilton Milwaukee City Center Hotel has held a block of rooms. Discounted rate is $129 + Tax, Discounted rate deadline is June 1, 2013. Discount Code is CDF. Phone 1-800-HILTONS or go to www.cornealdystrophyfoundation.org website, click on Symposium link, click on the Hotel link.
Parking is available at the hotel for $15/day. Shuttle service from Milwaukee Airport to hotel is $14/person.

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2013 SYMPOSIUM REGISTRATION FORM

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We will return your call at our earliest convenience and take your information over the phone.
If you are attending the 2013 Symposium and have a story to tell, consider having it videotaped. Check out the stories that are now on our YouTube Channel at: http://www.youtube.com/user/cornealdystrophy to get an idea. A 2 minute story would be perfect....practice.....practice.

**Thrivent Choice.** The Corneal Dystrophy Foundation is listed in Thrivent Financial Thrivent Choice Catalog and we are very appreciative of Thrivent members who directed their Thrivent Choice dollars to this 501c3 organization. Thank you.

**TO:**

**THREE WAYS TO REACH US**

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| mail    | 6066 McAbee Road SAN JOSE, CA 95120 |
| email   | newsletter@cornealdystrophyfoundation.org |

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The Corneal Dystrophy Foundation  
6066 McAbee Road  
San Jose, CA 95120

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.

*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.*

Our Mission is to give hope through educational programs, patient on-line support groups, partners in the medical field, hospitals, surgeons, eye and tissue banks.