President’s Corner - Sharing

By Monica H. Bellizzi

As a young child we are told to share; whether it is our toys, books or time. This allows for relationships to be formed, character to be built, commonality to begin.

At a recent Corneal Dystrophy Foundation Symposium, held in Milwaukee, Wisconsin, sharing was the key. Stories were exchanged, support was given, even hugs happened. First time attendee or repeat visitors showed an in depth level of sharing. Evaluations were answered by the attendees. The common purpose stated became...”I am here to learn...meet the Surgeons...talk in person to those I only talk to online.” It became sharing on a closer level.

We thank the speakers who so generously give their time to make this event happen. The inside pages contain articles from two of our speakers. This newsletter reflects some of the knowledge learned and shared at our July 2013 Symposium.

Time Well Spent!

I'm Mark, a 56 year old male in good health. I have been diagnosed with Fuchs' Dystrophy for over 15 years. The condition has worsened over the last few years and I am now considering corrective partial corneal transplant surgery. Driving and now reading are becoming harder to do and my family is getting concerned for my well being. I know the condition will not correct itself. My family and I live in suburban Chicago.

I attended the Corneal Dystrophy Symposium 2013 in Milwaukee with my wife. She too was eager to understand more about Fuchs'. This after getting a tip from my Mother-In-Law who saw an advertisement in the local paper and knew of my malady. Our goal in attending was to gain a better understanding of the disease, to be clear on the procedure and to chat with people who could understand my plight. Further, to speak with champions of the advancements in diagnosis, specifically the pioneering surgeons, folks from the Eye Bank, those who have had the procedure and like me, those who are considering surgical options.

It was a day well spent. I came away with a better understanding of my condition but more so, a clearer vision (pardon the pun) on the advancements/treatments and how others like me have moved forward. I am now more confident and look to a day of clear vision as I will have the procedure in the coming months. I wish to thank the organizers of the symposium, the speakers and the friends I made at the event. God bless us all.

July 2013 Symposium - Milwaukee, WI

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Endothelial Regeneration
By Steven B. Koenig, M.D., Professor of Ophthalmology, Cornea and Refractive Surgery Service, Froedtert and Medical College of Wisconsin

The endothelium consists of a single layer of hexagonal shaped cells that line the back surface of the cornea. Metabolic pumps within the endothelial cell membranes create an osmotic gradient that help maintain corneal clarity. It is widely held that human corneal endothelial cells do not divide and that loss of endothelial cells due to Fuchs’ dystrophy, inflammation, infection or trauma may lead to irreversible corneal edema and loss of vision. The current surgical management of corneal edema includes selective replacement of either Descemet’s membrane and endothelium (DMEK) or Descemet’s membrane, endothelium and a thin layer of donor corneal stroma (DSAEK). However, there have been a number of recent case reports describing spontaneous resolution of corneal edema following accidental removal of the central Descemet’s membrane or following complicated DMEK/DSAEK in which the donor failed to attach to the host cornea. These reports suggest that the human cornea may be capable of repairing itself.

The literature contains a number of case reports describing spontaneous corneal clearing following accidental removal of the central Descemet’s membrane and endothelial cells in otherwise healthy eyes undergoing cataract surgery. In most cases, the cornea gradually clears over a period of months with the patient’s own endothelial cells moving in to cover the defect and restore corneal clarity. Others, including us, have described spontaneous corneal clearing after partial removal of the central Descemet’s membrane and endothelium in eyes with Fuchs’ dystrophy and posterior polymorphous dystrophy.

Our patient maintained excellent visual acuity for 16 years after her surgery! Other investigators, including the Netherlands, have described spontaneous corneal clearing in eyes with Fuchs’ dystrophy after complicated DSAEK and DMEK surgery in which the donor lenticule or Descemet’s membrane scroll failed to attach to the host cornea.

The human cornea endothelium is believed to possess the ability to divide within the body but under normal conditions cell division remains arrested. It is generally believed that human corneal endothelial wound healing occurs through cell migration rather than proliferation of new cells. However, there is evidence that endothelial stem cells may reside at the edge of the back surface of the cornea. In Fuchs’ dystrophy, removal of a small area of central diseased endothelium and Descemet’s membrane may allow healthier peripheral endothelial cells to migrate and cover the defect. Alternatively, endothelial cell regeneration may occur as a result of stem cell regeneration, although this remains unproven. Researchers in Japan are currently investigating the removal of the central diseased endothelial cells in Fuchs’ dystrophy and treatment with a Rho-kinase inhibitor, a molecule that may affect the movement and proliferation of endothelial cells. If removal of the central diseased endothelium and Descemet’s membrane and/or treatment with Rho-kinase inhibitors proves to be effective, it may alter our approach to the treatment of Fuchs’ dystrophy by allowing the patient’s cornea to heal itself without the need for a transplant. This could simplify surgery, eliminate the risk of graft rejection, and provide a treatment option to patients with Fuchs’ dystrophy who have no access to donor corneal tissue.
I Tried That, It Didn’t Work For Me

By Dennis W. Siemsen, OD, MHPE, Low Vision Rehabilitation Specialist & Medical Optometrist, Dept. of Ophthalmology, Mayo Clinic, Rochester, MN

When people ask me what I do in life, I often respond, “I work with visually impaired persons.” Then I get a glassy-eyed look, when they realize they don’t have any idea what I am talking about. I’m used to this by now, because after 35 years of practicing low vision, I still feel as though there is a great misconception about low vision rehabilitation and what it can do.

Simply stated, a low vision specialist takes the vision a person has and helps them do the things they want to be able to do. Many people automatically associate low vision with magnifiers. To be sure, sometimes it includes magnifiers and glasses, but not always. For those of you with glare and contrast issues from a corneal disorder, you know that making things bigger isn’t always better. There is much more to it than that.

In order to rehabilitate a person, we need to know several things. Acuity alone does not adequately describe the loss in function. Let’s consider what some terms commonly used in the rehabilitation community really mean in the context of a corneal condition:

Disorder (Corneal Dystrophy)
Impairment (reduced visual acuity)
Disability (limitation in driving)
Handicap (can’t get to the store)

In low vision rehabilitation, we can intervene in any or all of the last three challenges (I will leave treating the actual dystrophy to my ophthalmology colleagues). For example, a patient with Fuchs’ Dystrophy may have reduced visual acuity resulting from glare. I might prescribe anti-glare coatings on the spectacle lenses, improving visual acuity. When driving, I would recommend a fit-over wraparound filter, and wearing a hat with a visor to reduce direct sun exposure. This would expand the types of conditions a person would feel comfortable driving. If none of those were appropriate, I would refer this person for additional services which might include transportation for handicapped persons or orientation and mobility training. For the person who is unable to leave home for other reasons, in home services like meals-on-wheels might be appropriate.

It is important to understand that this is a rehabilitative process. Although the low vision specialist might be the focus of that process, other professionals are likely to be included. These may include a social worker, an ophthalmic technician, a teacher of the visually impaired, an orientation and mobility specialist, and an occupational therapist. Which services are needed will be determined during an intake interview and subsequent review by the low vision specialist.

Some patients, when low vision rehabilitation is recommended, say, “I tried that, it didn’t work for me.” If their perspective that low vision is only testing with magnifiers, that may be so. But try and think of low vision rehabilitation in a broader sense with the goal of achieving independence. Success is not determined by how many devices are prescribed. It is measured by identifying goals and developing a rehabilitation plan to achieve them.
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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!

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Meet our Corneal Dystrophy Board!
(left to right) Back Row: Shirley Landen, Robert Bellizzi, Monica Bellizzi, Signe Maximous, Alex Manos, Front Row: Mary Luby, Deloris Axelrod, Carole Vits

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.