BOSTON FOUNDATION *for* SIGHT

Last Sunday Kelli developed a fever.

David's Journal | March 22, 2004 – She toughed it out for a couple of days, but Monday night she called me (I was at a conference in Atlanta – my first trip away from her and Zoe in 2 years) and said I might need to come back if she didn't feel better in the morning.

March 23, 2004 | Tuesday night she developed a rash on her back. It extended to her arms and face later in the night. By early Wednesday morning it was looking pretty bad and she was feeling even worse, so we went to the hospital.

A fever of 106.5°
Antibiotics
Big doses of steroids
Morphine for the pain

Kelli and David, successful Internet entrepreneurs and the parents of a two-year-old daughter, Zoe, were living a happy life. Out of nowhere, Kelli, 36, contracted toxic epidermal necrolysis syndrome (TENS), a rare disease thought to result from an adverse reaction to medication or a virus — or some combination of the two. In Kelli's case, the cause would remain unclear, and the next six years would prove to be a monstrous ordeal.

A sky-high fever and painful rash that would soon cover 70% of Kelli's body landed her in intensive care. An alert resident recognized the condition, which has a frightening mortality rate of 30-40%. The rash had begun to blister, and the top layer of her skin was sloughing off; infection was a deadly threat. TENS, a severe form of Stevens Johnson syndrome (SJS), also attacks the mucous membranes, including the ocular surface of the eye, causing extreme pain, ulcerations, light sensitivity, and potentially blindness.

David, a self-professed geek, went into overdrive, surfing the web for leads on effective treatments for this mysterious condition. He found an Internet user group whose members urged him to make sure that Kelli's eyes were looked after. They also told him about a specialist in Miami who could advise on amniotic membrane transplantation to save and possibly rehabilitate her corneas. Kelli's medical team was hopeful and, in consultation with the specialist, performed the surgery twice in six weeks.

March 25, 2004 | The doctors had pretty much worked out that this was classic TENS (toxic epidermal necrolysis syndrome) and suggested we either transfer to intensive care or move to the burn center of a local hospital.

Cardiac arrest: Kelli is revived
Intravenous Immunoglobulin (IVIG)
Pig skin xenograft to replace and regenerate her skin
Atrial fibrillation
Pneumonia

Doctors put Kelli into a drug-induced coma to manage her unrelenting pain. They also administered a sedative that would erase her short-term memory to reduce the trauma she'd experienced.

April 29, 2004 | Another amniotic membrane transplant onto the cornea. Surgery went just fine. Did as promised under light general anesthetic. One area in right eye off to the side was also affected, so patched that. Plugged all 4 tear ducts. Did patch both eyes to help healing.

June 4, 2004 | Recovery will mean regaining a lot of the ground. But not necessarily all of it... One small symblepharon (adhesion) in lower corner of right eye. Injured tissue remodels. Scarring can develop in this phase.

July 20, 2004 | Eyelid margins are not good. Tear film compromised. As part of disease course.

December 1, 2004 | 20/20 in good eye

Her medical team's herculean efforts saved Kelli's life. David's research and advocacy played no small role. Considering what might have happened, her visual acuity was barely compromised. In fact, the vision in her "bad" eye was 20/30. However, the disease had damaged her ocular surface system, resulting in trichiasis, a condition in which the eyelashes grow into the cornea, causing excruciating pain with every blink and leading to corneal ulcerations. TENS also caused severe dry eye and its related chronic pain and extreme sensitivity to light.

David and Kelli learned about scleral lenses, which rest on the less sensitive sclera, or white of the eye. Although she couldn't fathom putting anything into her fragile eyes, in the fall of 2005 she made an attempt to be fitted. It was not successful, and she entered into a long period of coping and despair. It was a foreign frame of mind for a young woman accustomed to being not only fully engaged in life, but absolutely driven.

"I went to bed every night at seven o'clock. I couldn't tolerate the pain. I was depressed, I have to admit. I was sleeping half my life because I couldn't function, but I had to because of my daughter." Kelli

In the summer of 2009, she spent ten days at the Boston Foundation for Sight.

And everything changed.

Knowing the emotional toll that her corneal disease (and TENS) had taken and the anxiety she felt about placing anything in her eyes, Kelli's medical team at BFS tailored her treatment to support her needs. This included more one-to-one sessions with her trainer — ten, in fact — to ensure that she could insert, remove, and care for the organization's innovative prosthetic devices with total confidence.

She was fitted with five trial devices from the 2,000 found in the BFS library. The refinement process continued with the custom fabrication of several devices, the last pair of which she wears comfortably every day.

"Having my corneas bathed in liquid all day has affected my whole body.... With my prosthetic devices, I forget that I had this terrible thing happen to me. It's really turned things around." Kelli

Kelli is now doing everything she did before she fell ill; in fact, she's venturing into new territory, having joined the gym and started swimming. Seeing her today, you'd never know what she's been through; you'd have no idea that seeing pain-free was the breakthrough she'd been waiting for.

Progress. Always in sight.

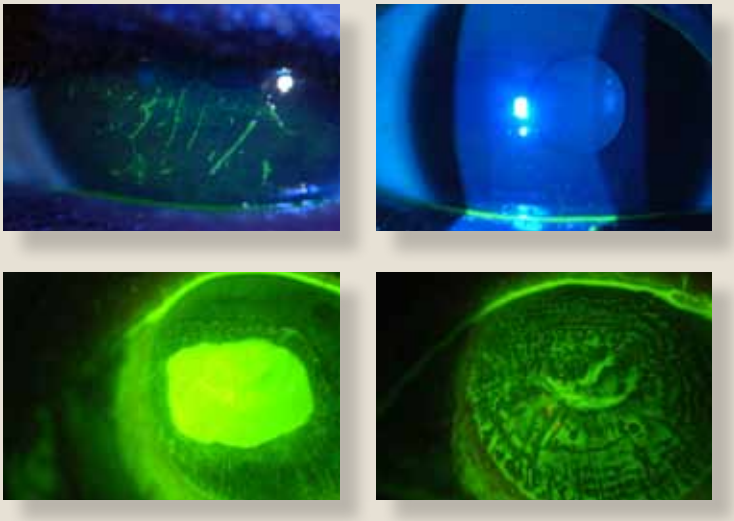
The cornea. Not often the center of attention, it plays a crucial dual role: it is essential to the eye's ability to focus, and it protects the eye from the environment.

It also happens to be one of the most sensitive parts of the human body. Complex corneal disease, a group of disorders afflicting millions of people each year, not only impacts vision but can also cause debilitating pain. It can be disabling.

Since 1994, thousands of people from all over the world suffering with the most complex corneal conditions have found answers, and in most cases, dramatic transformation, at the Boston Foundation for Sight.

The Boston Foundation for Sight is a highly specialized not-for-profit organization emphasizing patient-centered care and quality of life. Our commitment spans insight, innovation, and involvement: we conduct advanced clinical research to drive medical treatment advances and continuous technological improvements; build resilient patient, family, and community support systems; educate medical professionals, patients, and the public; provide unparalleled patient-centered care at the heart of our unique treatment called PROSE (prosthetic replacement of the ocular surface ecosystem); and continue to expand an international network of top-ranked medical partners to bring this successful model to as many people as possible.

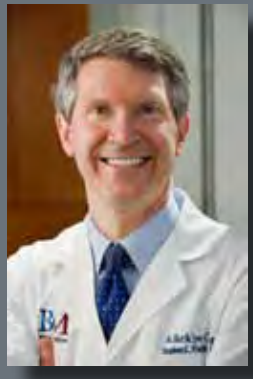
PROSE uses FDA-approved custom designed and fabricated prosthetic devices to replace or support impaired ocular surface system functions that protect and enable vision. The devices create a smooth, transparent optical surface over the irregular, damaged, or diseased cornea and form an expanded artificial tear reservoir that provides constant lubrication while allowing in oxygen — both of which are vital to the eye's health.



Complex Corneal Disease: Naming Names

Complex corneal disease encompasses a number of conditions and disorders and can also stem from a systemic illness like Stevens Johnson syndrome or TENS. The shared symptoms include vision impairment, dry eye, pain, and light sensitivity, and the course of treatment tends to be long, uncertain, and challenging. The following are among the most common conditions experienced by our patients:

Dry eye syndrome
Chronic ocular graft versus host disease (GVHD)
Stevens Johnson syndrome (SJS/TENS)
Sjögren's syndrome
Keratoconus and other corneal dystrophies and degenerations
Post-corneal transplant complications
Post-LASIK complications



Partner POV:
Stephen C. Pflugfelder, M.D.
Alkek Eye Institute
Baylor College of Medicine

It was ten years ago. Dr. Stephen Pflugfelder hadn't worked with the PROSE treatment model, but his patient's dry eye was so severe that he doubted what he thought was a standard lens would be any help. In fact, he cautioned that it could exacerbate the problem. However, his patient, feeling desperate, decided to make the trip to Boston, and he was treated successfully.

"I was amazed by how well he did. It opened my eyes," Dr. Pflugfelder said, adding that many eye professionals still have "a naive understanding of PROSE treatment."

Renowned for his expertise in ocular surface disease, Dr. Pflugfelder is a professor of ophthalmology, a researcher and a clinician who became one of the Boston Foundation for Sight's strongest professional advocates. When the opportunity arose for Baylor to become a BFS partner site, "we jumped at it," he said. In its first year, the PROSE clinic at Alkek Eye Institute treated more than 200 patients, and that number is expected to grow significantly.

The PROSE treatment model expands the possibilities because it allows for far greater control of the environment on the surface of the eye. It has produced dramatic results. One Baylor patient, a young man who'd suffered a chemical injury that blinded him in both eyes, had his vision restored, with one eye corrected to 20/15. "He can see his baby. It's just totally changed his life," Dr. Pflugfelder said.

There's a direct connection between our heritage and our mission. More than 30 years ago, our founding president and vice chairman, Dr. Perry Rosenthal, was an assistant clinical professor of ophthalmology at Harvard University. There he founded the Contact Lens Service at the Massachusetts Eye and Ear Infirmary, a Harvard Medical School teaching hospital, and led the development of new oxygen-permeable rigid contact lens materials, which improved comfort and eye health by allowing the cornea to breathe. These materials were a major breakthrough; still, the debilitating nature of complex corneal disease remained a challenge.

In 1994 Dr. Rosenthal founded the Boston Foundation for Sight to bridge the worlds of optometry, ophthalmology and medical technology and address these challenges head on.

At BFS, we've assembled an interdisciplinary medical staff that brings their expertise to bear on these pernicious conditions. Each patient treatment team includes a cornea specialist ophthalmologist, an optometrist who has completed an intensive nine-week PROSE Clinical Fellowship at BFS, and medical assistants, trainers, and prosthetic device manufacturing engineers and technicians to tailor the solution to the patient's specific needs.

At the same time, our dedicated professional staff focuses on providing an exceptionally supportive experience. We create opportunities for peer support, conduct specialized outreach, education, and training for patients and their families and friends, and host special events.

As a result, our patients tell us that we "get it." We make every effort to understand what they're going through, and we're driven to help them overcome the vision impairment, pain, dry eye, and light sensitivity that plague them.

How does complex corneal disease really impact people's lives? Consider that 90% of the information people take in is visual. Losing the use of your eyes likely means you can no longer work. Driving is out of the question. Beyond the visual impairment, there's pain. The quest for help begins, but more often than not, the three most common treatment options, artificial tears, oral antibiotics, and topical steroids, are ineffective.

Consequently, people often become frustrated and discouraged; many give up. Retreating from life and becoming isolated, they may feel misunderstood and descend into depression. Complex corneal disease affects their relationships with family and friends, their economic stability if they can no longer earn a living — in short, their whole world.

A visit to the Boston Foundation for Sight or one of our partner sites can turn night into day. In a recent online patient survey, 95% of BFS patients reported success with our PROSE treatment, success that extends beyond improving visual acuity to transforming the overall quality of life for our patients and their families. And we strive to improve that number every day.

At the Forefront

Our expertise as cornea specialists and an emphasis on compassionate care are complemented by our commitment to innovation.

We enjoy educational partnerships with the renowned Massachusetts Eye and Ear Infirmary and the New England College of Optometry. Each year Cornea Fellows and Optometry Residents come to BFS to be educated in the latest advances in the treatment of corneal disease, and they join our medical staff in cutting-edge clinical research on the next generation of tools to rehabilitate and restore function of the ocular surface system.

Our 12,000 square foot facility in Needham, Massachusetts includes a state-of-the-art manufacturing lab. Our doctors and BFS Clinical Fellows use our proprietary Design to Fit™ CAD/CAM system to meticulously control the design and ensure that each prosthetic device precisely fits the patient's unique eye shape to maximize comfort and ocular surface system function. Devices are then manufactured using Precitech ultra-precision computer numerical control (CNC) diamond lathe machines, which are typically used to make high-tech parts for the aerospace industry. By incorporating the most sophisticated design and manufacturing practices into our model, we can produce a patient's device within hours.

Expanding the Vision

Before 2010, only those patients who could come to our clinic in greater Boston could benefit from our PROSE treatment model. They represent a small fraction of the millions of people worldwide suffering from complex corneal disease.

To remedy this, we've established groundbreaking partnerships with top-ranked specialty eye care clinics located in academic medical centers in the United States and around the world. This growing network includes the Baylor College of Medicine's Alkek Eye Center in Houston, the University of Southern California's Doheny Eye Institute in Los Angeles, Brooke Army Medical Center in San Antonio, the Kellogg Eye Center at the University of Michigan, Ann Arbor, Weill Cornell Eye Associates at Weill Cornell Medical College, New York, The Illinois Eye and Ear Infirmary, University of Chicago Medical Center, Chicago, The North Shore Long Island Jewish Health System, Long Island, NY, as well as the L V Prasad Eye Institute in Hyderabad, India, The Eye Superspecialties in Mumbai, India, and the Nagoya Eye Clinic in Nagoya, Japan. Each clinic is extensively trained in the PROSE treatment model but is independently operated by our partners.

Complex corneal disease is aptly named. A variety of diseases and conditions with disabling symptoms, each disorder calls for an innovative, multifaceted response: the Boston Foundation for Sight's PROSE treatment model. For most people, it is in fact the only promising path to restoring the function of the ocular surface system — to improving vision, alleviating pain, and reclaiming lives.

Meet the patients, physicians, and staff who make the Boston Foundation for Sight so invaluable and discover the latest advances in the fight against complex corneal disease at **www.bostonsight.org.**

Join the conversation and our community by subscribing to the BFS e-Bulletin at www.**bostonsight.org/ebulletin.**

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