



BOSTONSIGHT

PROSE EYE VIEW

BOSTONSIGHT'S MONTHLY E-NEWS. WELCOME TO OUR COMMUNITY OF SIGHT!

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SJS Care Weeks - Thank You!

Our annual patient networking and outreach event, SJS Care Weeks 2016, has come and gone. We were gratified to welcome nearly 40 SJS survivors and their loved ones to BostonSight, our largest group ever.

Over the course of the two weeks, some patients required a completely new customization of their prosthetic devices, while others needed a little tweak, or just an annual evaluation. Regardless of their treatment need, each patient received the medical treatment necessary for their compromised eyes.

BostonSight thanks our resilient SJS survivors. As always, you came together as a community and shared your personal stories and knowledge with one another. As valuable as it is to bring our patients together, it is also an opportunity for family members and loved ones, often the caretaker after an SJS diagnosis, to share their experiences.

The planning committee at BostonSight works diligently to make this event happen each year. Coordinating all of the moving pieces of SJS Care Week is a painstaking process, but each member of the committee is committed to creating the best experience possible. Thank you!

The BostonSight administrative staff is adept at working through the many different types of questions that may pop up. Whether it is an inquiry about the hotel accommodations, medical insurance, or simply where to get a good burger, our staff was available to answer questions and lending a helping hand. We are grateful for their hard work and devotion.

Finally, a deeply sincere acknowledgement of the skilled clinicians, and ophthalmic and lab technicians at BostonSight. It is only thanks to their high level of dedication, training and skill that SJS patients are able to reclaim their lives through the gift of sight.

We look forward to welcoming everyone in 2017.

Best wishes,

The PROSE Eye View Editorial Team



LIMITLESS

Lindsay Hendrix - a patient's story

For almost 20 years, Lindsay Hendrix's poor ocular health limited what she could do and where she could go. After surviving toxic epidermal necrolysis (a severe allergic reaction that is fatal to 30% of those who contract it) at age 10, her ability to enjoy her life on any given day was dictated by the condition of her damaged eyes.

In grade school, her main symptoms were excessive tearing and severe light sensitivity. "I had a really hard time," remembers Lindsay. "I had red puffy eyes and looked like I was crying all of the time. I was embarrassed." Lindsay eventually got tired of explaining her situation and would simply say that she had allergies.

As Lindsay entered college, her symptoms had stabilized, which allowed her to develop a consistent treatment routine. She had her eyelashes plucked monthly and applied her eye medications regularly. But even with some improvements, Lindsay's painful eyes forced her to make adjustments to her lifestyle and workload. "I knew that staying up late was difficult, so I avoided making plans. I knew I couldn't go outside without sunglasses, so I brought them everywhere."

Lindsay tried BostonSight PROSE treatment, but, "I had a difficult time inserting the prosthetic device, and the idea of shoving a piece of plastic into my irritated eye confused and scared me. Dr. Jacobs and I weighed the



pros and cons and decided that I didn't need PROSE yet."

Despite her challenges, Lindsay earned her Doctorate of Physical Therapy and joined the adult working world. But her eyes kept getting worse, and around 2014 her symptoms changed. "My main issue was dryness; it felt like someone was holding a fan in front of my eyeball." Her left eye dried out each day, and by early evening it would completely close. Over time, her eye began to close earlier and earlier in the day, and soon Lindsay could no longer drive at night. She started to really worry about her future, and the future of her eyes.

When Lindsay became engaged to be married in February 2015, she, like most brides, wanted to look and feel her best for her big day. "I remember expressing my concerns to Dr. (James) Chodosh. 'Would I be able to keep my eyes open on my wedding day?'" Dr. Chodosh performed a punctal occlusion, but when the dryness returned, he suggested that Lindsay give PROSE treatment another try.

Lindsay did just that, and now she wears a PROSE device in her more symptomatic left eye; she applies the device 2-3 times each day, for several hours at a time. She got the beautiful wedding day that she so wanted, and got rid of something even more important – limits. "I got my freedom back to do whatever I want to do. I can live the way I used to, without having to worry. As long as I have my BostonSight "blue bag" of PROSE supplies, I can go anywhere and do anything!"



EDUCATION AND RESEARCH

BostonSight PROSE doctors at AAOpt - Part I

The 95th Annual Meeting of the American Academy of Optometry (AAOpt) will be held November 9 – 12, in Anaheim, CA; many of our BostonSight PROSE clinicians will be on hand to teach and learn from their peers. The following is a list of the continuing medical education (CME) courses being presented by our doctors at the meeting. Check back next month for a list of relevant posters and presentations.

- *Basics of Scleral Contact Lens Fittings: It's as Easy as 1-2-3.* Karen Lee, OD, FAAO, FSLs, University of California, San Francisco
- *Video Grand Rounds: Specialty Contact Lenses.* Karen Lee, OD, FAAO, FSLs, University of California, San Francisco
- *Long Term Effects of Scleral Lens Wear: The Good and the Bad.* Karen G. Carrasquillo, OD, PhD, FAAO; and Alan Kwok, OD, FAAO, BostonSight
- *Scleral Lenses for Ocular Surface Disease.* Ellen Shorter, OD, Illinois Eye and Ear Infirmary (pictured left)

At the Academy, BostonSight Medical Director Deborah S. Jacobs, MD, will participate in a joint symposium of the American Academy of Optometry and American Academy of Ophthalmology, entitled *Corneal Infections and Contact Lens Wear: An Evidence-Based Approach to Navigating the Risks and Complications..*

Educating New England eye doctors about PROSE

In our ongoing effort to educate the professional ophthalmology and optometry communities, BostonSight clinicians are taking in several professional outreach opportunities in September:

- On the 9th-10th, Crystal Remington, OD, FAAO (pictured left), will staff an informational table at the Vermont Optometric Conference.
- BostonSight Director of Clinical Care, Karen G. Carrasquillo, OD, PhD, FAAO, will travel to Maine, to share information about BostonSight PROSE at the 15th Annual Downeast Ophthalmology Symposium.
- On the 30th, Chirag Patel, OD, will be joined by BostonSight staff members Gillian Fontana and Melissa Hatch, at an informational table in the exhibit hall at the Fall 2016 meeting of the New England Ophthalmological Society (NEOS).





EDUCATION AND RESEARCH

Dr. Jacobs at TFOS

Next month, BostonSight Medical Director Deborah S. Jacobs, MD (pictured below, with a patient), will attend the 8th International Conference on the Tear Film and Ocular Surface (TFOS), to be held in Montpellier, France on September 7th – 10th. She will moderate a session on neuropathic pain; she also joins an international group of physicians on a poster about chronic corneal pain.

Physicians from many members of the BostonSight Network will also participate in the conference, including a keynote address given by Victor Perez, MD, of Bascom Palmer Eye Institute. A poster on PROSE treatment, created by doctors at Northwell Health in Great Neck, NY, will be presented.

Dr. Jacobs and other members of the Tear Film and Ocular Surface Society (TFOS) have been working for the past year to update the 2007 Report of the International Dry Eye WorkShop (DEWS), which was an encyclopedic review of dry eye disease and a guide to dry eye resources available on the internet. DEWS II seeks to expand upon and update this important work, which will be published in a professional journal upon completion. Dr. Jacobs is a member of the Pain and Sensation sub-committee, and co-author of their preliminary report. Each of the 12 sub-committees will present such reports at the September meeting during a half day session devoted to DEWS II.





COMMUNITY RESOURCES

GVHD telephone support group

In February, we let you know about some improvements that were being made to our Needham headquarters to improve BostonSight patient experience. Since then, we have continued to replace flooring and painted the walls; this project is expected to be completed in the fall with the renovation of our exam hallway and front end. We have also replaced much of the furniture in our patient and community waiting areas. The overall effect is a more comfortable, inviting, and visually pleasing atmosphere. We hope you enjoy it!

Apps for the visually challenged, and more, on BostonSight blog

In the first in a series of occasional blog posts about mobile applications, or apps, that are designed for those with visual impairments, this month we did some research on apps that use your mobile device to distinguish between colors. Please note that BostonSight is not associated with these applications in any way, nor does it endorse or take responsibility for any of the content or functionality. This information is provided for the convenience of our blog readers.

Other recent blogs include information on SJS Awareness Month; and a study to determine if an association exists between keratoconus, socio-demographic factors, and common systemic diseases.



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