



PROSE Eye View - Issue 5 Vol 2 May 2011

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Sponsor a Child: SJS Kids Week 2011!

Have you had the pleasure of meeting an SJS Kid?

They are just like any other kid. Smart, funny and lively. They have diverse interests – theatre, music, sports, art. They are beloved by parents who would do anything for them. Sounds like any other kid you know, right?

But there is a unique difference. These kids (and their families) are survivors. They have survived one of the most frightening medical journeys that anyone could take – Stevens Johnson syndrome (SJS), an intense immune sensitivity reaction that primarily affects the skin and mucus membranes, including the eyes. SJS randomly strikes an estimated 33,000 people every year – 20% of them children. In severe cases, the disease has been described as burning the body from the inside out – causing severe pain and leaving permanent scars and tissue damage that can result in blindness. Many victims do not survive.

We wanted to create a community of support for these special BFS patients by addressing the traumatic impact that Stevens Johnson syndrome can have on every member of the family—children, parents, and siblings. With help from the [SJS Foundation](#), we held our first [SJS Kids Week in the summer of 2010](#) - the only program of its kind in the world for pediatric survivors.

For one week in August this summer, our SJS children and their families will live, eat, learn and play together on a beautiful campus at the nearby Walker Center. While medical treatment is the focus of the week, it will also be filled with fun activities, facilitated conversations, group dinners and engagement projects, helping them to heal both physically and emotionally. In 2011, we hope to double the number of families who can attend SJS Kids Week to 25.



These are ambitious plans. And we need your help. Sponsorship for one family to participate in this amazing experience free of charge is \$2,500. Our goal is to raise \$50,000 in the next month. Together we can make a profound difference in the life of an SJS child.

To make an online donation of any amount, click here to [DONATE NOW](#). If you'd prefer to donate by check, please mail it to: Tara Stepanian, Boston Foundation for Sight, 464 Hillside Avenue, Suite 205, Needham, MA 02494. Please make your generous gift today!

Research and Education News

BFS and PROSE Partners Present Six Posters at ARVO Annual Meeting in Ft. Lauderdale!



The photo above was taken at a presenters dinner hosted by BFS. Collegial atmosphere and good food were enjoyed by all.

We are proud to announce that doctors and researchers from BFS and our PROSE partners in [Houston, TX](#), [Los Angeles, CA](#) and [Hyderabad, India](#) presented six posters at the 2011 Annual Meeting of the Association for Research in Vision and Ophthalmology (ARVO), May 1-5, in Fort Lauderdale, FL.

- **Prosthetic Replacement of the Ocular Surface Ecosystem for Ocular Surface Disease.** Kristen M. Hawthorne, Hong-Gam Le, Deborah S. Jacobs
- **Initial Experience of Prosthetic Replacement of the Ocular Surface Ecosystem (PROSE) in Cancer Patients.** Janhavi M. Modak, A. Kingham, V. Arevalo, A. Gire, S.K. Kim
- **Fluid Ventilated Scleral Contact Lenses In Pediatric Patients: Challenges and Outcome.** Varsha M. Rathi, P. Mandathara, S.D, P. Vaddavalli, V.S. Sangwan
- **Prosthetic Replacement of the Ocular Surface Ecosystem (PROSE) Treatment at Doheny Eye Institute (DEI): Clinical Evaluation of Partner Clinic.** Kristen O. Chapman, S. Khashabi, G. Chiu, S.C. Yiu
- **OCT Guided Design and Fitting of an Ocular Surface Prosthetic Device.** Hong-Gam T. Le, M. Tang, Ryan Ridges, D. Huang, Deborah S. Jacobs
- **Dry Eye-like Symptoms Without Dry Eyes Is A Neurological Disease.** Perry Rosenthal, James Bradley

Dr. Rosenthal Presents at SOBLEC Brazilian Congress

Dr. Perry Rosenthal was invited to be a guest speaker at The Brazilian Society of Contact Lens, Cornea and Refractometry (SOBLEC) in Curitiba, Brazil. His presentation, **Dry Eye: Current Understanding**, was extremely well received.

Please see page 6 to read more research and education news.

PROSE Partner News

New PROSE Clinic Opening This Summer on Long Island!

We are pleased to announce that our newest PROSE partner clinic, North Shore- Long Island Jewish Health System (North Shore-LIJ) will begin seeing patients later this summer.

Corina Busuioc, O.D., from North Shore-LIJ is our newest PROSE Clinical Fellow; she began her nine-week fellowship at BFS on May 2. Corina graduated from the University of Houston College of Optometry (UHCO) in 2005. She completed a contact lens fellowship from UHCO in 2006. Corina has worked as Adjunct Clinical Faculty at UHCO since 2005 and at a private practice, Eye Contacts, in Houston, since 2006.



Please visit our website to learn more about the [PROSE partner network](#).

Clinic Updates

Making the Referral Process Easier: New Tools for Medical Professionals

We are pleased to share two new tools we have created to help streamline our patient referral process and make it easier for doctors and their patients to access comprehensive information about our treatment. Medical professionals wishing to refer a patient can complete the [Physician Referral Form](#) online. We also have a new **Physician Referral Hotline** for **urgent** patient referrals: 781-726-6033.

Our new [PROSE Materials Order Form](#) makes it easy for medical professionals to order complimentary PROSE materials and resources including:

- PROSE Guide: Information for Patients and Doctors (available for BFS and all US partner clinics)
- Copies of our disease specific brochures for *Dry Eye*, *Chronic Ocular Graft-Versus-Host Disease (GVHD)*, *Stevens Johnson Syndrome*, and *Keratoconus and Corneal Ectasia*
- Demo PROSE device
- Device removal plungers

If you are not a medical professional and wish to request copies of any of our brochures, please email Melissa at webmistress@bostonsight.org. Please note that PROSE demo devices and sample plungers are available for medical professionals only.

Visit the [For Doctors section of our website](#) for more information!

BFS Staff Updates



Goodbye Gislaine

BFS Lab Technician Gislaine DaSilva's last day was May 13. After spending several months in her home country of Brazil, Gislaine plans to concentrate on her handmade jewelry business. We thank Gislaine for her service to Boston Foundation for Sight and wish her the best of luck!!

Congratulations Manny!

BFS Lab Technician Manny Carvalho was recently promoted to Lab Manager. Congratulations on your new position Manny!



Welcome Back Trisha!

We are pleased to welcome Trisha Hussoin back to BFS! Trisha, a former Research Assistant, will be working in the clinic this summer while on break from optometry school.



Introducing Our New Ophthalmic Technician

Kristina Somers will be joining BFS on June 6 as an Ophthalmic Technician and she is "very pleased to be joining the team at Boston Foundation for Sight." Kristina has been working in the field of ophthalmology for eight years and enjoys working with patients to help them get the best out of their vision. In addition to her love of the great outdoors, in her spare time Kristina likes to read, knit and sew. Welcome, Kristina!

Patient Support Resources

New Connected Visions Blog Post

Please visit our blog to read the latest informative post - [Sjogren's Syndrome Foundation Brings National Dry Eye Conference to MA](#). Please note that the previously reported date for the conference has been changed; it will now be held on June 25 in Andover, MA.

Social Security and Disability Resource Center

[The Social Security and Disability Resource Center](#) provides information on the federal disability benefit programs, SSD (social security disability, mandated under title II of the social security act) and SSI (supplemental security income, mandated under title 16), in addition to answering questions about social security retirement benefits and providing resource links on topics such as Medicare.

Please visit the [financial resources section of our website](#) to read about more organizations that can help.

Patient Profile - Mark Fleck

Dear Boston Foundation for Sight Staff,

My wife of almost 30 years, Georgiann, is a constant companion and we share our lives in everything we do. Our life may seem simple to some but to us it is very full and enjoyable. I operate two businesses. We have a maple sugar grove with 200 taps set the old fashioned way with buckets and spiles. We love to ice fish, cook, cruise in our antique trucks, haunt yard sales, walk through the woods looking at wildlife, and spend time at our remote camp.

In 2002 I was involved in a car accident and it was through that that I found out I had myelodysplasia (MDS), which is a collection of disorders in which the bone marrow does not produce enough blood cells. I was told that I had six months to live unless I had a bone marrow transplant. Needless to say I did go through with the transplant and it was considered a success. However, since then I have been in constant pain due to severe dry eye syndrome and flare ups of graft versus host disease (GVHD), which took away so much of the beauty around me that I enjoyed so much.



Mark Fleck stands next to the sculpture he made for BFS, which hangs in our lobby.

In December of 2010 I had a flare-up which was so bad that it debilitated me to a point that I did not dare drive. Even the lights from the TV hurt so bad. The only thing I could do was lay on the couch with compresses on my eyes to ease some of the pain. This went on for days. I had become so depressed that I was ready to take my own life. Desperate to get me help, my wife contacted Toni, an amazing nurse at the Dana Farber Cancer Institute, who immediately arranged for me to come to Boston Foundation for Sight for PROSE treatment.



Mark and Georgiann Fleck with Dr. Lynette Johns

Just five days later we traveled from our home in Bridgton, Maine to Needham, which takes about four hours each way on the interstate. The first time we got lost on the way home. The second time I plowed snow all night, got home at 1:00 a.m., was up at 2:30 a.m. and out of the house at 3:00 a.m., traveling in a snow storm to make it for our 8:00 a.m. appointment. This is quite a trip for us seeing as we come from a town with one traffic light.

Your staff did everything possible to accommodate us and decrease our trips. It was also very enlightening to meet other patients in the lounge and kitchen and converse with them about the challenges that they have encountered in their lives. The facility is very relaxed and the staff makes sure that everyone is very comfortable.

For the first time in six years I was home in Bridgton and got to wear the devices all day beginning at 6:00 a.m. At 5:30 that night I was in the kitchen with my beautiful wife, cooking over a glass of wine and dancing to vintage vinyl. We were twirling each other, hugging and laughing. And I was pain free thanks to PROSE!

I thank you from the bottom of my heart. - Mark Fleck

Visit the [Patient Profiles section of our website](#) to read more inspiring stories!

Research and Education News Continued

UIC Cornea Symposium: PROSE and GVHD Presented

The University of Illinois at Chicago held a Cornea Symposium entitled Management of Difficult and Complicated Cases in Cornea, April 22 - 23, 2011, at their medical center campus. Among the presenters was BFS Medical Director Deborah S. Jacobs, MD, who gave the Timothy McMahon, OD Endowed Lecture, **Opportunity for Impact: Therapeutic Lens and Ocular Graft-versus-Host Disease**.

Ellen Shorter, OD, PROSE Clinical Fellow and lead optometrist at the [PROSE clinic at UIC](#), gave a presentation entitled **Prosthetic Replacement of the Ocular Surface Ecosystem (PROSE) Treatment**.

Lynette Johns, O.D., Appointed Fellow of SLES; Presents Webinar

On April 12th Dr. Lynette Johns was appointed a fellow of the Scleral Lens Education Society (SLES) and presented a webinar entitled:

- **Scleral Lens Complications and Troubleshooting.** Melissa Barnett, Mindy Toabe, Lynette Johns

Congratulations Dr. Johns!

Deborah Jacobs, M.D., Presents at 2011 IOSS Annual Meeting

Dr. Debbie Jacobs presented at the 14th Annual meeting of the International Ocular Surface Society (IOSS) held in Hollywood, FL on April 30th. The IOSS is headed by Dr. Steve Pflugfelder, cornea specialist for the [PROSE Clinic at Alkek Eye Center, Baylor College of Medicine](#). Dr. Jacob's presentations included:

- **Design of an Ocular Surface Prosthetic Device in the Rehabilitation of Penetrating Keratoplasty**
- **Systemic Treatment as an Adjunct to Local Treatment for Ocular Surface Disease Complicated by Corneal Neuropathy**

Please visit the [research section of our website](#) to view our published peer-reviewed papers, posters and presentations!

Our mailing address is:
Boston Foundation for Sight
464 Hillside Avenue, Suite 205
Needham, MA 02494

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