



PROSE Eye View Issue 7 Vol 2 July 2011

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From the Desk of Gene Bonte, CEO



As we approach the end of July, I wanted to follow-up on my introduction in last month's PROSE Eye View and take a few minutes to update you on events here at BFS. After six weeks at the Foundation, I have had the pleasure of talking with the staff, enjoyed meeting our patients and learned a great deal about what BFS does and how we do it.

I'm particularly excited to be able to participate in SJS Kids Week. Our patients and their families will be arriving this coming weekend for an experience of a lifetime. Between treatment, therapeutic discussions and fun activities like a BBQ, Halloween in August and a scavenger hunt, it is going to be a wonderful time for patients, their families and our staff.

We are also pleased to announce that through the pro-bono work of our Chairman of the Board, Gary Knaak, and his company, Post Central, we will be creating a video that will be an invaluable tool in educating others about SJS, the ocular complications of the disease and how the PROSE treatment can help. Much of the filming will be done during SJS Kids Week.

Special thanks to Dr. Lynette Johns who conceived of SJS Kids Week and to Tara Stepanian, Beth Beard and Melissa Hatch for bringing her vision to life in conjunction with the entire staff at BFS. It is a testament to what we do best – deliver world class treatment combined with compassionate care.

Finally, August is a big month for vacation time – and so we have decided to give PROSE Eye View the “month off” as well. Be on the lookout for our next edition at the end of September. Enjoy this issue of PROSE Eye View and enjoy the rest of your summer!

Two PROSE Parents: One Mission

SJS Awareness Month Declared in 16 States

Jean McCawley's life changed forever one August day in 1994 when she learned about [Stevens Johnson Syndrome](#), an intense autoimmune sensitivity reaction to infections or medications that primarily affects the skin and mucous membranes, including the eyes.

Jean's ten-month-old daughter Julie lay blistered and swollen in a hospital bed having a rare allergic reaction to medication she had taken to treat seizures. "I was up there at the hospital with Julie day in and day out all by myself. I would have given anything to meet someone else [who could relate]." SJS was so rare that doctors told Jean she would probably never meet anyone else with the disorder. Wanna bet?

Seventeen years later, Jean McCawley is the heart and soul of the [Stevens Johnson Syndrome Foundation](#), a nonprofit dedicated to supporting and educating people dealing with SJS. "I couldn't let someone else go through it alone. That's why I did it." When Julie was diagnosed, Jean could only find one SJS-focused article in a medical library. If you Google SJS today, the SJS Foundation will come up among the top five results.



True to its mission, the SJS Foundation connects patients and their loved ones to information in a variety of ways including with SJS Awareness Month. Since awareness of SJS and its symptoms is thought to be a crucial part of decreasing the severity of an SJS reaction, Jean has been lobbying Governors across the country to proclaim August as SJS Awareness Month, and in [16 states and counting](#) she is succeeding (recently added but not yet listed are Oregon, New Jersey and Nevada)!



It all started with a simple letter asking her Governor to make August SJS Awareness month in the state of Colorado. The help from her father on the wording of the letter must have been just right because much of it was used in that first proclamation that is now the template for proclamations in other states.

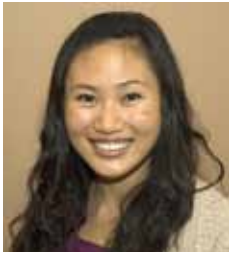
Jean is not alone in her desire to support others and spread awareness. Across the country in Maryland, Jill Kleeman's adult son Brandon was diagnosed with SJS in 2009 after reacting to a medication to treat a basketball injury. After some excruciatingly difficult weeks in the hospital, Brandon was able to go home. However, damage to the epithelial layer of one of his eyes left him severely photophobic, a corneal ulcer was emerging and the need for hourly eye drops was severely affecting his independence.

Please turn to page 6 to continue this story.

BFS Staff and Board Updates

Two Doctors from the New England College of Optometry Join BFS Residents Program

Dr. Alan Kwok, head of the BFS [Optometry Residents Program](#), is pleased to welcome the two latest additions to our program, Dr. Yin-Yin Aung and Dr. Rutvi Doshi.



Dr. Yin-Yin Aung graduated from The New England College of Optometry, where she also worked as a contact lens lab teaching assistant and a clinical and didactic tutor. She was awarded the Vistakon Award for Excellence in Contact Lens Patient Care. Throughout her optometric career, she has volunteered abroad in optometric humanitarian missions in the Dominican Republic and the Philippines.

Dr. Rutvi Doshi's interest in Optometry began at a very young age and after receiving her BS, she continued her education at The New England College of Optometry (NECO), where she received her doctorate in 2011. While at NECO she had the opportunity to participate in two humanitarian missions, to Mexico and the Dominican Republic, providing care to thousands in need. She is thrilled to be part of the Optometry Residents program at BFS.



BFS Research Assistant James Bradley is Headed to Medical School

Congratulations to James Bradley, who has worked at BFS as a Clinical Research Assistant since July 2009. James will be attending medical school at Mount Sinai School of Medicine in New York, NY this fall. We are very proud of James and wish him much success in his medical career.



Meet Leslie Wu, Clinical Research Assistant

This month we welcomed Leslie Wu to BFS as our newest Clinical Research Assistant. Leslie graduated in 2011 from Brandeis University magna cum laude and Phi Beta Kappa, with a Bachelor of Science degree in Biology and Chemistry. She worked as a teaching assistant for general and organic chemistry for two years and did research on Huntington's Disease with Dr. Jason K. Pontrello. Welcome, Leslie!

Ophthalmic Technician Karen Zeiger To Leave BFS

Clinic Technician Karen Zeiger's last day at BFS will be July 29. Karen has worked at BFS since 2008, and she is moving to Florida to be closer to her family. Please join us in wishing Karen the very best!

Dr. Amy Croteau Watts Joins Mass Eye and Ear Staff

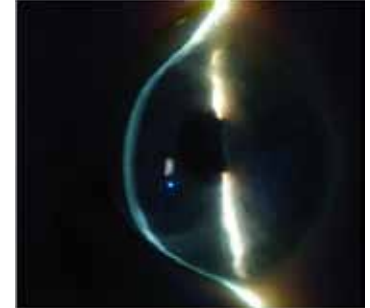
Dr. Amy (Croteau) Watts will be leaving BFS on July 29 to accept an exciting full-time position at the Massachusetts Eye and Ear Infirmary (MEEI). Dr. Watts worked at BFS from 2003 - 2005, and rejoined the staff in 2010. But she is not going far. She will continue to work closely with BFS' Medical Director, Dr. Jacobs, who has been a member of the Cornea Service Faculty at MEEI since 2003 and runs a PROSE Clinic on site two days per month.

Research & Education

Dr. Lynette Johns on I-Site: Frustration or Fenestration?

[Frustration or Fenestration?](#), an article written by BFS Optometrist Dr. Lynette Johns, was published in the July 2011 edition of the online newsletter I-Site. In the article, Dr. Johns discusses a technique for fitting patients who have previously undergone corneal transplants and shares her extensive expertise in this area.

Late Breaking News...Dr. Johns' latest feature article, [Fitting Scleral Lenses for Ocular Surface Disease](#), was published today in Contact Lens Spectrum's Annual Dry Eye Issue.



Dr. Deborah Jacobs to Present at Schepens Cornea Conference

BFS Medical Director Dr. Deborah Jacobs will be a presenter at the Schepens Eye Research Institute's [27th Biennial Cornea Conference](#), to be held on September 30th - October 1st at the Starr Center for Scientific Communications in Boston. The session, *Dry Eye and Ocular Surface Disease*, will be on Friday the 30th.

Patient Resources

BMT Infonet Conference- We Hope to See You in Atlanta in September!

BFS is proud to sponsor [Celebrating a Second Chance at Life, National Symposium for Bone Marrow, Stem Cell and Cord Blood Transplant Survivors](#), presented by BMT Infonet.org in Atlanta, GA, on September 10 - 11, 2011. BFS' Dr. Deborah S. Jacobs will present a workshop entitled *Chronic GVHD and the Eyes*, and we will also have an informational table hosted by Beth Beard, our Director of Communications. Scholarships are available for those who cannot afford the \$25 symposium fee. Please visit their website at <http://www.bmtinfonet.org/atlanta2011> for more information or to register to attend. We hope to see some of you there!

Connected Visions - the BFS Blog

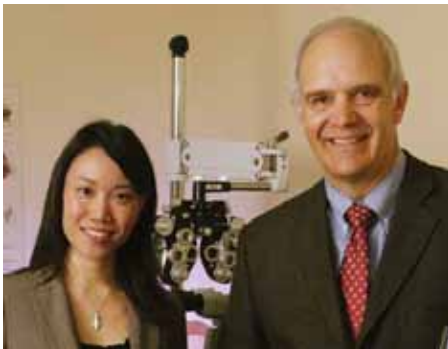
Do you ever have trouble seeing the computer screen? Check out our latest blog entry for help: [Making the Computer Easier to Use](#).

In the News

SJS Kids Week Makes the News!

When Joe Sorrentino, a producer for the Needham Channel cable news station, first heard about Boston Foundation for Sight and SJS Kids Week from one of our staff, he knew ours was a story he needed to tell. [The piece](#), which aired mid-June on four local stations, includes interviews with Dr. Perry Rosenthal, Dr. Lynette Johns and Beth Beard, Director of Communications.

PROSE Featured in Doheny Annual Report



Dr. John Irvine, Dr. Gloria Chiu and the Perry Rosenthal PROSE Clinic were prominently featured in the [Doheny Eye Institute's 2010 Annual Report](#). "PROSE is another notable example of Doheny experts seeking new cures for blindness through innovation," said Dr. Ronald E. Smith, Chairman of the University of Southern California's Department of Ophthalmology, which is currently ranked 9th in the country among ophthalmology programs by *U.S. News & World Report*.

Let There Be Sight: A Chemist Opens Her Eyes to the World of Optometry

Last week, Dr. Karen G. Carrasquillo was profiled on the blog CENTral Science. [Let there be sight: a chemist opens her eyes to the world of optometry](#), chronicles Dr. Carrasquillo's path from receiving a PhD in chemistry to becoming an Optometrist at BFS. It's a great read!

PROSE Partners

North Shore- Long Island Jewish Health System PROSE Clinic Now Seeing Patients!

We are excited to announce that the newest [PROSE Clinic at the North Shore - Long Island Jewish Health System](#) (NS-LIJ) is now open. The PROSE Clinic is located in the new [Ocular Surface Center](#), which is the only center of its kind in the Long Island area specializing in the treatment of complex ocular surface disorders. Led by Anne Steiner, MD, Director of the North Shore - LIJ Ocular Surface Center, their highly skilled specialists evaluate and successfully treat a wide range of ocular surface diseases and conditions.

PROSE Clinical Fellow Corina Busuioc (pictured at right) and PROSE Clinic Coordinator Monica Falconi are available to answer questions and schedule appointments.



Tech Tips Corner

Q. I have two PROSE devices. How can I distinguish between the left and the right?

A. For patients with devices for both eyes, the RIGHT device is marked with ONE black dot. The LEFT device will have either NO dot at all or TWO black dots. When either device has one or two black dots, such device should be inserted with the dot(s) oriented at the 12 o'clock position unless instructed otherwise by your doctor.

Q. What kind of eye make-up can I safely use while wearing my PROSE devices?

A. Download this chart: [Contact Lens Compatible Make-Up](#) for guidelines that are also appropriate for PROSE patients.

Please visit our website for more [Frequently Asked Questions!](#)

Two PROSE Parents: One Mission - Continued

“I’m constantly online researching ways to help him be more comfortable, connecting with other parents.” Online research is how Jill learned about the SJS Foundation, which informed her about PROSE treatment via [Julie McCawley’s success with PROSE](#). After six months of not working and constant assistance from friends and family, PROSE enabled Brandon to be working again and no longer in need of a constant support. Jill has since become an SJS Foundation support group facilitator and she takes the lead on renewing the SJS Awareness Month proclamation for the state of Maryland.

In conjunction with SJS Awareness Month, BFS is holding our [second annual SJS Kids Week](#), during the first week of August. SJS Kids Week is a pediatric outreach event dedicated to the treatment of complex corneal disease and the emotional support of SJS patients and their families. Julie, Jean and Jill all participated in SJS Kids Week in 2010 and Jill shares that it was, “...one of the best times of my life. It was so therapeutic to talk to others who went through this.”

Even if it is just for this one week, these families will become part of a larger community who share this experience.

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