



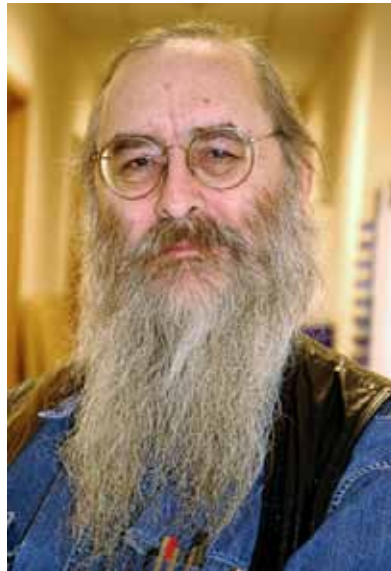
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BFS has a new channel on YouTube! Check it out by clicking the icon below.



## In Memory of Chris Ducharme



With great sadness we share the news of the recent passing of BFS employee Chris Ducharme on August 23 after a long illness.

Chris partnered with BFS Founder Dr. Perry Rosenthal for 40 years. As our in-house mathematician, he developed the patented Design to Fit™ CAD/CAM system that serves as the fundamental architecture of the prosthetic devices used in PROSE and which allows devices to be customized to each eye, regardless of the shape of the cornea.

Dr. Rosenthal said of his long time collaborator, “Chris Ducharme is the unsung hero of BFS. We worked together for over 40 years and it was his genius that developed the unique breakthrough technology that made PROSE possible. Each life that it has changed is his legacy.”

Thousands of people have had their sight restored thanks to Chris’ innovative work, and we are deeply grateful for his contributions to Boston Foundation for Sight. Our deepest condolences go out to his wife Denise and daughter April.

## BFS Staff Updates

### Welcome Sandra Hewitt to BFS!



Please extend a warm welcome to Sandra Hewitt, MHA, PT, who recently joined Boston Foundation for Sight in the newly created role of Director of Clinical Operations. She is responsible for ensuring efficient and effective systems that positively impact services provided to our patients.

Earlier in her career, Sandra practiced as a physical therapist and has since had extensive operational, planning, and consulting experience in the health-care field. She served in a variety of roles, including Director of Management Consulting Services at Spaulding Rehabilitation Hospital; Director of Clinical Program Development at Emerson Hospital; Vice President of Planning and Business Development at The Rehabilitation Hospital of the Cape and Islands; and Director of Ambulatory Operations and Internal Consultant at Beth Israel

Deaconess Medical Center.

Sandra holds a BS in Physical Therapy from Boston Bouvé College of Northeastern University and a Masters in Healthcare Administration from Framingham State College. As a community volunteer, she has most recently served as a nonprofit management consultant through the Newton Community Service Center.

### Transition in New Patient Affairs



Brenda Diaz's last day at BFS was Friday, September 16. Brenda (pictured at left) worked for BFS for the past four years in a variety of roles, most recently in New Patient Affairs. Please join us in wishing Brenda all the best.

Nancy Lemist (pictured at right), who has been with BFS for the last year in the role of Scheduling Coordinator, will serve as our Patient Intake Coordinator on an interim basis.



# SJS Kids Week 2011

## A Week of Hope, Sharing and Treatment

*"It's the best time that I've ever had! Thank you for helping my sister to smile again!"*

You don't often hear unbridled enthusiasm out of the mouth of a teenager. That superlative is what the brother of a pediatric patient and Stevens Johnson syndrome (SJS) survivor had to say about his experience at our second annual SJS Kids Week.

Traveling from as near as the greater Boston area and from as far away as Canada and Mexico, thirteen families came together at the nearby Walker Center in Auburndale, MA to experience a one-of-a-kind pediatric outreach event dedicated to the treatment and emotional support of SJS patients and their families.



Often an allergic reaction to medication, mild cases of SJS can cause irritation and dry eyes; in severe cases, it can lead to extensive tissue damage and corneal scarring that can result in blindness, chronic severe pain and light sensitivity. Also a disease of the skin, SJS often leaves visible burn scars on the face, hands and other parts of the body. Approximately 15% of victims do not survive.

SJS Kids Week provides support to young SJS patients and their families. It was born from the need for children who survive this rare disease to be able to meet one another, share their stories and advice, and for at least one week of the year, feel as though they are part of a larger community who understands and accepts them. This year's event was funded in part by a charitable contribution from Bausch + Lomb and the generosity of individual donors.

Much like a summer camp, each day was scheduled full of activities including: Halloween in August where the kids made their own costumes and masks and went trick-or-treating at the BFS clinic; a scavenger hunt; a water balloon fight; an afternoon of swimming; shared meals; laughter; tears; and unbridled joy. Facilitated therapeutic conversations, workshops and shared time together rounded out the week between medical appointments at the clinic.

A ground-breaking project associated with SJS Kids Week was the creation of a [documentary-style educational video](#). SJS and its ocular complications are largely unknown to the general public and, more surprisingly, within the medical community. Though the pro-bono work of Post Central from Rochester, NY and at the behest of its president, Gary Knaak (also the Chairman of the BFS Board) this video will engage and inspire while communicating a basic understanding about the disease, its effects and treatment needs.

"Thank you to everyone at BFS for making SJS Kids Week happen. I can't tell you how much it means to us to be able to meet other families and survivors. You have made a difference in many lives and have brought together many new friends." ~SJS Kids Week parent participant

[Visit our website](#) or the [BFS Facebook page](#) for hundreds of photos of this special event!

## BFS Hero of the Month

An update on Ralf Jarchow, a lawyer from Brampton, Ontario, who recently undertook a journey across Canada on his bicycle to raise money and awareness for Boston Foundation for Sight. We're thrilled to announce that his efforts have raised more than \$21,000!

Ralf's journey from Calgary in Alberta to Brampton was a marathon endurance event of over 2,112 miles to express his gratitude for the excellent care and support that BFS patients receive, including Ralf's own daughter, Megan.

Ralf rode 8-10 hours a day, averaging about 125 miles per day, all in the middle of a severe heat wave. Despite the challenge, he persisted and has come to marvel the human body and what it can achieve.

For his incredible accomplishment, we honored Ralf as our BFS Hero of the Month in August!

Visit the [community fundraising section of our website](#) to learn how you can plan a BFS fundraiser in your own community!

To read more about Ralf, please read [Biking for BFS](#) on the BFS blog, or check out Ralf's day by day journal here: [Keeping an Eye on Ralf](#).



## PROSE Partners

### New Optometrist Joins BAMC PROSE Clinic



Please join us in welcoming Dr. Evelyn Reyes-Cabrera to the PROSE clinic network. Dr. Reyes-Cabrera is our newest PROSE Clinical Fellow, and she will be replacing Dr. Jeffrey Cleland as the PROSE optometrist at Brooke Army Medical Center in San Antonio, TX; Dr. Cleland has been re-assigned.

Dr. Reyes-Cabrera is a Fellow of the American Academy of Optometry and holds numerous academic degrees and honors, including a Doctorate of Optometry from the Inter American University of Puerto Rico School of Optometry, where she graduated cum laude. She has been in the United States Army for almost ten years and holds the rank of Major.

Please visit our website for more information on the [PROSE clinic at Brooke Army Medical Center](#).

## Patient Resources

### Updated Device Care and Use Guide Available

We have published an updated version of [PROSE Treatment Guide: Prosthetic Device Use and Care](#). This version includes updated instructions on inserting and removing your devices. Please note that PROSE Treatment Guides are marked at the bottom of each page with a date and version number, and the most up to date version can always be found on our website at: [www.bostonsight.org/device-care](http://www.bostonsight.org/device-care).

### New Patient FAQ's Now on our Website

Check out the [new Frequently Asked Questions \(FAQ\)](#) section on our website for new patients who are interested in learning more about PROSE.

### Connected Visions, the BFS Blog

Get caught up on our latest blog posts here: [Illness Begets Art](#) and [Biking for BFS](#), mentioned elsewhere; [Caregiver Support](#), which focuses on the importance of self-care for caregivers; and [BMT Infonet T-Shirts](#).

### International White Cane Day

In 1931, the Lions Club began promoting the use of white canes for people who are blind as a national identification program. To commemorate International White Cane Day (October 15) and raise awareness of the White Cane Law, a celebration will be held on Friday, October 14 from 10:00 am - 12:00 p.m., on the Grand Staircase of the Massachusetts State House, located at the corner of Beacon Street and Park Street, Boston. For more information please call the Orientation and Mobility Department at the Massachusetts Commission for the Blind at 617-626-7581.

## Our GVHD Community

### Recovery - An Exhibit



The photography of Willard Traub, a BFS patient, is on display at the Danforth Museum of Art in Framingham, MA, through November 6. Willard, a cancer survivor, uses his photography to tell the story of his journey through cancer diagnosis, bone marrow transplant and recovery.

Please visit the [Danforth Museum website](#) to learn more about this wonderful exhibit, appropriately titled *Recovery*, or read our blog post, [Illness Begets Art](#), about Willard.

## Our GVHD Community - Continued

### Reconnecting at the Transplant Survivors Reunion

Some people in the BFS community are cancer survivors struggling with chronic ocular graft versus host disease (GVHD), an unfortunate potential side effect of various kinds of transplants that treat cancer. On July 23rd, we went to Seattle, WA to attend the 5+ year transplant survivors reunion hosted by the [Fred Hutchinson Cancer Research Center](#) and [Seattle Cancer Care Alliance](#). And what a reunion it was!

We were reunited with Robert Strom, a PROSE patient from many years ago, who once told us that, “My bone marrow transplant gave me back my life. But I wasn’t able to enjoy that life until I got PROSE.” It is many years later and he is still enjoying all that life has to offer.

We also ran into Richard Watkins who, having lost all vision in his right eye and on the brink of having his left eye sewn shut, decided to go for a BFS consult. He walked proudly about the reunion with his beautiful family and his PROSE-enabled left eyesight intact.

We sent our Online Community Advocate, Janice M. Epstein, and [Doheny Eye Center partner clinic](#) PROSE provider, Gloria Chiu, O.D., to the reunion to be available for those who are searching for answers to their eye health questions. We set up an information table with posters and handouts. Some reunion participants walked by and quietly browsed the materials, while others came by and asked a few questions before moving on. Then there were the visitors our past patients sent to the table. They were eager, had many questions and were hungry for information.

Our past patients knew just who needed to hear more about PROSE. They have a shared history with others experiencing eye disease and they know it when they hear it. The reunion provided a forum for reconnecting, celebrating and information sharing, but the survivors are the ones that provided the hope.



### BFS Sponsors BMT Infonet Conference

Boston Foundation for Sight is proud to have been a supporting partner for [Celebrating a Second Chance at Life](#), a national symposium for bone marrow, stem cell and cord blood transplant survivors. The symposium, hosted by BMT Infonet, was held in Atlanta, GA, September 10 - 11, 2011. The conference featured sessions on a variety of topics and included a well-attended presentation by BFS Medical Director Deborah S. Jacobs, M.D., entitled *Chronic GVHD and the Eyes*. BFS also had an educational table set up in the exhibit hall. Special thanks to BFS patient Cheryl for spreading the word about PROSE to her fellow attendees!

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