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Patient Profile - In Memory of Dr. Richard O'Neil

It is with heavy hearts that we memorialize PROSE patient Dr. Richard O'Neil, who passed away on January 15, 2011. Dr. O'Neil was diagnosed with leukemia in October 2007 and developed chronic graft versus host disease (GVHD) after a bone marrow transplant in March 2008. Rich was very active on the GVHD email group (Listserv), where, as a physician, he was particularly helpful in answering medical questions posed by other community members. Rich "was a great contributor and help to all of us. He had a great medical understanding and a unique ability to make things easy to understand," wrote Greg from Ohio. Rich charted the ups and downs of his disease on his inspirational blog (<http://richoneilsblog.blogspot.com>), where, despite his ever-changing health condition, Rich remained upbeat and positive, continually expressing his love of his life, his family and God.



After his transplant in 2008, Rich suffered from severe dry eye, a common complication of GVHD. His dry, gritty, stinging eyes caused him a great deal of pain and presented continuous challenges; intense light sensitivity made it almost impossible to enjoy his favorite outdoor activities, including biking, golfing and running.

Please see page 6 to continue reading about Rich.

BFS Staff News and Updates

Please Welcome Ilene Knopping to BFS



Our new PROSE Clinic Network Director is Ilene Knopping—a career-long ophthalmology administrator and consultant. She will be leading our efforts to both initiate new partner relationships and to support and collaborate with existing partners on all aspects of PROSE Clinic development, operations and growth. Ilene joins BFS after completing a consulting project for us. She has more than 25 years experience with consulting to, managing and leading eye institutions and ophthalmological practices across the U.S., including Massachusetts Eye and Ear Infirmary, New England Eye Center at Tufts Medical Center, Bascom Palmer Eye Institute and Eye Centers at Duke and Boston Universities and the Lahey Clinic. We are incredibly pleased to have Ilene join our team.

Jinny Bellevue on Leave

Jinny Bellevue, Patient Insurance Coordinator here at BFS, will be taking a leave of absence beginning February 28th. In her absence please contact Donna Kelleher at 781-726-7430 or dkelleher@bostonsight.org; or Lynn Carter at 781-726-7505 or lcarter@bostonsight.org for any insurance-related inquiries.

Research and Education News

We are very proud to announce that BFS' Dr. Karen Carrasquillo will be part of Inspiring Minds: Meet Women in Science 2011 at the Museum of Science, Boston. The event, being held April 28, 29 and 30 at 9:00 am, is an opportunity for children to meet dynamic woman in science, listen to them speak about their careers, and then try out related experiments. This is a wonderful learning experience and a great way for girls and boys to become more interested in science. The event is free when you purchase a regular Exhibits Hall admission. Please visit http://www.mos.org/events_activities/events&d=4849 for more information.



A Slice of Life

Dr. Stephen Pflugfelder - A Man of Many Talents



Did you know that in addition to being a skilled cornea specialist for the PROSE Clinic at the Alkek Eye Center, Baylor College of Medicine, Dr. Stephen Pflugfelder is also a member of DOUBLE VISION? This Houston based dance band's repertoire includes music from The Beatles, The Go-Gos, The Police, The Rolling Stones, Stevie Wonder, The Bangles, Fleetwood Mac, Jimmy Buffett, and many more. Double Vision has seven members, including three ophthalmologists, one neurologist, a dentist, a former medical information specialist, and an executive recruiter.

Dr. Pflugfelder, who plays lead guitar and sings back-up vocals, received his first guitar for Christmas when he was 11 years old. In high school, Steve formed a rock band called Hard Knocks with some of his classmates. His love of music and passion for live performance continued through college at SUNY Upstate in Syracuse, NY. His interest in music was re-kindled when his wife bought him a Fender Stratocaster for his 40th birthday.

Please visit <http://www.doublevisionband.com> to read band biographies, see the band's repertoire and to listen to a sample. We here at BFS look forward to checking them out next time we are in Houston!

Patient and Community Support Resources

2011 Sjogren's Syndrome National Conference

The Sjogren's Syndrome Foundation is holding its' 2011 National Conference on April 1 - 2, in Reston, Virginia. The two-day event will feature presentations from physicians, dentists, eye care professionals and researchers on a number of topics, including:

- Dry Eye and Dry Mouth Issues
- OB-GYN Issues and Sjogren's
- Lung Complications
- Sjogren's Survival: A Patient's Perspective

The conference offers an early bird discount to those who register by March 7. Please visit their website at <http://www.sjogrens.org/> for more information or to register.

What's New in Communications?

Please Review BFS on Yelp!

We hope you will take a moment to check out the BFS page on Yelp! In case you don't know, Yelp is a great resource for reviews of restaurants, auto mechanics, salons and yes, doctors and medical facilities. Because Yelp often filters out reviews from first-time reviewers, we are particularly interested in having seasoned Yelpers share their thoughts about and experiences with BFS. Please visit <http://www.yelp.com/biz/boston-foundation-for-sight-needham> and share your opinion today!

Curriculum Vitae Now Available for BFS Doctors

We have recently added complete curriculum vitae (resumes) for all of our BFS doctors to our website. Each listing includes information on education, work experience and professional associations and publications. Please visit our website at <http://www.bostonsight.org/doctors> to read more.

New Supports for You at Connected Visions Blog!

Do you ever have days when you don't know where to turn for support; days when you feel like no one else truly understands what you are experiencing; or, maybe even days when you feel compelled to take action but don't know how to do so?

If you answered yes to any of these questions, you are not alone. BFS hopes to go beyond basic medical care by creating the space for an active community - a place you can turn to for support, resources, networking, and advocacy ideas. Our Connected Visions blog for those living with or affected by corneal disease recently made the following posts for you to ponder:

- Welcome to Connected Visions, 1/11/2011
- Emotional Empowerment, 2/10/2011
- Study Aims to Improve Transplant Survivors Quality of Life, 2/18/2011

We would love to hear your thoughts, responses, and suggestions, so if you are inspired to do so, please visit <http://www.bostonsight.org/blog> to register and post comments on the blog!

New Community Fundraising & Events Program

Want to Plan an Event to Benefit BFS? Here's How!

Thanks to all of you who donated in support of BFS in 2010, we are grateful for your support! In 2010, 64% of our support came directly from patients and their family/friends. BFS relies on fundraising and philanthropic support to improve and expand our efforts – from patient treatment and care, to community engagement and networking, to expansion of the PROSE Partner Clinic network in order to provide treatment to those patients who are unable to travel to Boston.

Our patients and their families and friends are our best advocates and their careful stewardship is critical to our success – supporting the mission with their donations and raising awareness within their communities about BFS and the miracles that happen here. Now we have a new toolkit in our philanthropic arsenal which promotes fundraising through community involvement programs and events that create impact; not only by raising money, but also by raising awareness and connection.

On the BFS web site, we have rolled out a brand new Community Fundraising and Events Program that will help you run a successful local fundraising event. If you've never done anything like this before, never fear! Our Community Giving Toolkit will guide you through the process – from deciding what type of event you'd like to organize, through a step-by-step process for planning and putting it all together; and ultimately how to have FUN with fundraising!

Fundraising and Event Ideas

One of the best ways to raise money and awareness is to host a fundraising event open to the general public. They can be very high-end or more laid back, but the goal is to create an enjoyable event where everyone has fun.

Here are some great ideas to help start you start brainstorming what you would like to do:



Bachelor/Bachelorette Auction

Recruit all your single friends to be auctioned off for a Valentine's Day date. Find a venue that will donate space for the night. Decorate, have beverages and snacks and also have a standard door charge for the evening. Each bid will go towards the cause, as well as the door charge and refreshments. Advertise in your local newspaper.

Breakfast With Santa

Have someone dress up as Santa and Mrs. Claus, perhaps even have a few elves. Advertise this event in your local newspaper. If this is going to be a bigger event, then ask a hall to donate space and have local restaurants donate breakfast foods. There should be a door charge for adults and children should be free. You can also take pictures with Santa, which people can purchase for \$5-\$10 extra. Keep it festive with holiday décor, music, face painting, etc.



Challenge Fundraiser

With some creativity, your fundraising group can pull off some "outside of the box" events. A fun example is putting together an event modeled on "The Amazing Race". Similar to the television show, teams are challenged to travel to various checkpoints and conquer many challenges, detours in order to make it to the finish line. Funds are raised through team registration fees, plus individual pledge donation requirements. Another "cool" idea is a Polar Plunge, where each participant is expected to raise a minimum amount through collecting a specific pledge donation requirement and then plunge into the chilly ocean in the winter.

Champagne/Cocktails and Dessert Party - Include local bakeries/pastry chefs showcasing their goods.



Chili Cook-off

Charge an entry fee for all cooks to show off their culinary talents. Offer donated prizes to the winners. Try to gather local celebrities to make up the judging panel (ala *Iron Chef*) and to attract more people to come. Have different categories for people to enter (best spicy chili, best vegetarian chili, best chili by a chef under the age of 16). Either invite the chefs to bring their own pre-cooked chili or provide a space for them to cook on-site. Sell bowls or samples of the different chili dishes for the audience to try and raise extra money.

Available tools and support include a readymade press release template and promotional materials to help you promote your event; a budget worksheet to help you get the most bang for your buck; more than a dozen ready-made creative "fun"raising event ideas; and phone and email support if you need additional help.

If you would like to explore the idea of doing a community event for BFS, please check out the information on our web site at <http://www.bostonsight.org/fundraising> or email Tara Stepanian at tstepanian@bostonsight.org or call her at 781-726-7512.

Richard O'Neil (continued from page 1)

With the support of his ophthalmologist at Stanford, Dr. O'Neil tried many dry eye therapies, including the use of topical steroids, antibiotics, Restasis, nightly ointments, punctal plugs. Lacriserts and autologous serum drops. He found little relief.

After a brief hiatus, during which most of his symptoms abated, Rich's GVHD returned in force in the fall of 2009. The vision in his left eye had deteriorated to 20/400, in part due to a persistent epithelial defect in his left eye. By the spring of 2010 his dry eye had become so severe that Rich was forced to take a leave of absence from his job as an anesthesiologist; shortly thereafter he was referred to Dr. Gloria Chiu at Doheny Eye Center, where he completed PROSE treatment. Happily, PROSE gave Rich significant relief from his symptoms, improved his vision to 20/20 in both eyes and supported healing his epithelial defect. Soon after finishing treatment Rich was able to go on a cruise and return to his job and the outdoor activities that he loved so much.

When BFS reached out to PROSE patients in December 2010, seeking inspirational stories for our special holiday e-bulletin, Dr. O'Neil responded. He wanted to help others by sharing his experience with Dr. Chiu – “She is remarkable” - with the BFS community, as well as a his appreciation for our treatment and the care he received at Doheny Eye Center. Sadly, he passed away soon after.

Comments from friends and colleagues highlight the incredibly positive impact that Rich had on others: “He was always having fun, and it was great to be in his company.” “Rich will always be remembered, especially for his great sense of humor.” “We loved Rich and were so inspired by his energy, optimism, compassion and faith.” “The way he dealt with his illness was incredibly inspiring.”

Dr. Richard O'Neil was the epitome of “living well with corneal disease” and we are proud to honor his life. Rich and his wife Laura celebrated their 25th wedding anniversary in July 2010. He is also survived by their three children, Katy, Meghan and Tommy; and by his mother and three sisters. Our deepest sympathies go to his family and loved ones.

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