Hemophilia Helped Shape My Life

While attending the National Hemophilia Foundation’s (NHF) 64th Annual Meeting, Mike Reuter-shan was especially intrigued by a session discussing the future of medical treatments for the joints of people with hemophilia. As a former high school basketball player with severe hemophilia A, Mike has always been a little worried about the wear and tear he placed on his joints during his playing years.

“It was really interesting for me to learn that ankle treatment for hemophiliacs may be moving toward replacement therapy instead of fusions,” says Mike, who was attending the meeting as a representative from the Boston Hemophilia Center. “It could really improve mobility for a lot of people. Fortunately I’m not there yet, but it’s nice to know the medical community is thinking about this now, just in case.”

Mike has been a member of Boston Hemophilia Center’s Consumer Advisory Board for the past three years, and last fall he was selected to travel to Orlando as the Center’s representative at the meeting. “The meeting was great, I feel really fortunate to have been able to attend,” he says. “It’s not every day I get to interact with people who also have hemophilia, never mind a whole conference full. I learned a lot and made some friends, it was a great experience.”

Growing up in Maine, Mike was diagnosed with hemophilia at nine months old. And while the diagnosis limited a few of his sport options as a child, Mike’s supportive family and friends ensured he never felt alienated because of it. “I played baseball and basketball all the time,” he says. “And when I needed to infuse before or after a game, my friends always wanted to watch. For me, growing up with hemophilia really wasn’t isolating, and there were times when I actually felt special because of it.”

Of course as a young athlete with hemophilia the occasional bleed was unavoidable; Mike and his parents took more than one trip to their local Emergency Department. And while he wasn’t aware of it at the time, those hours in the hospital as a child ended up having a profound effect on him.

“Most kids are scared if they need to go to the hospital, but it was routine enough in my life that I never developed that fear,” he says. “I really liked being around the doctors and nurses, and in time they became role models to me.”

As Mike grew, so did his admiration for the medical profession. When he reached high school it manifested itself as an interest in life science, with a specific focus on how biology related to his hemophilia and other diseases. By the time he was ready for college, Mike had excelled in his high school’s science courses, a tradition that continued at Bowdoin College, where he completed his premed requirements.

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World Hemophilia Day Celebration and Twinning

Close to 60 people attended our World Hemophilia Day celebration at the Taj Hotel in Boston. Our speakers included Kapil Saxena, MD, MS, from the Boston Hemophilia Center (BHC), Sudhir Mehta, MD, MNAMS, FICP, from SMS Medical College and Hospital in Jaipur, India, and Robert Leung, from the World Federation of Hemophilia. The talks concentrated on hemophilia patients’ current state of care of in Rajasthan and our Twinning partnership with SMS Medical College and Hospital. There was a lively discussion after the presentations and then a delicious lunch of Indian and American dishes. The Taj was just lovely and the kids had a great time keeping busy with arts and crafts projects.

Dr. Mehta and his colleague, Dr. Sandhya Gulati, the pathologist from the coagulation lab in Jaipur, then spent three full days learning about comprehensive care and how the coagulation labs run at Brigham and Women’s Hospital and Boston Children’s Hospital. Their visit to Boston was the realization of our Twinning program’s first year plan. The goals of the first year are to improve the diagnostic capability of the current lab in Jaipur and familiarize Dr. Mehta with our comprehensive care model.

Dr. Saxena and Laura Gray and the BHC team look forward to working with our colleagues in Jaipur to enhance the care for people who have hemophilia. We will keep you updated on our progress.
Recent Changes in Our Medical Teams

**Aric Parnes, MD** (at right, top) has joined our adult team at the Boston Hemophilia Center. After completing medical school at Trinity College in Dublin, Ireland, he went to Dartmouth for his internship and residency in Internal Medicine. From there, a fellowship in Hematology and Oncology led him to Yale, Brigham and Women’s Hospital and Dana-Farber Cancer Institute. Over the next number of years, Dr. Parnes took a winding path back to Dana-Farber/Brigham and Women’s. First, he practiced hematology and oncology in a small community in Connecticut and then practiced inpatient care at Beth Israel Deaconess. He’s delighted to be back and is now an Instructor in Medicine in the Hematology Division, and eager to care for patients with bleeding disorders. He and his wife, an allergist at BWH, have 3-year old twins that occupy any free time they once had.

**Maura Padula, RN, BSN, CPON** (at right, center) joined our pediatric team in July as the Hemophilia Program Nurse. A lifelong Boston resident, Ms. Padula earned her nursing degree at Boston College in 1999 and has spent most of her nursing career working at Boston Children’s Hospital in the Hematology, Oncology and Stem Cell Transplant units. What not at work she enjoys gardening, restoring old furniture and spending time with her husband, children and calico cat. She looks forward to collaborating with the dedicated hemophilia team and she can’t wait to meet you and your families!

**Kapil Saxena, MD** (at right, bottom) accepted a position in the industry and will no longer be full time in the Hemophilia clinic at Boston Children’s Hospital after October 2013. He will however continue to see patients occasionally in the comprehensive hemophilia clinic. We wish him the very best in his new leadership position.

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An inside look at the National Hemophilia Foundation’s 64th Annual Meeting

By Mike Reutershan

Last fall I was the lucky winner of the Boston Hemophilia Center’s (BHC) sponsored trip to the National Hemophilia Foundation’s (NHF) 64th annual meeting in Orlando, Florida. It was my first time at NHF, and it was exciting to be part of one of the largest meetings for our community. NHF’s annual meeting brings together patients and professionals who care for those with bleeding disorders, and it offers sessions designed to train and educate consumers, chapter staff, medical professionals and family members. I spent the majority of my time at sessions for consumers and medical professionals.

This year’s theme was Mapping Our Future. Aligned with this theme was the introduction of an innovative collaboration aimed at understanding the role of genetic testing for hemophilia called My Life, Our Future. This collaboration brings together the NHF, the American Thrombosis and Hemostasis Network, Puget Sound Blood Center and Biogen Idec Hemophilia. Together, they will offer free or low-cost genetic testing and analysis to patients with hemophilia. The goal is to advance research at the intersection of genetics and hemophilia, which may help determine inhibitor risk and discover new treatment approaches. For more information, you can go to mylifeouroffuture.org.

Because of my personal struggles with my right ankle, one of the most informative sessions for me was a discussion on ankle replacement therapy. Georgetown University Hospital’s Paul Cooper, MD, who has performed more than 1,000 ankle replacements, discussed the Scandinavian Total Ankle Replacement and offered his views on the advantages of ankle replacement over ankle fusion. I had been unaware that early generations of STAR have been approved for use since the late 1970s, and I’m intrigued that, with each decade, STAR continues to improve.

Although the educational component at NHF is important, the meeting is also about networking and enhancing our already strong community. This meeting offered a unique chance to see many BHC staff outside of the clinic. It also offered an opportunity to meet new friends at events such as Social Infusion and the final night event, a street party at Universal Studios. But it was also nice to catch up with old friends at lunch, dinner or in between sessions. I even got a chance to visit with some of the medical professionals I used to see growing up in Maine. With a full schedule of seminars and meetings on various topics, NHF offers something for everyone and is a great experience for our whole community—one that I am happy to be a part of.
Go Sox!

Over 100 people from the Boston Hemophilia Center community attended the Red Sox/Cleveland Indian game on May 26th at Fenway Park. Our own Michael Donovan was on the field and smiling on the big screen before the game as the BHC was honored for sending so many people to the game. What a fun day! Families came with brother sisters, parents and grandparents. Our staff had a wonderful time also. The weather was a bit chilly but that didn’t dampen the wonderful spirit of the get-together. Here are some pictures from the day.

Some attending (clockwise from upper left), the Morse family, the Nielsen family, the McLaughlin family, enjoying the game was Ellis, Loren, Kate and Kristy, and the Boutin family.

Mike Reutershan >>> continued from page 1

“No one in my family is even remotely interested in the sciences, at least not on a professional level, so I think my passion for it could be tied to growing up with hemophilia,” he says. “What started as a teenager’s interest in knowing how my body functioned differently than other people’s eventually guided my career path as an adult.”

These days Mike’s career is based in medicine, but not as a doctor as he originally imagined. During his sophomore year a single course altered the trajectory of his studies forever.

“Organic chemistry changed my life,” he says with a smile. “A lot people in the medical field find the topic boring, but I had a professor who specialized in bioorganic research, which I found fascinating. It wasn’t until that became my focus as well.” Within a few months Mike changed his major to biochemistry, with a minor in sociology, and never looked back.

He’s been working as a medicinal chemist for over six years, developing compounds that could eventually become marketable drugs. But studying compounds isn’t the only chemistry in Mike’s life—he was recently married to his college girlfriend, who now practices environmental science. The couple was wed at the Bowdoin College chapel this August, and as they make preparations for their new lives together, Mike says he’s thankful for everything that has gotten him to this point, even the medical condition he’s lived with since infancy.

“There were times as a kid, like when I had to sit and watch other kids playing when I had a bleed, when I wished I didn’t have hemophilia,” Mike says. “But now, when I think about how the condition has shaped my life, and where my life has taken me, I wouldn’t change a thing about growing up with hemophilia.”
Prize winners announced: Steve and Carole Place

Steve Place won the drawing! He and his wife, Carole, will attend the National Hemophilia Foundation’s (NHF) annual meeting in Anaheim, CA in October. We all look forward to reading about his experience in our winter 2014 edition of Centerpoints.

Place submitted the following letter as part of the drawing: “It would be a great joy to represent Boston Hemophilia Center (BHC) at the NHF annual meeting this October. It would be my first trip to the West Coast. At 58 years old, I have experienced many things common to most with a bleeding disorder and many things uncommon to hemophiliacs. Since my hemophilia is mild, I live a very normal life with few exceptions. I believe my input and interaction with others would be beneficial to all. I have been married for 35 years, have two adult children, own a successful handyman business, have a strong faith in God and just love to meet new people. I would be out-of-my-mind happy to be chosen to attend this meeting. It would be great if Carole could come too. BHC would be represented well with my attendance.”

Congratulations Steve and Carole!

Keep It Cool with a BHC Cooler Bag

These durable bags are available in royal blue, navy blue and orange at no charge to you from the Boston Hemophilia Center.

Features:
- 12-can capacity
- Insulated and leak resistant
- Lots of pockets, with an adjustable shoulder strap and the BHC logo

If you’d like to have one sent to you, please contact Bryana Berry:
E-mail: BBERRY1@partners.org Office: 617-732-8537.

www.bostonchildrens.org was launched on September 18th! Check out:

- The new navigation structure designed to get patients, prospective patients and referring physicians to the information they need faster
- The improved search function
- The revamped “Find a Doctor” feature, including improved search functionality, clinician and team profiles plus custom URLs and much, much more…

How many factor prescriptions do I really need?

In the past year, insurance companies have become ever-more strict in denying or delaying refills of factor, based on the actual prescription and number of prescribed doses. For patients on prophylactic or preventative factor VIII (for example every other day, or 15 doses per month), or factor IX (for example, twice a week, or 9 doses per month), this limitation comes into play if a patient also has a bleed during the month, and needs additional doses.

The impact of this is that if you use some of the factor designated for prophylaxis for a bleed, you may not be allowed to refill the prescription for your regular prophylaxis infusions even though you have run out!

What to do to avoid this: 1) Get a separate prescription for 4 doses for a major bleed and two doses for a minor bleed and keep that factor separate from your prophylaxis factor. 2) Call your pharmacist and find out what your prophylaxis refill prescription designates so you are not caught off guard.