Wendell Bourne's journey with hemophilia started with a slight bump on the lip, and ended nearly six decades later with a complex medical procedure that made the history books. And according to Wendell, it's the perspective he's gained in between that truly defines him.

In 1950, just barely 1 year old and still learning to walk, a young Wendell fell as he explored his Cambridge home, cutting his mouth. His mother, Abney, placed ice and pressure on the cut, and grew concerned as, hours later, his mouth continued to bleed. When she brought Wendell to the Emergency Department at Boston Children's Hospital, Abney couldn't imagine what was wrong—the Bournes had no family history of hemophilia—so her son's excessive bleeding was a total mystery. All her questions were answered when a few routine blood tests showed that Wendell had severe hemophilia A with a factor VIII inhibitor.

As he grew, Wendell was actively encouraged to never let his condition define him, but he also had to learn what activities he could and couldn’t safely participate in. (This wasn’t the easiest lesson for a young, adventurous boy. More than one pickup basketball game ended in a trip to Boston Children’s Emergency Department.) But by the time he was a teenager, Wendell’s interests had become more academic—math, science, debate and Glee club were among his favorite activities—and eventually led to his acceptance to Northeastern University.

While studying history at college, Wendell met a young nursing student named Margo; later they married and had four beautiful children. But as wonderful as his life with Margo and the children was, it was a far cry from a fairy tale existence.

Like many people his age with hemophilia, sometime in the 1980s Wendell acquired Hepatitis C from a contaminated batch of factor. The diagnosis didn’t affect his health for many years, until 2006 when doctors at Brigham and Women’s Hospital and Massachusetts General Hospital found a small, cancerous tumor growing on his liver. The liver has many jobs, including producing the protein factors that help the blood clot. Hepatitis C causes the liver to inflame and can accelerate the rate at which cancer cells spread. In Wendell’s case, it was clear that his overly compromised liver could have serious health repercussions.

After much thought, Wendell’s doctors decided that a liver transplant was his best bet at a healthy future. But the decision to transplant is never made lightly, especially when the patient has a bleeding disorder. To successfully give him a new liver, surgeons would need to control his bleeding during the procedure and devise a way to prevent recurrence of...
the inhibitor after the surgery. Even if the transplant were a complete success, Wendell would still have to undergo a lengthy recovery process and take anti-rejection medication for the rest of his life.

Fortunately, Wendell’s medical team at Massachusetts General Hospital rose to the occasion and a few months later his new liver was not only functioning perfectly, but also his blood was clotting at a normal level, leaving him free of hemophilia.

Given the complexity of his case, and the strength he showed in recovery, Wendell’s case was documented in the prestigious New England Journal of Medicine.

“There are only two types of cases that get written about in medical journals: good cases and bad ones,” he jokes. “If you’re lucky you get to read your own case. I was lucky.”

Years later, Wendell is still adjusting to his new life, something that has gotten easier with time. “Living without hemophilia, after 58 years of having the condition, was weird,” he says. “I’m still getting used to it in a sense. My first day back from the hospital I banged my leg on the table, and when nothing happened, I was kind of shocked. It was surprisingly disconcerting, but in a good way.”

As a man in his early 60s, Wendell still deals with the occasional arthritis flare up in his joints, but now his method for dealing with pain has entirely changed. “When my elbow used to bother me, I knew exactly how long it’d be before the factor took affect and the pain went away,” he says. “Nowadays, I just need to wait it out. It can be frustrating.”

Aside from the occasional joint pain, Wendell is living a healthy life as a retired schoolteacher and loves spending time with his family, especially his twin grandchildren, Eric and Arin, who live in Atlanta. Eric has spina bifida, for which he has had multiple, successful, corrective surgeries. And, like his grandfather before him, Eric also has hemophilia. Wendell says that he and Eric have a special bond as a result of their shared experiences with the disease, but as much as they have in common, Wendell is also amazed by their different experiences growing up with hemophilia.

“Treatment has come so far since I was young,” he says. “Eric’s life is vastly different from what mine was at his age,” he says. “He only takes a factor booster about once a week, and it’s done quickly, whereas I was in and out of the hospital for hours at a time. He takes karate and is very active, where I limited myself. I’m so heartened by the medical progress that allows him to do the things I never could.”

In fact, Wendell is so impressed by the progress in treating and managing hemophilia, he’s optimistic that one day his grandson will follow in his footsteps by living a hemophilia-free life—without needing transplant surgery.

“Spending time with Eric and seeing how little the condition affects his life has really opened my eyes to what’s possible for people with hemophilia,” he says. “It makes me hopeful that a cure can’t be too far off.”

Until that day comes, Wendell plans to impart his grandson with the same wisdom his mother passed to him as a child: With faith, perseverance and hard work you can be anything you wish to be, regardless of how your blood clots.

“I never saw my condition as something that happened to me—it was just a part of who I was,” he says. “I never spent much time feeling bad for myself. That attitude gave me a real perspective of what’s truly important, and I hope I can help Eric see it that way too.”

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**Exciting New Partnership Approved!**

The World Federation of Hemophilia (WFH) has approved the joint Twinning Program between the Boston Hemophilia Center and SMS Medical College and Hospital in Jaipur, India. The WFH will grant financial support to the partnership each year, for the next four years. The main goal of our collaboration is to establish a comprehensive hemophilia treatment center encompassing both the pediatric and adult hospitals at SMS Medical College.

Our goal is that upon the completion of the partnership, all the components of a comprehensive care system will be in place: dedicated staff, a coagulation laboratory and day infusion centers at both hospitals.

We are anticipating a visit from one or two team members from India this year. Our first objective is to develop the coagulation lab in Jaipur. Their current lab lacks the facility to test factor levels and inhibitor levels, which is essential for accurate diagnosis of bleeding disorders as well as for any surgical procedures to occur in the future. Over the next four years, we plan to conduct workshops on bleeding disorders for medical professionals in India by visiting doctors, physiotherapist or Nurse Practitioner as well as conduct educational sessions for patients and families about hemophilia and other bleeding disorders. We are already developing educational materials on hemophilia and Von Willebrand disease for families in India. In 2013, the team from India will be visiting us in Boston for in-depth clinical training and to gain expertise in running a coagulation lab.

We are very excited about this partnership and it is most gratifying for us to share our knowledge with our new partner. We will keep you updated with our progress.

*(left to right) Robert Leung, WFH, Dr. Sudhir Mehta, SMS Medical College, Dr. Kapil Saxena and Laura Gray*
leaders were familiar with 340B through their work with 340B Community Health Centers. Over the past seven years working with Eaton Apothecary, we have found them to be a tremendous asset to our program, in helping our clinical teams deliver excellent care for BHC patients.

What Being a Part of 340B Means

Because we participate in the 340B program, two requirements guide the way we operate. The first is that with products bought under the 340B program, we may only serve patients of the BHC. The second is that we enter into contracts from operating the Factor Program must fund BHC services and programs that benefit our patients.

Our Growth and Team

Over the past few years, we have undertaken disaster planning, which is an essential element of ensuring consistent and continual care to our patients. We have also undertaken quality improvement initiatives to further improve our level of service. We use tried-and-true methods, as well as new technologies and strategies, to support BHC patients in the best ways possible.

This quality of care is possible due to our incredible staff, who feel honored to serve the BHC community. The bonds we form with the patients we serve extends beyond simple professionalism, to include a genuine personal concern for each person’s well-being. When patients use our Factor Program services, they participate in a dynamic form of care and support the very structure that makes our expertise possible.

Our dedicated pharmacy staff at Eaton-BHC consists of Pharmacy Manager, John Pelkowsky, RPh, Pharmacy Manager, Yuliya Bratnikov, PharmD, and Pharmacy Technician, Christine Chau, RPT. John is one of the most dedicated people I have met. He is constantly thinking of two things: protecting our patients and improving our service. Yuliya is extremely intelligent and continually seeking to expand her skills and knowledge base. Christine tirelessly organizes and packages order after order with extraordinary attention to detail. She is the center of our pharmacy communications and keeps our pharmacy stocked with everything needed to serve our patients at a moment’s notice.

The staff of the Brigham and Women’s Physicians Organization (BWPO) handles our insurance authorizations and billing. Denise Rhodes and Veronica Hinds make up our phenomenal authorization and billing team. Day in and day out they spend time talking with insurance companies to get clear information and straighten out issues. Mary McGaffigan and Marsha Jones do our billing follow-up and doggedly pursue our claims, getting to the bottom of payment issues with insurers. Despite facing constant billing challenges, their demeanor is always cheerful and constant.

Our administrative team starts with our Division Administrator, Deb McNamara. Deb’s background in social work preceded her rise to executive status in a major hospital system in the Midwest. With superlative organizational skills, she manages to parse projects into their simplest structures and prepare them for dispatch. From contracting to compliance to technical issues of all kinds, not a day goes by in which she doesn’t work her way through them. Also on the team is me, Cliff Haas, Operations Manager and after-hours nursing student. I wear many hats in my role. I see every day as an opportunity for growth and positive change, and I am always seeking ways to improve our customer service.

Tom Arabia is our Financial Coordinator, which hardly does justice to describing the essential role that he plays. His keen analytical abilities are matched by his wit and genuine concern for others. Many in our community also know Laura Gray, LICSW, BHC Project Manager, who has helped tremendously with our disaster planning and in writing many policies. Finally Bryana Berry is our newest recruit; she joined us as Project Assistant and has quickly become an integral member of our team.

A note to all parents interested in sending their child to Hole in the Wall Gang Camp for summer 2013:
The Boston Hemophilia Center (BHC) is streamlining the application process to camp this year. This is how it will work:

- Print the application from the “for campers” section of the Hole in the Wall Gang Camp website (www.oholeinthewallgang.org)
- Fill out the application(s) and either send or email it to Kate Quint, Boston Children’s Hospital, 300 Longwood Avenue, Fegan 7, Boston, MA, 02115. kate.quint@childrens.harvard.edu
- The BHC will complete the medical part and send the entire application to the camp
- If you choose to complete the application on-line from Hole in the Wall Gang Camp’s website, please email or call Kate Quint to alert her of this. She will then ensure the medical section is completed and faxed to camp. Please call Kate at 617-355-0794 with any questions.
Please Check Your Factor And Supplies

The staff at the Boston Hemophilia Center hopes all of you and your family and friends are recovering from Hurricane Sandy. Our hearts go out to everyone who lost homes or whose lives were impacted by this severe storm. Hurricane Sandy is a reminder that when you hear bad weather is coming, check your factor and supplies and order what you need well ahead of the storm. Also, please make sure to put your order in before major holidays, such as Christmas and New Year’s, as ordering ahead is critical to insure against problems in the delivery of your factor and interruption of your treatment.

The Boston Hemophilia Pediatric Center Reorganizes

We are happy to report that we have filled staff vacancies, so for the first time in more than a year we will have a full staff of nurses and nurse practitioners to assist our pediatric patients. We are now able to reorganize to make the system more efficient.

As of January 17, when you call the main number (617-355-6101) of the Boston Hemophilia Center (BHC) at Children’s, you will have new menu options that will best target your call. There will also be a new nursing coverage system for all hematology patients. Loren D’Angelo will still be the primary pediatric nurse practitioner for the BHC, but the rest of the Nursing staff will also be available to answer your questions and troubleshoot issues.

These changes will increase the accessibility and efficiency of the BHC and our Hematology Department at Children’s. Our five hematology nurses are joining together to cover the phones, refill prescriptions, see patients in clinic and respond to questions and requests. There will no longer be direct number access by telephone to Loren. Instead, all calls will be routed to the Boston Children’s Hospital Hematology and Hemophilia Program phone tree. We will have a nurse on the phone during regular business hours to triage your phone call, whether it is for a bleeding issue, prescription, travel letter or another matter. For emergencies call 617-355-6363 and page the on-call hematology attending or fellow.

We hope that you will be pleased with this new system, as you will always be able to reach someone or receive a call back within one hour.

Save the Date!

Boston Red Sox vs. Cleveland Indians game on Sunday, May 26th at 1:35pm. We have reserved the right field roof box! Look for the invitation in May.