To become an Eagle Scout, a young man must pledge to be a responsible citizen, and use his influence to inspire others to do the same. For Christian Mund, a 17-year-old Eagle Scout, making the pledge was easy. After all, he’s been shoulder ing more responsibility than many kids his age for most of his life.

At 2 weeks old Christian was diagnosed with moderate hemophilia A, but it wasn’t until he was in grade school that he became really aware of his condition. As his friends began getting more serious about contact sports, Christian found himself on the sidelines.

“Part of me really wanted to be out there on the football field or hockey rink, but I knew it wasn’t an option for me,” he says. “I never resented the fact I couldn’t play the same sports as some of my friends, but I definitely became more aware of my hemophilia at that point.”

But even at young age, Christian knew that putting his health first was more important than doing what all his friends were doing. Once he and his parents deemed that contact sports were out of the question, Christian quickly focused on which sports he could play, rather than dwell on what he couldn’t.

He eventually chose soccer and quickly fell in love with the sport. His soccer career lasted for a number of years, but after he suffered a particularly bad bleed after a collision on the field, Christian was forced to reevaluate his dedication to the game. “That bleed was tough, and the decision to stop playing soccer was even harder,” he says. “But after much thought I realized the negatives of staying on the soccer team far outweighed the positives.”

Like he had done years before, Christian opted to explore new options instead of lamenting his limitations. This time he looked to family for inspiration. Christian’s uncle had been a rowing coach for as long as Christian could remember, so Christian decided to give crew a try, as rowing seemed like a safe sports option for him.

After a few weeks as a rowing coxswain, Christian had found his true sports calling. The combination of strategy, motivation and leadership required to make a quality coxswain lent itself naturally to Christian’s personality: “It was a tough switch at the time,” he says. “But looking back, moving from soccer to crew has been one of the
best things to ever happen to me.”

The strong personality traits Christian shows when leading his crew team to victory are reflective of his time in scouts, which impart in young people the importance of taking responsibility for one’s actions and striving to be a leader among their peers. It may seem like a lot to ask of a teenager, but for Christian it felt very natural.

“Organization and responsibility are really important for progressing in Boy Scouts, so naturally you need them to become an Eagle Scout as well,” he says. “I think the responsibility I’ve learned from managing my hemophilia has definitely carried over into my life as an Eagle Scout.”

Christian first began self-infusing at 12 years old. While his friends were playing video games and sports, Christian was learning medical techniques that could possibly save his life. At first he practiced injections on bananas and his father, but quickly moved on to his own body.

“The first time I self-infused I was nervous, but it was definitely more nervous energy and excitement than fear,” he says. “It was pretty empowering. A lot of kids that age aren’t given very much responsibility at all, but knowing I was playing a part in my own medical care was really cool.”

Using medical conditions as an empowerment tool isn’t just a concept Christian pays lip service to, it was instrumental in acquiring his rank of Eagle Scout. Before becoming an Eagle Scout each participant must complete a service project that benefits his community. To fulfill his project, Christian directed and edited two educational videos, explaining and demonstrating what life is like with diabetes and hemophilia. Titled “Diabetes: The Way Things Are,” and “Hemophilia: The Way Things Are,” the movies are aimed at elementary school and junior high students, and are currently being shown in classrooms throughout his hometown of Groveland.

“The point of the project was to make a video for younger kids that explained not only what the conditions were, but also how they impacted the lives of people who have them,” he says. “It was cool to feel like I was spreading the word about hemophilia, and giving an accurate view of what life is like for kids who have it.”

Looking ahead, Christian was recruited to coxswain for the Syracuse University crew team, where he just began college. He admits the prospect of coxswaining a college boat is slightly intimidating, but like many other aspects of his life, he’s confident he’d be capable of stepping up to the challenge. As inspiration he cites Colin Groshong, a respected coxswain who crewed at the University of Pennsylvania and Oxford. “Like Collin, I’ve always been somewhat of a little guy myself, so seeing him achieve that level of success is inspiring,” he says. “Hemophilia aside, I just want to do my best. Seeing people I respect working for the same thing keeps me going and pushes me to try that much harder.”

Staff spotlight

Expertise comes in threes

Ellis Neufeld, MD, PhD, is the medical director of the Boston Hemophilia Center and is associate chief of the Division of Hematology/Oncology. Dr. Neufeld’s PhD concerned the function of platelets. After completing training in pediatrics, medical genetics and hematology, Dr. Neufeld joined the faculty at Children’s Hospital Boston in 1990. He is presently the Egan Family Foundation Professor of Transitional Medicine at Harvard Medical School. He has more than 20 years of experience treating bleeding and clotting disorders including ITP, hemophilia and thrombophilia. His research focuses on genes for inherited blood diseases, and clinical studies in bleeding disorders and iron overload. A particular interest related to his professorship and his long-time role in the hemophilia center is transition from pediatric to adult medical settings for life-long blood disorders.

Kapil Saxena, MD, MS, is associate director of the Boston Hemophilia Center (BHC). He is also a member of the Division of Pediatric Hematology/ Oncology at Children’s Hospital Boston and Dana Farber Cancer Institute. Dr. Saxena did his fellowship in pediatric hematology and oncology at Children’s Hospital at the Ohio State University, and his Residency and Internship in Pediatrics at Case Western Reserve University in Cleveland. He moved to the BHC from the University of Oklahoma where he was the director of the Hemophilia Treatment Center for five years.

He is very passionate about the care of patients with bleeding disorders and has a strong interest in clinical research. He is looking forward to meeting all the patients and their families at our center. His wife is also a physician at Children’s. His family is very happy with their move to Boston and his daughters love their new school.
Keeping that smile A dental Q&A

What causes dental problems?
Dental disease is caused by plaque, a sticky, transparent bacterial film that forms on teeth. If plaque isn’t removed each day by brushing and flossing, it accumulates and eventually leads to gum irritation and the formation of dental caries (cavities). Bleeding gums, often an early sign of dental disease, can be caused by gingivitis, a painless, often unnoticed condition that leaves gums red and inflamed. If untreated, it can progress to a more severe type of gum disease called periodontitis. Dental plaque also promotes tooth decay by turning consumed sugars into an acid that attacks tooth enamel and dentin, resulting in cavities that, if left untreated, can progress to pain, infection and swelling. Treating advanced dental disease requires interventions that cause bleeding, so these conditions are of particular concern for patients with hemophilia.

What can I do to help prevent dental disease?
The good news is that, unlike many other health issues, dental problems are largely preventable. You should brush and floss at least twice a day and as often as possible after meals. You should also visit your dentist every six months for checkups and cleanings. When flossing is initiated, minor bleeding is normal and typically stops within a week. If it continues longer, you should contact your hemophilia treatment center (HTC).

Ask your dentist about how to ensure that you are getting enough fluoride, which protects teeth from decay. Under certain circumstances, fluoride supplements—such as fluoride tablets, mouth rinses, drops, or tray applications—may be used. It is also important to limit your intake of sugary or acidic foods and beverages, which can cause plaque and tooth decay. Try to include these items only during mealtimes. Sugars found in milk, fresh fruit, and vegetables may be consumed more frequently. Additionally, chewing sugar-free gum after snacks helps remove dental plaque and also increases saliva production, which can protect against plaque acids. And don’t smoke! Aside from everything else, it can cause periodontal disease and oral cancer.

Find a dentist with whom you feel comfortable, someone who is familiar with hemophilia or willing to learn about it. By practicing healthy habits and visiting your dentist regularly, most dental disease can be fully prevented.

How should I prepare for my dental visit?
If your visit involves more than a cleaning, let your HTC know. Safe dental care requires close communication between your dentist and HTC team. Depending on the type of dental procedure and the severity of your bleeding disorder, it may be necessary to modify your dental treatment. You may require factor infusions and/or other treatment modalities to help prevent excessive bleeding.

Be sure that your dentist knows how to get in touch with your HTC. He/she should know the type and severity of your bleeding disorder and whether you have any infectious diseases, artificial joints, or venous access devices. Your dentist should also keep an updated list of your medications.

I have a prosthetic joint. Do I need to take antibiotics before my visit?
According to the American Dental Association website, “there are differing opinions on the need for antibiotic prophylaxis.” If you have an artificial joint, make sure that your dentist and orthopedic surgeon communicate prior to your procedure so that they can determine whether or not antibiotics are appropriate for you.

My child has hemophilia. Is there anything specific I should know?
You should schedule your child’s first dental appointment as soon as baby teeth appear. Teeth rarely causes bleeds, but it is normal for gums to appear bluish and swollen. If minor bleeding or oozing does occur, be sure to contact your HTC. Permanent teeth begin to come in at around 6 years of age. Whenever possible, baby teeth should be allowed to fall out on their own without extraction. Teach your child good oral hygiene, and ask your dentist about sealants and fluoride applications. Also, if your child needs braces, let your orthodontist know about his bleeding condition so that special care can be taken to avoid cutting or irritating the gums.

— Nat Treister, DMD, DMSc, director of Oral Medicine at Brigham and Women’s Hospital, and Stephanie Slate, DMD, associate director of Oral Medicine at the Boston Hemophilia Center (BHC). Dr. Lin also provides clinical hematology care and medical education teaching at Brigham & Women’s Hospital, Dana-Farber Cancer Institute, and Harvard Medical School. Originally from New York, she is a graduate of Massachusetts Institute of Technology. She completed medical school at State University of New York and Internship/Residency in Internal Medicine followed by Hematology Fellowship at Los Angeles County + University of Southern California Medical Center in Los Angeles, CA. Dr. Lin also spent a year of residency at Mount Sinai Medical Center in New York in 1993, where she first encountered patients with hemophilia who received their care at Mount Sinai’s hemophilia treatment center during the HIV epidemic, and this left a lasting impression on her and a motivation to become a hematologist.

Her current interests include improving clinical comprehensive care, teaching and collaborative research in bleeding and clotting disorders. She conducts clinical research trials in hemophilia, von Willebrand disease, inhibitors, factor XIII deficiency and HIV in hemophilia. Together with BHC Director, Ellis Neufeld, MD, PhD, she conducts NIH network studies on platelet and thrombotic disorders. Outside of medicine, Dr. Lin has interests in music (violin, voice), arts, gardens, swimming, running, yoga, and community volunteer work and international relief. She conducted a hemophilia clinic in Bermuda in 2006 and has served in medical disaster relief in Haiti.
Christine Mitchell receives fellowship

Christine Mitchell, our adult social worker is the recipient of the National Hemophilia Foundation (NHF) 2010–2011 Social Work Excellence Fellowship. All fellowship applications are subjected to a rigorous peer review process. Applications are critiqued on scientific merit and relevance to NHF research priorities. They are reviewed and scored in terms of significance, approach, innovation, investigator and environment.

Mitchell will use her fellowship grant to conduct a study about socialization and quality of life of persons with congenital bleeding disorders. If you are a man 21 or older with Hemophilia A or B and would like to participate please contact the study team at PWCBDDstudy@partners.org or 617-278-0377.

Upcoming events

National Hemophilia Foundation’s 63rd Annual Meeting
November 10-12, 2011
Chicago, IL

On April 17, more than 40 of us gathered together to celebrate World Hemophilia Day at the Renaissance Boston Waterfront Hotel. Our pediatric hematologist, Kapil Saxena, MD, MS, associate director of the Boston Hemophilia Center, talked briefly about the history of World Hemophilia Day and gave an overview of how care varies so greatly around the world. A panel of speakers from our center then shared their stories about what care for hemophilia was like for them or their child in Cape Verde, Brazil, India and Sweden.

The audience learned so much and realized from these stories how fortunate we all are to live in the United States with access to excellent medical care and factor replacement therapy. We then gathered for a “global feast” where we chatted, shared more stories and felt the connection with others around the world that we knew were also celebrating and feasting! The Boston Hemophilia Center plans to make this celebration an annual event so mark your calendars and save the date, April 17, 2012, for next year’s World Hemophilia Day celebration!