

Centerpoints

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Director's Corner



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Keeping joints and muscles healthy is important for everyone, but individuals with bleeding disorders often need to pay special attention to bleed prevention

and regular physical activity so that movement, strength, and flexibility are not compromised. For those with more severe bleeding disorders, such as hemophilia A, hemophilia B, and type 3 VWD, starting prophylaxis early is an important part of maximizing musculo-skeletal wellness.

Integrating regular physical activity and athletics into your daily life is important at all ages- toddlers, school-aged children, and adults too! Whether you enjoy group or individual sports or prefer to focus on daily walking or stretching, having a routine to ensure consistent activity is key.

Prophylaxis options for hemophilia patients continue to expand. We now have multiple treatment categories that can be used for bleed prevention for those with severe bleeding symptoms, including factor concentrates, gene therapy, and non-factor therapies (such as bispecific antibody/FVIIIa mimetics).

Recently, both a new, truly long-acting factor VIII concentrate (Efanesoctocog alfa / Altuviio) and a gene therapy for hemophilia A (Roctavian), have been approved by the FDA...

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Back to School & Bleeding Disorders

by Maura Padula, RN

It's back to school season! As your child prepares to head back to the classroom, it is imperative that you communicate some important information about your child's condition to the caregivers who are responsible for your child's well-being outside your home. What and how you communicate with your child's school depends on your child's specific circumstances, your family's preferences, and often your school or district's requirements for information and documentation. This can come in many forms —some are listed here.

Provide General Information About Your Child's Bleeding Disorder

Many schools appreciate some general, factual information about your child's bleeding disorder. It can help ease a lot of anxiety and misconceptions that caregivers may have. Ask your HTC what they can provide.

Individualized Health Care Plan (IHCP)

An IHCP is a document tailored to your child. Written by your child's hematology provider, it provides basic info about their condition, what kind of treatment she or he gets, and what caregivers should do in an emergency. Your school may require it. Depending on your child's needs, an IHCP may range from simple to complex. Let your providers know if your school would like to put this in place.

504 Plan

There are circumstances which your child with a bleeding disorder may experience that can limit their full access to curriculum and services offered at school. If you feel this is the case for your child, ask your school leadership about a 504 plan. They will help you identify accommodations which will ensure your child is able to fully access their education...

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Director's Corner

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Each of these new therapies, along with our other proven effective hemophilia treatments, give patients and their providers an opportunity to discuss the goals of their bleed prevention/prophylaxis regimen and the risks and benefits of the different treatment types and select the one that makes the most sense for the individual patient. There are many variables to consider when making this decision. A single treatment product or dosing scheme will not work for every patient.

You can learn more about newly approved therapies to prevent bleeding, other treatment options, and physical activity recommendations from your HTC team members. There are also educational resources through NBDF on staying active. [<https://www.hemophilia.org/educational-programs/education/online-education/playing-it-safe-physical-activity-with-a-bleeding-disorder>].

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Orders for Medication in School

If you plan to keep bleeding medications in school (factor, intranasal desmopressin, or antifibrinolytics like amicar or tranexamic acid) for prophylaxis and/or bleed treatment, you will need to provide medication orders detailing the specific circumstances in which they are appropriate, and instructions for administration. School medication orders need to be completed and signed by your child's hematology team.

Sports Participation/Communication with Coaches

NBDF's guidelines about sports participation recognize the importance of physical activity on muscle and joint health, cardiovascular health, and social development. For these reasons, participation in 'safe sports' is encouraged. Your child's school may ask you to obtain clearance from providers. Work with your HTC provider to discuss how your child's treatment can be optimized to best allow successful and safe participation in their chosen sports and activities.

Documentation of Restrictions or Absences Due to Bleeding Disorder

Hopefully your child's bleeding disorder doesn't interfere on a regular basis with their participation in all that school has to offer. But bleeds happen, and with them, so do restrictions, emergency room visits, appointments, and even hospitalizations at times. Please communicate with us when your child has a bleed. Not only do we want to weigh in on evaluation and treatment, but we can also provide documentation for missed school, or temporary activity restrictions. If we don't know about it, we cannot provide this important documentation to your school.

Is Hemophilia New to Your School?

If your child is new to their school, or if your child's treatment is complex, your HTC is here to provide education and support to school nurses and teachers. This can be in the form of written information or in some cases, an in-service for staff can be provided.

As always, feel free to get into contact with us ahead of your child's school year to set them up for success! We're here to help!

BHC Patient Spotlight: Donovan Guerrero on Attending Washington Days 2023

Washington Days, an event hosted by the National Bleeding Disorders Foundation (NBDF) every March, is an opportunity for those living with an inherited blood or bleeding disorder to advocate on behalf of themselves and their community on Capitol Hill. Participants travel from across the country from nearly every state to D.C. where they meet with legislators and staffers to address issues related to federal funding for bleeding disorders programs, as well as relevant healthcare and insurance policies that greatly affect patients' access to care.

This year, our patient Donovan Guerrero participated in Washington Days. Donovan, a mechanical engineering student at Wentworth Institute of Technology and active member of the bleeding disorders community, has participated in this event three times now, stating that it is one of his favorite opportunities aside from camp. "It gives me so much confidence... not only for myself, but for the whole Hemophilia community because I'm going to Washington. I'm going down with, like, 300 advocates, and we're really making a difference."

Donovan explained that participating in Washington Days is a multi-day process that includes a prep day and a full day of meetings with staffers and legislators. Volunteer advocates are broken up into groups based on your state of residence, and these groups meet with those responsible for their state. These groups are often comprised of NBDF staff, patients with bleeding disorders, and their parents. Some of the patients that attend Washington Days are as young as seven or eight years old.

Donovan emphasized how important it is to be an advocate and how he has seen firsthand the impact that those advocating for the bleeding disorders community can have...



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"People all the time will say, 'oh, I can't affect this', when it comes to politics or pollution or whatever, but you actually can. You really can. I do it every year. [One] might not think that the one trip that I take and the four meetings that I have mean a lot... but it does because I have people reaching out to me months after the meetings asking to talk again... And also, bills actually get signed. There's action that gets taken."

Donovan's biggest piece of advice? To try to be involved in the community. This can range anywhere from attending camps to taking the leap to attend Washington Days. He says, "getting involved with the community is really important... you just receive a lot of support and help. I think a big reason why the community is set up the way it is, is because we're here to help each other- it's not good to let somebody suffer alone. My advice to somebody would be to get involved some way. Try things."

Community Events Recap

Chris Bombardier Talk - April 2023

In April 2023, Chris Bombardier gave a presentation to our team at BHC. Chris discussed his life experiences, including his documentary, Bombardier Blood. The documentary follows Chris, who lives with hemophilia, as he prepares and summits Mount Everest in his mission to climb the Seven Summits. Aside from discussing his climbing expeditions, Chris also shared his experiences with his bleeding disorder, the ways his family has supported him throughout his journey, his exposure to the difficult circumstances some bleeding disorder patients are born into around the world, and his advocacy work. Now the executive director of the international nonprofit Save One Life, Chris provides direct financial aid to patients with hemophilia in developing countries. To learn more about their mission, and how you might help, please visit their website at: <https://saveonelife.net/>



Scan the QR code to watch the full webinar!

Managing Infusions, Injections, and Blood Draws: A Collaboration - April 2023

The Family Medical Coping Initiative and members of the Bleeding Disorders Team at the Boston Children's Hospital hosted an online educational webinar and discussion for patients related to fear surrounding needles. Some of the topics discussed included general information about needle phobia (aka trypanophobia), medical preparation, coping skills for anxiety, relaxation techniques, and action plans for your child's future treatments. This webinar is a fantastic resource to those dealing with stress and anxiety related to infusions and injectable treatments. To watch the full webinar, you can scan the QR code with your phone's camera.

Hill Day - June 13, 2023

The Hemophilia Alliance hosted its annual Hill Day on June 13, 2023 in Washington, DC. Staff from member Hemophilia Treatment Centers (HTCs) attended the event accompanied by a number of patients. These attendees broke up into regional groups and visited with their respective federal representatives, senators, or aides. Advocates shared their experiences and concerns regarding the issues faced by members of the bleeding disorders community. A primary concern is the need to continue the support of HTC 340B programs which provide more affordable treatments and medications to bleeding disorders patients. These programs are especially important because they provide the primary funding for many HTCs across the nation. When HTCs were established in the 1970s, most funding was provided by federal sources including grants from the Centers for Disease Control (CDC) and Maternal and Child Health Bureau (MCHB). As these grants diminished over the years, the federal government allowed certain entities, such as HTCs, to create pharmacies that could help fund said entities. The future of HTCs heavily rests with the future of 340B pharmacy programs. Representing the Boston Hemophilia Center this year at Hill Day were: Cliff Haas (Factor Program Operations Manager), Greg Schiurring (Project Manager), and Megan Candito (Communications Specialist).



Some Big News...

We would like to share the bittersweet news that Debra McNamara, the Director of Hemophilia Programs here at the Boston Hemophilia Center, has announced her well-deserved retirement at the end of 2023. Deb has served in senior administrative roles at our center for over 15 years, and has been an incredible advocate for our center, our patients, and the larger hemophilia community. Her efforts have been essential in building up the Boston Hemophilia Center into what it is today.

We would be remiss to not also celebrate how Deb has assisted Hemophilia Treatment Centers throughout New England. In her role, she's helped new treatment centers across our region find their footing and prosper – allowing the essential services provided by HTC's to reach even more bleeding disorder patients.

We at the Boston Hemophilia Center will miss Deb dearly. We thank her for the leadership, openness, and all the incredible work she has accomplished over her tenure.

Here's to Deb writing the next chapter of her life, and taking on her next big job: watching after her grandchildren.



New Staff



Welcome Raegan!

Raegan Baillargeon joined the Boston Hemophilia Center in February of 2023 as Patient Navigator after previously working as a Certified Dental Assistant for 4 years. She is excited to take on her new role and help the team wherever she can. Born and raised in New Hampshire, Raegan received her degree from Southern New Hampshire University in Health Science. In her free time, she enjoys spending time with friends and family, reading, and weightlifting.



Welcome Olivia!

Olivia Olayiwole joined the Brigham and Women's Hospital Hematology Division as a Data Manager in March 2023. Olivia is a recent graduate of the University of Massachusetts Amherst with a BSc in Public Health. She looks forward to supporting and coordinating ongoing research studies within the Division of Hematology. She was born in Boston and has spent most of her life here in Massachusetts. In her free time, she enjoys reading, cooking, and being active. She is excited to be entering the clinical research field and is eager to contribute to the team.



Welcome Arielle!

Arielle Lavi joined the BWH Division of Hematology as a Data Manager in July 2023, where she is involved in many ongoing clinical studies. Originally from Connecticut, she recently graduated from Brandeis University with a Bachelor of Science in Biology and a minor in Psychology. Outside work, she is looking forward to exploring the Boston area and experimenting with cooking.



Welcome Justin!

Justin Gomez-Stafford joined Boston Children's Hospital as a Genetic Counselor in August 2023. He will be integrated into the provision of genetic services within the Hematology/Oncology Division. Justin is originally from New Haven, CT and graduated from Stanford University with a master's degree in Human Genetics and Genetic Counseling. Justin has clinical experience in genetics services related to fertility, adult/pediatric oncology, cardiovascular, neurological, hematology, prenatal, variant interpretation, general genetics, and insurance. He also enjoys DEIJ/social justice advocacy, traveling, and creating new experiences with those around him.