



In this issue:

Back to school (pg. 2) Some Big News (pg. 4)

Centerpoints

Issue 24/Fall
2024

Director's Corner



Stacy E. Croteau, MD,
MMS, Medical Director

Physical Wellness and You

Our *Prophy and You* educational event earlier this year was an excellent opportunity to reflect on how far we have come with

bleeding disorder treatments and also to consider how to continue to improve and individualize our approach to care. The range of sports and activities our bleeding disorders community participates in continues to expand. Physical activity is not only important for supporting overall muscle and bone (musculoskeletal) health but also for creating strong social bonds and teaching teamwork. Participation in summer camps and weekend family camps is another great way to get outside and ensure regular movement and team building. Look for some fun summer highlights later in this newsletter.

There are still many questions about how bleeding disorders affect muscle and bone health (even without obvious bleeding symptoms). Studying musculoskeletal health in individuals with bleeding disorders is an ongoing focus for several types of clinical studies including this one, NCT05022459 *Prevention of Bleeding in Patients With Moderate and Severe Hemophilia A Playing Sports: A Comparison Between Factor VIII and Emicizumab Prophylaxis*, led by our HTC colleagues at Wayne State University in Michigan.



Strengthening and Protecting Joints: Fall Fitness Strategies for People with Bleeding Disorders

Kristen Benya, PT

As the leaves change and temperatures drop, fall presents a perfect opportunity to focus on strengthening and protecting your joints. For individuals with bleeding disorders, maintaining joint health through safe and effective physical activity is crucial. Here are some ideas of how you can adapt your exercise routine this season.

Engaging in strength training can significantly benefit those with bleeding disorders by building muscle around joints, providing extra support and stability. Light weightlifting or resistance band exercises are excellent choices to promote muscle strength gains. If you are new to resistance training, it's important to begin with light to moderate weight to avoid a muscle or tendon injury or in the worst-case scenario, a breakthrough bleed. Another important component in a general conditioning routine is incorporating flexibility training, such as yoga or targeted stretching exercises, which will improve your muscles' mobility and tolerance to activity. This combination of flexibility and strengthening efforts will maximize your ability to participate in your recreational activities while lowering your risk of injury.

Take advantage of the pleasant fall weather by participating in outdoor activities like walking or gentle hiking. The crisp air and scenic views can make exercise more enjoyable and is a great opportunity to bring friends and family along. However, it's essential to dress in breathable layers that allow for temperature regulation during the often unpredictable weather patterns in the Northeast. With these more dynamic activities in different environments, it's also important to consider joint protection. To minimize strain on vulnerable joints, modify activities with standing or sitting rest breaks, make a plan for alternate routes if you are less familiar with the area, and find the terrain too challenging. Support tools like braces, compression wear, and walking poles can provide additional protection that can easily be added or stored in a backpack during the day as needed. Always prioritize proper technique and listen to your body to avoid overexertion, even light to moderate activity has positive impacts on musculoskeletal and cardiovascular health.

(continued on page 2)

(continued from page 1)

If you're struggling with where to start, consulting with your HTC's Physical Therapist can help tailor an exercise plan to your individual needs. Customized plans ensure that you are engaging in the safest and most effective exercises for your condition. If you already have a PT or athletic trainer you work with outside of your healthcare team, we are always happy to collaborate with them to help you reach your physical fitness goals safely. Not sure what outdoor activities would suit your interests? Local outdoor recreation stores like REI and Public Lands have a diverse list of community-based outdoor activities that can get you started. Activities range from relaxing outdoor movie nights to courses that teach you skills for backpacking, paddleboarding, biking. Don't know how to change a bike tire or orient yourself using a map and compass? Take the free workshops and meet some outdoorsy locals that are here to help! Want to explore the Harbor Islands of Boston during the last warm days of September? Join the kayak tour led by one of the knowledgeable REI staff members for a fun day of aquatic exploration! These activities are often free or provided at a very low cost to members of the community and sponsored by local towns and cities to get people out and enjoying the natural spaces of our beautiful state.

By incorporating these joint-friendly exercises and taking seasonal precautions you can strengthen and protect your joints, enhancing your overall health and well-being. Embrace the fall season as an opportunity to invest in your joint health, stay active, and engage in your community!

Upcoming Events:



Bleeding Disorders Conference September 12-14, 2024:

The National Bleeding Disorders Foundation 76th Annual Bleeding Disorders Conference (BDC) will take place September 12-14, 2024 at the Georgia World Congress Center in Atlanta! Join the bleeding disorders community for three incredible days of educational sessions, valuable networking opportunities, and exciting exhibits.

NEHA 15th Annual Unite for Bleeding Disorders Walk September 28, 2024

The New England Hemophilia Association (NEHA) is excited to host the 15th Annual Unite for Bleeding Disorders Walk taking place on Saturday September 28 at Prowse Farm in Canton, MA! Everyone in the New England bleeding disorders community, their families, friends, supporters, HTCs and others from all six New England states are invited to join!

Boston Bleeding Disorders Center Fall Event - TopGolf Event October 5, 2024

Join us for our second patient event of 2024 - TopGolf! Skill session with a Pro and lunch will be included! Please be on the lookout for our save the date with more information coming soon!

Latino Hispanic Heritage Month Event October 5-6, 2024

The New England Hemophilia Association (NEHA) invites the Latino community with a bleeding disorder to celebrate Hispanic Heritage Month with a lecture entirely in Spanish for adults and in English for children and teens.

Back to School Reminders:

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.

- Provide general information about your child's bleeding disorder to teacher, nurse, staff.
- Provide an IHCP (individualized health care plan) provided by your Hematologist.
- If appropriate to your child's need, consider asking the school leadership about a 504 plan.
- Orders for medication in school detailing specific circumstances where appropriate and include instructions for admins.
- Communicate with coaches when deciding to participate in sports.

Institutional/HTC Resources:

We wanted to highlight some resources that are available to our pediatric and adult patients. If you are curious about any of the following resources, make sure to ask your bleeding disorder team or social worker!

Pediatric, BCH Corner:

Center for Families

<https://www.childrenshospital.org/patient-resources/hale-family-center-families>

Child Life Services

<https://www.childrenshospital.org/programs/child-life-services/our-specialists>

Interpreter Services

<https://www.childrenshospital.org/patient-resources/interpreters>

Patient Financial Services

<https://www.childrenshospital.org/patient-resources/financial-and-billing-matters/frequently-asked-billing-questions>

Adult, BWH Corner:

Interpreter Services

<https://www.brighamandwomens.org/patients-and-families/patient-resources/interpreter-services>

Patient Family Relations

<https://www.brighamandwomens.org/patients-and-families/patient-resources/patient-and-family-relations>

Patient Financial Services

<https://www.massgeneralbrigham.org/en/patient-care/patient-visitor-information/financial-assistance>

Community Events Recap:

Bleeding Disorders: Prophy & You 2024! An Educational Event

The Boston Bleeding Disorders Center team enjoyed welcoming you to our spring education event focused on prophylaxis for bleeding disorders. Drs. Croteau and Connell provided education on current and anticipated bleeding disorders treatment and were then joined by a dynamic group of patients (kids and adults!) who share their experiences with their bleeding disorder and prophylaxis. Much work was put into working with Davio's Northern Italian Steakhouse to host our event, which included a private room, great food and catering service as well as day of event coordination. The team also engaged directly with patients and their families to participate in our panel discussion, where they were able to answer questions and discuss their own treatment history and use of specific prophylaxis therapies. As everyone's journey is different, it was a great opportunity for our community to share their own experiences, engage with each other and make new connections. The BBDC team worked hard create a fun and interactive experience for all!



NEHA Consumer Medical Symposium 2024

The New England Hemophilia Association (NEHA) Consumer Medical Symposium was held on Saturday, March 16 and Sunday, March 17 at the Sheraton Nashua in Nashua, New Hampshire. This event was created to help better understand what current and potential medical advancements are available to treat bleeding disorders and what they may mean for you and your family.

"The Boston Bleeding Disorders Center (formerly The Boston Hemophilia Center) Pharmacy and Administrative staff attended in the vendor arena, embracing the opportunity to meet and interact with the patients we serve each day." - Factor Program Operations Manager, Cliff

"As someone who attended for the first time, it was cool to see patients and families in the bleeding disorders community have a space to come together, network, and learn more information about current and emerging therapies. There were activities for the kids as well, so there was really something for everyone" - BBDC Patient Navigator, Raegan

Hemophilia Alliance Washington Hill Day Advocacy in Washington D.C. 2024

Our Boston Bleeding Disorders Center team participated in the 2024 Hemophilia Alliance 'Hill Day'. Team members spent time educating Senators and Representatives and their staff members (many of them new to their role on Capital Hill) about bleeding disorders and the importance of the 340B Program to our community and comprehensive healthcare model of Hemophilia Treatment Centers. Bleeding disorders are rare and costly to treat. Ensuring that policymakers understand our issues and continue to support access to expert clinical teams and lifesaving therapies is critical.

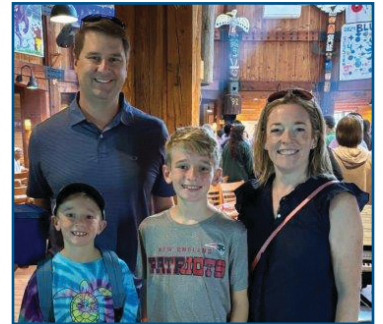
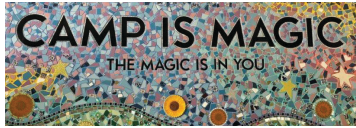


Camp Corner:



“Fun! Silly! Exhilarating! Adventurous!” - “MadDog” a.k.a Maddox

Those are the words Maddox used to describe his time at NEHA's Family CAMP. Maddox is a first-time camper and he was accompanied by his parents, sister, and brother. He and his siblings were able to partake in activities such as woodshop, archery, and even beach days. While they were off having fun, there are sessions for the adults that are more informative. Maddox's favorite part of camp was the Willy 500 where they make a car out of wood and slide it down a ramp. Maddox is working towards the BIG stick, awarded to all those who successfully self-infuse. He received a certificate for his first time learning to infuse and he's also learning how to draw his medications. Maddox made a lot of friends and certainly recommends going to CAMP!



If you're interested in attending a camp, there are a couple Fall Family weekends hosted by Hole in the Wall Gang. There is also a Bleeding Disorder Weekend taking place from September 20th – 22nd, 2024. Make sure to check out: <https://www.holeinthewallgang.org/programs/weekend-programs/Application-and-Schedule/>

If you're interested in attending a summer camp next year, be on the lookout for application released in early 2025 by Hole in the Wall Gang and NEHA.

New Staff:



Welcome Michelle!

Michelle Pena joined the Boston Bleeding Disorders Center in May 2024 as a Communications Specialist. Michelle is a bilingual professional delivering strategic communications to reach business objectives for more than 15 years. Born and raised in Boston, she graduated from Northeastern University with a Bachelor's in Digital Communication and Media. In her free time she loves nature, reading books and spending time with her daughter and dog. She looks forward in engaging and supporting the BBDC team.



Welcome Rashmit!

Rashmit Kaur Banga joined the Boston Bleeding Disorders Center in July 2024. Rashmit moved to Boston in 2023. She enjoys travelling, cooking, hiking, checking out new coffee shops, exploring diners and everything outdoors. She has previously worked with KPMG, Shah and Taparia and Crisil. We are excited to have her join the team and help us continue our positive work.

Physical Wellness Tips:

- Strength training: Light weightlifting or resistance band exercises
- Flexibility training: Yoga or targeted stretching exercises
- Participate in outdoor activities: walking or gentle hiking
- Discuss your physical activity goal with the HTC's Physical Therapists who can help tailor an exercise plan to your individual needs.
- Local outdoor recreation stores have a diverse list of community-based outdoor activities that can get you started.

Feedback!

We want to hear from you! Do you have ideas for future educational events or supports/services that the Boston Bleeding Disorders Center can provide? We welcome your ideas and feedback on how we can better serve you and your family. Please share your thoughts with us by email at bostonhtc@bwh.harvard.edu or use this QR code to submit comments electronically.



Stay in the know by checking out our [Web](#) and [Facebook](#) page!

Website: <https://www.childrenshospital.org/programs/boston-hemophilia-center/> / Facebook: Boston Hemophilia Center