New Staff at BHC

**IRIS RICHARDS-DAVIES** joined the BCH team in March of 2019, as an Administrative Associate. She graduated from Cambridge College with a B.S. in Human Services. Continuing her education in Nursing, she is completing prerequisites and looking forward to getting into an accelerated nursing program in the near future. Iris is very interested in ensuring patient satisfaction, from direct interaction and scheduling to administrative support, as they each play a role in the patient’s experience.

Iris and family members created a group called “Exchange for Change” which would provide blessing bags to the homeless.

Iris was born and raised in Dorchester, Massachusetts. She is excited to learn the administrative side of patient care. Iris enjoys reading about personal growth, spending time with family, and finding new activities to enjoy in the city. You can reach Iris at 617-919-2139.

**KATE JOLLEY** has recently joined the BHC team as a Clinical Research Coordinator after graduating with a BA in Biology from College of the Holy Cross. Outside of her studies, she was a peer tutor and a laboratory teaching assistant. Additionally, Kate volunteered at a variety of organizations in Worcester, including Let’s Get Ready and the Quinsigamond Village Community Center. In her spare time, Kate enjoys reading, hiking, and traveling.

Kate was raised in Stoughton, Massachusetts, where she currently lives. She hopes to attend medical school in the future and is excited to be working at the BHC. She can be reached at 617-525-0033.
I just returned from visiting NEHA family camp. It was a beautiful, sunny day. Campers were splashing and boating in the crisp, clear water of Lake Winnipesaukee among other skill building activities with their peers and families. I enjoyed an afternoon education session with parents and community members discussing new and investigational treatments for patients with hemophilia, von Willebrand disease, and rare coagulation disorders. I have given similarly titled talks for the Boston HTC, other NEHA events, and as an invited speaker at other hemophilia treatment centers and national meetings over the past year, but the pace of new information in bleeding disorders ensures that I never have to give the same presentation twice!

In all of these venues many similar questions arise. How are newly FDA approved factor products different from those we already have available? Is there a benefit specifically to me or my child in switching to a new factor? How do these new “non-factor” therapies differ from the factor replacement that I am used to? Are there differences in safety or long-term health outcomes that I need to consider? When will other non-factor therapies and gene therapy be FDA approved? These are all very good questions. Below I highlight some considerations of new and emerging therapies and answer some of those questions listed above.

As we think about new frontiers in bleeding disorders, new treatments are only one aspect of how we are trying to improve the diagnosis and care of individuals with bleeding disorders. I also spotlight a few of other ways your HTC team is engaged in other facets of improving the care that we deliver to our patients and families with bleeding disorders. Since I only have limited space I have included some links to allow you to explore topics in more detail. Remember your HTC team is always happy to engage in discussions of the shifting landscape of bleeding disorder care.

Bleeding Disorder Therapies

We continue to see new approvals of factor concentrates, the most recent just a few months ago. The list of factor replacement options can be daunting. The benefit of all of these options is that rather than prescribing a similar regimen to everyone, we can focus on the needs of the individual. This means identifying a product, dose, and infusion schedule that will minimize your risk of bleeding while maximizing your ability to participate in the activities that are important you. One tool that has helped us and HTCs across the global personalize patient prophylaxis regimens is WAPPS-Hemo. This tool, developed by colleagues at McMaster University in Canada, uses population pharmacokinetics (PopPK) to help us predict how an individual patient will respond to prophylaxis with different factor products. Stay tuned to how new applications like myWAPPS may help us to continue to tailor care to you.

Emicizumab (Hemlibra) is the first non-factor therapy to be approved for prophylaxis in individuals with hemophilia A with or without inhibitors. I enjoyed seeing many of you this fall at the Boston HTC educational seminar we held on this new therapy. Dr. Parnes and I teamed up with NEHA to present a webinar with similar content.

Gene therapy continues to be another hot topic. Looking back through our newsletter archives I came
Bleeding Disorders: New Frontiers <<< continued from page 1

across an article discussing gene therapy that Dr. Neufeld wrote for the Summer 2012 edition! While it is true that hemophilia gene therapy has been anticipated for decades at this point, we are closer than ever. Several phase 3 (licensure) clinical trials are ongoing or just about to begin enrollment.

Clinical Research

There are many clinical trials investigating new drugs for bleeding disorders enrolling patients. In addition to your clinical team, Clinicaltrials.gov is a good source of information about ongoing clinical trials. Many observational clinical studies are also underway to learn more about bleeding disorders in general as well as how patients are doing on new therapies. Boston HTC is leading and participating in many of the clinical research studies. Checkout our website or ask your clinical team for more information.

Women with Bleeding Disorders

Young Women’s Bleeding (YWB) Clinic is a collaborative clinic among hematology (myself and Loren D’Angelo, NP), pediatric gynecology, and adolescent medicine at Boston Children’s Hospital. This monthly clinic focuses on diagnosing and developing individualized treatment plans for young women with abnormal bleeding symptoms. For patients that would otherwise need to take time away from school and work to see multiple specialists, this is an opportunity to have an expert, integrated medical team with coordinated visits at one time and location. Development of a similar clinic concept on our adult side is also underway.

Developing Skills for Independence (Transition)

Over the past several years the pediatric team has focused on improving our in clinic education and preparation for “medical independence” particularly for our teenaged patients. With our HEMO-milestones tool, we have worked to be more deliberate and transparent about the transition to adult care process. We continue to refine this process. We understand that changing medical teams and transferring to an adult care model is scary and anxiety provoking. The pediatric and adults teams continue to work together to make this transition as seamless as possible. This is an area where we are focusing our quality improvement work, so we look forward to receiving feedback from you on the transition process between the pediatric and adult side of the HTC.

We continue to update our new website: http://www.childrenshospital.org/centers-and-services/programs/a-_e/boston-hemophilia-center

Access the latest educational information, program updates, clinical research opportunities, and HTC publication links. Please visit us there in between newsletters or to view a newsletter from the archives! 💣

That’s a Wrap!

The vWD Connect Foundation Conference was held in Palm Beach Gardens, Florida, from June 28 to July 1, 2019. This Foundation was established by Directors, Jeanette Cesta and Ed Kuebler, MSW, to serve the needs of individuals with Type 3 and other severe types of von Willebrand disease.

This was the third year that bleeding disorders specialists, including physicians, nurses, social workers and other professionals, provided educational and supportive sessions over four days. What a success it was! Over one hundred consumers and family members participated and the feedback was tremendously positive. 💣

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From left to right: vWD Connect Foundation Conference Social Work staff: Sabrina Farina, LMSW, (Gulf States Hemophilia and Thrombophilia Center), Connie Thibodeaux, MSW, (Louisiana Center for Bleeding and Clotting), Ed Kuebler, MSW, (Director), Jeanette Cesta, (Director), Laurel Pennick, LCSW, (Arizona Hemophilia and Thrombosis Center) and Peg Geary, LCSW (Boston Hemophilia Center).
It may feel like the kids just started their summer vacation, but the new school year is just around the corner. Having a child with a bleeding disorder adds many items to your September to-do list.

As your child get older, the amount of time they spend in someone else’s care increases. Therefore 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-school nurses, teachers, and coaches.

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.

**General information about your child’s bleeding disorder**

Many schools appreciate some general factual information about your child’s bleeding disorder – it can help dispel 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 his/her condition, what kind of treatment he or she 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 hamper his/her 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.

If you plan to keep bleeding medications in school (factor, Stimate, 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**

NHF’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 his or her 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 his/her 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 his/her 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.

Let us know how we can help to get your child’s school year off to a great start! ✨
Save the Date

*Boston Hemophilia Center Patient and Family Symposium*

*Advocacy in the Bleeding Disorders Community*

The Inn at Longwood Medical

Thursday, November 14, 2019, from 6:30 pm to 8 pm

**Key Note Speaker:** Joseph D. McKenna  
*State Representative – 18th Worcester*

With a guest panel.  
Dining and Parking provided.  
Invitation and more details to follow.

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**Bowling at its Best!**

King’s Bowling in Dedham, MA, was the place to be this past March 31st, when about 80 adults, parents and children joined the BHC team in a fun-filled afternoon to celebrate World Bleeding Disorders month in our local community. There was something for everyone! Teams of people showed their skills at bowling while kids and adults alike competed in the game room. Participating in these sports and games provides important physical activity to enhance musculo-skeletal health and coordination. In addition, the social contacts help children make the most of the sports-centered team activities. And everyone enjoyed the food and company! As one of our mothers noted, “It was great to meet other people whose kids are dealing with the same thing as mine!”

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*From left to right: Amanda Stahl, BHC adult social worker, with her daughter, Claire, Aric Parnes’ (adult hematologist) daughter, Fia, Dr. Parnes, and his son, Kai.*

*From left to right: Anastasia Bobos, BHC Project Manager, with her twin boys, George and Paul.*
That’s a Wrap!

HFA Annual Symposium

Hemophilia Federation of America (HFA) held their annual symposium in beautiful San Diego, CA, from April 4 – 6, 2019. And what a wonderful conference it was! The size and scope of the conference have grown tremendously over the years. In proof of this, the numbers of attendees, educational sessions, and social events were impressive.

At the meeting, they hosted research poster sessions, as well as, several research-based educational presentations headed by national experts. The entire conference was interesting, dynamic and full of fun!

Peg Geary, BHC project manager, attended the symposium to present a poster, “Obstacles to Caregiving in the Bleeding Disorders Community”, which she authored with Aric Parnes, MD, adult hematologist at BHC.

Massachusetts Advocacy Day

About 50 patients, family members, and medical professionals joined the New England Hemophilia Association (NEHA) at the Massachusetts State House on May 8, 2019. A training session was conducted by NEHA staff and consultants to prepare participants for their visits.

Advocates were organized into small groups and spent the day going to their respective Massachusetts Representatives’ and Senators’ offices to talk with the politicians about issues that concern the bleeding disorders community: extension of the copay assistance programs, the end of step therapy in the case of treatment for patients with bleeding disorders and offering support to the National Institute of Health’s hope to establish a new council on rare diseases.

Amanda Stahl, MSW, adult social worker at Boston Hemophilia Center (BHC), and Peg Geary, BHC project manager, attended the event and were very impressed by the enthusiasm, commitment and personal experiences shared by patients and families. What an exciting day in our exciting city!

Hill Day

Hemophilia Alliance hosted its annual Hill Day on April 30, 2019 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 with and concerns about the issues faced by members of the bleeding disorders community. A primary concern focused on the need to continue the support of HTC 340b programs which provide products to bleeding disorders patients. These programs are very important since 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 fund the entities. The future of HTCs heavily rests with the future of 340b pharmacy programs.

Mike Miller, BHC Financial and Administrative Manager, and Cliff Haas, BHC 340B Factor Program Operations Manager, attended the Hemophilia Alliance semi-annual meeting and Hill Day.