March is Bleeding Disorders Awareness Month!

by Rich Pezzillo, NEHA Executive Director and Peg Geary, BHC Project Manager

For more than 30 years, the bleeding disorders community celebrated March as the unofficial Hemophilia Awareness Month. In 2016, this designation became official when the National Hemophilia Foundation (NHF) petitioned the US Department of Health and Human Services to have this designation included on its National Health Observances list for March. Throughout the month, national organizations like the NHF and the Hemophilia Federation of America (HFA) and regional chapters, such as the New England Hemophilia Association (NEHA), spread awareness about bleeding disorders using various advocacy campaigns.

For the third year in a row, Massachusetts Governor Charlie Baker issued a proclamation that declared March as Bleeding Disorders Awareness Month in 2019.

Each state must have either a proclamation or a resolution issued yearly to declare Bleeding Disorders Awareness Month on a local level. A proclamation is a formal announcement that recognizes a topic or issue to educate the general public. A resolution is a non-binding written motion adopted by a legislature to recognize or honor an event to the general public to generate awareness. Both a proclamation and a resolution are issued by a governor, a mayor, or another executive official.

Massachusetts Representative Joseph McKenna, who has been very committed to the recognition and welfare of the bleeding disorders community, works directly with the Governor’s office to ensure that the Bay State issues a proclamation to officially declare this important recognition each year.

What a wonderful tribute to persons with bleeding disorders and their families in this commonwealth!

In honor of Bleeding Disorders Awareness Month, Rich Pezzillo, New England Hemophilia Association (NEHA) Executive Director, and Peg Geary, Boston Hemophilia Center (BHC) Project Manager, decided to look at the successful collaboration of their respective organizations.

The relationship between the Hemophilia Treatment Center (HTC) and its local/regional chapter is very important for the bleeding disorders community. Both nonprofit organizations focus on the health and wellbeing of the consumer and their successful collaboration provides a powerful force that benefits the members of this community and strengthens the consumer network across the US.

BHC and NEHA focus on increasing and maintaining the quality of life of members of the bleeding disorders community. BHC provides its clinical expertise through medical, physical and psychosocial assessments, care and treatment. The multidisciplinary team, whose core members consist of the hematologist, the nurse and social worker along with other medical experts, provides a wholistic view and course of treatment for consumers.

While BHC focuses on the medical care and health of individuals, NEHA works on the non-medical aspects...
of consumers’ quality of life. NEHA works diligently to provide an amazing calendar of community events that rotate throughout all six of the New England states. Most of these are professional educational events while some are also fundraisers for the organization, as well as the community. The biggest coordinated multiday program is Family Camp, where clinical staff, professional speakers and NEHA personnel provide opportunities for education and social support for ever-increasing numbers of people with bleeding disorders and their families. Besides educational programming, NEHA also helps consumers in need of financial assistance and provides scholarships for individuals and families to attend important community events such as NHF’s Washington Days and other national meetings.

BHC and NEHA have built a positive institutional relationship by working together and supporting each other for the good of the consumer. In recent years, both administrations and staffs have devoted themselves to planning quality educational events, sharing ideas and resources, and supporting each others’ programs. The personnel work on committees and projects together to assist each other financially and physically.

NEHA’s Consumer Medical Symposium is a perfect example of planning and working together. This symposium is in its third year of providing groundbreaking exposure to the host of medical treatments and factor products that are in clinical trials or have already entered the market. NEHA took the reins as the two institutions planned the event together, recruited knowledgeable speakers, and put on the first program of its kind in this community.

It is difficult to remember a better time in the history of the bleeding disorders community. It is an era of hope and optimism for the future. With that in mind, advocacy is more important now than ever. Insurance coverage is vital. A couple of years ago, NEHA started a coalition called the, New England Bleeding Disorders Advocacy Coalition (NEBDAC), with the goal of informing, training and leading advocacy efforts with government representatives in New England. NEBDAC is made up of consumer volunteer representatives from each New England state and professionals from the regional HTCs and NEHA. Their grassroots efforts recently succeeded in convincing the politicians in the state of Massachusetts to approve the extension of pharmaceutical copay assistance programs, a much-needed financial assistance program used by many individuals in New England.

The collaboration of BHC and NEHA has strengthened the direction and power of bleeding disorder care, treatment and education in New England. It is quite a testament to the determination, motivation and level of cooperation between organizations who care about and for these consumers.

For more information about the events NEHA hosts, please visit their website or call their office at: www.nehemophilia.org or 781-326-7645.

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NEHA 2019 Community Dates

- **March 9**, Consumer Medical Symposium, Portland, ME
- **April 27-28**, Couples Retreat, Stowe, VT
- **June 8**, 10th Annual Walk, Canton, MA
- **June 26-29**, Family Camp, Moultonborough, NH
- **July 27**, Murder Mystery Dinner, Dedham, MA
- **August 2-4**, Women’s Retreat, Chester, CT
- **August 13-14**, BLeaders Teen Retreat, TBD
- **September 9**, Golf Tournament, Boylston, MA
- **September 28**, Hispanic Heritage Month Event, Boston, MA
- **October 26-27**, NEHA FallFest, Warwick, RI
- **November 9**, vWD Retreat, Portsmouth, NH
- **December 1**, Holiday Party, Newburyport, NH
**March is National Social Work Month!**

We all know that March is Bleeding Disorders Month in Massachusetts and across the country, but did you know that it is also National Social Work Month? What a wonderful time to recognize our Social Workers (SWs) for the services they provide to our patients and families at the Boston Hemophilia Center (BHC).

Historically, SWs have been invaluable members of a Hemophilia Treatment Center’s (HTC’s) multidisciplinary team. The role of HTC SWs includes a wide range of services including psychosocial assessments, casework services, supportive counseling, financial and insurance assistance, patient education, information and referral, and patient advocacy. Even beyond that, these professionals are also involved in such academic pursuits as psychosocial research, local and national presentations, writing articles, and participating in national projects.

At Boston Hemophilia Center (BHC), we are fortunate to have two clinical social workers: Jackie Miranda, our pediatric SW, located at Boston Children’s Hospital and Amanda Stahl, our adult clinical SW, working out of Brigham and Women’s Hospital in Boston. We appreciate the altruistic work that they do for the members of the bleeding disorders community every day.

Below, we have asked the BHC social workers to talk about themselves and their work.

**Jackie Miranda, LICSW, BHC Pediatric Social Worker**

Greetings! My name is Jackie Miranda and I have been involved with the Boston Children’s Hospital Hematology Pediatric Program for the past 23 years. For many years, I worked with the Spanish-speaking pediatric patients of the Boston Hemophilia Treatment Center, but in 2016, after the departure of our longtime hemophilia social worker, I assumed the full-time position as the program’s social worker. I was thrilled to have the opportunity of becoming more involved with this patient population. My passion has always been to work in the setting of healthcare, and specifically with patients and families living with challenging chronic illnesses.

I continue to be part of the multidisciplinary team of the Boston Hemophilia Treatment Center, providing comprehensive psychosocial support to the patients and families facing the many challenges of living with hemophilia. I have the honor and privilege of supporting the parents of our patients, as well as completing annual psychosocial assessments, connecting families with local and national resources, assisting with education/advocacy and providing supportive counseling as needed.

I continue to feel extremely fortunate to work with this amazing and resilient group of children, teens, young adults and parents. I have learned so much and am forever amazed at the strength and comradery of the New England Hemophilia community. I look forward to my continued work and collaboration in the Boston Hemophilia Center and the great advances in the treatment of this challenging condition.

**Amanda Stahl, LICSW, BHC Adult Social Worker**

Hi Everyone! My name is Amanda Stahl and I have been the social worker for adult patients at the Boston Hemophilia Center for just over 3 years. I have always been naturally curious about people and am lucky to channel this curiosity into a career. I like trying to understand what motivates people, what challenges them, how they heal, and how they are resilient. I am so fortunate to have found a career where I get to witness people overcome immense setbacks and make progress in ways they never thought possible. It’s such a privilege to be reminded of human resilience in that way.

As you know, psychosocial support is part of our multidisciplinary team approach at the Boston Hemophilia Center. Many people experiencing chronic illness face challenges outside their medical condition; it is the social worker’s role to assess these challenges and brainstorm interventions. My social work efforts mainly consist of assessing resource needs, connecting patients to said resources, problem solving, education, advocating, helping with insurance issues, work place issues, school issues, offering emotional support as it relates to depression, anxiety, pain, stress, substance abuse, and all the above. While I am qualified as an LICSW (licensed independent clinical social worker) to provide therapeutic counseling, I typically refer those patients in need of ongoing therapy services to someone in their community.

It has been such a privilege getting to know all the patients at our center over the years. We have the most interesting, articulate group of patients and I feel so lucky to continually learn so much from all of you.
New Staff at BHC

**RACHEL GAUFBERG** was hired as a Clinical Research Coordinator at the Boston Hemophilia Center (BHC), part of Brigham and Women’s Hospital’s Division of Hematology. In May, 2017, she graduated from Clark University, where she received a B.A. in Psychology after successfully completing the Pre-Med track. Rachel has a great interest in global and community health. While at Clark University, she helped lead public health initiatives in Leogane, Haiti, with the non-profit organization, YourStory International, and interned at the Family Health Center of Worcester, MA. In her spare time, she is a scuba diver, skier, and musician. Rachel hopes to attend medical school in the near future. She can be reached at #617-525-8038.

**JAKE GOLDSTEIN** recently graduated from Boston University with a B.S. in Human Physiology and a minor in Public Health. Outside of his studies, he was on the governing board of Global Medical Brigades and was a member of the pre-health honor society, Alpha Epsilon Delta. Jake was very involved in various volunteer programs locally, at Boston Medical Center and internationally, in Guatemala, Honduras, and Estonia.

Jake was born and raised in Delray Beach, Florida, and has been living in Boston for three years. He is very excited to work in research at BHC and hopes to pursue a career in medicine. In his spare time, he enjoys playing basketball, practicing yoga, working out, and reading. He can be reached at #617-525-0033.

**OLIVIA SEARS** joined the BHC team as a Clinical Research Coordinator in November, 2018. It is her goal to help develop therapies for patients with a clinical unmet need. To do this, she has conducted cancer research in basic, translational, and clinical settings. In the spring of 2017, Olivia received Bachelor Degrees in Neuroscience and Marine Biology from Northeastern University where she served on the executive board of the neuroscience academic club and as a preschool teaching assistant in Roxbury.

Olivia was born and raised in Massachusetts and looks forward to pursuing a career in medicine. She enjoys thru-hiking, field hockey, and comedy shows. Olivia looks forward to working with patients and their families and learning more about the experiences they have at BHC. You can reach Olivia through her email address: Olivia.Sears@childrens.harvard.edu.

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A Timely Tip To Avoid Delay of treatment!

Call ahead of time!

Call your BHC 340B pharmacy or specialty pharmacy 2 or 3 days BEFORE you or your child need your factor shipment! Most insurances require prior authorization for your prescriptions to be approved, filled and delivered. This process may take a few business days to complete.

Call ahead and save yourself the stress!
That’s a Wrap!

Washington Advocacy

In the spring of 2018, the National Hemophilia Foundation (NHF) sponsored “Washington Days” and Hemophilia Alliance held “Hill Day” for the purpose of facilitating advocacy efforts for the bleeding disorders community. Both organizations hosted patients, family members, and HTC and chapter professionals who were trained to visit and speak with their state representatives and senators about issues affecting them.

These advocates were wonderfully successful in educating the politicians about their medical conditions, pharmaceutical needs and financial/insurance concerns. Specific community concerns included the need to stop the use of step therapy by insurance companies in the payment of factor products and the need to allow the continued use of copay assistance with factor products. Cliff Haas, BHC 340B Operations Manager, and Peg Geary, BHC Project Manager, and patients from BHC and many other HTCs across the nation attended these events.

Educational Event

On October 4, 2018, BHC sponsored an exciting educational event, “Pros and Cons of Emicizumab Therapy for Hemophilia A.” Held at the Harvard Center, the event featured Dr. Stacy Croteau, pediatric hematologist and Associate Medical Director of BHC, and Dr. Aric Parnes, adult hematologist and Associate Medical Director of BHC. The physicians explained the results of the Emicizumab (also known as HemLibra) clinical trials. Two patients also spoke about their individual experiences with the factor product. Approximately 80 patients and family members enjoyed the talks and discussion. With new products on the market and more on the horizon, participants seemed to appreciate the information and rated the event a success.

BHC worked with NEHA to provide a follow-up webinar for people who missed the event. Drs. Croteau and Parnes re-enacted their talks on a link that NEHA presented from their website on Nov. 20, 2018. The webinar can still be accessed on NEHA’s YouTube channel: https://www.youtube.com/watch?v=3tFpu536-YA.
Results of the Second National Patient Satisfaction Survey

PATIENTS ARE HIGHLY SATISFIED WITH SERVICES AND CARE AT THEIR HTCS

In 2018, over 4,700 Hemophilia Treatment Center (HTC) patients and caregivers responded to a patient satisfaction survey, rating the care and services they received from their respective HTCs. This survey was based on the first questionnaire sent out a few years earlier.

Over 125 HTCs mailed out these questionnaires to their patients. Participants were asked to rate their satisfaction with HTCs in various areas, including HTC care, their multidisciplinary team, HTC services, teen transition process, insurance issues and language problems, and 340b factor programs.

Over 95% of those patients who took the survey nationally were “usually” or “always” satisfied with their HTC care and services, in general. Over 85% were “usually” or “always” satisfied with their HTC hematologist, nurse or nurse practitioner, social worker and physical therapist. About 92% of 12-17 year olds reported that they were “usually” or “always” satisfied about how the HTC staff talked about how to care for themselves and become independent. About 13% said that insurance issues were “usually” or “always” a problem.

The results of the survey are helpful in giving the HTC staff feedback about what they are doing successfully, as well as, where they need to make improvements. This important information and data will be further analyzed, studied and shared.

For more information, go to www.htcsurvey.com.