NEHA Joins Hemophilia Federation of America (HFA)!

Washington, D.C. – The Hemophilia Federation of America (HFA), a community focused national organization serving the needs of individuals and families with bleeding disorders since 1994, is pleased to announce the addition of the New England Hemophilia Association (NEHA) as its newest member organization. NEHA is the second chapter in New England to become an HFA member organization, making them the 35th to join HFA.

“The New England Hemophilia Association is a vibrant chapter filled with energy, knowledge and a desire to work together to better serve the bleeding disorders community,” said Kimberly Haugstad, HFA Executive Director. “Our member organizations are HFA’s foundation and I’m pleased that we continue to expand our network. The need for partnerships among organizations is crucial to ensure our community is safeguarded from harmful cuts in services.”

“NEHA is very excited about becoming a member of the Hemophilia Federation of America. I believe that this new partnership will enhance the quality of programs and services we provide in New England. Our membership has expressed strong interest in joining HFA, and we all appreciate the value that this new relationship brings to our community.” said Kevin R. Sorge, NEHA Executive Director.

NEHA member Diane Lima from Acushnet, MA, has been selected by the NEHA Board of Directors to represent NEHA as a member of the HFA National Board. We anticipate that members of NEHA will see some new activities using HFA resources during the coming year.
Dear NEHA Member,

The calendar year is nearing its end for 2012, and despite the fact that NEHA’s fiscal year ends in September, the arrival of the early winter months usually allows for pause and reflection on the past year’s events – specifically where we were able to meet our challenges successfully, things that we might have done better, and of course opportunities for growth.

It never ceases to amaze me how much the organization is able to accomplish, due in large part to the generosity and caring of our community and sponsors, and certainly our incredible staff. All of that said, there is a small matter that we need your help with.

Many of our events require advanced reservations and booking in order to secure dates. NEHA typically provides a registration process in advance for these events, and this list of registered attendees becomes our yardstick for gauging attendance, managing the budget, and confirming our event space and speakers.

Several of our events this year resulted in “no show” status from members, and in some cases this occurred more than once by the same member or family. In these cases, NEHA generally pays for additional space, meals, and usually speakers or guests resulting in resources that are underutilized - but we must still pay for. Going forward, we ask that you kindly help us by cancelling your reservation in advance, which will allow the organization to take appropriate, alternative steps to optimize our funds, required space, and guest speakers accordingly.

With that said, we fully realize that life is not always predictable, so we do expect there to be situations where last-minute changes prohibit attendance. However, your help and sensitivity to NEHA on this particular matter is very greatly appreciated.

Well wishes for a very safe and enjoyable holiday season!

Patrick Mancini
NEHA President
My name is Daniel Ducasse and I am 10 years old with Severe Hemophilia A. I was able to represent NEHA in the Baseball 2012 Gettin’ in the Game Junior National Championship. I went with my dad.

It was neat to meet people with hemophilia from all over the US.

On the first day in Texas, there was a baseball clinic in the back of the hotel. At the clinic, there were three athletes and all of them have hemophilia. They were Peter Dyson, Ivan Sada, and Jesse Schrader. Ivan was the first JNC Champion.

The second day was competition day. All the competitors go on the bus to go to the historical LaGrave Field home of the Fort Worth Cats. It was cool to hear your name be announced in the pro baseball field. The first part of the competition for my group was hitting. Then we went to fielding. Finally we went to my favorite part, which is pitching. When we finished, we were put into teams to play a game. Part of the game was that each member was able to hit the ball once. My team was up to bat first. I hit a single. When my team took the field, I played 3rd base. I made a great catch during the first play. It was hard to catch the ball when someone threw it to me because I was not used to the older kids throwing the ball fast to me.

At dinner that night, I met the Parker brothers, Corey and Perry. They both have hemophilia. Corey has a ball in the Baseball Hall of Fame for hitting five consecutive homeruns. Perry is a pro golfer.

Thank you, NEHA, for allowing me to go. It was fun!

Twenty years ago a group of 19 families with school-aged children affected by bleeding disorders met in Maine for a weekend retreat. The families enjoyed spending time together sharing stories and experiences, but no one had any idea that the weekend was just the beginning of many Family Camps to come!

This summer, Family Camp, a joint collaboration between New England Hemophilia Association (NEHA) and the New England Hemophilia Treatment Centers (HTCs) celebrated its 20th Anniversary with about 250 campers, parents, counselors, and volunteers.

Since its early days, Family Camp has evolved into a wonderful mix of fun, education, and support for families in the bleeding disorders community. An on-site daycare is offered for the littlest campers, while campers ages 3 to 12 are assigned to small groups led by counselors and participate in a variety of traditional camp activities like arts & crafts, woodshop, archery, field games, waterfront activities, music and movement/yoga and more. Youth ages 13 to 15 years old participate in Adventure Club, where the young teens enjoy some favorite camp activities and an off-site field trip and other activities not available to the younger campers. There is also a Junior Counselor Training program for 16 and 17 year olds. While the campers are with their counselors during the day, the parents have time to relax with other families and attend formal and informal sessions on a variety of educational topics relevant to our community.

What makes this camp so different from a typical camping experience is that there are five different self-infusion (Continued on page 9)
Retreat, Connect, and Breathe: A Reflection on The Women’s Retreat
By Bonnie Boomsma-Hall

With kids to feed, bills to pay, papers to write, exams to take, pets to walk, laundry to fold, lunches to pack, and dishes to wash it can be difficult to commit to one more thing. Sometimes while in the midst of the ever-consuming responsibilities of motherhood and nursing school I inhale sharply, catch my breath, and wonder if it is possible to forget to breathe. Add in the financial, emotional, and physical complications that come with having a bleeding disorder and I become psychologically hypoxic.

When my already over-flowing email inbox lit up with an invitation to a women’s retreat I scoffed—“who has time for one more thing?” According to Merriam-Webster Dictionary, a retreat is an act or process of withdrawal, especially from what is difficult, dangerous, or disagreeable. When framed by this definition, a retreat is not an added responsibility— it is the temporary reprieve from the current ones. I knew I could definitely use a brief escape. Child and pet care negotiated, transportation arranged, clothes haphazardly thrown into a backpack and I was ready to make the trek to Connecticut.

The Retreat for Women with Bleeding Disorders provided me with an opportunity to stop, reflect, learn, and breathe alongside other remarkable women. Aside from being indulged with vast amounts of food that I did not have to prepare or clean up, workshops provided nurturance for the mind, body, and soul. I left with a heightened awareness of current legislation under a heated political climate and was empowered to advocate for my community and myself in this arena. Education on emergency preparedness, my bleeding disorder and treatment options were addressed at length by capable, knowledgeable staff. The psycho-social effects of living with a bleeding disorder were shared and opportunities were provided to tap into my often neglected and overlooked creative side. Finally, we were encouraged to manage stress in healthy ways, to meditate...and to breathe....!

can interfere with prioritizing self care and needs. I ask that all women with bleeding disorders reconsider their to-do list to include this and other opportunities to be educated and nurtured in the bleeding disorder community. And if you attend next year’s retreat, be prepared to meet some phenomenal women...and to breathe....!

NEHA Advocacy Update
By Laura Salomons, Advocacy Coordinator

Advocacy is the act of working for or against a cause, policy, law, or idea. That cause could be the well being of yourself and your family. If you were able to attend Fall-Fest and the Pulse on the Road workshop, you learned what to look for in order to choose the health insurance provider that will best meet your needs. Providing NEHA members with tools to better advocate for themselves is just one of the jobs of the NEHA Advocacy Coordinator. If you haven’t yet checked out the new “Helpful Resources” section on the NEHA website under the Resources tab, I urge you to do so. There are over 30 different topics from Financial Assistance to Career Planning to Social Media - Emotional Support. Within each section are referrals to websites, articles, newsletters, and even videos. Included are helpful checklists, such as what to pack when traveling, factors to consider when choosing a college, and questions to ask when deciding which homecare company to use. Sample letters, plans, and forms like an Individualized Health Plan you might put in place for your child at school or an Emergency Form to have completed with helpful information if ever you find yourself in the Emergency Room are also referenced. I suggest browsing through the various topics just to see what is there, so when you need help, you will know where to start.

Did you vote on November 6th? Every vote really does count. In the 6th Congressional District in Massachusetts, John Tierney won re-election by 3,650 votes, which is less than 1% of those who voted. NEHA communicated with members before the election, ensuring that members had information about how and by when to register to vote, who was running for Congress and Senate, and where to go to find out where the Presidential candidates stood on health care issues. As the information about the new Congress and state legislatures becomes available, I will be in touch with those who have signed up to be part of NEHA’s Advocacy Alert Network to update you on who your elected officials are. Since

(Continued on page 12)
I first heard about the Leading Edge program at NEHA Family Camp, and I was excited to sign up because I knew I was going to be able to spend more time with the other counselors I had worked with during camp. This was my second year as a junior counselor, and I am excited about returning as a counselor when I turn 18 in 2013. Most of my time at Family Camp as a counselor is spent in training sessions and making sure the campers have a good time.

I was told the Leading Edge weekend was an opportunity for all of the counselors to get together again and spend time as a group. I was under the impression it would be more of a weekend camping trip with less leadership exercises, but I loved the way our time together was set up. I was able to participate in a wide variety of challenge courses in just about twenty-four hours. I was honestly terrified to even attempt some of the ropes courses, mainly because I have been afraid of heights for as long as I can remember. The members of our group were the main reason I ended up trying different elements of the course. They assured me I would be fine, and that I would regret it if I didn’t try.

The person I relied on for help on one of the ropes courses was Darian Ross, another counselor I have known for a few years now and one of my good friends. To keep our balance on two separate wires in the trees, we had to work together and slowly walk farther away from each other trying to keep our balance. I was so nervous, and never would have gotten past the goal myself without Darian and everyone telling me I could make it across the wires. There were several other points during the weekend where I needed help from my peers, and they did not fail to help me out whenever I needed it.

Pat Torrey, known as "Big Dog", was a huge contributor to our trip. We talked about goals each of us could set for ourselves, and ways we could accomplish them. This was around the same time I was beginning to apply to colleges, and it really boosted my confidence.

All the different challenges we did over the weekend definitely brought the whole group of counselors much closer, which in the end, will end up helping us make Family Camp a better experience for the campers and their families. Everyone agreed at the end of the weekend that we wanted to become more involved with NEHA, and I felt the same way. I was very happy that I attended the Leading Edge weekend, and hopefully I will be able to go again next year.

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Women with VWD Risk Postpartum Hemorrhage
Source: PRNewswire, July 11, 2012

Results from a new study suggest that current postpartum strategies do not adequately boost von Willebrand factor (VWF) levels, contributing to potential postpartum hemorrhage in women with von Willebrand disease (VWD). Current strategies do not increase VWF levels to the normal range or even to levels of women with milder, untreated VWD. The principal investigator of the study was Andra James, MD, Professor of Obstetrics and Gynecology at the University of Virginia in Richmond. James, who was lead investigator while still at Duke University, presented early study findings at the World Federation of Hemophilia’s 2012 World Congress, July 9-12th in Paris, France.

The study, supported by a $1.2 million unrestricted grant from CSL Behring, was designed to compare changes in blood levels of VWF proteins postpartum between 31 women with and 40 women without VWD.

(Continued on page 11)
As Puerto Ricans, are we truly American citizens, and do we have rights? For a person living with hemophilia in Puerto Rico, like me, these are questions that make you wonder. Unfortunately, suffering from severe hemophilia A with inhibitors, the message I receive from my healthcare providers and health insurance representatives is that the level of healthcare that can be provided depends on the cost of the factor. This means using a less effective factor for me because it costs less, although it will be costlier in the long run because more doses will be needed. Every time a nurse or doctor comes to see me, they remind me of how expensive my medication is.

I’m writing this article while admitted at the only hemophilia treatment center (HTC) in Puerto Rico, the Hospital Universitario Centro Médico de Puerto Rico. I have compartment syndrome—a bleed in a muscle in my forearm that has swelled, and is putting pressure on the blood vessels and nerves in my arm. It’s June 9, 2012. My forearm has been cut open from wrist to elbow to relieve the pressure. I’ve been here for 29 days, and I haven’t received any kind of factor for the past five days. When I ask why, there is always some excuse: the pharmacy hasn’t bought it, or the doctor hasn’t posted the order to the chart. I may not be the only patient under the staff’s care, but I expect to be treated responsibly. How many times have I requested to speak to a doctor, and they send some young intern who has no clue how to treat the situation and tells me, “Let me consult and I’ll get back to you.” Meanwhile, my treatment is not progressing, and it may take 24 hours to have an answer to my questions. Waiting to administer the factor has put my life in jeopardy.

Does the price of factor determine my health and well-being, or am I entitled to the same rights as other Americans? Although we are Americans, it’s like we are the ugly duckling or the black sheep of the family. I know they have factor in the hospital pharmacy, but they want to save it for my upcoming surgery because of the cost.

Compare that to the experience I had in New York City in 2008. I left Puerto Rico to seek a knee replacement, following a doctor’s recommendation, because there was no hematologist specializing in inhibitors on the island. In New York, I started the long process of having my two knees replaced, after a battery of studies and tests. I had the first knee replaced in January 2010, receiving NovoSeven®RT every two hours for several months of rehabilitation.

That same year I had the second knee replacement in May, and I was very surprised by the personal care, pain management program, facilities, and equipment available for me. It was like checking into a hotel—better yet, because I was getting the best treatment available in the States, like the rest of the hemophilia population living in the US. After the second knee replacement, I learned that my bilateral knee replacement cost a little over $6.2 million. But that’s nothing compared to the chance of walking normally again and a much-improved quality of life. In the States, no one badgered me about the cost of treatment. No one constantly reminded me how expensive my treatment was. The treatment was supplied, without making me feel that I was not worthy of it. That’s the big difference between being a Puerto Rican with hemophilia, living in Puerto Rico, and being an American with hemophilia, living in the States.

Osvaldo Ocasio Rodriguez is 27 and lives in San Juan, Puerto Rico.

NEHA Membership Drive: Now Open for 2013

As the calendar year comes to an end, it’s time to renew your NEHA Membership Dues for 2013! Payment of membership dues enables NEHA to focus its efforts on our community and use these funds to pay for expenses not typically supported by industry or corporate sponsorship money. Payment of dues also demonstrates your support and commitment to NEHA. As in the past, NEHA membership allows our members to attend our educational and social events at no cost. While we would never turn away an interested non-member family, we do ask them for a nominal fee to attend these events.

Individual dues are $25/person, and family dues are $50/family. Your 2013 Membership is valid from the date of enrollment until Dec. 31, 2013. There are also additional opportunities to support NEHA at higher levels of membership for those individuals or families able to do so.

You may renew your Membership Dues online by clicking HERE, or mailing in the Membership application, or renew by contacting the NEHA office at 781-326-7645. Membership is an important way to support the good work of NEHA! Please renew your dues for 2013 now!
The No-Show Dilemma! What would you do?

By Kevin Sorge

You’re hosting a birthday party off-site for your 10 year old. You’ve invited 30 classmates and 24 have responded that they will be attending. Based on that number, you order food, gifts, some personalized t-shirts, and other fun stuff. On the day of the event, 17 children show up with 7 no-shows. Would you be upset? What if you had spent $20 per kid in advance, and were now out $140 for meals and supplies, etc. that weren’t used?

NEHA lives through this scenario at each of its events! Events are marketed to our mailing lists, and advance registration is often taken through an online system or written RSVP. A deadline approaches and based on those who respond (say 180), NEHA staff orders food for meals and breaks, bought supplies, and possibly booked hotel rooms and meeting rooms, based on that attendance number. Everything is reserved in advance because that it what is required by hotels or event locations. So NEHA reserves everything for about 180 people, makes the financial commitment for food, hotel space, materials, speakers, etc…

And then 138 people show up!

So what happens to the costs for the meals, hotel rooms, supplies, etc. that were reserved, and paid for, for 180 people. Well, it’s like throwing that money in the garbage. It’s not refundable; we can’t get it back. We pay the facility for 180 people even thought only 138 showed up! Would you be upset?

Would you be more upset if you knew that the funds wasted were from hard-earned donations given to NEHA? What if we wasted over $2,000 in paying for people that never showed up? Well, that’s what actually happened last year at NEHA’s SpringFest.

How do we deal with this dilemma of No-Shows?
These are not people who cancel ahead of time, because we usually have time to re-adjust resources so we don’t incur expenses. But these are No-Shows: individuals or families that simply do not show up at an event after they have reserved their space. In these cases, NEHA is forced to incur expenses because that lack of notice does not give us enough time to make adjustments. So how can you help?

1. Always register for the NEHA event so we know to expect you and can reserve the meals, hotels, supplies or whatever are needed to provide you with a great experience. If we don’t know you’re attending, we may be short on food at lunch, there may not be any hotel rooms left, we may not have enough chairs in the meeting room, etc…It is your responsibility to make sure NEHA knows that you are attending. Please do this by the deadline date, because that’s when we need to confirm numbers with the hotel or sites. If we tell the hotel 100 people are coming for lunch, and then 112 show up, someone may not be eating lunch! Be sure that NEHA knows you are attending, by the deadline date!

2. Cancel by the deadline date, so that we can re-adjust our attendance numbers. Cancelling the day before does not give us an opportunity to make adjustments and save money. Nor does it give us time to find someone else that may be interested.

3. Never just fail to show or attend. Please call the site, hotel or even NEHA’s office number, and leave a message that an emergency has come up, and you will not be attending. Our staff checks these sources for calls. If there is no emergency, then you’re expected to attend! After all, you reserved your space.

Individuals and their families that fail to show for events without notice may lose the ability to reserve space or even attend future NEHA events. Please sign up if you’re interested, and be sure that you attend!

Vehicle Donation Program

We are thrilled to announce a brand new way to support NEHA. Our new Vehicle Donation Program makes donating your vehicle virtually hassle-free. If you have a vehicle you no longer need, donating it to NEHA is the perfect solution!

The process is easy. Simply fill out the online vehicle donation form located here (hold Control key and click) or call 1-855-NHF-4-CAR. Your vehicle (running or not), is picked up free of charge, sold for you, and a portion of the proceeds come directly to NEHA. This unique giving opportunity not only helps you clean out your garage but also supports our mission to fund vital research and provide key educational programs and public policy initiatives for people with bleeding disorders.
NEHA recognizes the following generous donors’ support that has helped us to achieve our mission of improving the quality of life for persons with bleeding disorders and their families through education support and advocacy.

**Major Donations received from October 2011-September 2012**

<table>
<thead>
<tr>
<th>Amount Range</th>
<th>Donors</th>
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<tbody>
<tr>
<td>$40,000 and over</td>
<td>Bayer Healthcare, Baxter, PACT Foundation Advocacy Grant, Novo Nordisk, Pfizer</td>
</tr>
<tr>
<td>$20,000 - $39,999</td>
<td>AHF, Baxter, Novo Nordisk, Pfizer</td>
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<tr>
<td>$10,000 - $19,999</td>
<td>Biogen Idec Hemophilia, Coram, CSL Behring, CVS/Caremark, Boston Hemophilia Center</td>
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<tr>
<td>$5,000-$9,999</td>
<td>Access Pharmaceuticals, Alnylam Pharmaceuticals, Colburn Keenan Foundation</td>
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<tr>
<td>$2,500 - $4,999</td>
<td>Boston Bruins Foundation, Give with Liberty, IBM, Inspiration Biopharmaceuticals, Inc.</td>
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<tr>
<td>$1,000 - $2,499</td>
<td>Community Health Charities of Maine, Charles Doherty and Dorothy Sparrow, James and Patty Doherty</td>
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Thank You, NEHA Donors!

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Unfortunately we do not have the space to list all donations to NEHA but do know that it takes donations of all kinds to make NEHA the special place that we all hold dear in our hearts.
classes for children ages 4 through adults including siblings. Having the opportunity to practice self-infusion skills in the relaxed camp environment combined with the positive peer-pressure and ideal role models often results in many "first sticks." These are celebrated with the Big Stick award presented on the final evening.

Glen Roy, RN with the Maine Hemophilia and Thrombosis Center was the founder of Family Camp 20 years ago, and still plays a critical role in its planning, management, and execution. When reflecting on the past 20 years, Glen said, "Camp has provided tremendous support and networking for the families. It has been great to see the growth of Camp and the benefit it has offered to the generations of families over the last twenty years. The fun, relaxed camp environment and support from the peers of those who have been self-infusing for years has led to many success stories of learning self-infusion leading to more independence in their lives."

Since this was Family Camp's 20th Anniversary, the Planning Committee chose to go with a Happy Birthday theme. This fun theme was woven throughout the four day event with birthday songs, make-your-own party hat activities, and lots of festive decorations. But, the big birthday party bash happened on Friday afternoon, when Family Camp alumni were invited to join the families for the festivities. The party was kicked off with Birthday Games on the Green complete with Pin the Tail on the Donkey, Pick-a-Duck, face painting, and piñatas! The piece de resistance at the birthday BBQ dinner was an amazing five-tiered neon birthday cake featuring a "slice of cake" with the Family Camp logo created and donated by one of the families. After dinner, in keeping with Family Camp tradition, awards were presented to all the campers and their counselors, to the children and adults who participated in the infusion classes, and to the Big Stick recipients.

This year, the visiting alumni were also honored for their part in growing Family Camp to what it has become, and a special 20-year Service Award was presented to Glen Roy. He also received a special anniversary quilt sewn together with fabric squares hand-painted by the campers and Reflections and Memories, a book containing pictures, memories and descriptions of the greatest "gifts" that Family Camp has given to families, campers, and staff from the past 20 years. The themes throughout the book reflect on the "gifts" of friendship, family, community, confidence, independence, laughter, positive peer pressure, and a sense of belonging.

Cathy Cornell, former NEHA Executive Director, and her husband Bob, attended the Friday party. Cathy was thrilled to have the opportunity to come home to camp.

"The Family Camp 20th Reunion was wonderful in many ways. It brought back many happy memories for me personally. It was wonderful to see old friends. What a wonderful community of people! It was wonderful to see so many kids who were learning self-infusion, and parents too. It was terrific to see how the program continues to involve so many families as volunteers, to train future leaders for the hemophilia community, and it is so much FUN! I continue to believe Family Camp is one of the most effective programs that NEHA provides, and I hope it will continue for many years to come. Thanks for inviting us back to experience it all again!"

Over the years, the location has moved from Camp Mechuwana in Maine to Geneva Point Center on beautiful Lake Winnipesaukee in New Hampshire, the number of attendees has more than doubled, and the programs have evolved to reflect a typical camp experience for the campers; however, some things have stayed the same. Family Camp is still only possible with the help of so many volunteers (over 50 per camp year) who share their talents in many roles as leadership staff, medical staff, counselors, activity directors, presenters, planning committee members, and all-around helpers.

(Continued on page 12)
Save the Date for the 2013 NEHA Walk!!!!

June 1, 2013

Bird Park in Walpole, MA

NEHA is gearing up for the 4th Annual NEHA Walk with plenty of SUNNY weather on tap!! This walk will be bigger and better than ever. The website will be open earlier than in years past, and we hope to raise the roof on registration!!! Start planning early and build your team….

Thanks to this year’s Presenting Sponsor, Baxter! We’ll also be joined by the Pacesetter Sponsor, Bayer; Official Sponsors, Grifols and Pfizer; and our Supporting Sponsor, Biogen IDEC, in 2013.

NEHA and our sponsors will supply many of the usual goodies, but we hope to have new and exciting things in store! We need YOUR enthusiasm to make this walk the best ever. Talk to everyone this holiday season and spread the word.

Let’s Raise That Thermometer!!!!

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Of the 14 women with VWD who were treated during the postpartum period, 12 were given VWF concentrate, one was given the synthetic hormone desmopressin plus VWF concentrate and one was treated with desmopressin alone.

In healthy women, VWF levels fell rapidly after childbirth, approached baseline one week postpartum and reached baseline three weeks postpartum. The pattern of decrease in these levels was consistent among all patient groups, but levels were significantly lower in women with VWD. VWF levels were lowest among treated VWD patients.

“While a rapid decrease in VWF levels after delivery is normal, significant decreases following childbirth can result in an increased risk for postpartum hemorrhage, especially since women continue to bleed for days to weeks after delivery,” said James “Given that current postpartum treatment strategies do not effectively manage VWF levels in the VWD patient, we hope to conduct further study into the benefits of prophylaxis treatment for preventing the potentially serious complication of delayed postpartum.”
**Advocacy** (Continued from page 4)

working at NEHA, I have been able to add over 30 members to this network, and it grows with every NEHA event. If you are not yet a part of this important legislative advocacy tool, please consider joining. Just email me at lsalomons@newengland-hemophilia.org with your name and street address.

After the start of the new year, I will encourage everyone to send introductory emails to U.S. and state Representatives and Senators to let them know who we are and what issues we are concerned about. At that time, NEHA will also research what health care related legislation is being filed in each state, so we are prepared to take action as needed.

With the end of the election, we now know that Health Care reform will continue to move forward. This is generally good news for those with hemophilia, but we must be vigilant in monitoring how each state implements Health Care reform to make sure that our medical needs are met. In particular, NEHA will be working to ensure that benefits provided through health care exchanges include access to a range of appropriate treatments and providers. Look for more information on what is happening in each New England state, as well as the status of grandfathered health care plans, in my upcoming December Advocacy Update.

Finally, we at NEHA want to communicate with our members about things that matter to them. We will tweet and post updates on Facebook on a regular basis. What do you want to know more about? Let us know so we can post relevant information to our members.

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**Camp** (Continued from page 9)

Family Camp is still about providing families with the opportunity to meet one another, to discuss and share problems and experiences, and provide a real Camp experience for children who might not otherwise get the opportunity.

When asked to reflect on how Family Camp has changed, Jane Smith, a mom who attended Family Camp for years and later served as Family Camp Director for ten years, said "My first camp was in 1999, a very different experience than what camp has grown to become. The spirit has always been the same – families coming together to support and learn from one another – but today’s camp is an enhanced version of what I first encountered. Everything is bigger and better: the number of families who attend, the education offered, the creative and fun activities, the strength and depth of bonds between us all. There is a generation of kids for whom Family Camp is one of their most important and cherished childhood memories. Family Camp is our community at its very best. Thank you Glen Roy and NEHA for this wonderful gift!"

Here's to the next twenty years, Family Camp!
A Customized-Care Approach For Managing Bleeding Disorders

- Over 30 years of experience
- In-home training and education
- 24/7 clinical support
- Experienced hemophilia nurse specialists
- Travel support from our nationwide locations
- Consumer advocacy program
- College scholarship program
- Spanish language services
- 99% Patient Satisfaction

2012 Press Ganey, Inc. Independent Survey Results

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WHAT IS YOUR ABR?
ANNUAL BLEED RATE

Minimize the impact of bleeds on your life.
The first step you can take to help lower your bleeds is knowing your ABR, or the number of times you bleed in one year.

Talk with your healthcare provider about your current ABR and how you can set goals to help reduce or eliminate it.

To learn more about ABR and ways to take charge of your health contact your Baxter representative today:

Andrea McSherry
(617) 780-4969
andrea_mcsheerry@baxter.com
The Homecare That Cares!
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AHF’s® homecare pharmacy works exclusively with bleeding disorders.

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Community Involvement
Year After Year
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Denise Mackey & Mark Zatyarka at: 800-243-4621
Introducing HemMobile™:

Log infusions, track bleeds, and more regardless of what factor you use or what type of hemophilia you have.

Developed with feedback from the community, HemMobile™ lets you log and share information at home or on the go with your iPhone®, iPod touch®, or iPad®.

With HemMobile™ you can:

- Record the date, time, location, and reason for every infusion
- Create a password to protect your data. Pfizer will not collect any of your personal information unless you choose to enroll in Hemophilia Village
- Capture the lot number and IU amount with your device’s camera
- Share reports and information with your care team
- Search for an NHF chapter or hemophilia treatment center (HTC)
- ... and more

*Pfizer factor products only.

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Mission Statement
The New England Hemophilia Association is a non-profit organization dedicated to improving the quality of life for persons with bleeding disorders and their families through education, support, and advocacy.

Services include:
- Information and referral
- Medical symposia and educational programs
- Social and recreational activities for children and families
- Family Camp
- Teen Programs
- Spanish-language programming
- Peer support groups
- Emergency financial assistance
- Advocacy and Legislative Support

Please contact the office for more information

Phone: (781) 326-7645
e-mail: info@newenglandhemophilia.org
Website: www.newenglandhemophilia.org

February 27, 28, March 1
Washington Days Lobby Event, Washington, DC

March 11, 2013
NEHA Board of Directors meeting, Waltham, MA

April 6, 2013
SpringFest, Portsmouth, NH

April 24-26, 2013
HFA Annual Meeting, Dallas, TX

June 1, 2013
Hemophilia Walkathon, Walpole, MA

June 10, 2013
NEHA Board of Directors meeting, Waltham, MA

July 23-27, 2013
NEHA Family Camp, Moultonborough, NH

September 9, 2013
NEHA Golf Tournament /Auction, Boylston, MA

September 23, 2013
NEHA Board of Directors meeting, Waltham, MA

October 2-5, 2013
NHF Annual Conference, Anaheim, CA

December 8, 2012
NEHA Holiday Party in Portland, ME

December 15, 2012
NEHA Holiday Party in Bangor, ME

January 14, 2013
NEHA Board of Directors meeting, Waltham, MA

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Electronic (.pdf) versions of this newsletter are available on request. Contact the NEHA office for information!