If I can infuse in a canoe, I can infuse anywhere!

*Matt*, age 15, severe hemophilia

READ MORE ABOUT FAMILY CAMP ON PAGES 13–19
Dear NEHA Community Members,

The holidays are upon us and we are thankful to have you and your family part of our strong community. We are proud of the strides and growth we’ve made - especially over the past year - by touching the lives of thousands of individuals through our programs and services, at our meetings, with print materials, and through social media.

In 2017, we celebrate 60 years of being a regional charitable health care organization! Join us in celebrating this milestone by investing in your community. When you become a NEHA member, 100% of all membership dues go back to the New England bleeding disorders community. Your membership includes:

• Free registration to most NEHA events
• $50 discount for Family Camp registration
• Eligibility for travel assistance to the National Hemophilia Foundation’s (NHF) Washington Days
• Access to “100 for 100,” a travel financial assistance program for FallFest and SpringFest
• NEW: Early registration to selected NEHA events
• NEW: Eligibility for hotel scholarships for two nights during the Hemophilia Federation of America’s (HFA) annual Symposium in Providence, RI, on April 6–9, 2017
• NEW: Annual recognition in our newsletter
• And as always and most importantly, investment in your community

To become a member, go to www.newenglandhemophilia.org. By doing so, you will give back to, and, invest in your community!

I hope you enjoy this latest NEHA Newsletter that highlights our Jedi Academy, and so much more. Happy Holidays!

Executive Director

Richard Pezzillo
This year, NEHA partnered with the Hemophilia Federation of America (HFA) to bring families to Washington, DC to share stories with their elected officials about issues that impact those with bleeding disorders. In June, New Hampshire residents, Kathy and her son Shane, who has moderate hemophilia, joined 15 other individuals from around the country to advocate on Capitol Hill. Then, in September, Mark, a hemophilia dad from Vermont, and Christian, a moderate hemophilia from Massachusetts, joined 20 other men who participated in HFA's Dads in Action and Blood Brotherhood program. Kathy, Shane, Christian, and Mark all advocated for the following pieces of legislation on a federal level:

1. **Patients’ Access to Treatment Act (H.R. 1600):** Which states that an insurance company cannot charge more for a drug they place on a specialty tier than they charge for drugs placed on their non-preferred brand tier.

2. **Access to Marketplace Insurance Act (H.R. 3742):** Which states that qualified health plans (QHPs) offered under the Affordable Care Act must accept premium assistance payments from charities.

Read on to learn more about Mark and Shane’s experiences on Capitol Hill.

**MARK JOHANSSEN**
Father of a son, Mason, with severe hemophilia A
White River Junction, VT

What does advocacy mean to you?
Advocacy means standing up and educating others on the past, present and future of the bleeding disorder community.

Have you been to Washington, DC prior to this trip?
Yes, for personal visits.

What did you think about walking the halls of the US House of Representatives and US Senate?
It closed the gap of what you see on the news and the human faces behind powerful decisions.

What advice would you give to others who have never talked to their legislators before?
Just remember you are the expert on your child and your experiences in the bleeding disorder community. They are the experts on policy.

What tools and resource will you take back to the New England bleeding disorders community?
The understanding you get from the advocacy class and the most effective way to communicate to our representatives.

Why should others get involved with these types of events?
At this time, it’s crucial to reach out to the actual individuals who are creating policies around the access and affordability of healthcare for our community.

Continued on the next page.
SHANE SECINARO
Teenager with moderate hemophilia
New Durham, NH

What does advocacy mean to you?
As someone with hemophilia, advocacy means looking out for my future health needs. Sometimes we need to step outside our comfort zone to make sure those making decisions are aware of what is going on in the world. In America, I have a voice and get to speak up for the rights of myself and others with a bleeding disorder. I should never take that for granted. We can’t sit around and complain if we aren’t willing to speak up and be heard.

Have you been to Washington, DC prior to this trip?
No, I hadn’t.

What did you think about walking the halls of the US House of Representatives and US Senate?
It was probably one of the coolest things I have done. Not everyone gets that opportunity to walk around in there and go into the offices of those that represent us. It was an opportunity to see the buildings, but also to see how things can get done in America.

What advice would you give to others who have never talked to their legislators before?
I was so scared to do it and tried to back out. I’m now glad I pushed forward and did it. It was much easier than I expected. You aren’t alone and you don’t have to come up with some speech to give. HFA helped us to learn about the topics and guided us in what to say before and during the discussions. It was business like, but also very laid back and comfortable. Oh, and wear good walking shoes!

What tools and resource will you take back to the New England bleeding disorders community?
I want to help encourage other kids to go to DC and have that experience. You will learn a lot and you will feel good about what you have done. I’ve learned that normal people can be advocates for themselves and for others. Be aware of the laws and how they affect you and your hemophilia treatment.

Why should others get involved with these types of events?
NEHA and HFA have taught me that we are family and family looks out for each other. Talking to legislators isn’t as scary as it seems. I learned that I have a voice and people want to hear it. They don’t know about hemophilia and how their decisions impact us. So we need to talk to them and let them know what it is like for us.

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SANDY WILLIAMS
PHONE | 774-275-0285
EMAIL | Sandy.Williams@octapharma.com
Over the last couple of weeks, many have contacted us about what the election results may mean for the bleeding disorders community. While there are many uncertainties at this time regarding the future of health care, we are here for you. For nearly six decades, NEHA has worked hard and without interruption to advocate for everyone with a bleeding disorder living in RI, CT, MA, ME, VT, and NH. We remain committed to keeping your family educated and supported with these often complicated issues.

A key piece of infrastructure currently missing in the New England bleeding disorders community is a region-wide advocacy effort. We have been working hard with the Hemophilia Alliance of Maine (HAM), and the Connecticut Hemophilia Society (CHS) to create a robust system to address advocacy needs across New England, especially policy and insurance issues.

On October 12, 2016, we held a stakeholder meeting that brought together the staff and board members from NEHA, HAM, CHS, policy advisors from NHF and HFA, and our industry partners’ state-based government affairs liaisons. From this meeting, we were proud to form a New England Bleeding Disorders Coalition that will work on:

- 2017 priority issues
- An action plan that engages community members in advocacy efforts
- A strategic three-year region wide advocacy plan

Over the next couple of months, you will learn more about this important coalition and how you can get involved.

**NEW ENGLAND BLEEDING DISORDERS COALITION**

**HEALTH CARE QUESTIONS**

by Rich Pezzillo, NEHA Executive Director

Each year, NEHA awards scholarships to several individuals to enable them to attend NHF’s Annual Washington Days, which takes place March 8-10, 2017. The application period will be opening soon for these scholarships. Go to [www.newenglandhemophilia.org](http://www.newenglandhemophilia.org) for more information.

Please be sure to report all insurance issues to HFA’s Project CALLS (Creating Alternatives to Limiting and Lacking Services). Although this resource provides you with guidance, it is also a means for collecting data about our community needs to enact change. Go to [www.hemophiliafed.org](http://www.hemophiliafed.org) for more information.

We are currently organizing several Legislative Days during 2017 that will take place throughout New England. Once details are released, show your commitment and attend these events.

- Continue to be an advocate for yourself and your family.

**SHARE YOUR VOICE:**

**MEN WITH VON WILLEBRAND DISEASE**

The National Hemophilia Foundation (NHF) has launched a new survey for males over 18 years old living with von Willebrand Disease (vWD). By taking this survey you will help NHF understand the unique needs men with vWD have. All of this anonymous information will be used to create new educational programming.

To take the survey go to [www.hemophilia.org](http://www.hemophilia.org)
One night when I wouldn’t stop crying, my mother thought I had an ear infection and took me to the pediatrician the next morning. When she was putting my jacket on she noticed I could not open my hand, it was swollen shut. The pediatrician took an X-ray to see if it was broken, but it was not. I was then sent to a hematologist and diagnosed with moderate to severe hemophilia A. For a kid who was very active this was a problem as I had to get used to my ankles and arms constantly being in casts and splints. Like your average boy, I ran around the house jumping off couches pretending to be one of the Power Rangers. This often cost reoccurring ankle bleeds, but it didn’t stop me from being a boy.

My parents were always concerned about me. Leaving me alone with babysitters was hard for them, they constantly worried. At least once a week I would be at the emergency room receiving an infusion. The doctors all knew me; I was a regular there. One day my mother questioned if I could be infused before I got hurt. That is when my doctor prescribed me prophylaxis treatment three times a week. This was a game changer for me, as I began to infuse less and my weekly hospital visits lessened.

Of course it was recommended that I only participate in non-contact sports like swimming. My doctor said this would be better for me, as there was less of a chance for injury. I did pursue swimming, but when I was 5 my two best friends registered for T-Ball and I wanted to try it too. Reluctantly, my mother signed me up. I fell in love. I began playing T-Ball and continued through to the collegiate level. I played varsity baseball in high school, at Lasell College and club baseball at Merrimack College. The summer of my junior year of college I also went to the Dominican Republic, where I played alongside many professional players.

Now at age 26 I am still actively playing baseball at a competitive level. I am the player and manager for the Stoneham Sabers, a team in the Yawkey Baseball League; where rosters are made up of collegiate players to former professionals. I continue to play over forty games a summer and have not missed a game in six years. I have been hit by a pitch 33 times in that span, probably because I often tend crowd the plate. I also work out three to five times a week and played in several different basketball leagues.

Many people ask me how I am able to do this as someone with hemophilia. The trick is, I infuse three times a week and during baseball season, I infuse before every game as a preventative measure. As I get older, I have become more aware of what injury may turn into a bleed and make sure I infuse before it gets worse. I have learned to become a responsible adult and to take ownership of my bleeding disorder. I try to be as cautious as possible, but sometimes you just take the risk of getting hurt. I don’t let hemophilia stop me from being me. I have learned that it is vital to never skip my doses. My mother continues to worry and is constantly telling me to be careful, but that’s what mothers are supposed
HEMOPHILIA WILL NEVER HOLD ME BACK, Continued

to do—worry. And that’s okay, because I know that I do not want to risk a serious injury. I am careful to do what I need to do to continue to stay healthy, and not let hemophilia hold me back to pursue what I love.

My advice to parents who may be struggling to let their children with bleeding disorders be active is to let them know that a bleeding disorder doesn’t have to define you; it’s just a part of you. Doctors today know far more, than they did years ago. Parents should not be hesitant to let their children go out and play sports after discussing the proper treatment regimen with their physician. Being active is not only important for someone who has a bleeding disorder, but for anyone. Hemophilia does not hold me back, nor should it hold anyone else back living with a similar condition. I am going to continue to play baseball and run until I physically cannot any longer. It is something I have a passion for and will continue to pursue. I hope every child with a bleeding disorder is able to pursue their passion as I have done for the past 26 years. If only my 6-year-old self could see me now; he would be proud.

Angelo Colucci has moderate/severe hemophilia A and lives in Stoneham, Massachusetts.
Scientists at Biogen are conducting laboratory research to study coagulation and to develop new therapeutics to treat hemophilia. To do this, some fresh blood must be obtained occasionally from volunteers diagnosed with hemophilia A or B.

The blood draw will be done at the Biogen Occupational Health Center in Cambridge (MA) and will take 30 minutes to 1 hour. You will receive a $250 reimbursement for your time and participation.

Please contact Nancy Moore at 617-914-6949 (nancy.moore@biogen.com) to find out if you are eligible to participate.

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With over 60 years of dedicated history to the Hematology and rare disorders communities, Shire has even more resources to bring to the bleeding disorders community. Supported by the passion, commitment and innovation that make a difference, we’ll continue to consistently pursue advancements in the treatment of bleeding disorders.

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August 2016 USBS/MG1/16-0651a
From Friday, September 30 through Sunday, October 2, 40 women in the New England bleeding disorders community gathered at the Wylie Inn and Conference Center at the Endicott College in Beverly, MA, for NEHA’s Annual Women’s Retreat. This important event is made possible by an educational grant from CSL Behring, and is in collaboration with several Hemophilia Treatment Centers throughout New England.

During the retreat, topics included reproductive health, menstruation through menopause, von Willebrand Disease diagnostic dilemmas, an overview of current and future therapies, and sessions about life transitions. Casual options such as a walk on the beach, sharing activities, and free time were also included in our agenda.

2017 RETREAT DATE AND LOCATION TO BE ANNOUNCED SOON!

THE STRENGTH OF WOMEN
IN THE BLEEDING DISORDERS COMMUNITY

by Mary Fitzpatrick

Approximately fifteen years ago I wrote an article for this newsletter about NEHA Family Camp entitled “We Are Family.” Recently I had the honor and pleasure of attending the NEHA Annual Women’s Retreat. During the weekend spent with around forty women from the bleeding disorder community, I was reminded of that time years ago when I felt such a strong connection of family. Within the first few hours, I felt that bond return. I am very grateful to NEHA and all those who make this retreat possible.

Attending the weekend retreat were women whom I had known for twenty-five years and women whom I just met. The friendship of women I met a long time ago has survived distance and time. The feelings of support, understanding, and friendship that I have for these women have only grown stronger over the years. The interesting part is that with the women I just met, I felt the same connection of comfort and understanding. As we chatted and shared stories over the weekend, I knew that here were more women that I could turn to in times of need and in times of happiness. One of the things that I have consistently been grateful for over the years is that there is no “age barrier” to the friendships I have made in this community. Some of my bleeding disorder friends are older than me and some are younger. It does not matter. We have a connection that goes far beyond age and is stronger than anything that might separate us. Our “blood connection” is similar to the strongest rope; it can withstand many storms and still keep us linked together as allies.

Why is it so important for women in the community to be together? Well, the fact is that men and women are simply not the same. Just as there is a “Dads in Action” group and a “Blood Brotherhood” group, women benefit from being together. Some women share in a very different way when surrounded by their sisters and away from the men in their lives. Other women may be single moms, daughters, or persons affected by a bleeding disorder. The freedom to talk about personal health issues was very apparent at this recent weekend. I feel certain that many women would not have felt as comfortable speaking about the issues we face with men in the room. We certainly all love the good men in our lives, whether it is our brothers, husbands, fathers, or sons. There is an important place for them in our hearts. There is also a time when we need something different to nourish ourselves. The women’s retreat offers that.
THE STRENGTH OF WOMEN IN THE BLEEDING DISORDERS COMMUNITY, Continued

This particular weekend is very beneficial in that it allows a woman to have some quiet time if she so chooses. She may go for a walk on the beach, take a nap, or spend time just chatting with a friend. As either a person with, or a caretaker for someone with a bleeding disorder, the significance of this personal time is very important. There is no pressure. It is a time to relax, breathe, share, and learn. With our busy lives, it is often difficult to find a few days where we can really do that. Throughout the weekend, I saw women cry together and women laugh together. I saw that family connection at its best. I would rate this time together as priceless.

There are so many benefits to the retreat weekend. Being with other intelligent, caring, and supportive women is very empowering. In addition, there is always more to be learned about bleeding disorders. Having been a part of this community since I was a little girl, it is amazing to see the changes that have occurred over the years. The point is that these changes continue to happen and we need to be aware of them. The importance of the educational sessions cannot be overstated. I learned much about diagnosing vWD, which I am using to help a personal friend. I learned about pain management as well as new developments in hemophilia. The sessions on nutrition and stress were enormously helpful within a community where women do experience stress and, at times, tend to neglect their own health. For many of us, being caretakers means putting our own needs on the back burner. It is important to have educators remind us of how, and why we should not do this. The various sessions were concise and offered something for everyone.

I came home with several sites that I can link to for help in caring for myself. I also came home connected to a number of wonderful new friends. One cannot put a value on that! As one of the long-time members of this community, I left feeling renewed and excited about being involved. I truly hope to connect with new families coming along behind us. My thoughts, as I drove home, were centered on “What can I do to help going forward?” And it felt just great.

Mary McKenna Fitzpatrick has been a volunteer with NEHA since she was a child, volunteering with her mother at the original NEHA office in Boston. Over the years she has volunteered in a variety of areas including Family Camp and Project Red Flag. Mary has two sons and lives in Concord, NH, with her husband, Scott.

YOUNG ADVOCATES MAKING A DIFFERENCE!

At Laconia’s annual New Hampshire Pumpkin Festival, Preston, severe hemophilia, and his sister Vivian, raised awareness about bleeding disorders by selling pumpkin hats at their dad’s orthodontic office (which is located near the festival). As a result, over $500 was raised for NEHA’s Holiday Party!

Thank you for being strong young advocates for our community, Preston and Vivian!
It’s Time to Help Support Your Hemophilia Treatment Center

Just make the choice to get your factor from the 340B Outpatient Factor Program at your HTC and you are helping to support your clinic team... it’s that simple! All proceeds go to support the specialized clinicians, physical therapy, training, and other essential services you and your family have come to depend on at your local HTC.

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- Shipments to your home or choice of location

Contact us at 800-291-0654. Ask for Cyndi Donate.
NEHA’s Annual Family Camp was held July 6-9, 2016, at Geneva Point Center in Moultonborough, New Hampshire. Family Camp continues to be the marquee program of the NEHA event schedule. This year we hosted a record 250+ individuals which included: 54 families, 36 counselors, 8 medical staff, 9 session leaders, and countless volunteers! For a family of four, it costs an average of $1,000 for food, programing, and lodging. NEHA proudly subsidizes 93% of that cost to make it affordable for families. Your participation in the popular annual; NEHA Walk and NEHA Gold Tournament are what enable us to provide that subsidy.

The goals of NEHA Family Camp are two fold; to assist youth with gaining or improving their self-infusion skills, and to build community. As one parent wrote, “I honestly just feel it’s the feeling of family, friendship, acceptance that sometimes we don’t get other places. We look forward to next year’s camp as soon as camp ends for the year; I think, it’s our second home.”
The theme of camp this year was Jedi Academy. In keeping with the theme, we challenged youth in developmentally appropriate ways to “Use the Force” to further expand their self-infusion skills. For the younger campers, the challenges may have been infusing in a new place or with a new person, for older youth, some of the infusion classes met outdoors. For the teenagers who were part of the Adventure Club program (ages 13-15), this meant infusing outside while in a kayak or a canoe.

The “Infusion on the Water” idea came from NEHA’s participation in NACCHO (North American Camping Conference for Hemophilia Organizations). NEHA had five representatives of Family Camp attend NACCHO: Amber Dawn Doiron, Alex Keiver, Leland Smith, Dean Vieira and Heather Case. At a session led by Pat Torrey of Gut Monkey, there was a lot of discussion regarding expanding our comfort zones and challenge by choice. With the help of Emily Bisson, APRN, CPNP at Yale Medical Center who has attended NEHA Family Camp for the past 5 years as volunteer hemophilia nurse, and who volunteered as a nurse for a Gut Monkey expedition, NEHA was able to incorporate infusions on the water as part of our challenge by choice approach in 2016.

The “Infusion on the Water” session was not immediately accepted as necessary. Initial feedback from some parents and youth alike sounded a lot like, “We don’t kayak. Why do we need to learn how to infuse on a kayak?” As the session was discussed further with parents and youth, the objectives became clearer, and the “Infusion on the Water” session took on a whole new feel. Each one of the 19 Adventure Club youth infused or assisted in a kayak or canoe while out on Lake Winnipesaukee. “Teens infusing on the water” and “real life infusion challenges” were commonly cited as the best part of camp in post-camp evaluations.

The experience of challenging yourself to try something new and potentially scary helped to build awareness and develop self-confidence. By helping these teenagers plan for their infusions by preparing what was needed and how to overcome any obstacle, youth developed a stronger sense of self-reliance. Camp evaluations have shown a strong desire to bring this session back as a tradition for the Adventure Club crew in the coming years!
save the date
25th Anniversary Of Family Camp
July 5–8, 2017

2016 fast facts
• 187 family members
• 49 staff
• 7 nurses (from 5 Hemophilia Treatment Centers)
• 8 external speakers

number of families from each state
(families only, does not include staff)
• 24 Massachusetts
• 12 Maine
• 9 Connecticut
• 5 New Hampshire
• 2 Vermont
• 1 New York
• 1 Rhode Island

SPECIAL THANKS TO OUR CAMP SPONSORS
We are here to make new memories and create experiences with other teenagers around New England who have a bleeding disorder. NEHA Family Camp is home.

• Shane, hemophilia, New Hampshire, and Carter, vWD, Maine

We are so excited that we got our Big Stick’s together at camp! We already can’t wait to come back next year!

• Isaiah & Eliajh, Maine

Year after year, Family Camp brings together our community in such a special way. We don’t have to explain to anyone what hemophilia is here. It’s our home.

• Ann Marie, hemophilia mom, Massachusetts

No matter the age, you learn here. Kids strive to earn their Big Stick and have fun. Adults build friendships and rekindle old ones. Thanks to this community, our family has grown so much!

• Lisa & Vince, hemophilia parents, Vermont

It’s great to watch the connections being made between the young kids and the counselors, and between the new families and those that are veterans. It’s also so much fun to see the young men find their inner boy and sing together at campfire. That’s what I learned in my school, Ya Hoy!

• Ann Marie, hemophilia mom, Massachusetts

We come to Family Camp each year because we can relate to everyone since we all have a bleeding disorder in common. My son in particular, Tyler, age 6, Type 1 vWD, feels at home here.

• Meagan, vWD mom, Rhode Island
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*Includes lodging and transportation costs

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Explore Bayer’s additional leadership opportunities, Step Up Reach Out and AFFIRM, at www.hemophilialead.net.
WHAT CAMP MEANS TO MY FAMILY

Interview with Carrie Greene, mother to Gillissa and two young boys with hemophilia, Hamilton and Emery. Carrie is on NEHA's Family Camp Committee and is an active community volunteer. Carrie and her husband, DJ, live with their three children in Maine.

Q What does NEHA Family Camp mean to you?

Carrie: Me and my family look forward to camp all year. We frequently sing the songs (well, the parts we remember). We talk about the events we enjoyed. We recall conversations with other moms, dads, friends and family members. And of course, as parents, we bring mention to strides the kids made toward independent infusion and advocacy, throughout the year.

There is something magical about camp that brings a focus to Hemophilia, but in doing that, the Hemophilia becomes nothing. Family camp means we get to spend some time with ‘normal’. It means no explanations; no need to advocate. It means we all just get to ‘be’ when we are there.

Q How have your experiences at NEHA Family Camp impacted your family?

Carrie: Our first experience at camp was a hard dose of reality that was raw, humbling and emotional. It was also the most influential with hemophilia in our family such that it changed everything for us.

We reluctantly went to camp with the feeling we were okay with the management of our family's Hemophilia diagnosis. However, during a sports presentation given by teens within the community, we quickly learned that our feeling was an illusion. It was within that presentation that we learned about the long-term aspects of hemophilia and bleeding episodes we hadn't considered. Fear took hold and I practically ran from the room once it was over so nobody would see me break down. I pulled myself together and attended the next session, which was a panel discussion for moms. It was then, I heard another mom talk about some things she learned. She said “it will be okay”. I didn't believe her. I didn't understand how they could be okay when I just learned in a sports discussion that a 16-year-old kid had never experienced a joint bleed, when my oldest son had experienced several and he was only 4. I immediately began to talk to as many of the other moms as I could and DJ talked to as many dads as he could. We learned we had to make it better.

Continued on the next page.
From that experience, I feel comfortable in saying that family camp was the most influential because it taught us the real truths about Hemophilia. That influence and truth has been vital to an evolution that brings us where we are today: we are a family living and managing a bleeding disorder. We play hard; we bleed; we infuse; we advocate; we just live. We may go from happy to sad; scared to confident and even get frustrated. But we have learned from family camp we are not alone and at the end, “it will be okay”.

Did your kid(s) learn to infuse at Family Camp? If so, can you please share the story.

**Carrie:** Yes, they did. Both of our boys earned their first stick award at Family Camp 2015. I can’t really share the story because I wasn’t present when it happened. I have pictures though. I wanted to be there so I could see it. But I also didn’t want to impact the process at all. You know, the “magic of camp”. So I opted to respect the counselors and my children by not going to watch and letting them have their moments. I asked our HTC nurse to snap a picture if it happened and she promised. But honestly, I didn’t expect either of them to get it.

Emery had said he was going to get it before we left the house. But, he hadn’t really been consistent with practicing his techniques at home and he has small veins, so I had my doubts it would happen for him. As for Hamilton, he was 5 and had only practiced poking me or DJ at home. While he had gotten us a few times, he was really awkward to hold the needle.

Obviously I was wrong. I’m glad I was wrong. While I wasn’t there, I still have a little information about it. It took Emery 3 pokes to get it that day. I was floored that he did this because in our house, no one person is allowed to try more than 2 times. Attempt 3 is made by the other parent and is always our final attempt. Emery broke his rules to get that first stick because he wanted it. Hamilton was a pretty straight-forward vein hit. He typically has good and beefy veins so that’s in his favor. I did learn that while he hit it, his technique was still awkward, but it works for him. We continue our efforts pertaining to the transition of self-infusion at home.

**What aspect of camp do you find most fulfilling?**

**Carrie:** It goes without saying that I love family camp as a whole. With everything that goes on at Family Camp and the structure of the breakout sessions; there is always something has to be done to prepare for the next thing. I usually start feeling like I haven’t been able to really play with my kids much after the first few days. So the family activity that happens on Friday afternoon is definitely my favorite. It’s a large block of time that we get to spend time together and participate in camp-related fun.

As I say that though, I recall how much fun we have at the Woody 500 too. Yeah, both of those aspects of camp would definitely be my favorite. Everyone gets to participate and we all usually have a great time together.

**How has your experience at NEHA Family Camp changed over the years?**

**Carrie:** Our first year at NEHA family camp seemed so daunting. It was overwhelming to meet so many people while also considering some new realities related to our bleeding disorder. It was scary. Comparable to now, there is no fear. Family camp is like a ‘homecoming’ or a family reunion. We look forward to seeing everyone at camp; participating in activities and just being together with others that share the same bleeding disorder.

Continued on the next page.
WHAT CAMP MEANS TO MY FAMILY, Continued

If you had to pick your favorite memory from family camp over the years, what would it be?

Carrie: My favorite memory at family camp actually happened the first year we went to camp. It was pouring rain and of course, it being our first year, we were totally unprepared for rain. We didn’t have anything more than rubber boots and umbrellas, which I usually keep in the car. We hadn’t even brought more than one pair of long pants each. Regardless, we went to campfire to roast marshmallows and have s’mores. So there we were, in the pouring rain, trying to roast marshmallows while huddling under the umbrellas. It was hysterical. I don’t think that there were any melted marshmallows that year, but we sure did laugh a lot in the process.

What are you looking forward to about the 25th Anniversary of NEHA Family Camp in 2017?

Carrie: I’m hoping the 25th anniversary will bring a reflective moment to camp relative to how many families have benefitted from their experiences at Family Camp. I’m sure the number is vast. I’m sure there are multiple stories of how family camp has impacted others in a positive way, like it has us.
An injectable medicine used to control and prevent bleeding in people with hemophilia A

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86°F FOR 12 MONTHS

Highest storage temperature for the longest time

Because you seek out new experiences, you need a treatment that is ready when you are. Designed to fit into your world, Novoeight® can be stored at up to 86°F for 12 months and up to 4 hours after being mixed.

David, 22 years old, lives with hemophilia A.

Please see Prescribing Information for complete storage instructions.

Indications and Usage

Novoeight® (Antihemophilic Factor [Recombinant]) is an injectable medicine used to control and prevent bleeding in people with hemophilia A. Your healthcare provider may give you Novoeight® when you have surgery.

Novoeight® is not used to treat von Willebrand Disease.

Important Safety Information

You should not use Novoeight® if you are allergic to factor VIII or any of the other ingredients of Novoeight® or if you are allergic to hamster proteins.

Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction: rashes or hives, difficulty breathing or swallowing, tightness of the chest, swelling of the lips and tongue, light-headedness, dizziness or loss of consciousness, pale and cold skin, fast heartbeat, or red or swollen face or hands.

Before taking Novoeight®, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII.

Your body can make antibodies called “inhibitors” against Novoeight®, which may stop Novoeight® from working properly. Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

Common side effects of Novoeight® include swelling or itching at the location of injection, changes in liver tests, and fever.

Visit Novoeight.com to learn about additional features and see how Novoeight® can fit into your world.

Please see brief summary of Prescribing Information on following page.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.
What should I tell my healthcare provider before I use Novoeight®?

You need to tell your healthcare provider about your medical condition or treatment. If you have questions about Novoeight® after reading this information, ask your healthcare provider.

What is the most important information I need to know about Novoeight®?

Do not attempt to do an infusion yourself unless you have been taught by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider’s instructions regarding the dose and schedule for infusing Novoeight® so that your treatment will work best for you.

What is Novoeight®?

Novoeight® is an injectable medicine used to replace clotting factor VIII that is missing in patients with hemophilia A. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

Novoeight® is used to control and prevent bleeding in people with hemophilia A. Your healthcare provider may give you Novoeight® when you have surgery. Novoeight® is not used to treat von Willebrand Disease.

Who should not use Novoeight®?

You should not use Novoeight® if you

• are allergic to factor VIII or any of the other ingredients of Novoeight®
• if you are allergic to hamster proteins

Tell your healthcare provider if you are pregnant or nursing because Novoeight® might not be right for you.

What should I tell my healthcare provider before I use Novoeight®?

You should tell your healthcare provider if you

• Have or have had any medical conditions.
• Take any medicines, including non-prescription medicines and dietary supplements.
• Are nursing.
• Are pregnant or planning to become pregnant.
• Have been told that you have inhibitors to factor VIII.

How should I use Novoeight®?

Treatment with Novoeight® should be started by a healthcare provider who is experienced in the care of patients with hemophilia A.

Novoeight® is given as an injection into the vein.

You may infuse Novoeight® at a hemophilia treatment center, at your healthcare provider’s office or in your home. You should be trained on how to do infusions by your hemophilia treatment center or healthcare provider. Many people with hemophilia A learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much Novoeight® to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may need to have blood tests done after getting Novoeight® to be sure that your blood level of factor VIII is high enough to clot your blood. This is particularly important if you are having major surgery.

Your healthcare provider will calculate your dose of Novoeight® (in international units, IU) depending on your condition and body weight.

Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

Development of factor VIII inhibitors

Your body can also make antibodies called “inhibitors” against Novoeight®, which may stop Novoeight® from working properly.

If your bleeding is not adequately controlled, it could be due to the development of factor VIII inhibitors. This should be checked by your healthcare provider. You might need a higher dose of Novoeight® or even a different product to control bleeding. Do not increase the total dose of Novoeight® to control your bleeding without consulting your healthcare provider.

Use in children

Novoeight® can be used in children. Your healthcare provider will decide the dose of Novoeight® you will receive.

If you forget to use Novoeight®

Do not inject a double dose to make up for a forgotten dose. Proceed with the next injections as scheduled and continue as advised by your healthcare provider.

If you stop using Novoeight®

If you stop using Novoeight® you are not protected against bleeding. Do not stop using Novoeight® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much Novoeight®?

Always take Novoeight® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you inject more Novoeight® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of Novoeight®?

Common Side Effects Include:

• swelling or itching at the location of injection
• changes in liver tests
• fever

Other Possible Side Effects:

You could have an allergic reaction to coagulation factor VIII products. Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction:

• rashes including hives
• difficulty breathing, shortness of breath or wheezing
• tightness of the chest or throat, difficulty swallowing
• swelling of the lips and tongue
• light-headedness, dizziness or loss of consciousness
• pale and cold skin, fast heart beat which may be signs of low blood pressure
• red or swollen face or hands

These are not all of the possible side effects from Novoeight®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

How should I store Novoeight®?

Prior to Reconstitution:

Store in original package in order to protect from light. Do not freeze Novoeight®.

Novoeight® vials can be stored in the refrigerator (36–46°F [2°C–8°C]) for up to 30 months or up to the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not exceeding 12 months.

If you choose to store Novoeight® at room temperature:

• Note the date that the product is removed from refrigeration on the box.
• The total time of storage at room temperature should not exceed 12 months. Do not return the product to the refrigerator
• Do not use after 12 months from this date or the expiration date listed on the vial, whichever is earlier.

If you do not use this medicine after the expiration date which is on the outer carton and the vial.

The expiration date refers to the last day of that month.

After Reconstitution (mixing the dry powder in the vial with the diluent):

The reconstituted Novoeight® should appear clear to slightly unclear without particles.

The reconstituted Novoeight® should be used immediately.

If you cannot use the Novoeight® immediately after it is mixed, it should be used within 4 hours when stored at ≤ 86°F (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about Novoeight® and hemophilia A?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use Novoeight® for a condition for which it is not prescribed. Do not share Novoeight® with other people, even if they have the same symptoms that you have.

For more information about Novoeight®, please call Novo Nordisk at 1-844-30-EIGHT.

More detailed information is available upon request.

Available by prescription only.

Revised: 09/2014

Novoeight® is a trademark of Novo Nordisk A/S.

For information about Novoeight® contact:

Novo Nordisk Inc.,
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Plainsboro, NJ 08536, USA
Manufactured by:
Novo Nordisk A/S
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1214-00024657-1 12/14
On September 24 and 25, NEHA held our third annual “Latino Festival- An Educational Symposium” event which celebrates Hispanic Heritage Month. This year’s event took place in Somerville, Massachusetts. There were 60 attendees representing 12 families across New England. During the two days, there were many educational sessions, including, “Tips to Improve Communication with Health Care Providers” and “10 Strategies to Overcome the Language Barrier.” A bilingual educator from NHF, Felix Olaya, led a discussion about the importance of playing an active role in the bleeding disorders community. Youth went to the New England Aquarium for their outing. We wish to extend a thank you to the companies who supported the event and the volunteers who assisted with the trip and translations.

We asked Marleny, an active member of NEHA’s Hispanic community to share in her own words what being part of the New England bleeding disorders community means to her. Note: This article was originally written in Spanish, and translated into English. The translation can be found on the bottom of page 24.

English Translation

By Marleny Vidal, Version in español

En el 24-25 de septiembre, NEHA tenia nuestra tercer evento anual de “Festival-Latino: Un Simposio Educativo” a celebrar el mes de la herencia Hispana. El evento estaba en Somerville, Massachusetts. Eran 60 personas representando 12 familias de Nueva Inglaterra. Durante los dos días del simposio, eran muchas sesiones educativas, como “Tips para mejorar la comunicación con los proveedores de salud” y “10 Estrategias para Superar las Barreras del Idioma.” También un educador bilingüe de NHF, Felix Olaya, condujo una discusión sobre “Involucrando a la comunidad”. Los jóvenes fueron al Acuario de Nueva Inglaterra para su actividad. Gracias por las compañías que apoyan el evento y los voluntarios que nos ayuden con el viaje al acuario y la transducción.

Preguntamos a Marleny, miembro activo la nuestra comunidad hispana de NEHA, a compartir en sus propias palabras lo que ser parte de la comunidad sangrado trastornos en Nueva Inglaterra significa para ella.
HEMOS ENCONTRADO UN HOGAR EN NEHA, 

unida es increíble y de todo corazón puedo decir que NEHA ahora forma parte de mi familia.

NEHA ha impactado a mi familia de una manera increíblemente positiva, la información que proveen, los programas que ofrecen tanto de educación como de diversión para hacer sentir a nuestros niños parte de la sociedad no tiene precio, cada vez que vamos a participar en alguna actividad de NEHA nos emociona mucho porque es tiempo para compartir con la comunidad que con los años forma una parte importante en nuestras vidas y sobre todo tener estos beneficios en tu propio idioma que más se puede pedir.

Puedo decir que con el paso de los años he visto muchos cambios especialmente en la comunidad hispana, hemos crecido y nos hemos unido con el propósito de darle una mejor calidad de vida a nuestros hijos y familiares con hemofilia, además el personal que se encarga de todos los eventos es increíble, el simple hecho de organizar cada una de las actividades y eventos de una manera que beneficie a cada uno de los miembros de la asociación es admirable porque para lograr eso se necesita mucha dedicación.

Uno de los momentos que más marco mi vida fue cuando participamos en la reunión anual de NHF, en el 2010, fue cuando me pude dar cuenta de lo que significaba ser parte de la Asociación y la importancia que tendría en mi vida ya que por mi hijo yo necesitaba informarme, y gracias a los programas que ofrecen, mi hijo tiene amigos con su misma condición y eso ayuda a que él no se sienta diferente porque aunque no estén alrededor todo el tiempo él sabe que hay una comunidad que siempre estará dispuesta a apoyarlo en lo que necesite y yo como madre me tranquiliza porque sé que no estamos solos.

Mi evento favorito es la fiesta de Navidad, porque hay mucha alegría, sonrisas, todo es felicidad, en general todos los eventos son increíbles pero en especial este porque no se habla del tema de la Hemofilia y ver a todo el mundo con espíritu familiar y navideño nos hace sentir parte de una gran familia.

Marleny Vidal vive en Massachusetts con su esposo, Pedro, y sus hijos, Giovanni y Deaondre. Giovanni fue diagnosticado de hemofilia severa a los 6 meses.

WE FOUND A HOME AT NEHA

by Marleny Vidal, English Translation

As an immigrant I came to this country with many illusions, I got married and started my own family, I have two beautiful children Deaondre 12 years old and Giovanni 9 years old. About at 6 months after Giovanni was born, he was diagnosed with severe hemophilia type A. At the moment they called me and they told me that he had hemophilia I had a lot of things going on in my mind, I did not know much about the condition, but I knew that being here in this country surrounded by specialists, everything was going to be okay. The fear that something could happen to him with his condition was present all the time, up until a representative of the pharmacy that was going to provide the factor talks to me about NEHA. For me to get in contact with NEHA was a 180 degree change, it made me feel that my family and I were not alone in this. The support they had given to us is unconditional, the work they do to keep the community together is incredible and I can wholeheartedly say that NEHA is now part of my family.
WE FOUND A HOME AT NEHA, Continued

NEHA has impacted my family in an incredibly positive way, the information they provide, the programs they offer both educational and fun to make our children feel part of the society is priceless. Every time we are going to participate in some of NEHA’s activity we get very excited because it is time to share with the community that over the years had formed into an important part of our lives and above all these benefits they are provide it in your own language. What else can we ask for?

I can say that over the years I have seen many changes especially in the Hispanic community, we have grown and we are very close to each other with the purpose of giving a better quality of life to our children and relatives with hemophilia, in addition the personnel that is in charge of All the events are incredible. The simple fact of organizing each one of the activities and events in a way that benefits each of the members of the association is admirable, because to achieve this takes a lot of dedication.

One of the moments that marked my life was when we participated in the National Hemophilia Foundation’s (NHF) annual meeting in 2010. That’s when I could realize what it meant to be part of the Association and the importance that would have in my life because I needed to get educated for my son. Now thanks to the programs they offer, my son has friends with the same condition which helps him not to feel different. Even when they are not around all the time he knows that there is a community that will always be willing to support him in what he needs and to me as a mother reassures me because I know we are not alone.

When I think of my favorite NEHA event throughout the year it is the annual Christmas Party, because there is a lot of joy, smiles, everything is happiness, in general all events are incredible but especially this one because we do not talk about the topic of Hemophilia and to see everyone with a family and Christmas spirit makes us feel part of a big family.

Marleny Vidal lives in Massachusetts with her husband, Pedro, and her two sons, Giovanni and Deaondre. Giovanni was diagnosed with severe hemophilia at 6 months.

RECOGNIZING MARK BORRELLIZ’S PUBLIC SERVICE EFFORTS

On November 16, Verrill Dana, LLP, awarded Mark Borreliz, an attorney and former NEHA board member, with their 2016 Roger A. Putnam Community Service Award for his charitable work in the bleeding disorders community. Mark currently serves as Secretary on the National Hemophilia Foundation’s Board of Directors and often spends time meeting with medical students, researchers and companies developing relevant drug therapies to educate them on the experiences of those living with hemophilia.

This year, Mark and his family, Team Hemotional Outburst, raised over $5,200 for our programs and services. Congratulations and thanks for everything you do for our community, Mark!
Indications and Important Safety Information

Indications
ALPROLIX® [Coagulation Factor IX (Recombinant), Fc Fusion Protein] is a recombinant DNA derived, coagulation factor IX concentrate indicated in adults and children with hemophilia B for:

- On-demand treatment and control of bleeding episodes
- Perioperative management of bleeding
- Routine prophylaxis to reduce the frequency of bleeding episodes

ALPROLIX is not indicated for induction of immune tolerance in patients with hemophilia B.

Important Safety Information
Do not use ALPROLIX if you are allergic to ALPROLIX or any of the other ingredients in ALPROLIX.

Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies and all your medical conditions, including if you are pregnant or planning to become pregnant, are breastfeeding, or have been told you have inhibitors (antibodies) to factor IX.

Allergic reactions may occur with ALPROLIX. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called “inhibitors” against ALPROLIX, which may stop ALPROLIX from working properly.

ALPROLIX may increase the risk of formation of abnormal blood clots in your body, especially if you have risk factors for developing clots.

Common side effects of ALPROLIX include headache and abnormal sensation of the mouth. These are not all the possible side effects of ALPROLIX. Talk to your healthcare provider right away about any side effect that bothers you or does not go away, and if bleeding is not controlled using ALPROLIX.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Brief Summary of full Prescribing Information on the next page. This information is not intended to replace discussions with your healthcare provider.
ALPROLIX [Coagulation Factor IX (Recombinant), Fc Fusion Protein], Lyophilized Powder for Solution For Intravenous Injection.

FDA Approved Patient Information

ALPROLIX® /all' pro lik's / [Coagulation Factor IX (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ALPROLIX and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment.

What is ALPROLIX?
ALPROLIX is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital Factor IX deficiency.

Your healthcare provider may give you ALPROLIX when you have surgery.

Who should not use ALPROLIX?
You should not use ALPROLIX if you are allergic to ALPROLIX or any of the other ingredients in ALPROLIX. Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using ALPROLIX.

What should I tell my healthcare provider before using ALPROLIX?
Tell your healthcare provider about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if ALPROLIX may harm your unborn baby.
- are breastfeeding. It is not known if ALPROLIX passes into breast milk or if it can harm your baby.
- have been told that you have inhibitors to Factor IX (because ALPROLIX may not work for you).

How should I use ALPROLIX?
ALPROLIX should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider. Many people with hemophilia B learn to infuse their ALPROLIX by themselves or with the help of a family member.

See the Instructions for Use for directions on infusing ALPROLIX. The steps in the Instructions for Use are general guidelines for using ALPROLIX. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedure, please ask your healthcare provider. Do not use ALPROLIX as a continuous intravenous infusion.

Contact your healthcare provider immediately if bleeding is not controlled after using ALPROLIX.

What are the possible side effects of ALPROLIX?
Common side effects of ALPROLIX include headache and abnormal sensation in the mouth.

Allergic reactions may occur. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: hives, chest tightness, wheezing, difficulty breathing, or swelling of the face.

ALPROLIX may increase the risk of forming abnormal blood clots in your body, especially if you have risk factors for developing blood clots.

Your body can also make antibodies called, “inhibitors,” against ALPROLIX, which may stop ALPROLIX from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all the possible side effects of ALPROLIX. Talk to your healthcare provider about any side effect that bothers you or that does not go away.

How should I store ALPROLIX?
Store ALPROLIX vials at 2°C to 8°C (36°F to 46°F). Do not freeze.

ALPROLIX vials may also be stored at room temperature up to 30°C (86°F) for a single 6 month period.

If you choose to store ALPROLIX at room temperature:

- Note on the carton the date on which the product was removed from refrigeration.
- Use the product before the end of this 6 month period or discard it.
- Do not return the product to the refrigerator.

Do not use product or diluent after the expiration date printed on the carton, vial or syringe.

After Reconstitution:

- Use the reconstituted product as soon as possible; however, you may store the reconstituted product at room temperature up to 30°C (86°F) for up to 3 hours. Protect the reconstituted product from direct sunlight. Discard any product not used within 3 hours after reconstitution.
- Do not use ALPROLIX if the reconstituted solution is cloudy, contains particles or is not colorless.

What else should I know about ALPROLIX?
Medicines are sometimes prescribed for purposes other than those listed here. Do not use ALPROLIX for a condition for which it was not prescribed. Do not share ALPROLIX with other people, even if they have the same symptoms that you have.

Manufactured by
Biogen Inc.
Cambridge, MA 02142 USA
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On August 10 and 11, young adults with a bleeding disorder from around New England and their siblings (ages 13-19 years old), participated in BLeaders, a NEHA new teen retreat at Pinnacle Leadership Center in New Hampshire. This program builds on Family Camp’s Adventure Club by providing teens with an opportunity to participate on a high-ropes course and other skill development group activities that allowed them to step outside their comfort zone and challenge them as a leader. Each teen had to build their own sleeping tents.

A sincere thanks to our volunteer staff: NEHA board members Joel Klein and Leland Smith, Kathleen Byrne, RN, Michael DeGrandpre, and Christopher Smith for providing and cooking all the food!

**GOALS OF THE PROGRAM**

NEHA worked with Pinnacle Leadership Center to develop these pillars as the goals of the BLeader program:

- **RESILIENT**
  
  Display resiliency, perseverance, and the ability to use failure as feedback.

- **RESOURCE FOCUSED**
  
  Recognize, access, and fully utilize the resources around them to achieve more.

- **POSITIVE RISK TAKERS**
  
  Take positive risks and make mistakes. Failure to reach a goal is feedback.

- **ACCOUNTABLE**
  
  Be accountable, especially when living with a bleeding disorder.

- **TEAM PLAYERS**
  
  Respect others, utilize cooperation, good communication, exhibit empathy and the ability to resolve conflict.

- **GOAL ORIENTED**
  
  Leaders begin with the end in mind and show strong commitment to their goals.
To patients on Helixate® FS
Antihemophilic Factor (Recombinant)

You can continue Factor VIII treatment with Kogenate® FS Antihemophilic Factor (Recombinant)

INDICATIONS

- Kogenate® FS Antihemophilic Factor (Recombinant) and Helixate FS® Antihemophilic Factor (Recombinant) are medicines used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A.
- Kogenate FS and Helixate FS are used to treat and control bleeding in adults and children with hemophilia A. Your healthcare provider may give you Kogenate FS or Helixate FS when you have surgery. Kogenate FS and Helixate FS can reduce the number of bleeding episodes in adults and children when used regularly (prophylaxis). Kogenate FS and Helixate FS can reduce the risk of joint damage in children without pre-existing joint damage when used regularly.
- Kogenate FS and Helixate FS are not used to treat von Willebrand disease.

IMPORTANT SAFETY INFORMATION

- You should not use Kogenate FS or Helixate FS if you are allergic to rodents (like mice and hamsters) or are allergic to any ingredients in Kogenate FS or Helixate FS.
- Tell your healthcare provider if you have been told you have heart disease or are at risk for heart disease.
- You could have an allergic reaction to Kogenate FS or Helixate FS. Call your healthcare provider right away and stop treatment if you get rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headed, dizziness, nausea or a decrease in blood pressure.
Important facts about Helixate FS and Kogenate FS

- The factor (active pharmaceutical ingredient and formulation) contained in Helixate FS is made by Bayer
- Bayer’s Kogenate FS and Helixate FS are bioequivalent—they contain the same factor
- Bayer’s supply agreement with CSL (the company that markets and distributes Helixate FS) will continue through December 31, 2017, at which point Helixate FS will no longer be manufactured
- Bayer will continue to manufacture Kogenate FS
- Kogenate FS and Helixate FS have different reconstitution systems

Kogenate FS is covered by all major insurance companies

- You can check with your insurance provider for any recent changes to the coverage status of Helixate FS

To learn more, visit ContinueFactor.com.

Talk to your healthcare provider to see if Kogenate FS may be appropriate for you.

IMPORTANT SAFETY INFORMATION (CONT’D)

- Your body can make antibodies, called “inhibitors,” against Kogenate FS or Helixate FS, which may stop Kogenate FS or Helixate FS from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.
- Other common side effects of Kogenate FS and Helixate FS are local injection site reactions (pain, swelling, irritation at infusion site) and infections from implanted injection device. Tell your healthcare provider about any side effect that bothers you or does not go away.
- Call your healthcare provider right away if bleeding is not controlled after using Kogenate FS or Helixate FS.

For additional important risk and use information, please see the Brief Summaries for these products on the following pages.

You are encouraged to report negative side effects or quality complaints of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.
Kogenate FS (kō-jen-ate)  
Antihemophilic Factor (Recombinant)  
Formulated with Sucrose  

**Brief Summary of Patient Product Information**

This leaflet summarizes important information about Kogenate FS with vial adapter. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about Kogenate FS. If you have any questions after reading this, ask your healthcare provider.

**Do not attempt to self-infuse unless you have been taught how by your healthcare provider or hemophilia center.**

**What is Kogenate FS?**

Kogenate FS is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called “classic” hemophilia). Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

Kogenate FS is used to treat and control bleeding in adults and children with hemophilia A. Your healthcare provider may give you Kogenate FS when you have surgery. Kogenate FS can reduce the number of bleeding episodes when used regularly (prophylaxis). Kogenate FS can reduce the risk of joint damage in children.

Kogenate FS is not used to treat von Willebrand Disease.

**Who should not use Kogenate FS?**

You should not use Kogenate FS if you

- are allergic to rodents (like mice and hamsters).
- are allergic to any ingredients in Kogenate FS.

Tell your healthcare provider if you are pregnant or breast-feeding because Kogenate FS may not be right for you.

**What should I tell my healthcare provider before I use Kogenate FS?**

Tell your healthcare provider about all of your medical conditions.

Tell your healthcare provider and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.

Tell your healthcare provider if you have been told you have heart disease or are at risk for heart disease.

Tell your healthcare provider if you have been told that you have inhibitors to factor VIII (because Kogenate FS may not work for you).

**What are the possible side effects of Kogenate FS?**

You could have an allergic reaction to Kogenate FS. Call your healthcare provider right away and stop treatment if you get

- rash or hives
- itching
- tightness of the chest or throat
- difficulty breathing
- light-headed, dizziness
- nausea
- decrease in blood pressure

Your body can also make antibodies, called “inhibitors,” against Kogenate FS, which may stop Kogenate FS from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

Other common side effects of Kogenate FS are

- Local injection site reactions (pain, swelling, irritation at infusion site)
- Infections from implanted injection device

Tell your healthcare provider about any side effect that bothers you or that does not go away.

Finding veins for injections may be difficult in young children. When frequent injections are required your child’s healthcare provider may propose to have a device surgically placed under the skin to facilitate access to the bloodstream. These devices may result in infections. These are not all the possible side effects with Kogenate FS. You can ask your healthcare provider for information that is written for healthcare professionals.

**How do I store Kogenate FS?**

Do not freeze Kogenate FS.

Store Kogenate FS at +2°C to +8°C (36°F to 46°F) for up to 30 months from the date of manufacture. Within this period, Kogenate FS may be stored for a period of up to 12 months at temperatures up to +25°C or 77°F.

Record the starting date of room temperature storage clearly on the unopened product carton. Once stored at room temperature, do not return the product to the refrigerator. The product then expires after storage at room temperature, or after the expiration date on the product vial, whichever is earlier. Store vials in their original carton and protect them from extreme exposure to light.

Reconstituted product (after mixing dry products with wet diluent) must be used within 3 hours and cannot be stored.

Throw away any unused Kogenate FS after the expiration date.

Do not use reconstituted Kogenate FS if it is not clear to slightly cloudy and colorless.

**What else should I know about Kogenate FS and hemophilia A?**

Medicines are sometimes prescribed for purposes other than those listed here. Do not use Kogenate FS for a condition for which it is not prescribed. Do not share Kogenate FS with other people, even if they have the same symptoms that you have.

This leaflet summarizes the most important information about Kogenate FS. If you would like more information, talk to your healthcare provider. You can ask your healthcare provider or pharmacist for information about Kogenate FS that was written for healthcare professionals.

Resources at Bayer available to the patient:

For Adverse Reaction Reporting contact:
Bayer Medical Communications 1-888-84-BAYER (1-888-842-2937)

Contact Bayer to receive more product information:
Kogenate FS Customer Service 1-888-606-3780
Bayer Reimbursement HELPlne 1-800-288-8374

For more information, visit www.kogenatefs.com
Helixate FS (he-liks-ät)
Antihemophilic Factor (Recombinant)
Formulated with Sucrose
Brief Summary of Patient Product Information

This leaflet summarizes important information about Helixate FS. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about Helixate FS. If you have any questions after reading this, ask your healthcare provider.

Do not attempt to self-infuse unless you have been taught how by your healthcare provider or hemophilia center.

What is Helixate FS?
Helixate FS is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called “classic” hemophilia). Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

Helixate FS is used to treat and control bleeding in adults and children with hemophilia A. Your healthcare provider may give you Helixate FS when you have surgery. Helixate FS can reduce the number of bleeding episodes when used regularly (prophylaxis). Helixate FS can reduce the risk of joint damage in children.

Helixate FS is not used to treat von Willebrand Disease.

Who should not use Helixate FS?
You should not use Helixate FS if you
• are allergic to rodents (like mice and hamsters).
• are allergic to any ingredients in Helixate FS.

Tell your healthcare provider if you are pregnant or breast-feeding because Helixate FS may not be right for you.

What should I tell my healthcare provider before I use Helixate FS?
Tell your healthcare provider about all of your medical conditions.

Tell your healthcare provider and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.

Tell your healthcare provider if you have been told you have heart disease or are at risk for heart disease.

Tell your healthcare provider if you have been told that you have inhibitors to factor VIII (because Helixate FS may not work for you).

What are the possible side effects of Helixate FS?
You could have an allergic reaction to Helixate FS. Call your healthcare provider right away and stop treatment if you get
• rash or hives
• itching
• tightness of the chest or throat
• difficulty breathing
• light-headed, dizziness
• nausea
• decrease in blood pressure

Your body can also make antibodies, called “inhibitors,” against Helixate FS, which may stop Helixate FS from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

Other common side effects of Helixate FS are
• Local injection site reactions (pain, swelling, irritation at infusion site)
• Infections from implanted injection device

Tell your healthcare provider about any side effect that bothers you or that does not go away.

Finding veins for injections may be difficult in young children. When frequent injections are required your child’s healthcare provider may propose to have a device surgically placed under the skin to facilitate access to the bloodstream. These devices may result in infections.

These are not all the possible side effects with Helixate FS. You can ask your healthcare provider for information that is written for healthcare professionals.

How do I store Helixate FS?
Do not freeze Helixate FS.

Store Helixate FS at +2°C to +8°C (36°F to 46°F) for up to 30 months from the date of manufacture. Within this period, Helixate FS may be stored for a period of up to 12 months at temperatures up to +25°C or 77°F.

Record the starting date of room temperature storage on the unopened product carton. Once stored at room temperature, do not return the product to the refrigerator. The product then expires after storage at room temperature, or after the expiration date on the product vial, whichever is earlier. Store vials in their original carton and protect them from extreme exposure to light.

Reconstituted product (after mixing dry products with wet diluent) must be used within 3 hours and cannot be stored.

Throw away any unused Helixate FS after the expiration date.

Do not use reconstituted Helixate FS if it is not clear to slightly cloudy and colorless.

What else should I know about Helixate FS and hemophilia A?
Medicines are sometimes prescribed for purposes other than those listed here. Do not use Helixate FS for a condition for which it is not prescribed. Do not share Helixate FS with other people, even if they have the same symptoms that you have.

This leaflet summarizes the most important information about Helixate FS. If you would like more information, talk to your healthcare provider. You can ask your healthcare provider or pharmacist for information about Helixate FS that was written for healthcare professionals.