



DATELINE

F E D E R A T I O N

Issue 52 | Volume 17 | Spring 2017



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KID CAPTAIN
Gives vWD the
Awareness it Needs

PAGE
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Everything you need to take
part in **Bleeding Disorders**
Awareness Month

PROJECT CALLS

Creating **A**lternatives to **L**imiting and **L**acking **S**ervices

**YOU ARE NOT
JUST A NUMBER;
you are part of a community
THAT CARES!**

If you have been experiencing issues with your insurance company, we want to hear your story!

Project CALLS is designed with a personal touch in mind. As a participant you will speak privately with a trained member of the HFA staff about your insurance issues. Depending on your preference, you may call the number below, send an email, or complete the form to be contacted.

Through your participation in Project CALLS, HFA will collect stories from the bleeding disorders community across the country, collate the data, identify trends, and use the information to build cases for change.

If you or a member of your family have been:

- Denied services or have received an exception,
- Forced by an insurance company to “fail” on a product before being allowed to use the product of your choice,
- Mandated to a pharmacy that is not meeting your needs, and/or
- Forced to go through a lengthy pre-/prior-authorization process,

Project CALLS is for you!

To contact us about your insurance issue, please call (202) 836-2530, email projectCALLS@hemophiliafed.org, or visit www.ProjectCALLS.org



Assisting and advocating for the bleeding disorders community since 1994.

Issue 52 | Volume 17 | Spring 2017

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Murai Johnson of the
Virginia Hemophilia Foundation



Dear Community Members,

I have lived in Virginia for all of my life. While I do love my home state, I am often jealous of families that have lived all over the United States. As you can imagine, that jealousy rears its ugly head toward the end of winter when my envy of those living in Florida is at its highest! It's taken me more than 40 years to decide that I'm officially **not** a cold weather person. March can be a wild time in Virginia, with everything from a snowstorm to a heat wave all in the same week. But I'm always excited as March approaches because, crazy as it is, it means spring in all its flowering beauty is right around the corner.

Along with the beauty of spring, March provides an opportunity for our community to blossom as well: it's Bleeding Disorders Awareness month! Our social media channels become chockful of information and educational opportunities, all aimed at spreading awareness. My personal favorite is seeing posted photos of people wearing their HFA T-shirts with the "I Love Someone with a Bleeding Disorder" graphic on the front. What an easy way to start a conversation about bleeding disorders in your town, workplace, or even the supermarket.

Advocacy is a word that can make people nervous. That's okay, even I get overwhelmed by the thought of advocacy at times. When I hear the word, I immediately think of going into a high ranking government official's office and talking about an important issue while answering difficult questions when I might not be fully confident in my answers. Scary! But, while this is one form of advocacy, there are many much-easier ways for you to make a difference.

Simply sharing your story can be an effective way of supporting the community. In this issue of *Dateline*, our Outreach team offers information about a story bank collection initiative that we've launched (p. 24). I hope you'll find some inspiration

in some of the examples we've provided and think of ways you can contribute to the project. While you might not be an expert on everything related to bleeding disorders, you are definitely an expert on your, or your child's, condition and the needs of your family, and that's what is most important! Tell your story! With your help, we can do greater good for the community.

In this issue, you'll find other pro-advocacy resources, too. Don't miss the Bleeding Disorders Awareness Month calendar (p. 16) where we provide you with a daily action or fact throughout the month. I suggest hanging this on your refrigerator or by the door where you can easily access the excellent, and timely, information. Josh Hemann's retelling of the day his daughter, Kinzie, was chosen as the Kid Captain of a University of Iowa football game will put a smile on your face (p. 19), as it did for me. The joy that she, and the entire family, felt that day is infectious, and their presence on that playing field gave our community visibility to an audience who knew little about bleeding disorders. That's advocacy—and a lot of fun—at work!

Symposium 2017 is right around the corner, and I hope to see you and your family at the event. If you can't make it in person, be sure to follow along on our social media channels where our team will be sharing the great work taking place in Providence, RI.

Warm regards,

Tracy L. Cleghorn

Tracy Cleghorn
Board Chair



Connect with us
on social media
for daily posts
and updates
about what's
happening
at HFA.



High Risk Pools: A Cautionary Look Back

By Katie Verb, JD

As of this writing, there is a lot of talk about repealing and replacing the Affordable Care Act, but there is little certainty about what replacement legislation will actually look like. One element of many replacement proposals is the re-implementation of high risk pools. High risk pools are plans for covering people with pre-existing conditions who have been locked out of individual market plans because of those conditions. These plans were used in 35 states prior to the implementation of the Affordable Care Act, and the bleeding disorders community, unfortunately, had long had experience with their shortcomings.

You might recall, in the pre-ACA era, that insurance companies could deny or delay coverage, and/or charge unaffordable high premiums, to individuals who had “pre-existing health conditions.” Serious and expensive chronic conditions like hemophilia all too often barred people from buying insurance on the individual market in most states. High risk pools were one of the few options available to people closed out from the private insurance market.

These pools, though, generally offered limited coverage, with high deductibles and low annual and lifetime coverage caps. Premiums could be prohibitively expensive (often 200% or more of the prevailing rate in the individual market) and many states were unable to make up the resulting shortfall in funding when premiums and deductibles didn’t cover costs of care for the high-need enrollees. Because so many high risk pools were chronically underfunded, they implemented enrollment caps and waiting lists that excluded many (sometimes most)

of the individuals who applied for coverage. Thirty-three states imposed lifetime caps and those with bleeding disorders who reached their cap were often forced onto state Medicaid.

Some pools also implemented tight restrictions on the scope of coverage—including pre-existing condition exclusions, the very thing they were designed to remedy. While high risk pools could offer a safety net for those who could not obtain coverage elsewhere, enrollment in these pools was notoriously low across the nation because of the high premiums.

Despite this history, recent ACA replacement proposals would re-establish high risk pools for individuals with pre-existing conditions who can’t get or maintain private coverage. Our concern with these replacement plans is that they repeat the pattern of underfunding these high risk pools. Analysts’ estimates vary, stating that between 15 million and 130 million Americans with pre-existing conditions who could face difficulty buying private health insurance. The cost of funding coverage for this population through high risk pools could reach, by one estimate, \$178 billion per year, yet two of the plans put forth would only provide short-term funding of between \$3-25 billion.

High risk pools, according to a former California administrator, were always intended as a stop-gap measure: “we were a holding place, a waiting area... We were always hoping [they] would go away with the advent of national insurance reform.” High risk pools, when underfunded, are not an affordable substitute for meaningful insurance coverage and protection from the costs of pre-existing conditions. ■■

“High risk pools, when underfunded, are not an affordable substitute for meaningful insurance coverage and protection from the costs of pre-existing conditions.”

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Staying Fit Through Weightlifting – A Q&A with Eric Burgeson

By Meredith Clark

By now, we all know that leading a healthy lifestyle can help reduce the frequency and severity of bleeds. However, staying fit and eating right is almost always easier said than done. We sat down with Eric Burgeson, a young adult with a bleeding disorder, to learn how he successfully puts this theory into practice, and what keeps him motivated to stick with it.

Q **Eric, you stay fit by doing a variety of activities. Tell us a little bit about your weekly fitness routine and what drew you to these activities in particular.**

Eric: I'm a huge fan of weightlifting. I work on a cycle of anaerobic hypertrophy training, lifting weights 5-6 days a week, working on different muscle groups on different days. This all started as an effort to repair damage done to my ankle when I was a child as a result of multiple bleeds, and it grew into a passion from there. I started doing yoga about six months ago. I picked yoga because, while weightlifting has been an excellent addition to my life, it doesn't really round out my fitness needs. Being strong doesn't mean much if I'm not flexible and able to keep my body pliable.

Q **What keeps you motivated to exercise and eat right?**

Eric: What started as an effort to repair joint damage quickly grew into a path of gradually strengthening and improving my overall health. I started weightlifting at the age of 16; before that I would have regular spontaneous joint bleeds, several a year. Since my weightlifting progressed past simple calf raises and weightless squats, I've only had one or two significant bleeds in the intervening eight years. That's pretty great motivation!

Q **What kind of precautions do you take in regard to your bleeding disorder when you are working out? Are there activities that are better for you? Ones that you avoid?**

Eric: Well, I always make absolutely sure to have infused on the day of, or the day prior to, weightlifting. If it's my scheduled third day of prophylaxis, I'll infuse before working out. And of course, maintaining proper form during all exercises is paramount, not just for hemophiliacs, but for everyone. For a long time, I avoided doing a lot of lower body weightlifting, like squats and deadlifts, because I thought it was more dangerous to my joints (or maybe I'm just a "lifting bro" who didn't want to do legs!). However, after I finally bit the bullet and started doing heavy lower body lifts, and doing them safely, I found it only positively impacted my joints. I was sold!

Q **As a person with hemophilia, what are the biggest challenges that you face when exercising?**

Eric: The biggest struggle for me was getting started in the first place. When you're already behind the eight-ball with joints that hurt, it's hard to get off the metaphorical and literal couch. Once I got into a rhythm of setting aside time to exercise, however, it's only gotten easier to stay on that routine.

Q **What is a common myth or misconception about people with bleeding disorders in regard to exercise?**

Eric: Ah, the touchy question. I'm aware that I'm a privileged hemophiliac. I had parents who cared exceptionally well for me, and I was lucky to not have too many spontaneous bleeds as a child. I'm impossibly fortunate. Many people within



“My go-to snack is super-easy and delicious. With some little tweaks, I’ve been eating this meal for a few years now.”

YOGURT PARFAIT

1 cup of non-fat Greek yogurt

1 cup of fiber and protein-rich cereal

Honey to taste drizzled over

Different fresh fruits to dress on top. (Raspberries are particularly delicious.)

the community still push back against heavy weightlifting, but I’ve found nothing but positive benefits. Still, I know I’m a really lucky severe hemophiliac not to experience many bleeds. A lot of people outside the community assume that heavy lifting would be unhealthy for me but I respond that there’s nothing that I do that others can’t.

Q Many people often lose interest in working out after a while. What would you suggest we do to keep boredom from sneaking up on us?

Eric: There are many resources out in the world to keep you engaged, like Reddit and on-line bodybuilding forums. Speaking as a weightlifter, all it takes for me to remain engaged is to find different programs for weightlifting. Going from lifting heavy weights for just a couple reps for a few months is exhausting. Switching up to five-pound weights and throwing them around for a couple billion reps is a lot of fun. It also gets results. It’s the results that keep me coming back for more.

Q Of course, in order to lead a healthy life, one must eat right in addition to exercising. Tell us a little about your diet.

Eric: Ha! The people in my office are already laughing reading this question. I value consistency and nutrition over everything (yes, even taste). My breakfasts include egg whites and bagels usually: a little mix of carbs and protein. I drink black coffee exclusively: almost no calories! Lunch is usually a bowl of rice and beans loaded up with a lean meat, such as chicken or beef, and a bunch of veggies. I’ll usually have a snack, like yogurt and granola, before going to the gym. Dinner is the one meal I’ll generally free-wheel on, but it’s usually a salad or sushi. Gotta get that protein in!

“Every step towards fitness is a positive step.”

Q Do you feel that a healthy diet helps with your hemophilia? If so, how?

Eric: Keeping my weight in check has been absolutely essential in keeping my joints feeling good. The better my diet is, the better I feel, and the better I feel, the more active and better my workouts are. It’s a positive loop, lots of synergy.

Q Many people struggle to find the time to exercise and cook healthy meals. How do you balance a busy schedule with a healthy lifestyle?

Eric: Like so many people, when I’m feeling a little overwhelmed, the simple answer is, sadly, takeout. But when I’m on top of things, I like to do weekly meal preps. This is something a lot of people in the fitness community have been focusing on lately. It’s not terribly creative or fun, but it keeps your nutrition predictable. Cooking a week’s worth of breakfasts and lunches on a Sunday is a time-effective strategy of eating well.

When it comes to committing to weightlifting for an hour, 5-6 days a week, it just comes part of your mindset. I adjust my workout times to fit my schedule. If I have a dinner planned, I’ll try to get up early and work out before work. Sometimes I fail, but more often, I get it done. Honestly, at the end of the day, it comes down to making a sacrifice and being okay with that. I’d rather be healthy and happy than have a really active after-hours social life, for example. I understand that’s not for everyone, but it works for me.

Q Lastly, what advice would you have to someone who is trying to eat right and get in shape?

Eric: Every step towards fitness is a positive step. I wouldn’t say that I’m a paragon of fitness, but I’ve been consistent. I view my fitness not as a short-term solution, but a life-long choice to be healthy and happy, and I always know that any setbacks I suffer are just temporary. It’s easy to let a bad day (or week or month) of reckless eating get you down, but I always know in the back of my mind that I can just get back into my familiar routine. ■■

Women's Bleeding Disorders

By Linda E Wyman-Collins BSN, RNC-NIC

It's a simple fact: you can't treat what you don't acknowledge. When it comes to hemophilia, we don't acknowledge to what extent women are actually affected. Across this country, and the world, women are under-diagnosed and under-treated and, not surprisingly, that translates into women suffering and dying. For so many years, women who actually have hemophilia have instead been labeled as "symptomatic carriers." Proper diagnosis needs to be based on documented factor levels and not on gender when it comes to hemophilia, but setting aside two centuries of medical lore is tough. Nowadays, we know that "symptomatic carrier" is not appropriate or accurate. Newer studies have shown women labeled as symptomatic carriers have low factor levels; fifty percent of females who are "carriers" for hemophilia have Factor VIII or IX levels below 50%. Women may show permanent joint damage even with factor levels that would be considered adequate. The vast majority of women who have a son diagnosed with hemophilia, do not know their own factor levels. And if a woman believes she is "just" a carrier, she may end up accepting sub-optimal treatment by her health care providers, from routine procedures like dental work, to surgeries and trauma care.

How is it that so many health professionals, as well as the general public, still are under the misapprehension that hemophilia is visited only on males? Genetics is a complex arena of research. Everyone knows that males have an X and a Y chromosome as their 23rd pair and females have two X chromosomes. It's also commonly known that the gene for hemophilia A and B is carried on the X chromosome. What is lesser known, even by health professionals, is a situation called "Lyonization" or "X inactivation" in which women can actually have the "clotting" gene shut off, leaving the X chromosome with only the hemophilia gene "turned on." The percentage of cells in a woman's body affected by this Lyonization can vary, leaving some women with very low levels of clotting factor.

Women are subject to many types of bleeding disorders. Here are some examples:

VON WILLEBRAND DISEASE (VWD)

Officials estimate that 1-2 percent of the general population has von Willebrand disease (vWD) and is living undiagnosed, making vWD the most common bleeding disorder in the world. It is found equally in men and women, but again is extremely under-diagnosed. Those with vWD may also have low factor VIII levels. Women can have deficiencies in other factors such as VII, IX (Hemophilia B), XI and XIII.

PLATELET DISORDERS

Platelet disorders are also a possibility when abnormal bleeding is present. Platelet disorders include Glanzmann's Thrombasthenia, Bernard-Soulier Syndrome, and Platelet Storage Pool Deficiency. Platelet disorders may involve low numbers, an inability to stick well to each other, or inability to travel to the site of the injury.

ABNORMAL UTERINE BLEEDING (AUB)

One common problem women, in and out of the bleeding disorder community, encounter is abnormal uterine bleeding. In the US, surveys report that 53 in 1000 women, ages 18-50 years of age, have had AUB. Abnormal uterine bleeding can be defined as bleeding for more than seven days, need to change pad or tampon every hour, passing clots larger than a quarter, blood loss greater than 80ml or daily activities limited due to heavy flow. AUB can impact women's quality of life, productivity, and utilization of healthcare services.

CONNECTIVE TISSUE DISORDERS

Women who have a connective tissue disorder such as Ehler's Danlos disease may have increased bleeding tendencies. They may have fragile blood vessels or loose joints that easily dislocate. This increases the chance of bleeding into soft tissues, muscles, and joints.

Do I Have a Bleeding Disorder?

In addition to AUB, a bleeding disorder shouldn't be ruled out if a woman experiences two or more of these symptoms:

- easy bruising (raised and larger than a grape in size)
- nosebleeds (frequent and or lasting longer than 10 minutes)
- prolonged bleeding after surgery or injury
- prolonged bleeding from dental work
- post-partum hemorrhage
- a family history of a bleeding disorder

When assessing a patient's bleeding disorder, it is important to ask about prior bleeding episodes and to characterize the type of bleeding.

- Bleeding into the skin and mucous membranes is associated with disorders of the platelets and blood vessels
- Bleeding into soft tissue, muscle and joints is associated with the presence of hemophilia or other disorders of coagulation proteins.

We encourage any woman who experiences unusual bleeding, or whose family history includes a bleeding disorder or suspected bleeding disorder, to get tested. The first step to treatment is understanding and acknowledging the condition. With your health, as with so many other aspects of your life, knowledge is power! ■■

Talk to your doctor to see if ADYNOVATE may be right for you.

For more information, please visit
www.ADYNOVATE.com


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A Patient's Perspective on a Fresh Osteoarticular Allograft

By Christopher Quesenberry

Having a rare condition like hemophilia has never held me back from pursuing an active lifestyle. The demands of maintaining a high level of activity, however, ultimately resulted in joint failure. My right knee has been considered a “target joint” since I was in the fifth grade. By the time I reached adulthood, that knee was failing. Of course there is no good time for joints to collapse, but the timing of my knee failure was less than ideal because I was also now in the middle of raising a young family. I found in myself in a quandary. Fortunately, I met Dr. James Stannard, the medical director at the Mizzou BioJoint Center at the Missouri Orthopaedic Institute (MOI). He took the time to discuss my options at length. He got to know me and what I considered a good quality of life. And he was more familiar with hemophilia than I anticipated, having performed procedures on others in the community.

Since I am very active, both raising two small children and pursuing active hobbies like hiking and fishing, we ruled out a fusion. We also ruled out an artificial knee replacement because the longevity of such a device didn't suit my needs. My clinical team was not optimistic that once the first artificial replacement wore down that I would be able to get another.

Dr. Stannard and I agreed that my quality of life would be significantly improved if we went with BioJoint's use of actual biological bone and tendons.

The MOI Team talked to me about the BioJoint option and what it entailed. It was going to mean a lot more work on my end, but the upside was the potential for a higher level of functionality and a much more natural joint that could last as long as 25 years, maybe even more. But, BioJoint can't replace an artificial knee, and you can't do either BioJoint or an artificial knee if you first elect a fusion. I needed to decide up-front which way I wanted to go, because changing the repair/replace strategy down the road was not going to be an option.

At the time of my procedure I was 31, so I was truly hoping for “a one and done” solution. I conferred with my Hemophilia Treatment Center, and while they were a bit reluctant, they eventually offered their seal of approval. As the ones direct-

ing the hemophilia management for the operation, my HTC was looped in on everything related to pre- and post-operation plans.

When I elected to go ahead with the procedure, I was placed on a transplant list. I was told that the wait could be anywhere from 3-6 months so I would have to be a patient patient! Patience has never been my strong suit, but I bided my time and, almost exactly six months from the day I went on the list, I received the approval call. The biological materials Dr. Stannard would need for my procedure were still being screened

for bacterial and viral contaminants, but once they cleared, I would need to be at the hospital and ready to go in five days. I received the surgery notification call on the Thursday right before Fourth of July weekend. Do you know how happy your HTC will be with you when you call the afternoon before a holiday weekend that you're having a major surgery early the following week? Yes, exactly! The final prep was hard on all of us. My wife and I needed to secure childcare, as well as help with our dogs and the house, and of course I put a lot on the HTC's shoulders by giving them such a short window in which to devise a plan. It all worked out, and I will be forever grateful for how everyone was able to come through on such short notice for me.

Tuesday, July 7, 2015 was the day I reported to the hospital. The joint they were going to implant cleared all its tests over the weekend. I was excited and nervous. My factor levels were where they should be and everything was set to get underway. The procedure took 10 hours and in that time the team replaced my entire tibial plateau, both menisci, and six fragments of my femoral condyles (medial and lateral), critical to providing joint stability. I can remember Dr. Stannard apologizing to me the next day for having put me through such a long surgery. Those ten hours didn't bother me in the least: they meant I could avoid multiple trips to the operating room down the road!

I spent four days in recovery at the hospital, attached to a Continuous Passive Motion machine for 8-10 hours each day. The CPM machine moved my knee without my having to engage





Chris's right knee before procedure. Chronic synovitis has prevented proper function of the joint.



X-ray of Chris's knee after the procedure.



Above, the Ribial Plateau from the cadaver. Below, Chris's Tibial Plateau. Note the contrast of what a typical 31-year-old's knee and that of a person with hemophilia's looks like.

the muscles around the knee. This continuous motion aids the healing process and prevents fibrous scar tissue from building up within the joint. I continued to use a CPM at home for about a month after surgery as well. My goals for my rehabilitation were to be able to re-engage my quadriceps and regain my range-of-motion. This proved more difficult than I thought. A year-and-a-half later, I continue to make progress and now I'm able to fully straighten out my knee. I am also positively increasing my flexion, or ability to bend, which is far better than it was before the surgery.

The biggest change for me has been learning to "listen" to the joint again. I do not have the same feelings inside my knee as I did before the procedure. Everything inside the joint except the patella was "new equipment" and it took some time before I got the feeling back. Even bleeds felt different, and it took some discussion with my HTC to figure out when I was having a bleed and when I wasn't. Before the procedure, I would feel

“Communication and collaboration with the patient in the center really does result in positive outcomes.”

the pressure and a slight tingling of pain inside the joint; now I have to look for other signs to help identify a bleed. Before the surgery, the weakness, pain and impediments to walking with a normal gait were clues of a bleed in progress. None of those things is fun but now I needed other markers to help me determine when bleeds were happening.

In the time since my operation, I've gone from constant pain and 2-4 bleeds every year in my knee, to zero bleeds in my knee since earlier this year. I can't remember the last time I had knee pain, and for the first time since high school, I can build the muscle around my joint to protect it from further injury. My right leg has always been smaller than my left as it was always injured but now my legs are starting to look similar in size and muscle mass, as the right gets stronger each day.

My follow-up x-rays were right on track, showing that the transplanted biological materials were adapting inside me so the likelihood of my needing follow-up surgeries was slim.

Now I can say I have a new life! I'm no longer sedentary and I can be the active and engaged father I've always wanted to be for my kids. My family and I are really happy with the positive changes in our lives after the procedure and I have not had one single regret regarding my decision to have the operation.

I am naturally very grateful to the team at the Missouri Orthopaedic Institute and the Jimmy Everest Center for Bleeding and Clotting Disorders. MOI and my HTC worked closely with me to create a path toward my health goals. I have been a patient my entire life and I have a keen understanding of what "Patient Experience" best practices look like. I can say without a doubt that my personal experience in knee replacement is exactly how the integrated framework for healthcare should look. Communication and collaboration with the patient in the center really does result in positive outcomes. ■■



Yes, You CAN Choose Your Family!

By Emily A. Roush-Bobolz

Hemophilia Federation of America and the bleeding disorders community are by nature an engaged group of people, passionate about advancing awareness for the entire community.

Membership in HFA—whether as an individual, business or member organization—is an excellent way to bring the community together, but it is far more than just belonging to an organization; it’s belonging to a family.

“My family not only belongs to HFA,” said hemophilia mom, Suzanne. “We **are** HFA!”

The bleeding disorders community is small, but that is what gives it the supportive, close-knit feeling. HFA recognizes the importance of this caring, cohesive feeling, so improvements to membership have recently been made to reflect that.

“We want to create even more of a community or family feel for our members,” said Development Director Sharon Meyers.

Community (n.): a feeling of fellowship based on common interests and goals.

Yep, that sounds like HFA! HFA Membership comprises people who are steadfast, loyal, and genuinely concerned about HFA and the work it does. No one chooses to have a bleeding disorder, so there is also a unique sense of empathy and kinship for other members and their families. If the bleeding disorder community had a motto, it might be “we are all in this together.”

We are Family — Now is the perfect time to become a member

Improvements in membership start with individual and family memberships. With these options, members have the opportunity to receive a free T-shirt. Not only is the newly-designed, exclusive-to-membership T-shirt a fun and fashionable gift of thanks to the member for joining HFA, but wearing it is a stylish way to show they are part of the family.

“Once I became an HFA member, I felt like I was officially a part of the family,” said Kari Peepe, who

became a member in 2013. “It was important to me to become a member in order to support HFA’s emergency financial assistance program, Helping Hands. And becoming an HFA member ensured I would get all of the latest information related to bleeding disorders, which I don’t want to miss!”

As Kari says, membership in HFA shows strong support for those living with bleeding disorders, but it has other powerful benefits as well. It gives members access to information necessary for their health, full access to HFA programs and services, regular print and electronic communications, and policy action alerts vital to the bleeding disorders community. Some of the newer benefits will include special opportunities for more HFA gear and gifts, unexpected perks throughout the year, special mailings, and future opportunities for discounts to HFA events.

Beyond the benefits, however, HFA membership gives those living with bleeding disorders a voice. Membership provides meaningful connections between HFA, other members, and membership organizations, and it offers opportunities to advocate. Advocacy is at the core of all HFA does, and, with support and direction from HFA, members can learn to advocate on their own behalf.

“Thank you, HFA, for making raising awareness so easy,” said Mark, the father of a child living with hemophilia. “Your images are so well done. I share them all the time on social media with my family and friends. I am a better advocate because of them.”

The interconnectedness of membership will help HFA build better relationships with our members, help HFA identify and solve problems within the community, identify professional and educational opportunities, and become a more highly-effective organization, which is a benefit to anyone involved in the bleeding disorders community.

You can expect to see a letter from HFA in your mailbox soon, asking you to renew your membership or, if you’re not currently a member, it’ll offer more information on how to become one. Individuals, businesses and organizations who wish to become involved with HFA can learn about membership and other opportunities at www.hemophiliafed.org/donate/become-a-member/.

Membership with HFA can be set up to recur automatically on an annual basis. Visit www.hemophiliafed.org/donate/recurring-payment-form/ to set up recurring membership.



Being a member of HFA is like being a part of a family. The newly-designed, member-exclusive T-shirts proclaim that family message.

“I’m so proud to be part of the HFA family!”

– hemophilia mom and Symposium attendee

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- Record Type of Treatment Used
- Period Reminder Alert
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- Easily Share Information with your Provider
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March is Bleeding Disorders Awareness Month



It was February 21, 1986 when President Ronald Reagan released Proclamation 5442, declaring March as National Hemophilia Month. That national attention came at a time when our community needed it most, given the turmoil that we were experiencing in the 80s. In 1982, the CDC reported the first cases of HIV/AIDS among people with hemophilia. By mid-1983, researchers isolated the virus that causes AIDS and manufacturers of plasma-derived clotting factor concentrates began attempts to kill the virus with dry heat, solvent detergent treatment, and pasteurization, with varying degrees of success. Manufacturers licensed and began developing heat-treated products, but because of high cost, perceived risk, and questions over efficacy, these were not widely available. Many in our community were isolated and ostracized because of public anxiety and ignorance related to HIV/AIDS, and their own fear of being stigmatized. Children, most notably Ryan White and the Ray brothers, were denied entry to school because of their diagnoses. By the late 1980s, over 50% of the hemophilia community had been infected with HIV/AIDS and/or hepatitis C; in those with severe hemophilia, the infection rate was over 90%. The decades-old concern over hepatitis was now far overshadowed by the HIV/AIDS epidemic.

Since then we've seen many changes throughout our community. HIV and AIDS is now treated as a chronic condition rather than an acute, always fatal disease. We've learned a lot about bleeding disorders in the past 25-30 years as well, as medical research teams invest time and money into focusing on them. While President Reagan's address stated that hemophilia "is almost exclusively a male disease," we now know that women can and do have bleeding disorders. The number of products on the market has grown as more pharmaceutical companies invest in treatments for bleeding disorders.

Since 1986, we've celebrated National Hemophilia Awareness Month. But, last March, along with our Member Organizations across the country, we recognized the first-ever Bleeding Disorders Awareness Month in an effort to shine a light on the many bleeding disorders, in addition to hemophilia, that impact our community. Last year, during the month of March, you helped us recognize the resilience of our community by sharing our fact-a-day social media campaign, updating your Facebook and Twitter profile images with our support ribbon, passing out our educational cards, and hosting fundraisers! With your help, we reached an astounding 800,000 people in 2016!

We encourage you to spread the word about this year's Bleeding Disorders Awareness Month by taking part in our campaign this year. On the following pages you'll find an advocacy calendar loaded with ideas on how you can advocate for yourself and your family. And each day during the month we'll be posting facts on our social media channels to educate and inspire. We hope you'll share these posts with your friends and families.

**Can we beat last year's 800,000 people reached?
Yes, we believe we can!**

Bleeding Disorders Awareness Month

ADVOCACY CALENDAR

By Sarah Shinkman

Show your support for Bleeding Disorders Awareness Month by making advocacy a priority throughout the month of March. From increasing your knowledge in a particular area of the community, to sharing your personal stories with others, to volunteering with bleeding disorders organizations in your area, there are many ways to advocate for yourself and the community. We suggest you pull out this page and hang it in a visible location to remind yourself of what you can do each day to join HFA on this advocacy journey.

1

National Bleeding Disorders Awareness Month starts! Kick off the month by contacting your local media outlet. Ask if they'll do a piece on bleeding disorders, what's happening in the community, and what this month means to you.

2

Advocacy Throwback Thursday (ATBT): In 2008, President George W. Bush signed the Genetic Information Nondiscrimination Act (GINA) into law. This act protects Americans against discrimination based on a person's genetic information when it comes to health insurance and employment.

3

Do you know who your representatives are? Find this information, and how to contact them, by using HFA's CQ Engage System on hemophiliafed.org.

4

Social Media Saturday! Do you use Facebook, Twitter, Instagram, or Snapchat? Follow HFA to increase your awareness and become more engaged.

5

Calling all community members with insurance issues! Share your story with HFA's Project CALLS and help build a case for change. Learn more at Project-CALLS.org or by calling 202-836-2530.

6

Want to be a stronger advocate? Volunteer! Contact your local bleeding disorders organization and learn about opportunities that fit your schedule and interests.

7

Toolkit Tuesday! HFA has several toolkits online. Topics include:

- Employment
- ER Visits
- Back to School
- Off to College
- Coping with Sibling Issues
- And many more!



8

NHF's "Washington Days" begins!

Today is International Women's Day. Give a blood sister or a hemo mom a big hug!

9

ATBT: On April 17, 1989, the first World Hemophilia Day was observed with the goal of increasing awareness and advocacy for the bleeding disorders community.

10

Use your research from last Friday to contact your legislators. Share your story by phone, email, social media, or in person.

11

Let people know about Bleeding Disorders Awareness Month by changing your Facebook profile picture to include a custom frame! Learn more @[hemophiliafed](https://www.facebook.com/hemophiliafed) on Facebook.

12

Plan a potluck for community members and friends to gather and discuss ways to advocate. What better way to bring people together than with food and fellowship?

13

What inspires you to be an advocate for the bleeding disorders community? Taking time to reflect on what motivates us helps maintain the momentum.

14

Know someone who is new to the bleeding disorders community? Reach out to them and see how you can be a resource and mentor.

15

Love to write or use social media? Ask your local bleeding disorders organization if you can write a piece for their newsletter or Facebook page.

16

ATBT: The Hemophilia Act of 1973 allowed the establishment of federally-funded, comprehensive Hemophilia Treatment Centers (HTCs).

17

Ask your representative to attend a local event to meet community members and learn more about bleeding disorders.

18

Have some hemophilia-related apparel? Wear it to spread awareness.



19

Join your local advocacy committee. If your community does not have a committee, there's no better time to start one than now!

20

Have insurance questions? Check out the resources on HFA's website to better understand healthcare coverage and how to file an appeal.

21

Educate others and spread awareness about bleeding disorders by forwarding HFA's action alerts or Facebook posts.

22

Webinar Wednesday! Did you know that HFA has webinars about advocacy? Search for HFA on YouTube and let the viewing begin!

23

ATBT: On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act (ACA) into law. This bill provides several protections to people in the bleeding disorders community.

24

Check out our engagement center and review active bills in your state being monitored by HFA!

Visit <http://cqrcengage.com/hemophilia/>

25

Did you know that March is also National Nutrition Month? HFA's FitFactor program can help you be a stronger—and healthier!—advocate through diet and exercise.



26

Have an advocacy question? Submit it to HFA's Dear Addy blog: DearAddy@hemophiliafed.org.

27

With Bleeding Disorders Awareness Month coming to a close, how will you continue being active? Make your own calendar or an advocacy to-do list.

28

Want to better understand the policy issues affecting the bleeding disorders community? Visit the policy priorities page on HFA's website.

29

Check out the Bleeder's Bill of Rights! Created by HFA's Care Access Working Group, this tool is intended for self-advocacy and empowerment. Find it on HFA's website.

30

ATBT: In 1973, a new test emerged to assess whether women carried the hemophilia gene. This built on the established test developed in the 1950s.

31

Stay informed year round! Sign-up for the *Friday Five*, HFA's monthly e-newsletter on our advocacy efforts.



Celebrations and a Heavy Heart

By **Cazandra Campos-MacDonald**

My son Caeleb has struggled with an inhibitor since he was 11-months-old. Despite the recommendations of many doctors, it has never been as “simple” as waiting to get below a 10 Bethesda unit measurement to start immune tolerance therapy (ITT). Caeleb developed a rare allergy to Factor VIII, one for which there is no known treatment or protocol. As precious to us as Caeleb is, treating bleed after bleed, enduring hospitalization after hospitalization, having him wheelchair-bound, and exhaustively exploring multiple opinions from different Hemophilia Treatment Centers (HTCs), all took a hefty toll on our family.

During our time at the Denver HTC, the hematologist suggested we see an allergist at National Jewish Health, a leading hospital in respiratory and allergy treatment. That suggestion changed the course of our lives! The allergist recommended a new injectable allergy drug every two weeks. After a slow escalation of Factor VIII being introduced to Caeleb’s system, he is now able to have 4,000 units of daily Factor VIII with no allergic reactions. The result? We could finally begin ITT. Over the course of many months, his inhibitor decreased to zero.

Yes, ZERO!

When the treatment center called me to tell me the news, I was speechless. As an inhibitor mom, I did realize that numbers fluctuate and inhibitors do often come back in full force, but I refused to worry about what might happen. I chose to celebrate! That night, we had pizza for dinner and cupcakes for dessert and I contacted everyone I knew on social media and by telephone to share the wonderful news.

But something odd happened in that moment of celebration: I found that my heart still hurt.



It hurt for the inhibitor community that had been a lifeline for me throughout the years. It hurt for the parents and children who were still struggling. It hurt for those wonderful, supportive people who would never know my joy for themselves. So yes, I was hesitant to share the wonderful news that Caeleb’s inhibitor was registering zero. I now had what so many in our community want—to *just* have hemophilia and to *just* treat a bleed with a dose of factor. Many with inhibitors long to use the RICE method (Rest, Ice, Compression, and Elevation) to be back on their feet within a few days, rather than dealing with the weeks, or even months, of healing needed when managing an inhibitor. I started to doubt whether I should have shared my elation with my inhibitor friends, but a wonderful thing happened: they whole-heartedly celebrated with me.

My community celebrated because they understood, all too well, the journey we had been traveling. It was a journey filled with birthdays and holidays spent in the hospital, missed family events because of hospitalizations, school absences and make-up work, a life (and house) full of walkers and wheelchairs, and a small boy who, for so long, couldn’t run and play like most children.

So, we may be at zero Bethesda units right now, but having had two sons with inhibitors, I know very well that “inhibitor mom” is part of who I am and will always be. I am indebted to the moms who answered my Facebook posts in the wee hours of the night when I was at my wit’s end in the hospital. There were nights that those posts, those moms and their support, gave me hope, and sanity.

A bleeding disorder is serious business. You don’t need to have an inhibitor to know the truth of that statement. My advice to other parents is: never compare and think that someone has it worse so you say to yourself “I shouldn’t complain.” Yes, there is always someone in a worse situation, but each of us has a unique journey with our children that is real and difficult in its own way. Always understand that the road you are traveling is no less real or profound than anyone else’s. When it’s bad it’s bad, but when it’s better, be sure to celebrate.

Cazandra lives with her husband, Joe, 20-year-old son, Julian, and 11-year-old son, Caeleb, in New Mexico. ■■



KID CAPTAIN

By Josh Hemann

Since before Kinzie was diagnosed with type 3 von Willebrand disease she has been a patient at the University of Iowa Children's Hospital (UICH). We have been blessed to have a hospital and treatment center that provide such excellent care for Kinzie, who is now seven. Our connection to UICH has other layers as well. All three of our children, shortly after they were able to walk, have joined my wife and me in cheering at the University of Iowa Hawkeye football games. Admittedly, I can get a little more carried away than their mother. Knowing both our appreciation for the care received and our family's fan status, when we found out the Children's Hospital selected honorary "kid captains" for each football game we decided to apply.

We applied for three years and this year Kinzie was selected as a captain for the first game of the year, UI Hawkeyes vs Miami (OH). Each year as I wrote the application essay and answered the questions, I felt a bit of an internal struggle. Two thoughts weighed heavily on my mind. My first thought was reflecting on some of the worst times of our lives in the first few years of Kinzie's life struggling with bleeds. We have had many ER visits, usually with a lot of anxiety for everyone and too many pokes just to infuse her factor.

We've had a few hospitalizations; an ambulance ride to Iowa City (a nearly two-hour drive from home); tubes placed in Kinzie's ears; her nose cauterized three times; two blood transfusions; and a night in the ICU. All of these experiences, albeit negative, ultimately provided us with something very important: perspective. The second thing on my mind while I completed the application was knowing we are still

blessed. Whether we were admitted to the hospital, just getting a checkup, or having an outpatient procedure, having these experiences with UICH afforded us a critical perspective. I realized that our worst times might very well be miles better than the best days of others. When Kinzie was admitted to the hospital, we'd stay on the same floor as the oncology patients. I recall one stay where I was feeling particularly down and frustrated. That afternoon, our two-

year-old Kinzie played in the same activity room as a girl a few years older. This girl seemed very downhearted, and it was with good reason, as I found out she spent more time in the hospital than at home. Reality hit me, hard. In just a day or two we would be discharged and headed home. Kinzie would still receive infusions at home, but would lead a fairly normal life. This girl, and many other children, would not. Her future was uncertain, even bleak. After thinking about what we had been through

All of these experiences, albeit negative, ultimately provided us with something very important:

PERSPECTIVE.

and then what other children and their families were dealing with, I finished the application. A couple of months later we received a call letting us know she was selected for this football season. I was hopeful that her selection was a good portent of things to come. Kinzie would gain a once-in-a-lifetime experience and we could raise awareness for bleeding disorders, von Willebrand disease, and women with bleeding disorders. And, long-term, Kinzie would be given that important gift of perspective.

When we were notified in June of her selection we were instructed not to tell anyone as the UICH wanted to announce all of the kid captains at once and they needed to make sure they worked with NCAA compliance. It was in the beginning of August when the video announcement was made on the hospital's website and Facebook page. We could finally tell our family and friends! We happened to be at our annual HTC clinic visit when the announcement was made, which was perfect timing, as it allowed Kinzie to be the one to show her nurses and doctor the video. Ever since diagnosis, we have been treated so well by the HTC, very much like family. Kinzie was excited with this announcement, but of course a bit nervous as she didn't know exactly what to expect.



A couple of weeks later we attended kid's day at the football stadium. This was a day the football team opens up their practice time for families to bring their children to the stadium for free. It is very much a kid-centered day. The kid captains were allowed to bring a few extra guests, so Kinzie brought two of her cousins, her eight-year-old sister Jaylah, her two-year-old brother Milo, and was nice enough to invite her mother, Heather, and me. When we met at the gates with all of the other families whose children were selected as kid captains, we were each assigned a guide. We were ushered up to the press box for an introduction and an opportunity to meet other families. During this time we were given a book showing each child and a synopsis of their story, gleaned from the application essays each family submitted. After that, we followed our guide for a tour of the visiting team's locker rooms.

We were surprised to see that the visitors' locker rooms were painted pink! Hayden Fry, a former long-time UI coach, believed pink was a calming color and would put the other team in a passive mood. This was a sight not many see, so we true fans found the tour very cool. After that tour, everyone was escorted to the home team locker rooms where a locker waited for each child. Each locker contained a jersey, a banner announcing them as a kid captain, and a couple other items. The look on Kinzie's face was priceless as she saw herself on the banner. We took plenty of pictures, talked to some of the other families and tried to soak up the experience. After a few minutes, the offensive line coach, Brian Ferentz, who is also head coach Kirk Ferentz's son, came to speak to the families. He spoke about how his players were big tough men, but not half as tough as these kids with their positive attitudes and smiles each day. As he said this I looked around the room at the jersey-resplendent kids. Some of these kids were in wheelchairs, some might not even make it out of childhood, and there was my daughter, standing next to me. Those two thoughts came flying back to me: knowing what Kinzie has dealt with and will deal with in her lifetime, and also knowing that even though not every day is guaranteed, we will be able to hold our baby tomorrow, next year and years into the future. The guides then allowed one parent to stay with the children and the rest left to wait outside the tunnel to the field.

Kinzie and I met many of the senior players: getting their autographs, talking to them, and taking a few pictures. Each of these young men was amazing with the kids. As they walked into their own locker room they sought out the children, engaging them in conversations, making eye contact, and, to this parent at least, showing genuine excitement to be part of this special day. Parents exited the tunnel before the children. Then the children all walked out proudly with the senior players, as they would do on their special game day. The football players held hands with the kid captains and swarmed the field. We saw many pictures after the event and the smile on Kinzie's face as she talked with a starting senior receiver warmed my heart. He was her new favorite player!

We gathered more autographs, watched some of the practice drills and met with other friends and family. It had been a long day. Our son Milo fell asleep in the van on the ride home, and I assumed Jayla and Kinzie would do the same, but they did not. I found out when we arrived home the girls had been reading the books we had received at the beginning of the day showing a synopsis of each kid's story. This sparked conversation at home as we talked about these kids and some of the issues they faced. The girls asked a lot of questions that evening. What is cancer? What is Down Syndrome? What does "terminal" mean? Will this child have to use a wheelchair forever? With all of this conversation we also talked about how happy these kids seemed earlier that



day, how nice they were and how happy we were for them. This was not an easy conversation to have, but they learned so much and, yes, gained perspective.

A few weeks later we arrived at the week of Kinzie's kid captain game, the week leading up to Labor Day. On the Sunday prior to the game, the video was released that included interviews with Heather and me, as well as a video of Kinzie by herself and with her siblings. Heather and I had seen the video a couple of days before as we were allowed to preview it and give them approval. I was a bit apprehensive, thinking it might be too dramatic, but it painted an accurate picture of how we felt, along with the love and appreciation we feel for our care team. The day they released the video was an infusion day for us. Our family had been working towards peripheral infusions since April and it was going fairly well. Heather was by far better at infusing than Kinzie and I were, but we were persistent and getting better. To help us with our learning process our home care nurse came regularly to coach and teach us. That morning our nurse, Stacy, Kinzie, and I worked on infusing after Heather left early for work. Jayla played with Milo as she often does to help entertain him so we can focus on infusing: everyone doing their part. We poked three times peripherally that morning. Kinzie did the first and missed, she cried both because readjusting after the poke hurt and because she missed. I didn't have to do this kind of thing when I was seven—I doubt I could have! She let me poke twice, getting it both times, with the first poke blowing the vein. Before my second poke she started to cry, not wanting to get poked again, but told me to stop so she could calm down, and she did. Afterwards I was proud, not just of myself for sticking her successfully, but of Kinzie for being better with this than I ever could have been at her age.

As this week went on we had an outpouring of support from family, friends and many people we didn't even know. One person commented on the hospital's video stating they didn't know anyone else with type 3 vWD. This person had felt alone in their diagnosis, so spreading awareness of vWD was definitely a benefit. Heather and I planned a tailgate party, though of course Heather did the lion's share of the planning! I thought she may have gone overboard, but it turned out great. Many of our friends and family, as well as treatment center staff stopped by to visit and say hello to Kinzie. The game had a 2:30pm start so we had plenty of time to enjoy the day. Our kids played with their friends, while Heather and I talked with friends and family.

When it was time to go in, Kinzie, Jayla, Heather, our HTC physician, whom Kinzie chose to join us, and I met our contact at the gate to be escorted in. The next hour or so was filled with many exciting moments and smiles. Many well-known figures in

the football program greeted Kinzie, a wild student section cheered her name, and those we knew in the crowd enjoyed this special moment with us. I watched as Kinzie's name was announced to the stadium, while she stood out at midfield with a former coach, and the cheers came roaring in. The announcers gave her background and told the crowd about her interests in soccer, flag football, and break dancing. As I could see the roof of the UICH peeking above the top of the stadium behind this scene of my daughter's special moment, it took me back to thinking of how uncertain our future had felt at one point and how very lucky we were.

Many times since then, I have had the opportunity to reflect again on everything that happened around this experience. I thought how lucky Kinzie was to be selected, to have this behind-the-scenes experience, and to be treated so well. I have looked at my family and seen the positive impact the experience had on each of us. Kinzie is a stronger, more resilient child because of this. Jayla is a very compassionate and caring sibling. Heather and I have learned to deal with things as they come and von Willebrand disease may have even made us better at working together. Milo, well, he is two after all, so he hasn't picked up on everything yet, but he knows Kinzie needs her medicine and his parents need to do that for her.

People often ask if I would I "cure" Kinzie's condition if I could. Without a doubt—absolutely! But, that's just not an option at this point. We can handle what comes our way with vWD, not always perfectly, but we manage. It all comes back to that all-important perspective. Perspective is something we both can carry with us and share with others. It gives us the impetus to consider, and to pray for, others whose situations are not as hopeful as our own. ■■

THE PLAN BEFORE THE CRISIS: Starting an Action Plan Before a Medical Emergency

By Kandyma Sar

Hemophilia and other debilitating diseases can devastate the lives of individuals and families in many ways. Not only are the medical effects life-changing but the financial aftermath of treatment can change a family's economic status from stable to completely chaotic.

When a medical emergency arises, concerns like deductibles, copays, prescriptions, supplies/equipment, taking time off of work, the risk of losing employment, and additional travel expenses to specialized treatment centers, all take a toll. Even without a medical emergency, these events can cause an unexpected financial burden. Some individuals and families confront one or two of these issues at a time, and some unfortunately encounter all of them at once. And that's not the end of the story, either. With the anxiety caused by a medical emer-

gency and/or an unanticipated financial burden, stress levels increase and may in turn exacerbate an otherwise-controlled medical condition, potentially causing flare-ups and additional complications and concern.

Everyone wants to avoid a worst-case scenario. It's hard enough to manage a chronic condition on a daily basis without having to deal with crises. Even just a few hours of planning and identifying resources can save a significant amount of money and any number of headaches. Imagine taking up to an hour each day to identify resources and solidifying an action plan. This small sacrifice of time, and the peace of mind that comes with it, are definitely worth the effort and can contribute to a healthier way of life.

**Steps do not have to be followed in the order below.*

STEP 1

Give yourself time, and practice a bit of persistence, in doing research and collecting information.

- You may not get the answers you need right away but do not get discouraged.
- Allot time every day if necessary to maneuver through sections of dense information.
- Reach out to family, friends and experts in the field to help you navigate. They can also serve as a support network to help you commit to your action plan.

STEP 2

Understand what is covered by your insurance.

- Thoroughly review your insurance coverage and call the company for clarification or further explanation of benefits.
- Decide if you need a form of specialized insurance.
- If you do not have insurance, seek advice on how to get a private insurance policy and see if you qualify for Medicare or Medicaid.

STEP 3

Know what's going on with your finances.

- Do you have a savings account? If not, start one today! Even a small, but steady, commitment can yield significant dividends down the road.
- Explore your disability benefits/insurance and long-term care insurance.
- Keep track of sick time you are allowed or have accrued.
- Do you qualify for the Family and Medical Leave Act?
- Create a spreadsheet of household income and expenses. This exercise may even help identify expenses that are not necessary, giving you an opportunity to save.

STEP 4

Create a budget.

- List all of the costs that can be associated with a medical emergency including hospitalization, medical visits and follow-ups, supplies, equipment, in-home care, and travel expenses.
- With that figure in mind, start building an emergency fund for a medical emergency.

STEP 5

Know the hardship policies of your creditors.

- Utility companies may be willing to defer or waive your payment because of financial hardship.
- Your landlord may have a policy in place for hardship situations and be able to offer a flexible payment plan.

STEP 6

Know the resources available to you.

- Are you able to secure temporary financial support from your family or close friends? It is worth a discussion?
- Know your local resources.
- Seek out condition-specific programs locally and nationally.

Remember that **YOU ARE NOT ALONE!**

Finally, remember that you are not alone! If you take a closer look, this action plan starts and ends with reaching out to the circle of people in your community. The more you prepare and reach out for support, the more you will realize that a wealth of information is readily available to help you on your quest for financial independence. Knowing that you have an action plan will help you materially, but also give you a sense of security, during some of the most vulnerable times in your life.

The action plan is not limited to your finances alone. You'll find that it can work together with other resources that will benefit other aspects of life for you and your family. Visit HFA's Resource Library, located at www.hemophiliafed.org, for a plethora of educational webinars and additional resources such as the "Navigating Patient Assistance Programs" section. ■■



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Share Your Story to Help HFA Advocate for the Community

By Miriam Goldstein, JD, Deema Tarazi, JD and Lori Long

No matter what your political views, one principle that isn't polarizing within our community is that we all need access to preferred providers, the ability to purchase affordable insurance coverage, and access to quality treatment. As individuals, we're in a position to educate people outside our community on our unique needs and to help them understand what it is like to live with a bleeding disorder. As an organization, HFA is committed to advocating on your behalf and to bringing your individual stories to the forefront of the national conversation

In the coming weeks, Congress is going to be making decisions that will affect how people with bleeding disorders are able to access quality health insurance. HFA will continue to

represent you and your needs to ensure that the community's collective voice is heard before any policies are put into place. We're asking community members to submit stories for our team to use in their advocacy and outreach efforts. By having your unique and personal story we can add a very important, very human voice to the call for quality health care coverage and quality of life. Please send your story to advocacy@hemophiliafed.org. Please indicate whether you give permission to share your story for advocacy and outreach purposes. In many settings, we're happy to change your name to protect your privacy, should that be of concern.

To start you thinking about what you could submit, here are some story ideas that might appeal to you.

We need to keep the ban on annual and lifetime limits because...

Many individuals with hemophilia will routinely use \$250,000 to \$1 million worth of life-saving clotting factor each year, depending on the severity of their individual conditions. An adult with hemophilia could hit a \$1 million cap in just two or three years; an individual experiencing inhibitors or other complications could reach that cap even faster. A ban on annual and lifetime limits is a critical protection for bleeding disorders patients against losing their insurance because of such caps.

We need to provide safety net coverage for individuals and families who cannot afford private insurance because...

Not everyone has access to, or the resources to buy, private health insurance. Yet anyone with a bleeding disorder will require health coverage in order to be able to cover the costs of their medication and treatment. Safety net programs make it possible for low and moderate income people to access the treatments they need to stay healthy.

We need to keep coverage for children up to 26 years old because...

As an expensive and chronic disease, hemophilia comes with a high, life-long price tag. Members of the hemophilia commu-

nity routinely hit the catastrophic out-of-pocket maximums on their health insurance plans. Bearing these catastrophic costs (on top of the premium costs to purchase insurance in the first place) is extremely difficult for almost anyone—but is nearly impossible for many young people early their work lives. Staying on their parents' insurance until age 26 allows young people with hemophilia a little time to become established in their careers before they have to shoulder the weighty burden of paying the year-in, year-out costs of their healthcare.

Insurance companies must be required to provide meaningful coverage and an appropriate scope of health benefits because...

Insurance is not meaningful unless people can afford it, and unless it covers the services and products people need in order to stay healthy. It used to be the case that some individuals with hemophilia only had access to insurance plans that excluded coverage for the medications and/or services necessary to control or prevent joint- and life-threatening bleeding episodes. This kind of under-insurance is functionally equivalent to a complete lack of insurance. Standards for what health plans must cover (prescription drugs, chronic disease management, etc.) are critical in order for insurance to be meaningful.

.....

Insurance companies must not be allowed to discriminate against people with pre-existing conditions because...

Bleeding disorders are genetic conditions that are present at birth. Disallowing insurance companies to discriminate on the basis of a pre-existing condition has made it possible for patients living with a bleeding disorder to buy the insurance necessary to properly manage their disorders. Not allowing insurance companies to increase premiums based on patients' health condition has ensured access to health insurance for those who most need it.

.....

We need reasonable limits on maximum out-of-pocket costs because...

Hemophilia medication is essential but expensive. As a result, hemophilia patients face significant outlays, year in and year out, in connection with their treatment. Most health plans charge patients a percentage co-insurance rather than a flat co-pay for their hemophilia medication—this results in out-of-pocket charges that total thousands of dollars every year. A reasonable limit on maximum out-of-pocket costs is absolutely critical to alleviate the financial toll imposed on patients with hemophilia and other chronic diseases.

.....

High risk pools cannot cover individuals who are uninsurable based on pre-existing health conditions because...

Before enactment of the ACA, 35 states operated high risk pools to cover people with just such health conditions. These pools, however, generally offered very limited coverage, with high deductibles and low annual and lifetime coverage caps. Premiums, too, could be prohibitively expensive, often 200% or more of the prevailing rate in the individual market. And yet the premiums and deductibles still didn't cover costs of care for the high-need enrollees—and states didn't make up the resulting shortfall in funding. Because so many high risk pools were chronically underfunded, they implemented enrollment caps and waiting lists that excluded many, sometimes most, of the individuals who applied for coverage. They also implemented tight restrictions on the scope of coverage—including pre-existing condition exclusions!

“Hemophilia medication is essential but expensive.”

Story ideas to raise awareness!

How does having a bleeding disorder affect you every day?

What was your best or worst moment with your (or your child's) bleeding disorder?

The story of when you were diagnosed...

Maybe you were diagnosed at birth and knew your family history. Maybe you weren't diagnosed until late in life. For each of us (or our children), the moment of diagnosis can be tumultuous, overwhelming, and rife with emotion. How did it happen? How did you feel about it? What is your family story about how your parents felt about it?

How you learned to infuse...

Maybe you went to camp and learned there. Maybe you learned at your local HTC. Maybe you learned from a homecare nurse. What was it like? What did you have to overcome? Who helped you?

How you transitioned to college or into the workforce...

What tools were helpful when you went to college or started your first job? Did you disclose your bleeding disorder to a roommate or co-worker and, if so, what was the outcome? Did you register with your school's Office of Accessibility Services? Did you tell your boss or HR department and ask for accommodations? If you missed class or work because of a bleed, how did your teachers or work supervisor and colleagues react?

The last time you had to “battle” your insurance company...

Did your doctor or pharmacy get removed from your network? Did you wait three months for pre-authorization? Did your pharmacy change their formulary and remove your medication? Who did you call? What did you do? And how did you feel?

The story of a surgery you had...

Was it to relieve pain or help mobility? Was your pain decreased or your mobility increased after recovery?

The story of convincing your child that an infusion is a good idea...

Whether you're talking a two-year-old into sitting still or helping your teen remain compliant with a medical regimen, the challenge can be frustrating, wonderful (when it works out), or even amusing (kids say the darnedest things)!



Member Organization Board President Spotlight:

Murai Johnson of the Virginia Hemophilia Foundation

By Carrie Koenig

HF A sat down with Virginia Hemophilia Foundation’s board president Murai Johnson, to discuss how she became involved in community organizing and what continues to motivate and inspire her to spread awareness.

1. How and why did you become involved in the bleeding disorders community?

Murai: I have close family members who are affected by a bleeding disorder and I am a carrier. At an early age, I started attending different educational sessions and events held by my local chapter. Once I became a mother, I realized that moms of healthy babies get so much support in all aspects of that first year and beyond. I knew that families of babies with bleeding disorders needed the same, if not more, support. Because my relationship with my HTC and local chapter had been so positive and beneficial, I wanted to be a part of that and share with others in my situation. It started for me with the National Hemophilia Foundation’s (NHF’s) “First Steps” program, now a part of “Steps for Living.” I became more active, started volunteering at my local chapter and HTC, and, understanding how important it is to stay abreast of advancements in the bleeding disorders community, I applied to be on the board of directors.

2. What was the journey like to becoming board president?

Murai: For my part, this journey has been filled with hard work and persistence. I have gained insight on what it takes to develop, plan fiscally, and manage. This work has instilled in me a greater awareness and understanding about our causes. My goal is to offer hope and empowerment to those with bleeding



disorders by ensuring they have a dedicated support network, along with the latest information on new drug therapies and breakthroughs. And one of the most important aspects of my job is to serve as an ambassador for our community.

3. What is your favorite part of being board president?

Murai: I really enjoy observing the growth and development of the bleeding disorders community.

4. What makes VHF a great place to volunteer?

Murai: We get to see the fruits of our efforts: improving outcomes and people’s quality of life, and creating comradery among our families in the bleeding disorders community. Everyone here gives 100% and that means we all benefit and prosper as a community.

5. What inspires you about the bleeding disorders community?

Murai: VHF “SPEACs” for the community we serve: we Support, Prevent, Educate, Advocate and Cure. We have a strong presence, providing a variety of personal, medical, and financial support; creating a safe environment for discussion regarding treatment, access to care, and quality of life; delivering quality educational programs; and offering resources based on needs of our community. VHF not only teaches about self-advocacy and advocates at local and national level, we apprise the community on advancements and innovations. We support research and keep the general public informed as well. Our community is motivated, dedicated and enthusiastic. We have such a great team working together that includes volunteers, VHF staff, our HTCs, other chapters, the scientific community, and national organizations like NHF and HFA. We’re also creating some GREAT leaders from our local chapters.

6. What advice would you give other community members who would like to volunteer at their local organizations but don’t know how?

Murai: Take that first bold step: join in and show your interest! Ask questions! Remember, “the smallest deed is better than the grandest intention.” ■■

AFSTYLA®, Antihemophilic Factor (Recombinant), Single Chain
For Intravenous Injection, Powder and Solvent for Injection
Initial U.S. Approval: 2016

BRIEF SUMMARY OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use AFSTYLA safely and effectively. Please see full prescribing information for AFSTYLA, which has a section with information directed specifically to patients.

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

- Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion on your own.
- Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing this medicine.

What is AFSTYLA?

- AFSTYLA is a 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.
- Does not contain human plasma derived proteins or albumin.
- Your healthcare provider may give you this medicine when you have surgery.
- Is used to treat and control bleeding in all patients with hemophilia A.
- Can reduce the number of bleeding episodes when used regularly (prophylaxis) and reduce the risk of joint damage due to bleeding.
- Is not used to treat von Willebrand disease.

Who should not use AFSTYLA?

You should not use AFSTYLA if you:

- Have had a life-threatening allergic reaction to it in the past.
- Are allergic to its ingredients or to hamster proteins.

Tell your healthcare provider if you are pregnant or breastfeeding because AFSTYLA may not be right for you.

What should I tell my healthcare provider before using AFSTYLA?

Tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to hamster proteins.
- Have been told you have inhibitors to Factor VIII (because this medicine may not work for you).

How should I use AFSTYLA?

- Administer directly into the bloodstream.
- Use as ordered by your healthcare provider.
- You should be trained on how to do intravenous injections by your healthcare provider or hemophilia treatment center. Once trained, many patients with hemophilia A are able to inject this medicine by themselves or with the help of a family member.
- Your healthcare provider will tell you how much 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 to be sure that your blood level of Factor VIII is high enough to clot your blood.
- Call your healthcare provider right away if your bleeding does not stop after taking this medicine.

What are the possible side effects of AFSTYLA?

- Allergic reactions may occur. Immediately stop treatment and call your healthcare provider right away if you get a rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headedness, dizziness, nausea, or decrease in blood pressure.
- Your body may form inhibitors to Factor VIII. An inhibitor is a part of the body's defense system. If you form inhibitors, it may stop this medicine from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.
- Common side effects are dizziness and allergic reactions.
- These are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

What else should I know about AFSTYLA?

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

Please see full prescribing information, including full FDA-approved patient labeling. For more information, visit www.AFSTYLA.com

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35041 Marburg, Germany

for:
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For adults and children with hemophilia A

REACH HIGHER

With the Long-lasting Protection of AFSTYLA

2x
WEEKLY
AVAILABLE

FDA-approved for dosing 2 or 3 times a week

ZERO
BLEEDS
(median ASBR*)

In clinical trials, whether dosed 2 or 3 times a week

COMPARABLE TO
NATURAL
FACTOR
VIII

Identical to natural Factor VIII once activated

Zero inhibitors observed—Low incidence of side effects in clinical trials

In clinical trials, dizziness and allergic reactions were the most common side effects.

Visit the CSL Behring Coagulation team at Booth 14 during this year's HFA Meeting to learn more!

*Annualized spontaneous bleeding rate in clinical trials (interquartile range [IQR]=0–2.4 for patients ≥12 years; 0–2.2 for patients <12 years).

Important Safety Information

AFSTYLA is used to treat and control bleeding episodes in people with hemophilia A. Used regularly (prophylaxis), AFSTYLA can reduce the number of bleeding episodes and the risk of joint damage due to bleeding. Your doctor might also give you AFSTYLA before surgical procedures.

AFSTYLA is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion. Carefully follow prescriber instructions regarding dose and infusion schedule, which are based on your weight and the severity of your condition. Do not use AFSTYLA if you know you are allergic to any of its ingredients, or to hamster proteins. Tell your healthcare provider if you previously had an allergic reaction to any product containing Factor VIII (FVIII), or have been told you have inhibitors to FVIII, as AFSTYLA might not work for you. Inform your healthcare provider of all medical conditions and problems you have, as well as all medications you are taking.

Immediately stop treatment and contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against FVIII, which could stop AFSTYLA from working properly. You might need to be tested for inhibitors from time to time. Contact your healthcare provider if bleeding does not stop after taking AFSTYLA.

In clinical trials, dizziness and allergic reactions were the most common side effects. However, these are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

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 the following brief summary of full prescribing information on the adjacent page, and the full prescribing information, including patient product information, at AFSTYLA.com.

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AFSTYLA®
Antihemophilic Factor
(Recombinant), Single Chain