Hemophilia Federation of America™

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DATELINE FEDERATION

Celebrating 20 Years of a Strong Grassroots Community!

DON'T MISS

Dear HFA Friends and Family,

Thank you for taking the time to invest in reading the first edition of *Dateline Federation* this year! We hope you get a lot out of this issue and that you keep reading throughout the year.

2014 is a milestone year for HFA. This year we celebrate our 20th anniversary and are deeply honored to still be here serving you! When a milestone like this comes along, reflecting on the years gone by is very natural. Our past is not an easy one; we were founded during some very difficult times in our community to provide voices for families who were not being heard. Our mission to assist and advocate for families with bleeding disorders remains the heartbeat of the organization.

As time passes, our community's need for awareness remains the same. Issues are different today than they were in the past, but issues and concerns remain.

"The time for action is now. It's never too late to do something." *~Antoine de Saint-Exupery*

We do not have the worries of HIV and HCV contamination like our community did in the 1980's, however we must continue to monitor and fight for what we need at all times. Access to the physicians that care for our family's and the pharmacies that provide our medication is not assured, and specialty tiers are placing high cost burdens on some families. As many new products emerge and begin to change the landscape of bleeding disorders medication, 30% of the hemophilia community are still forming inhibitors. The list goes on.

Frankly, there is a lot happening and we hope you are paying close attention to the changes and how they are impacting you and your family personally. At HFA, we encourage you to be involved, proactive, and engaged!

In an effort to keep bringing awareness of issues at hand, HFA pledges to continue to bring tools and resources like toolkits, issue briefs, Dear Addy, and other support through our advocacy and programming activities. Let's keep working together!

Warm regards,

Matthew T. Compton
Board President

Kimberly Haugstad, MBA
Executive Director

MISSION
The Hemophilia Federation of America is a national non-profit organization that assists and advocates for the bleeding disorders community.

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DISCLAIMER
The material provided in *Dateline Federation* is provided for general purposes only. HFA does not give medical advice or engage in the practice of medicine and recommends that you consult with your physician or local treatment center before beginning any form of treatment.

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TAKE ACTION

YOUR TOOLBOX

Tools for success

By Katie Verb

Specialty Tiers? We're Here For You!

As many of you know, tiering is a cost-sharing strategy employed by insurers that places drugs into groups called "tiers" based on criteria determined by the insurer. A three-tiered drug formulary is traditionally used by many prescription drug plans. These tiers have fixed co-pays—for example, a $10 monthly prescription refill for a generic drug. For drugs in specialty tiers, however, instead of requiring flat rate co-pays, insurers often require patients to pay a percentage of the cost of a drug. This is known as co-insurance. Specialty tier co-insurance rates can vary from 20% to 50% or more.

The most common drug tiering structure used by insurers categorizes drugs in the following way:

Tier I
Generic Drugs, typically the lowest, flat rate copay

Tier II
Preferred Drugs, typically a medium, flat rate copay

Tier III
Non-Preferred Drugs, typically a higher, flat rate copay

Tier IV or Tier V Specialty Tier
Unique, high cost drugs, patients charged coinsurance percentage of cost

Are you finding that your factor is being placed on a specialty tier within your prescription drug plan? Is your prescription drug plan charging you a percentage of the cost for your factor? If so, this issue greatly affects you. On a national level, HFA is deeply involved with coalitions that advocate for *HR 460, The Patient's Access to Treatment Act*. HR 460 would limit the amount that can be charged for drugs placed on specialty tiers. However, many states are developing their own legislation to combat the issue.

If you live in a state that has pending legislation regarding the use of specialty tiers in prescription drug plans, HFA is here for you! We have posted tools, briefs, and talking points on our site to help you in your local fight against specialty tiers, and we are always just a phone call away to help you advocate for your community!

We want to know about the insurance challenges you face!

When you or a family member is denied coverage of a service or payment for a service, or learn that a provider is not covered by your insurance plan, you need a remedy FAST. The bleeding disorders community is fortunate that help is often available through a variety of organizations. These organizations can give you access to a limited supply of drugs, pay an insurance premium or out-of-pocket cost, or provide other needed assistance. It is great help if you can get it!

However, it is important that your insurer hears about and understands the problem you experienced. Until an insurer knows a particular policy creates problems for individuals with bleed-

ing disorders, and until there is a record of the pattern, it is very difficult to work on a solution. The goal is to educate the insurer so steps can be taken to improve policies for the future. Doing so will not only help you, but others who experience the same situation.

One way to get on record and advocate for your needs is to file an appeal and/or grievance with your insurer.

Grievance = To express concern or disagreement with some aspect of your coverage or how you were treated.

Appeal = An attempt to get a different result to a decision that your insurance company has already made about your care, payment, service limit, choice of provider, etc. Appeals generally must be made within certain time frames.

Please tell HFA about your experience with a denial of service or denial of payment for a service and what you did about it! While we cannot file an appeal or grievance on your behalf, we do monitor denials of services and payments happening across the country and advocate on the community's behalf to make these denials a thing of the past! ▪▪

Your Voice, Be Heard.
http://appeals.hemophiliafed.org

TAKE ACTION

1. Learn about Specialty Tiers
2. Share Your Story
3. File a Grievance or Appeal

Visit **www.hemophiliafed.org** for more information!

SUMMER INTERNSHIP

Apply for our summer policy and advocacy internship!

Apply today at **www.hemophiliafed.org**

HFA Hemophilia Federation of America

The Next Generation of Leaders

AFFIRM (Adult Fellowship for Integrating Responsible Mentors) is a three-year leadership development program targeting men ages 25 to 35 from around the world. In its second term, ten men have demonstrated dedication and leadership within their local community to improve the lives of those with a bleeding disorder (see list below). Twice a year, the men in AFFIRM are introduced to key stakeholders to help better understand how the community functions, and provides services to those affected by a bleeding disorder; while at the same time learning about and enhancing their own leadership skills. The information and resources obtained in training are then taken back to their local chapters, foundations, and national member organizations as helpful tools in developing their own programming germane to the needs of their communities. In the next several editions of *Dateline* you will learn about some of their experiences as they travel and meet different leaders of the bleeding disorders community!

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AFFIRM Adult Fellowship for Integrating Responsible Mentors

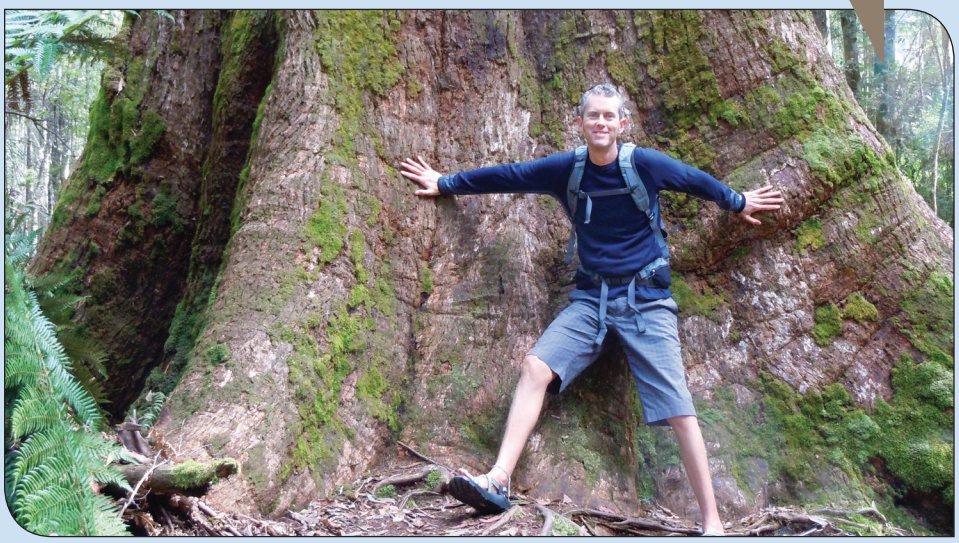
Food for Thought

By Joe Walsh

One of the most important things you can do for your health is to maintain a proper diet. What you put into your body affects how you look and feel. Maintaining a healthy weight is especially important for individuals with a bleeding disorder. Being at a healthy weight can reduce the number of bleeding episodes you experience, and eating healthy foods can help you build strong muscles, keep your bones healthy, and help you recover faster from a bleed or when you are feeling sick.

In this article, Joe Walsh, a blood brother from Pennsylvania, shares his motivation, experience, and success with a healthy style of eating that works for him and his family. Do the foods you eat help you to feel great physically and emotionally? Is it time to start making changes in your own diet? Here is some food for thought...

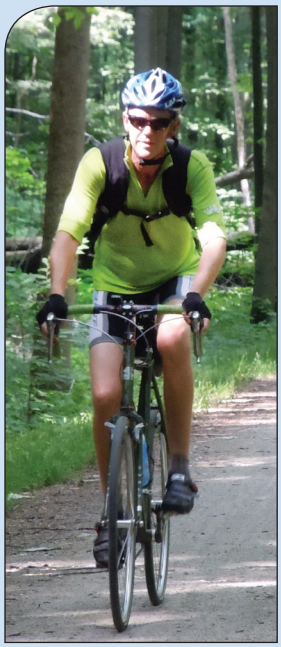
I received my liver transplant in 1996 after thirty-two years of living with severe Hemophilia B and Hepatitis B. It is the gift of life for which I am thankful every single day. But thirty-two years with hemophilia had really taken a toll on my joints. In fact, I had already had a total knee replacement on my left knee in 1992 and an arthroscopic clean out of my right ankle in 1995. After my liver transplant, I was much more circumspect about my overall health. I was able to remain healthy by getting plenty of sleep, making sure I ate the "right" foods, and getting what exercise I could tolerate without being laid up for a few days with excruciating pain in my "crunchy" ankles and rickety right knee.



About two years after my transplant, I started to really be aware of my digestive system since it didn't seem to work like it had in the past. I used to mention it to the doctors, but I thought it was a small price to pay for not being dead. It was an ongoing, but not debilitating, part of my life. My doctors thought there was nothing really to be done, but it did leave me with questions about the possibility that it was food-related. In 2004, I had my right knee replaced and, after an intense rehabilitation, I was able to ride my bike again for the first time in about fifteen years. I was still in pain, but rode as much as I could tolerate because it was one of the few things I could do that did not make my ankles scream.

In 2006, just before her seventh birthday, my daughter was diagnosed with type 1 diabetes. After a lifetime of grappling with hemophilia, I had to develop the same level of mastery over diabetes—the understanding and management of which are entirely about metabolism and food. Careful thought must be given to every single thing that goes in your mouth because it all has an impact. The deeper I got, the more I realized that conventional nutritional wisdom doesn't hold up. Almost all of the mainstream nutritional information is not based on sound science. Some things have been repeated so often and for so long that people simply assume they are true. Here is what I know.

The calories in, calories out model—or the energy balance model that we have learned—is not the way to monitor your diet. It presupposes that all calories are treated the same by your body. Peer reviewed science has found that this is not the case. All calories are not equal.



I JUST TURNED FIFTY, AND I HAVE NEVER FELT BETTER.

So, if that paradigm is wrong, what can you do? The main factor to consider is how the body uses fuel for energy. In order to see how this works, you have to understand a bit of the science of metabolism. Your body needs to burn food for fuel. While It prefers to burn fat, it can only do that in the absence of carbohydrates. Because your body was not designed to deal with carbohydrates (other than vegetables), it burns them first to get them out of the system. Your body "sees" all carbs the same: "healthy whole grains," soda, potatoes, candy bars—it doesn't matter. They all throw your metabolism out of balance, causing you to gain weight and promoting inflammation. This, as a hemophiliac, is where I took notice, because I know all about inflammation. My chronic pain and inflammation made me wonder how that would be affected by a dietary change.

What I discovered is that reducing carbohydrate intake is a key component to reducing the chronic inflammation (pain) and weight gain that most of us see as an inevitable part of life. One of the most important carbs to avoid in our diets is wheat. Recent science has begun to pinpoint that the gluten/gliaden proteins found in wheat (and several other grains) cause a wide range of inflammatory responses in the body. Rashes, skin problems, arthritic symptoms, headaches, and digestive issues can all be manifestations of the body's underlying intolerance to this ingredient that the body does not see as "food." Removing wheat from my family's diet had the most immediate and dynamic impact of any of the changes we have made.

What my family and I have been eating has had a profound impact on our health and well being. It is relatively simple and could work for everyone. We eat well-sourced animal protein (grass-fed beef, fish, pork, game meats, lots of eggs), heaps of healthy fats (coconut oil, butter from pastured cows, lard, olive oil, duck fat, etc.), and all the non-starchy vegetables we want. That is it in a nutshell. We eat a lot of nuts too, but not peanuts, as they are actually legumes. We do not eat grains, industrial oils (canola, safflower, peanut, corn) or legumes.

This way of eating has been a boon to my diabetic daughter. Her blood sugar is well controlled and she uses much less insulin. For me, the change has been nothing short of remarkable. While my ankles still bother me, my thoughts of ankle replacement are gone. The digestive issues that plagued me have all but disappeared. While I am a huge fan of what medical science has done for my health, I have been amazed at what such a simple change—not endorsed by mainstream science—has done to improve my daily living.

This past May, I had my third knee replacement. My left knee replacement had worn out, due in part to my increased activity level. Three months to the day, I was back on my bike, and I feel good enough to ride almost every day. I just turned fifty, and I have never felt better. ■■

Joe Walsh was born and raised in Philadelphia, but has spent many summers attending, and later working, at Camp Bold Eagle in Michigan. He had Hemophilia B for 32 years, until his liver transplant in 1996. He now spends his time studying the science of nutrition and metabolism, riding his bike, cooking, and spending time with his wicked awesome family.

*While extensive efforts are made to ensure accuracy of the content of each FitFactor article, these entries are not intended to be construed as medical advice or the official opinion/position of HFA, its staff, or its board of directors. Readers are strongly encouraged to discuss their own medical treatment, diet plan, and physical activities with their healthcare providers.

Project RED: Reaching Everyone Directly

By Lori Long and Jill Packard

Jill Packard, MS is the mother of two sons, ages 6 and 9, who have Hemophilia A. Jill is most passionate about her family, connecting people, and building sustainable communities. Founding and current President of the Hemophilia Alliance of Maine, Jill is also passionate about supporting rural communities where she attempts to shine a light on health care equity disparities.

Lori Long lives in the Southwest and has Hemophilia B. She is also raising a son (age 10) with Hemophilia B. She is passionate about building community and believes strongly in community strength making a difference in the world (even if it's just her little corner of it). Her interest in serving rural communities stems from the number of blood brothers and sisters she has in her area who live without phone, Internet, and even water service. Her interest in serving in general is inspired by her father, who died at the age of 68 from a head bleed due to a lack of access to factor.

A word that we hear frequently right now is "access"—access to quality care, resources, education, community, and other people affected by a bleeding disorder. Our Blood Brothers and Sisters everywhere have these concerns.

The recent rise in the number of bleeding disorder organizations around the country (4 new chapters and member organizations) in the last 5 years is clear evidence that there are issues with access to care. Stories and experiences that those of us without easy access to the community share are further evidence. How many of us have heard of someone in the community who thought they were the only one out there like them, living alone with their bleeding disorder? Some have not even been diagnosed until much later in life.

In response to our bleeding disorders community's demonstrated need, we formed the Care Access Working Group (CAWG) in February of 2013. Working alongside the CHOICE Project, the CAWG is finding ways to give voice to the under-served and support our member organizations' efforts to serve everyone directly.

Our merry band of advocates originally set out to serve our Blood Brothers and Sisters in rural areas, but by the end of our first call, we realized that those in large cities have many of the same issues. So we created our first initiative, which is called Project "Reaching Everyone Directly" (RED).

Our mission is to identify solutions to the lack of access to care and connection to community experienced by all members of the bleeding disorders community, focusing on rural members. We will be accomplishing our mission through the following actions:

- **Research the impact living in rural areas poses on members of the bleeding disorders community.**
- **Find means of access to care, education, and other support through community-based mechanisms that increase empowerment, efficacy, and community.**
- **Create a national network of support for those living in rural communities.**
- **Work to establish an "ombudsman" system for communicating with HTCs when needed.**

We went to various communities looking for personal stories and have published some highlights here. Look for more in upcoming issues of Dateline (names and locations have been, and always will be, changed to protect privacy). One way that you can help is by sharing your access stories, both problems and successes, with CAWG so that we can start a dialogue and, together, support each other and ensure better access for all! ■■

EVA and ELI

Living "out in the middle of nowhere" definitely has its positives and negatives...especially when you are a family living with hemophilia. Our 6-year-old son, Eli, was diagnosed with hemophilia A at birth, at a hospital that was 3 hours away. The whirlwind of emotions was overwhelming those first few days. On the drive home, as we got further and further from those doctors and nurses with their years of hematology experience, the panic set in. How can we do this without daily help? What if something happens? What if Eli needs factor? Has the hospital at home even HEARD of hemophilia? How will we know if he has a bleed that we can't see or feel?

Eli's first few months seemed pretty "normal." But once he started crawling, the hemophilia really manifested. He had bleeds from high chairs, head bonks, and, of course, bruises and bleeds that just occurred without explanation. That's when the emergency room (ER) visits started. And finding a vein on Eli was like trying to find a blond hair in a sea of milk.

Our first few trips to the ER were not fun. There were lots of questions about his bruises, lots of blown veins, lots of confusion, and lots of tears (from both Eli AND his mom, Eva). Each time we went in, we got a different doctor...a different nurse...and a different "protocol." It was incredibly frustrating. And of course, everything seemed to happen at night... during our HTC's "on-call" hours.

After a few months, we decided that we would call the shots at our local ER. We also decided to no longer have an "us against them" attitude. We used each ER visit as an opportunity to teach the staff. We told them about previous ER visits—what worked and what didn't. We would ask about their family, and we made a point to get to know them. Over the next year, we became a team. We would call ahead to the ER to give them a heads-up. Soon, we realized that we knew the staff, and they knew us. They have watched Eli grow over the last 6 years, and, as funny as this may sound, the ER is now a place of comfort for us. The feeling we get when we walk in, and they give our son high fives, know which room he likes best, hand him the remote control before he even asks, and remember that he likes the purple popsicles is just...good.

> Living in a rural area **does not have to be scary** when it comes to treatment for your child.

Living in a rural area does not have to be scary when it comes to treatment for your child. Be an advocate for your son/daughter, and team up with your local ER. And do not be afraid to get to know them. Often, they are who you see for bleeds that need extra attention. You just might be surprised how comforting the ER will grow to be. ■■

LUCY

Lucy was diagnosed with vWD at the age of 18. Her mother was diagnosed at the age of 32. At the time, they both lived in a big city. Late diagnosis is problematic because so much damage can already be done to joints from years without treatment. By the time she was 24, Lucy was living in a rural area and finishing up medical school. She was having complications with bleeding despite treatment. Her doctors chose to stop treating her vWD rather than looking for an additional cause of bleeding because the treatment wasn't working (so they thought she must not have vWD after all). Instead, they put her on pain medication, which caused her to be accused of being "med-seeking." The lack of treatment caused a great deal of joint bleeding, which led to severe arthritis and 782 days of physical therapy. In the end, she found a specialist who figured out that she had a rare platelet disorder in addition to vWD. ■■

...continued on page 12

JANIE and JOE

When members of the hemophilia treatment center (HTC) behave erroneously or unethically, there is no one to file a complaint to that could cause a change in behavior.

When my son was born, I felt unsure about blood transfusions. Because members of the HTC team disagreed with my reservations, I felt isolated and likewise, the HTC felt that I was incapable of parenting a hemophiliac. There was no one to "translate" my concerns to them. When a child's life is in danger, neither the parent nor the doctor really wants to gently convince the other on the best course of treatment. Neither side is willing to do the most important thing: reason. The result? Both sides get angry.

Because I didn't feel heard, I was angered by anything that had to do with the HTC, and, as a result, limited visits there. Then, one day the HTC social worker invited me to a parenting class. All barriers to attendance were removed (e.g., childcare, transportation, food, and lodging were provided for free).It was a non-judgmental atmosphere where I learned much more than how to raise my hemophiliac son better. I learned what the HTC thought about me and about parents in general. It was not always what I'd assumed. They were concerned about my skills as a parent because I didn't articulate well to them what my thoughts, predicaments, and plans were. To this day, I believe that there are times when this HTC can be more likely to ignore the parent. But this is only because they *lack access* to the true desires of the patient for one reason or another.

I knew Joe had an inhibitor long before he was diagnosed by the HTC. Despite several trips to the HTC, they didn't want to test him for inhibitors. He got worse with each visit. He almost died three times. Here's why:

1. I had no access to education on inhibitors. I had no one to talk to about this besides the HTC team, who felt that I did not need information on inhibitors.

2. I had no words to explain what I really felt to a medical team.

3. I wavered in getting my son the treatment he needed and doubted I had the right to do so.

4. I felt that I owed the HTC the right to tell me how to treat my son because they'd saved his life. They'd saved his life several times. I felt a sense of loyalty to them that caused me to ignore what I knew and follow their conclusions to an extent.

5. I didn't know about the Bioethical Committee. I thought that the HTC was the end of the line for complaints.

I researched inhibitors all I could and slowly became sure that Joe had one. During HTC visits, they would check Joe by touching his injuries and documenting his response or lack thereof. I saw him trying not to show pain. They thought he was pretending and not responding to what was supposedly hurting him. I described bruising. They said that they didn't see it, so they weren't sure that it was from hemophilia. I took pictures, which got us into the exam rooms again. Nurses would "check" Joe and say things like, "Maybe you should take his video game access away and he'd feel better," or, "He's probably having issues with wanting to go to school, that's all." This environment made me defensive.

After weeks of this, we were there after-hours for physical therapy, and Joe needed a wheelchair. Knowing there'd be one in the HTC, I stopped by. The lights were on, so I went in and saw a hemophilia nurse. I literally begged her to look at my son and to test for an inhibitor. Previously, when under review, the swelling and bruises didn't show because I had been treating him *frequently* for bleeds—unknowingly making the inhibitor stronger. I'd now been reduced to allowing him to swell on HTC visit days so that I could have a better chance of having *proof* that what I was seeing was real. I swear to you, just writing that breaks my heart. It's oxymoronic: I had to allow him to hurt to stop him from hurting. Still, I was thankful that I'd done that on this day. That nurse stood looking in awe at the bruising and immediately drew Joe's blood.

The next day, Joe couldn't walk. Skipping factor for one morning the previous day had caused so much pain that he couldn't sleep, so I gave him a treatment that night. It seemed to have not worked well after an hour or so. Because of his consecutive days of not eating and sleeping due to his fear of causing or aggravating a bleed by having to use the restroom, I was worried and called the clinic. Again, they saw nothing.

Then they had an *official* meeting with me. I sat with specialists and medical personnel as they said that it was highly unlikely that he'd have an inhibitor because he was moderate (1.6% factor), and my father never had an inhibitor. They thought I was being duped by my son. For weeks I hadn't slept for more than an hour at a time. I was at the end of my rope. My whole body shook, and I yelled responses throughout much of the conversation. I explained that my father never even received care until he was 30! I knew inhibitors were transient from my personal

research and told them that they had no way of knowing whether my father experienced this or not. They stated that there was no *physical* problem and even intimated that Joe was being abused either sexually or physically. I don't remember exactly what happened after that. I remember indescribable feelings and rushed thoughts and police. And shame, seeing personnel scatter as I slammed open the door to find huge guys with guns and handcuffs. I remember being escorted by security into the lobby of the HTC, where my son was playing with toys, and the doctor (who had kindly watched my son during the meeting) trying to be polite to me. Joe showed no signs that he knew what was happening, and I was grateful for that.

When I got home, I felt more fear because I thought that they might let Joe die—that *I* might let him die. I knew I would not survive this loss. I had already lost children, but those deaths were sudden. Though I still experience guilt, I know that it is irrational; I had no time to save them. But I had time to save *Joe*—months. And if *he* died, there would be no reasoning the guilt out of my mind. I had no idea of what to do next.

Shortly after I treated him again (which didn't help), the HTC nurse who had secretly done the inhibitor test called me. She said that Joe needed to come back in. Just minutes after that, *another* nurse called and said, "The doctor says that she really heard your plea, and she's changed her mind. She wants to test Joe for an inhibitor." It was like a weight had been lifted. He would survive! But I knew the real reason we'd received that sudden call and why the doctors had had a sudden change of heart: that first nurse had tested his blood *already*, and he had *already* been diagnosed.

On the way to the HTC, I thought, what if it's not an inhibitor? I wanted a solution! If it was an inhibitor, I knew that they would know what to do. It was, and they did. And in 4 months, we were clear of our inhibitor. The HTC never admitted that they were wrong and they never apologized.

Many of these problems could have been solved through access to education of inhibitors, access to understanding of patient rights, access to HTC ethical commitments, and access to proper/useful communication techniques.

Janie and Joe's story (yep, there's more) will be continued in our next article! ■■

Supportive Dad With Creative Solutions

By Ron Mell

What is a father to do when he has grown up with an intense needle phobia and now discovers his first-born son has been diagnosed with severe hemophilia?

Well, in the Mell home we got very creative. Our family has always made it a point to face our daily struggles as a complete unit, relying on each family member's strengths to help guide us down our path. I have always been the "fixer"—if something was broken, incomplete, or out of order, my kids and wife expected me to fix it. As most of you are aware, you can't "fix" the bleeds, pain, or sadness associated with hemophilia. We sometimes see all those things in our son Tristan's eyes, but we treat proactively to do our best to avoid the bad times.

For the first several years, we worked as a team, infusing via port-a-cath. Kendra, my wife, infused while I distracted Tristan and encouraged mom. As time went on, and I got more "comfortable" with taking on the task of infusing, Kendra and I would "tag team" when it came to port infusing (as we do with most of our everyday tasks).

Tristan decided after six and a half years he wanted to be port free, so we had to face a new challenge: learning how to poke a vein. It doesn't matter how many veins you practice on, fake arms' or friends', your spouse's or your own—none of that prepares you for learning to stick your seven-year-old son's veins.

During this process, we discovered that there was not one tourniquet that Tristan was able to release easily. I wanted to help more with Tristan's medical treatment. It hurt not being more involved. So, I decided to be what I had always been: supportive. And in being supportive, I found that I had a new position! A loving supportive father can provide the right amount of pressure in the right places to make those veins juicy and easier to stick, and I can gently release the pressure when needed. I became the tourniquet that never failed. As Tristan notes, "Factor is Fun, but with my dad being the tourniquet, it makes PUMPING UP veins!"

Vein infusions are still a work in progress for me, but knowing that I am helping and making a positive difference in my son's medical care is very encouraging for the whole family. Tristan loves having mom, dad, and even his little sister working as a team to make each infusion just a little easier on everyone. Tristan has started

learning how to self infuse. He has seen my emotional struggle through this process. I feel that allowing him to see me overcome this hurdle has empowered him to know he can and will be as successful as his father; not just in his infusions, but in all situations he faces throughout his life. ■■

Ron Mell grew up in Ohio and moved to Texas in 1996. He has been married to Kendra for 14 years. Seven years ago, they were blessed with a wonderful son, Tristan. Tristan was diagnosed with severe Hemophilia A at 5 months old. They also have a darling and energetic five-year-old daughter, Kiernan.

> "Vein infusions are still a work in progress for me, but knowing that I am helping and making a positive difference in my son's medical care is very encouraging for the whole family."

Tips and Tricks for Smoother Infusions

Peripheral Sticks

Get Hydrated: Drink water. Then drink more water. Make it silly—try fun straws and fun cups. Your child doesn't want to chug liquid? That's okay—popsicles are also a great way to hydrate.

Hot Towel Treatment: Wrap your hand and lower arm in a hot, steamy towel for about 20 minutes before you poke. This helps the veins to be very visible.

Swing High, Swing Low: Swing your arms up and down to increase blood flow. You can also dangle your arms low.

Too Tight: Don't tighten or tie the tourniquet too tight (or for too long—generally not for longer than a minute). It can create too much pressure in the vein and make it easier to "blow." Sometimes using a blood pressure cuff is better than the tourniquet. Or you could try double tourniquets.

Sight and Feel: Ask friends and family members to let you feel for their veins and learn to find veins by touch on your own arms. Don't just look, feel. Sometimes the very best veins aren't visible to the eye.

Check Your Angles: You may be going right through the vein. You only need to insert the needle tip just within the vein. Shallow out that angle. Select the smallest gauge needle you can use. Position the catheter tip bevel up. Approach angle to skin at 10–15 degrees, as if imagining the needle is an airplane landing on a runway. Deeper veins need a greater angle. Superficial veins require a lesser angle. Lower the angle once blood return is observed. Remember, the whole needle does not need to be in the vein!

Tap, Tap: Apply the tourniquet. Lightly tapping the skin or area where you see veins will help expand the vessel.

Stroking: Stroke the vein toward the hand so that the blood flows through the vein, helping you to spot a vein.

Pump, Pump, Pump It Up!: Have your child open and close his/her fist while you are looking for a vein, but then have them keep the arm relaxed during venipuncture. Sometimes it is helpful to squeeze a squishy object, like a stress ball.

Palpation: Apply the tourniquet. Use your index finger to palpate the veins. Press directly on the vein with your index finger, assessing for vein softness and volume. Then release the pressure slowly without lifting your finger and feel the vein bounce back to your index finger. Repeat often to ensure you have found a suitable vein. Don't stick without palpating the vein!

"Mark" the Spot: Palpitate for the vein, and don't move your eyes from the spot. Then wipe and put the alcohol wipe in a diamond shape so a corner is pointing right where the vein is.

Anchor Away: Once you've decided on the exact point of entry, get in the habit of placing a thumb a few inches distal to the site and pulling traction. Pull harder than you think is necessary. You're trying to anchor down all that flesh and eliminate the possibility of movement. All veins roll.

Practice, practice, practice.

Let it Go: Give yourself permission to fail sometimes. Nobody gets every poke, every time. When it happens, pull out the needle and apologize, "I'm sorry, that one didn't go where we needed it." Then start looking for the next site. Advice from an EMT: "Once you drop that failed needle in the sharps box, forget about it. The previous failure has no bearing on your next attempt. Don't let it haunt you... your last IV attempt is already in the history books. The next one is still a question mark. That makes the next one immeasurably more important. Go get the next one."

Patience is a Virtue: Take the time to find and assess veins. Some veins are located deep. Veins won't change position just because you are in a hurry.

Take a Deep Breath: Both you and your child! Let them know when you are ready to stick and tell them to take a deep breath and blow it out slowly. This will distract them from the stick and help the tension in their arm.

Making the Procedure Easier, No Matter How You Are Infusing

Numbing Creams/Cold Sprays: Many people use a numbing cream such as EMLA or Ela-Max. Prescription PainEase cold spray seems to help some. Most creams work better if they are on for about an hour. A word of caution about numbing creams: they can make the veins compress and flatten out due to the constriction effects from the active ingredients, so if you or your family member have very difficult veins, numbing cream may not be a wise option for you.

Sticker Charts/Prizes: Your child may enjoy placing the sticker on the chart after each infusion. You could give him or her a special treat after so many successful infusions. You know your child, and you can work together to find what special treat works best. Other families choose not to reward for pokes—do what works best for you.

Routine and Distraction: Watch a movie to distract little kids or let them indulge in some screen time to help ease anxiety. Fun fact: If you pop a VERY sour candy in your mouth right at the time of the stick, the brain focuses on the sour sensation and reduces the nerve response at the site of the pain. Strange but true! Keep your routine fairly constant—kids thrive knowing what to expect.

Be Honest: Don't say, "This won't hurt." Needle pokes hurt—they aren't fun, and when you say it's not going to hurt and then it does, your child loses trust in you and the process increases their fear and anxiety. Be matter-of-fact. It's totally okay to say, "This is going to sting a little," or "Let's count to five together and the poke will be over by then."

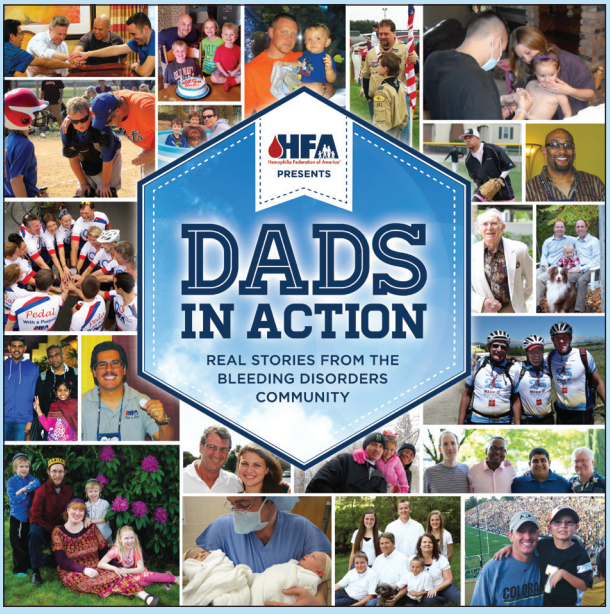
Don't Expect Bravery: It's okay for kids to cry, it's okay to be angry that this is happening, and no one can always put on a brave face. Tell your child that showing feelings about the situation is okay, but throwing tantrums or refusing to do it is not. Let them know the infusion has to happen and it's going to be a lot easier if everyone cooperates.

Let Them Ask Questions: If they have concerns, talk through them BEFORE the stick or procedure.

Kids Follow Your Cues: Be matter-of-fact. Don't increase their anxiety by feeling sorry for them and worrying over them. Focus on getting it done.

Praise 'Em When They are Good (And Even When They Aren't): It doesn't matter if it went spectacularly or horribly, tell your child "Thank you" and "Good job for trying," every time. If they could cooperate more or do better, let them know if there was improvement from the time before, and then tell them how much they improve each time. If it was just a bad day, let them know they did great, especially since it was a particularly tough day.

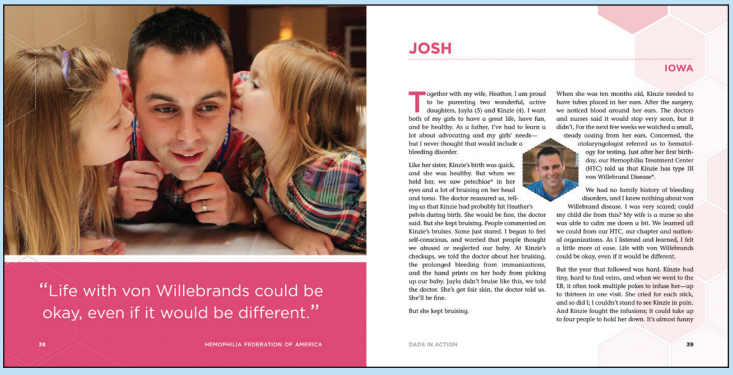
Give Yourself Some Credit: This is HARD! You did it. You and they got through it. It can be just as stressful on us as it is for them. You'll be able to do it next time too.



A NEW one-of-a-kind book dedicated to all dads in the bleeding disorders community!

Become a Dad in Action and get a copy today!

http://dads.hemophiliafed.org



A Carrier Seen Through a Father's Eyes

By Trevor Ekema

Having hemophilia is an interesting challenge for an individual. Throughout my life, I have tried to learn as much as I could about this condition and find a way to overcome the adversities it often presents. I thought I had this thing down to a science, but I had no idea what to expect as the father of a daughter who carries the hemophilia gene.

When my wife Tori and I first learned we were having a baby, we were excited and scared like any new parents, regardless of hemophilia. I knew the basics, like how someone with hemophilia passes down the gene to their kids through the chromosomes. As a hemophiliac, I knew that having a boy would mean removing hemophilia from our family tree, but having a girl would mean that she would be a carrier. Like many new fathers, I hoped to have a boy for two reasons: first, to stop the hemophilia in our family tree, and second, to have someone more like myself to help teach and grow into a young man. I hoped to have someone to do "boy things" with like playing sports, getting dirty, going to the beach, and so on. However, after we found out we were having a girl, I realized how I was thinking about it all wrong.

For the most part, I do not treat her any differently than if she was a boy (she is so funny and has such a cute little personality that makes it hard not to love her all the time). I encourage her to do all of the things that she enjoys and let her pursue her passions. She plays soccer, golf, dances, and even does gymnastics.

Tristan, who is now four years old, knows her daddy has hemophilia and has to give himself shots every so often. She is still too young to understand what being a carrier means, but she tells everyone that she has the hemophilia gene (which is pretty cute). At first, I was scared that she might exhibit some bleeding or bruise easily like her Grandma (my mother). Thankfully, we have not seen that thus far, but I know we still have a long road to go as she grows up, gets married, and starts to have kids.

My hope is that by the time that she has kids (30 years from now!) there will be far more advances in treatment and technology—**maybe even a cure**. I've accepted that if she decides to have kids, there will be a 50/50 chance of her son having hemophilia. I worry about this, but I also know that it's out of my control if this were to happen. If it were, I would be able to give him advice and support as someone who really gets what it's like to live with a bleeding disorder.

One of the positives of hemophilia is the community. I have learned so much about compassion, care, and strength growing up in this strong community. I would not be the person I am today if it wasn't for the people who create advocacy groups, educate through symposiums, and foster the spirit that the bleeding disorder community has had for years. A big challenge

> "When I look at my sweet four-year-old girl, I hope that she will not see hemophilia as a challenge, but instead as an opportunity to **grow**, **learn**, and become **a better person**."

for me was learning to self-infuse. It was one of the scariest things I have ever done. With the help and encouragement of great friends, I was able to learn a skill and overcome a challenge I never thought I could. I'm excited for Tristan to be involved in this community as she grows up and meets more of the people that have helped me become who I am.

It's not easy being a father of a daughter who is a carrier of the hemophilia gene. However, when I look at my sweet four-year-old girl, I hope that she will not see hemophilia as a challenge, but instead as an opportunity to grow, learn, and become a better person. ■■

Trevor Ekema has mild Hemophilia A and currently lives in Texas with his wife Victoria and 4-year-old daughter Tristan. Trevor has attended hemophilia summer camp since he was 7-years-old and is now a counselor at camp in Texas. Trevor was part of NHF's NYLI (National Youth Leadership Institute) and is currently a mentor of the Big Brother, Big Sister Program.

Thank You!

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The Unexpected Financial Burden of Bleeding Disorders

By Lauren Neybert

When a family receives the diagnosis of a bleeding disorder for their child, the news can be overwhelming—especially for those without any family history of a bleeding disorder. While there are certainly physical and emotional challenges to living with a chronic condition, financial struggles can also abound due to missed wages from work, unexpected costs from long hospital stays, and high medical bills.

In January 2014, Helping Hands received a referral for a young family with a three-month-old with severe Hemophilia A with inhibitors. After their son's circumcision, he experienced excessive bleeding and had to be air lifted to a major health care facility, as their local hospital was not equipped to help their young son. Due to his son's hospitalization, the father missed three weeks of work. As the sole income earner in the household, this was a major financial setback. Shortly thereafter, it was discovered their son had developed an inhibitor. In order to help with his infusions, their son had surgery to implant a port. The father missed an additional ten days of work, and the family continued to make routine visits to their treatment center for follow-up care. The loss of income coupled with the additional expenses of transportation, parking, and food during the hospital stays, left this family with concerns over making their upcoming rent payment. Thankfully, their son's bleeding was becoming better managed and the father was back at work, but the prior loss of income still posed a financial burden.

Helping Hands was able to assist this young family with their upcoming rent payment and support them during their temporary financial crisis. With plans to seek alternative employment offering higher pay, as well as additional financial resources, the family was on their way to getting back on track.

HFA's Helping Hands program is designed to establish a rapid, non-invasive source of relief for emergency situations or urgent needs to persons who are affected by hemophilia or von Willebrand disease. Each year, Helping Hands aids hundreds of families with emergency/urgent funding to assist in crisis situations such as housing, transportation, and utility bills. Additionally, Items Reimbursement assists families with medically necessary items and durable medical equipment. Learn more about Helping Hands and Items Reimbursement at **http://assist.hemophiliafed.org**

In 2013, Helping Hands and Items Reimbursement served over 275 families. You can help keep our community's safety net intact! Become a member of HFA and support bleeding disorder families in need! ■■

What the community is saying about Helping Hands:

"Thank you and God bless you for your services!"

"Thank you so much for taking the time to help us."

"I want to thank you for assisting me with my rent. I had to take off work for close to two weeks because my son had to have a port placed. This helps me a great deal."

"Thank you for your consideration and assistance regarding my financial situation that has been onset by hemophilia."

"I was unable to pay my rent this month due to medical issues. I am so appreciative of this, it's such a massive help, so thank you again."

"I want to thank you for everything your organization has done to help our family during this difficult time."

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HFA

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Gears for Good is a charity bike ride offered by HFA to raise funds for it's one-of-a-kind assistance program, Helping Hands. The West Virginia to DC ride has been a success since 2011. Riders that have participated enjoy meeting new people, building strong friendships, and raising funds for this important cause. In 2014, we are adding a regional ride in New England!!! Be part of the fourth annual ride in DC or the first annual Gears for Good charity bike ride in New Hampshire!

Learn more and join us for an incredible experience!

www.hemophiliafed.org

Every Person You Meet is a Chance to Change the World

By Ashley Druckenmiller

65

"Infusing Love"

entries since February 2013

Follow us on Facebook for a new posting each Wednesday!

As I sit in the Palm Springs airport waiting for my flight back to the frozen tundra of Iowa, I can't help but think about how many other people in the airport might be affected by a bleeding disorder. Or, what if all of them had hemophilia, spent tens or even hundreds of thousands of dollars on clotting factor products per year, and had no choice of where to get their factor from? Or what if the guy sitting next to me has hemophilia and for years he went without health insurance just hoping he wouldn't get a bleed? Those are just some of the many things I think about when the word "awareness" comes to mind.

March is Hemophilia Awareness Month. When I think about how hemophilia has impacted my life, there really are no words to describe it. I am an only child born

to loving parents in a very small town in rural Iowa. In our hometown, my dad was the only person with hemophilia and, in the early 1980s, he was one of very few people affected by AIDS. He passed away when I was three years old, and for the next nineteen years, the only time hemophilia came to mind was when I would share my father's story. The only thing I knew about hemophilia was that it meant my father's blood did not clot properly.

My first born child was seven months old in the fall of 2006, and he became irritable and unwell. After four days and four different doctors telling us over and over again, "You are first time parents, babies cry sometimes—take him home and he will be fine," our sweet baby boy had stopped moving his entire body. In a twenty-four hour whirlwind we were told, "Your baby has a broken vertebra," and then, "Your baby has an inoperable tumor and won't live long." The next shocking declaration came, "He doesn't have a tumor. He has an infection in his spinal column," and then finally a doctor told us after running lab tests on his blood, "Your son's blood is not clotting properly." Realization setting in, I looked at my mother sitting right next to me, jumped up and said, "My dad had hemophilia."

At that moment, hemophilia re-entered my life in a big way. At the time, I was pregnant with my younger son, who would also enter this world with hemophilia. Their father and I became quickly skilled in accessing ports, mixing factor, and ordering supplies, and I knew the rest of my life would be focused on bleeding disorders and making more people aware. I joined my local chapter, became a member of the board of directors, taught myself as much about health insurance as possible, and used my degree in social work and experience with non-profits to research assistance programs, Medicaid, and disability programs.

...continued on page 24

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In the fall of 2007, I also started a Carepages.com website when our second baby boy was having open-heart surgery (he has Tetralogy of Fallot, which is completely unrelated to hemophilia). When I think how many people have been educated about hemophilia through our Carepages site, it astonishes me. We have 441 users who read it and have learned about our story with hemophilia. Those people have shared our stories with others. I can't begin to count how many times I have been asked "How are the boys?" Sometimes, I'm not sure what kind of answer they want, but then I remember the people asking these questions have followed our journey for a long time. They probably remember parts of our lives better than we do. They know about hemophilia because we shared our story with them. They know about our struggles with health insurance, traveling 250 miles to receive specialized medical care for our children, how much clotting factor costs. But most of all, they are **aware** of hemophilia.

We spend many nights in hospitals, and attend hemophilia camps and conferences when we are able. At all of those places, we meet many doctors, residents, and staff members. Even though some residents at the hospitals have heard our crazy diagnosis story, they often ask to hear the whole thing from beginning to end. Other times, someone will ask how I found out my sons have hemophilia, and it gives a great opportunity to share. Part of my purpose in sharing our diagnosis story is the realization that we were lucky—not everyone with similar stories is; other folks with spinal column bleeds have serious lifelong side effects.

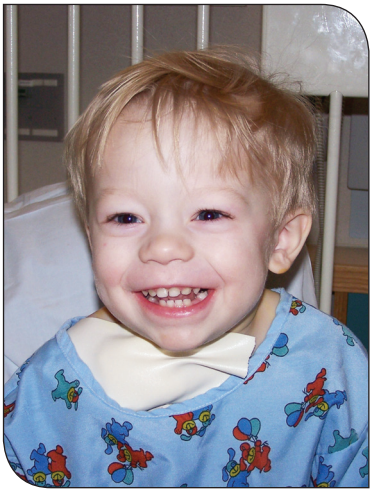
But if just one of those four doctors we saw in four days knew more about hemophilia, we might have been diagnosed earlier in the process. As a result of the large amounts of factor our oldest received due to the spinal column bleed, he also developed a high titer inhibitor within a month of our initial hemophilia diagnosis. It's possible we could have lessened his exposure to factor with an earlier diagnosis.

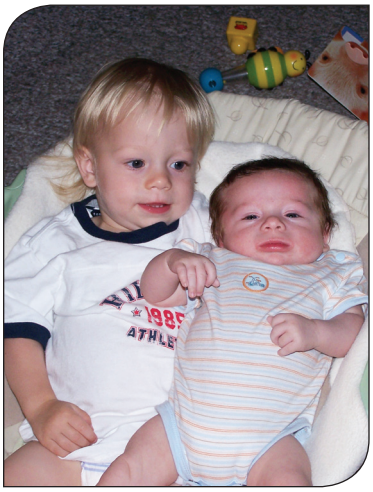
> "Creating awareness is an empowering tool to educate others about what living with a bleeding disorder really means."

I also think about how other people have used their story to create awareness and help others. Some of those things have included creating a walk team to support their local hemophilia chapter, setting up a blog to share their story and educate others, or starting a non-profit from scratch to provide more information to patients, caregivers, and health insurance companies.

Take a moment and think about what the word awareness means to you. It might mean telling your neighbor of five years for the first time that someone in your house has hemophilia, or it might mean attending a local, state or national advocacy day to talk to your elected officials. I challenge you to take the time to inform and be informed. You'll be glad you took that step—it's empowering to educate others about living with a bleeding disorder. ■■

Ashley Druckenmiller lives in rural Iowa and has two boys, Bode, age 8, and Brystol, age 6, who have severe hemophilia with a history of inhibitors. Ashley grew up on a farm showing cattle and enjoys traveling and scrapbooking in her spare time. Her boys are very active and play sports as their hemophilia allows. She spent many years working in the nonprofit field and currently works as a patient advocate.





In Memoriam

Bob Marks (1959–2013)

Former president and vice president of HFA from 2000-2004. Bob was a champion of HFA as a voluntary board member, executive officer, and chair of the Publications Committee. Bob will always be remembered by his friends at HFA for his motto, "Have fun, be happy and most of all, enjoy life."

Kerry Brooks (1957–2014)

Former president of the Texas Central Hemophilia Association and past member of HFA's board of directors. Kerry was a strong advocate who worked tirelessly on legislation to better the lives for those living with a bleeding disorder.

Loretta Cordova (1959–2014)

Devoted mother and dedicated leader of the New Mexico bleeding disorders community. Loretta was the executive director of the Sangre de Oro Hemophilia Foundation of New Mexico since 2005, and served on the board of directors from 1995-2005.

Scholarship Opportunity

Each year, HFA awards **TEN $1,500 SCHOLARSHIPS** to promising students in the bleeding disorders community. In order to be eligible for a scholarship, prospective students must submit a completed application in one of the four scholarship categories:

- **Educational Scholarship**
- **Sibling Continuing Educational Scholarship**
- **Parent Continuing Educational Scholarship**
- **Artistic Encouragement Grant**

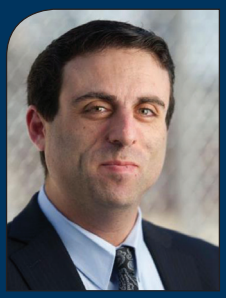
**Note: We no longer accept paper applications, everything must be submitted electronically.*

For more information about these scholarships and others available for the bleeding disorders community visit: **www.hemophiliafed.org** or email **scholarships@hemophiliafed.org**

APPLY TODAY! Deadline April 30th

Laughing Away the Pain

By Matt Porges



I was diagnosed with severe Hemophilia A at birth in New Jersey. During my childhood, I moved around often with my family. Needless to say, these experiences have taught me how to adapt. I have been treated at several different hemophilia treatment centers, and every time I changed my center, I had to learn a new set of doctors, nurses, and clinic procedures. In a way, it was like moving and learning new schools with new teachers and new classmates.

I experienced all the awkward years of my childhood being overly concerned about how people viewed because of my physical limitations. I tried to meet other hemophiliacs as much as possible (since there was no Facebook back then), because I did not want to be alone with this rare disease. I always looked forward to social events at the hemophilia treatment center and trips with other hemophiliacs.

Best of all, when I was young, I attended summer camps and had a lot of fun participating in sports, theatre, arts and crafts, and games with other kids who had bleeding disorders or other physical limitations due to blood-based illnesses. The counselors and the medical staff knew my limitations and how to handle any medical situation.

One of the tools I picked up along the way is what Patrick James Lynch (star of Stop the Bleeding!) describes as "powering through." I view "powering through" as mentally pushing your mind and body to keep moving forward rather than getting bogged down in physical pain. There are days when you are in a lot of pain or you feel like you will never stop bleeding. These days, you just have to remember that it will pass and to not give in to pain and self-pity. I've discovered that if you do, you will never reach your full potential or happiness. The same is true for all new parents of children with bleeding disorders. There will be some bad days, weeks, or months, but you will get through it.

Another important thing that I have learned, especially from my parents, is that "laughter is the best medicine." Once you tune into your favorite sitcom, comedy program, movie, or even just sit around and laugh with your friends, the stresses and pains of having a bleeding disorder lessen significantly. I am not a doctor, but I know they'd agree. When I was younger, I used to watch something silly, like The Three Stooges or the Police Academy movies, to distract myself from the pain. I do the same

HFA's Blood Brotherhood is a national program for adult men with bleeding disorders providing education and support, promoting good health, and establishing a sense of community for adult men. Get involved online with HFA's Blood Brotherhood private online forum, or in person at one of HFA's fifteen local Blood Brotherhood site locations.

Blood Brotherhood Program Impact

A fall 2013 survey of Blood Brotherhood participants showed the following impact of the Blood Brotherhood program:

	Baseline Results*	Follow-up Results**	Change
Respondents felt they could count on someone for emotional support "every day" or "almost every day"	73.2%	82.7%	+9.5%
Respondents felt "socially connected" or "very socially connected"	55.3%	66.9%	+11.6%
Respondents indicated they "never" or "hardly ever" felt overwhelmed by their hemophilia-related concerns	53.7%	61.5%	+7.8%
Respondents participate in moderate physical activity at least 30 minutes per day	48.8%	62.3%	+13.5%

*Survey Responses upon enrollment of the Blood Brotherhood program

**Survey Responses after one or more years of involvement in the Blood Brotherhood program

today by lying down on the couch and watching reruns of Seinfeld or catching late night television.

In the past year or so, I have become more involved with the bleeding disorders community, both nationally and locally in the New York City area. I have especially enjoyed working with HFA's Blood Brotherhood program, which allows me to connect with other adult males with bleeding disorders while having fun through laughter, exchanging stories, or just relaxing after work.

The Blood Brotherhood site with HANY (Hemophilia Association of New York) has blood brothers aged 25 to 60 from several different ethnic and cultural backgrounds. With the Blood Brotherhood, I sought the position of site coordinator within my local brotherhood because I wanted to further my involvement in the community and plan events for my fellow blood brothers. I also wanted to foster collaboration and link men from among different groups in the bleeding disorders community. Recently, multiple New York City Blood Brothers attended local chapter educational events while two others will be attending the HFA Symposium for the first time ever! Through these and other events we've organized, like a Broadway show, spa nights, and dinners out, members are able to connect with men from several different careers and backgrounds as brothers and share their experiences.

As an adult with a bleeding disorder, there are many simple ways to feel less alone and less different from others. You can connect through local social groups and events (especially through HFA's Blood Brotherhood or Blood Sisterhood programs), national meetings, or even on social media. I encourage you to get involved and be part of the community; no matter your age or where you live! I'm confident it will change your life! ■■

Matt Porges is the current Site Coordinator of the HFA Blood Brotherhood site at the Hemophilia Association of New York (HANY). He is 36 years old and has severe hemophilia A. Matt is a lawyer with his own law firm in New York, where he also currently lives.

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