

Recognizing HEMOPHILIA AWARENESS Month



EXECUTIVE CORNER



Dear HFA Family and Friends,

Welcome to our first issue of HFA's 2013 Dateline Federation newsletter! We are excited to be mailing this issue on the heels of Hemophilia Awareness Month.

In 1986, President Ronald Regan designated the month of March as Hemophilia Awareness Month to bring awareness, attention, and encourage the development of improved treatment for those living with a bleeding disorder. HFA is committed to addressing the evolving needs of the bleeding disorders community to help create a better quality of life for all persons with bleeding disorders.

If you are actively on the Internet and social media, you may have seen a new initiative that we began to observe Hemophilia Awareness Month. During the month of March, HFA posted a fact a day on social media about hemophilia and the community to help educate and raise awareness. During the first week, we had a remarkable response from the community when our weekly total of people reached on Facebook was well over 300,000 people! Remember, every little bit counts in building awareness!

Self awareness begins by being alert to what you're eating and exercising to staying healthy. These are just as important as taking time to learn the new policy changes impacting you in your state!

We hope you find this issue of our newsletter filled with bits and pieces that build your own awareness and provide you with tools and resources to further your knowledge and get involved in advocacy in your own unique way. We all have a voice if we choose to use it!

Warm Regards,



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Talking to Your Provider About Pain

By Angie Lambing MSN, Np-C

People with hemophilia know about pain, especially in a joint after a bleeding episode. You may know what that feels like. There is that everyday pain: you wake up in the morning stiff, it hurts to move, and you have to wait until you loosen up before you can even get going on your day. There's also the pain you may feel after a particularly busy day. You have been on your feet, and that knee or ankle that always bothers you is "talking" to you more today than usual.

So how do you talk to your provider about how best to manage your personal pain experience? There are several tips and tools you can use.

First, pain is a personal experience that can be difficult for others to truly understand, so it is up to you to help your provider understand your pain experience. In doing so, you have a better chance of working as a team to best develop a good pain management program that will work for you.

Can you describe your pain? When you put it into words that others can relate to, it helps others to understand better. For example, when you say that the pain is "throbbing," "sharp like a needle," or "burning," these descriptions better help others to visualize, relate to, and understand what it feels like. Does the pain move around, or does it stay in the same place all the time? Can you point to a specific spot where it hurts, or does it just seem to be the whole area?

You know what has worked or not worked for you in the past as you have made attempts to relieve your pain. Make a list. Talk about what medicines or treatments you have used that may or may not have made a difference. Why repeat a treatment that never really worked before? Making a list of what works and what doesn't can help.

Quantifying your pain can provide additional information. You may be familiar with the pain rating scale of 0 being no pain, and 10 being the worst you could imagine. Sometimes it is hard to put a number to your pain, but it gives your provider a starting point. When treatments have been started, and by using a number scale for pain, we can identify if it is improving or not. For example, if you rate your daily pain as 5 out of 10, then that suggests that you are living with a fair bit of pain every day. Most people can relate to that. Say you start a planned therapy, and

"You have a better chance of working as a team to best develop a good pain program that will work for you."

as a result, your daily pain level is now 3 out of 10. It's better, but more importantly, it provides a framework of where you are and where you want to be. If the rating scale doesn't work for you, think of a word list that can help, such as tolerable being the least amount of pain at one end, and excruciating being the most amount of pain at the other end. Some people find describing a percentage of improvement is helpful. "Using ice on my joint, helped decrease the pain by 50%." Work with your provider to find the best rating system that works for you.

You should have a pain goal in mind. This doesn't necessarily mean that you should be absolutely free of pain or 0 out of 10. That may not be possible, especially if you experience a level of pain every day. But,

you should target a goal that is manageable. Another way of describing a measurable goal is to say, for example, "I want to be able to get dressed in the morning with 50% less pain than I am feeling now." This provides a target to strive for and you can know when you have reached it.

It is also important to discuss what activities you do which make the pain better or worse. "I can walk 1 block just fine, but I just have too much knee pain when I try to go to the store to do some shopping." This example provides information that your provider can relate to—how far you can go before it hurts. Keep in mind that even though you may be having pain in your joints that you think is hemophilia-related pain, you could still have other damage or other health issues going on. We never want to assume it is always hemophilia-related pain. Additional information is always helpful.

You may be asked to keep a journal of your pain, or complete pain logs. This may seem like a waste of time, but speaking from a provider's point of view, I find them very helpful. A pain log helps me with a visual trend in the plan of pain management. If you have to discuss your current plan of care after 1 month of treatment, it might be hard to remember how everything worked for you.

Information To Place in a Pain Log:

- a) Prescribed treatment is working
- b) Treatment is working, but doesn't last long enough
- c) On the weekends, treatment plan is not working
- d) Treatment plan is not working

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Spring Training: Time to Get Off the Couch

By Jeffrey Kallberg, PT

Spring is a time for new opportunities. Days are getting longer, trees are budding, and those cool breezes are finally turning warm. Spring is an opportunity to revitalize ourselves and get back into action after winter's long hibernation. With more opportunities for exercise and outdoor activity, spring is a great time to get off the couch and get back into shape and to get ready for our favorite summer activities. But getting ready for summer may take a little planning. You can't expect to turn off the video games, hop off the couch, and pick up where you left off last fall. A little preparation can help you to be more successful.

Take a lesson from the pros. Baseball's spring training began in early February for an opening day on March 31st. Yes—even elite athletes plan on 6 or more weeks of training to get back in top shape for the coming season. Should we “normal” folks expect to recover from our winter off season quicker than these guys? Having a few problem joints myself, I would expect even longer time to get back into shape. Jumping into a new sport or activity without preparing your body is a recipe for disaster. Well, maybe not disaster, but you'll probably be more successful with a little spring training for yourself. So, here are a few tips to get going.

Getting Ready

I know this may sound like a canned liability disclaimer, but it is as important as any other step in the process. Getting checked out by your doctor or physical therapist (my bias, of course) is a good idea, especially if you have a bleeding disorder and any problem joints (or muscles). The pros have a training staff to check them out, so why would we require less? Physical therapists do more



Nicolas Cleghorn, age 10, playing baseball

than just teach exercises—we can identify potential problems ahead of time, so you can not only avoid injury, but perform better as well. Polishing up an old problem before it becomes a new problem again is good preventative maintenance. This goes for young and old alike.

That time spent on the couch last winter may have done more damage than you think. With decreased use, muscles get tight, lose strength, and our endurance drops. Having a good, solid plan to follow will make sure all those problems are reversed in time for summer. I can almost guarantee that if you get off the couch this spring and head to the driving range and drive long balls for 2 hours, you will be sore. Being out-of-shape also puts you at a higher risk for injury. Would you want to strain your back or pull a hamstring in the preseason, or do you want to compete intensely for the whole season? Take time to learn what muscles are tight and how to stretch them out in the best way, what muscles are weak and how you should strengthen them, and how to regain your skill and coordination.

Not only do different muscles and muscle groups in our bodies perform differently, muscles themselves have different types of fibers that behave differently. Some fibers contract quickly to give us speed and power (sprinting), some fibers perform more slowly but provide for long endurance (distance running) and some bridge the gap between these fiber types.

Start Moving

The different activities or exercise programs we participate in during the off season won't necessarily help us when we resume last summer's activities. For instance, swinging a baseball bat or driving a golf ball are intense movements that require a great deal of muscle power. Our muscles and connective tissues also act as big springs during these power activities. Those motions require exercises that stimulate them to prepare the muscle for that type of activity. Those activities place a high stretch on muscle fibers and can easily strain a muscle or ligament. In comparison, cardio exercise on an elliptical machine takes much more endurance, enhances those endurance muscle fibers, and places lighter loads on the muscles and ligaments. Doing this in the off-season is good for your heart, but doesn't necessarily prepare your back and shoulders for those days on the golf course. Doing the right exercises at the right intensity will help grow stronger muscles, tendons, and ligaments and will help you perform better—whether your activity of choice is baseball, golf, or mowing the lawn.



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So, are you ready to start a new exercise program to get ready for summer? First, let's check out our equipment. I'll be pulling my lawn mower out of storage soon. Should I sharpen the blade, change the oil, and clean the air filter, or should I just start it and go? Just like with my exercise equipment, I do a little maintenance first. Take a look at your shoes, for instance—are they more than 6 months old? Are they dirty and worn? Are the soles worn on one side more than the other? Do the heels or toes push out over the soles? If so, throw them out and start fresh. Shoes that don't provide a good stable base for our feet contribute to ankle, knee, hip, and back pain and injuries.

So, as the start of spring, consider a fresh start for yourself. Sign up for an exercise group at your local YMCA, tune up your bike for a smooth ride, or start cross training for a well-balanced body. Most importantly, have fun doing it, and don't be afraid to ask for help. Just like the pros need coaches and trainers, so do we. ■■

Jeffrey Kallberg, P.T. specializes in physical therapy and physical fitness for people who have hemophilia and bleeding disorders, and has severe hemophilia himself. He received his degree in Physical Therapy from the University of Minnesota in 1994, and has worked in many settings and with patients of all ages and diagnoses before settling into his own private practice in Savage, MN. Jeff speaks on the topic of physical fitness and managing the problems associated with hemophilia across the country, and has been featured in NHF's HemAware magazine. He is also a black belt in Taekwondo, trains in various martial arts, and uses exercise to manage his own joint problems. He has developed a program at Accua in Savage, MN to provide specialized PT and fitness services to our population using state-of-the-art equipment and facilities.

Left, Michael Pezzillo, 24,
Right, Anthony Pezzillo, 27,
practicing Taekwondo



Parent-to-Parent: Coping with A Child's Diagnosis

By John Bruno

My first child, Alexander, will celebrate his first birthday next month. In some ways, it's hard to believe that it's been a year already. In other ways, it feels like so much longer. As Alex has grown, my wife and I have grown along with him—and often in areas that we never could have anticipated just twelve months ago. Our story will sound familiar to a lot of parents in the community who had no known history of bleeding disorders in their family. An oozing heel stick, unexplained bleeding after circumcision, delayed discharge from the hospital, and eventually the words that would change our life—abnormal blood work. We were very concerned because the doctors wouldn't tell us anything except that it was abnormal, and that they wanted us to see a specialist in Boston. The bleeding finally stopped and we got to go home. It was Easter Sunday and we spent most of the day by ourselves with our son.



When we got to the appointment the next day, it was at a hematology and oncology office. We were very concerned. We didn't know why we were here, and we saw little children who were clearly very sick. As the doctors and nurses took blood for more testing, the thought of our son having something wrong with him was terrifying. The doctor checked him out and the nurse took blood for more testing. The next hour and a half went by extremely slowly, and it seemed like forever. We just sat in the room and were praying for the doctor to come back and tell us that our son was fine. When the doctor finally returned, he was with the nurse and he told us he had the results. Our son had severe hemophilia A.

I had never heard of hemophilia and had no clue how I should feel, what I should think, how to help my son, or what was actually wrong with him. The doctor and nurse explained what was going on and then the doctor told us that Alex could not play sports and he would have to be on medicine for his whole life. I asked the doctor if my son would be able to do martial arts, since his father and grandfather both own schools. The doctor said that no, he could not. This is when I kind of lost my mind—thinking how my son would not be able to participate in something that his family was so involved in made me a little crazy.

The doctor left us so that we could have some time alone to think. The nurse quickly came back in and started to explain that with medication, hemophilia could be very manageable. She was great—she got us to relax a little and told us to try and focus on the fact that we had a happy little guy and that he would be okay. She also gave us a book called *Raising a Child With Hemophilia: A Practical*

“Six weeks after our son was born, we ‘walked’ our way into a whole new world of people who were all united through hemophilia.”

Guide for Parents. We went home not knowing what to tell the rest of our huge family, who were all calling and concerned. I quickly explained to my sister and father-in-law what the nurse had told us, and had them fill in the rest of the family. We didn't want to see anyone or have to answer a million questions about something we knew nothing about.

I spent all of my free time reading this book that the nurse had given us, and learned as much as I could about my son's condition. The book was amazing. A few days later, we met with a different doctor who would ultimately become Alex's primary hematologist. This meeting had a very different feel than the first. It was positive and encouraging and made us much more comfortable with the whole situation. At this point, I was ready to talk more to my family about it. I didn't know the answers to all of their questions, but I was determined to find out. It made me feel better enough about everything to talk about it.

A couple of weeks after Alex was born, my aunt told us about a hemophilia walk that was being hosted by our local chapter, the New England Hemophilia Association. Six weeks later, we literally “walked” our way into a whole new world of people who were all united through hemophilia—something I had never heard of prior to a few months earlier. We also found out that the brother of a friend had hemophilia. His mother contacted us and asked to sit and talk with us. She brought us a lot of pamphlets on camps and all kinds of things for people with hemophilia, but the best part was that she brought along her son, who was home from college, and we got to talk to someone personally about how they managed hemophilia.

NEHA introduced us to some other parents who then filled us in on hemophilia support groups on Facebook. We learned so much from these groups and started to talk to so many families. It was incredible how they shared so many stories—some sad, some happy, some inspiring. The best thing that I realized about these groups is how everyone supported each other. People who have never met are still connected and there to support each other. It is truly a big family.

I started thinking about all the people and children that have struggled with hemophilia and what I could do to help. I decided the best way for me to get involved and help the community was to do fundraisers and to make people outside the community more knowledgeable about hemophilia. I spent a ton of time setting up a website for our group from the hemophilia walk. I wanted this site to help educate people about hemophilia. I also started contacting people I knew in other states about becoming a state representative for our group and helping with our mission. So far, we've held six events and have raised over \$7,000. More importantly, we have spread awareness about hemophilia across several states and have educated friends, family and even relative strangers about bleeding disorders. We made rubber bracelets to draw traffic to our website and, through family and friends, have sold those for \$3 each in ten different states.



As we started to talk to more and more people about our son and his hemophilia and, we quickly realized that most people knew nothing about it. So while I was busy organizing fundraisers, my wife, Diane, was busy putting together a presentation. When she was done, we called some family and friends together and had them come to the house. We were nervous because we had not talked to most of them yet about hemophilia. We had 39 people show up and Diane gave a great PowerPoint presentation that was about 40 minutes long and had a ton of information. At the end, people asked a lot of questions, and it made us feel good to help educate them. They thanked us for having the meeting and soon other friends and family that couldn't make it started asking about a second presentation. Some of the people from the first one called and asked if they could come again so that they could ask more questions.

Since that time, Diane has done four presentations and has also made one for children so that they can understand and know how they can be involved and help. We're taking a trip to Florida in June and she has even arranged to give a presentation to family and friends while there. As of right now, it looks like there may be even more than the 39 people who attended the first presentation. It's all pretty amazing.

In the past 11 months, we have learned many things about hemophilia, the community, and from just being parents. Along the way, we've found families in our same situation and talked to people from all around the world to see how they handle situations in other countries. We have found other children with bleeding disorders that participate in all kinds of sports—including martial arts. Are we still worried every time our son falls or we see a new bruise? Absolutely, but we are becoming much more aware. We know what signs to look for (like personality changes) and more often than not, we are double and triple checking our son when he is moody to make sure we didn't miss something. All in all, Alex does every single thing every other 11-month-old child does. The



best advice I can give to new parents is to get involved. You may not want to go crazy deep into it like I did, but you can always be part of the Hemophilia community and read stories about what others have gone through and prepare yourself. Knowledge is power—the more you know, the better you will be able to handle any situation that may come up.

Everyone has different ways of coping or dealing with situations. For me, jumping in and helping in any way I can is how I was raised and how I can get through things. I was taught to go 100% or not at all so in terms of hemophilia and the community, we are full speed ahead. ■ ■

John Bruno and his wife Diane live in Methuen, MA and are the proud parents of a young boy with hemophilia, Alexander. Since there was no family history of bleeding disorders, Alex's diagnosis of severe hemophilia A was a surprise. After the initial shock wore off, they dived into educating themselves as well as friends and family. Within six weeks of Alex's birth and diagnosis, they put together the third largest team at the New England Hemophilia 2012 Walk and were awarded the Jump Right in Award. John and Diane have mobilized representatives in ten states to help fundraise and spread awareness about hemophilia. To date, they have held five events raising over \$7,000 for the bleeding disorders community.

The Secrets of Living A Long, Full Life

By Bob Newman

Blood Brotherhood is a national program for adult men, living with hemophilia or von Willebrand Disease (vWD). It is designed to be a multi-avenue outreach, to provide education and support, promote good health, and establish a sense of community for adult men.

Men who have the opportunity to talk with others experiencing similar challenges and journeys are better able to manage their bleeding disorder, cope with life stress, and have better health outcomes. Providing a platform of social support for older men with bleeding disorders, who often feel isolated as a result of their condition, results in significant mental and physical health outcomes.

Everyone has a story. When someone with a chronic condition, like hemophilia, shares their stories with others going through something similar, many say that it helps promote better health and enriches the quality of life for those living with the condition.

Bob Newman's story is no different. Bob will be turning 84 years old this May, and may be one of the oldest adult men living with hemophilia in Minnesota. Bob credits his long life to modern medicine, activity with moderation, a careful approach to diet, the loving care of his wife of 37 years, and a positive and spiritual attitude. Bob asked to share his story to help others with hemophilia -- young and old -- draw inspiration from his life experiences.

Today, I choose to live.

I was born of young parents in 1929. My folks first found out that I had hemophilia when my first baby tooth fell out. After a week of bleeding,

the doctor gave me a direct transfusion from my dad's arm to mine in the dentist's office. The doctor told my parents that my chance of seeing my teenage years was slim. The only treatment for bruises or bleeding in those

"I credit my long life to modern medicine, activity with moderation, a careful approach to diet, the loving care of my wife of 37 years and a positive and spiritual attitude."

days was pressure and ice on the affected site and aspirin was given for pain! When I was five years old, I was told to never run, jump, or climb trees—but, of course I didn't listen.

Activities as a youngster included drawing, painting, boy scouts (instead of hiking, I passed my 14 mile hike by rowing), fishing, (my grandparents owned a lake cabin), sling shooting, bb gun shooting, and playing drums in the high school orchestra and Dixieland band. Constructing model airplanes also kept me busy when I was laid up. My fifth grade teacher told my mother that I had an unusual amount of "pluck and tenacity."

When I was in the fifth grade, I fell while skiing and got what the doctor called "water on the knee." Not wanting to tap it for fear of bleeding, he put it in full leg plaster cast for three months. The leg was about as big around as my forearm, and I could not straighten it. I walked the next five years on crutches. There were no professional physical therapists in my small town in Minnesota, but I thought



“Life is about living your dreams and never giving up despite what life gives you.”

that by strapping a heavy weight (my mother’s flat iron) on my foot as I walked on the crutches, it would eventually straighten my leg—which it did. Playing a full set of drums was also good exercise for all of my joints.

My aunt gave me a few brushes and tubes of oil paint when I was confined to bed with rheumatic fever at age 14 and that started me on a career in art. I also had a brief career as a radio announcer. Three years out of high school, I started studying commercial art at Minneapolis School of Art and got my first job in an advertising agency. From there, I went to work as an industrial illustrator (technical artist) for a farm machinery company and eventually started my own business, Manual-matic Company, Inc., which I operated for 43 years. I also became a professional musician in a traveling dance band and as a jazz drummer for 40 years. In 2004, I closed my business and started oil painting (something I had wanted to do since art school).

Life is about living your dreams and never giving up despite what life gives you. It is also truly what you make of it. We have a choice each day regarding our attitude. **Today, I choose to live.** ■■

I Had One of The Best Days of My Life

By Andy Matthews

Lin Aurand was a talented and giving member of the hemophilia community.

I got to spend some time with Lin Aurand this past fall and I had one of the best days of my life. He picked me up in his almost new Ford handicap-equipped van that his parents kindly bought him. They wanted to make life easier on Lin and for him to have a somewhat normal life. Keep in mind, he suffered from a bad inhibitor he had for years. He also was confined to a wheelchair due to an accident years ago when he was in his twenties. He took me on an amazing drive through the Rocky Mountains near his home in Sheridan, Wyoming.

Lin was the kind of man who could talk about all kinds of things, even some that he had never gotten to enjoy due to his disability, because he had so many friends and he took pictures of what they were doing. He could talk all day about wildlife and guns. He was a talented wood craftsman who created hand carved pens and lamps. He was a sketcher and painted beautiful paintings of animals. Life was hard on Lin but never did he complain. I lived with Lin only for a day but really got to see what life was like for a guy living in a wheelchair. I remember that he needed to go to the bathroom and we stopped in the local Walmart and it took us about thirty minutes just for what would have taken you and I about five minutes.



In Memoriam

Lindell “Lin” Aurand

June 27, 1963 –
February 17, 2013

Last month, Lin had a massive brain hemorrhage. Lin was a dear friend and member of the community and will surely be missed by many. When you think your life is bad, he really put a new light on it and showed you that there are still so many things one can do. He always talked about others and hardly ever about himself. He was just one of those souls that you could talk to for hours about many subjects and you could always learn a lot from him. ■■

“Life is truly what you make of it.

We have a choice each day regarding our attitude.

Today, I choose to live.”

Poorly Understood: Women and Bleeding Disorders

by Dana Brayshaw

While bleeding disorders like hemophilia and von Willebrand Disease (vWD) can affect men and women, these conditions present unique issues for women because of heavy or abnormal bleeding during menstrual cycles and after childbirth. Many areas crucial to the diagnosis and treatment of bleeding disorders in girls and women are poorly understood. According to the CDC, it is estimated that nearly 1% of women in the United States may have a bleeding disorder and are unaware of their condition.

In 2004, The National Heart, Lung, and Blood Institute convened a working group of scientific experts to identify the research directions needed to address the problems in the diagnosis, treatment, and health management for women with bleeding disorders.

The group determined that “undiagnosed and untreated bleeding disorders in females have a negative impact on their health and quality of life. Studies have documented increased morbidity due to excessive bleeding in girls and women.”

Fact: Girls Have Bleeding Disorders

Many are surprised that women are not only carriers of the hemophilia gene, but

can present symptoms of hemophilia and are even clinically proven to have it. They are often called symptomatic carriers or are diagnosed with mild hemophilia. A carrier is a female who has the genetic mutation for hemophilia on one of her X chromosomes. Carriers with clotting factor levels of less than 50% may have symptoms similar to a male with mild hemophilia. Females with the hemophilia gene also have a 50% chance of passing the gene on to their child. Approximately one third of carriers experience bleeding symptoms.

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A female who carries the hemophilia gene has the genetic mutation for it on one of her X chromosomes. Approximately one third of carriers experience bleeding symptoms.

Bleeding disorders among females may present special challenges because of the bleeding associated with menstruation and childbirth. Menorrhagia is abnormally heavy and prolonged menstrual periods, and is the most common symptom among females with a bleeding disorder.

A Symptomatic Carrier's Perspective

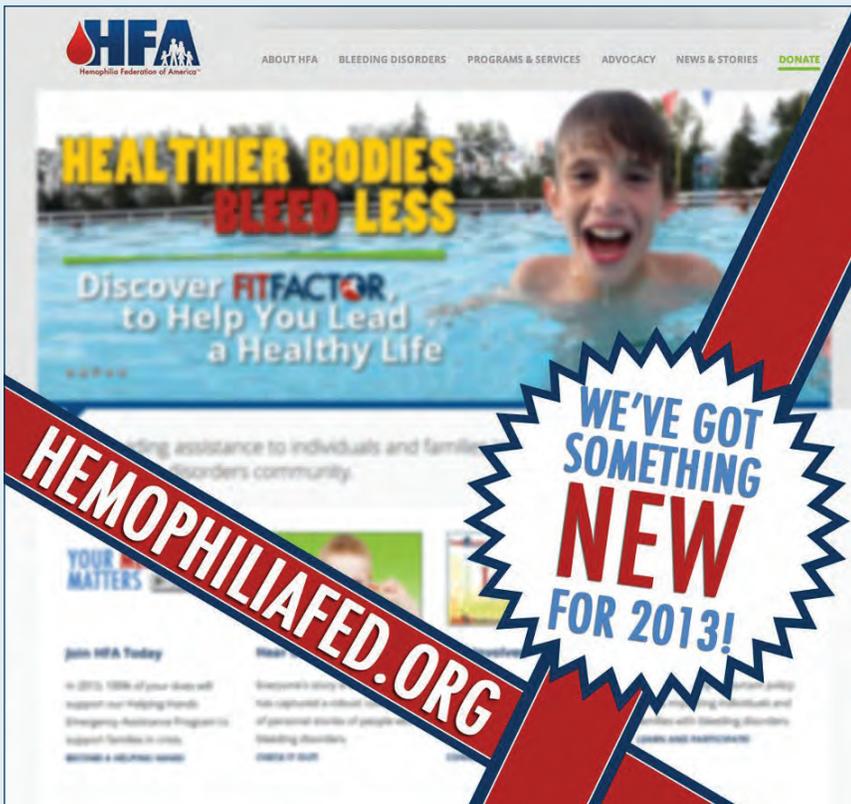
My childhood was not much different than that of any of my friends. Since my older brother has severe hemophilia, for as long as I can remember, our family has always been active in the bleeding disorders community. My brother would treat at home and almost always participate in activities with the rest of the family. From swimming to skiing, Paul was, and still is, just as fit as (if not more than) the rest of us.

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“As a woman with a bleeding disorder, I know that I am my own biggest advocate when it comes to raising awareness.”

--Dana Brayshaw





News & Stories Section – Find all of your bleeding disorder related information here! Features great stories and info that affect and can benefit you.

Design - User friendly, sections easier to find, concise, clean, yet full of information.

FitFactor - Relaunch of our wildly successful FitFactor program website. Find great info to help you improve your lifestyle with physical activity and nutrition.

Bleeding Disorders Section – Detailed information about different types of bleeding disorders written in simple, easy to understand paragraphs and diagrams.

Community Look – HFA always focuses on the community and as such, we love to highlight real community members.

Calendars – Introducing a new, full-blown webinar and event calendar! Includes events for all HFA programs and events across the country ■■

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Medicaid Expansion in Your State

By Eboni Morris

The Medicaid program is a federal and state partnership to provide health insurance for those who are financially and medically needy. It is a vital safety net in our health care system. Federal law sets a baseline of eligibility categories for states to follow, but states have the flexibility to cover above that baseline by applying for a waiver from the Centers for Medicaid and Medicare Services (CMS) to expand health coverage. Children are one of the main groups that states have sought to expand coverage to.

Originally, the Affordable Care Act (ACA) called for a mandatory expansion of the Medicaid program for all individuals up to 133% of the federal poverty level (FPL). However, the Supreme Court ruled this past summer that states cannot be mandated to expand eligibility or face financial penalty. This ruling essentially made expansion an option for states. If a state chose to expand the program, they would receive the matching funds that come with expanded coverage. The Congressional Budget Office (CBO) predicted that 11 million Americans would have gained coverage by 2022 through mandatory Medicaid expansion.

HFA recognizes the potential benefit of Medicaid expansion to the bleeding disorders community. Optional expansion has the potential to leave many low income adults without health insurance. Adults with incomes between 100% and 138% FPL will be eligible for subsidies to purchase health insurance through the health insurance exchanges beginning in 2014, but those with incomes below 100% FPL will not be eligible to receive subsidies to purchase insurance in the exchange.

This may lead to the following scenario: a childless adult that has an income 95% of FPL and lives in a state where their income needs to be 85% of FPL to be eligible for



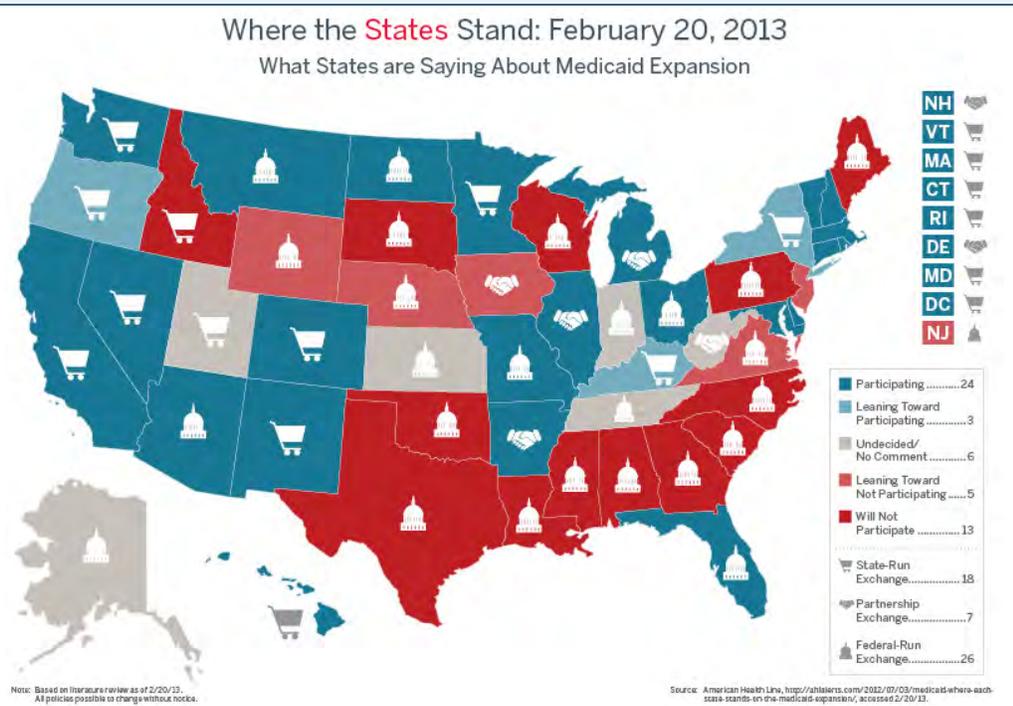
Medicaid would potentially go without insurance. Their income is too high for Medicaid and too low to qualify for subsidies in the health insurance exchange. It is also important to note that in 40 states, childless adults cannot currently qualify for Medicaid, regardless of their income level.

States are now weighing in on whether or not to expand Medicaid under the ACA. Some states have expressed concern that expanding Medicaid to more adults poses great fiscal challenges. Others raise concerns about the federal government's ability to permanently maintain their fiscal commitment.

What you can do to promote Medicaid expansion in your state

- Do your research on your state's Medicaid program. Research coverage options and eligibility guidelines. This will help you gain a full understanding of how the program works for your state.
- Explain to your state legislators and executive branch how important Medicaid is to the bleeding disorders community in your state. Be prepared with data on how many people with bleeding disorders are currently on Medicaid and how many more could potentially benefit.
- Advocate for the long haul. Medicaid expansion may not happen immediately in your state, but could very well happen in the near future. Keep up the pressure on state decisions makers. ■■

Check out the [advocacy section](http://www.hemophiliafed.org/advocacy/) of HFA's redesigned website:
<http://www.hemophiliafed.org/advocacy/>
 Let us know what you think! Contact us at: advocacy@hemophiliafed.org



INFUSING LOVE: A MOM'S VIEW

A blog dedicated to mothers of children with bleeding disorders.

In February, HFA launched its latest blog, "Infusing Love: A Mom's View," dedicated to all things mom! In this safe spot, moms of a child with a bleeding disorder will be able to read stories and draw inspiration from like-minded moms like themselves. In recent years, moms who have a child with a bleeding disorder have begun turning to online outlets for sources of friendship, camaraderie, and support. Moms are looking for a quick place to share and see reflections of themselves – and online connections have blossomed! HFA hopes that this blog will be an honest look into the lives of moms and families with bleeding disorders. By sharing these insights, we can educate one another within our own bleeding community and teach our friends and family outside of the bleeding world that it's not all bruises and bleeds. In the coming months, we'll be adding more moms to this blog and look forward to having a conversation each Wednesday! ■■

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Taking Control of Your Health: A Testimonial of Perseverance

Community Voices

Maintaining a balanced diet, staying physically fit, and managing stress are important for everyone, especially those living with a bleeding disorder. A regular, safe exercise program protects the joints, and can even help decrease bleeding episodes.

Matt Stinger, 29, a patient with hemophilia, a registered nurse, and participant in HFA's 2012 Gears for Good annual bike ride, talks about how exercise is the key to staying healthy, protecting joints, and decreasing bleeding episodes.

Were you active growing up and throughout college?

As a kid, I always swam and biked with my family to stay healthy. After graduating from nursing school in 2006, I found that I wasn't as active as I once was. I was working in the emergency room and was constantly on my feet, but on days off I found myself on the couch, not motivated to workout. I fell into a period where I wasn't really doing much of any physical activity. Looking back, I noticed that I was getting increasingly more spontaneous bleeds, especially in my joints. In 2008, I had a left elbow synovectomy. I recovered from surgery by going through a lot of physical therapy, but quickly found myself back in my old routine.

Was there something that helped you to make the decision to start living a healthy lifestyle again?

During the time I wasn't active, my brother kept bugging me to join a gym, but I would always find excuses why it wasn't the right time, until I finally decided to buy a gym membership in February of 2012. After going a couple of times, I started to notice a difference, and it soon became addicting. It was awesome. I lost between 35-40 lbs within the first 6 months and the passion I had for life was back.



Matt Stinger at the 2012 Gears for Good Annual Bike Ride.

What differences have you noticed since you started living a healthy lifestyle again?

Aside from my physical appearance and increase in confidence, I've noticed that I bleed less. When I was less active and heavier, I was infusing more often due to frequent bleeding episodes, but since I've lost the weight, I now use less medication and make sure that I follow my treatment regiment. If I think that I have a possible injury I stop, infuse, and rest for a couple of days. Listening to your body is key to staying on top of your condition.

What do you now do to maintain your healthy lifestyle?

I swim, bike, and work on core and muscle strengthening three to four times a week. I travel often but find ways to make sure I get my workouts in. I don't want to lose the progress that I made, and on days that I can't workout, I try hard to choose healthy food options and cook my own meals.

Now that you are living a healthy lifestyle, what keeps you motivated?

I stay motivated and on track because I now know the consequences of living a sedentary and unhealthy lifestyle. There are little things I do such as taking the stairs or parking a further distance away and I make sure, whether its swimming, biking, or muscle

strengthening that I fit in on those days. It also makes a difference if you have someone to work-out with to help motivate one another. I have been using HFA's Get in Gear app to track my accomplishments over the past year. The app has an award-based system that rewards you with badges based on the duration and distance of your workouts over time. I just received the 100-mile swimmer badge and as silly as it sounds, I was on a mission to obtain as many of these badges as I could. Staying fit is one of the best things that you can do for yourself and make sure to find a routine that works for you. My hemophilia has in turn played less and less of a role in my life since getting back in shape.

What advice would you give to someone with a bleeding disorder reading this who was in the same place you were?

Having an overall healthy lifestyle is essential. You won't experience change overnight, but it will happen if you stick with it. When you are bleeding less, you can do more, and be held back less. It's worth all the time invested because it makes you stronger in your physical appearance, attitude, and mental stability.

Every body is different, but listen to yourself and tailor your workouts accordingly. If your ankles aren't in the best shape, then you probably shouldn't run, but don't let that stop you from doing something. Use an elliptical, swim, or do anything that you enjoy. Remember, it's not what you can't do in life; it's what you can do. ■■

Words to Remember:

"The only thing standing between YOU and YOUR goals are the excuses you keep telling yourself as to why you can't achieve them."

Frequently, I have had patients tell me that their pain management plan is not working, yet when we review the journal together, we find that there was some success to the plan, but we might just have to tweak it a bit. Also, by taking the time to document what is going on, you demonstrate a level of commitment to working with your provider. It doesn't have to mean that you have to keep records forever, just when needed.

Also, keep in mind that even though you may have a plan for pain management that works for you today, it will need constant reassessment. Your life and health issues may change, requiring an adjustment in your overall plan of care from time to time.

Development of a good pain management program requires a team effort from you and your provider. It may also involve others: your family, your significant other, and maybe other members of your hemophilia comprehensive care team. Pain can involve your whole being. If you are stressed



or anxious, your pain experience can be intensified. Living with daily pain can be exhausting and leave you feeling depressed. These emotions can be normal. Acknowledge them and get help to manage them. Being aware of these other feelings can help you better manage your pain and help you be in control.

If you feel that your hemophilia treatment center (HTC) can't get a good handle on your pain and manage it in the way that it is needed, get additional help. Seek out a pain clinic or pain management team—both experts on pain management. Just because you have hemophilia doesn't mean you have to live with the pain that may go with it. Your hemophilia treatment center can work with other specialists as a team to help improve your care. ■■

Pain Checklist for Your HTC Visit:

1. Use words to describe your pain
2. Point to where the pain is located
3. Does the pain stay in the same place or move around
4. Describe your level of pain
5. Make a list of what treatments have worked, and what has not worked for you
6. Write down what activities makes the pain worse or better
7. List a pain goal you have in mind
8. Be prepared that it may take time to find a pain program that works best for you
9. Bring this list with you!
10. Be patient!

“If you are stressed or anxious, your pain experience can be intensified”

Angie Lambing, NP *Angela has been a nurse practitioner for the past 21 years. She has worked as the hemophilia nurse coordinator at Henry Ford Health system for the past 11 years. Her passions in hemophilia care are focusing on the aging issues in hemophilia and pain. She has participated in research, lectured and authored many articles related to the hemophilia pain experience.*



Given my brother's status, I was aware that I could possibly be a carrier, but I had never had any health situations that had truly "challenged" me. I will admit, I was also in a bit of denial, despite the fact that I had abnormal bleeding (nosebleeds and heavy menstrual cycles), but I never really wanted to face the facts.

Last year, I had a health emergency, and since I wasn't aware of any condition, I was not properly treated. Although I had immediately explained my family history to the doctors, they were very hesitant to attempt any treatment. It wasn't until I had bled for several hours straight that the doctors began treatment of clotting factor. It was because of this very stressful and scary situation that I learned to be aware of my condition as a carrier.

With this information, I can properly treat my bleeds by notifying my doctors of my condition. I try to make sure to wear a medical bracelet or have some information on me that notifies people in any case of emergency that I carry the hemophilia gene and have bleeds. This also makes me more aware of the issues I will deal with in my future when I decide to have children. I want to make sure I am fully prepared for what I could possibly have to deal with if I have a child with hemophilia.

I am lucky enough to have a family that is very supportive and encourages me to be a proud person no matter what my circumstance. Since my diagnosis, I have become more active in the community and am very interested in meeting other women with my condition. I think it is really important that other women in my situation, especially female siblings, get tested early so that they are not caught unaware of their medical situation like I was.

In the past, hemophilia has been seen as a "man's disease," when in reality, many women deal with it as well. I think it is extremely important for women with low factor levels to continue to come together to share stories. It is empowering and helps to prevent a crisis from occurring. ■■

Common Symptoms of Females with a Bleeding Disorder:

- Frequent nose bleeds
- Prolonged bleeding from minor cuts
- Easy bruising (unexplained bruising)
- Excessive bleeding with dental work or tooth extraction
- Menorrhagia (abnormally heavy and prolonged menstrual period)
- Post-partum bleeding (excessive bleeding after giving birth)



Congratulations to Linda "Lew" Wyman-Collins, RN



Lew recently received the Cherokee Inspired Comfort Award. This award is given nationally to five healthcare professionals who have impacted the lives of others through extraordinary care, sacrifice, and innovation. Lew was also recognized as one of 100 nurses selected as the 2013 Great Nurses of the Dallas-Fort Worth area.

Lew is a clinician, lobbyist, educator, community activist and volunteer that has dedicated herself to improving the lives of those living with hemophilia. Her passion and commitment to education and awareness about bleeding disorders is evident by state and national legislation she has championed. Among her many notable achievements, she successfully lobbied the Texas Legislature for the reestablishment of the Texas Bleeding Disorders Advisory Council. Lew currently resides in the Dallas-Fort Worth area with her husband, Ray Dattoli, and sits on HFA's board of directors.

"Every human has four endowments- self-awareness, conscience, independent will and creative imagination. These give us the ultimate human freedom... The power to choose, to respond, to change."

Stephen Covey





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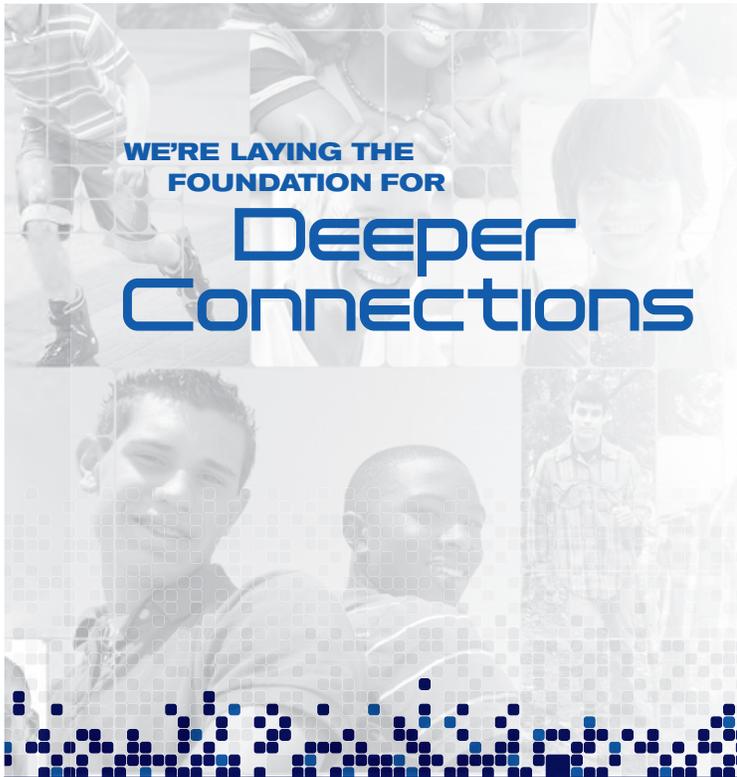


**Please note that an internet connection is required to receive infusion reminders.*

This app is not intended to offer or replace professional medical advice. Speak to your nurse or physician if you have any health concerns. 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.



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HEMOPHILIA

A Little Help Can Go A Long Way

By Janel Johnson Momanyi

In January 2013, an applicant to the Helping Hands program needed \$186.00 for a utility bill payment. The applicant suffered a job loss the first week of December 2012, and had been living off of savings income. The applicant's son developed an inhibitor at the age of eighteen months, and for two years, this applicant missed at least seven days of work every month caring for him. In 2012, the applicant's son was hospitalized five times. In June of 2012, the son was hospitalized for two weeks. In July of 2012, the son was hospitalized for an additional fourteen days, and between October of 2012 & November of 2012, he was hospitalized for over 30 days because of port surgery.

During all of these hospitalizations, this applicant's employer reduced her hours from full-time to part-time, because of all the missed days from work. And in October of 2012, after three years of employment, the applicant was terminated. Luckily, the applicant had a second part-time job, but because of all the missed days from work, the applicant was terminated from the second job in December of 2012. At the time of the Helping Hands application, the applicant was looking for new employment, and the son had an active bleed that required physical therapy three days a week.

If you are in need of help, please consider contacting these resources:

ORGANIZATION	PROGRAM DESCRIPTION	PROGRAM WEBSITE & INFORMATION
Helping Hands Program	HFA's Helping Hands program is designed to establish a rapid, non-invasive source of relief for emergency situations (such as housing, transportation, and utility bills) for people affected by hemophilia or von Willebrand Disease.	www.hemophiliafed.org
Patient Services Inc.	Since 1989, Patient Services has helped people who live with certain chronic conditions locate suitable health insurance coverage and access ways to satisfy expensive co-payments.	www.patientservicesinc.org

This applicant is a single parent who is not receiving any child support. The son is receiving disability benefits, but with the loss of employment, all of the household bills could not be paid. In January of this year, this applicant received \$186.00 from the Helping Hands program, and it made a positive difference for this household.

In February of this year, this applicant was asked to return to work by the previous part-time employer! The work hours were increased, so this applicant will be able to pay all of the household finances.

This applicant constantly informed the supervisor when the son had bleeds. Now the supervisor is educated about hemophilia and, perhaps the next time an employee is affected by hemophilia, the employer may be more understanding.

Many families suffering financial hardships apply to the Helping Hands program. Whether the Helping Hands program can provide assistance to applicants or not, it is important to remember that help can come in many forms. ■■

ITEM'S REIMBURSEMENT UPDATE

As of March 1, 2013 we have made some important, yet exciting updates. Listed are the items we now reimburse. More information about our Approved Items List is on our website: www.hemophiliafed.org.

- Medic Alert Jewelry
 - o Applications must be sent directly to Medic Alert
 - o Applicants will be reimbursed up to \$30.00 along with membership fees
- Braces & Support
- Walking Support
- Heating & Cooling

Any questions regarding these changes, please contact us!



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- Artistic Encouragement Grant (1 grant)

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April 30TH

hfasc scholarship.hemophiliafed.org



CHOICE: Your Voice Matters!

By Wendy Owens

What if, in less than 40 minutes, you could help improve the lives of everyone in the bleeding disorders community? It is possible, but if you let your voice be heard. The time is now. The CHOICE Project survey is ready. Take it online, on paper in English or Spanish, and let your voice be heard.

Through a cooperative agreement with the Centers for Disease Control and Prevention (CDC), HFA is running the CHOICE (Community Having Opportunity to Influence Care Equity) Project. The focus of the CHOICE Project is to collect information regarding health experiences of people who have a doctor-diagnosed bleeding disorder and do not receive care at a federally funded hemophilia treatment center (HTC). HFA is asking everyone in the bleeding disorders community to participate in this project by taking the CHOICE survey.

Together, HFA and the CDC hope what we learn will help us assure equity in the care received by all members of the bleeding disorders community. The more participants enrolled in this project, the more information we can gather. With more information, we have a better chance of learning what we can do to improve the health of people with bleeding disorders. This includes possibly identifying medical and social issues that require further study. There is power in this knowledge—power to change lives, improve medical care, and help assure access to the services people with bleeding disorders need.

“With more information we have a better chance of learning what we can do to improve the health of people with bleeding disorders.”

Since 1998, the CDC has collected information on the health status of people with bleeding disorders who receive care at HTCs. Much has been learned from this information. However, a study from the mid-1990s showed that a third of people with bleeding disorders received care outside of the HTC network. Little is known about the health experiences of people who do not receive care at HTCs. Because of this, HFA and the CDC decided to learn more through the CHOICE Project.

HFA member organizations are a key component to the CHOICE Project's success. HFA has teamed up with seven of its member organizations in Texas, Illinois, Arizona, New Mexico, and New York to help identify people to take the CHOICE survey. The survey itself is available in English and Spanish and takes roughly about 20 minutes to complete. People can take the survey online or in paper format.

The CHOICE survey asks questions about diagnosis, bleeding history, treatment, insurance coverage, quality of life, and quality of care. The information collected from the survey will be used to understand the health of people with bleeding disorders who

do not receive care at HTCs. It will also be used to identify issues that need further understanding, such as where care is being obtained, what complications are being experienced, and what treatment is being used.

Personal privacy of the survey-takers is of the utmost importance to HFA. HFA will collect all survey information. Personal information will not leave HFA's secure, password-protected database. HFA will compile paper-based surveys into this database and will shred and recycle the paper documents. HFA will share de-identified data with the CDC. Data shared with the CDC will include a unique identifier code, but will not contain personal identifiers, such as name or address. Information from this project may be published. However, no information will be published that could identify a survey-taker.

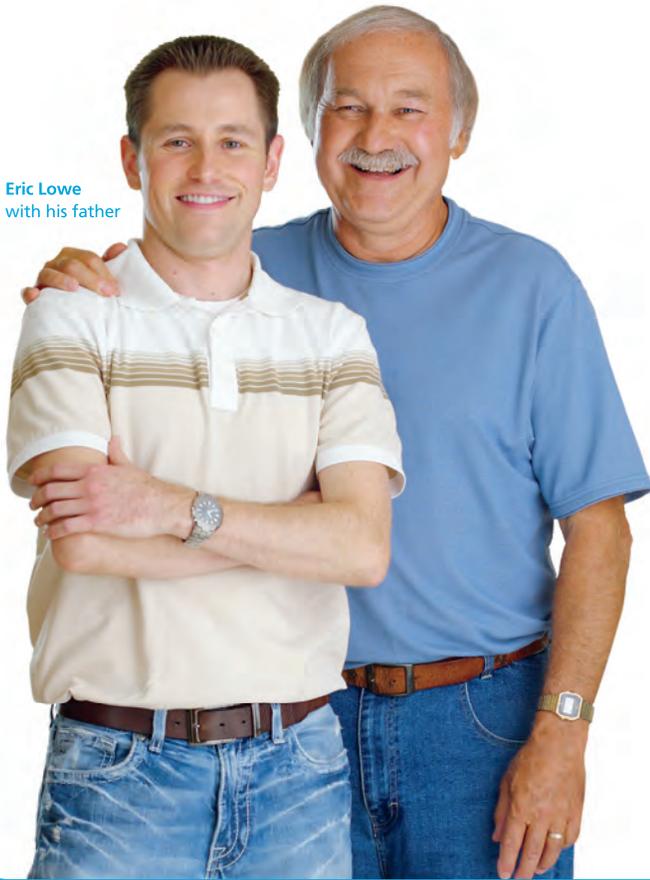
If you have a bleeding disorder, your voice should be heard – no matter where you get your care. You matter, and it is your choice to participate in the CHOICE Project. To find out how to take part in the CHOICE project, call 800-230-9797 or go to choice.hemophiliafed.org. ■

33%

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with his father



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Welcome to the Bleeding Disorder Community...

Janet Chupka, RN, Program Coordinator



Janet started with HFA as a Program Consultant on the FitFactor program in October 2011 and has helped to promote and grow the program. Janet holds a Bachelor of Science degree in Nursing from the University of Wisconsin-Milwaukee. Janet worked for the University of Wisconsin-Milwaukee in community health and as a mentor for undergraduate nursing students. She has also worked in a variety of health care settings including: geriatrics, administration, management, urgent care and most recently, wellness. Janet will now share her passion for wellness along with her expertise as a R.N. as a part-time employee to continue to develop the FitFactor program. She resides in Wisconsin, with her husband and their three children.

Sadaf Ahmad, Policy and Advocacy Manager



Prior to joining HFA, Sadaf was a National Urban Fellow at National Organization for Rare Disorders (NORD), where she tracked legislation affecting the rare disease community. She has over 7 years of experience in the non-profit sector, including managing an affordable health care plan for the uninsured in Chicago. Born in India and raised in the US, she enjoys elevating the stories of diverse patient populations. She is thrilled to be working in DC on federal health policy and patient advocacy for the bleeding disorders community. Sadaf earned a BA from Williams College and MPA from CUNY – Baruch School of Public Affairs.

Athena Harrison, Program Coordinator



Athena graduated from Marymount University in Arlington, VA in 2011 with a double BA in graphic design and creative writing. Over the past two years, she has used her design and writing skills for various businesses around the DC metro area. Prior to joining HFA, Athena was the Director of Graphic Design and Branding at DeMorais International. She is excited to be working at HFA, where she plans to use more than just her design skills to help those in the hemophilia community. Athena currently resides in Alexandria, VA.

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Pursuing life without bleeds

Learn more about Baxter resources and support at ThereForYou.com.



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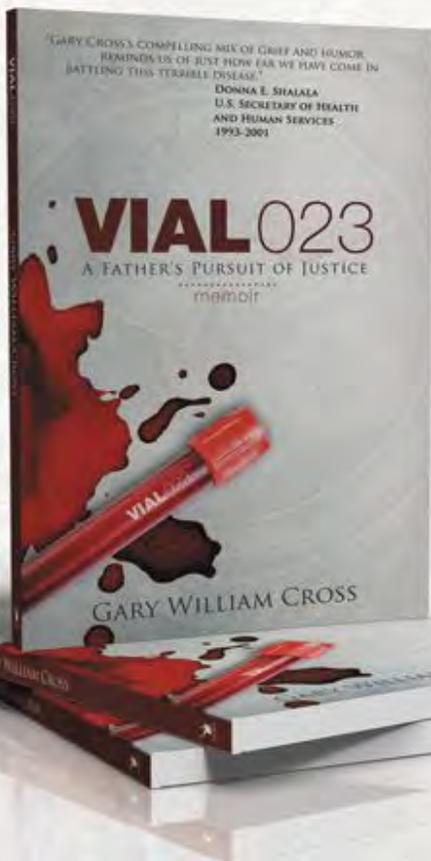
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