Ring in the New Year!

Since 2015 is just around the corner, I thought this was a great opportunity to look back on a busy and wonderful 2014 and look ahead to 2015.

2014 was full of amazing growth:

• We welcomed Washington, Alaska, Michigan, and Eastern Pennsylvania as new member organizations. We are now proud to be 41 member organizations strong!

• We held our 1st annual regional Gears for Good bike ride in New Hampshire and our 4th annual 156 mile West Virginia to DC ride, raising over $90,000 for HFA’s emergency assistance program for families.

• We are currently in our 3rd year with our CHOICE project — Community Having Opportunity to Influence Care Equity. CHOICE is a project supported by the Centers for Disease Control and Prevention aimed at collecting information regarding health experience of people who have a doctor-diagnosed bleeding disorder and do not receive care at a federally-funded hemophilia treatment center. Over 500 people have completed the online or paper-based survey and shared their experience with us in both English and Spanish!

Plans are in full swing for our 21st annual Symposium to be held March 26 – 28 in beautiful St. Louis. Registration is open! Go to www.hemophiliafed.org for more information.

Perhaps now is the time that you’re thinking about some year-end giving ideas. Bleeding disorders such as hemophilia and von Willebrand Disease are extremely costly. By supporting HFA, you help educate, empower, and support families affected by these disorders. You can donate online in memory or in honor of a loved one.

Are you currently a member of HFA? If not, now is a great time to join or renew your membership for 2015. As a member, you have access to our programs and services, and will receive regular print and electronic communications and policy action alerts for the bleeding disorders community.

A huge thank you to every one of YOU for making 2014 a wonderful year for HFA. Best wishes to you and your family for a joyful holiday season, and a healthy 2015. I look forward to seeing you in St. Louis!

Warm regards,

Tracy Cleghorn
Board President

Join or renew your HFA membership in 2015!

www.hemophiliafed.org/member
On Monday, September 22, members of the bleeding disorders community were given the opportunity to share their treatment experiences with the Food and Drug Administration (FDA). As part of the renewal of the Prescription Drug User Fee Act (PDUFA V) in 2012, the FDA must incorporate the patient perspective into their regulatory decision-making. To accomplish this, the FDA is holding a series of Patient Focused Drug Development meetings seeking the input of patients in 20 disease groups to assess drugs and treatment options. Patients provide an important and unique context for the FDA as they develop their new approach to rulemaking using the Benefit-Risk Assessment Framework. This assessment for drug approval gathers information from multiple sources including physicians, scientific data, and patients, then weighs the benefits and risks of a certain treatment.

HFA worked with partners like NORD, PPTA, and NHF to ensure that our community was effectively represented. Patients and advocates of every age, background, and with several different conditions came out to share with the FDA their hopes, fears, and trials in treating their conditions. So many great opinions were shared, covering two open-ended topics set by the FDA.

The first topic dealt with the effects of bleeding disorders that matter most to patients. The FDA sought information on which symptoms had the most impact on daily life, which specific activities were negatively impacted by having a bleeding disorder, and how symptoms have evolved over time.
The second topic focused more on treatments: which treatments were most popular, how well they work, what were the most significant disadvantages of current treatments, how they’ve changed over time and what aspects of life have been improved by treatment regimens.

One of the most significant things that patients spoke about at the meeting was their experience with inhibitors. We heard the frustration patients feel with the lack of understanding about how inhibitors are developed, and how difficult they are to manage. There was a call among the community for more focus on the treatment and diagnosis of inhibitors.

The Patient Focused Drug Development meeting for those with a bleeding disorder has ended. However, patients can continue to be heard and help the FDA develop a better understanding of inhibitors by reporting the formation of an inhibitor to the FDA through the FDA Adverse Event Reporting System (FAERS). Consumers are encouraged to report adverse side effects to drugs that are approved by the FDA and can do so via the FDA’s Consumer Voluntary Reporting Form found on the FDA site. Once a negative side effect is reported, it is evaluated by clinical reviewers at the Center for Drug Evaluation and Research (CDER) and the Center for Biologics Evaluation and Research (CBER).

Excerpts from community members’ testimonies during the FDA Meeting:

“A subcutaneous shot would be great because of the ease of use. I’m very worried about the longevity of my veins, as they are in rough shape already. It would also be extremely helpful to have a device, similar to a glucose meter folks with diabetes use, that people with hemophilia could use to check their factor levels. Invest in the children living with hemophilia. Invest in me, and invest my daughters’ future children. Invest in finding a cure.”

— Mark, adult man living with hemophilia, hepatitis C, and HIV

“The most critical treatment concern for members of our community is that treatments are safe. We do not forget the staggering impact HIV/hepatitis C tainted products had on this community. The emotional impact was not only on the health of those affected but also on the entire family unit.”

— Kimberly, HFA Executive Director
Regular testing for an inhibitor is important because the treatment to get rid of the inhibitor is more successful when an inhibitor is identified early. By reporting inhibitors as an adverse event, regulatory agencies will be able to compile and study more data to determine the best actions to treat and prevent inhibitors. You could be responsible for improving product safety by encouraging the FDA to communicate new safety information to the public, update a product’s label, and/or restrict use of the drug. In very rare cases, the FDA may pull the drug from market.

Continue to be heard by reporting your inhibitor as an adverse event to the FDA by visiting www.hemophiliafed.org/inhibitors

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**Important information about inhibitors:**

Recently, a six year study was released by the Centers for Disease Control and Prevention (CDC) had six key findings about inhibitors:

- All people with hemophilia are at risk for developing inhibitors.
- One-third of newly-developed inhibitors were found in people with non-severe hemophilia.
- One-half were over the age of 5 years.
- One quarter had used infused factor for more than 150 days.
- Six out of ten people with hemophilia with an inhibitor had no symptoms.
- Regular screening of people with hemophilia for early detection of an inhibitor by the CDC laboratory is feasible, and will inform efforts to measure rates of this complication.

**The CDC found these critical gaps:**

- Because there is no effective monitoring system, the actual number of people with hemophilia with an inhibitor in the United States is not known.*
- The impact of risk factors (characteristics, conditions, or behaviors that can increase or decrease the risk for developing an inhibitor) on inhibitors is not fully understood.*
- An estimated 60% of people with an inhibitor do not have symptoms, but may develop health problems from an undetected inhibitor.*
- People with hemophilia receiving care in federally funded hemophilia treatment centers (HTC) will be tested each year for an inhibitor by the CDC Division of Blood Disorders laboratory as part of the blood monitoring program called Community Counts.*
- The thousands of hemophilia patients who are not cared for through an HTC may not be screened.

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“We need much better inhibitor surveillance. Currently, we don’t know how many people get inhibitors and which products might have higher risks. A recent study in Europe revealed the inhibitor rate in previously untreated, severe hemophilia A patients is 32%. Think about it, 1 out of every 3 patients. Is this acceptable? I think maybe we need some new approaches. What if, we set a goal to eliminate inhibitors within the next 10 years? If we work together, and look for solutions, I believe they can be found. Only then, will we ALL be able to participate in the dream of a better future.” — Debbie, mother of a son with hemophilia and an inhibitor

“I’ve seen treatment progress from dried plasma to fractionated plasma, to plasma concentrates, to recombinant clotting factor, to long lasting factors. In 2002, I was a test subject for gene therapy. With each leap, the condition became easier to manage” — Dan, adult man living with hemophilia, hepatitis C, and HIV

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HFA’s CHOICE Project is heading into its fourth year. 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. We have about 6 more months left to get as many people as possible involved in the project by having them take the survey. Each person who takes the survey helps improve the lives of everyone in the bleeding disorders community.

For those who have yet to take it, 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, both those who do not receive care at federally-funded HTCs and also those who receive HTC care. 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.

Though the primary 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 take the CHOICE survey. So here is a call to action: please contact anyone you know with a bleeding disorder, including carriers, and ask them to take the CHOICE survey. The 20 minutes they spend answering the survey questions can make a genuine difference in the lives of others.

A big thank to all of the community members who have taken the CHOICE survey so far. A special thanks to all of the women with bleeding disorders who have taken the CHOICE survey and made us aware of the issues you face. The data you shared, as well as your forthright and insightful feedback, is helping us identify issues women with bleeding disorders face nationally and at the local level. Hearing from women via the CHOICE survey is critical to advancing our legislative and personal advocacy efforts on behalf of women!

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.
Baxter’s Vision:
PURSUING A LIFE WITHOUT BLEEDS
one person at a time

Our pursuit will continue until a life without bleeds is a reality for all.

OUR PROMISE TO YOU CAN BE SEEN IN EVERYTHING WE DO.

For more than 60 years, Baxter has consistently pursued advancements in the treatment of bleeding conditions. Through our leading investments in research, vast array of programs and support, and people who are dedicated to serving you every day, we partner with you on your life’s journey to thrive toward our vision.

We have a bold vision for the future of bleeding conditions: “A Life Without Bleeds.” We’re passionate about this vision—it inspires us, motivates us, and defines us. Baxter is dedicated to doing everything we can to help make your life better by delivering cutting-edge treatments and an extensive selection of critical resources. We have more than 10 ongoing clinical trials, including those in hemophilia A, hemophilia B, inhibitors, von Willebrand disease, and acquired hemophilia A. For people with bleeding conditions, the future has never been brighter.

Our proven past, the advancements we’re making today, and our passion for the future fuel the Baxter promise: Our relentless pursuit continues until a life without bleeds is a reality for all. This promise to you can be seen in everything we do, and this is what makes us the company we are.

Learn more about Baxter resources and support at www.NAVA.Baxter.com
Since its inception, the Helping Hands program has assisted countless families during their time of need. In the past year, Helping Hands has received over 200 requests for assistance in basic living expenses and medically necessary items and equipment. As 2014 comes to an end, Helping Hands revisited some of these families to see how things have changed.

Early this spring, Helping Hands met a young family on the brink of foreclosure after a series of events caused the family to fall behind in their expenses. We were introduced to a family of six, whose two sons have hemophilia A. The family got behind on their mortgage payments after different family members experienced one illness after another, which resulted in multiple hospitalizations. The family became dependent on the mother’s income after her husband was laid off; but in order to take care of her family, she missed many work days. During this time, one of her sons experienced a prolong bleed that resulted in multiple hospital visits. When the family thought they had the opportunity to get a breather and her husband had secured a temporary position, the family’s only car broke down. This unexpected expense caused their already tight budget to crumble. Soon, they defaulted on their mortgage, and they found themselves on the brink of foreclosure. Helping Hands was able to assist the family in paying part of the minimal payment to avoid foreclosure as the parents worked on picking up extra hours to make ends meet.

Since Helping Hands stepped in, the family has been able to secure a job placement, her son experienced several bleeding episodes that resulted in multiple trips to their hemophilia treatment center and doctor’s office. The demands of caring for her son strained her job search, but she was finally able to secure a job by the time she was referred to Helping Hands. Helping Hands was able to assist her pay the past-due electric bill to avoid shut off, allowing her to focus on starting her new job and maintaining a warm and stable home for her children.

Thank you for everyone who has supported the Helping Hands program. Your support allows HFA to continue the crucial safety net for the bleeding disorder community!

Since 2008, Helping Hands has given this amount back to members of the bleeding disorders community.

$500,000+

Thank you for your assistance. I appreciate all you do for the community.

—Helping Hands Recipient

more Helping Hands on page 10...
As you roll ahead in life with hemophilia B

Imagine a different experience

Emergent BioSolutions is a specialty pharmaceutical company focused on improving the lives of people with rare conditions. We are a different type of company, and are determined to make a difference for people with hemophilia B and those who care for them.

Sign up for updates at:
EmergentBioSolutions.com/hemophiliaB
What Helping Hand applicants have to say:

“Between paying bills and everything else, I didn’t think I could afford this Medic Alert bracelet. Knowing that my child has the bracelet gives me some security that he can be treated correctly if he gets into any accident or gets hurt. THANK YOU.”

“THANK YOU so much. We have been without power for the last week and it has been so rough going back and forth to my parents’ home. Thank you from the bottom of my heart for getting my lights back on.”

“Oh wow. I don’t know what to say. THANK YOU. You have no idea how this helped my family.”

“Both of my ankles are shot and I had no way to pay for these shoe inserts and braces. THANK YOU for helping out!”

“THANK YOU so much. You guys were my last hope. I really didn’t know how I was going to pay rent.”
The bleeding disorders community is made up of dedicated caregivers. However, caregivers can often feel stressed, overwhelmed and burnt out. Therefore, it is important for caregivers to remember to take time just for them. Caregivers often feel guilty or selfish for paying attention to their own needs. But despite these common feelings, prioritizing a little time for yourself each day can go a long way in managing stress—which will better equip you to take care of yourself and others. To recognize November as National Caregiver Month, HFA shared stories from moms, dads, grandparents, spouses, and other family members about their unconditional love, dedication, and support to those living with a bleeding disorder. Below are some practical tips for caregivers, and two powerful perspectives written by a 16-year-old about his younger brother, and from a wife of a man who has hemophilia.

**REMINDERS FOR CAREGIVERS TO PRACTICE SELF-CARE:**

**MOVE YOUR BODY.** Take a walk, stretch, run, dance, practice yoga, play a sport. Do whatever you enjoy doing to get your body moving.

**LEARN TO SAY ‘NO.’** If adding something else to your already busy plate is going to induce more stress, learn that it is okay to say “no.” You’re only one person, you can’t do everything.

**EAT WELL.** Caregivers are often so focused on making sure everyone else is fed and eating nutritiously that they often forget about themselves. Eat a balanced meal and take time to enjoy eating rather than gobbling it down between tasks.

**PRIORITIZE ‘ME TIME.’** Take a little time for yourself each day. Read a book, meditate or engage in a prayer or spiritual practice if that comforts you, write in a journal, or listen to music. Even if you only have 5 minutes per day to spare, do something just for you.

**FORGIVE YOURSELF.** When things don’t go as expected or planned, we often place blame on ourselves. Take a moment to acknowledge these feelings, but then release them. None of are perfect.

**REMIND YOURSELF OF THE POSITIVE.** Take some time each day to remember the positives in your life, such as family, friends, or whatever else makes you feel happy. Keep this in mind.

**ASK FOR HELP.** Talk to trusted family members and friends when you need help or just need someone to listen. Do not feel shameful if you think you might need to talk with a professional like a psychologist or social worker. Taking care of your mental health is just as important as going to the doctor for a physical check-up.

**A Caregivers Perspective: The Unaffected Sibling**

*By Noah Workman*

My brother Evan was born on July 3rd, 2007. Two days after he was born, he was diagnosed with severe hemophilia A. I was eight years old when he was born and had never heard of this condition. It was difficult for me to grasp that my little brother would not live a 'normal' life. I remember crying to my mom and saying “How could this happen?” Every time I made a wish in a fountain, I wished that my little brother could be healthy. That’s all I wished for. Why couldn’t my wish come true?

When Evan was about one-and-a-half years old, he had a head bleed and was sent home with a PICC line for my mom to give him factor until he was able to get a port. He was admitted to the hospital a couple of weeks later because he had a fever. During his second day hospitalized my dad and I went to spend the day with him and my mom.

Evan was playing in the toy room. I was put in charge of watching him when my parents stepped out for a minute. Evan had his eyes fixed on the TV, staring at it with his right hand on a...
Wearing Advocacy On Your Sleeve

“Who knew being an advocate could be so much fun?”

“I’m proud to support this HFA awareness campaign!”

“I love supporting my friends with a bleeding disorder!”
During Hemophilia Awareness Month, our “I Love Someone with Hemophilia/vWD/Bleeding Disorders” images became an instant icon for our community, reaching over 300,000 people on social media. But the advocacy didn’t stop there! You asked us to help you spread the word further and wider, so this summer we began selling these designs on shirts and hoodies through limited edition campaigns.

With your support, we sold over 1,000 shirts & hoodies, raising over $10,000 to help bring the programs and services you love. More than that, you’ve found some amazing, inspiring, and creative ways to spread awareness with these shirts. Here are a few samples you’ve shared with us. Remember: advocacy can be fun!

“This shirt helps me be an advocate wherever I go!”

Dominican Republic
Mexico
Taiwan
Saudi Arabia
Canada
Puerto Rico
Community Spotlight: Beards for Bleeders

By Sonji Wilkes, HFA Programs Coordinator

John Bruno is truly a Dad in Action. HFA recently asked John a few questions about his involvement in the community. John sets a great example for all of those affected by a bleeding disorder. “I'm just looking for a way to do my part in supporting this great community.”

Join John in his efforts by participating in Beards for Bleeders or the Cherry Pie Challenge and consider choosing HFA as the benefactor – funds raised go directly back to support our programs and services for people living with a bleeding disorder.

**HOW DID YOU GET INVOLVED IN FUNDRAISING?**

**JOHN B:** Initially spurred by encouragement from our extended family, we have set up more than six fundraising events ranging from a brew fest, horseshoe tournaments, scavenger hunts, card tournaments, and March Madness bracket challenges.

The idea for the Beard challenge was born when I noticed how long my cousin Steve’s beard had grown in a short six months. Steve, my father-in-law Joe, and I began making plans to raise money by having people sponsor them to grow out their beards for six months; we just needed a good excuse to grow one. When another cousin of mine joined in, I realized I might be on to something.

**HOW DOES BEARDS FOR BLEEDERS WORK?**

**JOHN B:** I started by posting it on Facebook in a few groups, and it quickly spread. We had to come up with some way to connect everyone that was asking questions, so I made a website (beardsforbleeders.org) and we came up with simple guidelines: six months to a year with no shaving, but participants can trim the neck and upper lip.

We also made it so each person who was going to grow a beard with us was in charge of their own sponsors, and could give the money they raise to any local, national, or world non-profits supporting bleeding disorders. This then became a reality as the emails started rolling in. We grew much faster and larger than the three of us had ever expected.

**HOW MANY PEOPLE ARE SIGNED UP FOR BEARDS FOR BLEEDERS?**

**JOHN B:** To date, Beards for Bleeders has 47 “growers,” in five different countries. At two weeks into the fundraiser, the website had over 2,000 views with donations rolling in.

“I’ve always wanted to try to grow in a full beard. This gave me a good excuse and to raise funds/awareness at the same time.”

— Eric, Ohio, father of a son with hemophilia
“Growing this beard is a great conversation starter. I love to do whatever I can to be an advocate for our cause.”
— Vaughn, Maryland, mild hemophilia

DO YOU HAVE OTHER FUNDRAISING INITIATIVES PLANNED FOR THE BLEEDING DISORDERS COMMUNITY?

**JOHN B:** I have started a new fundraising initiative, “The Cherry Pie Challenge.” Much like the viral “Ice Bucket Challenge” that swept social media this summer, the Cherry Pie Challenge consists of participants getting “pied” in the face for a $10 donation, or $100 to avoid being “pied.”

I am again encouraging participants to give to any bleeding disorders non-profit of their choice. A group of friends recently completed the Challenge, including several young men with hemophilia gleefully “pieing” their parents with a cherry pie.

“**At first my coworkers were not on board. However, once I started showing the flyers I made and telling them why, most thought it a wonderful cause. My boss is also fully behind the idea.”**

— Shawn, Maryland, father of a son with hemophilia and an inhibitor
Building Confidence, Muscle, and Friendship
By Randi Clites, NOHF Program/Advocacy Manager

In August 2014, the Northern Ohio Hemophilia Foundation (NOHF) celebrated its seventh anniversary awards banquet for the summer youth golf program. As many youth with bleeding disorders realize, they can now participate for the first time shoulder to shoulder with many of their peers in most non-contact sports with the use of prophylactic treatment. Because golf is a sport that provides benefits throughout a lifespan, NOHF replaced traditional youth support programs with a wellness activity that has reaped some awesome rewards.

The goal of HFA’s FitFactor program is to motivate individuals & families in the bleeding disorder community to engage in regular moderate physical activity, and to maintain a healthy weight and lifestyle through proper nutrition.

Our mantra has been, “healthy bodies bleed less.” At HFA we believe this to be true and we believe that healthy behaviors begin in childhood.

The CDC recommends that children get at least one hour of physical activity each day. Children with hemophilia and other bleeding disorders should be encouraged to find physical activities that are safe and that they enjoy doing. Starting a regular exercise program is key to staying healthy and protecting your joints.

Tips to Encourage Physical Activity for Kids:

- Promote and provide opportunities for your kids to be physically active. Even better, join in the fun with them—be good role models!
- Make it part of your routine. Daily physical activity will become a habit.
- Offer positive feedback or a small reward for exercise.
- Make it fun! Be creative & silly, play tag, “keep it up” with a balloon, or create silly dances.
- Allow some choice. Let your child be the guide on what sport or activity that is of interest to them.

Regular Physical Activity Helps Children:

- develop stronger muscles and bones
- reduce the number of joint or muscle bleeds they might experience
- increase self esteem
- balance their moods
- be academically motivated
- decrease the chance of developing: diabetes, high blood pressure and high cholesterol
- decrease stress
- sleep better
- maintain a healthy weight

School Age and Older

- golf
- swimming
- dancing
- walking
- yoga
- tai chi
- tennis
- running
- hiking
- baseball
- cycling (with a helmet)
- non-contact martial arts

Toddlers and Preschoolers

- playing in the sandbox
- playing catch
- playing at a park
- patty cake
- moving like animals
- yoga
- dancing
- playing
- swimming
When the summer youth golf program began, the goal was to teach young bleeding disorders patients and their siblings a sport that they could use to build confidence and help increase muscle tone and overall strength and flexibility. This would protect them from target joints bleeds. As the program grew, a core group of young patients became more engaged in the bleeding disorders community and encouraged one another to try more safe activities.

Throughout eight weeks, from mid June through the beginning of August, NOHF members between 10 and 18 years old meet at a central location one day a week for three hours of programming. Typically, the program has 15-20 participants. When they first meet in the morning, the physical therapist works them through an appropriate stretching routine for the group before they head out onto the course. The players then get small group instruction from a college-level golf coach/professional. They have two hours of time with the golf pro at the driving range, putting green, and on a 9-hole, three-par golf course. After being on the course, the kids come together for lunch and an educational discussion provided by a local HTC nurse, NOHF staff member, physical therapist, or mentor. At the end of the summer, NOHF holds a family awards celebration and each participant is welcome to invite an adult to go out on the course and golf a full round of play with them to show off their new skills!

We've found that the relationships built through our golf program continue to grow year-round. The youth participants look forward to connecting at other NOHF sponsored events and even make plans to spend time together at their own homes. They are also more likely to attend camps or other wellness sessions when they have a friend participating. Participants have told us that they feel more connected through the golf sessions than any other NOHF program!

One of the added benefits to the program is having a physical therapist on hand to teach participants how to take part even if they are recovering from a bleed. This skill is essential for our kids to get up and take action, both on the course and in life.

With the success of the golf program, NOHF decided to make youth wellness programs a priority, adding a winter swim program two years ago. Now, in addition to the eight-week sum-
mer golf program, there is an eight-week winter swim program held at three locations throughout the NOHF area. Each of the locations provides a 45-minute instruction to the participants based on skill level. The winter swim program runs from the middle of January through the middle of March, and is open to any aged patient and their sibling or caregiver. So far, the program has brought in 20-25 participants each winter. To help with safety and awareness, NOHF provides bleeding disorders awareness training, coordinated with the local HTC, to each of the participating pools before the program begins. At the end of the three regional sessions, an end of season swim meet and awards ceremony is held. The meet is full of fun activities for the whole family to enjoy!

NOHF’s Program/Advocacy Manager, Randi Clites, oversees both the summer and winter wellness programs. Randi has been a staff member of NOHF for three years, after serving as a consumer board member for six years. During her time on the board, she was active in planning newly diagnosed family events along with youth programs. Randi lives in northeastern Ohio with her husband of 19 years, Matt, and her 12-year-old son Colton (Hemophilia A). She is currently a senior at Hiram College, pursuing her degree in Business Management with a minor in Political Science.
**Thank You!** Your support makes it possible to serve our community nationwide!

## 2014 HFA Funders and Sponsors

### VISIONARIES
$500,000+
CDC Collaborative Partners
*Supports:*
- Blood Brotherhood
- FitFactor
- CHOICE Project

### CHAMPIONS
$300,000+
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150,000+
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$75,000+
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- Pfizer Pharmaceuticals

### BELIEVERS
$25,000+
- AHF, INC.
- Kedrion
- National Cornerstone Healthcare Services

### FANS $10,000+
- Accredo’s Hemophilia Health Services
- ARJ Infusion Services
- Biomed Pharmaceuticals
- Emergent Biosolutions
- Hemophilia Alliance
- Octapharma

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to get in touch with a CoRe Manager and learn more about these options.
4th Annual Gears for Good DC Ride

3 DAYS
4 STATES (WV, MD, VA, DC)
24 RIDERS
156 MILES
HUNDREDS OF STORIES SHARED
HUNDREDS OF LAUGHS ALONG THE WAY
$90,000+
RAISED

“156 miles for my dad who passed away from hemophilia and complications of hepatitis C, and for my son who also has hemophilia. THIS RIDE WAS AN AMAZING BONDING EXPERIENCE WITH OTHERS IN THE COMMUNITY, something I will never forget.”

— Dawn Evans, Hemophilia Foundation of Michigan
THANK YOU TO OUR CORPORATE SUPPORTERS:
$10,000 level: Baxter • Grifols
$3,000 level: Bayer • Octapharma • Biogen
CVS Caremark • Emergent Biosolutions

THANK YOU TO OUR FOLLOWING MEMBER ORGANIZATIONS FOR SUPPORTING THE CAUSE:
Hemophilia Foundation of Michigan, Hemophilia of Indiana, Connecticut Hemophilia Society, Florida Hemophilia Association, Central California Hemophilia Foundation, Hemophilia Alliance of Maine (HAM), and New England Hemophilia Association (NEHA), Hemophilia Foundation of Maryland

“This was my first major fundraising event and the longest bike ride I had ever done – it was an amazing experience! The wonderful people I met and the stories we shared will stay with me for the rest of my life. I AM PROUD TO HAVE RAISED FUNDS FOR HELPING HANDS in such a fun, exciting, and enjoyable way!” — Grant Belsham, Emergent Biosolutions

“When it comes to a chronic condition, you never know when you will be in need of an assistance program.” — Dennis Mackey, Connecticut Hemophilia Society

“This was my first ride, and while I was a little anxious beforehand, THE RIDE TOTALLY EXCEEDED MY EXPECTATIONS. The sense of community and support from all of the riders was inspiring and helped me get through some of those tough miles. Knowing that all of the funds raised were going to sustain HFA’s Helping Hands program through the end of the year and support our families in need was empowering.” — Lauren Neybert, HFA Staff

“I ride because my passion for the hemophilia community drives me to do more. It is very rewarding to be able to give back to the community that I love so dearly. I LOOK FORWARD TO RIDING AGAIN NEXT YEAR.” — Carletha Gates, Hemophilia Foundation of Maryland

“I RODE FOR GEARS FOR GOOD TO GIVE SOMETHING BACK TO THE BLEEDING DISORDERS COMMUNITY because my family and I have received so much from community members in the past. Riding in Gears for Good is like riding with an extended family... and meeting family members you never knew you had has been terrific!” — Susi von Oettingen, New Hampshire


DAY RIDERS: Carletha Gates, Stephen Long, Mark Antell, Harvey Gates
Transitioning to Adulthood: Voices from the Community

By Lauren Neybert, HFA Programs Manager

This year, HFA launched Google Hangouts for young adults with a bleeding disorders (ages 18-35). These interactive forums provide an unique opportunity for young adults to connect on important topics from their computer screen. HFA recently hosted a hangout focusing on employment and school advocacy. Our Young Adult panelists share their experiences:

Did you choose to disclose your bleeding disorder to your employer?

**Shelly:** Yes, I disclosed to my current employer after I was hired. I said, “Since we will be working closely together, I wanted to let you know that I have von Willebrand disease, which is a bleeding disorder in which my blood takes longer to clot than normal. I have it mostly under control, and I am living a pretty normal life.” I also let him know that there may be some days I have to miss when I have a bleed, and he was fine with that, and very understanding.

**Ajie:** Yes, I disclosed my condition to my immediate co-workers and boss. We run a two-person system which means that coverage or replacements could be tough if an emergency arises. Because of our tight and complicated situation, I had to let my boss know that this situation might come up and it might hinder me to work for a day. At our first managerial meeting with our new boss, I disclosed it so we could operate as a team, be familiar with each other, just in case I have a bleeding episode—a long explanation wouldn’t be necessary for me to get coverage for my shift.

What suggestions would you recommend to someone with a bleeding disorder when choosing a college/university?

**Tuyen:** I think choosing a college that has a culture you are comfortable with and finding people that you connect with are important—especially so for someone with a bleeding disorder. The first year will be difficult because you are entering a new territory, but having people you enjoy being around makes it easier. It’s also easier to disclose your condition. I found that because my school was very inviting and inclusive, and I associated myself with the culture, my condition was a non-factor, and no one viewed me differently.

**Shelly:** I would recommend a couple of things: 1) Make sure you have a hemophilia treatment center within reasonable distance and meet the staff before you have an emergency situation, so they know you. 2) See if the university has a disability resource center. Let them know who you are, and have them help you with any accommodations you may need.

How else do you advocate for yourself at work/school?

**Tuyen:** I am proactive in communicating that I am a hemophiliac in school because I am proud of the strength of the bleeding disorders community. I think more people need to know that hemophiliacs face a lot of difficulties but are stronger because of them. The community has provided me so many opportunities to build leadership skills and just have fun. I make sure to communicate that while hemophilia in no way defines me, it definitely is a part of who I am. This is especially true for interviews with employers. I use hemophilia as a strength and leverage it as something that makes me stand out and exhibits my resilience.
Know Your Rights at School and Work:

- Your rights at school and work are protected by The Americans with Disabilities Act (ADA). Individuals with disabilities who can perform the essential functions of their jobs are entitled to equal opportunity.

- Essential Functions are the primary duties for which you are hired. Attendance is typically an essential duty for most jobs. Keep in mind: if your condition results in frequent absences from work, you generally will not be protected by the ADA.

- Reasonable Accommodations must be accepted by employers and schools for modifications or adjustments to the individual’s job duties or work environment to help her/him meet the essential functions of the job/assignment.

- Employers are not required to make accommodations for an employee with a disability if it would cause an undue hardship—a major impact on the operation of the business or would impose a significant expense.

- The ADA prohibits employers from asking medical questions during interviews. Once the employee is hired, employers can ask certain medical questions or require a medical exam, but only if all employees with the same type of duties are required as well.

- The Family Medical Leave Act (FMLA) requires employers with 50 or more employees to grant eligible employees with unpaid leave for the birth/care/adoption of a child, to care for a child/spouse/parent with a serious health condition, or for the employee’s own serious health condition. A serious health condition for a person with a bleeding disorder could be a bleeding episode that would keep the employee from performing essential functions of the job for at least 3 consecutive days and require ongoing treatment.

- The ADA and FMLA are federal laws. Your state may offer even greater protection, but not less, than the federal laws.

- Call Patient Services Inc.’s (PSI) free and confidential Legal Support Hotline at 877-851-9065 with questions.

What is a Google Hangout?
Google Hangouts is a free instant messaging and video chat platform developed by Google and available via Google Plus. You can connect via your computer as well as your mobile device. In order to fully participate in HFA’s Young Adult Hangout, you must have a Google Plus account.

Who are they for?
All members of the bleeding disorders community between the ages of 18-35 years old are encouraged to attend.

When do they happen?
In 2015, HFA will host six Young Adult Hangouts throughout the year. The next Google Hangout is on February 3, 2015 and the topic is: Dating and Relationships.

Can I suggest a topic?
Absolutely. Please submit your suggestion to programs@hemophiliafed.org. For more information go to www.hemophiliafed.org

Developed by Bill Leach, of Patient Services Inc., A.C.C.E.S.S Program
You Know You Are a Hemo Mom When...

Compiled by Infusing Love bloggers

Everyone finds coping mechanisms to get through stressful situations. Moms quite often bear the brunt of the stress as caregivers, and many moms of children with bleeding disorders find humor, and especially sarcastic humor, to be a helpful way to deal with the day-to-day issues of hemophilia or other bleeding disorders.

They see the irony in the bumps and bruises and can’t help but laugh at the crazy things hemo moms say and think to themselves. Humor has long been seen as a complimentary and beneficial medicine for those faced with chronic illness; HFA’s “Infusing Love” Mom Bloggers agree, and compiled a list of those moments that are as funny as they are true.

Bumps, Bleeds and Bruises

- You can spot the slightest limp a mile away.
- You can identify the varying stages of bruising and can tell how old one is by color and size.
- You admire veins of friends, family, and complete strangers... and you let them know it!
- You can tell by the way someone walks that they’re bleeding before they do!
- You assess any injury by the number of boxes of factor it will take to get it to stop.
- You start assessing a bleed on another kid/adult before you realize that they don’t have a bleeding disorder.

Laundry Day, aka: Nose and Mouth Bleeds

- You brag to everyone when your child manages their first nosebleed totally on their own.
- You are looking for something in your purse and you pull out nose pinchers.
- You have a red washcloth/towel handy in the car or in your child’s backpack.
- You’ve learned how hard it can be to get blood stains out of clothes or car seats.
- You have learned not to freak out at the site of what looks like a crime scene on a pillow case, or when your child wakes up with dried blood everywhere.
- You have learned that a little peroxide, dishwashing liquid, and a soak in cold water for several hours will make that blood stain smaller and smaller to where it eventually becomes unnoticed.

Need Supplies?

- Your carry-on bag is factor and medical supplies — NOT clothes.
- The contents of your refrigerator cost more than your house and everything else in it.
- When the ER bag is packed for the grab and go... or you can “pack” for a trip or ride in less than 5 minutes.
- You always have a Sharpie marker, tape measure, syringe, saline flush, band-aid or tourniquet in your purse and every drawer in your house.
- You understand the power of a character on a Band-Aid and how much of a difference it can make.
- You see something and think it would make a great ice pack.

School Daze

- Your child has a permanent pass to the school nurse and the front office waves you through without going through the normal check-in procedures.
- Your child has their name on an icepack in the nurse’s office.
- The school nurse calls to see if you have any extra ice packs you’d like to donate because the ones you have work so well.
- You count the number of days your child completes a FULL day of school.
Headed to the Hospital

- You are on a first name basis with every nurse at the hospital.
- You get the employee discount in the hospital cafeteria.
- You have to remind people that you are not a nurse and have no medical training outside of hemophilia.
- You have an amazing confidence and empowerment when you are telling nurses and physicians what hemophilia is, the tests that need to be run, the rules for sticking or who will access the port, and what IV antibiotic is used when waiting for port infection results.
- You can interpret blood tests and CBC results.

Me, An Advocate?!

- You have learned the art of advocacy and standing up for your child, and have an active voice in your local and national bleeding disorder member organization even if you were once reserved and quiet.
- You learn how to lobby when you have never had an interest in politics and law.
- You can translate insurance terms and Explanation of Benefits (EOB).
- You learn how to fight for your choice in providers and manufacturers.
- You have an official health insurance representative that no longer asks for your ID numbers or what you are calling about... they just apologize for processing the claim incorrectly and get it fixed.

Life With A Bleeding Disorder

- You measure days between infusions, not days of the week.
- You have family contests about who has the biggest bruise or you play “what’s that shape?” with bruises (much like laying in the grass looking at clouds).
- You get through a tough infusion morning and get them off to school before you have a good cry.
- Your adult son thanks you for all the needles, all the adventures, all the support you give him.
- It’s not uncommon to randomly cry because you hate watching them suffer, even if there hasn’t been an issue in days or weeks.
- You can put together a wheelchair with one hand (and blindfolded).
- It seems easier to get routine things done in crisis mode than when there’s plenty of time.
- It’s only after your “other” friends eyes glaze over do you realize that you and the hemo moms have been talking in “hemo speak.”
- You can properly spell hemophilia.
- You find ways to reach out to other hemo moms that can relate to or understand what it’s like to find strength when you are tired and frustrated or you are able to give tremendous support without even realizing it just because you listen and have been there.
- You have become part of a new and extended family after a bleeding disorder diagnosis!
shelf and his left hand on his side. He was just so fixated on that TV. My dad came in and tried to get Evan’s attention, but he wouldn’t budge. My brother’s face started to lose color and slowly turned blue. We rushed him over to the nurses that were down the hall, where they said “He isn’t breathing!” One of the nurses gave him the breath of life which got him breathing on his own again. I stood there watching, thinking my brother had died. Evan suffered another seizure later that night, and had to be moved to the PICU. My brother ended up being OK, but this was one of the scariest moments of my life.

Even though my family and I have gone through so much relating to my brother’s hemophilia, we’ve never treated him as different. My brother has been so brave in talking about his condition with people who are curious about his port protruding from his chest. There have been conversations about why he shouldn’t play certain sports. However, at family events, when everyone plays football and soccer, I have been truly amazed at how my family remains aware of his needs and includes him in everything.

One of the hardest questions I have ever been asked is “If you had a magic wand that could take away your brothers hemophilia, would you?” And, I feel as though I shouldn’t be the one to decide if he ‘should’ or ‘should not’ have hemophilia. Selfishly, hell yes. Without a doubt, in a heartbeat I would take that away for him. But, hemophilia has become so much more for my brother, myself, and my family. It is a community, a vessel for my brother to become the person he is today.

Hemophilia has become a part of our family, and most importantly, it’s the reason why my brother has met so many amazing, brave, smart, and funny people. So, no, I guess I would not take away his hemophilia. I would however, use my magic wand to make his factor cost significantly less money.

**My wishes for my brother as he grows up are:**
- For him to know that he should never be afraid or ashamed of who he really is.
- For him to not allow himself to set boundaries because they will stop him from living life the way he truly wants to live.
- For him to never let hemophilia be a boundary, but instead a reminder that he can do anything he sets his mind to.

Noah is 16 years old and lives in Tampa, FL with his family.

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**Having issues with co-pays or gaps in coverage for your hemophilia A treatment??**

We may be able to help.

Bayer offers a range of programs that can help you navigate insurance questions about your hemophilia A treatment. If you’re having issues with co-pays or gaps in coverage, we may be able to offer assistance. Speak with one of our case specialists to find out more.

Call 1-800-288-8374 and press 1 to speak to a trained insurance specialist!
A Caregivers Perspective: 
Hemo Wife Uncorked

By Stephanie Johnson

I worry when he’s late coming home and I haven’t heard from him in a while. I worry when I can’t get a hold of him on the phone for hours. I worry when he boards a plane for a trip. I worry when we do any physical activity where there’s a possibility he might get hurt. I worry when he bumps his head or has a headache. I worry when he’s walking with even the slightest limp. I do a lot of worrying.

Reading this, you might think I’m a mom, but I’m not. I’m the wife of a hemophiliac. He is the love of my life, my best friend, my soul mate and I can’t imagine life without him. He brings immense joy to my life everyday and can make me laugh at the drop of a hat. My husband is the best husband I could ever dream of and I wouldn’t trade him for the world.

That being said, marriage is sometimes hard and the “perfect” relationship is a myth. Relationships aren’t ever actually perfect. The truly best relationships are the honest ones where both people never give up, and the wife of a hemo never gives up.

Being married to someone with a disability can at times be even harder than your typical relationship, especially when it’s a disability that the average person cannot see or may have never heard of. Explaining to others the short notice for canceled plans due to a bleed or educating them on how my husband’s medicine isn’t just taken like a pill can be tiring, and not many people understand, but that’s okay. We have a community here that does.

There’s a reason why my husband calls his hemo friends, especially his blood brothers, his “hemohana” — a term he coined by combining “hemo” with “ohana,” the Hawaiian word for family. They’re all our family, our “hemohana” because no one is forgotten, no one gets left behind. Having that kind of support and quiet empathy during those tough times when all you want is a shoulder to cry on is a relief we all can understand, “hemo” and “clotter” alike.

It’s safe to say I have a love/hate relationship with hemophilia itself. I hate the pain my husband deals with on a daily basis. I hate that it takes him away from activities he’d love to participate in but can’t due to the high risk of a bleed or a bleed that he’s currently recovering from. I hate my frustration at explaining why he can’t just take more Vitamin K and be cured.

But even with the negatives, there are always positives, and in this case, there are quite a few. I love our hemohana and the wonderful people I’ve met through this community, who astound me with their strength and wisdom. I love the fact that because of hemophilia and what it has brought to my husband’s life, it has made him who he is today. The loss, sorrow and joys of his experiences living with hemophilia have made him into an amazing man whom I adore with all my heart. I am proud to be his wife and am honored to continue to grow in this life with him by my side.

A great quote from an unknown author said, “A great marriage doesn’t happen because of the love you had in the beginning, but how well you continue building love until the end.” Every day is a blessing, good or bad, that I may have the pleasure of knowing and loving my hemophiliac. I love my hemo-honey and I couldn’t ever imagine my life without him or without hemophilia.

Stephanie and her husband Jeff live in Oregon.

Stephanie and her husband Jeff, who has hemophilia.
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