



# DATELINE

F E D E R A T I O N

Issue 50 | Volume 16 | Fall 2016



**AN UNEXPECTED TURN IN  
OUR "LUCKY" ROAD pg. 11**



# WE'RE STRONGER WITH YOUR SUPPORT!

There are many ways you can make a contribution to Hemophilia Federation of America as the end of year approaches. Donations are tax-deductible and support the organization's efforts to advocate for the bleeding disorders community.



## Annual Giving | November 15-December 31

- Donate online at [www.hemophiliafed.org](http://www.hemophiliafed.org) or send a check to HFA at 820 First Street NE, Suite 720, Washington, DC 20002.
- All donations will support Helping Hands, HFA's financial assistance program.
- Be sure to ask your employer if they match employees' charitable gifts: a great way to double your gift!



## Cyber Monday | November 28

- Participate in one of the biggest online shopping days of the year, and support HFA by making your purchases using Amazon Smile.
- When you shop on Amazon Smile, you'll find the same low prices and vast selection as on Amazon, with the added bonus that Amazon will donate a portion of the purchase price to HFA.
- All it takes is three easy steps:
  - Sign up for Amazon Smile through your Amazon account at [smile.amazon.com](http://smile.amazon.com).
  - Designate Hemophilia Federation of America as your charity of choice.
  - Make holiday purchases on Amazon Smile and a percentage automatically goes to HFA.
- Amazon Smile is available year-round so be sure to designate HFA as your charity of choice today.



## Giving Tuesday | November 29

- Take part in this annual, international day of giving as the holiday season kicks off and show your support for HFA.
- Donate online at [www.hemophiliafed.org](http://www.hemophiliafed.org) and receive special acknowledgment of your gift.
- Share your giving spirit on social media and encourage others to give by using [#givingtuesday](https://twitter.com/givingtuesday).



## Annual Membership

- Renew or initiate an individual, professional, or corporate membership.
- Individual memberships start at \$25.00.
- Visit [www.hemophiliafed.org](http://www.hemophiliafed.org) today.



## Other ways to give:

- When making holiday gift purchases, ask if the store will donate a portion of the sale to a charity.
- In lieu of giving a physical present, consider making a Tribute Gift in the name of a loved one.
- Ask your employer if they match employee charitable gifts

With your help, HFA will be able to deliver educational programming, help families experiencing a financial crisis, advocate for the bleeding disorders community, and so much more. Thank you in advance for your generosity and support.



Assisting and advocating for the bleeding disorders community since 1994.

Issue 50 | Volume 16 | Fall 2016

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## Dear Community Members,

Our first trip out as a family after we brought Nicholas home from the hospital was to our HTC. A few of the typical warning signals had gone off at the hospital that our newborn baby could have some clotting issues and a blood test revealed he had a very high clotting time. Your first trip out with a newborn is an experience in itself. Having it be to the Hematology/Oncology unit at your Children's Hospital is not ideal for a woman who's just had her first child.

As we were waiting to be called, a nurse came out for another patient and was just so excited to see her. She marveled at how much the child had grown and how wonderful she looked. My husband and I looked at each other, with teary eyes, and said that we didn't ever want them to talk to us like that. We knew that in order for them to talk to us like that, they would have to really know us—and for them to know us that well meant that we'd have to have spent a lot of time there. This was definitely one place we did not want to spend a lot of our time. It was nothing personal about anybody there, but we didn't want to have a need to be there.

At that point, we didn't yet know that we wouldn't have a choice, that we'd end up spending lots of time at what we would come to refer as "our" HTC. Never in our wildest dreams did we think our little baby would end up getting so many needle sticks that we came to be on a first name basis with all the members of the IV Therapy Team. In fact, we were such frequent fliers, we had no problem asking who was on duty and requesting our favorite. But we did on numerous occasions.

Fast forward 13 years to a few months ago. It had been quite some time since Nicholas had had a factor recovery study done and the doctor felt it was time. The study was going to take an entire day and Nicholas was not happy. I wasn't too thrilled about it myself, but we had no choice so I kept my thoughts to myself.

When we went to our HTC, the conversation I heard was pretty close to the same I had heard during our first visit so many years ago, except that this time they were talking to my son. They expressed shock at how much he had grown since his last visit and gushed about what a handsome boy he was. Once again, I had tears in my eyes, but this time, along with the tears, I had a smile full of pride and happiness. Not only had

Nicholas grown, but his dad and I had grown a lot as well. Our growth was more emotional than physical and that emotional development we can credit in large part to those kind, caring people at the HTC. Yes, those same people we really didn't want to have to see on a regular basis. Now I can't imagine our lives without them.

Time can give you perspective on so many things. In this issue, we look at the what we've learned through Project CALLS as we continue to build cases for change for the community (p. 14). We also take a deep dive into the data we've pulled from

**“Yes, those same people we really didn't want to have to see on a regular basis. Now I can't imagine our lives without them.”**

the Helping Hands program as we benchmark our efforts to further assist families facing financial hardship (p. 17). I'm grateful for the community members who have taken time to share their stories with us, including David Tignor who discusses how he copes with pain (p.19), Kari Peepe who highlights a women's retreat where nutrition and peer support was at the

forefront of combating anemia (p. 24), and Shari Luckey, whose heartwarming story about the adoption of her son Luke gives us all hope for the children who don't have access to medication or a loving family (p. 11).

And finally, the hemophilia community lost a true champion recently: blood brother John Reed. John had a childhood similar to so many blood brothers with limited physical activity, painful injuries, and too many days hooked to an IV pole. But what John also had was a remarkably positive attitude and the belief that you shouldn't focus on the bad but be thankful for good. A remembrance of this exceptional man can be found on page 26. While this has been a difficult year as we mourn the passing of many men, young and aging, in our community, it is together as a community that we must carry the pledge to never forget.

*Warm regards,*

*Tracy L. Cleghorn*

**Tracy Cleghorn**  
Board Chair



# Member Organization Spotlight: Hemophilia Foundation of Southern California

*HFA sat down with Michelle Kim, Esq., the executive director of the Hemophilia Foundation of Southern California, to talk about the organization's services and plans for the future.*

## **HFA: What areas of Southern California do you serve?**

► **Michelle:** We serve nine counties in the Southern California Region: San Luis Obispo, Santa Barbara, Los Angeles, Orange, Riverside, Kern, Ventura, San Bernardino, and Inyo.

## **HFA: What are some of the biggest challenges faced by your organization?**

► **Michelle:** Insurance issues continue to be a big problem, but actually, outreach to the teen and young adult population is proving to be a real challenge. For people in that age group, their treatment protocols are stabilized and many do not want to be associated with having a medical disorder. To address this issue, we initiated a Teen Leadership Program, hosting six teenagers for one week at a nearby hotel. The group worked in our office, created a public service announcement video, was trained on résumé development and interview skills, and met with an HTC. HFA staff member Janel Johnson-Momanyi led the group in an advocacy training session to prepare them to meet with a local legislator. And, happily, that legislator ultimately voted in favor of the Senate Bill we were supporting.

## **HFA: You've incorporated HFA's Dads in Action and Blood Brotherhood programming into your organization's offerings. What kind of impact has that had on the organization and your local community?**

► **Michelle:** One of our goals was to build up a community we felt had been disenfranchised and disengaged: dads and Blood Brothers. Our board of directors gave us the flexibility to create appealing, new activities and we made use of the impressive roster of knowledgeable speakers from HFA. Many of our members had been requesting programs like these for years, so when we managed to launch them, the response was extremely favorable. So far in 2016, we have hosted 11 HFA programs including a one-day retreat titled "Growing Older with Hemophilia and Sports" which included fun and unusual activities like mining for geodes. The men also did some freshwater fishing, catching the tilapia that they then grilled





for dinner. While enjoying their well-earned dinner, they listened to a presentation on emergency preparedness, a topic of particular interest and importance in our earthquake-prone region. The men continue to request more activities; one dad even shared with us that participating in these activities had allowed him to become aware of, and overcome, a private barrier that existed in one of his personal relationships.

### **HFA: What makes your organization unique from other Member Organizations?**

► **Michelle:** Our incredibly diverse member population makes us not only unique but very special! Despite our seeming differences, we have the common thread of community that binds us. We recently hosted Hispanic Celebration Day, featuring HFA staff member Martha Boria, attended by more than 300 members. More than 20 countries were represented that day, something of which we are tremendously proud, and we happily displayed that international diversity on an interactive map at the event. We are so lucky to have access to the incredible resources that Southern California offers; we've had retreats in Malibu, special team events with the LA Lakers and LA Dodgers, and outdoor events that included swimming for our members. We're hoping to get surfing and tennis incorporated into an upcoming event. Fortunately for our event planners, but unfortunately for our region, we rarely have to worry about the rain ruining our outdoor events.

### **HFA: What inspires you about the bleeding disorders community?**

► **Michelle:** My true passion is to connect people with resources that they need. I love that this community, in turn, is immediately responsive to other people's needs as well. People are quick to offer help and solutions. Recently, we registered as an official charity of the Long Beach Marathon, and we quickly signed up more than 50 people to participate and fundraise for our scholarship fund. I was stunned at the response and we ended up being able to distribute three additional scholarships! My vision is to ensure our members have total access to HTC treatment, dental needs fulfilled, and any barriers to education removed. I also want our teens and young adults to be not only gainfully employed but also pursuing their dreams, knowing their disorder just makes them stronger and uniquely situated in a competitive world! ■■

After a week of advocacy training and efforts, the teens celebrate when Assemblyman Chris Holden tells them, **“You have convinced me that I must support SB 586!”**



# PROJECT CALLS

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

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

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

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

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

**If you or a member of your family have been:**

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

**Project CALLS is for you!**

**To contact us about your insurance issue, please call (202) 836-2530, email [projectCALLS@hemophiliafed.org](mailto:projectCALLS@hemophiliafed.org), or visit [www.ProjectCALLS.org](http://www.ProjectCALLS.org)**

# HFA Goes to College

By Sarah Shinkman, Staff Member

**T**ransitioning from high school to college is a big step in anyone's life. For young adults living with a bleeding disorder, this time also challenges them to learn how to manage their health and treatment independently. In August, HFA's Young Adult Program recorded a Google Hangout on the topic of going to college. Three panelists shared valuable insights on planning for school, preparing for the unexpected, and practicing self-advocacy both in and out of the classroom.

## SHELLY, TENNESSEE

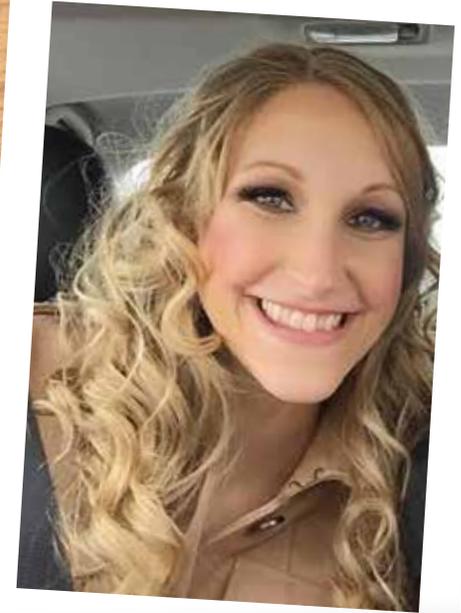
“When preparing to transition to any new place, college especially, it's good to be proactive about the care of your bleeding disorder. Find out if there will be a Hemophilia Treatment Center near you, and if there is, have your medical records transferred there and go meet the staff, well in advance of emergency. If there is no HTC nearby, see what recommendations your home HTC might have for hospitals, clinics, ordering factor, and medical care in general while you are away from home.”

## SACHIN, NEW YORK

“Hemophilia doesn't have to mean not being physically active. As long as you take the proper precautions, keep up-to-date with your treatments, and prepare for the possibilities, you can get out there and push hard in whatever you're doing. There's a lot you can do to set up the environment to your advantage.”

## SAMI, WISCONSIN

“Make finding a school that fulfills your bleeding disorder needs as important as choosing one that has the best financial aid package or academic availabilities. It will make adjusting to your new environment so much easier, and you won't have to worry about medical or accommodation 'what ifs.' Instead, you'll be able to focus on learning, making new friends, and the fun of campus life.”



## Go through HFA's checklist and consider how prepared you are to thrive at college:

### ☐ **Managing care**

Ask your current medical provider about care at school. Make a treatment plan and contact the student health center on campus to discuss your plan.

### ☐ **Record keeping**

Purchase a notebook to document your research, including contacts, locations, and action items. Organize any paperwork you will need before going to school.

### ☐ **Know your rights on campus**

Register with your school's Center for Disabilities or Office of Accessibility Services.

### ☐ **Stock Up**

Make sure you have everything you need to manage your disorder. For example, what supplies do you need to infuse and how far in advance do they need to be ordered?

### ☐ **Disclose**

Sharing information about your bleeding disorder with others is a personal decision and an important one to consider while on campus. College offers many opportunities for independence, but you do not have to give up the support of others during this transition.

### ☐ **Freshmen 15**

Make a plan for maintaining a healthy diet and exercise during college. Most schools now offer fitness classes, in addition to a traditional gym.

## GOT TEN MINUTES?

**Listen to HFA's new Young Adult podcast! Three episodes will be released this fall about healthy eating, strength training, and yoga. Find them at [www.hemophiliafed.org](http://www.hemophiliafed.org).**



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# Remembering John Reed



It is with a heavy heart that HFA mourns the loss of John Reed, who, at the time of his death, was serving on the Board of Directors. He passed away on October 15 after struggling with multiple complications from a joint replacement.

In our community's history, John shone as a resilient champion and a committed advocate. John was an HFA supporter from the founding days of the organization. A pharmacist as well as a community member, John was a long-standing member of HFA's medical advisory team, a chair of Blood Brotherhood, and he returned as a board member just a few years ago.

John was a good and gracious gentleman. He was a humble, loyal and dedicated servant-leader, and a true community friend and family member. He will be greatly missed and will be remembered with love. We send our thoughts and prayers to his wife, Carol, and their family. ■ ■

HFA's Annual Symposium is heading to  
PROVIDENCE, RHODE ISLAND!  
April 6-9, 2017



Put it in your calendar: this is  
a city you won't want to miss.

REGISTRATION OPENS IN NOVEMBER  
[www.hemophiliafed.org](http://www.hemophiliafed.org)



## CYRIL HOME CARE PHARMACY

We only have one  
motto and mission.

We would like for you to be  
able to look back and say:

*“My life with  
hemophilia is better  
today than it was  
before we ever met.”*

*John and Carol Reed*



John Reed DPh

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# An Unexpected Turn in Our “Luckey” Road

By Shari Luckey



**E**ight years ago, if someone had asked if we were planning to have more children, I would have laughed and politely responded, “No.” Three children was actually one more than we had planned for as we had already gotten a bonus when I gave birth to twins when our first-born was six years old. Besides, we have faced our share of challenges as a family. I am a carrier of hemophilia B and my older brother, who had severe hemophilia B, passed away from complications from AIDS in 1993. Our oldest son has severe hemophilia B with inhibitors and suffers from an anaphylactic reaction to factor IX. One of our twin daughters has mild hemophilia, like me. We had all that we could handle and our family was complete, or so we thought.

In March 2009 we received an email that introduced an unexpected hairpin turn in the middle of our family’s roadmap. The email told us about a delicate, sweet-natured young boy, living in an orphanage in Nanjing, China. He had hemophilia and had spent many weeks in the hospital. His situation spoke to my husband and me so we requested more information. After receiving his file and learning that he had hemophilia A, we made a prompt decision as a family to make him a Luckey.



We swiftly completed all of the steps necessary to adopt him. In order to complete the adoption, we needed pre-approval from China and a home assessment from a local adoption agency. We also had to take online training for older and special needs children, complete various legal papers and forms, and get everything expedited to China for authorization and approval.

From start to finish, the process took about nine months. The cost associated with an adoption from China is currently around \$30,000 including travel. Understandably, many people are put off by the high cost of international adoption but there are numerous grants available to help cover a large percentage of the cost.

It was January 25 when we first met Luke in China. He was frail and had a slight limp, as his right knee had repeatedly bled over the years and was extremely swollen. During our visit, he spent the majority of his time in a borrowed wheelchair, giving him a sense of freedom he had never before experienced. After spending 20 days together in China, we flew home to the US. Immediately upon stepping off of the plane, Luke became an official US citizen, and he was automatically covered by our private health insurance. We spent the first few



days alone with just the family, letting the children get to know each other while we recovered from our jet-lag.

Within a week of coming home, however, we took Luke to our hematologist for an evaluation. We had arranged this appointment ahead of time and requested a Mandarin-speaking translator to help ensure a smooth visit. The lab work was completed that day and severe hemophilia A was confirmed as the diagnosis. He had developed a toe bleed so he received a dose of factor VIII and, upon waking the next morning with his toe feeling better, he gave us a happy thumbs up for his new medicine. Luke soon began physical therapy for his knee and began prophylaxis twice a week. Over the course of the next several months, he made amazing progress, growing physically stronger and regaining full use of his knee. The first summer Luke was with us, he was able to attend Camp Bold Eagle where he learned to self-infuse and he is now independent with his infusions. Because he experienced occasional breakthrough bleeds at that time, the hematologist increased Luke's prophylaxis to three times per week. In the six years since, he has not experienced one bleed.

Integrating into everyday life was naturally a process for us and for Luke. He had to learn to live within a busy family with varying agendas and often hectic schedules. This was challenging because he was used to living in a more regimented community on a strict schedule so it took him some time to learn how to handle spontaneity and "go with the flow." He had never been allowed to be physically active at the orphanage, so he had to adjust to doing things he had never been allowed to do. Now, almost seven years after the adoption, life for Luke is much different. In his freshman year of high school, he earned excellent grades, played violin in the school orchestra, and even participated in team sports. He is now physically strong and healthy, and has family and friends who love him dearly.

Luke's story has inspired the director of his adoption agency to start advocating for children with hemophilia who are living in China and seeking adoption. The agency now routinely searches for boys with hemophilia, and then contacts me and several other moms in the community who then go to work championing their adoptions. In just this past year, we have matched more than ten boys to families and encouraged other adoption agencies to begin representing children with hemophilia. Through my involvement, I have met many amazing people; one mom who adopted her son a few years ago started the Hemophilia Adoption Facebook page. This group consists of people who have adopted, are considering, or are in the process of, adopting a child with a bleeding disorder. We are creating a network of advocates, mentors, and experts in hemophilia-related adoptions. I am blessed to be a part of this growing community. ■ ■

*Shari lives in Michigan with her husband Dave, 22-year-old son Jay, 16-year-old twin daughters, Anya and Isabella, and her 16-year-old son Luke. For more information about her hemophilia adoption efforts, Shari can be reached at [sluckey@hfmich.org](mailto:sluckey@hfmich.org).*

# HFA Awards \$10,000 in Educational Scholarships

Each year, HFA awards scholarships to promising students in the bleeding disorders community. A total of four scholarships ranging from \$2,000 to \$4,000 is awarded in these three categories:

## Educational Scholarship

Two educational scholarships were awarded in the amount of \$2,000 each to students with a bleeding disorder who were seeking a post-secondary education from a college, university or trade school. Applicants were asked to submit an essay answering the questions: What are your goals and aspirations? How has the bleeding disorders community played a role in your life?

## Parent/Sibling/Child Educational Scholarship

One scholarship was awarded in the amount of \$2,000 to the immediate family member of a person with a bleeding disorder who was seeking a post-secondary education from a college, university or trade school. Applicants were asked to submit an essay answering the questions: What are your goals and aspirations? How has the bleeding disorders community played a role in your life?

## Medical/Healthcare Services Educational Scholarship

One scholarship was awarded in the amount of \$4,000 to a student pursuing a degree in the medical/healthcare services field. Applicants were asked to submit an essay answering the questions: Why did you choose to study in this field? Why do you think it is the right path for you?

## 2016 EDUCATIONAL SCHOLARSHIP RECIPIENTS:

### Trevor Martin

**HFA Educational Scholarship**  
**Belmont University | Nashville, Tennessee**



"I am honored to have received this educational scholarship! I have severe hemophilia A and must work daily to maintain a healthy lifestyle. I'm currently studying voice, with particular interest in music as a business. My goal is to become a recording artist someday. Fingers crossed! I love and appreciate the hemophilia community and I'm looking forward to giving back to this community that has helped me so much!"

### Chetan Bafna

**HFA Educational Scholarship**  
**University of Arizona | Tucson, Arizona**



"My freshman year at the University of Arizona was one of the most rewarding times of my life. Having the support of my community meant that I could attend the National Hemophilia Foundation's Advocacy Days in Washington, DC as well as the national hemophilia meeting in Orlando, FL. I will forever be indebted to the bleeding disorders community for all they've given me. Thanks to this scholarship, I can continue to attend my dream school. I also plan to continue my advocacy for funding in higher education and for my community as a whole."

### Abby Poole

**HFA Parent/Sibling/Child Educational Scholarship**  
**Huntington University | Huntington, Indiana**



"This scholarship will help me fulfill my lifelong dream of participating in medical missions. I'm currently a nursing student and this scholarship will assist me in achieving my goal of becoming a nurse practitioner. My involvement in the bleeding disorders community has allowed me to become a part of something bigger than myself. I hope that my training will help me to be a positive influence within our country's health care system at large, most especially as I continue to advocate for our very special bleeding disorders community."

### Emma Rickey

**HFA Medical/Health Services Educational Scholarship**  
**Malone University | Canton, Ohio**



"When I was diagnosed with a bleeding disorder, my eyes were opened to new perspectives and my heart now beats with a renewed compassion for others who are suffering. With the help of this wonderful scholarship I plan to work hard in my medical studies so I can ultimately provide aid and comfort to others, just as I have been sustained and helped myself. I'm very proud to be a contributing member of the bleeding disorders community, and I'm honored to be so generously supported by this admirable foundation." ■■



# PROJECT CALLS 2.0

## Creating Alternatives to Limiting and Lacking Services

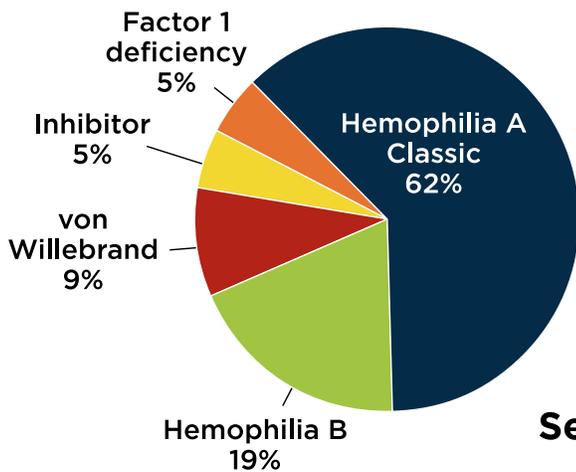
By Katie Verb, JD, Staff Member

In August 2015, Hemophilia Federation of America launched Project CALLS, an initiative designed to help the bleeding disorders community collect data and stories about how changes in insurance company policies are impacting the care of those with bleeding disorders. Since the launch of Project CALLS, HFA has spoken with more than 50 members of the bleeding disorders community, allowing their voices to be heard. HFA started Project CALLS in an effort to create a more accurate picture of the types

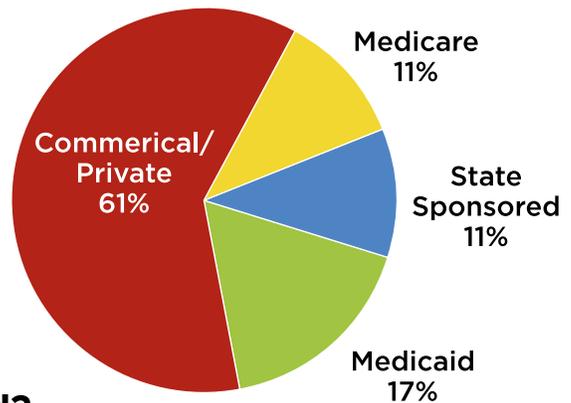
of insurance issues encountered by the bleeding disorders community.

In the first iteration of the Project CALLS survey, HFA learned that the community was having more issues with their insurance than first imagined and decided to significantly expand their data sets. In Project CALLS 2.0, HFA is gathering data about network adequacy, deductibles, premiums, and balance billing in addition to information about prior authorization and specialty pharmacies.

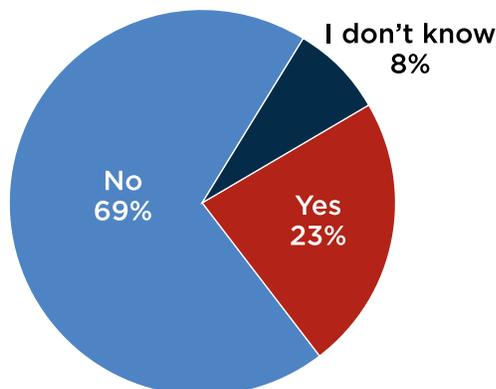
### Diagnosis



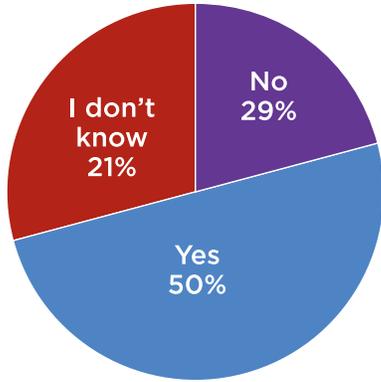
### Type of Insurance



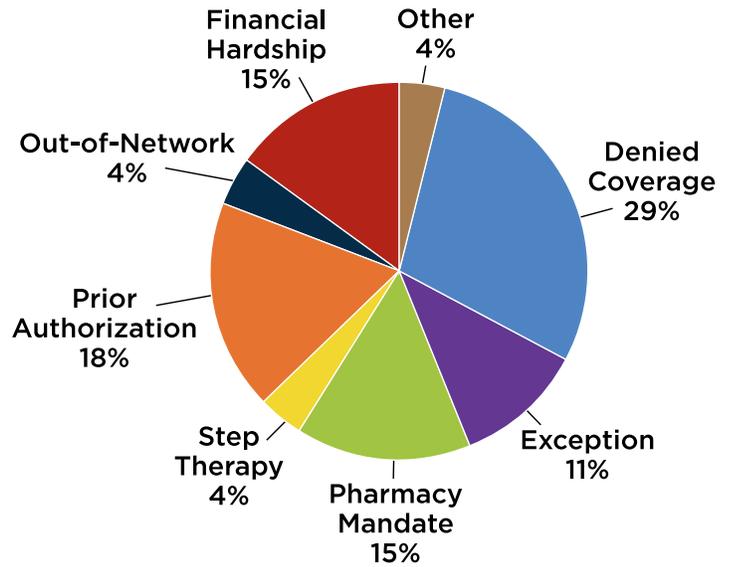
### Self-Insured?



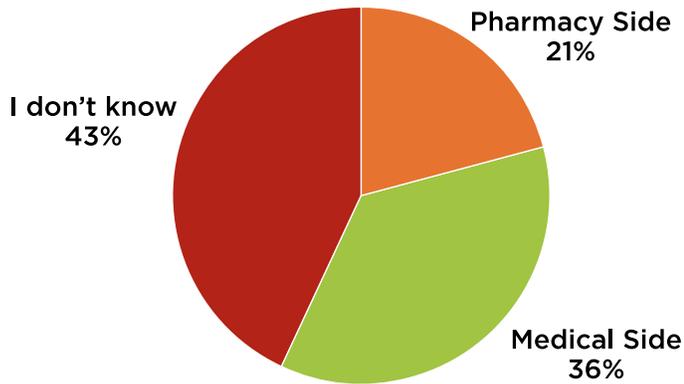
### Specialty Pharmacy Mandate



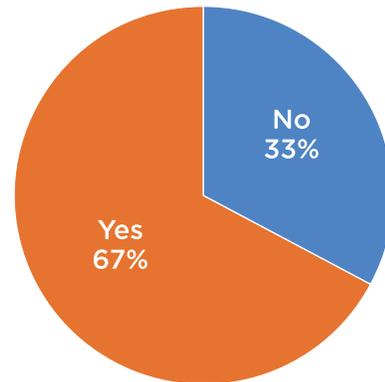
### Issue Reported



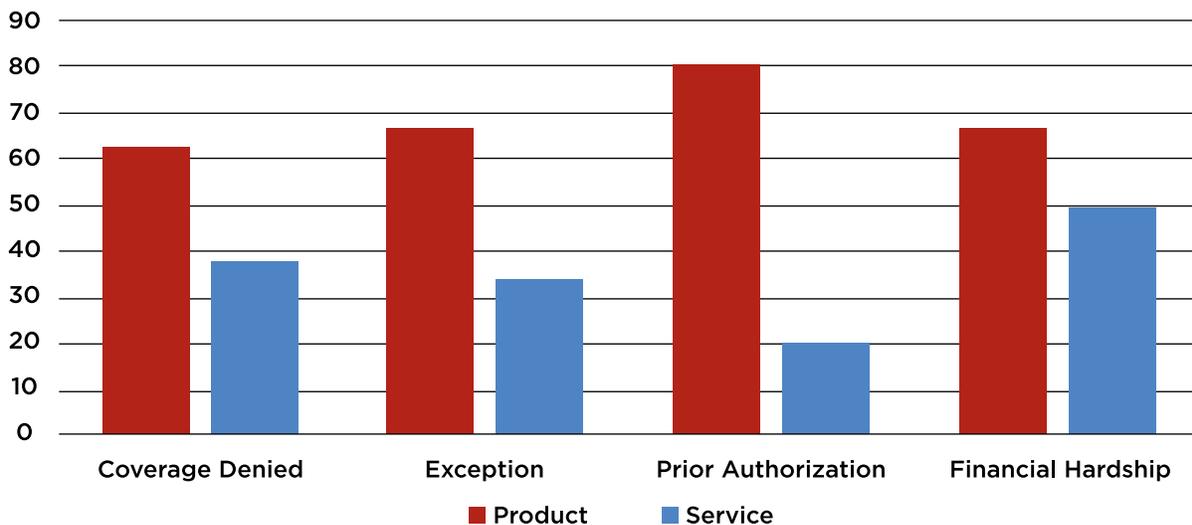
### Pharmacy or Medical Billing for Product



### Delayed Care?



### Product or Service?



# Project CALLS Personal Story

By Angel Parrett

**I**n August 2015, HFA launched Project CALLS (Creating Alternatives to Limiting and Lacking Services), a patient-centered advocacy initiative focused on collecting stories from individuals who have experienced barriers to care or believe their bleeding disorder has been mismanaged because of limitations or mandates set by their insurance company. Angel, a Project CALLS participant, shares her story:

My journey in life with a bleeding disorder has been an uncommon one.

I have severe factor 1 deficiency (afibrinogenemia), a very rare bleeding disorder for which, until 2009, there was only one treatment available. Given the lack of treatment options and the fact that I was on and off state Medicaid until 2012, navigating private insurance and considering what products best fit with my coverage wasn't really a concern of mine, until recently.

I switched to a new factor product in November 2014, again only having one choice of treatment. None of my insurance plans have made it easy to start coverage for this factor. Every plan I have been on, including three private group plans and two plans through the Affordable Care Act, has required prior authorization. What should be routine infusions have been delayed or suspended because of the restrictions my HTC puts on adminis-

tering preferred product unless they know insurance has paid for it. This was particularly an issue last year when I was uninsured for the better part of three months.

This year, I experienced further issues with having my factor covered for home use. This forced me to put the process of home infusion on hold. Along with issues with my policy, registration at the hospital that houses my HTC has also made accessing treatment difficult. I have had routine care blocked, or attempted to be blocked, twice. Once my care was denied because there were no orders allowing for infusions outside the prophylaxis schedule; the other time the denial of care was due to the insurance company's failure to investigate the status of products covered.

Through all of this, Project CALLS has been helpful while I navigate the insurance system. Having a place to express my concerns and clarify where I am experiencing gaps in care is the support I need. I am grateful for their service and hope that one day many of these obstacles will be eliminated.

**Your participation in Project CALLS will allow HFA to collect stories like Angel's, collate the data, identify trends, and use the information to build cases for change. For more information, visit [www.hemophiliafed.org](http://www.hemophiliafed.org) or call (202) 836-2530. ■■**



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‡People with private, commercial health insurance may receive co-pay or co-insurance assistance based on eligibility requirements. The program is on a first-come, first-served basis. Financial support is available for up to 12 months. Eligible patients can re-enroll for additional 12-month courses. The program is not for patients receiving prescription reimbursement under any federal-, state-, or government-funded insurance programs, or where prohibited by law. All people who meet these criteria are encouraged to apply. Bayer reserves the right to discontinue the program at any time.

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# What We've Learned from Two Years of Helping Hands Data



By Elaine Chan, MSW, Staff Member

**H**FHA created the Helping Hands Program in 1997 to provide assistance for individuals with bleeding disorders who were experiencing financial difficulties. Applications for assistance are evaluated individually and, if approved, provide assistance with basic living expenses such as housing, utility bills, transportation, and other urgent needs. Helping Hands serves as a safety net to families during critical times and seeks to provide them with the tools and resources needed to maintain financial stability in the future. In 2012, Helping Hands added "Items Reimbursement" as an additional support category to assist individuals and families with the costs of durable medical items like medical identification products and walking supports. While monitoring and assessment of the program happens year-round, every two years HFA takes a deeper look into the data it receives through applications and surveys. Below, you'll see what HFA has learned after analyzing the data from 2013 and 2014.

## Application Breakdown

**744** APPLICATIONS WERE RECEIVED

**447**

for emergency assistance

**297**

for reimbursement requests

- Close to three-quarters of applications were funded, totaling more than **\$220,000** in assistance.
- **9%** of households that requested emergency assistance were affected by an inhibitor.
- **19%** of households that requested reimbursement were affected by an inhibitor.

## Many households utilize public benefits to supplement their incomes.

- **26%** receive Social Security/Disability (SSDI).
- **28%** receive Supplement Security Income (SSI).
- **47%** receive benefits from the Supplement Nutrition Assistance Program (SNAP).

## Access to health insurance:

- **73%** utilize Medicaid/Medicare.
- **30%** are covered by private insurance.
- **9%** reported not having health insurance coverage.

*\*The total percentage exceeds 100% because of certain households where some members have no insurance or a combination of insurance programs.*

## Survey Results

HFA conducted outreach efforts to survey the 297 households that received emergency assistance from January 1, 2013 through December 31, 2014. The program survey yielded a 31% response rate. Survey respondents answered questions on a variety of topics including health, education, financial circumstances, employment status, and their level of satisfaction with the Helping Hands program processes. The survey yielded some key findings:

**36%** reported an improvement in their financial situation after receiving assistance.

**48%**

*indicated their financial situation remained the same but have not experienced more financial hardship.*

- Among respondents who indicated no improvement in financial status, the top three reasons were attributed to loss/change of employment, unexpected or increased medical bills, or an increase in other household expenses.
- Those who reported an improvement attributed it to stable work, increase in income, better financial management, and/or no significant medical issues or hospitalization.

**71%** *reported being current on their monthly expenses. The other 29% of respondents reported mainly experiencing acute (0-3 months) financial hardship.*

**53%** *reported not having to seek assistance from other sources or charitable organizations. Those who do seek assistance reached out to their local bleeding disorders organization.*

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# How I Cope with Pain

By David “Tigg” Tignor



**P**ain is a serious medical concern in our country. Approximately 100 million Americans suffer from chronic pain. For those living with bleeding disorders, pain as a result of a bleeding episode can result in acute (short-term) and/or chronic pain issues. Everyone will experience significant and recurring pain at some point in their lives, but it's important to remember that you're not alone. HFA shares the experiences of Blood Brother, David “Tigg” Tignor and how he manages his pain.

## What is your personal experience with pain?

I have lived with pain all my life. Pain from needles, trauma, bleeds, arthritis, etc. There are a lot of different ways and levels of pain we experience when living with severe hemophilia. A big, and consistent, source of pain is my ankles, which are basically bone-on-bone at this point. The last time I saw an orthopedic surgeon, he said ankle fusion was my only option and I said "No thank you, I'll deal with the pain." People are often surprised when I let them know I'm in pain because I've become so good at hiding it. I'm always in pain; when I wake up in the morning my ankles hurt pretty badly. In the past, once I started walking, the pain would go down a notch or two, but it never went away. This was classic chronic pain. In recent months my baseline has intensified so that even with walking I can't seem to lessen the pain level.

If I'm on my feet all day, or have participated in strenuous activities the pain gets worse. Sometimes, after resting for a bit after being on my feet a long time, I'll get a stabbing sensation, like a large hot needle hitting the bone. That kind of acute pain can drop me to the ground. That kind of pain, well, it'll get your attention pretty quick.

Of course I have pain beyond just my ankles. Because my ankles are inflamed, the muscles all the way up my shins have become inflamed and painful as well. And when

**“Pain is a subjective experience.**

**It does not have to be affiliated with actual tissue damage and you don't have to demonstrate damage to have pain.**

**Pain can't be seen or heard. Pain is different for each and every person.”**

– Dr. Kim Mauer, Comprehensive Pain Management Center and Adult Inpatient Pain Service at Oregon Health and Science University (OHSU)

This article is for educational purposes only and is not intended to be construed as direct medical advice or the official opinion/position of HFA, its staff, or its Board of Directors. Readers are strongly encouraged to discuss their own medical treatment with their healthcare providers.



muscles are inflamed, they tend to atrophy from lack of use. That's something people notice: if ankles are damaged, calves tend to be skinnier than normal. If it's the elbows that are inflamed, biceps will tend to be smaller.

When I was in college, I fell in love with rock climbing. I would wear Aircasts on my ankles, hike a couple of miles to climbing sites, climb several routes, and hike back out. Of course, that night, and usually the following day, I would not be able to walk at all. I would literally sit on my kitchen counter in order to cook my meals. I would crawl on the floor, pushing my plate to the couch, and continue to crawl around until I could put weight on my ankles again. Luckily I did my rock climbing and hiking on Saturdays, so by the time Monday rolled around, I was able to limp to class. I was in pain but it was pain I could tolerate. Why did I do this to myself? Well, rock climbing was something new and exciting; it tested my strength, agility, limitations, and, yes, my mental toughness as well. When I was able to accomplish any route no matter the difficulty, I was exuberant! The feeling of accomplishment and happiness gave me goosebumps. A man can put up with a lot of pain for that kind of joy.

### How do you manage pain?

For the most I've suffered, endured, and tolerated the pain. It was, and is, not easy. Acetaminophen couldn't touch my arthritic pain. In middle school, I wore a cast for a month on one ankle and wore several types of braces. In high school I discovered Aircasts and they worked the best with the boots I wore at the time. They stabilized and supported my ankles up, down, left and right. I still had pain moving from class to class but the Aircasts helped. By high school, I was taking ibuprofen almost every day and it was a life saver. I know ibuprofen is not recommended for people living with hemophilia, but it worked for me and I always took it on a full stomach.

As I got older, I graduated out of Aircasts and into a kind of boot that provides me with the support I need. I discovered, though, that I was getting soft tissue bleeds from consuming all that ibuprofen. A hematologist prescribed hydrocodone, but that gave me terrible headaches, which wasn't a worthwhile trade-off. Now when I need pain medication, I take Tramadol and ibuprofen to get me through the day. I cannot recommend this treatment to anyone else, in fact my hematologist has told me specifically not to use ibuprofen. But I don't want to take stronger narcotics and risk addiction. In addition to the Tramadol and ibuprofen, I use cold gel packs for topical relief and my shins and ankles are regularly massaged by my wife.

### What has been your experience with pain management treatment options?

Treatment options have mostly come in pill form: acetaminophen, didn't work for me; Celebrex, worked well, but hurt my kidneys; naproxen was great, but it gave me too many bleeds; hydrocodone and oxycodone gave me headaches; ibuprofen I could tolerate well; and finally, Tramadol. I do find it worrisome that some doctors will write prescriptions for strong narcotics to members of our community, seemingly carelessly. I've seen Blood Brothers on very strong opiate pain medication, and it is troubling. While strong narcotics are necessary in many situations and are taken under the guidance of medial professionals, the risks associated with them are what worry me.

### Which day-to-day activities help you cope with your pain?

Exercise is always good; I try to do it at least twice a week. What helps the most is doing things that keep my mind off the pain: playing and listening to music, going to the movies, reading books, watching favorite TV shows, and playing video games are all good distractions. I like outdoor activities like fishing, too. Being in nature and

enjoying the fresh air are great. I'd recommend that to anyone: just go outside and watch your kids play. Find something you enjoy to distract you from the pain.

### What tips would you share with others to be more successful when talking with healthcare providers about pain?

Someone once said, "Some people think that to be strong is to never feel pain. In reality, the strongest people are the ones who feel it, understand it, and accept it." That's my advice, in a nutshell. If you are living with a bleeding disorder, you are going to have to deal with pain your entire life, whether it be from vein sticks, bleeds, or joint damage. Once you accept that you will have to deal with pain, life will become a little easier for you. Try alternative therapies and distractions before turning to narcotics. If you must look to opioids, be very careful, they are addictive and can bring you and your family a whole other world of pain down the road. ■ ■

*David (AKA "Tigg") lives with his wife, Christy, and two children Lily (15) and Zachary (8) in Tennessee. He has been actively involved with the bleeding disorders community both locally and abroad for more than 25 years.*



### Pain can be divided into three main categories:

1. **Neuropathic:** Examples include nerve pain/damage.
2. **Nociceptive:** Examples include arthritis, bone pain, tumor pain.
3. **Inflammatory:** Examples include pain from infections and dental pain.

Most hemophilia pain would be a combination of inflammatory and nociceptive.

Opioid medications refer to medications such as morphine, oxycodone, Tramadol, Percocet, and hydromorphone. They do provide pain relief and are probably some of the best pain medications we have, however they have many side effects, including:

1. Decreased REM sleep
2. Decreased testosterone
3. Decreased estrogen
4. Risk of dependence
5. Risk of opioid-induced hyperalgesia (heightened sensitivity to pain)
6. Risk of depression
7. Risk of infertility

It is critically important for you to have an ongoing conversation with your healthcare provider about your pain. The decision to use opioids is a serious one so you need to have an open and honest discussion with your doctor to determine if they are right for you in your pain management. ■ ■

*Dr. Kim Mauer works in the Comprehensive Pain Management Center and Adult Inpatient Pain Service at Oregon Health and Science University (OHSU). She regularly works with the hemophilia treatment center at OHSU, helping patients manage the pain associated with hemophilia in both inpatient and outpatient settings. Her center is focused on well-being and health as well as integrative care. Patients are treated not only with medications, but also acupuncture, chiropractic care, nutrition, massage, and biofeedback. Dr. Mauer has been active in chronic opioid research and education regarding the use of these therapies.*

If you or someone you know needs help, call the Substance Abuse and Mental Health Administration's (SAMHSA) National Helpline, a confidential and free information service available in English and Spanish for individuals and family members facing mental health or substance use issues, at 1-800-662-HELP (4357). The helpline is open 24 hours a day, 365 days a year.

# Healthy Eating Tips

By Jenny Helman, Holistic Nutrition Consultant



Here are some simple tips you can incorporate into your everyday life that can make a difference in how you feel. Be sure to pick organic foods as often as possible, they do make a difference.

**1. For breakfast, eat foods high in protein.** Try scrambled eggs with vegetables, or a smoothie made with plain yogurt or your favorite protein powder. Protein is more important than most people think. It plays a critical role in providing the building blocks for growth, repair, and maintenance of muscles, blood, skin, hair, and nails. For a snack during the day, consider hummus and veggie sticks, and when planning for dinner, you might try braised, wild salmon with leeks. Whenever you eat higher protein foods, it will help curb sugar cravings and keeps you fuller longer, so try eating protein throughout the day.

**2. For every one serving (four ounces) of protein you eat, also eat three portions of veggies and one serving (1/2 cup) of grains.** The Standard American Diet (SAD) tends to be very acidic and our bodies need a more alkaline diet to be healthy. Two things that help bring your body chemistry back into balance are eating in these proportions and eliminating processed foods. A big plus side of eating more green, leafy—and deliciously crunchy—vegetables is that they are so low in calories that you can eat plenty and not have to worry about your waistline. And most vegetables add needed fiber into your diet that's essential to keeping you active by keeping you regular.

**3. Drink plenty of water every day.** Maintaining proper hydration supports virtually all of your bodily functions. The level of fluids in your body impacts your digestion, circulation, production of saliva, transportation and proper absorp-

tion of nutrients, even body temperature, so water intake is crucial. How much should you drink? Divide your weight in half and that is how many ounces of water you should be drinking each day. So a 150-lb. person should consume 75 ounces, or around nine cups of water a day. Or, if you don't want to keep count, just drink enough water so that when you go to the bathroom, your urine comes out clear. Filtered water is best, if you can manage it, as some people believe that the chlorine in tap water can kill the beneficial bacteria in our gastrointestinal tracts. Herbal teas and clear broth count toward your daily water total, as does eating particularly juicy fruits and veggies. Try to minimize your caffeine intake and avoid consuming sodas and other sugared beverages.

**4. It's tough, but try to decrease your intake of processed foods.** These are foods that contain refined and artificial sugars, white flour products, unnatural fats, added hormones, preservatives, artificial colors, and antibiotics. Processed foods have been stripped of the nutrients your body needs and are basically empty carbohydrates—and therefore empty calories. Our bodies need a diversity of whole foods in order to absorb and assimilate the minerals, vitamins and other nutrients they offer. Yes, it's hard to cut everything out at once, so start slowly and gradually continue to cut back. Try eliminating sodas as a first step. Bottled salad dressings, usually full of sugars, preservatives and other detrimental ingredients, are another easy way to cut back. Try squeezing a fresh lemon on steamed vegetables or make your own fresh salad dressing with olive, flax, avocado or walnut oil and balsamic vinegar. Delicious!

**5. Slow down! Enjoy your food!** Focus on chewing, rather than inhaling, your food. By doing this you are actually helping your digestive system process what you're eating. When we eat on the go, in our cars, over the sink (or our keyboards), or robotically in front of the TV, our bodies are not in the best position for optimal digestion. Plus, distracted eating usually means we eat too fast and, ultimately, too much. Use dinner time as an opportunity to connect with your family and friends, and enjoy one another's company. It also gives you the opportunity to reflect and be grateful for all that you have. So set the table and light some candles. And bon appétit!



## Cashew Cardamom Balls

*based on a recipe from mindbodygreen*

### Ingredients:

- 1 cup lightly toasted cashew pieces
- ¼ teaspoon ground cardamom
- 1 cup finely chopped dates
- Finely grated peel of ½ orange
- 1 cup unsweetened coconut

### Directions:

1. Toast the coconut in a small heavy skillet over low heat, stirring often until it is golden and fragrant. Let cool.
2. Place the cashews and half the coconut in the food processor and process until the cashews are very finely ground and the coconut is almost powdered.
3. Stir in the cardamom, dates, and orange peel. Knead the mixture with your fingers until it is a uniform consistency, then roll one-inch balls in the remaining coconut until coated.

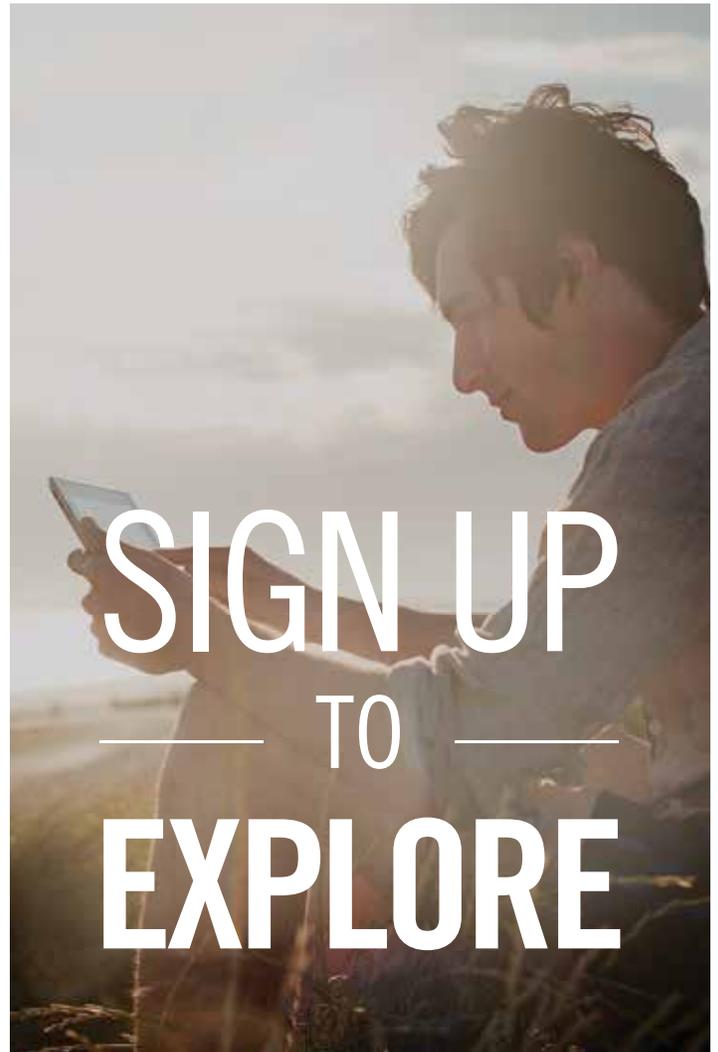
### Did you know?

**Cardamom**, used as a spice around the world, is actually an herb. Its seeds are ground up and used for medicinal purposes as well. Some people find that ingesting a bit of cardamom can ease digestive problems like constipation, heartburn, and irritable bowel syndrome (IBS).

**Dates**, loaded with dietary fiber, are an excellent source of iron and potassium as well. Because of their fiber content, they combat constipation and can improve overall digestion. Dates, while high in sugar content, are a good source of antioxidants which are believed to offer some protection from various forms of cancer.

**Cashews** may be high in calories but they're also high in nutritional benefits, providing many trace minerals, essential vitamins, and antioxidants. Their "heart-friendly" fatty acids can help lower harmful (LDL) cholesterol while boosting good (HDL) cholesterol in your blood. And, of course, they're delicious! ■■

*Jenny Helman is an award-winning Holistic Nutrition Consultant who operates a private practice in Healdsburg, CA. After a successful 25-year career in the Sonoma County wine industry, Jenny changed career paths to combine her passion for healthy eating with a desire to help others change their health through better nutrition. Jenny has personal experience with managing her own pain by changing to a healthy diet and lifestyle. She now provides advice through individualized programs on nutrition to help people feel their best. In April 2016, Jenny was awarded the Going Up award from The National Association of Nutrition Professionals (NANP) in recognition of the visibility, success and distinction she has achieved in the Holistic Nutrition Industry. She is a graduate of Bauman College in Penngrove, CA.*



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# Combating Anemia Through Education and Peer-to-Peer Support

By Kari Peepe

**D**iet and nutrition have always had a major influence in my life. But it wasn't until after my two children were born that I became severely anemic and had to start paying attention to the balance of specific vitamins and nutrients in my daily diet. Fast forward a few years later to when my daughter, who has a platelet storage pool disorder, started a vegetarian diet. It was a challenge for me to get up-to-speed on how to integrate the correct levels of iron, protein, and other vitamins into her diet so that she stayed healthy. I knew if I didn't get it right, she wouldn't have the necessary nutrition to keep her growing at a healthy rate along with her peers. This proved to be more of a challenge than I expected and it is something that I continue researching.

My interest in nutrition has also influenced my involvement with the bleeding disorders community. While brainstorming ideas to host a local Female Factor event, I recalled the talks I'd had with other members of the community, specifically the

discussions around diet. They too were trying to process all of the information available about what constitutes healthy eating. Some people had noticed that certain foods seemed to help alleviate bleeding and bruising while other foods seemed to make them worse. Many people mentioned the extensive lists that doctors provide, outlining what supplements to take and which to avoid. Everyone shared a natural concern about the potential for suffering from a lack of iron and other vitamins and nutrients, and agreed that the community had an obvious need for education on healthy eating.

After a few short conversations and some hunting for the perfect location to host an event to bring everyone together, Female Factor planned Girls Getaway, our first-ever overnight campout for women with bleeding disorders. The event agenda would be filled with educational sessions focused on women's health, exercise, general well-being, and most importantly, tips on how to combat anemia.



The mid-summer weather couldn't have been more beautiful! The retreat we chose was nestled in the rolling hills of Marin County just north of San Francisco and a couple of miles inland from the picturesque Northern California coast. By the time I pulled in to our paradise in the woods, the coastal fog was clearing and the sun was peering through. I was the last to arrive and was pleasantly surprised to walk into a room already filled with laughter and faces, everyone relaxed and comfortable in their new surroundings.

The outdoor retreat was set up much like the family camps most of us remember as kids. Quaint, rustic, woodsy cabins named after local wildlife were scattered around the property. We had basketball courts, rooms for arts and crafts, fire pits, hiking grounds, picnic areas, and a food hall. It had everything we needed for a tranquil mini-vacation among friends. After quick introductions, the group unpacked their bags and headed to the food hall for lunch. We were like kids at summer camp: telling stories, asking questions, and laughing as we ate our way through slices of vegetarian pizza, salad, and soup. After our bellies were full, we set off for a hike through the beautiful grounds. We shared our personal stories with one another while taking in the charming views and collecting items from nature we could later use in a craft projects to decorate our tables.

By the time we returned it was time for the highlight of the day: the nutritionist who would offer a talk on anemia and then lead us in a cooking demonstration provided by HFA's Blood Sisterhood Program. As routine as this program may sound, it turned out to be an amazing experience and one I know I'll never forget. After her presentation, the 12 of us split into groups of two to prepare some of the delicious recipes she had brought along. The smell of ginger, cilantro, coconut, and mint immediately filled the kitchen. While we made our dinner for the evening, the nutritionist spoke about the importance of maintaining a healthy, well balanced diet, and highlighted the need for it to

be easily manageable and yet interesting and delicious. In just over 90 minutes, we were sitting down to enjoy the exquisite dishes that we had prepared.

The night finished up with great conversation around a campfire. As soon as the sun started to set we grabbed blankets, flashlights, and glow bracelets and headed over for a night of star-gazing, marshmallow-roasting, and storytelling. It is difficult to convey the level of comfort, sympathy, and understanding felt amid this group of women. They listened to my personal story, understood my truths, and connected with me in ways more fundamental than those of some people I've known all my life.



The next morning came too quickly and it was time to say goodbye. We headed down to the food hall one last time for breakfast and then everyone had to get ready to go their separate ways. Our idyllic Girls Getaway came to an end.

As I walked away from this event, I felt energized, empowered, and ready to take on the world and its challenges. I anxiously await the next time I get to hang out with my Female Factor friends. Every day I count my blessings that they are in my life.

When I returned home from camp I sat down with my eight-year-old daughter who, to my delight, was eager to hear about the weekend and talk about what I had learned. We talked about high-protein and high-iron foods, among many other things. Most exciting, she was willing to try some of the new recipes I learned! Some have already become new favorites of hers! ■■

*Kari Peepe lives with a platelet storage pool disorder (PSPD) and has been actively involved with the bleeding disorder community since 2012. As a blogger, she has worked to spread awareness of how platelet and bleeding disorders impact women. She is the director of a pre-school and resides in California with her husband Ryan, son Walker, and daughter Scarlett who also has a PSPD.*



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**BRIEF SUMMARY OF PRESCRIBING INFORMATION**

These highlights do not include all the information needed to use AFSTYLA safely and effectively. See full prescribing information for AFSTYLA.

**INDICATIONS AND USAGE**

AFSTYLA®, Antihemophilic Factor (Recombinant), Single Chain, is a recombinant, antihemophilic factor indicated in adults and children with hemophilia A (congenital Factor VIII deficiency) for:

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

Limitation of Use

AFSTYLA is not indicated for the treatment of von Willebrand disease.

**DOSAGE AND ADMINISTRATION**

For intravenous use after reconstitution only.

- Each vial of AFSTYLA is labeled with the amount of recombinant Factor VIII in international units (IU or unit). One unit per kilogram body weight will raise the Factor VIII level by 2 IU/dL.
- Plasma Factor VIII levels can be monitored using either a chromogenic assay or a one-stage clotting assay – routinely used in US clinical laboratories. **If the one-stage clotting assay is used, multiply the result by a conversion factor of 2 to determine the patient's Factor VIII activity level.**

Calculating Required Dose:

$$\text{Dose (IU)} = \text{Body Weight (kg)} \times \text{Desired Factor VIII Rise (IU/dL or \% of normal)} \times 0.5 \text{ (IU/kg per IU/dL)}$$

Routine Prophylaxis:

- Adults and adolescents (≥12 years): The recommended starting regimen is 20 to 50 IU per kg of AFSTYLA administered 2 to 3 times weekly.
- Children (<12 years): The recommended starting regimen is 30 to 50 IU per kg of AFSTYLA administered 2 to 3 times weekly. More frequent or higher doses may be required in children <12 years of age to account for the higher clearance in this age group.
- The regimen may be adjusted based on patient response.

Perioperative Management:

- Ensure the appropriate Factor VIII activity level is achieved and maintained.

**DOSAGE FORMS AND STRENGTHS**

AFSTYLA is available as a white or slightly yellow lyophilized powder supplied in single-use vials containing nominally 250, 500, 1000, 2000, or 3000 International Units (IU).

**CONTRAINDICATIONS**

Do not use in patients who have had life-threatening hypersensitivity reactions, including anaphylaxis to AFSTYLA or its excipients, or hamster proteins.

**WARNINGS AND PRECAUTIONS**

- Hypersensitivity reactions, including anaphylaxis, are possible. Should symptoms occur, immediately discontinue AFSTYLA and administer appropriate treatment. (5.1)
- Development of Factor VIII neutralizing antibodies (inhibitors) can occur. If expected plasma Factor VIII activity levels are not attained, or if bleeding is not controlled with an appropriate dose, perform an assay that measures Factor VIII inhibitor concentration.
- If the one-stage clotting assay is used, multiply the result by a conversion factor of 2 to determine the patient's Factor VIII activity level.

**ADVERSE REACTIONS**

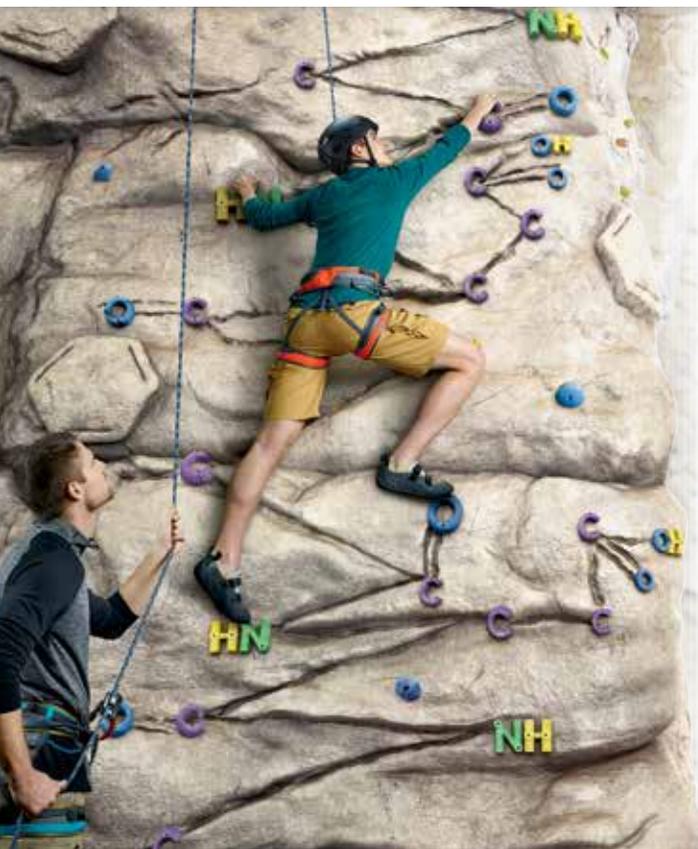
The most common adverse reactions reported in clinical trials (>0.5% of subjects) were dizziness and hypersensitivity.

To report SUSPECTED ADVERSE REACTIONS, contact the CSL Behring Pharmacovigilance Department at 1-866-915-6958 or FDA at 1-800-FDA-1088 or [www.fda.gov/medwatch](http://www.fda.gov/medwatch).

**USE IN SPECIFIC POPULATIONS**

- Pediatric: Clearance (based on per kg body weight) is higher in pediatric patients 0 to <12 years of age. Higher and/or more frequent dosing may be needed.

Based on May 2016 version



For adults and children with hemophilia A

# REACH HIGHER

With the Long-lasting Protection of AFSTYLA

**2x**  
WEEKLY  
AVAILABLE

FDA-approved for dosing 2 or 3 times a week

**ZERO**  
BLEEDS  
(median AsBR\*)

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

COMPARABLE TO  
NATURAL  
FACTOR  
VIII

Identical to natural Factor VIII once activated

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

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

Visit [AFSTYLA.com](http://AFSTYLA.com) to sign up for the latest news

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

### Important Safety Information

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

AFSTYLA is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion. Carefully follow prescriber instructions regarding dose and infusion schedule, which are based on your weight and the severity of your condition.

Do not use AFSTYLA if you know you are allergic to any of its ingredients, or to hamster proteins. Tell your healthcare provider if you previously had an allergic reaction to any product containing Factor VIII (FVIII), or have been told you have inhibitors to FVIII, as AFSTYLA might not work for you. Inform your healthcare provider of all medical conditions and problems you have, as well as all medications you are taking.

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

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

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

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

Please see the following brief summary of full prescribing information on the adjacent page, and the full prescribing information, including patient product information, at [AFSTYLA.com](http://AFSTYLA.com).

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**AFSTYLA**®  
Antihemophilic Factor  
(Recombinant), Single Chain