

# DATELINE

F E D E R A T I O N

Issue 45 | Volume 15 | Summer 2015



**INSIDE:**  
Recap of 2015  
**SYMPOSIUM**  
in St. Louis | pages 3-5

**S**ymposium 2015 is officially in the books! It was wonderful to be in St. Louis and to have the opportunity to partner with the Gateway Hemophilia Association for our annual Symposium.

We kicked off Symposium with our Recognition Luncheon – a great time to welcome everyone and take a few minutes to honor those in the hemophilia community with our annual awards.

I was able to take a few minutes to share my personal feelings and perspective on being a mother of a child with hemophilia. As a mother, we tend to establish our routines and go through the day-to-day, sometimes on auto-pilot! Every once in a while we hit a speed bump. It could be a bleed or some other difficulty. For me, that speed bump came a month or two before symposium. I was taping my executive committee “candidate video” and my son, Nick, blurted out: “I hate hemophilia.” Wow. How do you respond to that?

I did my best and I reminded him of all the wonderful blood brothers and sisters he has now and how our life has been so enriched by those people and experiences. Even more importantly, I reminded him that some of the qualities I admire most in him, he has because he has hemophilia. **Hemophilia doesn’t define him, but it certainly has made him who he is today.**

The wonderful thing about Symposium is that I can walk up to any one of those blood brothers or sisters and tell them that I hate hemophilia too. And that’s okay – because we’re all in this together. Every year is an exhausting whirlwind and I hear from so many people that they can’t wait until the next year. The next HFA Symposium is in Las Vegas and we hope you will join us!

Finally, after 2016 and Las Vegas, where are we headed? I don’t mean the 2017 Symposium location, I mean where are we heading as a community? 2014 and 2015 have seen tremendous changes in treatment options. What will we see in 2016 and how will we respond? What if gene therapy were here today – would you take advantage of it?

Take some time to think about these questions as you read this edition of *Dateline*. Remember the community lies in you to be involved, ask questions, and take action!

**Warm regards,**



**Tracy Cleghorn**  
Board President



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# EDUCATIONAL ANNUAL SYMPOSIUM

Our annual educational Symposium is a family-friendly meeting dedicated to improving the lives of those living with and affected by a bleeding disorder. Living with hemophilia, von Willebrand Disease, or any other type of bleeding disorder is a lifelong journey that requires diligence and flexibility in dealing with the challenges along the way. Symposium is designed to encourage mentoring, sharing, and learning from one another, all while providing the necessary tools to become stronger self-advocates!

This year, Symposium was in beautiful St. Louis, Missouri. For the first time ever, we partnered with our member organization, Gateway Hemophilia Association, to help bring over 850 members of the bleeding disorders community from around the country to Symposium! This meeting was our biggest yet, and would not have been possible without support from our sponsors.



## Highlights from Symposium 2015 Include:

- Over 100 first time attendees received scholarships.
  - An educational track for inhibitor patients.
  - A teen program where young advocates learned the power of self-advocacy and starred in Season 4 of “Stop the Bleeding: A Comedy Web Series.”
  - A FitFactor Wellness Lounge that included: martial arts, massages, yoga, and strength training.
  - An interactive and live Dear Addy session. For the first time, community members unable to attend Symposium were able to submit questions via social media and were given a response.
  - (Art Factor), a one-of-a-kind gallery, was debuted. This display featured art and photography from community members that was inspired by their bleeding disorder. The exhibit also included art created by children at Symposium.
  - An interactive and educational kids program that included games created by HFA that are specific to bleeding disorders.
  - More than 50 educational sessions dedicated to providing families with vital information and resources.
- Throughout this edition of *Dateline*, you will find more highlights and information from sessions that occurred during Symposium. ■■



“This is the one meeting I look forward to EVERY YEAR!”





**"I'm so proud to be part of the HFA family."**



**"As a first time attendee, I learned so much and left empowered."**



**"This was the best kids program anyone in the bleeding disorders community has done. My kids love it!"**



# HFA Annual Awards

Each year, HFA recognizes the service of special volunteers who have stretched above and beyond with their contributions to make a difference in the bleeding disorders community. Nominations are collected across the country through HFA's board and 43 member organizations. HFA's board of directors has the responsibility of casting the vote for who will receive these awards.

## **Charles Stanley Hamilton Legacy Award:**

**David Huskie**

Award for extraordinary lifetime service that encompasses volunteerism, professionalism, and leadership.

## **TEA (Teach, Empower, and Advocate) Award:**

**Dr. Robert Sidonio, Jr.**

An award to an outstanding member of the bleeding disorders community who supports women's bleeding disorders issues.

## **The Terry Lamb Health and Wellness Award:**

**Vaughn Ripley**

Award for exceptional commitment to supporting and encouraging health, nutrition, and wellness behaviors in the bleeding disorders community.

## **Ron Niederman Humanitarian Award:**

**Michelle Burg**

Award for extraordinary service to the community via one's professional service and work.

## **Michael Davon Community Service Award:**

**Lori Long**

An award for extraordinary service to the community via one's volunteerism and charitable giving.

## **Volunteer of the Year Award:**

**Maryann May**

## **President's Award:**

**John Reed**



*From left to right: Michelle Burg, Dr. Robert Sidonio, Jr, John Reed, Vaughn Ripley, Lori Long, David Huskie, Maryann May*

# Thank You

TO ALL OF  
**OUR SPONSORS,  
FUNDERS, AND  
VOLUNTEERS!**

This meeting would not have been possible without your support.

# SAVE THE DATE!

**SYMPOSIUM 2016  
LAS VEGAS**

**March 31 – April 2, 2016**

For more information go to:  
[www.hemophiliafed.org](http://www.hemophiliafed.org)

# 3rd Party Payers in Jeopardy

By Katie Verb, JD

HFA Policy & Government Relations Associate Director

**U**nder the Affordable Care Act (ACA), the Center for Medicare and Medicaid Services (CMS) has the right to make rules about what Qualified Health Plans (QHP) can and cannot do. QHPs are insurance plans that are on the Exchange and rules are essentially laws that are made by executive agencies like CMS.

In March of 2014, CMS issued an interim final rule, (which has the force of law), that lists entities from which insurance companies **MUST** accept premium assistance payments. Unfortunately, nonprofits were not on the list. Starting in 2014, some insurance companies began using the rule to deny premium assistance payments from nonprofits like Patient Services, Inc. (PSI) and the American Kidney Fund. As many of those in the hemophilia community are aware, PSI provides premium assistance for the bleeding disorders community all over the country. The first company to deny assistance payments was in Louisiana; today, plans in more than 22 states are denying these payments.

Most of the patients who need premium assistance have chronic and expensive disorders. Aside from bleeding disorders, PSI provides help for patients with cancer, immunodeficiency conditions and genetic disorders. Plans have cited “plan management” as their excuse for instituting this policy and have asked that patients find other plans. This has the effect of pushing those with chronic and expensive diseases off of their plans and on to others. By refusing to allow these payments, they are essentially able to weed out the patients who cost the most and need the most help.

In multiple statements clarifying the issue of third party premium assistance, CMS has said they are trying to discourage hospitals and medical providers (both for-profit and nonprofit) from providing premium assistance payments. They still very much encourage private nonprofits to keep premium assistance programs that help patients in need. However, their clarification and encouragement has not stopped insurance companies from using the rule to deny payments.

HFA, along with PSI and other patient groups, has been tirelessly advocating for including nonprofits on the list from which insurance companies must accept premium assistance payments. PSI is hoping to introduce federal legislation that compels CMS to add nonprofits to their list. Premium assistance programs that help patients all over the country are in severe jeopardy. It is incredibly important that those with chronic and expensive conditions can afford the types of insurance plans they need to keep healthy!

James Romano, Director of Government Relations and Advocacy for PSI, says “This issue, in essence, reverses the reform of the preexisting condition exclusion which is the much-touted centerpiece of the Affordable Care Act for patient advocacy groups like HFA and PSI. By allowing the insurance provider to discriminate against those who utilize charities like PSI, CMS is allowing another exclusion to exist rendering the law useless for many patients.”

**• In March 2014, CMS issued an interim rule, which has the force of law, that lists three entities from which insurance companies **MUST** accept premium assistance:**

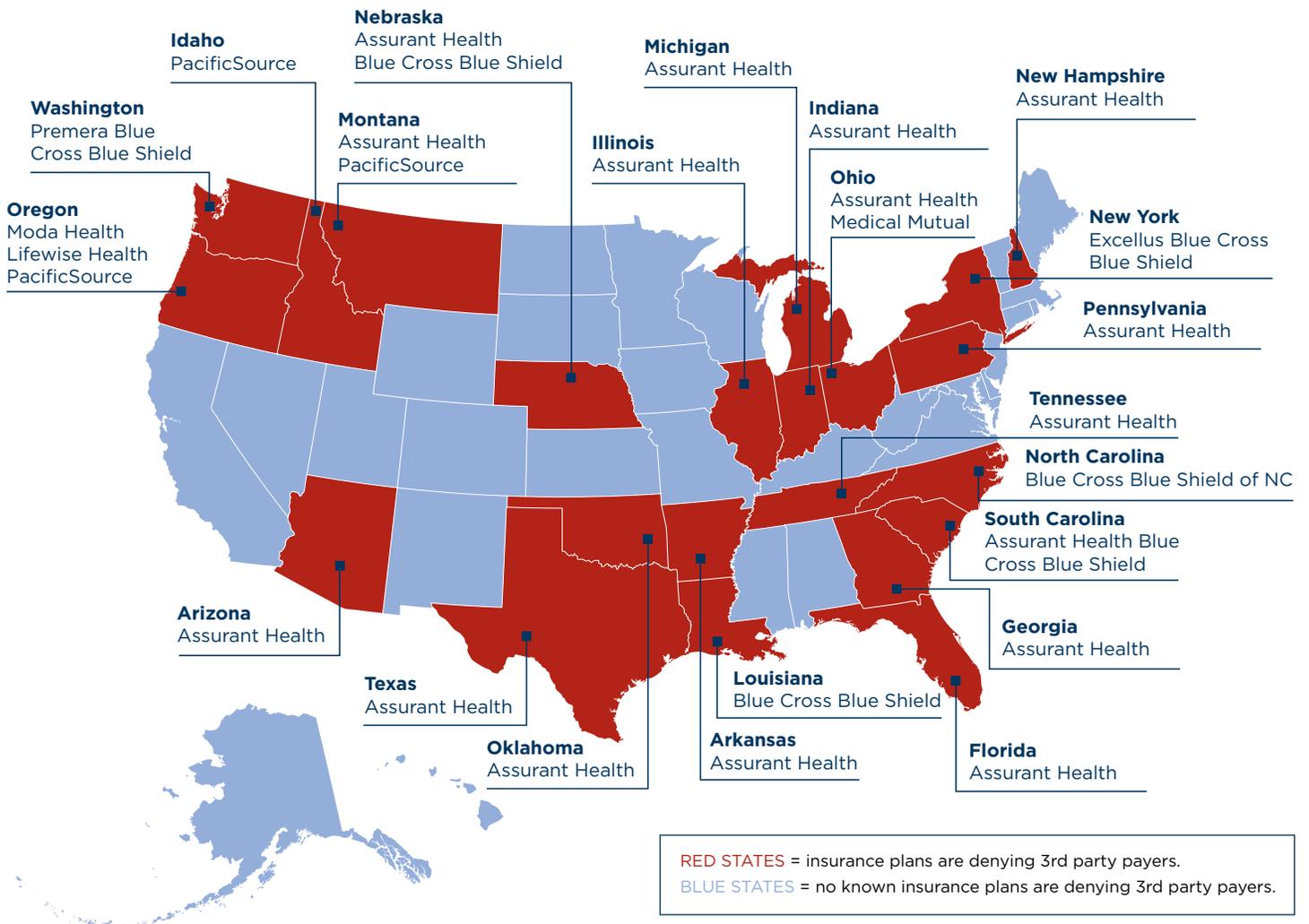
1. Ryan White HIV/AIDS Program
2. Indian tribes, tribal organizations and urban Indian organizations
3. Federal and State entities

**• Plans have encouraged nonprofits to issue payments directly to patients. The problem with that solution is two-fold:**

1. Any direct payments made to patients may be construed as income by the Internal Revenue Service (IRS), and
2. The reputation and internal audit capabilities of the nonprofit are placed in serious jeopardy if a patient does not use the payment for their premium. ■■

## Today, plans in more than 22 states are denying these payments.

# Insurance Plans Banning Patient Assistance\*



\*chart updated as of June 17, 2015

## Importance of PNS: A Reminder

For the first time in more than 10 years, the U.S. Food and Drug Administration (FDA) in July closed down a Miami blood bank due to several HIV-related violations. HFA commends the FDA for making this decision, and for putting the safety of patients first.

This FDA decision is a reminder why everyone with a bleeding disorder should register for the Patient Notification System (PNS). In the event that clotting factor or any other related

It is estimated, that

# 70%

of the bleeding disorders community is currently NOT registered for PNS.

supplies are recalled, this free and confidential system will notify you within 24 hours with the details. This fast, no-cost and reliable system is a vital resource for any patient treating a bleeding disorder. However, it is estimated that 70% of the bleeding disorders community is currently NOT registered for PNS.

Change that by registering today:  
[www.hemophiliafed.org/PNS](http://www.hemophiliafed.org/PNS)

# Project RED: The Sequel to the Sequel

By Lori Long

President of Sangre de Oro, Bleeding Disorders Foundation of New Mexico

The Care Access Working Group (CAWG) has been hard at work! We continue to gather stories from folks in rural areas facing challenges, and we created a Bleeders' Bill of Rights for you to bolster your confidence when experiencing conflict with your insurance company, your pharmacy, or even your doctor. Use it as a reminder that you have a right to informed consent. You can access the Bleeder's Bill of Rights on Hemophilia Federation of America's (HFA's) website. In this issue, we give you the story of a new family living in a rural area, and explain how they connected to the community, and what that did for them.

## GAVIN and MADELINE

In 2010, Madeline's son, Gavin (age 8), had sinus surgery. After many hours, the doctor said that they couldn't control Gavin's bleeding, and he would likely need a blood transfusion. A "quick" out-patient surgery turned into two days of hospitalization, with gushing nosebleeds, unanswered questions, and a lot of fear. After two months, they had a diagnosis: Type I von Willebrand Disease (vWD) with a platelet disorder. Both Madeline and her daughter were also diagnosed with a platelet disorder, so they were sent to a hemophilia treatment center (HTC).

Madeline's first HTC visit was not comforting. She was hoping for answers. The nurse gave her pamphlets and flyers about vWD, told her that Gavin couldn't play any contact sports, and didn't offer much advice other than that. The HTC's social worker wasn't any better. "When we first walked in, the social worker shut the door in my face and told me I wasn't allowed to be in the room with my son while she questioned him. I was so upset." Here she was, at this professional facility designed to help families with bleeding disorders, and on day one, she was feeling even more upset and confused than before.

Madeline recalls being overwhelmed and feeling guilty. "As a mother, I felt terrible putting Gavin through sinus surgery. Had we known about his bleeding disorder, we wouldn't have gone through with it."

Madeline herself shows signs of vWD, but to date she has not yet been diagnosed. "I've always bruised easily; experienced heavy 10-day long menstrual cycles; and my cuts seem to take longer to heal than most. I even had to have a hysterectomy after 5 female surgeries." Yet the HTC refuses to have her vWD levels checked again, saying that only one test was needed, and her levels were fine. Ongoing symptoms indicate otherwise so Madeline feels like she isn't getting the care that SHE needs, and unfortunately, living in a rural area, her options for a second opinion are very limited.

For the next three years, Madeline and her family felt stuck with a diagnosis that they didn't understand and an HTC that didn't give them what they needed. HTC visits were tough for Gavin. "He became fearful of any doctor he visited... soon, we had to make a tough decision: to cut back on all the 'extra' doctor visits." It was taking both an emotional and a financial toll on their family. They felt so alone.

At a local event, Madeline finally connected with another woman whose family lives with a bleeding disorder. This past March, they were able to attend the HFA's Symposium together, where Madeline was able to share her story with other women. This created a lot of new friendships, and the resources these women shared with her were amazingly helpful.

Gavin is 12 now, Madeline is getting more involved in the community, and she's learned a lot. "You have to be the best advocate for yourself and your child. You know your situation better than anybody. Don't give up. Learn to be active, and meet others in the community so you don't feel like you're alone." What has helped Madeline is doing her own research. HFA, the National Hemophilia Foundation (NHF), and local chapters/member organizations are all great places to start.

One final word from Madeline to those newly-diagnosed families in rural areas, struggling, feeling alone and confused: "Take notes, write down questions, ask for copies of medical records so you have them on hand, and most importantly, find a way to get to local and national events, and SHARE YOUR STORY! That's the only way to get the help you need. If I hadn't opened up and shared my story, I definitely wouldn't know what I know now." ■■

**“SHARE YOUR STORY!”**  
THAT'S THE ONLY WAY TO GET THE HELP YOU NEED.

# THE BLEEDERS' BILL OF RIGHTS

This tool is about self-advocacy and empowerment. It is a document for us, the people of the bleeding disorders community, as we face major barriers to healthcare access. Use it to remind yourself of your rights, your choices, and your power. The Bleeders' Bill of Rights identifies the real needs of the bleeding disorders community, in our own language. In this, we recognize our ability, responsibility, and right to have a voice — and our responsibility as a community to raise our collective voice.

Let us be heard. 

## MEDICAL CARE

- ◆ You have the right to routine, excellent, and timely care.
- ◆ You have the right to care that does not discriminate, respecting your individual culture, background, preferences, and diversity.
- ◆ You have the right to holistic care for both body and mind/spirit.
- ◆ You have the right to safe therapies and access to a viable patient notification system for product recalls, including immediate notification of a recall or withdrawal of a bleeding disorders product or its ancillary supplies.
- ◆ You have the right to qualified medical professionals.
- ◆ You have the right to be included in decision making regarding your plan of care.
- ◆ You have the right to have your medical information kept private.

## INFORMATION

- ◆ You have the right to having all information about your bleeding disorder, treatment, and care explained by a medical professional in an easy-to-understand manner.
- ◆ You have the right to have medical information about your bleeding disorder presented in the language with which you feel most comfortable, including the right to an interpreter.
- ◆ You have the right to real-time information regarding your insurance coverage, including changes in policy or coverage.
- ◆ You have the right to request and receive complete information about your therapy and care options.

## SUPPORT AND ADVOCACY

- ◆ You have the right to connect with your local and national communities of individuals and families with bleeding disorders.
- ◆ You have the right to care that is specific to your bleeding disorder.
- ◆ You have the right and the responsibility to question your care.
- ◆ You have the right to request and receive access to a valid, documented complaint system, including proper follow-up, should any of these rights be breached.
- ◆ You have the right and responsibility to be an advocate for yourself and/or your family.

### Acknowledgments and Special Thanks:

HFA wishes to recognize the Care Access Working Group for their unrelenting dedication and thoughtful commitment to this project. This volunteer committee is comprised of co-facilitators Jill Packard and Lori Long and committee members, M. Barusch, Juanita Fish, Wendy Owens, and Lianne Lapierre.

Approved by HFA Board of Directors (March 4, 2015)

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# Medical IDs: Do I Really Need To Wear One?

By Elaine Chan, MSW, MPH  
HFA Programs Coordinator

## What are Medical IDs?

A medical ID is an item that can help an emergency responder or medical professional quickly identify any medical condition(s) a person may have in case of an emergency. Traditionally, medical IDs have been made out of stainless steel or sterling silver and today come in various forms in addition to bracelets and necklaces.

## Why do I need one?

In a true emergency, when a person is unable to communicate, a medical ID can be a life-saver, especially in our community. For individuals with bleeding disorders, a medical ID can quickly let the medical professionals know that you have a bleeding disorder so they can administer factor to stop the bleeding.

## What information should I include?

Depending on the type of medical ID you select, the information you provide will be different. Some information to consider: full name, medical condition, allergies, and at least one emergency contact number.

## How can I get one?

- Look for signs at your local pharmacy
- Ask your doctor or Hemophilia Treatment Center for recommendations
- Search online for different options and vendors that best fit your personal needs.

*See the next page for available options.*



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Types of Medical IDs:	Average Price Range*:	Description:
Traditional Medical ID	Ranges from \$20.00 to \$50.00 depending on material and styles	The most common form of medical ID where a short inscription of a medical condition is etched into a bracelet or necklace.
Membership Medical ID Jewelry	Starting at \$20 and up and annual membership fee	Usually a bracelet/necklace inscribed with a member identification number and contact number for a particular medical information organization
USB/Flash Drive	From \$25.00- \$50.00	USB/ flash drive comes pre-loaded with a software for the individual to fill in medical history and emergency contact information.
Quick Response (QR) Code	From \$20.00 to \$60.00	The QR code can be scanned and links to a web service that contains the individual's medical history, medication information, and emergency information.
Medical Alarm	From \$25.95 to \$69.95	This consists of a wireless alert system, usually worn within a home. During an emergency, the user can send a signal to get help.
Alternatives  <i>* Prices vary from vendor to vendor.</i>	From \$0 and up	Other available option includes: Wallet cards, stickers, magnets, smartphone applications, and temporary tattoos.

## “THE MEDICAL ID FOR MY CHILD GIVES ME A SENSE OF SECURITY.

If anything were to happen and I'm not there, I am hopeful that the bracelet will let the doctors and nurses know that my child has a bleeding disorder and must use factor.”

— father of a daughter with vWD

“I'd rather be safe than sorry when it comes to my son. He doesn't like to wear it but I keep on insisting.

## YOU NEVER KNOW WHAT CAN HAPPEN.”

— mother of a son with hemophilia



Blood  
Sisterhood



Blood  
Brotherhood

## The Docs Weigh In: Important Medical Updates

In the early 1900s children born with hemophilia and other bleeding disorders had a life expectancy only into their teenage years. Because of the advancements and availability of safe and effective treatments, individuals with hemophilia and other bleeding disorders are now experiencing a normal life expectancy.

In planning for our educational sessions at this year's Symposium, we took the results of several recent surveys to offer sessions that address the evolving needs of both men and women living with a bleeding disorder. Many of our Blood Brotherhood and Blood Sisterhood sessions focused on joint health and brought in experts from around the country to share their knowledge and expertise in this area with our attendees. These experts share some of the highlights and important take-aways from their presentations:

### BLOOD BROTHERHOOD SESSION HIGHLIGHTS



#### Managing Arthritis with Hemophilia: Prevention & Treatment

Annette von Drygalski, MD, PharmD, *Assistant Clinical Professor of Medicine and Director of the Hemophilia and Thrombosis Treatment Center at the University of California, San Diego*

- Pain in hemophilic joints can have multiple reasons, not all is bleeding. New point-of-care imaging with musculoskeletal ultrasound can determine if pain is associated with joint bleeding and if synovitis is present. Correct diagnoses will empower patients and physicians to guide treatment decisions.
- Appropriate physical exercise to maintain cartilage lubrication and range of motion is important. Impact sports should be avoided to limit irreparable harm, but innovative concepts such as rock climbing to increase muscle strength, coordination, flexibility and balance may be beneficial.
- The pathobiology of hemophilic joint disease is not completely understood. We need to investigate and understand what happens on a molecular level in the joint after bleeding to create new therapies for the prevention of arthropathy.



#### Orthopedics: A Hemophilia Case Study Perspective

James V. Luck, Jr., MD, *Director of Surgical Services and Rehabilitation at the Orthopaedic Hemophilia Treatment Center and Clinical Professor/Residency Program Director at UCLA/Orthopaedic Institute for Children, Department of Orthopaedic Surgery, David Geffen School of Medicine at University of California Los Angeles*

- Hemophilic arthropathy is one of the more aggressive forms of arthritis resulting in fairly rapid joint surface destruction and stiffness. Prophylactic factor replacement definitely helps but some patients still develop arthropathy.
- Early intervention to prevent destruction of the joint by chronic synovitis is essential. If prophylactic factor replacement does not resolve it, radiosynovectomy should be considered.
- In more severe cases, joint replacement may be needed. The results are very good and durable as long as late infection does not occur. One of the main causes of late infection is IV self-infusion which can introduce bacteria into the blood stream. This can be prevented by careful and thorough sterile prep of the skin and good aseptic technique. Arthrofibrosis with restricted range of motion even after surgery remains a problem but recent basic science research shows promise for treatment of arthrofibrosis at the molecular level.

## BLOOD SISTERHOOD SESSION HIGHLIGHTS



### Bleeding Tendencies in Hemophilia Carriers

Robert Sidonio, Jr., MD, MSc., *Associate Director of Hemostasis and Thrombosis at Emory University/Children's Healthcare of Atlanta.*

In a cross-sectional study (Sidonio, et al. *AJH*) we investigated the joint range of motion of females with FVIII or FIX deficiency who were enrolled in the UDC study (now closed and not to be confused with the female UDC study, another sub-study).

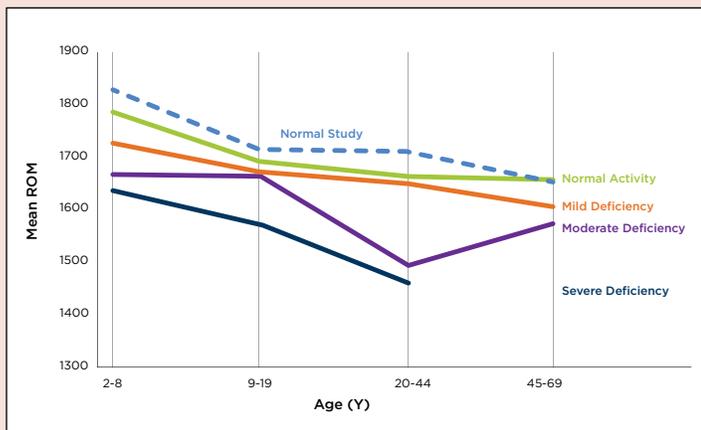
We included any enrolled female hemophilia carrier age two and older with a BMI <35, as a >35 BMI may lead to reduced joint range of motion and this group was excluded in the normal comparison group.

To address the gap in knowledge between the high rate of self-reported joint bleeding in my previous studies and the perception that carriers do not have clinically significant bleeding, we tested the hypothesis that female hemophilia carriers enrolled in the UDC project had reduced joint range of motion compared with historic controls from the Normal Joint Study.

Joint range of motion was measured by local HTC trained individuals (mostly PT physical therapists) as per protocol for males with hemophilia. The primary outcome was overall joint range of motion and our secondary outcome was joint range of motion difference.

A total of 670 females with FVIII or FIX deficiency were enrolled in the UDC project from 1998 to 2010. After excluding individuals who had incomplete data, high BMI (>35) or those with poor documentation on their FVIII or FIX deficiency, we analyzed 303 and 148 females with FVIII or FIX deficiency. (Remember that there were participants who had a normal FVIII or FIX levels as most carriers do who were enrolled in this study.)

### Joint Bleeding in Hemophilia Carriers



Sidonio, et al. *AJH*, 2014

There was a statistically significant reduction in mean overall joint range of motion in nearly all severities and age groups compared with normal participants in the Normal Joint Study. Furthermore this study suggests that subclinical joint bleeding might be occurring in the adolescent years in both female carrier groups, more so likely in the carriers with FVIII or FIX <40%.

In a subsequent study (Gilbert, Sidonio, et al. *Haemophilia*) performed in a small sub-group of adult hemophilia A carrier with normal FVIII activity (>40%) at the time of enrollment and reduced joint range of motion compared to normal women, we were able to demonstrate mild early findings of soft tissue, cartilage and joint damage. The joints mostly affected were the ankles and knees.

In this study we noted that of the ankles that were imaged by MRI, 11 out of 12, or 92%, had evidence of early soft tissue or joint damage. This is in line with what one would see in a male with mild hemophilia A or B at the same age. (See chart below)

### Joint Changes in Adult Hemophilia A Carriers

Joint MRI	# Performed	# IPSG Abnormality	IPSG* Score Range
Ankle	12 joints (6 paired)	11 (92%)	0-4
Elbow	2 joints (1 paired)	2 (100%)	1-2
Hip	16 joints (8 paired)	5 (31%)	0-1
Knee	6 joints (3 paired)	6 (100%)	1-2

\* International Prophylaxis Group

Gilbert and Sidonio, et al. *Haemophilia* 2014

In summary our research group has demonstrated that hemophilia A carriers have an increased bleeding tendency and this translates into poorer quality of life. We were able to demonstrate that hemophilia A carriers with normal FVIII activity as adults may be at higher risk for subclinical joint disease in their early childhood and adolescent years. I hypothesize that the carriers in our study may have had FVIII levels in the mild hemophilia range as children and over time their levels have risen into the normal range thus reducing their current risk of bleeding but explaining their previous history of bleeding including overt and subclinical joint bleeding.

*continued on next page...*



## Joint Health for Women

Sue Geraghty, RN, *Former nurse coordinator at the University of Colorado Denver Hemophilia and Thrombosis Center, retired*

### 4 Basic Components of Joint Health:

1. **Stretching/Flexibility** – always protect your joints. The old adage “no pain, no gain” is not true. You can have gain without pain.
2. **Aerobic Training** – low to moderate exertion levels over a period of time. Try 20 minutes of continuous exercise at least 3 times per week.
3. **Weight Training** – focus on the:
  - Facility (Supervision and Safety)
  - Setting of Goals
  - Program: Lighter weights with more repetition and good form.
4. **Nutrition/Hydration** – a healthy diet is one that:
  - Is balanced and includes a variety of foods.
  - Does not exclude any food group.
  - Is moderate in fat, sugar, and processed foods.
  - Is controlled in portion size.

- Meets the daily requirements for vitamins, minerals, and fiber.

Exercise and weight management are directly related to:

- Joint health
- Osteoporosis
- Bleeding episodes

Being only 10 pounds overweight increases the force on the knee by 30-60 pounds with each step. Examples include:

- Excessive strain on joints.
- Contribute to bleeding when a trauma occurs.
- Can lead to osteoarthritis.

All of these components play an important role in the health of your joints. Focus should be on health and fitness, not on one’s appearance.

Joint issues in individuals with bleeding disorders are common. Early diagnosis of both the bleeding disorder, and joint disease are key in preventing further damage. Swift and proper treatment, as well as the implementation of a regular exercise program and a healthy diet are key factors in preventing and reducing many joint related issues. ■ ■

## The Journey, Celebrated

Life is made of small moments that inspire, motivate, and make us feel that our work is worthwhile.

As a company, as a team, and simply as individuals, we strive to discover, enable, and celebrate more of them.

Today, possibility is in the air.

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#hemdad



meet our new addition #happiness



my



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# 5 New Developments in Hemophilia

By Ellis Neufeld, MD, PhD

Hematologist at Dana-Farber/Boston Children's Cancer and Blood Disorders Center

**F**rom new longer-acting drugs to promising gene therapy trials, much is changing in the treatment of hemophilia, the inherited bleeding disorder in which the blood does not clot.

## 1. Many more treatment products are being introduced, including some that last longer.

People with hemophilia lack or have defects in a “factor” — a blood protein that helps normal clots form. Of the approximately 20,000 people with hemophilia in the US, about 80 percent have hemophilia A, caused by an abnormally low level of factor VIII, and most of the rest have hemophilia B, caused by abnormally low levels of factor IX. Many patients with severe hemophilia give themselves prophylactic IV infusions of the missing factor to prevent bleeding (which otherwise can lead to crippling joint disease when blood seeps into the joint and enzymes released from blood cells erode the cartilage).

Hemophilia factors traditionally have such a short half-life that we tend to treat patients every other day with factor VIII and twice a week with factor IX. The first two longer-lasting products came onto the market within the past year, and more are on the way. So now, with factor IX, it is possible to get an infusion just once a week and not bleed. This is really changing how we think about the disease. So far, the longer-acting factor VIII products are not yet long-lasting enough to make as dramatic a difference in the frequency of infusions. And creating really long-acting factors remains a challenge.

## 2. Other new products are coming to market as factors go off patent.

The expiration of patents opens up a field that was limited to a few products as recently as 2014. Some companies are considering making bio-similars — generic-like products for complex protein molecules — for the more expensive factors.

Meanwhile, clinicians are trying to cut through the hype that often accompanies the introduction of new products to help patients understand what's actually happening. I am about to lead an observational study for the American Thrombosis and Hemostasis Network that will follow patients as they switch to the newer products and evaluate how well the products perform in terms of safety and how well they prevent bleeds. We're trying to take this kind of observational study out of the exclusive hands of drug companies, which conduct proprietary studies of their particular products, and instead collect data that cuts across brands.

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*This article first appeared on Vector, a blog of Boston Children's Hospital.*

## 3. Gene therapy is the next big thing.

Gene therapy is progressing much faster for factor IX than for factor VIII, because the factor VIII gene is so physically large that it doesn't fit perfectly into the vector that delivers gene therapy. In the case of factor IX, however, the vector can be delivered through an IV infusion. It then travels directly to the liver, which is where the factor is produced. The therapy appears to be very safe, according to early results published in 2011 and updated in 2014. Although it doesn't work for everybody, researchers are getting to the point where they believe they can reliably turn severe hemophilia into moderate or mild disease. If they can really turn severe hemophilia into mild hemophilia with one IV infusion, it would completely change the whole field of hemophilia, making factor prophylaxis a thing of the past. The gene therapy trials are starting with adults; therapy will be more difficult in children because the added gene would get diluted by the growing liver.

## 4. New regimens require less frequent prophylactic infusions, even with less long-lasting products.

Traditionally, U.S. clinicians had patients infuse themselves two or three times a week to boost the missing factor to one percent of their blood, under the theory that this was the threshold needed to prevent bleeds. Canadian researchers showed you can start treating only once a week, and a number of US centers are now following this regimen. If it prevents bleeding, then the patient stays on a once-a-week regimen even if his factor level is below one percent. If it doesn't prevent bleeding, then the frequency of infusion is increased. We now often use this regimen with our young children. If once a week works, a home care nurse can come in and give an IV instead of surgically inserting a port. It also helps us learn what the patient really needs.

## 5. The biggest challenge: reducing the risk of inhibitor antibodies that keep factors from working.

If a patient's body treats the factor as a foreign protein and makes an antibody that keeps it from working, it's as if he hadn't even been given a dose. We can get rid of inhibitors in two-thirds of patients who get them through Immune Tolerance Induction — by giving enough factor (daily, for months or even years) to confuse the immune system and make it forget it's a foreign protein. About 10 percent of patients, however, are left with high-titer inhibitors that we can't overcome, which is life-altering and can be terrible. There are hints from experiments in mice that some of the newer factors might lower the incidence of inhibitors in people with severe hemophilia. But mice aren't people. If this does turn out to be true in humans, it would be a major breakthrough. ■ ■

# VOLUNTEER SPOTLIGHT:

## Heroes in the Hills Golf Tournament

Shelley and JC Clawson are passionate about raising awareness and helping others! On March 30, in honor of Hemophilia Awareness month, the Clawson family hosted the first annual “Heroes in the Hills Golf Tournament” in Austin, Texas. The event brought together their family, friends and professional network to raise awareness about hemophilia and support the Helping Hands program from Hemophilia Federation of America (HFA). The Helping Hands program gives financial assistance to those in crisis within the bleeding disorders community.

HFA’s Development Director, Susan Swindle, asked Shelley a few questions about the tournament and why it was important to support Helping Hands.

### What is your connection to the community?

Our son, Jace, has severe hemophilia A.

### Reason behind going with a golf tournament over another type fundraiser?

We were looking for other ways to get local businesses and local friends more involved. Golf seems to bring out the business men and women who wouldn’t normally get involved in other charity events.

### How did the golf tournament work?

We focused on local businesses and our friends. The course didn’t hurt either. Cimarron Hills is a highly acclaimed private golf course and it’s hard to get on there. So giving the opportunity to play there was a huge plus!

### How many golfers participated in the Tournament?

When I arrived at the course the morning of the event, I’ll admit that I was a bit nervous about how many would actually show up to play. As they started to arrive, it was evident that not only had those registered showed up to play, but they also brought friends for a total of 72 individual golfers. We were so pleased with the turnout.

### How many sponsors did you have?

We ended up with about 25 sponsors. Not all of them played golf but they were happy to support the cause.



The Clawson family during a recent family vacation. Photo courtesy of Shelley Clawson.

### Any other fundraisers on the horizon?

Yes, we LOVE NHF’s hemophilia walk, which is coming up in September. We have walked every year since Jace was 8 weeks old. He just turned 4 in July — how time flies!

### Why did you choose Helping Hands as the program to support for the donation?

We chose HFA Helping Hands because it’s a reputable national organization and because of the things it has done for our local families. We knew the support we raised might directly benefit someone we know in the Austin area.

# 10 TIPS from Shelley for hosting a tournament!

1. **PICK A COURSE.** where you or someone close to you has some relationship. If they know you, they're more apt to help.
2. **PICK A DATE.** Many private courses only allow tournaments on Mondays when they're normally closed. If you give enough notice, people will show up. I promise!
3. **CREATE A THEME/NAME FOR THE TOURNAMENT.** We picked "Heroes in the Hills" because we wanted our golfers to feel like heroes!
4. **ASK FOR HELP!** I reached out to several people in the hemophilia community, but I also asked my friends who have creative minds and connections to help.
5. **SPREAD THE WORD.** We made a Facebook page, my husband JC carried fliers around with him at work, and the country club allowed us to post fliers around as well.
6. **PLAN YOUR FOOD AND BEVERAGES ACCORDINGLY.** The whole point is to raise funds, so we decided to ask a local company to donate the soft drinks, and the cost for food was negotiated with a local café.
7. **HAVE MULLIGANS (AN EXTRA GOLF SWING) AVAILABLE AT REGISTRATION.** Golfers are suckers for extra tries! We raised about \$1,800 on mulligans alone.
8. **DEVELOP A LIST OF GOLFERS.** and keep reminding them of the upcoming event. The list makes it much easier to register each one as they show up.
9. **SWAG!** We gave out swag bags with various items I had gotten donated along the way. We found the golfers don't necessarily care so much about them, but they love being able to bring something home to their families.
10. **THANK EVERYONE.** Offer some awesome prizes and items for them to win. Along with gift certificates, we had a HUGE YETI cooler donated that we raffled off at the end. ■■



Photos on this page are from the Heroes in the Hill Golf Tournament. Photo courtesy of the Clawson family.



## HFA's Circle of Friends

Shelley and JC Clawson have joined other exceptional individuals and families who give or get a monetary donation of \$500 or more annually to support HFA programs of support and advocacy for people with a bleeding disorder nationwide.

Learn more about how you can become part of "Circle of Friends:"  
[www.hemophiliafed.org/donate](http://www.hemophiliafed.org/donate)



# Hi Ho, Hi Ho, It's Off to Work (I Don't) Go

By Sonji Wilkes

*HFA Programs Manager*

**T**he phone rings and it's day care asking you to come pick up little Johnny — he's taken a bad fall and needs an infusion.

You sigh as you tell your boss that you have to leave work, again, to take care of your child. You notice the look on his face. As you drive to the day care, you are worried — for your son's well-being, for the security of your job, and for your family's financial well-being as missed time off work means missed pay.

Many families with bleeding disorders face this uncertainty every day.

Employment issues in chronic illness aren't uncommon. A study by the Agency for Healthcare Research and Quality found that 48% of the population lives with some kind of chronic condition and of those people, 60% of them work either full or part-time.<sup>1</sup>

Fortunately there are protections in place that can help families and patients living with a bleeding disorder: The Family and Medical Leave Act (FMLA) allows employees to take up to 12 weeks off every year for medical or family emergencies, but it's time off without pay. The Americans with Disabilities Act (ADA) requires employers to make reasonable accommodations for disabled workers. Unfortunately it's not always easy for workers to understand eligibility requirements for these federal regulations or to navigate the employer's policies and procedures for time off and disability plans.

Since President Bill Clinton signed FMLA into law 20 years ago, workers have utilized the protections more than 100 million times. While the law secures an employee's position during leave, it does come with drawbacks and weaknesses. Carri Nease of Maryland, found obtaining FMLA protections through a former employer relatively easy, but even with that security, her job situation changed as she needed more and more time off.

"I told them about my boys and hemophilia at my interview before I was even hired. I know that some say it's not something you want to tell a prospective employer, but I wanted them to understand that I have children with chronic medical needs and they called me back and hired me even with this knowledge. At first my employer was very understanding, and even let me bring my children in once in a while when they had bleeds and needed infusions every two hours, but that quickly stopped. Other employees could bring their children in and keep them there all day or for several hours, but I was told mine couldn't come 'due to the liability of the matter.' Early in my employment, they let me use my accrued vacation and sick time to cover the time off, but I wasn't allowed to use any of that time until I 'earned it' — even though other employees could use any of their expected time at the beginning of the year. It was explained to me, 'We don't want you to owe any money, since we don't know where you'll be at the end of the year.'"

Despite Carri's good faith efforts to disclose her family's medical needs and initial accommodations from her employers, Carri felt she needed the protections of FMLA. "I put in the papers for FMLA when the understanding started waning and I started getting a feeling that my position was in danger. Suddenly the 'we'll work with you' went away. If I hadn't understood how to use FMLA from my previous employer, I



*Photo courtesy of the Nease family.*

<sup>1</sup> Beatty, Joy E.; Joffe, Rosalind. "An Overlooked Dimension of Diversity: The Career Effects of Chronic Illness." *Organizational Dynamics* No. 2 (2006): pp 182-195. [www.sciencedirect.com](http://www.sciencedirect.com). 2 June 2015.

likely would have lost my job before ever putting the papers in place since I was led to believe that they were willing to work with me. I tried hard to not need to use the hours, but the boys were in kindergarten and first grade and both had inhibitors, so I was often called away. The process involved filling out the paperwork for FMLA, then sending it in to the main office and providing any paperwork as proof that I needed to use the time. I'd give notice where I could if there was an appointment, but hemophilia can't always be scheduled."

.....

## “It’s not a question of IF you’ll need it, but WHEN.”

.....

Carri eventually left the position after 3 years. “While I didn’t lose my job outright, I was the only receptionist and suddenly had my full time job downsized ‘due to sequestration cuts’ and was offered 20 hours a week, with the option to spread the hours as I saw fit, but with no benefits at all.” Carri believes that, “FMLA was easy to use in theory, except that I had to keep hearing how other employees who had FMLA were abusing it, and how difficult it was to tell when someone really needed it or was abusing the system. I just didn’t feel certain about my job security.”

Because of requests from patients and caregivers across the bleeding disorders community, HFA recently compiled a toolkit of resources related to employment issues. Included in this toolkit are recordings of past presentations featuring experts discussing rights you have as an employee. An representative from the United States Equal Employment Opportunity Commission (EEOC) spoke during the HFA Families webinar, “Hi Ho, Hi Ho, It’s Off to Work I (Don’t) Go,” which included an overview of ADA. The webinar also covered the provisions of the Genetic Information Nondiscrimination Act (GINA), which prohibits the use of genetic information to discriminate in employment, as well as a thorough explanation of FMLA from a Department of Labor FMLA investigator. Also included in the toolkit are downloadable handouts and links from a variety of sources to help you navigate your career path while living with a bleeding disorder.

After Carri left her former job, she found a position where she can work from home. She knows that’s a luxury that not all in the bleeding disorders community can have. “I encourage other parents to learn more about FMLA protections and get the paperwork in place before you need it – because it’s not a question of if you’ll need it, but when.”

**On page 20, there is more information about FMLA.**



**TAKE ACTION**



**ASK QUESTIONS**



**BE INVOLVED**

The HFA Families program offers quarterly webinars on a variety of topics related to raising a child with a bleeding disorder. Past webinar topics have included:

- **I Can’t Fight This Feeling: Anxiety & Depression**
- **Dazed & Confused: Coping with Stress**
- **Tackling Pain & Anxiety: Parents as Coaches for Coping**
- **Ouch! Does it Always Have to Hurt?**
- **Stop Sibling Quibbling**

If you missed these webinars live, watch the recorded versions on HFA’s YouTube channel.

To sign up to attend future webinars, enroll in our Moms in Action and Dads in Action programs. Visit HFA’s website at [www.hemophiliafed.org](http://www.hemophiliafed.org) to learn more. ■■

# CYRIL HOME CARE PHARMACY

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*John and Carol Reed*



*John Reed DPH*

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# The Basics of FMLA

(Excerpted from *National Partnership for Women & Families Q&A FMLA Guide*. View the entire guide in HFA's Employment Issues Toolkit on [www.hemophiliafed.org](http://www.hemophiliafed.org))

## Q. When can I take family or medical leave under the FMLA?

If you are covered by the FMLA, you may take leave under the following circumstances:

- If you have a serious health condition
- If you are caring for your new baby, or caring for a newly adopted or newly placed foster child
- If you are caring for your child, spouse or parent with a serious health condition
- If you are caring for a wounded service member or veteran or if you need time away from your job to address particular circumstances arising from the deployment of a service member or a member of the armed forces.

The FMLA allows you to take time off (“leave”) without losing your job, your seniority or your employer-provided health insurance.

**Note:** You must work for an employer that is covered by the FMLA and meet certain eligibility requirements to qualify for FMLA leave.

## Q. Who counts as “family” when I need to take FMLA leave?

Under the FMLA, “family members” for the purposes of family leave are:

- Your **children** — when they are born, adopted, placed with you as a foster child, or when they have a “serious health condition”
- Your **parents** — when they have a “serious health condition”
- Your **spouse** — when she or he has a “serious health condition” and
- Your **next of kin** — for wounded service member leave only.

## Q. How do I know if I can take family or medical leave under FMLA?

You qualify for unpaid, job-protected leave under the FMLA if you meet three criteria:

**First**, your employer has 50 or more employees on the payroll for 20 work-weeks during the current or preceding calendar year. (To determine whether your employer is covered, find out how many employees are on the payroll, including those who are on leave or working part time.) All 50 employees need not be on site at your worksite, but your employer

must have at least 50 employees across all of its worksites within a 75-mile radius.

**Second**, you have worked for your employer for at least 12 months and for at least 1,250 hours during the last year. (If you have worked 25 or more hours for 50 weeks in a year, you have worked the required total of 1,250 hours. However, certain rules do apply to teachers, highly paid employees and airline flight crew members.)

**Third**, you are taking time away from your job to address your own “serious health condition,” the “serious health condition” of a covered family member, to care for a new child, to care for a wounded service member in your family, or to address particular circumstances arising from a covered family member’s deployment or call to active duty in the armed forces.

## Q. How much leave can I take under the FMLA? And what if I need more time?

The FMLA allows you to take either **family leave**, **medical leave** or **qualifying medical leave**, or any combination of the three, for up to a total of 12 weeks per year. This means that if you are on family or medical leave or on qualifying exigency leave and away from your job for a total of up to 12 weeks in a year, your job is protected.

## Q. Will I get paid while I’m on FMLA leave?

The FMLA does not require your employer to pay you during leave. You may be entitled to use any paid annual, vacation or sick leave that your employer provides. Your employer’s policies determine whether you may — or must — use that leave in conjunction with your FMLA leave.

Some states have state-based paid family and/or medical leave programs and other laws that require your employer to allow you, if you choose, to use accrued paid sick, vacation or other time off during a period of FMLA leave.

In addition, workers with serious health conditions relating to pregnancy must be treated the same as other employees with serious health conditions. For example, under the Pregnancy Discrimination Act, if male employees get paid while they are on leave because of serious health conditions like heart attacks, female employees on leave due to pregnancy- or childbirth-related conditions must get paid too. Under most short-term disability policies, women are entitled to six weeks of paid disability leave for vaginal deliveries and eight weeks for Cesarean sections. ■ ■



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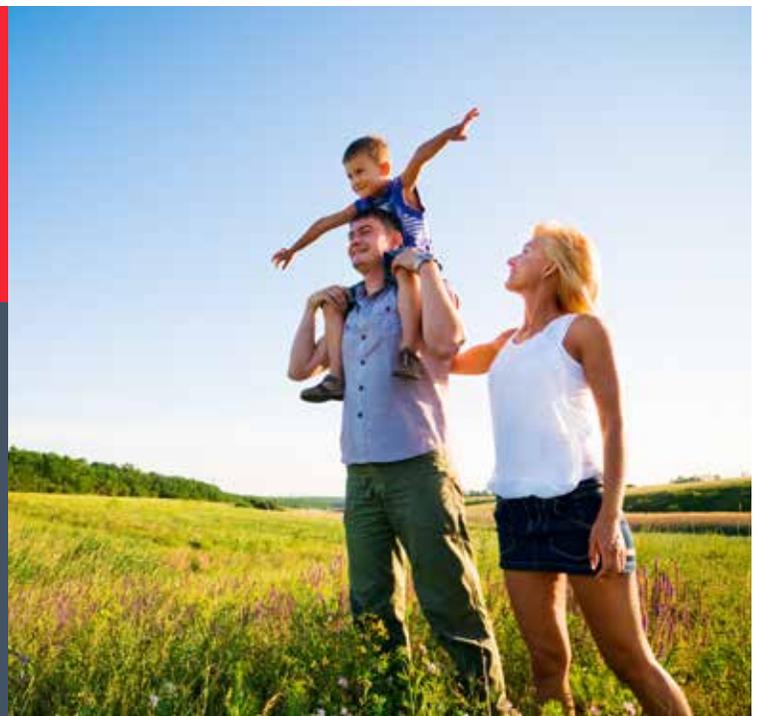
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# The Wellness Lounge: Fitness Dos and Don'ts

**I**t is important for individuals with a bleeding disorder to find a form of physical activity that they enjoy. When muscles are used during exercise it helps keep them flexible and strong. Physical activity also helps individuals maintain a healthy weight minimizing the stress on the joints. Exercise has even proven to reduce the number of bleeds a person may experience.

At Symposium 2015, HFA's FitFactor program brought together experts in the areas of yoga, martial arts, personal training, and massage to offer participants an opportunity to learn about and try these different types of activities. Our fitness experts share some dos and don'ts of each activity.

FROM MICHELLE MORATH



## Things to consider when starting a strength-training program:

### Benefits of Strength Training:

**Stronger Joints:** Strengthening muscles around a joint will reduce the likelihood of injury and a joint bleed.

**Weight Management:** Regular strength training and exercise in general will help with weight loss and weight maintenance which will decrease the amount of force on your joints and therefore decrease pain

**Increase Energy:** With regular exercise, you will notice having more energy to do the things in life that you enjoy.

**Strong Core:** When you have a strong core, you feel stronger throughout your entire body. You are able to do your daily activities with ease.

**Improved Health:** Exercise greatly reduces the risk of many diseases such as diabetes, osteoporosis, and heart disease. It can also actually improve your quality of sleep and mental well-being.

**Start Slow and Gentle:** When beginning a strength-training routine, start with one set of 8-10 repetitions. Over time, gradually increase your repetitions or increase to two sets.

**Have Patience:** "No pain, no gain" is NOT a motto by which to live. Doing too much, too fast can cause injuries. Progressing slow and steady will get you to your goals and greatly improve your quality of life.

**Maintain Consistency:** Along your path of getting stronger, you may experience some setbacks in maintaining your routine. Just know that life can and will get in the way. The key to being successful long-term is to not beat yourself up about miss workouts and just get back to your exercise routine as soon as you can.

**Joint Bleed:** If you are currently experiencing a joint bleed, do not exercise the affected joint. You may, however, be able to do other exercises. For example, if the affected joint is your knee, you may be able to do upper body or core exercises instead of leg exercises.

**Personal Trainer:** When looking for a personal trainer, make sure he or she is certified through an accredited organization. If he or she does not have experience working with someone with a bleeding disorder, be sure that the personal trainer specializes in post-rehabilitation.





## Benefits of Yoga:

**(Body) Physical:** By practicing yoga you can strengthen your joints and improve joint flexibility.

**(Mind) Psychological:** One of the oldest definitions of yoga is the process of ‘Stilling the fluctuations of the mind’. Yoga can help you navigate chaotic 21st century living — a big reason why there is an expanding interest in yoga, as people become increasingly inundated in a hyper-connected world.

**Learn Limitations:** Reflecting on the body through yoga helps avoid injury in daily life.

**Breathing:** Connecting the breath with movement increases resolve and focus. Learning yoga breathing techniques can increase awareness and reduce sensations of pain.

**Determine Origin of Bleeds:** Medical professionals unintentionally reinforce a fallacious idea that bleeding is something that ‘happens’ to us or is spontaneous. *Only by creating greater bodily awareness and spatial understanding of our environment do we have the ability to prevent bleeding altogether.* It is the mindfulness and knowledge of your own body that will prevent you from the vicious cycle of injury.

## Things to consider before starting a yoga program:

### Find Local Classes:

- Look for yoga classes in your hometown, and ask about special introductory offers. A good class that is in your neighborhood might be better than a GREAT class all the way across town.
- You can find classes in community centers, at specialized yoga studios, or in fitness gyms. Ask around.

### Try it More Than Once:

- Commit yourself to a few months of yoga, practicing every day if you can. (This could be for as little as 15 minutes a day at home).
- If you are unable to go to studio classes, locate classes on DVD, YouTube, or Netflix, etc.

### Start with Beginner Classes:

- Stick to introductory or beginner classes to start. For those of you with advanced joint disease and limited range of motion, ‘chair yoga’ classes would be the best place to begin. In time, your strength and range of movement may allow you to participate in more demanding classes.
- Teachers in beginner classes will give you more hands-on instruction regarding proper form.
- Disclose injuries/limitations with instructors. Whenever you begin a class with a new instructor, be sure to let them know beforehand what joint limitations you have. The instructors may be able to give you some ideas on how to modify postures to make them work with your anatomy.
- Keep in mind that few things in this world happen by accident. You will not improve your body by accident. It will take dedication and persistent effort to improve your joints, body, and mental health.



## Benefits of Martial Arts:

- Builds muscle tone, flexibility and general health
- Builds self-esteem, self-confidence, and self-control
- Teaches responsibility and respect
- It is FUN!!

## Things to consider before starting a martial arts program:

- Become educated about the practice and do your research to find a qualified instructor and a program that is safe and right for your needs.

- Always disclose your bleeding disorder and any other relevant medical information.
- Consult with your physician, physical therapist or HTC before beginning any physical activity or exercise program.

It is important for individuals with hemophilia or von Willibrand Disease to find the right form of activity for their type, severity, and body. Individuals and families should **always** talk with their doctors or physical therapists prior to starting any exercise regime to help determine what types of physical activity might be acceptable for them.

A healthy body and doing something you enjoy are the goals. Here is a list of “don’ts” to keep in mind before starting any physical activity.

*continued on next page...*



## Don't:

- **Forget to Infuse** — Try to coordinate infusions on the same days you attend classes, just in case. Exercise injuries are not uncommon, especially with beginners who do not yet know their limitations.
- **Overdo It** — Be smart, and don't let your ego tempt you to try things for which you are not ready.
- **Forget Safety** — Be sure to use the proper safety equipment suggested for each activity to protect your body from injury.
- **Buy Lots of 'Gear'** — Before spending a fortune on equipment, try the activity and make sure it is something you like and will stick with. Consider renting or finding second-hand equipment to use when trying an activity for the first time.
- **Compare Yourself to Others** — This is not a competition. Your physical activity should be a very personal practice. In yoga, for example, elegant postures are nice to aspire to but the goal should be to make small improvements day by day, not standing on your head.
- **Be Too Close Minded** — You might hear some things in a gym or yoga studio that do not sync with western medicine or philosophy. It never hurts to keep an open mind to unfamiliar ideas!
- **Get Frustrated and Give Up** — You will run up against walls both physically and mentally over and over again in your new fitness endeavors, but persistence will yield ample rewards.

## Benefits of Massage:

- Can help reduce or relieve stress
- May improve sleep
- May help reduce or ease muscle pain
- May boost immune function
- Can help ease anxiety and/or depression

## Things to consider before getting a massage:

- Always disclose your bleeding disorder and any other pertinent medical information to the massage therapist before they begin.
- Point out target joints or any muscle problems before the therapist begins.
- Keep in mind that deep tissue massage can cause bleeding in some individuals with bleeding disorders.
- If the massage is painful or uncomfortable be sure to inform the therapist right away.

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# About Our Fitness Experts:



## Corey Pierce

Corey has long been involved with the hemophilia community. He has been a counselor at the Hemophilia Foundation of Oregon (HFO) camp since 2002 and served as an administrative assistant in 2010. He is a severe hemophiliac and recently completed a master's degree in epidemiology in the Netherlands. While interning with Bayer Health Care/Pharmaceuticals, he proposed the Living Fit! A Joint Effort program to advocate for greater physical fitness for children with bleeding disorders. Corey is also a registered yoga instructor. He has taught yoga classes both at camp and to parents of children with bleeding disorders.



## Michael Pezzillo

Michael is a Chief Instructor for Mastery Martial Arts in Rhode Island. He has trained in the martial arts for 19 years. Although he does not have hemophilia, it has affected him personally as his two brothers were born with it. Michael shares, "Growing up with Richard and Anthony and watching the challenges, pain, and limitations they endured motivated me to find a way to make people with hemophilia have some kind of normalcy in their lives." Michael finds the martial arts to be both rewarding and challenging. He is thrilled to bring the martial arts to the bleeding disorders community because he believes it builds confidence in students of all ages, races, and with different physical abilities or limitations.



## Michelle Morath

Michelle is the owner of JourneyFit, LLC, [www.journey-fit.com](http://www.journey-fit.com), in Albuquerque, New Mexico. She is currently enrolled in the Doctor of Naprapathy program at the Southwest University of Naprapathic Medicine. She was awarded a Bachelors of University Studies degree with emphasis in Exercise Science and Business, summa cum laude, from the University of New Mexico in 2010. Michelle has been a nationally Certified Personal Trainer since 2003 through National Strength & Conditioning Association and since 2004 through National Academy of Sports Medicine. She is certified as a Corrective Exercise Specialist through National Academy of Sports Medicine, certified in Heart Zones Levels 1 & 2, and is CPR and AED certified.

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**Miriam**  
Caregiver, Miami, FL

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June 2015 US857/MG1/15-0381

# Why I Chose To Become A Member of HFA

By Samantha Costa, M.S.

HFA Development Coordinator



**K**ari Peepe is a proud member of HFA. She is active in HFA's Moms in Action program, a regular blogger for *Infusing Love: A Mom's View*, a member of the Blood Sisterhood program, stays active through FitFactor, and has taken the CHOICE survey. Over the last three years, Kari has given so much to the bleeding disorders community, yet this year's Symposium in St. Louis was the first she was able to attend. Kari illustrates what it means to be a selfless volunteer while supporting and rallying awareness for HFA's membership campaign. What motivates Kari for her outstanding involvement? Kari tells us in her own words:

## Q. WHAT IS YOUR CONNECTION TO THE BLEEDING DISORDERS COMMUNITY?

In 2011, my daughter, Scarlett, and I were diagnosed with Platelet Storage Pool Disorder (PSPD), a rare bleeding disorder. As a woman living with a bleeding disorder, I noticed that there were very few stories being shared. That is why I decided to start my own blog called, *A Touch of Scarlett* in 2011.

## Q. HOW AND WHEN DID YOU GET INVOLVED IN HFA'S INFUSING LOVE MOM'S BLOG?

I started blogging for HFA's *Infusing Love* in 2014. I had been following the blog since stumbling upon it while browsing around HFA's website. I felt there was a need for a voice of those with rare bleeding disorders who do not have a treatment plan.

## Q. WHAT MOTIVATED YOU TO BECOME AN HFA MEMBER IN 2013?

I became a member for the first time in 2013 after making frequent visits to the website with hopes of becoming more involved and eventually even meeting

some other members of the bleeding disorder community. Once I became an HFA member, I felt like I was officially a part of the family. It was important to me to become a member in order to support HFA's emergency financial assistance program, Helping Hands, as 100% of the dues go towards the program. In addition, becoming an HFA Member ensured that I would get all of the latest information related to bleeding disorders, which I don't want to miss!

## Q. HOW WAS YOUR FIRST SYMPOSIUM EXPERIENCE?

St. Louis was a great introduction to HFA's Symposium, and I am so grateful I was given a first time attendee scholarship to attend. I was able to connect with so many people I had been in contact with via social media as well as learn new tools and techniques to managing my bleeding disorder. It was so wonderful to have such a focus on women with bleeding disorders and I can only hope sometime in the near future there will be a focus on those diagnosed with storage pool disorders as well.



Photo courtesy of Kari Peepe.



Photo courtesy of Kari Peepe.

**“Once I became an HFA member, I felt like I was officially a part of the family.”**

**Q. WHAT TOPICS WOULD YOU LIKE HFA TO EXPLORE MORE?**

I would love to see some more focus and research done on PSPD. I would love to somehow see more education on women’s bleeding disorders get to a greater number of physicians, OB/GYNs, dentists, and ER staff.

As the voice of the bleeding disorder community, we encourage you to have your voice heard like Kari’s! Become a HFA member today for only \$25/individual or \$50/family. 100% of the funds goes to Helping Hands program, which directly provides financial assistance to any family from the bleeding disorders community who is experiencing a crisis. ■■



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# Empowering Inhibitor Patients With Information

By Sonji Wilkes

HFA Programs Manager

Through input from the 2013 Symposium and a survey launched in the summer of 2013, HFA heard from those living with or caring for someone with an inhibitor and developed a dedicated inhibitor track at our annual Symposium. At HFA, a core value is listening to the community's voice — and the inhibitor community spoke loud and clear that more in-depth, higher level education was needed for those who are dealing with a long-term inhibitor.

With that in mind, an advisory committee began meeting to plan the agenda, based on feedback from a 2013 HFA survey. From these beginnings, the committee put together an inaugural Inhibitor Track for the 2014 HFA Symposium. The 2014 Inhibitor Track proved to be very successful and a similar track was planned for this past spring's Symposium.

The inhibitor community told HFA that while they needed time among themselves, they also still wanted to be part of the "normal bleeding community." With that in mind, HFA planned the inhibitor track for Thursday afternoon to allow participants the opportunity to take part in HFA Families, Blood Brotherhood or Blood Sisterhood, Young Adult or Partners/Spouse tracks later in the Symposium agenda. Those wishing to attend the inhibitor track could apply for a scholarship when registering for the overall Symposium.

The 2015 Inhibitor Track included Dr. Shannon Meeks from Emory University answering several common questions on inhibitors, such as, "Why does my doctor say every patient with hemophilia A and an inhibitor is different?" and "How am I going to stop bleeding now that I have an inhibitor?" Dr. Meeks led the audience

through novel clinical approaches to treatment for difficult-to-eradicate inhibitors. One participant later shared, "I appreciate Dr. Meeks's willingness to think outside the box. Those creative, 'let's try it' approaches are often taken out of presentations, but that's often the very thing the inhibitor community needs to hear about. Thank you!" The Inhibitor Track also included a presentation by popular HFA Families presenter, Dr. Dave Robinson, who shared tips and techniques for dealing with worry, stress, and anxiety. This session was revamped for the broader hemophilia community later this spring and presented as a webinar. "I Can't Fight This Feeling" can be viewed on the HFA YouTube channel.

The track wrapped up with Debbie Porter, inhibitor mom and founder of Reduce Inhibitor Development (RID), sharing her family's history of hemophilia and inhibitors, and inspiring the audience to get involved in advocacy efforts, including how patients can report inhibitors to the FDA. Debbie explained the current issues concerning inhibitors and gave the community tips on how to get involved. The day concluded with an expert panel discussion of providers, community advocates, and a representative from the Centers for Disease Control as well as a rap session in which moms, dads, spouses and patients with an inhibitor could share openly about the issues of most concern to them. The inhibitor track presentations can be found on HFA's inhibitor information pages on the HFA website at <http://www.hemophiliafed.org/bleeding-disorders/inhibitors/>.

Those in attendance felt the inhibitor track was very positive. The spouse of an adult man with an inhibitor shared, "Thank you for making an inhibitor track. Finally, a meeting tailored to inhibitor patients! Meeting and hearing other stories from people who are going through the same complications was very helpful."

**"Love hearing from other families. We need to improve advocacy for inhibitors within the rest of community."** — Mom of child with inhibitor



**“Stress can take over a person’s mental state. Learning new ways to deal with that stress will help us all in the long run.”**

— Adult patient with inhibitor



## Tips for Reporting Problems to the FDA:

(Adapted from FDA Consumer Health Information, “Your Guide for Reporting Problems to the FDA”)

1. Report what happened as soon as possible after you discover a problem. Be prepared with the following information:
  - names, addresses, and phone numbers of people affected
  - your name, postal and e-mail address, and phone number
  - name, address, and phone number of doctor or hospital if emergency treatment was provided
  - product codes or identifying marks on the label or container
  - name and address of store where product was bought and date of purchase
  - name and address of company on the product label
2. Do not discard the product packaging and labeling. These provide codes, numbers, and dates that will help FDA trace the product back to the plant.
3. In addition to reporting to FDA, the agency recommends reporting the problem to the manufacturer and to the store where the product was purchased.
4. When in doubt about how to report a problem, call your local FDA Consumer Complaint Coordinator
5. Consumers can also visit FDA’s Safety Reporting Portal to report a safety issue.

**“The most beneficial thing about the inhibitor track was the personalization; there are real people behind inhibitors. IT IS PARAMOUNT TO TELL YOUR STORY.”**

— Caregiver of a son with an inhibitor



### Type of Problem

- Serious adverse event (side effect)
- Product quality problem (like a medication having a suspicious odor)
- Product use error (such as mixing up products with similar drug names or packaging)

### Type of Product

- Human health care products:
- Human drugs
  - Medical devices
  - Blood products and other biologics (except vaccines)
  - Dietary supplements
  - Infant formulas
  - Medical foods such as nutritional supplements

### Report a Problem

- MedWatch by calling 1-800-332-1088
- FDA Consumer Complaint Coordinator in your geographic area. See list at: [www.fda.gov](http://www.fda.gov)
- FDA’s Reporting Problems. More information can be found at: [www.fda.gov](http://www.fda.gov)
- Your health care professional for medical advice.



## Anyone Can Form An Inhibitor. Everyone Should Be Tested Yearly.

In July, HFA Families program hosted an educational webinar, "Inhibitors: What You Need to Know." This informative session, led by a former HTC nurse coordinator provided a basic overview of what it means to have an inhibitor, the risk factors for developing one, the treatment challenges, and overall day-to-day management.

Watch the entire webinar in its entirety on HFA's YouTube channel: [www.youtube.com/user/VoicesHFA](http://www.youtube.com/user/VoicesHFA)

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# CURING THE WANDERLUST: Traveling Safely with a Bleeding Disorder



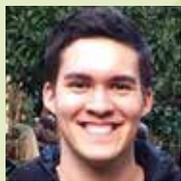
In 2014, HFA launched Google Hangouts for young adults with bleeding disorders (ages 18-35). These on-line hangouts provide young adults an opportunity to connect across the country on important topics. In June, HFA hosted a hangout featuring three panelists who shared their personal tips for safely traveling abroad with a bleeding disorder. Our three panelists emphasized that with careful preparations, bleeding disorders are not a roadblock to getting out there and seeing the world!

## Michelle, Wisconsin



“An important part of advocating when abroad is to remember that, only you know your body best. If you get hurt or feel a bleed coming on, and you are traveling with others, be sure to communicate that so you can treat it effectively and enjoy your time. It is better to speak up and treat, than to say nothing and have a bleed that prevents you from enjoying your travel time to its fullest.”

## Alex, Nevada



“The two reasons why I always contact my HTC before international travel: one, it gives me the chance to review my bleed dose, which in turn allows me to bring enough factor should I have a worst-case scenario. Two, my HTC updates my travel letter just in case I need to see a physician or airport security questions my intentions.”

## Sean, Colorado



“Hemophilia has never been an issue for me when it comes to traveling. As long as you prepare for your trips well and stick to a healthy treatment schedule you shouldn't worry about going on new adventures!”

## Top Five Travel Tips

1. Do your homework beforehand — what are my insurance benefits away from home? Where are the closest hemophilia specialists?
2. Inform your healthcare provider/HTC of your travel plans and ask how you can prepare.
3. Obtain a travel letter from your healthcare provider/HTC and carry it with you.
4. Pack your factor, supplies, and other medications in your carry-on bag — not your checked bag.
5. Wear your medical identification jewelry at all times.



Join HFA  
for an upcoming  
Young Adult Hangout!

**Tuesday, August 4th**

Managing and Treating Inhibitors:  
A Young Adult Perspective

**Tuesday, October 6th**

Maintaining Boundaries:  
Employment in the Bleeding Disorders Community

**Tuesday, December 1st**

Strong Bodies Bleed Less!  
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**For more information go to: [www.hemophiliafed.org](http://www.hemophiliafed.org)**