Spring is upon us! If you’re reading from the Northeast, I’m sure you are extra delighted to have summer on the horizon!

**Don’t Hold Back.** As you receive this issue of Dateline, World Hemophilia Day and Hemophilia Awareness Month has wrapped up. Did you get involved, even in a small way? I hope so! Maybe you’re teaching others about our history, or what it’s like to live with a bleeding disorder today. Maybe you became a member of HFA to show your support for an organization that exclusively focuses on you, the community. Even sharing a Facebook post with friends and family outside of the bleeding disorders community can help build awareness, one person at a time. It matters! Did you attend Symposium this year? If so, thanks for attending! It was our biggest and best meeting yet!

**It is Okay.** My son, who turns 12 this year, was born in the spring and I always think back to his birth and then diagnosis of severe hemophilia. With no family history, we really had no knowledge of hemophilia and had so many questions! Our providers were helpful, answering them and making themselves accessible for any new questions we had. Asking questions has never stopped for us. There have been numerous changes in hemophilia over the last 12 years. Between health care and treatment options, life with hemophilia is quite different than it was when my son was born and significantly different for his older blood brothers and sisters. With change comes uncertainty. Thankfully, our community has many resources at our disposal to help with that change and uncertainty. Take advantage of them—ask questions!

**The Most Critical Step.** We are all, in some way, an advocate in this community. We advocate at school, at work, with our insurance companies, for our medical care, and among our local communities. You may even participate in legislative advocacy at times. Never forget those profound words by Margaret Mead, “a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.”

Thank you for being part of the HFA community!

Warm regards,

Tracy Cleghorn
Board President

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

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

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With Your Help, We Do Great Things!

In April we celebrated National Volunteer Week by thanking the hundreds of volunteers who organize fundraisers, serve on our board and committees, and who donate their talents and time to HFA. Although living with a bleeding disorder can be challenging, being part of such a giving, supportive, and resilient community helps to make it easier. We can’t say it more simply: thank you!

There are so many ways to be involved, ask questions, and take action. Throughout this edition of Dateline you will learn how to be active and have your voice heard in the bleeding disorders community!

BE INVOLVED

• Follow us on Facebook, Twitter, Instagram, and Pinterest by searching for @hemophiliafed.
• Register to receive our bi-weekly emails.
• Participate in our annual Gears for Good charity bike rides.
• Spread awareness by wearing your “I Love” shirt wherever you go.

ASK QUESTIONS

• Learn more about all of our programs and services.
• Explore our interactive historical timeline.
• Find an HFA member organization in your area.
• Submit a question to Dear Addy to become stronger advocates.

TAKE ACTION

• Ask your Member of Congress to keep factor affordable for families.
• Let your voice be heard. Take the CHOICE survey.
• Register for the Patient Notification System (PNS).
• Become a member of HFA.
Dear Addy: An Advocacy Corner for Real Community Questions

By Wendy Owens and Stephen Fitzmaurice, MPS

When it comes to navigating insurance, there’s so much to consider. Whether you’re weighing benefits, out-of-pocket-maximums, or the extent of your network, health insurance is a complicated issue for anyone, especially families treating a bleeding disorder. Luckily for you, Addy is in your corner! Below are three questions that Addy has recently covered to help you with your insurance conundrums.

Every other week, our Advocacy & Government Relations team answers questions received from patients like you! You can catch the latest edition of Dear Addy under the News and Stories section of our website: www.hemophiliafed.org

Dear Addy,

My factor is moving from the medical benefit to the pharmacy benefit this year, and I’m worried. What should I watch out for?

From,
Jermane, severe hemophilia B

Thanks for writing, Jermane.

We are seeing many insurers around the country making this switch. In several instances, insurers are placing treatment products for hemophilia and other bleeding disorders into specialty tiers on their drug formulary. You can learn more about specialty tiers and their impact on patients on HFA’s website, at www.hemophiliafed.org.

Placing medications on a specialty tier allows an insurer to charge coinsurance for factor. A coinsurance is when you assume a percentage of the medication’s cost (say, for example, 30%) rather than a small, fixed amount (a copay). This information can be found in your plan’s formulary.

Unfortunately, it is possible for you to be required to pay the full $6,600 maximum annual out-of-pocket in the first month your insurance policy is effective. Some people taking high-cost medications like factor may have to pay a deductible in addition to a copayment and coinsurance. The cost of healthcare and medication for some people can easily total over $6,660 in a month depending on their circumstances. See my last letter to learn more about out-of-pocket maximums, and how you can afford them.

Open Enrollment, the period where you can search for and compare insurance plans for you and your family, closed on February 15. However, there are many circumstances, or “qualifying life events,” that allow people to change health insurance plans outside of the enrollment period. For example, if you get a new job, you are able to change insurers in order to be covered by the plans offered by your new employer. Your company will have a complete list of qualifying life events that allow you to change your coverage.

To learn what you should look for in a plan, be sure to read my post on Open Enrollment, and check out HFA’s webinar on insurance tips and pitfalls, available on our webpage.

Remember, whether you keep your current health insurance or enroll in a new plan, READ YOUR POLICY. This is critical because the health insurance plan you choose, will be yours for 12 months unless you have a qualifying life event.

Sincerely,
Addy
Dear Loretta,

The term “out-of-network” refers to those doctors, hospitals, and other health care providers with whom a patient’s insurance company has NOT contracted to provide care. Insurers contract with doctors, hospitals, or other health care providers to provide care at a set cost as part of their cost saving measures.

For example, if you use an out-of-network provider for care, your insurer may require you to pay higher co-pays, deductibles, and co-insurance for that care, or they may not pay for any part of the out-of-network care you receive. This means that you likely will pay more to see an out-of-network provider at your HTC or have to pay for the care out of your own pocket. How much you pay to see an out-of-network provider will depend on the type of plan you have. You will need to contact your human resources department or your health insurance provider directly to learn what applies in your case.

For more information about open enrollment, and for a health insurance plan checklist to help you get the most out of your plan, visit our www.hemophiliafed.org.

Sincerely,

Addy

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Dear Sonya,

This is a question many people are asking, especially those with chronic diseases. Before the Patient Protection and Affordable Care Act (ACA) set annual limits on out-of-pocket expenses for health care there were no set limits. So you could say we are all better off now by having the limits we have. The thinking behind limiting out-of-pocket costs is that individual and families could budget for potentially incurring the full limit over the course of a year. Unfortunately, there is the potential for someone with a bleeding disorder to incur the full out-of-pocket limit in a single month.

So what to do? Planning is critical. Review your health insurance policy carefully at each open enrollment period. You may find it better to pay a higher monthly premium to spread costs out over the year than to have a hefty deductible and have the deductible cost come due all at once, for example.

Otherwise, if you are facing this hurdle, there are many programs that are willing to assist with payments. Check out HFA’s list of Patient Assistance Programs at www.hemophiliafed.org. We update this page every month, so be sure to check back often.

Our Advocacy & Government Relations team is working year round on bills that address out-of-pocket costs. To stay up to date, sign up for our email updates on our website.

Sincerely,

Addy

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If you have a question for Addy, please contact us at www.hemophiliafed.org/ask-dear-addy

Don’t worry, your name will be changed in our response.
HFA believes the Patient Notification System (PNS) is a valuable resource for patients and families with bleeding disorders.

Recalls and withdrawals for medical products and the associated ancillary supplies do occur.

When a recall or withdrawal is announced, each manufacturer and supplier has their own internal process for notifying pharmacies, clinicians, and patients. However, the PNS is the fastest way to learn about medication and associated ancillary product withdrawals.

### WHY SHOULD I REGISTER?

Whether you use plasma-derived or recombinant therapies, there are many reasons that your therapy might be recalled.

Past recalls and withdrawals include:

- Defective sterile water vials
- Improperly packaged alcohol wipes
- Problems with the product potency and shelf life
- Mislabeled products
- Problems with clotting factor
- And many more

**THIS SERVICE IS FAST, FREE, and CONFIDENTIAL, but FEWER THAN 1 IN 3 PATIENTS are signed up for it!**

REGISTER TODAY:  
www.patientnotificationsystem.org

278+ number of patients that have registered since February 2015.
Don’t Miss Out: Have Your Voice Heard!

CHOICE (Community Having Opportunity to Influence Care Equity) is a project driven by the Hemophilia Federation of America (HFA) and supported by the Centers for Disease Control and Prevention. CHOICE collects information through an online and paper-based survey.

This survey gathers data about the health experiences of people who have a doctor-diagnosed bleeding disorder. HFA’s goal for the CHOICE Project is to put the survey results to work to improve the lives of those in the bleeding disorders community who do not receive care at a federally-funded hemophilia treatment center.

Don’t Miss Out: Have Your Voice Heard!

481 SURVEYS have been completed as of April 14, 2015

Please take the CHOICE survey today, and help us improve the lives of everyone with a bleeding condition.

www.hemophiliafed.org/choice

Bringing innovative therapies to patients around the world

For over 30 years, we have been focused on developing high-quality, life-saving products that support the health and well-being of patients around the world.

Get to know Octapharma better
Visit www.octapharma.com
Items Reimbursement 101

By Elaine Chan, MSW, MPH

Over the years, Helping Hands have assisted many families during their time of need from assistance in housing to utilities. In 2012, Items Reimbursement was incorporated into Helping Hands with a focus to assist members of the bleeding disorder community in obtaining medically necessary items to help manage their bleeding disorder. Here is a useful guide to understand what Items Reimbursement is.

What is Items Reimbursement?
Understanding the financial impact of managing a bleeding disorder, Items Reimbursement is a service designed to assist individuals in the bleeding disorders community with the cost of medically necessary items. In 2014, Items Reimbursement assisted over 90 households in obtaining important items such as protective gear, braces and supports, walking supports, and heating and cooling items.

FAQ’s:

How soon will I receive the reimbursement?
HFA makes every attempt to complete the application within 30 days.

Do you reimburse for Medic Alerts or Road IDs?
Yes, we can reimburse medical identification items such as Medic Alert or Road ID. We reimburse your full membership and up to $30.00 in medical identification accessories, less shipping and handling costs.

What if I can’t afford the items upfront?
On a case by case basis, HFA can assist in paying the medical durable item(s) upfront, with the exception of medical identification items such as Medic Alert and Road ID. Please contact HFA at (202) 675-6984 or assist@hemophiliafed.org for additional information.

What if I have an item that is not on the list of approved items?
Please contact HFA at (202) 675-6984 or assist@hemophiliafed.org to discuss any specific request.

How is Items Reimbursement different from Helping Hands?
Items Reimbursement is a direct reimbursement service for medical necessary and durable items while the Helping Hands Program provides urgent financial assistance for basic living expenses, such as housing, utilities, and transportation related expenses, through a review process.

Will I be eligible for Items Reimbursement if I have used the Helping Hands funds in the last year?
Completion of a Helping Hands application does not mean you are ineligible for reimbursement for medical durable items.

Are there any deadlines that I should know?
Applicants have 30 days to submit their receipt(s) from the date of their order/purchase.

How do I know if my reimbursement was received and approved?
Our program coordinator will contact you within a week from the time of application submission to confirm the application.

Do I need a medical note for each item I request for reimbursement?
Yes, every Items Reimbursement request requires a medical note of necessity from a medical practitioner.

Important note: You must have a doctor-diagnosed bleeding disorder to apply.

STEPS TO APPLY:

• Step 1: Obtain a proof of bleeding disorder
• Step 2: Get a medical note or letter from your doctor indicating medical necessity for item requested for reimbursement
• Step 3: Order invoice/receipt for reimbursement
• Step 4: Complete an Items Reimbursement application online (you or a professional in the bleeding disorders community, i.e. social worker, home care representative, etc.)
List of Approved Items*

Medic Alert Jewelry
- Applicants must submit applications and pay directly to Medic Alert (www.medicalert.org)
- Items will reimburse applicants up to $30.00 for jewelry, along with membership fees

Protective Gear
- Helmets (bicycle, comfy caps)
- Ankle Pads
- Elbow Pads
- Knee Pads
- Wrist Pads

Braces & Support
- Ankle
- Elbow
- Knee
- Wrist (braces, Heelbo’s, knee togs, sleeves, supports)
- Wraps/bandages

Walking Support
- Canes
- Crutches
- Accessories (arm pads, hand grips, cane/crutch tips)

Heating & Cooling
- Hot/Cold packs (instant, reusable)
- Cryo Cuff/Cooler

*This is a list of some of the approved items.

"Items Reimbursement is such a great resource for our community. I have patients who simply have so much on their plate in managing their hemophilia and to know that they have this service is a blessing in disguise."
- Helpings Hands referrer

"This process was a lot smoother than I expected. Thank you for making our lives a little easier."
- adult hemophilia patient

"Our little guy is very active and having the Comfy Cap have given us and his day care a peace of mind. Thank you."
- parent of a young child with von Willebrand Disease
HFA’s mission is dedicated to improving the lives of those with a bleeding disorder. During Hemophilia Awareness Month, it was especially evident that the community is full of strong advocates that know how important it is to be involved, ask questions, and take action.

With your help, we can continue to do great things! With your support, we are able to keep our Helping Hands emergency assistance program open year-round, helping individuals and families experiencing a financial crisis get back on their feet. Your membership matters and makes a difference.

“My family not only belongs to HFA, WE ARE HFA.”

-Suzanne, hemophilia mom

You can become a member of HFA for only $25, have full access to our programs and services, receive regular print/electronic communications, and policy action alerts vital to the bleeding disorders community.

As a thank you, we will send you this pin as a reminder that your voice is important and will continue to be heard!

To become a member go to: www.hemophiliafed.org/donate
Females can and do have bleeding disorders. The type and severity of symptoms experienced by a female with a bleeding disorder depends upon the diagnosis and severity of the disorder. Some of the symptoms women may experience include:

- Heavy menstrual bleeding
- Frequent nosebleeds
- Prolonged bleeding following a dental procedure
- Post-partum bleeding (excessive bleeding after giving birth)

While some women experience bleeding symptoms monthly or even more frequently, other women may go years before bleeding issues are recognized, making a diagnosis even more difficult. Jennifer was a hemophilia carrier for 33 years before she had her first bleed. She shares the emotional and physical pain she endured as she struggled to get a proper diagnosis and treatment. Here is Jennifer’s story:

For 33 years I was just a hemophilia sibling and a carrier. Being a carrier never frightened me. I grew up around hemophiliacs. In fact, hemophilia didn’t scare me until a year ago when I not so gracefully fell on my knee. I immediately knew something was wrong. That fall would change my life forever. The swelling just kept getting worse and elevation and ice weren’t helping. Even though it had been over 20 years since my brother’s death from AIDS due to contaminated factor products, this seemed all too familiar.

As if having a bleed for the first time isn’t painful enough, I was bombarded with questions from people who don’t understand how you can live 33 years without a bleed. I’ve always known I was a carrier with a low factor level. I have factor, but my body has to be reminded to make more and now that I’m older, sometimes it just can’t make enough.

I went to an orthopedist who did x-rays but saw nothing to explain the pain and swelling. As it got worse, I thought, maybe it was a bleed. It was warm to the touch, pain was excruciating, swelling was starting to affect my thigh, but I had never had a bleed before. I got online and shared my experience and symptoms with hemophilia Facebook groups, family, and friends. Everything I described pointed to a bleed. My hematologist checked my factor level which was around 80%. He never touched my knee and only looked at it because I pulled my pants down in agony and frustration. After a couple weeks, the swelling and pain worsened. I called my hematologist to give me DDAVP to see if it would help. For four days I went to the outpatient center at a hospital and infused for 2-3 hours. After a week of DDAVP, the pain and swelling started to subside.

I realized that it would be helpful to visit my local HTC, so if I ever had another bleed I would be prepared. However, that turned into a horrible and incredibly shocking experience.

As women, we need to be vigilant, educated, and vocal about hemophilia.

I knew my family wasn’t exactly welcomed at the HTC since our participation in the lawsuit against the pharmaceutical companies and doctors in the 1980s. But I also felt this was a medical establishment with a sole purpose of treating hemophilia, I spent 6 hours in a room where I was visited by a social worker who asked me, “How do you think your life would be if your brother never had hemophilia?” I’ve been seeing therapists for over 25 years (I’m not ashamed of this) and I have never been asked that question. Then finally I saw the lead doctor instead of the head doctor, it was an intern. I had made this appointment 3 months in advance to see the hematologist and she wasn’t there. No one had read my medical records. The intern didn’t even physically examine me or touch my knee. Disappointment and confusion quickly turned to anger.

It took me three months of phone calls to get my blood work results. I was told by the nurse, not a doctor, that my factor level was 80% and I was therefore not a carrier of hemophilia. According to her I had no indications that I had any hemophilia issues. I didn’t argue, I just hung up with disappointment, doubt, and major confusion.

continued on page 26...
HFA’s Blood Brotherhood program is a national program serving adult men with bleeding disorders by providing local face-to-face events at participating HFA Member Organizations, a private Online Forum, educational webinars, and supportive resources for adult men.

With the arrival of new and promising Hepatitis C treatments, comes the worry of affordability. Many manufacturers of HCV treatments offer co-payment and product assistance programs to assist patients with the high cost of these important treatments.

<table>
<thead>
<tr>
<th>Program Name &amp; Contact Information</th>
<th>Limit Total</th>
<th>Notes</th>
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<tbody>
<tr>
<td>Genentech/Roche Co-Pay Assistance PEGASYS Co-Pay Card 1-888-202-9939</td>
<td>$1,500-$2,400 per year (Depending on income) Card covers 80% of your co-pay for PEGASYS after the first $25 has been paid</td>
<td>• Patient must have a prescription for PEGASYS to treat chronic hepatitis B or C • Patient must be 18 years of age or older • Patient must not reside or receive treatment in Vermont • Patient must not participate in any federal or state-funded health care programs (e.g. Medicaid, Medicare) • Patient must not participate in other charitable funding sources (e.g. Genentech Access to Care Foundation)</td>
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<tr>
<td>Genentech/Roche Product Assistance Genentech Access to Care Foundation 888-941-3331</td>
<td>Call for further details</td>
<td>• Provides assistance for eligible patients without coverage for Genentech medicines and underinsured patients whose out-of-pocket costs for Genentech medicines account for greater than or equal to 10% of their annual household adjusted gross income • Certain financial and medical criteria must also be met</td>
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<tr>
<td>Gilead Co-Pay Assistance 1-855-769-7284 Harvoni Support Path Sovaldi Support Path</td>
<td>Co-Pay coupon program will cover out-of-pocket costs of Harvoni or Sovaldi after you pay the first $5 per prescription fill, up to a maximum of 25% of the catalog price of a 12-week regimen of Harvoni or Sovaldi</td>
<td>• For residents of USA, Puerto Rico, Guam, and the Virgin Islands • Co-pay coupon not valid for prescriptions eligible for reimbursement in whole or part by federal/state health care programs (e.g. Medicaid/Medicare) or for commercial health coverage that will cover entire cost of prescription</td>
</tr>
<tr>
<td>Gilead Product Assistance Support Path Patient Assistance Program 1-855-769-7284</td>
<td>Call for further details</td>
<td>• Provides Sovaldi or Harvoni at no charge for eligible patients with no insurance coverage</td>
</tr>
<tr>
<td>Good Days from Chronic Disease Fund Co-Pay Assistance 1-877-968-7233</td>
<td>Call for further details</td>
<td>• Provides assistance with out-of-pocket costs for Hepatitis C Virus prescriptions (Note: Program may open and close throughout the year depending on funding)</td>
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<td>Company / Program</td>
<td>Co-Pay Assistance / Product Assistance</td>
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| **Olysio**        | Co-Pay Assistance                      | Pay no more than $5 per fill. $50,000 annual maximum benefit or 12 months from card activation date, whichever comes first | • Must have commercial insurance coverage  
• Not valid for patients enrolled in Medicare or Medicaid |

| **Olysio**        | Product Assistance                     | Call for further details | • Provides Olysio for patients that do not have public or private prescription drug coverage  
• Must meet income eligibility guidelines |

| **Merck & Co**    | Co-Pay Assistance                      | Up to a maximum benefit of 20% of the catalog price of each Victrelis prescription on up to 12 prescriptions | • Coupon is only valid for patients with commercial insurance plans  
• Not valid for Medicare/Medicaid or any other federal/state health plans  
• Not valid for patients living in Massachusetts  
• Valid only for patients residing in USA or Puerto Rico |

| **Merck & Co**    | Co-Pay Assistance                      | Up to $200 savings off of the copayment for each PegIntron prescription up to 12 prescriptions | • Coupon is only valid for patients with commercial insurance plans  
• Not valid for Medicare/Medicaid or any other federal/state health plans  
• Not valid for patients living in Massachusetts  
• Valid only for patients residing in USA or Puerto Rico |

| **Merck & Co**    | Product Assistance                     | Call for further details | • For patients with prescriptions for PegIntron or Victrelis  
• Must be a US resident  
• Must be uninsured or have no coverage for Merck prescription medicine  
• Must meet income guidelines |

| **Patient Access Network (PAN) Foundation** | Co-Pay Assistance | $15,000 per year | • Patient must be insured  
• Medication must treat HCV directly  
• Patient must reside and receive treatment in USA  
• Patient’s income must fall below 500% of Federal Poverty Level  
• Sovaldi, Harvoni, Ribavirin, Olysio, PegIntron, Pegasys, Incivek, and Victrelis are all eligible medications. Call PAN if you take another medication to treat your HCV |

| **Patient Advocate Foundation** | Co-Pay Assistance | Up to $7,500 per year | • Patient should be insured and insurance must cover the medication for which patient seeks assistance  
• Patient must have a confirmed diagnosis of Hepatitis C  
• Patient must reside and receive treatment in the USA  
• Patient’s income must fall below 400% of the Federal Poverty Guideline (FPG) with consideration of the Cost of Living Index (COLI) and the number in the household |

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**Join our Blood Brotherhood online forum on the second Tuesday of every month at 8PM ET.**

**HFA makes every attempt to provide accurate information regarding patient assistance programs and resources. However, since program policies often change, please contact the manufacturer directly for the most updated information. Chart updated 4/2015.**
Pedal With a Purpose: Gears for Good

In 1997, we began our Helping Hands program to provide financial assistance for basic living expenses (housing, utilities, and transportation related costs) to individuals and families experiencing hardships related to their bleeding disorders. We work with applicants to connect them to their local community resources and empower individuals and families to advocate for themselves.

In 2014, Helping Hands assisted 275 households and distributed over $124,000 in direct aid to families! Read how this program is changing lives.

To help sustain and support Helping Hands while raising awareness for bleeding conditions and promoting healthy living, we created our annual Gears for Good charity bike ride. 100% of the money raised by our riders goes to this important program.

Second Annual Regional Ride
Our second annual regional ride! This ride through central Connecticut will take you past beautiful sites while you team up to ride alongside friends and supporters from around the community. Join us June 27-28!

Fifth Annual National Ride from WV to DC
For the fifth year running, we are riding from West Virginia to Washington, DC along the C&O Canal. This three-day ride is an experience like no other. Join us September 25-27!

Learn more at www.hemophiliafed.org

REGISTER NOW!

SECOND REGIONAL
June 27-28 CT

FIFTH ANNUAL
September 25-27 W.V. to D.C.
Meet **NAVA**, your new best friend
Like a best friend, Baxter’s NAVA program will be your...

**Guide** who provides personalized service, connecting you with resources when you need them.

**Mentor** who can share insights, thoughts, and experiences about life with a bleeding condition.

**Partner** who provides one-on-one coaching to help you plan and achieve your goals.

Baxter’s NAVA program is free for anyone whose life has been touched by a bleeding condition, regardless of treatment.

Join for free at nava.baxter.com, or by calling 1-855-322-NAVA (6282) today and let’s make this the start of a beautiful friendship.

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**QUALITY**

**WHERE IT COUNTS**

**IN 25 YEARS**, we’ve developed a reputation. To families, we’re a team who offers the highest-quality care. And to bleeding disorders organizations, we’re a supporter whose commitment and contributions have never stopped.

We’re not here to boost. **We’re here to promise.**

**AHF is proud to be**

**HFA’s largest homecare donor.**

**CALL 800.243.4631** | **EMAIL ahf@ahinfo.com** | **VISIT ahinfo.com**

**AHF Hemophilia Services**

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Healthy Bodies Bleed Less!
By Janet Chupka, BSN, RN

Getting physically fit doesn’t have to take a lot of time or cost a lot of money, but it can make a big difference in how you feel, your overall health, and time & money spent on dealing with a bleed.

Adults aged 18-64 should get at least 2 hours and 30 minutes (150 minutes) of moderate intensity physical exercise each week. That’s just over 20 minutes a day and can even be completed 10 minutes at a time. Children need at least one hour of physical activity each day.

HFA’s FitFactor program supports good health and quality of life. We strive to strengthen the bleeding disorders community by increasing motivation and influencing lifestyle choices, especially related to physical activity and diet. Our goal: to motivate individuals and families to achieve and maintain a healthy weight and lifestyle through engaging in regular moderate physical activity and proper nutrition.

BE INVOLVED

HFA’s FitFactor tools and resources provide many opportunities and services that assist community members in learning about and engaging in healthy behaviors. There are many ways and opportunities for you to get involved:

• Visit our website to view weekly educational web posts
• Attend one of our educational sessions at local member organizations across the country
• View our motivational and instructional exercise videos
• Register for the Gears for Good bike rides to benefit HFA’s Helping Hands program
• Download and use our FREE Get in Gear mobile app

Please visit us at: www.hemophiliafed.org/programs/fitfactor/

*As with any new activity, or if you are having joint or bleeding problems, make sure you check with your physician or physical therapist to be sure you are ready to get started.

Make 2015 Your Year to Get in Gear

HFA recently launched an update to our wildly popular Get in Gear app! Get in Gear version 3.3 is now available for download in both the iTunes store and Google Play store. This FREE mobile app helps track fitness activities while raising awareness and funds for the bleeding disorder community.

Download the app & check it out!!

The app has a fresh, updated look and new useful features, which our users asked for, including:

• User based account—view and use your account from multiple devices, multiple users on a single device. Each user has their own unique account which is portable between devices.
• Track speed, weight, and calories burned.
• Track and log pain/bleeds experienced with an activity for better communication with your provider.
• Record your pain level using the Wong-Baker FACES® Pain Rating Scale

In addition to the easy-to-use original features which include:

• Track duration and/or distance of fitness activities (with the option to submit fitness activities manually after an activity ended)
• Listen to your favorite music playlist as you work out
• Keep an ongoing history log of all of your fitness activities
• Receive encouraging achievements as you reach important fitness milestones
• Share your fitness activities & achievements with your friends on Facebook
• Access important health news, videos, and information on exercise, nutrition, recipes and wellness topics
• Learn more about Hemophilia, von Willebrand Disease, and HFA’s charity work
• Each time you use this app, you support HFA’s charity programs and services
The Get in Gear app has motivated me to maintain working out and improved my quality of life. NICE JOB!

– Benjamin W.

I have been using Get in Gear for 15 months. I record every workout into the app. This helps me stay focused and motivates me to get to the gym every day.

GET IT IN GEAR AND DOWNLOAD THE APP TODAY.

– Chris R.

But don’t take our word for it, here’s what some of our users are saying about the app:

“This app seems to do everything. I can track my walks, but I can also use it to track other activities such as biking or playing on the Kinect. I really like how the achievements reward me for doing the workouts. It is really encouraging!”

– Matthew L.

What are you waiting for? Download the app today and see how easy it is to make 2015 your year to Get in Gear!

www.getingearapp.com
Kelly and Brian Pintarelli of Oregon never expected their son, Bubba, to have severe hemophilia A, and they certainly never expected Bubba to experience the complications of an inhibitor and chronic pain in his childhood. Kelly shared the family’s experiences with HFA and hopes that other families can learn from their experiences.

**Q.** HOW DID YOU FIND OUT ABOUT BUBBA’S DIAGNOSIS?

After nineteen hours of labor, Bubba turned sideways in the birth canal and was stuck, so I had an emergency C-section. Afterwards, I remember looking him over and over and he appeared perfect until a nurse came in took off his beanie hat. I remember thinking, “What’s wrong with his head? Are those bruises? Is that swelling?” In that moment I believe the nurse was thinking the same thing, as she immediately took a measuring tape out of her pocket and measured Bubba’s head. The look she had on her face was pure terror. Without saying another word she rushed Bubba away from me and down to the NICU. I knew whatever was going on was not good. All I could do was cry.

It seemed like hours before a doctor came back to let me know what was going on. The nurses just kept telling me that Bubba had suffered a skull fracture, that his head was swelling and they were trying to stop the swelling and figure out what was causing it. Finally, a doctor came in and that an MRI showed a skull fracture and a Subgaleal Hematoma and that he was going to need a blood transfusion. From that point on, our lives were flipped upside down. It was like a nightmare I could not wake up from. Finally on day three they were able to determine Bubba had severe hemophilia A (no family history). Bubba then spent the next seventeen days in the NICU fighting for his life.

**Q.** WHEN DID BUBBA DEVELOP AN INHIBITOR?

When Bubba was 10 months old, we made the four-hour drive to our HTC and they prepped Bubba for port surgery. Right before they were going to take him back, his hematologist told us we were not going to be able to do the surgery that day. We were confused and asked why? The dreaded words: high titer inhibitor came out of his mouth. Brian and I had no idea what an inhibitor even was. Even after he explained it, I was still confused. His first port was then placed two months after his first birthday.

**Q.** WHEN WAS THE FIRST TIME BUBBA HAD TO DEAL WITH PAIN ISSUES? WHAT HELPS MAKE HIM MORE COMFORTABLE? HOW WELL DOES IT WORK?

Bubba has developed target joints in both of his ankles. He usually has a bleed every seven to ten days. Bubba requires large amounts of clotting factor to stop bleeds and that comes with side effects. He has suffered serious complications from receiving large volumes of factor such as blood clots and a possible mini stroke. Sometimes people don’t think about other consequences that can occur from hemophilia and using factor products.

I think Bubba had significant pain in his ankles very early. I remember many nights holding him and rocking him when he was little when he was little and could not communicate his pain level, but would be fussy and would not eat; I could not soothe him, and Tylenol/RICE would not work. We would give factor, but then I would still have to stay up with him either rocking him, singing to him, rubbing his back, giving lavender baths, playing music from the radio. As he got older we would watch movies, give him hand held games, play board games, or my husband and I would just be goofy, and would sing and
dance for him. Distraction! Distraction! Distraction! As Bubba started to grow older, the pain in his ankles became excruciating for him. I felt like every other weekend we were in the ER because we could not control the pain. My usual, smiling, happy son would be crying and screaming "Mommy, why, why, why is this happening to me? Mommy please makes it stop." By the time we got to the ER his blood pressure was just through the roof, he would get IV pain meds and a narcotic prescription to go home with.

Q. HOW MUCH HAVE YOUR DOCTORS AND OTHER PROVIDERS TALKED WITH YOU ABOUT PAIN MANAGEMENT?

During a comprehensive visit when Bubba was 5 years old, Brian and I decided we were going to come up with a plan to get Bubba's pain under control.

The physical therapist was able to show us that Bubba was losing range of motion in his ankles, and it was getting worse at every six-month check-up. The physical therapist recommended insole orthotics to support Bubba's ankles and hopefully cut down on the bleeding. He has had so many bleeds in those ankle joints that the blood has started to erode the bone, causing deformities, chronic inflammation, bone marrow edema, and osteoarthritis. In continued on next page...
the morning when Bubba gets out of bed he looks like an old man. He is stiff, has numbness, and pain. We know that the numbness is probably due to neuropathy and we are scheduled to see the pediatric neurologists again.

Another more preventative option we looked into was aqua therapy. Bubba absolutely loves it! This strengthens those muscles in a safe way, increases flexibility and gives him something to look forward to.

Q. HAS BUBBA HAD AN ANXIETY WITH POKES? IF SO, HOW HAVE YOU DEALT WITH THAT?

Bubba has anxiety over pokes. This is hard because at the very minimum he gets a poke every day. We always use numbing cream, which I’m not sure it even numbs the site anymore, but we continue to use it because it comforts him. I always tell him step by step what I’m doing before I do it. I never lie about the pain. If I see a hematoma over the port, I let him know what to expect. I also always let him yell or scream after we are done. We often make up “funny” bad words to call the port or the needle. I just always want him to be able to identify what he is feeling and put words to it. Emotional health and development is just as important and any other type of development.

Honestly, it’s all about giving him as much control as possible, being open and honest about what is going to happen and letting him express his anger, sadness, and frustration over it.

“Emotional health and development is just as important and any other type of development.”
Q. HOW DOES BUBBA TALK/DESCRIBE HIS PAIN?

Bubba is not always forthcoming with his pain, as he does not want to have to stop playing, or going to school, or whatever activity he is engaged in. Is he grumpy for no reason? Is he walking funny? Is he grinding/clinching his teeth? Is he not using the body part in question? If Bubba does tell us that something is hurting that usually means he is already in a lot of pain. When pushed he will say that his ankle feels, heavy, tight, like its bubbling or popping. We can also visually see the swelling; it’s hot to the touch or sometimes even red. Bubba will also use both the face scale and the pain scale; however he uses his own pain scale that is 1-5 and instead of the regular faces he asks if he can draw the way he is feeling.

Q. WHAT ADVICE DO YOU HAVE FOR OTHER PARENTS WHOSE CHILDREN ARE FACING PAIN?

Be proactive and start with prevention. Joint bleeds appear to be the most painful, so find a way your child can safely build strength, balance and flexibility. If your child starts having chronic bleeds get consultation immediately on what you can do to minimize the bleeding. One joint bleed is one too many. When your child says he or she is in pain, listen! Also, get to know your child’s pain level and how they show pain so you can act accordingly. Research both the physical and emotional effects that narcotics and non-steroidal inflammatory can have on your child. And don’t be afraid to ask for a second opinion.

Kelly Pintarelli lives in Southern Oregon with her husband Brian, eight-year-old son, Bubba and two boxer dogs, Nubz and Zeva. Bubba is in 2nd grade and has Severe Hemophilia A with High titer inhibitor.
## POKES & PAIN: AT A GLANCE

(Compiled from Child Life Council’s Comfort Tips & Tricks Handout)

<table>
<thead>
<tr>
<th>Infants (Use a combination of behaviors to signal pain. These signs may occur when the infant is not in pain, but combinations are usually present in an infant with pain.)</th>
<th>Signs of Pain</th>
<th>Distraction Techniques</th>
<th>Comfort Positions for Pokes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Irritable, restless</td>
<td>• Sugar solution for pacifier</td>
<td>• Family/Caregiver Lap</td>
<td></td>
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<tr>
<td>• Whispering</td>
<td>• Swaddling</td>
<td>• Nursing or bottle-feeding</td>
<td></td>
</tr>
<tr>
<td>• Crying continuously or intensely</td>
<td>• Rocking in chair or other movement</td>
<td>• Swaddled</td>
<td></td>
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<tr>
<td>• Facial grimacing</td>
<td>• Nursing or bottle-feeding</td>
<td></td>
<td></td>
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<tr>
<td>• Clenched fists</td>
<td>• Interactive toys</td>
<td></td>
<td></td>
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<tr>
<td>• Keeping their body rigid</td>
<td>• Blowing bubbles</td>
<td></td>
<td></td>
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<tr>
<td>• Refusing to eat</td>
<td>• Light Wands</td>
<td></td>
<td></td>
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<tr>
<td>• Unable to sleep</td>
<td>• Singing</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>• Ice pack or Buzzy tool</td>
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</table>

<table>
<thead>
<tr>
<th>Toddlers</th>
<th>Signs of Pain</th>
<th>Distraction Techniques</th>
<th>Comfort Positions for Pokes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Describe the pain</td>
<td>• Interactive toys</td>
<td>• Family/Caregiver Lap</td>
<td></td>
</tr>
<tr>
<td>• Cry</td>
<td>• Blowing bubbles</td>
<td>• Hugging and hand-holding</td>
<td></td>
</tr>
<tr>
<td>• Show facial grimacing</td>
<td>• Light Wands</td>
<td>• Restraint may increase level of pain/anxiety</td>
<td></td>
</tr>
<tr>
<td>• Keep their body rigid, refuse to crawl or walk</td>
<td>• Singing</td>
<td>• Avoid child laying on back – may increase anxiety</td>
<td></td>
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<tr>
<td>• Be more easily frustrated</td>
<td>• Ice pack or Buzzy tool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Be aggressive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Be restless or unable to sleep</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Preschool Children</th>
<th>Signs of Pain</th>
<th>Distraction Techniques</th>
<th>Comfort Positions for Pokes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Describe the pain</td>
<td>• Deep Breathing</td>
<td>• Family/Caregiver Lap</td>
<td></td>
</tr>
<tr>
<td>• Show facial grimacing</td>
<td>• Blowing Bubbles</td>
<td>• Hugging and hand-holding</td>
<td></td>
</tr>
<tr>
<td>• Keep body rigid or refuse to move</td>
<td>• TV/Video Games/Handheld Electronic Devices</td>
<td>• Restraint may increase level of pain/anxiety</td>
<td></td>
</tr>
<tr>
<td>• Not want the area touched</td>
<td>• Books</td>
<td>• Avoid child laying on back – may increase anxiety</td>
<td></td>
</tr>
<tr>
<td>• Cry</td>
<td>• Counting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Be restless or irritable</td>
<td>• Singing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Have nightmares</td>
<td>• Ice pack or Buzzy tool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Hesitate to admit pain if they view it as a punishment, or fear the treatment for it</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>School Age Children (Can talk more directly about the cause, type, and amount of pain.)</th>
<th>Signs of Pain</th>
<th>Distraction Techniques</th>
<th>Comfort Positions for Pokes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Holding still or guarding the area that hurts</td>
<td>• Deep Breathing</td>
<td>• Sitting on a chair or parent lap</td>
<td></td>
</tr>
<tr>
<td>• Flat-faced expression</td>
<td>• TV/Video Games/Handheld Electronic Devices</td>
<td>• Hand-holding with a parent/caregiver</td>
<td></td>
</tr>
<tr>
<td>• Facial grimacing</td>
<td>• Joke Telling/Conversation/Counting</td>
<td>• Give the child some control – ask him/her what position they’d like best</td>
<td></td>
</tr>
<tr>
<td>• Emotional withdrawal</td>
<td>• Rub/Stroke near infusion site</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Irritability</td>
<td>• Ice pack or Buzzy tool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Restlessness, thrashing</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>• Disrupted sleep</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>• Nightmares</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Teens (May show a combination of adult and childlike behavior.)</th>
<th>Signs of Pain</th>
<th>Distraction Techniques</th>
<th>Comfort Positions for Pokes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Change in activity level</td>
<td>• Deep Breathing</td>
<td>• Offer choice of positions</td>
<td></td>
</tr>
<tr>
<td>• Decreased cooperation</td>
<td>• TV/Video Games/Handheld Electronic Devices</td>
<td>• Hand-holding with a parent if requested</td>
<td></td>
</tr>
<tr>
<td>• Change in eating or sleeping patterns</td>
<td>• Electronic Devices</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Irritability, restlessness</td>
<td>• Music</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Anger or withdrawal</td>
<td>• Book</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Ice pack or Buzzy tool</td>
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</tbody>
</table>
Pain Checklist for Your HTC Visit

- Use words to describe your pain
- Point to where the pain is located
- Does the pain stay in the same place or move around?
- Describe your level of pain
- Make a list of which treatments have worked, and which have not worked
- Write down what activities make the pain better or worse
- List a pain goal that you have in mind
- Be prepared

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Pain is a very personal experience. Everyone has their own definitions, feelings, and memories associated with pain. Some pain is greater than others. Some pain paralyzes you, and some pain motivates you. How someone chooses to define and cope with pain is molded by his/her experiences throughout a lifetime. Below is a story of one man’s journey with pain throughout his life as a hemophiliac, a father of two daughters who are carriers, and a grandfather to a young child with severe hemophilia.

My Journey with Pain

By Robert Seaton

If you’re a hemophiliac, you know pain; and if you know pain, you’ve used pain meds. How you choose to use your pain meds is based on the severity of the moment. The one thing I’ve learned about hemophilia in my life is that it hurts, but it’s also a motivator. It breeds intelligent thought processing and maturity developed early in life that gives you a head start over time.

Now in my sixties I have an arsenal of stories that have caused me a great deal of pain in life. I’m here to tell you that the pain builds character and combined with a competitive and positive attitude along with a little curiosity, you can dream big and set lofty goals. Life with hemophilia can become an asset, as you become mentally tough from a young age. You learn to make it work for you. I DID.

Growing up in the fifties with Hemophilia was spotty at best. Treatment went from whole blood transfusions in a hospital to factor treatment within the span of 30 years. The change in treatment process truly amazes me. Factor has truly changed how young patients are living and treating hemophilia today.

Soon after college, I found a career in the apparel industry on the West Coast. The career was demanding and grueling as I had to travel to different department, chain, and specialty stores to showcase different fashion lines for which I was in charge. The hours were long and the physical demands were rough, as there days where I had to carry heavy garments and run around to 3-4 appointments in a day, with each appointment lasting 2-3 hours. Despite the physical demands of being a commission salesman, it was a race to get the commission. I remember there was one instance where I experienced a severe elbow bleed, but I refused to take the day off. I knew if I took a day off, I would lose out on a potential sale. I vividly remember going to the emergency room to get my elbow drained and proceed to visit the ortho department to get an elbow cast, but then proceeded to continue on to the hustle and bustle. Pain was override by my drive to succeed.

When my career began to take off and I was married for several years to my wife, Lynette, I experienced a severe setback in my health. One day, our new home got caught on fire and I experienced burns on over 30% of my body. The pain management was difficult and was complicated by my hemophilia. Throughout the recovery period, I was fortunate to have my wife by my side. She motivated me to take better care of my health, and she became my main support. She dedicated her time to take me to my medical appointments and make sure I was responsible to my health. During this time, her support was my motivator for pain management.

After years of pain treatment, I have become an expert in talking about pain management.

After my recovery, we decided to have the conversation about starting a family. We met with my hematologist and left with the knowledge that if we have girls, there was a good likelihood that they would become carriers. Despite our concerns, our doctor reminded us of the advancements in hemophilia treatment, and reassured us that our children would have better lives. Lynette and I were blessed with two beautiful, talented, kind, respectful, and tenacious daughters. The decision to have children was the greatest decision that my wife and I had made, and I would not change it, even though they indeed became carriers. During the subsequent years, my wife and I focused on building a loving family and raising our daughters to the best of our abilities. There were many episodes of joint bleeds and internal bleeds, but the setbacks did not stop my drive to provide for my family, even with the development of inhibitors.
When the inhibitors developed, it was a difficult period of my life. At that time, the treatment options for inhibitors were limited, and I was thrown back into the “dark ages” of treating bleeds with ice packs and ace bandages. R.I.C.E.—rest, ice, elevation, and compression—became my treatment motto. Inhibitor management was difficult despite having access to great care at my local hemophilia treatment center. The inhibitor caused me to have multiple joint bleeds and severely impacted my existing arthritis. Pain treatment was difficult as I had to go through many different pain medications to ease the pain from the bleeds. At times, my pain was dictating where I would go and the type of activities I engaged in.

After years of pain treatment, which include a knee replacement, I can honestly say I have become an expert in talking about pain management. In recent years, I have had the luck to get access to NovoSeven, which has helped me with my treatment. I am truly impressed with the advancement of treatment options within my lifetime. Our community has learned a lot about treatment and pain management. The knowledge and skills that we pass on to our community’s next generation is a testament to the how far we’ve come, to the successes we’ve achieved.

When my grandson, Lawson, was born, my family and I had first-hand experience with the support our community openly gives. It was hard for everyone, especially me, when I learned that my beloved grandson has severe hemophilia. As my daughter and her husband became more involved in our community, our fears were calmed. This community is so supportive, and so willing to share information and experiences, that our family is truly prepared to treat Lawson’s severe hemophilia as he grows. With the arrival of Lawson, I found myself learning with my daughter and son-in-law on the evolving treatment of hemophilia. It is my hope that my grandson will not have to experience the degree of pain I have had to face in my life. After all that is said and done, I’ve had a full and charmed life. I have been blessed with a loving family, loyal friends, and people I love and trust. With a little luck and God’s willing, we just might put this hemophilia thing out of business.

Robert, 61, is a severe hemophiliac (Hemophilia A with an inhibitor) residing in Northern California with his wife of 39 years, Lynnette. Robert and Lynnette have two wonderful and caring daughters, Julia and Elizabeth, who are both carriers. Robert and Lynnette have a grandson, Lawson, who also has hemophilia A. Since his retirement, Robert has spent time with his wife and family in supporting activities of the Hemophilia Foundation of Northern California. He is excited to be part of the newly established Dads In Action program and share his experiences with other dads. He is also an avid music lover and plans to one day teach Lawson how to play the guitar with his baby blue ’79 Fender Stratocaster.

Register to become a Dad in Action at www.hemophiliafed.org
I’m not good at math, but 80% factor level wasn’t 100%. I’ve previously had levels ranging from 20%-70%. So how can a hemophilia treatment center tell me I’m not a symptomatic carrier or even a carrier?

One day going up the stairs led to my knee swelling for 4 months. After my first experience I knew I’d have to see the orthopedist first. At my appointment, he mentioned a possible torn meniscus and ordered an MRI. The MRI ruled out a tear and it was back to begging my hematologist for treatment. He called the HTC for recommendations and was told by the nurse, not the HTC hematologist, that I did not have any hemophilia factor issues and that they would not treat me for hemophilia. The emptiness and outrage I felt when he repeated that to me cannot be described.

I continued in horrific pain, with my entire leg now swollen. I decided to go to the ER and was finally prescribed a daily dose of DDAVP. I was using a walker because the pain and swelling was so severe.

Then my angel came to my rescue. She works in Utah and could be my doctor as long as a local doctor would agree with her treatment plan. Dr. Danielle Nance is not just a hematologist, she is also a female with hemophilia!

When I brought this treatment plan to my local hematologist, he fired me as a patient. Yes, I got fired by a medical doctor during a health emergency. I had done nothing. I had not told him that I thought he was incompetent because I knew I needed him. I did not say a word when I sat in a wheelchair in his office with tears rolling down my face waiting for 3 hours to see him. I kept my anger, frustration, exhaustion, and painful thoughts to myself.

I went to my general practitioner hoping he would be willing to treat me. He had spoken to Dr. Nance and agreed with her recommendations but thought it best that my hematologist work with her. As we waited he called my “ex-hematologist.” My general practitioner told the hematologist he truly believed I was having a hemophilia bleed and that giving me factor could only help.

I was prescribed a factor product, had outpatient surgery to have a PICC line inserted, and began infusing for the next 4 weeks. After the PICC line was removed, I visited Dr. Nance. I made some incredible friends that were female hemophiliacs. A year later, I have learned that I have severe arthritis and a bone spur in my knee as a result of not receiving the correct treatment. Of course I’m angry and really frustrated, but I’m hopeful. Hopeful, that by sharing my painful and extremely long journey it
will spare even one person the pain and emotional roller coaster I endured.

There is a stigma that comes with chronic illnesses. You realize that with each setback, you miss the chance to do "normal" activities. It’s the realization that it’s no longer mind over body, but body over mind. It’s crucial that when you finally accept your illness that you accept there are going to be many days that you can’t fight your body, you have to listen to it and do what needs to be done. It’s not a daily struggle, but rather a struggle every minute of every day. You have to learn to speak up and become your own advocate, because no one knows your body better than you.

This journey—this one bleed—it’s left me vulnerable. My heart aches with each step I take because I am full of fear that I’ll feel the dark pain again. I’m almost afraid to walk. I’m guarded in every movement.

As I reflect back on the journey of my first bleed, I am reminded of my legacy. A legacy that I have a responsibility to carry on. I wouldn’t have felt safe receiving factor if it weren’t for my parents, Dr. Dana Kuhn, Jan Hamilton, and others that took the steps necessary to allow me to receive clean blood products. I owe it to not just to them, but the thousands of hemophiliacs who continue to be advocates for the community. We need to be vigilant, educated, and vocal about hemophilia.

Jennifer Rhea Cross is a 34 year old Freelance Writer from Louisiana. The daughter of Gary W. Cross, author of Vial 023: A Father’s Pursuit of Justice and chairman of the PSI Board of Directors, and Karen Isaminger Cross, incredible mother and empathetic caregiver. Jennifer is an advocate for hemophilia, AIDS, and chronic illness. She is a dog lover and Maltese enthusiast.
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