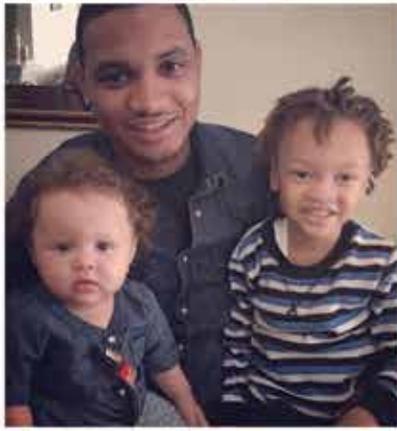




DATELINE

F E D E R A T I O N

Issue 48 | Volume 16 | Spring 2016



Supporting **BLEEDING DISORDERS
AWARENESS MONTH!**

LEARN ABOUT
HFA'S CAMPAIGN pg. 4

Dear Community Members,

Together we are resilient. For months, these four words, the official theme to Symposium 2016, have served as a rallying cry for HFA staff, board members, and community members to come together in support of our annual conference. Resiliency defines our community, for we embody the ability to rebound or spring back stronger after a struggle. We learn and grow, and with each set-back we return even more dedicated and focused on our goals.

Togetherness is the other key component of our theme. Whether it be your spouse, family member, child, HTC, doctor, or community organization, in the HFA community you always have someone to lean on to work through difficult times. Ours is a small community, but boy, are we tough! I may not feel very resilient on my own but with the support of this community I am able to bounce back from adversity. If I have a question or need advice or support, I have this group of people who are happy to lend a helping hand, sympathetic ear, or strong shoulder. With that kind of community at your side, how can you NOT feel strong?

As is obvious, I'm thankful for and appreciative of this beautiful community we share. And that appreciation is keenly felt each year as we plan Symposium. After all, Symposium does not simply happen, it takes months of planning. To our staff, volunteers, and sponsors who make it happen, thank you for your hard work and dedication. To the families who make investment and commitment to travel with us, I hope you find your time worthwhile. Without you all, there is no bleeding disorders community. Together, we are not only resilient, but we are fantastic! We are HFA!

And our theme doesn't stop with Symposium: your input and willingness to come together all year 'round is vital to the work we do. In this issue, we are pleased to include work from:

Wendy Owens, HFA's Director of Research, who outlines for us our organization's research projects and solicits input from community members. I hope her overview of our community-centered, -focused, and -driven research program encourages you to get involved. Where should we focus our efforts? It's up to YOU to decide!

Katie Verb, HFA's Policy Director, shines a light on the data we've been collecting through the Project CALLS initiative. If you are experiencing any issues with your health insurance, please let us know. Through Project CALLS, we'll identify trends and use the information to build a case for change.

Lauren Neybert, HFA's Programs Director, outlines the more than 90 Blood Brotherhood sessions scheduled during the year ahead which will be hosted by more than 25 member organizations. With 950+ men enrolled in the Blood Brotherhood program, this peer-to-peer network is clearly thriving as we celebrate 10 years in 2016.

As you read this Spring issue, I hope the approaching warmer weather meshes with our announcement of the 2016 Gears for Good bike rides! We're thrilled to add a third ride to our 2016 calendar. In 2015 alone Gears for Good, currently in its 5th year, raised more than \$100,000 for HFA's Helping Hands program. So, pump up those bike tires, strap on a helmet, and explore your neighborhood or local bike path

as you warm up for the Gears for Good ride! I hope you participate in one of this year's rides: the trails are beautiful, the company unrivaled, and the cause more than worthwhile.

Warm regards,



Tracy Cleghorn
Board President



“And our theme doesn't stop with Symposium: your input and willingness to come together all year-round is vital to the work we do.”

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RECOGNIZING *Hemophilia* Bleeding Disorders AWARENESS MONTH

*Community member voices reshaped
the annual celebration.*

For the past 30 years, the bleeding disorders community has unofficially recognized Hemophilia Awareness Month during the month of March. The name originated from a proclamation made by President Ronald Reagan in 1986. HFA's messaging has always aimed to educate community members and the general public with information about all bleeding disorders, so the organization was pleased to support a renaming of this yearly celebration.

The National Hemophilia Foundation (NHF) recently petitioned the US Department of Health and Human Services to have Bleeding Disorders Awareness Month placed on its National Health Observances list for March, and succeeded. HFA congratulates NHF on their effort to recognize all people living with bleeding disorders with a more inclusive message.

Before we changed the name of our awareness campaign here at HFA, however, we felt it was critical to hear what community members thought first. HFA is a national, yet community-based, organization so we wanted input from our community to determine how best to serve its needs. In February, HFA conducted a survey among its members asking if they wanted to recognize March as Bleeding Disorders Awareness Month, Hemophilia Awareness Month, or if there was an alternative name they would wish to see. More than 260 individuals responded to the community's awareness month survey! Bleeding Disorders Awareness Month was the strong community preference and HFA proceeded accordingly with renaming the annual celebration.

Each year, HFA's social media campaign on Hemophilia Awareness Month reaches 300,000+ people and last year it caught the interest of Sanjay Gupta, MD at Everyday Health, a provider of digital health and wellness solutions. In 2014, Dr. Gupta's staff saw our efforts on social media and reached out to us about working together on an educational piece about hemophilia. HFA is pleased to have garnered this recognition and was proud to partner with Dr. Gupta and Everyday Health.

What We Heard

Many respondents offered thoughtful comments on the survey and HFA appreciates all the input. Some of the commonly shared views included:

Thank you so much for asking and listening to what the community thinks.

Never forget hemophilia and hemophilia's history.

Don't lose the messaging of hemophilia being a rare condition.

Hemophilia Month should be in April to coincide with World Hemophilia Day on April 17th.

"Bleeding disorders" is inclusive and feels encompassing, reinforcing that we're all a part of a group.

Be unified in how we advocate as a community.

The Survey:

Do you want HFA to recognize March as:

- Bleeding Disorders Awareness Month,
- Hemophilia Awareness Month, or
- Is there another option you'd rather see?

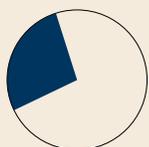
Survey Responses:

BY THE NUMBERS



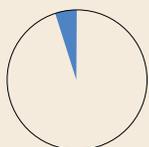
68%

In favor of **Bleeding Disorders Awareness Month**



27%

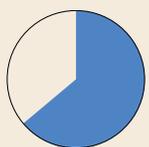
In favor of **Hemophilia Awareness Month**



5%

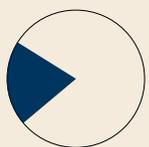
Provided **other suggestions**

WHO PARTICIPATED?



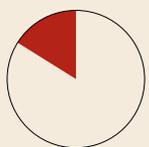
64%

of participants identified as people with a bleeding disorder and/or a family member



20%

of participants identified as providers



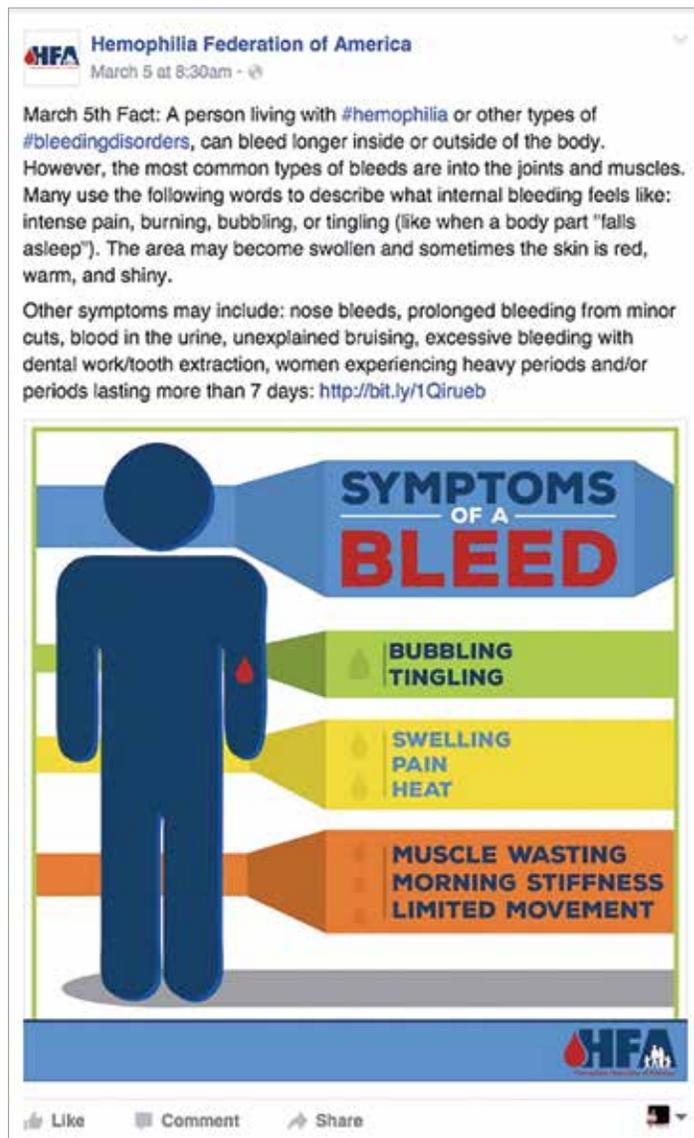
16%

of participants identified as members of the media and general public

The 2016 Awareness Campaign

This year, to recognize Bleeding Disorders Awareness Month, HFA again harnessed the power of social media and provided community members with information and resources to learn more about bleeding disorders, to educate themselves and others on our community's evolution, and to honor our past leaders and activists.

Educational Content:



Hemophilia Federation of America
March 5 at 8:30am · 🌐

March 5th Fact: A person living with #hemophilia or other types of #bleedingdisorders, can bleed longer inside or outside of the body. However, the most common types of bleeds are into the joints and muscles. Many use the following words to describe what internal bleeding feels like: intense pain, burning, bubbling, or tingling (like when a body part "falls asleep"). The area may become swollen and sometimes the skin is red, warm, and shiny.

Other symptoms may include: nose bleeds, prolonged bleeding from minor cuts, blood in the urine, unexplained bruising, excessive bleeding with dental work/tooth extraction, women experiencing heavy periods and/or periods lasting more than 7 days: <http://bit.ly/1Qirueb>

SYMPTOMS OF A BLEED

- BUBBLING TINGLING**
- SWELLING PAIN HEAT**
- MUSCLE WASTING MORNING STIFFNESS LIMITED MOVEMENT**

HFA
Hemophilia Federation of America

Like Comment Share



HemophiliaFederation @hemophilafed · 14h

3/9: Treating #hemophilia ranks among the most expensive chronic conditions in the US, averaging \$350K/year! bit.ly/1pxwoLu

View summary

RECOGNIZING Hemophilia Bleeding Disorders AWARENESS MONTH

Educational Content:

HemophiliaFederation @hemophilafed · Mar 3
 Print & share these cards to educate friends abt #vWD for #BleedingDisorders Awareness Month bit.ly/1Sm1LUA

Heard of Bleeding Disorders?
 20,000 people in the U.S. live with hemophilia...
A person with hemophilia...
 • Is missing a clotting protein called factor
 • Bleeds longer, not faster
 • Is not contagious
 • Has treatment, but no cure

von Wille - disease?
 1-2% of people live with von Willebrand Disease...
A person with vWD...
 • Affects males and females equally
 • Can't form a platelet plug
 • Is not contagious
 • Has treatment, but no cure

HFA www.hemophilafed.org

Hemophilia Federation of America
 March 8 at 7:24am · 🌐

March 8th Fact: To recognize International Women's Day, today's fact is devoted to all women living with a bleeding disorder.

A woman who is a carrier of #hemophilia has the genetic mutation on one of her X chromosomes (there are rare spontaneous mutation cases when women carry the hemophilia gene on both X chromosomes). Approximately one third of women have been diagnosed as "symptomatic carriers," and experience bleeding problems like: nose bleeds, heavy menstrual cycle... [See More](#)

IF A WOMAN HAS CLOTTING FACTORS OF 50% OR LESS, SHE HAS HEMOPHILIA.

HFA

Like Comment Share

HemophiliaFederation @hemophilafed · Mar 2
 3/2: In 1986, President Ronald Reagan designated that March as "National #Hemophilia Month." #BleedingDisorders. bit.ly/1vSMJFO

🔄 4 ❤️ 2

Hemophilia Federation of America
 March 7 at 7:30am · 🌐

March 7th Fact: Von Willebrand Disease (vWD) is the most common #bleedingdisorder (1-2% of the world's population), and affects males and females equally. Many people with vWD are under or misdiagnosed because of mild symptoms. Those with vWD have lower or malfunctioning von Willebrand Factor activity, and thus cannot form a proper platelet plug. Depending on the type and severity of the condition, someone with vWD can experience mild, moderate, or severe bleeding episodes... [See More](#)

von Willebrand Disease Types 1 & 2 Inheritance Patterns

Legend: ■ Unaffected ■ Affected

Affected Father (dark blue) × Unaffected Mother (blue)

Offspring: Affected Son (dark blue), Unaffected Daughter (blue), Unaffected Son (blue), Affected Daughter (dark blue)

HFA

Like Comment Share

Hemophilia Federation of America
 2 hrs · 🌐

March 10th Fact: Inhibitors are antibodies that the immune system develops to destroy the factor before it has time to stop the bleeding (seen in the bottom illustration). Developing an inhibitor continues to be one of the most serious and costly complications of hemophilia.

Approximately 30% of people with severe #hemophilia A, and 2-3% of people with hemophilia B, form an inhibitor to clotting factor; little is known as to why this occurs. One of the key findings of the... [See More](#)

WHEN CLOTTING FACTOR WORKS

WHEN AN INHIBITOR FORMS

LEGEND
● CLOTTING FACTOR REPLACEMENT
Y ANTIBODIES (INHIBITORS)

HFA

Like Comment Share

Twibbon Campaign:

HFA asked community members to help generate awareness for the bleedings disorders community by adding a banner to their Facebook and Twitter profile photos.

Community Voices:



More than 4,000 people added HFA's ribbon to their profile photo.



“Thank you for supporting our campaign!”
 To get involved in other awareness campaigns, please go to www.hemophilafed.org

Information is Key: Navigating the Medical Field

By Sonji Wilkes

In the bleeding community, patients and their parents should know that they are not alone. Everyone, from Hemophilia Treatment Center (HTC) staff, other medical providers, home health care providers, and pharmaceutical companies, to staff members of local and national organizations, and the patients themselves, has the same goal in mind: the best care and outcomes for the individual directly affected by a bleeding disorder. Whether you are newly diagnosed with a bleeding disorder or are looking to make a change in your treatment or service provider, it's important to examine and thoroughly understand what is important to your family in terms of service.

For a family facing a new diagnosis, the sudden influx of people into your life can be intimidating. Knowing who the players are can be a big help. You may be asking yourself, "Why do they want to help me? What's in it for them? What's in it for **me**?" Simply put, learning how to live with a bleeding disorder is much easier with the support of a dependable team of professionals. Developing a strong relationship with your medical provider can ease many of the challenges you may face over your lifetime.

Shannon Brush, a mom of a son with hemophilia B shares, "Once we had received the diagnosis of severe hemophilia for our son, both his new hematologist and nurse practitioner sat

with us for several hours in the clinic office at a separate appointment and answered all the questions we could think of. They gave us a good idea of what to expect in the upcoming months and years. They were patient, compassionate, and sincere in their approach, making sure we had enough information to feel we could care for our son. In that first year, we called and brought him in whenever we had a concern; sometimes he needed treatment, sometimes he didn't, but we always felt heard. It was very comforting to know they were always willing to see our son and help us to understand this new normal."



Eric Frey of Ohio, a dad of son with severe hemophilia A with inhibitors, explains, "We could not do what we do without the support of our HTC and their staff. They have guided us through initial diagnosis, multiple surgeries, and the development and tolerization of high titer inhibitors. They are our team. They trust us and we trust them. There is give-and-take in the relationship. We sometimes do things differently than what we think is ideal because [our medical providers] are committed to a course of action, and we trust **them**. They sometimes agree to a plan that they do not prefer because they trust **us**. It is a two way street; the trust is mutual. We are in it together and it works. We truly couldn't be where we are without them."



MEET THE PLAYERS

	Hemophilia Treatment Center (HTC) Staff	Home Health Care Providers	Pharmaceutical Companies	Local Member Organization Staff & Volunteers	National Organization(s) Staff (HFA, NHF, COTT, Coalition for Hemophilia B)
What's their role in the community?	<p>Provide comprehensive medical care</p> <p>Notes: Could include</p> <ul style="list-style-type: none"> • Hematologists • Nurses • Physical Therapists • Social Workers • Orthopedists • Laboratory Personnel <p>Sometimes offer 340B pharmacy (factor replacement therapy provider)</p>	<p>Home based delivery of factor replacement therapy, often in conjunction with skilled nursing services</p> <p>Notes: You may or may not have a choice of provider based on your insurance plan</p>	<p>Research, development, manufacturing, clinical trials, marketing and seeking FDA approval of factor replacement therapies and other novel therapies</p>	<ul style="list-style-type: none"> • Provides support, education, and advocacy on behalf of community • Often provides programming and services • Can help facilitate relationships among consumers 	<ul style="list-style-type: none"> • Provides support, education, and advocacy on behalf of community • Provides programming and services direct to consumers and by supporting local member organizations • Can help facilitate relationships among consumers

It is overwhelming when a loved one is first diagnosed. Adding to the burden of learning a new language of hemophilia or von Willebrand Disease, you may be faced with choosing which company to use as your factor product provider. While many insurance plans limit which company individuals can use, it is important to note the key components for service to bleeding disorders families. Shannon had a great experience with her home health care company when her son was first diagnosed. “Our homecare rep came to our home, gave us numbers for the local support organization, and helped coordinate nursing visits when needed. Getting hooked into this new community, from other parents to HTC’s to homecare providers, allowed us to feel like we were not alone and would be able to handle whatever came our way.” Eric’s family has used the 340B program at their local HTC and says, “We’ve been so happy with their service that we have not even examined other options.”

Just as having a bleeding disorder is a very individualized diagnosis, what each family needs from a home health care provider or factor replacement therapy provider varies. These helpful hints can help you navigate the decision-making process:



Things you should expect from your home care company or HTC 340B pharmacy, and their employees:

- ◆ Provide, in a timely fashion, prescribed products, supplies, and support as directed by the prescribing medical provider
- ◆ Contact the prescribing medical provider immediately to confirm the need for any new products/supplies the family requests that the prescribing medical provider has not previously prescribed
- ◆ Contact the prescribing medical provider to obtain prior approval for appropriate substitutions if prescribed products or supplies are not available
- ◆ Conduct follow-up needed to ensure adequate inventory of home products and supplies
- ◆ Render services only to the patient for whom they have specific orders from the prescribing medical provider
- ◆ Provide the prescribing medical provider with regular statements of products and supplies issued to the patient
- ◆ Have any contracted nursing service or other representative contact the prescribing medical provider for education, guidance, and orders regarding patient care

Things your home care company or HTC 340B pharmacy and their employees should NOT do:

- ◆ Pressure patients or families to change their current factor distributors
- ◆ Limit access to services for patients and families
- ◆ Contact patients and families to whom their employees previously provided services as representatives of other home care companies or HTC factor programs
- ◆ Provide medical or professional grade psycho-social guidance
- ◆ Make referrals to agencies and community services without working in collaboration with the prescribing medical provider*
- ◆ Provide any non-bleeding disorder products, supplies or support unless ordered by the specific physician who assumes responsibility for the order
- ◆ Provide inducement such as, but not limited to, vacations, payment of household expenses, cell phones, refrigerators, and medical provisions for other family members
- ◆ Waive payment of insurance copays and deductibles without obtaining required financial information

**This does not include mandatory reporting as required by law*

*Adapted from: “What You Should Expect From Your Chosen Home Care Company or HTC Factor Distribution Program,”
Developed by the Region III Federally Funded Hemophilia Treatment Centers*

As new factor replacement and other novel therapies are released into the market, patients and families are considering changing products. There are two types of products currently on the market: plasma-derived therapies and recombinant therapies.

- Plasma-derived therapies are made from human plasma. Plasma is collected by various manufacturers at plasma collection centers, pooled and then separated into different products through a process called fractionation. The fractionation process gives the manufacturer multiple products, including factor VIII (for hemophilia A) and factor IX (for hemophilia B).
- Recombinant therapies are genetically engineered factor VIII and factor IX. The human genes that contain the code necessary for making factor VIII or IX are isolated and then inserted into baby hamster kidney cells or Chinese hamster ovary cells. With the necessary code, these cells are then able to produce factor VIII or IX and scientists are able to separate and purify the cell culture and use it to make factor replacement therapies.

When discussing a product switch with your health care provider, these are some considerations and things to ask about:

Things to Consider When Choosing A Factor Replacement Product

Always consult with your HTC/health care provider to find the best product for you.

Purity

- Plasma-derived vs. recombinant
 - If recombinant, is it first, second or third generation?
- Discuss with your healthcare provider which may be most appropriate for you or your child and the differences in the generations of products.

Efficacy

- Does it work to control bleeding?
- Rate of recovery
- Incidence of inhibitor
- Adverse effects

Convenience

- Longer-acting factors (potentially resulting in fewer infusions)
- Available dosing strengths
- Diluent volume
- Needleless mixing devices

- Storage (expiration date and refrigeration requirements)

Cost

- Are the benefits of using a newer or more expensive product worth the extra cost?
- Are there any proven benefits for using a more costly product?

Experience and commitment from company

- Clinical experience and research
- Commitment to bleeding community
- Do they offer support resources? Insurance help?

What works for you?

Eric explains that choosing a factor product was done in consultation with his son's HTC. "Our only choice was to switch from a standard factor to an extended half-life factor. After doing our research, it was clear to us that this was best for our child, so we made the switch."

Many insurance plans are limiting the choice of home health providers and specialty drugs. HFA has fielded calls and concerns from families who have been denied services, forced to use a product that wasn't their first choice that did not work for them, mandated to use a pharmacy that did not meet their needs, or forced to undergo lengthy prior authorization processes. It can be an alienating and isolating experience so, with this in mind, HFA established Projects CALLS (Creating Alternatives to Limiting and Lacking Services).

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

Through your participation in Project CALLS, HFA will collect stories from the bleeding disorders community across the country, collate the data, identify trends, and use the information to build cases for change. If you have been experiencing issues with your insurance company, we want to hear your story! This is an opportunity for you to share your story while helping the entire bleeding disorders community.

You should never feel alone in the process of learning about this sometimes-complex chronic condition. It's not just learning how to identify bleeds or when to seek help, but also knowing that there are professionals who are willing to help you navigate these decisions. Your job as the patient or parent is to gather information and make informed decisions about all aspects of your or your child's disorder. ■■

More about the patients quoted:

Shannon lives in Texas with her husband, Alan, and three boys, Jacob, Peyton (severe IX), and Barrett. She is a former President of the Board of, and currently the Communications and Walk Manager for, the Texas Central Hemophilia Association.

Eric lives in Toronto, Ohio with his wife, Antonina, and their three children, Pax, (8), Pierce, (7), and Pria, (5). Antonina is a first grade teacher and Eric is a theologian.

Young Adults Google Hangouts: Healthy Living

By Lauren Neybert, MSW



We all know we need to do it: move our bodies more and fill our plates with fruits and vegetables. However, proper nutrition, combined with safe and effective exercise, is especially important to maintain good health in people with bleeding disorders. Another incentive for people with bleeding disorders to adopt a healthier lifestyle? Healthier bodies *bleed less!*

In December, HFA hosted a Young Adult Hangout on the topic of incorporating regular physical fitness into your weekly routine. You missed it? Here are the top five tips shared by young adults living with bleeding disorders:

1. De-stress: Regular physical fitness helps you cope with the everyday stress and anxiety of life.

2. Get social: Getting involved in sports and fitness helps you stay socially connected and meet new friends.

3. Prevent bleeds: Working out regularly and appropriately for your body makes your muscles stronger, protects your joints, and ultimately results in fewer bleeds.

4. Be patient: The best way to stay motivated is to keep focused on your goal. Results of your hard work may not be apparent at first, but you have to be patient and stick with it. Enjoy the process and choose an activity you know you're going to enjoy doing regularly.

5. You don't have to spend a lot of cash: Becoming more active and physically fit doesn't always have to be expensive. Do your homework. For instance, nearby schools and

community centers may offer reduced rates to use their gyms or pools. Try contacting your insurance company to see if they provide any wellness benefits or ask your employer if there are any corporate gym discounts. Check deal sites such as Living Social or Groupon for reduced prices on gym or fitness classes. Finally, remember that simply going outside and walking or running is always free!



How much physical activity do I need?¹

When it comes to weight management, people vary greatly in how much physical activity they need. Here are some guidelines to follow:

- **To maintain your weight:** Work your way up to 150 minutes of moderate-intensity aerobic activity, 75 minutes of vigorous-intensity aerobic activity, or an equivalent mix of the two each week. Strong scientific evidence shows that physical activity can help you maintain your weight over time. However, the exact amount of physical activity needed to do this is not clear since it varies greatly from person to person. It's possible that you may need to do more than the equivalent of 150 minutes of moderate-intensity activity a week to maintain your weight.
- **To lose weight and keep it off:** You will need a high amount of physical activity unless you also adjust your diet and reduce the amount of calories you're consuming. Getting to, and staying at, a healthy weight requires both regular physical activity and a healthy eating plan.

★ HFA's Young Adult Google Hangouts Series 2016

HFA's Young Adult Hangout series was designed to empower, educate, and support young (ages 18-35) adult men and women living with bleeding disorders. As the future of the bleeding disorders community, your voice is important!

Join HFA and other young adults from the community for a Google Hangout! Google Hangouts is a free instant messaging and video chat platform developed by Google and available via Google Plus. You can connect using your computer or mobile device.

May 3: Honoring Our Past, Building Our Future: A Young Adult Perspective

August 2: Get Schooled! Continuing Your Education

October 4: How to Advocate for YOU! ■■

¹ Information sourced from the Centers for Disease Control and Prevention

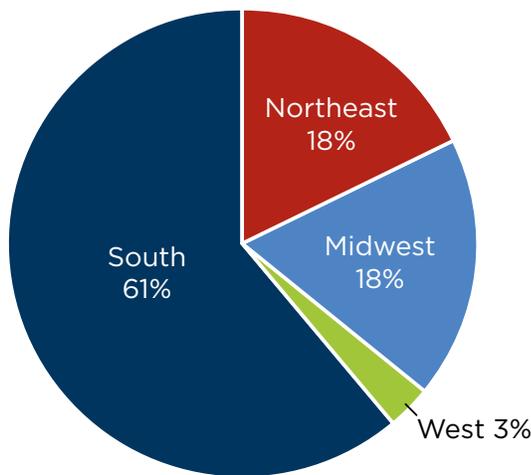
Project CALLS: Collecting Data to Advocate for You

By Project CALLS Team

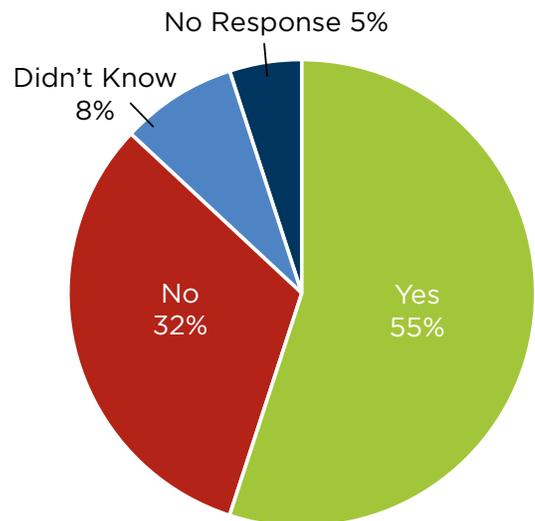
In August 2015, HFA launched an initiative designed to help the bleeding disorders community collect data and stories about how changes in insurance company policies are impacting the care of those with bleeding disorders. Since the launch of CALLS, HFA has spoken with more than 50 members of the bleeding disorders community, allowing their voices to be heard. HFA started CALLS in order to create a more accurate picture of the types of insurance issues encountered by the bleeding disorders community. The more data we had, the better equipped we knew the community would be. Here is what we've seen so far from completed surveys.

CALLS BY THE NUMBERS

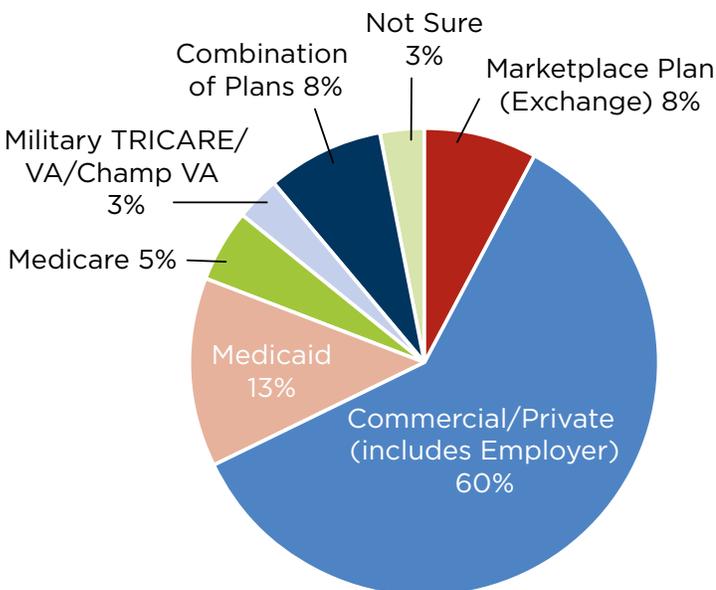
Where did participants live?



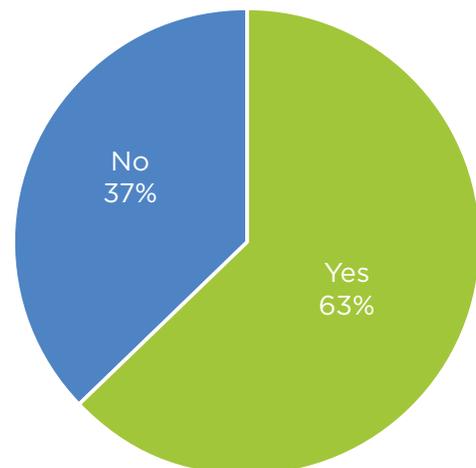
Are participants being mandated to use a particular specialty pharmacy?



What types of plans did participants have?



Did participants' insurance issue lead to delayed care?*



The following 3 issues were reported the most frequently*:

1. Insurance company mandated participant to a pharmacy that is not meeting participant's needs.
2. Insurance company forced participant to go through a lengthy prior authorization process.†
3. Participant was forced to “fail” on a product before being allowed to use the product of their choice.†

HFA will continue to update the community on what we are seeing through Project CALLS. In the meantime, if you are experiencing any issues with your insurance, even if those issues have been solved, please let us know! This data is vital to the advocacy efforts of HFA. Through Project CALLS, HFA will identify trends and use the information to build a case for change across the country.

“My son orders his factor as instructed from our new Specialty Pharmacy, but the pharmacy ships later than requested and sometimes not at all. This has caused him to miss treatment, experience a bleed, and visit the doctor.”

“Insurance refuses to cover home infusion per information from the manufacturer.”

“My insurance is requiring medication to be administered by a doctor and they won't allow self-infusion.”

PROJECT CALLS

Creating Alternatives to Limiting and Lacking Services

Contact the Project CALLS team if you have:

1. been denied services or have received an exception,
2. been forced by an insurance company to “fail” on a product before being allowed to use the product of your choice,
3. been mandated to use a pharmacy that is not meeting your needs, and/or
4. been forced to go through a lengthy prior authorization process.

Once community members have participated in CALLS, they will be sent an Insurance Logbook full of tips on how to gain exceptions and file an appeal, and a glossary of insurance terms. Keeping careful track of every conversation you have with your insurance company is vital to making sure your needs are met—let HFA's logbook help!

To participate in Project CALLS, visit the HFA website, www.hemophiliafed.org/project-calls, and share with others in the community. ■ ■

*of participants asked this question

† question did not differentiate between factor and other medications

The Link Between Sexual Health and Other Chronic Health Risks

HFA Interviews Kevin L. Billups, MD

This is a time of immense positivity in the bleeding disorders community. With advances in treatment and care, men with bleeding disorders are living longer and more productive lives. However, if you are an aging man with a bleeding disorder, it is important to keep other chronic health risks in check to maintain good health and thwart the onset of other chronic conditions such as heart disease or diabetes. Dr. Kevin Billups, Director of the Men's Health and Vitality Program at Brady Urological Institute at Johns Hopkins, recently spoke with HFA to address the importance of men's preventative health and how sexual health issues are surprisingly often a tell-tale sign of larger chronic health risks.

Q: What are the most common sexual health issues facing men today?



Dr. Billups:

First off, the ability to have satisfying sex is an important marker to physical and mental health. Sex is good for you.

The most common sexual health issues include:

- *Erectile dysfunction, or ED:* difficulty achieving or maintaining a satisfactory erection.
- *Premature ejaculation:* having early ejaculation with or without erectile dysfunction.
- *Low testosterone, also called hypo-gonadism:* includes ED, reduced sexual desire, fatigue, depressed mood, reduced muscle mass, and weight gain.
- *Enlarged prostate (benign prostate enlargement):* causes lower urinary tract symptoms (LUTS) and includes frequent/urgent urination, incomplete bladder emptying, issues starting/stopping urination, and weak streams.

Q: Why are these sexual health issues an important overall health marker?

Dr. Billups:

Each of these sexual health issues can be an early warning or marker for a number of chronic health conditions such as obesity, hypertension, heart disease, or diabetes. Sexual health issues can also be a sign that a condition, such as diabetes, is not very well controlled. All of these conditions are linked together, however, sexual health issues are often-times going to get the attention of the man and his partner more quickly than other chronic health risk factors. For instance, men and their partners will easily notice the symptoms of ED. ED is caused by a lack of relaxation of blood vessels and vascular tissue (smooth muscle) in the penis. The inability to keep a firm erection is often called a "venous leak," but the real problem is poor relaxation of penile smooth muscle, a process that's closely linked to cardiovascular disease. Cardio symptoms can often surface three to four years after the first complaints of ED. As a result, any man who is suffering from any sexual health issue should speak with his healthcare provider immediately about his concerns and insist on a full heart and vascular checkup at the same time to prevent other chronic health issues.

Q: What does this mean for men living with bleeding disorders?

Dr. Billups: As men age, they are susceptible to other chronic diseases, such as obesity, hypertension, heart disease, and diabetes. It is important therefore to understand the correlation between sexual health issues and chronic health conditions. Risk factors also increase for men living with co-occurring HIV and hepatitis C.

Q ■ What are some easy ways for men to start improving their health and preventing other chronic health conditions?

Dr. Billups:

Most chronic conditions (e.g., hypertension, diabetes, etc.) are not solely related to genetics, but to lifestyle. Men can start to improve their health by engaging in the following:

- **Maintaining a healthy diet.** This includes smaller portion sizes, a focus on fresh rather than processed foods, decreased intake of sweets, regular consumption of lean meats instead of meats high in saturated fats, low-fat dairy products in small portions, increased consumption of vegetables, fruits, legumes, and whole grains, moderate amounts of nuts, olive oil and fish high in healthy mono-unsaturated and omega-3 fats.
- **Regular physical activity.** For cardiovascular health the American Heart Association recommends least 30 minutes of moderate-intensity aerobic activity at least five

days per week for a total of 150 minutes OR at least 25 minutes of vigorous aerobic activity at least three days per week for a total of 75 minutes, or a combination of moderate and vigorous-intensity aerobic activity AND moderate to high intensity muscle-strengthening activities at least two days per week.

- **Quit smoking.**
- **Aim for at least 7 hours of sleep per night.** Sleep issues such as sleep apnea or insomnia are also tied to sexual health issues, so please discuss sleep concerns with your healthcare provider.
- **Reduce alcohol intake.** Men should embrace moderation. This means no more than two standard drinks per day (12 oz. beer, 5 oz. wine, or 1.5 oz. distilled spirits). ■■

Kevin L. Billups, MD is a urologist specializing in Men's Health and Sexual Medicine. He is currently an Associate Professor of Urology and Medicine at Johns Hopkins and is director of the Men's Health and Vitality Program.

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CHOICE Project & Beyond: Patient Driven Research at HFA

By Wendy Owens



Through a cooperative agreement with the Centers for Disease Control and Prevention (CDC), HFA ran the CHOICE (Community Having Opportunity to Influence Care Equity) Project from October 2011 to September 2015. The focus of the CHOICE Project was to collect information regarding health experiences of people who have a doctor-diagnosed bleeding disorder and do not receive care at a federally-funded hemophilia treatment center (HTC). Because most community members were not sure whether they received care at a federally-funded HTC, HFA opened the survey to everyone in the bleeding disorders community, including undiagnosed women who have children with a bleeding disorder.

To those who participated in the CHOICE Project, thank you! More than 150 community members participated in the development of the survey and more than 850 people took the survey. HFA could not have achieved this level of participation without the enthusiastic support of our chapters and community.

What's Next for CHOICE?

Data collection on the CHOICE survey closed on July 31, 2015. Since then HFA, together with the CDC, has organized that data into a format that is ready for analysis. HFA will ask questions of the information collected with the purpose of improv-



ing the lives of our community members. As HFA completes the analysis of the CHOICE data in the months to come, the results will be made available to the community. In addition, HFA will develop abstracts, posters, and manuscripts for publication in order to make the CHOICE results available to a large, global audience that can learn from our work and apply it to their efforts to improve the lives of people with bleeding disorders.

The CHOICE Project was the first of its kind in which the CDC asked patients, not their providers, to report directly on their health outcomes. According to the US Food and Drug Administration, *patient-reported outcomes* is defined as information "...that comes from the patient about the status of a patient's health condition without amendment or interpretation of the patient's report by a clinician or anyone else."

Using patient-reported outcomes has resulted in HFA focusing on *patient-centered outcomes research*, research that "...helps people and their caregivers communicate and make informed health care decisions, allowing their voices to be heard in assessing the value of health care options," according to the Patient Centered Outcomes Research Institute (PCORI). PCORI was formed as a result of the Affordable Care Act and funds research projects that are patient-driven and that utilize patients as disease experts and compensate them for participation. CHOICE is a perfect example of patient-centered outcomes research. Thanks to your participation in CHOICE, HFA is on the leading edge of this type research.

New Research Program at HFA

We heard from you, loud and clear, and will keep listening. HFA recently created a department to focus on patient-centered outcome research, adding to the organization's functions that include Programming and Advocacy. Using the data from the CHOICE Project as a springboard, HFA intends to initiate 2-4 research projects in 2016. We will undertake each research

"We heard from you, loud and clear, and will keep listening."

project with the goal of using the results to improve the lives of our community, including health outcomes and personal advocacy capabilities, among other advancements. To achieve these goals, it is critical to have the community involved. For this reason, HFA is calling on you for your input on research ideas, to formulate questions for further study, and to participate personally in this exploration.

Community Centered, Focused, and Driven: You Ask the Research Questions

Because our research is about you, we can't do it without you. HFA's research program is community centered, community focused, and community driven. Ideas abound on what research topics HFA should focus but we want to hear from the community on what topics are most important to them.

Where should we focus?

Let us know! The sky is the limit! You can reach us at research@hemophiliafed.org. Also, look for this question on Facebook, Twitter, and our website. ■■

Thank you to our CHOICE contracting member organizations for all their hard work and commitment to making the CHOICE Project a success. We could not have done it without you.

- Arizona Hemophilia Association
- Connecticut Hemophilia Society
- Hemophilia Outreach of El Paso
- Hemophilia Association of the Capital Area
- Bleeding Disorder Alliance of Illinois
- Lone Star Hemophilia Chapter
- Sangre De Oro, Inc.
- New York City Hemophilia Chapter
- Hemophilia Foundation of Oregon
- Texas Central Hemophilia Association

“HFA’s research program is community centered, community focused, and community driven.”

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Educating Providers. Changing Lives.

By Ann-Marie Nazzaro, PhD and Kerry B. Funkhouser, EdD

How well you and your doctor talk to each other is one of the most important aspects of your health care.

You are no doubt already aware that bleeding disorders affect both men and women. But did you know that the consequences of bleeding disorders can be more dire for women because of the reproductive life-stage events of menstruation, pregnancy, childbirth, and menopause?¹ For a woman, living with an untreated bleeding disorder presents unique issues at every life-stage and increases her risk for life-threatening complications such as postpartum hemorrhage, a five-fold increased risk of transfusion, and maternal mortality rates that are 10 times higher than those for other women.²

Some healthcare professionals are unaware that symptoms often manifest in the reproductive tract, causing the condition to be misdiagnosed as a gynecologic problem rather than an underlying bleeding disorder. That is why it is critical for you to make sure your doctor knows both your symptoms and bleeding disorder status. It is vital that you receive the appropriate type of care.

Describe a Day in Your Life: The Symptoms of a Bleeding Disorder in Women

Symptoms of a bleeding disorder in women have some similarities to symptoms in men, e.g., prolonged bleeding after dental surgery or other surgical procedures, easy bruising; however, there are significant differences. Heavy menstrual bleeding is one of the most common symptoms a woman with a bleeding disorder will have. According to the Center for Disease Control and Prevention (CDC), heavy menstrual bleeding affects more than 10 million women each year. If you experience bleeding that lasts longer than seven days or experience any of the symptoms listed on the right, you need to let your doctor know right away. If you have any surprising symptoms, ask your doctor about them. For example, if you are a hemophilia carrier and experience joint pain, tell your doctor when it started, where you felt it, how long it lasted, what made it better or worse, and how it affected your day-to-day activities. Don't assume your symptoms are a part of normal daily life or the aging process. Your doctor needs to know how you feel.

Get a Proper Diagnosis

Receiving a bleeding disorder diagnosis can be a big relief for most women. That's because many women have struggled with the symptoms such as excessive menstrual bleeding since they were adolescents. Knowledge is the first step toward getting the right treatment. It means access to resources and support.

After discussing your symptoms, go over a treatment plan with your doctor. Find out more about what tests are required, what they will identify, if there are any dangers or side effects, and how you should prepare for testing. For example, a hematologist who is well-trained and experienced in hemostasis—how bleeding stops naturally and when it is necessary to apply hemostatic agents—and who works with a competent laboratory, will know that testing for von Willebrand Disease and other bleeding disorders can require repeated testing for accurate results. Additionally, you may be required to stop certain medications before being tested.



Signs and Symptoms of a Bleeding Disorder:³

- Bleeding that lasts longer than seven days
- Passing clots larger than the size of a quarter
- Changing tampons or pads every hour or more
- Experiencing “flooding” or “gushing” of blood
- Bleeding after dental procedures or surgery
- Easy and frequent bruising

Understand Your Diagnosis and Know Where to Go for Help

Once you receive your diagnosis, make sure you really understand it. Understanding your condition will help you make better decisions about treatment, and knowing what to expect can make it easier to deal with the condition.

Bleeding disorders are complex and require a team approach in their treatment and management. In the US, there is a network of 135 specialized Hemophilia/Thrombosis Treatment Centers (HTCs) which bring together a team of healthcare professionals who are trained in treating bleeding disorders. Today, several of them offer clinics specifically for women and girls with bleeding disorders.

Your doctor can refer you to an HTC but may be unaware of the closest one. In Spring 2016, they will be able to access an online Directory of Services that identifies the availability and range of services specifically devoted to the care of women and girls with blood disorders at these federally-funded HTCs. The directory will be a free resource for both you and your provider. It will be published on fwgbd.org, the website of the Foundation for Women & Girls with Blood Disorders (FWGBD), a non-profit organization that is working hard to make healthcare professionals aware of the signs and symptoms of bleeding disorders. By providing healthcare providers with the training and tools necessary to identify symptoms, the FWGBD is working to ensure that more undiagnosed women get proper diagnosis and treatment.

About the Foundation for Women & Girls with Blood Disorders



Started by three internationally recognized physicians in women's blood disorders – Drs.

Andra James, obstetrics/gynecology, and Barbara Konkle and Roshni Kulkarni, hematology – FWGBD's mission is to ensure that all women and girls with blood disorders are correctly diagnosed and optimally treated and managed at every life stage. It achieves this goal using a multi-faceted program of education activities that focus on educating a spectrum of healthcare providers on a variety of blood disorders including von Willebrand Disease (VWD), rare factor deficiencies, hemoglobinopathies, thrombophilias, sickle cell disease (SCD) and sickle cell trait (SCT), immune thrombocytopenic purpura (ITP) and anemias.

Webinars, symposia, and cutting-edge articles and coagulation animations are among the resources available on the website. One special feature is *Ask the Experts*. At fwgbd.org, healthcare providers are able to pose specific questions to FWGBD



experts and receive a reply within 48 hours. These experts include FWGBD founding board members, and their Medical Advisory Committee of specialists, researchers and educators who are at the top of their respective fields, including hematology, thrombosis, sickle cell, obstetrics/gynecology, genetic counseling and emergency medicine.

Be the Messenger

If you have an ob/gyn make sure he or she is aware of FWGBD, its resources and the upcoming online Directory. Also, have them work closely with your hematologist so that a safe healthcare plan is created especially for you.

Remember that a successful doctor-patient relationship is a partnership. Work with your doctor to learn as much as you can about your condition. Together, you can get your life to a better place. ■ ■

Ann-Marie Nazzaro, PhD, Executive Director of FWGBD, has more than 20 years' experience in the non-profit sector, including serving as Executive Director of a regional non-profit focused on the health of women and senior citizens, and as VP for Education at the National Hemophilia Foundation, where she inaugurated and developed the first awareness campaign for vWD in women.

Kerry B. Funkhouser, EdD, Director of Education of FWGBD, has 20 years of experience in developing, writing, and implementing health promotion and disease prevention programs for children and adults. Kerry held the position of Visiting Professor for the School of Public Health at Reykjavik University in Iceland.

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New Patient Advocacy Coalition Forms

By Katie Verb, JD

Patient advocacy groups announced on Thursday, December 3, the launch of Partners for Better Care (PBC), a non-partisan coalition representing more than 10 million patients who seek to advance a common goal: better health care for all Americans. HFA is a charter member of PBC and is honored to stand with patients and patient groups seeking to improve access to quality medical care.

Statistics show that for most Americans, affordable, patient-centered care remains out of reach. “High quality medical care is available in the United States, but many Americans are unable to access the care they need,” said Mary Richards, PBC Executive Director. “Access to affordable, patient-centered care is critical.” Among insured adults in 2014, 20 million had a medical problem yet did not visit a doctor or clinic, 12 million did not get needed specialist care, and nearly half of middle-class

workers skipped healthcare services or fell into financial hardship because of health expenses.

Seeking to improve health care in the US, PBC’s inaugural members—AIDS United, American Liver Foundation, Amputee Coalition, the Christopher & Dana Reeve Foundation, Hemophilia Federation of America, The MAGIC Foundation, National MS Society, Parkinson’s Action Network, and United Cerebral Palsy—coalesced to bring about strong and effective patient advocacy leadership. Initial support for the coalition was provided by Novo Nordisk.

The first step as a coalition was the release of a Patient Charter. The Charter outlines the grounding principles for action to improve availability, transparency, and affordability of health care for all.



Patient Charter

1. Patients will have an active and formal voice in health system transformation including payment and delivery system reform. Systemic efforts to contain costs, assess the value of care and treatment, and generate the best outcomes at a reasonable cost should be patient-centered.
2. Patients have the right to dignified, culturally competent quality health care.
3. Patients will have limited cost sharing and will have predictable and affordable total out-of-pocket costs, including deductibles, co-pays, co-insurance, premium costs or contributions to premiums across care settings.
4. Patients will have easily understood and accessible up-to-date information about covered services, providers, formularies and out-of-pocket costs in all insurance plans during enrollment periods and throughout the year.
5. Patients will have reasonable and timely access to all necessary providers in their network and network providers will be within a reasonable distance.
6. Patients will pay in-network rates with payments credited to out-of-pocket limits for all services provided at in-network settings.
7. Patients will have access to necessary medications, services, devices, and other care without discrimination created through unreasonable tiering or excessive cost-sharing.
8. Patients will not be subject to cumbersome preauthorization and renewal processes that restrict access to care and therapies — including prescriptions and devices.
9. Patients will have easily understood and accessible up-to-date information and guidance regarding appeals, including timely access to a rapid and fair appeals process.

Given the history of HIV/AIDS in the bleeding disorders community and the deep connection between the two communities, HFA is proud to be working with organizations like AIDS United. Michael Kaplan, President and CEO of AIDS United, explains the need for improvements to patient care. “AIDS United is proud to be a founding member of Partners for Better Care. After more than three decades of HIV impacting the US — and more than 1.2 million Americans now living with HIV—we’ve finally reached the point where we have the science and treatment both to extend the lives of those of us living with HIV to rival the lifespans of those uninfected, and to stop new infections. Today, the solution is about access to care and treatment—and it can only be realized through transparent and comprehensive health care, fair and equitable access to medicines, assuring patients’ rights to dignified and culturally competent care, and stable and reasonable costs. At AIDS United, we believe this can all be achieved through speaking with a collective voice and working across diseases. We believe this can be achieved, and that PBC will provide us a critical path to ensuring that it comes about.”

While Partners for Better Care seeks to improve health care for all Americans, each member organization is also driven to improve the system for the patient groups for whom they serve as advocates. ■■

“Access to affordable, patient-centered care is critical.” – Mary Richards, PBC Executive Director

Food for Thought

By Lynn Moore RD, LD, CNSC

“Let food be thy medicine and medicine be thy food” —Hippocrates

It is true that there is no magic bullet to cure all that ails you; however, the lifestyle choices we make can have a profound impact on our quality of life. Though no one specific diet can be recommended for people with bleeding disorders, good nutrition promotes a healthy body, and healthy bodies bleed less. Achieving a balanced diet and maintaining a healthy weight reduces stress on joints while improving our mood and mental abilities.

We’ve all seen books, products, websites, and even prominent figures like Dr. Oz, claiming miraculous outcomes from specific foods. But, the truth is that the foods you eat are like puzzle pieces that, when combined, can lead to good health. Both over-consuming and under-consuming of a particular food group or item can cause more harm than good.

Changing your diet won’t eliminate all discomfort caused by inflammation but there are foods proven to decrease it. Plant-based diets, most notably the Mediterranean Diet, have anti-inflammatory properties and have been shown to reduce the risk of diabetes, Alzheimer’s, and cognitive decline, while also helping with rheumatoid arthritis, weight loss and cholesterol levels. Feeling your best is about diet and lifestyle as a whole, not about eating one particular food or following one exercise regime.

Losing weight will decrease the inflammation throughout your body and the strain on your joints. On level ground, your knees feel 1-1/2 times your body weight. When walking up and down stairs they bear 2-3 times your body weight. Even just a 5- to 10-pound loss of weight will result in a 10- to 30-pound decrease of pressure on your knees. Small changes to your diet and exercise regime can have a huge, positive impact on your joints.

Changing up your routine can improve your health and well-being while decreasing inflammation, obesity, and associated joint pain. Focus on how you want to feel to motivate you through those challenging nutrition pitfalls. Habits can make or break us — make the right choice today to bring on a healthier tomorrow!

Looking to fight inflammation through your diet? Consider the following tips:

- Aim for 5-10 servings of fruits and vegetables daily.
- Decrease saturated fats and trans fats (found principally in processed foods and high fat meats).
- Eat omega-3 fatty acids – found in salmon, tuna, and walnuts. (Check with your doctor before consuming any fish oil supplements which may worsen the symptoms of a bleeding disorder.)
- Make your bakery and cereal choices whole wheat and whole grain.
- Choose leaner meat and lower-fat dairy products.

Iron Consumption and Nutrition:

People with bleeding disorders must be mindful of their iron intake as blood loss can result in an iron deficiency. An iron deficiency will cause fatigue, weakness, and possibly inflammation. It can impair immune function.

General recommendations for iron consumption are, for women 19-50 years of age, 18mg/day (27mg if pregnant), and 8mg/day for men under 19 years and women over 50 years. It is important to note, however, that specific conditions may warrant taking iron supplements. A 15ml blood loss = ~7mg iron loss.

Iron-rich foods (>2mg iron/serving) to help replace iron losses include:

- 3oz. beef, shrimp, clams or oysters
- 3/4C fortified cereal or oatmeal. Some cereals (Total, 100% Bran, Product 19 and Grape Nuts, for example) have ~18mg iron/serving.
- 1 baked potato with skin
- 4 dried prunes
- 1C spinach

Consuming vitamin C with iron-rich foods can help with absorption, while caffeine and calcium in dairy products can impair iron absorption. If you are eating iron-fortified cereal to take advantage of the iron content, try eating it dry with a glass of orange juice on the side.

Revitalize Your Routine

- **Try a Meatless Monday** – Legumes are high in protein and make a great meat substitute, and they work well in a variety of soups and casseroles. Kidney, lima, lentil, navy and soybeans all have >2mg iron per serving. Try stuffed bell peppers (high in vitamin C) with legumes and rice!
- **Hide Your Vegetables** – Replace half the meat in your tacos, hamburgers, and spaghetti sauce with mushrooms instead. Chop the mushrooms finely and you may not even notice the difference as they absorb the flavor of the sauce or seasoning.
- **Pass on Processed Foods** – There's a reason processed snack foods are so popular: they're easy! Instead, try having an inviting bowl of fruit or veggies in the fridge or on the dining room table. Easy access means easy to consume.
- **Get Down with Brown** – Replace white bread, flour, rice, and pasta with the heartier brown rice and whole grain varieties. The extra protein and fiber provided by whole grains are added benefits that will keep you fuller longer without adding calories. Commit to three weeks of healthy eating and reap the benefits of how good you feel.

Healthy Habit Makeover Tips

1. Week 1 – Rethink Breakfast.

Include at least 3 food groups (1 being high fiber).

Examples: Peanut butter on whole wheat toast with a glass of milk, oatmeal with blueberries and yogurt, eggs on a whole wheat English muffin and an apple

2. Week 2 – Lighten up Lunch.

Halve the portion of your sandwich or entrée. Fill up on vegetables and fruits for the rest of the meal. Eat what is most nutritious first – which will typically be a higher fiber vegetable or side. Your stomach will fill with the healthier food, making it easier to relax and savor the half-size entrée.

3. Week 3 – Dining in for Dinner.

Use smaller salad plates when eating at home. Follow the plan used during lunch for week 2 and halve the entrée amount. Vegetables are unlimited and eaten first. ■■

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Lynn Moore has been a Registered Dietitian for 16 years and a Certified Nutrition Support Clinician for seven years, working with all ages and populations in inpatient and outpatient settings. Currently a Clinical Nutrition Manager for Memorial Hermann Greater Heights in Houston, TX, Lynn covers both adult ICU and neonatal ICU. She has been an annual presenter for the Blood Brotherhood Group of Houston and has spoken at several national conferences over the past few years. Lynn enjoys helping people navigate healthcare and understand how nutrition can promote a happier, healthier life.



Blood Brotherhood Celebrates 10 Years

By Lauren Neybert, MSW



Since 2006, adult men living with bleeding disorders have found a community network in HFA's Blood Brotherhood Program. Through the Blood Brotherhood Online Forum and face-to-face local events hosted by HFA member organizations, the program has provided educational and social support while promoting health and wellness. This year, HFA is proud to celebrate 10 years of the Blood Brotherhood program! Thank you to all of our participating member organizations, sponsors, and of course, the adult men who participate in the program!

Stay tuned throughout the year for information about 10 year celebratory events and get involved in the festivities!

How Can I Participate?

Join the Blood Brotherhood Private Online Forum

HFA is proud to host a secure site for adult men with diagnosed bleeding disorders to meet other Blood Brothers from across the country. In this private forum, men with bleeding disorders can share their experiences and learn from each other. Visit www.hemophiliafed.org to register today.

Participate in an Upcoming National Webinar or Online Event

Connect with other men during one of our upcoming online events. HFA will host two educational webinars in 2016 on issues that are important to men like you. The Blood Brotherhood Online Forum hosts monthly live chats (the second Tuesday of every month at 8:00pm Eastern) to provide a safe environment for men to learn and share their experiences of living with a bleeding disorder.

Find a Local HFA Member Organization

HFA has partnered with more than 25 member organizations to host over 90 Blood Brotherhood sessions throughout the country in 2016. Blood Brothers meet face-to-face several times per year to participate in education, social activities, and discussions and activities that focus on wellness. Visit www.hemophiliafed.org to find a member organization near you.



2016 by the numbers:

25+

HFA Member Organizations
hosting Blood Brotherhood
Sessions



90+

HFA Blood Brotherhood
Sessions Scheduled



950+

Men Enrolled in HFA's
Blood Brotherhood
Program



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For information on Bayer's Educational Patient and Community Resources, contact your Hematology Account Executive by calling **1-888-79-BAYER.**

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Bayer HealthCare

FDA's Completed Revision of the Donor Deferral Policy for Men Who Have Sex with Men

By Katie Verb, JD



The Food and Drug Administration (FDA) is responsible for recommending policies and making rules regarding the donation of blood and blood products. During the 1980s, when it became clear that transmission of Acquired Immune Deficiency Syndrome (AIDS) happened through blood, the FDA began recommending policies that would decrease the risk of transmission of the AIDS virus (human immunodeficiency virus or HIV) through the blood supply. These policies included providing donors with educational materials on risk factors and deferring donors who participated in behaviors that were deemed to increase their risk of contracting the AIDS virus. At the time, testing methodologies and pathogen inactivation procedures for HIV/AIDS had not yet been developed and donor education and deferral were the only ways to decrease risk of transmission.

In September of 1985, the FDA recommended that all blood establishments defer male donors who have had sex with another male (MSM) since 1977 from donating blood. Males who had sexual contact with other men were deemed high risk given the high rates of HIV infection in that particular population. In 1992, the FDA recommended the continuation of the deferral, as well as a deferral for commercial sex workers, and those who have injected illegal drugs. The combined use of donor education, donor deferral policies, and advances in HIV testing

led to a significant decrease in transmission of the HIV/AIDS virus from blood transfusion.

Recent advances in both HIV testing and pathogen inactivation procedures led some groups to ask the FDA to revisit the donor deferral policy for men who have had sex with men as some groups viewed the policy as discriminatory. In 2010, after years of public meetings, workshops, and the recommendation of the Advisory Committee on Blood Safety and Availability, an interagency Blood, Organ, & Tissue Safety Working Group on MSM (BOTS Working Group) was assembled to look at scientific data on the subject. The group, consisting of members of the Centers for Disease Control, Health Resources Services Administration, National Institute of Health, Health and Human Services Office of Civil Rights, Office of the Assistant Secretary for Health, and the FDA, decided to review blood donation deferral criteria research and establish a national blood safety monitoring system.

The BOTS Working Group recommended scrutinizing a number of studies on the deferral policy, one of which showed that other countries that had changed to a one-year deferral policy experienced no change in risk of exposure. Other studies focused on the Donor History Questionnaire and the feasibility of implementing a blood safety surveillance system. In 2014, based on this data, the BOTS Working Group recommended

the change to a one-year deferral policy. Based on their review of the data, the Advisory Committee on Blood and Tissue Safety also recommended the policy change. FDA's Blood Products Advisory Committee met to review the policy and the potential value of a Transfusion Transmissible Infections Monitoring System (TTIMS), a laboratory test to detect recently acquired HIV infections. Many members of BPAC noted that a change to the deferral policy would be acceptable with the concurrent implementation of TTIMS. The FDA stated that it intended to establish such a system in collaboration with the National Heart, Lung, and Blood Institute that will be used to refine blood safety measures further and monitor upcoming potential donor risk factors.

In their Guidance Document published on December 21, 2015, the FDA finalized the policy change, stating that evidence supports changing the current system to a one-year deferral for MSM donors. This means male donors may not donate blood for one year from the date of sexual contact with another man. The FDA will continue to monitor the safety of the blood supply with the implementation of the TTIMS System.

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Changes to Persons with Hemophilia Deferral Policy

The December 2015 announcement noted other changes that have a direct impact on those with hemophilia. Prior to this announcement, it was recommended that people with hemophilia, and their sexual partners, be deferred from donating blood based on their risks for HIV infection. However, given the increased safety of both the blood supply and clotting factor, the FDA announced that the sexual partners of those with hemophilia were no longer recommended for deferral. Because of the risk of injury from large needles, the FDA is still recommending the deferral of persons with hemophilia.

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HFA Action

In 2014, in conjunction with members of the American Plasma Users Coalition (APLUS), HFA provided comments and testimony about the importance of keeping our nation's blood supply safe. Through our work with APLUS, HFA will monitor the implementation of the TTIMS system and continue to work with the FDA to ensure that it is implemented in a timely manner and in a way that ensures patient safety is the highest priority. ■■

NOW APPROVED

For more information,
please visit www.ADYNOVATE.com

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What is Helping Hands?

By Elaine Chan, MSW, MPH



At any point, families living with a bleeding disorder can experience financial hardship because of their medical situation. HFA's Helping Hands Program has become a safety net for thousands of families throughout the years. Helping Hands has provided many families with assistance for expenses like housing, utilities, and transportation. In addition to assistance for these basic living expenses, Helping Hands has helped individuals and families to obtain durable medical items for the care of their bleeding disorders.

Families affected by inhibitors are faced with unique, and often unexpected, medical and financial needs. The inhibitor community is especially challenged with bleed management, joint damage, venous access concerns, pain issues, and social and emotional distress. The financial burden can be great, even catastrophic. In 2016, Helping Hands expanded to provide support for families affected by inhibitors through the addition of Inhibitor Support.

This chart was created to help you navigate all the coverage Helping Hands provides:

	EMERGENCY ASSISTANCE	ITEMS REIMBURSEMENT	INHIBITOR SUPPORT
What is covered?	Basic living expenses: housing, utilities, transportation	Durable medical items (i.e., medical IDs, protective gear, braces, cooling/heating supplies, fitness support)	Educational travel, medical travel, tutoring/educational supplies
How often?	Once per year	Throughout the year, depending on needs/ requests	Throughout the year, depending on needs/requests
Referral or Self-Apply?	Referral from eligible referrer*	Both	Both
Who can apply?	Individuals and families with a diagnosed bleeding disorder	Individuals and families with a diagnosed bleeding disorder	Individuals and families with a diagnosed bleeding disorder and an inhibitor with measurable titer and/or shortened half life

*Please reach out to our Helping Hands team for additional information regarding eligible referrer.



“Thank you all for the assistance given to my family. I am thankful we have Helping Hands

which truly helps us continue the fight.”



“I have had a very bad year. My husband and I both lost our jobs, and my son with hemophilia had surgery. It took us a while to find new jobs.

We are all very grateful for your help. Thank you so much.”



“I greatly appreciate Helping Hands and what they have done for me and my children. We get to keep a roof over our heads during this cold winter. Thank you so much.”

“Helping Hands is truly an amazing program. They helped us when we needed it the most.”

FAQ's:

Q ■ If I apply for the emergency assistance, am I allowed to apply for items reimbursement?

Completion of an Emergency Assistance Application does not render you ineligible for reimbursement for durable medical items. Refer to “Items Reimbursement” on the website for complete eligibility details: www.hemophiliafed.org/programs/helping-hands.

Q ■ Can I apply for inhibitor support if I had an inhibitor before and is tolerized?

Unfortunately, inhibitor support is only available to those with an active inhibitor: a measurable titer and/or shortened half-life.

Q ■ Can I apply for all three Helping Hands assistance areas if my family member has an active inhibitor?

Yes! All households affected by inhibitors are eligible to apply for all components of HFA's Helping Hands Program including emergency assistance, items reimbursement, and inhibitor support.

Q ■ How long does it take to get assistance or reimbursement?

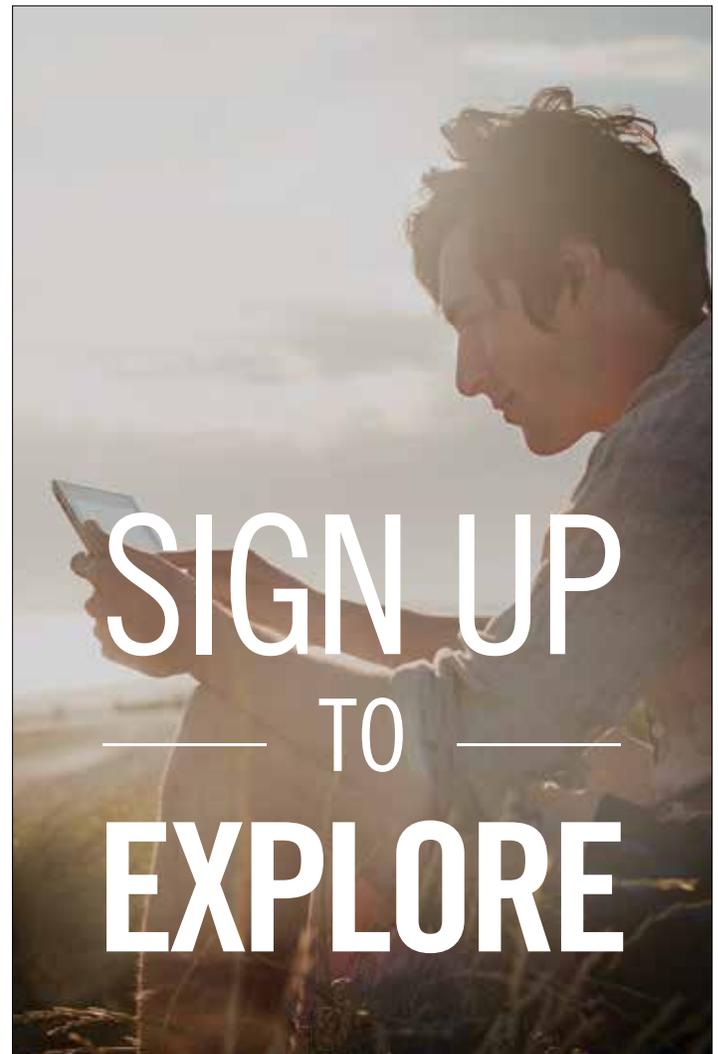
Emergency assistance requests are generally completed within two weeks. Items reimbursement and inhibitor support requests are generally completed within 30 days.

Q ■ How do I know if my request for help was received?

Our program coordinators will contact you within five business days complete a phone interview for your request of assistance.

Q ■ I need help with my hospital bill and the copay for my medication. Can I get help for those?

Unfortunately, we do not offer assistance in medically related expenses such as medical bills, co-payments, insurance premiums, deductible, etc. Please visit our website, www.hemophiliafed.org, to access our “Navigating Patient Assistance Programs” guide for alternative resources and programs. ■■



Here at Genentech, we're currently researching a potential new way to treat hemophilia.

We're excited to share with you what's happening and hear back from you.

Register at GenentechHemophilia.com and we'll keep you updated.

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Gears for Good 2016

Annual Fundraising Bike Ride Just Got Bigger!



HFA is thrilled to expand our annual Gears for Good bike rides in 2016, adding a third ride hosted in Northern Ohio. We hope you'll join us for one, two, or even all three of the events and help raise much-needed funds for our Helping Hands Program. 100% of the contributions raised by all individual donors will go to providing families and patients in need with limited immediate financial assistance for expenses like housing, utilities, transportation, and medically-necessary goods.



It's a ride, not a race.

All three events are designed to allow riders to ride at their own pace. Riders of all skill levels are encouraged to participate.

Use our intuitive and user-friendly fundraising platform.

Fundraising for your ride is made easy with a personal, customizable fundraising page. Family, friends, and coworkers can make contributions towards your goal online using our secure platform. We're here to help you!

This full-service tour experience makes participating easy.

Fundraising goals cover indoor lodging and tour meals. Bring your own bike or rent one from our ride coordinator. You should be prepared for incidental costs, such as transportation to and from the trip start, bike transport to/from the start, meals classified as non-tour, and hotel incidentals. We'll provide you with resources and tools to educate your peers about bleeding disorders and to solicit contributions.

For more information, and to sign up, please visit www.hemophiliated.org.

New England Regional Ride

Connecticut to Massachusetts
Farmington Canal Heritage Trail
June 4-5, 2016

National Ride

West Virginia to Washington, DC
C&O Canal
Sept. 23-25, 2016

Northern Ohio Ride

Independence to Akron
Ohio and Erie Canal Towpath
October 15, 2016



Renew Your Annual Membership!

Not a member? Join Today!

As a member, you have access to our wide array of programs and services. In addition, you receive *Dateline Federation*, email updates, and policy action alerts for the bleeding disorders community.

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

- Kari P.

**We appreciate your membership! It's about people.
It's about making a difference.**

RENEW YOUR MEMBERSHIP OR JOIN TODAY!

Individual: \$25 • Family: \$50 • Professional: \$100

Online: visit www.hemophiliafed.org

By Mail: Please make checks payable to Hemophilia Federation of America and send to
820 First Street NE, Suite 720
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