



# DATELINE

F E D E R A T I O N

Issue 51 | Volume 16 | Winter 2016



**INSIDE:**

## **Blood Brotherhood Program Celebrates 10 YEARS!**

pages 14-15



**April 6-9, 2017**

# SYMPOSIUM 2017 Registration is Open!

Join us in Providence, RI for the largest family-friendly conference for the bleeding disorders community.

Symposium offers community members the opportunity to learn and grow. During our powerful sessions, community members can meet and bond on a personal level with other community members and presenters.

Don't miss out on this opportunity to connect with others, learn, and advocate!



**Register Now! [www.hemophiliafed.org](http://www.hemophiliafed.org)**

**“I enjoy the interaction. Not just between the speakers and the attendees, but among the attendees themselves.”**

**“The speakers know how to communicate with the Spanish-speaking community.”**

**“My favorite part of Symposium was the knowledgeable speakers who could easily and effectively answer the questions and concerns expressed during the presentations.”**



Assisting and advocating for the bleeding disorders community since 1994.

Issue 51 | Volume 16 | Winter 2016

EXECUTIVE LEADERSHIP

Board Chair

Tracy Cleghorn

President & CEO

Kimberly Haugstad, MBA

PRODUCTION TEAM

Editor

Kyle McKendall

Copy Editor

Kit Salisbury

Design & Layout

Kristin Mitchell Design, Inc.

CONTRIBUTORS

- M. Barusch
Meg Bradbury, MS, CGC, MSHS
Angela Burton, MSW, Staff Member
Meredith Clarke, Staff Member
Miriam Goldstein, JD, Staff Member
Ann LeWalk, Staff Member
Lori Long, Staff Member
Sharon Meyers, Staff Member
Lauren Neybert, MSW, Staff Member
Sarah Shinkman, Staff Member
Deema Tarazi, JD, Staff Member
Katie Verb, JD, Staff Member
Nick Vosburg
Randy Vosburg

The information printed in Dateline Federation is provided for general purpose use. 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.

Requests for permission to translate or reprint contents of Dateline Federation should be directed to info@hemophiliafed.org.

820 First Street NE, Suite 720
Washington, DC 20002
800.230.9797
info@hemophiliafed.org

©2017 Hemophilia Federation of America. All rights reserved.

In This Issue:

4 Executive Corner

6 Gears for Good 2016



8 Pedal Towards Good Health

9 Words Matter

10 HFA Policy, Post-Election

11 Okay, So What Can We Do?

12 Understanding Advocacy: Reflections and Tips from HFA's 2016 Advocacy Intensives



13 Millennials Get Busy, Advocacy for Young Adults



14 HFA Celebrates 10 Years of Blood Brotherhood!

16 Celebrating the Past and Making Memories for the Future, HFA Hosts Blood Brotherhood Camp Out

19 Bringing Light and Hope

20 Adopting the Unadoptable: Our Family's Journey into the Bleeding Disorders Community

22 Project CALLS: Q4 Report

23 Make HFA Your Charity of Choice

25 Genetic Counseling: What You Never Knew You Needed to Know

## Dear Community Members,

**H**appy New Year! I hope you had a wonderful holiday season and very happy start to the New Year! Can you believe it's 2017 already? The year ahead will be full of change for our nation as a whole, but also specifically for our bleeding disorders community. We all lived through a very unusual election cycle this past year, one that left our community, and our country, in a state of transition, uncertainty, and, for some, even fear.

When I wasn't glued to the election coverage, however, I disconnected from the pundit-chatter and watched more entertaining fare. One show I've completely fallen in love with is NBC's *This Is Us*. Each hour-long episode is full of emotional, touching moments, along with a few surprises, and, happily, I always find themes within the narrative that speak to our community. In a recent episode, one of the young boys in the show had taken up martial arts and was being introduced into the class along with his father. The class initiation involved the father doing push-ups with the boy lying his father's back. What initially seemed like a strange ritual turned out to provide a powerful realization for the boy. His classmates and his father would be there to carry him, on their backs if necessary, whenever he was in need. The teacher then spoke up and said "The world isn't always a kind place. We are your community. When things get hard, we are going to be the ones who hold each other up."

**“It's always amazing to see how a small community like ours can come together to do great things to support one another.”**

What a powerful statement! It speaks to my view of our beautiful bleeding disorders community. It's always amazing to see how a small community like ours can come together to do great things to support one another.

This issue of *Dateline* highlights some of the great work that is being done across the country by the HFA staff, local Member Organizations, volunteers, and individuals like you! Nick and Randy Vosburg share their story of how their family grew after they adopted three beautiful boys, one with hemophilia (p. 20). Their commitment to provide a loving family and home to those who had been labeled "unadoptable" is simply heartwarming.

To address some of the post-election questions many of you have, our staff offers a look ahead at health policy (p. 10), and provides advice on how best to work with your congressional delegation to make an impact (p. 11). Don't miss our timeline of the Blood Brotherhood program, as we look back on the past 10 years of serving adult men living with bleeding disorders (p. 14). This just skims the surface of what this issue has in store, so I hope you'll turn the page and keep on reading.

As we enter this time of change and uncertainty, I am hopeful for the future, and I am reassured by the notion that "when things get hard, we are going to be the ones who hold each other up."

**Warm regards,**

*Tracy L. Cleghorn*

**Tracy Cleghorn**  
Board Chair



**Now Available!**



# NUWIQ<sup>®</sup>

Antihemophilic Factor  
(Recombinant)

## Want to Learn More?

Call 1-800-554-4440 for information about our Free Trial Program

©2016, Octapharma USA Inc. All rights reserved.  
Date of preparation: 2/2016, NUW-012-CAD

**octapharma<sup>®</sup>**  
For the safe and optimal use of human proteins

### SHIRE'S COPAY ASSISTANCE PROGRAM



# Are you eligible to save up to \$12,000\* every 12 months?

Shire's CoPay Assistance designed for you!

**Let us help you pay for your out of pocket medication costs in 3 simple steps.**

1. Call us at 1-888-229-8379.
2. Answer a few simple questions, and let Shire handle the rest.
3. Receive eligibility information in the mail.

\* Full terms and conditions apply. Call 1-888-229-8379 or visit [www.hematologysupport.com](http://www.hematologysupport.com) for more information.

## We've got you covered

Call 1-888-229-8379 or visit [www.hematologysupport.com](http://www.hematologysupport.com).

© 2016 Shire US Inc., Lexington, MA 02421. All rights reserved. 1-800-828-2088.  
SHIRE and the Shire Logo are registered trademarks of Shire Pharmaceutical Holdings Ireland Limited or its affiliates.  
We've got you covered is a trademark or registered trademark of Baxalta Incorporated, a wholly owned, indirect subsidiary of Shire plc.  
S25904 11/16





# Gears for Good 2016

In 1997, we began our Helping Hands program to cover the cost of utilities and transportation to individuals and families experiencing financial hardships related to their bleeding disorders. We've expanded the scope of our assistance over the years but we continue work with applicants to connect them to their local community resources and empower individuals and families to advocate for themselves.

To help sustain and support the program while raising awareness of bleeding disorders and promoting healthy living, we created our annual Gears for Good charity bike ride.

In 2016, we hosted our 6th national ride, 3rd regional ride in New England, and the very first 1st annual regional ride in the great state of Ohio! Thanks to our amazing riders, volunteers, and corporate sponsors, we reached our goal of raising over \$133,000 for our Helping Hands program.

One hundred percent of the contributions raised by individual donors will go to providing families and patients in need with immediate financial assistance for expenses like housing, utilities, transportation, and other medically necessary items.



## **6th ANNUAL NATIONAL RIDE** West Virginia to Washington DC Chesapeake and Ohio Canal Trail

**3 days**  
**156 miles**  
**20 riders**

## **3rd ANNUAL REGIONAL RIDE** New England Farmington Heritage Canal Trail and Farmington River Trail

**2 days**  
**70 miles**  
**30 riders**

## **1st ANNUAL REGIONAL RIDE** Ohio Ohio and Erie Canal Towpath

**1 day**  
**50 miles**  
**22 Riders**





## National Sponsors

Thank you to our national sponsors! Without their generosity and support, the rides would not have been possible.

### Platinum

CSL Behring

### Gold

Bayer

Octapharma

Grifols

Shire

### Silver

Anylam Pharmaceuticals

Aptevo Therapeutics

CVS Specialty

Dimension Therapeutics

HEMA Biologics

# Pedal Towards Good Health

By Meredith Clarke

**F**inding the right workout activity to fit your needs can be challenging depending on factors like available time and resources, and your body's demands and limitations. Bicycling is often recommended as one of the safest types of exercise for people who have hemophilia. Cycling — either outside or on a stationary bike — is a great way to get in a non-contact, low-impact workout that can be done individually or in groups. With little pressure on bones and joints, it is easy on the body compared to traditional high-impact activities like running, walking, soccer, and gymnastics. Cycling works several muscles in your legs, principally calves and hamstrings, as well as your shoulders, back and core. It's an aerobic activity so it improves your cardiovascular endurance, helps with weight loss/management, and builds muscle tone. Because cycling is easy on the joints, it's a healthy and enjoyable form of exercise for people with bleeding disorders.

Aside from the many physical benefits, cycling is a great way to clear your head and appreciate the outdoors. It's also one of the best ways to see and appreciate places you may not normally go. Along with other forms of exercise, bicycling can reduce stress and anxiety and improve your overall mood. Exercise releases endorphins, and it's therefore considered to be an effective and natural anti-depressant.

Riding a bike instead of driving reduces pollution and improves everyone's air quality. HFA encourages bicycling as an alternative mode of transportation to a motor vehicle whenever possible. It uses no gasoline, requires no pesky disposal of motor oil or toxic batteries, and takes a lot fewer resources to fabricate than a car. Not to mention cutting back on traffic congestion and gridlock!

Children and adults alike must be cautious when cycling outdoors. Always ride defensively to allow yourself time to make adjustments if a motorist makes a mistake. It's important to follow the rules of the road and take precautions to avoid collisions and injury. Most cities require cyclists to obey the same rules of the road as cars (stopping at stop signs, signaling turns, etc.), however now that bikes are becoming more commonplace, many cities have bicycle-specific laws. It's critical for bicyclists and motorists alike to know these laws to ensure a safer environment for everyone on the road.

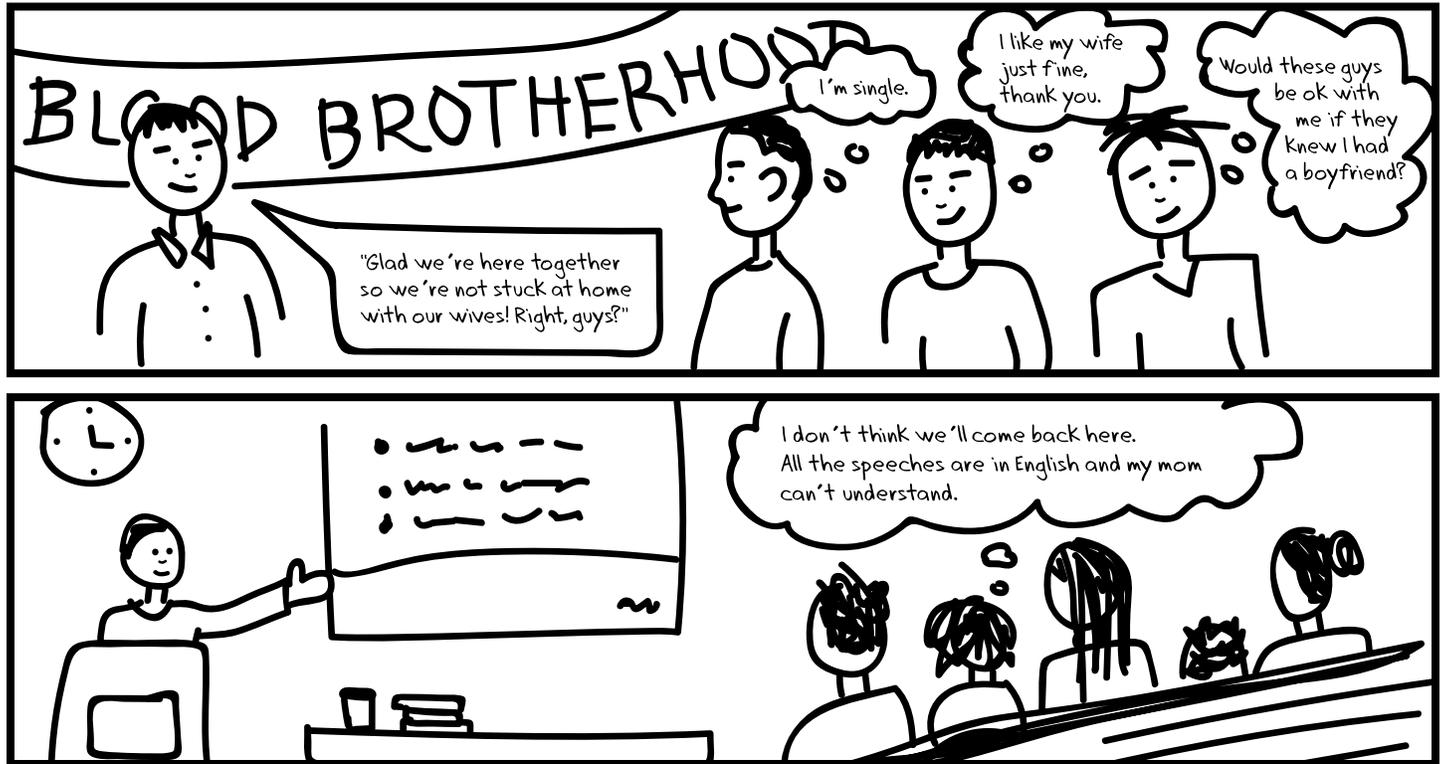
When riding, continuously scan the area to the sides and in front of you for any road hazards, cars pulling out, and car doors opening suddenly. Attach a bell to your handlebars so you can alert pedestrians that you are coming up behind them and communicate with other riders if you are passing them. Before you turn, use hand signals to indicate to motorists that you are changing direction. If the road is wet or icy, go slowly and give yourself plenty of time to brake.

## Before you ride, remember to:

- **Always check with your physician or physical therapist** prior to beginning any physical activity.
- **Make sure your bike fits you properly.** Having a bike that fits will not only allow your body to perform at its optimum but will decrease the likelihood of injury. Some bike shops will offer a free bike fitting. Simple, minor adjustments can be made to your handlebars and saddle so that your bike is more comfortable for you.
- **Plan your route ahead of time.** There are plenty of phone apps, websites and maps that provide good bike routes and trails so that you are not caught on busy roads. If there are no bike lanes, stay to the right side of the road and keep up as best you can with the flow of traffic.
- **Check over your bike before you leave to make sure everything is functioning properly.** Test the brakes and check the air pressure on your tires (the minimum and maximum PSI – pounds per square inch – are labeled on each tire). Fully inflated tires increase your handling ability and reduce the risk of your having a flat.
- **Stretch your body dynamically to loosen up before you ride.** Dynamic stretches relax your connective tissue for the exercise ahead. Some of these stretches include lateral lunges, leg swings, alternating toe touches and knee highs.
- **Wear bright colors so you can be easily seen.** Make sure you have both front and rear reflectors and attach lights to your bike if you go out after dark.
- **Wear a helmet.** It protects your head and brain from injury if you happen to fall.
- **Carry a small pump and patch kit,** or even an extra inner tube, in case you get a flat tire on your ride.
- **Always listen to your body** — it knows how much exertion it can handle and when it's time to stop for the day. ■■

# Words Matter

By M. Barusch



**W**e know the bleeding disorders community is small and there may be just one group or organization where we live. We all want to do our best to include everyone, but it's challenging. Many of us have felt alone, like no one could possibly understand our situation, and we feel pressured to remain silent just to fit in or be accepted. But how often have we left others out? Often, when we hurt each other it is by making an assumption that inadvertently leaves another person out of the conversation. Here are some ideas to avoid making assumptions.

**1. Use open-ended language.** In conversations with people in the community, and when talking online, try to use language that is as inclusive as possible. You probably won't know a person's race, religion, gender, sexual orientation, relationship status, or relationship to the bleeding disorder community until you get to know them better.

**2. Recognize that every family is different.** Maybe a family is headed by a mom and a dad, a single parent, a grandparent, two moms, two dads, foster parents, or a guardian. One way of talking about a family in an open-ended way is to just talk about the family as a unit. The adults in the family can be parents, guardians or caregivers, so until you know otherwise, you could simply refer to them as "adults."

**3. Allow people to self-identify.** Are you hosting an event for Spanish-speakers, women, men, people of color, people with bleeding disorders, partners or parents of people with bleeding disorders? If you don't know for sure who to include in the invitation, invite everyone, and let the people in the requested group identify themselves. Think critically about the groups you're choosing. Is the current "mother's group" really targeted at mothers or might you want instead to include all "primary caregivers?"

**4. Step up!** And encourage others to step in. We all make mistakes but most of us do not want to hurt someone, or make someone feel left out. So, if you see someone accidentally making an assumption about someone else that might be hurtful, be sure to mention it so that they can realize their mistake and do better next time. And maybe the one who was hurt will feel more welcome in the bleeding disorders community after seeing that they are respected.

The Care Access Working Group (CAWG) serves the bleeding disorders community with a focus on rural communities and those who have difficulty accessing quality care. Please contact [cawg@hemophiliafed.org](mailto:cawg@hemophiliafed.org) if you have questions or ideas about inclusive language. ■■

# Health Policy, Post-Election

By Katie Verb, JD; Miriam Goldstein, JD; Deema Tarazi, JD

In the aftermath of the 2016 presidential election, we are in a time of substantial uncertainty about the future of the US health care system. While we can't predict the future, it's safe to say that many of the proposed changes will be challenging for people with chronic conditions. The Affordable Care Act (ACA) contained many provisions that have become vital to those with bleeding disorders, including guaranteed access and issue, the elimination of lifetime caps, and extended coverage for young adults. In the coming months, it is vital for our community to stay informed and at the ready to take action when necessary.

## Repeal and Replace

President-elect Trump campaigned on a promise to “repeal and replace” the Affordable Care Act (ACA), but we have no way of knowing how far and how fast the incoming administration and Congress will move toward that goal. Recently, Speaker Paul Ryan suggested that the transition could take longer than expected in order to ensure that those who rely on the ACA are not left without coverage. The Trump transition team has issued one page of talking points affirming its intention to repeal and replace ACA. The “replacement” policies listed in that document (Health Savings Accounts, insurance sales across state lines, and high risk pools for high-cost individuals) would not come close to providing the same level of coverage to the same number of people as does the ACA. Congressional Republicans have proposed multiple “replacement” proposals but many of them appear less comprehensive in scope than the ACA, and legislators have failed to coalesce around any one of them. While President-elect Trump and Speaker Ryan have expressed general support for keeping specific ACA patient protections (a ban on coverage exclusions for pre-existing conditions and allowing children up to age 26 to stay on their parents' insurance), it is not clear how effective those protections would be if separated out from the broader ACA framework, or if they remain in some form, how much insurers might charge for those protections.

## Medicaid

The President-elect and Congressional Republicans have also committed to “block-grant” or cap federal funding for Medicaid. It is unclear at the moment whether they will also seek an outright rollback of the ACA's Medicaid expansion. Vice President-elect Mike Pence has suggested that, in lieu of repeal, the Trump Administration might instead grant states additional leeway to modify their expanded Medicaid programs. Both the block-grant proposal and repeal of the

ACA's Medicaid expansion could endanger coverage for millions of Medicaid recipients—and at the same time drastically, and negatively, impact state budgets.

## Medicare

Speaker Ryan and House Budget Committee Chairman/Health and Human Services (HHS) nominee, Tom Price, have also announced plans to fast-track, via budget legislation, a far-reaching overhaul of the Medicare program. This would, among other things, raise the age of eligibility for future Medicare beneficiaries from 65 to 67 and replace the current Medicare program with a premium support or “voucher” plan under which seniors would get a fixed sum to buy healthcare coverage on the private insurance market.

Our greatest concern is that all of these proposals—insurance reform repeal, Medicaid funding changes, Medicare overhaul—would weigh heaviest on the people who most need good healthcare coverage, including those with high-cost chronic disorders. Check out the Transition Tracker on our website, [www.hemophiliafed.org](http://www.hemophiliafed.org), to stay informed of potential changes.

# CYRIL HOME CARE PHARMACY

We only have one motto and mission.  
We would like for you to be able to look back and say:  
“My life with hemophilia is better today than it was before we ever met.”



John Reed DPh

118 E. Missouri Ave. • PO Box 676 • Cyril, OK 73029  
Toll Free: 888.258.2453 • Fax: 877.464.3108  
[chcp@tds.net](mailto:chcp@tds.net) • [www.cyrilhomecare.com](http://www.cyrilhomecare.com)

# Okay, So What Can We Do?

By Lori Long and Sarah Shinkman

*“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.” ~ Margaret Mead*

To find an example of the type of group Margaret Mead speaks about in her famous quote, look no further than our bleeding disorders community. From the 1990s with the passage of the Ricky Ray Hemophilia Relief Act, to the enactment of the Affordable Care Act in the 2000s, community members have demonstrated a strong commitment to action and grassroots advocacy for decades. If the recent election reaffirmed anything for our community it is that a grassroots approach to advocacy is going to be crucial.

One of the great lessons of the 90s was that connecting people directly to their legislators and policy makers has an incredible impact; it’s the founding principle of HFA. With adversity, comes resilience. As we continue to act on behalf of our community, we should always consider those who fought before: what would Ryan White or the Ray brothers do?



## Contact your legislator.

Use HFA’s website to contact your representative directly to share your support for, or against, policies that affect you. Check out your senator or representative’s website, or even pay them an in-person visit! When writing to or speaking with legislators, be sure to make it personal and share your story. Remember, policy comes from ideas and concerns expressed by constituents. You have the power to make a change.



## Use HFA as a resource.

HFA offers many advocacy tools, including guidance on legislative days in your state, action alerts, Dear Addy blog, CQ Roll Call, issue briefs, and much more. Connect with HFA on social media channels and subscribe to our email newsletters.



## Hold yourself accountable, just as we hold our representatives accountable.

Make an advocacy calendar or outline goals to provide yourself with direction and to maintain focus and momentum. Form a committee to delegate tasks and use members to mobilize their contacts in the community. Group or peer advocacy is critical to ensuring accountability.



## Meet people where they are.

What makes people act in your community? Getting people to follow through on advocacy goals can be challenging given life’s many other commitments. Consider strategies that have been effective before and use these to engage community members.



## Make advocacy enjoyable.

Plan a community meal and invite people to bring their ideas. Creating an atmosphere that brings people in the door, while providing a forum to make plans, is a win-win.

The key to grassroots advocacy is participation. Please forward our emails to your community members, share posts on social media, plan letter writing campaigns, and host phone banks. Together, we can build a case for change. As Families USA Executive Director Ron Pollack said, “Don’t agonize, organize.” Challenge accepted!

# Understanding Advocacy: Reflections and Tips from HFA's 2016 Advocacy Intensives

By Deema Tarazi, JD

During September and October, HFA brought 21 community members from around the country to Washington, DC to participate in two advocacy intensives: one for Dads in Action and Blood Brothers, and the other for Moms in Action and Blood Sisters. Participants spent three days learning how to advocate for themselves and the bleeding disorders community. They gained new perspectives on a variety of topics relating to advocacy, including best practices when meeting with an elected official, writing an “elevator speech,” using social media to advocate, and how to advocate at home.

In conjunction with their training, participants spent time on Capitol Hill, talking to staff members from different Congressional offices. Blood Brotherhood and Dads in Action participants met with six different offices to practice asking for Congressional support for Bill HR 3742, also known as the *Access to Marketplace Insurance Act*. Blood Sisterhood and Moms in Action participants sat down with members of Senator Cory Booker's health staff for an educational meeting about working on Capitol Hill. The women also shared personal stories of resilience and the challenges they face because of bleeding disorders. Both groups had fruitful conversations with legislative staff and gained valuable experience.

Here's what a few of our participants took away from the experience:

*“Throughout history we have made major progress in the bleeding disorder community. We must continue to advocate, however. During this intensive advocacy training, I have learned that it does not matter whether you are a severe bleeder or a mild bleeder; we are all a part of the bleeding disorder community, and we must continue to advocate for a cure.” ~ Chelsea*

*“The advocacy intensive was a great experience. I learned how to advocate for my cause using the proper chain of command and then found out what goes on behind the scenes afterwards. When we advocate, lots of the time we go away feeling uncertain. Do they care? Will I get the help I need? How long will it take? And, will it make a difference? This training answered all of my questions. What I took from the training is how to pass on your knowledge to others so they understand your position. Most important, I learned to keep the fight going because help is on the way.” ~ Andrea*



**Advocacy is important and anyone can do it, regardless of training, experience, and proximity to DC or your state capital. Grab your walking shoes and get ready to take action with the following tips.**

**BE PREPARED:** Before scheduling a meeting with your representative, take time to research the topic you plan to discuss and create talking points or an “elevator speech.” An elevator speech is a concise explanation of the situation for which you're an advocate and what you're looking for from the listener: a speech short enough to last the length of an elevator ride. By being prepared, the meeting will likely go most smoothly and you will be able to engage in a productive conversation with your representative about the issues.

## **STAY RELAXED, YOU ARE THE EXPERT:**

It can be nerve-wracking talking with an elected representative or their staff. But remember, you are the expert on bleeding disorders and people will be interested to learn from your experience and knowledge. Elected officials are people too, and they are going to look to you for guidance about all things related to hemophilia and bleeding disorders.

**MAKE POLICY PERSONAL:** Sharing with your representative how specific legislation impacts you and your family will help personalize whatever bill might be up for consideration. Representatives know the language of the bill but your individual story brings it to life.

**FOLLOW UP:** Stay in contact with your representative after your visit by sending a thank you note or email. Follow-up notes are an effective tool to remind the representative about the issues you discussed. To ensure you have the correct contact information, ask for a business card after the meeting. Or, prepare a hand-written note ahead of time and leave it with information on bleeding disorders as you depart.

**STAY INFORMED:** Continue to track the issue, both in your state and at the federal level, and stay in contact with your representative. With each new Congressional session, be aware that new issues will arise that could impact the bleeding disorders community. ■■

# Millennials Get Busy

## Advocacy for Young Adults

By Sarah Shinkman

**L**earning how to advocate is an important life skill at any age. Whether you are practicing personal, peer, or group advocacy, you have the power to influence decisions that may affect you and others.

HFA's final Young Adult Hangout of 2016 featured two community advocates and a health insurance overview by Erin Hamlin of Young Invincibles, a national organization focused on engaging young adults on issues including health care, higher education, and jobs. Here's what our panelists shared about why they advocate and tips on how to get involved:



**William, Tennessee**

"I advocate for the bleeding disorders community to provide help for our families, education for people who do not know about bleeding disorders, and for my son to have a better life while dealing with his severe hemophilia type A.

A tip on how to get involved in advocacy would be to contact your local chapter to see what they offer. My advocacy effort was kick-started by HFA and my chapter, the Tennessee Hemophilia and Bleeding Disorders Foundation. Another tip is not to be scared or nervous to get involved in advocacy. Let your voice and opinions be known on the issues that impact you. Talking or writing to your elected officials is just like talking to anyone else. Treat them with respect. Tell your story and explain the importance for their constituents."



**Eric, Virginia**

"I advocate for the community and myself because I know with the ever-changing world, being engaged and tuned-in is more important than ever. The excellent thing about getting involved as a young adult is that it is incredibly easy to do in this community.

Find a project or event (advocating on Capitol Hill, or writing a letter to your congressman) that interests you, take the plunge, sign up, and go!" ■■

## Test Yourself

Being a strong advocate involves educating yourself and sharing information with others. HFA partnered with Young Invincibles for our Advocacy Hangout to encourage greater awareness of health coverage, especially for community members transitioning from adolescence to adulthood. Visit [www.hemophiliafed.org](http://www.hemophiliafed.org) and search for "Young Adults" to find Erin's presentation. Watch it, and then test your knowledge by defining these keys terms:

**Deductible:**

---

**Co-insurance:**

---

**Premium:**

---

**Co-payment:**

---

**In-network vs. out-of-network:**

---

**HMO vs. PPO:**

---

Learn more by visiting the Young Invincibles website at [www.younginvincibles.org](http://www.younginvincibles.org). Be sure to view their #healthyadulthood toolkit.

## DID YOU KNOW

### HFA has a podcast for Young Adults?

This fall, we launched a three-part podcast series on strength training, yoga, and healthy eating. Listen on iTunes or Google Play.

# HFA Celebrates 10 Years of Blood Brotherhood!

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 sessions 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 men who participate in the program!

## Blood Brotherhood | Then and Now

**2006:** Awarded Collaborative Agreement with the CDC to create a support program for adult men.



**2008:** HFA launches local Blood Brotherhood sessions via HFA Member Organizations. Six (6) sessions were hosted with 34 local Member Organizations and 102 registered Blood Brothers.



**2010:** Sixty-two Blood Brotherhood local sessions were held with 11 Member Organization sites and 182 registered Blood Brothers.

2006

2007

2008

2009

2010

2011



**2007:** HFA launches Blood Brotherhood Online Forum.



# The History of Blood Brotherhood

By Carl Weixler, excerpted from HFA's Blood Brotherhood 10th Anniversary Book

The HFA Blood Brotherhood concept started from two Blood Brothers talking about how strong this bond was between us, but there was no outlet or structure to facilitate that connection. As the desire to reach out and spend time with our Brothers became stronger, we thought it would be great if HFA, our consumer-centric national organization, could create a way for us to connect. Susan Swindle, then HFA Executive Director, heard the request and submitted a grant proposal to the Centers for Disease Control (CDC). Much to our surprise, the grant

was approved, and now we had a way for Blood Brothers around the country to meet in person and online. Some meetings were held at HFA's national annual Symposium and some at local Member Organizations. These meetings offered educational sessions and fun activities, but more importantly, they offered time for us to connect to one another about pressing issues as well as past concerns. It makes such a profound difference when you can speak to someone who has walked ten miles in your shoes.



**2016:** Ninety Blood Brotherhood local sessions delivered at 29 Member Organizations with more than 1,000 registered Blood Brothers.

HFA hosts Blood Brotherhood Camp Out to celebrate 10 years of Blood Brotherhood!

2011

2012

2013

2014

2015

2016

**2011:** Monthly live chats begin on the Online Forum.



**2013:** Seventy-three Blood Brotherhood local sessions delivered at 15 Member Organization with 306 registered Blood Brothers.



# CELEBRATING THE PAST AND MAKING NEW MEMORIES FOR THE FUTURE

## HFA Hosts Blood Brotherhood Camp Out



Nearly 40 men with bleeding disorders gathered together in Breckenridge, CO in early November for HFA's Blood Brotherhood Camp Out to celebrate 10 years of the Blood Brotherhood program. The weekend incorporated educational sessions, health and wellness activities, evening campfires, and many opportunities for Blood Brothers from across the country to meet new friends and renew old friendships. A few of the Blood Brothers who attended have shared their thoughts about this weekend of peer support:



**“Between the formal educational sessions and the more informal gatherings, we all enjoyed much-needed rest, relaxation and rejuvenation. There were times of sadness, reflection, and joy. Yes, we had differences of opinion, but in the big picture we shared camaraderie because of our common bond.”** ~ Bobby, CA



**“The most amazing men I know are those who constantly endure unimaginable pain yet still manage a genuine smile that lights up an entire mountain! I am both humbled and honored to call these men my Blood Brothers. Thank you, my brothers! My life is better for having each of you in it!”** ~ Earl, TN

“in the truth of our blood  
the challenges ongoing  
the love never ending  
surviving trauma  
thriving uncertainty  
embracing community  
as varied as experience  
as united as now  
vital and yes  
the body remembers  
and we never forget  
the darkness spent  
and the light shaking  
our essence awake”

~ Billy, MN



“It’s nice to meet fellow Blood Brothers you have never met before.”

~ John, NC



“The Camp Out brought us all  
together and made us stronger.  
Blood Brotherhood stands strong  
and together.” ~ Brandon, TN

“A milestone anniversary of bonding, fun and learning in beautiful  
Breckenridge.” ~ Murali, IL





## **BAYER** **access solutions**



Don't let insurance or financial challenges get between you and your treatment

- **Free Trial Program\***: Talk to your healthcare provider about requesting a free trial
- **Access to Therapy**: You may be able to receive the prescription treatment at no cost if you experience challenges getting insurance coverage for a Bayer product†
- **\$0 Co-pay Program‡**: You may be able to receive up to \$12,000 in assistance per year
- **Live Helpline Support**: Our experts are waiting to help you with any insurance coverage questions you may have†

\*The Free Trial Program is available to newly diagnosed patients and patients who are currently using other therapy. Participation in the Free Trial Program is limited to 1 time only. This program is complimentary and is not an obligation to purchase or use a Bayer product in the future. Reselling or billing any third party for the free product is prohibited by law.

†The program does not guarantee that patients will be successful in obtaining reimbursement. Support medication provided through Bayer's assistance programs is complimentary and is not contingent on future product purchases. Reselling or billing any third party for free product provided by Bayer's patient assistance programs is prohibited by law. Bayer reserves the right to determine eligibility, monitor participation, determine equitable distribution of product, and modify or discontinue the program at any time.

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

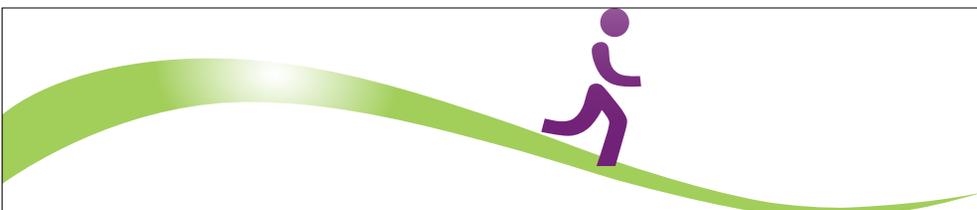
 **CALL 1-800-288-8374**

8:00 AM-8:00 PM (ET) Monday-Friday. Spanish-speaking Case Specialists are also available.

Bayer and the Bayer Cross are registered trademarks of Bayer.

© 2016 Bayer. All rights reserved.

Printed in USA 03/16 PP-775-US-0085



# Happy Birthday

## ADYNOVATE

[Antihemophilic Factor  
(Recombinant), PEGylated]

## THANKS FOR A GREAT YEAR!



© 2016 Shire US Inc., Lexington, MA 02421. All rights reserved. 1-800-828-2088.  
SHIRE and the Shire Logo are registered trademarks of Shire Pharmaceutical Holdings Ireland Limited or its affiliates.  
Adynovate is a trademark or registered trademark of Baxalta Incorporated, a wholly owned, indirect subsidiary of Shire plc.

S17536 10/16

# Bringing Light and Hope

By Angela Burton, MSW

Last fall, a bleeding disorders organization reached out to HFA's Helping Hands to refer a family in need (one of the recommended ways to seek assistance). The family of four had a young son with severe hemophilia and their story is one that many within our community can relate to. He was in and out of the hospital for hemophilia-related complications and issues. During their first hospital stay, he was admitted in the hospital for over a week as his doctors treated a spontaneous bleed. The family lived more than two hours away and the daily travel was taxing on everyone. Both parents worked and had the responsibility of taking care of their other child. Mom and dad had exhausted all of their personal time-off on hospital visits for other bleeds earlier in the year and the additional worry of how

they'd be able to be there for their son, while still bringing in income, began to intensify.

He was discharged and things were back to normal, but just two weeks passed before they found themselves back at the HTC with another bleeding episode. As exhausted and stressed as they were, the parents buckled down and got back into their routine: one would go to work while the other stayed with their son. Although this routine helped the family in managing some of the income, the use of unpaid days off finally took its toll and the family found themselves short on their home payment.

HFA provided the family with a contribution that allowed them to make their home payment on time. Several months after receiving assistance, we were able to follow up on the family's progress. Despite a few complications with another bleed and a port infection, the family was doing well and was extremely thankful.

Their gratitude was rooted in the fact that despite all they had experienced through the hospital stays and the emotional and financial difficulties, they had become stronger. Their family developed richer relationships with family and friends who stepped up with support; they came to experience, and appreciate, the kindness of others; and they learned the value of community. Through their struggles, this family has learned to tackle their son's situation one bleed at a time and reach out to the community in times of need. ■■



is now brought to you by

---

**Aptevo Therapeutics—a company that's anything but ordinary**

---

**At Aptevo, we pride ourselves on:**

Providing high-quality, specialized therapies for people with rare conditions

Connecting with people to learn about their needs

Developing empowering programs that enrich peoples' lives

---

**For more information about IXINITY, visit [IXINITY.com](http://IXINITY.com)**

---



Aptevo BioTherapeutics LLC, Berwyn, PA 19312.

IXINITY [coagulation factor IX (recombinant)] and any and all Aptevo BioTherapeutics LLC brand, product, service and feature names, logos, and slogans are trademarks or registered trademarks of Aptevo BioTherapeutics LLC in the United States and/or other countries.

©2016 Aptevo BioTherapeutics LLC. All rights reserved. CM-FIX-0060

# Adopting the Unadoptable: Our Family's Journey into the Bleeding Disorders Community

By Nick and Randy Vosburg

**W**e are Nick and Randy Vosburg, dad and daddy to three amazing sons we adopted through the foster care system. Our journey has been difficult and frustrating at times, but despite the challenges, it has been so amazingly rewarding. There are no words to express the joy and sense of fulfillment that these children have brought to our home, but we'll try!

Most people assume that potential adoptive parents want newborns or babies, but we were always drawn to older children who had been left behind, or labeled as "unadoptable" or were at risk of "aging out" within the foster system. Having faced individual challenges in our own lives, we both knew how important it is for children to have a loving and supporting family. Our first adoption was in 2011 with David, a seven-year-old boy. He had been overlooked, discounted, and disappointed with several failed adoptive placements. Despite some initial behavioral issues as the result of demons from his past, David is a sweet and loving little boy with no medical issues who desperately needed a family. After about a year and a half of transitioning into our role as parents and stabilizing our new family unit, we knew we wanted to open our home once again, so we began the adoption process for a second child.

The average age of children in the foster care system in our area is between 11 and 14. In 2013, we met our second son, Frankie, when he was 11 years old. He actually chose us at a meet-and-greet and we knew immediately that we needed to make him part of our family. Frankie came to us with a host of medical concerns, a result of a trauma-induced stroke

when he was an infant. Navigating the medical system and the many specialists required for Frankie gave us insight into parenting a child with special needs. While it wasn't easy, it was manageable. It was during this process that we met his hematologist and began to learn more about this particular area of medicine.

Once we had addressed Frankie's immediate medical needs and got him on track to a healthy life ahead, we again felt drawn to adopt another child. In 2015, we began the preliminary process for our third adoption. Coincidentally, without our prompting, we were contacted by the same agency that had placed David with us. They had an at-risk placement of a nine-month-old boy. We had never considered an infant, initially wanting a younger child perhaps around seven-to-ten to go along with our then 11- and 13-year-old boys.

After several days spent discussing the possibility and what it would mean for our family, we agreed to meet with the agency. The initial match meeting was perfect, and we couldn't have asked for a better outcome: we were selected as a match for the baby boy. As the process commenced immediately following the match, the agency learned more about our experience with Frankie's special medical needs and our calling to parent children who were virtually unadoptable. As a consequence, they asked us to consider meeting a different child.

The case worker told us about a two-year-old boy no other families were interested in because of his medical condition. She told us that he had hemophilia B and that, given our experience, we might just be the right fit for him. In addition to having hemophilia, he was virtually non-verbal and of mixed race. With scant information, we were once again faced with a dilemma. Despite the fact that we felt like we were having to choose one child over another, we knew that the nine-month-old had other interested parents and the toddler with hemophilia had no one. We had the will, but also a long list of questions that needed answers before we could move forward.

What exactly is hemophilia? Would this be something we could handle? And, it'll sound funny, but the biggest question we had was "Can we handle a toddler?" We began researching hemophilia and seeking counsel from family and friends. We reached out to Frankie's hematologist for information and guidance since we had developed a close relationship with her while we handled his medical conditions. She knew how hard we had worked to get Frankie's medical issues sorted out and was confident that we could handle the medical challenges of a child with hemophilia. We would later learn that Frankie's hematologist was also the treating physician for the toddler.





As we learned about infusions and special medical precautions, it became obvious that Nick must have been preparing for this child since he was in college. While studying for his undergraduate degree, Nick had worked as a phlebotomist and had specific experience in pediatric patients. With our hematologist's confidence and our family's unwavering support, we decided to move forward and adopt Trent, a two-year-old boy with severe hemophilia B.

From the first moment we met Trent in May of 2015, this sweet little toddler stole our hearts. After just one home visit, we knew he was our child and the process to assimilate him into our family was fast. Prior to finalizing his adoption, we had a home health nurse who came once a week to do Trent's infusions. As we studied his condition and the process of intravenous infusions, we decided to learn how to administer them ourselves. By July, we were giving Trent his infusions. This was definitely a team effort, as one of us would infuse while the other would distract Trent with Cheerios. To be fair, our boy is the most amazing patient. He doesn't engage in histrionics when it is time to infuse, but calmly sits in his chair and patiently allows us to take care of his "boo-boo." Sure, he'll occasionally utter an "owie," but there are no tantrums or meltdowns.

We have both shed a tear or two in sympathy for his situation, but we know he will overcome any challenge posed by his condition. And he will thrive. He faces a lifetime of 'boo-boos,' but he doesn't let that get him down. He is brave, funny, and, for the most part, unaffected. He is every bit a normal toddler who runs and jumps, swims like a shark, rides his Minion Hot Wheels, loves to play with cars, and read books. He is now completely verbal, can count, knows his letters and, with a little help, can even write his name.

In a few months, Trent will turn four. His infusions have now become routine. Rewards have graduated to Oreos and raisins.

We recently started a new breakthrough medication that has lengthened the time between infusions to every 14 days, which will halve the number of sticks he must endure and lessen the damage to his veins that frequent injections can cause. As life goes on, we hope for more breakthroughs and advances in understanding and treating his condition, and look forward to guiding him through the process to a self-sufficient adulthood.

In just a short period of time, we have learned a lot about hemophilia. We read everything we can get our hands on. We attend seminars, support groups, and advocacy symposiums. Trent's two older brothers have also learned about hemophilia and have taken an interest in educating others as well. As a family, we participate in every event in our area, every get-together, every walk-a-thon or 5K, and every meeting. We are in this for the long haul.

As soon as he's old enough, Trent will attend Camp Boggy Creek where he'll learn about his condition and eventually learn how to infuse himself. Nothing can stop him and we feel blessed to be a part of his journey. We're so thankful to the case worker who matched us with our beautiful son. We truly believe that we answered a special call to "adopt the unadoptable," and we now teach other prospective parents the ins-and-outs of the adoption process, with a special emphasis on adopting children with special needs.

Many people believe that our children were fortunate. We know we're the fortunate ones. Being a part of their lives has forever changed us: our hearts, our minds and our souls. We are blessed to be the parents of these special boys, and will always be grateful for the opportunity to be a part of something bigger than ourselves. ■ ■

# PROJECT CALLS: Q4 Report

## Creating Alternatives to Limiting and Lacking Services

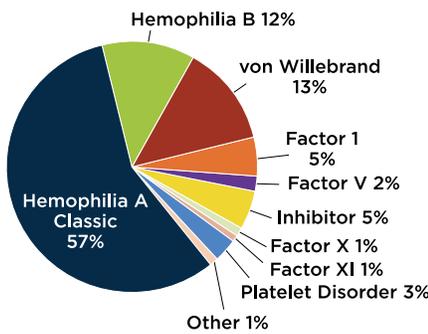
By Katie Verb, JD

In August 2015, HFA launched Project CALLS, an initiative designed to help the bleeding disorders community collect data and stories about how changes in insurance company policies are impacting the care of those with bleeding disorders. Since the launch of Project CALLS, we've received more than 100 individual reports of issues affecting the bleeding disorders community.

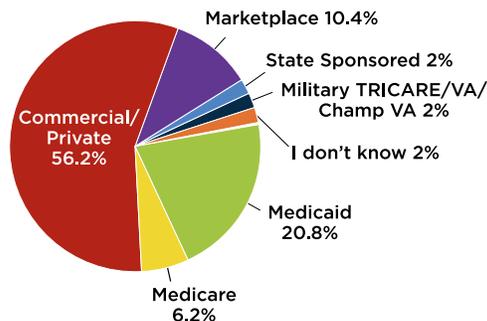
From the beginning, it became clear that the community is

having more issues with insurance than first imagined. We have gathered data about network adequacy, seen a huge increase in the number and length of prior authorizations for factor, and received one of the first patient-reported instances of step therapy in the community. In 2016, we were able to use CALLS data to support advocacy efforts at both state and federal levels and we will continue to report our findings to the community what we are finding. ■■

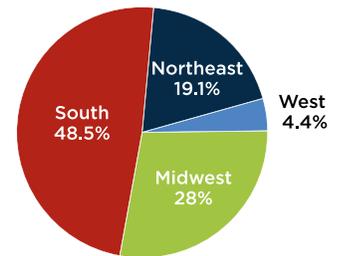
**Diagnosis - n100\*\***



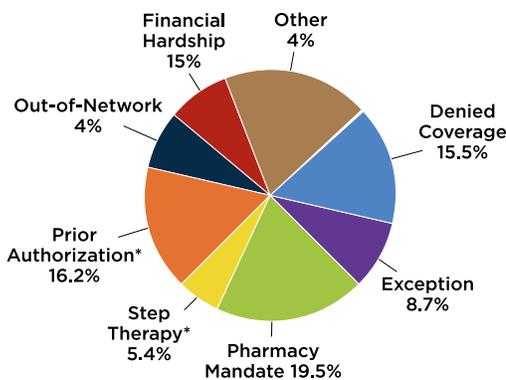
**Type of Insurance - n48\*\***



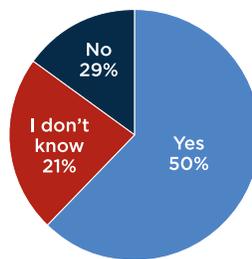
**Region - n68**



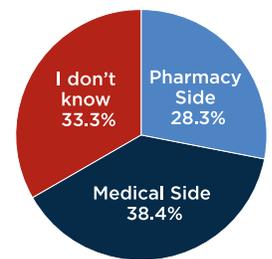
**Issue Reported - n148\*\***



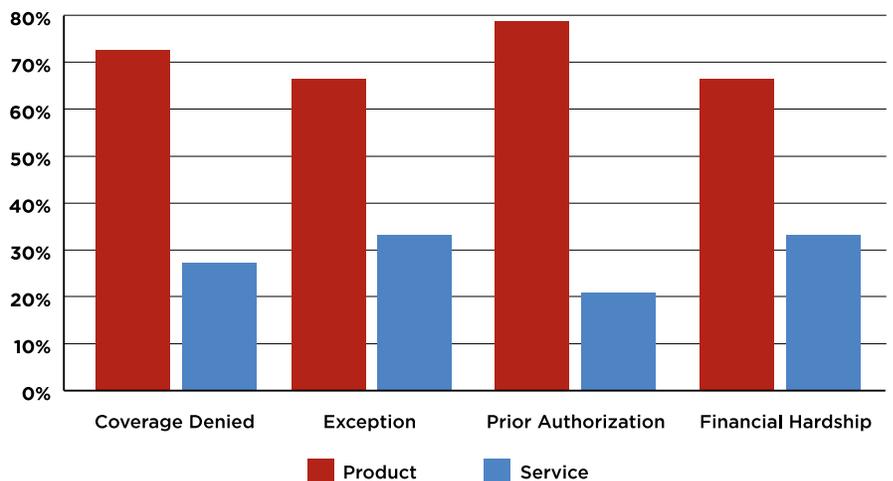
**Specialty Pharmacy Mandate - n82**



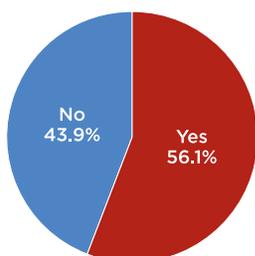
**Pharmacy or Medical Billing for Product? - n39**



**Product or Service?**



**Delayed Care? - n41**



\*all reports not for bleeding disorder treatments

\*\*percentages do not add to 100 because multiple answers reported

# Make HFA Your Charity of Choice

By Ann LeWalk and Sharon Meyers

As the new year unfolds, many people are looking for ways to make charitable donations and plan for tax credits for the coming year. While deciding where to direct their support, donors should take some of the following into consideration: the kind of work the non-profit does, the population the charity serves, the organization's mission and whether it aligns with their personal values, and the charity's record of stewarding donors' funds. All that said, we are naturally asking you to make HFA your charity of choice for 2017!

HFA is committed to being a good steward of our donors' support. In an effort to maintain donor confidence, HFA sought an evaluation from Charity Navigator, the largest independent charity evaluator in the United States. In 2016, we earned a coveted 4-star rating from Charity Navigator, whose ratings provide donors with clear, objective, and reliable assessments of the financial health and accountability, along with the transparency, of charities. Attaining a 4-star rating verifies that HFA exceeds industry standards and out-performs most charities, according to Michael Thatcher, President and CEO of Charity Navigator. This exceptional designation sets HFA apart from its peers and demonstrates its trustworthiness to the public. We are pleased to report that only one in four rated charities has achieved this endorsement!



HFA's President and CEO, Kimberly Haugstad, said "we are proud to earn this distinction from Charity Navigator and remain committed to assisting, and advocating for, the bleeding disorders community while being transparent and responsible

with the monies donated to us. Donors can be assured that we are honored to be entrusted with their dollars to best serve the needs of patients and families with a bleeding disorder," she explained. "Our Board of Directors and staff seriously evaluate how monies are spent and remain committed to maintaining the high standards set by Charity Navigator."

Over the past year, HFA has focused on maintaining a donor-centric approach to development by responding to the changing ways in which people like to support our organization. There was a time when people wrote checks to charities with the direction to "use where most needed." While this still happens on occasion, the more common occurrence now is that people make a donation wanting to feel a sense of the impact of their gift by witnessing the outcomes. For many, it is not enough to just write a check or click on a donate button, they want to have hands-on involvement in the resulting benefit.

This new attitude toward giving provides charities with both opportunity and challenges. The opportunity is to turn donors into volunteers or volunteers into donors, an exciting prospect for non-profit organizations. Yet, at the same time, it provides a challenge when trying to balance the donors' wishes with the needs of the communities they serve.

Faced with this new outlook on giving, HFA seeks to provide donors with innovative methods of support to satisfy their interests while continuing its mission to assist and advocate for the bleeding disorders community. Following is a list of ways you can make a difference. ■■

## 12 Ways to Give

### 1. Become an HFA Member

Individual, Family, or Professional memberships are available starting at just \$30/year. As an HFA member, you will receive our quarterly newsletter *Dateline Federation*, regular email updates on programs and services, and early bird notice of Symposium registration. All members receive an exclusive HFA membership T-shirt. Wear it with pride!

Visit [www.hemophiliafed.org/donate/become-a-member](http://www.hemophiliafed.org/donate/become-a-member) for additional information and to join.

### 2. Set Up a Sustaining (Recurring) Gift

Many donors want to give a certain amount within a calendar year, but do not want to make a lump-sum donation and certainly don't want to be bothered with writing out a check each month. As we ring in 2017, decide what you would like to give for the year and we can break it down to monthly electronic fund transfers (EFT). Enter your information in once and the rest is done for you automatically!

To set up your recurring gift to HFA, visit [www.hemophiliafed.org/donate/donate-online](http://www.hemophiliafed.org/donate/donate-online).

### 3. Support a Gears for Good Rider

■ Make a donation to one (or all) of our annual charity bike rides and you will help to provide emergency financial assistance to community members in need. Your gift will show participants that you support their efforts to ride 50, 70, or even 156 miles while they raise funds and awareness for HFA. Stay tuned for information about the 2017 Gears for Good rides.

### 4. Make an In-Kind Donation

■ Are you a business owner who has a product or service which could benefit members of the bleeding disorders community? Items like airline tickets, frequent flyer miles, health club memberships, or medical supplies can be used to help community members who find themselves in sudden need. Printing services, specialty items, etc. can help to support Gears for Good and Symposium.

Contact us at [info@hemophiliafed.org](mailto:info@hemophiliafed.org) to discuss in-kind donations.

### 5. Participate in a Matching Gift Program

■ Why not double your donation through your employer's matching gift program? Check with your Human Resources Director to see if this is something your employer offers, then add HFA to your company's charity list! Encourage co-workers to make a contribution to HFA to make an even larger impact.

### 6. Host a Fundraiser

■ Hobbies and social group activities are great ways to raise funds for HFA. Funds from garage sales, craft fairs, card parties, fraternal organization activities, and holiday gatherings can be donated to support HFA programs and services. Work with friends, family, your sorority or fraternity, or other social groups to support HFA!

### 7. Shop and Give Back

■ Did you know that you can support HFA without adding any extra expense to your budget? Select HFA on Amazon Smile ([smile.amazon.com](http://smile.amazon.com)) when you make purchases and Amazon will send us a percentage of each purchase at no additional cost to you. When shopping with Kindred Jewelleria ([www.kindredjewelleria.com](http://www.kindredjewelleria.com)), designate HFA as your charity of choice and we'll receive a portion of the proceeds.



Some retailers, Kroger and Target for example, give back to their communities by donating a percentage of the purchases made by their loyalty club members to a charity of the shop-

per's choice. Check with the stores you frequent to see if they have such a program.

### 8. Donate a Vehicle

■ Donate a car to Charity Motors and provide a vehicle for a less fortunate person, earn a tax credit for the fair market value of the car, and help HFA with the proceeds of the sale. For more information, visit [www.hemophiliafed.org/donate/car-donation](http://www.hemophiliafed.org/donate/car-donation).

### 9. Inquire About Payroll Deduction

■ Ask your employer if they provide an option to deduct an amount from your pay to be donated to HFA. Many companies have systems in place to make this an easy and seamless process. We're proud to participate in the Combined Federal Campaign for federal employees. If you work for the federal government, simply select HFA as your charity of choice for payroll deduction.



### 10. Consider Stock Gifts

■ A gift of marketable securities is an attractive option for donors who have appreciated stock. Donors may be able to claim the fair-market value of the security as a charitable contribution and avoid paying taxes on capital gains. It is HFA's policy to liquidate stock gifts as quickly as possible upon receipt. The process is simple, and it is a great way to make a charitable donation without using disposable income.

### 11. Include HFA in Your Estate Planning

■ Add HFA as a beneficiary on your life insurance policy, or talk with your estate planning team about leaving a legacy gift to HFA in your overall estate plans. Contact HFA for more information.

### 12. Honor a Loved One

■ Make a gift to HFA in honor or memory of a loved one. Memorial gifts are a thoughtful way to pay tribute to the life of a loved one while supporting programs which serve others in the bleeding disorders community.

Of course there are many ways to support HFA, but we hope you will find these suggestions helpful as you make your plans for your 2017 giving. For more information on any of these ways to give, or to share your ideas, please contact [development@hemophiliafed.org](mailto:development@hemophiliafed.org).

For those who have been sustaining donors, we thank you for your generosity and ask for your continued support in the coming year. For those who have not yet supported HFA, we ask that you make HFA your charity of choice in 2017!

For more information about charitable giving with HFA,  
visit [www.hemophiliafed.org](http://www.hemophiliafed.org) or email [dev@hemophiliafed.org](mailto:dev@hemophiliafed.org).



# Genetic Counseling: What You Never Knew You Needed to Know

By Meg Bradbury, MS, CGC, MSHS

**G**enetic counselors are trained healthcare professionals with a degree in genetics and counseling which enables them to provide personalized guidance to people who may need to make decisions about their own, or their family's, health. These counselors have received training primarily from accredited programs focusing on coursework in psychology, statistics, counseling, developmental anatomy, biochemistry, genetics, and clinical research, as well as rotations of clinical training. After the training these newly-minted genetic counselors often go on to complete an examination and an evaluation of their clinical portfolio offered by the American Board of Genetic Counselors (ABGC) to ensure that standards have been met to provide competent genetic counseling services. Genetic counselors have expertise in genetic testing, research, disease management and prevention, risk assessment, and how inherited diseases and conditions such as bleeding disorders affect families. Currently there are more than 4,000 certified genetic counselors in the US.

With so much to learn about genetic counselors and how they work within the bleeding disorders community, we've put together a comprehensive list of questions, and even provided the answers! You may not have known what you needed to know but that's about to change!

## What is the role of a genetic counselor?

Often, genetic counselors serve as medical advocates who use their expertise to assist clients and families to understand the natural history, inheritance patterns, and inheritance risk of bleeding disorders. They use the family's history and information about the disorder to determine the recurrence risk and the benefits or limitations of genetic testing. Genetic counselors, because of their training, have an ability to adapt to the needs of the patient and work as a liaison with the other clinicians by helping to identify and provide resources and support. They often serve as a bridge between medical specialties and are able to provide a clear understanding about complex medical information. Genetic counselors can aid patients and families to absorb those thorny medical concepts and figure out what options might be best integrated into their own care.

## What does a genetic counseling session look like?

Typically, genetic counseling sessions last between 30-60 minutes and comprise a number of elements including contracting, information gathering, risk assessment, education, psycho-social assessment/counseling, privacy concerns, and case management. Ideally, a relationship with a genetic counselor should involve a number of meetings and include pre- and post-test sessions. One of the goals in pre-test counseling is to develop a testing strategy and help the patient or family to figure out the best options for them.

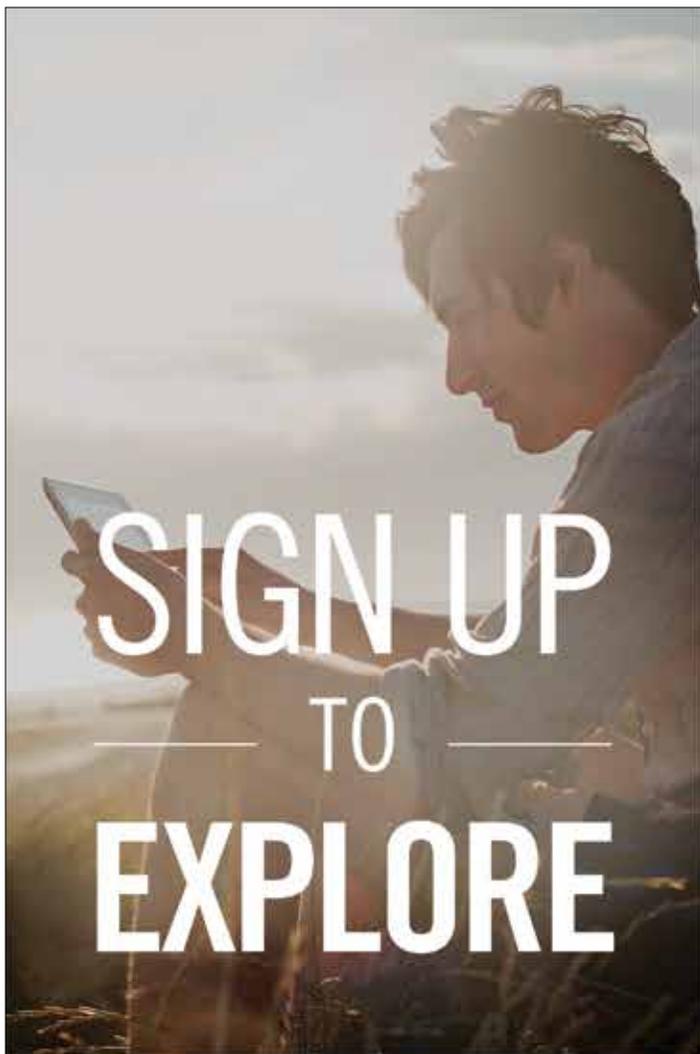
## As a woman in a family with a bleeding disorder, what special considerations should I know about?

Women who are at-risk for being a carrier should complete genetic testing prior to conception or early on in their pregnancy. This allows the family to take additional steps during the delivery process, such as having factor on hand to prevent hemorrhaging or complications during birth for either the mother or the newborn. Prenatal testing might be of interest for the parents and a genetic counselor would discuss some of these tests such as chorionic villus sampling (CVS) and amniocentesis (Amnio). However, these tests are only an option if a familial pathogenic genetic variant is known.

For women who are not yet pregnant there are also pre-conception options to discuss with a genetic counselor such as in vitro fertilization (IVF) and pre-implantation genetic diagnosis (PGD). For IVF, fertilization of the egg with sperm occurs within a laboratory to form a blastula, or embryo, and then at the early cell stage of development PGD can be used to identify which embryos carry a pathogenic variant that causes a bleeding disorder. The parents can choose to implant only those without a pathogenic variant, or to prepare to raise a child with a bleeding disorder.

## What is genetic testing and how is it done?

As many within the community may know, testing for hemophilia includes the measuring of how much factor VIII and



# SIGN UP TO EXPLORE

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](http://GenentechHemophilia.com) and we'll keep you updated.

**Genentech**  
A Member of the Roche Group

©2016 Genentech USA, Inc. All rights reserved. GPT/022516/0074

factor IX protein is circulating in an individual's blood. This result can be diagnostic in males but in females who may be carriers factor level alone may not be informative. Women were previously thought to be asymptomatic carriers but have now been shown, in some cases, to be symptomatic and receive a diagnosis of hemophilia. Genetic testing looks specifically at genes, such as factor VIII and factor IX, that can carry a pathogenic variant and lead to hemophilia A or hemophilia B, respectively. Having the results from this gene test allows for molecular confirmation of the clinical diagnosis and it can therefore be used for targeted genetic testing in other at-risk family members. This can be of particular importance for carriers in which factor level might not be revealed.

Genetic confirmation of the diagnosis can be useful to an entire extended family, and prompt testing of other individuals at risk for being carriers and also for future reproductive planning and prenatal diagnosis. A molecular or genetic diagnosis can also be used for enrollment in clinical trials or research studies. Results can take several weeks to be reported back to the clinician.

Genetic test results can be dense and complicated, but a genetic counselor is specifically trained to help interpret and translate this complex information in comprehensive clinical notes. These notes can be used as a resource to speak with other providers and help explain risk, diagnosis, and genetic results. Some genetic results have been associated with certain clinical presentations and may provide information about disease progression or severity, or inhibitor risk. This type of information in medicine is called genotype-phenotype correlation. Genotype refers to the gene pattern instruction in an individual and phenotype refers to the clinical presentation, like factor levels. Not all variants identified in a gene are considered disease-causing or pathogenic. For example, some variants or changes found within our genes are considered benign (variant likely benign, or VLB) while others may be considered variants of uncertain significance (VUS), a status about which we know little at this time. Genetic counselors are trained to help interpret these genetic results in relation to the diagnosis and how they may relate to the family. Often genetic counselors have this discussion about possible result outcomes prior to testing in order for patients and families to be prepared for whatever the result may be. Genetic counselors can also help develop letters to other family members who may have questions or be interested to know their own risk.

## Are genetic counseling services covered by insurance?

Genetic counseling is typically paid for by health insurance and in many cases insurance also pays for genetic testing when

it is recommended by a clinician. It is important to check with your health insurance company to verify coverage and benefits including out-of-pocket deductibles before beginning the process. Depending on the type of insurance and the company's policies, you may also need a referral from your provider. Insurance companies have different policies and may vary in coverage for genetic testing. Some companies require meeting with a genetic counselor prior to genetic testing. Genetic counselors can work with families to figure out who should be tested first in the family for the more targeted testing which can be more cost effective. Support organizations and/or research studies may also offer genetic testing. It is important to discuss these opportunities with your clinical team to determine how these may be appropriate for you or your family.

### How to find a genetic counselor?

Genetic counselors work in a variety of settings including hematology clinics, genetic testing laboratories, hospitals, research studies, clinical trials, insurance companies, or through telemedicine in which you can connect with a genetic counselor remotely from any location, including your home. As clinicians, genetic counselors may also practice within your local hemophilia treatment centers (HTCs), seeing individuals or entire families, or they might specialize in particular areas, like prenatal, pediatrics, neurology or oncology.

### Looking for a genetic counselor in your area?

1. Contact your local HTC and ask to schedule an appointment with the genetic counselor.
2. The National Society of Genetic Counselors (NSGC) has a service resource entitled, *Find a Genetic Counselor Directory*. This directory was developed to assist physicians, patients and other genetic counselors in locating genetic counseling services, and for students curious about the profession. Visit the NSGC website at [www.nsgc.org](http://www.nsgc.org) and use the search function to search by "Types of Specialization" in which you can select 'Hematology' as an option.

#### About the Author

Meg Bradbury is a Lead/Senior Genetic Counselor at GeneDx in the Neurogenetics Department. She graduated from the genetic counseling program at University of Wisconsin-Madison in 2005. Prior to GeneDx, Meg worked as a genetic counselor at Children's National Medical Center at a multidisciplinary neuromuscular disorder clinic. She went on to get her Masters in Clinical and Translational Research at George Washington. She is a member of the National Society of Genetic Counselors. She is a board member of the Hemophilia Association of the Capital Area (HACA) and the Genetics Work Group of the American Thrombosis and Hemostasis Network (ATHN)/National Hemophilia Program Coordinating Center (NHPCC). ■■



### Meet Team Novo8™

The patient ambassadors for Novoeight® are ready to connect with you. Each team member shares their history, their diagnosis, and their unique stories that can inspire you and your caregivers.

Visit [Novoeight.com](http://Novoeight.com) to learn more about each team member's journey.



Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.  
Novoeight® is a registered trademark and Team Novo8™ is a trademark of Novo Nordisk Health Care AG.  
Novo Nordisk is a registered trademark of Novo Nordisk A/S.  
© 2016 Novo Nordisk All rights reserved. USA16HDM02406 July 2016

**novoeight®**  
Antihemophilic Factor  
(Recombinant)

# SHE SHARES HIS SYMPTOMS, but not his solutions.

- ✓ Below-normal factor IX levels
- ✓ Chronic pain
- ✓ Prolonged bleeding after dental work or surgery
- ✓ Easy bruising
- ✓ Joint damage from bleeding



I knew I was a carrier, and I was having symptoms for years, but I wasn't diagnosed until the age of 36.

— 46-year-old woman with hemophilia B

## Women and girls can—and do—have hemophilia B.

Traditionally classified as carriers, women can have the same bleeding symptoms as men with hemophilia B.

They also face challenges all their own, like abnormally heavy and long menstrual cycles with large blood clots, excessive bleeding after giving birth, and anemia.<sup>1,3</sup>

Don't let the wrong diagnosis be one of those challenges.

Early diagnosis and the right treatment can help or even prevent bleeding problems and improve quality of life.<sup>2</sup>

That's why Aptevo Therapeutics worked with women who have hemophilia B to create a quick guide that focuses on how this condition affects women, girls, and their families.

With help from this guide, you can feel confident talking about your symptoms with your doctor or nurse.

Download a women's guide to hemophilia B at [WomenWithHemophiliaB.com](http://WomenWithHemophiliaB.com)

**References:** 1. Clark D. Women with hemophilia. Coalition for Hemophilia B. Available at <http://static1.squarespace.com/static/566b210340667a1cc1623840/t/56792e35a2bab8836bd402dc/1450782261872/Women-with-Hemophilia.pdf> Accessed June 28, 2016. 2. Rhynders PA, Sayers CA, Proseley RJ, Thierry JM. Providing young women with credible health information about bleeding disorders. *Am J Prev Med*. 2014;47(5):674-680. 3. Hemophilia Federation of America. Are women affected by bleeding disorders? Available at: <http://www.hemophilialf.org/bleeding-disorders/can-women-have-bleeding-disorders>. Accessed August 5, 2016.

**Aptevo**<sup>™</sup>  
Therapeutics

©2016 Aptevo BioTherapeutics LLC. All rights reserved. CM-FIX-0072